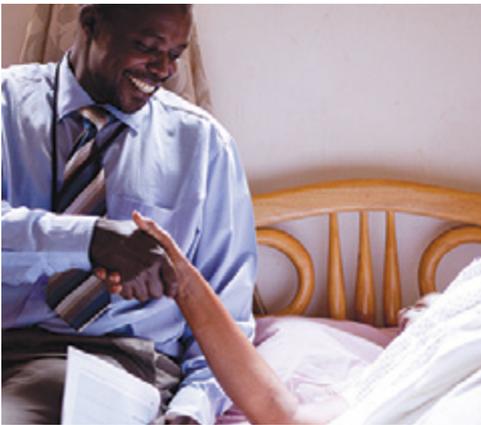




DIFFERENTIATED CARE FOR DIVERSE COMMUNITIES



AFRICAN PALLIATIVE CARE ASSOCIATION

ANNUAL REPORT

2015-16

ABOUT APCA

The 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.

OUR VISION

“Access to palliative care for all in Africa”.

OUR 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.

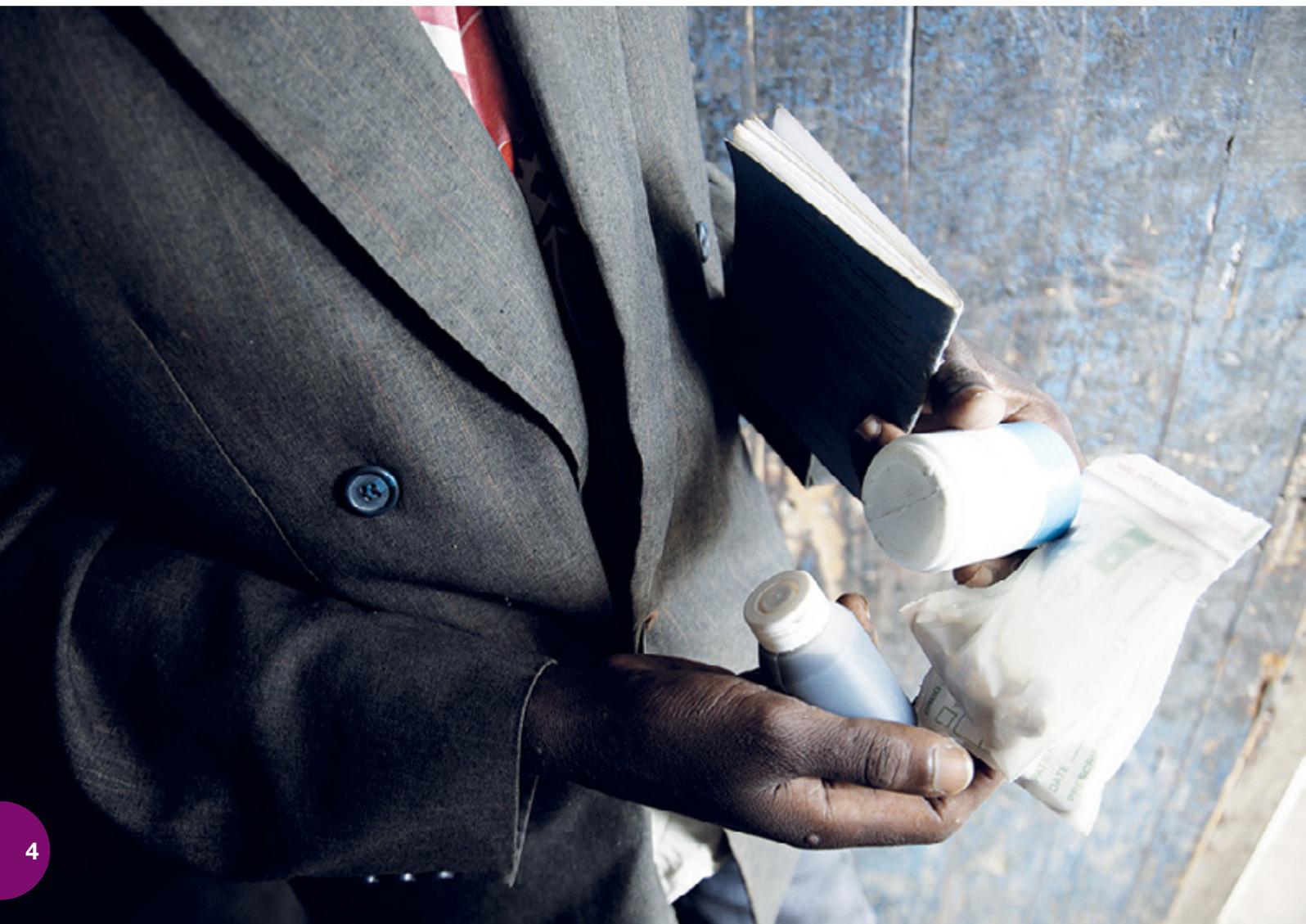
STRATEGIC OBJECTIVES

- 1 To develop and implement an information strategy on palliative care for all levels of stakeholders in Africa.
- 2 To provide leadership and coordination for palliative care integration into health policies, education programmes and health services in Africa.
- 3 To develop an evidence base for palliative care in Africa.
- 4 To develop and implement a financial sustainability framework for APCA.

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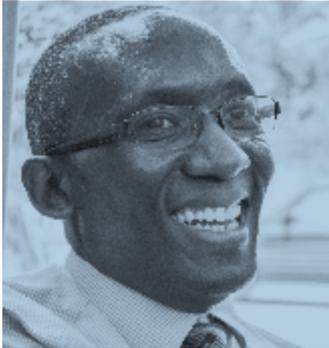


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WELCOME MESSAGE

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



Dr Emmanuel Luyirika



Dr Bernard Tei Dornoo

Dear partner,

With the 5th International African Palliative Care Conference being hosted during August 2016 in Kampala, we cannot but acknowledge and celebrate the achievements chalked up through our strategic partnerships. This annual report seeks to reflect these valuable successes, for which we owe gratitude to our partners for their continued support and collaboration.

We know that for quality palliative care services to reach the masses it cannot stand isolated as a discipline, but needs to be embedded into a fabric of global frameworks and political commitments – nationally, regionally and globally.

This annual report therefore highlights our institutional progress against the backdrop of the World Health Organization's six building blocks for health systems, the public health strategy for the effective integration of palliative care, and the World Health Assembly's 2014 (WHA 67.19) resolution on palliative care.

