

### **Palliative Care Association** of Uganda (PCAU)



#### **PROGRAMME**

# World Hospice and Palliative Care Week 2022 Theme:

# Healing Communities, Touching lives, Society Transformation

Day	Events by Ministry of Health & PCAU
Monday 3/Oct/22	Press conference on the current state of palliative care in Uganda
Tuesday 4/Oct/22	A Twitter Space session on "Healing Communities, Touching lives, Society Transformation"
Wednesday 5/Oct/22	Public Lecture on alleviation of pain and suffering in patients with life-limiting conditions streamed on different media
Thursday 6/Oct/22	A community engagement and meeting with Members of Parliament on the Health Committee
Friday 7/Oct/22	Radio and Television Talk Shows
Saturday 8/Oct /22	Commemoration of the WHPCD with a National Palliative Care walk





PALLIATIVE CARE ASSOCIATION OF UGANDA (PCAU)

**ANNUAL REPORT 2021** 









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**Financial Report** 

### **PCAU Team at the Secretariat**



	Name	Designation
1	Mark Donald Mwesiga	Country Director
2	Anita Balikobaku	Programs Manager
3	Joyce Zalwango	Capacity Building Officer
4	Lisa Christine Irumba	Advocacy & Research Officer
5	Cynthia Kabagambe	ICT and Data Quality Officer
6	Rita Nannyomo	Finance Officer
7	Fiona Siima Karakire	Membership and Partnerships Officer
8	Zaitun Nalukwago	Communications Officer
9	Zipporah Kyomuhangi	Administrative Assistant
10	Stephen Kasula	Program Assistant Road to Hope
11	Doreen Nalwadda	Accounts Assistant
12	Margaret Kabajungu	General Assistant
13	Jaffa Mohamed	Driver
14	Ismail Kyagulanyi	Security Officer
15	Tom Echodu	Security Officer
16	Ronald Kanyike	Locum Driver
Staff Supported by PCAU at New Life Hospice Arua		
1	Lucy Agaboru	Palliative Care Nurse
2	Ejoii Stanley	Administrator



#### **OUR VISION**

Palliative Care for all in need in Uganda



#### **Our Mission**

To accelerate the integration of palliative care in the Uganda health care system through capacity building, advocacy, research and resource mobilization.

#### **REGISTER AS A PCAU MEMBER**

PCAU is Com posed of 24 Member Organizations and 1200 Individuals. You too can join PCAU. Our Membership is open to Senior Professionals, Junior Professionals, Community Based Health Workers, Community Health caregivers, volunteers and leaders at all levels.

	Membership Category	Subscription (UGX)
1	Individual Member	20,000
2	District Palliative Care Initiative/ Community Based Organization (CBO)	500,000
3	Life Member	1,000,000
4	Institutional Members/Non- Governmental Organization/ Hospital	1,000,000

#### **REACH US ON**

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#### **Brief information about PCAU**

The Palliative Care Association of Uganda (PCAU) is the National Association for Palliative Care providers in Uganda.



#### **OUR CORE VALUES**

**Service Provider Focus:** We are committed to the development and empowerment of Palliative Care providers to their highest professional potential. Service providers are the principle target of PCAU work.

**Collaboration and Networking:** We seek to use the limited resources to maximum advantage through partnerships and collaborations, pursuing networks and harnessing the potential of all our partners and members for the common good.

**Integrity:** We carry out our duties in a responsible, honest and accountable manner to all stakeholders including donor, government, members as well as patients and families.

**Volunteerism:** We recognize the support and commitment of volunteers as an essential element in scaling-up of Palliative Care work and empowering service providers.

**Professionalism:** We strictly observe the highest ethical and professional standards in providing training, mentorship, supervision and support.

#### The Key Focus Areas of PCAU





Dr Henry Ddungu President and Board Chair- PCAU



Mark Donald Mwesiga
Country Director - PCAU

# Message from the PCAU President and Country Director

**Dear** PCAU Members and Friends,

Thank you for your continued support for the association. Welcome to our Annual Report 2021. This report highlights our achievements for the year 2021 as well as what we accomplished during the PCAU Strategic Plan 2017 – 2021. In the last five years, we achieved a lot together. Detailed information is available in the Summative Evaluation Report for the PCAU Strategic Plan 2017 – 2021 on our website.

In 2021, we worked amidst the Covid-19 Pandemic. We made our contribution by participating in the national and district Covid-19 task forces. We supported the continuity of palliative care as an essential service in Uganda in many ways including providing logistical support to our Member Organizations.

At the last AGM, members elected new members to the Board. We thank all members who participated in this process. In the same year, we hosted the 3rd Uganda Conference on Cancer and Palliative Care. We are grateful to Uganda Cancer Institute for the partnership in hosting these scientific conferences.

We are grateful to all PCAU Donors. We are grateful to the Center for Hospice Care/Foundation, American Cancer Society, Open Society Foundations, African Palliative Care Association, Global Partners in Care, Hanna & Joseph Gonzalez, and, all individual donors who supported PCAU through the Global Giving Platform.

Specially also, we thank all of you PCAU Life Members. You have signed up to support PCAU sustainability initiatives. One of the needs PCAU has, is larger premises for our secretariat. We need more life members and partners to realize this.

We commiserate with all of you who lost loved ones in the past year. We also commend all of you and the entire health workforce at the Covid-19 front line.

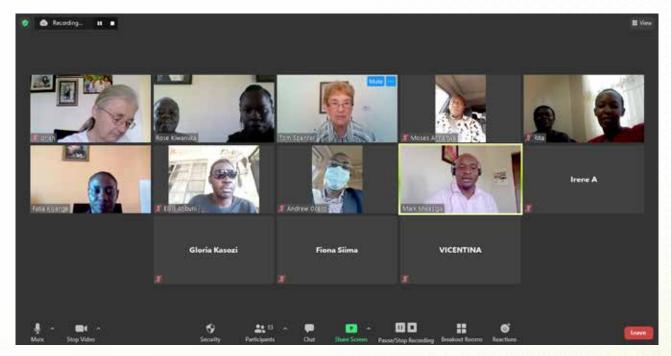
Thank you all.



# The Board of Directors of the Palliative Association of Uganda



During the AGM held on May 28<sup>th</sup>. 2021, PCAU Members elected into office new members of the Board of Directors. In the photo from left: Mr. Gerever Niwagaba, Dr. Miriam Ajambo, Dr. Gloria Kirungi, Dr. Henry Ddungu, Hajjati Mwazi Batuli, Mrs. Josephine Kampi Tatyabala, CPA. Dr. Timothy Basimampora, Mr. Mark Mwesiga (Country Director), and Mr. John Muwonge. One member Ms. Grace Nayiga is not in this photo.



Screenshot of the meeting for the 1st PCAU Life Members Assembly on May 20th, 2021. Life Members of PCAU are key stakeholders who have committed to supporting the initiatives for the sustainability of the association. The funds generated through Life Membership contributions and subscriptions will support PCAU to acquire larger office premises which are key strategic action in the next 2 years.

