



Report of the Proceedings of
All Ireland Institute of Hospice
and Palliative Care
**Global Colloquium on
Palliative Care**

October 14th - 15th 2015, Dublin Castle

Executive Summary



AIHPC

All Ireland Institute of
Hospice and Palliative Care



**World Health
Organization**

Foreword

All Ireland Institute of Hospice and Palliative Care (AIHPC) was delighted to host the Global Colloquium on Palliative Care and are indebted to the World Health Organisation for their co-sponsorship of the event.

The Global Colloquium on Palliative Care was a key initiative for AIHPC. The purpose of the Colloquium was to gather an assembly of national level policy and clinical experts from across the world to explore palliative care issues and to provide a context for purposeful discussion of the World Health Assembly Resolution (WHA67.19) which calls on member states to strengthen the integration of palliative care services into national health services.

Themes that were explored during the Colloquium included a public health approach to palliative care, models of palliative care provision, palliative care and chronic illness throughout the lifespan and the integration of palliative care into various care settings and the challenges for palliative care leadership, research, education and practice.

Among the delegates in attendance were members of Voices4Care, AIHPC's panel of palliative care users and carers who brought unique insights about palliative care which were invaluable to discussions at the Colloquium about palliative care service design, development and implementation.

The Global Colloquium provided an exciting and timely opportunity for debate and discussion of how the recommendations of the World Health Assembly Resolution (WHA67.19) are being addressed while also setting out the vision for the continued strengthening and integration of palliative care into national health systems.

The report of the proceedings of the Colloquium (www.aiihpc.org) includes the speaker's presentations, discussion, deliberations and participant responses to key questions related to the WHA Resolution. We hope that the report of the proceedings will inform the reporting of the progress of the Resolution when the World Health Assembly meets in May 2016.

We are indebted to the work and contribution of the members of the Colloquium Steering Committee.



Prof Philip Larkin
Chair, AIHPC



Ms Paddie Blaney
Director, AIHPC

Executive Summary – Day 1

Welcome

Paddie Blaney, Director, All Ireland Institute of Hospice and Palliative Care (AIHPC), welcomed delegates to the colloquium, which was an opportunity for the Institute to showcase to the global community its achievements and to debate and discuss how to ensure people around the world could receive the best possible palliative care. The World Health Organisation's (WHO) co-sponsorship of the event represented a major endorsement of the Institute's work and the contributions made by Northern Ireland and the Republic of Ireland to palliative care.

World Health Organisation

Dr Ed Kelley of the WHO observed that there was now broad recognition that the issue of palliative care touched almost everyone who came through health systems and that it was not just an issue for countries that had reached a certain level of economic development. This colloquium would be the first international opportunity for the WHO to discuss and try to advance the implementation of the resolution on palliative care that had been passed by the World Health Assembly (WHA), and was an opportunity to push both from the disease perspective and from an integrated, people-centred perspective.

Minister of Health's Remarks

Dr Leo Varadkar, TD, Minister for Health, Republic of Ireland, welcomed delegates to the Colloquium, which he saw as a great opportunity to discuss the ground-breaking resolution that had been passed by the WHA, to share experiences and to feed into the work of the WHO.

A national clinical programme for palliative care had been implemented in an effort to standardise and improve palliative care in Ireland. All services now provided specialist palliative care on the basis of need rather than diagnosis. The framework had been developed in partnership with the AIHPC, among other bodies. The Minister summarised some of the policies that had been implemented under the framework.

The fact that many more people were living much longer meant a growing number of people had chronic or life-limiting conditions, and societies needed to plan now to meet future demand for palliative care. The Irish Government sought to ensure that everyone in Ireland could access the type of palliative care that was most appropriate to them, regardless of their circumstances. Big improvements had been made in recent years, but many challenges remained and there was no room for complacency.

The Minister acknowledged the work being done by the AIHPC; it had only been possible to develop palliative care services in Ireland because of the longstanding positive relationship between the Government and the voluntary sector. He wished delegates success in their discussions.

SESSION 1: WHO INITIATIVE ON PALLIATIVE CARE

What is the WHA Resolution About?

Dr Belinda Loring, Technical Officer in Palliative Care at the WHO, reflected that most people in the world who needed palliative care currently had no chance of accessing it. This was a huge global challenge, which would only grow. There were many inequities in provision of palliative care; vulnerable groups were missing out. The WHA resolution marked the first time all 194 member states had joined together to make a unanimous commitment to palliative care. Ministers had acknowledged that palliative care needed to be available for all people of all ages with all diseases.

What Has the WHO Been Asked To Do?

The WHO's support had been requested on five priority actions:

- Integrating palliative care into the core work of other WHO programmes.
- Developing tools and guidance for member states.
- Supporting member states to improve access to medicines.
- Building the evidence base for models that work, especially in low and middle-income settings.
- Improving monitoring and tracking progress.

This was a cross-cutting issue involving staff across the WHO; the organisation was trying to encourage the idea that palliative care was everybody's responsibility. The WHO was very grateful for the support of its partners in the field.

What Have Countries Been Asked To Do?

The resolution asked countries to:

- Develop and strengthen palliative care services integrated in all levels of health systems.
- Ensure all health professionals had basic competence in palliative care.
- Support families, care givers and volunteers.
- Improve access to medicines.

Summary

Palliative care is not just an important health issue, but an avoidable humanitarian crisis. There was no reason that a country of any income level could not do more to reduce suffering. The resolution recognised that action was especially urgent in settings where access to early detection and treatment was a long way off. The WHO would continue to focus on supporting countries to implement these commitments, but delegates also had an important role to play in reminding their governments of their commitments, and were encouraged to look for opportunities to ensure palliative care remained on the agenda.

Palliative Care and Integrated People-Centred Services

The Global Context

Dr Kelley stated that he had recently returned from Sierra Leone, where he had met an Ebola survivor who was now taking care of her deceased daughter's children while suffering from blindness and extreme joint pain. The global context was one of increasing ageing, with the incidence of non-communicable diseases rising worldwide, urbanisation and costs increasing, and climate change having an effect. There was also increasing innovation, and a general increase of the 'consumer voice' in healthcare delivery.

Constraints

Constraints such as misaligned financing, service fragmentation and a lack of engagement still existed, and the health workforce was sub-optimised. Services needed to be people-centred; health professionals globally were being trained in ways that militated against this, and carers were often not given proper advice on how to provide care or navigate the healthcare system.

Integrated Service Delivery Model

The new integrated service delivery model was person-centred, with the family and community acting as support networks, and services aligned around these. There had been a call from healthcare managers for better integration and data. As per the resolution adopted in 2014, lack of access to opioids and strengthening capacity would be two focus areas; manuals, communication tools and demonstration projects would be produced and reviewed. Ultimately, this was a matter of rights and equity; while remaining cognisant of the limitations posed by global economic development, those present would need to consider how to provide palliative care to people like the woman Dr Kelley had met in Sierra Leone.

Palliative Care in the Eastern Mediterranean Region

Regional Context

Dr Ibtihal Fadhil, Regional Advisor, WHO/EMRO, stated that non-communicable disease, including cancer, was a major issue in the Eastern Mediterranean region. In Tunisia, Egypt and Lebanon, up to 85% of death was premature. Incidence of cancer was anticipated to increase in the region by 200% by 2030. Most cancer cases occurred before the age of 55, and most were advanced when patients presented. The most common cancer in females was breast cancer, and colorectal cancer was very common for men, along with lung and bladder cancer. This was a consequence of the popularity of smoking in the region.

Regional Developments

One of the major milestones in the region had been the 2011 UN High-Level Meeting on Non-Communicable Diseases. This had been transformed into a regional framework for action, with work divided into four areas: governance, prevention, surveillance, and healthcare. Within healthcare, the focus was on palliative care, assessing individual countries' responses, and providing technical advice and support. A lot of this work had been ongoing prior to the resolution; in 2008 and 2009, a cancer strategy had been developed consisting of capacity-building, improving the accessibility of pain management, and home-based and community palliative care services, which were preferred to institutional care in many Eastern Mediterranean countries.

Principal Regional Challenges

The key challenges in palliative care were:

- Misconceptions among individuals and the medical community in the region.
- A lack of qualified staff.
- A lack of awareness.

Challenges of Access to Opioids in the Eastern Mediterranean Region

Regional Variances and Statistics

Dr Marthe Everard, Coordinator, Essential Medicines and Health Technologies, WHO Regional Office for the Eastern Mediterranean, stated that the Eastern Mediterranean was a very diverse region, with high-income, middle-income, and low-income countries and failed states. Only Iran was above the global mean for opioid consumption; all of the other countries in the region were far below the mean. The WHO was reliant on data provided by the International Narcotics Control Board (INCB), but some countries did not report yearly, which meant that morphine consumption in some countries was not measurable. Consumption had increased by 10% or more in some countries, although a 10% decrease had been seen in Lebanon, Libya and Tunisia, for unclear reasons.

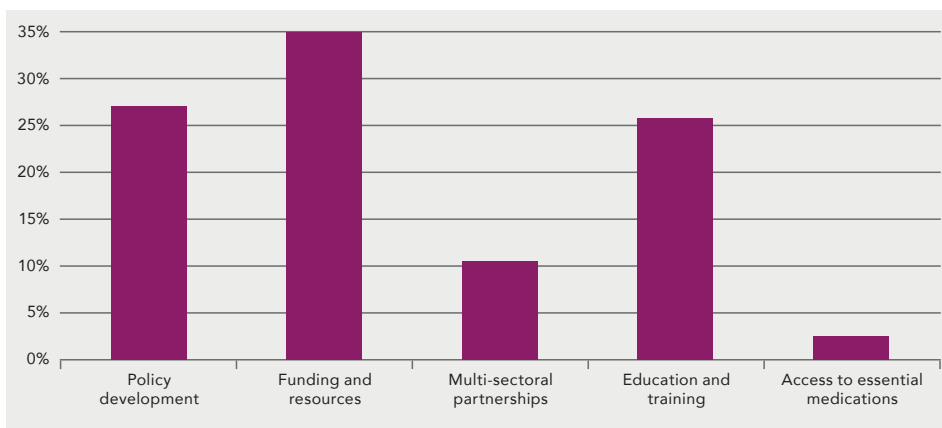
Multi-Factorial Approaches

Barriers to access were multi-factorial, and both the health side and the policy side would need to be addressed. There were problems with inadequate education, an exaggerated fear of opioids and addiction, and problems in the supply chain; there were also legal and regulatory barriers, policy barriers, restrictions arising from knowledge and societal attitudes, and economic aspects to the problem.