This latter resolution, a manifestation of the right to quality care for adults and children with life-limiting illnesses, outlines the responsibilities of WHO member states based on nine key areas frequently addressed in this report and at our conference:

1. Evidence-based palliative care policies
2. Funding and allocation of human resources
3. Basic support to all caregivers – families, volunteers and others
4. Education and training at all levels
5. Assessing basic palliative care needs, including pain medication requirements
6. Revision of national and local legislation and policies for controlled medicines to improve access
7. Updating national essential medicines lists
8. Fostering partnerships
9. Implementing and monitoring palliative care actions included in the WHO's Global Action Plan for the Prevention and Control of NCDs 2013–2020.

In the determined pursuit of attaining these nine mandates in the earliest possible time, we extend an open invitation to a greater diversity of players, to harness support and empower decision makers to act on the resolution's targets.

Whether we are the patient, the health care worker, the donor, the businessperson, the non-profit administrator, the legislator, the academic or non-profit organisational leaders and workers, we need all hands to come on deck to make this resolution a reality, in Africa and globally.

It is our hope that some of the projects reflected in this report, presented in relation to the WHO's six building blocks for health systems, will inspire you. May they spur you on to new creativity and engage both your mind and heart to join us in delivering the report's theme to the patients who await it: Resolution to Action: Differentiated Care for Diverse Communities.

For sharing our vision, for partnering with us consistently, and for taking landmark steps with us, we thank you for joining us.

Sincerely,

Dr Emmanuel Luyirika, Executive Director, APCA
Dr Bernard Tei Dornoo, Board Chair, APCA



BUILDING BLOCK 1

PALLIATIVE CARE SERVICE DELIVERY

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

We therefore provide technical assistance for its integration into existing health services, including public, private and NGO health facilities. This is undertaken through capacity building of health care providers and quality improvement interventions.

APCA HAS SUCCESSFULLY
MANAGED SMALL
GRANTS SINCE 2009,
IMPACTING
10,217
PALLIATIVE CARE
PATIENTS

SUPPORTING PATIENTS, STRENGTHENING CARE

APCA has successively managed small grants since 2009, impacting **10,217 palliative care patients**. These include adults, young people and children who have been reached with various palliative care initiatives, improving their quality of life as they battle with terminal illnesses. To date, APCA has administered 12 cycles of small grants, supporting **104 palliative care health facilities and organisations in 21 African countries**.

Over the course of the year 2015/16, these grants supported **18 palliative care service delivery sites** and organisations and a total of **53 health facilities**. Interventions included the provision of medical equipment for patients, palliative care for children and young people, palliative care medicines, capital improvement costs, increasing access to palliative care in rural areas, and training courses for palliative care service providers in Africa.

The nine countries impacted by these improved services included **Botswana, Ghana, Kenya, Mozambique, South Africa, Swaziland, Tanzania, Uganda, and Zimbabwe**.

FACILITY 'FACELIFTS'

We have found that capital improvements can correlate with significant improvements in both health administration and patient outcomes. For example, in **Ghana**, Tetteh Quarshie Memorial Hospital refurbished one of its old blocks where the palliative care unit was located, which made the provision of palliative care services smoother for both health workers and patients navigating health care services.

In **Swaziland**, support to The Rocking Horse Project created a child-friendly environment in one of the waiting rooms at the Baylor College of Medicine Children's Foundation. With this refurbishment, among other interventions, there has been an increase in the referrals of children to this centre of excellence.

These capital improvements have attracted more health workers to palliative care departments and to the palliative care discipline, and further improved service delivery both in the number of people served and the quality of the palliative care services provided.

MAKING HOSPITALS 'PAIN FREE'

We believe that ensuring pain relief in a hospital setting is a necessity that is attainable in Africa just as it is in other parts of the world.

Piloting the Pain Free Hospital Initiative in **Botswana**, **Ghana** and **Uganda**, APCA has strengthened pain assessments in eight public hospitals with support from the American Cancer Society, which are listed as follows:

- Botswana: Princess Marina National Referral Hospital and Nyangabwe Hospital
- Ghana: Upper East Regional Hospital, Tetteh Quarshie Memorial Hospital and Korle Bu Teaching Hospital.
- Uganda: Uganda Cancer Institute, Gulu Regional Referral Hospital, Mbale Regional Referral Hospital

Following the launch of this initiative, three of the eight facilities have begun routinely assessing the pain of their patients, both in the ward and in outpatient departments. At the Uganda Cancer Institute, where the project is already up and running, pain assessment has now become a routine service offered to patients on a daily basis. Both the **Uganda Cancer Institute** and **Gulu Regional Referral Hospital** have carried out pain assessments, involving a total of **328 patients**.

At each of these hospitals, the average patient's pain score has been reduced since the commencement of the initiative. This was made possible because health workers have been given the necessary knowledge and skills to manage their patients' pain appropriately.

So far, **208 health care professionals** working in these facilities have been trained in pain management. Gulu Regional Referral Hospital has also obtained an average baseline pain score for patients (5.8/10) across their wards. It is expected that with further training of their staff, this score will reduce to indicate an improvement in easing patients' pain. Initial pre- and post-test results have shown significant improvement in the knowledge of health workers in pain management, and it is anticipated that this will have a positive impact on reducing patients' pain scores.

INCREASING ACCESS TO JUSTICE

In Uganda, APCA has supported the integration of legal support within palliative care services, with **170 palliative care patients** accessing legal services. This initiative has taken place through APCA's collaboration with the Palliative Care Association of Uganda (PCAU) and the Uganda Network on Law, Ethics and HIV/AIDS (UGANET).

Legal services were also provided by trained paralegals in 10 districts of Uganda, working in partnership with palliative care teams that were trained in the integration of human rights and legal issues into palliative care service provision. Through this collaboration, three models for the provision of legal services to palliative care patients and their families emerged:

- 1 Legal aid clinics have been established within hospice sites, with clear schedules for a visiting lawyer.
- 2 A district-based model has been developed where paralegals visit and provide legal services to patients seen in hospital-based palliative care units.
- 3 Paralegals extend legal services to patients at home.

A regular interface (often involving patient referrals) between paralegals and health workers has increased the number of patients accessing legal services and the demand for these services in the districts of Uganda where new approaches have been applied.

In **eastern Uganda**, a strategic exposure meeting was conducted with health workers who have direct contact with patients at health facilities, and the paralegals that identify and refer patients for both palliative care and legal services.

The meeting drew both health workers and paralegals from four districts in Uganda, with the aim of strengthening collaboration at the facility and community levels to increase the number of palliative care patients reached and to ensure they receive quality holistic services.

