# INCREASING THE RELEVANCE OF PATIENT REGISTRIES TO THE PUBLIC

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Master of Science in Health Informatics

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# Declaration

I declare that the work described in this dissertation, is except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university. I further declare that this research has been carried out in full compliance with the ethical research requirements of the School of Computer Science and Statistics

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# Abstract

Healthcare today requires that information is accurate, reliable and timely. Large amounts of data are collected every single day in the provision of care. The consumers of healthcare, who include the public, are increasingly aware of the availability of the multitude of data collections and are eager to harness the information to provide the best evidenced care for patients. Cancer registries, for example, collect information relating to cancer incidence and produce reports on cancer incidence and survival statistics. They are principally used nationally and internationally as powerful information sources to direct planning for cancer services. They are not traditionally concerned with providing information about cancer and cancer prevention to the public at large.

The question the research sought to answer, through the lens of the National Cancer Registry of Ireland, was how can the relevance of patient registries be increased for the public? Answering this question required an analysis of patient registries in general and cancer registries in particular. It was clear from this analysis that there is significant potential to increase the value and relevance to the public of information in patient registries. This led to a consideration of the role which information can play in patient empowerment and hence also the importance of health literacy to ensure that the information being provided can be understood. A representative sample of key stakeholders were interviewed to identify the opportunities for increasing the relevance of data collection such as registries to the public. The results were analysed according to the themes identified.

As the research used the National Cancer Registry of Ireland (NCRI) as the lens through which to consider the research question, the recommendations developed in order to increase the relevance of patient registries to the public were targeted at the NCRI. Based on the international review and the interviews with stakeholders, three key recommendations were identified, namely to include members of the public on the advisory council of the NCRI, run an information campaign aimed at the public to raise awareness of the role and content of the NCRI, and to make the registry more health literacy friendly.

Cancer registries are a valuable information source of information and can be used to further enhance the engagement of the public into supporting their own health and wellbeing. The research identified a need for recognising the requirement for the evolution of the NCRI through a set of recommendations that are evidence based. It was concluded that empowerment of the patient and health literacy are central to increasing the relevance of cancer registries for the public.

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# Abbreviations

AACR - Australasian Association of Cancer Registries

AIHW- Australian Institute of Health and Welfare

CARDI – Centre for Ageing Research and Development in Ireland

CCR- Canadian Cancer Registry

CHIQ – Centre for Health Information Quality

CPHA – Canadian Public Health Association

CSO - Central Statistics Office

DALY – Disability Adjusted Life Year

DIABE-DS – Diabetes Data Strategy

DOH - Department of Health

FAQ - Frequently Asked Questions

GDP – Gross Domestic Product

HI – Healthy Ireland

HIPE - Hospital Inpatient Enquiry System

HIQA- Health Information Quality Authority

HL7- Health Level 7

HMN- Health Metrics Network

IG – Information Governance

IACR- International Association of Cancer Registries

IARC - International Agency for Research on Cancer

ICD-03 – International Classification of Diseases for Oncology

ICD-10 – International Classification of Diseases Version 10

ICS – Irish Computer Society

ICT- Information Communication Technology

IPPOSI- Irish Platform for Patients Organisations, Science and Industry

ISQua- International Society for Quality in Healthcare

ITU – International Telecommunications Unit

JAMA – Journal of American Medical Association

NALA – National Adult Literacy Association

NCCP- National Cancer Control Programme

NCRI - National Cancer Registry of Ireland

NCSCH - National Cancer Statistics Clearing Warehouse

NICR – Northern Ireland Cancer Registry

NPCR – National Programme of Cancer Registries

ONS - Office for National Statistics

PARENT – Patient Registries Initiatives European Joint Action

PiF - Patient Information System

TRO - Tumour Registration Officer

UKACR - United Kingdom Association of Cancer Registries

WHO - World Health Organisation

# Glossary of Terms

Core Indicators: standard measures used across states to assess the outcomes of services provided to individuals and families.

Disability Adjusted Life Year: a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death.

Gross Domestic Product: the market value of all officially recognised final goods and services produced within a country in a year, or over a given period of time

Information Governance: the set of multi-disciplinary structures, policies, procedures, processes and controls implemented to manage information at an enterprise level, supporting an organization's immediate and future regulatory, legal, risk, environmental and operational requirements

Health Metrics Network: a global partnership that facilitated better health information at country, regional and global levels.

HL7: a set of international standards for transfer of clinical and administrative data between Hospital information systems

Proxy Indicator: an indirect sign or measure that can approximate or can be representative of a phenomenon without the presence of a direct sign or measure.

# Chapter 1 Introduction

## *1.1 Background*

Information collection and reporting has become an integral part of the structure of the Irish health system and defines the capabilities of each sector of society as to how the existence, performance and achievements of various sectors of healthcare are acknowledged. With the increasing technology in healthcare, the opportunity exists to improve and educate the wider community with available data. Patients have a sense of empowerment with the increased access to healthcare knowledge and as a result, are in a greater position to question the way in which services are provided.

The Health Information Quality Authority (HIQA) is an independent body that was established in 2007 to drive continuous improvement in Irelands Health and social services (www.hiqa.ie). HIQA (2013) published the Guiding Principles for National and Social Care Data Collections and defined a national health and social care data collection 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* ". The document serves as the guiding reference for the dissertation. Health information sources are required to report a metadata analysis of their information to HIQA to allow for easier access and awareness of data sources in the Irish healthcare system. HIQA recently published an updated version of the catalogue of data collection in healthcare, which has grown substantially since its first publication in 2010.

## *1.2 Data Collection in Irish Healthcare*

Healthcare is information intensive and sees lots of information gathering from various sources for multiple purposes, which ranges from direct patient care to clinical audit to planning and research. As a result of the acknowledged deficiencies in the Irish healthcare infrastructure, it is required that a clear and integrated approach to identifying the gaps is taken to overcome this shortfall. In response to this HIQA published an updated version of the catalogue of data collection that was reported in 2010. There are now 108 reported data collections for health information in Ireland (HIQA, 2014a). Some examples of reported national health information sources include: National Cancer Registry Ireland (NCRI), Cervical Check, Cystic Fibrosis Registry of Ireland, National Perinatal Reporting System and Hospital In-Patient Enquiry (HIPE). As indicated, this report contains patient registries, which are the data collections of significance to this dissertation. A Patient registry is defined as *"an organised system that uses an observational study method to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical , or policy purposes. A registry database is a file (or files derived from the registry" (Gliklich, 2011).* The vision for the assimilation of all data collections into one document was for the purpose that everyone could readily access this information easily. This would help increase awareness and use of national data collections to help improve the quality and safety of health and social care services in Ireland.

Patient registries are generally designed to record details of patients with a particular condition e.g. NCRI – cancer. The purpose of registries is to support research and to assist in the surveillance and planning of cancer services and to improve outcomes for patients. They are therefore aimed primarily at clinical researchers and service planners and also to provide data for international reporting. There is a wealth of data that can be used for the publics' reference once it is tailored accordingly. In recent years there has been a growing consensus surrounding the importance of patient empowerment to enable patients to be active participants in their care and to make better decisions about their care. HIQA (2012b) identified this in Standard One of the National Standards for Safer Better Healthcare – Person Centered Care and Support. Patient empowerment is central to this and is crucially dependant on the availability of accurate, accessible and understandable information. This dissertation will identify the ways in which it may be possible to use the data to further increase the relevance of a patient registry for the publics benefit through the lens of the NCRI.

## 1.3 Research Aims

- To explore the area of data collections in healthcare with specific reference to the National Cancer Registry Ireland (NCRI);

- To identify key pieces of literature both national and international, that will be relevant to the area of research being investigated;
- To carry out a thematic analysis following interviews with various stakeholders with an interest in data collections, cancer registries, patient advocacy and health literacy;
- To develop a set of recommendations for the suggested evolvement of the NCRI to enhance the publics understanding and perception of health information.

