



# ANNUAL REPORT



PALLIATIVE CARE AND  
UNIVERSAL HEALTH COVERAGE

APRIL  
2019



MARCH  
2020



**THIS YEAR, APCA IMPLEMENTED ACTIVITIES IN PARTNERSHIP WITH 31 ORGANISATIONS AND INSTITUTIONS IN 14 COUNTRIES ACROSS AFRICA.**

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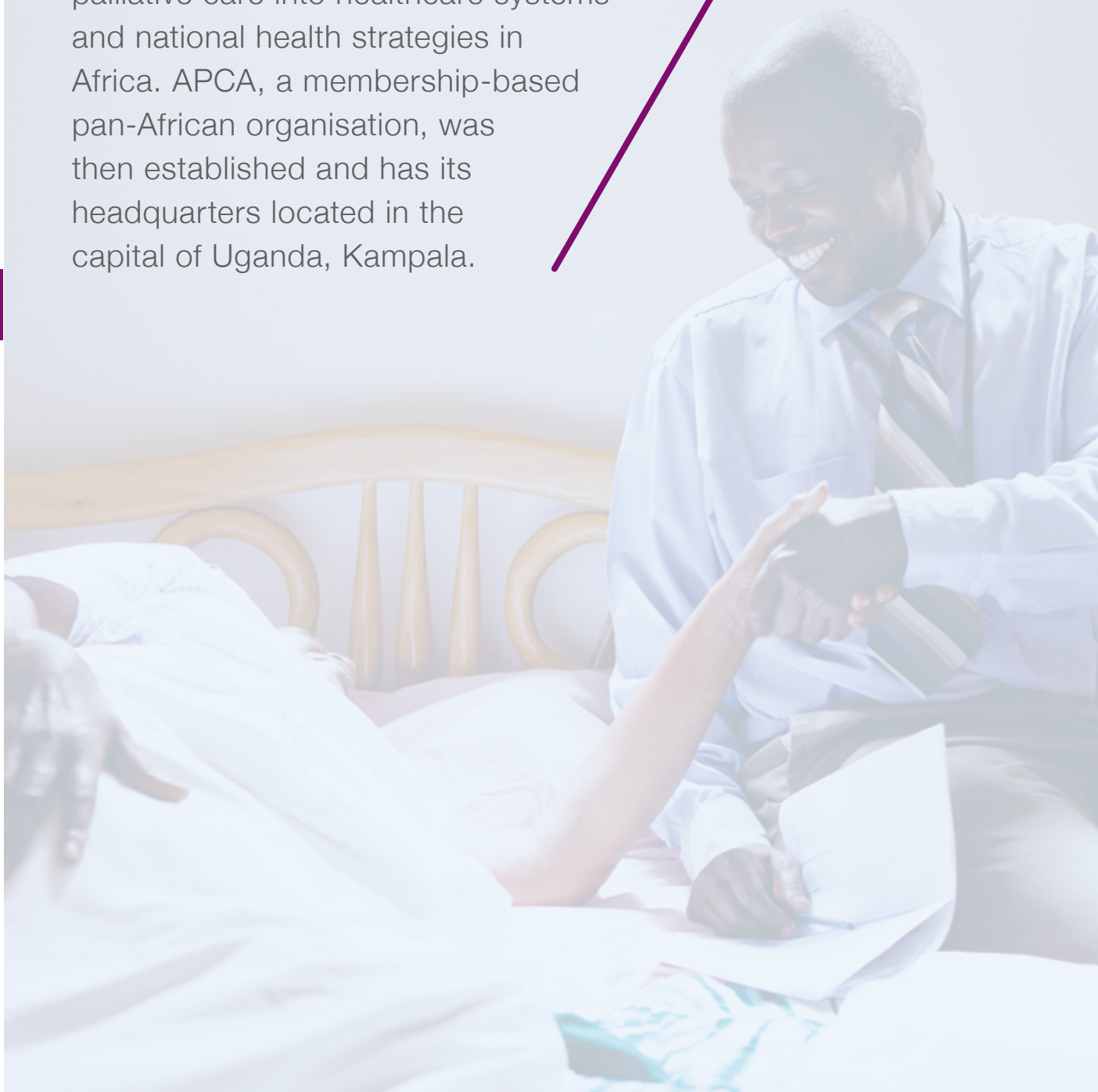
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# WHO WE ARE

Founded in 2004, the African Palliative Care Association (APCA) originated at a meeting of 28 palliative care trainers from across the African continent, who met in Cape Town, South Africa, in 2002. These trainers produced a declaration calling for the integration of palliative care into healthcare systems and national health strategies in Africa. APCA, a membership-based pan-African organisation, was then established and has its headquarters located in the capital of Uganda, Kampala.



# / VISION

Access to palliative and comprehensive chronic care for all in Africa

# / MISSION

To ensure palliative and comprehensive chronic care is understood and integrated into health systems at all levels to reduce pain and suffering across Africa. Since its opening in 2004, APCA has established a continent-wide reach and built strong partnerships globally, regionally and at national levels that have enabled it to deliver on its objectives. All APCA's activities and decisions are underpinned by core values that have built a very strong governance structure, robust accountability systems and a commitment to the people served.

At the core of the work of APCA are patients, their families, their carers and the multidisciplinary teams of health workers who deliver the services. APCA's new strategic plan for 2020-2030 is intended to orchestrate action at regional, national and local levels to ensure that there is access to these services for all who need them without necessarily having to face risks of out-of-pocket costs in line with the global Universal Health Coverage 2030 agenda.

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# / WHY APCA

APCA is uniquely placed to drive forward the palliative and comprehensive chronic care agenda across the continent given its track record, a very rich and diverse membership, experienced professional staff and a great opportunity to work

with its members, national palliative care associations, academic institutions, organisations of palliative care beneficiaries, ministries of health across Africa and global palliative care organisations.

**READ MORE ABOUT US AT  
[WWW.AFRICANPALLIATIVECARE.ORG](http://WWW.AFRICANPALLIATIVECARE.ORG)**

# WHAT WE DO

ALL ACTIVITIES WERE GEARED TOWARDS CONTRIBUTING TO OUR FOUR STRATEGIC OBJECTIVES, NAMELY:

01

INCREASING KNOWLEDGE AND AWARENESS OF PALLIATIVE CARE AMONG ALL STAKEHOLDERS



02

STRENGTHENING HEALTH SYSTEMS BY INTEGRATING PALLIATIVE CARE



03

BUILDING THE EVIDENCE BASE FOR PALLIATIVE CARE IN AFRICA






04




ENSURING THE ECONOMIC SUSTAINABILITY OF APCA



Our mission and objectives remain aligned to global strategies that relate to palliative care, namely; the 2014 World Health Assembly resolution to strengthen palliative care as a component of comprehensive care throughout the life course; the 2017 World Health Assembly Resolution on Cancer, the Sustainable Development Goals (SDGs), including good health and wellbeing and palliative care as pivotal in achieving Universal Health Coverage.

-  1. Health service delivery
-  2. Health workforce
-  3. Health information systems

Our approach is guided by the World Health Organisation's public health strategy that focuses on policy, education, access to essential medicines and service implementation for effectively integrating palliative care into a country's health system. Our interventions directly contribute to the six WHO health systems building blocks, and this annual report highlights our success stories in the year in line with the building blocks, namely;

-  4. Access to essential medicines, vaccines and technologies
-  5. Health systems financing
-  6. Leadership and governance

This year, APCA implemented activities in partnership with 31 organisation and institutions in 14 countries across Africa. The countries are as follows: Burundi, Democratic Republic of Congo, Eswatini, Ethiopia, Kenya, Madagascar, Malawi, Mozambique, Rwanda, South Africa, South Sudan, Tanzania, Uganda and Zimbabwe. This has been possible through the very generous support of our donors and partners within and outside Africa who are mentioned later in the report.

Interventions were implemented mainly through formal partnerships and collaboration with Ministries of Health, National Palliative Care Associations, palliative care service providing organisations, public and private not-for-profit health facilities including cancer centres and professional associations, civil society as well as academic institutions.

