

Established in 1993, The **Irish Association for Palliative Care** (IAPC) is an all island body that exists to promote palliative care nationally and internationally through opportunities for networking, education, publications, and representation on national bodies.

As the sole membership organisation for those involved in the provision of palliative care, the IAPC is the primary collective and expert voice for palliative care in Ireland. Its mission is to drive national policy for patient-centred, equitable, accessible and accountable palliative care for all who need it.

A multi-disciplinary organisation, the membership reflects the multi-disciplinary team which delivers palliative care, and includes also those with an interest in the provision of palliative care.

Led by a Chairperson and Board of Directors elected by the Association's members, the IAPC is organized around a number of specialist fora and working groups. These groups provide individual disciplines with the opportunity to consider specific issues relevant to their own area of interest and expertise. The working groups are designed to create a forum for shared best practice and learning opportunities, and for members to further their professional development, education and research.

Current IAPC working groups include the Education and Research Forum, the Palliative Nursing Forum, the Ethics Working Group, the Children's Palliative Care Special Interest Group, the Palliative Care Pharmacists Group and the Palliative Care Social Work Group.

## Irish Association for Palliative Care

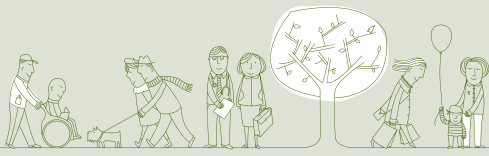
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# **IRISH ASSOCIATION FOR PALLIATIVE CARE EDUCATION AND RESEARCH FORUM**

Survey of Perceived Facilitators and Barriers  
to conducting Palliative Care Research in Ireland

# Contents

## Preface

Foreword

IAPC Education and Research Forum: research project subcommittee/the authors of the report

Acknowledgements

## Executive Summary

## Survey Report

Section 1: Background and Introduction

Section 2: Methodology

Section 3: Results

3.1 Response rate and Demographics

3.2 Research Experience

3.3 Attitudes to Research

3.4 Factors which facilitate conducting Research

3.5 Barriers to conducting Research

3.6 "What can the IAPC do for you?" (Qualitative data)

Section 4: Discussion

Section 5: Conclusions

Section 6: References

## Irish Association for Palliative Care (IAPC) Response

**Appendix 1** - Survey Questionnaire

**Appendix 2** - Responses to questions on attitudes to research

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## Foreword

Established to promote palliative care nationally and internationally, the Irish Association for Palliative Care (IAPC) is the sole professional membership organisation in Ireland for those involved in the provision of palliative care. A multidisciplinary organisation, the membership reflects the multidisciplinary team that delivers palliative care services across Ireland and includes also those with a professional interest in palliative care. As such, it is the primary collective and expert voice for palliative care in Ireland.

Developing and building professional capacity in palliative care at the individual and sector level is core to the IAPC mission.

A working group of the Association, the **IAPC Education and Research Forum** is a prime enabler of the IAPC's strategic focus on developing capacity in palliative care through education and research initiatives and sharing and learning networks. The purpose of the Forum is to promote evidence-based research, and to build and increase research capacity in palliative care.

The Forum consists of 12 active members of the IAPC who are nominated to the Forum by their peers in palliative care. Members join the Forum for a period of three years and the Chair of the Forum rotates annually. In line with the Forum's Terms of Reference, each year the Forum agrees a work agenda with the key objective of promoting and accelerating the undertaking of research among palliative care practitioners and researchers across Ireland.

In line with this objective, the IAPC Education and Research Forum formed a subcommittee which undertook the project to conduct research into specialist palliative care professionals' perceived facilitators and barriers to conducting research. There is little systematic information available on Irish palliative care professionals' experience of research, and the study has sought to identify specialist palliative care professionals' perceived barriers to conducting research, as well as factors which help facilitate research in this area. A further aim of the study was to profile research experience and involvement amongst specialist palliative care providers.

*The Survey of Perceived Facilitators and Barriers to conducting Palliative Care Research in Ireland* represents a major undertaking and is a work output for the Education and Research Forum spanning two years (2010, 2011).

The survey is the first of its kind in Ireland.

The publication of the survey findings and report makes a significant contribution to the knowledge base on Irish palliative care professionals' experience of research and the perceived barriers to conducting research.

The IAPC commends the members of its Education and Research Forum 2010, 2011 for their achievement. This work deepens our understanding of how we can address the needs of palliative care practitioners towards their engagement in much needed evidence-based research, and it highlights how such engagement can be facilitated at local and sector level.

Mary Ainscough  
Chief Executive  
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November 2011

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## Executive Summary

The Irish Association for Palliative Care (IAPC) Education and Research Forum, under its terms of reference, has undertaken a nationwide survey of perceived facilitators and barriers to conducting palliative care research in Ireland. It is the first time a study of this kind has been conducted.

The importance of on-going research to inform clinical practice is well recognised amongst health and social care professionals working in specialist palliative care (SPC). However, the paucity of research literature in this specialty is also acknowledged. Through this questionnaire survey, the IAPC Education and Research Forum sought to assess the level of research experience and attitudes to research among Irish palliative care professionals, as well as identifying both facilitators and barriers to conducting research.

The questionnaire was developed following a comprehensive literature search and it incorporated elements of existing validated questionnaires, modified for the Irish setting. It was distributed electronically. The response rate was 30% (136/455). Both quantitative and qualitative data were generated and analysed using the SPSS 18.0 statistical software package and thematic analysis respectively.

The findings are reported under four main headings: research experience; attitudes to research; factors which facilitate research; barriers to conducting research. The extent to which certain factors influence these four parameters was also examined. These factors included: work setting (hospice, home care, acute hospital, etc.); profession; academic qualification; number of years working in SPC. In addition, respondents were asked to give a "free text" answer to the question "What can the IAPC do for you?" and a thematic analysis of this data is outlined.

Fifty two percent of respondents are currently undertaking research and up to 84% have undertaken research at some stage in their professional career. Those working in education and research or in a combination of settings were more likely to be involved in research than those working exclusively in hospice, home care or acute hospital settings.

The most common types of research undertaken were audit (94%) and survey/questionnaire studies (92%). Many respondents had presented their work nationally and internationally. Over half of respondents had published research in a peer reviewed journal. Those with postgraduate qualifications, as well as those working in education and research, or in a combination of settings, were significantly more likely to have published research.

Respondents' attitudes to research were positive overall, particularly in relation to research influencing changes in practice, respondents' desire to undertake a research project, and perceived attitudes of organisations to evidence based practice. Research involvement appeared to have a significant impact on attitudes to research. Those who were more involved in research were more likely to be confident in their ability to evaluate the quality of research papers and less likely to find difficulty in applying research findings to clinical practice.

The most commonly identified facilitator to research in palliative care was the provision of protected time for research (ranked as the number 1 facilitator by 70% of respondents). Working in an organisation that values research, being assigned a mentor, and getting full funding to do courses were prominently ranked also. Respondents were asked to outline any additional factors that would facilitate research in a "free text" box, thus generating qualitative data. Themes included: the creation of a research "hub"; potential structures within which research could be undertaken; the role of the individual researchers and stakeholders; access to information and resources; and the impact of research.

The most commonly identified barrier was lack of time to devote to research (ranked as the number 1 barrier by 63% of respondents). Patient factors such as the research studies causing an intrusion on patients and families, and concerns about patients' ability to give informed consent were also prominently ranked. "Free text" responses outlining any additional perceived barriers to research revealed the following themes: lack of resources (including support, education, training and supervision); patient factors (attrition rates, sample size); lack of time (mirroring the quantitative findings); difficulty with the ethical approval process; respondents' own attitudes to research and also the perceived attitudes of others; and finally, environmental factors (institutions' perceived lack of appreciation of research, and the sense that the physical environment may not be conducive to conducting research).

Survey participants displayed a good understanding of existing IAPC research initiatives, such as the annual IAPC Education and Research Seminar and IAPC research workshops. Many useful suggestions for future initiatives were made by respondents. These will be taken on board by the IAPC through the IAPC Education and Research Forum and other IAPC working groups.

The survey confirms Irish palliative care professionals' commitment to both the conduct and application of research. It highlights the particular challenges faced in building an evidence base to inform clinical practice, as well as identifying ways of overcoming these challenges.

The IAPC's strategic objective to develop and build capacity in Palliative Care through education and research and learning networks will be informed by the survey's findings, as we collectively embrace the challenges arising.

# Survey Report

## Section 1: Background and Introduction

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### Background:

Established to promote palliative care nationally and internationally, the Irish Association for Palliative Care (IAPC) is the sole professional membership organisation in Ireland for those involved in the provision of palliative care. A multidisciplinary organisation, the membership reflects the multidisciplinary team that delivers specialist palliative care services and includes also those with a professional interest in palliative care. As such, it is the primary collective and expert voice for palliative care in Ireland. Core to the IAPC's mission is developing and building professional capacity in palliative care at the individual and sector level in Ireland.

The IAPC Education and Research Forum is a working group of the Association. It represents a major strand in implementing the IAPC's objectives on education and research. The role of the Forum is to promote and accelerate the undertaking of research among palliative care practitioners and researchers on the island of Ireland. It seeks to promote evidence-based research, and to build and increase research capacity in palliative care (IAPC, 2011).

Against this background, the Forum has undertaken research into specialist palliative care professionals' perceived facilitators and barriers to conducting research. There is little systematic information available on Irish palliative care professionals' experience of research. The objective of this study was to identify specialist palliative care professionals' perceived barriers to conducting research, as well as factors which help facilitate research in this area. A second objective was to profile research experience and involvement amongst specialist palliative care providers.

The findings of this study will assist and guide the IAPC Education and Research Forum's future work agenda, in enhancing facilitators and overcoming barriers to conducting research in palliative care.

### Introduction:

The importance of high quality research in palliative care is widely acknowledged (Kirsch et al, 2004) and has been a priority from the outset of the modern hospice movement (Saunders, 1965). A commitment to evidence-based practice and the clinical application of research findings is an essential part of health and social care professional codes of conduct (Irish Medical Council, 2009) and has been identified as part of the development of an effective palliative care service in Ireland (Department of Health and Children, 2001). As a relatively new and evolving specialty, the process of building an evidence base for clinical practice in palliative care is at a relatively early stage. Large multi-centre studies in this field, particularly randomised controlled trials, remain relatively low in number (Kaasa, Hjermstad, & Loge, 2006).

A review of the literature reveals many barriers to undertaking research, as experienced by other health and social care practitioners and palliative care professionals in other countries. These include: lack of training at undergraduate and postgraduate level in undertaking research (Robinson G & Gould M, 2000); lack of time to devote to research (Kirsch et al, 2004; McColl A, Smith H, White P, & Field J, 1998; Peterson GM, Jackson SL, Fitzmaurice KD, & Gee PR, 2009); lack of awareness of research opportunities (Peterson GM, et al., 2009); lack of access to bibliographic databases and the world wide web; lack of awareness of journals, review publications and databases (McColl A, et al., 1998).

