



THE UNIVERSITY of EDINBURGH
Global Health Academy



An evaluation of palliative care nurse prescribing: A mixed methods study in Uganda

Prof. Julia Downing PhD RGN

Downing J, Nabirye E, Ojera A, Namwanga
R, Katusabe R, Dusabimana M and the
Evaluation Research Team

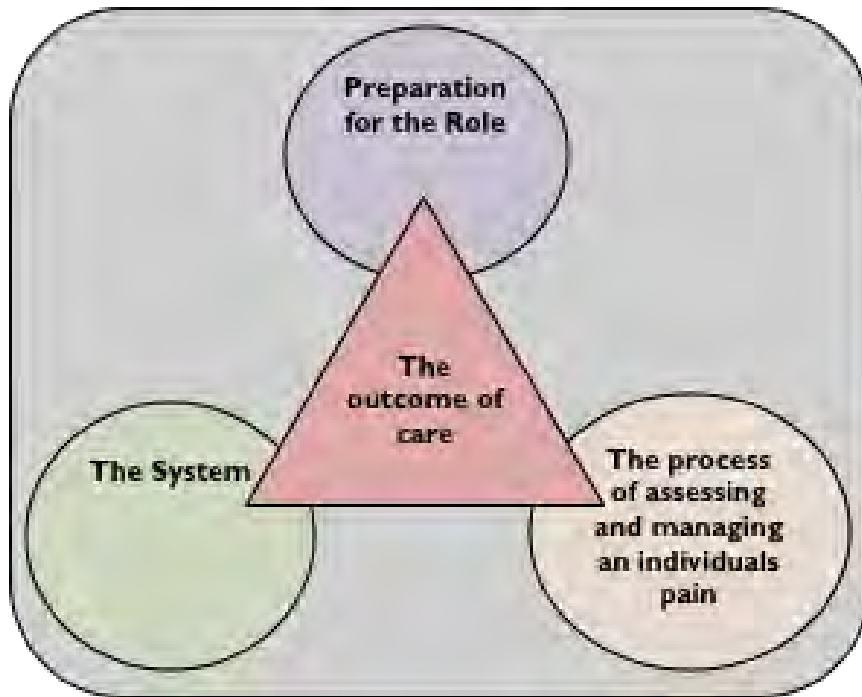


Background

- Specially trained PC nurses in Uganda have been able to prescribe since 2004
- Thus increasing access to PC
- Of Global Interest but no full evaluation to determine effectiveness of nurses role.



Conceptual Framework



- The preparation of the nurses for the role.
- The actual process of assessing and managing the patients' pain, including the prescription of oral morphine and patient outcomes.
- The system in which the nurses are working.

Ethical Approval

Institute of Hospice and Palliative Care in Africa (IHPCA)

Hospice Kampala (HKA): Kampala
Plot 130 Malindi Road, Makindye

Mobile Hospice Mbarara (MHM): Mbarara
Plot 2A/4A/5A Kabasere Rd

Little Hospice Hoima (LHM): Hoima
Plot 2A Kigungu Hill



IHPCA

P.O. Box 7757 Kampala, Uganda
Tel: +256-414-268867
+256-414-268387
+256-701-968098
+256-392-768867

Email: education@ihpcafrica.org
info@ihpcafrica.org

Website: www.hospiceafrica.org

3rd May 2016

Category of review undertaken

Initial review

TO,
Professor Julia Downing,
Makerere University,
College of Medicine,

Dear Madam,

RE: APPROVAL OF RESEARCH PROTOCOL HAUREC-023/16

Greetings from Hospice Africa Uganda Research and Ethics Committee (HAUREC). Following the review of your study protocol entitled **"A study to evaluate the specialist nurse's role in palliative care in Uganda"**, the committee has approved your research project. This approval is valid until 3rd May 2017, after which you will be required to request for extension through chairman of HAUREC in case of continuation with the research. Application for extension should be submitted 2 months before expiry date of approval.

Any serious problem related to the execution of research should be promptly reported to HAUREC. Changes to the research protocol should not be implemented without approval from HAUREC, except when necessary to remove apparent immediate hazards to the research participants.

It is a requirement by the institution that you submit a final report after completion of the study.

Note; you are advised to submit your research protocol and approval letter to the administration at the study site (s) for administrative clearance

Wishing you well in your research while protecting human participants.


