LANCET COMMISSION ON GLOBAL ACCESS TO PALLIATIVE CARE AND PAIN RELIEF

BACKGROUND DOCUMENT

TECHNICAL NOTE AND DATA APPENDIX FOR REPORT

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1. Estimation of global burden of serious health-related suffering

We estimated the global burden of serious health-related suffering (SHS) by means of a deliberate process that entailed identification of the International Classification of Diseases, 10th edition (ICD-10) conditions that most often generate SHS, identification of the specific types of suffering associated with each condition, estimation of the duration of each type of suffering associated with each condition, estimation of the number of patients with each condition who experience each type of SHS associated with each condition, and calculation of the number of days of each type of SHS associated with each condition. Each step was informed by a literature search and reviewed by one of two panels of experts in clinical palliative care who work in low- and middle-income countries (LMICs). One panel provided feedback via in-person interviews, the other via an on-line Delphi process described in detail below and in section 7. All estimations, calculations and conclusions were reviewed and discussed by the Commissioners on multiple occasions. Section 4

1.1 Selection of 20 conditions that most often generate a need for PC

Our first step toward estimating SHS was to identify the health conditions from the ICD-10 that most commonly result both in death and in suffering severe enough to require palliation (**Table 1A**). The ICD-10 is a global classification system of health conditions that is endorsed by WHO and used to determine health trends and calculate global health statistics. We chose to work with the ICD-10 classification of health conditions because prevalence studies of associated symptoms most commonly use this classification. We recognized, however, that SHS also is common among patients who do not die in a given year, and that there is an ethical responsibility to prevent or relieve this suffering as well.

1.1.1 Selection Criteria

With this in mind, we developed the following criteria to refine the list of conditions that most often produce symptoms or other problems requiring palliative care:

- A major cause of death (according to WHO Global Health Estimates mortality data) that also typically causes SHS, or
- A common cause of SHS even if:
  - The patient's condition can be cured (drug-resistant tuberculosis, some hemorrhagic fevers such as Ebola, some malignancies, some inflammatory diseases of the central nervous system)
  - The patient can recover (serious injuries)
  - The patient may survive for a year or more with chronic severe disability (cerebrovascular disease, congenital malformations, injury, birth trauma)
  - The condition can be controlled for many years (HIV/AIDS, some musculoskeletal disorders) or may have a slowly progressive course over years (dementia, Parkinson's disease, multiple sclerosis)

The list was reviewed by a panel of 10 senior physicians chosen for their expertise and experience in providing palliative care in LMICs.

The recommended list of 20 conditions was finalized upon review by the Commissioners.

In the course of the deliberations among the panelists and the Commissioners, there was extensive discussion of several conditions including diabetes mellitus and conditions involving neonates. It was decided that deaths attributed to diabetes mellitus typically result from diabetic ketoacidosis or hyperglycemic hyperosmotic non-ketotic syndrome, both of which typically result in death so rapidly that there is no time to institute palliative care. On the other hand, deaths from sequelae of diabetes mellitus typically are attributed to the proximal cause. These include cerebrovascular disease, cardiomyopathy and heart failure, chronic ischemic heart disease, renal failure, and atherosclerosis. Therefore, diabetes mellitus was not included among the 20 conditions.

We did include on the list of conditions extremely premature and very low birth weight (VLBW) newborns whose survival is unlikely and babies born with severe hypoxic ischemic encephalopathy (HIE) or congenital anomalies not compatible with life. The Commission finds that efforts to assure the baby's comfort and to comfort distraught parents should accompany aggressive life-sustaining treatments if such treatments have a reasonable chance of providing more benefit than burden. Palliative care also must be available as an alternative to noxious life-sustaining treatment when a baby is moribund.

Table 1A. Health conditions from the International Classification of Diseases, 10th edition (ICD-10) that most commonly result both in death and in suffering severe enough to require intervention.

Table 1. ICD 10 conditions that most often generate a need for palliative care	
A96,98,99: Hemorrhagic fevers	
A15-19: TB / the 13% of deaths (190,000) from M/XDR TB (100% of those)	
A15-19: TB / the 80,000 with M/XDR TB on treatment who have not died (100% of those)	
A15-19: TB / the 87% (1.3 million) who died from TB that was NOT MDR (90% of those)	
B20-24: HIV disease / 100%	
C00-97: Malignant neoplasms (except C91-95)	
C00-97: Malignant neoplasms (except C91-95) Survivors	
C91-95: Leukemia	
F00-04: Dementia	
G00-09: Inflammatory dz of CNS	
G20-26; G30-32; G35-37; G40-41; G80-83 Extrapyramidal & mvt disorders; other degen dz of CNS; Demyelinating dz of CNS; Epilepsy; Cerebral palsy & other paralytic syndromes /	
I60-69: Cerebrovascular diseases	
I05-09; I25; I42 & I50: Chronic rheumatic heart diseases; Cardiomyopathy & Heart failure	
I25: Chronic ischemic heart disease	
J40-47; J60-70; J80-84; J95-99: Chronic lower respiratory dz; lung dz due to external agents; interstitial lung dz; other dz of resp system	
K70-77: Diseases of liver	
N17-19: Renal failure	
P07; P10-15: Low birth weight & prematurity; Birth trauma	
Q00-99: Congenital malformations	
S00-99; T00-98; V01-Y98: Injury, poisoning, external causes	
I70: Athrosclerosis	
M00-97: Musculoskeletal disorders	
E40-46: Malnutrition	

1.1.2 Mortality data for ICD-10 conditions

Health conditions that are major causes of death usually also generate a need for palliative care. Thus, mortality per condition is a useful starting point for estimating the burden of suffering and the need for palliative care. However, complete mortality data are not available for ICD-10 conditions. Therefore, we used the WHO Global Health Estimates,[1] which has complete data on mortality by health condition, to estimate burden of suffering by condition (WHO 2015). Because GHE conditions are not always identical to ICD-10 conditions, we used a conversion document from WHO to estimate as precisely as possible the number of deaths from each of the selected ICD-10 conditions from corresponding GHE categories (**Table 1B**). (WHO 2015) [2]

The analysis was originally done using the international mortality database from the World Health Organization: Global Health Estimates 2012. In early 2017, WHO released it's new mortality data base: Global Health Estimates 2015, and made major changes to the mortality data, taking into account more data sources from countries, regional and other UN agencies, and the Global Burden of Disease 2015 database from the Institute of Health Metrics and Evaluation. GHE 2015 took a much closer look at data sources such as death registries and regional studies from China, India, and a few other countries. It also reviewed more carefully mortality from a few conditions, including HIV, TB, cancer, and a few neglected tropical conditions, all of which are included in our analysis as major causes of SHS requiring palliative care or pain control. We thus updated our analysis using the new GHEdata base.

The GHE 2015 database radically revised the estimate of global deaths due to HIV and dementia. According to the WHO technical report on methodology of GHE 2015 dataset,[3] the reduction in the estimate of HIV deaths was mainly due to:

1) Extra effort to "ensure consistency of all cause and HIV mortality estimates across the period 2000-2015 in the 2016 revision of WHO life tables and all-cause mortality "envelopes"" in the 43 countries with high HIV prevalence rates, especially in South Africa;
2) Updated data from country death registries, with misclassification of HIV being accounted for using time series analysis of causes;
3) Updated data from UNAIDs estimated HIV/AIDs mortality.

The increase in the estimate of dementia mortality was mainly due to the assumption that in the previous GHE 2012 database, many deaths that were caused by "Alzheimer's disease and other dementias" were misclassified into "other neurological conditions." This caused inconsistency across countries in the percentage of "other neurological conditions" among all deaths coded to neurological causes for years 2000-2015. Thus, an adjustment was made based on a "regression of the log of the 'other neurological conditions' death rate against the log of the death rate for dementias, excess "other neurological" deaths above the predicted rate were shifted to the dementia category."[4]

Besides changes in the total numbers for a few conditions, there also were shifts in mortality estimates from specific causes within countries that did not alter significantly the total number

of death. Those changes are reflected in the results of the Avoidable Mortality calculation; see section 1.10 for details.

Table 1B. Conversion formula from GHE to ICD-10 codes

Table 1B. Conversion from GHE database to ICD-10 conditions

				Survivors			
	ICD 10 conditions that most often generate a need for pc	GHE category used	Multiplier	Non-decedents needing PC relative to decedents needing PC_updated	Non-decedents relative to GHE decedents	Non-decedents needing pc relative to total non-decedents	Multipler of PC needs for non-decedents relative to GHE decedents
1	A96,98,99: Hemorrhagic fevers	370: Other infectious disease	5%	100%			
2	A15-19: TB / deaths from M/XDR TB	30. TB-MDR (13% of all TB deaths)	100%		0.074000000	100%	
2b	A15-19: TB / deaths from TB that was NOT MDR	30. TB (non-MDR)	90%				
3	B20-24: HIV disease	100: HIV/AIDs	100%		29.75	50%	
4	C00-97: Malignant neoplasms (except C91-95)	610: Malignant Neoplasms (-77 Leukemia)	90%		2.06840982	28%	
					1.03420491	20%	
					0.517102455	15%	
					0.310261473	10%	
					0.206840982	5%	
5	C91-95: Leukemia	770 Leukemia	90%				
6	F00-04: Dementia	950 Alzheimer's Disease and other Deme	80%		62.96978973	10%	
7	G00-09: Inflammatory dz of CNS	50 syphilis	70%				
		150 measles	50%				
		160 tetanus	100%	50%			
		170 meningitis	30%				
		180 encephalitis	30%				
		230 Trypanosomiasis	100%				
		320 Rabies	90%				
8	Extrapyramidal & mvt disorders; other degen dz	960 Parkinson's disease	65%		53.19110209	10%	
		970 epilepsy	50%				
		98 multiple sclerosis	100%		121.0390715	2%	
		1010 other neurological conditions	65%				
9	I60-69: Cerebrovascular diseases	1140 Stroke	65%		3.869325547	15%	
10	diseases; Cardiomyopathy & Heart failure	1110 rheumatic heart disease	65%				
		1120 hypertensive heart disease	70%				
		1150 cardiomyopathy, myocarditis and endocarditis	40%				
		240 chagas disease	30%				
11	I25: Chronic ischemic heart disease	1130 ischemic heart disease	5%				
12	respiratory dz; lung dz due to external agents;	1180 COPD	80%				
		1200 other respiratory dz except asthma	50%				
13	K70-77: Diseases of liver	1230 cirrhosis of liver	95%				
		1250 other digestive disease	30%				
		250: schistosomiasis	70%				
14	N17-19: Renal failure	1271 Acute glomerulonephritis	45%				
		1273 Other chronic kidney disease	45%				
15	P07; P10-15: Low birth weight & prematurity; Birth trauma	500 preterm birth complications	75%				
		510 birth asphyxia and birth trauma	40%				
16	Q00-99: Congenital malformations	1400 Congenital anomalies	60%	100%			
17	S00-99; T00-98; V01-Y98: Injury, poisoning, exte	(1520 unintentional injuries + 1600 inten	30%	200%			
18	I70: Athrosclerosis	1160 other circulatory disease	35%				
19	M00-97: Musculoskeletal disorders	1340 musculoskeletal diseases	70%	200%			
20	Protein-Energy Malnutrition	550: Protein-energy malnutrition	100%				

Note: the multiplier is the percentage we applied to the total number of deaths in each condition to calculate the number of decedents who need palliative care:

Number of decedents who need palliative care = Number of total deaths * multiplier

1.1.3 Annual Number of decedents and non-decedents in need of PC

We estimated the percentage of patients who die from one of the 20 conditions during the focus year (2015) who have SHS that requires palliative care or pain control. We began with an extensive literature review on each of the conditions. Estimates produced from this review were then reviewed by the 10-member LMIC palliative care clinical expert panel described above, and the estimates were then adjusted based on consensus of the panel. We recognize that the percentages of patients with each condition who need palliative care or pain relief may vary by country income level. Thus, we estimated a global average.

Next, we estimated the need for palliative care by "non-decedents:" patients with SHS related to one of the 20 conditions who did not die in 2015. As noted above, patients with several conditions may not die but still may have SHS requiring palliative care or pain control:

- Conditions that may have been cured but from which SHS persists in some cases (drug-resistant tuberculosis, some hemorrhagic fevers such as Ebola, some malignancies, some inflammatory diseases of the central nervous system);
- Conditions from which patients recover but that caused SHS in some cases (serious injuries);
- Conditions with which patients survive for a year or more with chronic severe disability and with SHS in some cases (cerebrovascular disease, congenital malformations, injury, birth trauma);
- Conditions that are controlled for a year or more but with SHS in some cases (HIV/AIDS, some musculoskeletal disorders)
- Conditions that have a slowly progressive course over years associated in some cases with SHS (dementia, Parkinson's disease, multiple sclerosis)

We estimated the non-decedent need for palliative care and pain relief in the same way. Initial estimates based on a literature review were then reviewed by our 10-member LMIC palliative care clinical expert panel described above, and the estimates were adjusted based on panel consensus.

Our estimates of need for palliative care or pain control for each condition, and key relevant references, are as follows:

- **Hemorrhagic Fever:** Based on available data, we estimate that palliative care is needed by approximately the same number of patients who recover from the disease as those who die from it. [5, 6, 7, 8, 9]
- **Multi-drug resistant tuberculosis (MDR-TB):**
    - MDR-TB decedents: 100% of patients who die from MDR-TB require palliative care.[10,11,12] MDR-TB deaths were estimated to be about 13 % of total TB deaths (from GHE database), calculated from the 2015 Global TB report:[13] 190k/1.5m = 12.67%
    - MDR-TB patients on treatment: 100% of patients on MDR TB treatment require palliative care.[14,15] MDR-TB patients on treatment were estimated to number about 7% of total TB deaths (from GHE database), calculated from the 2015 Global TB report:[16] 111k/1.5m = 7.4%
    - Drug-susceptible TB decedents: PC is required in 90% of drug-susceptible TB deaths. Regular TB deaths were calculated using total TB deaths minus MDR-TB deaths a described above.

- **HIV/AIDS:**
    - Decedents: 100% of people who die from HIV/AIDs require palliative care.[17, 18, 19, 20, 21]
    - Non-decedents: We estimated that 50% of people living with HIV (PLHIV) (non-decedents in 2015) needed some type palliative care.[22, 23, 24, 25] PLHIV were

calculated by applying the survivor vs. deaths ratio generated from the UNAIDs 2015 report.[26] Data from 2014 show that there were 36.9 million people living with HIV/AIDS (PLHIV) in 2014 of whom 1.2 million died. Thus, the non-decedent to decedent ratio is (36.9-1.2)/1.2 = 29.75.

- Note: we did not exclude PLHIV on anti-retroviral therapy (ART) or those without confirmed diagnosis. As explained further in Section 2 of the report, those who are diagnosed, on ART or not, are living with a life-threatening and highly stigmatized condition, and various studies have shown a prevalence of reported pain of over 50% and other symptoms in this population.[27] Further, our panel felt it necessary to consider the often impoverished and vulnerable group of undiagnosed PLHIV, most of whom have not been diagnosed because of severe barriers to access health care and/or unwillingness due to stigma, yet still suffer and require PC in addition to their need for ART.

- **Malignant neoplasms (except leukemia):**
  - Decedents: 90% of patients who die from malignant neoplasms (except leukemia) require palliative care.[28, 29, 30, 31]
  - Non-decedents: According to IARC, there were 32.6 million people older than 15 who were alive with a cancer diagnosis within the previous 5 years in 2012.[32] Shi, et al.,[33] report that 28% of people who survive one year with cancer have a "high-symptom burden." We assumed that people with a high-symptom burden need palliative care. Zucca, et al.[34], report that few people who survive cancer for more than five years have symptoms that require palliative care unless they have a recurrence or another disease. We were unable to find data on the percentage of the 32.6 million non-decedents who survive 1, 2, 3, 4, and 5 years, nor on the need for palliative care at years 2, 3, 4, or 5. The International Agency for Research on Cancer (IARC) has data on survivorship from selected cancers in selected countries,[35] but in the absence of global data, we estimated the number of non-decedents by year since their cancer diagnosis and the percentage of these non-decedents who need palliative by year since cancer diagnosis (**Table 1C**).

Table 1C. Need for palliative care among cancer survivors (non-decedents) by year since diagnosis.

Years since cancer diagnosis	Number of non-decedents (% of 5-year total)	Estimated percentage of non-decedents in need of palliative care	Number of non-decedents in need of palliative care
1	16,300,000 (50%)	28%	4,564,000
2	8,150,000 (25%)	20%	1,630,000
3	4,075,000 (12.5%)	15%	611,250
4	2,445,000 (7.5%)	10%	244,500
5	1,630,000 (5%)	5%	81,150
TOTAL	32,600,000 (100%)		**7,130,900**

- **Leukemia:** 90% of patients who die from leukemia require palliative care.
  In general, the palliative care needs of people with leukemia are of shorter duration or lower intensity than those of people with solid tumors. An exception is some patients in HICs with chronic, difficult-to-control graft-versus-host disease. We took this globally unusual need into consideration when estimating the duration of need for palliative care among leukemia patients.

- **Dementia:**
  - **Decedent:** We estimate that approximately 80% of people who die from Alzheimer's disease or other dementias require palliative care in the year they die.[36,37,38,39,40]
  - **Non-decedent:** The data on the number of people living with dementia and the percentage of those with advanced or late dementia are from the World Alzheimer's Report 2014.[41] In 2014, approximately 44 million people who were living with dementia did not die of dementia (or of any other cause) in that year. Approximately 25% of these people had advanced or late dementia. Moens et al.[42] found that 40% of persons with advanced or late dementia had symptoms requiring palliative care (the need for psychological and social support for caregivers likely would yield a higher percentage of need for palliative care, but data on this need are lacking).

- **Inflammatory disease of central neural system:** 70% of patients who die from syphilis + 50% of patients who die from measles + 100% of patients who die from tetanus + survivors from tetanus (half as many as those who die of tetanus per year) + 30% of patients who die from meningitis + 30% of patients who die from encephalitis + 100% of patients who die of trypanosomiasis + 90% of patients who die from rabies.
  - **Survivors:** we estimate that for every two patients who die from tetanus and require palliative care, there will be one patient who survives tetanus that requires palliative care

- **Extrapyramidal & movement disorders; other degenerative disease of CNS; demyelinating disease of CNS; Epilepsy; Cerebral palsy & other paralytic syndromes.**
  - **Decedents:** 65% of patients who die from Parkinson's disease + 50% of patients who die from epilepsy + 100% of patients who die from multiple sclerosis + 65% of patients who die from other neurological conditions.[43,44,45,46,47,48,49,50,51,52,53,54,55]
  - **Non-decedents**

- **Parkinson's disease:** Advanced disease and the attendant distressing symptoms occur approximately nine years after symptoms first appear,[56] and we estimate conservatively that 25% of patients survive long enough to have advanced disease and do not die in a given year. Based on the work of Moens, et al.,[57] we estimate that 40% of these patients require palliative care. The number of people living with Parkinson's disease was calculated by applying a ratio of global survivors : deaths. The number of people living with Parkinson's disease is from the European Parkinson's Disease Association,[58] which estimates a global prevalence of Parkinson's Disease (PD) of 6.3 million. The ratio was generated from the total number of survivors of Parkinson's Disease globally and the deaths from the Global Health Estimates (GHE) mortality database (updated to 2015).
- **Multiple sclerosis (MS):** MS has a long prognosis and shortens life by only 0 – 6 years. Thus, we estimated that 5% of people with MS who do not die in a given year have end stage disease. Based on the work of Moens, et al.,[59] we estimated that 34% of these patients require palliative care. The number of people living with multiple sclerosis was calculated by applying the ratio of global survivors: deaths. The number of people living with multiple sclerosis is from the National Multiple Sclerosis Society which estimates a global prevalence of MS of 2.3 million.[60] The non-decedents to decedents ratio was then generated based on the global number of survivors and the total deaths from MS that came from GHE database (updated to 2015).

- **Cerebrovascular diseases:**
  - Decedents: 65% of people who die from stroke.[61,62,63,64,65,66,67,68,69]
  - Non-decedents: Approximately 15% of stroke survivors have severe disability, defined as a modified Rankin score of 4 or 5, and thus require palliative care.[70] The number of people living with stroke was calculated by applying a global survivors: deaths ratio. The number of people living with stroke is derived from the Institute for Health Metrics and Evaluation, which estimated that there were approximately 25.7 million stroke survivors in 2013.[71] The non-decedents to decedents ratio was then generated based on the global number of survivors and the total deaths from cerebrovascular diseases that came from the GHE database (updated to 2015).

- **Chronic rheumatic heart disease; Cardiomyopathy & heart failure:** 65% of patients who die from rheumatic heart disease + 70% of patients who die from hypertensive heart disease + 40% of patients who die from cardiomyopathy, myocarditis and endocarditis + 30% of patients who die from Chagas disease.[72,73,74,75,76,77,78]

- **Chronic ischemic heart disease:** 5% of patients who die from ischemic heart disease require palliative care.[79]

- **Chronic lower respiratory disease; lung disease due to external agents; interstitial lung disease; other disease of respiratory system:** 80% of patients who die from COPD + 50% of patients who die from other respiratory diseases except asthma.[80,81,82, 83]

- **Diseases of liver:** 95% of patients who die from cirrhosis of liver + 28% of patients who die from other digestive diseases.[84,85,86,87,88]

- **Renal failure:** 45% of patients who die from kidney disease.[89,90,91,92]

- **Low birth weight & prematurity; birth trauma:** 75% of patients who die from preterm birth complications + 40% of patients who die from birth asphyxia and birth trauma.[93,94,95,96, 97]

- **Congenital malformations/anomalies:**
    - Decedents: 60% of patients who die from congenital anomalies require palliative care.[98,99,100, 101]
    - Non-decedents: We could find no data on the prevalence or longevity of patients with severe congenital malformations. We estimated that, in a given year, at least the same number of patients who die of congenital malformations do not die but need palliative care.

- **Injury, poisoning, external causes:**
    - Decedents: 30% of patients who die from injuries (intentional and unintentional).[102,103] We reasoned that many patients die so quickly that there is no time to institute palliative care or pain control
    - Non-decedents: We estimated that, in a given year, at least twice the number of patients who die of injuries do not die yet need palliative care or pain control.

- **Atherosclerosis:** 35% of patients who die from other circulatory disease require palliative care.[104,105]

- **Musculoskeletal disorders:**
    - Decedents: 70% of patients who die from musculoskeletal diseases require palliative care.[106]
    - Non-decedents: We estimated that, in a given year, at least twice the number of patients who die of musculoskeletal disorders do not die yet need palliative care. We do not include in this category patients with mild pain or with symptoms that do not significantly disrupt social or occupational functioning.

- **Malnutrition:** 100% of deaths from protein-energy malnutrition.[107,108]

1.2 Major types of suffering experienced by patients who require palliative care

Having identified the 20 conditions that most often generate a need for palliative care or pain control, and having estimated the percentage of patients with each condition who require palliative care or pain control, we were able to use the GHE mortality data to determine the number of patients in need of palliative care or pain control in each country across the world. However, the number of patients in need of palliative care or pain control is not an accurate measure of the burden of health-related suffering. Patients' suffering varies by type, severity, and duration.

A clinically, economically and strategically useful measure of SHS requires estimation not only of the number of patients who suffer but also at least of the **type and duration of their suffering**. Therefore, we also identified the specific types of suffering associated with each condition. The palliative care literature typically divides suffering into four categories as a means of encompassing the full spectrum of human suffering:

1) Pain and other physical suffering;
2) Psychological suffering;
3) Social suffering;
4) Spiritual suffering (WHO Definition of Palliative Care).

Almost all of the identified ICD-10 conditions can cause any of the four categories of suffering. In addition, psychological and social distress can be a cause of at least some of the ICD-10 conditions.[109] To estimate SHS as precisely as possible, it was necessary to identify within each category of suffering the most common specific types (such as pain, dyspnea, and nausea as types of physical distress) and to estimate the prevalence and duration of each type due to each condition or its treatment.

We began by reviewing the literature on the types of suffering associated with each of the 20 conditions. There are numerous studies of physical and psychological symptom prevalence among cancer patients. There are fewer such studies among patients with most other serious, complex or life-limiting health problems, and only a few meta-analyses. Literature on social and spiritual suffering due to specific conditions is scant. However, based on the available literature, we drafted a list of specific types of physical, psychological, social, and spiritual suffering. We chose to focus on estimating the prevalence and duration only of physical and psychological types of suffering (symptoms) because we did not believe we could find enough published literature or expertise to produce reasonable estimates of the prevalence and duration of each type of social and spiritual suffering.

We also did not make specific estimates of the types, prevalence, or duration of psychological, social, or spiritual suffering of the main family caregiver who typically is female and unpaid. We recognize that, especially in LMICs, a main family caregiver typically provides many hours of daily care to patients with serious chronic, complex, or life-limiting health problems and must remain with the patient when admitted to the hospital. It has been shown that caregiving can itself be a source of suffering.[110,111]Therefore, we think it is important to estimate the psychological, social, and spiritual suffering of the main caregiver of patients in need of

palliative care. Because of the scant literature and expertise on this topic, we did not venture to make these estimates.

After we drafted a list of physical and psychological types of suffering (symptoms), we then asked our panel of palliative care physician-experts from LMICs to review the draft list. Based on consensus of this panel, we finalized a list of 11 types of physical suffering and 4 types of psychological suffering. (**Table 1D**)

Table 1D. Most common types of physical and psychological suffering associated with the 20 conditions that most often generate a need for palliative care.

Table 2. Major Sufferings from People in Need of Palliative Care
Physical Sufferings:
Bleeding
Constipation
Diarrhea
Dry mouth (Xerostomia)
Shortness of breath (Dyspnea)
Fatigue
Nausea and /or Vomiting
Pain (Mild vs. Moderate or Severe)
Itching (Pruritus)
Weakness
Wounds
Psychological Sufferings:
Anxiety / worry
Depressed mood
Confusion / delirium
Dementia

Of note, dementia appears both in the list of **conditions** (Alzheimer's disease and other primary dementias) and as a **symptom** of other conditions (HIV/AIDS, cerebrovascular disease and other neurologic conditions). Thus, the term is used in two ways, and we have endeavored to make clear how it is used in each instance.

1.3 Prevalence of each type of physical and psychological suffering by condition

The prevalence of each type of physical and psychological suffering by condition was determined by means of a systematic literature review (**Table 1E**) followed by review by our panel of 10 palliative care physician-experts from LMICs (names and home countries provided in **Table 7A** below). Most published data on symptom prevalence comes from high or upper-middle income countries where both disease-modifying and palliative treatments are most accessible. Thus, we believe that the review by experts from LMICs was particularly important.

Existing data, mostly from high income countries, indicate that well over 50% of patients who die of malignant neoplasms and AIDS experience pain, and that pain also is common among

those who die of heart disease, COPD, renal failure, neurologic disease and dementia. [112, 113] Dyspnea is especially common among people who die of COPD and heart failure and only slightly less common among those who die of malignant neoplasms and AIDS.[114] Depressed mood and anxiety also are quite common among patients with a variety of advanced life threatening illnesses as well as among patients with traumatic brain injury, orthopedic trauma, or burns.[115,116] Data on prevalence of social and spiritual distress among these patients is scant. A US study found that 44% of advanced cancer patients experienced spiritual pain.[117] In an impoverished rural district in Malawi, 76% of patients receiving palliative care needed social supports (see section 3), while roughly 50% of German patients receiving palliative care needed them[118,119]

Table 1E. Literature review on prevalence of the most commonly reported types of physical suffering among patients with serious, complex or life-limiting health problems.

