

# QUALITY HEALTH SERVICES AND PALLIATIVE CARE

Practical approaches and  
resources to support policy,  
strategy and practice



Quality health services and palliative care: practical approaches and resources to support policy, strategy and practice

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# ACRONYMS

PHC primary health care  
UHC universal health coverage  
WHO World Health Organization

# KEY MESSAGES

Delivery of quality palliative care is a moral imperative and a human right. Quality health services and palliative care are inextricably linked and both vital for achievement of universal health coverage (UHC).

## What do we mean by quality?

Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with evidence-based professional knowledge. Quality health services should be effective, safe, people-centred, timely, equitable, integrated and efficient.

## What is palliative care?

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness or serious health-related suffering. It includes, but is not limited to, end-of-life care. It is not the “last resort”, but should be integrated early in the care of people affected by a life-threatening condition.

## Summary of key actions for quality palliative care



### National level:

- Incorporate quality considerations into all levels of palliative care planning, including policy, strategy and service delivery plans with attention to resources, implementation and monitoring.
- Align national palliative care planning with a clearly articulated national strategic direction on quality.
- Integrate palliative care across the health system, embedding it in a primary health care (PHC) approach, across relevant health programmes and all levels of the health system.
- Develop robust measurement systems, aligned across the health system, to drive improvement in the quality of palliative care; use this measurement to drive further action, including advocacy, resource mobilization and service planning.
- Utilize existing quality assurance mechanisms such as licensing, registration and quality standards to assure quality palliative care services. Account for special considerations in palliative care such as multiple providers, opioids and task shifting.



### District level:

- Commit to quality palliative care at the district level, acting as a strong linkage point between national plans and operational activity at the point of care.
- Use data at the district level to improve the quality of palliative care with a particular focus on understanding and addressing health inequalities at the district level.
- Engage communities to improve the quality of palliative care, creating models of service delivery that are truly people-centred and addressing misconceptions about palliative care.



### Point-of-care level:

- Maintain and improve quality palliative care, including care provided at home, through adaption and implementation of evidence-based quality interventions at the point of care.
- Collect and use data at the point of care to drive improvement efforts.
- Integrate quality improvement methods into usual practice at the point of care, focusing on provision of compassionate care to those facing serious health-related suffering.



# BACKGROUND

Palliative care improves the lives of patients and their families who face the challenges associated with life-threatening illness and serious health-related suffering, which includes but is not limited to, end-of-life care. Each year, it is estimated over 56.8 million people, including 25.7 million in the last year of life, are in need of palliative care, of whom 78% live in low- and middle-income countries (1). Worldwide, only 12% of palliative care need is being met and the global need will continue to grow as a result of ageing populations and the rising burden of noncommunicable disease (1). By 2060, the need for palliative care at the end of life is expected to nearly double(1).

In response to the growing need for palliative care worldwide, in 2014, the World Health Assembly (WHA) adopted resolution 67.19, which requires Member States to provide palliative care across multiple disease types and all age groups, including children (2). This global commitment also insists on the urgent need for equitable palliative care services to be provided by Member States through comprehensive primary health care (PHC) services (2). The Astana Declaration on Primary Health Care, adopted in 2018, included a call to strengthen palliative care within PHC by meeting peoples' health care needs across the life course from prevention, promotion, curative care, rehabilitation to palliation. This is to be achieved through integrated health services with a focus on primary care and essential public health functions, multisectoral policy and action, and empowered people and communities. The political declaration on universal health coverage (UHC) adopted during the United Nations General Assembly in September 2019 (3) reiterated the need to include palliative care in UHC, as well as the need for continued attention to the quality of all health services.

Quality and palliative care are both linked and embedded at the heart of the global ambition to achieve UHC. As countries commit to achieving UHC, it is imperative to ensure that the design and delivery of palliative care services focus attention on quality of care. These considerations need to address all domains of quality health services: effective; safe; people-centred; timely; equitable; integrated; and efficient care. To ensure quality 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. Providing compassionate, dignified and person-centred palliative care is a moral imperative and an "ethical responsibility of health systems" (2). Progress towards UHC is at risk unless urgent action is taken to increase the provision of quality palliative care to relieve serious health-related suffering and guarantee dignity during the end of life for all people, irrespective of income or social status, and including marginalized groups and those living in fragile, conflict-affected and vulnerable settings.

## **Objective**

This document provides a practical resource to support implementation of sustainable improvements in the quality of palliative care through:

- describing approaches to quality policy, strategy and planning for palliative care programmes and services;
- presenting learning on quality of care arising from palliative care programmes in low- and middle-income countries;
- highlighting essential World Health Organization (WHO) resources available that further support the development of quality palliative care services; and
- presenting considerations on measurement of quality palliative care services at all levels of the health system.

## **Audience**

The audience for this document is a general one that includes policy-makers, palliative care service planners, managers, practitioners and health care providers at all levels, particularly in low- and middle-income countries, including those working in fragile, conflict-affected and vulnerable settings.

## **Scope**

Despite increasing attention globally to quality of care, there remains a significant need for action on quality across the whole spectrum of services under UHC, particularly health promotion and palliation. Likewise, there remains a significant focus within the palliative care community on access with less emphasis specifically on quality of care, despite palliative care being a world leader in terms of the provision of person-centred compassionate care. Therefore, this document seeks to bring together these two communities, drawing on existing sources of knowledge and guidance and synthesizing this for a quality palliative care audience. It seeks to highlight a range of important topics relating to quality palliative care, though it does not explore each of these topics in great depth. The most recent and relevant WHO resources were selected for synthesis in this document however the selection of resources was not intended to be exhaustive. As such, this document is expected to be the first in a series of publications on quality palliative care that warrants greater exploration, in-depth research and learning gathered from country implementation.

The illustrative actions presented in this document do not constitute normative guidance; instead they are adapted from recognized existing research and guidance on these topics. It is expected that countries will select from the actions presented here those that are most pertinent to their settings, based on an assessment of their needs regarding quality palliative care and the capacity of their health system and governance models.





### **Cross-cutting actions**

The layout of this document provides illustrative actions on quality palliative care separated by the national, district and point-of-care level. However, some actions cut across all levels of the health system such as those on measurement and community engagement. For each context, the role of each level in these cross-cutting elements must be clearly defined. Action must be carefully aligned from the national level through to the point of care, to ensure a coordinated approach to the development of quality palliative care, preventing duplication and increasing efficient use of available resources. In particular, district health teams have a vital coordination and linkage function to play in these cross-cutting elements.



# WHO TECHNICAL PRODUCTS ON DELIVERING HIGH-QUALITY PALLIATIVE CARE SERVICES

This document synthesizes critical points from multiple key palliative care and quality resources and describes a consolidated set of actions that can advance the delivery of quality palliative care. These technical products described here provide useful overviews on the topics of quality, palliative care, or both. They are essential starting points for further reading and contain within them a wealth of links and references to other literature or resources on the topic.

## **Planning and implementing quality palliative care services**

The WHO *Quality health services: a planning guide (4)* is a crucial reference document for those working to enhance quality health services at a national, district or facility level. The guide provides additional direction on the key actions required to improve the quality of health services for the entire population. It highlights the need for a health systems approach to enhance quality of care, with a common understanding on the activities needed by all stakeholders. A summary of the quality planning guide at a glance is shown in Annex.

This guide can be used alongside the WHO *Planning and implementing palliative care service: a guide for programme managers*, which is a practical manual on how to plan and implement palliative care services, integrated into existing health care services, at the national or subnational level (5).

## Quality palliative care in fragile, conflict-affected and vulnerable settings

It is an ethical and medical imperative that quality palliative care is provided to all populations, including populations living within fragile, conflict-affected and vulnerable settings. Two key WHO resources explore context-specific approaches that can be implemented to start to address quality of palliative care in these complex settings:

- *Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises: a WHO guide (6)*

This guide provides practical guidance on integrating palliative care and symptom relief into health care systems. Other manuals included in this series of WHO publications on palliative care look at the integration of palliative care into paediatric (7) and PHC services (8).

- *Quality of care in fragile, conflict-affected and vulnerable settings: taking action (9)*

This publication provides a starting point for multi-actor efforts and actions to address quality of care in the most challenging settings. This includes practical approaches to action planning and implementation of a contextualized set of quality interventions. The accompanying *Quality of care in fragile, conflict-affected and vulnerable settings: tools and resources compendium (10)* presents a curated, pragmatic collection of tools and resources to support the implementation of interventions to improve the quality of care in such contexts.

