



**INTERNATIONAL ASSOCIATION OF HOSPICE AND
PALLIATIVE CARE (IAHPC)**

2020 -2024 STRATEGIC PLAN

August 2019

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Message from the Board Chair and the Executive Director

We are delighted to share the 2020-2024 strategic plan of the International Association for Hospice and Palliative Care (IAHPC)— a bold and clear plan that outlines where we have come from, where are going, how we will get there, and what it means to all of us. The overarching goal of a world free of health-related suffering and the four areas of work and expected Outputs will keep us focused on our future direction, as well as our day-to-day work.

Our strategic plan is the culmination of a process we began in the summer of 2018. Under the expert lead of Doctor Faith Mwangi-Powell and based on careful assessment of current programs and projects as well as current and future resources, we had thought-provoking work sessions and completed the strategic plan in June 2019, with a new mission and vision for our work in global palliative care.

We have better data than when we adopted the previous strategic plan, data that shows the still yawning access abyss in palliative care that leaves millions of patients to live and die with preventable suffering. These fundamental divides will not resolve themselves without focused attention and resources. In developing our 2020-2024 Strategic plan we re-examined our strategic priorities against the current global health policy landscape and considered where the organization could have a more meaningful role.

Throughout a robust engagement and planning process, we heard from our members, directors, officers, volunteers, researchers, donors, and representatives from partner organizations. In building this blueprint for the future, we remained true to what we heard, and we hope that you see your voice reflected here. We are also committed to receiving your ongoing input and feedback as we journey through this plan and its priorities together.

Our new mission not only articulates our primary purpose to inspire and inform, but also to influence and empower individuals, governments and organizations to increase access to, and optimize the practice of palliative care. Our new vision for the IAHPC's future is simple, clear, and focused on the relief of suffering. Although it uses only a few words, the refined vision builds on the IAHPC tradition of dedication to improving the quality of life of patients and caregivers worldwide. IAHPC subscribes to the values of commitment, excellence, efficiency, creativity, compassion, respect and service to others. These values underline our principles of aspiring to be a strong network that is person centered and empowering, building communities of practice and supporting behavior change to drive demand for palliative care so it becomes available to all those who need it.

If we continue to uphold these values as the foundational principles for our endeavors, they will foster unity in meeting our mission, vision and the four expected Outputs identified in this strategic plan.

This strategic plan serves as an important guide that will help the IAHPC succeed in the face of challenges. It is an opportunity to strengthen our institutional capacity and support innovation. As we roll out this next five-year plan, we know that our work will not move in a linear trajectory. We will learn from our experiences and partners and adjust as we monitor and evaluate results. We know that our strategic planning decisions affect many, and we commit to transparent communications as our funding priorities evolve.

Many thanks again to Doctor Mwangi-Powell for her excellent facilitating and leadership skills and to all the others who engaged in this planning process, shaping the contents and enabling this dynamic guide for the future.

Lukas Radbruch, MD
Chair, Board of Directors

Liliana De Lima, MHA
Executive Director

What is Palliative Care?

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹ The International Association of Hospice and Palliative Care (IAHPC) has refined this definition through a global consensus process, describing palliative care as the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, especially of those near the end of their lives. It aims to improve the quality of life of patients, their families and their caregivers.²

The recent *Lancet Commission on Global Access to Palliative Care and Pain Relief* reported that the burden of serious health-related suffering (SHS) is significant.³ Approximately 25.5 million of the 56.2 million people who died in 2015 experienced SHS, with another 35.5 million experiencing SHS due to life-threatening and life-limiting conditions.⁴ Moreover, a disproportionate number (>80 percent) of these 61 million individuals live in low-income and middle-income countries (LMICs), where access to any palliative care interventions—including simple oral morphine for pain relief—is severely limited.⁵ This is a serious impediment to service provision that the Commission sought to challenge by designing an essential and affordable package of palliative care medicines, basic equipment, and human resources to alleviate much of avoidable suffering in LMICs.

The situation is exacerbated by the fact that palliative care provision is not fully integrated into public health systems, required for the implementation of Universal Health Coverage (UHC)⁶. Services are primarily provided by faith-based or non-governmental organizations (NGOs), charities, and hospices. These organizations have highly limited, and often irregularly available resources at a time when the palliative care donor landscape has significantly shrunk over the last ten years, with relatively minimal funding relative to patient need and the donor dependency of service providers. Lastly, public, professional and policy

¹ World Health Organization. WHO definition of palliative care. www.who.int/cancer/palliative/definition/en/.

