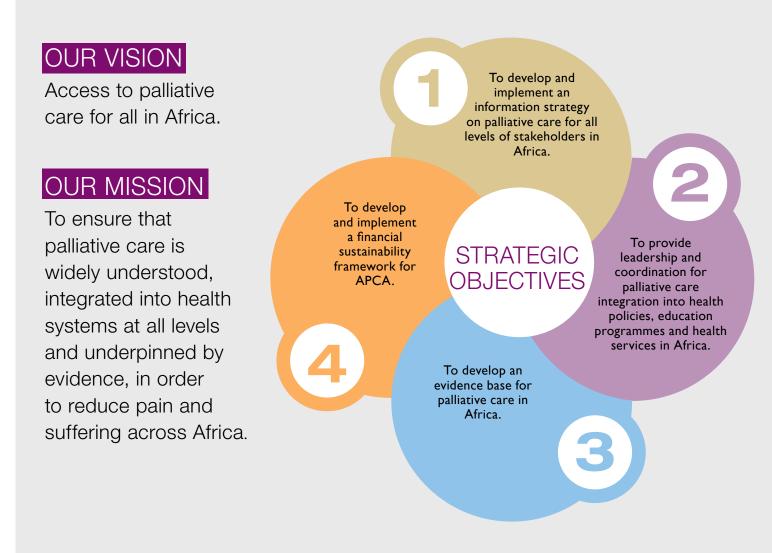
# AFRICAN PALLIATIVE CARE ASSOCIATIONANNUAL REPORTBUILDING



# **ABOUT** APCA

he impetus for APCA's founding in 2004 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 health care systems and national health strategies. APCA, a membership-based pan-African organisation, was then established and has its headquarters located in the capital of Uganda, Kampala.



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# WELCOME MESSAGE

Message from the APCA Executive Director and Chair of the APCA Board

V elcome to the 2017/18 edition of our annual report. It is at this this time of year that we take stock of our achievements with great appreciation for the generous support from our partners worldwide.

This report's theme, "building bridges", first acknowledges the hard work of those who labour to bring palliative care services and its ethos to a patient's bedside - whether at home, or in a clinical setting. We honour the nurses, doctors, caregivers, other members of the multidisciplinary team and the patients themselves who work tirelessly to prevent or manage the pain and suffering that come with life limiting illness.

Secondly, the theme of building bridges honours the many African ministries of health who have made great advances this year in increasing access to pain relief and palliative care services. National healthcare systems across Africa, even those undergoing the most challenging of hardships, carry

"AS A PAN-AFRICAN ADVOCATING INSTITUTION, OUR LABOUR IS PRINCIPLED IN BUILDING A BRIDGE BETWEEN POLICY AND ITS IMPLEMENTATION TO MAKE PALLIATIVE CARE AND PAIN RELIEF AFFORDABLE AND ACCESSIBLE - WHETHER PHYSICAL, PSYCHOSOCIAL OR SPIRITUAL."

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the administrative infrastructure to make care for their most vulnerable populations a reality. African governments know intimately the disease burden of their own people.

African institutions and service delivery agencies are further stretched to address the spectrum of symptoms that come with disease: acute and chronic physical pain, psychological, social and spiritual distress in the midst of suffering.

"WE ARE AT THE FOREFRONT OF GROUNDBREAKING RESEARCH TO ENSURE NEW TECHNOLOGIES AND INNOVATIONS BUILD BRIDGES TO STREAMLINE THE NEEDS OF SYMPTOM MANAGEMENT WITH ACCESSIBLE PATIENT RESOURCES."

We know, through the tenets of the World Health Organization, that these struggles are universal. However, in Africa, where resources are limited for services that support a patient's navigation through their disease - these services require tenacity and funding to be sustained.

At APCA, we see a landscape of increased leadership where policy makers are more committed than ever to provide pain relief to their populations since the passing of WHA67.19. We are at the forefront of groundbreaking research to ensure new technologies and innovations build bridges to streamline the needs of symptom management with accessible patient resources. Further, we are working to train more lawyers, health workers, pharmacists, nurses, doctors and other professionals than ever before to ensure the common man, woman and child have access to life-affirming supports in the midst of pain and suffering.

While these prospects are celebrated, we must be transparent in our struggles. We are at a tipping point where

"AT APCA, WE SEE A LANDSCAPE OF INCREASED LEADERSHIP WHERE POLICY MAKERS ARE MORE COMMITTED THAN EVER TO PROVIDE PALLIATIVE CARE AND PAIN RELIEF TO THEIR POPULATIONS SINCE THE PASSING OF WHA67.19"





decreases in donor funding are having a direct trickle down effect upon the most vulnerable of populations.

We as a pan-Africa institution -- as well our national partners across the African countries, are asking hard questions around how patients in the Global South will continue to receive services that reflect human rights values.

To answer these questions, I boldly invite you to institutionally and individually support our efforts to change this trajectory. Institutionally, we need support in accessing new partners who can financially support our work to promote good governance in healthcare, research in pain and symptom management, as well as advocacy and training initiatives, further reflected in this report.. Individually, we invite you to consider donating to our work, joining our free membership programme, attending and/ or supporting an African doctor, nurse, lawyer or social worker to attend our 6th African International Palliative Care Conference, hosted in Kigali, Rwanda from 17th to 20th September, 2019. This conference is where mutual learning will be achieved, and where the bridges of collaboration are forged for improved patient outcomes, with a focus on palliative care services as part of Universal Health Coverage.

We thank you sincerely for supporting us to make palliative care services accessible across Africa. With your support, we will get there.

"Everyone needs to be valued. Everyone has the potential to give something back." Diana, Princess of Wales

#### **HOW YOU CAN PARTNER WITH APCA**

We believe in the value of partnership and collaboration in order to make a difference – bringing together the strengths and resources of multidisciplinary stakeholders to make our collective voice stronger.

