Assessing the development of palliative care worldwide: a set of actionable indicators

World Health Organization

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Foreword

The World Health Organization (WHO) is currently implementing its 13th General Programme of Work (GPW13) to support countries in reaching all health-related Sustainable Development Goals (SDG). GPW13 is structured around three interconnected strategic priorities: achieving universal health coverage (UHC); addressing health emergencies; and promoting healthier populations. Palliative care, which has been identified by the World Health Assembly as an "ethical responsibility of health systems" (WHA67.19), is part of this global effort towards UHC. However, it is still not accessible to the great majority of the people, adults and children who need it.

Facing the escalating global burden of serious health-related suffering, WHO has been developing a series of technical documents providing countries with practical guidance on integrating palliative care into health-care systems. As requested by the Declaration of Astana, adopted by Member States in 2018, special emphasis has been given to the strengthening of palliative care within primary health care.

The provision of good palliative care to all people who need it, across disease and age groups and in all contexts, including humanitarian emergencies is possible only if health systems are adequately prepared; this requires considering several important dimensions, described in this document. This technical report aims to provide countries with concrete modalities to assess the development of palliative care and address gaps in a timely manner. The proposed set of indicators is the result of experiences from the field and lessons learned across the world; it also includes innovative approaches and pays attention to the engagement of people and their communities. Suggestions to use these indicators in a strategic way will have to be adapted to specific settings and improved over time through knowledge sharing between countries; but this document is underpinning our common effort to understand better and address in a comprehensive way the needs of the people facing the problems associated with life threatening illness. It is strongly in line with our commitment to leave no one behind.

Zsuzsanna Jakab
Deputy Director-General
World Health Organization

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Acronyms

LMICs	low-and middle-income countries
NCD	noncommunicable disease
PC	palliative care
PHC	primary health care
UHC	universal health coverage
WHO	World Health Organization

Glossary

Community: A unit of population, defined by a shared characteristic (for example, geography, interest, belief or social characteristic), that is, the locus of basic political and social responsibility, and within which everyday social interactions and most life activities of the people takes place.

Empowerment for health: The process of supporting people and communities to take control of their own health needs resulting, for example, in the uptake of healthier behaviours or an increase in the ability to self-manage illnesses.

Engagement for health: The process of involving people and communities in the design, planning and delivery of health services, thereby enabling them to make choices about care and treatment options or to participate in strategic decision-making on how health resources should be spent.

Evaluation: A process that systematically and objectively assesses the relevance, effectiveness and impact of activities in light of their objectives and the resources deployed. Several varieties of evaluation can be distinguished, such as evaluation of structure, process and outcome.

Feasibility of an indicator: The degree to which users could easily obtain or collect an indicator.

First level of care: The entry point into the health-care system at the interface between services and community; when the first level of care satisfies several quality criteria, it is called primary care. See: primary health care.

Global score (GS): A single indicator showing palliative care development at the national level.

Health care benefits package: The type and scope of health services that a purchaser buys from providers on behalf of its beneficiaries.

Health literacy: The level of health-related knowledge and personal skills that enable someone to act confidently to improve personal and community health.

Indicator: Explicitly defined and measurable metric that helps in the assessment of the structure, process or outcomes of an action or a set of actions.

Integrated health services: The management and delivery of health services so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services through the different functions, activities and sites of care within the health system.

Monitoring and evaluation: Information systems that generate reliable data and support the use of information for improved decision-making and learning by local, national and global actors.

Person-centered care: Approaches and practices in which the person is seen as a whole, with many levels of needs and goals; the needs being derived from their personal and social determinants of health.

Primary health care (PHC): A whole-of-society approach to health that aims to maximize the level and distribution of health and well-being through three components: (i) primary care and essential public health functions as the core of integrated health services; (ii) multisectoral policy and action; and (iii) empowered people and communities.

Regulation: The imposition of constraints upon the behaviour of an individual or an organization to force a change from preferred or spontaneous behaviour.

Relevance of an indicator: The degree to which the indicator is related to palliative care development at a national level.

Stakeholder in health care: An individual, group or organization that has an interest in one or multiple aspects of the health system.

Universal health coverage (UHC): Ensured access for all people to needed promotive, preventive, resuscitative, curative, rehabilitative and palliative health services, of sufficient quality to be effective, while also ensuring that the use of these services does not expose any users to financial hardship.

Definitions in this glossary are obtained from the following sources:

Operational framework for primary health care: transforming vision into action. Geneva and New York: World Health Organization (WHO) and United Nations Children's Fund (UNICEF): 2020 (https://apps.who.int/iris/handle/10665/337641, accessed 5 June 2021). Licence: CC BY-NC-SA 3.0 IGO.

Arias-Casais N, Garralda E, López-Fidalgo J, de Lima L, Rhee JY, Pons JJ et al. Brief manual on health indicators monitoring global palliative care development. Houston: IAHPC Press; 2019 (http://hdl.handle.net/10171/56523, accessed 5 June 2021).

Executive summary

56.8
MILLION

Each year, it is estimated over 56.8 million remain in need of palliative care, of whom 78% live in low- and middle-income countries

Palliative care is concerned with relieving serious health-related suffering for people of all ages with severe illness. Each year, it is estimated over 56.8 million remain in need of palliative care, of whom 78% live in low- and middle-income countries (LMICs)(1). The availability to palliative care services remains limited for patients with noncommunicable diseases (NCDs) globally, with only 39% of countries reporting general availability(2).

The World Health Assembly resolution 67.19 (3) recognizes palliative care as an ethical responsibility of health systems and calls for World Health Organization (WHO) Member States to assure its delivery through comprehensive primary health care (PHC) services. Palliative care is embedded within the Declaration of Astana (4) and the comprehensive approach for PHC through three interrelated and synergistic components that: (i) meets peoples' health care across the life course from prevention, promotion, curative care, rehabilitation through to palliation; (ii) addresses the broader determinants of health grounded in evidence-based multisectoral policies and action; and (iii) empowers individuals and communities to be more involved in decision-making about health services and their own health. PHC is on the critical pathway towards the achievement of UHC, and is fundamental to its successful implementation(5).

Although opioids are vital for pain relief in palliative care, they are only one component required for the development of robust palliative care systems.

Monitoring the existence and maturity of palliative care services in many countries is most often measured by assessing the consumption of opioid analgesics. Although opioids are vital for pain relief in palliative care, they are only one component required for the development of robust palliative care systems. Recent works such as the *Brief manual on health indicators monitoring global palliative care development*(6), undertaken by the ATLANTES Global Palliative Care Observatory, have provided a foundation for developing a range of indicators to provide for a more comprehensive assessment of palliative care provision. This document builds upon these efforts and aims to provide a globally applicable and robust set of palliative care indicators to Member States that can be used to assess and monitor the provision of palliative care services in countries worldwide.

Reliable data derived from robust indicators can support decision-making by informing health priorities, resource allocation and ongoing palliative care strengthening activities.

Reliable data derived from robust indicators can support decision-making by informing health priorities, resource allocation and ongoing palliative care strengthening activities. Data derived from indicators can be utilized as a powerful advocacy tool to mobilize resources for palliative care at a national and international level as well as providing transparency and accountability to the public and funders when resources are allocated. At a global level, harmonizing data across countries provides a clearer picture of global needs and challenges in palliative care, such as inequity.

Measurement is also a starting point for identifying success stories and extracting learning from countries for designing effective improvement strategies and application in other settings. The recommended indicators for palliative care monitoring presented in this report align with the menu of indicators of the WHO PHC measurement for improvement *Monitoring framework and indicators* (WHO forthcoming), which accompanies the WHO and UNICEF *Operational framework for primary health care: transforming vision into action*(5).

Methods

A consensus-building process was conducted to identify a refined set of indicators to monitor the development of palliative care programmes in different contexts, especially in countries where palliative care is at an initial stage of development. The refined set was chosen from a long list of existing validated indicators being used in different settings across the world. Consensus was built among a panel of international experts representing all WHO regions through a series of meetings, group work and a two-round Delphi process.

Findings

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palliative care indicators were established to be used by any country, according to their needs and existing data systems.

A working concept of palliative care development was agreed by the group that fed into an updated palliative care development conceptual model. The proposed model highlights six essential components required to provide optimal palliative care for those people with serious health-related suffering: (i) robust health policies related to palliative care; (ii) use of essential palliative care medicines; (iii) provision of palliative care within integrated health services; (iv) education and training for health workers and volunteers providing palliative care; (v) empowered people and communities; and (vi) palliative care-related research.

Applying the updated palliative care development conceptual model, a menu of 18 palliative care indicators was established (Table 3). These indicators can be selected and used by any country, according to their needs and existing data systems. In addition, two distinct subsets of indicators were developed. First, 10 core indicators (Table 4) that are considered to be essential indicators for the measurement of palliative care both in-country and for global comparative analysis were identified. The second subset are strategic indicators, a group of nine indicators that are the most feasible and important to measure in countries where palliative care is only in the initial stages of development.

Implementation

Countries can use this report to guide the selection of palliative care indicators and integrate them within the monitoring frameworks of national strategies, policies and plans. The indicators should be selected and adjusted according to the country context, considering elements such as the stage of palliative care development, input from stakeholders and alignment with existing health information systems. To implement the indicators, stakeholder engagement will be required, raising awareness of their importance, developing systems of accountability and building capacity for data collection, analysis and use. Careful identification of robust and available data sources must be undertaken. It is vital that indicators are then used for learning, decision-making and informing action on broader efforts to strengthen palliative care development in the country as an integrated component of overall health systems strengthening and monitoring through a PHC approach.

The proposed indicators are based on a diversity of experiences and expertise from all WHO regions. However, it will be crucial to conduct in each country a specific analysis on the feasibility and relevance of the proposed indicators in practice. Several factors may limit their implementation, including data availability, the heterogeneity of registration systems and/or units of measurement and the acceptability of indicators. It is particularly important that indicators measuring research and community empowerment are piloted before full adoption as these components are new additions to the assessment model for palliative care development and are, therefore, untested in practice.

Introduction

What is palliative care?

Palliative care is 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, whether physical, psychosocial or spiritual(7). Palliative care offers holistic care (medical, psychological, social and spiritual) for people with pain and serious health-related suffering due to severe illness(8). It is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications(8).

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes(9).

What is the state of palliative care provision worldwide?

2.5

MILLION CHILDREN

This gap in paediatric palliative care provision is especially underreported and almost 2.5 million children die with serious health-related suffering every year

In 2020, it was estimated that around 56.8 million adults and children experienced unnecessary suffering that can be addressed and treated by palliative care(1). This number is expected to drastically increase over the coming decades, especially in low- and middle-income countries (LMICs). According to the 2019 World Health Organization (WHO) NCD Country Capacity Survey(2), the availability of palliative care services remains limited for patients with noncommunicable diseases (NCDs) globally, with only 39% of countries reporting general availability. Oral morphine is reported as generally available in 44% of countries worldwide. In 2019, only 50% of countries globally report having palliative care within their national NCD policy that is operational and 68% have dedicated funding for palliative care. Palliative care is generally available to patients in need in primary health care (PHC) facilities in 50% of countries where funding is specifically allocated as compared to 15% of countries where there is no dedicated funding for palliative care.

There is a substantial gap in funding and availability of palliative care among country groups by income as well as an urgent need to scale up palliative care services in LMICs through policies, resources and services in primary care and access to morphine(2). This gap in paediatric palliative care provision is especially underreported and almost 2.5 million children die with serious health-related suffering every year, 98% of these children live in LMICs(9).

