



# ANNUAL REPORT 2021-2022

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# FORWARD FROM HEAD OF UNIT

Palliative care (PC) relieves serious health-related suffering for people of all ages. The need for PC is larger than ever before: around the world, 56.8 million remain in need of such care, of whom a disproportionate number 78% live in low- and middle-income countries (LMICs). The availability of PC services also remains limited for patients with non-communicable disease. Yet the burden of serious health-related suffering can be alleviated with greater PC and pain relief services. Our Palliative care Education and Research Consortium (PcERC) aims to improve access to quality, evidence-based PC for patients and families through delivering integrated clinical services, education and training, research, and advocacy.

Globally, there has been continued reduction of funding for PC, which is a challenge to our work. There is urgent need for government to improve PC specific funding as it is a core component of Universal Health Coverage (UHC). We extend our appreciation to the Ministry of Health, all our friends, partners, and donors who contributed generously to support our work. However, we appeal for more as we look forward to the future with big plans and hopes.

**Elizabeth (Liz) Nabirye**

**Clinical Lead**

## Strategic Plan 2018-2023 Overview



**1. Clinical Service Provision.** To provide and scale-up an integrated clinical service to patients and families.



**2. Education.** To provide education, training and capacity building for healthcare workers and allied healthcare professionals and volunteers at all levels.



**3. Research.** To continue to expand the evidence-base for palliative care by promoting the prevailing research culture and increasing research collaborations within and outside palliative care service provision.



**4. Advocacy.** To enhance and promote academic and clinical credibility for palliative care.



**5. Sustainability.** To develop a well-resourced Palliative Care Unit, with the human resource capacity and infrastructure capable of sustainably supporting a Ugandan-led palliative care programme.



# MEET THE PCERC TEAM



**Pictured from left to right:** Ronald (volunteer), Vicky (volunteer), Florence Nalutaaya, Dr Kate (six-month volunteer), Elizabeth (Liz) Nabirye, Dr Elizabeth (Liz) Namukawaya, Prof Julia Downing, Grace Kivumbi, Josephine (volunteer), Jennie Twesige, and Toko Friday Santiago.

**Not pictured above:**



Dr Mhoira Leng



Dr Peace Bagasha



Dr Jack  
Turyahikayo



Hannah Ikong



Cathy Magoola



Maria (volunteer)



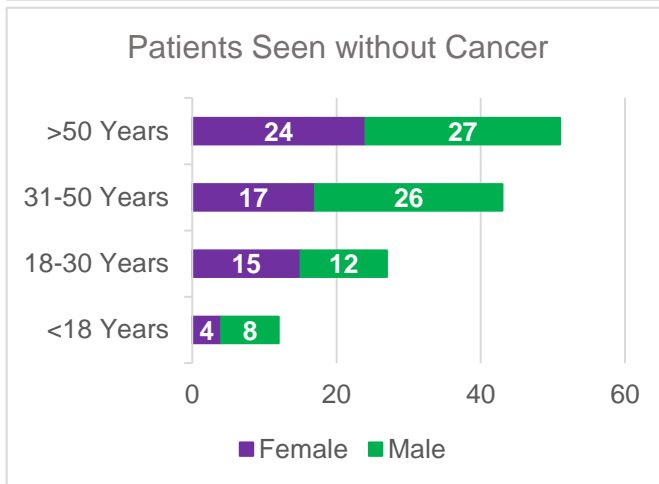
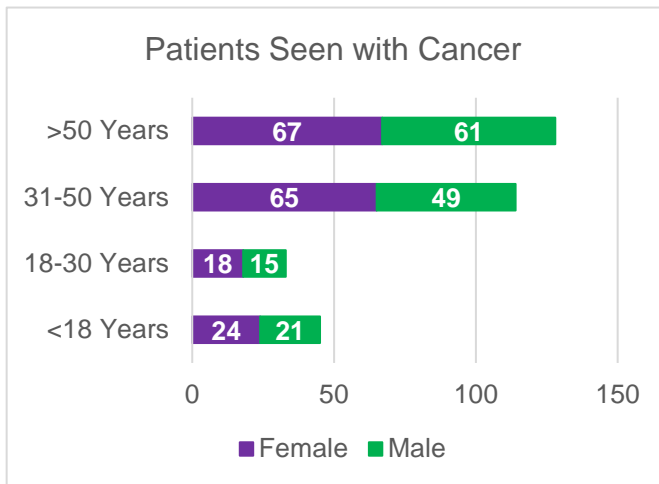
Teddy (volunteer)



Vicky (volunteer)

# CLINICAL SERVICE PROVISION

“To provide and scale-up an integrated clinical service to patients and families.”