APCA is seeking new partnerships to strengthen its support to African palliative care service delivery and leadership training. To establish a partnership with us, please email <u>patricia.batanda@africanpalliativecare.org</u>.

TO JOIN APCA'S FREE MEMBERSHIP BENEFIT PROGRAMME, EMAIL: members@africanpalliativecare.org

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## **Building bridges to implement policy** frameworks on palliative care

At APCA, our work aims to support and facilitate African countries to implement:

- The World Health Assembly resolution to strengthen palliative care as a component of comprehensive care throughout the life course (WHA67.19; May, 2014);
- The World Health Assembly resolution on cancer, which recognised pain relief and palliative care as a key response in cancer prevention and control (WHA70.12; May 2017)
- International, regional and domestic laws and legal frameworks on palliative care.

We do this through the application of the World Health Organization's (WHO) public health strategy for integrating palliative care into a country's health system and the WHO's six building blocks of health systems strengthening outlined below:

- leadership/governance/appropriate policies
- service delivery
- health workforce/education
- health information systems
- access to essential medicines and technologies, and
- financing.

This year, APCA supported and implemented palliative care activities in **I3 African countries** namely; **Botswana**, Ghana, Kenya, Liberia, Mozambique, Nigeria, Rwanda, South Africa, Tanzania, The Gambia, Togo, Uganda, and Zimbabwe.

Interventions were implemented mainly through formal partnerships with African ministries of health, palliative care service providing organisations, public and private-not-for profit health facilities, including cancer centres and professional associations, as well as academic institutions.

In total, we worked with more than 20 institutions across Africa to promote palliative care integration into health systems strengthening initiatives in alignment with our 10 year Strategic Plan (2011 - 2020).

APCA believes that the most effective way to roll out palliative care is to integrate it into existing health systems as this is the most sustainable way of reaching more patients and their families who are in need of palliative care.

**TO THIS** 

PROVIDES **TECHNICAL ASSISTANCE IN** 

AREAS

#### **POLICY AND STRATEGY DEVELOPMENT, GOVERNANCE** AND LEADERSHIP

We provide support for the inclusion of palliative care into national policies and the implementation of national palliative care programmes.

#### PALLIATIVE CARE **EDUCATION** AND TRAINING

We provide education training resources and tools to support the implementation of national palliative care education programmes. We also support specialist training through bursaries.

#### **MEDICINES AVAILABILITY**

We provide guidelines and tools for health care providers and advocates, legislation guidance on use of opioids, education and training to ensure practical steps are taken towards ensuring pain relieving medications are made END, APCA available to patients in need.

#### SERVICE DELIVERY

THE FOLLOWING APCA provides the technical assistance for the integration of palliative care in existing health services including public health facilities and NGO health facilities. This is undertaken through capacity building of health care providers and

quality improvement interventions.

**BUILDING BRIDGES** 

The images in this annual report were donated courtesy of The Diana, Princess of Wales Memorial Fund, which closed its doors in December 2012. APCA is currently seeking new donors to help us continue to tell the story of African patients in order to advance palliative care on the continent, and globally.

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## **BUILDING BLOCK 1** PALLIATIVE CARE SERVICE DELIVERY

We at APCA believe that the most effective way to roll out palliative care interventions is to integrate its services into existing health systems. As a sustainable approach, more patients and their families who are in need are able to access palliative care services locally.

Therefore, we focus our efforts on providing technical assistance for its integration into public, private and NGO health facilities. This is undertaken through capacity building of health care providers and quality improvement interventions.

This year, APCA supported **60 health facilities** in **eight African countries** to establish, improve, or expand palliative care services. The countries reached through these projects spanned across south, east and west Africa, specifically: **Botswana, Ghana, Kenya, Mozambique, South Africa, Swaziland, Tanzania, and Uganda.** 

Through these initiatives, APCA and its partners worked to ensure that health facility management teams were oriented in palliative care principles, and that healthcare workers were adequately trained in palliative care service provision.

Throughout the year, APCA staff also provided ongoing support and mentorship to key palliative care stakeholders in these eight countries through **Continuing Medical Education (CMEs) support**, conducting organisational capacity assessments and providing start-up support for morphine production, as well as improving data collection systems.

These interventions were primarily supported through a small grants programme that has been supporting palliative

care initiatives across Africa since 2009; a morphine technical assistance programme, and a project that extended support to African countries as they implement their national palliative care frameworks.



"THIS YEAR, APCA SUPPORTED 60 HEALTH FACILITIES IN EIGHT AFRICAN COUNTRIES TO ESTABLISH, IMPROVE, OR EXPAND PALLIATIVE CARE SERVICES."

Resulting from these and other interventions, over 9,700 palliative care patients engaged in comprehensive care assessments and received palliative care services. The assessments examined pain levels, access to pain management, access to oral morphine, as well as psychosocial care and support. These patients were from 15 health facilities in Botswana, Kenya, Mozambique, South Africa, Swaziland, Tanzania, Uganda, and Zimbabwe.

#### INCREASING ACCESS TO JUSTICE AND PALLIATIVE CARE SERVICES

In **Zimbabwe**, a model of legal support that is integrated into palliative care services was piloted to ensure access to justice by palliative care patients, in collaboration with the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ).

Gleaning lessons from similar projects in **Kenya**, **Malawi**, **South Africa and Uganda**, the project involved the training of lawyers in palliative care and connecting legal service institutions to palliative care programmes.

Consequently, **12 palliative care patients** were referred to legal services from trained lawyers and received pro bono (free) legal care. A cross-section of patients' legal needs addressed by the lawyers included: inheritance rights, child maintenance, succession planning, property grabbing, terminal benefits at work, evictions, school fee challenges and polygamous marriage issues.

