

ANNUAL REPORT 2022



Highlights of our achievements for the year.



- PCAU Toll Free: **0800 399 100**
- Email: **pcau.admin@pcau.org.ug**

■ ***Touching lives, healing families,
transforming community***



PCAU Staff with some members of the Board.

Members of the Board of Directors 2022

- | | |
|-----------------------------|------------------|
| ○ Dr. Henry Ddungu | Chairperson |
| ○ John Muwonge | Vice Chairperson |
| ○ Josephine Kampi Tatyabala | Treasurer |
| ○ Grace Nayiga | Secretary |
| ○ Gerever Niwagaba | Member |
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| ○ Dr. Miriam Ajambo | Member |
| ○ Gloria Kirungi Kasozi PhD | Member |
| ○ CPA Timothy Basiima, PhD | Member |



Some of the PCAU Staff with Dr. Anne Merriman the founder Hospice Africa Uganda (HAU).

Members of Staff 2022

- | | |
|------------------------------|----------------------------------|
| ○ Mark Donald Bikosa Mwesiga | Executive Director |
| ○ Anita Balikobaku | Programs Manager |
| ○ Ritah Nannyomo | Finance Officer |
| ○ Joyce Zalwango | Capacity Building Officer |
| ○ Lisa Christine Irumba | Advocacy & Research Officer |
| ○ Cynthia Kabagambe | ICT & Data Quality Officer |
| ○ Fiona Siima Karakire | Membership & Partnership officer |
| ○ Zipporah Kyomuhangi | Administrative Assistant |
| ○ Doreen Nalwadda | Accounts Assistant |
| ○ Margret Kabajungu | General Assistant |
| ○ Jaffar Mohamed | Driver |
| ○ Tom Echodu | Security Officer |
| ○ Ismail Kyagulanyi | Security officer |

Volunteer Staff PCAU West Nile Branch / NELIHA

- | | |
|---------------------|-----------------------|
| ○ Agaboru Sebi Lucy | Clinical Team Leaders |
| ○ Ndemaru Patricia | Administrator |

Message from the **Board Chairperson and the Executive Director**

Dear

PCAU members, partners, and friends,

Thank you for your continued support of the work of palliative care in Uganda.

This year marks 30 years since Dr. Anne Merriman introduced specialist palliative care in Uganda. The country has registered several milestones of palliative care recognition and growth across health policies, education, training, access to medicines, and research. We need to recognize and appreciate everyone that has contributed to the milestones since 1993.

The need for palliative care will continue to grow because of the aging population and the rising burden of diseases. Integrating palliative care at all levels of the health care

system is important. The government of Uganda has taken a commendable step by creating some positions for palliative care providers in the civil service up to Health Centre III. More health workers need to attain qualifications to take on the positions.

In 2022, PCAU launched a new strategic plan. The association will focus on accelerating the provision and integration of palliative care in Uganda's healthcare system through capacity building, advocacy, research, governance, and resource mobilization.

PCAU has invested in strengthening palliative data collection to improve the evidence base for decision-making. The Ministry of Health has already integrated palliative care indicators into the Health Management Information System. We appeal

to leaders of public and private health facilities to report on palliative care.

The work of palliative care is facing reduced donor financial resources, and this affected the quality of care. Several standalone hospices have scaled down home care programs. We must find ways of improving the quality of the service.

We appreciate the **American Cancer Society (ACS)**, the **Center for Hospice Care (CHC)**, and the **Open Society Foundations** for their financial support to PCAU over the years.

As we gather for PCAU's 24th AGM, let us be energized to focus on our vision of *'Palliative Care for All in Uganda'*.

“ *We are grateful to all PCAU Members, partners, the Board, staff, and volunteers for their commitment to the association.”*



Dr. Henry F. Dunga
PCAU Board Chairperson



Mark F. Donald Mavesiga
PCAU Executive Director

Thank you!

Thank you for your generosity and support through the PCAU donation boxes and purchase of PCAU branded items.



PCAU donation boxes

are placed at **Quality Supermarkets**

in Kitende, Lubowa and Ntinda and at the **Departure lounge at Entebbe International Airport.**

Thank you!



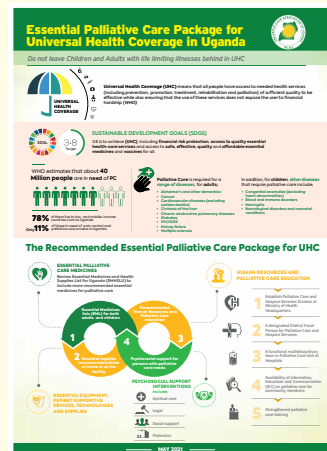
We are grateful to all **PCAU partners and donors** for the financial and other resources support in 2022.



GlobalGiving



PCAU Information, Education and Communication Materials (IEC) 2022



PCAU Programs Achievements 2022

Capacity Building Focus Area

The aim of PCAU capacity-building initiatives is **to strengthen the capacity of palliative care providers in Uganda through supporting training, continuous professional education, mentorship, and supervision.**

Of the 146 districts and cities in Uganda, PCAU's capacity-building initiatives have reached 107 which is slightly over 73% coverage. These districts have at least one health facility offering palliative care. In 2022, PCAU continued support to the work of pioneering the **Advanced Diploma in Palliative Care Nursing (ADPCN)** at Mulago School of Nursing and Midwifery. The program is fully established and has attracted applicants from districts across all the regions of Uganda. A total of 21 with full scholarships graduated with the ADPCN in January 2022. Of the 21 ADPCN graduates in 2022, 19 have already succeeded in establishing Palliative Care Units at their workplaces.

To increase the number of palliative care providers, PCAU offered a total of 28 scholarships for palliative care education for Diploma, Bachelor's Degree, and MSc in Palliative Care in 2022.

