

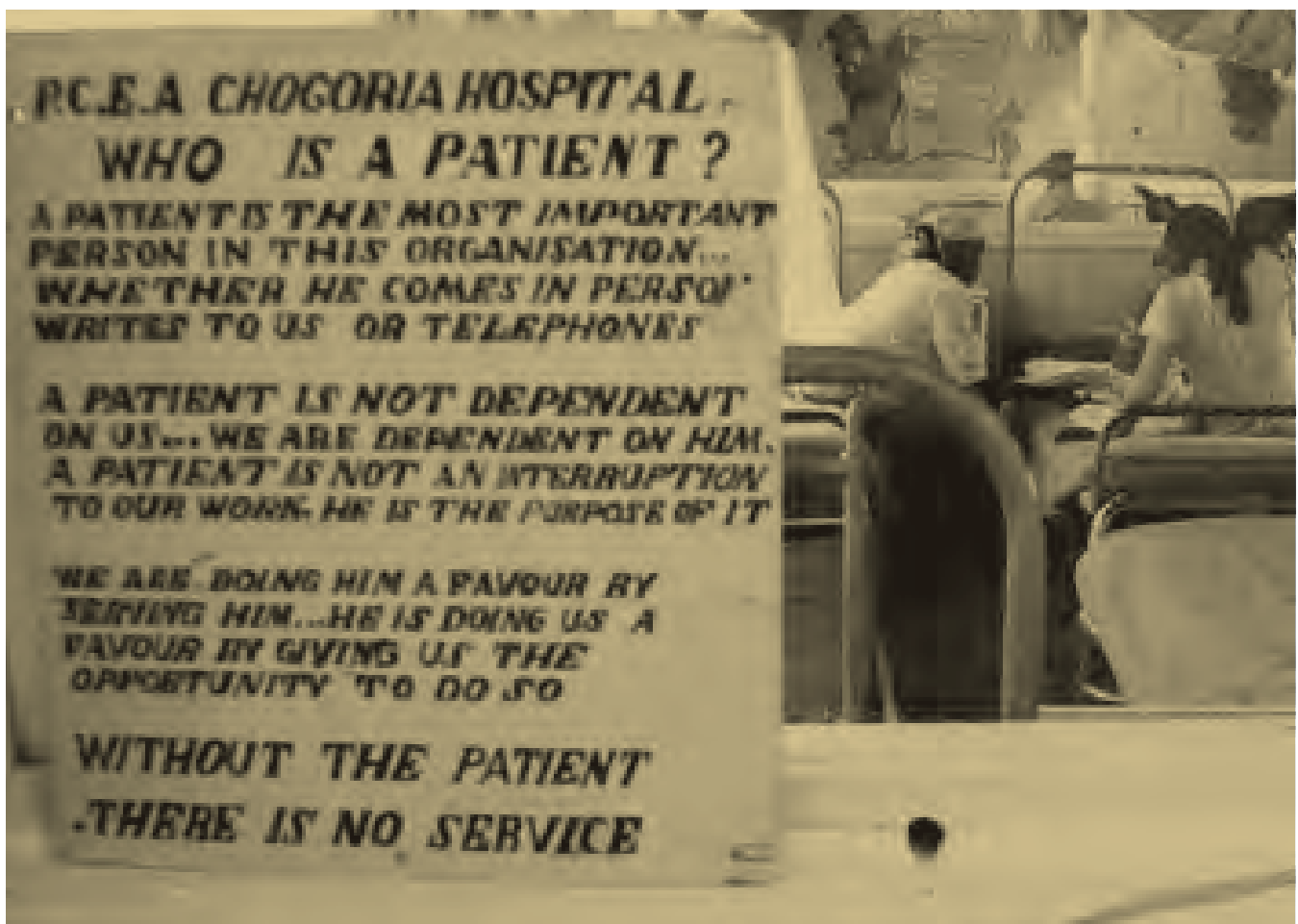


# ANNUAL REPORT

Towards Universal  
Health Coverage

April 2018 - March 2019





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A warm welcome to this special 2018/19 edition of the annual report.

# TO OUR PARTNERS

## MESSAGE FROM THE CHAIR OF THE BOARD



Mr Andre Wagner  
Chair of the Board

### WE WOULD LIKE TO THANK OUR STAFF, PARTNERS AND DONORS.

As members of the board, we ask you to partake in APCA's vision as it works at the helm of palliative care integration here, on the African continent.

Dear partner,

A warm welcome to this special conference edition of the annual report.

We did it. APCA, together with its dedicated partners, produced a legacy of activities to support patients and caregivers across the African continent. We did it in the midst of fiscal constraint which necessitated creativity and dedication to bring about the greatest impact within limited resources.

As we all work together towards a common aim of palliative care as a basic right and service under Universal Health Coverage, I invite us to take pause. To consider the caliber of leadership

and scope of dedication that it will require for us all to get there.

As members of the board, we ask you to partake in APCA's vision as it works at the helm of palliative care integration here, on the African continent.

They do this by engaging governments and partners through technical support - an essential aspect to ensure palliative care is delivered with quality and consistency.

Through the pages of this report, we celebrate the milestones of care that APCA is providing to patients across Africa. Thank you for your continued engagement and support.

**WE DID IT IN THE MIDST OF FISCAL CONSTRAINT WHICH NECESSITATED CREATIVITY AND DEDICATION TO BRING ABOUT THE GREATEST IMPACT WITHIN LIMITED RESOURCES.**

# FROM THE EXECUTIVE DIRECTOR



Dr Emmanuel Luyirika  
Executive Director

Welcome to this conference edition of our annual report.

We hope that through this year's many activities, you would be inspired as partners and co-investors in the report's theme "Towards Universal Health Coverage."

We know that for UHC to become a reality in Africa and globally, an investment in palliative care needs to happen at the governance level.

This has been our institutional focus, despite fiscal challenges this year.

We have ventured into new strategic partnerships -- building support for palliative care within the East African Legislative Assembly, engaging with parliamentarians and African ministers of health, and working to mobilise regional bodies towards the implementation of UHC.

While we look to the future for strengthened support for palliative care under UHC, we also have kept our pulse on the present, as the needs of patients and their caregivers are imminent.

Across Africa, we have supported the training of a health care workforce, essential to the delivery of palliative care services.

**WE THANK OUR MEMBERS, PARTNERS AND DONORS FOR ENGAGING IN OUR WORK MEANINGFULLY FOR THE BETTERMENT OF PATIENTS ACROSS THE AFRICAN CONTINENT.**

## NUMBER OF LOCAL PARTNERS ENGAGED

# +54

**WE BELIEVE PALLIATIVE CARE UNDER UNIVERSAL HEALTH COVERAGE WILL BE MORE SUSTAINED THROUGH OUR EFFORTS AND THROUGH YOUR ONGOING PARTNERING SUPPORT.**

We have also supported national associations and implementing partners to meet the needs of patients under their care. We have done this through the administration of small grants and engagement in innovative research to find digital solutions to assess patient and caregiver needs.

As we contribute to the development of Universal Health Coverage schemes across the continent, we believe palliative care will be more sustained through our efforts and through your ongoing partnering support.

For this, I thank our members, donors, partners and board of directors, for engaging in our work in meaningful ways for the betterment of patients across the African continent.

We look forward to working with all of you as, together, we move towards palliative care becoming an integrated service under UHC -- in Africa and beyond.





**MISSION:** To ensure that palliative care is widely understood, integrated into health systems at all levels and underpinned by evidence, in order to reduce pain and suffering across Africa.

# ABOUT APCA

## VISION: ACCESS TO PALLIATIVE CARE FOR ALL IN AFRICA.

Founded in 2004, 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 health care 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.

During this year, the African Palliative Care Association (APCA) continued to implement its 10 year Strategic Plan (2011 - 2020) in alignment with global frameworks and strategies.

### OUR WORK IS DRIVEN BY THE FOLLOWING FOUR STRATEGIC OBJECTIVES:

- 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 WITH GLOBAL STRATEGIES**

# 50

## THE NUMBER OF AFRICAN PARTNERS BENEFITTING FROM APCA'S TECHNICAL SUPPORT IN PALLIATIVE CARE.

This year, our interventions contributed to the WHO'S six building blocks for health system strengthening in **19 African countries**.

Our broad network of formal partnerships has included collaborations with ministries of health, palliative care service providers, public and private-not-for profit health facilities, cancer centres, professional associations, civil society groups as well as academic institutions.



## THIS REPORT IS ALIGNED WITH THE WHO'S 6 BUILDING BLOCKS FOR HEALTH SYSTEM STRENGTHENING



### Service delivery

We supported both the increase in coverage for palliative care services, as well as quality improvement across 19 African countries.



### Health workforce/education

We trained health workers to deliver palliative care across healthcare settings in Africa.



### Health information systems

We are developing an evidence base for palliative care in the region, while supporting emergent researchers across Africa.



### Access to essential medicines and technologies

We are working to increase access to essential medicines and technologies for the attainment of Universal Health Coverage by 2030.



### Financing

We contributed to resource mobilisation for advocacy, capacity building, research, service expansion and quality improvement.



### Leadership/governance/ appropriate policies

We provided technical support for the inclusion of palliative care into national policies, strategies, and laws.



# BUILDING BLOCK 1

## SERVICE DELIVERY

This year, APCA supported both the increase in coverage of palliative care services, as well as its quality improvement. The following organisations and institutions benefitted from this support in the form of small grants, technical assistance and mentorship:

In **Kenya**, a small grant was awarded to the Kenya Hospices and Palliative Care Association. The small grant enabled the establishment of palliative care services in three hospitals located in marginalised and hard to reach counties: Isiolo County Hospital; Elgeyo Marakwet, Iten Hospital, and Vihiga County Referral Hospital.

In **Uganda**, a small grant to Hospice Africa Uganda and African Humanitarian Action initiated a processes of awareness creation and advocacy for the integration of palliative care services within their health programming for refugees.

In **Mozambique** and **eSwatini**, we provided further support to Chibuto Rural hospital (CDH) and Raleigh Fitkin Memorial Hospital (RFM) towards the institutionalisation of palliative care and pain relief services, building upon last year's interventions.

