



STRATEGIC PLAN

2022 – 2026



UNIVERSAL
HEALTH
COVERAGE

CONTENTS



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List of Abbreviations and Acronyms

| | |
|----------------|---|
| AIDS | Acquired Immuno-deficiency Syndrome |
| APCA | African Palliative Care Association |
| ADPCN | Advanced Diploma in Palliative Care Nursing |
| CHC | Center for Hospice Care |
| FIA | Financial Intelligence Authority |
| HIV | Human Immuno-deficiency Virus |
| HMIS | Health Management Information System |
| mHealth | Mobile Health |
| MDA | Ministries, Departments and Agencies |
| MoES | Ministry of Education and Sports |
| MOH | Ministry of Health |
| MoIA | Ministry of Internal Affairs |
| MoU | Memorandum of Understanding |
| NCHE | National Council for Higher Education |
| NDA | National Drug Authority |
| NSSF | National Social Security Fund |
| PC | Palliative Care |
| PCAU | Palliative Care Association of Uganda |
| PESTEL | Political, Economic, Social, Technological, Environmental and Legal |
| RRHs | Regional Referral Hospitals |
| SDGs | Sustainable Development Goals |
| SP | Strategic Plan |
| SWOT | Strength, Weaknesses, Opportunities and Threats |
| UPF | Uganda Police Force |
| UPR | Universal Periodic Review |
| URA | Uganda Revenue Authority |
| URSB | Uganda Registration Services Bureau |
| WHO | World Health Organization |

Foreword

Since its establishment in 1999, the Palliative Care Association of Uganda (PCAU) has advocated for and supported the integration of palliative care into Uganda's health system.

Evaluation reports of the previous PCAU Strategic Plans show that great achievements have been registered at the national, district, health facility and community levels. The organization therefore continues to be relevant in this space at both national and international levels. Uganda's palliative care work has been ranked highly at the global level and the work of PCAU is mirrored by these rankings including the Global Palliative Care Atlas, Global Quality of Death Index, Cross Country Comparison of Expert Assessments of the Quality of Death and Dying, African Palliative Care Atlas and others.

Over the years, PCAU's advocacy has yielded the following: a Division of Palliative Care and Hospice Service, established at the Ministry of Health; recognition of indicators and data collection tools for integration into the HMIS and DHIS2; the reporting on the right to palliative care in The Uganda Human Rights Commission's

(UHRC) 20th annual report; the introduction of Advanced Diploma in Palliative Care Nursing at a public nursing school; the improvement of access to essential palliative care medicines; the expansion of availability of palliative care to 226 health facilities in 107 districts; the growth of PCAU membership currently with 25 organizations and 1300 individuals.

Notwithstanding, PCAU is yet to acquire larger office premises as had been envisioned. The COVID-19 pandemic affected the implementation of some activities and paused financial and operational challenges to some of the PCAU member organizations. Resource constraints amidst so much need for the services continue to be a key challenge.

This Strategic Plan focuses on increasing the provision of palliative care across the country. The organization intends to enhance capacity building, advocacy, research, governance and financial sustainability.

The Strategic Plan was developed through a consultative process of all PCAU stakeholders to whom we are grateful. The successful implementation requires a concerted effort by all PCAU friends, partners and members.

We thank our partners and look forward to working with all of you to implement this plan.

Thank you



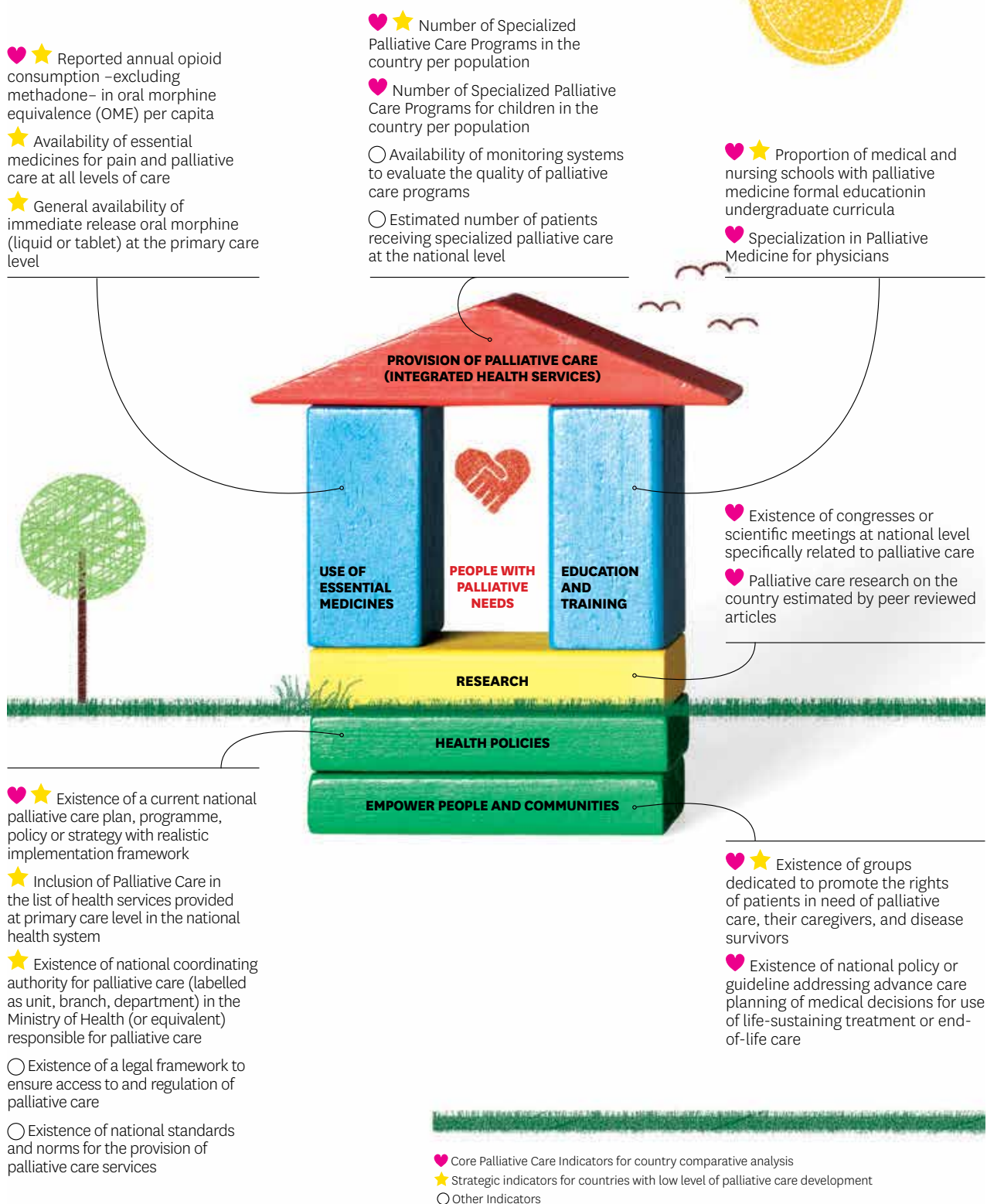
Dr. Henry Ddungu
Board Chairperson – PCAU



Mark Donald Mwesiga
Executive Director – PCAU

The WHO Palliative Care Development Conceptual Model and Sets of Indicators Released in 2021

FIGURE 5. RELATIONSHIP BETWEEN THE SETS OF INDICATORS AND THE PALLIATIVE CARE DEVELOPMENT CONCEPTUAL MODEL



Introduction

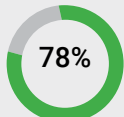
By end of 2021,
PCAU was
composed of

25
organizations and
1300
individual members



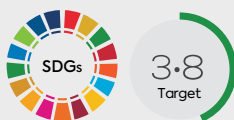
Globally,
it is estimated that over

56.8 million
remain in need of
palliative care annually



live in low- and
middle-income
countries (LMICs)

2.5
million Children
worldwide die in need
of palliative care and
pain relief



Sustainable
Development Goals

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 coordinate civil society efforts in supporting the government and to integrate palliative care into the national health care system at all levels. By end of 2021, PCAU was composed of 25 organizations and 1300 individual members that included health care professionals, caregivers and community members across the country. The association's secretariat operates from owned premises in Kitende on Entebbe Road and runs 10 regional committees (branches) in the country.

Globally, it is estimated that over 56.8 million remain in need of palliative care annually. A disproportionate number, 78% of these live in low- and middle-income countries (LMICs). The availability of palliative care services remains limited for patients with Non-Communicable Diseases (NCDs) globally, with only 39% of countries reporting general availability.

Furthermore, nearly 2.5 million children worldwide die in need of palliative care and pain relief, with more than 90% of pediatric deaths associated with serious health-related suffering being avoidable.