We also leveraged technical support from APCA's members and partners in the different regions of Africa where we implemented activities. This year the organisations which contributed technical support towards our interventions include;

### **National palliative care associations**

- Palliative Care Association of Malawi (PACAM)
- Palliative Care Association of Uganda (PCAU)
- Hospice Palliative Care Association of Zimbabwe (HOSPAZ)
- Mozambique Palliative Care Association (MOPCA)

### **Ministries of health**

- Ministry of Health – Malawi
- Eswatini Ministry of Health – Eswatini
- Ministry of Health – Uganda

### **Other international partners**

- World Wide Hospice and Palliative Care Alliance (WHPCA)
- Global Partners in Care
- WHO Geneva

### **Palliative care service providers**

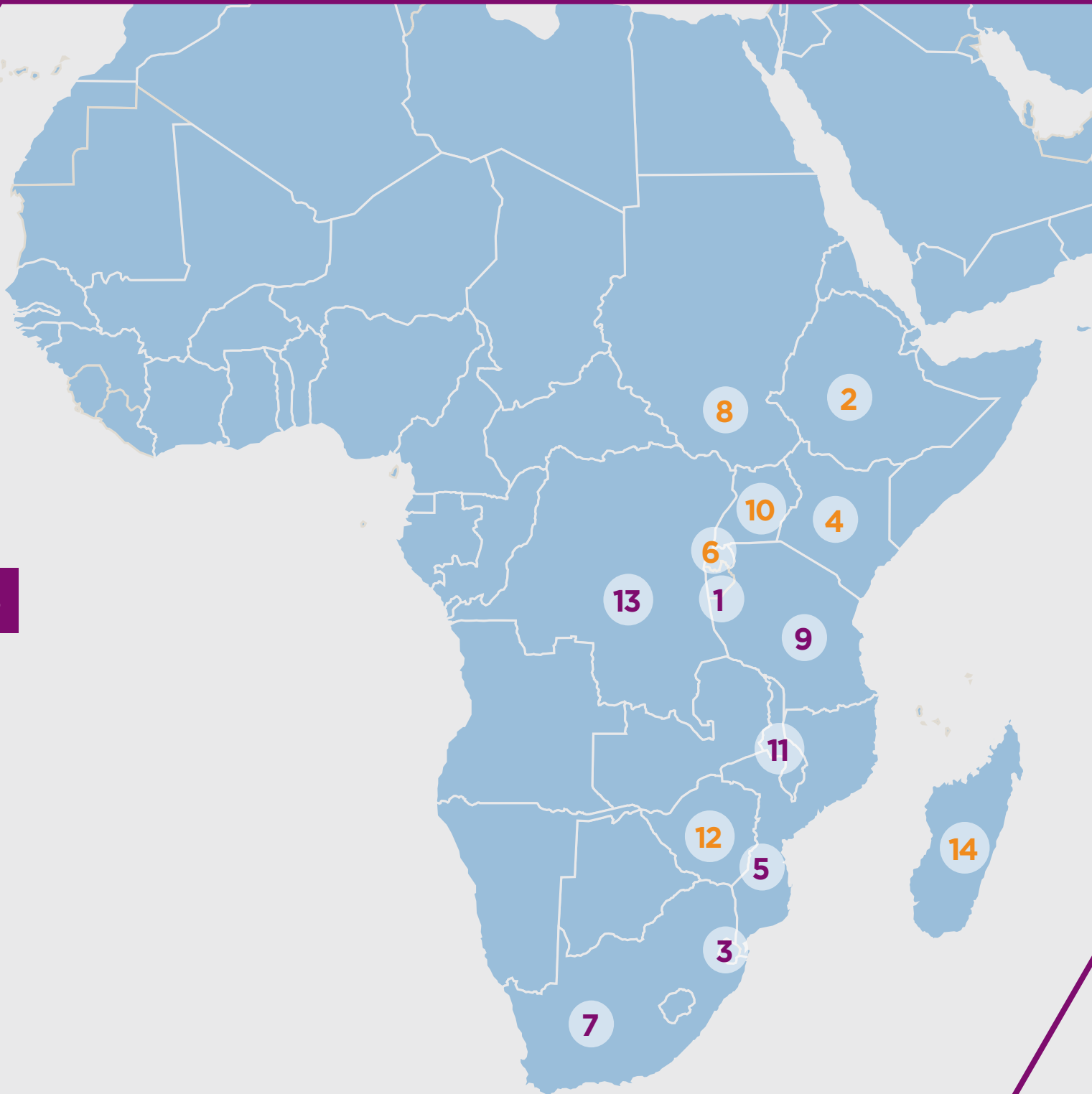
- Makerere Palliative Care Unit (MPCU)
- Hospice Africa Uganda (HAU)
- Island Hospice Zimbabwe
- Centre for Palliative Care, Nigeria (CPCN)

### **Academic institutions**

- University College Hospital Ibadan – Nigeria
- University of Leeds – UK
- Cicely Saunders Institute, King's College – London
- Queen's University – Belfast, UK
- University of Rotterdam – Netherlands
- Gauteng Centre of Excellence – South Africa

**OUR APPROACH IS GUIDED BY THE WORLD HEALTH ORGANISATION'S PUBLIC HEALTH STRATEGY THAT FOCUSES ON POLICY, EDUCATION, AND ACCESS TO ESSENTIAL MEDICINES AND SERVICE IMPLEMENTATION FOR EFFECTIVELY INTEGRATING PALLIATIVE CARE INTO HEALTH SYSTEMS**

## SUMMARY OF COUNTRIES AND IN-COUNTRY PARTNERS SUPPORTED IN THE YEAR



8

**31** NUMBER OF LOCAL PARTNERS SUPPORTED IN AFRICA



# SUMMARY OF COUNTRIES AND IN-COUNTRY PARTNERS SUPPORTED IN THE YEAR

COUNTRY	NUMBER OF PARTNERS	PARTNERS SUPPORTED
1. Burundi	01	<ul style="list-style-type: none"> <li>East African Health Research Commission</li> </ul>
2. Ethiopia	01	<ul style="list-style-type: none"> <li>Hospice Ethiopia</li> </ul>
3. Eswatini	03	<ul style="list-style-type: none"> <li>Ministry of Health</li> <li>Raleigh Fitkin Memorial Hospital</li> <li>Shiselweni Home-based Care</li> </ul>
4. Kenya	02	<ul style="list-style-type: none"> <li>Kenya Hospices and Palliative Care Association</li> <li>Ongata Ngong Palliative Care Community Organisation</li> </ul>
5. Mozambique	02	<ul style="list-style-type: none"> <li>Mozambique Palliative Care Association</li> <li>Associação Nacional Dos Enfermeiros de Moçambique</li> </ul>
6. Rwanda	02	<ul style="list-style-type: none"> <li>Rwanda Biomedical Center</li> <li>Rwanda Ministry of Health</li> </ul>
7. South Africa	08	<ul style="list-style-type: none"> <li>Hospice and Palliative Care Association of South Africa</li> <li>Helderberg Hospital</li> <li>Lambano Sanctuary</li> <li>The Tygerberg Hospice Trust</li> <li>Breede River Hospice</li> <li>Centurion Hospice Association</li> <li>Goldfields Hospice Association</li> <li>Thembalitsha Foundation</li> </ul>
8. South Sudan	01	<ul style="list-style-type: none"> <li>Mind for Community Development Organisation</li> </ul>
9. Tanzania	02	<ul style="list-style-type: none"> <li>Nyakahanga Designated District Hospital</li> <li>Machame Council Designated Hospital</li> </ul>
10. Uganda	02	<ul style="list-style-type: none"> <li>Palliative Care Association of Uganda</li> <li>Uganda Cancer Institute</li> </ul>
11. Malawi	02	<ul style="list-style-type: none"> <li>Diocese of Dedza</li> <li>Palliative Care Association of Malawi</li> </ul>
12. Zimbabwe	02	<ul style="list-style-type: none"> <li>Hospice Palliative Care Association of Zimbabwe</li> <li>Life Empowerment Support Organisation</li> </ul>
13. Democratic Republic of Congo	02	<ul style="list-style-type: none"> <li>Centre Hospitalier Aru Cite</li> <li>Focus Droits Et Acces</li> </ul>
14. Madagascar	01	<ul style="list-style-type: none"> <li>Douleurs Sans Frontieres</li> </ul>



## MEMBERSHIP

By September 2019, APCA had built its membership to 2,034 institutional and 4,310 individual members globally. At the General Assembly held in Kigali, Rwanda in September 2019 a decision was taken to introduce paid membership as a way of contributing to its sustainability. APCA is therefore in the process of building a paid individual and institutional membership portfolio with effect from January 2020.



