



World Hospice and Palliative Care Day
WITH VOICES FOR HOSPICES

EVALUATION OF WORLD HOSPICE AND PALLIATIVE CARE DAY 2005

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January 2006



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Executive Summary

This evaluation of the first World Hospice and Palliative Care Day (WHPCD) held on 8th October 2005 was funded by Help the Hospices and conducted by Dr Liz McDermott and Professor David Clark from the International Observatory on End of Life Care at Lancaster University.

The aim of the study is to assess the impact of WHPCD on its stated aims of raising the awareness of hospice and palliative care; raising funds to support and develop hospice and palliative care services; and increasing the availability of hospice and palliative care worldwide. The evaluation was conducted through a global online questionnaire, interviews with key people in global national associations of hospice and palliative care, and an analysis of web-based materials, international reports and Help the Hospices data and documentation.

We found that WHPCD was extremely successful, with 74 countries across 5 continents organising activities for the day, and a further 28 countries signing the petition. We estimate that there were around 1100 WHPCD events organised worldwide, plus 500 Voices for Hospices concerts in 60 countries. These activities were wide-ranging and included, for example, music and arts performances, seminars and conferences, organised walks, school competitions, TV documentaries, religious services and active lobbying of state officials. Key outcomes from and linked to WHPCD include:

- Opiate regulations and policy change in Romania and Colombia
- Worldwide media coverage of WHPCD in most of the 74 participating countries
- Increased awareness and understanding of hospice and palliative care in the general public, among state and health officials, professionals and business
- New service developments e.g. Philippines, Nigeria, Hungary, India
- Guatemala celebrated the opening of the country's first palliative care unit
- Increased demands on services e.g. Moldova, South Africa
- Widening access to already existing services
- Advocacy with government and state officials e.g. Slovenia, Austria, Kenya,
- Capacity building e.g. launch of African Palliative Care Association in Uganda
- New hospice and palliative care collaborations e.g. Brazil
- Funds raised e.g. a concert in Trichur, India raised US\$5000
- Over 5500 signatories to the WHPCD petition
- The province of Ontario in Canada announced \$115 million for end of life care
- Broadened international palliative care network e.g. Jordan

Summary recommendations:

- The successes of the day need to be disseminated widely as a platform for building purpose and motivation for WHPCD06

- Increasing participation through: organising the day via more than one language; targeting non-participating countries and providing support and encouragement to participate; ensuring small grants are available to resource-poor countries to ensure participation
- Maximising the impact of WHPCD through: a focus on media work including the translation of materials and dissemination of successful media strategies; a focus on advocacy work with the petition, and sharing experiences of successful advocacy strategies and tactics
- Future world days need a specific global focus/theme which is internationally relevant and can be adapted by individual countries. Suggestions include: access; pain relief; children; families.

1. INTRODUCTION

The first World Hospice and Palliative Care Day (WHPCD) was held on the 8th October 2005. It was initiated by the UK-based charity Help the Hospices and organised through a committee with representation from a range of international hospice and palliative care organisations. The motivation for the day was recognition of the millions of people around the world living with terminal illness who experience unnecessary pain and distress because they are either unaware of or unable to access palliative care. Hospice and palliative care is an issue which affects everybody on the planet and it is this global humanitarian perspective which gave rise to WHPCD.

The aim of WHPCD is to generate a collective global voice to raise awareness of the many issues affecting hospice and palliative care around the world. The organisers stated the specific objectives of the day as:

- To share our vision to increase the availability of hospice and palliative care throughout the world. To create opportunities to speak out about the issues which affect provision of hospice and palliative care around the world, to influence opinion formers including health care funders and policy makers
- To raise awareness and understanding of the needs – medical, social, practical, spiritual – of people living with a terminal diagnosis and their families. To explain how hospice and palliative care can transform people's lives and show how it can help to meet those needs
- To raise funds to support and develop hospice and palliative care services around the world – particularly through Voices for Hospices events

The aspects of hospice and palliative care which WHPCD attempts to address include: the inclusion of palliative care in national health care programmes; funding of palliative care; availability of low cost opioid analgesics for pain and symptom control; widening of palliative care to diseases such as HIV/AIDS; availability of palliative care in resource-poor countries; access for marginalised communities such as prisoners and the homeless; integrating palliative care into health care professional training.

The evidence from the evaluation highlights the phenomenal success of the day, with estimates of over 1100 events organised in 74 countries worldwide; and a further 500 Voices for Hospices events in 60 countries. There was a wide range of activities organised for the day including art and photography exhibitions, hospice openings, theatre productions, family days, health professional seminars and meetings with government officials. We estimate that hundreds of thousands of people celebrated the inaugural World Hospice and Palliative Care Day on 8th October 2005 and read Archbishop Desmond Tutu's message of support for the day. The impact of the day on palliative care reverberated around the globe: it precipitated the province of Ontario in Canada to announce \$115 million to end of life care; in Romania new opioid legislation

was adopted; the Indian Association of Palliative Care launched its online version of the Indian Journal of Palliative Care; the African Association of Palliative Care was officially launched; and all around the globe new connections and collaborations were made in an attempt to make palliative care available to all.

The purpose of this report is to examine the organization, activities and outcomes of WHPCD and assess which aspects were successful and which could be improved. The report then makes some recommendation about strategies to strengthen the positive and improve the less successful elements of the day.

2. AIMS

The aim of the evaluation process was:

1. To measure the impact of World Hospice and Palliative Care Day against its three stated aims:

- To share our vision to increase the availability of hospice and palliative care throughout the world. To create opportunities to speak out about the issues which affect provision of hospice and palliative care around the world, to influence opinion formers including health care funders and policy makers
- To raise awareness and understanding of the needs - medical, social, practical, spiritual - of people living with a terminal diagnosis and their families. To explain how hospice and palliative care can transform people's lives and to show how it can help to meet those needs
- To raise funds to support and develop hospice and palliative care services around the world - particularly through Voices for Hospices events

2. To identify and describe events and activities that have been particularly successful

Key questions:

What events were organised, where and by whom?

Who participated in these events?

Did any state officials participate in WHPCD events?

What press and media coverage was generated – nationally and internationally?

What messages of support were received from and by whom?

Where and in what context were statements presented to government officials or policy makers?

Did the events increase awareness of the need for hospice and palliative care day?

How was awareness raised? (among local people, health professionals, government, state or district officials)

Where, how, by whom and in what amounts were funds raised through WHPCD?

Can the day be seen to have had any impact on national health care programmes and health policies?

Has the day had any impact of officials' understanding of hospice and palliative care?

Has the day opened channels of communication e.g. concerning the need for opioid analgesics, health professional training?

In what ways has the day impacted at the country or local area level e.g. enquiries about volunteering, new interest from health professionals, new campaigns, new service developments or training?

3. METHODS

The evaluation employed three methods:

1. Global online questionnaire.
2. Interviews with key people in global national associations of hospice and palliative care.
3. Analysis and synthesis of web-based materials, international reports, Help the Hospices data and documentation.

3.1 GLOBAL ONLINE QUESTIONNAIRE

The online questionnaire was selected as an appropriate research method because, potentially, it could generate a global sample and provide access to respondents worldwide. This type of questionnaire would produce data from different international perspectives and supply retrospective data on WHPCD. In addition, WHPCD was organised mainly through web-based activities and therefore an online questionnaire was likely to be appropriate for the people who participated in the day. The software used for the questionnaire was PHP2

The questionnaire was designed to provide the opportunity for people who organised WHPCD events to record details about their activities, share their experiences and views, and also to offer their opinion about future WHPC days. The questionnaire was made available in five languages: English; Spanish; Chinese; Portuguese; French. These versions of the questionnaire were distributed alongside the English version (appendix A).

The sampling frame for the survey was a convenience sample, as opposed to a probability sample (random). In other words, the questionnaire was distributed through known international hospice and palliative care online networks rather than more widely circulated through, for example, general health care networks. The aim of the questionnaire was to generate 'indicative' and 'descriptive' data rather than large scale, probability-based data, suitable for complex statistical analysis. The questionnaire was disseminated through: posting the web-link address on appropriate web sites e.g. European Association for Palliative Care; email lists e.g. hospice information; and online newsletters e.g. International Association of Hospice and Palliative Care. For the full distributed list see appendix B. In total, there were 62 responses to the survey, in the

following languages: 50 English; 5 Spanish; 4 French; 2 Chinese; 1 Portuguese. The data was downloaded and analysed using both quantitative and qualitative techniques.

3.2 INTERVIEWS

The interviews with key people in global national associations of hospice and palliative care were conducted at a national associations of hospice and palliative care steering group meeting, organised by Help the Hospices, on November 2nd 2005 in Henley, Oxfordshire. The group had come together to discuss future development and strategy for the national associations. Interviews were conducted by Dr Liz McDermott after a long day of business and were kept to brief 15 minute time slots. A semi-structured interview schedule was used to guide the interview (appendix C). The interviews were digitally recorded and agreement was reached with interviewees that permission would be sought if any quotes were used in the final evaluation report. The interview recordings were down-loaded onto IOELC files and listened to by the researcher only. Due to time constraints the interviews were not transcribed. The interviews were analysed using a structured thematic framework which evolved from the evaluation research questions.

3.3. ANALYSIS OF OTHER DATA/DOCUMENTATION

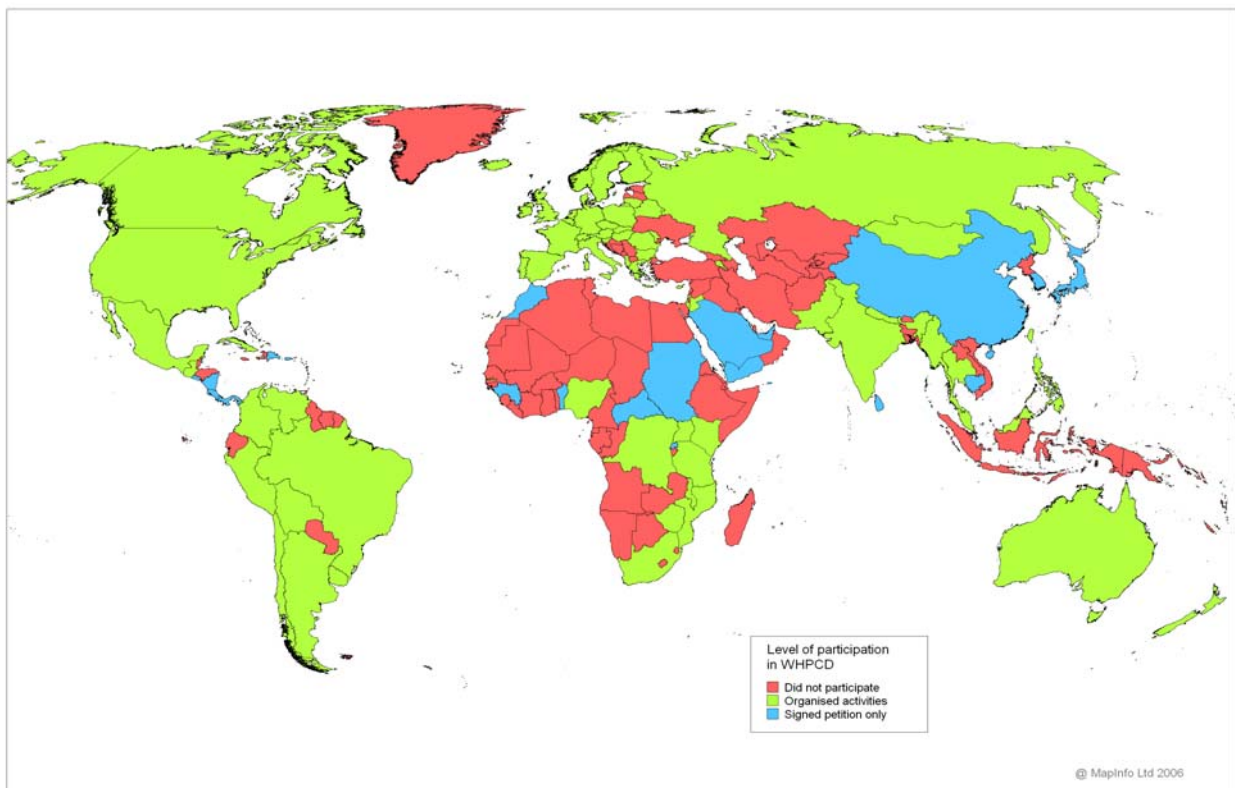
The online questionnaire and the interview data were supplemented by a range of other data which included photographs; feedback reports about activities; online newsletter reports; Open Society Institute grant reports, web-based materials, international reports; data collected by Help the Hospices, media reports and other documentation. All of the data were used to identify countries which had successfully organised for WHPCD.