The Balanced Policy Approach

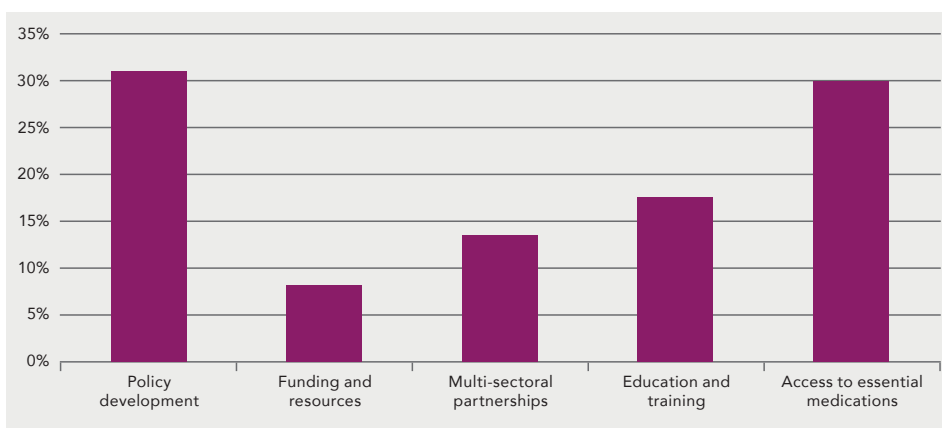
A study undertaken by the INCB had found that there had been so much emphasis on abuse of opioids that countries were afraid to put systems in place that would allow for their use. Countries would need to both ensure opioid availability and protect populations against abuse and dependence, taking a 'balanced policy approach'.

SESSION 1: PARTICIPANT RESPONSE



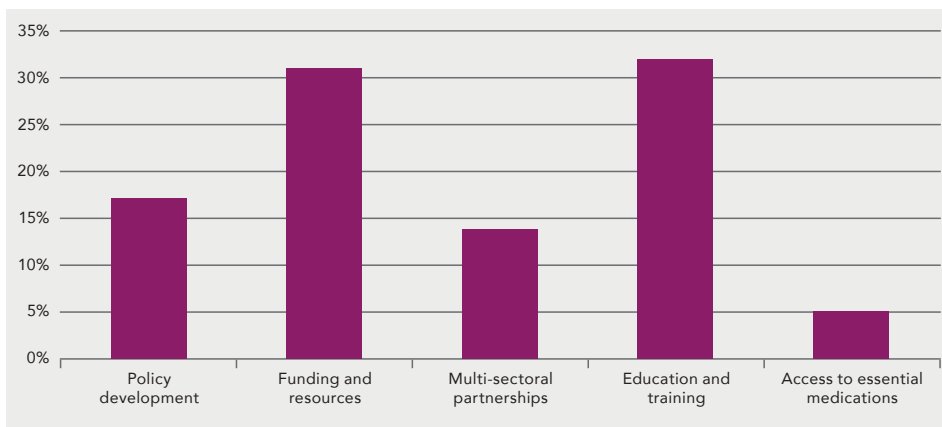
Chairs Question

In your opinion, what aspect of the WHO initiative related to WHA Resolution (A67_R19) would you say is most important in your country/region?



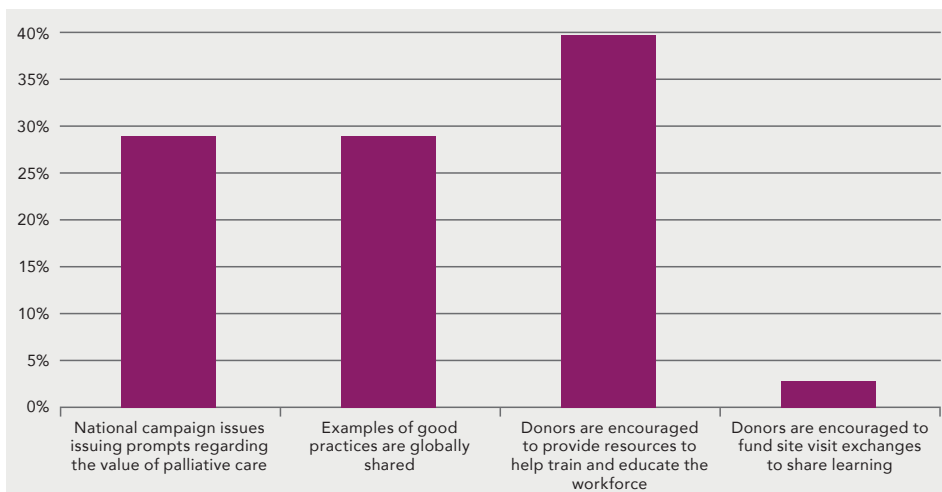
Question A

In your opinion, what aspect of the WHO initiative is most well developed in your country/region?



Question B

In your opinion, what aspect of the WHO initiative needs most development in your country/region?



Question C

In your opinion, what activity would facilitate your country's/region's ability to strengthen palliative care as a component of integrated treatment throughout the life course?

SESSION 2: THE GLOBAL HEALTH APPROACH TO PALLIATIVE CARE

Implementing the Palliative Care Revolution

Dr Emmanuel Luyirika of the African Palliative Care Association (APCA) stated that his focus would be on identifying stakeholders: globally, nationally, and in the palliative care 'orchestra'. The key global players were member states; training and education institutions; civil society; the Director General of the WHO; and patient associations and family members. A number of 'Ps' were vital to consider when identifying stakeholders, including person-centricity, policies, place, primary care, and what problems existed. The most important concept to bear in mind was that of partnerships. National stakeholders included ministries of health; health service commissions; universities and allied health worker training institutions; professional councils; and national palliative care associations. Hospices, and community and home-based care providers, also needed to be involved.

National and Regional Variations

There were variations across Africa: in Uganda, for instance, there was one doctor for every 20,000 people. The Global Atlas of Palliative Care highlighted countries in which nothing was happening and it would not be easy to identify stakeholders in these countries, but this work had to be done. In Africa, 21 countries now had national palliative care associations, and particularly good progress had been made in these countries. Population distribution and specific social-cultural contexts needed to be considered; various models had been advanced, and in Botswana, for instance, a model had been introduced in which retired nurses provided palliative care in the community. Dr Luyirika noted that nurses were key stakeholders in Africa and needed to be empowered to provide opioids.

Challenges

Major challenges remained, including limited funding, poor coverage, poor access to opioids, and ignorance among the public and health workers; to make progress, good systems needed to be built, and health worker training had to be strengthened, among other things. The APCA would work with everyone possible to make sure that this happened.

Global Health Approach to Palliative Care

The Changing European Context

Professor Luc Deliens, Professor of Palliative Care Research and Director of the End of Life Care Research Group, stated that no perfect model for palliative care had yet been established in Europe. There had been substantial changes in culture: increasingly, people with long-term conditions wanted more control over their healthcare. More legal frameworks now supported these changes in values, with laws on patients' rights and palliative care. The cultural background of professionals was also changing.

A Cultural Revolution

Healthcare systems and medical schools were disease-centred, with doctors addicted to 'diagnosticism', which made integration with palliative care more difficult: palliative care professionals delivered patient-centred, generalist care and focused on quality of life. There needed to be a 'cultural revolution' in order to make palliative care easier to provide, which the WHO had already initiated. There needed to be clarity about what was meant by palliative care, differentiating between specialised and generalist palliative care; all health workers should be trained in the latter. Palliative care in the community would also need to be integrated into healthcare systems. The areas of research, practice development, and community development would all need to go through a revolution.

A comprehensive approach was already being taken in the Netherlands, which proved that there was money available for palliative care in Europe. Four themes had been prioritised:

- Awareness and culture
- Organisation and continuity of care
- Care innovations and quality
- Patient participation and support

The projects that this scheme incorporated cut across the sectors of research, education and practice development.

Summary

As medicine always involved supporting patient and family, palliative care should be a core competence of professionals and should be more prominent. Global healthcare reform would be necessary to make sure that this happened.

Transfer or Translation?

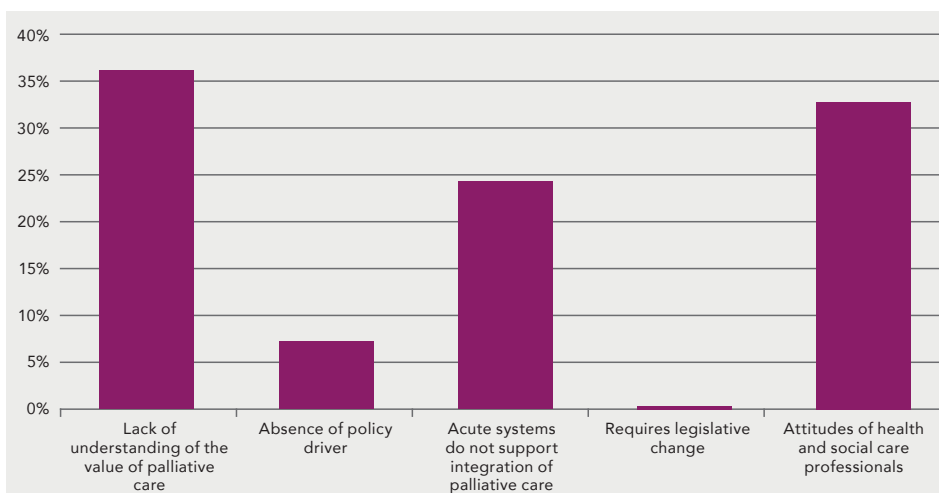
Dr Shahaduz Zaman observed that end-of-life care would have major global importance during the 21st century, but there remained a dearth of interest in the global health agenda. While it was important to keep palliative care in mind as a global health challenge, there were huge global differences:

- Countries were in different demographic stages and at different levels of health system preparedness.
- Local moral worlds were different; for example, there were differences in the understanding and meaning of death.
- Different politico-legal systems existed around dying.
- The availability of evidence was variable.

