

# Programme and Abstract Book



## Palliative Care and Universal Health Coverage

6th International African Palliative Care Conference

**17-20 SEPTEMBER 2019**

**Kigali, RWANDA**



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

REPUBLIC OF RWANDA



Ministry of Health



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## Welcome and Message from the Minister of Health of the Republic of Rwanda

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**Dr Diane Gashumba**

**Minister of Health**  
Republic of Rwanda

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Dear Delegates,

I warmly welcome you to Rwanda on behalf of the Government of Rwanda.

As we gather for the 3rd African Ministers of Health Session on Palliative Care and the 6th International African Palliative Care Conference, the Ministry of Health of Rwanda and the African Palliative Care Association (APCA) warmly welcome you to Kigali Convention Centre and Rwanda, the country. The conference theme *Palliative Care and Universal Health Coverage (UHC)* comes at an opportune moment as countries across Africa are working on national UHC plans, policies and programmes. This conference will remind us of our shared obligation of ensuring that all people, especially the marginalised and most vulnerable members of our society have access to all essential health services, without being impoverished. It is at this conference that we will reflect on fulfilling the UHC principles of '*leaving no one behind*', including those facing the adversity that comes with serious life-limiting and life-threatening illnesses.

Our deliberations at this conference and the research evidence to be shared will enable most of the delegates to engage meaningfully with governments to include palliative care and all other essential health services – promotive, preventive, treatment and rehabilitation in national UHC plans and national health programmes.

We therefore look forward to a very productive time at the conference and we hope every delegate will be empowered to play their rightful roles in the respective countries to make palliative care in UHC a reality, along with other essential health services.

Murakoze cyane. Asanteni sana. Merci beaucoup. Thank you very much.

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## Welcome and Message from the Executive Director of the African Palliative Care Association

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**Dr Emmanuel Luyirika**

**Executive Director**  
African Palliative Care Association

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Our dear Delegates,

I warmly welcome you to the 3rd African Minister's of Health Session on Palliative Care and the 6th International African Palliative Care Conference here in Kigali, Rwanda. I would like to thank the Government of the Republic of Rwanda for the collaboration and hosting these important events for Africa. The focus of this conference on "Palliative care and Universal Health Coverage" is very timely in Africa. Palliative care addresses the pain and suffering associated with serious chronic illnesses, throughout the disease trajectory from the point of diagnosis through end of life care, for those who succumb to these conditions.

Each year, an estimated 40 million people are in need of palliative care and only about 14% currently receive it. Majority of those who need this service (78%) live in low- and middle-income countries. Although it is a key component and one of the essential health services defined in UHC, majority of adults and children who need this care do not access it in Africa. The lack of access to palliative care has significant impact on families, the health systems and economy. It affects population health and therefore productivity, resulting from disabilities and the care giving burden at the family and community level.

This conference is organised to enable us share research evidence, best practices, challenges, solutions and innovations through which access to palliative care, and other essential health services can be improved. The management of serious chronic illnesses is very costly. Therefore, UHC is best placed to ensure that all those who need palliative care in Africa are able to access it without experiencing financial hardship.

I hope that we will all leave this conference with renewed inspiration and better equipped to ensure that those with serious chronic illnesses are not left behind in country UHC policies, strategies and schemes.

I wish you all a fruitful week of the conference.

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# 6th International African Palliative Care Conference

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

## Acknowledgements

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We sincerely thank the many institutions and individuals whose support in the various forms has made this conference a reality.



## Abstract reviewers

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**Mr Andre Wagner**, Board Chair, African Palliative Care Association  
**Dr Christian Ntizimira**, City Manager, City Cancer Challenge Foundation, Rwanda  
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**Dr Emmanuel Luyirika**, African Palliative Care Association  
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**Ms Eve Namisango**, African Palliative Care Association  
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**Dr Francois Alinon**, Ministry of Health and Social Protection, Togo  
**Dr Hellen N. Kariuki**, University of Nairobi, Kenya  
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**Mrs Lacey Ahern**, Global Partners in Care, USA  
**Mr Lameck Thambo**, Palliative Care Association of Malawi  
**Dr Elizabeth Namukwaya**, Makerere Palliative Care Unit, Uganda  
**Ms Mackuline Atieno**, African Palliative Care Association  
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**Dr Peter May**, University of Dublin, School of Medicine, Ireland  
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\*Abstract reviewers and conference organising committees are hereby listed alphabetically, according to first name

## Conference organising committees

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### SCIENTIFIC COMMITTEE

**Ms Fatia Kiyange**, African Palliative Care Association (Committee Chair)

**Prof Liz Gwyther**, Hospice Palliative Care Association of South Africa and Worldwide Hospice Palliative Care Alliance (Committee Co-chair)

**Dr Zipporah Ali**, Kenya Hospices and Palliative Care Association

**Claire Morris**, Worldwide Hospice Palliative Care Alliance

**Ms Mackuline Atieno**, African Palliative Care Association

**Prof Julia Downing**, International Children's Palliative Care Network

**Dr Jose Pereira**, Board Member, African Palliative Care Association

**Prof Olaitan Soyannwo**, Nigeria

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**Ms Mwhaki Loise Ng'ang'a**, Partners in Health, Rwanda

**Ms Plaside Habinshuti**, Rwanda Partners in Health, Rwanda

**Mrs Diane Mukasahaha**, Rwanda Biomedical Center, Rwanda

### FUNDRAISING COMMITTEE

**Dr Emmanuel Luyirika**, African Palliative Care Association (Committee Chair)

**Dr Stephen Connor**, Worldwide Hospice Palliative Care Alliance

**Fr Richard Bauer**, Maryknoll Fathers and Brothers

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**Dr Joseph F O'Neil**, Independent Consultant, USA

**Dr Jose Pereira**, Board Member, African Palliative Care Association

### COMMUNICATIONS & PUBLICITY COMMITTEE

**Ms Wedzerai Chiyoka**, African Palliative Care Association (Committee Chair)

**Mr Francis Kayondo**, African Palliative Care Association

**Mr Gaspard Habarurema**, Ministry of Health Rwanda

**Ms Irene Namwase**, African Palliative Care Association

**Ms Shelley Enarson**, African Palliative Care Association

**Ms Cyndy Searfoss**, Global Partners in Care, USA

### FINANCE AND LOGISTICS COMMITTEE

**Ms Josephine Kampi**, African Palliative Care Association (Committee Chair)

**Ms Naome Namusoke**, African Palliative Care Association (Committee Co-chair)

**Ms Mable Namuddu**, African Palliative Care Association

**Ms Patricia Batanda**, African Palliative Care Association

**Ms Pamela Nahurira Kalema**, African Palliative Care Association

**Mr Frank Kayondo**, African Palliative Care Association

**Ms Julius Nganizi**, African Palliative Care Association

# Palliative Care Conference Programme

## PRE-CONFERENCE ACTIVITIES

<b>Board and other meetings for APCA and partners</b>	
Monday 16th Sept 2019	<b>APCA Board of Directors Meeting Room AD7</b>
	<b>Strategic Advocacy for the Inclusion of palliative care in Universal Health Coverage: Follow-up meeting for global, regional and national partners in Kenya, Uganda &amp; South Africa. OSF/OSIEA/ APCA (on invitation) Room AD1</b>

## PRE-CONFERENCE SESSIONS: Tuesday 17<sup>th</sup> September 2019

<b>08.00 – 09.00</b>	<b>Registration for Pre-conference sessions/workshops</b>	
<b>09.00 – 10.30</b>	Research Workshop – hosted by the African Palliative Care Research Network <b>[AD12]</b>	Ministers of Health session <b>[MH2 on invitation only]</b>
	Partnerships and collaboration workshop – Hosted by African Palliative Care Association & Global Partners in Care, USA <b>[AD10]</b>	<b>Hosted by:</b> Hon. Dr Diane Gashumba, Minister of Health, Republic of Rwanda
	Multidisciplinary pain management workshop – sponsored by the International Association for the Study of Pain <b>[AD1]</b>	<b>Co-chair:</b> Mr Andre Wagner, Board Chair, African Palliative Care Association <i>[Detailed programme available]</i>
<b>10.30 – 11.00</b>	TEA BREAK	
<b>11.00 – 13.00</b>	Workshops to continue	Ministers of Health session <b>[MH2 on invitation only]</b> <b>Hosted by:</b> Hon. Dr Diane Gashumba, Minister of Health, Republic of Rwanda <b>Co-chair:</b> Mr Andre Wagner, Board Chair, African Palliative Care Association <i>[Detailed programme available]</i>
<b>13.00 – 14.00</b>	LUNCH	
<b>14.00 – 17.00</b>	Workshops continue	Ministers of Health session, Continued
<b>17.00 – 17.30</b>	TEA BREAK	
<b>18.30</b>	<b>Ministerial Dinner [Sponsored by the Open Society Initiative for Eastern Africa]</b>	
<b>Conference registration and collection of bags 14.00 – 18.00</b>		

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## MAIN CONFERENCE PROGRAMME: 18<sup>th</sup>- 20<sup>th</sup> September 2019

### Wednesday 18<sup>th</sup> September 2019

<b>07.00 – 08.00</b>	<b>Registration</b>	
<b>PLENARY SESSION ONE: [MH3&amp;4]</b> <b>MC: Keteera Fred, PIH, Rwanda &amp; Dr Paul Mmbando, ELCT, Tanzania</b> <b>CHAIRS: Dr Gilles Ndayisaba, Rwanda Biomedical Center &amp; Mr Andre Wagner, Board Chair, African Palliative Care Association (APCA)</b>		
<b>08.00 – 08.25</b>	Dr Emmanuel Luyirika, Executive Director, APCA	Welcome remarks & Presentation of the East African Documentary of Palliative Care
<b>08.25 – 08.40</b>	Dr Githinji Gitahi, MBS, Global Chief Executive Officer, Amref Health Africa	What is Universal Health Coverage and why we need it in Africa?
<b>08.40 – 08.55</b>	Dr Liz Gwyther, Assoc Prof Liz Gwyther, convener programmes in palliative medicine, Faculty of Health Sciences, University of Cape Town, South Africa	Palliative care and access to pain relief – a human rights issue.
<b>08.55 – 09.10</b>	Eric L. Krakauer, Director, Global Palliative Care Program/ Massachusetts General Hospital; Assoc Prof of Medicine and of Global Health & Social Medicine, Harvard Medical School/ Consultant in Palliative Care, WHO	Palliative care in achieving Universal Health Coverage and the Essential package.
<b>09.10 – 09.40</b>	Palliative care beneficiaries panel discussion (Kenya, Uganda, Rwanda)	Our needs and how health systems can address them through Universal Health Coverage
<b>PLENARY SESSION ONE: [MH3&amp;4]</b> <b>MC: Keteera Fred, Partners In Health, Rwanda</b> <b>CHAIRS: Dr Gilles Ndayisaba, Rwanda Biomedical Center &amp; Mr Andre Wagner, Board Chair, African Palliative Care Association (APCA)</b>		
<b>09.40 – 09.50</b>	WHO Country Representative, Rwanda	Remarks on palliative care, an essential health service in Universal Health Coverage and invitation of the representative of WHO Regional Office for Africa
<b>09.50 – 10.00</b>	Dr Jean-Marie Dangou, Coordinator, NCD Prevention Programme, WHO Regional Office for Africa	Opening address: The state of Universal Health Coverage and the inclusion of palliative care and other essential health services in the Afro Region
<b>10.00 – 10.15</b>	Dr Marie-Charlotte Bouësseau, Adviser, Integrated Health Services, WHO, Geneva	Key note address: Palliative care - a key component of Universal Health Coverage
<b>10.15 – 10.25</b>	Dr Sabin Nsanzimana, Director General, Rwanda Biomedical center	Remarks on Rwanda's progress on the 2014 World Health Assembly Resolution on palliative care and access to palliative care within the National Health Insurance Scheme
<b>10.25 – 10.40</b>	Guest of Honour	Official Opening of the Conference

10.40 – 11.00 TEA BREAK & SNAPSHOT PRESENTATIONS				
BREAK AWAY SESSIONS				
	<b>TRACK 1</b> <b>Palliative Care in Universal Health Coverage</b> <b>[MH3&amp;4]</b> <i>Chairs: Dr Zipporah Ali, Kenya; Dr Jim Cleary, USA</i>	<b>TRACK 2</b> <b>Strategic Advocacy for Palliative Care in UHC</b> <b>[MH2]</b> <i>Chairs: Dr Stephen Connor, WHPCA; Dr Stephen Watiti, Uganda</i>	<b>TRACK 3</b> <b>Health Financing and Palliative Care</b> <b>[AD10]</b> <i>Chairs: Lucy Sainsbury and Jo Ecclestone Ford, The True Colours Trust</i>	<b>TRACK 4</b> <b>Effective Partnerships and Collaborations in Enhancing Access to Palliative Care as a Component of UHC</b> <b>[AD12]</b> <i>Chairs: Rose Kiwanuka, Uganda; Lacey Ahern, Global Partners in Care;</i>
<b>11.00 – 11.10</b>	M-palliative care link: Improving symptom control and information exchange among specialists and local health workers treating late stage Tanzanian cancer patients <i>Prof. Twalib Ngoma et al, Tanzania</i>	Implementing the World Health Assembly Resolution on palliative care: From no palliative care to national palliative care programmes in Togo, Liberia and The Gambia <i>Ms. Fatia Kiyange et al, APCA</i>	The vision and aims of True Colours' Africa Small Grants Programme <i>Lucy Sainsbury</i>	Strategic Partnerships, a Key to Achieving Palliative Care as part of Universal Health Care: Lessons from Zimbabwe <i>Dr. Portia Manangazira &amp; Elias Masendu, Zimbabwe</i>
<b>11.10 – 11.20</b>	Evaluation of Patients with Palliative Care Needs Presenting at the Emergency Department, University College Hospital, Ibadan: A Year Review <i>Dr. E.B Olusoji et al, Nigeria</i>	'Without good data, we're flying blind. If you can't see it, you can't solve it' Kofi Annan <i>Mr. Emmanuel Sibomana Kamonyo et al, Canada/ Rwanda</i>	This is what good looks like: case studies and films <i>Jo Ecclestone Ford</i>	The benefits of outreach clinics in palliative care <i>Ms. Nabitaka Josephine et al, Uganda</i>

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<p><b>11.20 – 11.30</b></p>	<p>Evaluating the Acceptability and Feasibility of Routine Use of Validated Cancer Symptom Assessment Instruments among Patients and Nurses in the Oncology Ward at Princess Marina Hospital, in Gaborone, Botswana</p> <p><i>Dr. Norman Carl Swart, Botswana</i></p>	<p>Experience of PACAM on Integration of Palliative Care Indicators into the Central Monitoring and Evaluation Department (CMED) System in the Ministry of Health in Malawi.</p> <p><i>Mr. Fred Chiputula &amp; Glenda Winga et al, Malawi</i></p>	<p>Community voices: panel discussion on providing palliative care at the local level and engaging with UHC (Small Grant Recipients)</p>	<p>Collaboration and partnership in developing palliative care integration plan for the country</p> <p><i>Mrs. Eunice Garanganga et al, Zimbabwe</i></p>
<p><b>11.30 – 11.40</b></p>	<p>Palliative Care in Mozambique: general knowledge, attitudes and physicians' practices in breaking bad news and end-of-life issues</p> <p><i>Dr. Emilia Pinto Miquidade, Mozambique</i></p>	<p>Opportunities for integrating palliative care in to Universal Health Coverage in Africa</p> <p><i>Dr. Asaph Kinyanjui, Kenya</i></p>		<p>Palliative Care Training Opportunity in Canada for Doctors in Rwanda and Neighbouring Countries</p> <p><i>Dr Subrata Banerjee, Canada</i></p>
<p><b>11.40 – 11:55</b>      <b>QUESTIONS &amp; DISCUSSION</b></p>				
<p><b>11.55 – 12:05</b></p>	<p>The prevalence of life-limiting diseases and the need for palliative care among adults at six hospitals in Sudan</p> <p><i>Dr. Nahla Gafer et al, Sudan</i></p>	<p>Integrating palliative care into health systems: the case of Rwanda</p> <p><i>Mrs. Mukasahaha Diane et al, Rwanda</i></p>	<p>Financing through small grants enables small organisations to contribute to achieving Universal Health Coverage,</p> <p><i>Pamela Kalema et all, APCA</i></p>	<p>Collaboration and partnership in capacity for palliative care.</p> <p><i>Mrs. Lidia Justino Mondlane, Mozambique</i></p>

<p><b>12:05 – 12:15</b></p>	<p>Availability of palliative care in a District Hospital of Rwanda – Case of Kibagabaga <i>Mrs. Mathilde Utumuliza et al, Rwanda</i></p>	<p>Developing a palliative care policy for South Africa <i>Dr. Charmaine Blanchard et al, South Africa</i></p>	<p>Small grant management and accountability. <i>Naome Namusoke, APCA</i></p>	<p>Networking, a strong tool for Palliative Care Advocacy; Experience at Aga Khan Hospitals <i>Dr. John Weru, Kenya</i></p>
<p><b>12:15 – 12:25</b></p>	<p>Pediatric Palliative Care in Rwanda: The Case of Butaro Cancer Center of Excellence <i>Mr. Jean Paul Balinda, Rwanda</i></p>	<p>Strengthening palliative care implementation in Botswana through hospice and palliative care policy development: one of the key pillars of World Health Organization (WHO) palliative care model <i>Mrs. Penny Sebuweng Makuruetsa, Botswana</i></p>		<p>Bereavement of a parent or sibling can be devastating for young people: an inter- hospice partnership enabled therapeutic, cross cultural sharing of experiences <i>Dr. Karilyn C, Edgar Ngelangela et al, Tanzania</i></p>
<p><b>12:25 – 12:35</b></p>	<p>Rationale and Study Design: A randomized controlled trial of early palliative care in newly diagnosed cancer patients in Addis Ababa, Ethiopia <i>Dr. Eleanor Reid et al, USA/Ethiopia</i></p>	<p>The nuts and bolts of advocacy for access to palliative care and controlled essential medicines under UHC <i>Dr. Katherine Pettus, International Association for Hospice and Palliative Care</i></p>	<p>Case Studies of small grants recipients:</p> <ul style="list-style-type: none"> <li>• Enabling the poor and unreached to access palliative care services. <i>Ms Sylvia Nakami and Dr Margretha Juncker, Uganda</i></li> <li>• The role of the hostels in increasing access to palliative care services. <i>Dr Sam Guma, Uganda</i></li> </ul>	<p>Integrating legal support for palliative care patients and their families in Zimbabwe <i>Ms. Julieth Musengi et al, Zimbabwe</i></p>
<p><b>12:35 – 12:45</b></p>	<p>Situation of palliative care in Cameroon: case of the palliative care unit of the Dominican hospital of Yaoundé <i>Mr. Christian Tsofie, Cameroon</i></p>	<p>Advocacy for access to controlled medicines - improve universal health coverage <i>Mr. Hieronimo Rweyemamu, Tanzania</i></p>		<p>Promoting universal access to palliative care through partnership: an Ethiopian &amp; UK link. <i>Dr. James Mumford et al, Ethiopia</i></p>
<p><b>12:45 – 13:00</b></p>	<p><b>QUESTIONS &amp; DISCUSSION</b></p>			

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<b>13.00 – 14.00</b>	<b>LUNCH &amp; SNAPSHOT PRESENTATIONS</b>			
<b>WORKSHOPS</b>				
<b>14.00 – 15.30</b>	<p>Palliative care for children and young people <b>[AD12]</b> <b>Chair/Facilitator:</b> <i>Prof. Julia Downing, ICPCN/Makerere University, Uganda and Giovanna Abbiati Fogliati, Fondazione Maruzza</i></p>	<p>Direct stakeholders (patient champions) as advocates for palliative care in UHC <b>[MH3&amp;4]</b> <b>Chair/Facilitator:</b> <i>Dr Stephen Watiti, Uganda; Wedzerai Chiyoka, APCA; Dr Stephen Connor, WHPCA</i></p>	<p>Getting to Resource Mobilization: building foundations for effective resource mobilization through partnerships <b>[MH2]</b> <b>Chair/Facilitator:</b> <i>Lacey Ahern, Global Partners in Care, USA &amp; Rose Kiwanuka, Palliative Care Association of Uganda</i></p>	<p>Video Based Modules for Palliative Care Education in Rural Uganda: Teaching Communication Skills to Health Workers <b>[AD10]</b> <b>Chair/Facilitator:</b> <i>Randi R. Diamond MD, USA</i></p>
<b>15.30 – 16.00</b>	<b>TEA BREAK &amp; SNAPSHOT PRESENTATIONS</b>			
<b>WORKSHOPS</b>				
<b>16.00 – 17.30</b>	<p>Developing mHealth tools to support palliative care delivery in the African region <b>[AD12]</b> <b>Chair/Facilitator:</b> <i>Matthew Allsop, UK; Eve Namisango, Uganda &amp; Richard Harding, UK</i></p>	<p>Direct stakeholders (patient champions) as advocates for palliative care in UHC continued <b>[MH3&amp;4]</b></p>	<p>Meeting of grantees and partners of the Open Society Foundations &amp; Open Society Initiative for Eastern Africa <b>Invitation Only [MH2]</b> <b>Coordinator:</b> <i>Sara Pardy, OSF, USA</i></p>	<p>The role of partnership and collaboration in developing centres of excellence for palliative care and improving the quality of existing services: Lessons from Eswatini, Mozambique and Zimbabwe <b>[AD10]</b> <b>Chair/Facilitator:</b> <i>Fatia Kiyange &amp; Mackuline Atieno, African Palliative Care Association</i></p>
<b>17.30 – 18.45</b>	APCA General Assembly <b>[MH3&amp;4]</b>			
<b>17.30 – 18.45</b>	<p>Wellness &amp; movement workshop for self-care: Deepening connection for health care workers <b>[AD12]</b> <i>Patricia Ann Repar, Associate Professor, Departments of Music and Internal Medicine Director, Arts-in-Medicine Program The University of New Mexico, USA</i></p>			

Thursday 19<sup>th</sup> September 2019

<b>07.30 – 8.00</b>	<b>Registration</b>	
<b>PLENARY SESSIONS TWO: [MH3&amp;4]</b>		
<b>CHAIRS:</b> <i>Dr Fredrick Asirwa Chite, AMPATH Kenya &amp; Dr Portia Manangazira, Zimbabwe</i>		
<b>08.00 – 08.30</b>	Dr. HAKIBA Solange, Deputy DG Benefits, Rwanda Social Security Board	Healthcare financing and the inclusion of palliative care in National Health Insurance – Lessons from Rwanda
<b>08.30 – 08.55</b>	Dr Ann Berger, Chief Pain and Palliative Care, National Institutes of Health Bethesda, Maryland, USA	The potential of health research in informing the integration of palliative care into health systems and Universal Health Coverage
<b>08.55 – 09.20</b>	Dermott McDonald, Consultant, Health and palliative care financing	Global Health Financing landscape and opportunities and mechanisms for positioning of Civil Society Organisations in Africa to access funding
<b>09.20 – 09.50</b>	Health Development Partners/ Donors & Governments	Global Health Financing landscape and opportunities for leveraging resources for palliative care and other essential health services in Africa. <i>Panel Discussion</i> <i>(OSF, OSIEA, CDC Rwanda, USAID Rwanda, World Bank Rwanda, DFID Rwanda, ENABEL, Partners In Health, CHAI Rwanda)</i>
<b>09.50 – 10.15</b>	Rt. Hon Ngoga Karoli Martin, Speaker, East African Legislative Assembly; Prof Yoswa Mbulalina Dambisya Director General; The East, Central and Southern African Health Community (ECSA-HC)	The role of regional bodies in achieving Universal Health Coverage in Africa: <i>Panel Discussion</i>
<b>10.15 – 10.30</b>	Celebrating the work of the small	The True Colours Trust, UK
<b>10.30 – 11.00</b>	<b>TEA BREAK &amp; SNAPSHOT PRESENTATIONS</b>	
<b>BREAK AWAY SESSION &amp; WORKSHOPS</b>		

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	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> [AD10] <i>Chairs: Fr Richard Bauer, Kenya &amp; Dr Christina Puchalski, USA</i> <i>Spirituality workshop</i>	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> [MH3&4] <i>Chairs: Eve Namisango, APCA &amp; Prof Richard Harding, UK</i>	<b>TRACK 2</b> <i>Strategic Advocacy for Palliative Care in UHC</i> [MH2] <i>Chair: Dr Liz Gwyther, South Africa &amp; Emmanuel Kamonyo, Canada</i>	<b>TRACK 3</b> <i>Health Financing and Palliative Care</i> [AD1] <i>Chairs: Dermott McDonald, UK; Dr Mubiligi Joel IMB, Rwanda</i>	<b>TRACK 4</b> <i>Effective Partnerships and Collaborations in Enhancing Access to Palliative Care as a Component of UHC</i> [AD12] <i>Chairs: Julie Ling, EAPC &amp; Emmanuel Luyirika, APCA</i>
<b>11.00 – 11.10</b>	<i>Spirituality workshop</i>	Using routine medical records in an African Health Information Exchange to identify patients eligible for palliative care  <i>Ms. Florence Malehlabathe Phelanyane, South Africa</i>	The value of advocacy for integration of palliative care in UHC  <i>Mr. David K. Musyoki, Kenya</i>	Using Big Data Analytics in Assessing the Technical Efficiencies Gained Through Integration of Palliative Care in Zimbabwe's Health System - A Protocol  <i>Mr. Chenjerai Sisimayi, Zimbabwe</i>	The Role of Religious entities in ensuring QoL of Patient with limiting illnesses via Palliative Care Services.  <i>Gasana Udahemuka Magnus, Rwanda</i>
<b>11.10 – 11.20</b>	<i>Spirituality workshop</i>	Barriers to treatment initiation after treatment prescription for breast and cervical cancer patients at Uganda Cancer Institute  <i>Ms. Mackuline Atieno, APCA</i>	Introducing Palliative Care in Guinea  <i>Mrs. Camilla Börjesson, Guinea</i>	Who takes care of the cost? Case report of abdominal wall defects among new borns at Homa Bay County Teaching and Referral Hospital, Kenya  <i>Dr Liru Meshack et al, Kenya</i>	Collaborating with technical partners to forge towards UHC for Older Persons  <i>Mr. Forster Matyatya, Zimbabwe</i>



<p><b>11.20 – 11.30</b></p>	<p><i>Spirituality workshop</i></p>	<p>Awareness of Non Malignant Disease Trajectory and Access to Palliative Care</p> <p><i>Dr. Abathun Ephrem &amp; Barbro Norrstrom Mittag-Leffler, Ethiopia</i></p>	<p>A review of Human Resources for Palliative Care in Eswatini</p> <p><i>Ms. Ntombi Ginindza et al, Eswatini</i></p>	<p>Promoting Private organisations in scaling up Palliative Care in higher learning institutions through Training and Research in Tanzania</p> <p><i>Dr. Owino &amp; Elvis Joseph Miti, Tanzania</i></p>	<p>Extending palliative care to the deaf community to enhance access to palliative care services in Uganda</p> <p><i>Ms. Rose Kiwanuka &amp; Mark Mwesiga, Uganda</i></p>
<p><b>11.30 – 11:40</b></p>	<p><i>Spirituality workshop</i></p>	<p>Bringing hope, changing systems, transforming lives; a 10 year review on the impact of integrated palliative care in the academic and national hospital setting in Uganda</p> <p><i>Dr. Mhoira Leng et al, Uganda/ Scotland</i></p>	<p>The need for and role of skilled health work force in achieving UHC that is inclusive of palliative care</p> <p><i>Pamela Kalema, APCA</i></p>	<p>Strategic advocacy through reporting economic outcomes at household level - Can palliative care support poverty reduction in LMIC?</p> <p><i>Dr. Mary Jane Bates, Malawi</i></p>	<p>The Role of Partnerships in Pain Education: The Kenyan Situation</p> <p><i>Dr. Hellen N. Kariuki, Kenya</i></p>
<p><b>11.40 – 11:50</b></p>	<p><i>Spirituality workshop</i></p>	<p>The first step is the hardest: Integration of Multidisciplinary Pediatric and Adolescent Palliative Care Services in Outpatient HIV/ AIDS Care in Tanzania</p> <p><i>Dr. Liane Campbell et al, Tanzania</i></p>	<p>Engaging Pharmacists in the strategic advocacy for Palliative Care in Tanzania</p> <p><i>Dr. Paul Zebadia Mbanda et al, Tanzania</i></p>	<p>Strategies for improving access to oral liquid morphine for palliative care patients in Tanzania</p> <p><i>Mrs. Theodora Lwanga et al, Tanzania</i></p>	<p>Doing more with less: Collaboration across three essential services (Palliative Care, HIV/ AIDS care, and cervical cancer screening) to co-ordinate preventive care for at risk HIV+ women and earlier palliative care for incurable disease</p> <p><i>Dr Leah Norgrove et al, Canada</i></p>

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11:50 – 12:05		QUESTIONS & DISCUSSION			
12:05 – 12:15	Spirituality workshop	Importance of Involving Public hospitals to contribute towards palliative care development as a clinical placement site. Experience of Ntcheu and Rumphu district Hospital in Malawi  <i>Ms. Idah Rajabu et al,</i>	Conservative treatment Vs. Interventions for Cancer and AIDS Pain Management  <i>Prof. Maged Elansary, Egypt</i>	Facilitating Poor People to Access Treatment for Cancer  <i>Mr. Mutaasa Allan &amp; Dr Margrethe Juncker, Uganda</i>	From N'Doro Project to the Gauteng Centre for Palliative Care: palliative care access at Chris Hani Baragwanath Academic Hospital  <i>Dr. Mpho Ratshikana-Moloko et al, South Africa</i>
12:15 – 12:25	Spirituality workshop	Recommendations from an evaluation into nurse prescribing in palliative care in Uganda.  <i>Prof. Downing Julia et al, Uganda/UK</i>	Impact encountered during initial implementation of Pain-Free Hospital Initiative (PFHI) in Rwanda  <i>Mr. Vedaste Hategekimana, Rwanda</i>	“Tools to help us identify patients with palliative care needs in intermediate care hospital”  <i>Mrs. Montserrat Soldevila, Spain</i>	The essence of partnerships: experience of paediatric palliative care within a paediatric haematology-oncology program in Malawi  <i>Mr. Rhahim Bank, Malawi</i>
12:25 – 12:35	Spirituality workshop	Palliative Care research for Cancer Patients in Sub Saharan Africa: A 10-year Review  <i>Ms. Angucia Bridget Sharon &amp; Annet Nakaganda, Uganda</i>	‘End of life care is everyone’s business’ – enabling up skilling of generalist in palliative care using adapted GSF Training Programmes from the UK to increase scope and reach of care  <i>Prof Keri Thomas, UK</i>	Timing of referral to specialist palliative care in a teaching hospital in Ghana.  <i>Dr. Kathryn Spangenberg, Ghana</i>	Financial Management of Multi Country and Multi Partner Grants-Experiences and Lessons From APCA  <i>Ms. Josephine Kampi, APCA</i>

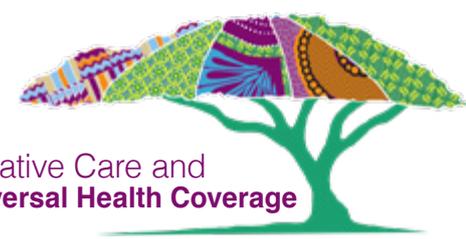


12:35 – 12:45	<i>Spirituality workshop</i>	MAPS (Modelling an Appropriate Pain Self-management intervention for adolescents with HIV/AIDS in Malawi)  <i>Dr. Kennedy Bashan Nkhoma et al, Malawi</i>	Developing a common Palliative Care language in Africa  <i>Mrs. Elizabeth Scrimgeour, South Africa</i>	Exploring experiences of caregivers of children with cancer at Ndimoyo Palliative care centre  <i>Mr. Rex Robert Chinzu, Malawi</i>	40 years' experience in palliative care; Island Hospice & Healthcare's Lessons from partnerships with government and CBOs  <i>Mrs. Franciscah Tsikai, Zimbabwe</i>
12:45 – 13:00	<b>QUESTIONS &amp; DISCUSSION</b>				
13.00 – 14.00	<b>LUNCH &amp; SNAPSHOT PRESENTATIONS</b>				
<b>WORKSHOPS</b>					
	<b>TRACK 1</b> <i>Palliative Care in Universal Health</i> [AD10]	<b>TRACK 1</b> <i>Palliative Care in Universal Health</i> [AD1]	<b>TRACK 2</b> <i>Strategic Advocacy for Palliative Care in UHC</i> [AD12]	<b>TRACK 3</b> <i>Health Financing and Palliative</i> [MH2]	<b>TRACK 4</b> <i>Effective Partnerships and Collaborations in Enhancing Access to Palliative Care as a Component of UHC</i> [MH3&4]

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14.00 – 15.30	Spirituality workshop contd.	<p><b>French workshop</b></p> <p><b>Chair/Facilitator:</b> <i>Dr Francois Uwinkindi, Rwanda; Anselme Mubeneshayi Kananga, Belgium/ DRC</i></p>	<p>Palliative Care in Medical Education in Rwanda: A Collaborative Initiative of the University of Rwanda and Partners in Health</p>	<p>Health financing, donor mapping and messaging for effective resource mobilisation</p>	<p>Multi-country and multi-level partnership to initiate and implement national palliative care programmes in Togo, The Gambia and Liberia</p>
		<p>Cross border collaboration with a Ugandan Palliative Care Team to access morphine for Cancer patients in Aru, North East Congo</p> <p><b>Dr. Patricia Strubbe; Dr Amanga Amaa Jacques; Madhira and Anguyi, DRC</b></p>	<p><b>Chair/Facilitator: Dr Vincent Cubaka, Director of Research and Training, Partners In Health, Rwanda &amp; Dr. Florence A. Bitalabehe, MD, Director of The Institute of Community Based Education at UGHE, School of Medicine &amp; Partners in Health, Rwanda; Prof Philp Cotton, University of Rwanda</b></p>	<p><b>Chair/Facilitator: Dermott Mcdonald, Netherlands &amp; OSF/OSIEA</b></p>	<p><b>Chair/Facilitator: Patricia Batanda &amp; Fatia Kiyange, African Palliative Care Association</b></p>
		<p>Evaluation de la prise en charge de la douleur physique chez les patients suivis en soins palliatifs au CNHU/HKM de Cotonou</p> <p><b>Gnintoungbe S, Agbodande KA, Dedo S, et al, Benin</b></p>			



