Primary Palliative Care in Ireland

Identifying improvements in primary care to support the care of those in their last year of life

THE IRISH HOSPICE FOUNDATION

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

ICGP

Primary Palliative Care in Ireland

Identifying improvements in primary care to support the care of those in their last year of life. Joint report from:

The Irish Hospice Foundation,
The Irish College of General Practitioners
and The Health Service Executive

Primary Palliative Care in Ireland is the report of the initial phase of the Primary Palliative Care programme. This is a joint programme between the Irish Hospice Foundation, the Health Service Executive and the Irish College of General Practitioners. The second phase will commence in 2012, and will be based on the implementation of the recommendations of this report.

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More information on the Primary Palliative Care programme can be found on the Development page of the IHF website: **www.hospice-foundation.ie**

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Chairman's foreword

Welcome to the report of the Primary Palliative Care Steering Committee. On behalf of the members of the committee, I am delighted to present this report.

The Irish people have long had a history of intertwining birth and death into the colourful fabric of life. We are laboured into, and out of, this world, and these two milestones embroider life's intricate quilt. It is against a backdrop of innate empathy and communal respect for the dignity of another in trouble, that the origins of Palliative Care developed in Ireland at St Patrick's hospital in Cork and Our Lady's hospice in Harold's Cross, Dublin in the 1870's. The subsequent international development of the modern palliative care movement, pioneered by Dame Cicely Saunders at St Christopher's in London, established Palliative Care as a core specialty of the worldwide medical spectrum.

There has been a carefully nurtured growth in Palliative Care in Ireland since its designation as a specialty here in 1995. This specialist care helped initially to compliment that of general practice, and the oncology and neurology services, and subsequently extended to the care of people suffering from a wider spectrum of non-malignant conditions. It is a holistic and multidisciplinary approach to care that has quietly seeped through various hospital specialties and influenced the manner in which people with advanced and progressive diseases are minded through the last furlong of their lives. In addition, the specialist home care teams have provided invaluable help and advice to staff in primary carer with regard to the care of people dying at home (since the establishment of the first specialist home care team in 1985).

Now, in recognition of the fact that 90% of the last year of life is spent at home, and that the expressed wish of most people (80%) with end stage disease in this country is to die at home, it is apparent that there is a great need to improve mechanisms for the provision of generalist Palliative Care at community level. This enhanced delivery of Palliative Care by Primary Care can result in an holistic and structured care that helps to keep patients in the community throughout their last journey.

The phased establishment and embedding of the Primary Care Team structure by the HSE now allows for a lattice work onto which these enhancements can be pinned. The educational input by the ICGP over 16 years has further helped to create a critical mass of enthusiasm and energy among Irish GPs. This will help to meet the increasing needs for community Palliative Care that will be required by an elderly population that will double in number over the next 20 years.

This report now aims to identify initiatives that will help all community-based health care professionals deliver enhanced Palliative Care to their patients at home. These initiatives should help to weave the various strands of palliative care delivered by Primary Care into a stronger thread and should result in enhanced cohesion in the care delivered to each individual patient, making for better care. The implementation of these initiatives is consistent with the aim in the programme for government 2011 'to deliver the right care in the right place'. It is entirely possible within the current fiscal restrictions and will help community-based health care professionals manage the care of patients with advanced progressive disease at home by doing the important things well.

Finally on a personal note, I would like to thank all the members of the steering committee for their input into this programme and their help in bringing this report to fruition.

Dr. Paul Gregan *Chairperson Primary Palliative Care. Half time Consultant in Palliative Medicine, Blackrock Hospice and half time General Practitioner.*

Endorsements

In Ireland, hospital services tend to dominate when the health services are being discussed. This is not surprising as, historically, the emphasis has been on hospital-based services, despite the ongoing achievements and developments in the primary care sector. However, health services around the world are changing. Many more services, traditionally only accessible in acute hospitals are now becoming more easily available within local communities. Central to the modernisation of the Irish health service, therefore, is the development of a greater range and volume of primary care services.

The Primary Care Strategy 2001 'A New Direction', set out a new direction for primary care as the central focus of the delivery of health and personal social services. The aim is to support and promote the health and wellbeing of the population by making people's first point of contact with the health services easily accessible, integrated and locally basis. At the heart of this community-based approach are Primary Care Teams whose main priorities are delivering cost-effective primary care based services. In addition the guidance emanating from the National Clinical Programmes is supporting the necessary service development in this area.

The HSE welcomes the focus and recommendations of this report as it seeks to outline and identify how Primary Care Teams can support and respond to the palliative care needs of those with advancing life-limiting disease in primary care based settings. This will help ensure that patients with life-limiting disease together with their families can easily access a level of palliative care that is appropriate to their needs in an integrated and co-ordinated way in primary care based settings and maintain care at end of life in the community as long as is practicable.

Mr. Brian Murphy HSE *National Primary Care & Social Inclusion Services Manager.*

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2004).

The Palliative Care Clinical Programme within the HSE aims to ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis. The Programme recognises that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist palliative care services.

In particular, it acknowledges the fundamental importance of the role of the General Practitioner and primary healthcare team. When diagnosed with a life limiting illness most patients have an existing relationship with a general practitioner and for many families, the relationship with a general practitioner continues until the death of the patient and beyond.

The Programme therefore welcomes the development of initiatives that support primary care providers to communicate and co-ordinate care on an ongoing basis in order to ensure streamlined and high-quality care for all patients. We look forward to collaborating with stakeholders to achieve these goals.

Dr. Karen Ryan *Consultant in Palliative Medicine; Clinical Lead for the Palliative Care programme, Clinical Strategy and Programmes Directorate, HSE.*

The Irish Hospice Foundation centres its work on building support for the hospice philosophy in all care settings.

For most of us, the vast majority of our health care is provided by primary health care professionals. For those nearing end of life, it is vital that these same staff have the confidence, competence and resources to ensure that the persons palliative care needs are anticipated, assessed and responded to. The person who has an advanced life-limiting disease, and their family must at all times remain central, be fully informed and have opportunities to engage with and plan the health care they receive.

This report has identified a number of initiatives that will support staff working in primary care settings deliver a more responsive, co-ordinated and person centred service. Over time, we believe this will lead to better integration of services , more cost efficient services and most importantly will enable these patients to have more choice regarding their place of care and preferred place of death. The report also signals more long term objectives which will support national developments in Primary Palliative Care, in collaboration with the HSE, ICGP, Department of Health and other key stakeholders. Over the coming years, we look forward to working with our partners to achieve a hospice approach in all primary care settings.

Ms. Sharon Foley *CEO Irish Hospice Foundation*.

Acknowledgments

The Primary Palliative Care committee would like to particularly thank

- All the health care professionals who responded to the questionnaire and participated in the consultation meetings
- The note-takers for each of the five consultation meetings
- The HSE Transformational Development Officers who assisted in organising the consultation meetings and distributed the questionnaire
- Dr Caroline Kelleher for carrying out the data analysis on the questionnaire returns.

Abbreviations

CIT	Community Intervention Team
COPD	Chronic Obstructive Pulmonary Disease
DoHC	Department of Health and Children
ePCS	Electronic Palliative Care Summary
GSF	Gold Standards Framework
GP	General Practitioner
HIQA	Health Information and Quality Authority
HSCN	Health and Social Community Network
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
LHO	Local Health Office
NACPC	National Advisory Committee Palliative Care
NHS	National Health Service
OOH	Out of Hours
PPC	Primary Palliative Care
PHN	Public Health Nurse
SPC	Specialist Palliative Care
TDO	Transformational Development Officer
WHO	World Health Organisation

Glossary of terms

Primary care

Primary care is an approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. These services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being. Primary care is the part of the health system that ensures that services are co-ordinated and integrated across the boundaries of health and personal social care to the benefit of the consumer in terms of better quality, better outcomes, better cost-effectiveness and better health status [1].

Primary care teams

A primary care team is a team of health professionals who work closely together to meet the needs of the people living in the community. They provide a single point of contact to the health system for the person. These professionals include:

- General Practitioner and Practice Nurse.
- Community Nursing Service – Public Health Nurse, Community Registered Nurse.
- Occupational Therapist.
- Physiotherapist.
- Home Help, and other support staff.

As required, the primary care team members' link with other community-based disciplines to ensure all health and social needs are provided for.

Palliative care approach

The palliative care approach aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles. The key principles of the palliative care approach include a focus on quality of life, which includes good symptom control; a holistic approach that takes into account the person's life experience and current situation; care that encompasses both the dying person and those who matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues [2].

Specialist palliative care services

Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs. Specialist palliative care services should be seen as complementing the care provided by other health care professionals in hospitals and community settings [2].

Primary palliative care

Primary palliative care is the clinical management, care co-ordination and referral using a palliative approach for patients with uncomplicated needs associated with a life-limiting illness and/or end of life care. This approach requires formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary [3].

Executive Summary

Executive summary

Introduction

Of the 27,000 people who die every year, the majority of their care in the last year of their life is provided for by the General Practitioner (GP) and members of the primary care team. However in Ireland, unlike other countries, there is no formal framework to support community-based health care staff to assist them identify and respond to the palliative care needs of those people who are facing death in the community. In 2010 the Irish Hospice Foundation, in partnership with the Irish College of General Practitioners and the HSE established the Primary Palliative Care (PPC) programme, in order to identify palliative care initiatives that will support primary care team's responses to adults living with advancing life-limiting diseases in the community. The national steering committee, which was established to support the work of the programme, was representative of professional groups and relevant HSE structures covering both primary care and specialist palliative care.

International developments

In other jurisdictions, for the past decade, there has been significant policy and strategic developments to support primary care teams in their response to the palliative care needs of those with life-limiting disease. The UK End of Life Care strategy, which was published in 2008, has provided the NHS with guidance and frameworks to support and monitor developments in the area of care at end of life in all settings, and these are co-ordinated from the National End of Life Care Programme. Examples of the various initiatives and projects supported by this strategy and programme are described within this report, and demonstrate the scale and extent of development required to support the delivery of quality end of life care in all care settings. The recent review of funding that has been linked to the implementation of the UK End of Life Care strategy has recommended that the models of funding and service delivery needs to ensure equity of provision in this area of care. 2011 has seen the emergence of international guidance and research structures to support the development of primary palliative care, including the establishment by the European Association of Palliative care of the Taskforce on Primary and Community Palliative care, and the publication of a report by WHO Collaborating Centre for Public Health Palliative Care. Research in delivery of primary palliative care has highlighted the need for greater role clarity amongst professional groups as to their responsibilities in 'generalist palliative care delivery' as well as further provision of education and training in communication and symptom control to enhance their service provision.

Irish context

The projected demographic shifts relating to life expectancy signal that people in Ireland will live longer, albeit with associated chronic illnesses. This coupled with an ageing population will result in greater demands on community-based health care, to ensure that they can remain living in the community despite their increasing frailty. Up to very recently, the domain of palliative care has traditionally being linked with cancer, and associated with specialist palliative care (SPC) services. However these services respond to those who are dying with complex and demanding care needs, and support approximately 23% of those who die in community settings every year. In 2001, the report of the National Advisory Committee on Palliative Care observed that GPs and community nursing services are the main provides of 'general palliative care' to those dying with life-limiting disease that do not require the services of SPC. This DoHC report recommended that SPC nurses should act as a resource to community-based health professionals, and that a 24-hour telephone advisory service should be available to support the provision of palliative care in all care settings.

Arising from the DoHC Primary Care Strategy, the primary care teams around the country are now gradually being established, and these teams are clarifying their relationships with the specialist services (including SPC) that form the health and social community networks. From a policy perspective, it is encouraging to see that there are a number of emerging governance and support structures that will direct the standards and clinical guidance necessary to ensure the quality delivery of palliative care in all care settings, for example HIQA, HSE national clinical programmes and the All Ireland

Institute of Hospice and Palliative Care. The PPC programme identified a small number of local primary care initiatives that are responding specifically to the palliative care needs of patients - these emerging models need to be evaluated and can inform relevant strategic developments.

Views of Irish community-based health care professionals

In seeking to ascertain the views of community-based health care professionals with regard to primary palliative care delivery, the PPC programme undertook a series of consultation meetings and conducted a survey across ten HSE Local Health Offices. The themes addressed referred to communication with patients and families; co-ordination of services and transfer of information; education and training needs; and access to medication and equipment. The need for enhanced communication systems, to assist the delivery of timely and consistent information to patients and their families with regard to their palliative care needs, was strongly supported by all respondents. There was recognition of a need to up-skill in aspects of clinical management of patients with palliative care needs, as well as providing a mechanism to identify people who are entering the palliative phase of their illness. Enhancing confidence and clinical skills amongst primary care staff will assist in addressing the uncertainty with regard to professional roles that emerged as a theme from respondents in the survey. Service enhancements were also identified as vital to the development of comprehensive primary palliative care – particularly with regard to community-based nursing services and advice and information from SPC outside of traditional working hours.

Recommendations

The majority of health care professionals who engaged with the PPC programme acknowledged their role within the delivery of primary palliative care; however they had difficulty in relating on how this ethos and practice of care existed within their care delivery. The recommendations of the first phase of the PPC programme are prioritised based on developments that would be helpful to clarify and support service delivery, without significant resource implications. They include

- Clarifying access to advice and information from SPC outside of traditional hours.
- The development of a resource system that will assist in identifying and supporting patients with palliative care needs in the community.
- The introduction of a formal mechanism for GPs to communicate to their local out of hours service providers with regard to the palliative care needs of their patient.

Proposals for responding to the education needs identified are also outlined, as well suggestions for developing greater awareness amongst professional groups as to their role in the area of primary palliative care.

Conclusion

In the next decade, there will be significantly more people living with advancing life-limiting disease in the community, and all of these people will require a palliative approach to their care. Irish health care professionals, who participated in this programme, have indicated they recognise that primary palliative care is a key aspect of their work; however they also acknowledge that they need more support, guidance and communication systems to enhance the care they deliver to their patients with palliative care needs. This report signals the imminent steps that need to be taken so that Ireland, in keeping with international practice, can begin to establish a framework to support the delivery of palliative care by community-based health care professionals.

CHAPTER 1

Introduction

> **‘Primary care professionals have the potential and ability to provide end of life care for most patients, given adequate training, resources, and, when needed, specialist advice. They share common values with palliative care specialists - holistic, patient centred care, delivered in the context of families and friends’**
>
> *Scott Murray 2004 [4]*

Chapter 1

Introduction

Context

The predominant responsibility for the care of people with life-limiting disease lies with General Practitioners (GP) and their community nursing colleagues, along with appropriate support from the specialist palliative care (SPC) service and allied health professionals. In recognition of this fact, in late 2009. The Irish Hospice Foundation (IHF), along with the Health Service Executive (HSE) and Irish College of General Practitioners (ICGP) established the Primary Care Palliative Care – hereafter named Primary Palliative Care (PPC) steering committee. The establishment of this committee and its subsequent work programme arose from informal contact between the IHF and a number GPs and SPC professionals. These individuals were aware of the need to provide more guidance to GPs and community nursing colleagues in their response to patients with advancing life-limiting disease that were living in community settings. The impetus for the establishment of the PPC was heightened by the awareness of international developments in primary palliative care as well as the impact of the forecasted demographic trends in Ireland. Both the ICGP and the HSE appointed representatives to the steering committee, and appropriate links were made with policy and service groups from these organisations, particularly the work of the HSE clinical programmes in Primary Care and Palliative Care.

Aim

The aim of the initial phase of the work programme was to identify palliative care initiatives that will support primary care teams’ responses to adults with advancing progressive disease who live in the community and are expected to die within twelve months. The emphasis of the work of the programme has deliberately been from a primary care perspective. This is based on the understanding that, when necessary, the appropriate support, advice and education can be accessed from specialists in palliative care, and elsewhere, to support the delivery of primary palliative care.

The terms of reference for the work of the committee can be found in Appendix 1, and the programme had a developmental focus. The membership of the committee included primary care professionals representing community nurses, GPs, pharmacists and SPC professionals. The committee was chaired by Dr Paul Gregan who works half-time as a GP and half-time as a consultant in palliative medicine. The full list of committee members can be found in Appendix 2. The committee met nine times between November 2009 and June 2011. In that time, the committee supported and contributed to the work of this programme, including hosting five consultation meetings that were held with community health care professionals - countrywide, assisting in the drafting and subsequent analysis of a questionnaire and the compilation of this report. In order to stay abreast of Irish and international service developments in this area, the committee members received presentations from relevant Irish initiatives, and a small delegation attended conferences in UK and Europe on this topic. In addition, the committee also assisted with the dissemination and awareness of its work by means of progress reports to their respective professional groups and poster presentations at Irish palliative care conferences.

Report content

To assist in providing a wider context to the potential scope and rationale for the development of palliative care within primary care settings, chapter two will describe a range of international initiatives in primary palliative care. Chapter three seeks to outline the Irish health structures and policy in primary care that can support the delivery of palliative approach to care, as well as some emerging initiatives. This chapter will also set out the implications of the changing demographics of people living with advancing life-limiting disease. Chapter four relates how the PPC programme gathered information and views from a selection of community-based health care professionals in Ireland. This chapter also summarises the findings from this process. The final part of this report details the prioritised recommendations. These are informed by international practice and emerging Irish research, the findings of the questionnaire and consultation meetings, as well as the indicative support and synergies with HSE structures and ICGP policy work. The final chapter outlines the structure and proposed implementation plan for phase two of the work of the primary palliative care programme, supporting the recommendations from this report.