Table 4. Literature Review Results for Prevalence of Suffering from Each Symptom by Disease

	Pain Mild		Pain Mod/Severe		Dyspnea		Fatigue		Weakness		Nausea and/or vomiting		Diarrhea		Constipation		Dry Mouth		Pruritus		Bleeding		Wounds	
	p	ref	p	ref	p	ref	p	ref	p	ref	p	ref	p	ref	p	ref	p	ref	p	ref	p	ref	p	ref
Hemorrhagic fevers	81%	Qin, E, 2015			14.30%	Qin, E, 2015	71.40%	Qin, E, 2015	100%	Qin, E, 2015	24.2% - 57%	Qin, E, 2015; Thomas, E, 2007 Thomas, E, 2007	66.70%	Qin, E, 2015					27.60%	Thomas, E, 2007	8-57%	Qin, E, 2015; Thomas, E, 2007		
TB/M/XDR TB					5.6-30%	Marais, B. J, 2005; Bark, C. M. 2011	16.70%	Marais, B. J, 2005																
HIV disease	30-98%	VietNam National Palliative Care Report; Harding, R., 2012; Solano, J. P., 2006; Moens, K., 2014; Vogl, D., Harding, R., 2012 Solano, J. P., 2006 Moens, K., 2014 Vogl, D., 1999	64-64.70%	VietNam National Palliative Care Report; Harding, R., 2012	11-62%	Harding, R., 2012; Solano, J. P., 2006; Vogl, D., 1999	43-95%	Harding, R., 2012; Solano, J. P., 2006; Moens, K., 2014	71.9-85.5%	Harding, R., 2012; Vogl, D., 1999	21-60.7%	VietNam National Palliative Care Report; Harding, R., 2012; Solano, J. P., 2006; Moens, K., 2014; Vogl, D., 1999	24.6-90%	Harding, R., 2012; Solano, J. P., 2006; Moens, K., 2014; Vogl, D., 1999	34-38.1%	Harding, R., 2012; Solano, J. P., 2006; Vogl, D., 1999	61.6-67.6%	Harding, R., 2012; Vogl, D., 1999	49-58.9%	VietNam National Palliative Care Report; Harding, R., 2012; Vogl, D., 1999				
Malignant neoplasms (except C91-95)	30-96%	VietNam National Palliative Care Report; Teunissen, S. C., 2007; Solano, J. P., 2006; Moens, K., 2014; Tranmer, J. E., 2003	66%	VietNam National Palliative Care Report	10-77%	Teunissen, S. C., 2007, Dudgeon, D. J., 2001; Solano, J. P., 2006; Moens, K., 2014; Tranmer, J. E., 2003	23-100%	Teunissen, S. C., 2007; Solano, J. P., 2006; Moens, K., 2014	60%	Teunissen, S. C., 2007	2-78%	VietNam National Palliative Care Report; Teunissen, S. C., 2007; Solano, J. P., 2006; Moens, K., 2014; Tranmer, J. E., 2003	3-29%	Teunissen, S. C., 2007; Solano, J. P., 2006; Moens, K., 2014; Tranmer, J. E., 2003	4-65%	Teunissen, S. C., 2007; Solano, J. P., 2006; Moens, K., 2014; Tranmer, J. E., 2003	40-82%	Teunissen, S. C., 2007; Tranmer, J. E., 2003	0-24%	VietNam National Palliative Care Report; Teunissen, S. C., 2007; Tranmer, J. E., 2003	15%	Teunissen, S. C., 2007		
Leukemia	28.2-54.3%	Collins, J. J., 2000; Huijer, H. A. S., 2013			21.90%	Collins, J. J., 2000	15.4-63%	Collins, J. J., 2000; Huijer, H. A. S., 2013			43.8+12.5% - 39.1+23.9%	Collins, J. J., 2000; Huijer, H. A. S., 2013	21.90%	Collins, J. J., 2000	6.30%	Collins, J. J., 2000	21.9-26.1%	Collins, J. J., 2000; Huijer, H. A. S., 2013	15.4-40.6%	Collins, J. J., 2000; Huijer, H. A. S., 2013				
Dementia	14-63%	Moens, K., 2014			12-52%	Moens, K., 2014	22%	Moens, K., 2014			8%	Moens, K., 2014			40%	Moens, K., 2014								
Inflammatory dz of CNS																								
Degeneration of CNS	42-85%	Moens, K., 2014			26%	Moens, K., 2014	42-80%	Moens, K., 2014			26%	Moens, K., 2014			24-46%	Moens, K., 2014								
Cerebrovascular diseases																								
Non-ischemic heart disease	14-78%	Solano, J. P., 2006; Moens, K., 2014			18-88%	Ahmed, A., 2006; Solano, J. P., 2006; Moens, K.,	42-82%	Solano, J. P., 2006; Moens, K., 2014			2-48%	Solano, J. P., 2006; Moens, K., 2014	12%	Solano, J. P., 2006	12-42%	Solano, J. P., 2006; Moens, K., 2014								
Chronic ischemic heart disease	41-77%	Solano, J. P., 2006			60-88%	Solano, J. P., 2006	69-82%	Solano, J. P., 2006			17-48%	Solano, J. P., 2006	12%	Solano, J. P., 2006	38-42%	Solano, J. P., 2006								
Lung Diseases	21-77%	Solano, J. P., 2006; Moens, K., 2014			56-98%	Solano, J. P., 2006; Moens, K., 2014	32-90%	Solano, J. P., 2006; Moens, K., 2014			4%	Moens, K., 2014			12-44%	Solano, J. P., 2006; Moens, K., 2014								
Diseases of liver																								
N17-19: Renal failure	11-83%	Solano, J. P., 2006; Murtagh, F. E., 2010; Moens, K., 2014			11-82%	Solano, J. P., 2006; Murtagh, F. E., 2010; Moens, K., 2014	13-100%	Solano, J. P., 2006; Murtagh, F. E., 2010; Moens, K., 2014			8-59%	Solano, J. P., 2006; Murtagh, F. E., 2010; Moens, K., 2014	8-36%	Solano, J. P., 2006; Murtagh, F. E., 2010; Moens, K., 2014	8-70%	Solano, J. P., 2006; Murtagh, F. E., 2010; Moens, K., 2014	69%	Murtagh, F. E., 2010	84%	Murtagh, F. E., 2010				
Low birth weight & prematurity Birth trauma																								
Congenital malformations																								
Injury, poisoning, external causes																								
Musculoskeletal disorders																								

1.4 Duration of each type of suffering by condition

A literature review was also conducted on the duration of each type of physical, psychological, social, and spiritual by condition. We found almost no data on this topic. Thus our initial estimates of duration of each type of suffering by condition were developed in consultation with our panel of 10 palliative care physician-experts from LMICs (names and home countries provided in **Table 7A** below). Given the lack of published data, we decided to vet these estimates further using a Delphi process (see entire survey below). We invited 16 physicians with extensive experience providing palliative care in LMICs to participate. Five of the participants had served on our 10-member panel of palliative care physician-experts from LMICs, and a few were either Commissioners or members of the Commission's Scientific Advisory Committee.

Table 1F shows the final estimates of duration of each type of physical and psychological suffering by condition.

After discussing the idea of ranking each type of suffering in terms of tolerability, we decided that the subjectivity involved in this endeavor would render the results of little use to measurement of SHS. Instead, we estimated the **total days in need of palliative care for each health condition**. However, recognizing that many patients experience more than one symptom or type of suffering simultaneously, and that the number of symptoms experienced simultaneously can be one way of measuring the amount of suffering, we also calculated the **total symptom-days for each health condition** by adding together the duration of each symptom or type of suffering associated with each health condition. The duration of each symptom was estimated as the average number of days during a year a patient of each condition experiences a certain symptom.

Table 1F. Estimates of duration of physical and psychological suffering by condition.

Table 3. Percentage and duration of sufferings for each disease condition

		Pain Chronic Mil		ronic Moderate		Dyspnea		Fatigue		Weakness		sea and/or vomi		Diarrhea		Constipation		Dry Mouth		Pruritus		Bleeding		Wounds		Anxiety / worry		Depressed moo		nfusion / deliriu		Dementia	
	Disease Conditions	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days	%	Days
1	Hemorrhag	60%	7	30%	5	46%	4	84%	7	84%	7	79%	7	77%	7	0%	0	20%	7	0%	0	35%	5	0%	0	80%	**9**	0%	0	9%	4	0%	0
2	M/XDR TB -	75%	270	40%	270	70%	180	100%	360	100%	360	50%	270	20%	270	0%	0	0%	0	10%	180	15%	90	10%	180	42%	180	52%	180	12%	180	0%	0
2b	M/XDR TB -	60%	45	25%	30	40%	45	80%	90	80%	90	50%	270	20%	270	0%	0	0%	0	10%	180	5%	30	5%	45	42%	180	52%	180	12%	180	0%	0
2c	Non-M/XDF	20%	14	10%	14	85%	21	100%	21	100%	21	10%	14	10%	14	0%	0	0%	0	5%	14	15%	21	10%	21	42%	180	43%	180	0%	0	0%	0
3	HIV	90%	160	45%	90	70%	30	100%	180	100%	180	30%	150	60%	180	0%	0	50%	30	30%	90	0%	0	35%	60	68%	180	49%	150	47%	14	25%	120
3b	HIV - nondecedents	50%	160	15%	90	10%	30	25%	90	25%	90	10%	30	15%	45	0%	0	10%	30	20%	60	0%	0	5%	30	50%	150	30%	150	2%	7	2%	30
4	Malignant	90%	150	80%	90	35%	90	90%	180	90%	180	20%	120	5%	90	35%	90	50%	30	5%	90	10%	90	20%	90	38%	150	47%	150	35%	14	0%	0
4b	Malignant neoplasms (except Leukimia) - non-	35%	150	20%	90	15%	90	50%	120	50%	120	15%	21	5%	21	20%	90	5%	60	2%	30	2%	30	5%	90	25%	150	18%	150	1%	5	0%	0
5	Leukemia	90%	90	35%	60	50%	60	100%	120	100%	120	20%	60	5%	60	25%	60	50%	30	15%	60	25%	60	5%	60	38%	90	47%	90	35%	14	0%	0
6	Dementia	30%	120	15%	60	40%	30	65%	150	90%	90	0%	0	0%	0	15%	60	30%	60	0%	0	0%	0	15%	60	40%	150	46%	150	100%	150	0%	0
6b	Dementia - nondecede	15%	60	5%	30	10%	20	35%	90	45%	45	0%	0	0%	0	10%	60	5%	30	0%	0	0%	0	2%	30	30%	120	25%	90	100%	120	0%	0
7	Inflammato	35%	15	10%	15	15%	15	20%	30	40%	120	20%	15	0%	0	0%	0	0%	0	0%	0	0%	0	10%	60	0%	0	0%	0	33%	14	0%	0
8	Degen dz of	50%	120	25%	120	50%	30	80%	120	100%	150	5%	30	0%	0	5%	90	0%	0	0%	0	0%	0	25%	120	38%	150	34%	150	10%	7	19%	**150**
8b	Parkinsons – non decedents	33%	90	10%	60	10%	30	50%	90	75%	120	0%	0	0%	0	15%	90	0%	0	0%	0	0%	0	0%	0	25%	120	20%	120	24%	7	10%	90
8c	Multiple sclerosis - nondecede	50%	120	20%	90	10%	30	40%	90	65%	120	5%	20	0%	0	15%	60	0%	0	0%	0	0%	0	0%	0	20%	120	7%	60	5%	7	0%	0
9	Cerebrovas	50%	60	20%	30	35%	15	80%	90	90%	90	0%	0	0%	0	20%	90	50%	30	0%	0	0%	0	35%	60	**15%**	**21**	**18%**	**21**	**29%**	21	18%	150
9b	Cerebrovascular diseases - nondecedents	33%	90	5%	90	5%	30	50%	120	80%	120	0%	0	0%	0	15%	120	2%	60	0%	0	0%	0	20%	120	5%	60	10%	60	15%	21	10%	120
10	Non-Ischen	65%	60	20%	30	80%	90	100%	90	90%	60	10%	60	0%	0	15%	60	20%	15	0%	0	0%	0	0%	0	25%	120	32%	150	31%	14	0%	0
11	Chronic isc	90%	120	75%	30	75%	30	80%	90	50%	30	20%	30	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	53%	120	60%	150	0%	0	0%	0
12	Lung Disea	25%	120	10%	30	100%	120	95%	90	50%	30	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	38%	**120**	47%	120	23%	14	0%	0
13	Diseases of	65%	90	30%	30	50%	60	80%	60	70%	30	35%	30	0%	0	0%	0	50%	15	20%	30	15%	90	0%	0	26%	30	25%	60	**70%**	21	0%	0
14	Renal failu	40%	30	5%	15	25%	15	90%	90	50%	30	20%	30	0%	0	15%	30	30%	15	10%	90	5%	30	0%	0	29%	90	**31%**	90	52%	14	0%	0
15	Low birth w	50%	15	25%	15	50%	15	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0
16	Congenital	50%	30	25%	30	20%	30	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0
16b	Congenital malformations - nondecedents	25%	60	5%	60	5%	60	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0
17	Injury	80%	15	65%	15	10%	15	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	39%	14	27%	14	0%	0	0%	0
18	Athroscler	67%	120	50%	60	10%	30	20%	30	20%	30	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	70%	2	30%	60	35%	60	0%	0	0%	0
19	Musculosk	70%	360	30%	360	5%	90	30%	30	30%	60	0%	0	0%	0	20%	210	20%	10	0%	0	0%	0	15%	60	13%	180	24%	180	0%	0	0%	0
20	Malnutritic	20%	5	0%	0	50%	3	0%	0	0%	0	0%	0	33%	5	0%	0	0%	0	0%	0	0%	0	20%	10	0%	0	0%	0	0%	0	0%	0

1.5 Number of patients in need of palliative care and SHS days, in all ages and in childrens only

We estimated the global burden of SHS in terms of number of patients in need of palliative care by condition and by income groups. See table 1G for the detailed information.

Tabel 1G. Number of patients, of children and all age, % breakdown and % of all ages in low income countries, low and middle income countries and worldwide

	Worldwide				LMICs				LICs			
	children PC patients	%	All age PC patients	% of All ages	children PC patients	%	All age PC patients	% of All ages	children PC patients	%	All age PC patients	% of All ages
1	11.98498638	0.2%	33.25827455	36.0%	11.90716113	0.2%	25.38896254	46.9%	3.32567458	0.2%	5.186262103	64.1%
2	95.116339	1.8%	1354.55067	7.0%	94.99975693	1.8%	1341.60224	7.1%	26.61156101	1.6%	217.5842345	12.2%
3	2110.81784	39.7%	16821.55901	12.5%	2110.442118	40.2%	16602.90758	12.7%	827.3184352	50.1%	4829.629051	17.1%
4	100.0460175	1.9%	14707.3458	0.7%	93.69132261	1.8%	10332.79027	0.9%	20.57673736	1.2%	616.933732	3.3%
5	26.25704107	0.5%	259.6233658	10.1%	24.85608397	0.5%	175.6845064	14.1%	1.65316428	0.1%	10.89072905	15.2%
6	0	0.0%	5627.084167	0.0%	0	0.0%	3069.255041	0.0%	0	0.0%	147.283874	0.0%
7	257.9001474	4.8%	380.7223098	67.7%	257.5872331	4.9%	378.0476093	68.1%	102.4770575	6.2%	138.7304114	73.9%
8	25.75920345	0.5%	957.7490289	2.7%	24.4035536	0.5%	349.1921579	7.0%	4.405679675	0.3%	29.55252373	14.9%
9	34.45916666	0.6%	7898.696965	0.4%	33.78347903	0.6%	6958.453041	0.5%	8.237275606	0.5%	401.9092853	2.0%
10	13.66069308	0.3%	1021.719923	1.3%	13.31243147	0.3%	873.9632136	1.5%	2.803180865	0.2%	67.64199998	4.1%
11	0.218279254	0.0%	436.3835207	0.1%	0.214249731	0.0%	352.7916781	0.1%	0.0290917	0.0%	15.521701	0.2%
12	20.6145953	0.4%	2709.075562	0.8%	20.26098869	0.4%	2213.942475	0.9%	3.37264458	0.2%	89.99889052	3.7%
13	30.37614752	0.6%	1226.013375	2.5%	30.24000761	0.6%	1030.2288	2.9%	5.64629525	0.3%	103.9376279	5.4%
14	9.801825417	0.2%	355.4065988	2.8%	9.694912617	0.2%	297.5523019	3.3%	1.905589395	0.1%	16.85078901	11.3%
15	1069.0859	20.1%	1069.085879	100.0%	1054.232512	20.1%	1054.23249	100.0%	231.4086239	14.0%	231.4086205	100.0%
16	679.998871	12.8%	775.2320441	87.7%	655.2777058	12.5%	733.14115	89.4%	140.5839709	8.5%	156.369065	89.9%
17	646.0135337	12.1%	4431.636222	14.6%	634.8479423	12.1%	3936.999199	16.1%	181.7485924	11.0%	545.699673	33.3%
18	5.963217922	0.1%	359.678698	1.7%	5.813434526	0.1%	210.7313677	2.8%	1.908300765	0.1%	27.69331118	6.9%
19	6.451586442	0.1%	325.2656467	2.0%	6.24448734	0.1%	226.5277151	2.8%	1.41075669	0.1%	8.301440098	17.0%
20	174.149647	3.3%	330.1048837	52.8%	174.0789813	3.3%	318.0525281	54.7%	86.1401416	5.2%	109.6188813	78.6%
Total	5318.675038	100.0%	61080.19195		5255.888362	100.0%	50481.48432		1651.562773	100.0%	7770.742103	

The global burden of SHS among children was estimated separately by considering the total number of patients under age 15 in need of palliative care, both decedents and non-decedents, and their respective SHS days, as calculated in previous sections.

The mortality data set for children under age 15 is from the GHE 2015 as well, and we used the same assumptions about the percentage of deaths that require palliative care, days in need of palliative care, and days sufferings from each of the SHS symptoms as those used on adults. We understand that the palliative care needs of children and their families tend to differ from those of adults and their families. This is a major limitation of our estimates of SHS days and of the palliative care needs of children. See table 1H below for detailed information.

Table 1H. Number of total patients, SHS days and pain days, in children and all ages , in low income countries, high income countries and worldwide

	Worldwide			Low income countries			High income countries		
	Total number of patients (000)	Total SHS days (million)	Pain days (million)	Total number of patients (000)	Total SHS days (million)	Pain days (million)	Total number of patients (000)	Total SHS days (million)	Pain days (million)
Children	5,319	964	296	1,652	336	101	63	8	3
All ages	61,080	21,155	4,838	7,771	2,369	639	10,599	4,238	868
%	8.7%	4.6%	6.1%	21.3%	14.2%	15.9%	0.6%	0.2%	0.3%

1.6 Suffering of family caregivers

In keeping with the WHO definition,[120] palliative care attends to the suffering not only of patients but also of family members. Palliative care team members may provide informal emotional support as well as social or spiritual support to family members without establishing formal patient-clinician relationships. In recognition that caregiving for patients with serious, complex or life-limiting health problems may result in or exacerbate poverty for the caregiver, we have included basic needs support for family caregivers in our essential package of palliative care and pain control (see below). The one situation in which a family member may become a formal patient of a palliative care clinician is that of complicated by grief when specialist mental health care is not accessible. Based on the existing literature from high income countries, this occurs among 7% of bereaved persons [121] However, the definition of complicated grief remains controversial and its manifestations are likely influenced by culture. Thus, the Commission chose not to include complicated grief among family caregivers as an additional type of psychological suffering requiring palliative care. We do, however, affirm that palliative care providers should try to anticipate complicated grief by exploring caregivers' previous experiences with death or recognizing types of deaths mostly likely to result in complicated grief (for example, violent or unexpected deaths). Where referral for specialist mental health care is not possible, palliative care providers have a responsibility to do their best to treat complicated grief, particularly when it manifests as depression.[122]

1.7 Summary indicators of suffering days

We recognize that "symptom-days" has limitations as a measure of the burden of suffering experienced by patients in the absence of a method to weight the tolerability of each symptom. As a contribution to measurement of this burden, we generated several "summary indicators" or ways to characterize the suffering experienced by patients.

1.7.1 Indicator 1: Total symptom-days by condition

- ***Description:*** The sum of the symptom-days from each symptom by condition.
- ***Assumptions and limitations:*** No weighting of tolerability of symptoms. Assumption that coinciding symptoms make the suffering worse and thus that the symptom-days from each coinciding symptom should be added together. This assumption generates an overestimation of the total number of days of a patient's suffering.

1.7.2 Indicator 2: AT LEAST symptom-days by condition

- **Description:** The symptom-days of the one symptom of longest duration. This would be the LEAST or minimal number of symptom-days experienced by the patient.
- **Assumption and limitation:** Assumes that any other symptoms began and ended during period of the symptom of longest duration. In most cases, this will be an underestimate of the total number of days of a patient's suffering.

1.7.3 Indicator 3: AT LEAST non-pain symptom-days by condition

- **Description:** The symptom-days of the one non-pain symptom of longest duration. This would be the LEAST or minimal number of non-pain symptom-days experienced by the patient.
- **Assumption and limitation:** Assumes that any other non-pain symptoms began and ended during period of the non-pain symptom of longest duration. In many cases, this will be an underestimate of the total number of days of a patient's suffering from non-pain symptoms.

1.7.4 Indicator 4: Total pain-days by condition

- **Description:** The sum of mild pain-days and moderate to severe pain-days.
- **Assumption and limitation:** The mild pain days do not overlap the moderate to severe pain-days. Thus, this indicator shows total days in pain. However, it does not include any other symptoms.

1.7.5 Indicator 5: Pain plus At LEAST non-pain symptom-days by condition

- **Description:** This indicator was generated by adding the total pain-days and the AT LEAST non-pain symptom-days (indicator 3).
- **Assumption and limitation:** This is one possible indicator of the burden of suffering for a patient.

1.7.6 Indicator 6: Total days in need of palliative care by condition

- **Description:** An estimation of days requiring palliative care by condition by palliative care experts with experience treating patients in LMICs using a Delphi process.
- **Assumption and limitation:** Based only on the opinion of clinical palliative care experts from LMICs in each region.

An additional measure of burden of suffering could be the estimated number of required ***palliative care visit-days***: the number of days in which a palliative care provider sees the patient or family caregiver. Severe, refractory, or poorly tolerated symptoms may require daily visits while well-controlled symptoms may require a visit only every 2 to 4 weeks. Yet ***symptom days*** measures only the days during which the symptom(s) persist(s) or is (are) being treated, regardless of whether a visit by or with a palliative care provider is needed. Thus, ***palliative care visit-days*** may be a better approximation of symptom tolerability in future research.

1.8 Transposing into country, region and income-group specific data

The GHE mortality data are reported by country. We then transposed these data into World Bank 2015 country-income-group specific data.[123]

For the 2015 calendar year:

- Low-income economies are defined as those with a GNI per capita, calculated using the World Bank Atlas method, of $1,025 or less;
- Lower middle-income economies are those with a GNI per capita between $1,026 and $4,035;
- Upper middle-income economies are those with a GNI per capita between $4,036 and $12,475;
- High-income economies are those with a GNI per capita of $12,476 or more.

1.9 Assumptions and limitations

Measurement of the global burden of SHS is, to our knowledge, unprecedented, and we recognize that it has many limitations. First, we included in our list of health conditions only those serious, complex or life-limiting health problems that generate symptoms that a clinician with at least basic palliative care training could be expected to palliate in a low-resource setting without support from other specialists. For example, chronic paranoid schizophrenia and other severe chronic psychiatric disorders generate severe suffering, and specialist treatment which is rarely accessible in LMICs. If a palliative care provider encounters such a patient where no specialist care is accessible, s/he has a responsibility to obtain the needed specialist treatment, and if this is not possible, to use all available means to treat the patient and palliate the symptoms as much as possible. However, specialist training in psychiatry cannot reasonably be added to basic, advanced, or even specialist palliative care training.

Second, because of a dearth of reliable empirical data on the types, prevalence, and duration of suffering in each health condition, we relied heavily on expert opinion. We challenge readers to devise better methods to measure the global burden of SHS. Third, some types of suffering, such as pain, depression, anxiety, inability to feed children, or loss of meaning, may be for most patients more difficult to tolerate that other symptoms such as weakness or anger with God. However, as noted above, we know of no universally applicable way to rank types of suffering by tolerability. Fourth, there are likely to be other important types or sub-types of suffering beyond those identified by our Commission. For example, we did not attempt to estimate the suffering of those forced to live in war zones or under threat of political, sexual, or ethnic violence. These types of suffering warrant much greater attention.

1.10 Avoidable mortality

1.10.1 Introduction

Advancements in medical technology and improvements in health system performance can save lives, as has been proven by the overall high life expectancy and low age-specific mortality

rate in high income countries [HICs] as compared to LMICs, especially in terms of infectious diseases. The concept of 'avoidable mortality' has been introduced and applied in previous studies, defined as the "deaths that should not occur in the presence of effective and timely health care".[124] We specifically define it as the number of deaths that can be averted if a specified "best" case scenario were to occur in all LMICs. Our analysis uses two different "best" case scenarios for comparison.

The notion of avoidable mortality is important in advocating for palliative care and to ensure that patients in need of palliative care do not become the victims of underperforming health systems as patients with 'incurable' conditions, which are in fact only incurable in certain local settings. Thus, we have attempted to calculate the avoidable deaths from all 20 conditions included in the analysis of SHS presented in this report. The purpose of the calculations is to demonstrate that the burden of suffering and the need for palliative care, at least among children and young and middle-aged adults, can and should be reduced with the advent of appropriate technology and health system strengthening.

It is noteworthy that for several non-communicable conditions, such as cancer, dementia, and atherosclerosis, the majority of LMICs actually have lower age-specific mortality rates than HICs. This may be due to aging populations in HICs or other factors such as under-diagnosis of those conditions and more prevalent infectious diseases acting as competing causes of deaths. It also suggests that some Low and Middle Income Countries have achieved better health outcomes in some particular diseases than the average of HICs, either due to better public health measures or better treatment.

1.10.2 Data set and methodology:

We used age specific mortality rates from the GHE 2015 database, which separated the age distribution into the following groups: 0-4, 5-14, 15-29, 30-59, 60-69. Age group of 70 and above were not included in the calculation under the assumption that all deaths above 70 are unavoidable, following previous publications. The database is updated to 2015.

- *Method one: using HIC's median age specific mortality rate as the "best" case scenario.*

$$ASMR_{(\text{age group i, condition j, country k})} = \frac{\text{Death Number (age group i,condition j,country k)}}{\text{Population (age group i,condition j,country k)}}$$

$ASMRbest_{(\text{age group i, condition j, country k})}$= Median (ASMR of all HIC countries defined by World Bank[125] and included in the WHO mortality database)

Counterfactual Death Number = $Population_{(\text{age group i, condition j, country k})} \times ASMRbest_{(\text{age group i, condition j, country k})}$

Age group i = [0-4, 5-14, 15-29, 30-59, 60-69]

For children's avoidable mortality calculation, age group i = [0-4, 5-14]

Condition j = [Hemorrhagic Fever, TB, HIV, Malignant Neoplasm, Leukemia, Cerebrovascular Disease, non-ischemic heart disease, ischemic heart disease, Dementia, other degenerative neurological disease, inflammatory disease of CNS, COPD and respiratory disease, disease of liver, renal failure, low birth weight and birth trauma, congenital malformation, injury, atherosclerosis, Musculoskeletal disorders and protein malnutrition]

Country k = [Low Income Countries, Lower-Middle Income Countries, Upper-Middle Income Countries]

Avoidable Mortality = Death Number – Counterfactual Death Number (if Death Number is greater than Counterfactual Death Number)

Potentially Unavoidable Mortality = Counterfactual Death Number (if Counterfactual Death Number is greater than Death Number)

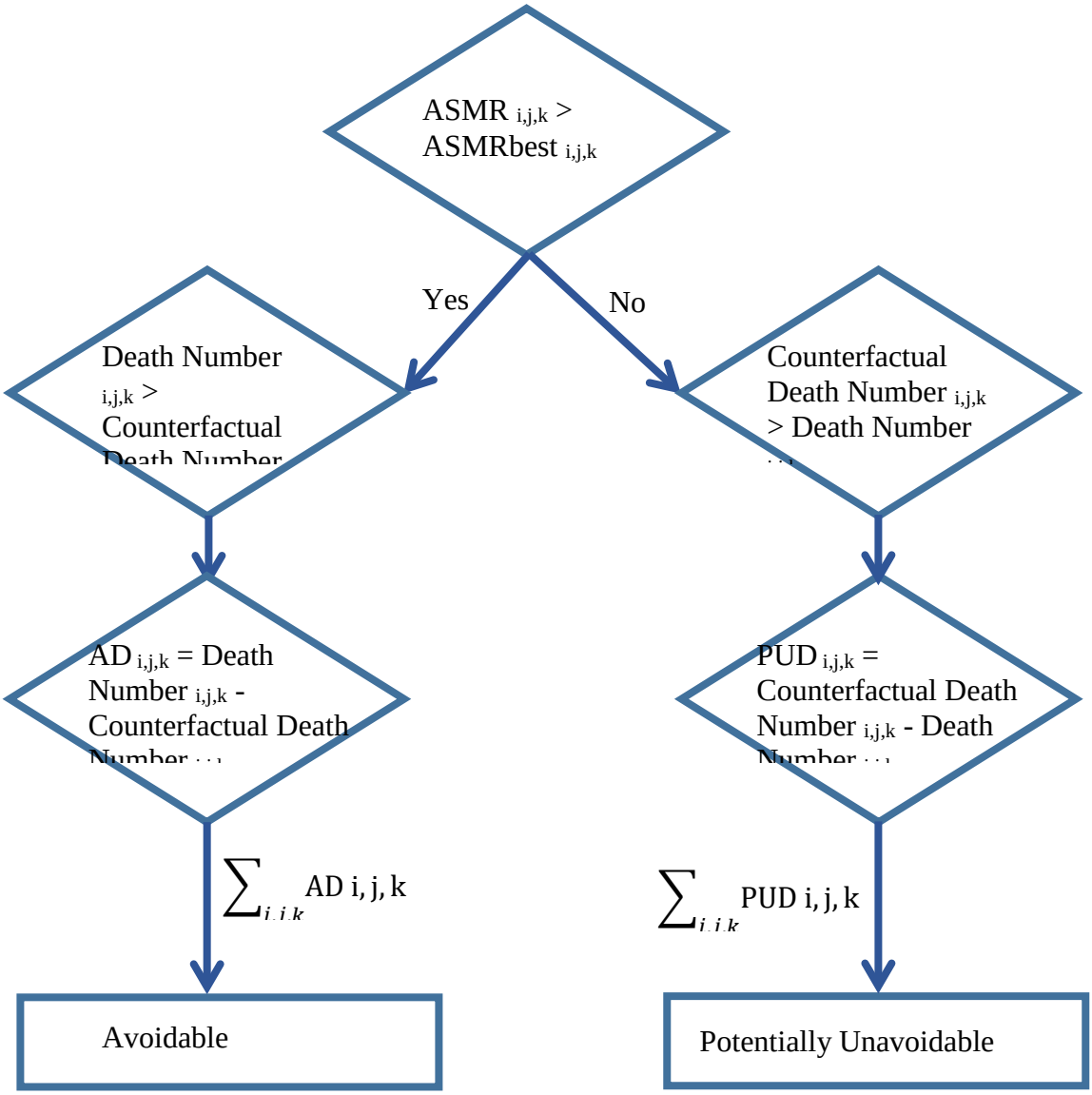

ASMR i,j,k > ASMRbest i,j,k
Yes
No
Death Number i,j,k > Counterfactual Death Number
Counterfactual Death Number i,j,k > Death Number
AD i,j,k = Death Number i,j,k - Counterfactual Death Number
PUD i,j,k = Counterfactual Death Number i,j,k - Death Number
∑ AD i, j, k
∑ PUD i, j, k
Avoidable
Potentially Unavoidable

Table 1I Country Classifications Used for Avoidable Mortality Calculation (World Bank, 2015)

Low Income Countries			
Afghanistan	Benin	Burkina Faso	Burundi
	Central African Republic	Chad	Comoros
D. R. Congo	Eritrea	Ethiopia	Gambia
Guinea	Guinea-Bissau	Haiti	DPRK
Liberia	Madagascar	Malawi	Mali
Mozambique	Nepal	Niger	Rwanda (a)
Senegal	Sierra Leone	Somalia	South Sudan
United Republic of Tanzania	Togo	Uganda	Zimbabwe
Lower-Middle Income Countries			
Armenia	Bangladesh	Bhutan	Bolivia (Plurinational State of)
Cape Verde	Cameroon	Congo	Côte d'Ivoire
Djibouti	Egypt	El Salvador	
Ghana	Guatemala		Honduras
India	Indonesia	Kenya	Kyrgyzstan
Laos	Lesotho	Mauritania	Republic of Moldova
Morocco	Myanmar	Nicaragua	Nigeria
Pakistan	Papua New Guinea	Philippines	
Solomon Islands	Sri Lanka	Sudan	Swaziland
Syrian Arab Republic	Tajikistan	Timor-Leste	Ukraine
Uzbekistan	Vietnam	Yemen	Zambia
Cambodia	Mongolia	Tonga	Tunisia
Upper-Middle Income Countries			
Albania	Algeria	Angola	Azerbaijan
Belarus	Belize	Bosnia and Herzegovina	Botswana
Brazil	Bulgaria	China	Colombia
Costa Rica	Cuba	Dominican Republic	Ecuador
Fiji	Gabon	Iran	Iraq
Jamaica	Jordan	Kazakhstan	Lebanon
Libya	The former Yugoslav Republic of Macedonia	Malaysia	Maldives
Mauritius	Mexico		Montenegro
Namibia	Panama	Paraguay	Peru
Romania	Serbia	South Africa	Suriname
Thailand		Turkey	Turkmenistan
Argentina	Equatorial Guinea	Georgia	Guyana
Russian Federation	Venezuela		
High Income Countries			
	Australia	Austria	Bahamas
Bahrain	Barbados	Belgium	Brunei Darussalam
Canada	Chile	Croatia	Cyprus
Czech Republic	Denmark		Estonia
Finland	France	Germany	Greece
Hungary	Iceland	Ireland	
Italy	Japan	Republic of Korea	Republic of Korea
Latvia	Lithuania	Luxembourg	Malta
Netherlands	New Zealand	Norway	Oman
Poland	Portugal	Qatar	
Saudi Arabia	Singapore	Slovakia	Slovenia
Spain	Sweden	Switzerland	Trinidad and Tobago
United Arab Emirates	United Kingdom	United States of America	Uruguay

In this method, we applied the HIC's median age specific mortality rate to all LMICs within each age group, and calculated the figure for deaths in each country and for each age group. If the number of deaths was lower than the actual deaths, the difference was added to "avoidable deaths." If not, they were added to "potentially unavoidable deaths." The avoidable number of patients in need of palliative care was calculated by using the same method as described above. The median number was used to eliminate the effect of a few outlier HICs that had either exceptionally high or low age specific mortality rates for certain diseases.

