



# 5° SIMPOSIO DE INTERDISCIPLINARIEDAD EN BIOÉTICA



Universidad de  
**La Sabana**

**Una mirada bioética a los cuidados paliativos:  
cultura, humanización y espiritualidad en la  
atención de enfermos**



**Viernes 15 de junio de 2018**



# **PAL-LIFE Project**

## **White Paper for Global Palliative Care Advocacy**

**Nunziata Comoretto, MD, PhD, LRS  
Pontifical Academy for Life  
Scientific Section  
(Vatican City)**

**UNA MIRADA BIOÉTICA A LOS  
CUIDADOS PALIATIVOS: CULTURA,  
HUMANIZACIÓN Y ESPIRITUALIDAD EN LA  
ATENCIÓN DE ENFERMOS**

Conferencia compartida con:  
Marta Ximena León Delgado. Médica,  
Especialista en Anestesiología, Dolor y Cuidados  
Paliativos.  
Universidad de La Sabana.



**5° SIMPOSIO**  
DE INTERDISCIPLINARIEDAD EN BIOÉTICA



**Fellows Colombia**  


## WHITE PAPER – **What is it the White Paper?**

The White Paper represents a **position statement** of the Pontifical Academy of Life and aims at presenting the most important **recommendations for the diverse stakeholders** groups involved in global PC development.

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# WHITE PAPER – Background

## JOURNAL OF **Palliative Medicine**

Journal of Palliative Medicine: <http://mc.manuscriptcentral.com/palliative>

### **White Paper for Global Palliative Care Advocacy: Recommendations from a PAL-LIFE expert advisory group of the Pontifical Academy for Life, Vatican City**

|                                     |   |
|-------------------------------------|---|
| Journal:                            | <i>Journal of Palliative Medicine</i>   |
| Manuscript ID                       | JPM-2018-0248.R1  |
| Manuscript Type:                    | Special Reports   |
| Keyword:                            | Symptom Control (other than pain), Spirituality, Policy & Finance Issues, Pain Control, Opioid Analgesics |
| Manuscript Keywords (Search Terms): | Palliative Care, Development, Advocacy, Global, Position Statement  |
|                                     |   |

## WHITE PAPER – Background

- The global population is ageing, and this, partnered with the increased prevalence of NCDs and the persistence of other debilitating chronic and infectious diseases reflects an alarming increase in need for PC provision at the global scale.
  - Estimates of unmet PC needs worldwide are around 26.8 million per year. Other data suggest an even greater need of up to 40 million people per year.
  - Various additional studies have highlighted a lack of access to PC as a major global health inequity issue.
  - This growing need is recognized by the WHO recommending for further PC development and support for global PC advocacy campaigns.
  - The Catholic Church's appreciation for the PC as an approach to take care of the vulnerable is evident in its Magisterium.
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## WHITE PAPER – **Aim**

This white paper represents a position statement of the PAV regarding PC, intended to be used for advocacy with local governments, healthcare organizations, leaders on-the-ground, and faith-based communities.

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## WHITE PAPER – Design

A process was developed to generate consensus among 13 PC experts on key recommendations for major stakeholders' groups, including ranking both the recommendations and the stakeholders' groups by importance, as well as providing suggestions for implementation.

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# WHITE PAPER – Design

Table 1 – Members of the PAL – LIFE ad hoc group

| Name                 | Title, Institution  | City       | Country     |
|----------------------|---|------------|-------------|
| Alsirafy, Samy       | Head of the Palliative Medicine Unit, Kasr Al-Ainy School of Medicine, Cairo University   | Cairo      | Egypt       |
| Bruera, Eduardo      | Chair, Dept. of Palliative Medicine and Supportive Care - UT MD Anderson Cancer Center  | Houston    | USA         |
| Callaway, Mary V.    | Board of Directors, IAHPC   | Houston    | USA         |
| Centeno, Carlos      | Director, ATLANTES Research Group, University of Navarra  | Pamplona   | Spain       |
| De Lima, Lilliana    | Executive Director, International Association for Hospice and Palliative Care (IAHPC)   | Houston    | USA         |
| Foley, Kathleen M.   | Attending Neurologist Emeritus, Memorial Sloan Kettering Cancer Center  | New York   | USA         |
| Luyirika, Emmanuel   | Executive Director, African Palliative Care Association (APCA)  | Kampala    | Uganda      |
| Mosoiu, Daniela      | Director, Casa Sperantei, Assoc Prof. Transylvania University   | Brasov     | Romania     |
| Pettus, Katherine    | Advocacy Officer, IAHPC   | Houston    | USA         |
| Puchalski, Christina | Director, The George Washington University's Institute for Spirituality and Health (GWish) Professor of Medicine GWU                              | Washington | USA         |
| Rajagopal, MR        | Director Pallium India, WHO Collaborating Centre for Training and Policy on Access to Pain Relief   | Trivandrum | India       |
| Sitte, Thomas        | CEO Deutsche PalliativStiftung  | Fulda      | Germany     |
| Yong, Jin-Sun        | Director, The Catholic University of Korea (CUK), WHO Collaborating Centre for Training in Hospice and Palliative Care. Professor of Nursing, CUK | Seoul      | South Korea |