As a result of our awareness and advocacy activities, the management teams in these hospitals and health facilities extended their support towards the integration of palliative care within their hospital services. These organisations and institutions reached approximately **11,545 patients with palliative care services**. **About 50% of these patients were children.**

**“YOU HAVE PUT SMILES ON MY FACE AFTER MY MOTHER WAS ABLE TO GET OUT OF HER BED.”**

Family caregiver, Nebbi Hospital Palliative Care Unit in Uganda

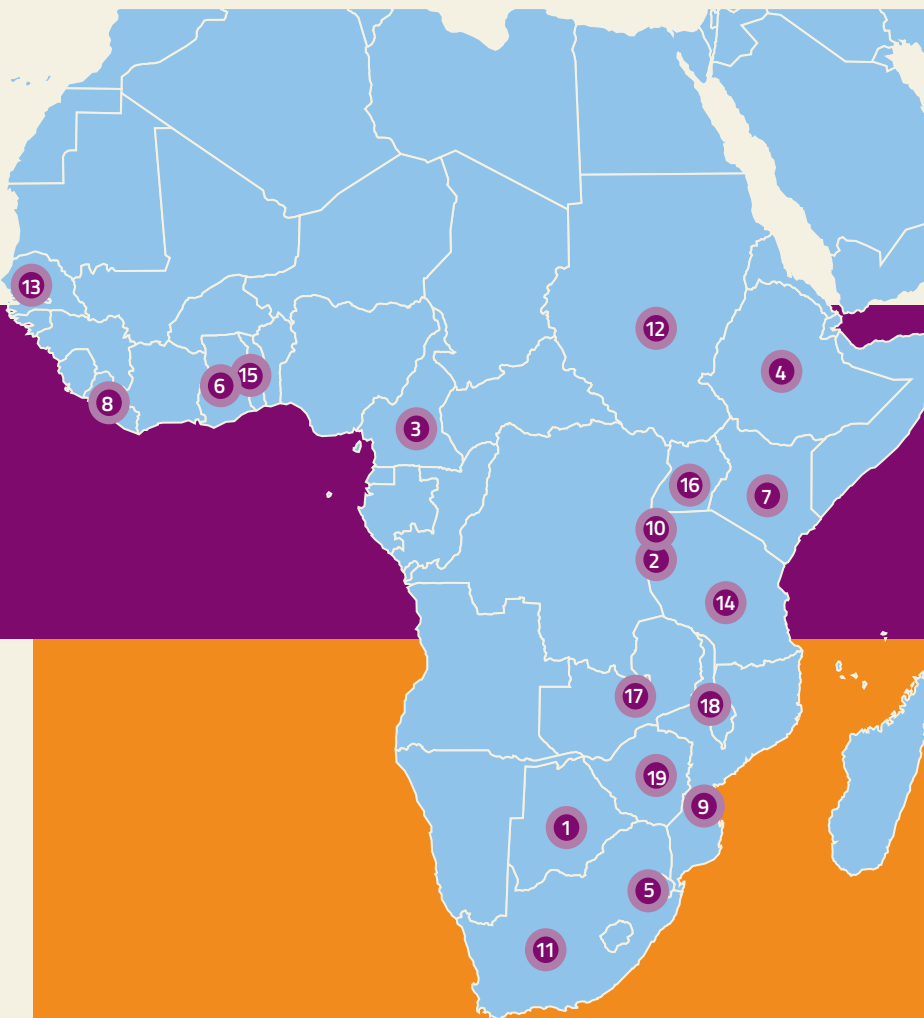
**“WITH THE MEDICINE THERE IS NO PAIN. AND IF I DON'T HAVE IT I COULD PULL MY HAIR OUT BECAUSE THE THROBBING PAIN IS SO SORE.”**

Edith Willox, patient with a facial tumour, beneficiary of Highway Hospice in South Africa.





## OUR GEOGRAPHICAL COVERAGE FOR THE YEAR 2018/19



## WE WORKED WITH 54 PARTNERS:

- 1. Botswana:** Ministry of Health
- 2. Burundi:** East African Health Research Commission; Palliative Care Association of Burundi
- 3. Cameroon:** Hopital De District De Bonassama
- 4. Ethiopia:** Hospice Ethiopia
- 5. eSwatini (former Swaziland):** Ministry of Health; Raleigh Fitkin Memorial Hospital
- 6. Ghana:** Ghana College of Physicians and Surgeons
- 7. Kenya:** Kenya Hospices and Palliative Care Association; Laikipia Palliative Care Centre; Living Room International; Meru Hospice Charitable Trust Fund; Nyeri Hospice; Vines Kenya
- 8. Liberia:** Ministry of Health; Redemption Hospital; Bong Mines Hospital; Home of Dignity
- 9. Mozambique:** Mozambique Palliative Care Association (MOPCA); Chibuto Rural Hospital in Gaza Province
- 10. Rwanda:** Rwanda Biomedical Center; Rwanda Ministry of Health
- 11. South Africa:** Highway Hospice Association; Hospice Rustenburg; South Coast Hospice Association; Leratong Hospice; Hospice Wits; Grahams Town Hospice Service; Msunduzi Hospice Association, Nightingale Hospice
- 12. Sudan:** University of Gezira
- 13. The Gambia:** Ministry of Health; Edward Francis Small Teaching Hospital; National Palliative Care Association in The Gambia
- 14. Tanzania:** Evangelical Lutheran Church of Tanzania (ELCT) Nyakahanga; ELCT in Arusha; East African Community Secretariat; Arusha Lutheran Medical Centre; Muheza Hospice Care in Tanzania
- 15. Togo:** Ministry of Health and Social Protection; CHU Sylvanus Olympio National Referral Hospital; Togolese Association for the Promotion of Health and Community Development
- 16. Uganda:** Hospice Africa Uganda; Uganda Network on Law, Ethics and HIV/AIDS (UGANET); Palliative Care Association of Uganda; African Humanitarian Action; Mildmay Uganda; Kawempe Home Care; Cancer and AIDS Relief Organisation; Kitovu Mobile
- 17. Zambia:** Ranchhod Community Services and Hospice
- 18. Malawi:** Concerned Youth Organisation and Christian Way Church; Rumphi Rural Palliative Care Services
- 19. Zimbabwe:** Hospice Palliative Care Association of Zimbabwe (HOSPAZ)

# 11,545

PATIENTS WERE REACHED WITH PALLIATIVE CARE SERVICES AS A RESULT OF APCA'S TECHNICAL SUPPORT. ABOUT 50% OF THESE PATIENTS WERE CHILDREN.



07

## BUILDING BLOCK 2

## HEALTH WORKFORCE

APCA is working to advance palliative care education to equip and enable health workers to deliver effectively on their mandate.

The limited number of palliative care trained health workers in all settings continues to be a challenge across Africa, which we are working to address in collaboration with our partners.

This year, we trained health workers in the following countries: **Kenya, the Kingdom of eSwatini, Liberia, Mozambique, Sudan, Tanzania, The Gambia, Togo, Uganda, and Zimbabwe.**

In each of these contexts, local capacity for palliative care training has been enhanced, most notably in **Liberia** and **Togo** where there was a previous void in palliative care trainers.

This year, trainings were delivered in the following formats:

- 1 introductory courses to enable health care workers to provide basic palliative care;
- 2 degree and diploma courses to create local leaders for service provision;
- 3 advocacy training and clinical placements to experience the practical delivery of palliative care services.

**Eleven participating health workers** engaged in specialist palliative care training offered by the Institute of Hospice and Palliative Care in Africa, with paediatric training conducted at Mildmay Uganda. These health workers were supported through our scholarship programme for nurses and social workers.

The training also resulted in an increase in patient referrals

for palliative care services and quality improvement in each of the benefitting institutions and countries.

In **Togo** and **The Gambia**, support was provided for the adaptation and implementation of national training packages.

In **Togo**, a team of three trainers participated in a 5-week palliative care initiators course for French speaking countries, hosted by Hospice Africa Uganda. These trainers are now recognised by the Ministry of Health and Social Protection (MoHSP) as senior trainers for palliative care in the country. They are also serving as lecturers in the Togo Nursing School, thereby increasing attention around palliative care as they teach palliative care principles to students.

Following the course, participants trained 25 HCWs from CHU Sylvanus Olympio Hospital and other health facilities in their country.

A palliative care service has now commenced at CHU Sylvanus Olympio Hospital for adults. Through this new service, 25 adult patients accessed palliative care services in 2018. Although the team is providing quality palliative care services, the availability and access to opioids for pain relief remains a challenge throughout the country.

**“THANK YOU FOR THE OPPORTUNITY TO SEE HOW SERVICES CAN BE PROVIDED WITH MINIMAL RESOURCE ALLOCATION. THE TEAM DID THEIR BEST TO IMPLEMENT WITH NO ADDITIONAL FINANCIAL RESOURCES AND MADE IT WORK.”**

Dr Mpho Ratshikana Moloko, Director Gauteng Centre of excellence for palliative care and mentors of trained health care workers in Chibuto Rural Hospital in Mozambique.



# 10

**THE NUMBER OF  
COUNTRIES WITH  
IMPROVED SERVICES AS  
A RESULT OF TRAINING**



📷 Professor Mofou Belo, Director, NCDs Division which supports palliative care in Togo.



📷 On return from a 5 week palliative care training course in Uganda, Dr Solange and her team returned to Togo to train health care workers in the CHU Sylvanus Olympio National Referral Hospital. This was the first national palliative care training of HCWs in the country and was highly publicised by local media.

## WHO DID WE TRAIN THIS YEAR ?

- NURSES
- DOCTORS
- PHARMACISTS, SOCIAL WORKERS
- DENTISTS, ANAESTHETISTS
- ONCOLOGISTS, CLINICAL OFFICERS
- COMMUNITY VOLUNTEERS
- HOME-BASED CAREGIVERS
- LEGAL PRACTITIONERS

## Equipping the legal and health workforce

In **Liberia**, 33 HCWs were trained in palliative care and 28 HCWs in **The Gambia** have contributed to the initiation and provision of palliative care services in their hospitals.

*"I am going back as supervisor of a medical ward, with passion to improve services and end of life care for our patients. The key word in palliative care is compassion."*

TRAINED DOCTOR, LIBERIA

*"I have been able to identify palliative care needs related to other diseases apart from cancer such as epilepsy."*

MENTAL HEALTH PHYSICIAN ASSISTANT, LIBERIA

In **The Gambia**, the training of HCWs resulted in a significant increase in the participation of hospital HCWs in palliative care activities, leading to the formation of a liaising team in the hospital.

This team, in collaboration with the national palliative care association, participated in the identification and treatment of palliative care patients in the hospital.

In total, 20 patients accessed palliative care services in 2018. The team also engaged hospital management and pharmacy authorities to ensure that essential palliative care medicines are available.

### ENSURING AVAILABILITY AND ACCESS TO ESSENTIAL PAIN RELIEF

**The Gambian** national palliative care association has reported consistency in the availability of and access to morphine tablets and syrup for use in pain relief.