- *Method two: using the lowest age-specific mortality rate in each income group as the "best" case scenario.*

In this method, we applied the lowest age specific mortality rate in each income group to all LMICs within that group and to each age division, calculating "avoidable deaths" per country, per condition and per age group, before adding them up. Since we used the lowest age specific mortality rate, there is no "potentially unavoidable" mortality. Avoidable number of patients in need of palliative care is calculated by using the same methods as described in method one.

$$ASMR_{(\text{age group i, condition j, country k})} = \frac{\text{Death Number (age group i,condition j,country k)}}{\text{Population (age group i,condition j,country k)}}$$

$ASMRbest_{(\text{age group i, condition j, country k})}$= MIN (ASMR of all countries in the same income group of k, defined by World Bank[126] and included in the WHO mortality database)

Counterfactual Death Number* = $Population_{(\text{age group i, condition j, country k})} \times ASMRbest_{(\text{age group i, condition j, country k})}$

Age group i = [0-4, 5-14, 15-29, 30-59, 60-69]

For children's avoidable mortality calculation, age group i = [0-4, 5-14]

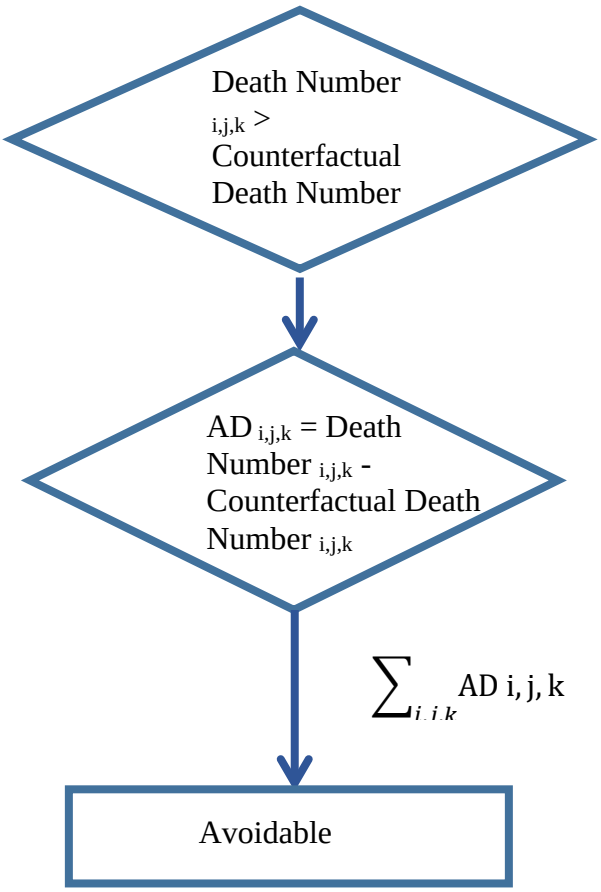
Condition j = [Hemorrhagic Fever, TB, HIV, Malignant Neoplasm, Leukemia, Cerebrovascular Disease, non-ischemic heart disease, ischemic heart disease, Dementia, other degenerative neurological disease, inflammatory disease of CNS, COPD and respiratory disease, diseases of the liver, renal failure, low birth weight and birth trauma, congenital malformation, injury, atherosclerosis, Musculoskeletal disorders and protein malnutrition]

Country k = [Low Income Countries, Lower-Middle Income Countries, Upper-Middle Income Countries]

Avoidable Mortality = Death Number – Counterfactual Death Number (if Death Number is greater than Counterfactual Death Number)

Potentially Unavoidable Mortality = Counterfactual Death Number (if Counterfactual Death Number is greater than Death Number)

*By definition, ASMRbest is the lowest among the income group, so Counterfactual Death Number is either equal or lower than the Death Number of that country, but not higher. So there is only the category of Avoidable Mortality using this method.



1.10.3 results:

Table1J.1 Avoidable mortality (0-69 yr) using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

Income groups	Total Death from 20 conditions (000)	Avoidable Mortality using HIC's median - not counting negative numbers (000)	%	Avoidable Mortality using the income group's best (000)	%
All Age Groups/ LMIC Total	21,242	13,558	63.8%	15,285	72.0%
Low Income Countries	2,814	2,265	80.5%	1,899	67.5%
Lower-Middle Income Countries	10,827	7,614	70.3%	8,273	76.4%
Upper-Middle Income Countries	7,601	3,680	48.4%	5,112	67.3%

Table1J.2 Avoidable mortality (0-69 yr) by condition using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

		1. Hemorrhagic Fever	2. TB	3. HIV	Malignant neoplasms(except	5. Leukemia	6. Dementia	Inflammatory diseases of CNS	Degenerative Diseases of CNS	Cerebrovascular diseases	Non-Ischemic Heart Diseases	11. Ischemic heart disease	12. Lung Diseases	13. Diseases of Liver	14. kidney diseases	15. Low Birth Weight	16. Congenital anomalies	17. Injury	18. Atherosclerosis	Musculoskeletal disorders	20. Protein-Energy Malnutrition
Deaths	All Age Groups/ LMIC Total	205.1976	1021.202	1033.967	3543.488	151.286	87.07224	682.6457	208.709	2121.664	681.7055	2824.742	877.9757	879.8377	344.5743	1726.014	604.2903	3719.227	240.258	56.05066	231.6976
	Low Income Countries	49.16629	162.2525	300.3317	262.3233	10.34364	3.249382	256.2367	35.63669	150.1683	57.60456	139.8675	47.09455	94.10197	24.84616	399.2824	129.5599	549.439	41.34005	3.13143	97.71353
	Lower-Middle Income Countries	125.639	761.2703	448.9421	1332.258	61.55623	31.62131	377.5442	107.4488	931.0418	342.1275	1564.151	489.0428	526.7534	209.8566	1118.798	332.511	1840.863	87.40519	28.15186	109.5683
	Upper-Middle Income Countries	30.39239	97.67878	284.6933	1948.907	79.38613	52.20154	48.86478	65.62346	1040.454	281.9734	1120.724	341.8384	258.9823	109.8716	207.9339	142.2194	1328.925	111.5128	24.76737	24.41579
Avoidable Mortality using HIC's median	All Age Groups/ LMIC Total	169.3215	1011.768	1013.708	676.6075	56.33483	30.90021	659.8544	67.55468	1705.19	500.1602	1660.84	605.1203	488.3214	291.4978	1547.195	388.1271	2345.988	83.51356	26.73684	229.7501
		83%	99%	98%	19%	37%	35%	97%	32%	80%	73%	59%	69%	56%	85%	90%	64%	63%	35%	48%	99%
	Low Income Countries	45.78364	161.623	298.9239	91.49479	3.785305	0.430983	253.811	20.89794	125.211	45.72014	72.28895	30.95841	66.72636	21.60139	369.0264	95.22589	435.2689	26.87011	1.516329	97.54919
		93%	100%	100%	35%	37%	13%	99%	59%	83%	79%	52%	66%	71%	87%	92%	73%	79%	65%	48%	100%
	Lower-Middle Income Countries	105.4322	757.2921	440.0987	225.8716	22.58645	8.913962	366.8884	34.19501	760.9242	266.2568	1092.289	379.0785	345.4564	188.187	1025.783	223.2184	1218.203	28.76928	15.71608	108.7261
		84%	99%	98%	17%	37%	28%	97%	32%	82%	78%	70%	78%	66%	90%	92%	67%	66%	33%	56%	99%
	Upper-Middle Income Countries	18.10569	92.85317	274.6859	359.2412	29.96307	21.55527	39.15499	12.46172	819.0547	188.1834	496.262	195.0834	76.1387	81.70939	152.3855	69.68285	692.5165	27.87416	9.504432	23.47475
		60%	95%	96%	18%	38%	41%	80%	19%	79%	67%	44%	57%	29%	74%	73%	49%	52%	25%	38%	96%
Avoidable Mortality using income group's best	All Age Groups/ LMIC Total	197.257	998.7665	1033.124	1633.154	143.6286	73.85941	628.3962	156.0064	1592.777	517.6409	1949.431	696.0986	812.7668	288.6711	1316.673	357.7827	2434.693	169.8998	54.82365	229.1545
		96%	98%	100%	46%	95%	85%	92%	75%	75%	76%	69%	79%	92%	84%	76%	59%	65%	71%	98%	99%
	Low Income Countries	45.92322	144.38	299.489	167.1554	10.17069	1.639722	230.3583	28.7212	81.82754	32.4495	70.73925	28.36556	51.74503	18.44852	216.145	55.17211	280.1477	38.29423	2.561057	95.188
		93%	89%	100%	64%	98%	50%	90%	81%	54%	56%	51%	60%	55%	74%	54%	43%	51%	93%	82%	97%
	Lower-Middle Income Countries	123.3521	759.0547	448.9421	521.7026	61.29147	24.54558	355.5873	83.01706	683.5817	272.1665	1269.868	403.6224	510.2086	195.0175	943.164	174.1825	1234.072	72.81101	27.53929	109.5507
		98%	100%	100%	39%	100%	78%	94%	77%	73%	80%	81%	83%	97%	93%	84%	52%	67%	83%	98%	100%
	Upper-Middle Income Countries	27.98171	95.33184	284.6933	944.2964	72.16645	47.6741	42.45061	44.26814	827.3676	213.0249	608.8236	264.1107	250.8132	75.20505	157.3636	128.4282	920.4732	58.79452	24.7233	24.41579
		92%	98%	100%	48%	91%	91%	87%	67%	80%	76%	54%	77%	97%	68%	76%	90%	69%	53%	100%	100%

Table1J.3 Avoidable mortality (0-14 yr) using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

Income groups	Total Death from 20 conditions (000)	Avoidable Mortality using HIC's median - not counting negative numbers (000)	%	Avoidable Mortality using the income group's best (000)	%
All Age Groups/ LMIC Total	4,269	3,754	87.9%	3,390	79.4%
Low Income Countries	1,166	1,080	92.6%	801	68.7%
Lower-Middle Income Countries	2,499	2,231	89.3%	2,069	82.8%
Upper-Middle Income Countries	604	443	73.4%	519	86.0%

Table1J.4 Avoidable mortality (0-14 yr) by condition using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

		1. Hemorrhagic Fever	2. TB	3. HIV	Malignant neoplasms(except	5. Leukemia	6. Dementia	Inflammatory diseases of CNS	Degenerative Diseases of CNS	Cerebrovascular diseases	Non-Ischemic Heart Diseases	11. Ischemic heart disease	12. Lung Diseases	13. Diseases of Liver	14. kidney diseases	15. Low Birth Weight	16. Congenital anomalies	17. Injury	18. Atherosclerosis	Musculoskeletal disorders	20. Protein-Energy Malnutrition
Deaths	All Age Groups/ LMIC Total	119.0716	96.28354	132.9412	53.62509	27.61787	0	475.8748	44.22173	26.60812	27.28465	4.284995	30.893	38.0788	21.54425	1726.014	546.0648	705.3866	16.60981	2.973565	174.079
	Low Income Countries	33.25674	26.97118	52.11455	11.77728	1.836849	0	191.3689	8.36442	6.487739	5.628235	0.581834	5.196651	7.911466	4.234643	399.2824	117.1533	201.9429	5.452288	0.671789	86.14014
	Lower-Middle Income Countries	77.43452	63.55597	66.40379	25.26931	13.1994	0	256.8946	25.96344	14.84191	13.32842	3.22809	21.65682	26.97852	14.05394	1118.798	305.1483	373.9557	5.855061	1.55453	71.13796
	Upper-Middle Income Countries	8.380347	5.756392	14.42289	16.57849	12.58162	0	27.61133	9.893874	5.278469	8.327998	0.475071	4.03953	3.188816	3.255665	207.9339	123.7632	129.4881	5.302463	0.747246	16.80088
Avoidable Mortality using HIC's median	All Age Groups/ LMIC Total	114.4392	96.14179	132.9412	26.20162	17.99143	0	467.646	24.97146	23.58967	21.84826	4.049952	27.32639	36.34312	20.40491	1547.195	366.1135	635.403	15.20464	2.422392	173.7509
		96%	100%	100%	49%	65%	N/A	98%	56%	89%	80%	95%	88%	95%	95%	90%	67%	90%	92%	81%	100%
	Low Income Countries	32.47773	26.94707	52.11455	7.07017	0.639681	0	190.0051	5.031607	6.00196	4.741658	0.543895	4.607992	7.628452	4.046438	369.0264	86.88208	190.6717	5.15233	0.585912	86.08343
		98%	100%	100%	60%	35%	N/A	99%	60%	93%	84%	93%	89%	96%	96%	92%	74%	94%	94%	87%	100%
	Lower-Middle Income Countries	74.93575	63.48224	66.40379	11.88716	8.123031	0	252.5967	15.17212	13.25918	10.47923	3.106285	19.76985	26.06223	13.45916	1025.783	211.4251	337.1869	5.354275	1.261048	70.96764
		97%	100%	100%	47%	62%	N/A	98%	58%	89%	79%	96%	91%	97%	96%	92%	69%	90%	91%	81%	100%
	Upper-Middle Income Countries	7.02567	5.712475	14.42289	7.244292	9.228715	0	25.04423	4.767742	4.328532	6.627371	0.399772	2.948553	2.652438	2.899308	152.3855	67.80627	107.5444	4.698032	0.575432	16.6998
		84%	99%	100%	44%	73%	N/A	91%	48%	82%	80%	84%	73%	83%	89%	73%	55%	83%	89%	77%	99%
Avoidable Mortality using income group's best	All Age Groups/ LMIC Total	116.0373	93.28191	132.7183	44.7456	27.06543	0	439.7905	39.08865	25.32957	24.34804	4.250693	30.36916	35.00054	20.42967	1316.673	309.4252	539.1985	16.53873	2.948119	172.3369
		97%	97%	100%	83%	98%	N/A	92%	88%	95%	89%	99%	98%	92%	95%	76%	57%	76%	100%	99%	99%
	Low Income Countries	31.29198	23.96954	51.89162	9.062135	1.677807	0	169.4056	6.505176	5.390517	3.887528	0.561183	4.958054	6.341924	3.426133	216.145	45.65147	130.6157	5.432608	0.646343	84.4156
		94%	89%	100%	77%	91%	N/A	89%	78%	83%	69%	96%	95%	80%	81%	54%	39%	65%	100%	96%	98%
	Lower-Middle Income Countries	76.65099	63.55597	66.40379	19.75921	13.01486	0	243.8365	23.59939	14.70968	12.57322	3.220836	21.54348	25.50745	13.87866	943.164	152.6603	296.6162	5.815906	1.55453	71.12044
		99%	100%	100%	78%	99%	N/A	95%	91%	99%	94%	100%	99%	95%	99%	84%	50%	79%	99%	100%	100%
	Upper-Middle Income Countries	8.094303	5.756392	14.42289	15.92426	12.37277	0	26.54839	8.984083	5.229375	7.887288	0.468674	3.867634	3.151161	3.124872	157.3636	111.1135	111.9666	5.290217	0.747246	16.80088
		97%	100%	100%	96%	98%	N/A	96%	91%	99%	95%	99%	96%	99%	96%	76%	90%	86%	100%	100%	100%

Table1K.1. Avoidable number of PC decedents patients (0-69 yr) using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

Income groups	Total PC decedents Patients from 20 conditions	Avoidable number of pc decedents patients using HIC's median - not counting negative numbers (000)	%	Avoidable pc decedents patients using the income group's	%
All Age Groups/ LMIC Total	12,233	7,656	62.6%	8,850	72.3%
Low Income Countries	1,699	1,383	81.4%	1,216	71.5%
Lower-Middle Income Countries	6,116	4,229	69.2%	4,629	75.7%
Upper-Middle Income Countries	4,417	2,043	46.3%	3,006	68.0%

Table1K.2 Avoidable number of pc decedents patients (0-69 yr) by condition using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

		1. Hemorrhagic Fever	2. TB	3. HIV	Malignant neoplasms(except	5. Leukemia	6. Dementia	Inflammatory diseases of CNS	Degeneratory Diseases of CNS	Cerebrovascular diseases	Non-Ischemic Heart Diseas	11. Ischemic heart disease	12. Lung Diseases	13. Diseases of Liver	14. kidney diseases	15. Low Birth Weight	16. Congenital anomalies	17. Injury	18. Atherosclerosis	Musculoskeletal disorders	20. Protein-Energy Malnutrition
PC decedents	All Age Groups/ LMIC Total	10.25988	932.0167	1033.967	3189.139	136.1574	69.65779	329.267	120.8352	1379.082	409.847	141.2371	679.3344	759.3073	155.0584	1054.232	362.5742	1115.768	84.09032	39.23546	231.6976
	Low Income Countries	2.458315	148.0825	300.3317	236.0909	9.309278	2.599506	126.5305	18.56582	97.60941	35.34212	6.993377	35.67823	80.16217	11.18077	231.4086	77.73593	164.8317	14.46902	2.192001	97.71353
	Lower-Middle Income Countries	6.281948	694.786	448.9421	1199.032	55.4006	25.29705	180.9239	62.97692	605.1772	214.1421	78.20753	380.145	464.5953	94.43545	694.3329	199.5066	552.259	30.59182	19.7063	109.5683
	Upper-Middle Income Countries	1.519619	89.14816	284.6933	1754.017	71.44751	41.76123	21.81264	39.29242	676.2951	160.3627	56.03618	263.5112	214.5498	49.44221	128.4909	85.33164	398.6775	39.02948	17.33716	24.41579
Avoidable PC decedents using HIC's median	All Age Groups/ LMIC Total	8.466076	923.4072	1013.708	608.9468	50.70135	24.72017	319.0047	37.1417	1108.373	298.8968	83.04199	468.8034	420.9977	131.174	944.1205	232.8763	703.7965	29.22974	18.71579	229.7501
		83%	99%	98%	19%	37%	35%	97%	31%	80%	73%	59%	69%	55%	85%	90%	64%	63%	35%	48%	99%
	Low Income Countries	2.289182	147.5079	298.9239	82.34531	3.406774	0.344787	125.3488	10.74142	81.38713	28.00236	3.614448	23.2983	56.43212	9.720626	213.875	57.13553	130.5807	9.404539	1.06143	97.54919
		93%	100%	100%	35%	37%	13%	99%	58%	83%	79%	52%	65%	70%	87%	92%	73%	79%	65%	48%	100%
	Lower-Middle Income Countries	5.27161	691.1553	440.0987	203.2844	20.3278	7.13117	175.7689	19.33603	494.6007	166.5819	54.61445	294.928	306.0595	84.68416	636.4312	133.931	365.4609	10.06925	11.00125	108.7261
		84%	99%	98%	17%	37%	28%	97%	31%	82%	78%	70%	78%	66%	90%	92%	67%	66%	33%	56%	99%
	Upper-Middle Income Countries	0.905285	84.74399	274.6859	323.3171	26.96677	17.24422	17.88693	7.064252	532.3855	104.3125	24.8131	150.5771	58.50603	36.76922	93.81433	41.80971	207.755	9.755956	6.653102	23.47475
		60%	95%	96%	18%	38%	41%	82%	18%	79%	65%	44%	57%	27%	74%	73%	49%	52%	25%	38%	96%
Avoidable PC decedents using income group's best	All Age Groups/ LMIC Total	9.862851	911.5409	1033.124	1469.839	129.2658	59.08753	302.9252	44.30996	1035.305	308.1525	97.47154	538.6795	701.3113	129.902	807.2007	214.6696	730.408	59.46492	38.37655	229.1545
		96%	98%	100%	46%	95%	85%	92%	37%	75%	75%	69%	79%	92%	84%	77%	59%	65%	71%	98%	99%
	Low Income Countries	2.296161	131.7708	299.489	150.4399	9.153625	1.311777	113.557	5.152533	53.1879	19.73446	3.536963	21.25617	43.74037	8.301835	125.279	33.10327	84.0443	13.40298	1.79274	95.188
		93%	89%	100%	64%	98%	50%	90%	28%	54%	56%	51%	60%	55%	74%	54%	43%	51%	93%	82%	97%
	Lower-Middle Income Countries	6.167605	692.7639	448.9421	469.5323	55.16232	19.63647	170.1273	22.77327	444.3281	169.9524	63.4934	313.8062	450.1584	87.75789	585.0005	104.5095	370.2217	25.48385	19.2775	109.5507
		98%	100%	100%	39%	100%	78%	94%	36%	73%	79%	81%	83%	97%	93%	84%	52%	67%	83%	98%	100%
	Upper-Middle Income Countries	1.399085	87.0062	284.6933	849.8667	64.94981	38.13928	19.24091	16.38416	537.7889	118.4657	30.44118	203.6171	207.4126	33.84227	96.92121	77.05689	276.142	20.57808	17.30631	24.41579
		92%	98%	100%	48%	91%	91%	88%	42%	80%	74%	54%	77%	97%	68%	75%	90%	69%	53%	100%	100%

Table1K.3. Avoidable number of PC decedents patients (0-14 yr) using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

Income groups	Total PC decedents Patients from 20 conditions	Avoidable number of pc decedents patients using HIC's median - not counting negative numbers (000)	%	Avoidable pc decedents patients using the income group's best (000)	%
All Age Groups/ LMIC Total	2,429	2,131	87.8%	1,944	80.1%
Low Income Countries	661	612	92.7%	466	70.6%
Lower-Middle Income Countries	1,429	1,273	89.1%	1,186	83.0%
Upper-Middle Income Countries	340	246	72.5%	292	85.9%

Table1K.4 Avoidable number of pc decedents patients (0-14 yr) by condition using HIC's median age specific mortality rate and the lowest age specific mortality rate within each income group

		1. Hemorrhagic Fever	2. TB	3. HIV	Malignant neoplasms(except	5. Leukemia	6. Dementia	Inflammatory diseases of CNS	Degeneratory Diseases of CNS	Cerebrovascular diseases	Non-Ischemic Heart Diseas	11. Ischemic heart disease	12. Lung Diseases	13. Diseases of Liver	14. kidney diseases	15. Low Birth Weight	16. Congenital anomalies	17. Injury	18. Atherosclerosis	Musculoskeletal disorders	20. Protein-Energy Malnutrition
PC decedents	All Age Groups/ LMIC Total	5.953581	87.87477	132.9412	48.26258	24.85608	0	238.0255	24.40355	17.29528	13.31243	0.21425	20.26099	30.24001	9.694913	1054.232	327.6389	211.616	5.813434	2.081495	174.079
	Low Income Countries	1.662837	24.61569	52.11455	10.59956	1.653164	0	96.75404	4.40568	4.21703	2.803181	0.029092	3.372645	5.646295	1.90559	231.4086	70.29198	60.58287	1.908301	0.470252	86.14014
	Lower-Middle Income Countries	3.871726	58.00541	66.40379	22.74238	11.87946	0	127.4543	14.39992	9.647242	6.84875	0.161404	14.46291	22.59755	6.324274	694.3329	183.089	112.1867	2.049271	1.088171	71.13796
	Upper-Middle Income Countries	0.419017	5.253667	14.42289	14.92064	11.32346	0	13.81717	5.597958	3.431005	3.660501	0.023754	2.425439	1.996161	1.465049	128.4909	74.25792	38.84642	1.855862	0.523072	16.80088
Avoidable PC decedents using HIC's median	All Age Groups/ LMIC Total	5.721958	87.74541	132.9412	23.58146	16.19228	0	234.0834	13.76488	15.33329	10.60366	0.202498	17.97844	28.97382	9.182207	944.1205	219.6681	190.6209	5.321623	1.695674	173.7509
		96%	100%	100%	49%	65%	N/A	98%	56%	89%	80%	95%	89%	96%	95%	90%	67%	90%	92%	81%	100%
	Low Income Countries	1.623887	24.59369	52.11455	6.363153	0.575713	0	96.05955	2.631312	3.901274	2.37516	0.027195	2.994	5.450769	1.820897	213.875	52.12925	57.2015	1.803315	0.410139	86.08343
		98%	100%	100%	60%	35%	N/A	99%	60%	93%	85%	93%	89%	97%	96%	92%	74%	94%	94%	87%	100%
	Lower-Middle Income Countries	3.746787	57.93813	66.40379	10.69845	7.310728	0	125.2736	8.448111	8.618467	5.322768	0.155314	13.21553	21.85701	6.056622	636.4312	126.8551	101.1561	1.873996	0.882733	70.96764
		97%	100%	100%	47%	62%	N/A	98%	59%	89%	78%	96%	91%	97%	96%	92%	69%	90%	91%	81%	100%
	Upper-Middle Income Countries	0.351284	5.213586	14.42289	6.519863	8.305843	0	12.7503	2.685456	2.813546	2.90573	0.019989	1.768909	1.66604	1.304688	93.81433	40.68376	32.26331	1.644311	0.402802	16.6998
		84%	99%	100%	44%	73%	N/A	92%	48%	82%	79%	84%	73%	83%	89%	73%	55%	83%	89%	77%	99%
Avoidable PC decedents using income group's best	All Age Groups/ LMIC Total	5.801864	85.13529	132.7183	40.27104	24.35889	0	219.7644	15.81564	16.46422	11.88528	0.212535	19.92893	27.92524	9.19335	807.2007	185.6551	161.7596	5.788556	2.063683	172.3369
		97%	97%	100%	83%	98%	N/A	92%	65%	95%	89%	99%	98%	92%	95%	77%	57%	76%	100%	99%	99%
	Low Income Countries	1.564599	21.8762	51.89162	8.155921	1.510027	0	85.56186	2.446703	3.503836	1.93881	0.028059	3.220584	4.560166	1.54176	125.279	27.39088	39.18471	1.901413	0.45244	84.4156
		94%	89%	100%	77%	91%	N/A	88%	56%	83%	69%	96%	95%	81%	81%	54%	39%	65%	100%	96%	98%
	Lower-Middle Income Countries	3.83255	58.00541	66.40379	17.78329	11.71337	0	120.8089	9.503494	9.561292	6.47053	0.161042	14.38823	21.39156	6.245398	585.0005	91.59616	88.98485	2.035567	1.088171	71.12044
		99%	100%	100%	78%	99%	N/A	95%	66%	99%	94%	100%	99%	95%	99%	84%	50%	79%	99%	100%	100%
	Upper-Middle Income Countries	0.404715	5.253667	14.42289	14.33183	11.13549	0	13.3936	3.865445	3.399094	3.475942	0.023434	2.320119	1.973517	1.406192	96.92121	66.66807	33.58999	1.851576	0.523072	16.80088
		97%	100%	100%	96%	98%	N/A	97%	69%	99%	95%	99%	96%	99%	96%	75%	90%	86%	100%	100%	100%

1.10.4 Discussion:

Using the HIC's median for all countries, it is evident that LICs have the highest percentage of avoidable deaths and avoidable number of patients in need of palliative care (decedents category only), while that percentage decreases for lower-middle income countries and further for upper-middle income countries. It is as expected that there are more avoidable deaths in LICs due to weaker health systems and underdeveloped economies, in general.

The condition-specific analysis shows a clear dichotomy of infectious diseases versus non-communicable diseases. Most of the avoidable mortality occurs in infectious diseases. For some

conditions, for example dementia, the mortality rate is expected to double or triple. It suggests that most of the burden currently in LMICs is from infectious disease, and it is going to shift to non-communicable diseases in the future as the epidemiological transition continues.
The proportion of child deaths with SHS that can be considered avoidable is particularly high. This is because of both the much higher survival rates for children in HICs with diseases like cancer, and the very low mortality rate from poverty-associated, preventable conditions and infections in HICs.

2 The essential package of palliative care and pain control

Based on our estimate of the global burden of serious health-related suffering (SHS) and the resultant need for palliative care, we designed an essential package of palliative care. This package is designed to relieve the most common and severe suffering related to serious, complex or life-limiting health problems, to be cost effective in low and middle income countries (LMICs), to provide financial risk protection for patients and families, to help strengthen health systems, to promote universal health coverage (UHC) and to be universally accessible by everyone, everywhere by 2030 in countries of all income levels.