### **Focus on Covid-19 Pandemic**

Following the PCAU Interventions Strategy for the Covid-19 Pandemic, we implemented a number of activities:

- Advocated for continuity of palliative care as an essential service
- Participated as members of committees at National and District level Covid-19 Task Forces
- Developed, printed, and disseminated SOPs to enable hospices to continue offering services
- Conducted training for staff in hospices and other palliative care organizations on SOPs
- Supported communications and facilitated Covid-19 vaccination drives
- Offered PPE and other items to 11 Member organizations of PCAU

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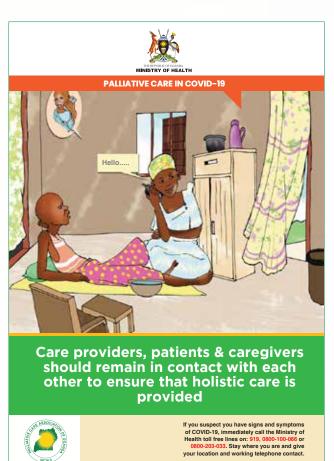


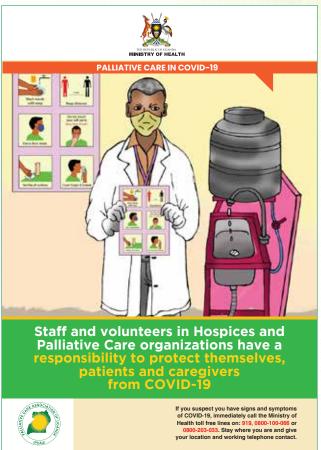
PCAU has issued several Covid-19 vaccination appeals to the community. We have produced audiovisual messages for social media, radio and TV adverts working with Joanita Kawalya the PCAU Goodwill ambassador.

#### A copy of the SOPs can be accessed on our website

Member Organizations supported	PPE and other Medical ite	ms offered
■ Hospice Africa Uganda	Hand Sanitizer	100 liters
■ Hospice Tororo	Gloves	150 boxes
■ Ibanda Central Clinic	Medical Masks	100 boxes
JOY Hospice Mbale	Face shields	100
¤ Kawempe Home Care	Temperature Guns	50
<b>x</b> Kitovu mobile	Triage Area Tents	11
Mulago/Makerere Palliative Care Unit	Triage Tables	11
Peace Hospice Adjumani	Chairs	22
	Bicycles	10
Rays of Hope Hospice Jinja	Umbrellas	200
Reach Out Mbuya	Medical Aprons	40
Santa Maria Hospice Mityana	Jik bleach disinfectant	100litres
	Pedal Bins	25
	Assorted Medicines	







PCAU advocates for the continuity of Palliative Care services during the Covid-19 Pandemic and has supported hospices to adhere to Covid-19 Standard Operating Procedures (SOPs).



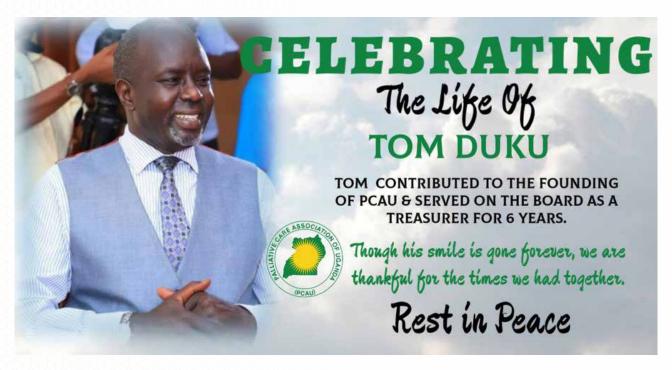


Leaders from Hospice Africa Uganda (HAU) left and Kitovu Mobile received assorted items to support the continuity of palliative care donated by PCAU.

#### Performance Challenges Posed by the Covid-19 Pandemic

The Covid-19 Pandemic posed numerous challenges to the work of PCAU and the delivery of palliative care in Uganda.

- Restrictions on transport led to reduced access to care by patients and families.
- PCAU Member organizations faced logistical challenges in shifting to work online.
- Normal communication and referral structures for patients were affected by restrictions.
- There was largely reduced donor funding to hospices that prevails.
- **m** Majority of hospices scaled down on operations affecting delivery and quality of care.
- **L**ike everyone else PCAU lost some members to Covid-19 and members lost loved ones too.



The late Tom Duku managed PCAU funds during the founding stages of PCAU. He later served on the PCAU Board for a period of 6 years from 2014. As PCAU celebrated 20 years in 2019 he was awarded for his great contribution to the work of PCAU. Read a tribute to Tom on <a href="https://ehospice.com/africa\_posts/a-hospice-in-grief-tribute-to-tom-duku/">https://ehospice.com/africa\_posts/a-hospice-in-grief-tribute-to-tom-duku/</a>



### **Capacity Building 2021 Achievements**



Overall, our Performance in the Capacity Building focus area for the strategic planning period 2017-2021 was excellent. We surpassed our set targets for over 90% of all set activities. Our highlight achievements are:

- Offered technical support for the introduction of a Palliative Care Diploma at Mulago School of Nursing and Midwifery.
- Offered full scholarships to 25 of the pioneer students of the Advanced Diploma in Palliative Care Nursing.
- **m** Offered support for training of 10 Tutors to teach Palliative Care.
- m Implemented the ACS Pain-Free Hospital Initiative in 17 of the largest hospitals in Uganda.
- **Supported clinical placements and practicum sites for palliative care students under training**
- Conducted support supervision to Palliative Care units in 112 districts

BIG congratulations to the pioneer class of Advanced Diploma in Palliative Care Nursing in Uganda. PCAU, with support from partners, offered full scholarships! PCAU is supporting each one of them to initiate Palliative Care in their districts.



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In 2021, we implemented the following activities:

- Held 4 National Palliative Care Update Meetings for Continuous Medical Education (CME)
- Held 4 Branch Update Meetings for PCAU Branches of Busoga and Hoima Regions.
- Implemented the Pain-Free Hospital Initiative (PFHI) in 3 larger teaching hospitals and trained 470 health care workers in Pain Management.
- Three (3) day Pain Management Training for 28 health workers from private health facilities in Kampala.
- Provided 14 Scholarships to the Advanced Diploma in Palliative Care Nursing students.
- Conducted a 5-day introductory course for 28 health workers from 6 hospitals in Kampala
- Conducted 5-day training for spiritual leaders for 29 participants in West Nile Region.
- Conducted 2 short pieces of training Health & Non-Health.

The **PCAU National** and **Branch Update Meetings** are quarterly gatherings for members intended for Continuous Medical Education (CME). The gatherings at the national and regional levels are also used as advocacy platforms. Due to Covid-19, these sessions were held online in 2021. The online meetings and webinars were attended by a total of 210 members and other health professionals.



Screenshot of the webinar on New WHO Resources for Palliative Care Organized by PCAU in November 2021. At least 70 PCAU Members from across the country attended this Webinar. Dr. Emmanuel Luyirika of APCA, Dr. Marie-Charlotte Bouësseau and Dr. Anne-Marie Ray of WHO spoke at the webinar.