Dr Zaman juxtaposed Jan Stjernswärd’s idea that there was ‘either one common future or none’ with Suresh Kumar’s assertion that no significant results would be achieved through the ‘conventional track’. When people talked about bridging the gap between developed and developing countries, there was an assumption the latter should catch up with the former. However, there was risk in this linear vision of the future.

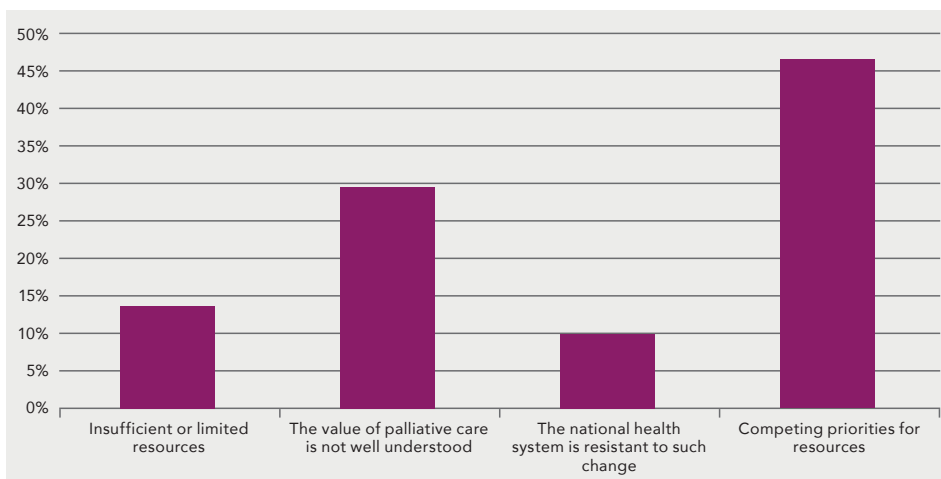
Dr Zaman presented two alternative approaches to development of palliative care: transfer and translation. There was an assumption that countries at the bottom of the Quality of Death Index should aspire to be like high-ranking countries, but there were questions about whether transferring models from high-ranking countries was an ideal approach. It was important to bear in mind that when a model, idea or technology developed in one context and transferred to another context, the receiving country engaged with it in different ways and, in doing so, translated it. It was important to look critically at the transfer and translation of different models, as palliative care was an intersubjective process, and the body of the dying person became an arena for conflicting cultures of providers, policymakers and relatives. More emphasis should be placed on translation in research and policy discussions.

SESSION 2: PARTICIPANT RESPONSE



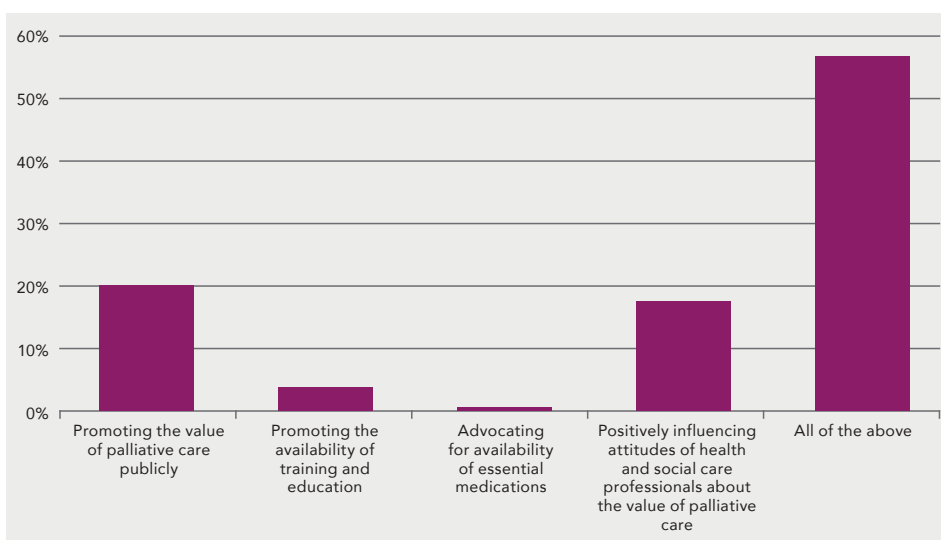
Chair’s Question

In your opinion, what is the most significant challenge your country/region faces in integrating palliative care into national health system(s)?



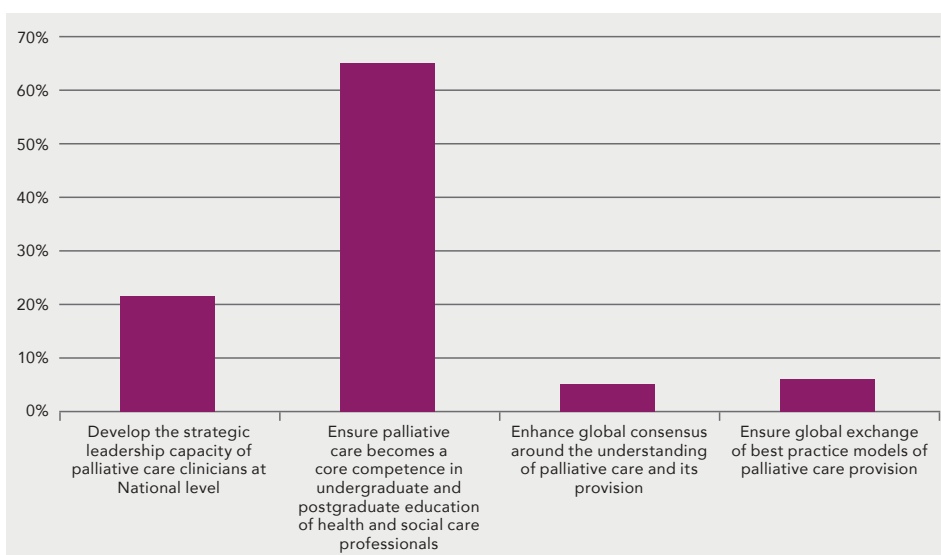
Question A

In your opinion, what are the challenges for policymakers in your country/region?



Question B

In your opinion, what role do international non-governmental organisations and advocacy organisations have in influencing the integration of palliative care into the national health system(s) in your country/region?



Question C

In your opinion, how best can palliative care as a specialty influence its integration into national health system(s) in your country/region?

SESSION 3: INTEGRATED MODELS OF PALLIATIVE CARE – A GLOBAL PERSPECTIVE

Integrated Models of Palliative Care

Important Statistics

Dr Stephen Connor, Senior Fellow, Worldwide Hospice Palliative Care Alliance (WHPCA), stated that palliative care providers needed to aim to integrate palliative healthcare more into the global healthcare system. 56 million people died per year, and of these, 40 million required palliative care, including 20 million children. The Global Atlas of Palliative Care, which had been produced in collaboration with the WHO, had identified that two-thirds of people who needed palliative care were older, and 6% were children. 78% lived in low and middle-income countries. 75% of countries had no, or very limited, palliative care delivery, and only 8% had good integration of it into their healthcare systems.

38 countries now recognised palliative care as a specialty or subspecialty, as opposed to 18 in 2010. As of 2012, there had been approximately 16,000 programmes delivering palliative care, serving about 3 million patients. The mapping exercise would take place again in 2016, with an update to the Atlas scheduled for 2018. The findings of the Economist IU Quality of Death Index would be incorporated into future work.

Models of Excellence

There were good examples of community-based primary care around the world, including in Kyrgyzstan, where excellent work was taking place on preventing and detecting cancer and palliative care. Success had also been seen in Kerala, Barcelona, and Tanzania, with the CHAT programme. In Tajikistan, palliative care was being incorporated in the training of all primary care physicians. The International Primary Palliative Care Network (IPPCN) aspired to ensure that families were always included in palliative care. One model had been proposed involving very small amounts of specialist care, with primary healthcare and care in the community comprising larger elements. The Australian model, which built on this, was the best model currently available.

Creating Integrated Models

To achieve a more integrated model, it would be necessary to increase the capacity of primary care providers to integrate palliative care into their work; one particular problem was that, in low and middle-income countries, professionals were often based in hospitals rather than going out to

the community. The WHPCA was endeavouring to amend this. Increased continuity of care would be vital; although palliative care needed to remain a specialisation, a lot of work needed to be done to integrate it more effectively.

Integrated Models of Children's Palliative Care

The Need for Children's Palliative Care

Joan Marston of the International Children's Palliative Care Network (ICPCN) stated that palliative care for children was still trying to catch up with what had been achieved in the adult sector, but promising models were being developed. The greatest need was in the developing world; work conducted in tandem with UNICEF had created a methodology that had been applied to countries containing 60% of the world's children. They had determined that 21 million children were in need of generalised care, and 8 million were in need of specialised care; the need varied hugely between countries, and was particularly acute in countries with high HIV prevalence. Less than 1% of the children globally who needed palliative care were receiving it.

Successful Models

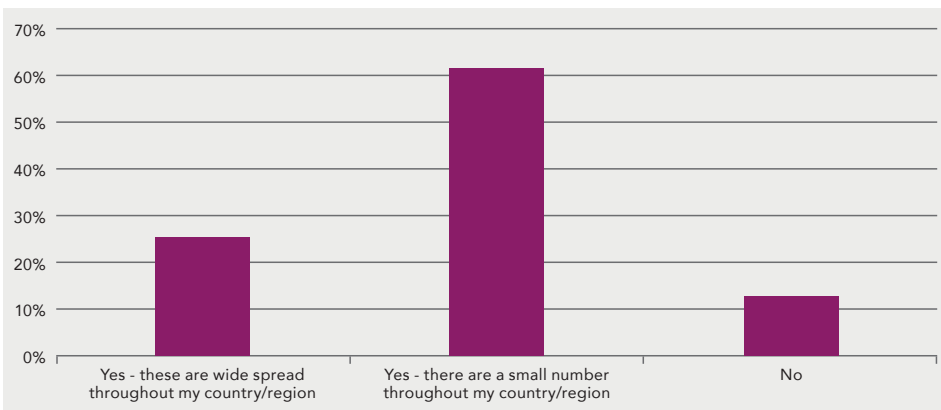
Individual programmes

A number of well-integrated programmes had been created, including one in the Maharashtra region of India that had succeeded in creating centres of excellence and changing healthcare policy and funding. Umodzi Foundation, an NGO in Malawi, had seen the model that it had developed advanced and expanded throughout the country, with children's palliative care being taken into the community. In Mangaung in South Africa, a hospice that had been founded to deal with HIV and AIDS was now linked to a university and government service.

