Strengthening and integrating Palliative Care into national health systems in 4 African countries.

Final Evaluation Report for the

INTEGRATE PALLIATIVE CARE PROJECT

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Glossary

APCA	African Palliative Care Association
CHAZ	Churches Health Association of Zambia
CHUK	Centre Hospitalier Universitaire Kigali
CHV	Community Health Volunteers
DPWMF	Diana Princess of Wales Memorial Fund
GRRH	Gulu Regional Referral Hospital
HBC	Home Based Care
HC	Health Centre
HMIS	Health Management Information System
KEHPCA	Kenya Hospice and Palliative Care Association
LPs	Lead partners (UoE, MPCU, APCA)
M&E	Monitoring and Evaluation
MDT	Multi-disciplinary team
MoH	Ministry of Health
MoU	Memorandum of Understanding
MPCU	Makerere Palliative Care Unit (Uganda)
MTRH	Moi Teaching and Referral Hospital (Kenya)
NCD	Non Communicable Disease
NCH	Ndola Central Hospital
NCTRH	Nyeri County Teaching and Referral Hospital
NPCA	National Palliative Care Association
OPD	Outpatients Department
PAMs	Professions aligned to medicine
PC	Palliative Care
PCA	Palliative Care Association
PCAR	Palliative Care Association of Rwanda
PCAU	Palliative Care Association of Uganda
PCAZ	Palliative Care Association of Zambia
RBC	Rwanda Biomedical Centre (Ministry of Health)
RHPCO	Rwanda Hospice and Palliative Care Organisation

SSA	Sub-Saharan Africa
ToT	Training of trainers
UNZA	The University of Zambia
UoB	University of Bristol
UoE	University of Edinburgh
UTH	University Teaching Hospital (Zambia)
VHT	Village Health Team / Village Health Technician
WHA	World Health Assembly
WHO	World Health Organization
WHPCA	Worldwide Hospice Palliative Care Alliance

1 Introduction

1.1 Background

1.1.1 Palliative Care

The World Health Organisation (WHO) defines PC as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[1]

1.1.2 Context

This evaluation is timely. In May 2014, the World Health Assembly (WHA) passed the first ever resolution to integrate hospice and PC services into every national health service, calling on national governments to recognise PC as an integral component of health systems.[2] The resolution called for the Director General to "encourage research on models of PC that are effective in low and middle-income countries, taking into consideration good practices". [2] p5

This evaluation provides a blueprint of activities, and exemplars of best practice across a number of different level hospitals in four African countries. It can be used as a resource to further advocate for, and inform implementation of national integrated PC plans.

1.1.3 Need for Palliative Care in Africa

Each year 300 million people are affected by end-of life care issues, amounting to 5% of the world population.[3] It is estimated that at least 60% of people who die each year would benefit from PC.[4] Of those living with cancer, 60% will experience significant pain. Already, three million patients die annually from AIDS.[5] With the rapidly aging world population and the associated increase of multiple non-communicable diseases (NCDs), the need for PC is likely to substantially increase in the next 50 years.[6] PC is an essential part of the package of care for people living with HIV/AIDS, cancer and other chronic life-limiting illnesses.[7] It was recognised by the WHA as an "urgent humanitarian responsibility"[7] and by the PC International Community as a human right.[8] The Global Action Plan for the Prevention and Control of NCDs 2013-2020, recognises PC as an essential component of care for people with NCDs along with prevention and reduction in mortality.[6]

Globally, Sub-Saharan Africa (SSA), despite the highest global HIV prevalence and a growing cancer and NCD burden, has the greatest gap between PC need and service provision.[9] Key indicators for PC provision (e.g. pain management, the development of national policies, and integration into the curriculum of health professionals and health services) point to fundamental gaps, most pronounced in rural regions or areas of severe deprivation. African countries use 1/20th of the global average for morphine use.[10]

The Cape Town declaration identified a particular need for PC in Africa.[11] Integration of PC into national health systems has been identified as a key step required in increasing access to PC in SSA.[12] This report describes a project carried out to strengthen PC in 4 African countries: Kenya, Rwanda, Uganda and Zambia.

1.1.4 Models of Palliative Care in Africa

Recent analysis of different models used within SSA has highlighted benefits and challenges of each.[13, 14] Integrated PC models can be positioned in different ways throughout the continuum of care and may address generalist, intermediate or specialist palliative care needs; often in combination. Examples of models of PC provision include:

1. ***Specialist palliative care services:*** Specialist services may be provided across the continuum of care at tertiary, secondary and primary levels of care. Such services provide an element of leadership, training, mentorship and supervision in addition to directly addressing complex needs for patients and families.
2. ***Hospital-based palliative care teams:*** These provide palliative care services within a hospital context and can offer generalist, intermediate or specialist functions. This may include both inpatient and outpatient services.
3. ***Home-based care:*** This may be provided through specialist PC teams that visit patients and support them directly in the home, or generalist or intermediate care delivered through home-based care services provided by community-based programmes. These may utilise trained volunteers and may have a clear partnership with specialist palliative care services.
4. ***Outreach services:*** Some PC providers have outreach services that support other organisations to provide PC, or provide roadside and mobile clinics.

1.1.5 Barriers to the delivery of Palliative Care in SSA

Key barriers to the delivery of effective PC services in SSA are the burden of disease, combined with low numbers of health workers per population. All four countries involved in this project were identified as having a critical shortage of health workers in the 2006 WHO report. [15] Given this shortage, the importance of integrated (as opposed to stand-alone) services is paramount. However, services are rarely integrated into mainstream health systems, often sporadic and geographically specific. 45% (21/47) of African countries have no identified PC activity, and only 9% (n=4) have services approaching integration with mainstream service providers.[16]

In each partner country, islands of excellence exist, but processes for scale-up to achieve national coverage are missing. Closing the inequitable gaps in global, regional and national patient outcomes is dependent on the strategic strengthening of the delivery capacity of health systems.[17] The UN review analysis of the MDGs in 2010 identified silo working as a

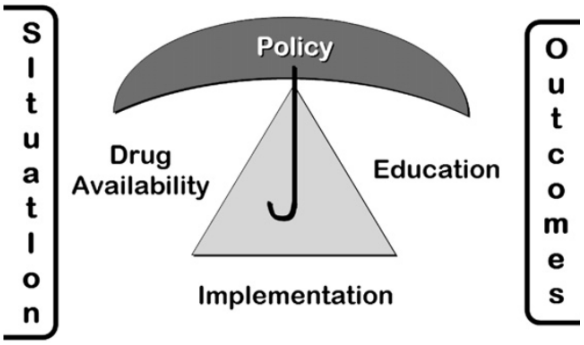
major obstacle to achieving the goals.[18] Integration of services into existing health systems is important in ensuring both accessibility and sustainability of services.[14]

1.2 Integration of Palliative Care in Health Systems

1.2.1 Public Health Approach to Palliative Care

PC is being reconceptualised as an important arm in global public health and health systems. The need to make it a mainstream concern for public health providers and policy makers has been recognized [3, 4] and this approach is central to the development of PC in Africa. The WHO enhanced model of PC states that services should be founded on appropriate government policy, education of health workers, availability of essential drugs and implementation of PC at all levels.[5] This is shown in the diagram below.

Figure 1: WHO Public Health Model



The four pillars shown above are all linked and it has been suggested that a fifth pillar is that of research. [19] Policy is shown as the overarching pillar, as policy needs to be in place before opioids can be imported. Similarly, drug availability issues need to be addressed before training and implementation programmes are undertaken. [5]

A public health approach necessitates incorporation of services by governments into all levels of their health care systems and ownership from the community.

In 2007, the Worldwide Hospice and Palliative Care Allliance updated a mapping of PC service integration in the Global Atlas of PC at the End of Life. [20] They identifed the following categories, expanded from the original 4 developed by Wright et al:[21]

1: No Known Activity

2: Capacity Buidling: evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for hospice-PC services to develop, some incipient service development but no service yet established.

3a: Isolated Provision: patches of PC activism, donor dependent funding and limited availability of morphine.

3b: Generalised Provision : PC activism in a number of locations; multiple sources of funding; the availability of morphine; hospice-PC service and training provision outside the healthcare system.

4a. Preliminary Integration: Countries where hospice-PC services are at a stage of preliminary integration into mainstream service provision.

4b. Advanced Integration: Countries where hospice-PC services are at a stage of advanced integration into mainstream service provision.

1.2.2 WHA resolution on Palliative Care Integration

The WHA resolution 67/19, adopted in May 2014, called for member states to implement the following:

1. **Policy**: develop, strengthen and implement, where appropriate, *PC policies* to support the comprehensive *strengthening of health systems*.
2. **Funding**: ensure adequate *domestic funding and allocation of human resources* for PC improvement initiatives.
3. **Supporting Communities**: provide basic support, to *families, community volunteers* and other caregivers.
4. **Training**: aim to include PC as an *integral component of care provider training*:
    a. *basic* training for undergraduate medical and nursing, and in-service training for all allied professional or care-givers;
    b. *intermediate* training for health care workers who routinely work with patients with life-threatening illnesses;
    c. *specialist* training should for those health care professionals who will manage integrated care for patients with complex needs
5. **Supply of essential medicine**: promote collaborative action to ensure *adequate supply of essential medicines* in PC, avoiding shortages;
6. **Control of essential medicine**: ensure *legislation and policies for controlled medicines* are in line with WHO and UN conventions.
7. **Policy on essential medicine**: update national essential medicines lists in the light of the recent WHO recommendations.[22]

8. **Partnership**: foster partnerships between governments and civil society to support PC services.
9. **Implementation of WHO 2013-30**: implement and monitor PC actions included in WHO's global action plan for the prevention and control of non-communicable diseases 2013–2020[6];

The WHO ad-hoc Technical Advisory Group on Palliative and Long-Term Care is supporting the WHO to develop manuals and frameworks for the implementation of this resolution. They are taking a health systems strengthening approach, whereby the WHA Palliative Care Resolution will be implemented through six building blocks. These building blocks, described in the WHO document "Monitoring the Building Blocks of Health Systems", [23] are:

1. Governance and Leadership
2. Service Delivery
3. Human Resources
4. Financing
5. Medicines, Vaccines and Technology
6. Strategic Information

This document provides examples of how these building blocks can be achieved. More information is given in the recommendations section of this report.

1.3 The Integrate Palliative Care Project

The THET ***Integrate*** Palliative Care Project (*Integrate Project*) is a multi-country partnership project on ***"Strengthening and integrating PC into national health systems through a public health primary care approach in 4 African countries to contribute to meeting the targets of MDG goal 6***". This project ran from April 2012- March 2015 and aimed to strengthen and integrate PC into national health systems in 4 African countries: Kenya, Rwanda, Uganda and Zambia. The lead partners (LPs) for this project were the University of Edinburgh (UoE), the African Palliative Care Association (APCA) and the Makerere Palliative Care Unit (MPCU).

The *Integrate Project* was based on the public health approach to service delivery as advocated by the WHO and delivered through a health systems strengthening and capacity building agenda. The intent of the project was to enhance the provision of quality and comprehensive treatment, care and support for adults and children living with life limiting illnesses in 4 African countries (Kenya, Rwanda, Uganda and Zambia) in order to contribute to achieving the targets of MDG 6.

1.3.1 Project Goal

The project goal was to support the development of a comprehensive public and primary health approach to PC that includes service provision, support systems and supply chain

mechanisms that are firmly integrated into the health system through modelling this in 12 national hospitals and their associated clinics.

1.3.2 Project Pillars

Working in partnership with the National PC Associations and the Ministries of Health (MoH) in each of the 4 countries, the LPs worked with 12 hospitals, 3 in each country, to advocate for PC, train and mentor staff, build community networks and referral pathways in order to integrate PC into systems, policies, practice and communities. The hospitals chosen were selected by the MoH, and included national referral hospitals, regional hospitals and district hospitals. The programme aimed to build on the different stages of PC development of each country.

A multi-layered approach was adopted working with hospitals and their associated health centres. The approach was built on the following four pillars:

1.3.2.1 Advocacy

The LPs supported advocacy at three levels:

- Supported the country PC associations to advocate for PC
- Supported each of the 12 hospital systems to advocate for PC within the hospital and its catchment area, and to local policy makers.
- Supported mentors and mentor hubs to advocate for and influence PC delivery in the UK.

Advocacy used the public health approach to PC in order to establish a whole system approach: inclusion of PC in budgets and policies, availability of essential medication, inclusion of PC in curricula and development of concrete plans to implement PC services throughout each country.

1.3.2.2 Staff Capacity

This focussed on strengthening the knowledge, skills and acceptability of PC among health workers (from senior policy and management to community practitioners) to deliver integrated holistic care through a range of on-site (hospital/health centre) multi-disciplinary, multi-cadre trainings, and the development and implementation of contextualised patient and provider resources. Training included:

1. **Basic training**: in PC to a critical mass of staff of different cadres and from different clinical, health and social care specialities. In three of these countries this training included a clinical placement to model clinical best practice.

2. **Advanced training:** This was normally a 3-5 day training course which built on the basic training in more detail, and included key areas such as children's PC and research.
3. **Training of trainers**: to snowball skills to health workers and the community.
4. **Specialist training**: for the future leaders of PC services. This included diplomas, degrees and Masters in PC and related specialities.
5. **Community Training**: Training of community members in PC awareness.

The training programme was designed to ensure the 12 hospitals would, over the 3 years, become strong service providers of PC with independent PC trainers, with the skills and resources to cascade training through their organisations and down to the community level.

1.3.2.3 Service Delivery

These activities included establishing and integrating pathways for diagnosis, treatment and care through a multi-level health care team alongside the development of protocols, planning templates for health service management, record keeping and patient documentation, in order to draw together all PC work. Specifically, this involved:

- Supporting the 12 hospitals and National Associations to develop, implement and embed PC policy, standards and protocols.
- Supporting the 12 hospitals to improve the patient pathway and develop clear referral processes.
- Supporting the National Associations to ensure the supply of essential PC medicines.

1.3.2.4 Partnership

The project was designed to develop and strengthen multiple partnerships through a multi-layered partnership approach. The LPs worked with the national PC associations (PCA) to support hospitals and to strengthen the PCAs' capacity to support the hospitals once the project had ended. The project leveraged UK mentors (generated through Edinburgh's extensive PC mentoring UK network) to facilitate and grow the Mentorship Programme with each hospital matched to a lead UK mentor and a small mentorship support network. There were 4 layers of partnership.

1. Lead Partners

This was the partnership between the three LPs:

1. **University of Edinburgh (UoE):** UoE was the UK lead partner accountable for the project. UoE also provided the delivery of UK mentors for this project.
2. **Makerere University Palliative Care Unit (MPCU):** MPCU operate the integrated PC service at Mulago Hospital, and the academic unit in Makerere University, Kampala and provided technical expertise in clinical skills, training, research and clinical systems

integration. In collaboration with APCA they supported local planning and coordination and training and teaching.

3. **African Palliative Care Association (APCA)**: APCA, in collaboration with MPCU supported local planning and coordination and training and teaching. APCA partners with PC associations in a number of countries across Africa, including the four involved in this project. APCA provided monitoring and evaluation and logistics support for this second level of partnership as described below.

2. Lead Partners and National Associations

The second level of partnership, which APCA led, was that between the LPs and the country PC associations or representatives. The role of these in-country partners was local implementation, project oversight and reporting. APCA developed sub-agreements with each partner. The partners were: 1) Palliative Care Association of Zambia (PCAZ), 2) Kenya Hospice and Palliative Care Association (KEHPCA), 3) Palliative Care Association of Uganda (PCAU). In Rwanda an initial partnership agreement was signed between APCA and the Palliative Care Association of Rwanda (PCAR). But a change in governance led to a new MoU being signed between the Rwanda Ministry of Health / Rwanda Biomedical Centre (RBC) and UoE. Following this MPCU led the co-ordination with RBC.

The National Associations were all members of APCA, providing a natural avenue for collaboration and multi-country partnership. Each of the country partners had local project teams with MoH representation. Country partners were part of a joint working group, co-ordinated by APCA and MPCU, meeting by skype and reporting to the steering group to ensure linkage.

3. National Associations and Hospitals

The partnership between each hospital and their National Association was core to the design of the project. Each hospital, working with their National Association or directly with the MoH, identified the way in which they wanted to develop their PC programme. National associations provided continued mentorship throughout the programme, a link between the three hospitals in each country, assisted with delivering training, advocacy and medicine supply chain issues.

4. Mentorship Hubs

Each hospital partnered with a small team of UK mentors through a mentorship “hub”: a relationship between an African hospital and a group of experienced PC professionals in the UK. The role of the mentors was to provide guidance and support to the hospitals in the implementation of their programme. The mentors were asked to be flexible to the needs of their partner hospital, offering clinical modelling, on-the-job training (OJT), advocacy support or input to policy and protocols depending on the need of the hospital at that time. The hubs

were also intended to offer experience and skills to the UK mentors to inform their practice in the UK. Mentors were linked via a website as a means of information sharing, and to generate a community of practice of those committed to PC which is designed to last after the project and will be available to other international links and organisations.

1.3.3 Project Indicators

Twenty seven key indicators were agreed, nine of them indicators for all DFID funded Multi-country partnership programmes and 18 specific to the Integrate PC Programme.
Table 1: Indicators for evaluating the *Integrate Project*

1	Palliative care referral networks mapping showing stronger linkages at the end of programme as compared to at the start.
2	Number of hospitals delivering an integrated community wide palliative care programme
3	Number of hospitals modelling a public and primary health approach to palliative care
4	Number of participating institutions demonstrating implementation of improved policies and professionals standards by end of the programme
5	Percentage of institutional health strategies and professional standards/protocols which have been approved and signed off by the end of the programme
6	Number of institutional health strategies and professional standards/protocols to which the project has contributed to (reviewing, updating or developing)
7	Number of clinical placement sites which have completed a standards audit and have a signed off quality improvement plan at the end of the project
8	Number of baseline and end of project situational analyses completed
9	Number of patients using palliative care services at 12 participating institutions
10	Morphine consumption at the 12 hospitals
11	Number of patients with a documented management plan of care
12	Number of health workers demonstrating improved performance following training
13	Number of health workers with skills to provide palliative care per 100,000 population
14	Number of health workers demonstrating improved knowledge or skills after training
15	Number of developing country health workers who participated in education / training
16	Number of trained professionals completing clinical placements
17	Number of Ministries of Health recognising palliative care in their national health plans
18	Number of advocacy / communication activities undertaken to influence the health agenda
19	Participating Associations influence development of Palliative Care in Africa
20	Number of UK volunteers demonstrating improved clinical and leadership skills
21	Number of new institutional health partnership MOUs in place

22	Number of UK health professional days spent volunteering overseas by end of programme
23	Number of UK health professional days spent providing remote support to overseas partners
24	Number of community people attending awareness training.
25	Number of community health awareness or mobilisation campaigns
26	Number of health professionals applying their skills and learning to benefit the local community.
27	Number trained as trainers

1.4 The *Integrate Project* Evaluation

1.4.1 Evaluation Process

This evaluation of the *Integrate Project* used an adapted collaborative evaluation process with both independent evaluators and members of the steering group working in partnership to deliver a joint assessment. There is increasing evidence for the value of collaborative, as opposed to distanced, evaluation in which key programme stakeholders are actively involved in the evaluation process. [24] The evaluation process included qualitative and quantitative methods and involved a review of all available data, quantitative reporting against the 27 agreed indicators and a final evaluation visit to each site.

1.4.2 Evaluation Team

The evaluation team, and their roles, are described below:

Figure 2: Evaluation Team Roles

Role	Name	Affiliation	
Lead Steering Group Evaluator	Liz Grant	University of Edinburgh (Lead Partner)	Liz Grant, as the lead of this project commissioned the evaluation, agreed the scope, acted as the link between the lead independent evaluator and the donor, signed off on the methods, the report format and the final report.
Lead Independent Evaluator	Mairead Murphy	University of Bristol (Independent)	Mairead Murphy co-ordinated this evaluation, designed the report format, analysed the qualitative evaluation data and wrote the first draft of the evaluation report.
Lead Indicator	Julia Downing	Makerere University	Julia Downing, as lead on the quantitative evaluation of the indicators, gathered all the

Evaluator		(Lead Partner)	indicator data, analysed it and wrote the indicators report, attached as Annex 2, and referred to in this report. She was also involved in the final evaluation visits and reviewed relevant sections of the final report, and contributed to the overall theming and modelling.
Supporting Evaluators	Mhoira Leng	Makerere University (Lead Partner)	The supporting evaluators all reviewed relevant sections of the final report, and contributed to the overall theming and modelling. They also each had a specific role in the final evaluation visits, as described below.
	Kaly Snell	UCL Zambia (Independent)	
	Jenny Hunt	Palliative Care Social Work Consultant (Independent)	
	Emily Kamugisha-Ssali	APCA (Lead Partner)	

Figure 3: Country Evaluators

Country	Evaluators	Date
Kenya	MM (UoB)	April 2015
	ML (MPCU)	
Zambia	JH (Independent)	May 2015
	KS (UCL mentor)	
	ML (MPCU)	
Uganda	E K-S (APCA)	May 2015
	JD (MPCU)	
Rwanda	JH (Independent)	June 2015
	JD (MPCU)	

Mairead Murphy, the lead independent evaluator, carried out the first set of visits in Kenya with Mhoira Leng. In this first visit the qualitative evaluation data was collected and the templates tested and refined. Mhoira Leng then supported Jenny Hunt and Kaly Snell with the evaluation visit in Zambia, and Emily Kamugisha-Ssali / Julia Downing carried out Uganda and Jenny Hunt/Julia Downing Rwanda. These teams ensured that there was consistency through the evaluations, with the same interview templates used, and the approach passed on between those evaluators who did more than one visit. It also ensured that each visit had a representation of independent evaluators and evaluators from the steering group.

1.4.3 Data Sources Used

This evaluation used the following data sources and methods:

Final Evaluation Report

1. Evaluation Qualitative Interview data x12
2. Baseline and End of project questionnaires x12
3. Interim Referral Pathway Documents x12
4. Presentations and final country wrap-up meetings x12
5. Mentor end of project questionnaires
6. Indicators Report

The Indicators report drew, in addition to 1 – 4 above, on the following data sources

7. Immediate and six-monthly pre and post course assessments
8. Most Significant Change Stories
9. Training Reports
10. Conference Reports
11. Mentor Manager and Mentor Reports

Additionally, the evaluation drew on published papers and reports. Through this report, where data was drawn from published reports, these are referenced in an endnote. Where information was drawn from the evaluation data listed above, the information source is referenced in a footnote.

1.4.4 Evaluation Objectives

The objectives of this evaluation were as follows:

1. To describe the models of care implemented in each of the hospitals (Section 3)
2. To report on project indicators and describe the extent to which they have been achieved. (Annex 2 / Section 4)
3. To describe the most important changes which occurred from the point of view of the project local implementers. (Section 5)
4. To describe the benefits which were realised for UK mentors and learnings which could be brought back to the UK (Section 6)
5. To describe the key ingredients which led to positive changes in hospitals and their communities. (Section 7)
6. To identify challenges for sustainability, lessons learned and areas of improvement. (Section 8)
7. To provide recommendations for implementation of similar projects in the future, including identifying the characteristics and components of the programme that

contribute to countries achieving national integrated PC as called for in the WHA resolution. (Section 9)

2 Countries of Operation

The four countries in this project, namely Kenya, Rwanda, Uganda and Zambia were described and categorised on a scale of 1-4 (1 – no known care- 4 comprehensive integration) in the report in the WHO/WPCA Global Atlas on palliative care published in 2014. The country with most advanced palliative care integration was Uganda, placed in Group 4b which has hospice and palliative care services at advanced integration into mainstream service provision. Kenya and Zambia were in Group 4a in the Atlas with hospice and palliative care services at preliminary integration into mainstream service provision. Rwanda on the other hand was in Group 3a with isolated palliative care provision. [20] According to the morphine consumption per capita data developed based on the International Narcotics Control Board data of 2012 and published by the Pain & Policy Studies Group University of Wisconsin Carbone Cancer Center WHO Collaborating Center in July 2015, only Uganda of the four countries was listed in the top 20 African countries in the fourth position.
The descriptions which follow are based on the best-known information as of project end, at May 2015.

2.1.1 Health System in Kenya

A: Population and Health Service Profile

Kenya has five medical health workers per 10,000 population. [25] Challenges to the health sector include a high staff attrition rate[26] and an increasing population (3%).[25] There is also an increasing burden of NCDs, increasing mortality due to violence/injuries[25] and an HIV prevalence of 6%. [27]

B: Structure of the Service

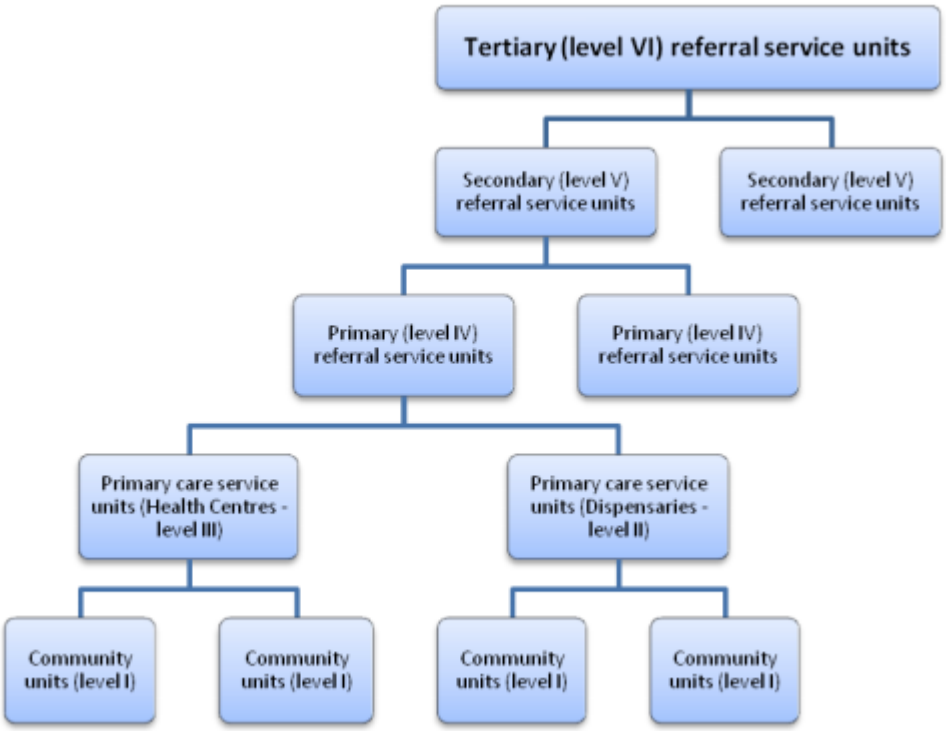
In 2010, the Government of Kenya enacted a system of devolved governance, which involved, inter alia, the devolution of the Kenyan health system to county level. Through this devolved structure, the country is refocusing on primary health services. The county roles include financing and staff employment. However, the education and regulation role remain with the central government. Each of the 47 counties now has its own MoH. These County MoHs hold their own budget, and are responsible for county health facilities and public health. National MoH are in charge of health policy, national referral health facility and capacity building and technical assistance to the countries.[25]

The first level of the health system is the primary care service units, which are comprised of level II (dispensaries) and level III (health centres). Level VI and V facilities are primary and secondary referral services, which allow a more comprehensive package of services. The tertiary level hospitals, (level VI facilities) provide specialised services and training.

Although not yet fully operational, The HSSPII has a vision that the foundation of the health service should be the “community unit”, which are population, rather than facility-based,

entities and work via a community volunteer and reporting system which uses the community unit to monitor health and sanitation problems, and also to link households at the community level to health facilities. This is shown in the diagram below.

Figure 3: Kenyan Health System



Source: Kenya Health Sector Strategic and Investment Plan: July 2013 – June 2017

On average, for every 5,000 population a community unit needs to be established, which would require over 8,800 to cover the entire population. [25] As of 2012, 439 community units were active. The target is to increase this to 3,000 by 2015. A UNICEF evaluation of the community health strategy noted that it was effective in increasing community access to healthcare. It also noted some practical difficulties in implementing it, including the need to incentivise and motivate the unpaid community health workers on which it is built. [28]

C: Financing

With the devolved system, the level VI hospitals receive a percentage of funds from the central government and supplies. The level V hospitals plan and budget for medicines from the hospital budget, forwarded to the county for approval before ordering for medicine from KEMSA. Morphine powder is included in the essential medicines list.

2.1.2 Palliative Care in Kenya

PC services began in Kenya 25 years ago with the development of Nairobi Hospice in 1990 in response to the growing needs of cancer patients in the country. By 2006 there were six established hospices in the country, with PC teams in two mission hospitals. The national PC association – KEHPCA (Kenya Hospice and Palliative Care Association) was formed in October 2004 and officially launched in 2007 with the aim to support the development of PC in Kenya.

Because of this established presence, Kenya was categorised in 2014 as 4a (preliminary integration) in the Global Atlas for PC. [20] However, coverage for PC provision across the country remains poor, most of the PC services are understaffed with very low human resource capacity, limited medicines, limited funds and logistics.

The Government of Kenya is supportive of PC, and is working closely with KEHPCA to ensure that effective policies are in place and appropriate medicines and other resources are available. PC services are recognised as part of the essential package of services which should be provided at county level hospitals.[29] There is a need for essential medicines, such as oral morphine to be available in Kenya, as highlighted in a recent report by Human Rights Watch[30], which reported how the government had failed to provide pain medication, showing that only 7 out of 250 public hospitals (2.8%) actually had oral morphine available.

2.2 Rwanda

2.2.1 Health System in Rwanda

A: Population and Health Service Profile

Rwanda has an estimated population of 11 million living in an area of 26.338km^2, a density of 350 inhabitants per km^2. Its economy is mainly agrarian though only 8.3% of the population live in rural areas.[31] The doctor patient ratio is about 1 physician to 17, 858 patients[32] although Rwanda is working towards Vision 2020 that calls for 10 medical doctors, 20 nurses, and 5 lab assistants for every 10,000 inhabitants.[33]

B: Structure of the Service

Within Rwanda, healthcare is based on a decentralised system with each Province and District having a system of health centres and hospitals. Levels of care are provided at different levels, including via Community Health Workers (Level 1), Health Centres (Level 2), District Hospitals (Level 3), Provincial Hospitals (Level 4) and Referral Hospitals (Level 5). There should be one health centre per sector, a sector being 10 villages, with each village having 2 Community Health Workers. There are 10-15 sectors in a District and there are 30 district hospitals. There are five provinces within the country and it is anticipated that there will be a provincial hospital in each of these. The majority of the referral hospitals are in Kigali, including the Centre Hospitalier Universitaire de Kigali (CHUK), King Faisal Hospital and the Military Hospital. There is also a referral hospital in the South of the country. There is a clear system of referrals

between the different levels of health care, and individuals are referred from one level to the next e.g. from level 2 to level 3 or level 3 to level 2. Normally individuals are referred to the next level and will not miss a level i.e. they will not be referred from the health centre to the provincial hospital, but from the health centre to the district hospital. Patients are only permitted to stay for 3 days in level 2 health centres and health workers are not allowed to intentionally permit patients to die in these health centres, but must transfer them out. This creates challenges for long-term PC service delivery and PC organisations are advocating to change this. There also exists an opportunity for strengthening community and home based PC systems.

C: Financing

All Rwandans, including patients with NCDs, are covered by the national health insurance meaning patients pay 10% of the fees for their services. However, in order to ensure that the 90% of the cost of care is paid by the national health insurance, referrals must be made through the national referral system, unless there are existing MoUs which enable other referrals to be made.[1]

2.2.2 Palliative Care in Rwanda

PC services were introduced relatively recently to Rwanda. In 2004 two nurses from Rwanda were supported to undertake the PC diploma at Nairobi Hospice in Kenya and to attend the first APCA PC conference in Tanzania. Subsequently the first introductory PC course was held for health professionals from hospitals and NGOs in 2006, organised by King Faisal Hospital and SWAA-Rwanda, funded by Help the Hospices through APCA.

Rwanda has made significant strides in recent years in the development of PC, and was the first country in Africa to develop a stand-alone national PC policy, which was launched in April 2011 together with a national PC strategic plan and standards.[34] Rwanda was categorised as 3a (isolated provision) in the 2014 Global Atlas for PC.[20]

The Palliative Care Association of Rwanda (PCAR) was established in 2006 in order to ensure the promotion and provision of acceptable, accessible and affordable quality PC throughout Rwanda. In 2010, Kibagabaga Hospital commenced the provision of PC through its integration into their services, initially with children, and then for adults as well. Similarly, the PCAR opened the Rwanda hospice and PC centre operating from the Kimironko Health Centre, Gasabo District. It provided home based care for patients with HIV/AIDS, Cancer and other life-limiting illnesses and their families from Kigali City and worked closely with the team at Kibagabaga Hospital. In 2013 the first in patient unit, the Centre for Palliative Care St John Paul 11, was opened in Kabuga with 22 beds and supported by the Polish congregation Sisters of Angels.

[1] Kibagabaga referral pathways document

In 2013, a second National Organisation was formed, the *Rwanda Hospice and Palliative Care Organisation (RHPCO).* During the period of the *Integrate Project*, this organisation developed an MoU with the Rwanda Ministry of Health (RBC) to provide home-based care services.

2.3 Uganda

2.3.1 Health System in Uganda

A: Population and Health Service Profile

The system of local government in Uganda is based on the district as the unit. A district is led by an elected local council V (LCV) Chairperson and an Executive. At district level, health services are co-ordinated by the District Health Officer (DHO). Districts are comprised of a number of ***counties***, which are in turn broken down into ***sub-counties***, ***parishes*** and ***villages***, each with their own elected Local Councillor, or Local Council. At a higher level, districts belong to regions.

B: Structure of the Service

The Uganda health facilities follow the government administrative system structure on a referral basis, with health facilities further up the referral ladder carrying the highest disease burden.

Figure 4: Table showing Government Health Facilities in Uganda [14], [15], [16]

Health Facility / Resource	Level	Description of resource and services which should be offered
Village Health Teams	Village/Zone	Volunteers at village level, who refer to health facilities. They do not have medications and are not functional in all places.
Health Centre II	Parish	Treatment of common diseases, immunization, ante-natal led by an enrolled nurse plus 2-4 other health workers
Health Centre III	Sub-County/ Division	HCII plus inpatient/maternity led by a senior clinical officer working with approximately 18 staff.
Health Centre IV	County/ Municipality	Provides HCIII services plus surgery. According to policy each district should have at least one of these although some do not. Some districts have more than one.
District General Hospital	District	Hospitals managed by general doctors: catchment of around 500,000 people.
Regional Referral Hospital	Region	Specialists in limited fields. They are also involved in teaching and research. There are 13 of these. Each has a catchment of around 2 million people.
National Referral Hospital	National	Provide comprehensive specialist services, health research and teaching. Each has a catchment of 30 million people (whole population). There are two of these, Mulago and Butabika (mental health).

The number of districts has doubled in the last 10 years from 56 to 112. Because of this, all districts do not have the targeted number of health services, but a programme of upgrading facilities is in place.

C: Financing

Health funding has been decentralised, with the DHO holding the district health budget. [35]

2.3.2 Palliative Care in Uganda

PC services have been developing in Uganda since 1993, when Hospice Africa Uganda started work in Nsambya Hospital.[36] Since then there has been great development in PC within the country, with PC being provided by a number of specialist organisations such as Hospice Africa Uganda (including Little Hospice Hoima, and Mobile Hospice Mbarara), Mildmay Uganda, Kitovu Home Care Team, Jinja Hospice and Joy Hospice. PC has also been integrated into the health system through the development of PC services in some district, regional and national referral hospitals, such as the Mulago Hospital/ Makerere PC Unit.

The Palliative Care Association of Uganda (PCAU) was established as a professional association in 1999 and later as an NGO in 2003 in order to support and promote the development of PC and PC providers. They work within the national framework for PC set out in the National Health Sector Strategic Plan and are mandated with scaling up PC throughout Uganda in conjunction with the MoH. PCAU undertook an audit of PC services in Uganda in 2009.[37] At that time, 32 out of 80 districts were offering PC and services were provided by regional referral and district hospitals, mission hospitals and some NGOs. 50 facilities were known to be providing PC across the country with services ranging from pain control and symptom management to bereavement services. 32 districts had oral morphine available, and many challenges for PC provision were identified. Since then, the number of districts providing PC has increased, but it is still not available in every district.

The Government of Uganda is supportive of PC, and is working closely with PCAU. Uganda was the first country in SSA to change the regulations so that PC trained nurses could prescribe oral morphine in order to increase accessibility and availability. PC has also been included in the Health Sector Strategic and Investment Plan (HSSIP) 2010/11-2014/15[35] and a PC policy has also been drafted.[38] Because of such integration, Uganda was categorised as 4b (advanced integration) by the 2014 Global Atlas for Palliative Care.[20] However, whilst much has been achieved in Uganda over the years, and Uganda is often seen as an example for PC development, the reach of PC across the country is still limited, and more needs to be done to ensure access to PC for all Ugandans, wherever they live in the country.[39]

2.4 Zambia

2.4.1 Health System in Zambia

A: Population and Health Service Profile

The health service system in Zambia is largely government driven with a significant contribution from Faith-Based Organisations and other private health care providers. The public health system is under the authority of the MoH and it plays a major role in health service provision, including prevention and research. The Churches Health Association of Zambia (CHAZ) provides about 35% of national healthcare but significantly provides 59% of health care in rural areas. There are also private-for-profit health care providers who constitute a smaller group, existing mostly in the very urban centres.

B: Structure of the Service

The Zambian public health care system is pyramidal, cascading down from tertiary institutions to provincial and other general hospitals (2nd level), to the district and other mission hospitals (1st level) which relate to the health centres and/or directly to the local communities and/or community based facilities. These institutions are described below:

First Level Hospitals: These are found in most, but not all, of the 72 districts and are intended to serve a catchment population of 80,000-200,000 with medical, surgical, obstetric, and diagnostic services and with all clinical services to support health centre (and health post) referrals.

Second Level Hospitals: These are general institutions at the provincial level. They are intended to serve a catchment population of 200,000 – 800,000 with capacity to provide services in internal medicine, general surgery, paediatrics, obstetrics and gynaecology, dentistry, psychiatry and intensive care. These hospitals are also intended to act as referral sites for first-level institutions, including the provision of technical backup and training functions.

Tertiary Hospitals: In addition to the national University Teaching Hospital, there are five tertiary hospitals, each serving a catchment population of 800,000 or more. They have sub-specialisations in internal medicine, surgery, paediatrics, obstetrics and gynaecology, intensive care and psychiatry. They have infrastructure for training and research.[40]

The table below shows the structures and responsibilities of the various levels of the health system.[41]

Table 1.2: Structures, roles and responsibilities in Zambia's decentralized health system

Level	Unit of the structure	Roles / Responsibilities
Central level	Ministry of Health (HQ)	Policy and regulation
	Central Board of Health	Implementation and purchaser of services (through contracting with DHMTs and Hospital Management Teams
Provincial level	Provincial Health Office	Administrative decentralization link between the central & district level ??
District level (hospital level)	District Health Management Team Hospital Management Teams	Technical support to the provision of services Support to hospital management
	District Health Board Hospital Management Board	Strategic orientation, decision making
Health centre level (community level)	Health Centre Committees	Community Participation to the management of health centres
	Neighbourhood Health Committees (NHCs)	Community participation in Health

C: Financing

By 2006, 42% of the health sector expenditure was coming from donors, 27% from households, 24% from government, 5% from employers and 1% from others.[42] The current Government costs for health is about 60% of public health funds.[40] There were also a number of parallel projects and vertical programmes, and the national health strategic plan for 2011-2016 has acknowledged the importance of integrated rather than vertical services in order to improve efficiency of services.