² Palliative Care Definition, (2019) <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/> accessed July 12th 2019.

³ Knaul FM, Bhadelia A, Rodriguez NM, Arreola-Ornelas H, Zimmermann C. The Lancet Commission on Palliative Care and Pain Relief—findings, recommendations, and future directions. *The Lancet Global Health*, 6, 2018: S5-S6.

⁴ Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, Arreola-Ornelas H, Gómez-Dantés O, Rodriguez NM, Alleyne GAO, Connor SR, Hunter DJ, Lohman D, Radbruch L, Del Rocío Sáenz Madrigal M, Atun R, Foley KM, Frenk J, Jamison DT, Rajagopal MR; Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018; 391: 1391-1454.

⁵ Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, Arreola-Ornelas H, Gómez-Dantés O, Rodriguez NM, Alleyne GAO, Connor SR, Hunter DJ, Lohman D, Radbruch L, Del Rocío Sáenz Madrigal M, Atun R, Foley KM, Frenk J, Jamison DT, Rajagopal MR; Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018; 391: 1391-1454.

⁶ Knaul FM. Integrating palliative care into health systems is essential to achieve Universal Health Coverage. *Lancet Oncol* 2018; 19: e566-e567.

maker understanding of palliative care remains poor, the discipline has struggled to attract public support and funding.

Although at the policy level, palliative care has enjoyed several global successes recently, the provider community has struggled to translate those wins into ground-level tangible actions. Such policy achievements are inclusion of palliative care in the Political Declaration on UHC,⁷ the World Health Assembly resolution for palliative care,⁸ the inclusion of palliative care in the Declaration of Astana⁹ and the opportunities presented by the Sustainable Development Goals (SDGs).¹⁰ The following challenges remain:

- There is limited access to palliative care services for the majority who need them. This is especially the case for children requiring palliative care, with a 2013 UNICEF study¹¹ estimating less than 1 percent of those in need were able to access services;
- A significant number of health care providers lack training and skills in palliative care;
- There is limited availability and accessibility to palliative care essential medicines, especially opioids;
- There is limited awareness and understanding of palliative care among the general public, medical practitioners and policy makers;
- There is limited integration of palliative care across the broad spectrum of health systems;
- There are limited resources—domestic and general funding—for palliative care initiatives;
- There are misconceptions about palliative care as only end-of-life care, resulting in the neglect of those in need from the point of diagnosis and those with limited personal funds, and;
- There are a few palliative care champions at all levels of care, from the community to the national levels.

To respond to these challenges, IAHPCC is collaborating with partners to drive the global development of palliative care and this document lays out the strategic direction that the organization intends to follow in the next five years to achieve its vision.

⁷ World Health Organization. Universal Health Coverage. Retrieved from: www.who.int/mediacentre/factsheets/fs395/en/

⁸ World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course. 67th World Health Assembly, Agenda 15.5, 24 May, 2014. Retrieved from: http://apps.who.int/gb/ebwha/pdf_files/wha67/a67_r19-en.pdf

⁹ World Health Organization. The Declaration of Astana (2018). Retrieved from: <https://www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf>

¹⁰ United Nations Development Programme. Sustainable Development Goals. Retrieved from: www.undp.org/content/undp/en/home/sustainable-development-goals.html

¹¹ UNICEF – ICPCN. Assessment of the Need for Palliative Care for Children: Three Country Report: South Africa, Kenya and Zimbabwe (2013). Retrieved from: <http://www.icpcn.org/wp-content/uploads/2014/02/Palliative-Care-Three-Country-Report.pdf>

About the IAHPC

IAHPC has its origins in the International Hospice Institute (IHI), founded in 1980 by Dr. Josefina Magno, a Philippine oncologist living in the USA. IHI members developed the International Association for Hospice and Palliative Care, with a perspective designed not to promote a one size fits all palliative care model, but to encourage and empower all countries to develop their own models of palliative care provision according to their unique resources and conditions. The IAHPC was first incorporated in New Jersey in 1997 and temporarily dissolved in 1999 when the board elected Professor Eduardo Bruera as the Chair of the Board of Directors and Liliana De Lima as the Executive Director, both of whom were living in Texas. The organization re-incorporated in Texas in 2000 and recognized as a 501c3 organization by the US Government that same year.

Since IAHPC's inception, we have addressed the legal, regulatory, political, cultural and economic barriers on access to care, lack of education, and access to controlled medicines for palliative care through a variety of different strategies. IAHPC entered into official relations with the World Health Organization in 2015 and was admitted into consultative status with the UN Economic and Social Council (ECOSOC) in 2017.