4. MAPPING WHPCD ACTIVITIES

4.1 GLOBAL INVOLVEMENT

This section examines the global participation rates for WHPCD. It maps those countries which have organised events for WHPC Day, those that signed the petition only, and estimates the numbers of countries which were not involved. An analysis of the varied data sources available for the evaluation indicates that 74 countries took part in WHPCD by organizing activities. This figure is elevated to 112 when we include the 28 countries which signed the petition but did not, too our knowledge, organize events. This is an impressive participation rate and is illustrated in Figure 1.

Figure 1. Global participation in WHPCD 2005



It is difficult to state with any certainty the exact number of events which took place on WHPCD 2005, but we estimate these at around 1100. In addition there were 500 Voices for Hospices concerts in 60 countries. The registration of events on the WHPCD website captured a large number of activities but this data relied upon individuals recording their activities electronically. It is likely that many activities across the world were not registered (language, access to technology and resources being probable barriers); 41% of

respondents to the WHPCD online questionnaire stated they had not registered their events with the website. Also, registered events may not have taken place or the nature of the final event may have altered.

In an attempt to overcome the difficulty of accurately mapping a global event which is aiming for maximum participation, we have generated ‘continental snapshots’ of activity levels. The purpose of these are: to give an indication of the participation levels across a continents; to demonstrate the types of organized events which took place; and to provide an insight on the day from the people who participated.

4.2 CONTINENTAL ‘SNAPSHOTS’

4.2.1 Africa

Figure 2. Africa participation in WHPCD



Africa participation:	11 countries organised activities	6 signed the petition only	ESTIMATED: 40 did not participate
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Many countries in Africa did not participate in WHPCD, but those that did were very active and had some successful outcomes. Countries with active national associations of hospice and palliative care, for example Uganda and South Africa, had the highest levels of participation in the day. Across Africa, activities for the day were used as a focal point for advocacy, raising awareness, making new connections, and developing palliative care in small steps and large leaps.

A particularly successful event was the launch of the African Palliative Care Association and its website. The launch was organized from Uganda and involved extensive media coverage, a press conference, and a major launch-event attended by the Minister of Health for Uganda, the Irish Ambassador and representatives from all potentially active donors. The purpose of the launch was, according to Faith Mwangi-Powell, to state:

This is what we are doing, this is what we are hoping to do, this is where we are going, this is how we have spent your money ¹

As a result of the event, new relationships with NGOs have developed. In Nigeria, where palliative care is in the very early stages of development, the Palliative Care Initiative, Nigeria (PCIN) organized a press conference, a walk for palliative care and a public symposium. There was wide media coverage of the day and the Commissioner of Health for Oyo state took part in the walk. These activities were immensely successful, and their impact includes: increased awareness in the public; greater cooperation and coverage from the press; new links forged with palliative care groups and NGOs; a pledge to provide accommodation and facilities for hospice and palliative care in the University College Hospital; and the Oyo State government pledge to integrate palliative care services in the care of terminally ill people².

In South Africa, a number of hospices held events, concerts and celebrations and many of these involved children. For example, at the Waterberg Welfare Society, the staff cooked lunch for the members of the HIV & TB Support Groups who attend the hospice meetings on a regular basis³. The media coverage for the day included TV, radio and 53 newspaper articles on hospice activities. Liz Gwyther from the Hospice Palliative Care Association, South Africa estimates that up to 9 million people were reached through these different media.⁴

Another important key to participation in Africa was funding, and grants from the Open Society Institute (OSI) enabled some countries to organize activities. Table 1 shows those African countries that received OSI grants and the events that took place.

Table 1.⁵

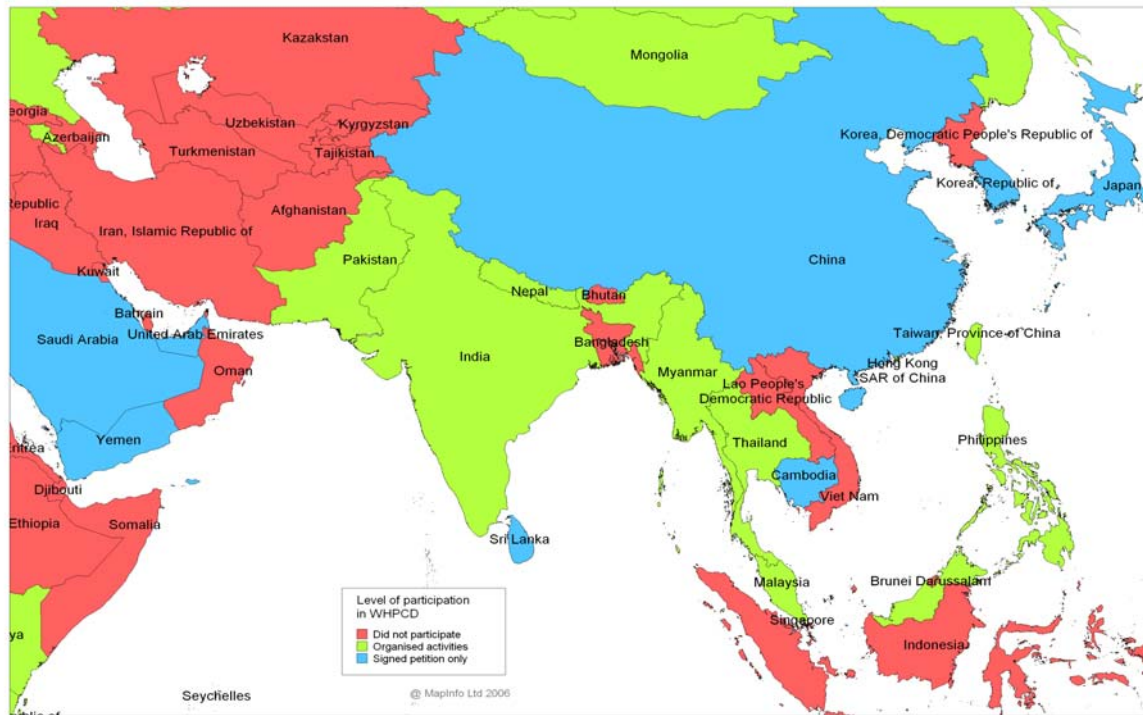
Country	Grant holder	Activity
Kenya	Eldoret Hospice	Run/walk marathon to raise public awareness about hospice services as well as funds
Tanzania	Ocean Road Cancer Institute	Palliative care and pain management sensitization forum for policy makers, health professionals, and the business community

	Selian Lutheran Hospital Hospice	Messiah Sing for Hospice fund raising concert, in which 11 choirs sang Handel's Messiah
Uganda	Hospice Africa Uganda	Voices for Hospices concert
Zimbabwe	Island Hospice Service	Leaflets describing and promoting hospice and palliative care services in Zimbabwe
Nigeria	Palliative Care Association	Nation-wide press conference to raise awareness of the need for hospice and palliative care services in Nigeria.
South Africa	Highway Hospice	Fund raising WHPCD Choir Festival to raise public awareness about hospice and palliative care, featuring the Drakenberg Boys' Choir and other professional choirs, community schools, and the Durban City Orchestra

African countries enthusiastically participated in the day but there were not many activities registered by African nations on the WHPCD website. In Malawi, for example, events were not reported on the website because of web-access problems⁶.

4.2.2 Asia

Figure 3. Asia participation in WHPCD



Asia Participation:	14 countries organised activities	8 signed the petition only	ESTIMATED: 28 did not participate
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WHPCD activity across Asia included countries with different levels of hospice and palliative care development. In India, a country containing one sixth of the world's population, a large number of events were organized in places where palliative care has been developing for the last 15 years. The Indian Association of Palliative Care supported WHPCD and its involvement alongside key palliative care activists, resulted in a high level of activity across the sub-continent. The Indian Association of Palliative Care chose to launch the online edition of the Indian Journal of Palliative Care on WHPCD.

A recent review of palliative care in India conducted by the International Observatory on End of Life Care has demonstrated that developments are uneven and concentrated more in the south of the country⁷. This was reflected in the pattern of activity for WHPCD, with most events occurring in south India. In northern Kerala, events were held in 80 different locations in the region and 43 of the 60 palliative care units in the network conducted awareness programs for the public through public meetings, the distribution of pamphlets and media work. The student initiative "Palliative Care in Campus" conducted displays, awareness meetings and distributed pamphlets in 26 college campuses. A major musical concert in Trichur raised about US\$ 5000⁸.

The Department of Pain and Palliative Medicine, Amrita Institute of Medical Sciences in Kochi, Kerala conducted competitions with: three city schools; Kudumbasree, a women-based poverty eradication programme; and medical students. In addition, the eleven Pain and Palliative Care units active in Ernakulam district organised a two-day 'All Kerala Workshop in Palliative Care' which had sessions on 'Home Care', 'Rehabilitation' and 'Palliation for HIV infected'. It was attended by doctors, nurses, social workers and volunteers interested in palliative care⁹.

A walk with nearly 1000 people was organized in the state of Karnataka which generated both TV and newspaper coverage. In Chennai, the Cancer Institute, Adyar (RCC) organised a marathon attended by more than 200 children from various schools. In combination with Jeevodaya Hospice's celebrations, TV, radio and newspaper coverage was generated. In Managalore, activities included an awareness program on 'total cancer care', a students' quiz, and the launch of a Home Care service⁹.

In northern India, a seminar was organized in Delhi and supported by the Ministry of Health & Family Welfare, the Government of India, and WHO. A souvenir journal was prepared by CanSupport with a message of support from the President of India. CanSupport also held a 'Voices for Hospices' concert¹⁰. In north east India, in Assam, the Guwahati Pain & Palliative Care Society organized a street procession, a public meeting, an evening concert, and held a debate on 'information about the cancer disease process should be withheld from patients?'. There was newspaper, radio and TV coverage of the events⁹.

In other countries of Asia, the enthusiasm and commitment for organizing events to celebrate the day were also evident. In Singapore, there was a week of activities which included: a memorial dinner; a series of professional lectures; public forums on palliative care; a large Voices for Hospices concert attended by the President of the Republic and the First Lady; and 150 cyclists participated in an 80km ride to celebrate the 20 year anniversary of the first hospice in Singapore¹¹. Other countries in the Asia Pacific Palliative Care Network (Malaysia, Hong Kong and Taiwan) held Voices for Hospices concerts with large video screens to show messages of greetings from around the region¹¹

Seventy people attended a tea party held for patients, care-givers and volunteers in Malaysia. The entertainment was provided by volunteer singers and musicians and a power point presentation of hospice friends in other places of Malaysia, China, Australia and Myanmar was presented¹². The Palliative Care Association, Kota Kinabalu Sabah, Malaysia organized a concert involving the Philharmonic orchestra, the St Francis Convent choir, ballet dancers, traditional songs, poetry and story telling. A map of the world was shown with all the countries taking part in the event highlighted¹².