2.4.2 Palliative Care in Zambia

PC services have been in existence in Zambia since 1997, with the inception of Mother of Mercy Hospice, Chilanga. Over subsequent years islands of community supportive and PC services have evolved. These services were largely faith-based or NGO run, and were, unusually for SSA, characterised by the prominence of the inpatient unit.[43] Due to funding cuts in recent years, many of these inpatient services had to curtail operations or even close. Some are now reopening adapted services with MoH financial support. The Palliative Care Alliance Zambia (PCAZ) was established in 2004 to support integration of PC services in Zambia through training, advocacy and standards setting. [44] In 2008, a situational analysis co-ordinated by PCAZ highlighted that PC remained 'an essential absent factor'. [44] The report found that Zambia could benefit from developing in all four aspects of the World Health Organisation's (WHO) pillars of establishing PC access.[5]

Since the report, PC has been recognised as an essential component of the HIV/AIDS continuum of care in Zambia.[40] PCAZ are part of a working group helping the government to develop policy on PC. Indeed, it is included in the draft National Strategic Health Plan 2016 – 2020. PC is also a component of the consolidated National Health Policy for Zambia. Implementation of this policy will be directed by the National PC Strategic Framework – the current draft is under review with the MoH. PCAZ have also been involved in training across

the country, with the launch of an introductory national PC training package. PC has also been incorporated into the national community volunteer training. Zambia, similar to many countries worldwide, had PC services existing in 'islands of excellence'.[20] Crucially PCAZ, was already working closely with the MoH to institutionalise PC and this is the context in which the ***Integrate Project*** was able to develop.

2.5 Selection and baseline description of the 12 centres

The project worked with representative hospitals from each country.

The hospitals were selected by the national associations in consultation with the MoH. The following criteria were used in the selection process:

1. The three hospitals were to be at different levels of service provision
    a. One district hospital in the early stages of setting up formal PC services
    b. One provincial/regional hospital that could support the district level and also strengthen the linkage to teaching/ referral hospitals
    c. One teaching hospital to support the development and sustainability of the capacity building pillar
2. At least one of these hospitals (either the teaching hospital or provincial/regional hospital) should be providing PC services, with a potential for developing a clinical placement site.
3. The selected hospitals should not be having similar funded activities.
4. The hospitals should have morphine available or permissible to be used.
5. The hospitals should be close to a developed clinical placement site i.e. hospice or hospital (where these exist in the country)

The hospitals were expected to sign a memorandum of understanding with the national association affirming their interest in the project. The project activities in the hospital were supported by experienced PC professionals from the UK via the UK mentorship hubs.

2.5.1 National Referral Centres

Three national referral centres were chosen. Two of these: CHUK in Rwanda, and UTH in Zambia are the main national referral hospitals in the country. The main national referral hospital in Uganda (Mulago) and in Kenya (Kenyatta) already had established PC units at the start of the project, and were therefore not selected for inclusion. In Kenya, the second national referral hospital – Moi Teaching and Referral Hospital (MTRH) - was selected instead. In Uganda, two regional referral hospitals were selected (see following section) and no national centre was selected in Uganda.

The national level hospitals have size and complexity in common. They are also all established and credible teaching institutions associated with large universities.

Figure 5: National hospitals

County	Hospital	Beds
Kenya	Moi Teaching and Referral Hospital (MTRH)	800
Rwanda	Centre Hospitalier Universitaire Kigali (CHUK)	600
Zambia	University Teaching Hospital (UTH)	1,600 – 1,800

Kenya: Moi Teaching and referral hospital

MTRH is a busy, large and complex 800-bed hospital with all major medical specialties. It is the second national referral hospital in Kenya, the first being Kenyatta, in Nairobi. It is the national referral centre for the Western region, and thus services a population of 16.24 million, covering Nyanza Province, North Rift and Western Province[45]. It describes its vision as "*to be a world class teaching and referral hospital*" with services supported by modern state of the art clinical and diagnostic equipment. [45] In February 2014 it conducted the 4th round of live donor renal transplants for the 7th and 8th patient in partnership with a surgical team from Amsterdam and KLM. On the other hand as a public hospital it cannot refuse admission and is thus overcrowded with often 2 patients per bed, some of whom are PC patients, while the bed occupancy is persistently above 110%.[2]

Centre Hospitalier Universitaire Kigali (CHUK)

Centre Hospitalier Universitaire Kigali (CHUK) is an MoH Hospital located in Kigali in the District of Nyarugenge. It is a 600-bed capacity Referral Hospital with a leading role in education of healthcare professionals in Rwanda. CHUK presently receives referrals from 40 district hospitals as well as the private King Faisal Hospital, , Rwanda Military Hospital, alongside the main psychiatric hospital and 2 further university hospitals. Changes in the health service structure may reduce the numbers of hospitals who can refer directly to CHUK to 20.

The hospital has the following departments: Internal Medicine, Surgery, Paediatrics, Gynae-Obstetrics, Emergency, ENT, Stomatology, Dermatology, and Ophthalmology. Health care staff in CHUK comprise of: 42 Doctors, 337 Nurses, 67 Midwives, 11 Social Workers, 2 Psychologists, 9 Physiotherapists, 1 speech therapist, and 1 Spiritual advisor. [3]

Zambia: University Teaching Hospital

University Teaching Hospital (UTH) is an MoH national hospital and Lusaka's main tertiary referral centre. It is home to 56 wards housing 1,600 – 1,800 beds; often with a capacity of 2,000 plus. 106 beds are allocated as 'high cost' for fee-paying patients. The four core departments are medicine, surgery, paediatrics and obstetrics and gynaecology; supported by

[2] Final mentor report
[3] CHUK referral pathways document

pathology, microbiology, radiology, pharmacy and physiotherapy. In practice UTH offers primary, secondary and tertiary level care to the district and beyond, covering a population estimated at 1,300,000. UTH is operating in a complex environment with a number of other providers and collaborators. Within the catchment area of UTH other providers include health centres administrated by the Lusaka District Health Management team (LDHMT) (including the Lusaka prison medical centre), Cancer Diseases Hospital (CDH) and Chainama (the mental health hospital). [4]

UTH compares with any big public hospital in the Southern African region. The hospital has a robust outpatient care programme with attendance of 310,527 in 2013. In the same time period 89,290 were treated as in-patients, with the most admissions in the department of obstetrics and gynaecology. (31,811).[46]

2.5.2 Regional Referral Centres

Four regional referral hospitals were chosen: one in Kenya, one in Zambia and two in Uganda. Two district hospitals were chosen in Rwanda in place of a regional hospital.

The regional hospitals vary in size, with Ndola substantially larger in size and complexity than Kabale. They all have a teaching component, although Kabale has been upgraded to include this only very recently.

Figure 6: Regional hospitals

Country	Hospital	Beds
Kenya	Nyeri County Teaching and Referral Hospital	300 [5]
Uganda	Gulu Regional Referral Hospital	300 [6]
Uganda	Kabale Regional Referral Hospital	250 [7]
Zambia	Ndola Central Hospital (NCH)	800 [8]

Kenya: Nyeri County Teaching and Referral Hospital

Previously “Nyeri Provincial General Hospital”, this has recently been upgraded to “Nyeri Country Teaching and Referral Hospital”. It is a level 5 hospital (secondary) in the central province, of Kenya. It has a bed capacity of 300 and serves five districts within the region and other neighbouring districts. It serves a population of 234,500 people, among whom there is a high prevalence of hypertension, diabetes and heart diseases.

[4] UTH referral pathways document
[5] Confirmed by APCA, August 2015
[6] Confirmed by APCA, August 2015
[7] Confirmed by APCA, August 2015
[8] Ndola Referral Pathways document

There are approximately 48 doctors working at the hospital, 289 nurses, and 100 other health workers.[9]

Uganda: Gulu Regional Referral Hospital

Gulu is a regional referral hospital and therefore accepts referrals from seven districts, serving a wide catchment area in the Acholi sub-region of northern Uganda (1.5M). The hospital faces challenges in terms of the high number of patients and the pressure on trained staff. [47] This sub-region is still recovering from years of war with the LRA.

There are two district hospitals within the region, plus St Joseph's Kitgum, the military hospital in Gulu, and the nearby Lacor Hospital. Inmates are also brought here from the local prison and referred where necessary to Murchison Bay Hospital. The hospital is funded from the national level, not the district level. It has approximately 300 health workers.[10] It serves as one of the two teaching hospitals for Gulu University.

Uganda: Kabale Regional Referral Hospital

Kabale Regional Referral Hospital is a busy MoH Hospital located in Kabale District in the south west of Uganda. It is a regional level hospital with 250 beds [11] but according to need often houses many more. The hospital wards include: a TB ward, Maternity ward, Psychiatric ward, General Surgical ward, General Medical ward and Paediatric ward. 500 outpatients are also seen daily Monday to Friday within the hospital. There is also a newly opened Private ward with 50 beds. The MoH employ 1 physician, 2 surgeons, 2 gynaecologists, 1 medical officer and 9 clinical officers in the hospital. The recent addition of a physician to the hospital has significantly reduced the number of referrals now made to Mulago Hospital in Kampala. An NGO funded HIV programme supports a further 3 medical officers and 1 clinical officer. Within the catchment area served by the hospital there are several other hospitals, some MoH and some NGO run hospitals. There are 8 Level Four Health Centres, and 23 Level Three Health Centres.[12] The hospital is in the process of being upgraded to a teaching hospital for Kabale University[48]

Zambia: Ndola Central Hospital

[9] Referral Pathways Document
[10] Final Evaluation Data
[11] Confirmed by APCA, August 2015
[12] Final Evaluation Data

Ndola Central Hospital is one of five MoH tertiary institutions in Zambia including the national referral hospital. It is a university teaching hospital, under the Copperbelt University, the second largest health institution in Zambia and is a referral centre for the northern part of the country.[49]

Ndola is located in the Copperbelt province of Zambia and is 350 kilometers from central Lusaka. It is an adult-only hospital with 800 bed capacity and inpatients tend to range beyond the bed capacity. Children's services are provided in a nearby children's hospital. The hospital has 3 departments and serves a catchment area of 514,000 people covering 21 health centres. Currently, there are 45 doctors working at the hospital, 62 intern doctors, 369 nurses and midwives, physiotherapists, 3 nutritionist, 11 pharmacists, 9 intern pharmacists and 101 paramedics alongside the administrative and support staff. [13]

2.5.3 District hospitals

Five district hospitals were chosen: two in Rwanda and one in each of the other three countries.

Figure 7: District hospitals

Country	Hospital	Beds[14]
Kenya	Homa Bay Country Referral and Teaching Hospital	300[15]
Rwanda	Rwanangama Hospital	220
Rwanda	Kibagabaga Hospital	230
Uganda	Gombe General Hospital	100
Zambia	Mazabuka District Hospital	160

Kenya: Homa Bay County Referral and Teaching Hospital

Homa Bay Hospital is a MoH District Hospital in Homa Bay District, Nyanza province. It is a 300 bedded hospital and offers a range of services including antenatal, ART, emergency obstetric care and caesarean sections, curative in and out- patient care for adults and children, family planning, HIV counselling and testing, home based care, integrated management of childhood illnesses, Prevention of mother to child transmission of HIV, Radiology services, TB care and youth friendly services. The hospital serves a catchment area of 57,000 people over 1,160 square kilometres covering 37 district health centres. There are approximately 13 doctors working at the hospital, 118 nurses, 1 social worker, 3 physiotherapists, 1 occupational therapist, 1 spiritual advisor alongside the administrative and support staff.[16] As of 2015 it is being upgraded to a county referral and teaching hospital (Level 5)

[13] Ndola Referral Pathways document
[14] Referral Pathways documents source for all of these apart from Homa Bay
[15] Confirmed by APCA, August 2015.
[16] Homa Bay referral pathways document

Rwanda: Rwamagana Hospital

Rwamagana Hospital is currently a MoH District Hospital (level 3) located in the Eastern Province of Rwanda with a catchment area of 330,000. It is anticipated that it will become a provincial hospital (level 4) but they are awaiting the necessary legal changes to enable this to happen – this will probably not happen until next year. There are 218 beds in the hospital and it has a new emergency unit and laboratory. They have 198 staff in total, with 20 doctors (including 7 interns) and around 90 nurses although this is set to increase as the hospital becomes a provincial hospital. Some of the doctors move on each year as they tend to go for their specialisation training in October. The hospital has 4 main departments (surgery – 1 ward, internal medicine – 3 wards, paediatrics – 1 ward, maternity – 3 wards including gynaecology), a private ward, and an Outpatients department that sees around 30-60 patients each day. The hospital supervises 14 health centres, and the health centres then supervise the VHTs in the community. They receive nursing and medical students from the new University of Rwanda. [17]

Rwanda: Kibagabaga Hospital

Kibagabaga Hospital is a MoH Hospital located in the Province of Kigali City. It is a District hospital with a 230-bed capacity. The hospital has four main departments along with MDR-TB and PC. The hospital serves a catchment area of 485,475 which covers 16 health centres and 489 villages. There are 18 doctors (5 specialists and 13 general physicians), 142 nurses and 13 social workers.[18]

Uganda: Gombe General Hospital

Gombe Hospital is a MoH District Hospital located in Gombe, Butambala in Central Uganda. It has 100-bed[19] capacity, and an average of 180 patients daily. The hospital has six departments – male, female, maternity, paediatric, outpatients and the ART department. The hospital serves a catchment area of 250,000 people, supervising 21 health centres. It receives around 1,200 referrals and refers 200 cases to Mulago national referral hospital each year. It is led by the medical superintendent, who is answerable to the district and also the Senior Principle Nursing Officer (nurse manager).

Zambia: Mazabuka District Hospital

Mazabuka General Hospital is located in the Southern province of Zambia, 120 kilometres from central Lusaka. It has been a MoH district hospital (primary level) for 40 years and was appointed as a general hospital (secondary level care) in 2014. It currently has a 160-bed

[17] Final Evaluation data

[18] Final Evaluation Data

[19] Confirmed by APCA, August 2015

capacity, although total number of inpatients tends to range from 70-120 patients. The hospital has five wards: male, female, labour/maternity, paediatric and isolation, along with a physiotherapy department, ARV clinic, antenatal clinic, mother and child clinic and general outpatients department. As of 2014, there were approximately 3 doctors working at the hospital, 1 medical licentiate, 7 clinical officers, 70 nurses, 25 midwives, 6 physiotherapists, 1 nutritionist, laboratory and pharmacy staff. Staff numbers were expected to increase over the following year. Staff attrition and movement is common. The hospital serves a catchment area of 275,000 people covering 32 rural health centres. Mazabuka district houses three parishes, with 22 church-funded Home Based Care (HBC) teams across three parishes. HBC is largely operated through community volunteers.[20]

[20] Final Evaluation Data

3 Integrated Palliative Care Service Models Implemented

3.1 Overview

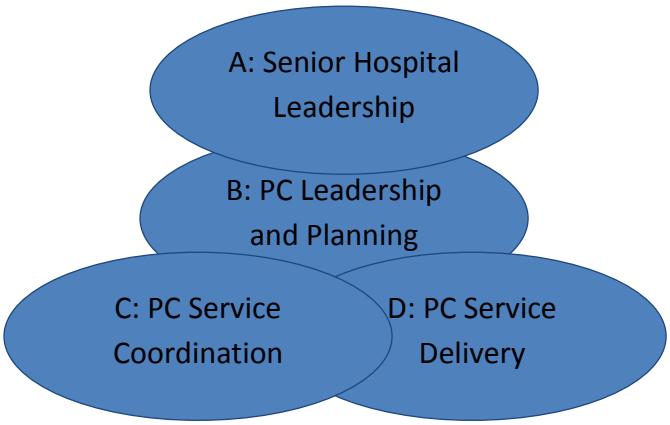
This section describes, for each hospital, the way in which that hospital is delivering a PC integrated service. There is one section for each hospital. The service delivered depends, inter alia, on the type of hospital (district, regional or national), the legacy of PC within the region, the structure of hospital leadership and staffing, country and district policy, hospital resources, the primary care system and the vision of the hospital for PC. Each is, therefore, unique, with no two hospitals having the same approach to integrating PC within their health system.

We have nonetheless noted common approaches and ingredients of success to the integration of services across the 12 hospitals. We have used two frameworks to describe these common approaches: 1) organisational components, and 2) PC processes. These are described below, and are referred to in each of the hospital specific sections.

3.2 Integrated Palliative Care Organisational Components

The successful integration of PC in all 12 hospitals depended on 4 organisational components being in place. These 4 components are shown in Figure 8 below.

Figure 8: Hospital Team Integrated Palliative Care Organisational Components



The diagram shows the organisational components within the hospital. It does not include other important partners: for example community partners or the MoH. This is because the purpose of the diagram is to show operational components of palliative care teams. The overlaps in the Venn diagram illustrate the overlap in the human resource executing these organisational functions: all PC programmes had senior hospital leadership commitment, some senior hospital leaders and managers have an active role in PC leadership and planning;

some core PC staff may be involved in all 3 areas of leadership and planning, service coordination and service delivery. This is described further in points A – D below.

A: Senior Hospital Leadership

The first organisational component is leadership for PC within the hospital. It is important that this leadership comes from the senior hospital management: i.e. the medical superintendent, head of nursing and hospital executive team. In all of the 12 hospitals, the successful implementation of the project depended on senior hospital management being engaged to:

1. Give final approval of PC presence and work within the hospital;
2. Open and close major project events within the hospital such as training and workshops to add credibility and importance to these events;
3. Liaise with and invite important external stakeholders into activities;
4. Give permission for staff to attend training and offsite events;
5. Commit hospital resource as a contribution to project, such as staff time and facility space for training;
6. Approve protocols and guidelines for use in the hospitals.

B: Palliative Care Leadership and Planning

The second organisational component is specific leadership for PC. This is a key ingredient for the ongoing sustainability of services and involves advocating and planning for PC, and steering the implementation and embedding of PC services. It also involves working to scale-up PC in the surrounding area, liaising within the hospital and with partner organisations to ensure the vision for PC is implemented. While some of this leadership comes from hospital management, in some hospitals, the senior management had named an "executive team" to carry out this role. The members of this team often include senior staff: for example management, in-charge nursing staff and doctors. These people often carried out service co-ordination and delivery roles (see C and D below) as well as that of leadership and planning.

C: Palliative Care Service Co-ordination

All hospitals had implemented a coordinating component, which was a named role, a designated individual or set of individuals who coordinated PC services on a day-to-day basis within the hospital. This function included:

1. Coordinating the range of PC provision, ensuring patients were admitted, identified for care, and linking with other staff members such as social workers and physiotherapists;
2. Managing the patient pathway through receiving and giving referrals within and outside the hospital;
3. Acting as the contact person at the operational level;
4. Overseeing data collection e.g. morphine usage;

5. Coordinating staff appraisals and staff assessments of their practice;
6. Liaising with National Associations;
7. Attending meetings on behalf of the hospital management;
8. Delivering sensitisation and advocacy activities at the hospital level.

Many hospitals referred to this coordinating service as their "PC Unit." regardless of whether there was a geographical physical presence in the hospital.

D: Palliative Care Service Delivery

All hospitals had implemented an effective model of PC service delivery. The staff members who took coordinating and leadership and planning roles were normally an essential part of this, and were actively engaged in providing PC services within the wards and within the unit if present, as well as supporting other staff to provide PC through modelling.

All models were integrated, and operated a service delivery model which included an extended team of staff, being those staff who have been trained in PC and who provide PC throughout the hospital integrated into their regular jobs. These staff linked with the PC coordinating function to do this. Different models of this were used, such as focal persons in each ward, link nurses, or a critical mass of trained staff across the hospital.

3.3 Palliative Care Coordination and Service Delivery Processes

We noted three broad models of PC coordination and service delivery within the hospitals. These are described below:

1. **Dispersed integrated palliative care team**: This team consists of identified staff who are recognised as a core PC team, who connect with each other, and who provide a service including receiving referrals. They may have PC in their job descriptions, but do not have a substantial amount of time dedicated to PC. They are authorised by supportive management to provide PC, and act as a clinical focal point within the hospital. They may have a physical space/office identified which acts as a hub for receiving referrals, and gives PC an identity within the hospital.
2. **Dedicated palliative care team/individual with integrated support**. This model has at least one staff member with a substantial amount of time dedicated to PC. Working with this staff member are other staff whose core remit is wider than PC but who deliver to PC objectives. The team has physical space, coordination and referral pathways, with links to the rest of the hospital through other trained staff.
3. **Specialist integrated palliative care unit**. This team consists of multi-disciplinary members some of whom have dedicated time offering specialist clinical care as well as

training. The team can show clear referral pathways in and out of the unit. These units may be hosted in a specific department.

The models represent different ways of implementing a service, rather than a continuum. A fully integrated service is possible with any of these three models, and the type of model implemented will depend on the hospital resource and vision as well as the needs of the population and position within the health system. We also recognise that there is much variability within each of the three models. In the section that follows we therefore have categorised each hospital according to one of these models for cross-comparison purposes, but also provide a detailed textual description of how the integrated PC service was implemented.

3.4 Format of this Section

The remainder of this section describes the model of integrated PC implemented in each hospital. Each of the 12 sections is formatted as follows:

A: History of Palliative Care prior to the *Integrate Project*: This section outlines the history of PC in the hospital prior to the implementation of the *Integrate Project*.

B: Implementation of the *Integrate Project*: This covers how the hospital implemented the project, including any modifications made to the activities to fit with local needs.

C: Palliative Care Team: This section describes the PC team as it operates and is named within the hospital.

D: Model of Service: This gives a description of how the model works in terms of how the teams interact and the referral pathways.

E: Services provided: This section gives an overview of the PC services provided through the model outlined in D above. This information was largely taken from the end of project questionnaires completed by each hospital, which asked questions about services provided. We have reported this information as provided by the hospital, though it has some limitations. For example, although all hospitals stated they provided bereavement support, this was minimal in some cases. Also, the social support services on the questionnaires focussed on material social care, rather than wider aspects, such as hospital provision family sessions, attention to family relationships and social network supports. Where additional information was given in the evaluation interviews, this is also included within this section.

F: Medicines: This section describes the essential PC medicines available at the hospital.

G: Reach into the Community: This section describes the extent to which the hospital referral pathway and PC services reach into the community either directly, through NGO partners or through referring health centres.

H: Future Vision for Palliative Care: This section covers how the PC leadership sees the service evolving within the hospital in the coming years and includes concrete next steps and plans where possible.

I: Lessons learned from this hospital: This describes particular lessons learned from this hospital, including exemplars of good practice which could be used for similar hospitals implementing integrated PC services.

3.5 National Referral Hospitals

3.5.1 Kenya: Moi Teaching and Referral Hospital (MTRH)

Hospital level:	National	Beds	800[21]
Location:	Eldoret	Population	16.24 million[22]
Hospital level description	MTRH is a Level VI hospital (tertiary referral centre). It is the second national referral hospital in the country after Kenyatta in Nairobi and is a teaching hospital in associate with Moi University		
PCU History	Established since 2010		
PC Organisational Components	Palliative Care Unit team of 3, responsible for coordination, service delivery and planning (supported by deputy chief nurse). Services provided by trained staff including focal staff on particular wards. (see C below for details)		
PC service delivery	Specialist Integrated Palliative Care Unit (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

The hospital established an adult PC unit in 2010, extending to a paediatric service in 2011. The unit is housed within the haemato-oncology service. The nearby Eldoret Hospice has been in existence since 1994, so PC has been available in the area for much longer than this. However, the catchment of Eldoret Hospice is much smaller than MTRH and it has limited capacity.

B: Implementation of the *Integrate Project*

MTRH implemented the *Integrate Project* in line with their overall vision, to be a centre of excellence in provision of PC services in Western Kenya Region. Under the leadership of the

[21] MTRH referral mappings document / Confirmed by APCA August 2015
[22] MTRH baseline questionnaire

deputy director of nursing, they adjusted the programme of activities to fit their needs as follows:

1. They developed a ***modular training programme*** to replace the standard ToT. Each of 3 modules had a classroom component followed by practice-based implementation supported by mentorship, with the aim to build capacity and sustainability within the hospital setting. It included basic training, ToT, research, M&E and psychosocial issues. 81 people were trained in at least one module.
2. In view of the fact that they are a national referral centre, (outside the county jurisdiction), they do not have direct referral links with the community. They therefore replaced the community sensitisations with a programme of ***basic training in 5 satellite hospitals*** (their surrounding country referral hospitals) to enable them to both correctly refer, receive referrals and provide services.
3. Additionally, the hospital has carried out a number of internal trainings through CMEs, and to nursing and medical students in its role as *a teaching hospital*. During the project, PC was introduced into the undergraduate medical curriculum, and MTRH will take medical undergraduate students on clinical rotation.

Full details of the activities carried out can be found in Annex 1.

C: Palliative Care Team

The PC team has a core staffing of 5: 1 social worker (who is the focal person, responsible for running the unit), 1 clinical officer, 1 nurse, 1 medical officer and 1 administrator. The nurse is currently doing a diploma in PC funded by the *Integrate Project*, and the other team members also plan further higher study.

D: Model of Service

The deputy Chief Nurse of the hospital is the main champion for PC in the hospital, and was instrumental in implementing the service model. The social worker head of the PCU liaises with her closely in terms of training and policy. The PC team is under the day-to-day management of the doctor who heads the department of haemato-oncology. The PC unit has an office within this department and is visible and known by all in the hospital. PC patients are seen on the wards and they do not have dedicated PC beds. They have a trained person in each unit, with focal staff who have received the modular training in paediatrics, gynaecology and orthopaedics.

E: Services provided

The unit provides both inpatient care for in-patients on the wards who are referred by a clinical team and a PC outpatient service. They also have an intermittent day-care service. They do not have the capacity to carry out home visits. The hospital has morphine readily available along with most essential PC medicines. The PC service provides pain and

symptom assessment and management with opioids, counselling and psychological support, spiritual support and care to the family.

The team has well-documented referral and discharge arrangements, which include assessment by a social worker. They also have a 24/7 mobile phone hotline which is used both internally for referrals and given to all patients for follow-up after discharge. There is a good patient register system and monthly reports are submitted to both the division of oncology and the executive office. Most of the patients they see are cancer patients. This is changing with increasing sensitisation and they are also called to see patients with renal failure / cardio vascular disease and other chronic conditions.

F: Medicines

They have both oral and injectable morphine available in the hospital. Consumption of oral morphine has increased from 1,560,000mgs in 2012 to 3,200,000 mgs in 2014. As a national hospital, they order directly from their own chosen supplier, outside the government system, and do not have stock-outs. Oral morphine is made *at a dose of 10 mg per ml.* and held in the Oncology pharmacy. Nurses from other units must go to oncology to fulfil their prescriptions. Some wards are given a small stock of morphine: this is a per patient stock, not a general stock. While the PC team uses morphine, some of the wards still have a tendency to use tramadol as a step 2. Patients purchase morphine at a subsidised fee (1.50 KSH per 10 mg), which is affordable. There is a waiver system for patients who cannot afford this.

They reported no stock outs of any medication in the last 6 months of 2014, and stock all reported on the baseline questionnaire including codeine, paracetamol, aspirin, NSAIDs, cortico-steroids, benzodiazepines, haloperidol, other anti-emetics, amitriptyline, anti-diarrheal agents, laxatives, hyoscine butylbromide and anticonvulsants.

G: Reach into the Community

The nearby Eldoret Hospice carries out home visits. The deputy Chief Nurse within MTRH has recently taken a place on the board of this Hospice and they have been invited to do joint ward rounds with MTRH to pick up patients on discharge. However, Eldoret Hospice has limited capacity, carrying out 1 – 3 home visits per day. MTRH would like to have the funding to carry out their own home visits. However, as a national centre, covering the whole of Western region, they recognise that they also need to build capacity of their referring hospitals. The training they carried out in their satellite hospitals has led to the establishing of new services. Three of the five have morphine available, and at least one has developed a dispersed PC team, which receives referrals, holds monthly clinics and run their own community sensitisation programmes. MTRH continue to act as mentors to all 5 centres.

H: Future Vision for Palliative Care

The continued vision of MTRH is to be a centre of excellence in provision of PC services in Western Kenya Region. They are well-placed to achieve this vision, given their position as the national referral hospital for the area, and the leadership for PC within the hospital coming directly from the hospital management.

They will continue the specialist PC unit model. This unit will, in future, be housed within the "Cancer and Chronic Diseases Centre" which is currently (May 2015) under construction. The hospital sees training and sensitisation as an ongoing process, and plans to carry out continuous CMEs and training of nursing and medical undergraduates using the skills and IT resources acquired through the *Integrate Project*. MTRH also plans to develop their modular training into a 3 month certificate and 18 month diploma in line with their vision.

I: Lessons learned from MTRH

MTRH provides a model example how vision and leadership can overcome the challenges of integrating a PC service in a large teaching hospital. The vision of MTRH as a centre of excellence for PC services in Western Region has driven the project, and the *Integrate Project* has been used as a vehicle for supporting MTRH to implement their vision. For example, the modular style of training, which was locally driven, led to a greater number of staff with a level of expertise in PC without them having to attend a specialist course. This local ownership has ensured that MTRH are continuing to implement their vision after the *Integrate Project* has finished.

Despite the great achievements made, the deputy Chief Nurse felt that the service was not yet truly embedded, and more needed to be done to continually sensitise medical staff. MTRH faced challenges in embedding the service due to the sheer number of staff, staff turnover and the relative intransigence of the more senior medical staff in a large teaching hospital. They have used stickers, posters, a physical presence within oncology and their 24 hour hotline to increase their profile within a large hospital.

Through their vision, they recognise the benefits of being a large teaching hospital as well as the challenges, in that, even while they are facing challenges in changing attitudes in their own hospital, they can continue to have impact on a wider scale by providing in-house specialist training, continuous sensitisation and by training and mentoring satellite hospitals.

3.5.2 Zambia: University Teaching Hospital (UTH)

Hospital level:	National	Beds	1600 - 1800[23]
Location:	Lusaka, Zambia	Population	1.3 million[24]
Hospital level description	The hospital is a tertiary level hospital, and the main national referral hospital for the country		
PCU History	None documented, though some trained staff and morphine available		
PC Organisational Components	Planning lead by executive team of 4, headed by doctor in internal medicine. Co-ordination role led by dedicated nurse, supported by palliative care "team of the day". (see C below for details)		
PC service delivery	Dedicated palliative care team/individual with integrated support (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

No systematic PC services, formal or informal, are documented at UTH prior to the *Integrate Project*. A number of staff were trained under the Diana Princess of Wales Memorial Fund (DPWMF) small grants initiative, including one to diploma level. However, there no current mapping of these personnel exists. Oral morphine was available due to a combination of work from the PCAZ and the legacy of a DPWMF funded project. A detailed evaluation of the impact of this latter project is available.[43]

PCAZ had previously worked with UTH to introduce PC into the hospital system to provide a continuum of care for its predominantly community home based PC strategy. PCAZ and UTH agree that these community-driven attempts were largely unsuccessful at integrating PC, and a more hospital-driven plan, which linked with the community was required. However, the ground laid by PCAZ and DPWMF provided the crucial context into which Integrate could develop. As one senior staff member said: "The ground was ready when THET came."

B: Palliative Care Team

The team operates through a number of layers:

Palliative Care Executive: This consists of 4 staff members; a doctor chair, a matron of medicine as vice-chair, a pharmacist and a nurse coordinator. The two nurses and the doctor all have, or are studying towards, PC specialist qualifications.

Palliative Care Unit: The PC unit, as it is referred to at UTH, was made operational in April 2015. The unit consists of the nurse co-ordinator member of the executive team, who is placed in an office in the heart of the medical wards. This is a point to use as a hub for

[23] Final evaluation visit report
[24] Baseline questionnaire: national population 2010 census

referrals/advice/patient/relative meetings. The team has yet to agree or formalise a defined operational plan/model of care. They have been piloting models, described in D below.

PC Team Members: The 51 staff who were trained in basic PC are all identified as part of the PC team.

C: Implementation of the *Integrate Project*

UTH implemented the *Integrate Project* programme largely as described in section 1.3.2. 53 NCH staff were trained in the basic PC course, and 9 staff received ToT training. In addition, 17 staff received research training, and one doctor and one nurse have completed diploma level training. They have not yet carried out community sensitisation. UTH also, unusually, had a long-term mentor, a PC consultant from the UK who was placed in Zambia for 1 year. This mentor supported the integration of PC into the undergraduate medical curriculum at University of Zambia (UNZA), School of Medicine. The teaching is integrated into years 3-7 of the 7 year course, with a bulk of teaching during year 6, and includes assessment. The doctor in internal medicine, who chairs the PC team has been appointed as PC academic coordinator, since the mentor's departure in June 2015.

Full details of the activities carried out can be found in Annex 1.

D: Model of Service

The model adopted for the PC team has been evolving throughout the project, as UTH seeks to find a model which works for their large and complex set-up. It is currently still evolving. The model which has been piloted and still evolving is described below.

A PC team started in October 2014 which worked as a liaison service – to respond to the patient needs identified through their informal inputs over the preceding months. Members included all 51 who had undergone basic training and had expressed an interest to be involved. The group operated in multidisciplinary teams (MDTs) of 10 (combination of doctors, nurses, social worker, chaplain, nutritionist and other MDT members) Mon-Fri. Referrals were sent by MDT members to a central collecting point at the medical social workers office. Referrals from within the hospital are usually initiated junior doctors or nurses. The PC assessment form is kept in the patient file, a carbon copy is kept for PCU records. Any follow-up is written directly into patient file and carbon copied into PCU notes.

A 'PC team of the day' collected the referrals and tried to see the patients, in addition to their usual duties. In practice around 10 of the 51 members of trained staff were involved in this work. These initial operations were largely a pilot to further sample the need and inform the next steps. The model under which this team will operate is still evolving. The piloting showed that it was difficult to operate this model in a hospital of this size without a named co-ordinator, and the appointing of a nurse coordinator in April 2015 is a major step forward.

E: Services provided

UTH provides pain and symptom assessment and management with opioids. They are also starting to provide counselling and psychological support, spiritual support and bereavement support. The social welfare team provides some social support in the form of food and clothing, but they are unable to provide transport, legal aid or income generation either themselves or by referral. They provide palliative surgery onsite, and radiotherapy and chemotherapy is provided by the nearby CDH.

The team accepts any patient with a life-limiting illness and in need of PC. Because the team has only recently become operational, there are still low numbers of referrals.

F: Medicines

They have oral and injectable morphine available in the hospital. Oral morphine consumption has increased from 320,000 mgs in 2012 to 402,230 mgs in 2014. There was a national stock-out towards the end of the project (see Mazabuka section for details).

They do not have Amitriptyline (due to a national stock-out) or bisacodyl (patients are asked to buy their own laxatives) They stock all other PC drugs reported on the end of project questionnaire, and have had no reported stock-outs in the last six months of codeine, paracetamol, aspirin, ibuprofen, cortico-steroids, benzodiazepines, haloperidol tabs and injections, other anti-emetics, amitriptyline, anti-diarrheal agents, hyoscine butylbromide and anticonvulsants.

G: Reach into the Community

A formal referral network linking PC patients in the community to UTH and vice-versa does not yet exist. Lusaka District Medical Team (LDMT) has some nurses and doctors who have been trained in PC by PCAZ, prior to the *Integrate Project*. The weekly case discussion meeting held at UTH is open to colleagues from the Cancer Diseases Hospital (CDH) and LDMT. There is regular attendance from CDH but it has not been possible for LDMT to attend yet. As a national referral hospital, links to the community are difficult to establish, and they are still working out how to do this.

H: Future Vision for Palliative Care

The Hospital future vision for PC includes formalising the model and consolidating the recently established team within the hospital, before extending the reach.

"Palliative care can only grow here and I want it to grow. We've started with the central coordinator, then we will need leads for each dept. (surgery, med, paeds, O&G), from there we will roll into community." Medical Director

I: Lessons learned from UTH

In terms of bed numbers UTH is by far the largest hospital that was involved in this programme. It is also a complex system with a large teaching responsibility, and a wide range of diseases and diagnoses including a linked national cancer treatment centre. The experience has shown that in such a hospital, a longer time may be needed to embed services. UTH has shown little increase in morphine consumption and a relatively low number of referrals within the 3 year period. However, the establishment of the PC Unit, in the form of a central co-ordinator has been a major step forward in the context of previous efforts to integrate PC in this hospital.

Another major step forward has been the integration of PC into the curriculum. The role of the long-term UK mentor who acted as on-site specialist, mentor, trainer and advocate was significant in helping to achieve this.

3.5.3 Rwanda: Centre Hospitalier Universitaire Kigali (CHUK)

Hospital level:	National	Beds	600
Location:	Kigali	Population	1M
Hospital level description	It is a Level 5 hospital, and the main national referral hospital for the county		
PCU History	Minimal service prior to the *Integrate Project*		
PC Organisational Components [25]	Coordination and planning role carried out by team of 5: including 1 desk coordinator. Service delivery supported by 2 link nurses in each ward, plus network of hospital volunteers. (see C below for details)		
PC service delivery	Specialist Integrated Palliative Care Unit (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*:

There were minimal PC services prior to the *Integrate Project*. Prior to the project CHUK had six staff who had received some introductory training on PC, but there was no coordination to develop PC within the hospital. Most of the advances in PC in the hospital have come about as a result of the *Integrate Project*.

B: Implementation of the *Integrate Project*:

CHUK implemented the *Integrate Project* programme largely as described in section 1.3.2. 40 staff were trained in the basic PC course, and 5 staff received ToT training. In addition, 10 staff received research training, 8 staff had training in children's PC and 3 staff were funded to do specialist training (2 the Diploma in PC and 1 Advanced Research Training). CHUK staff were trained to provide clinical placements and gave clinical placement to 9 people.

Full details of the activities carried out can be found in Annex 1.

C: Palliative Care Team:

CHUK took longer than many of the other hospitals to implement the work plan and develop the service. This was in part because of the change in national leadership, with RBC taking over the role from PCAR in May 2014, and partly because of CHUK's own size and complexity. In the past year the *Integrate Project* trained staff provided an informal but hospital recognised PC service. This has recently been formalised with the appointment of a desk officer and a team is being established. The team described below is not fully operational, but in the process of mobilisation.

[25] The team described here is not yet fully operational, but is currently being mobilised, as of June 2015. We have chosen to describe this future team, as opposed to the current model, because it is currently being implemented (as opposed to planned, or promised) with a 6 month workplan in collaboration with RBC.

Executive Team: Not formally constituted, the executive function is led by the PC desk officer, who is a clinical psychologist, and recognized as the lead for PC in the hospital. Leadership also comes from the hospital executive in collaboration with RBC.

Core PC Team: This consists of a desk co-ordinator (clinical psychologist), a doctor, two nurses who have done specialist training, a data manager and the pharmacist. This core team will function as a specialist unit, supplemented by others who have had training in PC but do not have dedicated hours to PC. These will include physiotherapists, social worker and volunteers.

Link nurses: There will be two link nurses per ward who will identify patients who need PC on their wards/ units and will provide generalist PC, referring to the PC team when they need more specialist input.

Volunteers: CHUK has a well-developed system of volunteers and organisations that support patients and they will work with these to support the PC programme, supporting the patients throughout the day.