Yours sincerely,
Pp. Dr. **Mbaraka Tumwine**
Chairman
HAUREC
P.O. BOX 7757, KAMPALA (U)

Hospice Africa Uganda
APPROVED &
VALID UNTIL
03 MAY 2017

OUR VISION
Palliative Care reaching all in need in Africa

www.hospiceafrica.org

OUR MISSION
To be a center of excellence providing and facilitating affordable, suitable and accessible Palliative Care in Uganda and other African Countries.



UNCST

Uganda National Council for Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

27th July 2016

Our Ref: HS 2088

Julia Dorothy Downing
Principal Investigator
Makerere University
Kampala

Re: Research Approval: A Study to Evaluate the Specialist Nurse's Role in Palliative Care in Uganda

I am pleased to inform you that on **11/07/2016**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period **11/07/2016 to 11/07/2017**.

Your research registration number with the UNCST is **HS 2088**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

As Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the research protocol or the consent form (where applicable) must be submitted to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval prior to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority.
4. Unexpected events involving risks to research subjects/participants must be reported promptly to the UNCST. New information that becomes available which alters the risk/benefit ratio must be submitted promptly for UNCST review.

LOCATION/CORRESPONDENCE

Plot 6 Kinera Road, Ninda
P.O. Box 6881
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 765500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: <http://www.uncst.go.ug>



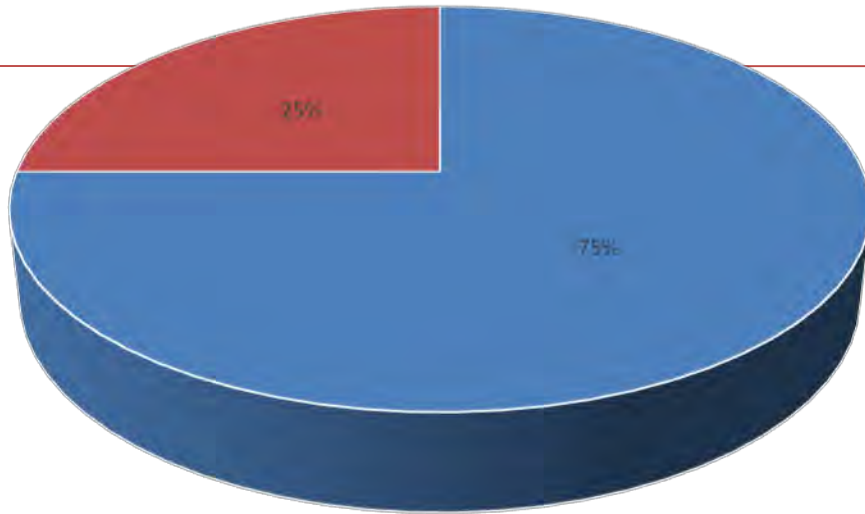
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1: Preparation of the nurses for the role

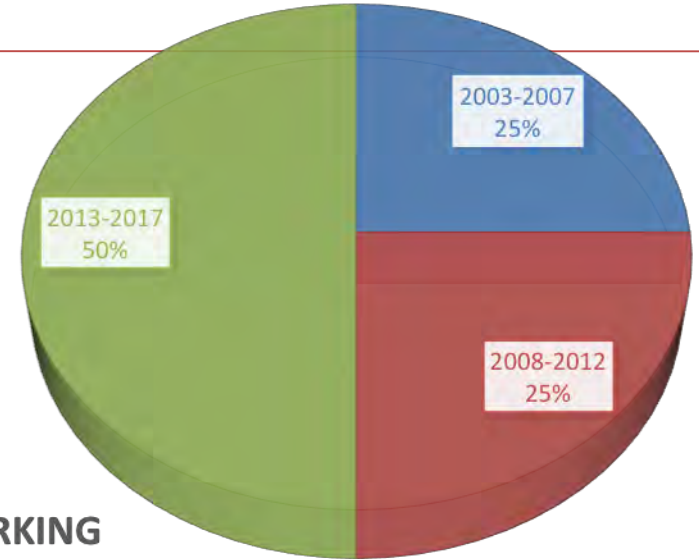
- *How are the nurses being prepared for the role?*
 - *Is it adequate?*
 - *Are there gaps?*
 - *Could it be done differently?*
- a) Semi-structured interviews
 - 12 nurses
 - 4 trainers
 - 1 MoH
 - b) Agreement of core competencies
 - c) Mapping of competencies / curriculum