Furthermore, additional challenges in conducting research with patients in receipt of, or in need of, palliative care services exist. The concept of "gate-keeping" can be a significant obstacle (Kirsch et al, 2004; Ross C & Cornbleet M, 2003). There may be concerns about terminally ill patients' vulnerability, dependency and compromised autonomy (De Raeve L, 1994). Symptom burden, including fatigue, cachexia and global deterioration (Fielding et al, 2006), patient attrition and lack of perceived equipoise regarding new or existing palliative care services, present considerable methodological challenges (Casarrett DJ & Karlawish JHT, 2000; Kristjanson L, Hanson EJ, & L, 1994; McLoughlin K, 2010). Funding for palliative care research is severely limited; across Europe, there is a distinct lack of national research strategies which allocate public money to research in palliative care (Kaasa, et al., 2006).

Clearly, there are a number of issues that need to be considered in order to ensure the continued expansion of the palliative care research literature.

For this reason, this study had two main objectives, the first being to identify facilitators and barriers to palliative care research in Ireland; and the second being to profile research experience and attitudes to research among palliative care professionals in Ireland.



## Section 2: Methods

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### Survey development

A quantitative, cross-sectional, on-line survey was carried out using a self-report questionnaire which was developed from the literature, incorporating elements of previously validated questionnaires (Kirsch et al, 2004; Peterson GM, et al., 2009) and modified for the Irish setting. In order to address validity, the questionnaire was reviewed by three external experts and by representatives from each of the IAPC fora and special interest groups. Furthermore, feedback was sought on the questionnaire from a representative sample. Amendments were made to the questionnaire based on feedback received. A copy of the final distributed survey is included in Appendix 1.

### Target population

All members of the IAPC and all health and social care professionals working in specialist palliative care in the Republic of Ireland were eligible for inclusion in the survey. All IAPC members were contacted. The IAPC's own database of palliative care professionals was also used for contact purposes. The IAPC Directory of Specialist Palliative Care Services was used to obtain contact details for all specialist palliative care services in the Republic of Ireland, these were then contacted to obtain contact details for specialist palliative care professionals who were not IAPC members. Following this process, email details were available for 510 contacts and postal contact details were available for a further 350 contacts. Ethical approval was obtained from the Trinity College Faculty of Health Sciences Research Ethics Committee.

### Distribution pilot

Email and postal pilot surveys were conducted. The questionnaire was emailed to 10% of the study sample for whom email addresses were available (n=51). A follow up email was sent 1 week later to maximise response rate. The questionnaire was posted to a further 10% to provide a comparison postal response. A follow up postal survey was not sent. The response rate from the email pilot was 39% (20/51) and from the postal pilot was 23%. Given such a low response to the postal pilot, the final survey was circulated electronically only. Those for whom email addresses could not be obtained were consequently not included.

### Data analysis

Data was analysed using SPSS version 18.0. Descriptive statistics were generated to illustrate respondents' previous and current involvement in research, attitudes to research, perceived barriers to conducting research, and factors perceived to facilitate research. Inferential statistics (chi-square tests) were used to establish if work setting, profession, educational qualification or length of service related to research involvement and research presentation. Similarly chi-square tests were used to check associations between research involvement, profession and attitudes to palliative care research. A factor analysis was used to produce a fifteen item attitudinal scale. A research involvement score was devised by assigning a score of 1 to all of the items pertaining to level of research involvement. Those items deemed to represent a higher level of involvement, namely being a principal investigator, being awarded funding to undertake research and publishing in a peer reviewed journal, were weighted by awarding a score of 2 each, in order to distinguish level of involvement between respondents.

Qualitative comments on barriers, facilitators and suggestions for IAPC actions were analysed using thematic analysis (Morse JM & Field PA, 1995).

## Section 3: Results

### Section 3.1: Response Rate and Demographics

#### Response Rate

Five hundred and one (501) questionnaires were sent. An 'out of office' reply was received in 46 cases. Therefore, 455 questionnaires were successfully transmitted. Of these, 136 were returned, giving a response rate of 30% (136/455). Returned questionnaires were anonymised, making analysis of non-responders impossible.

#### Demographic data

Details of respondents' age, gender, work setting, profession, highest academic qualification achieved and length of time working in specialist palliative care ("length of service") are outlined in Table 3.1.1 below.

Table 3.1.1 - Demographic Data\*

		Number (%) n=136
Age	≤ 25 years	1 (1)
	26-35	29 (22.5)
	36-50	71 (55)
	≥ 51 years	28 (22)
Gender	Female	116 (88)
	Male	16 (12)
Work Setting	Hospice	30 (25)
	Home Care	26 (22)
	Acute Hospital	38 (32)
	Education and Research	14 (12)
	Combinations	10 (8.5)
Profession	Doctor	25 (19)
	Nurse	66 (50)
	Other	40 (30.5)
Qualification	Undergraduate	45 (34)
	Postgraduate	87 (66)
Length of Service	≤ 10 years	65(55)
	≥ 10 years	53(45)

\* Categories collapsed for statistical analysis

### Section 3.2: Research Experience

Fifty eight respondents (52%) are currently undertaking research. At some stage in their professional career, 84% have been involved in research, while 77% have been involved in research specifically in the field of palliative care. Experience of applying for ethical approval and funding/research grants varied considerably. (see *Figure 3.2.1*)

A significant proportion of respondents (81%) had been a principal investigator on a research project, whilst 53% had been a research assistant and 90% had been a member of a wider research team.

The most common types of research undertaken were audit (94%) and survey/questionnaire study (92%). The levels to which these had been presented or published varied considerably (see *Figure 3.2.2*).

#### Factors influencing Level of Research Experience:

##### 1. Previous involvement in research

Fifty five percent of respondents (n=63) had worked in specialist palliative care (SPC) for up to 10 years, with 73% (n=46) having undertaken palliative care research during that time. Of the 53 respondents with more than 10 years' SPC experience, 45 (85%) had undertaken research. There was no statistically significant association between number of years' experience in specialist palliative care and previous involvement in research in general ( $\chi^2 = 0.089$ ,  $p = 0.765$ ) or research in palliative care ( $\chi^2 = 2.407$ ,  $p = 0.121$ ).

Sixty six per cent (n=87) of respondents are qualified to above degree level. Involvement in palliative care research did not depend on level of academic qualification. Forty per cent (n=18) of those with an undergraduate qualification (n=7) who reported involvement in research, had applied for ethical approval compared to 66% (n=56) of those who had a postgraduate qualification. This was statistically significant ( $\chi^2 = 8.038$ ,  $p = 0.005$ ). Those with postgraduate qualifications were considerably more likely to have been involved in writing a research proposal ( $\chi^2 = 10.135$ ,  $p = 0.001$ ). This group were also more likely to have successfully applied for funding for a research project ( $\chi^2 = 9.407$ ,  $p = 0.002$ ).

Eighty eight per cent (n= 22) of doctors who responded to the survey had undertaken palliative care research, compared with 81.5% (n=53) of nurses and 66.7% (n=26) of other professionals. Of those doctors who were involved in palliative care research, 86% (n=19) had applied for ethical approval, although interestingly, only 59% (n=13) had actually been involved in writing a research proposal. All (n=8) of those who applied for funding were successful in their application.

When compared with doctors and other professionals, a higher proportion of nurse respondents, who had undertaken research, were involved in writing a research proposal (79%). A smaller proportion had applied for ethical approval (62%). However, these differences did not reach statistical significance ( $\chi^2 = 1.701$ ,  $p = 0.427$  and  $\chi^2 = 4.739$ ,  $p = 0.094$  respectively). Of those nurses who applied for funding, 86% (n=19) did so successfully.

The vast majority of respondents from professions other than medicine and nursing who had undertaken palliative care research had been involved in both writing a research proposal (96%, n=25) and applying for ethical approval (88%, n=23). Of those who applied for funding, 71% (n=10) did so successfully.

Table 3.2.1 shows the various roles that had been played by respondents on the research team.

## 2. Current involvement in research

Those who work exclusively in education or research or in a combination of settings were more likely to be currently involved in research than those working solely in hospices, home care teams or acute hospitals ( $\chi^2 = 11.811, p = 0.017$ ). Doctors were more likely to be involved in on-going research than nurses or other disciplines, but this did not reach statistical significance ( $\chi^2 = 5.055, p = 0.08$ ). Highest academic qualification or number of years working in specialist palliative care did not appear to influence current involvement in palliative care research. (see Table 3.2.2).

## 3. Types of research undertaken

Table 3.2.3 displays analysis of the factors that may influence the type of research studies participants had undertaken. Doctors were more likely to be involved in randomised controlled trials, while nurses and other professionals were more likely to have undertaken qualitative research. However, none of these associations reached statistical significance ( $\chi^2 = 4.543, p = 0.107$  and  $\chi^2 = 4.493, p = 0.118$  respectively).

Those with a postgraduate qualification were more likely to have undertaken randomised controlled trials ( $\chi^2 = 3.415, p = 0.065$ ) and qualitative research ( $\chi^2 = 2.991, p = 0.084$ ), but this was not statistically significant. No association was found between academic qualifications and audit, survey or other quantitative research apart from randomised controlled trials.

Respondents with more than 10 years' experience in specialist palliative care were significantly more likely to have conducted a survey ( $p = 0.032$ ) or a qualitative research study ( $\chi^2 = 9.105, p = 0.003$ ).

## 4. Presentation of research

Those with postgraduate qualifications were more likely to have presented their work at research conferences. This was statistically significant for oral presentations at national conferences ( $\chi^2 = 5.505, p = 0.019$ ) and oral presentations at international conferences ( $\chi^2 = 5.372, p = 0.020$ ) (see Table 3.2.4). Those who work in education and research were more likely to have done both oral and poster presentations. Those working exclusively in home care were least likely to have presented their work. Profession or number of years working in SPC did not appear to influence the likelihood of having done a presentation at a research conference.

## 5. Publication of research

Having a postgraduate qualification had a statistically significant impact on publication of research in a non-peer reviewed journal ( $\chi^2 = 7.251, p = 0.007$ ). Those with postgraduate qualifications were more likely to have published work in peer-reviewed journals but this did not reach statistical significance ( $\chi^2 = 3.086, p = 0.079$ ). Work setting also impacted significantly on publication of research (see Table 3.2.5).

