



RESEARCH AGENDA

2022 - 2026





APPROVAL

The research and information agenda, 2022- 2026 to guide PCAU investment in research was approved by the Board of Directors during the sitting in September 2022.

Mark Donald Mwesiga
Country Director

Dr. Henry Ddungu
President and Chair of the Board

ACKNOWLEDGMENTS

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LIST OF ACRONYMS

APCA	African Palliative Care Association
HSSDP	Health Sector Strategic Development Plan
MoH	Ministry of Health
PC	Palliative Care
PCAU	Palliative Care Association of Uganda
RA	Research Agenda
REC	Research and Ethics Committee
SP	Strategic Plan
WHO	World Health Organization
HMIS	Health Management Information System

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.



EXECUTIVE SUMMARY

High quality palliative care is best informed by methodologically strong research efforts that generate a strong and robust body of evidence. Developing such an evidence base is a necessity due not only to its capacity to support and direct care, but also to effect changes in practice.

The PCAU Research Agenda (RA) provides focus and direction for Palliative Care Research and strategic information by the Palliative Care Association of Uganda (PCAU). The development of the research agenda was accomplished through a consultative process covering a wide range of stakeholders and is aligned to the PCAU strategic plan (2022-2026), APCA's 2020-2030 strategic plan and Uganda Ministry of Health's specific objective four of the HSDP 2015-2020. The RA is a basis for research, resource prioritization and information sharing and will provide evidence-based solutions to PC service provision. Working in partnership will be central in achieving its objectives.

In order to become a hub for PC research in Uganda, PCAU research agenda will be guided by the following strategies

1. Grow PCAU in the international stature and enhance international exposure and opportunities for collaboration which will be achieved through:
 - Finalizing and actualizing the research agenda on palliative care.
 - Developing a research policy for PCAU.
 - Publishing research studies on palliative care.
 - Developing a peer-reviewed journal on palliative care.
 - Increasing and mobilizing research funding at PCAU.
 - Establishing a physical and digital information center for PCAU.
 - Establishing the PCAU digital information palliative care App.
 - Conducting the Biennial PC conferences.
2. Enhance PC capacity and skill development that meets the needs of patients and their families through:
 - Conducting periodical research studies on PC.
 - Strengthening research collaboration, learning and adaptation with relevant stakeholders.
 - Adoption and integration of innovative and efficient interventions
 - Structured dissemination of palliative care research and information.
3. Strengthen monitoring and evaluation by fast-tracking the audit of the Human Resources for Palliative Care demand and supply in the public and Private health Sector through:
 - Establishing a Research Ethics Committee for PCAU.
 - Strengthening the management of National PC data
 - Creating and publishing the biennial Uganda palliative care Directory.

The RA will address the urgent need for palliative care research that informs practice and policy. It will as well strengthen collaboration between palliative care practitioners within the country to better position them for global opportunities that are available.

A. BACKGROUND

According to the World Health Organisation (WHO), Palliative Care (PC) is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness.

The Palliative Care Association of Uganda (PCAU) is a civil society organisation established in 1999 to support and promote the development of palliative care and palliative care providers in Uganda the PCAU strategic plan for 2022-2026 has five focus areas:



The strategic objective of focus area three is “To be a hub of research and information, through the carrying out and/or hosting relevant Palliative Care (PC) research and leading the collection, storing, analysis of data and by regularly disseminating information to improve PC services.” A key result under focus area three is to “Articulate and publish the PCAU research agenda.”

The development of the Research and Information Agenda was a participatory process. Representatives from member organizations, APCA, MoH and other partners, as well as PCAU staff, contributed ideas in a brainstorming meeting, a zoom meeting and by completing an online questionnaire. The data generated from the brainstorming and from the questionnaires as well as from the zoom meeting was then used to synthesize a draft agenda with themes and suggested research questions. The draft agenda was presented to the PCAU board who suggested modifications before the final document.

B. REVIEW OF KEY ACHIEVEMENTS & CHALLENGES

Achievements

The strategic plan (SP) which had Research as one of its foci had several achievements from 2017 – 2021 which included:

- Recruitment of a Research officer who established a research desk at PCAU.
- Conducting and/or hosting -specific research projects and activities.
- Scaling-up of the m-Health program which promoted improvement of national data collection on PC and inclusion of PC service indicators in the national Health Management Information System.
- Publishing of the PC Newsletter and regular update of the PCAU Website
- Organizing Biennial National Conferences on cancer and palliative care to bring together partners and stakeholders to in Uganda and share best practices.