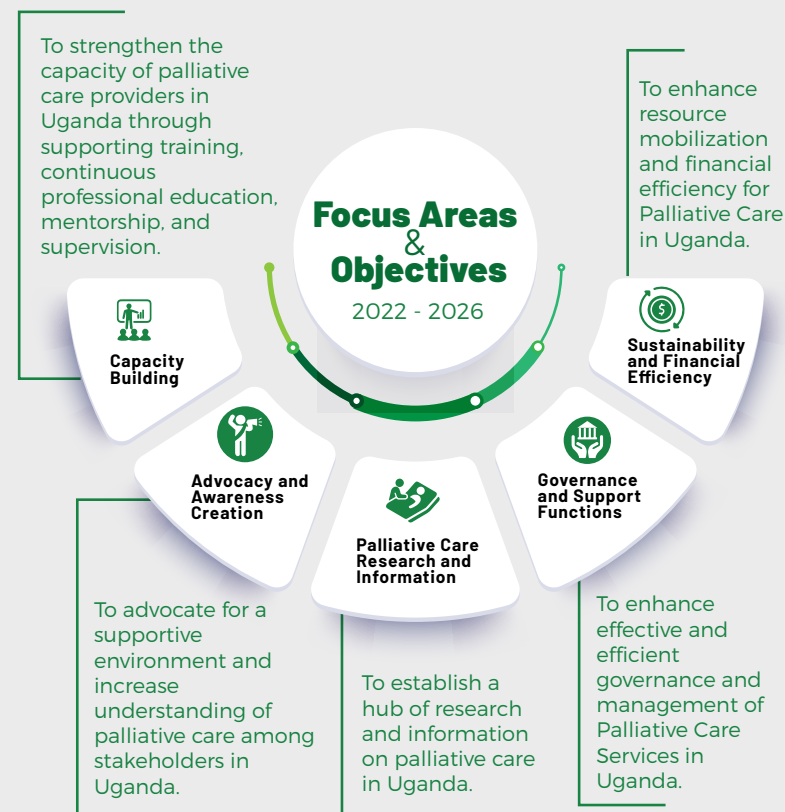
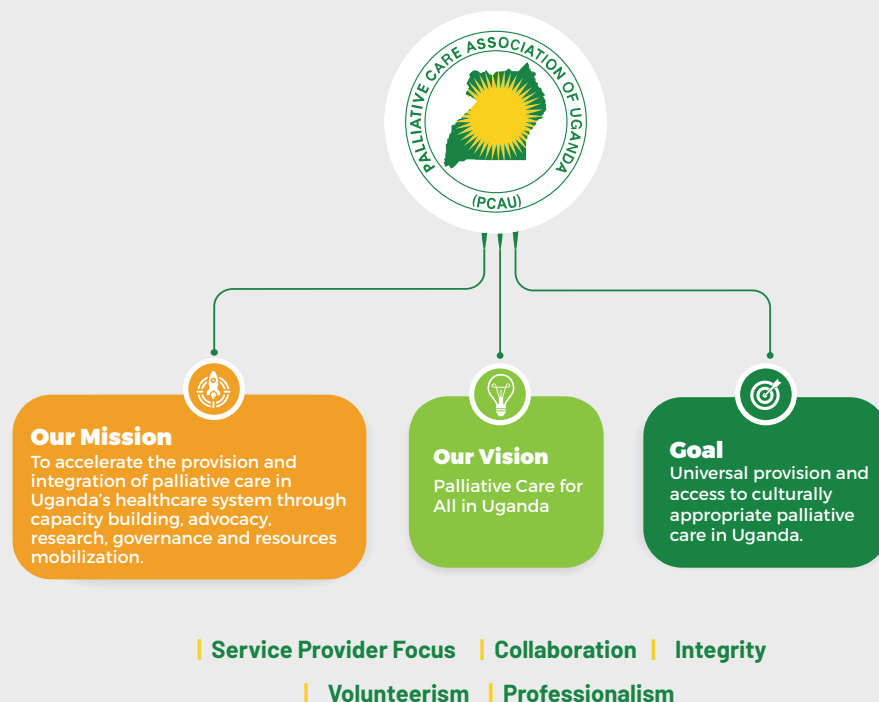


PCAU Scholarships for Palliative Care Training 2022

2022 ADPCN Graduates with scholarships from enrolled in 2020 and 2021	21
2002 full scholarships offered for ADPCN	13
Bsc Palliative Care	07
MSc Palliative Care	07
Health Tutor	01