General principles

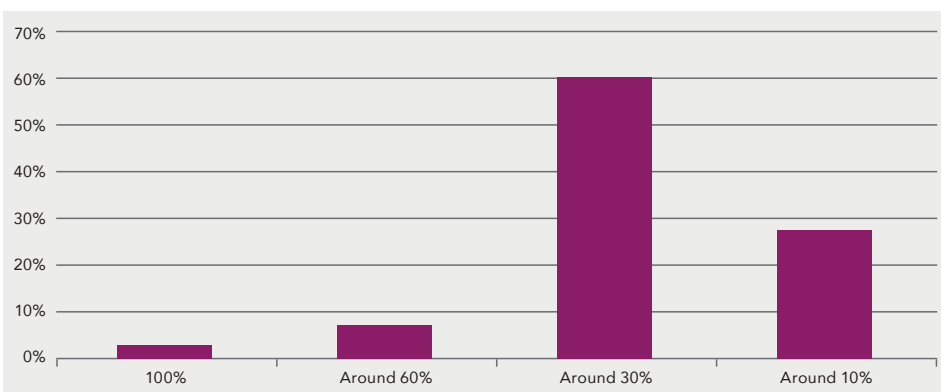
Programmes often started with a specific, limited vision and grew over time, with focuses and models changing. In general, the WHO definition of palliative care for children had been used, incorporating other factors, such as the child's development, child protection, and specific cultural factors. Successful programmes did not envision themselves as isolated, but as part of a larger healthcare system. Ultimately, they succeeded because the people who worked in the programmes were 'both passionate and compassionate' about the children they cared for.

SESSION 3: PARTICIPANT RESPONSE



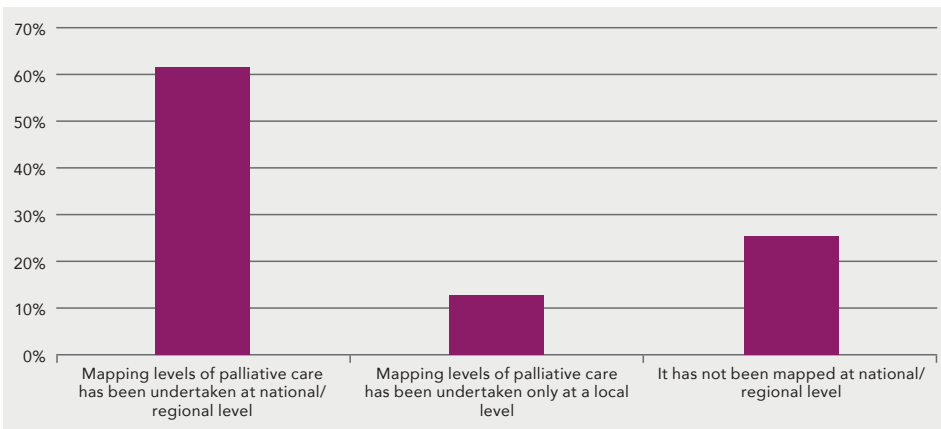
Chair's Question

In your opinion, are there good examples of generalist and specialist palliative care integration in your country/region?



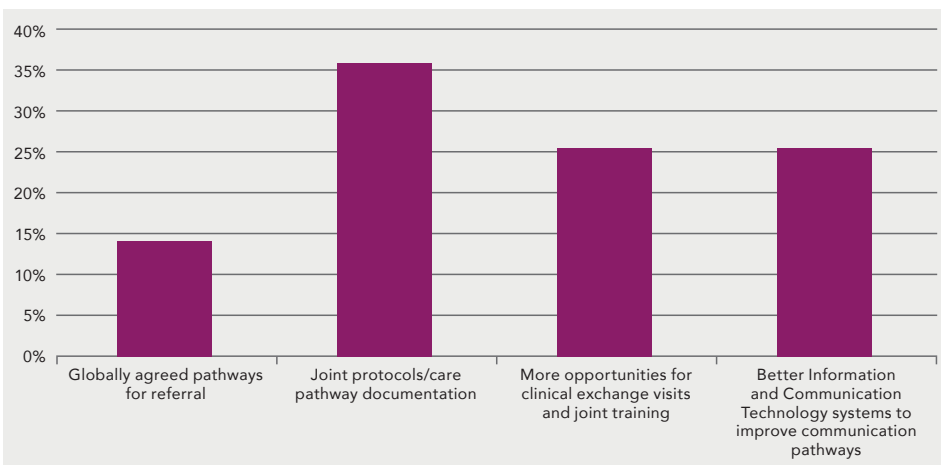
Question A

Taking palliative care needs as a whole, in your opinion, what proportion should be provided by specialist palliative care providers?



Question B

From your understanding, how has the level of palliative care development been measured in your country/region?



Question C

In your opinion, how can generalists and specialists work best together to ensure palliative care is accessible and coordinated?

SESSION 4: MODELS OF PALLIATIVE CARE – EXPERIENCE OF LOW INCOME COUNTRIES

Hospice Casa Sperantei, Romania

Dr Daniela Mosoiu provided delegates with some background information about Romania. Hospice Casa Sperantei had been founded in 1992 by a British-Romanian charity; it had received support from the UK but had been developed with a focus on the needs that existed in Romania. It now employed 225 staff and had cared for over 17,000 patients and their families free of charge. The hospice began by providing home care, since that was where the patients were; over 80% of patients, when surveyed, had said they wanted to remain at home with support. Over 87% of patients died at home in Romania; it was necessary to acknowledge this and to develop services that retained this culture. After 10 years, the organisation had developed inpatient and outpatient units, day centres and mobile hospital teams for adults and children. In 2002, the hospice had been recognised as one of five centres of excellence in Eastern and Central Europe, and as one of the models for delivering care in low and middle-income countries.

The WHO Triangle

Education

The WHO Triangle model had helped to structure the organisation's work. HOSPICE had begun to run training programmes in 1997, since when it had trained over 17,000 people. In 1999, it had been named as the centre to run training for palliative care as a medical sub-specialty, which 396 doctors now had attained. The organisation had succeeded in ensuring that the undergraduate nursing curriculum contained 120 hours' compulsory training in palliative care, and it had also developed standardised training material and a curriculum for nurse training, although it was still fighting to have palliative care recognised as a specialty for nurses at undergraduate level. Five universities now provided palliative care training to those who sought to train others in the specialty. A programme had been developed to train the general public, and HOSPICE was also one of the centres providing training courses in the European Palliative Care Academy.

Drug availability

It had taken five years for a law to be passed in parliament, followed by another two years for the regulation specifying the details of the law to be put in place, but this had resulted in opioids being available for prescription for any pain, with no

maximum dose. Doctors had been trained in how to prescribe, albeit there remained problems with the way in which the law was implemented.

National coordinated strategy

The National Association of Palliative Care had put in place the national palliative care standards; together with service providers, they had succeeded in bringing palliative care into the costing framework and in developing a strategy, which consisted of three levels: support for self-care, basic palliative care through GPs or hospital doctors, and specialised palliative care. Support for development and education cut across all three levels. The World Bank loan for health reform in Romania had a palliative care element, and a number of pilot programmes had been put in place with the aim of delivering against this.

Summary

Dr Mosoiu stated that she would like to see the WHO monitoring in a structured way how the WHA resolution was being implemented, in order to assess whether Romania had made progress on the various elements and to identify good practice.

The Case of Kenya

The Kenyan Context

Dr Zipporah Ali, Executive Director, Kenya Hospices and Palliative Care Association (KEHPCA), stated that the population of Kenya was roughly 44 million, and 40,000 new cases of cancer developed every year, with 38,000 dying within their first two years of the disease. HIV/AIDS prevalence was 5.8%; about 50% of hospital admissions were from non-communicable disease, and 63% of hospital deaths were from these diseases. 45% of countries in Africa had no palliative care, although this was changing, and there were significant gaps in areas such as access to opioids.

Integrating Palliative Care in Kenya

KEHPCA's initial focus had been trying to integrate palliative care into hospitals; it was also now focusing a lot on community-based organisations. In Kenya, and most countries in Africa, hospices provided outpatient and some inpatient facilities, although the latter were rare and expensive, and some home visits. Integration work in Kenya had begun in 2010, as the result of discussions with government ministers, two of whom had been cancer sufferers and understood the needs of patients. The reason for focusing on government

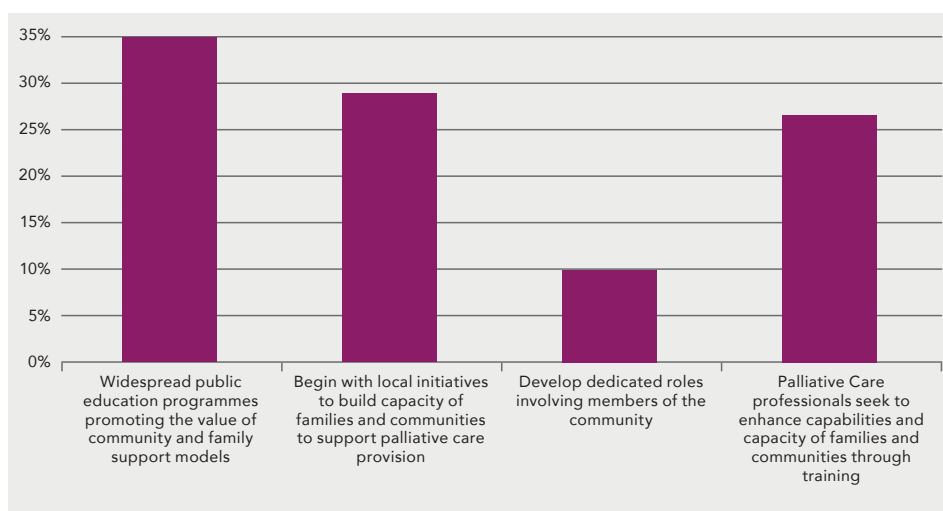
hospitals had been that there was an existing structure in place, which helped greatly. Now, hospice staff helped in the hospitals, identifying patients who needed palliative care.