		The civil society at the heart of the development of palliative care for cancer patients in D R Congo  <i>Anselme Mubeneshayi Kananga, Belgium/ DRC</i>			
12:45 – 13:00	<b>QUESTIONS &amp; DISCUSSION</b>				
13.00 – 14.00	<b>TEA BREAK &amp; SNAPSHOT PRESENTATIONS</b>				
<b>BREAK AWAY SESSION &amp; WORKSHOPS</b>					

	<b>TRACK 1</b>	<b>TRACK 1</b>	<b>TRACK 2</b>	<b>TRACK 3</b>	<b>TRACK 4</b>
16.00 – 18.45	<i>Palliative Care in Universal Health</i> [AD10]	<i>Palliative Care in Universal Health</i> [AD1]	<i>Strategic Advocacy for Palliative Care in UHC</i> [AD12]	<i>Health Financing and Palliative</i> [MH2]	<i>Effective Partnerships and Collaborations in Enhancing Access to Palliative Care as a Component of UHC</i> [MH3&4]
	Free papers  <b>Chairs:</b> <i>Dr Eke Gracia, Nigeria; Dr Jane Bates, Malawi</i>	French workshop continued  <b>Chair/ Facilitator:</b> <i>Dr Jean Paul Rwabihama, Rwanda; Anselme Mubeneshayi Kananga, Belgium/DRC</i>	Implementation of palliative care standards and guidelines in Africa: activities, outcomes, lessons and the future  <b>Chair/ Facilitator:</b> <i>Andre Wagner, HPCA; Prof. Liz Gwyther, University of Cape Town; Mackuline Atieno, African Palliative Care Association</i>	Health financing, donor mapping and messaging for effective resource mobilisation continued  <b>Chair/ Facilitator:</b> <i>Dermott Mcdonald, Netherlands &amp; OSF/OSIEA</i>	Community home based palliative care: Experiences and lessons from Rwanda  <b>Chair/ Facilitator:</b> <i>Mr Godfrey Ngoboka, RBC &amp; Grace Mukankuranga, Palliative Care Association of Rwanda</i>

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<p><b>16:00 – 16:10</b></p>	<p>“To investigate the Need for Palliative care in Cerebrovascular Accident (stroke) patients at Ladysmith Regional Hospital”</p> <p><i>Dr. Mohammed Jamil Hossain, South Africa</i></p>	<p>Initier les soins palliatifs dans les Hôpitaux de 4ème et 5ème catégorie de la région du Littoral: Projet Esop-Fosal</p> <p><i>Dina Bell Mbassi E, Kwedi Mangan Felix et al, Cameroon</i></p>			
<p><b>16.10 – 16:20</b></p>	<p>Planning for palliative care in complex humanitarian response: qualitative analysis of patient and provider experiences of palliative care in humanitarian crisis settings</p> <p><i>Dr. Kevin Bezanson, Canada</i></p>	<p>Groupe Technique de Travail pour le Plaidoyer et l'avant Projet de loi sur les Soins Palliatifs au Cameroun.</p> <p><i>Dr Mabokou Tabeng Ariane</i></p>			
<p><b>16.20 – 16:30</b></p>	<p>Use of Locally Filmed Video-based Educational Modules to Enhance PC Communication Skills in the Rural Ugandan Setting</p> <p><i>Dr. Randi R. Diamond et al, USA</i></p>	<p>Increasing awareness of the Palliative Care provision by an Anglican health care provider in North East Democratic Republic of Congo with radio broadcasts</p> <p><i>Rev Madhira Wadri &amp; Mr Anguyi Obhidha, DRC</i></p>			

<p><b>16.30 – 16:40</b></p>	<p>Advance care planning discussions and meeting spiritual needs in hospital settings</p> <p><i>Prof. Mark Thomas &amp; Keri Thomas, UK</i></p>				
<p><b>16.40 – 16:50</b></p>	<p>The impact of nutritional support among patients receiving palliative care from Rays of Hope Hospice Jinja</p> <p><i>Ms. Logose Harriet, Uganda</i></p>				
<p><b>16:50 – 17:00</b></p>	<p>Improving access to palliative care through strengthening community based surveillance</p> <p><i>Dr. Agasha Doreen Birungi et al, Uganda</i></p>				
<p><b>17:00 – 17:30</b></p>	<p><b>QUESTIONS &amp; DISCUSSION</b></p>				
<p><b>17.30 – 18.45</b></p>	<p>Wellness &amp; movement workshop for self-care: Deepening connection for health care workers <b>[AD12]</b></p> <p><i>Patricia Ann Repar, Associate Professor, Departments of Music and Internal Medicine Director, Arts-in-Medicine Program The University of New Mexico, USA</i></p>				
<p><b>19.30</b></p>	<p>Conference Fundraising Gala Dinner: <i>Lemigo Hotel, Kigali [Dress Code – Traditional or Formal]</i></p>				

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Friday 20<sup>th</sup> September 2019

<b>07.30 – 08.30</b>	<b>Registration</b>			
<b>PLENARY SESSION THREE [MH3&amp;4]</b>				
<b>CHAIRS:</b> <i>Antoine Kambanda, Archbishop of Kigali &amp; Dr. Prof. Julia Downing, ICPCN/Makerere University, Uganda</i>				
<b>08.00 – 08.40</b>	H.E. Archbishop Vincenzo Paglia, President of the Pontifical Academy for Life, Vatican	The PAL-LIFE Project on the Diffusion and Development of Palliative Care in the World and the White Book for Palliative Care Advocacy		
<b>08.40 – 09.10</b>	Dr Fredrick Asirwa Chite, Head of Oncology Project, AMPATH	Partnerships and collaboration in achieving UHC that is inclusive of palliative care		
<b>09.10 – 10.10</b>	Panel discussion – National palliative care associations & key players	Successes, challenges and lessons for advocacy towards the integration and implementation of palliative care in UHC (Kenya, Uganda, South Africa, Zimbabwe, Rwanda Biomedical Center, Malawi, Tanzania & APCA)		
<b>10.10 – 10.30</b>	<b>QUESTIONS &amp; DISCUSSION</b>			
<b>10.30 – 11.00</b>	<b>TEA BREAK AND SNAPSHOT PRESENTATIONS</b>			
<b>BREAK AWAY SESSIONS</b>				
	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> [MH3&4] <b>Chairs:</b> <i>Dr John Weru, Kenya &amp; Dr Nicola Ayers, Ethiopia</i>	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> [MH2] <b>Chairs:</b> <i>Dr Doreen Agasha, Uganda &amp; Prof. Israel Kolowole, Nigeria</i>	<b>TRACK 2</b> <i>Strategic Advocacy for Palliative Care in UHC</i> [AD10] <b>Chairs:</b> <i>Eunice Garanganga, Zimbabwe; Esther Muinga, Kenya</i>	<b>TRACK 4</b> <i>Effective Partnerships and Collaborations in Enhancing Access to Palliative Care as a Component of UHC</i> [AD12] <b>Chairs:</b> <i>Ntombi Ginindza, eSwatini; Rose Gahire, Rwanda</i>



<p><b>11:00 – 11:10</b></p>	<p>Involvement of Palliative Care Link Nurses to leverage palliative care delivery - Case of Kibagabaga Hospital, Rwanda. <i>Dr. Eugene Ruberanziza et al, Rwanda</i></p>	<p>Increasing access to pain relief medicine in Malawi by reviewing restrictive laws and regulations <i>Mr. Rabson Mvula et al, Malawi</i></p>	<p>Home Based Care of Palliative Care Patients at Kigali <i>Dr Mukeshimana Olive et al, Rwanda</i></p>	<p>Community engagement &amp; local partnerships as an integral component to improving coverage and effectiveness of palliative care as a component of UHC in Mutare, Zimbabwe <i>Ms. Lenah Mudada, Zimbabwe</i></p>
<p><b>11:10 – 11:20</b></p>	<p>Physiotherapy: Palliative and Hospice Care Integration in the Zimbabwe Universal Healthcare System <i>Dr. Lubayna Fawcett, Zimbabwe</i></p>	<p>Social workers multi-dimensional roles in providing palliative care to patients with life-limiting illnesses towards enhancing universal health coverage: A Namibian Perspective <i>Dr Rachel Freeman, Namibia</i></p>	<p>How to Integrate Palliative Care into Primary Health Care <i>Mrs. Mercy Wachiuri, Kenya</i></p>	<p>Developing a model for training of trainers (ToT) courses <i>Mrs. Ruth Wooldridge et al, UK</i></p>
<p><b>11:20 – 11:30</b></p>	<p>Experiences of Palliative Care Patients and their Family Caregivers in Sub-Saharan Africa. An Integrative Review <i>Ms. Bisi Adewale, Ghana</i></p>	<p>Exploring lived experiences of patients with advanced cervical cancer <i>Mr. Natuhwera Germans, Uganda</i></p>	<p>Exploring the process and experiences of nursing care of patients at the end of life: An ethnographic-case study of a medical unit <i>Mr. Dalhat Sani Khalid, Nigeria</i></p>	<p>Empowering other African countries to initiate and/or integrate African palliative care into their health care systems <i>Ms. Dianah Basirika, Uganda</i></p>
<p><b>11:30 – 11:40</b></p>	<p>Understanding the role of digital technologies to enhance palliative cancer care delivery in sub-Saharan Africa <i>Dr. Kennedy Bashan Nkhoma et al, UK</i></p>	<p>Evaluating Palliative Care training in the oncology registrar program <i>Dr. Rene Krause et al, South Africa/Dr Kennedy Nkhoma, UK</i></p>	<p>Community Systems Strengthening for Increased access to Palliative care for Children with Disability <i>Mr. Willy Kanya &amp; Edith Akankwasa, Uganda</i></p>	<p>Exploring nurses' experience on the use of pain assessment tools at national referral hospital, Hhohho region, Swaziland <i>Mrs. Felicity Lukhele, Eswatini</i></p>

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<p><b>11:40 – 11:50</b></p>	<p>The palliative care needs of Drug-resistant tuberculosis (DR-TB) patients that go unmet during their treatment journey</p> <p><i>Dr. Shannon Odell et al, South Africa</i></p>	<p>Developing Generalist Palliative Care Communication Skills with a Brief Interactive Educational Session</p> <p><i>Dr. Millicent Korir &amp; Phanice Jepkemoi et al, Kenya</i></p>	<p>Psychosocial issues experienced by parents of children with cancer in Southern Nigeria</p> <p><i>Dr. Gracia Eke, Nigeria</i></p>	<p>Palliative care multidisciplinary team in Princess Marina Hospital.</p> <p><i>Dr. Babe Eunice Gaolebale, Goitseone Mburu, Botswana</i></p>
<p><b>11:50 – 12:05</b></p>	<p><b>QUESTIONS &amp; DISCUSSION</b></p>			
<p><b>12:05 – 12:15</b></p>	<p>The benefits of Palliative Care for patients with chronic heart failure</p> <p><i>Mrs. Joy Hunter, south Africa</i></p>	<p>Does health care professionals views on illness, death and dying impact on the PC that they give?</p> <p><i>Prof. Downing Julia et al, Uganda/UK</i></p>	<p>Challenges and Opportunities for integrating palliative care into humanitarian health interventions among health care workers in Uganda</p> <p><i>Mr. Nasur Buyinza, Uganda</i></p>	<p>Joining together to spearhead the advancement of Children's Palliative Care for all in Eswatini</p> <p><i>Ms. Raquel da Silva &amp; Dr. Denise Mortlock, Eswatini</i></p>
<p><b>12:15 – 12:25</b></p>	<p>Assessing the palliative care needs of elderly patients seen at the University College Hospital, Ibadan, Nigeria</p> <p><i>Dr. Omoyeni N.E et al, Nigeria</i></p>	<p>Life After Loss Rwanda – a grief program serving palliative care families through Rwanda Palliative Care and Hospice Organisation</p> <p><i>Ms. Rebecca Resnick, Rwanda</i></p>	<p>Towards person-centered, quality care for children with life-limiting and life-threatening conditions: Self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study</p> <p><i>Ms. Eve Namisango et al, APCA</i></p>	<p>Prevalence and predictors of cervical cancer in rural Uganda</p> <p><i>Ms. Nita Chai, Uganda</i></p>
<p><b>12:25 – 12:35</b></p>	<p>Palliative care in universal health coverage; mitigating psychological trauma, depression and stigma for people living with HIV and aids through the narrative approach</p> <p><i>Mrs. Susan Njuguna &amp; Dr. Sylvia Tuikong, Kenya</i></p>	<p>Improving bereavement outcomes in Zimbabwe: A feasibility cluster trial of the 9-cell Bereavement Tool</p> <p><i>Ms. Jenny Hunt, Zimbabwe</i></p>	<p>Assessment of Referral system for patients in need of palliative care service at Kibogora Hospital.</p> <p><i>Mrs. Mukantagara Madeleine, Rwanda</i></p>	<p>Current situation of palliative care services in rural communities of Lesotho: A qualitative analysis</p> <p><i>Dr. Mwabury Tonny, Lesotho</i></p>

12:35 – 12:45	Non-Communicable Diseases; an emerging epidemic requiring palliative care, where are religious leaders? <i>Mrs. Doris Frank et al, Tanzania</i>	The use of traditional herbal medicines among palliative care patients at Mulanje Mission hospital, Malawi <i>Dr. Joseph Chisaka et al, Malawi</i>	Universal Health Coverage and HIV Palliative care in Africa - what is the missing link? <i>Mr. Mohammed Barry &amp; Pascal Akahome, The Gambia</i>	Membership engagement in shaping priorities for palliative care service development in resource limited settings: Developing best practices <i>Ms. Irene Namwase et al, APCA</i>
12.45 – 13.00	<b>QUESTIONS &amp; DISCUSSION</b>			
13.00 – 14.00	<b>LUNCH &amp; SNAPSHOT PRESENTATIONS</b>			
<b>Chairs:</b> <i>Dr Martha Mukaminega, Rwanda &amp; Malik Jaffer, APCA Board [MH3&amp;4]</i>				
14.00 – 15.00	Global & Regional Bodies – WHPCA, ICPCN, EAPC, University of Indiana, Asia Pacific Assoc of Hospice & PC	The role of Global and Regional Bodies in Achieving UHC at country level: <i>Panel Discussion</i>		
15.00 – 15.15	Prof Julia Downing, UK & Fatia Kiyange, APCA	Summary of deliberations from the 3 <sup>rd</sup> Ministers of Health Session of 17 <sup>th</sup> September 2017 and the 16 <sup>th</sup> African International Palliative Care Conference		
15.15 – 15.45	<b>Dr Emmanuel Luyirika, African Palliative Care Association &amp; Dr Diane Gashumba, Minister of Health, Republic of Rwanda</b>	<b>Conference Closing</b>		

## Snapshot presentations

Wednesday 18<sup>th</sup> September 2019

**TIME: 13.20 – 13.50**

Time	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> <b>Station No.1</b> <b>Facilitator:</b> <i>Asaph Kinyanjui, KEHPCA; Blaise Uhagaze, Rwanda</i>	<b>TRACK 2</b> <i>Strategic Advocacy for Palliative Care in UHC &amp; Track 1</i> <b>Station No.2</b> <b>Facilitator:</b> <i>Claire Morris, WHPCA &amp; Mark Mwesiga, Uganda</i>	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> <b>Station No.3</b> <b>Facilitator:</b> <i>Chamaine Blanchard, South Africa; Nahla Jaffer, Sudan</i>	<b>TRACK 4</b> <i>Effective Partnerships and Collaborations in Enhancing Access to Palliative Care as a Component of UHC&amp; Track 1</i> <b>Station No.4</b> <b>Facilitator:</b> <i>Cyndy Seafoss, Global Partners in Care; Matyatya Forster, Zimbabwe</i>
<b>13.20 – 13.25</b>	A095: CPE Triage system for integrating Paediatric Palliative Care into a tertiary level children's hospital in Cape Town, South Africa  <i>Dr Michelle Meiring, South Africa</i>	B030: Increasing demand and access to palliative care in Uganda.  <i>Anna Mirembe, Doreen Agasha, Christopher Ntege, Uganda</i>	A127: Capacity building to enhance palliative care: An Experience from Butaro District Hospital  <i>Umutoni Victoria, Esperance Benemariya, Habimana Olivie, Habinshuti Placide, Ng'ang'a Loise &amp; Rusangwa Christian, Rwanda</i>	D019: Deepening Connection for Healthcare Workers: Creative Workshops in Movement and Touch  <i>Dr. Patricia Ann Repar, Mexico</i>
<b>13.25 – 13.30</b>	A083: Improving health outcomes in children through the use of a digital pain assessment tool  <i>Suzanne Boucher &amp; Julia Downing, ICPCN</i>	B013: "Speak Up - There's an Elephant in the Room": A public awareness campaign  <i>Su Ming Tham, Malaysia</i>	A128: Palliative Care integration in CHUK  <i>Gasana Udahemuka Magnus, Rwanda</i>	D043: Impact of palliative care course training for oncology residents at Joliot Curie Institute, Senegal  <i>Coumba Gueye, Senegal</i>

<p><b>13.30 – 13.35</b></p>	<p>A031: Psychosocial support of child care givers for cancer and HIV patients <i>Nakawuki Lydia, Uganda</i></p>	<p>B022: Palliative Care as a Human Rights issue: What role can law students Play? <i>Betty Odur Lee et al, Uganda</i></p>	<p>A122: Increases in breast cancer knowledge after a patient support group at Butaro Cancer Center of Excellence, Rwanda <i>Ndayisaba TA et al, Rwanda</i></p>	<p>D045: Partnerships for Organisational sustainability, a case study of a regional NGO <i>Patricia Batanda, APCA</i></p>
<p><b>13.35 – 13.40</b></p>	<p>A109: Pain management in children with disabilities in resource-constrained environments: Problems, Perspectives, Prospects and Practicalities <i>Andrew Amata, United Kingdom</i></p>	<p>A099: Palliative care in universal health coverage in Kenya <i>Félix Omare, Kenya</i></p>	<p>A092: Follow up of palliative care trainees on clinical placement at The Institute of Hospice and Palliative care in Africa-Hospice Africa Uganda <i>Dorothy Adong Olet, Nasur Buyinza, Bernadette Mander and Racheal Dipio, Uganda</i></p>	<p>D025: Virtual Learning To Enhance Quality And Teamwork: The Blantyre-Fife Case-Based Discussion Experience. <i>Chimwemwe Kabaghe et al, Malawi</i></p>
<p><b>13.40 – 13.45</b></p>	<p>A120: Exploring the Feasibility of the Family-Centered Health Care (FCHC) a Palliative Care Approach for caring older people in Tanzania: A Quasi-experimental study <i>Manase Frank et al, Tanzania</i></p>	<p>A124: How Canada's Palliative Care compares with Other Universal Health Care Systems. <i>Dr Subrata Banerjee, Canada</i></p>	<p>A130: End of life care and illness understanding among advanced cancer patients at the Centre of Excellence for Palliative Care, Chris Hani Baragwanath Academic Hospital, Soweto <i>Mpho Ratshikana-Moloko, and South Africa</i></p>	<p>D039: Impact of Multidisciplinary team in improving Better quality of life to the patients with life threatening illnesses a case study of Kinihira PH, Rwanda 2015-2018 <i>Bolingo J Berchmas, Rwanda</i></p>
<p><b>13.45 – 13.50</b></p>	<p>A070: Reaching the unreached <i>Naleba Irene, Uganda</i></p>	<p>A148: Meaning and Utilization of Palliative Care among the Luo Linked to Chulaimbo Sub County Hospital, Kenya <i>Mackuline Atieno, APCA</i></p>	<p>A017 - Knowledge, Attitude and Associated factors towards end of life care among nurses' working in Amhara Referral Hospitals, Northwest Ethiopia: A Cross-sectional study <i>Addisu Taye Abate, Ethiopia</i></p>	<p>A052: Integrating palliative care to community health care <i>Barbra Dirikwe, Zimbabwe</i></p>

# 6th International African Palliative Care Conference

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

## TIME: 15.40 – 16.00

Time	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> <b>Station No.1</b> <b>Facilitator:</b> <i>Mhoira Leng, Uganda</i>	<b>TRACK 2</b> <i>Palliative Care in Universal Health Coverage</i> <b>Station No.2</b> <b>Facilitator:</b> <i>David Musyoki, Kenya</i>	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> <b>Station No.3</b> <b>Facilitator:</b> <i>Ruth Wooldridge, UK</i>	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> <b>Station No.4</b> <b>Facilitator:</b> <i>Vincent Karamuka, Rwanda</i>
15.40 – 15.45	D040: Development and implementation of a novel introductory training course to strengthen community workers perspectives on palliative care <i>Monowara Gani, UK</i>	A141: The profile of cancer patients admitted in Palliative Care programme at Kibogora Hospital in Rwanda <i>Ndahimana Paul, Rwanda</i>	Significance of family support to improve quality of life for patients in palliative care and to strengthen palliative care program in Rwanda <i>Nisingizwe Philemon, Rwanda</i>	A012: In precariousness, think differently about palliative care <i>Regine ROCHE, Rwanda</i>
15.45 – 15.50	A027: Experience of the pain free hospital initiative in Butabika National Referral Mental Hospital In Uganda. <i>Nyegenye Justine, Uganda</i>	A051: Palliative Care Surveillance in Uganda: Using mHealth technology for Palliative Care data collection and management. Cynthia <i>Kabagambe, Uganda</i>	A058: Experiences of Home-based Caregivers of Advanced Cancer Patients from a Regional Faith-based palliative Care Center in Kenya <i>Faith Lelei-Mailu, Kenya</i>	<b>A102:</b> The vital impact of Music Therapy in people with long term and life threatening health problems <i>Luther Kaigarula, Tanzania</i>

Thursday 19<sup>th</sup> September 2019

**TIME: 13.20 – 13.50**

Time	<b>TRACK 1</b> <i>Palliative Care in Universal Health Coverage</i> <b>Station No.1</b> <b>Facilitator:</b> Dr Fred Amegashie, Liberia; Scrimgeour Elizabeth, South Africa	<b>TRACK 2</b> <i>Strategic Advocacy for Palliative Care in UHC</i> <b>Station No.2</b> <b>Facilitator:</b> Penny Makruetsa, Botswana; Edson Rwagasore Rwanda	<b>TRACK 3</b> <i>Health Financing and Palliative Care</i> <b>Station No.3</b> <b>Facilitator:</b> Dr Karen Groves, UK; Eric Kabisa, Rwanda	<b>TRACK 4</b> <i>Effective Partnerships and Collaborations in Enhancing Access to Palliative Care as a Component of UHC</i> <b>Station No.4</b> <b>Facilitator:</b> Denise Mortlock, eSwatini; Paul Mmbando, Tanzania
<b>13.20 – 13.25</b>	A152: Prevalence and factors associated with domestic violence among palliative care patients: A systematic review  <i>Fatia Kiyange &amp; Colette Cunningham, Uganda/ Ireland</i>	A028: Clinical experience in improving quality of life to patient with fungating malignant wounds.  <i>Caren Kasera, Kenya</i>	A104: Diagnostic and Prognostic Awareness Amongst Caregivers and Women with Metastatic Breast Cancer in Kampala, Uganda: A Qualitative Analysis.  <i>Dr Jack Turyahikayo, Uganda</i>	A038: Barriers to accessing Oral Morphine for palliative care patients in district hospital in Malawi  <i>Mr. Patrick Phiri, Malawi</i>
<b>13.25 – 13.30</b>	A040: The Seven Safe Staircase Exercises (3SE): A manual for Sexually Abused Chronically ill patients  <i>Elvis Joseph Miti, Tanzania</i>	A053: Prosthetics and Orthotics in palliative care  <i>Emmanuel Mayakah Onduso, Kenya</i>	A076: What has been the impact of the Ugandan Palliative Care Leadership Programme eighteen months following completion?  <i>Downing Julia et al, Uganda/UK</i>	A144: An Evaluation of the Patient Dignity Question in Three Palliative Care Settings  <i>Allison Chabassol, Dr Robin Fainsinger, Dr Cheryl Nekolaichuk, &amp; Ms Viki Muller, Canada</i>
<b>13.35 – 13.40</b>	A113: Factors associated with preferred and actual place of death of terminally ill cancer patients in South Africa  <i>Charmaine Blanchard, South Africa</i>	A007: Palliative care and obstacles in a private hospital in Nigeria.  <i>Olusanya Abiodun, Nigeria</i>	A123: Caregiving of Persons with life limiting illnesses in Gaborone, Botswana: Challenges in meeting Dietary needs  <i>Miriam Sebegu; Fungai M. Mthombeni; Maria S. Nnyepi, Botswana</i>	A077: Development and feasibility testing of a novel community-based enhanced care intervention (ECI) to improve person-centred outcomes for people living with HIV/AIDS in Ghana  <i>Mary Abbooh-Offei, UK</i>

## 6th International African Palliative Care Conference

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

<b>13.45 – 13.50</b>	A032: Cultural Beliefs and Practice Toward End Of Life Cancer in Hausa/Fulani and Kanuri People living in some selected part of Northern part of Nigeria <i>Datti Alfa Saidu, Nigeria</i>	A057: Improved access to palliative care services and health outcomes as a component of UHC at Island Hospice & Healthcare Bulawayo branch <i>Busisiwe B. Mashiri, Zimbabwe</i>	A111: Palliative Care and Medical Anthropology: Researching palliative care service provision in a Tanzanian cancer hospital <i>Andrea Buhi, Tanzania</i>	B002: Raising Palliative Care Awareness for Children and NCD patients <i>Ddungu Davis Joel, Uganda</i>
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## Social Programme

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### MINISTERIAL DINNER

DATE Tuesday 17<sup>th</sup>  
 TIME 18:30  
 INVITED GUESTS. ONLY

### FUNDRAISING GALA DINNER

DATE Thursday 19<sup>th</sup>  
 TIME 19:30  
 PLACE Lemigo Hotel  
 DRESS CODE Traditional or Formal  
 GUEST SPEAKER Dr Stephen Watiti from Uganda

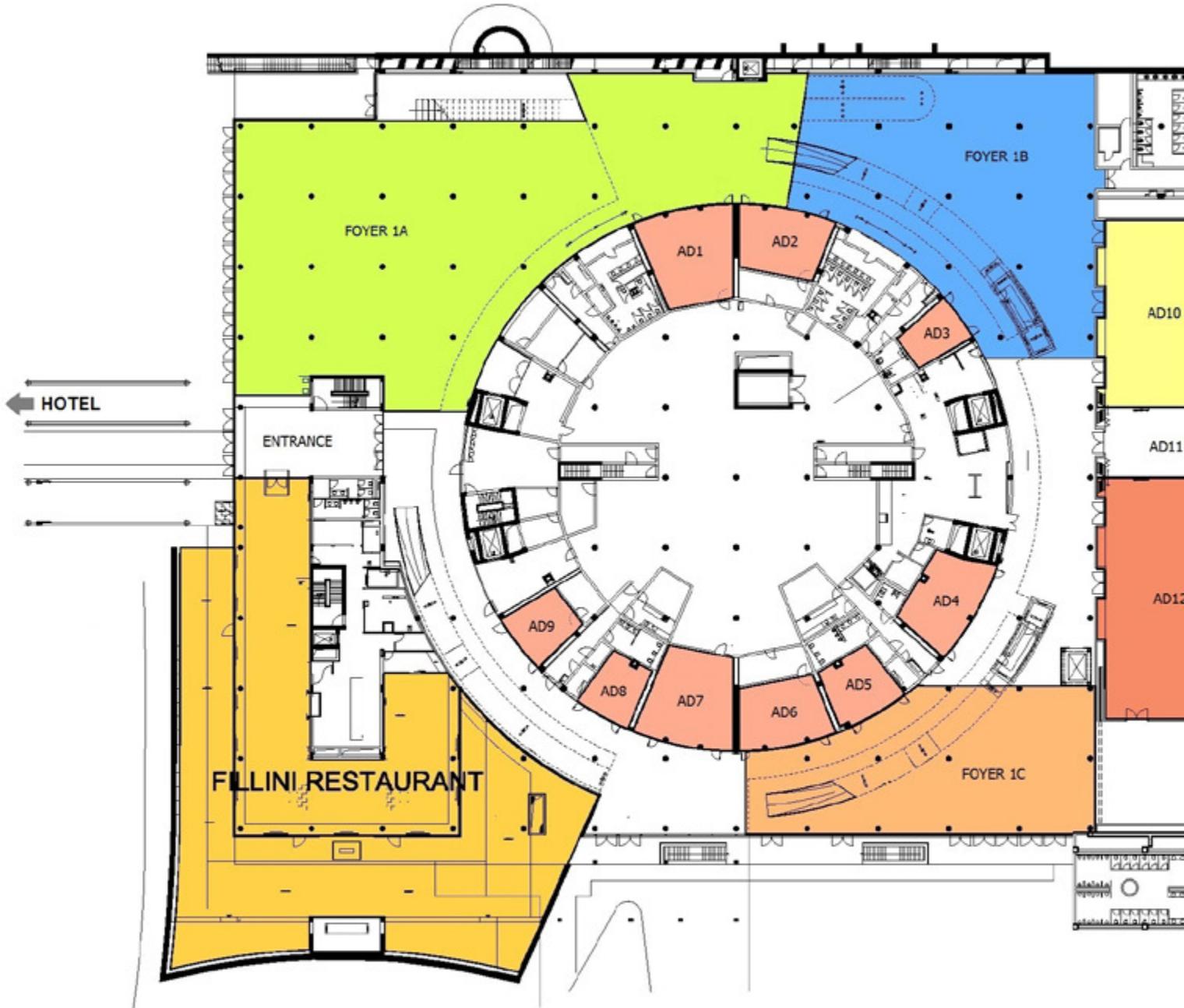
*Conference delegates are invited to take part in the gala dinner to celebrate all that has been achieved at the conference. Entertainment will include the Inganzo Ngari Cultural Troupe and a local DJ.*

## INGANZO NGARI CULTURAL TROUPE

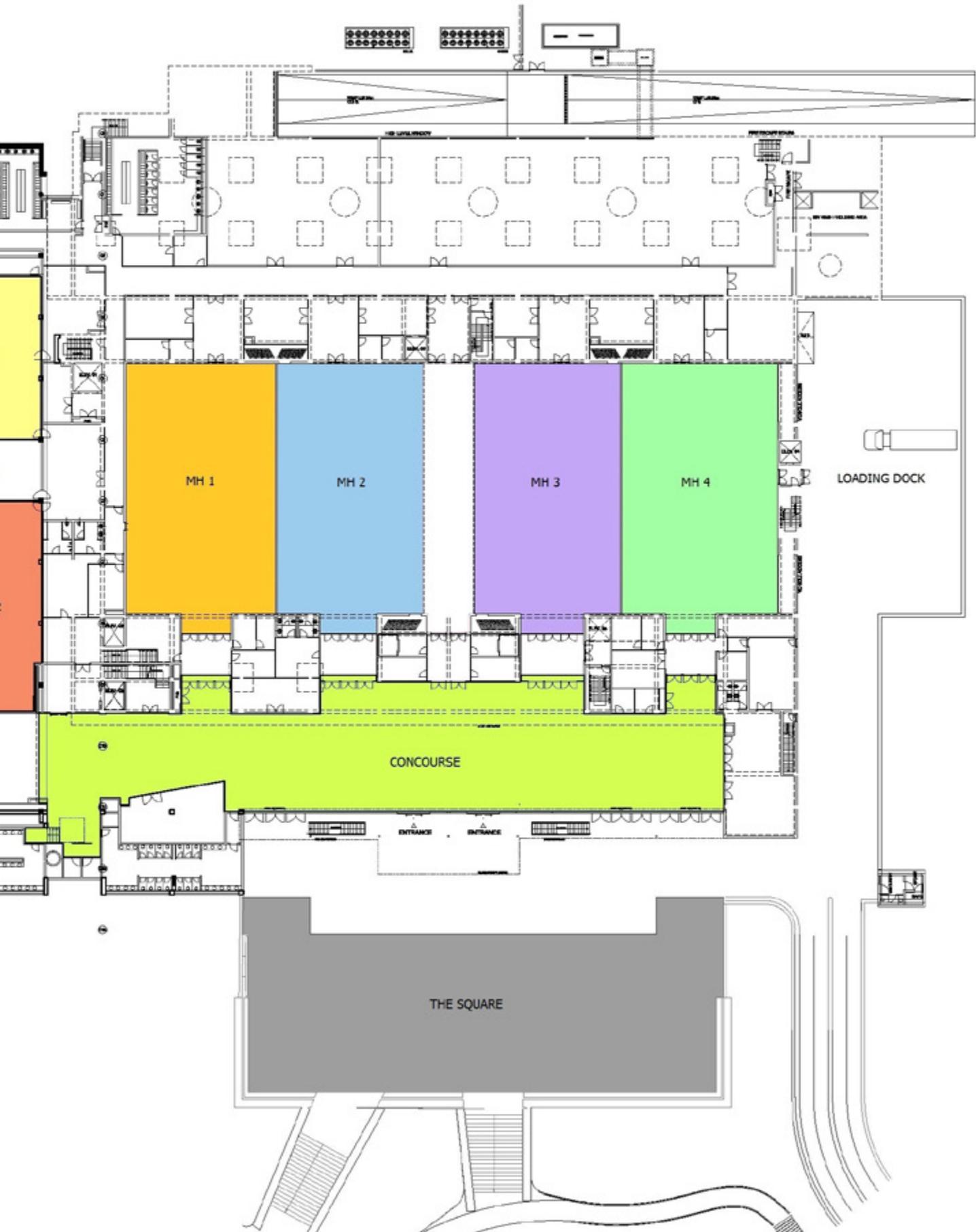
INGANZO NGARI is a statutory traditional dance troupe that was created in 2006. The main purpose of its creation was to promote the Rwandan folkloric dance among the youth and their welfare through art. Since its creation, INGANZO NGARI officially reigns as the best of the existing troupes, and this accreditation is done through a series of competitions and evaluation by competent bodies. This prize list has recognition on the professional scene where the troupe is regarded as professional and talented group. And among the Rwandan community, INGANZO NGARI has already left footprints and has become the favourite troupe. Moreover, just some time after its creation, INGANZO NGARI started enjoying international podiums where it emerged as the best world folkloric dance troupe, during its participation in the International Folkloric Festival of Mallorca in Spain (2009), South Africa, Turkey(twice), Singapore, Russia, Nigeria, Gabon and more and more African countries.