Sustainable Development Goals (SDGs) target 3.8 aims to achieve Universal Health Coverage (UHC) including financial risk protection, access to quality health care services and access to safe, effective, quality and affordable essential medicines and vaccines for all. The World Health Organization (WHO) defines UHC

as ensuring access to needed services of sufficient quality and effectiveness for all persons, while also not exposing the user to financial hardship.

In reflection, the previous PCAU Strategic Plan 2017 – 2021 documented numerous achievements, to include: the establishment of the Division of Palliative Care at the Ministry of Health due to PCAU advocacy efforts; the identification of UHRC profiled Palliative Care as a Human Rights issue; the improvement of access and availability of essential palliative care medicines including oral liquid morphine; increasing the number of health facilities provided palliative care across the country; palliative care education and training including introducing specialist training for government nursing training institutions was scaled up; increasing the number of trained palliative care providers; establishing national palliative care indicators and data collection tools; increasing PCAU membership and collaboration with various partners in Uganda and abroad.

The hampering of some of the implementation of the last strategic plan was due to some of the following factors: decreased funding for palliative care; lack of an approved national standalone palliative care policy, COVID-19; limited human resource at PCAU and delays by the public service to recognize palliative care workers in the public service structure.

The reality for palliative care in Uganda, Africa and beyond is that the need is increasing. This Strategic Plan focuses PCAU on achieving the universal provision of palliative care across Uganda.

PCAU Strategic Direction



Our Mission

To accelerate the provision and integration of palliative care in Uganda's healthcare system through capacity building, advocacy, research, governance and resources mobilization.



Our Vision

Palliative care for All in Uganda



Goal

Universal provision and access to culturally appropriate palliative care in Uganda.

Focus Areas & Objectives

2022 - 2026



Capacity Building

To strengthen the capacity of palliative care providers in Uganda through supporting training, continuous professional education, mentorship and supervision.



Advocacy and Awareness Creation

To advocate for a supportive environment and increase understanding of palliative care among stakeholders in Uganda.



Palliative Care Research and Information

To establish a hub of research and information on palliative care in Uganda.



Governance and Support Functions

To enhance effective and efficient governance and management of palliative care services in Uganda.



Sustainability and Financial Efficiency

To enhance resource mobilization and financial efficiency for palliative care in Uganda.

Service Provider Focus | Collaboration | Integrity | Volunteerism | Professionalism

Core Values:

Service Provider Focus:

PC service providers are our principal targets to develop and provide high-quality services across the country. PCAU therefore commits to developing these to the highest professional potential.



Collaboration and Networking:

PCAU harnesses maximum advantage from partnerships, networks and collaborations with local and international entities to support and promote PC within Uganda.



Integrity:

PCAU members and staff will uphold the highest levels of integrity ensuring honesty and accountability in all activities and engagements with all stakeholders, patients and their families.



Volunteerism:

PCAU recognizes the support and commitment of volunteers as an essential element in the scaling up of PC work and empowering service providers.



Professionalism:

PCAU members and staff commit to observing the highest ethical and professional quality standards in implementing programs and activities.



Brief on Palliative Care Situation in Uganda

According to recent global palliative care reports, Uganda is a model for palliative care services in Africa. Uganda is at the top of African countries on the Cross-Country Comparison of Expert Assessments of the Quality of Death and Dying of December 2021. The Quality of Death Index published by the UK's Economist Intelligence Unit ranked it 35th out of 80 countries in October 2015. The 2020 and the 2014 Global Palliative Care Atlases published by WHO and the World Hospice and Palliative Care Alliance (WHPCA) all ranked Uganda among countries with advanced palliative care integration.

Since the introduction of specialist palliative care in Uganda in 1993, Uganda has registered progress in expanding coverage and access to the service. At the policy level, the National Health Policy recognizes palliative care as an essential clinical care service.

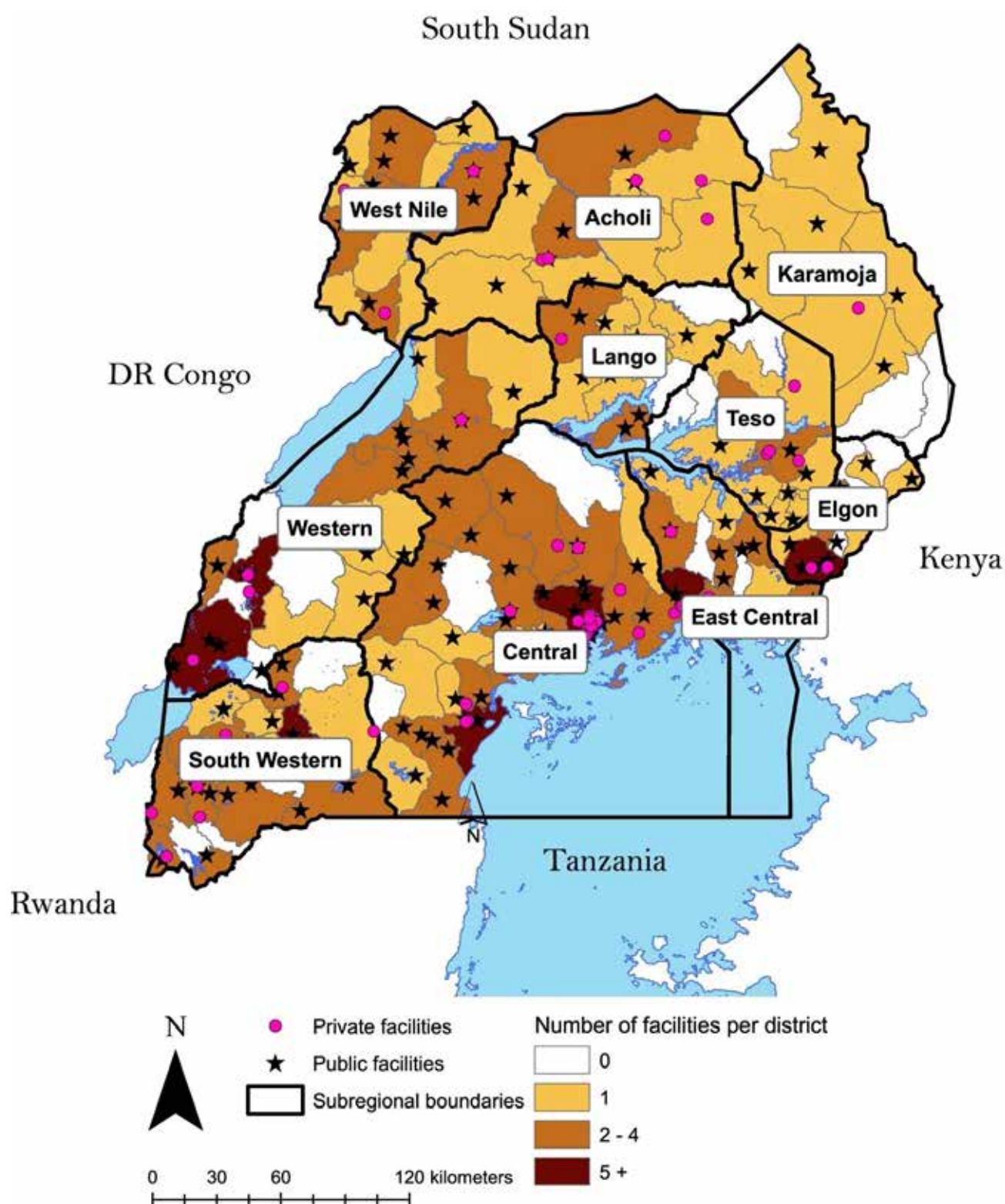
Two Acts of Parliament recognize the need for palliative care: The Uganda Cancer Institute Act 2016 and the Uganda Heart Institute Act 2016 both highlight the importance of representation of a palliative care specialist at the helm of the Boards. Unfortunately, Uganda is yet to establish a standalone National Palliative Care Policy. The Ugandan government pays for oral liquid morphine which is supplied and availed to patients in need at no charge. Education for palliative care has been enhanced to include diplomas, degree, and masters' courses in the country. Most recently, the Ministry of Health established a Division of Palliative Care among its administrative structures.

Access to palliative care in Uganda is still limited with reports showing that only 11% of those in need access the service. By December 2021, a total of 226 facilities had been accredited to offer palliative care in Uganda, and of them, 154 were public facilities and 72 were private facilities. At least 40 districts had no health facility offering palliative care. The challenges that lead to low access to palliative care in Uganda include a lack of National Palliative Care Policy and implementation strategy, low funding, lack of sufficient data on the need, the limited number of palliative care human resources, low awareness and understanding of palliative care amongst stakeholders and low integration of the service into the national health system.

These barriers must be overcome for the country to contribute to SDG 3.8 which focuses on improvements in the health services coverage, access to essential medicines, human resources for health destiny and health financing as well as research and development on health issues that primarily affect developing countries.

PCAU still realizes the need to be proactive in dealing with the above context for palliative care in the period 2022-2026, hence the value of this Strategic Plan.