In the Philippines, the Hospice and Family Care Foundation held a motorcade to start the day which had 15 cars adorned with streamers and balloons and was led by two trucks containing drummers, harpists and lyre players. An event was then held at the hospital

which was attended by 200 people including the Governor's Representative. In Jordan, a week of workshops and seminars was held¹³.

A grant from the Open Society Institute (OSI) facilitated the celebrations organized by the Mongolian Palliative Care Society with 5 hospices in Ulaanbaatar and 1 Hospice from Darhan city. Approximately 400 people attended a public celebration at the 'Freedom Square' with the Minister of Health, a WHO representative and District Governors. The event had TV and newspaper coverage¹⁴. In Myanmar, a celebration was attended by over 100 guests including three Ministers, representatives from the World Health Organization and embassy officials.

4.2.3 Europe

Figure 4. European participation in WHPCD



Europe participation:	33 countries organised activities	2 signed the petition only	ESTIMATED: 17 did not participate
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Europe had a high number of countries actively organising to celebrate WHPCD. These countries included those with established hospice and palliative care services such as the United Kingdom and the Netherlands, as well as countries with few hospice and palliative care services such as Romania, Moldova and Slovakia. The European Association for Palliative Care (EAPC) announced that Volume 19 of Palliative Medicine was available online free of charge until the end of January 2006 in recognition of WHPCD. Similar to other continents, those countries with active national associations of

hospice and palliative care were most likely to participate in the day; and small grants from the OSI made it possible for countries with few resources to organise events. Table 2 shows those countries which received OSI grants, along with their activities.

Table 2⁵ Countries which received OSI grants

Country	Institution	Activity
Albania	Korca Family Healthcare Organization	Palliative care and pain management training to regional doctors and nurses; follow-up meeting six months later
Armenia	Husaber Charitable Foundation	Conference and photography exhibition
	The Pain Control & Palliative Care Association	Develop a website; conduct a palliative care roundtable discussion with public health experts and government representatives
Bulgaria	The Medical College of Plovdiv	Write and publish information leaflets about palliative care
Czech Republic	Mobile Hospice Cesta Domu	Raise awareness about hospice and palliative care services; Voices for Hospice Concert; raise funds for the Cesta Domu Mobile Hospice
Hungary	Erzsebet Hospice	Raise awareness through an exhibition and children's art competition.
Lithuania	Palliative Medicine Association of Lithuania	Publish and distribute a book on the palliative care activities of the Palliative Medicine Association of Lithuania in celebration of it's tenth anniversary
Moldova	Charity Foundation for Public Health, Angelus Hospice	Inscribe and install donation boxes in five public locations in Chisinau to raise awareness and funds for Angelus Hospice
Poland	Hospice Foundation	National news conference, regional meetings with media.
Romania	Emanuel Hospice	Palliative care seminar for local health care professionals; develop/distribute a leaflet on palliative care; create a promotional hospice video; "Voices for Hospices" concert.
	Hospice Casa Speranti	Identify and use local and national media to raise awareness; hold the fifth "Voices for Hospices" concert.
Russia	Inter-regional Palliative Care Association	Press conference; concert to raise awareness of palliative care in Russia.
Slovakia	Dignity	Organize a palliative care seminar for health care professionals, policy makers, business groups, and the public, and hold a "Voices for Hospice" concert
Slovenia	Palliative Care Development Institute	News conference where all Slovenia's palliative care institutions presented;

		photography exhibit; publish a series of articles; develop a leaflet
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In countries with newly developing hospice and palliative care services, activities were focused upon raising awareness through events and media work, fund-raising and attempting to influence state officials and national policy.

In Bulgaria the Medical College in Plovdiv widely disseminated the WHPCD materials and set up four public information desks in the busiest parts of the town centre. They also had media coverage on national television and in a number of newspapers¹⁵. Slovenia had a large news conference attended by over 300 people, a photography exhibition and collaborated with a national newspaper to produce articles on palliative care. In Moldova, there were two TV programme debates on palliative care, a Voices for Hospice concert and fund-raising activities such as 'buy-a-brick', and selling a calendar made by local school children¹⁶. Poland and Belarus both held week long national campaigns culminating in WHPCD and Voices for Hospices concerts⁶.

The Emanuel Hospice in Oradea, Romania held a seminar for local professionals, produced for the first time a brochure and video on their services and held a singing event which raised \$700¹⁷. Activities in Lithuania included: a conference with 500 participants; a special meeting of the Palliative Medicine Association of Lithuania with representatives from Parliament, Government, Municipality, and the Archbishop; at the Opera House of Kaunas, "La Traviata" was performed and dedicated to WHPCD; members of the Palliative Medicine Association of Lithuania talked on the radio, and TV and articles about palliative care were published in the media; a 10 year history of the Palliative Medicine Association in Lithuania was published¹⁸.

A press conference was held in Greece which involved the Greek Minister of Health. An open letter regarding palliative care was published and more than 140 personalities coming from the political, artistic, scientific and intellectual Greek society responded. Media coverage included TV, radio and newspaper. More than 450 people attended the 7th Panhellenic Congress on Regional Anaesthesia, Pain Therapy & Palliative Care. An exhibition of photography entitled "Palliative Care" took place and a patient's booklet was distributed in hospitals.

Across the United Kingdom, the tradition and commitment of people involved in hospice and palliative care was demonstrated through an impressive array of organized activities and Voices for Hospices concerts. A WHPCD launch event was attended by HRH the Princess Royal, 200 Voices for Hospices concerts were held and a further 200 concerts, sponsored by Glaxo Smith Kline, were performed by Music in Hospitals. A 6th form schools pack was distributed to all secondary schools and a specially written song by service user Maxi Edgington and Billy Bragg was released. Other activities included: open days; candlelit ceremonies; local schools sponsoring a hospice nurse; tea parties; a coffee morning for Hospice Care Kenya; shopping centre collections; and social evenings. A day care walk involving approximately 9 hospices in the UK is described by a UK respondent to the online questionnaire:

I arranged a walk for our day hospice patients, to raise awareness of palliative day care. Each days patients were invited to take part when they attended day hospice in the week leading up to 8th October. Wheelchair patients were pushed by members of staff and volunteers. Some patients requested sponsor forms, although this wasn't the initial intention. Our theme for the day was "chariots of fire". We played the theme tune prior to setting off. Those in wheelchairs had posters of "chariots of fire", on the back of their wheelchairs. Those who wanted to, waved posters saying, "we love day hospice". We walked around the gardens of the children's hospice. There was a real buzz and the whole event was enjoyed by all the patients, staff and volunteers involved. Photographs were taken and displayed in day hospice. We raised £1,118 for the hospice!¹²

Media coverage in the UK was particularly strong with extensive national TV, radio, and newspaper involvement and the BBC World Service (radio)

4.2.4 North, Central and South America

Figure 5. Americas participation in WHPCD



- North and Central America

North and Central America participation	5 countries organised events	10 signed the petition only	ESTIMATED: 16 countries did not participate
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In North and Central America, countries which have well developed hospice and palliative care services organised events as did some countries with very little palliative care. In Canada, the province of Ontario announced \$115 million for end of life care on WHPCD. The National Hospice and Palliative Care Organisation, USA, in partnership with the Foundation for Hospices in Sub-Saharan Africa hosted a “Soul of Africa” celebration. This was a three-hour, multi-cultural event which brought together more than 15 faith communities throughout the Washington, DC area — to celebrate victories in the battle against AIDS as well as highlight those areas of Sub-Saharan Africa which are hardest hit by the pandemic disease¹⁹.

The International Association of Hospice and Palliative Care (IAHPC) provided a small grant to facilitate activities in Mexico which included: a new website for the palliative care organization; a number of conferences; radio programmes; a TV documentary; newspaper articles; a palliative care course; and a symposium with 80 people, a musical presentation and stories on palliative care in children¹⁶. In Cuba, 400 professionals attended a week of educational activities and the National Opera and a Ballet Company dedicated their programme to WHPCD²⁰.

- South America

South American participation	8 countries organised events	0 signed the petition only	8 countries did not participate
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In South America, there was a great deal of activity for WHPCD. The majority of the countries involved are at the early stages of developing hospice and palliative care services and in many cases their involvement was facilitated by small grants from the IAHPC (see table 3 below), strong leadership from the Latin American Association, the IAHPC and some extremely committed individuals such as Liliana De Lima, Roberto Wenk and Cisio Brando. An important feature of the participation was IAHPC’s willingness to send out updates and reminders in Spanish to the Latin American Association encouraging them to write letters to governments and organise activities⁶.

In Argentina, there were radio and TV interviews, a TV film was made, and a concert and inauguration ceremony took place¹⁶. World Hospice and Palliative Care activities were carried out in Brazil, which does not have an active national program in palliative care. In Sao Paulo in the south east there was an open lecture to the community, titled “Who needs palliative care?” In the city of Goiania, in the central region of Brazil, there was a lecture for health professionals regarding the importance of palliative care. In the north

west region of Brazil, in the city of Fortaleza, a Women's Network Volunteers Training Program was scheduled with a positive impact on the local media and politicians ¹⁶.

WHPCD events were organized in six cities across Colombia: Bogotá, Cali, Medellín, Barranquilla, Cartagena and Bucaramanga. In each, there were academic seminars and cultural events. The seminars attracted between 150 and 300 persons each, with the attendance of doctors, nurses, sociologists, social workers, students, patients, ethics committees and the general community. In Bogotá the National Secretary of Health participated. A children's art contest for the National Poster Theme and WHPCD among children with HIV and Cancer was organised. There were more than 100 drawings from children in Bogotá, Cali and Medellín and funds were raised from a private foundation for the prizes. In addition, movie forums, art exhibitions, painting contests, writing contests and musical sessions were organised¹⁶.

After almost a year of work and proposals for WHPCD, Guatemala celebrated the establishment of the country's first Palliative Care Unit in the Cancer Hospital INCAN¹⁶. A celebratory event was also organized in Uruguay with speeches, music and dance organized by the Sociedad Uruguaya de Medicina y Cuidados Paliativos, and the support and help of the volunteers group "Damas Rosadas" from the Hospital Clinicas. The event was attended by the interior Minister of Health, the Director of the National Cancer Control Program and the President of the Sociedad Uruguaya de Medicina y Cuidados Paliativos¹⁶.

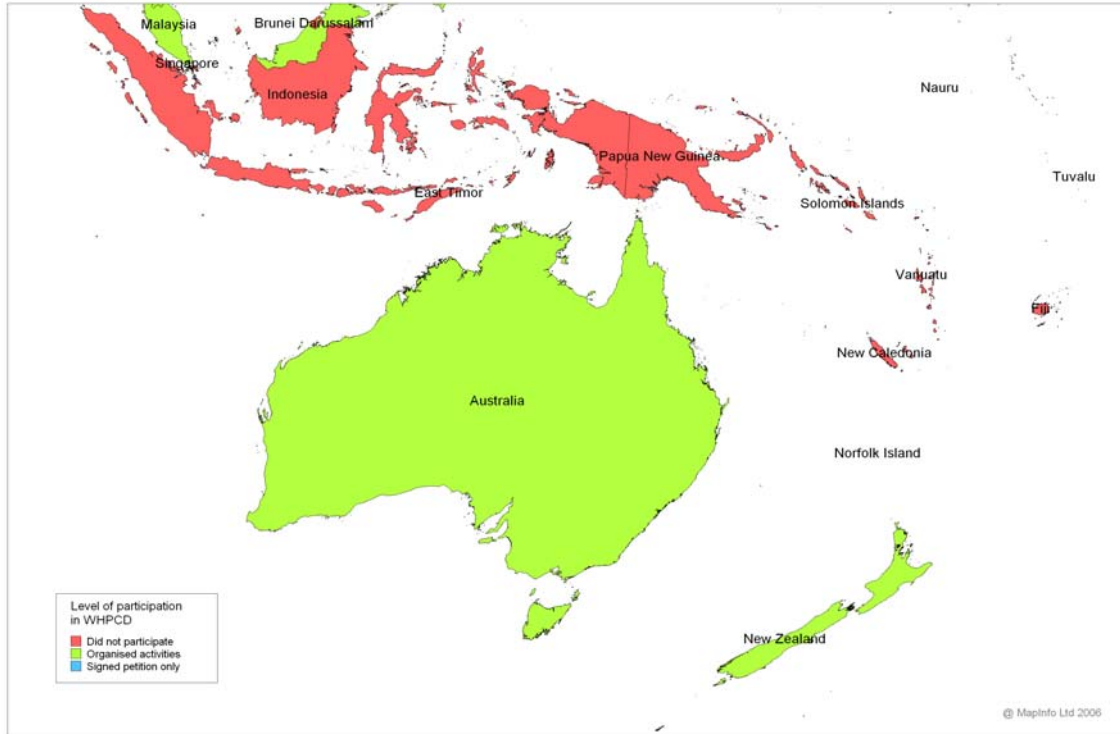
In Venezuela, the Foundation for the Development, Support and Research for Palliative Care (Fundación Desarrollo, Apoyo e investigación a los cuidados Paliativos – FUNDAICP) coordinated the media activities and a concert to celebrate WHPCD¹⁶.

