

wpca
worldwide hospice palliative care alliance

ANNUAL REPORT

2019-2020

We impact people's lives on the ground.

We influence policy at the highest levels.

We are building a diverse and strong movement demanding care for all.



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About the front cover



The report's front cover shows the breadth of the palliative care that takes place globally in low and middle income countries to alleviate pain and suffering in local communities. The smiles illustrate the palliative care can improve quality, if not quantity of life.

Executive summary

Welcome to our 2019/20 annual report. Although this report would normally cover 30th March 2019 1st April 2020, because of the impact of COVID-19 on the global population, we felt that it was important to highlight in this report the effect is has had on our work.

The WHPCA's focus this year has mostly been on adjusting to life during a pandemic. We started in 2019 planning to build on ensuring a clear pathway to access palliative care services through Universal Health Coverage however this was set back due to COVID-19. In spite of this we have accomplished a great deal including continuation of our projects in Bangladesh, Ethiopia, Russia, South Africa, Kenya, and Greece. In partnership with the International Children's Palliative Care Network (ICPCN), the International Association for Hospice and Palliative Care (IAHPC), and Palliative Care in Humanitarian Aid Situations and Emergency Network (PalCHASE) we carried out a series of webinars on palliative care and COVID-19. They are all on the WHPCA website http://www.thewhpca.org/covid-19 and www.globalpalliativecare.org

The 2020 World Hospice & Palliative Care Day was successful this year, despite COVID-19, with over 104 (mostly virtual) events in 43 countries. During World Day we also began the launch of the 2nd Edition of the Global Atlas of Palliative Care, in cooperation with the World Health Organization. In spite of all the restrictions we face with the continuing pandemic WHPCA is busier than ever. COVID-19 has highlighted the weaknesses in our health care systems and the importance of palliative care as we experience an unprecedented number of untimely deaths and difficult bereavements.

We impact people's lives on the ground



The WHPCA continues to have an impact on the lives of people in Bangladesh.

We been working to develop innovative, compassionate community-based programmes to improve the quality of life of people experiencing serious health-related suffering.

Korail, Bangladesh

Korail is one of the largest informal settlements in Dhaka. The Compassionate Korail community home-based palliative care project has 12 locally trained palliative care assistants (PCAs) who support people with palliative care needs and their families. A nurse and doctors from Bangabandhu Sheikh Mujib Medical University (BSMMU) also visit patients and hold outpatient clinics. The team has supported nearly 600 palliative care patients over three years. There is a focus on building community awareness about palliative care and encouraging the existing informal community support systems to care for neighbours with palliative care needs.



A trader provided a space for a women with palliative care needs to set up a stall selling eggs and other small items. This example of a compassionate community response means that she has income and is able to cover her basic needs. She continues to be supported by the palliative care team but is happy to be able to earn a living.

An important part of palliative care is supporting the patient's carers. The team has focused on building support for carers and providing them with the chance to share their stories and concerns. As one carer said:

> *"I used to think that only me and my family is suffering but today I understood that there have been others like us or even worse. This discussion session allowed us to share our feelings, thoughts and sufferings. Now, I am feeling light from inside. Thank you so much for arranging such a useful meeting for us."*

An important part of the work in Bangladesh is raising awareness of what palliative care is and why it is an important part of Universal Health Coverage (UHC). The team has continued to raise awareness in Korail bringing together neighbours in courtyard meetings, holding celebrations for World Hospice Palliative Care Day, and other community events reaching over 3,800 people. To raise awareness of palliative care in the wider community, the BSMMU palliative care team participated in the 2nd International Symposium of Community Health Workers and organised a photography exhibit called My Care, My Right at the Bangladesh National Museum.

"An important part of palliative care is supporting the patient's carers. The team has focused on building support for carers and providing them with the chance to share their stories and concerns.



Narayanganj, Bangladesh

In Narayanganj, the palliative care team has cared for 256 (58% women) patients in its first two years and supported 997 family members.

One of the priorities for the team has been to conduct sensitisation workshops to raise awareness of what palliative care is and why it is important that it be included in the national health provision. The team held workshops at schools and colleges and for nurses, doctors and local tradespeople, reaching more than 1,800 people.

As a direct result of awareness raising, over 200 people were interested in receiving further training on palliative care to enable them to support patients and carers as volunteers. About 40 volunteers are actively engaged in the project. They visit patients, listen to them and help them with any chores. Importantly they are also playing a vital role in awareness raising with the population and in gaining credibility with Ward Councillors. The biggest achievement this year was the decision by the volunteers to form the Narayanganj Palliative Care Society. This is a very important step in local ownership and for sustainability after external funding comes to an end.

We work in partnership with the Department of Palliative Medicine of the Bangabandhu Sheikh Mujib Medical University (BSMMU) is supported by funds from UK AID Direct and an anonymous donor.

UKaid
from the British people

COVID-19 Update

At the end of the reporting year, COVID-19 hit Bangladesh. This raised many challenges for the local teams. The Department of Palliative Medicine quickly arranged training to ensure that they were well informed with factual information, and most importantly in how to protect themselves and patients with proper handwashing and use of personal protective equipment (PPE). Narayanganj was one of the first hotspots for the virus and was put into lockdown early on. This meant the team could not carry out home visits, but they quickly adapted to ensure that patients were still supported. This included regular phone calls by the PCAs to the patients with follow up calls by nurses and doctors. The team increased the size of the food parcels because it became evident that people's livelihoods were suffering and there was no way for them to substitute the loss of employment. Arrangements were made with local traders for people to collect food parcels near their homes. The team also produced videos and information resources to combat the disinformation on COVID-19 that was rampant.



Palliative Care Assistant Arifa Akter during a home visit Patient Sufiya Begum said (Age: 70) "Without you, I would have died due to breathlessness. If you want to stop the service from now, I will die soon. I have no one but you. With your services, I may be able to live a few more years. Please, don't leave me."