## Patient Numbers and Outcomes

Over the last twelve months, we have seen 453 patients at both Kiruddu and Mulago Hospital sites. We have noted that some 71% of our patients have cancer as a primary diagnosis, which broaden our services to include a follow-up of our patients, at times, at the Uganda Cancer Institute (UCI). 40% of our patients are 50 years old and above, while one out of eight patients are children below 18 years most of them with the highest rate of having childhood cancer as the primary diagnosis (79%). **More information on patients with cancer and non-cancer diagnoses can be found on the left.**

From the patients seen, 62% (283) were discharged from the hospital to the palliative care (PC) units or centres for continuity of care. Although some were already known to the PC services in their home area, we noted that we have challenges with referral pathways for patients who need PC but have a non-cancer diagnosis (i.e. heart, kidney, and lung diseases).

## Our Clinical Services and the COVID-19 Pandemic

We are proud to offer clinical services throughout the pandemic, even working closely the Department of Medicine at Makerere as they cared for COVID-19 patients, as we self-raised funds for protective wear (PPE) and safe transportation (see **Sustainability** for more information.) With these efforts, from July 2021 to June 2022, we had 2,711 in-person patient reviews and made 1,332 telephone reviews. These reviews included symptom control, multidisciplinary consultations, and psychosocial and bereavement support, and were completed by the clinical staff, which includes local and international volunteers.

We have five local volunteers who are trained in basic PC with a social worker background. In addition to the reviews listed above, they visited patients and their families 1,047 times on their own to ensure quality, ongoing services like counselling and practical support. **To the right, volunteer Teddy is pictured with a patient with lung disease; she has a special relationship with her because they share the same name.**





# EDUCATION AND TRAINING

**“To provide education, training and capacity building for healthcare workers and allied health professionals and volunteers at all levels.”**

As a specialised PC unit under the Department of Medicine in the College of Health Sciences of Makerere University, we prioritise educational partnerships to provide palliative care (PC) classroom training, clinical modelling, and mentorship. Most of our trainees come from Makerere University (MUK), the Islamic University in Uganda (IUIU), and the School of Nurses and Midwives Mulago. We have also been able to train health professionals, village health teams (VHTs) and mentors in Adjumani and Obongi districts in basic PC with our partners Peace Hospice Adjumani and Cairdeas IPCT. Funded by ICPCN and Laura Case Trust, we trained and mentored 42 healthcare professionals in Children’s PC. Then along with Hospice Africa Uganda (HAU), we participated in training students pursuing a Master’s or a Bachelors of Science in PC, as well as hosted 10 healthcare workers undergoing PC Initiators’ Training from different countries for clinical modelling in hospital-based PC. **Please see the table on the right for our education activities in Uganda.** (A few staff members in PcERC have also conducted trainings abroad.)

Student Type	Number
Allied professionals (COME)	16
Healthcare workers (HAU, Obongi and Adjumani, Children’s PC)	104
Nurses (Mulago Hospital)	17
Postgraduates (HAU, Family and Internal Medicine at MUK)	24
Undergraduates (HAU, IUIU, MUK)	305
VHTs and VHT Mentors	100
<b>Total</b>	<b>566</b>



**Top left to right:** Our team with international healthcare workers from Hospice Africa Uganda; Florence and healthcare workers in Obongi district. **Bottom left to right:** Healthcare workers training with Peace Hospice Adjumani; Florence teaching the COME training. **Centre image:** Nurses trainees undertaking an Advanced Diploma in PC, on clinical placement with our PC unit.

# RESEARCH

**“To continue to expand the evidence-base for palliative care by promoting the prevailing research culture and increasing research collaborations within and outside palliative care service provision.”**

## Transform Project

The Transform research project in northern Uganda has been made possible through our partners Cairdeas IPCT, Peace Hospice Adjumani, University of Edinburgh, and the International Children's



Palliative care network, the Ministry of Health, and it is funded through UKAID. Our research protocol is titled, *“Exploring palliative care needs among refugee and host communities with chronic illness and VHT’s experiences of providing Palliative care in Obongi and Adjumani districts in Uganda.”*



In 2021, we trained 100 Village Health Teams (VHTs) and instructed a further 22 VHT mentors in the Photovoice research methodology during a one-day training. We have also done a Rapid Systems Review (RSA), a baseline assessment, and a PC Needs Assessment of patients with serious health related suffering in partnership with our stakeholders. To date, we have screened 350 individuals with PC needs from over 20 villages and townships, and from the screening, we recruited 231 to the study. **From top to bottom: Liz (2<sup>nd</sup> on the left) listens to stories from the Obongi district community; Godfrey and Chris (right and 2<sup>nd</sup> right) support the VHTs in Adjumani district.**

## Needs Assessment in the Emergency Department

Our research then extended to the emergency department of Kiruddu Hospital, where we investigated the prevalence of holistic care needs in patients with chronic and life-limiting illnesses. The research project was done collaboratively with Yale University and led by Yale student Dao Ho and funded through Yale University, while the PcERC team assisted in data collection and analysis. Between October and December 2021, our team surveyed 100 patients with PC needs and conducted interviews with 11 healthcare workers in the emergency department of Kiruddu Hospital. The data was analysed by Dao Ho and presented in her Master’s Thesis of *“Understanding Palliative Care Delivery in a Ugandan Emergency Department and United States Emergency Department.”* The data results are also being compiled into a manuscript specifically for emergency department use in Uganda.

