

3rd Worldwide Summit for national associations of hospice and palliative care

17 – 18 September 2007

Safari Park Hotel, Nairobi, Kenya



Executive Summary

The third Worldwide Summit for national hospice and palliative care organisations took place in Nairobi, Kenya in September 2007 bringing together 67 individuals from 32 countries. Delegates included representatives from national hospice and palliative care associations, regional hospice and palliative care associations, international funders, academics, other non-governmental organisations and multilateral agencies.

The purpose of the seminar was to review the work done to date by the work groups of the Worldwide Palliative Care Alliance (WPCA), to discuss and reach agreement on the future structure of the WPCA and to listen to the needs and suggestions of national associations to form the basis of the WPCA business plan. In addition, the Summit aimed to provide practical support to national associations with their work in supporting service delivery in their countries.

The major part of the meeting involved participatory discussion within work groups to ensure that individual voices of national associations were heard and were engaged. Posters were presented by national associations as well as other materials highlighting their work. Workshops were held on fundraising, advocacy and brand identity while experts in these three fields were available throughout the conference for one-to-one advice and support.

Presentations were given by the co-chairs of the WPCA on its background, the challenges and future plans. There was the opportunity for discussion and questions from the participants.

The major outcome of the meeting was the universal agreement by the participants that the WPCA become a formal legal organisation. It was also clear that there was a need for a participatory approach that ensured the membership were consulted and listened to. It was repeatedly voiced that the WPCA had a clear role in being the voice for national associations at the global level, at the same time as providing practical and relevant support and mentorship at the national level.

Additional outcomes of the meeting were:

- Suggestions from participants on all areas of WPCA work that will contribute to the WPCA work and business plan
- The development of a fundraising toolkit for national associations
- A successful submission to UNAIDS and WHO requesting that palliative care be included in its report *Financial resources required to achieve universal access to HIV prevention, treatment, care and support*.
- A detailed brief for the branding consultant on the branding requirements for the WPCA
- Consultation on the Community Based Toolkit for palliative care
- Launch of the World Hospice and Palliative Care Day media toolkit

Following the meeting, it was agreed that the steering group and working group would incorporate the ideas and suggestions of national associations to create the constitution, business plan and work plan of the Worldwide Palliative Care Alliance. The WPCA would be registered as a separate legal entity and invitations to join would be circulated to national associations in 2008. The next Summit will take place in Delhi, India in 2009.

Contents page

Executive Summary	2
Contents page.....	3
Registration and welcome dinner	4
Introduction.....	4
Connecting the world to improve palliative care	5
Background.....	5
The Worldwide Palliative Care Alliance – the story so far	5
Workgroups	7
Policy/Advocacy	8
Education and training	10
Children.....	11
Quality and Standards.....	13
World Hospice and Palliative Care Day	14
Budapest Commitments	16
Fundraising	17
Branding.....	18
Spreading palliative care – the challenges for national and pan-national associations	19
Background.....	19
The challenges	19
Summary of the work of the WPCA.....	20
Potential duplication	22
Discussion	22
The future structure of the Worldwide Palliative Care Alliance.....	23
Membership	23
The board	24
Committee structure.....	25
Next meeting.....	25
Discussion	25
Inclusion of government as non-voting members.....	25
Definition of a national association	25
Funding and the finance mechanisms.....	25
Patron	26
Translation	26
Definition of palliative care.....	26
Close.....	27
Conclusion.....	27
Appendix 1 – Delegate list 2007	
Appendix 2 – Funder’s charter	
Appendix 3 – Korea declaration	

Sunday 16 September

Registration and welcome dinner

The 3rd Worldwide Summit for national associations of hospice and palliative care opened with a drinks reception, registration and dinner at the Safari Park Hotel, Nairobi, Kenya.

67 delegates representing 32 countries around the world participated in the Summit. National associations, pan-national organisations and representatives from key organisations connected with palliative care including funders and academic institutions were present.

Dr Faith Mwangi-Powell, Executive Director of the African Palliative Care Association and Dr Bactrin Killingo, Chair of the Kenya Hospice and Palliative Care Association warmly welcomed the delegates to the conference and to Kenya.

Monday 17th September

Introduction

Cynthia Goh, co-chair of the Worldwide Palliative Care Alliance and Honorary Secretary of the Asia Pacific Hospice Palliative Care Network

Cynthia Goh welcomed delegates and outlined the key discussion areas that would be covered over the two days. National Associations last met in Seoul in 2005 where there was excitement about the potential for the development of palliative care through increased collaboration between national associations. At this last meeting, the need and possibilities for progress were not questioned, although it was agreed that further discussion was necessary on the details of what national associations could do together and the structure within which this work would take place.

The purpose of the third meeting of the national associations was to reflect on what had happened since Seoul 2005 and discuss and agree how national associations could work best together to further the advancement of hospice and palliative care globally.

Connecting the world to improve palliative care

David Praill, co-chair of the Worldwide Palliative Care Alliance and Chief Executive of Help the Hospices, presented on the current situation of hospice and palliative care worldwide and the story so far of the Worldwide Palliative Care Alliance.

Background

It is estimated that 115 countries have some form of palliative care service availability. According to the International Observatory on End of Life Care, approximately 35 have some level of national integration and 41 are at the early stages of building service capacity.