# EXPLORING DEFINITIONS OF QUALITY PALLIATIVE CARE

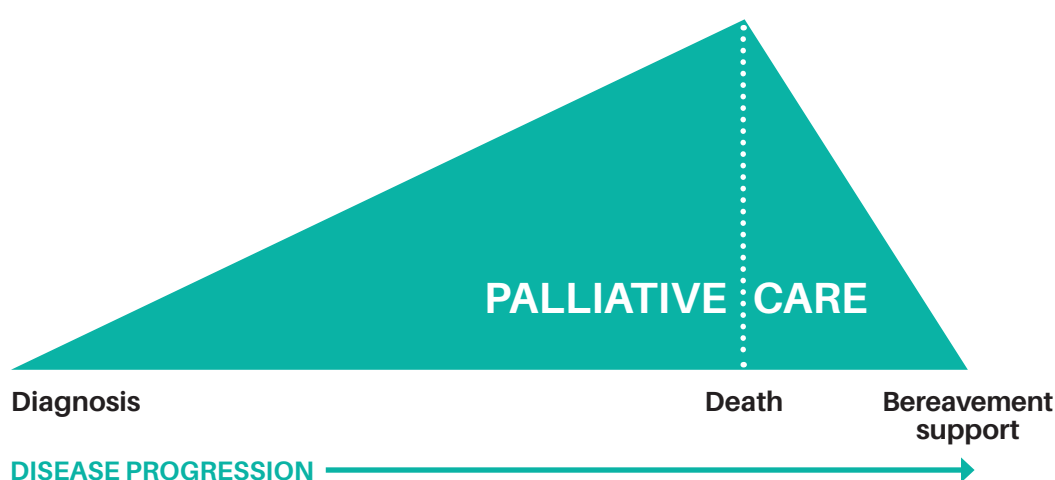
## What is palliative care?

WHO defines palliative care as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness or serious health-related suffering. Palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (11).

To further clarify the comprehensive nature of palliative care, the *Global atlas for palliative care at the end of life* provides the following additional explanations (12):

- palliative care is needed in chronic as well as life-threatening conditions;
- there is no time or prognostic limit on the delivery of palliative care;
- there is a need for palliative care at all levels of care (primary, secondary and tertiary); and
- palliative care is not limited to any single care setting.

**Figure 1. When is palliative care needed for those with life-threatening illness?**



Source: WHO (13).

As Figure 1 shows, palliative care is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life and provides accompaniment for the patient and family throughout the course of illness. After the patient's death, it also supports bereaved family members.

## What do we mean by quality health services?

There is growing acknowledgement that quality health services across the world should be (14):

- **effective:** providing evidence-based health care services to those who need them;
- **safe:** avoiding harm to people for whom the care is intended; and
- **people-centred:** providing care that responds to individual preferences, needs and values.

In addition, to realize the benefits of quality health care, health services must be:

- **timely:** reducing waiting times and sometimes harmful delays for both those who receive and those who give care;
- **equitable:** providing care that does not vary in quality on account of age, sex, gender, race, ethnicity, sexual orientation, geographic location, religion, socioeconomic status, linguistic or political affiliation;
- **integrated:** providing care that is coordinated across levels and providers, and makes available the full range of health services throughout the life course; and
- **efficient:** maximizing the benefit of available resources and avoiding waste.



## Exploring quality palliative care: a patient's perspective:

### EFFECTIVE



I'm often breathless, but my doctor has prescribed me morphine and that really helps to settle my breathing.



### SAFE



My family and I have been taught how to measure out the right dose of morphine I need to take. We've been taught how much extra medicine I can take safely when my pain gets bad and when we need to talk to a nurse about increasing my dose.

### PERSON CENTRED



I feel listened to. A doctor explained my diagnosis and gave me a chance to ask questions compassionately. I know now I have a say in my own care. I want to spend the life I have left at home with my family, not in hospital. I know my wishes will be respected.



### TIMELY

I got a call from a palliative care team the same day I received my diagnosis. She explained to me that even while I am having my chemotherapy, managing my pain would be a priority of treatment.

### EQUITABLE



I've been able to access the care I need even though I have limited finances. I find it comforting to know that my family will not be left in significant debt because of my illness.



### INTEGRATED



I don't always have to attend the hospital that diagnosed me for my appointments because my community clinic provides most of the care I need. I am grateful because care is close to my home and can draw on hospital expertise as required.



### EFFICIENT



I feel reassured that as my family and I learn more about self-care, the nurses that support me can have more time to provide palliative care for others like me.



### FAMILY PERSPECTIVE



It's challenging caring for my wife as she becomes more unwell, but it's made easier by the fact we have been shown how to administer all her treatment and we understand her condition. I feel empowered to help her with her pain relief when she's really suffering. The doctors and nurses are working together so we don't have to attend so many appointments, which means I can keep working to support the family. I am prepared for what may come next and we have started to settle her affairs.

## Exploring quality palliative care: key questions for policy-makers and programme managers

Figure 2. WHO palliative care development conceptual model










Source: (15)

The WHO palliative care development conceptual model shown in Figure 2 can assist policy-makers and programme managers consider how to strengthen and integrate palliative care throughout their health system, including social and long-term care. Like previous iterations, this model highlights the need for appropriate policies, essential medicines that are affordable and accessible, as well as education and programmes for health workers. It is imperative these activities are funded and implemented within the context of the culture, disease demographics, socioeconomics and the health care system of the country (16). Research in palliative care and the importance of empowering people and communities were added to the model in 2021, both as foundational elements to support all other action on palliative care (15). In addition, in the development of palliative care, it is essential that policy-makers and programme managers carefully consider all seven domains of quality care. The questions presented in Table 1 can be used to stimulate closer examination of palliative care services according to all domains of quality to inform policy and action at the point of care.



**Table 1. How is quality being considered in the provision of palliative care?**

<p><b>EFFECTIVE</b></p> 	<ul style="list-style-type: none"> <li>• In what ways is the health care system facilitating access to evidence-based palliative care through effective legislation, research, licencing of medical staff, procurement and medicine supply chains?</li> <li>• What quality interventions can be considered to improve the effectiveness of palliative care delivery at the point of care (such as clinical guidelines, training and supervision, and standards)?</li> </ul>
<p><b>SAFE</b></p> 	<ul style="list-style-type: none"> <li>• How do we ensure that palliative care policy and legislation enables essential medicines, such as morphine and other opioid analgesics, to be procured, stored, prescribed and administered safely, while not creating barriers to access for those with genuine medical need?</li> <li>• What is known about the key patient safety issues for palliative care patients within various settings and contexts? How are we addressing common patient safety issues, such as pressure sores and medication errors (17, 18)?</li> </ul>
<p><b>PERSON-CENTRED</b></p> 	<ul style="list-style-type: none"> <li>• In what ways does our current policy and legislative environment impact the ability of practitioners and patients to construct robust advance care plans to ensure patients receive care that is consistent with their values and preferences (19)?</li> <li>• In the communities we serve, where would most patients like to receive care and how can we adapt our service provision to meet patient preferences and the need for compassionate care?</li> </ul>
<p><b>TIMELY</b></p> 	<ul style="list-style-type: none"> <li>• What are the rate-limiting steps in the health system that prevent timely diagnosis and treatment of chronic and life-threatening conditions? How can these be addressed?</li> <li>• How do we ensure that for those with life-limiting illnesses, palliative care and symptom control is incorporated into care from the time of diagnosis across the health system?</li> </ul>
<p><b>EQUITABLE</b></p> 	<ul style="list-style-type: none"> <li>• Is palliative care viewed as a human right in policy and legislation? How do we ensure individuals and communities receive the health services they need without suffering financial hardship?</li> <li>• Which population, disease or age groups experience unequal access and treatment and satisfaction within our palliative care services and how can this be rectified?</li> </ul>
<p><b>INTEGRATED</b></p> 	<ul style="list-style-type: none"> <li>• How do we ensure that palliative care is integrated into all levels of the health care system, including long-term care, with an emphasis on PHC?</li> <li>• How can we strengthen referral and information sharing between different levels of the health system and types of health provider to ensure that patients experience integrated palliative care?</li> </ul>
<p><b>EFFICIENT</b></p> 	<ul style="list-style-type: none"> <li>• What mechanisms are in place to ensure simple, cost-effective palliative care interventions which provide wide-reaching benefits to the community are prioritized?</li> <li>• How do we bring together all palliative care providers, both government and nongovernmental, to maximize the use of available resources for service users?</li> </ul>



### Spotlight on compassion and quality palliative care

Compassion is described in many ways. One description highlights five key elements: recognizing suffering; understanding the universality of human suffering; feeling for the person suffering; tolerating uncomfortable feelings; and motivation to act/acting to alleviate suffering (20). Simply summarized, compassion may be considered as empathy translated into action.