Many legal issues that are common to palliative care patients have presented themselves in this programme. They include domestic violence, land disputes, property inheritance, stigma and discrimination, malicious damage to property, reclamation of withheld salary, succession planning, support and child protection, among others.

This access-to-justice initiative for palliative care patients and their families has potential for replication in the rest of Uganda's districts and across Africa, where the majority of people – especially the very vulnerable – cannot afford the cost of access to legal services. The impact of legal service provision to palliative care patients is demonstrated in the success story below, as narrated by one of the paralegals in eastern Uganda.

“I can now confidently express the rights of patients with palliative care needs within the medical team and also when I feel that a medical decision is not in the best interest of a palliative care patient.”

Social Worker, Namibia, Diploma in Palliative Care, IHPCA

Story of John Kapatula (pseudonym)

Mr John Kapatula, a palliative care patient who is a teacher by profession, had lost hope of living a dignified life until a paralegal, Mr William Kamba of Pallisa district in Uganda, came into his life.

John had been abandoned by his two wives because his wound had turned septic and unbearably smelling, and he was left to die alone in his home. Mr Kamba was informed of John's condition during an outreach by a community member and quickly took action by visiting the patient and further referring him to a local health centre, where his wounds were treated.

While he was receiving treatment, Mr Kamba located both of John's wives and counselled them on the importance of social support and why they should go back to their home and take care of their husband without discriminating against him. The wives returned home, giving John the support he needed. Because he felt loved again and since he was able to access treatment, his condition improved. The paralegal assisted him in processing his pension paperwork, and he used the resultant money to buy himself a car in order to increase his mobility.

John also planted a tree in his compound in remembrance of the situation and in appreciation of the support that his health worker and Mr Kamba had rendered to him during the most difficult season of his life.



APCA SUPPORTED
THE TRAINING OF 876
HEALTHCARE WORKERS
AND VOLUNTEERS IN
PALLIATIVE CARE, LEGAL
AND HUMAN RIGHTS
ISSUES



As the global health community turns to strengthen human resources for health (HRH), we support palliative care training to ensure patients and families receive holistic care, even – and especially – where resources are limited.

APCA supported the training of 876 healthcare workers and volunteers in palliative care, legal and human rights issues (see chart right). This unique training was conducted in eight African countries: Cameroon, Ghana, Nigeria, South Africa, Swaziland, Tanzania, Uganda, and Zimbabwe.

In **South Africa**, palliative care academic training was delivered to **453 undergraduate and postgraduate medical students** from the University of Kwazulu Natal's third to sixth year students. This was accomplished through a small grant that was awarded to Umududuzi Hospice, which ensured that the students' training had a practical as well as a theoretical component.

Umududuzi Hospice went a step further by formulating palliative care examinations for the university's paediatric department students. By integrating a testing component to the training, this initiative was a major step towards the integration of palliative care into the medical education curriculum.

In **Uganda**, APCA supported the Uganda Christian University located in Mukono, to develop an outline for a palliative care course that is to be introduced for all students in its Faculty of Humanities, Department of Social Work and Social Administration. The course outline is currently undergoing an approval process.

NURSE AND SOCIAL WORK SCHOLARSHIPS

In the 2015/16 year, APCA provided education scholarships to **3 nurses** and **3 social workers** to obtain training and qualifications in palliative care. The nurses were from **Kenya, Swaziland, and Uganda**, while the social workers were from **Namibia, Uganda, and Zimbabwe**. Feedback from scholarship beneficiaries shows how this support for training has enabled them to improve their knowledge, practice and attitude in their work.

The education programmes undertaken included: Diploma in Clinical Palliative Care (Hospice Africa Uganda), BSc Palliative Care (Institute of Hospice and Palliative Care in Africa – IHPCA), Diploma in Higher Education in Palliative Care (Nairobi Hospice) and the Palliative Care Initiators Course (IHPCA).

Among those that were granted a scholarship in 2015/16, the following expressed their sentiments about the practical difference that their training made:

Felicity Ntombifuthi Lukhele

NURSE, SWAZILAND, BSC PALLIATIVE CARE,
MAKERERE UNIVERSITY/IHPCA

I was taught a lot on how other low-resourced African countries are operating, sustaining and spreading their palliative care services in different ways.

[My fellow] staff will acquire knowledge on palliative care, they will have an opportunity to attend onsite trainings and provide the service with confidence and effectively. I shall mentor them on palliative care and assist them to develop skills and confidence in providing the services, enabling them to work autonomously.

Mary Nyabate

NURSE, KENYA, DIPLOMA IN HIGHER EDUCATION IN
PALLIATIVE CARE, NAIROBI HOSPICE

I did not know that when assessing a patient for pain, it is done holistically. Also I did not know that there is good and bad death. I can now participate meaningfully in developing treatment care and support policies and strategies. My involvement in designing, organising and facilitating training programmes, workshops and support groups has become of

great benefit to my organisation. I am also able to advocate for the psychosocial needs of patients and their families through developing meaningful project proposals and, where necessary, make referrals even outside the organisation in order to ensure continuity of care for the patients and family members.

