Dr Mhoira E F Leng; bio

• Trained in the UK as *internal medicine* physician then as a *specialist in palliative care* MBChB from Aberdeen University; MRCP and FRCP (Glas and Edin) UK CCST Palliative Care

• Worked over 20 years in 5 continents to build capacity and tomorrow’s leaders through developing integrated palliative care models, building evidence based practise and research capacity, demonstrating values based changes within academic curriculums and mentorship.

• Expert in palliative care health systems strengthening and palliative care integration particularly in resource limited settings where health systems are under stress such as complex humanitarian settings.

• Currently **senior advisor for palliative care Makerere University, Uganda, Medical Director (founder) Cairdeas International Palliative Care Trust**, board **International Association for Hospice and Palliative Care** and senior advisor **Global Health Academy, University of Edinburgh**.
MMPCU KEY ACHIEVEMENTS:
Integrating evidenced-based quality palliative care

Dr Mhoira EF Leng
Palliative Care, Makerere University, Kampala
Cairdeas Palliative Care Trust, Scotland
Global Health Academy, University of Edinburgh
International Hospice and Palliative care Association
Introduction

• Makerere and Mulago Palliative Care Unit (MPCU), Kampala Uganda
  • Aims to be a centre of excellence to improve access to quality, evidence-based palliative care (PC) for patients and families
  • By delivering an integrated clinical service within the national referral hospitals site; carrying out research, training and capacity-building in collaboration with partners and developing leaders in PC

• Values based transformation; individuals, practices, systems, societies
Background

• 25 years ago palliative care started in Uganda
  • MOH, HAU, PCAU, then APCA
  • Dr Anne Merriman, Prof Katibira, Dr Jack Jagwe…. 
  • progress in community models, international programmes, regulations and access to oral morphine, nurse prescribing, education and training, advocacy …. 
  • no fully functioning hospital base model

• Steering group formed, 4 nurses appointed, consultant engaged to agree plan
  • interviews with appointment of head, registrar, alongside nurses…**MMPCU was founded**
  • initial international partners Cairdeas IPCT, WHI, University of Edinburgh
Objectives and methods

**Objectives**: To evaluate and assess outputs and outcomes from the **MMPCU Strategic plan 2011-2016**

**Methods**: A review of *indicators* using the database and *outcomes* integrated within the research agenda including capacity building, training numbers, and collation of impact assessments. A review of research capacity included online survey, qualitative interviews and qualifications attained by MMPCU staff.
## Achievements

<table>
<thead>
<tr>
<th>Strategic Objective</th>
<th>Outputs and outcomes</th>
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<tr>
<td>Clinical service provision</td>
<td>9,858 patients cared for plus their families</td>
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<tr>
<td>Education and training</td>
<td>4,630 trainees from 9 countries (1,223 outside Uganda)</td>
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<tr>
<td>Research</td>
<td>192 abstracts and 53 publications, research agenda and network</td>
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<td>Advocacy</td>
<td>Contribution to national and international strategic and educational fora</td>
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<tr>
<td>Sustainability</td>
<td>Building staff capacity (5 BSc, 2 Masters, 1 PhD) partnerships, PcERC.</td>
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Achievements

1. Clinical care
   - 3,189 patients seen directly by MPCU with additional 6,669 seen by link nurses (731 referred)
   - Level 3&4 care; Specialist consult team
   - Level 1&2 care; link nurse and pharmacist programmes, postgraduate training, symptom protocols, medicines availability, mentorship
   - integrated model in national hospital setting with cancer institute
     - situated in department of internal medicine
     - cancer and non-cancer; adult and paeds
     - referral on for home care and OP
Achievements

1. Clinical care
   • levels of care and empowerment
Achievements

1. Clinical care

• link nurses; increase in patient numbers being supported by 80%, empowered staff, replicated nationally 12 hospitals, internationally 15 in 4 countries

• “Before I had the training patients who were dying could be neglected as the staff thought they could do nothing for them. But since the teaching I realised there is much I can do for these patients…It has changed me. It has changed my attitude.”
Swaibu’s story

‘when I see you coming with the team I feel so much better. God has answered my prayers and I know that he cares for me. I no longer feel angry and sad. I can sleep at night instead of crying. I now have hope. Thank you.’
Simon’s story

“It is like my world is full of pain and suffering I am alone and nobody seems to care. It feels like life had no meaning.”

