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Title: Re-framing Global palliative care advocacy for the Sustainable Development Goal era: a qualitative study of the views of international palliative care experts.

Authors:

Joseph Clark, Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, United Kingdom.

Amy Barnes, Section of Public Health, School of Health and Related Research, University of Sheffield, United Kingdom

Clare Gardiner, The School of Nursing & Midwifery, University of Sheffield, United Kingdom

Corresponding author:
Dr Joseph Clark
Research Fellow in Palliative Care
Wolfson Palliative Care Research Centre
Allam Medical Building
University of Hull, Cottingham Road,
Hull, United Kingdom
HU6 7RX
T: +44(0)1482 47538
E: joseph.clark@hyms.ac.uk

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ABSTRACT

Context: The World Health Assembly Palliative Care Resolution in 2014 and the inclusion of palliative care within the Sustainable Development Goals raised optimism that palliative care would no longer be a peripheral aspect of global health. However, no funding, accountability measures or indicators for palliative care development accompanied these policy developments. This risks health actors continuing to prioritise the attainment of better known, target-driven aspects of healthcare.

Objectives: To explore the attitudes of international palliative care experts regarding how the future development of palliative care can be accelerated.

Methods: Sixteen international palliative care experts were interviewed for their epistemic expertise. Participants were interviewed face to face or via skype. Interviews were recorded, transcribed non-verbatim and analysed using a thematic approach (NVIVO).

Results: Participants strongly supported the rollout of national palliative care policies around the world for two reasons: 1) to ensure palliative care attracts national funding streams and 2) to attract global funding for palliative care. The absence of a global indicator for palliative care development was considered a severe impediment to the inclusion of palliative care within global efforts towards Universal Health Care (UHC). Advocacy partnerships, using human rights approaches with economic ‘frames’, were considered the most effective methods of influencing policymakers.

Conclusions: Palliative care represents a value proposition which is not currently being maximised by advocacy. Advocates should consider palliative care developmentally, focussing upon ‘key asks’ for development and consider how palliative care can contribute to other international development priorities, in particular poverty reduction.

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INTRODUCTION

In 2014, the World Health Assembly (WHA) ratified a Palliative Care Resolution calling for national governments to integrate palliative care as an essential component within all levels of health systems.[1] This is an ambitious aim, which seeks to deliver the WHO definition of palliative care. Our project adopts the WHO definition of palliative care as an approach that improves the quality of life of patients and their families, applicable to any life-limiting illness and appropriate from diagnosis.[2]

The WHA Resolution situated palliative care as a 'component of comprehensive care throughout the life course', ending years of neglect from global policymakers. WHA Resolutions may be considered important political statements. However, they are not enforced by any global agency and are reliant upon member-state implementation. Moreover, no funding was made available for implementation and no targets were set within the new global health priorities, the Sustainable Development Goals (SDGs) for the attainment of the Resolution. This risks palliative care being overlooked by national policymakers as they may prioritise direction of limited funds towards the attainment of more established, measurable global health policy goals.[3]

In the absence of palliative care and effective pain relief, patients are under-treated (through the absence of palliative care) or over-treated as expensive, potentially distressing, curative treatments are continued beyond a time that they are likely to be effective.[4] In both circumstances, people with serious illness may suffer extremely and unnecessarily with health spending poorly directed. To date, palliative care has predominantly developed in high-income countries, where funding for services has largely come from national health budgets and charitable sources.[5] Most low and middle-income countries do not have national palliative care policies and access to services is extremely limited. The challenge of implementation of the Resolution is therefore significant as many healthcare systems around the world face significant challenges in the provision of other basic services, without 'adding' palliative care provision. Additional resources will therefore be required for the implementation of the WHA resolution.

Many health systems in low and middle-income countries are funded through a combination of national-funding and external funding from bilateral international aid and global health agencies such as the World Bank.[6] With national-resources extremely limited – and already allocated towards other health concerns – there appears to be a necessity for engagement from global funders. In a market-place of competing claims for resources, a key challenge for advocacy will therefore be to 'frame' palliative care in an acceptable manner to global funding agencies.