CHAPTER 2

International Developments

Chapter 2

International developments

Introduction

When considering the rationale and significance of ensuring that people in Ireland with advancing life-limiting diseases have their palliative care needs identified and responded to in community-based settings, it is helpful to look at emerging developments in primary palliative care in other countries. Throughout the course of its work, the PPC programme sought information on such developments from UK and further afield. A range of policy, practice and research initiatives from UK, Australia, Canada and the WHO public health palliative care programme are described in this chapter, for the purpose of providing a wider context to the PPC programme. This account does not attempt to provide an in-depth appraisal of these developments, which is beyond the scope of the PPC programme.

2.1 United Kingdom

2.1.1 End of Life Care Strategy

In July 2008 the UK Department of Health launched the End of Life Care strategy which included a focus on primary care [5]. Arising from this strategy, the NHS developed a National End of Life Care programme, to work with health and social care services across all sectors to improve end of life care for adults. In this regard they have developed a comprehensive website for professionals and public: http://www.endoflifecareforadults.nhs.uk/.

The UK End of Life Care strategy outlines the following key areas where primary care teams can enhance end of life care:

- Identification of people approaching the end of life and their inclusion on a 'palliative care register' held in a GP practice.
- Having conversations with patients and their families to find out their wishes and preferences in relation to their end of life care – it is acknowledged that these conversations can be difficult at times.
- Planning together as a team to provide co-ordinated care.
- Delivery of high quality services in all locations
- Managing the final days sensitively and appropriately.
- Supporting people at the end of life, and their families and carers.

To support the measurement of quality outcomes, the End of Life Care Programme produced a document stating the key performance indicators for delivery of end of life care. This includes a section on primary care [6]. Many of the programmes that are included in the End of Life Care strategy refer to supporting people at the end of life in the community – and references to four of these programmes are described in more detail below:

2.1.1.1 Gold Standards Framework

The Gold Standards Framework (GSF) is a systematic evidence-based approach to optimise the care delivered by generalist providers to patients nearing end of life. It is concerned with helping people to live well until the end of their lives and includes a focus on care in the final years of life for people with any life-limiting illness in any setting. The GSF was developed and pioneered in 2003 by a GP - Professor Keri Thomas - and was piloted for 3 years [7]. It now has specific education programmes and 'tool kits' tailored for residential settings and acute hospitals, and is a key component to the UK End of Life Care strategy [8]. Recent reviews and evaluations of the GSF have noted that this framework assists co-ordination within primary care teams. These reviews have also noted that the delivery of palliative care within community settings is dependent on good team relationships, leadership and robust processes, and all quality measures must monitor change in patient care as well as system change [8-10].

The Palliative Care Register is one dimension of the GSF. This is a system designed to identify and assess patients in need of a palliative care approach, and to proactively plan their care. The key components of the introduction of a register includes: staff training; systems to maintain the register; regular multidisciplinary meetings to assist co-ordinated and anticipatory care, and review of care following death. The British Medical Association has recognised that there are considerable benefits in attempting to identify the point at which an illness becomes advanced or ‘end stage’ in order to mobilise best care for patients, and address their likely health and social care needs and those of their families [11]. In 2009 an audit of their use indicated that 27% of all deaths were included on palliative care registers. Based on these findings, the audit report recommended that teams need more help to identify and predict which people may be nearing the end of life – particularly those who do not have cancer [8].

2.1.1.2 Marie Curie Delivering Choice Programme

Working with the NHS and social services, the Marie Curie Delivering Choice Programme aims to develop patient-centred, 24-hour service models that offer quality, equitable care for palliative care patients and offer choice regarding place of care and of death. Independent evaluations of their programmes have demonstrated that these interventions are associated with an increase in home deaths, as well as a corresponding decrease in hospital deaths, when compared with previous years. This shows that a more strategic use of local services can transform care at the end of life [12].

2.1.1.3 Macmillan GP Facilitators

In recognition of the need to support the care of patients with life-limiting diseases at home Macmillan Cancer Support and the Royal College of General Practitioners piloted the concept of GP Facilitators in palliative care in the 1990’s. Macmillan GPs, who work two sessions a week in this role, have traditionally acted as change agents within their locality in the area of primary palliative care and are encouraged to develop their roles in leadership, strategy, service redesign and communication [13]. In 2009 there were 120 Macmillan GPs employed throughout the UK - nine of these in Northern Ireland. Although this service was initially developed to provide education and support to staff caring for patients with cancer, it has since extended to all patients with palliative care needs. Macmillan has developed a range of resources for patients and professionals, including a ‘GP and out of hours resource pack’. Macmillan have also funded community-based palliative care initiatives for older people, to enable them be cared for and die in their own home [14].

2.1.1.4 Electronic palliative care summary, NHS Scotland

The electronic Palliative Care Summary (ePCS) builds on the Emergency Care Summary GSF Scotland projects. The Emergency Care Summary is an electronic patient record, enabling NHS health care staff to access important information about medicines and allergies when treating patients, and can be accessed by emergency and out of hours (OOH) services.

The ePCS will, with patient/carer consent, allow automatic twice-daily updates of information pertaining to palliative care, to be sent from GP records to a central store, from where they will be available to OOH services, Accident and Emergency Departments and, in the future, to the Scottish Ambulance Service. This will allow vital, structured information to support these patients and their families to be available 24/7 basis. In 2010 the ePCS was in use in over 32% of practices across 11 Health Boards in Scotland [15].

An independent review of the ePCS was published in 2011. This review noted that most GPs were using the ePCS for cancer patients, and that the patients, carers and health professionals viewed the system positively and believe it offers benefits to all concerned. Some GPs recognised the advantage of completing this form for enhancing overall communications. The difficulties they encountered related to knowing when it was appropriate to broach the subject of completing the ePCS with their patients, particularly those with non-cancer diagnosis. The recommendations included further training and involvement of community nurses in the process [16]. As well as establishing a formal system to communicate electronically with regard to the palliative care needs of patients, the ePCS has also facilitated general practices to build up anticipatory care plans for patients, which may include reference to the:

- Medical diagnoses as agreed between GP and patient.
- Patient and carer understanding of diagnosis and prognosis.
- Patient wishes on preferred place of care and also resuscitation.
- Information on medication and equipment left in the patient's home [17].

2.1.2 Other developments in the United Kingdom

2.1.2.1 Dying Matters Coalition

The Dying Matters Coalition was established in 2009 and set up by the UK National Council for Palliative Care to promote public awareness of dying, death and bereavement in the UK. As part of their work programme, they introduced a pilot project to support GPs in their initial discussion about patient wishes when the subjects of death, dying and bereavement arise. They held workshops and communication training for GPs, and also involved them in the development of communication materials to support conversations. The evaluation of this pilot project reported that these initiatives enhanced GP's confidence and their ability to have difficult conversations regarding end of life matters. There was also an increase in the number of patients who were able to communicate openly about their needs and preferences at end of life [18]. Based on the findings of this pilot project in 2011, the Dying Matters Coalition launched a national campaign '*Find Your 1%*' to encourage GPs to deliver quality end of life care. As part of the campaign they have developed a website with tool kits and resources under the following headings: providing a good death; how to identify patients at the end of life; having the conversation; how to help your patients plan; supporting carers to cope [19].

2.1.2.2 The Kings Fund

As part of an enquiry into the quality of general practice in England, the Kings Fund focused on the role of general practice in end of life care. In their report (published in 2010) they outlined the following 'markers' to ensure that GPs can provide end of life care through the total patient care pathway

- A strategic plan for end of life care.
- Mechanisms for identifying patients approaching the end of life.
- Mechanisms for assessing and recording individuals needs and preferences in relation to end of life care.
- Training for staff involved in discussing end of life issues.
- Access to appropriate medication.
- Needs assessments for carers and relatives.
- Effective discharge process to enable timely discharge [20].

2.1.2.3 Palliative care funding review

An independent review of the funding of dedicated palliative care for adults and children in England on behalf of the Secretary of State for Health was published in 2011. The recommendations of the report propose a new model of funding for patients with palliative care needs to assist in the equity of provision in this area of care [21].

2.2 Australia

A framework for palliative care service planning was developed by Palliative Care Australia (2003). It outlined the role of primary palliative care, and is explicit about the need for primary care staff to have further education to deliver a palliative care approach [22]. As a result of the project '*Supporting Primary Care Providers in Palliative Care*' , which took place in 2006, a range of resources and fact sheets were developed to assist primary health care professionals in this aspect of their work [23]. In addition, a study published in 2008 reported that case conferencing between GPs and palliative care services can improve quality of life for patients [24].

The 2010 Australian National Palliative Care Strategy states that the scope of palliative care extends to the care offered through primary care providers in a variety of settings [25].

The Australian Government Department of Health and Ageing has funded a palliative care knowledge network called 'CareSearch' (www.caresearch.com.au). This web based resource has sections for GPs and community nurses, as well as a section for patients and families [26]. This resource is one mechanism to address some of the systemic barriers to the routine provision of palliative care in primary care settings that still exist in Australia [27].

2.3 Canada

The Canadian Pallium Project was established in 2000. The purpose of this project was, through collaborative and co-operative methods, to extend palliative expertise and resources in the context of an expansive and resource-constrained country. Over the past decade this project has been recognized as a strategic mechanism for facilitating improved primary care supports in service delivery to those who are seriously ill and dying.

The Pallium Project has successfully enabled collaboration between key stakeholders throughout Canada to build 'Hospice Palliative Care' capacity. This has been achieved through the development of practice resources and action research projects to build capacity in the area of palliative care in community-based settings [28].

2.4 WHO Collaborating Centre for Public Health Palliative Care

In April 2011, the WHO Collaborating Centre for Public Health Palliative Care Programmes – Catalan Institute of Oncology, produced a report on the design, implementation and evaluation of palliative care programmes and services with a public health perspective. This report provides direction for the development of such programmes, and gives specific guidance as to how general palliative care measures can be introduced as a component of primary care services. The report suggests how to define the model of care based on the multidimensional palliative care needs of the patients and families. It recommends the introduction of a number of measures, and suggests using an adapted version of the GSF to assist in defining the patients requiring a palliative approach to care [29].

2.5. Primary palliative care research

2.5.1

An international Primary Palliative Care Research Group was established in 2005. This group comprises of GPs, primary care practitioners and researchers from a range of disciplines representing Australia, Canada, South Africa and Europe. The objectives of this group include; advocating for improved recognition of the role of primary care in the delivery of palliative care; encouraging researchers to present their work; fostering greater international collaboration; and supporting the development of palliative care in developing countries [30]. Arising from the work of this group, in 2011 the European Association of Palliative Care agreed to form a Taskforce on Primary and Community Palliative Care. Also in 2011 WONCA (the world general practice and primary care body) announced the establishment of a Cancer and Palliative care special interest group [31].

2.5.2

In 2011, a review article in Palliative Medicine focused on GP – patient communication. This article noted that the perceived barrier for good communication related to the availability of GPs, as well as the ambivalence from both patient and GP towards discussing bad prognoses [32]. In considering how to improve generalist end of life care, Shipman et al noted that more evidence is needed to define models of good practice, along with greater commitment in the provision of education and training [33].

2.5.3

A qualitative study based in Cardiff (2010) explored information exchange and communication issues with regard to GPs working out of hours and palliative care.

This research concluded that OOH services need to be more informed about the palliative care patients they may be called to see. This study acknowledged deficits and difficulties for GPs working out of hours with regard to access to palliative medication, and the need for specific information on prescription protocols for palliative medication [34].

2.5.4

A further qualitative study, from a nursing perspective (2010), explored how different groups of community nurses understand their own and each other's role with regard to the delivery of community palliative care from the perspective of best practices described in the GSF. This study noted the dearth of research establishing how community nurses perceive their responsibilities in palliative care. This study recommended better integration of the different types of community nursing, so as to draw as effectively on all their skills and knowledge [35].

2.5.5

In 2011 Gott et al, reported on the perspectives of health care staff (including primary care staff) in England and New Zealand on the meaning and remit of palliative care. They concluded that these countries health care policies on universal palliative care provision, do not easily translate into service delivery and individual clinical practice. The authors have recommended more work to explore and determine the value of different models of organisation and service provision that empower 'generalists' to provide palliative care. In relation to consistency in language and terminology, they observed that the lead should come from policy makers for clarity of definitions used in this sector [36].

2. 6. Summary

- Many developments in primary palliative care have emerged from local practice, with support of voluntary organisations. These have subsequently been supported by national policy and health service funding streams.
- In response to identified need, supportive frameworks for professionals and health delivery have been developed and continue to emerge, to assist in the delivery of primary palliative care.
- Access to comprehensive 24/7 community-based services is seen as pivotal in terms of delivering consistent and equitable palliative care in primary care settings.
- Challenges with regard to role recognition, communication and symptom control are common, and reflect the need for on-going education and training, as well as ease of access to resources, to support patient care.
- Evaluation of all primary palliative care programmes is beneficial to determine that any service enhancement will lead to better patient care.

CHAPTER 3

Irish Context

Chapter 3
Irish context

This chapter sets out the changing demographics in relation to people that are living with advancing life-limiting diseases in Ireland, and the consequent implications for the need for primary care services to have structured supports for responding to palliative care needs of their patients. It also describes the existing and emerging health service delivery and policy developments in Ireland that have relevance for delivery of primary palliative care.

3.1. Implications of changing demographics

3.1.1 Irish mortality rates

When considering the role of and requirement of palliative care in primary care settings, it is helpful to get a picture of how and where people die in Ireland as well as anticipating the shifts in current trends.

Every year approximately 27,000 people die in Ireland, 77% of these deaths are in the over 65 age group, and about 22,500 follow a period of chronic illness [37]. In Ireland each GP could expect between 10 and 20[1] deaths per year in their practice. As the majority of care (90%) of patients in their last year of life is provided for in the community, predominantly by GPs and members of primary care teams [38], health care staff in the community are pivotal in supporting people that are living with progressing life-limiting disease.

The projected demographic changes, relating to life expectancy and ageing profiles, are important considerations in health care delivery. The changes in life expectancy of the Irish population, which are partly due to the success of health care interventions, have resulted in many people now living longer with co-morbidities and chronic diseases. By 2036, it is anticipated that 25% of the population will be over 65, whereas in 2006 the proportion of over people over 65 was just 11% [39, 40]. The National Cancer Registry has predicted that the number of cancers diagnosed in Ireland will almost double between 1998 and 2020 [41].

In relation to cause of death, it is worth noting that in 2010; nearly 56% of deaths in Ireland are caused by respiratory and cardiovascular disease, with 29% of deaths relating to cancer (Figure 1) [37] .

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[1] This figure is based on the number of GPs in Ireland and average number of deaths per annum. The number will vary depending on size and demographics of each general practice.

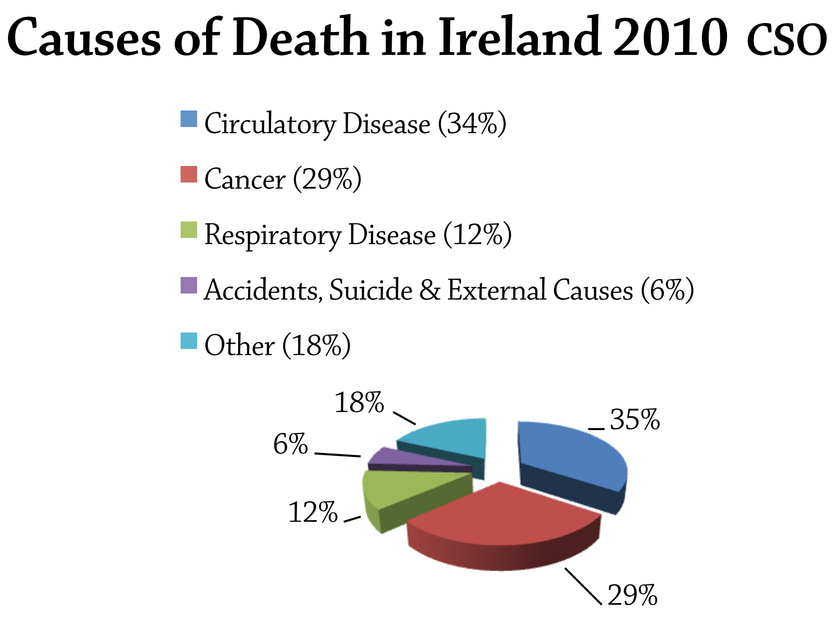

Figure 1: Causes of death in 2010 CSO

While the majority of deaths take place in acute hospitals (48%), there are still a high proportion of deaths taking place in the community, as 25% of people die in the home, and 20% of deaths take place in long stay facilities [42]. As such GPs and community health professionals would be involved in delivering a substantial amount of the care of these people at end of life.