# WHITE PAPER – Design

## Identification of Stakeholder Groups (through a Delphi consensus process)

**Table 2 – Ranking of Stakeholder groups (1)**

| <b>Stakeholder group</b>                  | <b>Points</b> | <b>Group K-Mean</b> |
|---|---------------|---------------------|
| Policymakers                              | 122           | 103.4               |
| Universities (academia)                   | 111           |                     |
| Health Care Workers                       | 103           |                     |
| Hospitals and Healthcare Centres          | 92            |                     |
| Palliative Care Associations              | 89            |                     |
| International Organizations               | 71            | 52.4                |
| Mass Media                                | 69            |                     |
| Philanthropic Organizations and Charities | 62            |                     |
| Pharmaceutical Authorities                | 59            |                     |
| Patients and Patient Groups               | 53            |                     |
| Spiritual Care Professionals              | 50            |                     |
| Associations other than Palliative Care   | 29            |                     |
| Pharmacists                               | 26            |                     |

(1) Scores on relative importance (range 1 to 156) and K-means for cluster analysis

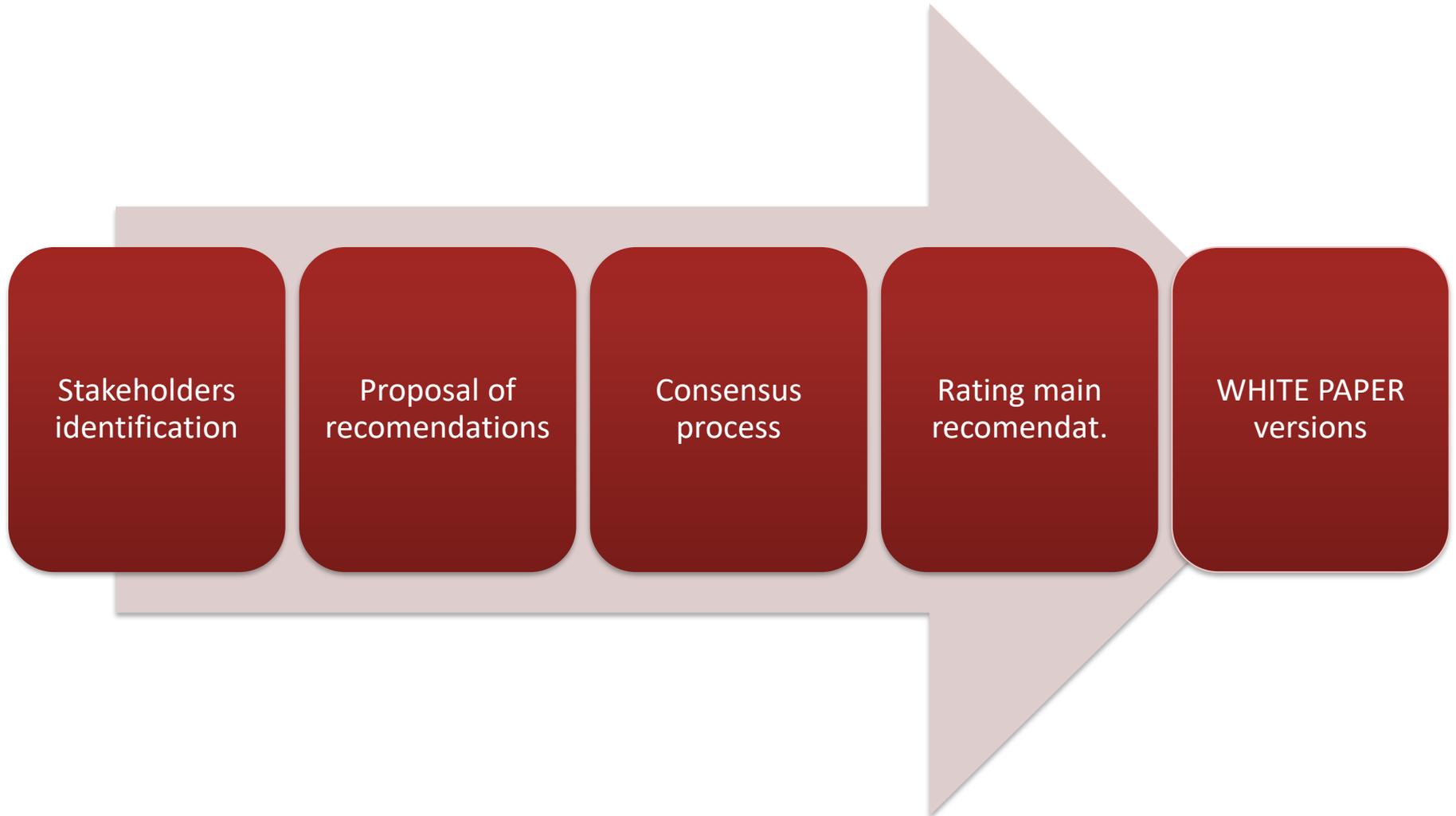
## WHITE PAPER – Design

- **Consensus process for the recommendations**
    - each member was contacted by e-mail and requested to provide 2-3 recommendations for his/her corresponding stakeholder group.