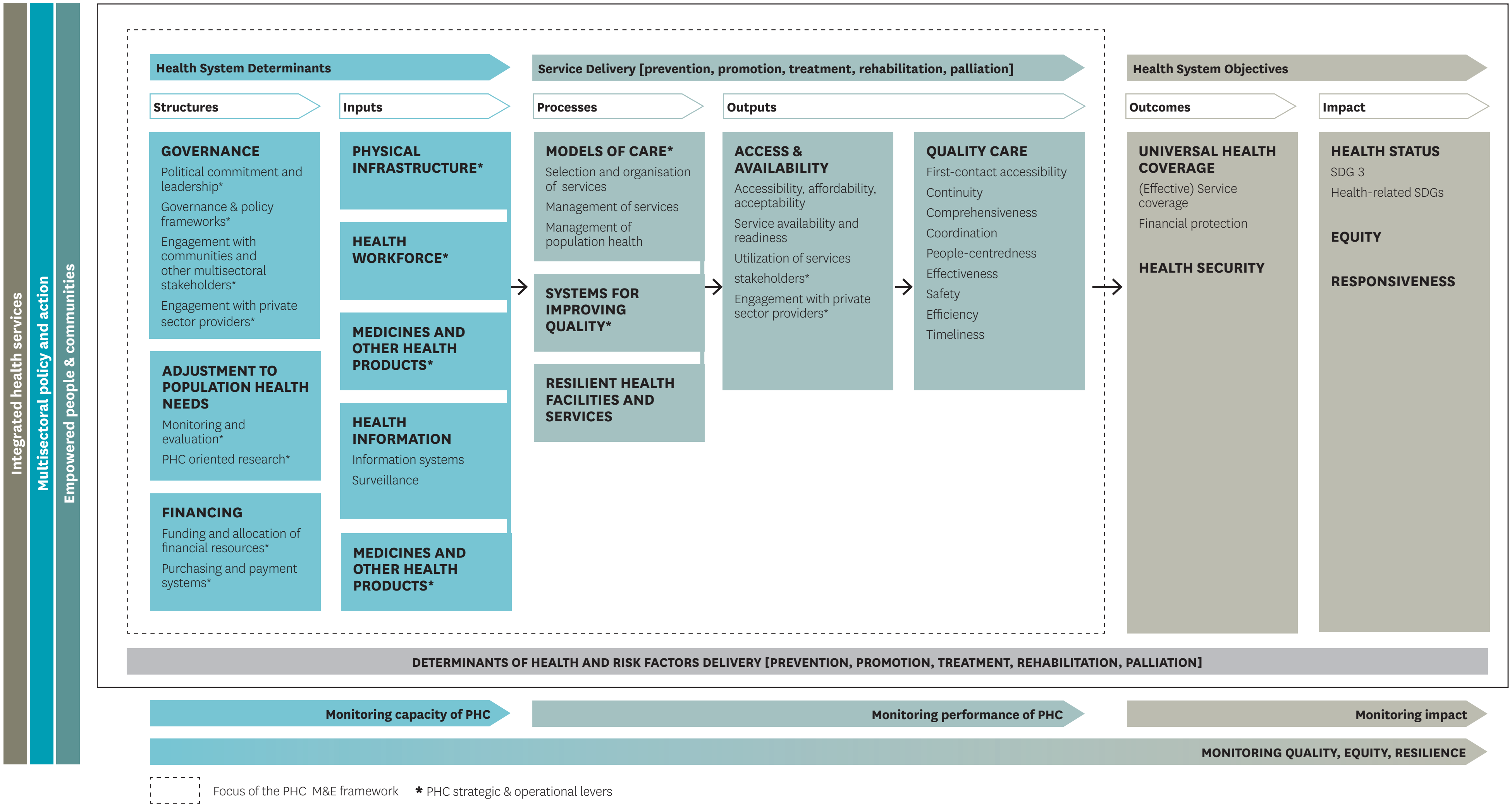
Why is palliative care an essential function of PHC towards UHC?

To ensure palliative care is part of UHC it has to be integrated through a PHC approach, in coordination with all levels and platforms of care, including with social and community-based care.

In 2014, the World Health Assembly adopted resolution WHA67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course(3). This global commitment acknowledges that “palliative care is an ethical responsibility of health systems” and insists on the “urgent need to include palliation across the continuum of care, especially at the primary health care level”(3). The Astana Declaration on Primary Health Care(10), adopted in 2018, included a call to strengthen palliative care within PHC by meeting peoples’ health care across the life course from prevention, promotion, curative care, rehabilitation to palliation, through integrated health services with a focus on primary care and essential public health functions. Empowering individuals and communities to be more involved in decision-making about their own care, and addressing the determinants of health through evidence-based multisectoral policies and actions are also central to the PHC approach (Figure 1).

The political declaration on universal health coverage (UHC) adopted during the United Nations General Assembly in September 2019 reiterated the need to include palliative care in UHC(11). To ensure palliative care is part of UHC it has to be integrated through a PHC approach, in coordination with all levels and platforms of care, including with social and community-based care. In this way, strengthening palliative care is an essential component to overall PHC-oriented health systems strengthening. The development of the WHO and UNICEF Operational framework for primary health care: transforming vision into action highlights the need to integrate palliative care into primary care, and notes key strategic and operational levers to support countries to take actions to strengthen PHC performance improvement(12). The framework also highlights the need for robust monitoring and evaluation through well-functioning health information systems that generate reliable data and support the use of information for improved decision-making and learning by local, national and global actors(12).

FIGURE 1. PHC MEASUREMENT FOR IMPROVEMENT: MONITORING FRAMEWORK AND INDICATORS (WHO FORTHCOMING)



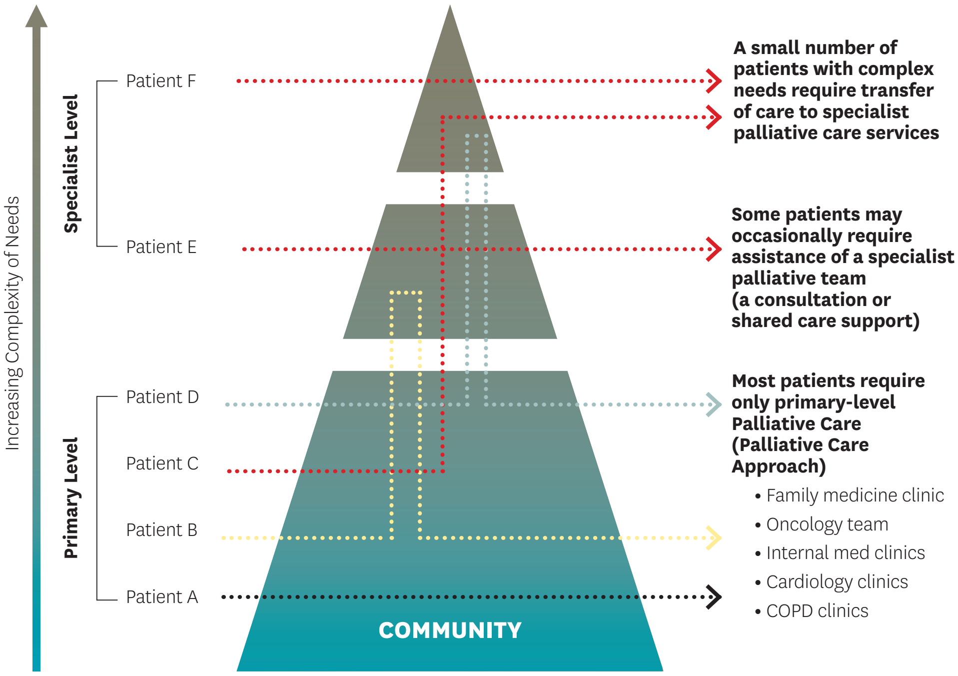
What can be done to address gaps in palliative care?

Palliative care development should be considered across all levels of health services to meet the differing needs of people requiring palliative care

The PHC approach aims to ensure that the full spectrum of health needs of individuals is met throughout the life span by assuring access to integrated promotive, protective, preventive, curative, rehabilitative and palliative services(10). The integration of palliative care within a national health system can be understood as its capacity to offer prevention and relief from serious health-related suffering, according to existing needs, with the right balance between available resources, whether specialized palliative care services or palliative care resources integrated into other areas of health services(13).

Palliative care development should be considered across all levels of health services to meet the differing needs of people requiring palliative care (Figure 2). At the primary care level, community-based resources and a palliative care approach are essential to support the needs of people with chronic diseases(14). To achieve this, it is necessary to have empowered people and communities, a PHC workforce trained in the basic approach of palliative care and the availability of medicines and health policies that integrate this focusing of the patient and the family as well as the referral of the patient when required. At the specialist level, the provision of palliative care in integrated platforms for the provision of health services implies the existence of a governance and policy framework that considers palliative care as an integral part of the care process and the availability of specialized models of care in palliative care for adults, children and essential medicines for symptom control.

FIGURE 2. DIFFERING PATIENT NEEDS FOR PRIMARY AND SPECIALIST PALLIATIVE SERVICES THROUGHOUT THE ILLNESS TRAJECTORY



Source: MacDonald 2019(15).

How to evaluate the development of palliative care?

New refined set of indicators that take into consideration the context where the monitoring of palliative care will take place.

In 1990, WHO developed a strategy for integrating palliative care into health systems, which was updated in 2007(16). This strategy consists of four basic components: palliative care policies; service provision; education; and essential medicine accessibility. The WHO Noncommunicable diseases global monitoring framework: indicator definitions and specifications for 2015–2020 has used the indicator of "morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from cancer" to measure access to palliative care(17). In recent years, indicators to assess palliative care development have been developed and applied in Africa(18), Latin America(19), Asia (20), Europe(21), the Eastern Mediterranean(22,23) and worldwide(24–26). Previous works such as the Brief manual of palliative care indicators monitoring global palliative care development(6), undertaken by the ATLANTES Global Palliative Care Observatory of the University of Navarra, provide a foundation for this effort by developing an international consensus for indicators to assess national-level palliative care development.

Based on the WHO definition of palliative care, this report considers palliative care interventions for both adults and children and proposes a new refined set of indicators that take into consideration the context where the monitoring of palliative care will take place. The report then presents practical recommendations to implement this work at the national or subnational level. It is important to note that these indicators are not an end point in themselves, but the data derived from their use will help to strengthen PHC working towards the achievement of UHC through driving expansion and quality improvement of palliative care programmes.

Why are palliative care indicators useful?

Data derived from indicators also inform decision-makers about the gaps and challenges in palliative care provision.

Reliable data on palliative care derived from indicators provide information on the progress of palliative care development within a country in a way that is specific and relevant to a particular context. Data derived from indicators also inform decision-makers about the gaps and challenges in palliative care provision and can be used to inform decisions about health priorities, policy gaps, resource allocation and ongoing palliative care strengthening activities. The inclusion of palliative care indicators within national health information management systems contributes to awareness raising and action on palliative care from health care managers and workers. Furthermore, data derived from indicators can be utilized as a powerful advocacy tool to mobilize resources for palliative care as well as provide transparency and accountability to the public and donors when resources are allocated.

At a global level, common indicators facilitate benchmarking and help to identify successful palliative care programmes that can serve as models for other settings. Good quality and harmonized data across countries provide a clearer picture of global needs and challenges in palliative care, such as inequity, which is a powerful advocacy tool towards integration of palliative care within UHC. The indicators, when used by countries to establish baselines and targets, can be used to monitor progress towards reducing global health inequities and to promote UHC to address the needs of people with serious health-related suffering. The indicators are built on a PHC approach and include equitable access to an essential package of medicines for palliative care, educational programmes, regulations, health policies, funding, people and community engagement in decision-making processes, advocacy and research. The application of a refined set of indicators will allow countries to identify the main barriers impeding the strengthening of palliative care and help facilitate the optimization of resources to focus on the most efficient interventions.

