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MINISTRY OF HEALTH MALAYSIA

NATIONAL PALLIATIVE CARE

POLICY AND STRATEGIC PLAN 2019-2030

A NATION CARING FOR EVERYONE BECAUSE THEY MATTER

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FOREWORD

Director - General of Health Malaysia

Malaysia is a nation that is progressing rapidly. We have seen much development in terms of infrastructure and the economy and we are launching into the 4th Industrial Revolution where information and communication technology has never been more advanced. Along with this, so too has our healthcare system advanced with increasing facilities and standards of care, the Malaysian healthcare system prides itself as one of the most efficient and effective healthcare systems in the world.

While upgrading facilities and modernising medical technology is central to maintaining a world-class standard of healthcare, it is equally important that we strive to maintain a high standard of compassionate and ethical care at the same time. Research has shown repeatedly that while more and more technical treatment is frequently being offered to people with serious illnesses, at certain points in a person's life, more is not always better and highly technical and expensive therapies do not always result in better care.

It is therefore very timely that this National Palliative Care Policy and Strategic Plan 2019-2030 has been developed by the Ministry of Health in collaboration with stakeholder and many other palliative care professionals from both the public and private sectors to serve as a roadmap for further development of compassionate and supportive healthcare system in Malaysia.

Based on global estimations, about 61 million people worldwide suffer from pain and other distressing symptoms due to chronic illnesses such as cancer, chronic organ failure, neurological disorders and frailty. Only about 14% of these patients receive the support and palliative care that they so desperately need. In Malaysia, our figures are proportional to that seen around the world. It is estimate that annually, about over 100,000 deaths or about 70% of total mortality in Malaysia are deaths of people requiring palliative care. This number will rise steadily each year as our population continues to grow.

As Malaysia moves forward as a developed nation, we are facing all the similar patterns of diseases such as seen in other developed countries where chronic non-communicable diseases (NCDs) are on the rise and that the population is becoming increasingly aged. At present over 70% of deaths in Malaysia are due to NCDs and it is only logical to assume that while we hope to be able to live long and productive lives, many of us will have to face the reality of chronic illness and disability in our twilight years. Such being the case it is only prudent that as a nation we start taking major steps to ensure that our people will continue to be cared for and supported adequately throughout their difficult times all the way till the very end.

Palliative care is therefore seen as a necessity that needs to be developed throughout the nation in a manner that will ensure coverage of all Malaysians regardless of where they may be. Patients need to be able to access such care not only in urban settings but also in rural villages and even in the home. As Malaysia is a signatory to the 2014 WHA 67.19 resolution on "Strengthening palliative care as a component of comprehensive care throughout the life course" it is hoped that this policy will therefore result in an integration of palliative care into our healthcare system and truly exemplify what is stated in the resolution.

The Ministry of Health will continue to stand firm in its support towards developing better palliative care services throughout the nation and will embrace new innovations to achieve our goals. Among such innovations will be the use of digital technology to improve coverage and to welcome stakeholders from throughout other government agencies, private sectors and also the public to work together to ensure that our nation is one that looks after its people in solidarity. As the wise Mahatma Gandhi said, " A nation's greatness is measured by how it treats its weakest members"

It gives me great pleasure to congratulate the national palliative care policy and strategy development team for their hard work, dedication and passion and I will offer all the support I can to enable the implementation of this policy to be a success.

DATUK DR NOOR HISHAM BIN ABDULLAH
DIRECTOR – GENERAL OF HEALTH, MALAYSIA

FOREWORD

Deputy Director - General of Health (Medical), Ministry of Health, Malaysia

Palliative care started developing in Malaysia since 1991 and what began as several voluntary services by Non - Governmental Organisations (NGOs) has now evolved into a recognised medical specialty, which is now become the cornerstone of palliative care development in the country. In 2019, there are a total of seven (7) specialist hospitals in the Ministry of Health (MOH) with resident palliative medicine specialists, four (4) of which have in-patient palliative care units. Apart from this, there are almost all of MOH state hospitals have also developed some form of palliative care service and in time, there will be resident palliative medicine specialists placed to all these hospitals as well.

Besides hospital-based palliative care, it is recognised that a large proportion of palliative care services comprise of community-based palliative care, as majority of patients prefer to spend most of their time at home. For the longest time, the charitable services of all NGOs have compassionately provided these services free of charge to the people of Malaysia. There are about 30 charitable NGOs providing palliative care services throughout the country. While MOH continue to support and encourage this partnership, MOH realizes the need to develop community palliative care services from within the MOH particularly in rural and remote areas where the NGOs are less able to reach in order to create more comprehensive and universal health coverage. Following this, in 2016, MOH has embarked on developing domiciliary palliative care programme at the MOH health clinic, which has piloted in the states of Selangor, Perak, Penang and Kedah. Eventually, the aim is to develop these services in every state so that every Malaysian wherever they may be will be able to access the kind of care they require when facing a life-limiting illness.

Apart from the MOH, the universities and medical schools also contribute an important role in the provision of palliative care to the nation. The contribution not only through patient care but also through the education of young healthcare professionals to ensure that future generations of doctors and nurses well versed with basic palliative care skills, which can be applied in their future practice. At present, five (5) medical schools have palliative care specialists within their faculties.

While palliative care often thought of as a need for the elderly population, it should not forgotten that there is also a need for palliative care in children. I am pleased to see that this national palliative care policy has explicitly included the development of paediatric palliative care. This is so important because as a caring nation we must remember that nobody should left behind.

This national palliative care policy and strategy has developed through the combined efforts of experts and stakeholders in the field of palliative care throughout the country. It is very encouraging to see the cooperation that has transpired among the various sectors of our healthcare system, which includes various sectors of the MOH, universities, non-governmental organisations and the private sector. For it is only when we work together as one nation can we hope to provide an effective and comprehensive palliative care network that aims to fulfil the needs of universal health coverage.

While congratulations are due to the team that has worked hard to develop this policy and strategy document, I believe the work is only just at the beginning and from this point on we will need to work even harder to realise the true worth of this document in its implementation. It is my sincere hope that in the next 10 years, palliative care in Malaysia will truly be integrated within our healthcare system so that no Malaysian will have to face the challenge of serious illness and deterioration without the support and care that they need.

DATUK DR HJ ROHAIZAT BIN HJ YON
DEPUTY DIRECTOR - GENERAL OF HEALTH (MEDICAL)
MINISTRY OF HEALTH, MALAYSIA

FOREWORD

National Head of Service Palliative Medicine, Ministry of Health, Malaysia

It gives me great pleasure to write this foreword for this National Palliative Care Policy and Strategic Plan 2019-2030 as it has indeed been an uphill task to get palliative care where it is today in Malaysia. I remember a time when healthcare professionals themselves had never come across the term “palliative care” and how challenging it was to stand up in a crowd to explain what it was. In the early days, many people viewed palliative care as a “voluntary service” and not really a full time profession. It was often felt that the role of palliative care was merely a charitable one which was something that should be done part-time when one felt they had time to spare. It was only till 1998 when the MOH decided to make a directive for all state hospitals to develop palliative care units that things began to take a more serious form. In 2005 finally, it became recognised as a medical specialty and since then more and more development has occurred in the areas of service development, human resource availability, drug availability and education in palliative care. At present, we have a growing number of trained palliative medicine specialists serving throughout the Ministry of Health and also in a number of major medical schools where they are not only serving patients but also educating other health professionals and conducting palliative care research in our local setting. Nurses and allied health professionals have also developed specialist training within their own fraternity and this is becoming more and more recognised. Apart from this, the community health programmes in the MOH have also recognised the need for greater involvement in community palliative care services and have initiated the domiciliary palliative care programme in several states. While much has been done for the care of adults and the elderly with life-limiting illnesses, the paediatric fraternity has also been developing the much needed field of paediatric palliative care since 2012.

I believe that with all the development that has occurred over the past 28 years, Malaysia is now ready to move towards integration of palliative care into our healthcare system. This is in line with the WHA67.19 resolution of “Strengthening of palliative care as a component of comprehensive care throughout the life course” and it is my sincere hope that over the next 10 years, through the implementation of this policy, this will truly become a reality. As palliative care then becomes more integrated with the healthcare system, what I hope to see is that all Malaysians who find themselves lost in the sea of uncertainty and suffering due to life-limiting illnesses will find support and comfort wherever they may be. I hope that palliative care in Malaysia will serve as a safety net that embraces everyone, be it in the concrete jungles of our cities or in the rural jungles of our interior, so that all people throughout the nation will be afforded comfort and dignity in every way possible towards the end of their lives. In order to do this, we all need to work together as a nation and this is where our National Palliative Care Policy had been developed with 7 key strategies in order to bring healthcare providers together not just from the Ministry of Health but also from the universities, civil societies, private sector and the lay community as well. The vision of our policy has deliberately been worded as “Providing compassionate care throughout the healthcare system” and this is because it is our intention to highlight that providing good palliative care is not merely the responsibility of a specialised group of healthcare providers but really the responsibility of all. Hence if all healthcare providers are given the basic tools and knowledge to provide compassionate care to every person they encounter, palliative care will indeed be integrated within our healthcare system.

As we look at this policy and reflect upon the need to provide good palliative care to our people, let us remind ourselves that we should not be thinking of people who need palliative care as those who are less fortunate than we are and the reason we are developing palliative care is for these unfortunate people who suffer so much. We must realise that those people who require palliative care will someday be you and I and we are all in the same boat. So we need to realise that by developing and integrating palliative care into our healthcare system, we are working towards ensuring our own comfort and support in our future years.

I thank all the members of the National Palliative Care Policy and Strategic planning committee for your excellent work and support throughout the development of this policy. It was an honour working with the multidisciplinary team involving members from MOH, universities and civil societies which hopefully makes this policy more meaningful to the people of Malaysia.

Malaysia has always been a nation of great compassion and kindness and this has been one of the key elements bonding our diverse nation together. So I look forward to the work to come as we go forth to implement this policy and strategic plan for I truly believe that as we strive to integrate palliative care into our healthcare system, the kindness and compassionate care that touches the hearts and souls of our most vulnerable members of society will bring Malaysians together and make us so much stronger and united as a nation. We should leave no one behind because every single person is important and as the late Dame Cicely Sauders often said, “You matter because you are you, and you matter till the end of your life.”

DR RICHARD LIM BOON LEONG
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TERMS AND DEFINITION

Community palliative care	a service who provides for the needs of palliative care assistance at home/in the community. the organizations that provide this service is commonly known as hospice organization or palliative care societies.
Compassionate communities	naturally occurring networks of support in neighborhoods and communities, surrounding those experiencing death, dying, caregiving, loss and bereavement. they are communities where citizens are encouraged to engage and become more informed about death, dying and care and adapt their practices and behavior to be active in supporting those at end of life.
Domiciliary palliative care	a community based palliative care service provided by the ministry of health
Life limiting illness	illness where it is expected that death will be a direct consequence of the specified illness
Palliative approach	an approach that aims to improves the quality of life for patients with life limiting illnesses and their families by reducing suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs.
Public private partnership	a form of cooperation between the public and private sector whereby a stand-alone business is created, funded and managed by the private sector as package that encompasses
Serious health related suffering	suffering is health related when it is associated with illness or injury of any kind. suffering is serious when it cannot be relieved without professional intervention and when it compromises physical, social, spiritual, and/or emotional functioning.
Terminal phase of dying	actively dying patients that are very close to death and exhibit many signs and symptoms of near death.
NGO hospices	non-governmental organization of hospices independent, non-profitable community palliative care providers

Basic competency	basic competencies are the minimum competencies that are expected of the different cadres following an introductory training in palliative care that is accompanied by support supervision and mentorship from more experienced care providers.
Intermediate competency	intermediate level competencies are those that care providers would be able to display after having undertaken further training, having had the opportunity to practice in their respective field and having had mentorship support from expert palliative care providers.
Specialist competency	specialist level competencies represent those that would be demonstrated by someone who has undergone formal specialist training on palliative care, has extensive practical experience, and is able to take responsibilities for a service or programme, train and offer expert support and mentorship for other care providers within their own team.
Symptom care plan	a step by step guide for parents and medical staffs for symptom management at home or at hospital which is equipped with the choices of drugs and the dosages, as well as non-pharmacological management.
Respite care	temporary institutional care of a sick, elderly or disabled person, providing relieve for their casual usual carer.
Advance care plan	documented discussion with a person and their healthcare providers with or without family members regarding their values and preferences for care in the future in the event they are unable to express themselves.
Accessibility	is the degree to which a medicine is obtainable for those who need it at the moment of need with the least possible, social or psychological barrier
Affordability	is the degree to which medicine is obtainable for those who need it at the moment of need at a cost that does not expose them to the risk of serious negative consequences such as not being able to satisfy other basic human needs. (WHO)
Availability	is the degree to which a medicine is present at distribution points in a defined area for the population living in that area at the moment of need. (WHO)

Essential medicines	essential medicines are those that satisfy the priority health care needs of the population. they are selected with due regard to public health relevance, evidence on efficacy and safety, and comparative cost effectiveness. essential medicines are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and the community can afford. (WHO)
Extemporaneous compounding	the process of preparing, mixing, assembling, packaging and labelling of a medicinal product based on prescription order from a licensed practitioner because a suitable registered product is not available.
Good manufacturing practice	part of quality assurance which ensures that products are consistently produced and controlled to the quality standards appropriate to their intended use and as required by relevant authorities. (WHO)
Manufacture	all operations of purchase of materials and products, production, quality control, release, storage, shipment of finished products and related controls. (WHO)
Pain free program	MOH pain free hospital initiative that emphasizes a multidisciplinary holistic pain management program incorporating anaesthesia and analgesia, modern surgical techniques and traditional and complementary medicine.
Registered product	a pharmaceutical product that has undergone all stages of production, including final packaging and is registered with the local drug control authority.
Shelf life	the period of time, from the date of manufacture, that a drug product is expected to remain within its approved product specification while stored under defined conditions.
WHO model list of essential medicines (EML)	a list, which is updated every two years, and is based on the criteria of safety, efficacy and cost effectivess of each medicine listed. the concept and the eml are presented to countries as expert guidelines which they can use to develop their own essential medicines policies and lists.

ABBREVIATIONS & ACRONYMS

APHM	Association of Private Hospitals of Malaysia
ACP	Advance Care Plan
ADPC	Advance Diploma in Palliative Care
APCA	African Palliative Care Association
BPKK	*Bahagian Pembangunan Kesihatan Keluarga* Family Health Development Division
BPL	*Bahagian Pengurusan Latihan*
BPP	*Bahagian Perkembangan Perubatan*
CKAPS	*Cawangan Kawalan Amalan Perubatan Swasta*
CME	Continuous Medical Education
CPD	Continuous Professional Development
CRC	Clinical Research Centre
DPC	Domiciliary Palliative Care
ECHO	Extension for Community Healthcare Outcomes
ED	Emergency Department
EML	WHO Essential Medicines List
FMS	Family Medicine Specialist
FTE	Full Time Equivalent
GMP	Good Manufacturing Practice
HM	Hospis Malaysia
HO	House officer
HOD	Head of department
ICT	Information and Communications Technology
IKN	*Institut Kanser Negara*
JCI	Joint Commission International
JKN	*Jabatan Kesihatan Negeri*
KK	*Klinik Kesihatan*
KPDNHEP	Ministry of Domestic Trade and Consumer Affairds
KPK	*Ketua Pengarah Kesihatan*
KSKB	*Kolej Sains Kesihatan Bersekutu*
KOSPEN	*Komuniti Sihat Perkasa Negara*
LHDN	*Lembaga Hasil Dalam Negeri*
LLI	Life limiting illness
LMIC	Lower- and Middle-Income Countries
MaHTAS	Malaysian Health Technology Assessment Section
MAMPU	*Unit Pemodenan Tadbiran dan Perancangan Pengurusan Malaysia*

MAPPAC	Malaysian Association of Paediatric Palliative Care
MHC	Malaysian Hospice Council
MMA	Malaysian Medical Association
MO	Medical officer
MOE	Ministry of Education
MOH (KKM)	Ministry of Health *(Kementerian Kesihatan Malaysia)*
MOU	Memorandum of Understanding
MOF	Ministry of Finance
MSQH	Malaysian Society for Quality in Health
MyPPC	Malaysia Paediatric Palliative Care Subcommittee
NCD	Non-communicable Disease
NEML	National Essential Medicine List
NGO	Non-Governmental Organisation
NICE UK	National Institute for Health and Care Excellence, United Kingdom
NICU	Neonatal Intensive Care Unit
PaPaS	Paediatric Palliative Screening Score
PC	Palliative Care
PHFSA	Private Healthcare Facilities and Services Act
PKD	*Pejabat Kesihatan Daerah*
PPC	Paediatric Palliative Care
PPP	Public Private Partnership
RESPIRE	National Institute for Health Research (NIHR) Global Health Research Unit on Respiratory Health
SGH	Sarawak General Hospital
SHS	Serious health-related suffering
SOP	Standard Operating Procedure
SPICT	Supportive and Palliative Care indicators tool
SCP	Symptom Care Plan
TSL	Together for Short lives
UHC	Universal Health Coverage
WHA	World Health Assembly
WHO	World Health Organisation
WPCA / WHPCA	Worldwide Hospice Palliative Care Alliance
WTE	Whole Time Equivalent

EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

Introduction

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness through the prevention and relief of suffering (WHO 2002). It is a field that has been developing in Malaysia since the early 1990s and over time has grown to a point where there is a good foundation of specialist training for doctors, nurses and allied health professionals. Specialised services have been developed in several state/ major specialist hospitals and NGO hospices are also available in almost all states across the nation.

Although these developments are significant, progress has been sporadic and lacking in standardisation. Many services are only available in urban areas while services in rural areas are literally non-existent. Hence there is no equity of palliative care in Malaysia.

In 2016, the National Strategic and Cancer Control Plan 2016-2020 included palliative care as part of its strategic plan however there is no separate policy for palliative care whereby the scope of care extends beyond cancer care alone.

For this reason, a national policy and strategy is needed to provide a framework for the development of a nationwide palliative care programme that is more outreaching and equitable for the entire population. The vision is to provide a minimum standard of palliative care for all who need it wherever they may be in the country. Vulnerable populations such as the poor, the less educated, the very young and the elderly are of particular concern. It is hope that this will serve as a safety net for these individuals in the event of serious illness in parallel with the target to achieve universal health coverage in Malaysia.

The need for palliative care in Malaysia

Research has estimated that as a nation develops, more palliative care is needed as more people tend to die from non-communicable diseases (NCDs). In Malaysia 73% of our total deaths in 2014 were due to NCDs. It is estimated that in a developed nation the need for palliative care is about 69-82% of the total mortality in the country. In a recent needs analysis by the MOH based on the national mortality data, it was estimated that the number of people requiring palliative care in 2014 was 100,034 and this number will steadily rise to a projected number of 239,713 by the year 2030.

In another study by a Lancet Commission for palliative care, researchers developed a methodology to look at needs from a perspective of serious health-related-suffering (SHS). The estimated need based on SHS in Malaysia is 223,832 people annually.

For paediatrics, due to the longer survival of patients in this group, a global cross-sectional analysis of prevalence by Connor et al (2018) estimated that 30,780 children aged between 0-19 in Malaysia require specialised paediatric palliative care annually.

Based on these figures and also rough data from dedicated specialist palliative care services and also NGO hospice services around Malaysia it is estimated that less that

10% of the total need for palliative care in Malaysia is being met.

Policy to integrate palliative care into the healthcare system

The WHA 67.19 resolution urges member states to integrate palliative care into the healthcare system as an essential strategy to provide universal health coverage. This call is reiterated in the WHO Global action plan for NCDs 2013-2020, the United Nations SDG Target 3.8 as well as the recent Declaration of Astana 2018. What this means is that palliative care should be developed as a service that is embedded into every level of the healthcare system so that access to palliative care will be available anywhere at any time whenever an individual develops a serious health problem. This requires that all healthcare professionals should have a basic awareness of how to recognise patients in need of palliative care and a minimum level of care and medications should be available to address these needs. It also requires a system so that patients may receive care from hospital to home and specialist care is made available when problems are more complex.

To fulfil this need to integrate palliative care into the healthcare system, the following national policy and strategic plan is proposed:

VISION
statement

"Providing compassionate care throughout the healthcare system"

It is therefore Malaysia's intention that through the joint efforts of the public sector, private sector, civil societies and individual members of society, that every Malaysian will have access to compassionate care that affords them comfort, support and dignity in facing serious health related issues at any level of the healthcare system in Malaysia. The development of such compassionate care will be based upon 3 key thrusts:

Equity
Every Malaysian suffering with a serious illness should be provided palliative care and afforded treatment with compassion and dignity regardless of their culture, age or background. Equitable care requires all patients to have adequate access to essential drugs and equipment to ensure a minimum level of comfort when facing a life-limiting illness.

Sustainability
Education, human resource and funding from the public sector, the private sector and the people of Malaysia should be sufficient to create a sustainable system of palliative care provision throughout the country. This system should ensure the continuous growth and development to meet the demands of the growing population in Malaysia.

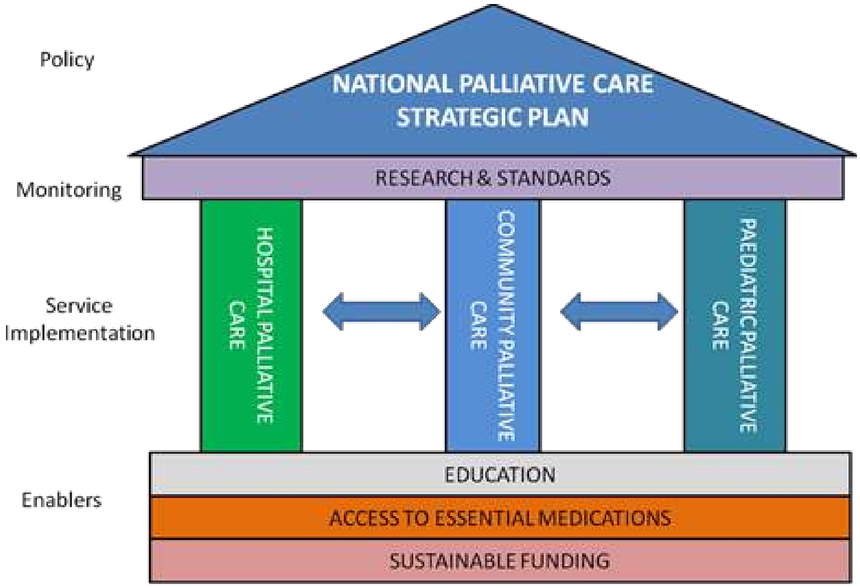
Quality
Every Malaysian deserves to receive palliative care which is of high quality and acceptable to the ethical standards of healthcare in the nation.

National Strategies for Palliative Care Development

THRUST	STRATEGY	RECOMMENDATIONS
Equity	**1** Palliative Care must be developed as part of universal health coverage as basic need of everyone in Malaysia	1. Minimum standards of care should be established in all healthcare services to ensure patients with palliative care needs will receive appropriate care. 2. Public-private partnerships should be developed to enhance the growth and development of palliative care services throughout the nation. 3. Palliative care provision should involve the private sector with clear regulation of the charges and control over the pricing of essential palliative care drugs.
	2 Ensure all people including children and older persons with life - limiting conditions who require palliative care should have their needs recognized within the healthcare system and community they live in	1. All healthcare services must develop policies/systems to recognize the unique needs of individuals with life-limiting conditions who are seen in their facility 2. Nurses, doctors and paramedical staff should be trained to access the needs of patients with life-limiting conditions 3. Public awareness on the importance of good palliative care should be promoted nationwide.
	3 Ensure all people including children and older persons who are recognized to have palliative care needs should be able to access the care and medications they require within the healthcare system and the community they live in	1. All hospitals both private and public should have policies and services that ensure basic palliative care needs of patients within their service are addressed. 2. Community palliative care services must be developed to enable people to receive care at home till death if desired. 3. All primary care clinics should provide basic symptom assessment and relief for patients with life limiting conditions and know how to refer patients for specialized care when necessary 4. Essential medications should be readily available and affordable to patients throughout the healthcare system. 5. Access to palliative care should also include care to address psychological, social and spiritual suffering.
	4 Develop a systematic network for continuity of palliative care and continuity of palliative care and sharing of information throughout the healthcare system to optimally support and minimize burdens to patients.	1. A network of palliative care services should be developed to ensure the continuity of care of patients and enable them to access care from the primary care level, to the secondary and tertiary and then back again to the primary care level. 2. Collaboration between private and public sectors is essential in creating an effective network of care 3. ICT should be employed to develop solutions for sharing essential information among palliative care professionals involved in patient care.

THRUST	STRATEGY	RECOMMENDATIONS
Sustainability	**5** Create palliative care education programme at appropriate levels for all individuals involved in caring for those with palliative care needs recognizing this skilled human resource and utilizing them in optimal manner.	1. Education in palliative care should be provided in all undergraduate and basic training of doctors, nurses and paramedical staff. 2. Specific mid-career training programme to up-skill medical officers and general specialists should be developed and continuous medical/nursing/paramedical education in palliative care must be provided on a regular basis throughout the nation. 3. Specialist training in palliative care should be enhanced and expanded to increase the number of skilled healthcare professionals in palliative care. 4. Healthcare professionals with specialized training should be deployed in a manner that allows the majority of the Malaysian population to benefit from such specialized training.
	6 Encourage community participation in the provision and promotion of palliative care for the nation	1. Community participation through civil societies must be encouraged in order to meet the needs of care for the nation. 2. Community participation can be encouraged through developing compassionate communities and promoting awareness in palliative care and advance care planning. 3. Appropriate engagement with faith communities and religious leaders is important to ensure that implementation of palliative care practices are culturally and socially acceptable.
Quality	**7** Establish standards of care based on best practices coupled with principles of good medical practice and incorporate the use of ICT to enhance development.	1. Palliative care practices must have appropriate standards of care based on current research data and best medical evidence coupled with good medical ethics relevant to the local setting. 2. Monitoring of standards of practice must be done regularly through key performance indicators and auditing. 3. ICT should be employed to enhance research, patient data registries, auditing, providing education and tracking of palliative care activities throughout the nation.

Strategic action plans over next 10 years



There are three (3) implementation strategies will include developing hospital based palliative care, community based palliative care and paediatric palliative care. These strategies can only be implemented with the enablers of education, access to essential medications and sustainable funding. Upon implementation, monitoring of services and standards is required to ensure quality of care.

Hospital Palliative Care

The development of hospital based palliative care is important as many patients with serious illness are initially treated in hospital settings. The plan therefore is to develop hospital based palliative care services at 3 levels: basic, intermediate and specialist. At the specialist level, services should be developed in every state hospital whereby these services will act as hubs to support other nearby hospitals within the same state. At present, specialist hubs have already been developed in Hospital Selayang, HKL, IKN, Hospital Ipoh, Hospital Pulau Pinang and Hospital Sultanah Bahiyah, Alor Setar. In hospitals without palliative medicine specialists, intermediate services can be set up whereby a trained medical officer and nurse can form a team to provide palliative care within the hospital at a level which is dedicated but not specialist palliative care. When advice is needed, specialists from the main state hub can be consulted.

For hospitals where there is no specialists or dedicated palliative care team, basic level palliative care should still be made available whereby a minimum standard of care for pain control and other basic symptoms are still provided for in the absence of any specific palliative care service. This is also known as the palliative approach. Private hospitals and private nursing homes should also be made to ensure that such minimum standards are also available in their facilities.

Community Palliative Care

Community palliative care is an essential component of the integrated palliative care service and involves home care which provides continuity of care to patients once discharged from a hospital. Community services help patients to remain at home for longer periods and help to reduce the need for emergency admissions to hospital. It also helps provide confidence to family to care for loved ones in their preferred place of care.

This strategy involves further developing the domiciliary palliative care programme based in government health clinics which will eventually evolve into dedicated teams focusing solely on homecare. To do this, more human resource will be required to develop these teams and further training needs to be done. Essential medications and equipment also need to be made available. At present this programme has been piloted in Selangor, Kedah, Perak and Pulau Pinang but should be made available in all states eventually.

