All Ireland Institute of
Hospice and Palliative Care

Needs Analysis Report of General Palliative Care Education in the Republic of Ireland and Northern Ireland

March 2014

All Ireland Institute of Hospice and Palliative Care (AIIHPC) is an all island organisation, comprised of a Consortium of partner organisations, including health agencies and universities, all working to improve the experience of supportive, palliative and end-of-life care on the island of Ireland, through enhancing the capacity to develop knowledge, promote learning and education and influence policy and practice in these areas.

The island of Ireland has an established leadership role in the promotion and development of palliative care education. The Institute aims to be a catalyst for change through supporting access to high quality education, and the development of a well-trained palliative care community with the skills and abilities to respond to a wide variety of palliative care needs in a range of settings. A coherent community of palliative care educators will work together, with meaningful user and carer engagement, to ensure efficient delivery of high quality palliative care learning. Ultimately, the creation of a well-educated workforce, will secure the future development of on-going excellence in palliative care

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EXECUTIVE SUMMARY

Background

A key activity of AIIHPC Education Programme is to promote the availability and accessibility of palliative care education. In order to achieve this AIIHPC in collaboration with its all-Ireland Education Network[1] designed a general palliative care needs analysis survey utilising Survey Monkey online survey software (See Appendix 1). The survey was sent to key personnel at senior management level in health and social care; representatives of care providers and education commissioners and funders across the island of Ireland were invited to respond (see Appendix 2). The needs analysis was aimed at those providing general palliative care at Level I and Level II (NACPC 2001) in both health and care settings in Ireland and Northern Ireland.

Survey

There were five sections in the survey. Section 1 gathered background information related to the organisation represented by the respondent, Section 2 related to how professionals currently accessed information about palliative care education, Section 3 asked respondents about current and future provision of palliative care education, Section 4 specifically asked respondents about what information and knowledge should be included in the all-Ireland Palliative Hub that AIIHPC was developing and Section 5 asked questions about staff's current skills, knowledge and competence as well as the level of priority the respondent would give to various general palliative care areas. This section drew from competences identified in the *Palliative and End-of-Life Care Competency Assessment Tool* (Northern Ireland, 2012) and the *HSE Palliative Care Competence Framework* (Republic of Ireland, 2014).

Results

A total of 120 organisations and individuals were contacted and invited to undertake the survey. AIIHPC received 102 responses of which 55% (56) were from the Republic of Ireland and 45% (46) were from Northern Ireland. Respondents represented 63 organisations providing palliative care or providing funding for palliative care education from across the island of Ireland. The majority of respondents were managers in clinical practice settings who had responsibility and oversight for funding continuing education and practice development for health and social care staff

In relation to accessing information about palliative care education the most popular source of information about palliative care education was 'advice from colleagues or other professionals'. Half of all respondents had recommended a particular programme to professionals with the majority of the programmes recommended to staff focussing on principles of palliative care and communication in palliative care. An additional preference was identified for training in Palliative Care for specific disease and population groups.

In terms of information and knowledge for the all-Ireland Palliative Hub development needs were collated under six headings: Resources, Education courses, Information, Nutrition related information, Research, Support.

In terms of competence the majority of staff were deemed to be both familiar with and able to use knowledge and skills, or proficient in the knowledge or skill and able to show others how to use it or have a high degree of skill and comprehensive knowledge. Respondents also indicated the priority level for general palliative care training for the next two years in a list of twenty five areas.

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[1] AIIHPC's all Ireland Education Network brings together a representative membership of palliative care educators, funders, commissioners and regulatory bodies including the universities and hospice education teams

Recommendations
Recommendations are aimed at senior managers, representative bodies and education commissioners and funders who should:

- Be aware of the need to ensure that service developments include education as a way of ensuring that competence to practice is developed and maintained
- Be responsive to the changing nature of care needs and how education will respond to prepare carers to meet these needs.
- Ensure that training and education is commissioned and delivered via a number of mechanisms including face to face training, online and blended learning.
- In light of demographic changes and increased needs for health and social care, continuing education for general palliative care must be a priority for all health and social care professions and year on year funding must be secured
- Be aware of current palliative care education provision and engage with education providers in order to highlight current and future needs and gaps
- Work collaboratively with education providers to ensure that the education and training they deliver is responsive to the changing needs of health and social professionals
- Promote and support greater collaboration between education providers in hospice education or at third level
- Encourage health and social care professionals to access education including provision which reinforces the value of multidisciplinary working and supports staff to maintain competence to meet the changing needs of service users
- Support greater collaboration between education providers to ensure that the identified palliative care education priorities for health and social care staff for the coming two years are met
- Ensure availability of quality programmes that meet health and social care professionals palliative care education needs
- Ensure that palliative care training and education is commissioned at a regional level so that any education provision is tailored to meet local need
- Ensure that a comprehensive range of suitable courses with appropriate capacity are available and avoid unnecessary duplication

Actions
- AIIHPC is working to promote greater access to online learning
- AIIHPC will continue to support and expand the Palliative Care Education Network, by bringing providers and consumers of education together to ensure that learning opportunities are available, accessible and of the highest quality.
- AIIHPC will support collaboration between palliative care education providers including the hospice education providers and the universities in order to promote a coherent approach to meeting the palliative care learning needs of health and social care professionals.
- AIIHPC will continue to support health and social care professionals to access palliative care education via the Palliative Hub
- AIIHPC will continue to develop and maintain the Palliative Care Education Database resource detailing online palliative care education available on the island of Ireland and internationally
- AIIHPC will support e-learning through the development and facilitation of a Learning Platform as part of the Palliative Hub

Needs Analysis Report

INTRODUCTION

All Ireland Institute of Hospice and Palliative Care (AIIHPC), is an all island organisation, comprised of a consortium of partner organisations, including health agencies and universities, all working to improve the experience of supportive, palliative and end-of-life care on the island of Ireland, through enhancing the capacity to develop knowledge, promote learning and education and influence policy and practice in these areas. The ultimate aim is to secure best care for those approaching end-of-life.

A well-educated and highly trained hospice and palliative care community will secure the future development of on-going excellence in palliative care delivery. AIIHPC supports access to high quality education and the development of a well-trained palliative care community with the skills and abilities to respond to a wide variety of palliative care needs in a range of settings through two work activities:

- Education Network for Availability, Accessibility and Transferability of Learning
- Leadership and Capacity Building through Individual Learning and Experience

AIIHPC Strategic Plan (2010-2015) outlined the education activities that would promote the availability and accessibility of palliative care education. In order to achieve this, the specific needs within palliative care education will be identified by:

- Working with existing providers to leverage expertise and minimise unnecessary duplication.
- Driving the availability of relevant education through commissioning of new palliative care education programmes where specific needs have been identified.
- Developing greater accessibility of existing education programmes through supporting the adoption of innovative delivery methods.

In August 2012 the Palliative Care Education Network was established bringing together providers and consumers of education to ensure that the required learning opportunities are available, accessible and of the highest quality. The Palliative Care Education Network has a representative membership of palliative care educators, funders, commissioners and regulatory bodies including the universities, hospice education teams.

The terms of reference for the Palliative Care Education Network identified that it would assist AIIHPC in developing a needs analysis of general palliative care education for those providing palliative care at Level I and Level II (NACPC 2001)(i.e. general palliative care) on the island of Ireland.

An education needs analysis is method to review learning and development needs and considers the skills, knowledge and behaviour that people need and how to address them effectively (Lundberg *et al,* 2010). An education needs analysis is considered the foundation for all training and learning activities and is essential in order to plan, design and deliver appropriate and effective training to meet the needs of individuals, organisations and the wider community (Reed & Vakola, 2006; Reid & Barrington, 1999). This education needs analysis has been undertaken to ascertain the general palliative care education needs and priorities as perceived by senior managers of health and social care services, representative bodies of care providers and education commissioners and funders on the island of Ireland.

DESIGN OF SURVEY

A key activity of AIIHPC Education Programme is to promote the availability and accessibility of palliative care education. Drawing on the expertise and experience of the Education Network, a facilitated workshop was held in February 2013 with purpose of developing an Education Needs Analysis Questionnaire for General Palliative Care Education and identifying the potential study sample. The

workshop was facilitated by Prof Max Watson with individuals attending in person and via teleconference. Following the workshop the draft questionnaire was sent to members of the Education Steering Committee and to an expert in quantitative research and analysis who provided constructive comments on the questionnaire design and tested face validity.

Once the final questionnaire was adopted it was made available for completion using Survey Monkey. Details of the survey and an explanatory note were e-mailed to key personnel at senior management level in health and social care agencies across the island of Ireland inviting a response to the questionnaire (Appendix 1). Guidance on completion of the questionnaire appeared at the front of the questionnaire (Appendix 2) with an instruction that questionnaire could be forwarded to a relevant colleague for completion.

The Needs Analysis of General Palliative Care Education was targeted at:
- Senior managers of health and social care services – who were in apposition to assess the overall average rating of their team's skills and competence in relation to providing general palliative care
- Representative bodies of care providers – in particular the lead on education or a senior manager whose role includes the direction and development of palliative care education
- Education commissioners and education funders (Appendix 2) – particularly the lead on education or a senior manager who has a role in directing the development of Palliative Care Education.

RESULTS

The results from the survey are presented in five sections. Section 1 gathered background information related to the organisation represented by the respondent. Section 2 related to how professionals currently accessed information about palliative care education. Section 3 asked respondents about current and future provision of palliative care education. Section 4 specifically asked respondents about what information and knowledge they would like to see included in the all-Ireland Communications Hub that AIIHPC is developing. Section 5 asked questions about staff's current skills, knowledge and competence as well as the level of priority the respondent would give to various general palliative care areas. This section drew from competences identified in the Palliative and End-of-Life Care Competency Assessment Tool (Northern Ireland, 2012) and the HSE Palliative Care Competence Framework (Republic of Ireland, 2014).

A total of 102 responses, representing 63 organisations, with a wide geographical spread across the island of Ireland were received. Of these 55% (56) were from the Republic of Ireland and 45% (46) were from Northern Ireland. Results from the data were analysed and are presented below.

Section 1: Background information

Questions in Section 1 (1.1-1.7) were used to gather background information related to the organisation represented by the respondent, the location of the organisation, the type of organisations represented, the respondent's role within the organisation, the health and social care professions represented by the respondents answers, whether the organisation receives, funds or provides palliative care education and the number of health and social care professionals employed by the respondent's organisation. What is evident is that the respondents represented organisations providing palliative care or palliative care education or funding for palliative care education.

Figure 1 shows the types of organisations represented by the respondents. It should be noted that respondents were advised that they could record more than one option for this question.