#### **APCA'S CONTRIBUTION TOWARDS ACCESS TO PALLIATIVE CARE SERVICES**



This year, we aimed to empower patients who could not afford legal fees with the ability to access justice services at a critical time in their lives. The impact of these services directly improves their quality of life as they seek to ensure their family members are cared for, as demonstrated by Mr Chuma's experience:

#### 'Make sure my children are protected': the Last Will of Mr Chuma

At age 67, Mr Chuma (pseudo name) was diagnosed with advanced esophageal cancer. His treatment plan included an insertion of a gastrostomy tube for food consumption. Mr Chuma was staying with one of his children while undergoing treatment; his original home was in a rural Zimbabwean village. As he was in a polygamous relationship with two wives, each wife had two children at the time of his referral to Island Hospice for palliative care. He was accompanied to the hospice for a holistic assessment by his first wife and their two grown children from his first marriage.

During the course of his holistic health assessment at the hospice, staff identified that apart from having physical pain, Mr Chuma also had emotional and social pain. His emotional pain emanated from the fact that he had been informed by the doctors that his disease was advanced and he was now aware of his impending death. He expressed that he feared dying and leaving his two young children from his second marriage, aged 8 and 12 years old, with no one to fend for them, as his second wife was unemployed. Speaking to the hospice social worker, Mr Chuma expressed his fears:

Sister, I am worried that when I die there won't be anyone to fend for my children from my second marriage, and most of my property is at my first home. My first wife has not forgiven me for marrying the second wife so I do not see her supporting my children after my death. Moreover, she has already influenced her children not to have anything to do with the two minors from my second wife.

With legal practitioners being an integral part of the palliative care team dedicated to his care, Mr Chuma was offered free assistance by a legal practitioner who was committed and passionate about helping him fulfill his last wishes prior to his death.

The legal practitioner started to visit his home, often using her own personal resources to do so. She managed to educate the patient's first wife as well as the grown children about the legal rights of the children from the second wife as well as the legal implications of not supporting them. Issues of entitlement were also discussed, emphasising the fact that the two young children were under the age of 18, and were therefore entitled to be educated and supported from their father's estate.

Mr Chuma was then assisted to write his Last Will and died four weeks thereafter. He had expressed happiness in knowing that his children from his second wife were going to be cared for even after his death and would also receive some of his cows, as stated in his will. The legal practitioner played a very important role in protecting the client's interests and remaining quality of life in his final weeks.

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## BUILDING BLOCK 2 HEALTH CARE WORKFORCE

t APCA, we work to bridge the tenets of WHA67.19 by supporting health workers and institutions to provide quality palliative care services locally and regionally.

#### CAPACITY BUILDING TO INCREASE ACCESS TO PAIN MEDICATIONS

With the aim of supporting APCA's partners to respond to increases in demand for palliative care services, APCA worked with a wide range of stakeholders to support a palliative care workforce. These included:

- policymakers and lawyers
- academics and teaching institutions
- health care workers
- hospital management teams
- the media
- community leaders
- and the general public.

## Here are some of the highlights from these initiatives:

**I13 healthcare workers** and **I7 lawyers** were trained in palliative care delivery through introductory palliative care courses and clinical placements in established palliative care centres. The programme was implemented in four health facilities in **Kenya**, **Mozambique**, **Swaziland** and **Zimbabwe**.

**I,572 health care workers from 33 health facilities** in three African countries were supported through APCA partners to attain pain management knowledge and skills. Participating health workers were from **Botswana, Ghana and Uganda**. **50 community volunteers** in **Kenya** and **South Africa** were trained in basic skills in palliative care service delivery, particularly in supporting home-based care for palliative care patients.

#### 3,625 patients from Botswana, Ghana, Kenya, and Uganda accessed pain medications, including morphine.

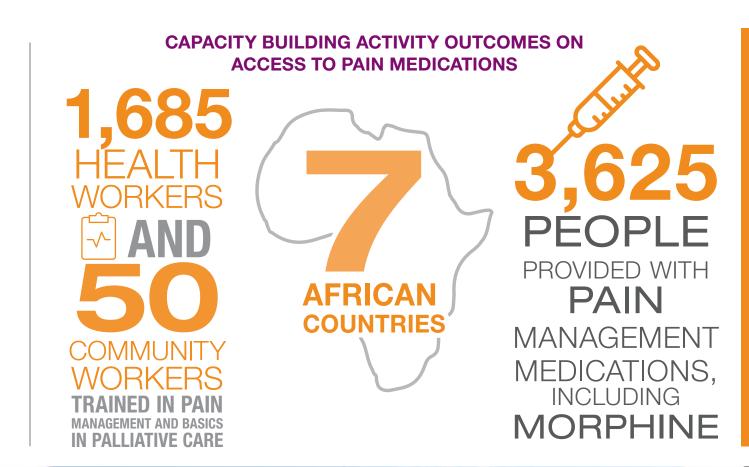


In Zimbabwe, a facilitator from the Cancer Association of Zimbabwe trained lawyers in palliative care legal issues and patient rights.

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"HOWEVER, IN AFRICA, WHERE RESOURCES ARE LIMITED FOR SERVICES THAT SUPPORT A PATIENT'S NAVIGATION THROUGH THEIR DISEASE - THESE SERVICES REQUIRE TENACITY AND FUNDING TO BE SUSTAINED."

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## **BUILDING BLOCK 3** PALLIATIVE CARE INFORMATION

he African Palliative Care Research Network (APCRN) is a research community that supports the strengthening of an evidence base for palliative care in Africa through collaborative research, capacity building, and knowledge translation.

The APCRN membership currently has **165 individual members**, with a record of **28 new individual members** joining this year from **six universities** across Africa, Europe and the United States.