PC Qualification

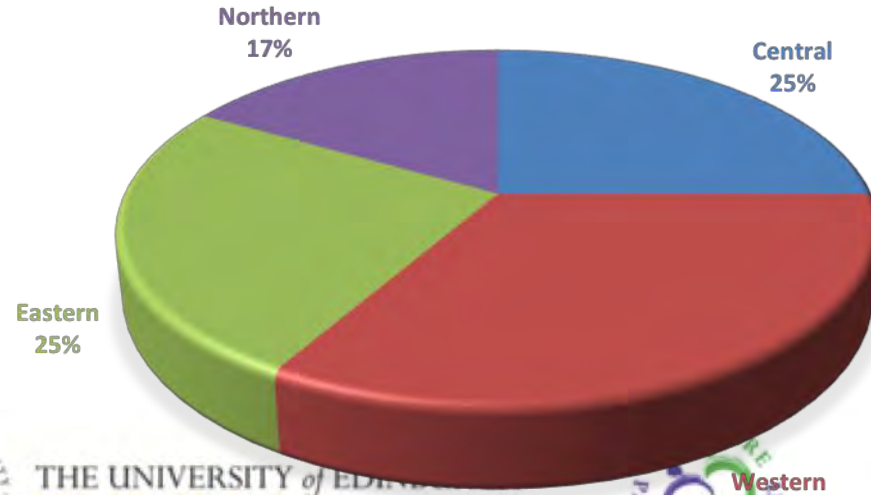


■ Diploma PC/DCPCN ■ BSc PC

LENGTH OF TIME SINCE QUALIFYING IN PC



WHERE WORKING



A Palliative Care Prescriber is someone who is legally permitted and has achieved and demonstrated the desired competencies for prescribing medications to those who have chronic, life limiting illness alongside other health care workers:

Domain	Competency
Therapeutic relationship	<ul style="list-style-type: none"> • Use advanced communication skills <ul style="list-style-type: none"> ○ to ensure that patients and carers are fully informed how to use morphine and other palliative care medication and their possible side effects ○ to explain and demystify myths, fears and misconceptions about medication used in palliative care ○ to ensure the unit of care is the patient including their family and carers supported by a genogram. • Offer appropriate adherence support for patients and families in the various settings • Explain use of appropriate charts (for example body charts and visual analogue charts) and medication records to patients and carers • Use evidence based practice
Clinical Care	<ul style="list-style-type: none"> • Undertake comprehensive and holistic (physical, social, psychological, spiritual) assessment and management of pain and other symptoms • Appreciate the WHO principles of chronic pain management including the use of opioids and adjuvant analgesics. • Manage side effects and toxicity of all palliative care medication • Reassess pain and follow up with appropriate management in regards to the effectiveness of any interventions • Appreciate the importance and involve family and carers in patient care
Collaborative Practice	<ul style="list-style-type: none"> • Understand and demonstrate the role of appropriate consultation in referring patients with pain and symptoms including those who have reversible causes of pain and symptoms, require joint management, need specialist interventions and include information regarding referral pathways in and out of the community setting. • Communicate and provide comprehensive feedback to other health care workers • Collaborate professionally with involved clinical team(s) and ensure sharing of skills within a multi-professional team, avoiding disempowering colleagues and ensuring the lines of clinical responsibility are respected.