Figure 3.2.1 - Experience of Research

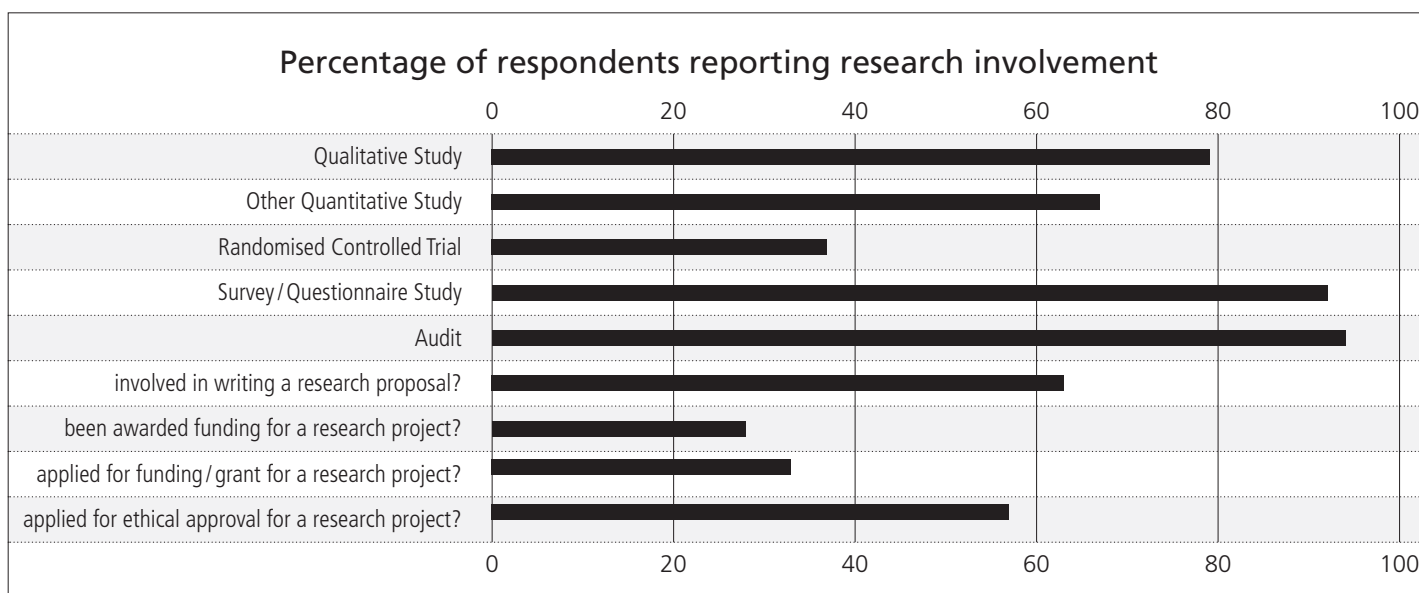


Figure 3.2.2 - Dissemination of Research

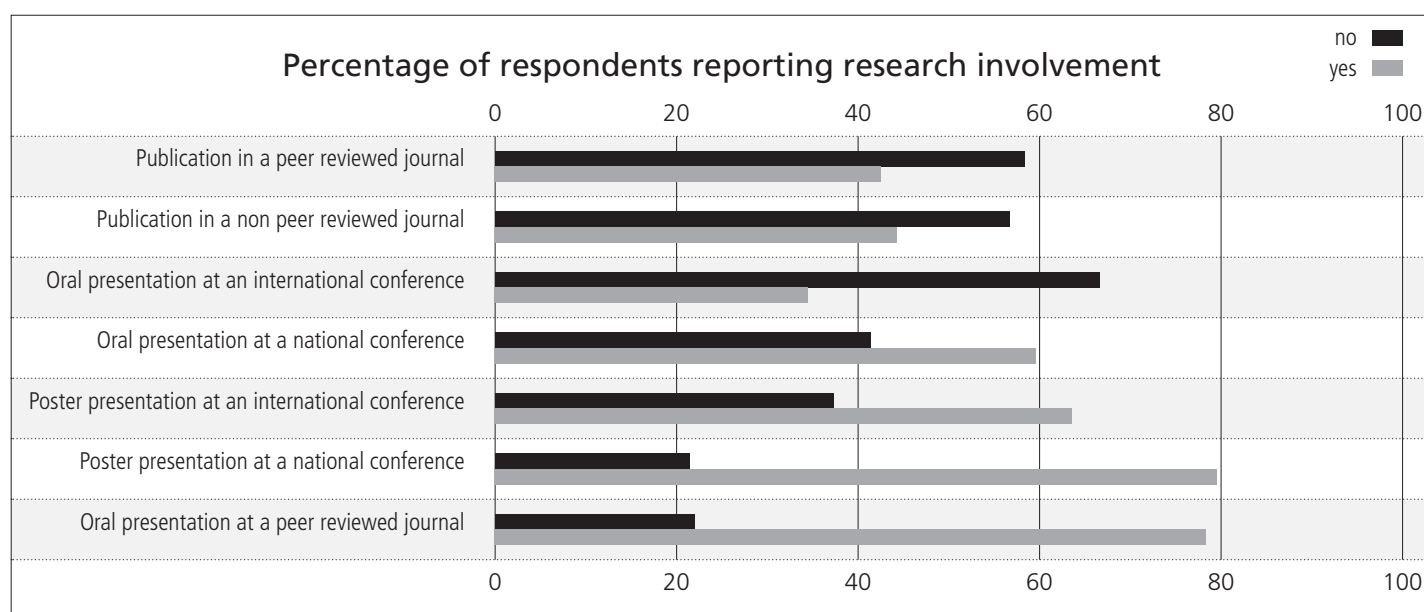


Table 3.2.1 - Relationship between roles played on the research team and work setting, profession, highest qualification achieved, and number of years working in specialist palliative care (ie "length of service")

	Principal Investigator	Research Assistant	Member of wider research team
<b>Work Setting</b>			
Hospice	17 (89%)	4 (44%)	12 (92%)
Home Care	9 (60%)	1 (14%)	11 (92%)
Acute Hospital	18 (78%)	10 (71%)	19 (86%)
Education and Research	8 (89%)	4 (57%)	10 (100%)
Combinations	9 (100%)	2 (33%)	7 (88%)
Chi-Square	6.682 <sup>β</sup>	6.892 <sup>β</sup>	1.739 <sup>β</sup>
p value <sup>a</sup>	0.117	0.135	0.886
<b>Profession</b>			
Doctor	9 (64%)	9 (64%)	14 (88%)
Nurse	31 (84%)	8 (44%)	34 (92%)
Other	21 (81%)	8 (53%)	16 (89%)
Chi-Square	0.206 <sup>β</sup>	1.245 <sup>α</sup>	0.282 <sup>β</sup>
p value <sup>a</sup>	0.937	0.537	0.868
<b>Qualification</b>			
Undergraduate <sup>b</sup>	20 (77%)	7 (50%)	19 (95%)
Postgraduate <sup>c</sup>	50 (82%)	19 (54%)	47 (89%)
Chi-Square	0.295 <sup>α</sup>	0.074 <sup>α</sup>	N/A <sup>γ</sup>
p value <sup>a</sup>	0.587	0.786	0.665
<b>Length of Service</b>			
0-10 years	35 (81%)	13 (52%)	28 (88%)
≥ 10 years	27 (82%)	6 (38%)	29 (94%)
Chi-Square	0.002 <sup>α</sup>	0.825 <sup>α</sup>	N/A <sup>γ</sup>
p value <sup>a</sup>	0.962	0.364	0.672

<sup>a</sup> Values ≤ 0.05 considered statistically significant  
<sup>b</sup> Certificate, Diploma, Higher Diploma or Degree  
<sup>c</sup> Postgraduate Diploma, Masters, MD or PHD  
<sup>α</sup> Pearson Chi Square  
<sup>β</sup> Fishers Exact Test  
<sup>γ</sup> p value calculated directly for a 2x2 table

**Table 3.2.2** - Relationship between current involvement in research and location of place of work, profession, highest qualification achieved, and number of years working in specialist palliative care (ie "length of service")

	Currently involved in palliative care research
<b>Work Setting</b>	
Hospice	11 (44%)
Home Care	6 (33%)
Acute Hospital	14 (44%)
Education and Research	10 (71%)
Combinations	9 (90%)
Chi-Square	11.811 <sup>β</sup>
p value <sup>a</sup>	0.017
<b>Profession</b>	
Doctor	17 (71%)
Nurse	24 (44%)
Other	15 (48%)
Chi-Square	5.055 <sup>α</sup>
p value <sup>a</sup>	0.080
<b>Qualification</b>	
Undergraduate <sup>b</sup>	21 (60%)
Postgraduate <sup>c</sup>	37 (49%)
Chi-Square	1.230 <sup>α</sup>
p value <sup>a</sup>	0.267
<b>Length of Service</b>	
0-10 years	21 (60%)
≥ 10 years	37 (49%)
Chi-Square	1.230 <sup>α</sup>
p value <sup>a</sup>	0.267

<sup>a</sup> Values ≤ 0.05 considered statistically significant

<sup>b</sup> Certificate, Diploma, Higher Diploma or Degree

<sup>c</sup> Postgraduate Diploma, Masters, MD or PHD

<sup>α</sup> Pearson Chi Square

<sup>β</sup> Fishers Exact Test

Table 3.2.3 - Relationship between types of research undertaken and location of place of work, profession, highest qualification achieved, and number of years working in specialist palliative care (ie "length of service")

	Audit	Survey	RCT	Other Quantitative	Qualitative
<b>Work setting</b>					
Hospice	20(100%)	16(94%)	7 (54%)	9 (75%)	10 (77%)
Home Care	16(100%)	12(92%)	0 (0%)	2 (29%)	9 (69%)
Acute Hospital	22(96%)	16(80%)	6 (38%)	16 (70%)	12 (57%)
Education and Research	6 (86%)	10(100%)	3 (60%)	3 (60%)	11(100%)
Combinations	9 (100%)	8 (100%)	2 (50%)	5 (71%)	8 (89%)
Chi-Square	4.219 <sup>β</sup>	3.427 <sup>β</sup>	7.166 <sup>β</sup>	4.727 <sup>β</sup>	8.215 <sup>β</sup>
p value <sup>α</sup>	0.287	0.454	0.117	0.339	0.071
<b>Profession</b>					
Doctor	21(96%)	17(85%)	11(58%)	13 (65%)	11 (61%)
Nurse	38(97%)	35(97%)	5 (28%)	15 (60%)	34 (85%)
Other	18(90%)	18(90%)	3 (25%)	11 (73%)	18 (86%)
Chi-Square	1.732 <sup>β</sup>	2.989 <sup>β</sup>	4.543 <sup>β</sup>	0.773 <sup>α</sup>	4.493 <sup>β</sup>
p value <sup>α</sup>	0.362	0.232	0.107	0.693	0.118
<b>Qualification</b>					
Undergraduate <sup>b</sup>	27(96%)	25(96%)	3(19%)	14 (67%)	16 (67%)
Postgraduate <sup>c</sup>	51(93%)	47(90%)	16(46%)	27 (66%)	47 (84%)
Chi-Square	N/A <sup>γ</sup>	N/A <sup>γ</sup>	3.415 <sup>α</sup>	0.004 <sup>α</sup>	2.991 <sup>α</sup>
p value <sup>α</sup>	0.658	0.657	0.065	0.949	0.084
<b>Length of Service</b>					
0-10 years	37(97%)	34(85%)	6 (25%)	19 (63%)	20 (59%)
≥ 10 years	34(97%)	28(100%)	9 (50%)	13 (62%)	30 (91%)
Chi-Square	N/A <sup>γ</sup>	N/A <sup>γ</sup>	2.8 <sup>α</sup>	0.011 <sup>α</sup>	9.105 <sup>α</sup>
p value <sup>α</sup>	1.000	0.039	0.094	0.917	0.003

<sup>a</sup> Values ≤ 0.05 considered statistically significant

<sup>b</sup> Certificate, Diploma, Higher Diploma or Degree

<sup>c</sup> Postgraduate Diploma, Masters, MD or PHD

<sup>α</sup> Pearson Chi Square

<sup>β</sup> Fishers Exact Test

<sup>γ</sup> p value calculated directly for a 2x2 table

**Table 3.2.4 - Relationship between presentation of research and location of place of work, profession, highest qualification achieved, and number of years working in specialist palliative care (ie "length of service")**