Question 1.4 asked the respondents to the questionnaire to identify their current professional role. As can be seen (Figure 2) a wide range of professions are represented by the respondents to the questionnaire. The majority of respondents were managers in clinical practice that had a gate-keeping role in the provision of funding for on-going education and development. Some of the respondents indicated that they had completed the questionnaire following consultation with clinical and/or academic colleagues.
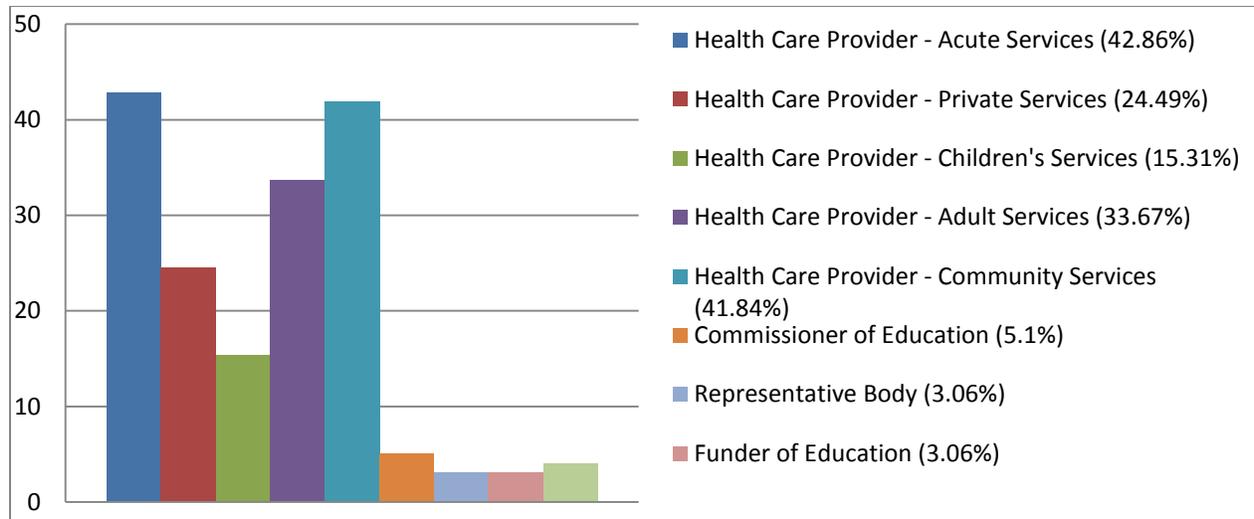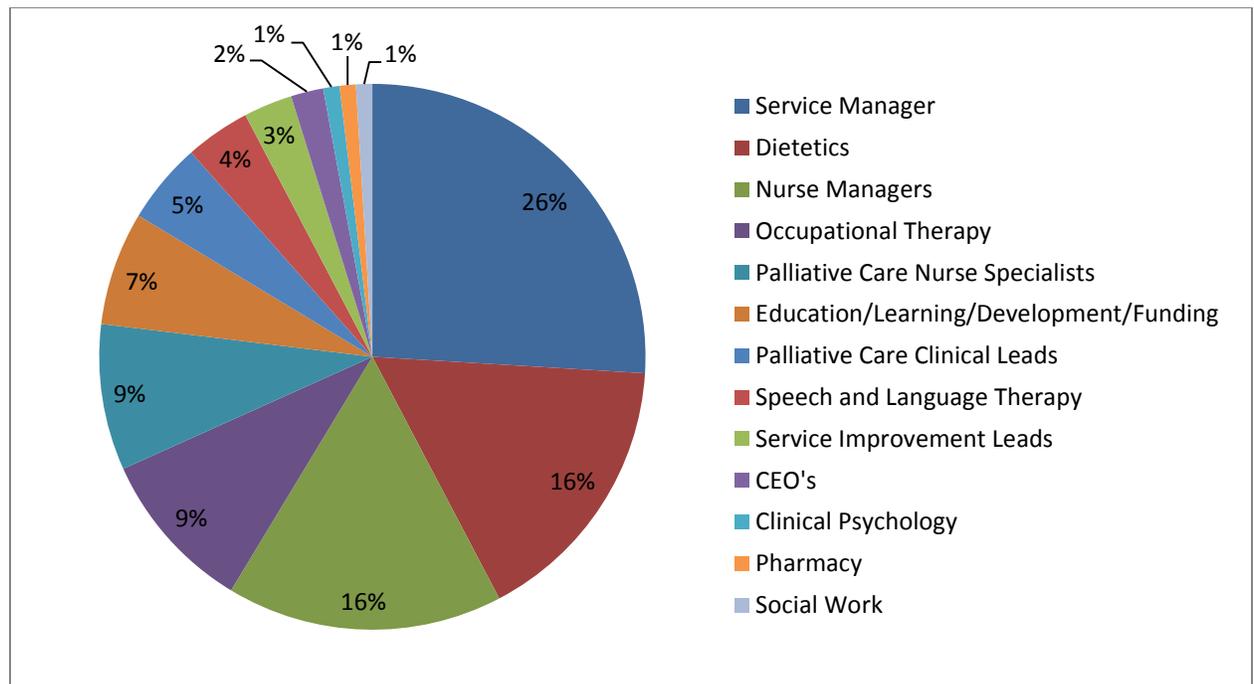

Figure 1: Type of Organisation

Legend:
- Health Care Provider - Acute Services (42.86%)
- Health Care Provider - Private Services (24.49%)
- Health Care Provider - Children's Services (15.31%)
- Health Care Provider - Adult Services (33.67%)
- Health Care Provider - Community Services (41.84%)
- Commissioner of Education (5.1%)
- Representative Body (3.06%)
- Funder of Education (3.06%)

Figure 2: Role of the person completing the questionnaire

Legend:
- Service Manager
- Dietetics
- Nurse Managers
- Occupational Therapy
- Palliative Care Nurse Specialists
- Education/Learning/Development/Funding
- Palliative Care Clinical Leads
- Speech and Language Therapy
- Service Improvement Leads
- CEO's
- Clinical Psychology
- Pharmacy
- Social Work

Question 1.5 asked respondents to indicate which health and social care professions were represented by their responses to the questionnaire (Figure 3). Respondents were advised that they could record more than one option for this question. As can be seen professional groups who have the potential to be involved in the care of people with life-limiting illness and their families are represented.

The survey went on to ask the respondents if the organisation they represented, in responding to the survey, received, funded or provided palliative care education. Respondents were advised that they could record more than one option for this question. Of those that responded 51 (68.92%) organisations reported that they were in receipt of palliative care education, 19 (25.68%) organisations funded palliative care education and 51 (68.92%) organisations provided palliative care education (Figure 4).
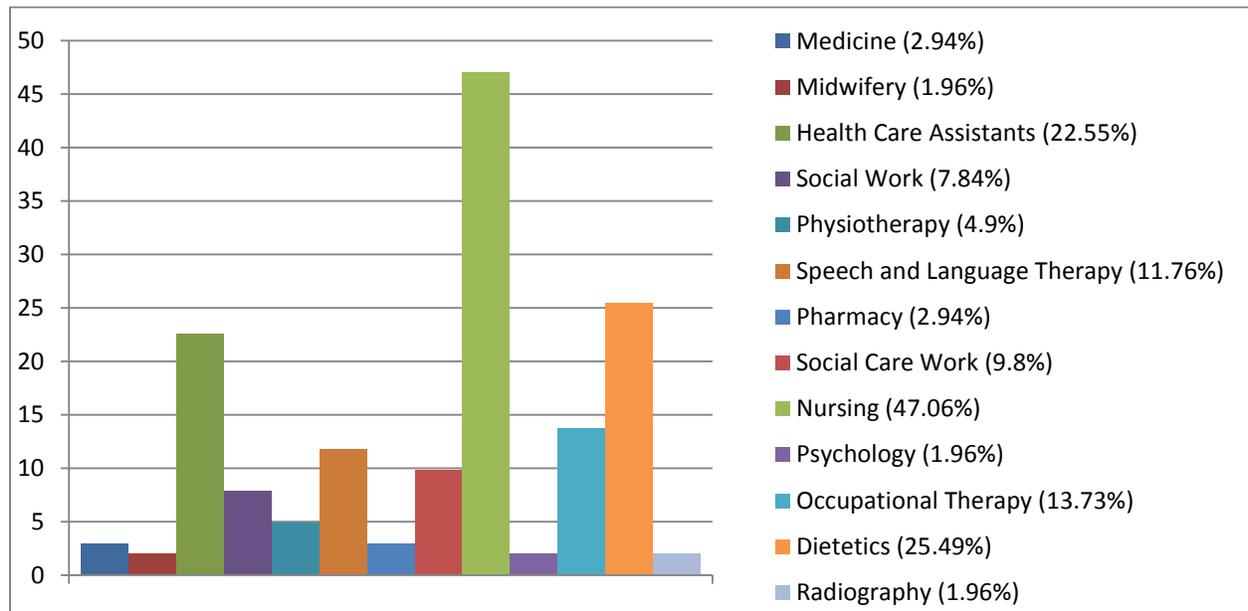
Figure 3: Health and Social Care Professionals represented in responses to questionnaire

Figure 4: Number of respondents in receipt of funding, provide funding or provide palliative care education

In question 1.7 respondents were asked to identify the number of health and social care professionals employed by their respective organisations. Taken together the number of health and social care staff represented by the respondents to the survey totalled 165,348.06 WTE[2]. At present over 100,000 in the Republic of Ireland and 110,000 in Northern Ireland work in health and social care. Approximately 60% of these work in frontline services. In the context of the response to this question it should be noted that this representative total is likely to include both generalist and specialist staff.

> **Key Points**
>
> - Respondents to Needs Analysis of General Palliative Care Education represent organisations who provide; palliative care services, palliative care education, or funding for palliative care education
>
> - The majority of respondents were managers in a clinical practice settings who had responsibility and oversight for funding continuing education and practice development for health and social care staff
>
> - Respondents represented a wide range of professionals who care for people with life-limiting conditions and their families

Section 2: Health and Social Care sourcing, accessing and funding for palliative care education

Questions in Section 2 (2.1-2.6) relate to how health and social care professionals currently access information about palliative care education courses. Questions in this section also related to the availability and type of support provided by organisations to staff undertaking palliative care education, whether palliative care education is seen as a priority within their organisation and the type of education programmes attended or funded by the respondents organisation in the last 3 years.

Question 2.1, asked respondents where do health and social care professionals employed by their organisation obtain information about palliative care education courses. Respondents were free to tick all of the options that applied to their organisation. The most popular source of information about palliative care education was 'advice from colleagues or other professionals' (87.01%) (Figure 5). The second most popular source of information was promotional materials from the education provider (55.84%). The least popular source of information was the Palliative Care Education Database (20.78%). It should be noted that in the past number of months (January – June 2013) considerable work has taken place on refreshing this database with aim of providing:

- a focal point for information regarding palliative care education courses
- a resource for providers to advertise their courses and programmes of study to health and social care professionals and the wider community
- a user-friendly search function and display of education programmes/courses, workshops, study day(s), seminars, conferences and meetings.