Map of accredited palliative care facilities in Uganda as of January 2020



Context of the Strategic Plan

PCAU embraces the opportunities that come with the SDGs 2030 Agenda, the African Union Agenda 2063, the East African Community Vision 2050 and Uganda Vision 2040. PCAU shall also tap into the opportunities that come with the 4th Industrial Revolution (4IR). In the pursuit of its mission, PCAU will lay emphasis on utilizing technology to support provision of services among community members.

The contribution of PCAU lies under Sustainable Development Goal (SDG) target 3.8 to achieve Universal Health Coverage (UHC) including financial risk protection, access to quality essential health care services, access to safe, effective, quality, affordable essential medicines and vaccines for all.

This Strategic Plan comes at a time when the WHO has disseminated a new palliative care development conceptual model. The model highlights six essential components required to provide optimal palliative care for those people with serious health-related suffering.

Additional facts on the need for palliative care in Uganda

The need for palliative care and pain relief in Uganda is increasing due to various factors including rises in NCDs and aging population.

34% of annual deaths are attributed to the five leading non-communicable diseases (NCDs),

namely cardio-vascular diseases (10%), cancers (9%), diabetes (2%), chronic respiratory diseases (2%) and other NCDs (11%). The prevalence rate of deaths of children less than 15 years attributable to NCDs is 2.0% (WHO 2018).

UNAIDS statistical estimates put HIV prevalence at 5.7%

7.1% for women and 4.4% for men; 2.8% among young women and 1.1% among young men.

Uganda's older persons are estimated at

1.5 million, constituting 3.7% of the total population of Uganda (UBOS 2021). Older persons

are at risk of age-related health conditions such as arthritis, stroke, dementia, hypertension, diabetes, ulcers, respiratory conditions and orthopaedic problems. Most common among older persons are cardiovascular disorders and cancer.

“

In the pursuit of its mission, PCAU will lay emphasis on utilizing technology to support provision of services among community members.”



The Strategic Planning Process



PCAU engaged consultants to support the end term review of the 2017-2021 Strategic Plan which led to the development of the 2022-2026 Strategic Plan. Consultations were made with the Board and Management Team, followed by 4 regional and 1 national consultative meeting as well as meetings with funding partners. Validation meetings were held with Management and the Board and Management.



Palliative care is an essential and needed health care service within Universal Health Coverage (UHC) as defined by the World Health Organization (WHO). UHC is defined as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

SITUATION ANALYSIS

| STAKEHOLDER | LEVEL OF INTEREST/ IMPORTANCE [L/M/H] | LEVEL OF AUTHORITY/ INFLUENCE [L/M/H] | STRATEGIES OF ENGAGEMENT AND MANAGEMENT |
|---|---------------------------------------|---------------------------------------|---|
| MoH, UCI | H | H | Establishing MoUs, involve them in PCAU planning meetings, project designs, activities (align our activities with these policies), participating in their meetings, engaging in technical working groups. |
| Other government MDAs (MoA, MoES, MGLSD, PM Office, Parliament, NDA, UPF, NCHE, NMS, professional councils, NGO Bureau, URA, URSB and FIA). | H | H | Engaging them in advocacy events, meetings, sharing reports and information, participating in their events and working group meetings, meeting statutory obligations. |

| | | | |
|---|---|---|--|
| Members of academia and institutions of higher education | H | M | Signing MoUs, and engaging them in meetings, sharing reports and information, engaging researchers in doing PC research, inviting them to attend our events and participating in their events, sensitization in schools, school clubs |
| Board members and staff of PCAU | H | H | Engaging them in staff meetings and, board assessments, HR function, team building, capacity building, staff welfare and benefits, implementing and monitoring the policies in place. |
| PCAU members - (Individual and organizations). | H | H | Providing periodic updates/ meeting minutes/AGM, revising and communicating members' benefits, annual PCAU get together meetings. Strengthening feedback mechanisms, strengthening membership management, involving them in grants lobbying. |
| Service provider organization- Provide services to aid program implementation | H | M | Timely payments, prequalification (open and fair selection of service providers) |
| Donors, partner organizations and individuals | H | H | Setting up a robust resources mobilization strategy and team that is charged with the responsibility of writing grants and proposals, periodic engagements, updates and reporting, feedback, implementation and accountability. |
| Media | M | H | Capacity building (know PC and ethics of PC), involving them in our activities, invite them to participate in get together events and other activities, periodic press conferences and briefing. |
| Persons living with palliative care needs (patients, caregivers and their families) | H | M | Increasing advocacy for PC services, awareness creation and having a robust PC data base to manage and follow-up with these clients, involving them in activities and linking them to health facilities. |
| PC Providers | H | H | Capacity strengthening, advocating for their rights, strengthening partnerships, working together, ensuring support, communication and feedback. |
| Health Facilities | H | H | Mentorship, providing them with data tools, sponsorship, medical sundries and support supervision. |
| Civil Society Organizations | H | H | Involvement in advocacy activities, capacity strengthening, partnership and collaborations. |

SWOT Analysis

| INTERNAL ENVIRONMENT | STRATEGIES |
|--|---|
| Strengths: <ol style="list-style-type: none"> 1. Fulfilled and updated legal status of PCAU 2. Vibrant and well positioned PCAU board 3. Experienced and committed staff 4. Ownership of a permanent home – office building and land for potential income generation 5. Large and passionate membership and regional presence across the country 6. National and international reputation 7. Excellent working relationship with the MoH and other government agencies | <ol style="list-style-type: none"> 1. Continue to adhere to legal obligations 2. Maintain strong functionality of the PCAU board 3. Strengthen marketing and advocacy to attract diverse members 4. Continuous staff capacity building and development and improve HR functions to retain staff 5. Initiate income generation in land 6. Strengthen collaborations and networks for PC 7. Maintain strong relations with MoH |
| Weakness: <ol style="list-style-type: none"> 1. Limited number of staff 2. Lack of a strong M&E system 3. Limited supervision of established PCAU branches 4. Limited funds 5. Limited capacity to utilize social media opportunity 6. Limited research management systems and collaborations 7. Limited capacity on resource mobilization at PCAU and PCAU member organizations 8. No staff SACCO to offer credit facilities | <ol style="list-style-type: none"> 1. Strengthen HR function at PCAU 2. Establish a robust M&E system 3. Strengthen management and expand PCAU Membership 4. Establish strong resources mobilization strategy 5. Strengthen internal management systems 6. Review and implement communication strategy 7. Enhance strong collaboration and engagement with media and social media in advocacy work 8. Strengthen research management systems and collaborations 9. Enhance resource mobilization at PCAU and its members, boost staff SACCO to support staff recurrent needs |
| EXTERNAL ENVIRONMENT | STRATEGIES |
| Opportunities: <ol style="list-style-type: none"> 1. Recognized by the relevant government ministries 2. Good political will towards PC 3. High demand for PC services across the country and region 4. Willingness to integrate PC training at Higher Institutions of Learning. 5. Strong international network 6. Continued interest in PC among nursing and university students across training institutions 7. Continued interest among donors to support PC | <ol style="list-style-type: none"> 1. Continuous engagement with government and other strategic partners 2. Engage politicians and parliamentarians in PCAU advocacy and activities 3. Advocate for the integration of PC training across training institutions 4. Support capacity building of tutors, lecturers and facilitators across universities and other training institutions on PC 5. Develop partnership and networks for PC 6. Set up PC clubs in nursing schools and universities 7. Rigorous grants writing and advocacy on PC services in the country |
| Threats: <ol style="list-style-type: none"> 1. Shrinking/reducing donor funding 2. Economic instability and inflation 3. Delayed recognition of PC professionals in the public service structure 4. Political uncertainties and shrinking civic space 5. Advanced remuneration and welfare of health workers in public sector | <ol style="list-style-type: none"> 1. Continuous engagement with key donors and partners 2. Strengthen advocacy and partnerships as well as networks for PC 3. Develop a sustainability strategy and explore resource mobilization options 4. Continued advocacy for PC providers recognition 5. Enhance risk management systems at PCAU to deal with instability and other uncertainties 6. Stakeholder mapping and awareness |