“These guys talk to you, they talked to me, encouraged me, and helped me to get medication. The pain has also become manageable. There was tremendous improvement. I did not feel like the way I was when they first found me,”
Diane’s story

‘Please keep coming to see me; that is all I ask’

‘When you have the skills it takes away the fear’
Catherine’s story

‘Please tell me what is happening to me…?’
Achievements

2. Education and training

- 4,630 individuals trained
- undergrad (medicine, nursing)
- postgrad / specialist
  - Diplomas, BSc Degree (with IHPCA/Hospice Africa Uganda)
  - MMed int med, family med, ENT, Fellowship gyn onc
- in-service short courses and placements including volunteers
- 1223 of those trained were in 8 additional countries to Uganda
- development of Palliative Care Curriculum Toolkit
Achievements

2. Education and training

'The palliative care training has made a huge impact; I now see the patient as a person and not a disease, I don't avoid difficult conversations, I don't order unnecessary investigations, I see them as part of a family, I do holistic care. It was not like that before.' MMed doctor Makerere.
Achievements

2. Education and training

‘Palliative care means dignity’
IUG med student

‘Our people are in pain we have no choice but to act’
Gaza Surgeon
Achievements

2. Education and training

“It has been a life changing experience that I will treasure, shaping my medical practice and my heart for my future career”

UK medical student
Results

3. Research

• online survey with 56 (of 130) respondents from 9 countries with qualitative interviews and internal outcomes review.
• research capacity built through training, supervision and mentorship
• 192 abstracts at national & international conferences & 53 papers published
• national, regional and international research collaborations research agenda and research network established
  • culture of research involving all team members
  • skills training including module in BSc programme, first African Advanced Research School, internal and external supervision and mentorship
  • joint grants including work in 9 additional countries
• enhanced credibility and opportunities
Results

3. Research

Research agenda:

1. Patient and family needs
   - experience of patients
   - needs assessments in national, district and oncology settings
   - outcome of PC interventions
   - spiritual support using a narrative approach

2. Healthcare worker and volunteer needs
   - educational impact, leadership training, motivation for volunteers

3. System issues
   - evaluation of integrated model including link nurses
   - service evaluations
   - morphine mapping and utilization
   - evaluation of nurse prescribing
Results

3. Research

• What are the multidimensional experiences of Ugandan patients with HF over the course of their illness through diagnosis, treatment and dying?

3. Research: outcomes of specialist PC interventions

**Outcomes in the Physical/Psychological domain among study patients receiving palliative care at visits one, two and three**

(i) Pain

- 5-overwhelming
- 4
- 3
- 2
- 1
- 0-none

Kruskal Wallis test $p < 0.001$

Study visit one, Study visit two, Study visit three

(ii) Symptoms other than pain

- 5-overwhelming
- 4
- 3
- 2
- 1
- 0-not at all

Kruskal Wallis test $p < 0.001$

Study visit one, Study visit two, Study visit three

(iii) Feelings of worry about your illness

- 5-overwhelming
- 4
- 3
- 2
- 1
- 0-not at all

Kruskal Wallis test $p < 0.001$

Study visit one, Study visit two, Study visit three
Achievements

4. Advocacy

- Attendance at national, regional and international conferences
- Member of Lead Country Team and contribution to national strategic documents
- Participation in national (e.g. PCAU) regional (e.g. APCA), international organisations (e.g. IAHPC, WHPCA, ICPCN and WHO)
- Contribution to international strategic policy, documents and resolutions
Achievements

5. Sustainability
- building staff capacity and succession planning
  - 5 BSc, 2 Masters, 1 PhD
- national, regional and international collaborations, partnerships and dissemination
- Cairdeas IPCT and Global Health Academy and Primary PC group, University of Edinburgh and others……
Transforming practice

- A humanitarian doctor ‘We appreciate your initiative, it has been a key lacking point. Many times there is a patient crying in pain. The approach of integrating palliative care into the medical practices of prevention and cure is the way to go. The more people we train, the more people we will reach in community.’
Transforming societies

• The hospitality.. reflects the heart of humanity in health providers. Learning from you empowers us to transform the whole Rwandan society in having a therapeutic culture. We don't doubt that other countries can learn from us as we have learned from you.’ Magnus Gasana, PC lead CHUK, Rwanda
Transforming lives

• Senior nurse in an Adjumani hospital: ‘Someone needs to speak for the voiceless. When help comes, people change. It is like losing hope — then hope appears suddenly like the sun.’

SNO Adjumani Hospital
Transforming lives

‘you gave me hope, you gave me pain control, you gave me love....thank you and please pray for me...make sure everyone in Uganda has this care.’
Conclusions

• Developing a strategic plan embedding a coherent and integrated approach to research allows evidence based practice to become routine and outcomes to be assessed. An integrated model allows generalist PC to be empowered with specialist support. Partnerships have allowed for wide project work and dissemination. This review is contributing to the next strategic plan.
Values based health care for all
Global palliative care

- Many thanks
  [www.cairdeas.org.uk](http://www.cairdeas.org.uk) for resources
Many thanks

- Namukwaya E, Murray SA, Downing J, Leng M and Grant L. (2017) 'I think my body has become addicted to those tablets'. Chronic Heart failure patients' understanding of and beliefs about their illness and its treatment: a qualitative longitudinal study from Uganda. PLOS One.
- Downing J, Leng M and Grant L. (2016). Implementing a Palliative Care Nurse Leadership Fellowship Program in Uganda. Oncology Nursing Forum 43(3) 395-398. DOI: 10.1188/16.ONF.395-398

- [www.cairdeas.org.uk](http://www.cairdeas.org.uk) (all results in Resources section)