The latest figures available for 2010 indicated that 27,144 people died in Ireland [37]. Information from the HSE, arising from the Minimum Dataset: Specialist Palliative Care in the Community, reported that 23% (6,188) of the total deaths were in receipt of SPC. A total of 2,611 (38%) of these deaths occurred at home 633; (10%) died in a community residential facility; and 645 (10.4%) died in a nursing home [43].

Allowing for the accidents and sudden deaths, it is reasonable to suggest that two-thirds of people who died in community settings with life-limiting disease last year, did not avail of SPC services, and it is expected that this figure is significantly higher for those who died in long stay residential facilities. It is certain that all of these deaths would benefit from palliative approach to their care, and that primary care teams can enhance this aspect of their service delivery by close working relationships with SPC services.

3.1.2 Disease trajectory focus on care in the community

The nature of advancing chronic illness, including chronic obstructive pulmonary disease (COPD), heart failure, dementia and chronic kidney disease, is that the disease trajectory can be unpredictable, with patients experiencing acute exacerbations that can be life-threatening. It is increasingly being recognised that people at the advanced stage of these diseases, as with those with advanced cancer, benefit from a palliative care approach [44].

In 2008 the HSE reported that 80% of GP consultations relate to chronic illness [39]. In line with current health care policy, it is anticipated that there will be even greater emphasis on the delivery of care to patients with life-limiting disease in community settings. This care will be supported with the final roll-out and consolidation of the HSE Primary Care Teams and the community-based Health and Social Care Networks (HSCN) [39, 45], the latter group supporting delivery of specialist care, including SPC.

3.2 Policy and strategy

3.2.1 Primary care

Primary care is usually the first point of contact that people have with the health and personal social services. The DoHC Health Strategy [46] published in 2001 set out a new direction for primary care as the central focus of the delivery of health and personal social services in Ireland. It sought to promote a team-based approach to community-based service provision, and also aimed to build capacity in primary care and contribute to sustainable health and social development.

As part of the DoHC's primary care strategy [1] which was also published in 2001, multi-disciplinary primary care teams were designed to provide access to a wide range of health and personal social services by a local community of up to 10,000 people. It was envisaged that primary care teams would be linked together by HSCN. Each network will support four to five primary care teams and will include a shared pool of specialised resources [47].

By the end of 2010 the HSE reported that there were 350 primary care teams in operation, providing services for almost 2.8 million people [48]. The total target of 527 functioning teams has been set for completion in the HSE 2011 service plan [45]. Related targets set for 2011 include enhanced service integration through the development of 134 HSCNs; the alignment of specialist and care group services; and implementing general principles of referral and shared care arrangements between the above groups [49]. SPC home care teams are one of the several specialist care groups that are located in HSCNs [1]. It should be noted that the existing primary care teams are functioning at varying levels, and some are at early stages of activity.

There are approximately 2,500 GPs working in Ireland and there is increasing engagement between GP practices and community-based health care professionals as the primary care teams become more established. The public health nursing service assesses the palliative care nursing needs of patients. They also co-ordinate the nursing service delivered to the patient in the community linking hospital, community and specialist services as appropriate.

3.2.2 Palliative care

In 2001, the publication of the report of the National Advisory Committee of Palliative Care (NACPC) heralded significant direction and vision for the development of palliative care services in Ireland. This report placed particular emphasis on SPC teams in the community, in hospitals and the need for specialist inpatient units in each region of the country. Although many of its recommendations have been delivered, there are still deficits and regional variations in SPC service provision.

Whilst the NACPC report focused on the development of palliative care as a specialist service, the report made a number of salient remarks signalling the management of the care of patients with advanced disease in the community. It stressed that clinical responsibility for the patient at all times remains with the GP, and that the GP and community nursing services are the main providers of ‘general palliative care’. It clarified that referral to SPC services in the community would be appropriate for complex symptom management or psychosocial issues and that the SPC nurse should act as a resource and provide support and education to primary care health professionals. It also outlined the need for a telephone advisory service to be established by SPC to provide 24-hour access to specialist advice [2].

Although there has been a significant investment in SPC services in recent years, only a few SPC teams meet the staffing recommendations in the 2001 DoHC report [50]. The regional disparity in the provision of hospice and palliative care services is still evident, particularly in the Midlands, North East and South East of the country, where there are no dedicated hospices/specialist inpatient units. There are also staffing deficits in several of the community-based SPC services from a medical, nursing and allied health professionals.

The requisite for primary care to incorporate a palliative approach to the care of people with all life-limiting disease has been documented and outlined in the DoHC primary care strategy [1] and the NACPC report [2]. The need to reduce inequalities in health care provision between population groups including palliative and end of life care has also been recognised in the 2009 HSE Service plan [51].

3.3 Service governance and support

3.3.1 HSE National Clinical Programmes

In 2010 the HSE introduced the Integrated Services Programme, which included a focus on effective working relationships across services, and the development of National Clinical Programmes. The latter were established to support clinical governance and integrated services, and to standardise service delivery by establishing national clinical guidelines in over 20 clinical care areas, including both Primary Care and Palliative Care [45, 52]. The relevance of their aims to the PPC programme is illustrated below:

Aim - Palliative Care National Clinical Programme

- To ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs, regardless of care setting or diagnosis [53].

Aim - Primary Care National Clinical Programme

- All patients with major chronic diseases to be managed in an integrated seamless fashion, allowing patients dignity and ability to stay in their communities.
- Maintain patients in the community and avoid costly hospital admissions by effective chronic disease management in primary care [52].

3.3.2 National Cancer Control Programme

The National Cancer Control Programme continues to develop and integrate cancer services nationally. A recent initiative, is the new Cancer Education Programme for Nurses working in Primary Care, which emphasises the development of services in the community and integration between designated cancer centres and local services. This education programme was developed following research carried out with nurses, which identified their education needs in this area. It is anticipated that this will lead to better communication and enhance the joint approach required to support the sharing of patient care between the cancer centre and the community/ primary care setting [54].

3.3.3 All Ireland Institute of Hospice and Palliative care

The All Ireland Institute of Hospice and Palliative Care is an all island organisation. It comprises of a consortium of twelve hospices and universities, all working 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. It was formally established in Oct 2010, and aims to secure best care for those approaching end of life by making meaningful, evidence-based contributions to the policy environment. This organisation will have a key role in supporting necessary frameworks and developments to underpin the PPC programme [55].

3.3.4 Health Information and Quality Authority (HIQA)

From a standards and governance perspective, the National Quality Standards for Residential Care for Settings for Older People in Ireland, published by HIQA, has a specific standard on End of Life Care [56]. Furthermore, in 2010 HIQA undertook a public consultation on the development of National Standards for Safer Better Healthcare and these are due for publication shortly. It is anticipated that these standards will further underpin the delivery of safe care at end of life in all care settings [57].

3.3.5 Record management

The HSE has acknowledged the need to co-ordinate and standardise information flow and healthcare records management in primary care settings with a commitment in its 2011 service plan [45] to review the code of practice for health care record management [58], and adapt this document for non-acute services.

3.4 Service provision and developing models

SPC teams throughout the country work with their colleagues in primary care settings to deliver care to patients with advancing progressive diseases. They are also available to provide advice, information and education to their colleagues to support the delivery of palliative care to those patients who may not require their clinical input [2]. Community-based SPC teams throughout the country are engaging at various levels with their local primary care teams to support them in their work. The level of interface can range from local education responses, telephone queries, joint case conferences and shared assessments.

From a primary care perspective, there are some evolving models and service initiatives that are responding to the needs of people who are living with an advancing life-limiting disease at home. Ensuring that these initiatives are linked with community-based SPC services will assist in the level of expertise available to these patients and create opportunities for more co-ordinated care.

There appears to be some regional variation in the degree of formal and informal contact between the primary care teams and the community-based SPC personnel, as well as differences in the scope of tasks that are undertaken. It is anticipated that the work of the HSE clinical programmes will seek to address these inconsistencies.

A number of the developing models are described below, which will further illustrate the foundations and potential to build and establish formal primary palliative care responses. It is important to note that these examples are indicative of the potential for practice, rather than an exhaustive list of service responses in this area.

3.4.1 Milford Care Centre (Limerick)

As a result of the Milford Care Centre Hospice at Home Service, (launched in January 2010), a number of initiatives have directly benefited the delivery of palliative care by primary care teams including:

- The development of a ‘Nursing Communication Guideline for the Management of Palliative Patients in the Community’.
- The development of an evidence-based communications skills training programme for health care professionals in respect of palliative care and end of life issues.
- Piloting a Health Promoting Palliative Care Project in Limerick City, aimed at working with communities to enhance capacity to deal with issues of death, dying, loss and grief [59].

3.4.2 Palliative Medicine Information Service, Our Lady’s Hospice (Dublin)

The Palliative Medicines Information service is a national telephone and email advice service providing information for health professionals on all aspects of drug therapy used in palliative care. This is a 2 year, pilot service based in the Pharmacy Department at Our Lady’s Hospice which commenced in Sept 2010. Enquiries to the service must be medicines related; linked to the treatment and symptom control of patients with life-limiting illnesses; and are accepted from healthcare professionals working with patients with palliative care needs [60].

3.4.3 Community Pharmacy Initiatives

Several SPC services in Ireland have worked collaboratively with pharmacists in their locality to facilitate access to palliative medicines for patients with life-limiting disease. One such initiative in the North East is described below

The North East Palliative Care Community Pharmacy Network is an initiative developed by SPC services and primary care HSE in consultation with community pharmacists in the North East. The purpose of this network is to provide multidisciplinary palliative education and training supports for pharmacists working in the community as well as timely access to essential palliative drugs for patients cared for at home. The network consists of thirteen pharmacies spread across counties Cavan, Louth, Meath and Monaghan. Each pharmacy network holds an approved stock of essential palliative medicines and has a nominated pharmacist with training in palliative care. This project is modelled on a similar scheme in Scotland and an evaluation of this initiative is pending [61].

3.4.4 Community Intervention Teams

A community intervention team (CIT) is a team of health professionals (general nurses, public health nurses, home help services) which can be accessed by participating GPs and emergency departments. This staffing complement is spread over a seven-day service, usually between the core hours of 8am and 10pm. CITs have successfully managed a range of illnesses, including those who require palliative interventions. The purpose of the CIT service is to provide a rapid response to patients in order to

- Avoid unnecessary referrals to emergency departments and/or hospitals;
- Facilitate delivery of care in the community setting.
- Enable early discharge from hospital.

In 2005, four Community Intervention Teams were established in Dublin North, Dublin South, Limerick and Cork. In early 2010 two additional CITs were set up in Clare and North Tipperary, along with expansion of the original four teams. New teams are planned for Carlow/Kilkenny, Galway, Mayo and Donegal. It is expected that, over time, all HSE areas will have access to a CIT [62].

A CIT service based in Dublin has reported that they are increasingly responding to referrals for patients with palliative needs, which has enabled people to be discharged home to die, and this trend is supported in an internal HSE evaluation of the CIT service. This unpublished report noted the overlap between generic community services and community SPC services, and reported that over a four month period 17% of referrals were for patients with palliative care needs [63].

3.4.5 Out of Hours Services

Out of hours (OOH) care is defined by the HSE as the provision of urgent GP services to patients of participating practices outside normal surgery hours, i.e. between 6pm and 8 am Monday - Friday and for the 24 hour period on Saturdays, Sundays and Bank Holidays [64]. In 2010 the HSE published a national review of the GP OOH services in Ireland, which made thirteen recommendations to strengthen and standardise the GP OOH service across the country. This report also referenced the need for greater out of hours availability of palliative care services and for access to the history of those patients with palliative care needs [64].

One OOH service provider (Care Doc) has reported that between 5% and 10% of calls received by their OOH service relate to patients with palliative care needs, and indicated that the service would benefit from a standardised electronic hand-over form. This would facilitate up-to-date information on patients requiring palliative care and any anticipatory needs [65].

A number of OOH service providers are developing links with the SPC teams, to provide a more structured approach to their communication channels, i.e., provision of telephone advisory support service from 5pm to 9am.

3.4.6 Advanced nurse practitioners

Advanced nursing is carried out by autonomous, experienced practitioners who are competent, accountable and responsible for their own practice. They are required to be highly experienced in clinical practice and are educated to master's degree level. An advanced nurse practitioner will demonstrate the core competencies of autonomy and expertise in clinical practice, clinical leadership and initiate research in his/her specialist area [66]. There are a number of advanced nurse practitioner posts in primary care and palliative care. The SPC advanced nurse practitioner in Our Lady's Hospice Harold's Cross, Dublin, provides a resource to community health care professionals who have palliative care queries. This role extends to close and collaborative work with relevant GP's, Public Health Nurses (PHN), community-based occupational therapists, physiotherapists and pharmacists with the aim to positively influencing patient care. This emerging role has significant potential to support the care of people with progressive life-limiting diseases in community settings.

3.4.7 Nurse prescribing

Since 2007 many nurses in Ireland have had the opportunity to receive training and qualifications to prescribe within their own chosen speciality. In both primary care and palliative care a number of nurses have successfully graduated as nurse prescribers. This developing service yields potential to enhance the access to medications for people with advancing progressive illness in the community [67]. A number of SPC clinical nurse specialists are completing their training in nurse prescribing, and this service will support developments in primary palliative care.

3.4.8 Healthlink

The national Healthlink project provides a web-based messaging service which allows the secure transmission of clinical patient information between hospitals, health care agencies and GPs. This project has been in operation since 1995 and has developed considerably since that time to its current status as national messaging broker [68]. The HSE, via Healthlink, is involved in a number of initiatives that encourage and facilitate electronic communications between primary, secondary and tertiary health providers. These include:

- The development, by the National Cancer Control Programme, of national electronic cancer referral forms with interface to GP software systems [69].
- The introduction of guidelines and a template for GP referral to the primary care team and from primary care to acute services. This can then be populated by GP software systems [70, 71].

3.4.9 The Irish Hospice Foundation

The IHF is a national charity, which focuses its work on building hospice philosophy in all care settings. It has a number of projects and programmes that will benefit the delivery of palliative care within primary care settings, including:

- The Palliative Care for All Programme, which is currently supporting the development of palliative care for people with advanced respiratory disease, dementia and heart failure via three action research projects, all of which have a primary care dimension [44].
- The Hospice Friendly Hospital Programme, which extends to community hospital and nursing home settings [72].
- The Forum on End of Life, which encourages public debate and awareness of the wider issues surrounding death, dying and bereavement and supports mechanisms for citizens to discuss and plan their future health needs [73].
- The on-going enhancement of bereavement supports and services, including training in bereavement and loss; education courses up to postgraduate level; and a bereavement information and networking service.

3.5 Recent Irish research

3.5.1

In 2010 a SPC registrar surveyed 414 GPs in HSE South on their practices and their views of mechanisms used to transfer information to their local OOHs co-operative regarding patient's end-of-life care needs. A 52% response rate was achieved. This study found that 82% of the GP respondents do not routinely transfer information on their palliative patients to the OOHs co-operative in their area. The primary reason given for lack of routine transfer was that GPs make themselves available when a patient is critically ill. Significantly, 96% reported that they would value a standardised means of transferring information to OOH providers. This research, which is awaiting publication, outlined other barriers to provision of end-of-life care in an out of hours context, including no anticipatory plan, difficulty caring for the unknown, time pressure and the lack of clarity as to who to contact in an emergency [74].

3.5.2

In 2008, in the Mid-West of Ireland, PHNs were invited as part of a postgraduate study to participate in a validated questionnaire to determine their level of generalist palliative care knowledge. The results indicate that they are reasonably well informed, but as found in similar research worldwide, the analysis revealed deficits in knowledge with regard to pain and symptom control. The recommendations from this research include more specific assessment and planning of education for PHNs in the area of palliative care [75].

3.6 Summary

- The projected demographic changes, advances in chronic disease management and increasing emphasis on provision of care in primary care settings will result in more people with advancing life-limiting disease being cared for in the community.

- Irish policy supports the provision of palliative care by health care professionals working in primary care settings.

- There have been some local efforts to support a palliative approach to care in primary care settings, despite the absence of a national service framework. These developments, along with new governance and organisational support structures, provide a basis for formalising future developments.

- Further studies would assist in highlighting the skill gaps, education needs and role clarification.

CHAPTER 4

Views of Irish health care professionals

Chapter 4

Views of Irish health care professionals

4.1 Gathering views

One of the key objectives of the PPC programme was to gather the views of health care professionals working in primary care with regard to how a palliative approach to care could be enhanced in community settings. It was therefore important to establish the level of awareness, professional competencies and existing practices which would inform and assist in prioritising future developments in primary palliative care. Consultation meetings and surveying primary care staff were the principal methods used to gather and gauge the views of Irish health care professionals. This chapter discusses the significant themes that emerged from this process.

The five consultation meetings were planned with the input of the members of the steering committee, as well as the emerging international developments and literature in this area. The themes that arose from the consultation meetings were instructive in the compilation of the questionnaire, the design of which also drew on the skills and experience of the steering committee, as well as input from individuals and professional groups with a particular interest in this area (Figure 2).