SWOT analysis

Strengths

- A critical mass of competent PC trained human resource from various disciplines
- Integration of PC in MoH structure
- MOE&S approving the Diploma in Palliative Care Nursing
- Nursing council registering Palliative care Nurses

Opportunities

- An innovative program for building national capacity in addressing the PC problems
- PCAU has a vast amount of research outputs that could be shared with other stakeholders nationally and internationally.
- Existing networks and partnerships for research collaborations
- Virtual learning and libraries without walls which allow the use of e-Learning and information sharing has revolutionized research

Weaknesses

- Limited access to journals, and published information
- Lack of a REC
- Limited research
- Integration of research in scholarship- every sponsored student should do research in PC as part of the conditions
- Coordination and collaborations?

Threats

- Decreasing financial resources
- PC Staff attrition
- Low Research uptake where the Research Findings are not being used by the intended users.

C. STRATEGIC DIRECTION

The purpose of the PCAU Research Agenda

A PCAU research agenda provides focus and direction for the focus area three: Palliative Care Research and Information. The agenda is aligned to the PCAU strategic plan (2022-2026), APCA's 2020-2030 strategic plan and Uganda MoH's specific objective four of the HSDP 2015-2020. It is a basis for research, resource prioritization and information sharing. The research agenda will assist in providing evidence-based solutions to PC service provision in Uganda.

Goal: The goal of this Research Agenda is to document palliative care areas with limited evidence and undertake research activities that will address the issues surrounding those areas.

Strategies

The PCAU Research Agenda (RA) provides focus and direction for Palliative Care Research and Information. The agenda is aligned to the PCAU strategic plan (2022-2026), APCA's 2020-2030 strategic plan, and Uganda Ministry of Health's specific objective four of the HSDP 2015-2020. This RA is a basis for research, resource prioritization and information sharing and will provide evidence-based solutions to PC service provision. Working in partnership will be central in achieving its objectives.

In order to become a hub for PC research in Uganda, the PCAU research agenda will be guided by the following:

1. Growing PCAU in the international stature and enhance international exposure and opportunities for collaboration which will be achieved through:
 - Finalizing and actualize the research agenda on palliative care.
 - Developing a research policy for PCAU.
 - Publishing research studies on palliative care.
 - Developing a peer-reviewed journal on palliative care.
 - Increasing and mobilizing research funding at PCAU.
 - Establishing a physical and digital information center for PCAU.
 - Establishing the PCAU digital information palliative care App.
 - Conducting the Biennial PC conferences.

2. Enhancing PC capacity and skill development that meets the needs of patients and their families through:
 - Conducting periodical research studies on PC.
 - Strengthening research collaboration, learning and adaptation with relevant stakeholders.
 - Adoption and integration of innovative and efficient interventions
 - Structured dissemination of palliative care research and information.

3. Strengthening monitoring and evaluation by fast-tracking the audit of the Human Resources for Palliative Care demand and supply in the public and Private health Sector through:
 - Establishing a Research Ethics Committee for PCAU.
 - Strengthening the management of National PC data
 - Creating and publishing the biennial Uganda palliative care Directory.

Expected results/products

1. Research agenda developed and operationalized, Routine dissemination of PC research and information using various platforms.
2. Research and information center developed.
3. Research policy for PCAU developed.
4. Biennial scientific conferences conducted.
5. PCAU will re-establish the peer-reviewed Journal through strengthening research collaboration, learning, and adaptation with relevant stakeholders and conduct periodical research studies on Palliative care in Uganda.
6. Strengthening the management of national PC data by increasing the 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,
7. A REC established.

PCAU research priority areas

The research thrusts to guide PCAU for the next five years are:

Access and availability to PC essential medicines and supplies	Access to safe, effective, quality, and affordable essential medicines is important in the provision of high-quality palliative care.
Level of PC development	It is essential to know how the PC services are developing to meet the unmet needs
Palliative care service delivery	This is an essential theme of a health care system covering the topics of availability, acceptability, accessibility, affordability, quality, models, and others. These are areas which when systematically researched, will yield evidence to underpin quality and affordable palliative care services in Uganda.
Palliative care financial resources	Financial resource is a key building block for palliative care service provision. Mobilization, gathering and allocation of financial resources is essential for provision of palliative care services. Research to understand the current and the potential financial sources will provide evidence for technology and innovation as well as resource mobilization for palliative care in Uganda.
Human resources for palliative care	Human resources are the most important input for palliative care services' provision. To be able to conduct relevant research and use the findings in evidence-based PC decisions depends on the availability of people with relevant knowledge, skills, and motivation
Palliative care education	This strengthens the provision of quality palliative care services through trainings, continuous professional education, mentorship, and support supervision
Palliative care for children	Children are vulnerable because they are totally dependent on others and have very limited autonomy. Children have distinct PC needs but the service is limited.
PC perceptions, experiences, and preferences:	The key stakeholders' perceptions, preferences and experiences influence the decisions they make about supporting and/or using PC services. It is therefore essential to have these systematically researched for evidence base decisions.
PC outcomes	Research to identify PC end result versus the desired outcomes informs decisions to improve and narrow the gap between these two.
PC in emerging setting	The context of PC is ever changing, and PC services should be able to adapt to change
PC Policy	Policy is critical for PC because it identifies what key the stakeholder, the government, will or will not do. It affects the organization and funding of the services. Research for policy analysis is therefore critical.
Advocacy	One of the focus areas of PCAU is advocacy. This is critical for PC because awareness is still a major hindrance to PC service provision