PESTEL Analysis

Table 1: PESTEL analysis for PCAU

| ITEM | STRATEGIES |
|---|---|
| Political Positives <ol style="list-style-type: none"> 1. Political stability 2. Good political will 3. Some level of good legislative and regulatory framework 4. Decentralized decision making Negatives <ol style="list-style-type: none"> 1. Limited funding and budget allocation in PC 2. Delayed PC policy approval 3. Bureaucracy 4. Low understanding of PC | <ol style="list-style-type: none"> 1. Continued engagements and information sharing 2. Engaging legislature for PC work 3. Engage districts leaders for community engagement 4. Engage leadership to the level of presidency <ol style="list-style-type: none"> 1. Lobbying and grants writing to donors and government 2. Fast track PC approval 3. Reduce levels of bureaucracy and engage leaders 4. Increase awareness for PC |
| Economic: Positive <ol style="list-style-type: none"> 1. Progressive improvement in budget allocation to cancer services 2. Conducive business environment 3. Positive government policy Negatives <ol style="list-style-type: none"> 1. Increased cost of science-based HR 2. Inflation 3. Increased cost of living | <ol style="list-style-type: none"> 1. Improve strategy on resource mobilization 2. Initiate income-generating activities 3. Create more opportunities for individual contributions 4. Develop PCAU Mbarara land <ol style="list-style-type: none"> 1. Widen revenue base (e.g., increased membership, local call for donations) 2. Provide staff remunerations like basic household supplies 3. Strengthen staff SACCO |
| Social/Cultural: Positives <ol style="list-style-type: none"> 1. Religious beliefs 2. Lifestyle trends 3. Access to free PC for all Negative <ol style="list-style-type: none"> 1. Myths and misconceptions based on culture and faith 2. Alternative for PC medication and treatments 3. Scarcity of PC services | <ol style="list-style-type: none"> 1. Increased advocacy 2. Community engagements 3. Involvement of lower community health influence 4. Engaging traditional, religious leaders and political leaders in PC activities 5. Expand availability of PC services across the country 6. Dissemination of PC research and procedures for treatment |
| Technological: Positive <ol style="list-style-type: none"> 1. Improved technology- social media broadcasts 2. Innovation 3. Research and information 4. Data collection and management 5. Increased access to services 6. Opportunity for innovation 7. Changes in technology-no cash payment 8. Knowledge gap 9. Telemedicine Negative <ol style="list-style-type: none"> 1. Misinformation 2. Costly technology resources/applications | <ol style="list-style-type: none"> 1. Integrating technology application in day-to-day PC service 2. Support funding for innovation into PC services 3. Standard directorate, official site of PC information 4. Attract and conduct research into discoveries of new solutions for PC services 5. Enroll online and offline data collection systems and apps 6. Utilize social media for more awareness and sensitization 7. Utilize technology for resources mobilization 8. Build capacity of PCAU staff and of PC professionals to harness technology 9. Embrace technology in enhancing knowledge and provision of telemedicine |

| ITEM | STRATEGIES |
|---|--|
| Environmental/Ecological: <ol style="list-style-type: none"> 1. Demographic changes 2. Disaster occurrences and disruptions in service 3. Limited access to PC in hard-to-reach areas | <ol style="list-style-type: none"> 1. Partnering with family planning providers to support ensuring a balance of population categories 2. Partner with other stakeholders in disaster response work 3. Conduct mapping for PC services for directed interventions |
| Legal Framework: Positive <ol style="list-style-type: none"> 1. Progressively conducive legal framework 2. Presence of legal aid support and representation 3. Opportunity of utilizing decentralized districts for creation of district bi-laws 4. Continuous recognition of PC as a human rights issue 5. Specific statutory instrument for PC-trained nurses to prescribe oral liquid morphine Negatives <ol style="list-style-type: none"> 1. No stand-alone national PC Policy 2. Low information on PC as a human rights issue 3. Few legal practitioners engaged in PC work | <ol style="list-style-type: none"> 1. Continued advocacy for establishment of the stand-alone national PC policy 2. Engage districts for support to PC work 3. Continuous advocacy for PC as a human rights issue 4. Engage more legal practitioners to participate in PC 5. Engage Parliament on resolutions on strengthening PC |



This Strategic Plan focuses PCAU on achieving the universal provision of palliative care across Uganda.

Mainstreaming for Cross-cutting Issues

| ISSUE | CAUSES | EFFECT | STRATEGIES FOR MITIGATION |
|---|--|--|---|
| Gender and equity: <ol style="list-style-type: none"> 1. Gender stereotyping and discrimination 2. Gender based violence 3. Violations of Sexual and Reproductive Health Rights (SRHR) | <ul style="list-style-type: none"> • Cultural beliefs • Poverty, increased cost of living • Low enforcement of related laws and regulations • Lack of sufficient knowledge and awareness • Low promotion and integration of SRHR in PC work in Uganda | <ul style="list-style-type: none"> • Poor advance care planning • Neglected and violated SRHR for PC patients and families | <ul style="list-style-type: none"> • Establish gender mainstreaming guidelines for PCAU and member organizations • Awareness creation, advocacy • Improved standard of living, promotion of IGAs among PC guardians • Inclusive environment • Integrate SRHR education and interventions in PC programming |
| HIV and AIDS: <ol style="list-style-type: none"> 1. OVC 2. High costs of treatment for NCDs 3. Gender-Based Violence 4. Poverty and deprivation 5. Stigma and discrimination | <ul style="list-style-type: none"> • Complacency • Low awareness among youth and teenagers • Unemployment | <ul style="list-style-type: none"> • Trauma and stress • High school drop-out rates • Inadequate money to meet household needs • High HIV/AIDS spread/infection rates • Poor diet | <ul style="list-style-type: none"> • Have an HIV workplace policy • Gender mainstreaming approaches and techniques • Income generation and enhancement approaches |
| Environment: <ol style="list-style-type: none"> 1. High drought and hunger among the local population 2. Poor infrastructures 3. Increase air pollution 4. Water pollution-chemicals, soil erosion 5. Swamp destruction | <ul style="list-style-type: none"> • Lack of prioritization of PC services • Industrialization • Economic activities-development of factories • Search for survival • Cutting trees for paper | <ul style="list-style-type: none"> • Poor PC delivery • Increased non-communicable diseases • Epidemics, cholera, land pollution • Non-biodegradable materials • Climate changes | <ul style="list-style-type: none"> • Prioritization of PC services • Awareness and sensitization • Promotion of sanitation and hygiene • Sensitization of communities • Campaigns on climate change |
| Pandemics: <ol style="list-style-type: none"> 1. Absence of protocols for pandemic emergencies 2. COVID -19 3. HIV/AIDS 4. Death due to pandemics 5. OVC | <ul style="list-style-type: none"> • Poor planning and unprepared to tackle this kind of emergence • Limited funds to support emergency situations • Limited capability in terms of staff preparedness to support tackling of these pandemic situations • Corona-virus | <ul style="list-style-type: none"> • Reduced work productivity • Reduced funding –economic shock, economic regulation at national and wider level-poverty • Orphans | <ul style="list-style-type: none"> • Policy on emergency situations and pandemics • Disaster preparedness • Enhanced planning and budgeting |
| Disability <ol style="list-style-type: none"> 1. Discrimination 2. Inequality 3. Poverty 4. Violation of rights | <ul style="list-style-type: none"> • Bias against disabled persons • Myths and misconceptions • Cultural norms • Social incapacitation • Unpopular policies • Lack of awareness | <ul style="list-style-type: none"> • Inaccessibility due to infrastructural designs • Income inequality caused by long term sickness and limited employment opportunities | <ul style="list-style-type: none"> • Inclusive development of programs |

Summary Strategic Objectives and Actions Under the Focus Areas



Focus Area I: Capacity Building

S01: To strengthen the capacity of palliative care providers in Uganda through supporting training, continuous professional education, mentorship, and supervision.

Activities:

- | | | |
|---|---|---|
| <ul style="list-style-type: none"> i. Support the training of tutors, lecturers and facilitators on PC at the tutor's college and across other higher education institutions in Uganda ii. Support the integration of PC training in universities and other higher institutions of learning iii. Assess and evaluate the delivery of PC course units and PC specialist training programs iv. Develop and review PC specialised short training curricula and training guides | <ul style="list-style-type: none"> v. Advocate and support the accreditation and provision of diploma and graduate programs vi. Partner with MoH to offer support supervision for PC vii. Support PC units to become practicum sites for PC training viii. Conduct quarterly National and Regional/ Branch update meetings ix. Offer mentorship to PC Specialists and graduates x. Conduct support supervision to PC units across the country | <ul style="list-style-type: none"> xi. Offer scholarships to increase PC human resources. xii. Accredite health facilities to offer PC and reassess PC-accredited health facilities xiii. Support strengthening of spiritual care among palliative care organizations and established PC units in districts (chaplaincy) xiv. Conduct short course PC trainings for health and non-health professionals xv. Scale up implementation of the Pain-Free Hospital Initiative (PFHI). |
|---|---|---|



Focus Area II: Advocacy and Awareness Creation

S02: To advocate for a supportive environment and increase understanding of palliative care among stakeholders in Uganda.

