

Mapping levels of palliative care development: a global update 2011





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Worldwide Palliative MAPPING LEVELS OF PALLIATIVE CARE DEVELOPMENT: A GLOBAL UPDATE 2011

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Background

In 2006, with support from Help the Hospices and the National Hospice and Palliative Care Organization and on behalf of the Worldwide Palliative Care Alliance, Professor David Clark and Dr Michael Wright from the International Observatory on End of Life Care (IOELC) presented a report that measured palliative care development in all countries of the world and classified them according to levels of palliative care development. The IOELC built on a basic description that had been produced earlier by the Hospice Information Service, but attempted to build more depth into the analysis by developing a four-part typology depicting levels of hospice-palliative care development across the globe:

- no known hospice-palliative care activity (group 1 countries)
- capacity building activity (group 2 countries)
- localised hospice-palliative care provision (group 3 countries)
- countries where hospice-palliative care services were reaching a measure of integration with the mainstream healthcare system (group 4 countries).

The work was subsequently published in the Journal of Pain and Symptom Management¹ and has been heavily cited as well as adopted as a tool for international palliative care advocacy. However, it was clear that the rankings might benefit from refinement and the method of categorisation could also be made more robust. To update the original findings and also address the definitional and methodological concerns, the 2006 mapping exercise has been repeated in 2011, with some new criteria. Within the typology, changes have been made to the criteria for level of palliative care development in groups 3 and 4 and these have been subdivided to produce two additional levels of categorisation (groups 3a and 3b/4a and 4b).

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¹ Wright, M Wood, J Lynch, T Clark, D (2008) Mapping levels of palliative care development: a global view. *Journal of Pain and Symptom Management* 35(5): 469-85.

Methods

The methods used for the project were twofold. First, data about the level of palliative care development within each country in the world was collected from the following sources:

- published articles in peer-reviewed and professional journals
- books and monographs
- palliative care directories
- palliative care websites
- data provided by the European Association for Palliative Care (EAPC)
 Task Force for the Development of Palliative Care in Europe
- IOELC reviews and databases
- grey literature and conference presentations
- the opinions of 'key persons' in the field of palliative care.

Data was analysed against the typology's key elements and each country was allocated to one of the following six categories on the basis of its level of palliative care development.

Group 1 countries:

No known hospice-palliative care activity: Although we have not been able to identify any palliative care activity in this group of countries, we acknowledge there may be instances where, despite our best efforts, current work has been unrecognised.

Group 2 countries:

Capacity building activity: In this group of countries, there is evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for hospice-palliative care services to develop, though no service has yet been established. The developmental activities include:

- attendance at, or organisation of, key conferences
- personnel undertaking external training in palliative care
- lobbying of policy-makers and ministries of health
- incipient service development.

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Group 3 countries:

- **3a) Isolated palliative care provision:** This group of countries is characterised by:
- the development of palliative care activism that is patchy in scope and not well-supported
- sourcing of funding that is often heavily donor-dependent
- limited availability of morphine
- a small number of hospice-palliative care services that are often homebased in nature and relative to the size of the population.
- **3b) Generalised palliative care provision:** This group of countries is characterised by:
- the development of palliative care activism in a number of locations with the growth of local support in those areas
- multiple sources of funding
- the availability of morphine
- a number of hospice-palliative care services from a community of providers that are independent of the healthcare system
- the provision of some training and education initiatives by the hospice organisations.

Group 4 countries:

4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision: This group of countries is characterised by:

- the development of a critical mass of palliative care activism in a number of locations
- a variety of palliative care providers and types of services
- awareness of palliative care on the part of health professionals and local communities
- the availability of morphine and some other strong pain-relieving drugs
- limited impact of palliative care on policy
- the provision of a substantial number of training and education initiatives by a range of organisations
- interest in the concept of a national palliative care association.

- 4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision: This group of countries is characterised by:
- the development of a critical mass of palliative care activism in a wide range of locations
- comprehensive provision of all types of palliative care by multiple service providers
- broad awareness of palliative care on the part of health professionals, local communities and society in general
- unrestricted availability of morphine and all other strong painrelieving drugs
- substantial impact of palliative care on policy, in particular on public health policy
- the development of recognised education centres
- academic links forged with universities
- the existence of a national palliative care association.