PCAU has established a new Strategic 2022- 2026

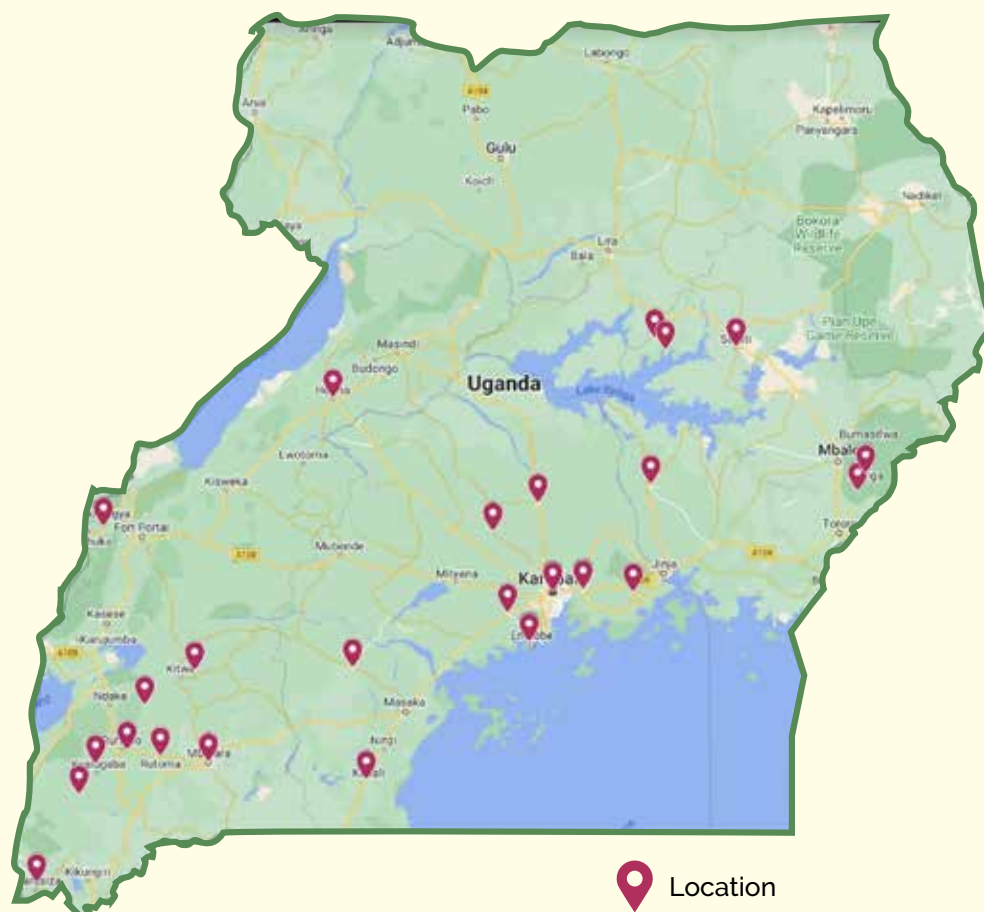
PCAU Strategic Direction



In 2022, **PCAU launched a 5-year Strategic Plan**. Through a rigorous consultative process, we revised our vision to: 'Palliative Care for All in Uganda'. PCAU's mission to 2026 seeks to accelerate the provision and integration of palliative care in Uganda's healthcare system through 5 focus areas of capacity building, advocacy, research, governance, and resource mobilization.

Location by name of health facility and District where 2022 graduates of the Advanced Diploma in Palliative Care Nursing (ADPCN) with full scholarships from PCAU work.

■ Map showing Districts of ADPCN graduates of 2022



GRADUATES	
Facility	District
Bwanza HC IV	kisoro
Bugobero HC IV	Manafa
Nsambya Police HC II	Mukono
Nagojje HC III	Mukono
Kasangati H/C IV	Wakiso
Nakasero Hospital	Mukono
Mpigi HC IV	Mpigi
Mulago NRH	Kampala
Bundibugyo Hospital	Bundibugyo
Life Link Hospital	Wakiso
Bowa HC II	Luwero
Mengo Hospital	Kamuli
Rakai Hospital	Rkai
Bushenyi HC IV	Bushenyi
Hoima R.R.H	Lira
Soroti R.R.H	Soroti
GradeA H/C IV	Wakiso
Ashock H/C III	Kampala
Kisiizi Hospital	Rukungiri
Rite Medic	Kampala
Kapeeka H/CIII	Kapeeka
Medical Centre	Wakiso
Najjembe H/C III	Buikwe
Mukono H/C IV	Mukono
Ngeribalya H/C II	Gomba
St. Francis Hospital Nsambya	Kampala
Lee Memorial Hospital	Wakiso

2022 PCAU **scholarships for Diploma, Degree, and Masters** in Palliative Care Disciplines.

2022 ADCPN Scholarships	
Place of work	Districts
Bitereko H/C III	Mitooma
Ibanda Central Clinic	Ibanda
Luwala Hospital	Kalaki
Lira RRH	Lira
Holy Innocents Children's hosp	Mbarara
Nsiika H/C IV	Buhweju
Kigarama H/C III	Sheema
Bududa Hospital	Bududa
Kisoro Medical Clinic	Kisoro
Otuboi H/C III	Kalaki
St. Francis Hospital Nsambya	Kampala
Soroti RRH	Soroti
Kiruddu NRH	Kampala

2022 Bsc in Palliative Care scholarships	
Place of work	District
Diagnostic Centre Mbuya	Wakiso
Devine Medical Center Namayumba	Kiboga
Kaberaimaido General Hospital	Kaberaimaido
Lira University Hospital	Lira
Mparangasi HC3	Hoima
Hospice Africa Uganda – Kampala site	Kampala
Kawempe Home Care	Kampala

2022 MSC Palliative Care scholarships	
Place of work	District
KISORO HOSPITAL	Kisoro
Hospice Africa Uganda	Kampala
Soroti Sch. of Comprehensive Nursing	Soroti
Little Hospice Hoima	Hoima
Life Embassy Medical Centre	Kampala
St Francis Hospital Nsambya Training Sch.	Kampala
Institute of Hospice and PC in Africa	Kampala



PCAU capacity building interventions

PCAU capacity building interventions continue to yield impact by strengthening the provision and access to palliative care across the districts of Uganda.

Continuous Professional Education (CPE) and Pain-Free Hospital Initiative

PCAU supported 13 palliative care diploma students to undertake clinical placements and held a total of 10 national and branch Continuous Medical Education (CME) sessions which were attended by a total of 180 health care providers.

To improve access to palliative care services in refugee settlement areas in West Nile Region, PCAU conducted an introductory palliative care course for health workers.

To improve the capacity of health workers to assess and manage pain, PCAU implemented the **Pain-Free Hospital Initiative (PFHI)** in 4 Regional Referral Hospitals and trained of 689 health workers on assessing and managing pain.