In global health research, it is known how funders prioritise 'tractable' issues (where a serious problem and solution are defined) and which are aligned with their organizational objectives. For example, the World Bank conceptualises health as a mechanism for economic growth and is therefore receptive to health interventions which promote human capital.[7] However, such perspectives have not yet been incorporated in to palliative care research and advocacy. In recent years global advocacy has focussed upon the need for palliative care as a human rights issue.[8,9] This is problematic, as funders like the World Bank are known to be resistant to rights-based claims. Moreover, 'palliative care' is a non-prescriptive approach, making 'access to palliative care', difficult to define and little is known regarding the effectiveness and feasibility of different models of palliative care in all settings.[10] Lastly, the outcomes of palliative care intervention are so varied that there is no single indicator to measure development.

New approaches to advocacy are therefore required which situate palliative care not as an issue in isolation, but as a key global health issue. Our qualitative study reports the views of international palliative care experts regarding the feasibility of implementing palliative care in all settings. Our study adds new perspectives regarding how problem of 'lack of palliative care' should be defined and how palliative care can contribute to broader global health goals.

The aim of this study was to explore:

- Expert views on how global palliative care advocacy efforts may be refined to ensure that palliative care makes gains within the global health priority of achieving Universal Health Care (UHC).

METHODS

Given the exploratory nature of this enquiry, a qualitative study design was used. In-depth, semi-structured interviews were conducted to elicit rich data from 15 international palliative care experts and a patient-representative with experience of international palliative care research. This approach was justified, as neither the questions nor analysis required quantifiable data.[11] Instead, the intention of interviews was largely to facilitate rich conversations.[12]

Participants and recruitment

We recruited a diverse study sample in terms of professional background and world region. Initially, a purposive sampling approach was used, contacting experts known by the authors to be active in palliative care internationally using email. Secondly, participants were recruited face-to-face at the European Association for Palliative Care (EAPC) international conference in Copenhagen, 2014, using a pragmatic approach based upon the recommendations of existing participants, with a purposive approach. All those approached agreed to take part and sixteen semi-structured interviews were conducted. The characteristics of the study population are presented in Table 1 including a public-patient representative, who was included to guard against reporting purely professional views. Recruitment was ended when interview data were reinforcing emergent themes and no new topics were emerging.

Table 1: Characteristics of study population (n=16)

Data collection and analysis

An interview guide was developed and piloted following a review of relevant literature and policy (Table 2). The interview guide aimed to explore attitudes towards a developmental approach to palliative care integration and aspects of a palliative care advocacy strategy.

Table 2: Key areas for discussion within interviews

Interviews were electronically recorded, transcribed non-verbatim and anonymised with transcripts (n=16) imported into 'NVivo 10.[13] Themes were developed using qualitative content analysis and informed by a Global Social Policy (GSP) theoretical perspective**Error! Bookmark not defined.** in a five stage process[14] consisting of: 1) sensitisation to the data, 2) double-free coding, 3) theme development, 4) review of themes and 5) an iterative approach to writing.[15]

Mind maps were used in order to draw out complexities and overlaps between codes[16] and a coding framework was developed with core and sub-themes identified.[17] Coding and theme development was conducted individually by JC/CG with an ongoing process of constant comparison, to reduce potential researcher bias and increase internal validity.[18] After this process, all data could be associated with established themes. Direct quotations have been selected to illustrate the issues raised by participants and are generally indicative of many responses.

Ethical Approval

The study was granted ethical approval from the School of Health and Related Research (ScHARR) ethics committee at the University of Sheffield. A Participant Information Sheet was presented to participants prior to interviews. All participants provided oral consent and interviews were audio-recorded. Interviews and the informed consent process were conducted by JC.

RESULTS

Three themes emerged from the data to inform global palliative care advocacy:

1) Organization and funding of services;

2) Global policies and leadership; and

3) Re-Framing palliative care advocacy

Organization and Funding of Services

Participants were highly supportive of the WHO’s public health approach and the need for additional resources for palliative care development. Participants emphasised the need for countries to have National Strategies for implementation, but had diverging views as to whether Strategies and advocacy should aim at securing national-level funding streams for palliative care or funding from alternative sources:

> *The funding for palliative care needs to come mainly from national governments. At least it depends, in some countries its healthcare insurance, in other countries it’s the government directly who finances healthcare and that’s the direction it needs to go in I feel. Pharmacist, Europe, (01)*

Participants acknowledged that worldwide, awareness of palliative care remains low and that health systems around the world face serious challenges in the delivery of healthcare. Yet, common views were expressed that the roll-out of palliative care is not only achievable through a reallocation of resources, but is itself a mechanism for cost-reduction and the ongoing sustainability of health systems.

