



National Policy Framework and Strategy on Palliative Care 2017 – 2022



health

Department:
Health
REPUBLIC OF SOUTH AFRICA



National Policy Framework and
Strategy on Palliative Care
2017 – 2022

Foreword by Minister



Palliative care brings dignity, reduces pain and suffering, and enables children and adults diagnosed with a life-threatening disease or condition to live a quality life for as long as possible. With the large disease burden we have in South Africa, we cannot overlook the importance of integrating palliative care as an essential component in the continuum of health service delivery. I am confident that the implementation of this National Policy Framework and Strategy on Palliative Care 2017-2022 will not only increase life expectancy but will enhance the quality of the lives of children and adults who require palliative care services.

Historically, palliative care was associated with services provided by Hospices that provided relief of pain and suffering of patients and their families or caregivers especially during the end-of-life. These services were primarily linked to care of patients suffering from cancer. However with the growth of HIV and thousands of people ill and dying in Africa, palliative care shifted emphasis significantly to dealing with pain and death arising from HIV and other relevant diseases.

We now recognize the need to create equitable access to palliative care for a range of both communicable and non-communicable diseases, and it is no longer an option that only certain communities benefit from such care. Palliative care, including appropriate pain management, should reach all children and adults in need. We can only achieve this access if we focus on strengthening services at a primary health care level, which includes our clinics, as well as care within our communities and in the homes of patients. Patients, families and caregivers must experience a seamless continuum of care which prevents repeat hospitalisation that occurs at great cost, not only to patients and families but to the health service as well.

I welcome the Resolution of the World Health Assembly 69.17 that calls for Member States to develop Policy which strengthens palliative care service. The Resolution also calls for partnerships and collaboration within a context of maintaining and respecting human rights. With ongoing engagement and support from relevant sectors, I am confident that this Policy will translate into services which are responsive, appropriate and ensure universal access on an equitable basis.

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DR P A MOTSOALEDI, MP
MINISTER OF HEALTH
DATE:

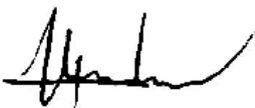
Acknowledgements by Director General



The World Health Assembly Resolution 67.19; “Strengthening of palliative care as a component of comprehensive care throughout the life course” was a milestone which brought hope to children and adults enabling them to live quality, pain-free lives for as long as possible. It was with pride that South Africa co-sponsored and participated in writing this resolution. As a country rich with lessons on human rights, this Resolution reminds us that access to integrated palliative care is a basic human right.

I firmly believe that the National Policy Framework and Strategy on Palliative Care 2017 -2022 will realise appropriate and accessible care and will be responsive to the needs of patients and their families or caregivers, especially those in greatest need. I am pleased to acknowledge the work undertaken by a writing group consisting of Dr Shaidah Asmall, Dr Charmaine Blanchard, Ms Sandhya Singh and Ms Laurie Schowalter under the co-ordination of the National Department of Health, Primary Health Care Branch. This Group consulted with all constituents of the Alliance for Access to Palliative Care, chaired by Dr Liz Gwyther. The development and publication of this document has been made possible with the support of the United States Centres for Disease Control and Prevention (CDC) and United States Agency for International Development (USAID) under the United States President's Emergency plan for AIDS Relief (PEPFAR).

Effective implementation of the Policy remains key and it is significant that this task will be overseen by the Steering Committee on Palliative Care which was appointed by the Minister of Health, Dr P A Motsoaledi in 2016. I am confident that the Chairperson, MEC Dr S Dhlomo and the Steering Committee comprising academics, researchers, experts, advocates and civil society will guide, support and ensure accountability on realising the objectives of this Policy.



MS MP MATSOSO
DIRECTOR- GENERAL: HEALTH
DATE:

Message Chair of Steering Committee on Palliative Care



It is an honour and a pleasure to chair the National Steering Committee on Palliative Care appointed by the Minister of Health, Dr Motsoaledi, to provide expert guidance on the implementation, monitoring and evaluation of progress toward achieving resolution WHA 67.19.

The Steering Committee members all feel immense pride that South Africa co-sponsored and participated in writing the WHA resolution 67.19 **“Strengthening of palliative care as a component of comprehensive care throughout the life course.”** This has been the foundation of the commitment to develop guidance to implement each of the nine recommendations of this resolution.

In a country whose history is so rich with lessons on human rights, the WHA Resolution reminds us that access to integrated palliative care is a basic human right, and that this right has been violated in our country, and in many low- and middle-income countries through neglect of palliative care as an integral part of the continuum of care. Using the Resolution as a guide, the Steering Committee has reviewed and developed the National Policy Framework and Strategy for Palliative Care and I believe that the most significant impact of the Policy will be a change in how palliative care is viewed generally - palliative care includes but does not equate to end-of-life care. The NPFSPC provides guidance on how to make optimal and cost-effective use of available resources with best health outcomes. We will no longer have the need to fragment service delivery by providing vertically-based disease-specific palliative care. More importantly, the Policy assists in creating equity in access to palliative care irrespective of the cause of the life-limiting condition. Palliative care and the standards of care are equally important for adults and children whatever the diagnosis – cancer, HIV/AIDS, TB, a Stroke or a disability.

We are grateful for the opportunity to appoint task teams to assist with important inputs into the process, including ethics, policy, vulnerable populations, medicines availability, education and training, and support for families and health care workers. The work of these teams has added valuable content in the process of developing the NPFSPC.

The National Policy Framework and Strategy for Palliative Care brings hope and a promise for patients to live as actively as possible with good quality of life as long as possible, despite the diagnosis of life-limiting or life-threatening illness. It also provides the framework to achieve the mandate set by Minister Motsoaledi “to create a revolution in health care through palliative care!”

We are aware that the WHA Resolution could simply remain that; just a Resolution which fails to touch the lives of people. Here in South Africa, we have accepted the obligation to translate the Resolution into action!

A handwritten signature in black ink, appearing to read 'M. Dhlomo'.

Dr S.M. Dhlomo
MEC for Health
KwaZulu-Natal

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Appendix C - Causes of premature death versus comparison locations, 2015

Appendix D - Performance Status and Level of Care for Palliative Care Patients

ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
BOD	Burden of Disease
CBOs	Community-based Organisations
CHW	Community Health Worker
DALY	Disability Adjusted Life Years
DBE	Department of Basic Education
DCS	Department of Correctional Services
DCST	District Clinical Specialist Teams
DHS	District Health System
DOH	Department of Health
DSD	Department of Social Development
EDP	Essential Drugs Programme
EML	Essential Medicines List
FTE	Full Time Equivalent
HBC	Home-based Carer
HCBC	Home and Community-Based Care
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association
HWSETA	Health & Welfare Sector Education & Training Authority
MDG	Millennium Development Goals
MDR	Multi Drug Resistant
MOU	Memorandum of Understanding
M&E	Monitoring and Evaluation
NCD	Non Communicable Diseases
NDoH	National Department of Health
NEMLC	National Essential Medicines List
NGO	Non-Governmental Organisation
NHI	National Health Insurance
OTL	Outreach Team Leader

PHC	Primary Health Care
PPC	Paediatric Palliative Care
SLA	Service Level Agreement
STG	Standard Treatment Guidelines
TB	Tuberculosis
U5MR	Under 5 Mortality Rate
UNCRC	UN Convention on the Rights of Children
UNCRPD	UN Convention on the Rights of Persons with Disabilities
YLL	Years of Life Lost
WBPHCOT	Ward-Based Primary Health Care Outreach Team
WHA	World Health Assembly
WHO	World Health Organisation
WHPCA	Worldwide Hospice Palliative Care Alliance

GLOSSARY OF TERMS¹

Palliative Care: In terms of this policy, palliative care is the holistic multi-disciplinary care of a patient and family affected by a life limiting or life-threatening illness and is applicable from the time of diagnosis for all adults and children across the life span and includes bereavement care for the family.

Life-limiting conditions: A condition that limits activities of daily living, for which there is no cure, and will most likely result in a shortened life-span. Examples include chronic renal failure, cystic fibrosis and motor neuron disease.

Life-threatening illness: A condition where there is a more immediate likelihood of death, for which curative treatment is feasible but which may fail. Examples include cancer, MDR TB, HIV.

Terminal Illness/Terminally Ill: An irreversible life-threatening or life limiting illness for which there is no cure and will result in an inevitable decline in function until death.

Disability Adjusted Life Years: Measures the “healthy years of life lost due to each incident case of disease or injury” by adding together “years of life lost (YLLs) due to premature mortality, and years of life lived with disability (YLDs) weighted according to the severity of the disability.”ⁱ

Long Term Health condition (LTHC): a condition that cannot, at present be cured; but can be controlled by medication and other therapies

Non-communicable condition: A medical condition or disease that is *non-infectious* or *non-transmissible*.

Person with disability: The UNCRPD does not attempt to define disability per se, but rather recognises disability as an evolving concept.

Disability is imposed by society when a person with a physical, psychosocial, intellectual, neurological and/or sensory impairment is denied access to full participation in all aspects of life, and when society fails to uphold the rights and specific needs of individuals with impairments.

Persons with disabilities experience three main types of interrelated barriers:

- Social (including high cost, lack of disability awareness, and communication difficulties);
- Psychological (such as fear for personal safety);
- Structural (including infrastructure, operations and information)

¹ Commonly used terms have been included but do not imply that this document subscribes to these definitions.

EXECUTIVE SUMMARY

Palliative care is a multidisciplinary approach to the holistic care and support for patients and families facing a life-threatening illness, improving quality of life while maintaining dignity from the time of diagnosis until death. For children, the spectrum of illness includes life limiting illnesses/conditions which may progress to death or may be severely disabling. Palliative care should be available to all patients as needed from birth until death and should be accessible at all levels of the health care service. Palliative care cuts across all health programs in the delivery of services.

With the quadruple burden of disease in South Africa, an estimated 50% of all people who die in South Africa could benefit from palliative care services. While there are health system challenges to providing equitable access to quality palliative care services, there are available resources as well as existing legislation and policies which support the principles of palliative care and will enable the implementation of the palliative care policy and strategy using the existing service delivery platform.

With guiding principles such as the right to health, patient centred and ethical care, equitable access, and quality evidence-based care, the vision of this policy is that all adults and children, including their families, facing the problems associated with life-threatening or life limiting illness will receive palliative care to maintain quality of life, dignity and comfort as well as manage pain throughout the course of the illness.

The needs of palliative care patients at different stages of the illness trajectory are described. Referral pathways have been identified. The services available will range from a palliative care approach in the community and clinics to a generalist palliative care service at district hospitals to a specialist palliative care service at regional and tertiary hospitals. Centres of excellence will be established at academic hospitals to support education and research in palliative care. Access to hospices or sub-acute facilities will be available from all levels of the health service. Packages of care for patients at different stages of the trajectory as well as at different levels of the service have been described.

Training in palliative care is essential and includes in-service training of existing health care workers in the palliative approach, undergraduate training, postgraduate training and the development of a palliative care specialty to support the need for the different levels of services and to provide a career path for interested health professionals, ensuring sustainability of services.

The goals and objectives have been developed based on the WHO health system building blocks for health services. The responsibilities of the National Department of Health are outlined with activities and targeted outcomes, which then guide the implementation plan for the provinces. The costs of setting up the service as well as of continued service delivery have been estimated, although ongoing mapping of services within provinces is required. The National Policy Framework and Strategy for Palliative Care is intended to assist policy makers, all relevant health programmes, professionals and workers in the health department as well as NGOs to understand the need for palliative care and to provide a guide to providing such care so that patients will experience a greater quality of life with less suffering while retaining their dignity when faced with a life-threatening illness.

1. Introduction

Palliative care is an approach which aims to improve the quality of life of patients, caregivers and families facing life limiting and life-threatening illness by preventing and alleviating suffering through early identification, assessment and management of pain and other physical, spiritual or psychosocial conditions.ⁱⁱ Since its recognition as a medical discipline in the 1980'sⁱⁱⁱ, palliative care has been framed within a human rights context, with an aim to support patient dignity, choice and autonomy at the end of life.

The national policy framework and strategy for palliative care serves to provide guidance and a framework within which to plan for the strengthening and implementation of palliative care services in South Africa. The evolution of the current palliative care services is discussed while indicating the population's need for palliative care and the challenges to such care in South Africa. A rationale for strengthening the palliative care service, using the national policy framework and strategy, is explored based on the strengths of the current national legislative and policy framework and service delivery platform. The care and support services needed for palliative care patients are described, the roles and responsibilities of the National Department of Health are delineated and an implementation plan for the provinces is provided; which will ensure that the goals and objectives for palliative care services are achieved; as we aspire to the vision of all adults and children, including their families, facing the problems associated with life-threatening or life limiting illness receiving palliative care to maintain quality of life, dignity and comfort throughout the course of the illness.

2. Evolution of Palliative Care in South Africa

Palliative care has its roots in the hospice concept with the first hospice being established in the UK in the 1960s in response to a need to alleviate suffering and to give people a voice in determining their care at the end of life, including how and where to die. Death is a natural process which cannot be predicted exactly. However with palliative care, it is possible to provide good pain and symptom control and support for the patient and family in the setting of their choice. Palliative care has historically been associated with cancer, and viewed as an "end of life" service provided by non-governmental organisations outside of the health service.

Palliative care for children represents a special, albeit closely related field to adult palliative care (See appendix A.) The WHO's definition of palliative care appropriate for children and their families is as follows; "the active, total care of the child's body, mind and spirit and also involves giving support to the family. Paediatric Palliative Care (PPC) begins when an illness is diagnosed, and continues beyond the death of the child during the bereavement period". The principles also apply to paediatric chronic disorders (WHO; 1998a).

Over time, the concept of palliative care has evolved beyond an "end of life" service to encompass a holistic service provided throughout the course of a life-threatening or life-limiting condition, from diagnosis through management, and to include support for caregivers and families (Diagram 1)^{iv}. This progression in thinking was borne out of an increased understanding that life-threatening or life-limiting conditions may have a long trajectory, and patients and their caregivers may have different needs over the course of an illness. It also reflects that people are living longer with life-limiting illnesses, and providing palliative care services earlier can improve the quality of life of patients and their families. Further, the shift has been driven by evidence that palliative care can reduce unnecessary hospitalisation and the use of health care services, which ultimately reduces health system costs.^v

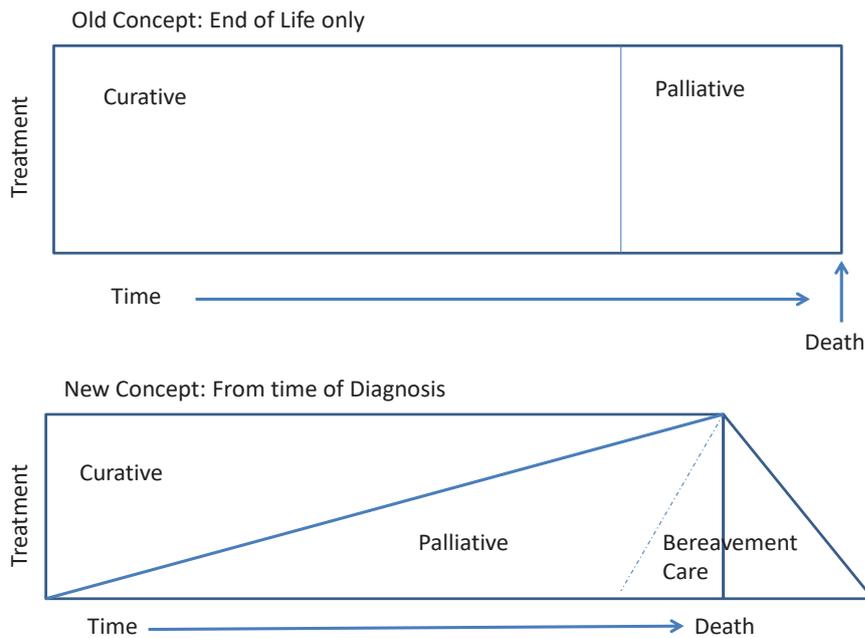


Diagram 1: Old and new concept of palliative continuum of care. (Adapted from J Lynn *et al.* 2003)

Diagram 2, (adapted from S.A. Murray *et al.* 2008), depicts the trajectories of illnesses which most likely would benefit from palliative care. A disease trajectory describes a patient’s health status or function over time. Disease trajectories may be affected by the availability of health services and treatments. With knowledge of disease trajectories, the health care provider, patient and family may have a better understanding of the progress of the illness, allowing for easier decision making as well as identifying when the “end-of -life” phase is reached. While cancer follows a fairly predictable course, organ failure as a result of a chronic illness often has periods of acute decline followed by recovery, although the overall function declines over time. It is not always easy to predict which acute exacerbation will be the final one resulting in death. Patients with dementia often follow a slow but inexorable decline in function, and care for these patients at home often proves to be quite a significant burden for the primary caregivers.

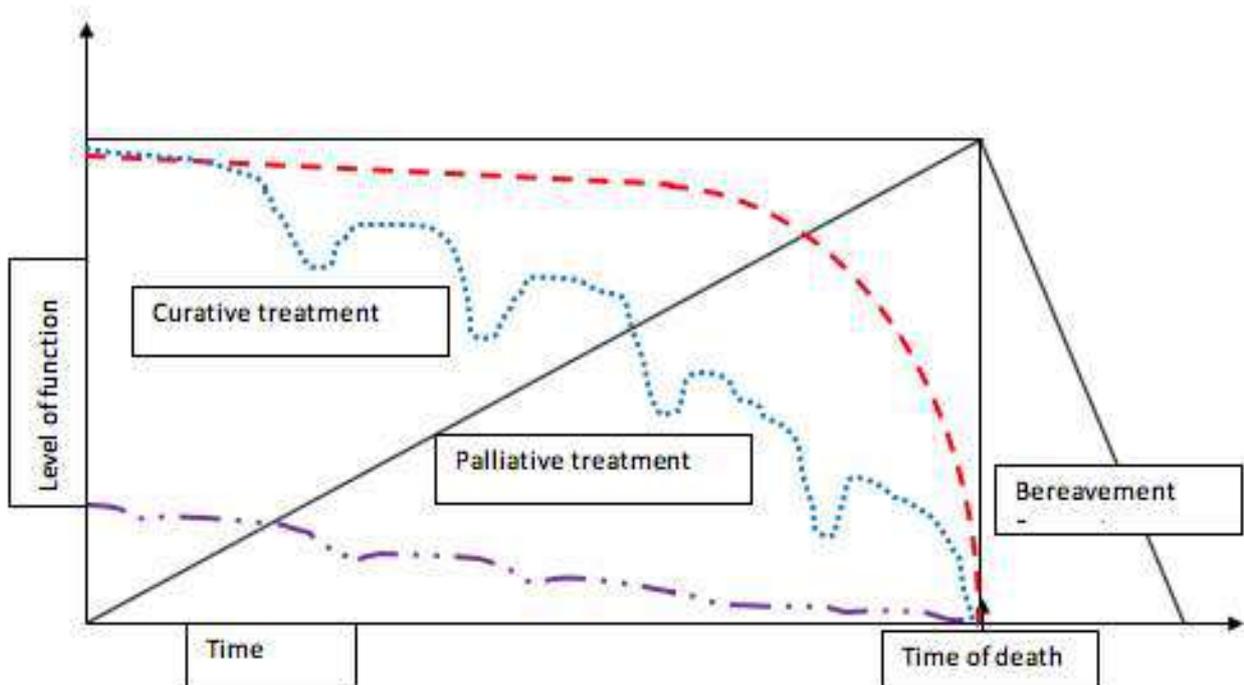


Diagram 2: The relationship of curative and palliative treatment with illness trajectories

- Cancer trajectory
- End-stage chronic illness trajectory (e.g. heart failure, renal failure, HIV)
- . - Dementia/ Frailty trajectory

Palliative care should be offered from the time of diagnosis. As function declines over time and cure is no longer possible, curative care becomes less significant and palliative care becomes more important until the time of death. The family is supported through the bereavement process.

South Africa has been active in providing palliative care since 1979 and is home to a strong palliative care community. Though initially focused on cancer, palliative care organisations mobilised to respond to the growing HIV epidemic in the 1990s, providing critical services to infants, children and adults dying of HIV. Services were largely provided by non-governmental organisations (NGOs), most of who worked in partnership with public health authorities as a part of a referral network, but outside of the health system. Increasingly, hospitals have developed palliative care services and there are a number of initiatives to integrate palliative care into the primary health care setting, both in community health centres and through community-based home care.

Donor funding has been instrumental to support palliative care services, but often is restricted to disease-specific initiatives and outcomes (e.g. HIV), which can result in inequitable and uneven service provision. The value that palliative care adds to health services, especially in supporting patients and their families to cope with life-threatening and life limiting illnesses, receives increasing recognition. Well-structured palliative care reduces the burden of cost of illness to families and costs to the health service; particularly at higher levels of care. These considerations support the need for a national palliative care policy. A number of models of palliative care services exist, which allow for palliative care to be provided in various circumstances or situations according to the needs of a particular community.

3. Patients in need of palliative care

3.1 Adult Palliative Care

Palliative Care is to be provided for patients who have been diagnosed with a life-threatening illness for which cure is not possible and who have significant symptoms – physical, psychosocial or spiritual.

As the patient’s disease progresses, the need for palliative care will increase and the level of curative treatment will decrease. It is often very difficult to determine the prognosis, especially for a patient who has an unpredictable disease trajectory. There are a number of assessment tools used to identify patients who have an increasing need for palliative care, *regardless of prognosis*.

The SPICT^{vi} (Supportive and Palliative Care Indicators Tool) and the Gold Standards Framework Prognostic Indicator Guidance^{vii} (GSF – PIG), are two validated tools which comprise general indicators and disease specific indicators of progression of illness and an increasing need for palliative care in patients. Based on these tools, a simple screening tool developed for use in South Africa would assist to recognize patients who may have unmet palliative care needs. As with any tool, this would need to be validated for use in all settings in South Africa.

A screening tool should be easy to use and be applicable to all patients across all diseases in all settings. Patients who are identified as needing palliative care interventions can then be further assessed by the appropriate health professional for specific needs which should be addressed.

An example of a South African palliative care screening tool to identify patients with palliative care needs is provided in table 1.

Step 1. Does the patient have any of the following illnesses?
<ul style="list-style-type: none">• HIV and/or TB• Cancer• Kidney Failure/Disease• Liver Failure/Disease• Heart Failure/Disease• COPD/ Respiratory Disease/ Respiratory Failure• Stroke/Cerebrovascular Accident• Neurological Disease such as Motor Neurone Disease/Multiple Sclerosis/Parkinson’s Disease• Dementia Alzheimer’s/ Other causes• Uncontrolled Diabetes Mellitus• Frailty with multiple co-morbidities (illnesses)(e.g. arthritis/osteoporosis etc)
If yes, move to step 2.
Step 2. Does the patient have any of the following problems? (ask the patient and/or their caregiver)
<ul style="list-style-type: none">• Decreasing activities of daily living<ul style="list-style-type: none">○ In bed for >50% of the day○ Increasingly relying on others for self-care (bathing/dressing/eating)

<ul style="list-style-type: none"> ○ Incontinence ● Has had repeated unplanned hospital admissions in last 6 months/1 year ● Multiple co-morbidities (co-existing illnesses) with complex problems ● Losing weight unintentionally over past 3 – 6 months/ clothes getting too big/ >10% unintentional weight loss/muscle wasting ● Losing appetite ● Has had a serious fall ● Becoming confused ● Patient or family request change in goals of care i.e. withdrawing active interventions ● Is experiencing serious social difficulties as a result of the illness ● Advancing disease – which is unstable and deteriorating – (for health care professionals, see specific criteria in appendix D)
<p>If a patient has one or more of the illnesses in step 1 and fulfills any of the criteria in step 2, the patient may need palliative care interventions and a more detailed assessment of need should be performed.</p>

Table 1: Questions to ask a patient and/or the caregiver to evaluate the need for palliative care

3.2 Paediatric Palliative Care

Identifying children in need of palliative care is different because of the different needs of children and their families, and the different disease trajectories.

