

Brief Methodological Report

Implementing the WHO Indicators for Assessing Palliative Care Development in Three Countries: A Do-It-Yourself Approach



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Abstract

Context. Palliative care is an essential health service, with over 56.8 million people needing it yearly, particularly in low- and middle-income countries. The World Health Assembly has recognized palliative care as an ethical responsibility and called for comprehensive primary health care. The World Health Organization has published a technical report titled "Assessing the Development of Palliative Care Worldwide," as a crucial first step in addressing palliative care. The report includes 14 indicators to help decision-makers identify service provision gaps and inform health priorities, piloted by WHO's ATLANTES in Benin, Morocco, and Uruguay as part of a global assessment.

Objectives. To describe, for the three countries, the primary outcomes and lessons learned to enable replication in further countries.

Methods. A step-by-step description of the assessment project, a summary of the main results obtained through evaluations, and a description of how the selected countries effectively implemented the WHO indicators through a six-step process, including a phase of action plan design. We advocated a 'Do-it-yourself' approach.

Results. The summary data from three country reports reveals national development at a national level. A SWOT analysis involving consultants and program managers was conducted. A stakeholder guide was developed, providing trigger questions and practical recommendations for assessing development using specific indicators. Full information can be found in the specific published reports.

Conclusion. The WHO approach has proven effective in identifying health system deficiencies and disseminating information about palliative care evaluation processes. The report provides a 'Do-it-yourself' approach, encouraging self-management without expert guidance. *J Pain Symptom Manage* 2025;69:e61–e69. © 2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Palliative care, Global health, Public health, Development, Assessment

Key Message

The report assesses global palliative care using 14 WHO indicators to identify health system strengths and

weaknesses at the country level. Pilot projects in Benin, Morocco, and Uruguay and a 'Do-it-yourself' approach offer valuable insights and applicable lessons for global

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palliative care development that can be replicated in other countries.

Introduction

Palliative care (PC) aims to alleviate serious health-related suffering for all ages. Over 56.8 million people require it annually, 78% in low- and middle-income countries for adults; when combined with children, the percentage increases to 82.5%.¹ However, noncommunicable disease (NCD) patients face limited availability, with only 39% of countries reporting this.²

Ten years ago, the World Health Assembly resolution WHA 67.19 acknowledged PC as an ethical responsibility and called for comprehensive primary health care (PHC) services.³ To include PC with Universal Health Coverage (UHC), assessing the impact of interventions and identifying country gaps is crucial. The World Health Organization (WHO) has provided practical guidance on integrating PC into health systems.⁴

The 2021 technical report titled "Assessing the Development of Palliative Care Worldwide: A Set of Actionable Indicators" presents a set of PC indicators that Member States can universally apply to monitor and evaluate the provision of PC services.³ The report applies the WHO's new framework for PC development, which includes six dimensions: empowering people and communities, health policies, research, education, essential medicines, and PC-integrated healthcare services. This new framework has been conceptualized as a house of PC (Fig. 1).



Fig. 1. The WHO's new framework for Palliative care Development: The House of Palliative Care³ (with authors' permission).

The updated PC development model has established 14 indicators for countries to use based on their needs and existing data systems.³ Two subsets of indicators were developed: ten core indicators for in-country and global comparative analysis and nine strategic indicators for countries in the initial stages of PC development (Supplementary file).

Data on PC development from indicators provides crucial information for decision-makers, aiding in healthcare priorities, policy gaps, resource allocation, and strengthening activities. Measurement improves service quality, raises awareness, mobilizes resources, provides transparency, and promotes universal health coverage (UHC).⁵ Further country comparisons should be made for benchmarking purposes.

The WHO and United Nations Children's Fund Operational Framework for PHC offers 14 actionable levers to guide countries in strengthening PHC towards UHC and health-related Sustainable Development Goals.⁶ A PHC approach enhances health and well-being distribution by prioritizing people's needs and preferences from health promotion to diagnosis, treatment, rehabilitation, and PC.⁶ The proposed PC indicators can monitor progress in reducing global health inequities and promoting UHC, impacting global PHC measurement efforts nationally.