Apart from developing domiciliary care teams from the MOH, community palliative care should also be developed by enhancing the existing NGO hospices that are already available. Smart partnerships between the NGO hospices and the MOH should be developed to ensure sustainability and effectiveness of these services. Sharing resources such as specialist expertise, training programmes, medication and funding should be considered. Coordination of services is also required in order to avoid duplication of NGO hospice and MOH services.

Paediatric Palliative Care

Children should not be excluded from palliative care services and it is estimated that over 2000 children in Malaysia die every year requiring palliative care. Developing nationwide paediatric palliative care services would be important to achieve universal health coverage. In the immediate implementation, paediatric palliative care can be developed by enhancing existing paediatric services in the country. Paediatric palliative care is now incorporated into general paediatric training and all paediatricians should be trained to provide the palliative care approach whenever necessary. Subspecialty training for paediatricians interested in focusing on paediatric palliative care should also be developed. Guidelines for paediatric palliative care should also be developed for local use so as to ensure the palliative care approach is used appropriately.

Community palliative care for paediatrics can be developed utilising existing community services by NGO hospices and MOH domiciliary care teams however as the nature of paediatrics may be unique, teams will undergo specific training through a “pop-up” or “in-time” training schedule meaning that only when the need arises, the paediatric palliative care specialist will train the specific team on how to care for this child based on his/her unique circumstances. A network of care to help children in need of palliative care to transition from hospital to home also needs to be developed.

Enablers of Implementation

a. Sustainable Funding

In general the government should still shoulder the bulk of responsibility to ensure compassionate care is provided to all its citizens. However, depending solely on government funding will definitely not achieve the vision of this policy and thus alternative sources of funding must be sought.

At present the amount of specific funding provided annually for palliative care services in the MOH is about RM 7.5 million. Another RM 0.8-1.2 million is awarded to NGO hospices as government grants. In order to further implement the above policy options, the estimated funding required for additional staff, facilities and drugs is about RM 30.4 million per year as well as a one-off expense of RM 10.4 million for development.

NGO hospices across the country together raise about RM 7-8 million per year for their operations. This serves as a very important resource for the nation and reduces the burden on government budgets significantly. This must be encouraged and incentives such as tax-exemptions and annual grant schemes should be considered.

Engaging corporate bodies to contribute to development is also an important approach and the private healthcare sector should also be made to provide palliative care at a reasonable price. Ultimately if a national foundation for palliative care could be developed this could be a source of sustainable funding.

b. Education

Education is key in provision of palliative care and as the objective is to develop palliative care services at basic, intermediate and specialist levels, training curricula needs to be developed at similar levels. Utilising the existing expertise available, regional education hubs can be formed for the north, central, south, east coast, Sabah and Sarawak. These hubs can then focus on implementation of training programmes such as basic palliative care awareness and short-course certification for intermediate level care. Specialist training sites should also be increased to allow more subspecialty trainees to train concurrently and closer to their original place of work. Once individuals have been trained workforce policies should be in place so that the expertise is utilised in the most effective manner.

In order to reach out to more remote areas, programmes using online and video-conferencing such as used in the project ECHO should be considered. Lastly, public awareness campaigns need to be developed nationwide in partnership with NGO hospices to create a deeper understanding among the population about the need for good palliative care.

c. Essential Medications

Essential medications in particular opioid analgesia are the tools to providing palliative care without which a palliative care service would simply not function effectively. Hence to ensure the implementation of this policy, the availability of morphine needs to be improved by developing better compounding procedures for a longer shelf-life of aqueous morphine as well as to increase education among healthcare workers on how to treat cancer pain using opioid analgesia.

Apart from this, policies around the use of essential medications for palliative care and its access need to be reviewed and improved upon to facilitate better access to these medications.

Research and Standards in Palliative Care

The provision of palliative care should be evidence-based and monitored to ensure continuous improvement in standards of care, cost effectiveness of service and up to date with latest technology.

Palliative care professionals should collaborate to prioritise and conduct research in areas needed by the country. This can be done through developing research links, mentorship, practical support for inter-institutional approval and funding applications. The culture of research should therefore become a norm in the development of palliative care in Malaysia.

Apart from this, nationwide standards and benchmarking should be done to ensure that a minimum standard of quality care is provided throughout the country and this should also involve those in the private sector.

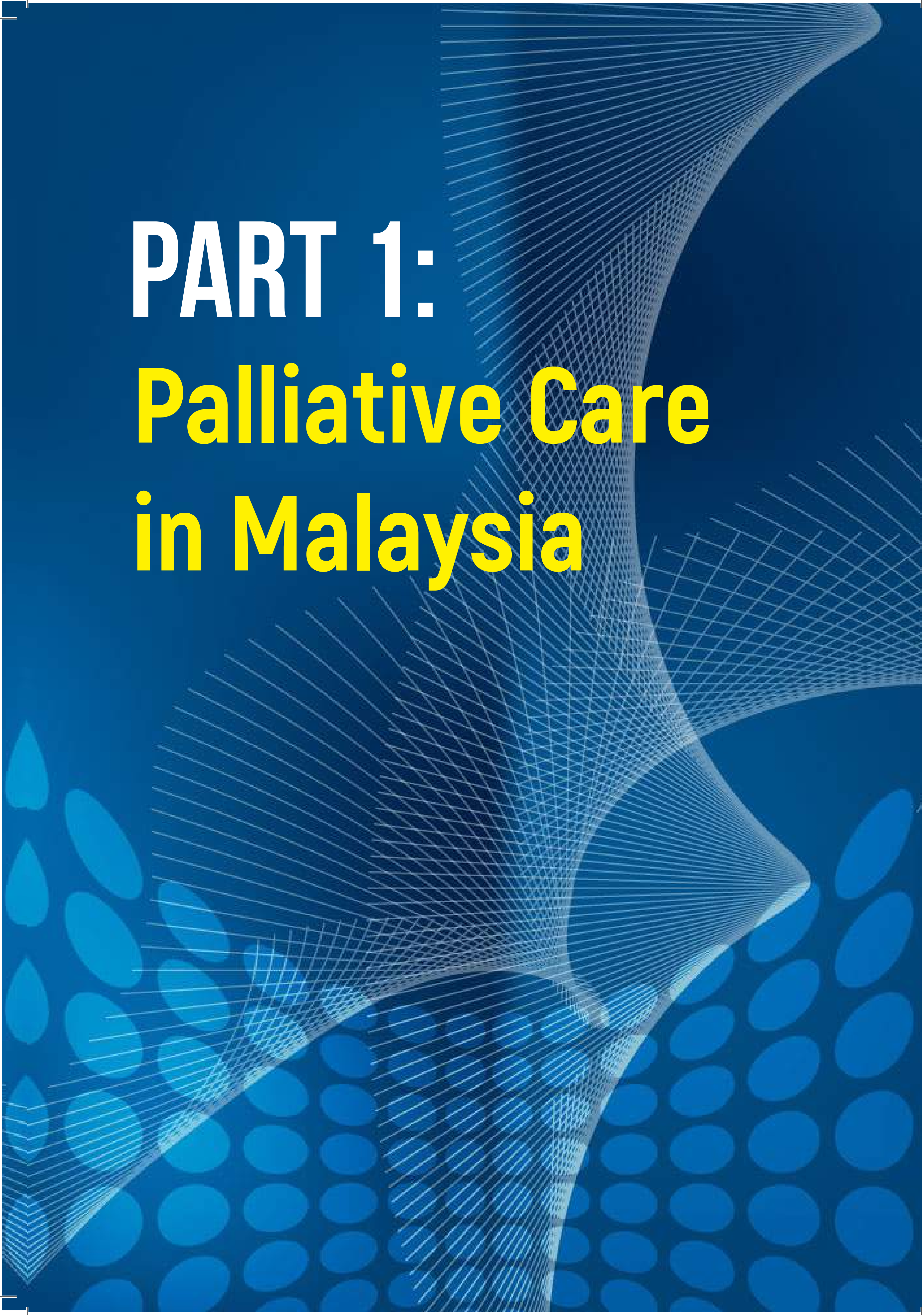
Finally, in order to bring palliative care research and standards forward in a significant manner it is suggested to develop an independent institution for palliative care research through a private-public partnership.

Conclusion:

The foundation of good palliative care has been established in Malaysia over the past 28 years and we are now on the verge of integration within the healthcare system. In order to bring this forward and to ensure the future comfort and dignity of every Malaysian as we face the scourge of non-communicable diseases and the aging population, a clear national policy and strategy for integrating palliative care within the healthcare system is very important. This is in parallel with the WHA 67.19 resolution, Declaration of Astana and the United Nations SDG as Malaysia working towards achieving universal health coverage and fulfil the objective of the United Nations Sustainable Development Goals 3.8.

PART 1:

Palliative Care in Malaysia



CHAPTER 1: INTRODUCTION

1.1 What is palliative care?

Since the very beginning, the focus of medicine has always been to relieve suffering and bring comfort to those ailing from diseases. While modern medicine has made major achievements with curative interventions for many of the communicable diseases, non-communicable diseases such as advanced cancer, chronic organ failure and degenerative disorders remain largely incurable. In these conditions, the focus of medical therapy is to prolong survival. However, it must be accepted that at some point, all people with chronic illnesses will eventually deteriorate and face the end of life.

The World Health Organisation (WHO) defines palliative care (Annex 7) as:

> ***"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."***

People with chronic life-threatening conditions frequently experience numerous problems throughout their illness. This includes distressing physical symptoms such as pain, breathlessness, nausea and disability. They may also experience psychological symptoms like depression and anxiety. Apart from this, there are many other social challenges that people with chronic illnesses face such as a lack of care and support in the community, financial catastrophes and family dysfunction. Last but not least, a chronic life-threatening condition often challenges an individual's spiritual wellbeing and problems such as demoralisation and loss of meaning in life are also common issues.

All these problems and more cause great suffering amongst tens of thousands of Malaysians each year and the numbers continue to rise annually as a result of our aging population and the increasing incidence of non-communicable diseases. At present, the vast majority of these Malaysians who are suffering do so in silence as there is a great lack of awareness and understanding for the role of palliative care and the need to provide equitable access to palliative care services throughout the country.

1.2 A global call to develop palliative care by the World Health Organisation

Worldwide it has been estimated that 60 million people are in need of palliative care annually and the vast majority of these people are living in under-developed and resource poor areas. Because of the magnitude of the need for palliative care worldwide, in 2014, the 67th World Health Assembly declared resolution WHA67.19 for the "Strengthening of palliative care as a component of comprehensive care throughout the life course". This resolution urges all Member States:

"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"

In the WHO Global Action Plan for the Prevention and Control of Non-communicable Diseases (NCDs) 2013-2020, palliative care is also explicitly recognized as part of the comprehensive services required for the management of NCDs.

"For comprehensive care of NCDs all people require access, without discrimination, to a nationally determined set of promotive, preventive, curative rehabilitative and palliative basic health services."

In the 2015 United Nations General Assembly, world leaders set the Sustainable Development Goals in which SDG target 3.8 refers to:

"Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all."

Based on this call to achieve universal health coverage (UHC), the provision of palliative care represents a major component as it is an intervention that focuses not only on health and wellbeing but also provision of essential medications and financial risk protection as core to its approach. This is clearly stated in the definition of UHC by the WHO.

"Universal health coverage means that all people receive the health services they need, including public health services designed to promote better health (such as anti-tobacco information campaigns and taxes), prevent illness (such as vaccinations), and to provide treatment, rehabilitation and palliative care (such as end-of-life care) of sufficient quality to be effective, while at the same time ensuring that the use of these services does not expose the user to financial hardship."

Most recently in the 2018 Declaration of Astana in the statement on 'Building sustainable primary care', Member States are urged to commit to:

"…meet all people's health needs across the life course through comprehensive preventive, promotive, curative, rehabilitative services and palliative care."

1.3 What are the benefits of palliative care?

Today there is a substantial body of evidence demonstrating the benefits of palliative care interventions within healthcare systems. In a recent economic assessment by Malaysia Health Technology Assessment Section (MaHTAS), it was reported that palliative care had significant effectiveness in the following areas:

1.3.1 Quality of life (QOL)

Studies showed that specialized palliative care in hospital based, community based, and home-based settings improved overall quality of life scores significantly in patients with life-threatening diseases including cancer, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF) and dementia. It also reduced caregiver burden, improved coordination of care, reduced hospital admissions and allowed patients to die in their preferred place of death.

1.3.2 Physical well-being

Palliative care interventions to address symptoms such as pain, dyspnea, nausea, vomiting and diarrhea have been found to significantly reduce these symptoms and improve physical wellbeing. Majority of these interventions include pharmacological management as well as palliative radiotherapy.

1.3.3 Psychosocial and spiritual well being

Psychosocial interventions commonly used in the palliative care setting such as counseling, supportive therapy, cognitive behavioral therapy and psychoeducation are effective in improving QOL and emotional wellbeing of patients with advanced cancer. Interventions such as therapeutic life review and dignity therapy have also been shown to relieve existential and psychological distress in patients near the end of life.

1.3.4 Reducing costs of healthcare

Health economic evaluations have also demonstrated that palliative care is cost saving. Patients receiving palliative care consultations had significantly lower hospital costs particularly if they had a diagnosis of cancer. Community based palliative care was also associated with reduced average in-patient hospital costs by about 7-10%. It was also associated with reduced acute admissions, bed days and healthcare costs in the last 1 year of life.

1.3.5 Patient survival

Interestingly, studies have also shown that apart from providing better quality of life at lower overall costs, palliative care also has a significant impact on patient survival. In a randomized controlled trial (RCT) looking at the effects of early palliative care in advanced lung cancer patients, it was found that patients receiving palliative care plus standard oncology care had significantly longer overall survival compared to those receiving standard oncology care alone (11.6 months vs 8.9 months; p=0.02).

1.4 Why is a National Palliative Care Policy and Strategic Plan needed in Malaysia?

As a signatory to WHA 67.19 resolution and being a nation that truly cares for its people, Malaysia has made significant progress in the development of palliative care services in Malaysia. In Malaysia, palliative care are approaching integration with mainstream medicine (World map of palliative care 2015). Malaysia also stands out significantly amongst many of its South East Asian neighbours.

However, in the 2015 Global Quality of Death Index published by the Economist Intelligence Unit, Malaysia ranked 38 out of 80 countries worldwide. This is because Malaysia still lacks equitable and effective palliative care services to meet the desperate needs of our population. Comprehensive palliative care services in hospitals and the community remain underdeveloped and seamless care delivery has not been achieved. While the inequity still exists among urban communities, the provision of palliative care is abysmal in rural areas. Availability of essential medicines is also still a problem and human resource are markedly lacking in this field, which is not yet popular among young doctors and nurses.

Palliative care has been developing over the past 27 years in Malaysia and has established a solid foundation for further development. This is an opportunity to move forward, expand care provision and reach out in a most meaningful manner. We are at the cusp of fully integrating palliative care into our healthcare system and it is hoped that by the year 2030, Malaysia will be able to truly achieve universal health coverage (including palliative care) for the nation.

This document outlines a national policy and strategic plan for the development of palliative care in Malaysia. Over the next 10 years it will serve as a framework to work towards achieving equitable nationwide palliative care service provision.

CHAPTER 2 : BACKGROUND OF PALLIATIVE CARE DEVELOPMENT IN MALAYSIA

2.1 Early development of palliative care in the 1990s

The concept of palliative care in Malaysia began in the early 1990s and was first initiated by non-governmental organizations (NGOs) which started hospice homecare services. The first two (2) organizations were based in Pulau Pinang and Kuala Lumpur. Following this, the concept grew and other charitable NGOs in other states throughout Malaysia also started providing palliative care mainly to advanced cancer patients at home. Gradually, some of these NGOs evolved to provide more professional services where fulltime nurses and doctors were hired and the semblance of a professional career path in palliative care began to develop. In 1998, several hospice organizations then founded the Malaysian Hospice Council (MHC) which still serves as the umbrella body for palliative care providers in Malaysia till today.

In 1995, the first dedicated in-patient palliative care unit was developed in Kota Kinabalu, Sabah. This pilot project at the Queen Elizabeth Hospital created greater awareness in the Ministry of Health (MOH) regarding the need for palliative care provision within government healthcare facilities and provided the impetus for further development. In 1998, a directive from the MOH ordered that all state hospitals should develop palliative care units by the year 2000. At that point, government funding was provided for education of doctors who would then develop palliative care services throughout the country. This led to the development of many palliative care units in government hospitals and by the year 2001, there were a total of 11 palliative care units and 49 palliative care teams throughout the Ministry of Health's hospitals.

A major shortcoming of this directive however was a lack of administrative leadership and technical expertise necessary to sustain the growth and development of these units and over the next 3 years after this directive only a handful of units and services remain. Recognizing the deficiencies of this programme, an enhanced approach to develop more effective palliative care services was taken through the development of the field of specialist palliative medicine.

2.2 Development of specialist palliative care

In December 2002, the palliative care unit of Hospital Selayang was developed and this became the first specialized palliative care unit in the Ministry of Health that was led by a specialist physician. In 2005, Palliative Medicine became recognized as a medical subspecialty in the Ministry of Health and a local 3 years fellowship programme was developed. Since then, a total of 21 palliative care specialists are now serving across Malaysia in the Ministry of Health, Ministry of Education and private institutions.

Several medical schools have also developed interest in the area of palliative medicine and are developing palliative medicine departments / units. The universities which currently have palliative medicine specialists within their medical faculty include UM, UKM, UiTM, USM and USiM. Among these universities, only UMMC has a dedicated palliative care ward.

2.3 Palliative care education and training

The development of palliative care as a field in medical schools is extremely important to increase knowledge and skills in palliative care within undergraduate and postgraduate medical and nursing programmes. The universities which currently have palliative medicine teaching within their medical faculty include UM, UKM, UiTM, USM and USiM.

In 2014, the Ministry of Health also pioneered in an advanced diploma in palliative care programme which was developed specifically to provide specialized knowledge and skills to nurses, occupational therapists and physiotherapists. Since its inception, the programme has trained close to 80 nurses and paramedical staff throughout Malaysia. It is currently based in the Kolej Sains Bersekutu Sultan Azlan Shah, Ulu Kinta, Perak.

2.4 Current status of palliative care services available in Malaysia

At present there are 7 MOH hospitals with resident palliative medicine specialists providing services within these hospitals. Only 4 of these hospitals however have in-patient palliative care units. Throughout the MOH however, there are a handful of hospitals with palliative care units which are remnants of the previous 1998 directive, but these units do not have specialist input and are sustained by the dedication of interested medical officers and nurses as well as supportive hospital directors. Wherever possible, the palliative medicine specialists that are available in the various major hospitals will also support nearby hospitals through visiting clinics and providing consultative cover. This is done either through the MOH cluster hospital programme or by a “hub and spoke” model initiated by the palliative care specialists themselves.

With regards to NGO hospice organizations, there is a total of 30 organizations functioning independently throughout the country in every state except for Perlis. The majority of these organizations (28) provide community palliative care (homecare) services and it should be noted that majority of community palliative care services in the country are provided mainly by these NGO services. Two (2) hospice organizations with in-patient stand-alone hospice units, which located at Pulau Pinang and Johor.

Although there has been significant growth of palliative care in Malaysia since the 1990s, it is obvious that there are still many deficiencies in terms of access to care. Much of the development by MOH hospitals and NGO hospice teams has focused on large urban areas and at present, access in smaller towns and rural areas of Malaysia is still abysmal. In 2016, the MOH initiated the domiciliary palliative care programme within government health clinics. This programme is still in its pilot phase and has been rolled out to states of Selangor, Kedah, Perak and Pulau Pinang. The objective of this programme is to increase access to community palliative care particularly in rural settings. While this is encouraging, much work needs to be done in order to create more staff that are skilled and to coordinate this programme in order for it to be effective. (A summary of palliative care services available in Malaysia is listed in Table 5b)

CHAPTER 3 : NEED FOR PALLIATIVE CARE IN MALAYSIA

3.1 Who needs palliative care?

In the initial period of development, palliative care was recognised mainly to fulfil the needs of patients with advanced incurable cancer. Much focus was on the management of cancer pain. Since then the scope of palliative medicine has expanded and today is relevant to any individual who experiences serious health related suffering due to any progressive life threatening condition. This includes conditions such as chronic organ failures, neurodegenerative disorders, chronic life-threatening infections, incurable genetic diseases and elderly people with multiple co-morbidities and frailty.

Apart from this, it must never be overlooked that children also have a great need for palliative care. Palliative care for children often involves 4 categories of conditions and while this does include incurable cancer, the majority of cases are from non-cancerous conditions such as cerebral palsy, congenital anomalies or inborn errors of metabolism and neurodegenerative disorders.

3.2 Assessing the need for palliative care in Malaysia

A common method of assessing the need for palliative care in a country is to extrapolate based on national mortality data. A recent study conducted by the MOH using a method to assess the minimum number of people requiring palliative care by Murtagh et al (2014), estimated that the population in need of palliative care in Malaysia was 100,034 in 2014 and will steadily rise to a projected number of 239,713 by the year 2030 (Yang SL et al 2019).

In another report by a Lancet Commission on global access to palliative care, the expert panel from the commission had concluded that palliative care needs estimated from mortality data alone would grossly underestimate the needs as there are many medical conditions which cause great suffering for patients yet are not fatal for many years. Hence they estimated the number of people around the globe requiring palliative care based on estimates of serious health related suffering (SHS) occurring in those who had died within the year (decedent) and also those who suffered but did not die (non-decedent). Based on this, the total estimates of SHS for Malaysia in both decedents and non-decedents was 223,832.

For the paediatric population, similar needs can be assessed using mortality and diagnosis as the criteria for needing palliative care. One difference however is that for many children needing palliative care, the period of follow up may be much longer than adults and therefore non-decedents make up a significant proportion of the need. A global cross-sectional analysis of prevalence by Connor et al (2018) estimates that 30,780 children aged between 0-19 in Malaysia require specialised paediatric palliative care annually.

3.3 How much of the need are we fulfilling?

While the estimates of need in section 3.2 clearly show how much suffering is occurring among our population, Malaysia has yet to develop a proper central registry to collect data on the number of patients cared for or supported by the various palliative care services available around the country. Limited collections of data from the various individual organisations and specialist palliative care centres are available however this data may not give an accurate depiction of how much palliative care support is being provided to our nation at present.

A report by the Malaysian Hospice Council stated that 19 out of 22 members had received a total of 3,660 referrals in 2017. Hospis Malaysia as the largest NGO hospice organisation recorded over 2000 referrals in 2017. Together with the referrals to the domiciliary care teams in the MOH, the number is less than 6,000 patients in total.

As for hospital based palliative care services, from the 7 specialist palliative care services in the MOH a total of 4980 referrals were seen in 2017. The majority of these patients were suffering from advanced cancer and about one third of all patients were non-cancer cases. The commonest non-cancer diagnosis was end-stage renal disease. In the teaching hospitals where palliative medicine is a recognised specialty (UMMC and HUKM), a total of 1648 patients were provided palliative care in 2017.

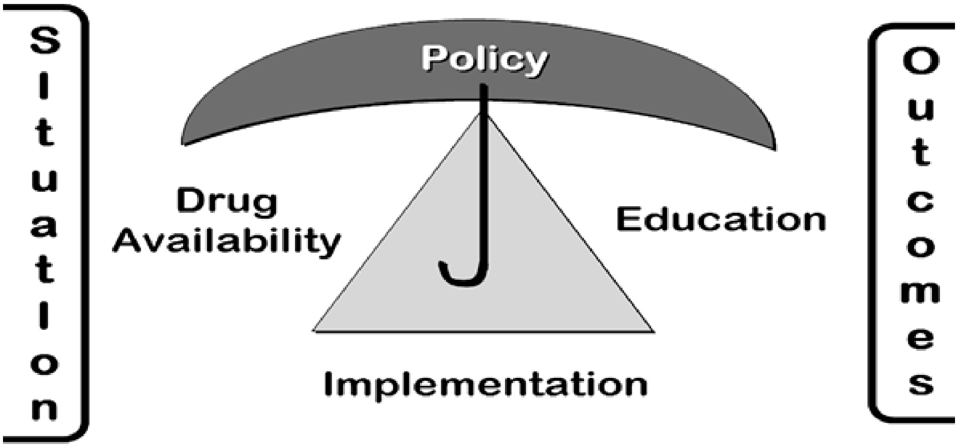
Among the paediatric age group, data from a national network of paediatricians working towards providing better palliative care services for children, a total of 315 cases were managed by doctors familiar with paediatric palliative care in 2014.

Based on this, it can be clearly seen that only a fraction of the need in the country is being met and at best only 10% of the need is accessing some form of palliative care service (annex 5). As the need is so great and the access to services at present still so lacking, it is imperative that palliative care be integrated into our existing healthcare system in order to ensure that majority of people suffering with life-limiting illnesses will be able to access good palliative care wherever they may be throughout the nation.

CHAPTER 4: CHALLENGES OF DEVELOPMENT AND DELIVERY OF PALLIATIVE CARE IN MALAYSIA

The WHO public health model for the development of palliative care services recommends that essential elements of a successful palliative care programme include a) drug availability, b) education and c) implementation. These elements must also lie under the umbrella of good policies by the higher administration in order to facilitate the development of these essential elements. (Figure 1)

Figure 1. WHO Public health model for palliative care



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4.1 Challenges in policy making

4.1.1 Commitment and support by higher administration

One of the main challenges in developing a good national policy for palliative care in Malaysia is the need for strong commitment and support by higher management regarding the development of comprehensive and effective palliative care services for the nation. A common misconception about palliative care is that it is an area that is not a true area of clinical medicine as people often think of it as only requiring soft skills. Another misconception is that palliative care is a non-essential service because it is not life saving and hence does not require much priority when considering financial budgets and human resource.

Hence, government leaders need to become more informed about palliative care and the important role it plays in creating a healthy and caring nation. They need to be aware that palliative care is a service that every single individual will require either directly or indirectly in their lifetime. Therefore, supporting the development of a good nationwide palliative care service will not only improve healthcare in the nation but will also improve the efficiency of healthcare spending while providing a safety net for everyone to ensure that appropriate care will be provided when the need eventually arises.

4.1.2 Ground research on palliative care needs assessment and cost effectiveness of healthcare systems

Although some policies are available in the National Strategic Plan for Cancer Control Programmes 2016-2020, there were based upon very superficial data and definitely to create more effective policies and planning, there is a need for good baseline data on the palliative care needs of the nation. Apart from this, there is also a need to look at the cost effectiveness of healthcare as a whole and with that, health-economic analyses must be conducted to show how palliative care may improve the efficiency of healthcare resources by reducing costs on inappropriate management and poorly coordinated care.

4.1.3 Public awareness and understanding of the role of palliative care

As Malaysia is a democratic nation, public demand for palliative care should be the driving force for creating a national policy for development. The public however may also have many misconceptions about palliative care such as issues of opioid analgesia causing addiction and palliative care being similar to euthanasia. There are also many taboos about even talking about death and dying in our Malaysian society and this will definitely have a negative impact on the development of a field like palliative care. Hence public awareness needs to be increased regarding the true nature of palliative care and dispel all the myths and misconceptions regarding it.

4.2 Challenges of Drug Availability

4.2.1 Access to essential palliative care medicines in rural and community healthcare facilities

Essential medicines for managing pain and other common symptoms are available in Malaysia, but there is a large discrepancy in medication availability and accessibility between different regions (urban versus rural) as well as healthcare settings.

4.2.2 Regulatory controls

Overly restrictive or excessively complicated regulatory controls can impede the timely provision of palliative medicines to patients. While regulations are important and are meant to prevent drug diversion and misuse, policies must take into account the needs of those in severe pain and distress in order to achieve a balance between proper control mechanisms and good palliative care.