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[2] This figure represents the total number of health and social care professionals employed by organisations represented by the respondents to the questionnaire. It should be noted that some of this number may have been represented by more than one respondent in their role as a service manager.
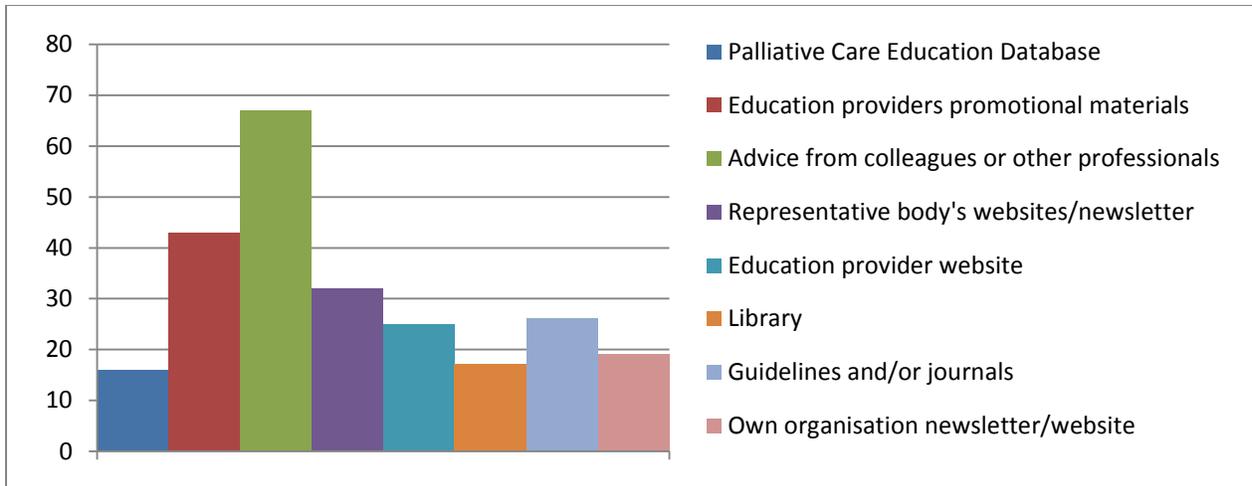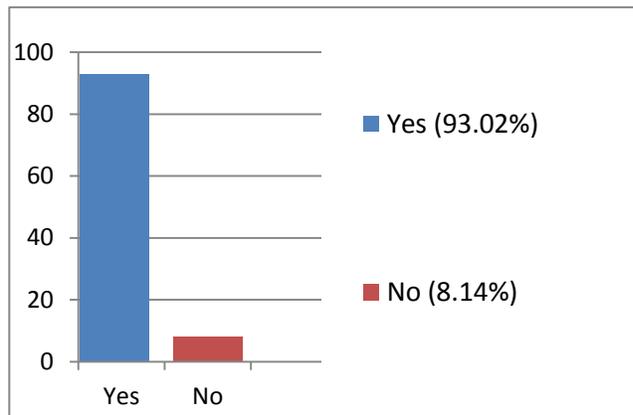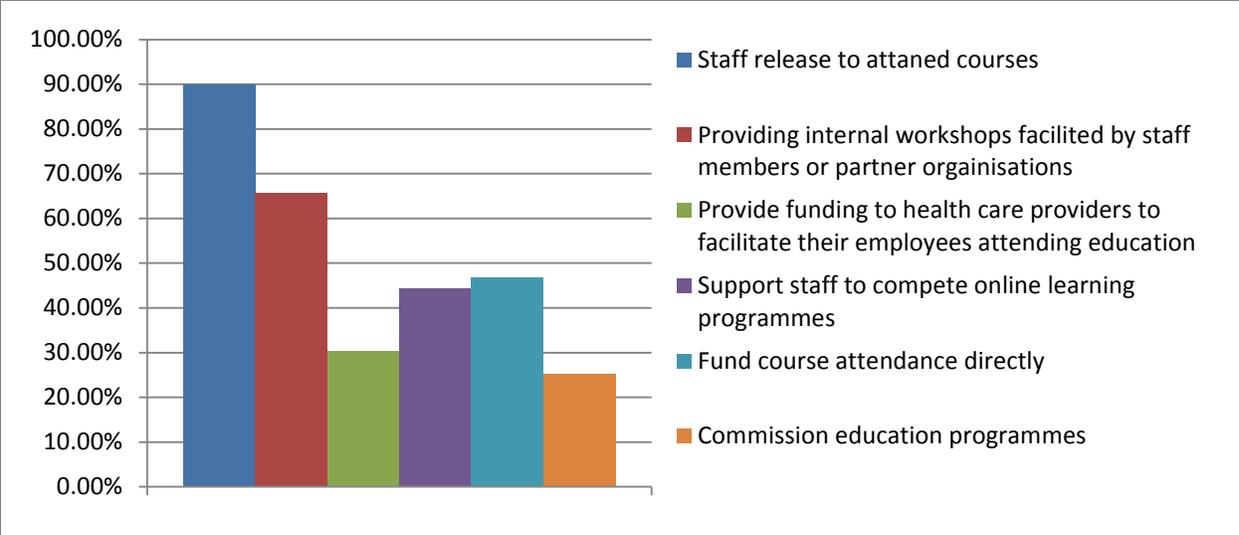
Figure 5: Where health and social care professionals obtain information about palliative care education courses.

Figure 6: Does your organisation support health and social care professionals to access continuing education?

Question 2.2 asked the respondents whether their organisation supported health and social care professionals to access continuing education the majority (93.02%) responded yes (Figure 6). This very positive response is positive in light of current and likely future economic pressure on availability of funding and support for education

The next question (Question 2.3) asked respondents who had answered yes to question 2.2, to indicate how their organisation supports education of health and social care professionals (Figure 7). Respondents were advised that they could record more than one option for this question. The majority of responses related to the organisations releasing staff to attend courses in work time (89.87%). The second highest response related to organisations providing education either internally or with a partner organisation (65.82%). Some organisations provide direct funding for attendance at courses (46.84%), whilst other organisations support staff that are completing online learning programmes (44.3%). Other organisations report that they receive funding to facilitate employees to attend education programme (30.38%).

Figure 7: Indicate how your organisation supports education for health and social care professionals
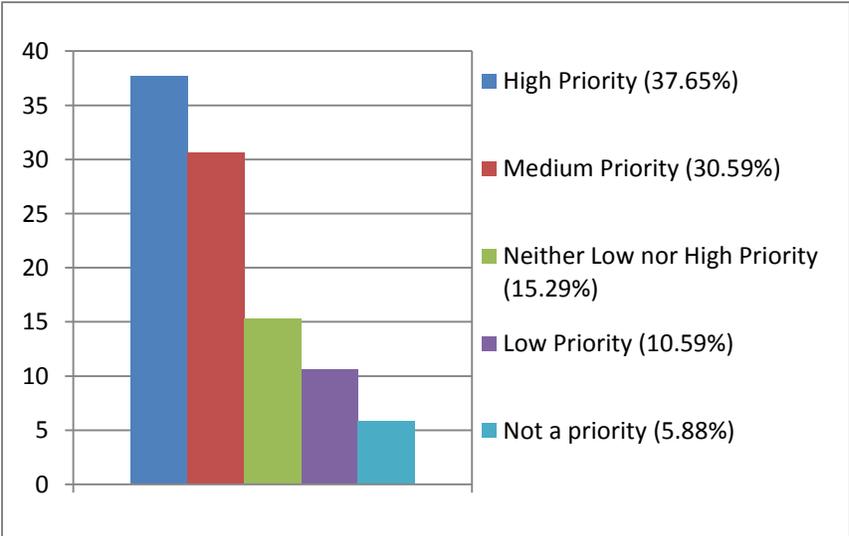

Figure 8: Extent to which palliative care is a priority for respondent's organisation

Question 2.4 asked respondents to consider whether palliative care education was a priority within their organisation (Figure 8). The majority of respondents indicated that palliative care education was of high (37.65%) or medium priority (30.59%). However a significant number of respondents did not see palliative care education as a priority (31.76%). Not seeing palliative care education as a priority may be indicative of the professional role of the staff represented in the survey response, as they may feel they are not directly involved in the provision of palliative care and therefore would not necessarily see palliative care education as a priority.

Question 2.5 asked respondents, particularly those who were responding as a health care provider, to identify, from a list provided, the type of palliative care education courses that their staff had attended in the last three years (Figure 9). Respondents were free to tick all of the options that applied to their organization. What can be seen is that the vast majority of staff attended conferences or seminars (69.86%). This may be indicative of the support available for release of staff to attend education events as normally conferences and seminars are one or two days in length. It is noteworthy that there appears to be little significant difference between those attending accredited study days (50.68%) and those attending non-accredited study days (54.79%).

Other education courses that staff attended were programmes of study that carried an academic award, FETAC/NVQ (12.33%), Postgraduate (Grad Dip; Grad Cert; MSc; PhD) (26.03%) or Undergraduate courses (6.85%).
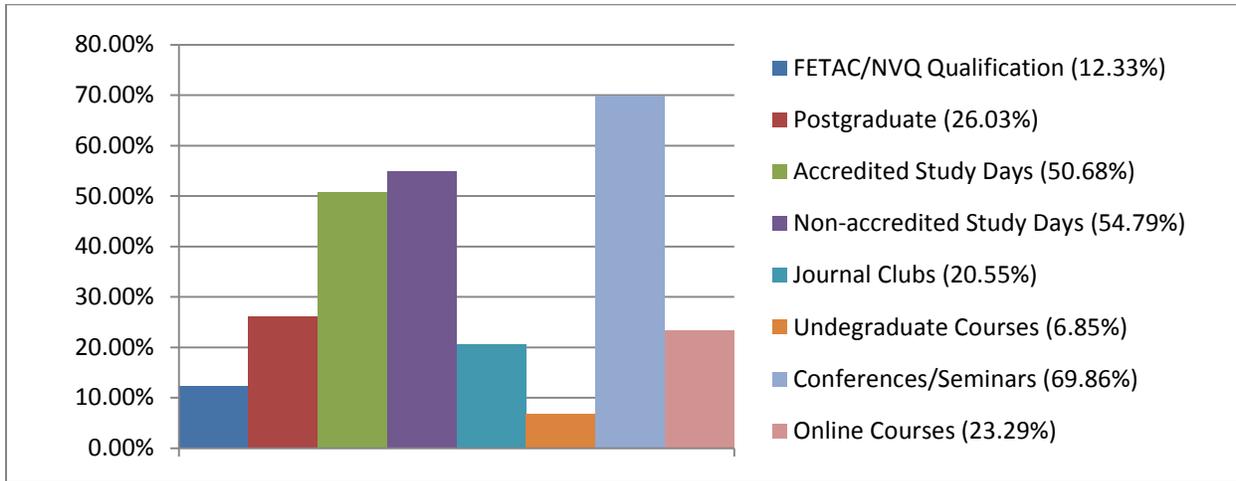
Figure 9: Type of palliative care education courses attended by staff in last three years