- | | | |
|--|--|--|
| <ul style="list-style-type: none"> i. Advocate for mainstreaming PC across the government MDAs ii. Advocate for availability and access to PC medicines, including oral liquid morphine iii. Advocate for access to essential equipment, patient supportive, devices, technologies, and supplies iv. Advocate for and support legal service provision for palliative care organizations and patients v. Advocate for increased budgetary allocation for PC by the government vi. Advocate for essential equipment, patient supportive devices, technologies and supplies vii. Review and implement the communication strategy viii. Advocate for recognition and recruitment of PC professionals | <ul style="list-style-type: none"> ix. Sensitize Uganda Police Force antinarcotics officers on controlled medicines for pain relief x. Conduct community sensitizations on PC xi. Advocate for a conducive legislative framework for PC in Uganda xii. Advocate for establishment of a national PC policy. xiii. Advocate for the Right to PC in Uganda xiv. Engage of media for advocacy xv. Engage religious groups, cultural institutions and opinion leaders to advocate for PC xvi. Conduct events to commemorate the World Hospice and Palliative Care Day xvii. Strengthen the empowerment program for child care-givers - | <ul style="list-style-type: none"> Road to Hope Program xviii. Advocate for and offer navigation support to children to access and continue cancer treatment xix. Enhance advance care planning in Uganda xx. Advocate for integration of PC in health and social care interventions during disaster and humanitarian situations xxi. Conduct strategic advocacy engagements at parliamentary and district local council Levels. xxii. Advocate for and support the establish of PC units in districts without palliative care offering facilities xxiii. Advocate for establishment and strengthening of specialized PC programs for children in health facilities |
|--|--|--|



Focus Area III: Palliative Care Research and Information

S03: To establish a hub of research and information on palliative care in Uganda.

- i. Finalize and actualize the PCAU research agenda
- ii. Develop a research policy for PCAU
- iii. Conduct periodical research studies on PC
- iv. Publish research studies on PC
- v. Develop a peer-reviewed journal on PC
- vi. Increase and mobilize research funding at PCAU
- vii. Establish an information centre for PCAU
- viii. Establish a research ethics committee for PCAU
- ix. Strengthen research collaboration, learning and adaptation with relevant stakeholders
- x. Embrace and integrate innovative ideas in PCAU's work
- xi. Strengthen the management of national PC data
- xii. Disseminate PC research and information
- xiii. Establish the PCAU digital information PC app
- xiv. Create and publish the biennial Uganda PC Directory
- xv. Conduct biennial international conferences in partnership with Ministry of Health and Uganda Cancer institute (UCI)



Focus Area IV: Governance and Support Functions

S04: To enhance effective and efficient governance and management of palliative care services in Uganda.

- i. Enhance the functionality of the PCAU Board
- ii. Support the functionality of the PC division at the MOH
- iii. Review and implement the PCAU governance policies
- iv. Strengthen the financial management systems at PCAU
- v. Establish and implement robust performance management policies PCAU staff and volunteers
- vi. Establish a robust M&E system
- vii. Conduct annual membership and stakeholder surveys



Focus Area V: Sustainability and Financial Efficiency

S05: To enhance resource mobilization and financial efficiency for palliative care in Uganda.

- i. Establish a national PC fund
- ii. Review and establish a new resource mobilization strategy
- iii. Develop the capacity of PCAU member organizations in resource mobilization
- iv. Strengthen PCAU networking and collaboration with public and private entities
- v. Strengthen the membership management at PCAU
- vi. Acquire at least 5 acres of land for PCAU office expansion within 30KM radius from Kampala
- vii. Establish a regional palliative care recreational facility for PCAU in Mbarara
- viii. Advocate for allocation of government funding for palliative care at all levels
- ix. Establish a reserve fund for PCAU
- x. Strengthen national and international membership and partnerships for PCAU



PCAU will continue advocating for the availability and access of essential medicines for pain and palliative care at all levels of care and general availability of oral morphine at the primary care level amidst growing levels of control against illicit use of these medicines.

FINANCING FRAMEWORK AND STRATEGY

Forecast of Revenue by Source for the Strategic Plan

| Source of Revenue | 2022 | 2023 | 2024 | 2025 | 2026 | Total in UGX |
|--|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| Donations/Grants | 1,445,383,777 | 1,280,000,000 | 1,385,000,000 | 1,405,000,000 | 1,450,000,000 | 6,965,383,777 |
| Income-generating activities | 100,000,000 | 105,000,000 | 110,250,000 | 115,762,500 | 121,550,625 | 552,563,125 |
| Membership & subscription fees | 13,000,000 | 13,600,000 | 14,332,500 | 15,049,125 | 15,801,581 | 71,783,206 |
| Other fundraising activities & in-kind donations | 20,000,000 | 22,000,000 | 24,358,821 | 25,000,000 | 30,000,000 | 121,358,821 |
| Conference income | 8,000,000 | 150,000,000 | 8,000,000 | 175,000,000 | 10,000,000 | 351,000,000 |
| Technical support /Training fee | 0 | 10,000,000 | 12,000,000 | 14,000,000 | 16,000,000 | 52,000,000 |
| Total Revenue In UGX | 1,586,383,777 | 1,580,600,000 | 1,553,941,321 | 1,749,811,625 | 1,643,352,206 | 8,114,088,929 |
| Amount in USD | 453,253 | 451,600 | 443,983 | 499,946 | 469,529 | 2,318,311 |

Forecast of Expenditure by Objective

| Key Focus Area/Objectives | 2022 | 2023 | 2024 | 2025 | 2026 | Total in UGX |
|---------------------------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| Capacity building | 349,204,115 | 375,191,650 | 394,367,126 | 415,062,825 | 433,703,059 | 1,967,528,775 |
| Advocacy & awareness creation | 481,714,191 | 501,782,647 | 501,782,647 | 501,782,647 | 501,782,647 | 2,488,844,779 |
| Research & information sharing | 319,025,952 | 209,679,072 | 206,731,752 | 217,338,320 | 282,843,146 | 1,235,618,242 |
| Governance | 219,988,401 | 270,424,455 | 281,329,167 | 292,435,459 | 321,492,691 | 1,385,670,172 |
| Sustainability & financial efficiency | 50,000,000 | 80,421,000 | 70,000,470 | 74,900,503 | 80,143,538 | 355,465,511 |
| Administration & overhead | 99,525,227 | 117,953,616 | 126,210,369 | 135,045,095 | 144,498,251 | 623,232,557 |
| Capital expenditure | 370,850,000 | 250,000,000 | 250,000,000 | 250,000,000 | 250,000,000 | 1,370,850,000 |
| Total in UGX | 1,890,307,886 | 1,805,452,440 | 1,830,421,531 | 1,886,564,849 | 2,014,463,332 | 9,427,210,036 |
| Total in USD | 540,088 | 515,844 | 522,978 | 539,019 | 575,561 | 2,693,489 |



INSTITUTIONAL ARRANGEMENTS FOR IMPLEMENTING THE STRATEGIC PLAN

PCAU Governance

The PCAU Annual General Meeting (AGM) is the top-most organ of the organization. The AGM appoints the Board of Directors of PCAU. The PCAU board is responsible for oversight, strategic direction policy-making and other roles as per the PCAU Constitution.

The board plays an oversight role, ensuring that the Executive Director delivers on the organizational mandate and engages in networking for purposes of resource mobilization and cross-organizational learning.