4.3 Challenges of Education

4.3.1 Numbers of health professionals well trained in palliative care

Since the development of the sub-specialty of palliative medicine, there has been a growing number of palliative care specialists in the country. Also, with the advanced diploma course in palliative care for nurses and allied health professionals, there is a growing palliative care workforce. Despite this however the numbers still remain small compared to other fields of medicine. Apart from the small numbers, another challenge faced is that those who have been trained are sometimes deployed to areas where their skills are not being utilised. This results in a waste of valuable resources as well as a waste on education programmes.

4.3.2 Coordination of informal training programmes

Apart from formal palliative medicine training for specialists, there are numerous informal palliative care training programmes for doctors and nurses who are not specialists in this field. These courses provide skills and knowledge in palliative care which can be very useful in general settings. These courses however may not translate into service enhancements if the participants of these courses are not working in an environment that will allow them to practice these skills and knowledge. Doctors and nurses who attend these courses may sometimes be sent to attend the courses merely to fulfil a requirement of obtaining CPD points but have no interest in the subject. Targeted training programmes to specifically enhance palliative care service provision would be more effective and meaningful for development.

4.3.3 Collaboration amongst palliative care educators

As there is a lack of trained professionals to provide palliative care education, it would be wise and efficient to work together with universities and also the NGOs to develop joint education programmes in order to pool resources and avoid duplication of work. The MOH, MOE and the NGO hospice groups must work together to develop effective and meaningful palliative care education programmes for the nation.

4.4 Challenges of implementation

4.4.1 Standards of palliative care provision

There is a great variation in the standards of care being provided in the numerous hospital based palliative care services and also the community based NGO services. Some hospitals have palliative care units with consultants in palliative care whilst others have only rotating medical officers in charge of the unit. Some NGO services have fulltime doctors and nurses while others depend solely on volunteers. Because of this there is a great variation in the standard and quality of palliative care provided. Hospitals and NGOs with less resources may not provide comparable care to a better resourced service. While something is still better than nothing, the problem that arises is that services providing sub-standard palliative care may in fact create negative impressions of palliative care which already has many misconceptions by the public. Therefore, there must be a minimum standard of care practiced by all palliative care providers so that patients will always receive appropriate care and the field of palliative care is not misrepresented in any way.

4.4.2 Provision of community based palliative care

Currently, the majority of community palliative care is being provided by NGO hospice groups and very little development in this area has occurred within the MOH. NGO services however only cover specific urban areas and are most active in large cities such as Kuala Lumpur, Klang, Ipoh and Penang leaving the vast areas of small towns and rural settings with no service provision at all. In 2016, the MOH piloted the domiciliary palliative care programme in the state of Selangor and is gradually being developed in other states. The development however has been very limited and the resources allocated to this programme are insufficient to develop meaningful community palliative care services. More support must therefore be given to the development of the MOH domiciliary palliative care programme and also to NGO hospice groups to continue to grow and reach out to more areas throughout the country especially in rural areas.

4.4.3 Resources and infra-structure to provide sustainable and meaningful palliative care

When planning the development of meaningful and sustainable palliative care services, adequate human resource should first be planned for and then made available along with a minimum level of infra-structure so that a fully equipped and effective service can be developed. Only when a service is completely developed can it provide proper and effective services that will reflect the true role and objective of palliative care.

4.4.4 Career structure for healthcare professionals

Until the development of the sub-specialty of palliative medicine, there was no career structure for doctors interested in palliative care. Today, due to the development of the field which is now listed in the National Specialist Register (NSR), there is a greater interest among doctors to become involved in the field. A similar structure needs to be developed for nurses in palliative care. With the development of the advanced diploma in palliative care for nurses, it is hoped that this will allow more dedication amongst nurses and to allow more clinical competence and better care delivery in palliative care services.

Apart from the development of palliative care specialists in hospitals, a similar sub-specialised area should be considered for community palliative care service providers in order to give due recognition and also incentive to develop clinical excellence in the area of community palliative care. At present the main pathway to palliative medicine specialised training is through the route of internal medicine. Alternative routes such as from family medicine should also be considered as a career path to palliative medicine.

CHAPTER 5: INTEGRATING PALLIATIVE CARE WITH THE HEALTHCARE SYSTEM IN MALAYSIA

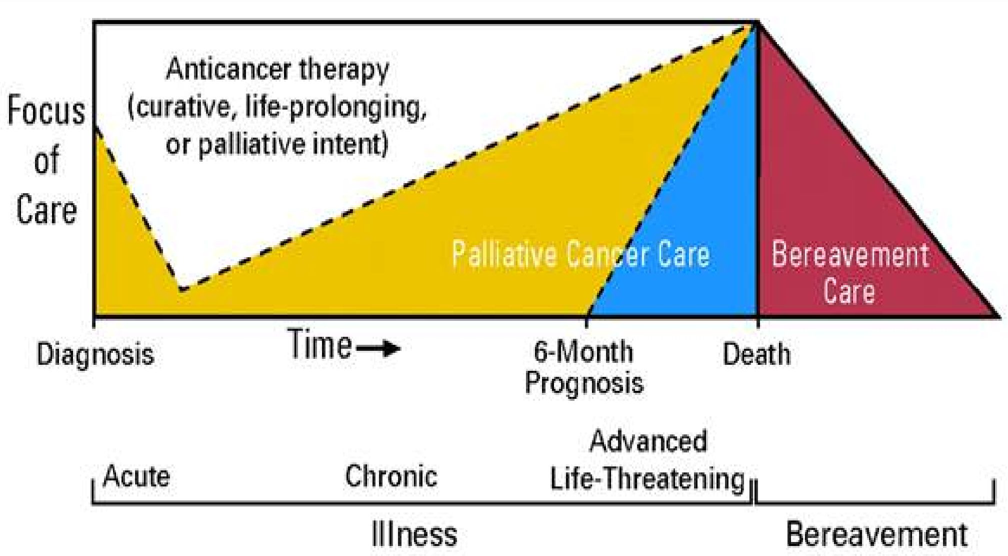
Serious health related suffering is an experience that every Malaysian will have to face at some point in time. Even if this is not experienced personally, every individual will have experienced a family member or a close friend who will experience it. It should also be realized that such suffering is an experience that cuts across all levels of society be it the rich or poor. Hence, palliative care is relevant to everybody and because of this the World Health Organization WHA 67.19 resolution calls for the integration of evidence-based, cost-effective and equitable palliative care services in the continuum of care across all levels of the healthcare system.

5.1 What does integration of palliative care mean?

Generally, integrating palliative care with the healthcare system refers to embedding concepts and practices of palliative care management into every level of the healthcare system (primary, secondary and tertiary) and to create a seamless network of care so as to allow patients to be supported continuously as they navigate through the healthcare system from their homes into hospitals and then back again.

During the early development of palliative care in Malaysia, palliative care services were developed as separate and distinct services from the mainstream healthcare system. Patients would therefore only access palliative care at the very end of their disease trajectory, often in the last few days or short weeks of life. This dichotomous model of palliative care has now long been considered an obsolete concept where today in the 21st century, a more patient centred and integrated model of palliative care is the current recommendation for the development of palliative care services worldwide. It should therefore be recognised that in this integrated model of palliative care, the provision of care evolves alongside the patient’s disease trajectory and is based upon the needs of the patient rather than the prognosis or availability of disease modifying interventions. In this way, patients should always be kept comfortable and supported throughout their illness and palliative care should not be considered a field associated only with failure to treat or cure a person of their illness.

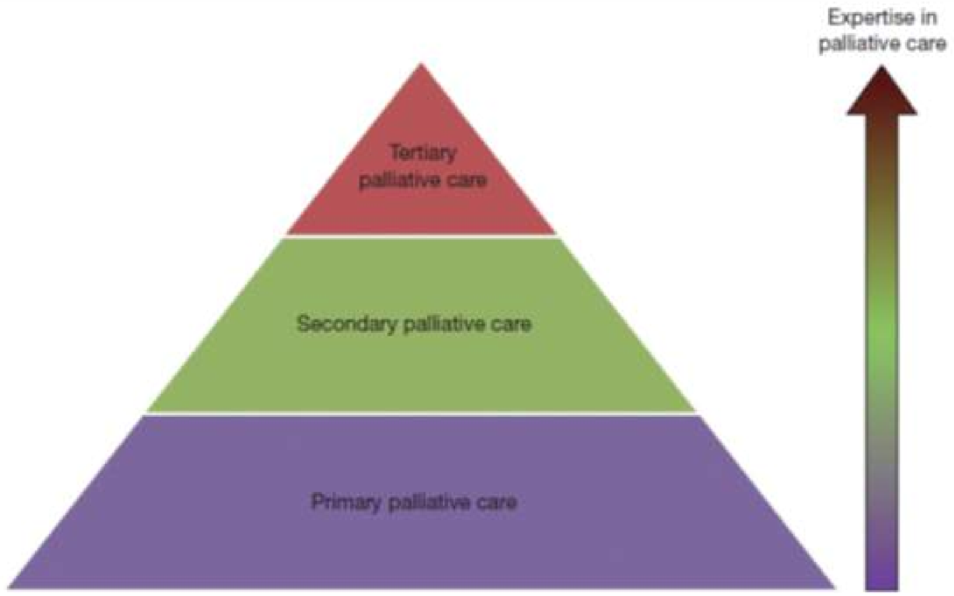
Figure 2: Integrated model of palliative care



Ferris F.D. et al 2009

Based on the integrated model of palliative care, the palliative care approach is applicable to patients throughout their illness. Hence, palliative care management must be made available to any patient requiring it anywhere within the healthcare system and not merely in large tertiary hospitals.

Figure 3: Levels of expertise in palliative care

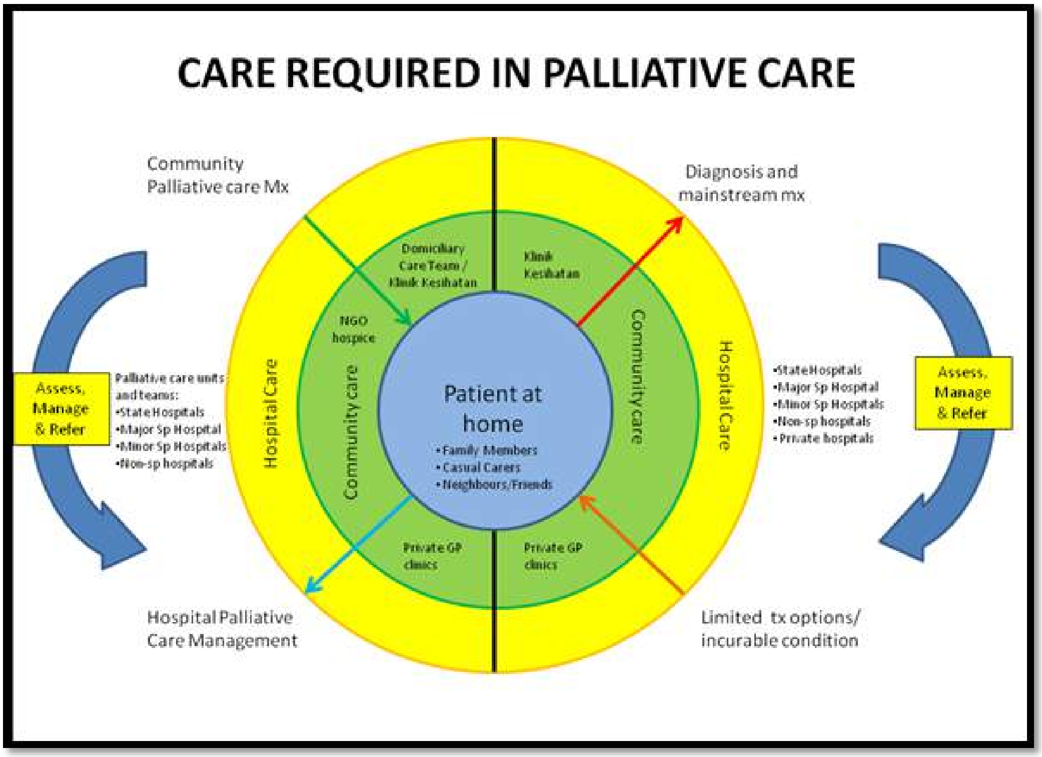


Hui D, Bruera E (2015)

At the most basic level (primary palliative care) all healthcare professionals should be aware of how to apply the palliative care approach similar to how all healthcare professionals should know basic life support. All healthcare providers should know how to identify, assess and treat basic symptoms. For doctors who frequently encounter patients with serious illnesses, they may undergo specific training to handle more complex cases and provide a higher level of care although they may not be involved in palliative care fulltime. This is considered secondary level palliative care and is most important in hospitals or community services where a specialist in palliative care is not available. Finally when there are trained palliative care specialists, tertiary palliative care can be made available particularly in major specialists hospitals and large community palliative care services.

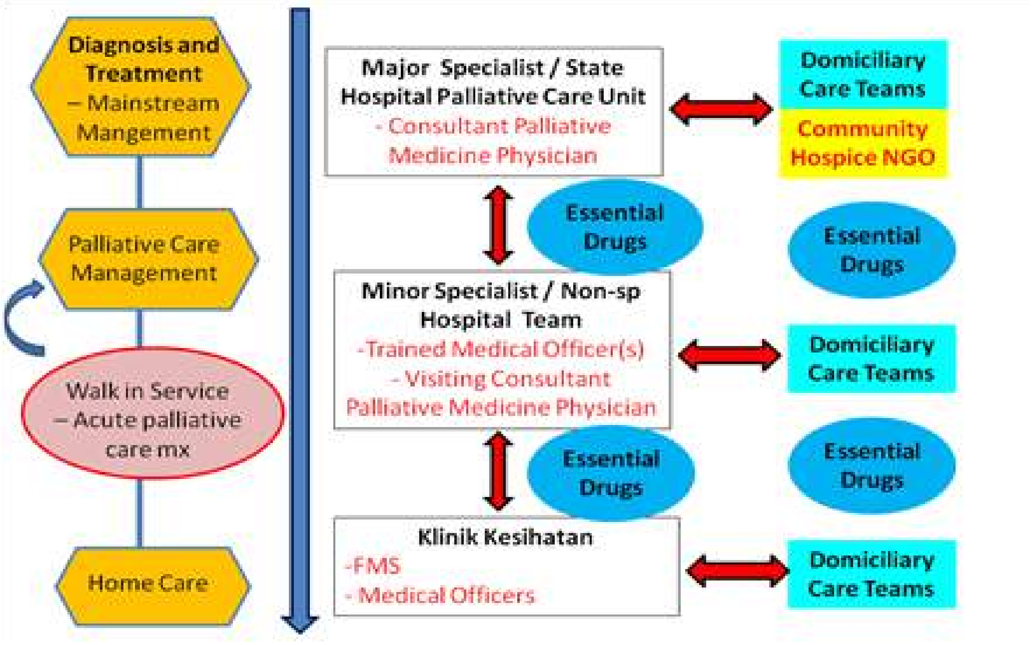
Thus in integrating palliative care within our healthcare system in Malaysia, healthcare providers at all levels should be equipped with basic knowledge and skills to recognised, assess and treat any patient with palliative care needs throughout the healthcare system.

Figure 4: Journey of patients from mainstream medicine to palliative care



Essential medications and equipments require to manage basic symptoms must be available at all these sites and a networking system must be established in every local setting to ensure that patients requiring higher levels of care can be navigated to tertiary palliative care centres. While those returning closer to home may receive continued care in the community, where they live and when necessary even at home. This concept of integration within the healthcare system as illustrated below.

Figure 5: Concept of integration of palliative care within the Malaysian healthcare system



5.2 Why is this necessary?

With the burden of care estimated at over 100,000 people per year, the only solution to improving access and bridging the large gap in palliative care is to integrate palliative care services into every level of the healthcare system and task shifting.

It should be understood that a person requiring palliative care is generally unwell, uncomfortable and often frail. Such patients find it extremely challenging to travel great distances to access palliative care in specialised regional centres. This is why integrating palliative care into the healthcare system as illustrated in Figure 5 is so important.

The WHA 67.19 resolution has urged member states to develop palliative care with an emphasis on primary care, community and homecare. This is a very important recommendation that must be emphasised in this national policy and strategy.

Research on where people prefer to spend their last days of life, repeatedly show that the home is significantly the preferred place of care and also death. This is also apparent in our local Malaysian setting whereby majority of patients who are sick and dying have a preference to spend their last days at home. A peaceful home death however cannot be achieved when there are inadequate homecare services and families are frequently forced to bring patients to hospital to die because they are unable to cope at home.

Looking at the Malaysian death statistics in 2016, only 85,637 out of 162,201 deaths were medically certified. If we assume that all medically certified deaths were deaths occurring in hospitals this would mean that almost half of deaths recorded in the country were deaths occurring outside hospital settings (76,564) of which a large proportion could have been at home. If this were the case it is hoped that all these Malaysians who died at home had some form of supportive care towards the end of their life as it would be of great concern to think that so many Malaysians facing the end of their lives are also facing terrible pain and suffering at home.

While a large proportion of Malaysians (75%) now live in urban areas and cities, it should not be forgotten that there are still the other 25% who live in rural areas which at present are grossly underserved with no access to palliative care at all. Patients living in rural areas are often less affluent and because of this, when they fall ill, some may not seek treatment in secondary or tertiary hospitals until the disease has reached an incurable stage. WHO has stated in the 2007 cancer control guide that

"Palliative care is particularly needed in places where a high proportion of patients present in advanced stages and there is little chance of cure."

Hence, the population requiring palliative care in rural settings is of particular importance and therefore, palliative care services should be integrated with minor and non-specialist hospitals and health clinics in these areas.

Ultimately the importance of integrating palliative care with the healthcare system in Malaysia is to create a safety net for everyone who falls seriously ill and experiences suffering from their illness. At present, without such a safety net, it can be assumed that for the vast majority of the population who die from serious illnesses do not receive adequate care and comfort at the end of life.

Access to palliative care and pain relief has been regarded as a basic human right based on many statements from international organisations and dates back as far as 1948 with the Universal Declaration of Human Rights by the United Nations General Assembly which states in Article 1:

"No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment."

Allowing patients to be left in pain and suffering can therefore be considered a form of neglect, inhuman and degrading treatment.

And in Article 25:

"Everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family"

Providing palliative care is the only way to provide wellbeing to a person who is sick and dying. It will also help to support the family in this very difficult time and maintain some form of wellbeing.

5.3 How can integration be achieved?

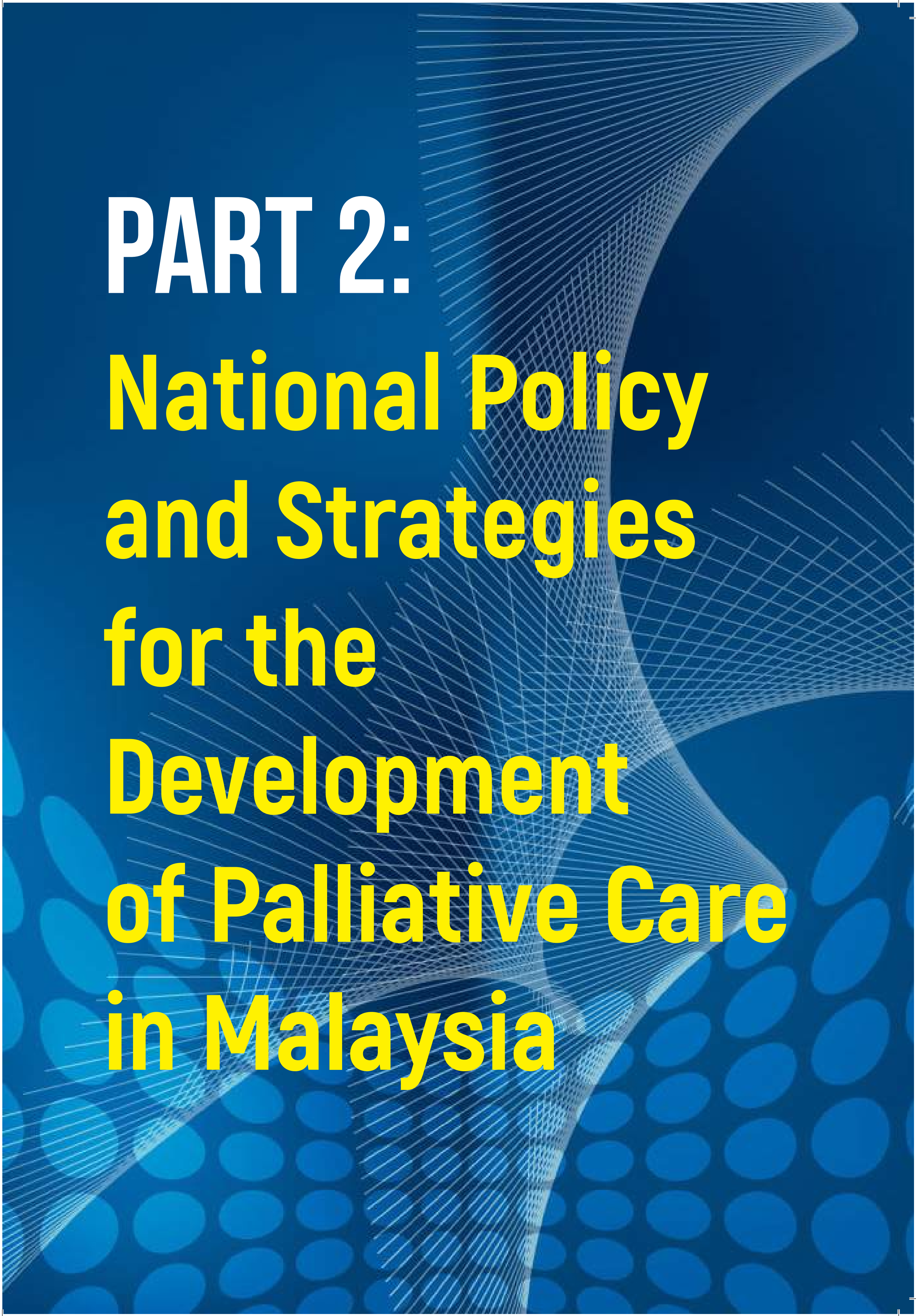
The Malaysian healthcare system currently has a widespread network of hospitals and health centres that have served to ensure almost universal coverage of the nation. Therefore, integrating palliative care services within the healthcare system, would only require an enhancement of existing services that are already in place.

Specialised training programmes for doctors, nurses and some paramedical fields have been developed and can provide the foundation for other primary and secondary level training programmes. With this, it will be possible to train doctors and nurses throughout the country to provide basic palliative care. For smaller hospitals where palliative care specialists are not available, other doctors such as surgeons, physicians or senior medical officers could be trained at a secondary level to provide more advanced care and to create dedicated services.

Essential medications in palliative care are also readily available and with enhanced policies and operating procedures, such medications could be made available at all levels of palliative care provision.

Rural areas may face challenges of a lack in skilled human resource and doctors posted to such centres often do not remain for long. Hence, strategies such as task shifting and the development of nurse led palliative care teams should be considered.

Malaysia is a nation of great strength and wealth from its caring people and their diversity which has made Malaysia resilient and yet adaptable to change. Integration of palliative care into the healthcare system is therefore highly achievable as long as there is sufficient political will. In order to facilitate this, a national policy and strategic plan is essential to provide the necessary support and direction for compassionate palliative care to be developed in an equitable manner throughout the country.



PART 2:

National Policy and Strategies for the Development of Palliative Care in Malaysia

CHAPTER 6: NATIONAL POLICY AND STRATEGIES FOR THE DEVELOPMENT OF PALLIATIVE CARE IN MALAYSIA

6.1 National Policy Statement

Vision:

Providing compassionate care throughout the healthcare system

It is Malaysia's intention that through the joint efforts of the public sector, private sector, civil societies and individual members of society, that every Malaysian will have access to compassionate care that affords them comfort, support and dignity in facing serious health related issues at any level of the healthcare system in Malaysia. The development of such compassionate care will be based upon 3 key thrusts:

i. **Equity**

Those suffering with a serious illness should be provided palliative care and afforded treatment with compassion and dignity regardless of their culture, age or background. Equitable care requires all patients to have adequate access to essential drugs and equipment to ensure a minimum level of comfort when facing a life-limiting illness.

ii. **Sustainability**

Education, human resource and funding from the public sector, the private sector and the people of Malaysia should be sufficient to create a sustainable system of palliative care provision throughout the country. This system should ensure the continuous growth and development to meet the demands of the growing population in Malaysia.

iii. **Quality**

Patients deserve to receive palliative care which is of high quality and acceptable to the ethical standards of healthcare in the nation.

6.2 Strategies for the development of palliative care in Malaysia

In order to achieve Malaysia's vision of compassionate care throughout the healthcare system and fulfilling the key thrusts of the national palliative care policy, the following strategies shall be applied:

Table 1: Key strategies for the development of palliative care in Malaysia

THRUST	STRATEGY
Equity	1. Develop palliative care as part of universal health coverage and a basic need of everyone in Malaysia. 2. Ensure all people including children and older persons with life-limiting conditions who require palliative care should have their needs recognised within the healthcare system and the community they live in. 3. Ensure all people including children and older persons who recognised to have palliative care needs should be able to access the care and medications they require within the healthcare system and the community they live in. 4. Develop a systematic network for continuity of palliative care and sharing of information throughout the healthcare system to optimally support and minimise burdens to patients.
Sustainability	5. Create palliative care education programmes at appropriate levels for all individuals involved in caring for those with palliative care needs recognising this skilled human resource and utilising them in an optimal manner. 6. Encourage community participation in the provision and promotion of palliative care for the nation.
Quality	7. Establish standards of care based on best evidence coupled with principles of good medical practice and incorporate the use of ICT to enhance development.

6.2.1 STRATEGY 1:

Develop palliative care as part of universal health coverage and a basic need of everyone in Malaysia.

Rationale:

Palliative care should be seen as a need that must be provided to everyone regardless of cultural or socio-economic background. It is a form of care that should be made available not only to people living in urban areas but rural as well. While this is the ideal, it is a fact that the healthcare services tend to be more developed in urban settings as the population density is much higher in these areas.

In order to provide more equitable care, there is a need to create a minimum standard of care so that palliative care is universally available throughout the nation. Therefore, while a rural hospital or clinic may not have access to a specialists trained in palliative medicine, care should still be provided to ensure the majority of patients in need will be managed appropriately.

Apart from the geographical location, measures should be taken to ensure that patients in need of palliative care should be able to access such care regardless of whether they are rich or poor. While the government and NGO sector that currently provides palliative care is highly affordable (almost at no cost to the patient), the private healthcare sector can also play an important role in the provision of palliative care. Many private clinics, nursing facilities and hospitals can contribute significantly to the palliative care needs of patients seeking private medical care if their healthcare practitioners are trained with basic palliative care knowledge and skills. In order to ensure that palliative care in the private sector is affordable, measures must be taken to regulate the charges for private palliative care services and also to control the price of essential palliative care drugs (especially opioid analgesia) in the private sector.

Public-private partnerships, especially between the MOH and NGO hospices is another important measure to ensure equitable care and to enhance the access to good palliative care. While NGO hospice groups provide an important resource for community based palliative care, many organisations struggle to gather sufficient funding to hire fulltime doctors trained in palliative care. Hence, a partnership where resources are shared will enhance the care provided at the community level as well as to support the sustainability of NGO hospices throughout the nation.

Recommendations:

a) *Minimum standards of care must be established in all healthcare services to ensure patients with palliative care needs will receive appropriate care.*

b) *Private-public partnerships should be developed to enhance the growth and development of palliative care services throughout the nation.*

c) *Palliative care provision should involve the private sector with clear regulation of the charges and control over the pricing of essential palliative care drugs.*

6.2.2 STRATEGY 2:

Ensure all people including children and older persons with life-limiting conditions who require palliative care should have their needs recognised within the healthcare system and the community they live in.

Rationale:

People with incurable life limiting conditions are often faced with many challenges. They experience distressing physical problems such as pain, breathlessness, poor mobility and weakness. Apart from this they also may experience many psychological symptoms such as anxiety and depression, social problems such as financial and carer issues and finally, spiritual issues such as fear of death and existential distress. All these challenges and more are the issues that encompass the scope of comprehensive and effective palliative care. Therefore, in order to create a healthcare system that supports all people living with incurable life-limiting conditions, the first step would be to create a healthcare environment that recognises the needs of such individuals and is sensitive to these needs realising the impact it has on the health of the nation.