Table 3.

South American countries receiving grants from the IAHPC
Argentina, Brazil, Colombia, Guatemala, Uruguay, Venezuela

4.2.5 Oceania

Figure 6. Oceania participation in WHPCD



Oceania participation	2 countries organised events	2 signed the petition only	ESTIMATED: 27 countries did not participate
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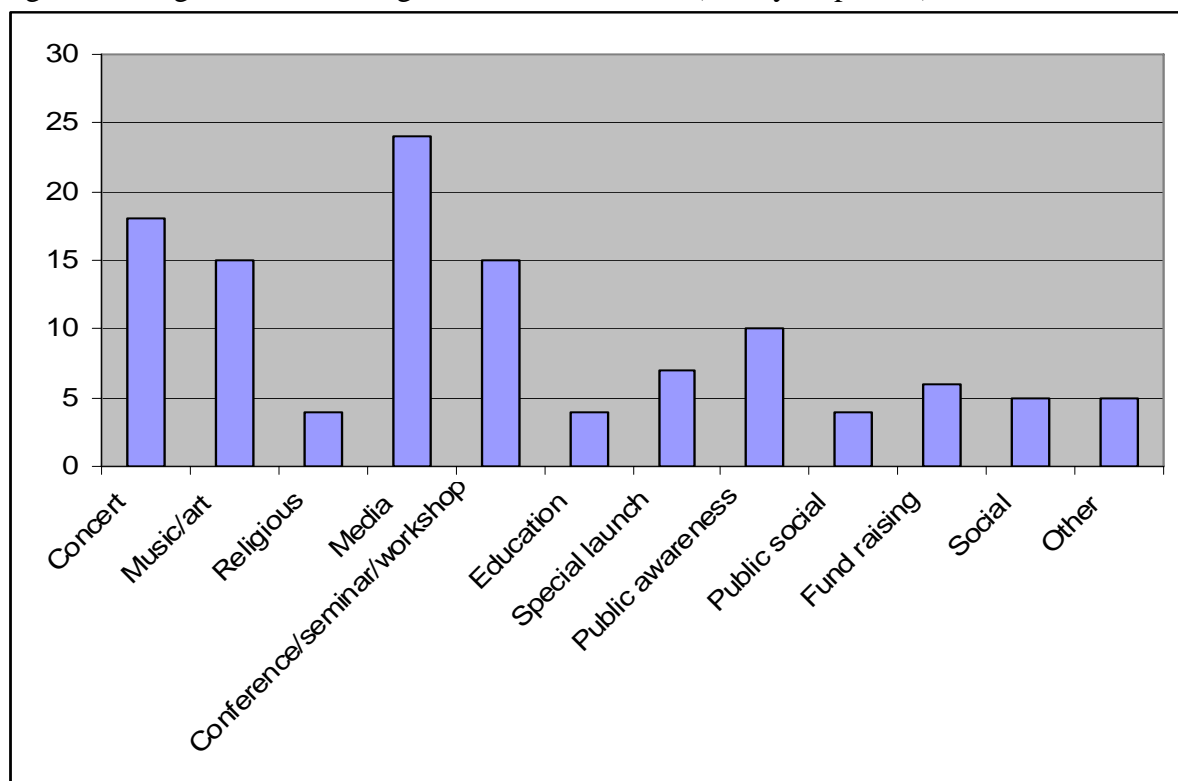
In Oceania, events were organised in Australia and New Zealand but the level of activity was lower than expected. This may have occurred because the Executive Director of Palliative Care Australia who was actively involved in the WHPCD steering group left the organisation in December 2004. There was not a re- appointment until mid 2005 and as a result, there was less communication to Australian and New Zealand Hospices⁶. David Currow of Palliative Care Australia suggests there may be a level of fatigue around organizing in countries which have an annual national palliative care week.

In New Zealand, 100 people in a Surf Lifesaving Club, the Hibiscus, with a coast Choir sang sea shanties and other songs together with performances from a poet, soloist and guitarist. The theme was sea/water/distance. The event raised about \$700 from a bucket collection.

4.3 GLOBAL RANGE OF ACTIVITIES

The analysis of the data show the large number of events organised worldwide for WHPCD, as well as an impressive range of event type. Organised events and activities were one of the key ways in which individuals and organisations raised awareness about hospice and palliative care, raised funds and in many cases made steps towards increasing the availability of palliative care. In Figure 7, data from the online questionnaire reveals the range of WHPCD activities. The most popular type of activities were music and art events; those involving the media; and conference/seminar/workshops

Figure 7. Range of activities organised for WHPCD¹² (survey responses)



It is difficult to represent fully the range and breath of activities and events which took place for the day but the following extracts from the online questionnaire illustrate the creativity and enthusiasm of people across the globe:

A series of colour posters were produced and distributed to the local library network in Ireland. These libraries had already been contacted with information packs and encouraged to organise exhibitions on the hospice movement and services to mark World Hospice and Palliative Care Day. Information packs were prepared for each library. A fundraising Nearest-The-Pin golf event was organised to mark the day and about 5,000 golfers in 114 golf clubs took part. Choral groups were contacted and encouraged to take part in the "Voices For

Hospice" global singing event. A programme of talks on the theme "Hospice, Hospitals and Information" for information professionals was organised on the eve of World Hospice and Palliative Care day. A statement on hospice services in Ireland was distributed to the media on the day (Ireland).

I held an autumn fair at a local hotel. The hotel provided the venue and food and drinks free. Many colleagues and friends volunteered their free time and there were various stalls including handicrafts, cakes, books, faux bijoux and kids corner. We raised £2,200 for palliative home care services provided by the Cyprus association of cancer patients and friends (Cyprus).

In the evening a concert was held which featured a talented singer of Indian music, Zila Khan. Saeed Naqvi, a well known journalist, recited Urdu poetry around the theme of 'Zindagi' ("Life"). Mr. Khushwant Singh, the celebrated writer, translated the poem, written by Iqbal, into English especially for the occasion. It was distributed to all those present so that they could participate in the recitation. The brother of a patient looked after by CanSupport's home care team lit the traditional lamp (India).

We opened in prayer and had a bible reading then we listened to a speaker from Ekurhuleni Municipality, one of our patients in our care spoke about her experiences. Then a youngster from the visitors spoke to us from the heart with regards to HIV/AIDS. We lit candles for those who have been infected or affected by HIV/AIDS. Shared in a meal together and then closed with a prayer (South Africa).

Global participation key points:

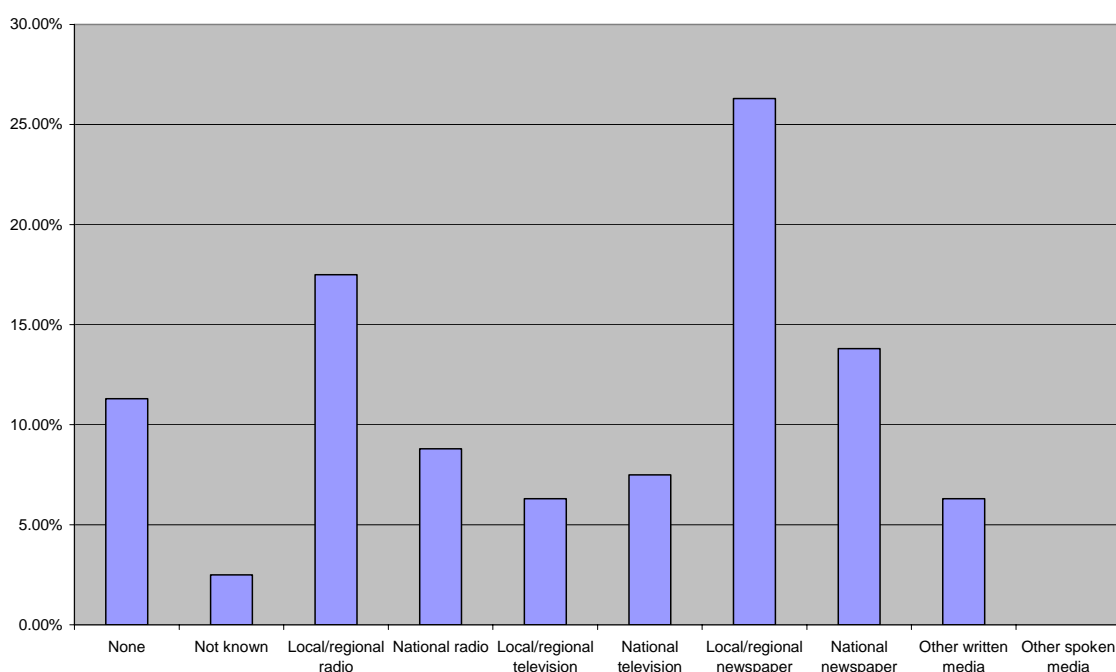
- Large numbers of activities were organised for WHPCD
- There was an extraordinary range of events undertaken
- Activity was facilitated in countries with active national associations
- Grant funding provided the means for many low-resource countries to participate
- Low levels of participation in developed countries may be due to World Day or palliative care 'fatigue'

5. RAISING AWARENESS, FUNDS AND AVAILABILITY

5.1 MEDIA

Evidence suggests that media activities were the focus of a large proportion of countries that were active in WHPCD. Results from the online questionnaire showed that only 11% of respondents indicated that their activities did not receive any media attention, with a further 2.5% stating they ‘did not know’. Figure 8 illustrates the types of media involvement with WHPCD events¹²

Figure 8. Types of media coverage for WHPCD activities (survey responses)



Even in countries at a very early stage of palliative care development, media activity was viewed as important, for example in Mongolia, events featured in both TV and newspapers¹⁴. In many cases media coverage of WHPCD events in countries with little palliative care provision were directly facilitated by grants from the OSI or IAHP. In Slovenia, Russia and Poland funds were granted to hold press conferences⁵. Slovenia's news conference was attended by over 300 people and initiated a range of collaborations with the media including: national newspaper articles on palliative care; a national TV program held a special round table; radio interviews; newspapers and journals reporting and special feature articles¹⁵

5.1.1.Examples of media involvement in WHPCD

India was particularly successful at involving the media. In northern Kerala, events were covered by local radio, local TV, and regional and national newspapers⁸. In Chennai, WHPCD was reported by: *The Hindu* (under the heading 'Hospices last hope for terminally ill - Palliative care eludes a majority of patients'); *The New Indian Express* (under the heading 'Easing pain through counselling and love'); and in a Tamil paper *Dhinamani*. In Managalore, events were covered by; *The Hindu* in the Sunday paper; the *Sun News* TV channel; the *Telugu Jyothi* newspaper in Andhra Pradesh; and in the local paper *Adyar Times*⁹. In Guwahati, Assam, the popular English daily *The Assam Tribune* published the article “Relevance of Palliative Care”, and the all India Radio & local TV channel aired an interview with Dinesh Goswami, the President of the Indian Association of Palliative Care⁹.