> *If there is a category of patients who are in pain, who are not treated for the pain now and need a lot of support almost continuously, healthcare systems or economies would save a lot of money if they treat the patients for their pain. And that can be either that a nurse can do something else, or you need less nurses or that a relative taking care of a person at home can go back to work or do other things. Pharmacist, Europe (P01)*

Lastly within this theme, many participants raised a key question about what a ‘minimum package’ of palliative care should be. Participants indicated that this was a key issue for palliative care advocacy and raised questions about the feasibility of rolling out holistic care and the relative importance, feasibility and acceptability of different aspects of ‘palliative care’.

> *The Universal Health Coverage movement and what we are all aiming for, you know, there’s a global movement for UHC, so one of the things is how we can get palliative care as a component of the Universal Health Coverage, they will also… want to know what is the*

> *minimum package that Universal Health Coverage needs to cover. Physician, South America (P09)*

> *In our research and advocacy, we've prioritized treatment of pain because it's often the most pressing issue for patient and family. Activist, North America (P12)*

Global Policies and Leadership

Many participants were satisfied with the global level leadership provided by the WHO and pointed to examples of 'pioneers' providing national-level leadership affecting positive change towards the further development of palliative care. Despite this, other participants reported both a need for more 'leadership' within nations and from global actors. There was acknowledgement of the need for increased and improved leadership at all levels, with examples of emerging international 'leadership' programs leading to positive change:

> *It's actually quite staggering what some of these people have done. Way beyond what a typical graduate in the UK, or the Unites States would do, these people are really advancing palliative care in their country, and they're often doing it with great difficulty. Physician, North America (P13)*

Participants were united in their positivity regarding the future of palliative care in the wake of the WHA Resolution. However, a key concern was the absence of an enforcement mechanism for the Resolution and of the ongoing regulation of essential medicines by the International Narcotics Control Board (INCB). In this regard, an ongoing role for civil society actors was suggested, to continue lobbying, forge partnerships and to use different approaches to engage policymakers:

> *Governments are actually a bit peeved when you come at them with human rights, it's a confrontational discussion, but that's one of the reasons why Human Rights Watch and World Hospice Palliative Care Alliance and International Association of Hospice and Palliative Care [IAHPC], have such a good partnership, because Human Rights confronts, and we [IAHPC] say 'how can we help you improve?' Physician, Africa (P07)*

As well as calls for increased leadership and critique of global level policies, participants expressed frustration that palliative care commonly continues to exist on the outskirts of the medical mainstream. In this regard, participants called for new sources of financing to move away from short-term charitable funding, towards a sustainable global model of palliative care development:

> *You can't really have an impact if you're going to be outside the system and you're going to just use charitable dollars to take care of a few patients, which somebody called, 'deluxe dying for the few'. Physician, North America (P03)*

> *It's time for governments, the UN and the World Bank to step up to the plate and stop letting us carry the water for them. Activist, North America (P02)*

Lastly, several participants strongly expressed the need for palliative care development to be 'measurable'. Thus, the lack of an indicator for palliative care within the SDGs was considered a serious blow for advocates at national and global levels.

> *Once we have an indicator, we can then go to our Ministry and say 'you need to be held accountable to this indicator', so you need this indicator to be part of your Country Operational Plan, then when we go to USAID, we can say 'this is part of the Kenyan Operational Plan, this thing is in the plan, please fund it'. Activist, Africa (P16)*

1) Re-Framing Palliative Care Advocacy

Participants were united in the view that in order to further the global development of palliative care, focussed advocacy was required, at micro (local), meso (national) and macro (global) levels of global governance. At national and local levels, participants emphasised the need for advocacy approaches that focussed upon raising awareness through story-telling, experiential learning and engagement with local communities:

> *I think the experiential effect of knowing somebody who has received palliative care, reverberates around the community, and that, changes perceptions, it raises expectation. I was looking after a Minister's mother, one of the Ministers in the government, and we provided palliative care to his mother and he said, 'now, if you can do this, why can't our hospitals do this? Because they had been in their own hospitals and private hospitals, 'you're providing a free service and you're doing what others can't do'. I said, 'that's a challenge to you, you're in a position of power…you make the change'. Physician, Asia (P05)*