Second, global hospice-palliative care development was categorised using the revised typology, country by country, throughout the world; this development is depicted in a series of world and regional maps. The maps presented here make use of the United Nations list of 234 'countries or areas', which are grouped into 21 regions (such as Central America) and then allocated to six 'major areas' designated as 'continents' (Africa, North America, Latin America and the Caribbean, and Oceania). Figure 7 shows a composite map with all levels of palliative care development worldwide.

The current number of providers of specialist palliative care services was obtained from the *Hospice Information Service Database*. The number of hospice-palliative care services was drawn from country reviews, hospice directories, and the opinion of 'key persons' in the field of palliative care; they not only give an indication of activity but, when shown as a ratio of services to population, provide another measure of palliative care development (see Figure 8).

Limitations

This approach has accompanying limitations; for example, there was an absence of data for some countries. Also, the way services are counted is problematic because two systems operate in tandem: services in five of the six continents are counted by provider, irrespective of the number of services; in Europe, they are counted by type (for example, home care, day care, inpatient units, hospital teams). Although this allows a degree of comparability for services in the countries of Europe and within and across the other five continents, it also inhibits any comparable worldwide analysis. Listing services by provider is by no means foolproof and could be a source of bias as a country with few but large-scale provider organisations would show a lower ratio of services per capita compared with a country having several small providers. We have attempted to address these issues by listing the number of providers and services in the same category of data under the heading 'services/providers', and attempting to glean clarification from 'key persons' and local palliative care experts.

The majority of data relating to palliative care development was self-reported by 'key persons' in each respective country, and this is acknowledged by the authors as a potential weakness as data provided in this way may be subject to bias or inaccuracy; in the limited number of cases when this was explicitly apparent, the perceived anomaly has been highlighted.

A further limitation to the project was that respondents often experienced difficulty in choosing between the divided categories 3a or 3b/4a or 4b. Some respondents suggested that their country 'did not fit into any category', that their country was 'somewhere on the border' between two categories, or that 'strengths and limitations' existed within each sub-category. This situation was reflected in a number of countries in Central and Eastern Europe/Commonwealth of Independent States (CEE/CIS), where national palliative care associations had been formed but because of financial problems and political changes that resulted in inconsistent public health policy, the progress of palliative care remained 'very slow'. Respondents from the Americas/Caribbean also experienced some difficulty in determining between the newly divided categories; for example, the respondent from Panama stressed that her country was 'not 3a at all, but cannot be categorised as 3b either'.

In the Asia Pacific and Oceania region, the respondent from Nepal experienced some difficulty in choosing between group 3a and 3b, while the respondent from Australia found differentiating between group 4a and 4b somewhat problematic. A number of Western European countries (for example, Austria, Denmark, Netherlands, and Spain) also had difficulty in categorising themselves in either category 4a or 4b, suggesting that they often 'scored differently for the different items' and were therefore 'somewhere in between'. In the Africa region, the respondent from South Africa proposed another sub-category within category 4 to further refine the typology.

Results

In 2006, 115 of the world's 234 countries (49%) had established one or more hospice-palliative care services; in 2011, 136 of the world's 234 countries (58%) now have one or more hospice-palliative care services established – an increase of 21 countries (+9%) from the previous project. In 2006, 156 countries (67%) were actively engaged in either delivering a hospice-palliative care service or developing the framework within which such a service could be delivered; in 2011, there has been a slight increase in this number to 159 countries (68%) – a rise of 1%.

Table 1: WPCA categorisation of palliative care development 2011 n=234

	1
Group 1	Afghanistan, American Samoa, Andorra, Anguilla,
No known	Antigua and Barbuda, Aruba, Benin, Bhutan, Burkina
activity	Faso, Burundi, Cape Verdi, Central African Republic,
N=75 (32%)	Chad, Comoros, Cook Islands, Djibouti, Equatorial
	Guinea, Eritrea, Falkland Islands, Faroe Islands, French
See Figure 1	Guiana, French Polynesia, Gabon, Greenland, Grenada,
	Guam, Guinea, Guinea-Bissau, Kiribati, Korea (DPR),
	Laos, Liberia, Libya, Liechtenstein, Maldives, Marshall
	Islands, Martinique, Mauritania, Mayotte, Micronesia,
	Monaco, Montserrat, Nauru, Netherlands Antilles, New
	Caledonia, Niger, 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,
	UZBEKISTAN (- from category 2), Vanuatu, Wallis and
	Fortuna, Western Sahara, Yemen.
Group 2	ALAND ISLANDS (- from category 3), Algeria,
Capacity	AZERBAIJAN (- from category 3), Bolivia, British Virgin
building	Islands, Democratic Republic of Congo, Dominica, Fiji,
NI-02 (100()	Haiti, Holy See (Vatican), HONDURAS (- from category
N=23 (10%)	3), Madagascar, Mauritius, MONTENEGRO (+ from
See Figure 2	category 1), Nicaragua, Oman, Palestinian Authority,
	Papua New Guinea, Qatar, Reunion, Seychelles,
	Suriname, Tajikistan, The Bahamas.