Investment had been made in training hospital teams. This had not just been in the area of palliative care, but also to enable them to train other people. Although no standalone palliative care policy yet existed, palliative care had been incorporated into other strategies, such as cancer management.

Challenges and Solutions

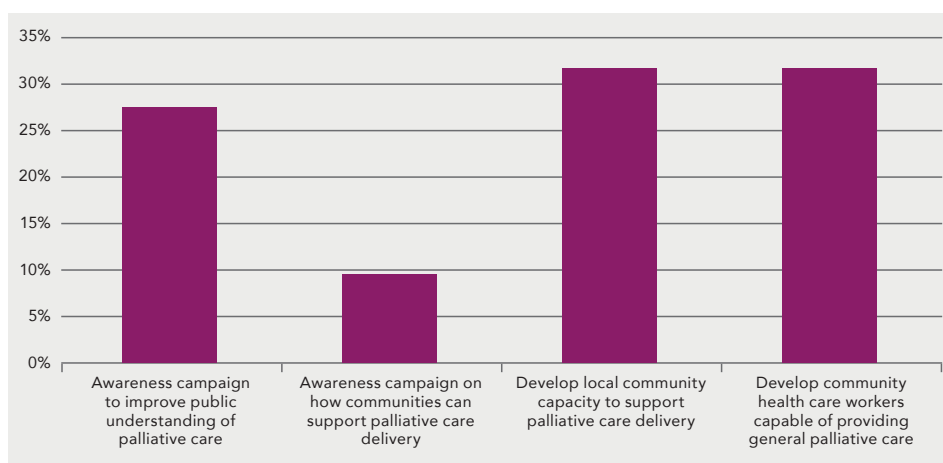
African palliative care providers faced a large number of challenges; training was a particular challenge. Dr Ali stated that it was very useful, when speaking to governments, to ‘step forward with solutions, not just with problems’.

SESSION 4: PARTICIPANT RESPONSE



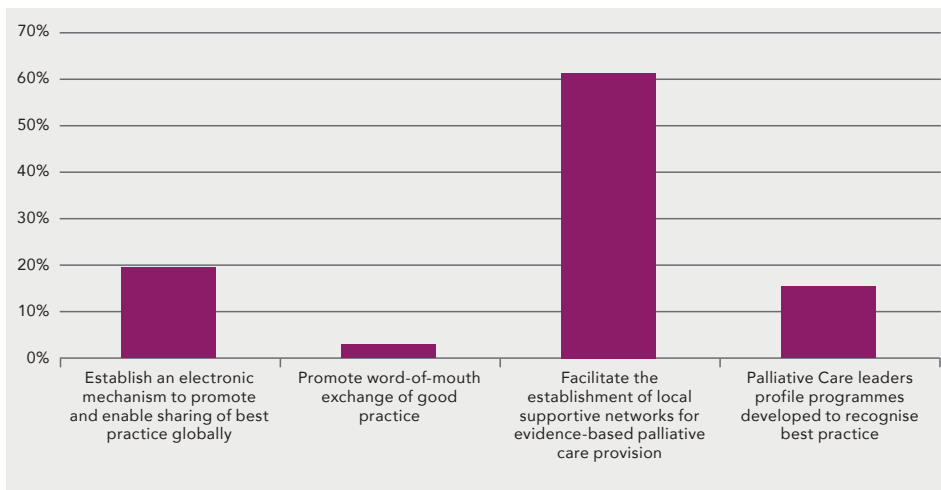
Chair’s Question

In your opinion, what is likely to be the most effective population level strategy to improve palliative care provision in low income countries?



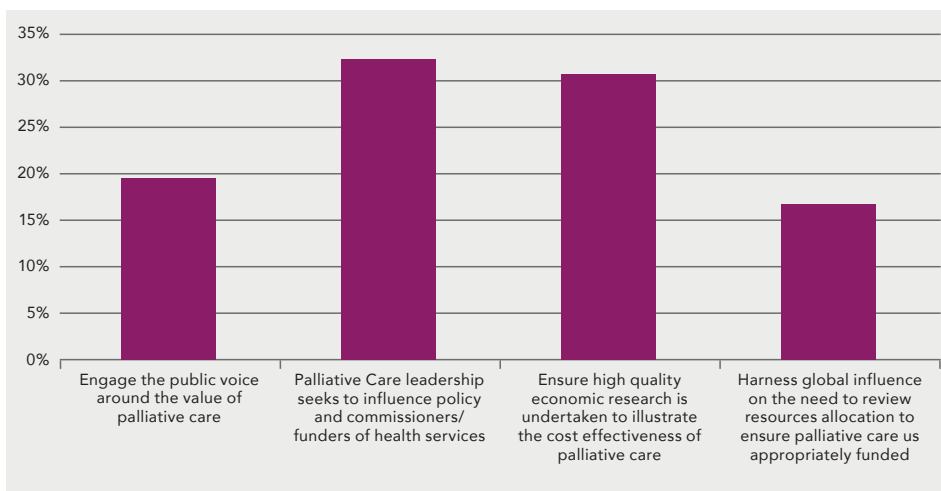
Question A

In your opinion, what are the most effective strategies for enhancing palliative care delivery through involving local communities in your country/region?



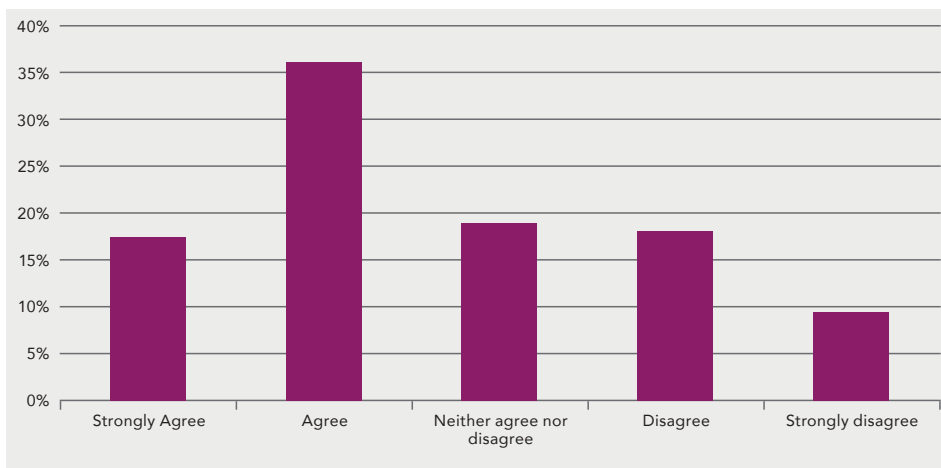
Question B

In your opinion, what are the best mechanisms for sharing best practice where resources are limited?



Question C

In your opinion, how can funding be more appropriately allocated between resources for disease prevention, cure and palliation in your country/region?



Question D

To what extent do you agree that the World Health Organisation uses access to essential medicines as an indicator of the development of palliative care in your country/region?

Executive Summary – Day 2

Welcome

Paddie Blaney, Director All Ireland Institute of Hospice and Palliative Care (AIHPC) welcome delegates to Day 2 of the Colloquium. This second day offers an opportunity to hear about innovative work, to reflect on the need for palliative care across the lifespan, especially for those with chronic illness, and to listen to the experience of a carer. We will also look forward to the role that leadership, education and research will play in the future of palliative care globally.

Dame Judith Hill

Dame Judith Hill, welcomed the delegates to the Colloquium on behalf of Northern Ireland, which she saw as an exciting opportunity to reflect on the WHA Resolution in order to try to put some flesh onto it and breathe life into it. Dame Judith acknowledged the work of AIHPC and its continued aim to improve the experience of individuals and families coping with life-limiting conditions.

Dame Judith summarised the palliative care policy and development work that has been taking place in Northern Ireland.

The concept of comprehensive care, physical, emotional and spiritual, is familiar to us and is something we have to build on. A changing demographic challenges us to look at how best we can provide this comprehensive care, this palliative care.

The Colloquium's programme, focussed on the life course, is looking at the concept of strengthening palliative care in health systems and how this can actually be achieved.

SESSION 5: COMMUNITIES IN PALLIATIVE CARE

Why community participation?

Dr Suresh Kumar reflected that patients need regular, continuous, seamless care throughout their life. This is supported by a medical system, with regular social, psychological and spiritual support. The best option for the patient is to have their needs met as close to home as possible.

The debate regarding general and specialist palliative care needs to be set aside – each patient seen is a potential patient for either specialist or generalist care – and so it cannot be either but rather both as they are part of the same continuum.

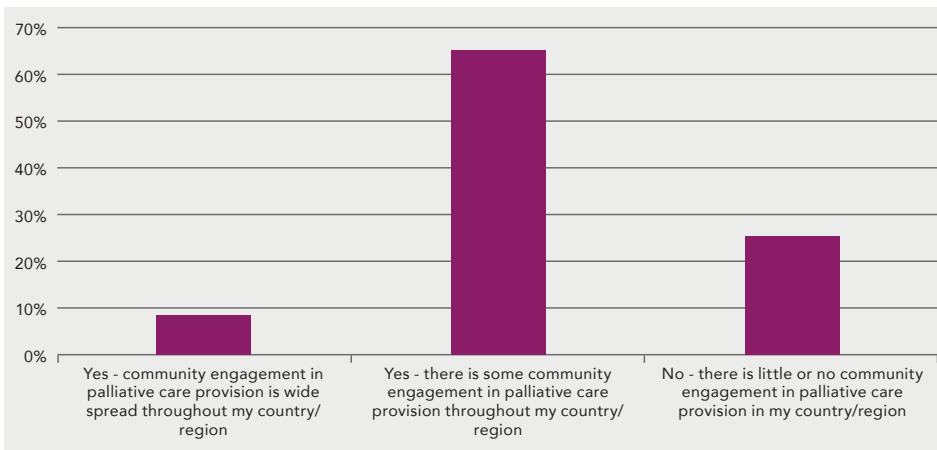
Lessons from India

Dr Kumar spoke about the foundation of the Neighbourhood Network in Palliative Care in Kerala, from its beginnings in 1993, to its formal launch in 1999 to its current work. An important thing for volunteers to the Neighbourhood Network to learn is how to do it – how to talk to a patient.