A key perceived barrier at the global level however, related to the difficulty of 'getting a seat at the table' in order to influence policymakers. When asked which organizations should be the targets for advocacy one participant reported:

> *The big UN agencies, of course, WHO, USAID, UNICEF, all of these we are acting with, at present, we actually have a side-event at the World Health Assembly in two weeks' time specifically for paediatric palliative care, so that's where we're really going to give the message around paediatric palliative care, but I think you know, also… global level funders, like Global Fund, USAID, the Gates Foundation, it's just finding a way to get in there. I'm sure if we could get in there we could make the argument, but it's not that easy… Nurse, Africa (P06)*

A proposed method of overcoming this was to forge partnerships. The importance of the need for a diverse range of arguments for the development of palliative care was also put forward alongside a change of language:

> *When you look globally, there's a lot of discussions around end of life care… [but] anything to do with death is not good, and whilst palliative care people are very open to talk about death and dying, the general population are not…. I think that's where we do need better, things like selling the product, marketing. Physician, Asia (P05)*

When asked how arguments for palliative care could be framed within existing global funding priorities, participants reported that in certain circumstances where patients do not access palliative care and pay for their healthcare, that expensive (and potentially futile) treatments lead to financial difficulty for families. Palliative care could contribute to both poverty reduction and poverty avoidance and was therefore relevant to broader priorities of international development:

> *In India I've seen it, where patients are referred to hospitals and for intensive treatment and families go into debt, and they become 'debt-slaves' that's what some of my colleagues call it. Activist, North America (P02)*

> *Some of the [patients'] symptoms once they are controlled… once pain is managed, some of these people are able to go back to productive work, so it's helping them make sure that these people stay as healthy, as pain free and as symptom free as possible, so that they can continue with their every day job. Activist, Africa (P16)*

Participants used rights-based language during discussions and support was expressed for access to palliative care to be a human right. However, there was also acknowledgement that existing human rights laws were not drafted to purposefully include palliative care. Participants suggested palliative care was an element of two existing human rights: the right to freedom from torture and the right to health:

> *You have to construct that right. You know, the right to the highest attainable level of physical and mental health and clearly, palliative care falls within that right. Activist, North America (P12)*

All participants presented access to pain and palliative care services as a moral imperative. Indeed, participants took a highly principled stance in all interviews arguing that it was incumbent upon richer nations to assist poorer nations in the provision of palliative care:

> *Under the principle of mutual and shared responsibility, which is a principle of international law, the more developed countries with money would finance, with technical assistance or whatever, whatever needs in the lower resource countries that they have, to develop their workforce and to develop their medical industries or whatever they need. Not as charity, but as mutual and shared responsibility. Activist, North America, (P02)*

Some participants suggested that for the purposes of advocacy, gains could be made by focussing upon the suffering which children endure in the absence of palliative care due to the emotional impact of such images. However, it was also suggested that advocacy should focus upon positive stories as opposed to an emphasis on human suffering:

> *If you look at the palliative care it has evolved showing lots of graphic images and people in pain and screaming and that is absolutely not good, it's counter-productive, and we don't want to show, to even increase vulnerability for people who are already vulnerable... I think sometimes we have used patients and used the circumstances to meet our own advocacy demands, but without any direct benefit to the people we have used, so I'm always very careful when we are using patients, if there is no direct benefit to that patient. Activist, Africa (16)*

DISCUSSION

This global qualitative study provides insight in to the challenges and opportunities for the global development of palliative care. The three themes reported, combine to demonstrate the inter-dependence of national and global health policies. National health policies are formulated within context of local need and a drive to attract funding, by directing policies towards the attainment of the SDGs. Yet, nationally-devised policies can also lead to engagement from global health funders, who operate within the obligations of the Paris Declaration on Aid Effectiveness to direct funding towards nationally-devised priorities.[19]