The development in palliative care service delivery worldwide has been accompanied by the growth in the number of hospice and palliative care national organisations. The latest estimate is that there are 79 national hospice and palliative care associations. There are various other organisations working to support hospice and palliative care development including pan-national organisations, international organisations, professional associations, foundations and funders, and academic institutions.

With globalisation and the increased recognition that governments and international agencies are not adequately addressing certain issues, there has been a rise in collaborative approaches in the form of global action networks to tackle specific concerns. These networks, largely made up of non-governmental organisations, are achieving great results in areas such as climate change, HIV and AIDS and the provision of water. Hospice and palliative care is no different. Continually a side-lined issue, the need for a global action network which can provide consensual knowledge and action among diverse stakeholders on hospice and palliative care with meaningful global participation and representation is without question.

The benefits of national hospice and palliative care associations working together are evident from sharing best practice, generating increased resources, promoting innovation, strengthening governance, setting standards, assuring quality, provision of education, increasing public awareness and using a collective voice and strength to influence global and national institutions.

The Worldwide Palliative Care Alliance – the story so far

The initial idea for the development of increased links and expertise sharing between national associations was the result of a conversation between David Praill and Tonia

Barnes, a previous Chief Executive of Palliative Care Australia. David and Tonia realised that there was a lot that their respective organisations could learn from each other and communication and networking between national associations was potentially a beneficial and productive activity.

The first meeting of national associations took place in The Hague in 2003 where 50 individuals came together from over 30 palliative care organisations representing 23 countries worldwide. This initial gathering took place with the purpose of sharing information and experiences and discussing how working together might promote palliative care globally. David Clark from the International Observatory on End of Life Care wrote up the report and the 'palpable buzz' in the opening plenary led to a first Global Summit where it was acknowledged that 'participants had increased their knowledge'. Following the summit, work groups were set up in key areas where it was felt that working together would enable knowledge to be built on to support the development of palliative care globally.

The second summit took place in Korea in 2005 where 72 individuals from 32 countries met. The outcomes of the meeting included the production of the Korea declaration, the launch of the advocacy toolkit, the initial formation of the International Children's Palliative Care Network and the creation of the funder's charter. It was at this meeting where it was agreed that the working groups should move forward with their work plans and discussion began around the future structure of a formalised network.

The steering group, as a result of the Korea meeting, met in 2005 in Henley with the remit of looking to the future of the network. The following strategic proposals were formulated and it was agreed that these would be presented at this Summit:

Name

The Worldwide Palliative Care Alliance (WPCA)

Vision

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

Mission

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

Working principles

- Promote understanding of palliative care
- Support national and regional organisations in the development and implementation of quality palliative care programmes

- Act as a resource for palliative care development
- Strengthen the voice of palliative care
- Support advocacy for palliative care at all levels (international, national, regional and local)

Membership of the steering group and current vacancies



Workgroups

The purpose of the work groups was primarily for participants to give suggestions on what the WPCA should be doing to support their work. Each of the chairs of the working groups gave a summary of their work to date and the feedback they were requesting from participants in order to plan their future activities. The delegates were then able to go to three of the workgroups throughout the afternoon. The chairs of the WPCA committees led the work groups and fed back to the plenary at the end of the sessions.

Individuals from national associations were encouraged to express an interest in joining the committees in their particular areas of interest and expertise.

Policy/Advocacy

The policy/advocacy work group is co-chaired by Sharon Baxter and Faith Mwangi-Powell.

Current membership

Sharon Baxter	Canadian Hospice Palliative Care Association	Canada
Mary Callaway	Open Society Institute	USA
Olivia Dix	Diana, Princess of Wales, Memorial Fund	UK
Henry Ddungu	African Palliative Care Association	Uganda
Liz Gwyther	Hospice Palliative Care Association of South Africa	South Africa
Faith Mwangi Powell	African Palliative Care Association	Uganda
Zodwa Sithole	Hospice Palliative Care Association of South Africa	South Africa
Franco Toscani	ACCD Associazione creonese per la cura del dolore	Italy

Work to date and outputs

The work of the Policy/Advocacy group has included the creation of the Korea declaration, increased palliative care inclusion in the World Health Assembly cancer resolution, a symposium and booth at the International AIDS conference in Toronto and campaigning UNAIDS on cost classification for palliative care to be included in their budget for universal access.

The key areas of work of the policy/advocacy group are:

1. To provide internal support to national associations to undertake their own advocacy effectively through the provision of resources and training materials, workshops, building advocacy capacity etc.
2. To influence the external audience e.g. multi-lateral and bi-lateral agencies such as WHO, the Global Fund, IAS, the World AIDS conference and UNAIDS.

Feedback and suggestions

Participants were asked to feedback on:

1. What do national associations need the WPCA to do to support their national initiatives in policy and advocacy?
2. What are the policy issues and advocacy areas that you want the WPCA to tackle at the global level?