In **Liberia**, a team at the Redemption Hospital provided palliative care to 28 patients, 10 of whom were children. We continue to monitor the availability of and access to opioids for pain relief in Liberia, which continues to be a challenge for the provision of a holistic service in the country.

In **Zimbabwe**, APCA worked with the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) to support the training and engagement of lawyers in the provision of free legal support for palliative care patients. Twelve lawyers from 8 legal and human rights organisations were trained through a 3-day blended

palliative care course to enable the further integration of legal aid into palliative care services in Zimbabwe.

HOSPAZ has worked with these lawyers and palliative care providers in Zimbabwe to develop legal materials and guidelines for legal aid integration into palliative care services.

### SUPPORTING HEALTH WORKER CLINICAL PLACEMENTS

With a growing number of palliative care centres of excellence regionally, APCA views clinical placements for trained health workers in these centres as a key approach to enhance the skills and competencies necessary for palliative care provision.

In **Mozambique**, health workers from Chibuto Rural Hospital had the opportunity to engage in clinical placements at the Gauteng Centre of palliative care excellence in South Africa.

Following this experience, 170 patients with chronic pain and other palliative care needs received palliative care services from Chibuto Rural Hospital, 49 of which were children. Chibuto Rural Hospital has also developed a strong relationship with the Gauteng centre of excellence, which is continuing to provide remote support and mentorship. These kinds of inter-country and inter-institutional support opportunities have demonstrated that centres of excellence can also draw upon lessons from new palliative care services.

### PATIENTS AND CAREGIVERS RECEIVING LEGAL AID HAD THIS TO SAY:

*"We didn't know that as girl children we are also entitled to our parents estates and belongings. Thanks to OSISA for the wonderful programme."*


NETSAI, 25, MAKONDE, ZIMBABWE

*"We never thought palliative care patients could access legal services free of charge. Thank you for the great initiative!"*

HASVINE, 41, ZVIMBA DISTRICT, ZIMBABWE.

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

LYN, CANCER ASSOCIATION OF ZIMBABWE



PALLIATIVE CARE



861

THE NUMBER OF HEALTH  
WORKERS TRAINED IN  
PALLIATIVE CARE



## BUILDING BLOCK 3

## PALLIATIVE CARE INFORMATION SYSTEMS

### HOW DID WE REACH NICHE POLICY AUDIENCES?

- NATIONAL STAKEHOLDER MEETINGS AND ADVOCACY WORKSHOPS
- COMMUNITY DIALOGUES
- HEALTH DEVELOPMENT PARTNER MEETINGS
- TEAM BUILDING SESSIONS
- MEDIA ENGAGEMENTS
- PROJECT REVIEWS
- INTERAGENCY LEARNING MEETINGS.

APCA continues to support the development of an evidence base for palliative care whilst building capacity for emergent researchers in the region.

We continue to mitigate misconceptions around palliative care as synonymous with end of life care, rather than a holistic approach that aims to improve the quality of life of patients and their families throughout the life course. This misunderstanding negatively impacts public support and the allocation of resources for this important service.

This year, APCA undertook more than **80** palliative care awareness raising activities in **11 countries** including: **Cameroon, Ethiopia, eSwatini, Kenya, Liberia, Malawi, Mozambique, Rwanda, Tanzania, Uganda and Zimbabwe**. Through these activities, we reached more than **54,000 people**.

We also developed Information, Education and Communication (IEC) materials and resources targeting various stakeholder audiences. Notably, the development of an East African documentary on palliative care was a major achievement. The 19-minute documentary captured palliative care practices in four East African countries: **Kenya, Tanzania, Rwanda and Uganda** at the patient, family, health worker and policy-maker levels.

The documentary has been a critical advocacy tool for the inclusion of palliative care in Universal Health Coverage in regards to the

value of investing in palliative care. The documentary was shown at an influential meeting with members of parliament in **Uganda** and at KEHPCA's 2018 national palliative care conference in **Kenya** (jointly organised by APCA, PCAU and UGANET). It was also shown at an APCA meeting with the East African Legislative Assembly in March 2019, as well as in other organisational level settings with health development partners.

Other materials developed included guidelines for the integration of legal services in palliative care (in **Zimbabwe**) and six video clips for World AIDS day that captured palliative care patient testimonials.

### INCREASING RESOURCE ACCESSIBILITY IN FRENCH AND PORTUGUESE

APCA translated its resources into French to make them available for use by partners in Francophone African countries to ensure equal benefit from each of APCA's programmes, including the small grants programme.

Translated materials included: the *APCA Atlas of Palliative Care in Africa*; *Guidelines for Clinical Placement in Hospice and Palliative Care in Africa*; *Palliative Care Core Curriculum*; *A Framework of Core Competencies for Palliative Care Providers in Africa*; *Guidelines for the Use of the APCA African Palliative Outcome Scale* for adults; a training methodologies guide; and the APCA technical assistance package brochure. These resources have been disseminated to 14 French speaking countries in Africa including: **Benin, Togo, Burundi, Brazzaville, Burkina Faso, Cameroon, Chad, Democratic Republic of Congo, Guinea Conakry, Mauritania, Niger, Senegal, Rwanda, and Tunisia**.

In **Mozambique**, we supported the translation of



THE EAST AFRICAN DOCUMENTARY IS ACCESSIBLE ON THE APCA YOUTUBE CHANNEL:

<https://www.youtube.com/watch?v=HGAZlbTkNms&t=24s>

# 14

## THE NUMBER OF FRENCH SPEAKING AFRICAN COUNTRIES BENEFITTING FROM TRANSLATED PALLIATIVE CARE GUIDELINES AND RESOURCES

materials for trained health care workers in their clinical practice. Through the Mozambique Palliative Care Association (MOPCA) a Portuguese translation of the *Beating Pain Pocket Guide* included the distribution of 150 copies as well as 200 translated pain assessment scales for Chibuto Rural Hospital and its referring clinics.

We also provided technical support for palliative care media training in **Ethiopia** and **South Africa**. This support focused on the development of a methodology and content for the media training, using APCA's experience from similar work previously undertaken in Uganda.

### APCA RECEIVES PRESTIGIOUS AWARD AT THE 2018 WORLD CANCER CONGRESS

At the 2018 World Cancer Congress held in Kuala Lumpur, APCA received the Union for International Cancer Control (UICC) Global Collaboration Award in recognition of its achievements and innovative practices. The award was based on APCA's collaboration in the implementation of national palliative care policies in three Southern African countries: **eSwatini, Mozambique and Zimbabwe**.

The award highlighted the following achievements: a 75% increase in access to palliative care services in Chibuto district, in **Mozambique** and a 90% increase in services in the densely

populated region of Manzini in **eSwatini**, over a 9 month period. More than 20 partners participated in this initiative at different levels, each performing different roles to achieve these targets.

More information about the award can be accessed at: [https://ehospice.com/africa\\_posts/celebrating-partnerships-and-collaboration-as-2018-draws-to-an-end/](https://ehospice.com/africa_posts/celebrating-partnerships-and-collaboration-as-2018-draws-to-an-end/)

We also hosted a symposium session at the 2018 Congress under the title: *Accelerating the implementation of the World Health Assembly Resolutions on palliative care and cancer*.

Among the presentations was one from our collaborative work with the Ministry of Health in **Togo**: *From No Palliative Care to a National Sustainable program – experiences from a Low- and Middle-Income country*, which was presented by Dr Francois Kokou N. Alinon, the focal person for palliative care in the Togo MoH.

Resulting from the participation and presentation made at the UICC Congress by Dr Alinon, the **Togo** Ministry of Health was selected as a beneficiary of the UICC sponsorship programme aimed at empowering organisations that contribute to the global fight against cancer. Through this initiative, we are pleased to report that the MoH will have access to UICC support and best practice resources from other UICC members to ensure that the MoH's vision around palliative care will continue to make progress.

### 7TH EAST AFRICAN HEALTH AND SCIENTIFIC CONFERENCE

Two APCA staff participated in the 7th East African Health and Scientific Conference, in Dar es Salaam, **Tanzania** which was themed: "Technology for health systems transformation and attainment of UN-Sustainable Development Goals."

This conference provided a forum for awareness creation among EAC partners through the dissemination of 100 copies of palliative care resources to more than 60 delegates who expressed interested in learning more about palliative care.

APCA's presentations focused on new frontiers and new technologies for strengthening pharmaceutical systems in palliative care. As a follow up, APCA is collaborating with the *East African Health Research Journal* to publish a series of articles on palliative care in October 2019. As this journal is open access, the evidence will be easily accessed by users in resource limited settings, thus addressing a critical research equity gap and building an evidence base for palliative care in the region.



APCA's Executive Director receiving the UICC Global Collaboration Award at the World Cancer Congress.

# RESEARCH DEVELOPMENT AND KNOWLEDGE TRANSLATION

## Dying well matters: The Quality of Dying and Death in Hospice Care in Uganda

APCA, in partnership with the Global Institute of Psychosocial Palliative and End of Life Care (GIPPEC), is completing a study aimed to establish the quality of death and dying in **Ugandan** hospices.

Using the Quality of Dying and Death (QODD) questionnaire, the study seeks to assess common death and dying experiences based on interviews with bereaved family caregivers who received care from Hospice Africa Uganda and Kitovu Mobile Home Care.

This is an interesting research project that is shaping the visibility of bereavement outcomes in sub-Saharan Africa and is raising awareness on the importance of quality care in regards to palliative care at the end of life. The study's results will be disseminated upon full completion.

## NEW TECHNOLOGIES, NEW FRONTIERS: DIGITAL HEALTH IN PALLIATIVE CARE

Given the growing interest in the use of technology to improve access to quality health care in Africa, APCA is keen to build an evidence base for digital health in palliative care.

This year, APCA collaborated with the World Health Organization on a study aimed at designing and evaluating an innovative mPalliative mobile phone application.

The application is designed to improve home-based care in resource-limited settings as a strategy for increasing access to palliative care in resource limited settings.

This is a promising model that promotes care that is sensitive to the needs and concerns of patients and their families. Most importantly, this model leverages a robust strategy that allows for task shifting the administration of patient-centred outcome measures to family and community caregivers.

THE MPALLIATIVE APP  
ALLOWS FOR REAL TIME  
AVAILABILITY OF PATIENT  
LEVEL DATA TO INFORM  
CARE PLANNING.



## mPalliative Dashboard



## WHO ARE THE PARTNERS ?

- UNIVERSITY OF LEEDS
- KING'S COLLEGE LONDON
- ISLAND HOSPICE
- ZIMBABWE
- UNIVERSITY OF ZIMBABWE
- LESO MANAGEMENT SERVICES
- PATH UGANDA
- UGANDA UK-HEALTH ALLIANCE
- UGANDA CANCER INSTITUTE
- MAKERERE UNIVERSITY PALLIATIVE CARE UNIT.