Within this context, participants stressed that roll-out of palliative care was feasible in all income settings. A key reason for this is that, whilst some health systems will require new sources of finance for palliative care, in others, health spending is currently poorly directed. Indeed, in all resource contexts, participants reported that in the absence of palliative care, participants reported extensive 'overtreatment' of serious illnesses at great financial cost. Even where palliative care services are available, patients and health professionals remain willing to continue (or commence) expensive curative treatments beyond a time they may be expected to be effective. This leads to unnecessary physical suffering for patients and, adverse economic consequences for households and health systems.[20]

Where services are available, it is an avoidable tragedy that palliative care is not commenced in favour of ongoing active treatments. Where access to services is low, development of palliative care – alongside curative services with appropriate referral pathways, represents the most cost-effective approach to high quality health delivery. Therefore, in some contexts advocacy should focus upon a reallocation of resources, whilst in low and middle-income settings, the emphasis may be upon securing new sources of finance for clinician training and service development. Yet, participants stressed that in all settings, there is still work for advocates to do in convincing a dubious public that palliative care can be viewed as a desirable treatment option.

In Theme 1, participants identified the establishment of national palliative care policies as a developmental priority and an essential element of securing sustainable funding for palliative care services in two ways. In countries with the resources to do so, national governments must be lobbied to provide the funding for service developments.[21] However, many health systems around the world are reliant upon Overseas Development Assistance (ODA) in order to continue to function. It is therefore essential that advocates and leaders push for palliative care to be included within National Health Strategies: for the dual purpose of attracting either national *or* global level funding.[22]

Theme 2 reveals optimism from some participants regarding global situation regarding: the ongoing leadership provided by the WHO and the International Association of Hospice and Palliative Care (IAHPC) amongst others and global policies such as the WHA Resolution. Yet, this study also identified a leadership gap in terms of how palliative care activists are engaging with global funding agencies such as the World Bank. This risks target-driven 'global health priorities' crystallised within the SDGs receiving the majority of global funding at the expense of palliative care development.[23] In the absence of an indicator for progress towards the WHA Resolution, civil society organizations retain a key role in holding governments that ratified the Resolution to their obligations. However, as funders increasingly operate 'results-based financing' approaches, it is essential that researchers work towards developing a consensus regarding what a palliative care indicator may look like.[24]

The recent Lancet Commission on Palliative Care and Pain Study Group report (2017) offers a timely response to such calls. The report moves beyond a focus upon pain to include other problems and symptoms, (e.g. breathlessness) through their articulation of a Serious Health-related Suffering (SHS) measure.[25] The report also offers guidance on just what an 'essential package' of palliative care looks like. Crucially, however, the Commission stopped short of quantifying SHS into a measurable indicator, which limits the usefulness of the report for the purposes of advocacy. Indicators relevant to palliative care do exist, for example, Opioid Consumption per capita and cancer mortality. However, these indicators do not provide a measurable indicator about either access to palliative care for all life-limiting illnesses, or quality of services.

Lastly, Theme 3 considers how activists should respond to this challenge by considering participants' views regarding current and future palliative care advocacy strategy. In recent years much global palliative care advocacy has centred on the notion that access to palliative care is a 'human right'.[26] In spite of general support amongst participants for this notion, there was also scepticism regarding the utility of rights-based approaches to advocacy. Some participants acknowledged that the 'right to palliative care' was something which has had to be 'constructed' within existing human rights legislation whilst others questioned the relevance of human-rights arguments to all world regions.[27]

Advocates should therefore adopting new approaches. Moving forwards, some participants encouraged learning lessons from other related advocacy campaigns regarding of how the problem of 'lack of access to palliative care' is defined.[28] This may mean advocates separating 'palliative care' into its constituent elements by focussing upon the problems caused by the absence of different elements of palliative care, how these problems may be addressed and the benefits which may accrue from doing so. Indeed the aggregated measure of SHS is at odds with the preference of some participants to think developmentally and prioritise issues based on their importance and 'solvability'. Whilst opioid medications remain heavily regulated,[29] access to pain treatment is not only the most pressing problem around the world, but the most tractable problem for presentation to policymakers. Advocates are able to clearly state the severity of problems faced by people due to lack of access to pain treatment for palliative care and other aspects of health (e.g. post-surgical care) and offer clear solutions such as appropriate regulations and prescribing. The benefits of effective pain management extend to promoting both human and social capital, arguments to which national policymakers and global funding agencies are likely to be responsive.[30]Poverty reduction and poverty avoidance are two key aims of international development.[31] Data from our study as well as emerging research suggests palliative care may be able to contribute to both of these goals.[32] Families around the world are known to experience severe financial hardship related to the onset of a serious illness.[33] Reduced costs benefit both health systems and poor families who pay for healthcare, whilst reduced caring burden and effective symptom management promote both human and social capital, freeing carers and patients to pursue economic gain and maintain usual functions. With the predominant care burden in many world settings falling upon women and children, a reduced caring role may promote school attendance and reduce inequalities. What is more, global funders such as the World Bank tend to be more amenable to health issues that promote 'human capital' as opposed to human rights and tend to fund projects with measurable outcomes.**Error! Bookmark not defined.** This raises the need for an indicator for palliative care development and reinforces that new approaches to advocacy are required in order to attract global-level funding. Such advocacy approaches must be supported by the research community to provide an evidence-base for economic claims.