To join APCA's membership benefit programme email: [members@africanpalliativecare.org](mailto:members@africanpalliativecare.org)

# PERFORMANCE AGAINST THE WORLD HEALTH ORGANISATION'S HEALTH SYSTEM BUILDING BLOCKS

During this financial year, April 2019 to March 2020, APCA continued to implement its 10-year Strategic Plan (2011 – 2020) in what was its final year.

## BUILDING BLOCK 1

### + PALLIATIVE CARE SERVICE DELIVERY



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Provision of and access to quality palliative and comprehensive chronic care services is the linchpin of palliative care. During the year, we supported both the increase in coverage for palliative and comprehensive chronic care services and quality improvement services. APCA supported thirty-one (31) organisations/institutions from 14 African countries of Burundi, Democratic Republic of Congo, Ethiopia, Eswatini, Kenya, Madagascar, Mozambique, Malawi, Rwanda, South Africa, South Sudan, Uganda, Tanzania, Zimbabwe to further strengthen and expand quality palliative care services as well as quality improvement. This support was given in form of small grants and/or technical assistance and mentorship.

#### Quality and standards in palliative care

Quality assurance in palliative and comprehensive chronic care services is one of APCA's core values, through which we work to bridge the inequity gap in access to quality services. APCA thus routinely supports partners to conduct audits to assess the quality of the services, and to identify areas for improvement. The audits are conducted using the APCA standards for quality palliative care services (<http://www.thewhpc.org/resources/item/apca-standards-for-providing-quality-palliative-care-across-africa>).

This financial year, we are delighted to share the success story from the Raleigh Fitkin Memorial Hospital (RFM) in Eswatini.



The palliative care unit at Raleigh Fitkin Memorial Hospital (RFM) instituted through the contribution of the OSISA project.

Raleigh Fitkin Memorial Hospital (RFM) in Eswatini, which is the birthplace of current King Mswati, is a 350-bed regional referral and teaching hospital situated in Manzini, the hub of Eswatini. The palliative care unit at the hospital was instituted during the life of a 2-year project that aimed to develop the hospital as a palliative care centre of excellence, with financial support from OSISA. A palliative care standards audit was thus undertaken to assess the quality of palliative care service provision at the hospital after efforts aimed at institutionalising palliative care at the hospital through support from this project. The process involved reviewing the status of palliative care services in different areas and making recommendations for improvement.

The audit was conducted in October 2019 through the leadership of Eswatini National AIDS Program (SNAP) in partnership with the Ministry of Health, an approach which promoted ownership of the process as well as use of the results and responsibility for quality improvement. The Ministry of Health had earlier adopted APCA standards as part of the quality assurance framework for palliative care service delivery at the national level.

Feedback from the audit identified areas for improvement and associated recommendations. These areas for improvement included; documentation, involvement of volunteers, community engagement, paediatric palliative care and research. The facility continues to work with SNAP and other donors to implement the recommendations.

### **Making palliative care services multi-disciplinary through integration of legal services**

APCA is at the forefront of integrating legal services into palliative care, building on our previous work on the legal needs for cancer patients highlighted a pressing need for legal services in palliative care. This financial year we are delighted to share our story on the impact of our work in Zimbabwe, which was undertaken in partnership with the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) provided local technical support, The program brought together lawyers and palliative care service providers in Zimbabwe to integrate legal care into palliative care services. The implementation in Zimbabwe built on lessons from Uganda following a successful implementation of a similar project.

The project design approach involved engaging the Legal Aid Directorate, the government arm of the legal department who organized the lawyers to address legal needs of palliative care patients.

As a best practice, the project made use of existing community structures that included police, social workers, child care workers, lawyers and mentor mothers. This approach was appraised through regular meetings and dialogues between palliative care and legal stakeholders that enabled cross learning and service improvement.

Through this program more than 40 lawyers from 17 organisations were sensitised on palliative care, many learning about it for the first time. Twelve (12) of these were further mentored to provide pro bono services to patients with legal needs from 11 palliative care organisations. Seventeen (17) patients were case managed through pro bono legal services and 68 household and community members benefitted from assistance with legal information (through group and one-on-one sessions held). In addition, guidelines for the integration of legal services into palliative care in Zimbabwe as well as legal awareness posters for various populations were developed to scale up the services. Cases that were supported included property ownership/dispossession, child custody, writing wills, the administration of estates, and other human rights related issues.

This initiative was widely welcomed as it brought about a change in attitude among the stakeholders involved from all sides, particularly the lawyers and health care workers. One stakeholder from the Cancer Association of Zimbabwe commented:

*‘This teaming up with lawyers to support our patients should be forever’.*

Having seen the great impact this had on the lives of patients, APCA is looking at more collaborations to expand the integration of legal services into palliative care services in other African countries.

**THE ZIMBABWE LEGAL PROJECT WAS A SYMBIOTIC STRUCTURE WHICH DEMONSTRATED THAT LAWYERS CAN OFFER PRO BONO SERVICES TO PEOPLE WITH PALLIATIVE CARE NEEDS THAT HAVE LEGAL ISSUES BUT COULD NOT AFFORD TO PAY FOR THE SERVICES.**

# BUILDING BLOCK 2



## HEALTH WORKFORCE



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The lack of a critical mass of healthcare workers who are adequately trained to deliver palliative care services in all settings of healthcare continues to be a challenge that APCA and its partners are addressing in Africa. APCA uses palliative and comprehensive chronic care education in the region to equip and enable health workers to deliver effectively on their mandate. This is a key component of our contribution to strengthening health systems. APCA has been supporting capacity building for health care workers through introductory trainings, facilitating mentorship exchanges, as well as scholarships given to health professionals to undertake specialized palliative and comprehensive chronic care courses.

### **Palliative Care introductory training in Mozambique and continuous mentorship**

Mozambique, which was hit by cyclone Idai early in 2019 is one of the countries with a great need for palliative care. APCA has been working with the Mozambique Palliative Care Association (MOPCA) for over 10 years to develop palliative care and improve access to palliative care medicines. From 2017, APCA has been working with MOPCA to develop Chibuto Rural District Hospital (CDH) in Gaza Province as a centre of excellence for palliative care in the country, through funding from the Open Society Initiative for Southern Africa (OSISA). This year 25 more health care workers from Chibuto Rural Hospital in Gaza Province and four of its health centres undertook a 5-day basic training in palliative care. The training conducted in April 2019 aimed to empower more health care professionals with palliative and comprehensive chronic care knowledge and skills to provide quality care to patients with palliative care needs. The trained team consisted of multidisciplinary cadres

including **4 doctors, 15 nurses, 3 pharmacists, 2 dentists and 1 anaesthetist**. This particular training focused more on spiritual and psychosocial issues which had been noted as areas that needed skills strengthening. Observations previously showed that patients with chronic conditions often had spiritual and psychological issues in addition to the physical conditions that impacted on their general quality of life. Support, supervision, and mentorship for these trained health care workers was ongoing, with site visits undertaken in September 2019. These trained healthcare workers added to those already trained to continue towards building a critical mass of healthcare workers with palliative care knowledge and skills. Thus, palliative care services at Chibuto Rural Hospital, and the other facilities whose workers were trained continue improving, with Chibuto serving as a centre of excellence for the provision of palliative and comprehensive chronic care.