<https://www.inganzongari.com>

CONVENTION CENTER



# CC. EXTENSION BUILDING



# PLENARY SPEAKERS: Biographical sketches and abstracts



## WEDNESDAY 18<sup>TH</sup> SEPTEMBER 2019



**DR EMMANUEL LUYIRIKA**

*Executive Director, African Palliative Care Association*

**08.00–08.25**

### WELCOME REMARKS & PRESENTATION OF THE EAST AFRICAN DOCUMENTARY OF PALLIATIVE CARE

Dr Luyirika is Executive Director of the African Palliative Care Association a pan-African palliative care organization. He is board member of the World Hospice Palliative Care Alliance, President of CoRSU Hospital in Uganda a charitable rehabilitation and plastic surgery service for children and adults with disability. He is also serving on a committee of the American Academy of Sciences, Engineering and Medicine.

Previously, he was clinical and country director of Mildmay International in Uganda, worked for the Department of Health in South Africa and lectured in Family Medicine at the Medical University of Southern Africa. He was involved on the Lancet Commission on Global Access to Palliative Care and Pain medicines. Over the last 17 years he has served on several technical committees at Ministry Of Health Uganda, Uganda AIDS Commission, WHO, UNICEF and UNAIDS and as Vice Chairperson of the Council of the Institute of Hospice and Palliative Care in Africa. He has also been part of International Atomic Energy Agency/WHO ImPACT missions to countries.

He studied medicine at Makerere University, Family Medicine at Medical University of Southern Africa, Public Policy, Policy Informatics and Management at the University of Stellenbosch in South Africa and HIV at the University of Witwatersrand.

He has been an investigator and published on several HIV, cancer and palliative care research projects and served on several Data Safety Monitoring Boards and technical steering committees of research trials in Africa. He has been a co-author of several chapters in cancer and palliative care books.



**DR GITHINJI GITAHI**

*MBS, Global Chief Executive Officer, Amref Health Africa*

**08.25– 08.40**

### WHAT IS UNIVERSAL HEALTH COVERAGE AND WHY WE NEED IT IN AFRICA

A passionate advocate for a pro-poor Universal Health Coverage, Githinji Gitahi joined Amref Health Africa as the Group Chief Executive Officer in June 2015. Amref Health Africa, founded in 1957, is the largest African-led international organization on the continent and reaches more than 11 million people each year through 150 health-focused projects across 35 countries.

Until his appointment to Amref Health Africa, Dr Gitahi was the Vice President and Regional Director for Africa, Smile Train International. Prior to that, Dr Gitahi was Managing Director for Monitor Publications in Uganda as well as General Manager for Marketing and Circulation in East Africa for the Nation Media Group. He held progressively senior positions at GlaxoSmithKline and worked at the Avenue Group and in the insurance industry.

Dr Gitahi is Co-Chair of the UHC2030 Steering Committee, a global World Bank and World Health Organization (WHO) initiative for Universal Health Coverage (UHC). He is also a member of the Private Sector Advisory Board of Africa CDC, the Global Health Investment Advisory Board, and of the World Health Organization's Community Health Worker Hub. He is member of the Board of Directors of The Standard Group and holds Board member positions across Amref Health Africa offices in Africa. Dr Gitahi has a Doctor of Medicine from the University of Nairobi; a Master's in Business Administration, majoring in Marketing, from United States International University and has a Certificate for Strategic Perspectives for Nonprofit Management from Harvard University.

Dr Githinji was recently issued the Moran of the Order of the Burning Spear (MBS), a presidential commendation given to recipients on the advice of the National Honours and Awards Committee in the Office of the President.

The President issued Dr Githinji the state commendation in recognition of outstanding contribution to the health sector at the helm of Amref Health Africa. Dr Githinji has been instrumental in promoting primary health care that is the core of Amref Health Africa's work across the country.

## WEDNESDAY 18<sup>TH</sup> SEPTEMBER 2019



### DR LIZ GWYTHER

*Assoc Prof Liz Gwyther, convener programmes in palliative medicine, Faculty of Health Sciences, University of Cape Town, South Africa*

**08.40–08.55**

### PALLIATIVE CARE AND ACCESS TO PAIN RELIEF – A HUMAN RIGHTS ISSUE

Prof Liz Gwyther has postgraduate qualifications in Family Practice and Palliative Medicine. She is Associate Professor of Palliative Medicine in the School of Public Health and Family Medicine at the University of Cape Town. She is the convener for the postgraduate programmes in Palliative Medicine and is responsible for research supervision and support for publications of the postgraduate students.

Liz was previously CEO of Hospice Palliative Care Association of South Africa; and is a director of the following organisations - African Palliative Care Association, ehospice and Pain Society of South Africa. She is the immediate past-chair of the Worldwide Hospice Palliative Care Alliance.

In 2007, she was awarded the SA Medical Association's Gender Award for Human Rights in Health and the SA Institute of Health Managers Leadership in Health Systems award.



### DR. ERIC L. KRAUKER

*Director, Global Palliative Care Program / Physician, Division of Palliative Care & Geriatrics, Massachusetts General Hospital; Assoc Professor of Medicine and of Global Health & Social Medicine, Harvard Medical School/Consultant, WHO*

**08.55–09.10**

### PALLIATIVE CARE AND ACHIEVING UNIVERSAL HEALTH COVERAGE AND THE ESSENTIAL PACKAGE

Eric L. Krakauer, MD, PhD, is Associate Professor of Medicine and of Global Health & Social Medicine at Harvard Medical School and a practicing palliative medicine specialist at Massachusetts General Hospital where he also directs the Global Palliative Care Program. In 2016-2017, he served as Medical Officer for Palliative Care at WHO headquarters in Switzerland. In this capacity, he edited WHO manuals on integrating palliative care into primary health care, into pediatrics, and into responses to humanitarian crises. He also has served on the Lancet Commission on Global Access to Palliative Care, on the Board of Directors of the International Association for Hospice & Palliative Care (IAHPC), and as a visiting medical staff member of the Kigali University Teaching Hospital (CHUK) in Rwanda. Currently, he is a consultant in palliative care for WHO and Honorary Chair of the Department of Palliative Care at the University of Medicine & Pharmacy at Ho Chi Minh City, Vietnam.

## PALLIATIVE CARE BENEFICIARIES – KENYA, UGANDA, RWANDA

**09.10-09.40**

### OUR NEEDS AND HOW HEALTH SYSTEMS CAN ADDRESS THEM THROUGH UNIVERSAL HEALTH COVERAGE

1. Suzanne Macharia, JM Kariuki Hospital, Nyandarua County, Kenya
2. Mukankomayombi Charirotte, Rwanda Palliative Care and Hospice Organization(RPCHO), Rwanda
3. Balikomyeeyo Sebastian OBODHA, Rays of Hospice Jinja, Uganda
4. Dr Amandua Jacinto, Palliative Care Association of Uganda
5. Dr Stephen Watiti, Uganda

**WEDNESDAY 18<sup>TH</sup> SEPTEMBER 2019**

**WORLD HEALTH ORGANIZATION WHO COUNTRY OFFICE, RWANDA**

**09.40–09.50**

REMARKS ON PALLIATIVE CARE, AN ESSENTIAL HEALTH SERVICE  
IN UNIVERSAL HEALTH COVERAGE AND INVITATION OF THE  
REPRESENTATIVE OF WHO REGIONAL OFFICE FOR AFRICA



**PROF JEAN-MARIE DANGOU**

*MD, Coordinator, NCD Prevention Programme, WHO Regional Office for Africa*

**09.50–10.00**

OPENING ADDRESS – THE STATE OF UHC AND THE INCLUSION  
OF PALLIATIVE CARE AND OTHER ESSENTIAL SERVICES

Jean-Marie Dangou has an international reputation for his work in Noncommunicable diseases (NCDs) and cancer in particular. He became the Regional Advisor for Cancer Prevention and Control at the WHO Regional Office for Africa in July 2007, and later on the Team Lead for the NCDs Integrated Management programme and, Coordinator of the NCDs Primary Prevention Programme Area. Jean-Marie worked as WHO Representative in Zambia, in Guinea and in The Gambia.

Before joining WHO, Professor Dangou held various positions on the academia and the Ministry of health of Senegal. Jean-Marie developed and implemented at the Ministry of Health of Senegal a national cancer control programme. For more than 20 years, Professor Dangou was the Head of the Pathology department at Grand-Yoff General Teaching Hospital in Dakar (Senegal) and at the Dakar Pasteur Institute. Jean-Marie teaches Health Sciences at the Faculty of Medicine of C. Anta Diop University of Dakar, and he participated in research activities. He is member for several medical societies and he has been Vice-President for Africa at the International Academy of Pathology (IAP) and President of the African French Speaking Division of the IAP. He has membership of editorial board for medical journals, and published at least 90 articles on different topics including cancer and for more than 80% of them in peer-reviewed journals.

Jean-Marie is a Medical Doctor, specialized in Histopathology, Cytology and Cytogenetic and, in Epidemiology. He received his training at the Free University of Brussels (Belgium), at the University of Bordeaux II (France) and, at the University C. Anta Diop of Dakar (Senegal). Among other, Jean-Marie undertook professional training and continuing education in different domains such as Cancer diagnosis, Cancer epidemiology and surveillance, Ultra structural pathology, Cytogenetic and antenatal diagnosis, Pedagogy including e-learning, Research methodology, Epidemiology, Communications, Global Health Diplomacy, Leadership and Management.



**DR MARIE-CHARLOTTE BOUËSSEAU**

*Director & Adviser, Integrated Health Services, Division of UHC and Life Course, World Health Organization, Geneva*

**09.50–10.00**

KEYNOTE ADDRESS – PALLIATIVE CARE, A KEY COMPONENT  
OF UNIVERSAL HEALTH COVERAGE

Marie-Charlotte Bouésseau, after receiving her Doctor of Medicine degree from Paris University, practiced cardiology in France for several years before undertaking postgraduate studies in epidemiology, social sciences and philosophy in France and Chile. Since 1995, her activities have been wholly focused on questions of bioethics and global public health. Until October 2002, she worked in Chile, where she took part in several projects of co-operation with Chilean institutions: at the request of the Chilean Government she set up a Bioethics Unit in the Ministry of Health.

In November 2002 Dr. Bouésseau joined the World Health Organization in Geneva for the creation of the Ethics and Health Unit established by the Director General. She led the activities of this team over a period of six years and coordinated numerous projects in the field of public health ethics and research ethics, especially in low- and middle-income countries, in close collaboration with the three levels of the organization, with the Global Network of WHO Collaborating Centers for Bioethics and with a number of other international organizations active in that field. In May 2013, she was asked to work with the WHO Department of Integrated Health Services, she contributes to a number of projects across programs with a focus on integrated people centered care. She leads the work on integrated palliative care and recently coordinated the publication of a series of guides aiming to strengthen palliative care services in countries (more information is available in <https://www.who.int/palliativecare/en/> )

## WEDNESDAY 18<sup>TH</sup> SEPTEMBER 2019



**DR SABIN NSANZIMANA**

*Director General, Rwanda Biomedical Center*

**10.15–10.25**

### REMARKS ON RWANDA'S PROGRESS ON THE 2014 WORLD HEALTH ASSEMBLY RESOLUTION ON PALLIATIVE CARE

Dr. Sabin is a Physician epidemiologist. He studied medicine and holds a Master degree in Clinical Epidemiology from the University of Rwanda and Doctor of Philosophy in Epidemiology from University of Basel, Switzerland.

Currently he serves as the Director General of Rwanda Biomedical Centre (RBC), the implementing entity of Rwanda Ministry of Health. He led the HIV and Hepatitis Division at RBC for over 8 years with an extensive experience in HIV program design, strategic planning, implementation, operational research with focus on global care and treatment of people living with HIV. Dr Sabin served as Principal Investigator for several large research projects including clinical trials in Rwanda and multi-country research collaboration. He recently studied analytically HIV diagnosis, linkage, retention and multidrug experienced patients in entire Rwanda national HIV program for over 2 decades.

He has served on several HIV guidelines development group panels of the World Health Organization. He is a peer reviewer for scientific journals and has published extensively on HIV, STI, TB, Viral Hepatitis and cancer in Rwanda and globally. Dr Sabin is a fellow at the African Scientific Institute (ASI) and serves as adjunct Assistant Professor of global health delivery at the University of Global Health Equity (UGHE) in Kigali, Rwanda.



**DR DIANE GASHUMBA**

*Minister of Health, Republic of Rwanda*

**10.25–10.40**

### OFFICIAL OPENING OF THE CONFERENCE

Dr. Diane Gashumba is the Minister of Health in the Republic of Rwanda and has been since October 4, 2016. Prior to this position, she served as the Minister of Gender and Family Promotion from March 29, 2016. Minister Gashumba is a pediatrician by profession bringing 17 years' experience in global maternal, new-born and child health with a focus on gender issues. She worked with USAID funded Rwanda Family Health Project as Senior Team leader for quality and as Deputy Chief of Party focusing on improving the quality of and access to services in Maternal, Child and New Born Health, Family Planning, Reproductive Health, HIV, Nutrition, Malaria, and Gender Equality.

Dr. Gashumba has a strong background in management and clinical experience especially in managing maternal, newborn and child health programs, including 3 years as Director of Hospital. As a strategist at building capacity and improving quality within the Rwandan Health system, she has led the design and implementation of the baseline assessment and midterm evaluation of the quality of Maternal Newborn and Child Health care in 2015 and participated to various surveys and abstracts, such as the health-seeking behaviors of pregnant women, Immunitum study, integration of HIV services into MCH, and assessment of available equipment in health facilities in Rwanda

## THURSDAY 19<sup>TH</sup> SEPTEMBER 2019



### DR HAKIBA SOLANGE

*Deputy Director General Benefits, Rwanda Social Security Board*

**08.00–08.30**

#### HEALTHCARE FINANCING AND THE INCLUSION OF PALLIATIVE CARE IN NATIONAL HEALTH INSURANCE – LESSONS FROM RWANDA

Dr. Hakiba Solange is the Deputy Director General in charge of Social Security Benefits in the Rwanda Social Security Board. As such, she strategically manages 5 schemes among which the Old-age pension scheme and two health insurance schemes respectively designed for the formal sector (enrolling both public and private sectors) and the informal sector (community-based health insurance). She also serves as the current Chairperson for the national Rwanda Health Insurance Association and Advisory Board Member of the International Decision Support Initiative (iDSI), a global network of health, policy and economic expertise working to achieve UHC and SDG3.

Prior to this, Dr Hakiba served as the Permanent Secretary in the Ministry of Health and Chief Budget Manager for the national health sector.

Her experience spans from policy and strategy development in government and international organizations leadership positions, in addition to working for/with Civil Society organizations operating in health and women/ girls empowerment.



### DR ANN BERGER MSN MD

*Chief Pain and Palliative Care, National Institutes of Health Bethesda, Maryland, USA*

**08.30–08.55**

#### THE POTENTIAL OF HEALTH RESEARCH IN INFORMING THE INTEGRATION OF PALLIATIVE CARE INTO HEALTH SYSTEMS AND UHC

Dr Ann Berger is the Chief of the Pain and Palliative Care at the National Institutes of Health Clinical Center, Bethesda, Maryland in USA. Here she has clinical, teaching, research and administrative responsibilities. She is a specialist in Pain Management, Hospice and Palliative Care. Dr. Berger coordinates a very successful hospice and palliative care fellowship at the NIH clinical center.

Dr. Berger earned her undergraduate degree, a B.S. in nursing, from New York University, followed by an M.S.N. in oncology nursing from University of Pennsylvania. After working as an oncology clinical nurse specialist for several years, she completed her medical training at Medical College of Ohio in Toledo. Dr. Berger next did an internship and residency at Hartford Hospital in Connecticut and a fellowship in medical oncology and pain/palliative care at Yale University in Connecticut.

As an assistant professor in medicine and anesthesiology at Yale, Dr. Berger started a palliative care service. Dr. Berger founded her second successful palliative care service while serving as an assistant professor in medicine and anesthesiology at Cooper Hospital/University Medicine and Dentistry in New Jersey. During her four-year tenure there, her service was actively involved in the care of patients and in education and research. She initiated a palliative care course for medical students, residents and fellows and also used her expertise while chairing the ethics committee.

In addition, Dr. Berger served as medical director of Lighthouse Hospice and as director of supportive care services at Cooper Hospital/University Medicine and Dentistry in New Jersey. During this time she received two grants as project director of a pain and palliative care scholars program and as project director for a project designed to develop pain/palliative care teams in New Jersey long-term care facilities.

Internationally, Dr. Berger has been involved with the NCI All-Ireland fatigue consortium, the NCI Croatian Cancer Consortium and the Mideast Cancer Consortium teaching palliative care in multiple different countries in the world. Dr. Berger has recently developed the new innovative NIH-HEALS which measures psychosocial spiritual healing of individuals with life threatening and life challenging situations. Dr. Berger has both published and lectured extensively in the field of pain and palliative care.

She has more than 40 select publications in books and journals. She also has several honors and awards in the field of palliative care.

## THURSDAY 19<sup>TH</sup> SEPTEMBER 2019



**MR DERMOTT MCDONALD**

*Health and palliative care financing Consultant:*

**08.55-09.20**

**GLOBAL HEALTH FINANCING LANDSCAPE AND OPPORTUNITIES AND MECHANISMS FOR POSITIONING OF CIVIL SOCIETY ORGANISATIONS IN AFRICA TO ACCESS FUNDING**

Dermott, is a Netherlands-based fundraising consultant and has worked in the international NGO sector since 2001, specialising in institutional funding. Previously an NGO senior manager, he has worked in partnership with a range of donors including USAID, DFID, EU and European donors and led institutional funding teams for a number of INGOs including VSO and Trocaire. He is now a consultant working with a wide range of INGOs on funding matters. He has substantial experience of applying for grant and contract funding from institutional donors, foundations and corporates. As a consultant Dermott has worked with over 20 NGOs, ranging from smaller organisations to large NGOs such as BRAC and War Child. He has undertaken a range of donor research assignments for clients, including mapping donor trends and analysis of strategic implications for fundraising and organisational development.

Dermott has particular development expertise (programme design and funding), in HIV, SRHR, key population health access (in Africa and Eastern Europe), UHC and palliative care. Since 2006 he has supported the international and African palliative care NGO sector including grant funding success with Mildmay International and WHPCA.

### PANEL DISCUSSION – HEALTH DEVELOPMENT PARTNERS

**09.20–09.55**

**GLOBAL HEALTH FINANCING LANDSCAPE AND OPPORTUNITIES FOR LEVERAGING RESOURCES FOR PALLIATIVECARE AND OTHER ESSENTIAL HEALTH SERVICES IN AFRICA.**

1. Open Society Foundations, USA,
2. Open Society Initiative for Eastern Africa,
3. USAID, Rwanda,
4. World Bank, Rwanda,
5. DFID, Rwanda,
6. CDC, Rwanda,
7. ENABEL, Rwanda,
8. Partners In Health, Rwanda,
9. CHAI, Rwanda

## THURSDAY 19<sup>TH</sup> SEPTEMBER 2019

### PANEL DISCUSSION – REGIONAL HEALTH, POLITICAL AND ECONOMIC INSTITUTIONS

**09.50-10.15**

THE ROLE OF REGIONAL BODIES IN ACHIEVING UHC IN AFRICA



#### RT. HON. NGOGA K. MARTIN

*Speaker, East African Legislative Assembly (EALA)*

The Rt. Hon Ngoga was elected the Speaker of EALA in December 2017.

Prior to his election, Rt Hon Ngoga served in the 3rd Assembly. He was previously Prosecutor General in Republic of Rwanda. In May this year, Rt Hon Ngoga added another feather to the cap when he was elected and confirmed by the congress of the global football body as deputy Chairman of the FIFA Ethics Committee in charge of investigatory chamber for a four-year term. The independent Ethics Committee is one of FIFA's judicial bodies primarily responsible for investigating possible infringements of the FIFA Code of Ethics.

The East African Legislative Assembly (EALA) is the Legislative Organ of the Community and has a cardinal function to further EAC objectives, through its Legislative, Representative and Oversight mandate. It was established in 2001 under Article 9 of the Treaty for the Establishment of the East African Community.

1. East African Health Research Commission of the East African Community
2. East African Community
3. West African Health Organisation of ECOWAS
4. WHO Regional Office for Africa (Bio earlier presented)
5. African Union Commission
6. The East, Central and Southern African Health Community (ECSA-HC)

### THE TRUE COLOURS TRUST, UK

**10.15–10.30**

CELEBRATING THE WORK OF THE SMALL

#### LUCY SAINSBURY

Lucy is the Founder and Chair of Trustees of the True Colours Trust.

The True Colours Trust is an independent grant-making trust based in London, UK. It was founded in 2001 to improve access to palliative care and pain relief in sub Saharan Africa and the UK. Each year the trustees approve grants to the value of approximately 2 million GBP.

As Chair, Lucy and her fellow trustees are responsible for True Colours' vision and overall direction; they set strategy, review proposals and approve grants. Lucy is a Special Educational Needs teacher by profession and has worked in a number of educational and health settings and has taught children with profound and multiple disabilities and palliative care needs.

## THURSDAY 19<sup>TH</sup> SEPTEMBER 2019

### JO ECCLESTONE FORD

Jo Ecclestone Ford is the Lead Executive at the True Colours Trust.

The True Colours Trust is an independent grant-making trust based in London, UK. It was founded in 2001 to improve access to palliative care and pain relief in sub Saharan Africa and the UK. Each year the trustees approve grants to the value of approximately 2 million GBP.

Jo advises the trustees on their strategy and grant making in the UK and sub Saharan Africa and has led True Colours' grant making team since 2011. Jo has been part of the Executive Team of the True Colours Trust, and its affiliated Trusts, since 2005. She has advised several of the Trusts on their global and domestic grant making. Before joining the team, Jo worked at the BBC's department of Political and Parliamentary Affairs and the UK's Charities Advisories Trust.

## FRIDAY 20<sup>TH</sup> SEPTEMBER 2019



### H.E. ARCHBISHOP VINCENZO PAGLIA

*President of the Pontifical Academy for Life, Vatican*

**08.00–08.40**

### THE PAL-LIFE PROJECT ON THE DIFFUSION AND DEVELOPMENT OF PALLIATIVE CARE IN THE WORLD AND THE WHITE BOOK FOR PALLIATIVE CARE ADVOCACY

Vincenzo Paglia, an Italian Archbishop, served as parish priest in the Basilica of Santa Maria in Trastevere in Rome from 1982 to 2000; he was also the ecclesiastical assistant of the Community of Sant'Egidio and was the postulator of the cause of beatification of the Archbishop of San Salvador, Saint Oscar Romero. On 2 April 2000 he was ordained as Bishop of Terni Narni Amelia in the Cathedral of St. John Lateran. Since 2002, he is president of the International Catholic Biblical Federation and, from 2004 to 2009, he was also chairman of the Commission Ecumenism and Dialogue of the Italian Episcopal Conference.

For his work in peace he received, in 1999, the UNESCO's Gandhi Medal in 2003 the Mother Teresa Prize of Albanian Government. He also received the Ibrahim Rugova award from the Kosovo government and the "Noble Amigo" award from the Government of El Salvador. He has collaborated with the Department of Contemporary History at the Sapienza University of Rome and has published studies and articles on the social and religious history as well as on the history of poverty.

On 26 June 2012, Pope Benedict XVI elevated him to the dignity of archbishop and appointed him president of the Pontifical Council for the Family. On 17th August 2016 has been appointed President of the Pontifical Academy for Life and Grand Chancellor of the Pontifical John Paul II Institute for Studies on Marriage and the Family. On 4th October 2017 has been appointed member of Congregation for Evangelization of People and on 11th January member of Congregation for Causes of Saints. He is author of many books, commentaries of the Holy Scriptures and homilies.



**FRIDAY 20<sup>TH</sup> SEPTEMBER 2019**



**PROF. FREDRICK CHITE ASIRWA MD**  
*Head of Oncology Project, AMPATH*

**08.40–09.10**

**PARTNERSHIP AND COLLABORATION IN ACHIEVING UHC  
THAT IS INCLUSIVE OF PALLIATIVE CARE**

of. Chite is a Consultant Physician, a Medical Oncologist & Hematologist. He is the Director for International Cancer Institute & Blue-Print for Program Success in Eldoret, Kenya. The Institute has activities and programs with various partners in Sub-Saharan Africa. He is the Director of Blue-Print for Success Program which brings various implementing partners together to work on a Cancer project in Eldoret and Meru Counties in Kenya.

Prof. Chite was previously the Director of Academic Model Providing Access to Health Care (AMPATH) Oncology and Hematology Programs between 2011 to 2019. This is a consortium of a group of North American Universities (including University of Toronto, Brown University, Duke University, UCSF amongst others) led by Indiana University collaborating with Moi University and Moi Teaching and Referral Hospital in Eldoret, Kenya.

He brought to fruition, a functional tumor registry; assisted in the development of a Medical Oncology fellowship curriculum; gynecologic Oncology curriculum; developed Oncology curriculum for Physician assistants (Clinical Officers) at Moi Teaching and Referral Hospital; established an ongoing Multiple Myeloma program; Breast Cancer screening and treatment program; Hemophilia and Sickle cell diagnostics, treatment & patient registry; Electronic medical records for Oncology point of care encounters; assisted in the implementation of electronic breast and cervical cancer screening program, amongst many other research activities and interest. He conceptualized, developed and implemented Oncology Nursing training program at Moi Campus (started training its first class in 2016) in Kenya and a Fellowship program for Medical Oncology at Moi University's Department of Medicine (starting 2019), both in-country trainings.

He has had formal training in coagulation and benign hematologic disorders including hemophilia and sickle cell disorders which are endemic in sub-Saharan Africa. He underwent and successfully completed formal fellowship training at an NCI-Designated Cancer Center having completed his Internal Medicine in the United States and a 3-year Hematology-Oncology fellowship training at Indiana University.

He is presently a Principal Investigator (PI) on many program development and research grants. Prof. Chite is the PI for a multi-national Lung Cancer study (Kenya, South Africa, Tanzania and Swaziland). He is also currently the PI of a multi-year Breast and Cervical cancer control program, Sickle Cell & Hemophilia program, Lung cancer control program, Lymphoma program and Multiple Myeloma Program

**PANEL DISCUSSION NATIONAL PALLIATIVE CARE ASSOCIATIONS AND OTHER KEY PLAYERS**

**09.10 – 10.10**

**SUCCESSES, CHALLENGES AND LESSONS FOR  
ADVOCACY TOWARDS THE INTEGRATION AND  
IMPLEMENTATION OF PALLIATIVE CARE IN UHC**

## FRIDAY 20<sup>TH</sup> SEPTEMBER 2019



### **DR ZIPPORAH ALI MD**

*MPH, MPC, HonDUniv, CEO, Kenya Hospices and Palliative Care Association*

Dr Zipporah Ali is the Executive Director of Kenya Hospices and Palliative Care Association (KEHPCA). She serves on the board of several organizations including; International Children's Palliative Care Network (ICPCN), Worldwide Palliative Care Alliance (WHPCA) and eHospice, Kenya Network of Cancer Organizations (KENCO), Cancer Alliance Kenya and Alzheimer/Dementia Kenya. Dr. Ali is involved in advocacy and creating awareness on pain relief and palliative care in Kenya for children and adults. In her leadership role as the Executive Director for KEHPCA, she has been instrumental in fostering strong relationships with the Ministry of Health to integrate palliative care into government hospitals. She has also been instrumental in advocating for palliative care to be integrated in undergraduate medical and nursing schools in Kenya. She is a strong advocate for cancer prevention, control and treatment and was instrumental in developing the first National Cancer Control Strategy and the National Guidelines for Cancer Management-Kenya.

Dr. Ali holds an MD from Aegean University, Izmir, Turkey, and a Master's Degree in Public Health from the University of Nairobi, a Higher Diploma in Palliative Care from Oxford Brookes University and a Masters in Palliative Care from the University of Dundee. She has completed the International Pain Policy Fellow program with the International Pain Policy Studies Group (WHO Collaborating Centre for Policy and Communication in Cancer Care, University of Wisconsin) as well as Higher Diploma in the International Palliative Care Leadership Development Initiative at The Institute of Palliative Medicine at the San Diego Hospice.

Awards: June 2018: Doctor of Law Honoris Causa-University of Dundee; May 2018: International Humanitarian Award-Women4Africa; April 2018 - Social Impact Award for the Sub-Saharan Africa region-British Council; June 2012: Honorary Doctor of the University by Oxford Brookes University; September 2013: Individual Advocacy Award by the African Palliative Care Association and Open Society Foundations



### **MS ROSE KIWANUKA**

*Country Director Palliative Care Association of Uganda (PCAU)*

Rose Kiwanuka is the Country Director of PCAU, a position she has held since 2006. She was the first Ugandan palliative care nurse and worked in senior clinical and education roles at Hospice Africa Uganda for 15 years before moving to PCAU. In her education role at Hospice Africa Uganda, she supported the development of the Education department which evolved into the Institute of Hospice and Palliative care in Africa (IHPCA).

Rose holds a Bachelor's degree in Nursing from Aga Khan University, Kampala, Uganda; a Diploma in Business Administration from London Executive Business College UK; a Diploma in Palliative care with Makerere University through Hospice Africa Uganda; a clinical Diploma in Palliative care with the Institute of Hospice and Palliative care in Africa and a Diploma in Registered Nursing from St. Francis Nsambya School of Nursing and Midwifery in Kampala, Uganda.

Rose is a strong advocate for palliative care at all levels of the Ugandan health system. Through her role at PCAU, She has provided leadership for the development of palliative care services in more than 95 districts of Uganda, and the establishment of hospital palliative care teams in 13 Regional Referral Hospitals. She has special interest in education and training, mentorship and support supervision as a way to enhance the integration of palliative care into the health care system in Uganda. More recently she has provided leadership for the development and approval of a National Advanced Palliative care Nursing Diploma curriculum, under implementation by Mulago School of Nursing in Uganda.

Rose is a founding board member of Rays of Hope Hospice Jinja; a board member of Uganda Heart Institute; a council member for the Institute of Hospice and Palliative care in Africa; and advisor of Mbale Regional Referral Hospital Palliative Care program committee. She is a member of International Association of Hospices and Palliative Care (IAHPC) and a Rotarian.

**FRIDAY 20<sup>TH</sup> SEPTEMBER 2019**

**DR LIZ GWYTHYER,**  
*CEO, Hospice Palliative Care Association of South Africa*

Earlier presented.



**MS EUNICE GARANGANGA**  
*Director, Hospice Palliative Care Association of Zimbabwe*

A Technical Adviser and Health & Palliative Care Specialist with over 30 years of experience in palliative care. Currently, an Executive Director with Hospice and Palliative Care Association of Zimbabwe, a national body that promotes palliative care and supports palliative care providers in Zimbabwe. The position provides overall direction, leadership, organizational management, donor and financial oversight including participating in national, regional and international fora influencing palliative care landscape. A member of the core team that has supported Zimbabwe Ministry of Health and Child Care to develop a comprehensive framework for integrating palliative care into the whole health delivery system, including into the pre-service training curricula of key health workers.

For two years, has worked and built capacity of the legal fraternity to provide pro bono legal services to patients and families facing life threatening illnesses and empowering patients, families and communities on their rights. The work has seen families being assisted to access justice and creating awareness within communities and forming strong partnerships with Legal Aid Directorate, an arm of Ministry of Justice, law firms, Ministry of Health and palliative care organisations.



**DIANE MUKASAHAHA**  
*Rwanda Biomedical Center, Rwanda*

Diane is the National Coordinator of Palliative Care in Rwanda Biomedical Center (RBC) /Rwanda Ministry of Health. Before this, she served as Director of Mildmay, International in Rwanda for 4 years with a specific role of advocating for palliative care in Rwanda. She joined Mildmay after working for 2 years in the position of Team Leader of HIV Mobile Voluntary Counselling and Testing at CDC, Rwanda. She also served as the Executive Director of Palliative Care Association of Rwanda.

Diane is a qualified Nurse and Public Health and Health Promotional Specialist. She graduated at University of Manchester UK. She coordinated the development of the National Palliative Care Policy of Rwanda in 2011, which was the 1st African Palliative Care Policy. She has strongly advocated for local production of oral liquid morphine for pain relief in Rwanda, integration of palliative care into the existing health system and its inclusion in Community Insurance. She is the Founder Member of Capacitar - Rwanda, Founder of Rwanda Palliative Care and Hospice Organization (RPCHO), Member of International Childrens Palliative Care Network (ICPCN) and International Association for Hospice & Palliative care (IAHPC), Vice -President and founding Member of Rwanda Women Cancer Relief Foundation, Founding Member of Rwanda Catholic Palliative Care Initiative (RWACAPCI).

## FRIDAY 20<sup>TH</sup> SEPTEMBER 2019



### **DR PAUL MMBANDO**

*Health Program Director, Evangelical Lutheran Church of Tanzania*

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Dr Paul Zebadia Mmbando is a Health Programs Director and the Head of Palliative Care Program at the Evangelical Lutheran Church in Tanzania (ELCT) – the largest Palliative care program in Tanzania – with about 25 active hospital-based Palliative Care Programs mostly in the rural setting of Tanzania.

Dr Mmbando is a Medical Doctor with advanced training as a Palliative Care Physician and a Public Health Specialist. He has over 15 years' experience in health and palliative care programs management, as a researcher, a trainer and a strong advocate for increased access to opioids, palliative care and health services especially for patients in the rural and less privileged communities in Tanzania. As an advocate for increased access to health services, Dr Mmbando is also serving on UN platforms as the Delegate for Commission for Population and Development (UN-CPD) since 2017 – where he has been representing ACT Alliance.