ATLANTES Global Observatory of PC-WHO Collaborating Centre (WHO-CC) supported three countries (Benin, Morocco, and Uruguay) in evaluating PC development by implementing the WHO indicator set. The goal was to guide these countries in assessing PC needs, identifying gaps in their healthcare systems, and collecting and disseminating learning on PC evaluation processes. This brief report endorses a 'Do-it-yourself' approach (DIY),⁷ drawing lessons from the country assessment projects. DIY is a movement that encourages any individual to carry out projects in a self-managed manner without the need for an expert to set the guidelines for the task to be carried out. This approach has proven to be effective, providing reassurance of its benefits. The main challenge is to engage the community through awareness campaigns, supply the required tools, and link clinical aid with community resources, all while systematically assessing the process and its long-term outcomes.⁸

Methods

The WHO Department of Integrated Health Services coordinated the assessment project (2023) with ATLANTES, WHO-CC based at the University of Navarra (Spain), and with PC focal points in Regional Offices and Country Offices. The WHO has chosen Benin from the AFRO WHO Region to pilot the indicators for the first time (Cotonou, February 2023) in agreement with the national health and education

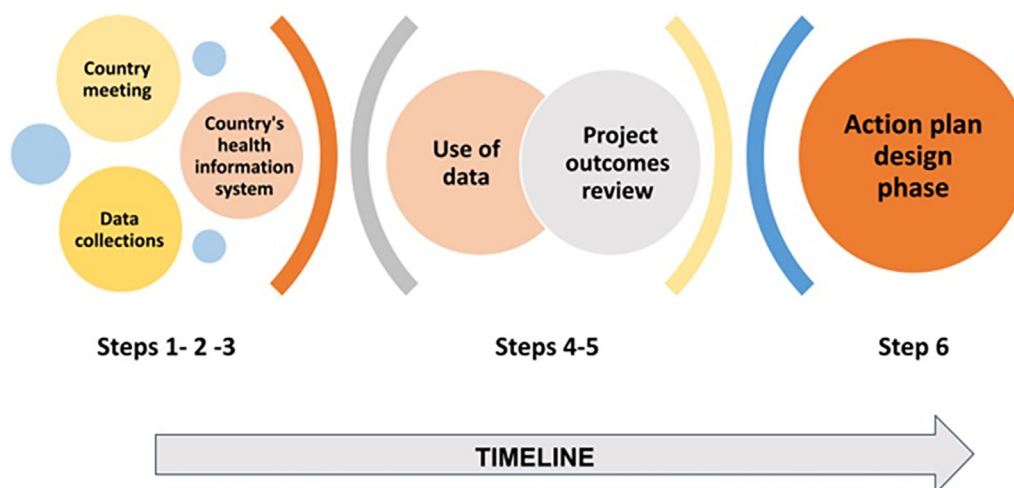


Fig. 2. Six steps of the country implementation project.

authorities, those responsible for the National PC Plan and the Benin National Association of PC. Morocco, from the WHO Eastern Mediterranean Region (EMR), was proposed secondly (Rabat, July 2023), and the third country assessed was Uruguay in Latin America (Montevideo, September 2023), from the Pan American Health Organization Region (AMRO/PAHO). These country projects were part of a more extensive global assessment in progress.

The selected countries successfully implemented the WHO PC indicators using a six-step process, including an action plan design phase (Fig. 2). The ATLANTES technical team developed additional resources, including a toolbox, scientific publications, a questionnaire, a glossary, teaching videos, and reference documents. To ensure that the outcomes meet expectations, DIYers could design the work process, use available tools, and act as evaluators.⁷

A two-day hybrid meeting was held in each participating country to adapt a project to their needs, with attendees from various sectors. The workshop aimed to identify country-relevant indicators for the project, focusing on cultural and language adaptation (conducted in French, Spanish, and English translation). Participants could vote on the relevance and feasibility of the indicators. Data collection was aligned with each country's healthcare information system (HIS), with a custom-made tool created for each country. The data collection process involved recruiting and training participants, developing country-specific tools, and analyzing data for quality control. The data was used to identify gaps in PC development in each country, aiding in strategic planning and prioritization of interventions. The study assessed data quality to identify shortcomings in integrating PC into PHC and access. Action plans were developed to address PC data system gaps, with assistance from WHO offices. While data was

not used to create a national action plan, a report was delivered for each country, highlighting PC needs and guiding strategic planning. The evaluation process took 60 days on average.