#### The CME topics during update meetings in 2021 were:

- The World Health Organization (WHO) New Resources for Palliative Care.
- The impact of the Covid-19 pandemic on palliative care service delivery in Uganda.
- The Community Empowerment and Engagement Strategy for Covid-19
- Comprehensive communication for Covid-19 in Palliative Care Services

#### Read about the new resources on the WHO website:

- Quality health services and palliative care: practical approaches and resources to support policy, strategy, and practice https://www.who.int/publications/i/item/9789240035164
- Assessing the development of palliative care worldwide: a set of actionable indicators <a href="https://www.who.int/publications/i/item/9789240033351">https://www.who.int/publications/i/item/9789240033351</a>



FIGURE 4. CONCEPTUAL MODEL OF PALLIATIVE CARE DEVELOPMENT

The new WHO palliative care development conceptual model includes four components already deemed essential to palliative care development in the literature: appropriate policies; adequate access to medicines; education of healthcare workers and the public; and implementation of palliative care services at all levels of the health system. To further strengthen this model and reflect international commitments to the PH approach, the expert group agreed on adding two other components: research; and empowered people and communities.



#### Pain Management Training for Health Workers in Private Hospitals in Kampala.

We held a training targeted for Health Workers in private health facilities on Pain Management. The training was to equip health workers in private health facilities with knowledge in pain assessment and management in children and adults.

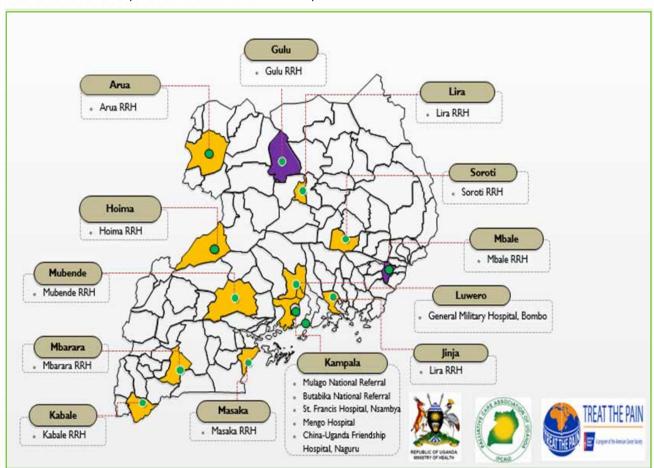
A total of **28 participants** including Doctors, Nurses, and Clinical Officers from **6 private hospitals** attended the online training.

#### The Pain-Free Hospital Initiative

The goal of the Pain-Free Hospital Initiative Project is to **integrate effective pain relief into hospital services** through the following objectives:

- **m** Motivate clinicians to evaluate and treat pain.
- Supply appropriate drugs to treat pain.
- Engage hospital staff to create awareness about pain.

We continue to implement the Pain-Free Hospital Initiative (PFHI).



PCAU implements the Pain-Free Hospital Initiative (FFHI) in partnership with the Ministry of Health with support from the American Cancer Society (ACS). Since 2016, 17 hospitals in Uganda have implemented the PFHI. This is a hospital-wide quality improvement initiative to integrate pain treatment into health service delivery.





In 2021, we implemented the PFHI in St. Francis Hospital Nsambya, Mengo Hospital and China Uganda Friendship Hospital – Naguru.

#### **Training for Spiritual Leaders in West Nile on Palliative Care**

In partnership with the Office of the District Health of Yumbe District and Yumbe Regional Referral Hospital, we conducted 5 days of training for spiritual leaders in the region. The spiritual leaders in these refugee-hosting communities play an important role of referring palliative care patients into care as well as offering palliative care.



29 Spiritual leaders were drawn from different denominations; they included Canons, Deacon, and Reverend
Brothers, Catholic Priests, Muslim Sheiks, and district cadres.

#### **Sharing Best Practices with Delegations from Africa**

Through partners the African Palliative Care Association (APCA) and members Hospice Africa Uganda (HAU), PCAU hosted several delegations from African countries to share experiences and lessons.

#### These included:

- Students of the Anglophone Initiators Course at the Institute of Hospice and Palliative Care in Africa (IHPCA).
- Delegation from Ethiopia on the functioning of the Oral liquid Morphine supply chain in the country.
- **Delegation** Delegation from Ghana for lessons on functioning national palliative care association.
- **Delegation** from the government of the Democratic Republic on initiating Palliative Care service.

#### **Scholarships for Palliative Care Training in Uganda**

Due to the Covid-19 Pandemic, the operations of training institutions were affected greatly. PCAU did not offer the target number of scholarships during 2021.

- Three (3) from the districts of Masaka and Butambala were offered scholarships to undertake the Advanced Diploma in Palliative Care Nursing at Mulago School of Nursing.
- **PCAU** supported clinical placements for students undertaking ADCPN at 3 palliative care sites.
- Held several engagements with Mulago School of Nursing and Midwifery on progress and evaluation of the ADCPN Program.



The staff of PCAU and Mulago School of Nursing and Midwifery in one of the meetings to evaluate the progress of the Advanced Diploma in Palliative Care Nursing (ADPCN).





Students undertaking the
Advanced Diploma in Palliative
Care Nursing at Mulago School
of Nursing and Midwifery
interacting with Sr. Florence
Nalutaya a Palliative Care Nurse
Specialist Makerere-Mulago
Palliative Care Unit. This was
during the clinical placement
period. PCAU supports students
undertaking palliative care
training to attend clinical
placement at designated
palliative care units.

In partnership with the Ministry of Health, PCAU conducted support supervision to at least 38 health facilities in districts across the country in 2021. These were mainly carried out in districts with new palliative care initiatives as well as new palliative care units.





The staff of PCAU during support supervision visits in health facilities and district leadership at the St. Francis Nsambya Hospital and the Palliative Care Unit of Yumbe Regional Referral Hospital.

#### **Focus Area on Advocacy and Awareness Creation**

Our advocacy work is aimed at increasing the awareness and understanding of PC issues among stakeholders and thus leading to a supportive environment for the providers and the services.

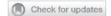
Our overall performance on the targets set for the period 2017 – 2021 was ranked 70.9% by the summative evaluation of the strategic plan.

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#### Special Article

#### Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021



Eric A. Finkelstein, PhD, Afsan Bhadelia, PhD, Cynthia Goh, MBBS, Drishti Baid, BA, Ratna Singh, MA, Sushma Bhatnagar, MD, and Stephen R. Connor, PhD

#### Find the article online:

https://www.sciencedirect.com/science/article/pii/S0885392421006734

Uganda was ranked 31<sup>st</sup> in the 2021 Cross Country Comparison of Expert Assessments of the quality of death and dying. The 2015 Quality of Death Index report ranked Uganda 35<sup>th</sup>.

Under this focus area, we excelled at profiling palliative care as a human rights issue, we advocated strongly access to essential palliative care medicines, the national palliative care policy, and supported accomplishing the national palliative care communication strategy.





Uganda Human Rights Commission (UHCR) in its 20<sup>th</sup> Annual Report had a chapter on the Right to Palliative Care in Uganda. Some of the recommendations made by the UHRC are still pending action to date. The report was presented to the Speaker of Parliament in 2018.