Target audience

The target audience of this report includes policy-makers, palliative care programme managers and health-care workers. The palliative care development conceptual model is aimed at supporting the establishment of palliative care services and guide their improvement within a broader UHC context.

Part A

Selecting indicators: methods, results and implications

Aim

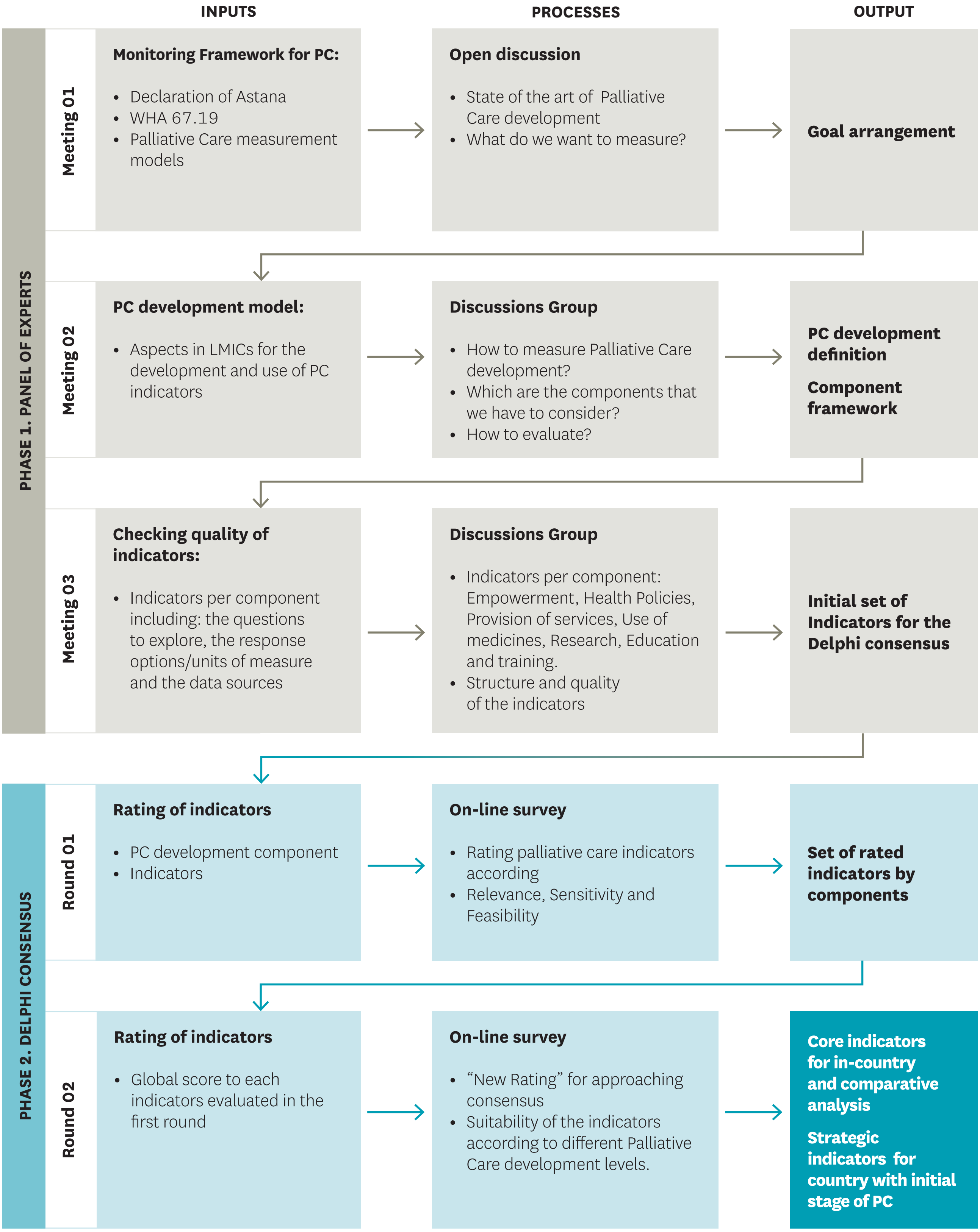
The aim of this report is to provide a refined set of indicators that can be used by countries to monitor and assess the development of palliative care, taking into account the diversity of settings, especially in countries at initial stages of palliative care development. The proposed indicators have been identified on the basis of their relevance and feasibility.

Methods

A consensus-building process was conducted to identify a set of indicators to monitor the impact of national palliative care programmes in different contexts. This consensus was built by a panel of international experts from all WHO regions through a series of meetings (phase 1) and a two-round Delphi process (phase 2).

Figure 3 gives an overview of the entire consensus-building process.

FIGURE 03. **OVERALL STRUCTURE OF THE CONSENSUS PROCESS**



		INPUTS	PROCESSES	OUTPUT
PHASE 1. PANEL OF EXPERTS	Meeting 01	**Monitoring Framework for PC:** • Declaration of Astana • WHA 67.19 • Palliative Care measurement models	**Open discussion** • State of the art of Palliative Care development • What do we want to measure?	**Goal arrangement**
	Meeting 02	**PC development model:** • Aspects in LMICs for the development and use of PC indicators	**Discussions Group** • How to measure Palliative Care development? • Which are the components that we have to consider? • How to evaluate?	**PC development definition** **Component framework**
	Meeting 03	**Checking quality of indicators:** • Indicators per component including: the questions to explore, the response options/units of measure and the data sources	**Discussions Group** • Indicators per component: Empowerment, Health Policies, Provision of services, Use of medicines, Research, Education and training. • Structure and quality of the indicators	**Initial set of Indicators for the Delphi consensus**
PHASE 2. DELPHI CONSENSUS	Round 01	**Rating of indicators** • PC development component • Indicators	**On-line survey** • Rating palliative care indicators according • Relevance, Sensitivity and Feasibility	**Set of rated indicators by components**
	Round 02	**Rating of indicators** • Global score to each indicators evaluated in the first round	**On-line survey** • “New Rating” for approaching consensus • Suitability of the indicators according to different Palliative Care development levels.	**Core indicators for in-country and comparative analysis** **Strategic indicators for country with initial stage of PC**

Phase 1. Experts group

A group of 35 experts were identified representing the different areas of needed expertise (i.e. public health, measurement and palliative care) and a large range of social, cultural and economic settings. The experts were convened for three online meetings organized by WHO and the University of Navarra, Spain, in April, June and September 2020. The online Delphi consensus process was carried out between December 2020 and January 2021.

Meeting 1
What do we want to measure?

The guiding question of the meeting was: What do we want to measure? Examples of health outcomes monitoring frameworks were reviewed in light of the PHC approach adopted in the Astana declaration and within the UHC framework. To ground the work on indicator development, the experts agreed on an updated concept of "palliative care development".

Meeting 2
How to measure palliative care development?

The guiding question of the meeting was: How to measure palliative care development? A palliative care development assessment model was developed through answering two questions: What are the key components of palliative care development? What are the main conditions for the use of indicators by countries, in particular LMICs or countries with initial level of palliative care development? The experts were divided into six subgroups and assigned two subgroups for each question. The results of this process were condensed into a conceptual model of the components that need to be evaluated to assess the development of palliative care. The existing 2007 public health strategy for integrating palliative care(16) was updated and reformulated to take into account the outputs of this meeting.

Meeting 3
What are the best indicators?

The guiding question of the meeting was: What are the best indicators? Building on the results of the first two meetings, an initial list of reference indicators was established covering all components of the proposed palliative care development conceptual model. The long list of reference indicators presented to experts for the consensus-building process was derived from systematic reviews of evidence and was composed of multiple indicators that have been previously used to monitor the activity of palliative care(27–30). A metadata template covering a wide range of indicators was prepared that detailed key components of each indicator (see example in Table 1).

TABLE 1. METADATA TEMPLATE USED TO PRESENT INFORMATION ON INDICATORS TO THE EXPERT PANEL: ONE INDICATOR IS LISTED AS AN EXAMPLE

NAME OF THE INDICATOR	WORKING CONCEPT	POTENTIAL QUESTION TO EXPLORE	ANSWER OPTIONS AND/OR UNIT	SOURCE OF INFORMATION	OUTPUT
Reported annual opioid consumption – excluding methadone – in oral morphine equivalence (OME) per capita	These data represent the amounts of opioids distributed legally in a country for medical use to health care institutions and programmes that are licensed to dispense to patients, such as hospitals, nursing homes, pharmacies, hospices and palliative care programmes	Opioid consumption milligram/capita/year – excluding methadone – in oral morphine equivalence (OME)	Milligrams per capita per year, expressed in morphine equivalence	International Narcotics Control Board (INCB)	Opioids consumption

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EXPERTS

A two-round Delphi consensus process was carried out with 27 experts to identify the most appropriate indicators to assess and monitor the development of palliative care.

The experts were asked to provide comments on the metadata proposal in advance of the meeting. During the meeting, six subgroups were formed to discuss the relevance, sensitivity and feasibility of indicators, particularly in countries at initial stages of palliative care development. The outputs of this meeting informed the development of a preliminary list of indicators to be later evaluated by the Delphi process.

Phase 2. Delphi process

A two-round Delphi consensus process was carried out with 27 experts to identify the most appropriate indicators to assess and monitor the development of palliative care. An online survey was designed listing all the preliminary indicators derived from Phase 1. For each indicator the concept, the questions to be explored, the unit of measurement and the data source were shown. During the first round, the experts scored the indicators on a scale from 1 to 9 based on three parameters – relevance, sensitivity and feasibility – represented in a single global score (GS), 9 being the most valid. The parameters were defined as follows:

- Relevance: the degree to which the indicator is related to palliative care development; the importance of the indicator for palliative care development.
- Feasibility: the degree to which data for an indicator could be easily obtained or collected by suggested data sources.
- Sensitivity: the degree to which an indicator can detect changes in the development of palliative care over time.

During the second round of the Delphi process, each expert was presented with the mean GS rating of the group and asked to re-rate all indicators based on this knowledge. During this round, the experts were also asked to indicate the applicability of the indicator in different stages of palliative care development. Experts selected the indicators they judged applicable in countries with no known or little palliative care activity (initial stage), countries with some palliative care provision (medium stage) and countries where palliative care is integrated to mainstream health care services (advanced stage).

Analysis of results

The details of the analysis applied for each output of the consensus process are considered in turn in the numbered sections that follow.

1. Conceptual model for palliative care development

A conceptual model was developed to include all the components deemed by the expert panel as essential for palliative care development. The structure and layout of the model considers the interactions between these different components and how components need to be implemented together to stimulate the development of palliative care. This analysis was informed by the *Operational framework for primary health care: transforming vision into action*(5).

2. Menu of agreed upon palliative care indicators

Under each component of the assessment model for palliative care development, indicators with a global score ≥7, plus interquartile range ≤1 and content validity index ≥0.70 were deemed to reach an acceptable standard of feasibility, sensitivity, relevance and consensus between experts. These indicators were selected to be included in the broad menu of indicators. Recognizing the importance of having a spread of indicators across all components of the assessment model, the relative strength of each indicator was compared only to other indicators included under the same component of the model. This meant, for example, "research" indicator scores were only directly compared with other "research" indicators, rather than ranking all long-listed indicators from highest to lowest. This method of analysis facilitated the consideration of a greater range of indicators, including less frequently used indicators that fall under the newly included components from the assessment model (output 1) such as palliative care research.

3. Core indicators for comparative and in-country evaluation

The indicators with the highest global score and the best consensus metrics were selected for a small subset of indicators that guide the basic areas of analysis of the national, subnational and global palliative care situation.

4. Strategic indicators for initial stages of palliative care development

A subset of strategic indicators for countries at initial stages of palliative care development was designed. For this subset, the 1/2 rule was used: as 27 experts voted, an indicator would be considered suitable for the initial stage of development when reaching 14 votes or more.