2.1 Generation of the essential package of palliative care and pain control

The development of the essential package of palliative care and pain control (EP PCPC) began with discussion among the Commissioners of the basic required components of the package. There was consensus among the Commissioners that the EP PCPC should include not only essential medicines, based on the 2015 WHO Model List of Essential Medicines for palliative care, and human resources, in keeping with the WHO public health strategy for palliative care.[127,128] It also should include some essential equipment and some social supports for those living in extreme poverty. The package was then created in direct consultation (in-person or by telephone) with the 10-member panel of palliative care physician-experts from LMICs described above. Next, as part of the Delphi process focused primarily on estimating the duration of palliative care need by condition (also described above), participants were asked to review the EP PCPC and to recommend any additions or deletions. The package was then reviewed by the Commissioners. Thus, final EP PCPC had undergone multiple reviews by experts in global health, healthcare economics, healthcare policy, and clinical palliative care from all economic settings.

The package specifies at which level of health care systems each item should be available and which types of palliative care provider should be on staff at each level. The needs for each item in the EP are based on estimates of the prevalence and duration of each type of suffering from each health condition identified in our model of SHS. We also determined the unit-cost of each item in the EP PCPC in several countries. This enabled us to estimate the cost of providing palliative care to everyone in need in each country.

2.1.1 Description of the essential package of palliative care and pain control (EP PCPC)

The package consists of the following:

I. **Essential palliative medicines** for adults and children based on the WHO Model List of Essential Medicines (EML) for Palliative Care that are inexpensive and easy to use but are effective to relieve the common symptoms related to serious, complex, or life-limiting health problems. Not all medicines in the EML section on PC and pain treatment are included in the EP, because the Commission's aim was to create a

minimum, least-cost list. Any deviations from the WHO list was made for one of several reasons:

- A medicine on the WHO list is seldom available in LMICs or has cheaper or more accessible alternatives judged to be of similar efficacy and safety. For example, the antihistamine diphenhydramine is recommended instead of cyclizine, and chlorpheniramine and dimenhydrinate are provided as possible alternatives.
- A medicine on the WHO list is not included because there is another similar medicine on the list; for example, the presence on the list of diazepam makes the less available midazolam less necessary.
- Medicines that appear elsewhere in the WHO Model List of Essential Medicines were added to the list to address specific types of suffering. For example, oral metronidazole, to be crushed into a powder, was added to eliminate the odor from malodorous wounds, and furosemide was added to treat dyspnea associated with pulmonary edema and pain from severe peripheral edema.

The following items are excluded from the EP:

- **Slow-release oral morphine or transdermal fentanyl**, because similar clinical effects can be achieved with immediate-release oral morphine, which is much lower cost, and because slow-release morphine and transdermal fentanyl are not appropriate for dose titration. While we advocate for the inclusion of slow-release morphine or transdermal fentanyl in an augmented package, these are not appropriate for initial dose titration, and we strongly recommend that countries avoid pressure to make available more costly, slow-release opioids until and unless more essential immediate-release oral morphine is universally available for patients in need.[156]
- **Docusate sodium**, a stool softener which is a weak and typically inadequate treatment for opioid-induced constipation is not essential if a stimulant laxative and an osmotic laxative are available; the EP already includes the laxatives lactulose and bisacodyl.
- **Midazolam**, a benzodiazepine available only as an injection, is often expensive in LMICs; the inexpensive anxiolytic diazepam is included instead in the EP.
- **Aspirin**, not needed as the EP includes ibuprofen, an effective NSAID.
- **Codeine**, a weak opioid with more side effects than strong opioids, is not needed when a strong opioid such as morphine is available.
- While **cyclizine** is included in the EML as an alternative antiemetic in addition to metoclopramide and haloperidol, the EP expert group criticized the lack of availability in many countries; the more widely-available diphenhydramine is instead included in the EP as an alternative anti-emetic.

II. Essential equipment

Equipment for the EP meets the following criteria: i) necessary for relief of at least one type of physical or psychological suffering ii) locally available iii) simple to use with basic training and iv) small enough to be located in a clinic. It should also be the most inexpensive, effective alternative. Our Commission researched and developed several innovative, low-cost alternatives (see text box 3.2 in Section 3 of the report).

The EP includes: oxygen, nasogastric tubes (vomiting refractory to medicines, administration medicines or fluids); urinary catheters (bladder dysfunction or outlet obstruction); foam, water, or air pressure-reducing mattresses (pressure ulcers and pain relief); opioid lock-box (secured to a wall or immovable object); flashlight with rechargeable battery (if no access to electricity for safe administration of medicines); and cotton and plastic bags, or adult diapers (to reduce risk of skin ulceration and infection, caregiver risk and burden).

III. **Essential human resources** at each level of the healthcare system. The Commission developed a minimum staffing model, based on published recommendations[157] and on the opinions of our clinical expert panel, for achieving significantly expanded coverage of the EP globally (Section 3 of the report).

2.1.1.1. Essential palliative medicines (Table 2A)

Medicines for the essential package were chosen using the following criteria:

- On the WHO List of Essential Medicines for Palliative Care for adults and for children, or in the same class as a medicine on the WHO List.
- The one medicine in its class that best balances accessibility on the world market, clinical effectiveness, safety, ease of use, and minimal cost.
- Deemed by a panel of physician-experts in clinical palliative care in LMICs to be essential for relief of at least one type of physical or psychological suffering identified in our estimation of global burden of SHS.

Table 2A. Essential palliative medicines, their indications for use by symptom, and the sites or "platforms" where they should be accessible.

Medicine	Indication / Typical starting dose for adults	Platform
Amitriptyline, oral	Neuropathic pain / 10 – 25 mg once per day Depression / 10 – 25mg once per day	All hospitals, community health centres
Bisacodyl (senna), oral	Constipation / 5 – 10 mg once or twice per day	All hospitals, community health centres
Dexamethasone, oral and injectable	Neuropathic pain (not first line) Nausea or vomiting of some causes	All hospitals, community health centres

	Pain from liver capsule stretch of some causes or from splenic capsule stretch of some causes or from increased intra-cranial pressure of some causes or from inflammation due to radiation therapy. Fatigue Anorexia Depressed mood Allergic reactions Oral: 2 – 20 mg in 1 – 4 divided doses depending on indication. Injectable: 2 – 20 mg in 1 – 4 divided doses depending on indication.	
Diazepam, oral and injectable	Seizure / 5 – 10 mg intravenous as needed Anxiety / 5 mg orally every 8 – 12 hours as needed; 2 – 5 mg IV every 8 – 12 hours as needed Agitation (not first line) / 5 mg orally every 8 – 12 hours as needed; 2 – 5 mg IV every 8 – 12 hours as needed Insomnia (not first line) / 5 mg orally or 2 – 5 mg IV at bedtime Painful muscle spasm / 5 mg orally every 8 – 12 hours as needed; 2 – 5 mg IV 2 – 3 times per day as needed	All hospitals, community health centres
Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate), oral and injectable	Nausea or vomiting (not 1st line) / 12.5 – 25 mg orally or IV 2 – 4 times per day as needed Allergic reactions / 25 mg orally or IV every 6 – 8 hours as needed Dystonic reactions / 25 mg orally or IV once	All hospitals, community health centres
Fluconazole oral	Odynophagia due to oropharyngeal or esophageal candidiasis / 100 – 400 mg once per day depending on situation	All hospitals, community health centres
Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline or citalopram), oral	Depression or chronic anxiety: 20 mg once per day	All hospitals, community health centres

Furosemide, oral and injectable	Dyspnea due to pulmonary edema or pain due to peripheral edema / 20 – 40 mg orally up to every 6 hours depending on the situation; 10 – 20 mg IV up to every 6 hours depending on the situation	All hospitals, community health centres
Hyoscine butylbromide, oral and injectable	Dyspnea due to terminal respiratory secretions / 20 mg every 2 hours orally or 0.4 mg every 2 hours IV as needed Intestinal cramping / 20 mg every 2 hours orally or 0,4 mg every 2 hours IV as needed	All hospitals, community health centres
Haloperidol, oral and injectable	Agitation / 0.5 – 2 mg orally or IV every 6 – 8 hours as needed or scheduled depending on situation Delirium / 0.5 – 2 mg orally or IV every 4 – 8 hours as needed or scheduled depending on situation Anxiety / 0.5 – 2 mg orally or IV every 4 – 8 hours as needed or scheduled depending on situation Insomnia / 1 – 2 mg orally or IV at bedtime Nausea of some types / 0.5 – 2 mg orally or IV every 4 – 8 hours as needed or scheduled depending on situation	All hospitals, community health centres
Ibuprofen (naproxen, diclofenac, or meloxicam), oral	Pain / 400 – 800 mg up to every 8 hours as needed or scheduled depending on situation	All hospitals, community health centres
Lactulose (sorbitol or polyethylene glycol), oral	Constipation / 15 – 30ml 1 – 4 times per days as needed or scheduled depending on situation Delirium due to hepatic encephalopathy / 15 – 30ml 1 – 4 times per days as needed or scheduled depending on situation	All hospitals, community health centres
Loperamide, oral	Diarrhea / 2 – 4mg once, followed by 2 mg up to 4 times per day as needed	All hospitals, community health centres
Metaclopramide, oral and injectable	Nausea or vomiting of some types / 5 – 10mg orally or IV every 6 hours as needed or scheduled depending on situation	All hospitals, community health centres
Metronidazole, oral tablets to be crushed for topical application	Crush 2 – 4 500mg tablets to fine powder and sprinkle on malodorous wound with each dressing change	All hospitals, community health centres

Morphine, oral immediate-release and injectable	Moderate or severe pain / 5 – 10mg orally every 4 hours as needed or scheduled depending on situation; 2 – 4mg IV every 4 hours as needed or scheduled depending on situation Terminal dyspnea / 2 – 4mg IV every 4 hours as needed or scheduled depending on situation	All hospitals, community health centres (assuming risk of diversion is small)
Naloxone, injectable	Respiratory depression due to accidental morphine overdose / 0.08 – 0.12mg IV every hours as needed	All hospitals, community health centres
Omeprazole oral	Chest or abdominal pain possibly due to gastritis, peptic ulcer disease, or reflux esophagitis / 20mg every 12 – 24 hours	All hospitals, community health centres
Ondansetron, oral and injectable	Nausea due to cancer chemotherapy or radiation therapy / 4 – 8mg orally or IV	Only hospitals that provide cancer chemotherapy or radiotherapy
Paracetamol oral	Pain / 500 – 1000mg every 6 – 8 hours as needed or scheduled depending on situation Fever / 500 – 1000mg every 6 – 8 hours as needed or scheduled depending on situation	All hospitals, community health centres
Petroleum jelly, topical	Wounds / apply to gauze with dressing changes	All hospitals, community health centres

Acceptable alternatives for some medicines in the essential package:

- **Bisacodyl**: Another stimulant laxative, senna, is an acceptable alternative but is less effective (no effect on small bowel).
- **Diphenhydramine**: Other 1st generation antihistamines – chlorpheniramine, cyclizine, or dimenhydrinate – are acceptable alternatives. Both an oral and an injectable formulation should be accessible.
- **Fluoxetine**: Other selective serotonin re-uptake inhibitors (SSRIs) sertraline or citalopram are acceptable alternatives.
- **Ibuprofen**: Others non-steroidal anti-inflammatory medicines (NSAIDs) – naproxen, diclofenac, or meloxicam – are acceptable alternatives.
- **Lactulose**: Other osmatic laxatives sorbitol or polyethylene glycol are acceptable alternatives but lack the added benefit of treating hepatic encephalopathy.

2.1.1.2. Doses chosen for estimating costs

After the list of essential palliative medicines was finalized, the global average dose of each medicine needed to treat the symptoms from each condition in 2015 was estimated by consensus or Commissioners with clinical expertise (**Table 2B**).

Table 2B. Estimates of global average dose of each medicine needed to treat the symptoms of each condition in 2015.

Table8. Amount of Medicine for patients per condition

		List of Drugs																															List of Equipment						
	ICD 10 conditions that most often genera	Amitriptyline	Bisacodyl	Dexamethasone oral	Dexamethasone parenteral	Diazepam oral	Diazepam parenteral	Diphenhydramine oral	Diphenhydramine parenteral	Fluconazole oral	Fluconazole parenteral	Fluoxetine or other SSRI	Furosamide oral	Furosamide parenteral	Hyoscine butylbromide oral	Hyoscine butylbromide parenteral	Haloperidol oral	Haloperidol parenteral	Ibuprofen	Lactulose (ml)	Loperamide	Metaclopramide oral	Metaclopramide parenteral	Metronidazole tabs or caps for topical care	Morphine oral	Morphine parenteral	Naloxone Parenteral	Omeprazole oral	Ondansetron oral	Ondansetron parenteral	Oxygen (days receiving on average 3L per minute)	Paracetamol oral	Petroleum jelly (applications)	Pressure Reducing Mattress	Nasogastric drainage or feeding tube	urinary catheters	Opioid lock box *	Flashlight with rechargeable battery	Cotton to make adult diapers	Plastic to make adult diapers
1	A96,98,99: Hemorrhagic fevers	0	0	4	4	8	12	25	50	0		0	0	0	80	3.2	4	8	0	0	8	40	40	0	40	40	0	80	0	0	1	8000	1	0	0	0		0	2	2
2	A15-19: TB / the 13% of deaths (190,000) from M/XDR TB (100% of those)	120	400	0	24	12	12	640	180	0	0	480	0	0	0	0	96	24	12,000	0	240	2400	180	1440	240	24	0	1800	0	0	7	60,000	24	1	0	1		1	10	10
2a	A15-19: TB / the 80,000 with M/XDR TB on treatment who have not died (100% of those)	45	18	0	9	1.8	0	293	90	0	0	180	0	0	0	0	60	9	4500	0	90	900	45	0	90	0	0	1800	0	0	0	22,500	0	0	0	0		1	0	0
2b	A15-19: TB / the 87% (1.3 million) who died from TB that was NOT MDR (90% of those)	45	52.5	0	2	10.5	10.5	0	0	0	0	21	0	0	0	0	5	10	1050	0	10	0	0	126	21	21	0	0	0	0	7	2100	21	1	0	1		1	5	5
3	B20-24: HIV disease / 100%	675	0	2.7	5.4	27	13.5	400	300	1600	1600	540	0	0	500	5.4	68	54	13,500	0	200	450	135	1620	540	135	0	540	0	0	7	67,500	54	1	0	2		1	50	50
3a	B20-24: HIV disease - nondecedent	675	0	0	0	27	0	400	0	1600	0	540	0	0	400	0	20	0	6,000		50	120	0	0	150	0	0	50	0	0	0	40,000	0	0	0	0		1	0	0
4	C00-97: Malignant neoplasms (except C91-95)	1125	1000	56	56	150	26.25	22.5	22.5	500	200	360	120	90	32	32	90	63	25200	180	3	360	90	1800	8100	900	0.002	1200	200	48	3	90,000	27	1	1	1		1	10	10
4a	C00-97: Malignant neoplasms (except C9	400	720	20	0	150	0	5	0	50	0	240	0	0	0	0	10	0	24000	180	16	200	0	0	480	0	0	900	200	24	0	120000	4	0	0	0		1	0	0
5	C91-95: Leukemia	90	270	45	45	4.5	4.5	293	146	200	200	180	90	90	90	1.8	23	18	0	90	0.9	180	45	270	900	90	0	900	90	45	1	45,000	9	1	0	0		1	3	3
6	F00-04: Dementia	0	180	0	0	9	5.4	0	0	100	100	0	0	0	0	0	400	36	3600	18	0	0	0	540	180	90	0	100	0	0	0	18,000	36	1	0	4		1	45	45
6a	F00-04: Dementia - nondecedents	0	50	0	0	0	0	0	0	0	0	0	0	0	0	0	150	0	3600	10	0	0	0	0	10	0	0	100	0	0	0	18,000	0	0	0	0		1	10	10
7	G00-09: Inflammatory dz of CNS	0	40	0	12	4.8	24	0	25	0	0	0	0	0	0	0	0	20	1000	0	0	0	0	0	120	40	0	0	0	0	0	18,000	0	0	0.3	2		1	10	10
8	G20-26; G30-32; G35-37; G40-41; G80-83 Extrapyramidal & mvt disorders; other degen dz of CNS; Demyelinating dz of CNS; Epilepsy; Cerebral palsy & other paralytic syndromes /	180	200	4.8	4.8	24	12	0	0	100	0	200	0	0	0	0	10	10	12,000	0	0	0	0	720	240	48	0	1200	0	0	0	60,000	48	1	0.25	3		1	45	45
8a	Parkinsons - nondecedents	0	90	0	0	0	0	0	0	0	0	40	0	0	0	0	5	0	6000	0	0	0	0	0	30	0	0	200	0	0	0	30,000	0	0	0	0		1	5	5
8b	Multiple sclerosis - nondecedents	60	120	4	0	15	0	0	0	100	0	80	0	0	0	0	0	0	8,000	0	0	0	0	0	80	0	0	300	0	0	0	45,000	0	0	0	0		1	5	5
9	I60-69: Cerebrovascular diseases	0	90	0	0	0	45	0	0	0	0	90	0	0	0	0.9	18	18	0	90	0	90	90	270	90	90	0	0	0	0	0	18,000	45	1	0.5	1		1	45	45
9a	I60-69: Cerebrovascular diseases - nonde	0	30	0	0	0	10	0	0	0	0	90	0	0	0	0	5	0	0	90	0	0	0	0	10	0	0	0	0	0	0	9000	0	0	0	0		1	5	5
10	I05-09; I25; I42 & I50: Chronic rheumatic heart diseases; Cardiomyopathy & Heart failure	0	240	0	0	12	6	0	0	0	0	120	2400	300	120	2.4	12	6	0	0	0	60	0	0	360	120	0	240	0	0	7	12,000	0	0	0	0		1	5	5
11	I25: Chronic ischemic heart disease	0	360	0	0	36	18	0	0	0	0	180	180	45	0	0	9	0	0	0	0	90	0	0	360	180	0	900	0	0	5	18,000	0	0	0	0		1	2	2
12	J40-47; J60-70; J80-84; J95-99: Chronic lower respiratory dz; lung dz due to external agents; interstitial lung dz; other dz of resp system	0	180	180	90	36	18	0	0	400	200	360	360	180	45	1.8	36	18	0	0	0	0	0	0	360	180	0	0	0	0	30	18,000	0	0	0	0		1	5	5
13	K70-77: Diseases of liver	0	90	0	0	0	0	563	281	0	0	90	900	180.0000	0.0000	0.9000	45.0000	23.0000	0	1350	0	180	45	0	180	90	0	1800	0	0	1	0	0	1	0	1		1	15	15
14	N17-19: Renal failure	0	45	9	0	9	0	281	90	0	0	90	1800	900	0	0.9	18	6	0	0	0	90	45	0	180	90	0	0	0	0	1	22,500	0	0	0	0		1	5	5
15	P07; P10-15: Low birth weight & prematurity; Birth trauma	0	0	0	0	1.4	1.4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	42	0	0	0	0	2	2100	0	0	1	0		0	0	0
16	Q00-99: Congenital malformations	0	15	0	0	3	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	24	60	0	0	0	0	0	4500	3	1	0	0		1	20	20
16a	Q00-99: Congenital malformations - nondecedents		15	0	0	5	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	24	0	0	0	0	0	0	9,000	0	0	0	0		1	10	10
17	S00-99; T00-98; V01-Y98: Injury, poisoning, external causes	0	50	0	0	10	5	31	63	0	0	0	0	0	0	0	0	0	2000	0	0	0	0	0	300	100	0.001	0	0	0	0	20,000	0	1	0	1		1	0	0
18	I70: Athrosclerosis	562.5	225	0	0	0	0	0	0	0	0	90	90	0	0	0.9	18	18	0	90	0	270	18	2700	1800	180	0	180	0	0	0	29250	54	1	0	1		1	5	5
19	M00-97: Musculoskeletal disorders	360	180	0	0	720	0	0	0	0	0	180	0	0	0	0	0	0	72000	360	0	0	0	0	360	36	0.001	1800	0	0	0	180000	0	0.1	0	0		1	5	5
20	E40-46: Malnutrition	0	0	0	0	2	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	2	2	0	0	0	0	0	2,000	0	1	1	0		1	5	5

2.1.1.3. Essential palliative equipment

Equipment for the essential package was chosen using the following criteria:

- Deemed by a panel of physician-experts in clinical palliative care in LMICs to be essential for relief of at least one type of physical or psychological suffering identified on our estimation of global burden of SHS.
- Easy to obtain
- Easy to use
- Inexpensive

This equipment consists of:

- Nasogastric tubes to relieve vomiting from bowel dysfunction or inoperable obstruction and, in some cases, to give medicines or fluids.
- Urinary catheters to relieve bladder dysfunction or outlet obstruction.
- Pressure-reducing mattresses to prevent or help treat pressure ulcers and relieve associated pain.
- Flashlight with rechargeable battery to enable safe administration of medicines and patient care in the home at night where there is no electricity.
- Cotton and plastic bags to make adult diapers to reduce risk of skin ulceration and infection and caregiver burden.
- Opioid lock-box that can be secured to a wall or immovable object.
- Oxygen to be used for dyspnea at 1 – 10 L/min via mask or nasal cannula as needed (for costing, 3L/min oxygen was used.).

Opioid lock-boxes that can be affixed to a wall of large piece of furniture are a critical part of a secure opioid supply chain recommended by WHO.[129]

2.1.1.4. Essential human resources for palliative care and pain control / Recommended model of palliative care integration into healthcare systems

We based our recommendations for palliative care human resources on the burden of SHS and on our estimates of the full-time equivalents (FTEs) of each type of staff member at each level of the healthcare system needed to palliate SHS. One step in making these estimates was to estimate the number of inpatient stays and outpatient visits at each level of the healthcare system required by each patient with each condition (**Table 2C**).

Table 2C. Number of inpatient stays and outpatient visits required by each patient per condition

Table9. Number of days receiving pc at different sites								
	ICD 10 conditions that most often genera	Total number of days rece		Referral Hosp	Provincial Ho	District Hosp	Communi	Home
1	A96,98,99: Hemorrhagic fevers	7	Inp	3	0	3	0	
			Outp	0	0	0	1	2 visits + 1 bereavement
2	A15-19: TB / the 13% of deaths (190,000) from M/XDR TB (100% of those)	180	Inp	30	15	15	0	
			Outp	4	4	4	4	(home visit frequency) every day (pc can be provided by DOT worker) + 1 bereavement=181
2a	A15-19: TB / the 80,000 with M/XDR TB on treatment who have not died (100% of those)	90	Inp	10	10	10	0	
			Outp	3	3	3	3	(home visit frequency) every day (pc can be provided by DOT worker) = 90
2b	A15-19: TB / the 87% (1.3 million) who died from TB that was NOT MDR (90% of those)	21	Inp	1	1	1	0	
			Outp	1	1	1	2	(home visit frequency) every day (pc can be provided by DOT worker)+ 1 bereavement =22
3	B20-24: HIV disease / 100%	160	Inp	7	7	7	0.25	
			Outp	5	5	5	6	(home visit frequency) 2 months everyday, 2 months 3 times a week, the rest 2 times per week+ 1 bereavement =116
3a	B20-24: HIV disease - nondecedent	210	Inp	1	1	1		
			Outp	3	3	3	6	(home visit frequency) 1 month 3 times per week, 1 month 2 times per week, the rest 1 time per week=41
4	C00-97: Malignant neoplasms (except C91-95)	120	Inp	10	0	14	0.25	
			Outp	3	0	6	4	(home visit frequency) 2 months everyday, 2 months 3 times a week, the rest 2 times per week+ 1 bereavement =88
4a	C00-97: Malignant neoplasms (except C9	150	Inp	1	0	0	0	
			Outp	2	2	3	4	(home visit frequency) once per week=21
5	C91-95: Leukemia	90	Inp	7	7	7	0	
			Outp	4	1	2	2	(home visit frequency) 2 weeks everyday, the rest of the time 3 times a week + 1 bereavement=48
6	F00-04: Dementia	150	Inp	3	3	3	0.25	
			Outp	1	1	1	5	(home visit frequency) 2 months everyday, 2 months 3 times a week, the rest 1 time a week + 1 bereavement= 92
6a	F00-04: Dementia - nondecedents	150	Inp	0	0	1	0	
			Outp	1	1	2	4	(home visit frequency) 2 months 3 times per week, the rest 1 time per week =40
7	G00-09: Inflammatory dz of CNS	30	Inp	12	12	4	0.25	
			Outp	0	0	0	0	(home visit frequency) 1 month everyday, the rest 3 times a week=30, + 1 bereavement
8	G20-26; G30-32; G35-37; G40-41; G80-83 Extrapyramidal & mvt disorders; other degen dz of CNS; Demyelinating dz of CNS; Epilepsy; Cerebral palsy & other paralytic syndromes /	120	Inp	2	2	8	0.25	
			Outp	0	0	4	5	(home visit frequency) 1 month everyday, 2 months 3 times a week, the rest 1 time per week+ 1 bereavement = 62
8a	Parkinsons - nondecedents	90	Inp	2	2	1	0	
			Outp	1	1	3	4	(home visit frequency) 1 month 3 times per week, the rest 1 time per week =21
8b	Multiple sclerosis - nondecedents	120	Inp	0	1	2	0	
			Outp		2	2	4	(home visit frequency) 1 month 3 times per week, the rest 1 time per week = 25
9	I60-69: Cerebrovascular diseases	90	Inp	4	4	7	0.25	
			Outp	1	2	4	2	(home visit frequency) 2 weeks everyday, the rest 3 times a week + 1 bereavement = 48
9a	I60-69: Cerebrovascular diseases - nonde	120	Inp	1	1	2	0	
			Outp	1	1	3	3	(home visit frequency) 1 month 3 times per week, the rest 1 time per week=25
10	I05-09; I25; I42 & I50: Chronic rheumatic heart diseases; Cardiomyopathy & Heart failure	120	Inp	5	5	3	0.2	
			Outp	2	2	2	3	(home visit frequency) 4 weeks everyday, the rest 3 times a week + 1 bereavement = 68
11	I25: Chronic ischemic heart disease	180	Inp	7	0	7	0.25	
			Outp	6	0	7	4	(home visit frequency) 2 weeks everyday, the rest of the time 3 times a week + 1 bereavement = 91
12	J40-47; J60-70; J80-84; J95-99: Chronic lower respiratory dz; lung dz due to external agents; interstitial lung dz; other dz of resp system	180	Inp	7	4	4	0.25	
			Outp	2	4	4	6	(home visit frequency) 1 month everyday, the rest of the time 3 times a week + 1 bereavement =94
13	K70-77: Diseases of liver	90	Inp	4	4	4	0.25	
			Outp	2	3	3	4	(home visit frequency) 3 weeks everyday, the rest of the time 3 times a week + 1 bereavement =52
14	N17-19: Renal failure	90	Inp	4	3	4	0	
			Outp	1	2	4		(home visit frequency) 3 weeks everyday, the rest of the time 3 times a week + 1 bereavement = 52
15	P07; P10-15: Low birth weight & prematurity; Birth trauma	14	Inp	7	6	0	0	
			Outp	0	0	0	0	3 visits total for emotional or bereavement support =3
16	Q00-99: Congenital malformations	30	Inp	10	5	0	0	
			Outp	1	1	0	1	(home visit frequency) daily + 1 bereavement = 31
16a	Q00-99: Congenital malformations - nond	120	Inp	3	2	2	0	
			Outp	2	2	2	4	(home visit frequency) 3 days per week for 1 month, the rest 1 day per week =25
17	S00-99; T00-98; V01-Y98: Injury, poisoning, external causes	10	Inp	5	5	0	0	
			Outp	0	0	0	0	1 bereavement for deaths
18	I70: Athrosclerosis	90	Inp	5	5	5	0.25	
			Outp	0	2	4	6	3 weeks everyday, the rest of the time 3 times a week + 1 bereavement for deaths = 52
19	M00-97: Musculoskeletal disorders	360	Inp	0	0	0	0	
			Outp	1	1	2	4	(home visit frequency) once per week=51, + 1 bereavement for deaths
20	E40-46: Malnutrition	10	Inp	2	3	5		
			Outp	0	0	0	0	(home visit frequency) 1 bereavement visit

Using these data and available recommendations on integrating palliative care and pain control into healthcare systems,[130, 131] we drafted an initial model of palliative care staffing throughout healthcare systems intended mainly for LMICs. This model was reviewed and refined by our

panel of physician-experts in clinical palliative care in LMICs, and reviewed a final time by the Commissioners (**Table 2D**).

Table 2D. Human resources needed to provide essential palliative care and pain control at each level of the healthcare systems in LMICs.

Table 2D. Human Resource Allocation and Capacity for Palliative Care					
	FTE of staff involved in providing pc at each site				
Team Membership	Referral Hospital	Provincial Hospital	District Hospital	Community Health Center	Home
Doctors	2	1	0.5	0.2	0.04
Nurses	2	1.5	1	0.85	0.15
Social workers and counsellors	1.4	1.2	0.6	0.2	0.15
Psychiatrist, psychologist, or counsellor	0.4	0.2	0	0	0
Physical Therapist	0.1	0.1	0	0	0
Pharmacist	0.4	0.2	0.2	0.1	0
Community Health Workers	0	0	0	0	1
Clinical Support Staff (diagnostic imaging, Lab)	0.05	0.02	0.01	0	0
Non Clinical Support Staff (Housekeeping, administration, Dietary)	0.5	0.25	0.1	0.05	0
Capacity inpatient/outpatient	20/30	10/15	4/10	1/5	5

The basic structure of the model is as follows:

- Levels of the healthcare system:
    - Referral and provincial hospitals: a multi-disciplinary palliative care team, ideally including at least one palliative care specialist physician, that:
        - Staffs an inpatient ward for patients with the most complicated or refractory SHS;
        - Staffs a palliative care outpatient clinic;
        - Provides palliative care consultation to any colleague throughout the hospital.
    - District hospitals: a small multi-disciplinary palliative care team that:
        - Staffs a small inpatient ward or a few inpatient beds for patients with SHS that cannot be controlled at community level but does not require specialist palliative care;
        - Staffs a palliative care outpatient clinic;
        - Provides palliative care consultation to any colleague throughout the hospital.
    - Community health centers: One or more doctors, nurses, social workers, and pharmacists with basic training in palliative care who:
        - Provide inpatient end-of-life care for a maximum of one patient at a time if higher level care is not required but the family cannot care adequately for the patient at home;
        - Provide outpatient palliative care;

        - Supervise community health workers;
        - Make home visits as needed.
    - Patients' homes:
        - Visits from community health workers as often as daily if needed:
            - To provide emotional support;
            - To monitor for uncontrolled SHS;
            - To monitor for unfulfilled basic needs such as food or shelter or clothing;
            - To monitor for flagrantly improper use of medications;
            - To report any of the above to a supervisor at the community health center.
        - Visits as needed from a doctor or nurse from the community health center.
- Communication between levels
    - The model emphasizes care in the community and at home where most patients are and wish to be and where the cost of care is lowest. Thus, integration of palliative care into standard, community-level primary care is of highest priority. However, it is crucial that staff at each level can obtain advice or consultation from staff members with more advanced training at a higher level up to referral centers. It also is crucial that patient transfers are made smoothly between levels with concomitant transfer of medical records. For example, when a patient is diagnosed with end-stage cancer at a referral hospital, symptoms are controlled by the palliative care team at that level and arrangements are being made for the patient to return home for end-of-life care. It is crucial that the health center in the patient's community be informed of the impending transfer, that all necessary medical information be sent with the patient, and that the community health worker in the patient's village or ward be informed about the patient and briefed on how to monitor the patient's well-being.