The approach to this strategy would be to increase the general awareness of the entire healthcare community about these needs and how to be sensitive in recognising them. Education should be targeted at a very basic level in nursing, paramedical and medical training.

There should also be systems integrated into the healthcare system to ensure that these needs are assessed. This may include policies such as assessment of pain as a vital sign and using tools such as a distress thermometer in such cases.

Apart from this, education should be extended to the general population to create more public awareness about these issues and people should be aware that if they are facing distress due to a life-limiting illness, they should express these problems to a healthcare professional or seek help from professional services that can provide them the relevant support.

The approach to this strategy must target both the private and public healthcare settings and should also incorporate public awareness.

Recommendations:

a) *All healthcare services must develop policies/systems to identify patient who require palliative care within their facility.*

b) *All basic level training of nurses, doctors and paramedical staff must include training in assessment of palliative care needs for patients with life-limiting conditions.*

c) *Public awareness on the importance of good palliative care should be promoted nationwide.*

6.2.3 STRATEGY 3:

Ensure that all people including children and older persons who are recognised to have palliative care needs should be able to access the care and medications they require within the healthcare system and the community they live.

Rationale:

Once the needs are recognised, it is unethical to leave these needs ignored. In our healthcare system at present unfortunately, many a time healthcare providers feel they are unable to help patients and address their needs because providing such care is felt to be beyond their ability or the system they work in does not provide such a scope of care. This is where there is a great need to increase the access of palliative care services in all our healthcare facilities.

Although there is the subspecialty of palliative medicine which has developed in Malaysia since the year 2005, it is obvious that the needs of palliative care in Malaysia cannot be met by specialists in palliative medicine alone. It must therefore be understood that palliative care must be delivered at all levels of healthcare which include primary, secondary and tertiary healthcare levels.

At the primary level, all health clinics in public and in private sectors should be able to provide a basic level of palliative care which can still address mild to moderate physical symptoms and possibly some of the psychosocial issues . At a secondary level, basic specialties such as internal medicine, general surgery, gynaecology and general paediatrics should be able to address palliative care needs as well and this may encompass more complex needs which may require in-patient care. At a tertiary level, specialists palliative care should be developed to address the very complex and difficult symptoms that a patient may face. At the tertiary level, specialists in palliative medicine should also provide expert advice and support to all the services at the primary and secondary level when necessary. They will also provide training to others in this field.

Another very important and essential component of palliative care includes community palliative care and this is an area of palliative care that should be developed as a dedicated field in itself. This is because majority of patients prefer to be cared for at home and due to their illness and deteriorating nature, accessing care at a clinic or hospital may become increasingly burdensome to the patient. Community palliative care should therefore be seen as an area of specialist need and logically, trained palliative medicine specialists should play a role in both hospital based care as well as community based care.

To address social and spiritual care needs, it is important to develop more expertise in this area and in tandem with the development of palliative care services in clinics and hospitals, those in the field of medical social work and community social work should also be engaged to develop unique expertise in the field of palliative care social work. Spiritual care is an area which is so desperately lacking in our current healthcare system and while some may argue that religious practices provide for this need, it must be understood that spiritual care goes far and beyond just religion alone. At present the number of experts in this area are very few and there is no such expertise in the Ministry of Health as no such position exists at present in the government service. This area however is of great interest especially among non-governmental organisations and lay-volunteers and a possible way of addressing this need is to encourage greater public-private partnerships with non-governmental organisations with expertise in order to address the spiritual issues of patients.

Recommendations:

a) All hospitals both private and public should have policies and services that ensure basic palliative care needs of patients within their service are addressed.

b) Community palliative care services must be developed to enable people to receive care at home till death if desired.

c) All primary care clinics should provide basic symptom assessment and relief for patients with life-limiting conditions and know how to refer patients for specialised care when necessary.

d) Essential medications should be readily available and affordable to patients throughout the healthcare system.

e) Access to palliative care should also include care to address psychological, social and spiritual suffering.

6.2.4 STRATEGY 4:

Develop a systematic network for continuity of palliative care and sharing of information throughout the healthcare system to optimally support and minimise burdens to patients.

Rationale:

Although palliative care patients are suffering from incurable life-limiting conditions, they often encounter acute problems during the course of their illness which could potentially be controlled or reversed with medical interventions . Many patients and families often go through this ‘roller-coaster’ of problems until the patient finally declines to a point where they are deemed to be in the terminal phase. As palliative care should ideally begin early in the course of an illness some patients may still have many months or even 1 to 2 years before entering the terminal phase. Such being the case, many patients who have acute problems in the earlier part of their trajectory should be provided appropriate care to treat these acute problems.

Some of the interventions could include surgical procedures or intensive medical therapies which require close collaboration with hospital based palliative care teams. Hence there is a need for a good network that links patients at all levels so that patients who receive care in a hospital may be followed up by community palliative care teams and general practitioners at the primary care level upon discharge. Likewise patients at a primary care level who have increasingly difficult problems to solve should be referred back to the nearest hospital where they can receive appropriate care.

In order for the network to be effective, there must be open channels of communication and relevant information regarding a patients problems /issues must be shared with the appropriate teams and/or individuals. This network should be established across both private and public healthcare settings.

The network should be developed according to the unique needs of each individual state in Malaysia taking into account the available healthcare services and resources. ICT should be employed to create solutions for the development of such networks.

Recommendations:

a) A network of palliative care services should be developed to ensure the continuity of care of patients and enable them to access care from the primary care level, to the secondary and tertiary and then back again to the primary care level.

b) Collaboration between private and public sectors is essential in creating an effective network of care.

c) ICT should be employed to develop solutions for sharing essential information among palliative care professionals involved in a patient’s care.

6.2.5 STRATEGY 5:

Create palliative care education programmes at appropriate levels for all individuals involved in caring for those with palliative care needs recognising this skilled human resource and utilising them in an optimal manner.

Rationale:

Education in palliative care is one of the key factors that form the foundation of effective palliative care. Without knowledge and skills in palliative care, the needs of palliative care in patients will not be recognised and the access to palliative care will not develop sufficiently to support the needs of the nation. Therefore, education in palliative care needs to be provided at all levels of healthcare professionals.

For all healthcare professionals including doctors, nurses, pharmacists and other paramedical staff, basic knowledge in palliative care and recognising needs should be taught at an undergraduate level in all medical schools, nursing colleges and paramedical training programmes.

In order to further develop dedicated palliative care services in settings where palliative care specialists are not available (e.g. health clinics, non-specialist and minor specialist hospitals), specific mid-career training programmes to up-skill medical officers and general specialists should be developed and recognised. Apart from this, continuing medical / nursing / paramedical education programs to increase knowledge and skills of practising healthcare professionals in palliative care should be provided on a regular basis.

For those who are passionate and aim to pursue a career in this field, specialist training should be made available. At present there is specialist training for doctors, nurses, occupational therapists and physiotherapists. These fields need to be enhanced and expanded upon. Other areas of healthcare that should develop specialist training include social work, grief and bereavement counselling and spiritual care.

Once healthcare workers have been trained in the unique skills and knowledge of palliative care, it is important that the trained personnel be allowed to practice their skills in a setting where they are most useful. Expertise should be deployed in a manner that enables optimal coverage of the nation so that majority of the population can benefit from their training.

Recommendations:

a) *Education in palliative care should be provided in all undergraduate and basic training of doctors, nurses and paramedical staff.*

b) *Specific mid-career training programmes to up-skill medical officers and general specialists should be developed and continuous medical/nursing/paramedical education in palliative care must be provided on a regular basis throughout the nation.*

c) *Specialised training in palliative care should be enhanced and expanded to increase the number of skilled healthcare professionals specialised in palliative care.*

d) *Healthcare professionals with specialised training should be deployed in a manner that allows the majority of the population to benefit from such specialised training.*

6.2.6 STRATEGY 6:

Encourage community participation in the provision and promotion of palliative care for the nation.

Rationale:

Palliative care is an area of need that by definition (100% human mortality rate) involves the whole community. This is a global phenomenon which follows the universal improvement of healthcare and the increasing life expectancy globally. In Malaysia over 70% of deaths nationwide are due to chronic NCDs and majority of these deaths would likely require some degree of palliative care. Hence, in order to meet the palliative care needs of our nation, it will require participation and contributions from much more than that which is provided by formal healthcare services alone.

The Malaysian community has always been at the forefront of the development of palliative care since the early 1990s when the first community palliative care services were started by NGOs. Since then, these NGOs have been almost entirely funded by charitable donations and funds generated from the public in order to give back to society this form of healthcare which is so desperately needed. Such contributions must be encouraged and supported as it not only reduces the burden on the government tax-based healthcare budget but also allows the community to participate significantly towards their own needs and care.

Public awareness on palliative care, the needs and the role that society can play is paramount to the success of an effective nationwide palliative care programme. Everybody should be made to feel that they have a role and a responsibility to ensure that the care that they themselves will one day require is readily available. Healthcare providers on the other hand should always recognise the community as an important member of the team that provides care to the nation.

While a significant contribution from society is often in the form of financial support to help fund non-governmental hospice organisations, the community can also contribute directly to care in the development of compassionate communities. This is a concept whereby individuals from a community can help in the caring of sick members of their community thereby sharing some of the burden of care with the family. If all members of the community contribute in a small way, a very large resource of care can be acquired for the nation. By creating such caring communities, not only will be help to improve the care of the nation but also improve the health of the nation as it promotes unity and harmony.

Another important area of community participation that should be encouraged is the practice of advance care planning. As medical technology continues to advance, the decisions to use such technology become more and more challenging especially towards the end of life as questions of quantity of life versus quality of life often arise. This is where advance care planning plays an important role in helping individuals maintain their autonomy and also reduce the burden of decision making on their family, loved ones and healthcare providers towards the end of life

Issues such as death and dying as well as advance care planning can be very sensitive especially in an Asian society. Therefore it is important that while public awareness is created through community participation, it must be done in a manner that is culturally, socially and spiritually acceptable.

Recommendations:

a) *Community participation must be encouraged through civil societies in order to meet the needs of care for the nation.*

b) *Community participation can be encouraged through developing compassionate communities and promoting awareness in palliative care and advance care planning.*

c) *Appropriate engagement with faith communities and religious leaders is important to ensure that implementation of palliative care practices are culturally and socially acceptable.*

6.2.7 STRATEGY 7:

Establish standards of care based on best evidence coupled with principles of good medical practice and incorporate the use of ICT to enhance development.

Rationale:

Palliative care is often seen as an act of altruism whereby care is being provided to the weakest members of society, namely, those who are facing the end of life. For those who practice palliative care, the work that is done often invokes a sense of personal satisfaction in the 'good deeds' that are being performed beyond what may seem as merely a job. While it is true that the motivation behind the work of palliative care may lie in its altruistic nature, it should be clearly understood that palliative care is still a form of healthcare which must be based on excellent clinical standards. Altruism alone is not enough to ensure that a patient gets appropriate care and so it must be coupled with excellent healthcare standards in order to ensure that one's 'good deed' is truly good.

Standards of palliative care should therefore be outlined in documents such as operating policies and practice guidelines which must be based upon current research and best evidence in medical practice. Palliative care however is a field which is humane as well as human and so while policy and guidelines should be based upon current research data and best available evidence, it must also be coupled with principles of good medical ethics relevant to the local setting.

Setting standards alone is insufficient to ensure that good care is always provided and therefore a process of monitoring will also be required using tools such as audits and key performance indicators to ensure that care providers continue to improve standards of care and are aware of how good their 'good deeds' truly are.

In order to improve standards and monitor standards, the use of ICT should be employed to enhance patient data registries, auditing, providing education and tracking of palliative care activities throughout the nation.

Recommendations:

a) *Palliative care practices must have appropriate standards of care based on current research data and best medical evidence coupled with good medical ethics relevant to the local setting.*

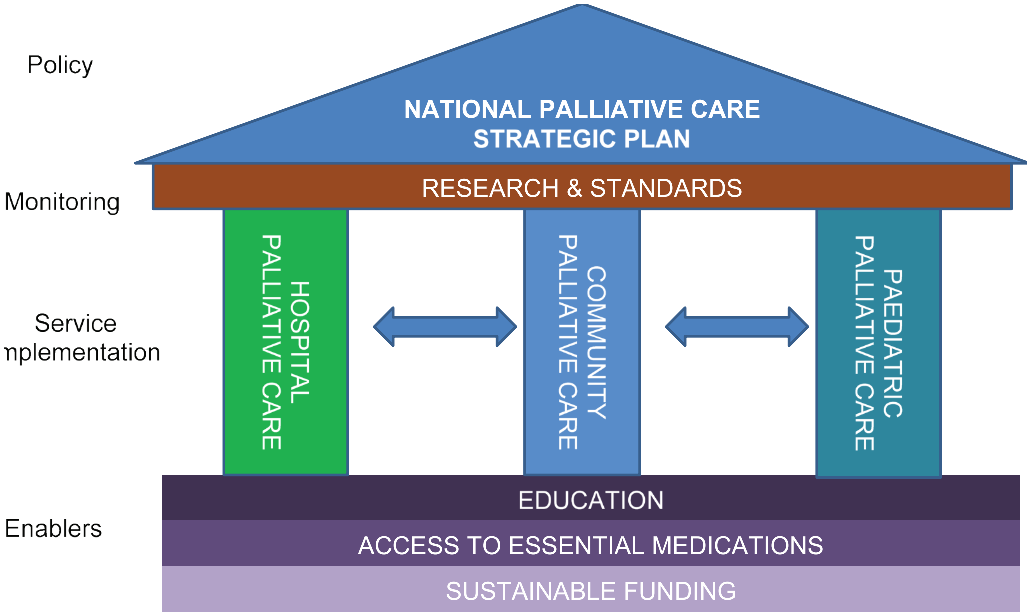
b) *Monitoring of standards of practice must be done regularly through key performance indicators and auditing.*

c) *ICT should be employed to enhance research, patient data registries, auditing, providing education and tracking of palliative care activities throughout the nation.*

6.3 Implementation of policy and strategies

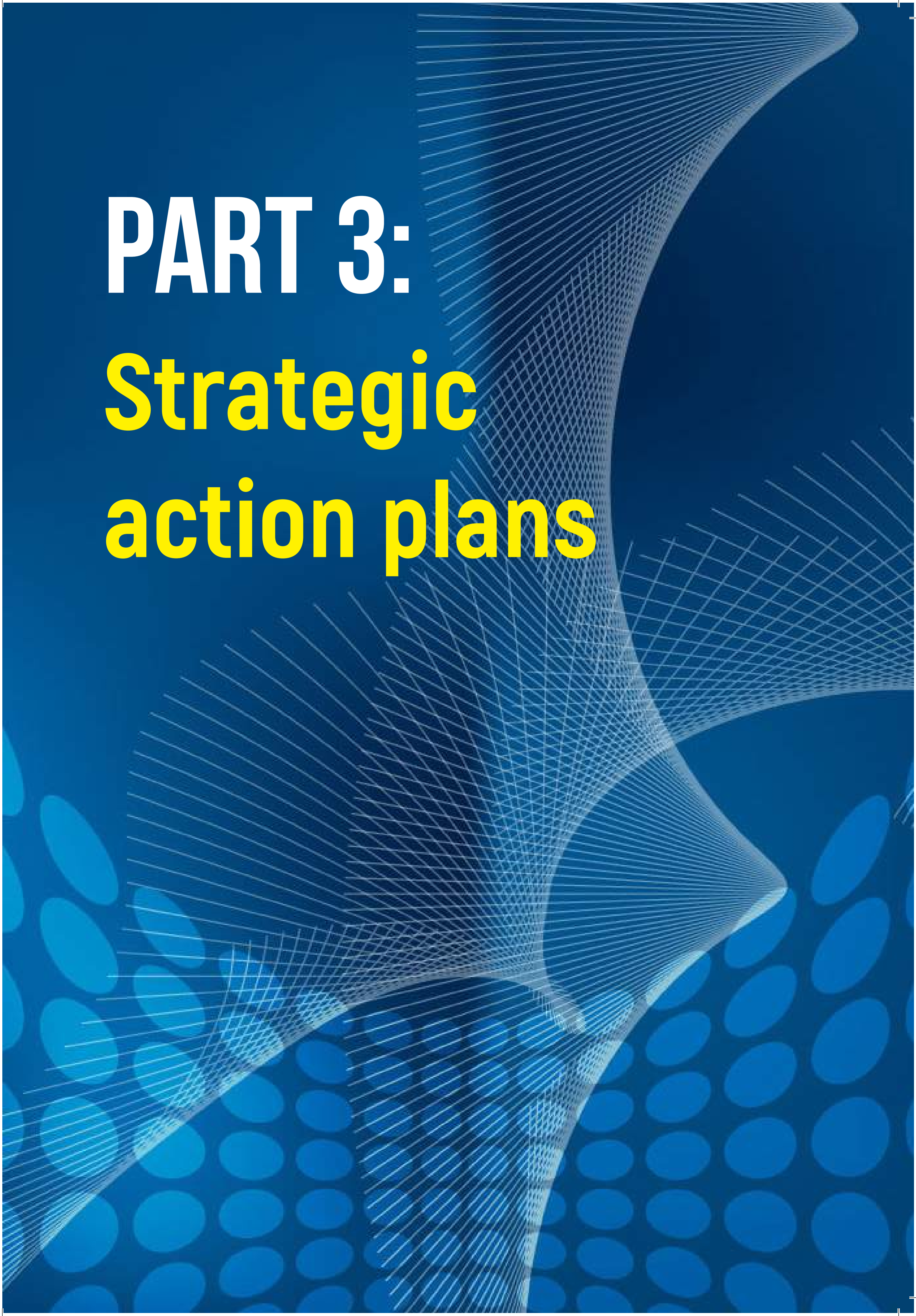
As Malaysia has been developing palliative care services since 1991, there is already an existing foundation for which the implementation of this policy and strategy need only enhance and build upon. A framework for implementation is illustrated in the diagram below:

Figure 6: National Palliative Care Strategic Plan



The action plans have been outlined in 7 key areas for the development over the next 10 years as below (Annex 6): -

i. Hospital Based Palliative Care
ii. Community Based Palliative Care
iii. Paediatric Palliative Care
iv. Education in Palliative Care
v. Access to essential medications in Palliative Care
vi. Research and Standards in Palliative Care
vii. Sustainable funding



PART 3:

Strategic action plans

CHAPTER 7 : HOSPITAL BASED PALLIATIVE CARE

7.1 Introduction

Although palliative care services first initiated by community-based NGOs, palliative care in Malaysia progressed more rapidly after the development of hospital based palliative care units within MOH hospitals. As hospital based palliative care developed, the specialist field of palliative medicine evolved and has now become the cornerstone of palliative care development in the country.

Hospital based palliative care services are essential as hospitals will always be the main focus of care for many patients with serious health problems. For many patients, hospital based palliative care services will be the first point of contact where they are initially identified, assessed and managed. The availability of a hospital based palliative care service provides an excellent opportunity for multidisciplinary care to occur where patients with serious illnesses can still be co-managed by other medical and surgical specialties.

Modern medicine is continuously evolving and so too is the field of palliative medicine. Therefore, the concept of palliative care can no longer be confined to mere symptom control with no other active interventions. Today, there are many new medical and surgical therapies that can help to improve the quality of life of a patient as well as to improve overall survival and to deprive patients of such therapeutic options may be deemed unethical. Hospital based palliative care services are therefore essential to facilitate and navigate all the appropriate investigations and interventions for patients in an era of ever evolving medical technology.

Apart from this, while majority of patients will be at home most of the time, there is still a need for the development of in-patient palliative care units as these serve as a dedicated place for patients to access support whenever they are unable to cope at home. These in-patient palliative care units however should not be modeled upon the classical ‘stand-alone’ hospice units such as seen in the United Kingdom but should be developed as integrated palliative care units within a hospital. This would provide the most cost-effective model of care and currently in the MOH, this is the model most frequently developed.

7.2 SWOT Analysis

STRENGTHS	WEAKNESS
• Well-structured network of hospitals throughout Malaysia with good infrastructure and facilities. • Existing model of hospital based palliative care in several state and major specialist hospitals. • There is an official Palliative Care Operational Policy in MOH since 2010. • Growing number of palliative medicine specialists. • Advanced Diploma in Palliative Care programme for nurses and allied health professionals since 2014. • Palliative care services are relatively easy to set up without requiring very expensive equipment or elaborate infrastructure. • Essential medicines for palliative care can easily be made available in all MOH hospitals.	• Palliative care seen as a low priority in many acute care hospitals. • Many state and major hospitals are overburdened with existing workload and have little capacity to expand services. • Lack of ward space for new Palliative Care Units • Lack of dedicated staff allocated for palliative care unit development.
OPPORTUNITIES	**THREATS**
• Malaysia is a signatory to the WHA 67.19 resolution. • Malaysia recognises Universal Health Coverage as a development goal. • Present day government has explicitly stated its support towards the development of palliative care centres around the country. • Several MOH hospitals have already developed palliative care services which can be further enhanced at minimal cost. • Increasing interest among medical schools in developing palliative care services within teaching hospitals	• Healthcare professionals viewing palliative care units as merely a place for dying. • Uncertain economic situation may limit the funds available to run this program. • Conflicting priorities of hospital directors in managing their hospital's needs.

7.3 Key goals to improve hospital based palliative care services

In order to improve hospital based palliative care services to a point of universal health coverage, there are three (3) key goals:

1. Establishing specialist palliative care services in all state/major specialist hospitals and teaching hospitals.

2. Ensure the palliative care approach is practiced at all levels of hospital based care.

3. Establishing a minimum standard of palliative care provision in private hospitals, healthcare institutions and long-term nursing care facilities.

1. Establishing specialist palliative care services in all state/major specialist hospitals and teaching hospitals.

Since the development of palliative medicine as a medical subspecialty in 2005, specialist palliative care services have currently been established in 9 government hospitals. These include the following:

- Hospital Kuala Lumpur
- Hospital Tuanku Ampuan Rahimah, Klang
- Hospital Raja Permaisuri Bainun, Ipoh
- Hospital Pulau Pinang
- Hospital Sultanah Bahiyah, Alor Setar
- Hospital Selayang
- Institut Kanser Negara (IKN)
- Pusat Perubatan Universiti Malaya
- Hospital Universiti Kebangsaan Malaysia

Within the next 3 years, another 5 state hospitals have been identified to set up specialist palliative care services. These are:

- Hospital Tuanku Jaafar, Seremban
- Hospital Melaka
- Sarawak General Hospital (SGH)
- Queen Elizabeth Hospital, Kota Kinabalu
- Hospital Sultanah Aminah, Johor Bharu

Hence by the year 2021, at least 9 of the 13 state hospitals in Malaysia will have resident palliative medicine specialists and over the next 5 years, further efforts will be made to identify specialists to serve in the remaining 4 states of Perlis, Pahang, Kelantan and Terengganu.

At the same time major specialist hospitals within each state will also be identified to develop specialist palliative care services and post resident palliative medicine specialists. This will be based upon an analysis of the needs of the population served and the specialties available in these major specialist hospitals.
Nevertheless, establishing an effective hospital based palliative care service needs strong support from the hospital administration to provide necessary resources for the service to function effectively. Adequate human resource in terms of nurses, medical officers and other allied health professionals is essential. Basic equipment, essential medications and infrastructure for an in-patient unit is also required. The provision of these resources will be planned for in advance as a new operational policy of the respective hospital.

As each state or major specialist hospital palliative care service becomes established, the respective hospital will then serve as a hub where further outreach services can be established in nearby hospitals within its cluster thus widening the area of service coverage. This is particularly important to extend services to minor and non-specialist hospitals in the region.

Teaching hospitals under major medical schools are also major centres for healthcare provision in the country and should therefore provide palliative care. At present only 2 teaching hospitals in the country have established palliative care services and thus with the numerous medical schools at present in both the government and private sector, teaching and providing palliative care should be made a standard requirement.

2. Ensure the palliative care approach is practiced at all levels of hospital based care.

While specialist palliative care services are important to handle many of the complex cases in state and major specialist hospitals, it is not possible for all patients requiring palliative care to be managed by specialists alone and achieving universal health coverage will never become a reality. This is where basic palliative care needs should be fulfilled by ensuring that healthcare providers at every level of hospital based care can apply the palliative care approach to identify, assess and manage patients requiring basic palliative care within their own area of practice.

Such a strategy will help to ensure that in the absence of a specialist palliative care service, patients will still be provided the comfort and dignity they require till the end of life regardless of the hospital they go to.

The palliative care approach utilises existing healthcare staff to deliver the care and therefore will not incur much added expenditure apart from the provision of education initiatives to upskill doctors and nurses in hospitals where specialist palliative care is not readily available.

Apart from education, a referral system and network to provide specialist input must be established in order to support hospitals where patient management is too complex to handle.

Eventually, a nationwide policy for all hospitals to practise the palliative care approach will be developed in a similar way that ‘Pain as the 5th Vital Sign’ and the ‘Pain Free Programme’ has been established in MOH hospitals.

3. Establishing a minimum standard of palliative care provision in private hospitals, healthcare institutions and long-term nursing care facilities

Apart from government hospitals, a significant proportion of the Malaysian population access healthcare at private hospitals and private nursing homes for those with chronic and debilitating medical conditions. Palliative care must therefore be provided in these facilities.

Private hospitals must be made to comply with a minimum standard of palliative care provision through policies and hospital accreditation standards. This can be achieved through discussions with Malaysian Society of Quality in Health (MSQH) and updating hospital accreditation standards to include the provision of palliative care as a general hospital requirement. These standards must ensure that essential medications are available and that systems to practise the palliative care approach must be in place. Doctors in private hospitals must be made responsible to ensure that palliative care needs in their patients are recognised and steps are taken to provide necessary support either by providing basic palliative care on their own or by referring to a palliative care doctor in the private or government setting. Education for private practitioners must be provided through CMEs and encouraged through provision of CPD points.

Nursing home facilities and stand-alone hospices must also be made to provide a minimum standard of palliative care within their facility so that patients in pain and distress are treated adequately.

This should be made a requirement for the renewal of operating licences and the Private Medical Practice Control Division (CKAPS) under the Medical Practise Division, MOH should work in collaboration with palliative medicine specialist in determining these requirements.

7.4 Cost Implications

The cost of developing hospital based palliative care units will incur the initial cost of developing infrastructure and equipment for an in-patient unit which is estimated around RM650,000 per unit. The annual operation cost for human resource is estimated to be around RM1.3 million per unit. Hence for development of 8 new units across the country an estimated cost of RM 15.7 million would be required in the first year. (Refer to Annex 1)

CHAPTER 8 : COMMUNITY-BASED PALLIATIVE CARE

8.1 Introduction

Although hospital-based care will always be necessary in situations of severe distress and complex symptom management, many people would prefer to receive care at home. Based on a Palliative Care Needs analysis in Malaysia, 53% of respondents preferred to receive the bulk of care at home while 61% preferred a home death.

Community-based palliative care teams are therefore essential, and research has shown how such teams can improve symptom control, quality of life, increase satisfaction with care and provide better outcomes for patients suffering from advanced illnesses and their families.

Support in the community has also shown to reduce the need for patients to access acute health care services while improving overall well-being. It also allows patients to achieve a home death if this is desirable.

At present, community palliative care in Malaysia is mainly provided by Non-Governmental Organizations (NGO), which are commonly referred to as hospice organizations or palliative care societies. In total there are 30 such NGO hospices functioning independently throughout the country and are in every state except for Perlis.

Almost all these NGO hospice organizations are based in large urban areas with little or no coverage in smaller towns and rural areas. Hence, in an effort to increase community palliative care services, particularly in rural settings, the Ministry of Health (MOH) initiated the domiciliary palliative care programme within government health clinics in 2016.