D. THE RESEARCH FRAMEWORK

FRAMEWORK

Focus area	Strategies	Milestones
1. Grow PCAU in the international stature and enhance international exposure and opportunities for collaboration	<ul style="list-style-type: none"> Finalize and actualize the research agenda on palliative care. 	<ul style="list-style-type: none"> Research Agenda Published and Percentage progress in the implementation of the PCAU research agenda
	<ul style="list-style-type: none"> Develop a research policy for PCAU. 	<ul style="list-style-type: none"> The PCAU research policy developed
	<ul style="list-style-type: none"> Publish research studies on palliative care. 	<ul style="list-style-type: none"> Number of research studies on pc published, research articles or book chapters published by PCAU and number of published research studies on PC contributed to by PCAU
	<ul style="list-style-type: none"> Develop a peer-reviewed journal on palliative care. 	<ul style="list-style-type: none"> A peer reviewed journal on palliative care published
	<ul style="list-style-type: none"> Increase and mobilize research funding at PCAU. 	<ul style="list-style-type: none"> Number of stakeholders engaged in mobilizing research funding for PC and number of research grant proposals developed, submitted and secured
	<ul style="list-style-type: none"> Establish an information centre for PCAU. 	<ul style="list-style-type: none"> PCAU Information centre established both physically and digitally
	<ul style="list-style-type: none"> Disseminate palliative care research and information. 	<ul style="list-style-type: none"> Number of research learning sessions on PC conducted, Number of learning outputs produced and disseminated
	<ul style="list-style-type: none"> Establish the PCAU digital information palliative care App. 	<ul style="list-style-type: none"> The PCAU digital information PC App established
	<ul style="list-style-type: none"> Create and publish the biennial Uganda Palliative Care Directory. 	<ul style="list-style-type: none"> Biannual Uganda PC Directory Published
	<ul style="list-style-type: none"> To conduct the Biennial conferences. 	<ul style="list-style-type: none"> Number of biannual conferences on PC held. Number of research launch events and number of research dissemination meetings/ webinars/workshops held

Focus area	Strategies	Milestones
2. To improve the delivery of research led palliative care short- and long-term capacity building that meets the needs of patients and their families through the following strategies.	<ul style="list-style-type: none"> Conduct periodical research studies on PC. 	<ul style="list-style-type: none"> Number of research studies on PC conducted
	<ul style="list-style-type: none"> Strengthen research collaboration, learning and adaptation with relevant stakeholders. 	<ul style="list-style-type: none"> Number of formal research collaborations for PC established.
	<ul style="list-style-type: none"> Embrace and integrate innovative ideas in PCAU work 	<ul style="list-style-type: none"> Number of innovations and practices adopted across the PCAU work
3. Strengthening monitoring and evaluation of research and learning process by fast tracking the audit of the human resources for palliative care demand and supply in the public and private health sector through the following strategies.	<ul style="list-style-type: none"> Establish a Research Ethics Committee for PCAU. 	<ul style="list-style-type: none"> An established Research Ethics Committee at PCAU with guidelines for ethical review and clearance by PCAU research ethics committee developed.
	<ul style="list-style-type: none"> Strengthen the management of national pc data 	<ul style="list-style-type: none"> 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, and annual pc provision trends developed by PCAU.
	<ul style="list-style-type: none"> Create and publish the biannual Uganda PC Directory 	<ul style="list-style-type: none"> Biennial Uganda PC Directory Published

Research Agenda Review and Evaluation

The RA will be reviewed annually to inform the planning and budgeting process. The RA will be evaluated by conducting an independent midterm review and a summative evaluation at the end of 5 years.

E. RESEARCH PROCESS

Steps

- **Solicitation:** PCAU will disseminate the RA widely among members of the academia and partners. All application and consultations for research shall be made through the PCAU Research and Information committee / department.
- **Eligibility:** PCAU will receive concepts from researchers (individuals/institutions/organizations) who may be from Uganda or from other countries.

Research grants will be eligible for only Postgraduate candidates undertaking research in line with the research agenda.