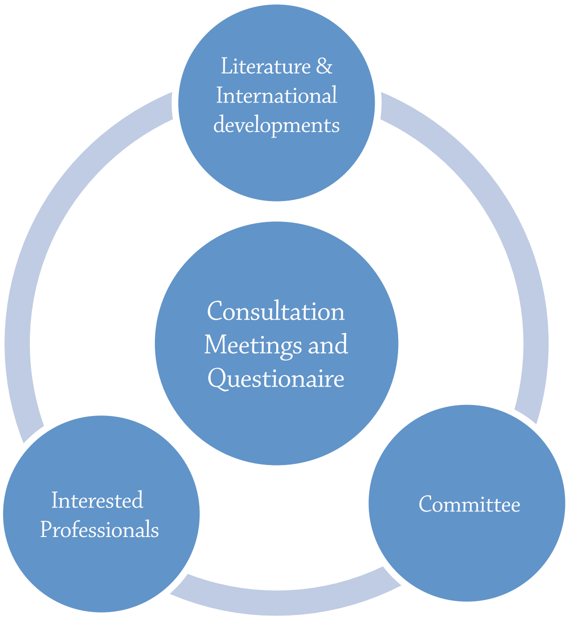

Figure 2: Indicates methods used for gathering the views of Irish health care professionals

Full details of methodology used for the consultation meetings and the questionnaire are outlined in Appendix 4, and this appendix also gives the complete results of the questionnaire. In total 123 community-based health care professionals participated in the consultation meetings, and 182 questionnaires were returned (27% response rate).

4.2 Themes

In order to respond to the primary palliative care needs of those people with life-limiting disease and their families, eight aspects of service development were identified from the analysis of the data from the consultation meetings and the questionnaire as follows:

- Enhancing communication skills of health care professionals.
- Strenghtening information transfer systems between health care professionals.
- Improving services outside of traditional working hours.
- Role clarity and resourcing.
- Developing professional competencies.
- Clarifying the role of palliative care for people with diseases other than cancer.
- Improving access to specialist equipment.
- Examining the response of the private sector.

These are visually demonstrated in Figure 3 and will each be discussed in detail.

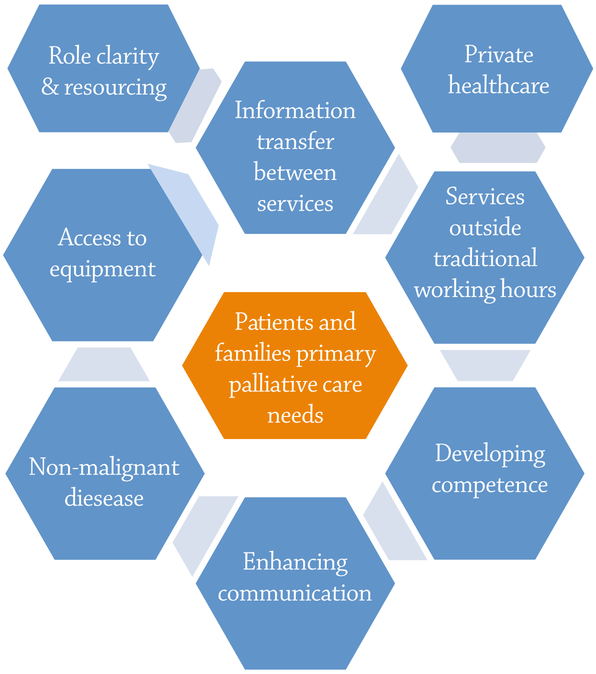

Figure 3: Aspects of service development identified from analysis of data from the consultation meetings and questionnaire

4.2.1 Enhancing communication skills of health care professionals

A predominant theme from the consultation meetings was the need for patients with advanced life-limiting disease and their families to receive consistent, sensitive and timely communication from all those involved in their care. The quotes below are telling reminders that full cognisance must be made of the need for patients to have several opportunities to receive the information they require so that they are aware of their prognosis and what to expect in the future.

> *'Even where diagnosis is adequately explained there is a need to be mindful of peoples level of comprehensions, people just hear one word and shut down, are absolutely terrified...'*
>
> *'No matter what you say it may be misinterpreted.... Consistent explanation at several points may be needed.'*
>
> *'It would be good to have a record book for patients like .... An information resource that would be personalised to the patient.'*
>
> *'I have made several home visits where it was obvious that the patient was in fact near death, yet neither the patient nor the family seemed to be aware of the gravity of the situation'*

The questionnaire analysis further highlighted the challenge that respondents have in discussing psychosocial issues with these patients, with just five out of ten participants indicating that they 'usually to always' felt competent in discussing psychosocial issues with patients with advanced life-limiting disease (52%, n = 149) and discussing the impact of bereavement with those who have been bereaved (60%, n = 149). There was even less confidence reported by respondents in having conversations about prognosis with patients with life-limiting disease. Just 40% (n=73) of the respondents indicated they 'always or usually' felt competent in this area. Figure 4 compares their competency in discussing prognosis with patients with advanced non-malignant disease and those with advanced cancer and this suggests that the complexity does not vary according to the presence of malignant or non-malignant disease.

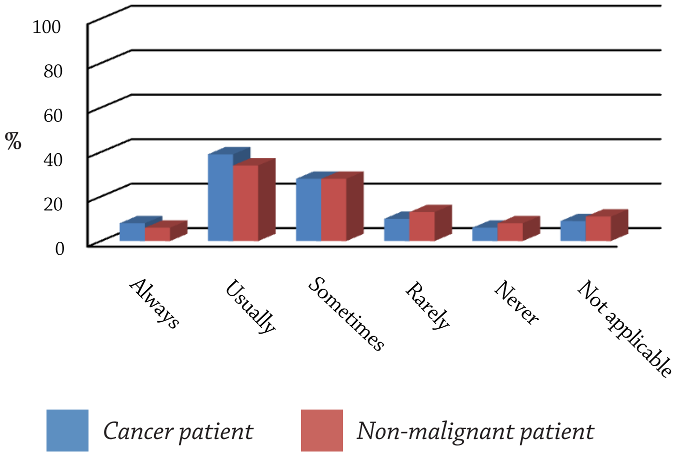

Figure 4: Bar chart comparing participants' responses (N=182) on whether they feel competent in discussing a prognosis with a patient with advanced cancer or an advanced non-malignant disease.

Not surprisingly there was strong interest in training and guidelines in skills to assist in end of life communications (43%, n=77); on how to break bad news (31%, n=56); and training in principles of bereavement support (44%, n=79).

Several practical initiatives were also identified to enhance communication with patients and families, including psychological support for patients and families (73%, n=129); the appointment of a health care professional to be nominated as key worker for patient nearing the end of life (66%, n=116); having a summary of patient notes to be available in the home setting (63% n=109); generation of personalised service contacts (55%, n= 95) and a regional service directory (44%, n=77). These are detailed in Appendix 4, Q 20 and 21.

> *'Better communication across service delivery boundaries. Named persons at key points who can be accessed for advice/information.'*

4.2.2 Strengthen information transfer systems between health care professionals

During the consultation meetings, there were several references to the need for improved mechanisms to assist the information transfer between primary, secondary and tertiary services, so that patient and family care could be enhanced. These are illustrated in the quotes below:

> *'If diagnosis of cancer is made in hospital there is delay in feeding this back to the GP. Patients families often attend the GP to discuss the diagnosis expecting him/her to know….'*

> *'I sometimes feel inadequate and unable to fulfil my role properly due to lack of information from hospitals.'* GP

In relation to nursing home care it was suggested that it would be helpful if there was greater planning and specific instruction prepared in the event of a patient becoming unwell, and this could prevent unnecessary admissions.

> *'Nursing home's first response is to call an ambulance for an unwell or dying patient and this needs to be addressed, possibly through planning with patients, families, staff leaving written instruction.'*

Satisfaction with methods used in information transfer between services was further explored in the questionnaire. It is noteworthy that health care professionals reported that they were more informed from secondary or tertiary care if a patient of theirs with cancer is at an advanced stage of their disease, when compared with patients with non-malignant disease. Similarly, more participants felt that they were 'usually or always' informed if the prognosis had been discussed with patients with advanced cancer (53%, n=98) when compared with their patients with advanced non-malignant life-limiting diseases (26%, n=48). Of particular note, four out of ten respondents reported that they were 'rarely or never' informed if the prognosis had been discussed with patients with advanced life-limiting disease (Figure 5).

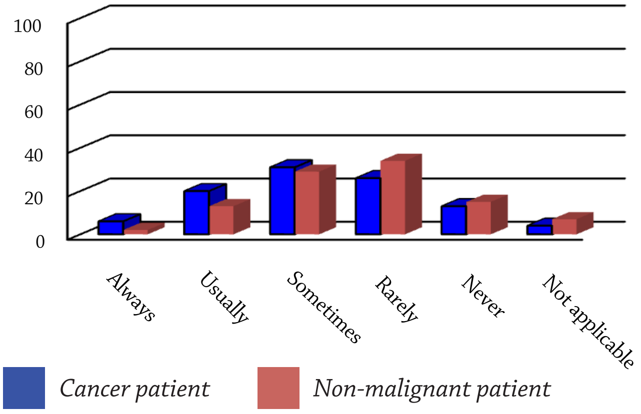

Figure 5: Bar chart comparing participants' responses (N = 182) on whether they are informed if the prognosis has been discussed with patients with advanced cancer or a non-malignant life-limiting disease.

With regard to communication out of hours, the questionnaire sought to elicit how frequently participants informed or updated their OOH services about patients in their care who were currently receiving/required palliative care and more than a third (34%, n=61) said they never informed or updated them. With respect to timely notification when a patient dies in a hospital or hospice setting, just 42% (n =117) of respondents felt that they 'usually or always' received this information in a timely manner, although some did note that hospitals in particular were less likely than hospice providers to notify them, and this could lead to insensitive contact for recently bereaved relatives. More details can be found in Appendix 4, Q 7. The following quote represents the dilemmas that present for community-based health care professionals.

> *'More comprehensive discharge details e.g. are family and patient aware? Do they want to die at home? Notification if patient dies in hospital or hospice so we don't knock on door!! We can provide support if we know of death.'* PHN

This data from the questionnaire analysis would support the view that communication between primary, secondary and tertiary care with regard to the advancing status of a patient's disease is not reliable, and this is more evident for those patients diagnosed with non-malignant disease. In addition, the transfer of up-to-date information from primary care to OOHs service providers, in relation to patients with palliative care needs, does not appear to be routinely considered.

When asked to rate initiatives to enhance information transfer, the development of an electronic communication system between primary, secondary and tertiary services to assist in prompt updates, inform of discharge and or death was selected by eight out of ten respondents (81%, n=141), and 63% (n=109) were in favour of a summary of patient notes to be available in the home setting. To support communication between OOH service providers, 44% (n=23) of GP respondents were in support of the introduction of an electronic communication system. It was encouraging to hear from one respondent about an initiative in a GP practice in Dublin to support identification of patients with life-limiting disease, based on the 'gold standard of care pilot'.

4.2.3 Improving services outside of traditional working hours

Patients with life-limiting disease and families can feel at their most vulnerable at night time or during the weekends, when they cannot access the expertise that is generally available to them during regular working hours. The need to for more comprehensive service provision outside of traditional working hours was identified as a theme from the consultation groups. This related to access to medical, nursing and pharmacy services and advice and information from SPC.

> *'The difficulty in accessing all services outside of traditional working hours for these patients is a problem.'*

> *'OOH locums can be very reluctant to prescribe medication… there can be a reluctance to give opioids at night time.'*

The majority of respondents, 74% (n = 135), reported that they could 'usually/always' access the advice and support of a SPC team when necessary, yet the overwhelming support for the development of a SPC 24 hour telephone service (72%, n=126) and the quotes below indicate the challenges experienced in this area, and that the level of access to SPC is not always satisfactory.

> *'Palliative care team nurses are excellent but out of hours cover is patchy, especially if new problem develops.' GP*

> *'I would hope that palliative care teams are more available out of hours to initiate/review patient's treatment.' GP*

> *'Contacting palliative care consultants and team out of hours is a problem.' GP*

The other highly rated initiatives identified to support patients with palliative care needs outside traditional working hours was an out of hours nursing service 76% (n=133); access to palliative care medications and equipment out of hours 58% (n=99); and access to syringe driver for use by GP and OOHs services 52% (n=89).

4.2.4 Promoting role clarity and resourcing

As with any emerging area of practice, new roles are developing for primary care professionals as they develop their confidence and competence in aspects of palliative care. During the consultation meetings, the requirement for greater clarity of roles between the various health care professionals in the provision of palliative care was expressed, particularly when SPC services become involved in the care of a patient.

> *'I tend to step back when palliative care becomes involved….. I have a sense of being disempowered and de-roled.' GP*

> *'GPs should not be taking over the SPC role – I may have just 2 patients per year on a syringe driver and therefore I am not skilled in using them and shouldn't be expected to play that role.'*

This was further elaborated on by comments in questionnaire returns:

> *'The hospice and home care system is excellent and I fully support it with enthusiasm. However as a GP to my patient I am still in a position of providing on-going supportive care to their immediate and extended families all of whom I know very well. This important aspect of a caring general practice has been side-lined by the total care of a palliative care system.'*

> *'Would like to see improved communication with primary care and hospice team in caring for clients/families at home with care planning and role definition.' Nurse*

The GPs respondents in the questionnaire indicated their commitment in remaining involved in the care of their patients whilst at the same time accessing the support and advice from SPC services at critical times, and welcomed opportunities for closer working relationships.

> *'GP should still be involved as communicator between hospice and patient and also as social support.' GP*

> *'Joint consultations with the palliative care team could be useful.' GP*

> *'I feel it would be beneficial for palliative care to integrate within primary care rather than separate service in providing holistic care for patients.' GP*

Several of the participants welcomed the fact that the consultation meetings provided them with the opportunity to meet members of the SPC team and to hear about the extent of the service they provided. Equally, members of the SPC team found it helpful to hear how primary care teams are supporting people with advanced life-limiting disease and what issues present for them. For many, the consultation meetings were the first forum for such dialogue and exchange, and further opportunities for relationship building were encouraged.

The responses in the questionnaire have highlighted examples of how SPC and primary care teams already collaborate:

> *'We access the syringe driver through palliative care team – last year we sought a member of palliative care team to educate our practice and they instantly updated us.' GP*

> *'I am hugely impressed with our local palliative care team – we have regular contact with them and have a close relationship which benefits staff and patients.' GP*

Despite evidence of collaboration from some, clarification and direction was sought from several respondents with regard to what detail can be discussed with regard to patient's prognosis, and clarity regarding pathways of care.

> *'Who makes the decision when the transition or introduction of a palliative approach is required?'*

> *'We need defined care pathway guidelines so everyone is aware of what to do and how to access specialist services etc.'*

When considering what would give confidence and direction in their provision of primary palliative care, significant value was attached to access to specialist advice with 72% (n=126) of the respondents identifying the development of a SPC 24 hour telephone service as a useful initiative. The development of guidance on documentation on medications and their compatibility (51%, n=86) and provision of a checklist that would prompt end of life care needs assessment (47%, n=82) was also highly rated, along with a number of education initiatives – these are discussed in paragraph **4.2.5.** and are detailed in full in Appendix 4 under responses to Q 21.

Not surprisingly, some of the feedback referred to the current resource challenges in providing more flexible, accessible and patient centred systems, that will support care delivery for those at home with advancing life-limiting illness. These are as highlighted by the quotes below:

> *'Not enough support in community settings for these patients.'*

> *'The main difficulty is of finding the time for domiciliary visits given the heavy day to day load so more resources in manpower would be helpful for GPs to be able to give this time.' GP*

> *'I feel there is a lack of GP support for symptom control in advanced care of chronic illness and reluctance for GPs to do house visits for patients who are house bound. On two occasions in the last month 2 GPs refused to see a patient at home for symptom control.' Nurse*

4.2.5 Developing professional competencies

The gaps in clinical confidence in relation to symptom management and communication at end of life that surfaced during the consultation meetings were further identified in the questionnaire.

> *'As GPs we would like to provide this care to our patients but we need training and support.'*

> *'Would love to be able to provide this service but do not feel I have the necessary skills to do so.' Nurse*

From a list of eleven options, participants were asked to identify four most useful education initiatives, and the responses are fully detailed in Appendix 4. Of note, the most popular education initiative with participants was training in symptom control, with almost two thirds of the sample (n = 119, 65%) endorsing this item. However GP respondents rated education in prescribing in palliative care as their second priority, with nurses indicating that they would value education in the care of imminently dying as their next most valued education request. Figure 6 below illustrates the comparison of the six most popular education preferences from the perspective of community nurses and GPs.

Responding to these identified educational needs can be achieved through formal and informal methods.