BY NUMBERS

THE POSITIVE IMPACT OF COMPASSIONATE KORAIL ON THE COMMUNITY *

1,149 FOOD PARCELS WERE GIVEN OUT



631 PEOPLE HAVE BEEN CARED* FOR

69% OF THOSE WERE **WOMEN.**



1,044 Community members reached through courtyard meetings.



226 people were reached through **school based palliative care awareness programmes**



196 VOLUNTEERS INVOLVED IN PATIENT CARE; FUNDRAISING AND RAISING AWARENESS OF PALLIATIVE CARE

1,254 PATIENTS were seen by doctors at the outpatient clinic

9,840 HOME VISITS to palliative care patients by palliative care assistants (PCAs), doctors and nurses, including 233 visits by physiotherapists



631 PALLIATIVE CARE PATIENTS WERE CARED FOR

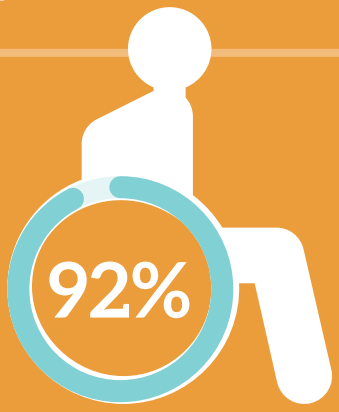
25 ARTICLES OR VIDEOS POSTED ON ELECTRONIC MEDIA AS PART OF AWARENESS RAISING OF PALLIATIVE CARE

THE POSITIVE IMPACT OF THE NARAYANGANJ PROJECT ON THE COMMUNITY *

997
FAMILY MEMBERS/ CARERS WHO HAVE BEEN SUPPORTED

256
ADULTS RECEIVING PALLIATIVE CARE

58% ♀ 42% ♂



OF PALLIATIVE CARE PATIENTS IN THE PROJECT HAVE REPORTED SOME LEVEL OF DISABILITY



COMMUNITY VOLUNTEERS HAVE BEEN TRAINED IN PALLIATIVE CARE TO HELP IDENTIFY AND SUPPORT COMMUNITY MEMBERS WITH PALLIATIVE CARE NEEDS.

+46 **72**

NURSES WHO COMPLETED BASIC PALLIATIVE CARE TRAINING.



+12 **44**

CARERS TRAINED IN HOW TO SUPPORT AND CARE FOR THEIR FAMILY MEMBERS.



1,845
COMMUNITY MEMBERS SENSITISED ON PALLIATIVE CARE

+17 **34**



DOCTORS HAVE BEEN TRAINED IN PALLIATIVE CARE.

**Figures reflect cumulative activity outcomes over the full course of the project.*

Bringing peace in a world of COVID-19



Roseline is 41 and lives in Nkowankowa Township

Palliative care adds life into days when it can't add days into life

Rosaline has lived with cancer for a long time but had no diagnosis from the hospital although she first went there for help in 2010. By the time she was diagnosed with liver cancer, it had spread to her bones. She lost the ability to walk and cried with the pain, unable to sleep because of it. Although she felt rejected by the hospital, they booked her an appointment with a doctor who referred her to CHoiCe, a health-based non-governmental organization (NGO) providing palliative care, serving the rural population of the Mopani District, South Africa.

Things were already difficult for Roseline, and when COVID-19 hit things got even harder. She was already too sick to work, she had two children and food became a problem, and she had no medication.

"Sis* Jamela from CHoiCe brought me medication because during COVID-19 long lines of people waiting for assistance formed, and I was unable to collect my medication myself. After two days I was pain free.

"I once had a breakthrough pain and sis Jamela realized that it was because I ran short of medication. She organized it for me and came to give it to me at home. The pain stopped. She explained that I need to take all the medication as prescribed, she also told me that if it happens that when my sister goes to collect the medication and find that some of the medication is not available, I must let her know so that she can make a plan because otherwise I will experience pain. Since then I make sure that I have all the medication and the pain is totally gone."

During the lockdown CHoiCe Trust also gave me food parcels which benefited me and my family a lot; Jamela kept her promise to be with me through everything.

Sis Jamela arranged a walking frame which helped me because I was able to stand up. I could go outside when it is hot and sit under the shade. I could go outside to the bathroom on my own. No more using the bucket at home.

On the 10th of September, it was my birthday. I requested my family to throw a small party to celebrate my improvement because by this month last year I was on death bed. I was in severe pain crying and screaming. My family agreed but have a problem of buying me a cake. I shared my birthday wishes with Antoinette and Jamela. I was surprised on the 10th of September to see sis Jamela bringing me a very huge cake that I never thought I will have. I was very happy and I would like to say thank you to sis Jamela and CHoiCe for the wonderful things that they did to me throughout this Journey. I know the cancer is still there, but I feel like I am healed".

I was helped by CHoiCe to be where I am today. I would tell the Minister of Health that the palliative care has helped me a lot. When I didn't have hope of recovering they brought me medication and food parcels. Now I sleep peacefully."

When I didn't have hope of recovering they brought me medication and food parcels. Now I sleep peacefully."





Above: Rosaline with her new walker, brought by nurse Jamela

Left: Rosaline and her family celebrating her birthday.

*Sister

Support for global palliative care development



Our work in Greece with the Ministry of Health and the palliative care community continued

During this year we continued to help increase palliative care development globally

Work in Africa and Bangladesh is described elsewhere, however we also are working with partners in Russia and the former Soviet republics, and in the Republic of Greece. Unfortunately, the UICC World Cancer Congress schedule for October was cancelled due to the pandemic, but we hope we will still have a track on palliative care. Our work in Greece with the Ministry of Health and the palliative care community continued with the completion of a "National Strategy and Action Plan for Implementation of Palliative Care for Adults and Children in Greece." We hope to begin the implementation of this plan with support from the Stavros Niarchos Foundation and the Ministry. The Russian government has committed significant funding for palliative care development and a partnership between the Russian Hospice Care Professionals Association was formed with WHPCA, the American Eurasian Cancer Alliance and a number of US universities to support development in Russian and former soviet republics. Quarterly case conferences are being held, work on research and quality measurement started, and regular partnership on education.