Results

Conceptual model for palliative care development

A consensus was reached on the core components required for the palliative care development conceptual model.

The working concept of palliative care development adopted by the expert group was:

Palliative care development aims to ensure access by all children and adults experiencing serious health-related suffering to timely and effective palliative care. It includes suffering prevention, managing symptoms and providing services focused on improving the quality of life through person-centred and integrated health services at all levels of health-care systems, and as part of the standard of care. The national strategy of palliative care strengthening should be part of the country's commitment to strengthen primary health care (PHC) towards the achievement of universal health coverage (UHC).

A consensus was reached on the core components required for the palliative care development conceptual model. This includes the adaptation of four components already deemed essential to palliative care development in the literature: appropriate policies; adequate access to medicines; education of health-care workers and the public; and implementation of palliative care services at all levels of the health system. To further strengthen this model and reflect international commitments to the PHC approach, the expert group agreed on adding two other components: research; and empowered people and communities (Figure 4).

FIGURE 4. **CONCEPTUAL MODEL OF PALLIATIVE CARE DEVELOPMENT**

6

Six components make up the palliative care development assessment model

Six components make up the palliative care development assessment model (see Table 2). At the core of this conceptual model, as its central focus, people with serious health-related suffering are depicted. For these people, palliative care provision is the ultimate goal of the model. For optimal service provision two components are essential: the use of essential medicines to relieve pain and other types of suffering; and the education of all health care providers involved in palliative care. Both of these components depend on two further fundamental components: favourable health policies regulating all of the above; and the empowerment of people and communities. Research rests on these foundations and informs evidence-based improvement in the use of medicines and professional education, enhancing palliative care provision to patients in need.

TABLE 2. COMPONENTS OF THE PALLIATIVE CARE DEVELOPMENT ASSESSMENT MODEL

COMPONENT	DEFINITION
Health policies related to palliative care	This component refers to the political commitment and leadership expressed in governance and policy frameworks (strategies, standards, guidelines). It includes the development of a legal framework and regulations that guarantee the rights of patients, access to palliative care services and essential medicines, and the financing and inclusion of palliative care in the national health service and benefits package. It also includes health system design and health care organization, in addition to stewardship and multi-stakeholder action.
Use of essential medicines	This component refers to the availability and access to essential medicines for palliative care across all levels of the health system, with special emphasis on the use of opioids for the management of pain and other symptoms, supported by respective risk management strategies. This list of essential medicines[1] includes: non-opioids and non-steroidal anti-inflammatory medicines; opioids analgesics; and medicines for other common symptoms in palliative care.
Provision of palliative care in integrated health service delivery platforms	This component refers to the capacity of the national health and social system to meet the needs of adults and children with serious health-related suffering. This entails services integrated into primary care and specialized services (hospice, home care, hospital, outpatient), its interaction with other areas of the health system, accessibility and commitment to private sector providers.
Education and training	This component refers to the availability of undergraduate education resources (integrated into curricula) in medicine and nursing schools, the existence of a specialization in palliative medicine and the existence of continuing education programmes for the development of basic and advanced skills in the care and treatment of people with palliative needs.
Research	This component is related to the development of research oriented to palliative care. Research aims at improving the level of scientific evidence to guide the care of people and decisions about the organization of health services.
Empowered people and communities	This component relates to the capacity of a country to empower individuals, families and communities as partners in the development of health and social services as well as in the engagement in shared decision-making about their own health. This entails the availability of advocacy resources to protect and enhance the participation of patients and caregivers in the development of palliative care programmes.

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[1] WHO Model List of Essential Medicines (eEML - Electronic Essential Medicines List (essentialmeds.org)).

The experts reached consensus on 18 of 35 proposed indicators.

Menu of agreed palliative care indicators

All the experts completed both Delphi rounds (27/27). After the two rounds, the experts reached consensus on 18 of 35 proposed indicators. In the case of the newly established components of the palliative care development conceptual model (research and empowered people and communities), none of the proposed indicators reached high global scores. However, as these elements were considered essential for developing palliative care by the expert panel, the study team agreed to include the indicators that scored closest to the prioritization cut-off point (Table 3).

TABLE 3. MENU OF INDICATORS FOR MONITORING PALLIATIVE CARE DEVELOPMENT

DIMENSION AND INDICATORS		GS (1–9)	IQR (0–2)	CVI (0–1)
Integrated palliative care services				
1	Number of specialized palliative care programmes in the country per population	**7.5**	1	0.7
2	Number of specialized palliative programmes for children in the country per population	**7.3**	1	0.7
3	Availability of monitoring systems to evaluate the quality of palliative care programmes	**7.0**	1	0.7
4	Estimated number of patients receiving specialized palliative care at the national level	**7.0**	1	0.7
Health policies				
5	Existence of a current national palliative care plan, programme, policy or strategy with defined implementation framework	**8.0**	1	0.8
6	Existence of a legal framework to ensure access to and regulation of palliative care	**7.5**	1	0.7
7	Inclusion of palliative care in the list of health services provided at the primary care level in the national health system	**7.5**	1	0.7
8	Existence of national standards and norms for the provision of palliative care services	**7.3**	1	0.7
9	Existence of national coordinating authority for palliative care (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care	**7.1**	1	0.7
Use of essential medicines				
10	Reported annual opioid consumption – excluding methadone – in oral morphine equivalence (OME) per capita	**8.1**	0	0.8
11	Availability of essential medicines for pain and palliative care at all levels of care	**7.5**	1	0.7
12	General availability of immediate-release oral morphine (liquid or tablet) at the primary care level	**7.4**	1	0.7
Education and training				
13	Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula	**8.1**	1	0.8
14	Specialization in palliative medicine for physicians	**7.7**	1	0.8
Empowerment of people and communities				
15	Existence of policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care	**6.8**	0.7	0.6
16	Existence of groups dedicated to promote the rights of patients in need of palliative care, their families, their caregivers and disease survivors	**6.5**	1	0.6
Research				
17	Existence of congresses or scientific meetings at the national level specifically related to palliative care	**6.8**	1	0.7
18	Palliative care research on the country estimated by peer reviewed articles	**6.2**	1	0.6

CVI: content validity index; global score: GS; IQR: interquartile range

Among these 18 indicators, two subsets of indicators were identified: (i) 10 core indicators for the comparative and in-country evaluation of palliative care development; and (ii) 9 strategic indicators, more relevant and feasible for countries at initial stages of palliative care development (Table 4).

TABLE 4. CORE AND STRATEGIC INDICATORS FOR MONITORING PALLIATIVE CARE DEVELOPMENT
(SEE ANNEX 1 FOR METADATA OF INDICATORS)

INDICATOR		CORE	STRATEGIC
Integrated palliative care services			
1	Number of specialized palliative care programmes in the country per population	√	√
2	Number of specialized palliative care programmes for paediatric population in the country	√	
Health policies			
3	Existence of a current national palliative care plan, programme, policy or strategy with defined implementation framework	√	√
4	Inclusion of palliative care in the list of health services provided at the primary care level in the national health system		√
5	Existence of national coordinating authority for palliative care (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care		√
Use of essential medicines			
6	Reported annual opioid consumption – excluding methadone – in oral morphine equivalence (OME) per capita	√	√
7	Availability of essential medicines for pain and palliative care at all levels of care		√
8	General availability of immediate-release oral morphine (liquid or tablet) at the primary care level		√
Education and training			
9	Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula	√	√
10	Specialization in palliative medicine for physicians	√	
Empowerment of peoples and communities			
11	Existence of groups dedicated to promote the rights of patients in need of palliative care, their families, their caregivers and disease survivors	√	√
12	Existence of national policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care	√	
Research			
13	Existence of congresses or scientific meetings at the national level specifically related to palliative care	√	
14	Palliative care research on the country estimated by peer reviewed articles	√	

Core indicators for comparative analysis and in-country evaluation

To facilitate the monitoring of palliative care development over time, especially in countries with different levels of palliative care development, and to conduct comparative analysis across countries, a set of 10 core indicators were identified.

Importantly, these indicators include elements related to PHC and the *Operational framework for primary health care: transforming vision into action*. Indicators of education in undergraduate curricula relate to the training of the future PHC workforce in palliative care. Indicators on health policies relate to the existence of governance structures, policy frameworks and regulations that promote the development of palliative care across all levels of the health system and the empowerment of people. Lastly, research indicators explore the dissemination of knowledge to accelerate the expansion of successful strategies to strengthen palliative care for PHC.

Strategic indicators for countries at initial stages of palliative care development

9

Nine indicators identified as “strategic indicators” were considered suitable in contexts where palliative care is at an initial stage of development

Nine indicators identified as “strategic indicators” were considered suitable in contexts where palliative care is at an initial stage of development and are especially relevant to guide policy decisions (see Table 4). Of note, no indicator included under the research component of the assessment model reached the required selection criteria for inclusion within this refined list. At an initial stage of development, key indicators are related to assessing the availability of essential medicines (especially oral morphine, especially in the first level of care); monitoring the existence of medical and nursing schools teaching palliative care; looking at the national palliative care action plan and the inclusion of services in the national health basic packages; and evaluating the access to specialized palliative care services in the country.

Both the set of core indicators and the set of strategic indicators, can be seen aside the components within the palliative care development conceptual model (Figure 5).

FIGURE 5. **RELATIONSHIP BETWEEN THE SETS OF INDICATORS AND THE PALLIATIVE CARE DEVELOPMENT CONCEPTUAL MODEL**

♥ ★ Reported annual opioid consumption –excluding methadone– in oral morphine equivalence (OME) per capita

★ Availability of essential medicines for pain and palliative care at all levels of care

★ General availability of immediate release oral morphine (liquid or tablet) at the primary care level

♥ ★ Number of Specialized Palliative Care Programs in the country per population

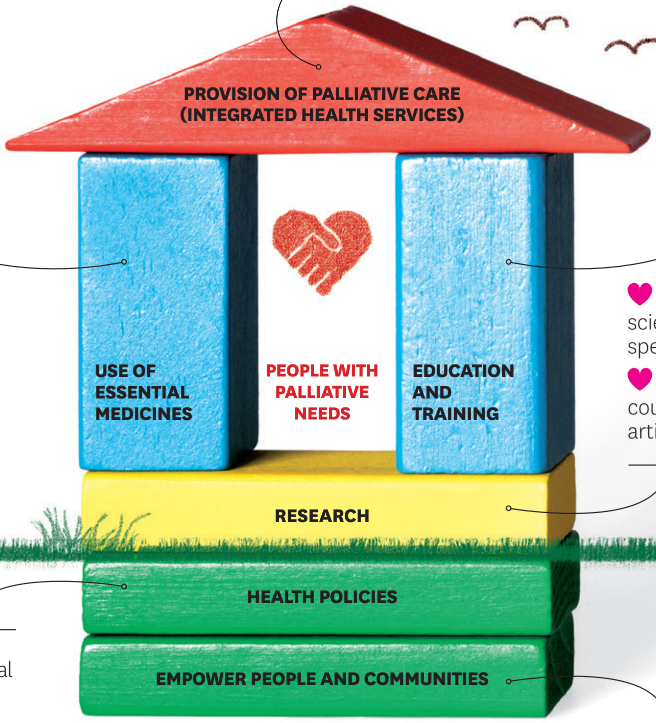
♥ Number of Specialized Palliative Care Programs for children in the country per population

○ Availability of monitoring systems to evaluate the quality of palliative care programs

○ Estimated number of patients receiving specialized palliative care at the national level

♥ ★ Proportion of medical and nursing schools with palliative medicine formal educationin undergraduate curricula

♥ Specialization in Palliative Medicine for physicians



♥ Existence of congresses or scientific meetings at national level specifically related to palliative care