	Poster presentation at national conference	Poster presentation at international conference	Oral presentation at national conference	Oral presentation at international conference
<b>Location of Place of Work</b>				
Hospice	16 (89%)	14 (78%)	14 (78%)	6 (43%)
Home Care	7 (50%)	4 (31%)	3 (21%)	1 (8%)
Acute Hospital	21 (75%)	14 (54%)	11 (42%)	4 (18%)
Education and Research	9 (82%)	8 (89%)	11 (92%)	8 (73%)
Combinations	8 (80%)	6 (60%)	6 (67%)	3 (30%)
Chi-Square	6.256 <sup>β</sup>	10.261 <sup>β</sup>	18.946 <sup>β</sup>	13.901 <sup>β</sup>
p value <sup>α</sup>	0.167	0.033	0.001	0.005
<b>Profession</b>				
Doctor	19 (86%)	19 (79%)	12 (55%)	8 (38%)
Nurse	36 (77%)	21 (55%)	24 (59%)	13 (34%)
Other	18 (78%)	14 (61%)	17 (65%)	6 (33%)
Chi-Square	0.852 <sup>β</sup>	3.724 <sup>α</sup>	0.614 <sup>α</sup>	0.121 <sup>α</sup>
p value <sup>α</sup>	0.745	0.155	0.736	0.941
<b>Qualification</b>				
Undergraduate <sup>b</sup>	20 (69%)	14 (50%)	11 (41%)	4 (16%)
Postgraduate <sup>c</sup>	53 (83%)	41 (70%)	43 (67%)	23 (43%)
Chi-Square	2.267 <sup>α</sup>	3.102 <sup>α</sup>	5.505 <sup>α</sup>	5.372 <sup>α</sup>
p value <sup>α</sup>	0.132	0.078	0.019	0.020
<b>Length of Service</b>				
0-10 years	35 (80%)	26 (61%)	24 (52%)	12 (31%)
≥ 10 years	26 (70%)	19 (59%)	21 (64%)	10 (33%)
Chi-Square	0.930 <sup>α</sup>	0.009 <sup>α</sup>	1.030 <sup>α</sup>	0.051 <sup>α</sup>
p value <sup>α</sup>	0.335	0.924	0.310	0.821

<sup>a</sup> Values ≤ 0.05 considered statistically significant

<sup>b</sup> Certificate, Diploma, Higher Diploma or Degree

<sup>c</sup> Postgraduate Diploma, Masters, MD or PHD

<sup>α</sup> Pearson Chi Square

<sup>β</sup> Fishers Exact Test

Table 3.2.5 - Relationship between publication of research and location of place of work, profession, highest qualification achieved, and number of years working in specialist palliative care (ie "length of service")

	Publication in a non-peer reviewed journal	Publication in a peer reviewed journal
<b>Location of Place of Work</b>		
Hospice	8 (57%)	8 (72%)
Home Care	2 (15%)	4 (27%)
Acute Hospital	5 (23%)	6 (26%)
Education and Research	5 (71%)	6 (60%)
Combinations	5 (56%)	5 (50%)
Chi-Square	11.338 <sup>β</sup>	9.462 <sup>β</sup>
p value <sup>α</sup>	0.019	0.046
<b>Profession</b>		
Doctor	10 (50%)	10 (50%)
Nurse	13 (39%)	17 (45%)
Other	8 (44%)	6 (33%)
Chi-Square	0.575 <sup>α</sup>	1.125 <sup>α</sup>
p value <sup>α</sup>	0.750	0.570
<b>Qualification</b>		
Undergraduate <sup>b</sup>	5 (21%)	7 (28%)
Postgraduate <sup>c</sup>	26 (54%)	26 (49.1%)
Chi-Square	7.251 <sup>α</sup>	3.086 <sup>α</sup>
p value <sup>α</sup>	0.007	0.079
<b>Length of Service</b>		
0-10 years	14 (38%)	16 (40%)
≥ 10 years	10 (37%)	11 (41%)
Chi-Square	0.004 <sup>α</sup>	0.004 <sup>α</sup>
p value <sup>α</sup>	0.948	0.952

<sup>a</sup> Values ≤ 0.05 considered statistically significant

<sup>b</sup> Certificate, Diploma, Higher Diploma or Degree

<sup>c</sup> Postgraduate Diploma, Masters, MD or PHD

<sup>α</sup> Pearson Chi Square

<sup>β</sup> Fishers Exact Test



## Section 3.3: Attitudes to Research

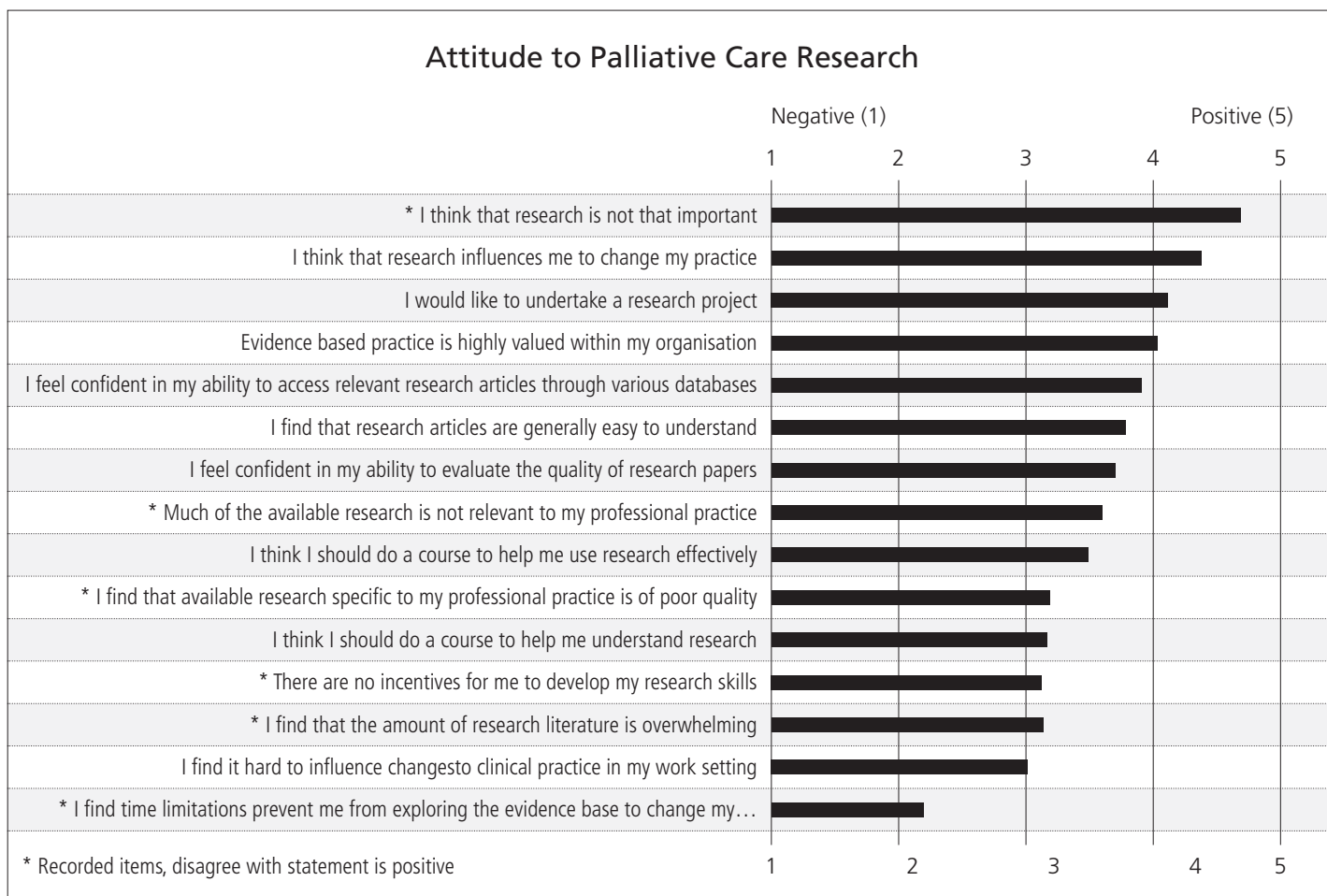
In this study attitudes towards research were assessed using a scale devised by Peterson et al (2009). Fifteen statements on the importance of research, its value within the organisation, research skill and using research to change practice were presented. Participants rated the extent to which they agreed or disagreed with each (see Appendix 2).

The relative strength of attitudes to different aspects of research is illustrated in *Figure 3.3.1*. The mean scores for each item are plotted (where 0 is the minimum and 5 the maximum). Overall, the Specialist Palliative Care professionals surveyed hold positive attitudes to research. It is viewed as important and highly valued within organisations, and as having an influence on changing practice. Participants agreed they would like to undertake research and that accessing and evaluating research papers were skills they possessed.

Less positive attitudes were evident around the application of research findings. Time to explore the evidence base and the ability to influence change were considered to be challenges (mean 2.18 and 3.01). Incentives to develop research skills were also limited (mean 3.1).

Given the relative consensus and positive disposition towards research activity, comparative analysis was undertaken to explore whether there was variation in the research attitudes of different professions or by degree of previous and current involvement in research.

Figure 3.3.1 - Mean values in descending order for palliative care professionals' attitudes to research



## Profession and attitude to research

There was no observable association between professional grouping and attitude to research. Only one item showed variance ( $\chi^2 = 28.8$ ;  $p < 0.0001$ ) with the vast majority of nurses compared to other professions disagreeing that they find 'available research specific to my professional practice is of poor quality'.

## Research involvement and attitude to research

Participants whose cumulative involvement in research was rated as 'high' were likely to be confident in their ability to evaluate the quality of research papers (97% compared to 47% of the low involvement group;  $\chi^2 = 39.6$ ,  $p < 0.0001$ ). These participants were less likely to want to pursue a research course to help them understand research effectively (41% compared to 79% of low involvement and 56% of the medium involvement group;  $\chi^2 = 13.51$ ,  $p = 0.009$ ) or a course to help them to use research (24% compared to 59% of low involvement group;  $\chi^2 = 13.24$ ,  $p = 0.010$ ). The high involvement group were less likely to agree that time limitations prevented evidence based change to work practices (43% agreed compared to 86% of low and 79% of medium involvement groups;  $\chi^2 = 27.9$ ,  $p = 0.000$ ) or that it was hard for them to use research findings to influence change in clinical practice (36% compared to 50% in the low involvement group;  $\chi^2 = 10.16$ ,  $p = 0.038$ ). Finally, the group with high involvement in research were more likely to disagree with the statement that much available research is not relevant to their professional practice ( $\chi^2 = 10.7$ ,  $p = 0.03$ ).

In summary, measured attitudes of respondents are generally positive, with those with less experience in research having relatively positive attitudes to learning and attending courses and those with high involvement in research feeling more empowered to interpret research papers and make evidence-based changes in practice, as well as finding cited barriers to be less of a concern.

## Factor analysis

The fifteen items of the attitude scale were subjected to factor analysis in order to identify main dimensions underpinning attitudes towards research.