    - all the recommendations were shared with the entire ad hoc group through an online survey tool (<https://es.surveymonkey.com>) and each member of the ad hoc group was asked to rank each recommendation on a Likert scale from 1 to 5 (1 being “not important at all” and 5 “extremely important”).
    - The results were preliminarily presented in a PC conference organized by the PAV in Rome in March 2018, and subsequently discussed by the ad hoc group in a new face-to-face meeting with a subset of the experts.
-

## **PAV endorsement of the recommendations and presentation of outcomes**

- The resulting recommendations from each stakeholder group were revised and agreed upon, then endorsed by the Board of Directors of the PAV. The endorsement will be announced during the plenary session of the annual meeting of the PAV (June 2018) as the official position of the Academy and as the recommendations of PAL-LIFE.
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# WHITE PAPER – How has it been built the White Paper?



## WHITE PAPER – Results

- **13 stakeholder groups were identified**
  - **43 recommendations were formulated**
  - **The ad hoc group considered all of them of the highest importance**
  - **The highest recommendation (per each stakeholder) was selected as MAIN REC**
-

## **Policymakers**

Recognize the societal and ethical value of Palliative Care and modify the existing health care structures, policies and outcome measures to ensure access to universal access to PC for all patients in need.

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LEY No. 1733

8 SEP 2014

**“LEY CONSUELO DEVIS SAAVEDRA, MEDIANTE LA CUAL SE REGULAN LOS SERVICIOS DE CUIDADOS PALIATIVOS PARA EL MANEJO INTEGRAL DE PACIENTES CON ENFERMEDADES TERMINALES, CRÓNICAS, DEGENERATIVAS E IRREVERSIBLES EN CUALQUIER FASE DE LA ENFERMEDAD DE ALTO IMPACTO EN LA CALIDAD DE VIDA.”**