Quality palliative care is the embodiment of compassion in health care. It is rooted in the recognition of our common suffering in illness and dying (21) where the compassionate response is to seek to prevent and relieve suffering of all forms and uphold dignity. Compassion is entwined and integrated into the delivery of palliative services, where practitioners are encouraged to spend time listening to patients to understand their physical, psychological, social and spiritual suffering. Action is then taken to respond holistically to their needs, seeking to ease suffering wherever possible, be it the provision of analgesia or the provision of blankets or food.

There is growing evidence that compassion has vast benefits for patients and staff across health services (22). Compassion can lead to quality services through patient and staff satisfaction, shared learning, mutual respect, accountability, transparent communication and effective patient care. Compassion is essential for quality health services and the drive towards UHC. Compassion contributes to all seven domains of quality health services, especially the domains of people centredness, safety and effectiveness. Compassion should sit at the heart of health service reform to deliver high-quality health services.

Those planning and delivering palliative care services may wish to work with stakeholders to consider how to promote, harness and monitor compassion within palliative care services. Furthermore, much can be learned from palliative care, which provides a robust example of how compassion can be integrated more broadly into health services and individual clinical practice.





# NATIONAL LEVEL



## ACTIONS FOR QUALITY PALLIATIVE CARE

This section highlights actions that can be taken at a national level to improve quality palliative care. The precise roles and actors responsible for national-level activities vary according to country context; however, in general, this includes Ministry of Health teams, the senior health system and political leaders, relevant steering committees or technical working groups and international partner organizations (technical and donor agencies). As quality and palliative care are both broad and cross-cutting areas, it is vital to avoid fragmentation and verticalization of efforts to improve quality palliative care. At a national level, this is likely to mean engagement and partnership work across a wide range of disease programmes and departments, including (but not limited to) quality, patient safety, PHC, COVID-19, cancer, noncommunicable diseases, healthy ageing, HIV and tuberculosis. Drawing on existing normative documents, illustrative actions are proposed here for policy-makers to consider, but each action will require contextualization. More detailed national actions to enhance quality can be found in the WHO quality planning guide (4).

### **ACTION:**

#### **Incorporate quality into palliative care planning**

National planning activities for palliative care help to set national direction, delineate priorities, define resources and coordinate action. While having a validated national direction on palliative care is important, it is not necessary for this to be a standalone plan. Reflecting the cross-cutting nature of palliative care activities, national plans may well be integrated with other policy or planning processes. Whatever form the plan takes, it is important that it is reflected in and aligns with the national health strategic plan; this will require focused engagement with broader national health planning processes to ensure the voices of palliative care stakeholders are incorporated. To address the quality of palliative care services, it will be important to incorporate quality concepts into all levels of palliative care planning: the national palliative care policy; strategic plan; strategic information framework; operational and service delivery plans across different levels.

Whether standalone or integrated meaningfully within other policies or plans, validated national direction on palliative care should: (i) include a defined set of quality palliative care interventions; (ii) consider the need for action across quality

planning, assurance and improvement; (iii) make strategic linkages with existing quality initiatives and interventions in the broader health system; (iv) be developed through an inclusive process involving key stakeholders, including communities; (v) be contemporary (e.g. developed within the last five years); (vi) have oversight by a recognized palliative care governance structure such as a directorate, department or focal point; and (vii) be validated by senior health system leadership.

### Other important planning actions at a national level:

- Use qualitative and quantitative data to understand unmet quality palliative care needs. Use the assessment of health needs to inform priorities and action planning.
- Allocate funds for palliative care within the national health budget.
- Define and include palliative care services in the health benefits package for UHC. This should include integration of palliative care into the package of health services provided at a primary care level.
- Workforce planning for palliative care to ensure equitable delivery of quality palliative care services by health care workers adequately educated and trained to meet palliative care needs. Consideration of how task shifting, primary care workforce and communities can be harnessed to deliver care.

## **ACTION:**

### **Support national palliative care planning by alignment with a clearly articulated national direction on quality**

A national quality policy and strategy represents an organized effort by a country to promote and plan for improving the quality of care across the health system. It can support leadership and ownership of quality palliative care efforts by national health authorities, ensuring integration with both broader national health planning and other disease- or population- specific programmes.

The WHO *Handbook for national quality policy and strategy: a practical approach for developing policy and strategy to improve quality of care* (23) outlines a non-prescriptive approach to developing policies and strategies to support quality health programmes and services. The handbook focusses on eight interdependent elements that can help countries set their national direction on quality of care (Figure 3). The WHO *Quality of care in fragile, conflict-affected and vulnerable settings: taking action* (9) document further explores a practical approach to quality action planning in the most challenging settings. Palliative care policy-makers can make valuable contributions to the development of national quality policy and strategy, for example, through sharing lessons learned on delivering person-centred and compassionate care. Furthermore, where a national strategic direction on quality exists, it is important for palliative care actors to support it, align with it and contribute to its implementation through applying and making use of the quality interventions it includes.

**Figure 3. Eight essential elements of national quality policy and strategy**



Source: WHO 2018 (23).



**Learning from Panama: national actions taken on quality palliative care**

Panama is making radical improvements to the way it delivers palliative care, where results are tangible and widespread (24). According to the *Global atlas of palliative care*, over the past five years Panama has progressed from isolated palliative care provision to generalized palliative care provision (1, 12). It has achieved this through a strong national focus on palliative care.

In 2011, Panama was the first country in Latin America to launch a national palliative care policy and strategy (25), which was one of the government’s top priorities (24). The concurrent formation of the National Programme of Palliative Care has led to amendments in the Controlled Substances Act to include opioid analgesics and other essential palliative care medicines in Panama’s list of medicine purchases (26). Other supportive national legislation for the delivery of quality palliative care includes Panama’s 2003 legislation on patients’ rights, which includes provisions for advance directives (25), essential for person-centred advanced care planning.

The National Programme of Palliative Care has modelled a system of sustainable palliative care delivery that is integrated into primary care, deliberately making use of existing health system structures and integration with the country’s broader offer of UHC free of charge (1). To support this integrated approach, palliative care is also embedded within the national cancer and primary care strategies (27). An annual evaluation of the programme, from local to national levels, identified opportunities for improving the quality of the care delivered and evaluation data informs ongoing policy-making (1,24).

**ACTION:**

**Take an integrated approach to palliative care across the health system**

Figure 4. Integrated approach to palliative care

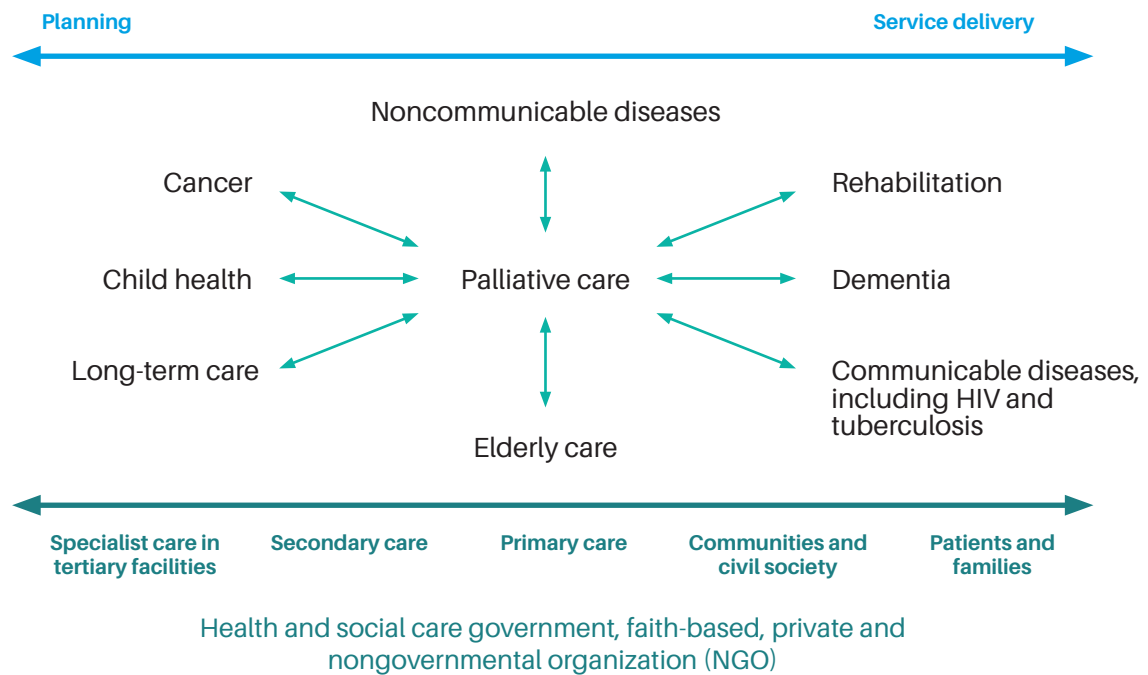


Figure 5: PHC components (30)



The delivery of integrated palliative care services is embedded in a PHC approach, which is the most efficient method to achieve UHC. Like palliative care, PHC addresses the broader determinants of health and focuses on the comprehensive and interrelated aspects of physical, mental, and social health and well-being (28). PHC provides whole-person care throughout the lifespan, including quality palliative care, as close as feasible to people’s everyday environment.