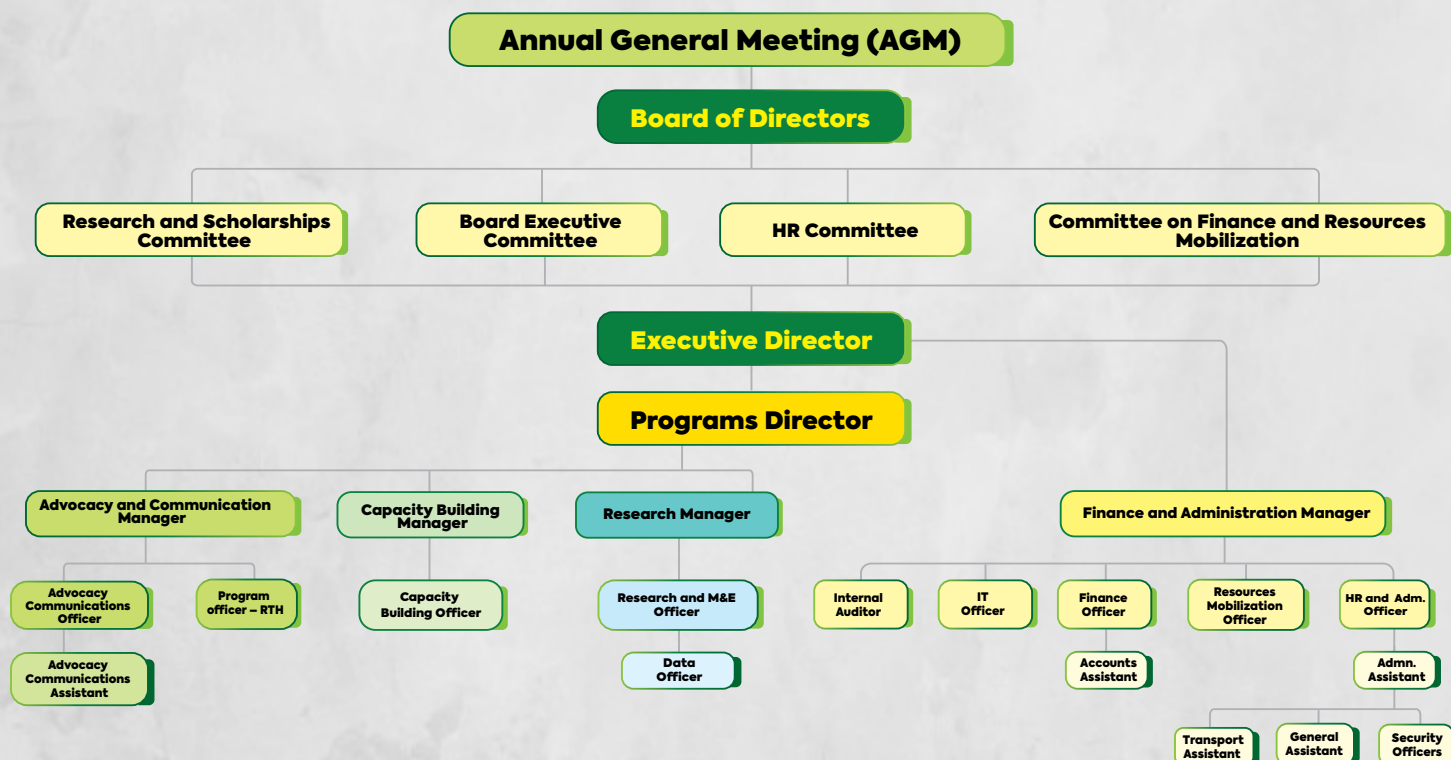
Management and Staff

PCAU implementation team is comprised of the Executive Director and the staff. The Executive Director oversees the entire implementation of the Strategic Plan, ensuring that initiatives are effectively implemented and adhere to PCAU's guiding principles, values, and practices.

Representation of the PCAU Organogram:



PCAU ORGANOGRAM 2022–2026



RISK MANAGEMENT

Risk analysis for PCAU

| Risk | Probability of occurrence [L/M/H] | Impact if it occurs [L/M/H] | Strategies of prevention and mitigation |
|--|-----------------------------------|-----------------------------|--|
| Donor pull-out | H | H | Diversity in our income, alternative sources of income. Accountability. |
| Shift of donor priority | H | H | Change of activities (paradigm shift), diversifying developing the PCAU land. Diversifying grants writing to link PC to human rights, livelihood, and other crosscutting issues. |
| Political instability | M | H | Protocols in place for emergency situations. |
| Shrinking civic space | M | H | Ensuring compliance with legal requirements. |
| Technological issues-data loss, theft, and fires | M | H | Embracing cloud computing, insurance of the equipment and regular backups. |
| Natural disasters/ pandemic | M | H | Emergency policies/ protocols. |
| Legal liabilities | M | H | Putting in place policies/ guidelines that can safeguard the organization, compliance MoUs, staff retention, employment and contract policies. |
| High staff turn over | H | H | Career growth, capacity building, improving staff welfare, conducive working environment (physical and mental). |
| Information insecurity | M | H | Information safety measures like insuring of equipment, installation of antivirus and ransom wares, creating back up storage on cloud databases. |
| Statutory penalties by URA, NSSF, NGO Bureau | M | M | Timely filling of tax returns and NSSF returns, submission of reports and Audited books of accounts to NGO bureau. |



Essential Palliative Care Package for Universal Health Coverage in Uganda



Do not leave children and adults with life-limiting illnesses behind in UHC



Universal Health Coverage (UHC) means that all people have access to needed health services (including prevention, promotion, treatment, rehabilitation and palliation) of sufficient quality to be effective while also ensuring that the use of these services does not expose the user to financial hardship (WHO)



SUSTAINABLE DEVELOPMENT GOALS (SDGS)

3.8 is to achieve (UHC), including **financial risk protection, access to quality essential health-care services** and access to **safe, effective, quality and affordable essential medicines and vaccines** for all.

WHO estimates that about **40 Million people** are in need of PC



78% of them live in low- and middle-income countries such as Uganda.
Only **11%** of those in need of pain control and palliative care access in Uganda.



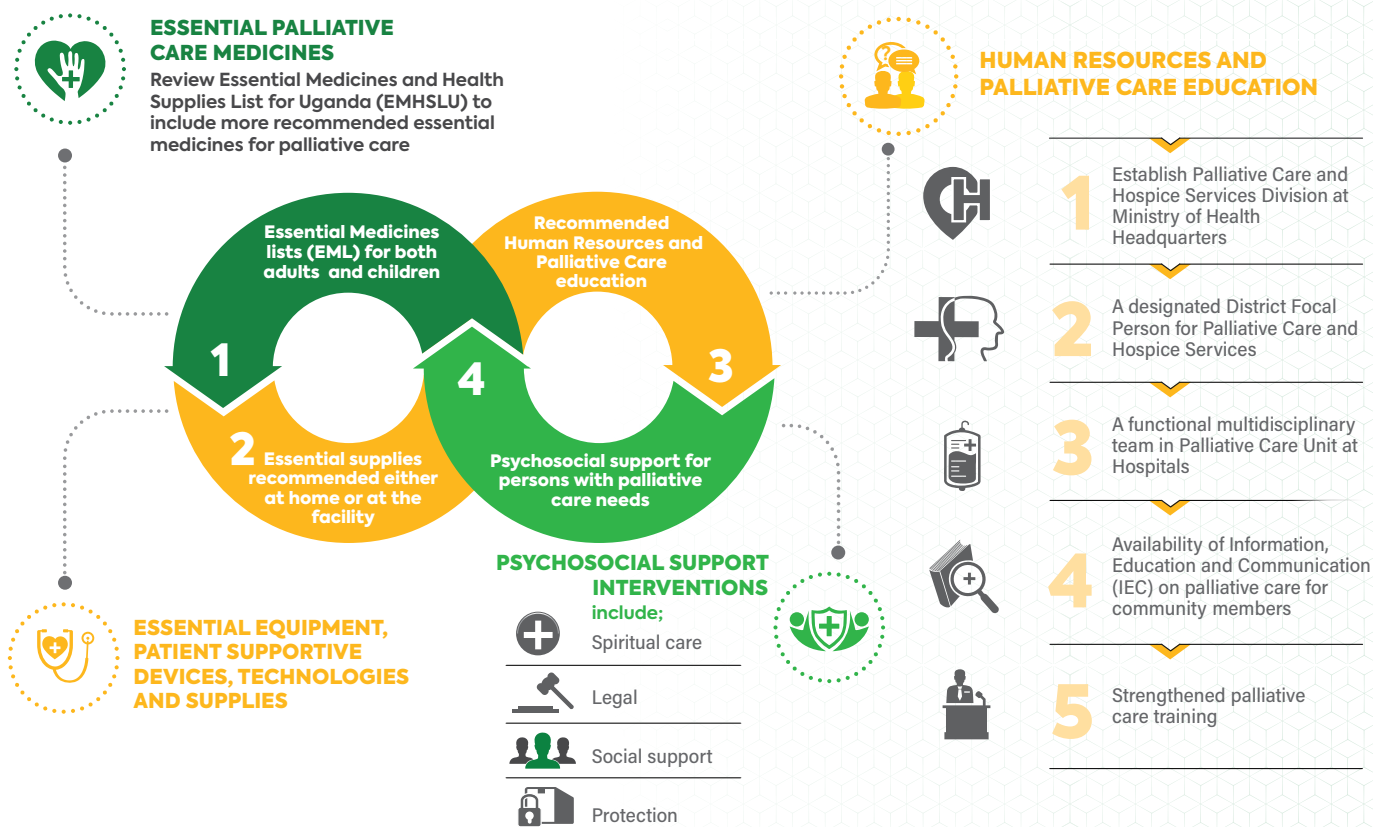
Palliative Care is required for a **range of diseases**, for **adults**;

- Alzheimer's and other dementias
- Cancer
- Cardiovascular diseases (excluding sudden deaths)
- Cirrhosis of the liver
- Chronic obstructive pulmonary diseases
- Diabetes
- HIV/AIDS
- Kidney failure
- Multiple sclerosis

In addition, for **children**, **other diseases** that require palliative care include;