### **MR LAMECK FRANK THAMBO**

*CEO, Palliative Care Association of Malawi*

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Lameck is the Executive Director of the Palliative Care Association of Malawi (PACAM) since 2008. He has provided leadership for advocacy towards the inclusion of palliative care in Malawi's health system. Through his leadership, a strong relationship exists between PACAM and the Ministry of Health in Malawi. The country has realized milestones through this partnership including the development and implementation of a National Palliative Care Policy; the development and implementation of a national palliative care package; establishment of a degree course in palliative care; the local reconstitution of oral liquid morphine for pain control and a national monitoring system for palliative care, among others.

Through his leadership and collaboration with the Ministry of Health in Malawi, more than 50 health facilities in Malawi, both Government and Faith Based are providing palliative care services.

Lameck holds a Master's of Public Health Degree from the University of Malawi, College of Medicine 2018; BSc Degree in Palliative Care, Makerere University, Kampala Uganda 2012; Diploma in Palliative Medicine, Oxford Brookes University, UK through Nairobi Hospice 2005 and a Diploma in Clinical Medicine, Malawi College of Health Sciences, Lilongwe 1998.

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### **DR EMMANUEL LUYIRIKA,**

*Executive Director, African Palliative Care Association*

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Bio earlier presented.

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**FRIDAY 20<sup>TH</sup> SEPTEMBER 2019**

**PANEL DISCUSSION GLOBAL & REGIONAL PALLIATIVE CARE BODIES**

**14.00–15.00**

**THE ROLE OF GLOBAL AND REGIONAL PALLIATIVE CARE BODIES IN ACHIEVING UHC AT COUNTRY LEVEL**



**DR JULIE LING**  
*European Association of Palliative Care*

Julie Ling is CEO of the European Association for Palliative Care (EAPC), which is based in Belgium. The EAPC is the leading palliative care organisation in Europe, representing 59 member associations from 33 countries and with individual members from 52 countries globally. Originally a nurse, Julie has worked in palliative care for the last 30 years in both adult and children's palliative care. She has held a variety of posts in clinical care, management, research, policy and the voluntary sector. She is currently Chair of the Worldwide Hospice and Palliative Care Alliance.



**DR EDNIN HAMZAH**  
*Asia Pacific Hospice Palliative Care Network*

Dr Ednin Hamzah is the current Chief Executive Director of Hospis Malaysia, the largest palliative care service provider in Malaysia. He graduated from the University of Newcastle upon Tyne, UK, in 1986 and worked in general medical practice until 1997 when he took the position of CEO / Medical Director of Hospis Malaysia.

Apart from his clinical role, he teaches palliative care at undergraduate and postgraduate levels at several universities and is a strong advocate for palliative care. He is active in teaching palliative care internationally and is the current Vice-Chair of the Asia Pacific Hospice Palliative Care Network as well as a board member of the Worldwide Hospice Palliative Care Alliance.



**DR STEPHEN R CONNOR**  
*Worldwide Hospice Palliative Care Alliance*

Dr Stephen R Connor is the Executive Director of the Worldwide Hospice Palliative Care Alliance (WHPCA), a global alliance of national and regional hospice and palliative care organisations advocating for hospice palliative care. He has worked in palliative care continuously for the past 40 years as a researcher, licensed clinical psychologist, consultant, author, educator, advocate and executive. He served for 11 years in the leadership of the National Hospice and Palliative Care Organization (United States) as vice-president for research and development, and now focuses on international palliative care development.

For the last 16 years Dr Connor has worked on global palliative care development in more than 25 countries in Eastern Europe, Asia and sub-Saharan Africa. He is a trustee of the International Children's Palliative Care Network, on the scientific advisory board of the (US) National Palliative Care Research Center, and is a member of the editorial board of Journal of Pain and Symptom Management. He has published more than 100 peer-reviewed journal articles, reviews, reports and book chapters on issues related to palliative care for patients and their families. He is the author of *Hospice: Practice, Pitfalls, and Promise* (1998) and *Hospice and Palliative Care: The Essential Guide* (2009), and is co-editor of the WHPCA/WHO Global Atlas of Palliative Care at the End-of-Life (201

## FRIDAY 20<sup>TH</sup> SEPTEMBER 2019



**DR PROF JULIA DOWNING**  
*CEO, International Children's Palliative Care Network*

Professor Downing is an experienced palliative care nurse, educationalist and researcher. She is the Chief Executive of the International Children's Palliative Care Network (ICPCN) and a Professor in Palliative Care at Makerere University, Uganda. She has extensive experience in research, presenting at conferences and writing for publication, and is on the editorial board of *ecancer*, *APM* and the *International Journal of Palliative Nursing* (IJPN). She has been working within palliative care for 28 years, with nineteen of those working internationally in Uganda, Africa, Eastern Europe and globally developing palliative care services for adults and children.

Professor Downing serves on the Boards of several NGOs including the International Association of Hospice and Palliative Care (IAHPC), the Worldwide Hospice and Palliative Care Alliance (WHPCA), the African Palliative Care Association UK, and the Palliative Care Research Society. She is a Visiting Professor at Edge Hill University and the University of South Wales in the UK and the University of Belgrade in Serbia. She is also a Senior Honorary Research Fellow with the Cicely Saunders Institute at King's College London, England. She was the recipient of the IJPN's Development Award in 2006, the Robert Tiffany lectureship from the ISNCC in 2014, the Pearl Moore "Making a Difference" International Award for Contributions to Cancer Care from the Oncology Nursing Society in 2015 and was recognised as one of eight 'Change Agents in Cancer Care' in a publication on Women as Change Agents in Oncology in 2016.

When not working in palliative care, Julia is a musician and is involved in running a music school in Kampala, and various local choirs and orchestras. She is also the Director of Music at her local church.



**JIM CLEARY, MD, FACHPM**  
*Professor of Medicine, Indiana University School of Medicine, Indianapolis, IN.  
Walther Senior Chair and Director of Supportive Oncology, IU Simon Cancer Center.*

A graduate of University of Adelaide Medical School, South Australia, Dr. Cleary trained in Internal Medicine and Medical Oncology at the Royal Adelaide Hospital followed by three years of opioid pharmacology research.

He moved to the University of Wisconsin-Madison in 1994, where he served as the founding Medical Director of the Palliative Care Clinical Program from 1996-2011. During that time, he also served as Program Director of Cancer Control at the UW Carbone Cancer Center, integrating palliative care into that program and as Chair of the UWCCC's Scientific Review Committee.

He was the 2004 President of the American Academy of Hospice and Palliative Medicine and serves as a North American Editor of *Palliative Medicine*, the Research Journal of the European Association of Palliative Care.

He was Director of the Pain and Policy Studies Group in 2011-2018 and co-lead the Global Opioid Policy Initiative that reviewed opioid availability in Africa, Asia, the Caribbean and Latin America, India, and the Middle East.

He was co-chair of the Breast Health Global Initiative (BHGI)'s resource stratified guidelines for Palliative Care and is currently a member of the WHO Cancer Pain Guideline Committee, the Lancet Commission on Palliative Care and is co-chair of ASCO's Resource-Stratified Guideline on Palliative Care. He was honored recently as one of 30 global Visionaries in Palliative care by the American Academy of Hospice and Palliative Care.

He retired from the UW in July, to commence work as Director of Supportive Oncology at the Indiana University Simon Cancer Center holding the Walther Senior Chair in Supportive Oncology.

## FRIDAY 20<sup>TH</sup> SEPTEMBER 2019

DR JULIA DOWNING & FATIA KIYANGE

**15.00–15.15**

SUMMARY OF DELIBERATIONS FROM THE 3RD  
MINISTERS OF HEALTH SESSION ON PALLIATIVE CARE  
OF 17TH SEPTEMBER 2019 & 6TH AFRICAN PALLIATIVE  
CARE CONFERENCE

**DR PROF JULIA DOWNING**

*CEO, International Children's Palliative Care Network*

Earlier presented.



**FATIA KIYANGE**

*African Palliative Care Association*

She is the Programmes Director at the African Palliative Care Association since 2010 and previously the Programmes Manager and Officer of the same organisation since 2005. She has worked in the area of palliative care and health for 18 years, including five years at Hospice Africa Uganda as the Education Administrator. Her role at APCA focuses on palliative care advocacy, policy development and implementation, education and training and programmes design and management. She works with a team of staff at APCA to deliver technical assistance to national and local partners across Africa, including ministries of health and national palliative care associations, among others.

Ms Kiyange is currently a member of the board of the Uganda Cancer Institute and member of the Advisory Committee of Global Partners in Care. She has previously served on several boards including: former president of the board of the Palliative Care Association of Uganda; member of International Trustees of the International Children's Palliative Care Network and Vice president of the National Executive Committee of the National Association of Social Workers of Uganda. Ms. Kiyange is a Public Health Specialist and Social Worker with a Masters of Public Health with University College Cork, Ireland and a Post Graduate Certificate in Health Protection with the same University. She also holds a Master's Degree in Social Sector Planning and Management of Makerere University, Kampala and a Bachelor of Arts Degree in Social Work and Social Administration of the same University.

## CONFERENCE CLOSING REMARKS

**15.15 15.45**

DR EMMANUEL LUYIRIKA, EXECUTIVE DIRECTOR,  
AFRICAN PALLIATIVE CARE ASSOCIATION; DR DIANE  
GASHUMBA, MINISTER OF HEALTH, REPUBLIC OF  
RWANDA

# ORAL PRESENTATIONS

## Break-away sessions



**WEDNESDAY 18<sup>TH</sup> SEPTEMBER 2019**

**TRACK 1: PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE**

**11.00 –11.10am**

**C010: M-PALLIATIVE CARE LINK: IMPROVING SYMPTOM CONTROL AND INFORMATION EXCHANGE AMONG SPECIALISTS AND LOCAL HEALTH WORKERS TREATING LATE-STAGE TANZANIAN CANCER PATIENTS**

*Prof Twalib Ngoma, Susan Miesfeldt, Elia Mmbaga, Mamsau Ngoma, Beatrice Mushi, Vikram Kumar, Habiba Mahuna, Ocean Road Cancer Institute, Tanzania*

**Email: [ngoma\\_tan@yahoo.com](mailto:ngoma_tan@yahoo.com)**

Technology can be utilised for progressive or deterring purposes. In Tanzania, steps are towards technology use to improve access to palliative care services. This presentation describes an innovative research on the use of technology to enhance patients' access to palliative care in Tanzania. The hypothesis is that since mobile phone use is ubiquitous in Tanzania, it can be used to improve access to high-quality palliative care by using a mobile device-based symptom assessment/control communication which links palliative care specialists to patients and caregivers to reduce symptom burden in late-stage cancer patients. This study is conducted in Dar es Salaam and the target is 'all-stage' cancer patients seen at Ocean Road Cancer Institute. The APCA POS was adapted and is used as a tool for patients and care givers using the patient's study-supplied mobile device. If found viable, this study will be scaled up as an approach which is sustainable and cost effective for use in patients with cancer and other chronic diseases.

**11.10–11.20am**

**D024: EVALUATION OF PATIENTS WITH PALLIATIVE CARE NEEDS PRESENTING AT THE EMERGENCY DEPARTMENT, UNIVERSITY COLLEGE HOSPITAL, IBADAN: A YEAR REVIEW**

*Dr E.B Olusoji, Dr. A.I Badru, Prof O.A Soyannwo, Prof S Amanor-Boadu, University College Hospital, Ibadan, Nigeria*

**Email: [euniceolusoji@gmail.com](mailto:euniceolusoji@gmail.com)**

Does the Emergency Department in your hospital effectively handle palliative care patients? This abstracts presents efforts of University College Hospital, Ibadan, Nigeria to study trends related to number of palliative care patients that report in the Emergency Department (ED) of this hospital and the extent to which optimal care is provided. Having patients with palliative care needs at the ED is inevitable although the numbers may reduce if palliative care is easily accessible at the community level. The study findings indicate that patients with palliative care needs who present to ED are not referred directly even if there is indication, and that more patients with non-cancer illnesses present at the ED than cancer patients. The recommendations of this study are: a) Health professionals in ED should be trained in basic palliative care so they can identify and meet the needs of patients with life-limiting illnesses, b) A comprehensive and coordinated palliative care referral system should be established especially in tertiary health settings to minimise the number of patients with palliative care needs being referred for curative management.

## 11.20–11.30am

### A065: EVALUATING THE ACCEPTABILITY AND FEASIBILITY OF ROUTINE USE OF VALIDATED CANCER SYMPTOM ASSESSMENT INSTRUMENTS AMONG PATIENTS AND NURSES IN THE ONCOLOGY WARD AT PRINCESS MARINA HOSPITAL, IN GABORONE, BOTSWANA

*Dr Norman Carl Swart, University of Botswana*

**Email: [swartn@ub.ac.bw](mailto:swartn@ub.ac.bw)**

Symptom burden negatively affects a large number of cancer patients' wellbeing globally. It is therefore important that nurses assess patients' symptom burden routinely through the use of validated symptom assessment instruments such as the Memorial Symptom Assessment Scale – Short Form (MSAS-SF) and the Visual Analogue Scales for Pain (VAS-P). This abstract presents an evaluation of 'acceptability and feasibility of oncology nurses using validated cancer symptom assessment instruments to assess the symptom burden of cancer patients in the oncology ward at Princess Marina Hospital in Gaborone, Botswana'. Data collection involved nurses, and cancer patients who consented to participate. The acceptability and feasibility results of this study provides the clinical and scientific rationale for the use of validated symptom assessment instruments as part of routine cancer nursing care in Botswana. This innovative study recommends that oncology nurses in an African context can integrate the MSAS-SF and VAS-P into routine clinical practice of assessing patients for symptom burden for quick referrals to symptom management experts, such as palliative care nurse practitioners and doctors.

## 11.30–11.40am

### A150: PALLIATIVE CARE IN MOZAMBIQUE: GENERAL KNOWLEDGE, ATTITUDES AND PHYSICIANS' PRACTICES IN BREAKING BAD NEWS AND END-OF-LIFE ISSUES

*Dr Emilia Pinto Miquidade, Mozambique, Maputo Central Hospital - Pain Unit, Mozambique*

**E-mail: [emiliapinto23@yahoo.com.br](mailto:emiliapinto23@yahoo.com.br)**

This abstract is based on a cross-sectional study to establish the general knowledge, attitudes, practices, breaking bad news and end-of-life issues among physicians from different departments in four hospitals in Mozambique. It was conducted between 08/2018 and 01/2019.

The median age was 38 years, 9 years of working experience. There was a predominance of females, resident physicians and surgery specialists; 83.8% answered that PC should be considered when patients can not be submitted to surgery, radiotherapy, chemotherapy or other anti-cancer therapies; 87.3% believed that early integration of PC can improve patients' quality of life; 72.7% informs the patient about the cancer's diagnosis; 50% knows what is a do-not-resuscitate order, and 51.3% know what palliative sedation is. But only 25% participants had correct answers for all general knowledge questions, and 24% knew all answers about euthanasia and related issues.

Mozambican physicians have insufficient knowledge toward palliative care and related issues. More interventions and training should be done.

## 11.55 – 12.05pm

### A097: THE PREVALENCE OF LIFE-LIMITING DISEASES AND THE NEED FOR PALLIATIVE CARE AMONG ADULTS AT SIX HOSPITALS IN SUDAN

*Dr Nahla Gafer, Khartoum Oncology Hospital, Mohja Khair Allah, Khartoum Oncology Hospital, Richard Harding, King's College London*

**E-mail: [nahla.gafer@yahoo.com](mailto:nahla.gafer@yahoo.com)**

Palliative care (PC) has been recommended as an integral part of Universal Health Care, as an important part of primary health care of cancer care. It has been proved that introducing PC affects patients and family experiences positively, strengthens health systems and economises health expenditure. In Sudan PC is provided at limited places despite the need. This abstract presents results of a study whose aim was to identify the proportion of adults with life-limiting illnesses in Sudan; to describe their demographics, and to generate evidence on their palliative care needs using a validated tool – the Integrated African Palliative Outcome Scale (IAPOS), and to compare the results with results from similar studies in other countries. The findings indicate gender distribution: males 49%; females 51%; diagnoses: cancer 62% of cases; others 38%; that 59% of patients knew their diagnosis, and 36% knew their prognosis. The most troublesome symptoms were pain (52%), fatigue (37%), poor mobility (32%), worry (40%), and family anxiety (57%), and that was according to the percentage of patients who scored 4 or 5 out of 5 in the IAPOS scale. There was a clear difference among the five hospitals engaged during the study. The referral hospital in the capital did the best among all dimensions, followed by the oncology centres, then the general hospitals in the rural setting.

The study recommends the importance of extending palliative care services at all levels of health care (especially for non-cancer patients) with an emphasis on training of health professionals in pain management, communication, psychological issues; conducting more in-depth research in order to understand why patients are not informed about the diagnosis and prognosis, and also to understand palliative patients' experiences and concerns.

**12.05 – 12.15pm**

### A117: AVAILABILITY OF PALLIATIVE CARE IN A DISTRICT HOSPITAL OF RWANDA – CASE OF KIBAGABAGA

*Mathilde Utamuliza, Manasse Nzayirambaho, Jean de Dieu Ngirabega and Eugene Ruberanziza, Rwanda Biomedical Center, Kigali, Rwanda*

**E-mail: [mutamuliza5@gmail.com](mailto:mutamuliza5@gmail.com)**

The Ministry of Health in Rwanda launched the National Palliative Care Policy in 2011. An assessment of availability of palliative care services at Kibagabaga District Hospital, Rwanda, since 2009 when the service was introduced, was done and this abstract provides a report of findings. Some of the findings indicate that at this hospital, medications offered were pain killers including acetaminophen, nonsteroidal anti-inflammatory drugs, and opioids such as tramadol, pethidine and injectable morphine. Psychosocial care was also reported in 93.8% of cases. However, there is shortage of injectable morphine, and home-based care was implemented in only one health center catchment area. The Ministry of Health in collaboration with its partners should accelerate the implementation of the national palliative care policy; prioritise home-based care, and ensure availability of morphine.

**12.15–12.25pm**

### A088: PEDIATRIC PALLIATIVE CARE IN RWANDA: THE CASE OF BUTARO CANCER CENTER OF EXCELLENCE.

*Jean Paul Balinda, Rwanda Biomedical Center, Rwanda*

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In 2012, the Rwanda Ministry of Health (MOH) in partnership with Partners In Health/Inshuti Mu Buzima, opened the Butaro Cancer Center of Excellence (BCCOE). Here, Rwanda has begun to integrate pediatric palliative care (PPC), learning with each implementation step so that a national pediatric model can be developed. This presentation shares experiences of PPC at BCCOE where multidisciplinary team has now been trained in palliative care (PC) to provide pain management, psychological, spiritual, social, and financial support to children and families. Three palliative care champions have been trained to train their peers at Butaro hospital and now 80% of health care providers including pediatric oncology ward staff received in service training on pain control and holistic pediatric palliative care. To date, 612 children have been diagnosed at this centre. It is recommended that Rwanda designs national standards, indicators, tools, and research to integrate PPC into the national health system and bring access to children in need.

**12.25 -12.35pm**

**A067: RATIONALE AND STUDY DESIGN: A RANDOMISED CONTROLLED TRIAL OF EARLY PALLIATIVE CARE IN NEWLY DIAGNOSED CANCER PATIENTS IN ADDIS ABABA, ETHIOPIA**

*Dr Eleanor Reid, Yale University School of Medicine; Yoseph Mamo, Ephrem Abathun & Tigineh Woldemagegnhu, Hospice Ethiopia; Liz Grant, University of Edinburgh*

**E-mail: eleanor.reid@yale.edu**

Demonstrating the economic value of palliative care is key to sustainability and crucial for guiding health care policy. This study provides the rationale and design of a randomised controlled trial (RCT) of early palliative care that is currently underway in Ethiopia. Its aim is to study the effects of early palliative care on health-related quality of life and health care utilisation, through conducting an RCT of standard oncology care versus standard oncology care plus palliative care in newly diagnosed cancer patients. Study findings will provide critical information on the effect of palliative care on improved quality of life, decreased patient-reported costs and health-care utilisation, in a low-resource setting. This may lead to widespread dissemination of an effective, sustainable and cost-saving public palliative care delivery strategy that would improve the quality of life for millions of people.

**12.35 – 12.45pm**

**A135: SITUATION OF PALLIATIVE CARE IN CAMEROON: CASE OF THE PALLIATIVE CARE UNIT OF THE DOMINICAN HOSPITAL OF YAOUNDE**

*Christian Tsoie, Cameroon, San Martin de Porres Dominican Hospital Center (CHDSMP), Cameroon*

**Email: tsoiechristian@gmail.com**

During these last decades, the number of chronic evolutive diseases is always growing. In Cameroon, the main cause of this is the increase in the prevalence of cancers and terminal AIDS. The development of affordable palliative care from a geographical and economic point of view remains the most appropriate solution to meet this humanitarian need that is becoming more urgent.

An observational cohort analytical study was undertaken to identify the components of palliative care existing in Cameroon, specifically the palliative care unit of the San Martin de Porres Dominican Hospital Center (CHDSMP). The hospital palliative care team composed of eight staff participated in the study.

Findings revealed that the hospital has a multidisciplinary team that manages pain and other symptoms, ensures psychosocial care for the patient and family, spiritual care for patients and families and accompaniment during bereavement. Accessibility of morphine, grief and bereavement support, the training of the caregivers are the aspects that should be improved.

**TRACK 2: STRATEGIC ADVOCACY FOR PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE**

**11.00 –11.10am**

**B034: IMPLEMENTING THE WORLD HEALTH ASSEMBLY RESOLUTION ON PALLIATIVE CARE: FROM NO PALLIATIVE CARE TO NATIONAL PALLIATIVE CARE PROGRAMMES IN TOGO, LIBERIA AND THE GAMBIA**

*Fatia Kiyange, Patricia Batanda, Mable Namuddu, African Palliative Care Association; Dr Fred Amegeshie, Florence Yahnquee; Non-communicable Diseases Division, Ministry of Health, Liberia; Dr Samba Ceesay, Non-communicable Diseases Division, Ministry of Health, The Gambia; Jerreh Drammeh, Alieu Badjie, National Palliative Care Association of the Gambia; Prof Mofou Belo, Dr Francois Alinon, Non-communicable Diseases Division, Ministry of Health, Togo.*

**E-mail: [fatia.kiyange@africanpalliativecare.org](mailto:fatia.kiyange@africanpalliativecare.org)**

In May 2014, the World Health Assembly (WHA) passed a resolution on strengthening palliative care as a component of comprehensive care throughout the life course. This resolution, which is a manifestation of the right to quality care for adults and children with life-limiting illnesses, has to be implemented at the country level to realise this right to health. In 2016, African Ministers of Health and their technical officials convened in Kampala, Uganda for their second session on palliative care where they renewed commitment towards the implementation of the WHA Resolution on palliative care through the Kampala Declaration. They pledged to provide leadership to ensure better access to services in their countries.

A follow-up project has been implemented in Togo, Liberia and The Gambia. Implementation of this project was through various strategies including situation analysis through country visits by APCA, equipping the Ministries of Health to conduct baseline surveys on service provision, advocacy meetings to influence policy, PC training of health care workers and clinical placements. As a result, in less than a year after training, 73 patients received PC services and 31 received morphine for pain relief across the three countries. Functional PC teams have been formed. There are also PC teams within Ministries of Health in each country. It is therefore possible to establish a national palliative care programme in a country with no palliative care activity. Awareness creation, engagement, goodwill and commitment from the top policy makers are critical. Using APCA champions as consultants providing technical assistance is an effective method of providing targeted support for countries. The project resulted into a firm and strategic foundation for the inclusion of PC in country UHC plans and interventions. Access to controlled medicines for pain relief remains a challenge for the countries and is a critical area for external support and intervention.

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## 11.10–11.20am

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### B015: 'WITHOUT GOOD DATA, WE'RE FLYING BLIND. IF YOU CAN'T SEE IT, YOU CAN'T SOLVE IT' KOFI ANNAN

*Mr Emmanuel Sibomana Kamonyo, Palliative care advocate; Dr Desia Colgan, University of the Witwatersrand; Mrs Nicola GunnClark, Children Palliative care advocate*

**Email: [healthrightsefrica@gmail.com](mailto:healthrightsefrica@gmail.com)**

Despite recognition of children's palliative care rights, policies fail to address existing needs. Less visible challenges are neglected and the paucity of data exacerbates this lack of understanding. Data gaps undermine a state's ability to develop policy, target necessary resources, implement and track programmes. Advocacy efforts are also undermined because, without data, the magnitude of the problem remains unseen. This study scrutinised the importance of attending to existing data gaps in order to effectively focus advocacy efforts when targeting paediatric palliative care (PPC) challenges. It examined the efficacy of advocacy and how groups address or plan to address data gaps which in turn influence the challenges confronting PPC. Findings indicated the need for states and organisations to utilise key players and build partnerships to develop policies based on facts. In developing PPC a human rights approach should be adopted and recognition given to the power of advocacy in building knowledge, growing awareness and providing evidence at all levels of engagement.

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## 11.20–11.30am

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### B012: EXPERIENCE OF PACAM ON INTEGRATION OF PALLIATIVE CARE INDICATORS INTO THE CENTRAL MONITORING AND EVALUATION DEPARTMENT (CMED) SYSTEM IN THE MINISTRY OF HEALTH IN MALAWI

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## 6th International African Palliative Care Conference

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

*Mrs Glenda Winga, Lameck Thambo, Fred Chiputula, Ida Lajabu, Palliative Care Association of Malawi; Immaculate Kambiya, Blessings Kamanga, Thoko Sambakunsi, Ministry of Health in Malawi*

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Developing a national status report on palliative care (PC) is easy if the country has a functional data management system. In this presentation, the Palliative Care Association of Malawi (PACAM) shares their journey to integration of PC indicators into the Central Monitoring and Evaluation Department (CMED) of their Ministry of Health. The process involves supporting the the Ministry through CMED to develop national PC indicators, integrating them in the District Health Information System (DHIS), review of PC registers, report and documents, development of data collection tools, training of data collectors, CMED officials, District PC Coordinators, and support supervision of data collection. More engagements were in refining of data collection tools and usage. Today the average reporting rate in Malawi is 90% and data is centrally available and accessible through an electronic data system

**11.30 – 11.40am**

### B029: OPPORTUNITIES FOR INTEGRATING PALLIATIVE CARE INTO UNIVERSAL HEALTH COVERAGE IN AFRICA

*Dr. Asaph Kinyanjui, Kenya Hospices and Palliative Care Association, Kenya*

**E-mail: [asaphkinyanjui@kehpc.org](mailto:asaphkinyanjui@kehpc.org)**

Most African countries are in the process of integrating Universal Health Coverage and are implementing it with no clear roadmaps, policies and objectives. This presentation suggests an opportunity of engaging palliative care champions to advocate for PC integration in pilot phases, policies and budgets. The champions can highlight the benefits of palliative care services, engage beneficiaries for increased access and educate policy makers for strategic policy reviews. They should however advocate from an evidence based perspective.

**11.55 – 12.05pm**

### B033: INTEGRATING PALLIATIVE CARE INTO HEALTH SYSTEMS: THE CASE OF RWANDA

*Diane Mukasahaha, Edson Rwagasore, Arielle Eagan, Francois Uwinkindi, Mhoira Leng, Julia Downing*

**E-mail: [diane.mukasahaha@rbc.gov](mailto:diane.mukasahaha@rbc.gov)**

Rwanda was the first African country to develop a stand-alone palliative care national policy and PC was integrated into NCDs strategy and chronic care to align the provision of PC alongside chronic care services. This presentation demonstrates a comprehensive approach of integration exemplified, showing the strategic steps taken by the Rwanda (MOH) through Rwanda Biomedical Center (RBC) to develop and integrate PC into its health system. The weaving of PC into Rwanda's National Health Sector Strategic Plan and NCDs' policy has allowed the MOH to allocate resources most effectively and avoid the duplication of efforts. Now PC is integrated into care delivery at all health system levels. To ensure the monitoring and evaluation system of PC at facility and national levels, newly developed PC indicators have been built into Rwanda's Health Management Information System.

**12.05 – 12.15pm**

### B032: DEVELOPING A PALLIATIVE CARE POLICY FOR SOUTH AFRICA

*Dr Charmaine Blanchard, University of the Witwatersrand, Faculty of Health Sciences, Centre for Palliative Care, Ms Sandhya Singh, Dr Shaidah Asmail and Ms Jeanette Hunter, National Department of Health, South Africa*

**E-mail: [charmaine.blanchard@wits.ac.za](mailto:charmaine.blanchard@wits.ac.za)**

There is need for a national PC policy to provide guidance to address the challenges of providing PC in all public health services in South Africa. In this presentation, South Africa shares steps taken to ensure that PC service provision is not

solely donor funded through non-government organisations, but integrated in the government health system. To date, the policy was drafted and presented to the National Health Council where it was approved with minor adjustments. This policy framework and strategy was based on the WHA Resolution 67.19 for Palliative Care and the WHO public health building blocks provides a strategy to implement palliative care across all levels of the health care system to all in South Africa across the life span. The National Policy Framework and Strategy for Palliative care in South Africa is based on the WHA Resolution 67.19 for Palliative Care and the WHO public health building blocks provides a strategy to implement palliative care across all levels of the health care system to all in South Africa across the life span. The development process requires active involvement of other government sectors, educational institutions and non-governmental organisations and civil society. It is a complex process. Finding the balance between the ideal and what is practically possible, given the resources is challenging, but essential if the policy is to be implemented successfully.

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## 12.15–12.25pm

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### A108: STRENGTHENING PALLIATIVE CARE IMPLEMENTATION IN BOTSWANA THROUGH HOSPICE AND PALLIATIVE CARE POLICY DEVELOPMENT: ONE OF THE KEY PILLARS OF WORLD HEALTH ORGANIZATION (WHO) PALLIATIVE CARE MODEL

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*Penny Sebuweng Makuruetsa, Ministry of Health, Botswana*

**E-mail: [Psmakuruetsa@gov.bw](mailto:Psmakuruetsa@gov.bw)**

In 2014 the World Health Assembly WHA67:19 passed a resolution on palliative care, urging member states to develop, strengthen and implement palliative care policies to ensure comprehensive health care systems. Botswana was amongst those countries that consented in May 2014. It operated with a palliative care strategy which was developed to guide the implementation in all the health care delivery systems, however, there were still major challenges faced by implementers. This prompted the development of a palliative care policy to enforce commitment of the policy decision makers as well as strengthening advocacy for hospice and palliative care. The abstract presents experiences of Ministry of Health in Botswana in developing and disseminating of the palliative care policy. This policy will ensure provision of culturally appropriate, evidence based, comprehensive hospice and palliative care services. It also seeks to ensure access to the highest attainable services at all levels of the health care system through a primary health care approach that integrates cancer prevention.

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## 12.25–12.35pm

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### B009: THE NUTS AND BOLTS OF ADVOCACY FOR ACCESS TO PALLIATIVE CARE AND CONTROLLED ESSENTIAL MEDICINES UNDER UNIVERSAL HEALTH COVERAGE.

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*Dr Katherine Pettus, International Association for Hospice and Palliative Care (IAHPC)*

**E-mail: [Kpettus@iahpc.com](mailto:Kpettus@iahpc.com)**

Advocacy is essential in influencing policy and practice. This presentation provides a bird's eye view of the landscape of international advocacy, the various institutions and institutional players IAHPC interacts with, followed by a review of the process and content of international advocacy to improve global access to palliative care. The presentation also sparks energies to learn more about advocacy, enrolment for the IAHPC basic course, and participation in global advocacy work. With training and engagement, change agents will emerge and these will be crucial for re-strategising, and retooling for effective advocacy for PC as part of UHC.

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## 12.35–12.45pm

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### B020: ADVOCACY FOR ACCESS TO CONTROLLED MEDICINES TO IMPROVE UNIVERSAL HEALTH COVERAGE

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*Hieronimo Rweyemamu, Nyakahanga Designated District Hospital, Tanzania*

**E-mail: [rweye014@gmail.com](mailto:rweye014@gmail.com)**

## 6th International African Palliative Care Conference

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In 2017 Nyakahanga hospital conducted a one year palliative care project. The aim of this project was to improve palliative care by making access to controlled pain medications including oral morphine available in Karagwe and Kyerwa districts, in Kagera region, Tanzania. This project resulted into a positive change in treatment-seeking behavior in the context of enrollment, referral and linkage. Trained 35 healthcare workers of 7 health facilities in Karagwe & Kyerwa districts to clear myths & misconceptions pertaining to the use of opioids including oral morphine – thus combating opiophobia. Key recommendations of this project include: Choosing the right people to join palliative care team is the KEY in building a successful palliative care programme. Assisting the team with knowledge and resources is crucial. Using available resources in the community can sustain palliative care in Universal Health Coverage.

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### TRACK 3: HEALTH FINANCING AND PALLIATIVE CARE

**11.00 – 1.00pm**

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#### LOCAL PALLIATIVE CARE ORGANISATIONS: ROLE AND FUNDING

*Chairs: Lucy Sainsbury and Jo Ecclestone Ford, The True Colours Trust*

This session will be chaired by the True Colours Trust which runs a small grants programme for local providers of palliative care in Africa. It will focus on the important work done by these organisations to improve community health and wellbeing, make a case for their ongoing support and consider their role in achieving Universal Health Coverage. It will include best practice case studies from the Small Grants Programme, a panel discussion with experts from the field and provide practical advice on small grant management and accountability.