Recommendation by UHRC	Status/PCAU Comment 2021
The Ministry of Health should expedite the passing of the National Palliative Care Policy in order to streamline the provision and regulation of palliative care in Uganda.	Policy not yet passed
The Ministry of Health should institute clear Monitoring and Evaluation strategies to fast-track implementation of the World Health Assembly Resolution (WHA 67.19) 2014 on 'Strengthening palliative care as a component of comprehensive care throughout the life.'	Overall progress on this has been slow.
The Ministry of Health should consider reinstating the legal instrument allowing specially trained nurses to prescribe morphine.	Ministry is yet to establish regulations for Narcotic Drugs and Psychotropic Substances Act, 2016 with emphasis on Statutory Instrument: The National Drug Authority (Prescription and Supply of Certain Narcotic Analgesic Drugs) Regulations, 2004.
The Ministry of Finance, Planning, and Economic Development should consider increasing the budgetary allocations to the Health Ministry to cater to palliative care services.	Low response
The Ministry of Health should ensure that the proposed National Health Insurance Scheme covers palliative care.	The proposed bill did/does not cover palliative care
Civil society organizations should work with the government to implement the various UN Resolutions on the provision of palliative care.	PCAU has led the civil society actors well to work with the government. All Hospices and civil society palliative care organizations work closely and even receive referrals of patients from public health facilities. The government needs to offer more support to hospices shouldering the home care programs.
The Ministry of Health should scale up training of palliative care human resource	Palliative Care training is available at Diploma, Degree, and Master's levels in Uganda. The Ministry of Health is not currently offering scholarships for palliative care training among the categories they support.
The Ministry of Health should strengthen national district coordination mechanisms for the provision of palliative care services across the country especially at health centers II which are more accessible to the rural population.	District coordination for palliative care is still extremely low. The majority of District Health Offices do not have specific officers allocated to follow up on palliative care. Public Health Facilities still do not offer home care. Village Health Teams' pieces of training do not necessarily integrate palliative care. Civil society actors are looked up to in regions for this support.
The Ministry of Health, working together with the Health Service Commission and the Ministry of Public Service should streamline palliative care specialists into the Public Service structure with a clear professional career development path.	The response has been slow.



#### Advocacy Activities in 2021 included:

### High-Level Advocacy Meeting on Education and Human Resource for Palliative Care in Uganda.



Group photo of Participants after the High-Level meeting on Education and Human Resources for Palliative Care in Uganda at Sheraton Hotel in Kampala.

We conducted a strategic advocacy event on the recognition of palliative care professionals in Uganda.

The engagement was attended by leaders from the following institutions:

Ministry of Health, Ministry of Public Service, Ministry of Education and Sports, Business Technical Vocational Education and Training, National Council for Higher Education, Ministry of Internal Affairs, Uganda Human Rights Commission, Mulago School of Nursing and Midwifery, Hospice Africa Uganda, Institute of Hospice and Palliative Care in Africa, Africa Palliative Care Association, Yumbe Regional Referral Hospital, Kawempe Home Care; Civil Society and Community.



Voila Ederu the Palliative Care Nurse at Yumbe Regional Referral Hospital speaking at the highlevel advocacy event at Sheraton Kampala Hotel. Highlight on actions being followed up by PCAU:

- Ministry of Health and Ministry of Public Service to work hand in hand to regularize positions for palliative care human resources within the public service.
- To scale up accreditation of health facilities across the country.
- To scale up implementation of palliative care up to HC IV level across the country.
- **x** Strengthening home care programs in communities across the country.
- PCAU to follow up with the National Council for Higher Education on accreditation for Palliative training at higher institutions of learning.

## Supporting Access to Pain Relief Medicines Including Oral OLiquid Morphine in Uganda

PCAU works to strengthen the supply chain for controlled medicines for pain control in Uganda as a key advocacy activity. PCAU coordinates meetings of the morphine partners in Uganda. The partners who meet bi-monthly focus on the continuous availability and access to oral liquid morphine for patients in need.

In 2021, amidst the COVID-19 Pandemic, oral liquid morphine was available in the country with no major stock out reported in national hospitals, regional hospitals, or hospices. The Morphine Partners Meetings in Uganda are attended by designated officers from the following key institutions: • Ministry of Health (MoH). • National Medical Stores (NMS). • Joint Medical Stores (JMS). • Hospice Africa Uganda (HAU). • National Drug Authority (NDA) • Three National Referral Hospitals (Kawempe, Kiruddu, and Mulago represent the larger consumers of the medicine. • Uganda Cancer Institute (UCI) • Palliative Care Association of Uganda (PCAU).

## Accreditation of Health Facilities to Order for, Stock, and Order Ford Liquid Morphine.

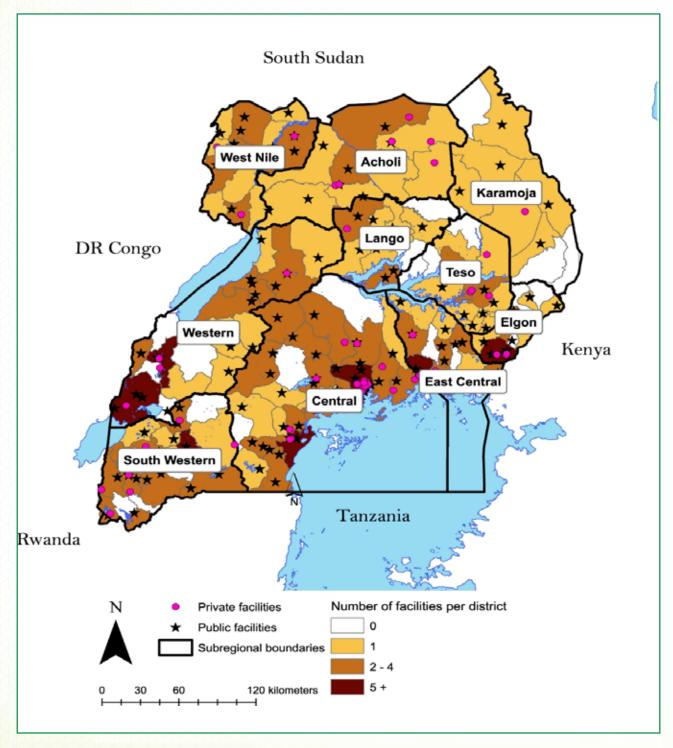
To accredit health facilities both private and public to offer Palliative care as well as to order, stock, and prescribe Oral Liquid Morphine. PCAU works in partnership with the Ministry of Health to accredit facilities to order for, stock, and prescribe oral liquid morphine.

- In 2021, PCAU conducted 12 health facility accreditation assessments with the Ministry of Health.
- Accredited 4 health facilities of which 2 were private and 2 were public.
- Supplied 26 health facilities with oral liquid morphine order books.



#### **Current Status of Accredited Facilities in Uganda**

By the end of 2021, at least 226 health facilities had been accredited across the country. On the basic criteria for accreditation: Presence of a prescriber (staff at the health facility), adequate storage facilities, management support and adequate medicines record keeping.