4.2.6 Clarifying the role of palliative care for people with diseases other than cancer

During the consultation meetings, there was an acknowledgment that the area of palliative care for diseases such as COPD and advanced heart failure was often overlooked, with the salient observation that this elderly cohort of patients often relies on support from their spouse who may have their own advancing medical issues. The participants also identified the need for training and education to support their work in this area, as demonstrated by the following quotes:

> *'In favour of this for non-malignant disease, although more difficult in these cases to identify those at terminal stage.' GP*

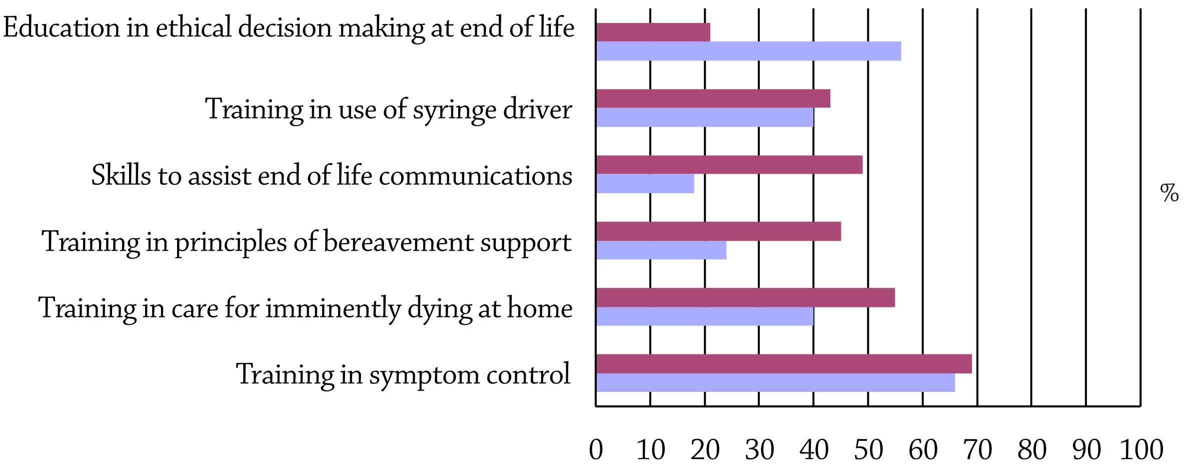

Figure 6: Comparison of the six most popular education preferences from the perspective of community nurses and GPs

> *'As a GP I would like education on how palliative care services would fit into the care of non-cancer patients.'*

The difficulty in broaching conversations on this topic was identified, noting reluctance from both health care professionals and patients:

> *'A non-cancer patient is less likely to ask "how long have I got?"' GP*

> *'Doctors and patients are afraid to talk about death and life expectancy but it is better to do so and be "up front" if the patient wants you to be.' GP*

The questionnaire analysis confirmed the variation in competence levels and additional training needs in the area of palliative care with just over 50% (n=149) of respondents indicating they would 'usually or always' feel competent in discussing the prognosis with patients with either advanced malignant or non-malignant disease (Figure 7), and 40% (n=182) of the respondents requesting further training in principles for non-malignant disease.These are detailed in full in Appendix 4 under Q 19.

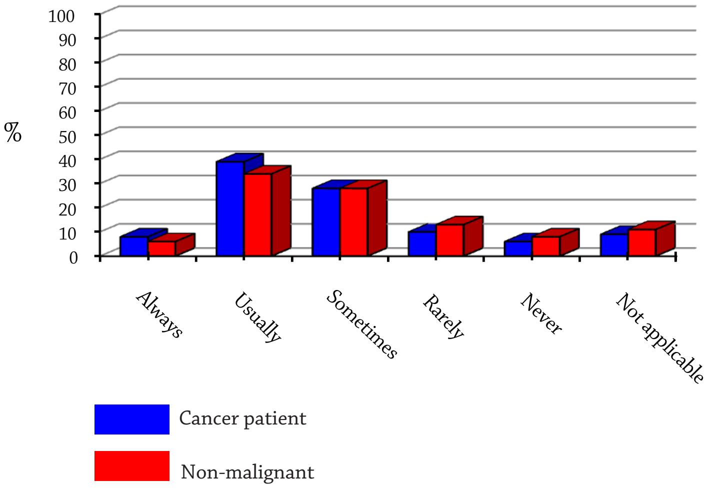

Figure 7: Bar chart comparing participants' responses (N=182) on whether they feel competent in discussing a prognosis with a patient with advanced cancer or an advanced non-malignant disease.

In addition, as outlined earlier in Figures 4 and 5, in the context of information transfer, this cohort of patients have less chance of having the extent of their diagnosis or prognosis communicated to primary care staff, than those patients with cancer. The endorsement of the need for services to ensure that appropriate levels of palliative care are available to those with diseases other than cancer is demonstrated by the following quotes below:

> *'My view is that it is a very important approach to this group of people and their families can find it difficult to accept that their loved one is terminally ill when they don't have 'cancer'.'*

> *'A palliative care approach for this patient group is an essential service much needed in society - needs are very different for each patients illness type.'*

> *'Should be the same as for those with cancer - nursing these clients and families can be difficult without the specialist support.'*

4.2.7 Improving access to specialist equipment and medications

During the consultation meetings, there were frequent examples given of delays and obstacles that present when seeking access to specialised equipment to support the discharge of a person home to die, and although it was suggested more planning could be done to anticipate this need, this is not always possible or practical, as illustrated by this example:

> *'We have encountered difficulties, whereby a patient may either decide suddenly that they wish to go home to die…..and where this requires the provision of certain equipment, such as a profiling bed ….we have problems! Community stores open from 10-12am and 2-4pm Monday to Friday… with no weekend cover…'*

Although 72% (n=108) state that they 'usually or always' could access specialist equipment in a timely manner, the need for more timely access to specialised equipment was rated as important by 87% (n=147), indicating that current access routes could be improved upon.

'I feel the hospice should have their own supply of equipment such as hoists, wheelchairs, cushions, shower commodes to facilitate prompt discharges. A short term loan facility would be good.'

The need for ease of access to a syringe driver to support care at home for patients with palliative care needs, was a prominent theme from all the consultation groups.

'Access to a syringe driver for use by GP and out of hours – in my area of work palliative care is an essential role and therefore it is necessary to be competent in this area.' GP

When this topic was further explored in the questionnaire, it was evident that there was significant variation in the level of access to and use of syringe drivers by GPs and community nurses (Figure 8).

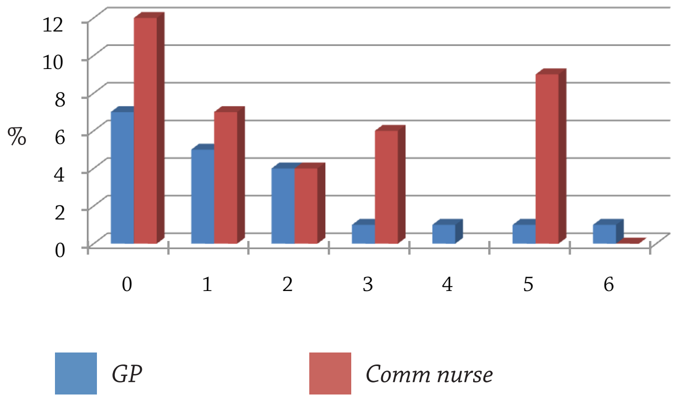

Figure 8: Bar chart illustrating the frequency of syringe driver use by GP and community nursing in a year

Finally, the difficulty in accessing palliative medications and need for safe disposal of same was identified as a significant issue for community-based health care professionals both during the consultation meetings and from the analysis of the questionnaire. One of the suggestions from the consultation meeting to address this issue, which was incorporated into the questionnaire, was to provide a stock of frequently used palliative medications and equipment in the primary care centre or GP surgery for use out of hours.

This was supported by 58% (n=99) of the respondents.

4.2.8 Examining the response of the private sector

A number of challenges were raised during the consultation meetings with regard to how the private health sector supported the palliative care needs of those with life-limiting disease, and they ranged from needs assessment, communication and co-ordination.

> *'Private hospitals are leaving clients with poor prognosis, unaware of support in the community and not referring to hospice – they* [the patients] *are in a frightened state and not aware of their diagnoses.'* Nurse

> *'Recently we have received large amounts of referrals from* [deleted name of clinics] *– the clients are usually only home 2-3 weeks when they pass away. I find the private patients are ill informed and the referrals arrive too late into the client's illness. I personally believe this is poor care for the client.'*

Whilst addressing the needs of the private health sector was beyond the terms of reference of the PPC, it is in the interest of all patients that these services providers are encouraged to engage with and support the findings and recommendations arising from this report.

4.3 Summary

The analysis of the data from the consultation meetings and the returned questionnaires has generated some direction for service improvement to enhance the delivery of primary palliative care. These are summarised below.

- It is vital that patients with life-limiting disease and their families receive concise and consistent information from all those involved in their care; this can be accommodated through the development of patient information packs; the introduction of a system that would plan, support and co-ordinate delivery of care; and enhanced by the development of more sophisticated communication systems between primary, secondary and tertiary services.

- Health care professionals have indicated they would like to increase their confidence and competence in order to enhance the palliative approach to the care they provide – particularly addressing end of life communications, symptom management, and the needs of those with non-malignant disease.

- The extent and range of services available, particularly outside of traditional working hours, needs to be more comprehensive; this can be achieved through clarifying and facilitating access to SPC advice and information on a national basis; the development of an OOH handover form between GP and OOH service provider and increasing the responsiveness of community nursing in this time period. There is also acknowledgement of the need for further psychological supports to be available to patients and their families.

- Patients and families benefit when there is close working relationships between the various health care professionals that are involved in their care. Although this programme's engagement with Irish health care professionals has demonstrated some examples of good working relationships, there is also evidence of the lack a clarity inconsistency with regard to professional roles and responsibilities when shared care is required. Opportunities to enhance and define local working relationships between health care professionals in primary care and SPC should be encouraged. In addition professional groups would benefit from clarifying their role in their delivery of end of life care.

- The practical responses to ensure the needs of those nearing the end of life cannot always be anticipated. Mechanisms to ensure that urgent access to specialised equipment and palliative medication are available should be facilitated, thus enabling patients to remain in their preferred place of care for as long as appropriate.

- There is an indication that the palliative care needs of the patients within private health care are not always routinely included in their assessment and their discharge planning process. Appropriate governance is required to ensure that private health care organisations respond comprehensively to the palliative care needs of their patients.

CHAPTER 5

Conclusion

Chapter 5
Conclusion

Irish policy in palliative care is broadly in keeping with international development. However the national frameworks to underpin policy implementation and consequent service developments appear to fall short of practices in the UK and further afield. The emergence of the HSE National Clinical Programmes provides an opportunity for strategic and clinical leadership, and guidance, to support the integration of appropriate levels of palliative care in all relevant care settings. Such developments are vital, as with the increase in emphasis on care in the community, primary care staff will require enhanced support and resources to deliver appropriate levels of palliative care, as part of the continuum of overall care to people with life-limiting diseases.

The traditional association of SPC services with cancer has somewhat overlooked the need for development of palliative care for patients with non-malignant disease – and this is evident in Ireland as well as the UK and Australia. The unpredictable trajectory of conditions such as advanced cardiac, respiratory, neurological disease and dementia should not be a reason for patients with these conditions to be denied a palliative approach to their care.

Developments in the area of primary palliative care in the UK and further afield can provide direction and encouragement for both primary and palliative health care professionals and planners in this country. Internationally, voluntary service providers have been successful champions in supporting palliative care initiatives in primary care settings. GP professional organisations have also played a pivotal role in supporting service initiatives in this area. From a palliative care perspective, the present report is very timely as in May 2011 the European Association of Palliative Care agreed to establish a taskforce in the area of Primary Palliative Care.

All new developments must ensure an outcome that will improve quality of life for patients with advanced life-limiting disease. They must also make certain that systems to enhance co-ordination and communication do not stifle or inhibit the sensitive and person centred care that the patient and family require.

Community-based health care professionals in Ireland and internationally have indicated that they would like more clarity with regard to their role in the delivery of palliative care. Several respondents to the PPC survey have reported that they feel de-skilled and 'deroled' in the delivery of end of life care. Others have stated that they need more education and support in this area. Permission and encouragement to deliver palliative care in community settings can be facilitated by strong leadership and commitment from professional groups, both from specialist palliative care and those based in primary care.
Such development could be primed through pilot projects and clinical guidance that would inform an overall framework for this aspect of care delivery.

It is, however, reassuring to see that the majority of primary care staff who engaged in the PPC programme, recognise that palliative care is an essential part of their role, and that they are aware of their skills deficit. This programme has identified a range of initiatives to support delivery of primary palliative care. Some of these could be addressed in the short term; others however require further consideration.

The sensitivity required in providing care to people who are nearing the end of life, cannot be over-estimated and patients and their families often require additional psychological and practical support. It is paramount that health care professionals involved in the care of these patients care can identify their palliative care needs, and that they are aware of and can access the necessary resources and services to ensure those needs are met. The recommendations outlined in Chapter 6 provide the initial steps to address the gaps identified in this report.

CHAPTER 6

Recommendations

Chapter 6
Recommendations

6.1 Introduction

The recommendations that have been identified for Phase two of the Primary Palliative Care Programme are described below. These are linked to the themes that arose from analysis of the data emerging from the survey process, and are also informed by developing work both nationally and internationally. In response to these themes the prioritised recommendations have been listed under the following headings:

- Communication and information transfer.
- Advice, guidance and service information.
- Education.

The remaining recommendations require more strategic input from key stakeholders and will receive further consideration in the next phase of the PPC programme. These longer term recommendations are listed under the following headings:

- Access to Services.
- Policy.
- Research.

6.2 Prioritised recommendations

6.2.1 Communication and information transfer

The identification of the palliative care needs of patients, and co-ordination of the delivery of their subsequent care, has been identified as a challenge and a priority. Holistic patient-centred care at end of life will be enhanced where there is reliable and efficient communication between health care professionals in all settings. The successful implementation of such a communication system, will need to be compatible with the emerging HSE IT infrastructure in this area (i.e. Healthlink). The projects below are initial steps to seek to address these identified needs.

a. Develop and implement a palliative care summary for communication with out of hours services

In order to provide a comprehensive 24-hour service to patients with palliative care needs in the community, it is vital that there is a formal communication system in place to update GP OOH services with relevant background information on such patients' changing needs. The development of a Palliative Care Summary which has potential to be communicated electronically will help to achieve this.

b. Create a system for primary care teams to identify patients with palliative care needs and respond appropriately.

Identification, communication, co-ordination and recording systems will be developed to support GPs and primary care team members to recognise and respond to patients who require a palliative care approach. These resources can be designed as a software package, downloadable on-line or via mobile technology, and may also be available in hard copy.

6.2.2 Advice, guidance and service information

Primary health care professionals occasionally require access to advice and information from Specialist Palliative Care to assist in their response to complex needs of patients. Access to such advice will help to deliver a quality, person-centred approach to patient care, particularly outside traditional working hours. There is, however, a lack of clarity with regard to the availability of advice from specialists.

This report also identified knowledge gaps on emerging palliative care medication as well as the need for more comprehensive information on the range of services that are available in primary care that would benefit patients with palliative care needs. The recommendations below seek to respond to these gaps.

a. **Clarify the extent and means of access to 24 hour SPC advice/ information.**
This recommendation will be pursued in consultation with the Irish Palliative Medicine Consultants Association and the HSE Clinical Care Programme in Palliative Care, in order to determine how best to clarify the extent and availability of this service.

b. **Compatibility of medications.**
An easily accessible interdisciplinary reference sheet will be prepared outlining the compatibility of medicines used in syringe drivers for patients with palliative care needs. Commitment has been given by the Irish Association for Palliative Care - Palliative Pharmacists Group to progress this.

c. **Provision of information supporting delivery of primary palliative care.**
Community-based statutory, voluntary and private health service providers need to clarify in their information literature how their services support and respond to the palliative care needs of patients with life-limiting illness and their families in the community.

6.2.3 Education

There is recognition amongst the majority of the community-based health care professionals who participated in the questionnaire that they would benefit from more education in the area of palliative care. Both formal and informal models of education delivery are encouraged, along with appropriate use of on-line education.

a. The professional bodies concerned with responsibilities for training and development of primary health care staff should signpost the existing education and training options available in palliative care and respond to the needs identified in this report.

6.3 Longer term recommendations

6.3.1 Access to services

Despite the recent emphasis on enhanced care in the community, the findings of this report have identified significant gaps in service provision to patients with palliative care needs in the following areas:

a. Flexible out of hours nursing for patients nearing end of life.

b. Streamline and standardise communication systems between primary, secondary and tertiary care providers to assist in timely information reguarding patients palliative care needs.

c. Psychological support for patients and families.

d. Timely access to specialised equipment and retrieval collection of equipment following death.

e. Formalising palliative approach to care within private health care sector.

The HSE National Care Programmes need to take full account of these findings and reflect the issues presenting in their work programmes.

6.3.2 Policy

The links between primary care teams and community-based SPC teams varies throughout the country. This variation can lead to inconsistencies in approaches to care and a lack of clarification of individual roles. The recommendation below will seek to address this matter.

a. The development of the HSE National Clinical Care Programmes in palliative care and primary care provide an opportunity to address these variations and offer leadership and governance in this area, so that there can be consistency and equity in the delivery of primary palliative care. This will help to bridge the gap that exists between health policy and service delivery.

b. Professional organisations can assist the staff they represent in primary care settings to further define their role and position in the area of primary palliative care. It is recommended that these groups would develop professional specific position statements and policy documents in palliative and end of life care. This will provide the necessary role clarity and professional guidance in this area.