**El Congreso de Colombia**

**DECRETA:**

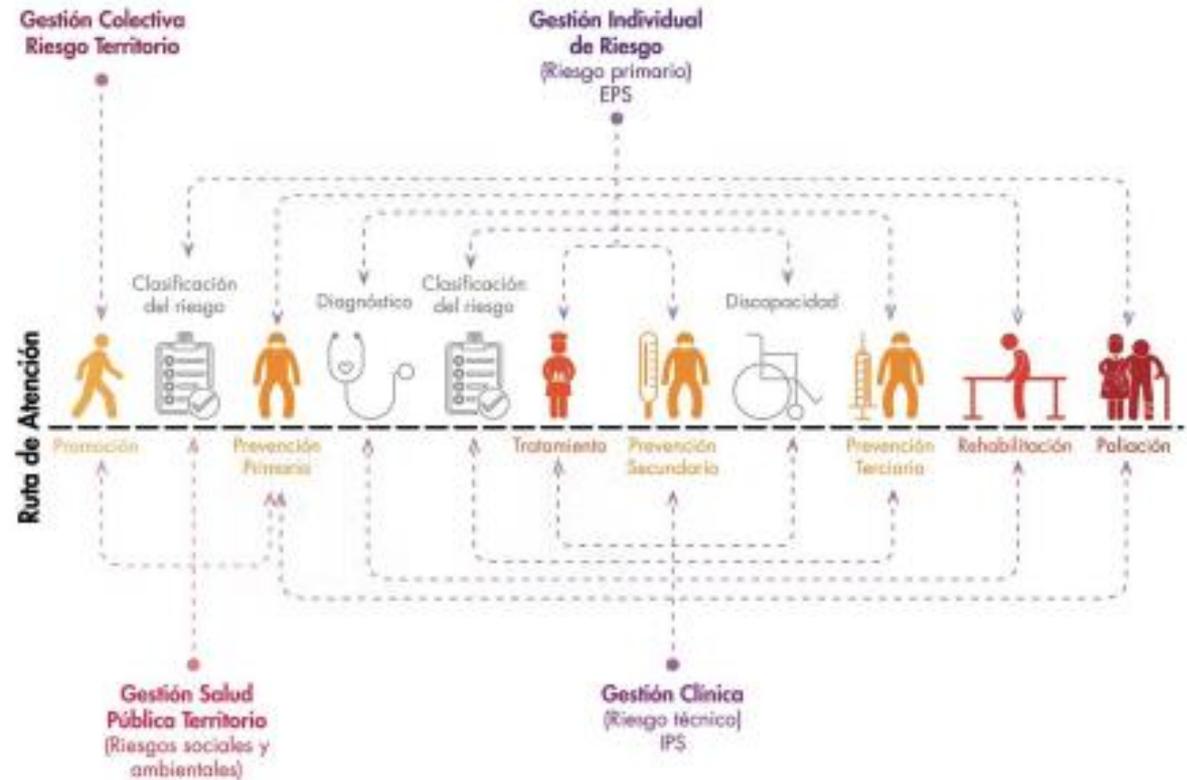
**Artículo 1º. Objeto.** Esta ley reglamenta el derecho que tienen las personas con enfermedades en fase terminal, crónicas, degenerativas e irreversibles, a la atención en cuidados paliativos que pretende mejorar la calidad de vida, tanto de los pacientes que afrontan estas enfermedades, como de sus familias, mediante un tratamiento integral del dolor, el alivio del sufrimiento y otros síntomas, teniendo en cuenta sus aspectos psicopatológicos, físicos, emocionales, sociales y espirituales, de acuerdo con las guías de práctica clínica que establezca el Ministerio de Salud y Protección Social para cada patología. Además, manifiesta el derecho de estos pacientes a desistir de manera voluntaria y anticipada de tratamientos médicos innecesarios que no cumplan con los principios de proporcionalidad terapéutica y no

**POLÍTICA DE ATENCIÓN INTEGRAL EN SALUD**

*"Un sistema de salud al servicio de la gente"*

Ministerio de Salud y Protección Social

Ilustración 10. Proceso para la Gestión Integral de del Riesgo en Salud



Fuente: MSPS, 2016.

## Universities (Academia)

All universities offering degrees in healthcare related fields, should include mandatory palliative care courses as part of the undergraduate curricula.

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| Código Institución | Nombre Institución                   | Estado Institución | Carácter Académico                      | Sector  | Puede Recibir Estudiantes Nuevos | Estado Programa |    |
|--------------------|--------------------------------------|--------------------|---|---------|----------------------------------|-----------------|----|
| 1117               | UNIVERSIDAD MILITAR-NUEVA GRANADA    | ACTIVA             | UNIVERSIDAD                             | OFICIAL | SI                               | ACTIVO          | AC |
| 1701               | PONTIFICIA UNIVERSIDAD JAVERIANA     | ACTIVA             | UNIVERSIDAD                             | PRIVADA | NO                               | INACTIVO        | IN |
| 1710               | UNIVERSIDAD PONTIFICIA BOLIVARIANA   | ACTIVA             | UNIVERSIDAD                             | PRIVADA | SI                               | ACTIVO          | AC |
| 1717               | UNIVERSIDAD DE SAN BUENAVENTURA      | ACTIVA             | UNIVERSIDAD                             | PRIVADA | SI                               | ACTIVO          | AC |
| 1729               | UNIVERSIDAD EL BOSQUE                | ACTIVA             | UNIVERSIDAD                             | PRIVADA | SI                               | ACTIVO          | AC |
| 1729               | UNIVERSIDAD EL BOSQUE                | ACTIVA             | UNIVERSIDAD                             | PRIVADA | SI                               | ACTIVO          | AC |
| 2702               | FUNDACION UNIVERSITARIA DE LA SABANA | ACTIVA             | INSTITUCION UNIVERSITARIA/ESPECIALIZADA | PRIVADA | SI                               | ACTIVO          | AC |