## *1.4 Overview of the Research*

This dissertation examines how the relevance of the NCRI can be increased for use by the public. In order to do this, a multifaceted approach will take place. It will be prudent to look at the NCRIs international partners in a compare and contrast method to identify common themes and to identify the various ways data is used internationally. It was appropriate to carry out interviews for further information gathering at this point.

As a starting point to the dissertation, it was necessary to carry out an initial literature review to ascertain what information was already in existence. This is the section of research where gaps were identified and allowed for a pinpointing of a gap in the market of using data collections for the use by the public. This literature review was not exhaustive at this stage and required to be revisited on many occasions throughout the course of the research study.

An important part of the dissertation was to carry out interviews with the stakeholders identified as important actors in a 360 degree view of the research. The list of stakeholders evolved also over time and it was important to acknowledge that some interviews proved to be important for their guidance for further reading as opposed to developing recommendations for the research.

Following the interviews and completion of the literature review, a thematic analysis was carried out by creating a table of questions that were asked and answered. This allowed for a clear identification of themes to emerge. The analysis formulated a clear line of recommendations that were identified for a public engagement process that could take place within the NCRI.

As the recommendations were identified, it was important to acknowledge that the recommendations were justified to gain strength to the argument. As per each recommendation, discussion and analysis was required to rationalise why these recommendation are being presented and the outcome of the research study.

## *1.5 Structure of Dissertation*

Chapter Two - Literature Review

This section comprised of a review of the literature. Key areas that were discussed include data collections and examples of where the secondary use of data collection has been successful. Patient registries were reviewed to understand their function and value. Patient empowerment was discussed in detail as this is a central theme and this is the decisive argument to make patient registries more relevant for the publics use. Health literacy is an important factor to empowering patient to use health information and this is evidenced in the literature review.

Chapter Three- Cancer Registries

This chapter provides background to the cancer registries. The burden and prevalence of cancer in Ireland and worldwide is discussed. There is a comprehensive review of 4 international cancer registries including the NCRI. The following topics are covered as points of discussion - the data collection method, the data set produced and the information contained on their website are discussed in detail.

Chapter Four- Research Methodology

This section details the interviews that were conducted and why this method was chosen. Included was the ethical aspect of using the various stakeholders for interviewing. There is a discussion on the method of using a thematic analysis to conclude results.

## Chapter Five- Results and Analysis

An analysis of the interviews and the questions asked takes place. It is at this point that apparent themes became visible. Recommendations are decided at this point. Each recommendation is discussed and analysed along with evidence from the literature to provide a solid and robust evidence base to the research.

## Chapter Six- Conclusion

A summary of the research that has been carried out is provided. Limitations of the research study are identified and discussed. This lead to the suggestion of what further work can take place in the area of data collection for the publics use as required.

# Chapter 2 Literature Review

## *2.1 Introduction*

"A literature review is a systematic, explicit, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars and practitioners" (Fink, 2010). Justification of the importance of carrying out a review of the state of the art literature and to provide a solid foundation for the area of research is echoed by various authors (Garrard, 2010 and Shaughnessy, 2009).

This literature review covers five main topics:

1. Data Collections and the reporting of data is a central theme to the dissertation. Examples of where the secondary use of data collection has been successful are noted and also HIQA's work in making this attainable and possible is described. Relevant policies and guidance documents are also discussed.

2. Patient Registries are at the heart of the dissertation and it is important to understand the background to registries in Ireland and internationally. The aim is to not only look at what the function of a registry is but to look at the extent as to how Ireland is working towards increasing the value and credibility of registries.

3. As patient empowerment through the availability of information is an integral part of the dissertation, there will be a review of relevant policies and guidance documents that are fundamental to the emergence of the informed patient.

4. The quality of the data and information used to inform and empower patients is clearly critical and hence the review of data quality is reviewed in this chapter.

5. Health literacy is an important part of understanding health information, it is therefore discussed in detail and its relevance in making patient registries user-friendly is explored.

Science Direct, Google Scholar, and Web of Knowledge were used as search engines for the basis of the literature review. Keywords such as health literacy, patient empowerment, data collection, information sources and cancer registries were words used when beginning the search for articles for the literature review. The search was limited to articles and websites in English. There was no limit applied to the publication year. This literature review section is intended to serve as an accompaniment to the qualitative field study contained later in this dissertation.

## *2.2 Data Collection*

*"High quality information lies at the heart of all good decisions concerning health. Health information must be relevant and accessible to all those who require it, must be presented in the most useful formats and must utilise the power of information and communications technology (ICT) to the full in its collection and dissemination. Good information empowers us all."*

(Health Information: A National Strategy, DOHC, 2004)

Information collection and reporting has become an integral part of the structure of the Irish health system and provides definition as to how the existence, performance and achievements of various sectors of healthcare are acknowledged. With the increasing use of information and communications technology (ICT) in healthcare, the opportunity presents itself to use existing data to improve and educate the wider community. Patients have a sense of empowerment with increased access to healthcare knowledge and, as a result, are in a greater position to be active participants in decision making concerning their care and to question the way in which services are provided.

In modern healthcare, data collection is a key component in the delivery and assessment of a healthcare system. Powell, Davis et al (2003) concluded that data which has been routinely collected and quantitatively analysed can be used to benchmark the quality of a healthcare system. In addition to the imperative to provide high quality information to support the direct delivery of care, this also explains why data collection is an integral part of healthcare systems. Garvin et al (2009) echoed many other authors in pointing out that complete and accurate data collection have a far reaching impact by identifying deficiencies in the system, which in turn improves the quality of care.

### 2.2.1 Diabetes Data Strategy Project (Diabes-DS)

Secondary use of data can be defined as "*the application of personal health data for uses outside of direct care delivery. It may include activities such as analysis, research, public health; payment marketing…it can enhance health care experiences for individuals and can strengthen understanding about effectiveness and efficiency of health care systems"* (Safran et al, 2006). When data is used many times, it allows a system to provide comparisons, identify areas to be targeted and allow for programme planning and thus evaluation as a means to gaining value from the collection of sets of data. This was demonstrated in the Diabetes Data Strategy (Diabe-DS) project formed in 2009 by the HL7 EHR Working Group to showcase disease specific data types for clinical care and secondary use which resulted in a model that provided data required for the current clinical environment being captured and thus supported multiple use of data (Barton et al. 2011). The importance of data collection is acknowledged owing to the large amount of statistics that can be produced from collecting data just once, thus coining the phrase "Collect Once, Use Many". The Diabe-DS example demonstrates that it is possible for a system to collate data for one purpose and the data can then be used for secondary purposes in a meaningful way and thus benefitting the public by saving the public purse. It can also signify that data collections can be used to extract data from and to use it for different purposes.

## *2.3 Making the Case for Information*

Health policy in Ireland and across the world now dictates the need for information in providing healthcare for the public. There are compelling moral, legal, ethical and financial incentives to providing high quality of information to the general public to allow them to manage and make decisions on their own healthcare. To acquire support and engagement from the public requires provision of access to good quality health information but also the support to use this information. This is evidenced in the World Health Organisation (WHO) report on "*The Need for Strong Information Systems"* (WHO, 2014). They describe the rationale for developing a Health Metrics Network (HMN) to help countries improve the availability and use of accurate health information. It is expected to produce smarter ways of gathering, analysing and using health information leading to better decisions, better financial outcomes and thus make it easier to track the status of health in a country.