SWOT Analysis

The ATLANTES team conducted a SWOT analysis for each country to assess the experience of piloting the assessment, identifying strengths, opportunities, weaknesses, and threats. The analysis focused on internal qualities and resources that supported positive outcomes, internal elements and resources that posed challenges, external elements that could benefit or be leveraged, and external elements that could threaten the country's PC development.

Results

We present summary data from each of the three country reports illuminating PC development at the national level. We focussed on the assessment process and the DIY approach. The information in this summary is not exhaustive. Complete information can be found in the specific country reports.^{9,10}

Benin

In Benin, more than 62,000 people require PC yearly.⁹ In February 2023, we organized a two-day workshop in Cotonou City to train the participants and identify relevant and feasible indicators for the countries. The workshop was attended by 36 people from different parts of the country and with various profiles: The Ministry of Health (MoH) = 9, NGOs = 1, Universities = 3, WHO = 6, ATLANTES technical office = 5, consultants = 1, clinicians = 4, national associations = 2, and others = 5.

A comprehensive national report on implementing the PC indicators was compiled and presented. It shed

light on Benin's current state of development, identifying gaps and proposing interventions for action plans. The report underscored the strengths and weaknesses of PC implementation, mainly two indicators related to the empowerment of individuals and communities. It highlighted the presence of PC advocates and patients' rights promoters and the absence of a national policy on advance care planning (ACP). While the five-year plan for PC was validated in 2022, the need for a monitoring mechanism for access remains. The MoH coordinates PC, but no scientific publications or PC-related research groups exist. Essential medicines were used in 34% of health facilities, but there was no official specialisation in PC for doctors. Training in PC needs to be improved, with no compulsory or optional modules offered in medical or paramedical schools. Despite these challenges, the report also revealed a moderate level of PC services, with 11 specialist PC teams, and the potential to establish national specialist pediatric programmes.¹⁰

Morocco

It has been estimated that more than 163,000 Moroccans need PC yearly.¹¹ In July 2023, a two-day hybrid meeting was organised in Rabat by the WHO-CC ATLANTES with WHO-Geneva, WHO-EMR and WHO-Morocco to examine and adapt a set of indicators to cultural realities. The WHO chose Morocco and involved health, secondary education, vocational training and higher education stakeholders, and the *Association Marocaine des Soins Palliatifs*. Around 30 people from different parts of the country participated, with different profiles: MoH = 17, Universities = 4, WHO = 2, ATLANTES technical team = 3, consultant = 1, clinicians = 2, national associations = 1. A national report on the implementation of the PC indicators was drawn up, showcasing the progress made in each area and providing a summary of the level of implementation. Two indicators focused on empowering people and communities with a solid national and subnational presence in defending PC and promoting patients' rights. However, a national guideline for ACP needs to be included. Morocco has guidelines on PC for NCDs and includes PC services in its national health policies. However, there is still a need for a monitoring mechanism to access these services. Research on PC was planned annually, but there are few scientific publications. The annual consumption of opioids is 1.34 milligrams Per Capita, and only a few patients with palliative needs have access to oral morphine. Training in PC is available in 3 out of 18 medical schools, but the speciality still needs to be recognized for doctors. The provision of PC is at an established stage, with 26 specialist teams located throughout the country. Full report in press.

Uruguay

The assessment of the current PC situation in Uruguay revealed the challenges faced by over 17,000

Uruguayans annually in need of PC (2023).¹² The report was developed following the ATLANTES guidelines, established in meetings before the Montevideo workshops, during the workshops on August 31, and September 1, 2023, and through three online sessions in September/October 2023. The National CP Programme hosted the workshop, assisting in preworkshop planning, inviting participants, organizing and moderating the workshop, and providing inputs for the ATLANTES report. Sixty participants from various backgrounds attended the workshop.

The report highlighted the presence of patient and family associations, the Uruguayan Society of Medicine and PC (SUMCP), and a national policy on ACP. The National PC Plan has been in place since 2013, and a national authority coordinates PC implementation in the National PC Programme. Uruguay has published 14 scientific articles in international and Spanish-language journals, and its healthcare system ensures the availability of essential medicines for pain and palliative symptom control. The country's annual consumption of the five main opioids is higher than the global and Latin American average (20.34 mg/capita/year). Furthermore, PC training was limited, with only 2 out of 3 medical schools offering compulsory undergraduate modules and 2 out of 3 nursing faculties providing basic training. There has yet to be an official specialization in palliative medicine for doctors. The country has 79 specialized PC teams, with a coverage rate of 69.7%, according to the National PC Survey 2023. However, PC provision is limited to some geographical regions. Despite the recent PC Law 20179/2023, many areas need improvement.¹³

SWOT Analysis

ATLANTES conducted a SWOT analysis of the country project experiences involving consultants and national PC programme managers based on subjective reflections identified by the final report's responsible parties.