	Hospital/Health facility	Total Trained
Pain-Free Hospital Initiative	St. Francis Hospital Nsambya	204
	China-Uganda Friendship Hospital Uganda	176
	Soroti Regional Referral Hospital	90
	Mengo Hospital	219
	Total	689
Update Meetings at National and Branches Level	2 Update Meetings at National Level	121
	Branch update meetings	
5 days short health professionals training on Palliative Care	Yumbe Regional Referral Hospital for Health Partners in Refugee Settlements	38

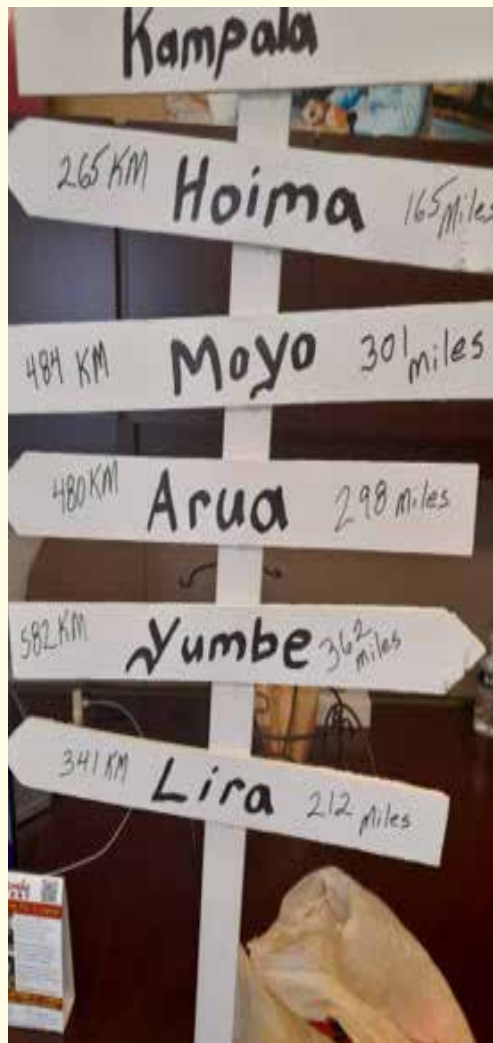


Support Supervision for palliative

PCAU advocates for, supports, and conducts support supervision to improve the quality of palliative care services across the country. In 2022, PCAU worked with the Division of Palliative Care at the Ministry of Health to conduct a total of **28 support supervision visits which led to improved palliative service delivery in 18 districts** of Uganda. The visits also offered an opportunity to address challenges impacting access to oral liquid morphine at health facilities.

The support supervision activity focused on improving the knowledge and skills of health staff with focus on the following:

- Ensuring uninterrupted availability of essential palliative care medicines at the health facilities.
- Continuum of care for patients and families in need.
- Use of the national palliative care data collection tools.
- Advocacy, networking, and communications for strengthening palliative care in regions.



Advocacy and Awareness Creation

PCAU's advocacy and awareness interventions are intended to create a supportive environment and increase understanding of palliative care among stakeholders in Uganda.

Advocating for availability and access to PC medicines, including oral liquid morphine

PCAU plays a key role in strengthening the supply chain of essential medicines for palliative care and pain relief including oral Liquid Morphine. PCAU coordinates meetings of the morphine partners in Uganda. The partners who meet bimonthly focus on the continuous availability and access to oral liquid morphine for patients in need. The Morphine Partners Meetings in Uganda include the Ministry of Health, the manufacturer (Hospice Africa Uganda) Distributors (National Medical Stores and Joint Medical Stores), National Drug Authority, high-consumption health facilities (Uganda Cancer Institute, Mulago National Referral Hospital, Kiruddu Referral Hospital, and Kawempe Specialised National Referral Hospital) as well as other partners like American Cancer Society.

Patients in need in Uganda receive oral liquid morphine free of charge.

Other Key roles by PCAU include strengthening the supply chain and supporting the accreditation of health facilities to stock oral liquid morphine. In 2022, PCAU supported the accreditation of 3 health facilities and conducted accreditation assessments at 44 health facilities in 20 districts in Uganda. PCAU established a toll-free line to ease correspondence and follow up with the public and community members access to pain medicines. In 2022, 36 patients were supported with referrals to access medicines through the toll-free line. At least 75 patients, health workers, and the community were offered palliative care information through the toll-free line.

The National Medical Stores (NMS) has integrated oral liquid morphine in their online medicines ordering portal which has drastically reduced the challenges of missed orders by public health facilities.



Nurse at Kitovu Mobile interacting with patient dring Home Visist



Medicines follow up, Dr. Muwanga



Oral Liquid Morphine

Advocating for and supporting patients and families to access essential equipment, patient supportive, devices, technologies, and supplies.

Advocacy for Delivery of essential medical supplies

PCAU advocates for universal access to essential equipment, patient-supportive devices, technologies, and supplies in Uganda. Many patients require medical sundries and devices which are not readily available at public hospitals and yet expensive to acquire. This compromises their quality of life as well as care at home. In partnership with palliative care units at 6 hospitals in Uganda, PCAU offered direct medical sundries support to 240 cancer patients. Access to these devices improved the quality of life for the patients and their families.

ITEMS	QUANTITY
Colostomy bags	2000
Gauze rolls 1kg	200
Cotton wool rolls 500mg	200
Clutches Axillary - Pairs	20
Clutches Elbow	13
Gloves	200
Aprons and mackintosh	50
Diapers	30



Masaka home visting

Strategic Advocacy for engagements at National and District Levels to enhance palliative care services.

In 2022, we conducted 10 strategic advocacy engagements at the level of the Parliament of Uganda, Government Ministries, Agencies, and Departments. The government heeded to PCAU's appeal and established a **Division of Palliative Care at the Ministry of Health**. We continued to coordinate meetings of the National Palliative Care Country Team that shaped the strategy and direction of palliative care work in the country.

PCAU strategic advocacy engagements centered on matters raised in the documented essential palliative care package for Universal Health Coverage (UHC) in Uganda.

The recommendations to the government by PCAU are:

- Establish a national palliative care policy, framework (strategies, standards, guidelines) for Uganda.
- Review the Essential Medicines and Health Supplies List for Uganda (EMHSLU) to include more recommended essential medicines for palliative care.
- Support education, training and recognize Human Resources for palliative care.
- Strengthen the provision of and access to essential equipment, patient-supportive devices, technologies, and supplies.
- Integrate and strengthen psychosocial support and social care for persons facing cancer including cancer care navigation.
- Support and improve data collection and information management for palliative care.
- Strengthen structural coordination structures for palliative care from the national, district, and community levels.
- Improve budgetary allocation for palliative care service delivery.