### 2.3.1 Health Information Quality Authority (HIQA)

The Health Act (2007) assigned a statutory requirement for HIQA for the development of standards, evaluation of information and to make recommendations surrounding all aspects of health information. The Act declares as follows:

- *Section 8(1) (i) Evaluate available information, respecting the services and the health and welfare of the population*
- *Section 8(1) (j) Provide advice and make recommendations to the Minister for Health and Children and the Health Service Executive (HSE) about deficiencies identified by the Authority in respect of the information referred to in paragraph (i)*
- *Section 8(1) (k) Set standards as the Authority considers appropriate for the HSE and service providers respecting data and information in their possession in relation to services and the health and welfare of the population.*

(Health Act, 2007)

Further to this, HIQA advises on the collection and sharing of information across our health care services (HIQA, 2014b). HIQA sets the standards that organisations need to apply and they provide guidance which is aimed at improving the consistency and quality of data collection in Ireland. As a result, it is the responsibility of the organisation to ensure that the data that they collate and report on is consistent and of high quality.

HIQA provides advice on the standardised collection and sharing of information across the Irish health service (www.hiqa.ie). As part of the Health Service Reform Programme, HIQA are at the forefront in the development of national guidelines and standards for health information governance (IG). In 2010, HIQA produced a report on IG in Ireland, that examined and outlined the legislative provisions relating to IG and the structures, alongside polices and also guidelines that are in place in the Irish social and healthcare sector. The report covered areas such as: confidentiality and data protection; information security; clinical information assurance; secondary use assurance; and freedom of information assurance (HIQA, 2010). Supplementary to this, HIQA produced the document *Guidance on information governance and social care services in Ireland* in 2012 (HIQA, 2012a). In the report, areas covered were: governance and management structures to support IG; data quality; privacy and confidentiality; information security and secondary use of information. This is a topic of importance as there is a requirement for regulation over data collections and a policy of best practice if the intention is to make information more accessible to the public and to ensure information cannot be manipulated in such a way that would be detrimental to the purpose of the data.

### 2.3.2 Guiding Principles for National and Social Care Data Collections

To an extent, there has largely been a fragmented and unstructured approach to data collection in Ireland. To allow for the development of a more coordinated response and approach to reporting, HIQA recognised this deficit in the lack of guidance to advancing towards a sustainable approach to data collection in Ireland. In 2013, HIQA developed the *Guiding Principles for National and Social Care Data Collections* in response to the recognition of the current largely uncoordinated and fragmented approach in the development of our national data collections (HIQA, 2013). These guiding principles were also aimed at improving the usability of the data collection for research and quality improvement. HIQA identified 4 key overarching objectives relating to health information which are:

1. Health Information is used to deliver and monitor safe and high quality care for everyone.
2. Health information should be of the highest quality and where appropriate collected as close as possible to the point of care.
3. Health Information should be collected once and used many times.
4. Data collection should be 'fit for purpose' and cost effective.

Other documents proved pivotal in the development of the guiding principles. These included the *Catalogue of National Health and Social Care Data Collections in Ireland*, which is a summary description provided by each data collection to the catalogue. A national data collection as defined by HIQA is "*a national repository of routinely collected health and social care data (including administrative collections, censuses, national surveys, and patient registries) in the Republic of Ireland"* (HIQA, 2014a). Other HIQA reports and documents of note include the 2011 reports, *International Review of Health Information Sources, the Identification of Themes for National Health Information Sources* and also *the Draft Standards for National Health Information Resources* (HIQA, 2011 a,b,c)

The 8 guiding principles as defined by HIQA for National Health and Social Care Data Collections in Ireland are contained in Table 2.1.

Table 2.1: 8 Guiding Principles for National Health and Social Care Data Collections in Ireland (Source: HIQA, 2013)

| | |
|---|---|
| **Principle 1** | Governance Arrangements |
| **Principle 2** | Statement of Purpose |
| **Principle 3** | Legislation and standards |
| **Principle 4** | Use of resources |
| **Principle 5** | Use of information |
| **Principle 6** | Data Quality |

| | |
|---|---|
| **Principle 7** | Information Governance |
| **Principle 8** | Workforce |

Principle 1: Governance Arrangements – They are put in place to provide a framework to guarantee that the data collection achieves its objectives.

Principle 2: Statement of Purpose - This is to identify why the data collection exists and what it does to achieve its stated objectives.

Principle 3: Legislation and standards – Those that are involved in the managing of the data collection are aware of the relevant legislation and standards pertinent to their organisation.

Principle 4: Use of resources - Those that are involved in the managing of the data collection are involved in the allocation and use of resources to achieve its stated objectives.

Principle 5: Use of information – The information that is collected should be accessible and disseminated as widely as possible to ensure greater appropriate use of the data.

Principle 6: Data Quality - By systemically monitoring, evaluating and continuously improving the quality of the data can ensure the effectiveness of the data collection.

Principle 7: Information Governance - Those that are involved in the managing of the data collection have arrangements in place that ensure the personal information of the public is handled legally, securely, efficiently and effectively.

Principle 8: Workforce - Those that are involved in the managing of the data collection have planned and organised its workforce to deliver its stated objectives.

(HIQA, 2013)

These principles do not stand alone as a driving force to highlight the need for high quality health information. The Department of Health has been behind the production of numerous documents such as:

- Quality and Fairness – A Health System for You (2001)

  The vision that was encompassed in this document was a complete reform of our health system building on the changes already underway. It was a document of reform and for development. As it was aimed at a system wide reform of the Irish health system, specific reference was needed to the incorporation of the health information function. Table 2.2 outlines Actions 115-121 that were identified in "*Developing Health Information"* It was acknowledged that good information systems are necessary to improving performance by supporting "*quality, planning and evidence based decision making in the health system"*. Key deliverables included availability of high quality health information that is accurate, time and accessible, investment in health information systems and development of an electronic health record.

Table 2.2: Actions 115-121Quality and Fairness - A Health System for You (Source: Dept of Health, 2001)

| | |
|---|---|
| **Action 115** | The Nation Health Information Strategy will be published and implemented |
| **Action 116** | There will be a sustained programme of investment in the development of national health information systems as set out in the National Health Information Strategy |
| **Action 117** | Information and communications technology will be fully exploited in the service delivery |
| **Action 118** | Information sharing systems and the use of electronic patient records will be introduced on a phased basis |
| **Action 119** | A national secure communications infrastructure will be developed for the health services |
| **Action 120** | Information system development will be promoted as central to the planning process |
| **Action 121** | Health information legislation will be introduced |

- Health Information: A National Strategy (2004)

  The key aim of the strategy was to identify the present deficiencies in our health information infrastructure. It looked at recommendations to develop the necessary frameworks to ensure the "*optimal development and utilisation of health information".*
  A key component of the strategy was the understanding that information is used to plan, develop and evaluate the delivery of high quality, timely and safe care to all individuals. To allow for the successful implementation of the document, the Strategy was divided up into 4 parts – Health Information in Context; Improving Health Information; Supporting Health Information and finally Implementation of the Strategy.

  1. Health Information in Context – A wide definition of Health Information was adopted to encompass all those who require information. The vision was that everyone could access information that was trustworthy and could be used appropriately.
  2. Improving Health Information – HIQA was designated as central to the implementation of the Strategy.
  3. Supporting Health Information – A Health Information Bill was to be published as existing legislation was not deemed sufficiently supportive of some aspects of health information governance.
  4. Implementation – For successful implementation of the Strategy, both the Department of Health and the health agencies must form appropriately aligned structures to support operational functioning at both local and national level

  (Dept of Health, 2004)

- Building a Culture of Patient Safety- Report of the Commission on Patient Safety and Quality Assurance (2008)

  This document was produced to provide recommendations for a framework of patient safety and quality which will lead to healthcare facilities that are governed effectively. With reference to health information, acknowledgement was also given to the

> requirement that information should be used and shared in the right way and at the right time. The introduction of the electronic health record was advocated and ensuring that the proper infrastructure is in place to allow for a smooth transition to an information rich environment. Also, one of the recommendations specifically identified was that "*Rapid progress must be made on the development and implementation of a unique identifier for the health system*"
>
> (Dept of Health, 2008)

These documents are in place to provide a foundation to building a solid information infrastructure that had major gaps with individual silos of information. The documents highlight the importance and also the need for better quality health information that would lead to improvements in the safety and quality of healthcare.