A three factor structure as set out in *Table 3.3.1* accounted for over 50% of the variance across ten items.

The items group together in three dimensions as follows: Factor One - Research skills; Factor Two - External barriers to research and Factor Three - Positive disposition to research. The extent to which these factors predict research involvement and the extent to which they are amenable to change would give direction for development of palliative care research interventions into the future.

**Table 3.3.2:** Factor analysis of attitude towards research scale

	Component		
	1	2	3
<b>FACTOR ONE: Research skills</b>			
I find that research articles are generally easy to understand	.705		
I feel confident in my ability to access relevant research articles through various databases	.690		
I feel confident in my ability to evaluate the quality of research papers	.717		
I think I should do a course to help me understand research	-.864		
I think I should do a course to help me use research effectively	-.828		
<b>FACTOR TWO: External barriers to research</b>			
There are no incentives for me to develop my research skills		.696	
I find time limitations prevent me from exploring the evidence base to change my work practices		.694	
I find it hard to influence changes to clinical practice in my work setting		.700	
<b>FACTOR THREE: Positive disposition to research</b>			
I would like to undertake a research project			.748
I think that research influences me to change my practice			.765

Extraction Method: Principal Component Analysis.  
 Rotation Method: Varimax with Kaiser Normalization.  
 a. Rotation converged in 5 iterations.

## Section 3.4: Factors which facilitate research

Having protected time to undertake research was clearly identified as the main facilitator to doing research in specialist palliative care, regardless of profession, qualification, area of work or length of time working in Specialist Palliative Care. It was ranked as the primary facilitator to doing research in specialist palliative care by 70% (N=85) of respondents who ranked this item (see Table 3.5.1). Working in an organisation that values research was ranked as the primary facilitator by a large proportion of respondents (36%, n=42). Being assigned a mentor/supervisor was ranked first by 27% of respondents (n=32), whilst getting full funding to do courses was ranked as the primary facilitator by 27% of respondents.

Mean and median rank positions are indicated on Table 3.5.1. Rank order was generally consistent across disciplines, excepting some differences in second rank ordering; doctors rated having a mentor/supervisor as the second greatest facilitator, whilst nurses and others professionals rated working in an organisation that valued research as the second most important facilitator.

**Table 3.5.1** – Facilitators to research arranged by mean and median rank where 1 is the most important facilitator

Median rank	Facilitators	N (%) Primary Facilitator	Mean rank (SD)
1	Having protected time to undertake research	85 (70%)	1.5 (.9)
2	Working in an organisation that values research	42 (36%)	2.4 (1.5)
2	Being assigned a mentor/supervisor for my research project	32 (27%)	2.6 (1.5)
3	Getting full funding to do courses on research methods	29 (27%)	2.93 (1.6)
4	Attending courses on research methods	21 (19%)	3.5 (1.7)
5	Getting partial funding to do courses on research methods	5 (5%)	3.73 (1.5)

### Qualitative results: Factors which facilitate research

Respondents were asked to outline any other factors which would facilitate doing research with specialist palliative care patients and their families in a “free text” box. Many of the facilitators that were listed in the survey were validated by the respondents in the free-text commentary, most particularly the importance of protected time to undertake research (5 respondents). Listed in order of frequency, other suggested facilitators were:

#### **Theme 1: RESEARCH ‘HUB’** (8 respondents)

Respondents suggested the creation of a research ‘hub’ that would direct the development of palliative care research in Ireland, through establishing research priorities and providing a support service to novice and existing researchers. A further envisaged role was liaison and collaboration between different hospice service providers and other stakeholders in order to generate research of national importance. In pursuing a joint research initiative, and through individual researchers contributing at varying levels to this initiative, a new generation of competent researchers would be developed.

*“Having an on-going full programme of research in an institution that requires the addition of novice researchers at each step/stage so that the programme not only generates research but also generates competent researchers” F27*

*“Joint research projects with different hospice service providers. A national palliative care approach to research” F9*

#### **Theme 2: STRUCTURE** (7 respondents)

Respondents spoke of the structures within which research is currently, or could be, undertaken. Potential structures identified as supporting research were inclusion of research within the framework of Masters or postgraduate Diploma programmes, provision of mentors, emphasis on stepwise development of research expertise during progression through professional career pathway and internal organisational structures such as regular monthly research meetings. Discussion of structures that support research also touched on themes of protected time, access to information, centralised ethics committee application and mentoring.

*“I feel that provision of a mentor would be most beneficial. Particularly for those who may not have had previous experience of doing research projects. It can be daunting and overwhelming. With nobody to ask you have no idea if you’re going about it in the right way.” F10*

*“Having organisational systems in place to involve staff in research i.e. use medical model where interns are involved in research under the lead of the consultant as part of their on-going work as opposed to an extra that is added in when time permits. Fortnightly/monthly meetings to discuss research related issues” F32*

#### **Theme 3: THE ROLE OF THE INDIVIDUAL RESEARCHERS AND STAKEHOLDERS** (6 respondents)

Respondents identified having a genuine interest and enthusiasm to undertake research as essential to the success of a research project. The role of key stakeholders such as patients, families and staff was seen as two-fold: first in the formulation of meaningful research ideas from clinical practice, and secondly, in ensuring that close collaboration, communication and involvement would better facilitate the research process itself.

*“Interest in the area chosen for research and relevance for clinical setting” F7*

*“Involvement of people with life-limiting conditions and their families as active partners in the research process- stakeholder involvement at all stages (from formulation of proposals onwards)” F22*

#### **Theme 4: ACCESS TO INFORMATION & RESOURCES**

(5 respondents)

Respondents identified access to information and resources as an important facilitator, varying from specific access needs (such as full text journals, library databases, statistical packages) to a centralized resource which would provide a starting point to obtaining research-related information (such as where and how to seek ethics approval, or typical timeframes involved in research projects) as well as a centralized source of information on what research is currently being undertaken within Ireland.

*"Having access to a research info pack, that could provide guidance in relation to where to access info, where to seek ethical approval, outlines of timeframes involved in same, where to access an appropriate research mentor etc. Therefore, if staff had research ideas, they would have access to a starting point." F5*

*"Open access to college library databases" F14*

#### **Theme 5: THE IMPACT OF RESEARCH**

(4 respondents)

Ensuring that the learning gained from research was applied within an organisation to the betterment of patient care or clinical services was identified as a facilitator to undertaking research. The need for research findings to promote change in practice, attitudes and services, both within and beyond the specialty of palliative care was seen to be important.

*"The use of research to improve clinical setting" F7*

*"Closer links between research in oncology and palliative medicine, ie attendance and presenting palliative research at oncology conferences and vice versa; after all we often share the same patient population" F11*

## Section 3.5: Barriers to Conducting Research

'Not having enough time to do research' was considered the greatest barrier to conducting research, having been clearly identified by all groups, across all areas and regardless of educational attainment/profession/length of time working in specialist palliative care. Of those assigning a rank, (63%, n=73) ranked it as number one. A smaller proportion (34%, n=38) rated patient factors as the largest barrier.

The rank orders were generally consistent across professions (although 'others' ranked 'staff not consulted' as their third barriers to doing research) and for education level, level of research involvement, area of work and length of time in palliative care. Mean and median rank positions are indicated on Table 3.4.1.

**Table 3.5.1 – Barriers to research arranged by mean and median rank where 1 is the most important barrier**

Median rank	Barriers	N (%) Primary Barrier	Mean rank (SD)
1	There is not enough protected time to do research	73 (63%)	1.8 (1.4)
2	It is too intrusive for patients and families	38 (34%)	2.8 (1.9)
3	Patients cannot give informed consent	9 (9%)	3.7 (1.9)
4	Staff are not consulted about doing research	2 (2%)	3.8 (1.5)
5	Research findings are not used to improve practice in my work place	1 (1%)	4.9 (1.8)
5.5	Having direct access to computer/internet facilities at work	9 (10%)	5.1 (2.5)
6	My organisation does not value research as a worthwhile use of time	5 (5%)	5.2 (2.1)
7	Undertaking research will not benefit my career	1 (1%)	6 (2)

### Qualitative Results: Barriers to conducting research

Respondents were asked to outline any other factors they felt acted as a barrier to conducting research with specialist palliative care patients and their families. Some of the barriers that were pre-listed as part of the survey were validated again by respondents in the "free text" commentary. In addition, other perceived barriers listed thematically in order of frequency included:

#### **Theme 1: LACK OF RESOURCES** (20 respondents)

*(Encompassing support, education, training & supervision)*

Overall themes that emerged included a lack of funding, support, guidance & training. Respondents identified lack of funding as a significant barrier to research, varying from specific costs (such as software packages, transcription costs, recording equipment, statistical advice, accessing literature) to a perception of general lack of overall funding.

Respondents also indicated lack of clear direction, encouragement and support from senior colleagues, and a lack of research priorities in palliative care generally, as significant barriers.

*"Difficult to access research funding" B20*

*"Mine (my) main barrier is lack of direct guidance" B35*

*"Lack of research priorities in palliative care" B38*

#### **Theme 2: PATIENT FACTORS** (17 respondents)

*(Encompassing attrition rates, sample size)*

The main patient-related factor identified by respondents as being a significant barrier to conducting research pertained to attrition rates, with loss of participants/subjects to death and/or rapid deterioration necessitating withdrawal from the study frequently cited. Inadequate numbers of patients on individual sites to adequately power studies plus prevalence of incapacity to provide informed consent were specifically cited as barriers by three respondents. Participant fatigue was also highlighted as a barrier.

*"The time aspect can be a big barrier with the risk of losing participants to death during your research study." B2*

*"Loss of subject's potential for high drop out rate loss of data due to patients being too unwell during data collection for same to take place." B3*

*"Often third level colleges have expectations of greater numbers of participants being available and are not cognizant of how quickly changes can occur in participants conditions" B42*

### Theme 3: LACK OF TIME

(16 respondents)

Time constraint was a frequent barrier identified by respondents in the “free text” commentary. Most respondents in this category cited the concept of “time or lack of time” as a significant barrier to conducting research.

This concept developed around three central themes:

- Difficulty striking a balance between clinical work and research
- The overall time-line for conducting research
- Too busy within the general working day

The concept of “protected time” to undertake research was identified as a facilitator to undertaking research.

*“Protected time” B35*

*“Time is main limitation” B9*

*“To me, the greatest barrier is the time involved in working up an idea to the proposal stage, applying for ethical approval and finding the time to carry it out in already busy work days” B42*

*“Being freed up from direct clinical work to have time to do research” B12*

### Theme 4: ETHICAL APPROVAL PROCESS

(12 respondents)

Respondents cited the general ethical approval process as a significant barrier to conducting research. Specific parts of the ethical process were identified; in particular, length of time, multiple ethics board for cross site research and ethics committees’ understanding of palliative care. Ethical considerations concerning inclusion criteria and the use of placebo were specifically highlighted as challenges.

*“Getting ethical approval in particular the length of time it takes” B39*

*“Ethics Committees are afraid of granting ethical approval to interview patients and families” B33*

*“Research involving a placebo would be difficult to sell to an ethics board?” B19*

### Theme 5: ATTITUDES

(10 respondents)

Responses revealed two clear themes emerging in attitudes towards conducting research in specialist palliative care: first, respondents’ own attitudes, and secondly, the attitudes of others.