We recognize that the FTEs can be divided in different ways. For example, the 2.0 physician FTEs at referral hospitals can be fulfilled by 2 physicians practicing palliative care full-time or by four physicians practicing palliative care, half-time. We also recognize that staffing should ideally be based on competencies rather than professions, and that task shifting in medicine and palliative care has been proven successful in some places. In Uganda, for example, nurses with special training are able to prescribe morphine.[132] However, our recommended staffing enables reasonable estimation of cost to integrate palliative care into healthcare systems and can be used as a starting point for countries where task shifting has not yet been introduced.

The essential package includes FTEs for psychologists. Basic psychological counseling may be provided not only by psychologists but also by physicians, nurses, or social workers at any level of the health care system with basic training in palliative care or psychological counseling. Recent data indicate that supervised and adequately trained community health workers also can provide basic mental health interventions.[158] However, the high prevalence of anxiety and depressive disorders in patients with serious, complex, or life-limiting health problems, and the

frequent effectiveness of psychotherapies for these disorders, makes participation of trained psychotherapists in palliative care essential. Similarly, psychotherapy has been shown to be effective in many cases of complicated grief.[133] For patients or family members with more severe psychiatric problems such as psychotic disorders or bipolar disorder, referral should be made to a psychiatrist, if possible. For spiritual counseling, hospitals should allow local spiritual counselors to visit inpatients if requested by the patient or family.

2.2 Assumptions and limitations

The essential package of palliative care and pain control is designed to be the minimum medicines, equipment, basic needs supports, and human resources required to relieve most remediable suffering of adults and children. It does not contain everything that could be useful in this regard, only what every country, including the lowest income, should make universally accessible. We recognize that, in some cases, some types of suffering may become refractory to all interventions made possible with the essential package. For example, cancer pain may sometimes become refractory to morphine regardless of dose and to all adjuvant pain medicines in the essential package. Major depressive disorder may become refractory to both classes of anti-depressants in the essential package. For this reason, augmented packages of palliative care should be created that include, for example, palliative radiation therapy and neuraxial analgesia for refractory cancer pain, and palliative sedation for the most extreme and refractory of suffering. These, however, are beyond the scope of this Commission. We also recognize that there may be differences of expert opinion about what medicines, equipment, basic needs supports, or human resources are essential, in part because clinical circumstances vary around the world. We welcome discussion of our recommendations and creation of essential palliative care packages for specific regions or populations such as children, the elderly, or victims of health emergencies and crises.

The Commission chose not to estimate separately the SHS of adults and children, nor to create separate essential packages of palliative care for adults and children. We did this in part to minimize the complexity of implementing palliative care for LMICs. However, the Commission recognizes that children are at particular risk of inadequate access to palliative care. Therefore, we took care to include an estimation of the SHS of children in our global estimates. For example, we include in our estimation of SHS exclusively pediatric conditions such as preterm birth complications, birth asphyxia and birth trauma. We also include the medicines, equipment, and human resources that we deem essential for pediatric palliative care in our essential package. We welcome and encourage efforts to estimate more precisely the specific SHS of children and to craft essential packages of palliative care specifically for children.

3 Costing the Essential Package of Palliative Care

Country-specific data were collected to complete an ingredient based costing framework and was constructed using the following elements: Drug costs, basic needs support costs, medical equipment costs and human resource costs. This corresponds to the itemized components of the package described in section 2.1.

3.1 Sources of costing data by country

A data collection form was created requesting information on the units necessary and the price per unit of the components of the package, as listed in table 3A, as well as time allocation towards palliative care and monthly salary information on different cadres of health workers, as listed in table 3B, was sent to one facility in Ho Chi Minh City, Vietnam. Further, costing data from Mexico and Rwanda were acquired through secondary sources as detailed below.

Sources of data:

- **Vietnam**:
  - Public sector wholesale buyer prices reported by Ho Chi Minh City Cancer Hospital, Ho Chi Minh, Vietnam.
  - In Vietnam, prices to the patient cannot by law be more than 5% higher than the price to the hospital. Thus, a mark-up of up to 5% may or may not apply.
- **Rwanda**:
  - Public sector retail prices reported by Kibagabaga Hospital, Rwanda, using the government tarification document, in which the Rwanda Ministry of Health regulated the retail price for all major medicines and medical equipment.
  - The wholesale buyer prices were calculated by dividing the retail price by 1.2, because according to a policy document, hospitals in Rwanda are allowed to add up to 20% to the costs they spend on medicines and medical equipment procurement.
- **Mexico**:
  - The public sector wholesale buyer prices of medicines, materials, supplies, and medical equipment were obtained from Compranet, the Mexican electronic system for government procurement,[134] which is available online and collected for the three main public institutions that provide services in Mexico (Mexican Social Security Institute - IMSS, Institute for Social Security and Services for State Workers - ISSSSTE, and the National Commission for Social Protection in Health – Seguro

Popular). The lowest price between these three major health providers for each medicine was used, and that each price includes delivering the medicine to the hospital.

- Human resource costs were obtained from annual data from the Ministry of Health.[135] Where we found several medical personnel salary price points, we used the lowest salary found among the different providers.

Table 3A. Data Collection Form on Costing of Palliative Care Essential Package_Medicines and Medical Equipment

Table3A. Data Collection Form on Costing of Palliative Care Essential Package			
Name of Drugs	**Unit**(mg per unit)	**Price per unit (in local currency)**	**Note**
Amitriptyline			
Bisacodyl			
Dexamethasone oral			
Dexamethasone parenteral			
Diazepam oral			
Diazepam parenteral			
Diphenhydramine oral			
Diphenhydramine parenteral			
Fluconazole oral			
Fluconazole parenteral			
Fluoxetine or other SSRI			
Furosamide oral			
Furosamide parenteral			
Hyoscine butylbromide oral			
Hyoscine butylbromide parenteral			
Haloperidol oral			
Haloperidol parenteral			
Ibuprofen			
Lactulose (ml)			
Loperamide			
Metaclopramide oral			
Metaclopramide parenteral			
Metronidazole tabs or caps for topical care			
Morphine oral			
Morphine parenteral			
Naloxone Parenteral			
Omeprazole			
Ondansetron oral			
Ondansetron parenteral			
Oxygen (days receiving on average 3L per minute)			
Paracetamol oral			
Petroleum jelly (application)			
Name of Equipment	**Unit**	**Price per unit**	**Note**
Opioid lock box			
Flashlight with rechargeable battery			
Cotton to make adult diapers			
Plastic to make adult diapers			
Pressure reducing mattress			
Nasogastric drainage tube			
Urinary catheter			

Table 3B. Data Collection Form on Costing of Palliative Care Essential Package: Monthly Salaries of Palliative Care Team Members

Table3B. Data Collection Form on Costing of Palliative Care Essential Package: Monthly Salaries of Palliative Care Team Members			
Team Members	Full-time / If part-time, please specify hours per week (estimate)	Monthly Salary (in local currency) **Gross salary**	Note
Doctors			
Nurses			
Social Workers			
Spiritual Counselor			
Psychologist or Psychiatrist			
Physical Therapist			
Pharmacist			
Community Health Workers			
Clinical Support Staff (Diagnostic Imaging, Lab)			
Legal Counsel Experts			
Non Clinical Support Staff (Housekeeping, Administration, Dietary)			

Table 3C. Reference country prices for medicines, equipment, human resources, and social supports (prices of drugs are per mg)

	PRICE PER MG IN COUNTRY'S CURRENCY			PRICE PER MG IN US$ CURRENT, 2015		
	Income country regions			Income country regions		
	Low	Lower-middle	Upper-middle	Low	Lower-middle	Upper-middle
Items included in each package	Rwanda	Vietnam	Mexico	Rwanda	Vietnam	Mexico
Medicine						
Amitriptyline (Tabs or caps 25 mg)	$2.80000	$8.40000	$0.02574	$0.00388	0.000387	$0.001624
Bisacodyl (Tabs or caps 5 mg)	$10.00000	$56.80000	$0.00565	$0.01387	0.002618	$0.00036
Dexamethasone Oral(Tabs or caps 0.5 mg)	$10.00000	$90.00000	$0.83133	$0.01387	0.004148	$0.05246
Dexamethasone parenteral (Ampoule 5 mg/ml)	$12.50000	$220.00000	$0.23625	$0.01734	0.010139	$0.01491
Diazepam oral (Tabs 5mg)	$3.00000	$25.00000	$0.02430	$0.00416	0.001152	$0.00153
Diazepam parenteral (Ampoule 5mg/ml)	$20.00000	$326.00000	$0.35856	$0.02774	0.015025	$0.02262
Diphenhydramine or cyclizine oral (Tabs or caps 25 mg)	$4.00000	$83.50000	$0.01400	$0.00555	0.003848	$0.00088
Diphenhydramine or cyclizine parenteral	$20.00000	$63.00000	$0.10970	$0.02774	0.002904	$0.00692
Fluoxetine or other SSRI (Tabs or caps 20 mg)	$100.00000	$125.00000	$0.01654	$0.13870	0.005761	$0.00104
Furosamide oral (Tabs or caps 40 mg)	$1.00000	$5.10000	$0.00244	$0.00139	0.000235	$0.00015
Furosamide parenteral (Ampoule 10 mg/ml)	$10.00000	$47.25000	$0.08680	$0.01387	0.002178	$0.00548
Haloperidol oral	$2.50000	$48.00000	$0.09500	$0.00347	0.002212	$0.00599
Haloperidol parenteral	$2.00000	$315.00000	$2.20020	$0.00277	0.014518	$0.13883
Hyoscine butylbromide oral (Tabs or caps 10 mg)	$3.00000	$100.00000	$0.07760	$0.00416	0.004609	$0.00490
Hyoscine butylbromide parenteral (Ampoule 20 mg/ml)	$30.00000	$418.80000	$0.05883	$0.04161	0.019302	$0.00371
Ibuprofen	$0.07500	$1.96000	$0.03104	$0.00010	0.000090	$0.00196
Lactulose (Bott 240 ml - 3.35 gr/ml)	$5.00000	$181.86667	$0.00181	$0.00694	0.008382	$0.00011
Loperamide (Tabs or caps 2 mg)	$10.00000	$63.00000	$0.08292	$0.01387	0.002904	$0.00523
Metaclopramide oral (Tabs or caps 10 mg)	$0.50000	$183.10000	$0.01120	$0.00069	0.008439	$0.00071
Metaclopramide parenteral (Ampoule 5 mg/ml)	$15.00000	$150.00000	$0.10200	$0.02081	0.006913	$0.00644
Metronidazole tabs or caps for topical care	$0.04000	$0.44800	$0.00021	$0.00006	0.000021	$0.00001
Morphine oral (IC, sustained-release. Tabs or caps 3 mg))	$13.33333	$199.50000	$0.11398	$0.01849	0.009195	$0.00719
Morphine parenteral (Ampoule 10 mg/ml)	$60.00000	$294.00000	$7.19920	$0.08322	0.013550	$0.45426
Omeprazole oral (Tabs or caps 20 mg)	$1.50000	$5.73333	$0.00807	$0.00208	0.000264	$0.00051
Ondansetron oral(Tabs or caps 4 mg)	$15.00000	$1,037.50000	$0.17500	$0.02081	0.047816	$0.01104
Ondansetron parenteral (Ampoule 2 mg/ml)	$150.00000	$1,062.50000	$0.52083	$0.20805	0.048969	$0.03286
Paracetamol oral (Tabs or Caps 500 mg)	$0.02000	$0.79800	$0.00050	$0.00003	0.000037	$0.00003
Petroleum jelly/ VASELINA gelatina	$0.60000	$1,166.66667	$5.94000	$0.00083	0.053769	$0.37480
Naloxone Parenteral (Ampoule 0.4 mg/ml)	$500.00000	$90,562.50000	9.85474	$0.69351	4.173854	$0.62182
Fluconazole oral (Tabs or caps 150 mg)	$6.00000	$66.66667	0.00423	$0.00832	0.003073	$0.00027
Fluconazole parenteral (Vial 2 mg/ml)	$75.00000	N/A	0.11967	$0.10403	N/A	$0.00755
Medical Equipment						
Air mattress	$8,000.00000	$199,000.00000	792.00000	$11.10	9.171534	$49.97391
Nasogastric drainage or feeding tube /	$500.00000	$7,560.00000	1.55000	$0.69	0.348426	$0.09780
Oxygen (days receiving on average 3L per minute) /	$15,240.00000	$6,090.00000	124.37500	$21.14	0.280677	$7.84786
urinary catheters/	$500.00000	$9,660.00000	89.17000	$0.69	0.445211	$5.62648
Basic needs/Social Support for families below extreme poverty line only[1]						
Cash payment & housing per month	n/a	n/a	$101.52000	$8.00000	$24.00000	$6.40575
Food Package per month	n/a	n/a	$101.52000	$5.00000	$30.00000	$6.40575
Funeral cost	$15,000.00000	$3,000,000.00000	$4,645.00000	$20.80516	138.264331	$293.09193
In-kind support	n/a	n/a	$222.90000	$5.00000	$5.00000	$14.06463
Transportation costs	n/a	n/a	$67.42000	$2.50000	$2.50000	$4.25409
Others						
Palliative Chemotherapy	n/a	n/a	4751.00000	n/a	n/a	$299.78035
Palliative Radiation Therapy	n/a	n/a	1091.00000	n/a	n/a	$68.84032
Palliative Surgery	n/a	n/a	3094.00000	n/a	n/a	$195.22636
Team Membership						
Doctors	n/a	n/a	n/a	1022	$350.00000	1325
Nurses	n/a	n/a	n/a	561	$300.00000	1202
Social Workers	n/a	n/a	n/a	389	$50.00000	1094
Spiritual Counsellor	n/a	n/a	n/a	389	$0.00000	1202
Psychologist or psychiatrist	n/a	n/a	n/a	561	$225.00000	1440
Physical Therapist	n/a	n/a	n/a	389	$200.00000	900
Pharmacist	n/a	n/a	n/a	561	$350.00000	1120
Community Health Workers	n/a	n/a	n/a	28	$50.00000	844
Clinical Support Staff (diagnostic imaging, Lab)	n/a	n/a	n/a	419	$300.00000	900
Non Clinical Support Staff (House keeping, administration, Dietary)	n/a	n/a	n/a	69	$300.00000	1194

Note: For costing in Rwanda, Fluoxetine was substituted with a lower-cost selective serotonin reuptake inhibitor (SSRI), and reusable cloth diapers were used instead of disposable. Costing in Vietnam does not include Parenteral Fluconazole as pricing for this medicine was unavailable in the country.

Based on the design of the essential package, we estimated the amount of each drug and medical equipment needed for patients of each disease condition. Combined with the pricing data from countries, and number of patients of each disease condition calculated from WHO country specific mortality database (GHE 2015), we estimated the total costs of drugs and medical equipment as follows:

$$DC_l = \sum_{j=1}^{20} DU\ lj * DCPU\ l$$
$$TDC = \sum_{l=1}^{32} DC\ l$$

$$MEC_l = \sum_{j=1}^{20} MEU\ lj * MECPU\ l$$
$$TMEC = \sum_{l=1}^{6} MEC\ l$$

DC_l: drug costs for drug l
DU_{lj}: drug unit required for drug l per patient in disease j
$DCPU_l$: drug costs per unit for drug l
TDC: total drug costs

MEC_m: medical equipment costs for medical equipment m
MEU_{mj}: medical equipment unit required for medical equipment m per patient in disease j
$MECPU_m$: medical equipment costs per unit for medical equipment m
TMEC: total medical equipment costs

*j: disease conditions = [Hemorrhagic Fever, TB, HIV, Malignant Neoplasm, Leukemia, Cerebrovascular Disease, non-ischemic heart disease, ischemic heart disease, Dementia, other degenerative neurological disease, inflammatory disease of CNS, COPD and respiratory disease, disease of liver, renal failure, low birth weight and birth trauma, congenital malformation, injury, atherosclerosis, Musculoskeletal disorders and protein malnutrition]
*l : drugs = [Amitriptyline, Bisacodyl, Dexamethasone oral, Dexamethasone parenteral, Diazepam oral, Diazepam parenteral, Diphenhydramine oral, Diphenhydramine parenteral, Fluconazole oral, Fluconazole parenteral, Fluoxetine or other SSRI, Furosamide oral, Furosamide parenteral, Hyoscine butylbromide oral, Hyoscine butylbromide parenteral, Haloperidol oral, Haloperidol parenteral, Ibuprofen, Lactulose (ml) , Loperamide, Metaclopramide oral, Metaclopramide parenteral, Metronidazole tabs or caps for topical care, Morphine oral , Morphine parenteral, Naloxone Parenteral, Omeprazole, Ondansetron oral, Ondansetron parenteral, Oxygen (days receiving on average 3L per minute), Paracetamol oral, Petroleum jelly (application)]
*m : medical equipment = [Flashlight with rechargeable battery, Cotton to make adult diapers, Plastic to make adult diapers, Pressure reducing mattress, Nasogastric drainage tube, Urinary catheter]
*s: social support = [Cash payment and housing, Food package, Funeral support, In-kind support, Transportation]
There is one exception with the calculation of opioid lock boxes. It is not calculated by applying a certain ratio to number of patients; instead, we assumed one opioid lock box for each community health center team, as detailed below.

The costs of human resources were calculated based on the number of outpatient and inpatient visits required by patients of each disease condition at each location of care: referral hospital,

provincial hospital, district hospital, community health centers and home visits team. Thus, we estimated the amount of work load required at each of those locations in order to meet the inpatient and outpatient service needed by palliative care patients.

$$OPV_i = \sum_{j=1}^{20} OPVPPi\ j * NPj$$
$$IPN_i = \sum_{j=1}^{20} IPNPPi\ j * NPj$$

OPV_i: outpatient visits required at location i
$OPVPP_{ij}$: outpatient visits per patient required for disease j at location i
NP: number of patients for disease j

IPN_i: inpatient nights required at location i
$OPVPP_{ij}$: inpatient nights visits per patient required for disease j at location i
NP: number of patients for disease j

*i: location of care = [referral hospital, provincial hospital, district hospital, community health centers, home]
*j: disease conditions = [Hemorrhagic Fever, TB, HIV, Malignant Neoplasm, Leukemia, Cerebrovascular Disease, non-ischemic heart disease, ischemic heart disease, Dementia, other degenerative neurological disease, inflammatory disease of CNS, COPD and respiratory disease, disease of liver, renal failure, low birth weight and birth trauma, congenital malformation, injury, atherosclerosis, Musculoskeletal disorders and protein malnutrition]

We also established assumptions on how many of each professional are required at each location and their work load capacity in terms of number of outpatients visits and inpatient beds per day:

$PCPFT_{ik}$: full time equivalent of palliative care profession k required at location i
$OPVC_i$ = outpatient visits capacity (monthly) at location i
$IPNC_i$ = inpatient nights capacity (monthly) at location i

*i: location of care = [referral hospital, provincial hospital, district hospital, community health centers, home]
*k: different professionals required on a palliative care team = [doctors, nurses, social workers, spiritual counselors, psychologist or psychiatrist, physical therapist, pharmacist, community health worker, clinical support staff, non-clinical support staff]

Combining the data collected from partner countries on the monthly salary of each of those professionals, we calculated the total human costs of this country:

$$HRC_i = (\sum_{k=1}^{10} PCPFT\ ik * FTMS\ k) * MAX\left(\frac{OPV\ i}{OPVC\ i}, \frac{IPN\ i}{IPNC\ i}\right)$$
$$THRC = \sum_{i=1}^{5} HRC\ i$$
$$TOLBC = MAX\left(\frac{OPV\ community\ health\ center}{OPVC\ community\ health\ center}, \frac{IPN\ community\ health\ center}{IPNC\ community\ health\ center}\right) * OLBCPU$$

HRC_i: human resource costs at location i
THRC: total human resource costs
$FTMS_k$: Full time monthly salary for professional k
TOLBC: total opioid lock box costs
OLBCPU: opioid lock box costs per unit

The costing data on drugs, equipment and human resources from each country is summarized in data appendix **table 3C**.

Total drug costs (TDC), total medical equipment costs (TMEC), and total human resource costs (THRC) for each of the reference countries (Rwanda, Mexico, Vietnam) were divided by total patients in need of PC in the respective country to calculate cost per patient of the essential package (EP). We also considered the most basic operational inputs that are required to support the provision of the EP at every level of care. These include a small proportion of the cost of infrastructure maintenance, administrative overhead, basic laboratory and imaging facilities, emergency room services, and PC facility costs. Based on a literature review,[136, 137, 138, 139, 140] we added 8% operational cost overhead to our overall figures on the cost of the EP.

Table 3D. Sources of lowest and highest reported international drug prices, 2014
International Drug Price Indicator Guide (Price per mg) in US$ current, 2015

	International Buyer Prices [1]			
Medicine	Lowest price	Institution or organization	Highest price	Institution or organization
Amitriptyline (Tabs or caps 25 mg)	$0.00048	South Africa Department of Health (SAFRICA)	$0.00164	Sudan National Health Insurance Fund
Bisacodyl (Tabs or caps 5 mg)	$0.00220	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)	$0.00446	Barbados Drug Service (BDS)
Dexamethasone Oral(Tabs or caps 0.5	$0.01680	Peru Ministry of Health	$0.10080	Mission for Essential Medical Supplies (MEMS)
Dexamethasone parenteral (Ampoule 5 mg/ml)	$0.01650	Democratic Republic of Congo Integrated Health Program (IHP) (DRC/IHP)	$0.01650	Democratic Republic of Congo Integrated Health Program (IHP) (DRC/IHP)
Diazepam oral (Tabs 5mg)	$0.00146	Mission for Essential Medical Supplies (MEMS)	$0.00520	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)
Diazepam parenteral (Ampoule 5mg/ml)	$0.00866	Democratic Republic of Congo Integrated Health Program (IHP) (DRC/IHP)	$0.03900	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)
Diphenhydramine or cyclizine oral (Tabs or caps 25 mg)	$0.00040	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.	$0.00040	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.
Diphenhydramine or cyclizine parenteral	$0.00040	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.*	$0.00040	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.*
Fluoxetine or other SSRI (Tabs or caps 20	$0.00038	Barbados Drug Service (BDS)	$0.00106	Barbados Drug Service (BDS)
Furosamide oral (Tabs or caps 40 mg)	$0.00015	Democratic Republic of Congo Integrated Health Program (IHP) (DRC/IHP)	$0.00065	Mission for Essential Medical Supplies (MEMS)
Furosamide parenteral (Ampoule 10 mg/ml)	$0.00150	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.	$0.01890	Mission for Essential Medical Supplies (MEMS)
Haloperidol oral	$0.00226	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)	$0.00962	Sudan National Health Insurance Fund (SUDANNHIF)
Haloperidol parenteral	$0.00226	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.	$0.00962	(Costa Rica Social Security—CRSS)
Hyoscine butylbromide oral (Tabs or caps 10 mg)	$0.00039	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)	$0.00486	South Africa Department of Health (SAFRICA)
Hyoscine butylbromide parenteral (Ampoule 20 mg/ml)	$0.00700	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.	$0.01713	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)
Ibuprofen	$0.00002	Mission for Essential Medical Supplies (MEMS)	$0.00009	Sudan National Health Insurance Fund
Lactulose (Bott 240 ml - 3.35 gr/ml)	$0.03710	Peru Ministry of Health	$0.04480	South Africa Department of Health (SAFRICA)
Loperamide (Tabs or caps 2 mg)	$0.00535	South Africa Department of Health (SAFRICA)	$0.01895	Mission for Essential Medical Supplies (MEMS)
Metaclopramide oral (Tabs or caps 10 mg)	$0.00043	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.	$0.00759	Mission for Essential Medical Supplies (MEMS)
Metaclopramide parenteral (Ampoule 5 mg/ml)	$0.00300	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.	$0.04900	CCSS (Costa Rica Social Security—CRSS)
Metronidazole tabs or caps for topical care	$0.00002	Mission for Essential Medical Supplies (MEMS)	$0.00006	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS) (OECS/PPS) - Opera en 9 países del Caribe
Morphine oral (IC, sustained-release. Tabs or caps 30 mg))	$0.00801	South Africa Department of Health (SAFRICA)	$0.03544	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS) (OECS/PPS) - Opera en 9 países del Caribe
Morphine parenteral (Ampoule 10 mg/ml)	$0.01460	South Africa Department of Health (SAFRICA)	$0.19800	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.
Omeprazole oral (Tabs or caps 20 mg)	$0.00050	Programa de Medicamentos Esenciales (PROMESE/CAL) - Dominican Rep.	$0.00258	Sudan National Health Insurance Fund (SUDANNHIF)
Ondansetron oral(Tabs or caps 4 mg)	$0.05275	South Africa Department of Health (SAFRICA)	$0.07408	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS) (OECS/PPS) - Opera en 9 países del Caribe
Ondansetron parenteral (Ampoule 2 mg/ml)	$0.02560	Peru Ministry of Health	$0.15600	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)
Paracetamol oral (Tabs or Caps 500 mg)	$0.00001	Democratic Republic of Congo Integrated Health Program (IHP) (DRC/IHP)	$0.00002	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)
Naloxone Parenteral (Ampoule 0.4 mg/ml)	$0.62175	South Africa Department of Health (SAFRICA)	$2.89750	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)
Fluconazole oral (Tabs or caps 150 mg)	$0.00027	Peru Ministry of Health	$0.00273	Organisation of Eastern Caribbean States Pharmaceutical Procurement Service (OECS/PPS)
Fluconazole parenteral (Vial 2 mg/ml)	$0.00755	South Africa Department of Health (SAFRICA)	$0.17250	Mission for Essential Medical Supplies (MEMS)

[1] 2014 prices in US$

*The buyer price for Oral Diphenhydramine or cyclizine was used because there were no registered buyers for the parenteral form.

Source: MHS, 2017. International Medical Products Price Guide. Online at: http://mshpriceguide.org/en/home/? Accessed: June 12, 2017.

The lowest and highest reported buyer prices in the 2014 International Drug Price Indicator Guide (prices and organizations listed in **Table 3D**), were used to calculate lowest and highest TDC of the EP in each reference country as shown in **Table 3E**. The TMEC and THRC from each country was held constant across reported, lowest, and highest EP price calculations.

Table 3E: Projected per patient cost of the EP by country income group, using country-specifc reported and lowest international price scenarios

	(all figures are $US current value, 2015)								
	Low Income			Lower-middle Income			Upper-middle Income		
	Rwanda pricing	International pricing[1]		Vietnam pricing	International pricing[1]		Mexico pricing	International pricing[1]	
		Lowest	Highest		Lowest	Highest		Lowest	Highest
Medicines	44	13	56	21	17	68	122	26	119
Morphine -oral or injectable- (cost per patient)	*12*	*5*	*30*	*9*	*8*	*51*	*90*	*14*	*86*
Total drug+equipment+HR costs *(using equipment and HR costs from reference country)*	197	165	209	106	102	153	757	661	755
Operational costs (*8% of total*)	16	13	17	8	8	12	61	53	60
TOTAL	**212**	**178**	**225**	**114**	**110**	**165**	**818**	**714**	**815**
% GDP [2]	0.42%	0.35%	0.44%	0.04%	0.04%	0.06%	0.09%	0.07%	0.08%
% public health expenditure[3]	17.2%	14.4%	18.2%	2.5%	2.4%	3.6%	2.5%	2.2%	2.5%

Notes:

1/ International Buyer Price as reported in the 2014 International Drug Price Indicator Guide, MSH (http://erc.msh.org/dmpguide/)

2/ Gross Domestic Product (of income group), World Development Indicators. The World Bank (http://data.worldbank.org/indicator/NY.GDP.MKTP.CD).

3/ Health expenditure, public (% of total health expenditure) of income group, World Development Indicators. The World Bank (http://data.worldbank.org/indicator/SH.XPD.PUBL)

Source: Author calculations based on Global Health Estimates 2015, World Health Organization.

We also calculated the projected costs of the EP for children aged 15 years or younger, by income group, as shown in table 3F.

Table 3F.Projected total cost of the EP for children (aged 15 years or younger, decedents and non-decedents) by income group

(all figures are $US millions current value, 2015)									
	Low Income			Lower-Middle Income			Upper-Middle Income		
	Children	Total (all ages)	children cost as % total	Children	Total (all ages)	children cost as % total	Children	Total (all ages)	children cost as % total
Medicines[1]	10.55	99.53	10.60	16.97	365.70	4.64	5.34	563.39	0.95
Morphine (oral or injectable)	*3.36*	*38.43*	*8.75*	*6.09*	*173.84*	*3.50*	*2.41*	*303.18*	*0.80*
Equipment (using reference country prices)[5]	39.33	242.43	16.22	9.24	94.54	9.77	15.98	546.15	2.93
Palliative care team (HR) (using reference c	186.68	942.05	19.82	176.74	1695.15	10.43	301.37	13109.74	2.30
OPERATIONAL COSTS	18.93	102.72		16.24	172.43		25.82	1137.54	
Total	**255.50**	**1386.74**	**18.42**	**219.18**	**2327.82**	**9.42**	**348.51**	**15356.83**	**2.27**
% GDP[2]	0.06	0.35		0.00	0.04		0.00	0.07	
% Public Health Expenditure[3,4]	2.7	14.4		0.23	2.4		0.05	2.2	

Notes:

1/ **Lowest Reported** International Buyer Price as reported in the 2014 International Drug Price Indicator Guide, MSH (http://erc.msh.org/dmpguide/)

2/ Gross Domestic Product, World Development Indicators. The World Bank (http://data.worldbank.org/indicator/NY.GDP.MKTP.CD).