This year, the network launched a new *Outcome Measurement* research interest group. The aim of this collaboration is to support capacity building in patient outcomes measurement and to roll out the integration of outcome measurement in clinical care.

APCA launched the first continuing medical education session on 'outcome measurement in paediatric palliative care' at Kawempe Home Care in **Uganda**. Kawempe Home Care is currently piloting the use of the <u>Children's Palliative Care</u> <u>Outcome Scale</u> in its routine care services.

We are pleased to celebrate a growing critical mass of researchers spanning across eastern, western, southern and northern Africa, across the four regional APCRN hubs. Two members of the APCRN attained post-graduate degrees and were mentored by the APCRN throughout the course of their studies. We would like to congratulate Rachel Freeman from Namibia who obtained her doctoral degree in social work from the University of Namibia and Dr Edwina Addo Opare-Lokko of Ghana, who graduated with a Master's degree.

#### FOCUS ON WEST AFRICA

In West Africa, APCA conducted a national situational analysis in **The Gambia** and in **Togo** to obtain a better understanding of the status of hospice and palliative care development in each of the countries. Areas of focus in the analyses included: policy frameworks, service delivery, essential medicines and technologies, health care workforce, information systems and financing as well as country priorities for the integration of palliative care services into their national healthcare systems.

The APRCN supported this initiative in collaboration with the Cicely Saunders Institute, King's College London through the BUILD care fellowship. This research initiative works with fellows from across the world to engage in innovative research relating to appropriate patient care packages. In **Togo** and **The Gambia**, fellows are addressing important research questions relating to which care packages are appropriate for patients with renal disease or multi-drug resistant tuberculosis.

#### ADVANCING THE USE OF TECHNOLOGY IN PALLIATIVE CARE

In collaboration with the World Health Organization, APCA is studying the use of a mobile phone application to improve palliative home care in resource-limited settings. In this pilot, the Africa POS will be administered to patients using a mobile phone platform and the data will be digitally transferred to a centre where data will be analysed and patients' needs addressed. The project is underway with the mobile app available and staff trained in data collection methods.

As care providers access this data through an interactive web-based dashboard, patients and family carers will have an increased sense of self efficacy to address gaps in their supportive care. From this pilot project, APCA will draw key recommendations to inform the task shifting agenda for incorporating patient level data into routine clinical care.



APCA staff working with WHO consultant Jordi Serrano-Pons, on the interactive application to be used in the WHO supported palliative care study.

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## **SYSTEMS**

#### **BUILDING AN EVIDENCE BASE FOR PAIN ALLEVIATION**

In Uganda, APCA facilitated the documentation of average patient pain scores and morphine consumption. This data has shed light on important information regarding disease and symptom characteristics as well as pain management trends over a nine month data collection period from the following three participating Ugandan hospitals: Gulu Regional Referral Hospital, Mbale Regional Referral Hospital and the Uganda Cancer Institute. APCA has an abstract on this project accepted for presentation at the 22nd World Congress of Palliative Care to be held in Montreal, Canada in October 2018.

The need for integration of palliative care into hospital settings is accentuated by an increased need for pain relief among inpatients in Uganda due to increased NCD incidence and prevalence and the interplay between NCDs and HIV.

#### **PUBLIC OUTREACH THROUGH** MEDIA MESSAGING

This year, APCA worked to increase awareness of services to the general public through culturally relevant media outreach messages.

To do so, APCA engaged in innovative approaches to reaching the public with palliative care messaging. In total, **29 palliative** care awareness sessions reached over I million people across seven African countries: Kenya, Liberia, Tanzania, The Gambia, Togo, Uganda and Zimbabwe. This was accomplished through face-to-face meetings, edutainment programming and 16 radio talk shows, which resulted in the highest population reach across the seven countries.

Pertinent themes addressed through these outreach activities allowed the public to express their questions around cancer identification and pain management medications.

WHEN LISTENERS FROM THE GENERAL PUBLIC WERE PROVIDED AN OPPORTUNITY TO SUBMIT QUESTIONS TO TALK SHOW HOSTS, THEY ASKED:

What causes cancer? What are the signs of breast cancer? What is the relationship between breast cancer and breast feeding? Is cancer contagious?

This initiative highlighted the importance of public education services in regards to disease management and symptom control and relief.

#### **APCA'S PARTICIPATION IN GLOBAL EVENTS**

APCA had the privilege of representation at several high level meetings this year in order to present on critical issues pertaining to the status and development of palliative care in Africa. Through these meetings, new relationships and networks were established. Innovative ideas for strategic advocacy on palliative care were also exchanged, including narrative framing which was discussed in-depth and has strengthened our advocacy efforts.

At each of these events, individual advocacy meetings focused on developing strategies to accelerate the integration of palliative care into African health systems based on the World Health Assembly Resolution 67.19 as set forth below:

World Hospice and Palliative Care Association's (WHPCA) board meeting and presentation at the Asia Pacific Palliative Care Network WHEN: July 2017 **WHERE:** Singapore **ATTENDEES:** Executive Director

Presentation on the APCA Palliative Care Standards at the invitation of Hospis Malaysia, during their meeting on Quality and Standards in Palliative Care WHEN: July 2017 WHERE: Kuala Lumpur, Malaysia

**ATTENDEES:** Executive Director

**Open Society Foundations/Open Medical Institute** Seminar on "Making Change Happen: Strategic Advocacy and Communications for Palliative Care" WHEN: December 2017 WHERE: Salzburg, Austria **ATTENDEES:** Programmes Director

AORTIC conference where APCA presented nine abstracts. The conference was very useful and provided a forum for sharing knowledge and updates about cancer. WHEN: November 2017 WHERE: Kigali, Rwanda ATTENDEES: Six APCA staff members

International Conference of the Palliative Care Network. The virtual conference focused on palliative care developments in Africa and attracted attention from professionals globally.