6.3.3 Further research

The findings from phase one of the PPC programme, as well as international trends have identified several aspects of practice that would benefit from further study. Two particular areas of practice have been highlighted below.

a. The management of syringe drivers by members of the primary care teams.

b. The benefit of the introduction of a GP or nurse facilitator post to enhance the co-ordination and delivery of palliative care by primary care teams.

Additional areas for research are addressed in Appendix 4.

CHAPTER 7

Implementation

Chapter 7

Implementation

The first phase of the PPC programme sought to scope out existing and potential initiatives to support the delivery of palliative care for adults in primary care settings. The next phase relates to the implementation of this report's recommendations, and advocating for research, policy and filling service gaps which have been signalled.

7.1 Proposed aim, objectives and draft terms of reference for phase 2 of the Primary Palliative Care Programme

7.1.1 Aim

To establish frameworks, tools, best practice and resources to equip community-based health care professionals to support the palliative care needs of patients in the community.

7.1.2 Objectives

a. Ensure that prioritised initiatives from Phase 1 are established, supported and governed.

b. Develop and establish linkages with other relevant projects from a policy, research, education and service development perspective to inform future work plan.

c. Develop repository of relevant information.

d. Ensure dissemination and awareness of the work of the programme.

7.1.3 Draft terms of reference for steering committee to oversee the work of phase 2 Primary Palliative Care Programme

a. Oversee implementation phase of the Primary Palliative Care Programme.

b. Establish implementation plan for individual projects identified.

c. Appoint sub-committees for each project.

d. Introduce governance and communication structures for each project.

e. Identify and establish links with Irish and International developments (strategic, policy and operational) that relate to the work of the of Primary Palliative Care programme.

f. Produce six monthly progress reports to ICGP and the HSE National Clinical Programmes in both Primary Care and Palliative Care.

g. Advocate for findings from Phase 1 that fall beyond the scope of Phase 2.

7.1.4 Proposed membership of steering committee phase 2

The committee should seek representation from the following programmes, organisations and professional groups, and in addition should consult with patient representative groups:

- HSE Palliative Care National Clinical Programme.
- HSE Primary Care National Clinical Programme.
- Irish Palliative Medicines Consultants Association.
- Irish College of General Practitioners.
- Irish Hospice Foundation.
- Irish Association for Palliative Care.

- Dir. of Nursing SPC National Group.
- Dir. of Pall Care Nursing.
- Irish Cancer Society.
- All Ireland Institute of Hospice and Palliative Care.
- Hospice Friendly Hospitals.

7.1.5 Governance

It is recommended that the Primary Palliative Care Programme will link strategically with the HSE National Clinical Programmes. Progress reports from the projects and programmes emanating from the implementation phase will be available to the HSE National Clinical Programmes. Information on the relevant work streams of the National Clinical Programmes would also inform the work of the committee and the projects. All sub-committees will reflect appropriate professional representation and expertise required.

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Appendices

Appendix 1

Phase 1 Aim and Terms of Reference

Patient target group:

The target population for this group are adults with advanced progressive diseases that live in the community - under the care of their GP and/or Primary care teams who are expected to die in the next 12 months. This target group could be living at home or in a community residential facility.

Aim of project

Phase 1

To identify palliative care initiatives that will support primary care teams responses to adults with advanced progressive diseases in that live in the community who are expected to die in the next 12 months.

Phase 2

The aim of phase two will be determined by the first phase, and will relate to implementation of the initiatives that have been prioritised.

Function / work of group

The Irish Hospice Foundation will act as a secretariat to this group.

A chairperson will be appointed, and sub groups may be formed as appropriate.

Terms of reference – Phase 1

1. Review and consider current level of palliative care provision within community care/ primary care structures in Ireland. This review will be based on questionnaires circulated to GPs, specialist palliative care, OOHs GP services and Dir of PHN nursing. Views of community pharmacy will also be gathered.

2. Identify mechanisms (both policy and service) to enhance current provision, considering evidence based practice

3. Agree, prioritise and communicate areas for action in appropriate format, bearing in mind cost efficiencies.

4. Ensure all relevant stakeholders are consulted in the work of the group and informed of final outcome

Appendix 2

Membership of the Primary Palliative Care Steering Committee (phase 1).

Name	**Representing**
Mary Bowen	Hospice Friendly Hospitals Programme, Irish Hospice Foundation
Mary Ferns	Irish Cancer Society
Dr Paul Gregan, Chairperson	Irish Palliative Medicine Consultants Association
Liz Hoctor	Irish Pharmacy Union
Dr Emer Loughrey	Irish College of General Practitioners
Marie Lynch	Irish Hospice Foundation
Dr Brian Maurer	Irish Heart Foundation
Michele Megan	Directors of Public Health Nursing
Edith McMahon	Milford Hospice at Home Service
Pauline Newman	Dir of Nursing SPC National Group
Dr Kevin O'Doherty	HSE Primary Care
Eileen O'Leary	HSE Palliative Care
Dr Eve O'Toole	National Cancer Control Programme
Ms Lorna Peelo-Kilroe	HSE Primary Care
Dr Ailis Quinlan	Personal Capacity
Anne Tan	Irish Association of Palliative Care
Grainne Tipping	Irish Palliative Pharmacy Group *(resigned from committee March 2011)*

Appendix 3

Copy of Questionnaire

SECTION A: INFORMATION TRANSFER

1. Are you informed by secondary / tertiary care if a patient diagnosed with cancer is at an ADVANCED stage of their illness?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

2. Are you informed if the prognosis has been discussed with patients with advanced cancer?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

3. Are you informed by secondary / tertiary care if a patient diagnosed with non-malignant, life-limiting disease eg Neurological Disease is at an ADVANCED stage?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

4. Are you informed if prognosis has been discussed with patients with advanced non-malignant disease?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

5. Do you inform or update the out of hours service about patients in your care who are currently receiving/require palliative care?

Daily ☐ Weekly ☐ Monthly ☐ Never ☐ Not Applicable ☐

6. Can you access the advice and support of a specialist palliative care team when necessary?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

7. Do you receive timely notification when a patient of yours dies in hospital or hospice setting?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

SECTION A: MEDICATION AND EQUIPMENT

8. Can you access specialist equipment (eg mattresses or home oxygen) in a timely manner for patients with end of life care needs?
Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

9. Do you receive information from secondary / tertiary care with regard to medications a patient has been prescribed on discharge?
Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

10. Do you have difficulty accessing palliative care medications out of hours?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

11. Does your primary care team have access to a syringe driver?

Yes ☐ No ☐ Unknown ☐ Not applicable ☐

12. Can you use a syringe driver?

Yes ☐ No ☐ Not applicable ☐

13. If you answered YES to Q 12 above please indicate how many times a year that you use a syringe driver

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ Other ☐

SECTION A: COMMUNICATIONS WITH PATIENTS AND FAMILIES

14. Do you feel competent in discussing prognosis with patients who have advanced cancer?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

15. Do you feel competent in discussing prognosis with patients with non-malignant disease e.g. advanced lung/neurological disease?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

16. Do you feel competent in discussing psychosocial issues with patients with advanced life-limiting disease?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

17. Do you feel competent to discuss the impact of bereavement with those who have been bereaved?

Always ☐ Usually ☐ Sometimes ☐ Rarely ☐ Never ☐ Not Applicable ☐

18. Please use this space for any further comments:

SECTION B: POTENTIAL INITIATIVES

19. In your opinion please tick the 4 most useful EDUCATION initiatives

☐ Training and guidelines on how to break bad news

☐ Skills to assist in other end of life communications

☐ Education in prescribing in palliative care

☐ Training in symptom control, eg: pain; emotional distress

☐ Training in palliative principles for non-malignant disease

☐ Training in use of a syringe driver

☐ Education in ethical decision making at end of life

☐ Education in hydration and nutrition at end of life

☐ Education to assist in prognostication at end of life

☐ Training in care for imminently dying patient at home

☐ Training in principles in bereavement support

20. In your opinion please tick the 4 most useful INFORMATION TRANSFER initiatives

☐ Electronic communication systems between primary, secondary/tertiary services to assist in prompt, updates, inform of discharge and or death, eg via health link

☐ Electronic communication with out of hours service providers

☐ Advance notification to community pharmacy of medication prior to discharge of patient from hospital

☐ Software application with information and guidance for palliative care practice within primary care settings

☐ A practice based register to assist in identification of patients with life-limiting disease eg COPD, Cancer, who may die in the next 12 months

☐ A summary of patient notes to be available in the home setting

☐ Localised and personalised service contacts for patients and family

☐ Regional service directory describing range of services available for patients nearing end of life and their families

21. In your opinion please tick the 4 most useful GUIDANCE/SUPPORT initiatives

☐ A health care professional to be nominated as key worker for individual patient who is nearing end of life

☐ A checklist prompting end of life care needs assessment

☐ A bereavement follow-up checklist

☐ Psychological support for patients and families

☐ Psychological support for staff

☐ Out of hours nursing service for patients nearing end of life (eg Community Intervention Teams) to facilitate home deaths

☐ Specialist palliative care 24 hour telephone service

22. In your opinion please tick the 4 most useful MEDICATION / EQUIPMENT initiative

☐ A box of palliative medications and equipment in the Primary Care Centre of GP surgery for use out of hours?

☐ Syringe driver to be available for use by GP and out of hour's services

☐ Timely access to specialised equipment and supplies to facilitate discharge home or continued home living at end of life, eg mattresses, home oxygen

☐ Localised directory identifying access points for medication out of hours

☐ Directory re regional availability of palliative medications in pharmacies

☐ Guidance documentation on medications and their compatibility

☐ Guidance re advance prescribing to assist access to medications out of hours

SECTION C INDIVIDUAL PERSPECTIVES

23. What are your views on providing a palliative care approach for people with advanced non-malignant disease ie advanced heart failure, dementia, advanced renal failure?

24. Please list any palliative care initiatives that you are aware of in the community/primary care setting.

25. Do you have any suggestions specific to your discipline that would help in the delivery of palliative care to patients in the community and their families?

Appendix 4:

Methodology and results

This appendix details the methods used for gathering views from community-based health care professionals via the five consultation meetings and the circulation of the questionnaire. It also gives the qualitative results from the questionnaires that were distributed.

Consultation meetings

Recruitment, rationale and strategy

Five consultation meetings were held in mid-2010, and these meetings targeted community-based health care professional staff who work with people with life-limiting disease. The sites selected for these meetings sought to achieve the balance between urban and rural locations, and also to ensure representation from the three regions in Ireland not served by a SPC in-patient unit. To facilitate maximum attendance and accommodate the work patterns of the targeted professionals, two of the meetings were scheduled in the evening, two at lunch-time and one during working hours.

Invitations to the consultation meetings were extended from the HSE Transformational Development Officer (TDO) who worked in the selected HSE Local Health Office (LHO) region. Staff representatives from the various groups of health care professionals working in the region were invited along with GPs, pharmacists and representatives of the local SPC service. Figure 1 indicates the locations and breakdown of attendances by region and Figure 2 provides professional representation.
A standard presentation was prepared for all five consultation meetings, delivered by representatives

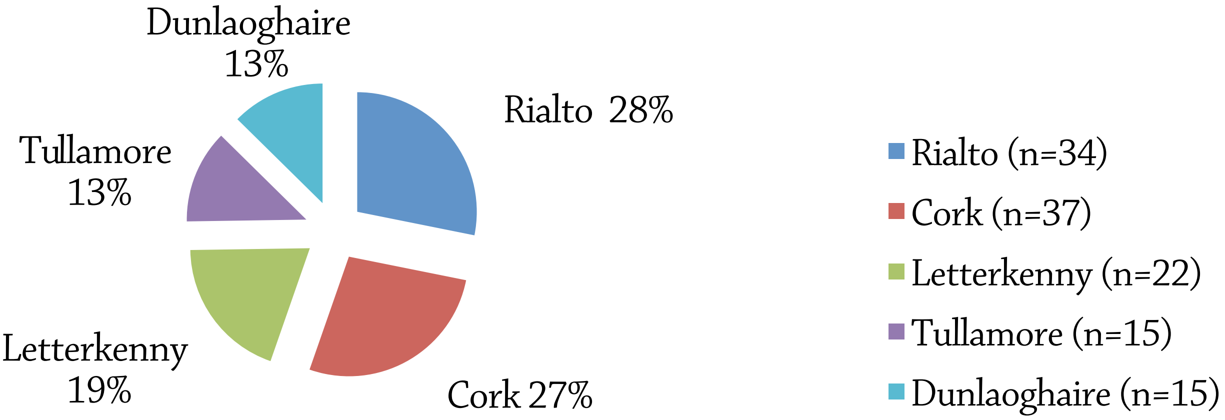

Figure 1: Location of meetings and attendances (N=123)

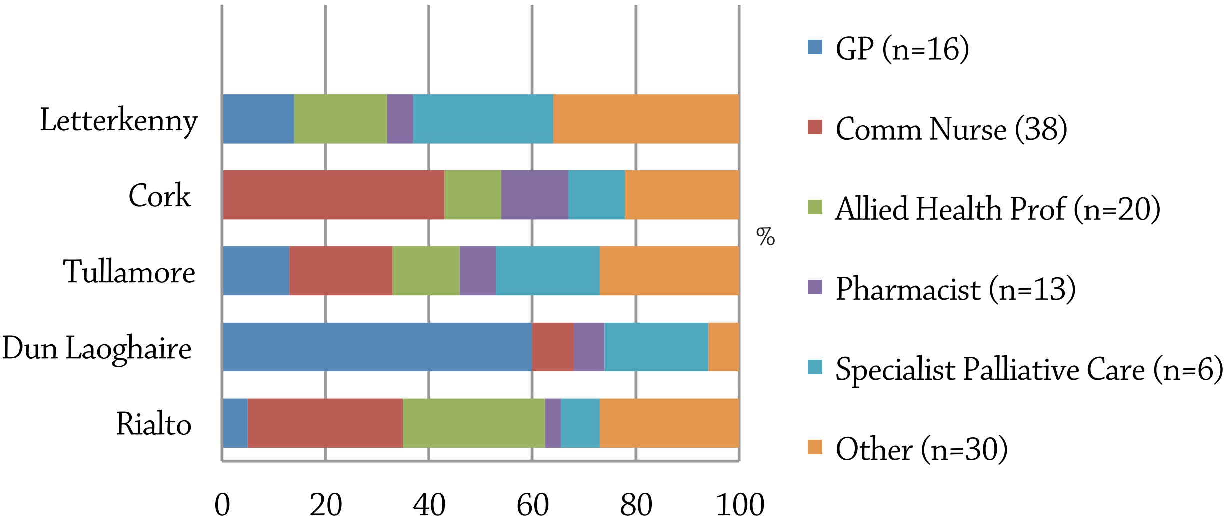

Figure 2: Professional representation at consultation meetings (N=123)

from the PPC programme along with members of the local SPC team. Following the presentation, participants were asked to discuss and reflect on their experience of responding to the needs of patients with advanced life-limiting disease in primary care settings. The following prompts were used for discussion and were chosen to reflect trends and issues identified in the literature on this topic. Participants were encouraged to identify potential solutions to these prompts. In the meetings with larger attendances, sub-groups were formed to facilitate discussion.

Prompts: Patients and Families

- Communication and acknowledging life-limiting diagnoses.
- Identifying transition to palliation in approach to care.
- The specific approach required for patients with diseases other than cancer.
- How families can be involved and supported.

Prompts: Medication and Equipment

- Access to palliative care medication.
- Information and advice.
- Syringe drivers.

Prompts: Patient Pathways at End Stage

- OOH services.
- Access to respite care.
- When to access SPC services.
- Communication with other team members.

The content of the discussions was transcribed by independent note takers and the themes and issues arising from each meeting were summarised and subsequently combined, using open coding.

Questionnaires

The content of the questionnaire was devised based on the themes emerging during the consultation phase; correspondence from professional groups; and input from the members of the PPC steering committee.

Recruitment rationale, sampling strategy and response rate

Five LHO areas were selected for the distribution of the questionnaire. These areas fulfilled the following criteria:

- Not an area where one of the five consultation meetings had taken place.
- A previous indication of primary care initiatives already taking place 'on the ground'.
- The five selected areas adequately represented the four HSE regions;
- Ensuring LHO's selected included those who had access to SPC in patient unit and where there was no access to this service.

The questionnaire was forwarded to GPs, PHNs and Allied Health Professionals (AHP) via the HSE TDOs (purposive and convenience sampling). This method was chosen as it had been successfully used by members of the project team on previous occasions. The LHO areas selected were Dublin North Central, Dublin West, Kerry, Limerick/North Tipperary and Cavan/Monaghan. A total of 685 questionnaires were distributed, of which 186 were returned. Overall, a response rate of 27% was achieved. Four of the questionnaires were removed from the final data set due to incompletion, resulting in a final sample number of 182 participants[2]. Table 1 displays the number of questionnaires distributed within each region and the associated response rate obtained.