The UK based Association for Children with life-threatening (ACT)^{viii} and life limiting conditions proposed four different categories of children requiring palliative care (Table 2). The classification is a useful guide for identifying children who may have palliative care needs and for developing care plans and deciding with families the appropriate levels of care and treatment; as well as what to expect over the trajectory of the illness (Diagram 3).

ACT Category I	Life-threatening conditions where cure is possible but may fail (e.g. Acute Lymphoblastic Leukaemia, Malnutrition, TB)
ACT Category II	Conditions for which premature death is inevitable, but long periods of wellness with reasonable quality of life are possible because of available treatments (e.g. HIV on HAART, Cystic Fibrosis)
ACT Category III	Progressive conditions where there is no known cure. Treatment is exclusively palliative from the outset (e.g.: some genetic disorders e.g. trisomy 13 and 18, inoperable congenital heart disease, inborn errors of metabolism etc)
ACT Category IV	Conditions that are irreversible but non-progressive and often associated with disability e.g. Cerebral Palsy, Down’s syndrome without major heart abnormalities

Table 2: ACT Classification of conditions requiring paediatric palliative care

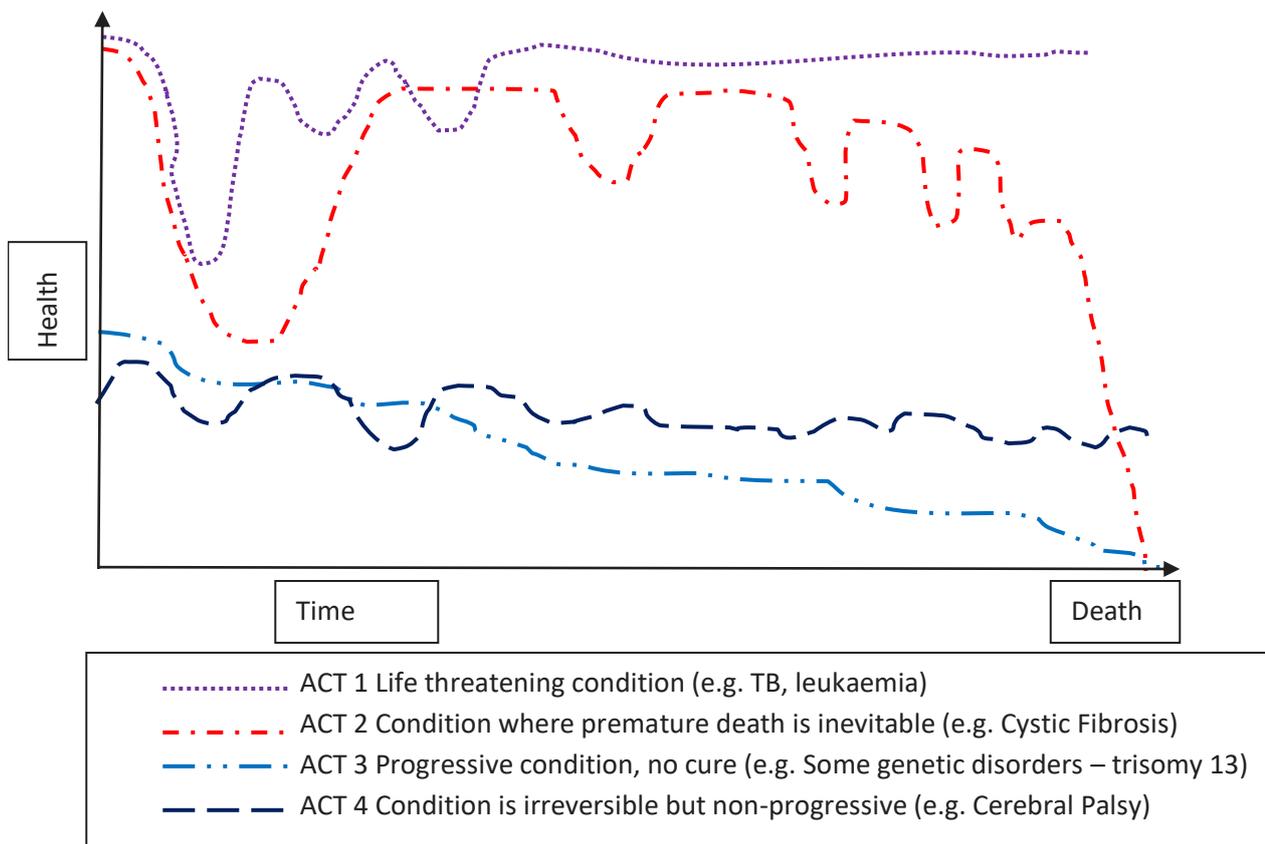


Diagram 3: Trajectories of Paediatric Diseases requiring palliative care

4. Special considerations

Palliative care services as outlined in this document must be accessible by all persons in South Africa as defined in the WHA resolution; and such is the intention of this policy. It is important to highlight those groups of people who require special consideration when planning the provision of such palliative care services so that no single group is forgotten in the process and the needs of all are provided for.

- **Persons with disabilities (PWD)**

There is an overall lack of understanding of the unique needs of PWD (both physical and intellectual), which makes it difficult for them to access appropriate palliative care. High levels of poverty, as a result of unemployment and underprivileged social conditions and difficulties with transportation make access to health care challenging. Additional challenges include inaccessible products, devices, services, or environments within the health care sector. To combat these challenges, health care facilities and institutions, services, policies and environments should adhere to universal design principles for PWD. The Ideal Clinic specifically creates access to facilities by PWD by including ramps and appropriate signage but this is not yet universally accessible.

Equitable access to home-based palliative care for PWD is not always possible due to a lack of disability specific training and because of stigmatisation. This is of particular concern for persons living in disadvantaged environments such as informal settlements and remote and rural areas. These persons with disabilities are at a higher risk of experiencing pain, suffering and loneliness due to the lack of access to services and the continuous decline in their social circumstances.

- **Children (including neonates and adolescents)**

According to a study conducted by UNICEF and ICPCN an estimated 801 155 children need generalist palliative care and 304 441 of these need access to more specialist services^x. Only 14 501 were accessing formalized services in 2013. Whilst paediatric palliative care is philosophically similar to adult palliative care, the diverse spectrum of diseases and the difficulties encountered with caring for children in general require that health care professional trained in their care are involved so that they are not treated as “small adults”. With the success of ARV rollout and PMTCT, the population of children needing palliative care increasingly consists of children with complex and sometimes rare conditions whose care is often concentrated in tertiary settings. Obstetric and peri-natal problems compound this need with a growing number of babies with cerebral palsy and other long term disabilities.

Children are vulnerable and unable to access palliative care due to a number of factors including their age or developmental stage, legal status, dependence on parents/guardians, cultural norms, illness, disability, poverty, orphanhood or abandonment, lack of trained health care providers, non-availability of essential palliative care medicines in paediatric formulations, and distance from health services.

Those caring for seriously ill children, including /especially young mothers living in poverty may not have sufficient support to enable them to provide care, and require comprehensive services to support themselves and their child/children. Children with chronic conditions who are identified as being “in need of care” end up being institutionalized in facilities governed by Social Development with insufficient input from health to manage their medical and especially end of life needs. Only a minority of South African hospices also provide palliative care for children.

Given the lack of competency of the children, adults make proxy decisions for them and persistent paternalism amongst some treatment providers (especially those that struggle to accept dying in childhood) may result in children experiencing a high burden of suffering both from disease and from futile treatment. There is a need to train the multidisciplinary healthcare workforce in palliative care tailored towards meeting the unique needs of children.

- **Older Persons including those living in residential care settings and frail care facilities:**

Persons over 60 years of age comprise an estimated 8% of the population but contribute to 40% of the total annual deaths per year in South Africa. Approximately 20% are in poor health due to multiple co-morbidities and declining vision, hearing, memories, mobility and incomes. At the same time, they experience increasing social isolation, depression and the side effects of inappropriate polypharmacy (multiple medications). Increasing numbers are being institutionalised in overcrowded, understaffed and poorly managed long term care facilities, and are rushed to casualty units of already overcrowded hospitals when they deteriorate. Many die in hospitals when they would prefer to die at home. There is little coordinated assessment and appropriate long term care planning by multi-disciplinary professionals with a palliative care approach.

Given these complexities older persons may require palliative care earlier in the disease trajectory long before the “terminal phase”. Symptoms may be misinterpreted as being due to “old age”, putting older persons at high risk of under- assessment and under-treatment of conditions that may affect their quality of life.

Additional challenges include poor access to health care services either due to socio-economic circumstances and or due to frailty and lack of mobility, similar to the challenges faced by people with disabilities.

- **Asylum seekers and refugees:**

Registered asylum seekers and refugees are afforded access to health care as determined by Constitutional and Legislative frameworks.

People with no legal status in South Africa, such as illegal immigrants or unregistered refugees and asylum seekers, who do not have legal documentation, suffer as they are denied access to the health or social services required for palliative care. Furthermore, it is difficult to meet the palliative care needs of this vulnerable population, given their lack of formal status and access to services.

- **Inmates of Correctional services**

The provision of palliative care in prisons is challenging because of the hostile environment with limited access to families and a lack of sufficient carers in prisons for terminally ill inmates. Most prisons only have access to nurses during day time so opioid administration at night is challenging.

It is recognized that the Department of Correctional Services has made progress in addressing palliative care in the facilities and the policies should be aligned with that of the Department of Health to ensure equitable palliative care services for all South Africans. It is also important that the issue of medical parole is addressed and that a strategy is developed for a multi-disciplinary team specialised in palliative care to be consulted on medical parole issues and in the implementation of comprehensive care.

- **Persons in long term care facilities such as TB and Psychiatric hospitals or residential care facilities:**

Patients in long term care facilities such as TB and Psychiatric hospitals, or residential care facilities are marginalised because of the lack of care pathways to medical and palliative care as well as staff who are not trained to recognize the palliative care needs of residents. Staff shortages may limit a multidisciplinary approach to care.

5. Models of Care

Internationally, different models of palliative care service delivery based on needs in a population have been developed (Table 3). In South Africa, palliative care is being broadened from a concept of end of life care to encompass a palliative approach to all life limiting illnesses and to those who need support and care while suffering from a chronic illness.

Different local needs and situations will require different models of care. Each province and district may adopt a model or combination of models that best suit their needs. Examples of existing different local models of care include the Abundant Life project at Victoria Hospital^x, an integrated community palliative care model initiated at South Coast Hospice in KwaZulu-Natal^{xi} and the Gauteng Centre of Excellence for Palliative Care based at Chris Hani Baragwanath Academic Hospital.

Model	Description
Home-based Palliative Care	A palliative care service provided by professionals and lay caregivers in patients' homes. Physical, psychosocial and spiritual care is offered. This consists of regular palliative assessment by a suitably qualified nurse, who supports the family and lay caregivers. Essential palliative care medicines are available for use. Referrals to the appropriate services are made. This is the commonest model of palliative care in Africa, especially for patients too frail to access care at a clinic. The community (family, friends and volunteers) are the major role players in care of the patient.
Mobile Outreach services	A mobile palliative care team visits remote health facilities linked to the parent health facility, to see patients who cannot travel long distances to access care. A referral system is in place to arrange visits to patients too sick to reach the mobile service, to be seen at home.
Outpatient Care	Palliative care is offered for ambulatory patients at clinics. Either a specialised palliative care team or health care workers at a clinic can provide palliative care. Clinics would range from the primary health care clinic to specialised clinics at a tertiary level hospital.
Inpatient palliative care facility	A specialist palliative care inpatient unit for the management of symptoms and pain unmanageable at home, as well as for respite care and for terminal care where death in the home is undesirable. The focus is on comfort which is different to that of an acute hospital ward.
Hospital based palliative care teams	A consultative palliative care service provided by a specialist fully multidisciplinary palliative care team. The patient remains the responsibility of the admitting and treating team, but is supported by the palliative care team.
Day Care Palliative services	Ambulatory patients spend one or more days at a centre, which may be independent or attached to another service (e.g. a hospital or a clinic). Programmes may be offered to assist patients and families with coping with the illness, Occupational therapy or skills training may be offered. Counselling and medical services are usually available. The day care is often supported by volunteers.
Frail Care and other care homes	Palliative care is offered in frail care and other care homes, either by a specialist team which may visit or by in house staff who have been trained in palliative care.
Workplace programs	Palliative care programs to provide bereavement support and information about palliative care. The programs are often initiated by the employer with support from palliative care professionals for any information or therapeutic interventions.
Correctional services	Palliative care services provided within correctional facilities either by the health care professionals within the facility or by visiting palliative care professionals.

Table 3: Models of Palliative Care

6. Why is a National Policy Framework and Strategy for Palliative Care (NPFSPC) required

In order to meet the needs of patients requiring palliative care, a national policy framework and strategy in line with the WHA resolution is required. Such a policy framework and strategy must address the structural challenge, burden of disease demands, health system challenges and social determinants of health.

6.1 Structural Challenges

- **Inequitable Access:**

As hospice services grew, palliative care was a service available only to a select group of individuals while others had no access to palliative care at all. Traditionally, palliative care was offered to patients when all else failed; meaning that palliative care interventions would not be effective as the illness was too far advanced

and the patient had already undergone significant suffering. It also meant that health services are often inappropriately utilised as families and health care workers fail to understand the illness trajectory. There is evidence that early palliative care, from the time of diagnosis of a serious condition, improves a patient's quality of life, reduces depression and may even have the capacity to prolong life^{xii}.

- **Social and Economic Costs:**

Government bears the cost of providing health care, social grants and support services. In addition to these costs, advanced illness contributes to other costs that are borne by employers due to absenteeism and high staff turnover from both morbidity and mortality.^{xiii}

The high cost of care-giving services means that a family member may need to give up professional or academic endeavours to look after an ill relative. This type of financial and personal commitment can often place significant strain on family relationships.

6.2 Burden of Disease Demands

According to the WHPCA, 37.4% of all deaths from causes worldwide need palliative care. In Africa it is estimated that 353 in 100,000 adults and 160 in 100,000 children need palliative care at the end of life^{xiv}.

Data from the most recent Statistics South Africa Mortality and Causes of Death in South Africa report (2017)^{xv} indicates that in 2015, more than half of all natural deaths (55%) were due to non - communicable diseases, 33% to communicable diseases and 11% to injuries. TB was the leading underlying cause of natural deaths at 7.2% with diabetes mellitus the second most common cause of natural death at 5.4%. HIV was the fifth most common cause of death (4.8%) after, TB, diabetes mellitus, cerebrovascular disease and other forms of heart disease.

South Africa's Under 5 Mortality Rate (U5MR) in 2013 was 40.5/1000 births (data.worldbank.org; 2016) which is a reduction by one third (33%) of what it was in 1990 (61/1000 births) but still far from the MDG of achieving a U5MR of 29/1000 by 2015. Although many of these deaths are preventable and every effort should be made to continue to reduce these deaths, these statistics also provide an indicator of the number of young children who may benefit from a palliative care approach and of the families who may need U5MR bereavement support.

Most of the reported deaths are due to illnesses that require palliative care, either from diagnosis or at later stages of the illness trajectory, depending on the severity of the symptoms and suffering. Palliative care is required for neonatal conditions that are life threatening, and may be indicated in the ante-natal period in some conditions where the outcome is expected to be distressing to the family. Palliative care for children is vital to support patients and their families while coping with the implications of their condition.

As a developing country South Africa is in a unique position of dealing with a quadruple burden of disease. Burden of disease refers to mortality, morbidity, injuries, disabilities and other risk factors which impact the health of a population.

The burden of disease (BOD) was categorised in 3 broad categories by the Global Burden of Disease study, with South Africa adding HIV/AIDS as a subgroup.

Group 1A: HIV/AIDS (the additional group in South Africa)

Group 1B: Pre-transitional causes, includes communicable diseases, maternal causes, peri-natal conditions, and nutritional deficiencies

Group 2: Non-communicable causes

Group 3: Injuries

There were 7 million people living with HIV in 2016, with on average 56% of HIV+ adults and 55% of children receiving ART^{xvi}. This is a large group of people that would benefit from palliative care services during their illness; in particular through education and treatment support to enhance adherence and to improve quality of life.

The 2002 WHO Definition of Palliative Care shifted the focus of palliative care to providing quality of life to all patients and their families throughout the course of an illness. This means that besides mortality data, it is necessary to measure the burden of disease in terms of morbidity and impact on individuals as well as families, support structure and communities. A metric for measuring burden of disease is the DALY (Disability adjusted Life Years), which measures the “healthy years of life lost due to each incident case of, disease or injury” by adding together “years of life lost (YLLs) due to premature mortality, and years of life lived with disability (YLDs) weighted according to the severity of the disability.”^{xvii}

With regards to individuals living with a disability, according to a report from Stats SA, released in 2016 “The national disability prevalence rate is 7.7% in South Africa. Persons with disabilities increase with age. More than half (73.1%) of persons aged 85+ reported having a disability.”^{xviii} The WHO estimates that prevalence rates of disabilities in adults 18 years and older was 15.6%. It is noted, however, that not all persons with disabilities require palliative care.

According to the 2nd National Burden of Disease Study, the five leading causes for premature mortality (YLL) in 2012 were: HIV (35.7%), cerebrovascular disease (4.8%), lower respiratory tract infections (4.6%), TB (4.6%) and interpersonal violence (4.6%).

A comparison between South Africa and similar locations in the world (based on GBD regional classifications, known trade partnerships, and income classifications), shows that South Africa’s burden of disease in terms of YLL is higher than the average of all these countries^{xix}. (See Appendix C)

This clearly places a huge burden on the finances, facilities and human resources required for individual care and highlights the need to introduce measures aimed at reducing the BOD.^{xx}

According to a report issued by the United Nations International Children's Emergency Fund (UNICEF) and the International Children’s Palliative Care Network (ICPCN) in 2013 an estimated 801,155 children in South Africa needed palliative care and 304,441 of them required specialist palliative care^{xxi}. Palliative care for children includes life limiting illnesses that may not directly result in death, such as severe cerebral palsy, as is indicated in table 1 and diagram 3. Therefore these figures do not only reflect mortality but also burden of disease. Currently, only 14,501 children in South Africa are accessing formalized palliative care services^{xxii} provided largely by NGO funded children’s hospices and palliative care programmes in hospital and home care settings.

6.3 Estimating the Need for Palliative Care in South Africa

Estimating need for palliative care in South Africa is a complicated process. The population statistics required to quantify the need for palliative care go beyond death registration statistics and include disease prevalence statistics as well as hospital admission statistics. However, these statistics are not readily available in many countries, including South Africa. Thus, an initial baseline assessment of need may be estimated using mortality data.

A recent paper written by Murtagh *et al* studied the different methodologies for estimating need for palliative care and will serve as a basis for the estimation exercise for this document. Need is defined as the ability of the population to benefit from palliative care, utilizing a normative (defined as a professional’s perspective) approach. The Murtagh group used death registration data with both underlying and contributory causes of

death to estimate the need for palliative care as a relatively simple method which did not require symptom information or hospital data.

The estimated need for palliative care in high income countries, using this method, was 69 – 82% of all persons who died^{xxiii}. Another multi-national study by Morin *et al* estimating palliative care need in 12 countries both high income and middle income, estimated a need ranging from 38% -74% across all countries^{xxiv}.

The Quality of Death Index Report^{xxv} used a mix of factors in calculating palliative care need:

- burden of disease (mortality rates combined with pain ratios for each disease),
- age dependency ratio
- and speed of aging of the population.

This may be a more accurate reflection of need but requires considerably more information.

Factors to consider when assessing the need for palliative care include:

- the conditions that would benefit from palliative care for adults and children;
- and the prevalence and severity of symptoms for these conditions;
- the intensity of care that would be required

Table 4, below represents the need for palliative care in South Africa using a modification of the Murtagh method as some of the ICD10 codes were not provided exactly as suggested by Murtagh *et al*. The mortality statistics which include all deaths, adult and paediatric (2014) were sourced from statsSA^{xxvi} Estimating palliative care need from mortality statistics alone only reflects end of life care need and therefore under-represents the total need from time of diagnosis of a life-threatening illness.

Underlying Cause of Death	ICD10	Number	Percentage
Total Deaths		453 360	100
Total Natural Causes		405 599	89
Malignant Neoplasm	C00 – C97	37 812	8.2
Heart Disease	I00 – I52	75 963	16.8
Renal Disease	N17, N18, N28, I12, I13	6 848	1.5
Liver Disease	K70-K77	4 173	0.9
Respiratory Disease	J06-J18, J20-J22, J40-J47 & J96	16 685	3.7
Neurodegenerative Disease	G10, G20,G35, G122 G903 G231	531	0.1
Alzheimer’s, dementia and senility	F01, F03, G30, R54	1 260	0.3
HIV/AIDS	B20 – B24	21 938	4.8
TB	A15 – A19	37 878	8.4
Total		203 088	44.7
<i>Diabetes Mellitus (not included in Murtagh method)</i>	<i>E10-E14</i>	<i>22 747</i>	<i>5.0</i>
Total including diabetes mellitus		225 835	49.7

Table 4: Mortality numbers in South Africa in 2014 due to diagnoses identified as requiring palliative care services

From calculations using the Murtagh method, the estimated need for palliative care in SA in 2014 would have been about 45% – 50% of all deaths. This is also within the range of estimates reported for middle to high income countries by Morin *et al.*

The estimate is also comparable to indicated need from the Quality of Death Index Report 2015^{xxvii}, which estimates that South Africa has a high demand for palliative care, similar to that of other high-income countries, possibly because of our unique quadruple burden of disease with a mix of non-communicable diseases, HIV and TB.

Limitations of this method of estimating need

As discussed previously, this estimate is only a crude calculation based on mortality data and does not include patients living with severe life limiting illness. It serves as a baseline from which more detailed studies can be implemented to better estimate the actual need in South Africa.

6.4 Health System Challenges

Along with the burden of disease there are a number of health system challenges in providing adequate palliative care services to adults and children with life-threatening or life limiting illnesses. This section explores the challenges utilising the WHO health systems building blocks as a framework; as depicted in diagram 4.

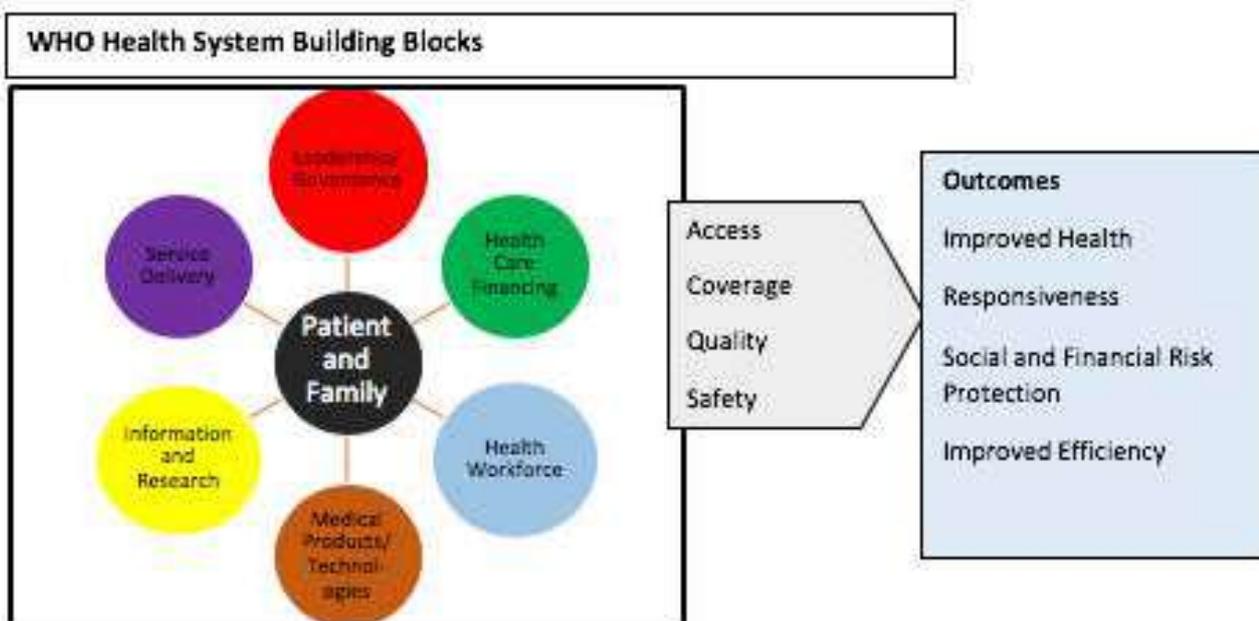


Diagram 4: WHO Health Systems Building Blocks

6.4.1 Service Delivery:

Currently, palliative care is not consistently provided within South African health facilities. In the absence of a policy, palliative care has been developed *ad hoc* by individual champions for service(s) to those in need; thus resulting in substantial sustainability issues.