Respondents’ attitudes: concerns about the appropriateness of conducting research and the fear of imposing/burdening a perceived vulnerable patient population:

*“Inappropriate for some patients and families in end of life care” B2*

*“Many are often too unwell” B13*

*“Patients are not always able to participate, is it fair for someone to spend time answering research questions when time may be of the essence for them and their families” B24*

Attitudes of others: the perceived fears of others who may act in a gate keeping capacity:

*“The perception that palliative care clients are too vulnerable, time wasting for them and that they would not have the strength do (to) undertake research” B7*

*“Fears of staff – the perception that patients will be burdened by the research” B40*

### Theme 6: ENVIRONMENT

(7 respondents)

Responses revealed two clear themes emerging in terms of the workplace environment: first, a perceived general lack of emphasis, appreciation and value placed on research within organizations which was augmented by a perceived general lack of support and direction when it came to conducting research within organisations, and secondly, the sense that the physical environment itself in some cases was not conducive to conducting research in this patient population.

*“Participation in research not being valued by staff” B3*

*“Within my discipline, not enough focus on undertaking or being part of ongoing research” B12*

*“Environment, it can be more difficult to engage in this in the acute hospital setting due to a lack of space & different patient expectations whilst in the acute setting” B30*

## Section 3.6: Qualitative results: “What can the IAPC do for you?”

Survey participants were asked to outline what they felt the IAPC could do for them in a “free text” box. Having identified their perceived facilitators and barriers to conducting research, respondents now focused on those areas that could be positively influenced by the IAPC. These findings, in particular, will help shape the work agenda of the IAPC Education and Research Forum.

### Theme 1: Education (32 respondents)

The role of the IAPC in education was strongly represented in the qualitative data (32 responses). Many responses were quite generalized, suggesting frequent research courses and workshops, with note made of the need for reasonable cost. More specific suggestions for educational needs related to “getting started” in research, the process of research (notably abstract-writing, ethics approval application, presentation skills and funding) and education around methodology and statistics. A number of respondents suggested liaison with accredited Universities.

*“run evening workshops to up skill staff in relation to different research activity, run optional masterclass pre/post annual education and research seminar”*

*“Courses on Research and how to begin with the basics”*

*“Series on methods for research in the newsletter”*

*“It would be helpful to have a symposium where experienced researchers could provide guidance on engaging in proposal writing, seeking funding, leading projects”*

### Theme 2: Facilitation (29 respondents)

The role of the IAPC as a direct facilitator to research within Ireland was viewed as two-fold. The first sub-theme is mentorship: 16 respondents envisaged the IAPC as providing access to mentors/supervisors for research projects, and to statisticians. This access was mostly seen as direct, such as ‘assignment’ of mentors, provision of a ‘list’ of statisticians and support from ‘directly-named’ researchers.

*“Having access to mentors (people with sound research experience) would be a huge help”*

*“Have list of mentors who are able to provide support to different disciplines”*

*“Perhaps access to a statistician or a list of possible statisticians who would help one with analysing the stats”*

The second sub-theme is networking (13 respondents). Some respondents saw a potential role of the IAPC in enabling the forging of a research alliance or network across various sites, both nationally and internationally. Others viewed the role as more directive; initiation and coordination of research projects by nationwide data collection, circulation of research to members to participate in, and establishment of research priorities. Some respondents referred to the role of the All Ireland Institute for Hospice and Palliative Care, but seemed uncertain as to what the interface with the IAPC would be.

*“Perhaps identify particular areas and identify these to members to consider when they are undertaking further education. Explore potential for getting multidisciplinary teams to conduct research. This may be best done in collaboration with The All Ireland Institute for Palliative Care. Generate ideas, perhaps gather (motivate) groups of people with varying skills to work together. Pool resources. Tall order I know!”*

*“IAPC could help set up interest groups and help those professionals that are interested in research to network to achieve similar goals”*

*“Involvement in research networks and facilitating Irish participation in multinational research trials”*

### **Theme 3: Funding** (24 respondents)

Funding was a prevalent response. Many respondents saw the IAPC as a potential provider of funding, in a variety of forms: direct funding of research projects, funding to attend courses and conferences and annual bursaries. Others envisaged a role in provision of a resource or guide (possibly on-line) indicating how to access funding within Ireland

*"Perhaps offer a guide on the website to research funding opportunities"*

*"Support in funding projects/Perhaps an annual research initiative aimed at each discipline working in clinical practice in palliative care, with bursaries for each discipline/area of research"*

### **Theme 4: Advocacy** (14 respondents)

Respondents affirmed the IAPC's role as an advocate for research in palliative care. This advocacy was evident in a general way through the promotion, support and encouragement of research projects within the speciality itself and in supporting a vision of a national approach to palliative care research in the context of healthcare as a whole.

In particular, the role of the IAPC in encouraging interdisciplinary research initiatives, and promoting a culture of research in disciplines where research has in the past been minimal, was highlighted.

The IAPC was also seen to have a specific advocacy role in areas such as lobbying for a centralised ethics approval system, research funding and protected time. Overall, respondents felt that the IAPC was performing well in this area, but should seek to increase its profile further: at undergraduate and post-graduate levels, and amongst other health professional groups and non-clinical organisations

*"Already doing so - I feel the IAPC is a great advocate in promoting and encouraging research. Encourage culture of interdisciplinary research. Medical colleagues are more likely to take the lead. In nursing and other disciplines, there is less of a culture of research and consequently people are less skilled and less confident"*

### **Theme 5: Dissemination of research** (12 respondents)

Respondents valued the role of the IAPC in facilitating the dissemination of research through the annual IAPC Education and Research Seminar and the IAPC newsletter. Augmenting this role to include initiatives such as actively encouraging people to publish their research findings, promoting the practice of local journal club meetings, and greater promotion of the Seminar nationally and internationally was suggested.

*"Continue annual research and education seminar, it provides an excellent showcase for research in the country"*

*"I think encouraging staff in the participation of journal clubs and delivering evidence based practice helps to stimulate research"*

### **Theme 6: Resource/Information Provision** (11 respondents)

Respondents felt the IAPC could have a more robust role as a resource provider for information relating to research and education, with emphasis on web-based provision of such services. An easily accessible online guide was suggested by several respondents that could include information on 'getting started' in research, links to funding opportunities and possibly an on-line support service. Such a forum could also provide information on services available and research being undertaken in different communities as well as a suggestion that it could serve as a 'noticeboard' for advertising available grants and posts. Online access to journals and library databases for IAPC members was sought by respondents

*"Provide support and perhaps on-line assistance and links for accessing information and assistance"*

*"Information sharing through email or online forums/websites - increased knowledge of services in the community/catchment area is hugely beneficial when working with both clients and their families"*

*"Library of resources"*



## Section 4: Discussion

The survey findings suggest that, despite numerous challenges, a significant number of palliative care professionals are involved in conducting research, either currently (52%) or in the past (77%). In fact, the vast majority of those who have been working in specialist palliative care for 10 years or more reported some involvement in palliative care research during their professional career.

Two thirds of respondents (n=88) have never applied for research funding which, given the level of involvement in research reported, suggests that much of the research is unfunded. It has been suggested that there is an overall lack of public funding for palliative care research (Kaasa et al., 2006). It is possible that respondents may be unaware of potential sources of funding or may not be eligible to apply for current funding streams (Bennett M, H, & Gluth J, 2009). The majority of survey respondents reported participation in clinical audit and questionnaire surveys which, provided they are small scale studies, can be carried out without additional funding.

Despite the fact that respondents with a postgraduate qualification were not significantly more likely to be involved in research than their peers, they were more likely to have presented their research in the form of an oral presentation at a national or international conference. Although a significant number of respondents have presented their work, a much lower percentage had successfully had their research published in a non-peer-reviewed or peer-reviewed journal.

Attitudes towards research are generally positive on the individual level, becoming more ambivalent with respect to named barriers such as lack of incentive, time limitations and difficulties in influencing work practice.

While respondents were open to the idea of research, they reported paternalistic/gate keeping attitudes.

Some palliative care professionals perceive research as too intrusive for patients and families, and that patients cannot give informed consent. These findings reflect those from previous studies (Kirsch et al, 2004; Peterson GM, et al., 2009). There is an association between positive attitudes and research involvement, with those most involved holding more positive attitudes and placing less emphasis on barriers.

Three factors were identified which underpin attitudes to research: research skills, external barriers to research, and positive disposition towards research. The extent to which these factors predict research involvement, as well as the extent to which they are amenable to change, would give direction for development of palliative care research interventions into the future. While some factors are under individual control (e.g. research skill) others indicate that even with individual effort, the external world may make it more difficult to conduct and apply research.

Perhaps unsurprisingly, the most prominent barrier to research identified was time to devote to research, while the most prominent facilitator was the provision of protected time for research. This is supported in the literature (Kirsch et al, 2004; McColl A, Smith H, White P, & Field J, 1998; Peterson GM, Jackson SL, Fitzmaurice KD, & Gee PR, 2009), including a recent European survey of research in end-of-life cancer care which found lack of time to be the second most important barrier after lack of funding (Sigurdardottir et al, 2010).

Concerns about the patient who might be the subject of research studies, such as research being too intrusive and patients being unable to give informed consent, were also considered to be particularly relevant in both this and previously published studies (De Raeve L, 1994)

Interestingly, factors that had to do with the staff themselves such as "Undertaking research will not benefit my career" and "My organisation does not value research as a worthwhile use of time" scored significantly lower. This suggests that, while staff attitudes to the concept of research are overall positive, they consider practical difficulties to be the greatest barriers to the conduction of research.

This was mirrored by the additional barriers highlighted in the qualitative results, with the most common themes being lack of resources, patient factors and lack of time. Lack of a support system for researchers, including guidance and encouragement from peers/senior colleagues was mentioned frequently, as was difficulty obtaining approval from research ethics committees.

Environmental factors and the perceived attitudes of institutions to palliative care research were the least prominent barriers identified in both the quantitative and qualitative data, although "working in an organisation that values research" was ranked second amongst the facilitators.

The additional facilitators suggested through the qualitative results are many, broad-ranging, and reflective of the current thirst for a national strategy to drive developments in palliative care education, research and policy.

Some themes, such as the creation of a 'research hub', the proposed structures that would support larger research projects and collaborative working, and access to research information and resources reflect a desire for a national palliative care research strategy in Ireland. Many of these themes are reflected in the aims and objectives of the All-Ireland Institute of Hospice and Palliative Care (AllHPC). Launched in October 2011, the Institute will drive strategic developments in education, research and policy in an effort to "improve the experience of supportive, palliative and end-of-life care on the island of Ireland, by enhancing the capacity to develop knowledge, promote learning, influence policy and shape practice" (All Ireland Institute for Hospice and Palliative Care, 2011). Specific work packages have been developed to pursue these aims, such as Research Capacity Building which makes provision for research mentoring, student scholarship and new investigator awards. An All-Ireland Palliative Care Communications Hub is planned, including the development and maintenance of an "online knowledge management and dissemination system as a resource for palliative care professionals, the general public, general health and social care workers, researchers, policymakers, the media etc." (All Ireland Institute for Hospice and Palliative Care, 2011).