Participants made the following suggestions:

Supporting national associations advocacy initiatives

- Technical assistance and workshops to support national advocacy
- Training the trainers to support advocacy nationally and in the community
- Investment in regional advocacy initiatives
- Creation of tools, resources to support advocacy e.g. case studies, position statements, templates
- Mentorship support
- Provide endorsements of national associations
- Provision of resources e.g. human, funding
- Develop visibility strategies
- Endorsement of home based care protocols

Policy and advocacy at the global level

- The need to create solid policies to improve rapid responses
- Advocacy around a global consensus on the definition of palliative care
- A commitment to a health systems approach
- Increased lobbying and campaigning
- Advocacy with key agencies particularly PEPFAR
- Develop policy statements linking in with key areas e.g. poverty reduction, palliative care within the Millennium Development goals etc.
- Engage with other relevant alliances e.g. Older people, children, people living with the diseases

Education and training

The Education group is chaired by Liz Gwyther.

Current membership

Liz Gwyther	Hospice Palliative Care Association of South Africa	South Africa
Roberto Wenk	Asociación Argentina de Medicina y Cuidados Paliativos	Argentina
David Currow	Palliative Care Australia	Australia
Bee Wee	Michael Sobell House	UK
Gustavo De Simone	Pallium Latinoamerica (NGO)	Argentina
Julia Downing	African Palliative Care Association	Uganda
Fiona Rawlinson	Department of Palliative Medicine (Princess of Wales Hospital)	UK
Ednin Hamzah	Hospis Malaysia	Malaysia
Odette Spruyt	Peter MacCallum Cancer Institute	Australia
Rosalie Shaw	Asia-Pacific Hospice Palliative Care Network	Singapore
Jose Pereira		Canada
Daniela Mosoiu	Romanian Association of Palliative Care	Romania

Work and outputs to date

The work of the education work group has included developing an international database of palliative care training providers and a draft palliative care toolkit to promote palliative care. The group aims to look into the possibility of long distance learning courses to educate health care workers and promote national associations to support the training.

Suggestions from participants

Participants were asked to feedback on:

1. What can be done for palliative care education and training by the WPCA together which can not be done by national associations on their own?

Participants gave the following suggestions:

- Develop standard curricula, quality assurance of curricula and advice on reviewing curricula
- Develop and promote interactive training methods for training the trainers
- Develop skill and knowledge about how to reach out and train health care professionals
- Transfer skills through mentorship, advocacy with employers, changing cultures in institutions and creating a training pool
- Develop a web-based course on training the trainer and ensuring training is culturally sensitive
- Develop and distribute of training materials and improving accessibility including translation of materials
- Support research on the evidence of palliative care, base education on this evidence and develop training in research methods.
- Develop and support methods by which palliative care can be integrated into undergraduate curriculum and support national associations activities in this area
- Provide skills in engaging doctors e.g. provision of an information booklet and clinical guidelines
- Support quality assurance in terms of assessment of courses, e.g. accreditation by national associations and the development of evaluation tools
- Support advocacy for palliative care training by providing training in institutions, engaging with regulatory bodies and promoting patient and community demand.
- Provide a forum for palliative care trainers on the website and encourage regional and international conferences to provide peer support
- Develop standardised courses in specialist training to promote the recognition and credibility of palliative care as a speciality

Children

The International Children's Palliative Care Network is chaired by Joan Marston.

Current membership

Joan Marston	Hospice Palliative Care Association of South Africa	South Africa
Rut Kiman	Area de Soporte Clinico y Cuidados Paliativos	Argentina
Barbara Gelb	Association of Children's Hospices	UK
Lizzie Chambers	Association of Children with Life Threatening Illnesses	UK

Sue Huff	National Hospice Palliative Care Organisation	USA
Nick Pahl	Help the Hospices	UK
Sabine Kraft	Bundesverband-Kinderhospiz e.v	Germany
Julia Downing	African Palliative Care Association	Uganda
Carol Quayle	Mercy Hospice and Werribee Mercy Hospital	Australia
Delia Birtar	Casa Sperantei	Romania
Maryann Muckaden	Tata Memorial Hospital	India

Work and outputs to date

The work of the International Children's Palliative Care Network has included the development of a steering group representative membership worldwide, successfully secured funding for a website which will be launched on World Day 2007, plans to recruit an information officer to be based in Cape Town and the development of a logo.

Suggestions and feedback

Participants were asked to feedback on:

1. What are the issues around children that the ICPCN and the WPCA need to address?
2. What resources need to be gathered to support the development of children's palliative care around the world?

The desperate need for resources and activity in the development of children's palliative care is without doubt. It was recognised that there is so much to do that work needs to be focus on what is currently achievable and to scale up.

Participants made the following suggestions:

- Promote World Health Organization paediatric definition of palliative care
- Promote the need for an individual responsible for palliative care in every national association
- Increase advocacy around children's palliative care as children are often unable to speak for themselves
- Create and circulate key messages around children's palliative care
- Include children's palliative care on all World Hospice and Palliative Care Day messages
- Advocate for increased access to children's palliative care

- Create a core package for children’s palliative care e.g. core competencies, training, specific models
- Identify skills that the WPCA has which can be disseminated
- Commit to creating a core message, core criteria for children’s palliative care and a children’s charter.

Quality and Standards

The quality and standards workgroup is chaired by Stephen Connor.