♥ Palliative care research on the country estimated by peer reviewed articles

♥ ★ Existence of a current national palliative care plan, programme, policy or strategy with realistic implementation framework

★ Inclusion of Palliative Care in the list of health services provided at primary care level in the national health system

★ Existence of national coordinating authority for palliative care (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care

○ Existence of a legal framework to ensure access to and regulation of palliative care

○ Existence of national standards and norms for the provision of palliative care services

♥ ★ Existence of groups dedicated to promote the rights of patients in need of palliative care, their caregivers, and disease survivors

♥ Existence of national policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care

♥ Core Palliative Care Indicators for country comparative analysis
★ Strategic indicators for countries with low level of palliative care development
○ Other Indicators

Discussion

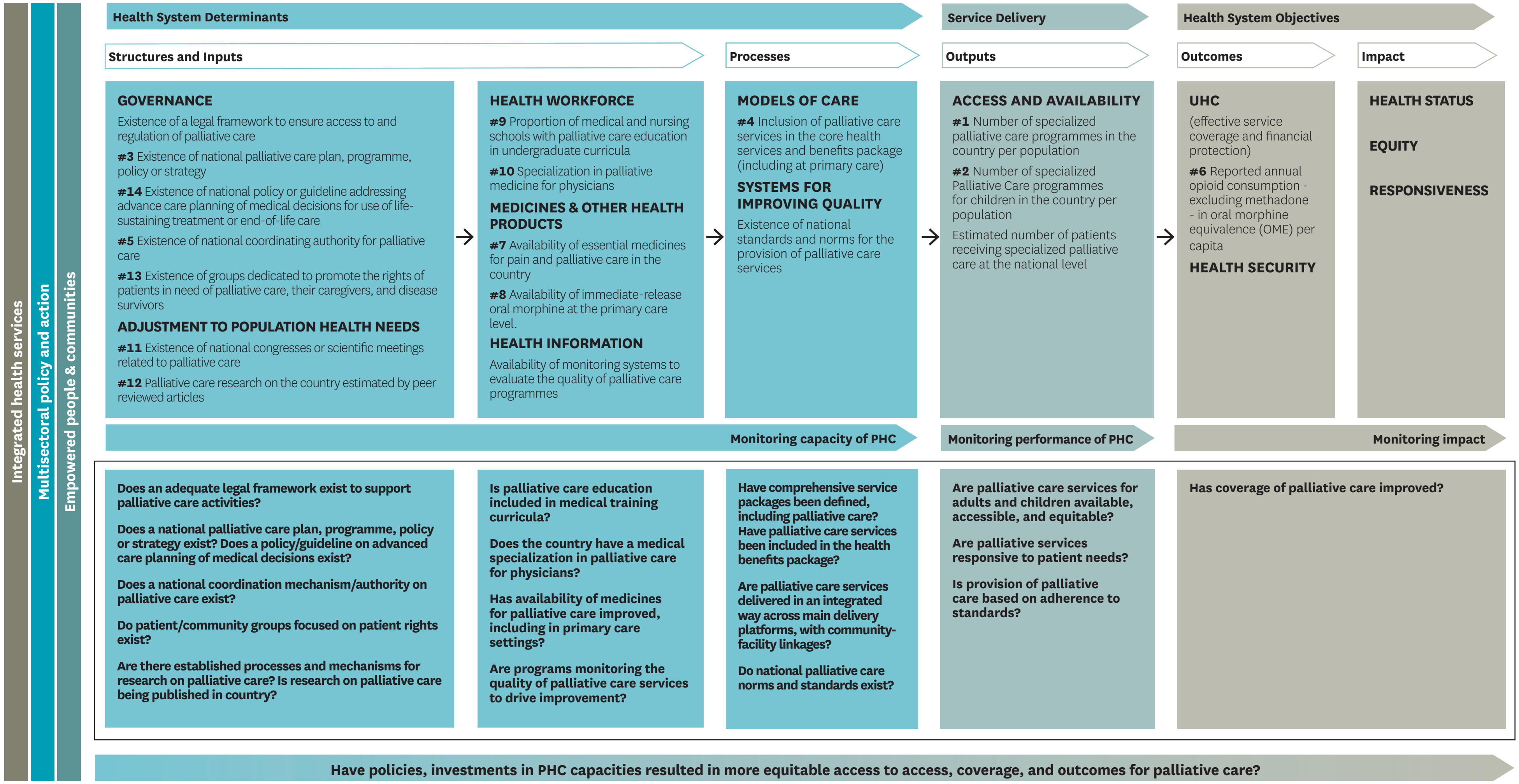
Palliative care development conceptual model

The conceptual model presented in this report, depicted now as a house (see Figure 3), is an attempt to show the relationship between the different components of the model.

Since 2007, some components of the new palliative care development conceptual model were depicted in the public health strategy for integrating palliative care, also commonly known as the "umbrella framework"(16). The conceptual model presented in this report, depicted now as a house (see Figure 3), is an attempt to show the relationship between the different components of the model. Health policies and empowerment of people and communities are the foundations of the house. Palliative care research is the floor of the building, where the professionals who attend to patient needs walk, because research is the basis of advanced medicine for people with serious health-related suffering. The walls of the house represent the essential medicines that should be available at all levels of care to prevent and relieve severe health-related suffering, and the basic and advanced education of health workers needed to provide quality care that is safe. These walls support integrated palliative care services addressing the needs of the patients and their families. The architecture of the palliative care house needs to reflect the particular context of each country: health system; social and cultural specificities; and resources. So, each country needs to build, with its own available materials and its particular style, the palliative care house: a home where intense suffering from serious illnesses is alleviated for the patient and their loved ones.

This palliative care development conceptual model connects with the *Operational framework for primary health care: transforming vision into action* (5) by emphasizing three elements (Figure 6). First, policies to guarantee resources and multisectoral actions related to education, empowerment and research. Second, integrated health services, especially in strategic indicators, by evaluating palliation in primary care. Third, the empowerment of people and community engagement, understood as fostering the capacity for action and decision of individuals, families and communities to promote their health and well-being. All activities included are in the pursuit of increasing population health coverage. The model can be used by stakeholders at the global, national and subnational level to guide improvement in palliative care services.

FIGURE 6. MAPPING PALLIATIVE CARE INDICATORS ON THE PHC MEASUREMENT FOR IMPROVEMENT: MONITORING FRAMEWORK AND INDICATORS (WHO forthcoming)



GOVERNANCE

Existence of a legal framework to ensure access to and regulation of palliative care

#3 Existence of national palliative care plan, programme, policy or strategy

#14 Existence of national policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care

#5 Existence of national coordinating authority for palliative care

#13 Existence of groups dedicated to promote the rights of patients in need of palliative care, their caregivers, and disease survivors

ADJUSTMENT TO POPULATION HEALTH NEEDS

#11 Existence of national congresses or scientific meetings related to palliative care

#12 Palliative care research on the country estimated by peer reviewed articles

HEALTH WORKFORCE

#9 Proportion of medical and nursing schools with palliative care education in undergraduate curricula

#10 Specialization in palliative medicine for physicians

MEDICINES & OTHER HEALTH PRODUCTS

#7 Availability of essential medicines for pain and palliative care in the country

#8 Availability of immediate-release oral morphine at the primary care level.

HEALTH INFORMATION

Availability of monitoring systems to evaluate the quality of palliative care programmes

MODELS OF CARE

#4 Inclusion of palliative care services in the core health services and benefits package (including at primary care)

SYSTEMS FOR IMPROVING QUALITY

Existence of national standards and norms for the provision of palliative care services

ACCESS AND AVAILABILITY

#1 Number of specialized palliative care programmes in the country per population

#2 Number of specialized Palliative Care programmes for children in the country per population

Estimated number of patients receiving specialized palliative care at the national level

UHC

(effective service coverage and financial protection)

#6 Reported annual opioid consumption - excluding methadone - in oral morphine equivalence (OME) per capita

HEALTH SECURITY

HEALTH STATUS

EQUITY

RESPONSIVENESS

Does an adequate legal framework exist to support palliative care activities?

Does a national palliative care plan, programme, policy or strategy exist? Does a policy/guideline on advanced care planning of medical decisions exist?

Does a national coordination mechanism/authority on palliative care exist?

Do patient/community groups focused on patient rights exist?

Are there established processes and mechanisms for research on palliative care? Is research on palliative care being published in country?

Is palliative care education included in medical training curricula?

Does the country have a medical specialization in palliative care for physicians?

Has availability of medicines for palliative care improved, including in primary care settings?

Are programs monitoring the quality of palliative care services to drive improvement?

Have comprehensive service packages been defined, including palliative care? Have palliative care services been included in the health benefits package?

Are palliative care services delivered in an integrated way across main delivery platforms, with community-facility linkages?

Do national palliative care norms and standards exist?

Are palliative care services for adults and children available, accessible, and equitable?

Are palliative services responsive to patient needs?

Is provision of palliative care based on adherence to standards?

Has coverage of palliative care improved?

Have policies, investments in PHC capacities resulted in more equitable access to access, coverage, and outcomes for palliative care?

\#ⁿ These numbers correspond to the order in which the core and strategic palliative care indicators are presented in Annex 1.

Palliative care development indicators

The initial stages of palliative care development are likely to place a special emphasis on the accessibility and appropriate use of opioids and other essential medicines (see Box 1), the teaching of palliative care at the undergraduate level, the inclusion of palliative care on the list of primary care services as a basic component of care, the equitable access to specialized palliative care services, and the existence of a national palliative care strategy.

The sets of indicators included in this report aim to strengthen analytical capacities and provide information to health care planners, implementers and managers. This indicator set provides a good starting point for decision-makers on how to holistically evaluate the health system's performance on palliative care provision. Such core indicators can also be drawn upon to facilitate cross-country comparison.

Given the enormous unmet need for palliative care particularly in LMICs(2)countries adopted the World Health Assembly Resolution 67.19 to integrate palliative care into national health policies-by revising laws and processes to improve access to opioids, and provide palliative care services through primary health care as well as through community settings with adequate resources. WHO is monitoring country progress on strengthening national capacity to prevent and manage noncommunicable diseases (NCDs, another subset of nine strategic indicators was identified to evaluate progress at the initial stages of palliative care development. Such strategic indicators can provide WHO Member States with a feasible and pragmatic starting point for developing strategic activities and measurement systems where palliative care provision remains very basic or non-existent. The initial stages of palliative care development are likely to place a special emphasis on the accessibility and appropriate use of opioids and other essential medicines (see Box 1), the teaching of palliative care at the undergraduate level, the inclusion of palliative care on the list of primary care services as a basic component of care, the equitable access to specialized palliative care services, and the existence of a national palliative care strategy.

BOX 1. RATIONAL AND SAFE USE OF OPIOIDS (31)

Appropriate use of opioids entails taking into account some considerations. Some strategies to maintain patient safety and minimize the risk of opioid misuse and abuse during chronic opioid use include: (i) caution when combining opioid medications with other medications that have a sedating effect; (ii) risk assessment prior to and during treatment through the use of appropriate tools and a comprehensive psychological evaluation; (iii) education regarding the potential risks and benefits of opioid therapy and regarding not sharing opioids with family members or friends; (iv) support for high-risk patients who exhibit one or more opioid misuse and abuse risk factors; and (v) education regarding safe manipulation, storage and disposal of controlled substances. These interventions contribute to maintaining a safe community and minimizing opioid misuse and abuse in the community.