Respondents identified access to research support as an important facilitator. Where lack of an appropriate culture or system to support research activities exists, mentoring has been identified as an essential element in the training and development of researchers (Peterson GM, et al., 2009).

Awareness of relevant information sources, as well as access to relevant databases and the world wide web are associated with improved attitudes towards evidence-based practice (McColl A, et al., 1998).

Journal clubs have played an active role in medical education for over a century (Linzer, 1987). A recent study examining the implementation and evaluation of a journal club meeting in a palliative care unit found that regular meetings stimulated discussion and reflection on clinical practice, and encouraged further reading and education (O'Connor, Bennett, Gardner, Hawkins, & Wellman, 2009). In this study, the journal club meetings were promoted by a dedicated facilitator with university links and a supportive organisational culture, and provided clinical nurses with a practical opportunity to explore evidence-based research in the area of palliative care. A further study describes a daily journal club format in a large Canadian palliative care program which served to increase emphasis on evidence-based practice, with high levels of satisfaction in the areas of clinical applicability, acceptability of the daily schedule and overall educational value amongst palliative medicine fellows (Mazuryk, Daeninck, Neumann, & Bruera, 2002). It is not known how prevalent regular journal club meetings are in palliative care in Ireland: this may be an area for further development in the drive to facilitate undertaking of research. Modern technology provides us with the potential for teleconferencing of journal clubs, or podcasts, a venture which may enable different centres to join together for meetings, with rotation between sites.

Other more specific proposed facilitators such as access to online journals and databases and centralised ethics committee approval are areas which have been targeted for development nationally. The Irish Hospice Foundation currently offers membership of its extensive library, including on-line journal access, for a small annual donation (Irish Hospice Foundation, 2011a).

In 2008, the HSE published a review of Research Ethics Committees (REC) in Ireland and recommended six to eight non-institutionally based RECs for the country (HSE, 2008). Whilst this process is on-going, a common application form has been developed, led by Beaumont Hospital and Science Foundation Ireland which has led to some improvement in the area.

Ensuring that research undertaken had meaningful impact, in terms of promoting change in practice, attitudes and services, was seen as important by respondents and reflects previous research findings (Peterson GM, et al., 2009). Having a genuine interest and enthusiasm for research was seen as a facilitator, but in contrast, gaining personal satisfaction or gratification was not cited in our study.

Respondents felt involvement of patients and their families in the research process was important and this is reflected in the literature. User involvement is seen as contributing to effective and meaningful research, particularly in helping researchers to remain connected to the real world in which research findings are applied (Lindenmeyer, Hearnshaw, Sturt, Ormerod, & Aitx2son, 2007).

This study had a number of limitations.

First, the response rate was relatively low (30%). Consequently, the study sample may be non-representative of Specialist Palliative Care professionals as a whole. Secondly, the results may be biased in that positive attitudes to research may be overestimated due to those with an interest in research being more likely to respond. Because the survey was anonymised, it was not possible to correct for non-response bias by carrying out an analysis of the non-responders. Thirdly, since at the outset of the study there is no up to date data of the numbers of all health and social care

professionals working in Specialist Palliative Care in Ireland, it was not possible to accurately define the entire target population.

In order to estimate the degree of representation of each discipline and clinical setting, the baseline characteristics of the respondents were compared with data from an Irish Hospice Foundation (IHF) study (collected in 2004 and published in 2006) describing hospice and specialist palliative care services in Ireland, including total numbers of palliative care staff in various settings (Irish Hospice Foundation 2006). Table 4.2.1 shows a comparison of data relating to profession and work setting of respondents. These figures imply that a relatively small number of nurses responded to this survey. This might have reflected the fact that staff nurses do not usually have individual work email addresses and therefore might not have received the survey. It is also worth noting that the number of professionals within each discipline might have expanded disproportionately between 2004 and 2011.

Table 4.2.1 Comparison of study participants' disciplines and Baseline Study\*

		IAPC Survey (2011)	IHF Study (2004)
Discipline	Doctor	25 (19%)	49.5 (10%)
	Nurse	66 (50%)	346 (73%)
	Other	40 (30%)	77 (16%)
Work Setting (nurses only)	Hospice	9 (15%)	149.5 (44%)
	Home Care	16 (26%)	148.5 (43%)
	Acute Hospital	18 (30%)	38 (11%)
	Education and Research	13 (21%)	Not available
	Combinations	5 (8%)	Not available

\*IHF study figures presented here do not include data relating to care attendants or secretarial staff as they were not included in the IAPC survey.

As well as displaying overall positive attitudes to research and a high level of involvement in research, respondents' comments displayed recognition of existing IAPC initiatives in promoting and showcasing research (e.g. the annual IAPC Education and Research Seminar and the abstract writing workshops). In addition, survey participants have provided the IAPC Education and Research Forum with direction for the development of future initiative in this very important area.

## Section 5: Conclusions

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The findings of this survey suggest that, despite numerous barriers, a significant number of palliative care research studies are being conducted in Ireland, as well as being presented both nationally and internationally and published in some cases.

Overall, attitudes to the conduct and application of research were positive.

Lack of time to devote to research was considered to be the single most important barrier to conduction of research. This was mirrored by the fact that protected time to undertake research was the highest ranking factor which facilitates research.

The palliative care community now faces a significant challenge to maintain and enhance research in this field. The IAPC Education and Research Forum looks forward to making a valuable contribution to the important task ahead.

## Section 6: References

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## IRISH ASSOCIATION FOR PALLIATIVE CARE (IAPC) Response to the findings of the Survey of Perceived Facilitators and Barriers to conducting Palliative Care Research in Ireland, Section 3.6: “What can the IAPC do for you?”

In 2010, in line with its strategic objective to build professional capacity at the individual and sector level in palliative care, the IAPC expanded the terms of reference of its working group, the IAPC Education and Research Forum. The Forum was thus enabled to undertake this unique survey of professionals delivering specialist palliative care (SPC) in the Republic of Ireland to ascertain perceived barriers to conducting research, and identify factors which would help and facilitate undertaking research in palliative care.

The purpose of the survey is to improve the IAPC's understanding of the needs of palliative care professionals in this area, and assist it to provide whatever supports are feasible to meet these needs.

In addressing the findings of the survey, the IAPC is pleased to respond to the question, ‘What can the IAPC do for you?’ as follows:

### Education

(ref Section 3.6: Theme 1)

Now in its 12th year, the annual IAPC Education and Research Seminar makes an annual call for abstracts, and the seminar itself provides an opportunity for those engaged in palliative care provision and related areas to share and to learn through attending the seminar and through platform and poster presentations. Both the submission of abstracts, the platform and poster presentations, along with attendance numbers at the annual seminar, have seen an increase year on year, with a significant increase recorded for 2011.

The annual seminar provides a valuable opportunity to gain experience in presenting research to a national audience before moving to an international arena such as the World Research Congress of the European Association for Palliative Care.

For the past several years, the IAPC annual evening *Abstract Writing Workshops* have been delivered by experienced researchers in centres around the country.

### New and planned initiatives:

- A new IAPC research-support initiative in 2011 was the *Writing Winning Proposals Workshop* delivered in Dublin. It is intended that this be an annual offering and that it be extended regionally.
- Collaborative links with Trinity College Dublin's School of Nursing and Midwifery have been established with a view to extending the University's research supports to IAPC members in 2012.
- Presentations skills workshops will be designed and delivered in 2012.
- On a pilot basis, *Basic Research Methods* workshops (for ‘getting started in research’) will be developed and delivered in 2012.
- In a planned collaboration with the IAPC Palliative Nursing Forum, a *Research Masterclass* will be offered as part of the annual Education and Research Seminar.
- Exploiting the potential of the IAPC website [www.palliativecare.ie](http://www.palliativecare.ie) to address the needs of budding researchers will be a priority in 2012.

### Facilitator

(ref Section 3.6: Theme 2)

A core objective of the IAPC is to facilitate networking to promote sharing and learning among palliative care professionals and thereby build professional capacity.

Through its two annual national events – the Annual IAPC Conference and the annual IAPC Education and Research Seminar – the IAPC facilitates personal and professional development for the palliative care community nationally.

While the IAPC could play a useful role at the level of establishing national research priorities and enabling research alliances nationally, this would be more properly an initiative of the new All Ireland Institute of Hospice and Palliative Care (AIHPC).

### Future Initiative

The Education and Research Forum is a cross-cutting inter-disciplinary forum and its recently expanded terms of reference enables it to develop its potential to instigate research initiatives (of which this survey is the first), which will develop the research skills and capacity of the Forum's membership and further motivate and support inter-disciplinary research through leading collaboration across the IAPC working groups.

### Funding

(ref Section 3.6: Theme 3)

The IAPC, enabled by its Premium Partner, pharmaceutical company Mundipharma, awards bursaries annually for best platform and poster presentations at the IAPC Annual Education and Research Seminar.

Due to IAPC's ‘small charity’ status and consequent overall financial constraints, the IAPC is not in a position to provide research funding from its own financial resources. However, it is willing to, and will, explore possibilities to expand partnerships to award research bursaries.

### **Advocacy/Dissemination of research** (ref Section 3.6: Theme 4/5)

Improving the capacity of its members to provide a higher level of care by facilitating the consolidation and assimilation of knowledge and expertise is a core strategic objective of the IAPC.

The IAPC's structures, particularly its working groups, are designed to promote and fulfil this objective. Its strategic relationships and linkages with other relevant stakeholders in palliative care on the island of Ireland, and internationally, seek to further this objective also.

As a multidisciplinary professional organisation the IAPC's membership encompasses all the disciplines that provide specialist palliative care, and the IAPC's working groups provide forums for each discipline to come together in learning networks.

The IAPC working groups have increased significantly in number over the past two years and now include the Palliative Nursing Forum, Ethics Working Group, the Palliative Care Social Worker Group, Pharmacists Group, and Children's Palliative Care Special Interest group. Each working group has stated objectives in relation to developing research skills and undertaking research within each discipline.

The IAPC's two main communication channels – *IAPC NEWS* and the IAPC website – have as objectives the sharing of information, knowledge and new developments in palliative care, and the dissemination of evidence-based research in digest form.

### **New Initiative**

The mission of the new and significantly enhanced IAPC website [www.palliativecare.ie](http://www.palliativecare.ie) is to support the professional development of IAPC members and the wider palliative care community through an accessible **Knowledge Centre** designed to disseminate palliative care research (including videos of the research presentations from the annual IAPC Education and Research Seminar) and dedicated Discussion Forums designed to promote professionals dialogue and provide information, increase knowledge and develop expertise.

### **Future Initiative**

The feasibility of a cross-discipline, cross-service research initiative involving all IAPC working groups will be undertaken in 2012. The Palliative Nursing Forum will take a lead role in this initiative.

### **Resource/Information Provision (ref Section 3.6: Theme 6)**

The IAPC's new website [www.palliativecare.ie](http://www.palliativecare.ie) is more properly described as a web application with features unique to such a site in Ireland. It is a most powerful resource for IAPC members and the wider palliative care community. It has the capability to address all current and potential demands for information and knowledge and online networking. The challenge is for the IAPC working groups to avail of its capacity and capability to promote the objectives of the groups.