Study participants include patients, family caregivers, and policy makers. Findings will shape strategies to accelerate the use of technology to stimulate palliative care service development in the region.



## LEARN MORE ABOUT THIS PROJECT:

<https://www.researchgate.net/project/Understanding-the-role-of-digital-technologies-to-enhance-palliative-cancer-care-delivery-in-low-and-middle-income-settings>



# 54,000

## THE NUMBER OF PEOPLE REACHED WITH PALLIATIVE CARE AWARENESS ACTIVITIES



APCA's Research and Development Manager, Eve Namisango, listens to a bereaved caregiver as he shares his deceased family member's death and dying experience.

**P.C.E.A CHOGORIA HOSPITAL  
WHO IS A PATIENT**

A PATIENT IS THE MOST IMPORTANT PERSON IN THIS ORGANISATION... WHETHER HE COMES IN PERSON, WRITES TO US OR TELEPHONES

A PATIENT IS NOT DEPENDENT ON US WE ARE DEPENDENT ON HIM.

A PATIENT IS NOT AN INTERRUPTION TO OUR WORK... HE IS THE PURPOSE OF IT

WE ARE NOT DOING HIM A FAVOUR BY SERVING HIM... HE IS DOING US A FAVOUR BY GIVING US THE OPPORTUNITY TO DO SO.

**WITHOUT THE PATIENT  
THERE IS NO SERVICE**



APCA's IT Manager, Francis Kayondo, registers a delegate as an APCA member at the 7th East African Health and Scientific Conference in Dar es Salaam.

## WHO DID WE REACH THIS YEAR ?

- POLICY MAKERS
- POLITICAL LEADERS AT THE NATIONAL DISTRICT AND REGIONAL LEVEL
- JOURNALISTS
- HEALTH CARE PROVIDERS
- VILLAGE HEALTH TEAMS AND COMMUNITY VOLUNTEERS
- LEGAL PRACTITIONERS
- RELIGIOUS LEADERS



### THE AFRICAN PALLIATIVE CARE RESEARCH NETWORK

The African Palliative Care Research Network aims to support collaborative research in Africa and beyond. APCA runs a methodological workshop every four months as part of an initiative to build a network of Africa-based palliative care researchers.

To date the APCRN base stands at 170 members and 8 special research interest groups.

### ASSESSING MHEALTH DATA INFORMATION NEEDS

APCA and its partners are implementing a research project which aims to establish the data information needs for palliative care to target mobile phone intervention development in **Uganda** and **Zimbabwe**.

We are delighted to highlight this cutting edge digital health research project, pioneered through the APCRN research interest group under the leadership of Dr Matthew Allsop, based at the University of Leeds.

### TOWARDS PERSON CENTRED CARE FOR CHILDREN

We celebrate the completion of a large multi-country study that aimed to identify symptoms, concerns and outcomes that matter to

children living with life-limiting and life-threatening illnesses in Africa.

This study was conducted in **Uganda, Kenya, Namibia** and **South Africa** and successfully recruited 61 children and 59 family caregivers. The study included interviews with over 30 family caregivers of children aged 0-5 years.

Traditionally, children have not been consulted regarding the symptoms and concerns that matter to them. This study therefore bridges a critical evidence gap for paediatric palliative care in the region.

### KNOWLEDGE TRANSFER AND TRANSLATION

In addition to building a robust evidence base, APCA strives to scale up knowledge transfer and translation.

This enhances increased access to information for policy and decision making, in addition to informing patient care.

This year, APCA supported small grant recipients with the aim of bolstering their strategic advocacy initiatives.


These small grants enabled partners to present their findings from accepted abstract submissions at the 2018 KEHPCA conference to learn more about the use of evidence in advocacy, and to network with other professionals in the field of palliative care.

**“I GAINED A DEEPER UNDERSTANDING OF ADVOCACY IN PALLIATIVE CARE AND THE CURRENT RESEARCH METHODOLOGIES WHICH I PLAN TO USE IN STRENGTHENING OUR ADVOCACY AND RESEARCH DEPARTMENTS AND TO TEACH MY COLLEAGUES WHO NEVER HAD A CHANCE TO ATTEND THIS CONFERENCE.**

**NASUR BUYINZA, HOSPICE AFRICA UGANDA**

presenting on “Integration of palliative care in humanitarian situations in Uganda: Identifying and bringing strategic partners on board for greater outcomes and sustainability.”



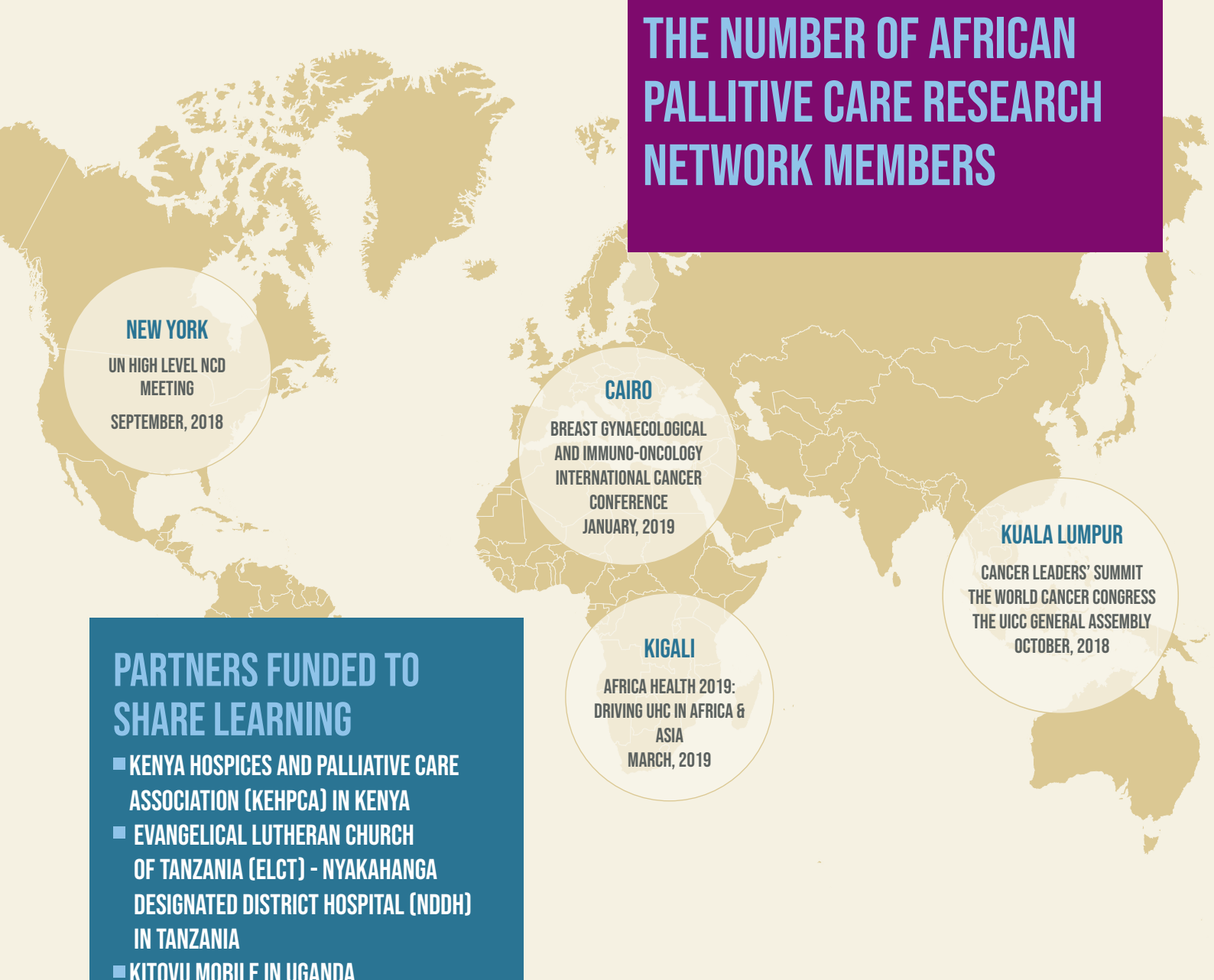
 Digital palliative care project team at the launch of the project at APCA's offices in 2018.



## APCA PARTICIPATED IN THE FOLLOWING GLOBAL EVENTS:

# 170

## THE NUMBER OF AFRICAN PALLIATIVE CARE RESEARCH NETWORK MEMBERS



### NEW YORK

UN HIGH LEVEL NCD MEETING  
SEPTEMBER, 2018

### CAIRO

BREAST GYNAECOLOGICAL AND IMMUNO-ONCOLOGY INTERNATIONAL CANCER CONFERENCE  
JANUARY, 2019

### KIGALI

AFRICA HEALTH 2019: DRIVING UHC IN AFRICA & ASIA  
MARCH, 2019

### KUALA LUMPUR

CANCER LEADERS' SUMMIT THE WORLD CANCER CONGRESS THE UICC GENERAL ASSEMBLY  
OCTOBER, 2018

## PARTNERS FUNDED TO SHARE LEARNING

- KENYA HOSPICES AND PALLIATIVE CARE ASSOCIATION (KEHPCA) IN KENYA
- EVANGELICAL LUTHERAN CHURCH OF TANZANIA (ELCT) - NYAKAHANGA DESIGNATED DISTRICT HOSPITAL (NDDH) IN TANZANIA
- KITOVU MOBILE IN UGANDA
- HOSPICE AFRICA UGANDA
- UGANET
- HEALTHY PEOPLE RWANDA
- ELCT IN ARUSHA TANZANIA.



## BUILDING BLOCK 4

## ESSENTIAL MEDICINES AND TECHNOLOGIES

Access to essential medicines and technologies is central to achieving Universal Health Coverage (UHC), and ultimately the 2030 Sustainable Development Goals.

APCA supported six countries (**eSwatini, Liberia, Mozambique, Tanzania, Togo and The Gambia**) to improve access to essential medicines and technologies for palliative care through advocacy, capacity building and technical support to improve supply chain systems.

APCA also supported **17 palliative care providing organisations in eight countries** to purchase medicines and supplies for their programmes. These included: **Cameroon, Kenya, Liberia, South Africa, Tanzania, Uganda, Zambia and Zimbabwe**.

The lack or limited availability and access to controlled medicines, especially opioids for pain relief and other essential palliative care medicines, remains a persisting challenge for palliative care service provision in Africa.