1. Benin has a national PC plan supported by political and healthcare authorities, including the MoH. The government's commitment is evident through a legislative framework and the expertise of ATLANTES. However, no budget covers the resources needed for the plan's implementation. Civil society components, such as the *Association de Lutte contre le cancer* and the *Association de patient atteint de VIH*, have not been included. More data on the number of patients needing PC in rural areas is also needed. Benin is the first country in the WHO-AFRO to experiment with indicator-based evaluation. Still, threats include a potential drop in motivation, resistance to change, and the potential for increased demand in sub-Saharan African countries.

2. Morocco has made PC an essential component of its health system, with the MoH and Social Protection (MHSP) integrating relevant actions and clinical standards. However, PC services are not included in the basic package of health services or health insurance schemes, and no funds are dedicated to PC in the national health budget. NGOs are addressing these shortcomings by providing PC to patients in various regions. Morocco's oncological PC offer is the most advanced, with a national program and significant care offer. To meet increasing demand, a comprehensive national strategy for PC is needed, integrating all morbidities and ensuring territorial equity. The plan should focus on increasing care provision, training specialized professionals, and providing necessary equipment. The strategy should operate in fixed, ambulatory, and mobile modes, integrating different health system sectors and the associative network.
3. Uruguay revealed strengths in developing PC, including high participation, experience creation, motivation, discussion, coordination capabilities, and national articulation. Opportunities include updating data collection in the National PC Survey, integrating speciality into healthcare, education, and management, and producing a report supported by WHO/PAHO. The analysis empowered the National PC Program, created reflection spaces, and allowed new planning instruments to standardize care. Threats included external actors guiding workshops. The analysis provides valuable insights into PC development's current and future potential in Uruguay.

Step-by-Step Guide for Stakeholders at the Country Level

The Country Implementation Project Scheme (Fig. 2) has been followed to propose a practical guide for countries to assess their PC development, with a step-by-step guide for stakeholders containing trigger questions and practical recommendations for evaluating development using specific indicators (Table 1).

Discussion

The report proposes a DIY approach to assess national PC development using the new WHO Conceptual Model and 14 indicators, encouraging stakeholders to evaluate and report on PC progress.³ The WHO assessment model was first implemented in Africa and Latin America, highlighting the potential for similar approaches in other regions with diverse cultural and socio-economic backgrounds.

The ATLANTES technical team collaborated with stakeholders to test development indicators and apply

an extended assessment method at regional and global levels. This experience was not an external audit but a practical recommendation for those wishing to assess without external agents. The evaluation process took two months, and regular reassessments ensure up-to-date information and digitalization of results. While international benchmarking is beyond the scope of this report, it presents an exciting opportunity for exploration and applied research.

PC professionals were crucial in the implementation and preparatory phases, facilitating contacts and validating informants. Community participation through civil society organizations and professionals was essential, with hybrid workshops demonstrating inclusivity and trust building. Despite challenges in data collection, country participation and initiatives led to the development of Steps 5-6, which involve detailed information search, evaluation, and future indicator integration.

The ATLANTES technical team was able to adapt and cope with different situations. However, they identified areas for improvement, such as uncertainty about new methods, inexperience with multilateral meetings, and workshop fatigue due to multiple languages, time management and travel. External factors such as the WHO and the MoH provided support, while a local consultant strengthened the team.

The report emphasizes the importance of PC evaluation and statements like the World Health Assembly, Lancet Commission,¹⁴ and Astana Declaration¹⁵ to encourage governments to integrate PC into their health plans. It highlights the relevance and feasibility of using WHO indicators in three-country projects. The DIY approach focuses on collaboration, learning, and sharing, building relationships and fostering community.¹⁶ DIY projects can include Knowledge Exchange Workshops, allowing individuals to teach others about specific skills or topics and helping them understand scientific concepts and the process of scientific inquiry. These activities can teach practical skills or academic issues. Policymakers and stakeholders must contextualize this approach into the broader initiative to measure PC development worldwide.