3/ Health expenditure, total (% of GDP), World Development Indicators. The World Bank (http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS)

4/ Health expenditure, public (% of total health expenditure), World Development Indicators. The World Bank (http://data.worldbank.org/indicator/SH.XPD.PUBL)

5/ Low Income reference country: Rwanda; Lower-Middle Income reference country: Vietnam; Upper-Middle Income reference country: Mexico. For equipment costing in Rwanda, reusable cloth diapers inste

3.2 Assumptions and limitations

This ingredient-based framework used for costing has its limitations.

- General Limitations that apply to all sections:
  - Costing data from Vietnam is from a major public hospital in Ho Chi Minh City. As a point estimate, it might not reflect the overall pricing for drugs, medical equipment and human resources in Vietnam. For Mexico, only public sector data were included.
  - The costing framework is based on the designed package and a certain implementation plan, both clinically and administratively. For example, we recommended certain doses

of medication and medical equipment per patient for each condition, and that a community health center should have at least one bed for in-hospitalization of minor conditions that need overnight care by a professional but do not need to be transferred to district hospitals at a distance. In countries where local clinicians follow different clinical practice guidelines, or where such health facility infrastructure or health care transport system is not in place with a focus on community and home-based care, costs for providing palliative care might be higher than the estimated figures. Further, the packages include a multi-disciplinary palliative care team that consists of doctors, nurses, social workers, spiritual counsellors, psychologist or psychiatrist, physical therapist, pharmacists, community health workers, clinical support staff and non-clinical support staff to effectively provide palliative care services.

- The costing framework assumes that the package designed is provided to all patients in need of palliative care from a total of 20 different health conditions (acute, chronic and terminal). For countries that provide palliative care to a limited selection of patients, the costs will be lower. Nonetheless, the Commission argues that palliative care should be accessible to all in need.

- Limitations in drug costs calculation:
  - The calculation does not take into account different packaging for drugs; when prescribing medications, patients might be given more than the estimates recommended in this framework due to packaging differences.

- Limitations in medical equipment costs calculation:
  - Different prices for different size of nasogastric draining or feeding tube and urinary catheters; the average was taken to be applied to the framework.
  - The costs for flashlight with rechargeable battery do not take into account the costs for recharging batteries.
  - Assumed that only patient below extreme poverty line as defined by WHO need provision of cotton and plastics to make adult diapers; in practice, there might be more people who cannot access or afford adult diapers.

- Limitations in other categories that we did not include:
  - The calculation does not include the initial capacity building efforts, for example, initial human resource training, regulation changes to ensure medication accessibility, drug supply chain building and the like. For a country where there is minimal capacity for palliative care delivery, it is critical to establish a basis on which palliative care can function effectively and sustainably.

3.3 Transposing into country, region and income-group specific data

Information from Rwanda, Vietnam, and Mexico was used to determine the overall cost of implementing the EP. Costing information for each of the income regions was projected from price information from Rwanda for low-income countries, Vietnam for lower-middle-income countries, and Mexico for upper-middle-income countries, according to the World Bank income

group classification in 2015.[141] Number of patients in need of palliative care for each income group were generated using the GHE 2015 and methods as explained in section 1.
Per patient cost information for each of the reference countries was multiplied by the total number of patients in need of PC in each income group.

The lowest and highest reported buyer prices in the 2014 International Drug Price Indicator Guide were used to calculate lowest and highest TDC of the EP for each income group. The TMEC and THRC from each reference country was used to project equipment and HR costs for each respective income group, and were held constant across reported, lowest, and highest EP price calculations.

3.4 Estimating Cost of Social Supports

Total social support costs (TSSC) were estimated for each country only for patients living in extreme poverty, defined by the poverty headcount ratio at $1.90/day (2011 PPP),[142] as follows:

$$SSC_l = \sum_{j=1}^{20} SSU\ lj * SSCPU\ l$$
$$TSSC = \sum_{l=1}^{5} SSC\ l$$

SSC_s: social support costs for social support s
SSU_{sj}: social support unit required for social supports per patient in disease j
$SSCPU_s$: social support costs per unit for social support s
TSSC: total social support costs

Table 3G shows total social support package cost estimates for families living in extreme poverty in each reference country and as % GDP and % health and public health expenditures. While the Commission considers social supports as essential complements of palliative care, these were not costed into the price of the essential package because these require intersectoral support and should not be financed from the health budget.

Costs for cash payment and housing, food package, in-kind support, and transportation in Rwanda were initially estimated by Commissioner Eric Krakauer, who then consulted with Dr. Michael Herce of Partners in Health Malawi for review (expert estimates). Rwanda funeral costs were reported by country experts.

For Mexico, cash payment and housing and food costs are per person, per month for Prospera anti-poverty food support and were collected from a national survey. In-kind support of different types were gathered from Prospera program information, and survey data on transport cost per health visits were used for transportation cost estimates. The column titled “with elder support” includes an additional monthly food stipend given in Mexico to households containing an elderly person (approximately 9% of households).

Table 3G. Social Support Cost Estimates in Rwanda and Mexico

Social Support Cost Estimates in Rwanda, Vietnam and Mexico			
	Rwanda	Mexico	
Social Support Components (cost estimates in US$, 2015)	Expert Estimates	Without elder support	With elder support
Cash payment & housing per month	8.00	6.41	6.41
Food package per month	5.00	6.41	8.51
Funeral cost one time	20.81	293.09	293.09
In-kind support per month	5.00	14.06	14.06
Transportation costs (per visit, 2 patient and aide)	2.50	4.25	4.25
Total patients in need of PC	92688	452616	
% living in extreme poverty in 2015[4]	60.4%	3%	
Social support cost per patient living in extreme poverty	$ 121.71	$ 143.71	$ 152.41
Total Social Support cost, as determined by number of patients and SHS days per condition, covering only those living in extreme poverty (US$, 2015)	**$ 6,813,608**	**$ 1,951,398**	**$ 2,069,429**
% GDP[1]	0.084	0.000	0.000
% health expenditure[2]	1.122	0.003	0.003
% public health expenditure[3]	2.945	0.005	0.006

Notes:

[1/] Gross Domestic Product, World Development Indicators. The World Bank (http://data.worldbank.org/indicator/NY.GDP.MKTP.CD).

[2/] Health expenditure, total (% of GDP), World Development Indicators. The World Bank (http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS)

[3/] Health expenditure, public (% of total health expenditure), World Development Indicators. The World Bank (http://data.worldbank.org/indicator/SH.XPD.PUBL)

[4/] Poverty headcount ratio at $1.90 a day (2011 PPP) (% of population), World Development Indicators. The World Bank (http://data.worldbank.org/indicator/SI.POV.DDAY)

4 Access to the Palliative Care Package/Morphine

4.1 INCB data on morphine production or imports

The availability of morphine – in country (morphine-equivalents excluding methadone - MEEM*i*)reported to INCB and Treat Pain, updated in 2013, was used.[143,144] These data do not correspond necessarily to consumption, but instead to the acquisition in kilograms (kg) or metric tons (1000 kg) that country j averaged over 2011, 2012 and 2013, and therefore is intended be a proxy for the availability of MEEM*i*. Furthermore, given the unavailability of information on the amount of morphine reserves of country j in any given year, averaging over the three years seeks to provide a more realistic measure of the average morphine availability of country j.

Opioid availability data are taken from a dataset distributed by the International Narcotics Control Board to accompany the report of narcotics consumption in 2014.[145] These data are provisional and subject to updates.

Morphine equivalent is a metric to standardize potency of opioids and allow combination and comparison of different medicinal opioids. It is calculated as: MorEq = (1*morphine) + (83.3*fentanyl) + (5*hydromorphone) + (1.33*oxycodone) + (0.25*pethidine) + (4*methadone)

Because of methadone's widespread use as opioid substitution therapy, non-methadone morphine equivalent is also used in some instances and is calculated as Non-meth Mor Eq = (1*morphine) + (83.3*fentanyl) + (5*hydromorphone) + (1.33*oxycodone) + (0.25*pethidine)

Morphine equivalency ratios of the defined daily dose (oral dosing for all except fentanyl, which is trans-dermal) are described in the WHO Collaborating Centre for Drug Statistics Methodology.[146]

The 2015 INCB narcotics drug report reports the following figures for 2011, 2012 and 2013 globally for these 5 opioids (natural and synthetic) as shown in the following table:

	Morphine equivalence factor	Year			Morphine equivalent excluding methadone (MEEM) Year		
		2011	2012	2013	2011	2012	2013
Morphine (Kg)	1	43059	45316	45641	43,059	45,316	45,641
Fentanyl (Kg)	83.3	1446	1280	1718	120,452	106,624	143,109
Hydromorphone (Kg)	5	4335	3452	4177	21,675	17,260	20,885
Oxycodone (Kg)	1.33	81741	94966	82049	108,716	126,305	109,125
Pethidine (Kg)	0.25	7185	6747	6670	1,796	1,687	1,668
Total					**295,698**	**297,192**	**320,428**
Average 2011-2013						**304,439**	

Average reported morphine equivalent global availability between 2011 and 2013 a was 304.4 metric tons. Considering only those countries for which we have mortality data, the total available morphine equivalent is 298.5 metric tons.

4.2 Estimates of morphine requirements

This estimate considered the number of patients for each of the 20 pathologies, based on the proportion of decedents and non-decedents requiring palliative care as determined in section 1.1.3.

Additionally, the total amount of morphine needed to treat the total number of estimated patients for each of the 20 pathologies was determined based on clinical judgment of the average duration of each patient and average consumption of morphine in milligrams (mg). This estimate corresponds to the total morphine need for pathology i.

$$TNM_j = M_j * d_j * TP_j$$

where:

TNM_j : Total morphine need in milligrams for disease j
M_j : Amount of morphine needed per patient per day for disease j
d_j : Average duration of disease j before the outcome
(Outcome refers to the advancement to the next stage of the disease in all cases)
TP_j: Total number of patients for disease j

$M_j * d_j$ was defined by Erik Krakauer.

Thus, the total morphine need (mg) in country *i* to meet the pain control needs of these patients corresponds to:

$$TNM_{ij} = \sum_{j=1}^{20} TNM_{ij}$$

4.3 Indicators of met and unmet need

a) MEEM$_i$ (in milligrams) per patient with palliative care needs in country *i*, as described in (2) above, which is estimated as:

$$MEEMppcp_i = \frac{MEEM_i}{\sum_{j=1}^{20} TP_{ij}}$$

where:

MEEMppcp$_i$: Average milligrams of MEEM (distributed) per patient with palliative care needs in country *i*.

b) The met need for morphine per patient with palliative care needs corresponds to:

$$MNMEEMppcp_i = \frac{MEEMppcp_i}{TNM_i/TPi} * 100$$

where:

MNMEEMppcp$_i$: Met need of MEEM per patient with palliative care needs, according to (2) above in country *i*, expressed as a percentage of the total need (TNM$_i$). This indicator is a positive number, which can be greater than 100, indicating that the met need exceeds the total need in country *i*.

c) The unmet need for morphine (UMNMEEM) per patient with palliative care needs expressed as a percentage of the total need. This indicator is constructed as the difference between the total need and met need divided by the total need. In other words, the percentage of the total need that remains unmet give the availability of MEEM and the number of patients with palliative care needs in the country. It is expressed in percentage relative to the total need. This is estimated as follows:

$$UMNMEEMppcp_i = \frac{TNM_j/TPi - MEEMppcp_i}{TNM_i/TPi} * 100$$

where:

UMNMEEMppcp$_i$: Unmet need for morphine (MEEM) in country *i*.

Note that for countries that do not have information on availability of MEEM, this value is

replaced by the average MEEM availability of the income group to which the country belongs, so as to not affect the corresponding maps.

4.4 Determining the cost of meeting the global unmet need for morphine

Upon the construction of the indicator UMNMEEMppcp$_i$ in country *i*, we proceeded to determine the cost of meeting this unmet need for morphine. To do this we proceeded to:

i. Identify the World Bank income region classification of each country (low income, lower middle income, upper middle and high income, in addition to low- and middle income (LMIC) which includes the first three).[147]
ii. Estimate the cost per country, per income region, and globally of the unmet need for morphine.

The cost of the unmet need for morphine *(CUMNMEEMppcp$_i$)* in country *i* is defined as follows:

$$CUMNMEEM_i = UMNMEEMppcp_i * TPi * Pr_g$$

where Pr$_g$ is the price per milligram of morphine in the region *g* where *g* ranges from 1 to 4. The following prices of morphine were used: 16 cents per 10 mg of morphine (MEEM) in low and lower-middle income countries, 10 cents per 10 mg of morphine in upper-middle income countries, and 3 cents per 10 mg of morphine in high income countries. These morphine prices were used according to De Lima, *et al*. 2014.[148]

The total cost of meeting the unmet need for morphine (MEEM) globally was estimated as

$$CTUMNMEEM = \sum_{i=1} \sum_{g=1} UMNMEEMppcp_i * TPi * Pr_g$$

To determine the total cost of meeting the unmet need for morphine (MEEM) unmet globally, two scenarios were developed: 1) Assuming the price of the income region Pr$_g$, (i.e. depending on the World Bank income classification of country *i*, the price of morphine for that income region morphine was used); and 2) considering the best price or "perfect availability" of morphine (MEEM) in the world, using the price of 3 cents per 10 mg available in the high income countries region.

Additionally, a new estimate was created using Western European countries' morphine consumption reporting method as a benchmark model. According to Duthey B and Scholten W (2014):[149]

"An adequate consumption level is defined by assuming that the mean per capita opioid

consumption of the top 20 countries of HDI is an adequate level"

For the purposes of this estimate calculation, we only considered Western European countries, most of which are among the top 20 countries of HDI, and excluded Canada and Australia on the grounds that the level of morphine in those countries would reflect overconsumption and move up the average consumption per capita. Also among the top 20 countries of HDI we also excluded New Zealand, Singapore, Hong Kong, Korea and Japan, to make room for other Western European countries that occupied the next HDI rank positions.

Using this method, the average total morphine need in Western European countries TNM_{WE} was estimated at 2,172.37 mg per patient, while milligrams of morphine-equivalent $MEEMppcp_{WE}$ was 18,315.80mg per patient. Considering the latter value as the appropriate level of consumption per patient with palliative care needs, we adjusted the need per country based on the following formula:

$$NABMMEEMppcp_i = \frac{TNM_i}{TNM_{WE}} * MEEMppcp_{WE} = \frac{TNM_i}{2{,}172.37} * 18{,}315.80$$

where $NABMMEEMppcp_j$ is the adjusted total morphine need of country *i* based on the benchmark model for morphine use in Western Europe.

Thus, the cost of meeting the unmet need for morphine in country *i* $CUMNABMMEEM_i$ based on the benchmark model for morphine use in Western Europe can be calculated as follows:

$$CUMNABMMEEM_i = NABMMEEMppcp_i * TP_i * Pr_g$$

While the total global cost adjusted based on the benchmark model for morphine use in Western Europe would be:

$$CTUMNABMMEEM = \sum_{i=1} \sum_{g=1} NABMMEEMppcp_i * TP_i * Pr_g$$

and where additionally and necessarily, $CTUMNABMMEEM > CTUMNMEEM$.

5 Extended Cost Effective Analysis

5.1 Identify the policy intervention of interest

To conduct an extended cost effectiveness analysis (ECEA), we started with identifying the policy intervention of interest: the implementation of the essential palliative care package, which is described in the report in section 3. It includes a detailed list of drugs, equipment and basic needs support for patients of health conditions that require palliative care, and every type of

professionals needed in a palliative care team at different levels of health facilities from referral hospital to provincial hospital, district hospital and home visit team. The subject of analysis was well-defined and quantified to enable the calculation of health gains and financial consequences.

Vietnam was picked as an example to calculate the potential impact of the implementation of the essential palliative care package. Local social-economic data were acquired from public databases to support the calculation of ECEA, as described in later sections.

5.2 Quantify health gains, in the unit of symptom-days averted

The health gains are not reflected in the metrics mortality or Disability Adjusted Life Years (DALY), and instead, we used an innovative approach of burden of suffering measurement, in the unit of symptom days. The percentage of patients in each condition category who would suffer from each of the 15 common symptoms and the duration of the suffering were estimated by palliative care specialists in a Delphi process, described in a later section of this appendix. Hence, we use the measure presented and developed in Section 2 – sum total of SHS days (for all symptoms) - to measure potential patient benefits of PC. See below for the estimates used in calculating the total symptom-days from patients in need of palliative care in Vietnam.

Table 5A. Total SHS days from patients in need of palliative care in Vietnam in 2015.

	ALL		Pain Chronic	Pain Chronic	Pain total	Dyspnea	Fatigue	Weakness	Nausea and/o	Diarrhea	Constipation	Dry Mouth	Pruritus	Bleeding	Wounds	Anxiety / wo	Depressed m	Confusion / d	Dementia	
	ICD 10 conditions that most	Total number of patients that	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	Total (in thousands)	ALL - TOTAL DAYS (millions)
1	A96,98,99	288.7283	1.212659	0.433092	1.645751	0.53126	1.697722	1.697722	1.596667	1.556245	0	0.40422	0	0.505274	0	2.078844	0	0.103942	0	11.81765
2	A15-19: M	15048.6	455.2527	233.8949	689.1476	477.7234	1028.501	1028.501	429.9589	182.0535	0	0	63.48171	65.53615	62.48881	1137.674	1214.343	66.1081	0	6445.516
2a	A15-19: M	3060.56	421.6862	217.1116	638.7978	263.7369	776.7518	776.7518	413.1756	165.2702	0	0	55.09008	27.77382	37.31392	231.3783	286.4684	66.1081	0	3738.617
2b	A15-19: N	11988.04	33.56651	16.78326	50.34977	213.9865	251.7489	251.7489	16.78326	16.78326	0	0	8.391628	37.76233	25.17489	906.2959	927.8743	0	0	2706.9
3	B20-24: HI	141985.4	11931.24	2158.29	14089.53	586.9475	4603.345	4603.345	801.6026	1863.977	0	533.2837	1837.984	0	387.3853	11072.85	6644.245	77.47707	348.1437	47450.12
4	C00-97: M	175099	16395.81	7866.545	24262.35	3935.425	19411.6	19411.6	2371.984	485.0749	4330.473	1573.022	445.5701	838.4669	1966.636	8268.767	8525.677	432.2105	0	96258.87
5	C91-95: Le	3885.632	314.711	81.59175	396.3028	116.5596	466.2386	466.2386	46.62386	11.65596	58.27982	58.27982	34.96789	58.27982	11.65596	132.878	164.3491	19.03808	0	2041.348
6	F00-04: De	119545	1439.746	280.3844	1720.13	373.8459	4655.056	3239.428	0	0	757.6967	401.6647	0	0	184.922	4627.033	3316.377	14749.67	0	34025.82
7	G00-09: In	1655.57	8.691742	2.483355	11.1751	3.725032	9.93342	79.46736	4.96671	0	0	0	0	0	9.93342	0	0	7.648733	0	126.8498
8	G20-26; G:	4480.647	194.4813	73.4805	267.9618	35.71933	294.7766	512.6033	2.954827	0	43.015	0	0	0	55.69346	183.5226	154.2906	5.481863	74.99519	1631.015
9	I60-69: Ce	120890.3	3609.601	639.803	4249.404	420.827	8019.791	10647.5	0	0	2176.025	1026.397	0	0	2709.774	372.2506	583.5628	568.5658	2408.65	33182.75
10	I05-09; I25	8295.428	323.5217	49.77257	373.2943	597.2708	746.5886	447.9531	49.77257	0	74.65886	24.88629	0	0	0	248.8629	398.1806	36.00216	0	2997.47
11	I25: Chror	2922.598	315.6406	65.75846	381.3991	65.75846	210.4271	43.83897	17.53559	0	0	0	0	0	0	185.8772	263.0338	0	0	1167.87
12	J40-47; J6(	18451.69	553.5506	55.35506	608.9057	2214.203	1577.619	276.7753	0	0	0	0	0	0	0	841.397	1040.675	59.41444	0	6618.99
13	K70-77: Di	16071.79	940.1995	144.6461	1084.846	482.1536	771.4457	337.5075	168.7538	0	0	120.5384	96.43072	216.9691	0	125.3599	241.0768	236.2553	0	3881.336
14	N17-19: R(	4494.619	53.93543	3.370964	57.30639	16.85482	364.0641	67.41928	26.96771	0	20.22579	20.22579	40.45157	6.741928	0	117.3096	125.3999	32.72083	0	895.6877
15	P07; P10-1	7015.404	52.61553	26.30776	78.92329	52.61553	0	0	0	0	0	0	0	0	0	0	0	0	0	131.5388
16	Q00-99: Cc	10800.12	162.0019	56.70066	218.7025	48.60056	0	0	0	0	0	0	0	0	0	0	0	0	0	267.3031
17	S00-99; T0	54209.63	650.5155	528.5438	1179.059	81.31444	0	0	0	0	0	0	0	0	0	295.9846	204.9124	0	0	1761.271
18	I70: Athro	2809.087	225.8506	84.27261	310.1232	8.427261	16.85452	16.85452	0	0	0	0	0	0	3.932722	50.56357	58.99083	0	0	465.7466
19	M00-97: M	903.1864	227.603	97.54413	325.1471	4.064339	8.128678	16.25736	0	0	37.93383	1.806373	0	0	8.128678	21.13456	39.01765	0	0	461.6186
20	E40-46: M	11.26738	0.011267	0	0.011267	0.016901	0	0	0	0.018591	0	0	0	0	0.022535	0	0	0	0	0.069294
	Total	708863.7	37856.2	12449.18	50305.37	9522.583	42186.07	41196.99	3922.717	2544.337	7498.309	3760.509	2518.886	1186.499	5400.573	27683.54	22974.13	16290.69	2831.789	239823

*The total was considered the sum total from all symptoms although we note that the symptoms are of different severity and they overlap.

For Vietnam, total SHS days are estimated to be 240 million days a year. We assume different

levels of “efficacy against suffering”, in terms of suffering days averted, by the EP: 40% and 80%. Thus, universal public finance of PC through the EP in Vietnam could alleviate 96 million (40% coverage) and 192 million SHS days (80% coverage).

5.3 Quantify the financial consequences for individuals and the health system

5.3.1 Medical Costs of providing the essential package

To quantify the consequences, we also required the information on health service utilization before and after the implementation of the essential palliative care package.

The costs of implementing the essential package are calculated using the same methods as described in earlier sections of the data appendix. The total costs are divided into 2 categories: 1) total medicine and medical equipment costs, that does not change before and after the implementation of the essential package; 2) human resource costs that will change after the implementation of the essential package; 2) is further divided into 2 sub-categories: 2.1) human resource costs at hospitals and 2.2) human resource costs at home.

Table 5B. Table of Human Resource Needs Distribution in Vietnam.

		Number of days receiving pc at different sites																					
	ICD 10 conditions that most often genera	Total Deaths in	Total number of p	Total number	Referral Hosp	Total days	Total visits	Provincial Ho	Total days/vi	Total visits	District Hosp	Total days/vi	Total visits	Communi	Total days/vi	Total visits	Home	Total visits	Transportation visit	Days at hospital (vi	Days at home
1	A96,98,99: Hemorrhagic fevers	2887	289	7	3	866		0	0		3	866		0	0					577	1877	144
					0		0	0		0	0		0	1		289	2 visits + 1 bereavement	722				
		37: Other infectious disease * 5% * 2																					
2	A15-19: TB / the 13% of deaths (190,000) from M/XDR TB (100% of those)	15252	1932	180	30	57957		15	28979		15	28979		0	0					28979	131370	216374
		3. TB-MDR * 13%	0		4		7728	4		7728	4		7728	4		7728	(home visit	349677				
2a	A15-19: TB / the 80,000 with M/XDR TB on treatment who have not died (100% of those)		1129	90	10	11286		10	11286		10	11286		0	0					13544	40631	60947
		3. TB-MDR * 13%	0		3		3386	3		3386	3		3386	3		3386	(home visit	101578				
2b	A15-19: TB / the 87% (1.3 million) who died from TB that was NOT MDR (90% of those)		11988	21	1	11988		1	11988		1	11988		0	0					71928	65934	185815
		3. TB-MDR * 87%			1		11988	1		11988	1		11988	2		23976	(home visit	263737				
3	B20-24: HIV disease / 100%		8944	160	2	62608		7	62608		7	62608		0.25	2236		(home visit			160991	283971	1147063
		10: HIV/AIDs * 100%			5		44720	5		44720	5		44720	6		53664	(home visit	1037500				
3a	B20-24: HIV disease - nondecedent		133041	210	1	133041		1	133041		1	133041			0		(home visit			1596497	1396935	26541765
		10: HIV/AIDs * 2	29.75		3		399124	3		399124	3		399124	6		798249	(home visit	5454699				
4	C00-97: Malignant neoplasms (except C91-95)	97012	87310	120	10	873104		0	0		14	1222346		0.25	21828					960415	2684795	7792455
		61: Malignant Neoplasms (-77 Leukemia) * 90%			9		261931	0		0	0		523863	7		349242	(home visit f	7683317				
4a	C00-97: Malignant neoplasms (except C91-95) non-decede		87789	150	1	87789		0	0		0	0		0	0					702309	570626	12597667
		61: Malignant Neoplasms (-77 Leukemia) * 200%			2		175577	2		175577	3		263366	4		351154	(home visit f	1843561				
			2																				
			1																				
			1																				
			0																				
			0																				
5	C91-95: Leukemia	4317	3885	90	7	27197		7	27197		7	27197		0	0					38853	99076	250603
		77 Leukemia * 90%			4		15541	1		3885	2		7771	2		7771	(home visit f	186495				
6	F00-04: Dementia	16844	13476	150	3	40427		3	40427		3	40427		0.25	3369					80854	178552	1842787
		95 Alzheimer's Disease and other Dementias * 80			1		13476	1		13476	1		13476	5		67378	(home visit f	1239754				
6a	F00-04: Dementia - nondecedents		106069	150	0	0		0	0		1	106069		0	0					530347	530347	15380062
		95 Alzheimer's D	62.96978973		1		106069	1		106069	2		212139	4		424278	(home visit f	4242776				
7	G00-09: Inflammatory dz of CNS	1656	30		12	19867		12	19867		4	6622		0.25	414					4967	46770	2897
		5 syphilis * 70% + 15 measles * 50% + 16 tetanus *			0		0	0		0	0		0	0		0	(home visit f	51153				
8	G20-26; G30-32; G35-37; G40-41; G80-83 Extrapyramidal & mvt disorders; other degen dz of CNS; Demyelinating dz of CNS; Epilepsy; Cerebral palsy & other paralytic syndromes /		1856	120	2	3713		2	3713		8	14852		0.25	464					12995	31096	191678
		96 Parkinson's disease * 65% + 97 epilepsy * 50%			0		0	0		0	4		7426	5		9282	(home visit f	115100				
8a	Parkinsons - nondecedents	461	2454	90	2	4908		2	4908		1	2454		0	0					19632	23313	197551
		96 Parkinson's d	53		1		2454	1		2454	3		7362	4		9816	(home visit f	51535				
8b	Multiple sclerosis - nondecedents	83	170	120	0	0		1	170		2	340		0	0					1021	1191	19227
		38 multiple scle	121		0		0	2		340	2		340	4		681	(home visit f	4254				
9	I60-69: Cerebrovascular diseases	98253	63864	90	4	255458		4	255458		7	447051		0.25	15966					638644	1261322	4486475
		114 Stroke * 65%			1		63864	2		127729	4		255458	2		127729	(home visit f	3065492				
9a	I60-69: Cerebrovascular diseases - nondecedents	57026	120		1	57026		1	57026		2	114052		0	0					456207	456207	6386900
		114 Stroke * 38%	4		1		57026	1		57026	3		171078	3		171078	(home visit f	1425647				
10	I05-09; I25; I42 & I50: Chronic rheumatic heart diseases; Cardiomyopathy & Heart failure		8295	120	5	41477		5	41477		3	24886		0.2	1659					74659	146829	848622
		111 rheumatic heart disease * 65% + 112 hyperten			2		16591	2		16591	2		16591	3		24886	(home visit f	564089				
11	I25: Chronic ischemic heart disease	58452	2923	180	7	20458		0	0		7	20458		0.25	731					43839	66489	459579
		113 ischemic heart disease * 5%			6		17536	0		0	7		20458	4		11690	(home visit f	265956				
12	J40-47; J60-70; J80-84; J95-99: Chronic lower respiratory dz; lung dz due to external agents; interstitial lung dz; other dz of resp system		18452	180	7	129162		4	73807		4	73807		0.25	4613					239872	429002	2892302
		118 COPD * 80% + 120 other respiratory dz except			2		36903	4		73807	4		73807	6		110710	(home visit f	1734459				
13	K70-77: Diseases of liver	16072	90		4	64287		4	64287		4	64287		0.25	4018					176790	293310	1153151
		123 cirrhosis of liver * 95% + 125 other digestive d			2		32144	3		48215	3		48215	4		64287	(home visit f	835733				
14	N17-19: Renal failure	9988	4495	90	4	17978		3	13484		4	17978		0	0					44946	65172	339344
		127 kidney diseases * 45%			1		4495	2		8989	4		17978			0	(home visit f	233720				
15	P07; P10-15: Low birth weight & prematurity; Birth trauma		7015	90	7	49108		6	42092		0	0		0	0					14031	91200	7015
		50 preterm birth complications * 75% + 51 birth as			0		0	0		0	0		0	0		0	3 visits total	21046				
16	Q00-99: Congenital malformations	9000	5400	30	10	54001		5	27000		0	0		0	0					21600	89101	72901
		140 Congenital anomalies* 60%			1		5400	1		5400	0		0	1		5400	(home visit f	167402				
16a	Q00-99: Congenital malformations - nondecedents		5400	120	3	16200		2	10800		2	10800		0	0					48601	64801	583207
		140 Congenital anomalies* 60%			2		10800	2		10800	2		10800	4		21600	(home visit f	135002				
17	S00-99; T00-98; V01-Y98: Injury, poisoning, external causes		54210	10	5	271048		5	271048		0	0		0	0					108419	542096	0
	Multiply the number of deaths by 3 for to	152 unintentional injuries + 160 intentional injur			0		0	0		0	0		0	0		0	1 bereaveme	18070				
18	I70: Athrosclerosis	8026	2809	90	5	14045		5	14045		5	14045		0.25	702					25282	59693	193125
		116 other circulatory disease * 35%			0		0	2		5618	4		11236	6		16855	3 weeks ever	146073				
19	M00-97: Musculoskeletal disorders	430	903	360	0	0		0	0		0	0		0	0					3613	3613	321534
		134 musculoske	etal diseases * 20% * 3		1		903	1		903	2		1806	4		3613	(home visit f	46364				
20	E40-46: Malnutrition	11	11	10	2	23		3	34		5	56		0	0					34	113	0
		55: Protein-energy malnutrition * 100%			0		0	0		0	0		0	0		0	(home visit f	11				
Total			708863			2325023	1287656		1214743	1123826		2456497	2130115		55999	2664740		31284919	6120445	9655432	84171189