In **eSwatini**, APCA supported a two-day refresher training on the prescribing and dispensing of opioid analgesics for 27 health workers -- doctors, pharmacists, nurses and dentists from RFM Hospital and Dvokolwako Health Centre. The aim of the training was to empower prescribers and dispensers on how and when opioid analgesics should be prescribed, dispensed and stored.

This training highlighted the different roles of multidisciplinary teams in the medicines supply chain to ensure patients in pain receive timely treatment. The training also empowered prescribers and dispensers to be accountable in managing their patient's pain effectively.

In **Mozambique**, advocacy and capacity building for the availability and access to pain medications continued in Chibuto Rural Hospital in Gaza Province. As a result, pain medicines (including injectable morphine) were consistently in stock, although oral liquid morphine continues to be unavailable. The pharmacist in this hospital has been using a forecasting software

to enable the timely ordering of medicines to reduce stock outs. An increase in consumption of analgesics was reported in the hospital for patients in pain.

Improved pain management and correct use of the WHO analgesic ladder to manage cancer and other pain was also reported. The country still needs financial and technical support to start the ordering of powder morphine and to set up a local oral liquid Morphine Reconstitution Unit. Currently, oral morphine is being produced by breaking ampoules of injectable morphine and diluting it to form an oral solution.

### FOCUS ON WEST AFRICA: ADVOCATING FOR ACCESS TO ESSENTIAL PALLIATIVE CARE MEDICINES

In **Togo**, APCA advocated to improve access to controlled essential palliative care medicines through the Central Purchasing Center for Essential Generic Medicines and the pharmacy directorate.

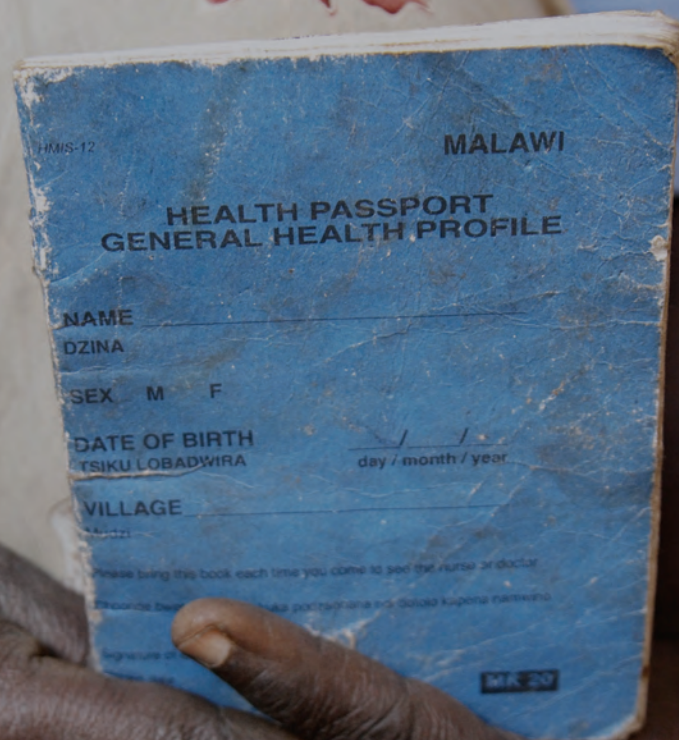
APCA partnered with the Ministry of Health and Social Protection Division of NCDs to identify and provide funding for the development of a local morphine production unit. The Togo Ministry of Health, through the Division of NCDs, also provided funds towards the purchase of morphine powder.

In total, 18 Togolese doctors and pharmacists were trained in opioid prescription and delivery in preparation for the establishment of a local morphine production unit, which is a priority for the MoH, CHU Silvio Olympio Hospital and the National Palliative Care Task Force -- each of whom serve as key players in the supply chain system.

Per the recommendation of Togo's National Palliative Care Task Force, a tripartite meeting between the NCDs Division, CAMEG and the Pharmacy Department was held in January 2019 to define the processes necessary to establish a morphine production unit in the country. An appropriate space for the local production of oral liquid morphine is being identified by these stakeholders.

# 17

THE NUMBER OF  
AFRICAN PARTNERS  
SUPPORTED TO  
PURCHASE PALLIATIVE  
CARE MEDICINES AND  
SUPPLIES IN  
EIGHT AFRICAN  
COUNTRIES.



In **The Gambia**, APCA advocated for the availability and accessibility of essential palliative care medicines, especially controlled medicines by engaging the Director, the Deputy Director of the Central Medical Stores, and the Drug Law Enforcement Agency (DREAG).

Barriers to the availability and accessibility of opioids for pain relief were discussed through the National Palliative Care Task Force, which is a member of the National Drug Enforcement Agency and National Pharmaceutical Services.

### STUDY VISITS FOR KNOWLEDGE SHARING

With the objective of drawing lessons for improved availability and accessibility to controlled medicines for pain relief, teams from **The Gambia** and **Liberia** were engaged in study visits to **Uganda** this year.

Participants included: two health care workers from Edward Francis Central Teaching Hospital (EFSTH); a registrar of Internal Medicine and Matron of Internal Medicine to **Nigeria**, and two executive officials of the National Association of Palliative Care (NaPCA) in **The Gambia**.

In **Liberia**, advocacy for access to controlled medicines for pain relief was undertaken by engaging the Chief Pharmacist in the Ministry of Health, the team from the drug supply chain, and the director of National Drug Services at the Central Medical Stores.

Persisting challenges for the availability and access to controlled medicines for pain relief and possible solutions were addressed and the national palliative care working group has continued with these discussions.

The national palliative care working group has specifically requested APCA's further technical support in this area through the MoH to address their challenges.

### TRAINING PHARMACISTS IN PALLIATIVE CARE SUPPLY CHAIN MANAGEMENT

Pharmacists play a central role in ensuring medicines availability and accessibility. They are in-charge of the medicines supply chain and their actions can either enhance the availability of palliative

care essential medicines or serve as a major barrier.

In **Tanzania**, APCA supported the Evangelical Lutheran Church of Tanzania (ELCT) in Arusha to conduct a first of its kind two-day national sensitisation workshop for pharmacists on palliative care and access to controlled medicines. This workshop was conducted in collaboration and with approval from the Tanzania Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC) and the Tanzania Palliative Care Association (TPCA).

The workshop drew 53 participants, including 20 pharmacists in different roles at the national, zonal referral hospitals, regional and district levels. Direct beneficiaries of palliative care services participated in the workshop as well as palliative care coordinators from ELCT facilities and other health facilities implementing palliative care.

The Principal Pharmacist at the **Uganda** Ministry of Health and Hospice Africa Uganda provided face to face technical support at the workshop on behalf of APCA.

Service access challenges in **Tanzania**, especially morphine shortages for pain relief, were widely published by journalists attending the workshop.

This media coverage resulted in a press release by the MOHCDGEC explaining to the public the reasons for the shortage and publically promising government action to address the problem.

Participating representatives from the Tanzania Food and Drug Authorities expressed willingness to work with more sites to issue permits in order to stock oral morphine and enable providers to reach more patients in need of these medicines.

Beneficiaries of palliative care and pain relief shared their real life experiences for pharmacists to understand the need for action, as highlighted in the quote below:

**"I WAS NEAR DEATH EXPERIENCE DUE TO PAIN WHENEVER MORPHINE WAS OUT OF STOCK AT NKOARANGA PALLIATIVE CARE PROGRAMME. I CALL UPON THE LEGISLATORS AND DECISION MAKERS TO USE THEIR AUTHORITIES TO STOP PEOPLE FROM DYING FROM PAIN."**

MIRIAM, METASTATIC ENDOMETRIAL CANCER & ON MORPHINE FOR SEVERAL YEARS.



Participants at the first awareness and advocacy workshop held in Tanzania for pharmacists, policy makers and other healthcare workers on access to palliative care and controlled medicines.



## WHICH MEDIA COVERED THE EVENT

- THE GUARDIAN
- INDEPENDENT TELEVISION (ITV)
- THE TANZANIA BROADCASTING COOPERATION (TBC)
- NIPASHE
- THE EAST AFRICAN
- HABARI LEO
- THE DAILY NEWS

# 53

THE NUMBER OF PARTICIPANTS IN THE PHARMACIST WORKSHOP ON ACCESS TO CONTROLLED PALLIATIVE CARE MEDICINES

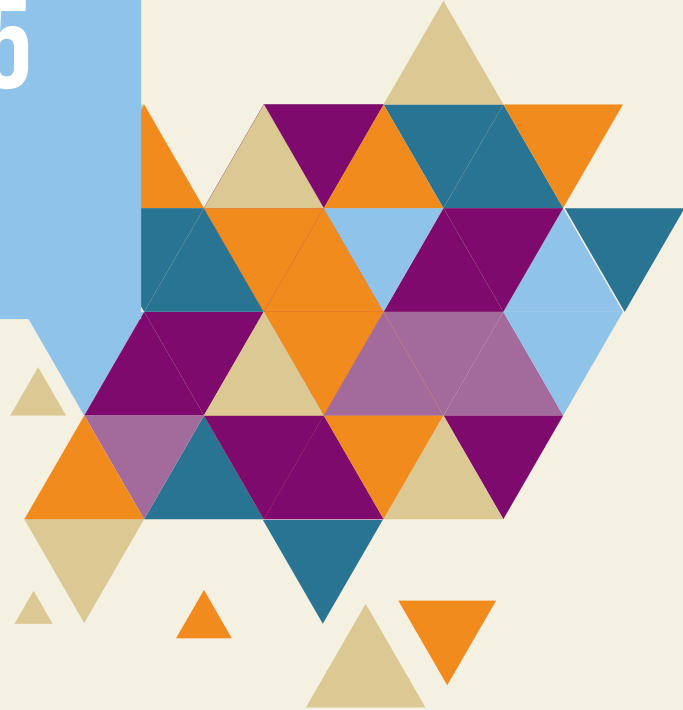
## WHO ATTENDED THE WORKSHOP ?

- DIRECT BENEFICIARIES OF PALLIATIVE CARE
- PRINCIPAL PHARMACIST AT THE UGANDA MINISTRY OF HEALTH AND HOSPICE AFRICA UGANDA, TANZANIA PHARMACY COUNCIL
- MEDICAL STORES DEPARTMENT (MSD)
- TANZANIA PHARMACY COUNCIL
- THE TANZANIA FOOD AND DRUG AUTHORITIES (TFDA)
- LEGAL AND HUMAN RIGHTS CENTRE (LHRC)
- PRESIDENTS OFFICE FOR REGIONAL AUTHORITIES AND LOCAL GOVERNMENTS (PO-RALG).
- THE MOHCDGEC WAS REPRESENTED BY THE CHIEF PHARMACIST AND THE ACTING COORDINATOR FOR NON-COMMUNICABLE DISEASES (NCDS)
- EVANGELICAL LUTHERAN CHURCH OF TANZANIA (ELCT)



## BUILDING BLOCK 5

## PALLIATIVE CARE FINANCING



Financing for palliative care is one of the persisting challenges for realising access to services for all those in need in Africa.