Question 2.6 asked respondents, particularly those who were commissioners or funders of education, to indicate the type of palliative care education that their organisation provided funding for in the last three years.   As can be seen (Figure 10) accredited study days (65.22%), conference/seminars (63.04%) and non-accredited study days (52.17%) respectively, were the top three education events/programmes that were in receipt of funding from the organisation represented by the individual respondents. The lowest level of funding was provided for FETAC/NVQ qualification (15.22%), journal clubs (8.7%) and Undergraduate programmes (6.52%) respectively. Some respondents provided comment in relation to this question, highlighting that in particular services, staff routinely self-fund on-going training and development.
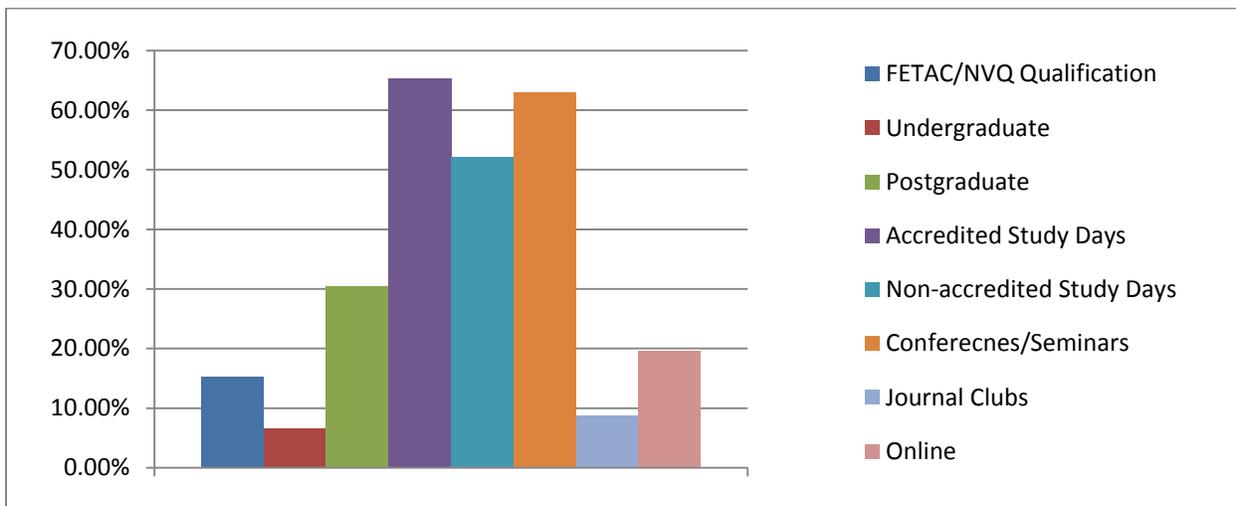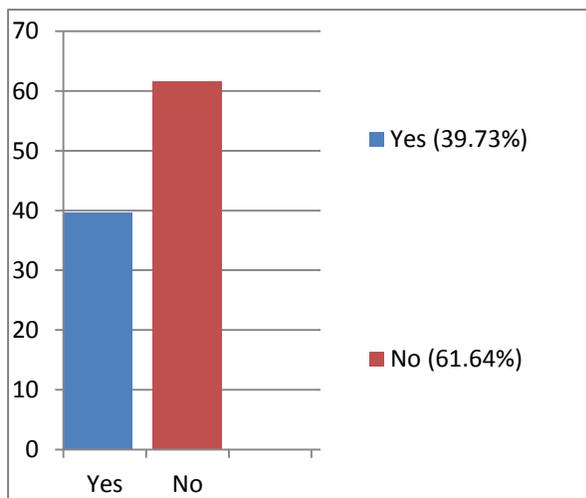

Figure 10: Type of palliative care education provided by respondent's organisation in the last three years

Current and future provision of palliative care education

Figure 11: Does current palliative care education provision meet the needs of health and social care professionals

Questions in Section 3 (3.1-3.3) were focussed on current and future provision of palliative care education. Question 3.1 asked respondents, based on their experience over the last three years, whether current palliative care education provision meets the needs of health and social care professionals. As can be seen (Figure 11) 61.64% answered no, indicating that they felt that current palliative care education provision is not meeting needs.

A significant number of comments were provided by respondents to this question. In some cases these reflected the availability and viability of programmes for staff working in a particular geographical area, whilst also reflecting that general palliative care education tends to be provided in a more informal way.

> I think under grad and post grad specialists palliative programme are meeting the needs, however in N.Ireland there are sometime issues of viability due to lack of numbers . In respect of general palliative care provision tends to be more in-house, informal and non-accredited

In other cases comments were provided about education programmes aimed at staff working in particular care settings. There was a general feeling that a particular programme was meeting the needs of the staff it was provided for, whilst also acknowledging that enabling staff to attend during work hours was positive.

> The recent Regional Palliative End of Life Care Learning and Development Programme f or Nursing Homes [Northern Ireland] which is a 3 day course provided free of charge has been very beneficial. The Home has released staff to attend this during working hours.

> … staff have recently attended a 3 day course - regional and palliative end of life care for nursing homes [Northern Ireland]…. excellent training

A comment was made regarding funding of programmes. Although many programmes offered are multi-disciplinary in nature the majority of attendees are nurses. This could be related to availability of funding.

> Programmes tend to be multidisciplinary in nature but in a large percentage of circumstances many of the health and social care professionals who attend are nurses. This may be attributed to the f act that much of the funding that is available tends to only be accessible f or nurses.

> To date, it has been very much nurse orientated and fails to address that there are other professionals involved with families (It is the traditional model of care – i.e. doctors and nurses)!

> Social care workers need more input. Most of the training has been directed at nurses.

> We are a hospital organisation and people dying form part of the core of our work. Palliative care is seen as very much a "luxury" item that people f und their own courses f or - particularly anything beyond study day level

A common issue for respondents was the need for greater access to education.

> Yes in some areas, no in others. It is unclear if there are education places f or all who need it but we f eel more access to education is needed.

> Training funded by the Northern Ireland Government is only available for staff nurses in nursing homes there is no provision within this funding f or Residential Homes. However people choose to die in residential homes as well. District nurses and GPS provide support when needed. But care assistants have to provide all the care between times some training on basic good palliative care would be of benefit to residential homes as well.

> The provision of some courses is for qualified staff only there is a lack of training f or the care assistants and ancillary staff

A number of respondents indicated a clear need for education which focussed on practice with targeted training related to clinical skills and procedures and equipment.

> … staff need more practical training re use of syringe driver, mixing of drugs etc.

Some respondents indicated that they had concerns regarding the level of understanding that some health and social care professionals have of palliative care. They felt that the level of understanding of the basics principles or essentials of palliative care was limited and that the knowledge needs of particular professions needed to be addressed.

> Further clarity required on essential palliative care training for social care staff

> Staff movement is continuous. Staff still do not understand the basic principles of palliative care provision

There was some evidence to suggest that there was insufficient education in specific areas where potential issues regarding care and care decisions need to be addressed, an example of which would be ethical issues associated with end of life decisions and care planning. In a number of cases where education was provided, sometimes it lacked structure and so the palliative care education needs of individual health and social care professionals were not being met.

> No structured education provided. Structured education in the area if the ethical aspects of feeding and hydration is particularly lacking

> No structured education programme delivery

A key concern for some respondents was the need to ensure that education programmes need to be interdisciplinary and directed to more than one or two professionals working in health and social care. As care is delivered by a multi-disciplinary team, education provision needs to reflect practice so that health and social care professionals can learn with and from each other. This type of education provision could address the concerns of some professionals who felt their discipline was being ignored by current palliative care education provision.

> Social care workers need more input. Most of the training has been directed at nurses.

> … pitched at appropriate level of need from awareness through to commissioned post reg programme - however big drawback is it is not multi-professionally directed as each discipline has their own isolated budget

Another concern expressed was the need for palliative care education to move beyond the needs of health and social care professionals caring for individuals with cancer. As such palliative care education needs to ensure that those providing general and specialist palliative care receive the relevant education to meet the needs of various client groups irrespective of diagnosis.

> More education is required to train and advise both commissioner and providers to deliver care in relation to the client group

Staff release is a problem.

> Need for further education opportunities - but lack of staff release from clinical area means staff have to attend education in their own time

Competing education needs e.g. mandatory training.

> Large workforce with some turnover of staff, competing educational priorities such as mandatory training/update, difficulty releasing staff to attend, cost of educational courses provided 'out of house'

These comments indicate that some health and social care professionals represented in the survey are in need of more education in respect of palliative care. However the realities of providing this training or supporting staff to attend are also apparent.

Figure 12: Percentage number of organisations who have recommended a palliative care education course/programme to staff

Question 3.2 asks respondents to identify whether their organisation had recommended palliative care education courses/programmes to health and social care professionals. As seen (Figure 12) half of respondents had recommended a particular programme to health and social care professionals. A number of comments were provided by respondents which specifically named a number of courses and programmes that were recommended for staff to attend, the majority of which were accredited and tended to focus on principles of palliative care and communication in palliative care.
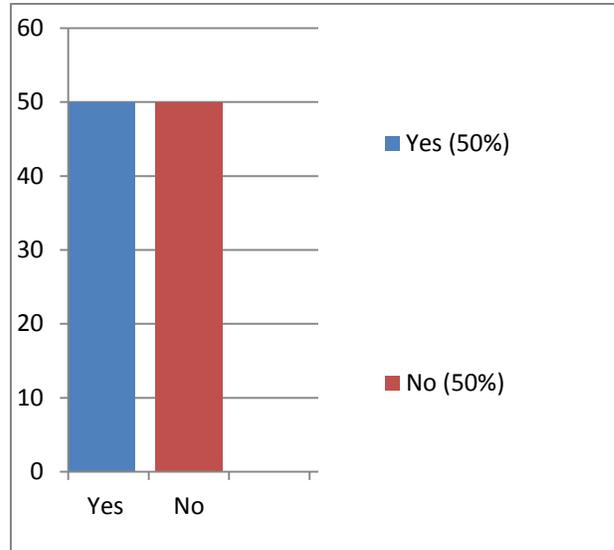
Question 3.3 Asked respondents if they had a preference regarding which palliative care education developments they would they like to see for health and social care professionals working in their organisations and Table 1 shows the results .

Table 1: Preference for palliative care education developments for health and social care professionals

Preference for Palliative Care education development	Additional comments by respondent
Mandatory training in palliative care	• Dedicated palliative care education facilitator • Basic principles of palliative care needs to be mandatory for all health and social care professionals • Mandatory general communication skills (graded to role and need) f or all staff (not just for 'professionals')
Access to current information on education courses and programmes	• Menu of courses available to support agreed levels of education required for all staff • Improved regional signposting, clarity and definition about courses available
On-going staff development	• Staff development programmes - e.g. supporting development from generalist to specialist • On-going education needs to be accredited and provided by specialist
E-learning programmes	• E-learning should be the approach rather than face to face. • E-learning programmes should be delivered with links to advancing knowledge and should be geared to provide programmes from basic to specialist level.
Provision of education to meet discipline specific needs. Specific professions were identified: dieticians, social workers, health care assistants	
Communication	
Multidisciplinary learning needs to be prioritised and promoted	• More opportunity for multi-disciplinary training • Increased links between education providers and clinicians in order to meet local palliative care education needs
Bereavement support and training	• Bereavement training and education; carer education programmes
Palliative Care for specific disease and population groups	• Palliative care education in dementia • Education/ training f or those working with 'hard to reach' clients e.g. people with a learning disability ; people who are homeless; people with multiple comorbidities; hostel/ care home residents
Children and young people	• Transitional care/care of young adults • Paediatric training and education may be needed
Self-care	• "Self-care" education/ training • Self-management strategies f or patients such as those used in the cancer survivorship initiative e.g. self-care, motivational interviewing, CBT
Protected time and funding	• Protected time needed for continuing professional development (CPD) and attendance at relevant study days and courses • Access to funding to support education • Increased funding for education and CPD

Key Points

- Current palliative care education provision may not be fully addressing the needs of health and social care professionals, despite the fact that a wide range of courses and programmes are available and are detailed on a database
- It is important that managers be aware of current palliative care education provision
- Palliative care education should be focussed on providing programmes and courses that are clinically relevant
- Palliative care education courses and programmes should be aimed at a multidisciplinary audience
- Palliative care programmes and courses should be designed to ensure that health and social care professionals providing general and specialist palliative care receive relevant instruction and training to meet the needs of individuals with life-limiting conditions and their families, irrespective of diagnosis

AIIHPC Communications Hub

A key work area for AIIHPC is the development of an on-line Palliative Hub, which has as one of its aims, a commitment to meet the needs of the health and social care professionals providing general palliative care. In order to assist with this development Question 4 asked respondents to consider what information and knowledge should be included for health and social care professionals providing general palliative care. As per responses, information and knowledge needs were collated under six headings: Resources, Education courses, Information, Nutrition related information, Research, Support. Specific needs are identified under each of the headings (Table 2). A total of 55 responses were received for this question.