> *"The Russian government has committed significant funding for palliative care development*

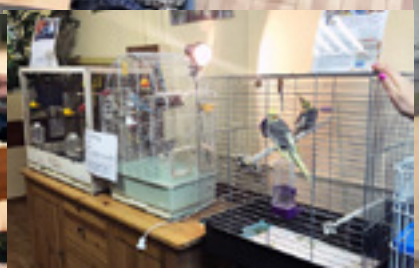
The WHPCA continues to focus on the support of hospice and palliative care development around the world. Here is a snapshot of this year's initiatives.



Partnering to support the Federal Palliative Care Centre launch in Moscow

Working together to support the development of palliative care in Russia, the WHPCA engaged with partners to support the launch of the Federal Palliative Care Centre in Moscow. The launch of the centre was the result of many years of work by Russian state and public organisations, and is significant as palliative care is identified as one of the Russian Federation's strategic areas of engagement within its health industry. The Russian government has also dedicated the equivalent of over USD $60 million annually to palliative care development across the Federation. An informal partnership to promote palliative care in Russia and former Soviet republics has been formed to include the WHPCA, the American Eurasian Cancer Alliance, Harvard Medical School, Johns Hopkins Medicine, Indiana University, Fox Chase Cancer Center, Hospice, the Hospice Care Professionals Association in Russia, and the Foundation for Palliative Care Education (PACED) in the United Kingdom.







Technical support for palliative care as a component of programme development



The WHPCA *Palliative Care Toolkit* and training manual continues to be a useful resource for partners developing palliative care programmes in limited resource settings and has been downloaded over 53,600 times.

This updated resource is available at: http://www.thewhpca.org/resources/item/palliative-care-toolkit-2016

Resources for programme development



The book *Building Integrated Palliative Care Programs and Services* (2017) co-developed by WHPCA has been downloaded 3,000 times. This book provides key information on how to develop both primary and specialised palliative care in existing health care systems and includes up to date clinical guidelines as well as program development resources.

This resource is freely available at: http://www.thewhpca.org/resources/building-integrated-palliative-care-programs-and-services

Building Partnerships

We know that a fundamental component of advocacy is building strong partnerships at all levels. This year we built alliances and facilitated new ways to engage and work. In July 2019, we supported Chatham House to organise a meeting on palliative care and Universal Health Coverage. With high level representation from the WHO, academia, global health civil society organisations, the private sector and, most crucially, people with lived experience of palliative care, there were frank conversations about how to progress the issue.



Read the Chatham House report "Closing the Global Access Gap in Palliative Care and Pain Relief: A Top Priority in Achieving Universal Health Coverage" https://www.chathamhouse.org/events/all/research-event/closing-global-access-gap-palliative-care-and-pain-relief-top-priority

Global Webinar

With a view to reach larger audiences and have open conversations in the global landscape we hosted our first global webinar on Universal Health Coverage and palliative care in October 2019. There were passionate presentations from Rob Yates from Chatham House, Felicia Knaul from the Lancet Commission on Palliative Care, Stephen Watiti, a person living with palliative care needs, Zipporah Ali from the Kenyan Hospice Palliative Care Association and Marie-Charlotte Bousseau from the World Health Organisation.




Rob Yates


Felicia Knaul


Stephen Watiti


Zipporah Ali


Marie-Charlotte Bousseau

Strengthening collaboration with partner institutions and alliances

We have been strengthening partnerships with regional and international organisations.

WE CONTINUE TO RESEARCH. We are also working with the Lien Centre for Palliative Care in Singapore on the next iteration of the Quality of Death and Dying Index. This third version of the Index will **rank over 170 countries** in the quality of end of life care using more sophisticated research methods than the previous versions.

WE CO-FACILITATE the Global Palliative Care Advocates Google Group of **181 members** which is used for real-time discussions on key global advocacy issues.

WE CONTINUED TO BUILD collaboration with civil society organisations where palliative care is not the primary focus such as the Action for Global Health, the NCD Alliance, the UICC, HelpAge International, Alzheimer's Disease International, Dementia Alliance International and the American Eurasian Cancer Alliance.

WE CONTINUE TO STRENGTHEN our partnership with the ICPCN and IAHPC.

We influence policy at the highest levels

This year, we worked to ensure that palliative care was prioritised at global policy fora and that the voices of people with lived experience of palliative care were heard. Our work at the global level is focussed on changing hearts and minds of those with power to make change happen.

Building political will and leadership



This year was a crucial year for building commitments and progress towards Universal Health Coverage (UHC) and the WHPCA worked with partners to ensure that palliative care remained central to the UHC agenda. UHC means that people can access the essential health services they need, from promotion, prevention, treatment, rehabilitation, and palliative care, without experiencing financial hardship. Our Executive Director, Dr Stephen Connor and representatives from the Kenyan Hospices Palliative Care Association attended the United Nations (UN) High Level Meeting on UHC civil society hearing and then the High Level Meeting itself in October 2019. Working with our partners and allies, we were delighted to ensure that palliative care was included in the UN political declaration on UHC, cementing policy leader's commitment to this issue and providing a vital advocacy tool for our partners working on advocacy at the national level all over the world.

Voices being heard on the world stage

Each year, world health leaders from all countries meet at the WHO executive board and at the World Health Assembly (WHA) and strive to ensure that people with lived experience are enabled to attend and speak out.

At the executive board, we supported Sharon Thompson to represent WHPCA, deliver her statement and meet Dr Tedros, Director General of the World Health Organisation (WHO). She is an author from Ireland whose daughter, Victoria, died aged 9 months old.