Donor funding for the health sector and more so for palliative care has continued to dwindle. In many African countries, there is limited to no government financing for palliative care within the national health system.

This year, we worked with our country partners to realise our shared goal of improving both access and quality of services at the country level.

APCA provided financial and technical support to palliative care service development and expansion and quality improvement to 37 organisations and institutions from 13 African countries through partnering donor entities.

We also administered three scholarships to support three HCWs from **Togo** to undertake palliative care training in **Uganda** and these participants have since become recognised as trainers in their country.

In **Togo**, funding from the American Cancer Society contributed

towards the establishment of a local morphine production Unit. In turn, the Ministry of Health in Togo funded the procurement of morphine powder for starting local production of oral liquid morphine.

Building upon this project, the MoHSP funded a project to improve paediatric palliative care in the country in collaboration with Médecin du Monde Switzerland. This project is implemented with guidance and support from the National Palliative Care Task Force established through an APCA supported initiative.

In April 2018, APCA organised an online Resource Mobilisation training for APCA partners entitled 'Secrets to Sustainable Funding in the NGO context'. The webinar was facilitated by Mr Bill Bruty, a professional fundraiser, who equipped participants with resource mobilisation skills.

The webinar was attended by 12 partner organisations from **Kenya, South Africa, Uganda, and Zimbabwe** with four APCA staff members represented.

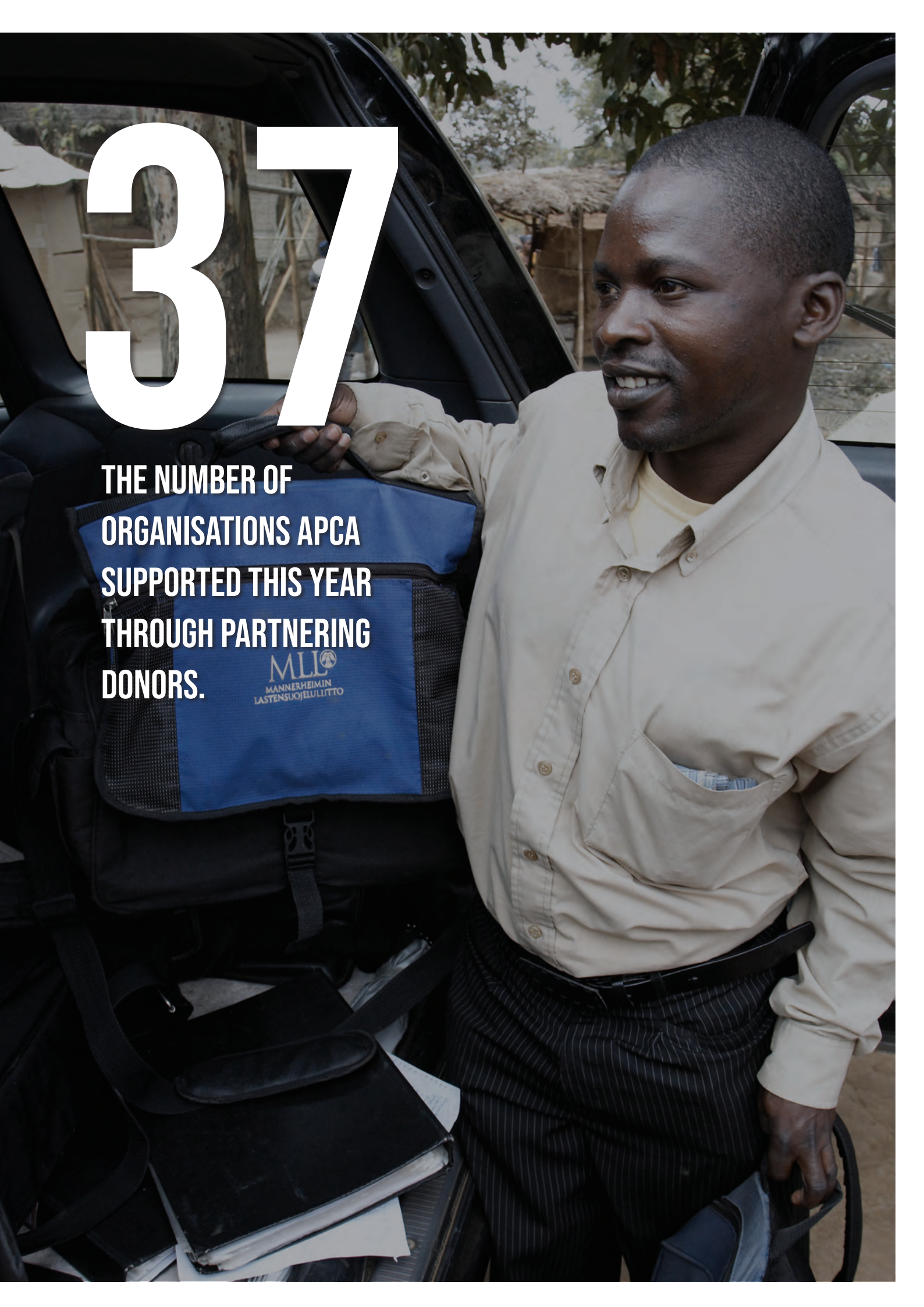
THIS YEAR, WE WORKED WITH OUR COUNTRY PARTNERS TO REALISE OUR SHARED GOAL OF IMPROVING BOTH ACCESS AND QUALITY OF SERVICES AT THE COUNTRY LEVEL.



# 37

THE NUMBER OF  
ORGANISATIONS APCA  
SUPPORTED THIS YEAR  
THROUGH PARTNERING  
DONORS.

MLI  
MANNERHEIMIN  
LASTENSUOJELULITTO





## BUILDING BLOCK 6

## LEADERSHIP AND GOVERNANCE

To ensure the successful and sustainable integration of palliative care in Africa's health systems, the institutionalisation of palliative care is critical. This includes the establishment of formal structures and executive palliative care roles within Africa's health systems.

This year, we advocated for the inclusion of palliative care on the health agenda of the East African Community through its East African Health Research Commission (EAHRC) and the East African Legislative Assembly (EALA).

More than 150 policy makers learned about palliative care for the first time and its value add once integrated into African health systems. These included: ministers of health, national and regional members of parliament, regional and district political and health leaders, legislators of economic and political bodies. This initiative has enhanced the understanding of palliative care at the policy level in these countries.

### GOVERNANCE TO SUPPORT RESOURCE ALLOCATION

Fundamental to the sustainable government allocation of funds are national policies, strategies and plans for palliative care, and its inclusion in existing health and other related policy frameworks.

In **Liberia, Togo and The Gambia**, APCA provided technical and financial support towards the implementation of national palliative care programmes with the leadership of the Ministries of Health through palliative care advocates.

In each of these three countries, clear leadership and coordinating mechanisms were formed along with multi-disciplinary, multi-sectoral national palliative care task forces. To support national level coordination, these taskforces were chaired by national health ministries.

In **Togo**, APCA supported the insertion of a strategic objective on palliative care which specified priority activities that were included in the new 2018 – 2022 Strategic Plan within the country's NCDs Division.

In **Liberia**, APCA supported two MoH officials to undertake a 5-day palliative care study visit to **Malawi**, hosted by the MoH and the Palliative Care Association of Malawi (PACAM). The aim of the visit was to benchmark strategic leadership at the national level in Malawi and to glean lessons for Liberia.

As an outcome from the visit, Liberian MoH officials developed an action plan to guide palliative care interventions in their country.

APCA also strengthened the institutional and technical capacity of the National Association of Palliative Care (NaPCA) of **Liberia** by supporting two executive officials to attend an organisational development learning visit to **Uganda**.

These officials interacted with the Palliative Care Association of Uganda (PCAU) and learning was informed by an Organisational Capacity Assessment (OCA) exercise which APCA administered.

In **Kenya**, the Ministry of Health and KEHPCA prioritised the development of a national palliative care advocacy plan as a result of advocacy meetings with policy makers. A technical working group (TWG) for policy development was formed to provide leadership and coordination for the policy development process.

National level multi-stakeholder meetings were also supported as part of the policy development process with the leadership of the MoH through the National Cancer Control programme that hosts palliative care.

### ENGAGING THE UGANDAN PARLIAMENT

In **Uganda**, APCA collaborated with PCAU and UGANET to create awareness and advocate for the inclusion of palliative care in country UHC plans with 17 Members of Parliament carefully selected from strategic parliamentary committees in November, 2018. In meeting with MPs, APCA aimed to engage them on palliative care as a core component of UHC and a basic health service.

# 150

**THE NUMBER OF AFRICAN POLICY MAKERS ORIENTED ON PALLIATIVE CARE AS A COST EFFECTIVE INTERVENTION ONCE INTEGRATED INTO AFRICAN HEALTH SYSTEMS.**



6th International African Palliative Care Conference

In **Rwanda**, APCA signed a Memorandum of Understanding with the Ministry of Health to collaborate in the ongoing integration of palliative care in the country's health system and to co-host in September the 6th International African Palliative Care Conference and the 3rd African Ministers of Health Session on Palliative Care.





## Engaging national and regional parliaments



### THE COMMITTEES OF PARLIAMENT REPRESENTED

- HIV/ AIDS & GENDER LABOUR AND SOCIAL DEVELOPMENT
- HEALTH COMMITTEE; PUBLIC SERVICE
- HUMAN RIGHTS
- AGRICULTURE AND FISHERIES;
- NATIONAL ECONOMY
- LEGAL AND PARLIAMENTARY AFFAIRS
- FOREIGN AFFAIRS AND HUMAN RIGHTS.

In **Uganda**, a meeting with members of parliament was attended by six parliament staff members and 15 officials from civil society organisations involved in palliative care, including representatives from the Ministry of Health. Subsequently, palliative care was raised on the floor of Parliament and the Cabinet was tasked to state where the process of developing the national palliative care policy had reached. This process has since been followed up and fast tracked by the Ministry of Health.

The Office of the Commissioner for Clinical Services in the MoH has convened three meetings with key stakeholders, including APCA, to review the policy and incorporate newly emergent issues and the cost implications of the policy. A WhatsApp group is hosted by PCAU for MPs and has served as a forum for communicating and providing updates on their commitments.