The COVID-19 pandemic has further highlighted the need for palliative care across the health system from intensive care units to care homes. The high numbers of COVID-19 deaths and those suffering with distressing symptoms such as breathlessness, have been overwhelming across many health systems, far beyond the capacities for specialist palliative care teams where they exist. This has highlighted the urgent need for integration of palliative care into every day practice, including basic training and access to essential palliative medicines.



With appropriate planning, the majority of palliative care need can be met through non-specialist services at the primary care level or through the patient's existing secondary care team. Some patients may occasionally require assistance from a palliative care specialist team, while only a small number with complex needs will require transfer of care to specialist palliative care services such as a hospice. For people to get the palliative care they need, when they need it, palliative care needs to be integrated throughout planning and service delivery processes as shown in Figure 4, including:

- coordination of policy and strategy within the national health plan and alignment across relevant health programmes, including social care;
- convergence of regulatory frameworks, particularly relating to palliative care medicines;
- integrated approach to the funding and allocation of resources;
- clear coordinating structures and governance mechanisms for palliative care across multiple providers and levels of care;
- inclusion of palliative care monitoring and evaluation into information systems;
- coordination of patient care, including care pathways, referral mechanisms and guidelines for specialist and non-specialist services;
- education, training and supervision of all health care workers in palliative care, with additional training for those providing specialist care;
- mainstreaming of palliative care research, including research into models of care for the delivery of integrated palliative care services; and
- engaging individuals, families and communities as recipients and providers of palliative care.



### **Rehabilitation as an essential component of integrated palliative care**

Palliative care requires a broad multidisciplinary approach that includes rehabilitation, defined as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment” (29). Suffering in life-threatening illness often relates to a decline in function and the related loss of usual roles and routines, independence, choice and sense of dignity. Rehabilitation is recognized as an essential health service, and when integrated into palliative care, it can slow decline and may reverse previous decline in physical and cognitive functioning. Integrated palliative and rehabilitative services represent a good investment, since improving a person's function rehabilitation can cut ongoing care costs and may prevent avoidable hospital admissions, length of stay and complication risk.



## **CROSS-CUTTING ACTION:**

### **Develop robust measurement systems to drive improvement in palliative care**

**Principles applicable to all levels of the health system**

Measurement is a vital component to improving the quality of palliative care services and the principles presented here are applicable to actors across all levels. When used well, measurement activities arm planners and implementers with the knowledge and tools needed to make informed action-oriented decisions. The role of national actors in palliative care measurement includes setting a coherent direction on measurement, streamlining data requirements and using data to inform policy, strategic direction and resource allocation. At the district and point-of-care levels, there are key roles in collecting and synthesizing data, as well as utilizing data within palliative care improvement efforts.



#### **Why is measurement important?**

- highlights for decision-makers gaps and challenges in palliative care provision;
- informs ongoing health priorities;
- informs resource and budget allocation decisions;
- feeds into continuous quality improvement activities to strengthen palliative care by identifying outliers and informing action planning;
- functions and serves as an advocacy tool to mobilize additional resources for palliative care; and
- provides transparency and accountability to the public and funders on performance and resource allocation.

#### **Aligning measurement efforts across the health system**

The WHO and United Nations Children’s Fund *Operational framework for primary health care: transforming vision into action* provides a series of 14 “levers” for action that can guide country efforts to strengthen PHC towards the achievement of UHC and the health-related Sustainable Development Goals (SDGs) (30). Accompanying the PHC operational framework is the WHO PHC measurement for improvement *Monitoring framework and indicators (WHO forthcoming publication)* which seeks to align work in monitoring UHC and the SDGs and create a comprehensive, coherent approach to measurement, minimizing country-level reporting burden and reducing duplication. Palliative care programmes, as a central component of PHC and UHC, must seek to align measurement efforts with existing endeavours and future reforms aimed at strengthening PHC monitoring.

To create strong alignment in measurement efforts, palliative care policy-makers, planners, programme managers and practitioners need to be engaged in decisions and implementation of national health system measurement efforts. It will be important to ensure that selected indicators within national frameworks include sufficient palliative care considerations (for example, within their metadata and/or disaggregation) to improve their utility in palliative care decision-making and improvement activities. For example, relevant indicators should be able to inform action on palliative care facilities, workforce, strategies and essential medicines.

Requirements for reporting on quality palliative care need to be agreed and coordinated across all levels. Public reporting of quality results can improve accountability and transparency and help drive quality improvement. In some settings, it may be appropriate to report overall quality results, in others more granular detail from districts or individual providers should be reported.

### Selecting national indicators for monitoring palliative care development

To complement the PHC monitoring framework, WHO has released a report on *Assessing the development of palliative care worldwide: a set of actionable indicators (15)*, which presents a refined set of indicators that covers the key components required to strengthen palliative care programmes: (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 providers of palliative care; (v) empowered people and communities; and (vi) palliative care-related research. This WHO report on palliative care indicators should be considered as a starting point for indicator selection, alongside the PHC monitoring framework, to compose an indicator set that is appropriate for the country's stage of palliative care development.



#### Key principles for indicator selection

- **Pragmatism:** Start small, be cautious of adding significant measurement burden.
- **Feasibility:** Within the country context, data are available or easily attainable. Build on existing data collection systems and measurement experience.
- **Relevance:** The indicator is relevant for monitoring improvements in palliative care.
- **Sensitivity:** The indicator is sensitive to detect changes over time.
- **Validity:** The indicator measures what it is intended to be measured.
- **Actionability:** The indicator is useful for performance improvement processes and can create “nudges” to address current gaps and priorities that lead to actions.
- **Alignment:** Palliative care indicators align with monitoring efforts for PHC and draw from and/or align with indicator frameworks from agreed global/regional monitoring efforts.

Source: PHC measurement for improvement: monitoring framework and indicators (WHO forthcoming publication)

## Special considerations for palliative care measurement

Although alignment of measurement efforts across the system is vital, there are some special considerations for measurement in palliative care. National measurement efforts seldom focus on measures that can capture the value of palliative care that includes the prevention and relief of physical, spiritual, psychological and social suffering, both for the patient and their families. Specifically, in palliative care, death is an expected and accepted part of care, therefore, outcome measures based on disease recovery or mortality averted are inappropriate (31). On the contrary, effective measurement of patient experience and patient-reported outcome measures is vital for capturing the value of palliative care. However, this task requires a reimagining of measures commonly used elsewhere in the health system due to the comparatively short length of service utilization and impairments in patient communication capacity often seen in palliative care. Involving families in measurement, such as post-death family evaluation of care surveys, is commonly used as part of person-centred measurement. Finally, how to include services that exist beyond the normal national health measurement infrastructure, such as nongovernmental organizations, needs to be considered.

There is a pressing need to learn how to efficiently and effectively capture the value added by palliative care to strengthen the recognition of the benefit it creates for patients, families and the health system, including how it can reduce costs related to unnecessary hospitalization. Although this may be challenging, palliative care can be used as a pathfinder for how to re-orientate measurement efforts to outcomes and experiences highly valued by patients. This is vital learning that should be applied across health system measurement efforts.

### **ACTION:**

#### **Assure quality palliative care services at a national level**

Quality assurance is a common term in many sectors and has different meanings in different contexts. In the context of delivery of health services, quality assurance refers to a range of activities related to systematic assessment and monitoring, intended to ensure that services are fulfilling stated requirements for quality.