WHEN: November 2017 WHERE: Virtual conference **ATTENDEES:** Programmes Director

APCA supported preparations of the joint international conference on Cancer and Palliative Care organised by the Palliative Care Association of Uganda (PCAU) and the Uganda Cancer Institute (UCI) under the theme: United Against Cancer: Prevention to End-of-Life Care. APCA presented on several publications at this event. WHERE: Kampala, Uganda WHEN: August, 2017 ATTENDEES: APCA staff

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#### DOCUMENTING PALLIATIVE CARE PROGRESSION IN AFRICA

In May 2017, the APCA Atlas for Palliative Care in Africa was launched at the 15th World Congress of the European Association of Palliative Care (EAPC) that took place in Madrid, Spain. The Atlas was developed in close collaboration with the University of Navarra, IAHPC and other partners and has been a very widely disseminated resource that is accessible through the APCA website:

#### https://www.africanpalliativecare.org/articles/apca-atlas-of-palliative-care-in-africa/

Through this development, APCA celebrates the progress made towards documenting the evolution and progress of palliative care in the region and now hosts the novel regional repository to track progress over time.

Notably, the development of the APCA Atlas of Palliative Care in Africa is based on unique indicators that speak to African health systems, affording countries the opportunity to tell their stories in service development and allowing for countrylevel comparison.

"THIS INITIATIVE HIGHLIGHTED THE IMPORTANCE OF PUBLIC EDUCATION SERVICES IN REGARDS TO DISEASE MANAGEMENT, SYMPTOM CONTROL AND RELIEF."



APCA's Research Manager and Executive Director with Professor Carlos Centeno from University of Navarra at the launch of the APCA Atlas in Madrid.



Ms Josephine Kampi, APCA's Resources Director presenting her poster on resource mobilisation and management at AORTIC, 2017.



Ms Irene Namwase, APCA's Membership Support Officer at APCA's exhibition desk at AORTIC, 2017.

#### **APCA CONTRIBUTIONS TO KEY PUBLICATIONS**



The Changing Face of Volunteering in Hospice and Palliative Care M MERMICHAL RESPONSE

Fatia Kiyange, Programmes Director, contributed a chapter titled Volunteering in Hospice and Palliative Care in Africa (Chapter 11) to the publication: The Changing Face of Volunteering in Hospice and Palliative Care: An International Perspective, published by the Oxford

University Press in April 2018.





Emmanuel Luyirika, Executive Director, was one of several contributing authors to a chapter in the book published by the World Bank: Disease Control Priorities, Improving Health and Reducing Poverty 3rd Edition (DCP3). The publication is accessible at the following link: https://openknowledge. worldbank.org/ handle/10986/28877

#### **KEY PUBLICATIONS**

#### Read more about APCA co-authored publications during the year:

- I. An Analysis of Palliative Care Development in Africa: A Ranking based on Region-Specific Macro-Indicators: https://www.sciencedirect.com/science/article/pii/S0885392418302380?via%3Dihub
- Developing Macro-Indicators of Palliative Care Development in Africa: A Process with In-Country and International Experts: <u>https://www.liebertpub.com/doi/abs/10.1089/jpm.2017.0207?url\_ver=Z39.88-2003&rfr\_id=ori:rid:crossref.org&rfr\_</u> <u>dat=cr\_pub%3dpubmed</u>
- 3. Factors Affecting Palliative Care Development in Africa: In-Country Experts' Perceptions in Seven Countries: https://www.ncbi.nlm.nih.gov/pubmed/29409870
- 4. Integrating Palliative Care into National Health Systems in Africa: a Multi-Country Intervention Study: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5475315/pdf/jogh-07-010419.pdf
- 5. Investigation of the Practices, Legislation, Supply Chain and Regulation of Opioids for Clinical Pain Management in Southern Africa: A Multi-Sectoral, Cross-National, Mixed Methods Study: <u>https://www.sciencedirect.com/science/article/pii/S0885392417306413</u>
- 6. Outcome Measurement in Paediatric Palliative Care: Lessons from the Past and Future Developments: http://apm.amegroups.com/article/view/19946/19806
- 7. Service Delivery Models to Maximize the Quality of Life for Older People at the End of Life: <a href="http://www.who.int/kobe\_centre/en/">http://www.who.int/kobe\_centre/en/</a>
- 8. The APCA Atlas of Palliative Care in Africa: https://www.africanpalliativecare.org/images/stories/pdf/APCA\_atlas.pdf



## BUILDING BLOCK 4 ACCESS TO ESSENTIAL MEDICINES

PCA provides legislative guidance to ensure practical steps are taken towards ensuring pain-relieving medications and technologies are made available to patients in need.

#### ACCESS TO ESSENTIAL PALLIATIVE CARE MEDICINES

APCA aims to support African countries to make essential medicines and technologies for palliative care available and accessible to patients in an affordable and timely manner.

This financial year, we focused our attention on providing technical assistance (TA) for the local production of affordable oral liquid morphine for pain management in nine countries, namely: Botswana, Ghana, Kenya, Mozambique, Nigeria, Rwanda, Swaziland, Togo and Uganda.

In each of these nine countries, APCA worked with different stakeholders in the medicines supply chain. APCA, in collaboration with local partners, brought these stakeholders on board, providing them with training and extending technical support to undertake their role in producing essential medicines, especially oral liquid morphine.

APCA's technical assistance specifically addressed supply chain management in oral morphine production and distribution protocols to ensure it is made available and accessible for pain relief in their respective countries.