## *2.4 Patient Registries*

### 2.4.1 What is a Patient Registry?

At their most basic, registries are lists of patients who share the same characteristics, such as a certain condition or medication regime. The term 'registry' is defined both as the act of recording or registering and as the record or entry itself. Therefore, "registries" can refer to both programs that collect and store data and the records that are so created. (www.meeriam-webster.com). Further to this, the term 'patient registries' can be used to distinguish registries focused on health information from other record sets and can be referred to by many different terms such clinical registries, clinical data registries and disease registries (Gliklich, 2010).

### 2.4.2 What is their purpose?

If used correctly and to its optimum benefit, a patient registry can be a very powerful tool. It can allow stakeholders to observe disease patterns, examine factors that influence prognosis and quality of life, monitor and measure quality of care at various levels (Labresh et al, 2003). Patient registries can be used in many different ways. For example, a physician may access a registry to collect data about disease presentation and outcomes so as to produce a real world picture of a certain disease, current treatment options and their outcomes. An organisation like a health insurer may use a patient registry to access information on large numbers of patients on how procedures, pharmaceuticals or devices are used and their effectiveness in different regions.

As treatments are advancing so rapidly, patients who previously would have died from rare diseases at a young age can be monitored and this evolving history of a disease can be monitored through a registry (Barranger & O Rourke, 2001). Gliklich (2010) described registries having 4 different purposes while noting that this is not an exhaustive list. They are: describing the natural history of the disease, determining clinical and cost effectiveness, assessing safety or harm, and measuring or improving quality of care. To determine effectiveness of treatments, clinical studies commonly use registries to obtain results that differ in opinion, depending on the commissioning agent and their requirement for carrying out a study and do not use age or race or sex to discriminate in its work. A registry can be an effective tool to assessing cost effectiveness of a treatment. This is a means to describe "*the comparative value of a health care product or service in terms of its ability to achieve a desired outcome for a given unit of resources*" (Eichler et al, 2004). To measure safety or monitor safety and harm, registries can act as a surveillance system for the occurrence of unexpected events (Gliklich, 2010). Quality of care can be measured through registries and are being used increasingly to assess differences between providers or patient populations based on performance measures that compare treatments provided or outcomes achieved with '*Gold Standards'* (Greene et al, 2009).

### 2.4.3 EU PARENT Project

HIQA have reported 108 health and social care data collections with 22 of these indicated as patient registries (HIQA, 2014a). It is imperative to utilise this data to its full extent that would cover crucial domains of care and also allow for international information sharing for the purposes of research, health service quality improvement and public health. The Patient

Registries Initiatives European Joint Action (PARENT) project highlighted that patient registries presented an underused resource to allow these functions to happen.

The general objective of the PARENT project is to rationalise the development and governance of patient registries, which will ultimately allow for the use of data for public health and research purposes in cross border settings. This could only be done by improving the ability of the patient registries to share data as well as improving the method by which registries obtained their information from their primary sources (PARENT, 2013). The ability to share data between registries is particularly important in the context, for example, of supporting research into rarer conditions where the number of patients with the particular condition is relatively small. The project lists 2 main goals that will help achieve their long term objectives:

1. Develop a set of guidelines, recommendations and tools that will support participants in the project with regards methodology, development, implementation, governance and improvements of national and local patient registries.
2. Develop activity plans, business model and policy proposals to ensure sustainability of cross border collaboration on usage of patient registry data.

(PARENT, 2013)

In notes prepared and available online in advance of the 2014 ISQua® (International Society for Quality in Healthcare), Yannis Skalkidis, as a representative of the PARENT Project described the work already undertaken. There have been over 500 identified patient registries at national and international level. Feedback was sought and received from over 120 of these registries. The key findings were as follows:

- There is virtually no cross border or even cross organisational secondary use of data for research and public health.
- There is little evidence of recommendations regarding interoperability of patient registry data.
- There is some reference work on standardising registry metadata.

- There are few projects that produce methodologies and tools to tackle interoperability and reuse of primary data.
- A registry of registries is an opportunity to map patient registries as a valuable data source with the removal of the various identifiable obstacles

The ultimate aim of the Parent Project is to enable all relevant stakeholders to fully maximize the valuable wealth of information that is available for the benefit of the public, by not only improving health outcomes but also by providing cost effective care. (Skalkidis, 2014)

### 2.4.4 Proposal for National Strategy for Registries in Ireland

IPPOSI (Irish Platform for Patients’ Organisations Science and Industry) is the organisation which is striving for the development of a national strategy for patient registries. IPPOSI was established to provide a platform for discussion between patients’ organisations, science and industry in Ireland on policy, legislation and regulation around the development of new medicines, products, devices and diagnostics for unmet medical needs. It is a unique partnership of patients’ groups/medical charities, science and industry. IPPOSI have a vision of where state of the art innovations in healthcare are available at the earliest stages to Irish patients. (IPPOSI, 2009)

Dr. Fionnuala Donohue conducted research into the requirements for a National Strategy for Patient Registries which were presented in 2011(IPPOSI, 2011). The aims and methodology of the research were to:

- Review international guidelines for Patient Registries
- Ascertain what Patient Registries are currently active in Ireland
- Draw up a survey to use with these Patient Registries, conduct interviews with relevant stakeholders
- Arrange focus groups with patients to establish their views on Patient Registries

Findings from the research concluded that: international registries encouraged fully informed consent, continuous evaluation of data standards and data validation is necessary.  There is a need for quality, consistent data to improve utilisation of registries. Appendix A provides a summary of guidelines used internationally for patient registries as presented by Dr Fionnuala Donohue. They are useful for any registry in terms of what is recognised as best practice from health systems with a well developed ICT infrastructure.

Focus groups that consisted of patients and their families were used as part of Dr Donohues research methodology to gain an insight from a public perspective. The groups generally had support for registries and were aware of the potential benefits such as improving quality of care, service planning and facilitating research for the development of new treatments. Patients also expressed support for registries that are properly regulated and for data linkage. The groups reported concern over situations where data may be collected but not used purposefully or appropriately. They also raised concerns over the current health services ability to integrate registries into the current system, given its current limitations and inefficiencies. The focus group supported the use of legislation and regulation to ensure that standards are maintained for the maximum benefit of registries. Concern was then expressed over health insurers or banks having access to their information, and how this could affect them in later life such as applying for a mortgage.

The most important conclusion in the final report on the research that was presented to the Irish government was that the public are in favour of registries under the proviso that they are properly regulated and that the data being collected is used for valid reasons (e.g. improving care, health service planning and delivery).

This  highlights the requirement for high quality data as poor data could prevent researchers from carrying out national studies of a longitudinal nature or comparative studies at an international level of a valid and robust nature .As participants in the EU PARENT project and with the newly published *Catalogue of National Health and Social Care Data Collections* (HIQA, 2014a) along with the preparatory work carried out by Fionnuala Donohue and

IPPOSI, Ireland is in a good position to move with our European neighbours to advance the work of patient registries.

## *2.5 Empowering the Patient through the use of Information*

Patient empowerment is a process through which patients are helped to use independent decision making in order to better manage their own illness and to gain control over their health and to remain socially integrated (The Lancet, 2012.) Aujoulat et al (2007) described patient empowerment as "… *a philosophy which views human beings as having the right and the ability to chose by and for themselves. Self determination therefore appears to be a strong guiding principle of empowerment based interventions."* The importance of patient empowerment is recognised as a valuable tool to keeping people well and out of hospital. The better informed a patient is, the more likely they are to access treatment early and therefore place less of a burden on the health system. WHO (2006) recognised that patient empowerment is not only an outcome in itself but it is also a step towards a long term goal, one of which can be viewed as keeping the patient well.