Current membership

Stephen Connor	National Hospice Palliative Care Organization	USA
Roberto Wenk	Asociación Argentina de Medicina y Cuidados Paliativos	Argentina
Andre Wagner	Hospice Palliative Care Association of South Africa	South Africa
Cynthia Goh	Asia Pacific Hospice Palliative Care Network	Singapore
Daniela Mosoiu	Romanian Association of Palliative Care	Romania
Anil Paleri	Indian Association of Palliative Care	India
Donna Daniell	Palliative Care Australia	Australia
Sue Cameron	Hospice Palliative Care Association of South Africa	South Africa

Work and outputs to date

The work of the quality and standards group has included the sponsoring of the mapping of a study on the existence of hospice and palliative care around the world, drafting of a resource toolkit on setting up national associations and initial research on measuring quality and standards in palliative care.

Feedback and suggestions

Participants were asked to feedback on:

1. What are the issues around the definition of palliative care?
2. What are the minimum criteria for palliative care services?
3. Feedback on the resource toolkit on setting up national associations.

It was recognised that to develop quality and standards internationally on palliative care which are culturally appropriate is a difficult feat. However, initial steps can be taken where the WPCA can do work.

The suggestions from the groups were:

- Create and agree on the minimum criteria for what a palliative care service is
- Research where countries do not currently have standards and support their development
- Find and agree two to three areas which enable simple measurement of palliative care services internationally
- Suggestions were given on the web based toolkit on the formation of national associations which will be implemented by the group.

World Hospice and Palliative Care Day

The World Hospice and Palliative Care Day committee is chaired by Marilene Filbet (In Marilene's absence, the sessions were led by Nick Pahl)

Current membership

Marilene Filbet	Centre Hospitalier Lyon Sud	France
Katalin Muszbek	Hungarian Association of Palliative Care	Hungary
Nick Pahl	Help the Hospices	UK
Anne Merriman	Hospice Africa Uganda	Uganda
Rose Kiwanuku	Hospice Africa Uganda	Uganda
Anthony Greenwood	International Observatory on End of Life Care	UK
Mary Callaway	Open Society Institute	USA
Fan Kwan	Society for the promotion of hospice care	Hong Kong
Sheila Hurton	Voices for Hospices	UK
Liliana de Lima	International Association Hospice Palliative Care	USA
Donna Daniel	Palliative Care Australia	Australia
Caroline Lynch	Irish Hospice Foundation	Ireland
Stephen Connor	National Hospice Palliative Care Organization	USA
Harmala Gupta	CanSupport	India
Faith Mwangi-Powell	African Palliative Care Associations	Uganda

Henry Ddungu	African Palliative Care Association	Uganda
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Work and outputs to date

The work of the World Hospice and Palliative Care Day group has included 2 World Hospice and Palliative Care Day in 2005 and 2006 involving events in over 70 countries around the world, agreement of co-sponsorship of the day by the World Health Organization, production of a report for each World Day, high profile support e.g. Archbishop Desmond Tutu and press coverage internationally.

Feedback and suggestions

Participants were asked to feedback on:

1. What should we do in the future?
2. How do Voices for Hospices and World Day work together?
3. Who else should we be working with on World Day?
4. What have national associations been doing for World Day and what has worked well?
5. Who should we be getting messages of support from?
6. What do national associations want to support their World Day activities?
7. What themes could we take forward for future World Days?

Participant's suggestions included:

- Increase the involvement of key individuals e.g. ministers and deans
- Promote events where key individuals can and will attend in order support advocacy
- Utilise fully WHO support through guidance on how the logo and their name can be used in promotion of activities
- Connect with WHO regional offices in partnership with national associations
- Develop tracking polls which show the affect World Hospice and Palliative Care Day has on public awareness
- Promote national events and activities as well as local activities
- Seek multi-national support e.g. coca cola and Toyota
- Provide letters of support to engage donors with the national events
- Continue with high level aspirations for large scale activities.

Budapest Commitments

The Budapest Commitments session was led by Lukas Radbruch.

Work and outputs to date

The Budapest Commitments is a joint venture between the Worldwide Palliative Care Alliance, the European Association of Palliative Care and the International Association for Hospice and Palliative Care. The project was agreed in June at the EAPC conference. National associations have been asked to commit to defining a goal that they can achieve within the next 2 years.

Feedback and suggestions

Participants were asked to feedback on:

1. What do participants think about the project?
2. Is the project feasible?
3. Would participants like to take part?

Feedback on the Budapest Commitments was received from participants from Nigeria and South Africa.

The participant's feedback was:

- The Budapest Commitments is a feasible project
- South Korea suggested they could set a goal for creating standards of education within the next two years
- Funding should be allocated to allow national associations to go to Vienna to present their ideas
- A two year timeline is potentially too tight to achieve a lot. It was suggested therefore that this timeline be extended.

Fundraising

The funding session was led by Neelam Makhijani from the Resource Alliance.

This purpose of the session was to support national associations fundraising and focussed on what the basic foundations were for doing good fundraising. This was followed up with a workshop on the development of fundraising strategies.

Feedback and suggestions

Participants were asked to feedback on:

1. Do you have institutional charters in place?
2. Do you have teams and the human resources in place?
3. Do you have leadership and a strategic plan in place?
4. Do you know who your stakeholders are and how you are communicating with them?
5. Do you have a strong and compelling case for support?