Map showing location of the accredited private and public health facilities in Uganda to order for, stock, and prescribe oral liquid morphine. Over 39 upcountry districts still do not have any facility accredited. (Source: 2021 study Palliative care in Uganda: a quantitative descriptive study of key palliative care indicators 2018-2020 <a href="https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-00930-7">https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-00930-7</a>)



#### **Highlight on Challenges to Adequate Access to Oral Liquid Morphine:**

More than 50% of the accredited facilities still do not stock oral liquid morphine due to several challenges that include: lack of a prescriber, lack of a palliative care unit, no oriented pharmacist, lack of adequate storage facilities for Class A medicines, missed filling of medicines orders (especially by public facilities), lack of adequate knowledge/myths and misconceptions low or no health facility management support among other reasons.

From: Palliative care in Uganda: quantitative descriptive study of key palliative care indicators 2018-2020

Subregion	Number of accredited facilities		
	Received morphine	Didn't receive morphine	Total
Acholi	4 (30.8%)	9 (69.2%)	13
Contral	27 (40.9%)	39 (59.1%)	66
East Central	6 (30.0%)	14 (70.0%)	20
Elgon	8 (42.1%)	11 (57.9%)	19
Karamoja	2 (33.3%)	4 (66.7%)	6
Lango	2 (22.2%)	7 (77.8%)	9
Southwestern	11 (33,3%)	22 (66.7%)	33
Teso	5 (31.3%)	11 (68.8%)	16
West Nile	4 (25.0%)	12 (75.0%)	16
Western	8 (28.6%)	20 (71.4%)	28
All Uganda	77 (34.1%)	149 (65.9%)	226 (100%)

#### **District Level Advocacy Meetings**

Our district advocacy meetings are intended to ensure the integration of palliative care in the health care system at the District Level. These meetings target the District Executive Committees, Office of the DHO and leaders of the main health facilities in the districts.

In 2021, we held physical contact meetings with 45 district leaders from 9 districts of the greater Bushenyi and Lango Region. We met the leaders in the districts of: Dokolo, Otuke, Kaberamido, Kalaki, Kaperebyong, Rubirizi, Mitooma, Buhweju and Bushenyi.



PCAU Staff, Ministry of Health Staff with District Leaders of Mitooma District After a District Sensitization Meeting on Palliative Care.



# **Supporting Cancer Patients with Essential Operative Supplies**

Even before Covid-19, cancer patients from indigent backgrounds faced challenges in accessing very essential supplies and some medicines that are not available free of charge in public health facilities. Covid-19 exacerbated this challenge. Families in poverty were pushed further into deprivation during the Covid-19 pandemic. The lack of these essential supplies often leads to undignified living. As we advocate that the government should improve investment in cancer services, we initiated a project to patients who are in dire need to access some supplies.

PCAU offered essential support supplies to at least 150 patients at the PC Units. Items included: 640 Colostomy bags, 50 Cotton wool rolls, 50 Gauze rolls and 10 pairs of Axillary crutches.

#### The Uganda Palliative Care National Policy

Uganda still lacks a National Palliative Care Policy.

PCAU continues to advocate for the establishment of the National Palliative Care Policy.

This process has taken over 10 years. In 2021, PCAU offered support for conducting the Regulatory Impact Assessment (RIA) for the National Palliative Care Policy. Several advocacy meetings were held with the Ministry of Health on the need for the Policy. On 18<sup>th</sup> April 2021, a Breakfast meeting was held to review the Uganda Palliative Care National Policy draft.

PCAU continues to advocate and appeal for fast tracking of the National Palliative Care Policy.

# Strategic Advocacy for inclusion of Palliative Care in Universal Health Coverage (UHC).

The Essential Palliative Care package for UHC in Uganda.

The Essential Palliative Care Package for Universal Health Coverage (UHC) is a basic guide for government and private entities as well as individuals on 'No leaving palliative Care behind' in the SDG movement. The package is contextualized for Uganda's health care system. This development for the package was highly consultative. The package was launched in May 2021 and has been disseminated to several mapped out SDG focused institutions. Access the package here: <a href="https://pcauganda.org/wp-content/uploads/2021/06/UHC-Package-for-Uganda.pdf">https://pcauganda.org/wp-content/uploads/2021/06/UHC-Package-for-Uganda.pdf</a>





Dr. Amone Jackson Commissioner Clinical services MoH, Mark Mwesiga PCAU country director, and members of the PCAU board launching the Essential Palliative Care Package for UHC in Uganda

#### Publications and articles contributed to or by PCAU in 2021:

Publication	Authors	Access
Progress Update: Palliative Care Development Between 2017 and 2020 in Five African Countries	E Luyirika, D. Lohman, Z. Ali, M. Atieno, A. Mahenge 4, P.Mmbando, Muinga, D.Musyoki,M. D.Mwesiga, E Namisango,P. Nosim, G.Opio, S.Pardy, A.Ruzima,E. Skowronska,B. Uhagaze,J Zalwango and Aggrey Aluso	https://pubmed.ncbi.nlm.nih.gov/34973351/
Current State of Palliative Care in Uganda	E.Namukwaya, A. D. Mwaka, E. Namisango, and M.D.Mwesiga,J. Downing	https://www.researchgate.net/publication/345942571
Cancer and palliative care in COVID-19 and other challenging situations—highlights from the Uganda Cancer Institute—Palliative Care Association of Uganda 3rd Uganda Conference on Cancer and Palliative Care, 23–24 September 2021, held in Kampala, Uganda and virtually	J.Downing, N.Niyonzima, E. Mwebesa, I.Mutyaba, H. Ddungu, L.C. Irumba, L. Zirimenya,D. Basirika, I. Mbarusha, C. Kobusingye, M.Happy,A. Jatho,D.O.Adong, C.Kabagambe,C. Mpamani, Z.Nalukwago,Z. Kyomuhangi, J.Zalwango,J. Orem, and M. Mwesiga	https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC8816507/

### **The Road To Hope Program**



The objective of our Road to Hope Program is to support children who are the primary caregivers for their sick parents or guardians to realize their full life potential. The program supports the educational, psychosocial, health, legal, and other needs of these children.

In 2021, this holistic support was given to 54 beneficieries in 34 families across 20 Districts in Uganda. The Districts are; Arua, Yumbe, Lira, Tororo, Butaleja, Jinja, Kamuli, Iganga, Busesa, Mayuge, Buikwe, Luwero, Masaka, Kakumiro, Kikuube, Hoima, Moyo, Luuka, Kagadi and Kyankwanzi.

Due to the Covid-19 pandemic and prolonged school closure, the program offered additional basic needs and food relief, homeschooling, and health support to the children and their families.

Activity/Item Description	Children supported in 2021
Children supported in 2021	54
Boys on the program	26
Girls on the program	27
Children supported in homeschooling	28
Children in Primary	24
Children in Secondary School	17
In Vocational schools	12
In University	1
Families receiving Palliative Care from hospices reached with food and other basic relief items	34
Most vulnerable families receiving palliative care and supported with social-economic interventions.	24





#### **Research and Information Dissemination**

PCAU aims at becoming a hub of research through the carrying out and/or hosting relevant palliative care research and leading the analysis of data as well as regularly disseminating Information to improve PC services.