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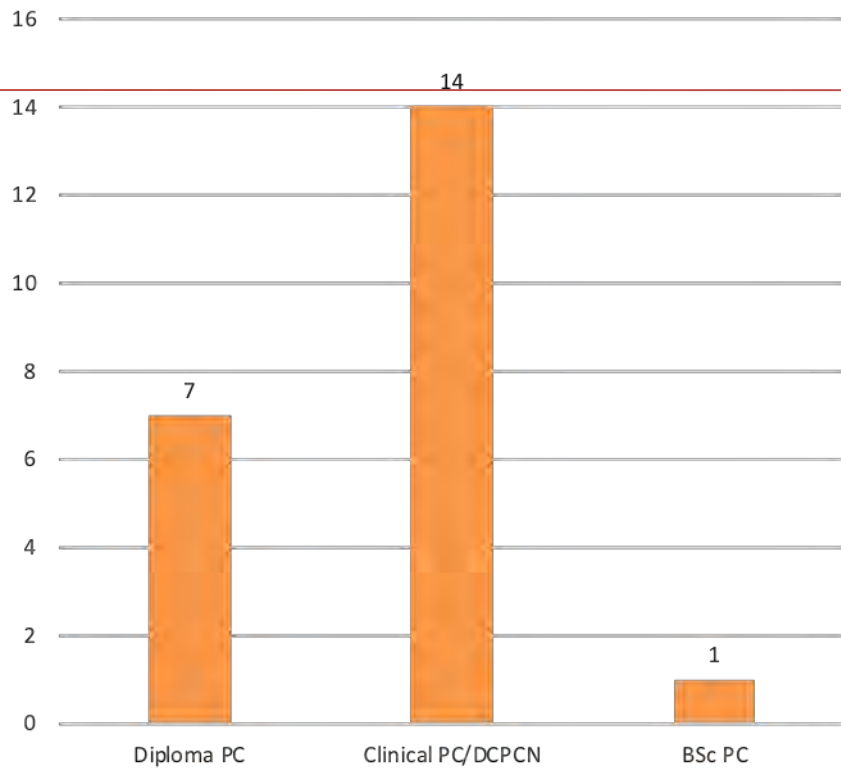


Leadership	<ul style="list-style-type: none"> • Teach, supervise and mentor colleagues on pain and symptom management • Identify good practice and disseminate results to colleagues and other stakeholders • Plan and implement audits or research to ensure ongoing good practice • Advocate for palliative care within and outside their organisation.
Professional Practice	<ul style="list-style-type: none"> • Understand the scope of their own prescribing responsibility in the context of shared clinical management • Fully document the pain and symptom assessment and use assessment tools e.g. body charts, visual analogue scales and numerical rating scales, POS, genogram. • Write prescription to comply with accepted legal requirements and clinical guidelines • Ensure and support appropriately the validated morphine procurement process and identify their role in the process.

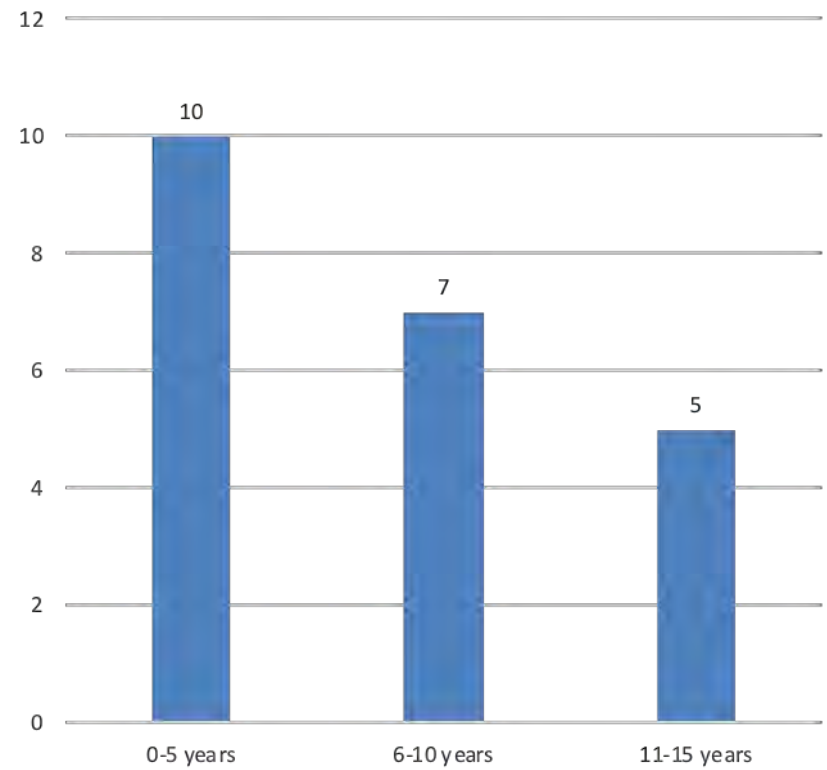
2: Evaluation of nurse prescribing

- *Are the nurses following the process for prescribing appropriately?*
 - *What are the outcomes of nurse prescribing (i.e. is the patients' pain controlled)?*
 - *What are the challenges for nurse prescribers?*
- a) Demographic form and self assessment re pain management
 - b) 22 nurses completing assessment and care of up to 20 patients each on 3 occasions
 - c) Administration of the APCA African POS
 - d) Semi-structured interviews – 11 nurses