National quality assurance systems comprise of organizations and processes, usually external to health care providers, aimed at defining, monitoring and improving the quality of care. These may include standard-setting bodies, guideline producers, professional registration and licensing bodies, external evaluation organizations and programmes, and provider licensing and regulatory bodies. It is important to consider how palliative care services can be integrated into established quality assurance mechanisms and how they can be linked into broader efforts to strengthen quality assurance as laid out in the national strategic direction on quality.

Quality assurance within palliative care programmes can have additional complexity as services are commonly delivered across a wide range of providers, including hospitals (public and private), primary care services, nongovernment and faith-based

organizations, often heavily reliant on volunteers and community health workers. In addition to drawing on existing national mechanisms for quality assurance, it is vital that palliative care programmes also consider what specific mechanisms can be used to set appropriate standards and build accountability for quality across *all* major providers of palliative care. This will involve meaningful stakeholder engagement and partnership work across sectors, seeking to maximize the valuable contribution of nongovernmental providers, while ensuring quality standards are consistently met.



### Quality assurance special considerations: opioid analgesics

Over 80% of the world's population still lacks adequate access to opioid medicines for pain control, the majority of whom live in low- and middle-income countries (1). The United Nations Single Convention on Narcotic Drugs of 1961 outlines the principle of balance for nations to employ on opioids: to minimize the risk of abuse, while ensuring their availability for medical and scientific purposes (32). The WHO Model List of Essential Medicines includes several opioid medicines such as morphine, codeine and fentanyl (33).

National governments should consider establishing a system to monitor the supply and use of opioids from import or manufacture to patient use to ensure the continued availability and safe use of these medicines (34). Governments should ensure that all physicians involved in patient care are both legally permitted and institutionally authorized to prescribe and administer opioids that are relevant to the medical needs of patients and in line with evidence-based guidelines for their safe and effective use (8). Health care professionals need education and training in safe prescription, dispensing and administration of opioids to ensure they are used safely and effectively, as well as to tackle associated taboos and increase confidence in their use among practitioners and patients. The WHO guide on integrating palliative care into PHC provides more information on legislation and assurance processes for opioid medicines (8).



### Quality assurance special considerations: palliative care teams of the future

Task shifting involves the rational redistribution of tasks among health workforce teams (35). When introducing or expanding quality palliative care to the community, task shifting can be an important intervention, alongside others, to make cost-effective use of the available health workforce and community assets. This may be of particular relevance during times of increased need or health service disruption such as the COVID-19 pandemic. A number of palliative care activities can be transferred from specialized doctors to other health professionals, for example, empowering nurses to prescribe, renew doctors' prescriptions or hold stock for patients to reduce bottlenecks in access to opioids. The WHO guide on planning palliative care services details tasks and roles that can be safely and effectively performed by different cadres of trained health workers (5).

It is vital that delegation of tasks are based on strong quality assurance mechanisms to ensure that there is no compromise in quality of care provided to patients. The following are WHO recommendations and guidelines on ensuring quality of care in task shifting highlight (35):

- Quality assurance mechanisms should be linked with existing quality infrastructure at a country level.
- Quality standards should be used to clearly define the roles and associated competency levels for all cadres involved in task shifting. These standards should underpin recruitment, training and evaluation criteria.
- Health workers require standardized and competency-based training to equip them to perform their defined tasks. Training should be accredited, needs driven and linked to certification, registration, supervision and career progression mechanisms.
- Regular supportive supervision and clinical mentoring should be provided for all health workers in the team. This should be implemented alongside performance assessment against clearly defined competency levels and standards.



### Learning from Uganda: a public health approach to palliative care development

Palliative care development in Uganda has been strongly led by civil society and community organizations. The country has been a regional leader on how to make opioids accessible at low cost for palliative care patients. Uganda imports opioid powder, which is cheaply and safely reconstituted in the country for medical use. Food colourings are used as a low-cost method to clearly identify the different concentrations of morphine solutions for safe administration by clinicians and patients (36). Recognizing the country's shortage of physicians and, therefore, limited access to morphine, a national statute was signed in 2004 authorizing the prescription of opioids by registered nurses (8,37). To assure the quality of opioid prescribing, the statute specified nurses must complete nine months of palliative care training and be registered with the Ministry of Health (36).

Palliative care development in Uganda has been based around the WHO public health model for palliative care (16) where increasing accessibility to opioids has occurred alongside strengthening education and under a supportive national policy for palliative care. With inclusion of palliative care in all medical curricula since 1994, Uganda has a medical workforce that is well informed about palliative care (36), with opportunities for specialisation (1). Furthermore, palliative care has been a priority highlighted in the country's national health plan (37), with specific national plans for palliative care and quality of care (38). In the National Development Plan for Health 2015/16–2019/20, palliative care and quality are clearly linked together in Uganda's goal for UHC (39).

Although Uganda still has a long way to go to increase access to quality palliative care for all those who need it (40), it was Africa's second highest-ranking country in the 2015 Quality of Death Index (24). The country has progressed in the *Global atlas of palliative care* rankings to a country with preliminary integration of palliative care into the health system (1), where in 2019 90% of its 112 districts had access to palliative care services (41).





# DISTRICT LEVEL



## ACTIONS FOR QUALITY PALLIATIVE CARE

This section describes activities that staff at the district level (particularly district health leadership and teams) can do to improve the quality of palliative care services. Interpretation of the term “district” varies depending on the country and local context. Within this document, the term refers to a clearly defined administrative area, where there are local government and administrative structures that take over many of the responsibilities from the national government and where there is a general hospital for referral. The WHO *Quality health services: a planning guide* (4) covers in additional detail a wide range of activities that district health teams can undertake to develop and maintain quality health services.

### **ACTION:**

#### **Commit to quality palliative care at the district level**

The district level should commit to deliver on national palliative care goals and priorities by developing, aligning and implementing operational plans with clear actions for district-level actors that aim to improve the quality of palliative care services delivered at the subnational level.

#### **Key activities**

- Commit to the district level aims and targets in support of the overall national goals and priorities for quality palliative care services. Support and identify adequate resource for the implementation of the district-level activities within the national plan for quality palliative care.
- Support coherence with national governance structures and commit trained human resources at the district level for palliative care based on the needs of facilities.
- Commit to and facilitate the documentation and sharing of learning on delivering quality palliative care within and across districts, and with the national level. This includes providing a forum to share learning across all major palliative care providers, including private and nongovernmental organizations.
- Ensure effective dialogue with facilities and communities to communicate national strategic goals and priorities. Working with local actors, contextualize national approaches to the local context for implementation of improvement plans.

- Facilitate the linkage between national and facility levels. Ensure national strategic direction on quality palliative care is informed by the health service realities encountered at the district and facility levels, across all providers.
- Advocate for quality palliative care at all levels, orientating the health and care workforce to key palliative care concepts.



### **CROSS-CUTTING ACTION:**

#### **Use data at the district level to improve palliative care**

**For broad principles of palliative care measurement, see measurement section under national actions**

The district has a vital role to play in the measurement of palliative care as the linkage point between national actors, who set overall direction on measurement, and the point of care, who often play a role in data collection, collation and input. As this linkage point, the district may inform national actors on the feasibility of the use of specific indicators at the point of care and collate, analyse and aggregate data from facilities to report to national actors. Districts also have a role in raising the awareness of measurement efforts and building capacity among facilities to partake in measurement activities.

District actors have an important role as data users. National indicators may be disaggregated at the district level to identify improvement priorities or variation in care and inform local decision-making.



#### **Uses of palliative care data at the district level:**

- understand the distribution of palliative care services across the district and the potential impact on equity;
- track local variation in key outcomes to identify facilities that are not achieving quality targets as a focus for improvement efforts;
- monitor access to and quality of palliative care received by specific priority populations within the district;
- identify areas of good practice within the district where learning can be extracted and shared amongst providers;
- inform decisions on resource allocation (human and financial) at the district level; and
- advocate for additional resource or actions needed at a national level.



### Spotlight on ethics: equity and justice

The principle of justice dictates that patients with similar conditions or symptoms must receive equal medical treatment. There should be no discrimination based on age, sex, gender, race, ethnicity, sexual orientation, geographic location, religion, socioeconomic status, linguistic or political affiliation. To achieve this equitable distribution of palliative care services, some patients who are particularly vulnerable due to poverty, stigmatization, social or political discrimination may require more intense services than others, or services delivered in different ways that account for their needs (6).