The proposed set of indicators are based on a diversity of experiences and expertise from all WHO regions. However, countries are encouraged to conduct a specific analysis on the feasibility and relevance of the proposed indicators in practice in order to adapt the assessment process to the specificities of each setting. Previous experiences in the field of health systems monitoring report several factors that may limit the implementation of these assessment models, including data availability, the heterogeneity of registration systems and/or units of measurement, and the acceptability of indicators, especially in countries at initial stages of palliative

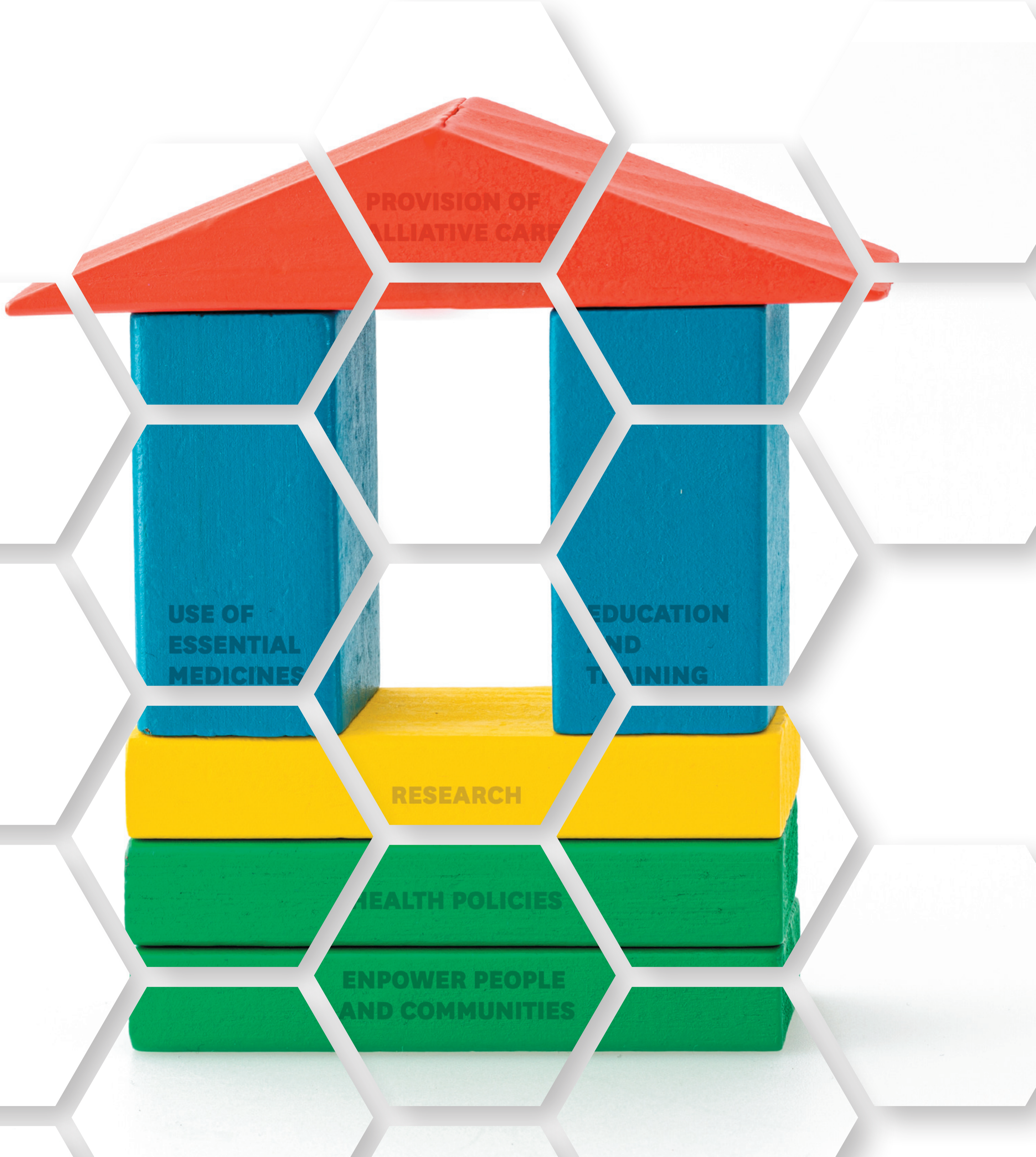
It would be desirable to focus indicators not only on structures and processes, but also on outcomes.

care development(29,30,32). It is particularly important that indicators that fall under the categories of research and community empowerment are piloted as these components are new additions to the palliative care development assessment model and are, therefore, untested in practice.

To improve the performance of national health strategies, it would be desirable to focus indicators not only on structures and processes, but also on outcomes, especially patient outcomes. However, this remains a significant challenge(33). Outcome indicators would allow countries to make decisions based on more sensitive and efficient measures, although this would demand much more detailed data on palliative care and may even require a functioning and quality national palliative care registry.

Part B

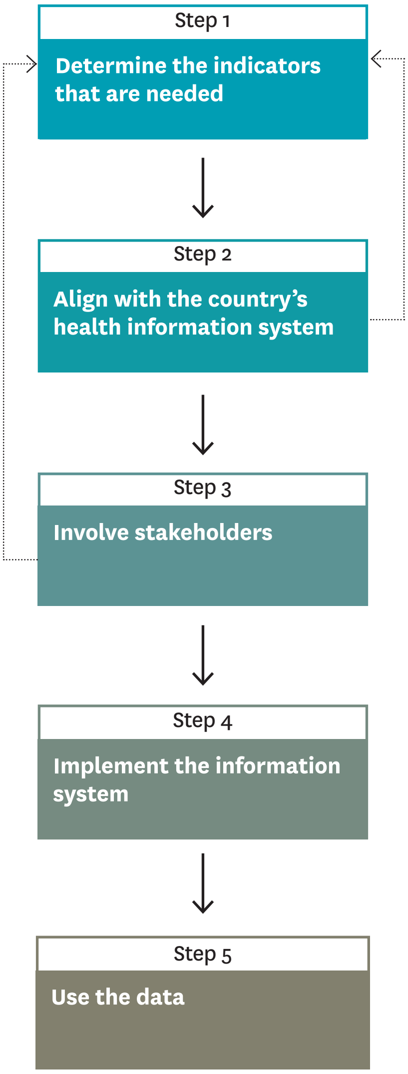
How to implement the indicators



Overview of indicator implementation

The monitoring of palliative care development can be conceptualized in a five-step process (Figure 7). The process begins by determining the indicators that are needed (core or strategic), and analysing the available information resources in country's information systems. This process requires the involvement of the different stakeholders in the planning and implementation of monitoring. Once indicators are selected, it starts the collection and generation of data, crucial for evidence-based decision-making. This process is aimed at leading the improvement of palliative care activity at the different components evaluated.

FIGURE 7. PROCESS FOR IMPLEMENTING THE INDICATORS



Step 1. Determine the indicators that are needed

How to select the indicators?

The palliative care development conceptual model was designed to inform the application of indicators by several stakeholders at the subnational (provincial), national (country) or international (regional/global) level. It is important to identify the level of palliative care development in each setting, to assist in the selection of the most relevant indicators for that context. Table 5 can be used to guide users as to which indicators may be most appropriate for their context.

TABLE 5. PALLIATIVE CARE LEVELS FOR SELECTION OF INDICATORS

PALLIATIVE CARE LEVEL	CONCEPT[2]	SET OF INDICATORS
Initial	Current indicators reveal no evidence of any palliative care activity nor any evidence of wide-ranging initiatives designed to create the organizational and workforce and policy capacity for the development of palliative care services. No service has yet been established.	Strategic
Middle	Palliative care activity is developed in several locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; several palliative care services from a range of providers; and the provision of some training and education initiatives by palliative care organizations.	Core
High	A critical mass of palliative care activity has been developed in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care on the part of health professionals and local communities; a palliative care strategy that has been implemented and is regularly evaluated; the availability of morphine and some other strong pain-relieving medicine; some impact of palliative care on policy; the provision of a substantial number of training and education initiatives by a range of organizations; and the existence of a national palliative care association.	

Although the indicator sets presented in this report act as a guide for users, the selection of indicators should be based on the relevance, usefulness for decision-making, responsiveness to change, and data availability within each setting. Where palliative care indicators have not been used previously, it is important to take a step-wise approach to initially selecting a small number of highly relevant indicators to ensure successful implementation and use.

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[2] Adapted from the world map of palliative care development(24)but service provision, supporting policies, education, and funding are incommensurate with rapidly growing needs. Objectives: The objective of this study was to describe current levels of global palliative care development and report on changes since 2006. Methods: An online survey of experts in 198 countries generated 2017 data on 10 indicators of palliative care provision, fitted to six categories of development. Factor analysis and discriminant analysis showed the validity of the categorization. Spearman correlation analyses assessed the relationship with World Bank Income Level (WBIL.

RESOURCES TO IDENTIFY THE LEVEL OF PALLIATIVE CARE DEVELOPMENT IN COUNTRIES OR REGIONS

- Global Atlas of Palliative Care, 2nd Ed 2020
- WHO guidelines for palliative care
- Regional palliative care atlases
- Monitoring, evaluation and review of national health strategies: a country-led-platform for information and accountability

Step 2. Align with the country's health information system

In many settings there are already multiple resources to obtain data on strategic and core indicators, including: subnational/national surveys; health facilities data; civil registration and vital statistics; administrative data; research; civil society and community reports; and mandatory reports to international authorities. It may be helpful to map the resources available within a country setting and list indicators already used to inform the initial selection of indicators for the setting. Using existing data sources and indicators will increase the feasibility of indicator implementation.

Once the set of indicators for monitoring palliative care has been selected, the data sources used in the country should be identified and existing data collection systems/mechanisms should be maximized to obtain data. This process optimizes resources, reduces the measurement burden and ensures the sustainability of the monitoring process. Correct identification of the existing information sources in the region is crucial for implementing monitoring, establishing information networks and for collaboration between stakeholders.

HEALTH INFORMATION SYSTEMS: AN EXAMPLE FROM INDIA

The Ministry of Health and Family Welfare of the Government of India established the National Program for Palliative Care 2012. This programme promotes the development of policies, opioids use and development of educational programmes for health professionals in the 35 subregions of the country. This initiative is articulated with the established mechanisms of programmes for the prevention and control of cancer and noncommunicable diseases, the ministries of health and finance, the Central Organization for the Control of Medicines Standards, and international and national cooperation agencies in the field of palliative care.

The burden of measuring 10 core indicators could be distributed by the institutions involved according to their area of specialty, considering that some of the indicators are currently monitored as part of the country's Health System Performance Assessment, for example:

- number of state-level multisectoral workshops
- number of states forming a steering committee following the workshop
- number of states utilizing allocated a central budget
- number of active state government-owned action plans for initiation and flow of activities within the states
- number of states untying the required budget from the state
- number of Recognized Medical Institution (RMI): hospital, hospice or other medical institution.
- number of professionals trained in each region of the country through the identified training hubs – nurses and doctors
- number of staff positions in palliative care within Regional Cancer Centre and medical colleges per state
- number of patients seen in department of palliative medicine – outpatient (OP)/inpatient (IP)/home based
- number of departments of palliative medicine within the private sector
- inclusion of supportive and home-based services within the state and centre-owned insurance bodies
- regular clear data on morphine consumption with a trend reflective of the estimated needs.

Core and strategic indicators focus on structure and processes, and some require data collection over time. Thus, it is important to consider the burden that data collection will place on participants in the monitoring process and the best timing for data collection. Nearly 50% of the indicators measure the existence of resources that allow palliative care development (for example, a strategic plan, specialization programmes, etc.), while some indicators require a series of readings to collect sufficient information to report on the output or outcome of a process. The latter of these require a greater effort and coordination between actors and, therefore, may not be initially feasible in all contexts.