Advocates may feel uneasy about conceptualising the value of palliative care economically. However, through the formation of partnerships and advocacy coalitions, diverse but mutually reinforcing arguments may be presented to policymakers.[34] Participants reported for example, how partnerships formed between different, but complementary organizations such as the WHPCA and Human Rights Watch were effective in promoting positive change in terms of national drug regulations. Further partnerships should be forged with lobbies outside of palliative care for mutual benefit. Combining moral necessity with an economic imperative may be a fruitful way to engage health policymakers at all levels of health governance.[35]

The present study had some limitations. First, data were collected at a single time-point in 2014 only. Second, data analysis was conducted by two European researchers meaning that there may be some implicit Eurocentric bias in our analysis in spite of ongoing reflection by JC/CG on such issues. For feasibility reasons, we were unable to collect further data to reflect changing views within the ever-changing global health landscape and were not able to return transcripts to study participants for verification. Our results should therefore be read only in the context presented.

In conclusion, palliative care appears to offer a value proposition which is not currently being maximised by research and advocacy. Advocates should consider their promotion of palliative care developmentally, focussing upon 'key asks' using different 'frames' to resonate with different policy actors.

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Table 1: Characteristics of study population (n=16)

Study ID	Region	Primary training / background	Illustrative international role(s) and expertise
01	Europe	Pharmacist	Senior pharmacist for International Organization
02	N. America	Activist	Advocacy Officer for International Palliative Care Association
03	N. America	Physician	Consultancy for International Palliative Care Associations
04	Asia	Physician	President of National Association of Palliative Care, International palliative care education coordinator
05	Asia	Physician	Medical Director of National Hospice, Consultant for International Palliative Care Associations
06	Africa	Paediatric Nurse	Chief Executive of an International Children's Palliative Care Association
07	Africa	Physician	CEO of national Hospice Palliative Care Association, Chair of International Palliative Care Association, Technical advisor to International Organization, Director of global palliative care media outlet
08	Europe	Project Manager	Project Manager of philanthropy organization funding European palliative care leadership training
09	S. America	Physician	Executive Director of International Hospice Association
10	Europe	Private Physician	EAPC Task Force Member of Regional Palliative Care Association, International Researcher, Pharmaceutical Consultancy
11	Europe	Patient-Public Representative (PPI)	PPI Representation on international palliative care study
12	N. America	Human Rights Activist	Associate Director of Health and Human Rights Organization
13	N. America	Physician	Board Member International Palliative Care Association
14	Australasia	Physician, Lawyer	International Human Rights Law, International palliative care capacity building consultant
15	S. America	Physician	President of Regional Palliative Care Association

16	Africa	Activist	Co-founder of Regional Palliative Care Association, Implementation and evaluation of palliative care services across Africa, Lobbyist and Advocacy Officer for International Philanthropy organization

Table 2: Key areas for discussion within interviews

- How to conceptualise the global need for palliative care.
- Examples from around the world where palliative care is working well and who benefits from this (and how).
- Key organizations/individuals/partners as targets for palliative care advocacy.
- Key arguments being made for palliative care at a global level (and who is making them).
- If present, location of palliative care within current global health priorities.
- Key objectives for global palliative care advocacy.
- Identification of key realistic changes that palliative care should aim for.
- Potential key partners for the palliative care lobby that do not work in palliative care currently.
- Potential barriers/arguments against the further roll-out of palliative care.