D: Model of Service:

The 4 layers of the PC programme will be fully integrated into the hospital. PC is seen as cross-cutting and so to start with they have situated PC as an independent desk under medical direction parallel to all departments. The desk co-ordinator is in charge of PC within the hospital but is working closely with other members of the specialist team. The two nurses in the specialist team will cover different parts of the hospital, and 50% of their time will also be the supervision of the link nurses to enhance their PC skills. If there is need for input from other members of the team they will call the appropriate person e.g. the doctor, physiotherapist, social worker etc. PC team members write in the main hospital notes and they do not have separate PC documentation. It is anticipated that PC will be integrated into the hospital documentation which is currently being reviewed. They will continue to keep a register of PC patients at both the specialist level (through the team) and the general level (through the link nurses).

Referrals come from provincial/district hospitals, although patients are usually not referred for PC, but rather identified as needing PC once they reach hospital. CHUK refers patients back to the provincial or district hospitals in accordance with the national referral system described in section 2.2.1.

E: Services provided:

CHUK provide comprehensive PC including pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and bereavement support. They have a good network of social workers and organisations that support patients within the hospital, so are able to provide social support in the form of food, transport or legal

aid themselves through the social workers and linked organisations. Hospital volunteers provide companionship and practical assistance. This cadre has the potential to strongly support the expansion of PC. The hospital is able to provide diagnostics and treatment on-site and provide limited chemotherapy – although a new cancer department is being developed at the hospital and services will be extended. Currently patients are referred to Butaro hospital which is a designated cancer centre and provides chemotherapy services. However patients need referral for radiotherapy to Mulago Hospital in Uganda. They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children. One of the challenges at the moment is that of data collection and registration of patients, and it is hoped that this will improve with the services of a data manager.

F: Medicines

CHUK has oral and injectable morphine available in the hospital. They did not have any oral morphine prior to the *Integrate Project*. 30mg tablets were received in October 2014, and 10mg tablets in November 2014. Morphine syrup became available nationally after project end, in June 2015, and they were planning to order it. Morphine is covered under the insurance system so patients only have to pay 10%. Consumption has increased from zero at project start to 77,800mg in 2014. They reported availability of all PC medication on the end of project questionnaire apart from codeine, which is not used. They did not have any stock-out in the last 6 months of the project. These medications included paracetamol, aspirin, diclofenac, cortico-steroids, benzodiazepines, Haloperidol tabs/injection, other anti-emetics, amitriptyline, antidiarrheal agents, bisacodyl, hyoscine butylbromide, anticonvulsants.

G: Reach into the Community:

National Referral hospitals have a limited role in providing direct care in the community, as referral systems from the hospital link to provincial and district hospitals in accordance with the national referral system. The hospitals work with RHPCO who have an MoU with the MoH and are providing some clinical community PC support within a limited catchment area. If they have patients from Kigali that are being discharged to a relevant district hospital they will recommend they are referred to RHPCO for home care. RHPCO provide care in the community with regards to pain and symptom management, side effects of chemo, psychological support, bereavement support etc. Currently RHPCO have two members of staff and other staff from CHUK contribute in their own spare time.

H: Future Vision for Palliative Care:

CHUK has a vision to become a centre of excellence for Rwanda: a vision that is shared by RBC. Concrete plans are currently being implemented to set up the team and model of service described above. A refresher course is to be provided for the senior doctors and nurses and the plan for PC at CHUK widely discussed, so that there is ownership throughout the hospital. They have a six month plan for how this will be rolled out and are liaising with RBC about this.

"We are going to be the Centre of excellence with research related to PC as we need the evidence base and the data and research so going to put effort into that." (Hospital Director)

I: Lessons learned from this hospital:

In common with UTH, the experience of CHUK has shown that in larger national hospitals, a longer time may be needed to embed services. However, the team was on the point of being mobilised, and there was a strong sense that the service described above would now be implemented.

CHUK will provide an exemplar service for PC in a national hospital with a strong multi-disciplinary focus, and volunteer ethos. It shows how "converted" leadership and support from the MoH can help to establish services in such a hospital. The hospital director said he was a "convert" to PC, and had developed his vision for CHUK partly through visiting MPCU and Mulago hospital. This made him understand what it was to integrate a PC service, and to also recognise the distinct advantages at CHUK:

We have an advantage as we have a wider MDT than in Uganda e.g. we have a clinical psychologist. He has understood and is willing to be appointed as the desk coordinator for PC. We have the team in place e.g. have social workers and organizations to help patients etc. – so we will use this opportunity to bring them together. (Hospital Director)

CHUK have seen substantial increases in the number of patients receiving PC over the 3 years, with oral morphine figures also showing a clear increase. They felt that the patient numbers reported were not reliable, and hoped to see a greater increase with the implementation of the new team, and an improvement in referrals and data collection.

3.6 Regional Referral Hospitals

3.6.1 Kenya: Nyeri County Teaching and Referral Hospital (NCTRH)

Hospital level:	Regional	Beds	300[26]
Location:	Central Province, Kenya	Population	234,500[27]
Hospital level description	Nyeri is a Level V hospital (secondary referral centre). It is a regional centre and referral point for the district hospitals. At project commencement, the hospital was "Nyeri provincial hospital." But has been updated to "Nyeri County Referral and Teaching Hospital"		
PCU History	Established since 2010		
PC Organisational Components	Team of 2 nurses and 1 doctor provide and co-ordinate the service, supported by 4 PAMs staff who assist with planning and co-ordination. Services provided by a critical mass of trained staff throughout the hospital (see C below for details)		
PC service delivery	Specialist Integrated Palliative Care Unit (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

PC started in 2010 following a directive from the MoH which instructed every level 5 hospital to develop PC units. The unit was set up attached to the oncology department, and PC is strongly associated with oncology in the hospital. Although the unit was established fairly recently, the longstanding Nyeri Hospice (established 1994) has developed a culture of PC in the area. Nyeri Hospice has been a crucial part of mentorship, training and modelling, and has long-term seconded staff members from NCTRH. Prior to the *Integrate Project*, PC trainings and sensitisations were coordinated by KEHPCA, funded by the Diana Princess of Wales Memorial Fund and True Colours Trust. The True Colours Trust project which was directed at all level 5 hospitals was run partly in parallel with the *Integrate Project* and included refurbishment and renovation of the PC rooms.

B: Implementation of the *Integrate Project*

NCTRH carried out the programme activities largely as described in section 1.3.2 of this document including training 41 Health Care Workers in basic PC training, 15 in ToT, and support through 40 UK volunteer mentorship days. They also carried out sensitisation with country health officials, community awareness sessions, radio shows, awareness and screening camps and training of their breast cancer survivors group. Their basic training included staff in two nearby hospitals, and they continue providing mentorship to one. Full details can be found in Annex 1.

[26] Confirmed by APCA, August 2015
[27] Baseline questionnaire. Population of 6 surrounding districts.

C: Palliative Care Team

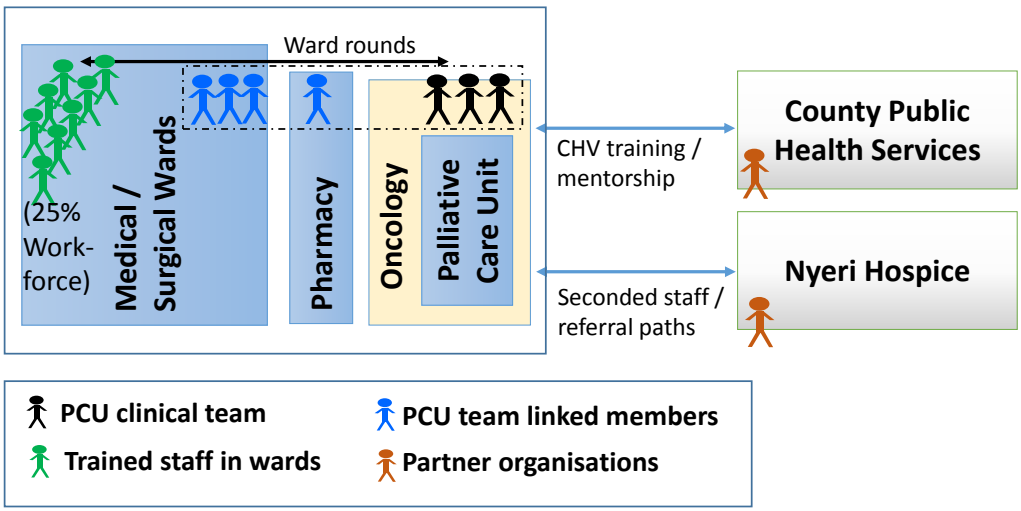
The core PC team consists of 2 full time PC/oncology nurses and a medical officer 3 days a week. The team run the oncology outpatient clinics and also do ward rounds throughout the hospital. They are supported by a link social worker, pharmacist, physiotherapist and nutritionist, who provide PC services in their speciality, and have a role in planning and implementation. The lead nurse is currently doing a degree course in PC funded through the *Integrate Project*, as is the nurse seconded to Nyeri Hospice.

The PC executive and planning function is carried out by the lead nurse of the core team, supported by her 4 linked staff and hospital management. The chief county medical officer provides the executive PC function at a county level.

D: Model of Service

The PC unit is a stand-alone building within oncology and, as such, is visible and known by all in the hospital. It is integrated in the hospital, seeing patients in the wards, and drawing on the skills of a linked multi-disciplinary team who are deployed throughout the hospital with focal persons in most of the clinical areas.

Figure 9: Nyeri Hospital Team and Model of Service



Patients can either be referred by a sub-county hospital, from within NCTRH or by Nyeri Hospice. Referrals can be written or by telephone call and some patients arrive through personal contacts. NCTRH is under the jurisdiction of the county MoH and all staff are employed by the county. They work closely with the county to provide training to other hospitals and to community health workers.

E: Services provided

The PC unit provides pain and symptom assessment and management with opioids, counselling and psychological support, and spiritual support. Although they do not provide social support in the form of food or transport, legal aid is available on referral to Nyeri Hospice. Nyeri Hospice also provides more extensive bereavement support, stoma clinic, training of carers and home-based care services.

Because the unit is housed in oncology, at present PC is very much linked with a cancer diagnosis. Palliative chemotherapy is available for both in-patients and outpatients. The hospital also carries out some palliative surgery. Radiotherapy is available only on referral to Kenyatta Hospital in Nairobi. There are few referrals and little provision of either intermediate or specialist PC to other patients with life limiting illness (e.g. renal, paeds). However, this is changing, and senior staff in the hospital recognise that improving PC to non-cancer patients and to children is a priority.

F: Medicines

Both oral and injectable morphine are available in the hospital. Morphine comes from the national supplier, KEMSA and is held in the oncology pharmacy. Morphine is made up from powder in small batches at a time, at a concentration of 10 mg per ml. Very little morphine is prescribed for children, and paracetamol is commonly used. Tramadol and DF118 are also used. They stock all medications reported on the baseline questionnaire including codeine, paracetamol, aspirin, NSAIDs, cortico-steroids, benzodiazepines, haloperidol, other anti-emetics, amitriptyline, anti-diarrheal agents, laxatives, hyoscine butylbromide and anticonvulsants. In the last six months, they have had stock-outs of laxatives and hyoscine butylbromide.

G: Reach into the Community

NCTRH have a good two-way referral system with Nyeri Hospice. On discharge from the hospital, patients continue with oncological treatment at Nyeri CTRH with support from the Hospice for HBC or specific support: e.g. legal support or stoma clinic services. Those who are not continuing treatment may be solely managed for supportive care by the Hospice if within their catchment area.

NCTRH has also trained the breast cancer support group in PC sensitisation and early detection, and have worked with the county MoH to formally integrate these volunteers into Kenya's primary healthcare system.

H: Future Vision for Palliative Care

NCTRH plans to continue their model of an integrated service housed within oncology, while continuing to train more staff to ensure all patients requiring PC receive care.

The lead nurse is liaising with the county MoH to scale-up PC services across the county. The MoH have included this vision in their latest strategic plan, with concrete plans to roll-out services to the facilities through training and capacity building, using NCTRH as an expert training resource and to integrate PC at community level. Training has been completed in one hospital and is commencing in another, as of April 2015.

I: Lessons learned from NCTRH

NCTRH provides an exemplar of partnership in a locality where PC services are approaching integration. With 25% of staff in the hospital already trained, a strong and established local hospice and a county MoH which has PC firmly on the agenda, NCTRH has sufficiently built internal capacity through the *Integrate Project* and other donor-funded projects to be seen as an expert resource in PC. The county MoH referred to NCTRH as "the centre" explaining:

> *We have the concept clearly. The challenge is now institutionalising it so that it is part of our health system. Another challenge is ensuring that the centre [Nyeri CTRH] retains the passion, because if the centre loses the passion we will not be able to continue. (County Minister, Nyeri)*

The integration of the breast cancer survivors group into the county government health services provides an example of how hospital PC teams can strengthen local health systems, by integrating hospital initiatives rather than continuing them in parallel.

3.6.2 Uganda: Gulu Regional Hospital (GRRH)

Hospital level:	Regional	Beds	300[28]
Location:	Northern Uganda	Population	1,520,000[29]
Hospital level description	It is designated as one of 12 regional referral hospitals under the government system.[50] It is also a teaching facility.		
PCU History	Minimal service available prior to the *Integrate Project*		
PC Organisational Components	A formally named executive team of 2: clinical officer and nurse provide leadership and planning and service co-ordination. The clinical officer is full-time and leads the co-ordination. Operating link nurse service delivery model. (see C below for details)		
PC service delivery	Dedicated palliative care team/individual with integrated support (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

There was a limited PC service provided prior to the *Integrate Project*. Although there were trainings a number of years ago, the service was characterised by one hospital staff member as "dying and not active" prior to the *Integrate Project*. Largely dependent on one trained nurse, PC was seen as the domain of this nurse, with a lack of ownership from other personnel. Since the *Integrate Project* there has been significant progress with a model which has included training many of the hospital staff, along with staff from Lacor hospital, a nearby mission hospital. There are no strong NGO PC models to act as partners although they work closely with Lacor hospital to provide PC across Gulu.

B: Implementation of the *Integrate Project*

Gulu regional referral hospital carried out the programme activities largely as described in section 1.3.2 of this document including training 45 Health Care Workers from Gulu hospital and 15 from Lacor Hospital in basic PC. They also trained 8 health workers in ToT, and their staff had link nurse training run by MPCU. 5 staff were funded to do specialist diploma level training (4 the Diploma in Clinical PC, and 1 the Diploma in Paediatric PC).

49 VHTs were trained, through community sensitisation. The VHTs targeted were those which link with Lacor hospital. It is difficult to establish whether or not these VHTs are actively referring patients, as referrals originating from a VHT may come via a health centre. Follow-up is required, as is more community sensitisation, and sensitisation of the health centres and district hospitals linking in with GRRH. Other community sensitisation activities carried out

[28] Confirmed by APCA, August 2015

[29] Baseline questionnaire: Population of Acholi sub-region, including Gulu, Nywoya, Amuru, Kitgum, Pader, Agapo, Lamor

through the *Integrate Project* include teaching and speaking at the university and Institute of Health Sciences, PCAU branch sensitisation activities and World Hospice and PC day activities.

Since the *Integrate Project*, they now have a room where the PC unit is based. This is helping to improve team ownership of PC rather than reliance on one individual.

Full details of the activities carried out can be found in Annex 1.

C: Palliative Care Team

They have a layered structure and integrated PC unit as follows:

Executive Team: This is a team of 2, both of whom carry the role of Chairman for the PC team. The role of this team is to organize the PC unit, organise meetings, plan for CMEs and lead the PC team. One of the chairmen is a Clinical Officer and is working full time in the PC unit. The other is a nurse and works on the medical/ TB ward.

Core Team: The core PC team was officially constituted in October 2014. This consists of the dedicated clinical officer and medical ward nurse who form the executive team plus 7 other staff at the hospital: 4 nurses, 1 dispenser / pastor, 1 pharmacy technician and 1 doctor. All of these individuals have had some form of PC training, with 4 of them being trained at the specialist level – 3 DCPC and 1 Diploma in CPC. Based on our evaluation visit, we observed a basic clinical core of at least 4: the dedicated medical officer, supported by nurses in clinical, surgical and paediatric, all of whom have done specialist training in PC.

Link nurses: There is a link nurse on each of the wards and ART and outpatients – they are identified as the contacts for PC and referrals are made to the team via the link-nurses.

PC trained nurses: These are the other nurses who attended the basic 5-day training programme who are dispersed throughout the hospital and help to identify patients needing PC, referring them to the PC team through the link nurses, and caring for them as appropriate.

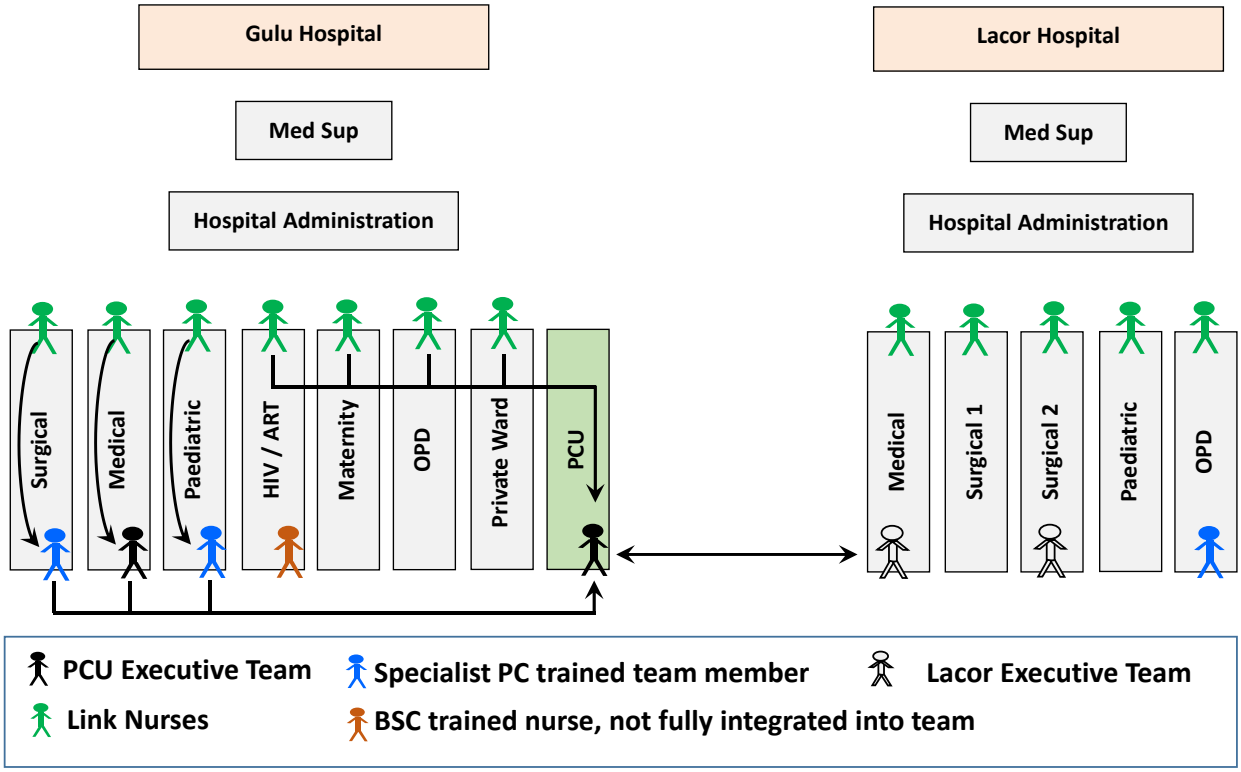
D: Model of Service

The 4 layers of the PC programme are integrated into the hospital. The team operates through the named link nurses on each ward, and all in-patients are jointly managed with the primary physician. On all the units throughout the hospital there are nurses who have basic training and they identify patients with PC needs and alert the link nurses (who also help to identify patients). The link nurses will manage some PC patients themselves on the wards, in collaboration with the primary team. When more expertise is needed they refer the patients to either the clinical officer working in the PC Unit or in the case of medical, surgical or paediatric wards to the specialist nurses working in these units. Referral is done by the primary team using the hospital referral forms. A register of patients is held in the PC office. Registers are also held in clinical, surgical and paediatric units, and the clinical officer in the PC units periodically collates the register figures for reporting purposes.

There are no specific PC ward rounds, but the specialist nurses participate in rounds in their own department, and the specialist CO in the PC Unit is invited to join other rounds as appropriate. Rounds are ad hoc according to patient need.

Gulu RRH works closely with Lacor Hospital and patients are referred between the two hospitals as appropriate. They receive referrals from 4 district health centres and the District Hospitals that link in to GRRH. They may also get referrals from other hospitals e.g. Mulago Hospital and Lacor Hospital. This model of service, including the link with Lacor, is shown in Figure 16 below.

Figure 10: Gulu RRH PC Team and Lacor Hospital PC Team



E: Services Provided

They provide pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and bereavement support. They are able to provide some diagnostics through referral to Lacor hospital and treatment on-site, and refer to Mulago (the national referral hospital in Kampala) for chemotherapy, radiotherapy and palliative surgery. They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children.

F: Medicines

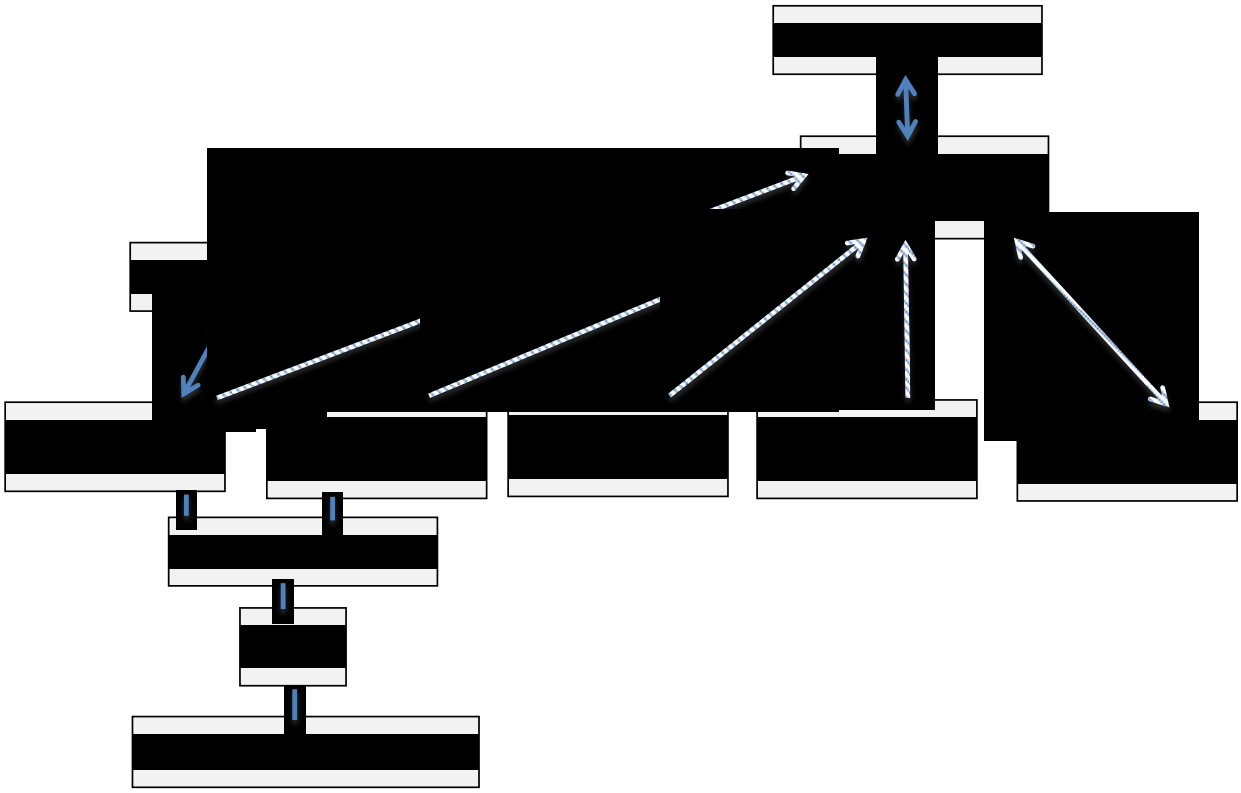
They have oral but not injectable morphine available in the hospital. The morphine is made up in a concentration of 5mg per 5ml. Consumption of oral morphine has increased from 0 at the

start of the *Integrate Project* to 198,225mgs in 2014. There have been no reported stock-outs in the last 6 months of 2014. Stock-outs used to be more frequent, but ordering systems have improved during the *Integrate Project*. They have access to some of the medications reported on the baseline questionnaire including, Paracetamol, NSAIDs, Benzodiazepines, Haloperidol tabs, Anticonvulsants, Amitriptyline, Bisacodyl. They have had stock-outs of the last two of these in the last 6 months. They do not commonly have access to Aspirin, Antiemetics, Antidiarrheal Agents or Cortico-steroids.

G: Reach into the Community

As a Regional Referral Hospital, Gulu Hospital does not have a direct working relationship with the community, instead linking with the VHTs through the district hospitals and health centres. Community mobilisation is poor and only some of the VHTs have been trained in PC. Despite the fact that they are a regional hospital, GRRH would like to start carrying out home visits themselves, as they are concerned about the lack of HBC services for PC in the area. However, given that they would not be able to cover the whole region, building the capacity of their referring health centres may be a more appropriate strategy.

Figure 11: GRR Hospital and Community Model of Service



H: Future Vision for Palliative Care

Future plans for PC in Gulu involve expansion of the team to include more dedicated members, and starting to increase reach into the community.

Their ideal model would include one medical and one full-time nurse on the PC team. However, the evaluator noted that current capacity may be adequate in such a resource-constrained context, and the expansion vision may be over-ambitious.

As described above, the team is aware of the need to link with community more, and that patients lack follow up on discharge. They do not yet have a clear plan on how to achieve this, although are discussing ideas. For example it is anticipated that more VHTs will shortly be trained in liaison with the appropriate health centres. They recognise that they need to strengthen their links with the District Hospitals and referring health centres so that they support the provision of PC in the community.

I: Lessons learned from Gulu Regional Referral Hospital

Gulu RRH provides a good example of PC moving from being associated with an individual to a service provided by a team. It also shows the impact of creating a physical space on visibility and profile within the hospital.

The model implemented, of a dedicated team of at least one individual with support from other specialist members, and fully integrated through link nurses, provides an excellent example of how a regionally-based hospital can effectively utilise scarce human resources to provide a services to all patients.

Their relationship with Lacor Hospital is a good demonstration of how two hospitals can work together to provide PC services.

3.6.3 Uganda: Kabale Regional Hospital

Hospital level:	Regional	Beds	250 [30]
Location:	Western Uganda	Population	2 million[31]
Hospital level description	It is designated as one of 12 regional referral hospitals under the government system.[50] It is also a teaching facility.		
PCU History	Minimal service prior to the *Integrate Project*, with no morphine available		
PC Organisational Components	A full time nurse co-ordinates the service, supported by 10 link nurses for service delivery. A specialist clinical officer supports with planning and leadership. (see C below for details)		
PC service delivery	Dedicated palliative care team/individual with integrated support (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

There were minimal PC services prior to the *Integrate Project*, and most of the advances in PC in the hospital have come about as a result of the project. Although prior to the project 4 people had been trained by HAU they were based in the Joint Clinical Research Centre HIV clinic which is not fully integrated into the hospital, and so they did not disseminate PC. Thus there has been significant progress since the start of the *Integrate Project* with a fully integrated model which has included training and sensitising many of the hospital staff, and staff from the associated health centres. Since the *Integrate Project*, many more people have been trained through different courses and many of the staff have been sensitised and are aware of PC. Thus there is a strong ownership of PC and care is seen as being provided throughout the hospital by a team with a specialist nurse working full time in the PC unit – an office which provides a focal point for PC.

B: Implementation of the *Integrate Project*

Kabale Hospital carried out the programme activities largely as described in section 1.3.2 of this document including training 60 staff in basic PC and 9 in ToT. Staff also received link-nurse training from MPCU. 4 staff were funded to do specialist training: 1 a diploma in paediatric PC, 1 the Diploma in clinical PC and one the Diploma in PC, and 1 the degree. 49 VHTs, including church leaders and traditional healers, were trained in 2 trainings, and radio talk shows have been broadcast.

Full details of the activities carried out can be found in Annex 1.

[30] Confirmed by APCA, August 2015

[31] Baseline questionnaire. Comprises 4 Districts of S.W Uganda (Kabale, Kanungu, Kisoro & Rukungiri)

C: Palliative Care Team

They have a layered structure and fully integrated PC unit as follows:

Executive Team: There is no official executive team, although the specialist nurse is 'leading' as she is working full time in the field, and there is a link nurse manager. A Clinical Officer, who is undertaking the BSc programme is also very involved in the leadership of PC in the hospital.

Core Team: There is 1 dedicated specialist nurse working full time in the PC unit. This is an office used for administration and as a focal point, but also for seeing patients.

Link Nurses: A team of eleven 'link-nurses' including the specialist nurse in the PC unit was officially identified by the hospital in July 2014. Each department has a link nurse and the term 'link-nurse' refers to any professional working in that position e.g. in the OPD it is a doctor rather than a nurse.

Trained personnel: These are the other PC trained staff on the wards.

D: Model of Service

The 3 layers of the PC programme are fully integrated into the hospital. Kabale Hospital does not have either separate inpatient beds or outpatients for PC, although patients who come to the OPD and have PC needs are sent to the PC unit. The team operates throughout the hospital, and all patients are jointly managed. Link nurses identify those patients who need PC and provide care in the wards. If specialist PC is needed, they refer to the specialist nurse in the PC unit who will work with the primary team to provide care. On discharge they are seen in the PC unit and given a date to come back for review. The unit is always informed of patients with PC needs, and therefore PC patients are captured in the numbers reported through the registry. The PC register is kept in the PC unit and data is entered into a database on their computer. They are also piloting the m-health PC system with PCAU which includes both general PC statistics as well as morphine data.

E: Services Provided

They provide pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and bereavement support. They are able to support patients in will writing, and often provide social support in terms of food etc. from their own pocket. They are able to provide palliative surgery on site but have to refer to Mulago for chemotherapy and radiotherapy. They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children.

F: Medicines

They have oral, but not injectable morphine, available in the hospital. The morphine is made up in a concentration of 5mg per 5ml. Consumption of oral morphine has increased from 36,000mgs in 2012 to 336,000mgs in 2014. They use the national procurement system through

NMS. Stock-outs are rare, and they have no reported stock-outs of morphine in the last 6 months. After being prescribed, morphine is kept at the patient's bedside. They do not have access to codeine or bisacodyl. They stock most other medications reported on the baseline questionnaire including, paracetamol, aspirin, NSAIDs, cortico-steroids, benzodiazepines, haloperidol, other anti-emetics, amitriptyline, anti-diarrheal agents, and anticonvulsants.

G: Reach into the Community

Kabale Hospital does not have a local Hospice or established Home-based care facility for PC referrals, although patients are referred to Hospice Mbarara if living within their catchment area. However they have begun expanding their reach into the community and carry out limited home visits themselves once or twice a month, with the support of the hospital. If needed they will also carry out ad hoc visits in between those times, transport permitting. They have also trained health professionals at their associated health clinics and some VHTs, to identify and refer PC patients to the hospital. These trained staff carry out home visits once or twice a month if the patients live locally.

H: Future Vision for Palliative Care

Kabale Hospital plans to continue the model of a dedicated integrated palliative care team with link nurses. They recognise the need for continuous training and sensitisation, and plan to do this through regular CMEs, training medical and nursing students and hospital sensitisation.

They may also move the PC office to a new building in order to create greater visibility within the hospital. They are considering expanding the holistic service offered through starting an income-generating activity, although this is still in very early planning stages.

I: Lessons Learned from Kabale

In common with Gulu, Kabale Hospital provides an example of how link nurses can be integrated with a dedicated individual to effectively utilise scarce human resources in providing services to all patients.

Kabale Hospital staff commented how the prescribing practices of doctors changed markedly during the *Integrate Project*, and this is backed-up by substantial increases in morphine consumption. They believe that the change in attitude necessary to make this happen was in part brought about by having a critical mass of staff trained to provide broad advocacy throughout the hospital on a daily basis.

3.6.4 Zambia: Ndola Central Hospital (NCH)

Hospital level:	National	Beds	800 [47]
Location:	Copperbelt, Zambia	Population	514,000 [47]
Hospital level description	The hospital is ranked as a tertiary level hospital, which is the highest level in Zambia (see section 2.4.1). It is one of 5 of these in addition to UTH and therefore sits between a national and regional hospital. It is also a University Teaching Hospital associated with the Copperbelt University		
PCU History	Specialist medical consultant providing services and increasing awareness since 2009, but no formal team in place. Nearby Cicetekelo Hospice established in 2000.		
PC Organisational Components	Palliative care committee of 6 senior clinical staff provide planning, co-ordination and service delivery. Services provided by trained staff throughout hospital, including focal persons on some wards. (see C below for details)		
PC service delivery	Dispersed Integrated Palliative Care Team (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

PC services have been available in the locality since 2000, when the nearby Cicetekelo Hospice was established. From 2009- 2011, the head of Cicetekelo Hospice and a medical consultant from NCH underwent diploma level training in PC funded by the Diana Princess of Wales Memorial Fund. Under their collaboration, and with support from hospital management, knowledge of PC within the hospital increased, a referral system was developed and oral morphine became accessible within the hospital and community.[43] This was also facilitated by the national advocacy carried out by PCAZ. PCAZ has been working with NCH since 2009, and as of 2014, 78 staff had undertaken various trainings in basic PC.[51] At the start of the *Integrate Project*, there was no formal team in place, although this local context existed from which the *Integrate Project* could take root.

B: Implementation of the *Integrate Project*

NCH implemented the full *Integrate Project* programme described in section 1.3.2. 15 NCH staff received training in research skills in June 2014. 64 individuals including NCH staff, Cicetekelo staff and staff from surrounding district clinics were trained in the basic PC course. In collaboration with APCA and the UK mentors, the NCH team carried out sensitisation trainings of 127 community members surrounding each of these 5 clinics (approximately 25 per clinic). The aim of this was to allow these surrounding clinics to receive referrals from their community, provide a basic PC service and refer high-need patients to NCH.

Full details of the activities carried out can be found in Annex 1.

C: Palliative Care Team

The executive and clinical roles are both implemented by a PC committee. This team has six members each housed in different departments. The head of the committee is the medical consultant, with a diploma in PC. The team also has three senior nurses who are undergoing specialist training funded by the *Integrate Project* (medical matron, surgical matron and a senior outpatients nurse) another nurse and a social worker. The committee were allocated an office, as of February 2015.

D: Model of Service

The PC committee members provide specialist PC services within their units as part of their normal jobs, and direct the trained staff within their units as appropriate. They identify patients who need PC from routine rounds (as opposed to specific rounds for PC) and routine outpatient clinics. They also continuously sensitise other health workers. The committee is supported by focal persons (ward in-charges who have received PC training). The training has not yet been comprehensive enough to have a focal person on each ward, but the reach is extending.

The NCH PC team does not use a specific 'PC' referral form – they receive referrals via existing hospital and community forms. Referrals come from focal persons, as well as staff who have not yet undergone training. Most referrals are for cancer patients, although services are available for all patients. Referrals can also happen 'in passing' e.g. in the corridor or by personal mobile numbers. Each ward keeps a register of patients who have been referred to PC (within the 'ward book') and an overall register of those that have been referred to the PC team is kept in the social worker's office. The hospital plans to start a patient database on the new *Integrate Project* funded computer. The committee was allocated a PC office, as of February 2015, but because no team member has time dedicated to PC, this office is used for committee meetings and is not yet a centre-point for PC referrals.

E: Services provided

As all children's services are provided by a nearby hospital, the service is for adults only. They provide inpatient and outpatient services as described above, but do not provide a comprehensive home cased care or outreach service. Morphine is readily available, although there was a national stock-out of liquid oral morphine from Oct 2014 – Feb 2015. The PC service includes pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and care to the family. They also provide social support in the form of food and clothes, meeting about 50% of demand. Bereavement support and spiritual support is provided on a generalist basis by the PC team and staff with basic training. Because the team lacks dedicated time, the service may vary, depending on demand and availability of trained staff but many personnel give PC support out of hours.

F: Medicines

They have oral, but not injectable morphine, available in the hospital (pethidine is used instead of injectable morphine). Oral morphine consumption has increased from 5,200 mgs in 2012 to 93,340 mgs in 2014. They also use tramadol. Morphine powder and tramadol are available from MSL free through the government system. Morphine controlled release tablets are available (30mg) and also morphine syrup 0.5mg/ml. There was a national stock-out of liquid morphine during the end of the project (see Mazabuka section for details). They do not have access to codeine. While they stock most other PC drugs reported on the end of project questionnaire, they also reported at least one stock-out of most of these in the last six months of the project. These medicines include paracetamol, aspirin, NSAIDs, cortico-steroids, benzodiazepines, haloperidol tabs and injections, other anti-emetics, amitriptyline, anti-diarrheal agents, bisacodyl, hyoscine butylbromide and anticonvulsants.

G: Reach into the Community

The team does not provide HBC services, apart from very limited visits for local patients. The local Hospice (Cicetekelo) closed recently due to financial pressures. It is opening again with government funded staff members and operating on a different model, being a day-care service rather than an inpatient one. The new service will not offer home-based care, but will act as a focus for community training.

The in-charges (nurses) at the 5 main district clinics were trained by the Ndola PC team in August 2014. The Community teams trained under the *Integrate Project* are starting to deliver PC, and it is anticipated that this will increase via the existing budgetary process. Reach into the community remains a challenge for the province.

H: Future Vision for Palliative Care

The future vision of NCH includes establishing a dedicated PC team. They consider it essential for credibility to have specialist staff who have completed a degree in PC to establish this team. Once the three nurses undergoing specialist training complete their degree course in August 2017, the hospital director plans to give them dedicated time for PC. There is also an agreement to allow NCH hospital staff to support the newly opened Chitekela hospital day care programme.

I: Lessons learned from Ndola Central Hospital

NCH provides an example of how a hospital can quickly increase the number of referrals through deployment of skilled and senior staff. NCH have access to relatively highly skilled staff with a passion for PC and leading clinical roles and strong, convinced hospital leadership. Through improving referral pathways and training and sensitisation throughout the hospital,

they saw the largest increases of all 12 hospitals in the number of patients receiving PC directly by the PC team, from 11 patients in 2012 to 462 patients in 2014. This does not include those seen by generalists whose service provided to patients may be variable, but who are able to recognise and refer patients.

The hospital have achieved this through use of a dispersed integrated palliative care team comprised almost entirely of senior clinical staff members, who have the direct power to change practice on wards on a day to day basis. This team has faced the challenges of a lack of PC "presence"; no proper PC desk for coordination and no dedicated time to formalise systems or continuously train staff. The team office, opened in February 2015, and chosen because of its placement in the middle of the hospital may improve both coordination and the profile of PC within the hospital.

3.7 District Hospitals

3.7.1 Kenya: Homa Bay County Teaching and Referral Hospital

Hospital level:	District	Beds	300[32]
Location:	Nyanza Province	Population	57,000[33]
Hospital level description	Level IV (primary referral centre) currently upgrading to Level V (secondary referral centre). Teaching hospital. Common diseases are HIV, HIV related cancers and sickle cell		
PCU History	None prior to the *Integrate Project*		
PC Organisational Components	A formally named executive team of 3 led by a paediatrician provides leadership and planning and service co-ordination. Operating link nurse service delivery model. (see C below for details)		
PC service delivery	Dispersed Integrated Palliative Care Team (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

There was no adult PC unit prior to the *Integrate Project* although PC services for children had recently commenced following training from the International Children's Palliative Care Network. Thus significant advances in PC in the hospital have arisen through the *Integrate Project*. The team identified that there were no strong NGO services locally to act as partners. Hospital staff are seeking to extend reach into the community in other ways.