Empowerment of the general public to understand the value of health information sources is key to the answering the research question and will enable the NCRI evolve into an information source that can be multipurpose and can be promoted as a complete information source that data can be extracted from for different purposes. If the public understand the information being presented, the resulting effect can be an integration of individual and group actions towards changes in health behaviours as determined by data collections (WHO, 2009).

In order to maintain focus on empowerment of the patient through the use of health information, Irish government policy is required to enable the movement towards "keeping the patient well. This section will discuss the frameworks and policies that influence Irish society to take charge of their own health through various methods and media, one of which is accessing health information to maintain good health.

### 2.5.1 EHealth Strategy

Information Communication Technology (ICT) is fundamental to the advancement of the healthcare sector in Ireland. The *eHealth Strategy for Ireland* was developed with the intention of integrating all information and knowledge resources involved in the delivery of healthcare via ICT systems, which would include patients and their records. It is seen as an important strand of tackling the budgetary and demographic challenges facing the healthcare sector (Mulholland, 2014).

It is important to understand that patients need to be aware of the information resources that are available in order to empower them to take charge of their health. The European Commission described eHealth as "*Information and Communication Technologies tools and services for health. Whether eHealth tools are used behind the scenes by healthcare professionals, or directly by patients, they play a significant role in improving the health of European citizens*" (European Commission, 2010). The Department of Health published the *eHealth Strategy for Ireland* in 2013 to ensure the successful adoption of eHealth in Ireland (Dept of Health, 2013a). The strategy proposes to prioritise e-prescribing, online referrals and scheduling, telehealth with a specific focus on chronic diseases and the development of summary patient records. To complement this publication is the *Health Identifiers Bill* which was also published in 2013. This will provide the legal basis for the introduction of Individual Health Identifiers and will be available to use in both the public and private sector. This will ensure that the right information is associated with the right individual at the point of treatment (Dept of Health, 2013b). According to the Irish Computer Society, the publication of the *eHealth Strategy for Ireland* will be a significant step towards patients taking control of their own health and managing their wellness as well their sickness (ICS, 2013).

### 2.5.2 Healthy Ireland

Healthy Ireland (HI) is a new national framework that was launched in March 2013 to help improve the health and wellbeing of the population of Ireland over the course of the coming generations (Dept of Health, 2013c). Four high level goals were identified to improving people's health and wellbeing and the route by which these will be achieved. They are identified in Table 2.3 below. The most valuable point here is that HI encompasses the concept of the patient taking responsibility for their own health and wellbeing. This will be done by using information in various forms.

Table 2.3: Goals of Healthy Ireland (Source: Dept of Health, 2013)

| | |
|---|---|
| **Goal 1** | To increase the proportion of people who are healthy at all stages of life |
| **Goal 2** | To reduce health inequalities |
| **Goal 3** | To protect the public from threats to health and wellbeing |
| **Goal 4** | To create an environment where every individual and sector of society can play their part in achieving a healthy Ireland |

HI are developing a research plan to build a knowledge base of information and will ensure the highest quality and most up to date data, scientific knowledge and evaluation tools to support the implementation and monitoring of the 64 actions required to achieve these goals (CARDI, 2013). Some of the actions are positioned to empower the patient to tackle their own health and wellbeing through the gathering of information to keep themselves well and also to visualise the access to information that perhaps was lacking prior to this. Some of these actions are outlined in Table 2.4. In summary, HI proposes a shift towards an integrated framework to health.

Table 2.4: Relevant Actions from Healthy Ireland (Source: Dept of Health, 2013)

| ACTION | |
|---|---|
| Establish a multi-stakeholder, Healthy Ireland Council which will provide a national advisory forum to support implementation of the Framework across sectors. | Address and prioritise health literacy in developing future policy, educational and information interventions. |
| Strengthen participation in decision making for health and wellbeing at community level. For example, through local authorities, community services funded by Government or through the health service user involvement strategy | Develop strategies to enhance social connectedness across the life course and to connect people most in need to resources, services, education and healthcare |
| Develop a Healthy Ireland Research Plan. The plan will develop specific measurement strategies to address knowledge gaps and capture data across the life course and identify actions for improved knowledge dissemination and implementation. | Develop an Outcomes Framework that will specify baseline indicators and targets, where appropriate. |
| Produce annual updates on health and wellbeing activity, including the preparation of an annual report. The Minister for Health will present these reports to the Cabinet Committee on Social Policy | Develop appropriate indicators on health status, health inequalities and access to health services in conjunction with the Department of Social Protection's Technical Advisory Group. |

### 2.5.3 Patient Information Forum

The Patient Information Forum (PiF) is a United Kingdom based association for professionals working in the field of health information. It promotes the usage of high quality health information and the engagement of the public by providing access to high quality information. This allows patients to make informed decisions about their treatment. They seek to do this through the sharing of best practice, ideas and knowledge.

The PiF produced a report 'Making the Case for Information' (2013), that outlined how providing information can improve outcomes, reduce costs and allows people experience a superior level of care. Research was commissioned to identify the benefits of investing in health information. The project sought to:

(1) Identify, collate and document evidence on the benefits of providing, high quality consumer health information and support to their patients and families, healthcare professionals and the wider healthcare system;

(2) Look at the business case for information provision, including any cost benefit analyses; and

(3) Identify any gaps in evidence and areas where more work was needed.

(Patient Information Forum, 2013)

For the purposes of the report, a review of the academic and grey literature was carried out as well as telephone interviews with policy makers, researchers, providers etc. 300 studies were analysed and referenced that showed justification for the investment of time, money and training in the provision of health information and support. Positive impacts included: costs on service use, substantial capacity savings and marked increases in return on investment through shared decision making, self care and self management of medical conditions. Recommendations from the report included: Further research and learning should be focused on identifying and evaluating what comprises quality health information services, the roles of specialist information staff and successful approached to establishing well managed, properly resources information services. Consideration should also be given to the requirement for a new clinical commissioning group for guidance on how to best proceed in securing quality health information and support locally.

An evaluation of the report is currently being carried out through phone surveys and a range of interviews. The results are envisaged to be published by late June 2014. Sarah Smith, Director of Operations, has stated that PiF are developing guidelines that people can use to ensure what they produce is of high quality. PiF hope to create online resources, tools and a best practice database.

## *2.6 Data Quality*

Referenced earlier in this chapter was Principle 6 of the *Guiding Principles for National Health and Social Care Data Collections in Ireland*. Principle 6 relates to Data Quality which indicates that systematically monitoring, evaluating and continuously improving the quality of the data can ensure the effectiveness of the data collection. If the quality of data is fundamental to patients being in charge of their own healthcare, it is imperative that patients can be comfortable in the knowledge that the information they access online is of good quality. There is a growing research base online that illustrates how to assess health information found on the web and this is valuable as it lends a degree of validity to the notion of gaining confidence in the health information that is available online.

According to the International Telecommunications Unit, there are over two billion internet users worldwide (ITU, 2013). This is compared to an estimated 10 million users in the mid 90s. At this time, studies addressed the concerns of users over the quality of information available on the internet. This is validated in a study by Wang et al. (2011) that carried out a comparative study on internet search engines to obtain medical information. They applied usability testing as a software engineering technique to compare the four major search engines – Google, Yahoo, Bing and Ask.com in obtaining health information. The keyword ‘Breast Cancer’ was used as a common search term and the top 200 links were saved from each search. Users evaluated the links that were returned and each website was scored based on the usefulness of the content in relation to ‘Breast Cancer’. In conjunction with this, a medical expert identified 6 websites in relation to breast cancer as standards. Also, the authors identified 5 other keywords associated with breast cancer and analysed their occurrence on the returned websites. Results showed that all search engines returned the 6 standard websites identified by the medical expert in the top 30 search results. There was a high overlapping rate amongst the search engines which was deemed positive but on the other hand, each search engine emphasized different types of content differently. This study identified that there is still room for improvement in obtaining accurate and reliable information.