IAHPC's Values

IAHPC subscribes to **commitment, excellence, efficiency, creativity, compassion, respect and service to others**. These values underline our principles of **always aspiring to build a strong network**, that is **person centered, empowering, builds communities of practice and supports behavior change to drive demand for palliative care so it becomes available to all those who need it**.

IAHPC Achievements in 2018

IAHPC led and coordinated several projects aligned with the organization's vision and mission. Some of these, which were either completed or ongoing during 2018 include:

- The consensus palliative care definition was completed and submitted for publication.
- The Opioid Price Watch Project (third report) was completed and published in Journal of Palliative Medicine¹²
- Pallipedia, the online palliative care encyclopedia is an ongoing project that is updated and nurtured by former Board Chair, Roberto Wenk.
- The Lancet Commission on Global Access to Palliative Care and Pain Relief Report:
 - The ongoing implementation group is responsible for implementation of the Report's recommendations. Focal person for this group is Katherine Pettus, with guidance from Liliana De Lima, Executive Director.
 - The launch group, which is ongoing, has organized presentations in Miami, London, Lima and Panama City, led by Dr. Felicia Knaul, PI of the Lancet Report.

¹² De Lima L, Arias Casais N, Wenk R, Pastrana T. Opioid Medications in Expensive Formulations are Sold at a Lower Price Than Immediate-Release Morphine in Countries Throughout the World: Third Phase of Opioid Price Watch Cross-Sectional Study Journal of Palliative Medicine 2018 Oct;21(10):1458-1465. DOI:10.1089/jpm.2018.0149

- The Pontifical Academy for Life PAL-LIFE Project published a White Paper in the Journal of Palliative Medicine ¹³ and distributed a White Book during the EAPC Congress in Berlin in May 2019.

IAHPC Thematic Areas of Work

Based on the results of the survey completed by IAHPC stakeholders (members, directors, patients, caregivers, funders, volunteers) and in order to refine our strategy, over the next five years, IAHPC will focus on four thematic areas:

- **Advocacy**, for integration of palliative care into primary health care, within the spectrum of universal coverage, and improved access to essential palliative care medications;
- **Education**, to increase the workforce skilled in primary health palliative care;
- **Research**, to gather data and evidence to inform palliative care development globally, and;
- **Information dissemination** to educate stakeholders and amplify impacts where change is happening, to increase demand for palliative care and inspire additional changes.

What IAHPC hopes to achieve 2020-2024

During this strategic period, we aim to **accelerate global access to palliative care for those who need it, in order to relieve serious health-related suffering.**

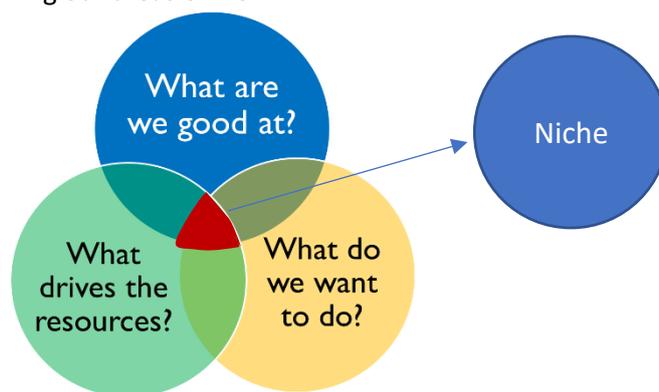
Three key questions will guide us to maximize our outputs (Figure 1):

What are we good at?

What drives our resources?

What do we want to do?

Figure 1 – Defining our areas of work



Based on the above and after discussion, it was agreed that our strategy will deliver on a common goal and four main outputs as described in Box 1.

¹³ Centeno, C., Sitte, T., De Lima, L., Alsirafy, S., Bruera, E., Callaway, M., ... & Puchalski, C. (2018). White Paper for Global Palliative Care Advocacy: Recommendations from a PAL-LIFE Expert Advisory Group of the Pontifical Academy for Life, Vatican City. Journal of Palliative Medicine, September 2018.

IAHPC's Strategic Plan: Goal, Outcome and Outputs

Box 1

Overview of IAHPC'S Strategic Plan: Goal, Outcome and Outputs

Goal (the high-level change that IAHPC is working towards)

- A world free of health-related suffering.