There are a few known hospital based providers in which palliative care service is offered. Some facilities provide an inpatient consultation service, some have palliative care wards, some provide emergency palliative care service, and others provide an outpatient service (including selected correctional services facilities). The Gauteng Centre of Excellence for Palliative Care is the only Department of Health funded specialist palliative care centre in South Africa providing service delivery, in the form of a hospital consultative service, an outpatient clinic, as well as a community outreach palliative care service; in addition to teaching and research in an academic institution.

In terms of public sector primary health care provision, there appears to have been a confluence of palliative care and home-based care. Home and Community-Based Care (HCBC) refers to health services rendered by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health. Yet, these two concepts of a home-based palliative care service (refer to models of care) and home-based care are not, technically, synonymous.

Spiritual care is a very important component of palliative care which is currently provided by volunteers from NGOs, or from the community. A spiritual approach to healing is usually an important practice by traditional healers.^{xxviii} Health services should partner with spiritual or religious counsellors and traditional healers to attend to the spiritual needs of patients and their families and thus provide a more holistic approach to healing.

NGOs, for example the Hospice Palliative Care Association (HPCA) of South Africa, are very active in providing a range of palliative care services for both adults and children through member hospices in many localities across the country. Hospices provide palliative care services in the community through home-based care models as well as some specialist inpatient services.

Home-based care provided by trained lay people does not include pain and symptom assessment but does provide support for the family.

Linkages to care:

With the *ad hoc* nature of services, there is a severe lack of effective communication and appropriately defined care pathways between service providers, resulting in large gaps in the continuum of palliative care. Persons in need of palliative care should be identified early and should be put onto a specific care pathway with clear referral processes up and down the tiers of healthcare to ensure continuity of care throughout the course of the illness. Early identification can be achieved through the use of a clinical screening tool (as discussed on page 14), which assists health care providers in identifying patients with palliative care needs, regardless of prognosis.

6.4.2 Health Workforce:

A major challenge in providing palliative care in South Africa includes a lack of recognised qualified home health care workers. There is also an absence of curricula, limited formal training and resources, and no clear definition of roles and responsibilities pertaining to the different cadres of health care workers. Hence medical personnel are unable to identify persons in need of care, assess their symptoms or alleviate their suffering through adequate management. Nurses and other health care workers within the multi-disciplinary team receive minimal training to enable them to recognise the needs of individuals seeking assistance for palliative care.

Given the relative scarcity of medical doctors in South Africa (0.77 per 1000 population); it has been argued that task-shifting is needed for the provision of equitable palliative care services. This would, for example, entail changes to prescription regulations that would allow nurses to prescribe opioids.^{xxix} Recently, a policy allowing for nurse prescribing of medication from the PHC STG and EML has been approved; however, it is not clear if prescribing of opioids would be included. Morphine or other opioids are required to provide adequate pain relief to patients including those with advanced illness. Severe human resource constraints result in nurses being the only health professionals available to provide palliative care in many rural and poorer areas of South Africa. Appropriately trained nurses can safely and effectively provide palliative care including prescribing of morphine. Because of inadequate numbers of suitably trained staff (5 nurses per 1000 population), it is difficult to carry out any task shifting which may make the provision of palliative care more accessible. As a consequence, it is the poorest and most marginalized patients, who are entirely dependent upon the public health sector, which may not receive the services they desperately need.

Palliative care is best provided by a multi-disciplinary team which includes health workers and allied health professionals and social workers. Currently there is no structured or formal mechanism in the public health sector to bring individuals together within a multi-disciplinary approach.

While there are a number of community-based health workers (CBHW) in the districts, it is not clear what their roles are in terms of provision of palliative care and there appears to be confusion as to the extent of their responsibility. Furthermore, CBHWs who are providing home-based care need better training, reasonable reimbursement and more support with regards to dealing with and/or preventing psychosocial suffering.^{xxx} A further challenge is that CBHWs do not have a career path opportunity, and care work as a profession is not regulated by any specific policy. Currently, CBHWs must perform their activities under the supervision of a registered nurse who is suitably qualified in palliative care. A shift in the way South African's approach the subject is beginning to change. Whilst palliative care was previously not included in nursing, allied health or medical school training, this has begun to change.

Palliative care is now included to varying degrees in the undergraduate curricula of medical and nursing students across the country. The University of Cape Town and University of the Witwatersrand (Wits Centre for Palliative Care) both have a robust palliative care curriculum embedded within the undergraduate medical curricula. However, there is no uniformity in the content or quantity of palliative care being taught. Currently, postgraduate training in palliative care is only offered by the University of Cape Town.

Palliative care courses are offered by other organisations, for example HPCA, for various cadres of professional and lay health care workers, social workers and spiritual counsellors.^{xxxi}

6.4.3 Medical products and Technologies:

A lack of knowledge concerning the need for essential palliative care medicines, most notably morphine, hampers the adequate provision of pain management. Currently the morphine allowance for South Africa is calculated on prior usage which does not imply that the need is met; particularly when there are problems of access to medicines due to supply chain disruptions and lack of adequate prescribers and pain assessment by health care providers. As mentioned there are problems with ensuring continuous uninterrupted supplies of medications to the patients either at supply chain management level or in the simple delivery of medicines to immobile patients in their homes. Complicating matters even further, paediatric formulations are often unavailable.

The Standard Treatment Guidelines (STGs) and Essential Medicines List (EML) *Hospital Level, Paediatrics* contains a section on palliative care, including a 'Three Step Analgesic Ladder'.^{xxxii} However, the latest WHO Guidelines for the Pharmacological Treatment of Pain in Children with Medical Conditions (WHO 2012) recommends a two-step approach for children.

The STGs and EMLs for *Hospital Level, Adults* and *Primary Health Care Level* do not contain specific sections on palliative care (although the latter does mention palliative care in the context of certain conditions, such as cancer).^{xxxiii,xxxiv}

6.4.4 Information and Research

It is difficult to identify government sources of palliative care information, or access to information/communication support with regards to the delivery of palliative care services.

Information is much more readily available from NGO sources (e.g. the HPCA website).

Research related to palliative care is carried out by a number of academic institutions, including University of Cape Town^{xxxv} and the University of the Witwatersrand.^{xxxvi} Furthermore, South African institutions are active in the African Palliative Care Research Network.^{xxxvii}

6.4.5 Governance and Financing:

The Minister of Health has already demonstrated a commitment to palliative care services, but the pledge to make it work effectively must also come from varying levels of health care providers. An obstacle to overcoming this challenge is that palliative care as a health service module has not been determined and therefore adequate funding has not been allocated for the delivery of care.

The cost of palliative care services has not been determined both for district health services and primary health care within district health services and at hospital level. Currently there is no costing model in place.

Existing service providers receive some subsidization from government sources which are not adequate for the need. Many of these organizations are largely reliant on donor-funding, making them particularly vulnerable to changes in donor patterns.^{xxxviii xxxix}

6.5 Social Determinants of Health

It is difficult to evaluate South Africa's morbidity and mortality without consideration of the social determinants of health, or the economic and social conditions which influence individual and population health outcomes.

Lack of access to water, sanitation, education and employment all impact the health of the population. It is impossible to have optimal health in South Africa for all, until these social determinants of health are addressed. These also impact on the provision of palliative care through lack of access to adequate resources to ensure the comfort, dignity and quality of life of patients being taken care of at home. Regrettably, the lack of access to care and services also perpetuate the cycles of poverty and inequity.

Health system reforms such as the re-engineering of primary health care and National Health Insurance (NHI) aim to address the structural inequities of the health system, but the challenges of poverty, unemployment and unequal access to education are increasingly recognised as influencing health outcomes. The National Development Plan 2030 (NDP) outlines the government's plan for eliminating poverty and reducing inequality by 2030, and is central to efforts to address social determinants of health. Palliative care addresses the psychosocial aspects of suffering in addition to the physical pain and other symptoms. Palliative care teams are instrumental in reducing the social burden of disease on a family by facilitating access to social services and encouraging family members to work together and to support one another.

7. South Africa's Response to Advancing Palliative Care

In 2014, the World Health Assembly (WHA) recognised the transition in palliative care services, adopting WHA Resolution 67.19, "Strengthening of palliative care as a component of comprehensive care throughout the life course."² The resolution describes palliative care as an approach that improves the quality of life of patients (adults and children) and their families, who face life-threatening illness by preventing and alleviating unnecessary suffering. It advocates for service integration within the continuum of care, across all levels of the health system, with a focus on primary health care. The resolution is ground breaking in that this is the first time member states have addressed the issue of palliative care.

The WHA resolution emphasises the shift in the WHO 2002 definition of palliative care from a service, provided to those dying from a life-threatening illness, to a life-affirming approach which values the quality of the life lived and seeks to support patients, families and caregivers throughout the course of illness. South Africa was one of the co-sponsors of the WHA resolution which was adopted unanimously by member states. (See Appendix B) The resolution has a 9-point guiding implementation in member states. It urges all (194) states to:

- 1) to develop and implement palliative care policies;
- 2) to ensure adequate domestic funding and allocation of human resources for palliative care initiatives;
- 3) to provide basic support to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals;
- 4) to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities;
- 5) to assess domestic palliative care needs, including pain management medication requirements, to ensure adequate supply of essential medicines in palliative care;
- 6) to review and revise national and local legislation and policies for controlled medicines;
- 7) to update, as appropriate, national essential medicines lists;
- 8) to foster partnerships between governments and civil society, including patients' organizations, to support the provision of services for patients requiring palliative care; and
- 9) to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of non-communicable diseases 2013–2020

In the South African context, the implementation of the resolution is particularly relevant given our quadruple burden of disease. The provision of palliative care as outlined in the resolution is also aligned to the NDP principles of overcoming inequity and poverty. A palliative care policy which is implemented by the health services in collaboration with other relevant departments and stakeholders, will address issues of universal health coverage, and the need to reduce suffering and promote development and dignity for all.

It is important to highlight that one of the main aims of palliative care is to relieve pain and other symptoms; and that pain is viewed as multidimensional. Dame Cicely Saunders^{xl} introduced the concept of total pain, which can be regarded as the cornerstone of palliative care, as it encompasses the whole palliative care approach. Pain is experienced as physical, emotional, psychosocial, cultural and spiritual and all of these aspects of a person's life need to be addressed to relieve pain and suffering. This requires a multidisciplinary team approach with an interdepartmental and multi-sectoral collaboration to address a patient's holistic needs. The WHA resolution for palliative care provides a foundation to ensure that adults and children have access to palliative care throughout South Africa. The WHA Resolution refers specifically to children as a group

² WHA resolution

requiring special attention and calls on UNICEF to work with civil society organisations to implement palliative care for children.

As a co-sponsor of the resolution, South Africa has been a vocal advocate for an integrated and holistic approach to palliative care services, and has committed to implementing a national palliative care policy which reflects the spirit and intent of the WHA resolution.

8. What will enable South Africa to deliver Palliative Care

South Africa already has many resources in place to deliver palliative care services. There is legislation and policies which support the principles of palliative care as well as an existing service delivery platform into which palliative care can be implemented. Special consideration needs to be given to certain vulnerable groups of our population, when planning the service delivery. With our guiding principles, the vision and mission of this policy framework can be achieved utilizing the goals and objectives set out in later sections. A comprehensive M&E framework will measure progress made towards a fully integrated palliative care service that reaches all who need care and support when faced with a life-threatening or life limiting illness.

8.1 Legislative and Policy Framework

This policy framework is underpinned by key South African legislation and policies and is guided by the values and principles embodied in the WHA resolution on palliative care. It supports the government's vision of "a long and healthy life for all South Africans", and aligns with key strategies and efforts to achieve improved health for all such as the primary health care re-engineering policy.

- **World Health Assembly Resolution 67.19**

The World Health Assembly's resolution 67.19 calls for the strengthening of the integration of palliative care services into national health systems, and defines palliative care as a basic human right. It advocates for a comprehensive service integrated throughout the continuum of care at all levels of the health system. South Africa is a co-sponsor of WHA67.19.

- **UN Convention on the Rights of Persons with Disability**

"Article 10 – Have the Right to life: States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others." And in Article 25: Health "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation."

- **Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013 - 2020**

Menu for Policy Options: Objective 4 (page 68): Develop and implement a Palliative Care Policy using cost effective treatment modalities, including opioids, analgesics for pain relief and training health workers.

- **Universal Health Coverage**

Universal Health Coverage (UHC) has been identified as target 3 of the Health Goal of the UN Sustainable Development Goals. UHC means that all people and communities can use the promotive, preventative, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while

also ensuring that the use of these services does not expose the user to financial hardship^{xlii}. The white paper on the NHI makes provision for palliative care to be included in the package of services

- **Constitution of the Republic of South Africa (Act No. 108 of 1996)**

State obligations are stated as follows:

- Section 10 of the Constitution states that “everyone has inherent dignity and the right to have their dignity respected and protected” and section 11 states that: “Everyone has the right to life”. Section 27 of the Constitution enshrines the right of access to health care, food, water and social security for all people, while Section 28 provides that all children have the right to basic health care services. The Constitution of South Africa binds the state to “take reasonable legislative and other measures within its available resources to achieve the progressive realisation of each of these rights” (stated under section 27).

- **National Health Act 61 of 2003**

The Act provides a framework for a structured, uniform health system taking into account the government’s obligations enshrined in the Constitution. It authorises the Minister to protect, promote, improve and maintain the health of the population and ensure the provision of “essential health services, which must at least include primary health care services”. Chapter 6, Section 41 (a) of the Act gives the Minister authority “to determine the range of health services that may be provided at the relevant public health establishments”.

- **National Patients’ Rights Charter**

Everyone has the right to access health care services^{xliii} that include: provision for special needs in the case of newborn infants, children, pregnant women, older persons with disabilities, patients in pain, persons living with HIV or AIDS, counselling without discrimination, palliative care that is affordable and effective in cases of incurable or terminal illness and a positive disposition displayed by health care providers that demonstrates courtesy, human dignity, patience, empathy and tolerance.

- **Medicines and Related Substances Act, 101 of 1965**

The Act provides for the registration of medicines and other medicinal products to ensure their safety, quality and efficacy. The Act enables a range of prescribers: Section 22A (5) outlines who can prescribe schedule 2-6 medicines, and states “a practitioner, a nurse or a person registered under the Health Professions Act, 1974, other than a medical practitioner or dentist, who may – (i) prescribe only the scheduled substances identified in the Schedule for that purpose; (ii) compound and dispense the Scheduled substances referred to in subparagraph (i) only if he or she is the holder of a licence contemplated in section 22C (1) (a). Section 22A (14) states, “(b)no nurse or a person registered under the Health Professions Act, 1974, other than a medical practitioner or dentist, may prescribe a medicine or Scheduled substance unless he or she has been authorised to do so by his or her professional Council concerned”.

- **Nursing Act (33 of 2005)**

This Act provides for the regulation of the nursing profession. Section 56 outlines the conditions under which the South African Nursing Council (SANC) may register a person, “to assess, diagnose, prescribe treatment, keep and supply medication for prescribed illnesses and health related conditions”

- **Traditional Health Practitioners Act (22 of 2007)**

This Act provides for a regulatory framework to ensure the efficacy, safety and quality of traditional health care services. The Regulations for Traditional Health Practitioners in Government Gazette No. 39358,

Notice No 1052 in terms of Section 47, read with Section 21 of the Traditional Health Practitioners Act prescribe the education requirements and the requirements for the registration of traditional healers.

- **National Development plan 2030**

The NDP sets forth a long-term vision for South Africa, outlining strategic goals to achieve by 2030. It outlines four long term health goals relevant to palliative care integration:

- Complete health system reforms;
- Primary health care teams provide care to communities and families;
- Universal health coverage; and
- Fill posts with skilled, committed and competent individuals.

- **DPSA: Employee Health and Wellness Strategic Framework for the Public Service. November 2012**

This document states that the provision of counselling services for employees are available and accessible in terms of employee psychosocial wellness (page 80)^{xliii}.

- **National Health Insurance Policy (National Health Act 2003) White Paper**

The NHI aims to achieve:

- People centred integrated health care service that takes into account socio-cultural and socio-economic factors whilst prioritising vulnerable communities
- Universal population coverage which ensures access to comprehensive quality healthcare services closest to where they live
- Health care services that will be accessed at appropriate levels of care and delivered through certified and accredited public and private providers

8.2 Organisational and Governance Structures

In order to successfully implement the Palliative Care policy and strategy, certain organisational structures must be in place to allow for proper governance.

- At the national level, the positioning of palliative care must allow for the engagement of all programs at all levels of care. The palliative care programme should not be implemented as vertical programs of service delivery i.e. silo implementation.
- At provincial level, the structures are to be aligned to the national structures to guide palliative care delivery at district level and to guide the integration of palliative care into the overall health plans.
- Consideration must be given for implementation of palliative care in the process of costing of the NHI service benefits
- The establishment of dedicated palliative care structures at the national and provincial levels are critical to the roll out of the palliative care policy.

8.3 Service delivery platform

Palliative care is to be available from conception to death across the continuum of care (Diagram 5). There is no age limit to those accessing palliative care as health begins from the time of conception until an individual's death. It is therefore critical that palliative care services are made available to all accessing the health care system. As a patient moves through the health system from one level to another and back home, there needs to be a co-ordinated, seamless transition of care with clear referral pathways and guidelines. The continuum of care is inclusive of health promotion, disease prevention, treatment, care and support, rehabilitation and palliative care underpinned by good environmental health within the context of the social determinants of health.

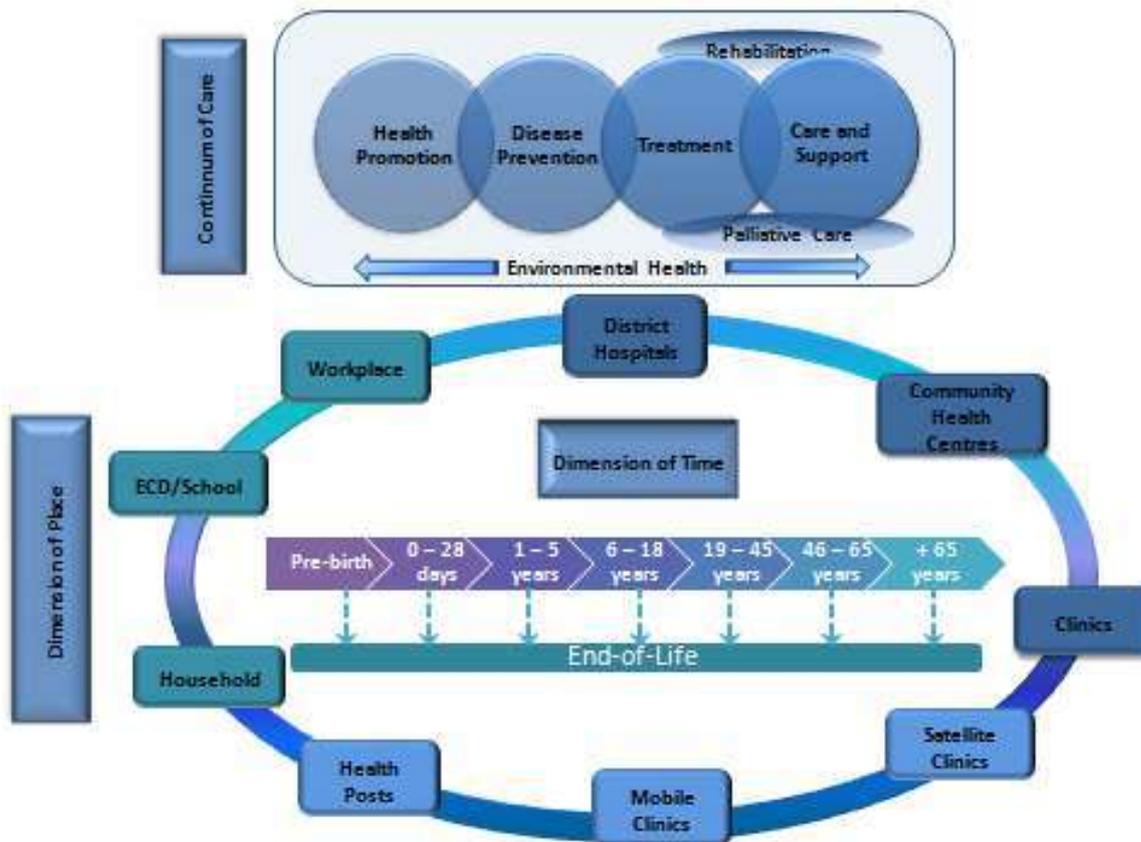


Diagram 5: Palliative Care fits within the continuum of care and throughout the life course (Draft PHC Package)

It is important that appropriate palliative care services are available at all levels of care from the point of diagnosis using appropriate clinical tools, and should be made available from tertiary hospitals through to community-based care. Palliative care is applicable from the time of conception through to old age.

Whilst it is important to have specialist level palliative care services available at tertiary institutions, most of the services will actually be provided at the district level within a community setting. As such it is important to include palliative care as an integrated and patient centered service that is based on health systems strengthening within the PHC re-engineering context (Diagram 6). Taking cognizance of the health system challenges, South Africa has embarked on the Ideal Clinic Realisation and Maintenance (ICRM) Program. An Ideal Clinic is equipped with good infrastructure, adequate staff, adequate medicine and supplies, good administrative processes and sufficient bulk supplies that use applicable clinical policies, protocols, guidelines to ensure the provision of quality health services to the community. An Ideal Clinic will cooperate with government departments and also, with private sector and non-governmental organizations to address the social determinants of health.