PREGRADO:



Universidad de  
**La Sabana**



Universidad del  
**Rosario**



Universidad  
del Valle



Universidad  
Industrial de  
Santander

EDUCACION CONTINUADA :



Universidad del  
**Rosario**



Fundación  
Universitaria Sanitas  
Organización Sanitas Internacional



UNIVERSIDAD  
EL BOSQUE



Universidad de  
**La Sabana**



# RED COLOMBIANA DE EDUCACIÓN EN CUIDADOS PALIATIVOS

MEMORIAS DEL I ENCUENTRO

Bogotá, Octubre 02 de 2015



## MEMORIAS

### II Encuentro de la Red Colombiana de Educación en Cuidados Paliativos:

#### Red y perspectivas nacionales

El día 4 de noviembre de 2016 se realizó el II encuentro de REDCOLEDUPAL, en las instalaciones de la Universidad Pontificia Bolivariana, sede Medellín, con el apoyo de las siguientes universidades: Universidad de La Sabana, Universidad El Bosque, Universidad San Buenaventura – sede Medellín, Universidad del Valle, Pontificia Universidad Javeriana, Universidad Industrial de Santander y Universidad de Cartagena.



Bogotá D.C. julio de 2017

**Estimados  
DECANOS Y DIRECTORES DE PROGRAMAS  
Facultades de Medicina, Enfermería y Psicología  
Colombia**

**Ref.: III Encuentro- Red Colombiana de Educación en Cuidados Paliativos**



BORHAMIR  
PROYECTO DE LEY \_\_\_\_\_ SENADO

*"Por medio de la cual se fortalece la atención en cuidados paliativos"*

**EXPOSICIÓN DE MOTIVOS**

De acuerdo con el Código de Ética Médica vigente en Colombia, el fin de la medicina es cuidar la salud del hombre, prevenir las enfermedades y mejorar la calidad de vida de la subjetividad<sup>1</sup>. En esa línea de pensamiento por cuidar la vida de las personas de vida, mediante la "Ley Comendador Dávila Soto" - Ley 1744 de 2014, se estableció que los cuidados paliativos, entendidos como un tratamiento integral del dolor, sean un derecho.

*Artículo 1°. Objeto. Esta ley reglamenta el derecho de las personas con enfermedades en fase terminal, crónicas, debilitantes e irreversibles, a la atención en cuidados paliativos que previene, alivia la calidad de vida, mejora de los síntomas que afectan estas enfermedades, como de sus familias, mediante un tratamiento integral del dolor, basado en el diagnóstico y otros síntomas, teniendo en cuenta sus aspectos psicológicos, físicos, emocionales, sociales y espirituales (...)*

Esta misma ley definió los cuidados paliativos en su artículo cuatro, como los cuidados apropiados para el paciente con una enfermedad terminal, crónica, degenerativa e irreversible, donde el control del dolor, apoyo emocional, apoyo social, espiritual, psicológico familiar, durante la enfermedad y el duelo.

Así pues, en el desarrollo de la Ley, la Resolución 1216 del 2013 desarrolló como acciones las personas con enfermedades en fase terminal, al derecho a la atención en cuidados paliativos para mejorar la calidad de vida, tanto de ellos (los pacientes) como de sus familias, mediante un tratamiento integral del dolor.

Este desarrollo normativo en Colombia fue un gran acierto, una consecuencia del desarrollo internacional sobre la materia. La Organización Mundial de la Salud (OMS), definió los cuidados paliativos como "el cuidado activo total de los pacientes cuya enfermedad no responde ya al tratamiento". En el desarrollo de la definición, se estableció que estos cuidados daban prioridad al control del dolor y a otros síntomas y problemas de orden psicológico, social y espiritual. Siendo el principal objetivo de estos cuidados, "proporcionar la mejor calidad de vida para los pacientes y sus familiares".

<sup>1</sup> Ley 23 de 1981, artículo 2.

## Pharmacists

Pharmacists should be able to prepare compounded opioid formulations, and find ways to make them available and accessible for the patient, especially for children, the elderly and when there are no generic/cheaper formulations in the country.