Mildred Ndamukaneyi Boshia

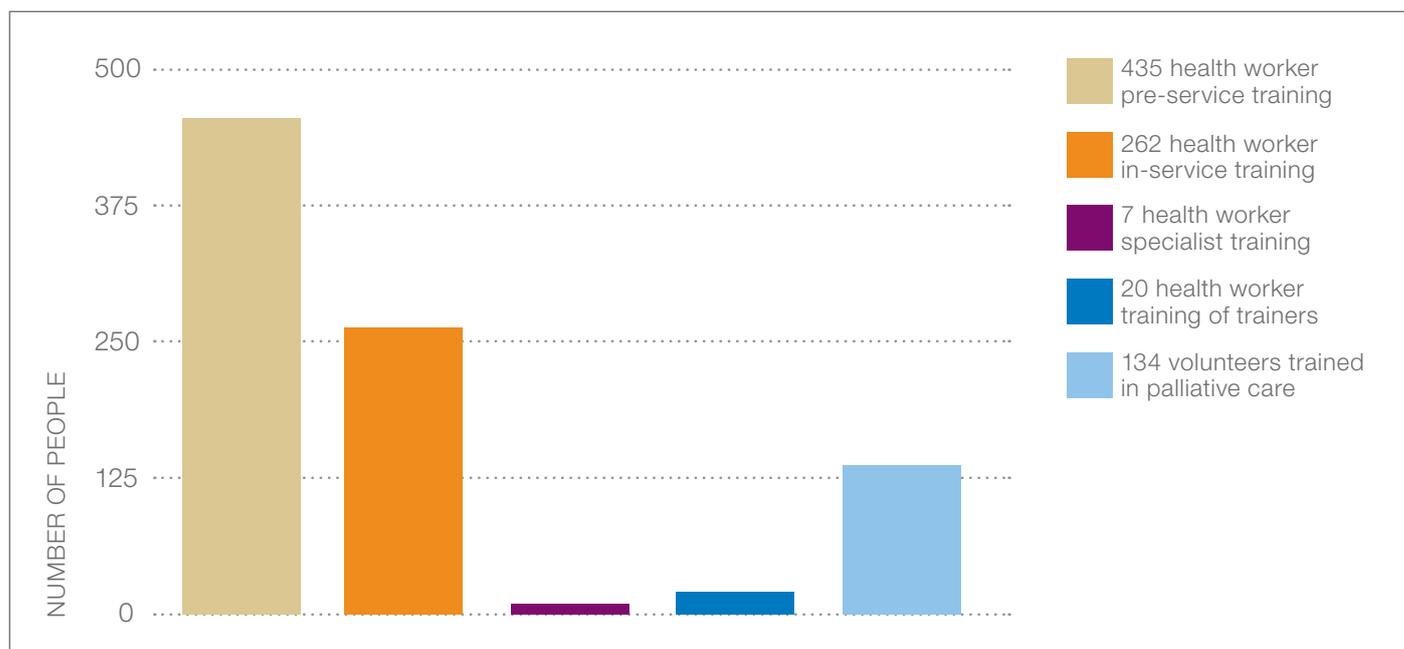
SOCIAL WORKER, ZIMBABWE, DIPLOMA IN
PALLIATIVE CARE, IHPCA

During the course and after completion, I have given feedback, shared and discussed with team members during staff meetings, clinical meetings and workshops. I have also become a resource within the interdisciplinary team at Island Hospice and Healthcare.

Peggie Chiwara

SOCIAL WORKER, NAMIBIA, DIPLOMA IN PALLIATIVE
CARE, IHPCA

I can now confidently express the rights of patients with palliative care needs within the medical team and also when I feel that a medical decision is not in the best interest of a palliative care patient.





BUILDING BLOCK 3

PALLIATIVE CARE INFORMATION SYSTEMS

APCA is determined to ensure that everyone understands palliative care and its role in the wider health care system. One of the ways we increase awareness around the discipline is through face-to-face meetings with policymakers, health, legal and media professionals, religious leaders and congregations, market vendors, palliative care patients and their families, community motorbike taxi drivers, and community members at the grassroots level.

DIRECT MESSAGING
ABOUT PALLIATIVE CARE
AND ITS IMPERATIVE AS A
HUMAN RIGHT IMPACTED

5,127

PEOPLE IN A TOTAL OF
296 FORMAL AWARENESS
MEETINGS

AWARENESS CREATION

Direct messaging about palliative care and its imperative as a human right impacted **5,127 people** in a total of **296 formal awareness meetings** across the following countries: **Botswana, Ghana, Kenya, Nigeria, Tanzania, Uganda, and Zimbabwe**. Various strategies were used, including continuing medical education (CME), home visits, and facility-based health education talks. This has facilitated an increase in access to palliative care in rural areas in the supported countries and communities, which has enhanced community linkages and referrals for people in need of care.

For example, in **Uganda**, meeting the heads of departments and staff of the Faculty of Social Sciences at the Uganda Christian University in Mukono has resulted in a decision by the Department of Social Work to establish a course on palliative social work, for which APCA is providing technical assistance.

In **Botswana, Ghana and Uganda**, awareness creation meetings have resulted in each country's Ministry of Health endorsing and supporting the implementation of the Pain Free Hospital Initiative (PFHI), which aims to train and motivate health workers to improve pain treatment in large hospitals in these countries.

Raising awareness around palliative care services on legal issues in health care has inspired the integration of, and thereby access to, legal support for patients and their families in public hospitals, hospices and other palliative care service sites in **Uganda**.

To this end, **1,065** patients and family members in Uganda, as well as health workers at hospices and other medical facilities, benefited from awareness sessions on:

- human rights in patient care
- how lawyers can provide legal assistance
- and the legal problems that legal intervention can address in palliative care.

Some of the sites that have benefited from an increased understanding of legal services include: Lira Regional Referral Hospital, Mbale Regional Referral Hospital, Joy Hospice in Mbale District and Hospice Tororo in Tororo District. This work is undertaken through partnerships among APCA, PCAU and UGANET.

In the year under review, APCA also supported the printing of various palliative care and human rights materials in **Uganda**. These included guidelines and posters aimed at providing palliative care information to patients and their families, to communities and to health care professionals. These have been disseminated in various health facilities across Uganda with the support of PCAU and UGANET.

ONLINE ENGAGEMENT

Key communications initiatives over the year 2015/16 included preparations towards the 5th International African Palliative Care Conference, hosted in Kampala, Uganda, on 16-19 August 2016. This included the launch of a conference website, and the development of publications and resources available for conference dissemination.

APCA continues to disseminate news around palliative care developments across Africa through the editorial oversight of the growing Africa edition of the global palliative care news site, ehospice, available at: www.ehospice.com. This site reaches out to a global palliative care and wider health journalist community. This year, the most popular articles on the Africa edition of ehospice addressed resources pertaining to grants, events and new educational resources.

On social media, APCA has seen an increase in constituent engagement through its newsletters, with **962 page likes on Facebook** and a total of nearly **2,000 followers on Twitter**. In addition, APCA's Executive Director is a regular contributor to the #hpmglobal tweet chat, contributing a pan-African perspective to this learning tool among palliative care professionals.

DATA DEMAND AND INFORMATION USE (DDIU)

Starting with **Namibia** and **Malawi** as beacon sites, APCA is building capacity for data demand and information use. Using novel findings on self-reported palliative-care-related problems for patients with cancer, diabetes and chronic respiratory/cardiovascular diseases, country teams

were supported to develop advocacy agendas geared towards increasing access to palliative care for patients with non-communicable diseases.

This initiative has provided the opportunity to pilot useful platforms for research translation in African settings. The structure of our approach is further explained in our recent publication on possible directions for palliative care research in Africa (see <http://pmj.sagepub.com/content/30/6/517.full.pdf+html>).

DATA MANAGEMENT

APCA has continued to strengthen and improve data management, particularly at the headquarters level. During the reporting period, the standard palliative care indicators that APCA uses to measure performance were further streamlined to improve the quality of data collected and reported. Furthermore, APCA used the data that has been collected over the past five years (2011 to 2015) to assess performance against its strategic plan.