The report on the DIY approach to public health assessment has limitations, including subjective SWOT analysis results and the need for cultural adaptation. However, it demonstrates the feasibility of the country's projects and three official WHO reports. This reassurance should instil confidence in health professionals, policymakers, and researchers involved in public health assessments and interventions.

Ethics approval and consent to participate

This study was conducted following the principles of the Declaration of Helsinki. It was approved by the

Table 1
Step-by-Step Guide for Stakeholders at the Country Level

Step	Trigger Questions	Recommendations
1	How should a motivated country organise a country meeting to evaluate PC national development?	• Recognize the need for quality PC based on WHO recommendations and assessments. • Involve all stakeholders, including government agencies (especially those under the MoH and Education), NGOs, PC agents from nonmedical backgrounds and civil society. • PC professionals and associations can contribute to understanding the field and specific needs. • Consider all opinions to raise awareness and engagement. • Present WHO's conceptual model for developing and evaluating PC. • Emphasise the importance of all development dimensions and practical indicators. • Discuss each indicator to meet national and regional requirements.
2	How do stakeholders know about a country's HIS?	• Understanding the sources of information is crucial. • It's essential to know who is responsible for the areas. • It's crucial to be aware of existing indicators of PC development or monitoring. • Data sources may come from MoH, education, NGOs, scientific publications, and international organisations. • Involving those responsible for these sources from the beginning is essential. For instance, the Department of Statistics in the MoH provides access to existing and official quality information.
3	How do key persons collect the data?	• It utilises the WHO and ATLANTES questionnaire, divided into six dimensions of the Conceptual Model of Development. • Includes 14 indicators: 10 core indicators for comparative evaluation and 9 strategic indicators for initial PC development. • Key evaluation personnel should have experience in public health, including PC or cancer-related programs. • Five years of survey and data analysis experience is desirable.
4	How do stakeholders use the data?	• Indicators inform decision-makers about gaps and challenges in PC provision. • Refined indicators help identify barriers to strengthening PC and optimise resources. • Target audience should include policy-makers and stakeholders in PC programmes. • Indicators establish baselines and targets, monitoring progress towards reducing global health inequities and promoting UHC. • Common indicators facilitate benchmarking and identify successful PC programs. • Good quality, harmonised data provides a clear picture of global needs and challenges in PC, aiding in its integration into UHC.
5	How do stakeholders review the project outcomes?	• All stakeholders should review results, information quality, and validated sources. • Aim for consensus on the assessment process. • Consider setting up a new discussion group for result validation. • Prioritise stakeholder commitment to validate results in the action plan phase.
6	How do governments design the action plan phase?	• Each country has its own legislation and action plans designed for specific periods and is responsible for them. • Governments could develop short-, medium-, and long-term strategies for developing PCs based on the results of systematic evaluations using validated and well-defined methodologies. • All programmes or strategies should include evaluation from the very beginning.

WHO = World Health Organisation; PC = palliative care; MoH = Ministry of Health; HIS = Health System Information; UHC = Universal Health Coverage; NGOs = Nongovernmental Associations.

ethics committee of the University of Navarre clinic, Spain, with code 2023.055 on 13.04.2023 under the title Protocol: Assessing Africa and Global Palliative Care Development V 1.1 April 17, 2023_20230417. Informed consent was not required since the study did not directly involve human participants and did not use tissue samples.

Author contributions

Conceptualisation: Vilma Tripodoro, Anna Ray, Marie-Charlotte Bouësseau, and Carlos Centeno; Methodology: Vilma Tripodoro, Carlos Centeno, Eduardo Garralda, Álvaro Montero, Fernanda Bastos; Formal analysis and investigation: Vilma Tripodoro, Eduardo Garralda, Álvaro Montero, Fernanda Bastos, Juan José Pons, Carlos Centeno; Writing - original draft preparation: Vilma Tripodoro; Writing -review and editing: Vilma Tripodoro, Marie Charlotte Bouësseau, Eduardo Garralda, Fernanda Bastos, Álvaro Montero, and Cristina Béjar; Funding acquisition: Carlos Centeno; Supervision: Vilma Tripodoro and Carlos Centeno. All authors reviewed the manuscript and approved the final version.

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Supplementary Table 1
Core and Strategic Indicators for Monitoring Palliative Care Development³

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

Core: for in-country and global comparative analysis.

Strategic: for countries in the initial stages of PC development.

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