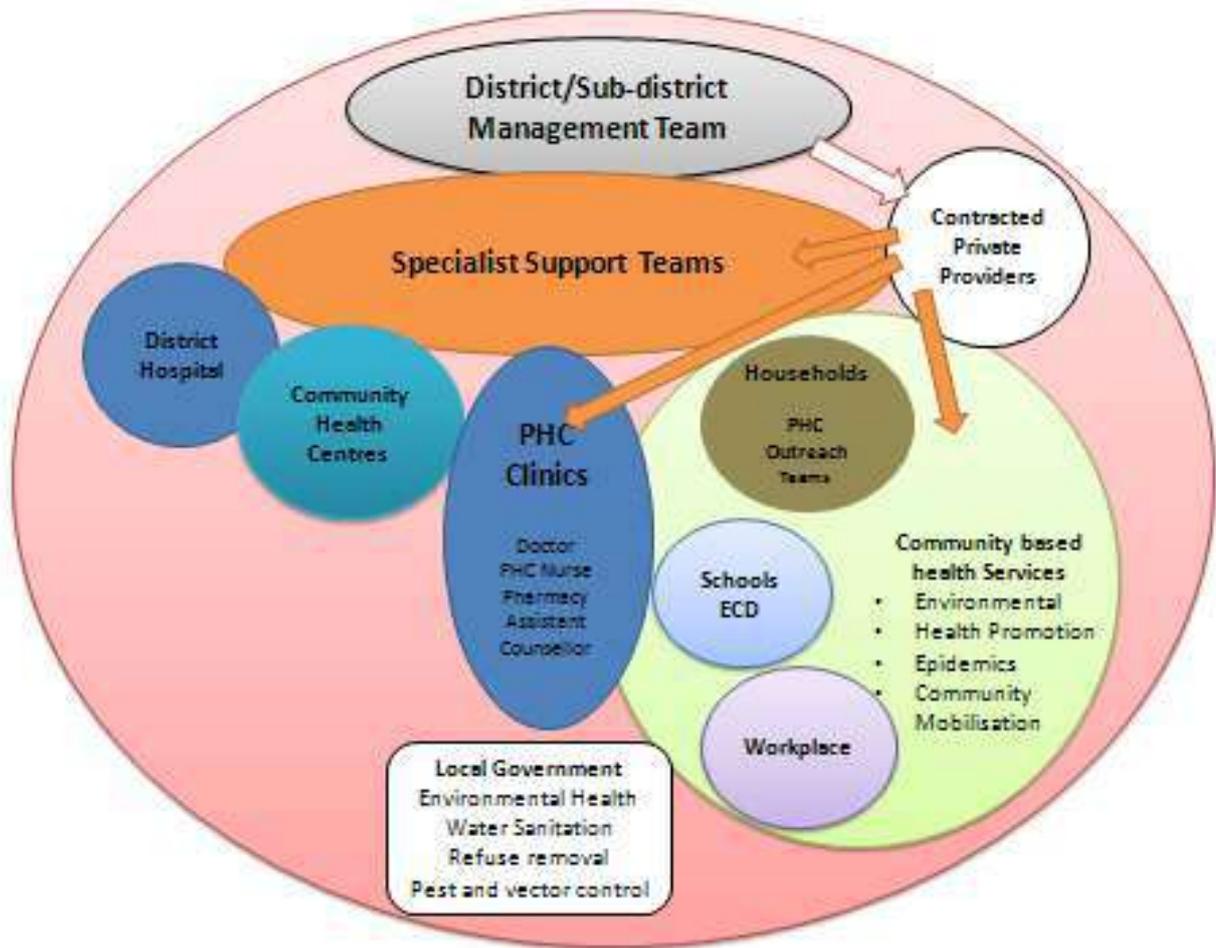


Diagram 6: Primary Health Care Re-engineering

This program endeavors to develop a platform for optimally functioning PHC to provide equitable access to all South Africans by prioritising health services to those in need. Community-based services are an integral part of PHC and must be complemented by appropriate PHC facilities and services. This platform is further strengthened by promoting sustainable public-private partnerships which are key to extending the continuum of care from the health facility to the community and patient’s home.

In strengthening the service delivery platform for palliative care, provinces should use the WHO building blocks approach for systematic strengthening of the health system.

8.4 Care and Support required for a Palliative Care Patient.

From the time of diagnosis, the patient with a life-threatening illness will need differing levels of support depending on their needs – physical, psychosocial and spiritual; and the intensity of the needs will change over time as the level of functioning changes and declines.

8.4.1 Packages of care for the patient

Table 5 shows the potential needs of a palliative care patient related to the level of function.

Packages of Care for a Palliative Care Patient – Related to level of functioning						
Medical	Psychosocial	Spiritual	Allied Services	Staff	Consumables/ Equipment	Transport
ECOG 0 to 2 (No limitation on activities, some limitation to activities of daily living, including inability to work to spending time in bed but <50%/day)						
Pain control Other symptoms controlled	Counseling – patient and family Education - patient and family ID documents/ Birth certificates Access to social grants as needed	Counseling and support for patient and family Advanced care planning	Access to allied services Physiotherapy Occupational therapy Speech Therapy Dietician/ Nutrition support	Nurses Doctor Allied Health Workers Nutritionists Social and Social Auxiliary Workers Psychologists Spiritual counselors	Morphine and other analgesics Other palliative medications Wound dressings	Patient and family transport to and from clinics/hospitals Public/private/ ambulance if acute need for admission
ECOG 3 (Unable to work. Spending >50% of day in bed. Needing some assistance with self-care)						
Pain Control Symptom control	Ongoing Counseling and education Social grants	Ongoing counseling and support	Ongoing access to allied services	Nurses Doctor support Allied Health Workers Nutritionists Social and Social Auxiliary Workers Psychologists Spiritual counselors Home-based Care Community Health Workers	Morphine and other palliative medications Wound dressings Zimmer frame/ walking (mobility) aids/ Wheelchair	Transport to and from clinic/hospital as above Transport for personnel doing home visits
ECOG 4 (Bedbound. Needs full assistance with self-care → moribund)						
Pain and symptom control Nursing care at home	Ongoing counseling and education for patient and family Support through the dying process Social grants	Ongoing counseling and support Funeral plans	Decreasing support from allied services	Home-based care Community Health workers Counselors – social and spiritual Nurses Doctor support	Morphine and other palliative medicines Wound dressings Decreasing need for walking aids and wheelchair Continence products (diapers, linen savers), gloves	Transport for personnel visiting homes. May need transport to a hospital/ sub-acute facility/ hospice (palliative ambulance)
ECOG 5 (Death)						
Certification of death	Bereavement counseling and support for family	Counseling and support Rituals	No further support	Doctor/paramedic/nurse to certify death		Transport to mortuary (usually for family to arrange)

Table 5: Packages of Care for a Palliative Care Patient

8.4.2 Levels of Care Required

Diagram 7 outlines the balance between complexity of need and the level of care required.

- The majority of patients (A) will have needs that can be adequately addressed at a community or primary health care level.
- Some patients (B) may have an acute exacerbation of pain or symptoms or experience psychosocial distress that requires a more specialized level of health care intervention (district or regional) to alleviate the need and will then continue care in the community.
- A very small proportion of patients (C) will have ongoing complex needs which require ongoing specialist level interventions – either at regional or tertiary level of care.

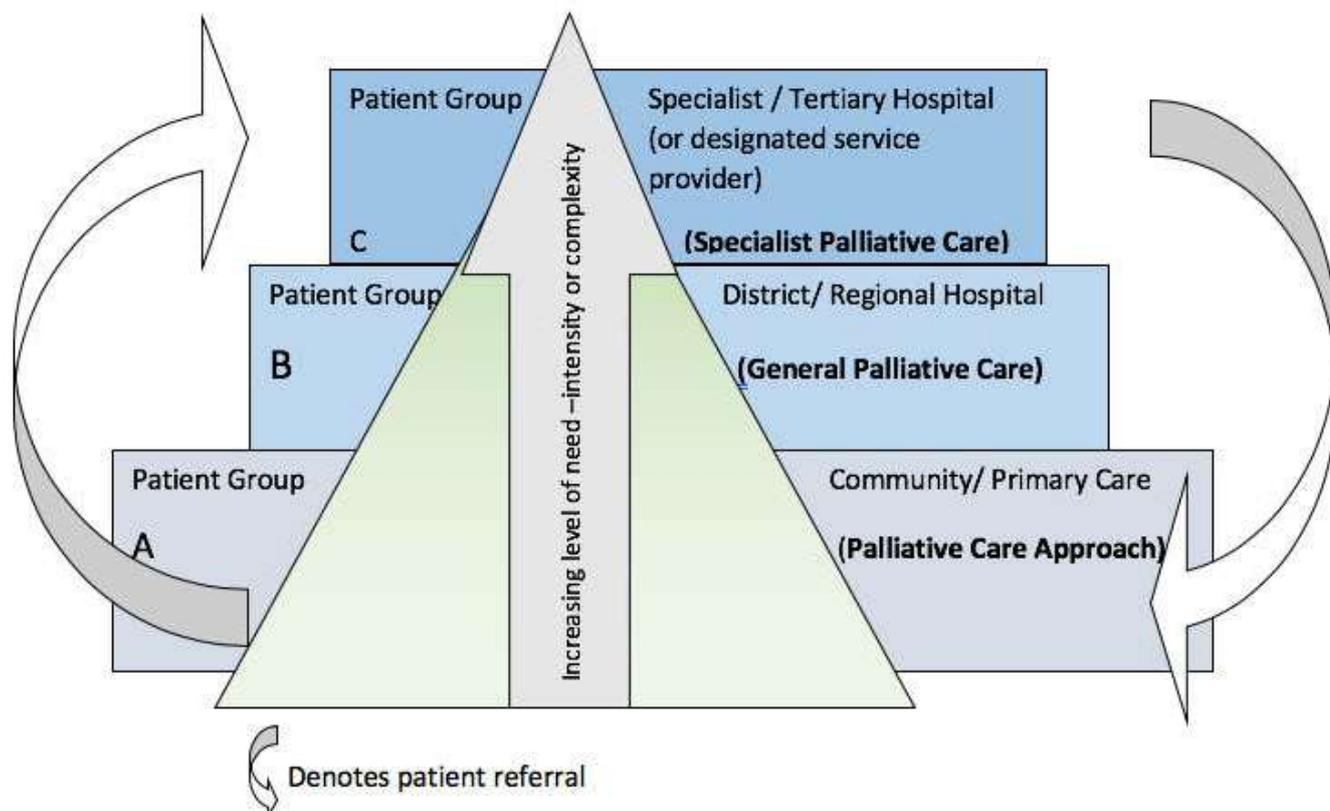


Diagram 7: Level of Need for Palliative Care and Level of Care

(Adapted from: Palliative Care Service Development: A Population based approach. Palliative Care Australia, 2005^{xliv}.)

Increasing level of need –intensity or complexity

Diagram 8 provides examples of patient pathways through the levels of care

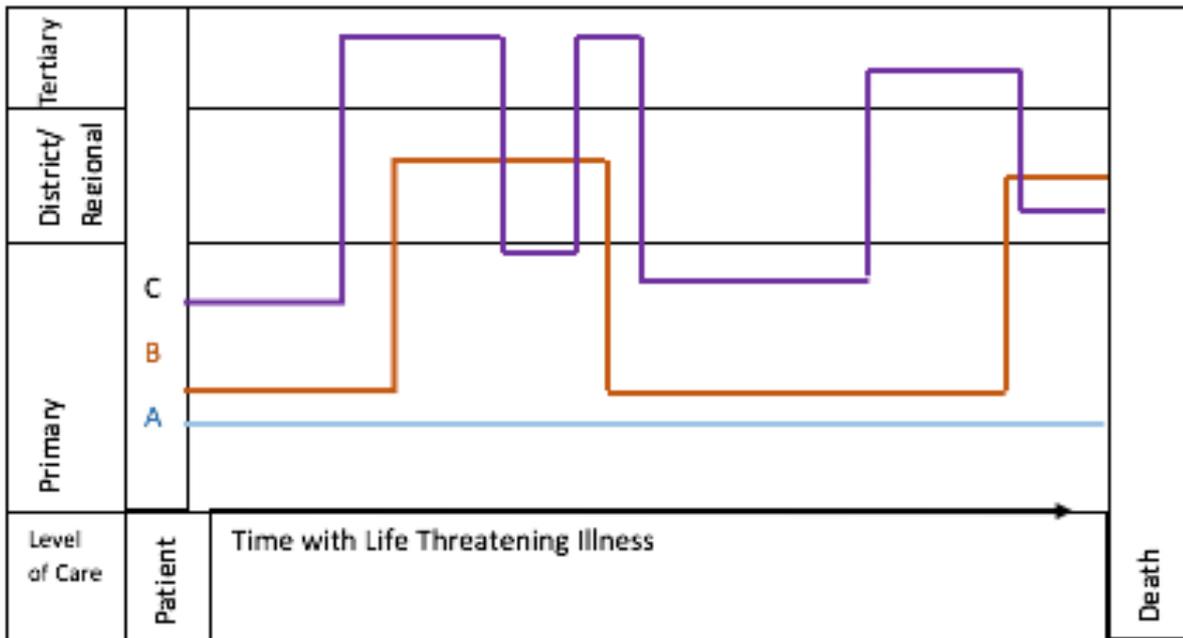


Diagram 8: Examples of patient pathways through the levels of palliative care
 (Adapted from: Palliative Care Service Development: A Population based approach. Palliative Care Australia, 2005.)

Health Care providers should be trained to offer differing levels of palliative care. Table 6, adapted from the Palliative Competence Framework^{xiv} (Dublin, 2014), describes the differing levels of qualifications of the various palliative care providers.

Levels of Palliative Care Expertise	Skills of Health Care Workers	Level of Health Service Delivery
Palliative Care Approach (All health care workers)	A Palliative care approach can be offered by any cadre of health care worker (HCW) at all levels of the health system. The palliative care approach should be included in all pre-service and in-service trainings. The undergraduate curricula of health professionals should include the palliative care approach. Most patients will have needs that can be adequately met by HCWs with this level of skill.	Community Primary care clinics Community Health Centres District hospitals Regional Hospitals Tertiary Hospitals (Non-Palliative Care Specialists)
General Palliative Care (Nurses, doctors, allied health)	General palliative care may be offered by HCWs who are not full time palliative care practitioners but have a higher level of training in palliative care (such as a postgraduate diploma or family physicians with appropriate training in palliative care).	Community Health Centres District hospitals Regional Hospitals
Specialist Palliative Care (Nurses doctors, allied health)	Specialist palliative care services are provided by full time palliative care specialists with relevant specialist postgraduate training in palliative care. (Master’s level or a specialist qualification in the future) These HCWs will care for patients with complex or high intensity needs at a tertiary level.	Specialist Hospitals

Table 6: Levels of expertise of Health Care Workers at each level of the Health Service

8.4.3 Care for the Carers

Caring for a patient with palliative care needs can be emotionally and physically exhausting. All those providing care, family members, friends and care workers, both professional and lay, need access to some form of support either through regular support groups or by one-to-one counseling sessions, to prevent “burn-out”.

- Stress management skills to be taught
- Improve or adjust working environment
- Sharing of responsibilities with other carers or family members
- Professional and emotional support
- Bereavement counselling
- Establish support groups for caregivers

8.4.4 Palliative care service delivery platforms

Diagram 9 depicts the integration of palliative care into the existing health services. Palliative care is currently provided on an *ad hoc* basis without all the necessary skills and resources available. Thus, this policy and strategy sets out to enable the systematic, co-ordinated and enhanced delivery of services as part of integrated and patient-centered care.

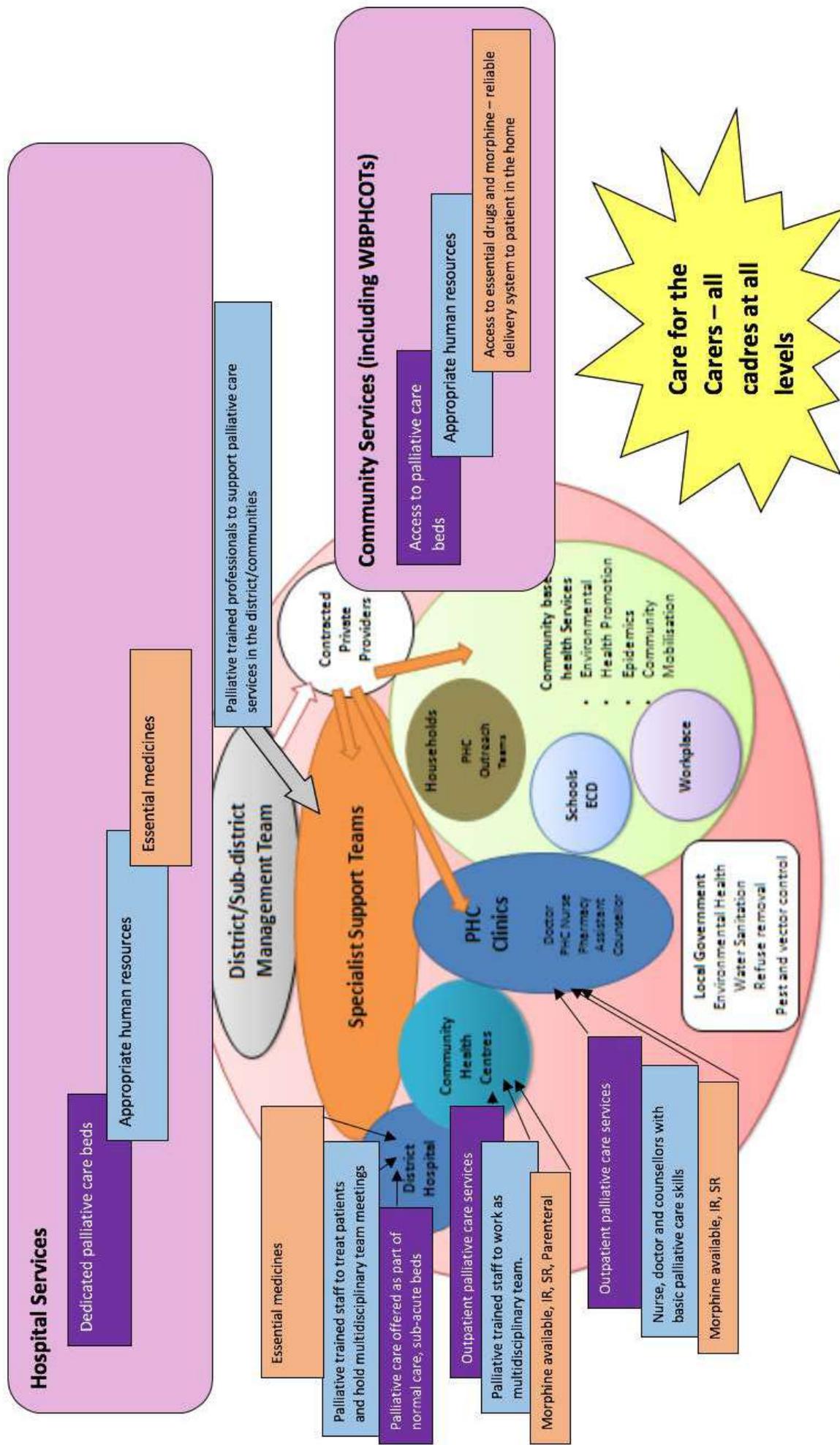


Diagram 9: Service Delivery Platform. (DHS Strategy 2015 with modification to include integrated palliative care services at hospital, district and community levels)

To explain diagram 9, table 7 below, outlines in broad terms the resources required at each level of the service i.e. services, human resources medication and consumables.

Table 7: Summary of resources required at different levels of health services

Hospital Services (Specialised, Tertiary, Regional, Secondary)		
Services	Human Resources	Medications
Access to beds in relevant wards for specialized palliative care services (should a patient be admitted for palliative treatment e.g. radiation/surgical services not possible at district hospital, etc)	<p>Tertiary Hospital Palliative care specialist teams</p> <ul style="list-style-type: none"> Will consist of at least 1 specialist palliative care doctor (preferably 2), at least 2 palliative care nurses and 1 social worker, depending on number of beds to be serviced. These teams would have specialist qualifications (Masters level or greater) in palliative care Dedicated to rendering will provide consultancy services within the tertiary hospital and the regional referral network to regional and district hospitals. 	<p>Morphine available oral IR, oral SR, parenteral (syringe drivers, IVI)</p> <p>Other specialist level palliative care medicines</p>
District - Hospital		
<p>Palliative care offered as part of normal care</p> <p>Palliative care beds if needed for step down care/ terminal care/ uncontrolled pain and symptoms -</p>	<p>District Palliative Care Team</p> <ul style="list-style-type: none"> 1 doctor with Generalist Palliative Care (GPC) training and 1 GPC nurse + other nursing staff Palliative care Doctor and palliative care nurse to have postgraduate training in palliative care at diploma level or equivalent In addition to other clinical responsibilities, this team will manage patients requiring palliative care either in external Sub-Acute facilities or within district hospitals and to provide support to the community-based palliative care services. 	<p>Morphine available, oral IR, oral SR, parenteral (syringe drivers)</p> <p>Essential palliative care medicines</p>
District – Clinics (CHCs, PHCs)		
Outpatient palliative care services	<p>Community palliative care services – Clinic level</p> <ul style="list-style-type: none"> Nurses and doctors in clinics to manage patients utilizing the palliative care approach Nurse, doctor and counsellors with basic palliative care skills. Identification and management of basic palliative care needs of patients as part of normal patient care Referral to social services (social workers and social auxiliary workers) as required and referral to district hospital as needed for more complex needs 	<p>Morphine available, oral IR, oral SR Parenteral morphine at CHCs</p> <p>Essential palliative care medicines</p>
District - Community		
<p>Patients cared for at home</p> <p>Sub-acute beds for palliative care (In hospital or sub-acute or contracted hospices.</p> <p>Hospice services, other NGOs, private care services – provide support/specialized services</p>	<p>Community-based Palliative Care Services</p> <ul style="list-style-type: none"> WBPHCOT – Community Health Workers and Home-based Care teams with a nurse team leader Lay health care workers trained in the palliative care approach CHWs identify and refer patients needing palliative care. HBC – caregivers for patients and families Under supervision of nurse team leader, referral to Social Services (Social workers and Social auxiliary workers) or clinic as required 	<p>Access to essential palliative care medicines and morphine: Collect at local clinic (dispensed from a hospital on named patient basis</p> <p>Reliable delivery system to patient in the home (for those who cannot access the clinics)</p>

8.4.5 Details of human resources and consumables required for palliative care

Community-based Palliative Care (Home Care)

Patients identified as needing palliative care may receive such care at home. It is expected that the majority of patients will fall into this category of care. The needs of the patient and family will determine the level of care required.

A mobile patient with few needs would be able to attend an outpatient clinic monthly or weekly. As the functional status declines and mobility becomes limited a patient would benefit from a monthly/weekly home visit by a nurse supervised by a doctor who may need to visit the patient at home.

A totally bedbound patient may need more frequent, weekly visits from a nurse and a daily home-based caregiver to assist with activities of daily living. The frequency and length of time the home-based caregiver would need to spend with the patient would depend on the severity of need and on the family's resources to care for the patient.

Table 8 below, details some of the resources required to provide palliative care within a community setting.

Human Resources		
Category of staff	Duties	Frequency of home visits
Caregiver/ Home-based care (Will spend at least 1 hour – 2 hours with a patient)	Washing, turning in bed, (pressure care, mouth care) feeding, giving medications, assistance with mobilising	According to need: Few hours a day/ full day (8 – 12 hours)/ full night/ day and night – Daily/ few times a week
Professional Nurse (First visit will be at least 1 hour, subsequent visits will depend on severity of illness – about 30 minutes) *case manager	Palliative assessments/ wound care/ catheter care/ supervising caregivers/ support family/ health education/ assess medications and compliance/ assess activities of daily living and progress or decline	Monthly/ weekly/ bi-weekly/daily according to need
Doctor (Supervision of nurses – prescriptions, arrange referrals)	Support professional nurse/ assessments/ prescriptions/ liaise with other health professionals/ referrals to clinics/hospitals as needed/ death certification (can be a family physician/GP)	As required, monthly/ weekly Usually have a weekly meeting with the nurses under their supervision to discuss all patients and arrange which need to be seen by doctor
Social Worker (Visits usually 1 hour)	Family support and counseling/ grants as needed/ documentation: home affairs / labour/ advance care planning/ estate planning/ care of minors/ burial policies	As required: monthly or weekly
Allied Health Nutritionist/Dietician (Visits typically 30 minutes)	Support to improve quality of life / maintain independence and mobility for as long as possible and reduce pain and symptoms: lymphoedema management/ assist with dyspnoea/ assist with swallowing/ speech/ appropriate diet	As needed: monthly, weekly, bi-weekly Only for patients who need allied services
Spiritual Care/Counsellors (Visits up to an hour – may be longer if family counseling needed)	For patients who need spiritual counselling and do not have access to counselors through traditional faith institutions or who prefer a qualified counsellor not aligned to any faith	As needed: monthly, weekly. Bi-weekly
Consumables/ Medications/ Oxygen/ Mobility Aids		
Linen Savers Adult diapers Wound dressings Gloves	Home Oxygen if (Dependent on oxygen saturation measurement) Commode, Wheelchair/Zimmer frame (walker)	Analgesics including opioids Other medications on EML for palliative care

Table 8: Resources required for palliative care within the community

Clinics CHCs and PHCs

Patients who are ambulatory and able to travel, will access palliative care services at a clinic. Clinic staff is trained in basic palliative care. Should a problem not be resolved, a specialist palliative care team at the relevant referral hospital should be consulted. Table 9 indicates the resources that are needed to provide palliative care at a clinic.