B: Implementation of the *Integrate Project*

Adult PC was introduced through the *Integrate Project* in 2012, using an integrated model. Since then, supported by the LPs and KEHPCA, Homa Bay have trained 44 HCWs in basic PC, including 1 from each of 10 local referring hospitals in the county, and they received 60 days of UK volunteer mentorship support. Three staff are undergoing the Higher National Diploma in PC run by Nairobi Hospice. They have carried out sensitisation at a county and community level, with PC incorporated in the community strategy and budgetary support promised by the country MoH. Through the project, they have renovated a play room for the paediatric PC service. 15 staff members have received ToT training, and are continuing to deliver training independently, both internally and in the community. Full details can be found in Annex 1.

C: Palliative Care Team

They have a layered structure and fully integrated PC unit as follows:

Executive Team: This is a team of 3: team leader, treasurer, and coordinator. This team are in charge of the management of any funds, and of referrals / monitoring PC patients. PC is

[32] Confirmed by APCA, August 2015
[33] Baseline questionnaire

integrated into the normal job roles of these 3 people. The team leader is a paediatrician with a normal paediatric caseload, the treasurer a physiotherapist and the co-ordinator a nurse with a role in hospital management. The roles they play in the PC team are recognised and will form a part of their appraisal.

Core Team: This consists of the executive team plus: 2 additional nurses, the Public Health Officer, the Social Worker, 1 Pharmacist Technician, 1 Laboratory Technician. These people are the PC contacts for their discipline and the specialists within the hospital, and also perform other roles (e.g. one of the nurses is in charge of communication).

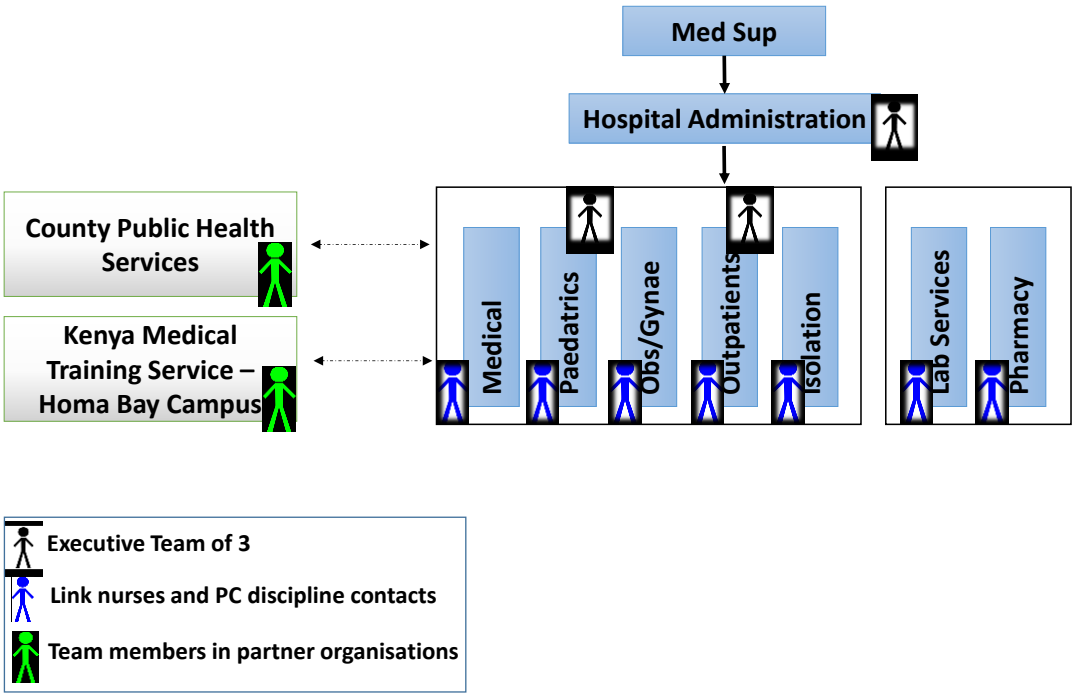
Extended team: This consists of all the people who received the 5 days basic training: focal persons on most wards, outpatients, physiotherapists, someone in mother and child health clinic, and staff from Kenya Medical Training College of Homa Bay (KMTC).

D: Model of Service

The 3 layers of the unit are fully integrated into the hospital, with no separate inpatient beds or outpatients for PC. The team operates through named link nurses on each ward, and all patients are jointly managed (although the extent of the input given by the specialist team members will depend on the needs of the patient, and can often be minimal).

Homa Bay lacks a Hospice or Home-based care facility for PC referrals. They carry out very limited home-based visits themselves. They are therefore currently expanding their reach into the community by training Community Health Volunteers (CHVs) to identify and refer patients and support them on discharge.

Figure 12: Homa Bay Hospital Team and Model of Service



E: Services Provided

The hospital provides pain and symptom assessment and management with opioids, counselling and psychological and spiritual support. They are unable to provide social support in the form of food, transport or legal aid, although they can facilitate advice on income generation through referral to other organizations. They are able to provide some diagnostics and treatment on-site and have to refer to MTRH/Kenyatta for some chemotherapy or radiotherapy. They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children.

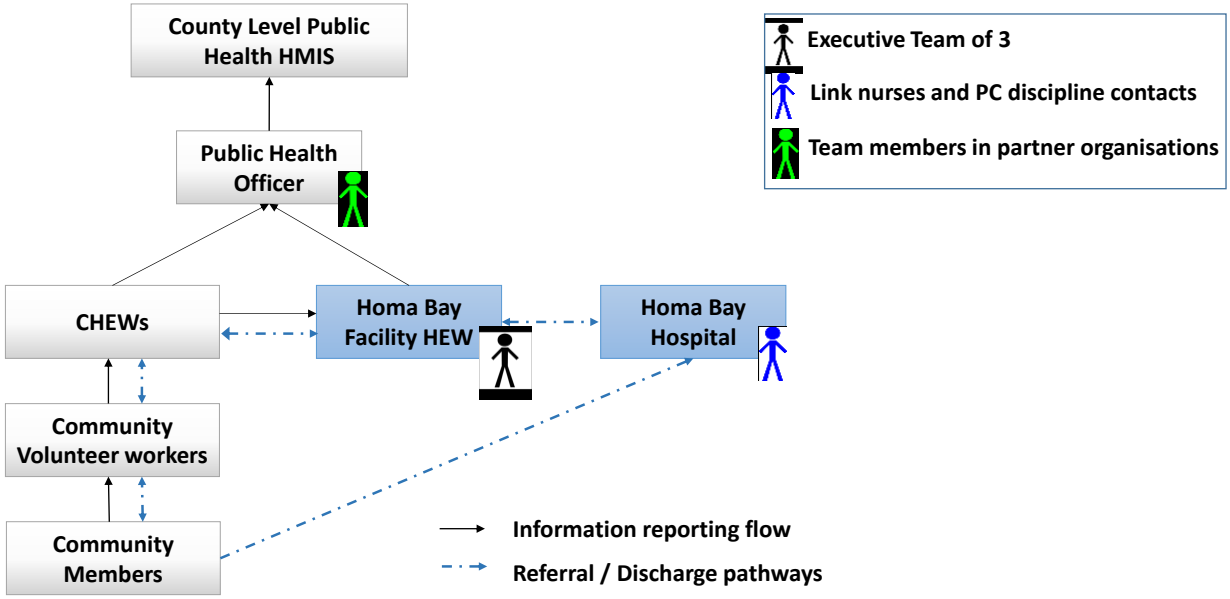
F: Medicines

Both oral and injectable morphine are available in the hospital. Oral morphine powder was made available through the *Integrate Project* and consumption has increased from zero at project start to 66,500 mgs in 2014. This is reconstituted onsite, in concentrations of 10 mg for adults and 5 mg for children. Morphine is held in the main pharmacy, which is open 24 hours. The use of weak opioids is reducing. Morphine is available through the government system (KEMSA), however, there have been stock-outs, and KEHPCA have provided the hospital with oral morphine during these periods. They stock a wide-range of PC medications, including paracetamol, NSAIDs, cortico-steroids, benzodiazepines, anti-emetics, anti-diarrheal agents, hyoscine butylbromide and anticonvulsants. They reported at least one stock-out of nearly all these medications in the last 6 months of 2014.

G: Reach into the Community

Homa Bay have extended their reach into the community through training CHVs. They have effectively used the national system of the community unit (described in section 2.1.1), led by Community Health Extension Workers (CHEWs) as a platform for sensitising, mobilising and referring patients in need of PC in Homa Bay Township (the area immediately surrounding Homa Bay town). The public health officer in charge of this township received 8 days training (5 classroom and 3 clinical placement) in PC through the *Integrate Project*, and is part of the PC extended team. In collaboration with the *Integrate Project* trained staff at Homa Bay hospital, he then sensitised the CHEWs and CHVs in the 8 community units in the township in PC to identify patients with PC needs, and refer them for PC services. They were also trained in nutrition, hygiene, legal/will-making and cancer awareness. The CHVs are actively referring patients to the health facility (Homa Bay hospital) for PC services, and, on discharge, the patient's CHV is informed through the CHEW.

Figure 13: Homa Bay Model to extend community reach



H: Future Vision for Palliative Care

Homa Bay hospital plan to continue and strengthen their model of a dispersed integrated PC Team, which has worked well for them in terms of embedding services in the hospital. They would like to increase the specialist capacity of this team, and, in particular, develop research skills. They are in discussions with the county MoH about the provision of dedicated staff for PC. Two staff members have been promised, in response to a concept paper. If these staff members are granted, the hospital may move towards the model of having a dedicated integrated PC team with support. This team would still be integrated within the hospital, and use the existing link-nurse model.

They have a vision to roll out the model of PC service provision and referrals using CHWs across all townships in Homa-Bay sub-county. The support of the county director and public health officer will help realise this vision. This vision includes the incorporation of PC into the county health management information systems, via the forms completed by the community health workers and cascaded up to county level through the CHEWs and public health officers.

I: Lessons from the Homa Bay Model

Homa Bay hospital provides an example of how a district/county hospital can very quickly progress from zero service to some level of integrated service, given the presence of committed champions within the hospital, at county MoH level, and the support of a strong national association. Due to these factors, they were able to quickly sensitise both internally and at policy-making level resulting in new services and changed practice within a relatively short time. Their use of the county MoH systems as a platform for extending services to the community (Figure 5) is an excellent example of integrating into and strengthening the existing health systems.

The rapidly implemented service also comes with unavoidable challenges: such services are reliant on a smaller number of PC champions within the hospitals, are more vulnerable and can struggle with service delivery problems. For example, despite commitment from the county MoH, morphine for Homa Bay has not always been available through the government system, and has instead been provided by KEHPCA. The ongoing partnership between Homa Bay hospital and KEHPCA provides an exemplar model of how national associations can support district hospitals with establishing services and overcoming problems.

3.7.2 Uganda: Gombe General Hospital

Hospital level:	District	Beds	100 [34]
Location:	Central Uganda	Population	250,000[35]
Hospital level description	It is designated as a district hospital under the government system.		
PCU History	Minimal service available prior to the *Integrate Project*		
PC Organisational Components	A formally named executive team of 2 staff, medical officer (lead) and nurse (secretary) provide service co-ordination, supported by a core team of 7. Operating link nurse service delivery model. (see C below for details)		
PC service delivery	Dispersed Integrated Palliative Care Team (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

There were minimal PC services prior to the *Integrate Project*, and most of the advances in PC in the hospital have come about as a result of the project. There has been significant progress with a fully integrated model which has included training and sensitising a significant proportion of the hospital staff, staff from the associated health centres and reaching into the community to the VHTs and religious leaders. Prior to the *Integrate Project* the PC programme was seen as the responsibility of one or maybe two people and it was seen as their project, and was dependent on them – there was no ownership from other personnel. Since the *Integrate Project*, more people have been trained and all of the staff have been sensitised and are aware of PC. Thus there is now strong ownership of PC and care is seen as being provided by a team and no longer dependent on individuals. There are no strong PC services to function as co-partners; however they are aware of this and are trying to maintain strong networks, in particular through the Palliative Care Association of Uganda (PCAU).

B: Implementation of the *Integrate Project*

Gombe carried out the programme activities largely as described in section 1.3.2 of this document including training 59 staff in basic PC, including 20 from their own hospital, and others from their "hubs", the health centres that refer to Gombe. 10 staff were trained in ToT. 2 staff from the hubs were funded to do specialist training (Diploma in Clinical PC), but none from Gombe Hospital itself. They therefore currently have no-one on the team at the hospital studying for a specialist level qualification. They carried out some VHT training and training for religious leaders, and would like to do more of this.

Full details of the activities carried out can be found in Annex 1.

[34] Confirmed by APCA, August 2015
[35] Baseline questionnaire

C: Palliative Care Team

They have a layered structure and fully integrated PC unit as follows:

Executive Team: This is a team of 2: team leader and secretary. This team is in charge of the management of any funds, and of referrals / monitoring PC patients, organising meetings and ward rounds. PC is integrated into the normal job roles of these 2 people. The team leader is a medical officer working in the hospital and the secretary is a nurse working in the ART clinic. The roles they play in the PC team are recognised and PC is seen as a vital part of their work.

Core Team: This consists of the executive team plus the other staff at the hospital who have been trained on the 5-day training programme. Initially this therefore included all 20 staff, however some of them are more active than others and it tends to consist of around 7 people: 1 pharmacy technician, and the rest nurses. These people are seen as the PC champions within the hospital although are not trained at specialist level. None of them is fully dedicated to PC and all of them also perform other roles within the hospital.

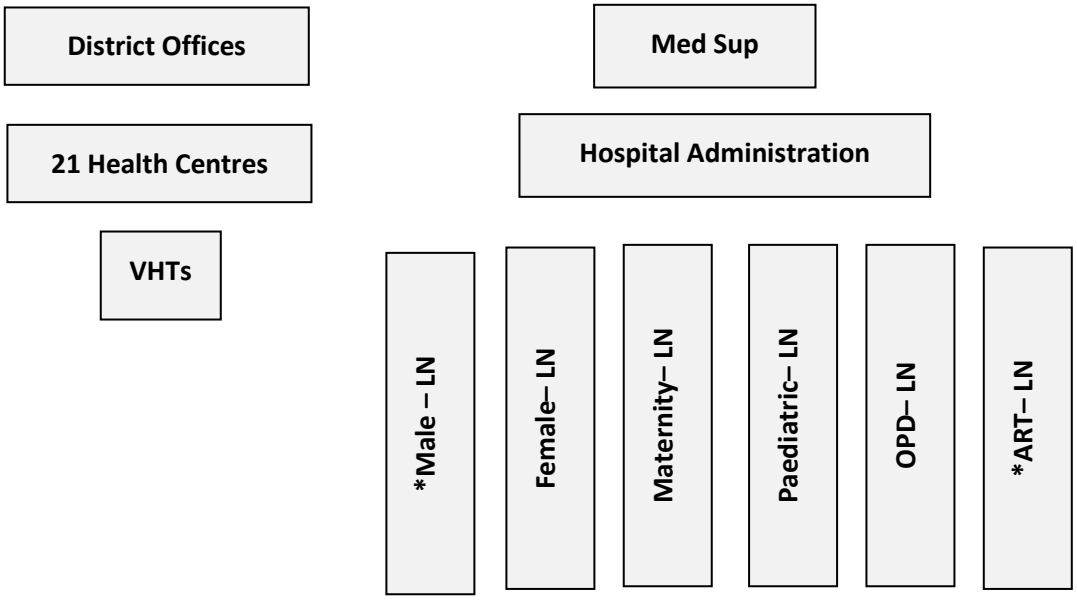
Link nurses: There is a link nurse on each of the 4 wards and outpatients – they are identified as the contacts for PC and referrals are made to the team via the link nurses. There is some overlap between the link nurses and members of the core team.

D: Model of Service

The 3 layers of the PC programme are fully integrated into the hospital. Gombe does not have either separate inpatient beds or outpatients for PC. The PC core team do twice weekly ward rounds and hold monthly meetings to discuss patients. They have named link nurses on each ward, and all patients are jointly managed. The team is always informed of patients with PC needs, and therefore PC patients are captured in the numbers reported through the registry. They are also piloting an online database with APCA through a tablet system.

Gombe Hospital does not have a Hospice or established Home-based care facility for PC referrals. However they have begun expanding their reach into the community by training CHVs to identify and refer patients and support them on discharge. They have also trained health professionals at their associated health clinics. It is hoped that the two specialist trained nurses (through the Diploma in Clinical PC) at two of these clinics, will develop services on their return from training. Currently they are only able to carry out very limited home-based visits themselves to those individuals who live near to the hospital and to whom they can visit without needing transport.

Figure 14: Gombe Hospital Team and Model of Service



* Executive team member

LN – Link Nurse

E: Services Provided

They provide pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and bereavement support, although bereavement support is generally only provided to those who live nearby. They are unable to provide social support in the form of food, transport or legal aid. They are able to provide some diagnostics and treatment on-site and have to refer to Mulago for some chemotherapy, radiotherapy and palliative surgery. They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children.

F: Medicines

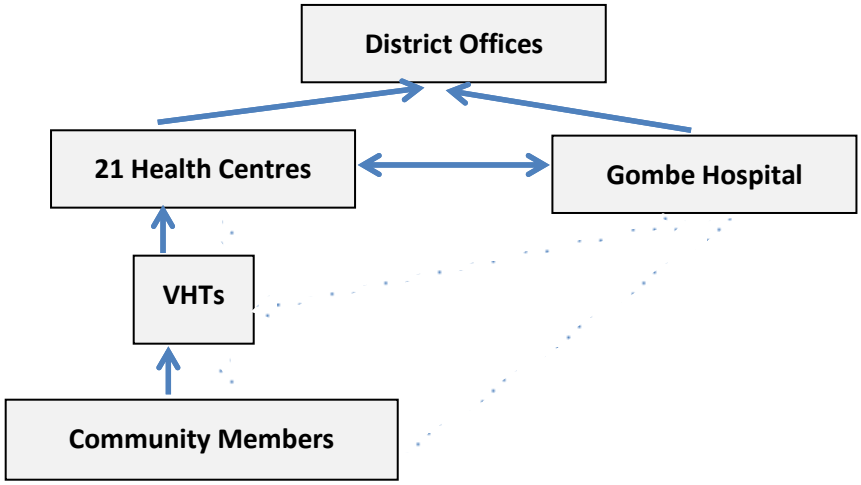
Oral, but not injectable, morphine is available in the hospital. Consumption of oral morphine has increased from 39,000mgs in 2010 to 118,000mgs in 2014. They use the national system of procurement through national medical stores (NMS). The morphine is made up in a concentration of 5mg per 5ml. Few children are on oral morphine for long-term pain as most of their children with life-limiting illnesses are seen at other health facilities. Adult patients have it by their bedside. They reported a stock-out of morphine in the last 6 months of 2014. They do not always have access to anti-diarrheal agents or laxatives (e.g. bisacodyl) and recently experienced stock outs. They stock all other medication reported on the baseline questionnaire including codeine, paracetamol, aspirin, NSAIDs, cortico-steroids, benzodiazepines, haloperidol, other anti-emetics, amitriptyline, hyoscine butylbromide and anticonvulsants. They reported stock-outs of some of these in the last 6 months.

G: Reach into the Community

There is no HBC service to refer to. The hospital team will provide HBC to patients who live within walking/ cycling distance but are not able to provide HBC for patients who live further away as they have no transport.

Gombe Hospital has begun to extend its reach into the community through training VHTs (Village Health Technician's). They have trained individuals from the different health centres to whom the VHTs are linked and refer, so that VHTs can refer PC patients to the clinics who will refer them to the hospital. Two of the health centres will also shortly have specialist PC nurses trained through the DPCC programme to form PC hubs as required. 19 VHTS have been trained through the *Integrate Project* and it is anticipated that more will shortly be trained. Other community sensitisation activities have taken place through the *Integrate Project* such as sensitisation of political leaders, radio talk shows, speaking to local media and training of spiritual leaders.

Figure 15: Gombe Hospital Model of Service



H: Future Vision for Palliative Care

Gombe plans to continue with its model of a dispersed integrated PC team connected via link nurses. They want to further develop links into the community using the VHTs.

I: Lessons learned from this hospital

Gombe hospital provides an excellent example of what can be achieved in setting up a PC service without either dedicated staff or trained specialists. Of the initial 20 trained personnel, seven became active core team members. The team now consist of people who are providing a service because of their passion for PC and they are able to work with the primary team to

provide PC. Their commitment, the support of the hospital management and the presence of a critical mass of staff trained in basic PC makes this work.

They also show how, in such a resource-constrained setting, simple systems can be adopted. For example, one health worker noted that they used to have clerk sheets which they completed when they first saw a patient but this was too complicated and did not work, so they adopted a register and write directly in the patient notes. The ability to adapt systems in this way is an essential part of making service sustainable.

The referral pathways which they are building from the community through to the hospital are an excellent example of health systems strengthening, and how a district hospital can access its communities. They recognise the need to strengthen these pathways further.

3.7.3 Zambia: Mazabuka General Hospital

Hospital level:	District	Beds	160 [47]
Location:	Zambia, Southern province	Population	275,000 [47]
Hospital level description	It has been a MoH district hospital (primary level) for 40 years, but in 2014 was appointed as a general hospital (secondary level)		
PCU History	Minimal service prior to the *Integrate Project* with no morphine available		
PC Organisational Components	Palliative Care committee jointly chaired by MGH physiotherapist and MGH nurse, with membership from the diocese, responsible for providing, co-ordinating and scaling-up services. (see C below for details)		
PC service delivery	Dispersed Integrated Palliative Care Team (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*

In 2012, a doctor and nurse had undergone 1 week of training in PC and 34 doctors, nurses and community health workers had been sensitised about PC through PCAZ. The hospital had minimal PC services available at this time, including limited pain and symptom assessment and limited psychological support and counselling along with nutritional support. The physiotherapist, who is the focal person for PC in the hospital had previously been based at Chilanga Hospice and was personally motivated to extend PC services throughout the hospital. Prior to the *Integrate Project* she had been working closely with the diocesan home-based care teams to help with PC training and sensitisation. The medical superintendent of the hospital and the district coordinator are both supportive of PC services in the district. For these reasons, the hospital was in a good position to quickly adopt PC services.

B: Implementation of the *Integrate Project*

MGH carried out the programme activities largely as described in section 1.3.2 of this document, with a focus on ensuring services extended out to the district health centres and down to the community level. 48 staff were trained in basic PC, across the hospital and the district, and 10 in ToT. 2 staff members were funded to do diploma level specialist training in Uganda.

Through the *Integrate Project* and previous PCAZ work more than 100 HBC volunteers have been sensitised to PC. These are faith-based and funded by the Church Association of Zambia (CHAZ), but link in to the government system through local health centres.

Full details of the activities carried out can be found in Annex 1.

C: Palliative Care Team

MGH has a PC Committee comprised of 6 roles, with members from MGH and the district. It is jointly chaired by an MGH physiotherapist (*Integrate Project* specialist trainee) and a MGH nurse (*Integrate Project* ToT trainee). The treasurer is a diocesan catholic nun who co-ordinates the local HBC service, and the district coordinator is also a member. The committee see themselves as being responsible for embedding PC within the hospital and district through training and sensitisation, as well as being PC providers themselves.

The committee members include *Integrate Project* trained representatives from across the hospital and district, clinics, wards, laboratory and a pastor.

D: Model of Service

PC has started to become part of normal practice in MGH. The primary teams caring for the patient often manage pain and give PC services without needing to refer to trained staff. The more complex patients are referred to one of the PC specialist trainees or doctors on the committee. Patients are referred to PC trained personnel via informal verbal communication and via a newly developed document. Because the hospital is relatively small, it was easier to integrate PC with combined informal/formal methods than in some of the more complex hospitals.

The *Integrate Project* specialist trainee and physiotherapist chair of the committee acts as a focal person for PC. A list of PC patients is kept by each ward and the focal-person for PC logs these names centrally on a monthly basis using a computer data base. The joint/integrated document incorporates referral, assessment, management and discharge planning to facilitate the movement of patients between hospital and community (i.e. the integrated service). This form was developed during an *Integrate Project* mentor visit. The system is relatively new and not yet part of routine practice.

Patients requiring hospital follow-up for PC are seen in the general outpatient clinic. Oral morphine is only available in Mazabuka district at MGH, so patients on morphine come for follow-up to MGH rather than other health centres.

E: Services provided

They provide pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and bereavement support. There is a funeral committee, which pre-dated the *Integrate Project*, but used to provide financial support alone. As a result of the *Integrate Project*, some of the members now feel able to counsel bereaved relatives.

They facilitate social support in the form of food and clothes through private donations, or from local individuals or groups. They can also facilitate support for income generating activities through referral to the HBC teams.

They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children.

They can provide HBC on referral to the CHAZ funded HBC teams. Chemotherapy and radiotherapy are available through referral to the Cancer Diseases Hospital (CDH) in Lusaka.

F: Medicines

They have oral, but not injectable morphine, available in the hospital. Oral morphine was made available during the *Integrate Project* and consumption has increased from zero at project start to 37,915 mgs in 2014. Morphine is available free through the government system from Medical Stores Limited (MSL). There was a national stock-out of morphine syrup during the end of the project, and slow-release morphine tablets (30mgs) were being used and often cut up to obtain correct dosage. This national stock-out has been an annual occurrence in recent years. It is thought to be multi-factorial, to an extent involving procurement processes. However, it is likely largely dependent on the supply/demand equilibrium governing international narcotics medical supply. For example, historically, morphine has not been prescribed/dispensed in large amounts in Zambia (to the extent that MSL have needed to discard significant quantities of unused, reconstituted morphine). Because the government cannot demonstrate demand, the allocated supply via the International Narcotics Board cannot yet increase. It is hoped that the *Integrate Project*, building upon the context laid by previous projects/PCAZ, will increase demand and hence, future supply.

Step 2 analgesic medications are difficult to obtain. They do not have access to either codeine or laxatives. They stock paracetamol, aspirin, cortico-steroids, benzodiazepines, haloperidol tabs and injections, other anti-emetics, anti-diarrheal agents, hyoscine butylbromide, anticonvulsants, NSAIDs and amitriptyline. They reported at least one stock-out in the last 6 months of 2014.

G: Reach into the Community

As described above, MGH has implemented the *Integrate Project* so as to reach their community in the district, as well as the hospital. The hospital serves a catchment area of 275,000 people covering 32 rural health centres. Mazabuka district houses three parishes (St Paul's, Assumption and Magoya). The 22 HBC teams, funded by CHAZ, are administered across these three parishes. The sister who coordinates St Pauls HBC sits on the MGH PC committee, and works closely with the focal person for PC.

Through the *Integrate Project*, members of the supportive HBC teams have received sensitisation on PC from the hospital PC team and closer working links have developed through better inter-team referrals and communication. The HBC workers are now referring patients to MDH and receiving referrals back into the community.

At a district level PC is now on the hospital service delivery aggregation form, reporting into the district health information systems. The data collection form has limitations, in that it is linked to particular treatments at present (surgery, chemotherapy, brachytherapy, radiotherapy and nuclear medicine). However, the form has a flexible comments field, which should be perused, and may lead to modifications over time.

H: Future Vision for Palliative Care

The future plans for PC include further embedding the service in the hospital and district. While some health workers expressed the desire to do this through "a proper PC unit" (i.e. dedicated staff members) with an attached hospice, this seemed more an expression of their passion for extending the service, rather than an expectation that this was realistic for a district hospital.

The future vision described by other committee members was one of using the existing model, and extending throughout the district. They have concrete plans to expand PC to their local population by starting with hospitals / services where they already have a relationship, and are receptive to the introduction of PC services. For example, the *Integrate Project* trained staff will shortly be carrying out PC training in Monze Mission Hospital, a general hospital which provides both 1st level and 2nd levels of care[52] (see section 2.4.2) and in Choma General Hospital. They are also in discussion about developing an outreach team for the local sugar estates.

Lastly they plan to broaden the holistic approach to include comprehensive protocols, and to address their identified need for ongoing communication skills training. They are also implementing internal staff support groups to more formally address the need for self-care.

I: Lessons learned from this hospital

Mazabuka provides an excellent example of joint working across the hospital and the diocesan (church-based) HBC service to provide a service across the district.

This was initially driven by pre-existing relationships between the two sectors, and the drive of individuals to provide PC. These relationships existed before the *Integrate Project*, however the *Integrate Project* crucially provided the funding platform, training, ongoing mentorship, technical support in delivering an integrated service and advocacy for morphine availability to facilitate the integration of the service.

3.7.4 Rwanda: Kibagabaga Hospital

Hospital level:	District	Beds	230
Location:	Kigali City Province	Population	485, 475
Hospital level description	It is a district hospital, which is level 3 in the Rwandan health system		
PCU History	Some service prior to the *Integrate Project* – first hospital in Rwanda to establish a service		
PC Organisational Components	Multi-disciplinary team (MDT) of 16 staff members, responsible for delivering and co-ordinating palliative care with focal people in most wards (see C below for details)		
PC service delivery	Dispersed Integrated Palliative Care Team (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*:

PC was started at the hospital in 2010 after some of the doctors and nurses were trained in PC in 2009. It started in the paediatric department with children with HIV and then it became further integrated across the hospital.

B: Implementation of the *Integrate Project*:

Kibagabaga hospital carried out a slightly scaled down programme activities as described in section 1.3.2 of this document due to previous PC training at the hospital. They trained 33 Health Care Workers in basic PC. Because they had already received ToT training through Mildmay, they did not attend the ToT part of the project. 6 staff had training in research methods, and 5 in children's PC. 3 staff were funded to do specialist diploma level training in Uganda.

They also trained more than 500 community health workers, collaborating with the *Integrate Project* and the Roros Foundation. They have also carried out advocacy at the district level and for World Hospice and PC Day. Additionally, they have published regularly on ehospice and use these publications as advocacy to the district and the MoH.

Full details of the activities carried out can be found in Annex 1.

C: Palliative Care Team:

They have a layered structure and fully integrated PC unit as follows:

Core Team: They have a multi-disciplinary PC team of 16 people, including 3 doctors, 3 social workers, 2 nurses doing specialist training, 4 additional nurses, 1 pharmacist, 1 physiotherapist, 1 psychologist and the CHW in-charge. These people are seen as the PC champions within the hospital although apart from three of them (one doctor and two nurses), they are not trained at specialist level. They do not have dedicated time and also

perform other roles within the hospital. Twice a month they have a team meeting to discuss patients (in addition to the ward rounds).

Focal Point: There is a focal point person in all of the departments who has been trained in PC, is active and who is responsible for PC on the ward. Sometimes they can provide all the PC that is needed and are therefore key in providing generalist PC on the wards. They also identify and refer patients that need to be seen by the team.

D: Model of Service:

The PC team is fully integrated into the hospital. Kibagabaga Hospital does not have either separate inpatient beds or outpatients for PC. Team members are situated within the different departments and so every day they are able to identify patients in need of PC, or the focal person in each department will refer patients to the team. If a patient is seen in outpatients and needs PC, but is not being admitted, then the OPD doctor/ nurse will contact the focal person, usually one of the doctors, in order that they will see them. There is a register for PC patients on each of the wards, and the names/ numbers of patients seen are collated from across the hospital on a monthly basis, for the monthly hospital report. Team members write in the appropriate part of the hospital notes, and also use the PC files approved by the MoH. They keep these PC files together in the ward unit manager's office for each ward. If a patient's needs are complex then several members of the MDT will see the patient together and decide on the course of action as appropriate. Referrals come from some of the health centres and occasionally from other hospitals for PC, although the majority of patients are referred to the team from within the hospital itself and generally patients referred from the health centres are sent for investigations or treatment other than for PC.

As described in section 2.2.1, they can receive referrals from hospitals one level up, or below. They also receive referrals from RHPCO if they live within the sectors where care is provided.

E: Services provided:

They provide pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and bereavement support. They are unable to provide social support in the form of food, transport or legal aid themselves but can refer patients to agencies as appropriate. They are able to provide some diagnostics and treatment on-site and have to refer to the national referral hospital for chemotherapy, radiotherapy (available at Mulago in Uganda) and some palliative surgery. They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children.

F: Medicines

They have oral and injectable morphine available in the hospital. They did not have any oral morphine prior to the *Integrate Project*. In 2013 they were given a donation of oral morphine and in 2014, oral morphine became available through the MoH normal distribution system due to the input of the *Integrate Project*. Morphine is covered under the insurance system so

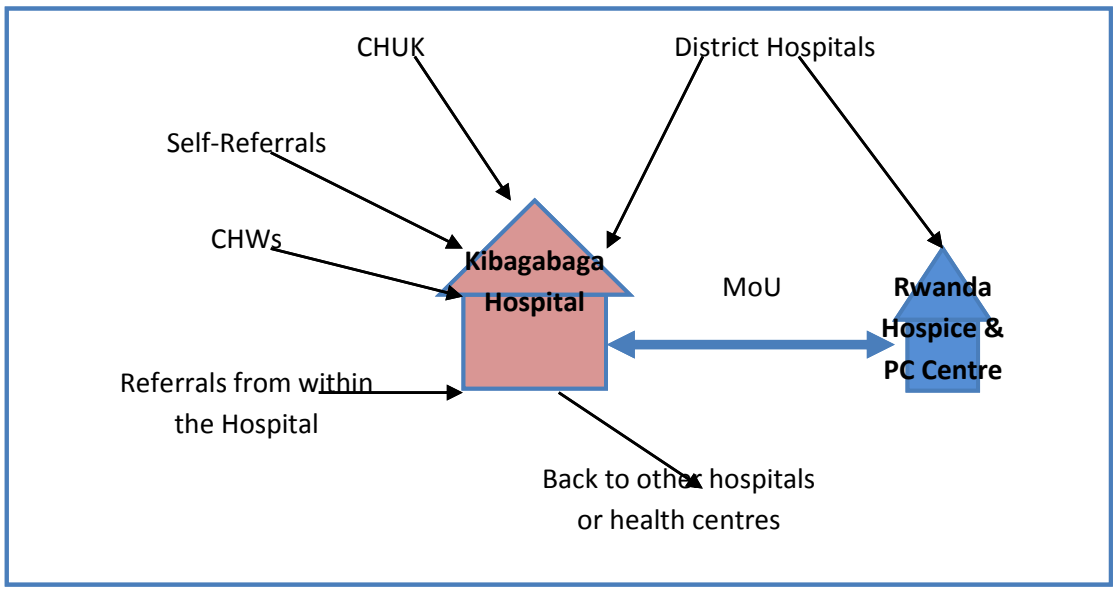
patients only have to pay 10%. They are using 30mg tablets, which they break and put in water for children (although now morphine syrup is available). They hope to get the 10mg tablets soon. Consumption has increased from zero at project start to 69,690 mgs in 2014. They reported availability of all PC medications on the end of project questionnaire apart from codeine, which is not used, and Haloperidol tabs/injection, because they use metoclopramide instead. They did not have any stock-out in the last 6 months of the project. These medications included paracetamol, aspirin, diclofenac, cortico-steroids, benzodiazepines, anti-emetics, amitriptyline, antidiarrheal agents, bisacodyl, hyoscine butylbromide, anticonvulsants.

G: Reach into the Community:

There is a local hospice to which Kibagabaga Hospital can refer as appropriate, and also two HBC programmes – however all of these are run outside of the government system. The medical team at Kibagabaga provides medical cover for the hospice. Recently RHPCO have started providing some HBC and the team at Kibagabaga will refer patients to them when appropriate.

As described in section 2.2.1, patients can only stay in health centres for 3 days, before being discharged. RHPCO have been working with RBC to change this for palliative patients. The health centre only has step 1 analgesics, and staff have had limited training. Health centre staff have been sensitized to PC and are keen for training so that they can provide PC in the home and in the health centre.

Figure 16: Kibagabaga hospital referral pathways[36]



[36] Sourced from Kibagabaga referral pathways document

H: Future Vision for Palliative Care:

They believe that they have already integrated PC throughout the hospital. Their future vision includes more training and supervision at the referring health centres. The chief nurse would like to see some nurses working full time in PC at Kibagabaga to give them more time with the patients, although this is not a concrete plan.

As the first hospital in the country to integrate PC, Kibagabaga see themselves as moving towards becoming a 'centre of excellence'. While RBC see CHUK as becoming more of a centre of excellence than Kibagabaga, they do see the hospital as a model for integration at a district level, and also as having an important ongoing role in health centre mentorship.

I: Lessons learned from this hospital:

Kibagabaga provides a good example of how a district hospital can move beyond a service provided by a few committed individuals to an integrated team service. The doctor who was the main advocate for PC in the hospital had left by the time the *Integrate Project* ended in May 2015. Despite this, there is a passion for PC in the hospital, and it appears to be integrated. The chief nurse asserted:

> *PC is a part of Kibagabaga and it is respected here (Chief Nurse)*

This was corroborated by the fact that everyone in the hospital who was interviewed in the evaluation visit knew about PC, had a basic understanding of what it meant and could identify the key PC people in the hospital.

The hospital also provides a good example of how a dispersed team can create visibility, despite lacking a physical location. On the doors of all the wards there is a list of all people in the PC team at the hospital, including phone numbers so anyone is able to contact them as needed.

Despite these developments, Kibagabaga did not see a big increase in referrals during the time of the project. However, the health workers interviewed believed that they were seeing all patients who needed PC at the hospital.

> *My nurses are providing nursing care to patients including PC patients – it is integrated with other activities" (Chief Nurse)*

Because of the integration of PC throughout the service, there may be many more patients receiving PC from generalists, although this is difficult to evidence.

3.7.5 Rwanda: Rwanangama Hospital

Hospital level:	District	Beds	220
Location:	Eastern Province, Rwanda	Population	330,000
Hospital level description	Currently a district hospital (Level 3) it is in the process of being updated to a provincial hospital (Level 4)		
PCU History	Minimal/None prior to the *Integrate Project*: 5 people had been trained but no service		
PC Organisational Components	Palliative care coordination and planning provided by executive team of 3: doctor, nurse and social worker. Nurse member is full-time focal person, supported by other trained staff in delivering services. (see C below for details)		
PC service delivery	Dedicated palliative care team/individual with integrated support (see D below for details)		

A: History of Palliative Care prior to the *Integrate Project*:

There was minimal PC service prior to the *Integrate Project*, and most of the advances in PC in the hospital have come about as a result of the project. Prior to the *Integrate Project* they had five people who had received some introductory training on PC, but they were not working together to develop PC within the hospital.

B: Implementation of the *Integrate Project*:

Rwamagana hospital carried out the programme activities largely as described in section 1.3.2 of this document including training 45 Health Care Workers in basic PC and 9 in ToT. 8 staff had training in research methods, and 6 children's PC. 2 staff were funded to do specialist diploma level training in Uganda. Through the *Integrate Project* there was a two day sensitisation workshop for 17 health centres and 984 VHTs were sensitised about PC during NCD week. Other community sensitisation activities have taken place through the *Integrate Project* such as sensitisation of political leaders, radio talk shows, speaking to local media etc.

Full details of the activities carried out can be found in Annex 1.

C: Palliative Care Team:

They have a layered structure and partially integrated PC unit as follows:

Executive Team: This is a team of 3: the focal person (nurse), the president (doctor) and the Customer Care Officer (social worker). This team is in charge of the co-ordination of services, and of referrals / monitoring PC patients, organising meetings and ward rounds. They are supported by the hospital director with ongoing planning for PC.

