Additional Indicators to Assess Palliative Care Development

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This is an appendix to the **Brief Manual on Health Indicators Monitoring Global Palliative Care Development**

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Appendix to the Brief Manual on Health Indicators Monitoring Global Palliative Care Development

Policy Indicators

Code: P7

1. Financial burden to patients accessing PC

Definition: This indicators aims to estimate if accessing PC in a specific country causes a financial burden to patients in need and to their families.

Suggested questions to explore it:

1. *How do patients pay to access the following PC services?*

Matrix (x)	(y)
Hospital care	Free of charge
Nursing home	Co-payment
Home-based care	Fee for service
External consultation	100% Out of pocket
	Not available

Additional information:

- Free of charge: Costs are covered through the national's health system financial strategy and/or included in the national pension or insurance scheme, thus patients do not need to do any additional payments.

- Co-payment: Patients need to do an extra payment to supply costs that are not covered by the national insurance scheme or equivalent. Such payments do not represent much burden.

- Fee for service: Patients pay according to the services or interventions received since they are not covered by the national insurance scheme or equivalent. These payments can cause economic burden.

- 100% Out of pocket: Patients need to bare the whole costs caused by accessing PC services.

- Wording for this indicator was derived from the EAPC Atlas of Palliative care in Europe, 2013; and completed with: Woitha et al. Policy on palliative care in the WHO European region: an overview of progress since the Council of Europe's (2003) recommendation 24, 2016, European Journal of Public Health.

Code: S14

2. Number of mixed palliative care support teams (estimate)

Definition: Mixed palliative care support teams provide palliative care service to patients both at the hospital and at home. They are multi-professional teams with at least one doctor and one nurse with specialist palliative care training. Other professionals like psychologists and social workers among others are usually part of these teams too.

Suggested questions to explore it:

1. *Number of mixed palliative care support teams (estimate)*

Additional information:

- Wording and definition for this indicator has been adapted from the EAPC Atlas of Palliative Care in Europe, 2013.

Code: S15

3. Number of day hospices or day care centers for palliative care

Definition: Day hospice or day care for palliative care are usually spaces within hospitals, hospices, PCUs or in the community designed to promote and host recreational and therapeutic activities for palliative care patients, their families and carers. It is usually staffed by a multi-professional team including nurses, doctors, psychotherapists and social workers among others and supported by volunteers.

Suggested question to explore it:

1. *Number of day hospices or day care centers for palliative care*

Additional information:

- Wording and definition of this indicator has been adapted from the EAPC Atlas of Palliative Care in Europe, 2013.

Code: S16

4. Number of programs or teams of volunteers dedicated to PC

Definition: The volunteer hospice team is part of a comprehensive support network or a palliative care service and collaborates closely with other professional services in palliative care. It is composed by specially trained volunteers that work under the supervision of at least one professional coordinator. These teams offer support and befriending to palliative care patients and their families in times of disease, pain, grief and bereavement.

Suggested question to explore it:

1. *Number of programs or teams of volunteers dedicated to PC*

Additional information:

- Wording and definition of this indicator has been adapted from the EAPC Atlas of Palliative Care in Europe, 2013.

Code: S7

5. Estimation of the number of palliative care patients cared for by specialized palliative care teams (per year)

Definition: Number of palliative care patients cared for by specialized PC services in the country.

Suggested questions to explore it:

1. *Estimation of the number of palliative care patients cared for (per year)*
2. *Source of the estimation (personal estimation OR official data. If data is official, please, give the database name and provide, if possible, a link to it)*

Additional information:

- Please try to provide an exact number if this information is readily available in your country's health databases. If this is not the case, follow this suggestion: Think of the number of patients cared for in the past year in palliative care services or hospices that you are most familiar with. You can then estimate the total number of palliative care services or hospices there are in your country. With these numbers, you can estimate the total number of patients cared for by palliative care services or hospices in the last year.

- Wording for this indicator was derived from the WHO: Number of palliative care patients cared for per 100,000 inhabitants. (WHO Planning and Implementing Palliative Care Services, 2016; http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf?ua=1) and from the APCA Atlas of Palliative Care in Africa, 2017. However, please give the TOTAL number of patients in the country, NOT per 100,000 inhabitants. We will do the calculation afterwards.

Code: S20

6. Number of physicians working in PC per population (estimation)

Definition: This indicator explores the health workforce's capacity to provide PC by estimating how many physicians work providing it, regardless specific PC training. Please provide an estimation without considering physicians' specific accreditation in PM.