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Group 3a	ANGOLA (+ from category 1), Armenia, BAHRAIN
Isolated	(+ from category 2), Bangladesh, Barbados, BELIZE
provision	(+ from category 2), Bermuda, Botswana, Brazil,
NI-714	BRUNEI (+ from category 2), Bulgaria, Cambodia,
N=74	Cameroon, Cayman Islands, Colombia, Congo, Cuba,
31.6%	Dominican Republic, Ecuador, Egypt, El Salvador,
See Figure 3	Estonia, ETHIOPIA (+ from category 2), GHANA
	(+ from category 2), Gibraltar, Greece, Guadeloupe,
	Guatemala, Guernsey, Guyana, Indonesia, IRAN
	(+ from category 2), Iraq, Isle of Man, Jamaica, Jersey,
	Kazakhstan, Korea (South), KUWAIT (+ from category
	2), Kyrgyzstan, Latvia, LEBANON (+ from category
	2), LESOTHO (+ from category 2), Macedonia, MALI
	(+ from category 1), Mexico, Moldova, Morocco,
	MOZAMBIQUE (+ from category 2), Myanmar,
	NAMIBIA (+ from category 2), Nigeria, NIUE
	(+ from category 1), Pakistan, Panama, PARAGUAY
	(+ from category 2), Peru, Philippines, Reunion, Russia,
	RWANDA (+ from category 2), SAINT LUCIA
	(+ from category 2), Saudi Arabia, Sierra Leone, Sri
	Lanka, SUDAN (+ from category 2), The Gambia,
	Thailand, Trinidad and Tobago, Tunisia, Ukraine,
	United Arab Emirates, Venezuela, Vietnam.
Group 3b	Albania, ARGENTINA (- from category 4), Belarus,
Generalized	Bosnia and Herzegovina, COTE D'IVOIRE (+ from
provision	category 2), Croatia, Cyprus, Czech Republic, Georgia,
N=17	India, Jordan, Lithuania, Malta, Nepal, Portugal,
7.3%	Swaziland, TURKEY (+ from category 2).
See Figure 4	
Group 4a	Chile, CHINA (+ from category 3), Costa Rica,
Preliminary	Denmark, Finland, Hungary, Israel, Kenya,
integration	LUXEMBOURG (+ from category 3), MACAU
N=25	(+ from category 3), MALAWAI (+ from category
10.7%	3), Malaysia, Mongolia, Netherlands, New Zealand,
Soc Figure 5	PUERTO RICO (+ from category 2), SERBIA (+ from category 3), SLOVAKIA (+ from category 3),
See Figure 5	Slovenia, South Africa, Spain, TANZANIA (+ from
	category 3), URUGUAY (+ from category 3), ZAMBIA
	(+ from category 3), ZIMBABWE (+ from category 3).
Cuore 11	
Group 4b Advanced	Australia, Austria, Belgium, Canada, France, Germany,
	Hong Kong, Iceland, Ireland, Italy, Japan, Norway,
integration	Poland, Romania, Singapore, Sweden, Switzerland,
N=20	Uganda, United Kingdom, United States of America.
8.5%	
See Figure 6	
See Figure 6	

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In 2006, there was no known palliative care activity in 78 of the world's 234 countries (33%); by 2011, this figure had decreased by a total three countries (-1%) to 75. The number of countries that were demonstrating capacity-building potential in 2006 was 41 (18%); by 2011, this number had decreased by a total of 18 countries to 23 – a decrease of -8%. Countries with localised hospice-palliative care provision in 2006 totalled 80 (34%); in 2011 the combined number of countries in categories 3a and 3b totalled 91 (39%) – an increase of 11 countries (+5%). Finally, the division of group 4 indicates that while 25 countries (10.7%) are now approaching integration with mainstream health service providers, only 20 countries (8.5%) have actually achieved this. In 2011, the total number of countries in category 4 is 45 (19%), as opposed to 35 (15%) in 2006 – an increase of 10 countries (+4%).