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### TRACK 4: EFFECTIVE PARTNERSHIPS AND COLLABORATIONS IN ENHANCING ACCESS TO PALLIATIVE CARE AS A COMPONENT OF UNIVERSAL HEALTH COVERAGE

**11.00–11.10am**

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#### D006: STRATEGIC PARTNERSHIPS, A KEY TO ACHIEVING PALLIATIVE CARE AS PART OF UNIVERSAL HEALTH CARE: LESSONS FROM ZIMBABWE

*Dr Portia Manangazira, Director of Epidemiology & Disease Control, Zimbabwean Ministry of Health and Child Care, and Elias Masendu, Finance and HR Manager, Island Hospice & Healthcare*

**E-mail: [Elias@islandhospice.co.zw](mailto:Elias@islandhospice.co.zw)**

One in sixty people in Zimbabwe need palliative care services. This service is included in the National Health Strategy 2016-2020 (NHS) but not integrated in the health delivery system. In an effort to address this gap, Island Hospice and Healthcare advocated for a Zimbabwean delegation including the Ministry of Health and Child Care (MOHCC) to visit Malawi. The purpose of the visit was to understudy how that country successfully integrated palliative care into its health delivery system. As a result, a national framework for palliative care integration into the health delivery system has been developed in Zimbabwe and some resources secured for implementation. Partnership opportunities including those across borders, disciplines and sectors exist and should be explored for developing evidence based strategies to achieve palliative care integration as part of Universal Health Care.

**11.10 –11.20am**

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#### A126: THE BENEFITS OF OUTREACH CLINICS IN PALLIATIVE CARE.

*Nabitaka Josephine, Resty Nakanwagi, Roselite Katusabe, Octivia Nazziwa, Martha Rabwoni, Agasha Doreen Birungi, Hospice Africa Uganda*

**Email: [jnabitaka@gmail.com](mailto:jnabitaka@gmail.com)**

Hospice Africa Uganda (HAU) has been in existence providing palliative care services since 1993 for patients with cancer and other debilitating illnesses. A holistic approach is used that includes physical, social, psychological and spiritual assessment and support. Services are provided through outpatient clinics, outreaches, home and hospital visits. Our outreach clinics aim to extend palliative care services to those in need outside the HAU catchment area and closer to the patient. The HAU team travels 50 to 90kms to an outreach center (a community hall, church building or health center) and offers care to an average of 30 to 50 patients of whom one fifth are usually new to the programme. The outreach clinics are conducted on a monthly basis.

Outreaches bring relief to patients who are further than HAU's 20km catchment boundary or are living in the hard to reach places. The outreach clinics provide advocacy for HAU by raising awareness for palliative care. Outreaches enabled HAU to network with other organisations particularly in the refugee camps which allowed for leverage of services to the benefit of the patient. We recommend that countries providing palliative care consider supporting service delivery through outreaches to reach the 'hard to reach' communities, the vulnerable and marginalised.

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**11.20–11.30am**

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## **D027: COLLABORATION AND PARTNERSHIP IN DEVELOPING PALLIATIVE CARE INTEGRATION PLAN FOR THE COUNTRY.**

*Eunice Garanganga, Shupikai Chisero, Julieth Musengi and Chriveria Chivodze, Hospice and Palliative Care Association of Zimbabwe (HOSPAPZ)*

**E-mail: [eunice@hospaz.co.zw](mailto:eunice@hospaz.co.zw)**

This paper presents one of the best practices; establishment of an inclusive National Palliative Care Integration Task Force whose initial role was to develop a PC implementation strategy to facilitate implementation of the National Palliative Care Policy in Zimbabwe.

A National Palliative Care Integration Task Force was successfully established with multiple stakeholders including Directorates of MOHCC, other government ministries, health professional councils, health regulatory bodies, medical teaching institutions, palliative care implementing institutions and umbrella bodies, faith-based organisations, funders/donors, NGOs. From the task force, thematic area sub-committees were formed. In order to ensure implementation of the palliative care integration strategy, MOHCC and its partners identified individuals, groups or organisations in each of the thematic areas for the integration initiative, and identified their roles and responsibilities in order to effect change. One the lessons is that leverage of resources through partnerships and collaborations proved very useful as funding partners leveraged on each the other. Formation of a National Palliative Care Integration Task Force and involvement of multiple stakeholders ensured no one was left behind. Establishment of National Integration Task Force enables progress and smooth running of the process as the task force forms the monitoring eye of the programme.

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**11.30 -11.40am**

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## **PALLIATIVE CARE TRAINING OPPORTUNITY IN CANADA FOR DOCTORS IN RWANDA AND NEIGHBOURING COUNTRIES**

*Dr Subrata Banerjee, Canada, Princess Margaret Hospital, University of Toronto,*

**Email: [subrata.banerjee@uhn.ca](mailto:subrata.banerjee@uhn.ca)**

The University Health Network, Toronto, Canada is one of the largest teaching hospitals in North America. The Princess Margaret Cancer Centre is one of the top five cancer research institutions in the world. The Princess Margaret in Toronto offers an Observership Programme in Palliative Care for international doctors and a Personalised Learning Programme in Palliative Care tailored to the individual needs of doctors. Over the years, we have partnered with doctors in Kenya and Uganda who have successfully completed the Observership Programme at Princess Margaret. Canadians in all parts of the country can access high-quality palliative care services as part of Canada's universal healthcare model. Rwanda similarly has made significant universal health insurance strides that are among the most dramatic the world has seen.

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Over the last five years, doctors from Kenya and Uganda have successfully completed this programme, and some of their comments and experiences are included in the poster. Most have felt that their observer experience at one of the biggest palliative care programmes in Canada has been life-changing, bringing compassionate patient-centred care into their practice when they returned to Kenya and Uganda. The programme explores opportunities for partnership with Princess Margaret in Canada and health organisations and individual doctors in Africa to provide optimal palliative care education.

**11.55 – 12.05pm**

### D022: COLLABORATION AND PARTNERSHIP IN CAPACITY FOR PALLIATIVE CARE

*Lidia Justino Mondlane, Associacao Mocambicana de Cuidados Paliativos – MOPCA, Mozambique*  
**E-mail: [Imonjane@yahoo.ca](mailto:Imonjane@yahoo.ca)**

This paper presents efforts of the Mozambique Palliative Care Association (MOPCA) and APCA to establish models for palliative care service provision through supporting Chibuto Rural District Hospital (CRH) in Mozambique to become palliative care centre of excellence, promoting capacity and competences to health care providers in palliative care. This initiative strengthened PC provision, both in hospital, and peripheral sites, the number of patients enrolled at CRH increased from 55 to 170, 255 patients were assisted in the community.

One of the lessons learnt is that an institution alone takes a long time to reach targets and involving partners in the same cause makes implementation more effective, given the shared wisdom and economies of scale. The trained palliative care health professionals are gradually integrating palliative care in the National Service. It is recommended that advocacy should be a constant action with Ministry of Health to fit palliative care in planning and budgeting.

**12.05–12.15pm**

### D016: NETWORKING, A STRONG TOOL FOR PALLIATIVE CARE ADVOCACY: EXPERIENCE AT AGA KHAN HOSPITALS

*Dr John Weru, Aga Khan University Hospital, Nairobi*  
**E-mail: [John.weru@aku.edu](mailto:John.weru@aku.edu)**

A prior study on the needs for PC within the Aga Khan Health Services; Kenya, Tanzania, Afghanistan, Tajikistan, Pakistan indicated that there was crucial need for PC services within the institutions and main challenges were lack of capacity – personnel trained in PC and limited infrastructure. This study demonstrates how Aga Khan University hospital utilised partnerships and collaborations as a component of UHC to improve service delivery. Training of medical professionals on palliative care combined with clinical placements facilitated appreciation of quality PC. Networking and collaboration among institutions – North-South; West-East a feasible process of growing PC services across the globe. There is need for regional but also global partnerships to enhance PC provision mentorship by well established institutions recommended for accelerated development and growth for palliative care.

**12.15–12.25pm**

### D015: BEREAVEMENT OF A PARENT OR SIBLING CAN BE DEVASTATING FOR YOUNG PEOPLE: AN INTER-HOSPICE PARTNERSHIP ENABLED THERAPEUTIC, CROSS CULTURAL SHARING OF EXPERIENCES

*Dr Karilyn C., St Michael's Hospice Hereford UK; Mr Edgar Ngelangela, Muheza Hospice Care Tanzania*  
**E-mail: [karilynandrichard@googlemail.com](mailto:karilynandrichard@googlemail.com)**

Bereavement in childhood is a subject that is difficult for us all to face. There has been a partnership between St Michael's Hospice in Hereford UK and Muheza Hospice Care in Tanzania and recent cross-cultural exchange visits by social workers working in bereavement with children and young people (YP) from each hospice, has led to a small group from St Michael's travelling to Muheza to share mutual experiences. The purpose of this arrangement is to connect bereaved

teenagers from different cultures, and enable them to share experiences of the death of a close relative, and to create understanding and empathy between the two groups. This programme will be the first time that cross-cultural grief experiences have been explored and the lessons learned will be presented in the paper. A film made during the 10 days will be used to role model youth volunteering and raise awareness of the impact of bereavement on the lives of children and young people in both cultures.

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**12.25–12.35pm**

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### **D032: INTEGRATING LEGAL SUPPORT FOR PALLIATIVE CARE PATIENTS AND THEIR FAMILIES IN ZIMBABWE**

*Julieth Musengi; Co-authors: Chriveria Chivodze, Shupikai Chisero, Eunice Garanganga, Hospice and Palliative Care Association of Zimbabwe (HOSPAZ)*

**E-mail: [julieth@hospaz.co.zw](mailto:julieth@hospaz.co.zw)**

Having realised human rights and legal issues were major barriers for marginalised patients with life-threatening illnesses to access palliative care services, HOSPAZ implemented a project on integrating legal aid into palliative care services. The goal was to develop sustained and expanded legal support for palliative care patients in Zimbabwe. After training of lawyers, collaborative visits to patients were done by lawyers. Achievements include: development of legal educational materials for patients and families; development of guidelines on integrating legal aid into palliative care; sensitisation meetings for community leaders on human rights and legal issues; joint project review meetings involving lawyers, palliative care practitioners and patients.

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**12.35–12.45pm**

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### **D011: PROMOTING UNIVERSAL ACCESS TO PALLIATIVE CARE THROUGH PARTNERSHIP: AN ETHIOPIAN & UK LINK.**

*Dr James Mumford, Market Surgery, Aylsham, Norfolk UK; Ephrem Abathun, Hospice Ethiopia; Susan Mumford, Priscilla Bacon Centre for Specialist Palliative Care, Norwich, UK*

**E-mail: [j.w.mumford@doctors.org.uk](mailto:j.w.mumford@doctors.org.uk)**

Many people throughout the world die with little or no palliative care, despite this being an essential component of Universal Health Coverage. Since 2011 a group based in Norwich, UK has been supporting the work of Hospice Ethiopia (HE) in Addis Adaba, with the aim of promoting palliative care in Ethiopia. The aim was to facilitate the promotion and expansion of palliative care services in Ethiopia by sharing experiences, providing financial support and facilitating links internationally. The partnership proved rewarding and successful to both sides. Today priority has shifted from education provision to funding, as local education provision. Promoting partnerships such as between HEUK and HE can help the sustainability of small hospices across Africa. In this instance it has resulted in the increased provision of palliative care for those suffering from life-limiting illnesses as well as providing centres of excellence with accessible palliative care education.

**THURSDAY 19<sup>TH</sup> SEPTEMBER 2019**

**TRACK 1: PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE**

**11.00am – 03.30pm**

**AD10: SPIRITUALITY WORKSHOP: AN INTRODUCTION TO THE INTER-PROFESSIONAL SPIRITUAL CARE EDUCATION CURRICULUM**

*Christina Puchalski, MD, FACP, FAAHPM, The George Washington University's Institute for Spirituality and Health (GWish), The George Washington University, Washington, DC, USA; Fr Richard Bauer, MM, BCC, LCSW, Maryknoll Fathers and Brothers, Kenya*

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Spiritual distress is highly prevalent in seriously ill and dying patients and families. Total pain cannot be fully addressed without addressing spiritual distress. The essential palliative care package must include evidence-based, person-centred spiritual distress screening, history, assessment and intervention. In this training workshop, clinicians will be taught the assessment skills for addressing spiritual distress. The second aim is to form a leadership group that will work with GWish in developing a five-year ISPEC initiative in Africa meeting the goals of the WHO resolution for whole-person holistic palliative care.

The workshop targets palliative care clinicians including sisters from ASEC who work with seriously and chronically ill patients. The clinician sisters are particularly targeted as ISPEC meets their goals of leadership and clinical skills training and since they are fully committed to integrating spiritual care and who can help with developing a CPE programme in Africa.

Learning objectives include: recognising the role of spirituality in clinical care, identifying communication strategies for eliciting spiritual issues, practicing a spiritual history tool called FICA, and recognising the role of spirituality as integral in the practice of compassionate presence.

**11.00 –11.10am**

**A115: USING ROUTINE MEDICAL RECORDS IN AN AFRICAN HEALTH INFORMATION EXCHANGE TO IDENTIFY PATIENTS ELIGIBLE FOR PALLIATIVE CARE**

*Florence Malehlabathe Phelanyane, University of Cape Town, Cape Town, South Africa*

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The provision of palliation in the Western Cape Province of South Africa relies heavily on comprehensive data to determine patient eligibility. The Provincial Health Data Centre (PHDC) is a health information exchange that collates administrative health data from multiple platforms daily, providing a current longitudinal record of every individual's clinical journey within the public health services. This data can inform a system-wide approach aiming to develop data-driven tools to identify patients in need of palliative care. The PHDC has defined query language to identify individuals with: (1) cervical, breast, lung, and prostate cancer; (2) nephrology conditions; (3) HIV and TB, eligible for palliative care.

The data describing palliative care eligibility for the described health conditions are informing the work of the provincial palliative care task team in order monitor and evaluate the rollout of the provincial Palliative Care Policy. This also speaks to the National Policy Framework and Strategy on Palliative Care's goal 3 that urge to establish and maintain systems for monitoring and evaluation of country's palliative care programme.

**11.10 –11.20am**

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## A147: BARRIERS TO TREATMENT INITIATION AFTER TREATMENT PRESCRIPTION FOR BREAST AND CERVICAL CANCER PATIENTS AT UGANDA CANCER INSTITUTE

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*Mackuline Atieno, African Palliative Care Association*

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Breast and cervical cancers remain the top killer cancers in women in Uganda, yet preventable with early detection and treatment. The Uganda Cancer Institute (UCI) provides cancer specialist treatment for the country and East African Region. Delayed treatment for breast and cervical cancers can negatively affect the outcome and decrease survivorship for these women.

This abstract presents a longitudinal study involving following up newly registered cancer patients referred to UCI up to treatment initiation.

Key barriers to treatment initiation after prescription included financial and navigation challenges. Psychosocial issues linking to self-image, change of sexual role and decision making also delayed starting of cancer treatment or prevented starting treatment. Exploring psychosocial issues in women with breast and cervical cancers can play a role in improving earlier treatment initiation and compliance. The study recommends availability of tailored counseling and psychosocial support mechanisms for women with breast and cervical cancers (and their families) a routine practice in cancer treatment centers.

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**11.20 –11.30am**

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## A098: AWARENESS OF NON MALIGNANT DISEASE TRAJECTORY AND ACCESS TO PALLIATIVE CARE

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*Abathun Ephrem, Hospice Ethiopia, Addis Ababa, Ethiopia; Barbro Norrstrom Mittag-Leffler, Dpt of Oncology, Visby Lasarett, Sweden & former chair Friends of Hospice Ethiopia*

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A change in life expectancy with ageing population and growing prosperity in less resourceful countries entails increased prevalence of nonmalignant diseases. Need and access to palliative care is obvious. The WHO renewed definition of palliative care has an extended objective including chronic nonmalignant diseases. Raised awareness, knowledge and action is required in Ministries of Health as well as amongst health care providers as a public health approach as is further research.

Clinical experience and published research, studies on Pub Med, Medline and Google databases were used to establish knowledge on non-malignant disease trajectory and access to palliative care. Key words as non-malignant disease, non-cancer, illness trajectory, palliative care, end of life were used. Results mainly found studies from more resourceful part of the world, as was expected.

Need of further knowledge of the extended WHO directive on securing palliative care for non-malignant diseases, of advance care planning, of informed consent, of do or do not resuscitate, of discussions regarding ventilator-assisted treatment and tracheostomies is recommended. All these issues are mandatory in implementing palliative care further.

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## 11.30 – 11.40am

### A101: BRINGING HOPE, CHANGING SYSTEMS, TRANSFORMING LIVES; A 10 YEAR REVIEW ON THE IMPACT OF INTEGRATED PALLIATIVE CARE IN THE ACADEMIC AND NATIONAL HOSPITAL SETTING IN UGANDA

*Dr Mhoira E F Leng, Liz Grant, Scott Murray, Julia Downing, Jack Turyahikyio, Peace Bagasha, Grace Kivumbi, Florence Nalutaaya, Mwazi Batuli, Josephine Kabahweza, Elizabeth Nabirye, Namukwaya Liz, Makerere University, University of Edinburgh, Cairdeas International Palliative Care Trust, International Children's Palliative Care Network, Palliative care Education and Research Consortium*

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To achieve integrated palliative care (PC) within UHC effective models within district, national and university teaching hospitals are crucial, as hubs for diagnosis and treatment and part of the continuum of care into the community. The Makerere model was developed 10 years ago to: 1) improve access to quality, evidence-based PC for patients and families, 2) develop a cadre of leaders through preceptorships, 3) offer clinical modelling, training & capacity-building and 4) build partnerships. This paper presents a 10-year review of the impact of this model in the academic and national hospital setting in Uganda. One of the lessons is that in a hospital setting, establishing a clear research plan in conjunction with a robust palliative care strategic plan, strong partnerships & focus on leadership, research training alongside clinical care can make a significant impact. Internally generated research evidence shows how PC teams can empower other hospital staff to integrate PC in routine practice referring appropriately for complex joint management. Mentorship and ongoing training is essential. High visibility, academic credibility and engagement in the work of the institutions supports ownership. Partnerships are essential to academic creativity and innovation.

## 11.40 – 11.50am

### A042: THE FIRST STEP IS THE HARDEST: INTEGRATION OF MULTIDISCIPLINARY PEDIATRIC AND ADOLESCENT PALLIATIVE CARE SERVICES IN OUTPATIENT HIV/AIDS CARE IN TANZANIA

*Dr Liane Campbell, Jason Bacha, Baylor College of Medicine International Pediatric AIDS Initiative at Texas Children's Hospital Houston, USA, Baylor College of Medicine, Houston, USA, Baylor College of Medicine Children's Foundation; Beatrice Malingoti, Nazarena Myenzi, Asulwisy Kapesa, Tanzania, Pediatrics, Mbeya, Tanzania*

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Integration of palliative care services into HIV/AIDS treatment programmes can effectively expand the availability of palliative care for children and adolescents living with HIV (CALHIV). In Tanzania improved antiretroviral therapy (ART) coverage has dramatically improved life expectancy of people living with HIV. However, CALHIV still present with significant AIDS-related morbidity that requires palliative care. Clinical staff members working at the Baylor Mbeya Center of Excellence (COE) established a palliative care programme to provide comprehensive care for CALHIV with life-limiting effects of HIV/AIDS, tuberculosis and malnutrition. The COE's multidisciplinary palliative care team created a first-of-its-kind standardised process for identification and enrollment of palliative care patients in Mbeya and began providing comprehensive services. Among CALHIV requiring palliative care, adolescents are an important group, often presenting with severe immunosuppression and advanced disease. Tuberculosis care and nutrition support are essential elements of comprehensive palliative care for CALHIV.

**12.05–12.15pm**

### **A090: IMPORTANCE OF INVOLVING PUBLIC HOSPITALS TO CONTRIBUTE TOWARDS PALLIATIVE CARE DEVELOPMENT AS A CLINICAL PLACEMENT SITE. EXPERIENCE OF NTCHEU AND RUMPHI DISTRICT HOSPITAL IN MALAWI**

*Idah Rajabu, F. Chiputula, L.Thambo, Palliative Care Association of Malawi; I.Kambiya, Ministry of Health of Malawi; Dr Steve Macheso, DHO Rumphu and Dr Nenani Chisema, DHO Ntcheu, Malawi*

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In most countries globally palliative care is championed by non-governmental and charity organisations. Majority of the population access health services through public health facilities. PACAM, with financial support from True Colours, worked with selected public hospitals to upgrade them to centers of excellence in palliative care and clinical placement sites. The aim was to increase access for quality, affordable and sustainable palliative care services and develop best practices for other public health facilities in Malawi.

PACAM implemented various capacity building activities in all the publicly funded district hospitals and at the end conducted an evaluation. Findings of the evaluation revealed districts that were doing well. These districts were recommended for further capacity building to attain a status of a center of excellence and accredited by the Ministry of Health. Hence, they became clinical placement sites for palliative care.

Both bottom up and top down approach targeting leaders and key decision makers for funding and strategy. The sites were audited and qualified to be centers of excellence. This initiative has demonstrated that all public hospitals are capable of providing quality palliative care since they all receive the same funding. This has led to an increase in number of centers of excellence and clinical placement sites in Malawi. Palliative care providers working in the clinics have developed confidence in managing palliative care conditions. Palliative care best practices must be replicated/scaled up in all the public hospitals in order to increase access for quality palliative care. Regular contact with the district through coordinators meetings and mentor-ship visits is key to sustaining gains.

**12.15 – 12.25pm**

### **A073: RECOMMENDATIONS FROM AN EVALUATION INTO NURSE PRESCRIBING IN PALLIATIVE CARE IN UGANDA.**

*Prof Downing Julia, Nabirye Elizabeth, Ojera Alex, Namwanga Rosemary, Katusabe Roselight, Dusabi-mana Mathias, Kalema Kelet, Yayeri Biira, Apollo Arishaba, Batuli Mwazi, Komunda Charlotte, Nabukalu Rashidah, Mwesige Jane*

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The World Health Organisation along with regional PC stakeholders are advocating for trained PC nurses to be able to prescribe oral morphine and other strong analgesics. However, no evaluation had been undertaken to demonstrate effectiveness.

A study was undertaken to determine the effectiveness of the specialist nurses role in PC in Uganda, and in particular nurses prescribing of oral morphine in order to make recommendations for future scale-up within Uganda and across the region.

Results show nurses can assess and manage pain to a high standard, including the prescription of oral morphine. 1) Themes identified with regards to the nurse's preparation for the role included: training, supervision, mentorship, competency, boundaries, beliefs and the system. The curriculum prepares the nurses well, with minor adaptations recommended. 2) Analysis and review of patient documentation demonstrates that the nurses can assess and manage pain ( $p < 0.001$ ) utilising appropriate medications. 3) Nurses are resilient and working in a system where access to medications can vary, where there is limited understanding of PC and myths persist about the use of morphine.

Recommendations include minor curriculum adaptations to ensure nurses are trained appropriately for their role. Formal telephone support is needed for the nurses so complex issues can be discussed where appropriate. Ongoing work is needed to strengthen the health system. Lessons learnt can be shared across the region so that other countries can implement nurse prescribing in PC.

## 12.25–12.35pm

### A082: PALLIATIVE CARE RESEARCH FOR CANCER PATIENTS IN SUB-SAHARAN AFRICA: A 10-YEAR REVIEW

*Angucia Bridget Sharon, Annet Nakaganda, Uganda Cancer Institute, University of Manchester UK*  
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An assessment of the trends, magnitude and outcomes of research in palliative care for cancer in Sub-Saharan Africa (SSA) over a 10-year period was conducted. A rapid literature review of palliative care for cancer patients was done in 49 SSA countries recognised by UN, for the period from 2008 to 2018. Of the 1088 articles identified, 10 met the inclusion criteria, which is relatively a small number. However, research into PC for cancer has been increasing from 10% in 2008 to 20% in 2018. 50% of the studies done assessed the PC needs of cancer patients, (2)20% evaluated knowledge of cancer pain management among clinicians and another (2)20% assessed models of palliative service delivery for cancer in SSA, and 1(10%) the effectiveness of PC medicine for cancer pain management.

Although research done in PC for cancer seems to be increasing over the years, the rate of increase is very low. This advocates for more research into PC for cancer patients in SSA so that treatment decisions are based on local evidence. It is also recommended that PC research assesses the ultimate goal of improved quality of life to inform the planning/evaluation of PC strategies in Sub-Saharan Africa. Training of oncologists, increased funding, and public awareness in cancer palliative care research would be a critical path to this.

## 12.35 – 12.45pm

### A133: MAPS (MODELLING AN APPROPRIATE PAIN SELF-MANAGEMENT INTERVENTION FOR ADOLESCENTS WITH HIV/AIDS IN MALAWI)

*Dr Kennedy Bashan Nkhoma, Katherine Bristowe, Richard Harding, King's College London, UK; Gertrude Mwalabu, Kamuzu College of Nursing, Malawi; Edgar Lungu, UNICEF, Zambia.*  
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UNAIDS estimates that adolescents account for 50% of new infections, with prevalence higher among those aged 15-17 years. It is well documented that HIV infection is associated with pain due to opportunistic infections and toxic effects of treatment. A cross-sectional study conducted in Malawi reported 27% pain prevalence. Pain among adolescents is often undertreated, underreported, and unlikely to be routinely assessed. Studies of pain relief interventions have mainly been conducted in adult population.

This project aimed to develop a feasible and acceptable pain self-management intervention for adolescents with HIV in Malawi.

This project is important to ensure rapid development of evidence based interventions for self-management of pain among adolescents with HIV in Malawi. The intervention will be evaluated using robust research methods which if found effective can be routinely incorporated into clinical practice.

## 04.00 – 04.10pm

### A016: TO INVESTIGATE THE NEED FOR PALLIATIVE CARE IN CEREBROVASCULAR ACCIDENT (STROKE) PATIENTS AT LADYSMITH REGIONAL HOSPITAL

*Dr Mohammed Jamil Hossain, University of Cape Town, South Africa*  
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This was a cross-sectional study using mixed methods-both quantitative and qualitative-interviewing patients, and family members of patients who had suffered from a cerebrovascular accident.

From the results of quantitative data analysis by using SS-QOL tools, it was identified that the physical, emotional and social dysfunctions were the major concern of the participants after survival from acute stroke. From the qualitative data analysis, it was found that patients' quality of life was poor and they needed assistance from different health care team. It was observed in the study that the integration of palliative care with the rehabilitation programme can deliver a better service to the stroke patients with residual disabilities and morbidities.

It is important to have effective, patient-centred palliative care services together with rehabilitation in place for stroke patients and by which patient can improve their quality of life with residual disabilities. Early transition for palliative care management is better for a stroke survivor. Health workers should be alert to the need of palliative care after survival from stroke and a need to advocate for home based care to be provided after discharge from hospital.

## 04.10 – 04.20pm

### A114: PLANNING FOR PALLIATIVE CARE IN COMPLEX HUMANITARIAN RESPONSE: QUALITATIVE ANALYSIS OF PATIENT AND PROVIDER EXPERIENCES OF PALLIATIVE CARE IN HUMANITARIAN CRISIS SETTINGS

*Dr Kevin Bezanson, Emmanuel Musoni, Sonya de Laat, Rachel Yantzi, Olive Wahoush, Wejdan Khater, Ibraheem Abu-Siam, Elysée Nouvet, Carrie Bernard, Laurie Elit, Lynda Redwood-Campbell, Ross Upshur, Matthew Hunt, Pathé Diallo, Fatoumata Binta Diall*

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Historically, the primary goal of humanitarian healthcare has been to save lives, yet there is a growing acknowledgment of the role of palliative care in humanitarian healthcare. This paper presents findings of field-based case studies that bring to light ethical and practical dimensions of palliative care with public health emergency survivors in Guinée, and with refugees in Rwanda, Jordan and Bangladesh.

Interviews were conducted with refugees in Rwanda, Jordan, and survivors of Ebola in Guinée, local and international humanitarian healthcare providers, to explore their perceptions of barriers and facilitators, and moral experiences of palliative care provision. Cross-cutting themes included: low access to symptom relief, the experience of 'social death', labyrinthine bureaucracies, the false dichotomy of palliative versus curative care, and the seemingly 'small' things that participants reported could make a world of difference. We also identified divergences among the case studies.

Key recommendations include: explicit inclusion and integration of palliative care within humanitarian healthcare; prioritising engagement of community and family care providers in guiding and providing palliative care; providing context specific training and guidelines to providers; ensuring provision and access to opiates/medications and equipment/supplies necessary for palliative care and streamlining systems to ensure timely access and reduce structural barriers.

## 04.20 – 04.30pm

### A013: USE OF LOCALLY FILMED VIDEO-BASED EDUCATIONAL MODULES TO ENHANCE PALLIATIVE CARE (PC) COMMUNICATION SKILLS IN THE RURAL UGANDAN SETTING

*Dr Randi R. Diamond, MD, Eison, MD, Lorien E. Menhennett, BS, Weill Cornell Medicine, USA; Prossy Nafula, DN, DPC, Saint Francis Naggalama Hospital, Uganda; Howard B. Lucy Bruell, BA, MS, NYU School of Medicine, USA*

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Communicating with patients and families with sensitivity and respect is a key competency in PC education. According to APCA (unpublished data), enhancing PC communication skills remains a challenge. More PC training courses are needed to expand and support the workforce especially in the rural setting.

This presentation is about findings of a study to test the efficacy of educational modules (based on video footage and printed educational guides) on confidence of rural Ugandan health workers in using PC communication skills for having difficult conversations with seriously ill patients. Average confidence in ability to communicate with seriously ill patients increased by 0.66, Average comfort in discussing death/dying and delivering bad news increased by 0.56 and 0.59

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respectively. Average comfort with responding to emotions increased by 0.66. Based on a 2-tailed paired t-test, the score changes were statistically significant ( $p < 0.005$ ). When separating providers who self-identified as nurses and those who self-identified in other healthcare roles, there was no difference between the groups ( $p > 0.05$ ) and the improvement remained significant.

Based on our preliminary results, we would favour continued development of additional educational modules on PC communication skills and wider distribution of the modules to other rural sites.

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**04.30 – 04.40pm**

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### A087: ADVANCE CARE PLANNING DISCUSSIONS AND MEETING SPIRITUAL NEEDS IN HOSPITAL SETTINGS

*Prof Mark Thomas, Keri Thomas, The Andrew Rodger Trust, UK*

**Email: [markthomas51@hotmail.co.uk](mailto:markthomas51@hotmail.co.uk)**

There is increasing international recognition within palliative care of the value of discussing goals, values, wishes and preferences as part of advance care planning (ACP) discussions. ACPs help create a space in which spiritual reflections may develop. Following an initial ACP workshop in Cape Town, with a focus on spiritual care and fostering resilience, an ACP support package was proposed. This initiative aimed to pilot and evaluate the development of an ACP package suitable for an African audience, including the assessment of spiritual needs, to be used by spiritual counsellors and social workers in a hospital.

An initial workshop on ACP was well received in a Cape Town hospital, with hospital spiritual counsellors, social workers and palliative care nurses. A 3-minute video was played and teaching on the theory and practice of ACP given. The opportunity to discuss spiritual care of patients, self-care of ourselves, developing resilience and how ACP can help was discussed. An ACP package for a Cape Town audience was discussed and a further pilot was suggested.

The use of a package of adapted advance care planning resources (video, flyers, poster, brochure, teaching), could help support ACP discussions, including the encouragement of spiritual care discussions and should be further evaluated. ACP and spiritual care discussions be promoted in African countries.

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**04.40 – 04.50pm**

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### A060: THE IMPACT OF NUTRITIONAL SUPPORT AMONG PATIENTS RECEIVING PALLIATIVE CARE FROM RAYS OF HOPE HOSPICE JINJA

*Ms Logose Harriet, Rays of Hope Hospice Jinja, Uganda*

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Cancer and HIV/AIDS cause disastrous effect on household food security and nutrition. Patients suffer from poor nutrition hence poor health due to weakened immunity. Proper nutrition contributes to improved drug adherence. This study shows efforts made to improve the food and nutrition security of the patients under the care of Rays of Hope Hospice Jinja to ensure good health. The aim of the study was to find out the impact of nutritional support to patients receiving palliative care from Rays of Hope Hospice Jinja.

The study found that good nutrition improved adherence to medicines among HIV/AIDS patients. The immunity of the patients greatly improved clinically hence suppression of the HIV virus. Patients who improved were now able to engage in productive to support their families. Children got opportunity to go back to school rather than looking after the sick parents. Food is an essential component in adherence to medicines among palliative care patients. Boosts immunity of palliative care patients. Improves quality of life of patients and families.

Palliative care service providers need to consider inclusion of food support in their funding arena to assist patients in accessing enough and quality foods. To have more education and discussions with families to have small scale farming which may be both commercial and home consumption.

**04.50 – 05.00pm**

## C006: IMPROVING ACCESS TO PALLIATIVE CARE THROUGH STRENGTHENING COMMUNITY BASED SURVEILLANCE

*Dr Agasha Doreen Birungi, Namwanga Rosemary, Susan Aloba Toolit, Okello Lwanga, Antonia Kamate Tukundane, Hospice Africa Uganda*

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This paper presents Hospice Africa Uganda's (HAU) efforts in strengthening community-based surveillance for palliative care. This ensures that the very poor, vulnerable, marginalised and stigmatised persons that need palliative care are linked to care. Community engagement increases access and utilisation of services. To reach more communities beyond the HAU catchment area, more community volunteer workers (CVWs) should be recruited in communities that haven't been reached. CVWs should be equipped with protective gear to enable them provide basic services for the patients. CVWs have potential to seek out children, refugees and other vulnerable populations that require palliative care.

## TRACK 2: TRACK 2: STRATEGIC ADVOCACY FOR PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE

**11.00 – 11.10am**

## B027: THE VALUE OF ADVOCACY FOR INTERGRATION OF PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE

*Mr David K. Musyoki, Kenya Hospices and Palliative Care Association (KEHPCA)*

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The quality of life of millions of people would have improved greatly if today's knowledge of palliative care was accessible to everyone. This paper presents advocacy efforts for palliative care integration in UHC package as part of the president's big 4 agenda in Kenya. Initiatives by KEHPCA and other stakeholders have seen the number of palliative care providers grow to over 70 (from 14 sites in 2010) currently serving over 10,000 persons living with palliative care needs annually. KEHPCA has been supporting scaling up palliative care services in the government hospitals across all levels of the health care system. The interventions over the years have included creating national palliative care guidelines, training professionals in Kenya, setting up clinical placement sites, supervision visits, engaging legal practitioners, community volunteers, opinion leaders and the media to raise awareness. It addresses policies; adequate drug availability; education of policy makers, health care workers, and the public; and implementation of palliative care services at all levels of care.

