

Mapping levels of palliative care development: a global view

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Executive summary

This pilot study builds on the IOELC study in Africa, during which we developed a four part typology depicting levels of hospice and palliative care development. The four groups within the typology are: 1) no known hospice-palliative care activity 2) capacity building activity (but no service yet) 3) countries with localised provision of hospice-palliative care, and 4) countries where hospice and palliative care activities are approaching integration with the wider health system.

Objectives and method

The project's objectives are: 1) to categorise hospice-palliative care development, using the Observatory typology, country by country throughout the world 2) to depict this development in a series of world and regional maps 3) to construct a second series of maps depicting crude death rates (CDRs), and 4) to determine and explore any correlation between CDRs and palliative care development

The maps presented here make use of the United Nations list of 234 countries that are allocated to six 'major areas' designated as 'continents': Africa, North America, Latin America and the Caribbean, and Oceania. The geographic extent of these countries ranges from 17 million square kilometres (Russia), to 0.44 square kilometres (the Vatican). The most populated country is China, with around 1.32 billion; the least populated is Pitcairn Island, with about 50 inhabitants.

Palliative care data have been gathered from five main sources: 1) books, journals, newsletters, directories, web sites 2) grey literature and conference presentations 3) opinions of local and regional experts 4) a task force of the European Association for Palliative Care and 5) IOELC reviews, interviews, surveys and databases. Crude death rates were obtained from the United Nations Population and Vital Statistics Report: Series A.

Findings

Around half of the 234 countries included in this review have established one or more hospice-palliative care services. Yet only 35 (15%) countries have achieved a measure of integration with wider mainstream service providers. In 78 (33%) countries, no palliative care activity can be identified.

The human development index (HDI) gives a multiple measure of a country's development, based on: longevity, knowledge, and standard of living. A strong association exists between palliative care and human development. Twenty nine (83%) of the 35 countries in Group 4 have a high level high human development; only 1 (3%) country is in the low development group. Among 78 countries in Group 1, only 2 (3%) have a high level of human development; 42 (54%) countries in this group have no HDI.

Countries in Group 4 have multiple services and within this group, the upper ratio of services to population is 1: 4.28 million (Kenya). Countries in Group 3, however, frequently have single service provision and the ratio of services to population reaches to 1: 157 million (Pakistan)

GDP per capita (International Dollars) among Group 4 countries ranged from \$1,088 in Uganda to \$40,336 in Sweden. A broad range of GDP per capita was also found among countries with no known service: \$386 in Liberia to \$48371 in Monaco.

Crude death rates ranged from 3.7 to 13.4 (per 1000 population) among Group 4 countries: this within an overall range of 1.8 to 20.5. A closer analysis of CDR data was hindered by the fact that death rates were missing for 93 (40%) countries.

Conclusions

More than 150 countries are actively engaged in delivering a hospice-palliative care service or developing the framework within which such a service can be provided. Yet development is patchy, with palliative care approaching a measure of integration with wider service providers in just 15% of countries; in countries with localised provision there are many instances where a service is mostly inaccessible to the whole population. Consequently, despite increasing calls for palliative care to be recognised as a human right, there is a long way to go before palliation is within reach of the global community.

The typology and its application provide a different perspective on palliative care development that might helpfully be used alongside other measures. Evidence here suggests that the instrument grouped parallel developments in both resource rich and resource poor settings, and across the north/ south divide. The strong correlation between palliative care and human development provides an indication that the typology has an element of validity and reliability.

The relationship between a country's wealth (GDP per capita) and palliative care development should be approached with caution, since high and low income countries are represented in each of the four groups of countries.

In addition to the well known barriers to palliative care development, factors associated with a country's size, population and infrastructure present formidable challenges. Moreover, palliative care development is not linear. A country's response to internal and extraneous pressures may result in movement between groups, as in the case of Zimbabwe.

To assist those engaged in policy and service development, more work is now needed to further develop the typology, its robustness and applicability; to construct a broader evidence base for informed decision-making; and to develop a cohesive system of service identification

Introduction

Since the latter part of the 1990s, there has been growing interest in a comparative view of palliative care development.¹ In Europe, the first study to review palliative care using comparative methods² reported in 2000. Focusing on seven countries in Western Europe, it paid attention a range of factors that included patterns of provision and policy integration. More recently, Birgit Jaspers and Thomas Schindler³ received a Bundestag commission to review palliative care provision in Germany (reported 2004) compared with 10 other European countries. A broader study, led by Reimer Gronemeyer at the University of Geissen, examined palliative care provision in 16 countries across Eastern and Western Europe, reporting not only on the number of services but also on the role of volunteers and the number of palliative care beds.⁴ And in 2006, a task force of the European Association for Palliative Care (EAPC), commissioned to map the development of palliative care in Europe, presented its initial findings at the EAPC research congress in Venice.

Alongside these initiatives is the work of the International Observatory on End of Life Care (IOELC). Established within the Institute for Health Research at Lancaster University (2003), the IOELC has adopted comparative methods in its reviews of hospice-palliative care activity, and used a common template to present research-based reports, country by country. Its aims are to:

- Provide accessible research-based information
- Disseminate this information through the Observatory website and other publications
- Undertake primary research studies and reviews
- Develop a small grants programme to support academic work, particularly in resource poor areas
- Work in partnership with key individuals and organisations, nationally and internationally.

To facilitate these aims, the IOELC:

- Focuses on different regions of the world and the countries within them

¹ Clark D, Centeno C. Palliative care in Europe: an emerging approach to comparative analysis. *Clinical Medicine* 2006; 6(2): 197-201.

² Clark D, ten Have H, Janssens R. Common threads? Palliative care service developments in seven European countries. *Palliat Med* 2000;14(6): 479-490.

³ Jaspers B, Schindler J. *Stand der Palliativmedizin und Hospizarbeit in Deutschland und im Vergleich zu ausgewählten Staaten (Belgien, Frankreich, Großbritannien, Niederlande, Norwegen, Österreich, Polen, Schweden, Schweiz, Spanien)*. Auftraggeber: Enquete-Kommission des Bundestages „Ethik und Recht der modernen Medizin“, 2004. See: <http://www.dgpalliativmedizin.de/pdf/Gutachten%20Jaspers-Schindler%20Endfassung%2050209.pdf> accessed 10 February 2006

⁴ Gronemeyer R, Fink M, Globish M, Schumann F (2005) *Project on hospice and palliative care in Europe: Helping people at the end of their lives*. Berlin: Lit Verlag (English edition).

- Traces the recorded and narrative history of palliative care, country by country
- Identifies in-country services by organisation and type
- Gathers information on pain relief and morphine consumption
- Highlights major ethical issues confronting palliative care workers
- Acknowledges the roles played by key activists.

By the summer of 2006, the IOELC had reviewed developments in Africa, Eastern Europe, Central Asia, India, parts of Latin America, and the Middle East. Around 90 countries were reviewed (although palliative care activity was not found in all of them) and more than 60 country reports have been published in paper form or on the IOELC web site.⁵

This pilot project builds on the IOELC study in Africa, during which we developed a four part typology depicting levels of hospice and palliative care development. The four groups within the typology are: 1) no known hospice-palliative care activity 2) capacity building activity (but no service yet) 3) countries with localised provision of hospice-palliative care, and 4) countries where hospice and palliative care activities are approaching integration with the wider health system (Table 1).

Table 1. Typology of hospice palliative care service types

1 No known activity	2 Capacity building	3 Localised provision	4 Approaching integration
	<ul style="list-style-type: none"> • Presence of sensitised personnel • Expressions of interest with key organisations (eg APCA, HAU, IAHP, Hospice Information) • Links established (international) with service providers • Conference participation • Visits to hospice-palliative care organisations • Education and training (visiting teams) • External training courses undertaken • Preparation of a strategy for service development • Lobbying: policymakers/ health ministries 	<p><i>A range of capacity building activities but also:</i></p> <ul style="list-style-type: none"> • Critical mass of activists in one or more locations • Service established – often linked to home care • Local awareness/ support • Sources of funding established (though may be heavily donor dependent and relatively isolated from one another, with little impact on wider health policy) • Morphine available • Some training undertaken by the hospice organisation 	<p><i>Capacity building and localised activities but also:</i></p> <ul style="list-style-type: none"> • Critical mass of activists countrywide • Range of providers and service types • Broad awareness of palliative care • Measure of integration with mainstream service providers • Impact on policy • Established education centres • Academic links • Research undertaken • National Association

⁵ See http://www.ioelc-observatory.net/global_analysis/regions_main.htm

Aims, objectives and method

The overarching aim of presenting a ‘world map’ of hospice-palliative care development is to contribute to the debate about the growth and recognition of palliative care services. We also wish to stimulate discussion about the typology and whether or not the key elements reflect sequential levels of palliative care development. We recognise that funders and donors play important roles nurturing and expanding palliative care and our work is intended to give a short-hand indication of activity in a particular country or region. Furthermore, the construction of a global database which, over time, tracks features such as the nature of provision, the ratio of services to population, education and training and policy recognition is intended to help monitor even small-scale changes.

The objectives of this study are:

- 1) To categorise hospice-palliative care development, using the Observatory typology, country by country throughout the world
- 2) To depict this development in a series of world and regional maps
- 3) To construct a series of maps depicting crude death rates (CDRs)
- 4) To determine and explore any correlation between CDRs and palliative care development

The maps presented here make use of the United Nations list of 234 countries that are allocated to six ‘major areas’ designated as ‘continents’: Africa, North America, Latin America and the Caribbean, and Oceania. The geographic extent of these countries ranges from 17 million square kilometres (Russia), to 0.44 square kilometres (the Vatican). The most populated country is China, with around 1.32 billion; the least populated is Pitcairn Island, with about 50 inhabitants.

Palliative care data are gathered from five main sources:

- Books, journals, newsletters, directories, web sites
- Grey literature and conference presentations
- Opinions of local and regional experts
- A task force of the European Association for Palliative Care
- IOELC reviews, interviews, surveys and databases.

These data are then analysed using the key elements of the typology. Where services are identified, we explore questions of coverage, public awareness, opioid availability, education and training, and reimbursement. Next, we focus on service types and settings; the impact of palliative care upon policy; links with academic institutions; the performance of research; and the relationship between palliative care services and other mainstream service providers. Finally, the country in question is allocated to one of the categories on the basis of its level of palliative care development.

Crude death rates have been drawn from the United Nations *Population and Vital Statistics Report*. Most of the report’s data are collected from national civil registration systems, but there is a marked difference in the completeness of the information that is

produced. Crude death rates are the total number of deaths per thousand persons which occur in the same year (Appendix 1).⁶

Other development indicators

To gain an enhanced view of a country's level of development, data were collected relating to: human development (HDI); gross domestic product (GDP); population size; and the number of in-country services:

- *Population size.* These figures were taken from the WHO website (192 countries) and supplemented by estimated figures from the World Fact Book (42 countries); these latter figures were supplied by the US Census Bureau and are also based on statistics from population censuses and vital statistics registration systems (Appendix 2).
- *Human development.* The human development index (HDI) gives an insight into a country's development in human rather than economic terms. Launched by the United Nations in 1990, HDI measures a country's achievements in three aspects of human development: longevity, knowledge, and a decent standard of living. It was created to re-emphasize that people - and their lives - should be the ultimate criteria for assessing the development of a country, not economic growth. Overall values⁷ range from 0.963 (Norway, 1/177 countries) to 0.275 (Niger, 177/177 countries). Countries ranked 1-57 are deemed to have a high level of human development; 58-145 a medium level, and 146-177 low development (Appendix 3).
- *Gross domestic product (GDP)* is indicative of a country's wealth; it is the market value of the total final output of goods and services produced in a country over a specific period, shown in this report in international dollars (Intl \$). (Appendix 4).⁸
- *The number of services operating in individual countries.* These data give a helpful insight into palliative care activity;⁹ and the ratio of services to population is illuminating. The counting of services, however, is problematic since two systems are currently in use. One method, favoured by the EAPC Task Force, is to count the number of services by type, for example: in-patient palliative care units; hospices; hospital care teams; day centres. An alternative

⁶ These data are regularly updated; they were accessed for this study on 15 March 2006.

⁷ See: United Nations Human Development Report, 2005

<http://hdr.undp.org/statistics/data/indicators.cfm?x=1&y=1&z=1>

⁸ WHO defines the international dollar as a common currency unit that takes into account differences in the relative purchasing power of various currencies. Figures expressed in international dollars are calculated using purchasing power parities, which are rates of currency conversion constructed to account for differences in price level between countries

⁹ The IOELC routinely collects this information during its country reviews; the EAPC Task Force has also gathered service data as part of its European Review.

The 35 countries in Group 4 are: Argentina, Australia, Austria, Belgium, Canada, Chile, Costa Rica, Denmark, Finland, France, Germany, Hong Kong, Hungary, Iceland, Ireland, Israel, Italy, Japan, Kenya, Malaysia, Mongolia, New Zealand, Netherlands, Norway, Poland, Romania, Singapore, Slovenia, South Africa, Spain, Sweden, Switzerland, Uganda, United Kingdom, United States of America.

Group 4 countries: examples of development

On the African continent, initiatives in South Africa towards the end of the 1970s resulted in palliative care services becoming established in Johannesburg, Cape Town, Durban and Port Elizabeth during the following decade. The forerunner of the Hospice Palliative Care Association of South Africa was formed in 1987 and by 2006 around 120 member organisations had become enrolled. Many of these organisations have branches which provide palliative care services in local settings. Service types include: in-patient care; home care; day care; clinics/ drop-in centres; hospital support teams; education and training; patient support groups; bereavement care; foster parent support groups; orphan support groups; hospice care for the homeless. Between 2003 and 2004, data returned to HPCA indicate that 24,613 patients were cared for, of whom 12,413 had an AIDS diagnosis whereas 9,233 had cancer. A national strategy and innovative mentoring programme, part funded by the President's Initiative (PEPFAR), have enabled palliative care to reach some of the more remote districts of the country.