Table 2: Gross changes in the number of countries in each category

Group	2006	2011	Change=n	Change=%
Group 1	78 (33%)	75 (32%)	-3	-1%
Group 2	41 (18%)	23 (10%)	-18	-8%
Group 3	80 (34%)	91 (39%)	+11	+5%
Group 4	35 (15%)	45 (19%)	+10	+4%/0

Table 3: Changes in palliative care direction by country 2006-2011

	Changes in palliative care direction COUNTRY
Group	2006–2011 (+/-)
Group 1	UZBEKISTAN (- from category 2)
Group 2	MONTENEGRO (+ from category 1)/ALAND
-	ISLANDS (- from category 3)
Group 3a	ANGOLA (+ from category 1) BAHRAIN (+ from
-	category 2) BELIZE (+ from category 2) BRUNEI
	(+ from category 2) ETHIOPIA (+ from category 2)
	GHANA (+ from category 2) IRAN (+ from category
	2) KUWAIT (+ from category 2) LEBANON (+ from
	category 2) LESOTHO (+ from category 2) MALI
	(+ from category 1) MOZAMBIQUE (+ from category 2)
	NAMIBIA (+ from category 2) NIUE (+ from category
	1) PARAGUAY (+ from category 2) RWANDA (+ from
	category 2) SAINT LUCIA (+ from category 2) SUDAN
	(+ from category 2)
Group 3b	COTE D'IVOIRE (+ from category 2) TURKEY
	(+ from category 2)/ARGENTINA (- from category 4)
Group 4a	CHINA (+ from category 3) LUXEMBOURG (+ from
	category 3) MACAU (+ from category 3) MALAWAI
	(+ from category 3) PUERTO RICO (+ from category
	2) SERBIA (+ from category 3) SLOVAKIA (+ from
	category 3) TANZANIA (+ from category 3) URUGUAY
	(+ from category 3) ZAMBIA (+ from category 3)
	ZIMBABWE (+ from category 3)
Group 4b	

Table 4: Changes in palliative care direction by region 2006–2011

Group	Changes in palliative care direction REGION 2006–2011 (+/-)
Group 1	1 x CEE/CIS (- from category 2)
Group 2	1 x CEE/CIS (+ from category 1)/1 x EUROPE
	(- from category 3)
	1 x CEE/CIS (- from category 3) 1 x AMERICAS/
	CARIBBEAN (- from category 3)
Group 3a	2 x AFRICA (+ from category 1) 7 x AFRICA (+ from
	category 2) 5 x MIDDLE EAST (+ from category 2)
	1 x ASIA PACIFIC/OCEANIA (+ from category 1)
	3 x AMERICAS/CARIBBEAN (+ from category 2)
Group 3b	1 x AFRICA (+ from category 2) 1 x EUROPE
	(+ from category 2)/1 x AMERICAS/CARIBBEAN
	(- from category 4)
Group 4a	2 x ASIA PACIFIC/OCEANIA (+ from category 3)
_	1 x EUROPE (+ from category 3) 4 x AFRICA
	(+ from category 3) 1 x AMERICAS/CARIBBEAN
	(+ from category 2) 1 x AMERICAS/CARIBBEAN
	(+ from category 3) 2 x CEE/CIS (+ from category 3)
Group 4b	

Discussion

Results from this mapping exercise of global palliative care development indicate that since 2006, there has been an increase in the number of countries of the world that have established one or more hospice-palliative care services (+9%), although only a slight increase has occurred in the total number of countries actively engaged in either delivering a hospice-palliative care service or developing the framework within which such a service can be delivered (+1%).

In summary, it appears that since 2006, 21 countries (9%) have moved from group 1/2 (no known activity/capacity building) into groups 3/4 (some form of palliative care provision). However, within the context of these results, there are many instances where palliative care remains inaccessible to the majority of a country's population.

A regional analysis of palliative care development between 2006 and 2011 indicates that the most notable regions involved in the change of direction from group 1/2 (no known activity/capacity building) to group 3a (isolated provision) are Africa (+9 countries) and the Middle East (+5 countries); another region involved in this change of direction is Americas/Caribbean (+3 countries).