During the strategic planning period 2017-2021, we performed beyond 60% on our targets set under this Key Focus Area. Our major achievement was the establishment of the new indicators for palliative care, service delivery and the development of the national palliative care data collection tools for Uganda. The process of integrating the palliative care data into the Health Management Information System (HMIS) and the District Health Information System is ongoing. This will address the huge need for national data and information on palliative care to inform decision-making at all levels.

The other achievements registered were:

- Recruited an officer responsible for this focus area.
- Hosted 6 Global Health Masters Scholars who conducted research on the PCAU Research Agenda aligned themes.
- Initiated and implemented the PCAU mHealth Project in 20 Hospitals and Hospices
- Established a research collaboration Memorandum of Understanding with Uganda Christian University.
- Maintained a strong collaboration with the University of Notre Dame USA through the partnership with the Center for Hospice Care and Global Partners in Care.
- Supported the dissemination of national palliative care data collection tools to 56 hospitals in 38 districts.
- Hosted 3 national conferences. The Uganda Conference on Cancer and Palliative Care in Partnership with Uganda Cancer Institute (UCI).
- Accomplished the summative evaluation of the PCAU Strategic Plan 2017-2021.



# The 3<sup>rd</sup> Uganda Conference on Cancer and Palliative Care

In a partnership with the Uganda Cancer Institute (UCI), we hosted the 3<sup>rd</sup> Uganda Conference on Cancer and Palliative Care in September 2021. Dr. Tedros Adhanom the Director-General of WHO, gave the keynote address, and Rt. Hon. Gen (Rtd) Moses Ali was the Chief Guest.





Conference panel discussion on Cancer and palliative care in COVID-19 and other challenging situations in Uganda: Experiences, observations, lessons and recommendations for future emergencies. Experts: Lt. Col. Dr. Kyobe Bbosa – National COVID-19 Incident Commander, Dr. Agasha Doreen Birungi –, Hospice Africa Uganda (HAU), Dr. Abrahams Omoding –Uganda Cancer Institute (UCI), Ms. Rose Kiwanuka – Palliative Care Nurse Specialist Dr. Victoria Walusansa –Uganda Cancer Institute (UCI). Panel moderated by Ms. Josephine Karungi

The theme of the conference was; Cancer and Palliative Care in COVID-19 and Other Challenging Situations. It was held virtually, with a mix of pre-recorded sessions, plenary sessions being broadcast live on by the Uganda Broadcasting Corporation TV, live speakers at the studio, and others presenting in real-time via Zoom.



Conference	Target	Achieved
Delegates	350	over 350
Abstract Submissions	50	46
Presentations Oral	60	47
Poster Presentations	30	21
Workshops	4	2
Side Events	2	0
Find the details in the published Covid-19 Report.		



Conference Closing Ceremony: Reflections on Universal Access to Cancer and Palliative Care Services in Uganda. Form Right: Ms. Fatia Kiyange – Executive Director - CEHURD, Prof. Charles Olweny – Board of Governors Chair, UCI, Dr. Henry Ddungu – Board Chair, PCAU, Dr. Jackson Orem – Executive Director, UCI, and Mark Donald Mwesiga – Country Director, PCAU.

#### Improving Palliative Care Data Collection in Uganda

In 2021 we continued to work with the Ministry of Health to develop and disseminate palliative care data collection tools.

The dissemination of data collection tools and training was conducted and a total of 38 health facilities in 27 districts of Uganda were reached. To date, a total of 43 health facilities in 38 districts have been reached.

Region	No. Districts	No. Health facilities in 2021	No. District and Health Facility staff trained.
Acholi-Lango	6	7	13
West Nile	5	9	14
Eastern	9	15	24
Western	7	10	17
South-Western	11	15	26
Totals	38	56	94



ANNUAL REPORT 2021

# Assessing the development of palliative care worldwide: a set of actionable indicators



#### IMPLEMENTING DATA COLLECTION: AN EXAMPLE FROM UGANDA

In Uganda, the ministry of health, in collaboration with partners, have adopted palliative care indicators and subsequently developed tools to support the collection of data on these indicators. The tools developed are two health management information systems:

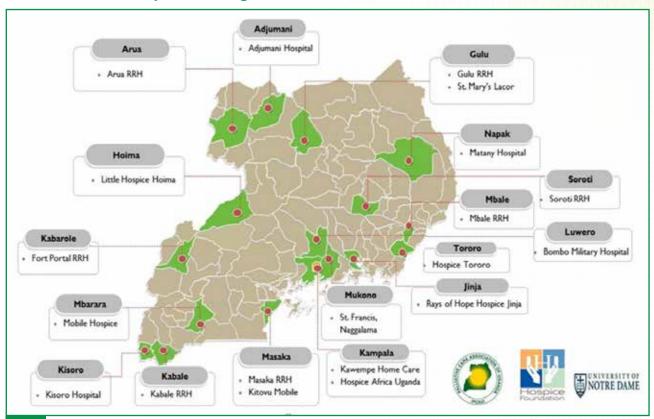
- 1) Outpatient Department 008 Unit palliative care register
- 2) 105C Health unit palliative care monthly report

The national association, the Palliative Care Association of Uganda (PCAU), has worked closely with the ministry of health information systems department to sensitize and train service providers on the indicators, the tools and the reporting. The service providers receive hard copy versions of the data capture tools from ministry of health to support data capture and reporting. The data are available via the national platform, and currently data are routinely generated and PCAU shares these with service providers to inform their planning and monitoring performance.

PCAU mHealth Project work cited in WHO important document



#### **PCAU mHealth Implementing Facilities**



#### Governance and Resource Mobilization - Focus Area

Under this focus area, PCAU aimed at strengthening documentation & implementation of sound policies in the areas of Human Resources, Leadership, Finance, and development of PCAU during the period 2017 – 2021.

During this period, we established:

- A realistic and well-articulated 5-year (2017- 2021) strategic plan.
- **Supported 3 member organizations to establish functional Boards.**
- Reviewed and implemented PCAU Policies the Human Resources, Financial.
- **¤** Established a new Board of Directors every after 3 years.
- **m** Held Board and committee meetings as per PCAU constitution.
- Increased individual, life, and organizational Membership of PCAU.
- Initiated and Held 5 PCAU Annual Members get-togethers and fundraising events.
- **m** Enrolled in Global Giving Online Fundraising Platform.
- Supported the establishment of New Life Hospice Arua to improve palliative care services in the West Nile Region.
- Conducted the End of Term PCAU Strategic Plan 2017-2021



#### Thank you for attending the PCAU Members Get together

We host the annual members' get-together in December. The event is used to reflect on the achievements of the year, give the PCAU Annual Merit awards, and fundraising.





During the 2021 get-together, we honored palliative care Nurses Martha Rabwoni and Catherine Nakasita who won the National Heroes in Health Awards and Dr. Barnabas Atwiine who received the best oral presentation award at the 3rd Uganda Conference on Cancer and Palliative Care.