Outcomes (changes that IAHPC is contributing towards)

- Accelerated access to palliative care for those in need globally.
- Increased global knowledge and evidence base for palliative care development

Outputs (IAHPC's broad areas of work)

- **Output 1: Increased access to palliative care** – Strengthening global advocacy to increase access to palliative care.
- **Output 2: Educated and skilled global workforce for palliative care delivery** – Strengthening palliative care education and skills among providers globally
- **Output 3: Evidence based decision making in palliative care** – Strengthening access to data, information and global knowledge around palliative care to inform programming.
- **Output 4: Positive stories and focused messaging to support and advance the palliative care global movement** – Strengthening palliative care messaging, information and communication to inspire change globally

IAHPC's Vision

The IAHPC vision of moving towards a world free from health-related suffering for all, is underpinned by the mission and an overview of the strategic plan, which is outlined below.

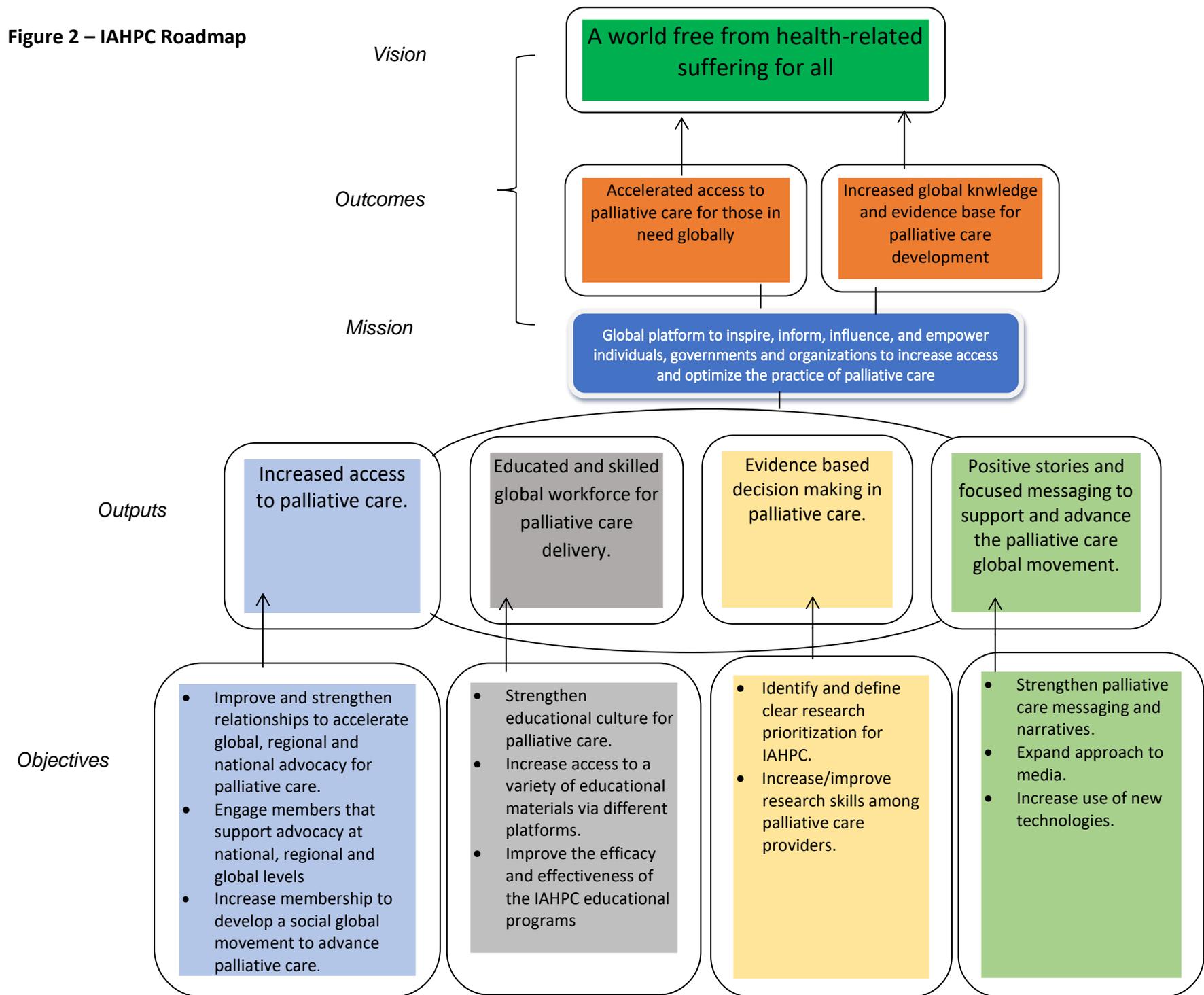
IAHPC's Mission

To serve as a global platform to inspire, inform, influence, and empower individuals, governments and organizations to increase access and to optimize the practice of palliative care.