Officials from PCAU and Ministry of Health in a group photo with Members on the Committee of Health Parliament of Uganda after an agament in July 2022



PCAU petitioning the Speaker of and Members of Parliament on Palliative Care in Uganda.



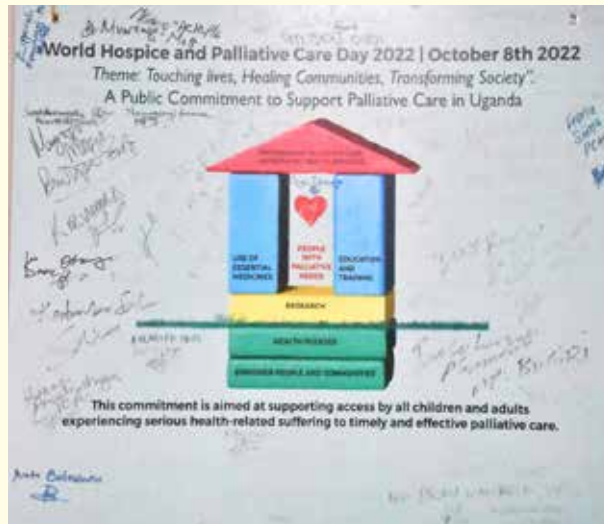
PCAU Staff with Dr. Diana Atwiine and Dr. Moses Muwanga the Permanent Secretary and the Ass. Commissioner Palliative Care at Ministry of Health.



Community Education, Empowerment, and Media Engagements

In October 2022, PCAU mobilized the country to commemorate the **World Hospice and Palliative Care Day (WHPCD)** in Uganda. We brought together over 60 organizations and over 500 people including national leaders mainly Members of Parliament who participated, received information, and pledged to support palliative care in their various communities.

The activities included, charity walk, voices for hospice choirs, exhibitions by palliative care organizations, health camps, corporate soccer between palliative care providers and members of parliament, radio and TV talk shows, twitter spaces and public lecture.



Leader who participated in the events to mark Word Hospice and Palliative Care Day 2022 committed to support access to palliative care in their areas.



H.E Kevin Colgan, Ireland's Ambassador to Uganda, Dr. Moses Muwanga, Mark Mwesiga, Hon Rachael Magola and Dr. Fred Sebisubi at the Voices for Hospice Concert 2022 at Hospice Africa Uganda.



Dr. Charles Olaro the Director Health Services at Ministry of Health Speaking amidst Members of Palliatment and other Ministry of Health Officials at the World Hospice and Palliative Care Day event 2022

Access to palliative care for **persons living with disability.**

In partnership with Light for the World Uganda, PCAU initiated a disability inclusion agenda in 2022 to champion full and effective participation and inclusion at palliative care organizations' workplaces and in their programming. The initiative entails promoting respect for difference and acceptance of persons with disabilities as part of human diversity and humanity and therefore ensuring equality of opportunities for them.

PCAU conducted a survey that established factors affecting access to palliative for persons living with disabilities and revealed several barriers. All the staff of PCAU were trained on disability inclusion in addition to 11 staff representatives from 7 PCAU member organizations. PCAU and member organizations will take deliberate steps on disability inclusion by ensuring equal opportunity in employment and programming.



The Palliative Care Association of Uganda (PCAU) was established in 1999 and registered as a Non-Governmental Organization (NGO) in 2003. PCAU was established to advocate and to coordinate civil society efforts in supporting the government and to integrate palliative care into the national health care system at all levels. Membership to the association is open to all individuals and institutions interested in palliative care palliative care.

**BECOME
A PCAU
MEMBER**

REGISTER TODAY!

Membership Fees		
Membership Type	Fee	Frequency
Individual membership	20,000/=	Annual subscription
District Palliative Care initiative & CBO membership	500,000/=	Annual subscription
Individual Life time membership	1,000,000/=	One time subscription
Institutional/Organizational membership	1,000,000/=	Annual subscription

Subscribe to become a member or give a generous contribution to PCAU through MTN MoMo Pay on +256 0789737786.

Advocacy for the protection and Support to **child caregivers across the country**

The Road to Hope Program supports child caregivers from financially poor backgrounds to access basic needs for their families and continue with education while caring for their chronically ill parents.

In 2022, PCAU supported 55 child caregivers. The program touches the lives of patients, heals families, and transforms society.

Schools Partnering with the Program	
Primary Schools	13
Secondary Schools	10
Vocational & Technical Education	4
Universities	2
Road to Hope Beneficiaries' levels of Education	
Boys	27
Girls	27
Total Child Caregivers supported in 2022	54
Total Families	35
Districts	20
Shelter/house support to families	3



Palliative Care Research and Information

The interventions of PCAU under this focus area are intended to establish a hub of research and information on palliative care in Uganda.

In 2022, PCAU launched its Research Agenda which stipulated the organization's research direction and interventions. Staff at PCAU Secretariat contributed to a total of 4 publications and articles and initiated **4** research studies on palliative care in collaboration with partners. PCAU hosted 1 international scholar.

One of the core businesses of PCAU is **to strengthen the management of palliative care data in Uganda**. Since 2015, PCAU has offered technical and financial support to a very successful rigorous process of establishing national palliative care tools in Uganda.

PCAU has supported the Ministry of Health to accomplish the development of the national palliative care collection tools for the HMIS OPD 008 register and the and DHIS2 – HMIS 105c (Health Unit Monthly Palliative Care Report). In 2022, the national palliative care data collection was fully integrated into the Health Management Information System. The Ministry of Health has included palliative care on the dashboard on the information management system.

- **500 Number of HMIS OPD Registers Printed.**
- **200 HMIS 105c Monthly palliative care monthly reports** were printed.
- **5 regional teams** of palliative care data champions mobilized.
- **180** health workers, biostatisticians, and records officers **trained on the use of tools.**
- **47 health public and private health facilities** were reached with tools.