THE PALLIATIVE HUB

An All Ireland Gateway to
Palliative Care Information

Table 2: Information and Knowledge to be included on Palliative Hub

Resources	• Best practice • Changes in Practice which support patients • Patients stories • Interviews with patients/carers/staff which highlight the positive and negative experiences of palliative care today and the challenges for the next 10 years • Q&A's which change regularly • Profession specific forums
Education courses	• Availability and providers • Upcoming education and training programmes • Signposting to education courses available • Access to free on-line learning which is accredited • Communication skills around difficult issues/situations • Communication with patients and families e.g. Breaking bad news • Managing family expectations • Ethics – nutrition/hydration • Reporting and recording symptoms • Self-care
Information	• Basic first line information e.g. When to introduce palliative care? • Key principles of palliative care • Access to referral forms • A list of Professionals working in Specialist Palliative Care and their area of research/clinical interest • Drug/Medication information and updates • Direction to relevant sources of information • Patient care plans • Useful information on palliative care for families and health and social care professionals • Contact details and out of hours information for Specialist Palliative Care • Signed off work from Clinical Care Programme for Palliative Care (HSE) • Role of each discipline • Signposting to quality up-to-date information sources e.g. Repatriation information/ Hospice and palliative care resources in other countries • Links to quality assured evidence based clinical information • New advances in palliative care • Fundamentals of palliative care including symptom management • What general palliative care is? • How does Specialist Palliative Care interact and liaise with the multi-disciplinary team • Sign posting services
Nutrition related information	• Guidance on ethical decisions regarding withdrawal/withholding food – guidance documents/best practice • Guidance on nutritional needs of those in receipt of palliative care • Nutritional needs for particular patients: MND, MS, Cancer, Dementia • Artificial feeding
Research	• Recent research findings on symptom control • Relevant journal articles • Access to key reports
Support	• For families coping with end of life and helping them to avoid unnecessary admissions • Support to carers

Competence

Question 5 asked respondents to rate their staff current skills, knowledge and competence in a range of areas. The areas referred to were drawn from the core competencies identified in the *Palliative and End-of-Life Care Competency Assessment Tool* (Northern Ireland) and the *HSE Palliative Care Competence Framework* (Republic of Ireland). The rating scale used was a 5 point Likert Scale (1 = No Current Knowledge; 2 = Some awareness, but not sufficiently competent to use it; 3 = Familiar with and able to use knowledge and skills; 4 = Proficient in the knowledge or skill and able to show others how to use it; 5 = A high degree of skill and comprehensive knowledge) (Appendix 2). A total number of 68 responses were received for this question. Results from Question 5 are presented under five headings: Core principles of palliative care and the palliative care approach, Communication, Identifying and responding to needs and working collaboratively, Responses to grief and Ethical issues and care preferences.
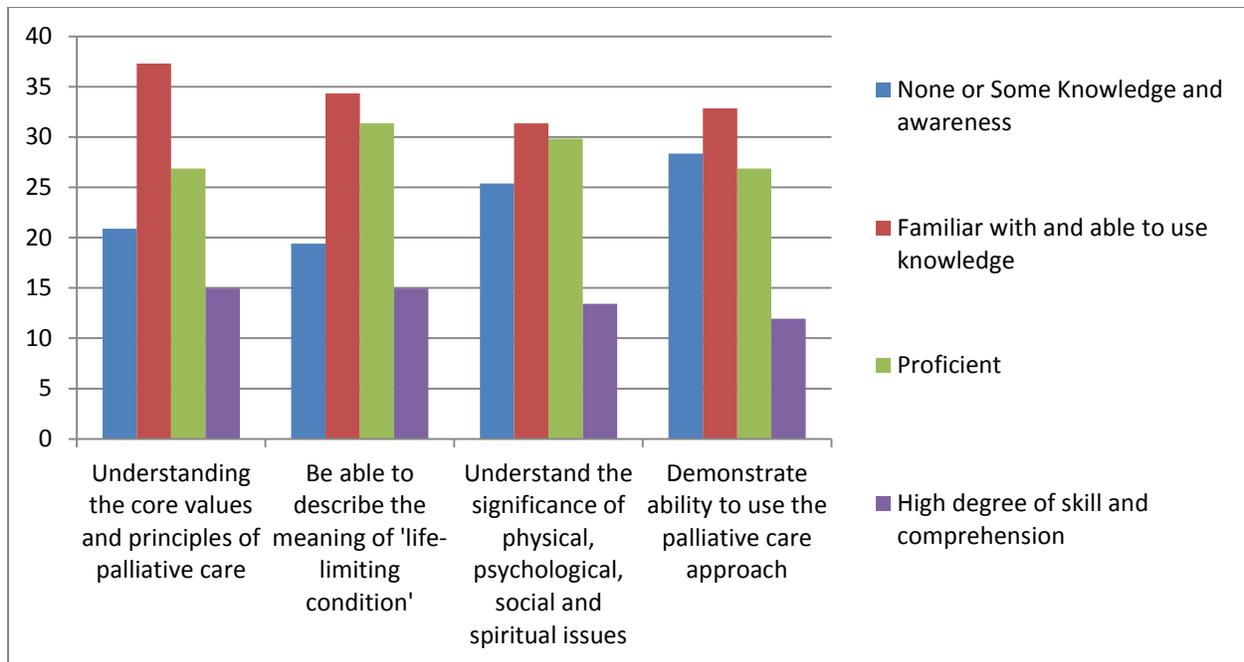
Core Principles of Palliative Care and the Palliative Care Approach

Figure 13 illustrates results from respondents who were asked to rate the current level of skill, knowledge and competence of their staff in areas related to the core principles of palliative care and using a palliative care approach. Respondents were first asked to rate current skill, knowledge and competence of staff as it related to understanding the core values and principles of palliative care. Although the majority of responses indicated that current staff are either familiar, proficient or have a high level of skill and comprehension in this area, a significant number (20.89%) indicated that staff had only some or no current knowledge or competence in this area.

Having the ability to describe what is meant by the term 'life-limiting condition' is important in the context of palliative care. Once again responses indicated a relatively good ability to describe what is meant by 'life-limiting condition.' However it is worth noting that 19.41% of respondents indicated that their staff had no current knowledge or competence regarding this topic.

Asked about staff understanding of the significance of physical, psychological, social and spiritual issues affecting the person with a life-limiting condition, 74.62% of respondents indicated that staff would be either familiar with and able to use skills and knowledge (31.34%), or would be proficient in knowledge and skills and able to show others (29.85%) or would have a high degree of skill and comprehensive knowledge (13.43%) related to this topic. Responses indicated that 25.37% of staff would have no current knowledge and competence or would have only some awareness but lack sufficient competence to use it as it relates to understanding of the significance of physical, psychological, social and spiritual issues affecting the person with a life-limiting condition. This response may reflect a lack of understanding of the concept of total pain which incorporates physical, psychological, social and spiritual elements. It may also relate to the perceived professional role of the staff represented in the survey response.

Respondents were asked to consider staff ability to demonstrate an ability to use the palliative care approach as early as is appropriate in order to facilitate person-centred practice that recognises the concerns, goals, beliefs and culture of the person with a life-limiting conditions and their family. Over a quarter of respondents (28.36%) indicated that their staff had no current knowledge or competence (4.48%) or had only some awareness but insufficient competence to use this knowledge (23.88%). This may be indicative of a lack of understanding of how when used the palliative care approach is a cost effective and efficient way to provide care to people with life-limiting conditions and their families irrespective of location of that care provision.

Figure 13: Staff current skill, knowledge and competence – Core Principles of Palliative Care and the Palliative Care Approach

Communication

Figure 14 illustrates the responses related to the perceived current skill, knowledge and competence in the area of communication. Respondents were asked to consider questions which related to the ability of their staff to communicate effectively with a person who has a life-limiting condition, their family and the other members of the inter-disciplinary care team. Respondents were also asked to consider staff ability to demonstrate their ability to be attentive listeners when caring for the person with a life-limiting condition and their families so that the individual and their family feel they have been heard. It also asked respondents to rate staff ability to act as an advocate for the individual with a life-limiting conditions and their family in order to ensure appropriate and timely palliative care intervention.

The results show that when asked if staff could demonstrate an ability to communicate effectively with a person with a life-limiting condition in order to establish, maintain and conclude a therapeutic relationship the majority of respondents (76.12%) felt their staff would be either familiar with and able to use skills and knowledge (32.84%), or would be proficient in knowledge and skills and able to show others (31.34%) or would have a high degree of skill and comprehensive knowledge (11.94%) related to this topic. These figures are also reflected in response to the questions related to staff ability to communicate effectively with the family of a person with a life-limiting condition and staff ability to communicate effectively with the inter-disciplinary team caring for a person with a life-limiting condition in order to establish, maintain and conclude a therapeutic relationship respectively. The majority of respondents indicated staff would be able to communicate effectively with the family of person with a life-limiting condition, with 80.6% demonstrating familiarity or proficiency or comprehensive knowledge related to this topic. In the case of staff ability to communicate effectively with the inter-disciplinary team caring for a person with a life-limiting condition, 83.58% indicated familiarity or proficiency or comprehensive knowledge related to this topic.