### **Mary Ainscough**

Chief Executive

Irish Association for Palliative Care

## Appendix 1 – Survey of Perceived Facilitators and Barriers to conducting Palliative Care Research in Ireland Questionnaire

1. Please answer the following questions relating to your involvement in research.

	Yes	No
Have you been involved in research in your professional career?	<input type="checkbox"/>	<input type="checkbox"/>
Have you been involved in research in Palliative Care?	<input type="checkbox"/>	<input type="checkbox"/>
Have you ever applied for ethical approval for a research project?	<input type="checkbox"/>	<input type="checkbox"/>
Have you ever applied for funding/grant for a research project?	<input type="checkbox"/>	<input type="checkbox"/>
Have you ever been awarded funding for a research project?	<input type="checkbox"/>	<input type="checkbox"/>
Have you been involved in writing a research proposal?	<input type="checkbox"/>	<input type="checkbox"/>

2. Do you think of clinical audit as a type of research? Yes  No  Don't know

If you have been involved in research please answer questions 3 to 6 in relation to all projects you participated in. If you have not been involved in research please move to question 7.

3. What role(s) did you have in this research? Please tick all relevant boxes.

	Yes	No
Principal Investigator	<input type="checkbox"/>	<input type="checkbox"/>
Research Assistant	<input type="checkbox"/>	<input type="checkbox"/>
Member of wider research team	<input type="checkbox"/>	<input type="checkbox"/>

4. What type of projects have you been involved in? Please tick all that apply.

	Yes	No
Audit	<input type="checkbox"/>	<input type="checkbox"/>
Survey/ Questionnaire study	<input type="checkbox"/>	<input type="checkbox"/>
Randomised Control trial	<input type="checkbox"/>	<input type="checkbox"/>
Other Quantitative study	<input type="checkbox"/>	<input type="checkbox"/>
Please specify:		
Other Quantitative study	<input type="checkbox"/>	<input type="checkbox"/>
Please specify:		

5. Have you participated in the following?

	Yes	No
Oral presentation of your research at a local journal club/meeting	<input type="checkbox"/>	<input type="checkbox"/>
Poster presentation at a national conference	<input type="checkbox"/>	<input type="checkbox"/>
Poster presentation at an international conference	<input type="checkbox"/>	<input type="checkbox"/>
Oral presentation at a national conference	<input type="checkbox"/>	<input type="checkbox"/>
Oral presentation at an international conference	<input type="checkbox"/>	<input type="checkbox"/>
Publication in a non peer reviewed journal	<input type="checkbox"/>	<input type="checkbox"/>
Publication in a peer reviewed journal	<input type="checkbox"/>	<input type="checkbox"/>
OtherPlease specify:		

6. Are you currently involved in research? Yes  No

7. Please indicate if you agree with the following statements.

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
I find that research articles are generally easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel confident in my ability to access relevant research articles through various databases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel confident in my ability to evaluate the quality of research papers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find that available research specific to my professional practice is of poor quality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find that the amount of research literature is overwhelming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think research is not that important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would like to undertake a research project	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think I should do a course to help me understand research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think that I should do a course to help me use research effectively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think that research influences me to change my practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There are no incentives for me to develop my research skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find time limitations prevent me from exploring the evidence base to change my work practices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to influence changes to clinical practice in my work setting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Much of the available research is not relevant to my professional practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Evidence based practice is highly valued within my organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Please indicate if you would be interested in any of the following in the future.

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
Attending a course on research methodology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being an investigator on a research project	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recruiting patients for a research project	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Developing skills in interpreting other people's research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



9. What do you consider the most important barriers to doing research with specialist palliative care patients and their families?

Please rank all that are applicable in order of importance, where 1 is the most important barrier, 2 is the second most important barrier, 3 is the third most important barrier, etc. Please leave a box blank if it does not apply.

It is too intrusive for patients and families	<input type="checkbox"/>
Patients cannot give informed consent	<input type="checkbox"/>
Staff are not consulted about doing research	<input type="checkbox"/>
Research findings are not used to improve practice in my work place	<input type="checkbox"/>
There is not enough protected time to do research	<input type="checkbox"/>
My organisation does not value research as a worthwhile use of time	<input type="checkbox"/>
Undertaking research will not benefit my career	<input type="checkbox"/>
Having direct access to computer/internet facilities at work	<input type="checkbox"/>

Please outline any other barriers to doing research with specialist palliative care patients and their families in the box below:

10. What do you consider the most important factors which facilitate doing research with specialist palliative care patients and their families?

Please rank all that are applicable in order of importance, where 1 is the most important facilitator, 2 is the next most important facilitator, 3 is the third most important facilitator, etc. Please leave a box blank if it does not apply.

Attending courses on research methods	<input type="checkbox"/>
Getting partial funding to do courses on research methods	<input type="checkbox"/>
Getting full funding to do courses on research methods	<input type="checkbox"/>
Having protected time to undertake research	<input type="checkbox"/>
Working in an organisation that values research	<input type="checkbox"/>
Being assigned a mentor/supervisor for my research project	<input type="checkbox"/>

Please outline any other factors which would facilitate doing research with specialist palliative care patients and their families in the box below:

Please answer the following questions relating to personal details:

11. What gender are you? Male  Female

12. Where do you work? Republic of Ireland  Northern Ireland

Other: Please specify

13. What age are you? ≤ 25  26-35  36-50  >51

14. What is your profession?

Doctor	<input type="checkbox"/>	Social Worker	<input type="checkbox"/>	Pharmacist	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	Chaplaincy	<input type="checkbox"/>	Complementary therapist	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	Psychologist	<input type="checkbox"/>	Speech & Language Therapist	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	Dietician	<input type="checkbox"/>		

Other: Please specify

15. What is your highest academic qualification?

Certificate	<input type="checkbox"/>	Degree	<input type="checkbox"/>	MD	<input type="checkbox"/>
Diploma	<input type="checkbox"/>	Postgraduate Diploma	<input type="checkbox"/>	PhD	<input type="checkbox"/>
Higher Diploma	<input type="checkbox"/>	Masters	<input type="checkbox"/>		

16a. Are you currently working in Specialist Palliative Care? Yes  No

16b. If yes, in what area of practice do you spend most of your time most weeks?

Hospice	<input type="checkbox"/>	Home Care	<input type="checkbox"/>	Acute Hospital	<input type="checkbox"/>
Research	<input type="checkbox"/>	Education	<input type="checkbox"/>		

Other. If so, please specify

17. How long have you worked in Specialist Palliative Care?

0 – 2 years	<input type="checkbox"/>	2 – 5 years	<input type="checkbox"/>	5 – 10 years	<input type="checkbox"/>	> 10 years	<input type="checkbox"/>
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18. Do you work? Full time  Part time

19. Do you have access a computer in your work place? Yes  No

If yes, approximately how many other people have access to this computer?

20. Do you have access to the internet in your work place? Yes  No

21. Are you a member of the Irish Association for Palliative Care (IAPC)? Yes  No

22. Have you ever been a member of the IAPC? Yes  No

23. Do you think there is anything the IAPC can do to help facilitate involvement in research in palliative care? Yes  No  Don't know

If so, please outline it here:

Thank you for taking the time to complete this questionnaire.

## Appendix 2 – Responses (n and %) to questions on attitudes to research

	Strongly Agree N (%)	Agree N (%)	Neither N (%)	Disagree N (%)	Strongly Disagree N (%)
I find that research articles are generally easy to understand	17 (13)	82 (61)	18 (14)	14 (11)	0 (0)
I feel confident in my ability to access relevant research articles through various databases	30 (23)	75 (57)	10 (8)	13 (10)	3 (2)
I feel confident in my ability to evaluate the quality of research papers	22 (17)	66 (50)	25 (19)	16 (12)	2 (1)
I find that available research specific to my professional practice is of poor quality	4 (3)	29 (22)	31 (23)	64 (48)	5 (4)
I find that the amount of research literature is overwhelming	6 (5)	27 (21)	45 (35)	49 (38)	3 (2)
I think that research is not that important	1 (1)	0	2 (1)	34 (26)	93 (71)
I would like to undertake a research project	47 (37)	56 (44)	17 (13)	5 (4)	2 (2)
I think I should do a course to help me understand research	17 (13)	38 (29)	35 (27)	28 (22)	11 (8)
I think I should do a course to help me use research effectively	24 (19)	53 (41)	20 (16)	23 (18)	8 (6)
I think that research influences me to change my practice	53 (40)	73 (56)	5 (4)	0 (0)	0 (0)
There are no incentives for me to develop my research skills	10 (8)	38 (29)	23 (18)	45 (35)	14 (11)
I find time limitations prevent me from exploring the evidence base to change my work practices	40 (31)	51 (37)	18 (14)	18 (14)	3 (2)
I find it hard to influence changes to clinical practice in my work setting	5 (4)	42 (33)	33 (26)	45 (35)	4 (3)
Much of the available research is not relevant to my professional practice	2 (1)	25 (19)	17 (13)	68 (52)	19 (14)
Evidence based practice is highly valued within my organisation	39 (29)	68 (51)	16 (12)	7 (5)	2 (1)

## The IAPC Education and Research Forum

The IAPC Education and Research Forum is a major strand of the IAPC's work agenda. The purpose of the Forum is to address Palliative Care education and research as arises under the IAPC's Mission to promote palliative care through education, representation and networking and thereby build capacity in palliative care at the individual and at sector level on the Island of Ireland.

Members of the Forum for 2011 are:

- **Ms Anne-Marie Corroon** (*Chairperson*),  
*Lecturer in Nursing, Trinity College, Dublin 2.*
- **Dr Margaret Clifford**, (*Vice-Chairperson*),  
*Specialist Registrar in Palliative Medicine, Marymount Hospice, Wellington Road, Co. Cork.*
- **Dr Lucy Balding**,  
*Specialist Registrar in Palliative Medicine, Our Lady's Hospice, Harold's Cross, Dublin 6.*
- **Ms Mary Buwalda**,  
*Medical Social Worker, Marymount Hospice, Wellington Road, Co. Cork.*
- **Ms Grainne Keating**,  
*Chief 11 Pharmacist, Dochas Centre, Our Lady of Lourdes Hospital, Drogheda, Co. Louth.*
- **Ms Orla Keegan**,  
*Head of Education, Research & Bereavement Services, Irish Hospice Foundation, Dublin 2.*
- **Ms Breda King**,  
*Coordinator Home Care Team, Galway Hospice, Renmore, Co. Galway.*
- **Dr Honor Nicholl**,  
*Lecturer, Trinity College, Dublin 2.*
- **Ms Morna O'Hanlon**,  
*Clinical Nurse Specialist, Palliative Care Service AMAU, St. James' Hospital, Dublin 8.*
- **Ms Claire Quinn**,  
*Lecturer, School of Nursing & Midwifery, NUI Galway.*
- **Dr Elaine Wallace**,  
*Specialist Lecturer in Palliative Medicine, Milford Care Centre, Castletroy, Co. Limerick.*
- **Ms Evelyn Whittaker**,  
*Lecturer in Palliative Care, Northern Ireland Hospice, Somerton Road. Belfast.*

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**Chief Officer: Mary Ainscough**,  
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