Roadmap

To achieve our vision and mission, we ensured our four outputs complement each other and from our results, a roadmap was developed (Figure 2). Together, the four outputs emphasize the central role of IAHPC as a global organization that inspires and empowers individuals and organizations to increase access to palliative care globally. The remainder of this document expands upon each of the outcomes and their corresponding objectives in detail.

Figure 2 – IAHP C Roadmap



Expected Outputs

Output 1: Increased access to palliative care

Strategic Overview

Through advocacy at multi-lateral meetings, the IAHPC, in collaboration with other organizations in consultative status and in official relations with the United Nations (UN) agencies, seeks to ensure that access to palliative care and to essential medicines for pain relief and palliative care, are included in international policy documents and strategies, as components of the right to health. Ideally national palliative care organizations can leverage these international documents, usually approved by members of their own governments, to improve palliative care delivery for their patients and secure public funding. The IAHPC works on the drafting and implementation of resolutions, agreements and strategies with special agencies of the UN, including the WHO and with governments (by invitation).

IAHPC also trains palliative care providers to undertake advocacy for specific needs in their countries and regions. Despite these efforts, access to essential medicines for palliative care, though improving, remains inadequate, with **millions of people globally experiencing a high burden of SHS. These challenges are underpinned by the fact that, in many countries, palliative care** is primarily delivered through charities, and it remains unfunded and not integrated into health systems. The emerging UHC global agenda is an opportunity for greater advocacy to ensure the integration of palliative care into. ***Building on our success to date, we are strengthening our advocacy approach to focus on three key strategic areas.***

Strategic Objective 1.1: Improve and strengthen relationships to accelerate global, regional and national advocacy for palliative care

Rationale

United Nations special agencies, such the WHO, the Commission on Narcotic Drugs (CND) and the International Narcotics and Control Board (INCB), are key partners in strengthening access to palliative care medication.

For example, in 2014 the WHO adopted a resolution (WHA67.19) urging its member states to work to integrate palliative care into national healthcare systems, across all levels, with an emphasis on primary, community, and home-based care.¹⁴ The resolution aims to ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to non-communicable diseases. Under international human rights law, it is the obligation of health care systems to ensure access to essential palliative care services and medicines.¹⁵

INCB reports and workshops have called on and supported governments to ensure the availability and accessibility of controlled substances for medical purposes and their rational use to prescribers and patient advocates. CND has also passed several resolutions articulating this imperative. For

¹⁴ World Health Organization. Strengthening of palliative care as a component of comprehensive care throughout the life course. [cited 2016 April 09]. Retrieved from: http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

¹⁵ United Nations. General Assembly: 217 A (III). Universal Declaration of Human Rights. [cited 2019 July 05]. Retrieved from: <http://www.un-documents.net/a3r217a.htm>

example, in 2010 and 2011, the CND adopted resolutions 53/4¹⁶ and 54/6¹⁷ with a view to promoting the adequate availability of internationally controlled substances for medical and scientific purposes, while preventing their diversion and abuse. In 2019, CND approved a resolution supporting INCB training of member states to improve technical capacity for improved availability while preventing diversion and abuse.¹⁸ Despite these recommendations, appropriate access to controlled medicines remains stubbornly inadequate globally. The IAHPHC will therefore continually engage these agencies to ensure the realization of these resolutions.

Specific activities for this objective will include participation in CND regular meetings and intersessionals and ongoing liaison with the INCB secretariat. We will solicit the input of providers and service users to provide testimony to CND during the sessions that review Chapter Two of the UNGASS Outcome Document. We will report to IAHPHC members about scheduled INCB trainings and activities in their countries, and we will encourage national palliative care associations to brief diplomats in their Vienna and Geneva missions about the unmet need for palliative care patients in the context of UHC, PHC and their human rights obligations.

In addition, the IAHPHC will continue to work in partnership with the global palliative care organizations [International Children's Palliative Care Network (ICPCN) and the Worldwide Hospice Palliative Care Alliance (WHPCA)] and aligned with their own strategic plans^{19, 20}. IAHPHC will continue to strengthen its collaborative ties with the regional associations, the African Palliative Care Association (APCA), the Asia Pacific Hospice Palliative Care Network (APHN), the European Association for Palliative Care (EAPC) and the Latin American Association for Palliative Care (ALCP for its Spanish acronym), as well as national associations and academic institutions to advance global palliative care.