In February 2019, a one day palliative care sensitisation meeting was held for 50 political and health leaders in Kabarole district hosted by the area MP. This triggered the need and commitment by district and municipal leaders to budget for palliative care at the district level.

#### EAST AFRICAN COMMUNITY ENGAGEMENT

At the regional level, APCA met East African Community (EAC) institutions. The EAC is made up of **Burundi, Kenya, Rwanda, South Sudan, Uganda and Tanzania.**

In February, APCA met with the Executive Secretary of the East African Health Research Commission (EAHRC), Professor Gibson Sammy Kibikies, to discuss the implementation of the World Health Assembly (WHA67.19)

Resolution on palliative care in East Africa and the integration of palliative care and pain relief within EAC Member State health systems.

The meeting was instrumental at getting palliative care on the agenda through presentations at the 7th East African Health and Scientific Conference which was held in Dar es Salaam in March, 2019. APCA is working to establish an East African Palliative Care Chapter at the EAC.

In March 2019, APCA held a palliative care awareness and advocacy meeting with the East African Legislative Assembly (EALA), with formal approval from the Rt. Honourable Speaker of the Assembly. APCA's seven member delegation was led by its Executive Director and included APCA's Director of Programmes, senior officials from KEHPCA, PCAU, the Ministry of Health of Tanzania, the Rwanda Biomedical Centre and the Evangelical Lutheran Church of Tanzania (ELCT).

The session was attended by 25 Members of the EALA representing all six member states and four EALA staff. APCA disseminated both hard and soft copies of various key frameworks on palliative care. A coordinated team of palliative care experts from East African countries was an effective approach for engagement of the EALA as they were able to have an overview of the status of palliative care in their countries and at the regional level. This enhanced consensus on key recommendations and actions from the EALA MPs at the meeting.



#### THE SESSION WAS CAPTURED BY NTV AND WAS DISSEMINATED ACROSS EAST AFRICA:

<https://www.ntv.co.ug/news/national/Palliative-care-providers-petition-East-African/4522324-5006776-11fd4rg/index.html>



The APCA led palliative care delegation pose for a photo with legislators of the EALA after the session.



Enthusiastic legislators asking important questions during the EALA plenary session.

## KEY EMERGENT FOCAL AREAS FROM THE SESSION INCLUDED:

- 01** A general lack of awareness on palliative care, even among NGOs operating in the health sector in the region.
- 02** The importance of palliative care inclusion within UHC, with special attention towards impoverished and other vulnerable populations, such as the elderly and disabled.
- 03** APCA was advised to seek observer status with the EALA to be more able to influence policy at the EAC level and to establish a palliative care chapter for the EAC.
- 04** Legislative input remains necessary from the EALA, in collaboration with the Council of Ministers and technical experts, and based on global and regional treaties and resolutions on palliative care.

*'We see patients suffering at home and can help. I passed through this experience with a sick mother. It was expensive at the hospital and at home we do not know how to care. I did not have the information for my mother to get palliative care. It was so painful for all members of the family.'*

HON. FRANCIN, EALA MP, RWANDA

*'I learnt a lot, you have managed to increase my knowledge of palliative care. I had some little knowledge as I nursed my husband who succumbed to cancer.'*

HON. JOSEPHINE S. L, EALA MP, TANZANIA

*'This was very informative. We have felt like we are not supporting this crucial health issue and have not played our role due to lack of information. It is our mandate in our Treaty.'*

HON. FATUMA, EALA MP, KENYA & HUMAN RIGHTS CHAMPION.

*'It is only now that I am realising how important morphine is for pain management.'*

HON. ABDIKADIR O. ADEN, EALA MP FROM KENYA

## KEY RESOURCES INCLUDED IN APCA'S PARLIAMENTARY ADVOCACY:

- THE 2012 AFRICAN UNION COMMON POSITION ON CONTROLLED SUBSTANCES
- THE 2013 JOHANNESBURG CONSENSUS STATEMENT ON PALLIATIVE CARE
- THE 2014 WORLD HEALTH ASSEMBLY RESOLUTION ON PALLIATIVE CARE
- THE 2016 KAMPALA DECLARATION ON PALLIATIVE CARE BY AFRICAN MINISTERS
- THE 2017 WHA RESOLUTION ON CANCER
- THE 2018 LANCET COMMISSION REPORT ON PALLIATIVE CARE AND PAIN RELIEF AND THE EAST AFRICAN DOCUMENTARY OF PALLIATIVE CARE, WHICH WAS VIEWED IN THE SESSION.

# SUSTAINABILITY AND ORGANISATIONAL DEVELOPMENT

## GOVERNANCE

APCA is governed by a Board of Directors that is currently comprised of 13 dynamic members from the following countries: **Canada, Cote D'Ivoire, Egypt, Ghana, Nigeria, South Africa, Uganda, the United Kingdom and the United States.**

These members bring with them a variety of skills that complement APCA's palliative care initiatives. Members of the board meet four times per fiscal year, three of which are held virtually with one face-to-face meeting.

This year, the board reviewed and approved a number of organisational policies including; the Board Assessment Tool, the Fundraising Strategy, the Communications Strategy, the Volunteer Staff Handbook and the Reserve Fund Guidelines.

In September 2019, five members of the current board will be stepping down during the General Assembly after serving their two terms. The General Assembly will be held at the 6th International African Palliative Care Conference in Kigali, Rwanda.

### MEET THE APCA TEAM

The small APCA team is comprised of vibrant individuals and is the back-bone of the organisation. Each member of the team comes with their individual strengths and expertise and we work together to achieve the organisation's vision and mission.

During the year, staff took time off for a one-day retreat at the Buloba Forest Resort as a time to refresh and reenergise.



APCA board members and the senior management team at the board meeting in Kampala in February, 2019.



APCA Chair of the Board, Mr Andre Wagner, meeting with staff during the year.




A time to refresh and reenergise.

## STAFF DEVELOPMENT

Staff also take time off their busy schedules to attend personal development sessions, sometimes not specifically related to palliative care:

- 01** How to balance relationships and work by Rev. Dr Sam Luboga, Emeritus Professor of Anatomy and Executive Director, Sustainable Leadership Institute
- 02** Microsoft Access Databases, a practical guide by Irene Namwase, APCA Membership Assistant
- 03** Ethics in palliative care (Global Health)- Guy Schofield, Research Fellow from University of Bristol UK
- 04** The communications team attended a training on external relations and partnerships organised by the American Cancer Society SOURCE programme. A donor relations guideline was developed following the training and is awaiting board approval.
- 05** An Organisational Capacity Assessment presentation from the Ghana Palliative Care Association by Michelle Sorenson, an MBA student from University of Alberta in Canada.
- 06** The finance team participated in periodic Continuing Professional Development (CPD) workshops organised by the Association of Chartered Certified Accountants (ACCA) and The Institute of Certified Public Accountants of Uganda (ICPAU), where new developments and changes in the International Financial Reporting standards (IFRS) were shared.



 APCA staff pose for a photo to show solidarity in creating awareness on paediatric palliative care.



## STAFF ACHIEVEMENTS

Staff have individually engaged in coursework as part of their personal growth and development.

Our Research Manager, Eve Namisango, is undertaking her PhD in palliative care at the King's College London; Mable Namuddu, the Finance Officer, completed a professional training course offered by the Institute of Certified Public Accountants of Uganda to be a Certified Public Accountant.

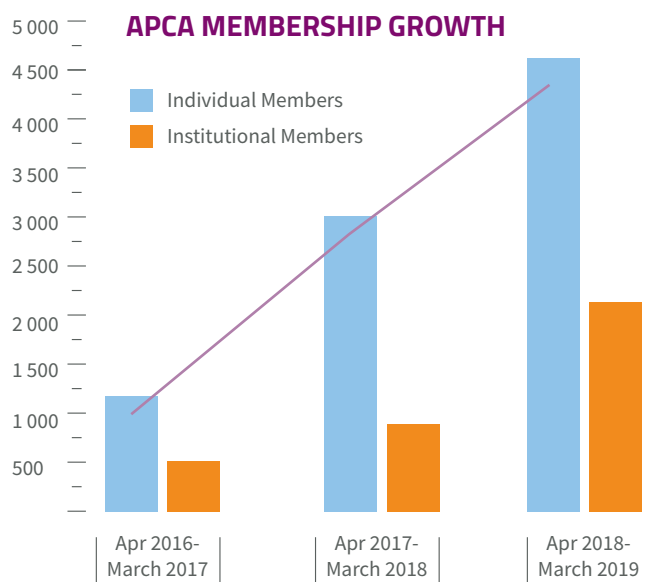
During the year, a number of APCA staff were also invited to join the boards of organisations, including;

- Ms. Josephine Kampi Tatyabala, the Director of Resources, was invited to serve on the board of the Palliative Care Association of Uganda
- Ms. Fatia Kiyange, Director of Programmes, was invited to serve on the board of the Uganda Cancer Institute
- Ms. Eve Namisango, the Research Manager, serves on the board of the International Association for Hospice and Palliative Care (IAHPC)
- Dr Emmanuel Luyirika, Executive Director, continues to serve on various boards including the board of the Worldwide Hospice Palliative Care Alliance (WHPCA) and also supports a number of initiatives as requested by different organisations.

# APCA MEMBERSHIP

APCA membership continues to be recognised as a valuable opportunity to be part of a unique, dynamic community of palliative care professionals and supporters across Africa. It provides partners with opportunities to receive support and the opportunity to contribute to the development of palliative care in Africa. Our membership base has grown from 3,000 to 4,698 individual members and from 950 to 2,175 institutional members from over 80 countries.

The table below shows growth of APCA membership from 2016 to 2019.