Staffing – clinic staff trained in palliative care may offer services		
Category of staff	Duties	Frequency of visits at clinic
Professional Nurse (Requires necessary palliative care training – does not need to see palliative care patients only – included in the daily routine)	Palliative assessments/ wound care/ catheter care/ supervising caregivers/ support family/ health education/ assess medications and compliance/ assess activities of daily living and progress or decline	Monthly/ weekly according to need
Doctor (Requires necessary palliative care training – not seeing palliative care patients exclusively)	Assessments/ prescriptions/ liaise with other health professionals/ referrals to clinics/hospitals as needed/ death certification	As required, monthly/ weekly visits Usually have a weekly meeting with the nurses under their supervision to discuss all patients and arrange which need to be seen by doctor
Social Worker (Requires necessary palliative care training – not seeing palliative care patients exclusively)	Family support and counseling/ grants as needed/ documentation: home affairs/ labour/ advance care planning/ estate planning/ care of minors/ burial policies	As required: monthly or weekly
Allied Health (Requires necessary palliative care training – not seeing palliative care patients exclusively)	Support to improve quality of life / maintain independence and mobility for as long as possible and reduce pain and symptoms: lymphoedema management/ improve mobility/ assist with dyspnoea/ assist with swallowing/ speech	As needed: monthly, weekly
Spiritual Care/ Counsellors (Requires necessary palliative care training – not seeing palliative care patients exclusively)	For patients who need spiritual counseling and do not have access to counsellors through traditional faith institutions or who prefer a qualified counsellor not aligned to any faith	As needed: monthly, weekly
Consumables/ Medications/ Oxygen/ Mobility Aids		
Linen Savers Adult diapers Wound dressings Gloves	Oxygen if needed (Dependent on oxygen saturation measurement) Commode Wheelchair/Zimmer frame (walker)	Analgesics including opioids Other medications on EML for palliative care

Table 9: Resources required to provide palliative care at a clinic.

Hospital – District to tertiary level

Patients may be identified in the wards or at the outpatient clinics at the hospital as needing palliative care.

At tertiary hospitals, the primary care team should be trained in basic palliative care and should initiate pain and symptom control. A specialist palliative care team comprising a doctor, professional nurses and a social worker will offer specialist services with staff members trained in specialist palliative care (postgraduate diploma). This will be the primary function of the team.

At district hospitals, family physicians are expected to have training in palliative care. Other staff members should be trained in basic palliative care which should be incorporated into their daily activities and services offered to the patients. Tables 10 and 11 indicate the resources required to provide palliative care at a hospital.

Staffing (Specialist Palliative Care Team) Tertiary/Regional Hospitals *will need separate offices and clerical staff but not separate beds.		
Category of staff	Duties	Frequency of ward consultations
Professional Nurse - Palliative Care (Requires necessary palliative care training. Sees only palliative care patients.)	Palliative assessments/ wound care/ catheter care/ supervising caregivers/ support family/ health education/ assess medications and compliance/ assess activities of daily living and progress or decline	Weekly/ Daily
Doctor – Palliative Care (Requires necessary palliative care training. Sees only palliative care patients)	New assessments/ ongoing assessments/ prescriptions/ liaise with other health professionals/ referrals to clinics/hospitals as needed	Weekly/ Daily Usually have a weekly meeting with the nurses under their supervision to discuss all patients and arrange which need to be seen by doctor
Social Worker – Palliative Care (Requires necessary palliative care training. Sees only palliative care patients.)	Family support and counseling/ grants as needed/ documentation: home affairs / labour/ advance care planning/ estate planning/ care of minors/ burial policies	As required: weekly/ daily
Allied Health (Requires necessary palliative care training – not seeing palliative care patients exclusively)	Support to improve quality of life / maintain independence and mobility for as long as possible and reduce pain and symptoms: lymphoedema management/ improve mobility/ assist with dyspnoea/ assist with swallowing/ speech	As needed: weekly/daily
Spiritual Care (Requires necessary palliative care training – not seeing palliative care patients exclusively)	For patients who need spiritual counselling and do not have access to counselors through traditional faith institutions or who prefer a qualified counsellor not aligned to any faith	As needed: weekly/ daily
Consumables/ Medications/ Oxygen/ Mobility Aids		
Linen Savers Adult diapers Wound dressings Gloves	Oxygen if needed (Dependent on oxygen saturation measurement) Commode Wheelchair/Zimmer frame (walker)	Analgesics including opioids Other medications on EML for palliative care

Table 10: Resources required to provide palliative care at a Tertiary/Regional hospital

Staffing: District Hospitals Palliative Care included in duties of all staff categories *regular/weekly multidisciplinary meetings to be held in wards to discuss patients		
Category of staff	Duties	Frequency of ward consultations
Professional Nurse - Palliative Care (Requires necessary palliative care training. Palliative care not exclusive responsibility.)	Palliative assessments/ wound care/ catheter care/ supervising caregivers/ support family/ health education/ assess medications and compliance/ assess activities of daily living and progress or decline	Weekly/ Daily
Doctor – Palliative Care (Requires necessary palliative care training. Palliative care not exclusive responsibility.)	New assessments/ ongoing assessments/ prescriptions/ liaise with other health professionals/ referrals to clinics/hospitals as needed	Weekly/ Daily Usually have a weekly meeting with the nurses under their supervision to discuss all patients and arrange which need to be seen by doctor
Social Worker – Palliative Care (Requires necessary palliative care training. Palliative care not exclusive responsibility.)	Family support and counseling/ grants as needed/ documentation: home affairs / labour/ advance care planning/ estate planning/ care of minors/ burial policies	As required: weekly/ daily
Allied Health (Requires necessary palliative care training – not seeing palliative care patients exclusively)	Support to improve quality of life / maintain independence and mobility for as long as possible and reduce pain and symptoms: lymphoedema management/ improve mobility/ assist with dyspnoea/ assist with swallowing/ speech	As needed: weekly/daily
Spiritual Care (Requires necessary palliative care training – not seeing palliative care patients exclusively)	For patients who need spiritual counselling and do not have access to counsellors through traditional faith institutions or who prefer a qualified counsellor not aligned to any faith	As needed: weekly/ daily
Consumables/ Medications/ Oxygen/ Mobility Aids		
Linen Savers Adult diapers Wound dressings Gloves	Oxygen if needed (Dependent on oxygen saturation measurement) Commode Wheelchair/Zimmer frame (walker)	Analgesics including opioids Other medications on EML for palliative care

Table 11: Resources required to provide palliative care at a District Hospital

Centres of Excellence

As the need for palliative care is addressed, it will be necessary to establish academic centres at the tertiary teaching hospitals. The staff at these centres will be involved in teaching, research, advocacy and service delivery (as the consultant specialist teams), as in the case of any other academic department. It is important to determine the levels of employment of the staff. Whilst palliative care is currently not recognized as a specialty, the head of the centre would need at least a master's degree in palliative care and a suitable level of post (for a non-specialist under HPCSA rules) would need to be decided until a specialty is developed when the post can be reviewed. The team would consist of doctors, nurses, social workers and counsellors, all of whom have specialist training in palliative care and who would be dedicated to providing palliative care.

8.4.6 Referral Pathways for Palliative Care

A patient may be identified at any level of the health care system as needing palliative care and will need to be referred to the appropriate level of care, which may be down-referral from hospitals to clinics or to home for ongoing care or up-referral from clinics to hospitals for more specialist level palliative care interventions. The table in Appendix D indicates the relationship between level of functioning and levels of access to care.

The first diagram (Diagram 10) shows the overall referral pathway for a palliative care patient from the community to the tertiary hospital. The subsequent diagrams (11 – 14) show the specific pathways for each level of care.

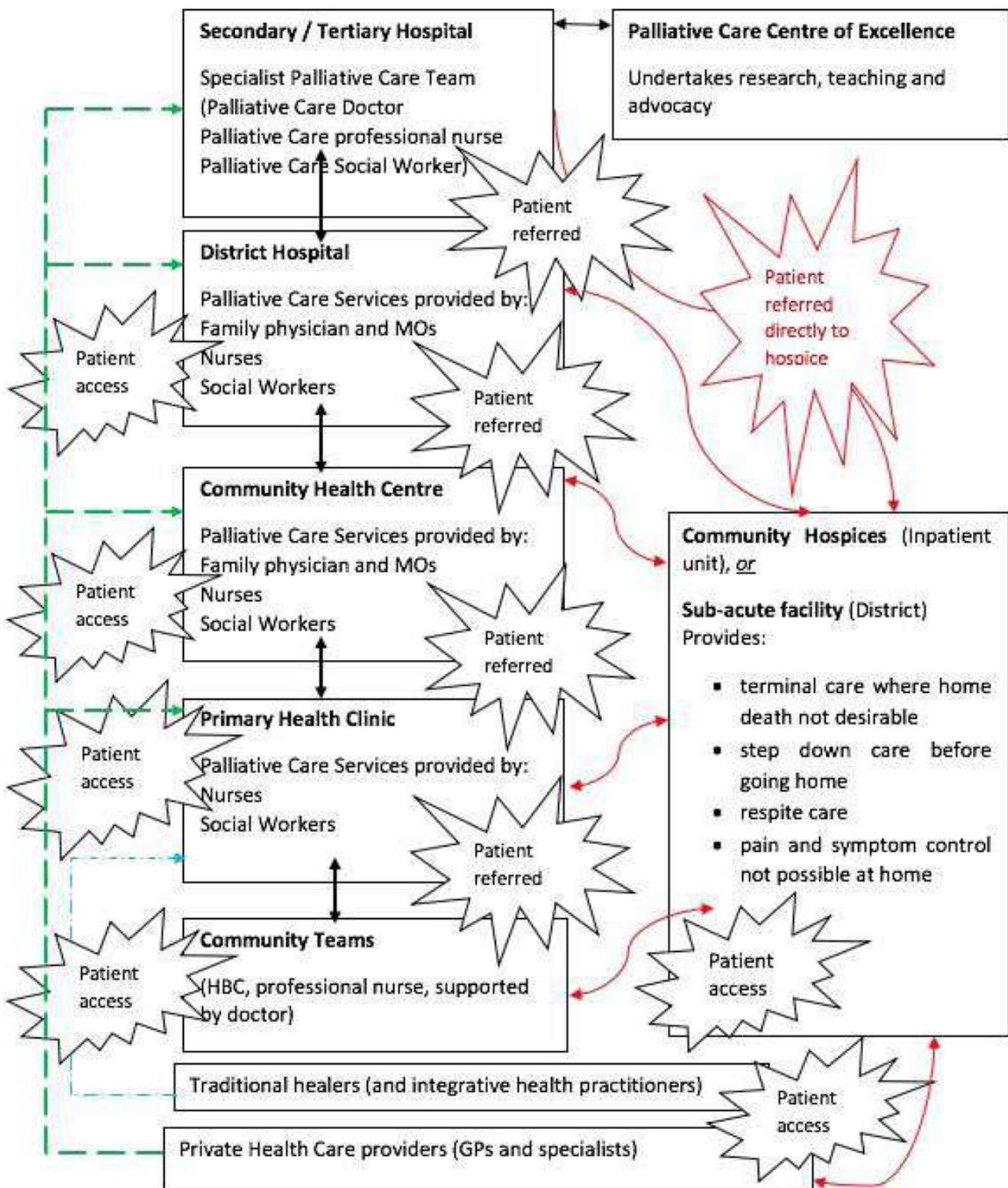


Diagram 10: General Referral Pathways for palliative care

Palliative Care Referral Pathway – Tertiary Hospital

The patient is identified by the primary care team as having palliative care needs, using an appropriate palliative care tool. Primary team initiates palliative care and consults with specialist palliative care team if specialist care is required.

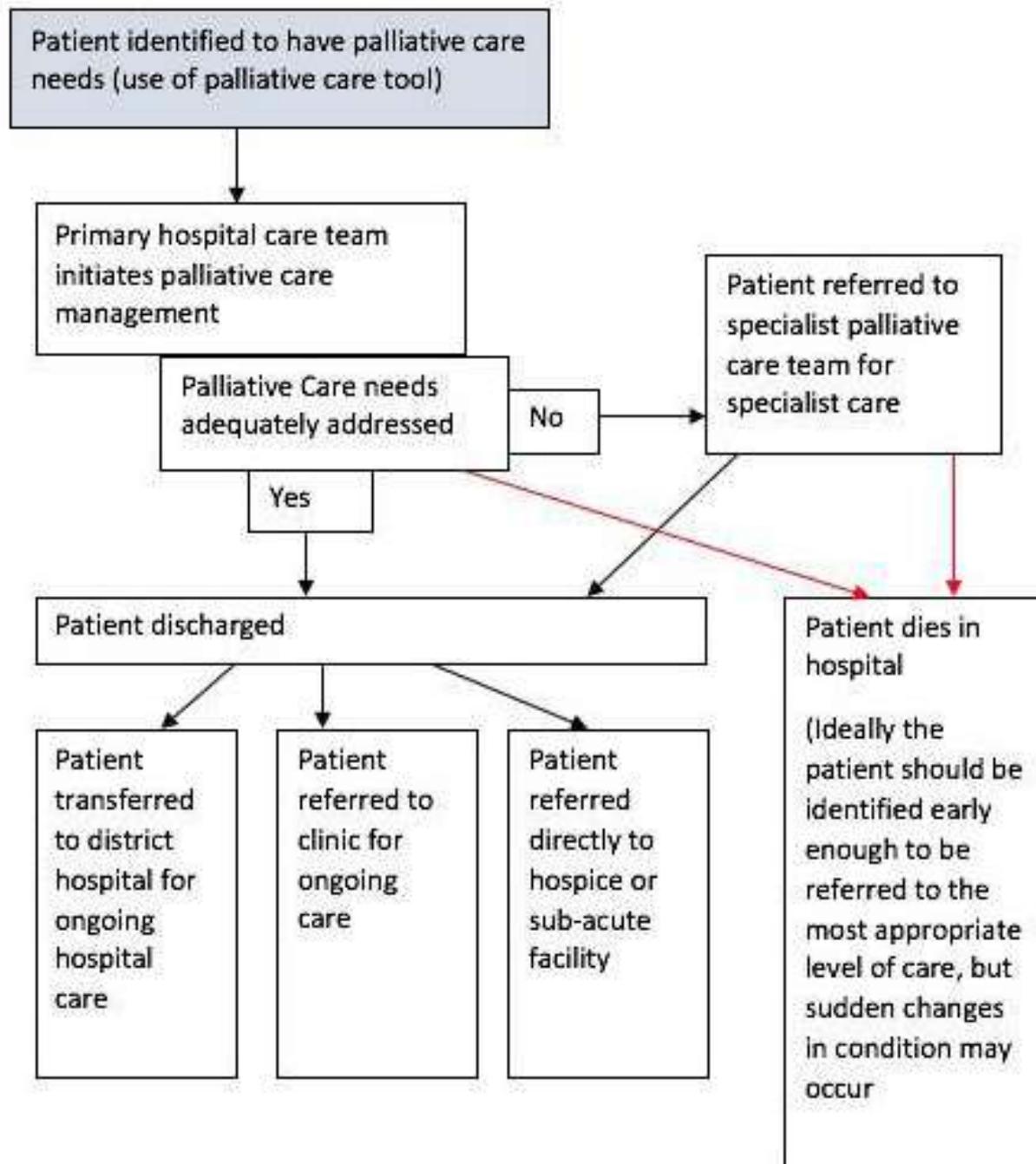


Diagram 11: Palliative Care Referral in Tertiary hospitals

Palliative Care Referral Pathway – District Hospital

Patient is identified as having palliative care needs. Palliative care is initiated by the hospital team in the ward. All health care workers in a district hospital should have sufficient knowledge to apply palliative care principles and to offer adequate palliative care services. Should they encounter a problem that cannot be adequately addressed, a specialist palliative care team at the referral secondary or tertiary hospital should be consulted for assistance.

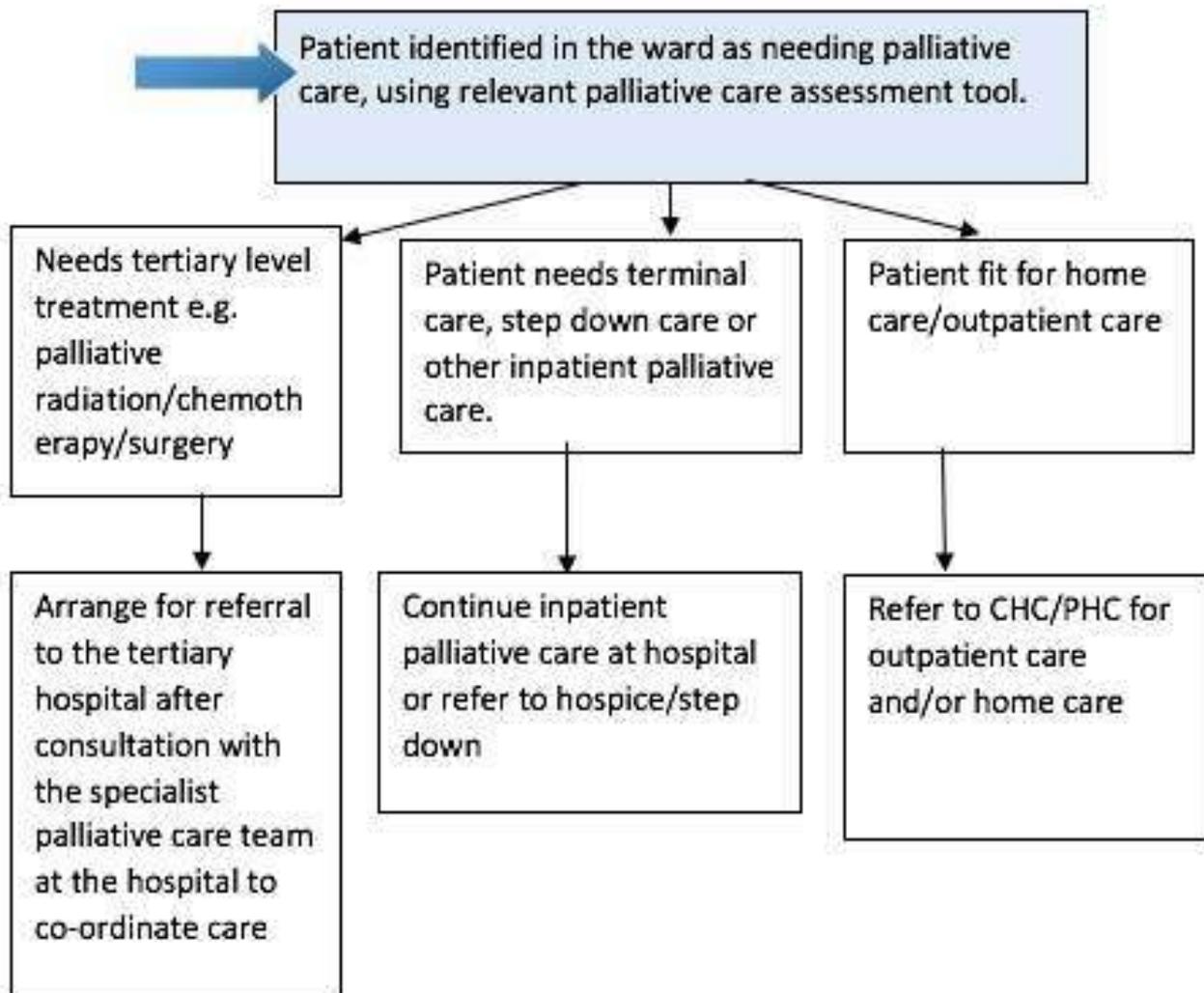


Diagram 12: Palliative Care Referral in District Hospitals

Palliative Care Referral Pathway – Clinic

A patient is identified at the clinic as needing palliative care or a patient is referred from a hospital for ongoing palliative care in the community. Staff at the clinic is trained in basic palliative care. Should there be a problem that is too difficult to address at clinic level, the specialist palliative care team at the relevant referral hospital is consulted. (For ECOG categories, refer to Appendix D)

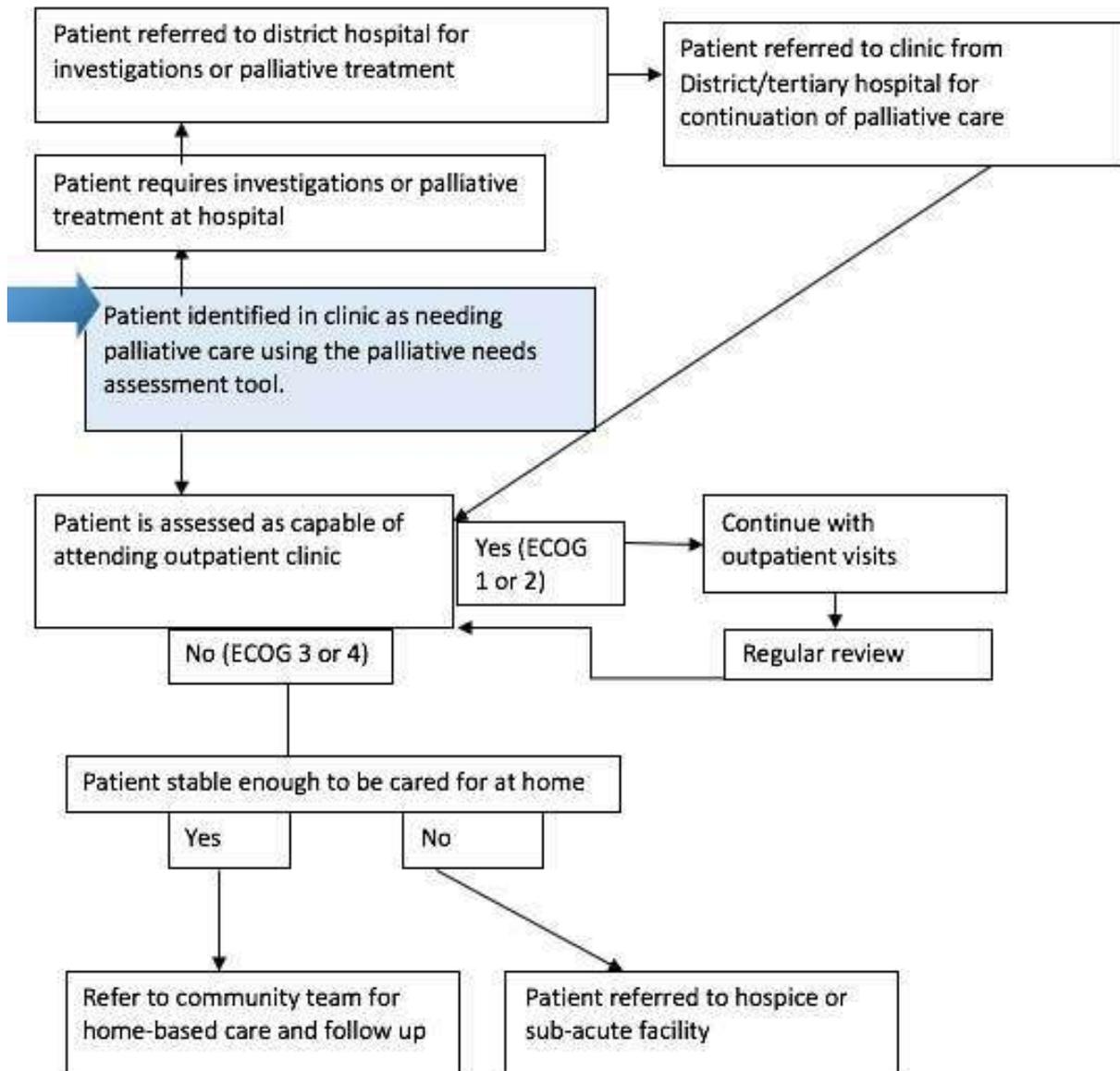


Diagram 13: Palliative Care Referral in Clinics

Palliative Care Referral Pathway – Community

A patient is identified as needing palliative care by the community health worker or DST, or the patient is referred to the community care teams from the clinic. The CHW has basic training in identifying a patient who may need palliative care. The nurse and doctor have basic palliative care training. (For ECOG categories, refer to Appendix D)