Suggested question to explore it:

1. *Number of physicians working in PC (estimation)*

Additional Information:

- For your information: wording for this indicator has been adapted from the ALCP Palliative care indicators, 2013

Education indicators

Code: E23

1. Medical schools including any kind of palliative care education in the undergraduate curricula

Definition: This indicator explores the non-mandatory inclusion of PC education in the undergraduate medical school curricula.

Suggested questions to explore it:

1. *Number of medical schools which offer an optional course or subject specifically dedicated to PC*
2. *Number of medical schools which offer an optional PC course or subject in combination with other subjects (i.e. Geriatrics and Palliative Care)*
3. *Number of medical schools which offer PC education not as a course or subject but as an assessable transversal competence of the medical curriculum present in several other courses or subjects*
4. *Number of medical schools which offer other kind of formal PC education, neither as a course or subject nor as an assessable transversal competence. Please indicate the kind of teaching: _____*

Additional information:

- An independent subject or course with the name "palliative" included in the title

- In combination with other disciplines, means that palliative care is taught in combination with related disciplines such as Oncology, Primary Care, Geriatrics among others. When this is the case, usually palliative care appears in the title of the course or subject (Oncology and Palliative Care), included in the denomination of the course.

- An optional component means that a component of palliative medicine is included as electives or optional teaching that are not required to graduate.

- For the purpose of this project, undergraduate education is defined as a course, or specific module within a course, which includes the basic aspects of palliative care. Basic aspects of palliative care include, as stated by the EAPC Recommendations for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools:
  - The identification, evaluation and treatment of the most frequent symptoms and its management
  - The physical, psychological, social and spirituals aspects of care
  - End of life ethical and legal issues
  - Communication issues with the patient, relatives and caregivers as well as teamwork and self-reflection.
  -

- The wording of this indicator has been adapted from the WHO: Proportion of medical schools which include palliative care education in undergraduate curricula (i.e. ratio of

medical schools with palliative care at undergraduate level to total medical schools) (WHO Planning and Implementing Palliative Care Services, 2016; http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf?ua=1). Further adaptation on the wording and its definition has been performed based on the EAPC Atlas of Palliative Care in Europe (2013), APCA Atlas of Palliative Care in Africa (2017) and the EAPC Recommendations for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools.

Code: E24

2. Years of experience offering palliative care education in undergraduate curricula in a country

Definition: This indicator assesses the expertise a country has in including PC at the undergraduate level in terms of time, and uses it as a proxy to development.

Suggested questions to explore it:

1. *When did PC education started to be included at the undergraduate level in medical schools in your country?*

Additional information:

Code: E26

3. Nursing schools including any kind of palliative care education in undergraduate curricula

Definitions: This indicator explores the non-mandatory inclusion of PC education in the undergraduate nursing school curricula.

Suggested questions to explore it:

1. *Number of nursing schools which offer an optional course or subject specifically dedicated to PC*
2. *Number of nursing schools which offer PC education not as a course or subject but as an assessable transversal competence of the medical curriculum present in several other courses or subjects*
3. *Number of nursing schools which offer other kind of formal PC education, neither as a course or subject nor as an assessable transversal competence. Please indicate the kind of teaching: _____*

Additional information:

- An independent subject or course with the name "palliative" included in the title

- In combination with other disciplines, means that palliative care is taught in combination with related disciplines such as Oncology, Primary Care, Geriatrics among others. When this is the case, usually palliative care appears in the title of the course or subject (Oncology and Palliative Care), included in the denomination of the course.

- An obligatory component means that a component of palliative medicine is included as mandatory or compulsory teaching for all nursing students in order to graduate.

- An optional component means that a component of palliative medicine is included as electives or optional teaching but are not required for all nursing students and are not required to graduate.

- For the purpose of this project, undergraduate education is defined as course or specific module within a course, which includes the basic aspects of palliative care. Basic aspects of palliative care include as stated by the EAPC Recommendations for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools:
    - The identification, evaluation and treatment of the most frequent symptoms and its management
    - The physical, psychological, social and spirituals aspects of care
    - End of life ethical and legal issues
    - Communication issues with the patient, relatives and caregivers as well as teamwork and self-reflection.