Districts are well placed to understand where clusters of vulnerable populations are situated and how to engage them. Such populations often excluded from adequate palliative care provision include those impacted by humanitarian crises (6,42), people experiencing homelessness (43,44) or particularly isolated rural communities. District health teams could:

identify which communities or populations in their district experience inequities in accessing palliative care compared with the rest of the population; seek to understand the problems these communities face related to palliative care; consider how resources can be used to reduce health inequalities such as mobile clinics, training on specific needs, and community outreach workers; and closely monitor the impact of actions taken to address inequalities.



### **CROSS-CUTTING ACTION:**

#### **Engage communities in palliative care**

#### **Principles applicable to all levels of the health system**

Community engagement can be undertaken by all levels of the health and care system, although districts are often in an ideal position to engage with the communities they serve. Community engagement recognizes that people are at the centre of any effort to create better health and is the cornerstone of safe, people-centred services (45,46). As a strategically managed process that combines quantitative and qualitative data, it facilitates continuous adaptation of health services and interventions that respect local needs and preferences.

### **Why is community engagement vital within palliative care?**

- A core challenge of delivering quality palliative care globally is addressing the misunderstandings and knowledge gaps regarding palliative care among health-care providers, patients, families and the general public (46). Misconceptions and myths easily develop in many settings because talking about death is viewed as taboo. This deters use and provision of appropriate palliative care services.
- Death and dying are heavily embedded within cultural norms, values and practices. Palliative care services must be appropriate for the given context and adapt to cultural norms and values to deliver true people-centred services that cater to the psychological, physical and spiritual health of patients and families (6).
- A significant proportion of palliative care is delivered by families, volunteers and communities within patients' homes. It is, therefore, essential to ensure they are included in the planning, implementation and evaluation of health services.

### **How can community engagement inform palliative care programmes?**

Effective engagement goes beyond "informing" and "teaching" communities towards seeking to ground services in "what matters" to the people ultimately using palliative care services (23). The following are some ways in which patients, families, communities and civil society can contribute to designing and delivering quality palliative care services:

- inform the feasibility and acceptability of service delivery models;
- contribute to the assessment of unmet palliative care needs;
- provide oversight on the performance of health facilities and services;
- inform policy and strategy formation and implementation;
- inform targeted messaging and appropriate delivery models for health education programmes; and
- provide clear direction for service improvement activities.

In palliative care, families and communities may not only contribute to quality assurance and improvement of formal palliative services, but often undertake the vast majority of the caring. It is vital, therefore, that families and communities receive relevant knowledge and skills training to be able to provide effective and safe care. This training may cover a whole host of issues, including safe moving and handling of patients, feeding, nutrition, medication administration and education on the disease and disease progression. Families and communities can be empowered and supported by the health system to provide this care through a range of interventions such as respite care, telephone support and clear escalation plans.



### **Spotlight on ethics: informed, autonomous, person-centred decisions**

Engaging patients and families in decision-making is a fundamental feature of quality palliative care where patients' goals and preferences shape care and treatment. Advance care planning is essential in view of the anticipated decline in many patients' mental capacity or ability to communicate their wishes near the end of life. In diseases such as dementia, patients may lose capacity to make complex decisions about their health and social care arrangements earlier in the course of the disease. It is, therefore, vital to have advance care conversations early and keep revising them to ensure they remain aligned to the patient's wishes. Advance care plans should be part of usual practice in palliative care and include conversations and documentation of patient's preferences about future care such as preferred location, important spiritual practices and practical matters surrounding death. Children should be involved in decisions where appropriate for their developmental age (7). Advanced care plans are not legally binding, but are used by the treating team to align care with the patient's wishes. Intentionally seeking to understand patients' preferences in this way is a model for other health services to learn from as they seek to be more person-centred.

In addition, countries must ensure they have robust legal frameworks in place to safeguard person-centred decision-making near the end of life. There is a range of terminology used to describe advanced directives (e.g. advanced decisions, living wills, advanced decision to refuse treatments) but they tend to be characterized by legally binding decisions to refuse specific care under specific circumstances, according to patients' wishes. Important legal powers for person-centred care also include the ability to nominate a Lasting Power of Attorney to make decisions on behalf of patients should they lose capacity during the course of their illness.



### **Learning from South Africa: a district mentorship programme in quality palliative care**

South Africa has achieved preliminary integration of its palliative care services into mainstream service provision (1) and has made significant advances in quality of care (24).

A number of quality interventions have been implemented in the country, including the introduction of Palliative Care Standards in 2005. These standards are used by the Council for Health Services Accreditation of Southern Africa (COHSASA), an independent body, to provide accreditation to hospices in South Africa based on the quality of care they provide both in facilities and care delivered in the patient's home (47).

The Hospice Palliative Care Association (HPCA) runs a district (provincial)-level mentorship scheme that has been vital for the successful implementation of hospice accreditation in South Africa. The district mentorship programme facilitates the fast tracking of compliance with palliative care standards and provides a mechanism to cascade good practice in quality care between hospices and partner organizations (47). COHSASA has provided surveyor training to district HPCA staff, who conduct internal surveys of palliative care facilities according to the national standards. On completion of an internal survey, hospices are assigned a star rating according to their development progress. When hospices have been supported to reach full compliance with the standards, an external survey is completed for full accreditation with COHSASA and a 5-star achievement certificate from HPSA is provided (47).

This district-led mentorship programme facilitates quality improvement and aims to prevent accreditation becoming a costly and burdensome process to hospice facilities, which in South Africa are often small nongovernmental organizations.









## POINT OF CARE

# ACTIONS FOR QUALITY PALLIATIVE CARE

This section discusses point-of-care actions to improve the quality of palliative care received by patients and families. In the field of palliative care, the point of care can refer to a whole range of settings, including specialist hospitals, general hospitals, hospices, PHC centres/clinics, respite units, long-term care facilities and home-based care. The organizations that provide care will also be drastically different between settings, from small community run voluntary organizations to large government institutions. It is important that every organization considers how they can act to improve quality palliative care, although the scale and type of action will depend on the scope for action, the sphere of influence and the resources available (financial, human and knowledge) in each facility/location.

### **ACTION:**

#### **Maintain and improve quality palliative care within the home**

Home-based palliative care provides care to people with chronic, life-limiting health problems such as cancer, advanced cardiac, renal, and respiratory diseases, HIV/AIDS and chronic neurological disorders, in the home in which the patient lives (5). In fact, home care is the predominant model of palliative care services in many settings, particularly in sub-Saharan Africa (48). There are several advantages to home-based palliative care. For instance, there is a naturally strong emphasis on person-centred care as many patients feel more comfortable in their home than a health care setting and home care increases the chances of patients being able to die at home, which is the preference for many (49–51). Furthermore, it maximizes community assets, integrating families and community members into the process of care, making care more accessible to patients and increasing the community's awareness of palliative care. However, home care can be challenging if not delivered holistically and effectively, as the bulk of the care burden falls to relatives and community members who can experience mental and physical ill health, as well as financial and social challenges as a result of providing care without sufficient support. These ill effects are experienced disproportionately by women as the predominant providers of family care worldwide (52). Details of establishing a home-based service can be found in the WHO palliative care planning guide (5). Of note, such a service requires much less physical infrastructure to establish and, therefore, is often a more feasible model in low-resource settings.

Some consensus exists on the essential components of quality home-based care such as ensuring an interdisciplinary team approach, providing timely and responsive care, and effectively managing pain and other distressing symptoms (5,53). What has yet to be explored extensively in research and practice is how quality can be effectively maintained and assured within the home. A recent study undertaken in India, Uganda and Zimbabwe found that a mobile application that enabled home caregivers to regularly report patient outcome measures to their palliative care team was acceptable, empowered caregivers to assess and communicate patient needs and enabled professionals to prioritize care based on need (54). The rise in availability and accessibility of digital technologies opens up a wider range of possible options for how to support and assure quality care within the home and merits consideration by those planning palliative care settings, accounting for local systems and capacity.

Despite the lack of specific research focussing on quality assurance within home-based palliative care, there is opportunity to apply existing evidence-based quality interventions and tools used in other health care settings to the home care environment. Figure 6 highlights illustrative quality interventions from existing WHO sources, considering how they may be applied and adapted at the point of care to provide palliative care within the home (9,23). This is not an exhaustive list, especially as many interventions that can assure quality within the home will be implemented at the district or national level such as national standards, licensing, accreditation and medicines regulation. Of note, it is likely that many of the interventions listed here will also be applicable across multiple palliative care settings such as hospices and primary care, with adaptations that can be made for each individual context.