During the training, the need for work tools and materials, was identified as one of the hindrances to palliative care provision. A total of 150 copies of Beating Pain Pocket Guide and 200 Pain Assessment Scales were disseminated. Following the training, the peripheral clinics around Chibuto Rural Hospital adopted a creative approach to documenting people in pain and in need of further management

through using a different colour in the patient registration book.

Mozambique still faces challenges of access to oral morphine for pain relief and APCA continues to provide technical support and looking for potential funders for oral morphine powder to initiate the maiden reconstitution of the medicine in-country.

### Palliative care education scholarships

During the year under review, APCA awarded **scholarships to 6 nurses** to attain bachelors and diploma courses at the Institute of Hospice and Palliative Care in Africa (IHPCA), based in Uganda and Kenya Medical Training College based in Kenya. The scholars came from Malawi, Uganda, Zimbabwe, Kenya, and these are; Akello Beatrice – Uganda; Innocent Chikafalimani – Malawi; Petronella Marume – Zimbabwe; Emmanuel Kizza – Uganda; Stellan Liza Gatwiri – Kenya; and Jacqueline Kawondera

– Zimbabwe. During these training sessions, the participants were empowered to deliver high quality care to patients and families, and to engage in leadership, advocacy and communication, all of which are critical skills for the palliative and comprehensive chronic care agenda in Africa.



This initiative is supported by our partner, Global Partners in Care (<https://globalpartnersincare.org/>).

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*“Being a nurse and a medical clinical officer already in practice, little did I know that palliative care was such a broad and an extensive course that could offer me the best knowledge on treatment of patients with life limiting illnesses.”*

Diploma in Palliative Care student

*“I thought palliative care was only for those at the end of life. We were not sure how to deal with children specifically with the same conditions. Now we are able to take on children with palliative care needs, we have so far provided care to 2 children under AML this year. In this position I improved advocacy skills, leadership skills, relationship skills and communication skills. My writing skills in various capacities have improved greatly. I can now write journals, abstracts and critique other articles”*

Catherine, APCA scholar 2019

### Psychological care and team building

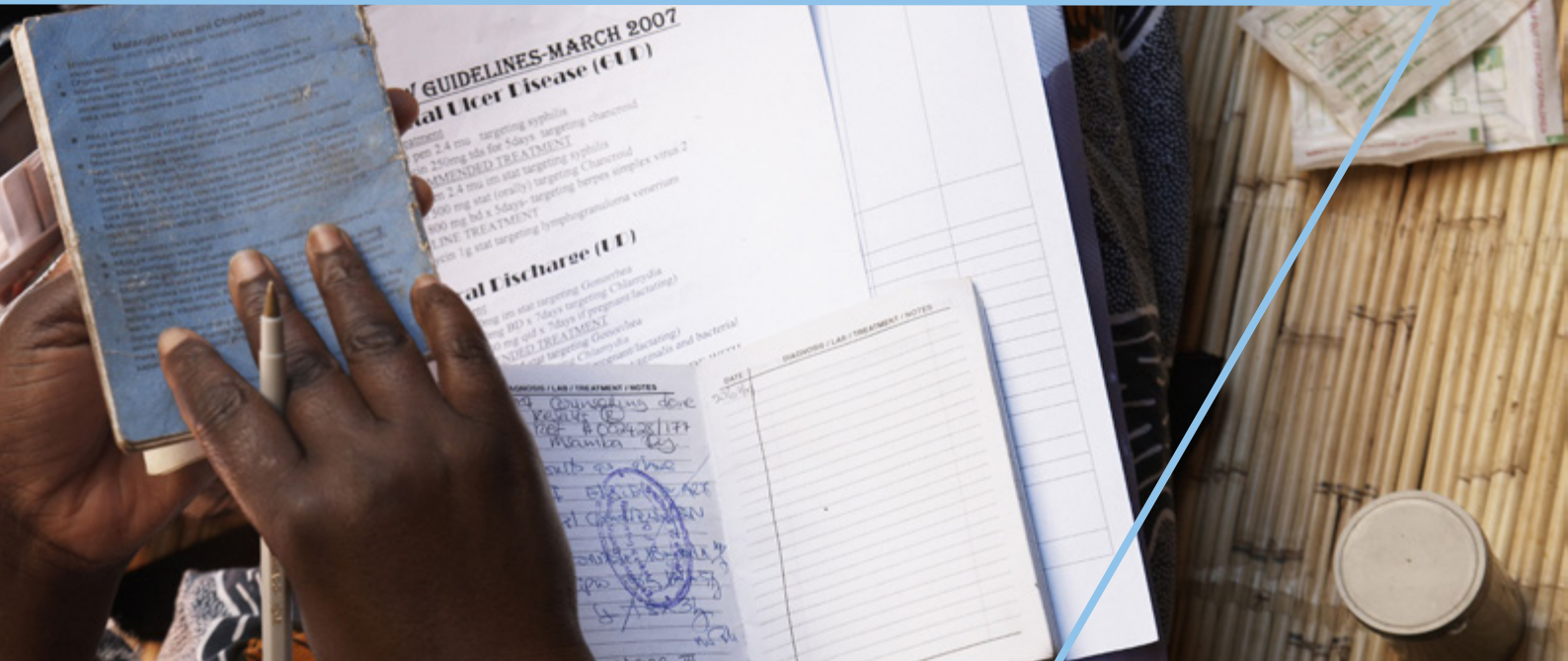
Caring for health care workers is essential. Therefore, APCA builds capacity for its partners to deal with burn out for healthier lives among health workers, and hence, sustained quality service. This year APCA supported one psychological care and team building activity for thirty-one (31) health workers in Raleigh Fitkin

Memorial Hospital (RFM) in Eswatini. As a result, the team’s social cohesion improved following the intervention. Participants reported improved self-awareness as they deliver care, and a better understanding of the concept of teamwork.

# BUILDING BLOCK 3



## HEALTH INFORMATION SYSTEMS



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Health information systems are essential for palliative care service development and monitoring and evaluation. The value for services must be demonstrated with data. APCA has aligned itself to the project on understanding the role of digital technologies to enhance palliative cancer care delivery in low- and middle-income settings, which provides very useful insights into what data is needed, how best such data can be collected, shared and used for decision making.

APCA worked in collaboration with Leeds University – UK, Island Hospice – Zimbabwe and the University of Ibadan – Nigeria to conduct a multi-country study on “*Understanding data and information needs for palliative cancer care*” with an

aim to target digital health intervention development in Nigeria, Uganda and Zimbabwe. Following this initiative, we contributed a chapter to the published book; “*Palliative Care for Chronic Cancer Patients in the Community: Global Approaches and Future Applications*”. The chapter discusses “*Routine data and minimum datasets for palliative cancer care in sub-Saharan Africa: Their role, barriers and facilitators.*”