The session sought to find out where national associations were in terms of fundraising and financial sustainability. Out of the five areas that were discussed the weakest areas for the national associations that were represented were:

- *Case for support*
- *Leadership and strategic plans*
- *Stakeholder analysis*

Participants who took part in the fundraising workshop the following day also raised the following suggestions for how the WPCA should support national associations fundraising:

- Support with fundraising strategic plan – mentorship
- Capacity building of fundraising
- Proposal writing workshop
- Funding for proposal writing workshops
- Tailor made fundraising training for specific national associations
- Networking and brainstorming
 - Online forum of hospice and palliative care fundraising
 - Newsletter specific to fundraising possibilities and news
- Ensure communication through APCA

- Half yearly meetings through APCA on fundraising strategy, plans and movements forward
- Fundraising sub-community of WPCA with communication
- Joint proposals e.g. DFID
- Fundraising toolkit specifically around hospice and palliative care
- Support in building marketing and PR skills
- Building monitoring and evaluation skills
- Distance learning programmes around fundraising for national associations
- Citing fundraising as an important thing to learn as an organisation
- Resource Alliance – develop specific course on fundraising on palliative care that is adoptable and adaptable
- Proposal writing service

Branding

The branding session was led by Dominic Lipka from Pentagram Design Limited.

The purpose of this session was to gather information from national associations about the Worldwide Palliative Care Alliance in order to support the development of the brand.

Feedback and suggestions

The participants who took part in the branding session made the following comments about the Worldwide Palliative Care Alliance:

- Needs to listen as well as to act
- Needs to gather feedback on its activities from the whole world stage
- Need to be transparent
- Should have a simple structure
- Committee needs to be qualified and committed
- Should be a global information centre
- Should help channel funds
- Should provide education and training
- The main audience should be government and policy makers
- Words that describe the WPCA are accessible, authoritative, concise and caring
- Needs to affect change, increase funding, deliver practical solutions and have an impact on the world stage

Tuesday 18th September

Spreading palliative care – the challenges for national and pan-national associations

Cynthia Goh, Co-chair of the Worldwide Palliative Care Alliance discussed the challenges that face national and pan-national associations in their missions to spread quality palliative care and the achievements of the Worldwide Palliative Care Alliance to date.

Background

Dame Cicely Saunders began the palliative care movement and travelled the world taking the messages of palliative care with her. This is the natural aspiration of palliative care advocates who have reacted against the increased technical and impersonal attitude to medicine.

Care needs to be brought back into medicine, treating the whole person and giving people the option about the care that they want and where they want to get it. It is about giving people control, empowering families, developing new expertise and ensuring universal access. How this can be achieved can be daunting in the face of such great need.

The challenges

The challenges facing hospice and palliative care organisations are numerous.

The lack of trained manpower worldwide is a key issue. There are huge challenges in attracting people to train in palliative care particularly due to remuneration issues and the lack of a clear career path. Many medical professionals do not want to go into a field which is often not fully recognised by other health professionals as a speciality. In addition, when people do want to be trained in palliative care there is often problems with getting the appropriate training or finding the resources to do it.

Funding continues to be a problem with few funders specifically supporting palliative care. Charging for services is often discussed and yet few patients at the end of life have the resources to pay for these services. In addition to this, the ethical issues around charging are numerous. Charitable foundations and individual donors need to be persuaded that the case for supporting palliative care is strong.

Governmental attitudes are often a significant barrier to the scale up of palliative care. The dying are often not seen as the priority and services to save lives are deemed more important in the face of limited resources. In addition, lack of understanding about and fear of morphine creates uncertainty and alarm towards palliative care services and practitioners.

Public opinion is another major barrier to palliative care. People often simply do not understand what palliative care is and see hospices simply as death houses. Many people believe morphine is addictive and that it kills you or that hospice and palliative care services carry out euthanasia. Underlying all of this is the fear and non acceptance of the dying process and death which pervades many societies.

Health professionals often hold similar unwarranted concerns around morphine. In addition, there is a misunderstanding about the speciality of palliative care and people do not understand the holistic approach but see the care as merely hand holding and kindness. At the same time, there is often a lack of understanding that palliative care should be alleviating pain through treatments such as chemotherapy and ARV and is not just about the end of life.

The isolation of palliative care providers is another challenge. Individuals within palliative care services face the issues of self reflection and self criticism. Palliative care providers are faced with continuous questions around whether the palliative care that is being provided is quality, how to measure outcomes, how to calculate cost and benefit and how to create new knowledge.

The answers to these challenges is networking and sharing - at the individual level among friends and colleagues, at the national level, at the regional level and worldwide.

The two questions that are raised out of this are:

What can we do better together than we can do on our own?

What value would the WPCA add to existing national and regional networks?

Summary of the work of the WPCA

The work of the WPCA to date and some of the key areas for future work were considered in order to look at the added value of the WPCA.