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[2] Please note that the variation in sample numbers throughout this report is as a result of omitted or missing data from participants.

Location	Questionnaires Distributed	Questionnaires Returned	Response Rate
Dublin (North Central & West)	327	91	28%
Kerry	60	7	12%
Limerick/North Tipperary	100	17	17%
Cavan/Monaghan	185	35	19%

Table 1: Questionnaire distribution and response rate by region[3].

Rationale and design

The design of the questionnaire was largely informed by the consultation process, subsequent committee discussions; international literature; and emerging practice. Items were also included that reflected existing Irish Hospice Foundation programmes informing the area of palliative care within primary care (e.g. Palliative Care for All, bereavement projects and the Hospice Friendly Hospital Programme).

As not all questions were relevant to all targeted professionals, (the focus was mainly on views of GPs and nurses), the frequency of 'not applicable' response was largely anticipated.

In terms of professional groups targeted, these too were guided by the consultation process. Pharmacists were deliberately excluded in this survey because of an existing pilot project involving this group, of which an evaluation was due (see **3.4.3**). Relevant SPC teams were informed about the survey process that was taking place in in their locality.

Importantly, the questionnaire was piloted with GPs (n=6) and PHNs (n=3). After the questionnaire pilot and review by an AHP and psychologist, minor adjustments to the content were made and the cover letter was shortened, prior to distribution to five LHO regions.

The questionnaire (Appendix 2) was divided into three sections as follows:

Section A

Information was sought on issues related to:

- Information transfer.
- Medication and equipment.
- Communications with patients and families.

Section B

From the perspective of primary palliative care, participants were asked to choose from a list of the 4 most useful initiatives grouped under the following headings:

- Education.
- Information transfer.
- Guidance/support.
- Medication/equipment.

Section C

Individual perspectives were sought on:

- Providing a palliative care approach for people with advanced non-malignant disease.
- Personal awareness of palliative care initiatives in the community/primary care setting.
- Discipline-specific suggestions that would help the delivery of palliative care to patients in the community and their families.

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[3] 32 (18%) valid questionnaires were returned with no location identified

Confidentiality and data analysis

Participant anonymity was guaranteed. Participants were invited to include information on their work location and profession, and had the option of providing further details if they so wished for dissemination purposes. Anonymity was further enabled by each questionnaire coded with a unique numerical identifier, and all data was securely stored.

The data was coded and entered into a computer using *SPSS* (Version 17), and was screened and cleaned prior to any analyses being carried out. Frequency analyses were conducted for the sample as a whole, and further exploration of the data, based on professional group and geographical location, were also carried out. All qualitative data was recorded and subjected to a separate content analysis, where relevant themes were identified.

Participants and settings

As evidenced by the data presented in Figure 3 below, half of the respondents (n=91) came from Dublin region, with the lowest response from Kerry (n=7).

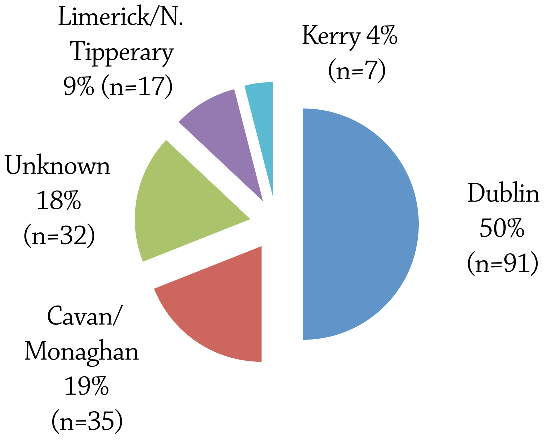

Figure 3: Percentage of respondents by location (N= 182)

The professional group with the highest representation was community nursing (n=73)[4] closely followed by GPs (n=50), (Figure 3). 19% of returns represented the AHP category (Speech and language therapists (n=5); occupational therapists (n=13); physiotherapists (n=14)). One in ten participants did not indicate which professional group they belonged to.

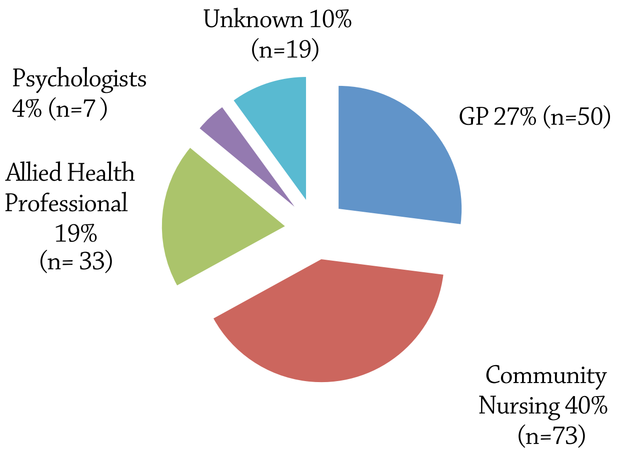

Figure 4: Breakdown of questionnaire respondents by profession (N=182)

Limitations:

A number of important limitations need to be considered when presenting the findings of this study, and these are addressed below.

When seeking to contact health care professionals to attend the consultation meetings and respond to the questionnaire, the purposive and convenience sampling method used generated differential responses across the regions. This variation may have been influenced by the level of contact achieved with the individual TDO's and degree of pre-existing relationship with members of the PPC programme.

In relation to the consultation meetings, each one had a different ratio of professional attendees and this would have influenced the depth and discussion around some of the topics.

Although each of the meetings had an independent note taker, each meeting had a different note taker,

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[4] Community Nursing represents composite responses from PHN, Community Intervention Teams, Practice Nurses, RGN and Nurse Managers

which would have influenced how data was recorded and transcribed.

Another limitation of the research is the numbers of participants and respondents was relatively low, and had a direct focus on GPs and nurses. Further engagement to gather the views from other health care professionals in the community, in particular OOH service providers and staff working in acute services is recommended.

Finally it must be noted that it was not possible to ascertain the views of patients or families in this study.

Qualitative results from questionnaires:

Q 1. Are you informed by secondary/tertiary care if patient with cancer is at an advanced stage of illness?

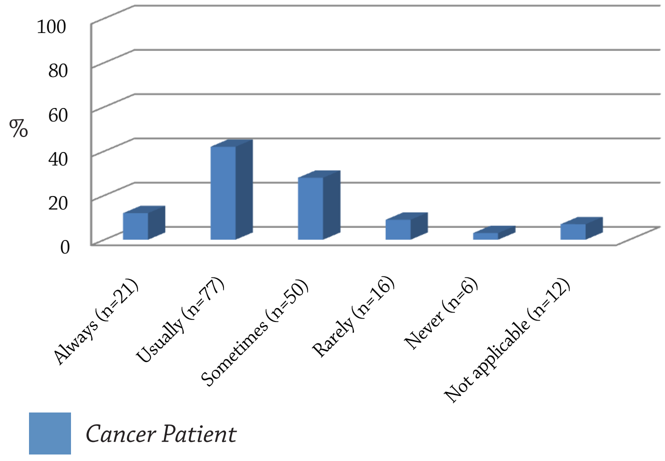

Figure 5: Bar chart detailing participants' responses (N=182) as to whether they are informed by secondary/ tertiary care if a patient with cancer is at an advanced stage of illness

Q 2 Are you informed if the prognosis has been discussed with patients with advanced cancer?

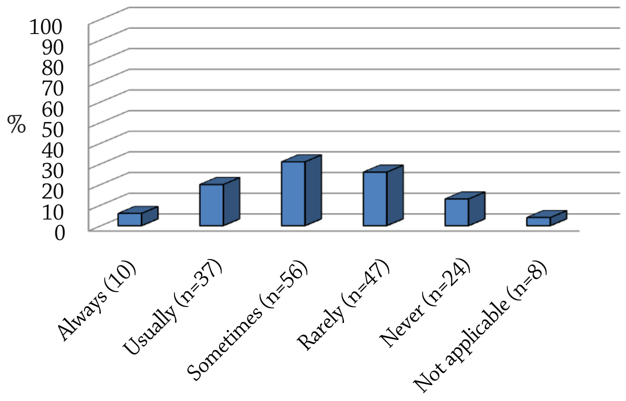

Figure 6: Bar chart detailing participants' responses (N=182) as to whether they are informed if prognosis has been discussed with patients with advanced cancer

Q 3 Are you informed by secondary/tertiary care if a patient diagnosed with non-malignant, life-limiting disease e.g. neurological disease is at an advanced stage?

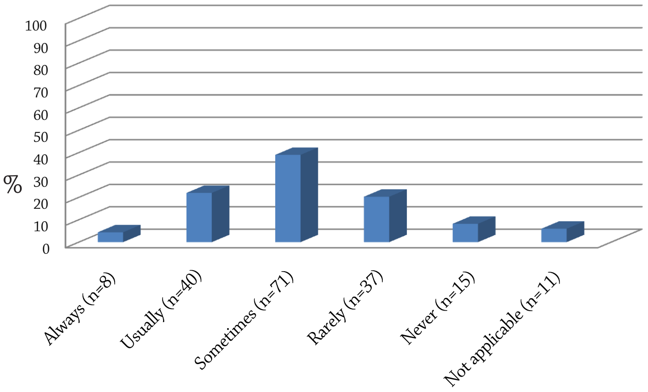

Figure 7: Bar chart detailing responses (N=182) of participants regarding whether they have been informed by secondary/tertiary care if a patient diagnosed with non-malignant, life-limiting disease is at an advanced stage.

Q 4 Are you informed if prognosis has been discussed with patients with advanced non-malignant disease?

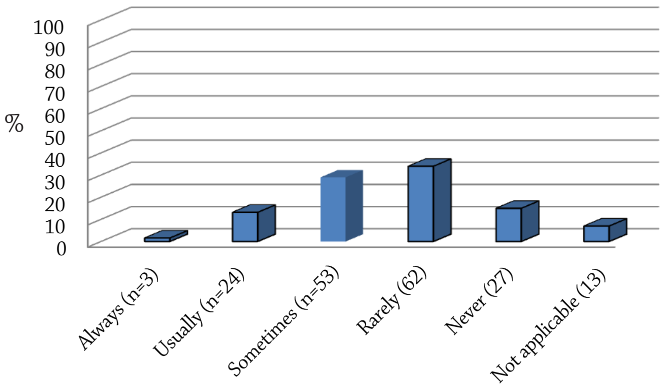

Figure 8: Bar chart detailing participants' responses (N=182) as to whether they are informed if prognosis has been discussed with patients with advanced non-malignant disease

Q 5 Do you inform / update out of hours services about patients in your care who are currently receiving/requiring palliative care?

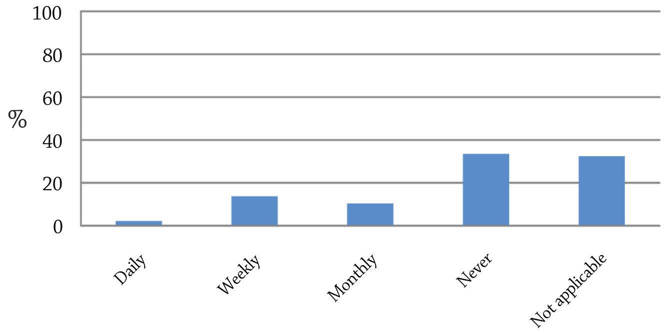

Figure 9: Percentage frequency of informing OOHs services re needs of palliative patient (N=181)

Q 6 Can you access the advice and support of a specialist palliative care team when necessary ?

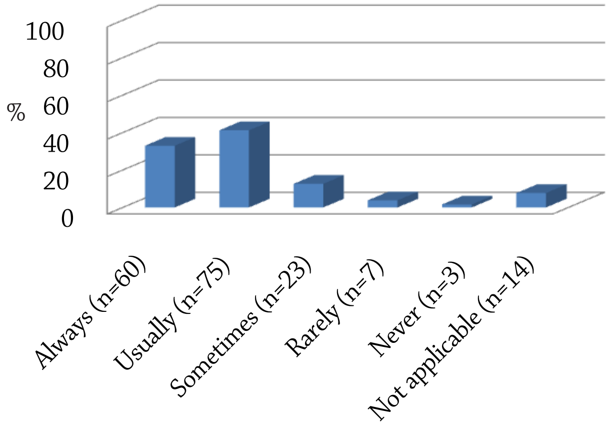

Figure 10: Bar chart detailing level of access by respondents (N=182) to advice and support of a specialist palliative care team when necessary.

Q 7 Do you receive timely notification when a patient of yours dies in hospital or hospice setting?

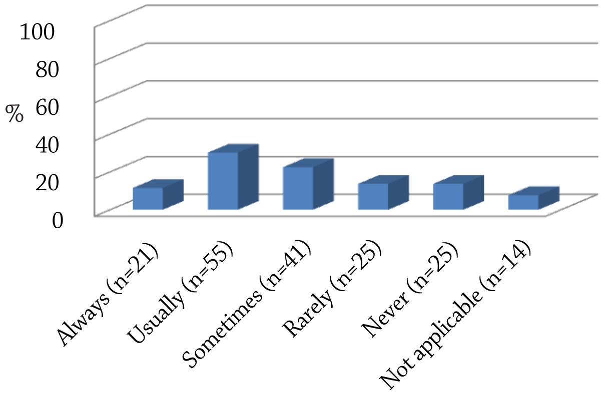

Figure 11: Bar chart indicating respondents' views (N=181) on timely notification when a patient of theirs dies in hospital or hospice setting

Q 8 Can you access specialist equipment (e.g. mattresses or home oxygen) in a timely manner for a patient with end of life care needs?

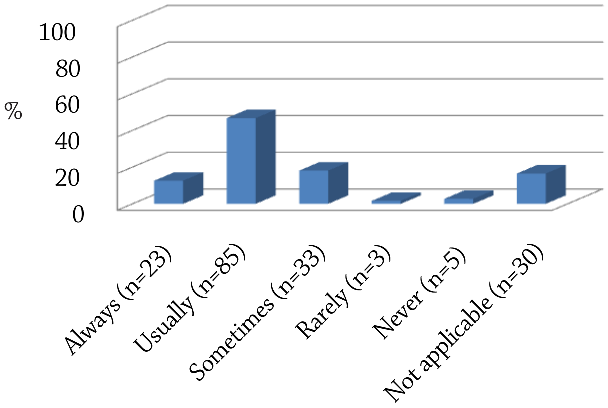

Figure 12: Access to specialist equipment in a timely manner for a patient with end of life needs (N=179)

Q 9 Do you receive information from secondary/ tertiary care with regard to medications a patient has been prescribed on discharge?

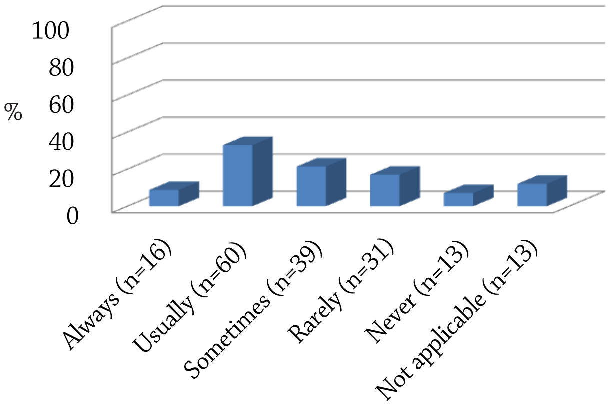

Figure 13: Participants responses (N=181) for the regularity of information received from secondary/tertiary care with regard to discharge medications prescribed to patients.

Q.10 Do you have difficulty accessing palliative care medications out of hours?

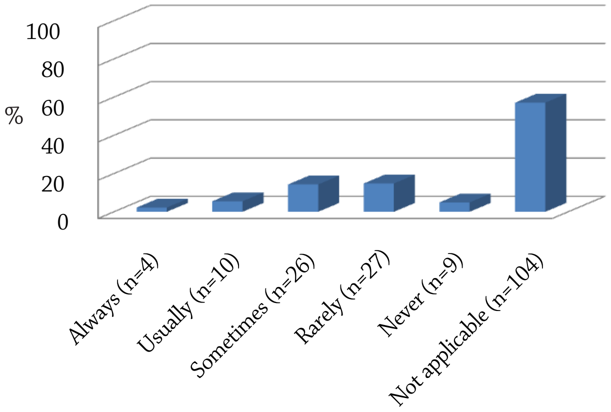

Figure 14: Represents difficulty accessing palliative care medication out of hours (N=180)

Q 11: Does your primary care team have access to syringe driver?

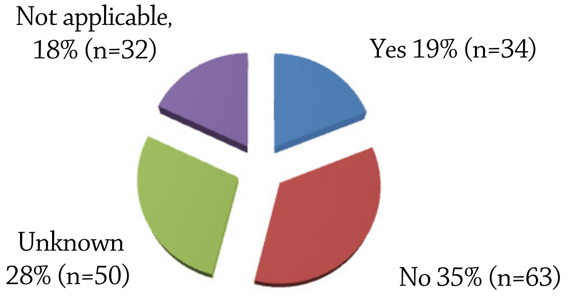

Figure 15: Pie chart indicating the level of access by primary care teams to a syringe driver (N=181).