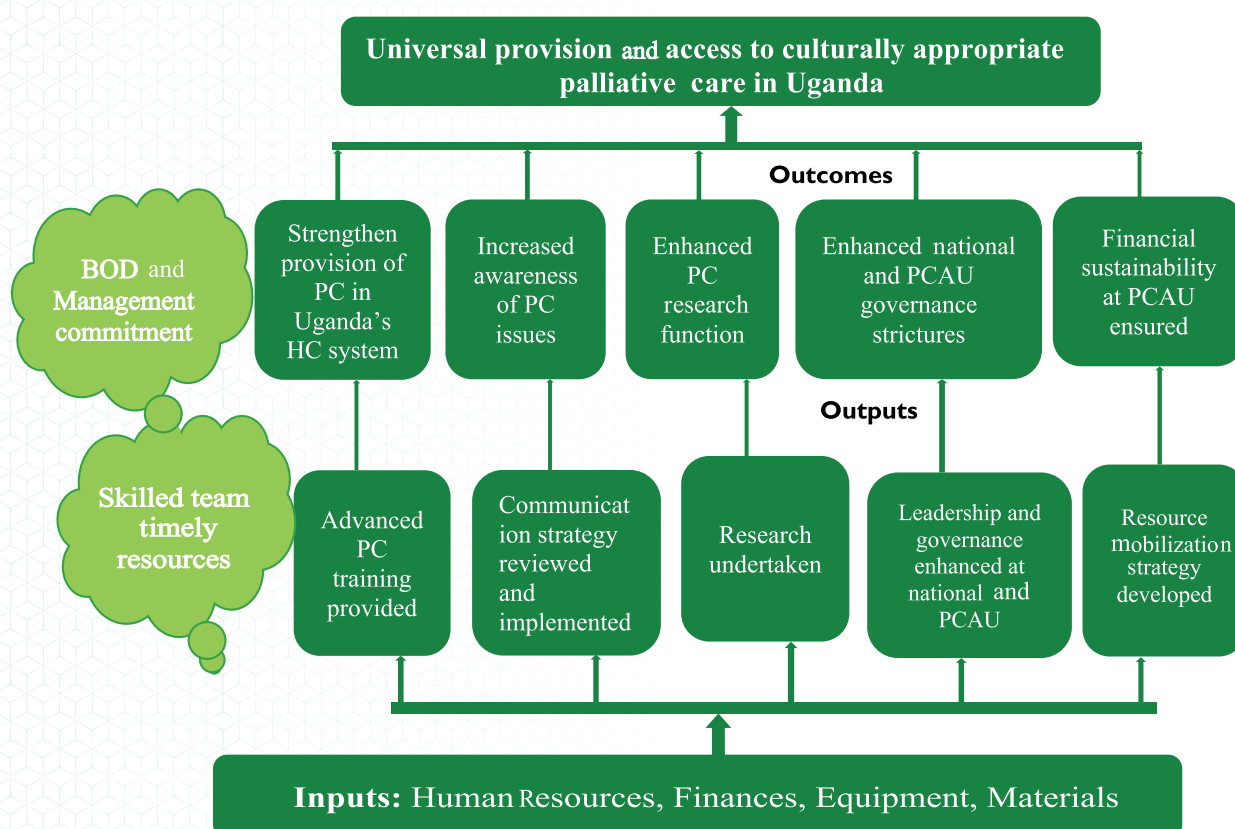
- Congenital anomalies (excluding heart abnormalities)
- Blood and immune disorders
- Meningitis
- Neurological disorders and neonatal conditions.

The Recommended Essential Palliative Care Package for UHC



PCAU has developed an essential palliative care package for Universal Health Coverage in Uganda and will continue to advocate for the utilization of this tool by both government and non-state actors.

PCAU Theory of Charge 2022 – 2026



The theory of change pre-supposes that once the required resources in terms of human resources expertise, financial resources, other resources including materials and technical assistance are provided in time, then PCAU shall be able to undertake the planned core activities and achieve the desired outcomes and impact.

Results Framework

RESULTS FRAMEWORK FOR PCAU STRATEGIC PLAN 2022 - 2026

Vision: Palliative Care for All in Uganda

Mission: To accelerate the provision of integrated palliative care in Uganda's healthcare system through capacity building, advocacy, research and resource mobilisation

Goal: Universal provision and access to culturally appropriate palliative care in Uganda

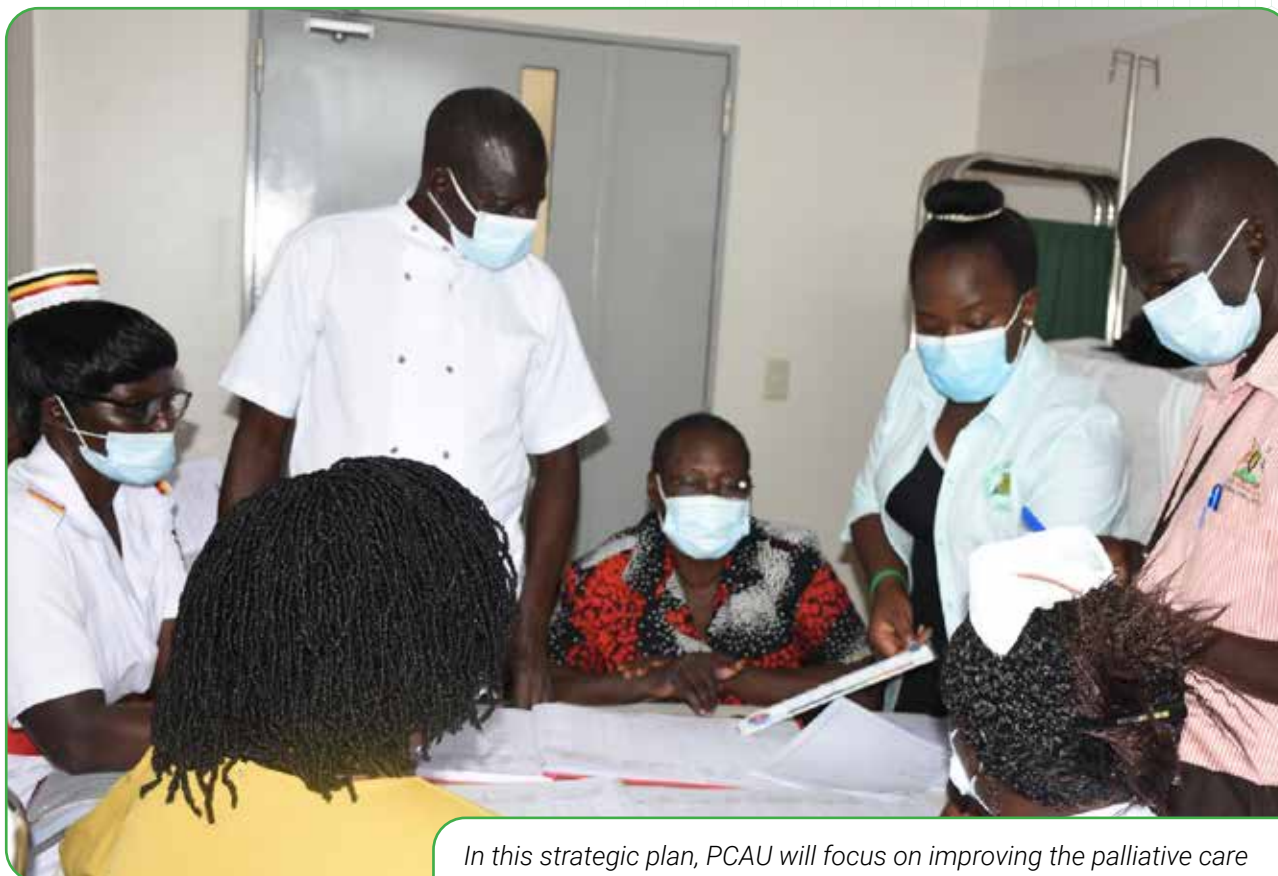
Impact:

- i. Culturally appropriate palliative care provided universally

Outcomes:

- i. Strengthened provision of PC in Uganda's HC system
- ii. Increased awareness of PC issues
- iii. Enhanced PC research function
- iv. Strengthened governance and management systems for PC in Uganda
- v. Enhanced financial sustainability for PC in Uganda

For monitoring and evaluation of this Strategic Plan, a set of performance indicators have been drawn for each of the objectives of this strategic plan. The performance on indicators shall be monitored every after 4 months and there shall be an annual progress report presented to PCAU members/stakeholders during the implementation of this plan. The strategic plan shall be evaluated by conducting an independent midterm review and a summative evaluation at the end of 5 years.



In this strategic plan, PCAU will focus on improving the palliative care evidence base by advocating and supporting processes for managing data at all levels of the health care system.

Performance indicators for Objective 1

SO1: To strengthen the capacity of palliative care providers in Uganda through supporting training, continuous professional education, mentorship and supervision.