### 2.6.1 Indicators of Quality

In order to understand if a website is providing health related information, indicators of quality were developed to guide patients towards information that was deemed to be reliable. Burkell (2004) indicated that there are “Core Indicators” that directly assess the quality of information. These are: currency, accurateness and completeness of the information and they are considered the gold standard in evaluating health information but their use is limited as assessment must be made by experts in the particular field. From this a system of “Proxy Indicators” was developed and these measured readability, and design which could be assumed would be indicators of quality. They are used more widely as they are objective measurements and are easy to assess. For example, Walsh & Volsko (2008) demonstrated that readability could be assessed using a number of methods such as the Flesh Kincaid reading level, which calculates readability using average sentence length and number of syllables per word.

### 2.6.2 Quality Evaluation Tools

While readability and design are important, by far the most important dimensions of data quality are the accuracy and reliability of the information. Scoring systems that indicate the order or rank of a piece of information are valuable to the public when assessing whether the information being presented is reliable. It is a quick way of seeing if an article is considered reliable by expert reviewers. A commonly used tool by JAMA (Journal of the American Medical Association) is one that uses a set of criteria through which health information could be assessed. Items include: Display of author name, date of update, source, disclosure of ownership, sponsorship, advertising policies and any potential conflicts of interest (Barker, 2010).

As Google® is the most popular search engine worldwide, the likelihood is that most people will use this search engine to access information on their condition. However, as there is so much information on any single condition, it is necessary to know if the first 20 articles are of reliable quality as it is likely that patients will not look through a complete history of results for their condition. For example, Google Scholar® returns 4,130,000 possible articles or websites in response to the word ‘Cancer’. Google bases the ranking on link popularity. The number of hyperlinks pointing to a website from other pages will improve its ranking (Zook & Graham, 2007). This is potentially a misleading method of evaluating health information as it is based more on popularity rather than quality.

It is clear that there is a growing need for a regulatory system for health information as it is impossible for the health profession to compete with Google, Wikipedia etc. It may be considered reasonable that there should be a system which guides patients towards information that is of high quality, is accurate and that is devoid of commercial bias. Healthcare professionals could obviously do this but this “quality filter” is manual and relies on individual opinion. To this end, patient registries are an excellent source of information from which patients (to whom the registry is relevant) can be assured of validated, high quality, accurate and reliable material through which empowerment by ownership of their own health and wellbeing can occur.

## *2.7 Health Literacy*

We have moved from a paternalistic model of healthcare under which the patient is a passive participant in their own healthcare to one in which the patient is actively involved in partnership with the healthcare professional. As discussed previously, in order for this to happen, patients need to be empowered through the use of good quality information, but to obtain this level of integration, the public must be able to understand it and this has resulted in the need for a health literate society. Health Literacy is defined as “*...the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health…improving peoples* *access to health information and their capacity to use it effectively and … is critical to empowerment*" (WHO, 2009). Section 2.6 identified that there are over two billion internet users in the world (ITU, 2013).This equates to 38.8 % of the world's population. It would be impossible to ignore the implications this should have for every health system. Health information needs to be tailored to its users. Consideration must be given to what level you tailor the information, especially if information is often adapted for corporate usage to service plan, detail budgets or for political understanding. Health information targeted at the general public, may therefore only be consumed by a certain portion of society that possesses a certain level of health literacy.  It is important to consider that health documents are often written with specific audiences in mind. For example, a document written for an academic journal may contain scientific or technical jargon relevant to the topic but a patient information leaflet about the same subject would typically use plain English to convey the chosen message. It is necessary to present information in a way that is appropriate to the user group.

### 2.7.1 NALA and Irish Policy

The National Adult Literacy Agency (NALA) are an independent charity that was set up in 1980 to help people with literacy and numeracy difficulties take full part in society and ensure they have access to learning opportunities that can meet their needs. They lead on campaigning and are a lobbying force for adult health literacy issues (NALA, 2014). Therefore it is encouraging to see the close connectivity that is being created between NALA and the introduction into Irish Health Policy of a requirement for action towards health literacy. This is especially important as research has shown that people with lower literacy levels are less likely to engage with preventative healthcare and are be less likely to identify a disease at its early stages. Furthermore, they are less likely to be able to access and use appropriate health services. (Dewalt et al., 2004).

As previously discussed in section 2.5.2, Healthy Ireland is a policy, published in 2013, to help improve the health and wellbeing of Ireland. Action 3.8 states that Healthy Ireland will "*Address and prioritise health literacy in developing future policy, educational and information interventions."*(Dept of Health, 2013c) A positive step here is that there is participation indicated a wide variation which includes the Department of Health, the HSE, statutory agencies and other sectors. NALA have identified a strong partnership with both the Department of Health and the HSE to ensure the success of Healthy Ireland and are formulating a structure to communicate these plans to address health literacy across all divisions in the future as a matter of priority.

### 2.7.2 European Health Literacy Survey

Ireland was one of 8 European countries (Austria, Germany, Bulgaria, Poland, Greece, Spain, Ireland and the Netherlands) that took part in the first European Health Literacy Survey. Each country surveyed 1000 people with a mean response rate of 69% from Ireland.

One of the overarching aims of the survey was to develop a tool to measure health literacy in Europe. To reach this objective involved a number of steps including:

1. A literature review was carried out to review existing definitions, concepts and tools.
2. A conceptual model was developed as a foundation for the completion of the survey.
3. To facilitate the development of the questionnaire, the Delphi procedure method was employed.
4. Ireland, the Netherlands and Greece carried out focus groups to test the questionnaire.
5. Ireland and the Netherlands carried out pilot interviews to test the questionnaire.
6. The questionnaire was reviewed by the stakeholders to make any final adjustments.
7. The questionnaire was translated to local languages.
8. Official versions were confirmed of the questionnaire HLS-EU-Q to be used in the European Health Literacy Survey.
9. The survey was then officially carried out in July 2011.

(Maastricht University, 2012)

From the countries surveyed, Ireland came 2nd with highest rate of health literacy, behind the Netherlands. However, as a cause of concern, with a combined total across Europe of nearly every second person (46%) having been shown to have problematic health literacy shows that there is still an issue of health literacy amongst certain sectors. Of the respondents in Ireland, a combined figure of 40% of people had either inadequate health literacy (10.3%) or problematic health literacy (29.7%) (See Figure 2.1) (Doyle et al, 2012).