In the Middle East, a good example of progress is provided by Lebanon, which moved from group 2 to 3a as a 12-bed inpatient palliative care unit had been established by a religious organisation in Beyrouth. In Africa, much progress has been initiated by the African Palliative Care Association (APCA), ably supported by funders such as The Diana, Princess of Wales Memorial Fund and the Open Society Foundation International Palliative Care Initiative (IPCI) among others. Angola moved from group 1 to 3a because APCA conducted an exploratory study there and initiated some palliative care contacts that resulted in one service being established. Ghana also moved from group 1 to 3a because a national palliative care association was formed and a number of palliative care services have since been established. Ethiopia, Namibia, Rwanda and Sudan all moved from group 2 to 3a because a palliative care infrastructure had been developed and isolated palliative care services provided, albeit at a low level; Cote d'Ivoire moved from group 2 to 3b for the same reason, although progress there is reported as slightly greater than in other countries of the region.

Another change in direction occurred from group 3 to 4a, with Africa once again being the most prominent region (+4 countries). Countries such as Malawi, Tanzania, Zambia, and Zimbabwe changed direction because of the work APCA and other partners have done to develop and scale up palliative care in those countries; APCA suggest that these countries have made 'tremendous progress' in recent years and envisage them being recategorised to group 4b (advanced integration) in the near future. Other

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African countries believed to be close to moving from group 3 to 4 include Botswana, Cameroon, Morocco and Nigeria. However, the impact that the withdrawal of support by the Diana, Princess of Wales Memorial Fund from Africa in 2012 will have on the continued development of palliative care in the region is as yet unknown.

Progress is also reported in a number of CEE/CIS countries following prolonged support from international funders such as IPCI; for example, two countries moved from group 3 to group 4a. Slovakia was recategorised for a number of reasons:

- a number of hospices had opened in the country
- hospice beds were now available in hospitals and teaching hospitals
- palliative care was gradually being implemented into postgraduate education for physicians and undergraduate education for nurses
- a chair of palliative medicine at Slovak Medical University had been established
- there was good availability of morphine
- there was a national association of palliative care (Slovakian Association of Hospice and Palliative Care) plus another organisation, the Chapter of Palliative Care of Slovak Society for Study and Treatment of Pain, which covered the palliative care educational needs of both physicians and nurses.

Serbia was recategorised because of the impact of their three-year National Strategy for Palliative Care Development, which would substantially increase the number of hospital/home-based palliative care teams and palliative care units throughout the country, provide education and training initiatives for both health professionals and the families of patients, improve the availability of oral morphine and other forms of opioids, and ultimately result in the integration of palliative care into the Serbian healthcare system.

In Western Europe, the respondent from Luxembourg recategorised the country from group 3 to 4a because of an increase in the number of hospice and palliative care units and the substantial development of palliative care education and training initiatives in the country; progress has also been due to the introduction of a new law relating to palliative care that was introduced in 2009.

In the Americas/Caribbean, Uruguay recategorised from group 3 to 4a for a number of reasons:

- the number of hospice/palliative care services had increased
- palliative care is now recognised in the National Health Program

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- a Diploma in Palliative Care had been introduced into the State University along with undergraduate palliative care programs in other universities
- the national association was 'developing rapidly'
- the availability of opioids was described as 'good'.

In contrast, although Argentina had made 'major advances in palliative care over the last 20 years', there was still only localised hospice-palliative care provision. According to geography and differing levels of complexity, areas still existed either where palliative care was inaccessible or there was 'great disparity' in the standard of care provided; as a result, Argentina was recategorised from group 4 to group 3b.

Summary

We have demonstrated that it is possible to map and measure levels of palliative care development, country by country, throughout the world, to facilitate cross-national comparative analysis and stimulate advocacy, policy making and service development. To provide a more refined view of existing levels of palliative care development, the previous mapping exercise from 2006 was updated, new data was collected and the typology amended. Limitations to the project included:

- an absence of data for some countries
- problems in the counting and categorisation of services
- self-reporting by 'key persons' may have been subject to bias or inaccuracy
- respondents experienced difficulty in choosing between the newly divided categories.

In 2011, 136 of the world's 234 countries (58%) now have one or more hospice-palliative care services established – an increase of 21 countries (+9%) from the previous project (2006). A regional analysis of palliative care development between 2006 and 2011 indicates that the most significant gains have been made in Africa, although the impact that the withdrawal of support by the Diana, Princess of Wales Memorial Fund from the region in 2012 will have on the continued development of palliative care is as yet unknown. A significant number of countries still have no hospice-palliative care provision and global development may best be described as 'patchy'. Although there are indications of palliative care interest on the part of national governments and policymakers, advanced integration of palliative care with wider health services has only been achieved in 20 countries globally (8.5%). Despite increasing calls for palliative care to be recognised as a human right, there remains much to be done before palliative care is accessible to the worldwide community.