At the WHA in May, one of our representatives at the meeting was Stephen Watiti who is a WHPCA board member from Uganda and a person living with HIV. He has also had cancer, tuberculosis (TB) and meningitis and knows first-hand the crucial importance of palliative care.

Stephen gave at powerful presentation at a side event the WHPCA co-organised with International Association for Hospice and Palliative Care (IAHPC) and other partners to ensure the perspective of someone with lived experience of palliative care was heard. Stephen is a powerful advocate for palliative care.

Stephen Watiti said "Universal Health Coverage and primary health care should be for people of all ages and through all stages of life and should cover promotive, preventive, curative, rehabilitative and palliative aspects. The role of community health workers and carers is absolutely crucial worldwide in providing palliative care to people in their homes and communities."



"Universal Health Coverage and primary health care should be for people of all ages and through all stages of life"



Above: Sharon Thompson with Dr Tedros.
Right: Dr Stephen Waiti

Meet the palliative care patient champions who are speaking to power



David Musyoki

Advocacy officer, Kenyan Hospices Palliative Care Association.

"I was in Uganda talking about the importance of Universal Health Coverage with Joseph who has rectal cancer. Here is Joseph's story.

Because Joseph could not access a colostomy bag from his local health centre, he was using a plastic bag taped to himself. This did not always work embarrassing him and affecting his dignity. He had to travel miles to the NGO run hospice to get the colostomy bag to enable him to live well. Therefore, we need palliative care services to be integrated into primary health care services.

As a palliative care worker in Kenya, every day I see some of the sickest people being left behind. Many of us do not like to admit or think about the fact that we are mortal or what care will be available for us if cure is no longer possible. UHC means essential services and quality care throughout our lives from promotion, prevention, treatment, rehabilitation and palliative care."



Joseph Egolet, a passionate advocate for palliative care, sadly died in July 2019



Dr Helena Davies, 59 lives with a severe complex auto inflammatory condition which affects many of her systems including nerves and muscles meaning that she depends upon a motorised wheelchair and am on multiple medications. Helena is in the top 5% of the "extremely vulnerable" group. Helena is a WHPCA trustee.



Sharon Thompson, an author from Ireland.

"In 2011, I gave birth to our beautiful girl Victoria. At the age of 3 months she became very unwell, at 6 months she was diagnosed with a rare Non Communicable Disease. No treatment was possible. Victoria had no nerve insulation which meant that she suffered from extreme pain all the time.

Despite being surrounded in care for Victoria's birth, when we found out Victoria would die, we had to fight for the medical support she needed. We were sent home but there were no palliative care nurses, we lacked confidence and we lacked equipment. But we fought for palliative care and Victoria got it. She had symptom management and a safe death at 9 months old. Because of the palliative care Victoria received I can talk to you, work, support other mothers like me and live well. Our family do not have to grapple with the memories of Victoria living and dying in pain. We have no regrets. I do not really use the term 'UHC' but I know what it means. And I know that worldwide mothers like me are being sent home alone with their life-limited children in pain with no support. Through my experience as a mother of a life-limited child, I know at a minimum we need nurses trained in palliative care, equipment and medicines in the community and support for family members.

I thank WHO for their inclusion of palliative care in the impact framework. An essential package of palliative care as part of UHC is low cost. As your budgets ensure care for people at birth so they must ensure palliative care for those towards the end of the lives … and this includes our children."

Sharon Thompsons' intervention to the World Health Assembly Executive Board January 2019

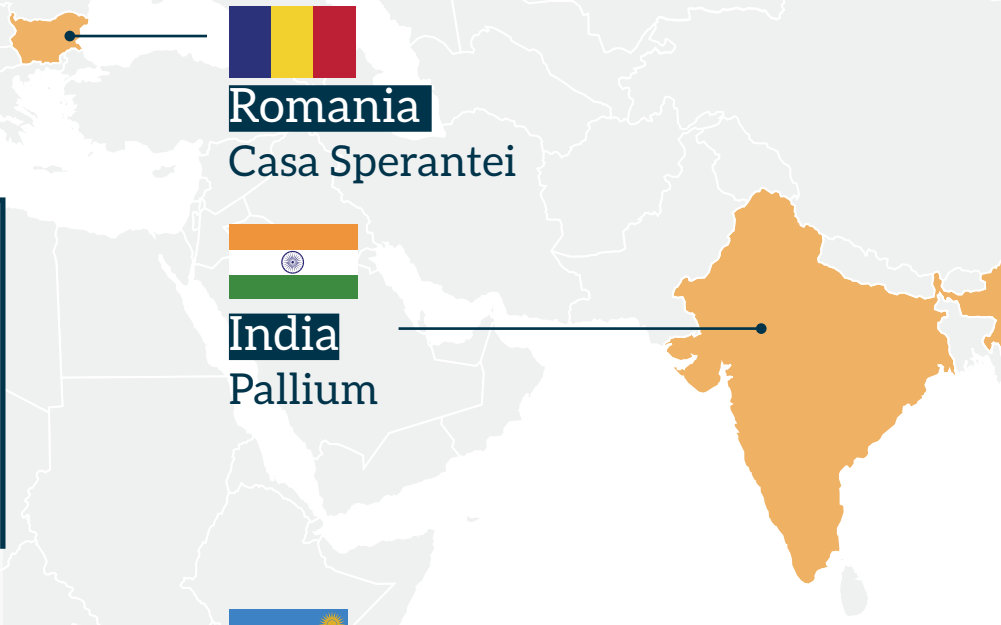
The WHPCA, with its allies, is also working to ensure that governments translate their promises into tangible progress in addressing the integration of palliative care services into Non-Communicable Disease (NCD) policies. WHPCA's Executive Director Dr Stephen Connor continues as a member of WHO's Civil Society Working Group on NCD. The remit of the Civil Society Working Group has been extended to 2021 to allow for civil society input into UHC deliberations from the UN High Level Meeting, and now includes a remit to support civil society engagement in the response to COVID-19.