Involving sectors other than health care (such as education or research) is essential to improve data collection on palliative care. These intersectoral efforts require the support of institutions capable of reporting progress in these areas. For example, the Ministry of Science or the responsible entity for research capacity in a country/region could incorporate an indicator on peer reviewed articles in palliative care into its monitoring programme. This requires close collaboration and developing a shared understanding of the importance and purpose of this evaluation.

Step 3. Involve stakeholders

The implementation of monitoring requires the involvement of different stakeholders and the definition of their roles in assessing palliative care activity. Stakeholders may include technical staff from ministries of health, statistical offices, policy-makers, researchers, health-care professionals, civil society groups, nongovernmental organizations, funding institutions, and others.

Different stakeholders will be linked to the planning and implementation of the monitoring process. Stakeholders may fulfill one or more of the following functions:

Indicator selection

The selection of indicators and their adaptation to local contexts require the participation of stakeholders. This process includes the analysis of partners´ capacities to provide information, the acceptance of the results and the use of data for decision-making. Involving key stakeholders in the selection of indicators will help decision-makers understand important feasibility considerations, increasing the probability of effective implementation.

Raising awareness among the target population or sector

It is important to work with stakeholders to build a shared understanding of the importance of data collection and analysis in palliative care(34). This requires collaborative work to ensure all stakeholders are motivated and empowered to participate in their roles in information management.

Collection and analysis of relevant information

Collection and analysis of palliative care data require coordinated efforts between health authorities, other government institutions in the areas of financing, education and social protection as well as representatives of social groups (patients, caregivers and family members). The creation of collaborative working groups, clearly assigned responsibilities, and clear communication, quality assurance and accountability mechanisms increase efficiency and use of the results. Structures, processes, policies and procedures need to be put in place to maintain the quality of data and prevent errors in interpretation or coding, data entry, transfer, or transformation accuracy and intention (validation and comparison against a standard).

Accountability

A variety of stakeholders can be involved in reviewing the progress made implementing indicators and the outputs from the indicators. These stakeholders can provide accountability to the process and identify actions and strategies to consolidate the monitoring process and strengthen components of palliative care activity in a community, country or region. Public reporting of indicators provides an additional layer of accountability from communities and civil society prompting further action on palliative care development.

INVOLVING STAKEHOLDERS: AN EXAMPLE FROM COLOMBIA

In 2016, a group of organizations, including universities, national palliative care scientific societies, national opioid authorities, research groups, human rights organizations, the National Institute of Cancerology, the national point of the Pan American Health Organization (PAHO), and the Ministry of Health, developed a national monitoring system called the Colombian Observatory for Palliative Care.

This strategy monitored palliative care activity across all 33 regions in the country. The information system offers data on health policies, services, use of opioids, professional activity, education and funding of palliative care. Stakeholders created a further developer group to gather official data from different entities and sources to evaluate palliative care progress on an annual basis. The main outcome of the Observatory is a national report intended to inform decision-making and setting up strategies and action plans.

Step 4. Implementing data collection/ generation

Identifying the strengths and limitations of available data sources is key to ensuring the most accurate data possible. Those responsible for the data collection process must ensure that the data originate from an information system that has the support and legitimacy of stakeholders and that data are collected in a transparent way.

The metadata of the selected indicators is available in Annex 1 of this report. The metadata provided describe possible sources of data for each indicator although these must be adapted to suit the local context. Undertaking a mapping exercise is helpful in selecting an appropriate data source as it examines the availability of data for the evaluation of palliative care development, the origin of the data (e.g. national/regional surveys, vital statistics, unofficial data), the units of measurement and the reporting frequency.

In general, it is possible to distinguish two types of information sources for the indicators of the assessment model:

Official sources: Data from government agencies or entities in charge of monitoring health services at the national or regional level, national statistics offices, official registries for the use of medicines, educational programmes, science and technology(32,35)

Unofficial sources: Data from research, consultation with national/regional stakeholders and experts in the evaluation areas, and civil society organizations.

Before starting the data collection, it is necessary to train responsible collectors in the conceptual and operational aspects of the indicator framework. This will improve the capacity of those involved to recognize the attributes that should be considered in the selection of information sources for each component.

ATTRIBUTES FOR SELECTING DATA SOURCES

Periodicity: data can be collected continuously, as in the case of health services surveillance systems, national/subnational health surveys, annual reports on the use of medicines, and standardized monitoring of educational programmes.

Validity: refers to the ability of the source to measure what it is intended to measure (absence of distortions, biases or systematic errors). The most relevant biases are those related to the selection of the medicine under study and the quality of the information collected.

Timeliness: refers to the availability and reliability of the data at the time when it is necessary to build the indicators. In this way, the possibility of developing timely indicators for decision-making related to health will be greater.

Stratification: many health-related problems require indicators stratified by subgroups or by areas of particular interest (e.g. type of services, undergraduate programme). The level of disaggregation available in the chosen data source generates multiple analytical interpretations.

IMPLEMENTING DATA COLLECTION: AN EXAMPLE FROM UGANDA

In Uganda, the ministry of health, in collaboration with partners, have adopted palliative care indicators and subsequently developed tools to support the collection of data on these indicators. The tools developed are two health management information systems:

1) Outpatient Department 008 Unit palliative care register
2) 105C Health unit palliative care monthly report

The national association, the Palliative Care Association of Uganda (PCAU), has worked closely with the ministry of health information systems department to sensitize and train service providers on the indicators, the tools and the reporting. The service providers receive hard copy versions of the data capture tools from ministry of health to support data capture and reporting. The data are available via the national platform, and currently data are routinely generated and PCAU shares these with service providers to inform their planning and monitoring performance.

Step 5: Use of data

The target audience should always be considered when deciding how to report data, as different audiences have different levels of understanding, technical expertise and requirements of what they need to take away from the monitoring. Reporting may entail communicating information to government officials, researchers, public health practitioners, policy-makers and/or others.

The most recent data for each indicator should be reported, however, where necessary, it is possible to present different time periods for each indicator. In general, it is recommended to report the most straightforward technical content wherever possible. Ensure data are accessible to end users such as policy-makers, to help them answer the question: What should be the current priorities for action in palliative care?

The assessment of palliative care development must be linked to improvement activities. Other sectors of government may be needed to take forward implementation activities relating to key components such as education of health-care professionals. Implementation activities may include changes to national or regional action plans for palliative care, re-assignment of budget or human resources to respond to gaps in palliative care development and using data to advocate for palliative care. It is important to facilitate a permanent and stable measurement process with defined periodicity to allow the monitoring of progress and inform continuous improvement processes.

USE OF DATA: AN EXAMPLE FROM LEBANON

Although palliative care has been shown to reduce the cost of health care, it has not been integrated into health insurance coverage as might be expected. Governments and third-party payers in many LMICs continue to restrict reimbursement of palliative care services in an attempt to avoid the associated costs. Many individuals and organizations have tried to advocate for integration of palliative care into health insurance plans with little success.

In Lebanon, Balsam, the Lebanese Center for Palliative Care, partnered with the American University of Beirut to generate local data on the impact of palliative care on health-care costs. The data were presented to the National Committee for Pain Control and Palliative Care to inform an initiative aimed at integrating palliative care services into health insurance. The data provided local evidence of cost savings that allowed the Committee to lobby for change. As a result, the Ministry of Public Health issued a Ministerial Decree in March 2019 defining criteria for reimbursement of hospital and home-based palliative care services and providing a blueprint for a reimbursement structure that could be adapted by all third-party payers.

Conclusion

The global consensus of experts has prioritized 18 indicators, 10 of them called core, for both comparative analysis and in-country evaluation, and 9 called strategic, to be used for regions at initial stages of palliative care development.

The palliative care development conceptual model includes six evaluation components that include: (i) integrated palliative care services; (ii) palliative care-related health policies; (iii) use of essential medicines; (iv) education and training; (v) palliative care-related research; and (vi) empowerment of people and community involvement. The new assessment model aligns with the orientation towards integrating palliative care into PHC, enabling people to receive palliative care when they need it and at all levels of the health system.

The global consensus of experts has prioritized 18 indicators, 10 of them called core, for both comparative analysis and in-country evaluation, and 9 called strategic, to be used for regions at initial stages of palliative care development. These indicators allow the monitoring and evaluation of the palliative care activity, according to the resources and capacities of each setting.

To operationalize the conceptual model, five steps are proposed that involve the identification of the set of indicators to be used, the availability of information sources in the setting, meaningful stakeholder engagement and the use of results in decision-making to improve palliative care activity.

The assessment model and the core and strategic indicators have been proposed in coherence with the *Operational framework for primary health care: transforming vision into action*(5), expecting to provide elements for decision-making at multiple levels, allowing the development of collaborative action plans that include those responsible for health actions, education, social promotion and advocacy to promote the development of palliative care and contribute to UHC, especially for individuals and families facing advanced disease.

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Annex

Annex. Indicator details

Integrated palliative care services

Indicator number	**#1**
Indicator name	**Number of specialized palliative care programmes in the country per population**
Component	Integrated palliative care services
Associated set	Core Strategic
Definition	Specialized palliative care (PC) programmes refer to health care programmes whose main activity is the provision of palliative care. These programmes often provide care for patients with complex needs or severe suffering and, therefore, require staff with specialized training. The staff generally includes at least one doctor and one nurse with training in palliative care, though in some areas, a specialized PC programme may be run only by a nurse with advanced or specialized training in palliative care. These programmes include, but are not limited to, free-standing hospices, hospices that are a part of public or private hospitals, any kind of other hospices or home care teams, hospital palliative care teams (consultation teams), palliative care units (with beds), inpatient units in hospices, etc. In this working concept of "PC programme", any branch of the same PC programme is considered a separate PC programme, e.g. a hospice with one home care team and one inpatient unit will be counted as two PC programmes.
Numerator	Number of specialized palliative care programmes in the country (estimate).
Denominator	Total population
Disaggregation	General population, key populations (e.g. chronic patients), age groups (15–24, 25–49, 50+ years), distribution (by province/district), ownership (public/private), type of programme (home care, inpatient palliative care units, inpatient hospices, hospital palliative care teams, mixed teams).
Unit of measure	Number of specialized palliative care programmes per 100 000 or 1 million habitants.
Method of measurement/ estimation	Total of specialized palliative care programmes/ population
Measurement frequency	Annual
Preferred data source	• national palliative care directory • district or national databases (of health facilities) available where health services registration is mandatory • key informant survey • official source at the Ministry of Health

Indicator number	**#2**
Indicator name	**Number of specialized palliative care (PC) programmes for children in the country per population**
Component	Integrated palliative care services
Associated set	Core
Definition	Specialized palliative care programmes for children refers to health care programmes whose main activity is the provision of palliative care for children. These programmes often provide care for children with complex needs or severe suffering and, therefore, require staff with specialized training. The staff generally includes at least one doctor and one nurse with training in paediatric palliative care, though in some areas, a specialized paediatric PC programme may be run only by a nurse with advanced or specialized training in paediatric palliative care. These programmes include, but are not limited to, free-standing hospices, hospices that are a part of public or private hospitals, any kind of other hospices or home care teams, hospital palliative care teams (consultation teams), palliative care units (with beds), inpatient units in hospices, etc. In this working concept of "PC programme", any branch of the same PC programme is considered a separate PC programme, e.g. a hospice with one home care team and one inpatient unit will be counted as two PC programmes.
Numerator	Number of specialized palliative care programmes for children in the country (estimate).
Denominator	Paediatric population (under 18 years old).
Disaggregation	Key populations (e.g. chronic patients), by age (<28 days, 28 days–5 years, 5–15 years, 16–18 years), distribution (by province/district), ownership (public/private), type of programme (home care, inpatient palliative care units, inpatient hospices, hospital palliative care teams, mixed teams).
Unit of measure	Number of specialized palliative care programmes for children per 100 000 or 1 million child habitants.
Method of measurement/ estimation	Total of specialized palliative care programmes/ paediatrics population.
Measurement frequency	Annual
Preferred data source	• national palliative care directory • district or national databases (of health facilities) available where health services registration is mandatory • key informant survey • official source at the Ministry of Health