This project has built on the original work of the IOELC, which was pioneered by Professor David Clark and Dr Michael Wright. It is hoped that the results of this project will serve to stimulate further discussion about the use of the typology for raising awareness of the need for integrating palliative care into existing healthcare systems. The increased interest in access to palliative care as a human right provides further justification for examining the relationship between palliative care services and their accessibility to the populations of individual countries.

Figure 1: Palliative care development level 1 Countries with no known hospice-palliative care activity identified

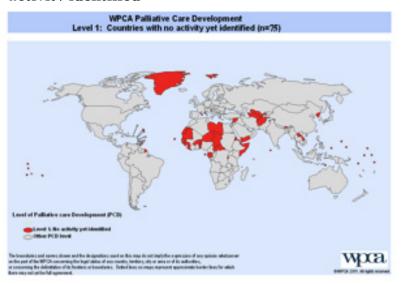


Figure 2: Palliative care development level 2 Countries with Capacity Building Activity

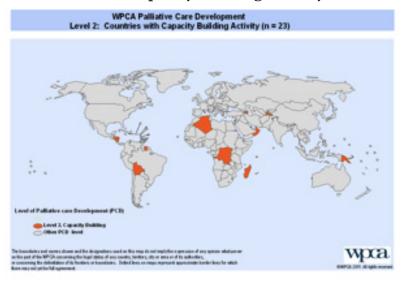


Figure 3: Palliative care development level 3a Countries with Isolated Provision

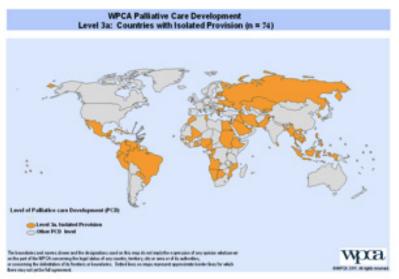


Figure 4: Palliative care development level 3b Countries with generalised provision

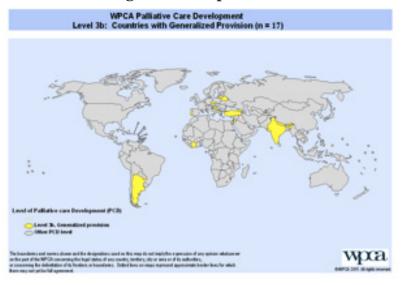


Figure 5: Palliative care development level 4a Countries with Preliminary Integration

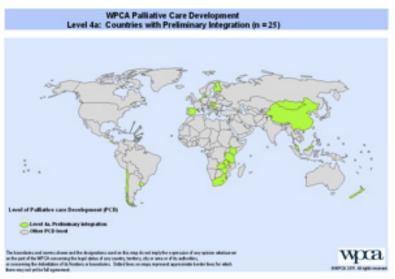


Figure 6: Palliative care development level 4b Countries with Advanced Integration

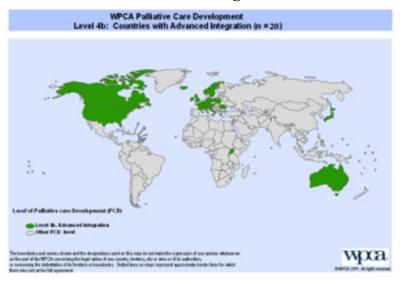


Figure 7: Palliative care development all levels All levels

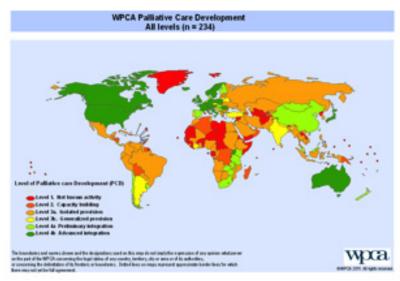
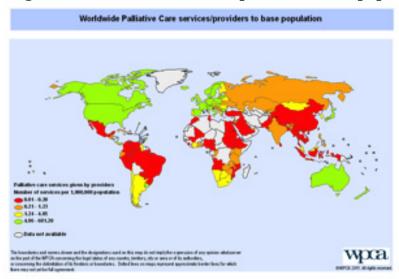


Figure 8: Palliative care development services/population



The Worldwide Palliative Care Alliance is the network of national and regional hospice and palliative care organisations around the world. The Alliance works to support efforts to develop hospice and palliative care services globally.

Vision – A world with universal access to affordable, high quality palliative care.

Mission – To promote universal access to affordable quality palliative care through the support of regional and national hospice and palliative care organisations.

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