Core Team: This consists of the executive team plus 10 other staff. The focal person, who is a nurse, is based at the HIV clinic and is the only member of staff who has dedicated time for PC

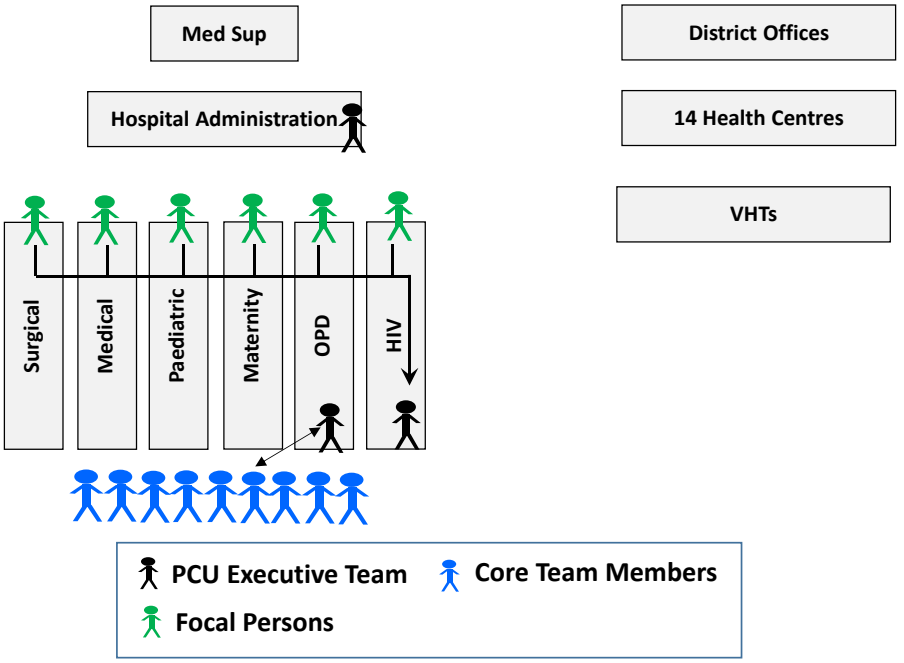
clinical activities. The other 10 staff are those who showed an interest after receiving basic training. They include 3 nurses, 2 social workers, 1 nutritionist, 1 pharmacist, 1 physiotherapist, 1 psychologist and 1 M&E person. These people are seen as the PC champions within the hospital although apart from two of them, they are not trained at specialist level.

Ward staff: There is a staff member (focal person) in all of the departments who has been trained in PC, is active and who is responsible for PC on the ward. Sometimes they can provide all the PC that is needed. They are therefore key in providing generalist PC on the wards, and also in identifying and referring patients that need to be seen by the team.

D: Model of Service:

The 3 layers of the PC programme are partially integrated into the hospital. Rwamagana Hospital does not have either separate inpatient beds or outpatients for PC. Every day the nurse focal person visits the wards to see if there are any PC patients and if so, she will complete an internal transfer – i.e. a written referral to the PC team using the hospital referral form. Staff on the wards also complete referral forms and take them to the focal person. If a patient is seen in the OPD and needs PC, but is not being admitted, then the OPD doctor/ nurse will contact the focal person and make a referral. Once she has received the referral form, the focal person assesses the patient and enters them onto the PC register. If there is a need for input from other members of the team she will call the appropriate person e.g. the doctor, physiotherapist, social worker etc. Once a week the team meets to discuss all the referrals and the care needed. PC team members write in the main hospital notes and as yet they do not have separate PC documentation. Referrals for PC come from Butaro hospital and CHUK. Referrals from health centres are for further investigations only, although these can provide an opportunity to identify PC patients.

Figure 17: Rwamagana Hospital Team and Model of Service



E: Services provided:

They provide pain and symptom assessment and management with opioids, counselling and psychological support, spiritual support and bereavement support. Bereavement support is a challenge. To visit families at home, it is culturally appropriate to bring a small gift (e.g. sugar) and without this it is difficult to visit homes.

They are unable to provide social support in the form of food, transport or legal aid themselves but can refer patients to agencies as appropriate. They are able to provide some diagnostics and treatment on-site and have to refer to the national referral hospital for chemotherapy, radiotherapy (available at Mulago in Uganda) and some palliative surgery. They accept any patient with life-limiting illness as having a PC need, including non-cancer patients and children although they recognise that paediatric PC is limited. One of the challenges at the moment is that only those patients provided with PC by the PC team are entered in the register so it is not known how many are receiving generalist PC through those trained on the ward. The numbers registered are small: only 43 patients were registered in 2014.

F: Medicines

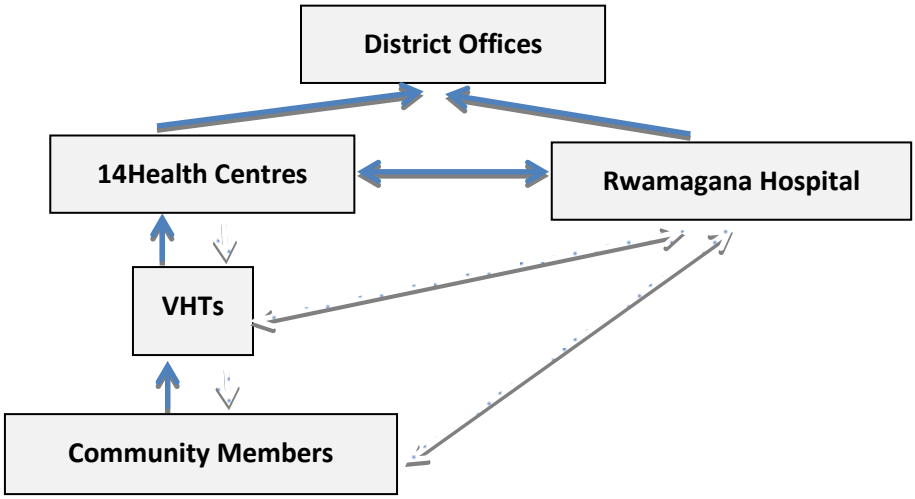
They did not have any oral morphine prior to the *Integrate Project*. 30mg tablets were received in December 2014. They therefore did not prescribe/dispense any morphine during the *Integrate Project* project period, but consumed 1,920mgs in the first quarter of 2015. Patients have to pay for Tramadol but morphine is covered under the insurance system so they only have to pay 10%.
They reported availability of all PC medications on the end of project questionnaire apart from codeine, which is not used. These medications included paracetamol, aspirin, NSAIDs, cortico-steroids, benzodiazepines, Metoclopramide IV. Promethazine, amitriptyline, loperamide, bisacodyl, hyoscine butylbromide, anticonvulsants and Haloperidol tabs/injection. In the last six months, they have had at least one stock out of bisacodyl and anticonvulsants.

G: Reach into the Community:

Rwamagana Hospital does not have a Hospice or established Home-based care facility for PC referrals. However within Rwanda there is a comprehensive service of health centres and VHTs. The health centre staff and VHTs have been sensitized to PC and are keen for further training so that they can provide PC in the home and in the health centre. Although 984 VHTs were sensitised about PC during NCD week, it is not clear if these are actively referring patients. There is, however, a structure in place to link with these VHTs and health centres, with 5 hospital supervisors who visits the centres. There is a need for follow-up through these supervisors (see G: future vision for PC).

At present the Rwamagana PC team are only able to carry out very limited HBC visits themselves to those individuals who live near to the hospital. However they have an active programme for supervision of HIV patients that includes home visits and something similar may be possible for PC.

Figure 18: Rwamagana Hospital Model of Service



H: Future Vision for Palliative Care:

Rwamagana are currently in an interim stage, where they are upgrading from a district hospital to a provincial hospital. This will influence their future vision and strategy, as it will move their advocacy to a more provincial/ national level.

It is anticipated that training will be carried out for the health centres and VHTs so that they can begin to provide PC. It is hoped that once staff have been PC trained in the health centres they may be able to keep patients in for PC as required, and for more than the 3 day limit that is currently imposed on keeping patients within the health centre without referral to the hospital or back home. This would also improve management of referral pathways.

The hospital director explained this thus:

> *"Our dream is to extend PC from the hospital to the health centre and communities so that patients can access it wherever they are." (Hospital Director)*

This development would be an extension of existing systems and has support from the PC desk at RBC/MoH.

In terms of integration within the hospital, they hope to identify an office station for the PC team. Some health workers felt an expansion of the PC team was desirable, ideally with 2 – 3 people doing full time ward rounds and doing home visits. With only 43 patients registered in 2014, this may not be realistic or necessary. However, the team believes that numbers will increase once they become a provincial hospital and have up to 7 other hospitals transferring patients to them.

I: Lessons learned from this hospital:

Rwamagana are seeing a relatively small number of patients. There was, however, clear enthusiasm from the PC team, and an ethos of PC throughout the hospital. The training of 50% of hospital staff will have contributed to this. The hospital director emphasised the benefits this brought not only to patients, but also to staff, as referral to the PC team provides an “alternative option” for health workers faced with terminal patients.

4 Project Delivery Pillars

This section describes the four pillars of this project and summarises the activities carried out under each of these pillars, and the outputs achieved. For more detail, please refer to Annex 1, which describes all activities carried out in each pillar by hospital, and Annex 2, which contains a breakdown of all project indicators by hospital. Indicator data relating to each pillar is included under the pillar heading.

4.1 Advocacy

Indicator 18. Number of advocacy and communication activities undertaken to influence the health agenda	218 (no target set)	✓

Overall, at least 218 advocacy and communication activities were undertaken to influence the national health agenda. This included a wide range of activities, taking place at international, national, district and community levels. A full list of activities undertaken by each hospital can be found in Annex 1. A description of the successes and leaning points is given below in terms of advocacy at 5 main levels:

1. **Ministry Advocacy**: This includes national and devolved level government, as well as the leaders of district services
2. **Community Advocacy**: This means community in the widest sense, being satellite hospitals and health centres, village health teams as well as individual community members. The community advocacy events are listed in the annex.
3. **Internal Advocacy**: This is advocacy within the hospital of operation.
4. **Educational institutional advocacy**

4.1.1 Ministry of Health Advocacy

Indicator 17. Number of Ministries of Health recognising PC in their national health plans	4 (100%)	✓

In each country work to integrate PC into the national health plans was ongoing, and contributed to by a number of organisations and individuals. The project target was that all 4 countries should have the MoH recognising PC in their national plans. This target has been achieved (100%) as all countries do recognise PC in their plans. Other achievement at ministerial and country level included the incorporation of PC in the strategic plan for Nyeri country in Kenya, development of a stand-alone policy for PC in Uganda and inclusion of PC in the national indicators in both Zambia and Rwanda.

It is important to note that whilst each country has recognised PC in the national health-plans this is not attributable solely to the *Integrate Project,* but is as results of the wider environment in which the project is taking place. There have been many factors and organisations working together in each of the countries to achieve this. Alongside the integration of PC into the national health plans, PC has been integrated into different policies and documents such as the HIV policy in Zambia and the National Cancer Control Strategy in Kenya.

In Rwanda, along with other stakeholders, the project contributed to the formation of a PC Desk at the MoH, which supported the project during the last 18 months. This led to inclusion of PC in the division plans, integration of a PC cluster group within the NCD technical working group, development of a morphine procurement framework, adoption of national clinical guidelines to be disseminated to the hospitals, inclusion of PC in the Health Management Information System (HMIS).

A number of successes, as well as challenges were observed in *Integrate Project* funded hospitals in terms of ministerial advocacy. The successes are summarised below, and the challenges at the end of this section.

1. Active role of *Integrate Project* hospital personnel:

In many areas, we observed very strong relationship between the *Integrate Project* hospital PC staff and the MoH, or district health officials, with the *Integrate Project* playing a role in planning activities at the Ministry level. The relationship between hospital staff and MoH staff is an integral part of the health system in the four countries, as hospital staff in district hospitals tend to be employees of the district, and those of the national referral centres employees of the MoH. In many cases staff within the *Integrate Project* hospitals used this role to advocate for PC, in their hospital and in their district. For example in Nyeri, PC had been incorporated into the strategic plan for Nyeri county during the course of the *Integrate Project*, and it was clear that staff from the *Integrate Project* hospital were seen as specialist resources with an ongoing role in training and mentoring.

2. Key champions at Ministry Level:

Key champions at the MoH level is an important part of ensuring PC remains on the agenda. Most countries have such champions through the years of advocacy and service delivery which has already taken place. Through sensitising more people to PC, and putting specialists in place, the *Integrate Project* has supported and facilitated these champions: One county official explained:

"We want to see PC embraced just like any other services. There is mother and child, there is immunisations, there is PC" County Official, Kenya

3. Support of National Association:

The National Associations were effective partners for advocating at the national level. With a life prior to, and beyond the *Integrate Project*, national associations were variously advocating for inclusion of PC on curricula, PC policies, publishing and implementing standards, and recognition of PC specialists. One National Association lead commented that the project had occurred at an expedient time, when the WHA had pushed integrating PC up the advocacy agenda:

"The WHA resolution is also pushing our ministry to do something and as they have to report to the WHA, the ministry is being vigilant about it – they are being pushed by the international community which is good – and it is no longer just us pushing them." (Co-ordinator, PCAU)

4.1.2 Community Advocacy

Indicator 24. Number of community people attending awareness training.	4153 (> 100%)	✓
Indicator 25. Number of community health awareness or mobilisation campaigns to which projects have contributed by the end of the programme	73	–

At least 4,153 community members attended awareness training through 73 different events. These events are listed in Annex 1, and included:

- Sensitisation for the hospital community
- Sensitisation at satellite hospitals (the hospitals that refer to the *Integrate Project* hospitals)
- Talks at community events such as burials, churches, community meetings
- Training of Community Health Volunteers

Successes in community advocacy included the following:

1. Integration in the Primary Health Care System

The greatest successes in community advocacy and sensitisation came when the existing primary healthcare system was used as a platform for the integration of PC. In the cases where this was effective this led, not only to greater sensitisation in the community, but strengthened referral pathways between the community and the hospital. For example, the model of the community unit in Kenya, and the Village Health Team in Uganda was used by both countries to train community staff to actively refer patients and support them in their communities. MTRH in Kenya identified their community as their local satellite hospitals, which are their referring community according to the structure of the health system.

2. Use of existing platforms for sensitisation

Hospitals effectively used existing platforms for sensitisation meetings in order to reach a large number of people. Church meetings, radio, and existing community events, such as the "Barraza" in Kenya: social gatherings held to raise awareness and share collective wisdom.

4.1.3 Internal (Hospital) Advocacy

Successes in internal advocacy included:

1. Involvement from the start:

A number of hospitals considered that advocacy across the hospital as the very first project activity was key to the success of integrating PC within the hospital. In particular it was seen as necessary to involve and sensitise senior medical staff before commencing project activities.

2. Continuous advocacy

While a single advocacy event at the start of the project was seen as key, the most successful hospitals recognised continuous advocacy as a necessary part of integrating care within a hospital. This continuous advocacy is not captured in the hospital figures, but those hospitals achieving a high level of integration have incorporated this into their normal activities, such as CMEs, and it is now self-sustaining.

4.1.4 Educational Institution Advocacy

A number of successes were realised in advocacy for the integration of PC in educational institutions during the period of the project. These are important developments, because they represent sustainable system changes to contribute towards the integration of PC in the long term:

National Teaching Institutions:

1. University Teaching Hospital, Lusaka, Zambia

With *Integrate Project* mentor support, PC has been integrated into the undergraduate medical curriculum at the University of Zambia (UNZA), School of Medicine. This involved collaboration with the Dean of the Medical School, PCAZ, and the Department for Medical

Education Development. The current curriculum was reviewed in order to identify existing PC topics and suggest mapping for topics that could be included. Recommendations were approved by the school of medicine and teaching was implemented during the 2014/2015 academic year. The teaching is integrated into years 3-7 of the 7 year course, with a bulk of teaching during year 6 (currently 120 students). The teaching has been coordinated by the UCH mentor, who was there for 1 year and also held a part time lecturer position at UNZA, and handed over to the head of the PC team on departure in June 2015. Other members of the PC team will be involved in tutoring the undergraduate students. The first round of students gave positive feedback to the training. Some of their quotes are shown in the box below:

Figure 19: UTH Students quotes on undergraduate medical palliative care training

We learnt what PC is….the importance. For me the helpful thing was morphine calculations

It was a wonderful to see [the specialist PC nurse] working – this motivated me to become a doctor in PC

I learnt about holistic care and finding out about what the patient needs….treating the patient as a person, not a case. Sometimes you feel you hit a brick wall, but PC taught me there is always something we can do

Since learning about PC, I ask more questions and try to strike a rapport with patients

As the quotes show, students found the training had an impact on clinical skills, interpersonal skills with patients and on their own motivation.

2. Moi Teaching and Referral Hospital, Eldoret, Kenya

In April 2015, PC was in the process of being introduced into the medical undergraduate training in the Faculty of Health Sciences at Moi University. PC has already, for some time, been part of the nursing training and in the postgraduate family medicine under the chronic disease component. The new undergraduate module will be taught from November 2015 as "Chronic disease management and PC" within the family medicine course. 90 students will rotate through PC and chronic disease care, training in MTRH and going out on home visits with Eldoret Hospice. The *Integrate Project* training has strengthened the ability of MTRH to absorb and train these students.

3. CHUK

PC has not yet been integrated into the curricula of teaching institutions in Rwanda. However, RBC see this as an essential next step and see CHUK as playing an important role in training students. The PC team at CHUK have recently become involved in teaching in the university for different faculties (e.g. medicine, nursing, clinical psychology). They have also been invited to participate in developing curricula for others e.g. VHTs, NCDs etc. They are therefore being recognised as PC resources and being utilised. Discussions have also begun with the University of Rwanda with regards to integrating PC into their undergraduate curriculum and the potential for an MSc in Palliative Nursing. Work on this is ongoing. With the suggestion of the Principal of the University of Rwanda, the Curriculum Toolkit mentioned below was developed.

Regional and District hospitals

As described in section 2.5, all the regional hospitals and some of the district hospitals also have a teaching component, in association with universities and teaching colleges. These hospitals also saw advocacy successes in terms of nursing and medical curricula. For example, in Kabale, PC was already in the nursing curriculum and the regional medical school at Mbarara University of Science and Technology prior to the *Integrate Project*, but the focus was on theory. Now, as a result of the *Integrate Project*, there is an emphasis on clinical learning, as when students come to the hospital, the PC teams involve the students in patient care where possible, and also in attending CME's. Similar successes have occurred in Rwamagana, Rwanda. In Gulu, the PC team teach medical student some practice on the wards, and are advocating for the inclusion of PC theory into medical training.

Kibagabaga hospital tries to model PC to their nursing and medical students. Students interviewed during the evaluation visit were all aware of PC, could tell us what it is and give examples of what they had seen at the hospital. Individuals from Kibagabaga are invited to curricula meetings from RBC. They are seen as key in any national developments for PC, and will be used for ongoing training and supervision as PC is rolled out across the country.

Curriculum Toolkit

To support palliative care integration into educational curriculums a Curriculum Toolkit has been developed as part of the Integrate project entitled **'A Palliative Care Curriculum Toolkit: A practical guide to integrating palliative care into Health Professional Education'**

The technical working group included technical experts in palliative care education and curriculum development from the University of Edinburgh, Makerere University, University of Capetown and University of Zambia. The latter 2 were also mentors within the Integrate project. This document is intended to guide those involved in curriculum planning and delivery

in integrating and strengthening palliative care education in their relevant programmes. It does not contain detailed information on educational theory, but focuses on the practical integration of palliative care into existing educational frameworks such as those published by APCA and the European Association for Palliative Care (EAPC). It includes resources that will be open access and will be available online through the Integrate website and the University of Edinburgh.

4.1.5 Issues Identified Going Forward

As well as successes in advocacy, the project met certain challenges. These present issues going forward for the participating hospitals, which will need to be addressed.

At a National Level:

1. **Implementation of Plans**:

Inclusion of PC in a national level plan is a first step in the integration of PC into the health system. The implementation of these plans is essential and each country is at a different stage of implementation. PC Champions within ministries and in National Associations can contribute substantially to ensuring plans are taken forward. In addition, empowering the national and regional referral hospitals is an important tool in national advocacy given their lead role in influencing policy and models of care.

2. **Translating support to budget**:

While most hospitals spoke very positively about the support of the national and district MoH, some staff expressed frustration that it was not always translated into a budget for supplies and resources. There were examples that budgetary support was becoming available, particularly in the form of a small number of funded staff members and essentially medicine. However, budget for services, such as outreach and home visits was often difficult to find. These resource constraints need to be taken into account when establishing PC service models.

3. **Ongoing Impacts at a National Level**

Some systemic changes required implementation at national level, in order for local level hospitals to be able to make and sustain service changes. For example morphine supply systems are established at a national level, as are health workforce numbers. Most of the *Integrate Project* activities took place at the hospital level, and most of the changes effected

were at this level. However, the project was also operating at national level through the National Associations and through the PC desk in the MoH in Rwanda. Ongoing support at this level is required for changes achieved to be sustained.

At a Community Level

1. Entrenched Beliefs

Some hospital staff commented that community sensitisation was difficult, because of entrenched myths surrounding cancer, HIV and use of morphine.

2. Weak Primary Health Care Systems.

While integration in primary healthcare systems is highlighted in the previous page as a success observed in the community trainings, weaknesses in this healthcare system are a challenge. For example, the model of the community health unit, which underpins the community health strategy in Kenya has poor coverage, with a target to cover only 1/3 population by 2015. Village Health Teams in Uganda are similarly not operational in all areas, and motivation of unpaid community health workers is sometimes a challenge. [28] This challenge highlights that use of the primary healthcare system, whilst a great strength, is not panacea, and may not be achievable in all areas, and other strategies may be required.

3. Need for follow-up.

The different implementation of these activities showed that, simply training community staff within the system is not enough, there needs to be a plan and procedure for follow-up and support. For example, a hospital in Uganda had trained the Village Health Technicians, but was not aware if they were actively referring patients as they had not been followed up.

At the hospital level

Internal advocacy seemed to be less of a challenge in district hospitals, which have a smaller number of medical staff. In national teaching hospitals, changing the mind-set of staff proved more difficult, and it is apparent that a concerted programme of advocacy was required in these hospitals, and will still be required, particularly in those hospitals who have further to go along the continuum of integration.

4.2 Training

Indicator 12. Number of health workers demonstrating improved performance following education or training	90% health workers (no target set)	–
Indicator 13. Total number of health workers with skills to provide palliative care per 100,000 population	Median:10.2 0.5 – 44 (no target set)	–
Indicator 14. Number of health workers demonstrating improved knowledge or skills following education or training	94.2% health workers (no target set)	–
Indicator 15. Number of developing country health workers who participated in education and training by the end of the programme	781 (>100% target)	✓
Indicator 16. Number of trained professionals completing clinical placements	520 health workers (no target set)	–
Indicator 26. Number of health professionals applying their skills and learning to benefit the local community.	625 health workers (no target set)	–
Indicator 27. Number trained as trainers	123 (51%)	✗

As the indicators above show, 781 developing health workers participated in education and training by the end of the programme. This was substantially more than the original target of 480, an achievement which was possible because trainings were cheaper than was budgeted. These included basic training in PC, training of trainers (ToT), research training, pharmacist training, children's palliative care training and specialist training. 520 of these health workers completed clinical placement in PC. 94.2% of health workers showed improved knowledge or skills following training, and 90% improved performance as measured by the pre-and post-tests. More detail can be found in Annex 1 and 2.

Total number of health workers with skills to provide PC per 100,000 population varied quite considerable across the hospitals, ranging from 0.5:100,000 at one of the national teaching hospitals to 44:100,000 at one of the district hospitals.

4.2.1 Basic Training

614 health-workers completed the basic training in PC. The majority of these also had a clinical placement.

The response to this basic training was almost overwhelmingly positive in all staff interviewed. The important successes which emerged were as follows:

1. **"Conversion" to Palliative Care:**

A large number of health care workers, in all countries considered the first time they received basic training as a "conversion" to PC. When asked about the impact of the basic training, many staff used language such as it was "life-changing", "it converted me", "and I am now infected with PC." Many people explained that they did not realise what PC was about prior to receiving training, and often they had negative perceptions of it as "giving up" on patients.

2. Improved Clinical Skills

A number of health workers described a step-change in their clinical skills as a result of receiving basic training. The changes expressed were:

1. **Identification of palliative care need**: Health workers conveyed how previously, they did not understand "total pain" and holistic care, and were unable to identify patients with a PC need, but the basic training changed this.
2. **Pain management**: A number of health workers explained how their practice of pain management had completely changed, since they learned that "pain is what the patient says it is."
3. **Breaking Bad News**: Health workers experienced an improved ability to break bad news to patients and their families as a result of the basic training.

Many of these staff also expressed the need for further training, describing the basic training as an "eye-opener" which did not "go deep", but gave them sufficient skills and knowledge to being to practice. The improvement in clinical skills is covered in more detail in section 5.2: changes in clinical practice.

3. Critical Mass of Staff

The 5-day basic training with a clinical placement model is not unique to the *Integrate Project*. While some hospitals reported that this was the first training that had taken place in their hospital, many others reported previous trainings funded by APCA, DPWF, True Colours and local National Associations. In many hospitals the *Integrate Project* built on this existing ground by training increased numbers of staff. In hospitals where there had been no prior training, the *Integrate Project* introduced PC for the first time. Having a critical mass of individuals trained at each hospital was seen as key in the integration and ownership of PC. In one setting, CHUK, this basic training was targeted at senior staff as a tool to influence the decision makers and leaders. This critical mass varies between the size and reach of the hospitals and is much more difficult to achieve and gauge in the national and regional teaching institutions yet the impact can still be seen.

4.2.2 ToT Training

123 staff were trained in ToT skills. These staff were taught how to prepare, plan and deliver a training workshop. Hospitals were also provided with laptop computers so that they could continue to deliver trainings after the project finished. Trainees spoke very highly of the ToT training. Successes noted were:

1. **Empowerment of trainees**:

Mainly trainees found the technical skills they gained through the training hugely empowering. The training in preparing a presentation in Microsoft PowerPoint and delivering it as a slide show was a particular success. The "demystification" of PowerPoint was the element which, for some trainees, led to the realisation "I also can do this!" One nurse expressed this with pride:

> *I was able to make my own slides and make them my way. I could even show someone how to do new slide the other a day – I was almost like an expert!* (Nurse, Mazabuka)

2. **Increased Confidence**

While some health workers already had confidence to present in front of their peers, a number reported that the ToT course provided them with, or increased this confidence. A health worker in Rwamagana explained how previously, she was not confident to stand up in front of a group of people to speak about PC, but since doing the ToT training, she now had this confidence.

3. **Continued use of skills and resources**

A large number of hospitals are now actively using their training skills to continue delivering training and sensitisation workshops through hospital CMEs, community sensitisations and trainings in district and satellite hospitals. More detail on the future plans of individual hospitals is captured in the hospitals section of this report (Section 3.4). Some were identified by district or national MoH as training leaders for PC. For example RBC had requested CHUK ToT staff to deliver a 2-hour training session to medical students.

4.2.3 Specialist Training

36 health workers were funded to do specialist training. The majority of these were either a diploma in PC (offered by 3 organisations in Uganda, and by Nairobi Hospice in Kenya), a

diploma in paediatric PC (offered by 1 organisation in Uganda) or a degree in PC at Makerere University Uganda. The noted benefits of this training were as follows:

1. **Increased specialist clinical skills**:

Virtually all specialist trainees reported the increased specialist clinical skills as a result of their training. Most trainees used the word "deep" or "deeper" to describe the training, reflecting that clinically it covers the same areas as basic training, but in much greater depth.

2. **Whole systems approach**:

Some specialist trainees said they now have a greater understanding of PC as a process, which requires policy, medicines, trained staff and implementation at all levels. This has made them take a whole systems approach to PC. Some comments made, and examples observed were as follows:

> *"The training helped me to approach people in politics, or senior level. Before, the chief county officer would not take my phone calls. They have also recognised us as specialists. Now I am interested what is in the strategic plan."* *(Specialist trainee, Nyeri)*

This staff member demonstrated during the evaluation visit that she was actively engaged at district MoH level in supporting the implementation of this plan.

Another trainee, in a Zambian hospital narrated how she took action when there was a morphine stock-out, and said that before her training, she would not have tackled this issue.

3. **Change in status in hospital:**

Some specialist trainees reported that they had seen a change in their status within the hospital, or expected to a see a change. Changes were mostly in the attitude of senior staff towards them, in particular doctors, as opposed to an official change of status. Health Workers thought changes resulted both from the paper qualification which comes with a diploma/degree, and also with their own increased knowledge. One nurse explained this as follows:

> *Doctors have recognised that me and the others [specialist trainee colleagues] are experts in some PC areas… people ask us to do counselling, especially. (Nurse, Ndola)*

Some nurse specialist trainees reported challenges in this area still, particularly with regards to prescribing or the ordering of diagnostic tests. However they also described an increasing ability to change practice and challenge doctors.

4. Pre-requisite for providing dedicated staff:

In some particular cases, the existence of a specialist trainee was a pre-requisite for a provision of dedicated staff. One hospital (Ndola) which is currently operating on a dispersed integrated team model, has a commitment from the hospital executive to release a staff member as a full-time co-ordinator once the requisite specialist qualifications have been gained.

4.2.4 Other Trainings

4.2.4.1 Research Training

81 staff undertook research training. Staff spoke of this very positively, although many said it was too brief. Many hospitals were keen to start carrying out their own research, although most staff trained did not feel sufficiently confident to embark independently on research projects without external support. The project has established partnerships with PC organisations and research institutions which will enable this support to be facilitated, and it seems likely that some research projects will be undertaken by *Integrate Project* hospitals in PC. Specialist trainees are carrying out research projects as a part of their diploma and degree, and this will further increase research capacity in the hospitals.

National hospitals, in particular, saw continued input into research as an essential part of their future activities:

> *We are going to be the Centre of excellence with research related to PC as we need the evidence base and the data and research so going to put effort into that (Med Director, CHUK)*

4.2.4.2 Children's Palliative Care Training

39 staff in Rwanda and Uganda received training in children's PC. There was no breakdown available for children receiving PC, so we were unable to confirm increased referrals resulting from this. However, health-workers reported benefits from the training, in particular, an increased understanding of how children feel pain. Surprisingly, a number of health workers articulated that, before paediatric PC training, they did not understand that children feel physically pain as intensely as adults, and therefore did not manage it.

Before they did not attend to children's pain because they didn't imagine they feel the level of pain that they do and they didn't know how to score it. But now they manage pain even in children. (Nurse, Kabale)

Some hospitals referred to management of pain for children with acute issues, and it was less clear what service was available for children with chronic life-limiting conditions.

Some health workers also felt that the paediatric training helped them appreciate what the families are going through (nursing in-charge, Rwamagana), and gave them skills to break bad news to parents and to the children themselves where appropriate.

There were some challenges noted in terms of paediatric dosing. For example, in Rwamagana, the paediatric nursing in-charge recounted how they were using 30 mg tablets of morphine which are much too big for children so they have been cutting them up into several pieces and so cannot be sure of the dose.

4.2.4.3 Training for pharmacists and hospital directors

70 pharmacists and hospital directors from across Rwanda were trained in palliative care and specifically the use of morphine. This training was an addition towards the end of the *Integrate Project* at the request of the MoH once morphine had become available. The end of course questionnaire demonstrated an increase in knowledge by the majority of participants, and the course was well evaluated, although it is too soon to know the impact of the training.

4.2.4.4 Most Significant Change Training

231 staff undertook Most Significant Change training. This is a project impact evaluation technique, not a PC technique. The process involves the collection of significant change (SC) stories emanating from the field level, and the systematic selection of the most significant of these stories by panels of designated stakeholders or staff. This is intended to uncover the most significant change that occurred as a result of a project, and is a method of assessing project impact.

Some health workers reported that this was a useful experience, and they learned to write and capture stories as a result. A large number of health workers misunderstood the purpose of the training, and interpreted it as a technique to elicit problems for patients, or to highlight case studies to be used for PC advocacy. Most of the change stories captured are individual patient stories. It was not evident from the evaluation interviews that any of the hospitals intended to use the skills in story writing in the future.

If the technique is used to evaluate future projects, it may be more beneficial for internal evaluators from the project team to write at least one round of stories rather than the hospital clinical staff. This will help them to understand what is expected.

4.2.5 Issues Identified Going Forward

As well as successes in staff capacity building, the project met certain challenges. These present issues going forward for the participating hospitals, which will need to be addressed.

1. Some staff not "converted":

Some hospitals pointed out that, because of a lack of interest, or a lack of additional payment by the hospital or the project for health-workers to support the PC activities at the hospital, many of the trained health workers did not become actively engaged in PC service provision because they did not see the personal benefits in it. For example, the evaluator in one hospital estimated that, out of the staff trained about 30% are fully engaged in delivering PC using the internal referral pathways and model in place. This is an estimation, and the number could be much higher in other hospitals, particularly where staff were strategically selected for training. One nurse said simply:

> "Those interested have been able to use their skills regularly to improve patient care but those that are not interested have not used these skills and knowledge". (Kabale)

This challenge has been highlighted, not as a project failure, but for the purposes of self-reflection and highlighting learning points. A high proportion of staff describing a short training as "life-changing" and "eye-opening" can only be regarded as a success. These are the staff who will actively implement a PC service within their organisations, regardless of financial incentive, whereas the remaining staff trained still demonstrate improved skills in PC and are therefore still likely to support this service, albeit to a lesser degree. The hospital director in Rwamagana recognised this explicitly saying:

> *Some nurses just haven't taken it on but this is not a waste…. (Hospital director, Rwamagana)*

He went on to say that, for these staff to have had the training has made them understand about PC, know about the team model and this helps with referral pathways and benefits patients.

2. Importance of Clinical Placement

Hospitals who raised the challenge of certain staff trained being less engaged that others noticed the importance of the clinical placement in the training, as this was the moment when they were "converted" and they truly understood how PC could transform their practice. The importance of directly observing and experiencing clinical modelling was repeatedly highlighted. One nurse explained the importance of going to MPCU and observing practise in Mulago hospital to see the link nurses there practicing:

> *"I did the Link nurse training in Mulago and it has changed my life - Now I have the heart of listening to the patients, talking, counselling and assessing them (Nurse, Gulu)*

3. **Strategic Selection**

Some hospitals reported strategically selecting staff for training, based on two factors "passion" and position within the hospital. More than one hospital reported that when a nurse "in-charge" was selected for training, the result was quite different than when more junior people were selected. Some also reported finding ways to manage a less enthusiastic 'in-charge' by training younger colleagues with leadership drive and opportunity.

4. **Coverage and Deployment**:

Hospitals which selected staff to provide a coverage of basic trainees across as many wards as possible show higher levels of integration. There is a need to ensure staff are deployed correctly following trainings. For the most part, staff seemed to have been deployed correctly. There were some exceptions to this noted in the evaluation visits. For example, one nutritionist, who had done modular training in MTRH was working in the new-born unit. She said:

> *Now I am in new-born unit it's like I am sitting on that skill. If I am placed in paediatric ward it will be OK.* *[Nutritionist, Kenya]*

This health worker then clarified that she did not anticipate any resistance from her HoD or hospital deportment if she asked to be redeployed, so there was not a suggestion that deployment was a particular problem in any of the areas.

5. **Variation in plans for ToT staff**

The future plans of the hospitals for ongoing training varied widely. While many hospitals were clearly using the skills they gained through ToT, some health workers enquired why the *Integrate Project* was completing before the ToTs had a chance to use their skills. Their expectation was that the *Integrate Project* should have funded the trainings of lower level health centres in PC. This expectation may stem from the culture of the hospital or district. It points to the need for PC leadership and vision within each hospital.

6. **Specialist Training**

Some staff expressed disappointment that their specialist qualification would not necessarily lead to a promotion, or an increment in salary. In the case of specialist trainees, this lack of financial incentive was not detracting from service delivery: these staff were all committed individuals, motivated to help their patients and were actively providing PC.

Other PC leaders in the organisations commented that specialist trainees, who in most organisations co-ordinate and lead the clinical service, could be incentivised in small ways,

such as a staff away-day, or simply ensuring that essential medical supplies and other resources were in place to help them do their job. PC Associations also noted this, with one lead commenting:

> People need to understand that incentivsation is not just about money …. (PC Association Lead)

7. Characteristics of national and regional hospitals and academic institutions

Large, complex institutions will need a wider range of interventions and training in order to reach a tipping point or critical mass. Engagement will also be needed within the associated academic institutions where provision and development of an evidence base will be essential for credibility. The lead time before change is visible will be longer in these large complex settings. This can be seen in this project where those who had already developed palliative care such as MTRH were able to quickly add leverage and show change. Those such as CHUK and UTH took considerably longer to develop the advocacy and critical mass and were showing change only towards the end of the project.

4.3 Service Delivery

This project had a number of service delivery outcomes, including improved referral pathways, improved availability of morphine, establishing of hospital policy and protocols. More detail on these can be found in Annex 1 and 2. A summary of the successes in each area is given below.

4.3.1 Referral Pathways

Indicator 1. # Palliative care referral networks mapping showing stronger linkages at the end of programme as compared to at the start.	12 (100%) ✓
Indicator 9. Number of patients using palliative care services at 12 participating institutions	>20% increase at 11 hospitals and 15% at 1 hospital (92%) ✘
Indicator 11. Number of patients with a documented management plan of care	Approx. 25% –

All hospitals showed stronger referral linkages at the end of the programme as compared to the start. This includes referral pathways within the hospital and to the community. This is in part evidence by an increase in the number of patients by more than 20% in 11 of the 12

hospitals. There was less room for such a large increase in the 12th hospital (Kibagabaga) as it had the most developed PC service of all of the hospitals at the start of the *Integrate Project*. Most of the hospital staff interviewed believed this was largely due to increased numbers of referrals. Many successes were observed. These included:

Within the hospital:

1. Establishing a central point for referrals

All hospitals had a central point for receiving and logging referrals by the end of the project. Sometimes this was a dedicated office for PC, often referred to as the PC "unit". Sometimes it was the office of a member of a dispersed PC core team.

2. Patient Documentation

All hospitals had established methods of documenting and tracking patients within the hospital by project end. All hospitals had a separate register for PC patients.

We estimate that approximately 25% of patients have a documented management plan of care. This is described further in the Annex. This is influenced to some extent by government guidelines. In Kenya, Zambia and Ugandan government hospitals there are clear guidelines as to who can write in the notes, what notes they can use etc. Some of the hospitals have separate notes for their PC patients e.g. at MTRH (Kenya) where they have separate assessment documentation etc. In some hospitals the doctors write directly in the notes, e.g. UTH and Ndola (Zambia). In Uganda, Gombe, they record details of each patient and what needs to be done for them, however the information recorded is minimal. The system in Rwanda enables health workers to write limited information in the notes such that there is a documented management plan. They are also looking at integrating more detailed PC patient assessments and this is being done at the national level.

3. Use of the "link nurse" model:

A number of hospitals used a "link-nurse" model to ensure clear referral pathways from the ward to the PC specialist individuals. Many of the specialist trainees had observed this model operating in the Makerere and Mulago Palliative Care Unit, Kampala, while they were on placement there, and put it into practice in their own hospital. The model involves a named "link-nurse" in each ward or unit, being the referral point in that ward/unit for patients with a PC need. Trained/sensitised staff on the ward will refer patients with PC needs to the link nurse, who in turn will refer patients to the PC unit. In Mulago hospital, the PC unit is a specialised unit within internal medicine, led by a consultant physician. In the *Integrate Project*

hospitals, the link nurses liaised with the hub for PC within the hospitals, which was sometimes a dedicated team, or named individuals dispersed in the hospital.