APCA supported UGANET, a human rights partner in **Uganda**, to review and upgrade its database to include data and information on legal services provided to palliative care patients. The staff were also oriented to the use of the data collection tool, as well as skills to transcribe that data into the upgraded UGANET online database. This system is currently operational and patient data is available, disaggregated by gender, age, nature of case and location, among other criteria. This has tremendously improved the quality of reporting and has made the follow-up of patients smoother for service providers.

“To this end, 1,065 patients and family members in Uganda, as well as health workers at hospices and other medical facilities, benefited from awareness sessions.”



BUILDING BLOCK 4

ACCESS TO ESSENTIAL MEDICINES AND TECHNOLOGIES

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

A total of 237 health care professionals were trained in pain management and use of opioid medicines in two African countries, Mozambique and Uganda. The training was delivered both through formal sessions and through CME models that have strengthened the skills of health professionals to be able to improve the quality of services offered to palliative care patients.

In **Mozambique** and **Swaziland**, in particular, APCA is providing technical assistance towards the improvement of access to pain medicines. In **Swaziland**, APCA has provided technical assistance to the Ministry of Health and to Mbabane Government Hospital to strengthen and improve its local morphine production unit. Technical assistance was also provided towards the improvement of the availability and accessibility to opioids for pain relief. In addition, APCA and the Uganda Cancer Institute provided technical assistance to the Ministry of Health of Swaziland and to Mbabane Government Hospital to establish and operate a chemotherapy unit for the first time. This support has included face-to-face training and mentorship of the staff at the unit, remote support, and exchange visits to Uganda.

In **Mozambique**, where there are currently serious shortages of morphine, the local production of low-cost oral liquid morphine has been central to APCA's ongoing technical assistance. In March 2016, APCA's Programme Coordinator for Medicines provided training for the key stakeholders of opioids in that country, including the Medicines Regulatory Authority. Technical assistance focused on the key areas of legislation, quantification of opioids, ordering and reporting, prescribing, availability, addressing access in relation to country quotas, formulation, acute/chronic pain management with opioids, systems challenges, and other impediments to access.

More widely, APCA and its partners have supported the purchase of various items of medical equipment including hospital beds, oxygen concentrators, wheelchairs, spacers, paediatric chairs, adult oxygen supplies and transducers. Hospital instruments such as vital signs monitors and accessories, shower commodes, slumber wedges, oral temperature probes, digital blood-pressure machines, stethoscopes, glucometers, crutches, bed pans and ventricular-peritoneal shunts have also been purchased for various grantees to further improve service delivery of palliative care services.

Some grantees were also supported with sundry items that are valuable in improving the quality of life of patients, and these included hospital mattresses, microscopes, hospital gowns, glucometer strips, sanitary towels and babies' nappies. Some of the grantee organisations were further supported with office furniture and computer equipment in order to make the job of the health workers more efficient as they deliver palliative care services.



BUILDING BLOCK 5

PALLIATIVE CARE FINANCING

Financing for the integration of palliative care and access to controlled medicines within African health systems has significantly reduced, posing a challenge in furthering the cause for this important public health issue. 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.

All efforts are being made by APCA and its partners to influence African governments to invest in palliative care, as it is an important public health and human rights issue. We also hope that new donors and development partners will garner interest in this issue and establish strategic partnerships for the further development of palliative care and pain relief services in Africa.

Through some of our programmes, such as the small grants programme, APCA has continued in 2015/16 to make financial contributions towards the work of its partners across Africa.

“ We also hope that new donors and development partners will garner interest in this issue and establish strategic partnerships for the further development of palliative care and pain relief services in Africa. ”





BUILDING BLOCK 6

LEADERSHIP AND GOVERNANCE IN PALLIATIVE CARE

To promote and ensure the integration of palliative care into health policies, guidelines and services, 17 meetings were conducted in Botswana and Uganda. These meetings were attended by more than 120 policymakers and other stakeholders of palliative care.

In **Botswana**, APCA provided technical support to the Ministry of Health, the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) through their Botswana country offices, to undertake a national situation analysis for hospice and palliative care. This informed the development of a national hospice and palliative care policy (final draft), which was part of the technical assistance that APCA provided. This latter undertaking was led by APCA, with full engagement of local stakeholders, including the Ministry of Health, CDC, WHO, hospice and palliative care service providers, government and private hospitals, academicians and researchers. The policy was reviewed and approved by the senior management team of the Ministry of Health and its Permanent Secretary. It is currently undergoing a review by the Botswana Government's Attorney General to ascertain legal alignment.

APCA also participated in the development of a palliative care communications strategy for **Uganda**, based on the draft national palliative care policy, which APCA supported in its development. The existence of a communications strategy is a prerequisite to approval of a national palliative care policy.

“In the determined pursuit of attaining these nine mandates in the earliest possible time, we extend an open invitation to a greater diversity of players, to harness support and empower decision makers to act on the resolution's targets.”



APCA ENGAGEMENT WITH INTERNATIONAL PARTNERS

APCA, through its staff, has been involved in national, regional and global palliative care efforts throughout the year 2015/16, as set out in the table below.

INTERNATIONAL MEETINGS AND CONFERENCES ATTENDED BY APCA STAFF	DATE	WHO ATTENDED
Board meeting of the International Children's Palliative Care Network (ICPCN) and 11 th Asia-Pacific Hospice and Palliative Care Conference Taipei, Taiwan	April/May 2015	Programmes Director
Lancet Commission Harvard University Boston, USA	May 2015	Executive Director
OSIEA meeting Nairobi, Kenya	May 2015	Executive Director
Palliative care situational analysis and policy development meetings, hosted by MoH Gaborone, Botswana	July 2015	Executive Director and Programmes Director
All Africa First Ladies Cancer Meeting Nairobi, Kenya	July 2015	Executive Director
Tropical Health Education Trust (THET) Project Meeting University of Edinburgh Edinburgh, UK	Aug 2015	Executive Director Programme Officer
Follow-up meetings for hospice and palliative care policy development, hosted by the MoH Gaborone, Botswana	Sept 2015	Executive Director and Programmes Director
HPCA Conference and APCA board meeting Durban, South Africa	Oct 2015	Board members, Executive Director, Administrative Officer and Resources Director
International laws on drugs and how these affect access at the national and regional level Geneva, Switzerland	Oct 2015	Programmes Director
AORTIC Conference Marrakech, Morocco	Nov 2015	Executive Director
Palliative Care Advocacy: New Opportunities and New Directions, a reflection meeting organised by the Open Society Foundations New York, USA	Nov 2015	Programmes Director
UNAIDS meeting Geneva, Switzerland	Jan 2016	Executive Director
APCA board meeting and fundraising event Dubai, UAE	Feb 2016	Board members, Executive Director, Programmes Director, Administrative Officer and Resources Director
Strategic meetings for potential collaborations and partnerships in Ireland combined with graduation ceremony for a Masters in Public Health Various locations, Ireland	Feb/March 2016	Programmes Director
UNGASS meeting New York, USA	April 2016	Executive Director