In Kenya, Nairobi hospice was founded in 1990 and by 2004 eight organisations were providing a total of 25 services. The government of Kenya does not yet have an official palliative care policy although it is supportive of palliative care in the country. The Ministry of Health is working on a five-year Health Sector Strategic Plan and has invited Nairobi Hospice representatives to sit on that committee. Nairobi Hospice is also consulting with the Ministry of Health on the development of a manual guiding palliative care for cancer of the cervix. The Government of Kenya supports the hospice in kind by paying for the salaries of three nurses seconded to the hospice by the Ministry of Health. It has also donated a plot of land on which the hospice can build its own offices. The training programmes offered by Nairobi Hospice are aimed at alleviating the continuing resistance to the use of morphine in Kenya amongst some doctors and nurses. Academic links have been established with Oxford Brookes University (UK) and in 2002 the first students received diplomas in palliative care.

Hospice Africa Uganda (HAU) was founded in 1993 to develop a model service for resource poor settings. Its services began in a two-bedroom house loaned by Nsambya Hospital and subsequently moved to alternative accommodation, donated free of charge by Henry Mary Kateregga, before the current premises were secured at Makindye (Kampala). In January 1998, the service was extended with the founding of Mobile Hospice Mbarara. An outreach clinic was established and supplemented by the inception of roadside clinics for those outside of the 20 kilometre catchment area. In June 1998, a third service was founded - Little Hospice Hoima – and as a result, an accessible and

affordable service reached out to the villages, supported by community volunteers. Clinical developments were supported by an education and resource centre and in 2002 a distance learning Diploma in Palliative Care was established in conjunction with Makerere University. Palliative care has had a long-standing place in government health policy, and the strategic plan for 2006-11 has recently been published. In recent years, HAU has developed a wide-ranging advocacy role and teams regularly visit other African countries to promote palliative care. Importantly, nurses and clinical officers trained at HAU may be licensed to prescribe morphine.

In Asia, hospice care in Japan dates back to the mid-1970s when Tetsuo Kashiwagi, a psychiatrist, set up a programme for care of dying patients in Osaka. After visiting Cicely Saunders at St Christopher's, he trained as a physician and subsequently opened a hospice in Yodogawa Christian Hospital in 1984. Meanwhile, a hospice unit had been established at the Serai Hospital in Hamamatsu (1981). As interest in care for the dying increased, the Ministry of Health, Welfare and Labour developed guidelines for cancer pain and palliative care. Recommendations included a programme of palliative care education and reimbursement through the national health insurance system. From 1990, funding became available for all patients receiving palliative care in IPUs. Palliative care standards were approved in 1997 and palliative care education can now be found in most medical and all nursing schools to support around 120 services country-wide.

In Singapore, a volunteer home care service began in 1987 as a result of an initiative from the Canossian sisters, a Catholic religious order. Activists formed themselves into the Hospice Care Group which came under the auspices of the Cancer Society. By 1989, the same group of people established the Hospice Care Association: a non-governmental organisation committed to hospice development. Initially, hospice services were funded by charitable organisations, with affordable contributions from the patient; yet from 1994, funding was made available by the Government from the Central Provident Fund. Around 13 organisations currently provide palliative care services in Singapore; palliative care modules have become part of the medical curricula; and all medical students undertake a palliative care placement as part of their training.

The hospice movement in Malaysia began during the early 1990s when Hospis Malaysia (based in Kuala Lumpur) and the Penang Branch of the National Cancer Society began to use charitable donations to provide home care services. In 1998, the Government took a lead when it required every district and general hospital to introduce palliative care provision: a factor that led to a rapid increase in palliative care units and hospital based palliative care teams throughout the country. And in the Central Asian country of Mongolia, a vast country with a population of just 2.6 million, collaboration between Government and activists has resulted in palliative care being incorporated into the national health plan. Around 400 doctors and 600 nurses have become sensitised to palliative care; palliative care modules have been included in the medical curriculum; and palliative medicine has been recognised as a separate discipline.

In North America, care of the dying had attracted attention in the US from the 1960s, but it was not until 1974 that Connecticut Hospice provided the first home care service. The

forerunner of the National Hospice and Palliative care organisation (NHPCO) was founded in 1978, with Zachary Morfogen as the first chairperson. Reimbursement for hospice patients through the Medicare programme became enacted in 1983, and by 2005, NHPCO estimated that 1.2 million patients were being cared for nationwide within hospice programmes. It was also in 1974 that the hospice-palliative care movement in Canada gathered momentum, prompted by the establishment of an in-patient unit at St Boniface General Hospital in Winnipeg. A Minister with Special Responsibility for Palliative Care was appointed in 2001, and the Compassionate Care Benefit – designed to enable Canadians to temporarily leave their jobs to care for a dying family member while being supported by the Employment Insurance programme – was announced in 2003. By 2006, the estimated number of services had risen to 500.

In Latin America, palliative care began to be offered in Argentina from 1982. Twenty years later, around 80 teams were operating countrywide and palliative care activity could be identified in each major and medium sized city throughout the country. In the main, palliative care services are hospital based, with few home care programmes. The Pallium Latinoamerica training initiative was launched in the early 1990s to support clinical practice, with courses offered at various centres across the country. Links have been established with the International Centre for Palliative Care in Oxford, and courses are accredited by the Universidad del Salvador School of Medicine (Buenos Aires). A major step forward was taken in 2000 when the Ministry of Health and Social Activities approved national standards for the organisation and implementation of palliative care services; palliative medicine was recognised as a specialty that same year. In 2001 a regional organisation known as the Latin American Association for Palliative Care was launched by six palliative care professionals: Hugo Fornells and Roberto Wenk from Argentina, Liliana De Lima and Rene Rodriguez from Colombia, Eduardo Méndez from Uruguay and Lizbeth Quesada from Costa Rica. The following year, the Association's first meeting was held in conjunction with the 6th Latin American Palliative Care Congress in Guadalajara.

Costa Rica is a small country with an established health system committed to providing good quality care at a reasonable price to every citizen. With a government-sponsored network of 29 hospitals and more than 250 clinics throughout the country, the Caja Costarricense de Seguro Social (CCSS) has primary responsibility for providing low cost health services to its 4 million inhabitants. The Clinic for Pain and Palliative Care was established in the Calderón Guardia Hospital in the early 1990s and later became recognised as the National Centre for Pain Control and Palliative Care (1999). A national pain control and palliative care policy was adopted in 2001.

In Europe, many commentators consider that the opening of St Christopher's Hospice in London (1967) marked the beginning of the modern hospice movement. As the hospice-palliative care concept became part of mainstream provision, health authorities were required to include palliative care services in their planning. Palliative Medicine became recognised as a medical specialty in 1987 and during the following decade, the Calman-Hine report (1995) provided a new focus by recommending the provision of multi-

professional specialist palliative care teams.¹¹ More recently, the publication of the NHS Cancer Plan 2000 and the End of Life Care Initiative, have further stimulated interest and funding. In 2006, the Department of Health provided added impetus with an investment of £12 million (spread over three years) to improve end of life care.

In France, the antecedents of palliative care date back to the mid-nineteenth century when Jeanne Garnier founded her first 'calvaire' for the dying in Lyon. Her work was recognised during the 1970s when concerns about end of life care led to the formation of the palliative care umbrella organisation *Associations de Soins Palliatifs*. In 1986, the *Circulaire Laroque* made wide-ranging recommendations about palliative care provision, particularly in the hospital context; and in 1999, palliative care at the end of life became incorporated into the laws of France as a human right.

In Hungary, palliative care was acknowledged as a human right when it was incorporated into health legislation in 1997. The hospice movement had begun six years earlier, in 1991, and after the preliminary years of discussion and education, gained ground rapidly. By 2006, no fewer than 52 organisations were providing hospice-palliative care in wide a variety of settings. In 1994, a national palliative care training programme became established, accredited by the Ministry of Health, that included both basic and advanced courses, each of 40 hours; since inception, more than 3,200 course participants have been trained. A landmark development occurred in 2004, when, for the first time, a new form of financing encompassed the wider hospice team. More recently, hospice-palliative care has been included in the national cancer control policy.

In Oceania, palliative care services began in Australia at the beginning of the 1980s although the Catholic Sisters of Charity had previously founded The Sacred Heart Hospice for the Dying (Sydney) in 1890. A century later, the modern hospice movement gathered momentum, driven partly by the raised awareness of Australian clinicians as a result of their overseas visits. But also, resistance to intrusive procedures at the end of life, particularly among nurses, encouraged a fresh perspective that gave rise to the varied lines of development which sprung up in the Australian states. Progress was rapid. In 1987, Ian Maddocks accepted the world's first Chair in Palliative Care at Flinders University (South Australia); three years later, he presided over the inception of the national hospice association, now called Palliative Care Australia (PCA). From 1988, Medicare has provided enhanced funding for palliative care services. And since palliative medicine became recognised as a medical specialty (2005), the organisation has updated its regulations to allow medical practitioners to be recognised as a specialist for the purposes of the Health Insurance Act (1973). A national palliative care strategy is in place and a planning guide to service provision has been published by PCA. In 2005, around 320 services were reported to be operational.

Hospice care in New Zealand began in 1979 when Te Omanga provided a wide range of services to the communities of Lower Hutt and Wairarapa, situated at the southern end of the North Island. By 2005, an estimated 41 services were delivering palliative care

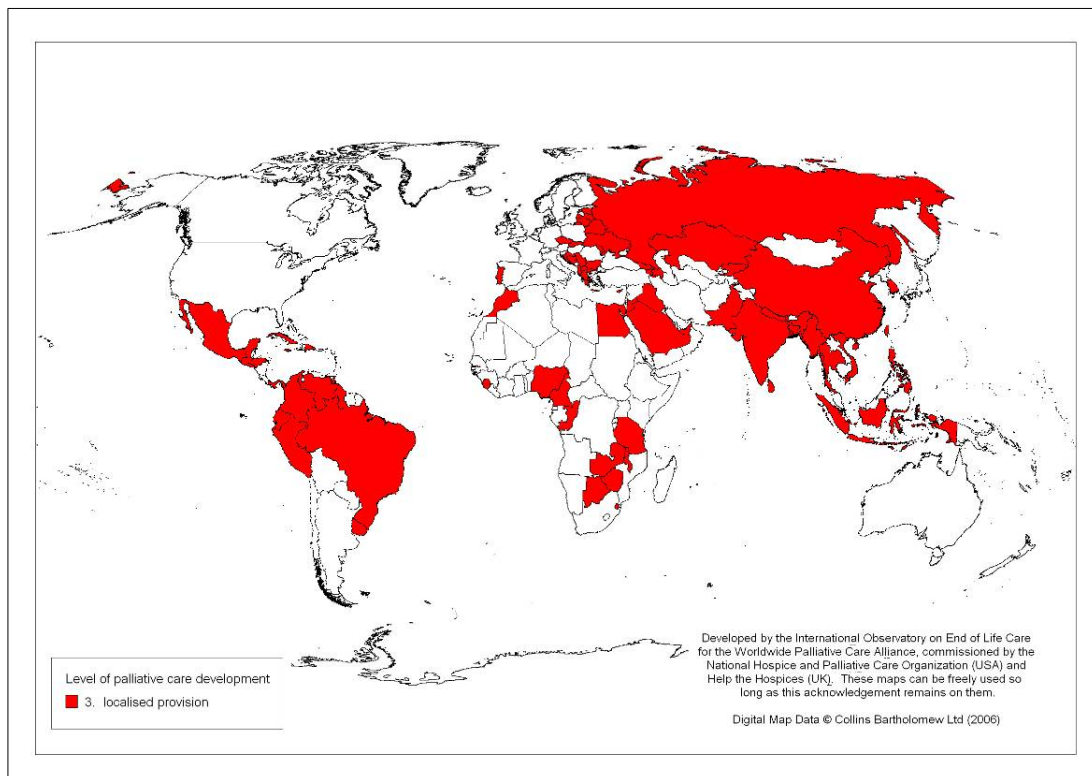
¹¹ *Report of the Expert Advisory Group on Cancers to Chief Medical Officers of England and Wales*. London and Cardiff: Department of Health and Welsh Office, 1995 (Calman-Hine report)

throughout the country. The late 1990s were formative years for the hospice movement in New Zealand. In 1998, the New Zealand National Advisory Committee on Health and Disability formed a working party to focus on ‘Care of people who are dying’. *Standards for the Provision of Hospice and Palliative Care* were published by Hospice New Zealand in 1999, and the following year, New Zealand’s first palliative care strategy was disseminated in a discussion document by the Ministry of Health. More recently, palliative medicine has been recognised as a medical specialty, a palliative care education programme has been developed for care assistants, and a new committee has been formed to focus on a national structure for palliative care.

Group 3: countries with localised provision

The review identified a further 80 countries with localised hospice-palliative care provision (Figure 2).