PC Qualifications



Length of time working in PC



PATIENT ASSESSMENT- INITIAL VISIT

Name		PC No:
Age	Sex	
Date		
Seen by:	Driver on first visit:	
Place of Assessment:		
Nationality:	Tribe:	
Contact Telephone:	Languages:	
Residence (permanent):		
Temporarily living at:		
Caregiver Names/Relationship:	Contact tel:	
CVW Name/Number:	CVW Contact Tel:	
Other Agencies Involved, e.g. ARV provider, cancer therapy provider (names and contact details)		
Referred by (Tick referral source and give address below)		
Dr Nurse CVW Self Other		
Give name: Address: Contact no.		

Reasons for referral

Pain and symptom control.....

Psychological support.....

End of life care.....

Chemotherapy fundingOther.....

History from: patient..... carer volunteers..... Other.....

PROJECT 2: EVALUATION OF NURSE PRESCRIBING

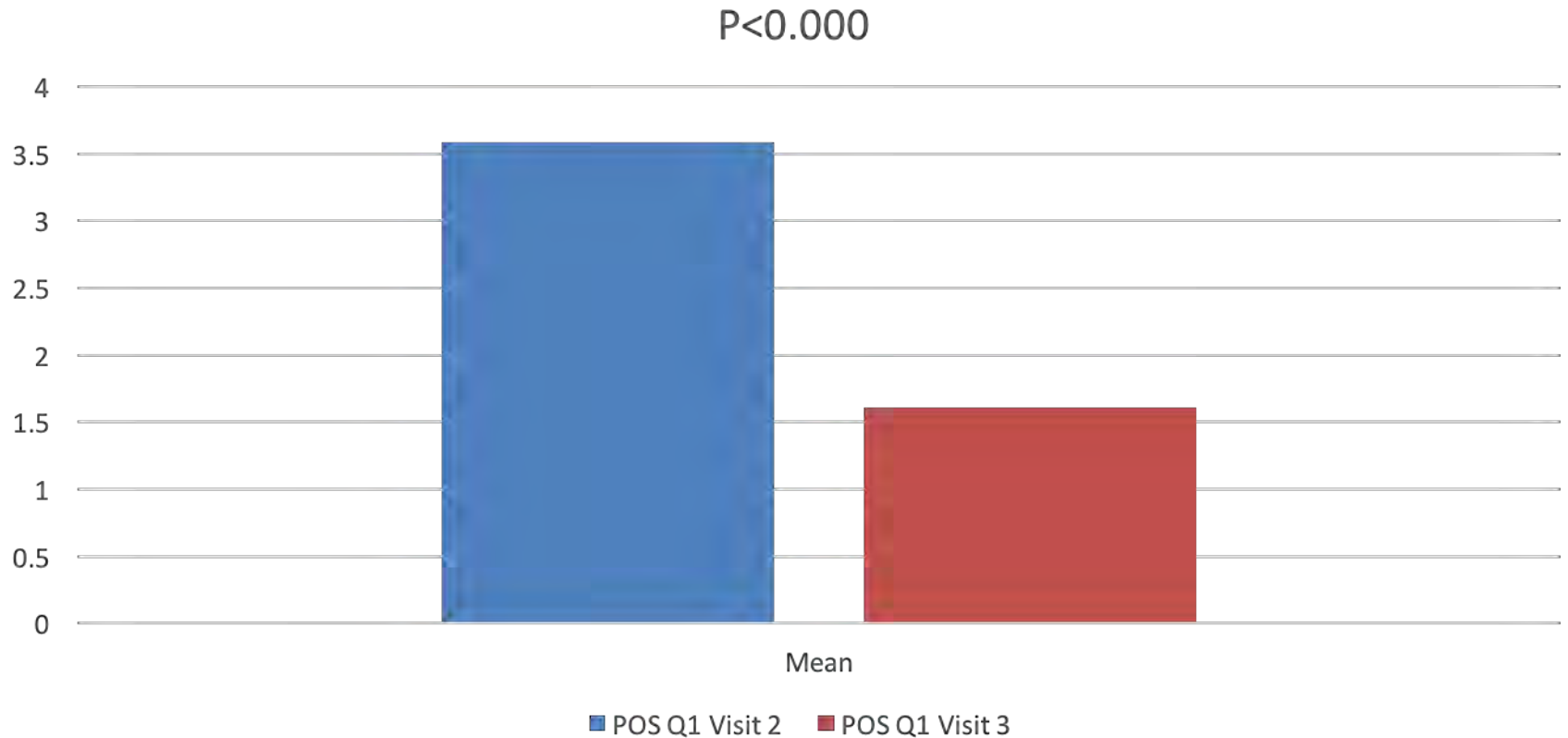
Data Extraction Form

1. Patient ID	<input type="checkbox"/>
2. Demographic Details	1 <input type="checkbox"/> Partially completed 2 <input type="checkbox"/> Completed 9 <input type="checkbox"/> Not completed
3. Reason for Referral	1 <input type="checkbox"/> Pain and Symptom control 2 <input type="checkbox"/> Psychological Support 3 <input type="checkbox"/> End of life care 4 <input type="checkbox"/> Other 9 <input type="checkbox"/> Not completed
4. Who were they referred by?	1 <input type="checkbox"/> Doctor 2 <input type="checkbox"/> Nurse 3 <input type="checkbox"/> Carer 4 <input type="checkbox"/> Self 5 <input type="checkbox"/> Other 9 <input type="checkbox"/> Not completed
5. Diagnosis	1 <input type="checkbox"/> Cancer 2 <input type="checkbox"/> HIV 3 <input type="checkbox"/> Cancer and HIV 4 <input type="checkbox"/> Other 9 <input type="checkbox"/> Not completed
6. History	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
7. Presenting Symptoms	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
• Symptoms identified	
8. Presenting Symptoms	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
• Pain identified as a symptom	
9. Presenting Symptoms	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> Some, but not all 9 <input type="checkbox"/> Not completed
• Symptoms scored	