When asked about staff current skill, knowledge and competence as it related to the ability to be attentive to the person through careful listening 86.56% indicated familiarity or proficiency or comprehensive knowledge related to this topic. Although 13.43% of respondents indicated that their staff had no current knowledge or competence (1.49%) or had only some awareness but insufficient competence to use this knowledge (11.94%), this may be indicative of a lower level of interaction between some health and social care professionals and people with life-limiting conditions and their families.
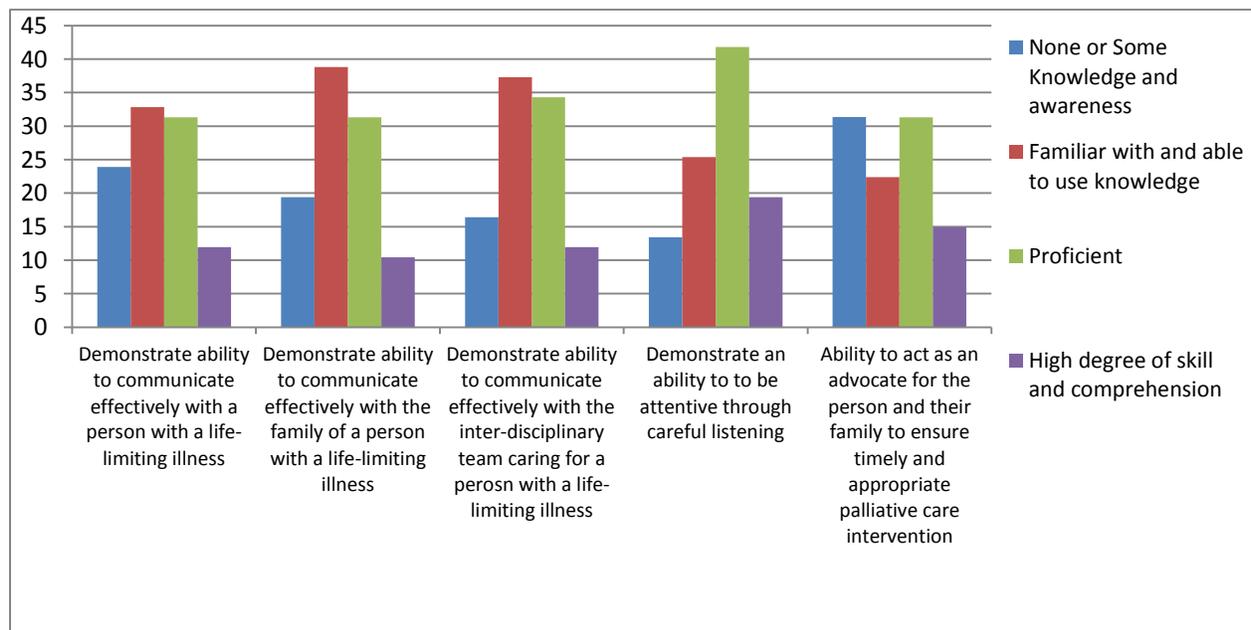
Respondents were asked to consider current staff skill, knowledge and competence in respect of their ability to act as an advocate for the person with a life-limiting condition and their family to ensure appropriate and timely palliative care intervention. Interestingly 31.35% of respondents indicated that staff would have no current knowledge or competence or only some awareness but insufficient competence to use this knowledge. Once again this may be indicative of indicative of a lower level of interaction between some health and social care professionals and people with life-limiting conditions and their families.

Figure 14: Staff current skill, knowledge and competence - Communication

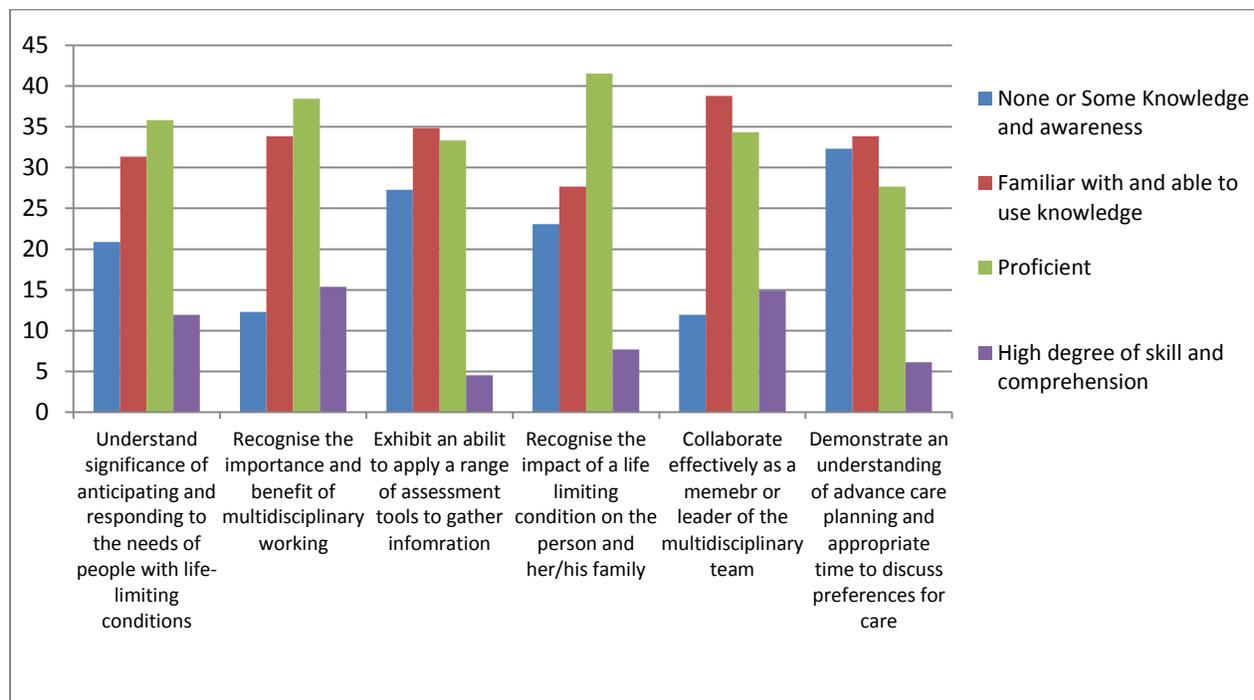## *Identifying and responding to needs and working collaboratively*

Respondents were asked questions related to identifying and responding to the needs of people with life-limiting conditions, working collaboratively and understanding advance care planning and the most appropriate time to discuss preferences for care (Figure 15). Result indicated that of those who responded 20.9%, indicated that current staff has no current knowledge or competence (4.48%) or only have some awareness but insufficient competence to use this knowledge (16.42%).

Questioned about the ability to understand the importance and benefit of multidisciplinary working to optimise comfort and enhance quality of life for the person with life limiting condition, the majority of responses (87.69%), indicated familiarity or proficiency or comprehensive knowledge related to this topic.

Over a quarter of the respondents indicated that current staff had no current knowledge or competence or only some awareness but insufficient competence in an ability to use a range of assessment tools to gather information (27.27%).

The majority of respondents (76.92%) indicated that current staff indicated familiarity or proficiency or comprehensive knowledge related to the ability to recognise the impact of a life limiting condition on the person and their family. However a significant number of respondents (23.07%) indicated their current staff would have either none or some knowledge and awareness of this topic. These results are also reflected in the fact that 88.07% of respondents indicated that current staff could demonstrate familiarity or proficiency or comprehensive knowledge related to being able to collaborate effectively as a member or leader of the multidisciplinary team in the care of the person with a life-limiting condition and their family.

Almost a third of responses (32.31%) indicated that their current staff would have no current knowledge or competence (9.23%) or only some awareness but insufficient competence to use this knowledge (23.08%) in the context of demonstrating an understating of advance care planning and an appreciation of the appropriate time to engage in discussion about preferences for care with the person with a life-limiting condition and their family.

Figure 15: Staff current skill, knowledge and competence – Identifying and responding to needs and working collaboratively

Responses to grief

Figure 16 illustrates the responses to related to loss and grief. Just over a quarter of respondents (25.37%) indicated that current staff would have no current knowledge or competence (5.97%) or only some awareness but insufficient competence to use this knowledge (19.40%) in the context of recognising the range of individual physical, psychological spiritual, emotional and social responses to loss and grief. Not surprisingly then, a greater number of respondents (39.39%) indicated that current staff would have none or only some knowledge and awareness of the factors which may put a person at risk of encountering difficulties in their grief, whilst also being aware of the resources and resiliencies that are particular to each and person with a life-limiting condition and their family.
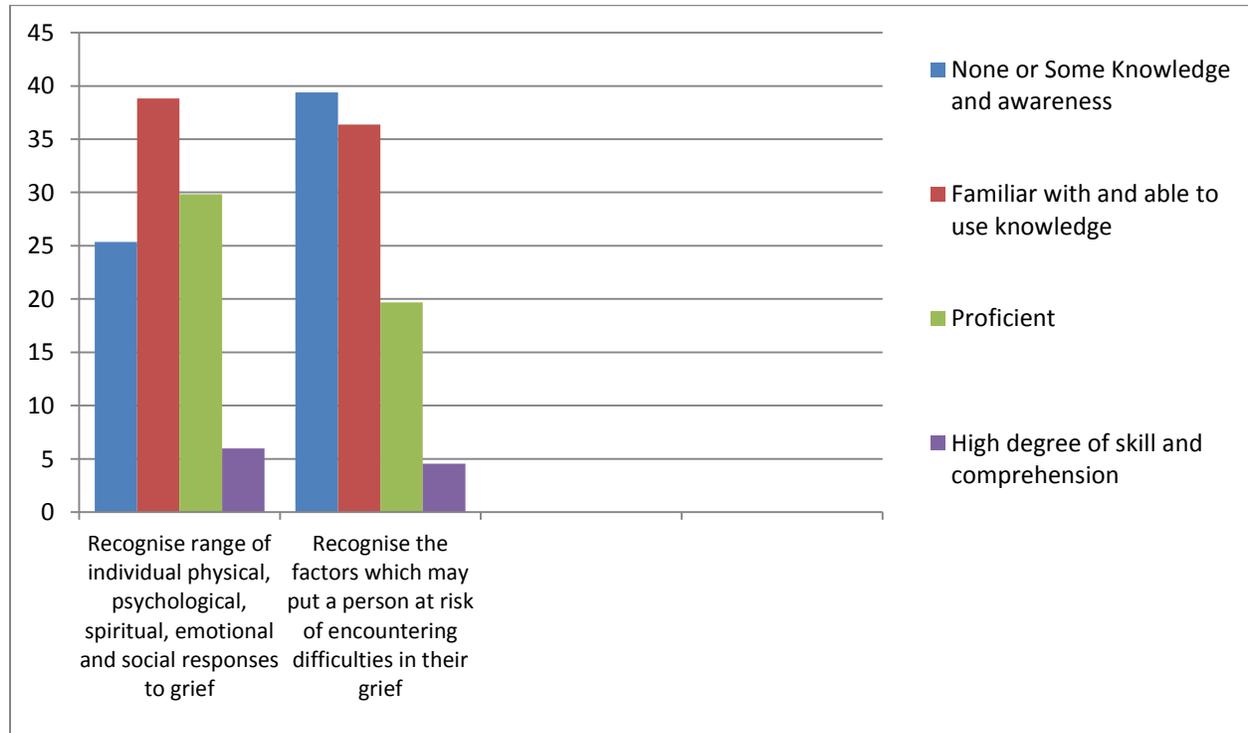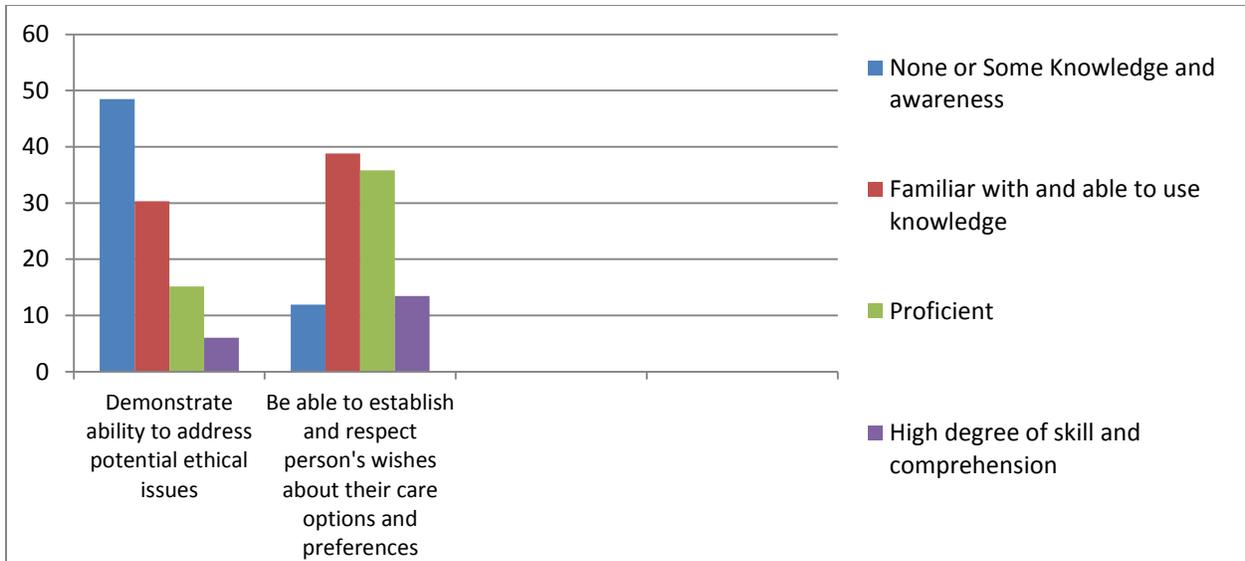