**11.10 – 11.20am**

## A062: INTRODUCING PALLIATIVE CARE IN GUINEA

*Camilla Börjesson, Specialist palliative care unit at Örebro University Hospital, Sweden Guinea*

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Before 2013, patients with non-curable diseases were suffering and dying with no access to pain relief in Guinea. Palliative care as a care model was not well known. Health care professionals lacked training in palliative care and there was no access to morphine or other essential drugs. The aim was to set up a palliative care team that was skilled to care for dying patients and their families and to increase the awareness of the need for palliative care in Guinea.

A small team was put together and received training based on the Worldwide Hospice Palliative Care Alliance (WHPCA) toolkit for palliative care in limited settings. The team started to visit patients in their homes providing symptom relief, pain medication, psychological and existential/spiritual care and support to caregivers. The team established contacts with medical staff at local hospitals advocating for the need of palliative care.

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In 2014 the organisation SOPAG was formed and has cared for 36 patients in their homes and the organisation is leading national level advocacy efforts for palliative care. It is possible to set up a team and provide palliative care in limited settings with small resources. Volunteers properly trained can perform holistic palliative care.

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**11.20 – 11.30am**

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### A139: A REVIEW OF HUMAN RESOURCES FOR PALLIATIVE CARE IN ESWATINI

*Ntombi Ginindza & Gugulethu Mandonsela, Ministry of Health; eSwatini National HIV/AIDS Program; Eve Namisango, Emmanuel BK Luyirika & Fatia Kiyange, African Palliative Care Association; Samuel Guma, Kawempe Home Care; Edward Mukooza, Uganda Christian University; Richard Harding, Cicely Saunders Institute, King's College London*

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Resource-limited settings continue to battle an increasing incidence and prevalence of and life-threatening illnesses; which are associated with avoidable health related suffering. WHO recommends palliative care as an essential care package for these patients, for which equitable access can be achieved via universal health care coverage scheme. The need for strengthening the human resource for palliative care is critical to match this increasing demand palliative care services. This study aimed to identify the nature and extent of availability of palliative care human resources in eSwatini.

Themes on human resource challenges included; high burden of HIV and other communicable diseases which are associated with high service utilisation; rural-urban imbalance in human resource distribution; low number of medical training institutions and lack of training curriculums, stigma associated with palliative care – some of the trained staff are hesitant to practice. Lack of recognition of palliative care as a specialty in the public service structure; lack of funding for palliative care. More so, the policies and guidelines lacked clear strategies for palliative care human resource development, deployment and retention. We also found high (1.8/1000) doctor to patient – nurse to patient (28/10000) ratios, with over 400 vacancies pending recruitment and no clear staffing norms for palliative care.

Palliative care service development should run in tandem with clear strategies for human resource for palliative care development, recruitment, and retention. Services cannot be sustained without a strong human resource foundation.

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**11.30 – 11.40am**

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### A145 - THE NEED FOR AND ROLE OF SKILLED HEALTH WORK FORCE IN ACHIEVING UHC THAT IS INCLUSIVE OF PALLIATIVE CARE

*Pamela Kalema, APCA*

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Nurses and social workers play a key role in providing holistic palliative care to people with life limiting illnesses and their families. However, there is still inadequate incorporation of this care into pre-service training for these cadres & a lack of clear career pathways for those trained in PC. There is also a lack of recognition, appropriate deployment and remuneration for those who have obtained PC qualifications by local ministries of health and their professional councils. In 2011 and 2012 respectively, the African Palliative Care Association (APCA), in partnership with Global Partners in Care (GPIC) in the USA, established the Palliative Care Education Scholarship Fund for Nurses and Social Workers. The programme was established to support the training of nurses and social workers in palliative care to enhance their knowledge and skills for service provision and training development in their work and local context.

The scholarship programme has benefited 23 nurses from 9 African countries. Seven social workers from 5 countries across Africa have benefitted through formal palliative care training. These nurses and social workers have become key champions for palliative care, advocates and lead service providers at their places of work and in their countries.

**11.40 – 11.50am**

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## **B017: ENGAGING PHARMACISTS IN THE STRATEGIC ADVOCACY FOR PALLIATIVE CARE IN TANZANIA**

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*Dr Paul Zebadia Mmbando, Evangelical Lutheran Church in Tanzania; Dr Sarah Maongezi & Mr Daudi Msasi, Ministry of Health, Community Development, Gender, Elderly and Children*

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Access to morphine and other essential palliative care medication has been a challenge in Tanzania for decades as numbers of facilities licensed to stock and prescribe morphine remains very small. However, the engagement of pharmacists from national, zonal and regional levels is quickly proving to be the most successful approach.

Lessons from this initiative in Tanzania are showing that pharmacists are in good position to improve access to controlled medicines by patients, but their knowledge and awareness of the need for PC services is very limited. More capacity building is required. There is need to direct PC trainings to more pharmacists and challenging them to be more involved in ensuring access to PC, beyond just providing medications.

**12.05 – 12.15pm**

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## **A116: CONSERVATIVE TREATMENT VS. INTERVENTIONS FOR CANCER AND AIDS PAIN MANAGEMENT**

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*Prof Maged Elansary, Egypt, Al Azhar University*

**Email: [maged@elansary.com](mailto:maged@elansary.com)**

In general, management of acute and chronic pain should start with conservative then interventional techniques. Interventional pain techniques and surgical solutions would form 10-20 % of cases. Post-operative pain could be managed by simple analgesics in minor and moderate surgeries. But in super-major surgery interventional techniques like epidural patient-controlled analgesia would be the technique of choice. Application of oral therapy using the WHO 3 steps analgesic ladder would be efficient to control 60 -70 % of cancer pains. Although this approach is known to a good percentage of pain specialists and oncologists, it is not completely fulfilled. A considerable number of pain doctors are not used to applying the WHO pain management approach. Most of the pain clinicians are anesthesiologists and prefer interventional techniques. It is also true that junior pain physicians would like to show their efficiency. Also, opioid availability in oral form is not easy to prescribe and dispense from the outpatient pain clinics. Interventional techniques are more profitable in private practice rather than adopting the WHO approach.

In conclusion, interventional pain techniques are over used in the Middle East and North Africa, but in the Sub-Sahara region, application of the WHO pain management approach is successfully applied. In developing countries like Africa simple methods for pain management should be adopted.

**12.15 – 12.25pm**

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## **A132: IMPACT ENCOUNTERED DURING INITIAL IMPLEMENTATION OF PAIN-FREE HOSPITAL INITIATIVE (PFHI) IN RWANDA**

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*Mr Vedaste Hategekimana, Rwanda Biomedical Center (RBC), Rwanda*

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Rwanda has clinical pain management guidelines, developed in 2012, as well as a national palliative care policy developed in 2011, with the goal that all people with life-limiting illness will have access to quality palliative care services delivered in an affordable and culturally appropriate manner by 2020. Even with the availability of pain relief, these medicines remain under-prescribed, particularly among patients reporting moderate to severe pain. Therefore, Rwanda's Ministry of Health (MOH) is partnering with the American Cancer Society (ACS) to integrate pain treatment into service delivery through

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the Pain Free Hospital Initiative (PFHI) by providing education for patients and staff, raising motivation and awareness among hospital staff, measuring and documenting pain levels, improving medicine supply, and communicating impact. All patients in need have the right to be pain-free. The MOH has collected data on patients' pain scores and consumption of oral morphine solution after a short term the initiative started in five hospitals.

Onsite training on pain assessment and management among health care providers has resulted in a significant increase in the consumption of oral morphine solution and a decrease in patients reporting pain scores indicating moderate and severe pain. Hospital leadership is key in sustainability of this quality improvement project.

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### 12.25 – 12.35

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#### A085: 'END OF LIFE CARE IS EVERYONE'S BUSINESS' – ENABLING UP SKILLING OF GENERALIST IN PALLIATIVE CARE USING ADAPTED GSF TRAINING PROGRAMMES FROM THE UK TO INCREASE SCOPE AND REACH OF CARE

*Prof Keri Thomas, National Gold Standards Framework (GSF) in End of Life Care, UK*

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The need for enhanced care in Africa for those in the last years of life is significant, Most is delivered by frontline staff, yet there is limited training in generalist palliative care skills. The Gold Standards Framework (GSF) Centre is the UK's leading training provider for generalist palliative care in hospital and community, enabling proactive, personalised systematic care.

This abstract aims to facilitate a discussion on the possibility of sharing the learning from our UK experiences, to enable generalists in the African context improve palliative care skills, through an adapted version of GSF, including advance care planning discussions.

Use of an evidence-based generalist palliative care training programme (GSF) can improve spread and quality of palliative care provision as evidenced in the UK. Building on this initial positive experience, further pilots of adapted GSF contextualised for African settings are suggested, modified tools and resources enabling greater reach for larger populations of people.

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### 12.35 -12.45pm

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#### B016: DEVELOPING A COMMON PALLIATIVE CARE LANGUAGE IN AFRICA

*Elizabeth Scrimgeour, Drakenstein Palliative Hospice, Paarl, Western Cape South Africa*

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The creation of symbols and defining palliative care in a visual language will enable us to bridge the language barrier and develop a common language to use and communicate palliative care for all. This abstract presents co-created definitions and services of palliative care to create a common language. Symbols have been created to describe 'African' holistic and palliative care.

The palliative care barriers were identified as was the basic palliative care services: Specialised Medical and Nursing Care; Home Based Care; In-patient Care; Psychosocial and Spiritual Care; Physical Care and Paediatric Care. The additional services such as PC Training, Advanced Care Planning, Chronic Medication, TB and HIV Adherence and Support and Private PC all have their own symbols. Symbols have been designed, for example to designate what makes PC unique, the core PC principles, a Systems Map was designed and core sustainability issues are documented.

Having an agreed understanding of symbols even by people who do not share a common language or culture. This is an essential element of ensuring the availability of quality palliative care for all.

## TRACK 3: HEALTH FINANCING AND PALLIATIVE CARE

**11.00 –11.10am**

### C004: USING BIG DATA ANALYTICS IN ASSESSING THE TECHNICAL EFFICIENCIES GAINED THROUGH INTEGRATION OF PALLIATIVE CARE IN ZIMBABWE'S HEALTH SYSTEM - A PROTOCOL

*Mr Chenjerai Sisimayi, DevIntel Advisory Services, World Bank*

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Zimbabwe is embarking on an ambitious initiative to integrate palliative care in the health system. This study aims to assess the cost-effectiveness of integrating palliative care in the system with a focus on patient outcomes in relation to provider costs through advanced analytics of electronic health records in service delivery. The findings are envisaged to contribute to a better understanding of opportunities to enhance implementation efficiencies in health care service delivery in Zimbabwe. Furthermore, the validation of the applicability of machine learning would make a strong case for integrating such algorithms within the EHR system in order to support early detection of inefficiencies and flag inappropriate care.

**11.10 –11.20am**

### C007: WHO TAKES CARE OF THE COST? CASE REPORT OF ABDOMINAL WALL DEFECTS AMONG NEWBORNS AT HOMA BAY COUNTY TEACHING AND REFERRAL HOSPITAL, KENYA.

*Dr Meshack W Liru, Dr Nyamoita Phylis Mongera, Linda Awino Tindi, Nyimbae Alice, Homabay County Teaching and Referral Hospital*

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It is important to sensitise authorities that investment in human, infrastructural and financial resources is needed for successful UHC. This presentation is based on experience at Homabay County Teaching and Referral Hospital where five neonates died before referral or shortly after surgery. None of the affected families had a medical insurance to cater for their treatment. The only tertiary center to handle such neonatal emergencies was situated about 200 km away. We need to build up human resource skills and knowledge to address such complex emergencies. We need to address infrastructural challenges and invest in transport incubators for neonates health insurance needs up-scaling to cover most families.

**11.20 –11.30am**

### B021: PROMOTING PRIVATE ORGANISATIONS IN SCALING UP PALLIATIVE CARE IN HIGHER LEARNING INSTITUTIONS THROUGH TRAINING AND RESEARCH IN TANZANIA

*Dr Owino, Ocean Road Cancer Institute & Elvis Joseph Miti, UZIMA Project Ndanda, Tanzania.*

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For more than 25 years, Tanzania has been working hard to make palliative care available to all. National policy guidelines and standard operation procedures are now in place. There are, however, some major challenges for officially training different professionals to provide this service. The Palliative Care Training and Research (PTR) in Tanzania was founded in 2012 to address this challenge.

There are a lot of individuals and institutions in Tanzania that would like to promote palliative care but there are still some challenging issues related to the traditional formal medicine and its practice in the country. It is important to encourage and support the skilling of service providers through different training and mentorship approaches.

### 11.30 – 11.40am

#### B019: STRATEGIC ADVOCACY THROUGH REPORTING ECONOMIC OUTCOMES AT HOUSEHOLD LEVEL - CAN PALLIATIVE CARE SUPPORT POVERTY REDUCTION IN LMIC?

*Dr. Maya Jane Bates, Department of Family Medicine, College of Medicine, Malawi. Liverpool School of Tropical Medicine, Malawi Liverpool Wellcome Trust*

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This is Safeguarding the Family Study to assess the relationship between palliative care, wellbeing and total household expenditure on health for households affected by advanced cancer in Blantyre, Malawi. This prospective, longitudinal, observational study will recruit >200 patients and their primary unpaid carers follows a first time diagnosis of advanced cancer at Queen Elizabeth Central Hospital, Blantyre. Data is collected at time of diagnosis, at one, three and six months (or to the time of death). Results are to be shared.

### 11.40- 11.50am

#### A056: STRATEGIES FOR IMPROVING ACCESS TO ORAL LIQUID MORPHINE FOR PALLIATIVE CARE PATIENTS IN TANZANIA

*Theodora Lwanga, Daudi Msasi, Sarah Maongezi, Ministry of Health-Tanzania; Nazma Darzhe, Mary Haule, Ocean Road Cancer Institute, Dar es Salaam, Tanzania; Kerenge Nyakangara, Monday Mwabulanga, Godlove Mbanji, Mbeya Zonal Referral Hospital-Tanzania; Christopher Ntege, Hospice Africa Uganda*

**Email: [thelwanga@yahoo.com](mailto:thelwanga@yahoo.com)**

Ocean Road Cancer Institute (ORCI) sees over 300 cancer patients monthly. Approximately 180g of morphine is needed monthly for the 300 patients. ORCI is reconstituting an average of 340g monthly. There is a huge gap to left to have greater coverage that requires approximately 30kg per year. Only 68 out of over 7000 health Units provide palliative care services in Tanzania.

The Ministry of Health, in partnership with key stakeholders seeks to increase availability and access to palliative care services and especially oral liquid morphine solution from the current 68 to 184 health Units in Tanzania. It is planning to enable four regional oral morphine reconstituting centers (KCMC, Mbeya Regional Referral Hospital, ORCI and Bugando Hospital), which will supply up to a targeted 184 health units countrywide. The Medical Stores Department will import the powder and supply to the 4 centers that will eventually supply the morphine to their respective catchment health units.

Ministry of Health Partners and stakeholders including the Evangelical Lutheran Church Tanzania (ELCT), African Palliative Care Association (APCA) and the Open Society Initiative for East Africa (OSIEA) have come together and initiated engagement with each other and with the Pharmacists to advocate for increased access. In March 2019 (Arusha) there was a strategic engagement of the pharmacists in advocacy for palliative care that aimed to seek ways to eliminate bottlenecks in access to PC and morphine. This meeting resulted in the creation of a pathway that will see oral morphine reconstituted in 4 regional sites, a move that will greatly increase access and service delivery.

### 12.05–12.15pm

#### A73: FACILITATING POOR PEOPLE TO ACCESS TREATMENT FOR CANCER

*Mutaasa Allan & Dr Margrethe Juncker, Rays of Hope Hospice Jinja, Uganda Uganda*

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People with cancer in rural areas of Uganda rarely access treatment. Rays of Hope Hospice Jinja enrolls many people who could possibly benefit from treatment but cannot access it due to financial and other constraints. A treatment programme was established to aid referral for interventions that would result into a cure or improve the quality of life of the patients. The aim is to improve the quality of life of poor cancer patients by facilitating their investigations, prescribed drugs, radiotherapy, chemotherapy, surgery, transport to the hospitals and upkeep while in the hospitals.

From 2016 to 2018, a total of 169 patients were supported to access testing and treatment at the Uganda Cancer Institute, HIV/AIDS specialised clinics and the regional referral hospitals. The most common reason for referral was the AIDS related cancers of Kaposi's sarcoma and cervical cancer. More than 75% of the patients improved and are now on their way back to health. Palliative care treatment improved the quality of life of patients. The average support given per patient was UGX 465,272 (US\$ 130), which goes to travel, investigation, treatment and upkeep while in the hospital.

With limited financial support, poor people can successfully be helped to access treatment interventions for their cancers.

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## 12.15 –12.25pm

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### A105: “TOOLS TO HELP US IDENTIFY PATIENTS WITH PALLIATIVE CARE NEEDS IN INTERMEDIATE CARE HOSPITAL”

*Montserrat Soldevila, Jordi Amblas, Joan Espauella, Emma Puigoriol, Santa Creu De Vic University Hospital, Spain*

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Over the years, in Catalunya we incorporated three key elements of modern palliative care: 1) Early identification of people with palliative care needs, using the instrument NECPAL (palliative needs); 2) In addition to cancer, including people with advanced organ diseases and advanced dementia 3) Incorporating the concept of advanced fragility as a transversal element.

The aim was to evaluate the correlation between hospital mortality and preliminary identification of the end of life through the NECPAL instrument and know the relation between fragility level and the hospital mortality with the help of Frail-VIG index (FVI).

272 patients were included in the study, of which 86 died during the hospitalisation (31.6%). 65.9% of patients NECPAL positive (identified as patients with advanced chronic disease) died during the hospitalisation; on the other hand patients NECPAL negative had 33.8% hospital mortality. Patient mortality without fragility (low FVI punctuation) was 17.3% while patient mortality of advanced fragility (high FVI punctuation) was 46.3%.

NECPAL tool detected 66 % of patients who died during the hospitalisation. The FVI has a good correlation with hospital mortality and can help at the moment of making decision on individual cases. The end of life is an individual process but having elements like NECPAL tool and Frail-VIG index help professionals to make decision. In geriatric patients, the fragility level and fragility progression are key elements at the moment of evaluations of the end of life.

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## 12.25 –12.35pm

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### A030: TIMING OF REFERRAL TO SPECIALIST PALLIATIVE CARE IN A TEACHING HOSPITAL IN GHANA

*Dr Kathryn Spangenberg, Michael Owusu-Ansah, Eseenam Agbeko, Alberta Delali Dzaka, Rasheed Oforu-Poku, Mary Owusu Appiah, Gladys Anyane, Komfo Anokye Teaching Hospital*

**Email: [alienph1215@gmail.com](mailto:alienph1215@gmail.com)**

The over-arching objective of palliative care is to improve the patient's and family's experience of chronic illness and their quality of life. An essential pre-requisite is a timely referral to specialist palliative care. The aim of this study was to determine the timing of referral to specialist palliative care in a teaching hospital in Ghana.

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Data was obtained from the registry of the palliative care team. Of the 78 entries made between August 2016 and September 2018, 39 of them had the date of first palliative care consultation and death completed. SPSS Version 20 was used to analyse the data.

Majority (31) were females, 66% were less than 60 years of age, and 35 (89.7%) were referred on account of an advanced malignancy. The referral of 28 (71.8%) of them had no specific reason for palliative care stated apart from the expression 'for palliative care'. Majority (61.9%) spent less than four weeks under the care of the palliative care team, and 69.2% had only one palliative care consultation before death. Patients tend to be referred for palliative care quite late and this may limit the benefits of improvement in quality of end-of-life care. Physician education and sensitisation may be required to improve referral practices.

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**12.35 -12.45pm**

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### A096: EXPLORING EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CANCER AT NDIMOYO PALLIATIVE CARE CENTRE

*Rex Robert Chinzu, Ndi Moyo Palliative Care Trust, Malawi*

**Email: chinzurexrobert@yahoo.com**

In Malawi, cancer care is provided in two main central hospital thus at Kamuzu Central Hospital in the capital Lilongwe and Queen Elizabeth Central Hospital in Blantyre which are 350 km apart. Caring for children with cancer has also impacted the life of carers when taking care of children with cancers. The caring role may affect the carers in the perspective of physical, psychological, social and spiritual aspects. The study aimed to explore the physical, psychological, social and spiritual experiences of carers of children with cancers at Ndimoyo Palliative Care Centre in Malawi.

Four key themes were identified from the data covering physical, psychological, social and spiritual issues with sub-themes under each of them. There was an overall theme of physical issues experienced by caregivers which included sub-themes of; inability to sleep, loss of appetite, weight loss, no preferred food for child with cancer and long distances to hospitals. Sub-categories that emerged from psychological theme included: fearing death of the child, loss of interest in other people and surrounding (depressed), anxiety of health status of the sick child and carers felt children with cancer were stigmatised subcategories that emerged spirituality: hope of cure from God, rejection from God and support from fellow church members.

Caregivers often have to balance competing needs and priorities and they may need support from health professionals to help them recognise and mobilise their own resources to take care of their child with cancer. The support should focus on the physical, psychological, social and spiritual aspects in helping carers of children with cancer in their caring role at home and hospital.

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## **TRACK 4: EFFECTIVE PARTNERSHIPS AND COLLABORATIONS IN ENHANCING ACCESS TO PALLIATIVE CARE AS A COMPONENT OF UNIVERSAL HEALTH COVERAGE**

**11.00 –11.10am**

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### D038: THE ROLE OF RELIGIOUS ENTITIES IN ENSURING QOL OF PATIENT WITH LIMITING ILLNESSES VIA PALLIATIVE CARE SERVICES.

*Gasana Udahemuka Magnus, Karamuka V, Kayitesi C, Hakizimana F, Munezero C, Tushaidi T, Mitsinga L, Nyirahirwa R, Mukasahaha D, Nyundo Martin, Rwanda*

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Integrating a palliative care programme in clinical settings has a significant interest in delivering good clinical services and assuring quality of life of patients and families. The aim of the programme was to change the clinical attitude of treating the disease and treating the person holistically.

A KAP (knowledge attitude and practice) study of the attitudes of practitioners in Kigali Teaching Hospital (CHUK) was conducted. It found that the programme improved significantly the pain management attitude and improved the practice of addressing patients holistic needs.

Reinforcing psycho education among health care providers in different departments and integrating palliative care in existing services has significant importance than stand alone service programme. Palliative care training needs to be given to in different disciplines (physicians and paramedicals) in order to enable students to perform during their professional time.

**11.10 –11.20am**

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## D029: COLLABORATING WITH TECHNICAL PARTNERS TO FORGE TOWARDS UHC FOR OLDER PERSONS

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*Forster Matyatya, Island Hospice and Healthcare Marondera Branch Coordinator*

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Universal health coverage (UHC) is about ensuring that people have access to the health care they need without suffering financial hardship. This presentation demonstrates how Island Hospice in collaboration with technical partners are using the human rights approach to promote UHC among older persons in Marondera District. Older persons (OP) have been empowered to claim their rights in health, improved access to quality health care and reduced the costs of accessing health care and economically empowered them to live better lives. Out-of-pocket spending on health by OP has reduced. The training of medical staff in geriatric health care and the use of older persons champions in monitoring the quality of health services being provided has positively influenced the attitudes of health workers towards OPs and quality of care provided. The main lessons are: establishing long-term relationships with strategic local organisations and government departments to press towards UHC for OPs is rewarding and brings improved quality of life to those in later years; active involvement of OPs who were perceived as the natural recipients of welfare handouts, and institutionalised services improves the value of OPs in society.

**11.20 –11.30am**

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## A136: EXTENDING PALLIATIVE CARE TO THE DEAF COMMUNITY TO ENHANCE ACCESS TO SERVICES IN UGANDA

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*Rose Kiwanuka & Mark Mwesiga, Palliative Care Association of Uganda*

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In Uganda, over 1,083,649 people are deaf, accounting for 3% of the total population. Their right to health is compromised because of communication challenges. The Palliative Care Association of Uganda (PCAU) together with the National Association for the Deaf (UNAD) agreed to introduce palliative care to the deaf community to align with the global agenda 2030 central theme of leave no one behind. The deaf are vulnerable with special palliative care needs that require attention. Lack of a common language between health workers and the deaf is a major barrier for the latter to access health care services. Deaf persons' conditions are mismanaged because of miss communication. Knowledge to basic sign language gives confidence to health workers to attend to the Deaf persons.

The aim of this initiative was to sensitise deaf persons about palliative care (PC), identify their needs, then sensitise palliative care practitioners, develop a deaf awareness module and train health care workers in basic sign language to bridge the communication gap.

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One cohort of nurses from two regions with high population of deaf persons were sensitised about the needs of deaf persons and empowered with basic knowledge and skills to communicate with the deaf persons. They are helping other health workers to communicate with the deaf. Stigma among the deaf is being addressed. Health workers are friendly to the deaf and the latter feel comfortable with nurses who can sign.

Sign language should be a mandatory module in the curricula of health Institutions; hospitals should have sign language interpreters; health workers should be quick and helpful to deaf persons; health workers need to be patient and mindful as they treat the deaf persons and sensitisation of health workers on the needs of the deaf is crucial.

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**11.30 -11.40am**

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### D033: THE ROLE OF PARTNERSHIPS IN PAIN EDUCATION: THE KENYAN SITUATION

*Dr. Hellen N. Kariuki, University of Nairobi*

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Non-communicable diseases (NCDs) are on the rise in Kenya with an inpatient bed occupancy of over 50% and majority require pain management. This presentation outlines the role of pain education partners and collaborators in pain education in Kenya. The players to date in the collaborative efforts of pain education include the Ministry of Health which launched the palliative care training curriculum that has six hours on pain and pain management. The university of Nairobi provides trainers and facilitators. APCA and KEHPCA availed the APCA pain tool and beating pain – a pocket book for pain management in Africa. KEHPCA has conducted training sessions in the hospices and private hospitals as well as in the palliative care units under the Ministry of Health around the country. Kenya Society for pain that convenes pain CMEs and has collaborated with Kenya Anesthesia Society to conduct pain education during their annual conference. International Association for the Study of Pain (IASP) availed eleven Pain Education in the Developing Countries grants over a period of nine years. The Pain-Free Hospital Initiative, a one-year hospital-wide quality improvement initiative that aims integrate pain treatment into routine hospital care trained over five hundred healthcare workers on pain in the country. Essential pain management in collaboration with the Anesthesia Society conducted ToT training and has invites to several hospitals. The Nairobi Hospice runs a diploma programme whose content includes pain and pain management. There is a need for innovative approaches and better integration of pain topics into medical school curricula and post basic training programmes.

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**11.40 – 11.50am**

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### D020: DOING MORE WITH LESS: COLLABORATION ACROSS THREE ESSENTIAL SERVICES (PALLIATIVE CARE, HIV/AIDS CARE, AND CERVICAL CANCER SCREENING) TO CO-ORDINATE PREVENTIVE CARE FOR AT RISK HIV+ WOMEN AND EARLIER PALLIATIVE CARE FOR INCURABLE DISEASE.

*Dr Leah Norgrove & Dr Ambrose March, Island Health Authority, Saanich Peninsula Hospital; Dr Violet Bakari, Care and Treatment Clinic Facility Incharge, Bombo Regional Referral Hospital, Tanga, Tanzania*

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In 2017 data at Bombo Palliative Care Project (BPCP) showed a shift away from HIV/AIDS as the most responsible diagnosis for palliative services, towards cancer as the leading diagnostic category. The most common female cancer was cervical cancer (48%) with undue burden of preventable death for women age 30-50. PC providers at the Bombo Regional Referral Hospital Care and Treatment Clinic for HIV/AIDS (CTC) work collaboratively with Canadian mentors/funders to provide supportive palliative services for all diagnoses in Tanga. Focus has now broadened to introduce cervical cancer screening (CCS) embedded in CTC care for at-risk women, to pursue diagnosis and treatment of pre-cancerous and earlier stage cervical cancer to reduce the most common cancer diagnosis on our palliative programme. Close collaboration between three essential services (PC, HIV/AIDS care and CCS) may help to streamline and organise care for at risk women in resource limited settings. Organising services under one roof (CTC) allows for improved access to preventive services, earlier referral for palliative care, improved continuity of care and cross-coverage of limited staff resources.

**12.05 –12.15pm**

## A129: FROM N'DORO PROJECT TO THE GAUTENG CENTRE FOR PALLIATIVE CARE: PALLIATIVE CARE ACCESS AT CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

*Dr Mpho Ratshikana-Moloko, Charmaine Blanchard, Keletso Mmoledi and Mfanelo Sobekwa, Chris Hani Baragwanath Academic Hospital, University of Witwatersrand, South Africa*

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South Africa faces a high burden of disease. Universal Health Coverage includes palliative care, but access is limited. The Gauteng Centre for Palliative Care is one of the few hospital-based palliative care services in South Africa, providing comprehensive palliative care consultations, training, research and advocacy. This review aims to evaluate progress on implementation of palliative care at the Gauteng Centre for Palliative Care compared to the initial N'Doro Project.

We conducted a desktop review of the initial proposal documents for the N'Doro Project, strategic documents and annual reports. These were compared with similar documents for the Gauteng Centre for Palliative Care. Patients information was extracted from the Access database and analysed using Stata version 15.

Since 2010, 32,485 patients visits were conducted. Annual visits increased from 1,500 to an average of 3,200. Over 1,500 medical graduates were trained in palliative care. Palliative care training has been introduced into the clinical associates and Family Medicine registrar training programmes. Over 20 research publications have been produced. Challenges encountered include resource limitations. Institutions should identify champions with passion to initiate palliative care programmes. Ministries of Health and local organisations can partner to ensure access to palliative care across all levels of care.

**12.15 –12.25pm**

## D036: THE ESSENCE OF PARTNERSHIPS: EXPERIENCE OF PAEDIATRIC PALLIATIVE CARE WITHIN A PAEDIATRIC HAEMATOLOGY-ONCOLOGY PROGRAMME IN MALAWI

*Rhahim Bank, Mercy Butia<sup>1</sup>, Global HOPE (Hematology-Oncology-Pediatric-Excellence), Baylor College of Medicine (BCM), Lilongwe, Malawi; Minke Huibers, Nmazuo Ozuah, Baylor College of Medicine (BCM), Texas Children's Hospital, Houston, USA*

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Childhood cancer in Sub-Saharan Africa (SSA) affects over 100,000 children annually. While the survival in Western countries is over 90%, in SSA, about 90% of the children die. Inadequacies in healthcare systems, late recognition of symptoms by guardians, delayed diagnosis as well as limitations in availability of chemotherapy and specialised care contribute to the dismal outcomes. Our programme aimed to demonstrate experience and challenges of establishing palliative care services in a pediatric hematology-oncology programme, and highlight opportunities for improvement.

Our programme has established that a key mission goal is screening all patients to assess needs, and providing palliative care to all who need it. Our strategies include – investing on training of staff to develop expertise, and collaboration with other institutions, and Palliative Care Association of Malawi, to strengthen the regional palliative network through education, outreaches and targeted workshops. In Malawi, currently specialised care is provided to children in the Northern and Central regions of Malawi, which includes about 300 new oncology diagnoses yearly.

Since 2017 Global HOPE Malawi has established pediatric palliative care services aimed at symptom recognition and management, and improvement in quality of life for children with cancer or hematological disorders and their guardians. Till date >40% of our patients have benefited from palliative care. We have had more success with inpatient care. This includes pain and nausea management, counseling and bereavement support. Although outpatient care has been challenging given the travel distances, and difficulties communicating with families upon discharge, we have succeeded in conducting about 9 home visits.

**12.25–12.35pm**

### D047: FINANCIAL MANAGEMENT OF MULTI COUNTRY AND MULTI PARTNER GRANTS- EXPERIENCES AND LESSONS FROM APCA

*Josephine Kampi, African Palliative Care Association*

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The civil society organisations (CSOs) remain the biggest providers / advocates of palliative care in Africa. These CSOs largely depend on donor funding to deliver on their mandates. Given the lack of big donors in the field, the majority rely on multiple grants which come with varying grant management requirements. The purpose of this presentation is to share best practices and lessons for effective financial management of grants from multiple donors with varying compliance requirements, which may be implemented in multiple country settings. Main lessons include: understanding donor compliance requirements is key in donor satisfaction; meeting statutory obligations; Continuous professional development (CPD) to be abreast with new accounting standards; practicing good accounting principles; use of the chart of accounts is useful in streamlining cost centres; having a centralised filing system. The key recommendations are: collaboration between Finance and Technical departments is key to financial compliance; streamlining accounting and finance management systems; regular budget tracking and variance analysis; a system for allocating and capturing a specific donor for each transaction made; use of a grants database to track and manage grants.

**12.35 -12.45pm**

### A008: 40 YEARS' EXPERIENCE IN PALLIATIVE CARE; ISLAND HOSPICE & HEALTHCARE'S LESSONS FROM PARTNERSHIPS WITH GOVERNMENT AND CBOs

*Franciscah Tsikai, Island Hospice and Healthcare Zimbabwe*

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Zimbabwe was the first country to practise palliative care in Africa through Island Hospice and Healthcare. However, the country is still lagging behind, as other countries are already teaching palliative care at tertiary institutions and nurses are prescribing morphine. In this 40th year of practice, Island has acquired funding necessary and is the technical lead in integrating palliative care into the nation's health delivery system. The aim is to meet the palliative care need within the constraining environment, address a gap in palliative care knowledge and provision in the country to ensure equitable delivery of palliative care by knowledgeable practitioners, and availability of palliative care medications.

Programme approach involves: partnering with the Ministry of health and Child care as well as Hospice Association of Zimbabwe (HOSPAZ), tertiary, pre-service institutions for medical and paramedical training, traditional and faith healers, clergy, as well as other CBOs providing palliative care; engaging the Medicines Control Authority of Zimbabwe to create regulations which will enable nurses to prescribe morphine for palliative care patients; develop palliative care curricula for different pre service cadres across the board and a training module for health professionals who are already practicing.