Figure 2. Countries with localised provision (n=80)



The countries with localised palliative care provision are: Aland Islands, Albania, Armenia, Azerbaijan, Bangladesh, Barbados, Belarus, Bermuda, Bosnia and Herzegovina, Botswana, Brazil, Bulgaria, Cameroon, Cayman Islands, China, Colombia,

Congo, Croatia, Cuba, Cyprus, Czech Republic, Dominican Republic, Ecuador, Egypt, El Salvador, Estonia, Georgia, Gibraltar, Greece, Guadeloupe, Guatemala, Guernsey, Guyana, Honduras, India, Indonesia, Iraq, Isle of Man, Jamaica, Jersey, Jordan, Kazakhstan, Korea (South), Kyrgyzstan, Latvia, Lithuania, Luxembourg, Macao, Macedonia, Malawi, Malta, Mexico, Moldova, Morocco, Myanmar, Nepal, Nigeria, Pakistan, Panama, Peru, Philippines, Portugal, Russia, Saudi Arabia, Serbia, Sierra Leone, Slovakia, Sri Lanka, Swaziland, Tanzania, Thailand, The Gambia, Trinidad and Tobago, Ukraine, Uruguay, United Arab Emirates, Venezuela, Viet Nam, Zambia Zimbabwe.

Group 3 countries: examples of development

In Africa, 12 countries provide evidence of the localised provision of hospice-palliative care in a context where small numbers of isolated services have gained a stronghold. In Southern Africa, palliative care services began in Botswana, at Holy Cross Hospice (Gaborone) in 1995 and by 2005, three organisations provided a total of 10 services. Although the number of services is still quite small, there is optimism that the government has established a suitable base for strengthening palliative care services in the future. Swaziland is another small country that has stimulated several hospice-palliative care initiatives: Hope House; Swaziland Hospice at Home; Parish Nursing; and the Salvation Army; in addition, several community based church organisations provide supportive care to terminally ill patients.

In Middle Africa, L' Association Congolese Accompagner was founded in Congo during 1996 by Sr Eliane Boukaka, of the Congregation Occiliatrise. The service cares for incurably ill persons, particularly those with AIDS and cancer and offers support in the hospital and in the home. In Cameroon, preparation for a hospice service began when the Baptist Convention Health Board obtained a permit from the Ministry of Health to purchase morphine powder. Patients were registered in January 2006, and in March of this year, funding from Hospice Africa Uganda helped the new service to progress. Based at Banso Baptist Hospital (a large referral centre) both home care and hospital based services are provided. The multi-disciplinary team is made up of a palliative care nurse specialist, a doctor, two nurses, two chaplains and a pharmacist.

To the west, palliative care is being introduced to Nigeria through the Palliative Care Initiative Nigeria (PCIN), based at the College of Medicine, University of Ibadan. PCIN is a multidisciplinary group of medical specialists formed in January 2003 and in addition to sensitising the public on the importance of palliative care, it has sponsored some of its members to attend palliative care courses and conferences in other countries. It operates a pain and palliative care clinic at the University College Hospital, Ibadan. In The Gambia, Future Care Hospice was officially registered as a charitable organisation in October 2004 and is the first service of its kind in the country. The hospice provides home care and day care services and the programme includes symptom control, domiciliary care and prevention advice.

In the east, palliative care in Tanzania began in the late 1990s and four organisations currently provide 11 services: Selian Hospital, Muheza Hospice Care, PASADA, and Ocean Road Cancer Institute. A national association was established in 2004. Faith-based organisations, particularly the church-related hospitals, provide 50% of the health care in the country and plans are in place to extend palliative care coverage into the around 82 Christian hospitals throughout Tanzania. Volunteers feature prominently. In Zambia, palliative care services began in 1992 and six organisations currently provide a total of 20 services. In-patient units have featured heavily in the way the country has developed its services. This is partly because death has to be certified in a hospital and transportation costs for the body are expensive, but also because migrant workers have few family members to care for them at home.

In North America, Agape House opened in 1990 as part of the Bermuda Hospitals Board's Continuing Care Programme at King Edward VII Memorial Hospital. In addition, the Patients Assistance League and Service (PALS) provides a home care team for cancer patients.

In Latin America, 14 services are operational in Brazil, the earliest of which began in Rio de Janeiro in 1989. In Mexico, the first of the country's 19 hospital-based teams began to operate in 1992. Home based care is rarely provided, due mainly to financial constraints, such as lack of funding for transport. In Colombia, early initiatives were led by psychologists such as Isa de Jaramillo - who created the Omega Foundation (Bogotá, 1987) - and Liliana De Lima, who established a palliative care programme in La Viga. When services expanded, hopes were pinned on 'Law 100', passed in the mid-1990s to integrate health services and give broader access to care. Yet it was poorly implemented and many thought an opportunity had been lost. A number of 'hospices' providing shelter and care for AIDS patients are operating in Guatemala. The first palliative care IPU, however, opened at the national paediatric hospital in 2005; an adult unit followed at the National Cancer Institute in 2006. Turning to the Caribbean: palliative care services began in Cuba at the beginning of the 1990s. Three services are currently operational: two in Havana, one in Cienfuegos. In 2005, the English academic Dr Richard Harding visited Cuba as a Travelling Fellow (IAHPC) and while there, helped to develop a programme of education. In Jamaica, the Consie Waters Cancer Care Hospice (8 beds) was founded in 1985 and initially maintained close contact with St Christopher's Hospice, London. Nearby Hope Institute is a hospital-based palliative care team led by a former medical consultant from England; both services are in Kingston.

In Southern Asia, Bangladesh held its first national seminar on palliative care in Dhaka in 2006. Three services are up and running, the first dating from 1992. Some clinicians from Bangladesh have undertaken training programmes in Calicut (India). A new cancer hospital is nearing completion which, when open, will incorporate a dedicated ward for palliative care. In Nepal, the first palliative care service opened in 2000 and to date, five services are operational; an added impetus has been provided by the involvement of the International Network for Cancer Treatment and Research. Turning south to India, over 138 organisations were known to be providing hospice-palliative care services in 16 states or union territories. These services are usually concentrated in large cities and

regional cancer centres - with the exception of Kerala, where services are more widespread. In total, there are 19 states or union territories where we found no evidence of palliative care provision. This exemplifies the disparity among services in large countries: a state such as Kerala has a highly developed structure for palliative care education and delivery - with up to 90% coverage in some districts; other states have no provision whatsoever.

In Central Asia, Kyrgyzstan has benefited from its partnership with the American International Health Alliance and from links forged between the Kyrgyz Ministry of Health and the University of Kansas Medical Centre (USA) that were developed in the late 1990s. Support has also been forthcoming from IAHPIC in the form of a Travelling Fellowship. By 2002 Kyrgyzstan had established three palliative care facilities with a total of more than 50 hospice beds. At that time, it was estimated that three physicians and three family doctors had received palliative care training and several therapists, chaplains and volunteers were also active in the field. The opening of a new hospice facility at the National Centre for Oncology in Bishkek was timed to coincide with this year's World Hospice and Palliative Care Day (7 October).

In neighbouring Kazakhstan, round-table discussions during 2003 – which included the Ministry of Health, Kazakhstani clinicians, WHO, and activists from Poland and Russia – focused on the care of the dying. By 2006, five hospices had become established and the palliative care workforce included 28 physicians, 68 nurses, 5 occupational therapists, 2 social workers, one physiotherapist and one psychologist. The Public Health Development Programme for Kazakhstan (2005-2010) includes the adoption of the hospice ideal - with the aim of opening a hospice facility in every city with a population in excess of 100, 000.

Further west, in the Caucasus, the Jewish Women's Hospice Organisation of Azerbaijan began a pilot project in 1998; despite funding difficulties, the home care service is still operating today. In neighbouring Georgia, developments have been assisted by the involvement of the Open Society Institute (New York) and the Hungarian Hospice Foundation. The IPU at the Cancer Prevention Centre in Tbilisi is designated a hospice-palliative care facility. During a stay in the unit, 80% of each patient's costs are provided by the Government, whereas 20 % are borne by the family.

In Saudi Arabia, services began at the King Faisal Specialist Hospital (KFSH) in 1992 and three services have been established in the country. An innovative fellowship programme has resulted in training for physicians at KFSH, who then translate the principles of palliative care into their own setting. King Faisal Specialist Hospital has been designated a WHO collaborating centre and the Ministry of Health is giving support for a national palliative care strategy. In Jordan, specialist palliative care services are offered by two organisations: the Al Malath Foundation for Humanistic Care and the King Hussein Cancer Centre (KHCC). Interest in palliative care in Jordan was initiated by Crown Prince Hassan in 1985. In 1986, two nurses from the UK charity the Macmillan Cancer Relief were commissioned to conduct an assessment of palliative care need. By 1992 a group of concerned health professionals was discussing how to set up

palliative care services. With the continuing support of Prince Hassan, Jordan's first hospice, the Al Malath Foundation, was established in 1993; the KHCC team was established in September 2004.

In Europe, most of the countries with localised provision are former communist countries in Central and Eastern Europe. A feature of this group is the way in which hospice-palliative care began as a patchwork of services after the collapse of communism at the end of the 1980s.

In Russia, the first hospice was established near St Petersburg in 1990 and gained the support of the city's board of health. By 2002, six in-patient hospices and 17 home care/ outpatient services were providing palliative care to patients and their families in 12 of St Petersburg's 19 districts. Across, the country, hospices were founded in other cities: Tula, Yaroslavl, Perm and Omsk and important gains were made by securing funding from local government. Running parallel to the hospice initiatives, The Moscow Centre for Palliative Care, led by Georgy Novikov, was established by the Ministry of Health in 1991. Palliative care developments are now said to be under way, mostly in the hospital context, in all the regions of Russia. Yet the economic constraints of the 1990s have left health services chronically under-funded. In what is the largest geographic country of the world, the combined hospice and palliative care services are currently estimated at around 125 and the challenges are acknowledged as considerable.

In Slovakia, the debate around hospice-palliative care services began in the late 1980s and the first services appeared in the middle of the next decade. Kristina Krizanova first introduced palliative care into a hospital setting when she established a dedicated 19-bed unit at the National Cancer Institute in Bratislava. Slovakia was a signatory to the Poznan Declaration (1998) and is a member of the Eastern and Central Palliative Task Force. Nevertheless, although the Government adopted a state health policy which regards palliative care as a priority, the commitment has not been matched by financial support. This has added further impetus to some 30 voluntary organisations that seek to establish hospital based and free-standing hospice facilities. A national association was founded in 2000. To date, around 10 hospice-palliative care services are operational.

The Belarusian Children's Hospice (BCH) was founded in Minsk by the child psychologist Anna Gorchakova during 1994. The Government of Belarus provided the hospice with office accommodation but no subsidies were forthcoming. Strong links have been formed with Warsaw Hospice for Children, led by Tomasz Dangel, and this relationship with Warsaw has helped with the education and training of staff. Since 1994, the hospice has opened four satellite services – in Gomel, Vitebsk, Mogily and Pinsk – and paediatric care is now provided in an in-patient unit, hospice facilities, hospital and the home. In 2005, BCH established a hospital support team and home care teams for adults.

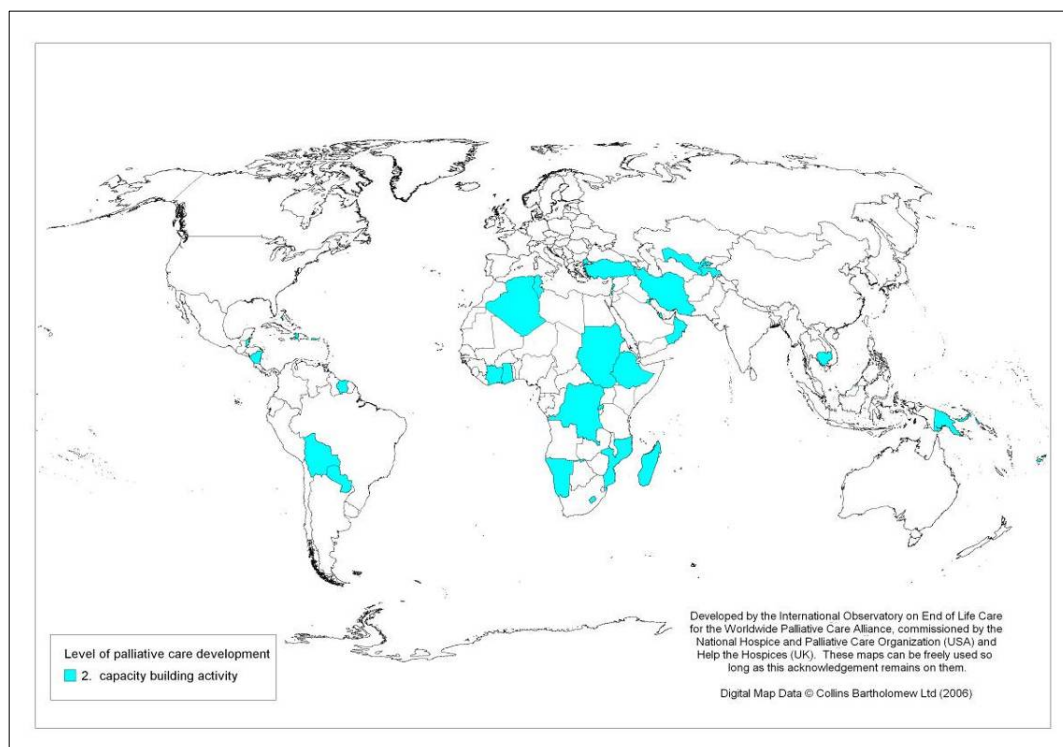
In the Mediterranean, the Malta Hospice Movement was founded in 1989 with the aim of providing hospice-palliative care to patients with cancer and motor neurone disease; the following year the service 'twinned' with Hayward House, Nottingham (UK). The

hospice currently provides home, hospital and day care, although there are no designated palliative care beds in the hospital setting. Around one third of referrals come from physicians, and two thirds from patients and their families. The multidisciplinary team consists of 6 nurses, 2 social workers, a physiotherapist, an occupational therapist and a spiritual leader; around 160 volunteers also contribute. The hospice is engaged in discussions with the University's Faculty of Medicine and the Department of Health to seek ways of including palliative care topics into medical curricula and develop palliative care expertise among medical practitioners.