MAJOR OUTCOME/PURPOSE
<p>APCA representation to ICPCN International Board of Trustees.</p> <p>APCA representation at Asia-Pacific conference and lessons learned for APCA's next conference.</p>
<p>This is an ongoing engagement and a paper about access to pain medications was drafted.</p>
<p>Represented APCA.</p>
<p>The situational analysis for palliative care was completed and a national hospice and palliative care policy was drafted and submitted to the MoH in Botswana for input from all local stakeholders.</p>
<p>A presentation on APCA's work was shared.</p> <p>Connections were established with International Atomic Energy Agency.</p>
<p>Worked with the Director of the Global Academy and her team on the final report for the THET Project.</p>
<p>A draft palliative care policy document was presented and discussed with all stakeholders in Botswana, including a meeting with the senior management team and the Permanent Secretary. The policy was approved at these levels and the MoH took over follow-up with other local approval processes.</p>
<p>Held a board meeting</p> <p>Participated in the HPCA Conference</p> <p>Benchmarked the conference in preparation for the APCA/WHPCA conference in August 2016.</p>
<p>To discuss findings of a PhD research project that was supported by APCA and for which Uganda was one of the study countries. Presented a paper on "Regional perspectives on access to controlled medicine: implementing palliative care models in Africa".</p>
<p>Co-chaired the PFHI session.</p> <p>Presented to the AORTIC Council about hosting the next meeting in Uganda.</p>
<p>Presented in a session on "Connecting global advocacy to national implementation".</p> <p>Presented on "Implementation advocacy at the national and regional level in Africa".</p>
<p>Represented APCA.</p>
<p>Held fundraising meetings with four companies.</p> <p>Held an APCA board meeting.</p>
<p>Met with potential partners and collaborators of APCA in Ireland, including University College Cork and other key players in hospice and palliative care.</p> <p>Made presentations to different audiences on the challenges of health care in contemporary Africa.</p> <p>Attended graduation ceremony – Masters of Public Health as one of the two Ugandan graduates.</p>
<p>Presented at the UNGASS Civil Society meeting on access to pain medicines.</p>



RESEARCH

Building the evidence base for palliative care remains APCA's priority, and our approach lends credence to the fact that research must be linked to action to influence policy and practice. This goal is implemented through the African Palliative Care Research Network (APCRN) with support from the organisation's Research Advisory Council. The mandate of the APCRN is to support the development of the research base for palliative care through field research, building capacity for research, knowledge synthesis and knowledge translation.

“Without research, palliative care is an art not a science.”

During this reporting period, a total of **18 new members** were registered to the APCRN, and these were from Germany, United Kingdom, Senegal and Namibia. This has therefore brought the total to **192 members of the APCRN in 27 countries: Botswana, Burundi, Canada, Côte d'Ivoire, Democratic Republic of the Congo, Ethiopia, Germany, Ghana, Kenya, Lesotho, Malawi, Mauritania, Morocco, Mozambique, Namibia, Nigeria, Senegal, South Africa, Swaziland, Sweden, Rwanda, Tanzania, Uganda, United Kingdom, United States, Zambia and Zimbabwe.**

The network has a highly successful mode of partnership that has continued to flourish, especially in Europe. During this reporting period of 2015/16, **two institutions came on board:** Imperial College London and the University of Leeds (Leeds Institute of Health Sciences). This therefore takes the total to **six institution research network partners**, the others being: King's College London (Cicely Saunders Institute), the University of Bonn (Department of Palliative Care) in Germany, MEASURE Evaluation in America, and HONEXUS in Australia.

RESEARCH SPECIAL INTEREST GROUPS

The APCRN has seven active research areas that have associated special interest groups:

- children's palliative care
- outcomes of care
- medicine availability and accessibility
- volunteers in palliative care
- mHealth in the Palliative Care Research Network
- spirituality
- health economics.

Through the relevant special interest groups, the network continues to engage in targeted field research and knowledge synthesis, together with associated capacity building for research. One of our recent mHealth research group highlights comprises a survey on the use of mobile devices in palliative care services.

RESEARCH PROJECT SUPERVISION

To support palliative care education, during 2015/16 APCA staff provided research project supervision to five students working towards the attainment of Masters degrees. The students supported were from: Uganda Christian University, Mukono (**Uganda**) Makerere University (**Uganda**), University of Nairobi (**Kenya**) and Imperial College London (**UK**), all undertaking research in the field of palliative care.

USING RESEARCH EVIDENCE TO INFORM POLICY AND PRACTICE

The World Health Organization's call for the need to strengthen links between health research, health policy and practice now shapes APCA's approach to research. Only by becoming aware of this shift in approach can palliative care research become more useful in informing policy and practice.

The APCRN's active engagement in knowledge synthesis and translation initiatives involves technical leadership for palliative care in the region through the Africa Center for Systematic Reviews and Knowledge Translation (part of Makerere University, Uganda). The long-term goal of the partnership is to build capacity and support for increased knowledge synthesis and translation, particularly in the field of palliative care. Some of APCA's joint activities have been to provide evidence for task shifting as a strategy for increasing access to mental health services in HIV care settings. For more details, see www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015025274.

RESEARCH HIGHLIGHTS

Two particular research projects from 2015/16 are highlighted:

1 Review of the status of palliative care in 10 southern Africa countries

With funding from the Open Society Initiative for Southern Africa, the African Palliative Care Research

Network conducted a survey on the status of palliative care in Southern Africa, during this reporting period. The review covered core areas of the WHO public health strategy, which covers drug availability, education and service implementation. Our findings demonstrated significant variation in palliative care development among participating countries. Details of the findings can be found at https://www.africanpalliativecare.org/images/stories/pdf/REVIEW_OF_THE_STATUS_OF_PALLIATIVE_CARE%20IN_TEN_SOUTHERN_AFRICAN_COUNTRIES_Report.pdf

2 Prevalence and severity of palliative-care-related problems among ambulatory patients diagnosed with cardiovascular diseases, cancer, chronic respiratory diseases or diabetes in two sub-Saharan African countries.