- The wording of this indicator has been adapted from the WHO: Proportion of medical schools which include palliative care education in undergraduate curricula (i.e. ratio of medical schools with palliative care at undergraduate level to total medical schools) (WHO Planning and Implementing Palliative Care Services, 2016; http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf?ua=1). Further adaptation on the wording and its definition has been performed based on the EAPC Atlas of Palliative Care in Europe (2013), APCA Atlas of Palliative Care in Africa (2017) and the EAPC Recommendations for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools.

Code: E27

4. Years of experience offering palliative care education in undergraduate nursing curricula in a country

Definition: This indicator assesses the expertise a country has in including PC at the undergraduate level in terms of time, and uses it as a proxy to development.

Suggested questions to explore it:

1. When did PC education started to be included at the undergraduate level in nursing schools in your country?

Additional information:

Code: E29

5. Professorship in PC in nursing schools

Definition: Number of professors specific to PC in the top three levels of the official academic lather.

Suggested questions to explore it:

1. Number of Full Professors in palliative care at nursing schools in your country (1st Level)
2. Number of Associate Professors in palliative care at nursing schools in your country (2nd Level)
3. Number of Assistant Professor in palliative care at nursing schools in your country (3rd Level)

Additional information:

- Full Professor: is a professor that counts with the highest level of official accreditation as a teacher granted by the Ministry of Education or equivalent responsible authority in the country. Depending on the country, different denominations are available for example Catedrático, Professor, Full Professor, etc. In some countries within the highest level of teaching accreditation categories might exist, grading Full Professors based on academic and professional achievement or performance.

- Associate Professor: is an accredited professor that counts with the official accreditation following the highest one available in the country, without it being the highest. The Ministry of Education or an equivalent responsible authority must grant the accreditation. This refers to the step before being a full professor, which means achieving the highest level of official accreditation.

- Assistant Professor: Is an accredited professor that counts with any other official accreditation.

- None of these categories include any other sort of academic positions, which can teach at Universities without official teaching accreditation.

- Wording and questions for this indicator are derived from: Noguera et al. How experienced professors teach Palliative Medicine in European Universities? A cross-case analysis of eight undergraduate educational programs, 2018, Journal of Palliative Medicine (accepted for publication)

Use of medicines indicators

Code: M31

1. **Total morphine consumption (Kilograms)**

Definitions: Total morphine consumption as defined and reported to the International Narcotics Control Board. Data to be obtained from: Narcotic Drugs: Estimated World Requirements from the International Narcotics Control Board.

Suggested question to explore it:

1. Total morphine consumption (Kilograms)

Additional information:

- Opioids included: Morphine only. Unit of Measure: Kilograms

- Wording of this indicator has been adapted from Human Rights Watch. Global State of Pain Treatment [Internet]. 2011.

2. Oral morphine available in >50% of pharmacies

Definition: availability of oral morphine (liquid or tablet) in over 50% of the pharmacies (estimate)

Suggested question to explore it:

1. *Availability of immediate release oral morphine (liquid or tablet) in >50% of pharmacies (estimate) (YES/NO)*

Additional information:

- The indicator has been modified from: Sharkey et al. National palliative care capacities around the world: Results from the World Health Organization Noncommunicable Disease Country Capacity Survey. 2018. Palliative Medicine

3. Cost of opioid analgesics to the consumer

Definition: Estimation of the opioid's cost a patient has to pay.

Suggested question to explore it:

1. *What percentage of the costs of the following medicines do patients have to pay for?*

Matrix

(X)	(Y)
Morphine (oral, immediate release)	Free
Morphine (injectable, immediate release)	<25%
Morphine (oral, prolonged release)	25-50%
Oxycodone (oral immediate release)	50-75%
Fentanyl (transdermal)	>75%

Additional information:

- Wording and the list of medicines presented in this indicator has been adapted from The World Health Organization's Essential Medicines in Palliative Care (2013), the Lancet Commission Report on Palliative Care (2017) and the N.I Cherny et al. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative (2010). Annals of Oncology

Code: M37

4. Use of opioids in S-DDD (statistical defined daily dose) per million inhabitants per day

Definition: S-DDD is a technical unit of measurement. It is calculated using this formula: annual use divided 365 days, divided by the population in millions of the country during the year, divided by the defined daily dose.