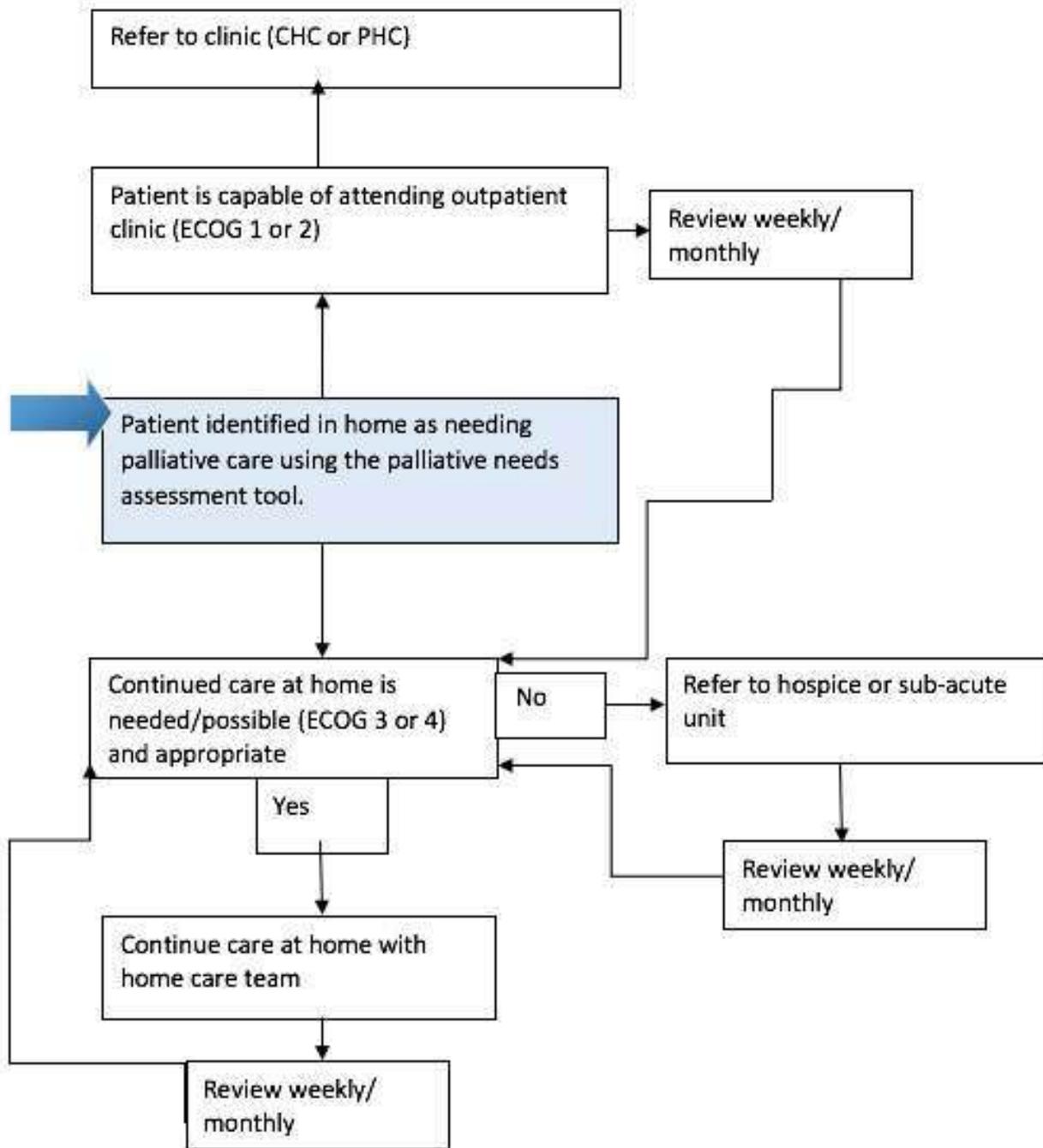


Diagram 14: Palliative Care Referral in the Community

9. Strategy

9.1 Vision

All adults and children, including their families, facing the problems associated with life-threatening or life limiting illness will receive palliative care to maintain quality of life, dignity and comfort throughout the course of the illness.

9.2 Mission

To improve the quality of life, well-being, comfort and maintain human dignity for individuals, through an age appropriate health service that values patients' need to receive personally and culturally sensitive information on their health status, adequate relief of suffering in physical, psychosocial and spiritual domains of care, while acknowledging their central role in making decisions concerning treatment.

9.3 Guiding Principles

The strategic policy framework, goal and objectives are informed by a set of overarching principles which envision a South Africa where no one suffers needlessly from pain; where patients and families are supported by a responsive, equitable, and quality health service; and where patient dignity, quality of life and human potential are valued and protected.

The Right to Health:

Palliative Care is recognised as part of the Right to Health as expressed in the International Convent on Economic, Social and Cultural Rights. Access to palliative services over the course of an illness to alleviate unnecessary pain and suffering is a basic human right. As such the state obligation to respect, protect and fulfil this right should be expressed.

Access to palliative services over the course of an illness to alleviate unnecessary pain and suffering is a basic human right. As such the state obligation to respect, protect and fulfil this right should be expressed as "A healthy life for all South Africans." South Africa's Constitution and legislative and regulatory framework supports the right to health services and emergency medical treatment for adults and children, and this commitment is embedded in all policies, strategies and plans for the health service. Section 10, 11, 12 & 27 of the Constitution enshrines the right to health care, food, water and social security for all people, while Section 28 provides that all children have the right to basic health care services.

Patient-centred and ethical care:

Palliative care aims to provide a care plan which is suited to the individual patient having discussed their expectations and the goals of care. The provision of palliative care must adhere to the principles of medical ethics, the codes of conduct of the professional bodies, the constitutional and legal prescripts and, at all times with respect for the individual. The provision of palliative care would be an absolute requirement in ensuring quality of life and dignity for all affected by the patient's illness from the time of diagnosis until death.

Equitable access:

All South African citizens should have access to the essentials of palliative care, both in the public and private health sectors and across all service levels. Patients should have access throughout the continuum of care, from diagnosis through treatment, and over the course of their life.

Holistic, comprehensive continuum of care throughout the course of life:

Palliative care requires a multi-disciplinary (inter-disciplinary) team approach inclusive of the patient to provide pain and symptom management, access to social services, counseling and resources required to ensure physical, psycho-social, emotional and spiritual wellbeing. This care should be available throughout the life course of each individual and be offered as a continuum of care throughout health services. The mother of a still born baby or who has suffered a miscarriage will benefit from a palliative care approach as much as any other person, child or adult, faced with a life limiting or life-threatening illness.

Integrated within the health system:

Palliative care shall be integrated into all health services at all levels of services including national and tertiary (specialist) hospitals, regional and district hospitals, community health centres, primary health care clinics, mobile clinics and community-based services including the WBPHCOTs. All health facilities should serve as a point of entry into supportive and palliative care services and care pathways. Palliative care should be available in homes for children, the elderly, and persons with disabilities.

Patients and families as partners:

Patients and families should engage in the planning of their care, act as full partners and take responsibilities for self-management, with the assistance of CHWs and other home-and community-based support. Young children cannot make decisions but their opinions, feelings and desires should be considered. In the case of very young children self-management is done by parents or carer takers.

Enacting of enabling legislation and development of new legislation:

Relevant legislation is to be reviewed to enable the provision of holistic palliative care services and where such legislation is not available; it is to be developed as required by Civil Society and community engagement and participation. Active engagement and participation by civil society and community members is essential to ensure that services are available to all, culturally appropriate, relevant, understood and utilised. Communities and community-based organisations should be encouraged and enabled to provide input and feedback into the development and delivery of services. Innovative partnerships are to be explored to ensure sustainable service delivery.

Multi-sectoral:

Palliative care will be developed and maintained through collaboration between relevant national departments (for example, health, social development, education and others). There will also be collaboration between government and non-governmental organisations, municipalities, traditional healers and community organisations. Palliative care should be accessible and available in social development facilities such as care homes for the elderly, children's home and care facilities for people with disabilities.

Quality and evidence-based:

Health care providers will be guided by evidence-based practice and locally developed guidelines. Ongoing research, monitoring and evaluation will be required to assess and refine quality standards and management and treatment guidelines.

9.4 Goals and Objectives

This section covers the goals and objectives of the palliative care policy as well as the processes which are required to achieve the vision of palliative care for all who need the service.

There are 5 overarching goals (Table 12) which seek to address the challenges in providing palliative care. The goals and objectives serve to address the health system challenges with reference to the WHO public health building blocks, discussed previously.

Goals	Challenges	Alignment to WHA
Goal 1: To strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.	Addresses the challenges of service delivery, and provision of medical products including medicines.	Aligned to WHA PC Resolution: Member state 1, 2, 3, 5, 6, 7.
Goal 2: Ensure adequate numbers of appropriately trained health care providers to deliver palliative care at all levels of the health service.	Addresses the challenges of an adequately trained health workforce in adequate numbers to provide palliative care services.	Aligned to WHA PC Resolution: Member state 4 (a), (b), (c).
Goal 3: Establish and maintain systems for monitoring and evaluation of South Africa's palliative care program.	Addresses the challenges of data available for planning and evaluating progress against plans	Aligned to WHA PC resolution: Member state 9
Goal 4: Ensure appropriate allocation of financial resources to strengthen and sustain South Africa's palliative care program.	Addresses the challenges of funding of South Africa's palliative care program	Aligned to WHA PC resolution: Member state 2
Goal 5: Strengthen governance and leadership to support implementation of the policy.	Addresses the challenges of governance and leadership required to ensure implementation of the palliative care policy.	Aligned to WHA PC Resolution: Member state 8, 9.

Table 12: Goals and challenges addressed

Goal 1: Strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable

Palliative care services are available unevenly across the country and are largely positioned outside of health services. The district health system, with its strong focus on primary health care and community-based services, is well placed to integrate palliative care into existing programmes. Transitions between the levels of care, e.g. specialist/tertiary hospitals, and across the care continuum, must be enabled and supported. The availability of and access to adequate pain and symptom management medication is a core tenet of palliative care.

Objectives:

- To publish a national guideline and standards for palliative care
- To develop care pathways linked to a national referral system;
- To provide equitable and sustained access to appropriate medications and related consumables, to deliver palliative care;

Goal 2: Ensure adequate numbers of appropriately qualified health care providers to deliver palliative care at all levels of the health service.

The availability of health care providers trained to provide supportive and palliative care services is critical to deliver evidence-based, high quality services. Patients should have access to a multi-disciplinary team, including community and home-based caregivers as well as social workers and pastoral/spiritual counsellors. Current pre-service and in-service training programmes should be strengthened to include comprehensive palliative care training, and post-graduate training programmes should be developed to provide for specialists in palliative care.

Objectives:

- To provide in-service training of current health care workers to deliver palliative care at all levels of service;
- To ensure that palliative care is included in the undergraduate/pre-service and post-graduate curriculum of **all** health providers;
- To strengthen post-graduate learning opportunities in palliative care for the health and allied workforce;
- To assess the feasibility of establishing a palliative care specialty for doctors and nurses.

Goal 3: Establish and maintain systems for monitoring and evaluation of South Africa's palliative care program.

Statistics on all facets of palliative care services are not readily available in many countries including South Africa. The continuous monitoring and periodic evaluation of the implementation of this policy framework and strategy does require that an appropriate information system is strengthened and where applicable, established to support planning and resource allocation.

Objectives:

- To review existing information systems related to palliative care with a view to integration
- To integrate palliative care indicators and targets into the District Health Information System (DHIS)
- To determine the need for and to undertake periodic audits of services

Goal 4: Ensure appropriate allocation of financial resources to strengthen and sustain South Africa's palliative care program.

Currently palliative care services are underfunded leading to inconsistent implementation. Funding is required for universal access and sustainability.

Objectives:

- Complete detailed costing of South Africa's palliative care program
- Incrementally increase the funding for palliative care to ensure a phased implementation of this policy

Goal 5: Strengthen governance and leadership to support implementation of the policy.

The successful implementation of this policy framework requires strong leadership and coordination to engage with other relevant departments, civil society and the community as a whole to ensure the successful delivery of palliative care to all. Coordination at the national provincial and district levels is critical to ensure seamless movement of the patient within the health care system.

Objectives:

- To establish an inter-government forum to engage with other relevant departments of government to encourage and facilitate equitable access to palliative care children and other vulnerable populations;
- To provide guidance, direction and leadership to ensure the implementation of a coordinated palliative care strategy by provinces and districts;
- To facilitate stakeholder engagement and partnerships with relevant role players for seamless transition to care.
- To monitor the routine reviewing of existing policies to include palliative care which will enable the implementation of an integrated palliative care service policy

10. Monitoring and Evaluation

Monitoring and evaluation is essential to ensure the continued growth and development of palliative care in South Africa. It serves to identify areas that are challenging which require added support, and allows for successes to be noted. Indicators to measure the success of implementing this policy and strategy are provided in table 13 below.

Policy goal	Indicators
Goal 1 Strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.	<ul style="list-style-type: none"> • National Palliative Care Guideline for adults and paediatrics • National Palliative care pathways established • Number of districts with a palliative care referral pathway • Number of palliative care beds in sub-acute facilities or available in hospices • NEMLC includes palliative care chapter • Number of palliative care EML stock outs • Oral morphine expressed as morphine equivalents, per PHC headcount per unit time per district
Goal 2 Ensure adequate numbers of appropriately qualified health care providers to deliver palliative care at all levels of the health service	<ul style="list-style-type: none"> • Number of district trainers trained in palliative care • Number of in-service palliative care trainings conducted per district • Number of health care workers trained. • Number of nurses trained to prescribe morphine • Standard objectives for a palliative care curriculum for nurses and doctors • Number of educational institutions implementing the standard palliative care objectives • Number of educational institutions offering post-graduate training in palliative care • Palliative care specialty competencies developed • Completed strategy for palliative care specialty
Goal 3 Establish and maintain systems for monitoring and evaluation of South Africa's palliative care program	<ul style="list-style-type: none"> • Data elements defined with numerators and denominators • Baseline for key indicators available for all provinces • Data elements integrated into DHIS • Periodic survey tool designed
Goal 4 Ensure appropriate allocation of financial resources to strengthen and sustain South Africa's palliative care program.	<ul style="list-style-type: none"> • Key activity milestones for strategy implementation are met • Interim standards for NGO service delivery developed • MOUs/SLAs to reflect approved interim standards • Regulations on standards for palliative care service delivery promulgated
Goal 5 Strengthen governance and leadership to support implementation of the policy	<ul style="list-style-type: none"> • Inter-government forum established • Number of social cluster policy documents which support palliative care established • Policy adopted • National program with FTE established • Number of awareness campaigns • Number of SLAs reflecting minimum standards • Number of policies revised or new; including palliative care per annum.

Table 13: Indicators for each policy goal

11. Roles and Responsibilities of the National and Provincial Departments of Health

The roles and responsibilities of the national and provincial departments of health are outlined in this section. An overview of the outcomes with associated time frames (Table 14), assist with visualising the progressive roll out of palliative care services over the next 5 years. The implementation of the palliative care policy is dependent on the appointment of a FTE for Palliative Care both at national and provincial levels. Because palliative care is a service offered at all levels of health service delivery, cuts across all programs in the health sector and requires collaboration across departments, a full-time post will be required with the necessary authority to achieve the targets set out in the tables below.

Time Frame	Key Activities (These are not sequential; some may occur in parallel and may apply to national and/or provinces.)				
2017-2018	Policy Adopted	Develop FTE job profile for National Manager Palliative Care	Advocacy <ul style="list-style-type: none"> • Politicians • HODs • HCPS • Public 	EML review	Initiate resource requirements <ul style="list-style-type: none"> • Capital investment • Human Resources • Training/Posts • Medicines/consumables
2017-2019	Develop M&E system <ul style="list-style-type: none"> • Determine Key indicators • Determine Baseline values for Key Indicators • Agree on routine reporting cycle • Integrate Indicators into DHIS 	FTE appointed	Initiate Establishment of palliative care teams at specialist, general and PHC levels <ul style="list-style-type: none"> • Job description • Job Evaluation • Posts Levels • Creation of posts • Establishment of posts • Appointments 	<ul style="list-style-type: none"> • National clinical guideline including palliative care referral pathways developed • Initiate Morphine and other palliative care medicines available to patients at all levels of health service 	Finalise resource requirements <ul style="list-style-type: none"> • Capital investment • Human Resources • Training/Posts • Medicines/consumables <p>Interim measure: Include in MOUs/SLAs with NGOs minimum standards for service delivery</p>
2018-2020	Curricula imperatives <ul style="list-style-type: none"> • Palliative Care Approach • Generalist Palliative Care content • Specialist Palliative Care content 	In-service Training <ul style="list-style-type: none"> • Training objectives • Review existing material • Develop training program • Implement training 	Finalise Establishment of palliative care teams at specialist, general and PHC levels <ul style="list-style-type: none"> • Job description • Job Evaluation • Posts Levels • Creation of posts • Establishment of posts • Appointments 	Finalise Morphine and other palliative care medicines available to patients at all levels of health service	Infrastructure planning <ul style="list-style-type: none"> • Hospital and sub-acute beds (Existing to be re-allocated) • Centres of Excellence x5 (2 existing, create 3 new one dedicated for children)
2020-2022	Education and Training implemented as per defined curricula	Staff at clinics implementing palliative approach	Hospital palliative care teams established and implementing specialised services	Initiate Palliative care career path established for health professionals including doctors, nurses, pharmacists and other allied professionals	Centres of excellence established at academic hospital complexes

Table 14: Key activities and time frames.

11.1 Roles and Responsibilities of the National DoH

Table 15 below outlines the responsibilities of the National DoH towards determining baseline indicators and instituting the implementation of this strategy.

Goal 1: Strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.				
Objective	Indicator	Targets 2017/2018	Targets 2018/2020	Targets 2020/2022
Objective 1.1 To deliver standardised clinical palliative care services	A national palliative care clinical guideline for adults and paediatrics available	TOR developed and service provider appointed to develop the clinical guideline	National clinical guideline including palliative referral pathways developed	100% districts implementing clinical guidelines
Objective 1.2 To develop and implement care pathways as per national referral policy	<ul style="list-style-type: none"> palliative care pathways established³ palliative care pathways included in Ideal Clinic Dash Board Number of districts with a palliative care referral pathway The number of palliative care beds in sub-acute facilities or available in hospices 		<ul style="list-style-type: none"> 30% of districts have implemented the national palliative care pathway 30% of districts have dedicated palliative care beds available 	<ul style="list-style-type: none"> 60% of districts have implemented the national palliative care pathway 60% of districts have dedicated palliative care beds available
Objective 1.3 To provide equitable and sustained access to appropriate medications and related consumables, to deliver palliative care.	<ul style="list-style-type: none"> NEMLC includes palliative care chapter Number of palliative care EML stock outs Morphine consumption per district health service headcount 	<ul style="list-style-type: none"> PHC and Hospital STG EML include a chapter on palliative care management/essential medicines 	Medicines and consumables are regularly available and prescribed in 50% of districts	<ul style="list-style-type: none"> Medicines and consumables are regularly available and prescribed in 100% of districts Audit to determine utilisation of morphine versus actual need.

³ The National palliative care pathway should note specific clinical requirements for different diseases

Goal 2: Ensure adequate numbers of appropriately qualified health care providers to deliver palliative care at all levels of the health service.

Objective	Indicator	Targets 2017/2018	Targets 2018/2020	Targets 2020/2022
Objective 2.1 Provide in-service training of current health work force to deliver palliative care at all levels of service	<ul style="list-style-type: none"> Number of district trainers trained in palliative care Number of in-service palliative care trainings conducted per district Number of people trained. 	<ul style="list-style-type: none"> TOR developed for national palliative care training manual aligned to clinical guidelines Initiate Baseline assessments of <ul style="list-style-type: none"> Number trained Training material available Master Trainers available Readiness of districts to train 	National palliative care training manual adopted	50% of health districts have provided in-service training in palliative care to at least 30% of the health workforce.
Objective 2.2 Nurse prescribing of medications	<ul style="list-style-type: none"> Number of nurses trained to prescribe morphine Number of nurses prescribing morphine 	Consultation toward revision of relevant legislation and regulations		<i>Depending on the revision of the act</i> , Identified nurses are trained and are prescribing morphine to patients appropriately.
Objective 2.3 Ensure that palliative care is included in the undergraduate/pre-service curriculum for all health care and allied workforce	<ul style="list-style-type: none"> Standard objectives for a palliative care curriculum for nurses and doctors Number of educational institutions implementing the standard palliative care objectives 	Stakeholder consensus on standard undergraduate palliative care curriculum objectives	Develop standard undergraduate curriculum for health care and allied workforce at all levels of care	50% Higher Education Institutions implement standard curriculum 100% of med schools implementing standard curriculum 100% of Diploma Nurses trained 80% of pharmacists and other allied workforce trained
Objective 2.4 Strengthen post-graduate learning opportunities in palliative care for the health	Number of educational institutions offering post-graduate training in palliative care	Stakeholder consensus on standard post-graduate palliative care curriculum objectives	The Council for Higher Education adopts the recommended standard objectives for a palliative care	25% of education institutions offer post-graduate training in palliative care for doctors,

Goal 2: Ensure adequate numbers of appropriately qualified health care providers to deliver palliative care at all levels of the health service.

Objective	Indicator	Targets 2017/2018	Targets 2018/2020	Targets 2020/2022
workforce (Post graduate diploma)			curriculum for health care and allied workforce at all levels of care	nurses, pharmacists and allied workforce
Objective 2.5 Develop a palliative care specialty for doctors and nurses	<ul style="list-style-type: none"> Palliative care specialty competencies developed Completed strategy for palliative care specialty 	Initiate engagement with relevant institutions e.g. Statutory Councils, College of Medicine to develop competencies for palliative care specialists in medicine and nursing defined	Define standard objectives and competencies for a palliative care specialist curriculum for nurses and doctors	The Council for Higher Education adopts the recommended standard objectives and competencies for a palliative care specialist curriculum for nurses and doctors, pharmacists and allied workforce

Goal 3: Establish and maintain systems for monitoring and evaluation of South Africa's palliative care program

Objective	Indicator	Targets 2017/2018	Targets 2018/2020	Targets 2020/2022
Objective 3.1 Determine baseline values for key indicators for palliative care.	<ul style="list-style-type: none"> Data elements defined with numerators and denominators Baseline for key indicators available for all provinces 	Data elements defined		Baseline data collection
Objective 3.2 To integrate palliative care indicators and targets into the District Health Information System (DHIS)	Data elements integrated into DHIS		Routine reporting cycles agreed upon with provinces Palliative care data elements integrated into DHIS	Routine data collection utilizing the DHIS
Objective 3.3 To determine the need for and to undertake periodic audits of services	Periodic survey tool designed			<ul style="list-style-type: none"> Survey tool completed and surveys initiated Ongoing survey and audits of palliative care services

Goal 4: Ensure appropriate allocation of financial resources to strengthen and sustain South Africa's palliative care program.