Integration is possible if the MOHCC owns the process as they are responsible for overseeing policy formulation and playing a regulatory role in collaboration with other regulatory authorities. The regularisation of the relevant laws is pivotal enabling nurses to prescribe. National Strategic Plan is important in guiding the implementation of palliative care in the country. Partnering with key players such as HOSPAZ and CWGH and other local CBOs is crucial as they play a role in advocacy.

**FRIDAY 20<sup>TH</sup> SEPTEMBER 2019**

## **TRACK 1: PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE**

**11.00 – 11.10am**

### **A036: INVOLVEMENT OF PALLIATIVE CARE LINK NURSES TO LEVERAGE PALLIATIVE CARE DELIVERY - CASE OF KIBAGABAGA HOSPITAL, RWANDA**

*Dr Eugene Ruberanziza, Rose Gahire, Grace Mukankuranga, Marthe Mukaminega, Consolée Mukamurenzi, Palliative Care Association of Rwanda (PCAR)*

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The Government of Rwanda has put efforts into integration of palliative care (PC) in public hospitals and availability of strong pain management drugs (opioids) in country. However, the need of essential palliative care package is still unmet. There are still huge gaps in patient care outside hospital ward.

The Palliative Care Association of Rwanda (PCAR) is implementing a one-year project involving Palliative Care Link Nurses (PCLNs) to leverage PC service delivery. Through trained PCLNs the project will attempt to i) promote best practices through education, clinical procedures and resource use; ii) follow up patients by health center staff, community health worker (CHW) cell coordinators and CHWs at village level to improve on continuum of care at levels.

All hospital wards were targeted for availing one to five nurses to be trained as PCLNs who will play key role in PC service delivery. In collaboration with the Rwanda Biomedical Center and Kibagabaga hospital, PCAR has organised the training of PCLNs followed by monthly follow up meetings with those trained. Quarterly meetings with health centers and CHW cell coordinators are also being conducted to establish the link between them and PCLNs. Registers used for data collection and monitoring were distributed to hospital, HCs and CHW cell coordinators.

**11.10–11.20am**

### **A084: PHYSIOTHERAPY: PALLIATIVE AND HOSPICE CARE INTEGRATION IN THE ZIMBABWE UNIVERSAL HEALTHCARE SYSTEM**

*Dr Lubayna Fawcett, Island Hospice and Healthcare, Zimbabwe*

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Physiotherapy is an essential component of quality palliative and hospice care delivery; yet, underutilised. The professional body of knowledge encompass the life-spectrum with emphasis on improving quality of life through symptoms management and rehabilitation. Island Hospice and Healthcare, the first established hospice in Africa recognised the value and took the initiative to integrate physiotherapists in the Zimbabwe Universal Healthcare system. The aim is to understand the importance of physiotherapy integration from its role and functions in the context of interdisciplinary approach application to best practice in palliative and hospice care delivery.

Within two years, Island Hospice and Healthcare, Zimbabwe: a. Achieved integration of palliative and hospice care with full endorsement by Zimbabwe Ministry of Health (MOH). b. Established physiotherapy services as essential component within palliative and hospice care interdisciplinary team. c. In collaboration with Zimbabwe University, conducted two-day workshops in three different regions on role and functions of physiotherapy in palliative and hospice care. d. Collaborated with Zimbabwe University to devolve entry-level curriculum for health science professions. e. Provided physiotherapy services to appropriate palliative and hospice patients. f. Selected for evaluation by the WHO on being a demonstration site. Physiotherapy is an essential component of interdisciplinary palliative and hospice care team.

### 11.20–11.30am

#### A063: EXPERIENCES OF PALLIATIVE CARE PATIENTS AND THEIR FAMILY CAREGIVERS IN SUB-SAHARAN AFRICA. AN INTEGRATIVE REVIEW

*Bisi Adewale, University of Alberta*

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In Sub-Saharan Africa, communities and families of palliative patients are usually laden with care for their relatives diagnosed with incurable diseases because of limitation in the health care systems. In the integrative review of experiences of palliative care patients and their family caregivers in Sub-Saharan Africa, it was found that females were mostly identified as family caregivers for palliative care patients. Family caregivers were found to perform tasks which required high-level skills when caring for patients. The burden that family caregivers experience during caregiving affects their social, physical and emotional wellbeing. In some cases, palliative patients mentioned how their family caregivers shoulder the responsibilities of caring for them alone, cry a lot, lose weight and also worry about them. Patients and family caregivers in the milieu of limited support from the health care system developed their own coping strategies. The individual's culture was found to play an important role in the decisions made on the role perform and the decision made on the advance care plan. Access to health care and other support systems was found to be an issue in some Sub-Saharan African countries.

### 11.30 –11.40am

#### A068: UNDERSTANDING THE ROLE OF DIGITAL TECHNOLOGIES TO ENHANCE PALLIATIVE CANCER CARE DELIVERY IN SUB-SAHARAN AFRICA

*Dr Kennedy Bashan Nkhoma, Kings College London, UK; Kehinde Okunade, David Akeju, University of Lagos, Lagos, Nigeria; Omolola Salako, Lagos University Teaching Hospital, Nigeria; Bassey Ebenso, Leeds Institute of Health Sciences, UK; Elizabeth Namukwaya, Makerere University, Kampala, Uganda; Mike Chirenje, University of Zimbabwe, Harare; Eve Namisango, Emmanuel Luyirika, African Palliative Care Association; Henry Ddungu, Uganda Cancer Institute; Lovemore Mupaza; Adlight Dandadzi; Eliza*

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This study seeks to engage key stakeholders in Nigeria, Uganda and Zimbabwe to define optimal mechanisms through which patient-level data captured via digital technologies can be used in the development of palliative cancer care in Sub-Saharan Africa. Mapping information and data needs across palliative care services will enable subsequent piloting and evaluation of digital health interventions and validation of data they capture, development of patient-focused digital health interventions (e.g. information provision and self-management support), and exploration of the influence of factors such as gender, intersectionality, disability and cancer type on utilisation and engagement with digital health approaches.

### 11.40am –11.50pm

#### A071: THE PALLIATIVE CARE NEEDS OF DRUG-RESISTANT TUBERCULOSIS (DR-TB) PATIENTS THAT GO UNMET DURING THEIR TREATMENT JOURNEY

*Dr Shannon Odell, Living Hope Hospice, Fish Hoek, Cape Town, South Africa; Dr Rene Krause, Associate Professor Liz Gwyther, Department of Palliative Medicine, School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa*

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The palliative care needs of DR-TB patients have been under-researched globally but are pertinent in the holistic management of these patients. The objective of this study was to

determine the palliative care needs of adult patients with drug-resistant tuberculosis living in the southern sub-district of Cape Town. DR-TB patients have significant palliative care needs regardless of the presence or absence of pain. These unmet needs jeopardise treatment compliance, infection control and thus TB eradication. In this sub-district of Cape Town context, drug- and gang-related violence threaten the provision of patient-centred care. A palliative care approach should

therefore be implemented from DR-TB diagnosis and throughout the treatment period – regardless of treatment outcome and not only at the end of life. Clinicians need education regarding the ethical obligation and benefits of providing palliative care to DR-TB patients. Budgetary provisions for palliative care and community safety require political will.

**12.05–12.15pm**

### A091: THE BENEFITS OF PALLIATIVE CARE FOR PATIENTS WITH CHRONIC HEART FAILURE

*Joy Hunter, University of Cape Town, South Africa*  
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Patients with end-stage heart failure experience similar clinical symptoms as patients with advanced cancer, including significant physical and emotional suffering. However, in the South African setting, palliative care is still mainly provided for people with cancer or HIV. The aim of the study was to investigate the benefits of palliative care for patients with chronic heart failure at a hospital-based palliative care service. Findings from this study supports the importance of palliative care for people with heart failure. The data supports the fact that early referral for palliative care resulted in greater symptom control and benefit to the patient long before hospice care is needed. Previous studies have proven to reduce re-hospitalisation rates of this population while reducing costs to the healthcare system.

**12.15 –12.25pm**

### A050: ASSESSING THE PALLIATIVE CARE NEEDS OF ELDERLY PATIENTS SEEN AT THE UNIVERSITY COLLEGE HOSPITAL, IBADAN, NIGERIA

*Dr Omoyeni N.E, Soyannwo O.A, University College Hospital, Ibadan, Nigeria; Liz Gwyther, University of Cape Town, South Africa*  
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Nigeria, the most populated nation in Africa (UN2005), now 190 million, with 5% of the total population aged 60 and above. Hence, there is the potential for a rapid growth rate of the older population in coming years. It will be difficult meeting the various needs of the elderly with limited number of healthcare professionals and care homes, hence, the importance of identifying the needs of the elderly. The aim was to assess the palliative care needs of and provision of care to elderly patients seen in the selected clinics of the University College Hospital, Ibadan, Oyo state, Nigeria.

A descriptive cross-sectional study was conducted over a 3-month period using an interviewer administered questionnaire after full consent was given by participants. 424 participants completed the questionnaire. The socio-demographic data described age, gender, marital status, education, place of abode and diagnosis. Most patients were recruited from the geriatric wards 330(77.8%) with a 2:1 female to male ratio. Most participants fell in the 60-69 age group. Most common symptom was pain in 240 patients with moderate pain in single or multiple areas. A high percentage, 45.8% were moderately worried about their disease condition and only 66 out of 422 freely discussed this feeling with their family members. Other symptoms observed were nausea, vomiting, constipation and loss of appetite.

Palliative care service should be made a priority and training of health professionals interested in this field should be supported to increase the resources to meet the needs of a growing elderly population. Palliative care education through institutional or country taskforce dedicated to enhancing global awareness and updating curricula to train healthcare professionals in palliative care.

**12.25 -12.35pm**

### A066: PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE; MITIGATING PSYCHOLOGICAL TRAUMA, DEPRESSION AND STIGMA FOR PEOPLE LIVING WITH HIV AND AIDS THROUGH THE NARRATIVE APPROACH

## 6th International African Palliative Care Conference

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

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Awareness of HIV and AIDS in Kenya is high but stigma is still experienced among people living with HIV and AIDS. The supportive environment created through support groups and providers of palliative care is correlated with reducing apprehension and depression among people living with HIV although psychological issues are not adequately addressed. The aim of the intervention was to demonstrate how palliative care interventions using the narrative approach can be used to mitigate the effect of depression, psychological trauma and stigma among people living with HIV and AIDS.

The finding was a reduction in the impact of event for all intervention groups on the impact of event scale (IES-R). On the depressive scale, all members in the intervention groups moved from severe depression to moderate 37(75%) and mild 13(25%). The stigma scale indicated that 30 (60 %) of the participants improved to moderate and mild while 20(40%) remained with severe stigma. The control group results showed no change on the indicators of depression, stigma and psychological trauma. Community level palliative care approaches can be used to mitigate psychological trauma, depression and stigma among people living with HIV and AIDS. Innovative ways of inclusion would facilitate access to people living with HIV and AIDS and contribute towards Universal Health Coverage.

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**12.35pm – 12.45pm**

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### **A095: CPE TRIAGE SYSTEM FOR INTEGRATING PAEDIATRIC PALLIATIVE CARE INTO A TERTIARY LEVEL CHILDREN'S HOSPITAL IN CAPE TOWN, SOUTH AFRICA.**

*Dr Michelle Meiring, Paedspal and University of Cape Town, South Africa*

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The provision of specialist paediatric palliative care to children with complex needs as part of Universal Health Coverage, needs an equitable and efficient approach. This enables children most needing this care to access it whilst those that can be managed by generalists still receive quality integrated palliative care. The aim of this project was to develop a triage system that helped an NGO-funded specialist consultative paediatric palliative care service provide a focused and efficient service to patients that needed them the most.

A CPE triage system was developed whereby we prioritised our teams' interventions and decided which patients needed to be seen by which team members and how often. Three key intervention domains were identified: C= Clinical, P = Psychosocial and E = Ethics. Following first assessment patients were prioritised into three levels for each domain. Level 1= top priority (urgent need for plan), Level 2 = intermediate priority (plan made, monitoring needed) and level 3 = low priority (problem resolved, or responsibility handed over). This enabled us to efficiently plan follow up both for our team and the primary health care team.

A comprehensive first assessment of a child and family is critical to planning comprehensive and timeous interventions. Focus needs to be planned to avoid time wastage. The use of a triage system, tools and forms helps to empower the primary team to provide generalist integrated palliative care so we can focus on more complex patients.

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### **D35: NON-COMMUNICABLE DISEASES; AN EMERGING EPIDEMIC REQUIRING PALLIATIVE CARE, WHERE ARE RELIGIOUS LEADERS?**

*Doris Frank, Selis Tarimo, aneth Kalinga, Sara Maongezi, Rev. Alick Mpele, Rev. Manford Kijalo, Emil Li-hawa, Rev. Lewis Hiza, Joel Bwemero, Grace Magembe; The Community Center for Preventive Medicine "CCPmedicine", Tanzania*

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Reports have shown non-communicable diseases (NCDs) are number one causes of deaths globally. They account for a 2/3 of global deaths and over 60% of deaths occurred in the lower income countries. High prevalence of NCDs increased the demand for palliative care nonetheless, capacities to offer the services country wide is very low. Engaging religious leaders is a critical step to meet the needs. This abstract aims to share the experience of working with religious leaders in addressing the burden of NCDs and scale up palliative care services in Tanzania.

Religious leaders were empowered with knowledge and skills in order to engage them in the fight against NCDs focusing on cardiovascular related NCDs: diabetes, hypertension, and stroke and cancers. Through series of focus group discussions, mechanisms of communicating health related issues among religious leaders and health providers were established. A mechanism of handling practical issues including referrals, consultations between the two was set to work. This led to increased volume of health related consultations between health professionals and religious leaders.

Religious congregations possess valuable and enormous resources that are yet to be explored to strengthen health systems.

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## TRACK 1: PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE (CONTINUED)

**11.00 – 11.10am**

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### D014: SOCIAL WORK INTEGRATION AND PERFORMANCE OF PALLIATIVE CARE AT THE AGA KHAN UNIVERSITY HOSPITAL; NAIROBI COUNTY; KENYA

*Mr Cosmas Kipkoech & Dr John Weru, Aga Khan University Hospital Nairobi, Kenya*

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This study examined the relationship between the integration of social work and the performance of palliative care. Focusing on the influence of “needs assessment, communication, inter-collaborative approach and sociocultural issues in palliative care.” The aim was to improve the quality of care of patients and families through multidisciplinary approach and to bridge the gaps existing in the health care delivery, and enlighten the other health care providers on the role of social worker in health care. The study established that social work integration and needs assessment in palliative care is very important. 93% of the respondents (n=67) agreed to the need of effective communication amongst the team and between the team, patient and family at the end of life. Similarly 83.9% agreed that understanding individual sociocultural, spiritual and beliefs is a significant factor in the provision of quality palliative care.

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### A094: INCREASING ACCESS TO PAIN RELIEF MEDICINE IN MALAWI BY REVIEWING RESTRICTIVE LAWS AND REGULATIONS

*Mr Rabson Mvula Trouble Kalua, Lameck Thambo, Fred Chiputula, Malawi*

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The backbone of health delivery service in Malawi are nurses and medical assistants who manage majority of patients with palliative care needs at all levels. These are not able to prescribe morphine, a gold standard drug for management of moderate to severe pain, due to regulations and restrictive laws. We set out to advocate for the increased access to pain relief medication through reviewing of laws governing morphine prescription in Malawi in order to allow nurses and medical assistants to be legal prescribers of morphine.

A participatory and consultative process was used in the process for reviewing the laws led by a consultant and supported by the Open Society Initiative for Southern Africa and the Palliative Care Association of Malawi. The Ministry of Health, NGOs in the field of health and human rights, beneficiaries of palliative care, and the media. Key law makers were involved to understand the implications on laws that restricts nurses, medical assistants and clinical officers to prescribe morphine. Several legal instruments and policy documents were reviewed. Advocacy with Members of Parliament using results was done. Advocacy for change of the restrictive laws continues using the results of the review of laws and is expected to lead to positive change.

**11.10–11.20am**

### A138: SOCIAL WORKERS MULTI-DIMENSIONAL ROLES IN PROVIDING PALLIATIVE CARE TO PATIENTS WITH LIFE-LIMITING ILLNESSES TOWARDS ENHANCING UNIVERSAL HEALTH COVERAGE: A NAMIBIAN PERSPECTIVE

*Dr Rachel Freeman, University of Namibia*

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This article provides insight on multi-dimensional roles of twenty social workers providing palliative to patients with life-limiting illnesses in six hospitals in primary care in Namibia. The absence of context-relevant Namibian literature on the role of the social worker in palliative care necessitated research. Research that identifies specificity in the application of the social workers' role in providing palliative care is fundamental to issues of universal health care, sustaining levels of care, quality of life and well-being. The aim was to explore social workers' perceptions of their role in providing palliative care to patients with life-limiting illness in order to capture the essence of that role as perceived by those carrying it out.

Social workers perform multi-dimensional roles in the provision of palliative care: including being an advocate, assessor, broker, counsellor, educator, facilitator, patient liaison, mediator, discharge planner and manager of in-country referrals. By bridging gaps in communication, social workers facilitate collaboration among many providers of patient care. Social workers work with patients and families at time of diagnosis through the end of life, assisting with transitions through clinical interventions, ensuring comprehensive and person-centered care. Palliative care social workers play an integral role in early intervention with these patients and families, utilising their expertise in clinical assessment of the impact of life-limiting illnesses.

The social work profession is well positioned to draw upon its values, culture and experiences (particularly from their clients) to get involved in creating a constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care. Understanding the importance of the multi-dimensional roles of social workers in the provision of palliative care to patients with life-limiting illnesses is critical.

**11.20 –11.30am**

### A131: EXPLORING LIVED EXPERIENCES OF PATIENTS WITH ADVANCED CERVICAL CANCER

*Mr Natuhwera Germans, Makerere University and Institute of Hospice and Palliative Care in Africa Uganda*

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Most of the research on cervical cancer has concentrated on screening, knowledge of about the disease and general experiences of living with cervical cancer, with little being known about what it's really like for patients to live with the advanced disease. This qualitative and exploratory study addresses this under-researched area. It aimed to explore the experiences of patients living with advanced cancer of the cervix with the intent to unearth their experiences and be able to develop the best care plan that addresses their needs.

Ten participants were interviewed. Six themes emerged from the data; demographic profiles of participants, experience of receiving cancer diagnosis, living with cancer, its symptoms and effects, health care system experiences, challenges and needs of women and, coping and positive living with cancer. Living with advanced incurable cervical cancer is a challenging experience for women. It is associated with suffering and substantial disruptions on all domains of life of the patients.

Most of the suffering and its causes patients go through is caused by practical challenges which can be mitigated and or improved. Prioritising palliative care for optimal control of patient's pain and symptoms and psychological support, improved health care system and access of care are all that can bring hope for patients, allow them to cope better and support them on their end-of-life journey.

**11.30–11.40am**

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## D005: EVALUATING PALLIATIVE CARE TRAINING IN THE ONCOLOGY REGISTRAR PROGRAMME

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*Dr Rene Krause, Jeanette Parks, Liz Gwyther, Nadia Hartman and David Anderson, South Africa (UCT)*  
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In 2016 the University of Cape Town together with South African College of Radiation Oncology identified the need to integrate palliative care in the oncology curriculum through a registrar survey and focus group discussions. This was supported by the South African Palliative Care policy stating that intermediate palliative care training must be integrated into specialities who work mainly with palliative care patients. A 12 module curriculum was introduced at five teaching hospitals in South Africa. This study evaluated this training programme; a 1-year Palliative Care course within the oncology registrar programme in South Africa.

The course demonstrated a change in knowledge, skills and attitudes of oncology registrars in palliative care. The evaluation forms gave valuable insight into how course material can be structured and developed in order to integrate palliative care in an effective and achievable manner. Students valued tutorial lecturers by facilitators and requested more practical sessions in order to align the theory and current practise in an African resource restricted environment. Communication skills impacted on students' learning experience and a supervisor commented that students felt more confident in having 'end of life' discussions with patients. Pain management and practical sessions on symptom control was valued for daily practise. Self-care training was included as a final module and feedback on this module emphasised the emotional burden students caring for patients with end stage cancer. Supervisors were satisfied that this curriculum was achievable in an already full oncology curriculum. There was overall a very positive reaction to the course from both the registrars and the supervisors and consensus that palliative care, is a separate but key component of oncology care.

**11.40am –11.50pm**

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## A080: DEVELOPING GENERALIST PALLIATIVE CARE COMMUNICATION SKILLS WITH A BRIEF INTERACTIVE EDUCATIONAL SESSION

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*Dr Millicent Korir, Phanice Jepkemoi, Silvanus Kibiwot, Daisy Rotich, Davinah Chepchumba, Susan Kipsang, Kenneth Cornetta, Lindsay Dow; Moi Teaching and Referral Hospital (Eldoret, Kenya); Indiana University School of Medicine (Indiana, US); Icahn School of Medicine at Mount Sinai (New York, US)*  
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Effective and empathic communication skills are essential to person and family-centered care. It is important that all clinicians who care for patients with serious illness acquire this skillset. Unfortunately, the best way to teach these skills has not yet been determined. Studies suggest that the key to building and improving communication skills is using deliberate practice rather than traditional lecture. The aim of this educational intervention was to improve confidence in communicating bad news and responding with verbal empathy via a brief interactive session, feasibly included in the workday of busy clinicians.

Methods of teaching communication in medical education (simulation, OSCE) are both time and resource-intensive. Drill-based teaching and practice provides an interactive method for deliberate practice that can be done without standardised patients, and in a short amount of time in interprofessional learning environments.

**12.05–12.15pm**

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## A074: DOES HEALTH CARE PROFESSIONALS VIEWS ON ILLNESS, DEATH AND DYING IMPACT ON THE PC THAT THEY GIVE?

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## 6th International African Palliative Care Conference

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

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Increased knowledge into the understanding of death and dying in Uganda provides an evidential base for the development of palliative care (PC) services. Insight gained from health professionals (HPs) providing PC will help identify how their understanding of death and dying shapes the provision of PC and will play a vital role in improving the allocation of scarce resources for PC. The aim is to understand the views of Ugandan HPs with regards to illness, death and dying and how this impacts on the provision of PC.

Six main themes were identified: 1) the impact of their role as health professionals within PC, both physical and emotional aspects such as lifting patients, feeling drained and worry; 2) how they see their role, being committed, motivated and caring, putting their patients first; 3) how they cope working in PC which ranged from through their faith to avoidance; 4) their understanding of illness; 5) beliefs about death and dying and its normality; and 6) beliefs. The issue of communication, how and what they communicate was an underlying cross-cutting issue, along with how each theme impacts the care given.

Whilst HPs understanding of illness, death and dying impacts on the care that they give, the provision of PC also impacts on their understanding of illness, death and dying. The emotional/physical impact of providing PC is great but is offset by individual's commitment and motivation to PC and underlying belief in the impact that PC has on quality of life.

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### 12.15 –12.25pm

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#### A045: LIFE AFTER LOSS RWANDA – A GRIEF PROGRAMME SERVING PALLIATIVE CARE FAMILIES THROUGH RWANDA PALLIATIVE CARE AND HOSPICE ORGANISATION

*Dr. David Slack, Dr Blaise Uhagaze, Rebecca Resnick, Kabisa Eric, Kyokunda, Peace, Rwanda Palliative Care and Hospice Organisation, Hospice Without Borders, Rwanda*

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Life After Loss Rwanda, (LALR,) is a grief and bereavement programme serving families under the care of and identified by Rwanda Mobile Palliative Care Unit (RMPCU) and working in collaboration with palliative care providers of Rwanda Palliative Care Hospice Organisation (RPCHO). The LALR programme acknowledges the essential need for grief and bereavement care as part of a comprehensive palliative care model. Participants in LALR appear to benefit from bereavement education and support. The dual process model of combining bereavement support and income generating activities training is effective in attaining objectives of community building during the 2-week period of LALR, however additional follow up may be important to sustain ongoing benefits of the programme.

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### 12.25 – 12.35pm

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#### A143: IMPROVING BEREAVEMENT OUTCOMES IN ZIMBABWE: A FEASIBILITY CLUSTER TRIAL OF THE 9-CELL BEREAVEMENT TOOL

*Jenny Hunt, Independent consultant; Barbara Mutedzi, Island Hospice and Healthcare Harare, Zimbabwe; Katherine Bristowe, Cicely Saunders Institute; Richard Harding, Kennedy Nkhoma, King's College London; Eve Namisango, African Palliative Care Association*

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The high burden of bereavement in Sub-Saharan Africa is largely attributable to HIV, cancer and other non-communicable diseases. However, interventions to improve grief and bereavement outcomes are rare. Given the high rates of mortality in the context of weak health systems, communities can provide peer bereavement support. The 9-cell bereavement tool was developed in Zimbabwe to improve community bereavement support. The aim of this study was to assess the

feasibility of implementing the 9-cell bereavement tool at community level and to determine the feasibility of evaluating the intervention using a cluster randomised control trial design. The intervention, designed to inform communities about grief and equip them to support the bereaved, was conducted with lay community supporters in one community. Their support of identified bereaved community members was measured against community supporters and bereaved participants in the control community. The study confirms the possibility of implementing the 9-cell bereavement tool at community level. This feasibility cluster randomised control trial assisted in determining an optimal design for a full trial in an area that is currently neglected in the literature but has enormous potential public health benefit. The study provides evidence that it is feasible to roll out the 9-cell intervention in Zimbabwe. It is recommended that the intervention be introduced to other African countries. Training in its methodology needs to be shared regionally with palliative care organisations and providers. The study provides evidence that could guide national bereavement strategies.

**12.35pm – 12.45pm**

### A005: THE USE OF TRADITIONAL HERBAL MEDICINES AMONG PALLIATIVE CARE PATIENTS AT MULANJE MISSION HOSPITAL, MALAWI

*Dr Joseph Chisaka, Rene Krause, University of Cape-Town, Sout Africa; M. Jane Bates, University of Malawi-College of Medicine, Malawi*

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Prevalence of use of traditional medicines (TMs) by palliative care (PC) patients is poorly documented. In 2002, the WHO estimated about 4 billion people (80% of world's population) used TMs for primary healthcare, with 90% from low- and middle-income countries. Studies in Africa have shown that patients on PC are more likely to use TMs especially after cancer diagnosis. The study aimed at describing the prevalence of and reasons for TM use amongst patients receiving PC at Mulanje Mission Hospital (MMH) and also exploring the common herbs used by this population.

A mixed method descriptive cross sectional study design was used. Use of TMs is high among PC patients mainly for symptom management and cancer. Traditional healers were the commonest source of herbs used at 81% followed by relatives (10%), vendors (7%) and friends (2%). More than 60% of participants did not know herbs they used but concomitantly used TMs and conventional medicines; this poses risk for potential detrimental herb-drug interactions.

Further research needed to investigate effectiveness of identified herbs and also assess their potential herb-drug interactions. Open and non-judgmental communication between healthcare workers and patients regarding use of TMs needs to be encouraged. Ongoing work including liaison with traditional healers would assist to formulate effective local PC management programmes that are sensitive to TM practices.

## TRACK 2: STRATEGIC ADVOCACY FOR PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE

**11.00–11.10am**

### B025: HOME-BASED CARE OF PALLIATIVE CARE PATIENTS AT KIGALI

*Dr Mukeshimana Olive, Dr Blaise Uhagaze, Cyokunda Peace, Rwanda Palliative Care and Hospice Organization*

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Rwanda Palliative and Hospice Organisation (RPCHO) came up with an initiative to deliver palliative care services at home. This project, the first of its kind in Rwanda, aims to bring at home the palliative care services that patients receive at the hospital except complex treatments like chemotherapy, radiotherapy, dialysis among others. In this initiative patients are visited in their homes to treat pain and provide an opportunity to voice out complaints including issues related to chronic diseases. Families are also updated on the status of their patient and how well to console and support him/her. All these are done periodically with assessment of past visit. During the visit, health care teams give social support, wound management, pain and symptom management. Those who need hospital care are transferred. Key recommendations of

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this presentation are: Home based Palliative Care is an important service to be incorporated in health system everywhere to achieve UHC; and Home based services should have more support from government and partners for their sustainability and improved services

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**11.10 – 11.20am**

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## A134: HOW TO INTEGRATE PALLIATIVE CARE INTO PRIMARY HEALTH CARE

*Mercy Wachiuri, Nakuru Level 5 Hospital, Kenya*

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Nakuru county has a population of approximately 2.1 million people, with only 1 hospice and 2 palliative care centres in government hospitals. Pain and other symptom control has been very challenging because of the long distances and few health care professionals trained in palliative care. The aim was to address the issues faced by 60% of people suffering from cancer and chronic illnesses and do not have access to palliative care in Nakuru county and its environs and to improve services at the community level.

Key interventions are: assessing the need at county level, use of available platforms for advocacy, gather political will, review existing workplan and guidelines, to show the gaps, define palliative care and what it needs, enlighten who funds the current provision, establish who oversees the county's changing profile, inclusion of a county committee, to advocate for palliative care budget to be included in county's budget.

Integration of Palliative care into primary health care achieves the sustainable developmental goal 3.8 (WHA 2014) which addresses universal health coverage. It is a sustainable health care system which reaches even the the lower income groups of people.

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**11.20–11.30am**

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## A003: EXPLORING THE PROCESS AND EXPERIENCES OF NURSING CARE OF PATIENTS AT THE END OF LIFE: AN ETHNOGRAPHIC-CASE STUDY OF A MEDICAL UNIT

*Dalhat Sani Khalid, Department of Nursing Sciences, Ahmadu Bello University, Zaria-Nigeria Nigeria*

**Email: [walidalhat@gmail.com](mailto:walidalhat@gmail.com)**

Nurses in Nigeria face several challenges associated with inadequate resources to care for patients at the end of life. This is evidenced in the recent ranking of palliative and end of life care across the world for the 2015 Quality of Death Index by the Economist Intelligence Unit; where Nigeria is at the position 77 out of 80 countries. This study aimed to explore the process and experiences of nursing care of patients at the end of life in Ahmadu Bello University Teaching Hospital Zaria-Nigeria from the perspectives of nurses, patients, and family carers. A qualitative ethnographic case study design was employed for the study and used semi-structured interviews with 40 participants.

Both nurses and family carers experienced distress and inadequacies, and often faced with numerous conflicting situations when the plan of care is perceived to be shifted to end of life care. Inadequate information generates tension and anxiety for both patients and their family carers because of fear of unknown circumstances. The nurses delivered care to patients at the end of life without a clear pathway or a definitive approach, due to the absence of policies and guidelines. Palliative and end-of-life care is not included in both undergraduate and postgraduate medical and nursing curriculum and is not integrated in the mainstream healthcare system in the country.

Healthcare professionals, policymakers, and all stakeholders need to collaborate to help patients and their family carers and strengthen the healthcare institutions. This could be achieved by introducing palliative and end-of-life care in both undergraduate and postgraduate medical and nursing curriculum, development of policies and guidelines, and integrating palliative and end-of-life care in the mainstream healthcare system in the country.

**11.30 – 11.40am**

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## **B026: COMMUNITY SYSTEMS STRENGTHENING FOR INCREASED ACCESS TO PALLIATIVE CARE FOR CHILDREN WITH DISABILITY**

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*Willy Kanya & Edith Akankwasa, Mildmay Institute of Health Sciences, Uganda*  
**E-mail: [Willy.kanya@mihs.ac.ug](mailto:Willy.kanya@mihs.ac.ug)**

A significant number of mothers deliver under supervision of traditional birth attendants (TBAs) in the communities. There is inadequate capacity among the health workers and the community own resource persons to detect child disability early and deliver facility based and community based rehabilitation services to children. Families with disabled children are generally poor and vulnerable, with limited social protection and economic ability to participate and benefit from palliative care. The need for raising the coverage of early child disability detection and rehabilitation with subsequent linkage into palliative care is real but given minimum attention. Mildmay Uganda implemented a programme for community systems strengthening for increased access to palliative care for children with disability. The key strategy was to develop the capacity of palliative care providers to offer child disability detection and disability rehabilitation services in the two districts – Mubende and Mityana Districts in central Uganda. The community systems were strengthened through training, mentoring and referral system establishment to increase access to palliative care services by the children with disabilities. As a result skilled birth attendance: The number of mothers delivering at the health facilities under skilled birth attendants improved, the PNC attendance increased, and the proportion of babies detected with defects increased. The project facilitated the successful piloting of in-service training in child disability detection and rehabilitation for nurses and midwives from the supported districts. Scale up of in-service and pre-service training for front line service providers in child disability detection and rehabilitation service delivery is possible through facility-based and district-led capacity development approach.

**11.40 –11.50am**

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## **A118: PSYCHOSOCIAL ISSUES EXPERIENCED BY PARENTS OF CHILDREN WITH CANCER IN SOUTHERN NIGERIA**

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*Dr Gracia Eke, University of Port Harcourt teaching Hospital, Nigeria, Nigeria.*  
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Parents of affected children have to cope with pressures and stresses of treatment often associated with a significantly increased risk of psycho-social issues. The study aimed to explore the experiences of parents of children with cancer and understand the impact of psycho-social issues they face as their child is diagnosed and undergoes treatment for cancer.

This qualitative study was conducted between June and November 2017. Data were gathered through semi-structured interviews held with 27 parents whose children were being treated for various cancers at the Paediatric Oncology Unit of the University of Port Harcourt Teaching Hospital, Nigeria

Prior to diagnosis, knowledge of respondent about childhood cancers was deficient. Shock, disbelief and anxiety were often experienced when diagnosis was made known, while fear of the unknown and fear of death were significant concerns. Financial cost was a great cause of distress. Family, neighbours and churches were important support systems, helping parents to cope with cancer therapy. Loss of job and business closure added to parents' distress. Positive behavioral changes in families were identified in the course of the child treatment.

Parents caring for children with cancer face distresses and need financial, psycho-social and spiritual supports to help them cope with their children's illness. These supports should be acknowledged as an important facet of care by healthcare providers.