Table 5C. Total costs of medicines and medical equipment in the Palliative Care Essential Package in Vietnam

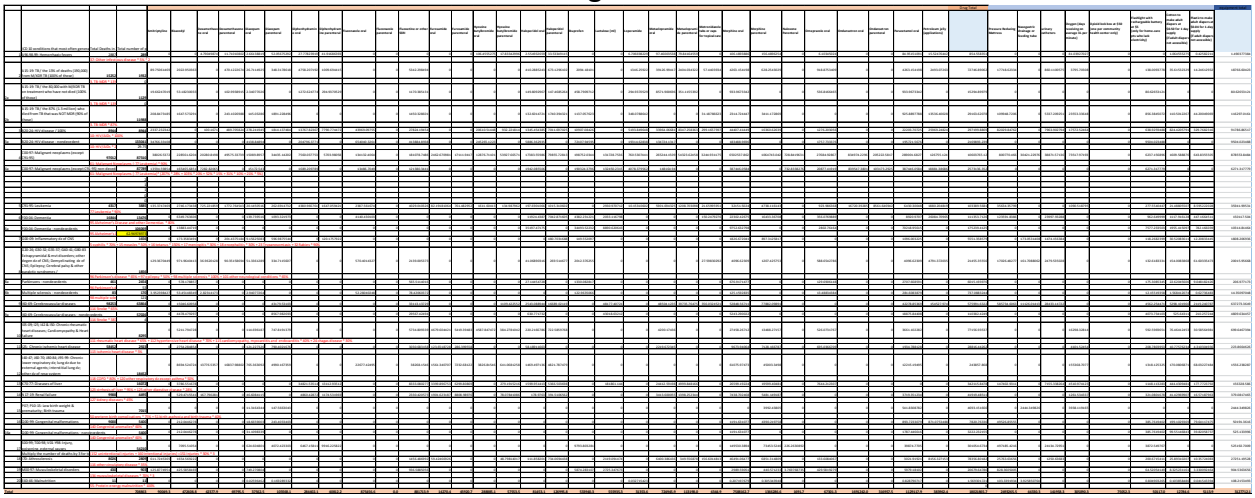


Table 5D. Total costs of human resources in the Palliative Care Essential Package in Vietnam

		FTE of staff involved in providing pc at each site									
Team Membership	Salary per month ($)	Referal Hospital	MPS	Provincial Hospital	MPS	District Hospital	MPS	Community Health Center	MPS	Home	MPS
Doctors	350	2	700	1	350	0.5	175	0	0	0.04	14
Nurses	300	2	600	1.5	450	1	300	0.85	255	0.15	45
Social Workers	50	1	50	1	50	0.5	25	0.2	10	0.15	8
Spiritual Counsellor	0	0.4	0	0.2	0	0.1	0	0	0	0	0
Psychologist or psychiatrist	225	0.4	90	0.2	45	0	0	0	0	0	0
Physical Therapist	200	0.1	20	0.1	20	0	0	0	0	0	0
Pharmacist	350	0.4	140	0.2	70	0.2	70	0.1	35	0	0
Community Health Workers	50	0	0	0	0	0	0	0	0	1	50
Clinical Support Staff (diagnostic imaging, Lab)	300	0.05	15	0.02	6	0.01	3	0	0	0	0
Non Clinical Support Staff (House keeping, administration, Dietary)	300	0.5	150	0.25	75	0.1	30	0.05	15	0	0
Total monthly costs per team			**1765**		**1066**		**603**		**315**		**117**
daily capacity inpatient/outpatient		20/30		10/15		4/10		1/5		5	
Total inhospital stays (patient-days) needed for pc patients (from sheet 1)		2325023		1214743		2456497		55999		31284919	
Total patient-visits needed for pc patients (from sheet 1)		1287656		1123826		2130115		2664740			
Total team*months of hospical service needed for pc patients		3875		4049		20471		17765		208566	
Costs of personnel in total		6839442.554		4316386.893		12343899.66		5595954.222		24297954.07	

5.3.2 Transportation Costs

Transportation costs are calculated assuming that each time patients need to travel to the hospital, either for in-hospital stay or for outpatient visit, it will cost them 2 people * 2 ways and each way for $2.50.

For each condition, it is assumed that:

1) If the patient needs to stay in-hospitalized for a few days, it is considered in total 1 trip that requires ground transportation;
2) If the patient needs to go to a hospital or health community center for a visit, each visit will require 1 trip that requires ground transportation.

5.3.3 Out of Pocket Expenditures and Medical costs for health systems

Financial consequences for individuals are estimated to include the total out-of-pocket (OOP) expenditure, which equals the total of 50% of the medical costs and transportation costs, and loss of Income.

The costs to the health systems equal 50% of the medical costs, based on data that show that OOP health expenditure equal about 50% of the total health expenditure[150].

Financial consequences for individuals and their families in need of PC are estimated at US$139 per patient in need of palliative care.

5.3.4 Loss of Income

It is estimated when the package is 100% implemented, meaning that all palliative care patients can receive the care they need, caregivers will need to leave work for caregiving for 100% of the days the patients are at the hospital, and 40% of the days the patients are at work; and when the package is not implemented at all, the caregiver needs to leave work for caregiving for 100% of the days the patients are at hospital and 50% of the days the patients are at work.

Since the implementation of the palliative care package will also decrease the number of days the patients are required to stay at the hospital, the averted loss of income for the caregiver comes from both the reduced days at the hospital, and the reduced percentage of days at home. 10% and 50% implementation of the package will affect this parameter proportionally.

5.4 Assumptions used in estimating the impact of implementing the essential package

The Impact of the package lies mainly in decreasing the number of days required at the hospital. It is estimated that 100% implementation of the package will decrease the number of days at hospital to 20%, while not changing the total days in need of palliative care service. 10% and 50% implementation of the package will affect this parameter proportionally.
This assumption, combined with the methods to calculate all indicators listed in section 5.3, leads to the matrices of assumptions that were used to construct the ECEA, see below for the details:

Table 5E. Matrix of Assumptions for Extended Cost-Effective Analysis

	100% coverage of EP	Status Quo	10% coverage	50% coverage
Hospital Costs	Total Costs from referal hospitals, provincial hospitals, distric	Cost per day at hospital * Days at	Cost per day at hospital * Day	Cost per day at hospital * Days at h
Home Costs	Total costs from home vists from EP	Cost per day at home * days at h	Cost per day at home * days a	Cost per day at home * days at hon
Medicine Costs	Total medical costs of EP	equal that in Column B	equal that in Column B	equal that in Column B
Medical Equipment Costs	Total medical equipment costs of EP	equal that in Column B	equal that in Column B	equal that in Column B
Total Costs	Hospital costs + home costs + medicine costs + medical equip	Hospital costs + home costs + me	Hospital costs + home costs +	Hospital costs + home costs + medi
Days at hospital	hospital inpatient days + 50% * hospital vists, calculated from	Days at hospital for Column B * 5	Daysa t hospital for column C	Daysa t hospital for column C - 50%
Days at home	Total days in palliative care - days at hospital, calculated from	Totay days minus days at hospita	Totay days minus days at hosp	Totay days minus days at hospital
Total days of palliative care	Days at hospital + Days at home	equal that in Column B	equal that in Column B	equal that in Column B
Costs per day at hospital	hospital costs divided by days at hospital	equal that in Column B	equal that in Column B	equal that in Column B
costs per day at home	hospital costs divided by days at home	equal that in Column B	equal that in Column B	equal that in Column B
Transportation times	IF(hospital stay per patient per condition >0,1,0)+hospital ou	proportional to Days at hospital	proportional to Days at hospit	proportional to Days at hospital
Transportation costs	Transportation time * 4 (patient plus one caregiver, back and	Transportation time * 4 (patient	Transportation time * 4 (patie	Transportation time * 4 (patient pl
Suffering days	N/A	Calculated from SHS days assum	N/A	N/A
Suffering days averted	80% of suffering days	N/A	10%*80% of suffering days	50%*80% of suffering days
OOP costs	50% total costs + transportation costs	50% total costs + transportation c	50% total costs + transportatio	50% total costs + transportation co
Health System Costs	50% total costs	50% total costs	50% total costs	50% total costs
OOP cost savings	OOP costs from status quo minus OOP costs from this column	N/A	OOP costs from status quo mi	OOP costs from status quo minus C
OOP costs saving as % of annual income	OOP costs saving divided by annual income as of each quintil	N/A	OOP costs saving divided by a	OOP costs saving divided by annua
Days of loss of income	100% of days of hospital + 40% of days at home	100% of days of hospital + 50% o	100% of days of hospital + (10	100% of days of hospital + (50%*40
Loss of Income (Equally distributed)	Days of loss of income * average daily income ($3.08)	Days of loss of income * average	Days of loss of income * avera	Days of loss of income * average da
Averted Loss of Income equally distributed	Loss of income from Status Quo minus that from this column	N/A	Loss of income from Status Qu	Loss of income from Status Quo mi
Loss of income (as in quintile)	Days of loss of income * daily income from each income quin	Days of loss of income * daily inc	Days of loss of income * daily	Days of loss of income * daily incor
Averted loss of income as in quintile	Loss of income from Status Quo minus that from this column	N/A	Loss of income from Status Qu	Loss of income from Status Quo mi

5.5 Extended Cost-Effective Analysis

We divided the population into 5 income quintiles. All people in need of palliative care in Vietnam were divided equally into the 5 groups. The income in each quintile was calculated from the national average income and the GINI coefficient.
Based on the above steps of quantifying the health gains and financial consequences, we were able to calculate them for each income group. See table 4.
We quantified for the Vietnam case, by income quintile, the effect of universal coverage through public finance of the EP of PC services in terms of: (i) SHS days averted expressed in total symptom-days averted, and (ii) the financial risk protection afforded by averting direct medical costs, transport costs, and indirect costs (income losses from patient and caregiver) per patient. These benefits were then compared to the total cost of delivering the EP to 100% of people in need of PC in a given year.

Table 5F. Extended Cost-Effectiveness Analysis of the Essential Package of Palliative Care Services in Vietnam.

Table 5F. Extended Cost-Effectiveness Analysis of the Essential Package of Palliative Care Services in Vietnam.		
		Value
	Total number of patients	710,000
	Average annual income ($) (from poorest to richest income quintile)	**$200, 600, 900, 1400, 2000**
Status Quo	Suffering averted (symptom-days)	0
	OOP costs ($ million)	396
	Loss of income (as in their quintile; $ million)	**9,** 23, 37, 55, 77
	Health system costs ($ million)	90
100% of palliative care need met	Suffering averted (symptom-days, in millions)	100 to 190
	OOP costs ($ million)	98
	OOP costs savings ($ million)	297
	OOP costs savings as % of annual income (from poorest to richest quintile)	190%, 70%, 44%, 30%, 21%
	Loss of income (as in their quintile; $ million)	5, 14, 22, 34, 47
	Health system costs ($ million)	37
OOP = out-of-pocket.		

Table 5G. Extended Cost Effectiveness Analysis for PC Essential Packages at different provision levels

	Quintile	I	II	III	IV	V
	Number of patients	141773	141773	141773	141773	141773
	Average annual salary ($)	**221**	**600**	**943**	**1414**	**1980**
Status Quo	suffering averted (symptom days in thou	0	0	0	0	0
	OOP costs - medical plus transportation (	79	79	79	79	79
	OOP costs savings (m)	--	--	--	--	--
	OPP savings as a % of annual income	--	--	--	--	--
	Annual Loss of Income (equally distribute	44	44	44	44	44
	Annual Loss of Income averted (m)	--	--	--	--	--
	Annual Loss of Income (as in their quintil	9	23	37	55	77
	Annual Loss of Income averted (m)	--	--	--	--	--
	HS costs (assuming 50% coverage)	18	18	18	18	18
10% of pc need met	suffering averted (symptom days in thou	3837.168124	3837.16812	3837.16812	3837.16812	3837.1681
	OOP costs - medical plus transportation (	73	73	73	73	73
	OOP costs savings (m)	6	6	6	6	6
	OPP savings as a % of annual income	19%	7%	4%	3%	2%
	Annual Loss of Income (equally distribute	42	42	42	42	42
	Annual Loss of Income averted (m)	1	1	1	1	1
	Annual Loss of Income (as in their quintil	8	23	35	53	74
	Annual Loss of Income averted (m)	0.3	0.8	1.3	1.9	2.6
	HS costs (assuming 50% coverage)	17	17	17	17	17
50% of pc need met	suffering averted (symptom days in thou	19185.84062	19185.8406	19185.8406	19185.8406	19185.841
	OOP costs - medical plus transportation (	49	49	49	49	49
	OOP costs savings (m)	30	30	30	30	30
	OPP savings as a % of annual income	95%	35%	22%	15%	11%
	Annual Loss of Income (equally distribute	36	36	36	36	36
	Annual Loss of Income averted (m)	8	8	8	8	8
	Annual Loss of Income (as in their quintil	7	19	30	45	63
	Annual Loss of Income averted (m)	1.6	4.2	6.7	10.0	14.0
	HS costs (assuming 50% coverage)	13	13	13	13	13
100% of pc need met	suffering averted (symptom days in thou	38371.68124	38371.6812	38371.6812	38371.6812	38371.681
	OOP costs - medical plus transportation (	20	20	20	20	20
	OOP costs savings (m)	59	59	59	59	59
	OPP savings as a % of annual income	190%	70%	44%	30%	21%
	Annual Loss of Income (equally distribute	27	27	27	27	27
	Annual Loss of Income averted (m)	17	17	17	17	17
	Annual Loss of Income (as in their quintil	5	14	22	34	47
	Annual Loss of Income averted (m)	3.4	9.1	14.3	21.5	30.1
	HS costs (assuming 50% coverage)	7	7	7	7	7

6 Health Systems and Palliative Care Innovations

The Commission established a working group on palliative care models and innovations, co-chaired by Liliana de Lima, Dr. MR Rajagopal, and Dr. Eric L. Krakauer, and a working group on health systems and universal health coverage, co-chaired by Dr. Rifat Atun and Dr. Felicia Knaul. The goal of the two working groups was to provide research support in identifying innovations around the world that address palliative care policy, training, implementation, financing, and research, opioid accessibility, and integration of palliative care programs into local health systems, and in extracting from those cases knowledge and experiences that can be applied to other settings. The two working groups developed frameworks that guided the research, and identified several models and innovations in LMICs that have impressively improved access or appear very promising in terms of sustainability, scalability, or reproducibility in other settings.

6.1 Developing frameworks for country cases

The working group on models and innovations developed its framework to guide the authors in writing country cases through collaboration with Dr. Joseph Rhatigan, Associate Professor of Medicine and Associate Professor of Global Health and Social Medicine, utilizing years of experience within Global Health Delivery projects in designing cases for research and educational purposes in global health.

A working seminar was organized on May 11, 2015, with the following participants:
Presenter: Joseph Rhatigan
Discussion Participants: Felicia Knaul, Eric Krakauer, MR Rajagopal (via phone), Liliana De Lima (via phone), Xiaoxiao Jiang Kwete, Afsan Bhadelia, Andrew Marx

Materials were distributed by Dr. Rhatigan on cases they have developed previously for global health delivery projects and discussions were held around how to develop a case that can be used to support program implementation, advocacy and policy changes in Low and Middle Income Countries.

A framework for the cases of models and innovations was developed as follows:

A. **Table with information on the country's demographics, economic status, health system, morbidity & mortality.**
B. **The history of the model or innovation (MI):**
    - **What problem did the MI address?**

        - **What was the understanding of the barriers to prevention/relief of suffering in the population served by the MI?**
    - **What was/is the goal of the MI?**
    - **What was/is the scope of the MI? National? Local?**
    - **What were/are the specific barriers to the MI, and how did/does it overcome them?**
    - What were/are the costs and savings from the MI (IF KNOWN CLEARLY)?
    - How did/does the MI grow or develop, or what enabled/enables it to grow or develop? Partnerships? Laws or regulations? Other catalysts?
    - **How does or could the MI fit into, relate to, influence, or strengthen the public healthcare system, if at all?** (If possible, consider how it might promote universal health coverage (UHC)?
    - **In what ways were sustainability and scalability considered?**
        - What are the threats to its sustainability?
    - How does/did it measure its outcomes? What are the outcomes?
    - How did/does it improve its outcomes or adapt to the evolving clinical or political situation?
    - Other key points?

The working group on Universal Health Coverage and Health Systems developed its framework based on years of research on health systems and a pilot case development project with Mexico. The framework was designed around the 4 core functions of health systems, and the country authors were expected to write how palliative care and pain control projects are integrated into their local health systems by each function. See table 6A for detailed information:

Table 6A. Framework for Health System Cases/Country Policy Brief:

Core function	Key Elements	
	Overall health system	**PCPC integration (examples)**
Stewardship and governance	• Legislation	• Discussion of key actors and their roles in PCPC
	• Regulation and guideline	• Legislation around opioid access and prescribing of opioids
	• Sectoral priority and policy-setting (needs assessment)	• Performance assessment for PCPC
	• Monitoring and evaluation	• Regulation and guidelines around controlled substances
	• Resource allocation	• Consumer and provider protection
	• Desentralization and sub-national stewardship	• Sectoral priority and policy-setting for PCPC (needs assessment)
		• Resource allocation for PCPC
		• Intersectoral advocacy
		• Accountability mechanisms - Reporting, monitoring and evaluation of PCPC
Financing	• Revenue generation and fund pooling: Who are the insurers and who is covered?	• Discussion of key actors and roles in PCPC – for example who finances and who insurers
	• Purchasing and payment methods)	• What components of PCPC are in each covered package or entitlement for each population
	• Packages of interventions and entitlements: what is covered (interventions, diseases) and for whom (populations)	• Detailed description of PCPC entitlements for different disease and population groups
		• How are PCPC services financed and services purchased
Service delivery	• Provision of health services	• Provision of PCPC services
	• Operational integration	• Operational integration of PCPC
	• Procurement	• Referral and counter-referral systems for PCPC
		• Care pathway for PCPC
		• Procurement of PCPC medicines and technology
Resource production and management	• Overall production and management of physical, human, technological and knowledge resources	• Needs and management of physical, human, technological and knowledge assets and resources required for PCPC
		• Supply chain allocation and management

6.2 Working group experts meetings and editing processes

6.2.1 Working Group Meeting in Boston, May 4-5, 2015

Agenda:

Thursday May 14

Harvard Faculty Club, 20 Quincy Street, Cambridge, MA 02138

2:00 – 2:30 PM Greeting & introductions

2:30 – 3:00 PM Goal, objectives, work plan
3:00 – 3:30 PM Format of the briefs
3:30 – 3:45 PM Break
3:45 – 5:00 PM Proposed models & innovations
- Proposals by country
- Discussion / Decision on topics

5:00PM Adjourn

Friday May 15
FXB Building, Room 710, 651 Huntington Avenue, Boston, MA 02115

8:30 – 9:00 AM Plans for the day
9:00 – 12:00 PM Outline & draft the briefs in small groups with facilitator
- Mexico: Mariana Calderon, Hector Arreola, Justice José Ramón Cossío Díaz / Liliana de Lima
- India: Srinath Reddy / M.R. Rajagopal
- Lebanon: Huda Huijer Abu-Saad / Afsan Bhadelia
- Rwanda: Shekinah Elmore, Liz Grant / Eric L. Krakauer
- Uganda: Emmanuel Luriyika / Virginia Lebaron
- Vietnam: Ngan Dinh, Stephane Verguet / Eric L. Krakauer
- Australia: Jim Cleary
- USA: Nancy Keating / BR Daubman

12:00 – 1:00 PM Lunch
1:00 – 2:20 PM Presentations of draft briefs with discussion: 20 minutes per small group
2:20 – 2:40 PM Break
2:40 – 4:00 PM Presentations of draft briefs with discussion: 20 minutes per small group
4:00 – 4:45 PM Next steps
4:45 PM Close

Participants:

- Co-Chairs of working groups:
  - Liliana de Lima, MS
  - MR Rajagopal, MD
  - Eric L. Krakauer, MD, PhD
- Commissioners:
  - Felicia Knaul (Chair of Commission)
  - James Cleary
  - José Ramón Cossío Díaz (TBC)
  - Huda Abu-Saad Huijer
  - Emmanuel Luyirika
  - M.R. Rajagopal
  - Srinath Reddy
- Scientific Advisory Committee:
  - Hector Arreola
  - Afsan Bhadelia (co-coordinator)

    - Mariana Calderon
    - Ngan Dinh
    - Shekinah Elmore
    - Liz Grant
    - Nancy Keating
    - Virginia LeBaron
    - Stephane Verguet
- Collaborators:
    - Bethany-Rose Daubman
- Harvard Global Equity Initiative:
    - Hilary Cook
    - Xiaoxiao Jiang
    - Andrew Marx
    - Tim McDonald

6.2.2 Working Group Meeting in Cuernavaca, Aug 1-3, 2016

Agenda:
AUGUST 3, 2016
HOTEL LAS QUINTAS, CUERNAVACA, MORELOS MEXICO
SMALL GROUP DISCUSSIONS ARE OPEN TO ALL
Buffet breakfast is available as of 6.30 am

GROUP 2: HEALTH SYSTEMS COMPARATIVE ANALYSIS (COSTA RICA, JAMAICA, MEXICO, SOUTH AFRICA, CHILE, RWANDA)
13:30-16:00 with lunch
Led by Felicia Knaul and Afsan Bhadelia

Participants:
Rocio Saenz, Silvia Allende, Stephen Connor, Dingle Spence, Silvia Allende, Afsan Bhadelia, Kathy Foley, Felicia Knaul, Julio Frenk, Jorge Jimenez, Mary Gospodarowicz, Christian Ntizimira, Maria Elena Medina-Mora, Pedro Cruz, Eric L. Krakauer, Hector Arreola, Xiaoxiao Kwete.

6.2.3 Working Group Meeting in Washington DC, Dec 8, 2016

Agenda:
Thursday, December 8, 2016
12:30pm WELCOME AND OPENING REMARKS Silvana Luciani, Advisor, Cancer Prevention and Control, PAHO Felicia Knaul, Director, University of Miami Institute for the Americas and Chair, Lancet Commission on Global Access to Pain Control and Palliative Care
1:00pm PRESENTATION OF THE COSTA RICA CASE STUDY Rocio Sáenz, Executive Director, Caja Costarricense de Seguro Social

2:00pm SESSION 1: REVIEW OF THE METHODOLOGY FOR THE CASE STUDIES Methodology and indicators to be used for developing case-studies Felicia Knaul and Afsan Bhadelia Discussion
03:00pm COFFEE BREAK
3:15pm SESSION 2: CONTEXT FOR THE CASE STUDIES Framework and purpose of the case-studies on palliative care in LAC Felicia Knaul, Director, University of Miami Institute for the Americas and Chair, Lancet Commission on Global Access to Pain Control and Palliative Care Perspectives of the IAHPC on the development of the case studies Liliana de Lima, Executive Director, International Association for Hospice & Palliative Care and Member, Lancet Commission on Global Access to Pain Control and Palliative Care The global context and how the case studies will support the WHO resolution on palliative care Eric L. Krakauer, Medical Officer for Palliative Care, WHO, and Member, Lancet Commission on Global Access to Pain Control and Palliative Care Discussion
4:00pm SESSION 3: PRESENTATION OF COUNTRY CASE-STUDIES MEXICO: Héctor Arreola Ornelas, Mexican Health Foundation
5.00pm Adjourn

Friday, December 8, 2016
9:00am RECAP of the discussions and results of the first day. Silvana Luciani, PAHO
9:15am SESSION 3 cont'd: PRESENTATION OF COUNTRY CASE-STUDIES CHILE: Pedro Emilio Pérez Cruz, Pontifical Catholic University of Chile COLOMBIA: Natalia Rodriguez, Harvard University
10:15am COFFEE BREAK
10:30am SESSION 4: WORKING GROUPS TO DEVELOP CASE STUDIES Work group discussions on the expectations of the case studies and plan to complete them
12:00pm NEXT STEPS Agreement on the timeline to complete and publish the case-studies CONCLUSIONS
12:30pm ADJOURN

Participants:

- Nicolas Dawidowicz, Coordinator of the Palliative Care Program, National Cancer Institute
- Pedro Emilio Pérez Cruz, Instructor of the Internal Medicine Department, Pontifical Catholic University of Chile
- Rocío Sáenz, Executive President, Costa Rican Department of Social Security contact
- Adriana Osorio, Collaborator, Dirección de Garantía de Acceso a los Servicios de Salud Ministry of Health
- Bernardo Villa Cornejo, Subsecretaría de Integración y Desarrollo del Sector Salud, Department of Health
- Héctor Arreola Ornelas, Economics Research Coordinator, Mexican Health Foundation (FUNSALUD)
- Octavio Gómez Dantés, Senior Researcher, National Institute of Public
- Gaspar da Costa, Coordinator of the Palliative Care Program, Ministry of Health
- Liliana de Lima, Executive Director, International Association for Hospice & Palliative Care (IAHPC)

- Afsan Bhadelia, Research Associate, Harvard University
- Xiaoxiao Jiang, Research Associate, Harvard University
- Natalia Rodriguez, Research Associate, Harvard University
- Felicia Knaul, Director, University of Miami Institute for the Americas
- Michael Graybeal, Senior Manager, Business Operations, University of Miami Institute for the Americas
- Lisa Stevens, Deputy Director, Center for Global Health, US National Cancer Institute
- Eric L. Krakauer, Medical Officer for Palliative Care, World Health Organization
- Silvana Luciani, Regional Advisor, Cancer prevention and Control Pan American Health Organization
- Bernardo Nuche-Berenguer, Specialist, Noncommunicable Diseases Control
- Tabatha Santos, Consultant contact: santostab@paho.org

6.2.4 Process for reviewing and editing the briefs for models and innovation cases:

- **First Review:** The first review will be done by the assigned editor (Ms. de Lima, Dr. Rajagopal, or Dr. Krakauer). The editor will provide comments or suggest revisions using "track changes" and return the brief to the author to prepare a revised version.
- **Second Review:** The revised version will be reviewed both by the assigned editor and by a second reviewer from outside of the M&I Group. Additional revisions may be suggested at this stage and the brief returned to the author to prepare a final version.
- **Final Review:** The author, editor, and second reviewer must sign off on the brief before it can be accepted for on-line publication.

6.3 List of cases for models and innovations and for health strengthening country cases

Table 6B. Palliative care models and innovations briefs: countries, authors and topics.

Table 6B. Palliative care models and innovations briefs: countries, authors and topics

M&I Case Studies		
Country	**Lead Author**	**Title/Topic**
Albania	Ali Xhixha	The case of Albania - How palliative care programs were implemented in four regional hospitals leading to better access for patients
India	MR Rajagopal	Essential palliative medicine accessibility, especially oral immediate release morphine
Jamaica	Dingle Spence	Essential palliative medicine accessibility, especially oral immediate release morphine
Lebanon	Huda Abu-Saad Huijer	Evidence building and palliative care research in Lebanon
Malawi	Noel Kalanga	Social and economic support are an essential component of integrated palliative care and cancer/AIDS/NCD treatment for the rural poor in Neno District, Malawi
Mongolia	Odontuya Davaasuren	Moving gears of palliative care policy in Mongolia
Nepal	Bishnu Dutta Paudel	Training in palliative care (health care providers and/or healthcare leaders), resulting in benefits for patients
Uganda	Emmanuel Luyirika	The journey of opioid availability for hospice palliative care in Uganda
United States	Stephen Connor	Development of the US Medicare Hospice Benefit
Vietnam	Luong Ngoc Khue	Making opioid pain medicines safely accessible in Vietnam: A balanced policy method

Table 6C. List of Policy Briefs for Health System Country Cases

Table 6C. Palliative care models and innovations briefs: countries, authors and topics

M&I Case Studies		
Country / State	**Writer: Health Systems**	**Writer: Palliative Care Expert**
Kerala State, India	Dr. MR Rajagopal	Dr. MR Rajagopal
Rwanda	Dr. Agnes Binagwaho, Dr. Paul Farmer	Dr. Eric Krakauer
Costa Rica	Dr. Rocia Saenz	Dr. Isaias Salas, Liliana de Lima
Mexico	Prof. Felicia Knaul, Dr. Hector Arreola	Dr. Marianna Calderón, Liliana de Lima
Chile	Dr. Jorge Jimenez	Dr. Pedro Perez-Cruz, Dr. Eric Krakauer
South Africa		Dr. Liz Gwyther, Dr, Marsha Orgill
Jamaica		Dr. Dingle Spence

7 Data strengthening exercises

7.1 In-depth clinical review with palliative care specialists

A clinical expert panel was held alongside the third in-person meeting of the GAPCPC Commission to discuss and review the criteria for selection of conditions, criteria for selection ofsymptoms, and criteria for selection of interventions and amounts by condition.

Further, we worked closely with palliative care clinicians (table 7A) who have experience providing palliative care services in LMICs. Each of them were asked to consider a typical patient with each of the 20 conditions noted in section 1.1 and draw on their daily experience to generate an estimate on the prevalence and duration of each symptom, amount of medication required, medical equipment required, basic social needs required, and number of days required of each cadre of health care workers at each level of the health system. Either in groups or individually, they vetted the data estimates and hence, provided content validity for estimation of the global burden of remediable suffering and on the essential package of palliative care. Table 7A. provides a summary of concerns and feedback provided in in-depth consultation with clinical experts and which was then incorporated to bolster the evidence garnered.