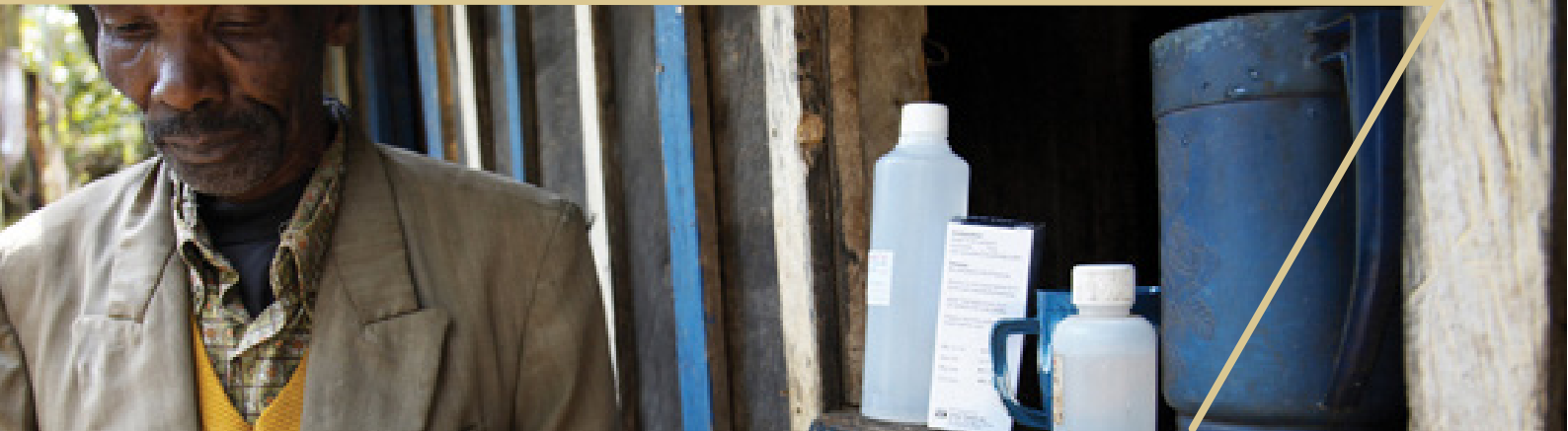
[https://www.researchgate.net/publication/339974961\\_Routine\\_data\\_and\\_minimum\\_datasets\\_for\\_palliative\\_cancer\\_care\\_in\\_sub-Saharan\\_Africa\\_Their\\_role\\_barriers\\_and\\_facilitators](https://www.researchgate.net/publication/339974961_Routine_data_and_minimum_datasets_for_palliative_cancer_care_in_sub-Saharan_Africa_Their_role_barriers_and_facilitators)

**HEALTH INFORMATION SYSTEMS ARE ESSENTIAL FOR PALLIATIVE CARE SERVICE DEVELOPMENT, MONITORING AND EVALUATION.**



# BUILDING BLOCK 4

## ACCESS TO ESSENTIAL MEDICINES



### Engaging pharmacists in the advocacy for palliative care and controlled medicines in Tanzania

Pharmacists have largely been left out of the advocacy efforts for palliative and comprehensive chronic care as well as access to essential care and controlled medicines, yet they are key pillars in ensuring availability and accessibility of all medicines including controlled medicines which are used for relief of moderate to severe pain and other symptoms. This year APCA, in partnership with Evangelical Lutheran Church of Tanzania (ELCT), implemented a project in Tanzania aimed at strengthening the capacity of pharmacists to advocate and address the current barriers and challenges for the availability of and access to controlled medicines for palliative care and other medical purposes. More than 20 pharmacists were involved in a capacity building programme that included workshops and mentorship to empower them to lead regional advocacy task force teams. In addition, 9 of these pharmacists undertook a learning visit to Ocean Road Cancer Institute to practically learn about the process of oral liquid morphine reconstitution and compounding. The purpose of the visit was to enable them to use the available resources back in their facilities, and the new skills learnt

to start oral liquid morphine production from powder. Following this project, four main zones/regions of Tanzania have established functional regional task forces that are responsible for improving access to controlled medicines, especially oral liquid morphine, for pain and other symptom management. A strong network was developed between key players in the supply chain including pharmacists, Medical Stores Department (MSD) and Tanzania Food and Drug Authority (TFDA) among others, who explored and agreed on ways in which they could collaborate towards access to essential medicines for patients in need, and put in place measures that limit abuse. This was a huge step that made coordinated efforts possible amongst all the key players in improving the availability and access to oral liquid morphine in Tanzania. In addition, more hospitals including Siha District Hospital in Moshi and Uwata Referral Hospital in Mbeya have since been issued with relevant permits to stock oral liquid morphine.

Testimonies from the beneficiary health facilities show the importance of involving pharmacists in the advocacy for access to controlled medicines for palliative care. One such testimony is from the Palliative Care coordinator for Ndolage Hospital who said:

*“For many years we have been taking morphine from Ocean Road Cancer Institute (ORCI) in Dar es Salaam, 1700 km from Ndolage. It wasn’t easy because we had to spend a lot of money to get only 5-10 litres of morphine which could last not more than 2 months; so we had to go back to ORCI frequently. Sometimes, morphine will be out of stock at ORCI, and we have to come back empty handed, with no other option but to wait. It was a torture to many patients in the community and to us too because seeing patients in pain is never easy, especially when they have been using morphine before and it worked well”.*

# BUILDING BLOCK 5



## PALLIATIVE CARE FINANCING



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Financing for palliative care is one of the persisting challenges for realising access to services for all those in need in Africa. Many African countries have no government financing for palliative care, and those that do, have very limited budgets. Donor funding for the health sector, particularly for palliative care, has continued to dwindle.

This year, with support from our donors, APCA provided financial and other forms of support towards palliative care service development, expansion, and/or quality improvement to 31 organisations and institutions from 14 African countries. APCA also provided materials and resources for palliative care advocacy, capacity building, and research, as well as funding for country partners to realise shared goals and objectives of improving access and the quality of services at the country level.

### Country level strategic advocacy

APCA engaged in various country-level strategic advocacy activities lobbying for governments to plan and budget for palliative care as part of their Universal Health Coverage plans through partnerships focused on the development of palliative care. These partnerships were opportunities for APCA to consolidate ongoing support in our countries of intervention and to national associations. Such initiatives included:

- **In Uganda APCA was part of the organisers for a planning meeting on strategic advocacy and communications the inclusion of palliative care in all processes towards the realization of Universal Health Coverage (UHC) in April 2019.**

A strategic advocacy framework was developed which recommended costing palliative care services and getting evidence for its inclusion into pending national health insurance. This framework has been welcomed at country level as a ready-to-use guide when lobbying governments and other local authorities, as well as potential donors.

- **APCA participated in the 3rd Kenya National Universal Health Coverage (UHC) Conference in Kisumu, Kenya in May 2019, with over 800 delegates attending.**

The theme of the conference was Revitalizing Primary Health Care (PHC) for sustainable Universal Health Coverage (UHC). This conference provided a forum to learn about the strides that Kenya has made towards implementation of their national UHC agenda. A key outcome from the conference was the consensus that in order to achieve sustainable UHC in Kenya, there had to be a proper mechanism for funding the services and involvement of all stakeholders in the process.



# BUILDING BLOCK 6

## LEADERSHIP AND GOVERNANCE



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Good governance and management structures are key to building credibility and accountability, coupled with the associated benefit for governments and organisations from putting funds to good use. APCA continues to provide leadership for palliative care integration into national health policies and frameworks.

### **The 3rd African Ministers of Health Session, Kigali, Rwanda:**

As part of efforts to strengthen palliative care in Africa, APCA and Ministry of Health Rwanda hosted a palliative care session for ministers of health in Africa in September in Kigali, Rwanda. In this meeting, the ministers adopted a basic palliative care package for Africa. The ministers that were present and other representatives of Ministries of

Health from different countries all gave input and committed to a resolution that would see more efforts made towards public financing for palliative care in their respective countries.

### **Engaging Parliament for inclusion of palliative care in the national budget in Uganda:**

APCA in partnership with the Palliative Care Association of Uganda (PCAU) held a meeting with the Deputy Speaker of Parliament of Uganda Hon Jacob Oulanyah to ensure that Parliament entrenches Palliative Care financing. PCAU then held subsequent follow up meetings with Members of Parliament from the Committee on Health and the office of the Prime Minister, thereby increasing visibility and prioritisation of palliative care to the legislators.

# International African Palliative Care Conference at Kigali, Rwanda



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# International African Palliative Care Conference at Kigali, Rwanda



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# STRATEGIC OBJECTIVES

## Increasing awareness and knowledge translation

Our key driver to increasing awareness and knowledge translation this year was organising our the 6<sup>th</sup> triennial International African Palliative Care Conference that was held in Kigali, Rwanda in collaboration with the Ministry of Health Rwanda, The Rwanda Biomedical Centre and Rwanda Development Bureau, from 17<sup>th</sup> to 19<sup>th</sup> September 2019. The Conference, whose theme was '*Palliative Care and Universal Health Coverage*', attracted over 488 delegates from 38 countries; 27 African and 13 other countries. The delegates included PC service providers, service beneficiaries (patients and their families), researchers, development partners, representatives of academic institutions, religious institutions and government representatives from Africa and the world at large.