There was substantial media coverage of WHPCD in South America. In Argentina, the presence of WHPCD on radio and TV was increased by the support of a well known influential journalist. A TV film was also made of a foundation's home, where it is planned to organize a day hospice. In Colombia, events were widely covered by the local, regional and national media through newspapers, radio and television^{16,21}. Similarly in Venezuela there was a week of interviews on the radio, TV, and articles in newspapers with large circulations¹⁶.

In Moldova, a live television programme featured an 'on-air' debate on palliative care¹⁶. Bulgaria had national TV coverage as well as a range of newspaper articles on the day¹⁵. Members of the Palliative Medicine Association of Lithuania talked on the radio and TV, and articles about palliative care were published in the media¹⁸. There was also local TV, radio and newspaper reports in Oradea, Romania¹⁷.

The Palliative Care Initiative, Nigeria (PCIN), organised a press conference which was attended by 16 different media organisations. PCIN reported not only excellent media coverage of WHPCD but the development and strengthening of media relations². Liz Gwyther, from the Hospice and Palliative Care Association, South Africa suggests that the success of media coverage in South Africa (estimated to have reached 9 million people) was partly due to the credibility of WHPCD being a global event but also she suggests:

There is a lot of sympathy for hospice, a lot of acknowledgement of the work that hospice does...we've been working with them for many years now, so we've developed a relationship with them⁴.

Several countries employed strategies to increase media coverage of WHPCD. The IAHPC identified a key person in some countries and asked them to locate suitable media contacts and work with them. In Colombia, a media expert was employed to organize all media coverage. Similarly in the UK, a designated PR consultant planned and organized the media strategy for WHPCD, and consequently the UK had an extremely successful

WHPCD media campaign including BBC TV Live Breakfast, BBC News 24 and BBC Radio 4.

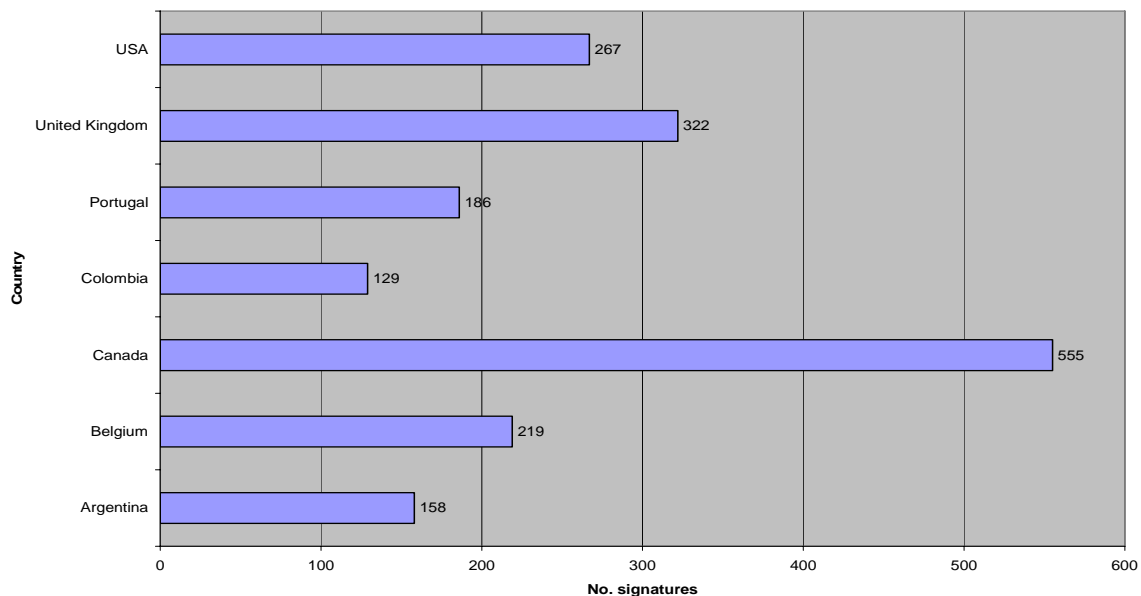
Media key points:

- Media involvement was a central feature of WHPCD activities for the majority of countries
- Successful media campaigns were characterised by: individual media expertise; pre-existing relations with media; legitimacy of a global event; designating individual responsibility for media collaboration; planned media strategy; time; funding (e.g. OSI & IAHPG grants) and resources
- Difficulties were experienced in stimulating media interest in non-English speaking countries which had English only versions of the WHPCD materials
- Media materials for future WHPCD could include useful examples of successful media campaigns in different international settings
- This is a key area for development

5.2 PETITION

The analysis of the available data suggests that the WHPCD petition was an extremely successful tool for raising awareness, availability and funds. Over 5500 people have now signed the petition; 2914 online, and 2650 on hard copies²². These signatures have been sent to national associations and hospice services to use as an advocacy tool with governments and policy makers. A breakdown of the online figures highlight the countries which were most active around the petition. Countries with over 100 signatures are represented in figure 9²³.

Figure 9. Countries with more than 100 petition signatures



The high numbers of signatories in Latin American countries (Argentina 158; Bolivia 4; Brazil 52; Chile 10; Colombia 129; Uruguay 30; Venezuela 27) are a result of the announcement that the petition could be signed in Spanish. The following comments were written on signing the petition online and demonstrate the strength of feeling from signatories worldwide²³:

I am a Hospice volunteer who firmly believes everyone has the right to receive the compassionate care provided by Hospice and Palliative Care. Wish it had been available for my parents thru their prolonged and terminal illnesses and for support of us the children and caregivers (Argentina).

People should have the right to die pain free and with dignity, in the comfort of their own home or in hospice as per their choice (Belgium).

I am happy to have the opportunity to sign this petition together with other people. Thank you for your advocacy for hospice care (Australia).

The online questionnaire reveals that 42% of respondents used the petition in their activities and described a variety of ways in which the petition was utilised on WHPCD. For example in India, the United Kingdom and Switzerland, signatures were actively sought from the public, palliative care staff, volunteers and supporters at various events. The petition was read at a conference and used for media work in Slovenia and Malaysia, and in Greece it was distributed to 'personalities'. A common tactic was to present the petition to a state or government official at a WHPCD event:

We had a school student read it out to the gathering. We all lit candles and held hands as the petition was read out. We later gave a copy of the petition to the government official present to pursue on our behalf. We have subsequently forwarded copies to the national government departments (online questionnaire, Kenya).

The petition was read by the MC while the guest of honour a minister declared the event open by lighting a candle in memory of all patients that we have looked after (online questionnaire, Malaysia).

We presented the declaration of Korea and we explained that in addition to our active participation in Seoul we signed the "World day petition" (online questionnaire, Israel).

Petition key points:

- The petition was a well utilized tool on WHPCD
- The petition was available electronically and as hard copy
- The petition needs to be available in different languages

5.3 MESSAGES OF SUPPORT AND OTHER WHPCD MATERIALS

Messages of support were received from a broad range of organisations and individuals in a number of countries. These supporting comments were sent from governments, patients, media, schools, church leaders, dignitaries, the public, and palliative care organisations. Only 33.3% of respondents to the online questionnaire indicated they had received messages of support. The message of support received from Archbishop Desmond Tutu was utilized in the majority of countries who participated.

The WHPCD logo was used successfully throughout the world and adapted for a variety of means such as t-shirts, poster and banners. There are some accounts of using the *Suffering at the End of Life – The State of the World* report when lobbying governments and state officials. The 'Letters to Governments' does not seem to have been widely used, 83.3% of respondents to the online questionnaire said they had not used the document. We have no data on the WHPCD online game.

5.4 STATEMENTS TO GOVERNMENTS/POLICY MAKERS

Influencing government and policy was an important focus for a significant proportion of the activity organised for WHPCD. The data indicates that in the majority of countries, state officials and health ministers were involved in the celebrations. The level of involvement of officials in these activities varied and included: official attendance at Voices for Hospices concerts (e.g. Singapore); actively debating in the media (e.g. Moldova); participating in events (e.g. walk in Nigeria); collaborating to develop hospice and palliative care policy (e.g. Romania, Colombia, Uruguay).

Although only 28.9% of the questionnaire respondents indicated they had presented statements to government and state officials, other evidence suggests that WHPCD presented an ideal opportunity for advocacy work. In most countries, regardless of the level palliative care development, the legitimacy of a global palliative care event provided palliative care activists with the opportunity to exert extra pressure on their governments and policy makers. The following extracts from the online questionnaire describe why officials were approached and some of the resulting outcomes¹².

Hospice and Palliative Care needs more financial support from the government. It is nice to have many volunteers, but it is not enough. Hospice and Palliative Care should be a part of the regular health care system in Austria. Response from the minister of health: We do what we can! (Austria)

"Letter to governments" was used and specific argumentation of Slovene problems and needed solution in the development of palliative care: call for responsible actions in order to implement organized palliative care in Slovene health care system, governmental financial support for proposed pilot model of implementation of clinical pathways in health care system. Minister approved this project. (Slovenia)

We asked the regional Minister of Health to make pressure on the national minister of Public Health to push the dossier concerning PC specialist nurses the answer was to address the same request to another minister in charge of education for French speaking continuous education for nurses, this is going on. (Belgium)

We demanded more government support for palliative care, in terms of funding, medical facilities and drugs. We also demanded tax free passage for drugs and other donations to the palliative care institutes. The officials present were very supportive of the issues and promised to take them up with the national departments of government. One government officer present accepted to join the hospice board in an ex-officio capacity to assist us to push for gains with the government. (Kenya)

We present our proposition to development of palliative care area in Israel and also our proposal about the specialty or subspecialty program. We didn't receive yet any response (Israel)

'President George Bush - unable to commit at that time. He was presented with the unifying statement and language to encourage palliative care. President Bill Clinton - his office applauded our efforts and wanted to support the event, but in view of the hurricanes and global disasters, he was unable to get back to us in time, but would be interested in the event in the future. (USA)

As these extracts reveal, approaching government and state officials on WHPCD had mixed results. Perhaps the most important aspect of this work is that WHPCD provided an opportunity to initiate, or further develop, a dialogue with the authorities about hospice and palliative care.