Challenges

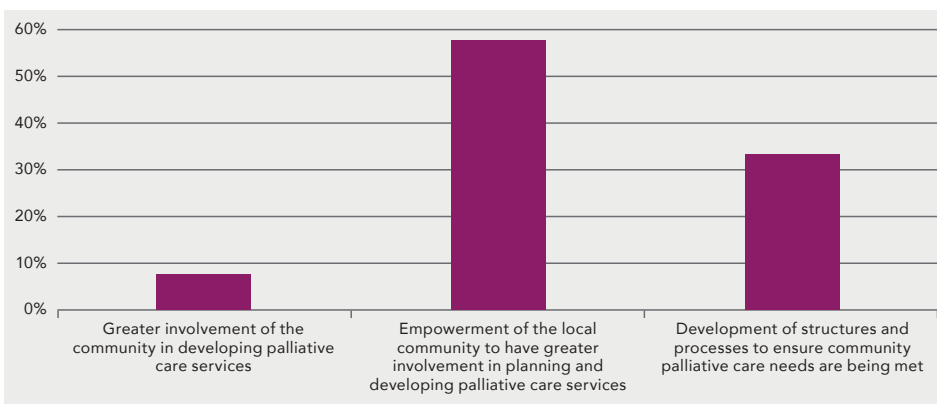
There are challenges to involving the community; among these is the challenge to keep motivation alive amongst the community volunteers.

SESSION 5: PARTICIPANT RESPONSE



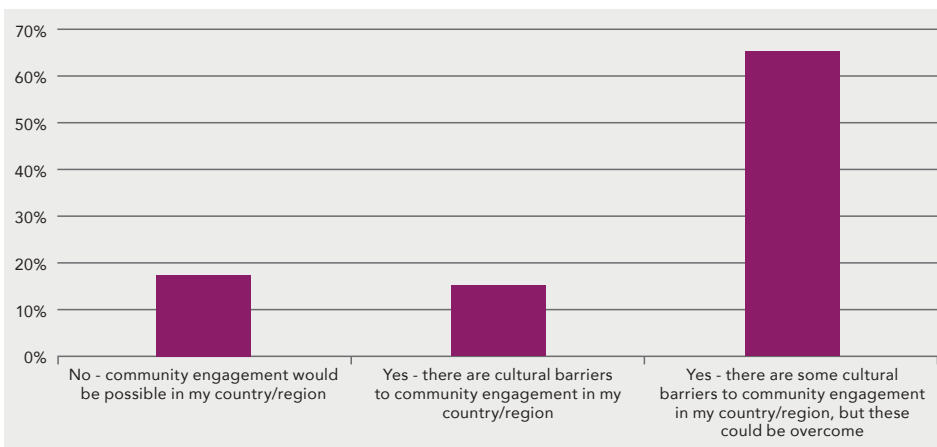
Chair's Question

In your opinion, is community engagement in palliative care provision widespread in your country/region?



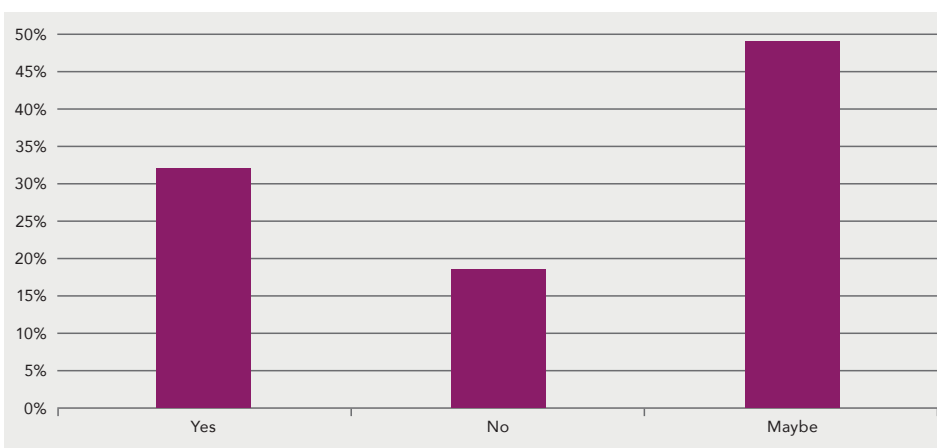
Question A

In your opinion, what might be the key factors to support community engagement in your country/region?



Question B

In your opinion, are there cultural differences in your country/region which would hinder community engagement?



Question C

In your opinion, do you think it is possible to develop a global measure of community engagement?

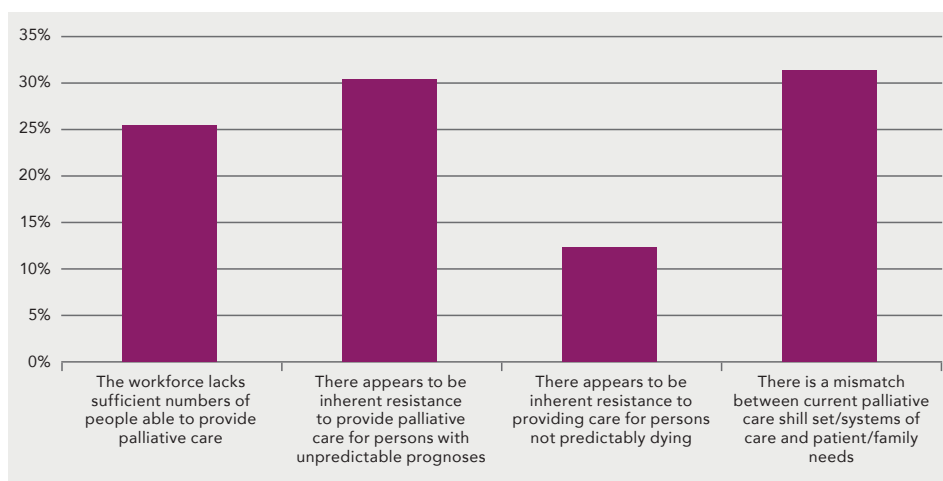
SESSION 6: PALLIATIVE CARE AND CHRONIC ILLNESS

Prof Lukas Radbruch focussed on his experiences of providing palliative care to people living with chronic illness. A key question to consider, in the context of palliative care provision, was what happens if patients have a longer prognosis, with months and year to live?

Prof Radbruch detailed a number of cases to highlight the issues which arose for his team when asked to consult and care for individuals with diverse conditions; Motor Neuron Disease, Dementia and Anorexia.

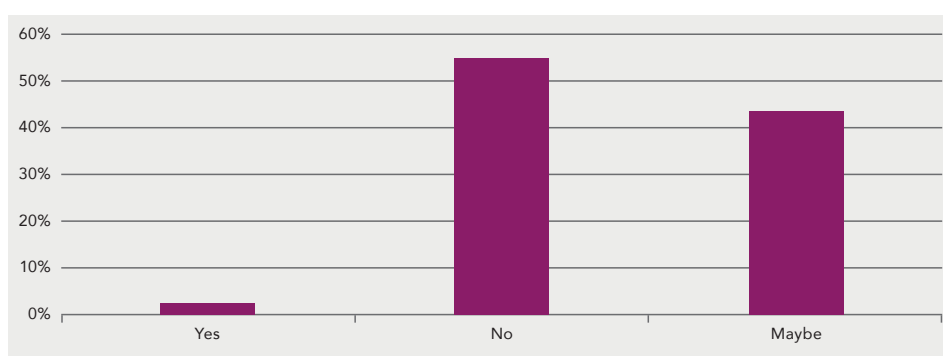
Using different approaches depending on diagnosis and need is helpful when deciding how best and for how long patients will be cared for by the palliative care team. In many instances intermittent consultation is most appropriate based on clinical need. It is important that palliative care is not seen as a competitor but rather as a collaborator with skills that can be useful in the management of chronic illness.

SESSION 6: PARTICIPANT RESPONSE



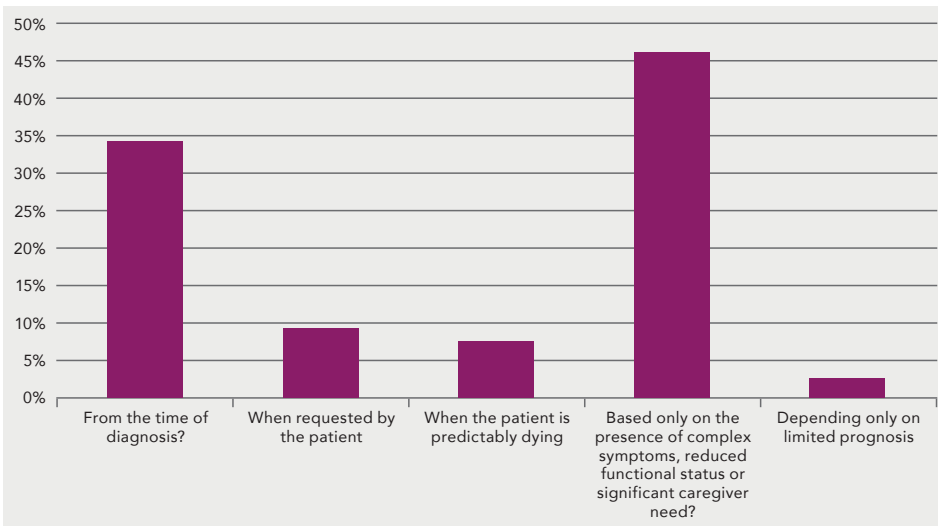
Chairs Question

What do you see as the major barriers to enhancing the delivery of palliative care for non-cancer diagnosis?