10. Medications:	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
• Non-opioid	
11. Medications:	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
• Adjuvant	
12. Medications:	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
• Opioid morphine	
13. Medications:	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
• Opioid other than morphine	
14. Medications:	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
• Laxative	

Example of Analysis

Reason for Referral	Pain and Symptom Control – 93.3%
Who Referred	Doctor – 41.7% Nurse – 17.4% Self – 19.5%
History completed	97.0%
Presenting symptom	Pain – 75.5%
Medications on referral	Non-opioid – 26.4% Morphine – 29.7% Opioid other than morphine – 6.7% Adjuvants – 24.5%
Pain chart	Completed – 91.7%
Causes of pain	Identified – 88.9%
Examination findings	Present – 64%
Pain management plan with correct dosages of medications	Completed – 86.7%

POS Q1: Please rate your pain during the last 3 days



3: Appraisal of the health system and context

- *What is the system in which nurse prescribing is taking place?*
- *Is the system having an impact on nurse prescribing and if so, in what way?*
- 10 Districts across Uganda
 - Patient and/or Caregiver
 - Senior Nurse – PNO
 - Senior Hospital Administrator/ MD
 - Records Officer
 - Pharmacist
 - Palliative Care Nurses
 - Nurses

Analysis

- Variety of approaches used
- Quantitative e.g.:
 - *Demographic data*
 - *POS – Wilcoxin Rank Test for significance*
 - *Data extraction tools for nurse prescribing*
- Qualitative e.g.:
 - *Coding of interviews*
 - *Agreement of competencies*



Results:

- Nurses are trained and competent to prescribe
- Agreement of nurse competencies and routes to prescribing
- Some minor curriculum changes recommended
- Importance of mgs vs mls
- Themes Identified:
 - improvements to training,
 - supervision and mentorship,
 - competency,
 - boundaries of practice,
 - beliefs and system issues

Prescribing and outcomes data analysis demonstrates ability to:

- *assess and manage pain*
– $p < 0.001$
- *give appropriate medications and reassess.*

Appraisal showed:

- *variability in access to medications with regular stock-outs,*
- *limited understanding of PC*
- *Opiophobia*