6th International African Palliative Care Conference

The conference provided a great opportunity for the dissemination of the itemized palliative care package for inclusion in UHC to the African Ministers of Health and the delegates. This package was developed by APCA in consultation with the global, regional and national partners as an advocacy tool that local, national and regional organisations can use for engaging politicians and other relevant decision makers to implement palliative care as part of UHC. There was an appreciation of the palliative care package for inclusion in UHC as an important advocacy and information tool for countries, which are ready to use the package. An outstanding feature of the conference was the level of patient representation; users of palliative care services took centre-stage in many sessions, and patient voices were heard throughout the conference.

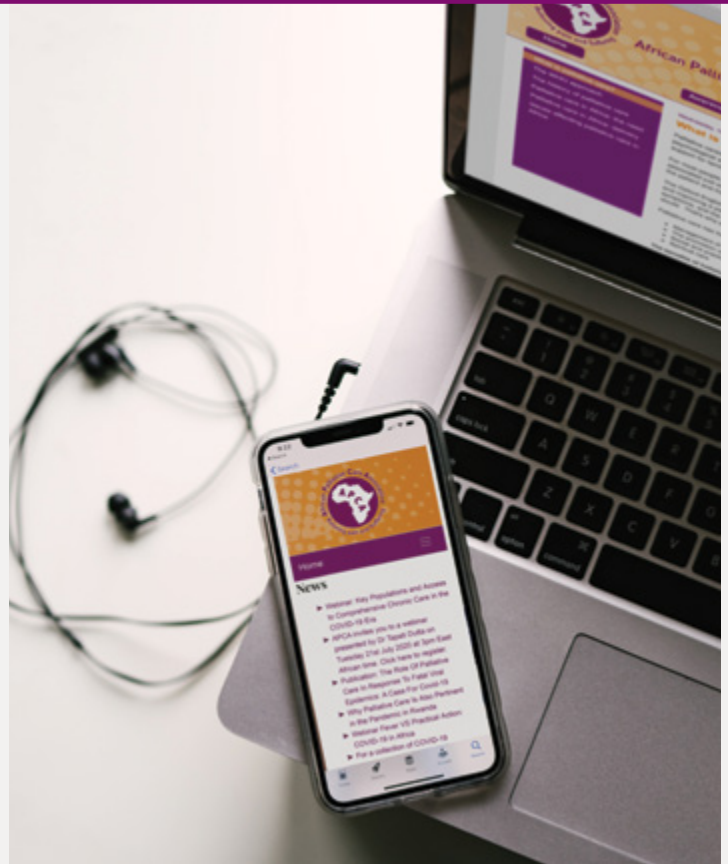
20 A number of pre-conference workshops were held on 17<sup>th</sup> September 2019 including Research, Partnerships and Collaboration, and the Multidisciplinary Pain Management Workshop. Another key event that was held on 17<sup>th</sup> September was the 3<sup>rd</sup> African Ministers of Health Session, which attracted 120 participants including delegations from 15 Ministries of Health in Africa. Participant feedback showed that the conference was successful; the objectives of the main conference and the pre-conference sessions were adequately met.

We continue to disseminate the palliative care package and it can be accessed at [https://www.africanpalliativecare.org/images/stories/pdf/PC\\_in\\_UHC\\_package.pdf](https://www.africanpalliativecare.org/images/stories/pdf/PC_in_UHC_package.pdf)



Participants' 'single-word' description of the 6th International African Palliative Care Conference

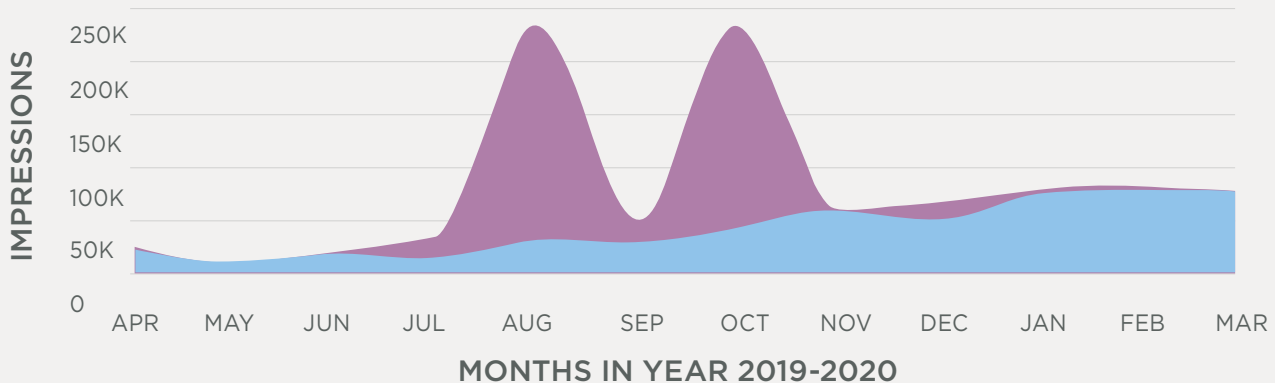
APCA continued to engage its members and online followers through targeted social media posts and campaigns. Post reach and engagements on both Facebook and Twitter were high throughout the year, peaking in the period preceding and immediately following the conference when volumes surged by more than 10 times the usual, as those participating in the conference and those who were not able to attend followed the developments closely online.



The table shows social media engagement.

## CROSS-NETWORK IMPRESSIONS

### Impressions, by Month



#### TOTAL IMPRESSIONS

**959,456**

↗ **39.7%**



Twitter Impressions

483,931

↗ **118%**



Facebook Impressions

475,525

↗ **2.3%**

The APCA website attracted over 2 million visits during the reporting period. These also peaked during the calls for small grants and the conference. A diverse number of ehospice articles were published on ehospice Africa Edition, representing stories and developments on the continent and beyond. The Communications team also focused on amplifying

patient voices through dissemination of materials developed in the **Patient Power Project** that APCA is implementing in partnership with the Worldwide Hospice and Palliative Care Alliance (WHPCA) in Ethiopia and South Africa, with funding support from the Joffe Family Trust.

# RESEARCH & DEVELOPMENT

At APCA, we endeavour to ensure that palliative care services are underpinned by robust evidence to optimise outcomes of care. APCA, therefore, continued to support the development of the evidence base for palliative care in the region, together with the requisite capacity building for emerging researchers in the region.

The perception of palliative care by all stakeholders at country and regional level remains a challenge, as many still see it as being synonymous with end of life care, rather than a holistic approach of care that aims to improve the quality of life of patients and their families throughout the life course. This negatively impacts on public support and the allocation of resources to this important service. APCA collaborated with Leeds University, UK, to conduct a qualitative study that sought to understand data and information needs for palliative cancer care to target mobile phone-based intervention development in Uganda and Zimbabwe. This work is informing our initiatives on how to leverage technology to improve palliative cancer care in Africa. This has become even more relevant and urgent now as service provision has had to be more accommodating to the use of technology to maintain access to care amidst the global COVID-19 pandemic.

APCA also partnered with the University of Ibadan, Nigeria and Leeds University to develop and evaluate an electronic platform for pain management education of medical undergraduates in limited resource settings. The study showed very positive results. This training positively impacted on the students' knowledge, and provided evidence for the

value of distance learning (e-learning) which can be used to enhance traditional learning methods.

APCA continues to prioritise older persons in palliative care, and we partnered with Global Partners in Care and the University of Alberta to carry out a formative research to explore the ways that individuals, entrepreneurs, governments and non-government organisations build and legislate the practice of elder care in Ghana. Further work on this is scheduled to focus on building a business model to support the development of quality care for the ageing population in Ghana. We therefore developed a white paper on global best practices in eldercare delivery models with gap analysis, relevance and application to current practices in Ghana, and this paper will guide the development of palliative care for older persons.