Self-reported data was collected from **457 patients (207 in Malawi and 250 in Namibia)**, all of whom were receiving outpatient care for non-communicable diseases (NCDs) in specialised units at tertiary hospitals. Challenging the common convention that patients with NCDs (except of cancer), might not need palliative care, self-reported data from ambulatory patients with diabetes, chronic respiratory and cardiovascular diseases demonstrated that they experience a high burden of physical and psychological symptoms. For three of the most prevalent physical symptoms, namely pain (68%–73% incidence), lack of energy (55%–74%) and feeling tired (62%–77%), the prevalence found in this study was higher than what has been reported in ambulatory HIV/AIDS patients (51.3% for pain, 60.3% for lack of energy and 61.9% for feeling tired).¹ Moreover, across the four diagnostic groups, more than half of patients reported significant psychological distress.

The findings echo the World Health Assembly argument for paradigm shift to increasing access to palliative care alongside standard care for patients with NCDs. The need to use a comprehensive approach to care, which should be inclusive of good psychosocial components, should be emphasised.

¹ Namisango E, Powell RA, Atuhaire L, Katabira ET, Mwangi-Powell F, Harding R, "Is Symptom Burden Associated with Treatment Status and Disease Stage among Adult HIV Outpatients in East Africa?", *Journal of Palliative Medicine* 17(3), 2014.

KEY PUBLICATIONS

Key publications involving APCA staff (highlighted below) during 2015/16 are as follows:

- **Namisango E**, Ntege C, **Kiyange F**, **Luyirika E** and Allsop M, “Strengthening pharmaceutical systems for palliative care services in resource limited settings: piloting a mHealth application across a rural and urban setting in Uganda 2016”. See <http://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-016-0092-9>
- Rawlinson FM, Gwyther L, **Kiyange F**, **Luyirika E**, Meiring M and Downing J, “The current situation in education and training of health-care professionals across Africa to optimise the delivery of palliative care for cancer patients”. *Ecancer* ref 8 492, DOI: 10.3332/ecancer.2014.492 [current-situation-in-education-and-training-of-health-care-professionals-across-africa-to-optimise-the-delivery-of-palliative-care-for-cancer-patients.php](http://ecancer.org/journal/editorial/36-collaboration-across-continents-to-produce-e-learning-for-palliative-care-education-in-sub-saharan-africa.php)
- Rawlinson FM and **Luyirika E**, “Collaboration across continents to produce e-learning for palliative care education in Sub Saharan Africa”. *Ecancer* ref ed36 / DOI: 10.3332/ecancer.2014.ed36 <http://ecancer.org/journal/editorial/36-collaboration-across-continents-to-produce-e-learning-for-palliative-care-education-in-sub-saharan-africa.php>.
- Allsop MJ, Powell RA and **Namisango E**, “The state of mHealth development and use by palliative care services in sub-Saharan Africa: a systematic review of the literature”, *BMJ Support Palliative Care*. 20 May 2016. pii: bmjspcare-2015-001034. doi: 10.1136/bmjspcare-2015-001034. See <http://spcare.bmj.com/content/early/2016/05/20/bmjspcare-2015-001034.long>
- **Namisango E**, **Kiyange F** and **Luyirika EBK**, “Possible directions for palliative care research in Africa”, *Palliative Medicine* 30(6):517–9, June 2016. DOI: 10.1177/0269216316647879. See <http://pmj.sagepub.com/content/30/6/517.full.pdf+html>
- Obuku E, **Namisango E**, Rwegerera R, Ssemata A, Nakitende J, Okello J, Akena D, Kinengyere A and Ssenono R. “Task shifting from mental health specialists to non-mental health specialists for screening and treatment of depression among persons with HIV/AIDS: a systematic review protocol”, PROSPERO 2015:CRD42015025274. Available at www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015025274.
- Results-sharing workshop and dialogue between stakeholders in Maputo, Mozambique on the topic: “What are the bottlenecks to opioid medicine access and how do we solve them to improve on access?”, March 2015.

“ The World Health Organization’s call for the need to strengthen links between health research, health policy and practice now shapes APCA’s approach to research.

Only by becoming aware of this shift in approach can palliative care research become more useful in informing policy and practice. ”



SUSTAINABILITY

APCA believes 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. The areas in which we provide technical assistance for organisational development include (but are not limited to): governance and management; financial and human resource management; strategy development and implementation; programme development and implementation; monitoring and evaluation to ensure quality services for African patients and their caregivers; fundraising; marketing and branding; and website development.

MEETING APCA'S STRATEGIC OBJECTIVES

Routine data collection and utilisation is important in documenting change and accounting to stakeholders. APCA has practised this during the current reporting period, where the data collected over the past five years was used to carry out APCA's 2011–2020 strategic plan so as to assess progress against the set objectives.

Overall, APCA has to date achieved more than 80% of the objectives set in that strategic plan and has reached 25 African countries over the period.

APCA used donor and partner reports to collect the required information, and the findings in percentage achievement of set targets are as follows:

■ Increasing knowledge and awareness of palliative care:	93%
■ Strengthening health systems by integrating palliative care:	55%
■ Evidence for palliative care:	100%
■ Ensuring economic sustainability for APCA:	100%

Having clear strategic objectives with set targets to work towards enabled APCA to contribute to palliative care development in Africa through targeted palliative care awareness raising among patients and their families, health workers, educators, researchers, policymakers (among others).

Health systems have also been strengthened through (among other things) improved palliative care policy frameworks, funding, medicine availability, research, development of service delivery models, improving the quality of services, and the expansion of palliative care service sites.

FOR APCA

APCA will continue to focus on the areas where it scored less at mid-term, utilise available research evidence and also incorporate new developments (such as the requirements of the 2014 WHA Palliative Care Resolution) to create palliative care sustainability in Africa.

STAFF DEVELOPMENT

Several APCA staff participated in staff development sessions:

- In June 2015, the Research Manager participated in a seven-day online training course in project planning and management, and the knowledge gained enhanced her skills in managing the different projects which she coordinates.
- In May 2015, the Programmes Assistant attended the Allied Professionals in Palliative Care course organised by Hospice Africa Uganda. This training gave her an opportunity to learn more about palliative care and to provide more specialised input into the projects that she manages.
- In August 2015, nine APCA staff members and 13 finance staff from seven partner organisations in Uganda were trained in the taxation of non-governmental organisations (NGOs) in Uganda by Destiny Consultants. The training provided updates on recent tax developments in Uganda as well as other key tax compliance issues. This was aimed at improving the organisations' tax compliance as the Uganda Revenue Authority becomes more stringent with NGOs.