Supporting Advocacy and the national and local level

In 2019/2020, Pallium India, Hospice Palliative Care Association of Zimbabwe, Casa Sperantei (Romania) and the Rwanda Palliative Care Hospice Organisation reported on the grants we awarded to them to increase the engagement of people with lived experience of palliative care in advocacy.

These grants were part of our project funded by the Open Society Foundations and they enabled the four organisations to explore and build relationships with groups of people with lived experience of serious illness. They enabled, facilitated and supported people with lived experience of palliative care to speak out.

This is part of our ongoing work to empower and strengthen the voice of people with lived experience in all our work.



Romania
Casa Sperantei

India
Pallium

Rwanda
Palliative Care Hospice Organisation

Zimbabwe
Hospice Palliative Care Association of

They enabled, facilitated and supported people with lived experience of palliative care to speak out.

Listening to Lived Experience is vital

We also attended the African Palliative Care Association meeting where we facilitated a workshop on the engagement of people with lived experience of palliative care in advocacy. Attended by over 70 delegates from all over Africa and the world, we worked with people with lived experience to enable a frank conversation on the opportunities and challenges of supporting people with palliative care needs to change the hearts and minds of policy makers.

PALLIUM INDIA - PROJECT AAROHAN

Empowering the voices of those who suffer

The word Aarohan means "to rise", and through this project, supported by a WHCPA grant, the aim was to strengthen the voice of direct palliative care beneficiaries and improve their impact as advocates to widen access to quality palliative care in their communities.

Pallium India conducted online sessions using the ECHO (Extension for Community Healthcare Outcomes) platform over a 5-month period, wherein participants were familiarised with various aspects of advocacy, related strategies and tools. This was in line with WHPCA's vision to improve the power balance and dynamics, and look at who is speaking on behalf of whom to develop a more impactful social justice movement on palliative care in low and middle-income countries, and worldwide.



What was the impact?

- 12 participants completed all sessions and are very active
- Participants have initiated advocacy activities such as public awareness programmes, written articles in local newspapers and magazines, collaborated with other organisations, engaged on social media, worked on advance care planning.
- One participant acquired a license to stock and dispense morphine.
- It has helped lay the foundations of the creation of national network of Palliative Care Beneficiaries.

> ***"We are not feeling as isolated now. We are able to talk with different people and groups with having the same kind of thinking. Also, we are enlightened in different legal aspects / issues that were very much needed. And finally, I am encouraged to take part for the advocacy of spreading palliative care in our state."*** Participant of Aarohan project.

Communicating our message and measuring impact

One of our key aims is to build our membership to be an empowered advocacy network for universal coverage of palliative care. We do this through engaging social media content, spreading palliative care stories and best practice through editing the international edition of ehospice and updating the WHCPA website. We also deliver a monthly e-newsletter to both organisations and individuals.

WHPCA Communications has also provided support to the Open Society Funded direct stakeholder project and the Joffe Charitable Trust project. We have used digital media to give voice to people with lived palliative care experience, with a view to to increase demand for, and access to, palliative care in Ethiopia and South Africa, the Compassionate Korail project in Bangladesh, and the implementation of the UK Aid Direct Project in Bangladesh.



Go to: www.ehospice.com/international

ehospice

The International edition of ehospice has supported WHPCA programmes and advocacy activity by reporting on: WHPCA programmes in Bangladesh, South Africa and Ethiopia, work on the Universal Health Coverage and the global Non Communicable Disease (NCD) agenda, palliative care as part of the WHO General Programme of Work, access to medications, rights of older persons, and advocacy at the WHO Executive Board Meeting and the World Health Assembly.



Growing our digital presence

Over the year we have increased our engagement on social media platforms, including Facebook and Twitter, with Twitter being the fastest growing platform. Social media has the ability to reach global audiences with key WHCPA messages and is a measurable communication tool.

Communication Tools

The WHPCA has continued to build up its communications tools.

Newsletter

Our monthly e-newsletter which is circulated to over 2,577 recipients in over 120 countries, up from 1,500 recipients in the previous year.

You can sign up to be kept up to date here: https://thewhpca.us15.list-manage.com/subscribe?u=7011dfc36f9d68a62dfde82aa&id=39accacaff

Website

We have been managing and updating our WHPCA website with regular news updates relating to hospice and palliative care worldwide.

Go to: www.thewhpca.org



10,000 downloads of the Global Atlas of Palliative Care 2nd Edition



Patient Power Project

The Patient Power Project, funded by the Joffe Charitable Trust continued to use digital media and the voices of those people who need, or are accessing palliative care, to tell their stories to raise demand among people who would benefit from it. The second aim is to encourage national decision makers to include palliative care in Universal Health Coverage plans.

For an insight into the project, you can read Roseline's story on page 10 or watch her film and that of other lived experience people in South Africa here https://www.thewhpca.org/about-us-3/anglophone-africa-project



World Hospice and Palliative Care Day

This awareness day is a key driver in building a strong and diverse movement demanding care for all. In 2019 it took place on 12th October with the theme, "My Care My Right." This highlighted the importance of palliative care as part of Universal Health Coverage.

HOW WE COMMUNICATED KEY MESSAGES

4,292 page likes on Facebook +123

6,106 followers on Twitter +1,185

theWHCPA.org had **59,403** SESSIONS AND **128,137** UNIQUE PAGE VIEWS BY **44,380** USERS

ehospice saw **160,519** sessions & **174,040** unique page views by **147,465** users +8,623 MORE USERS

2019 WORLD DAY HAD **170 EVENTS** ACROSS **65 COUNTRIES** +14

Monthly newsletter had **2,577** recipients in over 120 countries +1,077

International ehospice published **60 articles**

Strengthening collaboration with partner institutions

The WHPCA has been strengthening partnerships with regional and international institutions.