#### More on working with others in 2021

4th Floor, 35-41 Lower Marsh, SE1 7RL: UK info@helpage.org www.helpage.org



August 2021

Dear Mark Donald Mwesiga

Thank you very much for your application to become a member of the HelpAge Global Network. The HelpAge Board of Trustees approved your application unanimously.

On behalf of HelpAge International and the board, I am therefore delighted to welcome 'Palliative Care Association of Uganda' into the network. All of us here at HelpAge International and the Global Network look forward to further developing our relationship with you.

PCAU joined the HelpAge global network in August 2021 and is working in partnership with other network members to advocate for and integrate matters of older persons in programing.



In 2021, PCAU signed up for 'Make 12.4% Work' which is an initiative driven by Persons With Disabilities and Organizations of Persons With Disabilities in Uganda to generate commitment and action from livelihood actors across government, private sector, and civil society in Uganda.





In 2021 we worked in partnership with the Bible Society of Uganda (BSU) and reached at least 20 families with palliative care needs to offer psychosocial and spiritual support. We worked with spiritual leaders among the teams at Hospice Africa Uganda in Kampala and in Mbarara as well as the Lweza Community Health program in Wakiso District to reach the families in need. The Bible Society Uganda offered donations of audio and handbook bibles as well as other Christian literature to the children and adults in need.



#### Thank your membership and payment of annual subscriptions to PCAU.

PCAU Membership Category	Dec. 2020	Dec. 2021
1. Individual Members	1063	1200
2. Life Members	4	20
3. Member Organizations	23	24
4. Active/paid-up Annual Subscription Individuals	80	232

#### List of PCAU Life Members as at December 31st, 2021

S/N	NAME	Tittle - Place of work
0001	Sr. Dr. Vincentina Achora	Obstetrician & gynecologist - Gulu University/ AruaRegional Referral Hospital (RRH)
0002	Elvis Athibuni	ICT Specialist
0003	Rose Kiwanuka	Palliative Care Nurse Specialist - Founding Country Director PCAU
0004	Prof. Julia Downing	CEO at International Children's Palliative Care Network
0005	Mark Donald Mwesiga	Country Director - PCAU
0006	Dr. Janet B White	Executive Director - JOY Hospice Mbale
0007	Dr. Henry Ddungu	Consultant Heamatologist/Oncologist-Uganda Cancer Institute
0008	Irene Atuhaire	Country Director - Seed Global Health
0009	Roberta Spencer	Volunteer Social Worker - Indiana USA
0010	CPA. Timothy Basiima (PhD)	Partner; Tax & Finance – Goldgate Certified Public Accountants
0011	Rita Nannyomo	Finance Officer - PCAU
0012	Joyce Zalwango	Capacity Building Officer - PCAU
0013	Anita Balikobaku	Programs Manager - PCAU
0014	Dr. Ekiria Kikule	Principal Institute of Hospice and Palliative Care in Africa (HPCA)
0015	Dr. Jackson Amone	Commissioner Clinical Service - Ministry of health.
0016	Hon. Jacklet Atuhaire	Commissioner - Human Rights Commission (UHRC)
0017	Sr. Leonora Torach	MSMMC-Director of Arua Diocese Counseling services
Partially F	Paid-up Life Members	
0018	Dr. Andrew Ocero	Deputy Chief of Party HSSPA -University Research Company
0019	Christine Ebong Akullo	Principal Advocacy Customer Care Officer – National Medical Stores (NMS).
0020	Dr. Nathan Kenya Mugisha	Executive Director - Walimu Uganda

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### Member Organizations as of 31st December 2021

S/N	Organization	Contact/Leaders	Names	Email	
1	Hospice Africa Uganda	Chief Executive Director	Dr. Agasha Doreen Birungi	infoug@hospice-africa.org	
	J	Board Chair	Joy Mirembe		
2	Mildmay Uganda	Executive Director	Dr. Barbra Mukasa	barbra.mukasa@mildmay.or	
	Hospital	Board Chair	Dr.Jeff Sebuyira Mukasa		
3	3 TASO Uganda	Executive Director	Dr. Etukoit Bernad	etukoitm@tasouganda.org	
		Board Chair	Juliana Nyombi		
4	4 Kitovu Mobile	Chief Executive Officer	Robert Yiga	ryiga@kitovumobile.com	
		Board Chair	Fr. Anselem Ssemwogerere		
5	Kawempe Home Care	Executive Director	Dr. Sam Guma	sguma@kawempehomecare.org	
		Board Chair	Dr. Victor Musiime		
6	Samaritan	Executive Director	Clement Esiat	clement.esiat@gmail.	
	Development Organization	Board Chair	Charles Francis Ikwarit		
7	St. Francis	Hospital Administrator	Sr. Jane Frances Nakafeero	srjfn@yahoo.com	
	Naggalama Hospital	Board Chair	Dr. Vincent Bwete		
8	Comprehensive	Executive Director	Naggi Davide	customercare@corsuhospital.org	
	Rehabilitation Services in Uganda (CoRSU) Hospital	Board Chair	Dr. Emmanuel Luyirika		
9	Mother Mary Cancer Palliative Care Centre	Executive Director	Issiah Muwanga	info@mothermarycarecentre.org	
10	Rays of Hope	Executive Director	Sylvia Nakami	hospicejinja@yahoo.co.uk	
	Hospice Jinja	Board Chair	Sabastian Balikomyeeyo	1.00	
11	Palliative Care Education and	Head of Clinic	Elizabeth Nabirye	nabiliza@gmail.com	
	Research Consortium	Board Chair	Mhoira Leng		
12	Joy Hospice Mbale	Medical Superintendent	Dr. J B White	drjanetbwhite@joyhospicembale.org	
		Board Chair	Enoch Osana		
13	Mengo Hospital	Medical Director	Dr. Rose Mutumba	rose.mutumba@mengohospital.org	
	St. Francis Nsambya Hospital	Chief Executive Officer	Dr. Andrew Ssekitooleko	andrew@img.co.ug	
14	1 lospitat	Board Chair	Prof. Freddie Ssengooba		
	Ibanda Central Clinic	Executive Director	Dr. J Bosco Byaruhanga	vivajohnbos@yahoo.com	
15		Board Chair	Matlida Agabemigisha		
16	Kabale Christian Care		Lianna Tanis	liannatanis@gmail.com	
		Board Chair	Ron Vande Vegte		
17	Mama Maria Health Centre	Executive Director	Biira Yayeri	yayeri.biira@yahoo.com	
		Board Chair	Masereka B Zakayo		
18	Kadama Widows Association	Executive Officer	Mary Lucy Otheno	amlucy@yahoo.com	
		Board Chair	Mary Kurong	dements of the "	
19	Ngora Hospice Program-FADO-T	Team Leader Board Chair	Samuel Amollo Okalebo Beatrice Agoro	sameulamollo@googlemail.com Agorojanet2019@gmail.com	
20	Health Care Alliance	Executive Director	Otim Jimmy	healthcarealliancelira@gmail.com	
21	Hospice Tororo	Executive Director	Stella Agembi	stella.agembi@gmail.com	
		Board Chair	John Fabian Olweny		
22	Peace Hospice Adjumani	Executive Director	Vicky Opia	vicky5opia@gmail.com	
20	· ·	Board Chair	Dr. George Bhoka	gdbhoka@gmail.com	
23	Kamuli Mission Hospital	Hospital Director	Dr. Faustin Maiso		
24	Reach Out Mbuya	Executive Director	Josephine Kaleebi	jkaleebi@reachoutmbuya.org.	
		Board Chair	Rev. Fr. Anthony Kimbowa		

### A Highlight on the Challenges that Affected Our Work in 2021 and our Recommendations

The PCAU Essential Palliative Care Package for Universal Health Coverage details our recommendations on palliative care service strategy and delivery in Uganda. This document is accessible on PCAU Website <a href="https://pcauganda.org/wp-content/uploads/2021/06/UHC-Package-for-Uganda.pdf">https://pcauganda.org/wp-content/uploads/2021/06/UHC-Package-for-Uganda.pdf</a>

Low access to Palliative care: We recommend that government puts in place a robust policy, legislative and national strategy for palliative care services.