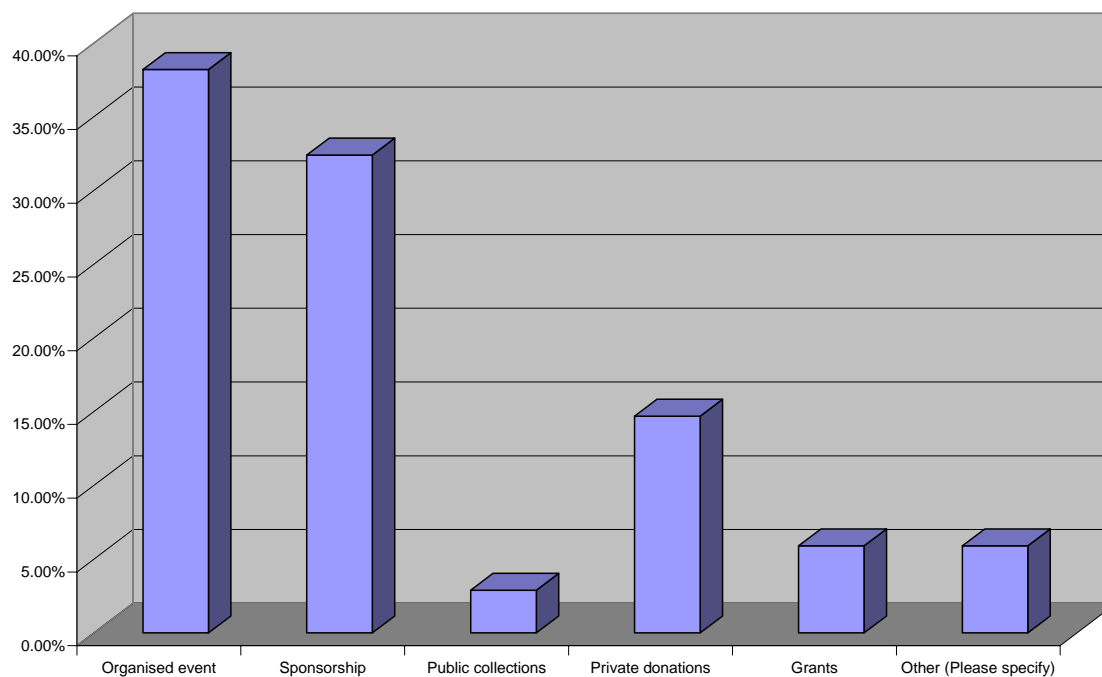
Statements to governments/policy makers key points:

- This was an important focus of WHPCD activity
- New channels of communication with government and state officials were initiated and developed
- The global nature of WHPCD enabled extra pressure to be exerted on authorities
- Advocacy material should remain central to WHPCD
- Specific material may not be appropriate in some countries e.g. only 16.2% of questionnaire respondents used the 'Letter to Governments'
- Experiences of success and failure could be usefully shared e.g. 'strategy and tactics'

5.5 FUND RAISING

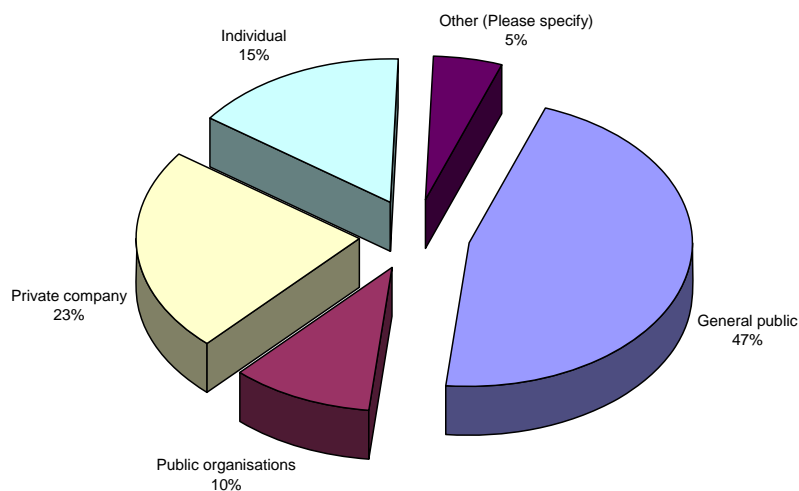
Fund raising was an integral part of WHPCD activities across the globe. In some cases generating income was the main focus of an activity, for example the 'Soul of Africa' event in the USA which was collecting funds for hospice and palliative care in Africa. The majority of events combined fund raising with celebrations, raising awareness and advocacy work. Figure 10 shows how funds were raised by respondents to the online questionnaire.

Figure 10 How funds were raised for WHPCD¹²



We do not have the data to estimate the *amount* of funds raised by WHPCD activities but Figure 11. illustrates the different *sources* of funds.

Figure 11. Sources of funds



Some examples of fund-raising include: £1,118p raised by St Oswald's Hospice, UK through a sponsored walk with 50-100 participants; US\$5000 in Argentina through music

and art events, a conference and a concert, attended by 100-200 people; 7000 people attended a concert in Mexico which raised 31,500 pesos; in Ireland 70,000 euros was raised through various events including a golf competition. Eldoret Hospice in Kenya organised a sponsored run with between 50 -100 people; it raised US\$ 5555 which was donated from individuals, public organisations, private companies and the general public¹². The event is described in the following extract:

We organized a charity run, with two categories, one for the junior and fun runners, and the other for professional athletes. The run spanned the town and gathered a lot of publicity. The turn out was very large and impressive. At the end of the marathon, we had performances that included skits on the effectiveness of hospice care, and we also had a few songs. The event was an outright success¹².

Fund raising key points

- Fund raising was a central feature of WHPCD activities
- The data is not available to estimate the amount of funds raised on WHPCD
- The Voices for Hospices evaluation process will provide figures of funds raised from the concerts
- Funds were raised from a variety of sources including the general public, private companies, public organisations and individuals

6. IMPACT – “What is this sunflower thing?”

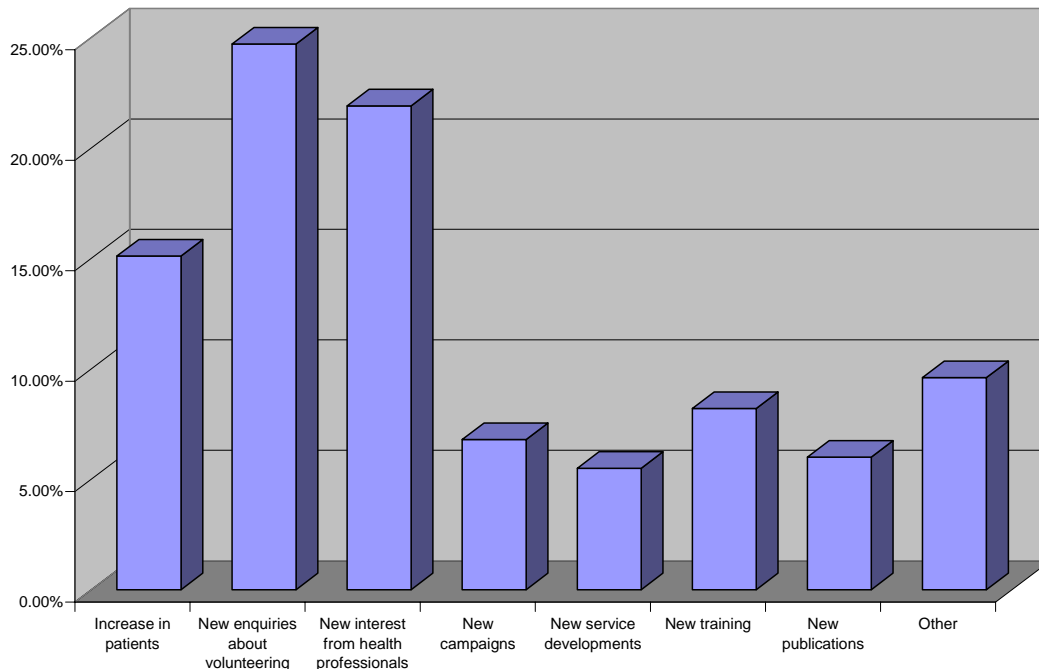
Mostly we impacted on people’s awareness...people kept asking ‘what is this sunflower thing?’ – Faith Mwangi-Powell, Uganda¹

Like ripples in a pond we believe this weekend will have far reaching consequences, beyond those whom have had direct contact with us or read an article about us. (Oradea, Romania)¹⁷

Because of the global scale of the event and its disparate character, it is difficult to measure accurately the impact of WHPCD on raising awareness of hospice and palliative care, on raising funds and on increasing availability of services. Through the evaluation process, there is however no doubt that the data collected demonstrate the significant impact of the day and some substantial outcomes.

The impact of WHPCD activities was achieved in many different ways. Figure 12 illustrates the ways in which respondents to the online questionnaire believed WHPCD had influenced palliative care in their locations. The most common effects of WHPCD were an increase in patients, new enquires about volunteering and new interest from health professionals

Figure 12. Impact of WHPCD on palliative care developments



The impact of WHPCD can be grouped into five broad categories:

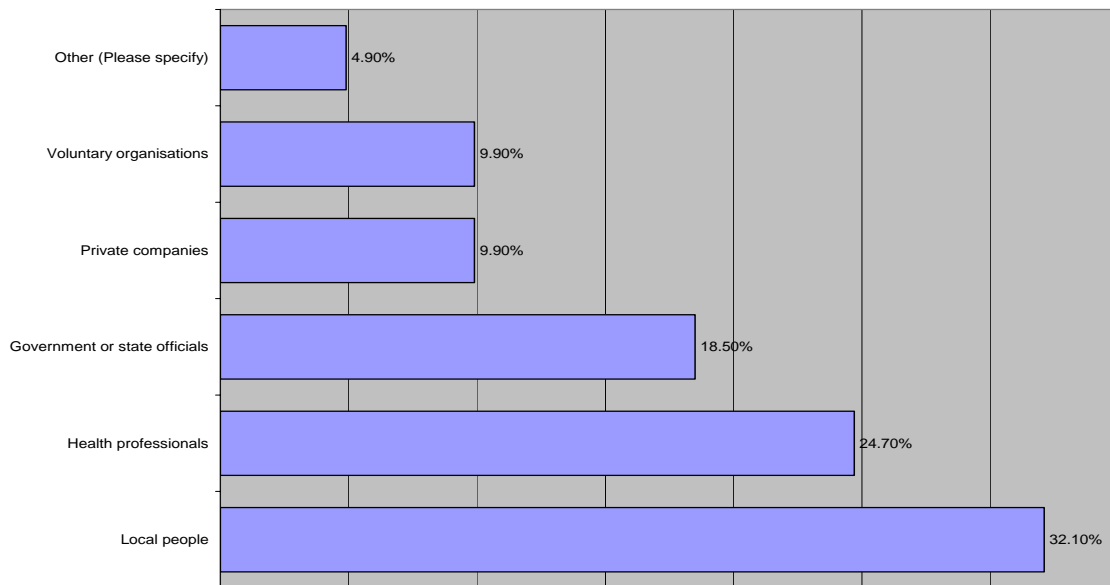
- Awareness
- Availability

- Funding
- Advocacy
- Development

6.1 Awareness

There is a great deal of evidence which demonstrates that WHPCD has increased the awareness of the need for hospice and palliative care around the world. Data from the online questionnaire shows that, in the view of our respondents, WHPCD had the desired effect: 87.2% believed their WHPCD activities had increased awareness of the need for hospice and palliative care. Respondents stated that the awareness and understanding of hospice and palliative care was increased in the general public, among state and health officials, professionals and businesses (Figure 13)

Figure 13. Groups with increased awareness of palliative care as a result of WHPCD activities¹²



Further evidence of increasing awareness is provided by the worldwide media coverage of WHPCD in most of the 74 participating countries. In Uganda, where the African Palliative Care Association was launched, a concerted media campaign culminated in widespread interest in hospice and palliative care day and new links being forged with NGOs¹. Likewise, Dr Císio Brandao who organised events in Brazil described WHPCD as:

a great and significant day in the history of palliative care in Brazil, and its consequences, keeps echoing on the media, medical magazines, journals, and newspapers as well. We are proud to have contributed with the main aim of the world celebration which was to raise awareness of the need for hospice and

palliative care across the world... This day, definitively changed the palliative care view in this huge continental country. There remains much work to be done in ensuring adequate professional training and access to palliative care in Brazil¹⁶.

Another way to verify an increase in awareness of hospice and palliative care is through a rise in demand for services. For example, in Moldova, after a live TV programme with an 'on-air' debate about palliative care, the number of telephone calls greatly increased to Hospice Angelus¹⁶. Edenvale Care Centre in South Africa had a similar experience¹². In Oradea, Romania, local media reports about the hospice resulted in a substantial increase in referrals from doctors, patients and family members. The hospice states:

While this is a positive thing, that we are gaining wider recognition, it has put added pressure on our small overstretched team and unfortunately we do not have the capacity to meet the extra demand at our present staffing levels¹⁷

6.2 Availability

The online questionnaire shows 36.1% of respondents stated that their activities had increased the availability of hospice and palliative care. This is a significant figure and is substantiated by reports on new service developments from countries around the world. In the Philippines, a Government representative attending a WHPCD event pledged designated funds for palliative care from the state and charities¹⁶.