### **CROSS-CUTTING ACTION:**

**Use data at the point of care to drive improvement**  
**For broad principles of palliative care measurement, see measurement section under national actions**

At the point of care, data are used daily to monitor patient progress, manage resources and assess the performance and capacity of local services. Unlike data that are collected at the district or regional level, these data are often granular, rich in detail about individuals or groups of patients. At the point of care, where data systems are designed appropriately, data can be used flexibly, quickly feeding into daily clinical and management decisions such as on the allocation of staff or equipment. Data are used to identify challenges and can be collected and used over relatively short timeframes to reactively address local problems. It is vital that the flexibility, reactivity and opportunities to use data at the point of care are effectively harnessed to drive local quality improvement activities.

**Figure 6. Applications of Illustrative quality interventions to home-based palliative care**

Illustrative quality intervention	Possible adaptation to deliver palliative care within the home
<b>Education and training</b>	<ul style="list-style-type: none"> <li>• Training on delivery of home-based palliative care to the health workforce.</li> <li>• Training and education of family and community caregivers on providing palliative care within the home.</li> </ul>
<b>Supportive supervision</b>	<ul style="list-style-type: none"> <li>• Supportive supervision of professional workforce as well as community volunteers delivering care in homes, and inclusion of palliative care considerations within supportive supervision for relevant PHC services.</li> </ul>
<b>Adverse events reporting</b>	<ul style="list-style-type: none"> <li>• Incorporate into adverse events systems those that happen within patient homes under the care of a home-based palliative care service.</li> </ul>
<b>Safety protocols</b>	<ul style="list-style-type: none"> <li>• Implementation of safety protocols relevant to homecare such as infection prevention and control within the home.</li> </ul>
<b>Clinical audit and feedback</b>	<ul style="list-style-type: none"> <li>• Audit against palliative care standards for the care delivered within the home.</li> </ul>
<b>Guidelines and protocols</b>	<ul style="list-style-type: none"> <li>• Apply clinical guidelines and patient/carer assessment tools relevant to patient care within the home.</li> </ul>
<b>Shared decision-making</b>	<ul style="list-style-type: none"> <li>• Use shared decision-making to formulate an advanced care plan. The advanced care plan should include preferences for location of care and preferred place of dying.</li> </ul>
<b>Patient experience of care</b>	<ul style="list-style-type: none"> <li>• Incorporate patient and carer-reported measures into evaluation of home-based care.</li> </ul>
<b>Patient self-management tools</b>	<ul style="list-style-type: none"> <li>• Tools and technologies for patients, relatives and carers that facilitate self-management of symptoms at home.</li> </ul>
<b>Engage and empower communities</b>	<ul style="list-style-type: none"> <li>• Incorporate patients and families receiving palliative care services within formal mechanisms to engage in planning, delivering and monitoring services.</li> </ul>

Sources: WHO 2020 (9,23)



### Key considerations for using data to drive quality improvement at the point of care

*Explore existing sources of data:* Where possible, use and adapt existing data sources to inform quality improvement efforts such as disease registries, clinical notes, admission records and patient complaint systems.

*Ensure data collection and use are pragmatic and feasible:* Where existing data sources are insufficient to address a local improvement priority, incorporate data collection into existing data systems or usual clinical activities. For example, to improve pain control for palliative patients, patient-reported outcome measures can be built into routine procedures of patient assessment. Be selective in data points collected, keeping the measurement burden to an absolute minimum.

*Strengthen the use of data:* All those collecting and interpreting data should have sufficient training in these activities. Ensure there is a mechanism by which data can inform decision-making and action, such as a review of data at team or management meetings.

*Ensure data are fit for purpose:* Different issues require different types of data to drive improvement (see principles for indicator selection under national level actions). Due to the smaller scale of data collection at a local level, data can be used very flexibly to meet the needs of the improvement activity. Consider when input, process, output or outcome measures may be most appropriate. Consider where qualitative methods (such as interviews) may be appropriate to gain a richer understanding of the acceptability and feasibility of an improvement method.

*Devise an appropriate timeline for data collection and use:* To prevent measurement becoming burdensome, carefully consider the optimal frequency for data collection. At the point of care, it may be possible to collect data at frequent intervals for much shorter periods than national measurement efforts. It is important there is sufficient time to establish a baseline measurement, identify the trend in improvement over time and establish when improvement has been achieved and maintained.

## **ACTION:**

### **Integrate quality improvement methods into usual practice at the point of care**

Quality improvement implies change. It is the action of every person working to implement iterative, measurable changes, to make health services more effective, safe and people centred. It involves the combined efforts of a variety of stakeholders to make changes that will lead to better programmes, systems and ultimately improved health outcomes for patients. It is a systematic approach to improving quality by measuring performance, using standardized indicators, selecting quality challenges, exploring their root causes, designing and implementing contextually appropriate solutions and assessing their impact using rapid, interactive tests of change (55).

There are diverse quality improvement models and tools available, and choice of method will depend on local capacity, resources, experience and availability of relevant tools. The following illustrative worked example shows how quality improvement methods can be applied to address quality issues at the point of palliative care service delivery.

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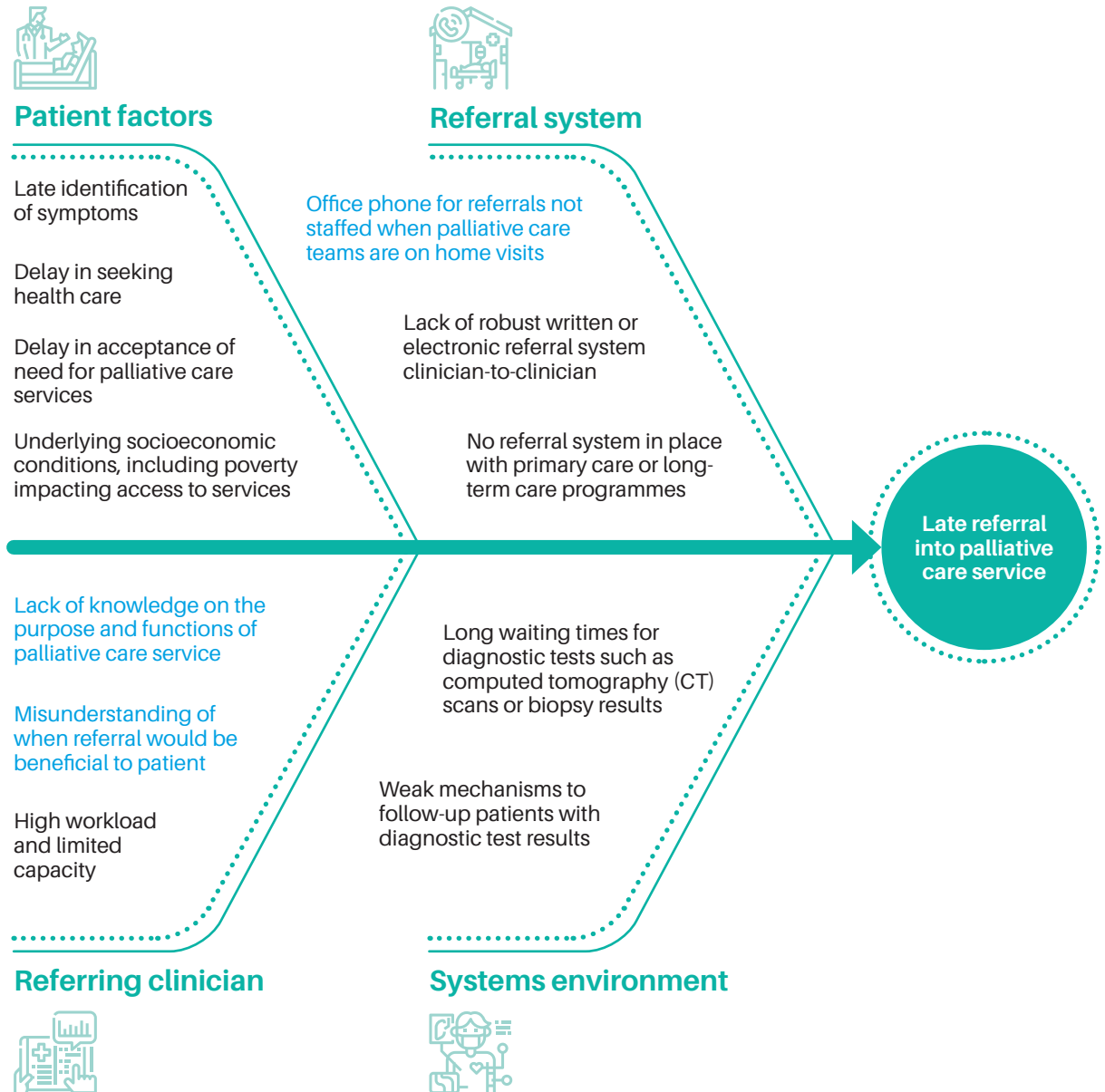
#### **Illustrative worked example: application of quality improvement tools to palliative care**

**Example problem:** The clinical lead of a palliative care service is concerned that most patients referred to the service have very advanced disease and are often in the final days or weeks of life.