Forms of this model were implemented in all hospitals in Uganda, in Homa Bay in Kenya, Ndola in Zambia and CHUK in Rwanda. Other hospitals implemented less formal variations on this model, including having focal-persons in each unit, or a critical mass of trained staff on each ward, but without a named "link" staff member. One health care worker, in MTRH related how, through undertaking the basic training, she automatically became part of an extended team and a referral network:

Before I didn't know how to liaise with the PC team. But then they gave us the mandate to be part of them. I could call them when I'm not able to handle some patients. The first time I needed to counsel a patient I called someone [from the core team] to assist me, then I did it myself, and then when someone asked me I did it with her. (Nutritionist, MTRH)

4. Written referrals:

A number of hospitals had very clear written referral processes. For example, Rwamagana described a process whereby every day the focal person visits the wards to see if there are any PC patients and if so then they complete a written referral to the PC team using the hospital form. These referrals are brought to the hospital focal person. This was a common process, and in the hospitals which had no service prior to the *Integrate Project*, these processes were implemented as a result of the project.

5. Telephone referral:

Most hospitals had some form of formal or informal telephone referral working alongside a written referral system. The informal model worked through committed individuals giving out their phone number so that they could receive referrals. The more formal model involved having a dedicated number, with the responsibility for manning the phone rotating among individuals. MTRH's 24-hour hotline is a good example of this. The phone number was advertised in posters throughout the hospital for internal referrals, as well as given to patients on discharge so that they had a link to the hospital from the community.

6. Case Meeting Discussions

Most of the hospitals had established a regular meeting to discuss patients. For example, Rwamagana have a weekly team meeting to discuss all of the referrals and their care, and whose input etc. is needed. Kibagabaga described similar twice-monthly meetings.

Between the hospital and community

1. **Strengthened links with palliative care partners**

Links were strengthened with local partners who also provided PC. When carrying out the basic training, many of the hospitals selected staff in surrounding hospices, or PC providing hospitals to participate in the training. For example, Gulu and Lacor hospital worked together to provide PC to the surrounding community, and both hospitals benefitted from training through the *Integrate Project*. Some hospital also started doing joint ward rounds with their local Hospice organisation during the course of the project (e.g. MTRH).

2. **Strengthened links at Community Level**

As described under section 4.1.2: community advocacy, a number of district hospitals greatly strengthened their links to community level through training community health workers to identify and refer PC patients. Establishing this link was much more difficult for regional and national level hospitals, some of which demonstrated little or no linkages directly with community level at project end (e.g. UTH in Zambia and Gulu in Kenya). However, given their position within the national health system a direct link with the community is not practical for such hospitals, and the PC leadership in the hospital felt that they first needed to integrate PC within their hospital setting before reaching out to the community through satellite hospitals / health centres.

3. **Strengthened links with satellite hospitals / health centres**

A number of national and regional centres had already begun the process of strengthening links between satellite hospitals and health centres. Both MTRH and Nyeri in Kenya had trained staff in their referring hospitals. Nyeri had improved the service and referral linkages in Nanuke hospital, and MTRH had supported Kapsopet to set up a service from scratch, which involved them providing PC to their community, as well as referring to MTRH for higher need.

4.3.2 Availability and Use of Essential Medicine

Indicator 10. Number hospitals where morphine consumption has increased	12 (100%)	✓

6 out of 12 hospitals had no oral morphine available at the start of the project, and all had it available by the end of the project. Morphine consumption increased in all 12 hospitals. The extent of this increase varied across the hospitals. More detail can be found in the Annex. Successes and ongoing challenges associated with this increase are:

1. **Availability and Procurement Systems**

Most hospitals reported substantial improvements in availability of morphine since the start of the *Integrate Project*. This may have been coincident with, rather than resulting from *Integrate Project* actions.

In Rwanda, oral morphine has been introduced fairly recently. As soon as it was available RBC supplied a quantity to all hospitals having PC teams. As of May 2015 hospitals were requested to use the normal supply chain through the central pharmacy.

2. Attitude to Morphine

Nearly all hospitals reported attitude changes to morphine during the course of the project. This was largely as a result of sensitisation of prescribers at the start of the project, and continuously through CMEs. A healthcare worker in Gombe hospital, in Uganda recounted how morphine previously used to expire due to the myths around it but now it is always used up. Homa Bay hospital described how the attitude change occurred when people saw it in action and found the effects "remarkable". This was also helped when there were no reported cases of addiction. It seemed to be easier to change attitudes in smaller districts hospitals than in larger national hospitals.

"We have no reports of adverse events. So people do not really fear it." (Doctor, Homa Bay)

In Rwanda, the law was changed in 2010, just a couple of years prior to the project, to make oral morphine a medical drug and therefore possible to use for PC. As part of the Integrate project a national morphine frameworks meeting was convened by the MOH which resulted in the first national procurement agreements for morphine access. At the request of the MOH there then followed the *Integrate Project* trainings for doctors and pharmacists, so attitudes had shifted substantially, although there is still a long way to go. CHUK health workers had observed some successes already:

> *One cardiologist who feared using morphine did the training of one week theory and then he did practical with the Integrate Project mentors. Afterwards he told everyone to use oral morphine (CHUK Desk coordinator)*
>
> *There has been significant change – I learnt so much at the Pharmacy training – the mentors from the UK in the training could share experiences of using morphine – it made a difference. (CHUK Pharmacist)*

3. Prescribing and Administering Morphine

As a direct result of the attitude change, most hospitals reported increased prescribing throughout the hospital.

A nurse in Ndola, Zambia related how, prior to her training through the *Integrate Project* a patient on regular analgesia requesting extra would have been told "you have already had

your pain relief", now she will advocate for a breakthrough dose when appropriate. She said "It has made me a better practitioner" (Nurse, Ndola)

One doctor, who was an *Integrate Project* specialist trainee reported how she continuously sensitised prescribers:

"I have been giving CMEs to my colleagues in paediatric PC … I have talked on morphine, pain and pain management. Initially we didn't know we were supposed to take care of pain for all of a patient's life. As of now, ***I have taught the group that there should be no pain in any patient****. … now we are able to prescribe morphine*. [Doctor, MTRH}

4.3.3 Protocols, SOPs and hospital documentation

Indicator 4. Number of participating institutions demonstrating implementation of improved policies and professionals standards by end of the programme	12 (100% hospitals) – no target set	–
Indicator 5. Percentage of institutional health strategies and professional standards/protocols which have been approved and signed off by the end of the programme	3 (75% countries) – no target set	–
Indicator 6. Number of institutional health strategies and professional standards/protocols to which the project has contributed to (reviewing, updating or developing)	35 – no target set	–
Indicator 7**:** Number of clinical placement sites which have completed a standards audit and have a signed off quality improvement plan at the end of the project	4 (100% target)	✓
Indicator 8: Number of baseline and end of project situational analyses completed	12 (100% target)	✓

All of the 12 participating hospitals demonstrated that they are implementing some of the guidelines and professional standards that have been approved by the MoH. They are also implementing some other protocols and ideas that have been shared by the *Integrate Project* team. These include:

Rwanda: Clinical protocols are being implemented nationally by RBC, based on MPCU / Mulago protocols shared through the *Integrate Project*.

Uganda: Clinical protocols observed in the 3 Ugandan hospitals, also based on MPCU protocols, and adopted by the MoH

Kenya: Clinical protocols observed in at least 2 of the Kenyan hospitals, which came from MPCU. During the evaluation visit, the head of KEHPCA committed to adapting these and sending them out to hospitals.

Zambia: *Integrate Project* funded posters and booklets available and visible in Ndola hospital.

The pain ladder, and how to assess pain was observed on the walls of the wards in a number of hospitals, including Kibagabaga and Homa Bay.

4.3.4 Other service delivery impacts

Other service delivery impacts noted included improved computerised systems and use of m-health. These were coincident with, rather than resulting from the *Integrate Project*.

Gombe hospital was chosen to help pilot the use of tablets and a computerised system for morphine and patient data by APCA. Although not part of the *Integrate Project*, they felt that they had been chosen because of the relationship developed through the Project. This was similar to Gulu and Kabale Hospitals who were involved in an m-health pilot through PCAU.

4.3.5 Issues Identified Going Forward

As well as successes in service delivery, the project met certain challenges. These present issues going forward for the participating hospitals, which will need to be addressed.

Referral Pathways:

1. Weak Primary Care Systems

As a health systems strengthening project, all of the *Integrate Project* hospitals integrated their services into the hospital, and strengthened referral pathways using existing platforms, rather than setting up new ones. The referral pathways are therefore necessarily limited by resource-constrained settings and weaknesses in the primary care system. A seamless pathway from community to hospital was therefore not expected within the timespan of this project. The implementing countries have respective implementation plan for strengthening the primary care systems, which will need to be carried out in tandem with further PC integration.

2. Documentation of referral source

The increased number of referrals is evidenced by indicator #9, which shows an increasing number of patients registered as receiving PC services. However, although many hospitals reported increased referrals from the community, through the healthcare system, the source of the referrals was not documented, so this was difficult to test for.

Morphine Procurement:

There are still challenges with the procurement of morphine, at a district level, and some at a national or international level. These seem to be related to the changing demand of morphine. For example, there was another national stock-out of oral morphine in Zambia

from October 2014 – February 2015, and slow release morphine tablets were being used instead and often cut up. There was a suggestion from some sites that this is an annual occurrence. It is thought to be multifactorial, to an extent involving procurement processes. However, is likely largely dependent on the supply/demand equilibrium governing international narcotics medical supply. For example, because of previous attitude to morphine it is not prescribed/dispensed in large amounts in Zambia (to the extent that Medical Stores have needed to discard significant quantities of unused, reconstituted morphine). Because the government cannot demonstrate demand, the allocated supply via the International Narcotics Board cannot yet increase. It is hoped that the seeds of the *Integrate Project*, grown from the context laid by previous projects/PCAZ, will drive up a demand and hence, future supply.

There were also some issues with morphine supply at a district and hospital level. For example, while some hospitals in Uganda and Kenya reported no stock-outs since 2013, Homa Bay reported some difficulties with getting orders cancelled by the district due to lack of funds. They are still in discussions with the District MoH on this. Kabale, Gulu and Gombe hospitals also had occasional stock-outs, due to a number of procurement-related factors including ordering cycles, distribution network challenges and increased demand.

Lastly, there were some reports of poor practice in procurement. For example, one hospital said they would occasionally use out-of-date morphine and another that they sometimes went "outside" to buy drugs, and were trying to stop this because they can't monitor the quality of the drugs purchased.

Morphine Prescribing:

Universal Access across the hospital

Some hospitals reported challenges in ensuring that pain relief was equally accessible throughout the hospital. For example, both MTRH and Nyeri in Kenya, who have their PC teams housed in oncology, reported that PC was perhaps more accessible for cancer patients than for patients with other life-limiting illnesses. One senior doctor related this in terms of the storage and production of morphine within the oncology pharmacy:

I think most people still think morphine is for terminally ill cancer patients. That is something we should fight and I don't think it would take a lot of effort. They could produce it and just give it to the other pharmacists. Or weigh it and send it to the other pharmacies. This would help a great deal – because I have come across patients who do not get morphine at the weekends. (Senior Doctor, MTRH)

Concentrations

There were challenges reported with morphine dosing, because of the availability of certain concentrations of doses. For example, despite the existence of 10 mg tablets in Rwanda, Rwamagana and Kibagabaga only had access to 30 mg tablets, making it a challenge for smaller doses. The RBC/MoH contact for PC confirmed that, as of June 2015, the standard for the oral morphine solution was approved so it will now be available to the hospitals.

Dosing by the clock

Dosing by the clock was an issue for some hospitals. In the three Ugandan hospitals, patients have their morphine by their beds and take it themselves. Kabale hospital explained that, because there had been no cases of addiction, there was not much concern about leaving it by the bedside.

Bedside medication varied across the Zambian hospital, and in Kenya, none of the 3 hospitals had bedside morphine, instead, asking the patient to remind the nurse when it was time for their next dose. Many of these hospitals have bed occupancy of above 100%. Ugandan hospitals deal with this by putting mattresses on the floor. However, in the Kenyan hospitals 2 patients often share the same bed which may raise concerns about bedside medication.

4. Availability and Use of Other Medication

The availability of other medications was variable across the hospitals. Some hospitals reported little use of step 2 analgesics. For example, in Mazabuka step two drugs are difficult to obtain, with ibuprofen being the commonest used and others usually unavailable. Others reported common and increasing use of step 2, for example Ndola reported substantially increased tramadol use over the course of the project, as did 2 hospitals in Kenya (Nyeri and MTRH). Other hospitals reported various gaps in their drugs, including antidepressants (amitriptyline) at Ndola and laxatives (bisacodyl) at Gombe. Ndola was planning to address shortages by working with pharmacy to develop a PC essential drugs list.

Attitude to Morphine

A number of hospitals reported that, although the attitude of some prescribers had changed, some had not. One nurse explained:

The attitude of the senior doctors has not yet changed. The junior doctors are different, I can remind them "Can you put this patient on morphine?" There was a senior doctor one who came and cancelled my patient's morphine – he put the patient on injectable pethidine. I negotiated with him and he restarted it. *(Nurse, MTRH)*

Most hospitals recognised that changing attitudes is an ongoing process. The need for continuous sensitisation was evidenced during the evaluation visit in one large hospital, with 9 pharmacies, where the pharmacists who were trained through the *Integrate Project* had moved on to other roles. Those interviewed during the evaluation visit had not yet been sensitised. One of them said *"It worries me when the nurses keep coming for morphine. What more can be done for these patient other than prescribing morphine?"* Another said it made him worried if he prescribed a month's worth of morphine, but the nurse returned for a repeat prescription before the month had passed. Despite this, the health workers of this hospital did not report any problems in accessing morphine from the pharmacy, and the PC leadership within most hospitals recognised continuous sensitisation as an essential part of their role.

4.4 Partnership

Indicator 21. Number of new institutional health partnership MOUs in place	0 (2 but no MoU in place) (no target set)	-

4.4.1 Level 1: Lead partners

The three LPs brought different skills and resources to the programme. UoE provided an overall management structure and programme governance, with staff delivering training support, academic input and overseeing the mentor exchanges. APCA functioned as the hub for communication, and programme activity delivery initially for the four countries and latterly for three. MPCU provided technical assistance supporting national associations and leads from each hospital to develop their yearly work-planners, training in skills and knowledge, clinical placement design and modelling of services. The LPs had strong working partnerships prior to the programme. The partners formed a steering group which met virtually through skype and face-to-face in Uganda regularly.

Going forward a stronger and more systematic mapping of communication pathways would add value given the quantity, complexity, and diversity of the communications.

4.4.2 Level 2: Lead partners and National Associations

The partnership between the LPs and the National Associations varied according to the country. 4 themes arose, each of which was characterised by successes and difficulties.

Communication

The layers of the project partnership meant that communication could take place at lots of levels. For example, there were 3 LPs linking with National Associations. Although the National

Associations were in-country leads, the LPs were also mentoring the hospitals directly which meant that sometimes the LPs were liaising with NAs, and sometimes with hospitals. The UK mentors communicated with National Associations, with hospitals directly and with LPs. All these potential channels of communication led to some confusion in the first year of the project. The National Associations did not see the 3 LPs as a unit, but as 3 organisations to be communicated to.

> *There should have been a communications chart. Sometimes I phoned APCA and was told to ask UoE. It would have been better to have a clear project initiation at the beginning with collaboratively done budgets, communication charts, work plans.*
> (National Association lead)

The National Associations lead referred to the need for clearer project management documentation, including communications documents, which were developed in a project initiation. Other National Associations agreed. One commented, that, although there was communication in stakeholders meetings, she did not attend these meetings, and so felt the lack of guidance on how to communicate and deliver the project at the beginning, although this changed as she began to understand the project. This National Association lead also referred to the need for a longer project initiation period:

> *It would have been helpful to bring together everybody from the start so key people involved knew what the project entailed and how it worked so that there was then clear communication (PC Association Coordinator)*

Most of the partners felt that the communications improved throughout the project. This was illustrated by the RBC representative's comments about how communication had worked since they took over national delivery in May 2014.

> *I like the way they approached us. They communicate and we know when they are coming, they have clear ToRs so good partnering and good communication.*
> (RBC PC Focal person)

Planning

In a similar way to communications, planning was seen to be weak at the start of the project, but improving over the period of the project

> *In-country work-planning wasn't done in the first two years. It would have been better to go country by country. By year 3 the work plan was clearer – also the relationship was better, so we were communicating better. (PC association lead)*

National associations spoke positively about the way that the LPs were flexible with planning, and did not rigidly impose activities, but allowed them to be shaped by individual country and hospital requirements. For example, MTRH were allowed to develop their own modular training.

Collaboration and Trust

The relationships between National Associations and the LPs were variable in terms of good collaboration and trust. Two of the countries described effective collaboration, and two more variable collaboration and a lack of trust. One National Association lead conveyed this as follows:

> *In a way, there was a lack of confidence in our capability. The partnership was not transparent. It felt like there was mistrust. Data collection was not clear at start, midway then we were asked for information and it was difficult to find. (National Association lead)*

The lack of trust expressed by the person above was linked to poor communication. It was also exacerbated by the difficulties with monitoring and evaluation of this project. Because the project was carried out across multiple sites in 4 countries, monitoring the project was complex. This may have strained relationships in an already complex multi-layered project.

4.4.3 Level 3: National Associations and Hospitals

Indicator 19. Participating Associations influence development of Palliative Care in Africa	4 (100% target)	✓

The National Associations were, in many ways, the lynchpin of project delivery and the main link between the steering group and the local hospitals. Most hospitals spoke extremely positively about their National Associations, describing them as an essential partnership which would continue to support them after the project ended. The relationship between the hospitals and National Associations depended on country-specific factors, such as the maturity of PC services in the country.

Kenya

The *Integrate Project* has strengthened relationships between KEHPCA and the participating hospitals. When describing the basic trainings delivered through the *Integrate Project*, many hospitals described them in terms of the National Association partner that assisted them (e.g. “the KEHPCA trainings”), and they spoke of their association as a supportive and co-ordinating

force. KEHPCA saw the *Integrate Project* as strengthening the relationship between them and the local hospitals, but also as making local hospitals more self-sufficient, so that they relied less on KEHPCA. They recounted the training MTRH had run independently in a satellite hospital as a great success, explaining:

We have never set foot in Kapsabet. But now MTRH has been in Kapsabet. We are trying to make the local partners have the skills to run their own training, because KEHPCA will not always be there. (National Association lead, KEHPCA)

Uganda

All 3 hospitals felt they had benefitted from partnership with PCAU and with APCA (which is Ugandan based). They described the benefits from the *Integrate Project*, including specialist training, conference attendance, ToT and mentorship. They have ongoing relationships with both PCAU and APCA, for example, PCAU have recommended Kabale for inclusion in a grant proposal for HBC, and Gombe hospital were chosen to help pilot the use of tablets and a computerised system for morphine and patient data by APCA. They felt that they had been chosen because of the relationship developed through the project.

Zambia

In Zambia, the leadership at the hospitals acknowledged the important role played by the National Association.

> "We have to work with them [the national association].....they have wider roots into community etc. that hospital alone cannot provide. We need to use them and vice-versa. They are very strong partners." (Hospital Medical Director, Zambia)

There were situations where themes of mistrust arose. This was due to a number of factors including personality issues, changes in service provision for palliative care, difficult funding environment and role changes. The challenging situation for PC in Zambia is described in section 2.4.2, a number of hospices and community services have closed, and the national Association are facing challenges with redefining their role following this.

Rwanda

In Rwanda, the project was managed over the last 18 months by the Rwanda Biomedical Centre (RBC) which is part of the MoH. The PC contact from RBC explained that they saw the *Integrate Project*, not as a stand-alone project, but as a health system project: now they have a country-wide model, in particular around training, protocols and policies which can be implemented across the country. RBC recognises CHUK as an emerging centre of excellence for

the country.

RBC took on this role mid-way through the project. When the *Integrate Project* began, the National Association role was being undertaken by the Palliative Care Association of Rwanda (PCAR). However, the MoH Rwanda, felt that the two layers of partnership between PCAR / APCA and PCAR / 3 hospitals was not working well, and was characterised by poor communication and project management.

As of May 2014, RBC set up a PC desk within the MoH, and took on the management of workplans and funds instead of PCAR. The PC focal person at RBC suggested that this was more transparent, with better co-ordination, and was also more sustainable, as RBC have a mandate to cascade PC throughout the country. She suggested that, for future similar projects, the in-country coordinating role should be played either by a government institution, or by another organization with a clear mandate from government. The hospitals in Rwanda, also saw clear benefits of working through RBC:

> *RBC can do things according to national policies… [we are] dreaming big, to have a Centre of Excellence so we need big and strong support to make this happen."*
> (Hospital Director, CHUK)

> *It has been easier since we have been working with RBC. It was hard before that when working with PCAR, as they did not have a national MoH remit.*
> (Health Worker, CHUK)

The successful project implementation, coordinated by RBC, shows that though there is substantial value in working through National Associations, it is one model, and working directly with Ministry to implement a health systems strengthening project such as this is another. The important characteristic of national implementing partners is that they have a mandate, and credibility with the implementing hospitals and the MoH.

4.4.4 Level 4: UK Mentors and Hospitals

Indicator 20. Number of UK volunteers demonstrating improved clinical and leadership skills by the end of the programme	22 (50% mentors – no target set)	–
Indicator 22. Number of UK health professional days spent volunteering overseas by end of programme	621 (no target set)	–
Indicator 23. Number of UK health professional days spent providing remote support to overseas partners by end of programme	145 (no target set)	–

We estimate, from the mentor and hospital reports that 22 (50%) mentors demonstrated improved clinical and leadership skills by the end of the programme. The impact of mentorship

on the UK is discussed further in Section 6. Participating hospitals noted the impacts of mentorship as being:

1. Improved Skills through Clinical Modelling

Health workers often found the on-the-job training and clinical modelling provided by the mentors extremely helpful. Health-care workers in Ndola noted this with regard to breaking bad news. One nurse explained how, after the basic training she would just "offload when the patient wasn't ready", but after observing the mentor breaking bad news to a patient with penile cancer, she changed her approach to model his, where preparatory questions sensitively approached the topic. Of the language he used, she said "it is still with me" (Nurse, Ndola). In Rwamagana hospital, health workers gave a description of how the mentors had helped with a specific patient, who had been "challenging", and how it helped having mentor assistance in dealing with this patient, as previously, they had not known how to help them.

A nurse in Kabale explained that it was the mentors who emphasised the importance of consistently completing the patient charts.

A doctor in MTRH described her increased clinical skills very enthusiastically with regards to the 1-1 clinical mentorship she received from an experienced doctor from the UK.

> *I learned about the use of morphine, we had a patient who was difficult to manage the pain – they prescribed the fentanyl patch. The dosing was difficult, and we learned how to do this. We did a lot of pharmacological work and learned how to put it into practice…. I really understand the importance of examining the patient – if they have oral thrush – I need to look and see, this might be why they have no appetite. (Doctor – MTRH)*

Another health worker considered this 1-1 mentorship as essential for building the clinical skills learned through the training, explaining: "*KEHPCA gave us the theory, and mentorship gave us the practice." (Health worker, Homa Bay)*

2. Building on existing systems

The evaluation visits demonstrated that, for the most part, mentors had been successful in identifying where there were gaps and meeting these, building on existing systems rather than coming up with new ideas to be forced onto the 12 participating hospitals. One nurse said:

> *They don't come with their ideas – they build on what we have. They looked at what we had in the pharmacy – discussed with us and helped us put together a formulary. (Nurse – Homa Bay)*

The PC lead in Zambia noticed the same thing with Ndola

In Ndola the mentors approached and asked how they can help – so they could be guided…. They had done the mentorship before and were experienced in this. They were clear they were not there to teach what they was already known." (PCAZ representative)

3. Increased Profile of Palliative Care

Some health care workers felt that the presence of international representatives increased the profile of PC and changed the attitudes of senior staff to the project. One health worker in Gulu explained this by saying *"If they come all the way to Gulu, it must be important".* Hospital staff described how this attitude increased their access to decision makers in order to better advocate for PC. A health worker at Gombe hospital related:

We had been reaching political leaders but they had not taken us seriously, however when we went with the mentors they took us seriously and now understand us better" (Doctor, Gombe hospital)

"Meeting the PMO [Provincial Medical Officer] back then would have been difficult without [the UK mentor] being there" (Nurse, Ndola)

4. Establishing Palliative Care as a medical speciality.

A large number of the UK mentors were doctors. In many of the participating countries, PC is seen as a job for nurses, and not a medical speciality. The presence of senior specialist PC doctors helped to change this perception.

5. Motivation of mentees

Many health-workers experienced increased motivation as a result of the mentor visits, and of the continued relationship with mentors over email. The hospital director in Rwamagana noticed how the passion of the mentors was infectious:

"The mentors ... have done PC for many years and have the necessary knowledge and know-how. This provides a sense of motivation; these people have been passionate about PC for many years and that impacts on the local team. They see their vision and how PC has made their lives" (Hospital Director, Rwamagana)

6. Helping to galvanise change

As a result of many of the themes illustrated above, the presence of the UK mentors acted as a catalyst which helped to galvanise change in areas where the hospital leadership and decision makers were supportive and amenable to such change:

"Mentors were a great support in the re-opening and government support of Cicetekelo Hospice" (Health Worker, Ndola)

Last year when they came – we didn't have a doctor. They [the mentors] saw a need for that. They went ahead and talked to the management… the deputy director called Millie [the doctor who subsequently joined the PC team] and asked if she was interested in joining the department. (Health Worker, MTRH)

4.4.5 Other partnership impacts

Many health workers saw benefits through partnership with other participating hospitals, both nationally and internationally. They felt that conference attendance and clinical placements had helped in this. For example, Gulu hospital was able to describe the model used in Lira in Uganda, what they had learnt from it, and how they thought theirs should be different. Mazabuka hospital in Kenya had a similarly beneficial visit to Livingstone in Zambia.

Health workers also experienced benefits from visiting similar sized hospitals in other countries. The hospital director from CHUK shared the impact of visiting MPCU and Mulago hospital.

> *Before I went to Uganda I wondered why we are going and what we would learn, but have seen PC in practice and we need to integrate it – that is the key issue"*
> *(Hospital Director, CHUK)*

As the quote illustrates, the doctor had found his visit to Uganda surprisingly illuminating. He described later that this was the moment he really understood what it was to integrate PC, and how he developed his own vision for CHUK.

A member of KEHPCA also mentioned the benefits for MTRH of visiting Mulago/Makerere, as it created the connection between them and another national teaching institution.

Health workers in nearly all hospitals recounted benefits of conference attendance. Many of the greatest advocates for PC described how they had been influenced by attendance at conferences.

The full list of conferences attended is shown in Annex 1. Some comments made are shown in the box below:

The trip to SA, is what tipped me. If I hadn't gone to Johannesberg (APCA conference, 2013)….I may not have supported this. (Doctor, UTH)

It was very useful going to the KEHPCA conference because PC is something that is done by nurses, and I got to meet doctors who were in PC. (Doctor, Nyeri Hospital)

Networking with other national associations was important... It was useful to share between Uganda and Kenya in the APCA conference. Things are done differently there. Ugandans

present good papers, they do a lot of papers and present well. It was good for KEHPCA to see that. (KEHPCA)

Conferences helped us to interact with other providers and we were able to share and discussed how we can overcome challenges, for example we learnt about working with religious leaders at the KEHPCA conference. (Health worker, Gombe)

4.5 Integration

Indicator 2. Number of hospitals delivering an integrated community wide palliative care programme	12 (100% target)	✓
Indicator 3. Number of hospitals modelling a public and primary health approach to palliative care	12 (100% target)	✓

All hospitals are delivering an integrated programme, in the sense that they have used existing hospital platforms to integrate their services into the health system, and are thereby modelling a public and primary health approach to PC.

The extent to which they are fully integrated throughout the hospital varies among the hospitals. The hospital sizes vary from Gombe, with 100 beds to UTH with 1600-1800 beds, and integration is clearly more difficult to achieve in the latter. So whilst some district hospitals have gone from zero level of service to a service approaching being fully integrated within 3 years, the timescale meant this was unachievable in much larger hospitals. However, ALL hospitals have achieved some level of integrated service.

5 Additional key changes identified by staff

This section describes the key changes identified by staff on the evaluation visits and during the most significant change stories. These are additional changes which occurred during the project, and are not fully captured through the four strands described in the previous section.

5.1 Changes in Staff Attitude

5.1.1 Development of Values-Based Care

Possibly the single most important change identified by health workers was the emergence of values-based care, and compassion for patients. A number of health workers explained how, prior to the introduction of PC, they did not treat their patients with care and compassion, but

this has changed. A nurse in Kabale, Uganda described how she "used not to mind much" about patients and was abrupt with them, but now she gives them time and listens to them. Another nurse in Zambia similarly said:

> *Before we would always be rushing…..always time conscious….we are now involving the patient's family more for them to be properly managed…..For me, now I am concerned if someone is crying……..to find out what is the problem….before, it was just one of those things if they were crying .. Now it is something I can help with.* (Health Worker, Zambia)

> *With most of my staff there is change – I see them working with passion. Before that they did not treat patients as people.* (Health Worker, Zambia)

5.1.2 Attitude to palliative care

Many staff saw a change in attitude towards PC in general, both within themselves and in their colleagues. For some, this change occurred during basic training, and it is described in section 4.2.1 as the "conversion" to PC.

Prior to this conversion, health workers saw PC as "giving up" on patients,

> *There used be a negative attitude that you are giving up on terminally ill patients by giving them PC. Sometimes they [clinicians] would say "this one is for the PC team" [dismissively]. Now, they are able to help these patients more.* (Doctor, MTRH)

One health worker spoke about her own attitude change, explaining that she used to "hate PC" due to prior trainings, which made her think PC was about the management of bed-sores and bed-ridden patients. After her *Integrate Project* training she recounted:

> *I understood PC in a holistic manner not just for dying patients but also the chronically ill. Understood that it meant social spiritual and psychological support. I (myself) went and spoke in churches, and went with a local organisation to do screening and PC awareness at the churches. Right now I have a passion for PC.*
>
> (Social worker, Nyeri)

Health workers realised that PC could make both their own, and their patients' lives easier:

> *Integrating PC does not make more work as the patients are not extra they are part of our work…. And because the patient is stable and not in pain it is easier for all" (Surgeon, CHUK)*

5.1.3 Attitude to morphine

Health Workers also changed their attitudes towards morphine. This is described extensively in section 4.3.2. The attitude change was substantial, but not universal. One surgeon narrated this as follows:

> *Before the training I was not that keen to prescribe morphine – I thought they would have respiratory distress and will die, but now after the training I prescribe without fear (Surgeon - CHUK)*

After explaining how he prescribed "without fear" the surgeon was asked if this was all patients: adults and children. He explained that he meant for adults, but that he rarely needed to prescribe for children. The combination of values-based care and change in attitude to morphine led to increased prescribing:

> *There is a difference in approach…we have that love and patience……we treat the patients differently…..especially in treating and taking care of pain ….patients receive morphine more.* (Nurse, Zambia)

5.2 Changes in Clinical Practice

5.2.1 Breaking Bad news

One of the key changes in clinical practice was around breaking bad news. Many of the mentorship reports in more than one of the countries noted that the local culture seemed to preclude talk of death, and the evaluation visits reinforced this. One health worker explained this:

> At first people used to think perhaps you are cursing the patient to die to break bad news, now we are breaking bad news we realise it is not true. (Health Worker, Mazabuka)

The health worker describes how it was not part of the custom and practice to break bad news, and to talk about death, as doing so implies that you are wishing death upon the patient. However, upon changing their practice, they felt things were better for the patient. Health workers in Uganda and Rwanda also experienced this:

> *There was a time when we gave counselling to both the patient and caretaker and we were just reassuring both caretaker and patient that the patient would be ok, even though they would not be, we told them not to worry, but their condition was deteriorating but after being trained we realised that we need to talk about this and tell them the truth* (Health Worker, Gombe)

> *Before if members of the family ask whether it is true that the patient is going to die we were not able to explain to them about that case as it was not easy to tell family*

members, but now we can explain and give advice and information – we no longer run away! (Health Worker, Rwamagana)

The project also highlighted that breaking bad news is a complex skill to learn, as it differs depending on the patient and family. It therefore requires continued support and mentorship. This was described in section 4.4.1, where a PC nurse who thought she had already learned to break bad news had her skills improved and refined through mentorship. One specialist trainee described the benefits of visiting different countries to develop these skills through sharing with others:

It was a great advantage coming together with nurses from different countries and cultures. We shared the different challenges that we face sometimes, for example, when the relatives don't want patients to be told the truth. That really helped. (Nurse, MTRH)

5.2.2 Assessing and Managing Physical Pain

The second most cited change in clinical practice was about management of pain. A number of health workers, when asked about what they learned at the basic training said "I have learned that pain is what the patient says it is." Health workers demonstrated that this was more than just a mantra, by describing how this changed their clinical practice, in terms of allowing patients to take extra doses for breakthrough pain, and increasing the dose, "without fear"

[Since the training] I know when and how to prescribe break through pain medication and when and how to increase the dose of morphine….Other doctors will refer patients to us - there is still a couple of Drs who fear to prescribe morphine so they refer the patient to me to prescribe" (Doctor – Kibagabaga)

Before we found it difficult to assess pain but now we are able to assess pain, (Health Worker, Rwamagana)

Much of the learning on pain management referred to prescription of morphine. However, PAMs also learned the ability to assess and manage physical pain in patients and how to deal with it. One physiotherapist explained this:

Before [the training] I tell my students that they shouldn't do anything for patients with pain due to metastases, but now I realize we have to something and can help re changing position, massage etc. We can intervene to give hope and not leave the patient - you have to do something to help with comfort etc." (Physiotherapist - CHUK)

The emergence of values-based care, combined with improved clinical skills also increased the focus on pain management. One nurse in CHUK noted that she now cannot bear to see people

in pain. She explained how sometimes the others nurses in the ward may forget but she always reminds them, using the treatment ladder to explain.

5.2.3 Bereavement Support

Bereavement support was the third area in which health workers saw a change. Reports around this were more variable than those on pain and breaking bad news. Some hospitals reported changes, and some felt there was still a long way to go in this area. However, awareness seemed to be raised in most hospitals. One nurse, at UTH explained this as follows:

> *Before, the way we were handling bereavement was not too good. People would expose themselves to danger (e.g. throwing themselves around and screaming in distress). When the patients passed away, no one seemed to care. We thought medical treatment stopped when the patient died. Now we realise the importance of explaining and talking to relatives.* (Nurse, UTH)

Many hospitals felt that, although they had increased awareness of bereavement support, they were challenged in effectively delivering it. For example, both of the district hospitals in Rwanda felt effective bereavement support should involve visiting families at home, but resources did not normally permit this.

5.2.4 Palliative Care part of practice

In the hospitals with the greatest level of integration (which were mostly the district hospitals) health workers described how practice had shifted across the hospital, such that PC had become a normal part of clinical practice.

For example, in Mazabuka hospital, a nurse in the paediatric ward did not recall receiving any specific PC training and seemed puzzled by the question. However, when asked how to manage PC problems and in particular paediatric pain she could immediately answer and show the guidelines. It seemed this was an integral part of her practise now and not being specifically labelled “palliative care”.

This was also noted in Rwamagana where the lead nurse said she did not want PC in individual job descriptions, as it should be a part of everyone’s job description. The pharmacist in the executive team at Nyeri had noticed the potential risk of making certain individuals responsible for PC:

Sometimes, when quite a lot of people have been trained, there is a tendency for people who have not been trained, to say "I was not trained in that" when asked to do anything for a patient. (Pharmacist, Nyeri)

He went on to explain how the integration of PC needed to be carefully managed to mitigate against this: health workers need to be sensitised to understand that basic PC is a part of their work. As described by the hospital director in Rwamagana:

PC does not add work, it means doing better what you have always been doing.
(Hospital Director, Rwamagana)

5.3 Benefits for Patients

5.3.1 Reduction of Physical Pain

All hospitals referred to decreased physical pain in their patients. Most attributed this to effective use of morphine: The chief nurse at Kibagabaga said:

Pain control - these days we are doing well. We have morphine and no stock outs… pain is well controlled." (Chief Nurse - Kibagabaga)

This project did not collect patient pain scores, and so it is not possible to quantify reduction of physical pain, apart from through morphine use as a proxy. However, one of the most commonly mentioned changes in all hospitals was that patients were no longer "crying" and "screaming" in pain. The box below shows some quotes which illustrate this:

We no longer have patients screaming – this is a change…before we used to take it lightly and we did not take the patient's pain seriously. We would see them agonising, but now we take it seriously (Nurse, Ndola)

The hospital reports used to show the patients crying. Now they show the patients quiet. (Doctor, Homa Bay)

We now look at the patient as an individual – we did not think about pain relief properly before. A lot of patients would be screaming in great pain, only prescribed paracetamol (Health Worker, UTH)

We now have access to oral morphine. Our patients are no longer in pain – the wards are quiet. (Nurse, CHUK)

The children used to cry before when dressing their burns and now they are more peaceful as we give them morphine before we do their dressings. (Health Worker, Gulu)

The children are no longer crying so much. (Health Worker, CHUK)

The staff are starting to understand that patients should not be screaming and crying in hospital! (Lead Nurse, MTRH)

5.3.2 Reduction of Non-Physical Pain

Some health workers felt that they saw a reduction of psychological pain in patients. For example, a health worker in Rwamagana believed that, although it had not been measured, depression in patients had reduced markedly. Patients had previously been marked as "difficult patients" when they were withdrawn, aggressive or had poor communication. Previously these patients had been called "un-cooperative and a bad patient". But health workers have realised since training that this is a psychological reaction to illness. A health worker narrated how she now used screening tools for depression (e.g. Shona Symptom Questionnaire) in HIV patients. This change was also noticed in other countries, with health workers using the same language of "difficult" patients:

> "I no longer label patients as being 'difficult', I will now try to find out why they are behaving in this way……do they have emotional pain?" (Nurse, Ndola)

A health worker in Kibagabaga described this in terms of helping the "whole person" including psychological, physical, spiritual, social pain. A specialist trainee from CHUK saw this as the greatest benefit of the specialist training:

> *I learned about impeccable holistic assessment for the patient - before I was speaking just about pain but now I know pain can be total.* (Specialist trainee, CHUK)

5.3.3 Patient Empowerment

Healthcare workers described how PC, in particular the increased knowledge which came with a patient knowing their diagnosis and prognosis, led to more empowered patients.

> *For those wanting to die in village, it is cheaper to travel alive, rather than dead. This is why PC seems to be working well - you can talk to the patient so they can plan.* [Nurse, UTH]

> *Patients and families are relieved of unnecessary expenditure as they stop unyielding interventions which are not helping them and recognise the stage of their disease.* [Nurse, Gombe]

One nurse in Kenya explained how continued sensitisation and training within hospitals was required to keep empowering patients like this:

> *There was another time I confronted the doctor. The patient had carcinoma of the bladder, he had metastasised. He was a palliative patient. The doctor wanted to order a CT scan. This was a 4th stage patient. I said to the doctor, do we really want to order the scan. The family had no money, so I said to him, lets discuss with you, the patient is not going to benefit. The family have drained all their resources. He was not happy, but he*

changed his mind. For most of them – the attitude still needs to be improved. [Nurse – MTRH]

The nurse felt that, despite training and sensitisation across the hospital, some doctors were continuing to order expensive diagnostic test, and that it required a continuous ongoing sensitisation to change this.