In Nigeria, the PCIN reported that its WHPCD activities had elicited a pledge to provide accommodation and facilities for hospice and palliative care in the University College Hospital, and an Oyo State government promise to integrate palliative care services in the care of terminally ill people². In Hungary, eight new hospice services were incorporated into the National Health Insurance Fund¹².

After almost a year of work and proposals on WHPCD, Guatemala celebrated the establishment of the country's first Palliative Care Unit in the Cancer Hospital INCAN¹⁶. In Managalore, India a new home care service was launched⁹. After some concerted lobbying of government and health officials in Romania, a new hospital based palliative care unit was set up in the north of the country.

Many respondents to the online questionnaire believed that by making individuals and local populations aware of where they can access hospice and palliative care they, therefore, made it more widely available¹².

6.3 Funding

Funds were raised to support hospice and palliative care across the world. The evaluation for Voices for Hospices 2005 will provide details of the amount raised from these concerts but the data is not available to approximate the total figure raised for hospice and palliative care across the world. Generally, concerts raised the largest amounts of funds, for example, in Oradea, Romania US\$ 700 was raised from a concert, and in

Trichur, India US\$5000 was raised. In some countries WHPCD was used to make key announcements on policy and financing issues. Notable among these was the province of Ontario in Canada which announced \$115 million to end of life care.

6.4 Advocacy

In many countries such as Slovenia, Austria, the Philippines and Lithuania, meeting and liaising with government and health officials through WHPCD led to the establishment of a new channel of communication through which hospice and palliative care can be developed in the future.

Opinion from the online questionnaire shows that WHPCD had impacted on state and government understanding of the need for palliative care (47.7%) and this had influenced national and health care programmes and policies (55.8%). The 5500 signatories to the WHPCD petition is further evidence of the importance of advocacy to the development of hospice and palliative care.

Evidence from Romania and Colombia shows that WHPCD helped bring to fruition work which had been on-going for a number of years. In an interview with Liliana DeLima (IAHPC) she explained that in Bogotá the National Secretary of Health participated in a WHPCD seminar and as a result, some important steps were taken towards the elimination of regulatory barriers in the use and prescription of opioids. The validity of a prescription for potent opioids has now been extended from 10 to 30 days. They are also working towards the inclusion of different opioids in the health system so they are provided directly to public hospitals without having to go through the administrative offices at the regional governments. In addition, the local secretary of health and two senators participated in the meeting in Cali and several outcomes resulted from their participation including a program to establish palliative care as part of the network in the local health care system^{16,21}. Asked if WHPCD had been a success, Liliana DeLima replied:

Yes, definitely, I may be biased...it was a great initiative, I see it as a way to open doors because it was not exclusive but inclusive, it disseminated across different cultures and different professions²¹

Daniela Mosiou, from the Romanian Hospice and Palliative Care Association, describes how the day was used to lobby the Romanian parliament and health commission. They had been waiting for new opiate legislation but there had been little progress in the government for over six months. During the week of WHPCD Dr Mosiou and her colleagues concentrated their energies on the authorities. They produce a pack for officials which contained the translated Korean Declaration²⁴, the petition and other documentation. They met with various officials over the week, using the pack to discuss the situation in Romania. As a result, the new opiate legislation was adopted by parliament, a government task-group was set-up and a person was specifically appointed for palliative care in the Ministry of Health to bring the opiate legislation into law.

6.5 Development

Evidence suggests that WHPCD had a special impact in those countries in the early stages of establishing hospice and palliative care provision. Some countries used WHPCD for ‘capacity building’ and strengthening hospice and palliative care developments. For example, in Uganda, the African Palliative Care Association was launched; a new website was set-up for the Indian Journal of Palliative Care; and another for palliative care in Mexico.

Palliative care training and education for health professionals was organised in a large number of countries. In Romania, as a result of WHPCD an ‘Introductory Course in Palliative Care’ for family doctors has been planned. Four hundred professional attended a week of seminars and workshops in Cuba. Jordan, Colombia and Brazil also had a series of such events. In India, the ‘All Kerala Workshop in Palliative Care’ was attended by doctors, nurses, social workers and volunteers. These events also helped to initiate and strengthen hospice and palliative care collaborations within countries.

A more hidden affect of WHPCD was the widening of international palliative care networks. For example, previously Jordan had not been part of these global networks. Dr.Mohammad Bushnaq, a physician in Jordan explains: “Thank you very much. It is a privilege for us to join world palliative care family. Thank you again”²³.

Key Points:

- WHPCD had a demonstrable impact on hospice and palliative care developments across the globe
- These impacts can be divided into five broad categories: awareness; availability; funding; advocacy; development
- Impacts were wide-ranging and included: legislative change; health-policy change; capacity building; increase in services and demands on services; raising awareness among the public, professionals and state/government officials; raising funds; new collaborations; developing media relations;
- These successes need to be communicated to the those who participated in the WHPCD
- These successes can be used to build future days.

7. CHALLENGES

The evaluation has, so far, demonstrated the overwhelming success of World Hospice and Palliative Care Day 2005, there were, however, some aspects of the day which presented certain difficulties and challenges.

7.1 Translation

Language barriers to participating in WHPCD were identified as a problem by a number of sources. For example, when the Latin American countries were informed that they could submit information to the WHPCD website in Spanish, the numbers dramatically increased. Those involved in organizing WHPCD became aware that only English language materials were a barrier to overcome:

Not speaking English fluently and embarrassment about inputting their event, I am sure has an impact on people registering their activities'⁶.

.. people were so keen to sign the petition I have just sent you the third sheet – they were even taking them home to their teams in Belgium, France and Switzerland to sign up so I think the will and interest are there if we break through the language barrier²⁵

Dr Marilène Filbert, Chef de Service Centre de Soins Palliatifs argues that the materials produced for the day need to be in a variety of languages, distributed earlier and this would make it easier to develop media interest²⁶.

7.2 Web-based organisation of WHPCD

WHPCD was organised mainly electronically through the internet and email communication. In reality this is a necessity and makes possible the organisation of a global event. However, there were large parts of the world which had difficulties accessing the web, for example some of the African nations, and this presented a major barrier to participation. The petition is a good illustration of the need to not organise exclusively electronically. The results of the petition showed that 2914 had signed online and 2650 had signed a hard copy.

7.3 Date of WHPCD

For some countries an October date for WHPCD presented difficulties. Data from interviews with national association personnel and the online questionnaire indicate that the date of the day was problematic because: it was too close to World Pain Day; it clashed with national holidays; some countries had an established hospice awareness week/month; it conflicted with school exams so children were unable to be involved.

Some respondents stated however that having a national hospice week did not present a problem to having a global WHPCD. In South Africa, Liz Gywther reported that they welcomed the further opportunity to raise awareness. WHPCD was viewed as distinct because the focus was global rather than national. She argued that WHPCD gave the opportunity for local services to connect to a broader global palliative care network.

It is unlikely that the issue of a suitable date will be easily resolved.

7.4 Focus for the day

The data analysis suggested that next WHPCD would benefit from a specific focus or theme which was appropriate to countries from around the world.

There is also some concern regarding confusion between Voices for Hospice and WHPCD. In countries such as Singapore, Uganda and India, Voices for Hospices concerts have been organised over many years, it is a 'brand' which is understood and established therefore helped in raising publicity for WHPCD in 2005. In the UK in particular, where most WHPCD activities were registered on the website, there was a lot of confusion about the difference between a Voices for Hospice concert and a WHPCD day event ⁶.

7.5 World day 'fatigue'

The UK Stroke Society pulled out of WHPCD because of the saturation and "fatigue" of world days in the UK. Similarly in Australia, David Currow reported that there was a lack of motivation for WHPCD which may be due to the number of World Days and also 'Hospice Awareness Weeks'²⁷. Evidence suggests that this fatigue is not experienced in resource-poor countries but rather WHPCD was taken as an opportunity to use a global event to effect change⁶.

In some developed countries, for example the USA and in some parts of the UK (e.g. within the International Observatory on End of Life Care, Lancaster), this world day saturation was addressed by organising WHPCD events to raise awareness and funds for hospice and palliative care in resource-poor countries such as Africa and India. This may be a successful strategy for future WHPCDs.

7.6 Funding

A substantial number of resource-poor countries were able to participate in WHPCD because they received grants and funding from national and international donors. These countries were all able to organise events and activities which had a palpable impact on hospice and palliative care developments. It is reasonable to speculate that there were a number of countries who did not participate because of a lack of funding.

8. CONCLUSION

This evaluation has demonstrated that the first World Hospice and Palliative Care Day, which took place on the 8th October 2005, was an extremely successful global event. The aim of WHPCD was to raise awareness and understanding of hospice and palliative care, to increase the availability of hospice and palliative care and to raise funds for the support and development of hospice and palliative care worldwide. WHPCD achieved all these aims to varying degrees.

The evaluation has collated, generated and analysed evidence showing that over 1100 events were organised in 74 countries across the globe. The event increased the awareness of hospice and palliative care in the general public, health professionals, school students, government and state officials, voluntary and community groups and the business community. WHPCD events brought about an increase in the availability of hospice and palliative care through new service developments and widening access to already existing services. Funds were raised to support and develop hospice and palliative care via a dazzling array of activities such as concerts, music and arts events, public processions, golf-competitions, bike rides, essay competitions and sponsored walks.

The key to future WHPCDs is in learning from this inaugural day and in building on the commitment, motivation and expertise of those that organised in 2005, in order to widen global participation and increase the impact of WHPCD on hospice and palliative care, worldwide

9. RECOMMENDATIONS

9.1 INCREASING PARTICIPATION

- There were some extremely successful outcomes from WHPCD 2005; these need to be widely disseminated and used as a motivation and an incentive for WHPCD 2006
- A variety of languages, apart from English, need to be used to organise the day
- Future WHPCD materials need to be translated and available in English, Spanish, Portuguese, French, Russian and Chinese
- The web-based organisation of WHPCD may have inhibited some countries from participation, this was particularly so for resource-poor countries. It may be useful to consider other ways (hard copy) of communicating with some identified countries which are known to have someone willing to organise for WHPCD.
- The evaluation has identified those countries which did not participate in WHPCD. For example, 28 countries signed the petition but did not organise for the day. It may be productive in 2006 to target non-participant countries with publicity material and liaise with key individuals to encourage and support them to participate.
- Funding and grants were essential to many countries participating in WHPCD. This issue needs to be taken very seriously to ensure small grants are available in 2006. It can be argued that a major focus of organising WHPCD 2006 should be the identification, generation and distribution of small funds to resource-poor countries to facilitate their participation.
- Countries with high levels of participation were characterised by the presence of either a national association or a national organiser or single committed individual. One way of stimulating global participation may be to devolve the organisation of WHPCD 2006 by employing, for example, key 'continent' organisers in other parts of the world where there is palliative care organisation. This may assist the organisation, communication of information and feedback for the day.
- The issue of world days 'fatigue' in developed countries needs to be addressed. One strategy may be to 'twin' developed and low resource countries/continents, for example USA/Africa; Canada/India; Australia/ Malaysia and this may provide motivation and focus for the day

9.2 MAXIMISING IMPACT

- The media is a key area for attention and development on WHPCD 2006 and media material needs to be available in different languages and distributed early.
- Media expertise was important to successful campaigns. It may be useful to provide examples of media strategies from different countries e.g. ‘what worked in South Africa or Moldova’.
- Small grants need to be available for low-resource countries to organise media events.
- Advocacy work was an important focus of the WHPCD activities and had a large impact on WHPCD aims; as such, it should remain central to WHPCD.
- Some of the WHPCD materials used for advocacy work were more successful than others. There are few accounts of the ‘Letter to Governments’ being useful but the petition was well utilised as an advocacy tool and should be repeated in 2006.
- An advocacy ‘strategy and tactics’ document or web-page which outlines experiences of using WHPCD in 2005 to influence governments and policy-makers may be useful.