8.2 SWOT Analysis

STRENGTHS	WEAKNESSES
• Existing NGO hospices providing community palliative care over the past 25 years completely free of charge. • Existing policy and directive to develop domiciliary palliative care services by the MOH. • Extensive network of health clinics throughout the country covering both urban and rural areas. • Availability of essential medications within the MOH that can be accessed at health clinics.	• Most NGO hospices are voluntary charitable bodies with limited capacity, funding and human resource. • No standard education or training modules available. • Many NGO hospices teams do not have medications available in their service. • Limited human resource, funding and training for MOH domiciliary care teams. • High turnover of trained staffs in NGO hospices, health clinics and domiciliary care teams. • Lack of essential equipment for patients to use at home. • Limited local research to guide best practice • Absence of registry
OPPORTUNITIES	**THREATS**
• Enhancing NGO hospices with better public-private-partnerships. • Sharing experience and expertise between NGO hospices and MOH services. • Expansion of the MOH domiciliary care programme throughout the country. • Increasing education through project ECHO. • Developing community palliative care as a subspecialty among family medicine specialists. • Using nurse graduates of the advanced diploma in palliative care as leaders for domiciliary care teams. • Encouraging private practitioners in primary healthcare to provide community palliative care	• Wide variation in quality and standards of care provided by NGO hospices and private practitioners. • Limited leadership or palliative care resource (palliative care specialist/ Family Medicine Specialist with interest) in all states for the provision of community palliative care • Multitasking of community health care providers leading to burnout. • Inadequate political support • Absence of incentives for credentialed providers • Unregulated community palliative care providers in the private sector. • Over reliance of NGO hospices on government grants.

8.3 Key goals to improve community-based palliative care services

Access to community palliative care can be improved by:

1 Nationwide development and strengthening of MOH Domiciliary Palliative Care (DPC) programme.

2 Enhancement and coordination of existing NGO hospices in collaboration with the public sector.

3 Establishing a comprehensive network of services to link patients within the community utilizing primary care providers from both the private and public sectors and collaborating with NGO hospices

1. Nationwide development and strengthening of MOH Domiciliary Palliative Care (DPC) programme.

The Domiciliary Care Programme, which was started by the MOH in 2014, is one of the best initiatives by the Malaysian government to facilitate community palliative care service development. It was initially developed to provide care to chronically ill patients with conditions such as stroke and traumatic brain injuries however in 2016; the scope was extended to include patients with life-limiting conditions requiring palliative care. It is currently under the governance of the Family Health Development Division (BPKK).

While the programme is still in its infancy, efforts must be stepped up to strengthen and expand this programme over the next 5 years. These efforts will include:

- Increasing education programmes for healthcare providers involved and to develop a standard education module.
- Enhancing referral and monitoring systems so as to improve numbers of patients and estimate burden of care.

- Enhance service provision by ensuring essential medication and equipment availability.
- Increasing trained human resource including nurses, medical assistants, doctors and allied health professionals to create dedicated teams focused on homecare alone.
- Establishing standards of care with outcome indicators for continuous quality assurance and quality improvement.

The pilot projects for this programme were in Selangor and Kedah mainly because of the availability of palliative medicine specialists in these states whereby training and monitoring of the programme would be more effective. In 2019, it was rolled out to Perak and Pulau Pinang as these states also have resident palliative medicine specialists. As more states in the next 3 years develop specialist palliative care services, so too will the domiciliary palliative care programme develop in tandem.

While the focus is to equip community providers with basic palliative care knowledge, the presence of family medicine specialists with sub-specialty training in palliative care will provide the skill sets necessary to manage complex patients in the community.

2. Enhancement and coordination of existing NGO hospices services in collaboration with the public sector.

For over 25 years, NGO hospices have been an important resource to healthcare in Malaysia as they have provided an area of need which has been neglected for such a long time. They have also helped to reduce the burden of care for the government by utilizing funding sourced from the community and reducing the strain on government tax-based health budgets. While the domiciliary palliative care programme will take many years to achieve nationwide coverage, these NGO hospices will continue to be major stakeholders in palliative care service provision for the nation.

Although there are 30 registered palliative care NGO hospices in the country, there is a wide variation among the standards and practices of these NGO hospices. Some have fulltime doctors and nurses while others may only depend on volunteers. Such differences make it difficult to ensure that the service that is provided is equitable throughout the country and therefore, more needs to be done to enhance and improve the standard of care provided by these NGO hospices. As charitable bodies however and limited funding, it is challenging for many to achieve good standards of care independently. For this reason, greater collaboration with the public sector must become the norm in order to create effective and sustainable growth of these NGO hospices.

Public-private partnerships to share resources such as providing technical support from government palliative medicine specialists to NGO hospices and providing education are core areas that will enhance care markedly. In addition, creating a system for patients to access essential medications from government facilities through these NGO hospices will also be of great importance.

3. Establishing a comprehensive network of services to link patients within the community utilizing primary care providers from both the private and public sectors and collaborating with NGO hospices from hospitals to the community

The main purpose of community-based palliative care services is to create continuity of care for patients from hospital settings going back to their homes. Hence, community palliative care services must be closely linked to hospital-based palliative care services and vice-versa.

Private General Practitioners in the community can play an important role in identifying patients with palliative care needs; provide basic care and linking patients to appropriate services.

An effective and comprehensive referral network system to link patients seamlessly through the healthcare system needs to be developed. The use of ICT and mobile technology could be useful for this purpose. Such a network must be able to link with hospital care providers and community palliative care providers from both the government, NGO hospices and private sectors. It should be used in the following key areas:

- Initial referral and diagnosis
- Basic contact information and care providers
- Medication history
- Main clinical problems
- Important information – goals of care / advance care plans

This system can also serve as a registry to track the number of patients accessing palliative care services and this information can be used for further planning of service development. Adequate policy should also be in place to ensure data safety and security

8.2 Cost implications

Numerous studies globally reported that the healthcare costs of people who are dying are extremely high particularly in the last year of life. Growing evidence suggests that inpatient and home hospice/community palliative care services can help to reduce these rising costs of healthcare.

Average daily costs for an in-patient in government hospitals in Malaysia for 2016 averaged at RM 1,757 excluding treatment cost. Depending on treatment received, the cost can range from RM 379.67 to RM 7,419.09 per patient (Data obtained from Hospital Administration Service Unit (Case mix).

Based on data from the Department of Statistics Malaysia, medically certified deaths in 2016 was 85,637. If we assume all medically certified deaths were admissions in hospitals, the daily cost of end of life care in hospitals would be about RM 150 million per year excluding treatment costs for all decedents. As research has shown that majority of people prefer to die at home, the impact on healthcare cost reductions could be phenomenal if adequate community teams were developed to enable people to receive end of life care at home.

Creation of new posts for dedicated DPC teams (2 nurses and 2 Assistant Medical Officers) in the 160 existing health clinics providing domiciliary health care services throughout Malaysia would cost about RM 22 million per year (Refer to Annex 2). At present, there are no dedicated teams and this programme is being run by existing staff that are multi-tasking to provide domiciliary care.

Yang et al. in 2019 estimated 137,935 individuals require palliative care at present while the Malaysian Hospice Council (MHC) reported only a total of 5660 people were referred to NGO Hospices in 2017. Hence, there is a considerable gap to fill in for community palliative care services at present. Taking into account an average of 5 new cases referred to a DPC team per week, creation of 160 dedicated DPC teams is projected to serve an additional 70,000 individuals per year in the community.

Therefore, developing community palliative care service, either DPC or enhancing NGO hospices services will not only enable patients to fulfill their wishes to be at home at the end of life but will also result in a significant reduction in healthcare costs.

CHAPTER 9 : PAEDIATRIC PALLIATIVE CARE

9.1 Introduction

a) What is Paediatric Palliative Care (PPC)

Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Palliative care's need for children is unique and very different from the adults, because

Types of health condition: There is wide range of childhood illnesses, especially chronic non-communicable diseases which originate from rare genetic and congenital conditions and not seen in adults. It needs a more integrated approach with intensive disease-modifying or life sustaining treatments due to unclear prognoses and life expectancy.

Development milestones: Patients have changing information, recreational, educational needs and modes of coping with their changing developmental milestones.

Difficulty in decision-making: Children's status as minors makes it difficult for them to be involved in decision-making, and most decisions are made based on parents, family members and healthcare professionals' discussion on what would be the best interest for the child and the whole family.

b) Who should provide PPC?

Echoing the 2014 World Health Assembly resolution (WHA67.19) it was emphasized that access to palliative care for children is an "ethical responsibility of health systems. In addition, the Lancet Commission on Global Access to Palliative Care and Pain Relief report 2017 stated that

- Palliative care for children is a human right – no child should be left in pain and suffering. However, the need for PPC has been largely ignored, especially those children in lower and middle-income countries (LMIC).
- PPC is an essential element of universal health coverage and all efforts should be focused on removing barriers towards PPC service development and access.

Palliative care should be part of comprehensive paediatric care. Most patients and family need basic PPC services which can be provided by well-trained general paediatricians, general practitioners, family doctors and paediatric nurses with basic training in PPC. Health system policies should make PPC as an official responsibility of these clinicians.

Meanwhile, specialist doctors who frequently care for children with serious life-threatening conditions, such as oncologists, cardiologists, intensivists and neonatologists, should receive intermediate-level training in PPC. The specialist PPC consultant and team should be involved if a child or young person has unresolved distressing symptoms especially when they approach the end of life. Hence, while PPC services should be provided by generalists, there is also a need for dedicated PPC specialists to be trained and recognized in order to further develop this field.

c) PPC in Malaysia

In 2016, 72.4% of infant deaths and 62.2 % of child deaths under five years old in Malaysia were attributed to life-limiting diseases originating from perinatal conditions, congenital malformations, deformations and chromosomal abnormalities. All these life-limiting diseases warrant PPC support. From a global cross-sectional analysis of prevalence, it was estimated that up to 80,000 children in Malaysia aged between 0-19 years require PPC support of which more than 30% need specialist PPC.

Although adult palliative care has been in existence since the 1990s, palliative care for children is still in its infancy. Initial provision of paediatric palliative care in Malaysia was ad hoc by individual paediatricians in hospitals and by non-governmental organisations (NGOs) in the community since 2008. In 2012, the Ministry of Health acknowledged the importance of palliative care for children and launched a National Paediatric Palliative Care Initiative that aimed to enable children to access palliative care. Under this initiative, the PPC national service plan was drafted and the first PPC subspecialty training fellowship programme was approved in 2014. Currently there are only a handful of paediatricians providing generalist/part-time PPC and just 3 fulltime dedicated PPC services (2 university hospitals, 1 MOH hospital). Community palliative care services are still not able to provide sufficient support for PPC (only a few NGO hospices accept referrals for children with life-limiting disease). In order to provide greater advocacy towards PPC, the MyPPC was formed under the Malaysian Paediatric Association and later the PPC Task Force committee was formed in June 2018 under Medical Development Division, Ministry of Health (MOH).

9.2 SWOT Analysis

STRENGTHS	WEAKNESSES
• Mostly hospital-based paediatrician leading in providing secondary or level 2 PPC services as part of their continuity and integration of PPC concept into paediatric medicine service • Partnership with adult palliative care	• Lack of awareness among paediatric healthcare providers regarding the concept of PPC and its role beyond end-of-life care • Small numbers of paediatricians trained in PPC, and difficulty to attract more trainees without recognition from the National Specialist Registry lack of a direct subspecialty fellowship trainee programme under MOH • Insufficient support of palliative care for children at home in the community. • No specific funding from the government to develop and sustain PPC services in hospital and community (Currently it is mainly from general paediatric allocation.) • Lack of public awareness of PPC amongst the public. • Very few community palliative care services offering PPC
OPPORTUNITIES	**THREATS**
• A new field in paediatric medicine which is still attracting new paediatricians • More NGOs to support PPC (such as Malaysian Association of Paediatric Palliative Care, MAPPAC). • Improving public awareness and interest in supporting PPC. • Partnership with the Ministry of Women, Family and Community Development to support community PPC.	• PPC remained at the hospital-based level 2 service. • Insufficient training for public health clinic staff to provide support at community level.

9.3 Key goals to improve national development of paediatric palliative care (PPC)

While PPC has many unique characteristics, there are still many commonalities with adult palliative care and therefore has been planned in accordance with the 7 overarching national strategies for the development of palliative care. This will allow PPC to develop concurrently alongside adult palliative care and similarly integrate with the healthcare system with the aim of achieving universal health coverage.

There are six (6) key goals which can be divided into 3 main areas of focus:

A. Hospital based PPC

1. Develop PPC services in every state hospital by integrating PPC as an enhancement of existing paediatric services.
2. Ensure appropriate education in PPC for healthcare workers involving children in all state hospitals
3. Initiate PPC services utilising existing available resources while continuing to develop new resources.
4. Ensure quality standards of service in hospitals

B. Transition PPC between hospital and community

5. Develop network for holistic and seamless PPC transition between hospital and community

C. Community based PPC

6

Systematically establish PPC services in the community

A. Hospital-based PPC

Hospital-based PPC service has a vital role in identification of children who will benefit from palliative care and ensure integration of the palliative approach throughout all spectrum of diagnosis as part of an overall enhancement of paediatric services.

1. Develop PPC services in every state hospital by adopting PPC as an enhancement of existing paediatric services.

Depending on the available resources, each state hospital should develop PPC services. This can be achieved by setting up full-time dedicated paediatrician-led PPC services or by involving general paediatricians to run PPC services in 6-monthly rotations.

2. Ensure appropriate education in PPC for healthcare workers involving children in all state hospitals.

Many of the studies in Malaysia have shown significant gaps in knowledge on PPC amongst healthcare professionals working in the paediatric setting. All doctors, nurses and allied health professionals involved in the care of children should receive education on the correct concepts and skills to provide PPC, targeting all state hospitals in particular.

Apart from this, there is also a need to promote specialised training in PPC and this should be developed through two (2) pathways. The first by developing fulltime specialists in PPC undergoing 3 years training similar to the structure of adult palliative medicine specialists. The second pathway would be as part of the subspecialty training in ‘General Paediatrics and Child Health’ whereby general paediatricians may train in PPC as a special interest for a full 1 year.

Through these education strategies, there will be a growing number of dedicated paediatricians to lead PPC services and develop training centres across Malaysia.

3. Initiate PPC services utilising existing available resources while continuing to develop new resources.

As there is an urgent need to develop PPC services, this will be initiated using the existing drug formulary and available human resources used in general paediatric services. At the same time, more PPC-specific resources will need to be developed such as creating an enhanced essential palliative medication formulary for PPC, policies for using parenteral medication in PPC, training of PPC pharmacists, applying for special PPC service budgets and networking with NGOs to enhance public-private partnerships for PPC service development.

4. Ensure quality standards of service in hospitals

Key performance indicators and standard operational policies for all PPC service providers must be developed. Research to gather local data to enable decision making for allocation of resources as well as prioritizing areas for service and education development will be conducted.

B. Transition PPC between hospital and community

Children with life-limiting conditions require holistic and seamless continuity of palliative care support as they frequently transition between hospital and their homes.

5. Develop network for holistic and seamless PPC transition between hospital and community

A referral system and communication network between hospital and community-based PPC must be developed. Good home care for children requires careful assessment of the child, assessment of the family’s needs at home as well as an assessment of the community’s resources and ability to provide the care. It also requires development of a comprehensive home care plan and continuous education of caregivers as well as good communication from both hospital and community care teams.

C. Community-based PPC

Dying children and their families deserve to receive care that is more consistent with optimal palliative care. Parents’ perspectives reveal a need for a systematic effort to train paediatricians and community service providers in all aspects of PPC.

At present, less than 1/3 of NGO hospices in Malaysia offer community palliative care services to children. These are mainly adhoc and under resourced. Only four accept paediatric patients with life limiting conditions other than cancer. In addition to meeting the criteria for age and disease, many services have limited areas of coverage e.g. 10km from their base of operations. Community PPC referrals were also found to be very late with many cases dying within 2 weeks of referral and often with untreated physical symptoms.

6. Systematically establishing PPC services in the community

The development of PPC services in the community should be systematically organized by each State Health Department involving a team of champions from family medicine, paediatrics, domiciliary care teams, community pharmacists, physiotherapists and occupational therapists. A state level technical committee should be formed for this purpose and to ensure good communication channels between hospital and community teams. NGO hospices should also collaborate more closely with hospital PPC teams in each state.

The community PPC team should comprise of a family medicine specialist, a medical officer and a nurse coordinator. These teams will provide continuity of care for patients after discharge from hospital, conduct minor procedures at home (e.g. nasogastric tube change etc) and maintain contact with hospital PPC teams on a regular basis. Community PPC teams may also provide urgent consultations to patients at home in case of emergencies.

Preparations for home death documentation (e.g. death certification) should be coordinated to minimize family distress and this may require collaboration with the local police.

CHAPTER 10: EDUCATION IN PALLIATIVE CARE

10.1 Introduction

Accessible and applicable palliative care education and training is imperative not just to equip healthcare professionals with the necessary knowledge, skills and attitudes in order to deliver high quality palliative care, but also to increase awareness and participation of the community to address serious healthcare related suffering that result from serious illness. With the scale of palliative care needs nationally, planning and training of human resource are vital as core ingredients to address this.

Workforce estimations from the UK (Association of Palliative Medicine of Great Britain and Ireland, 2012), Ireland (National Doctors Training & Planning, 2017) and Australia (Palliative Care Australia, 2018) propose the necessary workforce for their populations. The design of their health services differ from Malaysia. Table 2 below summarizes the medical workforce estimates from these documents. Further details on related disciplines including nurses and allied health professionals (psychology, social work, bereavement support, pastoral care, speech therapy, dietician, physiotherapy, occupational therapy, pharmacist and other therapist) can be found in the respective documents

Table 2. Palliative care workforce norms in Australia and United Kingdom

Palliative Care Australia (2018)	
Palliative Medicine Specialists	2.0 Full Time Equivalent (FTE) for COMMUNITY OR 1.5 FTE for CONSULTATIVE SERVICE OR 1.4 FTE for DESIGNATED PALLIATIVE CARE BEDS
Registrar	1.0 FTE for COMMUNITY OR 1.0 FTE for CONSULTATIVE SERVICE OR 1.0 FTE for DESIGNATED PALLIATIVE CARE BEDS
Medical officers	0.25 FTE for DESIGNATED PALLIATIVE CARE BEDS
Health & Safety Executive (2017)	
Palliative Medicine Consultants	0.9-1.8 per 100,000 population
Commissioning Guidance For Specialist Palliative Care Uk (2012)	
Palliative Medicine Consultants	2 Whole Time Equivalent (WTE) per 250,000 population OR 1 WTE per 250 bed hospital
Registrars/trainees	2 WTE per 250,000 population

COMMUNITY refers to per 100,000 population
CONSULTATIVE SERVICE is per 125 hospital beds
DESIGNATED PALLIATIVE CARE BEDS is for every 6.7 beds within an acute hospital

Comparing norms of palliative medicine specialists and medical officers in Australia and the UK, we can estimate similar norms by comparing the human development index of Malaysia, which is 0.802 with that of Australia, which is 0.939, and the UK, which is 0.922. It would be reasonable to estimate a norm for palliative medicine consultants of 1.7 WTE per 250,000 population. This would come to a need of approximately 218 palliative medicine consultants for a population of 32 million Malaysians.

Recognizing the need to develop palliative care in different healthcare settings (community and hospitals, both government and private), and in all professionals (medical, nursing, social, work, physiotherapy, occupational therapy, pharmacy, dietician, psychology and administration), a comprehensive education and training plan needs to be developed and implemented in order to achieve the overarching aims of the national strategy. The World Hospice Palliative Care Association (WHPCA) recommended in 2014 that education be integrated as a mandatory component of undergraduate and postgraduate training, as well as continuing professional development, in disciplines working with people with life limiting conditions (WHPCA 2014, Gomez-Batiste & Connor 2017). Alongside training, clear policies and plans have to be established to ensure trained personnel are deployed to the correct areas of work in order that their skills may be utilized most effectively. Over time, palliative care services need to have the workforce capacity to deliver around the clock services in all settings in order that serious healthcare related suffering can be addressed in a responsive fashion.

Based on the Health Facts 2018 published by the Planning Division, Ministry of Health in October 2018, there are 144 government hospitals and special medical institutions, 1,085 government health clinics (of which 160 offer domicilliary care), 200 private hospitals and 7,571 private clinics in Malaysia. All healthcare personnel working in all settings (primary, secondary and tertiary) and regardless of discipline must be able to deliver basic palliative care. This strategy aims to promote basic palliative care at the undergraduate stage of learning after which it will be continued into the workplace setting. Basic level practitioners should be able to identify people with palliative care needs, be able to have conversations to support patients and families, be familiar with basic symptom management and refer patients and families to higher-level services as needed.

Some practitioners may have a special interest in palliative care within their field of practice and may undergo further training to enhance their skills in order to deliver a higher level of palliative care (Intermediate Level). These practitioners will have a deeper level of knowledge of palliative care related issues and have more developed skills in dealing with people with palliative care needs.

Finally, a further group will undertake further training to work in a sub-specialised fashion in the field of palliative care where their core work activity will be dealing with people with complex palliative care needs (Specialist Level). Palliative care subspecialists working in hospitals and the community are experts in the field contributing to clinical service delivery, education, research, innovation, advocacy and strategic development.

Alongside professional educational development, public education and awareness regarding palliative care and its related issues are also a health priority. Enabling and empowering the public in making good healthcare decisions relating to treatments, engagement in advance care planning and building caring communities are areas to focus on in developing a sustainable healthcare environment. Caregivers also require access to effective training in preparing them to look after loved ones.

It is envisaged that education and training may be delivered from training hubs across the country where palliative care providers (university, hospital and community specialists from multiple disciplines) may deliver training together, linking with NGO to deliver a seamless, cohesive and collaborative network of training across Malaysia. Opportunities for further study with well-delineated pathways for career progression also need to be established as part of workforce development.

10.2 SWOT analysis

STRENGTH	WEAKNESS
• Passionate and motivated personnel in palliative care • Expertise available within many parts of Malaysia with expanding workforce • Strong overseas networks/ agencies • Malaysian Healthcare Delivery structure - top down implementation • Strong international backing/ network for the development of palliative care (for UHC)	• Limited manpower • Lack of collaboration/partnership between Public-Private-NGOs (lack of cross-sector working) • No proper standards of care • Absence of accrediting body • Absence of palliative care related research institution to guide development • Absence of coordinated cohesive palliative care teaching • Poor public awareness in palliative care • Poor policy structure to manage placement • Malaysian Healthcare Delivery structure – rigid structure/lack of flexibility • Limited multidisciplinary expertise • Lack of ongoing mentoring/support to follow-up progress of education • Training systems/opportunities for placements restrictive • Lack of funding
OPPORTUNITIES	**THREATS**
• National strategy bringing people together across sectors. Coordination opportunities and cross sector working • Increasing political support • Project ECHO collaboration • Policy change e.g. Deployment of trained personnel to the correct places with the right tools, enable cross-sectoral working • Innovation - unique challenges delivering palliative care across the country	• Disparity of palliative care development in hospital versus community • Potential palliative care providers reluctant to deliver palliative care (not trained, stretched/overworked, lack of efficiency) • Fragmentation of development and widening chasms • Public perception – need to address misconceptions

10.3 Key goals to improve palliative care education

The five (5) key goals to improve palliative care education in the country looks at education initiatives at all levels from undergraduates until specialists training in palliative care as well as nursing and paramedical staff. It proposes a structure to deploy trained palliative care personnel and lastly education of the Malaysian public.

1. Establishment of curriculum/education development teams and resources
2. Formation of educational hubs in six (6) regions across Malaysia
3. Implementation of training programme
4. Establishing workforce policies
5. Increasing public awareness and training compassionate communities

1. Establishment of curriculum/education development teams and resources

Stakeholder engagement

As a first step towards curriculum content development, it is essential that engagement take place with all stakeholders (Ministry of Health, Ministry of Education, Private Universities and other palliative care providers) to jointly establish working groups to promote palliative care education in all disciplines. Alongside this, approval and endorsement by accrediting bodies such as the Malaysian Medical Council, Malaysian Nursing Board, National Conjoint Training Boards and Malaysian Qualifications Agency is also imperative to mandate training of the core competencies.

Core content development

In order that palliative care education may be delivered uniformly across the country, educational content has to be developed that is appropriate to the needs of the Malaysian public. Such core content needs to be developed by multidisciplinary working groups that define the standards expected of a Basic, Intermediate and Specialist palliative care providers, which is relevant to each discipline. It may not be feasible for some disciplines to have workers practicing entirely in the field of palliative care (Specialist level) and training has to be designed accordingly. Training and exposure to palliative care also has to reach practitioners from the undergraduate to postgraduate level and provide a continuum of training aligned with professional developmental needs. The working groups will also need to regularly review and update content as palliative care as a field advances both nationally and internationally.

Table 3. Working groups to develop palliative care curricula at various levels

EDUCATIONAL CONTENT	WORKING GROUPS
Basic Level Undergraduate level/Early post graduate	Medical Nursing Occupational therapy Physiotherapy Speech therapy Social work Pharmacy Dietician Other related disciplines
Intermediate Level Postgraduate special interest areas Postgraduate advance diploma/Masters study	
Specialist Level Postgraduate specialization/ subspecialization	

Resource compilation

A wide variety of educational resources in palliative care is available online. The establishment of an online training portal that links to such resources would enable further Continuous Professional Development in palliative care to facilitate further learning.

2. Formation of educational hubs in six (6) region across Malaysia

Designation of regional training hubs

Training at present is fragmented and delivery may be better coordinated across the country. Palliative care providers within the Ministry of Health, Ministry of Education and community hospices currently deliver training in various forms however, this may be more cohesive and systematic once clear syllabus are defined.

By forming regional hubs, it is planned that the defined core curriculum content may be delivered collaboratively by palliative care providers to support development regionally and link organizations and resources while providing closer support and mentoring with local personnel. Regional hubs are intended to bring people together and will be responsible for all aspects of palliative care training in their localities including organization, publicity, CPD application, feedback and quality improvement. While the hubs may generate income for sustainability, they will require start-up funding to initiate activities. Undergraduate training institutions may also engage the regional hubs to assist with education delivery. The hubs may also seek support from neighbouring regions to deliver more uniform palliative care training nationally.

A proposed network of training hubs is shown below linking hospitals with palliative care services and local palliative care providers. A main contact/lead organization to co-ordinate regional training will need to be agreed and appointed for each region. There will be a scope to expand the list as more organizations are established and partnered over time.

Table 4. List of potential palliative care training hubs

REGION	TRAINING ORGANIZATIONS
North (Perlis, Penang, Kedah, Perak)	Hospital Sultanah Bahiyah Persatuan Hospis Kedah Hospital Pulau Pinang Penang Hospice Society Charis Hospice Pure Lotus Hospice Hospital Raja Permaisuri Bainun Perak Palliative Care Society Taiping Palliative Society Manjung Hospice
Central (Selangor, Wilayah Persekutuan)	Hospital Selayang Hospital Kuala Lumpur Hospital Tengku Ampuan Rahimah Institut Kanser Negara University Malaya Universiti Kebangsaan Malaysia Hospis Malaysia Kasih Hospice Care Society Assisi Palliative Care Hospice Klang
East (Kelantan, Pahang, Terengganu)	Persatuan Hospis Negeri Kelantan Persatuan Hospis Terengganu Persatuan Hospis Pahang

South (Negeri Sembilan, Johor, Malacca)	Hospital Tuanku Ja'afar Seremban (2020) Pertubuhan Hospis Negeri Sembilan Hospis Melaka Palliative Care Association of Johor Bahru Persatuan Hospice Ark
Sarawak	Sarawak General Hospital (2021) Kuching Cancer Care Two Tree Lodge Hospice Palliative Care Association of Miri
Sabah	Hospital Queen Elizabeth (2021) Home Care Hospice Programme Sabah Palliative Care Association of Kota Kinabalu Hospice Association of Sandakan Persatuan Hospis Tawau Persatuan Hospice St Francis Xavier

Besides delivering training, the hubs will also maintain a register of trained personnel to engage as trainers for future training sessions and to become champions for promoting palliative care in their institutions.