[**Table 7A.** meetings with palliative care specialists around the world]

Table 7A. In-depth review with Palliative Care Specialists

PC Physician	Health Conditions / % of decedents needing PC	Types of Suffering	Essential Package
Christian Ntizimira (Rwanda)	- Higher # of cancer survivors	Add cough either to dyspnea or as separate type	
	- Dementia 70%		
	- Rabies 60%		
	- Lung dz 100%		
	- Premies & HIE 100%		
	- Atherosclerosis 60%		
Egide Mpanumusingo (Rwanda)	- Dementia 80%		- Meds: Add naloxone, topical lidocaine, nystatin SS
	- Rabies 80%		- Social supports: Add health insurance coverage for uninsured, school fees for HIV orphans, cash transfers for essential costs
			- In-kind support: add flashlight with rechargeable battery
			- Equipment: add adult diapers, WCs
MR Rajagopal (India)	- Estimates are a starting point for refining measurement of GBRS		
	- Note importance of old age frailty		
	- Rabies 100%		
Quach Thanh Khanh (Vietnam) *	- Dementia 70%	Add insomnia	Social supports: add clothes, clean water
	- Rabies 100%	Add cachexia	Equipment: add flashlight with rechargeable battery, plastic & cotton for adult diapers, bed pan, urinal
	- Encephalitis 50%		
	- Rheumatic heart dz 80%		
	- Chr ischemic hrt dz 50%		
	- Renal failure 75%		
	- Atherosclerosis 30%		
	- Musculoskeletal 20%		
Pham Van Anh (Vietnam)*	- Dementia 70%	Add insomnia	Social supports: add clothes, clean water
	- Rabies 100%	Add cachexia	Equipment: add flashlight with rechargeable battery, plastic & cotton for adult diapers, bed pan, urinal
	- Encephalitis 50%		
	- Rheumatic heart dz 80%		
	- Chr ischemic hrt dz 50%		
	- Renal failure 75%		
	- Atherosclerosis 30%		
	- Musculoskeletal 20%		
Than Ha Ngoc The (Vietnam)*	- Dementia 70%	Add insomnia	Social supports: add clothes, clean water
	- Rabies 100%	Add cachexia	Equipment: add flashlight with rechargeable battery, plastic & cotton for adult diapers, bed pan, urinal
	- Encephalitis 50%		
	- Rheumatic heart dz 80%		
	- Chr ischemic hrt dz 50%		
	- Renal failure 75%		
	- Atherosclerosis 30%		
	- Musculoskeletal 20%		
Ednin Hamzah (Malaysia)	- Dementia 80%		Meds: add generic antibx: fluconazole, ciprofloxacin, cephalexin
	- Rabies 90%		Equipment: add dressing supplies, stoma bags, garbage bags and cotton for adult diapers
	- Parkinsons 80%		
	- Other neuro 75%		
	- Cardiomyopathy 65%		
	- Renal failure 85%		
	- Atherosclerosis 50%		
	- Musculoskeletal 60%		
Silvia Allende (Mexico)	- Cancer survivors: 20%		- "Generic NSAID" ibuprofen or diclofenac or naproxen
	- Stroke 80%		- "Lactulose or other osmotic laxative"
	- Atherosclerosis 50-60%		
Dingle Spence (Jamaica)	- Cancer survivors: 20%	Add sleep disorders	- "Generic NSAID" ibuprofen or diclofenac or naproxen
	- Dementia 100%	Add anorexia/cachexia	- "Lactulose or other osmotic laxative"
			- Fluconazole
			- Adult diapers of some type
Claudia Burlá (Brazil)	- Cancer survivors: 20%	Add sleep disorders	- "Generic NSAID" ibuprofen or diclofenac or naproxen
	- Dementia 100%		- "Lactulose or other osmotic laxative"
	- Parkinson's 100%		
	- Chagas 60%		
	- COPD 95%		
	- Atherosclerosis 50-60%		

* denotes consensus of all 3 experts on all feedback

7.2 Two-stage Delphi process with palliative care specialists

The Delphi method is an iterative process that permits systematic means of acquiring questionnaire responses from a group of experts with the purposes of: 1) reducing the range of responses to a question, and 2) to approximate consensus among experts.[151] Specifically, it is a method used for assuring content validity. For our research, Delphi was used to assess: 1) components of the proposed palliative care packages and 2) duration of palliative care required for each of the 19 conditions out of 20 conditions (malnutrition was added after the Delphi review was completed) as indicated in section 1.1. Specifically, the Delphi enabled us to estimate the number of days ("symptom-days") of suffering and thus of need for palliative care in each disease condition.

7.2.1.1 Methodology

The classic Delphi method was applied in a two-stage process – open-ended questions were posed to experts in a first round to acquire group responses that were presented in the second round for re-review by experts.[152] Both rounds of the Delphi requested 18 LMICs palliative care experts to complete an anonymous online survey (see Appendix X) with the option to provide their name and with full essential and augmented package details. The questions requested experts to estimate the number of days of palliative care that would be required for a patient for any reason with each of the 19 out of 20 selected conditions and whether any medicines should be added, removed or edited in the essential or augmented packages. After the specific set of qualitative questions on the packages, the survey included a question on whether the participant had any other comments on the packages. This sought to provide an opportunity for incorporating areas that might have been otherwise neglected. Experts were requested to provide a range of figures – lower and upper bound – for estimates of numbers of days of palliative care. The responses were then pooled to identify a group average range and standard deviation for each condition. The second round of the Delphi presented respondents with the average range of number of days of palliative care with confidence intervals for each parameter. Experts were asked to re-respond to the questions based on knowledge of the group response for each question. The response rate for round one was 83% and for round two was 27%. Results from each round are presented in Tables 7B and 7C. The results were used to strengthen data analyzed for and presented in the Commission report.

7.2.1.2 Expert selection

Experts were purposively sampled and were considered to be 'informed individuals'[153] and 'specialists'[154] within their field, in this case palliative care.[155] The use of experts, individuals considered to have specialized content knowledge in areas related to the research, is to ensure face validity. Specifically, for this survey, experts were defined as palliative care specialists (clinical) with experience providing care to patients in LMICs. Through consultation with Commissioners, 18 experts were invited to participate in the Delphi review process.

7.2.1.3 Results

Table 7C.1 Delphi Survey on Palliative Care Needs Assessments Round1 Preliminary Results

Table7B. Delphi Process Results from Round1

Participant Number	1	2	3	4	5	6	7	8
Name	Anonymous	Anonymous	Anonymous	Anonymous	Anonymous	Anonymous	Anonymous	Anonymous
1. Should any medicines, equipment, or social supports be added to, or removed from, the essential/highest priority package? If yes, please provide details below.								
Please provide information on what medicines should be added to or removed from the essential/highest priority package:	should add codein, tramadol, carbamazepine	added: Diclofenac tabs,Tramadol tabs	It would be important to add Acid Tranexamic in my opinion, I do not see so important Fluoxetin or other SSRI if we have Amitriptillin in the list.	added: Midazolan I.V. and Lorazepam oral, Ketorolaco I.V., Metamizol I.V. Olanzapina IV and oral. Paracetmol parenteral. Removed: Diazepam	Nebulization medicines for breathlessness	Should be added: Fentanyl patch and Octeotride parenteral / Should be removed: Loperamide	1. Entacyd (with Simethicone) oral 2. Body Lotion 3. Antifungal oral 4. Anti fungal ointment	
Please provide information on what equipment should be added to or removed from the essential/highest priority package:	convert a suspention cot	NonSterile Gloves, thermometer, BP machine, stethoscope	Antidecubitus materials or medications like Duoderma and Colostoma I do see as high priority to be added	equipment of paracentesis,equipment healing of ulcers and wounds butterfly needles for subcutaneously	nebulizer	Should be added: wheelchairs and 3 positions beds. Bathroom and bath chairs. / Should be removed: Nasogastric drainage or feedin tube	Small kit containing few gauze pads, 1 nail cutter, 1 scissor, 3 syringes - 3 cc, 5 cc, 10 cc, one adhesive micropore	
Please provide information on what social support should be added to or removed from the essential/highest priority package:	enough	None	I don't have any suggestion in this respect	chapel, hostel for families, relaxation room for families,	Ok	Costa Rica provides a special license (Law 7756) for the patient relative who takes care of the terminal patient, during the time he stays alive at home / Should be removed: Cash payment and housing	Education support for 1/2 dependants of the patient	
2. Should any medicines, equipment, or social supports be added to, or removed from, the augmented (second tier) package? If yes, please provide details below.								
Please provide information on what medicines should be added to or removed from the augmented package:	should add endocrine therapy	added: fentanyl patches, Imodium tabs, Multivitamin, Ion tabs	Not anything to say	added: Midazolan I.V. and Lorazepam oral, Paracetmol parenteral. Removed: Diazepam	Some alternative medicines like prednisolone,pheniramine, spironolactone,	Should be added: Fentanyl patch and Octeotride parenteral / Should be removed: Loperamide	Same as 1	
Please provide information on what equipment should be added to or removed from the augmented package:	convert a suspention cot	added: Wounds dressing packages, NonSterile Gloves	Not anything to say	equipment of paracentesis,equipment healing of ulcers and wounds butterfly needles for subcutaneously	Pulse oximetry	Should be added: wheelchairs and 3 positions beds. Bathroom and bath chairs. / Should be removed: Nasogastric drainage or feedin tube	Same as 1	
Please provide information on what social support should be added to or removed from the augmented package:	should add psychologic support		Not anything to say	chapel, hostel for families, relaxation room for families	Ok	Costa Rica provides a special license (Law 7756) for the patient relative who takes care of the terminal patient, during the time he stays alive at home / Should be removed: Cash payment and housing	Same as 1	
3. Please state any suggestions, comments, or concerns you have about the essential/highest priority package.	delivering and using morphine at home	Very good list especially for LMICs needs in PC	ondansetron oral, scopolamine parenteral	Really it would be great if our governments will adopt this package, it would be great for patients and families also for our teams and for the health system	in my country is very important human resource, often exists but there is no way to pay it. Institutions could be responsible for paying the salaries of doctor, nurse and psychologist in palliative care. We also have a small space in the units to meet.	This is highly appreciating work. But I am 100% sure that this will not be universally accessible by everyone everywhere by 2020.	Suggestion: The creation of a "goverment opiod law deliver" for the whole population of terminal patients in low/medium income countries.	Essential/highest priority package should be distributed through a committee formatted by government and non-government members
4. Please state any suggestions, comments, or concerns you have about the augmented package.	control breakthrough pain with rapid onset opioids	I would suggest to add package of education program & activities (counseling, nutrition education, advocacy...)	Radiology tests, CT Scan or MRI would be very important when these are indicated or needed	in my country is very important human resource, often exists but there is no way to pay it. Institutions could be responsible for paying the salaries of doctor, nurse and psychologist in palliative care. We also have a small space in the units to meet.	There should be action oriented plan!	The principal concern is about the use of Nasogastric drenaige (an invasive method in these stage of a patien illnes) as an option for nutrition.	Same as above	
5. For questions 5.1-5.22, please provide your estimated range of the number of days that patients with each condition noted below would require palliative care for any reason. NO RESEARCH REQUIRED, ONLY YOUR EXPERT OPINION.	OK but the questions need to be discussed in a session to define at which moment "Palliative care" should start. LMICs & HICs have different approaches.	15 días	During the whole process of the patients decease					
5.1 Hemorrhagic fevers (Includes patients who do								
Lower bound for average number of days requiring	3	7	1	7	2	7	15	10
Upper bound for average number of days requiring	7	30	10	60	12	90	60	30
5.2 Tuberculosis (TB) (Death from TB)								
Lower bound for average number of days requiring	N/A	15	30	60	15	90	60	180
Upper bound for average number of days requiring	N/A	90	120	180-270	60	365	180	730
5.3 Tuberculosis (Death from MDR TB / XDR TB)								
Lower bound for average number of days requiring	N/A	10	30	few weeks	2	30	240	180
Upper bound for average number of days requiring	N/A	60	90	few months	12	180	1825-3650	730
5.4 Tuberculosis (On-treatment for MDR TB / XDR TB (outcome uncertain, both cure and death possible)								
Lower bound for average number of days requiring	N/A	8	30	30	2	180	730	180
Upper bound for average number of days requiring	N/A	90	180	180	12	365	3650	1000
5.5 HIV/AIDS								
Lower bound for average number of days requiring	N/A	15	30	180	2	180	730	1000
Upper bound for average number of days requiring	N/A	90	180	365	10	365	3650	1000
5.6 Malignant neoplasms (Death from malignant neoplasms)								
Lower bound for average number of days requiring	5	8	30	180	5	30	120	10
Upper bound for average number of days requiring	30	30	90	365	20	365	730	100
5.7 Malignant neoplasms (Survivors of malignant neoplasms)								
Lower bound for average number of days requiring	7	7	30	90	10	365	730	10
Upper bound for average number of days requiring	90	60	180	730	60	1825	3650	1500
5.8 Leukemia								

Table 7C.2 Delphi Survey on Palliative Care Needs Assessments Round1 Results_1/3

DELPHI ROUND 1 RESULTS: DURATION PALLIATIVE CARE IS REQUIRED CONDITION	Mean lower bound (days)	SD +/-	Mean upper bound(days)	SD +/-
5.1 Hemorrhagic fevers (includes patients who do not die)	8	4	34	24
5.2 Tuberculosis (TB) (Death from TB)	63	49	223	200
5.3 Tuberculosis (Death from MDR TB / XDR TB)	67	81	505	823
5.4 Tuberculosis (On-treatment for MDR TB / XDR TB (outcome uncertain, both cure and death possible)	132	209	620	1049
5.5 HIV/AIDS	223	315	699	1078
5.6 Malignant neoplasms (Death from malignant neoplasms)	42	50	188	187
5.7 Malignant neoplasms (Survivors of malignant neoplasms)	109	194	750	1039
5.8 Leukemia	62	99	329	501
5.9 Dementia	194	510	643	1069
5.10 Inflammatory disease of CNS	160	499	350	954
5.11 Following disease types: (a) Extrapyramidal & movement disorders, (b) Other degenerative diseases of the CNS, (c) Demyelinating disease of the CNS, (d) Epilepsy, (e) Cerebral palsy & other paralytic syndromes	228	508	1279	2147
5.12 Cerebrovascular disease	189	496	496	985
5.13 Following disease types: (a) Chronic rheumatic heart diseases, (b) Cardiomyopathy & Heart failure	59	95	461	929
5.14 Chronic ischemic heart disease	68	94	599	1127
5.15 Following disease types: (a) Chronic lower respiratory disease, (b) Lung disease due to external agents, (c) Interstitial lung disease, (d) Other diseases of the respiratory system	114	275	702	1132
5.16 Diseases of the liver	90	183	635	1119
5.17 Renal failure	78	182	455	831
5.18 Following disease types: (a) Low birth weight & prematurity, (b) Birth trauma	36	48	667	1227
5.19 Congenital malformations	86	121	1427	2470
5.20 Injury, poisoning, external causes	47	93	185	495
5.21 Atherosclerosis	95	105	877	1245
5.22 Musculoskeletal disorders	146	291	631	1046

Table 7C.3 Delphi Survey on Palliative Care Needs Assessments Round1 Results_2/3

Delphi Round 1 Results: Essential Package

- ***Medicines***
  - **ADD** codeine OR tramadol oral, tramadol, carbamazepine, diclofenac, acid tranexamic, lorazepam oral, ketorolaco IV, metamizol IV, olanzapina IV, oral paracetmol parenteral, nebulization meds, fentanyl patch, octeotride parenteral, entacyd (with Simethicone) oral, body lotion, antifungal oral, antifungal ointment, duoderma and colostoma, bisacodyl or senna oral, midazolam parenteral, gabapentin oral, lidocaine parenteral, at least two antibiotics, one antifungal agent like fluconazole, one inhaled bronchodilator, phosphate enema, docusate (instead of lactulose), levomepromazine, lidocaine injectable and ranitidine injectable, metronidazole, chlorpromazine PO, methadone PO/IV/SC
  - **REMOVE** fluoxetin or other SSRI since amitriptillin included, diazepam, loperamide, ondansetron, lactulose
- ***Equipment***
  - **ADD** suspension cot (instead of air mattress), non-sterile gloves, thermometer, BP machine, stethoscope, antidecubitus materials, equipment of paracentesis, butterfly needles, nebulizer, wheelchairs, bathroom chairs, kit containing gauze pads, nail cutter, scissor, syringes drivers - 3 cc, 5 cc, 10 cc, adhesive micropore, egg crate foam mattress, basic equipment for pleural tap/paracentesis i.e. cannulas, giving sets, urine bag, morphine pump, stents
  - **REMOVE** Nasogastric drainage or feeding tube, air mattress (add foam instead)
- ***Social support***
  - **ADD** chapel, hostel for families, relaxation room for families, home care, educational support for children of families impoverished by treatment costs, psychosocial/spiritual support and bereavement support, child care grant
  - **REMOVE** cash payment and housing, education support for 1/2 dependents of the patient
- ***Overall comments***
  - Lymphoedema support should be added with appropriate basic equipment e.g. bandages
  - Essential technologies, i.e. mobile phone central to patient follow-up, tracking access to medicines, handling of referrals and family support. This needs to appear somewhere.
  - I am not sure that it is fair to suggest a SSRI; SNRI could well be preferred today.

Table 7C.4 Delphi Survey on Palliative Care Needs Assessments Round1 Results_3/3

Delphi Round 1 Results: Augmented Package

- ***Medicines***
  - ADD endocrine therapy, imodium tabs, multivitamin, ion tabs, midazolan I.V. , lorazepam oral, paracetemol parenteral, alternative medicines such as prednisolone, pheniramine, spironolactone, octeotride parenteral, entacyd (with simethicone) oral, body lotion, antifungal oral, antifungal ointment, oxycodone or fentanyl transdermal and parenteral, escitalopram, quetiapine, SNRI (instead of SSRI), mirtazapine, gabapentine, pregabalin PO
  - REMOVE loperamide
- ***Equipment***
  - ADD suspension cot (instead of air mattress), wound dressing packages, non-sterile gloves, equipment of paracentesis, pulse oximetry, wheelchairs, positions beds, bathroom chairs, portable toilet (commode), surgical sets for procedures like excision of slough, peritoneocentesis, plurocentesis, syringe drivers, morphine pump, stents, radiotherapy equipment/linear accelerator,
  - REMOVE nasogastric drainage or feeding tube
- ***Social support***
  - ADD psychological support, chapel, hostel for families, relaxation room for families, home care, psychosocial/spiritual support/care and bereavement support, child care grant, disability grant, family care grant, counseling for children when family member sick as well as basic needs assurance for food, education and general care
- ***Overall comments***
  - Better define point at which PC should begin since LMICs and HI countries have different approaches
  - Add lymphoedema support
  - Essential technologies, i.e. mobile phone central to patient follow-up, tracking access to medicines, handling of referrals and family support. This needs to appear somewhere.
  - Excluding radiotherapy is not a good position to take.

Table7D.1 Delphi Survey on Palliative Care Needs Assessments Round2 Results_1/3

Table 7D.1 Results from Delphi Round 2

DELPHI ROUND 2 RESULTS: DURATION PALLIATIVE CARE IS REQUIRED CONDITION	Mean lower bound (days)	SD +/-	Mean upper bound(days)	SD +/-
5.1 Hemorrhagic fevers (includes patients who do not die)	13	12	40	35
5.2 Tuberculosis (TB) (Death from TB)	80	68	184	133
5.3 Tuberculosis (Death from MDR TB / XDR TB)	75	31	168	97
5.4 Tuberculosis (On-treatment for MDR TB / XDR TB (outcome uncertain, both cure and death possible)	83	39	288	283
5.5 HIV/AIDS	150	117	316	216
5.6 Malignant neoplasms (Death from malignant neoplasms)	44	26	178	76
5.7 Malignant neoplasms (Survivors of malignant neoplasms)	195	140	768	634
5.8 Leukemia	85	56	249	132
5.9 Dementia	148	79	599	328
5.10 Inflammatory disease of CNS	78	32	241	111
5.11 Following disease types: (a) Extrapyramidal & movement disorders, (b) Other degenerative diseases of the CNS, (c) Demyelinating disease of the CNS, (d) Epilepsy, (e) Cerebral palsy & other paralytic syndromes	173	111	578	361
5.12 Cerebrovascular disease	150	117	419	229
5.13 Following disease types: (a) Chronic rheumatic heart diseases, (b) Cardiomyopathy & Heart failure	95	62	433	327
5.14 Chronic ischemic heart disease	83	67	349	275
5.15 Following disease types: (a) Chronic lower respiratory disease, (b) Lung disease due to external agents, (c) Interstitial lung disease, (d) Other diseases of the respiratory system	83	67	696	800
5.16 Diseases of the liver	85	66	433	327
5.17 Renal failure	88	65	436	219
5.18 Following disease types: (a) Low birth weight & prematurity, (b) Birth trauma	32	22	443	705
5.19 Congenital malformations	123	111	430	332
5.20 Injury, poisoning, external causes	27	7	202	98
5.21 Atherosclerosis	88	65	324	83
5.22 Musculoskeletal disorders	83	67	479	291

Table7D.2 Delphi Survey on Palliative Care Needs Assessments Round2 Results_2/3

Delphi Round 2 Results: Essential Package

- ***Medicines***
  - **ADD** Tramadol, Acetaminophen oral, ketorolac IC or SC, tramadol oral, nebulization meds, methadone IV, topical antifungal (mouth), midazolam IV, evomepromacine tablets, queatipine tablets, antifungical agent, metronidazole cream, octreotide parenteral
  - **REMOVE** olanzapine IV, octreotide parenteral, entacyd (this is a brand name), replace with "simethicone preparation", duoderma and colostoma (not medications/terms not in English)
- ***Equipment***
  - **ADD** BP instrument and stethoscope, butterfly needles, equipment of paracenthesis, wheelchairs, bathroom chairs, "agree with all"
- ***Social support***
  - **ADD** Home care, psychosocial support for patients and families, chapel and relaxing rom for families, "agree with all"
- ***Overall comments***
  - It is important to have a wider variety of analgesic medicines. Midazolam IV is essential for palliative sedation. Nebulization meds and topical antifungals for algorra is important due to its frequency.
  - I am concerned that the addition of wheelchairs and bathroom chairs to the essential package may be difficult to achieve. Too costly for many countries.
  - I'm removing the octreotide, but I want to add atropine ophthalmic drops for sublingual use for management of gastrointestinal secretions.

Table7D.3 Delphi Survey on Palliative Care Needs Assessments Round2 Results_3/3

Delphi Round 2 Results: Augmented Package

- ***Medicines***
  - **ADD** Fenthanyl patches, gabapentin oral and levopromacine tablets, "all good"
- ***Equipment***
  - **ADD** Paracentesis and thoracocentesis equipment, urine bags, morphine pump, plurocentedis, "all good"
- ***Social support***
  - **ADD** Chapel and relaxation room for the families
- ***Overall comments***
  - Paracenthesis and thoracocenthesis are procedures that can provide immediate relief. Due to the skills needed and its complexity, should be available in the augmented package.

7.2.1.4 Limitations

The Delphi method survey results on duration of symptoms had several limitations. First, we noticed that estimations of duration of need for palliative care in two conditions did not fit with clinical reality. Estimates of duration of need for palliative care in “injury or poisoning” ranged from 27 to 202 days. Yet we included this condition primarily because of the large unfulfilled need for palliation of acute suffering among patients who usually either die within hours or days or no longer need palliative care within days to weeks. We believe that most long-term sequelae of injuries for which palliative care is needed are captured in the category of “musculoskeletal disorders.” We concluded that the “injury or poisoning” category was insufficiently clear to the Delphi survey participants, and we therefore discarded the results. Similarly, we concluded, based on the nonsensical results, that the category of “inflammatory diseases of the central nervous system” was insufficiently clear to the survey participants, and we discarded these results as well. Our initial estimates were within the range of estimated duration of palliative care need for 12 of the remaining 16 conditions and within one standard deviation of the upper or lower bound for all 16 conditions. Details of the Delphi process are described in section 5.

Delphi Survey on Palliative Care Packages

I. BACKGROUND

The Lancet Commission on Global Access to Palliative Care and Pain Control (GAPCPC) has drafted two packages of palliative care services as part of its work on economic evaluation and metrics. The packages seek to promote government provision of palliative care services.

We are asking palliative care physicians like you who work in LMIC countries to comment on these packages through the Delphi method for structured input and consensus building.

II. INSTRUCTIONS

Please review the descriptions of the two packages and the list of their respective components as summarized in Table 1. Then, please complete the survey. The survey should require approximately 30 minutes. Please note that the information provided herein is a draft for comment only and not for circulation.

III. INFORMATION ON PALLIATIVE CARE PACKAGES

1. Essential/Highest Priority Package (HPP)

- Designed to relieve the most common and severe suffering (physical, psychological, social, or spiritual) related to illness or injury, to be cost effective in low and middle income countries (LMICs), to help strengthen health systems, and to protect patients and their families from catastrophic health expenditures. Items can and should be provided at any level of care.
- Consists mainly of medicines on the WHO List of Essential Medicines for Palliative Care for adults and for children that are inexpensive and easy to use but that also are effective to relieve the common symptoms of serious chronic, complex, or life-limiting health problems.
- Also includes some small, inexpensive equipment, and, for the poorest patients and families, five types of support to satisfy basic needs.
- **Should be made universally accessible by everyone everywhere by 2020 in countries of all levels of income.**

2. Augmented Package

- Consists of the essential/highest priority package supplemented with basic palliative surgery, palliative radiotherapy, and basic palliative cancer chemotherapy. Some items can be managed at the secondary or district level of care, but there are items requiring a tertiary hospital setting.
- **Should be made universally accessible as soon as possible and ideally in upper middle income countries by 2020.**

The specific health care and basic needs support items proposed for inclusion in each package are listed below.

The necessary health system platforms, including human and physical resources and health system stewardship, must be in place to support the delivery of a high-quality package of services. These are not separately listed in the package but will be clearly descried in the Commission report. Most are not exclusive to palliative care (i.e. only a % of the service is dedicated to palliative care).

Table 7E: Components of the proposed Essential/Highest Priority Package (HPP) of palliative care for all countries including low and middle income countries (LMICs).

Items included in each package	Essential/ Highest Priority Package
Medicine	
Amitriptyline	√
Bisacodyl	√
Dexamethasone oral	√
Dexamethasone parenteral	√
Diazepam oral	√
Diazepam parenteral	√
Diphenhydramine or cyclizine oral	√
Diphenhydramine or cyclizine parenteral	√
Fluoxetine or other SSRI	√
Furosamide oral	√
Furosamide parenteral	√
Haloperidol oral	√
Haloperidol parenteral	√
Hyoscine butylbromide oral	√
Hyoscine butylbromide parenteral	√
Ibuprofen	√
Lactulose	√
Loperamide	√
Metaclopramide oral	√
Metaclopramide parenteral	√
Metronidazole tabs or caps for topical care	√
Morphine oral	√
Morphine parenteral	√
Omeprazole oral	√
Ondansetron oral	√
Ondansetron parenteral	√
Paracetamol oral	√
Petroleum jelly	√

Medical Equipment	
Air mattress	√
Nasogastric drainage or feeding tube	√
Oxygen (days receiving on average 3L per minute)	√
Urinary catheters	√
Cash payment and housing	√
Food package	√
Funeral support	√
In-kind support	√
Transportation costs	√

I. SURVEY QUESTIONS

Name (Optional): _____

1. Should any medicines, equipment, or social supports be added to, or removed from, the **essential/highest priority package**? If yes, please provide details below.

   Please provide information on what **medicines** should be added to or removed from the **essential/highest priority package**:

   Please provide information on what **equipment** should be added to or removed from the **essential/highest priority package**:

   Please provide information on what **social support** should be added to or removed from the **essential/highest priority package**:

2. Should any medicines, equipment, or social supports be added to, or removed from, the augmented (second tier) package (EP)? If yes, please provide details below.

Please provide information on what **<u>medicines</u>** should be added to or removed from the **augmented package**:

Please provide information on what **<u>equipment</u>** should be added to or removed from the **augmented package**:

Please provide information on what **<u>social support</u>** should be added to or removed from the **augmented package**:

3. Please state any suggestions, comments, or concerns you have about the **essential/highest priority package**.

4. Please state any suggestions, comments, or concerns you have about the **augmented package**.

5. For questions 5.1-5.22, please estimate the average number of days that patients with each condition would have a need for palliative care for any reason. Please give a lower bound and an upper bound for the average number of days. NO RESEARCH REQUIRED, ONLY YOUR EXPERT OPINION.

    A. Hemorrhagic fevers (includes patients who do not die)

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**
_____ days	_____ days

B. Tuberculosis

i. Death from tuberculosis (TB)

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**
_____ days	_____ days

ii. Death from MDR TB / XDR TB

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

iii. On-treatment for MDR TB / XDR TB (outcome uncertain, both cure and death possible)

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

C. HIV/AIDS

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

D. Malignant neoplasms

i. Death from malignant neoplasms

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

ii. Survivors of malignant neoplasms

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

E. Leukemia

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

F. Dementia

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

G. Inflammatory disease of CNS

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

H. Following disease types: (1) Extrapyramidal & movement disorders, (2) Other degenerative diseases of the CNS, (3) Demyelinating disease of the CNS, (4) Epilepsy, (5) Cerebral palsy & other paralytic syndromes

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

I. Cerebrovascular disease

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

J. Following disease types: (1) Chronic rheumatic heart diseases, (2) Cardiomyopathy & Heart failure

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

K. Chronic ischemic heart disease

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

L. Following disease types: (1) Chronic lower respiratory disease, (2) Lung disease due to external agents, (3) Interstitial lung disease, (4) Other diseases of the respiratory system

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

M. Diseases of the liver

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

N. Renal failure

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

O. Following disease types: (1) Low birth weight & prematurity, (2) Birth trauma

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

P. Congenital malformations

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

Q. Injury, poisoning, external causes

Lower bound for average number of days requiring palliative care	**Upper bound for average number of days requiring palliative care**

R. Atherosclerosis

Lower bound for average number of days requiring palliative care	Upper bound for average number of days requiring palliative care

S. Musculoskeletal disorders

Lower bound for average number of days requiring palliative care	Upper bound for average number of days requiring palliative care

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