- Number of tutors, lecturers and facilitators trained to with the support of PCAU.
- Number of education institutions supported by PCAU to train tutors, lecturers and facilitators on PC.
- Number of engagements organized targeting higher institutions on PC training.
- Number of leaders and managers from universities and other higher institutions of learning engaged in advocacy events on PC training.
- Number of universities and other higher institutions of learning offering courses and programs on PC.
- Number of courses and programs on PC offered across universities.
- Number of PC specialists recruited or assigned to teach on PC courses.
- Number of assessments and evaluations on PC course units conducted.
- Number of specialist training curriculums on PC developed.
- Number of PC short courses curriculum developed/ reviewed.
- Number of training guides on PC developed/ reviewed with the support of PCAU.
- Number of diploma and graduate programs on PC accredited by NCHE.
- PC integrated into the National Support Supervision guidelines of MoH
- Developed PC support supervision guide for PCAU
- Number of trained PC supervisors with support from PCAU.
- A mentorship guide developed to use in mentorship of ADCPN graduates.
- Number of graduates mentored using the mentorship guide by PCAU.
- Number of CPDs supported at the health facility level with support from PCAU.
- Number of short courses conducted on PC by PCAU.
- Number of PC units supported by PCAU to become practicum sites.
- Number of students supported on clinical placements.
- Number of PC professionals who have attended CPDs sessions organized by PCAU.
- Number of national update meetings on PC conducted.
- Number of regional/ branch meetings on PC conducted.
- Number of hospitals implementing PFHI with the support of PCAU.
- Number of scholarships offered by PCAU segregated by cadre.
- Number of PC accredited health facilities assessed.
- Number of PC units supported to strengthen the spiritual care component

Performance Indicators for Objective 2:

S02: To advocate for a supportive environment and increase understanding of palliative care among stakeholders in Uganda.

- Number of MDAs that mainstream interventions on PC.
- Updated essential medicines list of PC medicines.
- Number of advocacy events organized on access to PC essential medicines.
- Number of national level budget advocacy events held
- Number of district budget advocacy events held by PCAU.
- Percentage increase of funds allocated to palliative care in the national budget.
- Number of advocacy engagements for PC in humanitarian situations.
- Number of advocacy events held on availability of essential PC equipment, patient support devices, technologies and supplies.
- The PCAU Communication Strategy reviewed and implemented.
- Number of IEC materials on PC developed and disseminated.
- Number of PCAU newsletters published.
- Number of PC stories published locally and internationally.
- A social media engagement plan developed and implemented by PCAU.
- Number of professional bodies recognizing PC-training carders.
- Number of PC- related positions included in public service structure.
- Number of private health facilities that have PC positions.
- Number of events conducted to commemorate the WHPCD.
- Number of community sensitization events on PC conducted by PCAU.
- Number of community members participated in the community sensitization events on PC conducted by PCAU.
- Number of new formal collaborations and networks established by PCAU.
- Number of formal existing collaborations and networks for PC strengthened.
- Number of advocacy engagement events with legislators held.
- The national PC policy approved by government of Uganda.
- Number of advocacy engagement events on PC as a human right.
- Number of participants in events on advocacy for PC as a human right.
- Gender, justice and women rights issues related to PC profiled by PCAU.
- Number of media houses engaged for PC advocacy work.
- Number of stories aired on different media houses.
- Number of engagement events held for religious groups, cultural Institutions, and influential/opinion leaders to advocate and create awareness on PC.
- Number of religious, cultural and opinion leaders engaged on PC.
- Number of child-caregivers enrolled on the Road to Hope (RTH) program.
- Number of children graduated off the RTH program
- Developed and implemented RTH policy
- RTH program registered at the district by 2023.
- Number of children supported to access and continue with cancer treatment.
- Number of strategic advocacy engagements conducted District local council levels.
- Number of new of PC units established in districts without palliative care offering facilities.
- Number of specialized palliative care programs for children.

Performance Indicators for Objective 3

S03: To establish a hub of research and information on palliative care in Uganda.

- A research agenda for PCAU published.
- Percentage progress in the implementation of the PCAU research agenda.
- The PCAU Research Policy developed.
- Number of research studies on PC conducted.
- Number of research articles or book chapters published by PCAU.
- Number of published research studies on PC contributed to by PCAU.
- A peer-reviewed journal on PC established.
- Number of research grant proposals developed and submitted.
- Number of research grants for PC research secured.
- Number of stakeholders engaged in mobilizing research funding.
- PCAU information centre established both physically and digitally.
- An established Research Ethics Committee at PCAU.
- Guidelines for ethical review and clearance by PCAU Research Ethics Committee developed.
- Number of formal research collaborations for PC established.
- Number of research learning sessions on PC conducted
- Number of learning outputs produced and disseminated.
- Number of innovations and practices adopted across PCAU work.
- Number of health facility staff trained on national PC data management with the support of PCAU.
- Number of on-site mentorship sessions for facility staff on PC data management held.

- Number of facilities equipped with HMIS tools with support of PCAU.
- Number of facilities reporting through DHSI2.
- Number of data champions oriented in the regions.
- Number of PC data review meetings held.
- Number of biennial conferences on PC held.
- Number of research launch events.
- Number of research dissemination meetings/ webinars/workshops held.
- The PCAU digital information PC app established.
- Biennial Uganda PC Directory published.

Performance Indicators for Objective 4

SO4: To enhance effective and efficient governance and management of palliative care services in Uganda.

- Number of PCAU board meetings held.
- Number of PCAU board committee meetings held.
- Number of PCAU board evaluations conducted.
- Number of country PC team meetings conducted.
- Number of institutional systems strengthening engagements for the PC division conducted.
- Number of PCAU policies reviewed and implemented.
- Number of new PCAU policies developed.
- The PCAU new financial accounting system upgraded.
- Number of training (internal and external CPDs) sessions for PCAU staff conducted.
- Number of exchange and other experiential learning visits conducted hosted by and those by PCAU staff.
- Number of team-building activities for PCAU staff and volunteers conducted.
- The PCAU staff welfare and benefits scheme reviewed and enhanced.
- An M&E Officer recruited/ designated at PCAU.
- A functional M&E system developed and established at PCAU.
- Annual Membership and stakeholder surveys conducted.

Sustainability and Financial Efficiency for Objective 5

SO5: To enhance resource mobilization and financial efficiency for palliative care in Uganda.

- A feasibility study for the PC fund conducted.
- A national PC fund established.
- A national PC fund management Committee established.
- Number of resource mobilization drives conducted.
- PCAU resource mobilization team constituted.
- Number of grants received by amounts and source.
- Annual percentage increase of PCAU reserve fund.
- Annual percentage increase of funds designated for reserve.
- Number of donation boxes placed across the country.
- Number of in-kind donations received by PCAU.
- Number of new donors engaged to support on PCAU work.
- Number of funding proposals submitted by PCAU.
- Number of PCAU financial investments set up.
- Number of resource mobilization meetings held.
- Annual percentage increase of amount from the sale of promotional items.
- Land obtained for PCAU office expansion in at most 30KM radius from Kampala center.
- Palliative care recreational facility for PCAU established in Mbarara.
- Number of budget advocacy activities conducted at national and district levels by PCAU.
- Annual increase in amount allocated for palliative care in national and district budgets.
- Number of national and international memberships subscribed to by PCAU.
- Number of fundraising trainings workshops held for PCAU staff.
- Number of leadership meetings PCAU member organizations.
- Number of MoUs signed with public entities.
- Number of organizations collaborating with PCAU.
- Number of corporate entities supporting the work of PCAU.
- The PCAU membership strategy developed and implemented.
- Number of new PCAU individual members recruited.
- Number of PCAU member organizations enrolled.
- Number of PCAU Annual General Meetings conducted.
- Number of PCAU life membership assembly meetings held.
- Number of PCAU members get-together events.



PCAU will continue to advocate for and empower caregivers, including children, to promote the rights of patients in need of palliative care, their caregivers (including children) and disease survivors.

By the **end of December 2021**, the following districts in Uganda did not have a health facility offering Palliative Care Services

| District | Region |
|-------------|---------|
| Buvuma | Central |
| Kalangala | Central |
| Kassanda | Central |
| Lyantonde | Central |
| Nakasongola | Central |
| Ssembabule | Central |
| Budaka | Eastern |
| Bugweri | Eastern |
| Bulambuli | Eastern |
| Kaberamaido | Eastern |
| Kalaki | Eastern |
| Kapelebyong | Eastern |
| Kween | Eastern |
| Luuka | Eastern |
| Namayingo | Eastern |

| District | Region |
|---------------|----------|
| Namisindwa | Eastern |
| Alebtong | Northern |
| Amudat | Northern |
| Dokolo | Northern |
| Karenga | Northern |
| Nakapiripirit | Northern |
| Otuke | Northern |
| Pader | Northern |
| Bunyangabu | Western |
| Kamwenge | Western |
| Kazo | Western |
| Kyenjojo | Western |
| Ntoroko | Western |
| Rubanda | Western |
| Rukiga | Western |

Funding support from PCAU donors continues to enable PCAU to enhance palliative care work in Uganda and this also enabled the development of this Strategic Plan.

PCAU acknowledges funding support from:


- Center for Hospice Care / Centre for Hospice Foundation.
- American Cancer Society (ACS).
- Open Society Foundations for the funding support.




**OPEN SOCIETY
FOUNDATIONS**

Palliative Care Association of Uganda (PCAU)

Block 383, Plot 8804 Kitende, Entebbe Road
P.O. Box 34985, Kampala, Uganda

 **WhatsApp:** +256 789 737 786

 **pcau.admin@pcau.org.ug**

 **Toll Free:** 0800 399 100

 **www.pcauganda.org**