By December 2022, 47 Health Facilities have received data collection tools following training of staff in the following regions:

Region	Number of Health Facilities	Registers & Monthly forms delivered
Elgon	10	73
Southwestern Uganda	6	90
Busoga	7	45
Greater Masaka	16	159
West Nile	8	60
TOTAL	47	427



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.



The Research Agenda

In 2022, PCAU published the Research Agenda. This was developed and accomplished through a consultative process that covered a wide range of stakeholders. The PCAU Research Agenda provides focus and direction for palliative care research and strategic information by PCAU. PCAU has set aside few research grants in line with the research agenda for 2023. Visit <https://pcauganda.org/pcau-research-grants-2023/> for more information.



Publications and articles contributed to or by PCAU in 2022

Publication	Author	Access
Palliative care in Uganda: quantitative descriptive study of key palliative care indicators 2018-2020	Ainur Kagarmanova, Mark Donald Mwesiga, Matthew L. Sisk, Cynthia Kabagambe, Sheba Nyakaisiki, Tom Marentette & Lacey N. Ahern	https://bmcpalliatcare.biomed-central.com/articles/10.1186/s12904-022-00930-7
Current status of African pediatric oncology education efforts aligned with the Global Initiative for Childhood Cancer	Jaques van Heerden, Irumba Lisa Christine, Julia Downing, Alan Davidson, Laila Hessissen, Judy Schoeman, Elena J Ladas, Hafeez Abdelhafeez, Shauna Georgia Odongo Arao, Atalay Mulu Fentie, Sherif Kamal, Jeannette Parkes, Thurandrie Naiker, Adri Ludick, Joyce Balagadde-Kambugu, Jennifer Geel	https://pubmed.ncbi.nlm.nih.gov/36083006/
Conference report on the 14th International Society of Paediatric Oncology African Continental Meeting, 16-18 March 2022, Kampala, Uganda	Jaques van Heerden, Lisa Christine Irumba, Karim Assani, Julia Downing, Alan Davidson, Laila Hessissen, Judy Schoeman, Trijn Israels, Sharon Cox, Hafeez Abdelhafeez, Shauna Odongo Arao, Jeannette Parkes, Joyce Balagadde-Kambugu and Jennifer Geel	https://ecancer.org/en/journal/article/1423-conference-report-on-the-14th-international-society-of-paediatric-oncology-african-continental-meeting-16-18-march-2022-kampala-uganda
The Declaration on Palliative Care in a Pandemic: report of the African Ministers of Health Meeting and the 7th International African Palliative Care Conference, held from the 24th to 26th August 2022 in Kampala, Uganda and virtually.	Julia Downing, Eve Namisango, Stephen Connor, Patricia Batanda, Lisa Christine Irumba, Berna Basemera, Alfred Jatho, Sylvia Nakami, Harriet Nalubega, Antonia Kamate, Dianah Basirika, Joyce Zalwango, Mable Namuddu, Wedzerai Chiyoka, Francis Kayondo, David Byaruhanga, Eugene Rusanganwa, Helena Davis, Stephen Watiti, Babe Gaolebale, Lacey N Ahern, Lydia Thomas and Emmanuel Luyirika	https://ecancer.org/en/journal/article/1474-the-declaration-on-palliative-care-in-a-pandemic-report-of-the-african-ministers-of-health-meeting-and-the-7th-international-african-palliative-care-conference-held-from-the-24th-to-26th-august-2022-in-kampala-uganda-and-virtually
"Understanding the Effects of the COVID-19 Pandemic on Palliative Care Provider Mental Health and Psychosocial Support in Uganda".	Mariah Horvath, Simon Kizito, Roya Ghiaseddin, , Lisa Irumba, Mark Mwesiga, Lacey Ahern, MPH	Not yet published

Participation at Conferences

In 2012, PCAU Secretariat staff offered significant contribution in organizing the 2 intentional conferences in Kampala.

The 14th International Society of Paediatric Oncology African Continental Meeting, 16–18 March 2022, Kampala, Uganda

PCAU staff participated and supported at the conference organizing committees, were session chairs, and attended the conference.

PCAU had an erected exhibition stall and hosted 150 visits by the conference delegates. All received information about the work of PCAU and palliative care in Uganda.

The 7th International African Palliative Care Conference 24–26 AUGUST 2022 Kampala, Uganda

PCAU staff participated and supported at the conference organizing the committees, were panelists, presenters, session chairs, and attended the conference.



Presentations by PCAU at the conference:

- ❖ Oral Presentation: Resource mobilization for Palliative Care Association of Uganda amidst the COVID-19 pandemic: **Zipporah Kyomuhangi, Administrative Assistant PCAU, Uganda**
- ❖ Plenary Presentation: Innovations and advocacy as catalysts for health systems strengthening and resilience in pandemics: Reflections from Uganda: **Mark Donald Mwesiga, PCAU**
- ❖ Poster Presentation: Psychosocial support for front-line palliative care providers during COVID-19 pandemic in Uganda: **Joyce Zalwango, Capacity Building Officer, PCAU.**
- ❖ Poster Presentation: Strengthening interventions to address challenges faced by child caregivers during COVID-19 lockdown in Uganda: A case of Road to Hope Program: **Anita Balikobaku, Programs Manager PCAU.**
- ❖ Poster Presentation: Increasing Membership: How Palliative Care Association of Uganda (PCAU) embraced technology amidst COVID-19 Pandemic: **Fiona Siima, Membership Officer, PCAU**
- ❖ Fast-tracking strategic advocacy for the inclusion of palliative care in universal health coverage amidst the COVID-19 pandemic at the Palliative Care Association of Uganda for Uganda; **Lisa Christine Irumba, Research and Advocacy Officer, PCAU**
- ❖ Our Oral presentation titled "Integrating Palliative Care Data into the Health Management Information System (HMIS) amidst COVID-19" was ranked the best presentation at the conference. **Cynthia Kabagambe – ICT & Data Quality Officer PCAU – Voted the best oral presentation at the conference.**

Governance and Support Functions

PCAU's initiatives under this focus area are intended to enhance effective and efficient governance and management of palliative care services in Uganda. In the year 2022, PCAU accomplished and launched a new strategic plan. We also initiated the process of reviewing the PCAU constitution to strengthen the governance of the association.