Group 2: countries with capacity building activity

In 41 countries there is evidence of a range of initiatives designed to create the organisational, workforce and policy capacity for hospice-palliative care services to develop – though currently, no services have yet been established (Figure 3).

Figure 3. Countries with capacity building activity (n=41)



Countries where capacity building activity is taking place are: Algeria, Bahrain, Belize, Bolivia, British Virgin Islands, Brunei, Cambodia, Democratic Republic of Congo, Cote

d'Ivoire, Dominica, Ethiopia, Fiji, Ghana, Haiti, Holy See (Vatican), Iran, Kuwait, Lebanon, Lesotho, Madagascar, Mauritius, Mozambique, Namibia, Nicaragua, Oman, Palestinian Authority, Papua New Guinea, Paraguay, Qatar, Reunion, Rwanda, Saint Lucia, Seychelles, Sudan, Suriname, Tajikistan, The Bahamas, Tunisia, Turkey, Uzbekistan, Puerto Rico.

Group 2 countries: examples of capacity-building activity

A common feature of this group of countries is the clearly apparent aim to create the conditions within which palliative care might become established.

Among the palliative care capacity-building countries of Africa, five of them (Cote d'Ivoire; Ethiopia; Mozambique; Namibia; Rwanda) are part of the PEPFAR programme, which is proving to be a key driver of hospice-palliative care innovation. In the Democratic Republic of Congo a nurse supported by an organisation called the International Youth Association for Development attended the 9th Congress of the EAPC in Aachen, and demonstrated the beginnings of a palliative care service in Kinshasa. A conference on the theme of *Pain and Supportive Care for the Maghreb* (Tunisia, Morocco and Algeria) was held in Tabarka, Tunisia, in September 2004 but it is reported that no home care provision exists for people with cancer. Opioid prescriptions are restricted to a period of one week and morphine is expensive and only available in sustained release form. There are no established palliative care services in Ghana; in the absence of formal structures, individuals in Ghana have begun to incorporate palliative care principles into home based care projects with AIDS and cancer patients. Concerned individuals committed to establishing palliative care services in Rwanda have sourced funding to send two Rwandan nurses to Nairobi Hospice for training; the British government paid for the same nurses to attend the African Palliative Care Association conference in Tanzania in June 2004.

Turning to Asia: in 2003 the Open Society Institute (New York) supported delegates from Uzbekistan to attend a palliative care training course at Hospice of Hope, Romania. The charity also supported delegates from Tajikistan to be trained in Poland and developments, though slow, are continuing to date. In the Palestinian Authority, there are no specific palliative care services. There are, however, several dedicated oncologists and volunteers who strive, wherever possible, to provide some palliative and psychosocial support for cancer patients at the end of life. There are six oncology units in general hospitals around the West Bank and Gaza Strip, which provide pain and symptom relief for adults: two of the units in the Gaza Strip also care for children. In East Jerusalem, the charitable NGO known as the *Patient's Friends Society - Jerusalem (PFS)*, which is located inside the Augusta Victoria Hospital, offers psychosocial support, advice and education to patients and their families. Efforts by the Middle East Cancer Consortium since the early 2000s have offered opportunities for a greater awareness of the need for specialist care and training at undergraduate and professional level. In Turkey, supportive care with hospice-palliative care is linked to the development of other services, particularly within hospital-based oncology units. There are no specialist palliative care

services in Turkey. Yet medical oncology units and departments of algology (pain) at major hospitals in the country provide pain control and symptom relief. Significantly, oncologists and pain specialists in 7 hospitals report actively working to establish the concepts of palliative care. Elsewhere, the annual report of the WHO regional director for the Eastern Mediterranean states that Bahrain, Kuwait Lebanon, Oman and Qatar were among 11 countries implementing measures and activities for the four major components of a national cancer control programme: prevention, early detection, treatment and palliative care.

In Latin America, the Pain and Policy Studies Group/ WHO Collaborating Center at the University of Wisconsin has been active in bringing together clinicians and policy-makers from countries throughout the region. For example, a workshop held in Ecuador in December 2000, assembled cancer and palliative care clinicians, national drug regulators and cancer control officials from Bolivia, Chile, Colombia, Ecuador, Peru and Venezuela to develop action plans aimed at ensuring the availability of opioid analgesics for palliative care.

In Belize, interest in palliative care has been expressed by a physician at the Karl Heusner Memorial Hospital, a large public hospital and referral centre. The Hospice Education Institute in Connecticut offered support and a comprehensive package of materials was dispatched. More recently, Dr. Beatriz Thompson has been working to establish a palliative care service within a cancer control programme. The first meeting of the Cervical Cancer Control National Committee was held in August 2006 when the issue of opioid availability was addressed. Developments in Nicaragua are at an early stage, but interest has been forthcoming from the country's Ministry of Health. A pain control unit has been established at the National Radiotherapy Center and the professional trained in pain control works there on a voluntary basis. Initiatives in Bolivia are also at an early stage, with activity centred on the Palliative Care Unit in Santa Cruz de la Sierra, where the National Cancer Institute is located. In 2005, the Association Boliviana de Hospicio y Cuidados Paliativos organised an event to mark World Hospice and Palliative Care Day. Journalists and representatives of national and local health authorities were invited to hear presentations and receive information about the importance of palliative care for the patient and family. Activists in Paraguay have issued a position statement favouring a public health approach to palliative care; initiatives are currently centred on the National Cancer Institute and the Hospital de Clinicas in Asuncion.

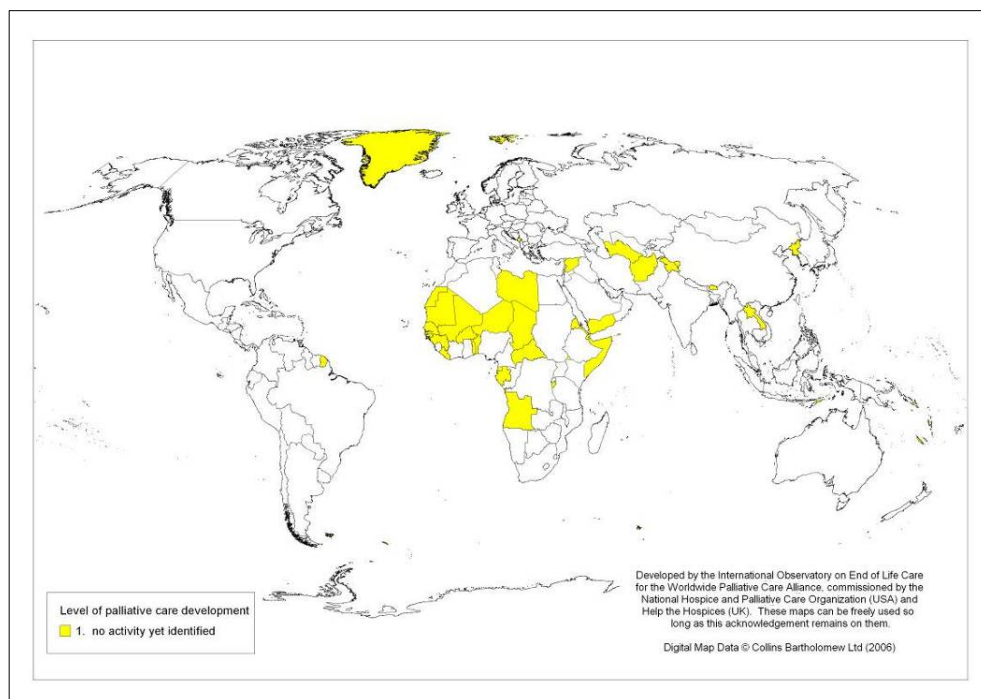
Foundations for palliative care services are also being laid in several Caribbean islands. In 2003, Wilma Falconer was awarded an IAHPC Travelling Fellowship to St Lucia. Invited by the St Lucia Cancer Society, she conducted workshops for health professionals and NGOs. A strategic committee was formed to carry the work forward and supportive links with Canadian 'palliateurs' were strengthened. In Dominica, Diana Callender has formed a broadly-based group with the intention of founding a palliative care service in the near future. Discussions have taken place with religious groups and the Ministry of Health, with favourable results; a conference is planned for February 2007 to help launch the project. In the meantime, Dr Callender attended a seminar in Stockholm titled *Palliative Cancer Care*, held under the auspices of the European School for Oncology.

Capacity building in Oceania is mainly centred on the Islands of Fiji and Papua New Guinea. The Fiji Cancer Society is attempting to raise funds for a hospice and during 2006, will generate income through ‘Fiji’s Biggest Morning Tea’ event; recipes and publicity materials have been produced by the Cancer Society. According to the campaign goals, the expected hospice ‘will eventually enable cancer patients to spend time during treatment and recovery in an atmosphere of respect and dignity, whilst maintaining self-esteem and independence regardless of race, religion, culture, lifestyle, gender or ethnicity.’ Ian Maddocks has a long-standing affinity with Papua New Guinea, having spent time there as a medical student, followed later by 14 years as dean of a medical school. He has maintained his links with the country and returns to teach and offer advice at regular intervals. In 2001, another Australian, Nell Muirden visited Port Moresby General Hospital and Angau Memorial Hospital in Lae. Working as an IAHPC Travelling Fellow, she increased awareness of palliative care and pain relief, producing recommendations that were accepted by the Pharmaceutical Advisory Committee.

Group 1: countries with no known hospice-palliative care activity

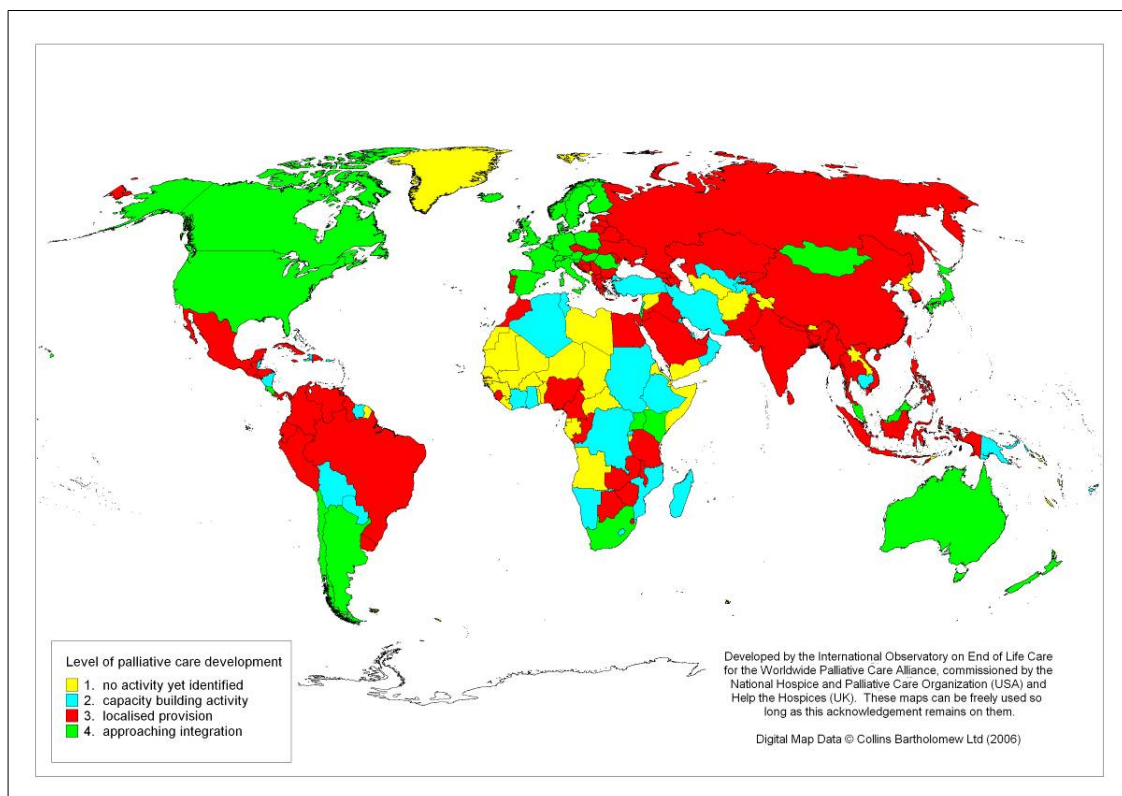
This review may have failed to identify hospice-palliative care activity in some countries where activity currently exists. On the evidence to hand, however, it is considered that there is no tangible activity in 78 countries (Figure 4).

Figure 4. Countries with no known hospice-palliative care activity



Countries with no identified hospice-palliative care activity are: Afghanistan, American Samoa, Andorra, Angola, Anguilla, Antigua and Barbuda, Aruba, Benin, Bhutan, Burkina Faso, Burundi, Cape Verde, Central African Republic, Chad, Comoros, Cook Islands, Djibouti, Equatorial Guinea, Eritrea, Falkland Islands, Faroes Islands, French Guiana, French Polynesia, Gabon, Greenland, Grenada, Guam, Guinea, Guinea-Bissau, Kiribati, Korea (DPR), Laos, Liberia, Libya, Liechtenstein, Maldives, Mali, Marshall Islands, Martinique, Mauritania, Mayotte, Micronesia, Monaco, Montenegro, Montserrat, Nauru, Netherlands Antilles, New Caledonia, Niger, Niue, Norfolk Island, Northern Mariana Islands, Palau, Pitcairn, Saint Helena, Saint Kits and Nevis, Saint Pierre and Miquelon, Saint Vincent and the Grenadines, Samoa, San Marino, Sao Tome and Principe, Senegal, Solomon Islands, Somalia, Svalbard, Syria, Timor-Leste, Togo, Tokelau, Tonga, Turkmenistan, Turks and Caicos Islands, Tuvalu, US Virgin Islands, Vanuatu, Wallis and Fortuna, Western Sahara, Yemen.