9.3 FUTURE DAYS

- Future days need a specific global focus/theme which is internationally relevant and can be adapted by individual countries. Suggestions include: access; pain relief; children; families.
- It is evident that many activities across the world were not registered on the WHPCD website due to difficulties with language and access to technology. It may be useful to introduce another reporting mechanism which does not rely on the internet. For example, hard-copy country reports from identified individuals.
- Continent-based accounts of WHPCD activities e.g. ‘what happened in Africa last year’ may help others to organise
- A very large range of events were organised in 2005, examples of these should be available to help people organise events.
- Petitions need to be again available online and as hard-copy
- The key message of support from an internationally respected figure was extremely well utilised and needs to be repeated

Appendix A. English version of the online questionnaire



World Hospice and Palliative Care Day
WITH VOICES FOR HOSPICES

EVALUATION QUESTIONNAIRE

International Observatory on End of Life Care with Help the Hospices

The aim of World Hospice and Palliative Care Day ('World Day') was to raise awareness of the need for hospice and palliative care across the world. The International Observatory on End of Life Care have been asked by Help the Hospices to evaluate the first World Hospice and Palliative Care Day. Your experiences and views of the day are very important and this questionnaire is to help plan future World Days.

Please take the time to complete the questions, there are five sections and it should not take more than 15 minutes. All the information you supply will be treated confidentially. Completed questionnaires will be submitted to Dr Liz McDermott at the International Observatory on End of Life Care, UK (www.eolc-observatory.net).

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SECTION A. ABOUT YOU:

1. Name

2. Name of Organisation

3. Address

4. Country

5. Telephone

6. Email

—

7. Website Address

**SECTION B. ABOUT WORLD HOSPICE AND PALLIATIVE CARE DAY
(‘World Day’):**

8. What did you do to celebrate World Day? (*Tick all that apply*)

- ☐ Concert
 - ☐ Music and arts events (*e.g. performances, readings, exhibitions, competitions*)
 - ☐ Religious event (*e.g. special mass, prayer*)
 - ☐ Media work (*magazine, journal, newspaper articles, TV, radio, celebrities*)
 - ☐ Conference/seminar/workshop
 - ☐ Education-based events (*e.g. schools, medical colleges*)
 - ☐ Special launch (*e.g. new service, building, publication, policy*)
 - ☐ Public awareness raising event (*e.g. surveys, displays, stalls, processions, street meetings*)
 - ☐ Public social events (*e.g. festivals, fairs, fetes, families day*)
 - ☐ Fund raising events (*e.g. walks, runs, auctions, collections*)
 - ☐ Social event
 - ☐ Other (*Please specify*)
-

9. Please describe you celebrations in more detail:

10. Where was the event held?

11. Who attended the event? (*Tick all that apply*)

- ☐ Public

- ☐ Volunteers
- ☐ Patients
- ☐ Professionals
- ☐ Hospice and palliative care professionals
- ☐ Students
- ☐ Children
- ☐ Government or state officials
- ☐ Celebrities
- ☐ Other. (*Please specify*) _____

12. Approximately how many people participated in your event? (*Please select one answer from the following list*)

- ☐ 1-10 people
- ☐ 10-50 people
- ☐ 50- 100 people
- ☐ 100 – 200 people
- ☐ 200 – 500 people
- ☐ 500 – 1000 people
- ☐ over 1000 people

13. Did your event get any press or media coverage? (*Tick all that apply*)

- ☐ No
- ☐ Don't know
- ☐ Local/Regional Radio
- ☐ National Radio
- ☐ Local/Regional Television
- ☐ National Television
- ☐ Local/Regional Newspaper
- ☐ National Newspaper
- ☐ Other written media (*Please specify*)

☐ Other spoken media (*Please specify*)

14. Did you receive any messages of support?

- ☐ No (*please go to question 17*)
- ☐ Yes

15. Please describe any messages of support?

16. Did you present any statements to government officials or policy makers?

☐ No (*please go to question 18*)

☐ Yes

17. Please describe what statements you presented, to whom, and their response

18. Did you use the World Day petition?

☐ No (*Please go to question 20*)

☐ Yes

19. Please describe how you used the World Day petition?

20. Did you use the World Day 'Letter to Governments'?

☐ No (*Please go to question 22*)

☐ Yes

21. Please describe how you used the 'Letter to Governments'

22. How did you find out about World Day? (*Please select one*)

☐ Newsletter/eNewsletter (*Please specify*)

☐ Website *(Please specify)*

☐ National media

☐ Palliative care professional

☐ Palliative care networks *(Please specify)*

☐ Conference *(Please specify)*

☐ Other *(Please specify)*

23. Did you register your event on the World Hospice and Palliative Care Day website?

☐ Yes

☐ No

SECTION C. FUNDRAISING

24. Did you raise any funds through World Hospice and Palliative Care Day?

☐ No

☐ Yes

If you answer “No”, please continue on the following page by clicking “next” below

25. What amount of funds (\$) did you raise?

26. How did you raise these funds? *(Please tick all that apply)*

☐ Organised event

☐ Sponsorship

☐ Public collections

☐ Private donations

☐ Grants

☐ Other *(Please specify)*

27. Which people donated funds? *(Please tick all that apply)*

☐ General Public

☐ Public organisations

☐ Private company

☐ Individual

☐ Other *(Please specify)*

28. What do you plan to use the funds for?

SECTION D. THE IMPACT OF WORLD HOSPICE AND PALLIATIVE CARE DAY

29. Do you think your World Day events increased awareness of the need for hospice and palliative care?

- ☐ No (*please go to question 32*)
☐ Yes

30. Who was made more aware of hospice and palliative care by World Day? (*Please tick all that apply*)

- ☐ Local people
☐ Health professionals
☐ Government or state officials
☐ Private companies
☐ Voluntary organisations
☐ Other (*Please specify*)

31. Please how explain how World Day increased awareness for hospice and palliative care

32. Do you think World Day has increased the availability of hospice and palliative care?

- ☐ No (*please go to question 34*)
☐ Yes

33. Please explain how World Day has increased the availability of hospice and palliative care

34. Do you think World Day has impacted on your government or state officials' understanding of hospice and palliative care?

☐ No (*please go to question 36*)

☐ Yes

35. Please explain how World Day has impacted on your government or state official's understanding of palliative care

36. Do you think World Day will have any impact on your country's national health care programmes and health policies?

☐ No (*please go to question 38*)

☐ Yes

37. Please explain how World Day will impact on your national health care programmes and policies

38. In what other ways has World Day impacted on hospice and palliative in your local area? (*Please tick all that apply*).

☐ Increase in patients

☐ New enquiries about volunteering

☐ New interest from health professionals

☐ New campaigns

☐ New service developments

☐ New Training

☐ New publications e.g. journal, magazine

☐ Other (*Please specify*)

SECTION E. FUTURE WORLD HOSPICE AND PALLIATIVE CARE DAYS

39. What date in the year would be best for your country to celebrate World Day?

40. Please specify any other ways in which information about the World Day could be disseminated

41. Do you have any other comments or suggestions about World Day?

42. Which of the following are important to World Day having a successful impact on hospice and palliative care? (*Please tick all that apply*)

- ☐ International collaboration
- ☐ Materials (*e.g. key messages, petitions, updates, reports*)
- ☐ Local media involvement
- ☐ International media initiatives (*e.g. Desmond Tutu World Service interview*)
- ☐ Date of World Day
- ☐ Your local and national palliative care policy initiatives
- ☐ Involving your national/regional hospice and palliative care association
- ☐ Involving government or state officials
- ☐ Involving local people
- ☐ Resources
- ☐ Other (*Please specify*)

Thank you for taking the time to complete this questionnaire. The results will be included in the evaluation report at the end of January 2006. DR LIZ MCDERMOTT, INTERNATIONAL OBSERVATORY ON END OF LIFE CARE, INSTITUTE FOR HEALTH RESEARCH, LANCASTER UNIVERSITY, B LANCASTER LA14YT

Appendix B. Online questionnaire distribution

Country/ Continent	Organisation
Europe	European Association of Palliative Care Questionnaire posted on http://www.eapcnet.org/
France	French national palliative care resource centre cdnfxb@croix-saint-simon.org French portal accessing the main three or four French websites
Switzerland	Swiss palliative Care Association Swiss palliative care information centre, CESCO, in Geneva.
Hungary	Hungarian online newsletter - newsletter@hospice.hu
UK	WHPCO UK online Hospice Information Help the Hospices website
Canada	Canadian newsletter
USA	NHPCO, USA
Latin America	International Association of Hospice and Palliative Care newsletter Latin American Association for Palliative Care newsletter
Australia	Palliative Care Australia
Asia	Asia Pacific Hospice and Palliative Care Network
India	Indian Palliative Care Association Suresh Kumar (Pain and Palliative Care Society website)
Hong Kong	Society for the Promotion of Hospice Care
Malaysia	Malaysia newsletter
Uganda	African Palliative Care Association
South Africa	Hospice and palliative Association, South Africa
International Children's Palliative Care Network	Lizzie Chambers could get something into their developing International Children's Palliative Care Network website - lizzie@act.org.uk

Appendix C. Interview schedule for members of national associations of hospice and palliative care

Structured Interview Schedule: National Hospice and Palliative Care Associations

(For digital recorder: Date, time and who is present at the interview)

1. Name
2. Name of Organisation
3. Country
4. Position
5. Profession

6. In what ways did your National or Regional Association take part in World Hospice and Palliative Care Day?

- Events

Did you organize any national initiatives/events?

Did you support any local events?

Did you invite/involve state officials

- Promotion

Did you promote WHPC Day through websites/enewsletter/ other media? To Whom?

Did you translate and disseminate any WHPC day materials? Which?

- Co-ordinators

7. What, if any, media coverage did your Association receive on World Hospice and Palliative Care Day?

8. Did you seek and/or receive messages of support from key figures and organisations within your country? Describe

9. Did your Association/organisation present letters, statements or declarations to government officials or policy makers in association with World Hospice and Palliative Care Day?

10. Do you think World Hospice and Palliative Care Day increased awareness of the need for hospice and palliative care in your country? How? Public, health professionals, government, state or district officials? If no, why not?

11. Did you use World Hospice and Palliative Care Day for fundraising? How?

12. In what ways, if any, do you think World Day has impacted upon hospice and palliative care in your country?

- advocacy: opening channels of communication; new campaigns; new policy or service initiatives
- fundraising
- Awareness
- Availability

14. What do you think the role of National Associations should be in World Day?

13. In what ways do you think World Day can be improved next year?

- Date of the day
- Information – dissemination, translation, type
- Focus of day – opioid, volunteering, HIV/AIDS
- Type of materials used to promote day (petition, letter etc)

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12. Acknowledgments

We would like to thank everyone at Help the Hospices for facilitating access to the data for this evaluation. Special thanks to Claire Morris who was an invaluable source of information and provided great assistance.

Our appreciation also goes to all those people involved in the design, production and distribution of the online questionnaire. Anthony Greenwood at IOELC for technical support and advice; Avril Jackson and Nirmala Canova for the French translation; Roberto Wenk for the Spanish translation; Cisio Brando for the Portuguese translation; and Fan Kwan for the Chinese translation. Our gratitude to everyone who took the time to complete the questionnaire and was prepared to be interviewed.

We would have been unable to produce this evaluation without the willingness of people from international hospice and palliative care networks to provide us with data, reports and documentation. Many thanks. Finally, thanks to Lynne Hargreaves at IOELC for her efficiency on the final preparation of the report.