5.3.4 System Improvements for all patients

Many of the changes narrated in terms of pain management were for acute cases (e.g. burns patients) rather than patients with life-limiting illnesses. Some health workers explicitly recognised this:

> *PC also benefits other non-PC patients, because it is changing the system for everyone. In Homa Bay, it seems like it is benefitting more non-palliative patients than palliative patients. For example someone with severe burns has good pain management, children have play, interpersonal and inter-patient relationship has really improved.*
> *(Paediatrician, Homa Bay)*

> *We are also using our skills broader than just for PC but for other patients as well*
> *(Health Worker, Rwamagana)*

The paediatrician had seen improved pain assessment and increased morphine prescribing across the hospital. Ndola hospital had changed from pethidine to morphine in the labour ward, and was therefore reducing pain for non-palliative obstetric patients.

As well as improved analgesics, improvements included values-based care, as the trained nurses are integrated in the hospital, and delivering care to all patients. One doctor observed this:

> *I noticed that in oncology she [the PC nurse] didn't send the patients with a note, she holds the patients hand and brings her to the doctor. Then I saw her do the same in Casualty.* (Doctor, Ndola)

This doctor had noticed that the compassion extended by the nurse was not limited to palliative patients, but was extended to all patients who were in need of it.

5.4 Benefits for Staff

5.4.1 Job satisfaction

A number of health workers described how they enjoyed their work much more since training in PC. Some comments made were:

Figure 20: Hospital quotes on improved job satisfaction

I enjoy talking to the patients and family more now. (Nurse – UTH)

As a nurse it feels good that I can now help people – I feel empowered (Nurse, Gombe)

*I find the effect of my new practice calming and more satisfying (*Senior Doctor – UTH)

PC completes me as a nurse (Nurse, Ndola)

Breaking bad news was so hard and tough from me. I didn't know where to start from. I did not tell the news but would join them in crying. For me now it is much easier, I know the steps (Nurse, Mazabuka)

Before the training I wanted to resuscitate more and more and not accept they may be dying. This used to make me panic….I don't panic now. I get the relief when I come together with the family. (Nurse, Mazabuka)

As the quotes above illustrate, staff who had previously been dealing with terminally ill patients without the requisite skills and resources to help these patients were finding their work draining and difficult. PC changed their working lives, as well as their patients. A doctor in Rwamagana explained how this benefitted all health workers:

> *It is a relief for health workers to know that there is someone they can turn to (the PC team)* (Hospital Director, Rwamagana)

The hospital director had noticed how his staff were relieved knowing that there is something which can be done for patients, and that they can be referred internally to a team with skills to assist them.

The downside of this is the immense pressure it can put on PC specialist staff. The PC core staff are often those who had the greatest passion for PC, who are motivated to work hard to improve the lives of their patients. While staff found this, on one hand, to be extremely motivating, they also found it emotionally and physically draining. One doctor described this as follows:

> *Our staff are burned out. Look at their faces. All we talk about is just PC. It is taking a leading role in terms of staff advancement and staff motivation. However, we have become exhausted. What has been keeping us going is seeing everything improving, we were forced to close down the play therapist. If other things close, if morphine is not available, it is very hard for us…. Please lobby for us for people to come in and support us.*

The importance of time for reflection and mutual support to deal with such burn-out was highlighted by one nurse:

> *I used to get very upset by my caseload. But now we have developed the practice of sitting and discussing difficult patients as a team. I learned that from the people on my diploma*. (Nurse, MTRH)

5.4.2 Benefits at Home

A number of health care workers related how the skills they learnt through training in PC helped them in their own lives at home, and not just in the workplace. The prevalence of HIV, cancer and other chronic illnesses, and the role of the extended family is these 4 countries is such that most people will have regular contact with family members with life-limiting illnesses. Staff in Nyeri described this:

> *The training was fantastic – life-changing. Not only in the workplace, but also at home. (Pharmacist, Nyeri)*

> *My mother, father and brother have the same issues, so it has even helped at home. (Physio, Nyeri)*

One nurse in Gombe hospital regretted that she had not been trained in PC earlier, as it would have helped her personally in dealing with her mother's terminal illness up until her death:

> *Before I went for the training my mum was sick with cancer of the pancreas…. we spent money and money on her until she died. We had to sell our land. Then I went for the training on PC and if I had known this before, we would have cared differently for my mother, by that time she could have stayed at home and died peacefully. Now I can support people in this situation. (Nurse, Gombe Hospital)*

A physiotherapist in CHUK expressed a similar regret:

> *My father died of cancer and the hospital gave me the morphine saying you can give it but I did not give it as thought I would kill my father - after the training and clinical experience I would have done it and my father would have died more peaceably (Physiotherapist, CHUK)*

Through the period of the *Integrate Project*, Mazabuka hospital developed increased awareness of staff bereavement which led to a support group. There are internal discussions being held in the hospital about compassionate leave conditions. Although funeral attendance has always been part of the culture, this is a shift in emphasis, which one nurse described as follows:

Many of the staff members or their families have been patients. We lost 3 staff members recently. This time was not just lighting candles. This time it was to be there – really being there, and seeing what we could do to help. There is now a group to support family of the sick staff. (Nurse, Mazabuka)

5.4.3 Career development

Some staff reported benefits in terms of career development. They were now recognised as a specialist within the hospital, given the opportunity to train in PC and travel and present at conferences. For example, in UTH the PC team lead is taking over the role of PC academic co-ordinator now PC has been introduced to the curriculum. Once he has finished his MMed, he is likely to be appointed as a lecturer, based in the Department of Medicine. 11 other members of staff have volunteered over the past year to help with the undergraduate training. Plans are underway to formally appoint these staff as UNZA teaching staff, which will involve recognition and remuneration.

There were also a lot of counter-examples to this where staff, although motivated by PC, felt that it did not offer enough in the way of career development, for example salary increments and clear career structure. One PC Association head saw this as about expectation management, explaining more sensitisation needs to be done so that understand that career path is not necessarily about getting a promotion or salary increment, but about being able to practice PC. In Rwanda, the PC contact at RBC felt that PC should become a part of the job description of all staff involved in chronic disease management, so the system was not reliant on a few individuals.

6 Benefits for Mentors and for the UK Health System

Although the greatest benefits from mentorship were to the 12 mentee hospitals, mentors also benefitted from the experience, and some of these benefits are being used to improve PC in the UK and globally.

Following a review, and initial theming of these mentor reports, a questionnaire was sent to mentors to detail these benefits. 14 responses were received which, with the original mentor reports and notes from a joint mentor meeting on 14th May, were reviewed and themed for benefits for mentors in the UK. Five key themes emerged:

1. Personal development and self-enrichment of UK mentees through the experience of mentoring.
2. Development of mentorship skills.

3. Learning for the UK from the models adopted in Africa, which could potentially be employed to improve the health service in the UK.
4. Ongoing plans of the mentees to use their learning to improve healthcare in the UK.
5. Ongoing plans of mentees to use their learning to improve healthcare in other countries.

6.1 Personal development

Mentors found the experience personally enriching. They described how it changed their views and, in some ways, enriched their lives.

6.1.1 Enriching experience

Mentors found the experience of partnering with hospitals to be personally enriching and said they would do it again. They found working with UK mentors from a range of backgrounds to be an interesting and enjoyable experience, where they learnt from the strengths of other mentors.

Working with staff from a different culture helped staff see things differently. One mentor explained:

> *Simple things like seeing somebody in their workplace and or home affects the way that I regard them*.

Mentors outlined how they learned through seeing these people provide a service in the face of constrained resources.

6.1.2 Attitude to Palliative Care

Mentors were all already committed to PC before participation in the *Integrate Project*, but some encountered a renewed passion. One mentor said, "I continue to grow more and more passionate as I see the scale of the need"

Some mentors were reminded of the compassion necessary to practice PC:

> *I learnt just to "be there" … the fact that someone took an interest, seemed to be enough for many patients*.

> *I was reminded of the value of small kind gestures*.

The mentors noted that the experience reminded them of the importance of holistic PC to include being there for the individual, not just management of physical pain.

6.1.3 Greater appreciation of healthcare in the UK

Mentors described a greater appreciation of the healthcare available in the UK. One mentor explained how the visit strengthened her belief that many positive aspects of the NHS are often overlooked by those who have not experienced healthcare in developing country settings, for example access to radiotherapy. Another mentor saw this in terms of end-of-life care:

> *It made me more appreciative of our NHS and all it offers, without payment at point of use. It gave me reassurance about medical help at end of life care.*

6.2 Impact on mentoring skills

This section explores how mentors improved their mentoring and related skills through the *Integrate Project*. Thirteen of the 14 mentor questionnaire respondents acknowledged some improvements to their skills, even those who were already experienced in working in such settings

6.2.1 Adaptation and Flexibility

A substantial number of mentors described the ability to be adaptable and flexible as an important skill that they developed during the project: Some comments they made in response to a question about what they had learned were:

Figure 21: Quotes on adaptation and flexibility

It has reinforced the importance of 'thinking outside the box' and considering more creative approaches.

You can make a difference in a limited amount of time with a limited amount of resources if you're prepared to step out of your comfort zone, be imaginative and take the risk.

[I have learned] to be flexible and to think on my feet.

It is important to have an open mind to a variety of ways of doing things and to be flexible

The four mentors above all noted important learning in flexibility and open-mindedness, as they needed to respond to the hospitals requirements. Some expanded on this describing how they had to think more creatively (outside the box) and stretch themselves by working in ways unfamiliar to them (out of your comfort zone).

6.2.2 Planning and Preparation

Although flexibility was an important learning for mentors, planning and preparation was also seen as essential. One mentor described this in terms of planning, but being ready to change if hospital requirements turn out to be different. Another explained:

> *The brief of the project, and expectation of the mentees must be clearly understood before the project commences [but] I learned that there is never enough preparation possible including speaking to people who have worked there before, listening, reading and understanding personal factors. Even this may not be enough.*

Mentors found an important learning was to communicate as much as possible with the organisations beforehand, in order to plan a visit which is appropriately tailored to the individuals and context, ensuring that any potential communication barriers (e.g. language) were addressed. Another reported advantage is the same mentors returning to a project, as planning and communication is facilitated by this continuity, and the partners can build on the work they did previously.

Some mentors indicated that they would have liked more support from the LPs in planning and preparing for the visit. For example, one mentor explained how, before the visit he hadn't appreciated quite how limited their access to internet was, which made follow-up between visits a challenge. He suggested that this indicated a mismatch between intended mentoring techniques and local resources, and better planning was required to establish practical communication avenues.

6.2.3 Communication skills

A large number of mentors described improvement in their communication skills. One mentor described how he had learned to continually check for understanding as even when English is the first language two cultures can interpret things very differently. He felt that it was important not to accept a nod of the head as an expression of understanding. Mentors also increased their confidence at communicating and mentoring at a distance via email.

Other mentors described learning the importance of listening as an element of communication. One explained:

> *I've been working in a cross cultural context for many years. The only thing I'd say in general is the longer I work in Africa the more I realise that there are cultural things*

that I don't understand and how important it is to really listen to what people are saying and not jump to conclusions based on my own experiences.

Her observation that in a cross-cultural context, listening carefully, and not making assumptions is the first step in clear communication was echoed by other mentors.

6.2.4 Mentorship in a cross-cultural setting

Mentors described a number of learned skills for mentoring in a cross-cultural context. One mentor referred to communicating in a culturally appropriate manner:

The experience enhanced for me the importance of modifying communication methods … in a cross-cultural setting

Mentors gave examples about how communication should be altered in relation to the particular culture of the countries. The UK is significantly more secular, particularly in the workplace, than many African countries. One mentor felt that he learned a greater respect for traditional views and religious priorities. Greeting appropriately, and addressing senior people with respect and in a formal manner is culturally shaped and the importance of respecting and engaging appropriately influenced the ongoing relationships.

Mentors expressed the importance of observing mentees for some time, encouraging them to demonstrate their skills, knowledge and attributes before giving any feedback. Mentors also learnt how to make suggestions for change as diplomatically and positively as possible, and to focus on the positive as well as making suggestions for change.

6.2.5 Mentorship in a resource-constrained setting

Mentors observed the importance of taking account of practical issues facing a resource constrained setting. One mentor described learning that patient anxieties and fears in resource constrained settings are often different from those faced by UK patients, and this would therefore influence the issues addressed with patients in counselling and social care. For example, the likelihood patients will need to make decisions about expensive and perhaps non-effective treatments. This mentor also observed the importance of rigorous clinical mentoring in resource-constrained settings, and how this could help health workers achieve accurate diagnosis despite the lack of resources.

One mentor noted that it was necessary to first learn what was possible, before making recommendations in a resource-constrained setting.

I learnt that "my idea" was not "the idea". Folk in a resource limited setting are very proud of their work and themselves (and rightly so). This must be seen first before ANY projects are undertaken.

This mentor also raised the important point:

> *There are barriers which are not able to be overcome. This is OK. We are not going to solve all the problems.*

As the mentor explains, he learned that, while it is the role of a mentor to help overcome barriers, and change systems, there is also a need to be realistic, and work within the existing system. Knowing the difference between constraints which can be overcome, and those which cannot is an important skill which comes with experience.

6.3 Potential Service Delivery Impacts

A number of mentors described learning which could lead to recommendations for changing service delivery in the UK. These are outlined below.

6.3.1 Scaling-up Palliative Care in UK hospitals

Some mentors noted that the experience of integrating PC in their partner African hospital had made them aware of the need to introduce PC earlier in the stage of disease in the UK, and also ensure it was fully integrated into UK hospitals so all patients with need received PC. One mentor, who had supported Ndola hospital-observed a greater openness about death in Ndola, a learning which was relevant for the UK in terms of integrating right across an organisation. This may be specific to Ndola, as in many of the evaluation reports for other hospitals, health workers observed an internal culture which avoided talking about death. (See section 5.2.1 on breaking bad news)

One mentor, from Kibagabaga described witnessing the difference that was made by training 70% of staff in PC,

> *Total integration of PC into the whole hospital is a big lesson that many UK hospitals would benefit from. The staff have a "feel good factor" that their hospital is something unique and they all worked together as a team.*

This mentor felt that introducing PC training across the hospital had created a culture change, and that this might be transferable to a UK context. Another mentor, from the same hospital also noted this, and suggested that PC training should be carried out in all cadres of the NHS to give a better understanding of patient care. He suggested that:

> *Mentorship showed me that the NHS is not good at teamwork. Training in PC is important for all health workers which was illustrated by Kibagabaga Hospital Rwanda and this is sadly lacking in the NHS.*

Another mentor, who supported Gombe hospital suggested that the mentorship visit reinforced the fact to her that most illnesses are palliative, in the sense that they are chronic, and PC needs to be introduced earlier, even in the UK.

6.3.2 Improving Referral Systems

Despite the fact that many of the hospitals were characterised by weak referral systems for PC, some mentors noted some lessons from the innovative solutions employed to improve these systems which could have applicability in the UK. Two main methods were noted:

1. The system of "link" PC nurses on all wards to identify patients with PC needs and liaise with a specialist service as appropriate.
2. Effective use of mobile phone support through a 24/7 "hotline" for discharged patients and their families as employed in MTRH.

Both of these innovations were described in section 4.3.1 of this document.

6.3.3 Scaling-up Palliative Care in UK hospitals

Many mentors considered that the experience had reinforced, or reminded them, of the importance of both a holistic and a multidisciplinary approach, and some mentors believed that both of these had been lost to some extent in the NHS. Aspects described were spiritual support, social worker support, involvement of families and use of volunteers.

6.3.3.1 Spiritual Support

One mentor described his learning from the cross-cultural setting in terms of spirituality:

> *[I have learned that] each person is a spiritual being with their own feelings and beliefs which need to be listened to with respect and empathy*.

For this mentor, the experience of being in the cross-cultural setting, where he was deliberately attuning to different spiritual beliefs, reminded him that all individuals' beliefs deserved respect and empathy. One mentor suggested that the NHS has lost the awareness of spiritual suffering in some individuals:

> *[the health system needs] an awareness at all levels of spiritual suffering as a major factor in severe illness. This is widely lacking in the NHS.*

This mentor went on to suggest that an understanding of a patient's religious beliefs, and support from religious leaders can influence the patients understanding of illness and

compliance with therapies. Additionally, it would enable a healthcare team to meet a patient-led expression of spirituality and requests for prayer using holistic team resources.

Interestingly, some senior staff in this hospital (MTRH) felt that spiritual support was lacking in the hospital, yet the mentor noted it as more developed than in the NHS.

6.3.3.2 Social Worker Support

Some mentors noted the value of a social worker in a PC team. The mentor in MTRH remarked on the fact that a social worker led the PC service there very effectively and was accepted as the service leader by all clinical staff. He noted that this is not common in the NHS, where dedicated social workers have been withdrawn from many PC teams. He suggested there may be an opportunity in the UK for a social worker to facilitate family meetings prior to complex discharge which could lead to a better awareness of the social conditions patients are returning to, and help them back into family life or into their community.

6.3.3.3 Community Volunteers

A number of mentors noted the effective use of volunteers from the community to benefit patients and relatives in *Integrate Project* hospitals. One mentor explained how this was part of the community culture:

> *[I saw] a real collective sense of responsibility from the community for the health and wellbeing of members of that community*.

Mentors saw opportunities to mobilise communities in the UK to have a similar collective sense of responsibility, through existing organisations and churches. Their experience would help them support "health promoting PC interventions" which are being encouraged by a few innovative hospices in the UK

Other mentors described specific ways in which community resources could be leveraged more in the UK. For example, one mentor suggested that trained volunteers could be used in NHS hospitals to support patients and families. Another proposed that volunteers could be employed in the community to be "the first line advocate for the patient." This mentor also suggested the need for a public debate about how limited resources are used in the NHS to best benefit patients, and her comments suggest that volunteers could be a cost-efficient way to improve access to support.

6.3.3.4 Involvement of Family

Some mentors noted the increased involvement of the family in the hospital in which they had mentored, and felt that this could be improved in the UK. One mentor described this as follows:

The family involvement in patient care is something that we in the UK could learn from. I think families often do not feel fully involved in the care of their family members and are restricted by health service protocols.

Some nurse mentors suggested that hospital guidelines, such as protected mealtimes, disempowered families and carers from being involved in hands-on care.

6.3.4 Improving mentorship in the UK

The experience made one mentor see opportunities for increased clinical mentoring in the UK:

I saw the potential for mentorships within our own NHS- I am now retired and maybe this is happening in some areas.

This had also been raised at the joint mentorship meeting. Mentors realised that, if mentorship becomes part of practice, every interaction between staff members should be a teaching and learning opportunity.

6.3.5 Improving clinical skills in the UK

Some mentors noted that the experience of working in a resource-constrained setting, where diagnostic tests were limited, had reminded them of the importance of physical examination and history taking as diagnostic tools.

The reliance on clinical skills and assessment of benefit vs burdens, without the dependence on radiology and blood tests is always a salutary lesson to incorporate in our work in the UK. [The UK has an] over reliance on investigations rather than clinical skills.

Mentors suggested that it was important to challenge use of inappropriate investigations and treatments especially when costly in the UK, as well as in African countries, and that diagnostic testing should always be preceded by a physical examination and history taking. One mentor described how the experience underlined the importance of listening to the patient and that monitoring satisfaction in the NHS may be assessed by a question like “have you been listened to in this hospital.”

6.4 Future plans of UK mentors for shaping service delivery in the UK

Many of the mentors active in the UK workplace had various plans to bring their learnings to the effect in the UK. These are outlined below.

6.4.1 Advocating for and making changes within own organisation

A number of mentors planned to advocate for change within their own organisation, from the NHS to charities, hospices and policy/training organisations. One mentor, who had worked in the small district hospital Mazabuka, explained how the relative flexibility of the system made her realise change was possible:

> *In the NHS we are often constrained by the attitude 'this is the way it has always been done so we must continue' Having seen how quickly change can happen in a resource limited setting when there is less bureaucracy to navigate – adopting a similar approach to bring about change is something that we could benefit from in the NHS. In my role I constantly look for ways to be flexible and to be proactive in persuading my colleagues that we must not be constrained by current protocols and practice if it is obvious that change would bring about positive results.*

This mentor is involved in integrating government policy recommendations through education/training and policy and process updates, and indicated that she would contribute her learning to this where appropriate.

Her observation, that change could be quickly effected, was in part because she was mentoring in a small hospital. Other mentors who were placed in district hospitals made similar observations. For example one mentor from Kibagabaga said she would share her observations with medical practitioners from her hospice on effective team work and training a critical mass of staff across the hospital.

Another mentor, who was placed in a regional hospital, and had observed the importance of mentoring, said she was currently advocating for a greater mentoring role within her organisation.

6.4.2 Lobbying policy-makers

As well as making changes within their own organisation, some mentors are now actively lobbying policy-makers. One mentor described how he would lobby MPs to advocate that PC training done for all cadres of the NHS would improve patient care for everyone.

Another mentor planned to involve herself in politics at both a regional and local level to debate how limited resources can be best used within the NHS, and how PC can be introduced earlier in a cost-effective manner.

One mentor, currently employed as a GP, developed plans to become involved with her regional Clinical Commissioning Group (CCG) as she believed this was the best way to effect change:

At a time when a universal healthcare service is increasingly under threat in the UK, the mentorship visit made me even more aware of just how necessary it is to fight for what we have. It also made me more aware of drawing distinctions between what constitutes essential services, and what doesn't… [I am] more likely to become involved with the local clinical commissioning group.

6.4.3 Raising awareness through teaching, talks and articles

A number of mentors, while not directly working with policy-makers or commissioners, are actively raising awareness of learning for the UK through teaching, writing and giving talks.

One mentor described this enthusiastically as follows:

"I keep talking about it everywhere I go. I have spoken to our local hospice and to many church groups."

The mentor was referring specifically to training a critical mass of staff across hospitals and improving teamwork. This mentor displayed an enthusiasm for promotion of PC both in the UK and internationally, and had been motivated by her visit to share this with others. Another retired consultant, who is the trustee of 2 charities, plans to advocate for greater involvement of the family, and more use of volunteers through "giving talks to various groups".

Some mentors with current teaching roles, described how they would incorporate their learning into this.

6.5 Future mentor plans for shaping and influencing service delivery overseas.

6.5.1 Advocacy and awareness raising

Mentors remained committed to PC integration in their partner countries. One mentor explained that although she had retired from UK practice she would continue to lobby for change in Africa:

I no longer practice in the UK. Nonetheless, my dedication to better pain and symptom relief for Africa is very strong and I shall keep lobbying.

Another mentor said she found the experience so motivating, that she tried to motivate her colleagues to also mentor overseas:

I find that I take every opportunity to motivate colleagues to seek similar opportunities and explain to them in what ways they would find the experience enriching and how it would benefit their professional development.

Other mentors intend to write articles on health in developing countries.

6.5.2 Ongoing partnership working with the *Integrate Project* hospitals

Of the 14 mentors who responded to the questionnaire, 9 reported ongoing supportive email contact with the hospitals they had mentored. Of the 5 who were no longer in contact, some had attempted to maintain contact, but had not received replies, perhaps because of poor internet connection or pressures of work as reported by many mentors.

The project has led to plans for formal linked agreements between two of the organisations mentors represent and hospitals in Rwanda. A number of ongoing informal contacts have been productive. One mentor from Mazabuka described "*constant email contact which is supportive.*" The support this mentor continues to give includes general advice; informing the hospital of announcements of new funding; discussing with them how they might meet practical needs for equipment, books, academic papers and computers; fundraising in UK to support the project hospital staff with small PC projects.

6.5.3 Partnership working with other overseas organisations

All mentors who responded to the questionnaire indicated that they would be very interested in future mentoring. One mentor explained: "*[the experience] has reinforced my desire to undertake further work in PC education, training and development in a developing country context".*

Some mentors already had plans in place in other funded projects. These were mostly mentors who had already had links with African hospitals. One mentor plans to visit Ghana, Tanzania and India, saying *"I will go anywhere to promote, teach and, mentor PC!"*

A few mentors are part of PRIME, a network of medical educators involved in international whole person medicine teaching, and will continue to teach and mentor overseas through this network. Some are linked to international palliative care opportunities through Cairdeas International Palliative Care Trust. Some mentors were based overseas developing and strengthening PC programmes, and would continue to do so after *Integrate Project* ended.

7 Key Ingredients for Effecting Change to achieve integration

This programme was based on four pillars of advocacy, staff capacity, service delivery and partnership. The ethos of the project was to deliver activities across all four pillars to strengthen the health system at all levels, thereby creating a sustainable platform for integration. The pillars were closely aligned to the WHO Health Systems Strengthening building blocks, of governance and leadership, human resources, service delivery, finances,

medicines vaccines and technology, and strategic information, which are described in the WHO report Monitoring the Building Blocks of Health Systems (The MBBHS report).[23] The staff capacity pillar aligns with the human resources building block, and the service delivery pillar encompasses service delivery, medicines and strategic information. The *Integrate Project* sought to influence all six building blocks through Advocacy and Partnership. The *Integrate Project* thereby provided a structure through which the WHO Health Systems Strengthening building blocks took shape.

We noted the following key ingredients for effecting change which strengthened the health system:

7.1 Ownership at a country and hospital level

7.1.1 Integration into existing systems

An essential ingredient for effecting change in this project was the model used, whereby PC was integrated into the existing hospital and community health systems. All 12 hospitals implemented a PC service which was integrated into the hospital with almost all the PC staff supporting those within the ward teams who had primary responsibility for caring for the patient, rather than taking over patient care. The majority of community trainings involved training existing community health workers under the various primary care systems in each country. This model is, in essence, sustainable as services have become part of the hospital and are owned by the hospital.

7.1.2 National Ownership

As described in section 4.4.4, integration is only possible when there is national ownership. Key to integration is the establishing of a national space whereby Ministries of Health can promote PC and commit hospitals and health services delivering PC services. Such leadership needs to emerge from government or an organisation that has the MoH mandate to cascade PC through the health system. This may be a national association, but could also be a government department.

The national ownership was particularly striking in Rwanda. Components of the training strategies used by the Integrate Project have now been adopted by the country, and will become part of a country-wide strategy, and some of the documentation used (for example the clinical guidelines) will come from Integrate Project documentation.

The layered support of the project partners meant that much of the training and support was delivered by national associations, and southern partner technical expertise, rather than external partners. These associations have an existence before and beyond the Integrate Project, and the model of using them to deliver the trainings has strengthened their capacity to deliver support and their relationships with the hospitals. As noted in section 4.4.3, a number of strong relationships have been developed between the hospitals and the national

associations and also with southern partners such as APCA and MPCU which will help to further drive change forward.

7.1.3 Hospital Ownership

Because the models were integrated into local systems, work-planning was carried out at a hospital level, and hospitals had control over the way in which activities were developed and implemented. Effective integration for change requires attention to hospital preparedness for engagement, and the most successful hospitals were those where staff created a culture and an environment for PC as part of the system of care. For example, in terms of cascading training down to the community level, each hospital identified who constituted their community and the process that worked best for their catchment area, and their staff capacity.

The hospital director at Rwamagana recognised this explicitly, saying *"The INTEGRATE project has been brave and supported something different" (Hospital Dir).* He went on to explain that the difference was the local ownership, which he saw as the LPs effectively saying "you state what you want to do and we will support you", following this up with training at different levels, mentorship, support supervision and commitment from the team.

Most of the hospitals had the seeds of PC already sown through work of committed staff who, for example, had been working with HBC teams to help with PC training and sensitisation. Rather than implementing new services when there were already nascent systems in place the *Integrate Project* provided the platform to incorporate and include programmes such as HBC, while adding structure, training, mentorship and credibility.

An example of the space given for innovation was in MTRH, where the deputy Chief Nurse adjusted the training programme, developing a modular programme specifically for that hospital. This has led to strong local ownership of the project. When articulating her future vision for the PC service and asked by one of the evaluators how she would achieve this now that the *Integrate Project* funding was at an end she replied "we will discuss with management and find another platform". She saw the project as the hospital's own and the *Integrate Project* as a partner in helping them to achieve a hospital goal, not a project goal.

7.2 Palliative Care Leadership

PC leadership was an essential ingredient to effecting change in the hospitals, and the greatest changes were noted in the hospitals with the most supportive and passionate leadership. By leadership we include leadership given by senior hospital management, as well as staff tasked with the executive PC role within the hospital. Some aspects of this are explored below.

7.2.1 Mandate from hospital medical leadership

In all 12 hospitals, the hospital management agreed to implement the *Integrate Project*, and therefore all hospitals had support from the senior hospital team to deliver PC. Some hospitals, particularly where PC was a new service, expressed the effect of this explicitly.

> *Our Senior Medical Superintendent has supported us to go flat out and give PC. Before we were questioned, "where are you going", now they are encouraging us.* (Nurse, UTH)

Prior to the mandate from the hospital executive, the nurse in question was questioned by her peers and more senior staff about the time she put into provision of PC. A number of hospitals saw it as essential to have a hospital-wide sensitisation event at the very start of the project to ensure that all hospital staff, particularly the prescribers, were aware of this mandate. The deputy nursing director in MTRH explained how the support of the hospital medical superintendent at the start of the project was an essential ingredient to successfully implementing it:

> *Our first intention was to sensitise management. We got the hospital director, I asked if we could have all the heads of department to come in for the sensitization. The director opened the forum and stayed right to the end. The heads immediately said "this is good! We have these patients in our wards, we don't know what to do with them, we are happy with this new approach to PC". This was so important to get this done right at the very beginning to get the heads on board. They recommended that we get the prescribers on board.* (Nurse, MTRH)

This nursing director felt that the support that the medical director showed by staying to the end of this first important meeting was key to the buy-in of the heads of department, and it was these heads who recommended that the prescribers then receive the same presentation.

7.2.2 Senior Champions for Palliative Care

As well as a mandate from the hospital medical superintendent, senior champions for PC are required to support the staff delivering PC and to drive the agenda forward. These champions may, or may not, be part of an officially constituted PC executive, or delivery team.

For the purposes of credibility, and changing attitude, it is important that doctors are included among these champions as well as nurses. For example, a nurse in Kabale hospital described how, at first, the trained PC staff "collided" with the doctors, in particular when they advised on morphine prescription, as the doctors undermined the lower cadres. A senior doctor, who was a champion for PC met with the hospital doctors, explained the *Integrate Project* training and convinced them that the PC team had good pain management skills. They then started trusting them to prescribe morphine.

The activities described in section 4, including conference attendance, and clinical placements in centres of excellence nationally and internationally was important in mobilising these senior champions in PC. A senior Kenyan surgeon, who championed PC in his hospital narrated:

> *The benefits of partnership and going to Mulago [national referral hospital in Uganda] for me, was to see the attitudes that have changed in Mulago. If we got a few Kenyan [medical] students to go there, it could really change their attitudes. The way they feel about end of life care.* (Doctor, MTRH, Kenya)

This surgeon felt that they needed to keep "growing" internal champions. He believed that MTRH (800 bedded hospital) needed at least 3 senior passionate medical champions for PC in order to support and advocate for services.

7.2.3 Clinical role models for palliative care:

Many health workers described the importance of clinical modelling for PC: both from their clinical placement, from the UK mentors, and from within their hospitals. As a nurse in Homa Bay explained this:

> We are role models. Once someone sees you are a role model then they try to emulate you. (Nurse, Homa Bay)

Homa Bay was an example of a hospital which managed to move from no adult PC service to an integrated service in a short period of time, with most doctors willing to prescribe morphine. They explained how clinical role modelling effected the change from pethidine to morphine in surgery, because the medical superintendent, who was involved at the very first *Integrate Project* planning meeting began by prescribing to his patients in Obstetrics and Gynaecology, and the other surgeons followed suit. Some clinical role models characterised this using the analogy of "infecting" their colleagues with PC:

> *You need to get sick first (with PC) and then infect others. Once that burning fire is in you, you can't do nothing, if it burns in you then it can't go out* (Physiotherapist, Mazabuka)

Other health workers used similar language to portray a change in ideology and values that occurred within them during the *Integrate Project* or before.

7.2.4 Continuous Sensitisation and training as part of practice.

Hospital staff noted that an essential element of effecting change, and continuing to effect change was through making sensitisation continuous and opportunistic as well as planned, and through embedding training as a core part of practice. Continuing with the example of Homa Bay, a doctor explained how they took this approach:

> *We demystified the fear of morphine. We invited all the prescribers to a meeting and sensitised them on the use of morphine. We grab all the opportunities. If there are any meetings we sensitise them.* (Consultant, Homa Bay)

Rather than seeing sensitisation as a one-off activity at the start of a project, this doctor recognised that it needed to become part of practice. One senior PC champion related this in terms of staff turnover:

> *The trainings have been very important. Through them people have become aware. But people leave. We employ new people and they don't know about it. But their attitudes will also change. And when they go, they will take their attitudes with them.* (Consultant, MTRH)

The empowerment of health workers to continuously train and sensitise, achieved through the ToTs is an important element in creating the will to do this in the hospitals. This was described in section 4.2.2

7.3 Building Blocks in Place for a Service

To achieve an integrated service, the essential health system building blocks need to be in place. This is described further below.

7.3.1 Policy

Appropriate policy is an essential ingredient for ensuring PC services are delivered, as recognised by the WHO Public Health model described in figure 1.2.1. This can be achieved through ministerial advocacy, as described in section 4.1.1 and through building champions through specialist training, as described in section 4.2.3.

7.3.2 Access to Medicines

Access to essential medicines in an essential ingredient for ensuring PC services are delivered, as recognised by the WHO Public Health model described in figure 1.2.1

7.3.3 Trained Staff

7.3.3.1 Critical Mass of Staff

Building a critical mass of trained staff was essential to ensuring the service was integrated throughout the hospital. Because of the staff numbers involved, this is much more difficult in larger hospitals. The deputy Chief Nurse from MTRH described this as follows:

> *What we have trained is a drop in the sea. We need to go in and reinforce. There are more than 3,400 staff in the hospital – about 2,400 of these are clinical. We need to do continuous sensitisation. The number that we have sent are maybe 1 in a unit.*

She had given this explanation in response to a question about whether PC was integrated in the hospital yet. In her opinion, it was not yet integrated because, although all leadership, local ownership and other building blocks were in place, the hospital had not yet reached a critical mass of trained people. The local ownership of projects is particularly important in this case, as MTRH do have a plan for continuing to train staff till they reach a critical mass.

Most district and many regional hospitals believed that they did already have an integrated service which had been achieved during the 3 years of the *Integrate Project*, and many explained this in terms of having a critical mass, or "enough" staff trained.

7.3.3.2 Strategic selection and deployment

As described in section 4.2.1, under basic training, strategic selection of staff for training to include the ward in-charges, high-need wards and a coverage of staff across the hospital is a necessary factor in training staff.

7.3.3.3 Multi-disciplinary Team

The multi-disciplinary aspect to many of the PC teams was an essential element in ensuring a holistic PC service, and one which was noted during the evaluation visits, and by some of the UK mentors. For example, (section 6.3.2.2), the mentor visiting MTRH noted the important role played by the social worker in facilitating family meetings prior to complex discharge. In Homa Bay, the physiotherapist team member recounted the impact of the project from her point of view, adding:

> *As a physio I am also happy. When patients are functionality active and can do activities of daily living that is what we want. PC helps patients to realise their own condition. When patients know what to expect it really helps them to become functionally active.* (Physio, Homa Bay)

Having a physiotherapist as a core member of the team enhanced the holistic service offered, as they stressed the importance of improving function in palliative patients.

An identified gap in some of the hospitals was with the spiritual component of care:

The spiritual component is very important, but it is missing in this hospital… You can ask for a chaplain to come and pray with that patient, but they are just too busy. (Doctor, Kenya)

This hospital had only one chaplain. Hospitals can potentially use volunteers to bridge this gap, as volunteers can support spiritual leaders by praying with patients on request.

Some hospitals made the MDT an integral part of their overall vision. CHUK vision of care was influenced by the visit of the hospital director to MPCU and Mulago hospital, but had more emphasis on the PAMs with inclusion of psychologists, social worker and physiotherapists as a core element of the team.

7.3.4 Engaging with complexity

To effect health systems change it is essential to recognise the need for flexibility and understanding of complexity. Simple, linear interventions can be measured but will seldom result in systems change. The complexity of this project was reflected in the partnership working, engagement with MoH and hospital leadership, role of national associations and resulting behaviour change at clinical levels. The more complex the systems such as the national and regional hospitals the longer this process can take, and the length of the *Integrate Project* is relatively short. Despite this, some substantial systems changes were noted, as described in previous sections.

7.4 Visibility of Service

The visibility and the presence of a credible PC service was an important ingredient for effecting change in all 12 hospitals. Hospitals achieved this in various ways. Some of these are described below.

7.4.1 Recognised Team

A number of hospitals described the importance of having a named team to create visibility of PC within the hospital: whether this team was a specialised unit, a team with support, or a dispersed team. Gulu RRH explained how before the *Integrate Project*, PC was seen as being the remit of an individual. Now, it is seen as a service associated with a team and practiced by a critical mass of people across the hospital. The pharmacist member of the PC team in Nyeri also saw this happen:

Initially everyone thought she [PC specialist nurse] was the PC person, and when she is not there nothing happened. I think the important change was the involvement of more people and making them realise they don't have to reply on one particular person. Sometimes when there is a pioneer everyone relies on that person. [Pharmacist, Nyeri]

It is important to note that, because PC pioneers, and passionate clinicians are so important in creating a team, this may be a natural progression for emerging PC services and teams may begin by being associated with an individual before moving towards full integration.

7.4.2 Advertised Service

A number of hospitals internally advertised the services of the PC team. This was very effectively done in MTRH, where posters with the 24-hour PC hotline were placed throughout the wards.

7.4.3 Physical presence

A number of hospitals found a physical presence an important part of increasing the visibility of the service. For example, the long-term UTH mentor saw the new PC office, in the heart of the medical wards, as an important development, describing how it would be used as a hub for referrals/advice/patient/relative meetings and its position should generally raise the profile of PC within the hospital.

Gulu RRH also described how the allocation of a room during the project shows that the need for the services has been recognised and has support from administration. It is also somewhere to go and centre PC activities, and patients know where to find them.

A physical presence may not be essential in all cases. For example, while a dispersed team may benefit from an office for giving a presence, and receiving and logging referrals there is no point in having an office if it is not used. In such cases other methods of creating visibility can be used, such as advertising a service as in Kibagabaga where the names of the team and their contacts were up on all wards.

7.5 Role of partnership in effecting change

7.5.1 Providing whole systems support

While hospital ownership was a critical ingredient for success (as described in 6.1.2), the role of the *Integrate Project* was much more than simply funding local initiatives, but about providing whole systems support to locally owned initiatives. This is covered in detail in section 4.3 on service delivery. Through ongoing mentorship, the *Integrate Project* provided technical expertise in implementing an integrated service, including example protocols, policies and models of service. This mentorship was in several forms and included national associations, LP technical visits and UK mentors. Its added value was in describing and

demonstrating how multiple activities and components of palliative care come together not simply as a service but as a system of better care for patients.

However, as described in section 4.1.1, on MoH advocacy, there were limits to the changes that could be effected in certain systems, which are nationally set, rather than set at the hospital level.

7.5.2 Providing a vision

Partnership helped the hospitals establish their vision for their own service. This was described in section 7.2.2 by the MTRH surgeon who saw how PC could be implemented after visiting Mulago, and in section 4.4.5 by the CHUK medical director. In the case of CHUK, this led to immediate changes:

> *The visit to Uganda made the Director understand … two days later I became the desk coordinator for PC." (Desk coordinator, CHUK)*

The hospital director confirmed this, saying *"Mentorship gives a clear picture of what PC really is". (Hospital Director, CHUK)*

7.5.3 Providing Technical Expertise and Credibility

Partnership provided the hospitals with technical expertise – both from with the LPs and the UK mentors. This was described in section 4.4.4 on UK mentorship and in the impact of training and clinical placements. Health workers felt that their clinical practice changed, particularly with regards to pain assessment and management, symptom diagnosis, and breaking bad news, and put this down largely to mentorship and clinical placements in other hospitals.