## MOVING TOWARDS PAID APCA MEMBERSHIP

Following the membership survey that APCA conducted in 2018, APCA will be introducing a paid membership programme beginning in January 2020. Based on member recommendations, the membership fees will be structured as follows:

	AFRICA	BEYOND AFRICA
INDIVIDUAL MEMBERS	\$100	\$150
INSTITUTIONAL MEMBERS	\$300	\$500
STUDENTS	\$20	\$50
GOLD MEMBERS	10% discount for more than 2 years of payment in advance	20% discount for more than 2 years of payment in advance



**TO JOIN APCA'S MEMBERSHIP BENEFIT PROGRAMME**

email: [members@africanpalliativecare.org](mailto:members@africanpalliativecare.org)





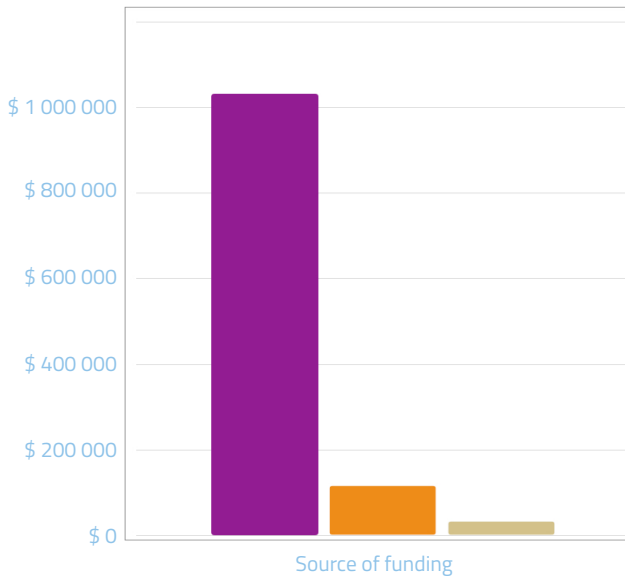
# APCA PUBLICATIONS

## APCA'S CONTRIBUTION TO PUBLICATIONS IN THE YEAR INCLUDED:

- 01** **Kiyange F**, V. Walusansa G. Mandosela, H. Nzereka Kambale, **E. Luyirika**, J. Orem. The Role of South-to-South Partnerships in Developing Cancer Services in Africa. *Journal of Global Oncology* 2018; 4: 163s-163s
- 02** Centeno C, Sitte T, de Lima L, Alsirafy S, Bruera E, Callaway M, Foley K, **Luyirika EBK**, Mosoiu D, Pettus K, Puchalski C, Rajagopal MR, Yong J, Garralda E, Rhee JY, Comoretto N. White Paper for Global Palliative Care Advocacy: Recommendations from a PAL-LIFE Expert Advisory Group of the Pontifical Academy for Life, Vatican City. *J Palliat Med* 2018; 21(10): 1389-97.
- 03** Krakauer EL, Kwete X, Verguet S, Arreola-Ornelas H, Bhadelia A, Mendez O, Rodriguez NM, Ali Z, Allende S, Cleary JF, Connor S, Danforth K, Lima Ld, Gwyther L, Hamzah E, Jamison DT, Khanh QT, Kumar S, **Luyirika EBK**, Merriman A, Mpanumusingo E, Nevzorova D, Ntuzimira C, Osman H, Perez-Cruz P, Rajagopal M. R., Radbruch L, Spence D, Stoltenberg M, Tapela N, Watkins DA, Knaul F. Palliative Care and Pain Control. In: Jamison DT, Gelband H, Horton S, Jha P, Laxminarayan R, Mock CN, Nugent R, editors. *Disease Control Priorities: Improving Health and Reducing Poverty*. 3rd edition. Washington (DC): The International Bank for Reconstruction and Development / The World Bank; 2017 Nov 27. Chapter 12.
- 04** Pettus K, De Lima L, Maurer M, Husain A, Connor S, Torode J, Ling J, Downing J, Rajagopal MR, Radbruch L, Pastrana T, **Luyirika EBK**, Goh C, Marston J, Cleary J. Ensuring and Restoring Balance on Access to Controlled Substances for Medical and Scientific Purposes: Joint Statement from Palliative Care Organizations. *J Pain Palliat Care Pharmacother* 2018: 1-5.
- 05** J Downing; G Kivumbi; E Nabirye; A Ojera; R Namwanga; R Katusabe; M Dusabimana; K Kalema; B Yayeri; A Apollo; M Batuli; C Komunda; R Nabukalu; J Mwesige; M Sekyondwa; M Kasirye; JO Amoris; E Nandutu; W Acuda; D Adong; **E Luyirika. E Namisango; F Kiyange;** R Kiwanuka; J Amandua; J Logan; E Haraldsdottir; B Moback; C Lesley; L Grant; M Leng. An evaluation of palliative care nurse prescribing: a mixed methods study in Uganda. *BMJ Supportive & Palliative Care*. 8(Suppl\_1):A6, MAR 2018
- 06** Olagunju AT, Fadipe B, Buraimoh RW, Ale OK, Umeizudike TI, Ogbolu RE, Buyinza N, Bayuo J, Mutedzi B, Nkhoma K, **Namisango E**, Bristowe K, Yi D, Downing J, Aina OF, Adeyemi JD, Murtagh FE, Harding R. A longitudinal cohort study of symptoms and other concerns among Nigerian people with stages 3–5 chronic kidney diseases: study protocol. *Ann Palliat Med* 2018. doi: 10.21037/apm.2018.10.03
- 07** **Namisango E**, Katherine Bristowe, Matthew Allsop, Fliss EM Murtagh, Melanie Abas Irene J Higginson, Julia Downing, Richard Harding. Symptoms and concerns among children and young people with life-limiting and life-threatening conditions: A systematic review highlighting meaningful health outcomes The Patient: Patient-Centered Outcomes Research- 2018
- 08** **Namisango, E.**, Bristowe, K., Allsop, M.J. et al. Patient (2018). <https://doi.org/10.1007/s40271-018-0333-5>
- 09** Downing J, **Namisango E**, Harding R. Outcome measurement in paediatric palliative care: lessons from the past and future developments. *Ann Palliat Med* 2018.
- 10** Fraser, BA; Powell RA; Faith N. Mwangi-Powell, FN; **Namisango E**, Hannon B; Zimmermann C. Palliative Care Development in Africa: Lessons From Uganda and Kenya. *Journal of Global Oncology* 2018.

# FINANCIAL REPORT

## Where the money came from 2018/19



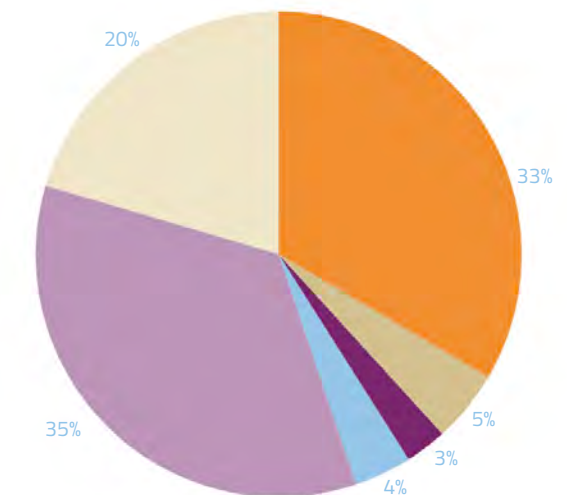
Sources of income	Balance b/f 1/4/18	Income for the period 04/18-03/19	Available funds 04/18-03/19	Percentage income by donor
Trusts and foundations	\$351 524	\$681 390	\$1 032 914	87%
Other donors	\$69 267	\$48 614	\$117 881	10%
APCA generated income	\$2 950	\$31 328	\$34 278	3%
<b>Total available funds</b>	<b>\$423 741</b>	<b>\$761 332</b>	<b>\$1 185 073</b>	<b>100%</b>



**3%**

**OF INCOME WAS GENERATED BY APCA**

## Where the money went 2018/19



Expenditure area	2018/2019 (Amount)	2018/2019 (Percentage)
Programme salaries	\$318 027	33%
Awareness creation	\$45 685	5%
Evidence	\$26 342	3%
APCA and partner sustainability	\$36 429	4%
Palliative care integration	\$330 243	35%
Administration & capital costs	\$194 420	20%
<b>Total</b>	<b>\$951 146</b>	<b>100%</b>

**35%** used for palliative care integration.

# DONOR APPRECIATION

Our 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.

We would like to thank every one of our donors for supporting our work for the relief of pain and suffering for patients across Africa. In particular these include:

- American Cancer Society
- The Bartlett Foundation
- Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC)
- Global Partners in Care
- King's College London
- Open Society Foundations- New York (OSF)
- The Open Society Initiative for Eastern Africa (OSIEA)
- The Open Society Initiative for Southern Africa (OSISA)
- The True Colours Trust
- University of Leeds
- World Health Organization
- Worldwide Hospice Palliative Care Alliance (WHPCA).

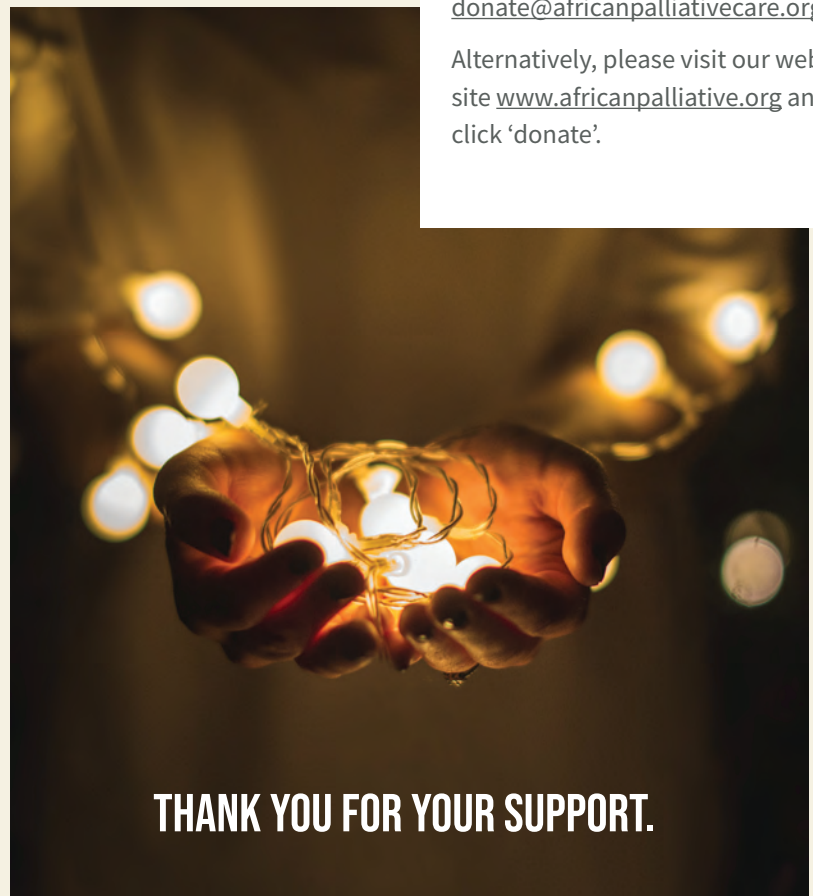
## MAKE A DONATION

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:

[donate@africanpalliativecare.org](mailto:donate@africanpalliativecare.org)

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



**THANK YOU FOR YOUR SUPPORT.**



## African Palliative Care Association

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