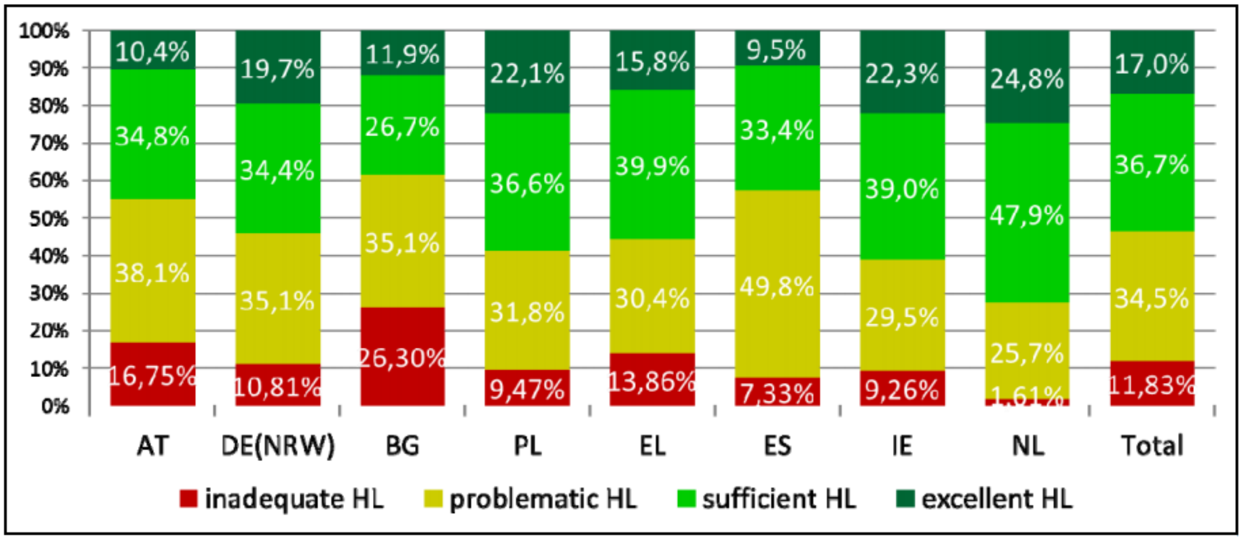


Figure 2.1: Percentages of different levels of the General Health Literacy Index, for 8 countries and the total sample. (Note: In Germany only the region North Rhine-Westphalia was interviewed)

Key findings presented from the study indicate that health literacy should be considered when developing any health initiatives and plain language should be the foundation with the cognitive ability required to understand and process the information being taken into account. It also highlighted that in the reporting media, standards should be employed with the consideration of aiding people in their understanding of health information.

## *2.8 Conclusion*

This chapter explored literature that was deemed both relevant and of significance to the subject matter. The topics covered which were identified in the opening paragraph included: the significance of data collections, patient registries and their function, patient empowerment through the use of health information, data quality as a tool to increase the participation in their own health and wellbeing and finally health literacy and its contribution to having a society that is as informed as possible about their own health.

This literature provides the foundation to understand why the public should be included more in their own healthcare and to understand that it is up to the individual to ensure that they are informed but equally, the system must endeavour to include the individual as a consumer of their products. In Chapter 3, the focus will shift to international cancer registries and also the NCRI where there will be a structured analysis of the registries to further inform the discussion contained within this dissertation.

# Chapter 3 Cancer Registries

## *3.1 Introduction*

Chapter 2 covered the literature surrounding data collections, health literacy, data quality and patient empowerment and also patient registries. This chapter will act as a supplementary chapter to analyse 4 different registries, explain what their different functions are, how they collect their data and how they use their website to present information to the public. This was carried out by reviewing the websites and published material related to the registry in question. To establish the context to this chapter, a section on cancer and its meaning to Ireland and to the world is included. There will be a discussion of its incidence and prevalence but also of its financial impact worldwide and in Ireland. It is hoped that by the end of the chapter, it will be clear that there is a gap in respect of the relevance to and use of data collections (with the NCRI as the example) by the public in Ireland.

## *3.2 Cancer*

"Cancer" is a term that is used to describe a whole group of illnesses that have certain common characteristics. Characteristics include: an overgrowth of cells that forms a tumour and there are over 200 different types of cancer (Irish Cancer Society, 2013). Other terms that can be used for cancer include malignant tumours and neoplasms. The one defining feature of cancer is "*the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs. This process is known as metastasis"* (WHO, 2014).

### 3.2.1 Worldwide Prevalence and Incidence of Cancer

The global burden of cancer continues to be problematic due to the increasing growth and aging of the world population. It is the leading cause of death in economically developed countries and the second leading cause of death in developing countries (WHO, 2008). This is proven by the fact that there are approximately 184 countries included in the most recent publication of the International Agency for Research on Cancer (IARC) online database, GLOBOCAN 2012, which reported 14.1 million new cancer cases for 2012 and 8.2 million cancer related deaths in 2012 (Ferlay et al. 2013). By 2030, it is projected that there will be approximately 26 million new cancer cases and 17 million cancer deaths worldwide (Thun, 2010). Although overall cancer incidence rates in the developing world are half those seen in the developed world in both sexes, the overall cancer mortality rates are generally similar. Cancer survival tends to be lower in under-developed countries. This is most likely because of a combination of a late stage of diagnosis and limited access to standard and timely treatment (Jemal et al, 2011).

The global economic burden of cancer paints a stark picture that cannot be ignored. The American Cancer Society in association with LIVE**STRONG®** conducted a study to explore the economic burden of all deaths globally and this included deaths from cancer. In 2008, the total economic impact of premature death and disability from cancer worldwide was 895 billion dollars (650 million Euros). This figure equates to 1.5% of the worlds Gross Domestic Product (GDP) (Rijo et al, 2010). The analysis did not include direct medical costs. The study was conducted using the disability adjusted life year (DALY) which combined the death and disability dimensions into one single concept and are a common measure to describe the burden of diseases. The economic value of a year of healthy life was estimated of a year of healthy life was measures to assess the overall impact of healthy lives lost to death and disability. It makes the assumption that each DALY can be valued at one year of the per capita GDP being studied.

As more data is being accumulated on cancer data not only through commissioning of global studies but also through cancer registries, it is apparent that there is a requirement to build a health portfolio that encompasses not only acute care, but also health promotion and education and integration of the public to combat the rise in cancers worldwide in an effective and sustainable manner. There is a growing body of evidence to show that many cancers are associated with particular lifestyles and that this therefore adds to the importance of making understandable information available to the public to help them lead a healthy lifestyle. (Shim et al, 2006, McCormack & Boffetta, 2011)

### 3.2.2 Ireland and Cancer

Similar to the global burden of cancer, Ireland maintains a similar trend in respect of cancer rates and its increase in incidence over the years. Each year, it is estimated that the number of cancer cases rise by 3% and the number of deaths by 1% annually. There were an average of 18,500 invasive cancers diagnosed annually between 2008 and 2010 with a total of 8,316 deaths from cancer recorded in 2010. Cancer is recognised as the second leading cause of death in Ireland, secondary to disease of the circulatory system. Ireland does not compare very well statistically against other countries. Ireland ranked amongst the top 10 in Europe for all invasive cancers combined and the 4 most common cancers (NCRI, 2013a). The Irish National Cancer Control Programme (NCCP) was established in 2007 to transform the delivery of cancer care, and to ensure that cancer services meet the highest standards based on successful international models (HSE, 2014).

In conjunction with the Irish Cancer Society, the NCRI carried out a financial impact report on cancer in Ireland in 2010. There were 6 objectives that the study sought to answer and they were:

1. To describe the main elements of additional costs that are incurred by patients with cancer and their families?
2. To describe the additional expense patients incur as a result of their diagnosis of cancer?
3. To describe the impact of cancer has on income?
4. To describe the proportion of patients that incur additional costs or that experience financial difficulties as a result of their cancer diagnosis?
5. To ascertain if certain groups of people are more vulnerable to incurring additional costs or difficulties as a result of having a cancer diagnosis?
6. To describe the consequences of the additional expenses for patients and their families?

(Sharpe & Timmons, 2010)

The study was carried out in 3 stages using both qualitative and quantitative methods. These included face to face interviews with key informants and patients and a postal survey that contacted over 1300 patients with a response rate of 54%. This allowed for a triangulation method of analysis. Results were not surprising in that costs were incurred as a result of receiving a cancer diagnosis. The survey also revealed that it is not only the Irish healthcare system that incurs costs but there are additional costs for the patients and their families. The costs included travel and costs associated with being absent from work. With an average of 18,500 diagnoses annually in Ireland, this can only equate to a significant burden on Irish society (Sharpe & Timmons, 2010).