Objective	Indicator	Targets 2017/2018	Targets 2018/2020	Targets 2020/2022
Objective 4.1 Mobilise adequate financial and other resources for policy and strategy implementation.	Key activity milestones for strategy implementation are met	Targets as per schedule of activities are met	Targets as per schedule of activities are met	
Objective 4.2 Minimum standards for palliative care service delivery by NGOs implemented	<ul style="list-style-type: none"> Interim Standards for NGO service delivery developed MOU/SLA to reflect approved interim standards Regulations on standards for palliative care service delivery promulgated 	<ul style="list-style-type: none"> Develop interim standards in Consultation on of standards with NGOs and Programmes 	<ul style="list-style-type: none"> Standards Adopted MOU/SLA reflects interim standards 	<ul style="list-style-type: none"> Processes for Regulation promulgation finalised Promulgated Regulation informs revised MOUs/SLAs

Goal 5: Strengthen governance and leadership to support implementation of the policy.

Objective	Indicator	Targets 2017/2018	Targets 2018/2020	Targets2020/2022
Objective 5.1 To establish an inter-government forum to strengthen delivery of palliative care services by other sectors including SAMHS, Correctional Services, DBE and DSD.	<ul style="list-style-type: none"> Inter-government forum established Number of social cluster policy documents which support palliative care 	Health Minister presents the palliative care policy and strategy to the social cluster of cabinet and obtains endorsement	Inter-government Forum established	All social cluster policies are supportive of palliative care service delivery
Objective 5.2 Provide guidance, direction and leadership to ensure the implementation of a coordinated palliative care strategy/plan	<ul style="list-style-type: none"> Policy adopted National Program with FTE established 	<ul style="list-style-type: none"> Process to create post or national manager (FTE) for palliative care completed and recruitment commences Palliative care advocacy commences at provincial level. 	<ul style="list-style-type: none"> NDoH palliative care unit established to oversee implementation of palliative care in health service FTE palliative care at NDoH appointed 	<ul style="list-style-type: none"> 30% of Provincial FTEs appointed 60% Provincial Plans completed. Ongoing support & guidance to
Objective 5.3 To create awareness, foster stakeholder engagement and	<ul style="list-style-type: none"> Number of awareness campaigns 	<ul style="list-style-type: none"> Initiate mapping of palliative care stakeholders 	<ul style="list-style-type: none"> Seamless referrals and coordination of services 	<ul style="list-style-type: none"> Seamless referrals and coordination of services

Goal 5: Strengthen governance and leadership to support implementation of the policy.

Objective	Indicator	Targets 2017/2018	Targets 2018/2020	Targets 2020/2022
develop partnerships with civil society and in the communities to ensure seamless transition of care	<ul style="list-style-type: none"> Number of SLAs reflecting minimum standards 	at national and provincial levels. <ul style="list-style-type: none"> Develop an advocacy strategy to increase awareness of policy 	between facilities and CBOs in 20% of Districts <ul style="list-style-type: none"> Finalise Map palliative care stakeholders at national and provincial levels 	between facilities and CBOs in 50% of Districts
Objective 5.4 Ensure palliative care is included in the review and revision of existing policies and inclusion in new policies to enable the implementation of an integrated palliative care service policy	Number of policies revised or new; including palliative care per annum	Policies for review identified NCD Strategy review initiated	3 Policies for priority health programmes reviewed and revised related to HIV and AIDS, TB MCWH	Other policies reviewed and revised to reflect palliative care.

Table 15: National DoH Roles and Responsibilities

11.2 Roles and Responsibilities of the Provincial DoH.

The roles and responsibilities of the Provinces are the implementation of the palliative care policy as guided by the National DoH. The implementation plan is a guide for the provinces to ensure that palliative care is available at all levels of health care in all districts. This section is intended to assist provinces to implement the policy based on the health systems building blocks (Diagram 15).

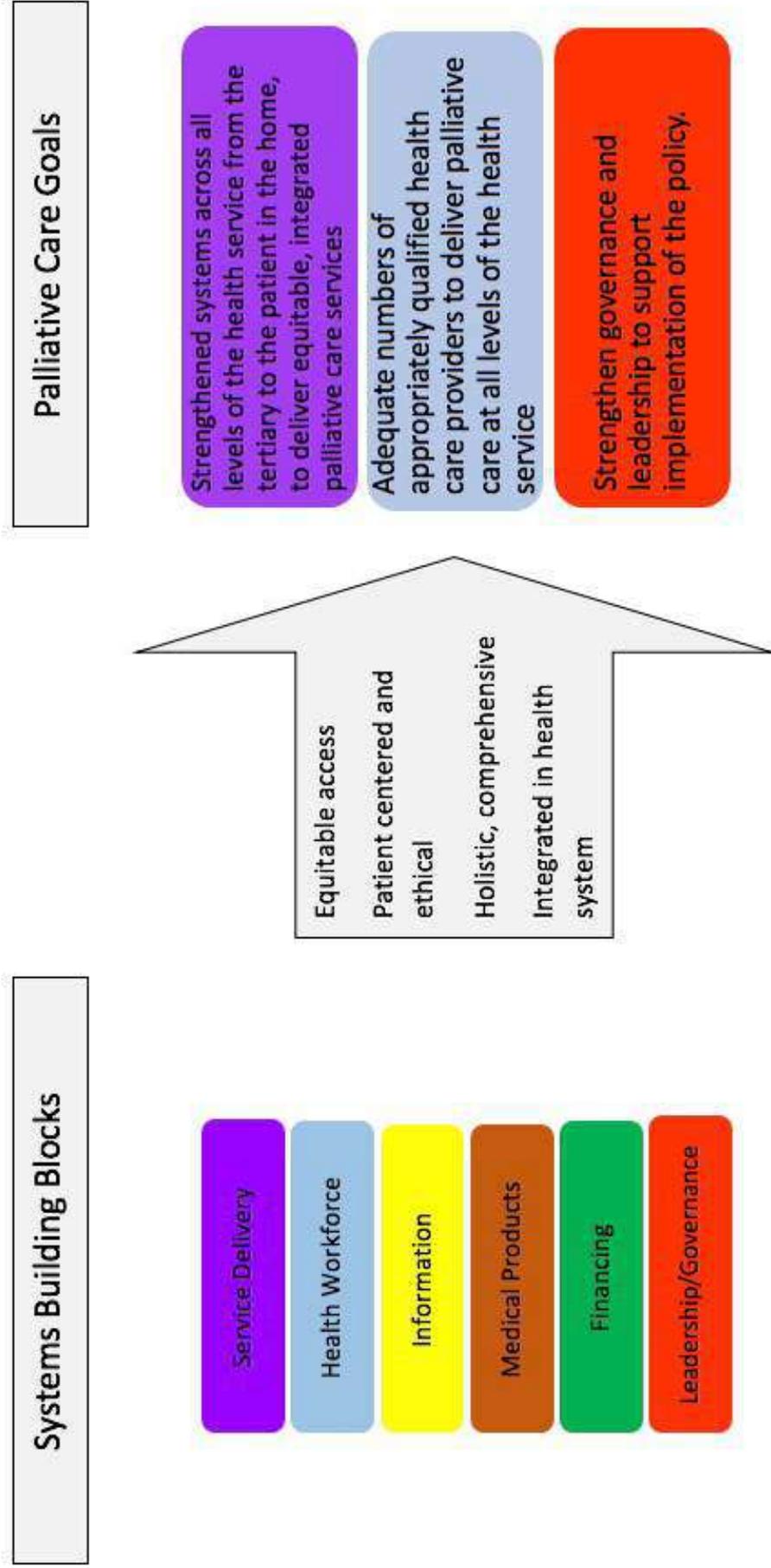


Diagram 15: Health Systems Strengthening for Palliative Care

The six building blocks are explained in the key to the implementation plan with different colours representing each block throughout the plan for ease of use. Indicators for the provincial implementation plan will reflect the activities at the level of the provinces and may differ from the indicators at national level. (Table 16)

System Building Blocks	Description of activities to strengthen the health system	Key indicators for the strengthening of palliative care services in the provinces.
Service Delivery (SD)	Good health services are those which deliver effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with minimum waste of resources.	Number of institutions offering holistic palliative care services at all levels of health care service delivery. Number of districts with fully integrated multi-sectoral palliative care services. Number of districts with established referral pathways with linkages to care. Number of palliative care beds available.
Health Workforce (HW)	A well-performing health workforce works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances. I.e. there are sufficient numbers and mix of staff, fairly distributed; they are competent, responsive and productive.	Number of health care workers trained in palliative care. Number of institutions with dedicated palliative care curriculum and number of graduates with palliative care training. Number of trained palliative care specialists.
Information and Research (IR)	A well-functioning health information system ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status.	Number of completed situation analyses and needs assessments. Number of palliative care public awareness activities in each district.
Medicines products and technologies (MT)	A well-functioning health system ensures equitable access to essential medical products, vaccines and technologies of assured quality, safety, efficacy and cost-effectiveness, and their scientifically sound and cost-effective use.	Morphine consumption in all districts. Number of facilities with morphine in stock.
Health Care Financing (F)	Financial planning to ensure adequate spending on health (relative to income at national, local government and household levels) and effective allocation of financial resources to different types of public and personal health services.	Number of funded palliative care beds (District Hospitals, sub-acute care facilities, funded community NGOS)
Leadership and Governance (LG)	Leadership and governance involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalition-building, the provision of appropriate regulations and incentives, attention to system-design, and accountability to ensure equity in access to services, quality of services, and patients' rights. Governance is also concerned with the roles and responsibilities of the public, private and voluntary sectors - including civil society - and their relationships with each other in pursuit of national health goals.	Number of policies and guidelines which include palliative care. Number of departments and sectors supporting palliative care with palliative care service delivery included in their policies and strategies. Number of established partnerships with MOUs in place for co-operative palliative care service delivery.

Table 16: Key to the Provincial implementation plan with indicators grouped into the six health systems building blocks.

11.3 Provincial Implementation of Key Activities

Goal 1. Strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.			
Objective	Activities	Outcomes 2017/2018	2018/2020
Objective 1.1 Deliver standardised clinical palliative care services	Adopt national palliative care guideline for adults and paediatrics		<ul style="list-style-type: none"> Awareness campaign to promote national palliative care guideline In-service training to include training in use of palliative care guideline
Risk identification and mitigation	Lack of awareness and lack of implementation of new guidelines – effective awareness and training programmes		
Indicator 1.1	Increase in morphine as a result of implementation of palliative care guideline		
Objective 1.2 To develop and implement care pathways linked to a national referral system	Adopt national standards to include clear clinical pathways for palliative care referrals	Support for the National DoH as required for the development of a standardised national palliative care pathway	<ul style="list-style-type: none"> Algorithms for screening, diagnosis, management and referral available at all levels (hospices, district hospitals, DCSTs). National palliative care pathway implemented in 30% of districts
	Identify unique needs and requirements for paediatric patients.	Paediatric needs and requirements identified.	Paediatric service fully functional in 60% of districts
	Determine the need for palliative care and current availability of services to support financial planning to support the growth in palliative care service delivery at provincial and district levels.	Palliative needs to be established with budget to be determined, guided by the NDoH	Palliative care services to be fully funded by the province.
	Situational analysis of existing palliative care services available	<ul style="list-style-type: none"> Map of palliative services (health system to NGOs) available for each health district. Situational analysis of palliative care provision in private sector. 	Ongoing review of available services.

Goal 1. Strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.				
Objective	Activities	Outcomes	2020/2022	
		2017/2018	2018/2020	
	<p>To integrate palliative care into the current services offered in the district through training and mentorship of current service providers.</p> <p>To establish and support specialist palliative care teams at the tertiary and specialist hospital level.</p>	<ul style="list-style-type: none"> The availability of service providers to train existing staff in palliative care is established. Provision is made for home-based carers (HBC) to be included in / or collaborate with the WBPHCOTs with responsibility for care of patients (separate to the screening of households). 	<ul style="list-style-type: none"> At least 50% of staff at PHC and CHC is trained to screen for palliative care need, assess and treat symptoms. WBPHC OTL is trained in palliative care; competencies for screening for palliative care needs included into WBPHCOT CHW training District hospital palliative care teams established according to minimum standards (e.g. doctors and nurses depending on size of hospital) social worker with auxiliaries, spiritual counsellor on call (interfaith). Specialist palliative care teams to be developed at tertiary facilities. Establish hospital palliative care teams based national norms and standards. 	<p>Fully functioning palliative care services with appropriately trained staff at 60 % all facilities.</p>
	<p>Integrate palliative care services into the district health system, with a focus on primary health care services. To develop and strengthen linkages between the DoH Facilities, NGOs and the private sector to enable seamless transitions in care across settings.</p>	<ul style="list-style-type: none"> Palliative care services are included in the PHC package of care. Palliative care is integrated into the Integrated Clinical Services Management (ICSM) model. District hospital norms and standards include palliative care integration. Linkages between hospices and PHC/hospitals established to facilitate 	<ul style="list-style-type: none"> PHC and CHC staff to be screening, assessing and treating pain and symptoms. All WBPHCOTs screen for palliative care; support and facilitate access to medicines and consumables between the PHC and home; and refer patients in need of specialized services accordingly. HBC services to be in place for patients in homes. 	<ul style="list-style-type: none"> A seamless transition of palliative care of a patient from tertiary level, the district and to the home in the community by utilizing effective referral and care pathways. Holistic palliative care services are available to all through the use of up to date, evidence based clinical guidelines.

Goal 1. Strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.			
Objective	Activities	Outcomes	2020/2022
		2017/2018 dispensing and prescribing and care.	2018/2020 <ul style="list-style-type: none"> • Counseling services to be available for patients and families. • Spiritual care facilities and referrals to be available to patients and families. • MOUs / SLAs outlining service linkages between public and NGO sectors in place. • Availability of palliative care in private facilities to be known encouraged and strengthened.
			2020/2022 <ul style="list-style-type: none"> • Specialist units for admissions for pain control with a palliative ward/beds in every hospital or linkage with a hospice inpatient unit. • Implementation of the clinical care pathways with clear referral systems on place.
Risk identification and mitigation	Poorly developed systems to offer palliative care including HR, finances and medicines for pain management		
Indicator 1.2	Limited access to linkage to care		
	Number of districts with established referral pathways with linkages to care		
	The number of palliative care beds in sub-acute facilities or available in hospices		
Objective 1.3 To provide equitable and sustained access to appropriate medications and related consumables, to deliver palliative care.	Ensure access and availability of essential palliative care medicines and consumables	<ul style="list-style-type: none"> • Review of consumables required for palliative care and available to patients from clinics (e.g. sufficient adult diapers, dressings etc.). • Review of current morphine usage through collection of prescription and dispensing data and to project required quotas for future use. • Review supply chain to remove restrictions to supply of palliative care medicines, especially analgesics. 	<ul style="list-style-type: none"> • Supply chain is strengthened and working adequately to ensure un-interrupted supply of medications, including Schedule 6, (controlled substance) to all health facilities. • Opioids/morphine is available in every hospital. • Procedures for delivery of medicines to home-bound patients established (dispensing package).
			<ul style="list-style-type: none"> • Opioids/morphine is available in every hospital. • Patients have access to palliative care medicines and other resources at all levels of care.

Goal 1. Strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.			
Objective	Activities	Outcomes	
	Ensure adequate facilities to provide palliative care (sub-acute wards, palliative units, transport etc).	2017/2018 For district services, to include planning for vehicles and communication (i.e. mobile phones) for outreach services	2018/2020 <ul style="list-style-type: none"> Palliative care beds are available at health facilities, either integrated within wards or as separate sub-acute facilities or contracted from hospices – or a combination of services. Vehicles and other resources are available for palliative care teams to visit patients in their homes for assessment and treatment as required.
			2020/2022 <ul style="list-style-type: none"> Patients have adequately managed pain at home. Patients have access to inpatient palliative care services as required Patients receive palliative care services at home as required by a qualified palliative care team.
Risk identification and mitigation		Stock-outs of essential palliative care medicines including opioids – improved M&E and supervision of stock management Lack of access to medications by patients in the community – processes put into place for better access to medications Lack of facilities for inpatient care – need for interim MOUs/SLAs with service providers while inpatient services are developed	
Indicator 1.3		<ul style="list-style-type: none"> NEMLC approves palliative care chapter Palliative care essential medicines list approved Hospital and PHC STG/EML include palliative care Number of palliative care EML stock outs Morphine consumption per district health service headcount 	

Goal 2. Ensure adequate numbers of appropriately qualified health care providers to deliver palliative care at all levels of the health service			
Objective	Activities	Outcomes	
		2017/2018 <ul style="list-style-type: none"> Plan and implement a communication strategy to inform health workforce about palliative care to motivate them for the training. 	2018/2020 <ul style="list-style-type: none"> Palliative care to be included in all in-service training with recognition of training through certification and recorded on HR records and other platforms (e.g. SkillsSmart).
			2020/2022 A health and social welfare workforce which is fully trained and competent in palliative care.
Objective 2.1 Provide in-service training of current health workforce and social welfare workforce to deliver palliative care at all levels of service	<ul style="list-style-type: none"> Determine minimum allocations of palliative care trained providers at all levels of the health system. Define palliative care competencies for health and social welfare providers across the continuum of care. 		

Goal 2. Ensure adequate numbers of appropriately qualified health care providers to deliver palliative care at all levels of the health service			
Objective	Activities	Outcomes 2017/2018	2018/2020
	<ul style="list-style-type: none"> Develop a training strategy for in-service training based on the national curriculum 		<ul style="list-style-type: none"> Continuing professional development (CPD) requirement in place for all health and social welfare providers (e.g. doctors, nurses, pharmacists, social workers).
Risk identification and mitigation	Lack of facilities to train current health professionals in service. Consider e-learning with support, telemedicine and innovative technology to support training. Train the trainer courses and clear manuals and guidelines for those who are competent in palliative care to train others.		
Indicator 2.1.	Number of district trainers trained in palliative care Number of in-service palliative care trainings conducted per district Number of people trained.		
Objective 2.2 Nurse prescribing of morphine	(National Activity to be supported by the provinces)		Subject to revision of the act, identified nurses to be trained and to be prescribing morphine to patients appropriately.
Risk identification and mitigation	Limited number of qualified academic palliative care trainers to facilitate training for nurse prescribers		
Indicator 2.2	Number of nurses trained to prescribe morphine Number of nurses prescribing morphine		
Objective 2.3 Ensure that palliative care is included in the undergraduate/pre-service curriculum for all health care allied workers.			<ul style="list-style-type: none"> 50% of Higher Education institutions implement the standard palliative care curriculum Palliative care taught across all teaching platforms at services linked to academic institutions/health education providers (e.g. services provided at all levels of the health and social welfare system to provide a platform for students to engage in palliative care learning with patients and clients at all levels of service).

Goal 2. Ensure adequate numbers of appropriately qualified health care providers to deliver palliative care at all levels of the health service		
Objective	Activities	Outcomes
		2017/2018
		2018/2020
		2020/2022
Risk identification and mitigation	Institutions are slow to include palliative care into the curriculum. Regulating bodies to be urged to include palliative care competency for graduating health professionals. Different curricula for palliative care with variable time allocated. A national curriculum for each profession is developed to be implemented by all institutions. Employment status of HBC unclear; raises the question of who holds responsibility to train them. Refer to scope of practice of HBC and curriculum developed in conjunction with PHC Directorate and HWSETA.	
Indicator 2.3	Standard objectives for a palliative care curriculum for nurses and doctors Number of educational institutions implementing the standard palliative care objectives	
Objective 2.4 Strengthen post-graduate learning opportunities in palliative care for the health workforce	National activity to be supported by provinces as required.	25% of education institutions offer post graduate training in palliative care 50% of education institutions offer post graduate training in palliative care
Risk identification and mitigation	Processes to approve post-graduate courses can slow the process – strategy to support the process of approval of courses	
Indicator 2.4	Number of institutions offering post-graduate training in palliative care	
Objective 2.5 Develop a palliative care specialty for doctors and nurses	Complete a needs and situation analysis for specialist palliative care, with a registry of all health care, and allied workforce currently holding qualifications in palliative care.	Provinces to determine provincial need for palliative care specialist teams, guided by NDOH. Ten year strategy to adopt a palliative care specialty with the relevant regulatory boards
Risk identification and mitigation	Limited number of qualified academic palliative care tutors/lecturers to develop and facilitate palliative care specialist training.	
Indicator 2.5	Completed strategy developed for palliative care specialty	

Goal 3. Establish and maintain systems for monitoring and evaluation of South Africa's palliative care program			
Objective	Activities	Outcomes	
	(National activity to be supported by provinces)	2017/2018	2018/2020
Objective 3.1 Determine the baseline values for key indicators for palliative care	Integrate palliative care into provincial information data sets		Palliative care included in provincial data subsets -source of data and data flow -evidence of the source
Risk identification and mitigation	Lack of knowledge of palliative care data to include – to be guided by NDoH		
Indicator 3.1	Data elements defined with numerators and denominators		
Objective 3.2 To integrate palliative care indicators and targets into the District Health Information System (DHIS)	Data elements integrated into the DHIS	Agree with National DoH on routine reporting cycles. Integrate palliative care data elements into DHIS	Integration in DHIS completed
Risk identification and mitigation	Lack of knowledge of palliative care data to include – to be guided by NDoH		
Indicator 3.2	Data elements integrated into DHIS		
Objective 3.3 To determine the need for and to undertake periodic audits of palliative care services	Periodic survey tool designed		Training on survey tool to be used for palliative care
Risk identification and mitigation	Lack of knowledge of palliative care data to include in surveys – to be guided by NDoH		
Indicator 3.3	Periodic survey tool designed		
			Surveys initiated utilising survey tool Ongoing surveys and audits of palliative care

Goal 4. Ensure appropriate allocation of financial resources to strengthen and sustain South Africa's palliative care program.			
Objectives	Activities	Outcomes 2017/2018	2020/2022
Objective 4.1 Mobilise adequate financial and other resources for policy and strategy implementation	Key activity milestones for strategy implementation are met	2018/2020 Targets as per schedule of activities are met (Guided by National DoH)	2020/2022
Risk identification and mitigation	National DoH to determine costing formulae – to start needs analysis while waiting for costing information		
Indicator 4.1	Fully costed palliative care service		
Objective 4.2 Minimum standards for palliative care service delivery by NGOs implemented	MOUs/SLAs for NGO palliative care service delivery to be aligned to National standards	MOUs/SLAs with NGOs to reflect interim standards determined by National DoH	<ul style="list-style-type: none"> 50% of NGOs meet required standards Monitoring of NGOs to ensure compliance with standards
Risk identification and mitigation	Monitoring of NGOs to comply with standards – monitoring strategy to be included in regulations		
Indicator 4.2	Promulgated regulations for standards for palliative care service delivery by NGOs		

Goal 5. Strengthen governance and leadership to support implementation of the policy			
Objectives	Activities	Outcomes 2017/2018	2020/2022
Objective 5.1 Establish an inter-departmental forum to strengthen delivery of palliative care services by other sectors including SAMHS, Correctional Services, DBE, DSD	(National Activity to be supported by provinces)		
Risk identification and mitigation	Lack of understanding of the importance of palliative care in all sectors and departments, leading to lack of prioritisation of establishing services. Seminars for management teams on palliative care and advantages of providing equitable access to services other than health care which support palliative care services.		
Indicators 5.1	All social relevant cluster policies support palliative care service delivery		

Goal 5. Strengthen governance and leadership to support implementation of the policy			
Objectives	Activities	Outcomes	
		2017/2018	2018/2020
		2020/2022	
Objective 5.2 Provide guidance, direction and leadership to ensure the implementation of a coordinated palliative care strategy/plan	<ul style="list-style-type: none"> Identify a responsible person to co-ordinate palliative care in the province, to liaise with and guide districts on implementation and to report on progress. Implement a monitoring and evaluation strategy to measure progress. 	<ul style="list-style-type: none"> Commence with provincial palliative care plan A robust reporting strategy for palliative care with relevant palliative care indicators is in place 	<ul style="list-style-type: none"> Process to create a post for provincial manager (FTE) for palliative care completed and FTE appointed Provincial palliative care plan completed
		<ul style="list-style-type: none"> Palliative care plan implemented with M&E processes in place Annual monitoring and evaluation of palliative care services is conducted. 	
Risk identification and mitigation	Lack of suitably qualified persons for the FTE post or for the expert panel. Need to headhunt for suitable candidate and encourage training for a palliative specialist. Lack of political will to prioritise palliative care. Refer to national guideline.		
Indicator 5.2	Annual progress reports		
Objective 5.3 Create awareness, foster stakeholder engagement and develop partnerships with civil society and in the communities to ensure seamless transition of care	Multi-sectoral collaboration with partnerships to support provision of services.	<ul style="list-style-type: none"> Map of palliative care stakeholders and service providers within the province Strategy for awareness and advocacy at all levels of society 	<ul style="list-style-type: none"> MOUs /SLAs with CBOs as determined by national standards for NGO based service providers
			Seamless referrals and co-ordination of services between health facilities and CBOs in 50% of districts
Risk identification and mitigation	Lack of compliance with standards for service delivery – monitoring of service standards by DoH as agreed in the MOU/SLA		
Indicators 5.3	Number of awareness campaigns Number of MOUs/SLAs		
Objective 5.4 Ensure palliative care is included in the review and revision of existing policies and inclusion in new policies to enable the implementation of an integrated palliative care service.	(National Activity to be supported by provinces)	Provincial policies for review identified	Ongoing inclusion of palliative care into existing or new policies
Risk identification and mitigation	Missed opportunities to include palliative care into policy reviews – vigilance for policies being reviewed and for opportunities for palliative care to be included		
Indicators 5.4	Number of policies (existing or new) which include palliative care		

Appendix A

WHO Definitions of Palliative Care for Adults and Children

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

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

Appendix B

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY WHA67.19

Agenda item 15.5 24 May 2014

Strengthening of palliative care as a component of comprehensive care throughout the life course

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course⁴;

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council's Commission on Narcotic Drugs' resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes⁵, and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines⁶;

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

Bearing in mind that palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;

Recognizing that palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' needs to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received;

⁴ Document 67/31

⁵ Document E/INCB/2010/1/Supp.1.