##### **Step 1. Develop a greater understanding of the problem**

Before taking action, it is important to develop a fuller understanding of the problem. Any available baseline data on the issue can be utilized, looking at trends and patterns to understand the extent and impact of the problem. It can be helpful to understand the perspectives of the people whom the problem impacts or relates to, for instance, in this case talking to the clinicians in charge of referring patients for palliative care. It is essential to gain an understanding of the immediate and root causes of the problem to generate a greater range of more effective solutions. A range of tools can facilitate the process of root cause analysis, including the “five whys”, decision tree analysis and cause-and-effect diagrams (56).

A cause-and-effect diagram is used to better understand the problem:



*Note:* The blue text identifies issues that the palliative care quality improvement team determined to be the most feasible to address at the facility level.

## Step 2. Select causes that can feasibly be addressed at the point of care

Once a good understanding of the problem has been gained, it is important to choose which causes of the problem can feasibly be addressed within the power, influence and resources available to the facility or organization. For specialist hospitals, there may be significantly more resources to invest in quality improvement, therefore, the scale and scope of improvement efforts may be large. For organizations with small teams or extremely limited resources, some problems may be improved at the point of care, others may need to be escalated to other levels of the health system.

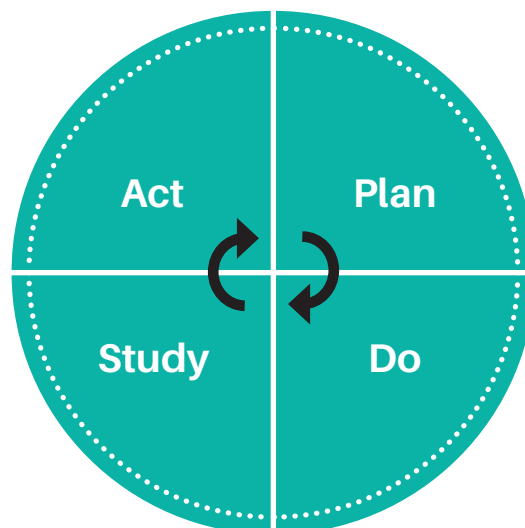
### Step 3. Choose and implement an appropriate quality improvement tool

A range of quality improvement methods exist that can facilitate action on quality issues, including but not limited to, clinical audit, plan-do-study-act cycles, model for improvement, six sigma and statistical process control (56). Each method has its advantages and types of problems it is best suited to address (56). It is important that the user(s) understand how to apply the methodology, therefore, using a familiar tool can be helpful. It is important to remember the methodology is a tool to facilitate action, rather than an end in itself.

For the illustrative worked example, a plan-do-study-act cycle is chosen and implemented, with the key components considered in the cycle shown in the diagram:

We will combine distribution of the "on-call" number with brief interventions delivered to clinical staff on palliative care and the appropriate timing of referrals.

Referrals were monitored. Referral numbers increased by 15%, but the proportion referred at the end of life remained the same.



Aim statement:  
Decrease proportion of patients referred to the service in the last weeks of life by 20%.

Develop intervention:  
on-call referral mobile phone.

Do: We have brought an "on-call" phone, distributed its number to key referring wards, and devised a schedule for staffing the phone.

### Step 4. Continuing cycles of improvement

Quality improvement is not a one-off action. It is not a tick-box exercise that can be undertaken and forgotten about. It is an ongoing process, a cycle, that continues until patients and families receive improved quality care. Some problems may be "quick wins", others more complex where progress occurs slowly over time. Some problems may require single solutions, but most will require a range of interrelated and additive actions to improve quality care. Measurement is a vital component of quality improvement to understand the problem and know when quality improvement goals have been met. Quality improvement processes should be embedded into the culture of palliative care teams, always seeking to address problems and challenges applying a systematic and thoughtful approach.

In this illustrative worked example, multiple iterations of the plan-do-study-act cycle were undertaken. Small changes and interventions that increased referrals were continued. Those issues that could not be addressed at the facility level were escalated to management for addressing at the district level.



### **Learning from India: expanding capability for quality improvement in palliative care**

Palliative Care–Promoting Access and Improvement of the Cancer Experience (PC–PAICE) was developed in response to the significant unmet need for quality palliative care in India (57). The programme promoted quality improvement education and collaborative learning among a number of palliative care centres in the country. Each palliative care centre was matched with an international partner that provided coaching, education and mentorship in quality improvement methods, meeting regularly virtually for teaching, exchange and problem solving.

PC–PAICE projects focussed on a range of improvement initiatives of local importance and international relevance such as early palliative care referrals, effective allocation of scarce resources, improving coordination between facilities and enhancing patient satisfaction (57). Throughout the programme, remote quality improvement interventional education was delivered and was shown to be feasible and effective, with most teams reaching their improvement goals (57). PC–PAICE has also been catalytic for an ongoing focus on quality palliative care in India. In 2019, the initiative transitioned into the Enable Quality, Improve Patient Care, India (EQuIP-India) programme. The EQuIP programme is being led and developed by India, rapidly developing its own national capacity for quality improvement mentoring. By June 2020, India had 22 palliative care and cancer teams with leadership capability in improvement methods (57).

This model of remote educational support from international partners to catalyse the development of initial quality improvement capabilities in palliative care may be a feasible model to consider adapting for use in other settings. The virtual training model, with ongoing coaching and mentoring delivered online, may also represent a feasible option for expanding the reach of national programmes increasing access to local expertise and leadership capabilities in quality improvement.



# CALL TO ACTION

Delivery of quality palliative care is a moral imperative and a human right. There is great opportunity to combine efforts on quality and palliative care to enhance the impact of efforts focused on UHC. This effort can also generate learning on quality across the whole system, especially on how to deliver truly person-centred and compassionate care.

Quality palliative care should be a central component of PHC approaches to achieve UHC, ensuring that palliative care is integrated into essential health services, long-term care and medicines packages worldwide. This integrated approach should stretch from palliative care planning to service delivery, systematically embedding palliative care training, guidance, information systems, care pathways, access to safe and affordable essential medicines, and culture into all relevant health programmes.

To facilitate this, financing and resourcing of quality palliative care should be integrated into health system budgets at all levels of care. The successful implementation of quality palliative care also strongly relies on a supportive policy environment and a clear national strategic direction on quality to provide quality infrastructure and frameworks that palliative care can draw from in the quality assurance and improvement of its services.

Actors across the health system must invest in tackling the challenges of measurement of palliative care to ensure local, district and national measurement efforts reflect the value of palliative care. These measurement efforts will demonstrate the enormous contribution of palliative care to patients, families and the broader health system, both in suffering relieved and cost saving from unnecessary hospital admissions. There needs to be clear accountability arrangements for review of data on quality of palliative care by decision-makers at different levels, and attention should be given to transparency and public reporting. Data generated should be used for resource mobilization, accountability and continuous improvement of services.

Above all, it is insufficient to simply expand access to palliative care; quality of care also must be at the core of the design and delivery of palliative care services. Delivering quality care is not a static process and relies on actors at all levels to be continuously striving to identify and address improvement needs. Patient, family and community engagement is essential in this process of developing high-quality palliative services and for breaking down barriers and taboos that prevent access and utilization. All quality interventions and improvement methods must be implemented with the patient and family as the central consideration, focusing on provision of compassionate care to those facing serious health-related suffering.



### A call to action on learning

This document is just a starting point for exploring quality palliative care. There is a vital need to initiate and increase efforts in generating learning on quality palliative care worldwide. This not only includes research, but importantly also country learning through case studies and communities of practice, as well as examining the complexities, challenges and successes of implementing quality palliative care across all levels of the health system. The WHO *Global Learning Laboratory for Quality UHC* aims to understand the stories behind improving health care quality, paying close attention to the interventions and actions applied to achieve desired health service improvement (58). This is an important forum for shared learning going forward as countries take action on quality palliative care.

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# ANNEX. PLANNING QUALITY HEALTH SERVICES AT A GLANCE

QI: quality improvement









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