Figure 16: Staff current skill, knowledge and competence – responses to grief

Ethical issues and care preferences

Respondents were asked to consider the skill, knowledge and competence of current staff in respect of their ability to demonstrate an ability to address the potential ethical issues that may be encountered when caring for a person with a life limiting condition and her/his family. Almost half of the respondents indicated that current staff would have no current knowledge or competence (9.09%) or only some awareness but insufficient competence to use this knowledge (39.39%). This may indicate that the staff represented by the respondents may have limited interaction with an individual with a life-limiting illness or their family and so may not have to consider the ethical issues that may arise in the context of the care being provided.

Not surprisingly the majority of respondents (88.06%) indicated that current staff could demonstrate familiarity or proficiency or comprehensive knowledge in the context of being able to establish and respect individual wishes about the care options and preferences.

Figure 17: Staff current skill, knowledge and competence – ethical issues and care preferences

Key Points
Key Points
• Understanding the core principles of palliative care and the palliative care approach is essential for all health and social care professionals
• Effective communication is key in palliative care so all staff need relevant skills, knowledge and competence in communication skills needed when caring for someone with a life-limiting condition and their family
• It is important that health and social care professionals understand that multidisciplinary team working is central to palliative care
• Staff need support to develop skills and knowledge in order to better understand advance care planning
• Staff need support to develop skills and knowledge in order to better understand responses to grief

Priority areas for palliative care education over the next two years

Question 6 asked respondents to indicate the priority level for health and social care professionals for general palliative care and training for the next two years in a list of areas. The rating scale used was a 5 point Likert Scale (1 = Not a priority; 2 = Low Priority; 3 = Neither Low or High Priority; 4 = Medium Priority; 5 = High priority). A total number of 61 responses were received for this question. Results are presented in aggregate, with the education topics listed in order or preference, from highest priority to least.

Table 3: Priority for general palliative care education for the next two years

	Palliative Care Education Topics ranked in order of priority
1.	Principles of Palliative Care
2.	Communication issues with people with life-limiting conditions
3.	Ethical issues in palliative and end of life care
4.	Multidisciplinary working in palliative care
5.	Advance Care Planning
6.	Palliative Care for Older People
7.	Pain assessment and management
8.	Communication issues at end-of-life
9.	Assessment and management of gastrointestinal symptoms
10.	Care in the last days of life
11.	Palliative Care for people with non-malignant conditions
12.	Assessment Tools used in Palliative Care
13.	Fatigue
14.	Palliative care for people with intellectual disability
15.	Palliative care for people with dementia
16.	Self-care strategies
17.	Managing breathlessness
18.	Cachexia Bereavement support and care for families of children and young people with life limiting conditions
19.	Rehabilitation in palliative care
20.	Bereavement support and care for adults with life limiting conditions, their families and carers
21.	Constipation
22.	Spiritual care and spirituality
23.	Palliative care for children and young people
24.	Assessment and management of palliative symptoms for children and young people
25.	Bereavement support and care for families of children and young people with life limiting conditions

CONCLUSION AND RECOMMENDATION ACTIONS

The survey used in this needs analysis was targeted for completion by senior managers of health care services on behalf of health and social care professionals working within their organisation; representative bodies of care providers, particularly the individual who leads on education or who as a senior manager has a role in directing the development of palliative care education; or funders or commissioners of palliative care education, particularly the individual who has a role in directing the development of Palliative Care Education. The respondents were broadly representative of health and social care professionals, with the majority of those completing the survey identified as senior managers working in clinical practice.

Generally continuing palliative care education for health and social care professionals is supported in the form of funding and/or study leave to attend an education programme or course.

Accessing information about palliative care education courses is important and respondents indicated that advice from colleagues was the most popular source of information about palliative care education programmes and courses. This may not however be sufficient and it will be important to ensure access to the most up to date and comprehensive sources of such information. This may be greatly assisted by the Palliative End of Life and Bereavement Education Database, which has been refreshed in recent months and now provides a comprehensive list of current programmes and courses offered across the island of Ireland. (http://www.aiihpc.org/education/70/palliative-care-education-database/).

The needs analysis provides valuable information about what is working well and what might be improved. The majority of respondents support access to palliative care education for health and social care professionals and see it as a priority. Support for health and social care professionals to access continuing education also appears to be well supported, with respondents indicating that this support is best exemplified by staff being released to attend study days and courses or by staff being provided with funding to cover course fee costs. The support for staff attendance for palliative care education through study leave and both direct and indirect funding is commendable and needs to continue.

Recommendation actions
• Be aware of the need to ensure that service developments include education as a way of ensuring that competence to practice is developed and maintained
• Be responsive to the changing nature of care needs and how education will respond to prepare carers to meet these needs.
• Ensure that training and education is commissioned and delivered via a number of mechanisms including face to face training, online and blended learning.
• AIIHPC is working to promote greater access to online learning

Whilst the majority of respondents indicated that palliative care education was a priority for their organisation, almost a third of respondents did not see this as the case. This is worrying given the changing demographic picture on the island of Ireland, in which we will see a substantive increase in the number of older people. This is likely to be accompanied by an increase in the numbers of people living with chronic and progressive illness and disease, which would benefit from being managed initially using the palliative care approach, to in time, progressing to increased palliative intervention being provided as needs arise (Lorenz *et al.*, 2008; Morrison & Meier, 2004).

Recommendation actions
• In light of demographic changes and increased needs for health and social care, continuing education for general palliative care must be a priority for all health and social care professions and year on year funding must be secured

Health and social care staff attend a wide range and variety of palliative care education courses. It is important that staff be supported to attend education programmes that are evidenced-based, and fit for purpose and award where appropriate.

It is also important that any programme of palliative care education should be designed and delivered in a way that supports the continued development of professional and personal competence in health and social care professionals who provide either generalist or specialist palliative care.

Recommendation actions
• Be aware of current palliative care education provision and engage with education providers in order to highlight current and future needs and gaps
• Work collaboratively with education providers to ensure that the education and training they deliver is responsive to the changing needs of health and social professionals
• Promote and support greater collaboration between education providers in hospice education or at third level
• Encourage health and social care professionals to access education including provision which reinforces the value of multidisciplinary working and supports staff to maintain competence to meet the changing needs of service users

It is most important to note that over 61% of respondents indicated that current palliative care education does not meet the needs of health and social care professionals. This clearly needs to be addressed and both service providers and education providers need to work more closely together in order for education needs and education provision to be best understood. It is clear that better understanding offers significant opportunity.

Table 3 identifies the priority areas for general palliative care education over the next two years. This list of priorities identified by respondents, does in fact reflect the range of programmes currently being offered by a number of education providers on the island of Ireland as listed on the Palliative Care Education Database.

The Palliative Care Education Database was refreshed and updated recently in a collaborative project undertaken by AIIHPC, the Irish Hospice Foundation and the Irish Association for Palliative Care.

Recommendation actions
• Support greater collaboration between education providers to ensure that the identified palliative care education priorities for health and social care staff for the coming two years are met
• Ensure availability of quality programmes that meet health and social care professionals palliative care education needs
• Ensure that palliative care training and education is commissioned at a regional level so that any education provision is tailored to meet local need

- Ensure that a comprehensive range of suitable courses with appropriate capacity are available and avoid unnecessary duplication
- AIIHPC will continue to support and expand the Palliative Care Education Network, by bringing providers and consumers of education together to ensure that learning opportunities are available, accessible and of the highest quality
- AIIHPC will support collaboration between palliative care education providers including the hospice education providers and the universities in order to promote a coherent approach to meeting the palliative care learning needs of health and social care professionals.

Results from the survey indicated that in general there is an appropriate level of skill, knowledge and competence demonstrated by staff in the context of the core principles of palliative care, using the palliative care approach and communication. Significant numbers of staff were identified as having limited ability to recognise the impact of a life-limiting condition on the person and their family.

In the context of responses to grief, respondents identified that well over a third of staff would have none or only some knowledge and awareness of the factors which may put a person at risk of encountering difficulties in their grief, whilst also being aware of the resources and resiliencies that are particular to each person with a life-limiting condition and their family. This is of concern as staff caring for any individual with a life-limiting condition and their family need to understand grief response and how best to manage those at risk of encountering difficulties in dealing with grief and loss.

Recommendation actions
- This learning need, in respect of limited ability to recognise the impact of a life-limiting condition on the person and their family should be recognised and addressed in general palliative care education provision
- This learning need, in respect of understanding the factors which may put a person at risk of encountering difficulties in their grief whilst also being aware of the resources and resiliencies that are particular to each person with a life-limiting condition and their family, should be recognised and addressed in general palliative care education provision

There was recognition that information needs for health and social care professionals could be met through the Palliative Hub currently being developed. This Palliative Hub should become the 'go to' place for information about palliative care on the island of Ireland. Specifically it will enable health and social care professionals to access information about palliative care education courses and programmes available on the island of Ireland and accessible online.

Recommendation actions
- AIIHPC will continue to support health and social care professionals to access palliative care education via the Palliative Hub
- AIIHPC will continue to develop and maintain the Palliative Care Education Database resource detailing online palliative care education available on the island of Ireland and internationally
- AIIHPC will support e-learning through the development and facilitation of a Learning Platform as part of the Palliative Hub

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APPENDICES

APPENDIX 1: <u>Survey - Education Needs Analysis Questionnaire of General Palliative Care Education</u>

Background and Introduction
All Ireland Institute of Hospice and Palliative Care is committed to supporting the delivery of high quality education, and the development of a well-trained palliative care community with the skills and abilities to respond to a wide variety of care needs in a range of settings.
AIIHPC is undertaking an Education Needs Analysis (ENA) of general palliative care education required by health and social professionals on the island of Ireland.
The Education Needs Analysis will facilitate the:

- analysis of the current provision of general palliative care education provided by under graduate, post graduate and continuing professional development programmes including consideration of how health and social care professionals source, access and fund courses. This will include consideration of current unmet education needs.
- identification of future general palliative care education needs of health and social care professionals.