Accreditation of training

Presently, there is no accrediting organization that recognizes each Level of palliative care provider. A national body is required in the form of a National Palliative Care Association, or a tripartite partnership between the Ministry of Health, Ministry of Education and Malaysian Hospice Council to recognize the completion of training by participants at each level.

3. Implementation of training programmes

Following the development of training, the programmes need to be implemented at all levels. This will include undergraduate training of basic palliative care in universities and healthcare provider engaged with palliative care patients in all settings. The palliative care elements of postgraduate training such as Masters programmes and informal courses, workshops and attachments will cater to those with special interest areas for further study. Ongoing speciality and subspecialty training will continue to be enhanced and expanded. It is suggested that targets be set for proportions of staff within organizations who have undergone palliative care training/exposure to promote the adoption of palliative care training nationally.

A regular programme of CPD activities that is disseminated from the hubs will enable participants to further training opportunities.

4. Establishing workforce policy

Having engaged and completed training to different levels, the deployment of staff to suitable areas of work will ensure that the additional skills and knowledge gained may be put to best use. Furthermore, recognition and possible remuneration for the additional responsibility and scope of work undertaken will promote expansion in the workforce.

It is strongly recommended that a working group be established to explore how the longer term continuity of services can be ensured both in hospitals and in the community. For example, exploring the possibility of specialists working between hospitals and the community will sustain both services while ensuring expertise is shared regardless of patient location. In doing so, a hospital-based specialist may spend several sessions a week with a community hospice that will fund the community aspect of the work.

There should be clear career development pathways for practitioners working in the field of palliative care. In addition, the employment structures within both the government and non-governmental sectors must be able facilitate further training, embrace alternative ways of working and plan succession for the longer-term future and sustainability of all palliative care providers.

5. Increasing public awareness and training compassionate communities

Palliative care is everyone’s right and raising public awareness of the existence and role of palliative care services enables deeper grassroots engagement that serves to augment the top-down approach to palliative care delivery. Many hospices have been established as a result of efforts of local communities to fill an unmet need by existing services. Palliative care seeks to empower patients and families to enable them to make informed choices that are right for them in order to improve quality of life and reduce suffering. Advance care planning may enable care to be delivered as desired by patients according to expressed wishes. It is also important that the public recognize that palliative care is relevant and applicable from early stages of illness and this may have a positive impact on illness contrary to the conventional view that it is solely for the end of life. Public education and advocacy are important to address misconceptions and increase the awareness of patient rights

CHAPTER 11 : ACCESS TO ESSENTIAL MEDICATIONS IN PALLIATIVE CARE

11.1 Introduction

An important element in the provision of palliative care is the availability and accessibility of palliative medicines in a manner that is timely, affordable and not burdensome. Palliative medicines are medications intended to treat and/or prevent the symptoms associated with a life-limiting and terminal illness, such as pain, shortness of breath, nausea and vomiting and depression. The classes of medications most commonly used in palliative care are analgesics especially opioids, antiemetics, laxatives, adjuvant medications, steroids and antidepressants. The World Health Organization (WHO) defines essential medicines as medications that satisfy the primary health care needs of the population. To advance the application of the concept, the WHO also developed a Model List of Essential Medicines (EML) which is updated every two years and is based on the criteria of safety, efficacy and cost effectiveness. This concept and EML are meant to be used by member countries as expert guidelines in developing their own essential medicines policies and lists. These medicines are integral to the treatment of the physical symptoms that account for about 70% of total serious health-related suffering.

Despite the presence of palliative care service providers since the early 1990's, Malaysia continues to face difficulties with equitable access to essential medicines in palliative care. A recent survey revealed that even among Ministry of Health (MOH) hospitals and institutes, 24 centres or 18% do not have readily available immediate-release oral morphine, the recommended treatment for moderate-severe cancer pain. This is a cause for concern as access to pain medicines is widely regarded as a human right. In fact, the Lancet Commission on Palliative Care and Pain Relief strongly advocated for the availability of immediate-release morphine in both oral and injectable formulations in the appropriate and necessary dose at all levels of healthcare.

This chapter describes some of the factors contributing to the lack of equitable access to essential medicines in palliative care and outlines recommendations addressing these limitations.

11.2 SWOT Analysis

STRENGTHS	WEAKNESSES
• Existing comprehensive MOH service networks • Available healthcare professionals/workforce • Multidisciplinary collaboration in the provision of palliative services (physicians, pharmacists, nurses) • Availability of wide range of medicines • Public-funded medications • Established community palliative care services (hospice)	• Inadequate trained human resource • Inadequate or unavailable palliative medicines in some medical facilities • Inequitable access to medicines • Inadequate networking system between hospital-community service providers especially related to referrals and prescriptions • Lack of a timely mechanism for medication delivery especially in the community • Wastage in returned unused medicines
OPPORTUNITIES	**THREATS**
• Increasing awareness & interest among healthcare professionals • Optimizing medication distribution network between facilities • Improving hospital-community partnerships • Strengthening medication-related policies including terminal discharge medications • Existing pain free programme in MOH as a nationwide policy.	• Restrictive regulatory process • Uncontrolled & increasing medication costs • Accessibility to unproven and unregulated alternative products claimed to have anti-cancer/ symptom-relieving properties

11.3 Key goals to improve access to palliative medicines

Three (3) key goals to improve access to palliative medicines in Malaysia are:

1. Make essential medicines in palliative care universally available and accessible
2. Optimize oral morphine formulation
3. Develop supportive legislation and policies

1. Make Essential Medicines in Palliative Care Universally Available and Accessible

The Malaysian National Essential Medication List (NEML) serves as a guide for healthcare facilities to develop local formularies. The NEML contains most of the WHO Model List of Essential Medicines. However, the NEML additionally recommends that these medicines be made available in different healthcare settings according to their levels of care as designated by the MOH (Table 5). Therefore, medicines not ranked as "universal", such as oral morphine which is designated as "secondary/tertiary", may not be readily kept at all healthcare facilities (Table 6). To enhance the delivery of palliative care, an updated NEML should promote better accessibility to these essential medicines.

Table 5: Definition of levels of care. Source: National Essential Medicines List Fourth Edition 2016, Pharmaceutical Services Programme, Ministry of Health

LEVEL OF CARE	EXPLANATION	EXAMPLE
U = universal	Primary, secondary and tertiary care	Health clinic and hospital
S = secondary	Secondary and tertiary care	Major/ minor specialist hospital
T = tertiary	Tertiary care	Major specialist hospital

Table 6: Opioid analgesics. Source: National Essential Medicines List Fourth Edition 2016, Pharmaceutical Services Programme, Ministry of Health

NO	CHEMICAL ENTITY	DOSAGE FORM	LEVEL OF CARE
2.2	Opioid Analgesics		
	Dihydrocodeine	Oral dosage form	U
	Morphine	Oral dosage form	S,T
	Tramadol	Injection	S,T
	Tramadol	Oral dosage form	S,T

The practice of palliative care internationally often involves the prescription of medicines for indications that are not registered with the local Drug Control Authority despite the availability of supportive evidence. The current process of prescribing medicines for off-label indications includes written patient consent, which translates to additional administrative steps and potentially delays in the management of the patient's symptoms. A national palliative medicines protocol that guides the evidence-based use of off-label medicines should be developed.

2. Optimize Oral Morphine Formulation

At present, the immediate-release oral morphine solution used by MOH facilities is extemporaneously compounded at local healthcare facilities. The final product is estimated to have a limited shelf life, and the practice of compounding is laborious, time-consuming and requires proper facilities, which may not be feasible especially in smaller healthcare centres. These may be among the reasons why up to 18% of MOH hospitals/institutes did not have immediate-release oral morphine readily available based on a survey done in 2018. This number did not include health clinics where the availability of oral morphine is expected to be worse.

Guidelines from the MOH as well as WHO recommend the extemporaneous compounding of medicines only when a registered product is unavailable, to ensure consistent product quality. However, the commercial oral morphine available in Malaysia is imported and very expensive. There is currently no suitable alternative, as other opioids, such as oxycodone and fentanyl, are similarly expensive options.

Possible solutions to address this problem can be divided into short-term and long-term options. The first in the immediate 1-5 years will be to improve and standardize the current compounded morphine formulation with the aims of stabilizing the product and increasing shelf life. However this method would still rely on individual facilities having to compound morphine which requires proper compounding facilities, as well as sufficient manpower.

A second and more sustainable option in the following 5-10 years, may be to source for a local Good Manufacturing Practice-certified manufacturer to produce oral morphine as a registered product at a reasonable cost. The pharmaceutical industry could be engaged in discussions to produce oral morphine for the needs of the country in an ethical manner that is affordable with enhanced stability and improved shelf life. This has previously been done with oral methadone, which has been available in Malaysia as a locally manufactured registered product since 2005. Such an initiative would result in greater availability of morphine in facilities unable to compound morphine.

3. Develop Supportive Legislation and Policies

While regulations and policies are necessary to ensure proper use of controlled medicines like opioids and avoid diversion, an overly restrictive or excessively complicated bureaucratic process can impede the timely provision of palliative medicines to patients.

Regulations and policies should be reviewed in order to:

i. strengthen the collaboration between hospital and community palliative care providers to ensure the timely and affordable provision of essential medicines for patients in need;
ii. develop practice guidelines and policies for the use of parental (injectable) essential medicines in the community for dying patients at home;
iii. make essential medicines in palliative care available to all patients without discrimination;
iv. regulate pricing of essential medicines in palliative care to ensure these medications remain affordable.

All these should happen concurrently with proper education and training on the appropriate use of essential medicines in palliative care. As availability and accessibility to pain medicines improve, it is important to be mindful of the potential for inappropriate use of opioids for chronic non-cancer pain. In order to minimise the risk of this potential outcome, education on the appropriate use of opioids for pain in cancer and non-cancer patients should be integrated with the MOH-wide Pain Free Program. Additionally, there should be regular monitoring of prescriptions of strong opioids for all patients to ensure safe and proper prescribing practices.

The National Medicines Policy aims to provide equitable access to quality, safe, effective and affordable medicines and to promote its rational use to improve health outcomes for all. Tasked to accomplish these goals, the Pharmaceutical Services Programme of MOH produced the report “Pharmacy Research Priorities in Malaysia” in 2018 which identified medication access as a priority research area. This supports the primary goals of the 11th Malaysia Plan, the Ministry of Health Strategic Plan 2016-2020 and the Pharmacy Programme Strategic Plan 2017-2020.

In summary, it is important that all stakeholders, from clinicians to policy-makers and the pharmaceutical industry, collaborate within the provisions of the local regulatory framework to ensure that palliative medicines are provided to all in need in a manner that is timely, affordable and not burdensome.

CHAPTER 12: RESEARCH AND STANDARDS IN PALLIATIVE CARE

12.1 Introduction

The provision of palliative care, similar to all fields of medicine, should be evidence-based. This includes improvement in areas of medical care, ensuring cost-effectiveness of service and compliance to international and national standards.

International studies indicate that palliative care improves the quality of life of patients while reducing healthcare costs, however there is limited local data to guide national service development. Data is needed to understand the unique palliative care needs of those living in Malaysia as well as the barriers faced in accessing care and the challenges in developing appropriate services. Evidence-based development of palliative care services is important to ensure access to high quality palliative care throughout the country.

Clinicians and academics involved in the many aspects of palliative care, should collaborate to prioritise and conduct research in areas needed by the country. This can be done through developing research links, mentorship, practical support for inter-institutional approval and funding applications.

The success of palliative care service delivery depends on the ability to provide access and respond to patients and families complex needs. To ensure that all palliative care service providers deliver good quality service to patients and their carers, an agreed standard must be adhered to. National Standards are essential in order to:

- Promote the provision of holistic high quality care to patients and families with life threatening illness
- Provide benchmarks for achieving quality palliative care
- Provide a framework for quality improvement

However, a national standard must be suited to be implemented locally, taking into consideration of the country's available resource and multi-ethnic and multi-cultural background.

As the private healthcare sector is gradually expanding into the area of palliative care as well, it is important that standards and outcome indicators be in place to monitor these services to ensure that quality care is being provided.

12.2 SWOT analysis

STRENGTHS	WEAKNESSES
Research • Existence of research networks with interest in palliative care e.g. RESPIRE • Ability to collaborate with academics from other disciplines • Support from CRC Standards • Palliative care is briefly mentioned in the standards of care by MSQH under patient and family rights. • Many hospitals are keen to obtain MSQH accreditation status.	Research • Lack of research experience • Time required to carry out research • Lack of access to good literature on palliative care evidence • Working in silos Standards • Currently there are no official standards of care for the provision of palliative care in the country. • Some organisations already providing palliative care may feel unable to improve services to meet standards • Many palliative care services do not measure outcome indicators

OPPORTUNITIES	THREATS
Research • A National Strategy can help to promote more research collaborations and promote research, which has a direct impact on patient related outcomes. • International collaboration with researchers well versed in palliative care e.g. King's College London. Standards • Existence of well-written standards developed in other countries which provide which have already been put into practice and can be adapted. • Willingness of some services to work towards improving care • Framework for standards under the auspices of the national strategy • Linking standards to funding and resource allocation.	Research • Lack of funds • Concurrent administrative and clinical responsibilities Standards • Tedious measurements which create too much administrative burden • Inaccurate data collection • NGO organisations ceasing service as unable to comply with rigid standards

12.3 Key goals to improve palliative care research & standards

As the number of palliative care research in Malaysia is limited, the best way forward to improve research is through working together to generate data, which will bring the greatest impact to the nation. As for standards, Malaysia has yet to introduce national palliative care outcome measures and has no proper database of these measures hence this would be the focus of the strategy in this area. The following are the key goals:

1 Create a culture of research for palliative care providers

2 Create minimum standards of care for all levels of palliative care service provision with a nationwide system for data collection and auditing

3 Establishment of an independent organization for palliative care research

1. Create a culture of research for palliative care providers

Since 2017, a small collaborative group of palliative care researchers from the MOH, universities and NGO palliative care providers has been formed in order to discuss and coordinate key research projects within the country. This group should be further enhanced so that:

a. Palliative care research in Malaysia can be better coordinated and researchers may be better supported at individual sites and institutions.
b. Measures to encourage new researchers to conduct high quality, necessary research.
c. Systematic collection of meaningful datasets on palliative care services and outputs may be better supported.
d. Applications for research grants can be facilitated and coordinated.
e. Past and future research publications from Malaysia can be compiled and archived for future researchers' reference

2. Create minimum standards of care for all levels of palliative care service provision with a nationwide system for data collection and auditing

Minimum standards of care need to be developed in order to ensure that care providers strive for clinical excellence and patients receive appropriate care. Such standards should be determined through a process of reviewing standards used in other developed countries and consider those most applicable to local settings.

Outcome measures will then be determined and implemented initially at the MOH and university level. Gradually these standards will be implemented at the NGO community palliative care setting as well as the private sector. The standards will later undergo a benchmarking process which will later allow all services to undergo regular audit cycles. As standards of care improve, these indicators will undergo further revision to ensure continuous quality improvement.

Once established, these standards will serve as a form of accreditation of palliative care services and in the next 5-10 years become a requirement for compulsory licensing of all private palliative care services. For government and charitable palliative care organizations, these standards will become the basis of on-going funding and resource allocation.

3. Establishment of an independent organisation for palliative care research

To achieve both strategic goals, an entity (such as a committee, organisation or institution) may be necessary to plan, map and register local research needs and enhance collaborations between other palliative care personnel and other parties. This entity can also be used to audit and monitor standards of service delivery by local palliative care service provider.

Such an organisation can be developed through private public partnership whereby funding may be sourced from NGO hospices as well as corporate donors which will reduce the burden of cost on the government. An outline of the cost implications is seen in Table 4a.

CHAPTER 13: SUSTAINABLE FUNDING

13.1 Introduction

Palliative care services must be developed in a way that is highly affordable apart from being accessible. While the cost of palliative care is merely a fraction of the cost of other forms of care such as oncology or haemodialysis, it should be acknowledged that due to the scope of palliative care which basically can involve majority of an entire population, there is a need to consider how developing palliative care services to achieve UHC will be funded in a sustainable manner.

At present, majority of funding for services developed within the Ministry of Health and Ministry of Higher Education are from tax-based funds from the government. This covers most medications, infra-structure, equipment, consumables, human-resource and education for these palliative care services. Funding for non-governmental hospice organisations on the other hand is largely from charitable donations and funding raising projects organised by these NGOs. Apart from this, since 2003, some hospice NGOs have received government grants annually to help support their activities. These grants have increased over the years and currently averages to about RM870,000 per year which is about 21.9% of the RM 4 million which is the total average operational expenditure of these NGOs annually. While it would be good if more could be given to the NGOs to further enhance and expand their services, it should be recognised how a significant proportion of sustainable funding can come from society itself through charitable donations and fund raising. From 2015-2017, the members of the Malaysian Hospice Council raised over RM 3 million annually to provide community palliative care to the nation which must be recognised as a significant contribution from society that helps to reduce the burden on the Ministry of Health's tax-based budget.

It is estimated that the funding required to run an average specialist palliative care service with about 12-15 beds would cost around RM2 million per year. This would include the cost of human resource (specialists, medical officers, nurses, attendants, drugs and consumables). The one of cost for developing the infrastructure and equipment will also cost around RM800,000 -1 million per unit. While this cost may not be very high compared to other disciplines, within the Ministry of Health, many disciplines will have to compete annually for a proportion of the limited funding allocated to service development. Funding is therefore a significant limiting factor to developing widespread palliative care services. Therefore, in order to realise the vision of providing equitable palliative care for the nation, an approach to create sustainable funding besides depending on government tax-based funding alone must be part of this national strategy.

13.2 SWOT analysis

STRENGTHS	WEAKNESSES
• Government subsidised healthcare • Growing interest from corporate sectors to fund palliative care activities • Ongoing annual government grants to NGOs	• Relatively low healthcare budget • Over dependence on government funding • Limited innovations towards alternative funding • Limited cooperation between NGOs and government agencies to share resources • Lack of good auditing of services • Lack of involvement by health insurance companies
OPPORTUNITIES	**THREATS**
• Contribution from corporate social responsibilities • Partnerships with NGOs to develop services together • Contribution from the public • Creating a National Palliative Care Foundation • Developing compassionate community programmes	• Indiscriminate crowd-funding • Poorly managed foundations • Bureaucratic barriers to partnerships

13.3 Key goals to improve sustainable funding

The main goals to improve a sustainable funding model for development of palliative care in Malaysia include:

1. Optimising current government funding
2. Create sources of alternative funding through partnerships with NGOs
3. Development of a national foundation for palliative care
4. Developing a programme for compassionate communities
5. Encourage private sector contribution

1. Optimising current government funding

Generally the government will still shoulder the responsibility of providing the best healthcare for its citizens and as the main healthcare provider for the nation, a large proportion of the services provided within the MOH will continue to be funded through government tax-based budgets. Thus in developing further palliative care services including hospital based units as well as domiciliary palliative care teams, an increase in funding is required. The estimated cost for developing specialist hospital based palliative care units in all state hospitals would then amount to an additional RM7 million for infrastructure and equipment as a one off expense for 8 new hospital units over the next 5 years. Staffing of these units would then cost RM9.5million per year. As for development of dedicated domiciliary care teams in 160 designated health clinics, the additional staffing would cost an additional RM12 million per year.

Budgets should be optimised by increasing efficiency and sharing of resources among services between hospitals and also with domiciliary care teams and clinics. This includes sharing of drugs and specialist expertise as well as task shifting.

Training programmes such as the advanced diploma in palliative care for nurses and paramedics should be expanded and encouraged among private sector to generate income through private candidates. This will help offset training costs for government.

2. Creating alternative sources of funding through partnerships with NGOs

NGO palliative care service development should be regarded as an important healthcare resource for the country as it complements the MOH services and allows civil societies to share the responsibility of providing palliative care to the nation. NGOs will continue to raise donations from the public and this can be enhanced by encouraging NGOs to do more with providing tax-exemptions and provision of annual grant funding. By providing annual grant scheme, it will encourage NGOs to raise more funds for development of palliative care at the same time the government can impose conditions to the grant that will ensure significant outputs of care and high quality care.

Through good partnerships with NGOs, funding from corporate social responsibilities and wealthy benefactors may also be used to help development through education activities, public awareness campaigns and even the development of infrastructure and procurement of equipment for hospital based units.

3. Development of a National Palliative Care Foundation

In years to come, the development of a national foundation to fund the needs of palliative care should be considered. This would require much organisation and management but is feasible if there is sufficient interest and support towards palliative care. Hopefully as public awareness increases and the Malaysian society understands the importance of palliative care in the country there will be sufficient drive to do this. Such foundations have been developed in many countries around the world and is indeed an important way of creating sustainable funding.

4. Developing compassionate communities

Compassionate communities is a programme whereby the lay public are trained to a basic level to provide care and assistance to those who are severely ill within their community.

This has been recognised as a very cost-effective source of human capital which can eventually be sustained by communities themselves. Currently the extended family is still the main source of care for people who are sick at home however, with the change in societal norms, many families do not live together and many people have no family to rely on. If people who eventually become sick cannot be cared for at home as there is nobody to help them then there will be a need to develop more nursing home facilities and hospitals may become even more crowded with such patients. Developing nursing home facilities would be more costly and thus, developing compassionate communities will help to reduce the need and cost for institutionalised care.

5. Encourage private sector contribution

The private sector can contribute significantly towards to care of Malaysians at the end of life and this should be recognised. However, the cost of private palliative care should be regulated to ensure that it is affordable. This in turn may encourage those who have the means to obtain care from the private sector and reducing the burden of government facilities. Essential medications such as opioid analgesia should also be subjected to price controls so that patients may be able to afford both consultation as well as medications from the private sector.

Private nursing homes and home nursing services should also have regulations over their charges as this again can provide a very significant contribution to palliative care for the nation. Therefore by regulating the cost, it will make access to such care less restrictive and more feasible to the general public.

Health insurance policies should be encouraged to consider inclusion of palliative care

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Annex 1

Table 1a: Equipment for 12-Bedded Palliative Care Unit

No.	Equipment	Unit price (RM)	Number	Total (RM)
1.	3 function bed	4800.00	12	57,600.00
2.	Ripple mattress with electric pump	400.00	12	4,800.00
3.	Mattress	800.00	12	9600.00
4.	Cardiac table	300.00	12	3,600.00
5.	Patient locker	200.00	12	2,400.00
6.	Filling cabinet	800.00	1	800.00
7.	Suction pump	5000.00	3	15,000.00
8.	Walking frame	100.00	3	300.00
9.	Wheelchair	245.00	3	760.00
10.	Commode Chair (Detachable)	765.00	1	765.00
11.	Commode chair	400.00	2	800.00
12.	Recliner wheelchair	700.00	1	2100.00
13.	Urinal	40.00	6	240.00
14.	Deck chair	210.00	10	2100.00
15.	Metal trolley	400.00	1	400.00
16.	Bed pan	120.00	6	720.00
17.	Oxygen concentrators	5000.00	6	30,000.00
18.	Glucometer	200.00	2	400.00
19.	Vital sign monitor	1500.00	1	1500.00
20.	Refrigerator	800.00	1	800.00
21.	Boiler	600.00	1	600.00
22.	Cardio life defibrillator	2500.00	1	2500.00
23.	Resuscitation trolley	800.00	1	800.00
24.	Nebulizer machine	250.00	1	250.00
25.	Pulse oxymeter	150.00	1	150.00
26.	Syringe pump	4000.00	2	8000.00
27.	Syringe driver	4500.00	3	13,5000.00
28.	Air conditioner	1200.00	4	4,800.00
29.	Stand fan	120.00	5	600.00
30.	Construction/Renovation	500,000.00	1	500,000.00
			TOTAL	**663,885.00**

Table 1b: Staffing per unit

No.	Position	Basic pay	Number	Total
1.	Medical Specialist UD 56	RM 6,504.00 + elaun RM 7,250.00 = RM 13,754.00	2	RM 27,508.00 x 12 =RM 330,096.00
2.	Medical officer UD 44	RM 3,422.00 + elaun RM 1,850.00 = RM 5,272	6	RM 31,632.00 x 12 =RM 379,584.00
3.	Pharmacist UF44	RM 3,611 + elaun RM 1,850.00 = RM 5,461.00	1	RM 5,461.00 x 12 =RM 65,532.00
4.	Head of Nursing U32	RM 2,331.00	1	RM 2,331.00 x 12 =RM 27,972.00
5.	Staff nurse U29	RM 1,797.00	12	RM 21,564 x 12 =RM 258,768
6.	Occupational Therapist	RM1,797.00	1	RM 1,797.00 x 12 =RM 21,564.00
7.	Physiotherapist	RM 1,797.00	1	RM 1,797.00 x 12 = RM 21,564.00
8.	Attendance U11	RM1,200	5	RM 6,000.00 x 12 = RM 72,000.00
9.	Community Nurse U19	RM2,200	5	RM 11,000 x 12 =RM 132,000.00
			JUMLAH	**RM 1,309,080.00**

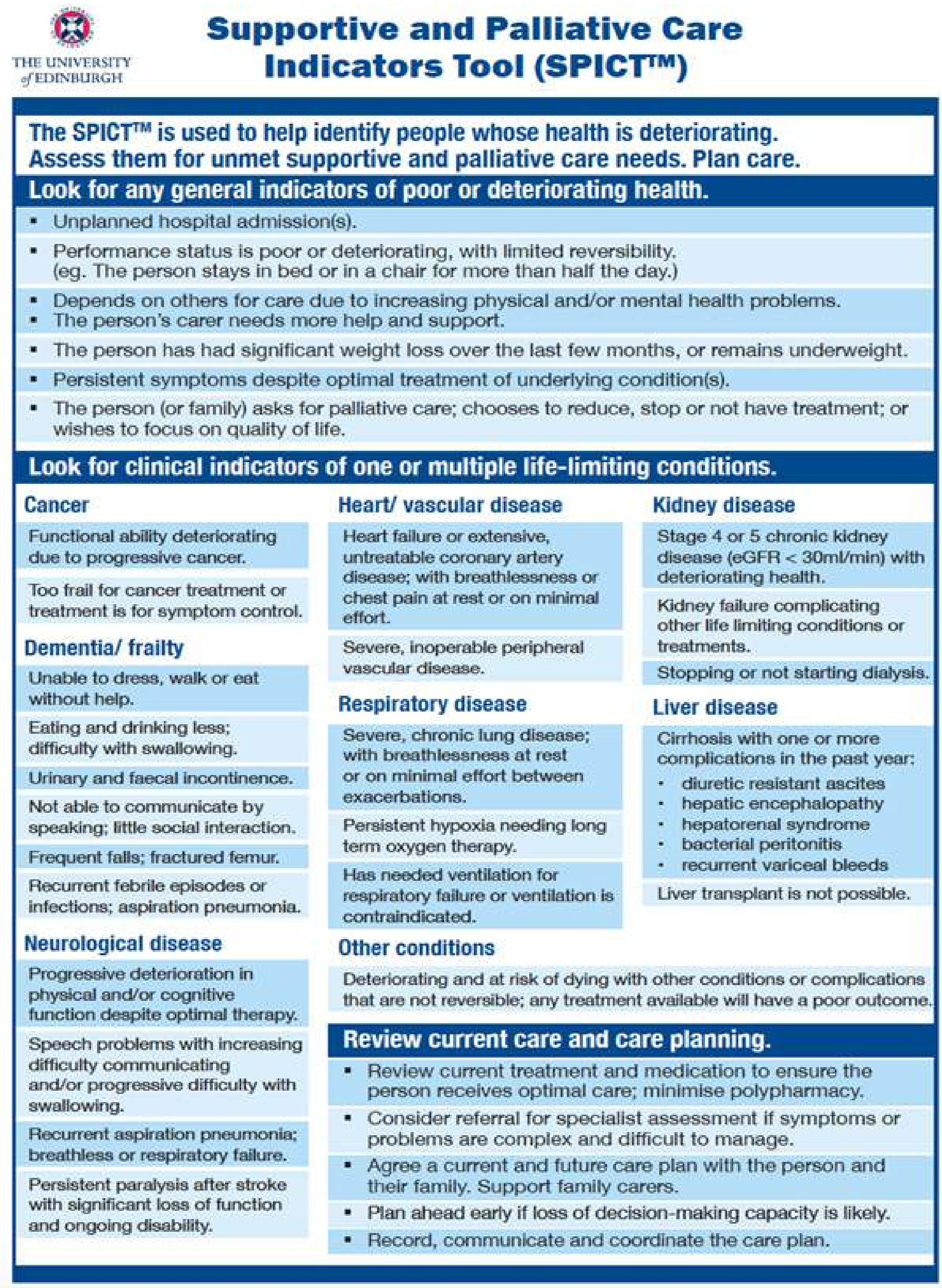
Cost of setting up 8 palliative care units in state/major hospitals
= (663,885 + 1,309,080) x 8 units
= 1,972,965 x 8 units
= RM 15, 783,720