As the organization responsible for the implementation of the recommendations of the Lancet Report, the IAHPHC will continue to work with the University of Miami (the Lancet Report Secretariat), where the Lancet Report is housed.

Strategic Objective 1.2: Engage IAHPHC members to advocate for improved access to palliative care at the national, regional and global levels

Rationale

Despite the huge unmet need for palliative care, the number of advocacy leaders who can support the field at national, regional and global levels remains limited. The IAHPHC has a well-developed advocacy strategy and skills framework that can be rolled out to support advocacy skills

¹⁶ CND. Promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse. (2010) Retrieved from : https://www.unodc.org/documents/commissions/CND/Drug_Resolutions/2010-2019/2010/CND_Res-53-4.pdf

¹⁷ CND. Resolution 54/6 - Promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse. (2011). Retrieved from: https://www.incb.org/documents/Psychotropics/Resolutions/CND_Res-54-6.pdf

¹⁸ INCB. Progress in ensuring adequate access to internationally controlled substances for medical and scientific purposes. (2018). Retrieved from: https://www.incb.org/documents/Publications/AnnualReports/AR2018/Supplement/Supplement_E_ebook.pdf

¹⁹ ICPCN Strategy 2019-2023. Retrieved from: <http://www.icpcn.org/about-icpcn/icpcn-strategy-2012-2015/>

²⁰ WHPCA Strategic Plan 2019-2021. Retrieved from <http://www.thewhpc.org/resources/item/whpca-strategic-plan-2019-2021>

development globally. As it will be challenging to support this agenda, key activities under this strategic objective will include:

- Defining the selection criteria for target countries and selecting at least 6 countries across the regions, representing different income levels;
- Developing a skill-building advocacy framework with structured outcomes and deliverables;
- Identifying areas of success and building replicable, scalable, models for advocacy skill-building;
- Developing linkages with regional and national associations to support members trained in advocacy on the ground;
- Developing an advocacy mentorship system to support advocacy trainees;
- Continue developing and implementing advocacy workshops, including webinars, mentorship, utilization of the *Lancet* Commission data and the Miami DeclarAction;²¹
- Linking trained palliative care professionals around the world to create cohorts of IAHPAC advocacy fellows and working with the fellows to develop annual advocacy goals for their countries and regions.

Strategic Objective 1.3: Increase membership to develop a social global movement to advance palliative care

In order to build a social movement for palliative care with maximize reach and impact, and to successfully advocate for the inclusion of palliative care in UHC, we must continually develop IAHPAC membership and convene new partnerships.

²¹ Knaul, F., Bhadelia, A., Horton, R. Health-related suffering: from Lancet Commission to DeclarAction. *The Lancet*. May 26, 2018, 391 10135, p. 2088-2089.

Output 2: Educated and Skilled global workforce for palliative care delivery.

Strategic Overview

It is generally recognized that there is a need for professional health education that incorporates palliative care education within undergraduate programs. This will help to meet the professional and personal demands made upon palliative care practitioners. Whilst historically, palliative care was confined to patients with cancer, it has now become a form of care offered to patients and families experiencing a chronic disease.²² The growing disease burden and limited provision of palliative care within the public health systems means that an increasing number of patients will require palliative care in a variety of settings including, home based care, nursing homes, hospices, and virtually every clinical setting. In many low- and middle-income countries, however, providers have limited skills as palliative care is infrequently integrated into the curriculum. IAHPHC will continue supporting providers by providing learning opportunities to increase the skills of those at the forefront of this agenda. Under this output IAHPHC will undertake three strategic objectives.

Strategic Objective 2.1: Strengthen educational culture for palliative care

Rationale

Limited integration of palliative care into the curriculum of health professionals globally indicates a weak education culture in this area. IAHPHC wishes to strengthen this through a series of activities that include:

- Continue nurturing the IAHPHC global educational [directory](#) and find creative ways to engage with current undergraduate and post graduate students.
- Develop an awards system to recognize academic institutions integrating palliative care into the curricula of health careers.
- Continue and finalize the project to provide institutional accreditation and individual certification to IAHPHC members.