Our research team was further involved in a project for mapping service pathways across the cancer disease trajectory in Kampala; a retrospective cohort study of timing and access to services. The study aims to depict the cancer pathway for patients from diagnosis to death in Kampala, Uganda, to examine the sources of referrals, and patterns of patient access to participating health facilities from diagnosis to death.

## Knowledge translation

### WEBINARS

Through the research network, we hosted a capacity building webinar on spirituality in palliative care. The webinar was attended by twenty experts in the region and the training materials were shared with sixty-four experts in the region. The network continues to run monthly webinars to increase access to information and to build capacity for research.

### TECHNICAL ASSISTANCE

The head of the research department was appointed to the WHO technical working group for developing the guidelines on chronic pain in children. Her role is to ensure that available evidence from the region is considered in the development of the guidelines.

## African Palliative Care Research Network



On 17th September 2019, the African Palliative Care Research Network hosted its triannual research workshop, which was attended by 56 delegates from 20 countries. The workshop was led by rising stars in palliative care, and we celebrated the capacity building that has happened in the region over the years. The African Palliative Care Research Network has 200 active members and continues to use the platform for shared learning, mentorship, capacity building and the use of collective bargaining power in the application for grants.

### CELEBRATING THE CAPACITY BUILDING INITIATIVE IN THE REGION



#### **JONATHAN BAYUO, PHD CANDIDATE**

Jonathan is a Burn Care Nurse from Ghana with postgraduate specializations in nursing from the University of Ghana, gerontology from the University of Southampton; and clinical fellowship from the Joanna Briggs Institute, University of Adelaide.



#### **DR KENNEDY NKHOMA**

Dr Kennedy Nkhoma qualified as a nurse in Malawi and worked as a general nurse at a local hospital in the northern part of Malawi. He holds a PhD in End of Life Care from the University of Nottingham.



#### **DR KRAUSE**

Dr Krause is a Family Physician with a masters degree in Palliative Medicine and a postgraduate diploma in Health Professional education. She is currently a senior lecturer in the Department of Family Medicine and Public Health (University of Cape Town) and convenor of the postgraduate diploma in Palliative Medicine.



#### **OLADAYO AFOLABI**

Oladayo joined the Cicely Saunders Institute of Palliative Care, Policy and Research in October 2018. He is a Registered Nurse (RN) in both Nigeria and the UK. He underwent his Bachelor of Nursing Science at Ladoko Akintola University of Technology in Nigeria, graduating in 2008. He proceeded on his MSc in Health Planning and Management at the University of Maiduguri, Nigeria.



#### **DR MARY A. D. ABBOAH-OFFEI, MSC**

Mary holds a PhD in Palliative Care, Policy and Rehabilitation, and an MSc in Nursing Education at the Queen Margaret University, Edinburgh.



#### **NASUR BUYINZA, MPH**

Nasur is a public health specialist with over 14 years of experience in clinical care, research, and healthcare management and 8 years of palliative care teaching. He works with Hospice Africa Uganda (Institute of Hospice and Palliative Care in Africa) a non-government organization based in Kampala Uganda as a Senior Lecturer.



#### **BARBARA MUTEDZI, MA**

Barbara is a Medical Anthropologist (Durham University, UK) with a background in Health and Community Psychology and Social Anthropology. Her MSc in Medical Anthropology and under the Ruth First full board scholarship, Barbara conducted a study advocating for adolescents and young people living with HIV in Harare, Zimbabwe.

## PUBLICATIONS

- **Namisango E**; Bristowe K; Murtagh, F.E.M; Downing J; Powell R.A; Abas M; Lohfeld L; Ali Z; Atieno M; Haufiku D; Guma S; **Luyirika E.B.K**; Mwangi-Powell F; Higginson I.J; Harding R. Towards person-centred quality care for children with life-limiting and life-threatening illness: self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study. *Palliat Med* 2020.  
 <https://journals.sagepub.com/eprint/Z4EK2NA7YAHPY3VBSDEX/full>
- Loth C; **Namisango E**; Powell RA; Pabst K; Mhoira Leng; Hamada M; Radbruch.  
“From good hearted community members we get volunteers” – An exploratory study of palliative care volunteers across Africa. In press *BMC Palliative Care* 2020
- Okunade K; Bashan Nkhoma K; Salako O; Akeju D; Ebenso B; **Namisango E**; Soyannwo O; Namukwaya E; Dandadzi A; Nabirye E; Mupaza L; **Luyirika E**; Ddungu H; Chirenje ZM; Bennett MI; Harding R; Allsop MJ. Understanding data and information needs for palliative cancer care to inform digital health intervention development in Nigeria, Uganda and Zimbabwe: protocol for a multicountry qualitative study. *BMJ Open*. 2019;9(10):e032166. 10.1136/bmjopen-2019-032166
- Bates MJ, **Namisango E**; Tomeny E; Muula A; Squire SB; Niessen L. Palliative care within universal health coverage: the Malawi Patient-and-Carer Cancer Cost Survey. *BMJ Supportive and Palliative Care*. <http://dx.doi.org/10.1136/bmjspcare-2019-001945>
- McNeil MJ; **Namisango E**; Hunt J, et al. Grief and Bereavement in Parents After the Death of a Child in Low- and Middle-Income Countries. *Children (Basel, Switzerland)* 2020; 7 2020/05/07. DOI: 10.3390/children7050039.
- Tim Baker; Carl Otto Schell; **Eve Namisango**; Raphael Kazidule Kayambankadzanja; Laura Hawryluck; Maya Jane Bates. Dying in Intensive Care in low-income countries. *The Value of Death*.  
<https://commissiononthevalueofdeath.wordpress.com/2019/12/14/dying-in-intensive-care-in-low-income-countries/>
- **Namisango E**; Bristowe K; Murtagh F.E.M; Downing J; Powell R.A; Abas M; Lohfeld L; Ali Z; Atieno M; Haufiku D; Guma S; **Luyirika E.B.K**; Mwangi-Powell F; Higginson I.J; Harding R. Towards person-centred quality care for children with life-limiting and life-threatening illness: self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study. *Palliat Med* 2020.  
 <https://journals.sagepub.com/eprint/Z4EK2NA7YAHPY3VBSDEX/full>
- Matthew J Allsop; John Black Kabukye; Richard Powell; **Eve Namisango**. The importance of routine data collection and implementing a minimum data set for palliative cancer care in sub-Saharan Africa. *Palliative Care for Chronic Cancer Patients in the Community: Global Approaches and Future Applications*

### We also celebrate the 2020 publication from our 2018 intern – Ms Carolin C. Loth

Namisango E; Powell RA; Pabst K; Mhoira Leng; Hamada M; Radbruch.

“From good-hearted community members we get volunteers” – An exploratory study of palliative care volunteers across Africa. In press *BMC Palliative Care* 2020.



## AFRICAN PALLIATIVE CARE RESEARCH NETWORK INTERNSHIP PROGRAM

Each year, we host 2–3 interns for exchange learning. In 2019 we hosted Lara Maria Reck from Germany. Lara supported our work on the further development of the children’s palliative care outcome scale (C-POS). She oriented palliative care providers at Kawempe Home Care on the importance of using person centred outcome measures in paediatric palliative care.



# SUSTAINABILITY AND ORGANISATIONAL DEVELOPMENT

## GOVERNANCE

APCA's biggest governance body is the General Assembly that is comprised of its members who meet once every 3 years, to coincide with the Triennial International PC Conference. The General Assembly was held in September 2019 in Kigali, with over 100 attendees, who moved to appoint new board members and also approved new external auditors for the next 3 years.