Limited national and international donor direct funding to palliative care: This is for both public and the private health sector and has been aggravated by the Covid-19 Pandemic.

Limited access to essential palliative care medicines, supplies, and equipment: We recommend a review of the review essential medicines and health supplies List for Uganda (EMHSLU) to include more recommended essential medicines for palliative care.

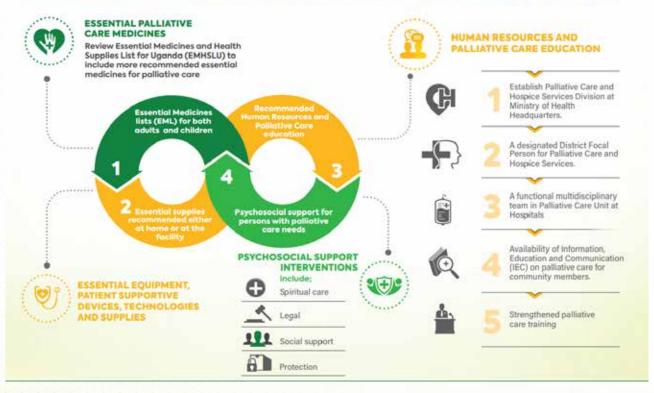
#### Low numbers of Human Resources for Palliative

**Care:** We recommend that government expedites positions for all cadre of training health professionals in the health service structures.

Limited knowledge and awareness about palliative care among various key actors.

This impacts the thriving of a conducive environment for palliative care. In our new strategic plan, we will diversify our focus on advocacy and awareness creation to bring as many actors on board.

#### The Recommended Essential Palliative Care Package for UHC



At organizational Level, PCAU is growing. **Office space at our owned home is small**. We are fundraising to purchase larger property. All who become Life Member of PCAU up to partner on this cause. We operate **old organizational vehicles**. We are fundraising for new vehicles. We need new strong and efficient vehicles to reach the over 40 districts without any health facility **offering palliative care** to advocate and support them to commence services.



Our **total income for the year 2021** was Uganda Shillings 1,214,415,732/USD 342,156.40. The amount was offered generously by PCAU donors including the Open Society Foundation (OSF), Open Society Initiative for East Africa (OSIEA), Center for Hospice Care (CHC), American Cancer Society (ACS), Global Partners in Care (GPIC) and African Palliative Care Association (APCA). Through PCAU Members subscriptions, donations by Ugandans, sale of PCAU branded items, and interest we raised 14% of the total income internally. We would like to thank all PCAU donors for their continued generosity.

We spent most financial resources on advocacy and awareness creation. Our advocacy entailed work on the continuity of palliative care as an essential service during the Covid-19 Pandemic.

#### STATEMENT OF FINANCIAL POSITION AS AT 3ST DEC 2021

	2021	2020
Funds Balance	Shs	Shs
NON CURRENT ASSETS		
Property and Equipment	334,039,754	367,218,486
CURRENT ASSETS		
Receivables & Prepayments	21,910,292	3,741,947
Cash and Bank	255,812,150	159,023,669
Other Current assets	911,737,560	820,131,522
Total Current Assets	1,189,460,002	982,897,138
Total Assets	1,523,499,756	1,350,115,624
Accumulated fund	1,013,628,296	1,004,595,484
Capital fund	(59,913,010)	(26,734,282)
Revaluation	25,000,000	25,000,000
	978,715,286	1,002,861,202
CURRENT LIABILITIES		
Payables and Accruals	34,890,522	23,068,138
Deferred Income	509,893,952	324,186,285
	544,784,474	347,254,423
Total Liabilities & Equity	1,523,499,760	1,350,115,625

#### PCAU STATEMENT OF INCOME AND EXPENDITURE AS AT 3ST DEC 2021

	2021	2020
INCOME	Shs	Shs
Restricted Income	1,054,225,908	
Unrestricted Income	60,304,512	941,354,665
Officestricted income	00,304,512	28,958,312
Other Income	99,885,312	91,285,687
Total Income	1,214,415,732	1,061,598,664
EXPENDITURE		
Restricted Program Expenses	992,452,241	0
Other Program Expenses	02 5 40 225	854,720,318
Other Program Expenses	92,549,225	63,146,750
Administrative Expenses	120,331,449	101,492,224
Total Expenditure	1,205,332,915	1,019,359,292
Surplus/deficit	9,082,817	42,239,372



Thank you to all PCAU friends who have supported the work of enabling children from indigent families to enroll and continue with their cancer treatment at the Uganda Cancer Institute (UCI). Working through Palliative Care Units, PCAU is supporting these children and their families. We have seen lives change. Follow this link for detailed reports and to offer your contribution https://www.globalgiving.org/ projects/pcauganda-org-road-tohope/.

#### Apply Now 🛭



Are you a health professional interested in advancing your training in Palliative Care?

Apply for PCAU Scholarship for Diploma in Clinical Palliative Care, Advanced Diploma in Palliative Care Nursing, BSc Palliative Care, and MSc Palliative Care for 2023 Scholarships.



#### Partner with us



During this time, we are seeking partners to support us to take palliative care and pain relief services to the most underserved communities in Uganda. There are 39 districts without any health facility offering palliative care.

We need to reach these districts in the next two years and to initiate district palliative care teams at their main health facilities.

These districts include the most (hard)

to reach areas in our land including islands. They also include island areas. In order to reach these areas, we need a strong and efficient vehicle. We are therefore fundraising for a new staff van. Every amount of money contributed counts.

All donations to PCAU can be made through the organizations bank account:

Account Number: 8708213487400

Account Name: Palliative Care Association of Uganda

Bank: STANDARD CHARTERED BANK UGANDA LIMITED Swift Address/Code: SCBLUGKA

Funds can also be received through MTN Mobile Money Platform on Telephone: +256 789 737 786 Or through MTN MOMO Pay





#### Send

a Generous contribution to PCAU Using

#### **Momo Pay**

Simply dial

\*165\*3#

**Enter Marchant Code** 

315849





#### Thank you for the continued support

Palliative Care for all in need in Uganda

- f Palliativecare association of Uganda
- pcauganda
- www.pcauganda.org

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pcau.admin@pcau.org.ug

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