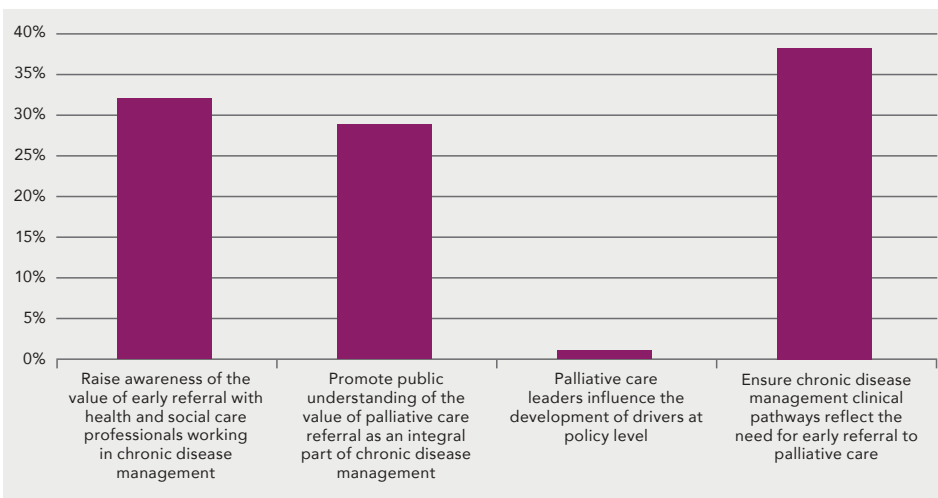
Question A

In your opinion, do chronic disease management policies in your country/region appropriately reflect the provision of palliative care?



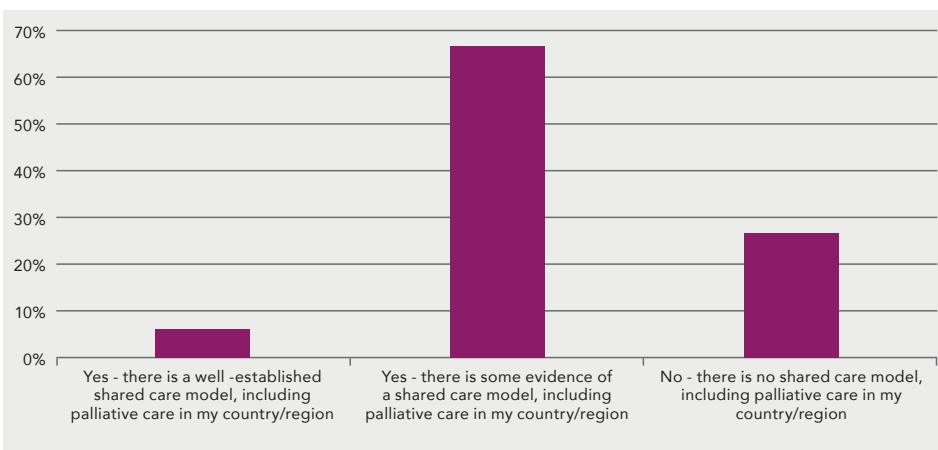
Question B

At what point should palliative care be delivered to people living with chronic illness?



Question C

In your opinion, how can early referral to palliative care be best promoted in the management of chronic illness?



Question D

In your opinion, how well is a shared care model including palliative care established in your country/region?

SESSION 7: IMPROVING PALLIATIVE CARE PROVISION IN VARIOUS CARE SETTINGS: HEARING THE VOICE OF THE USER AND CARER

A carer's voice

Anne Molloy, a member of vocies4Care, an initiative of AllHPC spoke movingly of her experience when caring for her father who died from cancer in 2011. For Mr Molloy, quality of life and not length of life were his priority when he learnt that his cancer had spread.

For Anne and her family the experience of caring for a loved one with a terminal illness was filled with a sense of not being about to cope, constantly realising that this was going to get worse and continuing to wonder how to cope when it did get even worse.

Anne reflected on the various types of palliative care received; at home, in hospital, in hospice. For her family the most valuable were the hospice visits at home, where her father was happiest. Palliative care provided support, incredible relief and a sense of not being left alone.

'Let's talk about' allowed people to tell their story and their experience of palliative care, both good and bad. A common experience emerged; if good care is possible somewhere, it is possible everywhere.

Assessing and addressing the support needs of family carers

Prof Gunn Grande spoke about the central role that family carers have in patient care and disease management. Often family carers are the conductors of care management at home and often are cast aside when their relative is admitted into hospital. Carers suffer adverse outcomes to their physical and psychological health because of their caring.

Carers need support to support the patient and themselves in their role. It may be that the time has come for a carer-led approach that adapts to generalist and specialist care that enables carers to define their support needs and potential solutions to meeting these needs.

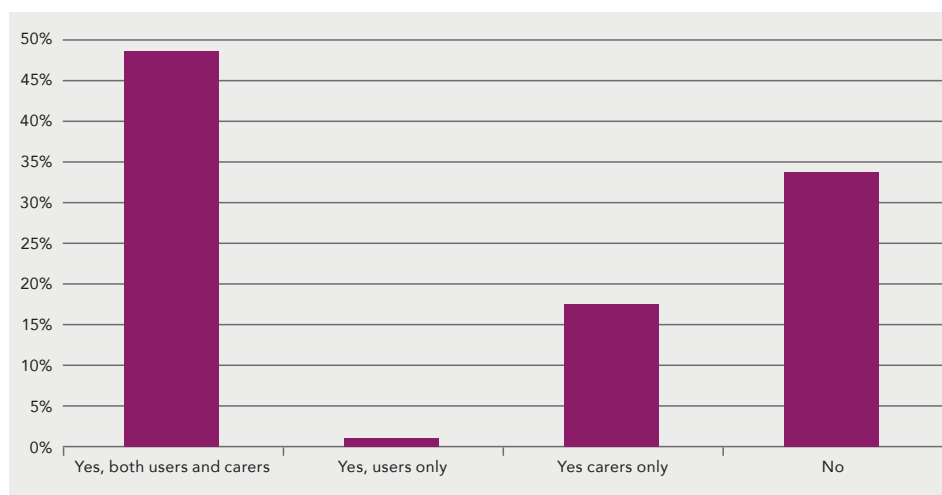
How can palliative care be provided in every setting?

Prof Scott Murray suggested that although there were a lot of challenges, there were also opportunities to provide palliative care well in all settings. The main challenge is the identification of people who need palliative care. The WHO definition of palliative care offers a hint of how we can do palliative care – by early identification and assessment.

Given the variance in disease trajectory it is difficult to prognosticate and so identification of those in need of palliative care becomes even more important.

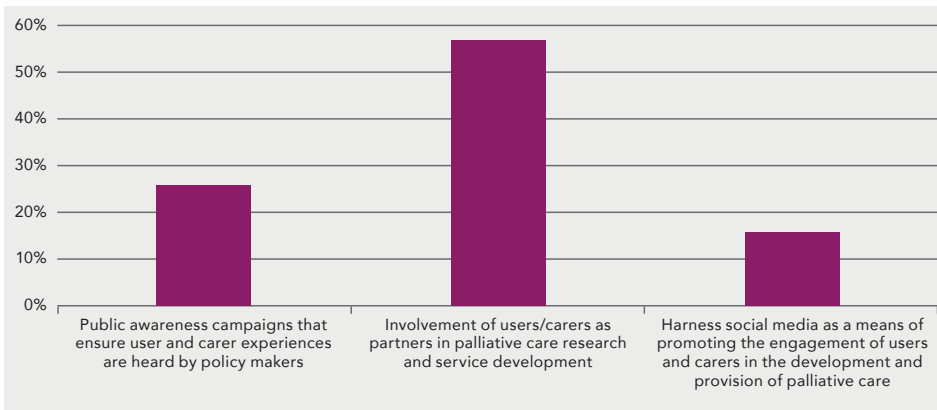
The challenge is identification, identification of all illnesses, earlier and identifying the issue that is causes the patient and their family most problems.

SESSION 7: PARTICIPANT RESPONSE



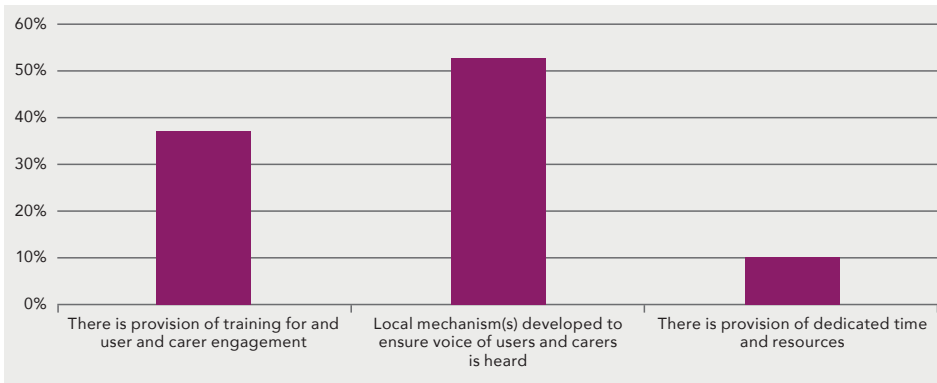
Chairs Question

In your opinion, does your country/region have a means of hearing about the palliative care experiences of users and/or carers?



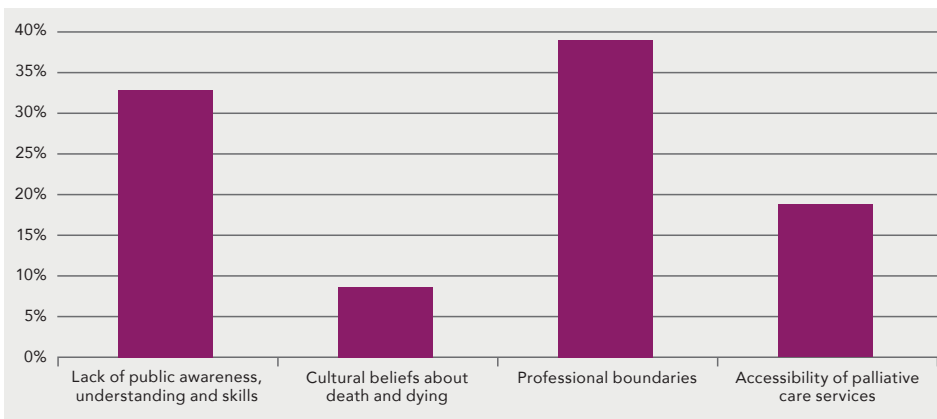
Question A

In your opinion, how can users and carers best influence the development and provision of palliative care in different care settings?