Annex 2

Table 2a: Staffing for 160 dedicated Domiciliary Palliative Care Team

No.	Position	Emolument		Number	Total Yearly
		Basic pay	Allowances		
1.	Head of Nursing, U32	RM 2,331.00	RM 820.00	160	RM 6,049,920.00
2.	Medical Assistant, U32	RM 2,331.00	RM 820.00	160	RM 6,049,920.00
3.	Staff nurse U29	RM 1,797.00 per month	RM 760.00 per month	160	RM 4,909,440.00
4.	Medical Assistant, U29	RM 1,797.00 per month	RM 760.00 per month	160	RM 4,909,440.00
				TOTAL	**RM 21,918,720.00**

Table 2b: Palliative Care Needs Screening Tool



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Supportive and Palliative Care Indicators Tool (SPICT™)

**The SPICT™ is used to help identify people whose health is deteriorating.
Assess them for unmet supportive and palliative care needs. Plan care.**

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

(reproduced with permission from the University of Edinburgh)

Table 2c: Essential Package For Domiciliary Palliative Care Programme In Health Clinic

Medications	Prescriber Category	Approximate Price (RM)
Prevention and relief of pain or other physical suffering, acute or chronic		
Amitriptyline 25mg	B	RM 0.30 (per tab)
Bisacodyl 5mg (tab) 5mg (suppository)	C	RM 0.30 (per tab) RM 0.70 (per supp)
Dexamethasone 0.5mg (tab) 4mg (tab) 8mg/2ml (injectable)	A	RM 0.10 (per tab) RM 0.33 (per tab) RM 2.20 (per vial)
Diazepam 10mg 5mg (Rectal Solution) 5mg/ml (Injection)	B C B	RM 0.80 (per tab)
Diphenhydramine 7mg/5ml (Peadiatric syrup) 14mg/5ml (syrup)		RM 4.30 (per bottle of 120ml) RM 2.50 (per bottle of 90ml)
Fluconazole 50mg 100mg		RM 2.10 (per tab) RM 4.00 (per tab)
Sertraline HCL 50mg (tab)		RM 1.30 (per tab)
Frusemide 40mg (tab) 10mg/ml		RM 1.40 (per tab) RM 2.80 (per ampoule)
Haloperidol 1.5mg (tab) 5mg/ml (injectable)	B B	RM 0.16 (per tab) RM 5.60 (per ampoule)
Hyoscine N-Butylbromide 10mg (tab) 20mg/ml	B B	RM 0.30 (per tab) RM 3.20 (per ampoule)
Ibuprofen 400mg (tab) 100mg/5ml (syrup)	B	RM 0.10 (per tab) RM 1.40 (per bottle of 60ml)
Diclofenac Sodium 50mg (tab)	B	RM 0.20 (per tab)
Lactulose 3.35 g/5 ml Liquid- Lactul Solution	C+	RM 14.50 (per bottle 200mls)
Loperamide 2mg (tab)	B	RM 0.20 (per tab)

Lorazepam 1mg (tab)	A/KK	RM 0.80 (per tab)
Metoclopramide 10mg (tablet) 10mg (injection)	B B	RM 0.03 (per tab) RM 0.64(per ampoule)
Metronidazole 200mg (tab) 400mg (tab)		RM 0.20 (per tab) RM 0.30 (per tab)
Morphine 2mg/ml (syrup) Morphine Sulphate (Injection) 10mg/1ml	B B	RM 0.03 RM 2.50 (per ampoule)
Naloxone HCL Mapin 0.4mg/ml Injection (1ml Amp)		RM 2.20 (per ampoule)
Omeprazole 20mg (tab)	A/KK	RM 13.85 (per tab)
Paracetamol 500mg (tab) 250 mg/5 ml Suspension	C+ B	RM 0.30 (per tab) RM 6.00 (per bottle of 90ml)
Petroleum jelly 30g package		RM 0.52 (per 30g package)
Prevention and relief of psychological suffering, acute or chronic		
Amitriptyline HCL 10mg (tab) 25mg (tab)	B	RM 0.20 (per tab) RM 0.30 (per tab)
Dexamethasone 0.5mg (tab) 8mg/2ml (injectable)	A	RM 0.10 (per tab) RM 2.20 (per vial)
Diazepam 10mg 5mg (Rectal Solution) 5mg/ml (Injection)	B C B	RM 0.80 (per tab)
Chlorpheniramine Maleate 4mg (tab) 4 mg/5ml (Syrup)		RM 0.10 (per tab) RM 5.00 (per bottle of 60ml)
Sertraline HCL 50mg (tab)		RM 1.30 (per tab)
Haloperidol 1.5mg (tab) 5mg/ml (injectable)	B B	RM 0.16 (per tab) RM 5.60 (per ampoule)
Lactulose 3.35 g/5 ml Liquid	C+	RM 14.50 (per bottle 200mls)

Equipment	Approximate Price (RM)
Pressure reducing mattress Minimum 2 mattresses	RM 200.00 (per mattress)
Nasogastric feeding tubes	-
Urinary catheters	-
Opioid lock box	Refer to Table 2d for list of medication recommended in Opioid Lock Box
Flashlights with rechargeable batteries	-
Adult diapers or cotton and plastic	-

Nursing Kit for Bowel and Bladder Care		
	Urinary Catheterisation Kit	**Quantity**
1	Dressing Set	2 sets
2	Foley Catheter	As required
3	KY Jelly / 2% Xylocaine Gel	1 tube
4	Sterile Gloves	As required
5	Syringe 10mL (SlipTip)	As required
6	Urine Bag	As required
7	Water for Injection 10mL	As required

	Wound Care Products	Quantity
1	Dressing Set	2 sets
2	Duoderm™ Gel	Subjected to availability
3	Duoderm™ Patch	Subjected to availability
4	Gauze	Subjected to availability
5	Kaltostat™	Subjected to availability
6	Metronidazole Powder / Tablet to be crushed	20 tablets
7	Micropore™	As required
8	Normal Saline 0.9% Solution	As required
9	Charcoal Tablet	20 tablets

	Bowel Care Products	Quantity
1	Examination Gloves	4
2	KY Jelly	1 tube
3	Glycerin/ NaCl Enema (Ravin)	6

	Subcutaneous Line Preparation	Quantity
1	Alcohol Swab	1 box
2	Dressing Label	6
3	IV Indwelling Cannula 24G	6
4	Micropore™ Surgical Tape	6
5	Extension Tubing (~150cm)	6
6	Syringes 10ml (Slip Tip)	6
7	Stopper (Red & Yellow)	6
8	Water for Injection	As required

Table 2d: Medication For Opioid Lock Box
(Opioid And Essential Medication For Acute Crises)

Medications	Approximate Price (RM)	Approximate Quantity
PSYCHOTROPICS (ORAL & INJECTABLES)		
Diazepam (rectal sol.) 5mg	NA	4
Lorazepam (tab) 1mg	RM0.50 per tab = RM 5.00	10 tablets
Midazolam (inj) 5mg/ml	RM 15.40 per amp = RM 61.60	4 ampoules
Morphine sulphate (inj) 10mg/ml	RM 2.70 per amp = RM 27.00	10 ampoules
Morphine (syr) 2mg/ml	Morphine Powder (APPL) RM115.00 Pack of 10g	120mls, 4 bottles
Tramadol HCL (caps) 50mg	RM 1.30 per caps = RM 26.00	20 capsules
NON PSYCHOTROPICS (INJECTION)		
Hyoscine N-Butylbromide (inj) 20mg/ml		10 ampoules
Haloperidol (inj) 5mg/ml	RM5.59 per amp = RM 55.90	10 ampoules
Metoclopramide HCL (inj) 5mg/ml	RM2.36 per amp (Hameln-10mg in 2ml) = RM 23.60 RM2.87 per amp (Primperan-10mg in 2ml) = RM 28.70	10 ampoules
TABLETS, CAPSULE, SUPPOSITORIES		
Bisacodyl (tab) 5mg	RM 0.30 per tab = RM 6.00	20 tablets
Bisacodyle (supp) 10mg 5mg (supp) 5mg (supp for paediatrics)	RM 0.70 (per supp) = RM 7.00 RM 1.45 (per supp) = RM 14.50	10 suppositories
Diclofenac (tab) 50mg	RM0.04 per tab (Dyfenac) RM0.15 per tab (Rhemofenac)	20 tables
Glycerin 25% & NaCl 15% enema	NA	6 suppositories

Haloperidol N-Butylbromide (tab) 1.5mg 5mg (tab)	RM 0.10 (per tab) = RM 2.00	20 tablets
Hyoscine N-Butylbromide (tab) 10mg	RM 0.30 (per tab) = RM 6.00	20 tablets
Lactulose (liquid) 3.35g/5ml	RM 21.90 (per bottle) = RM 87.60	4 bottles
Loperamide (tab) 2mg	RM 0.20 (per tab) = RM 4.00	20 tablets
Paracetamol (tab) 500mg	RM 0.30 (per tab) = RM 9.00	30 tablets
Paracetamol (supp) 250mg	RM1.32 (per supp) = RM 13.20	10 suppositories
Tranexamic acid (caps) 250mg	RM 0.60 (per caps) = RM 18.00	30 capsules

Annex 3

Table 3a: Core palliative care competencies for Palliative care providers

1.	Identifying early any suffering due to serious or life-threatening illness or injury (Using SPICT. UK)
2.	Assessing palliative needs; physical, psychological, social and spiritual needs
3.	Preventing and relieving of the most common and distressing symptoms associated with serious or life-threatening illness or injury, which have been identified as:
4.	Knowing when to refer a patient to a higher level of care
5.	Providing emotional support and future care planning for patients and families that is sensitive to each patient's and family's culture, values and prior experiences with death.
6.	WHO suggests training requirements for PHC staff members who provide palliative care as follows: -

Adapted from Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers 2018

Annex 4

Table 4a: Cost implications of developing independent palliative care research centre

No.	Item	Unit price (RM) per month	Unit price (RM) per unit (once-off)	Total (RM) per year
1	Rental of premise	2,000.00		
2	Utilities	1,000.00		
3	Office equipments:			
	Furniture	-	50,000.00	
	Electronics	-	50,000.00	
	Stationeries	1,000.00	-	12,000.00
	Online services (server, website etc)	2,000.00		24,000.00
4	Salaried staff (basic plus allowance):			
	Director	15,000.00		180,000.00
	Secretariat (2 paxs)	10,000.00		120,000.00
	Research Assistants (2 paxs)	4,000.00		48,000.00
	Support staff (2 paxs)	4,000.00		48,000.00
5	Maintenance:			
	Central research database, website development	-	50,000.00	12,000.00
	Research training and collaboration efforts	1,000.00		12,000.00
	Standards monitoring and auditing activities	1,000.00		
		TOTAL	**150,000.00**	**481,200.00**

Annex 5

Table 5a: Total number of cases cared for by various palliative care services in Malaysia

Palliative care services providers in Malaysia	Total number of patients
Specialist Palliative care services in MOH (7 centres)	4,980
Teaching Hospitals (UMMC & HUKM)	1,648
NGO hospices under Malaysia Hospice Council (19 out of 22 members)	3,660
Hospis Malaysia	2,000
MOH Domiciliary palliative care service	122
Paediatric palliative care services	315
Estimates Total numbers of patients cared for	**12,725**

Table 5b: List of Palliative Care Services in Malaysia

Service typ	Provider
Inpatient Palliative Care Units	*(With resident specialists)* 1. Hospital Raja Permaisuri Bainun, Ipoh 2. Hospital Pulau Pinang 3. Hospital Selayang 4. National Cancer Institute, Putrajaya 5. University of Malaya Medical Centre *(Without resident specialists)* 1. Hospital Batu Gajah 2. Hospital Bukit Mertajam 3. Hospital Tengku Ampuan Afzan, Kuantan 4. Hospital Melaka
Hospital Consultation Services	1. Hospital Sultanah Bahiyah, Alor Setar 2. Hospital Tuanku Ampuan Rahimah, Klang 3. Hospital Kuala Lumpur 4. Hospital Ampang 5. Hospital Tuanku Jaafar Seremban 6. Hospital Universiti Kebangsaan Malaysia 7. Gleneagles Hospital, Kuala Lumpur 8. Prince Court Medical Centre 9. Sunway Medical Centre

Community Home Care	1. Persatuan Hospis Kedah 2. Charis Hospice, Penang 3. Penang Hospice Society 4. Perak Palliative Care Society 5. Manjung Palliative Care Society 6. Taiping Palliative Society 7. ASSISS Palliative Care, Petaling Jaya 8. Assisi Palliative Care, Petaling Jaya 9. Kasih Hospice Care Society, Petaling Jaya 10. Klang Hospice 11. Faith Hope Love Hospice, Petaling Jaya 12. Hospis Malaysia, Kuala Lumpur 13. Pertubuhan Hospis Negeri Sembilan 14. Hospis Melaka 15. Palliative Care Association of Johor Bahru 16. Persatuan Hospis Pahang 17. Persatuan Hospis Terengganu 18. Persatuan Hospis Negeri Kelantan 19. Yayasan Orang Kurang Upaya Kelantan (YOKUK) 20. Palliative Care Association of Kota Kinabalu 21. The Hospice Association of Sandakan 22. Persatuan Hospis Tawau 23. Home Care Hospice Programme, Sabah 24. Persatuan Hospis St Francis Xavier, Keningau 25. Palliative Care Association of Miri 26. Kuching Cancer Care (NCSM Sarawak Branch) 27. Sarawak Hospice Society 28. Two Tree Lodge, Kuching
Community Inpatient Hospices	1. Persatuan Hospis Ark, Johor Bahru 2. Pure Lotus Hospice of Compassion, Penang

*Organizations in italics have visiting palliative care specialists

Annex 6.

Action plan tables for implementation of national palliative care strategy

Table 6a: Hospital Based Palliative Care

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
1. All State/ Major Specialist Hospitals and teaching hospitals to Develop Palliative Care services	**a) Develop specialised palliative care service in all states/major hospital** i. Identify and train specialist to be posted to each state/ major specialist hospital • Hospital Tuanku Jaafar, Seremban • Hospital Melaka • Sarawak General Hospital (SGH) • Queen Elizabeth Hospital, Kota Kinabalu • Hospital Sultanah Aminah, Johor Bharu • H. Tengku Ampuan Afzan, Kuantan • HRPZII, Kota Bharu • HSNZ, Kuala Terengganu • HTF, Kangar	3 years 5 years	100% of all state hospitals with resident palliative care specialist by 2030 At least 2 trainees/ year	National sub speciality training program

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	ii. Each state/major hospital should have allocated dedicated palliative care beds or units	To be done within one year of specialist posting	50% of state hospitals to have specialist palliative care units/allocated beds by 2025 (Minimum of 8 allocated beds)	JKN / Hospital Level / Department level
	iii. Develop an operational policy for palliative care service within the hospital (scope of care; cancer, non-cancer, paediatrics • Individual palliative care specialist of the service to determine the scope of care and SOPs • Develop a system for the continuation of care appropriate for the local setting	Within 6 months of development		

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	b) Develop specialised palliative care service in all major specialist hospital or cluster hospital / visiting service in hospital without resident palliative care specialist			
	i. Perform needs analysis to prioritise which major specialist hospital or cluster hospital to develop specialised palliative care service based on population, specialties involved and relevance to National Strategic Plan	Complete analysis in 1 year	Every hospital with resident palliative care specialist to develop visiting services in at least 1 major hospital by 2025 50% of major hospitals to have visiting specialist palliative care services by 2030	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	ii. Develop palliative care specialist visiting service • H. Ampang • H. Sg. Buloh • H. Serdang • H. Seberang Jaya • H. Sg. Petani • H. Taiping • H. Seri Manjung • H. Likas	Visiting services within the next 3 years		
	• HSI, Pandan • H.Teluk Intan • H. Temerloh • H.Muar • H. Batu Pahat • H. Sibu • H. Miri • H. Tawau • H. Sandakan	Visiting services within the subsequent 5 years		
	iii. Develop a visiting consultative service prior to posting of a resident palliative care specialist in major hospital	6 months prior to establishing new service		Hospital director / JKN

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	c) Ensure development of Palliative Care in all Teaching Hospitals i. Establish a Palliative Care Service in all government teaching Hospitals. Already established in: • UMMC • HUKM • UiTM • USIM Yet to be established: • HUSM • IIUM • UPM • UMS • UniMAS • UPNM	To establish within the next 5 years		
	d) Ensure good quality care is provided by hospital based palliative care service i. Develop indicators and standards for monitoring of hospital-based palliative care services	2 years	SOP and policy papers are prepared	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	ii. Have regular audits of the indicators and standards iii. Establish benchmarking at the national level with feedback to the hospital	2 years	All hospitals to conduct at least one audit per year	
	e) Ensure adequate staffing in all centres i. Perform needs analysis to determine number of staffs required per patient bed. This would include medical personnel, nursing, allied health and pharmacist	2 years	National policy is established within 2 years of needs analysis	Nursing Division, MOH Allied Health Sciences Division, MOH Pharmaceutical Services Programme, MOH Training Management Division (BPL) Human Resource Division

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	ii. Develop a national strategy for the planning and development of palliative care nursing and allied health professionals trained for palliative care (include recognition of specialist nurses and a coordinated posting for them)	2 years		Nursing Division, MOH Allied Health Sciences Division, MOH
	f) Ensure appropriate drug availability for the hospital-based palliative care i. Engage hospital pharmacy department to identify essential drugs available and gaps ii. Establish operational budget for drugs require in palliative care iii. Reallocation of existing operational budget for palliative care drugs if necessary			
	g) Development of human capital to be part of the specialist palliative care service i. To create firmer roles and positions for nurses and allied health professionals who are skilled in their areas for palliative care.	ongoing		Nursing Division, MOH Allied Health Sciences Division, MOH

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	g) Public Private Partnership (PPP) i. Engage in Smart Partnerships with NGO / private institutions / corporate bodies to help finance development of inpatient units	1st project to be completed in next 2 years	Report on PPP in palliative care by 2 years	Medical Development Division, MOH Division of Finance, MOH Corporate sector NGO / MHC
	ii. Official visiting palliative medicine specialist/MO from hospitals to assist with community palliative care in nearby hospices (e.g. once/week)	Policy statement to be established within 2 years	Report on PPP in palliative care by 2 years	
	iii. Allied healthcare professionals/volunteers from NGOs/private hospitals to provide supportive services to patients in hospital palliative care unit (e.g. music therapy, massage therapy, spiritual care etc)	Ongoing		

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
2. To ensure palliative care approach is practice across at all level of hospital services (including those without those without specialized palliative care service)	**a) All healthcare professional to practice the palliative care approach** i. Ensure adequate training of the following: • Identify who needs palliative care • Management of palliative care • Communication in palliative care • Refer when needed	Ongoing activity over the next 5 years.	Every state with palliative medicine specialists to organize training in at least 2 minor/ non specialist hospitals per year Number of training conducted in minor/non specialist hospitals per year	Medical Development Division, MOH State Health Department, MOH Hospital Directors Academy of medicine

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	ii. Develop tools to improve identification of patient who needs palliative care: - • Surprise question • Palliative care needs screening tool (e.g. To use SPICT as an assessment tool, and paediatric palliative screening scale PAPAS), • Campaign / training module for the utilization of tools by healthcare provider • Train the trainers	To establish a concept similar to pain as the 5th vital sign & pain free program		
	iii. Develop guideline and revise existing guideline in clinical management of palliative care. For example: - • Cancer pain CPG • Handbook of Palliative Care • A Quick Reference guide for End of Life Care (EOLC)	Revise CPG and handbook within next 3 years Revise Handbook of Palliative Care within 2 years		
	iv. Improve communication skill in palliative care through activities as below: - • Organize regular workshop • Develop guidelines for clear documentation of Goals of Care • Create awareness for Advance Care Planning	To start standardized ACP training in next 2 years.	Number of ACP workshops conducted per year.	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	v. Improve referring system for palliative care • Establish a network of referral system with specialized palliative care unit (from state or major hospitals) • Prepare guidelines to assist in identifying patients for referral	Within 6 months of established specialized palliative care service	Referral guideline to be established	
	b) Leverage on hospital accreditation as a means to increase the palliative care approach i. Engage MSQH to establish the palliative care approach as part of its standards	2 years	Palliative care approach in the revised standards	MSQH Medical Development Division, MOH MMC CKAPS BPL
	ii. To organize Palliative Care Awareness Month to enhance awareness among patient, relative and healthcare staff	Ongoing	At least once a year in every state	
	iii. Encourage private centres to send nurses for training (e.g. ADPC)	Ongoing	Increasing number of private centres sending nurses to ADPC	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	c) Develop palliative care services in minor specialist and non-specialist KKM hospitals i. Harmonise services among these hospitals • Mapping exercise of palliative care service • Create guidelines and standards for providing palliative care • Establish KPIs	Mapping exercise within a year Establish guidelines and KPIs within 2 years	Report on mapping exercise Guideline to be established and rolled out	
	ii. Engage Hospital Directors and establish a plan of development • Establish operational budget • Operational policies	Within 6 months of starting service	Number of hospitals with minimal standards of palliative care service	
	iii. Identify and train Healthcare professional to function as liaison officers (doctors, nurses) • Develop a short course certificate training - 6 weeks (procedure, equipment, opioid usage, communication skills)	2 years		
	iv. Establish a visiting specialist clinics and ward rounds – by specialist from state or major hospital	From the beginning of service		

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	v. Ensure medication and consumables availability – to be supported by major / state hospitals • Essential medication list • Consumable list • Operational budget	1 month before service begins	90% of essential medications should be available	
	vi. Ensure basic equipment needed for palliative care is available (eg. Syringe drivers, oxygen concentrator, commode, etc	Within 1 year of service	Number of basic equipment obtained	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
3. Establishing minimal standard of palliative care in private hospitals and other institutions	**a) To ensure palliative care is provided in private hospitals**			APHM MSQH JCI MHC MMA APHM
	i. Palliative Care Accreditation for private hospitals • either local or international accreditation • to ensure minimum standards	Target all private cancer centres in next 5 years	Percentage of private cancer centres with palliative care service	
	ii. Availability of essential palliative medication • Survey of medications availability during hospital accreditation • Stock and ensure availability of medications according to the Essential Palliative Medication List	3 years	Percentage of private hospitals with essential medications	
	iii. To increase awareness of referral system to specialized palliative care services, hospices or community palliative care services	3 years	Percentage of private hospitals referring to community palliative care services.	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	b) Providing Palliative care education to private practitioners i. To promote palliative care CME throughout the country to private practitioners through CPD points	2 years	Number of CMEs conducted	
	c) To ensure minimal standard of palliative care for stand-alone hospices • CME for staffs • Evaluation for standards of care with basic KPIs • Essential medications to be available • Network with hospital palliative care service for assistance	Standards to be developed under PHFSA in 3 years		Medical Practice Division, MOH
	d) To ensure minimum standard of palliative care for nursing homes i. To set standards of care for nursing home providing palliative care service - equipment - staff qualification and training ii. Provide teaching, guidance and certification			Medical Practice Division, MOH MHC

Table 6b. Community Based Palliative Care

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
1. Nationwide development and strengthening of Domiciliary Palliative Care (DPC) programme	Extension of DPC programme to all states in phases in states with Palliative Medicine Specialist and Family Medicine Specialist (FMS) with palliative care training	Ongoing Selangor 2017 - ongoing Kedah 2017 - ongoing Pulau Pinang and Perak 2019 – ongoing Negeri Sembilan 2021 Sabah, Sarawak, Melaka, Johor 2022 Other states will follow	Number of health clinics implementing domiciliary palliative care services	Family Health Development Division, MOH (BPKK) State Health Department (JKN) and District Health Office (PKD)
	Identify and train specialist to be posted to each state for extension of DPC programme	Ongoing – 10 to15 years	Number of palliative medicine specialist in all state hospital	Medical Development Division, MOH Training Management Division, MOH

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Establish dedicated Domiciliary Palliative Care team under Domiciliary Palliative Care Programme	5 years	Number of dedicated DPC teams developed over next 5 years	Family Health Development Division, MOH (BPKK) Public Service Department, Malaysia (JPA) Human Resource Division, MOH
	Create operating procedure and standard referral work processes to access DPC	1 year	Audit of referral work process	Family Health Development Division, MOH (BPKK)
	Increase identification of patient needing palliative care in community using SPICT tool as a standard tool for patient identification. (Table 2b)	Ongoing	Number of patients identified in community and absorbed into DPC programme	Family Health Development Division, MOH (BPKK) State Health Department (JKN) and District Health Office (PKD)

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Recommendation for Essential Package for Palliative Care for Primary Health Care (Table 2c) to be included in standard operating procedure document for DPC	1 year	Number of centres with essential package available	Family Health Development Division, MOH (BPKK) State Health Department (JKN) and District Health Office (PKD) Pharmaceutical Services Programme, MOH
	Availability of Essential Package for running DPC in health clinic with DHC including medicines and minimum equipments	5 years	Percentage of essential equipment available at DPC services	Family Health Development Division, MOH (BPKK) State Health Department (JKN) and District Health Office (PKD)

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
				Pharmaceutical Services Programme, MOH Medicines Subcommittee
	Continuous Education and Training Programme			
	1. Scheduled standard education and training programme for DPC teams • Identify patients needing palliative care using SPICT Tool (Table 2b) • Patient assessment • Management • Communication	Ongoing	Number of DPC team trained At least yearly educational session	BPKK JKN, PKD Organized by BPKK and JKN for respective state
	2. Individual attachment of DPC team with state PCU/ Palliative Care Physician following education and training session to strengthen new skills	3 years	Within one year for every new team developed	
	3. Project ECHO training for DPC from urban and rural areas	3 years	Number of DPC teams utilizing ECHO project for case discussion	MHC BPKK, JKN, PKD

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Clinical Support for DPC			
	1. Outreach community visits by state PCU/ Palliative Care Physician to support DPC team and aid complex cases management	1 year	At least once a year upon each new DPC team development and as needed until team matures	Family Health Development Division, MOH (BPKK) State Health Department (JKN) and District Health Office (PKD)
	2. Regular meeting coordinated at state level to discuss clinical and administrative issues	1 year	Once a year	Family Health Development Division, MOH (BPKK) State Health Department (JKN) and District Health Office (PKD)
	Monitoring system and data collection to estimate burden of care and monitor standards of care delivery	1 year	Audit of data collection	BPKK JKN and PKD

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Increase trained human resource including nurses, doctors, pharmacists and other allied health professionals dedicated to home care alone	10 years	Number of dedicated DPC team in health clinics with specialized services	Family Health Development Division, MOH (BPKK) Public Service Department, Malaysia (JPA) Training Management Division, MOH (BPL)
	Established training pathway for palliative medicine subspecialty training in primary care for Family Medicine Specialist (FMS)			
	Identification nurses for ADPC training and posting back to community to lead DPC team			
2. Enhancement and coordination of existing NGO hospices services in collaboration with the public sector	Coordinate services among NGO Hospice and DPC • Mapping exercise to avoid duplication of services in states with both services	Ongoing	Report on mapping exercise	Family Health Development Division, MOH (BPKK) MHC
	Establish a work process on standard workflow for referrals between NGO hospice and DPC	1 year	Report on standard workflow published in Guidelines on DPC Service	BPKK MHC