Strategic Objective 2.2: Increase access to a variety of educational materials, including via different platforms

Rationale

In this era of technological growth and given the diverse nature of training needs among palliative care providers, it is important to explore various avenues for delivery of palliative care education and to take advantage of the growing use of social media and online technology. The IAHPHC membership is worldwide and reachable through multiple channels and platforms. The IAHPHC will therefore undertake the following activities:

- Linking educational workshops to regional and international conferences.

²² Addington-Hall J, Altmann D Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses? J Adv Nurs (2000) 32: 799-806

- Continuing to develop and disseminate the online resources developed to date, Pallipedia, CINAHL, PC Essentials, Opioid Price Watch etc., and informing members and others to increase visibility.
- Making posters and presentations of grantees available online.

Strategic Objective 2.3: Improve the efficacy and effectiveness of the IAHP educational programs

Rationale

Palliative care education, where offered, is generally expensive and inaccessible to the majority of potential trainees. Since its formation, the IAHP has provided grants to more than 580 individuals, underwriting their travel and participation in educational and research conferences (through the Traveling Scholarship program), or their travel as invited teachers in palliative care settings in a low- or middle-income countries (through the Traveling Fellowship program). This has proven to be a useful strategy for expanding the base. Now more than ever it is critical to focus on a results-oriented strategy by carefully selecting a smaller number of grantees annually, while developing deeper partnerships and collaboration, with the goal of improving education, access to services, access to medicines and national policy.

In view of that IAHP will focus on:

- Modifying the application and selection process of the Traveling Scholarship program to identify potential leaders in selected countries who will be assigned a mentor(s) to work with for a period of two years. This TS will include the opportunity to travel to a conference and present a poster, but the scope will be broader and deeper.
- Modifying the application and selection process of the Traveling Fellowship program to match the fellow with the long-term advocacy strategy described in Output 1.

Output 3: Evidence based decision making in palliative care

Strategic Overview

Over the past two decades, palliative care has developed as a field that addresses the needs and priorities of patients with serious health related suffering. Notwithstanding this progress, there has been a misalignment between clinical development, evidence, and research to underpin programming. The literature suggests that continued development of the field will require strategic and high-quality research to guide clinical practice and public health policy, and while substantial strides have been made, knowledge gaps and in system deficits persist. IAHPHC will therefore focus on formative research to inform programming, work that will be underpinned by two strategic objectives:

Strategic Objective 3.1: Identify and define research priorities for IAHPHC

Rationale

Empirical knowledge about palliative care provision and the needs of people with SHS is extremely limited, as is the availability of research resources, including expertise and funding.²³ The lack of research activity is, in part, attributable to limited resources, competition with other health-related priorities, and lack of infrastructure to connect the limited number of researchers in this field. Also missing is a guiding global framework that prioritizes a palliative care research agenda firmly grounded in the perceived needs and preferences of key stakeholders, both providers and end users. Although several regions have developed thematic research agendas, there are still deficits at the national, (some) regional, and international levels.

IAHPHC will spearhead this by:

- Developing a white paper/position paper on global palliative care research priorities. This can be adapted at country level to ensure its localized relevance such that palliative care programs are evidence-based and contextually appropriate.
- Developing a position paper on the IAHPHC research strategy that identifies a few key questions.
- Seeking resources to support selected research questions in at least 6 countries of different income levels and located in different geographical regions, in collaboration with regional, national associations and universities.

Strategic Objective 3.2: Increase research skills among palliative care providers

Rationale

Most palliative care development takes place outside academic institutions and is primarily focused on service development. This means that most palliative care studies have been small and descriptive, lacking the necessary rigor for support of evidence-based medicine. To improve palliative care research nationally and internationally, it is necessary to train health scientists in

²³ Kaasa S, Radbruch L. Palliative care research--priorities and the way forward. *European Journal of Cancer*. May 2008;44(8):1175-9. doi: 10.1016/j.ejca.2008.02.036.

palliative care and systems research and to give these scientists the possibility of permanent research posts, or combined clinical and research posts, after the research training period.

Given that IAHPC is not an academic institution, there is need for us to work in close collaboration with academic institutions so we can strengthen research skills among providers.

Our activities will include:

- Increasing access to high level research capacity by securing funding for IAHPC MSc/PhD scholarships and creating a resource hub for such scholars using webinars, signposting resources and linkages with mentor;
- Working with academic institutions to develop a curriculum for a research summer school with a focus on research in LMICs;
- Building research faculty which is linked to other research forums such as EAPC, APCA Palliative care research network and others;
- Continue and finalize current IAHPC research projects (institutional accreditation, online database) and implement new research projects including evaluation of the success of IAHPC programs and the effectiveness of the communication strategy presented in Output 4 in this document.