## 12.05 –12.15pm

### B007: CHALLENGES AND OPPORTUNITIES FOR INTEGRATING PALLIATIVE CARE INTO HUMANITARIAN HEALTH INTERVENTIONS AMONG HEALTH CARE WORKERS IN UGANDA

*Nasur Buyinza, Hospice Africa Uganda*

**E-mail: [buyinzan@yahoo.com](mailto:buyinzan@yahoo.com)**

The aim of this study was to explore health workers' challenges and opportunities for integrating palliative care services into humanitarian health care interventions in Uganda. Palliative care needs of refugees were identified through a survey – no palliative care services identified at the time of data collection, no palliative care trained staff among health implementing partners, no clear referral for chronic care among refugees, high cost of chronic care on United High Commission on Refugees (UNHCR) for patients who would otherwise need palliative care partners working with humanitarian organisations including UNHCR had never been oriented to palliative care. The high competition for resources and the differing health priorities among health implementing partners working with refugees may affect the time and resources allocated for palliative care service delivery. All key stakeholders appreciated the need for palliative care and pledged support for our future endeavours. The refugee population presents unique challenges for palliative care.

## 12.15 –12.25pm

### A0142: TOWARDS PERSON-CENTERED, QUALITY CARE FOR CHILDREN WITH LIFE-LIMITING AND LIFE-THREATENING CONDITIONS: SELF-REPORTED SYMPTOMS, CONCERNS AND PRIORITY OUTCOMES FROM A MULTI-COUNTRY QUALITATIVE STUDY

*Eve Namisango, King's College London, UK & African Palliative Care Association; Katherine Bristowe, Fliss E M Murtagh, Julia Downing, Richard A Powell, Melanie Abas, Mackuline Ateino, Faith N. Mwangi-Powell, Zipporah Ali, Desiderius Haufiku, Lynne Lohfeld, Samuel Guma, Emmanuel BK Luyirika, Irene J*

Pediatric palliative care (PPC) is recommended as quality care and improves processes and outcomes of care, but its effectiveness is yet to be demonstrated. Robust outcome measures are thus urgently needed to stimulate evidence-based service development. For measures to be relevant, they should be underpinned children/family-driven framework of what matters in terms of outcomes. The study aimed to identify the symptoms, concerns, and other outcomes that matter to children with life-limiting and life-threatening illnesses and their families to inform development of person-centered services and to advance outcome measurement. It was a four-country interpretive descriptive qualitative study.

We conducted N=120 interviews (children n=61, caregivers n=59). Children had advanced HIV (23%), cancer (19%), advanced heart disease (16%), other endocrine blood and immune disorders (13%), advanced neurological conditions (12%), sickle cell anaemia (10%) and advanced renal disease (8%). Themes identified as important outcomes for children and their families were: physical symptoms – symptom distress and meaning of symptoms; psycho-social concerns – family and social relationships, age-appropriate social activities such as play and attending school, normalcy, positive and negative feelings; existential concerns – worry about death, loss of ambitions; health service factors – information and communication, and child- and adolescent-friendly services. There is variation in psychosocial concerns by developmental age, with older children expressing a greater number of such concerns.

This study provides an evidence-based, multi-dimensional child-centered framework of symptoms, concerns, and other outcomes to inform service development and construct underpinnings of measures of person-centred outcomes in PPC.

## 12.25 -12.35pm

### A140: ASSESSMENT OF REFERRAL SYSTEM FOR PATIENTS IN NEED OF PALLIATIVE CARE SERVICE AT KIBOGORA HOSPITAL

*Mukantagara Madeleine, Kibogora Hospital, Rwanda*

**Email: [madomukantagara@yahoo.fr](mailto:madomukantagara@yahoo.fr)**

Various studies conducted globally have revealed need for early palliative care referrals and interventions along with oncological treatments to improve the quality of life as compared to receiving oncology care alone. Some of the cancer patients at Kibogora Hospital have been diagnosed very late leading to early death. Early identification of cancer will lead to adequate palliative care and universal health coverage. The aim was to assess the internal referral process of patients to multidisciplinary team and to find out the causes for delays in internal referral of patients to palliative care programme at Kibogora district hospital.

A retrospective approach was used to review files of 40 patients referred in palliative care just at the beginning of the programme and moving onwards until when the study project started. Then, for the prospective data, 40 patients chosen randomly were included in the study.

87.5% of the respondents strongly agreed that they were referred in palliative care programme just for symptom management. Referral delay has an impact on several patients as reported leading to isolation due to bad smell for instance cervical cancer patients. There is a need of early referral in palliative care programme as a patient may be in need of advice on symptom management, counseling, a takeover care, shared care or some further investigation. Among different causes of delays in internal referral, there is lack of appropriately qualified for the level of service offered, lack of effective collaboration and partnerships which needs to be improved. The current study reveals that 72.5% of the respondents strongly agreed that providers should appropriately be qualified for the level of service offered.

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**12.35 -12.45pm**

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### **B003: UNIVERSAL HEALTH COVERAGE AND HIV PALLIATIVE CARE IN AFRICA – WHAT IS THE MISSING LINK?**

*Mohammed Barry, York University, Pascal Akahome, University of Benin*

**Email: MO160319@MY.YORKU.CA**

The critical role played by communities to increasing equity in health in the HIV response is well documented particularly in the area of palliative care in the African continent. Currently, countries are planning major changes to their systems for health as they move to implement Universal Health Coverage and the commitments in the sustainable development goals. In this process, it is imperative that the best practices and lessons learned in the HIV response are not lost: best practices that focus on strengthening community capacity and ensuring meaningful community engagement of those most affected by health and social injustices and lessons about the dangers to health, dignity, and well-being that are created when health programmes fail to consider or center the needs of the most marginalised people. The aim of this study is to meaningfully identify best practices and lessons from the AIDS response with regards to palliative care, and make recommendations for ensuring health for all under the SDGs and UHC to ensure that it reflects the needs for palliative care.

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### **TRACK 4: EFFECTIVE PARTNERSHIPS AND COLLABORATIONS IN ENHANCING ACCESS TO PALLIATIVE CARE AS A COMPONENT OF UNIVERSAL HEALTH COVERAGE**

**11.00 –11.10am**

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### **D013: COMMUNITY ENGAGEMENT & LOCAL PARTNERSHIPS AS AN INTEGRAL COMPONENT TO IMPROVING COVERAGE AND EFFECTIVENESS OF PALLIATIVE CARE AS A COMPONENT OF UHC IN MUTARE, ZIMBABWE**

*Lenah Mudada, Island Hospice & Healthcare, Zimbabwe*

**E-mail: lenah@islandhospice.co.zw**

## 6th International African Palliative Care Conference

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

In efforts to ensure that services provided were in line with the centre of excellence that Island is known for in 2017 the organisation brought all its branches together operating under one entity. The approach to achieving this in Mutare entailed community engagement and partnership. The approach adopted in Mutare comprised community engagement through participatory approaches which included multiple community meetings, the establishment of partnerships, and training and mentorship of health workers to deliver services. Local partnerships with key stakeholders and feedback community meetings were held regularly and over a period of a year. Training and mentoring included practical application of theory which contributed to improved coverage, impact and effectiveness in palliative care service provision in Mutare.

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**11.10 –11.20am**

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### A046: DEVELOPING A MODEL FOR TRAINING OF TRAINERS (TOT) COURSES

*Ruth Wooldridge, Gillian Chowns, Stephen Chowns, George Smerdon, Palliative Care Works, UK*  
**Email: [mjminton@doctors.org.uk](mailto:mjminton@doctors.org.uk)**

To establish palliative care as part of UHC requires not only a body of committed practitioners, but a cohort of skilled educationists able to turn practitioners into effective trainers. Attending a course in palliative care does not itself qualify a practitioner to teach that self-same course to others. The need for a substantial body of skilled trainers is vital. This paper examines the development of ToT courses in the last decade from earlier largely didactic formal presentations towards an innovative interactive course involving micro-teaching and video replay designed to improve actual performance. The video replays had a positive impact: the opportunity to see trainees (to become trainers themselves) in action, to critique their performance, and receive guidance over and over from experienced trainers translated into significantly improved confidence levels and quality of teaching. Use of technology with a single video camera and a television for playback can maximise the impact and effectiveness of a ToT course. The opportunity to practise skills and techniques in a supportive environment can contribute to building a body of confident, competent trainers who will train and enthuse future palliative care workers.

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**11.20 -11.30am**

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### A081: EMPOWERING OTHER AFRICAN COUNTRIES TO INITIATE AND/OR INTEGRATE PALLIATIVE CARE INTO THEIR HEALTH CARE SYSTEMS

*Dianah Basirika, Anne Merriman, Silvia Dive, Berna Basemera, Hospice Africa Uganda*  
**Email: [dbasirika\\_87@yahoo.co.uk](mailto:dbasirika_87@yahoo.co.uk)**

Palliative care (PC) is an important aspect in alleviating suffering for all patients with serious or life threatening illness yet many countries in Africa still have no services. Although access to PC should be culturally appropriate and affordable to all in need, many services are often established as “islands of excellence” and are sometimes inaccessible to many patients. International Programmes (IP) of Hospice Africa (HA) aims to empower African countries to initiate and/or expand PC in Africa by supporting them to initiate or integrate culturally appropriate and affordable PC into country healthcare systems.

International Programmes offers PC trainings and clinical mentorship using the Hospice Africa Uganda (HAU) model. It advocates for integration of PC services in country healthcare systems. It fosters PC sustainability through follow ups and networking with international and local partners to promote equitable PC access. It also advocates for the use of oral liquid morphine to control moderate to severe pain. Short PC courses are held in English and French in Uganda.

Over thirty African countries have initiated PC and thirty five now declare they have it in their country. A few countries have established national palliative care associations to advocate and coordinate PC services in their countries. Some countries have integrated PC in the country mainstream health care in various ways; for example Rwanda has a national palliative care policy. Other countries like Malawi run their own PC courses adapted from the HAU initiators' course. Twenty-two African countries now have affordable oral liquid morphine compared to only 3 in 1993 when HA commenced some of which manufacture it internally.

**11.30 –11.40am**

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## A106: EXPLORING NURSES' EXPERIENCE ON THE USE OF PAIN ASSESSMENT TOOLS AT NATIONAL REFERRAL HOSPITAL, HHOHHO REGION, ESWATINI

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*Felicity Lukhele, The Eswatini National Referral Hospital, Eswatini*

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Pain assessment had been adopted by other international health facilities as the fifth vital sign and policies are applied to include pain assessment in each patient. However, at the National Referral Hospital in Eswatini it had been noted that pain score is not recorded in the charts for the patients being referred to the palliative care unit for pain management. The study was conducted to explore the experiences of nurses in using the pain assessment tools after being trained on pain management at the National Referral Hospital (NRH).

The participants mentioned two commonly used pain assessment tools is self-report and the behavioral observation, they had insufficient knowledge about the tools and less skill. Majority of the participants (n=7) stated that they rarely used the tools. Only two indicated to be using it always. The participants raised unavailability of the tools in their departments, patients' level of education and the long time consumed by use of these tools as the main cause for poor utilisation of these tools. Nurses are underutilising pain assessment tools in the NRH despite them being trained on their usage.

Key recommendations are: adding more tools to the departments and continuous professional development in pain assessment may improve pain assessment in the facility; lection of focal people as ambassadors for palliative care in all the hospital departments; onsite training to capacitate the majority of the nurses on pain management; mentoring and coaching of the nurses to improve skill and consistence in using pain assessment tools and distributing and monitoring of pain assessment tools in the departments.

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**11.40 -11.50am**

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## D031: PALLIATIVE CARE MULTIDISCIPLINARY TEAM IN PRINCESS MARINA HOSPITAL

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*Dr Babe Eunice Gaalebale, Goitseone Mburu, Princess Marina Hospital, Ministry of Health and wellness, Botswana*

**E-mail: [gaalebalebegg@gmail.com](mailto:gaalebalebegg@gmail.com)**

In November 2017 a fortnightly palliative care multi-disciplinary (MDT) clinic was initiated for complex palliative care patients in Princess Marina hospital. The MDT clinic comprises of a specialist palliative care doctor and nurse, psychologist, community home based care nurse and social worker. The team also has other experts who join in as needed. Since the establishment of the clinic 45 patients have been discussed with issues mainly being mostly psychological (82%) and social (78%). Other issues that were identified were economic, physical with least being spiritual at 44%. Patients had a variety of diagnoses and were adults as a paediatric clinic was only established in 2018. Palliative care multi-disciplinary clinic is of utmost importance as it addresses cases that are complex and challenges that are faced by patients with life threatening illnesses. This is possible through a coordinated team approach despite the limited resources. The platform also enables patients to access much needed services that are limited due to the high demand in referral centers.

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**12.05–12.15pm**

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## D023: JOINING TOGETHER TO SPEARHEAD THE ADVANCEMENT OF CHILDREN'S PALLIATIVE CARE FOR ALL IN ESWATINI

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*Raquel da Silva & Denise Mortlock, The Rocking Horse Project (RHP); Eswatini*

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## 6th International African Palliative Care Conference

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

The Rocking Horse Project (RHP) is the only organisation in Eswatini whose focus is to advance children's palliative care (CPC), create awareness and advocate continuously for CPC. This is impossible to achieve without the necessary collaborations. Therefore, it is even more essential that collaborations and partnerships are formed to achieve UHC in a country. "Without palliative care, health coverage is not universal..." (Connor 2017). We evaluated the success of the projects that the RHP has been involved in and how they have assisted in the progression of UHC. We linked the goals and objectives of the RHP to those of UHC. Collaboration and partnerships have made RHP successful. They are key part in long-term development and sustainability of the organisation. Each collaborator in a partnership plays an important role from policy formation to the administration of palliative care, the healthcare aspect, the parents/caregivers of the child involved and to the children themselves. The role of each partner is vital in achieving the best outcomes for these children and their families.

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**12.15 –12.25pm**

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### PREVALENCE AND PREDICTORS OF CERVICAL CANCER IN RURAL UGANDA

*Nita Chai, Rays of Hope Hospice Jinja, Uganda*

**Email: [hospicejinja@yahoo.co.uk](mailto:hospicejinja@yahoo.co.uk)**

In Uganda, cervical cancer accounts for 20% of new cancers and 35% of female cancers – many presenting at advanced stages. Rays of Hope Hospice Jinja (RHHJ) provides palliative care for people in rural Uganda and started a screening programme for rural women with little access to these services. The aim of this study was to quantify the gynecological profiles of women in rural Uganda and determine prevalence and predictors of cervical cancer in the area.

Of the 700 women who attended, 576 were screened for cervical cancer. 85.2% were VIA-negative. 9.9% were VIA-positive and received on-site cryo- or thermotherapy. 2.4% were suspicious for or had cancer and were sent for biopsy. Fourteen women received Pap smears. Based on the VIA results and gynecological and histology samples analysed, 11.5% of women screened were positive for pre-cancerous or cancerous cells. Among the risk factors, HIV status was not associated with a positive result.

Among the key lessons is that rural Ugandan women would not consent to a pelvic exam. We found that women were very interested in being screened and grateful and enthusiastically encouraging other women. Future camps should incorporate same-day volunteer HIV testing to more accurately measure HPV-HIV/AIDS co-infection. At our screening camp, treatment was free-of-cost and all women received treatment. Researchers should investigate whether rural women are willing/able to pay for treatment.

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**12.25 -12.35pm**

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### A079: CURRENT SITUATION OF PALLIATIVE CARE SERVICES IN RURAL COMMUNITIES OF LESOTHO: A QUALITATIVE ANALYSIS

*Dr. Mwabury Tonny, Lesotho, Najojo Better Living Missions Association, Lesotho*

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When dealing with patients affected by life-threatening or life-limiting conditions, symptoms control is just the beginning of the journey. The true aim is symptoms relief and patients' quality of life improvements. Najojo Better Living Mission Association is a relatively recent organisation, founded two years ago only with limited resources. As one of the sole generalist palliative care services providers in Lesotho, we felt the urge to expand this basic health care services to a growing number of communities. On our way to sustainability, we were awarded a fund from True Colours Trust through APCA last year. This was decisive in entering a new phase of our project "Dignity on Wheels". The acquisition of a car for transporting patients and the mindful allocation of wheelchairs allowed our organisation and our patients to gain independence. Also, people who needed diapers to use on daily basis were given enough supply as a way of improving their hygiene hence, improving quality of life. We conducted regular follow ups on the wheelchairs receivers and the feedback we were presented with, were extremely positive and enthusiastic. This reinforced our cause and efforts in providing such services. It was also possible to enroll new patients into the programme. We are currently looking forward to starting a collaboration with some factories in Lesotho.

Najojo Better Living Missions Association has tried to integrate palliative care services at the community level by training 24 community village health workers around Ha Mphele. The trained volunteers were chosen by the village chief and they included spiritual leaders, community village health workers and traditional healers. These volunteers have been a great source of our success in the delivery of palliative care services in the communities around Berea District. This programme has reduced unnecessary hospital admissions at Berea District hospital as well as CEHAL private hospital, among other achievements.

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**12.35 – 12.45pm**

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## **C009: MEMBERSHIP ENGAGEMENT IN SHAPING PRIORITIES FOR PALLIATIVE CARE SERVICE DEVELOPMENT IN RESOURCE LIMITED SETTINGS: DEVELOPING BEST PRACTICES**

*Irene Namwase, Dr Eve Namisango, Dr Emmanuel Luyirika, African Palliative Care Association*

**E-mail: [namwase.irene@africanpalliativecare.org](mailto:namwase.irene@africanpalliativecare.org)**

Membership engagement is a catalyst for maintaining relevance of any membership organisation. The African Palliative Care Association (APCA), being a membership-based regional organisation rolled out a model of vibrant engagement of its members in 2017, to give them a voice in shaping services.

This abstract presents findings of a survey aimed to pilot the use of a low-cost digital-based membership survey approach to benchmark the drivers for membership uptake and to prioritise members' support needs across the WHO health system building framework. The survey targeted all the 800 individual and 134 institutional level members of APCA. We report one top priority per health system building block; health service delivery – support to develop home-based palliative care core packages; health workforce – palliative care training including basic, pre-service and specialist palliative care; health information systems – data management and use; access to essential medicines and technologies – local production of oral morphine; health financing – need for scholarships for training and knowledge exchange and small grants to support service development; leadership and governance – support in the development of government policies and guidelines.

Cross-cutting themes included support to integrate legal services into palliative care. The key recommendation is that membership-based organisations should adopt demand-driven approaches to develop technical support priorities to support palliative care service development in resource-limited settings.

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# WORKSHOPS



**WEDNESDAY 18<sup>TH</sup> SEPTEMBER 2019**

## **TRACK 1: PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE**

**14.00 – 15.30pm**

### **AD12: PALLIATIVE CARE FOR CHILDREN AND YOUNG PEOPLE**

**Chair/facilitator:** *Prof Julia Downing, International Children's Palliative Care Network/ Makerere University, Uganda*

**Speakers:** *Prof Julia Downing, Uganda; Rex Robert Chinzu, Ndimoyo Palliative Care Centre, Malawi; Eunice Garanganga, Zimbabwe*

Some of the key issues within children's palliative care will be explored. The workshop will also explore children's understanding of illness, death and dying, symptom management across the continuum of care, the multi-disciplinary team, and the rights of the child and the experiences of caregivers. There will be opportunity for discussion and how this impacts on the provision of children's palliative care and Universal Health Coverage.

**16.00 – 17.30pm**

### **AD12: DEVELOPING MHEALTH TOOLS TO SUPPORT PALLIATIVE CARE DELIVERY IN THE AFRICAN REGION**

**Chair/facilitator:** *Matthew Allsop, UK, Eve Namisango, Uganda, Richard Harding, UK*

**Speakers:** *Professor Richard Harding, King's College London; Eve Namisango, African Palliative Care Association; Mark Mwesigwa, Palliative Care Association of Uganda; Adlight Dandanzi, University of Zimbabwe*

An overview of current trends in digital health development will be provided, alongside the evidence base behind the use of digital technology in palliative care across Sub-Saharan Africa. Examples of mobile phone-based interventions will be presented, outlining how such approaches have extended and improved delivery of palliative care.

## **TRACK 2: STRATEGIC ADVOCACY FOR PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE**

**14.00 – 15.30pm**

### **MH3&4: DIRECT STAKEHOLDERS (PATIENT CHAMPIONS) AS ADVOCATES FOR PALLIATIVE CARE IN UHC**

**Chair/facilitator:** *Dr Stephen Watiti, Uganda; Rose Kiwanuka, Uganda; Wedzerai Chiyoka, APCA; Shelley Enarson, WHPCA*

**Speakers:** *Dr Stephen Watiti, Uganda; Rose Kiwanuka, Uganda; direct beneficiaries of palliative care from Kenya, Rwanda and Uganda*

Direct stakeholders are the most powerful advocates for hospice and palliative care, but have not been well engaged in palliative care advocacy in Africa and globally. This workshop aims to share learning from the project: 'Using digital media and direct stakeholder voices to increase demand for and access to palliative care in two Anglophone African countries' – taking place in Ethiopia and South Africa, and explore how direct stakeholders are being or could be engaged as powerful advocates for palliative care as part of UHC in other African countries.

**16.00 – 17.30pm**

**MH3&4: DIRECT STAKEHOLDERS (PATIENT CHAMPIONS) AS ADVOCATES FOR PALLIATIVE CARE IN UHC CONTINUED.**

## **TRACK 3: HEALTH FINANCING AND PALLIATIVE CARE**

**14.00 – 15.30pm**

**AD10: GETTING TO RESOURCE MOBILISATION: BUILDING FOUNDATIONS FOR EFFECTIVE RESOURCE MOBILISATION THROUGH PARTNERSHIPS**

**Chairs/facilitators:** Lacey Ahern, Global Partners in Care, USA & Rose Kiwanuka, Palliative Care Association of Uganda

**Speakers:** Michael Schmidt, USA; Ephrem Abathun, Ethiopia; Denis Kidde, USA; Mark Mwesiga, Uganda; Cyndy Searfoss, USA

Partnerships can be one way to mobilise additional resources needed to enhance access to palliative care. This session will guide participants to identify resources within their own organisations and build strong foundations with partners that will allow them to successfully mobilise resources. We will cover internal resource assessment, relationship-building and strategic planning, examining two partnerships as case studies.

**16.00 – 17.30pm**

**MH 2 INVITATION ONLY: MEETING OF THE GRANTEES AND PARTNERS OF THE OPEN SOCIETY FOUNDATIONS (OSF) AND OPEN SOCIETY INITIATIVE FOR EASTERN AFRICA (OSIEA)**

**Coordinator:** Sara Pardy, Open Society Foundations, USA

## **TRACK 4: EFFECTIVE PARTNERSHIPS AND COLLABORATIONS IN ENHANCING ACCESS TO PALLIATIVE CARE AS A COMPONENT OF UNIVERSAL HEALTH COVERAGE**

**14.00 – 15.30pm**

**AD11: VIDEO BASED MODULES FOR PALLIATIVE CARE EDUCATION IN RURAL UGANDA: TEACHING COMMUNICATION SKILLS TO HEALTH WORKERS**

**Chair/facilitator:** Randi R Diamond MD, Weill Cornell Medicine, USA

**Speakers:** Prossy Nafula, St. Francis Naggalama Hospital, Uganda; Randi R. Diamond MD, USA

Education is essential for integrating palliative care into UHC. This session introduces an innovative training tool for rural health workers in culturally sensitive PC communication. An overview of the modules, developed by a US-Ugandan PC team, incorporate video clips of actual patient visits in the villages by the St. Francis Naggalama Hospital PC team will be shared and opportunities for replication in rural Africa.

**16.00 – 17.30pm**

## AD10: THE ROLE OF PARTNERSHIP AND COLLABORATION IN DEVELOPING CENTRES OF EXCELLENCE FOR PALLIATIVE CARE AND IMPROVING THE QUALITY OF EXISTING SERVICES: LESSONS FROM ESWATINI, MOZAMBIQUE AND ZIMBABWE

**Chair/Facilitator:** *Fatia Kiyange & Mackuline Atieno. African Palliative Care Association*

**Speakers:** *Fatia Kiyange, Mackuline Atieno, APCA; Lidia Justino Mondlane, Mozambique Palliative Care Association; Ntombi Ginindza, Ministry of Health; Eswatini National HIV/AIDS Program, Kingdom of Eswatini; Eunice Garanganga, Hospice Palliative Care Association of Zimbabwe*

This workshop is based on a successful multi-partnership and multi-country project implemented in Eswatini, Mozambique and Zimbabwe. The project focused on the implementation of national PC policies by improving access to and the quality of palliative care services. The partnership approach, key interventions, outcomes and lessons for adaptation in other African countries will be shared.

**17.30 – 18.45pm**

## AD12: WELLNESS & MOVEMENT WORKSHOP FOR SELF-CARE: DEEPENING CONNECTION FOR HEALTH CARE WORKERS

**Chair/Facilitator:** *Patricia Ann Repar, Associate Professor, Departments of Music and Internal Medicine Director, Arts-in-Medicine Program, The University of New Mexico, USA*

The workshop will allow participants to release the stress of the day, prepare for an enjoyable evening, and a more restful sleep. The workshops will also provide knowledge and experience in various types of movement that promote health and well-being. The workshop is entirely participatory and will focus on three movement types: 1) simplified stretches borrowed from Iyengar yoga; 2) free movement from Gabrielle Roth's Five Rhythms for aerobic and full body warm-up; and 3) deep breathing and meditative movement from Qi Gong, a movement practice from traditional Chinese medicine.

**THURSDAY 19<sup>TH</sup> SEPTEMBER 2019**

## TRACK 1: PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE

**14.00 – 15.30pm**

## AD10: SPIRITUALITY WORKSHOP: AN INTRODUCTION TO THE INTER-PROFESSIONAL SPIRITUAL CARE EDUCATION CURRICULUM

**Chair/Facilitators:** *Christina Puchalski, MD, FACP, FAAHPM, The George Washington University's Institute for Spirituality and Health (GWish), The George Washington University, Washington, DC, USA; Fr Richard Bauer, MM, BCC, LCSW, Maryknoll Fathers and Brothers, Kenya*

Spiritual distress is highly prevalent in seriously ill and dying patients and families. Total pain cannot be fully addressed without addressing spiritual distress. The essential palliative care package must include evidence-based, person-centred spiritual distress screening, history, assessment and intervention. In this training workshop, clinicians will be taught the assessment skills for addressing spiritual distress. The second aim is to form a leadership group that will work with GWish in developing a five-year ISPEC initiative in Africa meeting the goals of the WHO resolution for whole-person holistic palliative care.

## 6th International African Palliative Care Conference

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

The workshop targets palliative care clinicians including sisters from ASEC who work with seriously and chronically ill patients. The clinician sisters are particularly targeted as ISPEC meets their goals of leadership and clinical skills training and since they are fully committed to integrating spiritual care and who can help with developing a CPE programme in Africa.

Learning objectives include: recognising the role of spirituality in clinical care, identifying communication strategies for eliciting spiritual issues, practicing a spiritual history tool called FICA, and recognising the role of spirituality as integral in the practice of compassionate presence.

**14.00 – 17.30pm**

### AD1: FRENCH WORKSHOP

**Chairs:** *Dr Francois Uwinkindi, Rwanda; Anselme Mubeneshayi Kananga, Belgium/DRC*

**Speakers:** *Dr Patricia Strubbe; Dr Amanga Amaa Jacques; Madhira and Anguyi, DRC; Gnintoungbe S, Agbodande KA, Dedo S, et al, Benin; Anselme Mubeneshayi Kananga, Belgium/DRC; Dina Bell Mbassi E, Kwedi Mangan Felix et al, Cameroon; Dr Mabokou Tabeng Ariane; Rev Madhira Wadri & Mr Anguyi Obhidha, DRC*

In this workshop, papers based on palliative care developments in French-speaking African countries will be shared.

## TRACK 2: STRATEGIC ADVOCACY FOR PALLIATIVE CARE IN UNIVERSAL HEALTH COVERAGE

**14.00 – 15.30pm**

### AD12: PALLIATIVE CARE IN MEDICAL EDUCATION IN RWANDA: A COLLABORATIVE INITIATIVE OF THE UNIVERSITY OF RWANDA AND PARTNERS IN HEALTH

**Chair/Facilitator:** *Dr Vincent Cubaka, Director of Research and Training, Partners In Health, Rwanda & Dr. Florence A. Bitalabeho, MD, Director of The Institute of Community Based Education at UGHE, School of Medicine & Partners in Health, Rwanda*

**Speakers:** *Richard Nduwayezu, School of Medicine and Pharmacy, University of Rwanda; Peter Barebwanuwe, Partners in Health, Rwinkwavu, Rwanda; Sylvia T. Callender-Carter, DrPH, MPH, Partners in Health, Rwinkwavu, University Global Health Equity, Butaro, Rwanda; Vincent Cubaka, Partners in Health, Rwinkwavu, Rwanda; Dr Christian Ntizimira, City Manager, City Cancer Challenge Foundation; Mieke Visser, FM, MD, Honorary Associate Professor Social Medicine and Community Health, School of Medicine & Pharmacy, University of Rwanda*

A partnership between University of Rwanda and Partners in Health based on a palliative care programme for medical students will be shared with a focus on the structure, content, challenges and future plans. We will engage participants in a discussion/reflection on best practices for better integration; delivery of palliative care training in medical schools and provision of palliative care at all levels, especially the community level in Africa.

**14.00 – 17.30pm**

### AD12: IMPLEMENTATION OF PALLIATIVE CARE STANDARDS AND GUIDELINES IN AFRICA: ACTIVITIES, OUTCOMES, LESSONS AND THE FUTURE

**Chair/Facilitator:** *Andre Wagner, Hospice Palliative Care Association of South Africa; Prof. Liz Gwyther, University of Cape Town; Fatia Kiyange, African Palliative Care Association*

**Speakers:** *Prof Liz Gwyther, University of Cape Town; Mackuline Atieno, African Palliative Care Association; Lameck Thambo, Palliative Care Association of Malawi*

The workshop will focus on the implementation of palliative care standards and guidelines in Africa. A focus on quality is important to patients and families, clinical staff and volunteers, managers, donors and policy makers. There are many organisations offering palliative care and home-based care, mostly based on some alternative interpretations of palliative care. It was therefore imperative for national associations to take the lead in the process of pursuing quality, so that the credibility of member organisations could be enhanced in the eyes of the formal health care sector and existing and potential donors. Experiences of South Africa, Malawi and APCA in developing and implementing standards will be shared. The workshop will also enhance an understanding of the importance of standards to ensure that member organisations gain a competitive edge in palliative care service delivery. Participants will also understand how standards can give organisations credibility with patients, stakeholders and donors and how they can protect patients, families and staff. The workshop will also create an understanding of how standards can provide reassurance to management and boards. Possible disadvantages of standards will also be discussed.

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## TRACK 3: HEALTH FINANCING AND PALLIATIVE CARE

**14.00 – 17.30pm**

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### MH2: HEALTH FINANCING, DONOR MAPPING AND MESSAGING FOR EFFECTIVE RESOURCE MOBILISATION

**Chair/Facilitator:** *Open Society Foundations & Open Society Initiative for Eastern Africa*

**Speakers:** *Dermott McDonald, Consultant, Health and palliative care financing, Netherlands*

Results from a donor mapping initiative focusing on palliative care in the context of global health financing will be shared. A guide to donor messaging to improve the positioning of civil society organisations in Africa for more effective access to funding will be discussed.

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## TRACK 4: EFFECTIVE PARTNERSHIPS AND COLLABORATIONS IN ENHANCING ACCESS TO PALLIATIVE CARE AS A COMPONENT OF UNIVERSAL HEALTH COVERAGE

**14.00 – 15.30pm**

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### MH3&4: MULTI-COUNTRY AND MULTI-LEVEL PARTNERSHIP TO INITIATE AND IMPLEMENT NATIONAL PALLIATIVE CARE PROGRAMMES IN TOGO, THE GAMBIA AND LIBERIA

**Chair/Facilitator:** *Patricia Batanda, African Palliative Care Association*

**Speakers:** *Fatia Kiyange, African Palliative Care Association; Dr Fred Amegeshie, Non-communicable Diseases Division, Ministry of Health, Liberia; Dr Samba Ceesay, Non-communicable Diseases Division, Ministry of Health, The Gambia; Jerreh Drammeh & Alieu Badjie, National Palliative Care Association of the Gambia; Prof. Mofou Belo & Dr Francois Alinon, Non-communicable Diseases Division, Ministry of Health and Social Protection, Togo; Prof. Olaitan A Soyannwo, Center for Palliative Care, Nigeria (CPCN)/ University College Hospital, Ibadan*

## 6th International African Palliative Care Conference

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

This workshop is based on a successful multi-partnership and multi-country project implemented in Liberia, The Gambia and Togo. The project focused on the implementation of the World Health Assembly Resolution on palliative care through the initiation and implementation of national palliative care programmes in the three countries. The partnership approach, key interventions, outcomes and lessons for adaptation in other African countries will be shared.

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**16.00 – 17.30pm**

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### MH3&4: COMMUNITY HOME-BASED PALLIATIVE CARE: EXPERIENCES AND LESSONS FROM RWANDA

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**Chair/Facilitator:** *Diane Mukasahaha, Rwanda Biomedical Center & Grace Mukankuranga, Palliative Care Association of Rwanda*

Experiences, best practices and lessons on a successful community home-based palliative care programme led by Rwanda Biomedical Center/the Ministry of Health and with support from partners.

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**17.30 – 18.45pm**

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### AD12: WELLNESS & MOVEMENT WORKSHOP FOR SELF-CARE: DEEPENING CONNECTION FOR HEALTH CARE WORKERS

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**Chair/Facilitator:** *Patricia Ann Repar, Associate Professor, Departments of Music and Internal Medicine Director, Arts-in-Medicine Program, The University of New Mexico, USA*

The workshop will allow participants to release the stress of the day, prepare for an enjoyable evening, and a more restful sleep. The workshops will also provide knowledge and experience in various types of movement that promote health and well-being. The workshop is entirely participatory and will focus on three movement types: 1) simplified stretches borrowed from Iyengar yoga; 2) free movement from Gabrielle Roth's Five Rhythms for aerobic and full body warm-up; and 3) deep breathing and meditative movement from Qi Gong, a movement practice from traditional Chinese medicine.

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REPUBLIC OF RWANDA



Ministry of Health

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