Specific areas of technical assistance included: engagement in the ordering and production process, production space assessments, experiential learning of appropriate distribution, selection of appropriate formulations, product quality assurance, access to raw materials, product distribution and reporting of consumption, among others. The ultimate goal was for countries to have sustainable access to essential pain relief medicines for patients in need.

This year, six countries namely; **Botswana, Kenya, Swaziland, Mozambique, Nigeria, and Togo** either made modifications to their morphine production space or identified space for their start of production as a result of the APCA's technical assistance.

In **Kenya**, APCA provided technical assistance to Kenyatta National Hospital (KNH) which scaled-up their production of oral liquid morphine by increasing the volume produced. As a result, the local team was able to produce a maximum of 200 litres of oral liquid morphine per batch to address the need for pain relief among the hospital's patients.

#### EXPERIENTIAL VISITS: LESSONS FROM UGANDA

APCA staff had an experiential visit to Rene Pharmaceutical Industries in Kampala, **Uganda** to further understand the medicines manufacturing process. Many of the essential medicines used in palliative care in East Africa are manufactured at this facility.



APCA staff with the Director of Rene Pharmaceutical Company in Kampala, Uganda.



The team from the Ministry of Health Botswana (seated) with the Palliative Care Association of Uganda (PCAU) Country Director Ms Rose Kiwanuka and APCA staff during a benchmark visit to Uganda.

## AND TECHNOLOGIES

APCA supported the Ministry of Health of **Botswana** to conduct a landmark visit to **Uganda** in March 2018, where **six officials** represented their country's palliative care working group.

This visit aimed at gathering key lessons for the local reconstitution of oral liquid morphine through various interactions with Ugandan stakeholders. The visit followed recent palliative care developments that had taken place in Botswana, which included the Government of Botswana securing a morphine powder tax exemption and the procurement of the first supply of 5 kilogrammes of morphine powder. The **Botswana** Ministry of Health had further appointed a technical working group to coordinate the morphine production process in the country, a pharmacist to lead the process, and the identification of possible sites where morphine production would take place.

#### FOCUS ON WEST AFRICA

In **Togo**, the government secured a budget for procuring morphine powder and identified space for morphine production in Le Centre Hospitalier Universitaire Sylvanus Olympio (CHU-SO), the national referral hospital. The hospital is also planning to procure basic morphine production equipment as a result of APCA's training and support.

In **Nigeria**, through collaboration with Hospice Africa Uganda (HAU), APCA developed and delivered a training workshop on Current Manufacturing Practice (cGMP) to staff members in the Food and Drug Administration of Nigeria's Federal Ministry of Health (FePMAL) to enable them to upgrade their facilities to accommodate large scale morphine production.





Il efforts are being made by APCA and its partners to influence African governments to invest in palliative care as an important public health and human rights issue.

Financing for the integration of palliative care and access to controlled medicines within African health systems has significantly reduced, posing a public health challenge in furthering access and availability to essential pain relieving medicines. Some of the traditional donors of palliative care have either closed or changed priorities, with palliative care and access to pain relief being dropped.

Currently, only a few donors are supporting palliative care and pain relief. To contribute to the mobilisation of financial resources for palliative care activities, APCA was able to identify funding that was used to implement palliative care interventions across **I3 African countries**. These interventions were undertaken through formal partnerships with ministries of health, national palliative care associations, palliative care service providing organisations, health facilities as well as academic institutions.

We are pleased to report that in **Botswana**, **Rwanda**, **Swaziland and Togo**, governments through their ministries of health, were able to allocate funding towards palliative care activities, resulting from APCA's advocacy efforts.



#### HOW YOU CAN PARTNER WITH APCA

APCA is seeking new partnerships to strengthen its support to African palliative care service delivery and leadership training.

To establish a partnership with us, please email: patricia.batanda@africanpalliativecare.org

## WHY JOIN APCA MEMBERSHIP?

Joining APCA means becoming part of a unique, dynamic community of palliative care professionals and supporters across Africa and internationally. APCA membership offers unparalleled opportunities to contribute to the development of life-changing palliative care, and to receive support in your work and career from a wide range of experts and professionals.

#### TO JOIN APCA'S FREE MEMBERSHIP BENEFIT PROGRAMME EMAIL: members@africanpalliativecare.org



BUILDING BRIDGES



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## BUILDING BLOCK 6 LEADERSHIP AND GOVERNANCE

PCA supports African governments to take leadership in ensuring better access to palliative care services for their citizens -- in fulfilment of their commitment to international, regional and national laws and legal frameworks.

This year, APCA worked with and supported ministries of health in **Botswana**, **Kenya**, **Liberia**, **Rwanda**, **The Gambia**, and **Togo**. Several advocacy meetings and activities were undertaken as detailed below:

#### **IN RWANDA**

- APCA held a meeting with the Minister of Health of Rwanda, Dr Diane Gashumba, and her team which included the Permanent Secretary and the Coordinator for Palliative Care in the Ministry of Health/Rwanda Biomedical Centre. APCA's delegation to this meeting was led by APCA Executive Director, Dr Emmanuel Luyirika, and included Fatia Kiyange, APCA Programmes Director, and Rosemary Canfua, APCA's Technical Programme Coordinator for Medicines.
- APCA supported the training of four board members of the Palliative Care Association of Rwanda in Kigali. The training was focused on strengthening the capacity of the board members in their governance and leadership to better support palliative care advocacy efforts at the national level.



APCA meeting with the Kenya Director of NCDS at Kenya MoH offices (left to right): Dr Kibachio, Director of NCDs MoH Kenya (extreme left), Dr Esther Muinga from KEHPCA, Dr Eunice Gathithu, Head of the Palliative Care Desk, MoH Kenya; Dr Alfred Karagu, the Head of Cancer Control; Dr Emmanuel Luyirika, APCA Executive Director; Dr Zippy Ali, Executive Director of the Kenya Hospices and Palliative Care Association.