Suggested questions to explore it:

1. *Use of opioids in S-DDD (statistical defined daily dose) per million inhabitants per day*

Additional information:

- International Narcotics Control Board data on availability of opioid analgesics will be assessed in terms of defined daily doses for statistical purposes. Data to be assessed following the methodology developed by Berterame et al and reported on this study: https://www.ncbi.nlm.nih.gov/pubmed/26852264

- Opioids included for this calculation are: codeine, dextropropoxyphene, dihydrocodeine, fentanyl, hydro codone, hydromorphone, ketobemidone, mor phine, oxycodone, pethidine, tilidine, and tri meperidine; we exclude methadone and buprenorphine

- Wording for this indicator has been adapted from Berterame et al: "Use of and barriers to access to opioid analgesics: a worldwide, regional, and national study "(LINK) https://www.ncbi.nlm.nih.gov/pubmed/26852264

Professional activity indicators

Code: V40

1. **Number of attendants to national Palliative Care Congresses or equivalent**

Definition: This indicator explores the attendance to national PC congresses and uses it as a proxy to professional activity (vitality).

Suggested question to evaluate it:

1. *Existence of a national palliative care congress or equivalent*
2. *How often is it celebrated?*
3. *Average of attendants to the last three national congresses (estimation)*

Additional information:

- By periodic national conference we are referring to conferences that have are organized or repeated every certain number of years, with at least one conference having taken place in the past.

- Wording for this indicator has been adapted from the APCA Atlas of Palliative Care in Africa, 2017.

Code: V41

2. Number of attendants to international Palliative Care Congresses or equivalent

Definition: This indicator explores the attendance to international PC congresses and uses it as a proxy to professional activity (vitality).

Suggested questions to explore it:

1. *How many representatives of your country attended the last EAPC international research congress (i.e. Bern)?*
2. *How many representatives of your country attended the last EAPC international congress (i.e. Madrid)?*

Additional information:

- By periodic international conference we are referring to conferences that have been organized by the EAPC or EAPC Research Network and are repeated every certain number of years, with at least one conference having taken place in the past.

- For countries that have hosted the venue during the current year, data from the previous year will be considered.

- Wording for this indicator has been adapted from the APCA Atlas of Palliative Care in Africa, 2017.

International Cooperation Indicators

Code: IC43

1. Existence of international cooperation in the form of training that supports palliative care development

Definition: International cooperation is understood as the support provided from one country to another (usually less well off) to help develop the provision of palliative care services in the last one. Such support can be in form of capacity building programs, training programs targeted at the health workforce or the community.

Suggested questions to explore it:

1. *Existence of international organizations, international NGO'S or academic institutions that provide palliative care training opportunities to health workforce **in your country** (YES/NO)*
2. *If yes, please comment on it and provide a link to it.*

3. *Existence of training programs **offered by your country** (i.e. Universities) to welcome scholars from other countries to train them on palliative care competencies (YES/NO)*
4. *If yes, please comment on it and provide a link to it*
5. *If yes, how are they financed?*

    - *Full scholarships available*
    - *Partial scholarship*
    - *Scholars need to cover all the expenses*

Additional information:

- These concepts are based on data for international cooperation from the Mac Master University

Code: IC44

2. Existence of international cooperation in the form of funds to support palliative care development

Definition: International cooperation is understood as the support provided from one country to another (usually less well off) to help develop the provision of palliative care services in the last one. Such support can be in form of donations or economic support such as loans or donations coming from NGO's, international cooperation agencies, foundations etc. Funds can be used to improvement of capacity building programs, enablement of training programs targeted at the health workforce or the community. It can also be used to the enablement of health information systems, softwares or Apps. And to support infrastructure construction, for example through donations of buildings for an inpatient unit or the acquisition of transport such as cars, ambulances or motorcycles to support the work of a home-care palliative care unit.

Suggested questions to explore it:

1. *Reception of international funds set to develop palliative care in the country (YES/NO)*
   If yes:
2. *Please comment on it and provide a link to the project.*
3. *Where are these funds coming from?*

Additional information:

Code: IC45

3. Existence of international cooperation in the form of donations or funding from others countries for palliative care services or other infrastructures

Definition: International cooperation is understood as the support provided from one country to another (usually less well off) to help develop the provision of palliative care services in the last one. Such support can be in form of donations or economic support such as loans or donations coming from NGO's, international cooperation agencies, foundations etc. Funds can be used to improvement of palliative care facilities and to support infrastructure construction, for example through donations of buildings for an inpatient unit or the acquisition of transport such as cars, ambulances or motorcycles to support the work of a home-care palliative care unit.

Suggested questions to explore it:

1. *Has your country received economic support in forms of donations or funding from other countries to build or enable palliative care services or other infraestructures?*

If yes

2. *Please comment on it and provide a link to the project.*
3. *Where are these funds coming from?*

Additional information: