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Using administrative health data for palliative and end-of-life care research in Ireland

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**UNIVERSITY OF
LIMERICK
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**Using administrative health data for palliative
and end-of-life care research in Ireland**

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Abstract

Using administrative health data for palliative and end-of-life care research in Ireland.

Maria Kelly

Administrative health data is under-used as a research tool for palliative care research in Ireland. The overarching aim of this thesis was to explore the potential of population based cancer registry data linked to hospital episode data and death certificate data to examine palliative and end-of-life care (PEoLC) for cancer patients, in Ireland. Research objectives include using the available linked data to identify vulnerable subgroups in need of palliative care, to identify and compare characteristics of those who receive palliative with those who do not and to explore the relationship between receiving palliative care and place of death. The knowledge gained was extrapolated to other non-cancer health and social care data collections to evaluate the potential and challenges of these data for PEoLC research and so develop guidelines to maximise its potential as a research tool while identifying the limitations of its use.

A population based study of lung cancer decedents found those patients who die within 30 days of diagnosis (short-term survivors) were older, (aged 80 years and over), had more comorbid disease and were more likely to present through the emergency department than those who survived longer. These characteristics are available at diagnosis and could be used to guide decisions on early assessment for palliative care for lung cancer patients at admission. Short-term survivors are more likely to die in hospital so reporting place of death by survival time may be useful to evaluate interventions to reduce deaths in acute hospitals.

A second study compared the characteristics and place of death of cancer patients receiving specialist palliative care in acute hospitals with those who do not. Almost two thirds of cancer patients who attended a cancer centre in 2016 and died in 2016 had an inpatient palliative care encounter. They were younger, less likely to be married, and more likely to be from a deprived area. Having accounted for sociodemographic factors, there was evidence of regional variation

in receiving palliative care. Place of death differed by palliative care encounter, 45% of those who were seen by the palliative care team died in hospital, 33% died in a hospice and 18% died at home. Of those who had no record of a palliative care encounter 50% died in hospital, 16% died in hospice and 28% died at home.

These studies demonstrate that Irish administrative health data can be used for PEO LC research however a thorough advance knowledge of the datasets to be used is critical. For each data set, information on how the data are organised (data models) and what data are collected (data dictionaries) are required. Knowledge of what is missing within each dataset is as important as knowing what is available. These considerations inform most aspects of study planning, design and implementation and were used to evaluate the potential of other national and social care data collections for PEO LC research. Efforts to identify and control for bias, both known and unknown are a particular concern when using administrative health data for research.

This thesis contributes to population based PEO LC research in Ireland and to the international body of work that uses administrative health care and social care data for PEO LC research. It can inform future use of Irish health data for population based research and has identified several avenues for further research. It is hoped the thesis findings will give impetus to ongoing initiatives to improve the research potential of Ireland's health and social data collections.

Declaration

I declare that this submission is entirely my own work, in my own words, and that all sources used in researching it are fully acknowledged and all quotations properly identified. It has not been submitted, in whole or in part, by me or another person, for the purpose of obtaining any other credit / grade.

Maria Kelly, February 2021

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List of abbreviations

AIIHPC All Ireland Institute for Hospice and Palliative Care

AJCC American Joint Committee on Cancer

CHO Community Healthcare Organisation

CCI Charlson comorbidity index

CSO Central Statistics Office

ESRI Economic and Social Research Institute

HIPE Hospital In-patient Enquiry system

HIQA Health Information and Quality Authority

HPO Healthcare Pricing Office

HSE Health Service Executive

ICS Irish Cancer Society

ICD International Classification of Diseases,

ICD-O3 International Classification of Disease for Oncology, 3rd Edition

IHF Irish Hospice Foundation

IHI Individual Health Identifier

IQR Interquartile range

NCPPC National Clinical Programme for Palliative Care

NCRI National Cancer Registry Ireland

PEoLC Palliative and End of Life Care

PCRS Primary Care Reimbursement Service

WHO World Health Organisation

Chapter 1: Introduction

1.1. Palliative care

The World Health Organisation (WHO) defines palliative care “as an approach that improves the quality of life of persons 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” (World Health Organization, 2020). WHO states “palliative care provides relief from pain and other distressing symptoms, affirms and enhances life, integrates the psychological and spiritual aspects of patient care and offers a support system to help patients and their families. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and it includes investigations needed to better understand and manage distressing clinical complications. Palliative care uses a team approach to address the needs of persons and their families, including bereavement counselling, if indicated”.

In Ireland, the National Clinical Programme for Palliative Care (NCPCC) have developed a Palliative Care Model of Care for the organisation of care for people with life-limiting or life-threatening conditions (National Clinical Programme for Palliative Care, 2019). The model of care recommends palliative care services should be structured in three levels of increasing specialisation:

Level 1: *Provided in any location or setting by all healthcare professionals as part of their role and using a palliative care approach. A palliative care approach aims to promote both physical and psychosocial wellbeing. 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.*

Level 2: *Provided in any location, using a palliative care approach by healthcare professionals who have additional knowledge of palliative care principles and use this as part of their role.*

Level 3: *Provided by healthcare professionals who work solely in palliative care, and who have extensive knowledge and skills in this specialty. Specialist palliative care services are*

provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine.

End of life care is the term used to describe care that is provided during the period when death is imminent, and life expectancy is limited to a short number of hours or days (The National Clinical Programme for Palliative Care, 2016). The term has been used to describe the last 12 months of life however NCPPC does not use the term in this way. Hospice care is a ‘term that may be used to describe both a place of care (i.e. institution) and a philosophy of care, which may be applied in a wide range of care settings’ and is often used interchangeably with ‘palliative care’. Hospice care aims to improve the lives of people whose illness is no longer curable. It strives to help people to live as fully as possible to the end and provides support to families. It also extends into bereavement care. Hospice care can be provided in a hospice, at home, in a hospital or in a nursing home.

Palliative care provision is underfunded in most developed countries (O’Dowd, 2015; Meier et al., 2017; Canada, 2018). There is an associated lack of high quality research in palliative and end-of-life care (PEoLC), partly due to lack of funding (Halpern, 2015; Higginson, 2016) but also related to sensitivities around the subject of death and dying (Fischer et al., 2012; Chen E. K., et al., 2014). A key challenge relates to the study population where it is difficult to recruit and retain subjects. This is compounded by ethical concerns for vulnerable patients who are often seriously ill as well as methodological concerns including loss to follow up, recall bias or difficulties measuring endpoints such as pain or symptom burden (Chen E. K., et al., 2014).

1.2. Administrative health data

Some of the challenges for PEoLC research can be addressed using routine data, which is defined as ‘non-targeted data obtained from ongoing data collection systems associated with health and social services’ (‘Routine Data’, 2020). Routine data typically include health event data such as birth and death registration, disease registries e.g. cancer registries, health surveys and health activity data that can include information on hospital admissions (Public Health Action Support Team, 2010). Administrative health data reflect the structure and organisation of the health systems from which they derive. The terms ‘routine data’, ‘administrative health care data’, ‘health care utilization data’, and ‘administrative claims data’ are used throughout the literature. The term ‘administrative health data’ is used throughout this thesis to mean routine data derived from a health system.

The use of administrative health data for research purposes is an area of growing interest and several papers have described the challenges and opportunities associated with it (Gavriellov-Yusim & Friger, 2014; Bradley et al., 2010; Bohensky et al., 2010). More recently, its use as a research tool for PEOLC research is an area of increasing international interest (Davies et al., 2016; Maetens et al., 2016; Tanuseputro, 2017).

Davies et al described a number of initiatives that use routine data for PEOLC research in England and elsewhere (Davies et al., 2016). Three priorities for future use of routine data were identified: i) safe and ethical access to data; ii) improved data linkage; and iii) improved PEOLC data collections. In Belgium, Maetens et al identified and described the steps to access, interrogate and link seven population level databases for end-of-life research (Maetens et al., 2016) while in Ontario, Tanuseputro et al used a range of routine data sources to examine the delivery of palliative care across acute care, outpatient clinics, and home care health sectors at the population level (Tanuseputro et al., 2017). Both Ontario and Belgium have almost universal health care coverage so that health insurance databases are generally population based where each individual is uniquely identified. In England, the National Health Service (NHS) is a publically funded (single payer) health care system that uses an NHS number as a unique patient identifier (Boyd et al., 2018). These studies demonstrate the potential of administrative health data for PEOLC research but also that the organisation of a healthcare system impacts what data are available and how it can be leveraged.

1.3. The Irish health service

Unlike most European countries, Ireland has a mixed public private health care system where publically funded health care is managed by the Health Service Executive (HSE) and funded through the tax system (Connolly & Wren, 2019). Those on lower incomes (means tested) are entitled to medical cards which permits free public health services. Individuals without medical cards are entitled to subsidised public hospital services and prescription medicines, but pay the full cost of general practitioner (GP) and other primary care services (Connolly & Wren, 2019). GPs are not directly employed by the government.

There are three types of hospitals in Ireland i) public hospitals which are owned and funded by the HSE, ii) voluntary public hospitals, most of whose income comes from the State but

can be privately owned and managed and iii) private hospitals that receive no state funding. The public health system is provided through HSE and voluntary hospitals, but these can also provide private medical services. On admittance to a public (or voluntary) hospital, patients choose to be treated on a public or private basis by their consultant. Private hospitals operate independently of the State health services and the cost of care must be paid either directly or through private health insurance (Citizensinformation.ie, 2018). In 2017, 33% of the population had a medical card and approximately 43% of the population are covered by private health insurance (Department of Health, 2018)

1.3.1. Structural issues in healthcare organisation and delivery

The mixed public, voluntary and private health system, ad-hoc development of data collections and lack of unique patient identifier has resulted in an information infrastructure that does not link easily across service providers leading to duplication, fragmentation and increased workload. Patients cannot be easily tracked from hospital to community based care leading to large gaps and silos of underused data (Health Information and Quality Authority, 2013). Gaps in data exist particularly from the primary and community care sector as well as from outpatient clinics and emergency department attendances that don't result in hospital admission. The lack of community and social care data is particularly relevant for PEO LC as a considerable amount of palliative care is delivered in the community. Similarly how data are managed and accessed across providers, many of whom are not part of the HSE, is not well defined. Private hospitals do not contribute to the HSE hospital admissions data collection so that studies based on HSE data cannot be generalised to the whole population. Data models describing how the data are stored and organised and/or data dictionaries describing what data are collected are often not available.

1.4. Thesis rationale

The starting point for this thesis was access to population based cancer registry data linked to hospital episode data and death certificate data, created by the process of cancer data registration.

1.4.1. The cancer registry

The National Cancer Registry Ireland, established in 1994, collects population based data on cancer incidence, treatment and survival in Ireland. Population based cancer registration is complex (Tyczynski & Démaret, 2003), to maximise value it is important to ensure all cancer cases are captured and that the data are as complete as possible. In Ireland, this is achieved by active data collection from hospital based medical records, pathology laboratories and general practitioners, supplemented by the interrogation of administrative health datasets including hospital episode data and death certificate data. This process creates a potentially useful but underutilised research resource in the form of a linked health dataset that is, population based cancer registry data linked to hospital episode data and death certificate data.

Ireland has a rapidly aging population and the proportion aged over 65 years has increased by over 19% between 2011 and 2016 (Central Statistics Office, 2019b). The impact of an aging population on the need for forward planning of palliative care services in Ireland has been recognised for serious illnesses (May et al., 2020) including cancer (National Cancer Registry Ireland, 2019a). Cancer accounts for about 30% of all deaths per year in Ireland (Kane et al., 2015) and this is likely to increase as the population ages. Population based cancer registry data linked to hospital episode data and death certificate data has been used for research (Kelly et al., 2012, 2013; McDevitt et al., 2013) but to-date its use for PEO LC research has been limited (Ó Céilleachair et al., 2011; Sharp et al., 2010).

1.4.2. Research aims and objectives

The overarching objective of this thesis is to explore the potential and challenges of using administrative health data for PEO LC in Ireland, more specifically in cancer patients using population based cancer registry data linked to hospital episode data and death certificate data. Informed by the international experience of using administrative health data for PEO LC research and with detailed knowledge of the available linked datasets, the research aims to

- Identify cancer subgroups in need of palliative care.
- Identify receipt of palliative care.
- Compare the characteristics of those who receive palliative care in acute public hospitals and those who do not.
- Explore the relationship between receiving palliative care and place of death.

- Extrapolate the knowledge gained to other health and social care data collections to evaluate the potential and challenges of these data for PEO LC research.
- Develop guidelines for using Irish administrative health and social care data for PEO LC research to maximise its potential as a research tool while identifying the limitations of its use.

This research should provide an added impetus to recent initiatives to improve the research potential of Ireland's health and social data collections (eHealth Ireland, 2018; Houses of the Oireachtas, 2017; Moran et al., 2016).

1.5. Thesis outline

The remaining chapters of the thesis are as follows:

Chapter 2 reviews the literature on the use of administrative health data for PEO LC research nationally and internationally. Chapter 3 provides information on the setting of the Irish health service and the development of palliative care services in Ireland. The permission received to use the data for research is described along with a detailed description of the administrative health datasets used and how the data are linked. The remainder of the chapter describes the methodology for each of the three studies undertaken including, where appropriate, the statistical methods used for data analyses. The results chapters are presented as published articles (Chapter 4 and 5) and an article under review (Chapter 6). The articles are presented with references given at the end of each chapter, formatted as published in the journals. Chapter 4 describes using administrative health data to identify indicators for early assessment for palliative care in lung cancer patients. Chapter 5 examines receipt of specialist palliative care in acute hospitals and place of death. Chapter 6 draws together the knowledge gained from using Irish administrative health data for PEO LC research. It documents in detail the strengths and weaknesses of available administrative health datasets as well as identifying where gaps occur. Chapter 7 draws together the findings from this thesis and summarises the potential and challenges of linked administrative health data for PEO LC research in Ireland and opportunities for further research.

Chapter 2: Literature review

The purpose of this literature review is to critically review how administrative health data are used internationally for PEO LC research. It will examine which data have been utilised for this purpose, identify common themes across the studies undertaken and identify differences in how the data has been used across regions. This in turn will provide insight on how administrative health data can be used for PEO LC research in Ireland and contribute to the international body of knowledge.

2.1. Methodology

2.1.1. Peer reviewed literature

The criteria for the literature review including concepts used, development of the search strategy, the databases searched and the inclusion criteria are given in Table 2.1. Because the primary data sources for this thesis are population based cancer registration data linked to administrative health data, there was a particular focus on cancer patients. The search criteria returned a large volume of material which was further categorised to those using population based data and those using administrative health data from just one or a few health care centres.

The population based material was reviewed in the first instance to identify relevant papers and from these further relevant studies were retrieved from the bibliographies. This iterative or ‘snowball’ methodology identified three key authors who have used administrative health data for PEO LC research at a national level. A number of common themes emerged from these and are described below. Of particular relevance to the thesis aims and objectives was how administrative health data could be used to i) identify the need for palliative care, ii) identify the delivery of palliative care and iii) prognosticate patient outcomes. Using the same snowball methodology all the literature was re-examined to identify how this was done. Throughout the literature review process, data syntheses from systematic reviews were prioritised over reviews of individual papers. The results from the two distinct phases of the literature review are described separately below. The literature review was first conducted in 2015 and repeated in 2017 and 2020.

Table 2.2 Search strategy development

Search Criteria Exploration and Development	Concept 1	Concept 2	Concept 3	Concept 4
	MeSH	MeSH		
	Cancer	'end of life'	administrative	'healthcare utilization'
	Neoplasm	'end-of-life'	'routine data'	'healthcare utilisation'
	Tumour	terminal	-	-
	Tumor	palliative	-	-
		hospice		
Search parameters	Cancer OR tumour OR tumor OR neoplasm	AND ('End of life' OR end-of-life OR 'terminal care' OR 'palliative care' OR 'hospice')	AND (administrative)	AND ('healthcare utilization' OR 'healthcare utilisation')
Databases	MEDLINE	CINAHL	EMBASE	
Fields searched	Title and abstract	Title and abstract	Title and abstract	
Inclusion criteria	Range: 2000-2020 English Language; Human; All Adult: 19+ years			

2.1.2. Grey literature

In addition to the peer-reviewed literature search, a broad search via search engine (Google) for relevant reports and outputs from government departments, health service providers, research institutes, university departments and charities involved in the provision of PEoLC was undertaken. The bibliographies of reports identified as relevant were also checked for any additional references (Appendix A).

2.2. Results

Recent studies indicate the use of administrative health data for PEO LC research is an area of increasing importance with examples from the United Kingdom (Davies et al., 2016), Belgium (Maetens et al., 2016) and Ontario, Canada (Tanuseputro et al., 2017). Their work builds on an established international body of literature and identifies a set of recurring themes that need to be addressed at a national/regional level in order to leverage administrative health data. These authors, and authors they cited, were examined first and used as a roadmap to guide the remainder of this review.

2.2.1. Using administrative health data for PEO LC research

Davies et al (2016) described a series of workshops whose aim was to highlight valuable examples of how administrative health data was used for PEO LC research in the U.K. (Davies et al., 2016). Data sources used included population based death certificate data, hospital activity data and primary care data mainly from general practitioners (GPs). The national hospital activity data set, Hospital Episode Statistics, covers all National Health Service (NHS) hospitals in England (*Hospital Episode Statistics (HES)*, 2020). The Clinical Practice Research Datalink is the largest available collection of primary care data, containing longitudinal medical records on a sample of around 10% of the UK population. Cancer registry data was noted as a national resource for PEO LC but no examples using cancer data were described. Although not strictly administrative health data, the usefulness of large nationally representative surveys to examine variation between groups and evaluate policy was highlighted. The authors drew attention to the lack of social care data and listed examples where locally collected data were used to fill the gaps. Three priorities for the continued use of administrative health data were indicated. These included safe and ethical access to the data, improved data linkage, and the need for more palliative and end of life care specific data.

In Belgium, exploring a similar theme, Maetens et al examined which full-population databases provided valid information about end-of-life care, the procedures in place to use these databases, and what was needed to integrate separate databases (Maetens et al., 2016). The study aim was to retrieve healthcare use data for all decedents for the two years prior to their death. Health insurance is legally mandatory in Belgium, so that reimbursement data of

all legal residents are available from a single agency that manages all healthcare insurers' data. In total seven databases were identified including three health insurance databases which do not have disease specific information; the Belgian cancer registry database which records all incidence of cancer; national death certificate data providing cause of death information; a national census database providing information on household composition, educational attainment and other socio-economic information and augmented by a second national fiscal database with additional socio-economic data. Although hospital activity data were available, they were not used as they only captured hospitalized patients. Instead, cause of death and clinical data abstracted from health care claims data were deemed sufficient to derive individual level data across the entire Belgian population. The authors described the procedures necessary to access the data where two types of approval were needed for every database: i) internal approval from database administrator organizations and ii) approval from the relevant Belgian Privacy Commission bodies. As of 2018, the Belgian Privacy commission has been replaced by the Belgian Data Protection Authority with increased regulatory power so that the requirements for GDPR can be properly enforced (De Smedt, 2017). The process of data linkage was undertaken by trusted third parties to guarantee data privacy. Data linkage was predominantly deterministic based on a common social security identifier across all data sources except for death certificate data. Here, data were linked using date of birth, sex, and municipality of residence.

In Ontario Canada, Tanuseputro et al (Tanuseputro et al., 2017) used linked administrative health data to examine the delivery of palliative care at the population level across all health sectors for all decedents over a two year period in Ontario. Ontario has almost universal health care coverage which includes cover for all residents for costs associated with acute care hospitalizations, physician visits, emergency room visits, long-term care, home care, and complex continuing care as well as medications for those over 65 years and for those receiving social assistance (Tanuseputro et al., 2015). The study population was identified from a population based health insurance database where encrypted health card numbers were used as unique identifiers to link across various administrative databases. Data are held and linked by ICES formerly known as the Institute for Clinical and Evaluative Sciences (Schull et al., 2020). ICES has a special designation under Ontario's *Personal Health Information Protection Act*, granted by the Information and Privacy Commissioner of Ontario which means health

information custodians can disclose personal health information to ICES without consent (ICES, 2020).

These three studies demonstrate the potential of administrative health data for PEO LC research but also highlight how the organisation of a healthcare system impacts what data are available and how it can be leveraged. Both Ontario and Belgium have almost universal health care coverage so that health insurance databases are generally population based and each individual is uniquely identified. This facilitates not only data linkage across databases but also facilitates the de-identification of individuals and anonymisation of the data. The level of health insurance coverage dictates what information is available. In Ontario, population based data are available across a wide range of out-patient services including physician home visits, home care and long-term care services. Both Maetens (Belgium) and Tanuseputro (Ontario) note that non-covered and out-of-pocket medical costs are likely to be missing in their datasets. England's NHS is a population based publicly funded (single payer) health care system that uses an NHS number as a unique patient identifier (Boyd et al., 2018) and so data linkage should be possible. However while infrastructures to link and share health data exist in the UK, many practical and legal obstacles remain (Mourby et al., 2019). Davies highlighted the need for improved data linkage through trusted third parties along with the establishment of a legal basis for the collection, linkage and use of data.

The themes common to these studies include identifying the available data, how that data can be safely and ethically accessed, safeguarding patient privacy, linking data across available datasets and finally recognising the inherent opportunities and limitations of how the data can be used.

2.2.2. Literature review outline

Tanuseputro describes three ways in which linked administrative health data can be used to improve palliative care delivery (Tanuseputro, 2017) These are i) identifying the need for palliative care, ii) identifying the delivery of palliative care and iii) prognostication of patient

outcomes including mortality, hospitalisation and institutionalisation so that those who need palliative care are identified and receive it.

The overarching objective of this thesis is to explore the potential and challenges of using administrative health data for PEO LC in Ireland. The thesis aims are mainly focussed on cancer patients because of the availability and access to population based cancer registry data linked at the person level to hospital episode data and death certificate data. The first two thesis objectives i) to identify cancer subgroups in need of palliative care and ii) to identify receipt of palliative care align closely with the uses of administrative data described by Tanuseputro.

Identifying the need for palliative care is examined in section 2.3. Internationally, studies that estimate the population need for palliative care rely predominantly on death certificate data. Studies focusing on the palliative care needs of the individual rely on a wider range of data sources and are concerned with capturing information on the patient experience in a predefined time period before death. This literature review focussed on studies that used measures derived from administrative health data that include death certificate data (cause and place of death), claims data (for chemotherapy billing, intensive care unit and hospice admission information) and hospital episode data (information on admission type, discharge location, clinical diagnosis and/or death in acute care setting). Subgroup analysis by a range of characteristics that can include combinations of age, disease type, method of presentation and place of death have been used as markers of appropriate or inappropriate care at end of life.

Section 2.4 is concerned with identifying receipt of palliative care. The extent to which palliative care receipt can be identified from administrative health data relies not only on how healthcare is structured and funded within a country but also the care setting e.g. hospital, home, hospice and/or the community. This section examines how palliative care receipt has been identified in different jurisdictions and in different care settings. The characteristics of those who receive palliative care is broadly described.

A more detailed examination of the relationship between patient characteristics, receipt of palliative care, place of care and place of death is given in section 2.5. Factors contributing to regional variation in place of death are considered including the role of healthcare organisation and policy.

Section 2.6 examines how linked administrative health data has been used internationally for prognostication of patient outcomes (mortality, hospitalisation and institutionalisation) so that those who need palliative care are identified and receive it. This was the third use of linked administrative health data identified by Tanuseputro to improve palliative care delivery (Tanuseputro, 2017). Section 2.7 reviews the literature around PEOLC research in Ireland with a particular emphasis on studies that have used administrative health data. The last section 2.8 summarises the findings and outlines the research gap this thesis addresses.

2.3. Identifying the need for palliative care

2.3.1. The need for palliative care at a population level

Identifying the need for palliative care at the population level has been researched extensively. Death certificate data either on its own or in conjunction with additional sources underpins this research and relies on the principle of quantifying at the population level mortality from diseases with an associated palliative care need. Death certificate data uses *International Statistical Classification of Diseases and Related Health Problems–10th Revision (ICD-10)* (World Health Organization, 2004) codes to record an underlying and contributory cause of death. Global estimates on the need for palliative care are based primarily on the ICD codes recorded on death certificate mortality data for diseases requiring palliative care, adjusted by estimated symptom prevalence for each disease category (Connor et al., 2014; Murtagh et al., 2014). The methodology was first described by Higginson (Higginson, 1997) and modifications of the methodology have been used to generate population based estimates.

In Australia, Rosenwax et al used mortality data linked to hospital admissions data to generate a minimal, an intermediate (based on all deaths hospitalised with the same condition certified

on the death certificate), and a maximal estimate of need (more disease categories included) (Rosenwax et al., 2005). In Spain, Gómez-Batiste et al used mortality data and either a flat rate percentage of 75% for all diseases and all deaths (Gómez-Batiste et al., 2012) or more recently directly measured prevalence of disease in chronically ill patients (Gómez-Batiste et al., 2014). Murtagh et al reviewed these methods and made a number of refinements including i) reviewing and updating the disease classification codes used in the models, ii) examining in more detail the role of the main and contributory causes of death and iii) considering the pattern of hospitalisations in the year before death (Murtagh et al., 2014). Diseases identified as having a palliative care need include malignant neoplasm, heart disease including cerebrovascular disease, renal disease, liver disease, respiratory disease, neurodegenerative disease that include Alzheimer's, dementia and senility and HIV/AIDS.

The methodologies were then compared by estimating the population need for palliative care using all deaths in England between 2006 and 2008. The refined method estimated a minimum of 63% of all deaths may need palliative care compared to just 37% using the Rosenwax method. Some of the differences are due to the inclusion of extra disease categories e.g. chronic heart disease and stroke and the expansion of others such as Alzheimer's to include other dementias.

In Germany, Scholten et al used the Murtagh and Rosenwax methodology to estimate palliative care need but did not have access to hospital episode data (Scholten et al., 2016). The Rosenwax method was used to compare the population based need for palliative care across 14 countries by Pivodic et al using 2008 death certificate data from each country (Pivodic et al., 2016). The relationship between place of death, cause of death, sociodemographic variables and health care characteristics for diseases which are indicative of palliative care need was investigated. These included cancer, heart/renal/liver failure, chronic obstructive pulmonary disease, diseases of the nervous system and HIV/AIDS.

Morin et al estimated the need for palliative care across 12 countries using three estimation methods, i) Rosenwax et al, ii) the Murtagh et al and one other (Morin et al., 2017). Irrespective of methodology used, the authors found home and nursing home were the two places of deaths with the highest prevalence of palliative care needs although it is not clear if there was any association with particular disease groups.

Brameld et al highlights that estimates produced often depend on the data sources used as there can be differences in the way data are recorded across data sources (Brameld et al., 2017). There is variation within diseases on how accurately they are recorded. For example, neoplasms are generally recorded across all data sources while COPD, renal disease and heart disease are underreported in death certificate data (Murtagh et al., 2014) but are more common in hospital episode data. Age and sex variations exist by data source and by disease condition, so that use of different administrative data sources can give varying results for the estimate of the size of the population in need of palliative care and the frequency of conditions needing palliative care. For example, the Brameld study population used death certificate data for people who died in Western Australia in 2009 and 2010 aged 20 years or older, linked to hospital episode data. It reported that between 43% and 73% of the 23,852 people who died had a condition potentially amenable to palliative care, depending on the information source(s) used.

These studies highlight the importance of death certificate data for service planning for palliative care needs at the population level.

2.3.2. Identifying the need of palliative care at the individual level

Death in an acute care setting was first identified as a quality measure for end of life care by Earle et al in 2003 (Earle et al., 2003). Using a mixture of literature review, focus groups and expert panel opinion, the authors identified and evaluated candidate quality performance measures that could be derived from administrative data to profile cancer care near the end of life (Earle et al., 2003). Three concepts of poor quality of care were identified: i) the initiation of new anticancer therapies or continuation of ongoing treatments very near death, ii) a high number of emergency room visits, inpatient hospital admissions, and days spent in the ICU near the end of life, and iii) a high proportion of patients never referred to hospice or only referred in the last few days of life, or death in an acute-care setting. These indicators relied on access to a variety of data sources including death certificate data as described above, claims data and hospital episode data. Based on this early work by Earle, numerous studies worldwide have used these measures to examine end of life care. These fall into two main categories: i) studies of the intensity of end of life care and ii) studies of healthcare utilisation at end of life.

The studies are informative because they seek to identify patients who may have received inappropriate care near death using administrative health data. Two systematic reviews examine most of this work, the first focusses on the intensity of care (Luta et al., 2015) and the second on healthcare utilisation (Langton et al., 2014) at end of life.

Luta et al summarised the features, characteristics of use and reported validity of measures across 58 studies investigating intensity of end of life care (Luta et al., 2015). Measures of intensity were defined as all quantifiable measures describing the type and intensity of medical care administered during the last year of life. Hospitalisations (44 studies), intensive care unit (ICU) admissions (39 studies) and chemotherapy use (27 studies) were the most commonly reported measures. Less than half (24 of the 58) of the studies reviewed were specifically concerned with measuring intensity of care, the remaining studies measured a variety of related measures including healthcare utilisation at the end of life, variation in care across different settings at end of life, population and time trends and the quality of end of life care. The time frames examined for intensity of care ranged from 48 hours to 12 months. Only four studies reported any information on validation of the measures used. Nearly all the studies used administrative data and the majority were in patients aged 65 years or over. The vast majority of studies were from North America (45 studies), with 8 from Europe, 4 from Asia and 1 from Australia. In the review the authors identified a number of limitations including a lack of agreement on the definition for intensity of end of life care, a lack of validation for the measures used and of most relevance to this thesis, little agreement on the end of life timeframe. Most studies were concerned with cancer patients (31 studies) but differences in survival and therefore end-of-life timeframe by disease and/or cancer subtype were not considered.

Langton et al reviewed 78 studies published between 1990 and 2011, that examined end of life resource utilisation and cost in cancer care (Langton et al., 2014). Of these, 14 were part of the 2015 systematic review by Luta et al (Luta et al., 2015). The study population comprised over 3.7 million adult cancer decedents with solid tumours. Resource utilisation included diagnostic tests, hospital admissions, emergency department visits, ICU use, and medications including chemotherapy, surgery and palliative care services such as hospice and community care. A number of studies (n = 15) examined resource use in terms of quality indicators of end of life which were generally classified as ‘aggressive’ or ‘palliative’. The majority were

focussed on care delivered in the last month of life. Across all studies the most common end of life period was 6 to 9 months (49 studies) but ranged from 3 days to 3 years. The majority of the studies originated in North America (55 studies) with 10 from Europe, 8 from Asia and 5 from Australia. The study population in 54 studies was decedents with any solid tumour cancer diagnosis (categorised using ICD codes). Decedents were identified from cancer registries (32 studies), administrative health claims (17 studies), death certificate data (10 studies), health insurance databases (4 studies) with the remainder from a combination of sources. In 50 studies, the decedents died from cancer. The most common resource utilisation measures were hospital admissions, ICU use and emergency department attendance. The review found an increase in service use as death approached, with hospital costs highest. Fifteen studies using quality of care indicators showed approximately 38% of cancer patient received chemotherapy or life sustaining treatments in the last month of life and up to 66% did not receive palliative care services (hospice or community care). Quality indicators for palliative care included hospice care, pain relief (opioids), and primary and community care at the end-of-life.

In Ontario Canada, Tanuseputro et al used population based administrative databases linked to death certificate data for all deaths from April 2010 – March 2013 inclusive (n= 264, 755 deaths), to examine health care use and cost in the last year of life across several healthcare sectors (Tanuseputro et al., 2015). These included inpatient, outpatient, long term and home care sectors. About 75% of decedents had inpatient care, 25% used long-term care and 60% used home care. Costs rose sharply in the last 120 days prior to death primarily for inpatient care.

Bekelman et al conducted a retrospective cohort study comparing site of death (acute care hospital), health care utilisation (hospitalizations in acute care hospitals, admissions to ICUs, emergency department visits, chemotherapy episodes) and hospital expenditures (from claims data, either commercial or governmental) in persons dying of cancer from seven developed countries (Belgium, Canada, England, Germany, the Netherlands, Norway, and the United States) in 2010 (Bekelman et al., 2016). Health care utilisation and hospital expenditure was examined during the 180 day and 30 day period before death. Separate analyses were conducted for i) decedents from all countries in those aged 65 year over, ii) for all ages in all countries

excluding the United States and iii) for all decedents with lung cancer aged 65 years or older. The data sources for this study included claims data, hospital episode data, cancer registry data and death certificate data. Death rates in acute hospitals ranged from 52% in Canada to just over 20% in the United States across the seven developed countries for decedents with any cancer aged 65 years and over. End-of-life care was more hospital-centric in Belgium, Canada, England, Germany, and Norway than in the Netherlands or the United States.

These studies highlight several limitations that need to be considered when using administrative health data for PEoLC research. The lack of consensus on the end-of-life time frame reported for all diseases (Langton et al., 2014; Luta et al., 2015) is unsurprising given the variation of survival times both across all diseases and by cancer subtypes (*Cancer Survival Statistics*, 2015). Some addressed this issue by doing a subgroup analysis by cancer type e.g. lung cancer patients (Bekelman et al., 2016). Although a number of studies had access to cancer registry data, none reported survival times or attempted to characterise end-of-life timeframes by cancer type. Looking forward from an event such as a cancer diagnosis (i.e. using date of incidence from cancer registry data) may be more informative than looking back from death, particularly for cancers with poor survival such as lung cancer (*Cancer Survival Statistics*, 2015). Langton et al stressed the importance of understanding features of individual health systems and study populations when making comparisons across health systems (Langton et al., 2014).

2.3.3. Palliative care need in vulnerable subgroups

Certain palliative care subpopulations have been identified as having less frequent access to specialist palliative care (Currow et al., 2008). These include the elderly, those in rural and remote areas, members of indigenous communities, people from non-English speaking backgrounds, people from lower socioeconomic backgrounds and those without caregivers. In a critical review of 10 studies from the USA, Canada, France, Australia and New Zealand, Wong et al highlighted an absence of evidence regarding the palliative care requirements of older patients particularly those presenting to emergency departments, with a call for more research to help improve service provision (Wong et al., 2014). Eight of the studies used a clinical diagnosis to identify patients with palliative care needs. Disease categories included

cancer, neurological diseases (Alzheimer's, Parkinson's and motor neurone), cardiopulmonary diseases including congestive heart failure and chronic obstructive pulmonary disease, organ failures (renal and liver), end stage liver disease and diseases of the immune system including HIV and AIDS. These are similar to those identified previously (Murtagh et al., 2014).

In Scotland, Brewster et al used cancer registry records linked to hospital discharge and death records to explore the characteristics of patients dying within 30 days of being diagnosed with breast or colorectal cancer in Scotland during 2003-2007 (Brewster et al., 2011). Being elderly and one or more emergency admission in the 30 days either before or after diagnosis were most strongly associated with dying within 30 days of diagnosis. Similarly McPhail et al used cancer registry data linked to hospital episode data and death certificate data to identify cancer patients diagnosed via emergency presentation for all newly diagnosed cancers in England between 2006 and 2008 (McPhail et al., 2013). Emergency presentation was predictive of short-term mortality in cancer patients even when age, stage, and co-morbidity were accounted for. Although similarly linked datasets are available in Ireland no such studies have been done. Using administrative health data to identify receipt of palliative care and thus compare characteristics of those who have and have not received palliative care is another way in which vulnerable subgroups might be identified.

2.4. Identifying receipt of palliative care

A value of administrative health data for PEOLC research lies in the ability to determine that palliative care has been received. Internationally studies that used administrative health data to identify receipt of palliative care are mostly from health regions with universal health care systems and rely on billing codes in claims data e.g. Ontario (Jang et al., 2015; Tanuseputro et al., 2017), Belgium (Maetens et al., 2016) and Taiwan (Chang et al., 2016).

2.4.1. Health insurance data

Using linked data from several population databases from Ontario, Jang et al investigated the association between receipt of palliative care and aggressive end of life care in patients with advanced pancreatic cancer (Jang et al., 2015). Physician billing data using Ontario Health

Insurance Plan (OHIP) database were used to identify receipt of palliative care consultation based on the use of a palliative care billing code (Ontario Medical Association, 2014). Just over 52.3% of n = 5381 patients received a palliative care consultation which was associated with lower odds of aggressive care.

Using a similar methodology Tanuseputro et al identified the delivery of palliative care from a documented range of billing and diagnostic codes used to capture aspects of palliative care delivery from a variety of data sources. These included the OHIP database, the Canadian Institute for Health Information Discharge Abstract Database, the National Ambulatory Care Reporting System, Home Care Database, long-term care facilities and Complex Continuing Care systems (Tanuseputro et al., 2017). The study population comprised all decedents in Ontario, Canada, from 1 April 2010 to 31 March 2012 (n = 177,817). Across all health sectors, just over 50% (n= 92,276) decedents had at least one record of palliative care in the last year of life and 84.9% received palliative care in acute hospitals. The authors acknowledge underreporting of palliative care is a limitation in all population-level administrative data but also that it represents one of the few methods to examine palliative care at the population level. Suggested reasons for under coding of palliative care in administrative data include a lack of awareness of palliative care billing codes so that regular visit codes are used instead. This is particularly true of nursing homes where patients are frail and approaching end-of-life but this care is seen as general health care and not coded accurately. Also the diversity of palliative care delivery models across multiple disciplines means the true extent of palliative and end-of-life care delivery is difficult to define and capture using administrative data alone (Hsu & Tanuseputro, 2017).

Palliative care is legally recognised as a right in Belgium where a highly organised palliative care system is underpinned by a legal framework (Keirse et al., 2009). Palliative care networks exist in all provinces in Belgium. Financial measures include the provision of a palliative care flat fee paid to the individual which covers additional costs for home care while procedures performed by general practitioners, nurses and physical therapists providing palliative care are also covered. Two types of palliative care facilities have been set up in hospitals. These include a small palliative care unit (providing approximately 400 beds for the whole country), and mobile teams who provide specific support to end-of-life patients who are hospitalised in other

departments. A similar palliative function has been created in nursing care facilities. The databases used by Maetens et al to investigate end-of-life care at the population level in Belgium (Maetens et al., 2016) included three health insurance databases, cancer registry data, national census data, death certificate data as well as national fiscal and education data. The authors stressed the need for adequate validation processes when using the data but noted services not covered by insurers are not included in the data; for example, there is no individual reimbursement for mobile hospital palliative care teams.

Taiwan has a universal health care system that ensures patients have free access to any health care system and provider they choose. Health care systems are reimbursed for services provided, and co-payment is waived for patients with recognized major diseases, including malignancy. By linking data from National Register of Deaths Database, Cancer Registration System database, and National Health Insurance claims database, population based data are available for study. Inpatient palliative care qualifies for reimbursement and enrolment in hospice services has been used as a marker for palliative care receipt (Chang et al., 2016; Chiang et al., 2017; Wang et al., 2016). Claims data are validated by the Bureau of National Health Insurance by randomly interviewing and reviewing the charts of one claimant for every 100 ambulatory care claims and one for every 20 inpatient claims. A number of studies using these administrative data have been included in the review by Luta et al (Tang et al., 2009) and Langton et al (Tang et al., 2010, 2010, 2011). Recent studies using this population level data investigate the differences between inpatient palliative care and acute hospital care for inpatients with pancreatic cancer (Wang et al., 2016), examining the readmission rates and experiences of patients who have received in-patient palliative care (Chang et al., 2016) and an examination of the effect of hospice care on quality of end-of-life care for patients with advanced cancer in Taiwan between 2002 and 2011 (Chiang et al., 2017).

2.4.2. Hospital based palliative care

Several studies from Australia used a consultation or care with the hospital based palliative care services from hospital episode data to identify receipt of specialist palliative care, (Sundararajan et al., 2014; Philip et al., 2015; Rosenwax et al., 2016). In Victoria Australia,

Sundararajan et al used linked hospital, emergency department and death data to examine the association between symptom burden and palliative care receipt (i.e. referral to a palliative care program or a palliative care consultation) from first hospitalisation until death in glioblastoma patients (Sundararajan et al., 2014). The datasets were linked by the Victoria Department of Health and data quality was checked by a series of internal logic checks and manual review of randomly selected case groups. Patients with high symptom burden were more likely to receive palliative care and those who did were less likely to die in hospital. In related work, Philip et al investigated the timing of palliative care for metastatic small cell lung cancer patients (Philip et al., 2015) and found patients had late engagement with palliative care. In both studies palliative care was defined as consultation or care with the hospital based palliative care service and used the 8th edition of the Australian Classification of Health Intervention Codes (*Australian Classification of Health Interventions (ACHI) 8th Edition*, 2016).

Rosenwax et al used de-identified and linked extraction of death records, hospital morbidity records and community-based care to examine who had access to specialist palliative care in hospital or the community in Western Australia (WA) in the last year of life ((Rosenwax et al., 2016)). Specialist palliative care was defined as receiving specific community-based or hospital-based palliative care. Community-based care data was defined as care provided by a single not-for-profit organisation that provides over 90% of all in-home health care and 100% of in-home palliative care in WA. Hospital-based palliative care in WA is classified as care in a hospital palliative care unit, in a designated palliative care program or under the principal clinical management of a palliative care physician, or when the clinical intent of care is palliation. Hospital-based palliative care was identified from hospital morbidity records where the episode of care was coded as palliative. In WA, the care type of an episode of care is determined by the medical practitioner responsible for the management of the patient care (Department of Health, Government of Western Australia, 2018). Currently there are 10 care types one of which is palliative care.

2.4.3. Death in an in hospice setting

Death in a hospice setting has also been used as a marker for receipt of palliative care (Coupland et al., 2011; Sleeman et al., 2016).

2.4.4. Characteristics of those who receive palliative care

The 2017 population based study of PEOLC in Ontario decedents across all healthcare setting by Tanusupetro et al found being female, middle-aged, living in wealthier and urban neighbourhoods, having cancer, and less multi-morbidity were all associated with higher odds of palliative care (Tanuseputro et al., 2017). Most palliative care (84.9%) was delivered in acute care hospitals and half of all palliative care was initiated in the last two months of life. A second study using the same data sources examined access to palliative care by disease trajectory. Three trajectories based on cause of death were considered i) terminal illness typical of cancer (high function with acute decline), ii) organ failure typical of heart and lung disease (high-medium function with acute intermitted exacerbations and partial recovery) iii) frailty typical of dementia (low function and gradual decline). Terminal illness decedents were more likely to receive any palliative care in the 12 months before death than organ failure or frailty decedents. Across all settings, 88% of those with terminal illness received palliative care and terminal illness decedents (76%) were twice as likely to receive palliative care, as hospital inpatients, than the other trajectories (Seow et al., 2018).

The 2016 Rosenwax study investigating receipt of palliative care in hospital or the community in the last year of life in Western Australia identified n = 12817 deaths in 2009 and 2010 from cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, Alzheimer's disease, motor neurone disease, Parkinson's disease, Huntington's disease and/or HIV/AIDS. (Rosenwax et al., 2016). The majority (69 %; n = 4928) of decedents with cancer accessed palliative care during the last year of life, while only 14 % (n = 729) of decedents with non-cancer conditions accessed specialist palliative care.

A detailed examination of inpatient hospice deaths in England using death certificate data showed just over 5% of all adult hospice decedents between 1993 and 2012 had a non-cancer diagnosis although the likelihood of non-cancer conditions increased over the time period. The study also found inpatient hospice death was more likely among decedents living in less deprived areas (Sleeman et al., 2016).

Coupland et al used cancer registry data linked to death certificate data to examine ethnic variation in place of death (Coupland et al., 2011). The study population included all lung, colorectal, breast and prostate cancer patient from South East England who died between 1998 and 2006. Only patients dying in a hospice could be identified as having received specialist palliative care and Asian patients were significantly less likely than White patients to die in a hospice.

Using the data infrastructure described previously (Maetens et al., 2016), De Schreye et al conducted a population-level retrospective observational study of all cancer decedents in Belgium in 2012 (n =26 400) to assess end-of-life care and risk factors for exposure to care (De Schreye et al., 2017). Almost half (47%) of the decedents received specialist palliative care (defined as admission to a hospital palliative care unit or receiving multidisciplinary home care) while 17% had palliative care initiated in the last fourteen days of life.

These studies indicate cancer patients are more likely to receive palliative care than non-cancer patients and this is partly due to the predictability of patient decline and the history of hospice care for cancer patients (Seow et al., 2018; Sleeman et al., 2016). However the relationship between patient characteristics and receipt of palliative care are complex. The disease type and associated trajectory often determines the place of care, for example dementia patients are normally cared for in a long-term care setting. Place of care can determine the availability of PEOC which in turn relies on the healthcare model (structure, organisation, funding) and healthcare policy. By definition, place of death is the final place of care and has been widely used as an indicator of how palliative care is organized and provided. Section 1.5 examines the factors affecting place of death.

2.5. Factors affecting place of death

In a literature review of 58 studies of terminally ill cancer patients, Gomes et al found that the network of factors related to where patients die was complicated (Gomes & Higginson, 2006). Three groups of factors were found to be important: those related to the individual, the illness and the environment. Individual-related factors included sociodemographic characteristics

(education, social class and income) and patient's preference for place of death. In terms of illness there was consistently strong evidence that patients with non-solid tumours were more likely to die in hospital, while those with a long illness trajectory and low functional status were more likely to die at home. The authors suggest the long illness trajectory might facilitate patient preference for a home death. Environment-related factors included healthcare input (e.g. home care, hospital and hospice bed availability, and hospital admissions), social support (e.g. a patient's living arrangements and social support network) as well as macrosocial factors (historical trends, health care policy, and cultural factors). Factors related to the environment (healthcare input and social support) were considered the most important.

Costa et al examined the evidence base to assess which factors are associated with place of death (Costa, 2014). The study examined two systematic reviews including the Gomes review and 29 observational studies from Canada, Asia, Europe, the United States, Mexico and New Zealand. Study participants were adults diagnosed with an advanced, life-limiting condition who were not expected to improve. Outcomes of interest included home death, hospital deaths, nursing home deaths, inpatient palliative care unit deaths and inpatient hospice deaths. Determinants of place of death included type of disease, hospital admission, functional status, pain, palliative care in place of residence, availability of beds, patient or family preference for place of death, marital status or living arrangements and characteristics of the caregiver. The study found the determinants varied depending on the place of death and the type of disease with cancer patients more likely to die at home. The availability of palliative care at any location improved the chances of dying at that location, but earlier referral (one month or more before death) reduced the likelihood of hospital deaths.

2.5.1. Individual level factors affecting place of death

A study of all cancer deaths in England from 1993-2010 found hospital the most common place of death throughout the study period (Gao et al., 2013). Patients with haematological cancers, not partnered and aged over 75 years were less likely to die at home or in hospice. Cancer type and marital status were most strongly associated with place of death. Patients from less deprived areas were more likely to die at home or in a hospice relative to those from more deprived areas. The study did not provide information on patient preference for place of death.

A study based on death certificate data of 20 710 cancer deaths in 2012 in Sweden found hospital the most common place of death for cancer patients where 50.9% of deaths occurred (Öhlén et al., 2017). Death at home was most common for upper gastrointestinal cancer (25.6% died at home) and least common for haematological cancers (15.2% died at home). Individuals living at home or in nursing homes who were married were less likely to die in hospital.

2.5.2. Palliative care and place of death

The evidence base for the effect of palliative care on subsequent place of death from administrative health data is limited. In a systematic review, Costa et al found the availability of palliative care at any location improved the chances of dying at that location, but earlier referral reduced the likelihood of hospital deaths (Costa, 2014). Patient preference for home death and advance care directives for nursing homes were important factors for death at those locations, suggesting access to palliative care allowed for patient and/or family preferences to be taken into account. A cancer diagnosis and a longer time between referral to palliative care and death increased the likelihood of inpatient hospice death.

Using data from a London-based electronic palliative care register, Orlovic et al examined determinants of dying in hospital in a retrospective observational cohort study of 21,231 individuals aged 18 or older who had died between March 2011 and July 2019 with a recorded place of death (Orlovic et al., 2020). Electronic palliative care registers are designed to record and share with relevant care providers a patient's preferences around place of death and resuscitation. Frail individuals and those with long-term diseases such as cancer had a higher likelihood of dying out of hospital relative to those with heart or respiratory disease, however documented end of life preference was most strongly associated with subsequent place of death. The likelihood of dying in hospital was higher in patients who did not have a documented preference for the place of death (OR = 1.43, 95% CI 1.26–1.62, $p < 0.001$). Individuals who were “not for resuscitation” had a 57% lower chance of dying in hospital while those with a documented preference for symptomatic treatment were 64% less likely to die in hospital compared to individuals who preferred full treatment.

Chen et al report that specialist palliative care may modify the effect of socioeconomic status (SES) on place of death in a narrative synthesis of nine observational studies from Spain, United States, Japan, Canada and New Zealand (Chen H., et al., 2016). Two of the seven studies found statistically significant differences in place of death by SES. The first study used retrospective administrative data from a hospice in New Zealand for 1268 patients of whom 82% had cancer, 72% were aged 65 years and older and 82% were European. All received home, outpatient and/or inpatient palliative care. Having a community service card was used as a crude marker of lower SES and was associated with increased odds of death in an acute hospital rather than at home. The second study used an administrative dataset from a hospice provider that operated 26 hospice programmes in eight states in the United States. Of 61,063 patients, 64.2% had cancer, 70.2% were White and 77.7% were aged 65 years and over. SES was categorised based on income. Patients received either standard home based specialist palliative care or more intensive needs based palliative care. The study showed the odds of non-home death increased as median annual household income decreased in those receiving standard care but no significant difference across income levels for those receiving more intensive needs based care.

2.5.3. Regional variation in place of death

The 2018 atlas of variation for palliative and end of life care in England (Public Health England, 2018) reported regional variation for all 29 indicators of palliative care need. The indicators cover three domains i) the need for palliative and end of life care with 10 indicators, ii) the role of hospitals in palliative and end of life care with 7 indicators, and iii) palliative and end of life care in the community setting with 11 indicators. Cancer care indicators included variation in the proportion of all people who died in 2015 with an underlying cause of cancer (need for palliative and end of life care domain), and variation in the proportion of all people that died in a hospice in 2015 with a recorded cause of death as cancer (palliative and end of life care in the community domain). The indicators for end-of-life-care in hospitals include deaths in a hospital, hospital admissions in last 90 days, 3 or more emergency admissions in last 90 days, admissions ending in death that lasted 8 days or longer, recognition of dying, communication about dying, holistic needs assessment and provision of face-to-face specialist palliative care. For every indicator there was geographical variation across England. The only

direct measure of specialist palliative i.e. provision of face-to-face specialist palliative care was derived from Royal College of Physicians (RCP) ‘End of life care audit – dying in hospital’ (Royal College of Physicians, 2016). Palliative care in the community indicators were derived mostly by analysis of place of death (care homes and hospice), general practitioner disease registers and examination of service levels e.g. number of care home beds in the community.

A study of all adult deaths (aged 25 years and over) in England in 2014 (Gao et al., 2019) found health service type (adult inpatient hospice, hospitals, general practitioner and care homes) and capacity (ratio of service facilities to user population, counts of services types within functional areas,) were the strongest predictors of the area-level variation in place of death. Service location, that is the distance from the residential address of the deceased to the nearest care facility, showed consistent effects on place of death. Overall, the increased distance to a specific institutional care setting was associated with a reduced chance of dying in that care setting, particularly for care home and hospice deaths. Data were derived from a variety of sources that included NHS England, Hospice UK, Hospice Aid UK website and the Care Quality Commission website. The study identified large gaps in data, for example there was no master list of hospices in England nor a central facility to collect national data on hospice capacity. The study highlighted the need to develop systems to collect robust national data on palliative and end-of-life care services to enable evidence-based service commission, planning, design and delivery.

In Sweden Öhlén et al reported large variations in the place of death between the different healthcare regions in the country (Öhlén et al., 2017). The authors suggest the cross-regional variation may be due to differences in healthcare organisation leading to variation in the development of hospice and specialized palliative care services nationally.

2.5.4. Healthcare organisation, policy and place of death

Cohen et al compared the place of death of people with cancer (ICD-10 codes C00-C97) using 2008 death certificate data from 14 countries: Belgium, Canada (excluding Quebec), Czech Republic, England, Wales, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, South Korea, Andalusia in Spain (data from 2010) and USA (data from 2007), (Cohen et al., 2015). The study reported between 12% (South Korea) and 57% (Mexico) of cancer deaths occurred at home, and between 26% (the Netherlands and New Zealand) and 87% (South Korea) of cancer deaths occurred in hospital. Cancer type (solid tumour) and being married were most consistently associated with home deaths across countries. The authors noted large country specific variations may be due in part to differences in health care resources, how the health care system is organised as well as cultural and social differences including health care policy specific to end-of-life care. Using the same data, a related 2016 study by Pivodic et al found for a number of diseases indicative of the need for palliative care, between 13% (Canada) and 53% (Mexico) of people died at home and between 25% (the Netherlands) and 85% (South Korea) died in hospital (Pivodic et al., 2016). Differences between countries in home versus hospital death were only partly explained by the factors examined so that place of death was not entirely attributable to sociodemographic characteristics, cause of death or availability of healthcare resources. The authors suggested a country's palliative and end-of-life care policies may influence where people die.

2.6. Prognostication of patient outcomes

Using administrative health data for prognostication of patient outcomes is well established with the development of the Charlson index of comorbidity (Charlson et al., 1987) and the Elixhauser index (Elixhauser et al., 1998). The comorbidities included in the Charlson index had been defined based on clinical data but have been translated into ICD codes used by administrative data such as hospital episode data (Quan et al., 2011). The Charlson index was designed to predict one-year mortality while Elixhauser was designed to predict length of stay, hospital charges, and in-hospital death (Sharabiani et al., 2012). Hsu et al used administrative health home care data from Ontario Canada to develop a mortality risk algorithm to predict survival time for community-dwelling older adults who may be nearing the end of life (Hsu et al., 2016).

The use of machine learning (ML) to improve palliative and end of life care using health administrative data is an area of growing interest. In a rapid review of published studies that use ML to improve palliative care, three studies were included in the final assessment (Storick et al., 2019). The data sources of the three studies included were US Medicare data (two studies) and data from electronic health records (EHR) from a six-hospital network in Minnesota. Outcomes of interest were survival, quality of life, place of death, costs, and receipt of high-intensity treatment near end of life. Depending on the data source, predictors included demographic data, ICD codes, chronic conditions, functional status, vital signs, blood count, and metabolic panel data. The review found ML approaches are powerful in predicting 12 month mortality in older and/or hospitalised adults and superior to traditional logistic regression but only when sufficient data (particularly physiological and biochemical data) are available.

2.7. PEOLC research in Ireland using administrative health data

Two systematic reviews of PEOLC research on the island of Ireland have also been carried out (McIlfatrick S. et al., 2018; McIlfatrick S. & Murphy, 2013).

The 2013 review identified 151 studies from 2002 to 2012 of which 66 were quantitative, 58 were qualitative, 27 used mixed methods and 6 were systematic reviews. Of the quantitative studies, only two were population based. These were from the National Cancer Registry Ireland and examined trends in place of death for colorectal cancer (n= 10175 deaths, 1994-2004) (Céilleachair et al., 2010) and lung cancer (n= 18078 deaths, 1995-2005) (Sharp et al., 2010) using cancer registry data linked to national death certificate data (hospital episode data were not used). In both cases, the number of deaths in hospital was unchanged over the study period (49% of colorectal deaths and 52.5% of lung deaths). For colorectal cancer decedents, hospice deaths rose between 1994 and 2003 while home deaths decreased but only in regions with inpatient hospice services. For lung cancer decedents hospital deaths were more common in areas without a hospice. A third quantitative study was a retrospective case review of n= 695 adult patients with cancer which examined reasons for death in acute hospitals in Northern Ireland. The study participants who died between July and December 2007 in 16 acute hospitals were identified through the Northern Irish Cancer Registry (Blaney et al., 2011). Three main reasons for acute hospital deaths were identified: i) over one quarter of

patients were diagnosed with cancer during their last hospital admission and were found to be older and sicker than the rest of the sample, and without a partner, ii) patients were very ill with over three quarters admitted as an emergency, requiring medical attention as a result of cancer-related and urgent physical symptom and iii) despite over one third of patients specifically requesting discharge to their usual residence, hospice or other hospital, this was not achieved. This led the authors to conclude that late diagnosis of cancer is a problem which requires further research.

The follow-up systematic review covered the period from May 2012 to April 2017 and identified 117 studies representing a 100% increase in palliative care research on the island of Ireland compared to the ten year period up to 2012 (McIlfatrick S. et al., 2018). The dominant research theme was a focus on specific groups, services, and settings. The most common conditions included cancer (12 studies), dementia (12 studies) and Parkinson's disease (6 studies). Hospice care was the theme for five studies and five studies focused on coordinating care across services. Research gaps around community based palliative care and out of hours' palliative care were identified.

Only three studies included in the review used administrative health data. The first (Kane et al., 2015) used death certificate data from the Central Statistics Office for the period 2007 – 2011 (n = 141 807 deaths) to estimate the potential population with generalist and/or specialist palliative care needs in Ireland using the methodology described by Murtagh et al (Murtagh et al., 2014). Over the study period, 82% of deaths from diseases identified as having a palliative care need were in decedents aged 65 years and over thus indicating an increased need for palliative care in Ireland given the rapidly aging population. As only the underlying cause of death was available from the dataset, a minimal estimate of need for palliative care was produced.

The second study was a national audit of End-of-Life Care in Hospitals in Ireland carried out in 2008/9 (McKeown et al., 2015). It was based on a sample of 1,000 deaths with data collected from nurses, doctors and relatives who spent the most time with the patient during the last week of life. The audit is a representative sample of 10% of acute hospital deaths and 29% of community hospital deaths in Ireland in 2008/9. The study showed significant

differences in how care outcomes, including pain, were assessed by nurses, doctors and relatives. This audit informed the development of a set of Quality Standards for End-of-Life Care (Donovan, 2010) in Irish hospitals by the Hospice Friendly Hospitals programme which was initiated by the Irish Hospice Foundation in May 2007.

The third study used individual-level patient records from the National Cancer Registry Ireland (NCRI) linked to prescription dispensing records from the HSE Primary Care Reimbursement Services (PCRS) pharmacy claims database to describe the changes in statin initiation and continuation prior to death in patients with breast or colorectal cancer in the five years prior to death (Smith et al., 2017). In patients with reduced life expectancy, there may be a substantial increase in pharmacotherapeutic burden. Statin use in these patients may be limited and should be considered for discontinuation. The study population were patients diagnosed with stages I–III, invasive breast (ICD-10 C50) or colorectal cancer (ICD-10 C18-C20), between 1 January 2001 and 31 December 2009 who had continuous eligibility for a means tested medical card starting at least 1 year prior to diagnosis. It was concluded that a significant proportion of patients will cease statin treatment in the months prior to a colorectal or breast cancer death. However, the number of patients initiating statin use did not differ between those who died of their cancer and those who did not.

The Irish Longitudinal Study on Ageing (TILDA) is a prospective nationally representative study of community dwelling adults, aged 50 years and over resident in the Republic of Ireland. (Kenny et al., 2010). The first wave of data collection surveyed a nationally representative sample of over 8500 people beginning in October 2009 with a further four waves of data collection in 2012, 2014, 2016 and 2018. Using TILDA data, May et al completed 375 end-of-life interviews with family members of TILDA participants who died between Wave 1 (2009) and Wave 3 (2014) (May et al., 2017) Nearly half (46%) of all decedents died in hospital, 27% at home, 11% in hospice and 10% in a nursing home. The study found characteristics other than illness burden, such as domestic living situation, may drive healthcare use and end-of-life experience at least as much as medical need.

May et al used cause of death from death certificate data and Irish population census projections (2016-2046) to estimate numbers of people dying from a disease with a palliative care need in Ireland to 2046. Further analysis combined these data with TILDA data to estimate to the year 2046 the numbers of people aged 50 years and over living and dying with diseases with a palliative care need. This analysis was used to estimate disability burden, pain prevalence and health care utilisation among people aged 50 years and over living and dying with diseases with a palliative care need. The authors report that prevalence of palliative care need will almost double over the next 30 years as the population ages. An 84% increase in people dying from a disease with a palliative care need and an 89% increase in those aged 50 years and over, not in the last year of life with a relevant diagnosis, are predicted by 2046 (May et al., 2020).

In a further study Ward et al linked death registration data with individual level records of TILDA decedents matching on name, address and month and year of birth (Ward et al., 2020). Over nine years of follow-up, 779 (9.1%) TILDA participants died (37% from cancer, 32.9% from diseases of the circulatory system, 14.4% from diseases of the respiratory system with the remaining 15.8% were attributed to all other causes). Mortality rates were higher among less educated participants, manual occupation social class groups, and those with lower average annual household incomes. The authors emphasise the potential of linked data to contribute to an understanding of the social, behavioural, economic, and health antecedents to mortality and to inform public policies aimed at addressing inequalities in mortality and end-of-life care.

2.8. Summary

Internationally identifying the need for palliative care at the population level relies primarily on the ICD codes recorded on death certificates for diseases requiring palliative care, adjusted by estimated symptom prevalence for each disease category (Connor et al., 2014; Murtagh et al., 2014). Diseases recognised as having a palliative care need include malignant neoplasm, heart disease including cerebrovascular disease, renal disease, liver disease, respiratory disease, neurodegenerative disease that include Alzheimer's, dementia and senility and HIV/AIDS (Murtagh et al., 2014).

Identifying the need for palliative care at the individual level relies on deriving indicators of quality and intensity of care received at end of life from a variety of administrative health data using methods first described by Earle et al in 2003 (Earle et al., 2003). This methodology has been used extensively to investigate end of life care. The populations studied, the measures used and the end-of-life timeframes vary widely depending on the specific study objectives and data sources available (Langton et al., 2014; Luta et al., 2015). There is an absence of evidence regarding the palliative care needs of older patients and/or those presenting to emergency departments (Wong et al., 2014) although older age (Brewster et al., 2011) and emergency presentation (McPhail et al., 2013) have been shown to be predictive of short-term mortality in cancer patients. Although several studies investigating the quality and intensity of care received at end of life in cancer patients had access to cancer registry data, none reported or characterised end-of-life care by survival time (Langton et al., 2014; Luta et al., 2015).

The structure and organisation of a healthcare system determines what administrative health data are collected. Jurisdictions with mandatory universal health insurance including Belgium (Maetens et al., 2016) and Ontario (Tanuseputro, 2017; Tanuseputro et al., 2017) are best placed to identify receipt of palliative care at the population level across healthcare settings. Elsewhere receipt of palliative care has been identified from hospital episode data (Philip et al., 2015; Rosenwax et al., 2016; Sundararajan et al., 2014) or by a palliative care service provider e.g. inpatient hospice (Coupland et al., 2011; Sleeman et al., 2016). Cancer patients are more likely to receive palliative care than non-cancer patients in Ontario (Seow et al., 2018; Tanuseputro et al., 2017), in Western Australia (Rosenwax et al., 2016) and in England (Sleeman et al., 2016). As well as having cancer, Tanuseputro reported being female, middle-aged, living in wealthier and urban neighbourhoods and having less multi-morbidity were all associated with higher odds of palliative care in Ontario (Tanuseputro et al., 2017) while Sleeman found inpatient hospice death was more likely among decedents living in less deprived areas (Sleeman et al., 2016). Using death in hospice as a marker for palliative care receipt, Coupland et al found some evidence of ethnic variation in dying in a hospice (Coupland et al., 2011). The relationship between patient characteristics and receipt of palliative care are complex. The disease type and associated trajectory often determines the place of care (for example dementia patients are normally cared for in a long-term care setting). Place of care can determine the availability of PEOLC which in turn relies on the healthcare model (structure, organisation, funding) and healthcare policy.

By definition, place of death is the final place of care and has been widely used as an indicator of how palliative care is organized and provided. Hospital is the most common place of death for cancer patients in England (Gao et al., 2013) and Sweden (Öhlén et al., 2017). In Ireland 46% of all deaths in those aged 50 years and over were in hospital (May et al., 2017), and specifically 49% of colorectal deaths between 1994-2004 (Céilleachair et al., 2010) and 52.5% of lung deaths between 1995-2005 (Sharp et al., 2010) occurred in hospital. Individual level factors that affect place of death in cancer patients include cancer subgroup (solid tumour v haematological cancer), marital status, age and deprivation. The availability of palliative care at any location improved the chances of dying at that location, and earlier referral reduced the likelihood of hospital deaths (Costa, 2014). Orlovic et al showed a documented end of life preference is strongly associated with subsequent place of death (Orlovic et al., 2020). Regional differences in service provision (Gao et al., 2014; Öhlén et al., 2017) as well as national differences in health care resources, health care system organisation, cultural and social differences that include health care policy specific to end-of-life care are also important (Cohen et al., 2015; Pivodic et al., 2016).

2.8.1. The gap in an Irish context

Increasingly Irish health administrative data are being used to investigate PEOLC. While population level estimates on the need for palliative care have been examined in detail (Kane et al., 2015; May et al., 2020), information on the need for palliative care need at the individual level is lacking. Internationally, patients with cancer are more likely to receive palliative care than those diagnosed with non-cancer diseases (Seow et al., 2018; Hsu & Tanuseputro, 2017; Rosenwax et al., 2016; Sleeman et al., 2016) but there is dearth of studies that examine end of life care in cancer patients who die shortly after diagnosis. All registered cancers in Ireland record a date of incidence so that in conjunction with death certificate data the survival times for subgroups of cancer patients can be determined (e.g. lung, prostate, colorectal and breast). Differences, if any, in the characteristics of patients who die shortly after diagnosis can be examined and potentially identify those who might benefit from early assessment for palliative care.

Identifying receipt of palliative care from administrative health data relies to a large extent on the data sources available. Prior to 2005 approximately half of all lung and colorectal cancer deaths occurred in hospital (Ó Céilleachair et al., 2011; Sharp et al., 2010) while more recent data (May et al., 2017) suggest the proportion of hospital deaths has not decreased in those aged 50 years and older. Hospital episode data linked to cancer registry and death certificate data presents an opportunity to determine whether the delivery of specialist palliative care to cancer patients in acute hospitals in Ireland can be identified. This would allow differences in the characteristics of those receiving specialist palliative care with those who don't to be examined in more detail including subsequent place of death. The role of structural factors that affect place of death (for example the availability and capacity of inpatient hospice (Gao et al., 2019)) could be examined in an Irish context for the first time.

To realise the potential of administrative health data for PEO LC research in Ireland, a thorough knowledge of how health care is organised, funded and delivered is necessary so that the most relevant sources of health administrative data for PEO LC research can be identified. The merits of each dataset in terms of the population it represents, the data available and equally important what is missing is required. By identifying and documenting the potential and challenges of administrative data for PEO LC research in cancer patients the knowledge gained can be extrapolated to other non-cancer health and social care data collections.

Chapter 3 presents the methods used to explore these gaps in the literature and address the aims of this thesis.

Chapter 3: Methods

In this chapter I lay out the materials and methods of my thesis. Section 3.1 summarises the Irish health context in which this research took place. This includes a description of the current public health service in Ireland and a brief overview of how that system evolved. This is followed by a description of the milestones in the development of palliative care services in Ireland. Section 3.2 briefly describes each of the three datasets used in the thesis studies followed by a description of the approval necessary to use the data (section 3.3). Section 3.4 describes the theories underpinning data linkage and the methodology used to link the data. The remainder of the chapter describes the studies undertaken using the linked health, in total three studies are described. The first aims to identify indicators for early assessment for palliative care in lung cancer patients, (section 3.5). The second study explored differences between cancer patients who did and did not receive specialist palliative care in acute hospitals, (section 3.6). For each, a detailed description of the study design and participants, data definitions, outcome measure and statistical methods are given. The third study (section 3.7) examines the potential of currently available administrative health and social care data for PEO LC research in Ireland. It describes how the organisation of the health care system affects what data are available and the implications when using administrative health and social care data for PEO LC research, particularly in the context of ongoing health service reforms and recent changes to data privacy laws.

3.1. The Irish Health Service

As described previously, Ireland has a mixed public private health care system where publically funded health care is managed by the HSE and funded through the tax system. Those on lower incomes (means tested) are entitled to medical cards which permits free public health services under the General Medical Scheme (GMS). Individuals without medical cards are entitled to subsidized public hospital services and prescription medicines, but pay the full cost of GP and other primary care services (Connolly & Wren, 2019). Those not eligible for a medical card may be entitled to a GP visit card, which is also means tested but with a higher income threshold. A GP visit card exempts the holder from GP charges; currently the card is available

to everyone aged over 70 and under 6 without an income test. GPs are not directly employed by the government.

There are three types of hospitals in Ireland: i) public hospitals which are owned and funded by the HSE, ii) voluntary public hospitals, most of whose income comes from the State and iii) private hospitals that receive no state funding. Voluntary public hospitals are sometimes owned by private bodies, for example, religious orders or are incorporated by charter or statute and run by boards often appointed by the Minister for Health. Most of these hospitals also provide private medical services but they must be able to distinguish between public and private care. On admittance to a public (or voluntary) hospital, patients choose to be treated by their consultant on a public or private basis. Private hospitals operate independently of the State health services and the cost of care must be paid either directly or through private health insurance (Citizensinformation.ie, 2018). In 2017, 33% of the population had a medical card and 10% had a GP visit card while approximately 43% of the population are covered by private health insurance (Department of Health, 2018).

3.1.1. History of the Public Health Service

Health service reform started in 2005 with the beginning of several reorganisations and configurations of the Irish health service. The HSE replaced eight health boards that had existed for more than 30 years previously (Department of Health and Children, 2001a; Department of Health and Children (DOHC) et al., 2003). This coincided with the 2004 National Health Information Strategy (Department of Health and Children (DOHC), 2004) which instigated a coordinated health information strategy that included the establishment of Health Information and Quality Authority (HIQA).

HIQA is an independent body that evaluates the quality of the information available on health and social care and makes recommendations to improve quality, minimise inconsistencies and fill gaps where data are not available (Health Information and Quality Authority, 2013, 2017a). HIQA advocates eight guiding principles for organisations collecting data that include formalised governance arrangements, facilitating appropriate access to the data to optimise its benefits, continuous monitoring/improvements of data quality and effective information

governance procedures. Standards for data quality include the use of data dictionaries, classification systems and clinical terminologies (Health Information and Quality Authority, 2013). HIQA produces a catalogue of national health and social care data collections using a standardised template to describe existing data collections (Health Information and Quality Authority, 2017b). National health and social care data collections are defined as national repositories of routinely collected health and social care data, including administrative sources, censuses, surveys and national patient registries in the Republic of Ireland (Health Information and Quality Authority, 2017b).

The National Cancer Control Programme (NCCP) was established in 2007 and is responsible for overseeing national services for treatment of cancer (Health Service Executive, 2018c). An early priority was the establishment of designated cancer centres for surgery, so that nearly all cancer surgery currently takes place in these centres. The NCCP ensures designated centres for individual tumour types have adequate case volume, expertise and concentration of specialist skills.

In 2015, voluntary hospitals and HSE public acute hospitals were reorganised into seven hospital groups (*Hospital Groups - List and Contact Details*, 2018). The hospital groups coordinate services between the different hospitals within the group and are linked with academic institutions. In addition, nine geographically distinct community health organisations (CHO's) were established (Health Service Executive, 2018b). The purpose of the CHO is to facilitate integrated care within community services, between the community and hospital services and with wider public service organisations e.g. local authorities, Child & Family Agency, education and local voluntary organisations. Each CHO serves a population of approximately 450,000-500,000 people.

3.1.2. Palliative care delivery in Ireland

The National Advisory Committee on Palliative Care (NACPC) was established in 1999 to report on palliative care services in Ireland. The report published in 2001 found there was limited information available on palliative care services in Ireland but that wide variation in the type, level and funding of services was apparent in each health board (Department of Health and Children, 2001b). It was noted demand for palliative care services would increase given

Ireland's ageing population and a projected doubling of the population aged 65 years and over by 2031. The report recommended there should be at least one specialist palliative care inpatient unit in each health board region, that all acute general hospitals should have a specialist palliative care service and that specialist palliative care services should be available to all people living in the community in all health board regions. Other recommendations included the need for increased education, training and research in specialist palliative care and a requirement to develop standards for all dimensions of service provision (structure, process and outcome of care) including a national minimum data set to standardise information on all patients using specialist palliative care services. The importance of effective communication with patients and their families, within the hospital services, within community services as well as between hospital and community health care professionals was highlighted. An immediate recommendation was to conduct a needs assessment for specialist palliative care services in each health board region to include the views of major stakeholders, including service providers, service users and purchasers/planners. The NACPC report described the development of a comprehensive specialist palliative care service that was adopted as official policy by the Department of Health.

Based on the needs assessment reports produced by the individual health boards following the NACPC recommendation, the IHF undertook a study of service activity and staffing levels for palliative care in Ireland in 2004 (Irish hospice Foundation, 2006). The Baseline Study reported large regional differences in the development of palliative care services where in some areas, service development was on target to match the model outlined by the NACPC while in others the basic elements required for hospice/specialist palliative care services were not in place. Service organisation, staffing levels, palliative care team composition and funding models varied significantly by health board region so that in 2004 several health board regions required significant service planning and development to achieve the service levels outlined in the NACPC report.

The National Clinical Programme for Palliative Care (NCPPC), established in 2010, marked the beginning of a nationally integrated approach to the management and organisation of palliative care services in Ireland. The NCPPC aims to provide appropriate levels of palliative care to those in need, irrespective of the care setting or diagnosis (Health Service Executive, 2018a). Current national NCPPC policy recommends a ratio of 8 to 10 specialist palliative care

beds per 100,000 population (National Clinical Programme for Palliative Care, 2019), however, in 2015, no CHO had the recommended ratio.

Historically the development of palliative care services in Ireland was ad-hoc and largely driven by local demand. The Irish Hospice Foundation, established in 1986, along with other voluntary and charitable bodies, played a significant role advocating for and developing local palliative care services and resources (O' Morain, 2006). As of 2020, there are 10 adult inpatient hospice units providing specialist palliative care in Ireland (Appendix B). The Irish Association for Palliative Care is an all-island body established in 1993 to promote palliative care through opportunities for networking, education, publications and representation on national bodies. It is a multidisciplinary membership organisation for those involved in the provision of palliative care in Ireland (*Irish Association for Palliative Care*, 2020). The All Ireland Institute of Hospice & Palliative Care is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. Its objective is to promote education, research and best practice to improve the palliative care experience of people with life limiting conditions and their families (Wescott, 2020)

3.2. The datasets

3.2.1. Cancer registry data

The NCRI is a publicly appointed body, established in 1991 by Statutory Instrument and funded primarily by the Department of Health¹. It actively collects information on all cancer cases occurring in Ireland since 1994. The registry identifies, collects, classifies, records, stores and analyses information relating to each newly diagnosed individual cancer patient and to each tumour that occurs. It also reports on the incidence and prevalence of cancer and related tumours in Ireland, facilitates the use of the data in approved research and in the planning and management of services.

¹ For relevant legislation see S.I. No. 19/1991 The National Cancer Registry (Establishment) Order, 1991 S.I. No. 293/1996: The National Cancer Registry (Establishment) Order, 1991 (Amendment) Order 1996 Health (Provision of Information) Act, 1997

Most registrations are based on ‘active’ data collection whereby trained Cancer Data Registrars (CDRs), based in hospitals around the country, access a range of data sources to identify all new cancer cases and register all relevant patient, tumour and treatment details. Hospital pathology reports provided to the NCRI shortly after diagnosis comprise the bulk of the data on approximately 85% of all new cases. Approximately 50% of pathology reports are processed electronically and followed up by the CDRs. The other 50% are registered manually by CDRs. Information on non-microscopically diagnosed cases is registered mainly from other hospital sources, principally the Hospital Inpatient Enquiry system as well as records from radiology and oncology departments, medical charts, and hospital cancer databases. Most cases ($\geq 95\%$) are initially registered in this way. Hospital systems and/or medical notes are accessed to provide information on clinical staging and treatment.

The main non-hospital source of case information is death certificate data. The NCRI is provided with all death certificates from the Central Statistics Office (CSO). All cases initially notified by death certificate are followed up with the hospital of death or the certifying doctor and most cases are subsequently found in other data sources. These are registered as active cases. Between 2009 and 2016 less than 1% of cases remain classified as notified by death certificate only (DCO), in keeping with international norms. Follow up of patients is passive, where cancer cases are linked to death certificate information provided regularly by the Central Statistics Office and the General Registers Office. In 2018, the censor date (the date to which all patients are followed up) is 31st December 2016. Although case data from pathology reports is registered almost immediately after diagnosis, data from other sources can take longer to obtain. This, together with essential case checking and data quality assurance, means that the NCRI normally produces definitive statistics for case data a minimum of 2 to 3 years following the end of year of diagnosis.

Incident cases are coded according to the third edition of the International Classification of Diseases for Oncology (ICD-O3) (Fritz, 2013). Before analysis, data is audited using international audit protocols from the International Association for Research on Cancer (IARC). Case data are recoded to the equivalent International Classification of Diseases version 10 (World Health Organization, 2011) and results are presented according to the single or grouped ICD10 codes relevant to each cancer.

Completeness for 2010 incidence of all invasive cancers excluding NMSC was estimated at 97.2% within five years of incidence. For the four cancers with the highest incidence, colorectal cancer, lung cancer, female breast cancer and prostate cancer, five-year completeness was estimated at 99.0%, 98.7%, 99.3% and 96.2% respectively (National Cancer Registry, 2020). For certain cancer sites, the NCRI can provide reliable figures within six months of year of incidence e.g. 99% of breast, 95% of colorectal and 94% of prostate cancers are usually microscopically verified and are therefore registered within a couple of months. However up to 20% of lung and 38% of pancreatic cancers are diagnosed clinically and it may take longer to register these cancers. While the number of cases for certain sites may be available at an early stage, complete information on treatments and staging are obtained from the medical records of the patients. This type of information will normally only be made available 2 to 3 years after the year of incidence, in keeping with international norms. The NCRI continuously assesses electronic data sources within hospitals such as cancer databases and radiotherapy databases as a data source for cancer registration.

The address of each cancer patient at the time of diagnosis is recorded by the NCRI. The address is stored as house name, house number, four address lines and county code. Currently eircodes, the Irish postcode system launched in Ireland in 2017, are not routinely captured by the NCRI (Eircode, 2015). Each address captured by NCRI is geocoded and subsequently assigned to an electoral division (ED) and former health board region but not to a CHO. Electoral divisions are the smallest legally defined administrative areas in the State (Central Statistics Office, 2019a).

A data model, data dictionary and minimum dataset are currently being developed. Information on the data collected are available at (*Data Fields We Collect | National Cancer Registry Ireland, 2020*) (Appendix C).

3.2.2. Hospital episode data

The Hospital In-Patient Enquiry system (HIPE) was established in 1971. It collects demographic, clinical and administrative data on discharges from, and deaths in, all acute public hospitals nationally. HIPE is the only source of morbidity statistics available nationally for acute hospital services in Ireland. The Healthcare Pricing Office (HPO) has overseen the administration and management of HIPE since January 1st, 2014. HPO is responsible for

overseeing all functions associated with the operation of HIPE including the development and support of the data collection and reporting software, training of coders and data quality audit, reporting, and responding to requests for information.

The patient medical record chart is the primary source of HIPE data. In 2016, the 8th Edition of ICD10-AM/ACHI/ACS (Healthcare Pricing Office (HPO), 2016) was used to code all discharges in Ireland. Trained clinical coders translate the medical terminology to the alphanumeric codes recorded in HIPE using strictly defined protocols. Additional documentation used for coding an episode of care includes nursing notes, consultation reports, progress notes, operative reports, pre- and post-operative reports and pathology reports. The entire chart is used to extract the conditions and procedures to capture all relevant details of the patient and their health care encounter. Data items collected include

- Medical Record Number
- Dates of Admission and Discharge
- Day case indicator
- Admission Type: booked or emergency
- Discharge Destination: home, transfer, self-discharge or death
- Sex
- Marital / Civil Status
- Area of Residence (coded by city and county)
- Diagnoses: Principal and up to 29 additional secondary diagnoses
- Procedures: Principal and up to 19 additional secondary procedures

HIPE began collecting Eircode data in January 2018 (Healthcare Pricing Office, Health Service Executive, 2018).

All HIPE discharges with cancer diagnoses i.e. ICD codes C00-D49 in any of the diagnoses fields are provided electronically to a dedicated server at the NCRI four times each year (January, April, July and October) by prior arrangement. The data are routinely linked to NCRI data on average twice a year. Allowing for delays, HIPE data for the preceding year are generally complete by end of April of the current year.

The diagnostic codes in HIPE include a code for palliative care. The Irish coding standards in use for HIPE coding in 2016 recommended that the diagnostic code *Z51.5 Encounter for Palliative Care* should be assigned as an additional diagnosis code when the intent of care at admission is 'for palliation', or if at any time during the admission the intent of care becomes 'for palliation', and the care provided to the patient meets the definition above (Healthcare Pricing Office (HPO), 2016) page 21. Further clarification stated the code *Z51.5 Encounter for Palliative Care* is to be coded when there is documentation that the patient has been seen by (or attended to) by the palliative care team as the phrase 'for palliation' may not be used. HIPE also provides a discharge destination code that records 15 discharge destinations including *discharge to hospice - not in the HIPE hospital listing*. There were 53 public acute and voluntary hospitals participating in the HIPE scheme in 2016, and in 2016 just under 84% of discharges were public patients (Healthcare Pricing Office, 2017). Public/private status relates to whether the patient saw the consultant on a private or public basis. It does not relate to the type of bed occupied nor is it an indicator of possession of private health insurance. There are 22 private hospitals in Ireland and these do not contribute to HIPE. These are listed in Appendix D.

3.2.3. Death certificate data

It is legally required that every death in Ireland is notified to the state within three months of death². The Department of Social Protection, CSO and General Register Office (GRO) collect and record date of death information including

- Date of death
- Address of residence (house name, house number, address lines 1-4, county)
- Place of death (house name, house number, address lines 1-4, county)
- Cause of death
- Occupation of deceased
- Age of deceased
- Sex of deceased
- Marital Status of deceased

The main cause of death is coded by the CSO using International Classification of Diseases version 10 (World Health Organization, 2011) while the underlying cause of death is provided

² See The Vital Statistics Act 1952 and Section 73 of the Civil Registration Act 2004

as text. Death certificate data is received electronically using a file transfer protocol each quarter by request from the NCRI and matched to NCRI data. There is no data dictionary available for death certificate data.

The death events publication services (DEPS) is a service that provides information on death events to public sector bodies. This information contains details on all deaths notified to the GRO. DEPS was developed so that notification of all registered deaths could be made available automatically and electronically to all relevant public sector agencies, allowing subscribing agencies including the NCRI to identify those persons on their registers who are deceased. It is updated weekly and improves the timeliness of data acquisition. Deaths are published on a weekly basis in a comma separated values file available for download.

3.3. Study approval

The NCRI has permission under the Health (Provision of Information) Act 1997 to collect and hold data on all persons diagnosed with cancer in Ireland without requiring individual consent. The use of that data for approved research is covered by the Statutory Instrument which established the Registry Board in 1991. Written permission to use the data sources for this thesis was obtained from NCRI management in April 2015 (Appendix E). Further permission for the continued use of the data was granted by the NCRI Data Research Application Committee in December 2018, following enactment of the 2018 Data Protection Act, (Appendix E). All datasets were de-identified prior to analysis

3.4. Data Linkage

3.4.1. Overview

Data recorded at the level of an individual (for example NCRI data) should not have duplicate records, that is every individual diagnosed with cancer should be recorded only once in the cancer registry database. Similarly unique events such as death should only be captured once so that each individual should have only one death certificate record. HIPE records hospital episode events so an individual can have many episodes over time and across hospitals. Usually, a patient has one medical record number within a hospital but this may differ across hospitals.

The level at which data is captured determines the frequency of events to be recorded and therefore data volume. Data captured over time and location are more sensitive to events that jeopardise data quality for example staff changes or technical issues that compromise data quality or prevent data transfer. Data quality and volume also affects the data linking process.

3.4.2. Types of linkage

There are two main types of data linkage (Dusetzina et al., 2014). The first is deterministic linkage where a pair of records are matched based on whether the record pair agree or disagree on a given set of identifiers. Agreement is assessed as a discrete “all-or-nothing” outcome. Deterministic linkage relies on the existence of one or a set of common unique health identifiers across the datasets to be matched. The use of individual health identifiers (IHI) was introduced by the Health Identifiers Act 2014 (*Health Identifiers Act 2014*, 2014) in Ireland however IHIs are not yet available in the NCRI, HIPE or death certificate datasets.

In the absence of IHI’s across the datasets to be matched, linking requires probabilistic matching techniques (Fellegi & Sunter, 1969). Probabilistic matching techniques rely less on the need for common valid identifiers in the datasets to be matched and because data are matched on a range of variables, it is more robust to changes in data quality and availability over time.

3.4.3. Probabilistic matching theory

Probability theory is used to assess the likelihood of a correct match between two data records. Given the values in for example first name, last name, birth date, and address, what is the likelihood that these are a match? Probabilistic matching uses three underlying concepts: (1) *m-probability* - the probability of a variable agreeing in a correctly matched pair expressed as 1 minus the error rate of the variable in the data set, (2) *u-probability* - the probability of a variable agreeing in an unmatched pair, that is agreeing by chance and, (3) *weights* - based upon the m and u values. Each variable and value has an agreement and disagreement weight associated with it. The number and frequency of values for each variable is used to determine the variable weights. In practice, variables that have a large range of values for example, a social security number, have a high m-probability weighting when they match across two datasets. Variables that have restricted range of values, e.g. gender recorded as ‘Male’, and ‘Female’, have a low u- probability when they agree across two datasets and a higher u-probability weighting when they don’t. For matching purposes, a record pair that match on

social security number across two datasets is likely to be the same person. A record pair that match on gender is not very informative whereas not matching on gender suggests the records pertain to two different people.

3.4.4. Data standardisation

Data is recorded or captured in various formats in different systems and data items may be missing or contain errors. The first step in data matching is data cleaning and standardisation. Poor quality data for example missing, inaccurate, or incomplete variables can result in missed or incorrect matches. A pre-processing phase that aims to clean and standardise the data is therefore essential in every linkage process. Data sets may also contain duplicate entries, in which case a data set may need to be de-duplicated before linkage with other datasets. Common standardisation techniques include

- Reformatting values, for example all date values formatted to dd/mm/yyyy
- Removing punctuation, for example hyphens, apostrophes, full stops and blank spaces
- Removing common codes used for missing and/or uninformative data for example 'UNKNOWN' in text fields.
- Removing commonly used abbreviations for example Ct with Court, Rd with Road etc.
- Phonetic encoding of alphabetic variable (such as a surname) to resolve differences in spelling e.g. 'Browne' and 'Brown'. Common phonetic algorithms used in record linkage are Soundex (*Soundex System*, 2016) and NYSIIS (Identification & System, 1967)
- Name and/or address standardisation where a name or address is broken down into individual components. For example an address can be broken down into its constituents such as street number, street name and street type.
- Resolving diminutive or nicknames using look up tables for example replacing 'Bobby' with 'Robert'
- Removing or investigating inconsistent data for example a female recorded with prostate cancer

The process of standardisation is generally governed by rules and refined over time as expert knowledge of the data to be matched develops.

3.4.5. Blocking

Blocking reduces the number of record to record comparisons by sorting the two datasets to be matched on a common variable(s). Comparisons are made between records with the same values for the blocking variable. Common examples include blocking on Surname alone or Surname and date-of-birth. Blocking reduces the number of comparisons to be made and considerably increases the efficiency of the matching process. This facilitates matching large volumes of data. Choice of blocking variable depends on expert knowledge of the datasets to be compared. Normal practice is to use the most reliable combination of blocking variables.

3.4.6. Checking for data anomalies

All datasets used in the matching process are different, even those from the same provider over time, so each matching project has to be tailored to the data available. In all cases, the parameters for established matching routines are continually assessed and revised in light of the changes in the source matching datasets. In this context, the expert knowledge built up over time is applied to each matching project. Checks to mitigate data anomalies include:

- Full investigation of each dataset to identify best blocking variables
 - Block on most reliable variables first
 - Careful choice of blocking variables in each pass
- Full utilisation of fuzzy logic capabilities of probabilistic matching to mitigate against minor spelling errors, juxta-positioned characters etc.
- Full exploitation of the capacity to set weights to increase levels of user review of possible matches based on experience of data quality
- Consider reviewing matches after each pass
- Exploit all available data sources to verify individual records, that is validity checking across data sources
- Look for opportunities to identify subsets of data where 100% matching would be expected (gold standard) and use these to estimate reliability of matching
- Look for guidance on numbers expected to match for each project based on previous experience
- Record limitations/weakness of individual matching projects

3.4.7. NCRI data linkage

The NCRI uses a standalone probabilistic matching software, Automatch (Matchware Technologies, Inc., Silver Spring, MD, USA) to routinely link registry data to HIPE and death certificate data. HIPE data are matched using medical record number, hospital ID and date of admission and/or discharge as the primary blocking variables. Others include surname, date of birth and patient address. HIPE records for which no match are found are actively followed up by CDRs to ensure no cancer cases are missed. Death certificate data are primarily matched to NCRI data using surname, first name, sex, date of birth and date of death as the blocking variables.

Automatch allows for up to 8 passes in each project where each pass contains one set of blocking variables. Normal practice is to use the most reliable combination of blocking variables in the first pass. Automatch parameters can be set to allow user review after each pass within a run or at the end of a run on completion of all 8 passes.

3.5. Study 1

3.5.1. Design

The first study used a retrospective cohort design to compare the characteristics of newly diagnosed lung cancer patients dying within 30 days of diagnosis with those who survived longer. The NCRI dataset was used as the primary data source, and the study sought to exploit the availability of acute hospital data to examine the characteristics and care experience of lung cancer patients from diagnosis to death. To identify indicators for early palliative care assessment we distinguished between characteristics available at diagnosis (age, gender, smoking status, marital status, comorbid disease, admission type, tumour stage and histology) from those available post diagnosis (tumour directed treatment, diagnosis episode discharge code and cause of death (lung cancer/other)). The variables chosen were guided by the data available and the literature review.

Lung cancer remains the most common cancer worldwide and was the cause of over 1.6 million deaths in 2012. In Europe 12.1% of all incident cancers in 2012 were lung cancer and it accounted for 20.1% of all cancer deaths (Ferlay et al., 2015). Typically lung cancer is characterised by short survival times, often attributed to late diagnosis (Coleman et al., 2011; Thomson & Forman, 2009). The UK and Ireland have the poorest one- and five- year relative

survival rates for lung cancer in Northern Europe (Francisci et al., 2015). Characterisation of lung cancer patients who die shortly after diagnosis aligns with the thesis aim of exploring the potential of administrative health data linked at the individual level to identify the need for palliative care in vulnerable subgroups.

3.5.2. Setting/participants

All incident lung cancer patients (ICD-O3:C34)(Fritz, 2013), who were diagnosed in Ireland between 2005 and 2012 and who died before 01-01-2014 were identified from the NCRI. In 2016, the censor date (the date to which all patients are followed up) was 31st December 2014.

3.5.3. Data definitions

The variables used in this, their source and how they were derived are shown in table 3.1.

The diagnosis episode was the inpatient episode during which the lung cancer diagnosis was made. For a small proportion of patients (10%), the diagnosis date didn't occur during an inpatient episode so the episode occurring in the interval from 7 days before to 14 days after the lung cancer diagnosis date was used.

HIPE records episode admissions as either emergency or elective. Emergency admissions occur when a patient requires immediate care and treatment as a result of a severe, life threatening or potentially disabling condition with the patient generally admitted through the Emergency Department. Elective admissions occur when the patient's condition permits adequate time to schedule the availability of suitable services to the patient (Hipe Unit, Health & Information Division, 2013).

A co-morbidity score for each patient, based on the updated Charlson index (Quan et al., 2011) was derived from all diagnoses recorded in HIPE for the diagnosis episode. The Charlson comorbidity index (CCI) predicts the one-year mortality for a patient who may have a range of 17 comorbid conditions. Each condition is assigned a score of 1, 2, 3, or 6, depending on the risk of dying associated with each one. Scores are summed to provide a total score to predict mortality. For every episode, HIPE records a discharge code describing where the patient was discharged to, including categories for home, nursing home, died with and without post mortem and transfer to another hospital. For this analysis we classified discharge code to 'Death' and 'Other'.

Table 3.1 Study 1 data definitions

Variable	Data Source	Comments
Age	NCRI	Age at diagnosis by age-group < 60 years, 60-69, 70-79, aged 80 and over
Gender	NCRI	Male, Female
Marital status	NCRI	Married, Other
Smoker status	NCRI	Ever smoker , Never smoker, Unknown
Date of diagnosis	NCRI	The date of diagnosis is taken as the date of incidence which is selected from a hierarchy of dates in the following order, the date of first histological confirmation of malignancy or in the absence of histological confirmation, the date of first treatment (excluding “seen but not treated”), followed by the date of admission to hospital because of the malignancy(National Cancer Registry, 2012; Tyczynski & Démaret, 2003).
Stage	NCRI	Stage at diagnosis is defined according to American Joint Committee on Cancer (AJCC) summary staging and recorded by NCRI and were manually recoded to 4 groups - Stage 0/I/II, Stage III, Stage IV, Un-staged
Histology	NCRI	Histological groupings were manually recoded based on the International Agency for Research on Cancer classification (Egevad L et al., 2007)
Tumour directed treatment	NCRI	Treatment data are classified to a yes/no category for any tumour-directed surgery, chemotherapy or radiotherapy received within one year of diagnosis by NCRI
Diagnosis episode	HIPE	Manually derived using date of diagnosis and HIPE admission and discharge dates. The diagnosis episode was the episode where the lung cancer diagnosis was made or the first episode occurring in the interval from 7 days before to 14 days after the lung cancer diagnosis.
Admission type	HIPE	Manually recoded to Emergency or Elective for the index diagnosis episode admission code
Charlson co-morbidity score	HIPE	Manually derived co-morbidity score for each patient, based on the updated Charlson index(Quan et al., 2011)from all diagnoses recorded in HIPE for the index diagnosis episode. Patients were classified to three comorbidity categories ‘None’, ‘1’ and ‘>1’ based on their Charlson score. The lung cancer diagnosis was disregarded when calculating the co-morbidity score.
Discharge code	HIPE	Manually recoded to Death or Other for the index diagnosis episode discharge code
Place of death	Death certificate	Manually derived from first line of place of death address, manually coded to Hospital, Home, Hospice, Nursing Home, Unknown and No death certificate
Cause of death	Death certificate	Manually recoded to Lung or Other from CSO coded main cause of death
Date of death	Death certificate	Used to determine survival time as the number of days from date of diagnosis to date of death.

3.5.4. Outcome variable

To identify early indicators for palliative care assessment, patients were classified to those who died within 30 days of diagnosis (short term survivors) and those who survived more than 30 days. The 30 day cut-off was chosen for a number of reasons: i) 30 day mortality has been used previously as an indicator of early mortality for newly diagnosed breast or colorectal cancer patients in Scotland (Brewster et al., 2011) and to assess factors affecting 30-day mortality in a national patient population of lung and breast cancer patients receiving systemic anti-cancer therapy (Wallington et al., 2016), ii) it aligns with the study objective of identifying patient cohorts who might benefit from early assessment for palliative care as these patients are unlikely to have gained survival benefits of treatment, iii) lung cancer is characterised by short survival times and in this study just over 20% of patients died within 30 days of diagnosis providing a natural cut point for this analysis and iv) it is easily derived from cancer registry data and can facilitate comparisons across health systems.

3.5.5. Statistical Analysis

Chi-squared tests for independence were used to test for significant associations between categorical variables i.e. patient demographic variables present at diagnosis (age, gender, smoking status and marital status); clinical variables at diagnosis (stage, histology and any comorbidities); characteristics of the diagnosis episode (admission type i.e. elective or emergency and whether death occurred in hospital during the diagnosis episode); post diagnostic characteristics including receipt of any tumour-directed treatment, cause of death and place of death; and survival time (≤ 30 days, > 30 days) using a 5% level of significance. Cramer's V was used as a measure of the strength of the association with nominal variables. Somers' D was used as a measure of the strength of the association between ordinal independent variables and stratified survival time.

Multivariable logistic regression analysis was used to predict death within 30 days of diagnosis (yes, no). The model was fitted in a two stage process; the first stage examined the impact of patient characteristics immediately available at presentation. Next, the impact of clinical variables (e.g. histology and staging of tumour) were assessed by adding these to the model. Model goodness-of-fit was checked using the Hosmer and Lemeshow test (Hosmer et al.,

1997). The R statistical package was used for data preparation and analyses (R Core Team, 2013), (Appendix F).

3.6. Study 2

3.6.1. Design

The second study was a retrospective cohort study where the exposure variable was receipt of palliative care and the outcome variable was place of death. The objectives of our study were to i) identify cancer patients who received specialist palliative care in acute hospitals in Ireland ii) to compare characteristics of patients receiving specialist palliative care with those who don't and iii) compare place of death for these two groups.

These study objectives align with the thesis aim to determine whether administrative health data linked at the individual level can be used to i) identify receipt of palliative care , ii) describe who receives and does not receive palliative care in acute public hospitals and iii) determine if receipt of palliative care affects place of death. A key part of this study was validation of the *Z51.5 Encounter for Palliative Care* code use in HIPE, (Appendix G).

3.6.2. Data sources

The data sources for this study were the National Cancer Registry Ireland (NCRI), the hospital inpatient enquiry (HIPE) database from the Economic and Social Research Institute (ESRI) and death certificate (DC) data from the Central Statistics Office (CSO). These have been described previously in section 3.2.

3.6.3. Validation dataset - Specialist Palliative Care Minimum Data Set

Specialist palliative care is delivered by the HSE along with a number of voluntary service providers working in partnership under Service Level Agreements. Specialist palliative care teams provide care in acute hospitals, community settings and specialist inpatient units (hospices) across the country. All services are required to return monthly data to a national office. In 2016 metrics were collected by four specialist palliative care services, inpatient units (IPU), community (homecare) services, day care services and acute hospitals (Weafer & Toft, 2017). These data constitute the HSE Specialist Palliative Care Minimum Data Set (SPC-MDS). MDS data is generally submitted by specialist palliative care services and collated and returned to a national office by primary care / hospital staff in the HSE.

Data collection from acute hospitals fully commenced in 2016 and each acute hospital provides monthly aggregate counts of in-patient new referrals to the specialist palliative care team. New referrals are further categorised to cancer and non-cancer by the treating clinician who decides which disease is prompting the referral to end of life care.

3.6.4. Study participants

The study population included patients with incident invasive cancer (ICD-O C00-C97), (Fritz, 2013) excluding non-melanoma skin cancer, diagnosed from 1994-2016 inclusive, who attended one of eight adult cancer centres in 2016 and died in 2016. The study population was restricted to patients who attended a designated cancer centre in 2016 because i) cancer centres meet required standards so that all the patients have had access to similar standards of care including specialist palliative care, ii) acute public hospitals began providing numbers of patients referred for specialist palliative care to the national SPC-MDS in 2016 and these numbers were used in a validation study and iii) specialist palliative care bed capacity is quantified by CHO regions which were established in 2015.

3.6.5. Data definitions

The variables used in this, their source and how they were derived are shown in table 3.2.

3.6.6. Statistical Methods

Validation study for encounter for palliative care

The number of cancer patients who had at least one indicator of palliative care recorded in their 2016 HIPE hospital data was counted for each of the eight adult cancer centres. This was compared to an aggregate count of new specialist palliative care referrals for cancer patients in the SPC-MDS in 2016 by hospital.

Comparison of study participants with cancer deaths in 2016

The demographic and clinical characteristics of the decedents in our study were compared to all 2016 cancer deaths using data from the CSO Vital Statistics Annual Report 2016 (Central Statistics Office, 2019c).

Table 3.2 Study 2 data definitions

Variable	Data Source	Comments
Age at death	NCRI	Age categories were chosen to match those used in the CSO Vital Statistics Annual Report 2016 (Central Statistics Office, 2019c)
Gender	NCRI	Male, Female
Marital status	NCRI	Married, Other
Smoker status	NCRI	Ever smoker , Never smoker, Unknown
Deprivation	NCRI	Address at diagnosis was used to assign a deprivation score using the Pobal HP deprivation index (Haase & Pratschke, 2017). The index measures the relative affluence or socio-economic disadvantage of a geographical area using information collected on education, unemployment and other socioeconomic factors from the 2016 Census of Population
Tumour group	NCRI	Tumour grouping were chosen to match those used in the CSO Vital Statistics Annual Report 2016 (Central Statistics Office, 2019c)
Former health board region	NCRI	Patients are assigned to a health board region based on their address at diagnosis.
Diagnosis code <i>Z51.5 - Encounter for palliative care.</i>	HIPE	Used as an indicator for palliative care receipt. Coding Standards for HIPE state “Palliative care should be assigned (as an additional diagnosis code) when the intent of care at admission is 'for palliation', or if at any time during the admission the intent of care becomes 'for palliation', and the care provided to the patient meets the definition above.” Palliative care is to be coded when there is documentation that the patient has been seen by the palliative care team (Healthcare Pricing Office (HPO), 2016).
Discharge Code <i>Transfer to hospice – not in HIPE listing</i>	HIPE	Used as an indicator for palliative care receipt. The HIPE discharge code describes the patient destination on discharge. Categories include home, nursing home, transfer to another hospital, and transfer to hospice and died.
Encounter for palliative care	Derived	Manually derived from HIPE data. Patients were categorised to two groups: Encounter for palliative care (yes, no) based on having at least one indicator for palliative care in their HIPE data for any acute public hospital in the year period preceding death.
Date of death	Death certificate/ DEPS	Used to determine age at death.
Place of death	Death certificate/ DEPS	Manually derived from first line of place of death address. Manually coded to Hospital, Home, Hospice, Nursing Home and Community care. Community care included nursing homes and other long-term residential care settings.

Comparison of characteristics and place of death by encounter for palliative care

Descriptive statistics are provided for categorical demographic and clinical variables for each group: encounter for palliative care (yes, no). Chi squared tests examined the association between categorical variables. Logistic regression analysis examined the association of sociodemographic factors and former health board region with palliative care encounter group. The choice of variables used in the model were guided by the available data and the literature, and in particular the population based framework described by Gao et al (Gao et al., 2018). Age, gender, marital status, smoking status, deprivation index, former health board region, and age at death were included in the model. Odds ratios (OR) and 95% confidence intervals (95% CI) are reported. Tumour groups were excluded from the model because of specialisation at certain cancer centres, so that tumour group is related to geographic region. Model goodness-of-fit was assessed using Hosmer and Lemeshow test (Hosmer et al., 1997). Place of death was examined by palliative care encounter group. Data preparation and analyses were carried out using R Studio, Version 1.0.143 (RStudio Team, 2016), (Appendix F).

3.7. Study 3

Study 3 synthesises the knowledge gained from the initial two studies. By using existing available linked data in an Irish context the potential and challenges of administrative data for PEOLC research in cancer patients are identified and documented. The knowledge gained is extrapolated to other non-cancer health and social care data collections so that the potential and challenges of using health data for PEOLC research, given the existing information infrastructure, the ongoing health service reconfigurations and recent changes to data protection laws are better understood.

The objectives for this study are i) to identify administrative health data available that may be useful for PEOLC research ii) to describe both the challenges and opportunities using these data for PEOLC based on our experiences to-date using administrative health data and iii) to describe how recent initiatives to improve the health information environment and changes to data protection laws will impact future use of administrative health and social care data in Ireland. Specifically we explore data validation, governance and protection and considerations for data linkage including individual and health service provider identifiers and postcodes.

3.7.1. Identifying potential datasets for PEO LC research

A recognised list of diseases with associated palliative care needs (table 3.3) based on a methodology by Murtagh et al (Murtagh et al., 2014) was cross-referenced with the latest HIQA catalogue of national health and social care data collections to identify datasets that may have potential as a resource for PEO LC research in Ireland (Health Information and Quality Authority, 2017b). Based on previous experience using cancer registry data, death certificate, hospital episode data and other datasets for research, we describe features of the datasets, including how the data are stored and organised (i.e. the data model) that affect how the datasets are used. These considerations will inform the use of administrative health and social care data collections both in Ireland and elsewhere.

Table 3.3 Conditions amenable to palliative care and their International Classification of Disease codes (ICD-10)

Condition	ICD-10 codes*
Malignant neoplasm	C00-C97
Heart disease, including cerebrovascular disease	I00-I52, I60-I69
Renal disease	N17, N18, N28, I12, I13
Liver disease	K70-K77
Respiratory disease,	J06-J18, J20-J22, J40-J47 & J96
Neurodegenerative disease	G10, G20, G35, G122, G903, G231
Alzheimer's, dementia and senility	F01, F03, G30, R54
HIV/AIDS	B20-B24

Source: (Murtagh et al., 2014)

*(WHO | *International Classification of Diseases, 11th Revision (ICD-11)*, 2020)

3.8. Conclusions

The results from these studies are presented in the following chapters as published articles (chapters 4, 5 and 6).

Chapter 4: Indicators for early assessment of palliative care in lung cancer patients: a population study using linked health data

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Chapter 4 is the Results chapters for the thesis from Study 1. It is presented as a published paper and addresses the broad PhD aim of identifying cancer subgroups in need of palliative care.

Abstract

Background

Analysing linked, routinely collected data may be useful to identify characteristics of patients with suspected lung cancer who could benefit from early assessment for palliative care. The aim of this study was to compare characteristics of newly diagnosed lung cancer patients dying within 30 days of diagnosis (short term survivors) with those surviving more than 30 days. To identify indicators for early palliative care assessment we distinguished between characteristics available at diagnosis (age, gender, smoking status, marital status, comorbid disease, admission type, tumour stage and histology) from those available post diagnosis. A second aim was to examine the association between receiving any tumour-directed treatment, place of death and survival time.

Methods

A retrospective observational population based study comparing lung cancer patients who died within 30 days of diagnosis (short term survivors) with those who survived longer using Chi-squared tests and logistic regression. Incident lung cancer (ICD-03:C34) patients diagnosed 2005-2012 inclusive who died before 01-01-2014 (n=14,228) were identified from the National Cancer Registry of Ireland linked to death certificate data and acute hospital episode data.

Results

One in five newly diagnosed lung cancer patients died within 30 days of diagnosis. After adjusting for stage and histology, death within 30 days was higher in patients who were aged

80 years or older (adjusted OR 2.46; 95%CI 2.05-3.96; $p<0.001$), patients with emergency admissions at diagnosis (adjusted OR 2.96; 95%CI 2.61-3.37; $p<0.001$) and patients with any comorbidities at diagnosis (adjusted OR 1.32 95%CI 1.19-1.46; $p<0.001$). Overall, 75% of those who died within 30 days died in hospital compared to 43% of longer term survivors.

Conclusions

We have shown a high proportion of lung cancer patients who die within 30 days of diagnosis are older, have comorbidities and are admitted through the emergency department. These characteristics, available at diagnosis, may be useful prognostic factors to guide decisions on early assessment for palliative care for lung cancer patients. Patients who die shortly after diagnosis are more likely to die in hospital so reporting place of death by survival time may be useful to evaluate interventions to reduce deaths in acute hospitals.

Keywords:

Lung cancer, palliative care, survival time, administrative health data

4.1. Introduction

Worldwide, lung cancer remains the most common cancer and was the cause of over 1.6 million deaths in 2012. In Europe 12.1% of all incident cancers in 2012 were lung cancer and it accounted for 20.1% of all cancer deaths [1]. Typically lung cancer is characterised by short survival times, often attributed to late diagnosis [2, 3]. The UK and Ireland have the poorest one- and five- year relative survival rates for lung cancer in Northern Europe [4]. In the UK just over one third of patients survive more than one year following a lung cancer diagnosis (2010-2011) [5].

Most patients with advanced cancer die in hospital [6] although a review of 210 studies from 33 countries found most people would prefer to die at home [7]. Bekelman et al. reported death rates in acute hospitals ranging from 54% in Canada to just over 20% in the United States for lung cancer decedents over 65 years of age in 2010 across 6 developed countries [8]. Early palliative care in patients with metastatic non-small-cell lung cancer has been found to improve survival times and lead to less aggressive care at end of life compared to patients receiving standard care [9]. It also improves patients understanding of their prognosis which may lead to more informed choices near end of life [10].

Identifying those in need of early assessment for palliative care involves understanding prognostic factors of survival i.e. factors measured before treatment that have an impact on a patient's outcome "independently" of received or general class of treatment (Paesmans, 2012). In the case of lung cancer clinical stage and functional status are two important prognostic

factors for survival while age and gender are, to a lesser extent, also important [11]. The potential of using linked routine health data for prognostication has increasingly been recognised [12]. Data from multiple sources (registries, death certificates, hospital and community-based healthcare records) can be used retrospectively to identify those with unique needs or at risk of poorer outcomes [13–16].

The aim of this study was to use linked routine data to compare characteristics of newly diagnosed lung cancer patients dying within 30 days of diagnosis (short term survivors] with those surviving more than 30 days. To identify indicators for early palliative care assessment we distinguished between characteristics available at diagnosis (age, gender, smoking status, marital status, comorbid disease, admission type, tumour stage and histology) from those available post diagnosis. A second aim was to examine the association between receiving any tumour-directed treatment, place of death and survival time.

4.2. Methodology

4.2.1. Data definitions

Information collected by the registry is coded and classified according to international guidelines including international classification of diseases (ICD) codes, definitions of incidence and how multiple tumours are handled [18]. The date of diagnosis is taken as the date of incidence which is selected from a hierarchy of dates in the following order, the date of first histological confirmation of malignancy or in the absence of histological confirmation, the date of first treatment (excluding “seen but not treated”), followed by the date of admission to hospital because of the malignancy [18, 19]. Stage at diagnosis was defined according to American Joint Committee on Cancer (AJCC) summary staging [20]. Histological groupings were based on the International Agency for Research on Cancer classification [21]. Treatment

data were classified to a yes/no category for any tumour-directed surgery, chemotherapy or radiotherapy received within one year of diagnosis.

The diagnosis episode was the inpatient episode during which the lung cancer diagnosis was made. For a small proportion of patients (10%) the diagnosis date didn't occur during an inpatient episode so the episode occurring in the interval from 7 days before to 14 days after the lung cancer diagnosis date was used. HIPE records episode admissions as either emergency or elective. Emergency admissions occur when a patient requires immediate care and treatment as a result of a severe, life threatening or potentially disabling condition with the patient generally admitted through the Emergency Department. Elective admissions occur when the patient's condition permits adequate time to schedule the availability of suitable services to the patient [22]. A co-morbidity score for each patient, based on the updated Charlson index [23] was derived from all diagnoses recorded in HIPE for the diagnosis episode. The Charlson comorbidity index (CCI) predicts the one-year mortality for a patient who may have a range of 17 comorbid conditions. Each condition is assigned a score of 1, 2, 3, or 6, depending on the risk of dying associated with each one. Scores are summed to provide a total score to predict mortality. Patients were classified to three comorbidity categories 'None', '1' and '>1' based on their Charlson score. The lung cancer diagnosis was disregarded when calculating the comorbidity score. For every episode, HIPE records a discharge code describing where the patient was discharged to, including categories for home, nursing home, died with and without post mortem and transfer to another hospital. For this analysis we classified discharge code to 'Death' and 'Other'.

4.2.2. Outcome variable

To identify early indicators for palliative care assessment, patients were classified to those who died within 30 days of diagnosis (short term survivors) and those who survived more than 30

days. We chose the 30 day cut-off for a number of reasons i.) 30 day mortality has been used previously as an indicator of early mortality for newly diagnosed breast or colorectal cancer patients in Scotland [25] and to assess factors affecting 30-day mortality in a national patient population of lung and breast cancer patients receiving systemic anti-cancer therapy [26], ii.) it aligns with our study objective of identifying patient cohorts who might benefit from early assessment for palliative care as these patients are unlikely to have gained survival benefits of treatment, iii.) lung cancer is characterised by short survival times and in our study just over 20% of patients died within 30 days of diagnosis providing a natural cut point for this analysis and iv.) it is easily derived from routine data and can facilitate comparisons across health systems.

The association between receiving any tumour-directed treatment, place of death and survival time as a continuous variable was explored graphically.

4.2.3. Setting/participants

All incident lung cancer patients (ICD-O3:C34) [24], who were diagnosed in Ireland between 2005 and 2012 and who died before 01-01-2014 were identified from the NCRI. These records were linked to HIPE and death certificate data.

4.2.4. Statistical Analysis

Chi-squared tests for independence were used to test for significant associations between categorical variables i.e. patient demographic variables present at diagnosis (age, gender, smoking status and marital status); clinical variables at diagnosis (stage, histology and any comorbidities); characteristics of the diagnosis episode (admission type i.e. elective or emergency and whether death occurred in hospital during the diagnosis episode); post

diagnostic characteristics including receipt of any tumour-directed treatment, cause of death and place of death; and survival time (≤ 30 days, > 30 days) using a 5% level of significance. Cramer's V was used as a measure of the strength of the association with nominal variables. Somers' D was used as a measure of the strength of the association between ordinal independent variables and stratified survival time.

Multivariable logistic regression analysis was used to predict death within 30 days of diagnosis (yes, no). The model was fitted in a two stage process; the first stage examined the impact of patient characteristics immediately available at presentation. Next, the impact of clinical variables (e.g. histology and staging of tumour) were assessed by adding these to the model. Model goodness-of-fit was checked using the Hosmer and Lemeshow test [27]. The R statistical package was used for data analyses [28].

4.3. Results

Of the 16638 incident lung cancer patients diagnosed between 2005-2012 inclusive, 14228 (85.5%) died before 01-01-2014. Of these, 383 cases were notified from death certificate data only and due to insufficient data are excluded from the analysis, leaving 13845 cases in the final dataset. Median survival time was 137 days with an interquartile range (IQR) of 44-339 days.

Almost one in five ($n=2595$, 18.7%) newly diagnosed lung cancer patients died within 30 days of diagnosis. Table 4.1 shows the characteristics of the short term survivors compared to those who lived more than thirty days. The strongest association with short term survival were emergency admission at diagnosis, comorbidities at diagnosis, tumour histology and tumour

stage. Compared with longer-term survivors, short term survivors were more likely to be admitted as emergencies at diagnosis (84% versus 52%), they were more likely to have comorbidities at diagnosis (18% versus 13% had a Charlson score of 1 and 19% versus 12% scored > 1), and were less likely to have their tumour characterised (37% versus 15% were histologically unspecified and 18% versus 11% were unstaged). Table 4.2 shows the results of the multivariable logistic regression analysis adjusted for characteristics available at the diagnosis episode. These include gender, marital status and comorbidities present at diagnosis. Older patients (OR 2.72; 95%CI 2.29-3.24; $p < 0.001$), those with emergency admissions at diagnosis (OR 3.92; 95%CI 3.47-4.44; $p < 0.001$) and those with comorbid disease at diagnosis were significantly more likely to die within 30 days of diagnosis; the odds increased from 1.23 (95%CI 1.08-1.41; $p = 0.002$) among patients with a CCI score of 1 to 1.41 (95%CI 1.23-1.62; $p < 0.001$) among patients with a CCI > 1. Table 4.3 shows the results of the regression analysis adjusted for the clinical variables stage and histology. After adjusting for stage and histological type, older age (adjusted OR 2.46; 95%CI 2.05-2.96; $p < 0.001$) emergency admission at diagnosis (adjusted OR 2.96; 95%CI 2.61-3.37; $p < 0.001$) and comorbid disease were still strongly associated with death within 30 days of diagnosis; the adjusted odds increased from 1.32 (95%CI 1.15-1.52; $p < 0.001$) among patients with a CCI score of 1 to 1.44 (95%CI 1.25-1.65; $p < 0.001$) among patients with a CCI > 1.

Table 4.4 describes treatment received post diagnosis, the discharge code for the diagnosis episode, the place of death and the cause of death by survival category. Only 16% of the short term survivors received tumour directed treatment post diagnosis compared to 72% of the longer term survivors. Increasing survival time was associated with a steady increase in the percentage receiving treatment (Figure 4.1a).

The proportion dying in hospital decreased as survival time increased to 90 days but tended to remain stable after 90 days survival (Figure 4.1b). Overall 75% of the short term survivors died in hospital compared to 43% of longer term survivors. The proportion recorded as dying from lung cancer was similar in both groups - 89% short term survivors and 90% longer term survivors had lung cancer recorded as main cause of death.

4.4. Discussion

One in five newly diagnosed lung cancer patients in our study died within 30 days of diagnosis and one quarter died within 44 days. Given the very short survival times, indicators for early assessment for palliative care are important to facilitate ongoing management and end of life care. We identified that older patients (aged 80 years and over), with any comorbid disease, who have emergency admissions at diagnosis are more likely to die within 30 days following diagnosis than younger patients, without comorbidities and admitted electively.

4.4.1. Survival time

Our study aimed to identify indicators for early assessment for palliative care using routine linked data to compare characteristics of short- and longer term survivors. Survival time is affected by many factors including patient age, functional status, tumour stage at diagnosis and the treatment modalities available to treat disease. The relationships between these factors are complex; treatment plans are optimised to the individual and patients well enough to receive curative treatment will derive a survival benefit from that treatment. Patients who die shortly after diagnosis may have had too little time for adequate assessment and appropriate care plans (curative or palliative) to be put in place however, this group has not been well

characterised at the population level. We are aware of only one population based study characterising short term survivors [25]. We have shown patients surviving longer are more likely to receive tumour-directed treatment which is associated with survival benefit, the proportion of patients receiving treatment increased steadily with increasing survival time.

Retrospective studies of cancer care often use look-back periods from death of six or twelve months [29]. Survival times vary considerably by cancer type and stratification by survival time from diagnosis could be more informative than look-back studies (using defined periods of time before death). For example when examining the care received at end of life, aggressive care may be completely appropriate in the early stages of treatment shortly after a cancer diagnosis however this information can be lost in look-back studies if survival time is not reported. Reporting survival time provides an added context to evaluate the care patients receive at end of life. As we have shown it can highlight opportunities to improve that care for patient subgroups, for example patients who die very soon after diagnosis.

4.4.2. Indicators for palliative care

Age and emergency admission

In a critical review of 10 studies from the USA, Canada, France, Australia and New Zealand, Wong et al highlighted the absence of evidence regarding the palliative care requirements of older patients particularly those presenting to emergency departments, with a call for more research to help improve service provision [30]. Similarly Brewster et al [25] found patients dying within 30 days of diagnosis were more likely to be elderly and have one or more emergency admission in the 30 days either before or after diagnosis. Our population based study supports the international evidence for high levels of emergency admissions and poorer survival in older cancer patients.

Sixty percent of patients diagnosed with lung cancer in our study presented as an emergency admission. McPhail et al also found emergency presentation remains predictive of short-term mortality in cancer patients even when age, stage, and co-morbidity are accounted for [31]. A prospective mixed methods single centre study of lung cancer patients presenting as emergencies reported palliative care needs were high and various information and support needs unmet [32]; the authors recommended a specialist palliative care assessment be routinely offered.

A lack of access to cancer diagnostics is a recognised short-coming in the Irish health system which has led to increased referrals of patients to emergency departments by general practitioners [33] and to initiatives to improve access to care. In 2012, the National Cancer Control Programme in Ireland initiated rapid access clinics providing direct access to consultant led assessment and diagnostic services for patients with suspected lung disease or cancer [34]. The clinics allow for suspect cases to be fast tracked and diagnosed on an urgent basis thereby facilitating earlier diagnosis and increased survival. Our study results (on patients diagnosed from 2005 to 2012) provides baseline data on stage at diagnosis and survival for patients diagnosed before the introduction of these rapid access clinics.

Comorbidity

Comorbid disease has been shown to delay diagnosis in colorectal cancer patients and particularly in older patients [35]; comorbid conditions were classified as ‘competing demands’ (unrelated to colorectal cancer) or ‘alternative explanations’ (sharing symptoms with colorectal cancer). In a prospective study across five US hospitals, earlier consultation with specialist palliative care teams was associated with lower cost of hospital stay for patients admitted with an advanced cancer diagnosis [36]. A second related study showed the effect was

larger for patients with higher number of comorbidities [37]. Comorbidity was measured using the Elixhauser comorbidity index [38] which counts the presence of thirty one serious conditions. We used the Charlson index [23] to derive a comorbidity score from the diagnosis episode as we did not have access to HIPE data before the cancer diagnosis. Furthermore under recording of comorbid disease in the HIPE data is a potential limitation and as other measures such as functional status were not available to us, it is probable we have under estimated the level of comorbid disease in our patient sample. Notwithstanding, we have shown short term survivors have more comorbid disease than longer term survivors and the odds of early mortality increases with increased comorbidity. Given this, earlier referral for palliative care assessment could not only improve the patient experience at end of life but might also yield economic benefits.

Stage

Our study also reports short term survivors were more likely to have tumours which are less well characterised, (i.e. not staged and histologically unspecified), than patients who survive longer. Current national guidelines recommend patients with stage IV non-small-cell lung cancer should be offered concurrent specialist palliative care and standard oncological care at initial diagnosis [39] (see recommendation 2.8.1.1 page 109). It further recommends all patients with advanced stage lung cancer should have their palliative care needs assessed. Using the stage IV criteria as an indicator for palliative care just over 50% of the short-term survivors from our study would be identified and this highlights the need for additional prognostic indicators for early assessment.

Place of death

Our rate of death in acute hospitals of 49% for lung cancer decedents is higher than that reported by Bekelman et al. for lung cancer decedents aged 65 years or older in acute hospitals in England (42.6%), Germany(45%), The Netherlands(29.5%), Norway (46.5%) and the United States (20.2)% and lower than Canada (54.1%)[8]. The higher percentage of hospital deaths in our study is partially due to the high rates in the short term survivors, but also the Bekelman study was restricted to deaths for one year (2010) while our study had a broader time frame of eight years and included all lung cancer patients. Moves to reduce deaths in acute hospitals adopted in the United States and the Netherlands (as described by Bekelman et al.) have been effective however without reporting place of death by survival time, it is unclear whether they benefit short term survivors.

In an economic evaluation of specialist palliative care services in three parts of Ireland which have heterogeneous structures and resources for these services, Brick et al found that an area with well-developed specialist palliative care services and, where its role is understood, is likely to have more referrals and that these will in general be earlier [40]. O’Leary et al, in a study of one specialist palliative care service in Ireland over a 6-month period found late referral to palliative care was associated with receiving specialist palliative care in one care setting only but receiving care across multiple settings supported people to stay at home for longer [41].

Death within 30 days of diagnosis means there is little time to determine and put appropriate care plans in place and death in hospital for these patients might be entirely appropriate. In this context triggers for early assessment of palliative care for newly diagnosed lung cancer patients are very important so that the best care can be provided as soon as possible whether in hospital, in the community or at home.

4.4.3. Strengths and Limitations

A strength of our study is the use of high quality population based cancer registry data which has been verified and augmented by linkage to hospital episode data to death and certificate data. Linked datasets provide novel opportunities for research at the population level, however there are limitations to their use. For data confidentiality reasons, we cannot access hospital episode data for patients before a cancer diagnosis, so cannot examine health care utilisation leading to diagnosis. This information would facilitate a more accurate profile of the short term survivors in particular; multiple morbidities, especially in elderly patients, might explain short survival and/or post-mortem diagnoses of lung cancer. In this study 10% of lung cancer cases recorded by NCRI had no corresponding HIPE record. Failure to find a match can occur for several reasons including: typographical errors in fields used for matching, missing data on either system or no mention of cancer on the HIPE record, in which case the record would not be made available to NCRI. A cross reference of HIPE data with death certificate data indicate 5% of patients with place of death recorded as hospital do not have a HIPE record and we estimated 3% of these died in private hospitals who do not provide HIPE data.

4.5. Conclusion

A major focus of end-of-life care research has been to identify cohorts of patients who may be near end of life and would benefit from palliative care [42, 43].

We have shown a high proportion of lung cancer patients who die within 30 days of diagnosis are older, have comorbid disease and are admitted through the emergency department. These characteristics, available at diagnosis, may be useful prognostic factors to guide decisions on early assessment for palliative care for lung cancer patients. Further research is needed on the palliative care needs of elderly patients admitted through the emergency department with suspected lung cancer.

Patients who die shortly after diagnosis are more likely to die in hospital so reporting place of death by survival time may be useful to evaluate interventions to reduce deaths in acute hospitals. It would also highlight sub groups of patients who might benefit from early assessment for and referral to palliative care.

Abbreviations

AJCC American Joint Committee on Cancer, **CCI** Charlson comorbidity index, **CSO** Central Statistics Office, **ESRI Economic** and Social Research Institute, **ICD** International Classification of Diseases, **ICD-O3** International Classification of Disease for Oncology, 3rd Edition, **IQR** Interquartile range, **HIPE** Hospital In-patient Enquiry, **NCRI** National Cancer Registry Ireland.

Declarations

Ethics approval and consent to participate

The NCRI has permission under the Health (Provision of Information) Act 1997 to collect and hold data on all persons diagnosed with cancer in Ireland without requiring individual consent. The use of that data for research is covered by the Statutory Instrument which established the Registry Board in 1991. All datasets were anonymised prior to analysis.

Consent for publication

Not applicable

Availability of data and material

The database on which the analysis was based is stored in the National Cancer Registry, Ireland. The datasets generated and analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests with respect to the research, authorship, and/or publication of this article.

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Authors' contributions

MK conceived the study, developed the concept, acquired the data, carried out the analysis and wrote the initial drafts of the manuscript. KOB provided statistical support, helped with interpretation of the data and results and draft the manuscript. ML helped refine the intellectual content of the paper. KCG helped draft the manuscript and refine the intellectual content of the paper. AH helped conceived the study, develop the concept, provide statistical support, helped with interpretation of the data and results and draft the manuscript. All authors contributed to the final draft of the manuscript. All authors read and approved the final manuscript.

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Table 4.1. Patient, tumour and admission characteristics at diagnosis, by survival category

	Survival category			Tests of association
	0-30 days n=2595	> 30 days n= 11250	All n= 13845	
Age (years)				
< 60	253 (10)	1990 (18)	2243 (16)	$\chi^2=268.78$, df(3), p< 0.001 Somers' d = 0.082
60-69	569 (22)	3240 (29)	3809 (28)	
70-79	950 (37)	3835 (34)	4785 (35)	
80+	823 (32)	2185 (19)	3008 (22)	
Gender				
Male	1606 (62)	6671 (59)	8277 (60)	$\chi^2=5.88$, df(1), p=0.015 Cramer's V = 0.021
Female	989 (38)	4579 (41)	5568 (40)	
Marital status				
Partner	1224 (47)	6193 (55)	7417 (54)	$\chi^2=52.66$, df(1), p< 0.001 Cramer's V = 0.062
Other	1371 (53)	5057 (45)	6428 (46)	
Smoker				
Ever	1803 (69)	8641 (77)	10444 (75)	$\chi^2=78.77$, df(3), p< 0.001 Cramer's V = 0.075
Never	219 (8)	915 (8)	1134 (8)	
Unknown	573 (22)	1694 (15)	2267 (16)	
Diagnosis episode admission^a				
Elective	360 (16)	3990 (46)	4350 (40)	$\chi^2= 635.33$, df(1), p< 0.001 Cramer's V = 0.242
Emergency	1823 (84)	4669 (54)	6492 (60)	
Diagnosis episode Charlson score				
0	1362 (62)	6481 (75)	7843 (72)	$\chi^2=134.08$, df(2), p< 0.001 Cramer's V = 0.114
1	403 (18)	1166 (13)	1569 (15)	
>1	418 (19)	1012 (12)	1430 (13)	
Stage^b				
Stage 0/I/II	183 (7)	2148 (19)	2331 (17)	$\chi^2=365.11$, df(3), p< 0.001 Somers' d = 0.098
Stage III	573 (22)	3246 (29)	3819 (28)	
Stage IV	1376 (53)	4606 (41)	5982 (43)	
Un-staged	463 (18)	1250 (11)	1713 (12)	
Histology^c				
Adenocarcinoma	447 (17)	3027 (27)	3474 (25)	$\chi^2=735.46$, df(5), p< 0.001 Cramer's V = 0.23
Carcinoma	254 (10)	1346 (12)	1600 (12)	
Large cell carcinoma	121 (5)	421 (4)	542 (4)	
Unspecified malignant	951 (37)	1715 (15)	2666 (19)	
Small cell carcinoma	449 (17)	1708 (15)	2157 (16)	
Squamous cell carcinoma	373 (14)	3033 (27)	3406 (25)	

^a The diagnosis episode was the episode where the lung cancer diagnosis was made or the first episode occurring in the interval from 7 days before to 14 days after the lung cancer diagnosis. Episodes outside this interval were excluded from the analysis, n=1591. There was no matching HIPE data for n=1412 decedents. The denominator data is n= 2183 for short term survivors and n= 8659 for longer term survivors.

^b Due to small cell numbers (n=11), 'Stage 0' classification was merged with 'Stage I/II' classification

^c Due to small cell numbers (n=21), 'Sarcoma' classification was merged with 'unspecified malignant' classification. Morphologies based on International Agency for Research on Cancer classification [21]

Table 4.2. Characteristics available at diagnosis associated with death within 30 days of diagnosis

Characteristic	Adjusted odds ratio	95% confidence interval		p-value for Wald test
Age group				
<60 years	1.00			
60-69 years	1.44	1.21	1.72	<0.001
70-79 years	1.91	1.62	2.25	<0.001
80+ years	2.70	2.27	3.22	<0.001
Marital status				
Partnered	1.00			
Other	1.19	1.07	1.31	0.001
Gender				
Male	1.00			
Female	0.81	0.73	0.90	<0.001
Smoker				
Ever	1.00			
Never	0.98	0.82	1.17	0.906
Unknown	1.48	1.29	1.68	<0.001
Diagnosis episode admission^a				
Elective	1.00			
Emergency	3.92	3.47	4.44	<0.001
Diagnosis episode Charlson score				
0	1.00			
1	1.23	1.08	1.41	0.002
>1	1.41	1.23	1.62	<0.001

^a The diagnosis episode was the episode where the lung cancer diagnosis was made or first episode occurring in the interval of 7 days before to 14 days after the lung cancer diagnosis.

Table 4.3. Characteristics and clinical data available at diagnosis associated with death within 30 days of diagnosis

Characteristic	Adjusted odds ratio	95% confidence interval		p-value for Wald test
Age group				
<60 years	1.00			
60-69 years	1.45	1.22	1.74	<0.001
70-79 years	1.99	1.68	2.36	<0.001
80+ years	2.44	2.03	2.94	<0.001
Marital status				
Partnered	1.00			
Other	1.15	1.04	1.28	0.007
Gender				
Male	1.00			
Female	0.77	0.69	0.86	<0.001
Smoker				
Ever	1.00			
Never	0.91	0.75	1.09	0.313
Unknown	1.27	1.10	1.46	<0.001
Diagnosis episode admission^a				
Elective	1.00			
Emergency	2.96	2.61	3.37	<0.001
Diagnosis episode Charlson score				
0	1.00			
1	1.32	1.15	1.52	<0.001
>1	1.44	1.25	1.65	<0.001
Stage				
Stage 0/I/II	1.00			
Stage III	2.12	1.73	2.62	<0.001
Stage IV	3.37	2.77	4.11	<0.001
Un-staged	3.47	2.76	4.37	<0.001
Histology				
Adenocarcinoma	1.00			
Carcinoma	1.17	0.97	1.41	0.095
Large cell	1.71	1.32	2.20	<0.001
Unspecified malignant	2.91	2.49	3.41	<0.001
Small cell	1.50	1.28	1.76	<0.001
Squamous cell	0.84	0.71	0.98	0.034

^a The diagnosis episode was the episode where the lung cancer diagnosis was made or first episode occurring in the interval of 7 days before to 14 days after the lung cancer diagnosis.

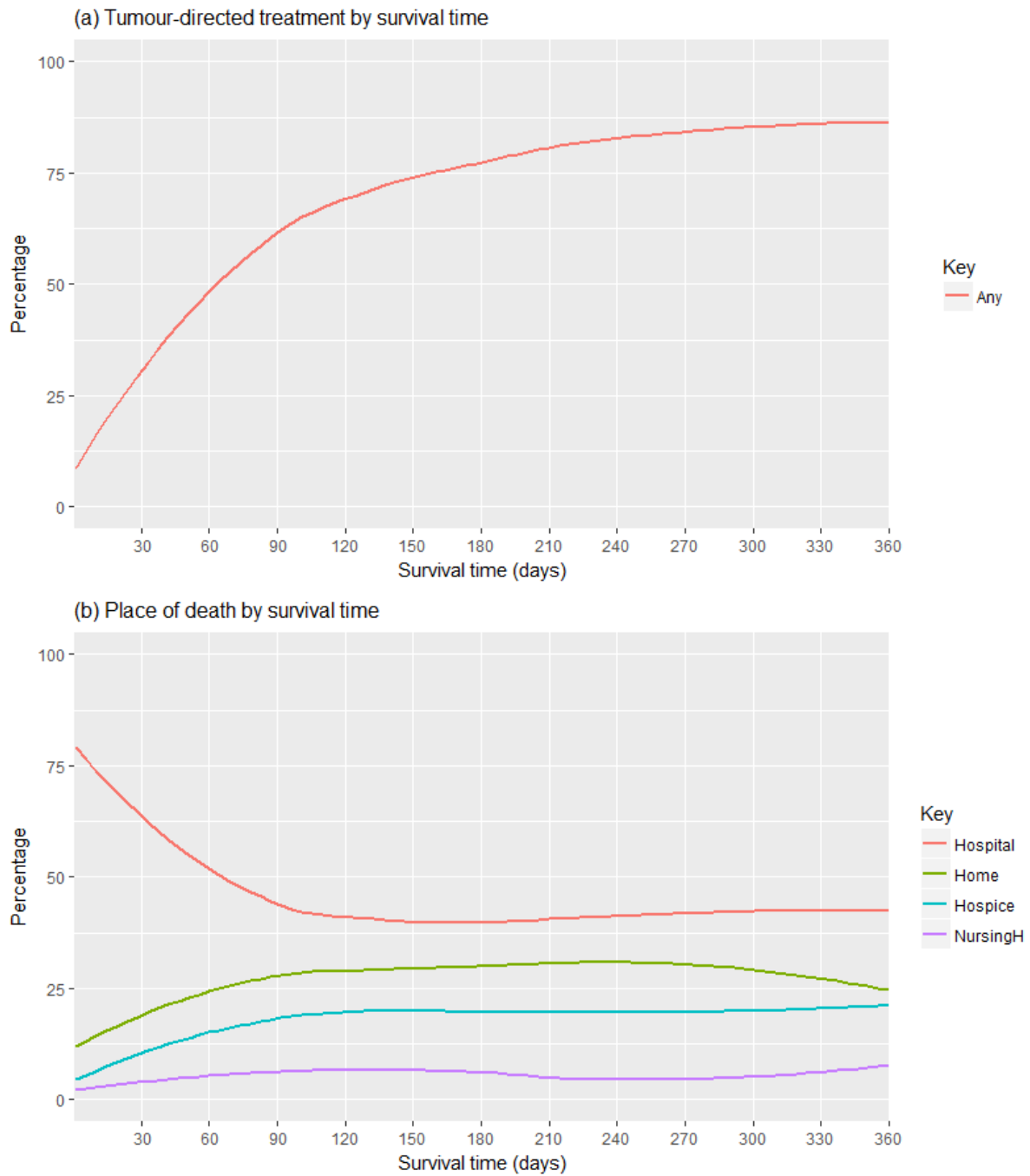
Table 4.4. Post diagnosis characteristics; treatment, place of death and cause of death.

Tumour directed treatment ^a	Survival category			Tests of association
	0-30 days n=2595	>30 days n= 11250	All n= 13845	
None	2169 (84)	3183 (28)	5352 (39)	$\chi^2=2718.36$, df(1), p<0.001, Cramer's V = 0.443
Any	426 (16)	8067 (72)	8493 (61)	
Diagnosis episode discharge code^b				
Death	1243 (57)	237 (3)	1480 (14)	$\chi^2=4345.6$ df(1), p<0.001, Cramer's V = 0.633
Other	940 (43)	8422 (97)	9362 (86)	
Place of death				
Hospital	1949 (75)	4850 (43)	6799 (49)	$\chi^2=876.52$, df(5), p<0.001, Cramer's V = 0.252
Home	338 (13)	3200 (28)	3538 (26)	
Hospice	185 (7)	2084 (19)	2269 (16)	
Nursing Home	65 (3)	688 (6)	753 (5)	
Unknown	34 (1)	339 (3)	373 (3)	
No death certificate	24 (1)	89 (1)	113 (1)	
Cause of death				
Lung cancer	2320 (89)	10081 (90)	12401 (90)	$\chi^2=0.096$, df(1), p=0.757, Cramer's V = 0.003
Other	275 (11)	1169 (10)	1444 (10)	

^a Refers to tumour directed treatment received within one year of diagnosis.

^b The diagnosis episode was the episode where the lung cancer diagnosis was made or the first episode occurring in the interval from 7 days before to 14 days after the lung cancer diagnosis. Episodes outside this interval were excluded from the analysis, n=1591. There was no matching HIPE data for n=1412 decedents. The denominator data is n= 2183 for short term survivors and n= 8659 for longer term survivors

Figure 4.1; Percentage (a) receiving tumour-directed treatment and (b) place of death by survival time



Chapter 5: Specialist palliative cancer care in acute hospitals and place of death: a population study

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Chapter 5 is the Results chapter for the thesis from Study 2. It is presented as a published paper and addresses the broad PhD aims of

- Identifying receipt of palliative care from administrative health data.
- Comparing the characteristics of those who receive palliative care in acute public hospitals with those who do not.
- Exploring the relationship between receiving palliative care and place of death.

Abstract

Objective

This study compares characteristics and place of death of cancer patients receiving specialist palliative care in acute hospitals with those who do not.

Methods

All patients with incident invasive cancer in Ireland (1994-2016 inclusive), excluding non-melanoma skin cancer, who attended a cancer centre and died in 2016 were identified from cancer registry data. Patients were categorised based on a diagnosis code 'Encounter for palliative care' from linked hospital episode data. Place of death was categorised from death certificate data. Data were analysed using descriptive statistics, Chi squared tests and logistic regression.

Results

Of n=4103 decedents identified, 62% had a hospital based palliative care encounter in the year preceding death. Age ($p < 0.001$), marital status ($p=0.017$), deprivation index ($p < 0.001$) and health board region ($p=0.008$) were independent predictors of having a palliative care encounter. Place of death differed by palliative care encounter group: 45% of those with an encounter died in hospital versus 50% without an encounter, 33% versus 16% died in a hospice and 18% versus 28% died at home ($p < 0.001$).

Conclusion

Almost two thirds of cancer patients who attended a cancer centre and died in 2016 had a palliative care encounter. They were younger, less likely to be married, and more likely to be from deprived areas. Having accounted for sociodemographic factors, there was evidence of regional variation in receiving care. Demographic, clinical factors and the provision of health services in a region need to be considered together when assessing end of life care.

Keywords:

Palliative care, place of death, health services, cancer

5.1. Introduction

Place of death is an internationally recognised measure to evaluate end of life care [1–4]. It is affected by patient sociodemographic and clinical factors and characteristics of the health service delivering care. An emerging body of evidence shows health service organisation must be considered when evaluating patient place of death [5–10].

A systematic review examining factors influencing death at home in terminally ill cancer patients found three groups of factors important: those related to the illness, the individual and the environment [9]. Environmental factors were considered the most important. A study of over 1.25 million cancer deaths in England in 2001-2010 by Gao et al [7] found large variation in place of death by geographical area of which less than 25% could be explained by sociodemographic or clinical characteristics of the patient. A subsequent report proposed a population based framework to evaluate the role of different aspects of healthcare services in place of death. This included health service characteristics such as service type e.g. adult inpatient hospice, hospitals, general practitioner and care homes, and capacity e.g. ratio of service facilities to user population, counts of services types within functional areas [8]. A study using the framework for all deaths in England in 2014 [6] found almost all health service characteristics studied were associated with some of the area-level variation in place of death with service type and capacity were the strongest predictors.

There is a lack of empirical studies examining the delivery of specialist palliative care to cancer patients in acute hospitals and whether this impacts place of death. The objectives of our study were to i) identify cancer patients who received specialist palliative care in acute hospitals in Ireland ii) to compare characteristics of patients receiving specialist palliative care with those who don't and iii) compare place of death for these two groups.

5.2. Methods

5.2.1. Setting

Ireland has a mixed public private health care system where publically funded health care is managed by the Health Service Executive (HSE) and funded through the tax system. All

residents are entitled to use the public health system. There are eight designated cancer centres at publicly-funded hospitals where most cancer surgery takes place.

The National Clinical Programme for Palliative Care (NCPPC), formed in 2010, recommends a ratio of 8 to 10 specialist palliative care beds per 100,000 population [11]. In 2015, no community health organisation (CHO) area had the recommended ratio [12] (table 5.1). The NCPPC defines specialist palliative care (level 3 care) as care provided by health care professionals who work solely in palliative care and have extensive knowledge and skills in this specialty [13]. Each of the cancer centres have a specialist palliative care team. In 2020, there are 10 adult in-patient hospice units providing specialist palliative care in Ireland. Neither the former Midlands nor South-Eastern health board region have an inpatient hospice (figure 5.1). Access to hospice is by general practitioner or hospital consultant referral.

5.2.2. Data Sources

The data sources for this study were the National Cancer Registry Ireland (NCRI), the Hospital Inpatient Enquiry (HIPE) database from the Health Pricing Office (HPO), and death certificate data from the Central Statistics Office (CSO), supplemented by data from the Death Events Publication Service (DEPS). We used a collated dataset from the Specialist Palliative Care Minimum Data Set (SPC-MDS) for the years 2015-2017 in a validation study of HIPE data. SPC-MDS provides data from each acute hospital showing the aggregate counts of inpatient new referrals to the specialist palliative care team. Data collection from acute hospitals fully commenced in 2016 [12].

The NCRI records demographic, clinical and treatment information for all cancers diagnosed in Ireland, using internationally accepted conventions [14].

HIPE is an electronic based information system that records demographic, clinical and administrative data on discharges from all acute public hospitals in Ireland. Data are abstracted from medical records by trained clinical coders and entered into the HIPE system. Data quality is critical to the work of HIPE so that coder training, data quality initiatives and the HPO software ensure that data are being constantly reviewed [15]. HIPE data captures cases that have not had a histological verification of the diagnosis, or for which the registry failed to identify a pathology report. For confidentiality reasons, only HIPE episodes that mention a cancer diagnosis are available to the registry.

Every death in the Irish State must be recorded and registered within 3 months with the General Registers Office. Non-registration is rare because of the necessity of a death certificate for many legal purposes [16]. Cause of death is coded using ICD-10 codes and a software system used across Europe to improve international comparability.

The NCRI routinely links HIPE data, DEPS data and death certificate data with registry data using probabilistic matching techniques, for case ascertainment and verification purposes. Completeness of case ascertainment is estimated to be 98.7% [17]. The NCRI has permission under the Health Act 1997 to collect and hold data on all persons diagnosed with cancer in Ireland without requiring individual consent. The use of that data for research is covered by the Statutory Instrument which established the Registry Board in 1991. All data were de-identified prior to analysis.

5.2.3. Data definitions

Demographic information collected by the NCRI at cancer diagnosis include patient name, address, gender, date of birth, marital status and smoking status. Clinical information is coded using international guidelines including international classification of diseases (ICD) codes [14,18]. For comparison purposes, age categories and tumour grouping were chosen to match those used in the CSO Vital Statistics Annual Report 2016 [19].

Address at diagnosis was used to assign a deprivation score using the Pobal HP deprivation index,[20]. The index measures the relative affluence or socio-economic disadvantage of a geographical area using information collected on education, unemployment and other socioeconomic factors from the 2016 Census of Population. Patients are assigned to a health board region based on their address at diagnosis.

5.2.4. Indicators for a palliative care encounter

ICD-10-AM Diagnosis code Z51.5 - Encounter for palliative care

Coding Standards for HIPE (page 36, [18]) state “Palliative care should be assigned (as an additional diagnosis code) when the intent of care at admission is 'for palliation', or if at any time during the admission the intent of care becomes 'for palliation', and the care provided to the patient meets the definition above.” Palliative care is to be coded when there is documentation that the patient has been seen by the palliative care team.

Discharge Code - transfer to hospice

The HIPE discharge code describes the patient destination on discharge. Categories include home, nursing home, transfer to another hospital, transfer to hospice and died.

5.2.5. Study participants

The study population included patients with incident invasive cancer (ICD-O C00-C97) [21] excluding non-melanoma skin cancer, diagnosed from 1994-2016 inclusive, who attended one of eight adult cancer centres in 2016 and died in 2016. The study population was restricted to patients who attended a designated cancer centre in 2016 because i) cancer centres meet required standards so that all the patients have had access to similar standards of care including specialist palliative care, ii) acute public hospitals began providing numbers of patients referred for specialist palliative care to the national SPC-MDS in 2016 and these numbers were used in a validation study and iii) specialist palliative care bed capacity is quantified by CHO regions which were established in 2015.

Encounter for palliative care

Patients were categorised to two groups: Encounter for palliative care (yes, no) based on having at least one indicator for palliative care in their HIPE data for any acute public hospital in the year period preceding death (figure 5.2).

5.2.6. Main outcome measure

Place of death was derived from DEPS data using place of death address. These were categorised to Home, Hospital, Hospice and Community care setting. Community care included nursing homes and other long-term residential care settings.

5.2.7. Statistical Methods and Analysis

Validation study for encounter for palliative care

The number of cancer patients who had at least one indicator of palliative care recorded in their 2016 HIPE hospital data was counted for each of the eight adult cancer centres. This was compared to an aggregate count of new specialist palliative care referrals for cancer patients in the SPC-MDS in 2016 by hospital.

Comparison of study participants with all cancer deaths in 2016

The demographic and clinical characteristics of the decedents in our study were compared to all 2016 cancer deaths using data from the CSO Vital Statistics Annual Report 2016 [19].

Comparison of characteristics and place of death by encounter for palliative care

Descriptive statistics are provided for categorical demographic and clinical variables for each group: encounter for palliative care (yes, no). Chi squared tests examined the association between categorical variables. Logistic regression analysis examined the association of sociodemographic factors and former health board region with palliative care encounter group. Age, gender, marital status, smoking status, deprivation index, former health board region, and age at death were included in the model. Odds ratios (OR) and 95% confidence intervals (95% CI) are reported. Tumour groups were excluded from the model because of specialisation at certain cancer centres, so that tumour group is related to geographic region. Model goodness-of-fit was assessed using Hosmer and Lemeshow test [22]. Place of death was examined by palliative care encounter group. Analyses were carried out using the R Studio, Version 1.0.143 [23]

5.3. Results

5.3.1. Identifying those with an encounter for specialist palliative care

In a validation study, n=3455 patients were identified as having a palliative care encounter from HIPE data compared to n=3688 patients from the SPC minimum dataset. This represents a 6% difference. Four of the eight cancer centres closely matched the SPC-MDS aggregate counts with greater variation in the other four.

For the main analysis, n=4126 decedents were identified (figure 5.2), representing 45% of all reported deaths in Ireland from malignant neoplasm in 2016 (n=9171) [19]. They were younger and a higher proportion (39% versus 33%) were from the former Eastern health board region (table 5.2). Decedents were broadly similar in terms of cancer diagnosis apart from cancers of the digestive organs (C15-C18) and blood cancers (C81-C96); 26% of study decedents versus 31% of all cancer decedents had cancer of the digestive organs while 11% of study decedents versus 8% of all cancer decedents had a blood cancer (table 5.2). In total 85% of the decedents in our study were diagnosed in the five year period 2012-2016.

5.3.2. Comparison by palliative care encounter group

Of the n=4126 decedents identified we excluded a further n=23 patients whose palliative care encounter occurred more than one year before death. Of the remaining n=4103 decedents, 62% had a palliative care encounter in the year preceding death and 38% did not, (table 5.3).

Age and deprivation showed the strongest association with a palliative care encounter (table 5.3). Overall median survival was 309 days (IQR 97-906 days). The palliative care encounter group had a shorter median survival of 296 days (IQR 93-850 days) versus 323 days (IQR 108-1012 days) in the no encounter group. Median time from the admission date of the last 'encounter for palliative care' episode to death was 28 days (IQR 13-53 days).

Of those with a Z51.5 code, 82% occurred at a cancer centre and 18% occurred in other acute hospitals.

The North Western region had the highest proportion (73%) of decedents in receipt of a palliative care encounter while the Midlands region had the lowest (57%), (table 5.4).

5.3.3. Logistic regression analysis

Decedents who were not married had increased odds of having a palliative care encounter (OR 1.22, 95% CI 1.07-1.39). Using the least deprived quintile as a reference, those in the most deprived quintile had increased odds of an encounter (OR 1.59, 95% CI 1.25-2.03), (table 5.5). Relative to those under 65 years of age odds of a palliative care encounter decreased as age increased from 0.78 (95% CI 0.66-0.92) in the 65-74 year age-group to 0.59 (95% CI 0.47-0.74) in the 85 years and over age-group. Accounting for sociodemographic factors, decedents in the Midlands and South East were significantly less likely to have a palliative care encounter relative to those in the Eastern health board region.

5.3.4. Place of death

Hospital was the most common place of death (47%) followed by hospice (27%) and home (22%), (table 5.6). Place of death differed between the palliative care encounter groups, 45% versus 50% died in hospital, 33% versus 16% died in a hospice and 18% versus 28% died at home in the encounter versus the no encounter group.

5.4. Discussion

Almost two thirds of cancer patients who attended an adult cancer centre in 2016 and died in 2016 had a palliative care encounter. They were younger, less likely to be married, and more likely to be from deprived areas than those who didn't. Proportions having palliative care varied by health board region. Hospital was the most common place of death across the groups, but those having a palliative care encounter were proportionately twice as likely to die in hospice.

5.4.1. Strengths and weaknesses

This study uses high quality population based cancer registry data, linked to hospital episode data and death certificate data and is population based, however there are some limitations.

Variables from the cancer registry dataset including marital status and smoking status are collected once at diagnosis. The majority (85%) of our study participants were diagnosed within the previous five years but these variables may have changed over that time.

Address at diagnosis was used to assign a deprivation score using the Pobal HP deprivation index [20], however 23% of 2016 decedents are classified as having an unknown deprivation score. This usually arises because the patient address cannot be resolved to a single geographic area.

Our study dataset represents 45% of all malignant cancer deaths reported in Ireland in 2016. Although broadly similar in characteristics, the decedents in our study were younger relative to the total population of 2016 cancer decedents. A smaller proportion (5%) had a cancer of the digestive organs and a higher proportion (3%) had a blood cancer diagnosis. It has been reported that patients treated at cancer centres are younger than those treated in other public hospitals. Differences in referral patterns has been cited as one explanation for this, for example patients considered better candidates for treatment [24]. The majority of decedents in our study were diagnosed in the 5 year period 2012-2016, 50% died within one year and 75% within three years of diagnosis which indicates our study population are representative of recently diagnosed cancer patients in the active phase of treatment.

Using HIPE to identify those having a palliative care encounter may underestimate the actual numbers seen. A single centre study in New York examined the validity of the ICD-9 code V66.7 (Encounter for palliative care) from hospital episode data [25]. The code had high specificity (99.1%) and low sensitivity (49.9%); sensitivity was higher in patients with non-metastatic cancer (61.9%), and metastatic cancer (66.3%). The authors concluded studies using this code would identify patients who have a high likelihood of having received care, but will not capture all patients who receive palliative care. We also cannot be certain a Z51.5 diagnostic code guarantees a patient received specialist palliative care i.e. care provided by health care professionals who work solely in palliative care. To mitigate this, we restricted our study population to decedents who attended one of eight cancer centres in 2016, each of which have specialised cancer services and specialist palliative care teams. We included discharge to

a hospice as an indicator for palliative care given the likely need for a consultation with the palliative care team before discharging to this setting. Lastly we undertook a validation study where HIPE patient-level counts at four of eight cancer centres closely matched the SPC-MDS aggregate counts with greater variation in the other four. For the SPC-MDS, the treating clinician decides which disease is prompting the referral to end of life care whereas the NCRI uses international guidelines to determine cancer [14]. The SPC-MDS counts are new referrals only while this distinction is not available from HIPE.

5.4.2. Comparison with other studies

Palliative care encounter and age

There was a trend of decreasing odds for a palliative care encounter with increasing age. This is consistent with results from a previous retrospective study of patients with advanced cancer at a single medical centre in Houston, Texas [26]. Access to palliative care for older adults is a recognised problem [27,28]. Reasons cited include attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources [27]. A qualitative study of older patients (aged 70 or older) reported that older patients may have less clear early signs indicating that they need palliative care and are not referred [28]. The authors noted the lack of a clear diagnosis of dying may explain why the palliative care needs of older patients in particular are not recognised. The patients in our study represent cancer patients in the active phase of treatment so further investigation of why the older decedents within this population were less like to receive a palliative care encounter is warranted. Calls to more fully characterise cancer patients treated outside these centres have also been made [24]. Our study can provide a baseline for comparisons, particularly for palliative care.

Palliative care encounter and marital status

We found patients who were not married were more likely to have a palliative care encounter. This differs from the results of a 2012 study that found married patients were more likely to have a palliative care consultation [26]. Demographic information including marital status was retrieved was from the medical charts for these patients. It is not clear if this happened at the date of diagnosis of cancer or advanced cancer for the n=816 patients in the study. That study like ours may suffer from misclassification bias.

Palliative care and smoking status

A perceived and implicit bias against patients with smoking-related lung disease has been reported as a potential barrier to palliative care [29]. Smoking status was unknown for 38% of our study population so we could not reliably examine the association between smoking status and receipt of palliative care in cancer patients, 22% of whom had cancer of the respiratory and intrathoracic organs. Removing smoking status from the logistic regression model did not change the results.

Palliative care encounter and deprivation

Although more than a quarter of the decedents in our study have unknown deprivation category, there is a clear positive association of a palliative care encounter with increasing deprivation. In England inpatient hospice death is more likely among decedents living in less deprived areas than among those living in more deprived areas [30]. A broader review suggested use of specialist palliative care in cancer patients may modify the effect of socioeconomic status on place of death [31]. Our study supports this, however access to specialist palliative care itself may be driven by socioeconomic factors.

Palliative care encounter and regional variation

Having accounted for sociodemographic factors, decedents in the South Eastern and Midlands regions had a statistically significant decreased odds of a palliative care encounter relative to the Eastern region. Regional-level variation in specialist palliative care services in Ireland is well documented [32,33]. Neither the South Eastern nor Midlands regions have an inpatient hospice and limited inpatient specialist palliative care beds which may explain why decedents from these regions have reduced access to specialist palliative care.

Palliative care encounter and place of death

Hospital was the most common place of death for all the decedents in our study which is broadly consistent with previous studies [6,7,34,35]. Interestingly, this was true for the group who had a palliative care encounter, although the proportions dying in hospital (45% versus 50%) and at home (18% versus 28%) were lower. This may be due to limited inpatient hospice care facilities and specialist palliative care beds which is a known problem in Ireland [11]. Studies to investigate differences in end of life care between the two groups particularly for those who die at home would be informative.

5.5. Conclusions

Access to specialist palliative care affects subsequent place of death. Demographic, clinical factors and the provision of health services in a region affect access to specialist palliative care in acute hospitals and need to be considered together when assessing end of life care.

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Competing Interests

None declared.

Contribution:

MK, AH conceived and developed the study. MK acquired the data, carried out the analysis and drafted the initial manuscript. KOB, AH provided statistical support, helped with interpretation of data and results. All authors contributed to manuscript revisions and the final draft. All authors read and approved the final manuscript. MK is guarantor and responsible for the overall content.

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Table 5.1. Estimation of Specialist palliative care bed (SPC) capacity by health board region based on reported capacity by Community Health Organisation area (CHO) for 2016.

Former health board region	CHO area	CHO SPC capacity (Beds per 100,000 population ^{*)}	Former health board region geographical overlap with CHO [†]	Estimated health board SPC capacity
North Western	1	4.1	Contained completely within CHO 1	High‡
North Eastern	1	4.1	Split between CHO 1 and CHO 8	-
North Eastern	8	0.0	Split between CHO 1 and CHO 8	-
Midlands	8	0.0	Contained completely within CHO 8	Low
Western	2	4.0	Same region	-
Mid-Western	3	7.9	Same region	High
Southern	4	6.6	Same region	
South Eastern	5	0.4	Same region	Low
Eastern	6	3.3	Split between CHO 6, CHO 7 and CHO 9	-
Eastern	7	6.5	Split between CHO 6, CHO 7 and CHO 9	-
Eastern	9	7.4	Split between CHO 6, CHO 7 and CHO 9	-

* Source: <http://hospicefoundation.ie/wp-content/uploads/2018/01/National-Survey-of-Patient-Activity.pdf>. Table 3, page 12. (Weafer JA, Toft S. National summary of patient activity data for adult specialist palliative care services in the Republic of Ireland, 2012-2015)

† See supplementary data file, figures 1 and 2 for additional information.

‡ All the specialist palliative care beds are in the two hospices located in the former North Western health board region.

Table 5.2. Comparison of clinical and demographic characteristics of all deaths from malignant neoplasm in 2016 with the study dataset.

Variables	Deaths from malignant neoplasms in 2016 (n= 9171)*	Attended a cancer centre in 2016 and died in 2016 (n=4126)
	Count (%)	Count (%)
Gender		
Female	4370 (48)	1867 (45)
Male	4801 (52)	2259 (55)
Age at death		
0–14	18 (0)	<10 (0)
15–24	15 (0)	<10 (0)
25–34	68 (1)	42 (1)
35–44	169 (2)	111 (3)
45–54	566 (6)	323 (8)
55–64	1369 (15)	747 (18)
65–74	2512 (27)	1255 (30)
75–84	2839 (31)	1195 (29)
85 & over	1615 (18)	442 (11)
Cancer type[†]		
C00–C14 (Lip, oral cavity and pharynx)	188 (2)	146 (3)
C15–C26 (Digestive organs)	2856 (31)	1221 (26)
C30–C39 (Respiratory and intrathoracic organs)	1985 (22)	1033 (22)
C40–C41 (Bone and articular cartilage)	31 (0)	11 (0)
C43–C44 (Skin)	263 (3)	117 (2)
C45–C49 (Mesothelial and soft tissue)	122 (1)	58 (1)
C50 (Breast)	763 (8)	405 (9)
C51–C58 (Female genital organs)	537 (6)	267 (6)
C60–C63 (Male genital organs)	531 (6)	341 (7)
C64–C68 (Urinary tract)	458 (5)	269 (6)
C69–C72 (Eye, brain and other parts of central nervous system)	344 (4)	178 (4)
C73–C75 (Thyroid and other endocrine glands)	46 (1)	26 (1)
C76–C80 (Ill–defined (secondary and unspecified sites)	316 (3)	136 (3)
C81–C96 (Lymphoid, haematopoietic and related tissue)	731 (8)	545 (11)
Former health board region		
Eastern	3038 (33)	1620 (39)
North East	819 (9)	265 (6)
South East	1060 (12)	471 (11)
West	892 (10)	509 (12)
Midlands	522 (6)	123 (3)
North West	586 (6)	148 (4)
South	1419 (15)	608 (15)
Mid West	835 (9)	382 (9)

*Source: <https://www.cso.ie/en/releasesandpublications/ep/pvsar/vitalstatisticsannualreport2016/deaths2016/> [19]

[†]Based on n= 4753 tumours in the study dataset.

Table 5.3. Patient demographic and clinical variables by palliative care group.

	No encounter for palliative (n=1545) Count (%)	Encounter for palliative (n=2558) Count (%)	Total (n=4103) Count (%)	Chi squared test of association
Smoker Status				
Ever	587 (38)	1100 (43)	1687 (41)	$p < 0.001$
Never	319 (21)	548 (21)	867 (21)	
Unknown	639 (41)	910 (36)	1549 (38)	
Marital Status				
Married	876 (57)	1354 (53)	2230 (54)	$p = 0.017$
Other	669 (43)	1204 (47)	1873 (46)	
Gender				
Female	667 (43)	1186 (46)	1853 (45)	$p = 0.046$
Male	878 (57)	1372 (54)	2250 (55)	
Deprivation				
1 Least	234 (15)	306 (12)	540 (13)	$p < 0.001$
2	208 (13)	302 (12)	510 (12)	
3	221 (14)	370 (14)	591 (14)	
4	195 (13)	373 (15)	568 (14)	
5 Most	242 (16)	513 (20)	755 (18)	
Unknown	445 (29)	694 (27)	1139 (28)	
Age at death				
<65 years	382 (25)	843 (33)	1225 (30)	$p < 0.001$
65–74	465 (30)	783 (31)	1248 (30)	
75–84	502 (32)	688 (27)	1190 (29)	
85 & over	196 (13)	244 (10)	440 (11)	
Tumour count per patient				
1 tumour	1306 (85)	2223 (87)	3529 (86)	$p = 0.034$
> 1 tumour	239 (15)	335 (13)	574 (14)	
Tumour group*				
C00–C14 (Lip, oral cavity and pharynx)	46 (3)	100 (3)	146 (3)	$p < 0.001$
C15–C26 (Digestive organs)	458 (25)	759 (26)	1217 (26)	
C30–C39 (Respiratory and intrathoracic organs)	357 (20)	668 (23)	1025 (22)	
C40–C41 (Bone and articular cartilage)	<10 (0)	<10 (0)	11 (0)	
C43–C44 (Skin)	47 (3)	70 (2)	117 (2)	
C45–C49 (Mesothelial and soft tissue)	17 (1)	41 (1)	58 (1)	
C50 (Breast)	157 (9)	241 (8)	398 (8)	
C51–C58 (Female genital organs)	74 (4)	192 (7)	266 (6)	
C60–C63 (Male genital organs)	157 (9)	183 (6)	340 (7)	
C64–C68 (Urinary tract)	100 (6)	168 (6)	268 (6)	
C69–C72 (Eye, brain and other parts of central nervous system)	63 (3)	114 (4)	177 (4)	
C73–C75 (Thyroid and other endocrine glands)	10 (1)	16 (1)	26 (1)	
C76–C80 (III–defined (secondary and unspecified sites)	64 (4)	72 (2)	136 (3)	
C81–C96 (Lymphoid, haematopoietic and related tissue)	253 (14)	289 (10)	542 (11)	

*Based on n= 4727 tumours.

Table 5.4. Palliative care group by former health board region.

Group	Easter n Count (%)	North East Count (%)	South East Coun t (%)	West Coun t (%)	Midland s Count (%)	North West Coun t (%)	South Coun t (%)	Mid West Coun t (%)	Chi squared test of associatio n
No encounter for palliative care	615 (38)	85 (32)	191 (41)	174 (34)	53 (43)	40 (27)	243 (41)	144 (38)	<i>p</i> = 0.008
Encounter for palliative care	1001 (62)	180 (68)	279 (59)	332 (66)	69 (57)	108 (73)	354 (59)	235 (62)	
Total	1616	265	470	506	122	148	597	379	

Table 5.5. Odds ratios and 95% confidence intervals for a palliative care encounter by sociodemographic factors and former health board region.

Variable	Odds ratio(95% CI)
Smoker status	
Ever	1.0
Never	0.97 (0.81, 1.15)
Unknown	0.77 (0.66, 0.89)
Marital status	
Married	1.0
Other	1.22 (1.07, 1.39)
Gender	
Female	1.0
Male	0.9 (0.79, 1.02)
Deprivation	
1 Least	1.0
2	1.1 (0.85, 1.41)
3	1.3 (1.01, 1.66)
4	1.46 (1.13, 1.89)
5 Most	1.59 (1.25, 2.03)
Unknown	1.26 (1.01, 1.56)
Age category	
< 65 years	1.0
65-74 years	0.78 (0.66 , 0.92)
75-84 years	0.63 (0.53, 0.75)
85 years and over	0.59 (0.47, 0.74)
Former health board region	
Eastern	1.0
North East	1.15 (0.87, 1.54)
South East	0.77 (0.62, 0.97)
West	1.12 (0.90, 1.39)
Midlands	0.66 (0.4 , 0.97)
North West	1.38 (0.94 , 2.05)
South	0.82 (0.67, 1.0)
Mid West	0.87 (0.68, 1.1)

Table 5.6. Place of death by palliative care group.

	No encounter for palliative (n=1545)	Encounter for palliative (n=2558)	Total (n=4103)	Chi squared test of association
Place of death	Count (%)	Count (%)	Count (%)	
Hospital	768 (50)	1159 (45)	1927 (47)	<i>p</i> < 0.001
Hospice	253 (16)	839 (33)	1092 (27)	
Home	434 (28)	472 (18)	906 (22)	
Community care setting	90 (6)	88 (3)	178 (4)	

Figure 5.1. Former health board regions in Ireland with inpatient hospice location indicated by black dots.

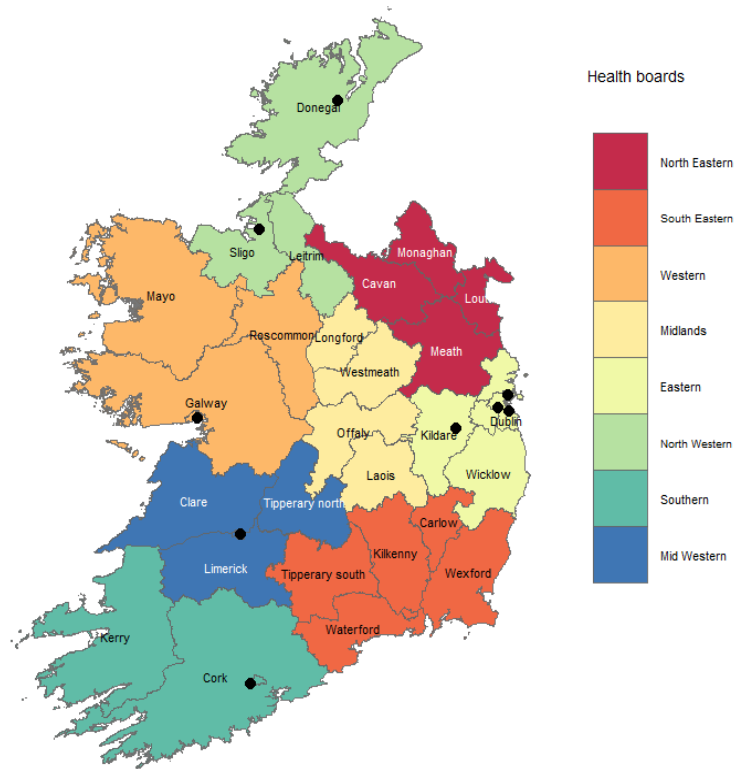
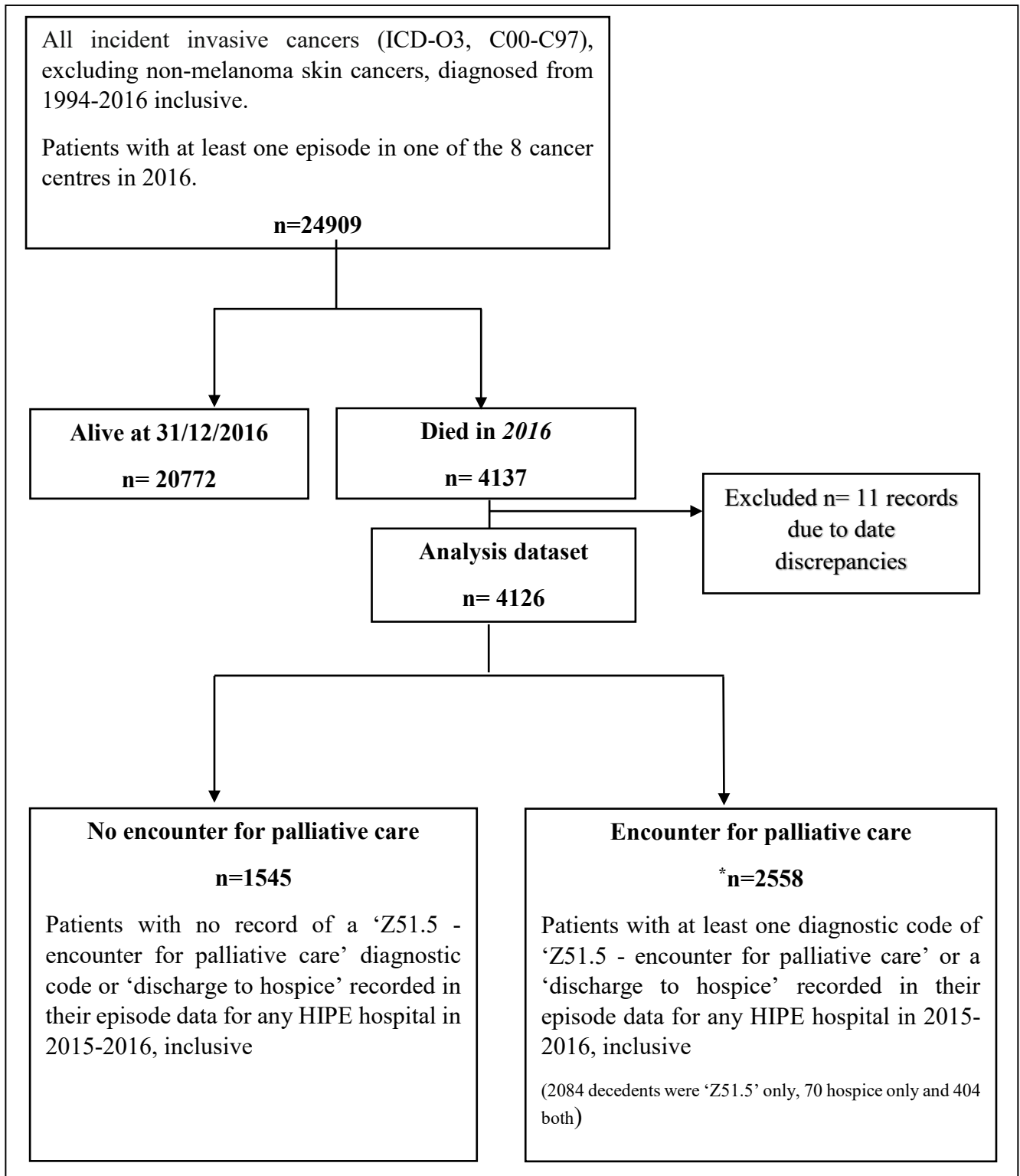


Figure 5.2. Development of the study dataset



* A further n= 23 cases were excluded where look back period from the date of death to the admission date of last palliative care episode was greater than one year. HIPE, Hospital Inpatient Enquiry.

5.7. Supplementary data

Figure 5.3 Former health board regions in Ireland with inpatient hospice location indicated by black dots.

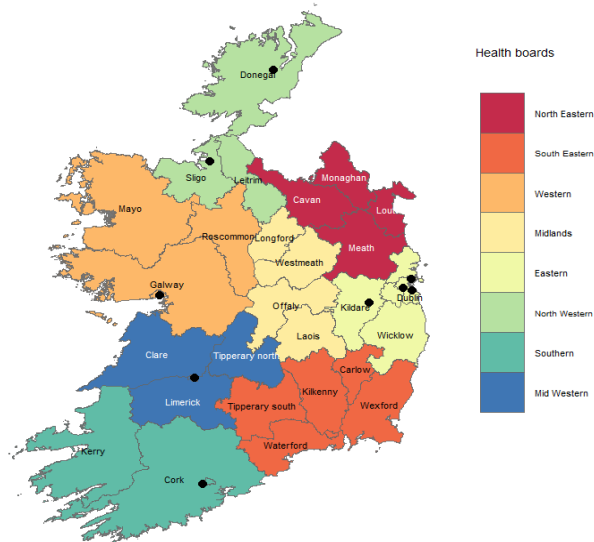


Figure 5.4 Community health organisation areas introduced in 2015 (source Health Service Executive)

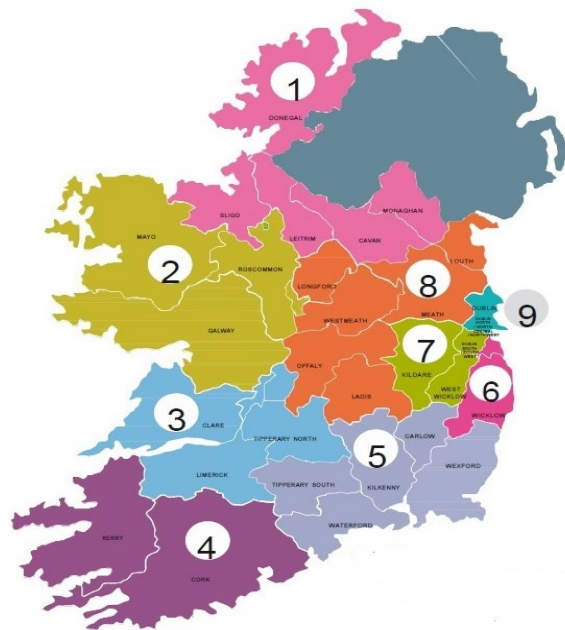
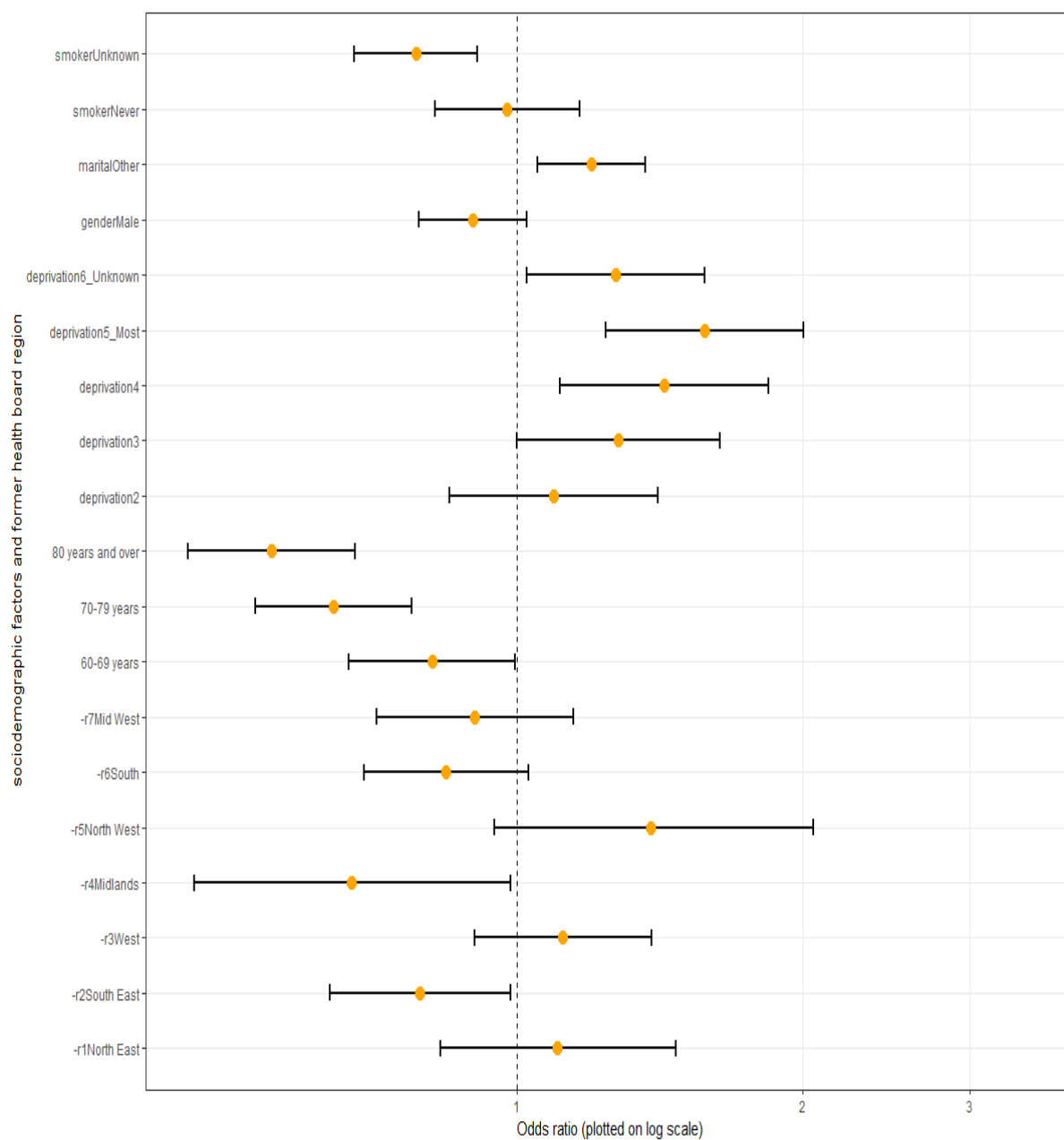
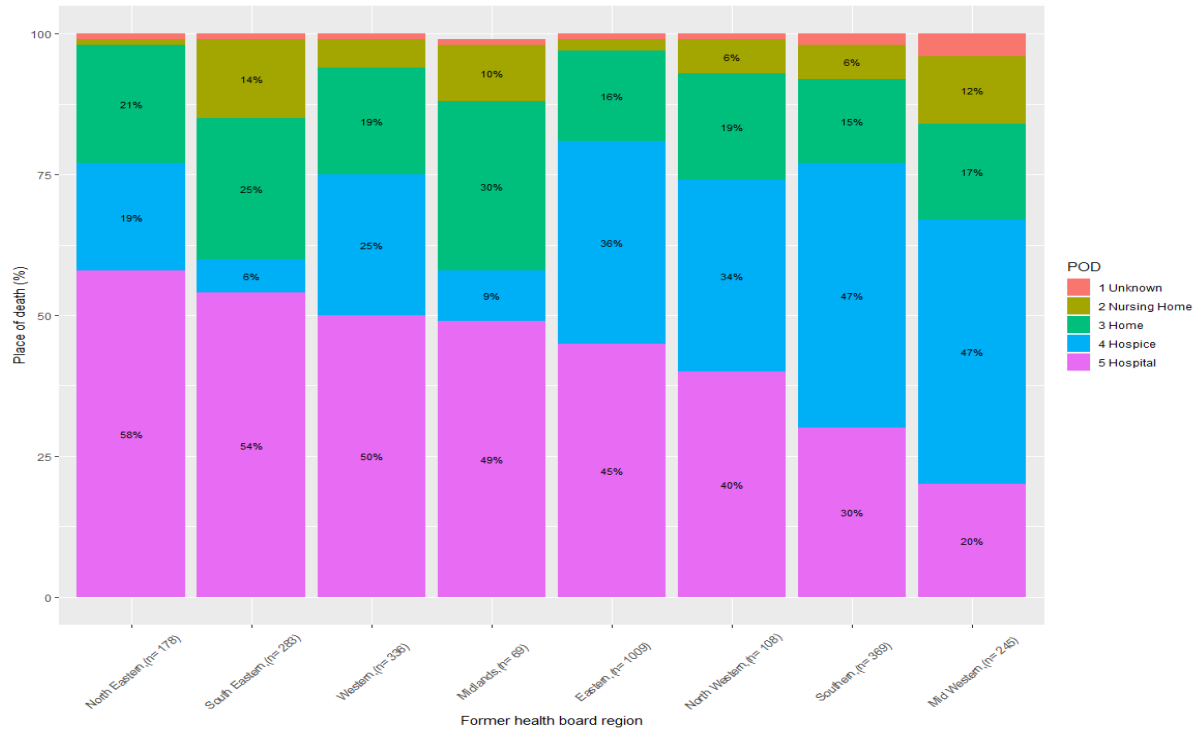


Figure 5.5 Odds ratios† and 95% confidence intervals for a palliative care encounter by sociodemographic factors and former health board region



†Reference: smoker-‘ever smoker’, marital status-‘Married’, gender ‘Female’, deprivation-‘deprivation1_Least’, age ‘< 60 years’, region-‘r8Eastern’

Figure 5.6 Place of death by former health board region for decedents who had an encounter for palliative care in acute hospital in 2016



Chapter 6: Using administrative health data for palliative and end-of-life care research in Ireland: potential and challenges.

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Kelly, M., O'Brien, K. M., & Hannigan, A. Using linked administrative health data for palliative and end of life care research in Ireland: potential and challenges. [Ref number 13215 – approved HRB Open Research - <https://hrbopenresearch.org/articles/4-17>]

Chapter 6 is the final Results chapter from the thesis. It draws together the experience of using administrative health data for PEOLC research in cancer patients and extrapolates the knowledge gained to evaluate the potential and challenges of other national non-cancer health and social care data collections for PEOLC research. It is presented as a published paper.

Abstract

Background: This study aims to examine the potential of currently available administrative health and social care data for palliative and end-of-life care (PEoLC) research in Ireland. Objectives include to i) identify data sources for PEOLC research ii) describe the challenges and opportunities of using these and iii) estimate the impact of recent health system reforms and changes to data protection laws.

Methods: The 2017 Health Information and Quality Authority catalogue of health and social care datasets was cross-referenced with a recognised list of diseases with associated palliative care needs. Criteria to assess the datasets included population coverage, data collected, data dictionary and data model availability and mechanisms for data access.

Results: Nine datasets with potential for PEOLC research were identified, including death certificate data, hospital episode data, pharmacy claims data, one national survey, four disease registries, (cancer, cystic fibrosis, motor neurone and interstitial lung disease) and a national renal transplant registry. The *ad hoc* development of the health system in Ireland has resulted in i) a fragmented information infrastructure resulting in gaps in data collections particularly in the primary and community care sector where much palliative care is delivered, ii) ill-defined data governance arrangements across service providers, many of whom are not part of the publically funded health service and iii) systemic and temporal issues that affect data quality. Initiatives to improve data collections include introduction of i) patient unique identifiers, ii) health entity identifiers and iii) integration of the eircode postcodes. Recently enacted general data protection and health research regulations will clarify legal and ethical requirements for data use.

Conclusions: Ongoing reform initiatives and recent changes to data privacy laws combined with detailed knowledge of the datasets, appropriate permissions, and good study design will facilitate future use of administrative health and social care data for PEO LC research in Ireland.

Keywords: Administrative health data, data linkage, palliative and end-of-life care

6.1. Background

Administrative health data is generated through the provision and administration of health and social care by health care service providers and other institutions.

Its use for research purposes is an area of growing interest ¹⁻⁵. Internationally initiatives to harness the potential of linked administrative health data for research purposes are well developed in Australia ⁶⁻⁸, the UK ⁹⁻¹¹ the Nordic countries (Norway, Sweden, Finland, Denmark, Greenland and Iceland) ¹² and Canada ¹³. However data linkage is a complex process and methodologies vary ^{14,15}. In Ireland the need to develop a coherent and integrated approach to health information ¹⁶ and the potential of routine data for health research ¹⁷ is recognised. Initiatives to harness that data for research purposes have started but these are at an early stage ¹⁸. The Health Service Executive (HSE), Ireland's public health and social care service provider, is developing an open data strategy in recognition of the fact that the data it holds are a valuable asset that can improve healthcare delivery and planning ¹⁹.

Kane *et al.* reported that 80% of deaths in Ireland between 2007–2011 were from conditions recognized as having associated palliative care needs, with 30% of deaths from cancer and 50% from non-cancer conditions including neurodegenerative disease and dementia ²⁰. Significant barriers to high quality palliative care research exist ²¹⁻²³. These include identifying and recruiting subjects, increased ethical concerns for vulnerable patients who are often seriously ill and methodological concerns including loss to follow up, recall bias or difficulties measuring endpoints such as pain or symptom burden ²². Some of these issues can be addressed using routine data. Davies *et al.* described a number of initiatives that use routine data for palliative and end of life care (PEoLC) research in England and elsewhere ². The study identified three priorities for the future use of routine data; these were i) safe and ethical access to data, ii) improved data linkage and iii) improved PEoLC data collections. In Belgium, Maetens *et al.* identified and described the steps to access, interrogate and link seven population level databases for end-of-life research ²⁴. In Ontario, Tanuseputro *et al.* used a range of routine data sources to examine the delivery of palliative care across acute care, outpatient clinics, and home care health sectors at the population level ²⁵.

In Belgium, health insurance is legally mandatory so that data discovery relied mostly on access to claims databases which are managed by a single agency. In Ontario, claims data from Ontario Health Insurance Plan database augmented by linkage to a number of other

administrative databases held at a single institute, formed the basis of data capture. These studies demonstrate that while there are universal challenges to using administrative health data for research, the context is local and requires examination at the local level. Initiatives to use administrative health and social care data in Ireland are beginning but to-date its use for quantitative PEOLC research ^{26,27} has been limited.

Our aim is to identify the challenges and opportunities of administrative health and social care data for PEOLC research in Ireland. The study is timely given the recent initiatives to realise the potential of Irish health data ^{18, 19} and the emerging body of international studies using administrative health data ^{2, 24, 25}. Our objectives are i) to identify administrative health and social care data available that may be useful for PEOLC research ii) to describe both the challenges and opportunities using these data for PEOLC based on our experiences to-date using linked cancer registry data, hospital episode data and death certificate data and iii) to describe how recent initiatives to improve the health information environment and changes to data protection laws will impact future use of administrative health and social care data in Ireland.

6.2. Methods

6.2.1. Setting

Ireland has a mixed public private health care system where publically funded health care is managed by the HSE and funded through the tax system. All residents are entitled to use the public health system. There are three private health insurance providers in Ireland and in 2018, 45% of the population had private health insurance ²⁸. Privately insured patients in Ireland may be treated in public or private hospitals. The HSE National Clinical Programme for Palliative Care oversees the management and organisation of palliative care services in Ireland ²⁹. Specialist palliative care is delivered by the HSE along with a number of voluntary service providers. Specialist palliative care teams provide care in acute hospitals, community settings and specialist inpatient units across the country.

6.2.2. Identifying potential datasets for PEOLC research

The Health Information and Quality Authority (HIQA) is an independent body that evaluates the quality of the information available on health and social care and makes recommendations to improve quality, minimise inconsistencies and fill gaps where data are not available ^{30, 31}. Quality is defined as data that are complete, valid, accurate, reliable, relevant, legible and available in a timely manner ³². HIQA advocates eight guiding principles for organisations collecting data that include formalised governance arrangements, facilitating appropriate access to the data to optimise its benefits, continuous monitoring/improvements of data quality and effective information governance procedures. Standards for data quality include the use of data dictionaries, classification systems and clinical terminologies ³⁰. A data dictionary is a descriptive list of names, definitions and attributes of data elements to be collected in an information system or database and aids in the standardisation of data definitions ³³. Related to the concept of data dictionaries, data models describe how the data are organised and stored within an information system or database. This affects how relevant data from different systems data can be identified, extracted and compared. Data dictionaries and data models hold data about the data, also called metadata.

HIQA produces a catalogue of national health and social care data collections using a standardised template to describe existing data collections ¹⁶. The 2017 catalogue was cross-referenced with a recognised list of diseases with associated palliative care needs ([Table 1](#)), based on a methodology by Murtagh *et al.* ³⁴. Given Ireland's aging population and identified future palliative care needs for cancer, neurodegenerative disease and dementia ²⁰ particular focus was given to disease registry collections. Criteria used to assess the datasets included an examination of population coverage, the data collected, the availability of data dictionaries and data models and information on how the data can be accessed.

6.3. Results

In total, nine datasets were identified from the HIQA catalogue with potential for PEO LC. These include population based death certificate data, hospital based episode data for all patients treated in public acute hospitals in Ireland, pharmacy claims data for all people eligible for medical cards, one nationally representative cohort study of people aged 50 and over, four disease registry collections and a national renal transplant registry. Four have data dictionaries and six have a process to request access to the data. To our knowledge there is no record of a requirement for payment (for non-commercial organisations) to access any of the data sources mentioned here ³⁶. Key characteristics of the datasets are described in [Table 2](#). Based on our previous experience using cancer registry data linked to death certificate data and hospital episode data ^{37, 38} we describe the strengths and weaknesses of these datasets for PEO LC research.

6.3.1. Death certificate data

Every death in Ireland is legally required to be notified to the state within three months of death, so death certificate data is population based at the national level. Death is a unique event so a person should only have one death certificate record. The Department of Social Protection, Central Statistics Office (CSO) and General Register Office collect and record date of death, address of residence of deceased, place of death, cause of death, occupation of deceased, age of deceased, sex of deceased, and marital status of deceased. Cause of death for all deaths registered from 2007 onwards are coded using ICD10 codes ³⁹. Place of death is recorded as an address and is not classified e.g. into home, hospital, hospice, or long-term care facility ⁴⁰. Information on how to access the data are available [here](#).

6.3.2. Hospital Episode data

The Hospital In-Patient Enquiry system (HIPE) collects demographic, clinical and administrative data on discharges from, and deaths in, all acute public hospitals nationally. Details of each episode of care is recorded as a single record so that over time an individual can have multiple records within and across HIPE hospitals. HIPE is the only source of morbidity data available nationally for acute hospital services ⁴¹. In 2016, 53 hospitals were contributing to HIPE. Data are not available in HIPE for emergency department attendances unless the patient is admitted to hospital. Data are also not available for 22 private hospitals. Clinical coders review the records of each patient and extract the relevant clinical data, and translate it into codes using the ICD-10-AM/ACHI/ACS 8th edition ⁴². As well as a source of clinical information for many chronic diseases with associated palliative care needs (e.g. dementia, neurodegenerative diseases and cancer), diagnostic codes include ‘Z51.5 - Palliative care’ recorded when a patient has been seen by the palliative care team ⁴². The guidance for recording palliative care in HIPE changed with the introduction of the 10th edition ICD-10-AM/ACHI/ACS from January 2020. Palliative care should be recorded only where there is documented evidence that the patient has been provided with palliative care ⁴³. Notwithstanding evidence of variation in how the code is used across hospitals, currently HIPE is the only available population level administrative dataset where a record of a patient being seen by a palliative care specialist can be identified ⁴⁴. Additional relevant information for PEO LC research include admission type (elective/emergency) and patient destination on discharge with categories that include home, nursing home, transfer to another hospital, transfer to hospice and/or died. Information on accessing data and a data dictionary for HIPE data are available from <http://www.hpo.ie/>

Opportunities for data validation

The Minimum Data Set (MDS) is a national survey of demographic and patient activity data for specialist palliative care services in Ireland ⁴⁵. Monthly aggregate data from specialist palliative care inpatient units, community (homecare) services, day care services and acute hospitals are returned to a national office. The Specialist Palliative Care MDS does not contain patient level data and is not listed in the HIQA catalogue. A summary analysis of MDS ⁴⁵ for the period 2012 to June 2016 reported several metrics including

- The number of new patients in receipt of inpatient specialist palliative care, community care, and day care.
- Place of care prior to admission to inpatient units.
- The number of admissions and discharges from inpatient units.
- Inpatient bed availability and occupancy.
- The provision of care to non-cancer patients.
- Wait times for inpatient care and community care.
- Specialist palliative care in the community and place of death.

Data from all acute hospitals was incomplete at the time of analysis and excluded from the report, however MDS aggregated data of specialist palliative care activity in acute hospitals in 2016 has been used to validate HIPE coding of palliative care ³⁸.

6.3.3. Primary Care Reimbursement Service data

The HSE Primary Care Reimbursement Service (PCRS) is responsible for making payments to healthcare professionals including general practitioners (GPs), dentists and pharmacists, for the free or reduced costs services provided to the public under the General Medical Scheme and/or other schemes ⁴⁶. Access to the schemes is means-tested on a rolling basis and/or determined by specified long-term disease. Qualifying individuals are given a medical card with a unique medical card number (MCN). Eligibility for a medical card can change with changing circumstances so that over time, one person can have had a number of medical cards. In 2018, 43.4% of the population (over 2 million people) were eligible for a medical or GP visit card ⁴⁷. The PCRS dataset is one of the few national datasets that collects data in primary and community care settings. All expenditures around pharmaceuticals (drugs/medicine costs) are recorded against an MCN so that the data are transaction based. A data model is not currently available for PCRS so it is not clear how an individual is linked with medical card(s) within the PCRS database or whether an individual or a medical card is recorded more than once; neither is a data dictionary available. Further information on PCRS can be found at <https://www.hse.ie/eng/staff/pcrs/>.

6.3.4. The Irish Longitudinal Study on Ageing

The first wave of data collection for the Irish Longitudinal Study on Ageing (TILDA) surveyed a nationally representative sample of over 8500 people, aged 50 years and over, beginning in October 2009 with a further four waves of data collection in 2012, 2014, 2016 and 2018 ⁴⁸. Each individual within the TILDA dataset has a unique identifier and a wide range of data on the health, economic and social aspects of participants' lives are collected through personal interviews, self-completion questionnaires and health assessment measures ⁴⁹. TILDA is unique in Ireland in that it contains detailed longitudinal data on education, income and occupation in this age group which is not readily available elsewhere.

TILDA data has been linked at the person level with death certificate data, matching on the basis of name, address and month and year of birth. Matching was performed for all individuals who died between Wave 1 (2009/2011) and March 2018, and of a total of 863 confirmed deaths among the TILDA sample, matching death records were obtained for 779 decedents (90.3%) ⁵⁰. By law every death is registered and this is reflected in the high match rate achieved. Matching allows for detailed research around end of life care given the depth and breadth of information collected prospectively before death by TILDA. This work demonstrates person level data linkage with the other datasets described here is feasible. Anonymised data and documentation on TILDA are available for download from the Irish Social Science Data Archive ⁵¹.

6.3.5. Cancer registry data

The NCRI collects data nationally for incident tumours recorded at the level of the patient, that is each patient should be recorded once only in the registry database. This relational data model simplifies data linkage where data are matched at the person level using demographic details. Over time a patient may have additional tumour and management data attached to their patient record. Information collected includes patient demographics (age and sex), type of cancer (site and staging), treatments and selected procedures, date and cause of death (from linked death certificate data). Clinical information is coded using international guidelines including international classification of diseases (ICD) codes ^{35, 52}. The focus of data collection is on the first year post-diagnosis with limited data collection thereafter. Completeness of case ascertainment is estimated to be 98.7% ⁵³. Information on accessing data from the NCRI is available from the website <https://www.ncri.ie/>.

6.3.6. Other disease registries

Population based disease registries are a good starting point for PEO LC research because selection bias is reduced since the whole population with the disease are identified. The Irish Motor Neurone Disease (MND) register was established in 1995 and collects data on all known patients diagnosed with MND each year and currently it holds information on over 2,200 patients ⁵⁴. Individual level demographic data are recorded so that linkage to HIPE, death certificate data and PCRS data should be feasible. Date of disease onset is also captured so that studies on the patient's PEO LC needs throughout the disease trajectory are possible.

The Cystic Fibrosis registry requires patient consent for data collection. In 2017 it was estimated the registry coverage of the cystic fibrosis population was just over 90% ⁵⁵. The characteristics of those patients not captured are unknown, so studies using the cystic fibrosis registry may be subject to selection bias. Detailed demographic information that includes name and address, date of birth and ethnicity are recorded. Additional information includes information on diagnostic tests, genotype, symptoms and method of diagnosis, age at diagnosis, number of hospitalisations between annual assessments, complications and other clinical data and social data. Data linkage to death certificate data, HIPE data and PCRS data should be feasible. The cystic fibrosis registry is unique among the datasets described here in that it collects ethnicity data ⁵⁶.

The Irish Thoracic Society Interstitial Lung Disease (ITS-ILD) Registry began collecting data in 2016. Patient written consent is required for data collection. The first annual report (2018) on 154 patients found 46% of patients with idiopathic pulmonary fibrosis were referred through primary care, 12% of patients were referred for lung transplant assessment and 13% were referred to palliative care ⁵⁷. A key finding is that most patients with idiopathic pulmonary fibrosis will need a lung transplant or palliative care. While only preliminary information on disease stage and no information on survival times were provided, the report demonstrates the value of disease registries in providing detailed information necessary to assess the need for palliative care services.

6.3.7. National Renal Transplant Registry

The National Kidney Transplant Service for the Republic of Ireland was established in 1986 and is coordinated through Beaumont Hospital ⁵⁸. The National Renal Transplant Registry collects data on parameters at time of transplant, renal disease and source of transplant. Patient

data collected includes gender, area of residence and date of birth. The information is used to assess graft survival and patient survival, monitor factors affecting outcome and monitor performance ¹⁶. Three further national transplant services exist in Ireland: the National Heart and Lung Transplant Service, the National Liver Transplant Service transplant and the National Pancreas Transplant Centre ⁵⁹. Person level data from the transplant databases has been linked to cancer registry data to examine cancer incidence after organ transplantation ⁶⁰.

6.4. Considerations for PEO LC research

6.4.1. Structural issues in healthcare organisation and delivery

The *ad hoc* development of the Irish health system has contributed to an information infrastructure that often does not link across service providers thus leading to duplication, fragmentation and increased costs. Patients cannot be easily tracked from hospital to community based care leading to large gaps and silos of under used data ³⁰. Gaps exist particularly from the primary and community care sector as well as from outpatient clinics and emergency department attendances that don't result in hospital admission. The lack of community and social care data is particularly relevant for PEO LC as a considerable amount of palliative care is delivered in the community.

6.4.2. Data governance

A second consequence of the *ad hoc* development of services means how data is managed and accessed across providers, many of whom are not part of the HSE, is not well defined. Private hospitals do not contribute to the HIPE national data collection so that studies based on HIPE data cannot be generalised to the whole population. Biases and omissions in the available data cannot be adequately assessed. Similarly inpatient hospice services in Ireland are mostly provided by charities, partially funded by the HSE but with separate and distinct governance structures ⁶¹. Data models describing how the data are stored and organised are generally not available so that gauging the workload to manage and link data can be complex. Data dictionaries are generally not available so the datasets usefulness for PEO LC research cannot be evaluated in terms of the data items potentially available.

6.4.3. Individual health identifiers

The 2014 Health Identifiers Act ⁶² mandated the creation of an individual health identifier (IHI) register so that all health service users can be uniquely identified. While work is ongoing to introduce IHIs across the Irish health system, they have not yet been widely incorporated into the national data collections described above. In the absence of unique identifiers, linking patient records across datasets requires probabilistic matching techniques ⁶³, comprehensive strategies to guide the process including data cleaning and standardisation techniques ⁶⁴ and detailed knowledge of the datasets to be linked. Address can be used in matching but over 35% of addresses in Ireland share their address with at least one other property. Eircode, Ireland's postcode system, was launched in July 2015 where a unique postcode is assigned to each residential and business address. The integration of eircodes will facilitate probabilistic data matching of administrative datasets and allow geospatial analysis of the data.

Issues affecting quality or completeness of data within each dataset can affect the efficacy and accuracy of probabilistic matching. Issues can be systemic e.g. how the data are organised and stored. Temporal issues can include health service reconfigurations, changes to eligibility criteria (e.g. eligibility for medical cards) and/or changes in classifications systems over time.

6.4.4. Health Service Providers Identifiers

The 2014 Health Identifiers Act ⁶² also legislated for the development of a national database to capture, maintain and publish quality assured and verified standard codes and identifiers for health related entities i.e. practitioners, organisations, services, locations, and information on the relationships between them ⁶⁵. The repository will hold up-to-date information on health sites/locations, health care providers and services provided by the HSE and Private/Voluntary Organisations in Ireland. The introduction of health service provider identifiers will facilitate classification and enumeration of services that will benefit PEOLC research.

Place of death is an important outcome measure at a population level. In PEOLC research, place of death is commonly standardised to Own Residence, Hospital, Care Home and Hospice based on the place of death address ⁶⁶. There are no standards in use for Irish mortality data ⁴⁰ so that categorising place of death based on the address of a healthcare facility can be difficult without local knowledge. Facilities range from specialised centres to large regional hospitals, general hospitals, community and district hospitals, public and private nursing homes. Some facilities provide different services on the same site e.g. nursing home and hospice services. Ambiguity

around place of death could be reduced by requiring institutions to self-categorise the main services they provide from a standardised list.

6.4.5. Electronic Health records

The introduction of a national Electronic Health Record (EHR) in conjunction with IHI's are a key part of the HSE's strategic e-Health Programme ⁶⁷. EHRs are the means by which data can be recorded and shared across organisations and care settings ⁶⁸. Core functions will allow electronic prescribing and case management as well as the ability to aggregate data from these systems into a comprehensive national record, accessible to health and social care professionals, patients, service users and carers.

The 2020 HSE National Service Plan commits to progressing procurement of an electronic health record (EHR) solution in the National Children's Hospital which will inform the procurement of an EHR solution for all health and social care services ⁶⁹, p. 20. To-date an electronic health record had been introduced at several maternity hospitals in Ireland ⁷⁰. Several projects benefitting from the improving electronic health infrastructure have already been realised ⁷¹.

In Scotland the availability of electronic medical records have been used to develop electronic palliative care summaries to improve patient care for those accessing out-of-hours services ⁷². In England the impact of advance care planning (ACP) discussions have been evaluated in a hospice setting where that information has been recorded in the electronic patient record ⁷³. A wider initiative that relies on the existence of electronic medical record has been in development for some time in England. The Electronic Palliative Care Coordination Systems aims to enable advance care planning, improve communication and coordination at end of life by providing up-to-date key information on patients believed to be in their last year of life ⁷⁴. These studies from other countries demonstrate the opportunities for PEoLC research in Ireland as the electronic health infrastructure improves.

6.4.6. Health region

Several reconfigurations of the Irish health service have occurred since 2005, each of which can impact the continuity and quality of data collected. For example health boards have been replaced by HSE administrative areas and more recently by Community Health Organisation areas (CHO). In 2019, the Sláintecare report recommendation for a ‘common unit of geography’ for data collection and integration to increase capacity for cross-organisational research (Information and Research, page 24) has been initiated with the announcement of six integrated health regions to replace the CHOs ⁷⁵. The data collection systems have not kept pace with these changes so that a patient cannot be accurately assigned to a CHO area using address data alone. Eircode postcodes could be used to assign every household to a distinct CHO and/or other geographical units. This would eliminate any ambiguity for both service providers and service users on where to seek health care in the first instance, help establish criteria for access to services and facilitate meaningful research around service provision by health region.

6.4.7. General Data Protection Regulations

In May 2018 the General Data Protection Regulation (GDPR) became law in the European Union ^{76,77}. It regulates the processing of personal data relating to individuals in the EU so that personal data are

- 1. Processed lawfully, fairly and transparently.
- 2. Collected for specific legitimate purposes only.
- 3. Adequate, relevant and limited to what is necessary.
- 4. Accurate and kept up to date.
- 5. Stored only as long as is necessary.
- 6. Protected with appropriate security measures, ensuring its integrity and confidentiality.

Included in GDPR is the principle of patient consent where by valid consent from individuals is required for the processing of their personal data. Consent must be a “freely given, specific, informed and unambiguous indication of the individual’s wishes”. GDPR force a stricter data governance regime on organisations so that data controllers i.e. the organisations collecting data, can be required to prove compliance with GDPR requirements.

The measures for data processing for health research are given more specific effect through Ireland's Health Research Regulations Act (HRR)⁷⁸. Some of the specific measures enshrined by HRR Act were considered restrictive⁷⁹. Of particular concern were the requirements for explicit consent or approval from the Health Research Consent Declaration Committee (HRCDC)⁸⁰ for ongoing research involving retrospective chart reviews, use of biobank materials and research with individuals who lack capacity to consent. In 2021 the Department of Health amended the HRR to address these issues and clarify situations where a health research declaration consent application is required⁸¹. Under the new amendments, low risk retrospective chart reviews that have been approved by a research ethics committee and meet specified transparency requirements, no longer require a health research consent declaration⁸².

The requirements for compliance with GDPR and in particular the HRR are complicated by the fragmented health data infrastructure. Guidance notes are available to assist data controller organisations when making an application to the HRCDC for a consent declaration. In addition a public log of HRCDC applications provide an insight to the working of the committee. Information on the decision process for existing applications that include the decision outcome, any specific conditions attached and/or additional recommendations can alert researchers to potential requirements and/or shortcomings in their own application⁸⁰.

6.5. Discussion

Ireland does not have a universal healthcare system so there are no population-level insurance claims databases with national coverage unlike those used extensively in Belgium²⁴ and Ontario Canada²⁵ for PEOLC research. The Irish health system is characterised by a fragmented information infrastructure so that only death certificate data and a small number of the disease registry data collections are fully population based with national coverage. In this context, the use of cancer registry data complete with information on date, cause and place of death from linked death certificate data is a valuable tool for cancer PEOLC research. Because there is full coverage, biases due to missing data in the linked datasets can be better assessed and evaluated.

Studies using cancer registry data linked to hospital episode data for PEOLC research have been published in Ireland. One study examined the palliative care needs of lung cancer patients³⁷

and a second evaluated the receipt of specialist palliative cancer care in acute hospitals ³⁸. A feature of these studies is careful study design driven by background knowledge of the data available. Cancer registry data allow cancer subtypes to be examined individually taking account of differences in survival, for example lung cancer is characterised by short survival times. For data protection reasons, only hospital episode data that mention a cancer diagnosis are made available to the cancer registry for linkage. Hospital episodes at or following cancer diagnosis and shortly before death, (particularly where cancer is a cause), are most likely to mention a cancer diagnosis and be provided to the cancer registry. In this context hospital episode data is more likely to be complete for cancers with short survival times, such as lung cancer.

Cancer registry data has also been linked to PCRS pharmacy claims data to examine the effects of drugs on cancer progression and survival ⁸³⁻⁸⁵. In PEOLC, a goal of anticipatory prescribing is to allow patients have their symptoms managed at home at end of life ⁸⁶. Anticipatory prescribing includes opioid for pain, sedatives for anxiety and agitation as well as anti-emetics for nausea and vomiting ⁸⁷. In this respect the PCRS database could be a valuable resource for PEOLC research in the community where there is a recognised lack of data. Although not fully population based, a number of studies have described how PCRS can be used to study specific populations ⁸⁸ and particularly those aged 70 years and over ⁸⁹.

The Irish MND registry has been used extensively for research ⁹⁰⁻⁹², including an examination of the role of palliative care within a broader multidisciplinary approach to care ⁹³. The evidence base for palliative care for neurodegenerative diseases in general is lacking for MND patients ⁹⁴. A recent study has suggested certain triggers may be used to recognize the end-of-life phase in neurological patients. These include recurring infection, weight loss, dysphagia and aspiration pneumonia ⁹⁵. Linkage to HIPE data to explore these triggers in MND patients may be one avenue for future research.

In recent years lung transplantation for cystic fibrosis patients has become more common as patients survive longer with advances in care and treatment ⁹⁶. The changing practices impact the location and intensity of end-of-life care of people with cystic fibrosis and warrants further examination ^{97,98}. The first report from the ITS-ILD Registry indicates most patients with IPF will ultimately need lung transplant or palliative care ⁵⁷. For both the cystic fibrosis and the ITS-ILD registries, data linkage to administrative health data including HIPE data and death certificate data could be used to examine changing patterns in treatment and/or place of death.

Patients requiring transplant have advanced illness and may have unmet palliative care needs ⁹⁹⁻¹⁰¹. While specific data sources for many of the diseases listed in Table 1 are not available in Ireland, data from the national transplant services (cardiopulmonary, liver and renal diseases) has been linked to cancer registry data ⁶⁰ and could be used to identify cohorts of patients with palliative care needs.

6.6. Conclusions

Health and social care data collections are a powerful tool for PEOLC research ^{1,2,24} and these are available in Ireland ¹⁶⁻¹⁸. Previous studies have shown that, with the appropriate permissions, detailed knowledge of the datasets and good study design, these data can be used for PEOLC research in Ireland ^{37,38}. Since 2018, more stringent requirements around data governance, data sharing and the requirement for informed consent arising from legislative changes to GDPR and Irish Health Research Regulations have impacted on the use of administrative health and social care data for research. The planned reforms of the Irish health services ^{17,67} together with the HIQA recommendations for standards for data quality ³⁰ should improve the Irish health information infrastructure and research potential of administrative health and social care data. Streamlining the existing fragmented health service should clarify data governance and ownership issues. Improved data standards requiring data models, data dictionaries and the development of minimum datasets will allow researchers to evaluate the research potential of a dataset in advance and gauge the level of effort required to access and use the data. The introduction of IHI's for both service users and providers will improve data privacy by negating the need to store identifiable data name and/or date of birth etc. more than once. The increased security provided by IHI's will facilitate data pseudonymisation while data linkage and data sharing based on a common IHI between datasets, i.e. deterministic linkage rather than probabilistic matching should be possible. The introduction of EHRs will transform data sharing across health care settings and IHIs are a key enabler of this. These changes will take time to fully implement but should allow the full power of administrative health and social care data for PEOLC research to be realised in due course.

Data availability

Underlying data

All data underlying the results are available as part of the article and no additional source data are required.

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Table 6.1 Conditions associated with palliative care needs and their International Classification of Disease codes.

Condition	ICD-10 codes *
Malignant neoplasm	C00-C97
Heart disease, including cerebrovascular disease	I00-I52, I60-I69
Renal disease	N17, N18, N28, I12, I13
Liver disease	K70-K77
Respiratory disease,	J06-J18, J20-J22, J40-J47 & J96
Neurodegenerative disease	G10, G20, G35, G122, G903, G231
Alzheimer's, dementia and senility	F01, F03, G30, R54
HIV/AIDS	B20-B24

Source: 34, * 35

Table 6.2. Health and social care datasets with national coverage potentially relevant for palliative and end-of-life care (PEoLC) research.

Name	Disease	Coverage	Brief description	Data level	Data dictionary	Minimum dataset	More information
Vital Statistics - Death Registration	All	National population based	Death certificates	Individual	No	No	Further information on data for research can be found at https://www.cso.ie/en/aboutus/lgdp/csodata/policies/dataforresearchers/
Hospital In-Patient Enquiry(HIPE)	All	National for all acute public hospitals	A HIPE discharge record is created when a patient is discharged from (or dies in) hospital. Administrative, demographic and clinical information are collected for a discrete episode of care in 53 hospitals	Episode of care	Yes	Same as data dictionary	Datasets for HIPE discharges are provided to a number of State agencies in order to address specific data requirements. Data requests can be submitted by email to HIPEData.Requests@hpo.ie Further information on HIPE can be found at http://www.hpo.ie/
Primary Care Reimbursement Service (PCRS).	All	Nationally to all population entitled to a medical card The data covers the main national health schemes throughout the country.	The PCRS is responsible for making payments to Healthcare Professionals, e.g. GPs, dentists, pharmacists and optometrists/ ophthalmologists, who provide free or reduced cost services to members of the public across a range of community health schemes.	Script based transactions	No	No	Reports based on PCRS data are available from the eHealth Ireland Open Data Portal at https://www.sspcrs.ie/portal/annual-reporting For more information see https://www.hse.ie/eng/staff/pcrs/

The Irish Longitudinal Study on Ageing -TILDA	Not applicable	A nationally representative sample of adults aged 50 and over, resident in Ireland n=8,504	TILDA collects information on all aspects of health, economic and social circumstances from people aged 50 and over in a series of data collection waves once every two years beginning in October 2009.	Individual	Yes	Yes	Information on accessing the datasets are available from https://tilda.tcd.ie/data/accessing-data/ Further documentation is available at https://tilda.tcd.ie/data/documentation/
National Cancer Registry Ireland database (NCRI)	Malignant neoplasm	National population based.	All incident tumours recorded	Individual	Yes	Yes	Anonymised aggregated data are available for download from the NCRI website. Requests for individual level data are examined on a case by case basis. See website for details https://www.ncri.ie/
Irish Motor Neurone Disease Register	Motor Neurone Disease	All known patients diagnosed with MND in the Republic of Ireland.	Hospital In-Patient Enquiry (HIPE) discharge data in all major hospitals are searched to ascertain and confirm all MND diagnosis. The Central Statistics Office (CSO) Deaths Register is searched to capture MND cases where the subject passed away shortly after diagnosis. The register is based on direct nationwide chart review/confirmation by the diagnosing physician.	Individual	No	No	Requests for data are considered on a case by case basis. Email: ResearchMND@tcd.ie Further information can be found at http://mnd.ie
Cystic Fibrosis Registry of Ireland (CFRI).	Cystic Fibrosis	All consenting persons with CF in the Republic of Ireland.	Participation is voluntary, enrolment is based on patient consent to have their medical record details added to the registry. Data is taken	Individual	On request	No	Further information and requests for registry data can be made by downloading and completing the CFRI Data Application Form

			from patient medical charts by registry staff				
Irish Thoracic Society Interstitial Lung Disease Registry	Lung diseases including Interstitial Lung Disease (ILD)	All consenting persons with ILD in the Republic of Ireland	Participation is by consent. The registry aims to identify, record, analyse, and store information relating to the prevalence, incidence, and treatment of ILD in the Republic of Ireland.	Individual	No	No	Further information available by contacting the Irish Thoracic Society at https://irishthoracicsociety.com/contact-us/ and the ILD website at https://irishthoracicsociety.com/lung-disease/interstitial-lung-diseases/
National Renal Transplant Registry	Recipients of renal and pancreas transplants	All consecutive renal transplants from 1964 to date	The registry is maintained for the recipients of renal and pancreas transplants	Individual level	No	No	For further information contact Beaumont Hospital Kidney Centre. http://www.beaumont.ie/kidneycentre-home

Chapter 7: Discussion

The overarching objective of this thesis is to explore the potential of administrative health data for PEO LC research in Ireland. Research objectives included using the available linked data to identify vulnerable subgroups in need of palliative care, to identify and compare characteristics of those who receive palliative with those who do not and to explore the impact of receipt of palliative care on place of death. By drawing together the experience of using administrative health data for PEO LC research in cancer patients the knowledge gained was extrapolated to other national non-cancer health and social care data collections. In this way several guiding principles for using Irish administrative health and social care data for PEO LC research have emerged that can maximise its potential as a research tool while identifying the limitations of its use.

Internationally over the last decade linked administrative health data has been used to examine three broad strands of palliative care research (1) identification of those in need of palliative care, particularly subgroups e.g. the elderly, the frail or the very young, (2) investigation of the delivery and effectiveness of palliative care - usually using large administrative claims databases, disease registers and/or hospital episode data and (3) prognostication of patient outcomes. In general these studies originate from countries with well-developed health systems, mature data collection infrastructures and where universal health coverage is available. Three studies examined the potential of administrative health data for PEO LC research at a country level (Davies et al., 2016; Maetens et al., 2016; Tanuseputro et al., 2017). Themes common to the studies include identifying the available data, determining how that data can be safely and ethically accessed and then using the data to examine the delivery and effectiveness of palliative care. Country specific studies are important because the organisation of a health system impacts how palliative care is organised and delivered. This in turn determines what administrative health data are available for PEO LC research and whether it has potential to drive evidence-based palliative care practice and policy at the national level. In Ireland no such studies have been conducted to-date and this thesis addresses that gap.

Informed by the international experience of using administrative health data for PEO LC research and with detailed knowledge of available datasets, population based cancer registry data linked to hospital episode data and death certificate data two studies were undertaken. The first examined whether cancer subgroups in need of palliative care can be identified from administrative health data and is broadly aligned with the international research agenda of identifying palliative care need in vulnerable subgroups. The second study examined whether receipt of palliative care can be identified from hospital episode data and so allowing a comparison of those who receive palliative care in acute public hospitals with those who do not. This study fits with the second strand of international research i.e. identifying receipt of palliative care from administrative health data.

These studies demonstrated the practical challenges of using linked administrative health data and their potential for PEO LC research. Based on the experiential knowledge from these, a broader examination of the potential of Irish health and social care datasets for PEO LC research and the likely impact of ongoing initiatives to reform the Irish health service formed the basis of a third study.

7.1. Palliative care in cancer subgroups

In Ireland lung cancer remains the leading cause of death in both sexes with a 5-year survival rate of 20%, also 70% of lung cancer patients are diagnosed at a late stage i.e. stage III or IV, (National Cancer Registry Ireland, 2019c). Our first study compared the characteristics of short-term lung cancer survivors i.e. those that died within 30 days of diagnosis with those who survived longer, for patients diagnosed between 2005 and 2012 and who died before 01-01-2014. Having adjusted for stage and histologic type at diagnosis, we showed short-term survivors were older (aged 80 years and over), had comorbid disease, presented through the emergency department and did not have a partner (Kelly et al., 2018). These results are consistent with evidence for high levels of emergency admissions in older (65 years and older) breast and colorectal cancer patients in Scotland diagnosed between 2003–2007 (Brewster et al., 2011) and contributes to the evidence base of the need for palliative care in the emergency department (McPhail et al., 2013; Wong et al., 2014)

In Ireland current national guidelines recommend patients with stage IV non-small-cell lung cancer should be offered concurrent specialist palliative care and standard oncological care at initial diagnosis (National Cancer Control Programme, 2017, p. 109). Using this criteria alone as an indicator for palliative care, just over 50% of the short-term survivors from our study would be identified. This highlights the need for additional prognostic indicators for early assessment for palliative care for lung cancer patients in Ireland. We have shown older age (aged 80 years and over) combined with comorbid disease and presentation through the emergency department may be useful prognostic factors for early assessment for palliative care. Further characterisation of emergency admissions that result in a cancer diagnosis, in terms of the reason for admission, the time (e.g. out of hours) and day of admission would indicate the urgency of the admission. Information on hospital presentations before a cancer diagnosis would allow an assessment of the impact of comorbid disease on delayed diagnosis and/or late presentation.

Bekelman et al reported death rates in acute hospitals ranging from 54% in Canada to just over 20% in the United States for lung cancer decedents over 65 years of age in 2010 across 6 developed countries (Bekelman et al., 2016). In our study 75% of the short-term survivors died in hospital compared to 43% of longer term survivors. Patients who die shortly after diagnosis may have had too little time for adequate assessment and appropriate care plans (curative or palliative) to be put in place. In this context, reporting by survival time provides an added context to evaluate care received at end of life and may help explain differences in the rate of death in acute hospitals across different health care settings. The interplay between survival time, treatment and place of death is another area for future research. Techniques such as quantile regression analysis that assess differences in characteristics of the patient cohort over specific percentiles (or quantiles) of survival time may be informative.

A major limitation of studies that use administrative health data is the lack of consensus on the end-of-life time frame (Luta et al., 2015). Few account for differences in survival times by disease type and/or disease subgroups. Retrospective studies of cancer have used look-back periods from death of six or twelve months and many do not distinguish differences in survival by cancer type (Langton J.M. et al., 2014). In Ireland, the NCPPC does not use end-of-life to refer to a defined timeframe before death (The National Clinical Programme for Palliative Care, & HSE Clinical Strategy and Programmes Division., 2014). Cancer registry data provides detailed information on cancer type, date of incidence and date of death so that survival time

by cancer type may be determined. A study that looks forward from an event such as a cancer diagnosis is more robust than looking back from death, particularly for cancers with poor survival such as lung cancer. The approach also mitigates potential biases in subject selection (Bach et al., 2004).

Our study for lung cancer patients could be replicated for other cancer types particularly those with short survival times including liver, ovarian and pancreatic cancer. Other areas for research include an evaluation of the impact of the rapid access lung clinics for suspected lung cases established in 2012 (Health Service Executive, 2020), using our study results (on patients diagnosed from 2005 to 2012) as baseline data. Outcomes could include (1) cancer stage at diagnosis for non-small cell lung cancers to determine whether patients are diagnosed earlier, and (2) the numbers of admission to the emergency departments to check for a reduction in patients diagnosed from admissions to the emergency departments. Further studies that examine the extent to which inadequate screening, late diagnosis and/or rapid decline from diagnosis contribute to poor prognosis are required. Patients who die shortly after diagnosis may have had too little time for adequate assessment and appropriate care plans (curative or palliative) to be put in place.

7.2. Identifying receipt of palliative care

A broad body of literature exploring biases in terms of who receives palliative care has emerged over the last decade. This includes barriers to receipt of palliative care based on age (Gardiner et al., 2011; Parajuli et al., 2020), race (Coupland et al., 2011; Gardner et al., 2018) and gender (Haviland et al., 2020). Other cited barriers are a reluctance by the healthcare provider to refer patients for palliative care, reluctance of the patient and/or family to be referred, as well as restrictive specialist palliative care service program eligibility criteria (Hawley, 2017). In order to explore these issues, the ability to identify and characterise who receives palliative care and who does not is increasingly important.

A strength of administrative health data for PEO LC research lies in the ability to determine that palliative care has been received. Internationally studies that used administrative health data to identify receipt of palliative care are predominantly from regions that provide universal

health care e.g. Belgium (Maetens et al., 2016), Ontario (Jang et al., 2015; Tanuseputro et al., 2017) and Taiwan (Chang et al., 2016; Wang et al., 2016). Ireland does not have universal health care insurance and while in 2017 approximately 43% of the population have private health insurance across three providers (Department of Health, 2018) health claims data were not available. Relative to other countries, this is a gap in Irish administrative health data.

Several studies from Australia used a consultation or care with the hospital based palliative care services from hospital episode data to identify receipt of specialist palliative care (Philip et al., 2015; Rosenwax et al., 2016; Sundararajan et al., 2014). Coupland et al used death in a hospice to identify patients in receipt of palliative care (Coupland et al., 2011). In our second study we used HIPE hospital episode data to derive two indicators for receipt of palliative care (Kelly et al., 2020). These were (1) HIPE ICD-10-Australian Modification diagnosis code Z51.5: encounter for palliative care and (2) HIPE discharge code: transfer to hospice.

Using HIPE to identify those having a palliative care encounter may underestimate the actual number of encounters. The annual National Audit of Hospital Mortality (NAHM) report produced by the National Office of Clinical Audit (NOCA) uses HIPE data to report hospital-based mortality data. The 2018 NAHM report describes variation in the application of the palliative care code between hospitals (National Office of Clinical Audit, 2019). This is partly because the Z51.5 code does not differentiate between treatment being provided by a palliative care specialist/team and an assessment being provided by the specialist/team where no further treatment is required. This ambiguity may result in under recording of Z51.5 as the 2018 NAHM report notes that accurate recording of the activity by the clinicians is necessary. Guidance to clinical coders states that the Z51.5 palliative care code should be assigned when there is documentation that the patient has been seen by or attended to by a palliative care specialist or palliative care team (Healthcare Pricing Office (HPO), 2016).

To mitigate these risks, our study population was restricted to decedents who attended one of eight cancer centres in 2016, each of which has specialised cancer services and specialist palliative care teams. We included the discharge to a hospice as an indicator for palliative care given the likely need for a consultation with the palliative care team before discharging to this setting and we undertook a validation study which compared HIPE patient-level counts at the eight cancer centres to SPC minimum data sets aggregate counts. The counts closely matched in four of the cancer centres with greater variation in the other four (Appendix G). Our

validation study cannot identify a situation within a hospital where there are roughly equal number of patients who have the ICD code but didn't get SPC (false positives) and patients who don't have the ICD code but did get SPC (false negatives) and therefore that aggregate counts would still match despite misclassification. In this context more robust validation of palliative care coding is required. Stubbs et al describe a single centre validation exercise of the Z51.5 code against health records which could be adapted for the eight adult cancer centres in the first instance (Stubbs et al., 2020).

In a further validation exercise we compared the demographic and clinical characteristics of the decedents in our study to all 2016 cancer deaths using data from the CSO Vital Statistics Annual Report 2016, (Central Statistics Office, 2019c). This showed that decedents in our study population were younger relative to the total population of 2016 cancer decedents. It has been reported previously that patients treated at cancer centres are younger than those treated in other public hospitals; this may be due to preferential referral of younger patients to the cancer centres as better candidates for treatment, (National Cancer Registry Ireland, 2019b). In our study mitigating against the risk of under estimation of palliative care encounters by focussing on cancer centres, introduced a population level selection bias against older cancer patients who are less likely than younger patients to be referred to these cancer centres. Furthermore it should be acknowledged that patients who receive palliative care were prospectively more likely to die so their death was more foreseeable, perhaps more planned and thus likely to occur outside hospital settings.

This cohort study is by definition non-randomised so the potential for further unobserved confounding must be considered. A myriad of complex factors determines who receives palliative care and who does not so that there may be systematic differences in the characteristics of these patient groups that are unobserved and not available from administrative health data (Kaufman et al., 2021). For example our study did not account for patient and family preference for palliative and/or curative care and where that care is given.

These considerations demonstrate the limitations of administrative health data for PEO LC research, particularly with respect to unobserved confounding and bias. To minimise the risks as far as possible it is important to have a detailed background knowledge of the health

administrative datasets to be used and a robust study design with external validation where possible. Data quality is particularly important and challenges remain when using HIPE data alone to identify palliative care receipt. The 10th Edition of the classifications used in HIPE, the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification/ Australian Classification of Health Interventions/Australian Coding Standards (ICD-10- AM/ACHI/ACS), introduced for all patients discharged from January 1st 2020 changes how the palliative care code is applied. The 10th edition states that the palliative care code will only be coded as an additional diagnosis when there is documented evidence that the patient has been provided with palliative care. To improve the quality of palliative care coding, the NCCP and HPO will develop guidance on the accepted documented wording to provide evidence of palliative care treatment for patients. A key recommendation of the 2018 NAHM report is that the guidance will be shared with all clinicians to ensure consistency in documenting palliative care treatment, (National Office of Clinical Audit, 2019, p. 47)

7.2.1. Specialist palliative care in acute hospitals

Almost two thirds of cancer patients in our study who attended a cancer centre and died in 2016 had a palliative care encounter. They were younger, less likely to be married, and more likely to be from deprived areas. This is the first time this information has been reported in an Irish context and we are aware of only one other study examining receipt of palliative care among cancer patients in an acute hospital setting. Hui et al report reported that 45% (n= 366 of 816) of advanced cancer patients at a single comprehensive cancer centre in Houston Texas had a palliative care referral before they died (Hui et al., 2012). The diagnosis date of advanced cancer and the first date of receipt of palliative care services was determined by expert review of patient medical records in the Hui study. Multivariable analysis showed that younger patients and married people were more likely to have access to palliative care.

Access to palliative care for older adults is a recognised problem (Gardiner et al., 2011; Lloyd et al., 2016). Reasons cited include attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources (Gardiner et al., 2011). In addition older patients may have less clear early signs indicating that they need palliative care and are not referred (Lloyd et al., 2016). Hui et al found no differences in referral to palliative care by ethnicity, education, and religion. These variables were not collected in the datasets

available to us and were not examined in our study. The lack of ethnicity data in many Irish health and social care data collections is a recognised limitation for equality monitoring (Hannigan et al., 2019). Also some variables, for example, marital status can change over time. In the NCRI dataset, information on variables such as marital status are collected only once at diagnosis so that changes over time are not captured.

7.2.2. Impact of health care organisation on palliative care receipt

Having accounted for available sociodemographic factors (age, gender, marital status and deprivation), there was evidence of regional variation in receiving palliative care. Decedents in the South Eastern and Midlands regions of Ireland had a statistically significant decreased odds of a palliative care encounter relative to the Eastern region. Regional-level variation in specialist palliative care services in Ireland is well documented (Department of Health and Children, 2001; Irish hospice Foundation, 2006; Brick et al., 2015; Irish Hospice Foundation, 2018). Neither the South Eastern nor Midlands regions have an inpatient hospice and limited inpatient specialist palliative care beds which may explain why decedents from these regions have reduced access to specialist palliative care.

In this study the level of palliative care services were categorised by CHO region, which replaced the former health board regions in 2015. The health administrative data collection systems have not kept pace with these changes so that for our study a patient could not be accurately assigned to a CHO using address data alone. Our study relied on the geographic overlap between the former health board region and the current CHO area to assess the relationship between service provision and access to specialist palliative care. Further reorganisation of the Irish health system is planned. The 2017 Sláintecare report on health service reform identified a lack of coordination between hospital groups and CHOs and proposed the establishment of Integrated Care Regional Organisations to coordinate acute, primary and social care (Healthcare, 2017), Section 3.8). In 2019 six new health regions were announced, two of these map directly to the existing CHO areas 3 and 4 which themselves map directly to the former Mid-Western and Southern health boards respectively (*Health Regions*, 2020). Maintaining data collection systems to keep abreast of service reconfigurations is challenging and some time lag is to be expected. As we have found, assigning patients to the appropriate health region or unit is problematic. The Eircode postcode system could be used to assign every household to a distinct CHO and/or other health unit. This would eliminate any

ambiguity for both service providers' and service users on where to seek health care in the first instance, and help establish criteria for access to services.

Health service providers identifiers (*Health Identifiers Act 2014*, 2014), will allow classification and enumeration of services in terms of service type, capacity and location. This combined with postcode data will allow a more in depth analysis of the role of health care service factors in access to PEO LC. The conceptual framework proposed by Gao et al evaluating the role of health service characteristics in place of death could inform the work (Gao et al., 2018). At the simplest level geographical distances to services such as inpatient hospice can be measured.

7.2.3. Palliative care and place of death

Hospital was the most common place of death for all the decedents in our study which is broadly consistent with previous studies (Gao et al., 2014, 2019; Ó Céilleachair et al., 2011; Sharp et al., 2010). Patients from more deprived areas were more likely to have a palliative care encounter in acute hospitals, and while a significant proportion (45%) died in hospital they were still less likely to die in hospital than the patients who didn't have a palliative care encounter in hospital. A systematic review of nine studies (Spain (1), United States (2), Japan (3), Canada (2) and New Zealand (1)) reported that the use of specialist palliative in any setting including hospice care, home care, inpatient or outpatient care in cancer patients may modify the effect of socioeconomic status on place of death (Chen H., et al., 2016) which is consistent with our study results.

The interrelationship between deprivation, receipt of palliative care, health service organisation and place of death is complex. A study of all deaths in England in 2014 (Gao et al., 2019) found health service type (adult inpatient hospice, hospitals, general practitioner and care homes) and capacity (ratio of service facilities to user population, counts of services types within functional areas) were the strongest predictors of the area-level variation in place of death. In our study, death in hospital, even for those who received palliative care, may be due to limited inpatient hospice care facilities which is a known problem in Ireland (Department of Health and Children, 2001; Irish hospice Foundation, 2006; National Clinical Programme for Palliative Care, 2019).

Eighteen percent of patients who received palliative care in acute hospitals died at home compared to 28% in the non-encounter group. Further investigation of the experiences of

patients who die at home and their families is warranted, in particular with regard to receipt of palliative care in the community where there are recognised large gaps in the availability of data (Health Information and Quality Authority, 2013)

In an economic evaluation of palliative care in Ireland, Brick et al present a detailed methodology to derive formal and informal costs per patient in receipt of specialist palliative care over the last year of life across three comparator health areas in Ireland (Brick et al., 2015). Local palliative care teams identified eligible study participants (decedent and key informants) and the study population comprised 215 participants who received SPC during the last year of life (2011), including 80 in the HSE Midlands, 75 in the HSE Mid-West and 60 in the HSE South East. Broadly the study reported the most costly component of care in the Midlands and South East health areas in the 12 months (first 9 month and last 3 months) before death was hospital care followed by informal care. In contrast in the Mid-West the most costly component of care in the three-month period before death was specialist palliative care, followed by hospital care and informal care. Variation in mean hospital costs in the three month periods before death suggested the ability to access in-patient hospice beds leads to savings within hospitals in the last three months of life and reduced inappropriate hospital admissions. Although total cost per patient were higher in the Mid-West compared to the other two areas, the number of decedents in the Mid-West sample who died in hospital was much lower. The authors concluded that given a clearly stated preference in most cases for a death outside of hospital it is likely that this higher cost is generally associated with a better experience for patients and families. Using HIPE data to identify patients in receipt of palliative care in acute public hospitals and the costing methods already described, a wider economic evaluation of palliative care services in Ireland should be possible.

7.3. The potential of Irish health and social care datasets for PEOLC research

Most authors who have used administrative health data for PEOLC research have cited the importance of knowing the data and the health service environment from which it derives (Langton et al., 2014; Luta et al., 2015; Davies et al., 2016; Maetens et al., 2016; Tanuseputro, 2017). Our experience using linked administrative health data in the first two studies facilitated a broader examination of the potential of Irish administrative health data for PEOLC research.

The health information infrastructure is a product of the health system from which it derives. Starting in 2005 the Irish health system has undergone several reconfigurations and currently the Sláintecare health service reform plan is three years into a ten year strategy (Burke et al., 2018). Each configuration affects the data infrastructure and has implications for data collection and the health information infrastructure. Our third study sought (1) to identify available administrative health data that may be useful for PEO LC research, (2) to describe both the challenges and opportunities using these data for PEO LC based on our experiences to-date using linked cancer registry data, hospital episode data and death certificate data and (3) to describe how recent initiatives to improve the health information environment and changes to data protection laws will impact future use of administrative health data in Ireland.

The HIQA catalogue of national health and social care data collections (Health Information and Quality Authority, 2017) cross referenced with a recognised list of diseases with associated palliative care needs (Murtagh et al., 2014) was used to identify datasets that may have potential for PEO LC research in Ireland. Including the datasets available for this thesis, (cancer registry data, hospital episode data and death certificate data) we identified and described in detail a further four data collections with potential for PEO LC research namely PCRS, Irish Motor Neurone Disease Register, National Hepatitis C database and TILDA. Of these TILDA has been used for PEO LC research (May et al., 2017).

The challenges of using linked administrative health data for PEO LC research arise from the social and political context in which the data are generated and used. In Ireland the challenges arise primarily due to structural issues with health care delivery and organisation against a background of recently strengthened data protection regulations. In Ireland's mixed public private health system, data outside the public system are often governed by individual institutions so identifying who owns the data and the mechanism for accessing it can require an individual approach to each institution. This is further complicated where an institution is financed from multiple sources including the HSE, privately and through fundraising. Often, there is little standardisation across institutions collecting data, so that even if the data were available for sharing, linking data from different sources would require considerable expert knowledge and oversight.

7.3.1. Recent developments

The need to improve Ireland's health information infrastructure is recognised and a coordinated health information strategy was instigated, in tandem with the health service reconfigurations that began in 2005. The 2004 National Health Information Strategy (Department of Health and Children (DOHC), 2004) included the establishment of HIQA (*Home | HIQA*, 2020) who have produced several reports with recommendations to improve Ireland's National Health and Social Care Data Collections (Health Information and Quality Authority, 2013, 2017a). Building on this, several developments to improve the Irish health information infrastructure have emerged in recent years. These include the HSE and Department of Health's eHealth strategy (eHealth Ireland, 2018) whose aim is develop safer, more efficient, high quality integrated healthcare systems. The eHealth strategy includes the Open Data Strategic Programme whose stated aims are to *facilitate transparency of the Public Sector while providing a valuable resource in the form of data that can drive innovation* (Health Service Executive (HSE), 2016a, 2016b). The eHealth Ireland Open Data Portal (eHealth Ireland, 2021), simplifies finding and accessing data from across the Irish Health Sector.

In 2016 the Irish Health Research Board (HRB) launched an initiative to explore Ireland's considerable but under-used resources of existing health datasets for research (Moran et al., 2016). The recognised challenges include concerns around data protection and good governance, and poor skills in preparing data so that is suitable for sharing. 'Proposals for an enabling data environment for health and health related research' published in 2016 proposed a model to link and make available health and related data in a safe, secure manner that protects the privacy and confidentiality of the data subjects with the aim of improving people's health and healthcare delivery. The DASSL (Data Access, Storage, Sharing and Linkage) model comprises seven main elements, designed to facilitate the conduct of research. Five are related to infrastructure and services (a health research data hub, trusted third party and data linkage service, safe setting/safe haven, a research support unit and disclosure control) and two (governance and public engagement) are related to the broad legislative and socio-cultural context needed to facilitate implementation of the model. In 2019 the HRB announced funding for secondary data analysis projects and funded a pilot project to design and develop the infrastructure needed to share and link health data securely, a proof of concept of the proposed DASSL model (Health Research Board, 2019).

The Sláintecare 10 year reform plan recognises the wealth of data within individual organisations and branches of the health system (Houses of the Oireachtas, 2017) and promises continued support for the eHealth strategy. In 2019, the Sláintecare report recommendation for a ‘common unit of geography’ for data collection and integration to increase capacity for cross-organisational research (Information and Research, page 24) has been initiated with the announcement of the six integrated health regions (*Health Regions*, 2020).

The increased regulations around data governance, privacy and sharing arising from the GDPR and the HRR Acts in 2018 against the fragmented landscape of the Irish health system adds further complexity to realising the potential of Ireland’s national and social care data collections for PEO LC research. The use of health administrative data for PEO LC research are subject to appropriate ethical approval and compliance with GDPR and HRR requirements. Of particular relevance is the requirement for explicit consent of the data subject for data processing which is unique to Ireland. Under HRR the use of personal data for health research that is of high public importance, and where obtaining consent from the data subject is not possible, is allowed in certain circumstances. A health research declaration consent can be sought for specific research projects where a data controller determines this is required for a particular health research project. Guidance notes are available to assist the data controller organisation when making an application to the Health Research Consent Declaration Committee (HRCDC) for a consent declaration. A publically accessible log provides information on the decision process for existing applications that include the decision outcome, any specific conditions attached and/or additional recommendations (Health Research Consent Declaration Committee, 2020). These can inform the application process and highlight areas requiring further consideration.

The Irish health system is in the middle of a major reform drive and a vision for a coordinated integrated health system, underpinned by a connected information systems infrastructure, is slowly emerging. The initiatives to improve the health information systems such as individual health identifiers, health service provider identifiers and the adoption and integration of postcodes across all data collection systems are a part of that vision. These reforms, combined with the requirements for improved data governance and data privacy arising from GDPR and the HRB initiatives to improve data sharing and linkage, will take time but should in due course provide a clearer roadmap for PEO LC research using linked administrative health data. This

thesis, exploring the potential of existing linked administrative health data created as part of cancer registration, is timely. It has demonstrated linked health data can be used for population based research, highlighted the challenges arising from the existing fragmented infrastructure and suggested how initiatives such as postcodes and health identifiers can be used to mitigate these challenges.

7.3.2. Guidelines for PEOLC research using health administrative data

The overriding principle of using administrative health datasets for PEOLC research is to develop and evaluate a research question with a thorough advance understanding of the datasets to be used. Related to this is identifying which dataset forms the starting point from which the study population is to be identified and derived. These two considerations will inform most aspects of the study planning, design and implementation. In particular the recommendations of this thesis are to:

- Examine the data dictionaries in detail to know what data items are available, any classification systems used including the versions used and the timeframes for each version across all datasets to be used in the study.
- Examine the data model to understand how the data are organised and stored so that the levels at which data are stored is known in advance. This will allow a more accurate estimate of data linkage workload and evaluate potential challenges in advance e.g. identifying a cancer diagnosis episode from all HIPE episodes for a particular patient.
- Anticipate and determine in advance what data are missing in any of the datasets to be used and the implications for the study. Examples include
 - The dataset only covers subsets of the population, for example PCRS records data for patients who have medical cards and eligibility to a medical card can vary over time.
 - Cancer registry data only has access to HIPE data that mentions a cancer diagnosis so that HIPE data prior to diagnosis or without mention of a cancer diagnosis are not available. This can include episodes post diagnosis for cancers with long survival times
 - Data may be missing within datasets over time for particular institutions for operational reasons

A second general principle arising from this work is that use of disease registries as a starting point and looking forward from an event (e.g. disease diagnosis) eliminates many of the biases associated with look back studies from death (Bach et al., 2004). A desirable feature of any disease registry is that each subject is recorded only once, i.e. is uniquely identified within the register. This simplifies the linkage process where a patient may be recorded many times in the dataset to be linked e.g. HIPE and /or PCRS data. For nearly all patient cohorts, HIPE hospital episode data can provide comprehensive longitudinal morbidity data for the subset of patients seen in public acute hospitals while PCRS data is currently the only source of community based longitudinal prescribing data for patients eligible for a medical card over the time frame of the study.

Thirdly, it is important to design the study to minimise biases as far as possible with full knowledge of the underlying datasets and to look for opportunities to validate the data wherever possible. Because observational studies using administrative health data are non-randomised particular focus should be given to the potential for unobserved confounding and bias.

Finally clear and detailed documentation is essential, listing the study strengths and weakness, including the types of bias and confounding that may be present.

7.4. Recommendations for future research

A 2020 systematic review identified a number of priorities for palliative care research internationally that included service models (particularly out of hours (OOH) and home care across all disease groups), continuity of care (transition of services) and inequality in access to care (Hasson et al., 2020). These are consistent with the research priorities for PEoLC on the island of Ireland reported in 2015 (McIlfatrick, 2015).

7.4.1. Service Models and continuity of care

O'Leary et al describes the place of care for n=507 patients from the date of SPC referral to death for a single regional specialist palliative care service in Ireland (O'Leary et al., 2017). Just over 84% had a cancer diagnosis, 55.5% received care in a single setting; 28.4% in hospital, 21.5% at home, 4.1% in a nursing home/community hospital and 1.4% in hospice. Late referral was associated with a single domain of care. Of the total, 39.3% died in hospital, 25.8% in hospice, 25.8% at home and 9.1% in a nursing home/community hospital. Data for

the study was retrieved from electronic databases at the hospice and four local tertiary referral hospitals by the study authors who provided care directly to the individual patients.

Information collected by specialist palliative care services include individual basic patient information, referral information, transfer and discharge information, activity in specialist palliative care in inpatient units (hospice), activity in specialist palliative day care/day hospice, activity in specialist palliative care in the community (home care), activity in acute hospital specialist palliative care teams and activity in specialist palliative care bereavement support however models of service provision vary greatly by CHO region (Weafer & Toft, 2017). The study by O’Leary et al suggest much of the community based data are held by the hospice in that specialist palliative care region (O’Leary et al., 2017) and illustrates the value of community based data for PEOLC research particularly around service models and continuity of care. The management and governance of the specialist palliative care services and the relationships between the different domains (hospice, homecare, day care and acute hospital) within a region are not clear. The data collected by the specialist palliative care services is not listed in the HIQA catalogue of national health and social care data collections (Health Information and Quality Authority, 2017). A data dictionary, data model and clarification of the governance and access arrangements for the data collected by the regional SPC services is required. This would allow opportunities for future research of the role of service models on access to palliative care, on continuity of care and on community care. Additionally, the monthly aggregated data that make up the SPC-MDS is an indication of service levels by service providers and should be made publically available at regular intervals. Clarification of the overlap between specialist palliative care region and CHO area and/or the six newly created health regions is also warranted.

7.4.2. Inequality of access

Currently HIPE is the only national data collection where information on palliative care receipt is captured. Using HIPE data we have shown that older cancer patients and patients from regions with fewer inpatient palliative care beds were less likely to be seen by the specialist palliative care team in the acute hospital setting (Kelly et al., 2020). The National Office for Clinical Audit use HIPE to develop hospital based standardised mortality ratios for six diseases (acute myocardial infarction, heart failure, ischaemic and haemorrhagic stroke, Chronic Obstructive Pulmonary Disease and pneumonia, (National Office of Clinical Audit, 2019). The 2018 National Audit of Hospital Mortality Annual Report found evidence of variation in the

application of the palliative care code between hospitals. The mean rate of palliative care code use for all admissions has remained relatively static from 2.2% in 2014 to 2.8% in 2018 with a year on year increase in mean rate for all deaths from 37.4% to 48.4% over the same period. Tabulation of the use of palliative care code by primary diagnosis and hospital for all admissions and all deaths in hospital is a feasible first step to explore this further and investigate whether disease diagnosis affects access to palliative care. HIPE variables including admitting and discharge consultant, consultants associated with diagnosis and procedures together with the consultant speciality code which includes Palliative Medicine may be useful parameters for internal validation of the palliative care code.

7.4.3. Out of Hours service

In the absence of community care data, HIPE remains the only data collection to investigate out of hour's service. Just over one fifth of n= 2558 patients who died in 2016, attended a cancer centre in 2016 and had an inpatient palliative care encounter were discharged to home and/or community setting excluding hospice (Kelly et al., 2020). This represents a transition in care. Investigation of readmission patterns for these patients in terms of type of admission (elective/emergency) and date and time of admission could identify week-end and/or OOH readmissions. The sampling frame could be broadened to all patients, with subgroup analysis by disease diagnosis, having a palliative care encounter in acute hospital and discharged home.

7.4.4. Prognostication and Machine Learning

The use of machine learning (ML) to improve palliative and end of life care using health administrative data is an area of growing interest. In a rapid review of published studies that use ML to improve palliative care, one study found measures derived from health administrative data such as demographics, ICD codes, chronic conditions, functional status, durable medical equipment and prior healthcare utilization enhanced the performance of the ML models when used to capture trajectories (disease duration, onset of functional limitations, emergency department visits etc.) (Storick et al., 2019). The reported studies found ML methods were superior to traditional logistic regression, but only when sufficient data were available, for example physiologic and biochemical data. We did not have access to HIPE data before a cancer diagnosis so could not examine patterns of attendance before the diagnosis nor was information on functional status available. Studies comparing traditional logistic regression and ML methods using Irish data may be warranted while exploring access to other

sources, for example electronic pathology data. Machine/statistical learning approaches, e.g. random forests/support vector machines, should now be routinely considered as possible techniques to use, particularly where logistic regression is indicated. Getting indicators about the accuracy of the model and using test and training sets in this manner could be informative.

The introduction of a national Electronic Health Record (EHR) in conjunction with IHI's are a key part of the HSE's strategic e-Health Programme (Health Service Executive (HSE), 2013). EHRs are the means by which data can be recorded and shared across organisations and care settings (*Electronic Health Record (EHR)*, 2020). Internationally ML and secondary use of EHR data are driving the development of predictive algorithms for disease detection and real-time prognostication of patient outcomes (Xiao et al., 2018). Avati et al describe a deep learning model that uses EHR data in California from approximately 2 million adult and paediatric patients to predict mortality within 3-12 months thus identifying patients who might benefit from palliative care (Avati et al., 2018).

There are recognised limitations with machine learning that warrant careful consideration, particularly in the context of its role in the medical decision making process (Lindvall et al., 2020). These include the potential of ML to exacerbate inequalities in access and delivery of care due to inaccurate predictions learned from historic data which is itself biased. Because machine learning predictive models are often inherently uninterpretable and complicated, (i.e. black box), the accuracy of the model cannot be adequately assessed (Rudin & Radin, 2019). Use of ML can lead to over confidence in automated results, so that careful comparison and evaluation with more interpretable traditional methods are warranted. As the health information infrastructure in Ireland develops, new opportunities for secondary use of health data will emerge.

7.4.5. Stakeholder involvement

A key recommendation from the NACPC report published 2001 was that patients and their carers as prime stakeholders should have input to the development of national and regional (Department of Health and Children, 2001b). Key stakeholders included service providers, service planners and service users (patients and carers). In light of this recommendation the IHF 2006 baseline study on the provision of palliative care services in Ireland (Irish hospice Foundation, 2006) sought input from service providers. The recommendations for future

research described here were identified from an international 2020 systematic review by Hasson et al, (Hasson et al., 2020) and are broadly consistent with the research priorities for PEOLC on the island of Ireland (McIlpatrick, 2015). The research priorities identified (OOH service, inequality of access, and continuity of care) are largely service orientated which Hasson et al suggest may be due to a dominant perspective from health care providers with less involvement from patients and caregivers (Hasson et al., 2020).

Public involvement is recognised as necessary for high quality research as it allows patient-focused research questions to be identified and prioritised (Johnson, Ogden, et al., 2021). When dealing with populations with life-limiting illness, a more considered approach is required to cultivate patient and public involvement. A qualitative study of an the institutional level strategy to develop patient and public involvement in palliative care research found focussing on building and carefully maintaining relationships, remaining flexible when dealing with individuals living in complex circumstances and involving the right people with appropriate experience to specific research projects were important, (Johnson, Ogden, et al., 2021). The authors concluded a strategic approach to develop adequate infrastructure and networks can facilitate public involvement in palliative care research.

Because a lot of palliative care research is concerned with secondary analysis of existing administrative health and social care data collections Johnson et al explored public views of palliative care research that uses large datasets in a one day workshop (Johnson et al., 2021). From this a number of opportunities to involve the public in ‘big data’ research were identified. These included raising public awareness of the existence of these data collections, education around key concepts such as data governance, data anonymisation, how data can be accessed and shared while maintaining patient confidentiality as well as seeking patient and public involvement in setting research priorities with the existing datasets.

The realisation of the Sláintecare health care reform programme coupled with the increased clarity around data protection issues provide by GPPR and HRR should facilitate increased use of Ireland’s national and social data collection for PEOLC research. In that context a wider involvement of data controllers, data managers, researchers and data scientists is needed. These data can give a broad population based perspective on PEOLC in Ireland, however to fully understand the complexity of PEOLC, involvement of all the stakeholders including patients, caregivers and the public is essential.

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Appendix A - Grey literature sources

All Ireland Institute of Hospice and Palliative care - <https://aiihpc.org/>

Australian Institute of Health and Welfare - <https://www.aihw.gov.au/reports-data>

Cancer Research UK (CRUK) - <https://www.cancerresearchuk.org/about-cancer>

Community Research and Development Information Service (CORDIS) -
<https://cordis.europa.eu/projects>

Irish Department of Health - <https://www.gov.ie/en/organisation/departments-of-health/>

Health Information and Quality Authority - <https://www.hiqa.ie/reports-and-publications>

Health Service Executive - <https://www.hse.ie/eng/health/az/>

Health Quality Ontario - <https://www.hqontario.ca/>

IC/ES <https://www.ices.on.ca/>

Irish Cancer Society - <https://www.cancer.ie/>

Irish Hospice foundation - <https://hospicefoundation.ie/>

National Cancer Registry Ireland - <https://www.ncri.ie/>

NHS Digital - <https://digital.nhs.uk/>

Public Health England - <https://www.gov.uk/government/organisations/public-health-england>

Royal College of Physicians, London (<https://www.rcplondon.ac.uk/>)

Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) - <https://seer.cancer.gov/>

The Irish Longitudinal Study on Ageing (TILDA) - <https://tilda.tcd.ie/>

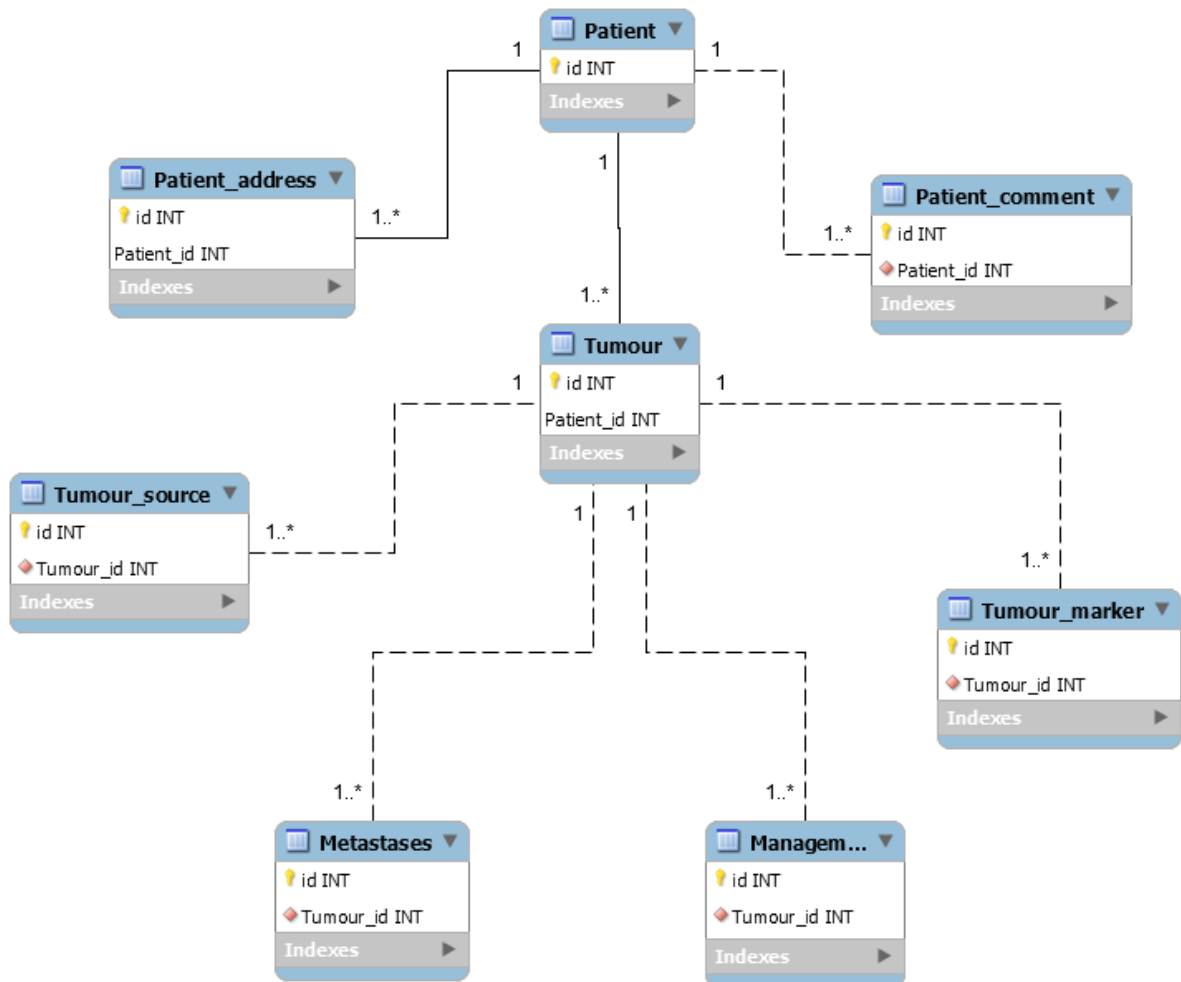
World Health Organisation (WHO) - <https://www.who.int/>

Appendix B - Inpatient hospices in Ireland

Name	Location	Catchment area	Funding	Capacity	Governance
Our Lady's Hospice Harrold's Cross	Dublin	Not stated	HSE and public	36 beds	Registered charity
Our Lady's Hospice Blackrock	Dublin	Not stated	HSE and public	12 beds	Registered charity
St Francis Hospice Raheny	Dublin	North Dublin city and county	HSE and public	19 beds	Registered charity
St Francis Hospice Blanchardstown	Dublin	Dublin north west	HSE and public	24 beds	Registered charity
St Brigid's Hospice	Kildare	Kildare and west Wicklow	HSE and public	13 beds	Registered charity
Marymount Hospital & Hospice	Cork	Cork city and county	HSE and public	44 beds	Registered charity
Milford Care Centre	Limerick	Limerick, Clare and North Tipperary	HSE and public	30 beds	Registered charity
Galway Hospice Foundation	Galway	Not stated	HSE and public	18 beds	Registered charity
North West Hospice	Sligo	Sligo, Leitrim, South Donegal, West Cavan	HSE and public	8 beds	Registered charity
Donegal Hospice	Donegal	Donegal	HSE and public	8 beds	Registered charity

Appendix C - Data models and Data Dictionary

National cancer registry core data - physical data model



Data Dictionaries

NCRI principal data items: - <https://www.ncri.ie/data/data-we-collect/data-fields>

NCRI data dictionary: - <https://www.ncri.ie/contact> available on request.

Hipe data dictionary (2016):-

http://www.hpo.ie/hipe/hipe_data_dictionary/HIPE_Data_Dictionary_2016_V8.1.pdf

Appendix D - Private hospitals in Ireland

Name	Address
Aut Even Hospital	Freshford Road, Co. Kilkenny
UPMC Beacon Hospital	Sandyford, Dublin 18
Blackrock Clinic	Blackrock Co. Dublin
Bon Secours Health System	
	College Road, Cork, Co. Cork
	Strand Street, Tralee, Co. Kerry
	Renmore, Galway, Co. Galway
	Glasnein, Dublin 9
	Barringtons Hospital, George's Quay, Limerick
Galway Clinic	Doughiska, Co. Galway
Hermitage Medical Centre	Old Lucan Road , Dublin 20
Highfield Healthcare	Swords Road, Whitehall, Dublin 9
UPMC Kildare Hospital	Prosperous Road, Clane, Co. Kildare
Mount Carmel Hospital	Braemor Park, Churchtown, Dublin 14
Mater Private Hospital	
	Mater Private Dublin, Eccles Street, Dublin 7
	Mater Private Cork, City Gate Mahon, Cork
St Francis Private Hospital	Ballinderry, Mullingar, Co. Westmeath, N91 FE40
St. Joseph's Hospital	Ray MacSharry Road , Garden Hill, Sligo
St John of God Hospital	Stillorgan, Co. Dublin
St Patrick's University Hospital	James's Street, Dublin 8
St Vincent's Private Hospital	Elm Park, Dublin 4
Sports Surgery Clinic	Santry Demesne, Dublin 9
Whitfield Clinic	Butlerstown North, Cork Road, Waterford

Appendix E - Project Approval

Initial Project Approval

The screenshot shows an email client window titled "FW: Project Approval - Message (HTML)". The interface includes a menu bar with "FILE" and "MESSAGE", and a toolbar with various actions like "Ignore", "Delete", "Reply", "Forward", "Meeting", "Rules", "OneNote", "Mark", "Category", "Follow Up", "Translate", "Find", and "Zoom".

The message header shows it was received on "Mon 16/07/2016 10:00" from "Maria Kelly" with the subject "FW: Project Approval". The recipient is "Maria Kelly (m.kelly@ncrl.ie)".

The main body of the email contains the following text:

From: Harry Comber
Sent: 21 February 2015 17:00
To: Maria Kelly <m.kelly@ncrl.ie>
Subject: RE: Project Idea

Maria
I have no problem with the principle that you would work on this in your own time, and with registry data, subject to the usual security and confidentiality restrictions. I have read the proposal in detail and have some comments, both general and detailed. I will save the latter for the moment.

On the general aspects:

1. This is a good concept, and I think has considerable potential.

---REDACTED---

None of the above is meant to be negative but I would like to be convinced that, if you decide to give up a large part of your life to this, you have a high probability of success. I'm happy to talk to you about this any time.
Harry

From: Maria Kelly [mailto:m.kelly@ncrl.ie]
Sent: 20 February 2015 10:29
To: Harry Comber
CC: Paul Walsh
Subject: Project Idea

Hi Harry

I have come up with an idea for a project that I would like to pursue as potential PhD project at my own expense (fees and work). I have spoken to Paul and Ailish Hannigan [Associate Professor Biomedical Statistics] from UL about the project who have both agreed to supervise should I decide to go ahead. I have attached the proposal above and would appreciate your assessment of it and whether you have any objections to me proceeding with this. It would involve me working at the registry with this data in my own time on my non-work days (currently Weds and Thursday). I would be looking to go a research and publication route rather than a thesis route though UL GEMS programme.

Regards
Maria

Maria Kelly
National Cancer Registry
Building 6800,
Cork Airport Business Park,
Kinsale Road.

At the bottom of the window, a status bar indicates "Maria Kelly scheduled release on 1/02/2016 to m2.ccs2016 - Monday, Dec 14th".

Additional approval sought following introduction of GDPR

Part 1 (Data Access Approval)

Application under consideration:

Cover page of application with contact details, date and reference number:

National Cancer Registry Ireland

APPLICATION FOR DATASET

Reference No 2018-12-MK1

Date received 02/11/2018

<<Above for office use only>>

(1) CONTACT DETAILS	
Requester's Full Name	Maria Kelly
Title (Mr/Ms/Dr/Prof/Other)	Ms
Job Title	PhD Student University of Limerick/Database Administrator, National Cancer R
Organisation Name	
Organisation Type <i>Please tick as appropriate and supply details</i>	<input checked="" type="checkbox"/> Government health dept/agency <input type="checkbox"/> Hospital/hospital group <input type="checkbox"/> Government department other <input type="checkbox"/> Local authority <input checked="" type="checkbox"/> Academic institution <input type="checkbox"/> Commercial <input type="checkbox"/> Charity <input type="checkbox"/> Media <input type="checkbox"/> Public <input type="checkbox"/> Other (<i>please specify</i>).....
Address	National Cancer Registry Ireland, Building 6800, Cork Airport Business Park, K T12 CDF7
Telephone/Fax Number	021-4548829
Email	m.kelly@ncri.ie

Date of acknowledgement of complete application: 02/11/2018

Date of research application committee meeting: 04/12/2018

Request reviewed by:

Paul Walsh
Conan Donnelly
Eamonn O'Leary
Katie O'Brien
Joe McDevitt
Sandra Deady

CRITERIA CONSIDERED FOR APPROVAL

(1) Summary information on the request

- Aggregated data*
 Anonymised dataset
 Patient identifiable data

(2) Has sufficient detail been provided to allow complete assessment of this request?

- Yes*
 No

(3) Has all associated documentation been provided (ethical approval, CV of principal investigator(s))?

- Yes*
 No

(4) Has full and complete justification been provided for all data items requested?

- Yes*
 No

(5) Can the NCRI provide the range of data and level of specificity required for this request?

- Yes*

- Yes but only if data is grouped/converted to a lower level of specificity, which will suffice for this research*
- No*

(6) Is this project a collaboration, where NCRI will have control of/input to the analysis and interpretation of results as well future publications?

X Yes

No (NCRI facilitating the research only by providing data/dataset)

(7) Is the quality of this research proposal sufficient to justify the resource requirements of the NCRI in providing the data/datasets as well as further collaborative involvement as appropriate?

X Yes

No

(9) Estimated time line for preparation of data/dataset

The data has already been matched and prepared for analysis (under existing permissions provided previously by Dr Harry Comber, former director)

(10) For requests from commercial sources, cost of request

N/A

(11) NCRI staff member responsible for delivery and further contact with requester

Sandra Deady

RESULT OF REVIEW

X Accepted

Accepted with some changes

Rejected

The request has been approved by the committee. The requester should sign the “Declaration by requester” form.

As this work is internal and the data is not leaving the NCRI, there is no need for a Data Sharing Agreement to be drawn up for this request.

It was noted by the committee that work on “place of death” could be of benefit to the general NCRI database and could potentially be included later in the flatfile.

Part 2 (Declaration by requester)

National Cancer Registry Ireland

APPLICATION FOR DATASET

Reference No 2018-12-MK1

Date received 02/11/2018

<<Above for office use only>>

(1) CONTACT DETAILS	
Requester's Full Name	Maria Kelly
Title (Mr/Ms/Dr/Prof/Other)	Ms
Job Title	PhD Student University of Limerick/Database Administrator, National Cancer R
Organisation Name	
Organisation Type <i>Please tick as appropriate and supply details</i>	<input checked="" type="checkbox"/> Government health dept/agency <input type="checkbox"/> Hospital/hospital group <input type="checkbox"/> Government department other <input type="checkbox"/> Local authority <input checked="" type="checkbox"/> Academic institution <input type="checkbox"/> Commercial <input type="checkbox"/> Charity <input type="checkbox"/> Media <input type="checkbox"/> Public <input type="checkbox"/> Other (<i>please specify</i>).....
Address	National Cancer Registry Ireland, Building 6800, Cork Airport Business Park, K T12 CDF7
Telephone/Fax Number	021-4548829
Email	m.kelly@ncri.ie

National Cancer Registry Ireland

APPLICATION FOR DATA/ DATASETS

Declaration by requester/ supervisor of research

I have read and understand the procedures and conditions of use of Cancer Registry data (<https://www.ncri.ie/content/confidentiality>) and am aware of the terms under which this information is being provided by the National Cancer Registry Ireland (NCRI).

I undertake that (unless the National Cancer Registry has been specifically requested and has given permission) the data supplied (as referenced in the Data Request Form cover page above):

1. Will be used only for the purposes specified in the completed Data Request form. Use of the information for a project or purposes other than that described in the completed Data Request form will not be undertaken without further NCRI approval.
2. Will not be transmitted or made available in any format (other than those set out in the completed Data Request form) to anyone not named in this request.
3. Will not be published in any format, prior to confirmation by the National Cancer Registry that the publication meets the criteria set out in this declaration. The National Cancer Registry will be sent a final draft of any publication or report based on the data, and will have the right to have any analysis breaching these conditions removed or modified.
4. Will ensure that, in complying with the conditions set out in this application, they also observe the relevant provisions of the Data Protection Acts, the EU General Data Protection Regulation and the Freedom of Information Act.
5. Where research conducted on the data/datasets provided is independent of further NCRI involvement (i.e. non-collaborative studies), will ensure that publications (print or online, limited circulation or otherwise) will include the statement “data for this analysis was provided by the National Cancer Registry, interpretation of the results are the authors own”.
6. If requested, the National Cancer Registry will archive the data/datasets provided for future availability in cases of peer reviewed public access requirements.

Where individual record datasets are provided, I will ensure that the data supplied:

7. Will not be used to identify or attempt to identify any individual, family, dwelling or institution and may not be published in a way which would allow any individual, family, dwelling or institution to be identified either directly or by linkage with other data.
8. Will not be used to contact any individual patients or their family members.
9. Will not be linked to any data not specified in the completed Data Request form.

10. Will not be transmitted outside the Republic of Ireland [if data is provided in response to a request from within Ireland].
11. Will be deleted or destroyed at the “End date of project” specified in the completed Data Request form. The requester agrees to contact the National Cancer Registry to confirm that this has been carried out.

Name: MARIA KELLY

(BLOCK CAPITALS)

Signature: M.B. Kelly Date: 11/12/2018

**FOR RESEARCH UNDER THE SUPERVISION OF A SENIOR
RESEARCHER/CLINICIAN,
PLEASE ENTER DETAILS AND SIGNATURE(S)**

Name: AILISH HANNIGAN

(BLOCK CAPITALS)

Signature: Aishi H Date: 10/12/18

Name: _____

(BLOCK CAPITALS)

Appendix F - Project code

The R code written for this thesis is available for download from

<https://github.com/mkelly-EOL/MyProjectCode>

Appendix G - Validation Study

Table G.1 Counts of specialist palliative care referrals from the Palliative Care Minimum Dataset and HIPE data for each of eight regional cancer centres in 2016.

Cancer Centre	PC-MDS Primary diagnosis cancer total	'Z51.5' HIPE patients	Discharge to hospice only HIPE patients, (discharge to hospice and 'Z51.5')	Total HIPE SPC count	Total HIPE SPC count as a percentage PC-MDS count
1	496	471	19,(114)	490	99
2	330	298	12,(40)	310	94
3	408	339	1,(3)	340	83
4	492	509	2, (18)	511	104
5	570	376	45,(148)	421	74
6	480	398	0,(1)	398	83
7	564	528	12, (99)	540	96
8	348	439	6, (82)	445	128