PCAU maintained strong working relations with the Ministry of Health through the Division of Palliative Care. We conducted a successful 2022 Annual General Meeting and held a total of 12 meetings of the Board and Committees. At the functional strategic level, we coordinated and held 2 meetings for the Uganda Country Palliative Care team meetings. All these strategic meetings strengthened the governance of palliative care in the year.

In 2022, PCAU installed a new accounting system at the Secretariat to enhance efficiency in financial operations. We held 6 staff capacity development training and team building initiatives to improve staff performance. ,

We held 2 high-level meetings with top executives of PCAU member organizations. To further strengthen partnership and shared vision for supporting palliative care work in Uganda, staff representatives from PCAU partners Centre for Hospice Care (CHC) through the Global Partners in Care (GPiC) visited PCAU in 2022.

In October-November 2022, two staff from PCAU also visited the USA for partnership engagements with the USA-based partners. The engagements strengthened PCAU partnership with partners in the USA.



Mark Mwesiga speaking at a staff meeting of Center for Hospice Care in USA in 2022



PCAU with CHC team with Dr. Henry Mwebesa the Director General Health Services and other top level officials at Ministry of Health

Sustainability for PCAU and Palliative Care Services

PCAU works towards enhancing resource mobilization and financial efficiency and sustainability for palliative care in Uganda.

In 2022, PCAU initiated the process of establishing a reserve fund policy for the association. PCAU maintained strong partnerships and understanding with her donors sought one new donor and maintained membership with 2 international palliative care associations. PCAU initiated

local fundraising activities and placed 4 donation boxes in public places and held a fundraising dinner in honor of palliative care for the Karamoja Sub region. PCAU strengthened membership work and growth to 26 member organizations, 30 life members, and 1350 individuals. We accomplished the land title transfer and valuation of land in Mbarara which was donated to PCAU through the Rotary Club of Kampala daybreak to PCAU.

SUMMARY OF MEMBERSHIPS BY CATEGORIES

Membership category	YEARS		
	2020	2021	2022
New Organisation	23	24	26
New Individual Members	1063	1200	1318
New Life Members	4	20	29



A look at issues that affected the work of PCAU in the year

PCAU's mission was affected by several challenges in the year 2022.

- **The Lack of a national palliative care policy**, strategy and standards still lead to fragmented approach to palliative care service delivery. PCAU has led the advocacy and support to Government to fast track the development and approval of the national palliative care policy. This appeal will continue.
- **The weak national monitoring and evaluation** of the provision of palliative care services affects the quality of services provided across the public and private health facilities in the country. PCAU continues to appeal to government to establish and strengthen by resourcing the palliative care coordination structures at the Ministry Health, Regional and District Levels.
- **Inadequate numbers of Human Resources and training** of palliative care providers results in limited access to palliative care across the country. PCAU appeals to the government to invest in human resources for palliative care by supporting training palliative care providers at all levels and the Health Service Commission should recognize palliative care as a medical, nursing, and allied health workers specialty.
- **Inadequate Access to Essential Medicines for palliative care** for patients in need. PCAU continues to appeal to government to review the Essential Medicines and Health Supplies List for Uganda (EMHSLU) to include more recommended essential medicines for palliative care.
- **Low resources for palliative care services** across public and private sectors and especially reduced donor funding to stand alone palliative care programs which has led to reduced home and community care programs.

PALLIATIVE CARE ASSOCIATION OF UGANDA (PCAU)

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Subscribe to become a member or give a generous contribution to PCAU through MTN MoMo Pay. **The PCAU Mobile Money number is +256 0789 737 786.**

Spotlight on PCAU New Member Organizations

In 2022, two organizations joined PCAU Membership.

Yotkom Medical Centre in Kitgum



Yotkom Uganda is registered in Australia with the **Australian Charities and Non for Profits Commission**. Yotkom is an Acholi word meaning "health". The medical Centre is in Kitgum, Northern Uganda. The mission of Yotkom Uganda is: ***"Partnering together to improve access and excellence in the provision of holistic healthcare to Northern Uganda."*** The leadership and management of the facility are guided by Christian values of compassion, truth, respect, and excellence. Among other specialized services at the facility, Yotkom Uganda has established a Palliative Care service to alleviate suffering and pain in the community. To contact the facility info@yotkom.com or visit the website <https://www.yotkom.com/>.

The Aged Family Uganda

The Aged Family Uganda (TAFU) is a registered Non-Government Organization whose mission is to advocate for and provide care to older persons from their homes or in hospitals. TAFU trains caregivers, to work locally within the country or in the Diaspora. They are in Nsambya Babies Home Building, after Sharing Hall, before St. Joseph Senior Secondary School, 2nd floor, Suite 24. Contact TAFU through agedfamilyuganda@gmail.com or visit their website <https://www.tafu.org/>.



Special thank you to Esther Namara a PCAU Intern.

Esther Namara a social worker joined PCAU through a collaboration between PCAU and Light for the World Uganda. Esther was seconded and facilitated by Light for the World to work with PCAU as an intern. She worked with PCAU for 6 months in 2022. Light for the World is an organization that works with persons living with disabilities (PWDs). Esther's role as advocacy assistant supported PCAU's work on inclusion initiatives for PWDs in addressing their palliative care needs. She was charged with bringing all PCAU member organizations on board to ensure that PWDs' needs are at the forefront of PCAU's programming. She led a survey to better understand challenges that hinder access to health care among PWDs in Uganda. She was instrumental in strengthening PCAU's partnership with 8 organizations that work with persons with disabilities. In addition, Esther supported advocacy and awareness work as well as the Road to Hope program. PCAU appreciates Esther for her contribution.