⁶ Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011

Affirming that access to palliative care and to essential medicines for medical and scientific purposes manufactured from controlled substances, including opioid analgesics such as morphine, in line with the three United Nations international drug control conventions⁷, contributes to the realisation of the right to the enjoyment of the highest attainable standard of health and well-being;

Acknowledging that palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care;

Recognizing that more than 40 million people currently require palliative care every year, foreseeing the increased need for palliative care with ageing populations and the rise of noncommunicable and other chronic diseases worldwide, considering the importance of palliative care for children, and, in respect of this, acknowledging that Member States should have estimates of the quantities of the internationally controlled medicines needed, including medicines in paediatric formulations;

Realizing the urgent need to include palliation across the continuum of care, especially at the primary care level, recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care;

Noting that the availability and appropriate use of internationally controlled medicines for medical and scientific purposes, particularly for the relief of pain and suffering, remains insufficient in many countries, and highlighting the need for Member States, with the support of the WHO Secretariat, the United Nations Office on Drugs and Crime and the International Narcotics Control Board, to ensure that efforts to prevent the diversion of narcotic drugs and psychotropic substances under international control pursuant to the United Nations international drug control conventions do not result in inappropriate regulatory barriers to medical access to such medicines;

Taking into account that the avoidable suffering of treatable symptoms is perpetuated by the lack of knowledge of palliative care, and highlighting the need for continuing education and adequate training for all hospital- and community-based health care providers and other caregivers, including nongovernmental organization workers and family members;

Recognizing the existence of diverse cost-effective and efficient palliative care models, acknowledging that palliative care uses an interdisciplinary approach to address the needs of patients and their families, and noting that the delivery of quality palliative care is most likely to be realized where strong networks exist between professional palliative care providers, support care providers (including spiritual support and counselling, as needed), volunteers and affected families, as well as between the community and providers of care for acute illness and the elderly;

Recognizing the need for palliative care across disease groups (noncommunicable diseases, and infectious diseases, including HIV and multidrug-resistant tuberculosis), and across all age groups;

Welcoming the inclusion of palliative care in the definition of universal health coverage and emphasizing the need for health services to provide integrated palliative care in an equitable manner in order to address the needs of patients in the context of universal health coverage;

⁷ United Nations Single Convention on Narcotic Drugs, 1961, as amended by the 1972 Protocol; United Nations Convention on Psychotropic Substances, 1971; United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances, 1988

Recognizing the need for adequate funding mechanisms for palliative care programmes, including for medicines and medical products, especially in developing countries;

Welcoming the inclusion of palliative care actions and indicators in the WHO comprehensive global monitoring framework for the prevention and control of noncommunicable diseases and in the global action plan for the prevention and control of noncommunicable diseases 2013–2020;

Noting with appreciation the inclusion of medicines needed for pain and symptom control in palliative care settings in the 18th WHO Model List of Essential Medicines and the 4th WHO Model List of Essential Medicines for Children, and commending the efforts of WHO collaborating centres on pain and palliative care to improve access to palliative care;

Noting with appreciation the efforts of nongovernmental organizations and civil society in continuing to highlight the importance of palliative care, including adequate availability and appropriate use of internationally controlled substances for medical and scientific purposes, as set out in the United Nations international drug control conventions;

Recognizing the limited availability of palliative care services in much of the world and the great avoidable suffering for millions of patients and their families, and emphasizing the need to create or strengthen, as appropriate, health systems that include palliative care as an integral component of the treatment of people within the continuum of care,

1. URGES Member States⁸:

- (1) to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes;
- (2) to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management;
- (3) to provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;
- (4) to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles:
 - (a) basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers at the primary care level, including health care workers, caregivers addressing patients' spiritual needs and social workers;
 - (b) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics and internal medicine;

⁸ And, where applicable, regional economic integration organizations

- (c) specialist palliative care training should be available to prepare health care professionals who will manage integrated care for patients with more than routine symptom-management needs;
- (5) to assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages;
- (6) to review and, where appropriate, revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance⁹, on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions;
- (7) to update, as appropriate, national essential medicines lists in the light of the recent addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children;
- (8) to foster partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care;
- (9) to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020;

2. REQUESTS the Director-General:

- (1) to ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases and universal health coverage, as well as being included in country and regional co-operation plans;
- (2) to update or develop, as appropriate, evidence-based guidelines and tools on palliation, including pain management options, in adults and children, including the development of WHO guidelines for the pharmacological treatment of pain, and ensure their adequate dissemination;
- (3) to develop and strengthen, where appropriate, evidence-based guidelines on the integration of palliative care into national health systems, across disease groups and levels of care that adequately address ethical issues related to the provision of comprehensive palliative care, such as equitable access, person-centred and respectful care, and community involvement, and to inform education in pain and symptom management and psychosocial support;
- (4) to continue, through WHO's Access to Controlled Medicines Programme, to support Member States in reviewing and improving national legislation and policies with the objective of ensuring balance between the prevention of misuse, diversion and trafficking of controlled substances and appropriate access to controlled medicines, in line with the United Nations international drug control conventions;
- (5) to explore ways to increase the availability and accessibility of medicines used in palliative care through consultation with Member States and relevant networks and civil society, as well as other international stakeholders, as appropriate;

⁹ Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011

- (6) to work with the International Narcotics Control Board, the United Nations Office on Drugs and Crime, health ministries and other relevant authorities in order to promote the availability and balanced control of controlled medicines for pain and symptom management;
- (7) to further cooperate with the International Narcotics Control Board to support Member States in establishing accurate estimates in order to enable the availability of medicines for pain relief and palliative care, including through better implementation of the guidance on estimating requirements for substances under international control¹⁰;
- (8) to collaborate with UNICEF and other relevant partners in the promotion and implementation of palliative care for children;
- (9) to monitor the global situation of palliative care, evaluating the progress made in different initiatives and programmes in collaboration with Member States and international partners;
- (10) to work with Member States to encourage adequate funding and improved co-operation for palliative care programmes and research initiatives, in particular in resource-poor countries, in line with the Programme budget 2014–2015, which addresses palliative care;
- (11) to encourage research on models of palliative care that are effective in low- and middle-income countries, taking into consideration good practices;
- (12) to report back to the Sixty-ninth World Health Assembly in 2016 on progress in the implementation of this resolution.

Ninth plenary meeting, 24 May 2014
A67/VR/9

¹⁰ International Narcotics Control Board, World Health Organization. Guide on estimating requirements for substances under international control. New York: United Nations; 2012

Appendix C

Causes of premature death versus comparison locations, 2015

This table shows the top 10 causes of premature mortality. It can be used to compare YLLs across locations relative to the group average. Comparison groups were chosen based on the GBD regional classifications, known trade partnerships, and income classifications^{xlvi}.

	HIV/AIDS	Lower respiratory infect	Ischemic heart disease	Diabetes	Tuberculosis	Interpersonal violence	Cerebrovascular disease	Road injuries	Diarrheal diseases	COPD
South Africa	14,831.0	2,334.4	2,259.0	1,961.4	1,913.8	1,807.7	1,783.3	1,764.0	1,074.1	809.1
Comparison group average	141.4	521.7	1,754.3	365.1	185.8	253.7	1,077.5	578.0	168.0	489.5
Argentina	166.9	993.4	1,903.8	384.3	40.5	277.1	850.2	617.8	45.6	502.5
Australia	13.7	137.1	1,000.2	173.4	3.2	60.1	384.7	323.5	10.6	273.5
Brazil	403.1	912.9	1,941.2	624.5	87.0	1,457.0	1,379.8	1,114.6	137.9	621.2
Canada	30.5	180.6	1,105.8	196.9	3.9	73.8	327.0	325.9	27.0	256.8
China	113.3	433.3	1,671.9	181.7	81.1	68.6	2,236.5	893.1	25.3	930.5
France	28.1	188.5	758.5	132.2	10.8	42.6	378.1	343.5	24.9	149.9
Germany	17.9	207.0	1,326.0	158.6	4.7	36.3	452.1	231.3	25.2	275.2
Greenland	123.2	533.3	1,958.6	169.3	78.0	482.9	1,342.1	281.4	62.3	753.4
India	486.0	1,872.0	3,744.6	812.0	1,358.5	155.0	1,854.3	990.6	1,634.4	2,283.2
Indonesia	316.5	817.3	2,809.2	1,185.3	1,349.2	52.3	3,445.6	899.9	862.3	600.9
Italy	33.0	115.6	940.6	192.3	6.7	41.6	484.6	342.2	7.4	189.3
Japan	4.3	419.5	622.1	45.8	13.5	27.7	589.3	180.7	15.2	100.2
Mexico	188.0	601.6	1,616.2	1,270.7	70.7	791.7	672.9	754.1	138.7	431.5
Russia	581.4	756.9	4,818.4	116.4	217.6	686.8	2,558.5	874.3	18.2	287.5
Saudi Arabia	64.7	560.2	2,172.1	200.9	79.9	27.3	964.7	1,103.4	48.5	138.7
South Korea	8.8	230.5	573.7	365.2	79.4	65.7	836.8	435.0	16.9	161.2
Turkey	10.9	309.8	1,598.7	372.1	34.4	125.8	782.5	548.5	40.8	474.3
United Kingdom	14.3	353.1	1,153.3	73.6	7.2	31.7	476.8	176.7	18.9	407.6
United States	82.0	290.6	1,617.0	280.8	4.4	315.6	456.7	556.3	31.9	463.8

 Significantly lower than mean
  Statistically indistinguishable from mean
  Significantly higher than mean

YLLs per 100,000, age-standardized, 2015

Appendix D. Performance Status and Level of Care for Palliative Care Patients^{xlvii}

Karnofsky Status	Karnofsky Grade	ECOG Status	ECOG Grade	Level of Care
Normal, no complaints	100	Fully active. Able to carry on all pre-disease performance without restriction.	0	Attend outpatient clinic May need admission to hospital/hospice/sub-acute care for clinical indications (e.g. palliative radiation, blood transfusion, etc.)
Able to carry on normal activities. Minor signs and symptoms of disease	90	Restricted in any physical strenuous activity but ambulatory. Able to carry our work of light or sedentary nature (e.g. light housework/office work.)	1	Attend outpatient clinic May need admission to hospital/hospice/sub-acute care for clinical indications (e.g. palliative radiation, blood transfusion, etc.)
Normal activity with effort	80		1	
Care for self. Unable to do normal activity or to do any work	70	Ambulatory and capable of all self-care. Unable to carry out any work activities. Up and about > 50% of waking hours.	2	May attend outpatient clinic. May need admission to hospital/hospice/sub-acute care for clinical indications (e.g. palliative radiation, blood transfusion, etc.)
Requires occasional assistance, but able to care for most of his needs	60		2	
Requires considerable assistance and frequent medical care	50	Capable of only limited self-care. Confined to bed or chair >50% of waking hours.	3	Home-Based Community Care May be able to be transported to a clinic for outpatient visit May need admission to hospital/hospice/sub-acute care for clinical indications (e.g. palliative radiation, blood transfusion, etc.)
Disabled, requires special care and assistance	40		3	
Severely disabled. Institutional care or active supportive care indicated although death not imminent	30	Completely disabled. Cannot carry on any self-care. Completely confined to bed or chair.	4	Home-based Community Care or Hospice/sub-acute care
Very sick. Active supportive care or institutional care necessary.	20		4	
Moribund	10		4	
Dead	0	Dead	5	Death certification

12. References

- ⁱ Bradshaw, D., Groenewald, P., Laubscher, R., Nannan, N., Nojilana, B., Norman, R., Pieterse, D. & Schneider, M., 2003. "Initial Burden of Disease Estimates for South Africa, 2000." Cape Town: South African Medical Research Council.
- ⁱⁱ WHO Definition of Palliative Care. <http://www.who.int/cancer/palliative/definition/en/> (accessed 15/08/2016)
- ⁱⁱⁱ <https://www.africanpalliativecare.org/awareness/the-history-of-palliative-care/> (accessed 20/06/2016)
- ^{iv} Lynn J, Adamson DM. Living well at the end of life: adapting health care to serious chronic illness in old age. Arlington, VA, Rand Health, 2003
- ^v Hongoro, C, Dinat N. A Cost Analysis of a Hospital-Based Palliative Care Outreach Program: Implications for Expanding Public Sector Palliative Care in South Africa. *Journal of Pain and Symptom Management*, Volume 41, Issue 6, 1015 – 1024.
- ^{vi} www.spict.org (accessed 20/01/2016)
- ^{vii} [http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General Files/Prognostic Indicator Guidance October 2011.pdf](http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf) (accessed 23/01/2017)
- ^{viii} ACT/RCPC. A guide to the development of children's palliative care services. 1. Bristol and London: ACT/RCPC; 1997. [http://old.rcpcf.ru/Files/pdf/ACT. A Guide to the Development of Children's Palliative Care Services.pdf](http://old.rcpcf.ru/Files/pdf/ACT_A_Guide_to_the_Development_of_Children's_Palliative_Care_Services.pdf)
- ^{ix} Assessment of the Need for Palliative Care for Children. Three Country Report: South Africa, Kenya and Zimbabwe. UNICEF, ICPCN. 2013. <http://www.icpcn.org/wp-content/uploads/2013/11/Assessment-of-the-Need-for-Palliative-Care-for-Children.-Three-Country-Report-South-Africa-Kenya-and-Zimbabwe.pdf> (accessed 21/08/2017)
- ^x DesRosiers T, Cupido C, Pitout E, van Niekerk L, Badri M, Gwyther L and Harding R. A Hospital-Based Palliative Care Service for Patients With Advanced Organ Failure in Sub-Saharan Africa Reduces Admissions and Increases Home Death Rates. *J of Pain and Symptom Management*. 2014;47(4):786-92. doi: 10.1016/j.jpainsymman.2013.05.021
- ^{xi} Defilippi K. Integrated community-based home care: Striving towards balancing quality with coverage in South Africa. *Indian J of Palliat Care* 2005; 11:34-6. <http://www.jpalliativecare.com/text.asp?2005/11/1/34/16643>
- ^{xii} Temel J *et al* . Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer *NEJM* 2010; 363:733-742
- ^{xiii} Hofman K. Noncommunicable diseases in South Africa: A challenge to economic development. *S Afr Med J* 2014;104(10):747648. DOI:10.7196/SAMJ.8727
- ^{xiv} http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf (accessed 20/06/2016)
- ^{xv} Mortality and causes of death in South Africa, 2015: Findings from death notification. <http://www.statssa.gov.za/publications/P03093/P030932015.pdf> (accessed 08/08/2017)
- ^{xvi} UNAIDS Data 2017. Joint United Nations Programme on HIV/AIDS (UNAIDS). http://www.unaids.org/sites/default/files/media_asset/20170720_Data_book_2017_en.pdf (accessed 08/08/2017)
- ^{xvii} Bradshaw, D., Groenewald, P., Laubscher, R., Nannan, N., Nojilana, B., Norman, R., Pieterse, D. & Schneider, M., 2003. "Initial Burden of Disease Estimates for South Africa, 2000." Cape Town: South African Medical Research Council.
- ^{xviii} Community Survey 2016, Statistical release P0301 / Statistics South Africa. Pretoria: Statistics South Africa, 2016. http://cs2016.statssa.gov.za/wp-content/uploads/2016/07/NT-30-06-2016-RELEASE-for-CS-2016-_Statistical-releas_1-July-2016.pdf (accessed 08/08/2017)
- ^{xix} <http://www.healthdata.org/south-africa> (accessed 04/03/2017)
- ^{xx} http://econex.co.za/wp-content/uploads/2015/07/ECONEX_NHInote_2.pdf (accessed 01/03/2016)
- ^{xxi} Assessment of the Need for Palliative Care for Children. Three Country Report: South Africa, Kenya and Zimbabwe. UNICEF, ICPCN. 2013. <http://www.icpcn.org/wp-content/uploads/2013/11/Assessment-of-the-Need-for-Palliative-Care-for-Children.-Three-Country-Report-South-Africa-Kenya-and-Zimbabwe.pdf> (accessed 21/08/2017)
- ^{xxii} Connor, S.R., Sisimayi, C., Downing, J., King, E., Ken, P.L.A., Yates, R. and Marston, J., 2014. Assessment of the need for palliative care for children in South Africa. *Int J Palliat Nurs*, 20, pp.130-4.
- ^{xxiii} Murtagh FEM, Bausewein C, Verne J, Groeneveld E, Kaloki YE and Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine* 28(1). 2014. 49-58
- ^{xxiv} Morin L, *et. al*. Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliative Medicine*. 31(6). 2016. 526-536

- ^{xxv} The 2015 Quality of Death Index Ranking palliative care across the world. A report by The Economist Intelligence Unit. Commissioned by Lien Foundation. [http://www.lienfoundation.org/sites/default/files/2015 Quality of Death Report.pdf](http://www.lienfoundation.org/sites/default/files/2015%20Quality%20of%20Death%20Report.pdf) (accessed 23/01/2017)
- ^{xxvi} Mortality and causes of death in South Africa, 2014: Findings from death notification/Statistics South Africa. Pretoria: Statistics South Africa, 2015.
- ^{xxvii} The 2015 Quality of Death Index Ranking palliative care across the world. A report by The Economist Intelligence Unit. Commissioned by Lien Foundation. [http://www.lienfoundation.org/sites/default/files/2015 Quality of Death Report.pdf](http://www.lienfoundation.org/sites/default/files/2015%20Quality%20of%20Death%20Report.pdf) (accessed 23/01/2017)
- ^{xxviii} Gray A, Vawda Y. Health Policy and Legislation. In: Padarath A, King J, Mackie E, Casciola J, editors. South African Health Review 2016. Durban: Health Systems Trust; 2016. URL: <http://www.hst.org.za/publications/south-african-health-review-2016>
- ^{xxix} Gonzalez LL. *Need to rethink palliative care in South Africa*. <http://www.health-e.org.za/2013/09/19/need-rethink-palliative-care-south-africa/> (accessed 24/04/2014)
- ^{xxx} HPCA. *Community Health Workers and Home-based Carers*. [http://www.hospicepalliativecaresa.co.za/pdf/legalbook/HPCA Chapter 11 v3.pdf](http://www.hospicepalliativecaresa.co.za/pdf/legalbook/HPCA%20Chapter%2011%20v3.pdf) (accessed 24/04/2014).
- ^{xxxi} HPCA. *Standardised Courses*. http://www.hospicepalliativecaresa.co.za/Training_Courses.html (accessed 24/04/2014).
- ^{xxxii} National Department of Health. *Standard Treatment Guidelines and Essential Drugs List for Hospital Level Paediatrics*. Pretoria: National Department of Health; 2006. <http://www.doh.gov.za/docs/guidelines/2013/stdguide-peads.pdf> (accessed 24/04/ 2014).
- ^{xxxiii} National Department of Health. *Standard Treatment Guidelines and Essential Drugs List for Hospital Level Adults*. Pretoria: National Department of Health; 2012. http://www.kznhealth.gov.za/pharmacy/edladult_2012.pdf (accessed 24/04/ 2014).
- ^{xxxiv} National Department of Health. *Standard Treatment Guidelines and Essential Medicines List for Primary Health Care*. Pretoria: National Department of Health; 2008. <http://www.kznhealth.gov.za/edlphc2008.pdf>
- ^{xxxv} University of Cape Town. *UCT Research Report 2012*. [http://www.publichealth.uct.ac.za/documents/School of Public Health and Family Medicine 2012 Research Report.pdf](http://www.publichealth.uct.ac.za/documents/School%20of%20Public%20Health%20and%20Family%20Medicine%202012%20Research%20Report.pdf) (accessed 24/04/ 2014).
- ^{xxxvi} University of the Witwatersrand, *Palliative Care. Research*. <http://www.wits.ac.za/academic/health/clinicalmed/internalmedicine/divisions/palliativecare/9475/research.html> (accessed 24/04/2014).
- ^{xxxvii} APCA. *African Palliative Care Research Network*. <http://www.africanpalliativecare.org/articles/african-palliative-care-research-network/> (accessed 24/04/2014).
- ^{xxxviii} Khan T. Hospices in South Africa cut capacity as US reduces funding. <http://www.bdlive.co.za/business/healthcare/2013/02/21/hospices-in-south-africa-cut-capacity-as-us-reduces-funding> (accessed 24/04/2014).
- ^{xxxix} HPCA. *Frequently asked questions*. <http://www.hospicepalliativecaresa.co.za/pdf/advocacy/FrequentlyAskedQuestions.pdf> (accessed 24/04/2014).
- ^{xl} <http://www.stchristophers.org.uk/about/damecicelysaunders> (accessed 20/06/2016)
- ^{xli} http://www.who.int/health_financing/universal_coverage_definition/en/
- ^{xlii} http://www.hpcs.co.za/downloads/conduct_ethics/rules/generic_ethical_rules/booklet_3_patients_rights_charter.pdf (accessed 20/06/2016)
- ^{xliii} [http://www.dpsa.gov.za/dpsa2g/documents/ehw/policy/EHW Review working JUNE-30July final \(2\).pdf](http://www.dpsa.gov.za/dpsa2g/documents/ehw/policy/EHW%20Review%20working%20JUNE-30July%20final%20(2).pdf) (accessed 03/30/2017)
- ^{xliv} Palliative Care Service Development: A Population based approach. Palliative Care Australia, 2005. ISBN: 0-9752295-3-2
- ^{xlv} Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, Keegan O, Larkin P, Lynch M, McEvoy D, McQuillan R, O'Donoghue L, O'Hanlon M, Reaper-Reynolds S, Regan J, Rowe D, Wynne M; Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive
- ^{xlvi} <http://www.healthdata.org/south-africa> (accessed 04/03/ 2017)
- ^{xlvii} <http://oncologypro.esmo.org/Guidelines-Practice/Practice-Tools/Performance-Scales> (accessed 20/03/2017)
- ^{xlviii} Murray S.A. and Sheikh A. Care for all at the end of life. *BMJ*. 2008 Apr 26; 336(7650): 958–959. doi: 10.1136/bmj.39535.491238.94 .

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