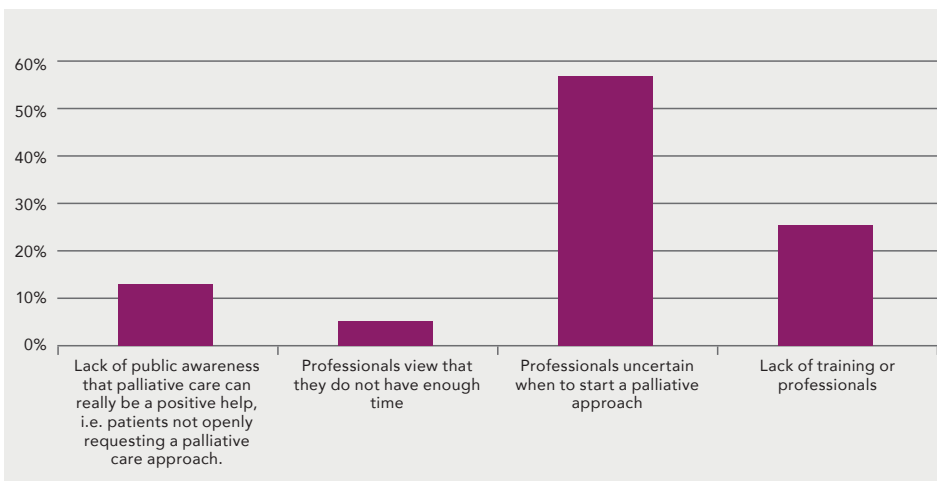
Question B

In your opinion, how best can professionals working in palliative care be supported to recognise the value of involving users and carers in the design and implementation of services?



Question C

In your opinion, what is the main barrier to integrating palliative care as an essential element across care settings?



Question D

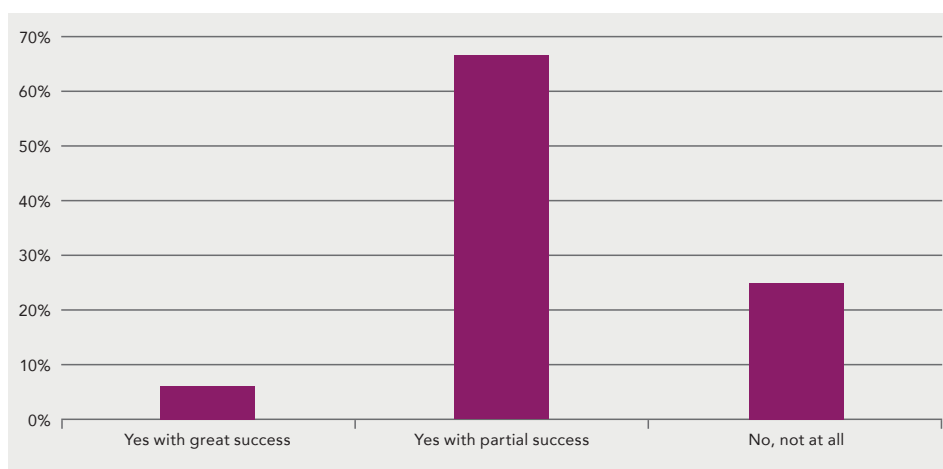
In your opinion, what is the main barrier to integrating palliative care early into the care of people with advanced illnesses?

SESSION 8: THE CHALLENGE FOR PALLIATIVE CARE: LEADERSHIP, RESEARCH, EDUCATION AND PRACTICE

Leadership, research, education and practice

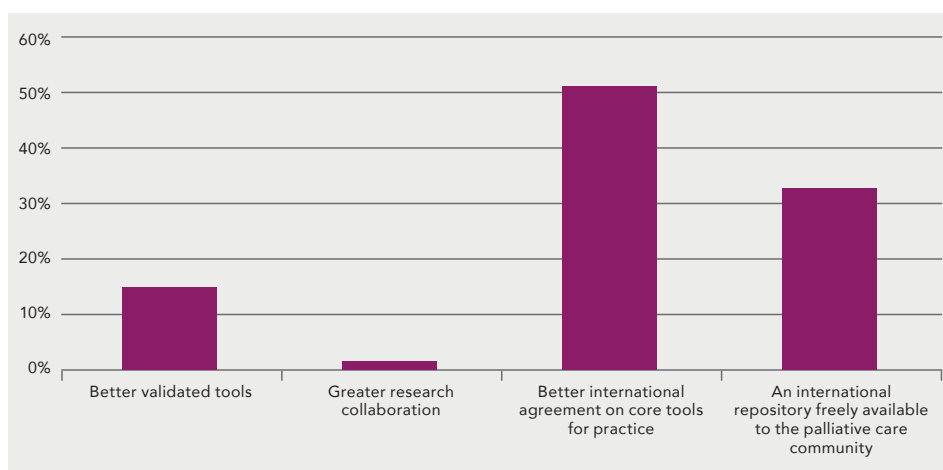
Dr Frank Ferris and Liliana De Lima reflected on how leadership, research, education and practice can help meet the challenge to incorporate palliative care into national health systems. The WHA Resolution asks governments to put in place education at basic, intermediate and specialist level. Implicit in the resolution is the importance of measuring the impact of care on patients to ensure a quality service is provided. The need for effective research is also highlighted by the resolution so that evidence for change in policy and practice is available. A key take home message is that everyone is a leader, everyone is a teacher and everyone is a change agent.

SESSION 8: PARTICIPANT RESPONSE



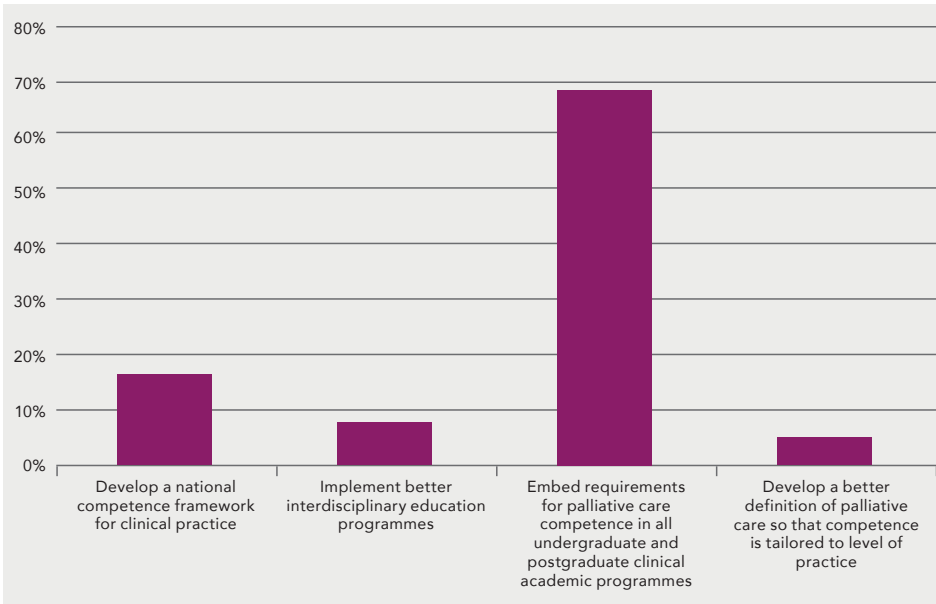
Chairs Question

In your opinion, have we provided for the training needs of the future generation of palliative care leaders?



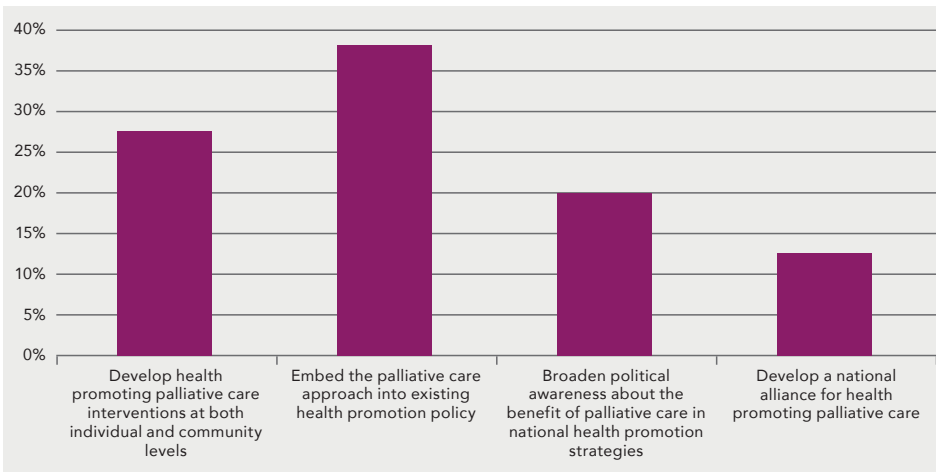
Question A

What in your opinion is the best strategy for getting palliative care providers to measure agreed key metrics in similar ways?



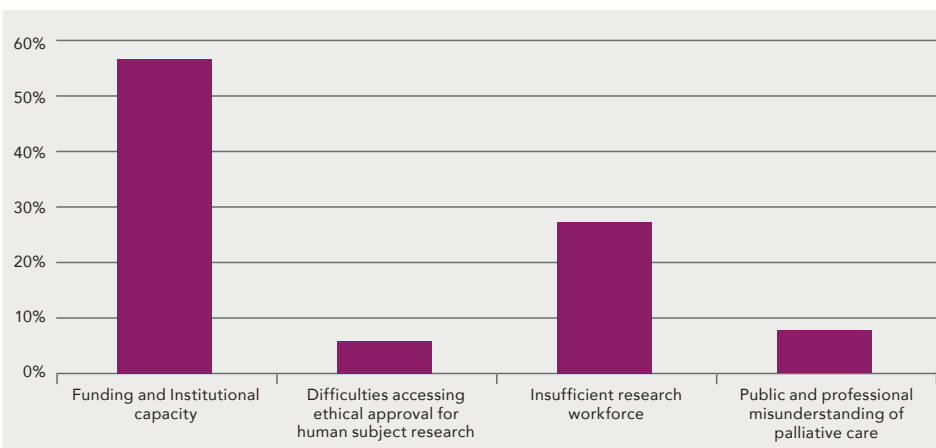
Question B

In your opinion, how do we ensure that all palliative care clinicians are competent to deliver quality palliative care?



Question C

In your opinion, how can health promoting palliative care be embedded in practice?



Question D

What are the barriers to undertaking research in palliative care?



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