Advocacy

- Korea declaration produced in March 2005
- World Health Assembly Cancer Resolution inclusion of palliative care

- Toronto International AIDS Conference 2006
- Department for International Development consultancy on palliative care and AIDS
- Advocacy with UNAIDS on the omission of palliative care from their costing exercise

Quality and standards

- Toolkit on setting up and developing national associations
- Work on the collection of a minimum dataset
- Critical study of definition of palliative care service

Education and training

- Create standardised education curricula
- Validate training methods
- Develop faculty/training materials
- Quality assurance on curricula and training
- Undergraduate and specialist training
- Facilitating research

Public awareness raising – World Day

- World Hospice and Palliative Care Day 2005 and 2006
- Merging of World Day with Voices for Hospices post 2007 under the umbrella of the WPCA
- Role in advocacy, publicity and education of specific target groups e.g. deans and government ministers in the future

Access to new funding

- A worldwide body should not compete for funding with national associations and service providers
- Tapping into new sources of funding from international charities and multinational corporations

All these activities are owned by the national organisations leading on them with the desire for them to come under the umbrella of a worldwide body thereby increasing their impact.

The question was put to the participants about whether these activities could have taken place without the WPCA and whether there is an added value in having a worldwide body.

Potential duplication

It is clearly important to ensure that there is no duplication of efforts by other organisations. The work of the International Association for Hospice and Palliative Care was initially identified as a potential area for duplication. However, considerable discussion and consideration has gone into looking at these issues between the IAHPC and other parties and it has been agreed that this is not the case.

The IAHPC are represented on the steering group of the Alliance by the Executive Director Liliana de Lima who also leads the information group. There are also core differences in the remit and the make up of the IAHPC and the Alliance which are detailed below. It is considered that the work of the two will not duplicate each other.

- The IAHPC is a body of palliative care professionals focusing on palliative care resources, education awareness and professional development
- The Worldwide Palliative Care Alliance is a network of national and pan-national organizations working on areas of common interest to develop the reach of palliative care globally.

Discussion

A question was raised about how young and fledgling associations would participate and contribute to the Alliance.

The Romanian national association was cited as an example of an organisation that was struggling to organise and that needed not just high level advocacy support but also practical support. Less established associations like Romania are on the steering group alongside more developed associations and it was agreed that the Alliance could be a beneficial network with strong organisations supporting the development of weaker organisations.

The Argentinian national association was started in 1990 and it was added that they would be happy to have all the information, resources and materials that the Alliance was able to provide to support its growth.

The Alliance should hear, listen and support the growth of the weaker organisations as this is where support was most needed. The steering group pledged to make a firm commitment to listening to the membership.

The future structure of the Worldwide Palliative Care Alliance

David Prail, co-chair of the Worldwide Palliative Care Alliance and Chief Executive of Help the Hospices, gave a presentation on the next steps, future structure and governance of the Alliance.

Participants approved without dissension the following recommended proposals from the steering group.

Legal status

The Worldwide Palliative Care Alliance will be registered as a charitable company in the UK. This was agreed by the steering group following research into which legal systems best support multi-national organisations.

Membership

At the beginning of 2008, an invitation to all national associations will be sent out inviting them to take up membership.

Voting members

These will be allowed to stand for election to the board.

National hospice and palliative care associations whose members are palliative care organisations as well as regional and pan-national associations
(National associations who only have membership of one professional group will not be included in this category)

Non-voting members

These will be able to fully participate in the meetings and activities of the WPCA but will not be able to vote.

- Other national hospice and palliative care bodies
- National professional associations
- National funders
- Other organisations working in palliative care e.g. IAHP, OSI
- Research bodies
- Government health departments
- NGOS
- Private sector

Supporters

This group will be kept informed about the activities of the Worldwide Palliative Care Alliance.

- Individual palliative care organisations

Membership fees

Membership will be free.

Membership obligations

The members will have minimal obligations to the WPCA although it will be required that they send basic information on their organisations e.g. accounts, contact information and service needs.

Membership termination

The WPCA will retain the right to terminate membership on key areas of misconduct e.g. bringing the WPCA into disrepute.

The board

The following was proposed and agreed:

- The steering group will become the new board
- Length of service will be 3 years renewable after 3 years
- Elections for vacancies on the steering group will take place for Africa, Europe (Central), Latin America and Asia Pacific (excluding the Indian Sub-continent)

It was recognised that there is a gap in the Middle East and in China but there are currently limited services in these areas. Therefore membership on the steering group for these areas will be considered at a later date.

ICPCN will always have a place on the board to represent children's issues and the board will have the power to co-opt individuals and representatives from key organisations.

Time commitment to the steering group was noted as one annual face to face meeting, teleconferences, involvement in one working group and attendance at the Worldwide Summit every two years.

Committee structure

The current committee structure will be retained and these committees will become committees of the board and will be chaired by board members. The WPCA will promote broader and wider representation on the committees and encourage national associations to take part in the committees.

New committees will be considered by the board as suggestions and ideas arise, e.g. IT and the development of an online journal.

Next meeting

The next meeting of the WPCA will take place in Delhi, India linked to the Indian Association for Palliative Care on the 11th -12th February 2009.

Discussion

Discussion arose around the following areas.