Figure 5: Levels of palliative care development: all countries



Levels of palliative care development: distribution of countries

Around half of the 234 countries included in this review have established one or more hospice-palliative care services. Yet only 35 (15%) countries have achieved a measure of integration with wider mainstream service providers. In 78 (33%) countries, no palliative care activity can be identified (Table 6).

Palliative care services have been found in 50% of the world's countries but these encompass 88% of the global population. Two countries, however, inflate this figure since one fifth of the world's population is found in China and one sixth in India (Table 2).

Table 2. Distribution of countries by group

	1 No known activity		2 Capacity building		3 Localised provision		4 Approaching integration	
	N	%	N	%	N	%	N	%
Countries/234	78	33	41	18	80	34	35	15
Population		4		9		70*		18
*In group three, two countries account for 37%:(China 20% and India 17%)								

Palliative care and human development

The human development index (HDI) gives a multiple measure of a country's development, based on: longevity, knowledge, and standard of living. A strong association exists between palliative care and human development. Twenty nine (83%) of the 35 countries in Group 4 have a high level high human development; only 1 (3%) country is in the low development group. Among 78 countries in Group 1, only 2 (3%) have a high level of human development; 42 (54%) countries in this group have no HDI (Table 3)

Table 3. Palliative care and levels of human development, by group

	Total countries		High development		Medium development		Low development		No HDI	
	N	%	N	%	N	%	N	%	N	%
Group 4 countries	35		29	83	5	14	1	3	0	0
Group 3 countries	80		20	25	41	51	7	9	12	15
Group 2 countries	41		6	15	23	56	8	20	4	10
Group 1 countries	78		2	3	19	24	15	19	42	54

Palliative care development and GDP

Among countries in Group 4, GDP per capita (International Dollars) ranged from \$1,088 in Uganda to \$40,336 in Sweden. A broad range of GDP per capita was also found among countries with no known service: Monaco had a GDP of \$48371; in Liberia it was \$386 (Table 4).

Table 4. Palliative care development and GDP, Group 4 and Group 1

Group 4 Countries	GDP per capita (Int \$)	Group 1 countries	GDP per capita (Int \$)
Sweden	40336	Monaco	48371
USA	39901	Equatorial Guinea	15707
Japan	30039	Cook Isles	11788
New Zealand	24643	Turkmenistan	5947
Israel	22731	Syria	2449
Argentina	13331	Laos	1878
Malaysia	10613	Korea, DPR	1339
Mongolia	2373	Niger	650
Uganda	1088	Liberia	386

Regional variations

An analysis of palliative care development, region by region, produces some striking variations, both in the levels of development achieved by neighbouring countries and the ratio of services to population within each country.

For example: in North America, both Canada and the US are in Group 4, whereas in Greenland, no palliative care activity could be identified.

In Latin America, the two southernmost countries, Argentina and Chile, fall into Group 4; Costa Rica, however, stands alone in Group 4 among the countries of Central America and the Caribbean (Figure 6).

Figure 6.
Palliative care development in the Americas and Caribbean

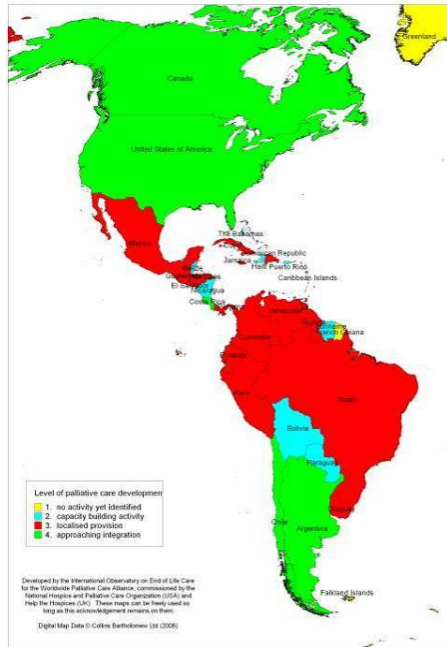


Table 5.
Indicative ratio of palliative care services to population: the Americas and Caribbean

Country	Services n	Ratio 1: 000s
Bermuda	2	33
Canada	500	65
Cayman islands	1	45
USA	3300	90
Costa Rica	26	166
Uruguay	17	204
Barbados	1	270
Guadeloupe	1	452
Argentina	80	484
Guyana	1	750
Chile	21	776
Trinidad + Tobago	1	1,305
Jamaica	2	1,326
Panama	1	3,232
Cuba	3	3,745
Ecuador	3	4,409
Colombia	7	6,514
Mexico	15	7,135
Dominican Rep	1	8,895
Peru	3	9,323
Brazil	14	13,315

In Europe, with the exception of Portugal, Luxembourg and a few small countries such as Andorra, all countries in Western Europe are in Group 4. In Central and Eastern Europe, with the exception of Hungary, Poland, Romania and Slovenia, all countries are in Group 3 (Figure 7).

Figure 7.
Palliative care development in Europe

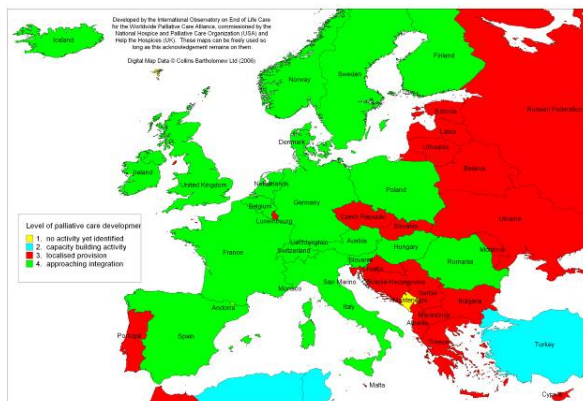
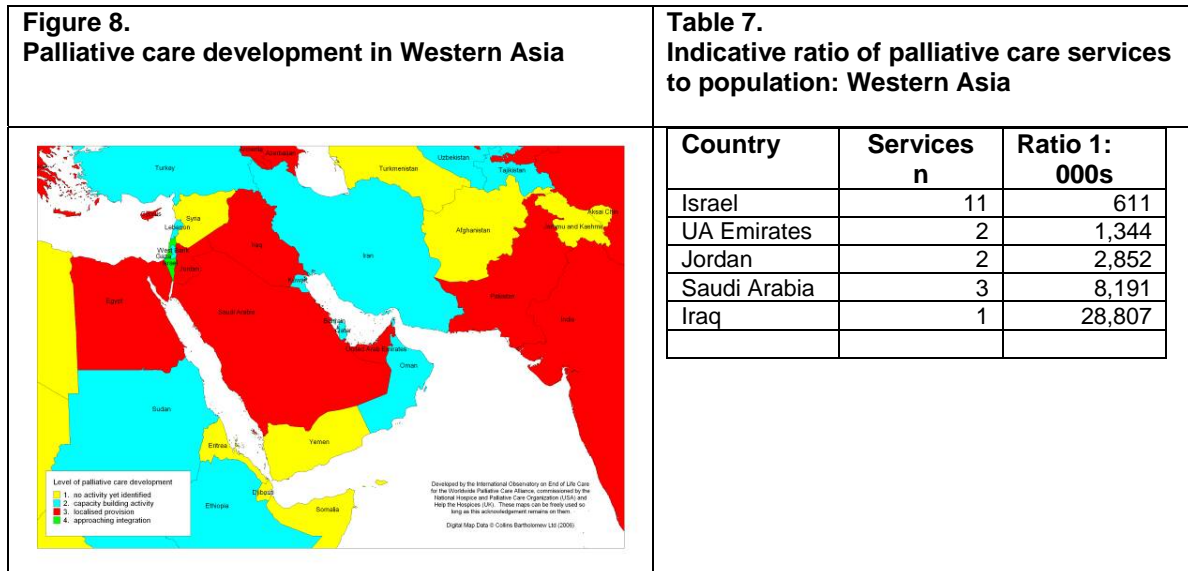


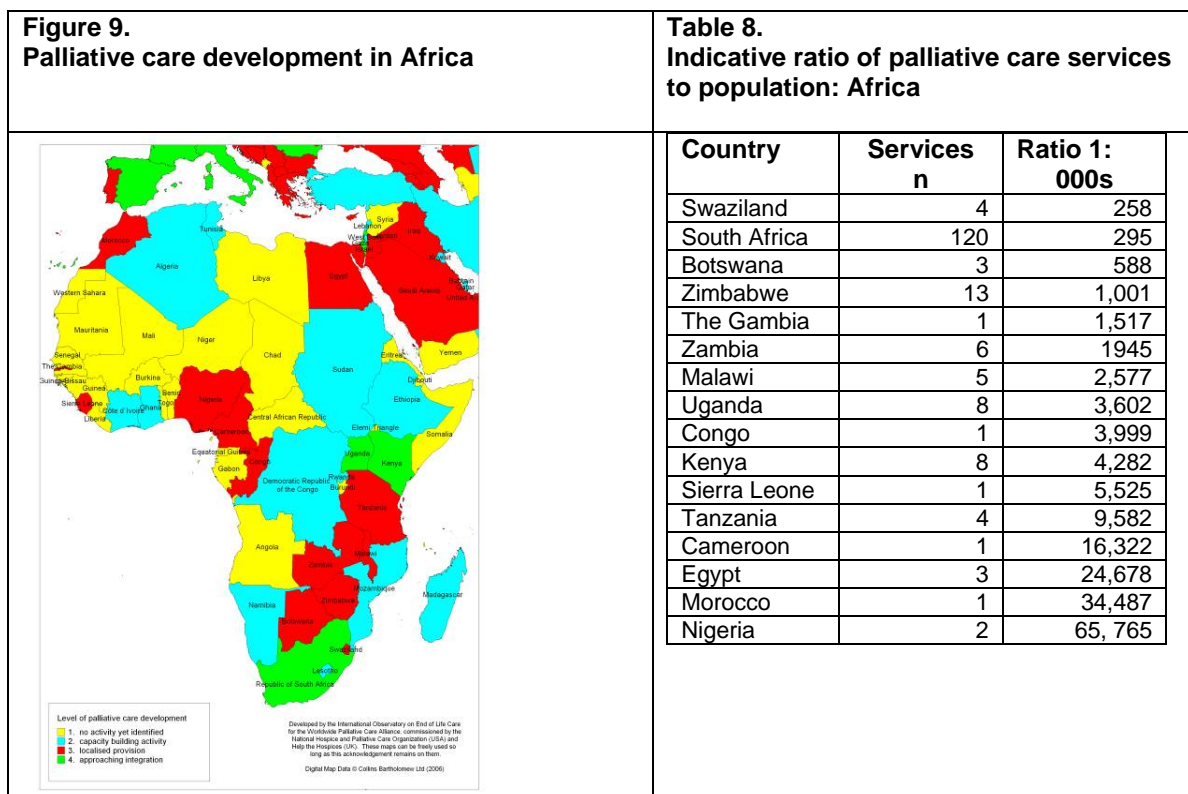
Table 6.
Indicative ratio of palliative care services to population: Europe

Country	Services n	Ratio 1: 000s
UK	1478	40
Iceland	6	49
Guernsey	2	65
Ireland	50	83
Poland	406	95
France	471	128
Hungary	50	202
Denmark	18	302
Czech Rep	16	639
Belarus	12	813
Portugal	10	1,50
Russia	125	1,146
Croatia	3	1,517
Ukraine	18	2,582
Kazakhstan	5	2,965
Azerbaijan	1	8,411

In Western Asia, only Israel is in Group 4; in many countries throughout the region no service could be identified (Figure 8).

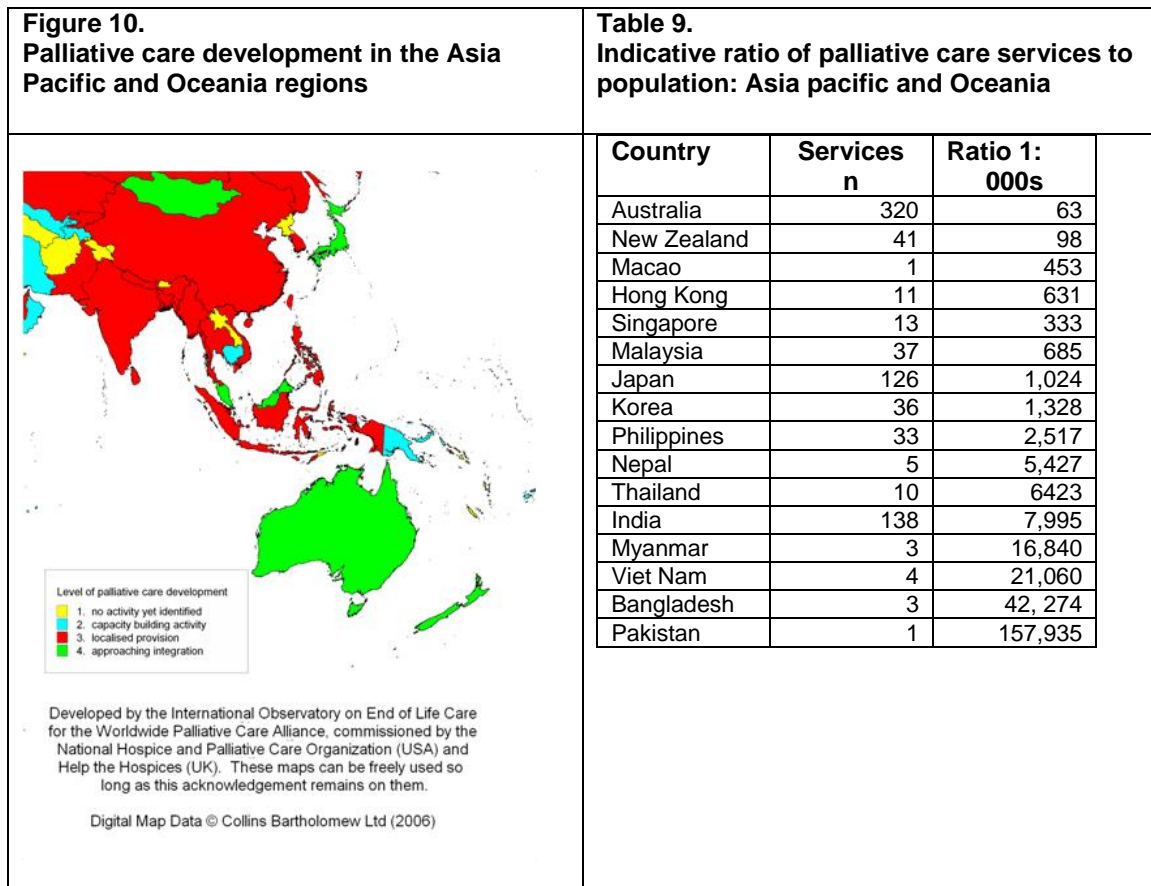


In Africa, only Uganda, Kenya and South Africa have achieved a level of integration with wider health services; in 32 of the 48 African countries no service could be identified.