Esther Namara
social worker

Thank you!
Esther Namara

PCAU Member organizations as of 2022

NAME OF THE ORGANISATION

Kawempe Home Care
Rays of Hope Hospice Jinja
Joy Hospice Mbale
Mengo Hospital
Hospice Africa Uganda
Kitovu Mobile
St. Francis Nsambya Hospital
Kabale Christian Care
Palliative Care Education and Research Consortium
Yotkom Medical Centre
The Aged Family Uganda
St. Francis Naggalama Hospital
Kamuli Mission Hospital
Reach Out Mbuya
Ibanda Central Clinic
Hospice Tororo
Peace Hospice Adjumani
Mama Maria Health Centre
Kadama Widows Association
Ngora Hospice Program-FADO-T
Health Care Alliance
TASO Uganda
CoRSU Rehabilitation Hospital
Mildmay Uganda Hospital
Samaritan Development Organization
Mother Mary Cancer Palliative Care Centre



Hospice Africa Uganda



Rays of Hope



Makerere Mulago Palliative Care Unit



Kabale Christian Care



YotKom Uganda



Kawempe Home Care

List of PCAU Life Members

PCAU Life Members contribute greatly to our work with their one-off subscription of shillings 1,000,000. This amount can be paid in small installments in one year. We count on all PCAU Life members as strong partners and supporters of the work to accelerate the availability and access to palliative care for all across Uganda. The life members share our vision of securing larger office premises for PCAU. We are working towards this vision with them. We request you to consider joining this category of friends of PCAU.



Sr. Dr. Vincentina Achora

Elvis Athibuni

Rose Kiwanuka

Prof. Julia Downing

Dr. Janet B White

Dr. Henry Ddungu

Dr. Irene Atuhaire

Roberta Spencer

CPA. Timothy Basiima (PhD)

Rita Nannyomo

Joyce Zalwango

Anita Balikobaku

Mark Donald Mwesiga

Dr Ekiria Kikule

Dr. Jackson Amone

Hon. Jacklet Atuhaire

Sr. Leonora Torach

Eleanor Mirembe

Dr. Eddie Mwebesa

Hajjat Mwazi

Irene Kibone

Rinty Kintu

Robinah Mwangale Mubeeke

PCAU annual dinner 2022



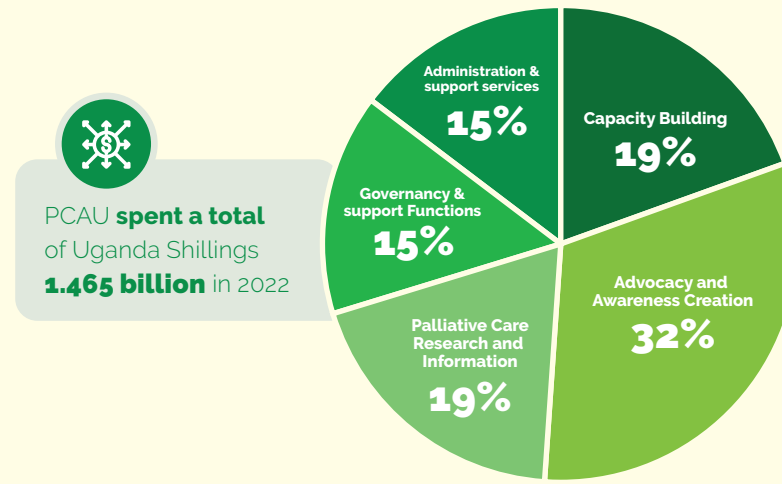
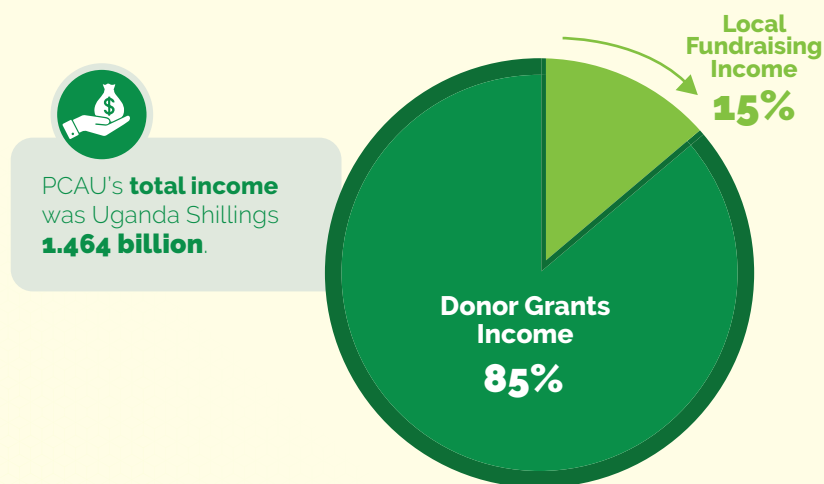
Our Finance Summary Report for 2022

In 2022, PCAU's total income was Uganda Shillings 1.464 billion. Of this amount, 85% was from PCAU donors who fund our programs and project. The 15% income was generated from local fundraising initiatives which included membership subscriptions, generous contributions to activities, PCAU branded items, get-together dinners, interest, and donation boxes.

PCAU spent a total of Uganda Shillings 1.465 billion in 2022. We spent more money 32% on advocating and creating awareness of palliative care. The rest of the amount, 19% was spent on capacity building, 19% on Research and information work, 15% on governance and support functions for palliative care work in Uganda, and 15% on the administration of PCAU.

All PCAU members can access the full audited financial reports of PCAU at the Annual General Meeting or by emailing the Executive Director (mark.mwesiga@pcau.org.ug) to receive a soft copy.

PCAU is grateful to all donors, members, and supporters for their generous contributions to PCAU.



Palliative Care Association of Uganda (PCAU)

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