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Observatorio Colombiano de Cuidados Paliativos



Observatorio Colombiano de Cuidados Paliativos

BUSCAR...



# Segunda versión

## Observatorio Colombiano de Cuidados Paliativos

### 2017



Dominios del Observatorio Colombiano de Cuidados Paliativos



Prestación de Servicios



Medicamentos y Tecnologías



Políticas Públicas

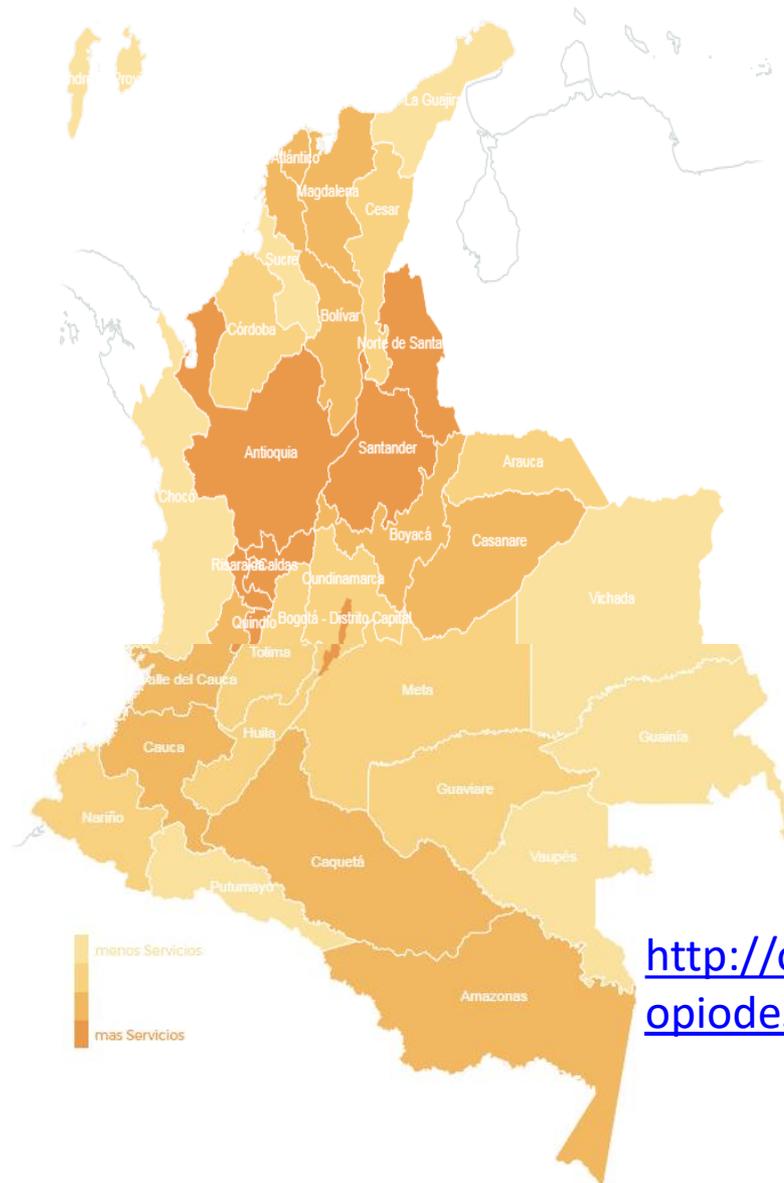


Educación



Cuidados Paliativos Pediátricos

# MAPA CONSUMO DE OPIOIDES

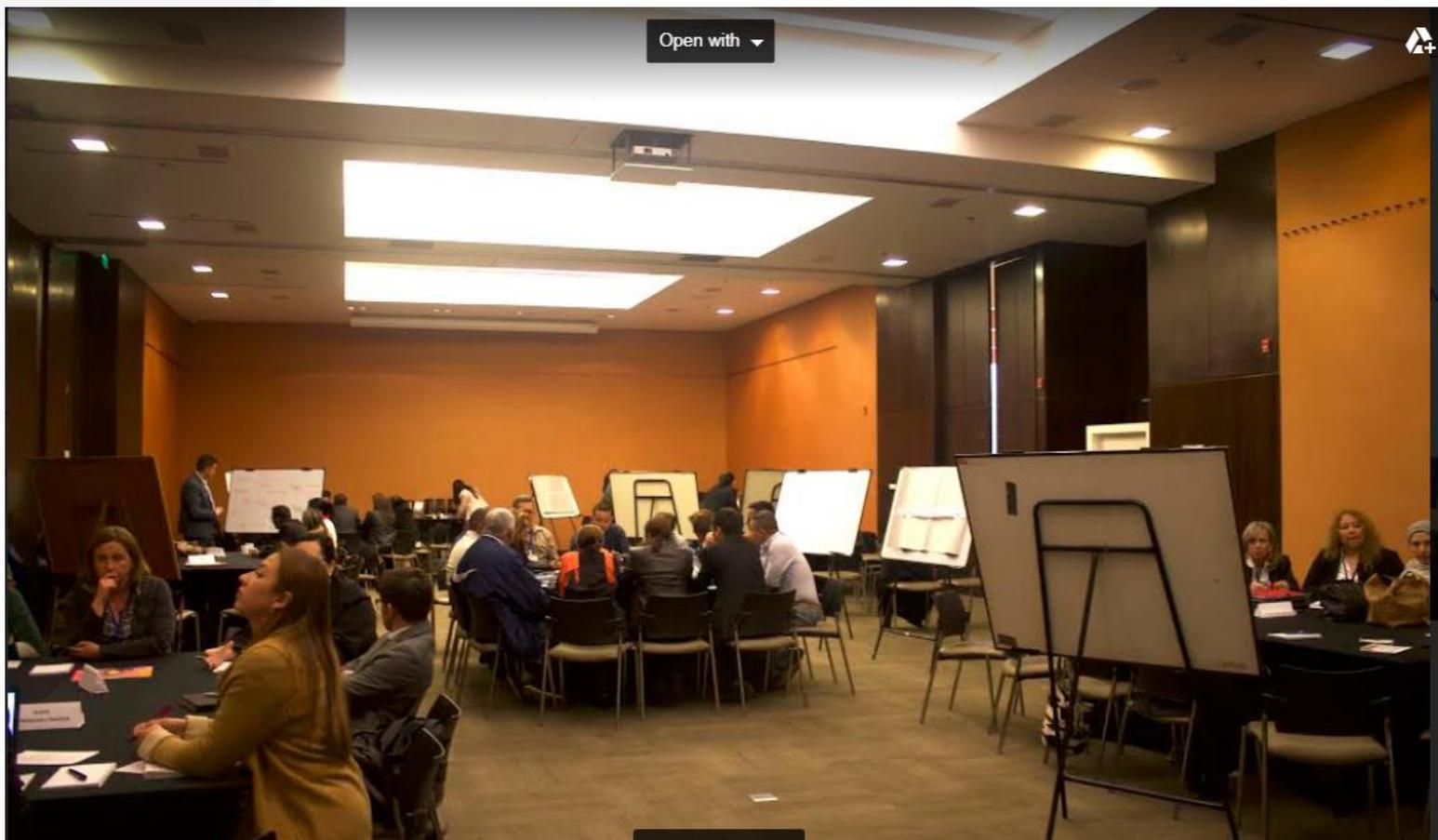


Observatorio Colombiano de Cuidados Paliativos

<http://occp.com.co/region/mapa-opioides/>



# Taller Nacional de Disponibilidad y Accesibilidad a Opiodes



# Professional Associations & Societies

Become effective advocates and work with their governments in the process of implementing international policy framework, including Conventions, Resolutions and Declarations in their countries.

Examples:

WHA PC Resolution (2014), Universal Health Coverage, the Sustainable Development Goals and the WHO Roadmap on Non-Communicable Diseases.

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# International Organizations

International organizations should encourage WHO Member states to develop policies and procedures to implement WHA Resolution 67/19 as an integral part of their strategies to implement Agenda 2030 for Sustainable Development, paying specific attention to the needs of children and older persons.-

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## Religious Institutions and Spiritual Groups

Advocate for the inclusion of spiritual care in PC on the local, state and country levels.

Ensure development of professional spiritual care providers or chaplains and **their employment stability** in health settings.

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# DIA MUNDIAL DE CUIDADOS PALIATIVOS

## JORNADA CUIDADORES

OCTUBRE 7 DE 2006

ENTRADA LIBRE

Lugar:

Dirección:



INFORMES:  
Universidad de La Sabana  
9615555, o a través del correo  
electrónico  
claudia.trujillo@unisabana.edu.co  
martha.leon@unisabana.edu.co

CON EL PATROCINIO DE:

FUNDACIÓN  
DE LIMA-BOMMER

ALCP  
Asociación Latinoamericana  
de Cuidados Paliativos

Universidad  
de La Sabana

International Association for Hospice & Palliative Care  
Promoting Hospice & Palliative Care Worldwide

GRÜNENTHAL  
ECUENAMA S.A.