Lancet Commission Report

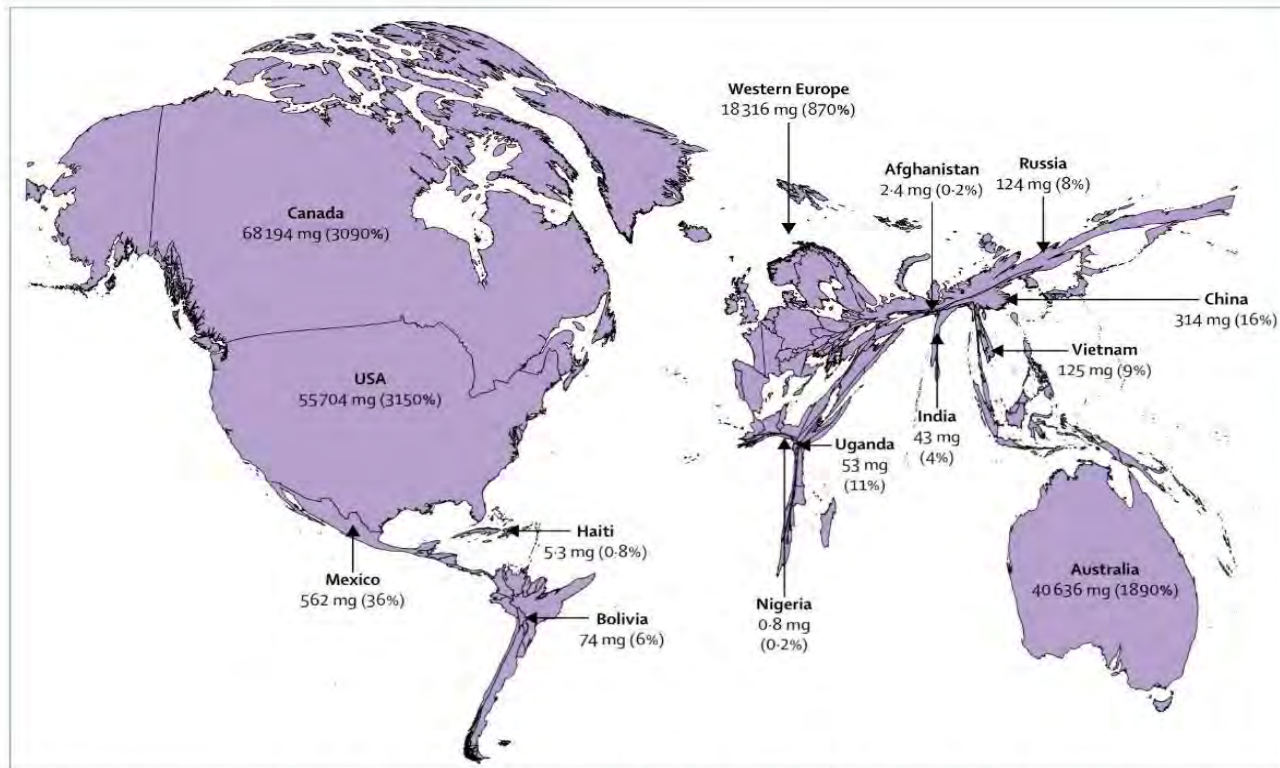


Figure 1: Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010-13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering

Source: International Narcotics Control Board and WHO Global Health Estimates, 2015. See additional online material for methods.

- Showed resilience and determination in nurses to overcome challenges and improve access to PC.
- This study has national and international significance





Evaluation Research Team

- Downing Julia, Nabirye Elizabeth, Ojera Alex, Namwanga Rosemary, Katusabe Roselight, Dusabimana Mathias, Kalemba Kelet, Yayeri Biira, Appolo Orishaba, Batuli Mwazi, Komunda Charlotte, Nabukalu Rashidah, Mwesige Jane, Sekyondwa Margaret, Kasirye Margaret, Amoris Jane Okoth, Nandutu Edith, Acuda Wilson, Adong Dorothy, Luyirika Emmanuel, Namisango Eve, Kiyange Fatia, Kiwanuka R, Amandua J, Logan J, Haraldsdottir Erna, McGannon Michelle, Moback Berit, Leslie Claire, Denham Paula, Shadat Rosie, Grant Liz, and Leng Mhoira.
- Plus all those involved e.g. the nurses who took part in the evaluation