Inclusion of government as non-voting members

A discussion arose around the inclusion of government departments as non-voting members in developing countries as these are often the people who hospice and palliative care organisations are lobbying against. It was noted that in some countries e.g. Moldova where no national associations exist, it is a palliative care taskforce within government which is fulfilling this role. It was also however pointed out that in countries such as Taiwan, Hong Kong and China, an issue may arise from enabling government to be involved. It was agreed that this should be considered.

Definition of a national association

It was recognised that there is a potential issue with the definition of a national association and there would need to be a degree of self-definition alongside recommendations from regional and pan-national bodies on membership eligibility.

Funding and the finance mechanisms

The funding sources for the WPCA and its funding mechanisms were queried by a participant. It was noted that funding would be sought from global foundations and multi-lateral bodies to support the WPCA business plan which would be fully costed including gifts in kind from national associations (e.g. staff time). National associations should not feel limited by lack of funding to participate and should discuss with members of the board the costs of their involvement in working groups if they have concerns.

Once funding is secured, it will be disseminated across all the regions for work carried out by national associations for the WPCA.

Patron

It was agreed that getting a patron and a list of supporters was part of building the case.

Translation

Translation of documents is key to enable inclusive and accessible communications. The steering group will be looking into the best way to translate documents to ensure meanings are not lost.

Definition of palliative care

Dr Liz Gwyther, Chief Executive of Hospice Palliative Care Association of South Africa and member of the WPCA steering group, led the session on analysing and discussing the WHO definitions of palliative care.

The groups fed back on the similarities and differences between the two definitions. This developed into a broader discussion around the meaning and uniqueness of palliative care and how this should be communicated to others.

The key points raised included:

- The development of the WHO definitions of palliative care was a result of extensive consideration and research. The result of this process is the books on palliative care published by WHO.
- Regions and countries should develop position papers to back up the WHO definition with details of palliative care in their own settings
- The solid facts of palliative care should be produced for other regions such as Asia, Africa and Latin America like the European publication
- It was suggested that it is appropriate to say that dying is an expected process rather than a normal process for children with life-limiting illness
- There needs to be increased discussion and definition on generalist and specialist palliative care
- It is important to stress the importance of palliative care in adherence to treatment
- A big part of palliative care is not just the skills that are developed but also the humanity and spirituality of sharing suffering

- The uniqueness of palliative care is the fact that the patients are life-limited, the expertise and focus on pain and symptom management and the holistic approach.

Close

Participants were informed that training sessions would be taking place on fundraising, advocacy and branding in the afternoon.

Cynthia Goh thanked the Kenyan Hospices and Palliative Care Association for their hospitality, the African Palliative Care Conference for their support, Help the Hospices for their organisation and the funders for making it possible for so many participants to attend. The participants were thanked for attending and for their contributions to the meeting.

In early 2008, an invitation to become a member of the Worldwide Palliative Care Alliance and the new constitution will be sent to all national associations.

The next Global Summit of the Worldwide Palliative Care Alliance will take place in Delhi in 2009 linked to the Indian Association of Palliative Care conference.

Conclusion

Participants at the Summit were enabled to share their vision for and expectations of the Worldwide Palliative Care Alliance while gaining a greater understanding of the work that had already been undertaken. There was a clear sense of anticipation about what could be achieved by the WPCA in the future and a good basis was set for the business planning process to begin.

The need for good communication, consultation with membership and ensuring that less established national associations were kept fully involved was clearly expressed. In addition, the need for a balanced approach to global advocacy and practical support was communicated, ensuring that practical support is appropriate and useful to national associations at different levels of development and from all different settings.

National and regional associations working together can begin to tackle some of the issues facing palliative care development worldwide by becoming a global voice on palliative care, tackling the isolation of palliative care organisations, generating resources and providing practical support for the development of national hospice and palliative care associations worldwide.

Appendix 1 – Delegate list 2007

3rd Worldwide Summit for national associations of hospice and palliative care 17-18 September 2007

Name	Organisation	Job title
Dr Seet Ai Mee	Singapore Hospice Council - Singapore	Chairman
Dr Zipporah Merdin Ali	Kenya Hospices and Palliative Care Association (KEHPCA) - Kenya	National Coordinator
Mr Alan Barnard	Palliative Care Society of South Africa (PCSSA) - South Africa	Chairperson
Ms Sharon Baxter	Canadian Hospice Palliative Care Association - Canada	Executive Director
Alphonse Baltazar	Tanzania Palliative Care Association	National Co-ordinator
Dr Michaela Bercovitch	Israel Palliative Medical Society - Israel	Chairperson of IPMS
Ms Morana Brkljadic	Croatian Society for Hospice/Palliative Care - Croatia	President
Ms Mary Callaway	International Palliative Care Initiative - Open Society Institute (OSI) - USA	Project Director
Ms Sue Cameron	Hospice Palliative Care Association of South Africa - South Africa	National Patient Care Manager
Wha Sook Choe	Korean Society for Hospice and Palliative Care - Korea	
Ms Sung Eun Choi	Korean Society for Hospice and Palliative Care - Korea	Team Coordinator
Dr Gillian Chowns	Oxford Brookes University - UK	Senior Lecturer in Palliative Care
Dr Stephen R Connor	National Hospice and Palliative Care Organization - USA	Vice President Research and International Development
Mr Carlyle Coash	National Hospice and Palliative Care Organization - USA	
Ms Colette Cunningham	Palliative Care Association of Zambia (PCAZ) - Zambia	Senior Technical Advisor Palliative Care
Ms Donna Daniell	Palliative Care Australia - Australia	Chief Executive Officer