We have initiated and co-led the Global Palliative Care Advocates Google Group, which has 181 members and is used routinely for real-time discussions on key global issues. A partnership with the ICPCN is in process of being more formalised with a memorandum of understanding. We have also strengthened collaboration with non-specific palliative care allies and networks such as the Action for Global Health, the NCD Alliance, the UICC, HelpAge International, Alzheimer's Disease International, the Global Alzheimer's and Dementia Action Alliance, and the American Eurasian Cancer Alliance. We are working to ensure a coordinated and collaborative voice on issues ranging from Universal Health Coverage to NCDs.

WHCPA Publications

Book

- Connor, S (Ed). (2020). Global Atlas of Palliative Care – 2nd Edition. London UK, Worldwide Hospice Palliative Care Alliance. http://www.thewhpca.org/resources/item/global-atlas-of-palliative-care-2nd-ed-2020

Book Chapters

- O'Neill J, & Connor S. (In-Press). Palliative and Supportive Care: The Global Context. In A. Burger and J. O'Neill (Eds). Principles and practices of palliative and supportive oncology – 5th Edition. Philadelphia: Wolters Kluwer.
- Connor S, & Shimshon-Rubin S. (In-Press). Epidemiology and Demographic Aspects of Palliative Care and Related Bereavement. In H. Chapple & H. Servaty-Seib (Eds). *The Body of Knowledge in Thanatology*. Minneapolis MN: Association for Death Education and Counseling.
- Connor S. (In-press). Policy in Palliative Care. In N. Cherny, M. Fallon, S. Kaasa, R. Portenoy, & D. Currow. *Oxford Textbook of Palliative Medicine – 6th Edition*. Oxford UK: Oxford University Press.
- Downing J, Connor S, Frazer L. (2020). The need for and gaps in provision of children's palliative care globally. *In Children's Palliative Care: An international case-based manual*. Springer
- Connor S. (2019). Global Palliative Care Development Research. In M. Silberman (Ed). Palliative care: The role and importance of research in promoting palliative care practices: Reports from developed countries, Vol 2. 157-166. Nova: New York.

Journal Articles

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Launch of the new Global Atlas of Palliative Care

2nd Edition

The new Global Atlas of Palliative Care is a follow up to the original Global Atlas of Palliative Care at the End of Life originally published with WHO in 2014 and has been downloaded more than 100,000 times. The Atlas is a product of our 'official relations' with WHO and helps to paint a picture of the status of palliative care worldwide.



The Atlas addresses the following questions:

1. What is palliative care?
2. How many people are in need of palliative care worldwide?
3. What are the main diseases requiring palliative care?
4. What are the main barriers to palliative care?
5. Where are the existing gaps?
6. How well is palliative care developed in each country?
7. Where is palliative care currently available?
8. What are the models of palliative care worldwide?
9. What resources are devoted to palliative care?
10. What is the way forward?





This new edition of the Atlas has been produced in cooperation with several partner organizations including the IAHPC, ICPCN, University of Miami, Walther Centre in Global Palliative and Supportive Care, Indiana University, and University of Glasgow. The original WHO methodology for determining the need for palliative care has been replaced with a modified version of the method used by the Lancet Commission on Palliative Care and Pain Relief. The original estimate of 40 million people needing palliative care has now been increased to almost 57 million annually. The number of palliative care services has increased from 16,000 caring for three million patients in 2011 to over 25,000 services caring for seven million patients in 2017.

Download here: http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care

GLOBAL ATLAS STATS

ALMOST 57 MILLION PATIENTS AND FAMILIES NEED PALLIATIVE CARE ANNUALLY

7% of people that needs palliative care annually are children

ONLY 12% of global palliative care need is being met

ALMOST 25% of those 57 million suffer from communicable diseases like HIV, TB, and even COVID-19.