Through this collaborative research project, we have received reports of inadequate PC training and challenges in delivering PC due to patient volume and understaffing from the emergency department healthcare workers. In the surveyed patients, we noted a high presentation of needs, with an average of 7 physical symptoms and 6 psychosocial or spiritual issues per participant. Other holistic needs (i.e., anxiety and depression in patient and their family, financial concerns) emerged in nearly 90% of our participants. All in all, we have seen the importance of further integration of PC training and services in the emergency department setting.



# CONFERENCES

- 23-24 Sept 2021 **3<sup>rd</sup> Uganda Conference on Cancer and PCAU:** Cancer and Palliative care in COVID-19 and other Challenging Situations. Presentations included:
- “Scattered: The Lived Experience of Patients with End Stage Kidney Disease in Uganda,” by *Dr Peace Bagasha*.
  - “Empowering Health Professionals Through Education and Mentorship to Improve Children’s Palliative Care Provision in Uganda,” by *Florence Nalutaaya*.
  - “Health Professionals’ Perceptions of Use of Digital Technology in Palliative Cancer Care: A Multi-Centre Study in Uganda, Zimbabwe and Nigeria,” by *Liz Nabirye*.
- 15-16 Oct 2021 **Medical Education in Palestine – A Holistic Approach.** Islamic University of Gaza, Faculty of Medicine, Scientific session. We presented the following:
- “Transformational education as an essential paradigm for medical education,” discussed by *Dr Mhoira Leng*.
- 2-4 Nov 2021 **ICN Congress: Nursing Around the World.** Our contribution includes:
- “The State of Palliative Care Services Around the World: How well are we doing?” by *Prof Julia Downing*.
- 2 Dec 2021 **Future Opportunity for the Pioneering Nurse,** Virtual Conference.
- “Provoking Change Through Pioneering: a journey of vision, courage, self-development and opportunity” by *Prof Julia Downing*.
- 17-18 Dec 2021 **6<sup>th</sup> ESCACOP Scientific Virtual Conference:** Building Resilience in Health Systems and Exploring Frontiers Beyond COVID-19. Our presentation was:
- “Integration of Palliative Care into Healthcare Provision for Host & Refugee Communities in the Fragile Settings of Adjumani & Obongi Districts, Uganda; A Situational Analysis,” by *Dr Mhoira Leng*.
- 11-13 Feb 2022 **29<sup>th</sup> IAPCON Virtual Conference:** Preconference workshop on 10<sup>th</sup> February was centred on Palliative Care and Planetary Health in Humanitarian Settings:
- “Ensuring Community Generated Data – Uganda,” by *Dr Mhoira Leng* and *Chris Smith*, using the data from the Transform project.
- 23-25 Feb 2022 **International Conference on Cancer Nursing,** Virtual Conference.
- “A Road Map for Developing Health Policy: Instructional Session” by *Prof Julia Downing*, *Dr Stella Bialous*, and *Yael Ben Gal*.
  - “Getting It Right for All Through Health Policy,” Plenary session by *Prof Julia Downing* and *Yael Ben Gal*.
- 9-11 Mar 2022 **14<sup>th</sup> Congress of SIOP Africa:** Innovating for Africa. Our contributions included presentations on the following topics:
- “The Principles of Palliative Care and Integration into the Management of Children with Cancer,” by *Prof Julia Downing*.
  - “Pain Assessment and Management in Children with Cancer,” by *Liz Nabirye*.
  - “Advanced Care Planning and End-Of-Life Care,” by *Liz Nabirye*.
  - “Communicating With Children in Palliative Care,” by *Florence Nalutaaya*.
  - “Managing Symptoms Other Than Pain,” by *Florence Nalutaaya*.



# ADVOCACY

“To enhance and promote academic and clinical credibility for palliative care.”