#### **IN BOTSWANA**

APCA worked with the ministry of health to increase the knowledge and skills of health care workers to manage pain relief among patients. APCA also supported the process for local morphine production.

#### **IN KENYA**

APCA's Executive Director joined the team at the Kenya Hospices and Palliative Care Association (KEHPCA) for a meeting with the Director of NCDs (Dr Kibachio) and his team at the ministry of health. The country's progress on the implementation of the May 2014 World Health Assembly Resolution on palliative care was discussed as well as the inclusion of palliative care in Universal Health Coverage (UHC). As Kenya plans to use the existing National Health Insurance Fund as a catalyst to make UHC accessible, this meeting was particularly relevant. During this meeting, APCA was introduced to the focal person for palliative care at the Ministry of Health, Dr Eunice Gathitu, and we are working with KEHPCA and other stakeholders to improve palliative care services in Kenya. The MoH and KEHPCA have since embarked on a process for developing a national palliative care policy in the country as the MoH has agreed to implement and mainstream palliative care as a crosscutting discipline in addressing NCDs and infectious diseases throughout the country.



APCA's Executive Director Dr Emmanuel Luyirika and his team at the meeting with Dr Diane Gashumba, the Minister of Health of the Republic of Rwanda (third from left), Permanent Secretary in the Ministry of Health (2nd from right) and Coordinator for palliative care in Rwanda Biomedical Center/ Ministry of Health, Diane Mukashaha (extreme right).

#### IMPLEMENTING WHA 67.19: Ongoing momentum from the 2016 Ministers of Health Session

In **Botswana**, the Ministry of Health is scaling up the integration of pain management in all their hospitals. Morphine powder has been procured in preparation for the start of local morphine production.



In **Ethiopia**, a needs assessment was conducted and a five year plan was developed to establish a model of palliative care delivery as well as a training programme for healthcare professionals. National palliative care guidelines have also been developed, as palliative care has been incorporated into the Ethiopian Hospital Service Transformation Guidelines and pre-service curriculum for nurses and medical students. This resulted from participation in both 2013 and 2016 Ministers session where a volunteer, Dr Nicola Ayers, was appointed to lead this effort.



In **Kenya**, APCA held a follow-up advocacy meeting with the officials who represented the Minister of Health, resulting in the appointment of a focal person for palliative care in the MoH and a further commitment to implement the WHA resolution on palliative care.



In **Mozambique**, the need to start local morphine production has been acknowledged by the MoH, the Mozambique Medicines Regulatory Authority, the Maputo National Referral Hospital Pain Unit and other relevant offices. The Minister's representative who attended the 2016 Ministers Session is behind these efforts.



In **Rwanda**, an advocacy meeting with the new Minister of Health resulted in a collaboration agreement to co-host the 2019 Ministers of Health Session and the 6th International African Palliative Care Conference in collaboration with the Ministry of Health of Rwanda.



In **South Africa**, momentum from the Ministers Session led to the first tracking of the national palliative care policy approved in 2017.



In **Tanzania**, the Tanzanian Member of Parliament (MP) who participated in the APCA 2016 Ministers Session has been instrumental to palliative care developments and access to morphine has been discussed several times on the floor of Parliament, pushing responsible authorities to take action.



In **Zimbabwe**, stronger collaboration and coordination with the Ministry of Health has resulted following the 2016 Ministers of Health Session.

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#### AFRICAN PALLIATIVE CARE ASSOCIATION

## **SUSTAINABILITY AND** ORGANISATIONAL DEVELOPMENT

PCA believes in the value of collaboration, bringing together the assets and resources of global partners to strengthen interventions that alleviate pain and suffering.

#### **ORGANISATIONAL GOVERNANCE**

APCA has continued to maintain good governance structures and procedures through its quarterly meetings with its board of directors virtually, with one meeting held in Entebbe, **Uganda** in February 2018. During this meeting, APCA staff met with the board members and engaged in discussions related to the sustainability of APCA. Topics that were addressed included: organisational development, funding and APCA's strategic engagement on the continent and globally.



APCA board and staff members during the board meeting held in Entebbe, Uganda in February, 2018.

#### **APCA STAFF CHRISTMAS GIVING**

In the spirit of Christmas giving, APCA staff brought joy and hope to children living with cancer at the New Hope Children's Hostel, at Kawempe Home Care (KHC) in **Uganda**. Staff donated items to the children, including toys, books, and food. It was an exciting moment for the children, and seeing the smiles on their faces was very fulfilling for both APCA and Kawempe Home Care staff. APCA staff were joined by some of the board members and well-wishers in this giving opportunity.



#### **APCA STAFF RETREAT**

APCA staff engaged in a one-day retreat to reflect on APCA's work, achievements, challenges and opportunities, while also strategising for the future. This was an opportunity to boost staff morale, productivity, and relax from our busy schedules.



APCA staff during a retreat at the Extreme Adventure Park in July, 2017.

#### APCA PROVIDES TECHNICAL ASSISTANCE FOR ORGANISATIONAL DEVELOPMENT THROUGH:

Governance and management

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Financial and human resource management



Strategy and programme development and implementation



Monitoring and evaluation to ensure quality services for African patients and caregivers



Fundraising for organisational sustainability



Online visibility development and support.

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#### **GROWING APCA'S MEMBERSHIP PROGRAMME**



The winner of the APCA membership recruitment campaign, Mr Ronald Kasandha from Uganda, receiving his tablet for recommending the most individuals to join the membership programme.

During the period April 2017 to March 2018, APCA's membership grew to over **3,000 individual members** in over **80 countries** and **950 institutional members** in **36 countries**. As a result of our membership survey, APCA's membership team has been better informed regarding ways to support our members with a variety of informational products.