- **Selection criteria:** Topics which are aligned with the PCAU research agenda shall be prioritized. The researchers will be encouraged to collaborate with the PCAU research office to develop a full proposal.
- **Ethical considerations:** All proposals shall be submitted to an accredited Research Ethics Committee for ethical approval. PCAU shall support the researcher in seeking permission from relevant offices to permit data collection. Data collection and report writing will then be proceed followed by dissemination of findings.
- **Dissemination:** The dissemination may be through stakeholder meetings, newsletters, and conferences. Publications in peer reviewed journals shall be prioritized as a dissemination channel.

F. RESEARCH GRANTS

- **Solicitation;** PCAU will also offer research grants to candidates undertaking PC research. Advertisements for research grants will be done online only when there is availability of fund. All applications for research grants shall be made through the PCAU Research and Information committee/department.
- **Eligibility:** PCAU will receive concepts from researchers (individuals/institutions/organizations) who will be from Uganda.

Research grants will be eligible for only Postgraduate candidates undertaking research in line with the research agenda.

- **Selection criteria:** Topics which are aligned with the PCAU research agenda shall be prioritized.
- **Notification of outcome:** upon receipt of the application, the applicant will be notified and given information on when to expect feedback from the Research and Information committee / department.

G. PROPOSED RESEARCH GAPS

The following are proposed research gaps and questions for consideration.

SN	Theme	Proposed Research questions
1.	Level of PC development	<p>Why has the level of PC development in Uganda deteriorated from advanced to preliminary health system integration?</p> <p>What policies and/or guidelines and strategies are available to support PC development and services in Uganda?</p>
2.	Availability	What is the availability and utilization of opioids for PC in Uganda?
		What is the distribution of PC services in the health care system in Uganda?
		What are the barriers to opioids availability and utilization in PC in Uganda?
		What are the opioids estimation and supply challenges in Uganda?
		What are the health system challenges affecting access to oral liquid morphine in Uganda?
	Need	What are the PC needs for older persons?
		What are the palliative care needs of non- cancer/ non-HIV/AIDS patients with chronic pain (Sickle Cell Disease and other severe painful Non-Communicable Diseases)?
		What are the PC needs of people with severe and enduring mental illnesses?
	Access	What are the barriers to access in Uganda?
		How effective are referral methods for palliative care patients?
	Equity	Who is not accessing PC services in Uganda?
		How accessible is PC to vulnerable populations in Uganda?
	Quality	What is the quality of PC in Uganda?
		What is the state of units in health facilities in Uganda?
	Models	Which is the most efficient and effective model for PC in Uganda?
		How can ICT be used to facilitate PC service delivery?
Data	How are the PC indicators being used to improve PC in Uganda?	
	Is there a need for more PC indicators to support M&E and service delivery?	

SN	Theme	Proposed Research questions		
3.	Palliative Care Financial resources	What resources are available for PC delivery in Uganda?		
		What does it cost to deliver PC services in Uganda?		
		How do the costs of facility-based PC compare with the costs of home-based PC services?		
		How can insurance companies be interested to include PC in their scope of coverage?		
		How can private-public partnerships be strengthened?		
4.	Human Resources for Palliative Care	What is the current situation of Human Resources for PC in Uganda?		
		What difference are trained palliative care workers making in their facilities?		
		What are the training needs of human resources for PC?		
		How has the training of PC health workers affected the PC delivery in Uganda?		
		What are the needs of PC providers – multidimensional?		
		What is the prevalence of depression among PC care givers?		
		What is the attitude and the factors for motivation of human resources for PC in Uganda?		
		Who are the care givers of palliative care at family and community level? What are their needs?		
	PC for children	What is the state of pediatric palliative care services in Uganda?		
		What are the needs for PC for children in Uganda?		
		What is the PC needs for children with nodding disease? – A census at regional referral hospitals is needed.		
		5.	Palliative Care perceptions, experiences, and preferences	What are the service preferences for PC patients in Uganda?
				What is the public/community's perception of PC?
What is the knowledge and attitude of policy makers towards PC?				
What is the level of knowledge of law enforcement officers' regarding controlled medicines as essential drugs for PC?				
What is the public's understanding and perceptions of PC?				

SN	Theme	Proposed Research questions
6.	Palliative Care outcomes	What are the main diseases requiring Palliative Care in Uganda?
		What are the Palliative Care outcomes in Uganda?
		What is the prevalence of opioid use disorder and adverse effects among PC patients in Uganda?
7.	PC in emerging settings	How has the COVID-19 pandemic affected the availability and access to PC in Uganda?
		Adapting PC to humanitarian situations such as among refugees.
8.	Advocacy	How can the concept of PC be sold to beneficiaries and other key stakeholders?

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