Output 4: Positive stories and focused messaging to support and advance the palliative care global movement

Strategic Overview and Rationale

Evidence suggests that a communications strategy positioning palliative care at the **core of public health** is required for palliative care to gain traction in **social, political and economic agendas**, in line with UHC.²⁴ The IAHP has a mandate to advocate for increasing access to palliative care for all those in need. The IAHP believes that palliative care advocates must shift the way they work internally and externally. Internally, there is a need to rethink the components of effective communication and advocates' critical roles in advancing palliative care priorities, acknowledging that palliative care stakeholders must be informed communicators at all levels. The IAHP palliative care communications and public advocacy strategy must be:

- Aligned with global policy frameworks and national policies
- Coordinated more closely with fundraising and resource mobilization strategies, understanding their mutuality, and;
- Designed to manage immediate and inclusive communication when necessary, including managing unforeseen situations and potential crises.

There is also consensus among palliative care leaders that effective communication requires palliative care providers and advocates to shift from more traditional agendas to a nuanced focus. This means a departure from:

- Awareness raising and public advocacy with general audiences to a more targeted audience, mapping and identifying the means to reach these audiences;
- Engaging audiences directly and through strategic partnerships to achieve specific results;
- Sharing messages that focus more on amplifying the voices of beneficiaries and their families, deepening conversations with constituents to compel greater attention and action.

This shift is known as **communicating to advocate**, which requires strong **frames, narratives and messages**. A key focus of the IAHP around strategic communication will be guided by the shifts outlined in Table 1.

²⁴ Knaul Felicia M. Integrating palliative care into health systems is essential to achieve Universal Health Coverage. The Lancet Oncology 19(11), PE566-E567, November 1, 2018. DOI: [https://doi.org/10.1016/S1470-2045\(18\)30600-4](https://doi.org/10.1016/S1470-2045(18)30600-4)

Table 1: Communicating to advocate: Proposed communications shifts to drive Palliative Care Advocacy

Shift from	Shift to
Working to change policies	In addition to working to change policies, also working to change behaviors, social attitudes and beliefs
Targeting governments, corporates and influencers	Powerfully communicating with governments, decision makers AND the broad general public
Informing	Inspiring and telling compelling stories
Telling	Listening and dialogues
Disseminating information	Communicating to drive change and move people to act
Focusing on traditional media	Developing and improving the IAHP content for digital, mobile, and broadcast media/social media
Knowledge brokering	Knowledge leadership
Everything	Targeted and focused prioritization at all levels
Silos and partnership initiatives	Broader fueling of social engagement and development of social movement and public buy-in

In view of this, under this strategic objective, the IAHP will focus on four strategies which include:

Strategic Objective 4.1: Strengthen palliative care messaging and narratives

Increase clarity and focus, connecting more directly and on a more human level: Knowledge of palliative care and its holistic nature is not well understood, making it hard for those outside of palliative care to generate interest in the issue. If palliative care is going to be embraced by more players than its current stakeholders, we need to increase awareness and offer new players opportunities to engage through coherent and generic messages that can be adapted and tailored to meet needs at national and local levels. Palliative care messaging must be **faster, sharper and have more compelling headlines and core messaging.**

Strategic Objective 4.2: Expand approach to media

Print, digital, mobile and broadcast media are rapidly converging, and the palliative care approach to media must also be integrated. In view of this, there is a need to analyze the key channels on which to focus, and recognizing that, in some contexts, traditional media still drives the majority of web and digital stories. There is also a need to increase the use of data visualization and infographics that can work across both traditional and digital platforms.

Strategic Objective 4.3: Increase use of new technologies

The use of new technology, innovations and the power of images in emerging channels will allow us to reach new audiences. This includes devising strategies to broadly disseminate the videos in the IAHPC YouTube channel and increase the number of visitors to the website, the IAHPC Facebook page and the followers on Twitter and other platforms. Apps for smartphone are resources which also serve as excellent tools to engage with palliative care workers from around the globe. We will need to use these innovations and approaches to reach new audiences, taking advantage of the opportunities presented by advances and growth in mobile technology and social media.

Monitoring Evaluation and Learning

For each of the outputs comprehensive monitoring, evaluation and learning (MEL) framework will be developed which will enable IAHPC to track results and share learning.

Lessons from the MEL will be shared frequently through various platforms which include, our website, monthly newsletter, social media platforms, conferences and workshops.