Ms Kath Defilippi	African Palliative Care Association (APCA) - Uganda	Chairperson
Dr Msemo Diwani	Ocean Road Cancer Institute - Tanzania	Consultant
Ms Thulile D Dlamini-Msane	Swaziland Hospice at Home - Swaziland	Director
Dr Julia Downing	African Palliative Care Association (APCA) - Uganda	Deputy Executive Director
Dr Kathleen Foley	International Palliative Care Initiative - Open Society Institute (OSI) - New York	Medical Director
Mr Eunice Garanganga	Hospice Association of Zimbabwe (HOSPAZ) - Zimbabwe	Board Member (APCA)
Dr Cynthia Goh	Asia Pacific Hospice Palliative Care Network - Singapore	Senior Consultant
Dr Liz Gwyther	Hospice Palliative Care Association of South Africa - South Africa	Director
Mr Kiera Hepford	International Palliative Care Initiative - Open Society Institute (OSI) - USA	Programme Assistant
Mrs Carla Horne	Family Health International - South Africa	Regional Senior Technical Officer
Setsabile Hwphe	Swaziland Hospice at Home - Swaziland	
Ms Miriam Igobwa	Kenya Hospices and Palliative Care Association (KEHPCA) - Kenya	Administrative Officer
Mrs Louise Isherwood	Help the Hospices - UK	Education and Training Manager
Dr Mark Jacobson	Selian Lutheran Hospital Hospice - Tanzania	Board Member (APCA)
Ms Wilhelmina Kafhita	MoHSS - Namibia	National PC Coordinator
Dr Bactrin Killingo	Kenya Hospices and Palliative Care Association (KEHPCA) - Kenya	Chairman
Dr Dae Kyun Kim	Korean Society for Hospice and Palliative Care - Korea	
Mr Steve Kirimi	The Resource Alliance - UK	Regional Representative East & Southern Africa
Dr Rose Kiwanuka	Ugandan Palliative Care Association - Uganda	National Coordinator
Dr Yoshiyuki Kizawa	University of Tsukuba - Japan	Assistant Professor

Sin Young Kwon	Korean Society for Hospice and Palliative Care - Korea	
Su Sin Koh	Korean Society for Hospice and Palliative Care - Korea	
Prof Beugre Kouassi	Centre Hospitalier Universitaire Cocody - Cote d'Ivoire	Professor of Neurology
Dr Suresh Kumar	Institute of Palliative Medicine - India	Director
Dr Mhoira Leng	Cairdeas International Palliative Care Trust	Medical Director
Mr Domenic Lippa	Pentagram Design Limited - UK	Graphic Designer & Partner
Miss Jessica Mack	Palliative Care Association of Malawi - Malawi	Programme Manager
Ms Neelam Makhijani	The Resource Alliance - UK	Programme Director
Mrs Joan Marston	Hospice Palliative Care Association of South Africa - South Africa	Paediatric Palliative Care Manager
Dr Anne Merriman	Hospice Africa Uganda - Uganda	Founder
Dr Aleksandra Modlinska	Hospice Foundation Poland - Poland	Board Member
Ms Claire Morris	Help the Hospices - UK	International Project Officer
Dr Daniela Mosoiu	Hospice 'Casa Sperantei' - Romania	Medical Director
Ms Mary Margaret Mpomba	Palliative Care Association of Zambia (PCAZ) - Zambia	National Coordinator
Ms Grace Mukankuranga	Rwanda	
Mrs Karla Muskovic	Department of Health and Social Welfare - Croatia	Advisor for Health
Dr Faith Mwangi-Powell	African Palliative Care Association (APCA) - Uganda	Executive Director
Ms Nadine Nolan	National Hospice and Palliative Care Organization - USA	
Miss Catherine O'keeffe	Mildmay International - UK	Executive Director of Education
Dr Tajudeen Olasinde	Ahmadu Bello University Teaching Hospital - Nigeria	Senior Lecturer/Consultant
Ms Mary Opare	Palliative Care, Ghana - Ghana	Senior Lecturer
Rev. Sr. Osheiza A Otonoku	St Ann's Hospice - Nigeria	
Mr Nick Pahl	Help the Hospices - UK	Development Director
Dr Anil Kumar Paleri	Institute of Palliative Medicine - India	Senior Registrar

Mr David Prail	Help the Hospices - UK	Chief Executive
Dr Lukas Radbruch	Klinik fuer Palliativmedizin - Germany	Chair/ Head of Dept
Dr Cecilia Sepulveda	World Health Organization - Switzerland	Senior Adviser Cancer Control
Dr Anna Towers	Montreal General Hospital - Canada	Director, Palliative Care Division
Mr Andre Wagner	Hospice Palliative Care Association of South Africa - South Africa	Organisational Development Manager
Mr Roberto Wenk	Programa Argentino de Medicina Paliativa-Fundacion FEMEBA - Argentina	Director
Chang Hwan Yeon	Korean Society for Hospice and Palliative Care - Korea	