APCA also conducted a membership recruitment campaign in September 2017 in an effort to grow its base. As part of this campaign, a raffle drawing was held and the winners were awarded with a prize of a Samsung tablet. For recruiting the most members, two Samsung tablets were awarded to Mrs Susan Kwamboka Ogeto in Kenya, and the institution **Le Groupe Chrétien Contre le SIDA au Togo (Togo)** while Mr Kasandha Ronald won the individual recommender's tablet.

"DURING THE PERIOD APRIL 2017 TO MARCH 2018, APCA'S MEMBERSHIP GREW TO **OVER** 3,000 INDIVIDUAL MEMBERS IN OVER 80 COUNTRIES AND 950 INSTITUTIONAL MEMBERS IN 36 COUNTRIES."

#### **APCA STAFF ACHIEVEMENTS**

During the financial year, APCA celebrated various staff academic achievements. The administrative officer and personal assistant to the Executive Director, Ms Patricia Batanda graduated with a bachelor's degree in public administration and management. Further, APCA's Director of Resources, Ms Josephine Kampi Tatyabala and APCA Programme Officer, Ms Pamela Nahurira

Kalema, attained masters degrees in business administration. We would like to congratulate these staff members on their hard work and achievements.



APCA staff role play during a fundraising workshop.

#### APCA STAFF DEVELOPMENT

Several staff development sessions covered topics such as: personal health and work-life balance, Uganda's succession law, will writing, wellness, ergonometric and work related injuries, medical insurance benefits for staff and management styles.

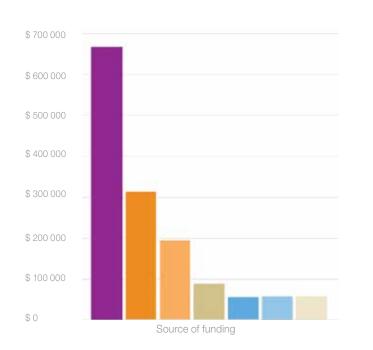
In June 2017, two staff members attended a training on the new Uganda NGO Act (2016) and taxation organised by the American Cancer Society's SOURCE programme. The training highlighted key features in the new law and compliance issues which are relevant to APCA as a non government organisation.

In July 2017, all APCA staff attended a 3-day training facilitated by a UK-based fundraising consultant in resource mobilisation. Through this workshop, staff acquired fundraising knowledge and skills and this has since increased the level of their involvement in proposal writing and general resource mobilisation activities.



## FINANCIAL MATTERS

#### Where the money came from 2017/18



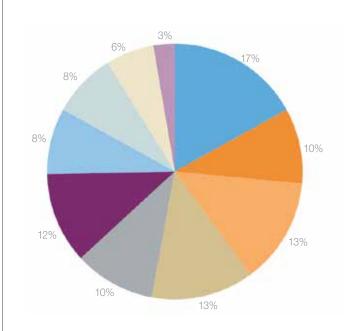
Sour	ces of income	Bal b/f 1/4/17	Income for the period AprI7- Mar 18	Total available funds Apr17 - Mar 18	Percentage income by donor
	The True Colours Trust	\$90 036	\$577 816	\$667 852	46%
	American Cancer Society	\$315 408		\$315 408	22%
	OSF/OSIEA	\$96 120	\$100 000	\$196 120	14%
	OSISA	(\$10 729)	\$100 000	\$89 271	6%
	The Diana Fund Legacy Grant	\$57 193		\$57 193	4%
	Other grants*	\$15 849	\$43 648	\$59 497	4%
	Internally generated income	\$31 333	\$27 966	\$59 299	4%
Tota	l available funds	\$595 210	\$849 429	\$1 444 639	100%

Accronyms:

OSF Open Society Foundations OSIEA Open Society Initiative for Eastern Africa OSISA Open Society Initiative of Southern Africa

\*Other grants APCA UK, American International Health Alliance (AIHA), Worldwide Hospice and Palliative Care Alliance, GIPPEC and Kings College London

#### Where the money went 2017/18



Expenditure area		2017/2018 (Amount)	2017/2018 (Percentage)
	Service delivery/ small grants	\$170 601	17%
	Admnistrative salaries	\$96 676	10%
	Research & M&E	\$135 077	13%
	APCA sustainability costs	\$130 594	13%
	Awareness creation	\$103 433	10%
	Policy/ Advocacy	\$115 832	12%
	Education	\$84 188	8%
	Admnistration & capital costs	\$82 045	8%
	Medicines	\$61 565	6%
	Partner sustainability costs	\$27 240	3%
Total		\$1 007 251	100%



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# **DONOR** APPRECIATION

ur work is made possible because of the generous contributions of our donors. APCA is committed to making sure every contribution is spent with patients and their families in mind. In particular, we would like to appreciate the following donors:

- American Cancer Society
- American International Health Alliance (HIV/AIDS Twinning Center)
- Global Partners in Care
- King's College London
- Open Society Foundations New York (OSF)
- Open Society Initiative for Eastern Africa (OSIEA)

- Open Society Initiative for Southern Africa (OSISA)
- The True Colours Trust
- Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC)
- World Health Organization
- Worldwide Hospice and Palliative Care Alliance, with support from The Joffe Charitable Trust

## MAKE A DONATION

All donations made to APCA, whether large or small, 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** and we will contact you with further details.

Alternatively, please visit our website **www.africanpalliative.org** and click **'donate'**.

Thank you for your support.



**AFRICAN PALLIATIVE CARE ASSOCIATION** 

# SAVE THE DATE!



## Palliative Care and Universal Health Coverage

#### 6th International African Palliative Care Conference 17-20 SEPTEMBER 2019 Kigali, RWANDA



#### HOSTED BY

African Palliative Care Association and the Ministry of Health of the Republic of Rwanda



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