Health policies

Indicator number	**#3**
Indicator name	**Existence of a current national palliative care plan, programme, policy or strategy with defined implementation framework**
Component	Health policies
Associated set	Core Strategic
Definition	There is a validated national strategic direction on palliative care, measured against these criteria: • includes a well-defined set of quality palliative care interventions • developed or updated within the last 5 years • developed through a consultative stakeholder process, inclusive of communities published in written form (either standalone or part of a broader national health strategy) • acknowledged by senior health leadership as finalized (completed any governance steps required to be validated for implementation) • a recognized palliative care directorate/department/unit/focal person to take forward the development and operationalization of the national direction on palliative care
Numerator	Which form of national palliative care plan (or programme or strategy) is/are available in your country/region?
Denominator	
Disaggregation	Type of plan or population coverage.
Unit of measure	• standalone national palliative care plan (or programme or strategy) • dedicated section on palliative care is contained within another national plan (or programme or strategy) such as national plans for cancer, noncommunicable diseases or HIV • no national palliative care plan (or programme or strategy) available in my country • do not know
Method of measurement/ estimation	Nominal (yes/no)
Measurement frequency	Every 3–5 years
Preferred data source	• key informant survey • official source at the Ministry of Health

Indicator number	**#4**
Indicator name	**Inclusion of palliative care in the list of health services provided at the primary care level in the national health system**
Component	Health policies
Associated set	Strategic
Definition	Usually regulated through national health laws, countries establish a catalogue of services that stipulates those that should be available and provided at the primary care level in the country. One of those services included in the list should be palliative care. Aimed at assessing only the inclusion of palliative care in the list of services provided at the primary care level, but not its implementation. The inclusion of the specific palliative care term in the list is compulsory in order to answer "yes" to this indicator.
Numerator	Is palliative care specifically included on the list of health services provided at the primary care level in the national health system?
Denominator	
Disaggregation	
Unit of measure	1. Yes 2. No
Method of measurement/ estimation	Nominal (yes/no)
Measurement frequency	Every 3–5 years
Preferred data source	• key informant survey • official source at the Ministry of Health

Indicator number	**#5**
Indicator name	**Existence of national coordinating authority for palliative care (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care**
Component	Health policies
Associated set	Strategic
Definition	Existence of a current designated person, desk, unit, branch or department within the Ministry of Health or equivalent government agency with responsibility for overseeing palliative care activities, development and/or growth in the country with an accompanying budget. Further criteria: • national coordinating authority(ies) accountable for coordinating, monitoring, integrating and implementing national palliative care strategies and policies • subnational/subregional operational capacity • adequate authority, budget and staff
Numerator	Are there are identifiable national authority(ies) for palliative care within the government?
Denominator	
Disaggregation	Disaggregated by the roles that the national authority(ies) undertake in relation to palliative care services and activities, that is: • coordination • monitoring and evaluation • implementation of national policy/strategy • budget holders • provide scientific or technical advice • do not know
Unit of measure	1. Yes 2. No
Method of measurement/ estimation	Nominal (checklist)
Measurement frequency	Every 3–5 years
Preferred data source	Official source at the Ministry of Health.

Use of essential medicines

Indicator number	**#6**
Indicator name	**Reported annual opioid consumption – excluding methadone – in oral morphine equivalence (OME) per capita**
Component	Use of essential medicines
Associated set	Core Strategic
Definition	These data represent the amount of opioids distributed legally in a country for medical use to health care institutions and programmes that are licensed to dispense to patients, such as hospitals, nursing homes, pharmacies, hospices and palliative care programmes.
Numerator	Opioid consumption milligram/capita/year – excluding methadone – in oral morphine equivalence (OME).
Denominator	
Disaggregation	By opioids included: morphine, fentanyl, hydromorphone, buprenorphine, oxycodone and pethidine.
Unit of measure	Milligrams per capita per year, expressed in morphine equivalence.
Method of measurement/ estimation	Data on opioid consumption are obtained from the latest available reported consumption to the International Narcotics Control Board (INCB).
Measurement frequency	Every year
Preferred data source	International Narcotics Control Board (INCB).

Indicator number	**#7**
Indicator name	**Availability of essential medicines for pain and palliative care in the country**
Component	Use of essential medicines
Associated set	Strategic
Definition	General availability for medicine is accessibility at the primary care level. The official WHO Model List of Essential Medicines for pain and palliative care (both for children and adults) is considered.
Numerator	Availability of medicines included in the official WHO Model List of Essential Medicines for pain and palliative care.
Denominator	
Disaggregation	• non-opioids and non-steroidal anti-inflammatory pain killers • strong opioids • other medicines for pain and palliative care included in the official WHO Model List of Essential Medicines (children and adults) • disaggregated by adult and paediatric formulations
Unit of measure	Yes or No (checklist)
Method of measurement/ estimation	• availability of non-opioids and non-steroidal anti-inflammatory medicines (NSAIDs) included in the official WHO Model List of Essential Medicines for pain and palliative care (children and adults) • availability of other strong opioids in the official WHO Model List of Essential Medicines for pain and palliative care (children and adults) • availability of medicines for pain and palliative care included in the official WHO Model List of Essential Medicines (children and adults), for other common symptoms in palliative care • availability of paediatric formulations • identification has to be done by medicine and dosage forms referred by the WHO Model List of Essential Medicines
Measurement frequency	Annual or biannual
Preferred data source	Ministry of health or Country expert in its national health benefits package

Indicator number	**#8**
Indicator name	**General availability of immediate-release oral morphine (liquid or tablet) at the primary care level**
Component	Use of essential medicines
Associated set	Strategic
Definition	General availability refers to immediate-release oral morphine available (always and usually) in over 50% in PHC facilities.
Numerator	Primary care-level facilities with availability (always and usually) of immediate-release oral morphine (liquid or tablet).
Denominator	Total number of primary care-level facilities
Disaggregation	Facilities type, facility managing authority (public/private), specific type of facilities presentation of immediate-release oral morphine.
Unit of measure	• always available • usually available • occasionally available • not available • not known
Method of measurement/ estimation	Ordinal (scale)
Measurement frequency	Annual or biannual
Preferred data source	• special facility surveys • routine facility information systems

Education and training

Indicator number	**#9**
Indicator name	**Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula**
Component	Education and training
Associated set	Core Strategic
Definition	Formal training in palliative care is taught to future physicians and nurses (either as compulsory or as optional). Formal training means a substantial number of hours.
Numerator	Medical and nursing schools with palliative care formal education in undergraduate curricula.
Denominator	Total medical and nursing schools.
Disaggregation	Medical schools Nursing schools
Unit of measure	% of medical and nursing schools with palliative care formal education.
Method of measurement/ estimation	•% of universities with compulsory teaching in palliative care (with or without other optional teaching) •% of universities with optional teaching in palliative care (without compulsory teaching)
Measurement frequency	Annual or biannual
Preferred data source	• key informant survey • official source at the Ministry of Health • Ministry of Higher Education

Indicator number	**#10**
Indicator name	**Specialization in palliative medicine for physicians**
Component	Education and training
Associated set	Core
Definition	Existence of an official specialization in palliative medicine for physicians, recognized by the competent authority in the country.
Numerator	Existence of an official specialization in palliative medicine, recognized by the competent authority in the country as specialty, subspecialty or special area of competence.
Denominator	
Disaggregation	If yes or in process, please indicate: • specialty • subspecialty • other denomination equivalent to subspecialty, e.g. special area of competence or other advanced training accreditation diploma (please indicate) with official and/or national recognition only exist with another type of professional training diploma, but without official and/or • national recognition (please indicate) • none of previous
Unit of measure	• yes, process established • certification in process (please indicate more information) • not yet
Method of measurement/ estimation	Nominal (checklist)
Measurement frequency	Annual or biannual
Preferred data source	• key informant survey • official source at the Ministry of Health • College of physicians or equivalent body

Research

Indicator number	**#11**
Indicator name	**Existence of congresses or scientific meetings at the national level specifically related to palliative care**
Component	Research
Associated set	Core
Definition	Research progress may be shown in a country by hosting diverse research activities such as national congresses/scientific meeting (within the country).
Numerator	Are there scientific meetings or congresses specifically dedicated to palliative care held in the country?
Denominator	
Disaggregation	
Unit of measure	• at least one national conference specifically dedicated to palliative care every 3 years • at least one non-palliative care congress or conference (cancer, HIV, chronic diseases, etc.) that regularly has a track or section on palliative care, each 1–2 years • only sporadic (non-regular) conferences or meetings related to palliative care take place • none detected
Method of measurement/ estimation	Ordinal (scale)
Measurement frequency	Annual or biannual
Preferred data source	• key informant survey • national palliative care association

Indicator number	**#12**
Indicator name	**Palliative care research on the country estimated by peer reviewed articles**
Component	Research
Associated set	Core
Definition	Number of peer reviewed papers published in any language in the past 5 years with at least one author from the country, reporting results of quantitative, qualitative or mixed-methods research on prevalence, incidence, symptoms or pain relief, including palliative care and pain (as terms). Also the prevention or relief of physical, psychological, social or spiritual suffering associated with serious illness, or systematic reviews of such studies, having the keyword or search term “palliative care” or “hospice” in PubMed, CINHAL and Embase.
Numerator	Scientific papers on palliative care in the country published in the past 5 years.
Denominator	
Disaggregation	Type of article, topic of research (relief of physical, psychological, social or spiritual suffering).
Unit of measure	Number of peer reviewed papers published in any language in the past 5 years with at least one author from the country.
Method of measurement/ estimation	Discrete (number)
Measurement frequency	Annual or biannual
Preferred data source	Scientific databases: PubMed, CINHAL, Embase

Empowerment of people and communities

Indicator number	**#13**
Indicator name	**Existence of groups dedicated to promote the rights of patients in need of palliative care, their caregivers, and disease survivors**
Component	Empowerment of people and communities
Associated set	Core Strategic
Definition	Associations or groups dedicated to representing, advocating for and promoting the rights of patients and caregivers who receive palliative care. They legally exercise the representation, participation, defence, advice and consultation of users in their scope of action. This includes associations of family members in paediatric palliative care.
Numerator	Are there any associations of palliative care patients, their caregivers or their advocates in the country?
Denominator	
Disaggregation	Type or organizations (parastatal organizations, nongovernmental organizations or social security agencies), ownership (public/private).
Unit of measure	Yes or not
Method of measurement/ estimation	Nominal (yes/no)
Measurement frequency	Every 3–5 years
Preferred data source	• key informant survey • official source at the Ministry of Health

Indicator number	**#14**
Indicator name	**Existence of national policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care**
Component	Empowerment of people and communities
Associated set	Core Strategic
Definition	To engage actively in decisions, people affected by serious or life-threatening illnesses should have, at an early stage the opportunity to: (i) receive transparent information about life-sustaining treatment and palliative care; and (ii) express in advance their values and preferences about life-sustaining treatment and the care they will receive. The process of advanced care planning process should also engage family members.
Numerator	Is there a national policy or guideline on advance care planning or advance directives? (select all that apply)
Denominator	
Disaggregation	Type or organizations (parastatal organizations, nongovernmental organizations or social security agencies), ownership (public/private).
Unit of measure	• existence of national policies or guidelines on living wills or advance care planning • existence of national policies or guidelines on surrogate decision-makers • existence of national policies on advanced directives • do not know
Method of measurement/ estimation	Nominal (checklist)
Measurement frequency	Every 3–5 years
Preferred data source	• key informant survey • official source at the Ministry of Health

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