ALMOST 45% of those 57 million are at the end of life

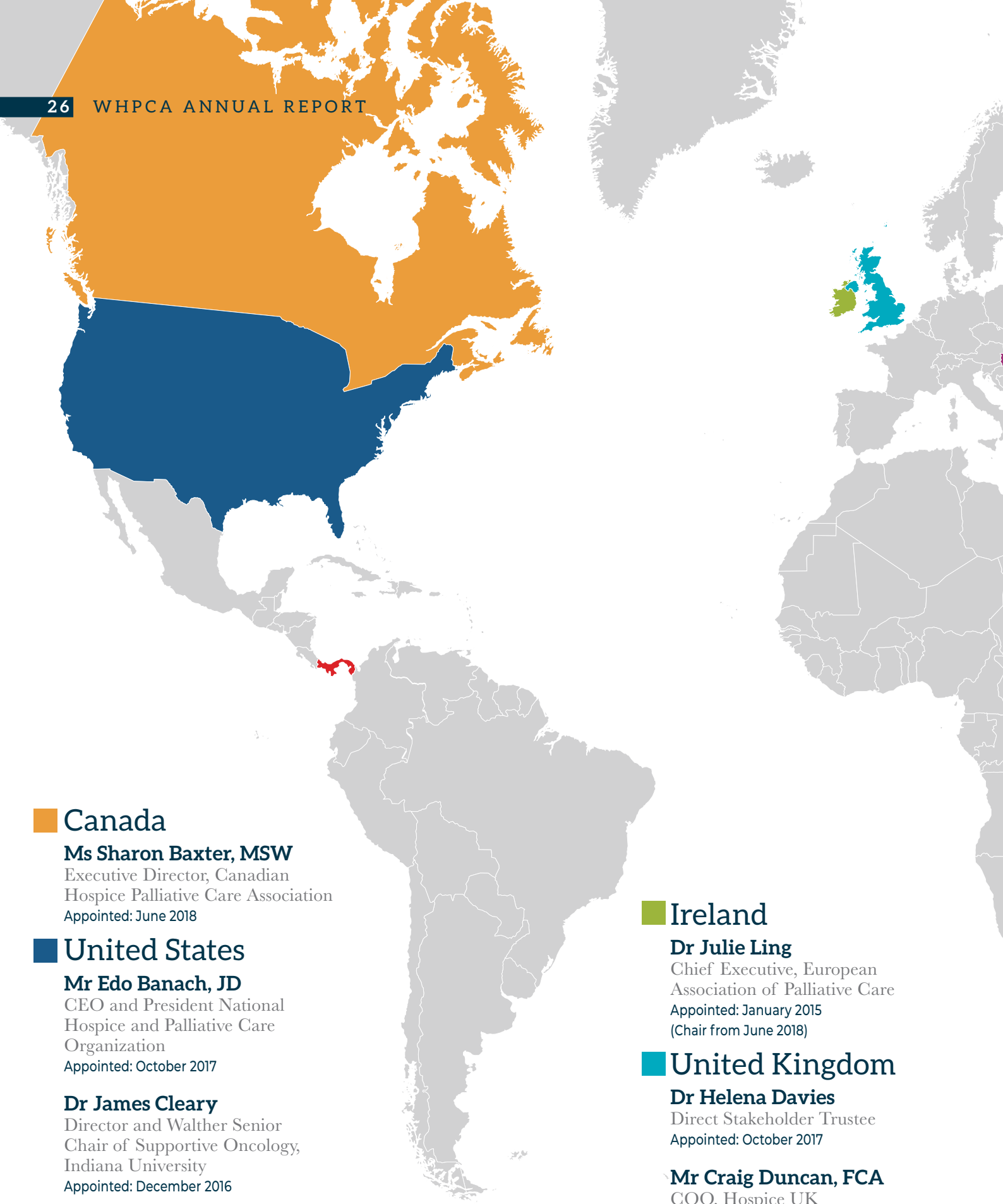
64% of countries have no or very limited provision of palliative care

76% of adult palliative care need is in low & middle-income countries

ALMOST 69% of people needing palliative care suffer from non-communicable diseases like cancer, dementia, stroke, heart-liver-kidney failure, lung diseases, or injuries

83% of countries have low to non-existent access to opioids for pain relief

87% The percentage palliative care is expected to increase by 2060



Canada

Ms Sharon Baxter, MSW
Executive Director, Canadian Hospice Palliative Care Association
Appointed: June 2018

United States

Mr Edo Banach, JD
CEO and President National Hospice and Palliative Care Organization
Appointed: October 2017

Dr James Cleary
Director and Walther Senior Chair of Supportive Oncology, Indiana University
Appointed: December 2016

Panama

Dr Nisla Camano Reyes
President, Panamanian Association of Palliative Care
Appointed: November 2018

Ireland

Dr Julie Ling
Chief Executive, European Association of Palliative Care
Appointed: January 2015
(Chair from June 2018)