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Continuous Education Opportunities Endorsed coordinated training attachments opportunities for DPC • DPC teams training attachment with NGO Hospice	ongoing	Number of training attachments conducted	BPKK MHC JKN PKD
	Accessible standard education and training module including Project ECHO training	3 years	Number of participants of ECHO project from community services	MHC Education subcommittee
	Setting of minimum clinical standard for operation and clinical services to guide NGOs Hospice registration with Private Medical Practice Control Section, MOH (CKAPS)	3 years	Percentage of NGO services registered with CKAPS	Palliative Care National Technical Group Medical Practice Division, MOH Medical Development Division, MOH MHC

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Increase medicines access and availability through public-private partnership	3 years	Number of services with access to essential medications	Pharmaceutical Services Programme, MOH Medicines subcommittee MHC
	Availability of essential equipments for community service	3 years	Number of equipments available in community services	NGOs/ MHC JKN PKD
	Enhancing coordination DPC and NGO Hospices through regular meetings	3 years	Number of meetings conducted annually	JKN/ PKD NGOs

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Registration of NGO Hospices with Private Medical Practice Control Section (CKAPS) under the Medical Practice Division, MOH to enhance public-private partnership	5 years	NGOs under Malaysian Hospice Council (MHC) registered with Private Medical Practice Control Section (CKAPS), Medical Practice Division, MOH	MHC Private Medical Practice Control Section (CKAPS), Medical Practice Division, MOH
	Development of outcome measures to monitor care delivery	5 years	Standard outcome measurement tool and yearly audit	BPKK MHC Education Subcommittee

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Technical support for NGOs – Palliative Medicine Specialist consult and allied health services from public sector	10 years	Government-endorsed work processes initiated by MHC. This is to allow specialist and allied health professionals to provide service (maximum one day per week) during working hours as part of public private partnership	MOH/ MHC
	Recognition of community palliative care providers - octors, nurses and allied health professionals	10 years	Creation of credentialing and privileging pathway	MOH/MHC

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
3. Establishing a comprehensive network of services linking patients from hospital to community utilizing private general practitioner, NGO hospice, and public community providers	Training private general practitioners to participate in community palliative care provision. • Identify patients needing palliative care using SPICT Tool • Basic patient assessment • Communication • Referrals for continuation of care	5 years	Number of general practitioner clinics registered to provide palliative care service	MHC Medical Practice Division, MOH Family Health Development Division, MOH (BPKK) Medical Development Division, MOH MMA
	Accessible standard education and training module including Project ECHO training	3 years	Number of private general practitioners or clinics undergone training	MHC

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Registration of private general practitioners with basic training through online registry under MHC website	5 years		MHC Medical Practice Division, MOH MMA MOH
	Referral system linking patient to DPC or NGOs	1 year	Number of hospitals engaging community palliative care services regularly	BPKK Local NGO/MHC
	Availability of network to link the hospital to health clinics and vice versa	10-15 years	Establishment of electronic medical record (TPC-OCHIS) in health clinics running the DHC/DPC	BPKK

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Recommendation for registry of palliative care patient in both government and non-governmental sectors including private practice	10-15 years	Availability of registry for palliative patient in both sector	MHC MOH National Palliative Care Association Private providers MAMPU

Table 2c: Paediatric Palliative Care

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
1. Each state hospital should have Paediatric Palliative Care (PPC) Service	**a) Integrate PPC as part of enhancement of paediatric service** i. Develop policy for the formation of either • Specialist (full time) PPC service • Generalist (part-time) PPC service	1 year after policy is implemented	Service provided 1. Specialist PPC Service (>50% working hours) - Inpatient consultation (with admission right) - Outpatient clinic (minimum twice per week) - Complex symptom care - Advance Care Planning - Transition Care & Home Visit - As regional training centre and supporting generalist PPC service in the same region - Multidisciplinary services - Office hours phone service - Minimum staff: one nurse, one medical officer (MO), one paediatrician with at least one year PPC training and at least one nurse attained Advance Diploma in Palliative Care	Medical Development Division, MOH Human Resource Unit, MOH Nursing Division, MOH All state Health Director All Directors of state Hospitals All Paediatric Head of Department (HOD)

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
			2. Generalist PPC (<50% working hours) - Rotation by general paediatrician every 6 months - Inpatient consultation (at least 3 hours per week) - Outpatient clinic (minimum once a week) - Symptom care (at least pain management) - minimum staff: one nurse, one medical officer, one paediatrician with at least attended two days paediatric palliative care workshop in the 6 months rotation	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
2. Ensure all health care workers have the correct concept of PPC (PPC approach) for all the state hospitals	a) Provide pathway for those paediatrician who want to be trained as Paediatric Palliative Care Specialist in total three years full time PPC experience			Medical Development Division, MOH Human Resource Unit, MOH All state Health Director All Directors of state Hospitals All Paediatric Head of Department (HOD)
	i. Allow to have PPC training for at least one year under subspecialty of "General Paediatric and Child Health"	Immediately	At least allow one applicant to go through this pathway every year	
	ii. Allow to apply for unpaid leave for at least one year for those who obtained overseas paid jobs for PPC			
	iii. Allow to do at least one year training PPC work under the direct supervision of either adult palliative care specialist or paediatric palliative care specialist in the same hospital			

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	b) Provide PPC education for General Paediatrician			All Paediatric Head of Department (HOD) All state Health Director
	i. Road show of PPC workshop for paediatrician (Three Regional workshop) • KL/Penang (West Malaysia region) • Kelantan (East Coast region) • Sabah/Sarawak (East Malaysia region)	At least one PPC workshop for each 6 month rotation of service in-charge paediatrician	Essential Topics of Workshop - Concept of PPC - Pain assessment and management - Compassion - Communication - End of life Care	
	ii. Clinical attachment opportunity to those hospitals with PPC services, especially for those paediatrician taking care of PICU, NICU, oncology and neurology patients (Three Regional centre) • KL/Penang (West Malaysia) • Kelantan (East Cost) • Sabah/Sarawak (East Malaysia)	Minimum one week clinical attachment	Essential skills in Clinical attachment - Introduction of PPC to patients and parents - Skills in pain assessment & - Management - Communication skills	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	c) Provide PPC education for paediatric Medical Officer (MO) and House Office (HO)			All Paediatric HOD
	i. MO undergoing training to be Paediatrician	To see PPC patients together with PPC team in any of their training posting	In the end of each posting, the MO should be able to discuss each PPC patients in term of - Concept of PPC - Symptom management - Family supports	All the Paediatricians involved in Mo's training
	ii. Working MO in a hospital with PPC service	Minimum 2 weeks to 1 month clinical attachment with PPC team	In the end of three months PPC posting, the medical officer should be able to do - Introduce PPC to patient and parents - Pain and basic symptom assessment and management -Home visit - Compassionate communication - End of life Care	
	iii. To come out with handbook of Paediatric Palliative Care for medical officer, house officer, nurses and allied health staffs	2 years		

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	d) Provide education for paediatric nurses and allied health staffs			All Paediatric Matron and sister in-charge of each paediatric wards and allied health staffs involved in PPC
	i. To provide training programme for each PPC liaison nurse from each ward and allied health staffs involved in PPC	Minimum one day PPC workshop for each liaison nurse and allied health staffs	The core clinical knowledge and skills of PPC liaison nurses and allied health staffs 1. Concept of PPC 2. Pain assessment 3. Feeding and bedsore prevention for bed bound patients 4. Airway clearance for patient with respiratory problems 5. Compassion 6. communication skills	
	ii. To come out with handbook of Paediatric Palliative Care for doctors, nurses and allied health staffs	2 years		
	e) Curriculum revamp at the medical school (Medical students) clinical training in hospital			
	i. PPC Theory in lecture ii. Clinical case discussion about paediatric patient with palliative care needs	Minimum 2 PPC theory in lecture and one clinical case discussion during 5 years medical posting	1. Understands the concept of PPC in children 2. Understands assessment of pain and use of appropriate measurement 3. Understands multidisciplinary team approach	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
3. To utilise the available resources to start PPC services while continue to develop new resources	**a) To prepare an essential medication list and drug dosage reference**			All Hospital Director
	i. To purchase the medication through department /hospital operational budget, except medication under KPK list (as per discussion with Paediatric HOD)	6 month after started PPC service in the respective hospital	Availability of all the drugs within the essential medication list (based on WHO essential palliative medicine list)	All Paediatric HOD
	b) Establish a national policy on parenteral medicines usage for children terminal care at home or hospice			PPC Task Force Committee, National Palliative Strategy committee, Pharmacy Board of MOH
	i. Establishment of national policy and SOP for parenteral medicines usage for children terminal care at home or hospice, in line with adult palliative care guideline	2 years	A national policy and guideline on home and hospice parenteral medicine usage	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	c) Identifying a key pharmacist for PPC in each regional training center			Pharmacy Board of MOH
	i. Assist and collaborate in the establishment of medicine availability issue and training in regional PPC training centre	1 year	Availability of key pharmacist in each regional PPC training centre	
	d) To engage Non-Government Organization (NGO) in supporting PPC services (Public Private Partnership)			NGO Hospital Director Paediatric HOD
	i. To engage NGO to support PPC service in Hospital	To engage NGO support within one year of started PPC service	NGO play the role in - Financial support for employment of PPC staffs including nurses and allied health staffs (e.g. art and music therapist) - Cooperation in the budget for volunteers training and service providing - Budget for psychosocial support programmes e.g. Outing activities	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
4. To Ensure Standard of Quality of Service in Hospital	**a) Each PPC service should provide the standard operational policy (SOP) of PPC within the hospital**			Paediatric HOD Lead Paediatrician
	i. The lead paediatrician should determine the scope of service and SOP, based on respective resource and setting	The SOP should be implemented within 6 months of PPC service started	SOP available within 6 months of service started	
	b) Develop indicators and standards for monitoring of hospital based palliative care services and ongoing research/data collection			
	i. Indicators of physical, psychosocial or spiritual care (e.g. review patient within 24 hours of referral; patient and parent's satisfaction)	Develop indicators and standards within two years after service started		

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	ii. The regular audit of the indicators	Regular audit/ data collection yearly after indicators decided		
5. Network for holistic and seamless palliative care (transition between hospital and community)	**a) Referral system** i. Establish a network of referral system within hospital, inter-hospital and between hospital and community health services (eg. Government/Private health clinic and hospital including NGO hospice)	To have SOP of referral system within each hospital To form national and local service directories of hospital and community services	Established a referral system and directories information (mapping) nationally by year 2022 and locally within 2 years of service started Establish referral guideline from hospital and community in each state	PPC National Task Force Committee Lead Paediatrician (local hospital) Lead community coordinator each state (FMS)

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	b) **Symptom Care Planning (SCP) and Advance Care Planning (ACP) as part of transition communication with the local community PPC services**			PPC National Task Force Committee HOD Paediatric Lead Paediatrician
	i. Establish national format of SCP and ACP	National format of SCP and ACP by 2021	Established national and local SCP and ACP	Lead of each local community PPC service
	ii. Establish individualized local hospital and community SCP and ACP	Local hospital and community SCP and ACP within 2 years of hospital PPC service established.		

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
6. To establish Paediatric Palliative Care (PPC) service in the community	**a) Development of policy and committee for PPC Service in the community**			Medical Development Division, MOH (BPP)
	i. MOH policy to engage community participation in patient care	1 year within implementation of policy (state level)	Policy available and distributed to community PKD, KK	Family Health Development Division, MOH (BPKK)
	ii. Formation of committee at state level to oversee development of PPC which consist of: • Hospital PPC Paediatrician • Family medicine specialist • Health Clinic Medical Officer Health Clinic Staff and Community Nurse / Medical assistant officer • Community allied health staffs		Formation of Technical Committee at state level and district level Multidisciplinary team present 50% Key worker (in the coordinating health clinic)	PPC Taskforce JKN PKD NGOs palliative care providers The Royal Police Malaysia

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	b) To improve identification of children with palliative care needs in the community and referral pathway			Referring hospital Health Clinic (KK)
	i. To establish tools to identify children with palliative care needs • Directory of life-limiting conditions (Hain and Devins, Cardiff, 2011) • 4 categories of children with palliative care need (TSL, UK) • Paediatric Palliative Screening Scale (PaPaS)	2 years	Tool utilization and referral letters available in 60% of the health facilities. Referral pathway from hospital to different community supports (appendix)	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	c) Education and training for paediatric palliative care providers in government health clinics			Hospital with PPC provider State lead coordinator JKN PKD KK
	i. Pop-up and on time training organized and coordinated by lead coordinator each state	1-5 years	Training session available whenever the need arises	
	ii. Establish a standardized training module for community paediatric care	1-5years	Standardized Teaching Module involved • Family medicine specialist • Medical officer • Nurses • Allied health care worker	
	d) Adequate resources needed to develop paediatric palliative care			Hospital with PPC provider Community paediatric palliative care NGOs providers
	i. To generate a minimum equipment needed specifically for paediatric palliative care in community • Nebulized machine • Milk infusion pump	1-5 years	Minimum equipment available in 50% of PPCT Coordinating Centre	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	e) Establish respite care service in the community to support family with children with chronic complex illnesses			Community paediatric palliative care NGOs providers Parental support groups Malaysian Association of Paediatric Palliative Care (MAPPAC)
	i. Develop a system and training programme for respite care	1 - 2 years	Respite care training programme available	
	ii. Approach NGOs to conduct a respite care training programme among volunteer	3-5 years	Respite care training conducted together with NGOs	
	iii. Establish the respite care service SOP in community	3-5 years	Respite care service and network available in 50% of coordinating centre	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	f) Establish collaboration with hospices or NGOs for paediatric palliative care in community			Community paediatric palliative care and NGOs providers Malaysia Hospice Council (MHC) MyPPC MAPPAC Parental support group
	i. Enlist their interest and collaboration towards working for children with palliative care need	1-5 years	80% of the existing hospices providing paediatric palliative care service.	
	ii. Listing their organization name under MyPPC (PPC subcommittee of Malaysian Association of Paediatric), MHC and MAPPC website		Participation of hospice PPC provider in yearly PPC workshop	
	iii. Conjoint training programme with Malaysian Hospice Council (MHC), MyPPC and MAPPAC for PPC training programme for hospices		Improve quality of care to children with palliative care needs and their family, in term of social, equipment, manpower and training	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	g) Standard care based on research/data in community and hospitals			Working with research subcommittee PPC Task Force
	i. National data/registry on paediatric palliative care in hospitals and communities in Malaysia (Partnership with Adult Palliative Care Teams)	1-5 years	National data on PPC available	Hospital PPC providers PKD /KK/Hospice
	h) Facilitate home death among children with palliative care need			PPC Community subcommittee Task Force
	i. Establish a national and regional policy of home death registration with Forensic Pathologists, police and Emergency department (ED) physician	1 – 2 years	Work process identified and formulated in a standard national and regional policy	Forensic pathologist ED physician The Royal Malaysia Police

Table 2d: Education in palliative care

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
1. Establishment of curriculum/ education development teams and resources	**a) Stakeholder engagement** Liaising with stakeholders for curriculum development and accreditation/enforcing bodies to get agreement on developing a national programme for palliative care at: - Undergraduate level - Postgraduate level	2019 - 2021	Establishment of a Joint Training Committee	Ministry of Health Ministry of Education Private universities Nursing College Malaysian Medical Council Malaysian Hospice Council
	b) Core content development Formation of working groups within each specialty discipline to develop materials building on existing international curricula and tailored to Malaysian priorities - Basic - Intermediate *Refer Annex 3 for suggested core competencies and hours of training	2019 – 2024 Basic piloted and reviewed by 2022	Completion of training core content materials with implementation plans for delivery 3 medical/Nursing/ allied health professionals	Palliative medicines specialists Palliative care nurses ADPC trained allied health professionals

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	for level 1 and level 2 as recommended by WHO	Intermediate piloted and reviewed by 2024	(AHP) institutions to pilot 100 doctors trained by 2024 100 AHPs completed ADPC by 2024	Palliative medicines specialists Palliative care nurses ADPC trained allied health professionals Academic staff from universities engaged in undergraduate MOE MOH MHC Hospis Malaysia BPL
	- Specialist Review and update sub-specialty training programme. Aspects include • Clear entry criteria process and exit interview • Formal trainees' orientation • Criteria for accreditation of centres • Supervisors training • Review of subspecialty training curriculum • Establish trainees in difficulty pathways • Online submission of trainees' assessment forms	Ongoing – 2020 (to be reviewed and updated every 5 years)	Draft to be reviewed and approved by national subspecialty committee and external reviewers Training of trainers for subspecialty supervisors	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
2. Formation of educational hubs in 6 regions across Malaysia	**a) Formal taught programme for personnel who are tasked to deliver palliative care at hospital and community level and personnel with special interest in enhancing palliative care skills at hospital and community** i. Centralized and coordinated training programmes for post graduate medical professionals in each states and regions ii. Training programmes need to be coupled with clinical guidance and supervision either by clinical attachment, site visit, teleconferencing or phone call support	Formation of Central Hub 2019 – 2020 Formation of Northern Hub 2021 – 2022 Formation of Southern Hub 2022 – 2023 Formation of East Malaysia Hub 2022 – 2023 Formation of East Coast Hub 2023 – 2025 (or when there is availability of palliative care specialists)	Establishment of core key personnel and organizations within regional hubs for planning and organization of training. All regional hubs conduct regular biannual meeting to plan for education programme.	Medical Development Division, MOH Family Health Development Division, MOH NGO Hospices MOE State Palliative Medicine Specialists

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
3. **Implementation of training programmes**	a) **Accreditation of training centres and trainers/ supervisors**			All Palliative Medicine Providers in MOH, MOE, community, MMC
	i. Establish a National Palliative Care Association to accreditate training centres and trainers	2025	Formation of National Palliative Care Association	
	b) **Innovative training methods**			MHC Education subcommittee MOE MOH
	i. Utilizing ECHO system to support palliative care providers in health clinic, hospitals without palliative care specialists and district hospital for learning and training purposes	2019 – 2020 Training of facilitators (Immersion Programme) 2020 – Pilot project of ECHO training programme among palliative care providers in Domiciliary Care Services and MHC	ECHO system is included as a formal means for education delivery	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	c) Online training module linked with MMC CPD points system			MOH MHC
	i. Online learning CME for private GPs, practitioners in private hospitals in identification of patients with palliative care needs and the access of specialist palliative care services	2021	Availability of the described online learning programme	Education subcommittee National Palliative Care Association
	ii. Online learning modules – 10 modules that includes core competencies listed in Annex 3 to complement face to face learning programme	2030 (10 years)	Availability of the described online learning programme	MMC
	iii. Compilation of useful resources websites for education	2025 – 2030 (5 – 10 years) Establishment of a host portal (MHC websites/ National Palliative Care Association)	Availability of link to such websites	MHC

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
4. Establishing Workforce policy	**a) National credentialing system to credential skilled palliative care providers in hospitals, primary care and community**			Training Management Division Competency Development Division
	i. Credentialing of trained doctors, nurses, pharmacists, physiotherapists and occupational therapist	2020 – 2025	Credentialing of all nurses. Physiotherapist and occupational therapist that have completed APDC	Family Health Development Division, MOH Medical Development Division, MOH Nursing Division, MOH
	ii. Credentialing of doctors that have completed basic or intermediate palliative care training with substantial hands on experience via attachment and supervision by palliative medicine specialist in both public and private sectors	2020 - 2030	Formation of Credentialing Body in government and private including NGOs Establish formal credentialing pathway and process	Allied Health Sciences Division, MOH Pharmaceutical Services Programme, MOH Education Subcommittee National Palliative Care Association

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	b) Registry of trained personnel i. Formation of a registry of trained personnel/ tracking (with consent) by discipline	2019 - 2024	Registry to include personnel from all states by 2024	MHC MOH Education Subcommittee National Palliative Care Association
	c) Ensuring palliative care trained personnel are deployed strategically to develop palliative care in the country i. Sharing of human resources across palliative care community in the country – Hospital based palliative medicine specialists and credentialed nurses to be able to work in the community e.g. Domiciliary services and NGOs ii. Ensure trained and skilled palliative care providers are able to work in area with high palliative care needs and development interest	10 years	Process and pathway of sharing human resources is made available More than 80% of ADPC graduates are retained and transferred to palliative care units in hospitals or palliative domiciliary programme credentialed	National Head of Service Palliative Care, MOH Medical Development Division, MOH Nursing Division, MOH Training Management Division Competency Development Division National Subspecialty Committee MHC HM

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
5. Increasing public awareness and training compassionate communities	**a) Supportive Government toward public palliative literacy and awareness programme**			Health Education Division MHC Hosp Malaysia
	i. Government to endorse public advocacy campaign and project that are NGOs initiated	10 years	Public Health healthcare provider's involvement with palliative portfolio assigned to the head of service. Annual meeting between NGOs and Public Health healthcare provider to plan and review public advocacy projects	

Table 2e: Access to essential medicines in palliative care

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
1. Make essential medicines in palliative care universally available and accessible	Within the NEML, designate essential medicines in palliative care as ‘’universal’ to encourage the availability of these medicines at all healthcare facilities.	1 year	Updated NEML list reflect palliative care needs	Pharmaceutical Services Programme, MOH
	Track the availability of essential medicines in palliative care from private and public health care facilities	3 years	List of hospitals with essential medicines in palliative care available	Public – MOH Private - Association of Private Hospitals Malaysia (APHM)
	Ensure centers identified as palliative care hubs have palliative medicines available in adequate quantities, and can serve as distribution center if needed	3 years	Every state with palliative care hub equipped with adequate supply of medicines, and an efficient distribution system.	Pharmaceutical Services Programme, MOH
	Develop a national palliative medicine protocol that guides the use of palliative medicines based on evidence and best practices	5 years	National palliative medicine protocol	National Palliative Care Working Group

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
2. Optimize oral morphine formulation	Evaluation of current trend of oral immediate-release morphine utilization	6 months	Report of morphine syrup utilization over 3 year within MOH available	Pharmaceutical Services Programme, MOH
	Optimizing and standardizing current compounding formulation with the aims of prolonging shelf life	1-5 years	Recommended formula available for use locally	MOH in collaboration with School of Pharmaceutical Sciences, USM
	Identify and develop alternative and sustainable methods of locally manufactured oral immediate-release morphine	5-10 years	Availability of locally produced and affordable morphine	Pharmaceutical Services Programme, MOH Health Technology Assessment Section, MOH Pharmaceutical Industry
3. Develop supportive legislation and policy	Development of Memorandum of Understanding (MoU) between community palliative care providers and MOH to enable better provision of medications to patient in need	5-10 years	MoU available	MOH & hospices

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
	Develop terminal discharge policies that guides the safe use of parenteral medicines in the community	3 years	MOH endorsed terminal discharge policies	Palliative Care Hospital Selayang/ Hospital & Community Subcommittees
	Remove restrictions on basic palliative care medicines for non-citizens	3 years	Exemptions allowed for palliative care in the policy pertaining to outpatient medicine prescription for non-citizens	Pharmaceutical Services Programme, MOH Division of Finance, MOH
	Develop mechanisms for price control of essential medicines in palliative care	5 years	Price control mechanism	Pharmaceutical Services Programme, MOH Ministry of Domestic Trade and Consumer Affairs (KPDNHEP)

Table 2f: Research and Standards in Palliative Care

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
1. Ensure minimum standards for palliative care providers according to levels of service	Review current standards available	End 2019	Summary table of standards reviewed	Research subcommittee
	Deciding standards applicable to Malaysian palliative care services	End 2020	Publication of Malaysian standards for palliative care	Standards subcommittee (relevant stakeholders including patient and carer representatives) 1. Working committee - to prepare draft of standards which are evidence based 2. Reviewing committee – to review and advise changes
	Implementation of standards	Early 2021	1. Availability of standards monitoring system 2. Produce regular audit report of Malaysian palliative care service according to the standards monitoring system	MOH MOE Hospice Malaysia (HM) MHC Private hospitals Nursing homes Patient and carer representatives
	Maintenance of standards	Continuous		

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
2. Engage healthcare workers and the general Malaysian population	Review methodology for national palliative care needs analysis	End 2019 (completed)	New palliative care needs analysis methodology	Research subcommittee
	Conduct 5 yearly national level population palliative care needs analysis	2019 (completed) 2025	5 yearly national palliative care needs analysis report – first report by end 2021	MaHTAS HM MOH
3. Identify a minimum set of palliative care outcome measures to be used across all palliative care settings to measure quality of care	Review evidence for palliative care outcome measures	End 2020	1. A summary table of palliative care outcomes reviewed 2. A palliative care outcome measures dataset draft	King College London, University of Wales Research subcommittee
	Form focus groups to discuss and formulate a Malaysian set of palliative care outcome measures	5 years	Availability of palliative care outcomes measurement	MOH MOE Hospice Malaysia (HM) MHC Private hospitals Nursing homes Patient and carer representatives
	Measure palliative care outcomes according to monitoring system	10 years	Availability of palliative care outcomes monitoring system	

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
4. Develop a centralized resource of palliative care information for patients, carers and healthcare providers	Set up a centralized website to make available information, guidelines and standards of care for patients, carers and healthcare providers	Mid 2020	Website launch at MHC in 2020	HM, MHC, MOH, MOE
5. Support local researchers in the conduct of high-quality palliative care clinical research	Conduct training and education sessions pertaining to palliative care research	ongoing	2 training sessions per year	MOH, HM, MOE, MHC

Table 2g: Sustainable Funding

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
1. **Optimise government funding**	Increase operational budgets for development of new MOH hospital units and domiciliary programme	On going	Funding allocated for palliative care activities in MOH	Medical Development Division, MOH Family Health Development Division Finance Division, MOH MOF
	Increase efficiency by sharing resources between hospitals and domiciliary care teams (drugs and specialist expertise) and through task shifting.	On going		
	Provision of annual government grant to encourage participation of NGO in providing palliative care	5 years	Number of patients served by NGOs Amount of public funding raised by NGOs	
	Increase participation of private sector in training programmes such as Advanced Diploma in Palliative Care (ADPC) in order to generate revenue for the sustainable funding of programme.	On going	Number of private candidates in ADPC programme	BPL KSKB Ulu Kinta APHM

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
2. Create sources of alternative funding through partnerships with NGOs	Corporate social responsibility to assist with funding of : - Education activities - Donation of equipment - Donations towards infrastructure development	Within 1 year and continuously	Number of corporate donors contributing to palliative care	MHC Hospis Malaysia Corporate bodies Financial bodies
	Enhance and encourage development of NGO services utilising public funding / donations through tax-exemption	3 years		MOF LHDN MHC
	Support NGO by sharing resources from government sector allowing doctors and nurses to cross over and assist NGO services through smart partnerships		Service KPIs for NGOs	MHC Hospice NGOs MOH

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
3. **Development of National Hospice Palliative Care Foundation**	Create National Palliative Care foundation to create greater awareness and source funding from public and all over the nation and then to distribute for the provision of services including: - Essential equipment - Essential Medications - Development of palliative care units - Training programmes	5 years	Annual funding accumulated and disbursed	Legal advisors Financial advisors MHC MOH
4. **Create compassionate community programmes**	Develop programmes to train members of a community to care for the sick within their own community thereby utilising readily available resources at hardly any cost. Cost may include training sessions however as programme matures the community will take care of its own.	Pilot within 2 years	Number of compassionate communities developed.	MOH KOSPEN MHC Ministry of women, community and family development Local council

Goals	Activities	Implementation period	Outcome indicator	Collaboration/ Coordinating agencies
5. Regulate private healthcare charges for palliative care and essential medications	Discussions to set limits to the fee schedule for provision of private palliative care and the essential medications. Regulation of private nursing home rates and home nursing rates	5 years		MMA MOH Medical Practice Division MMC Insurance industry MOH Pharmaceutical Division
	Inclusion of palliative care into private health insurance benefit packages.	5-10 years		

Annex 7

WHO Definition of Palliative Care (2002)

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 patients 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.

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