- In July and September 2015, respectively, the Finance Manager and the Resources Director each attended an annual continuing professional development seminar organised by the Institute of Certified Public Accountants of Uganda (ICPAU).
- In January 2016, the Programmes Director completed an online Masters in Public Health (MPH) degree through a scholarship from University College Cork, Ireland. The new skills will add to the positioning of APCA as a technical assistance organisation in health and to the skill set available within APCA.

OTHER DEVELOPMENTS

APCA worked towards improving its membership function in order to remain relevant to its constituents. In September 2015, APCA developed an online membership registration and subscription process, as well as an online database to enhance this key role. Furthermore, APCA has continued to maintain its ICT infrastructure in order to ensure efficient communication with all its partners and key stakeholders that are located in different geographical areas around the world.

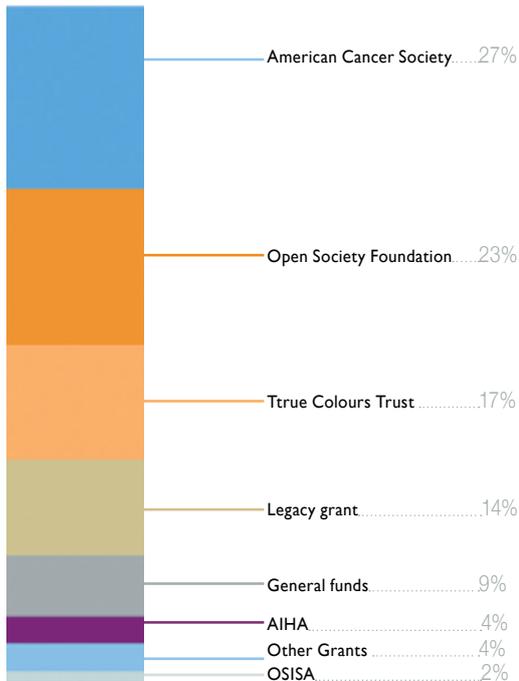
APCA upgraded its accounting system in order to maximise the system's functionalities and improve efficiency. The finance team was then trained in the use of the upgraded and reconfigured version.



The images in this Annual Report were donated courtesy of The Diana, Princess of Wales Memorial Fund, which closed its doors on 31 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. If you are interested in supporting this initiative, kindly email: communications@africanpalliativecare.org.

FINANCIAL MATTERS

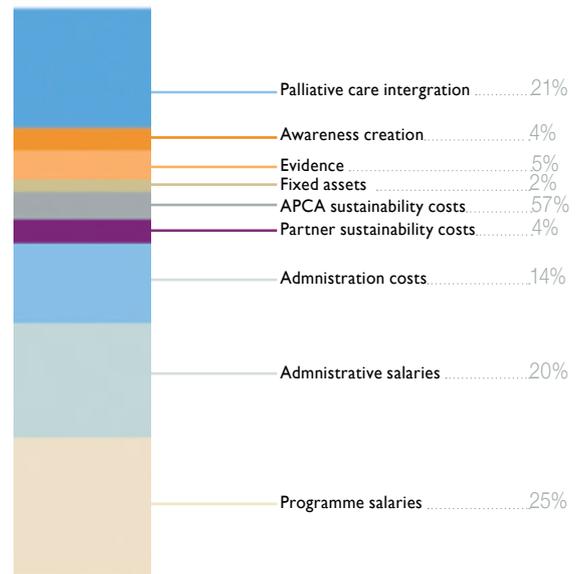
Where the money came from 2015/16



Sources of income	Bal b/f 1/4/2015	Income Apr 2015-Mar 2016	Total available funds 2015/2016	Percentage of total income 2015/2016
American Cancer Society	\$10,096	\$655,114	\$665,210	27%
Open Society Foundation	\$241,063	\$323,000	\$564,063	23%
True Colours Trust	\$274,103	\$143,990	\$418,092	17%
Legacy grant	\$341,167	-	\$341,167	14%
General funds	\$134,927	\$88,891	\$223,818	9%
AIHA	-\$1,715	\$102,997	\$101,282	4%
Other Grants	-\$111,971	\$198,462	\$86,491	4%
OSISA	-\$17,926	\$55,000	\$37,074	2%
Total	\$869,744	\$1,567,454	\$2,437,197	100%

AIHA- American International Health Alliance / Twinning Center
OSISA- Open Society Initiative of Southern Africa

Where the money went 2015/16



Expenditure area	2015/2016 (Amount)	2015/2016 (Percentage)
Palliative care intergration	\$244,332	21
Awareness creation	\$51,696	4%
Evidence	\$53,805	5%
Fixed assets	\$24,099	2%
APCA sustainability costs	\$53,100	5%
Partner sustainability costs	\$51,121	4%
Administration costs	\$161,783	14%
Administrative salaries	\$234,070	20%
Programme salaries	\$294,769	25%
Total	\$1,168,774	100%

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.

APCA would like to thank every one of our donors for helping us to turn our resolve into action for the relief of pain and suffering for patients across Africa. In particular, our donor list includes:

- American Cancer Society
- American International Health Alliance (HIV/AIDS Twinning Center)
- Global Partners in Care
- Open Society Foundations - New York (OSF)
- Open Society Initiative for Eastern Africa (OSIEA)
- Open Society Initiative for Southern Africa (OSISA)
- The Global Health Academy and University of Edinburgh with support from DFID
- The True Colours Trust
- University of Edinburgh, THET – Tropical Health Education Trust
- University of Wisconsin – Madison, Pain and Policies Study Group.

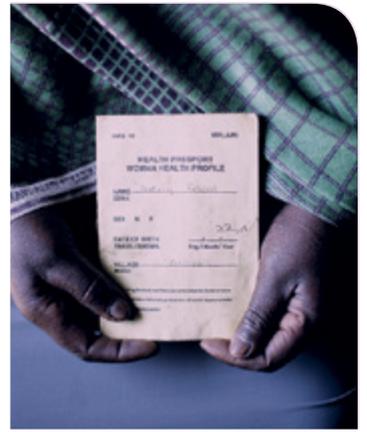
Make a donation

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 and we will contact you with further details.

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

Thank you for your support.



African Palliative Care Association

PO Box 72518 | Plot 95 | Dr Gibbons Road | Makindye | Kampala | Uganda

Tel: +256 312 264978 | +256 312 265978

info@africanpalliativecare.org

www.africanpalliativecare.org

NGO Registration Number 4231