Hospitals also talked about the credibility brought by mentors and members of the LP. The hospital director at CHUK described this as essential, particular in a large teaching hospital:

> *The important thing is that the mentors need to be credible, specialists, credible at the university level, and work within the culture.* (CHUK)

7.5.4 Establishing and Supporting Networks

Partnership helped to establish in-country networks, which can continue to integrate PC after the *Integrate Project* has ended. This was described in section 4.4.3, on the partnership between hospitals and their national associations. In-country leads elucidated concrete plans for continuing to develop PC services. For example, KEHPCA indicated that they would continue to both support the hospitals and call on them to assist with training. RBC described

the ongoing programme with all hospitals, in particular CHUK to be developed as a centre of excellence.

Hospitals also benefitted from intra-country partnership including the building of academic networks for research and training supported by the specialist courses. While these do not have as clear a platform for continuation as the in-country partnership do, benefits were already achieved in terms of providing a vision. The specialist trainees also described how they continued to communicate and support one another through Whats App, a free instant messaging service.

7.5.5 Increasing the profile of Palliative Care

Lastly, partnership helped to increase the profile of PC, which sometimes helped to galvanise change. This was particularly true of international partnership, as the presence of international senior staff gave PC increased status. This was described in section 4.1.1.

8 Sustainability

8.1 Sustainability Successes

This project had sustainability at the heart of its design. As a health systems strengthening project which was nationally owned, it used existing systems and staff on the government payroll to deliver the project. The project was designed to build on what was available in each hospital, rather than introducing services which were dependent on external funds and staffing. This is inherently sustainable: as one health worker described *"[PC] is part of what we do now, we're not going to stop it."* (Nurse, Rwanda)

Successes in sustainability are described below in terms of the six WHO Health Systems Strengthening building blocks which are described in the WHO MBBHS report.[23]

8.1.1 Governance and Leadership

The *Integrate Project* leveraged existing leadership. National Associations/ MoH have committed to follow up and support as part of their ongoing role. It also embedded services within existing governance systems: PC teams were part of hospital structures and governed by the same systems as other hospital teams. As described in section 4.1.1, the MoH in all 4 counties recognise PC in their national plans. In Rwanda, a PC Desk has been formed at the MoH. Working within national systems of health, the *Integrate Project* demonstrated how such work enhances all services and care systems (see section 5.3.4). This has led to ongoing commitment from leaders in a number of the hospitals.

8.1.2 Human Resources

781 staff received PC training through this project. As described in section 4.2, the training was effective in mobilising staff to deliver PC, by "converting" them, and equipping them with the necessary skills. In most district and regional hospitals, there are now a "critical mass" of staff trained, such that PC has become integrated: i.e. fully embedded within everyday practice. In some regional and national hospitals, while there is not yet this critical mass, there are plans to continue training within the hospital and surrounding community to scale up services. The project encouraged a culture of continuous sensitisation, training and appraisal of staff, which should continue after the *Integrate Project* has ended. The project has provided the skills and resources to sustain this, at least in the medium term. Some hospitals are establishing themselves as "training hubs", and with the support of district MoH (e.g. Nyeri), National MoH (e.g. CHUK) and PCAs (e.g. Homa Bay) will continue training in their communities and satellite hospitals.

As described in section 4.1.4, the *Integrate Project* has, in conjunction with other organisations, influenced the training institutions, such that PC has been introduced into nursing and medical curricula, which is a sustainable change for the future.

8.1.3 Service Delivery

A PC team is now in existence at each of the 12 hospitals. As described in section 3, each of these teams has a sustainable and continued existence. Protocols and guidelines are now accepted as standards within the hospital. As also described in section 3, each hospital has improved the referral pathway, and extended links into the community, using existing primary care staff and systems. All of these changes are sustainable.

The MBBSH report set out eight characteristics of good service delivery in a health system. Strengthening PC will also strengthen many of these. For example:

1. **Quality**: This project demonstrated that training in PC changed the approach of some health workers, causing them to deliver more values-based care, centred on patients' needs and patient safety.
2. **Person-centeredness**: PC services are, by their nature, person centred, as they are based on care for an individual, not just management of a disease. This project demonstrated that introduction of PC services improved person-centred care, at least in the opinion of the clinicians.
3. **Continuity / Coordination**: PC hospital teams managed the patient in collaboration with the patents primary hospital team. This facilitates continuity for the patient, and coordination of care. The referral pathways set up through this project can affect the whole health system, as improving referral pathways for PC also improvise them for the system as a whole

8.1.4 Finances

The project has demonstrated that PC can be successfully delivered within national health systems. No funds were put into human personnel staffing provision at any of the hospitals. The services should continue to be delivered once the project has stopped. There is no reason why the number of patients, the morphine consumption or the quality of service should reduce.

8.1.5 Medicines Vaccines and Technology

The medicines being used are, in general, on government medicine lists (with some exceptions, such as bisacodyl). Morphine is free or highly subsidised. The medicines model is therefore sustainable.

8.1.6 Strategic Information

PC has been put on the national indicators in both Zambia and Rwanda. The process for monitoring, tracking and counting patients within each hospital was set up simply, and adjusted to hospital needs. It is therefore sustainable, and we believe this information will continue to be collected post-project.

8.2 Issues identified going forward

The great strength in the sustainability of this project was the use of existing platforms to deliver services. However, this means that the sustainability of the project is dependent on the strength of this platform. These successes therefore need to be considered in the context of the existing health service.

8.2.1 Governance and Leadership

Although sustainable successes were observed in governance and leadership, a number of issues were identified for sustainability. As described in section 4.1.5, inclusion of PC in a national level plan is only a first step. The implementation of these plans is then necessary.

8.2.2 Human Resources

This project took place in the context of a health worker crisis. In 2004, Chen et al defined a critical shortage of health workers as fewer than 23 health care professionals – including doctors, nurses and midwives – per 10,000 population.[53] The bulletin of the World Health organisation in 2009 identified all 4 participating countries as having trained health workers below this level, with a maximum of 1.4 physicians per 10,000 population, and 20.1 nurses and

midwives (physicians: Kenya (1.4), Uganda (0.8), Zambia (1.4) Rwanda (0.5). nurses and midwives: Kenya (11.4), Rwanda (4.3), Uganda (7.2), Zambia (20.1))[54]

The sustainable successes in human resources for PC need to be considered in the context of this overall health worker crisis. Sustainable for PC cannot be implemented without sustainable and properly resourced health systems overall.

8.2.3 Service Delivery

The sustainable successes in service delivery need to be taken in the context of the service delivery challenges facing the whole of the health system in each of the 4 countries. While PC was integrated into most of the 12 hospitals, the sheer scale of need means that country-wide integration is a slow process. For example, despite palliative care being introduced in Uganda in 1993, even with strong MoH support and sustained advocacy from a number of stakeholders, the country had services in less than 50% of districts by 2009. [37]

8.2.4 Finances

While this project demonstrated that PC could be delivered within existing resources, there is still a requirement for ongoing financial commitment from MoH budgets to support training and mentorship of staff, and to continue to make essential medicine available. While most hospitals spoke positively about national and district MoH leadership, some staff expressed frustration that it was not always translated into a budget for supplies and resources. There were examples that budgetary support was becoming available, particularly in the form of a small number of funded staff members and essentially medicine. However, budget for of services, such as outreach and home visits was not apparent. These resource constraints need to be taken into account when establishing PC service models. This project takes place in the context of underfunding of health care services in general: while health spending in Rwanda and Zambia has reached the Abuja target, to allocate at least 15% of their national budgets to public health by 2015.spending in Uganda and Kenya still falls short of this. [55]

8.2.5 Medicines Vaccines and Technology

Subject to the caveats described in section 8.1.5, no additional issues were identified for sustainability in medicines vaccines and technology.

8.2.6 Strategic Information

Subject to the caveats described in section 8.1.6, no additional issues were identified for sustainability in strategic information.

9 Recommendations

The recommendations which follow focus on methods to implement the WHA resolution: to integrate PC services into every National Health Service. This resolution called for the director general to "*encourage research on models of PC that are effective in low and middle-income countries, taking into consideration good practices*" [2] p5 and it is through the evaluation of 12 such models that these recommendations arise. The recommendations are structured around the 6 building blocks of health systems strengthening, through which the resolution can be implemented. The recommendations from the project have been categorised for 3 audiences as follows:

1. **For new services**: these are recommendations for hospital leadership seeking to integrate PC services
2. **For Ministries of Health**: These are recommendations for the MoH in partner countries, or in any southern country seeking to implement the WHA resolution.
3. **For similar projects**: These are recommendations about the project management of similar future projects.

9.1 For New Services

9.1.1 Governance and Leadership

PC services should be integrated into the hospital, and subject to the same governance procedures surrounding staff training, medicines management, patient information and referral systems.

There is a need for a leader and/or a co-ordinating group for the PC team within the hospital. This role should be formally constituted and given the mandate to provide and co-ordinate PC services. As well as coordinating services, the leader needs to plan for ongoing PC training and supervision within the hospital. Hospital management should recognise the influence PC has on all services through driving the adoption of values-base care (see section 5.1.1). Hospital leadership should act as an example of values-based care, and plan for clinical modelling to become part of ongoing training to facilitate its expansion through the hospital.

9.1.2 Service Delivery

As just described, a leader/coordinator for PC services should be identified, and staff should be mobilised in a multi-disciplinary team. However, the model for this team will depend on the hospital: it will not normally need to be a dedicated specialist unit, but could be a dispersed team (see section 3 for description). Integration within the hospital will mean some form of shared care: with the PC team advising/ providing care in conjunction with the primary team on the ward in charge of the patient. To encourage new units to develop appropriate models, links with a similar size hospital should be made, and, if possible, hospital management should

visit this hospital to observe the PC team in operation and assist with developing the vision for PC. The model implemented should be pragmatic for the hospital in question, starting with where there is an "open door": for example, a hospital with an incipient service already within a cancer centre may choose to house the team within oncology.

The PC team will require visible and a physical presence within the hospital: ideally through a space (office, consultation room, desk within a ward) to co-ordinate activities and seen as a central for PC within the hospital. Hospitals should consider using a "link nurse" model (see section 4.3.1), whereby an individual on each ward is responsible for identifying and referring PC patients to a central point, as well as providing PC.

Providing a service requires clear referral pathways in accordance with the national health system, both within hospitals and between health facilities and communities. Hospitals should recognise the importance of working with partners to develop these pathways: national and district hospitals should train their referring health centres, and district hospitals should train their community health workers. Even where existing systems are weak, it is more sustainable to strengthen existing platforms (such as an existing network of community workers) than to develop new ones. However, incipient networks operating outside the health system should not be stifled, but supported and encouraged where possible to incorporate themselves within the overall health system. (An example of this is Nyeri breast cancer survivors group, which developed a community referral support service, before formally being incorporated into the primary healthcare system of community volunteer workers).

Clinical protocols should be made available. These should be practical and short enough for regular use: which may mean using 2 versions, e.g. laminated sheets for use on wards and more detailed protocols for reference and training.

9.1.3 Human Resources

PC training should be carried out at both basic, intermediate and specialist levels if possible. The basic training should include a clinical placement in a hospital with well-developed PC services. A range of cadres should be trained, including doctors, nurses, pharmacists, social workers, physiotherapist and other allied professionals. Staff should be strategically deployed, in high-need wards following training, particularly intermediate and specialist training. Trained staff should be mobilised in a multi-disciplinary team. For PC to become a normal part of service delivery, a "critical mass" of staff should be trained: around 25% of all hospital staff. Training and sensitisation needs to become part of practice for this to be possible in most hospitals. Staff should be equipped with ToT skills and resources to implement ongoing training, and training should be endorsed and supported by hospital management, including provided with space and resource to carry out the training (including a computer and data projectors) and ensuring trainees are strategically selected and instructed to attend. PC should become an integrated part of the performance management system and annual staff appraisal.

Modelling of integrated PC is an important part of capacity building. This modelling can be internally provided: from trained staff within the hospital to recent trainees. It can also be provided through mentorship provided at national level, through regional centres of excellence and by international networks. Mentorship is about enabling staff to embed what they have been taught into practice (not doing the training itself). Face-to-face mentorship provides the best opportunity for modelling PC, but mentorship can also be carried out remotely, following a first face-to-face session. Opportunities should also be provided, where appropriate, for sharing within countries and outside of the country.

Volunteers are an important human resource, which should be utilised as appropriate: e.g. in the provision of spiritual support (e.g. praying with patients who request it). The national system of community volunteers, if it exists, should also be given basic training, and existing systems used to refer and support patients on discharge.

9.1.4 Medicines, Vaccines and Technology

Hospitals introducing PC services need to build staff confidence in prescribing and dispensing PC medications and can do thus through mentorship and modelling. Pharmacists and senior doctors should be trained in PC together, in addition to other members of the multidisciplinary team, as this enables them to all become clear about the appropriate and effective utilisation of medications such as oral morphine. Training should focus not only on prescribing, but should include supply chain mechanisms, including ordering processes and strategies to avoid stock-outs, particularly for newly introduced medications. It is important to train enough people, the right people and strategic individuals, who influence and manage procurement as well as clinical leadership.

9.1.5 Finances

Hospitals should ensure that sufficient budget is allocated to PC training and essential medicines.

9.1.6 Strategic Information

Hospitals should establish mechanisms to document information related to PC e.g. morphine use, patients seen. Data collection should be done routinely and consistently with clear instructions and guidance as to what to collect and how.

Patient documentation should be put in place, both for tracking and referral purposes and for reporting purposes. Such documentation should always be completed. In cases where there is a dispersed team, with limited time to dedicate to PC, this may mean use of short and simple forms. (Completed simple documents are better than detailed ones which are not complete.) While there may be separate referral documents / patient information forms for PC, these should be held on the main patient file as well, so that the primary team taking care of the patient has sight of all relevant patient information.

Hospitals should take the opportunities if they arise to utilise technology (e.g. mhealth) to collect and analyse data.

9.1.7 Cross-cutting

Service leaders should have an openness to what others are doing and what can be drawn from other projects to help fulfil integration. However, they should note that they will be unlikely to set up an identical model to another hospital. Across all these recommendations, there is a need, when setting up new services, to be flexible and adapt boundaries as required. The exact configuration of the team, the referral pathways to strengthen and the partners to engage with and train will be unique to each hospital. Section 3 gives 12 more detailed model case studies for reference which illustrate this uniqueness.

9.2 For Ministry of Health in partner countries

9.2.1 Governance and Leadership

MoH need to take ownership and leadership of PC services in the country. More specifically, the MoH should ensure PC is in country strategic plans, and in budgets. The MoH should also be the overall body driving the integration of PC services. This can be achieved by establishing a PC desk in the MoH (as happened in Rwanda in this project), or by giving another organisation (normally a PC National Association) the mandate to co-ordinate training, sensitisation and service delivery roll-out through a formal Memorandum of Understanding.

9.2.2 Service Delivery

Palliative patients exist throughout the health system. PC should be integrated into all the different levels of the health system: tertiary referral settings, regional referral hospitals and district health centres, alongside the community. Integrating PC into these levels can also strengthen health services. We therefore recommend that PC is integrated into existing health services and systems. This is best achieved through a 'hub' i.e. a hospital hub with its associated health centres and community.

9.2.3 Human Resources

Scaling up numbers of trained staff through hubs: MoH should support the training of large numbers of health workers in basic PC through encouraging the development of hospital "hubs", facilitating them to sensitise and train in their referring health centres and communities. Both ongoing mentorship, and modelling of PC are important for sustainable PC service provision. This can be achieved through the use of the hub model.

Strategic Deployment: The MoH (or other ministry responsible for deployment of public sector workers) should ensure strategic deployment for staff trained in PC at an intermediate or specialist level. The MBBSH report recommended that countries should have a

comprehensive Human Resources Information System (HRIS) to guide decision-making on human resource, including deployment. [23] Incorporating PC into such a system, through recognition of intermediate and specialised training, will facilitate correct deployment.

Volunteer Workers: MoH need to ensure provision for volunteers to be part of the PC team

9.2.4 Finances

This project demonstrated that it is possible to integrate PC into the health system by utilising existing staff and procurement systems. The main financial implications are related to capacity building, mentorship and supervision. These should be incorporated into country MoH budgets.

9.2.5 Medicines Vaccines and Technology

MoH should ensure that the PC essential medicines are on the country essential medicines lists. They should ensure appropriate policies and guidelines, procurement and processes are in place for access to essential medicines. They should also ensure that there are enough prescribers around the country which may include extending regulatory frameworks and competency training to include cadres other than doctors, such as nurses.

9.2.6 Strategic Information

MoH should include PC in the HMIS, such that all facilities need to report on it, and provide national level tools for data collection, and support and supervision in this.

9.3 For future evaluation and research

1. **Research using APCA POS**: The APCA Palliative Outcomes Scale (APCA POS) is a patient reported questionnaire which captures health-related quality of life (HRQL) information which is particularly relevant to palliative care patients, such physical and psychological symptoms, spiritual, practical and emotional concerns. As it was a capacity building project, rather than a research project, The *Integrate Project* did not collect pre and post-intervention HRQL information from patients. There is a need for more such quantitative research in palliative care. Efforts should be made to support the specialist staff trained to the *Integrate Project* to carry out such future research, and consideration should be given to collecting HRQL information in future similar projects as this would provide rich data for evaluation purposes.

2. **Follow-up evaluation:** As described in section 3, PC services took longer to implement in the national hospitals than in the district hospitals. UTH and CHUK both established their model of service towards the end of the 3 year project. MTRH had a well-established model, but had ongoing plans to further integrate the service. An evaluation of the 3 national level hospitals in 3 years time would enable the impact of the Integrate Project on these services to be more fully assessed.

Annex 1: Detailed Activity Reports

A1.1 Kenya

Hospital	Homa Bay	Nyeri	Eldoret: MTRH	National Level
Advocacy	➢ Community Sensitisation: - Hospital sensitisation covered 132 people ➢ Sensitisation of political leaders ➢ Community outreaches: 400 people ➢ Speaking on local radio: 400,000 people ➢ Local sensitisation about pain and PC ➢ Internal hospital advocacy ➢ End of project meeting: national ➢ Took videos of patients for use in advocacy ➢ Medical superintendent advocate for a PC room	➢ Community sensitisation ➢ Church talks: 220 people ➢ Burials and community sensitisation: 1000 people ➢ World cancer day: 250 people ➢ Radio shows: 500,000 people ➢ Local political leaders ➢ In hospital sensitisation: 34 people ➢ Breast cancer survival group ➢ End of project meeting ➢ County MoH reached (Nyeri County)	➢ Community sensitisation: 229 (in 5 sites – steering group at the launch meeting and held 2 sessions including a journal club ➢ Church talks for the women ➢ Burials and community sensitisation ➢ In hospital advocacy ➢ University advocacy – highest level of representation from medical and nursing ➢ Local political leaders and chiefs ➢ End of project meeting ➢ PC stickers for PSV, cars/buses ➢ Sensitisation for doctors: 20, HODS: 48, interns: 17 – 85 people ➢ High level meeting with MTRH management and Eldoret Hospice, started ordering morphine ➢ Met the Eldoret hospice board chairman	➢ National launch meetings ➢ Bought a camera for KEHPCA ➢ End of project meeting ➢ Made a video of the whole project ➢ KEHPCA conference attendance 330 delegates from 9 counties ➢ Through the *Integrate Project,* with KEHPCA support, Homa Bay got oral morphine
Capacity Building	➢ Basic training: 44 people ➢ TOT: 15 people ➢ Exchange visit between Homa Bay and Gulu ➢ Specialist training: 3 people ➢ Most significant change training: 3 people ➢ Community volunteers training: 20 ➢ 60 mentorship days ➢ Mentors: 4 people from UK	➢ Basic training: 41 people ➢ TOT: 15 people ➢ Specialist training: 2 people ➢ Most significant change training: 3 people ➢ Community volunteer training: 20 ➢ 40 mentorship days: 4 mentors ➢ Remote mentorship days: 8 ➢ Clinical placements: 41	➢ Did a modular course for basic training, TOT, Research, M&E psychosocial issues: 83 people in all ➢ TOT: 16 people ➢ Research: 16 people ➢ Most significant change training: 3 people ➢ Specialist training: 3 people ➢ 10 satellite sites training as an approach (10 County hospitals) ➢ Community volunteers training	➢ 1 national level officer trained at specialist level ➢ KEHPCA conference reached the MoH in person at the meeting ➢ Kenyan minister is an advocate for PC ➢ Steering group members supported research training for specialist training trainees

Hospital	Homa Bay	Nyeri	Eldoret: MTRH	National Level
	➢ Remote mentorship days: 8 ➢ Clinical placements: 44 people, 3 days (Siaya Hosp, Kisumu Hospice and Kisumu Dist Hosp) ➢ CMEs by KEHPCA ➢ Conferences: KEHPCA, APCA, PCAU, Kenya Paediatric Association Conference	people, 3 days ➢ CMEs ➢ Conferences: KEHPCA, APCA (SA)	➢ 45 mentorship days from 3 mentors – 6 remote mentorship days ➢ MTRH is integrating PC into BSc nursing course and postgraduate courses ➢ Clinical placements: 42 at the same hospital for 3 days ➢ CMEs over 100 people – 9 pharmacies sensitised ➢ Conferences: KEHPCA, PCAU, APCA (SA) ➢ Review of training and materials ➢ Exchange visits: 2 doctors from MTRH went to Mulago in Uganda	
Service Delivery including medicine	➢ Protocols: 11 clinical protocols ➢ Bought cameras supported by KEHPCA ➢ Guidelines ➢ Patients reached: ○ 2012: 27 patients: ○ 2014: 163 patients ➢ Morphine: ○ 2012: 0 mg, ○ 2014: 66,500mg ➢ Patient registers ➢ Patient referral systems ➢ Developing a community delivery model ➢ Developing a paediatric PC service ➢ THET supported the play room and PC unit equipping and provided 100 plastic chairs and a video camera for recording advocacy messages	➢ Protocols: 11 protocols ➢ Patients reached: ○ 2012: 151 patients: ○ 2014: 413 patients ➢ Morphine: ○ 2012: 40,000mgs: ○ 2014: 220,000mgs ➢ Development of the model improvement ➢ They are a clinical placement site approved by the nursing council ➢ Capital Development: Renovated a tent for day care patients and bought a TV and DVD player for educational sessions for patients while waiting	➢ Protocols: 11 clinical protocols ➢ Developed a PC SOP ➢ Patients seen: ○ 2012: 687 patients: ○ 2014: 1030 patients ➢ Morphine: ○ 2012: 1,566,000mgs: ○ 2014: 3,200,000mgs ➢ Patient registers ➢ Patient referral systems ➢ Developing the model ➢ Did a standard audit ➢ Capital development: Purchased a laptop, printer, projector, 100 plastic chairs and tent to support training and psychosocial support of patients	➢ National cancer control strategy/Not funded by this project ➢ National curriculum

Hospital	Homa Bay	Nyeri	Eldoret: MTRH	National Level
Partnership	➢ Steering group – Partner in Emblem Study ➢ UK mentors ➢ KEHPCA and Homa ➢ ICPCN – International children's PC network partnerships ➢ Partnership with Kemri especially as the paediatric PC unit was developed ➢ County govt/Kenya medical training college	➢ Partnership with the hospice at Nyeri ➢ KEHPCA ➢ Nanyuki County Hospital ➢ Kenyata National Hospital – oncology unit ➢ Other hospices	➢ MTRH partners with AMPATH to host the PC unit ➢ MTRH and Eldoret hospice ➢ MTRH and Moi university ➢ Kambilio hospital ➢ Kapsabet hospital ➢ Referrals to other hospitals – for step down care – step up care at Uganda Cancer Institute	
Other	➢ Collection of MSc stories	➢ Partnership with the hospice	➢ Discussed with Eldoret hospice on how to fundraise by steering group	➢ All sites received a desk top computer ➢ Teaching hospitals received a computer and projector ➢ The minister committed to a PC budget ➢ Development of legal and human rights collaborative and guidelines, funded by OSEIA

A1.2 Rwanda

Hospital	Kibagabaga	Rwamagana	CHUK	National Level
Advocacy	• Community sensitisation – 548 people • Hospital and health centre sensitisation – 20 people • Regular publications on ehospice • WHPC Day activities • Local in-hospital sensitisation • Meetings with local stakeholders • Mentors and Steering group visits – meeting with key people • Feedback from standards audit	• Community sensitisation – 984 people • Hospital sensitisation – 59 people • WHPC Day activities • Local in-hospital sensitisation • Meetings with local stakeholders • Mentors and Steering group visits – meeting with key people • District and provincial level advocacy	• Hospital sensitisation – 13 people • Sensitisation of senior staff at CHUK • Pain and opioid workshop – 59 people • WHPC Day activities • Local in-hospital sensitisation • Meetings with local stakeholders • Mentors and Steering group visits – meeting with key people • Director going on a placement to Mulago hospital was the key turning point	• Project launch meeting • Opioid frameworks meeting • Meetings with the Minister of Health and other key personnel at the Ministry • Media campaign on national radio (Q&A) ➢ WHPC Day Activities
Capacity Building	• Basic training – 24 people • Specialist training – 3 people • 43 mentorship days, 14 remote mentorship days from 4 mentors • Clinical placements –3 in Uganda • MSC training – 5 people • Children's PC training – 5 people • Research training – 6 people • Steering group support to students on diploma/ degree • Conferences – APCA, KEHPCA, Eindhoven pain conference	• Basic training – 48 people • Specialist training – 2 people • 45 mentorship days, 20 remote mentorship days from 4 mentors • Clinical placements – 3 plus 2 in Uganda • MSC training – 5 people • Children's PC training – 6 people • Research training – 8 people • ToT training – 9 people • Steering group support to students on diploma/ degree • Conferences – APCA	• Training senior personnel – 13 people • Basic training – 46 people • Specialist training – 3 people • 50 mentorship days, 11 remote mentorship days from 6 mentors • Clinical placement days – 9 and 7 in Uganda • MSC training – 5 people • Children's PC training – 8 people • Research training – 10 people • ToT training – 5 people • Steering group support to students on diploma/ degree • Conferences – APCA • Trained the CHUK staff to provide clinical placements and gave clinical placements to 10 people.	• Training for a pharmacists and doctor from every hospital in Rwanda on morphine use - 70 people • 64 national level mentorship days from 2 mentors • Report re a PC strategy for the Ministry which was taken to the cluster meeting • Training materials initially developed by Mildmay/ Intrahealth utilised • National clinical guidelines developed which included PC • Developing curricula for community workers • Inputting PC into the national NCD curricula
Service Delivery	• Protocols	• Protocols	• Protocols	• The national supply system

Hospital	Kibagabaga	Rwamagana	CHUK	National Level

	• Guidelines
	• Patients seen
	  ○ 2012- 80
	  ○ 2014 – 92
	• Oral morphine access
	  ○ 2012 – 0mgs
	  ○ 2014 – 69,690mgs
	• NB received a one off donation of morphine tablets from hospices without borders and these were used in 2013 and also used by other hospitals
	• Development of the model of PC
	• Patient registers on each ward
	• Utilisation of national PC documentation
	• Standards audit undertaken
		• Guidelines
		• Patients seen
		  ○ 2012- 4
		  ○ 2014 – 41
		• Oral morphine access
		  ○ 2012 – 0mgs
		  ○ 2015 1Q – 1,920mgs (only received it in Dec 14)
		• Development of the model of PC
		• Patient registers on each ward
		➢
			• Guidelines
			• Patients seen
			  ○ 2012- 85
			  ○ 2014 – 104
			• Oral morphine access
			  ○ 2012 – 0mgs
			  ○ 2014 – 77,800mg
			• Development of the model of PC
			• Patient registers with the team
			• Inputting into new documentation for the hospital
			• PC desk authorised and Clinical Psychologist in-charge
				for morphine now provides 10mg and 30 mg tablets along with a syrup.
				• National roll out of morphine
				• Replicating the model nationally

Partnership	• PCAR initially and the Rwanda Hospice • Rwanda Hospice and PC Organisations (RHPCO) • Hospice without Borders • Partners in Health • ROROS • Local hospice • Pain fellowship support from APCA and University of Wisconsin • APCA AND DIFID before 2013 • RBC	• APCA mHealth • Hospice without Borders • Kibagabaga (clinical placements and remote support ➢ CHUK (remote support)	• RHPCA • Hospice without borders • Partners in health • HRH • University of Rwanda ➢ Partnership with several CSO to support their patients etc.	• RBC/Ministry of Health • PCAR initially • Rwanda Hospice and PC Organisations (RHPCO) • Hospice without Borders • Partners in Health • ROROS • Pain fellowship support from APCA and University of Wisconsin • Lancet Commission • University of Rwanda
Other	• Moved from individuals to a team approach		• Teaching at the University of Rwanda • Inputting into curricula where appropriate	• A PC cluster formed within NCDs • Ministry now has a PC plan • MoH now co-ordinating PC

Hospital	Kibagabaga	Rwamagana	CHUK	National Level
				within the country through RBC • Initiatives to include PC into the national health insurance scheme. • All hospitals received a computer from the project and laptops from the mentors. • National association received a camera to document the project

A1.3 Uganda

Hospital	Gombe	Gulu/Lacor	Kabale	National Level
Advocacy	➢ Community sensitisation: 19 people ➢ Sensitisation of political leaders ➢ Speaking on local media ➢ WHPC Day observed ➢ PCAU launch sensitisation meetings ➢ Internal hospital advocacy and meeting ➢ End of project with MOH/RDC ➢ Attendance at APCA conference by the Medical Superintendent/District Health Officer	➢ Community sensitisation: 49 people ➢ Sensitisation of political leaders ➢ Speaking at the University/Institute of Health Sciences ➢ PCAU branch sensitisation ➢ Sensitisation of hospital community: 63 people ➢ Ongoing hospital sensitisation ➢ End of project meeting with stakeholders, MOH and resident district commissioner RDC ➢ WHPC Day	➢ Community sensitisation: 49 ➢ Sensitisation of political leaders including area MP ➢ Speaking on local media ➢ WHPC Day observed ➢ PCAU launch sensitisations ➢ Internal hospital advocacy for management including resident surgeon ➢ Met the district health officer ➢ End of project meeting with MOH etc.	➢ Launch meetings – MOH ➢ APCA conference: minister – staff ➢ PCAU, KEHPCA ➢ PCAU wrist bands ➢ PCAU T-shirts ➢ MOH: end of project meeting held and attended ➢ Bought a camera for PCAU
Capacity Building	➢ Basic PC training: 59 people including HCs ➢ TOT: 10 people including HCs ➢ Specialist training: 2 from HCs ➢ 25 UK mentorship days ➢ Remote mentorship days: 8 ➢ Clinical placements: 59 people – 3 days ➢ Conferences: Kenya, PCAU, ACPCA, other ➢ Community volunteers training: 19 ➢ Link nurse training 3 days ➢ MSC training: 3 people ➢ Researcher	➢ Basic training: 60 people (including Lacor Hospital) ➢ TOT: 8 people ➢ Children's palliative: 5 people ➢ Specialist training: 5 people (one paediatric) ➢ 51 mentorship days from 4 mentors ➢ Clinical placements: 60 – 3 days ➢ Remote mentorship days: 10 days ➢ Conferences: Kenya, PCAU x 2 APCA ➢ CMEs: lots ➢ Community volunteers training: 49 people ➢ Link nurse training	➢ Basic training: 60 people ➢ TOT: 9 people ➢ Children's PC ➢ Specialist training: 4 people ➢ 40 mentorship days from 4 mentors ➢ Remote mentorship days: 8 days ➢ Clinical placements: 60 people over 3 days ➢ Conferences: KEHPCA, PCAU, APCA and others ➢ Community volunteers training: 49 people ➢ Link nurse training: ➢ MSc training: 3 ➢ VHT training: 30x2	➢ Training ➢ Utilisation of TOT trainers to develop skills by PCAU ➢ Ongoing sensitisation of mentorship by PCAU ➢ National training curriculum ➢ Sharing of experiences by the participants ➢ Steering group supported research training for specialist trainees

Hospital	Gombe	Gulu/Lacor	Kabale	National Level
	➢	➢ MSc training ➢ Dr from Homa Bay visited Gulu as an exchange visit		
Service Delivery including medicine	➢ Protocols: 11 clinical protocols supported by PCAU ➢ Guidelines ➢ Patients: ○ 2012: 43: ○ 2014: 157 ➢ Access to morphine: ○ 2012: 39,000mgs: ○ 2014: 118,000mgs ➢ Referral documentation ➢ Patient assessment form ➢ Patient registers ➢ Developing the delivery model 14 home visits near the hospital	➢ Protocols: 11 clinical protocols supported by PCAU ➢ Guidelines ➢ Patients: ○ 2012: 140: ○ 2014: 240 ➢ Standard audit done in Gulu ➢ Morphine consumption: ○ 2012: 0mgs ○ 2014: 198,225mgs ➢ Referral documentation ➢ Patient assessment forms ➢ Patient registers ➢ Developing the delivery model ➢ PC signage within the hospital ➢ Home visits near hospital ➢ Worked closely with Lacor hospital and church hospital ➢ Involvement of volunteers in service delivery ➢ Full time clinical officer in place for PC	➢ Protocols: 11 clinical protocols supported by PCAU ➢ Guidelines ➢ Patients: ○ 2012: 0 patients: ○ 2014:315 patients ➢ Morphine consumption: ○ 2012: 36,000mgs ○ 2014: 336,000mgs ➢ Referral documentation ➢ Patient assessment forms ➢ Patient register ➢ Developing a delivery model ➢ Community/home visits ➢ Linked in with Kisiizi and other hospital ➢ One full time PC nurse for PC	
Partnership	➢ Steering group ➢ UK mentors → hospital: 4 mentors ➢ PCAU – hospitals: ongoing ➢ Link to community and church	➢ Steering group ➢ UK mentors within the hospital: 4 mentors ➢ PCAU and hospital partnership ongoing ➢ Gulu hospital and Lacor Hospital ➢ Gulu Hospital with Gulu University and Institute of Health Sciences ➢ Gulu Hospital with Lacor Hospital for clinical placements	➢ Steering group ➢ UK mentors ➢ PCAU and plan to do home-based care ➢ Teaching medical students ➢ Partnership with nursing school to run 2 placement shifts	➢ Steering group: UoE, APCA and MPCU ➢ Linkage between hospitals ➢ MOUs at different levels

Hospital	Gombe	Gulu/Lacor	Kabale	National Level
Other	➢ Linkage to homeless project funded by APCA ➢ Collection of most significant change stories	➢ One of the mentors did a PC needs assessment ➢ Collection of most significant change stories ➢ The chaplain of the hospital started a small MGO to support patient make wills ➢ The chaplain is also a community volunteer ➢ Piloting mobile phone technology for service delivery funded by PCAU	➢ PC needs assessment done with other funding ➢ Collection of most significant change stories ➢ Piloting mobile phone technology for service delivery funded by PCAU	➢ Regularly assess skills and knowledge after training ➢ Demonstration of knowledge retention and skills pre-post ➢ Each site received a desk top computer and a projector for a teaching hospital - Gulu

A1.4 Zambia

Hospital	Mazabuka Hospital	Ndola Central Hospital	University Teaching Hospital (UTH)	National Level
Advocacy	• Community sensitisation – 50 people • Interviews on the radio • WHPC Day activities • Local in-hospital sensitisation • Sensitisation of political leaders • Mentors and Steering group visits – meeting with key people	• Community sensitisation – 127 people • Interviews on TV • WHPC Day activities • Local in-hospital sensitisation • Meetings with local stakeholders • Mentors and Steering group visits – meeting with key people • Provincial level such that the PMS wants to roll out PC to other sites • Through advocacy they have a dedicated PC unit • Feedback from standards audit	• Hospital sensitisation – • Key stakeholders meetings • CDH and Paeds department • WHPC Day activities • Local in-hospital sensitisation • Mentors and Steering group visits – meeting with key people • Having PC specialist working with them	• Project launch meeting • End of project meeting • National sensitisation supported by mentors • National health policy integrating PC ➢ Increased shelf life of oral morphine
Capacity Building	• Basic training – 48 people • ToT training – 10 people • Specialist training – 2 people • 58 mentorship days, 14 remote mentorship days from	• Basic training – 48 people • ToT training – 10 people • Specialist training – 3 people • 60 mentorship days, 20 remote mentorship days from 4 mentors	• Basic training – 53 people • Specialist training – 3 people (1 also being trained outside of the project) • 45 mentorship days, 2 remote	• Mentoring the trainers of PC • National curriculum development • APCA/UoE supported

Hospital	Mazabuka Hospital	Ndola Central Hospital	University Teaching Hospital (UTH)	National Level
	5mentors • Clinical placements – 48 plus 2 in Uganda • MSC training – 16 people • Research training – 10 people • Steering group support to students on diploma/ degree • Conferences – APCA • Visited Livingstone and Choma hospitals to share lessons learnt • Trained 105 caregivers	• Clinical placements – 48 plus 3 in Uganda • MSC training – 23 people • Research training – 15 people • Steering group support to students on diploma/ degree • Conferences – APCA	mentorship days from 2 mentors • Clinical placement days – 53 plus 3 in Uganda • MSC training – 15 people • Research training – 17 people • ToT training – 9 people • Steering group support to students on diploma/ degree • Conferences – APCA • Review of undergraduate curriculum and insertion of a module on PC	PCAZ to document and publish on ehospice
Service Delivery	• Protocols • Guidelines • Patients seen ○ 2012- 0 ○ 2014 – 319 • Oral morphine access ○ 2012 – 0mgs ○ 2014 – 37,915mgs • Development of the model of PC • Patient registers in the team • Review and development of PC documentation	• Protocols • Guidelines • Patients seen ○ 2012- 11 ○ 2014 – 462 • Oral morphine access ○ 2012 – 5,200 mgs ○ 2014 – 93,340mgs • Development of the model of PC • Patient registers and utilisation of documentation • Standards audit completed	• Protocols • Guidelines • Patients seen ○ 2012- 0 ○ 2014 – 26 • Oral morphine access ○ 2012 – 320,000mgs ○ 2014 – 402,230mgs • Development of the model of PC • Patient registers with the team • Working with MDT across UTH, Paediatrics and CDH	• Adopted guidelines, protocols, wall charts etc. for PC and printed
Partnership	• Diocese of Monze • Zambia Sugar Private Hospital • Social Welfare Mazabuka • PCAZ • Choma and Livingstone General Hospital (Referrals) • APCA through PCAZ • MPCU	• MoH • Tropical Disease Research Centre • TB Care • Copperbelt Education • ZESCO • Bank of Zambia • Hope Humana • Isubiro Home based care • Citikelo Hospice • Mitanda Hope for the Aged	• University of Zambia • CDH • EGPAF • Tiny Tim and Friends • THET Zambia for paediatric work • ICPCN	• ICPCN • APCA

Hospital	Mazabuka Hospital	Ndola Central Hospital	University Teaching Hospital (UTH)	National Level
		• Arthur Davidson Children's Hospital • APCA through the PHRMA project with Global Partners in Care • APCA/RHAP		
Other				• All hospitals received a computer from the project and laptops from the mentors. • National association received a camera to document the project

Annex 2: Detailed Indicator Report

(attached separately)

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