Q 12 Can you use a syringe driver?

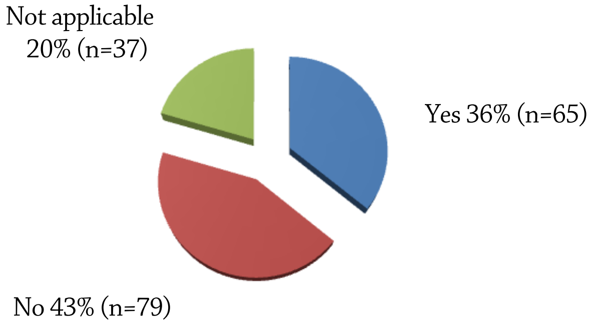

Figure 16: Pie chart indicating respondents (N=181) ability to use syringe driver

Q 13: If you answered yes to Q 12, please indicate home many times a year that you use a syringe driver

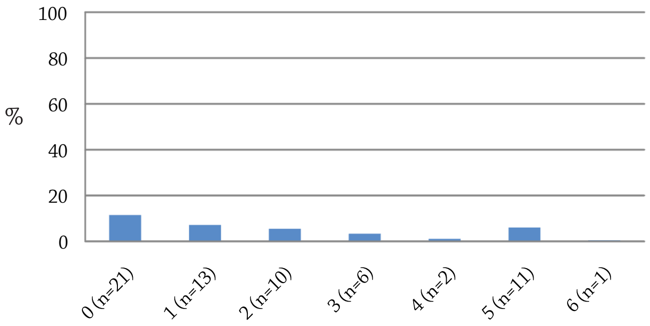

Figure 17: Bar chart illustrating the annual frequency of syringe driver use in this sample (N=64).

Q 14 Do you feel competent in discussing prognosis with patients who have advanced cancer?

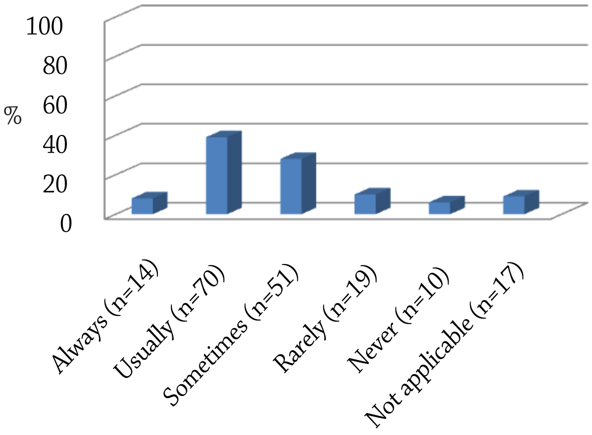

Figure 18: Bar chart responses (N=181) on rating competence in discussing a prognosis with a patient with advanced cancer.

Q 15 Do you feel competent in discussing prognosis with patients with non-malignant disease? e.g. advanced lung/neurological disease.

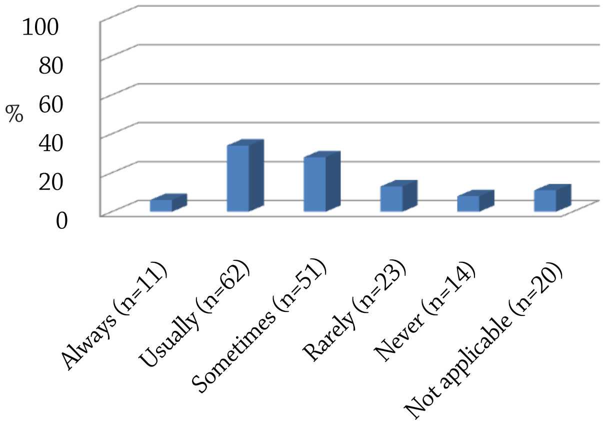

Figure 19: Bar chart responses (N=181) on rating competence in discussing a prognosis with a patient with non-malignant disease.

Q 16 Do you feel competent in discussing psychosocial issues with patients with advanced life-limiting disease?

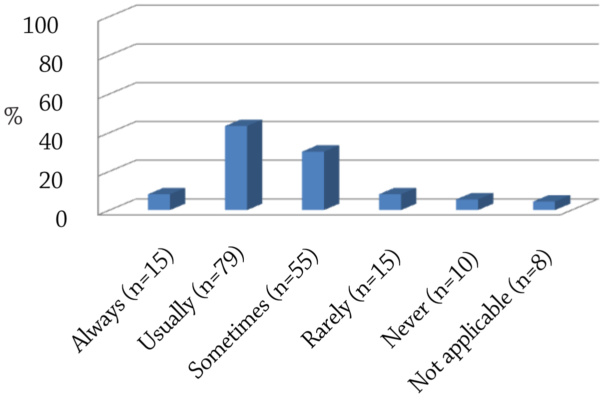

Figure 20: Bar chart (N=182) indicating competence of respondents in discussing psychosocial issues with patients with advanced life-limiting disease

Q 17 Do you feel competent to discuss the impact of bereavement with those who have been bereaved?

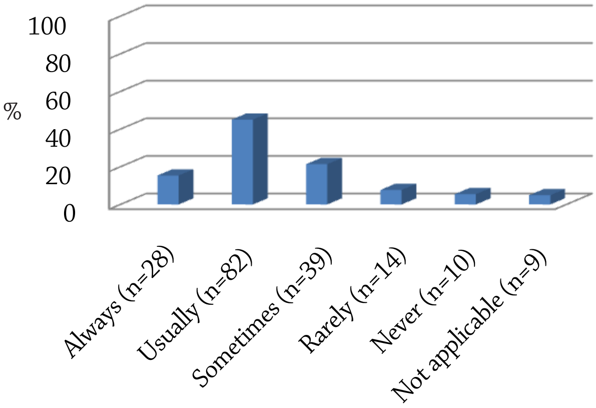

Figure 21: Bar chart (N=182) indicating competence of respondents in discussing impact of bereavement

Q 18 – Please use this space for further comments.

This qualitative data was gathered, themed using open coding and referred to in chapter 4.

Q 19 In your opinion please tick the 4 most useful education initiatives

		%	N
19.A	Training and guidelines on how to break bad news	(31%)	56
19.B	Skills to assist in other end of life communications	(43%)	77
19.C	Education in prescribing in palliative care	(31%)	56
19.D	Training in symptom control e.g. pain; emotional distress	(66%)	118
19.E	Training in palliative principles for non-malignant disease	(40%)	72
19.F	Training in the use of a syringe driver	(22%)	40
19.G	Education in ethical decision making at end of life	(23%)	41
19.H	Education in hydration and nutrition at end of life	(29%)	52
19.I	Education to assist in prognostication at end of life	(16%)	29
19.J	Training in care for imminently dying patient at home	(47%)	84
19.K	Training in principles in bereavement support	(44%)	79

Table 2: Indicating % and (N) of respondents for each education initiatives

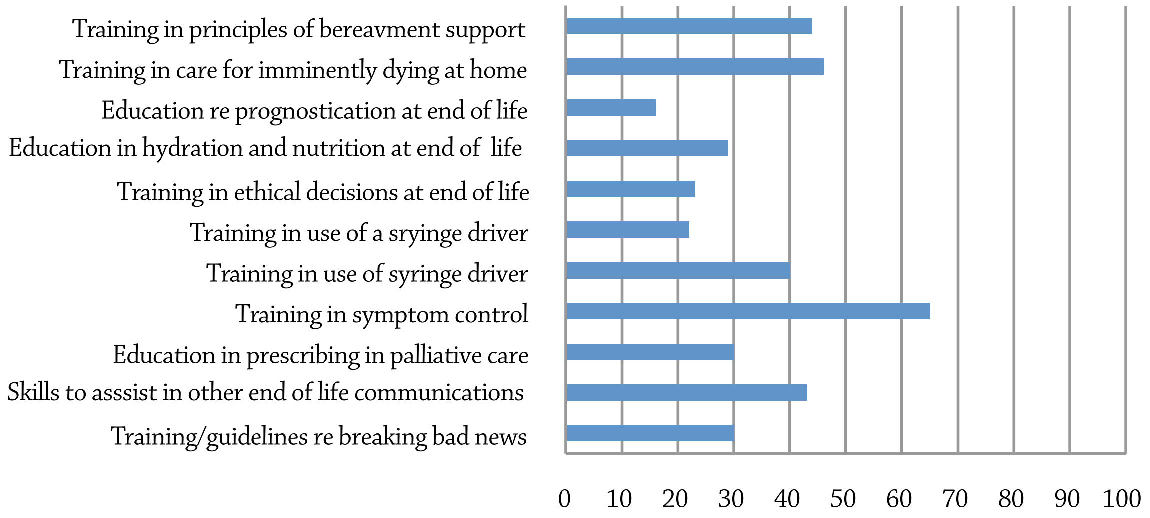

Figure 22: Bar chart visually demonstrating respondents rating of education initiatives (N=180)

Q 20 In your opinion please tick the 4 most useful information transfer initiatives

		%	N
20a	Electronic communication systems between primary/ secondary/ tertiary services to assist in prompt updates, inform of discharge and or death e.g. via health link	81%	(141)
20b	Electronic communication with OOHs service providers	33%	(58)
20c	Advance notification to community pharmacy of medication prior to discharge of patient from hospital	32%	(55)
20d	Software application with information and guidance for palliative care practice within primary care settings	38%	(66)
20e	A practice based register to assist identification of patients with life-limiting diseases e.g. COPD, cancer who may die within 12 months	39%	(68)
20f	A summary of patient notes to be available in the home setting	63%	(109)
20g	Localised & personalised service contacts for patients/family	55%	(95)
20h	Regional service directory describing range of services available for patients nearing end of life and their families	44%	(77)

Table 3: Indicating % and (N) of respondents for suggested information transfer initiatives

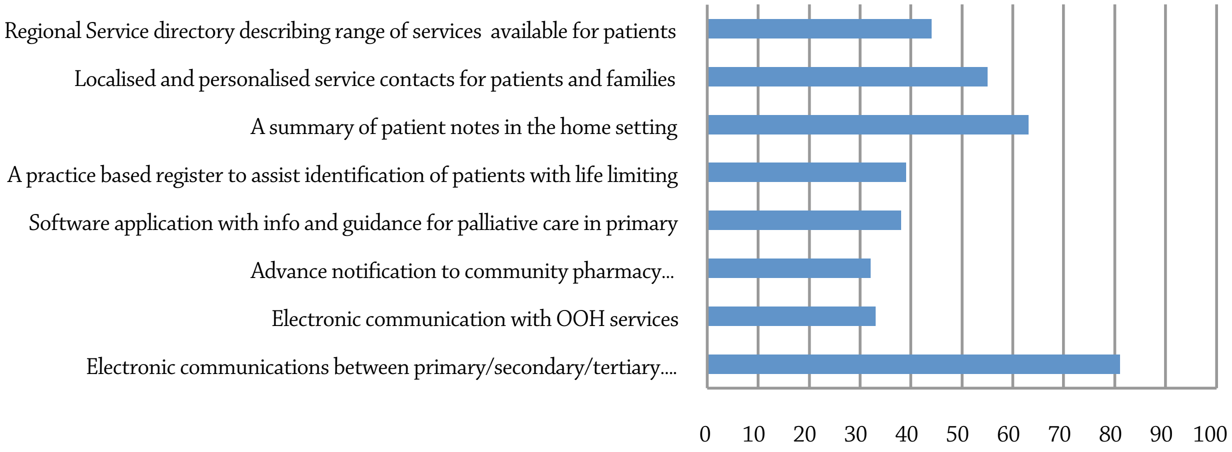

Figure 23: Results of participant ratings of the most useful information transfer initiatives (N=180).

Q 21 In your opinion please tick the 4 most useful guidance/support initiatives

		%	N
21a	A health care professional to be nominated as key worker for individual patient who is nearing end of life	66%	(116)
21b	A checklist prompting end of life care needs assessment	47%	(82)
21c	A bereavement follow up checklist	22%	(39)
21d	Psychological support for patients and families	73%	(129)
21e	Psychological support for staff	29%	(51)
21f.	OOHs nursing service for patients nearing end of life to facilitate home deaths (e.g. CIT)	76%	(133)
21g	SPC 24 hour telephone service	72%	(126)

Table 4: Indicating % and (N) of respondents for suggested guidance/support initiatives

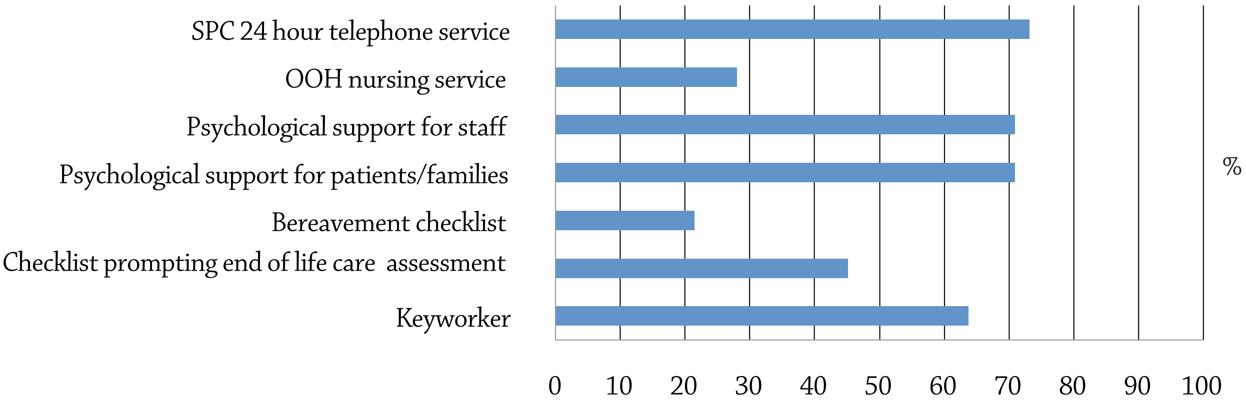

Figure 24: Bar chart indicating respondent's ratings for guidance and support initiatives (N=176)

Q 22 In your opinion please tick the 4 most useful medication/equipment initiatives

		%	N
22a	A box of palliative medications and equipment in the Primary Care Centre of GP surgery for use OOHs	58%	(99)
22b	Syringe driver to be available for use by GP and OOHs services	52%	(89)
22c	Timely access to specialised equipment and supplies to facilitate discharge home or maintain continued home living at end of life e.g. mattresses, home oxygen	87%	(147)
22d	Localised directory identifying access points for medication OOHs	44%	(75)
22e	Directory re regional availability of palliative care medications in pharmacies	17%	(28)
22f	Guidance documentation on medications and their compatibility	51%	(86)
22g	Guidance re advance prescribing to assist access to medications OOHs	34%	(57)

Table 5: Indicating % and (N) of respondents for most useful medication/equipment initiatives

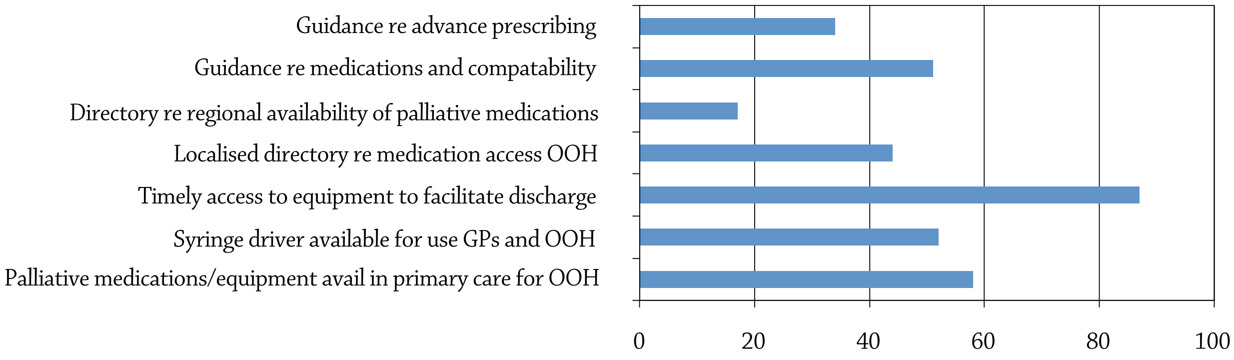

Figure 25: Bar chart depicting results of participant ratings of the most useful medication and equipment initiatives (N=170).

Q 23 What are your views on providing a palliative care approach for people with advanced non-malignant disease, i.e. advanced heart failure, dementia, advanced renal failure?

Q 24 Please list any palliative care initiatives that you are aware of in the community/primary care setting

Q 25 Do you have any suggestions specific to your discipline that would help in the delivery of palliative care to patients in the community and their families?

Data gathered from the responses to Q 23,24 and 25 were themed, using open coding, and referred to in chapter 4.

Primary Palliative Care in Ireland

Identifying improvements in primary care to support the care of those in their last year of life