## Integrating Palliative Care into Health Systems

Uganda continues to be a regional leader of palliative care (PC), with active support from the Ugandan Ministry of Health (MOH). They have instituted both PC policies as well as government appointments of a PC Division and desk office, and an Assistant Commissioner. In 2021, the MOH asked all hospitals to establish a functioning PC unit. The MOH has now created and distributed Health Management Information Systems (HMIS) reporting books specific to the PC unit, which

allows us to input our data into the hospital’s reporting systems. The HMIS reporting books will become an advocacy tool for further PC inclusion in the MOH system regarding budgeting, human resources deployment, essential medicines availability, and allocated office space. **Pictured above, nurses Florence and Cathy review our HMIS book in our Kiruddu Hospital office.**

## Advocacy Outcomes at Kiruddu and Mulago Hospitals

Our advocacy for clinical credibility and support involved engaging with executive directors at Kiruddu and Mulago Hospitals and other leaders through meetings and official letters. As a result of these, one nurse, Cathy Magoola, was deployed and dedicated since March 2022 to do PC with our unit in Kiruddu Referral Hospital. We also have been allocated an office space on Level 4B in the Mulago National Specialised Hospital which has given us visibility and interning doctors have been deployed to work with our PC unit on a 2-week rotation. These rotating internships have given us an opportunity to both mentor the young medical officers in PC as well as to boost access to PC services as they offer generalist care to patients, thus improving quality of life for patients and their caregivers. **Pictured to the right is our nurse Josephine and social worker Toko Friday seeing a patient with Dr Fred, one of the interning doctors.** From our new office space to added human resources, we now have increased visibility, availability, and integration for PC services in clinical care.



## Ongoing Advocacy within the PcERC Team

We continue to engage with both Kiruddu and Mulago Hospital pharmacies to ensure continuous availability of oral morphine and other Essential PC medicines for Universal Health Coverage (UHC) at both hospitals. With the HMIS reporting system in place, we foresee other advancements in the support of our PC unit as well as our patients and their families. We also continue to engage with our partners through regular communication (including quarterly reports) and we appreciate their continued support.

# SUSTAINABILITY

**“To develop a well-resourced Palliative Care Unit, within the human resource capacity and infrastructure capable of sustainably supporting a Ugandan-led palliative care programme.”**

## Resource Mobilisation and Sustainability

Financial sustainability has advanced through three methods: working on our organisation’s official status, partnering with others, and exploring self-fundraising as we continue applying for grants. First, in November 2021, we completed our long-awaited full registration as a Non-Governmental Organisation (NGO) and gained a permit to operate for the next 5 years. This achievement opens fundraising opportunities for us with more sponsors and corporate donors.

Then, we continue to partner with the Department of Medicine of the College of Health Sciences at Makerere University and the Mulago and Kiruddu Hospital sites. These partners provide office space, including paying for utilities of water and electricity, and Kiruddu Hospital in March 2022 has furthered our financial sustainability through deploying nurse Cathy Magoola. Collaborations with international partners have also been vital, from advancing our clinical services during COVID-19 lockdowns to partnerships in research to better understand our patients and their families. Our collaborations include individuals as well, from our five local volunteers to international volunteers who have provided their expertise in clinical, educational and research work. **Pictured to the right are Dr Kathleen McGeough and Dr Kate Howorth, who served as clinical lecturers for four and six months respectively during 2022.**



Finally, we found an outlet to reach new audiences and self-fundraise through Global Giving. Over the last three years, we have posted projects of [“Bringing Hope Through Palliative Care in Uganda”](#) and [“Covid-19 Bringing Hope Through Palliative Care”](#) which has, in total, raised over \$68,000 to support our PC unit. These funds are used to cover staff time, training costs, as well as communication expenses with the patients and families.

## Challenges and Lessons Learned

There have been a few barriers in maintaining our unit’s sustainability. We continue to face delays from our hospital sites in requested human resources and other in-kind resources. Our funding is often short-term and so we struggle to find continued resources for staff time and volunteer facilitation. In addition, there has been the global struggles of the COVID-19 pandemic, affecting overall funding, the reach of our work, and further burdening our patients and their families.

In face with these challenges, we have learned the benefit of continued advocacy with hospital sites and the importance of technology, such as engaging with donors more through building our own [website](#) and self-fundraising. We also have noted that long-term funding can occur while networking, which is how we have built donor relationships with Global Health Academy, ICPCN, Laura Case Trust, and UCT-UK. Finally, we appreciate our partners, including Cairdeas IPCT, Hospice Africa Uganda, Peace Hospice Adjumani, PCAU, and Yale University, who have helped us accomplish much work that we could not do on our own.



# THANK YOU

We have much to be grateful for in this last year from July 2021 to June 2022.



We extend our appreciation to the many partnering organisations and individuals in Uganda and around the world.

From stakeholders to donors to policymakers, we are thankful for your support to bolster accessible and quality palliative care services for all.



For our fellow healthcare professionals and social workers, we encourage you to continue to pursue compassionate and holistic care in your fields while being lifelong learners.



To our patients and families, thank you for allowing us to walk alongside you in this season of life.

Everything we do – education and training, research, advocacy, creating sustainability and more – contributes to our mission of excellent palliative care.



It is truly an honour to serve you.