AIIHPC will utilise the results from the needs analysis questionnaire to inform key stakeholders including providers, funders, and commissioners of palliative care education regarding the current and future needs of health and social care professionals working within health and social care on the island of Ireland
Results from the analysis will inform the future planning of general palliative care education including the potential to commission specific programmes to meet identified needs.
Guidance on who should complete Education Needs Analysis within following organisation types:

a. **Health care providers** who employ health and social care professionals[3] – The ENA should be completed by a senior manager on behalf of health and social care professionals working within their organisation by *assessing the overall average rating of their team's skills and competences* in relation to providing general palliative care.
b. **Representative bodies** which represent care providers - The ENA should be completed by the lead on education or a senior manager who has a role in directing the development of palliative care education
c. **Funders or commissioners** of palliative care education - The ENA should be completed by the lead on education or senior manager who has a role in directing the development of Palliative Care Education

<u>Definitions</u>
Palliative Care
'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO, 2002)
General Palliative Care
Care provided by health and social care professionals who, although not engaged full time in palliative care, apply the principles of palliative care in the course of their work. Some health and social care professionals providing general palliative care will have additional training and experience in palliative care

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[3] Health and social care professionals who provide generalist palliative care from the following professions; medicine, nursing, midwifery, health care assistants, social work, speech and language therapy, occupational therapy, physiotherapy, dietetics, radiography, pharmacy etc.

1. Background Information	
1.1 Name of the Organisation	
1.2 Location of organisation	

1.3 Type of organisation (please tick all that apply):		
	Health care provider – acute services ☐	Health care provider – community services ☐
	Health care provider – private services ☐	Health care provider – adult services ☐
	Health care provider – children services ☐	Commissioner of education ☐
	Funder of education ☐	Representative body ☐
	Other (please state)	

1.4 Name, role and grade of person completing this questionnaire	

1.5 Indicate which of the following health and social care professions you are completing the form on the behalf of (please tick all that apply):		
	Medicine ☐	Nursing ☐
	Midwifery ☐	Psychology ☐
	Health Care Assistants ☐	Occupational Therapy ☐
	Social Work ☐	Dietetics ☐
	Physiotherapy ☐	Radiography ☐
	Speech and Language Therapy ☐	Other please state ☐
	Pharmacy ☐	
	Social Care Worker ☐	

1.6 Does your organisation receive, fund and/or provide palliative care education (please tick all that apply):	Receive ☐ Fund ☐ Provide ☐

1.7 How many health and social care professionals are employed by your organisation? **If you are not a health care provider please skip to question 2.2**	

2. Health and Social Care sourcing, accessing and funding for palliative care education				
2.1 Where do health and social care professionals employed by your organisation obtain information about palliative care education courses: (please tick all that apply) **If you are not a health care provider please skip to question 2.2**	Palliative Care Education Database (IHF / IAPC)	☐	Education provider websites	☐
	Education providers promotional materials	☐	Library	☐
	Advice from colleagues or other professionals	☐	Guidelines and/or journals	☐
	Representative bodies websites / newsletters	☐	Own organisation newsletter / website	☐
	Other (please detail)			
2.2 In your opinion, does your organisation support health and social care professionals to access continuing education? (please tick) **If you answered Yes to this question please complete the next question; if no please skip to question 2.4**	Yes	☐	No	☐
Only answer if you ticked yes to question 2.2 2.3 Please indicate how your organisation supports the education of health and social care professionals (please tick all that apply)	Staff released to attend courses in work time	☐	Support staff to complete online learning programmes	☐
	Providing internal workshops facilitated by staff members or partner organisations	☐	Fund course attendance directly	☐
	Provide funding to health care providers to facilitate their employees attending education	☐	Commission education programmes	☐
	Other … please detail			
2.4 Please indicate the extent to which palliative care education is a priority within your organisation.	Low priority	☐	Neither Low or High Priority	☐
	Medium priority	☐	Not a priority	☐
	High priority	☐		

2.5 In the last 3 years, what type of palliative care education courses have your staff **attended** (please tick all that apply) **If you are not a health care provider please skip to question 2.6**	FETAC/NVQ qualification	☐	Undergraduate course	☐
	Postgraduate (Grad Cert, Grad Dip, MSc, Phd.)	☐	Accredited study days	☐
	Non accredited study days	☐	Conferences / seminars	☐
	Journal clubs	☐	Online	☐
	Other … please detail			

2.6 Please indicate the type of palliative care education your organisation provided funding for in the last three years (please tick all that apply) **If you are not a commissioner or funder please skip to question 3.1**	FETAC/NVQ qualification	☐	Undergraduate	☐
	Postgraduate education programmes (Grad Cert, Grad Dip, MSc, Phd.)	☐	Accredited study days	☐
	Non accredited study days	☐	Conferences / seminars	☐
	Journal clubs	☐	Online	☐
	Other … please detail			

3. Current and future provision of palliative care education

3.1 In your opinion, does current palliative care education provision meet the needs of health and social care professionals (based on your experience over last 3 years)?	Yes ☐	No ☐
	Yes, please briefly explain how you arrived at this conclusion?	
	No, please briefly explain how you arrived at this conclusion	

3.2 Has your organisation ever recommended a palliative care education course/ programme to health and social care professionals?	Yes ☐	No ☐
	If yes, which one(s)?	
	Why did you recommend them?	

3.3 If you had a preference, what palliative care education developments would you like to see for health and social care professionals within your organisation?	

4. AIIHPC Communications Hub [Palliative Hub]

AIIHPC is currently developing a Communication Hub, which will be an online access point for information and knowledge regarding palliative care. In your opinion what information and knowledge, should be included in the Communications Hub [Palliative Hub] for health and social care professionals providing general palliative care?	

5. Competence

Indicate how you would rate your staff current skill, knowledge & competence in the following areas: (Please tick the most appropriate box for each statement in the table below) 1 = No current knowledge or skill; 2 = Some awareness, but not sufficiently competent to use it; 3 = Familiar with and able to use knowledge and skills; 4 = Proficient in the knowledge or skill and able to show others how to use it; 5 = A high degree of skill and comprehensive knowledge

	1	2	3	4	5
Understand the core values and principles of palliative care					
Be able to describe the meaning of the term 'life-limiting condition'					
Understand the significance of the physical, psychological, social and spiritual issues that affect people with life-limiting conditions and their families throughout the continuum of care					
Demonstrate the ability to use the palliative care approach as early as is appropriate in order to facilitate person-centred practice that recognises the concerns, goals, beliefs and culture of the person and her/his family					
Demonstrate the ability to communicate effectively with the person with a life-limiting condition in order to establish, maintain and conclude a therapeutic relationship					
Demonstrate the ability to communicate effectively with the family of a person with a life-limiting condition in order to establish, maintain and conclude a therapeutic relationship					
Demonstrate the ability to communicate effectively with the inter-disciplinary team caring for a person with a life-limiting condition in order to establish, maintain and conclude a therapeutic relationship					
Demonstrate an ability to be attentive to the person through careful listening to help the person and her/his families feel they have been heard					
Ability to act as an advocate for the person and their family to ensure appropriate and timely palliative care intervention					
Understand the significance of anticipating and responding to the needs of people with life-limiting conditions and their families (e.g. physical, psychological, social and spiritual) in a proactive and timely manner					
Recognise the importance and benefit of multidisciplinary working in optimising the comfort and enhancing the quality of life of the person with a life limiting condition and her/his family					
Exhibit an ability to apply a range of assessment tools to gather information					
Recognise the impact of a life-limiting condition on the person and her/his family and be able to provide support in order to help the individual to adapt to the changes in her/his condition					
Collaborate effectively with others as a member or leader of a multidisciplinary team					
Demonstrate an understanding of advance care planning and an appreciation of the appropriate time(s) to engage in discussions about preferences for care with the person with a life-limiting condition and her/his family					
Recognise the range of individual physical, psychological, spiritual, emotional and social responses to loss and grief					
Recognise the factors which may put a person at risk of encountering difficulties in their grief, whilst also remaining aware of the resources and resiliencies that are particular to each person and family					

Demonstrate the ability to address potential ethical issues that may be encountered when caring for the person with a life limiting condition and her/his family such as: Do Not Attempt Resuscitation Orders, withdrawal and withholding of treatment, use of artificial hydration and feeding, palliative sedation and requests for euthanasia					
Be able to establish and respect people's wishes about their care and options/ preferences					

6. Indicate the priority level for health and social care professionals for general palliative care education and training in the following areas within the next 2 years (Please tick the most appropriate box for each area in the table below) 1 = Not a priority; 2 = Low priority; 3 = Neither Low or High Priority; 4 = Medium priority; 5 = High priority

	1	2	3	4	5
Principles of Palliative Care					
Pain assessment and management					
Assessment and management of gastrointestinal symptoms					
Palliative Care for people with non-malignant conditions					
Palliative Care for Older People					
Communication issues with people with life-limiting conditions					
Communication issues at end-of-life					
Assessment Tools used in Palliative Care					
Advance Care Planning					
Ethical issues in palliative and end of life care					
Multidisciplinary working in palliative care					
Constipation					
Fatigue					
Cachexia[4]					
Care in the last days of life					
Bereavement support and care for adults with life limiting conditions, their families and carers					
Managing breathlessness					
Spiritual care and spirituality					
Rehabilitation in palliative care					
Self-care strategies					
Palliative care for people with intellectual disability					
Palliative care for people with dementia					
Palliative care for children and young people					
Assessment and management of palliative symptoms for children and young people					
Bereavement support and care for families of children and young people with life limiting conditions					
Other issues to be prioritised, Please provide details:					

Thank you for taking the time to complete this questionnaire. It is greatly appreciated.

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[4] 'Cancer cachexia is a complex, multifactorial wasting syndrome involving loss of skeletal muscle and fat that is caused by an abnormal host response to tumor presence or tumor factors.' (Stewart *et al.,* 2008)

APPENDIX 2: Invitation letter to complete survey

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**All Ireland Institute of
Hospice and Palliative Care**

14th May 2013

Re: Needs Analysis for General Palliative Care Education

Dear Colleague
All Ireland Institute of Hospice and Palliative Care (AIIHPC) is committed to supporting the delivery of high quality education, and the development of a well-trained palliative care community with the skills and abilities to respond to a wide variety of care needs in a range of settings.

At present on the island of Ireland developments regarding the provision of palliative care education to all health and social care professionals are underway. Central to this is the development of Palliative Care Competence Frameworks in each jurisdiction. In Northern Ireland this work reflects the implementation of Palliative Care Living Matters: Dying Matters; A Palliative and End of Life Care Strategy for Adults in Northern Ireland (2010). In the Republic of Ireland this work is part of the Health Service Executive Palliative Care Programme.

As part of on-going collaboration in palliative care across the island of Ireland, AIIHPC is undertaking, a needs analysis of general palliative care   education to ascertain the current level of general palliative care education provided to health and social care professionals.

The results from the needs analysis will inform key stakeholders including providers, funders, and commissioners of palliative care education regarding the current and future needs of health and social care professionals working within health and social care on the island of Ireland.

I would be grateful if you, or a representative of your organisation, would complete a short survey using the link provided below and in the accompanying e-mail. The survey should take no longer than twenty minutes and should be completed on or before Friday June 7th 2013.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Dr Michael P. Connolly
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