## **Hospitals and Health Care Centres**

Every hospital and healthcare center should ensure affordable access to palliative care medicines included in the WHO Model List of Essential Medicines, particularly to opioid analgesics such as morphine.

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libertad y orden

# UAE - Fondo Nacional de Estupefacientes

## Ministerio de Salud y Protección Social



**MINISTERIO DE LA PROTECCIÓN SOCIAL**

**RESOLUCIÓN NÚMERO 000952 DE 2006**

**( 29 Marzo 2006 )**

Por la cual se Aclara y Modifica Parcialmente la Resolución No 4651 de diciembre 15 de 2005

**EL MINISTRO DE LA PROTECCIÓN SOCIAL**

En uso de sus atribuciones legales y en especial las conferidas por la Ley 9 de 1979, Capítulo IV de la Ley 30 de 1986 y el Decreto 3788 de 1986, y

**CONSIDERANDO**



libertad y orden

Ministerio de la Protección Social  
República de Colombia  
Dirección de Calidad de Servicios  
Grupo de Medicamentos e Insumos

Código 13100  
Bogotá, D. C.

2 1 8 6 5 4

Doctora  
**MARIA XIMENA LEO**  
Grupo Dolor y Cuidados Paliativos  
Universidad de la Sabana  
Facultad de Medicina. Edificio H. Campus Universitario  
Puente del Común  
Chía, Cundinamarca

**URGENTE**

Respetada Doctora María Ximena:

En atención a su solicitud enviada al Consejo Nacional de Seguridad Social en Salud y posteriormente al Comité Técnico de Medicamentos y Evaluación de Tecnología, me permito informarle el concepto de evaluación sobre los medicamentos Dihidromorfona, tabletas 5 mg, y Morfina Clorhidrato vial 3% el Comité ha evaluado:

## **Patients and Patients' Groups**

There needs to be a health literacy campaign to increase the understanding of PC and their role in the decision making process for all patients with palliative care needs and their families.

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*Amese*

Apoyo a mujeres con enfermedades del seno



FUNDACIÓN  
SIMMON

Sinergias Integradas para el Mejoramiento del Manejo Oncológico



## Healthcare Workers

Healthcare professionals working in PC should receive appropriate certification while actively participating in continuing education to maintain the adequate competency levels.

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## Philanthropic Organizations & Charities

Philanthropic organizations and charities should support PC development and implementation.

Recommended areas of funding include:

- Increase in PC education and training of all healthcare professionals
  - Adequate policies revising government health policy to include PC
  - Improving availability and access to opioid analgesics
  - Raising public awareness about the need for PC, and service delivery at home, in hospital and hospices
-

## **Other Non-PC Professional Associations & Societies**

To encourage human rights organizations to take into account existing declarations, and implement strategies whose aim is advancing PC development worldwide within the Human Rights framework.

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## WHITE PAPER – Discussion

- The Christian movement has developed and built large care networks which include hospitals, clinics, and health centres throughout the world.
  - Faith-based hospitals and healthcare institutions, from local clinics to tertiary research institutions, are all sites where PC fits in as part of the concept of care and solidarity, as well as a component of care within the health system.
  - In many countries, regardless of the most prevalent professed faith, a significant number of health care facilities are operated by the Catholic Church and other Christian denominations. With such a large network, the Church has the opportunity to lead a major movement to relieve the suffering of millions of patients and their families.
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## WHITE PAPER – Discussion

- This White Paper may be used as a checklist for countries or regions to identify and implement basic strategies to improve the care for patients and families with PC needs.
  - It can also serve as the basis for development of a more comprehensive list of recommendations adapted to the institutions or groups within each stakeholder group, or specific geographical contexts.
  - It will be useful for advocacy with local governments, faith-based communities, and others.
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## WHITE PAPER – Conclusion

- This White Paper emphasizes the responsibility of health care systems and stakeholders to recognize access to pain relief and PC as a basic right of the person and the family, and the responsibility of all elements of the health care system.
  - The support of faith-based and philanthropic organizations, nongovernmental and governmental actors, and human rights organizations is needed to support PC integration. In short, **a civil society response is needed.**
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# WHITE PAPER



**Thank you for your attention**

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