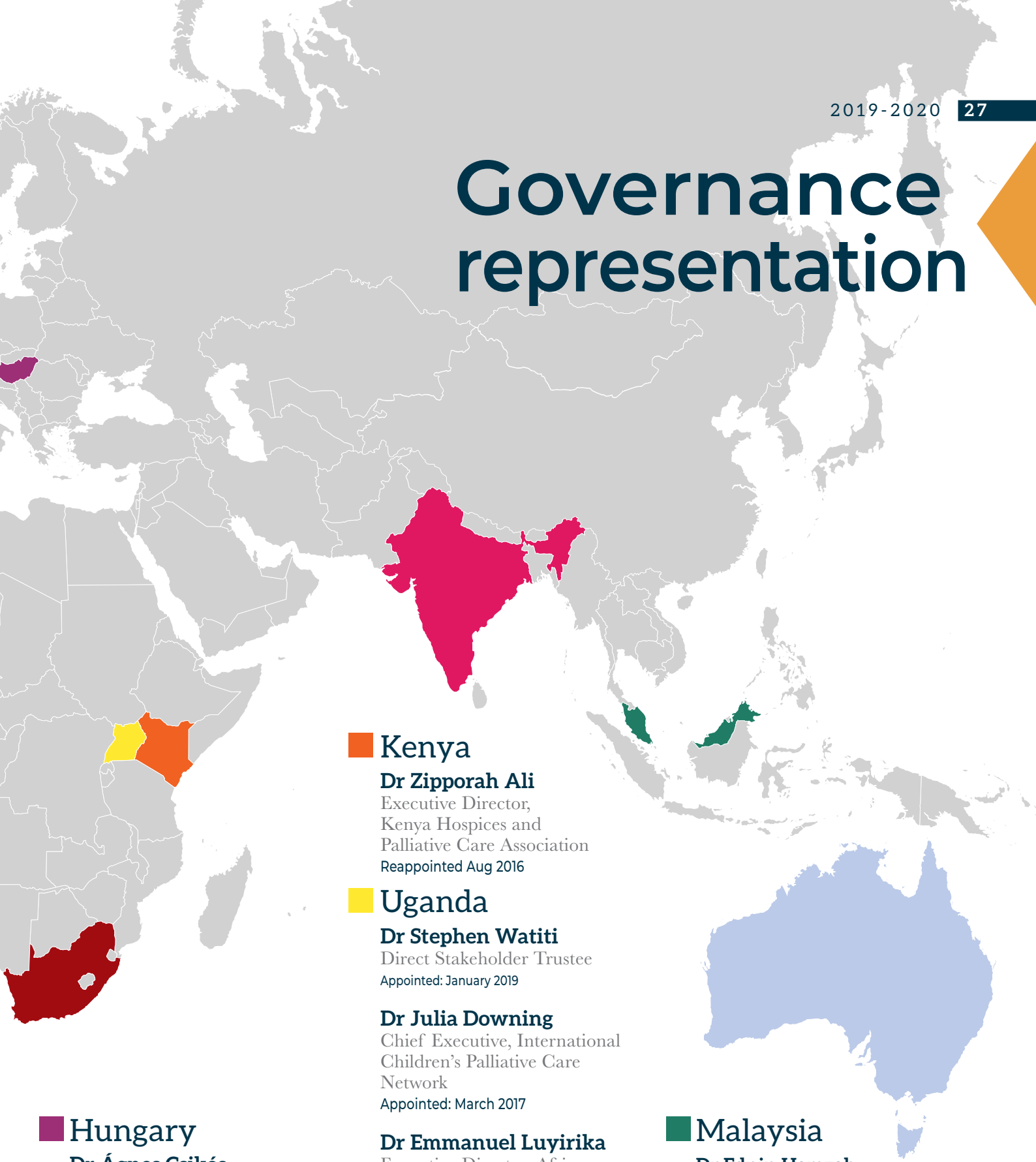
United Kingdom

Dr Helena Davies
Direct Stakeholder Trustee
Appointed: October 2017

Mr Craig Duncan, FCA
COO, Hospice UK
Appointed: August 2016

Dr Richard Harding
Cicely Saunders Institute, King's College London
Appointed: August 2016

Governance representation



Kenya

Dr Zipporah Ali
Executive Director, Kenya Hospices and Palliative Care Association
Reappointed Aug 2016

Uganda

Dr Stephen Watiti
Direct Stakeholder Trustee
Appointed: January 2019

Dr Julia Downing
Chief Executive, International Children's Palliative Care Network
Appointed: March 2017

Dr Emmanuel Luyirika
Executive Director, African Palliative Care Association
Reappointed August 2016

India

Dr Abjihit Dam
Secretary Indian Association of Palliative Care
Appointed: October 2017
Resigned: June 2020

Hungary

Dr Ágnes Csikós
Pecs-Baranya Hospice Foundation, Hungary
Appointed: March 2017

South Africa

Dr Elizabeth Gwyther
Professor, University of Cape Town (Former Chair WHPCA Board)
Completed Terms: June 2020

Malaysia

Dr Ednin Hamzah
Vice-Chair Asia Pacific Hospice Palliative Care Network
Appointed: October 2013
Reappointed August 2017

Australia

Dr Frank Brennan
Physician
Appointed: December 2016

Challenges and Opportunities



The opportunity is for health systems to realize the value that palliative care brings to health care especially the prevention and management of serious health related suffering, the art of having difficult conversations and breaking bad news, and the importance of helping the bereaved to effectively grieve in situations where there was no opportunity to say goodbye to loved ones. As we look beyond the pandemic, which likely will not be the last one, we can do more to help low and middle-income countries to incorporate palliative care into health care systems using culturally appropriate indigenous models of care that are folded in to universal health coverage schemes. What is needed is political will and the realization that palliative care is not a new burden but part of the solution to a health care crisis that will see more and more people with non-communicable and communicable illnesses where palliative care is a model for how to provide the right care at the right time.

> ***We are seeking new funders to support an expansion of research and advocacy initiatives to meet the global demand for palliative care services.***

Thank You

We would like to thank our donors without whom our work would not be possible

WE EXTEND OUR APPRECIATION TO:

1. Open Society Foundations – Public Health Program
2. UK Aid Direct
3. Joffe Charitable Trust
4. Stavros Niarchos Foundation
5. United States Cancer Pain Relief Committee
6. True Colours Trust
7. Anonymous Donor



Etsegenet is 50 and accessed palliative care at Hospice Ethiopia

After my diagnosis, I found myself in a severe physical, psychosocial & spiritual distress. But after accessing palliative care, my suffering was holistically relieved.

Palliative care must be accessible because there are numerous people suffering from life threatening illness in developing counties like Ethiopia, especially women with breast and cervical cancer. After I accessed palliative care, I got the initiative, courage and psychological readiness to start from the beginning again. I used to give up on myself, I never saw that I would be here today. I advise and encourage people to not give up on themselves.

Financial Report

For the year ended 31 March 2020

Statement of financial activities

(Incorporating an income and expenditure account)

				2020	2019
		Unrestricted	Restricted	**TOTAL**	TOTAL
	NOTE	£	£	**£**	£
Income					
Donations and legacies	*2a*	5,504	267,214	**272,718**	367,656
Income from charitable activities	*2b*	0	0	**0**	6155
TOTAL INCOME		**5,504**	**267,214**	**272,718**	**373,811**
Expenditure					
Raising funds	*3*	1,350	0	**1,350**	18
Charitable activities	*3*	(4,834)	346,796	**341,962**	359,963
TOTAL EXPENDITURE		**(3,484)**	**346,796**	**343,312**	**359,981**
Net income / (expenditure) in the year		8,988	(79,582)	**(70,594)**	13,830
Reconciliation of funds					
Total funds brought forward		22.614	209,454	**232,068**	218,238
TOTAL FUNDS CARRIED FORWARD	*11*	**31,602**	**129,872**	**161,474**	**232,068**

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above.

Balance Sheet

	Note	2020 £	2019 £
Tangible Fixed Assets	*8*		879
Current assets			
Cash at bank and in hand		158,157	151,393
Debtors	*9*	6,164	80,678
		164,321	232,071
Liabilities			
Creditors: amounts due within 1 year	*10*	(2,847)	(882)
Net current assents		161,474	231,189
Net assets		161,474	232,068
Funds			
Restricted funds		129,872	209,454
Unrestricted funds		31,602	22,614
TOTAL CHARITY FUNDS	*11*	161,474	232,068

© November 2020 Worldwide Hospice Palliative Care Alliance

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About the photo
A nurse from CHoiCe in South Africa, dresses a wound in the patient's home, while his mother looks on.