In the Asia Pacific region, a patchwork of initiatives has been identified, but only a small number of countries are approaching integration with wider health services.

In Oceania, only Australia and New Zealand have achieved such integration (Figure 10).



Palliative care development and crude death rates (CDRs)

Crude death rates ranged between 1.8 (deaths per thousand population).and 20.5 (Figures 11 to 15)

It was noticeable that among the four groups of countries, the upper value in Group 4 countries was lower than that in the other 3 groups. A comprehensive analysis was hindered, however, by the fact that death rates were missing for 93 (40%) countries. Countries without a CDR rose from 9% in Group 4 to 59% in Group 1 (Table 10).

Table 10. Palliative care development and crude death rates (CDRs)

	CDR: range	Countries with CDR (n)	%
Group 4 countries	3.7 to 13.4	32	91
Group 3 countries	2.0 to 18.5	55	68
Group 2 countries	1.8 to 20.5	22	55
Group 1 countries	1.8 to 18.4	32	41

Figure 11. World map showing crude death rates by country

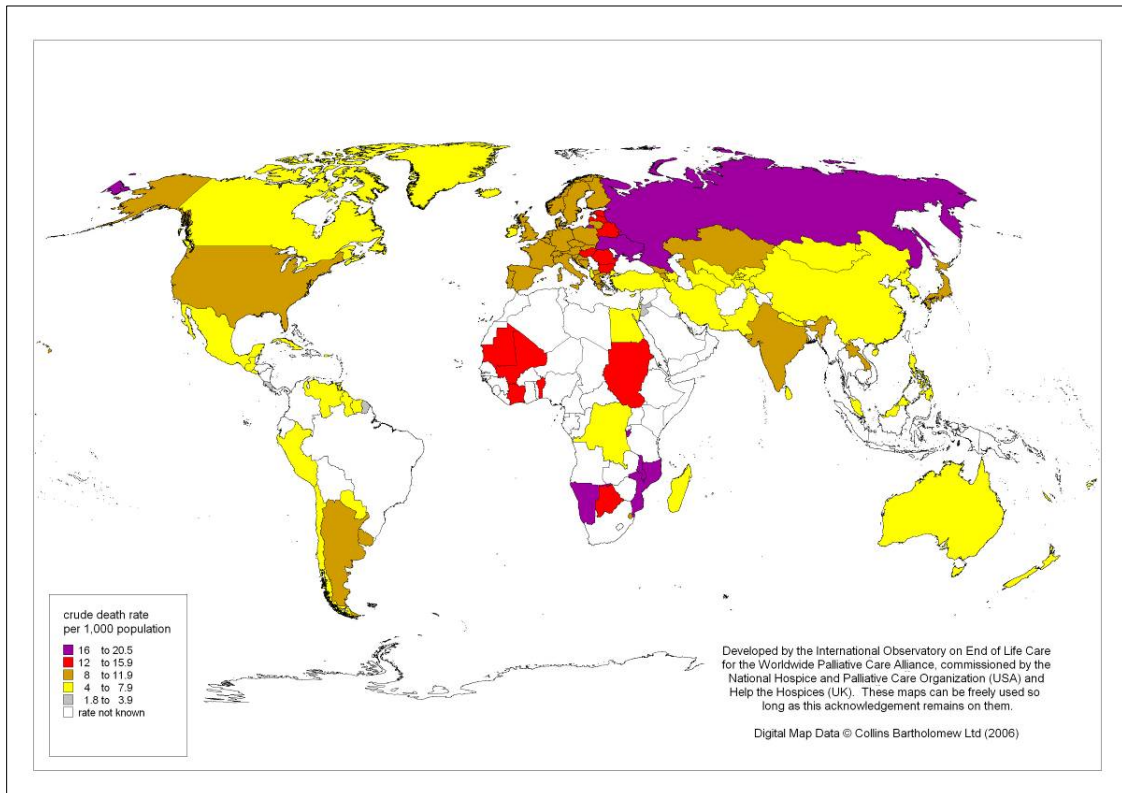


Figure 12. Crude Death Rates: the Americas

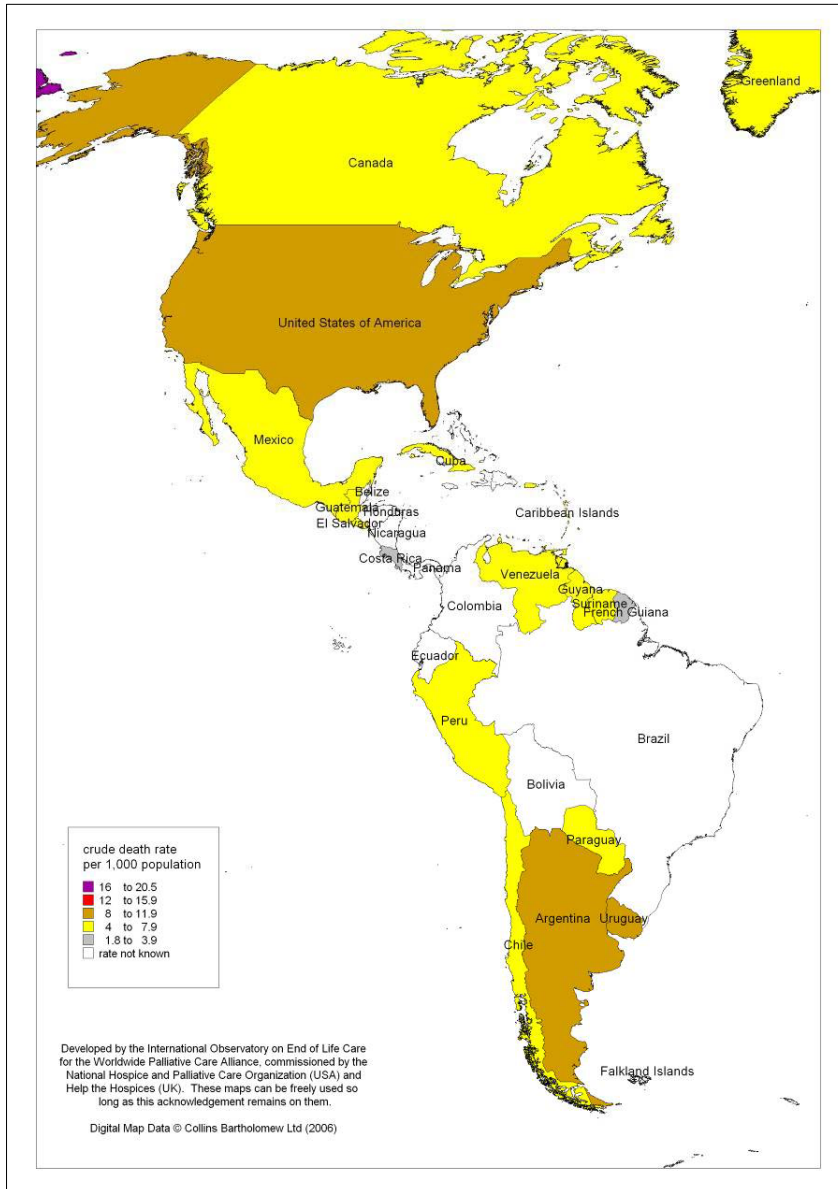


Figure 13. Crude Death Rates: Africa

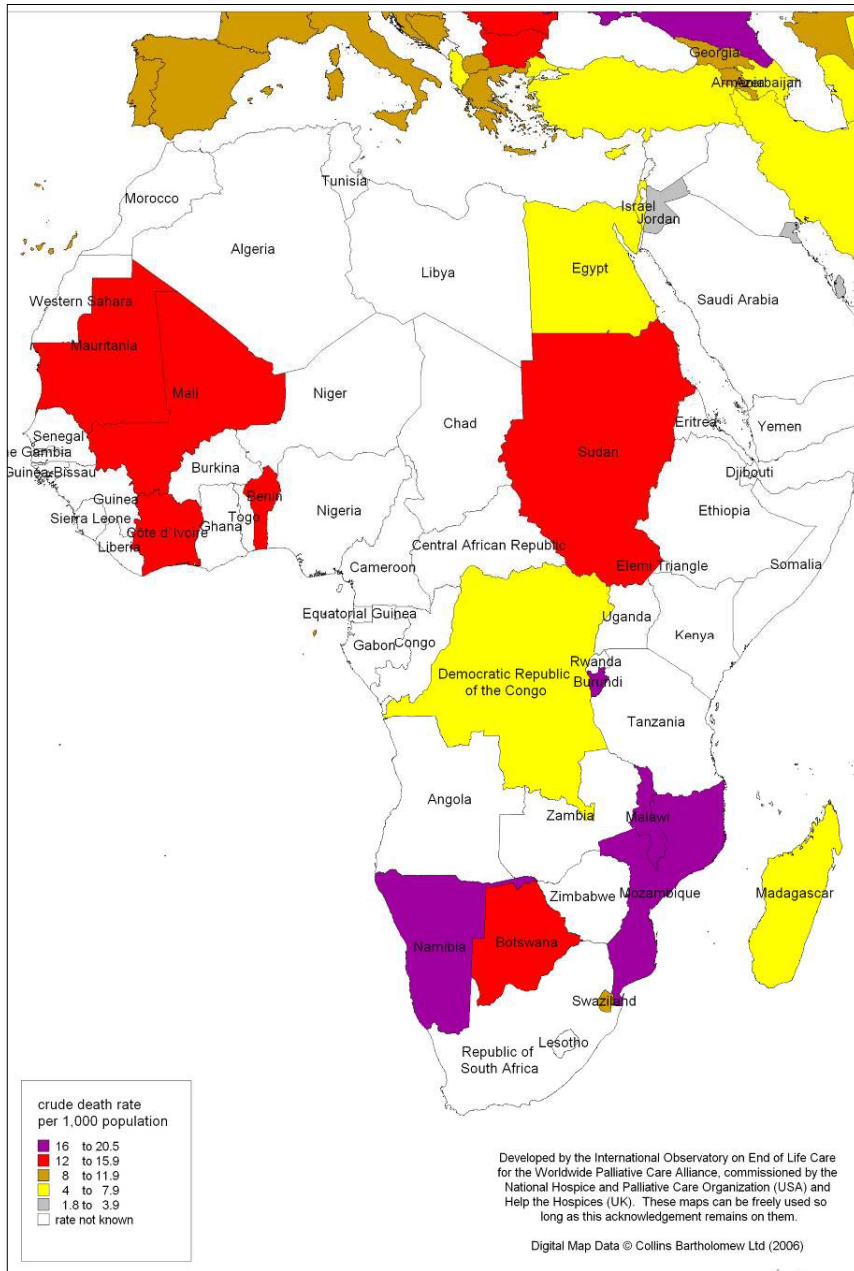


Figure 13. Crude Death Rates: Asia

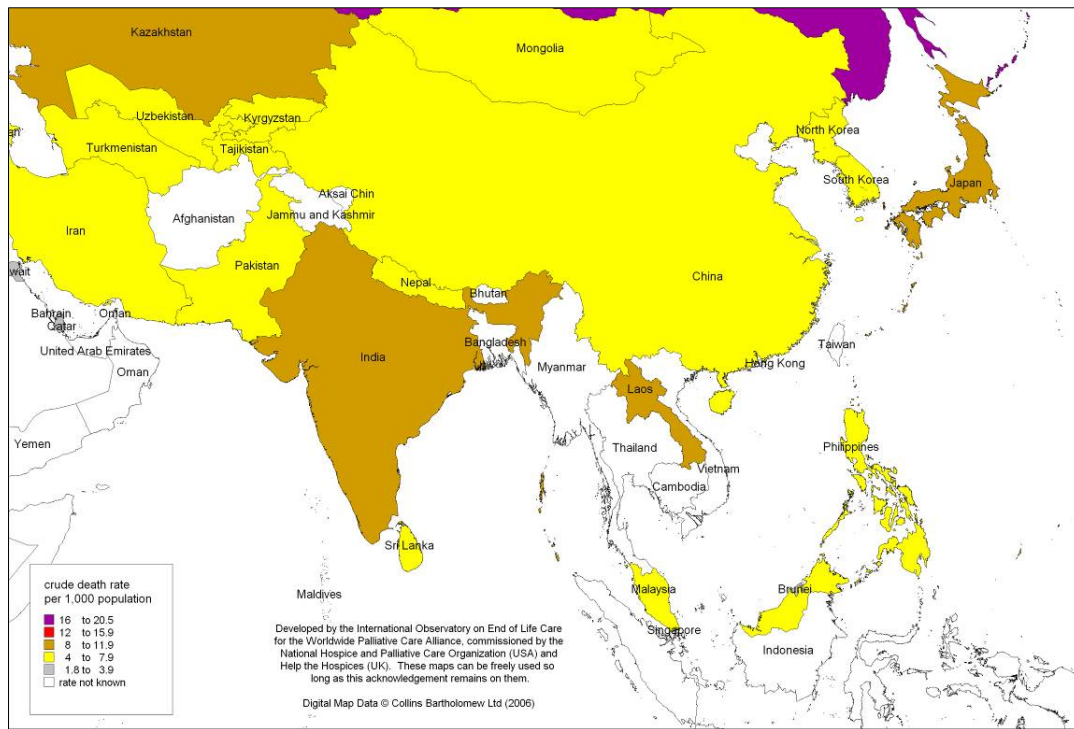
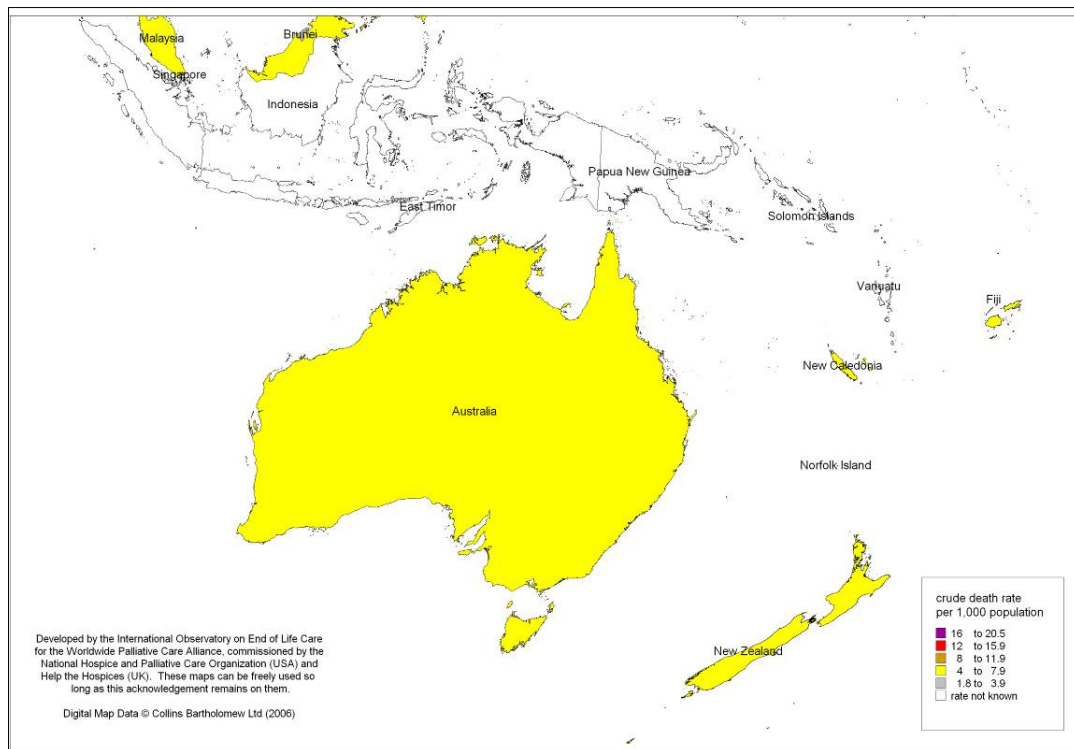


Figure 13. Crude Death Rates: Oceania



Challenges and opportunities

In the global context, palliative care activists point to a broad range of challenges, which may be summarised as follows:

- Political, social and economic instability
- Low public awareness
- Care for people with life limiting diseases is not seen as a priority
- Uncommitted government/ Ministry of Health
- Absence of policy/ legislation
- Unavailability of opioids
- WHO pain ladder not in use
- Lack of funding
- Entrenched attitudes within the medical profession
- Palliative care seen as a less prestigious discipline
- Absence of palliative care modules/ placements in medical curriculum
- Small number of professionals entering the field
- Uncertainty about the relationship between palliative care and other specialties
- Difficulty recruiting psychologists
- Demands of multidisciplinary team work
- Cultural change
- Education and training of staff
- Accreditation
- Absence of standards
- Taboo around death/ disclosure of diagnosis
- Coverage

It is important not to assume that countries experiencing these challenges are located in a particular category or geographic region, for most of these challenges appear in one form or another throughout the world and in all groups of countries. For example, the so-called foundation principles of education, drug availability and governmental policy are at the core of palliative care development, yet reports from activist frequently express concern in these areas.

In countries such as Dominica (Group 2) and Sudan (2) education is regarded as an essential precursor to the founding of a service, but in capacity-building states, there is no in-country source and pioneers depend heavily on assistance from the international community. Such support has developed the skills of staff in countries like Malta (3), Kazakhstan (3) and Cameroon (3) but on-going education remains crucial to service development. Among countries in Group 4: the UK is facing a shortage of skilled staff; Ireland has acknowledged a deficit in terms of education and training which in future will impact negatively on recruitment; and in Italy, attention has been drawn to the need for more palliative care modules in medical curricula.

In many countries, the unavailability of opioid drugs and prejudices around the use of morphine present serious barriers to palliative care. In Africa, around 25 of the 48 countries did not report morphine consumption to the International Narcotics Control Board for 2003. Accessibility remains problematic in many Latin America countries and in some of them, such as Nicaragua (2), morphine is only available in injectable form. Elsewhere, accessibility is made difficult by particularly strict controls. In India, regulations governing the procurement, transportation, storage and prescribing of morphine have rendered it unavailable in some states. In Zambia (3), morphine can only be prescribed in an in-patient facility. And enforcement of the legislation has been delegated to a group of clinical officers, given powers of imprisonment without question if a community health worker or patient is found in possession of the drug.

Coverage is problematic in many countries. Palliateurs in Armenia (3) point to a lack of resources, whereas in Russia (3) an under-funded health care system, together with the country's size and climate exacerbate the difficulties. Among countries in Group 4: palliative care is not yet accessible to the whole population of France; in New Zealand, concerns surround the unmet need in the North Island; and in Australia, an integrated service is still not available in some of the regions. This issue is particularly striking in Canada where, in 2004, only 5% to 15% of Canadians had access to palliative care services; it has also been noted that residents with disabilities and those living in remote areas have only limited access.

Political, social and economic factors also impact upon services. For example: during the late 1990s, health care in Argentina (Group 4) suffered from the effects of corruption, rising inflation and political instability; in South Africa (4) public opposition in Durban led to the developing service at Greta Schoeman's home being blockaded by angry neighbours; in Colombia, local residents went further and a newly-opened hospice in Bogota was vandalised and torched; in Sierra Leone (3), The Shepherd's Hospice was destroyed during the country's civil war; and in Zimbabwe (a country we placed in group 4 in 2005), the deteriorating in-country conditions has led to a perceived reduction in services and consequently a re-location to Group 3.

Despite the seriousness of these challenges, it should be acknowledged that palliative care is still a young discipline. It is not yet 40 years since Cicely Saunders opened St Christopher's Hospice in London, and less than 20 years since palliative medicine was first recognised as a specialty. So it is remarkable that palliative care services have become established in 115 countries and capacity-building activity is evident in a further 40 countries. Reasons for this rapid growth may be listed as follows:

- The emergence of palliative care champions
- A desire to provide better care for the dying
- Freedom from pain being viewed as a human right
- The growing awareness of new possibilities
- The practical needs of an ageing population
- A changing political climate (within the Council of Europe, for example)
- Advocacy has become sharply focused

- Support from volunteers
- Good patient and family experiences
- Better access to education and training
- Strategic planning and implementation
- Changes to the laws governing opioids
- Leadership initiatives are having an effect on policymakers
- Improved communication systems give easier access to information
- Broader support networks are becoming established
- Funding has become available.

As far as opportunities are concerned, two scenarios are influencing the development of hospice-palliative care, frequently described as ‘bottom up’ and ‘top down’ approaches. The ‘bottom up’ model is characterised by an energised group of activists identifying local need and deciding to meet it. This is how the first steps were taken in countries like Poland, where parishioners from the Lord’s Ark Church in Nowa Huta (Krakow), began to visit the sick in their local hospital (1976); in Zimbabwe, where Maureen Butterfield was motivated to begin a service when she saw the lack of provision for her daughter, Frances, who died of cancer in 1977; and in Myanmar, where U Hla Tun founded a service in 1998 after his only child died of leukaemia the previous year.

The ‘top down’ model is where the Ministry of Health becomes involved at an early stage and, in collaboration with clinicians, policy-makers, the House of Insurance, and other partners, sets in train the strategic and legislative procedures to incorporate palliative care into the national health system of the country. This is the approach which has been used to good effect in countries such as the Philippines, Mongolia and Kazakhstan, and was a central feature of the WHO project in Africa. Whichever model is favoured, however, it is when the two mesh together, combining local energy with national policy that opportunities are maximised for coverage, education, opioid availability and growth.

Conclusions

We have demonstrated that it is possible to map and measure the levels of palliative care development in any given country. More than 150 countries are actively engaged in delivering a hospice-palliative care service or developing the framework within which such a service can be provided. Yet development is patchy, with palliative care approaching a measure of integration with wider service providers in just 15% of countries; in countries with localised provision there are many instances where a service is mostly inaccessible to the whole population. Consequently, despite increasing calls for palliative care to be recognised as a human right, there is a long way to go before palliation is within reach of the global community.

The typology and its application provide a different perspective on palliative care development that might helpfully be used alongside other measures. Evidence here suggests that the instrument grouped parallel developments in both resource rich and resource poor settings, and across the north/ south divide. The strong correlation between

palliative care and human development provides an indication that the typology has an element of validity and reliability.

The relationship between a country's wealth (GDP per capita) and palliative care development should be approached with caution, since high and low income countries are represented in each of the four groups of countries.

In addition to the well known barriers to palliative care development, factors associated with a country's size, population and infrastructure present formidable challenges. Moreover, palliative care development is not linear. A country's response to internal and extraneous pressures may result in movement between groups, as in the case of Zimbabwe.

To assist those engaged in policy and service development, more work is now needed to further develop the typology, its robustness and applicability; to construct a broader evidence base for informed decision-making; and to develop a cohesive system of service identification

Appendix 1: Crude Death Rates, 2006

Country	CDR
Qatar	1.8
Turks and Caicos Islands	1.8
Kuwait	2.0
Brunei Darussalam	2.8
Jordan	3.1
Cayman Islands	3.2
Macao, SAR of China	3.4
Maldives	3.5
Singapore	3.7
Costa Rica	3.8
French Guiana	3.8
American Samoa	3.9
Andorra	3.9
Anguilla	4.2
Guam	4.2
Malaysia	4.4
El Salvador	4.4
Mexico	4.5
Fiji	4.5
French Polynesia	4.5
Nepal	4.6
Venezuela	4.6
British Virgin Islands	4.9
Congo, The Democratic Republic of	4.9
Philippines	5.0
Tajikistan	5.0
New Caledonia	5.0
Korea, Republic of	5.1
Chile	5.3
Hong Kong, SAR of China	5.3
Reunion	5.3
Uzbekistan	5.3
US Virgin Islands	5.3
Guatemala	5.4
Guyana	5.4
Korea, DPR	5.4
Israel	5.5
Iran, Islamic Republic of	5.5
Saint Pierre and Miquelon	5.6
Albania	5.7
Sri Lanka	5.8
Azerbaijan	6.0
Guadeloupe	6.0

Saint Lucia	6.0
Peru	6.1
Turkmenistan	6.1
Antigua and Barbuda	6.2
Iceland	6.3
Mongolia	6.4
China	6.4
Liechtenstein	6.4
Egypt	6.5
Tonga	6.5
Australia	6.6
Suriname	6.6
Palau	6.7
Pakistan	6.8
New Zealand	7.0
Bermuda	7.0
Cuba	7.0
Mauritius	7.0
Turkey	7.0
Cape Verde	7.0
Martinique	7.0
Kyrgyzstan	7.1
Paraguay	7.1
Saint Vincent and the Grenadines	7.1
Ireland	7.2
Cyprus	7.2
Dominica	7.2
Grenada	7.2
Canada	7.3
Puerto Rico	7.3
Greenland	7.3
Madagascar	7.5
San Marino	7.5
Luxembourg	7.6
Trinidad and Tobago	7.6
Saint Kitts and Nevis	7.6
Malta	7.7
Netherlands Antilles	7.7
Argentina	8.0
Japan	8.0
Armenia	8.0
India	8.0
Switzerland	8.1
Seychelles	8.1

Bosnia and Herzegovina	8.3
Sao Tome and Principe	8.3
Netherlands	8.4
United States of America	8.4
Barbados	8.4
Gibraltar	8.4
France	8.6
Macedonia, FYR	8.9
Finland	9.1
Norway	9.1
Swaziland	9.1
Uruguay	9.1
Spain	9.2
Slovenia	9.3
Channel Islands: Guernsey	9.3
Italy	9.4
Austria	9.5
Poland	9.5
Zimbabwe	9.5
Greece	9.6
Slovakia	9.6
Portugal	9.7
Belgium	9.8
Channel Islands: Jersey	9.9
Sweden	10.1
Denmark	10.3
Germany	10.3
United Kingdom	10.3
Kazakstan	10.4
Georgia	10.6
Lao PDRc	10.6
Czech Republic	10.9
Croatia	11.2
Lithuania	11.9
Romania	12.3
Cote d'Ivoire	12.3
Botswana	12.4
Montserrat	12.4
Mali	12.5
Sudan	12.6
Benin	13.0
Estonia	13.2
Hungary	13.4
Serbia	13.5
Latvia	13.8
Bulgaria	14.2
Belarus	14.5
Mauritania	15.1