APCA is governed by a Board of Directors who get their mandate from the General Assembly. The Board holds regular meetings both virtually and face-to-face as mandated by the APCA Constitution. Five Board members who had served two 3-year terms stepped down on the sidelines of the 6<sup>th</sup> International African Palliative Care Conference in Kigali, Rwanda, in September, 2019. At the same event and after a rigorous nomination process, a new Board of Directors was sworn in. We proudly introduce the APCA Board of Directors 2019–2022;

- Mr Andre Wagner  
*Board Chair*
- Ms. Jacqueline Busingye  
*Honorary Treasurer of the Board*
- Dr Martha Gyansa-Lutterodt  
*Honorary Secretary of the Board;*
- Ms. Mary Callaway
- Prof Maged El Ansary
- Prof Jose Pereira
- Dr Rene Krause
- Ms. Irene Among

## APCA Advisory Council:

The APCA Board of Directors approved the establishment of an Advisory Council that would be comprised of a wide selection of palliative care technical experts whose role would be to advise both the board and the staff in programmes development and organisational mandate. Since APCA is a membership organisation the Council is drawn from the Membership as a way of increasing stakeholder engagement and collaboration. The Advisory council holds regular virtual meetings and currently consists of 9 members who have been instrumental in advancing the APCA agenda.

- *Joan Marston*
- *Mark Jacobson*
- *Fr. Rick Bauer*
- *Prof Joseph O'Neill*
- *Prof Olaitan Soyannwo*
- *Prof Elly Katabira*
- *Prof Beugre Kouassi*
- *Prof Liz Gwyther*
- *Malik Jaffer*



## Staff Development

APCA Staff continue to pursue personal growth and development both at an individual level and as an organisation. During the year, Pamela Kalema and Josephine K. Tatyabala both graduated with Master's in Business Administration from the Uganda Management Institute; Dr Eve Namisango completed her PhD in Palliative Care from King's College, London; Patricia Batanda also completed her Master's in Public Administration & Management from the Uganda Management Institute.

This being an extremely busy year with conference preparations, staff were unable to attend as many staff development sessions but managed to attend and participate in the following;

- Financial literacy sessions held by National Social Security Fund (NSSF) and Stanlib Uganda on how to manage and invest money.
- M&E Fundamentals: This session was presented by Prof Fabian Nabugomu.

In October, staff took a much-deserved 3-day trip to Ssese Island off the shores of Lake Victoria as a way to re-energise after the immense effort put into the conference. It was a fun-filled and relaxing trip.



## APCA Staff

It was an incredibly busy year for all staff as everyone was involved in the preparations for the 6<sup>th</sup> International African Palliative Care Conference in September 2019, while also continuing with their usual daily tasks. Thanks to the efforts of the staff, the conference was a huge success with exciting reviews that further validated the role played by such a platform. Sadly we had to bid farewell to two staff; Ms. Mable Namuddu, the Finance Officer who left in October 2019 after serving APCA for 6 years; and Ms. Fatia Kiyange, the Programmes Director who left at the end of December, 2019, after serving for 15 years.



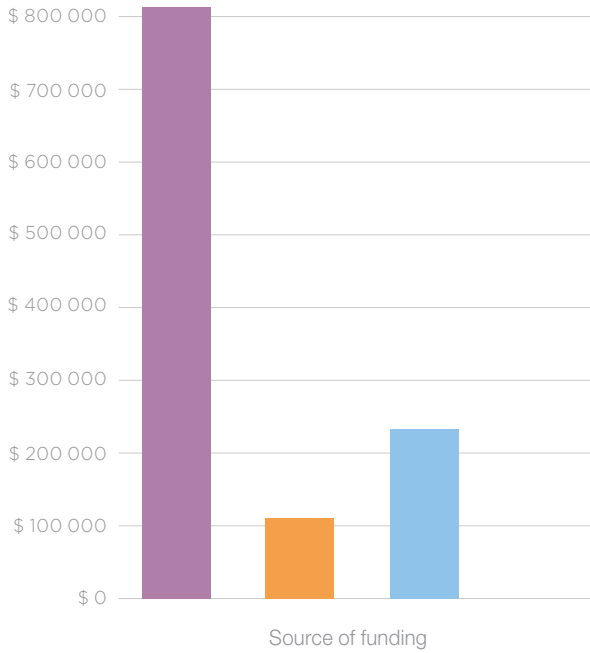
## The SOURCE Programme

In June, 2019, APCA, together with 16 other cancer-focused NGOs in Kampala, celebrated the completion of a 3-year competency-based organisational development intervention of the American Cancer Society (ACS) at a graduation ceremony held at Hotel Africana, which was officiated by the American Ambassador to Uganda. The ACS SOURCE (Strengthening Organisation for a United Response to the Cancer Epidemic) pilot programme was launched in Uganda and Kenya in 2016. In Uganda the Programme was led by the Mabadiliko Change Makers (MCM).

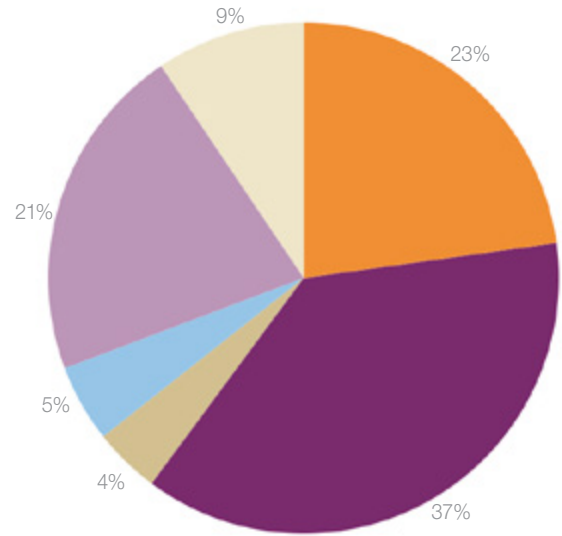
APCA was awarded a distinction for having met 99% of the prescribed benchmarks, which included; Governance, Operations and Administration, Human Resources Management, Financial Management, Financial Sustainability, Program Management, External Relations and Partnerships, and Workplace Effectiveness and Excellence.

# FINANCIAL SECTION

Where the money came from 2019/20



Where the money went 2019/20



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Sources of income	Bal b/f 1/4/19	Income for the period Apr19-Mar 20	Total available funds Apr19 - Mar 20	Percentage income by donor
Trusts and Foundations	\$284,831	\$519,725	\$804,556	70%
Other Donors	\$1,006	\$109,360	\$110,366	10%
APCA Generated Income	\$65,106	\$163,828	\$228,934	20%
<b>Total available funds</b>	<b>\$350,943</b>	<b>\$792,913</b>	<b>\$1,143,856</b>	<b>100%</b>

Expenditure area	2019/2020 (Amount)	2019/2020 (Percentage)
Administration Salaries	\$205,791	23%
Awareness Creation	\$337,078	37%
Evidence	\$37,989	4%
APCA and Partner Sustainability	\$44,219	5%
Palliative Care Integration	\$192,372	21%
Administration & Capital Costs	\$85,160	9%
<b>Total Expenditure To date</b>	<b>\$902,609</b>	<b>100%</b>

**20%**  
Of Income was generated by ACPA

**37%**  
Were used for awareness creation

# DONOR APPRECIATION

Our work is made possible because of the very generous contributions from our donors. APCA is committed to making sure every contribution is spent with palliative care patients and their families in mind. We are a good steward to all the donations to the organisation.

We would like to thank all our donors for supporting our advocacy for the relieving of pain and suffering for patients across Africa.

- Global Institute of Psychosocial, Palliative and End- of -Life Care (GIPPEC)
- Global Partners in Care
- Open Society Foundation – New York (OSF)
- Open Society Initiative for Eastern Africa (OSIEA)
- Open Society Initiative for Southern Africa (OSISA)
- The True Colours Trust
- The University of Leeds
- Worldwide Hospice and Palliative Care Alliance (WHPCA).

## Make a donation

All donations made to APCA, are greatly appreciated and will be used in a transparent, accountable and effective way.

If you would like to support APCA financially, please let us know by emailing [patricia.batanda@africanpalliativecare.org](mailto:patricia.batanda@africanpalliativecare.org) and we will contact you with further details.

Alternatively, please visit our website [www.africanpalliativecare.org](http://www.africanpalliativecare.org) and click 'donate'.

Thank you for your support.



## African Palliative Care Association

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NGO Registration Number 4231