Russian Federation	16.0
Ukraine	16.0
Burundi	18.4
Malawi	18.5
Mozambique	18.8
Namibia	20.5

Source: UN Vital Statistics Report: Table 3 updated 13 March 2006 (accessed 17 March 2006). See:

<http://unstats.un.org/unsd/demographic/products/vitstats/serATab3.pdf>

Appendix 2: Countries of the world - estimated population

Country	Population 000s
China	1315844
India	1103371
United States of America	298213
Indonesia	222781
Brazil	186405
Pakistan	157935
Russian Federation	143202
Bangladesh	141822
Nigeria	131530
Japan	129085
Mexico	107029
Viet Nam	84238
Philippines	83054
Germany	82689
Ethiopia	77430
Egypt	74033
Turkey	73193
Iran	69515
Thailand	64233
France	60496
United Kingdom	59668
Italy	58093
Congo DR	57549
Myanmar	50519
Korea, Republic of	47817
South Africa	47432
Ukraine	46481
Colombia	45600
Spain	43064
Argentina	38747
Poland	38530
Tanzania, Utd Rep	38329
Sudan	36233
Morocco	34478
Kenya	34256
Algeria	32854
Canada	32268

Afghanistan	29863
Uganda	28816
Iraq	28807
Peru	27968
Nepal	27133
Venezuela	26749
Uzbekistan	26593
Malaysia	25349
Saudi Arabia	24573
Korea, DPR	22488
Ghana	22113
Romania	21711
Yemen	20975
Sri Lanka	20743
Australia	20155
Mozambique	19792
Syria	19043
Madagascar	18606
Cote d'Ivoire	18154
Cameroon	16322
Netherlands	16299
Chile	16295
Angola	15941
Kazakhstan	14825
Cambodia	14071
Niger	13957
Mali	13518
Burkina Faso	13228
Ecuador	13228
Zimbabwe	13010
Malawi	12884
Guatemala	12599
Zambia	11668
Senegal	11658
Cuba	11263
Greece	11120
Portugal	10495
Belgium	10419

Czech Republic	10220
Tunisia	10102
Hungary	10098
Belarus	9755
Chad	9749
Guinea	9402
Serbia	9396
Bolivia	9182
Sweden	9041
Rwanda	9038
Dominican Republic	8895
Haiti	8528
Benin	8439
Azerbaijan	8411
Somalia	8228
Austria	8189
Bulgaria	7726
Burundi	7548
Switzerland	7257
Honduras	7205
Hong Kong, SAR of China	6940
El Salvador	6881
Israel	6725
Tajikistan	6507
Paraguay	6158
Togo	6145
Laos	5924
Papua N G	5887
Libya	5853
Jordan	5703
Sierra Leone	5525
Nicaragua	5487
Denmark	5431
Slovakia	5401
Kyrgyzstan	5264
Finland	5249
Turkmenistan	4833
Norway	4620
Croatia	4551
Utd Arab Emirates	4496
Georgia	4474
Eritrea	4401
Costa Rica	4327

Singapore	4326
Moldova, Republic of	4206
Ireland	4148
Cent Afr Rep	4038
New Zealand	4028
Congo	3999
Pal. Authority	3942
Puerto Rico	3927
Bosnia and Herzegovina	3907
Lebanon	3577
Uruguay	3463
Lithuania	3431
Liberia	3283
Panama	3232
Albania	3130
Mauritania	3069
Armenia	3016
Falkland Isles	2967
Kuwait	2687
Jamaica	2651
Micronesia	2646
Mongolia	2646
Oman	2567
Latvia	2307
Bhutan	2163
Macedonia, FYR	2034
Namibia	2031
Slovenia	1967
Comoros	1798
Lesotho	1795
Botswana	1765
Djibouti	1739
Bahrain	1727
Guinea-Bissau	1586
The Gambia	1517
Gabon	1384
Estonia	1330
Trinidad and Tobago	1305
Mauritius	1245
Swaziland	1032
Timor-Leste	947
Fiji	848
Cyprus	835

Qatar	813
Reunion	787
Guyana	751
Montenegro	630
Cape Verde	507
Equ Guinea	504
Solomon Isles	478
Luxembourg	465
Macao, SAR of China	453
Guadeloupe	452
Suriname	449
Martinique	436
Malta	402
Brunei	347
Maldives	329
The Bahamas	323
Iceland	295
French Polynesia	274
Western Sahara	273
Barbados	270
Belize	270
Neth Antilles	221
New Caledonia	219
Vanuatu	211
Mayotte	201
French Guiana	199
Samoa	185
Guam	171
Saint Lucia	161
Sao Tome/ Principe	157
Saint Vin't+ Gr'dines	119
US Virgin Isles	108
Grenada	103
Tonga	102
Kiribati	99
Jersey	91
Northern Mariana Isles	82
Antigua/ Barbuda	81
Seychelles	81
Dominica	79
Isle of Man	75
Aruba	71
Andorra	67

Bermuda	65
Guernsey	65
Marshall Isles	62
Am Samoa	57
Greenland	56
Faroe Isles	47
Cayman Islands	45
Saint Kitts/ Nevis	43
Monaco	35
Liechtenstein	33
Gibraltar	28
San Marino	28
Aland Islands	27
Brit Virgin Isles	23
Turks/ Caicos Isles	21
Palau	20
Cook Isles	18
Wallis/ Fortuna	16
Nauru	14
Anguilla	13
Tuvalu	10
Montserrat	9
Saint Helena	7
Saint Pierre/ Miquelon	7
Svalbard	3
Holy See	1
Niue	1
Norfolk Island	1
Tokelau	1
Pitcairn	()

Source: WHO/ World Fact Book

Appendix 3: Human development, countries rank order

Country	HDI rank
Norway	1
Iceland	2
Australia	3
Luxembourg	3
Canada	5
Sweden	6
Switzerland	7
Ireland	8
Belgium	9
United States of America	10
Japan	11
Netherlands	12
Finland	13
Denmark	14
United Kingdom	15
France	16
Austria	17
Italy	18
New Zealand	19
Germany	20
Spain	21
Hong Kong, SAR of China	22
Israel	23
Greece	24
Singapore	25
Slovenia	26
Portugal	27
Korea, Republic of	28
Cyprus	29
Barbados	30
Czech Republic	31
Malta	32
Brunei	33
Argentina	34
Hungary	35
Poland	36
Chile	37

Estonia	38
Lithuania	39
Qatar	40
Utd Arab Emirates	41
Slovakia	42
Bahrain	43
Kuwait	44
Croatia	45
Uruguay	46
Costa Rica	47
Latvia	48
Saint Kitts/ Nevis	49
The Bahamas	50
Seychelles	51
Cuba	52
Mexico	53
Tonga	54
Bulgaria	55
Panama	56
Trinidad and Tobago	57
Libya	58
Macedonia, FYR	59
Antigua/ Barbuda	60
Malaysia	61
Russian Federation	62
Brazil	63
Romania	64
Mauritius	65
Grenada	66
Belarus	67
Bosnia and Herzegovina	68
Colombia	69
Dominica	70
Oman	71
Albania	72
Thailand	73
Samoa	74
Venezuela	75
Saint Lucia	76

Saudi Arabia	77
Ukraine	78
Peru	79
Kazakstan	80
Lebanon	81
Ecuador	82
Armenia	83
Philippines	84
China	85
Suriname	86
Saint Vin'+ Gr'dines	87
Paraguay	88
Tunisia	89
Jordan	90
Belize	91
Fiji	92
Sri Lanka	93
Turkey	94
Dominican Republic	95
Maldives	96
Turkmenistan	97
Jamaica	98
Iran	99
Georgia	100
Azerbaijan	101
Pal. Authority	102
Algeria	103
El Salvador	104
Cape Verde	105
Syria	106
Guyana	107
Viet Nam	108
Kyrgyzstan	109
Indonesia	110
Uzbekistan	111
Nicaragua	112
Bolivia	113
Mongolia	114
Moldova, Republic of	115
Honduras	116
Guatemala	117
Vanuatu	118
Egypt	119

South Africa	120
Equ Guinea	121
Tajikistan	122
Gabon	123
Morocco	124
Namibia	125
Sao Tome/ Principe	126
India	127
Solomon Isles	128
Myanmar	129
Cambodia	130
Botswana	131
Comoros	132
Laos	133
Bhutan	134
Pakistan	135
Nepal	136
Papua N G	137
Ghana	138
Bangladesh	139
Timor-Leste	140
Sudan	141
Congo	142
Togo	143
Uganda	144
Zimbabwe	145
Madagascar	146
Swaziland	147
Cameroon	148
Lesotho	149
Djibouti	150
Yemen	151
Mauritania	152
Haiti	153
Kenya	154
Guinea	156
Senegal	157
Nigeria	158
Rwanda	159
Angola	160
Eritrea	161
Benin	162
Cote d'Ivoire	163

Tanzania, Utd Rep	164
Malawi	165
Zambia	166
Congo DR	167
Mozambique	168
Burundi	169
Ethiopia	170
Cent Afr Rep	171
Guinea-Bissau	172
Chad	173
Mali	174
Burkina Faso	175
Sierra Leone	176
Niger	177

Source: UN Development Report 2005

Appendix 4: GDP per capita, international dollars

Country	GDP
Luxembourg	57938
Monaco	48371
San Marino	40552
Sweden	40336
United States of America	39901
Norway	38813
Andorra	36535
Ireland	36371
Switzerland	34087
Iceland	32590
Denmark	31664
Austria	31648
Belgium	31481
Australia	31454
Canada	31389
United Kingdom	31308
Netherlands	31143
Finland	30415
France	30093
Japan	30039
Singapore	28848
Germany	28075
Italy	27952
Qatar	27284
New Zealand	24643
Spain	24325
Israel	22731
Bahrain	21441
Greece	21437
Korea, Republic of	20901
Slovenia	20326
The Bahamas	19930
Brunei	19767
Portugal	19475
Utd Arab Emirates	18754
Czech Republic	18598
Malta	18308
Kuwait	17451

Barbados	16240
Hungary	15828
Equ Guinea	15707
Cyprus	15602
Saudi Arabia	15307
Trinidad and Tobago	14903
Slovakia	14310
Estonia	14102
Oman	13651
Saint Kitts/ Nevis	13633
Argentina	13331
Poland	12647
Lithuania	12572
Chile	12505
Mauritius	12306
Belarus	11807
Latvia	11802
Cook Isles	11788
Croatia	11406
Antigua/ Barbuda	10907
Russian Federation	10865
Malaysia	10613
Seychelles	10245
Mexico	10158
Kazakstan	9982
Romania	9884
Uruguay	9630
Palau	8646
South Africa	8506
Costa Rica	8494
Thailand	8373
Iran	8367
Bulgaria	8269
Tunisia	8162
Brazil	8140
Panama	8103
Libya	7703
Turkey	7688
Botswana	7344

Lebanon	7336
Colombia	7319
Belize	7151
Grenada	7022
Saint Vin't+ Gr'dines	6855
Maldives	6440
Nauru	6401
Fiji	6240
Ukraine	6216
Guyana	6198
Albania	6158
Venezuela	6104
Saint Lucia	6084
Turkmenistan	5947
Gabon	5942
Namibia	5921
Swaziland	5893
Macedonia, FYR	5892
Philippines	5856
Armenia	5697
Peru	5671
China	5581
Dominica	5241
Dominican Republic	4986
Jordan	4947
Algeria	4860
Georgia	4829
El Salvador	4793
Tonga	4771
Ecuador	4620
Morocco	4557
Iraq	4554
Guatemala	4486
Serbia	4372
Micronesia	4358
Azerbaijan	4337
Jamaica	4330
Suriname	4329
Paraguay	4276
Egypt	4274
Cape Verde	4244
Samoa	4151
Papua N G	4008

Bosnia and Herzegovina	3845
Indonesia	3840
Sri Lanka	3800
Marshall Isles	3673
Cuba	3649
Viet Nam	3298
Kyrgyzstan	3287
Uzbekistan	3125
Vanuatu	2877
Nicaragua	2832
Bolivia	2762
Honduras	2748
Moldova, Republic of	2709
Syria	2449
Mongolia	2373
Ghana	2250
Lesotho	2152
Pakistan	2151
Bangladesh	2098
Bhutan	2035
Kiribati	1973
Myanmar	1949
Angola	1942
Solomon Isles	1913
Laos	1878
Cambodia	1839
India	1830
Tajikistan	1816
Guinea	1809
Yemen	1653
Cameroon	1606
Cote d'Ivoire	1602
Zimbabwe	1588
Kenya	1586
Niue	1586
Mauritania	1531
Sudan	1361
Korea, DPR	1339
Djibouti	1323
The Gambia	1288
Nepal	1277
Timor-Leste	1271
Tuvalu	1247

Burkina Faso	1236
Senegal	1232
Congo	1223
Chad	1199
Cent Afr Rep	1182
Sao Tome/ Principe	1139
Eritrea	1132
Togo	1123
Haiti	1100
Uganda	1088
Nigeria	1085
Mozambique	1053
Sierra Leone	1039
Zambia	1013
Comoros	985
Madagascar	965
Rwanda	893
Benin	836
Mali	830
Guinea-Bissau	815
Tanzania, Utd Rep	732
Niger	650
Malawi	519
Burundi	507
Afghanistan	430
Liberia	386
Congo DR	382
Ethiopia	381

Source: WHO