## *3.3 Cancer Registries*

### 3.3.1 History of Cancer Registries

The International Association of Cancer Registries (IACR) is a non-governmental organisation founded in 1966, with official relations to the World Health Organisation since 1979 (IACR, 2014). Their chief objective is to foster the aims and objectives of cancer registries worldwide. As all cancer registries must conform to accepted best practice and standards, as per the IACR, they must support information exchange between registries internationally, so as to improve the quality and completeness of data. The exchange of information between registries is of increasing importance when comparing prevalence of certain cancers or to see if peaks or troughs in rates are directly applicable to the same sample from another registry. This may not be relevant to the public but it allows cancer programmes to be proactive in their planning if they see a pattern developing in other countries, for example.

### 3.3.2 Functions of a Cancer Registry

A cancer registry has many functions in cancer control. Its primary role is to maintain a register of all cancers occurring within a population, defining its clinical and pathological characteristics. These are collected on a continuous basis and are systematically documented for clarity of purpose. The American National Program of Cancer Registries (NPCR) maintains that it is the registry’s responsibility to analyse and interpret the data on a routine basis to provide information on specific cancers but also to report notifable variations in incidences of cancers occurring. This information also serves to assist in the planning and evaluating of health services for the prevention, treatment and diagnosis of cancers (NCPR, 2014).

### 3.3.3 Evolution of Cancer Registries

As ICT is a presumption rather than an additional benefit in healthcare, this is linked to the rapid evolution of the importance of cancer registries. As databases are now the norm within which cancer registries operate, this has allowed for the capture of information beyond the traditional registry dataset (Parkin 2006). With this comes an expectation of good quality data and this is evaluated through assessing its completeness, timeliness and validity (Bray & Parkin, 2009). Completeness should be as close to 100% as possible so that incidence rates both within and between registries can be comparable over time to reflect true differences in cancer risk. Validity of a cancer registry may be maintained by carrying out logical and consistency checks regularly on the recorded data.

Earlier in this chapter (Section 3.3.2), it was noted that one of the functions of a cancer registry was to calculate rates of incidence in a particular area, to allow for comparison against neighbouring states or countries. This role has evolved from its basic function to include studies of cancer cause and prevention and to provide information needed for the planning and evaluation of cancer control programmes. To determine effectiveness in prevention measures, this is usually inferred from observations after the introduction of programmes (Bray & Møller, 2006). This would involve comparing expected incidence rates versus observed incidence rates which is reported via cancer registries. Data from cancer registries is often used to evaluate and monitor screening programmes and can only be correctly judged by the extent to which the objective of reduced mortality is achieved (Jemal et al, 2010).

Cancer registries are recognised as a valuable component of any cancer control programme and the expansion of registries to carry out studies that monitor factors that influence outcomes (such as survival and quality of life) highlights the requirement for a dataset that includes many variables to ensure the quality of the data being reported in studies. In the next section of this chapter, there will be in depth analysis of cancer registries that include both the

NCRI and international cancer registries. This will highlight the practical work that registries do and will also explain how other registries have integrated the public into the work that they do.

## *3.4 Case Studies*

As stated previously in Section 3.2.1, there are a reported 184 cancer registries in existence. This provided a large pool of resources from which samples were chosen to showcase registries where the NCRI may find information that would allow for further integration and collaboration with the public. The following registries were used as case studies for analysis: Australia, Canada and the United Kingdom. They are analysed under the following headings: background, function, data collection and their websites. The registries were chosen for 4 reasons:

(a) All registries report in the English language.

(b) All registries had websites that were easy to navigate.

(c) All registries were in existence for the same period of time as the NCRI, if not longer.

(d) Dr Harry Comber, Director of the NCRI, recommended the registries as examples of good quality registries.

### 3.4.1 Australasian Association of Cancer Registries (AACR)

The first case study is the Australasian Association of Cancer Registries (AACR) which is a collaborative body that represents the 8 states of Australia, the New Zealand Cancer Registry and the Australian Institute of Health and Welfare (AIHW). The Registry was formed in 1982 for the formal collection, classification and collation of cancer data and to ensure uniformity in its collection. The National Cancer Statistics Clearing House (NCSCH), which was established by the AIHW, collaborates with the AACR to coordinate national cancer statistics. (AIHW, 2013b)

### 3.4.1.1 Functions of AACR

The functions of the AACR are to:

- To analyse and report on the data in its national repository of cancer incidence and mortality statistics;
- To support research based on these data; and
- To develop and improve cancer statistics generally.

(AIHW, 2013a)

### 3.4.1.2 Data Collection and the AACR

Within the AACR, the NCSCH operates the collection of data as advised by the AACR Executive Committee. All members of the AACR (8 states of Australia and the New Zealand Cancer Registry) have their functions laid down in legislation that makes reporting of all cancers mandatory. Exempt from this piece of legislation is reporting of squamous and basal cell carcinomas. The AACR and AIHW have an agreed data set for each member to submit to annually as described in Table 3.1. The data submitted usually reports up to 3 years previous to submission date. Data from all members is loaded into one central database where they are checked for consistency and duplication. Once analysis is made of the data, it is made available for public viewing via the national website (www.aihw.gov.au). A biennial report is then published on cancer in Australia. This report includes information on cancer indigence and mortality, projections, prevalence, survival rates, burden of cancer and information on specific selected cancers. (AIHW, 2013a)

Table 3.1: Australian Cancer Database agreed minimum data set (AIHW, 2013)

| **Personal Level Attributes** | **Tumor Level Attributes** |
|---|---|
| State/territory person id number | State/territory tumor id number |
| Surname | Date of diagnosis |
| First given name | Date of diagnosis accuracy indicator |
| Second given name | Age at diagnosis |
| Third given name | ICD-O-3 topography code (a) |
| Sex | ICD-O-3 morphology code (a) |
| Date of birth | ICD-10 disease code (b) |
| Date of birth accuracy indicator | Most valid basis of diagnosis |
| Indigenous status | SLA at diagnosis |

| | |
|---|---|
| Country of birth | Postcode at diagnosis |
| Date of death | Melanoma thickness size (Breslow) |
| Age at death | Tumor size (breast cancers only) |
| Cause of death | |

(a) International Classification of Diseases for Oncology, 3rd version

(b) International Statistical Classification of Diseases and Related Health Problems, 10th Version

### 3.4.1.3 Website

Reporting cancer statistics can be found on the Australian Institute of Health and Welfare website (www.aihw.gov.au). This is a website that provides authoritative information and statistics to promote better health and wellbeing. Navigation of the website is easy. On the left side of the screen, you are directed towards statistics on various topics and this leads you to choose “Risk factors, diseases and death” which in turns allows one to choose cancer (http://www.aihw.gov.au/cancer/). This leads to a public friendly webpage depicting statistics on cancer rates, prevalence, survival rates etc. (see figure 3.1). The right hand side of the screen has a menu bar to find out further information on cancer as a disease, cancer screening programmes and links to other websites of importance. There is also a Frequently Asked Questions (FAQs) section on the site that covers general information about cancer, cancer data, accessing cancer data and screening for cancer.

### 3.4.2 Canadian Cancer Registry (CCR)

The Canadian Cancer Registry (CCR) is a collaborative approach between the 13 Canadian provincial and territorial cancer registries and the Health Statistics Division of Statistics Canada. It is an administrative database that collects information on cancer incidence from all provincial and territorial cancer registries in Canada. The registry commenced in 1992 with a primary function to produce standardised and comparable cancer incidence and survival data for each primary site of cancer (Statistics Canada, 2012).

### 3.4.2.1 Functions of CCR

The functions of the CCR are:

- To study cancer patterns and trends;
- To monitor differences in cancer risks among different populations;
- To provide information for descriptive and analytical epidemiological studies;
- To identify risk factors for cancer;
- To plan, monitor and evaluate a broad range of cancer control programs and
- To conduct research in health services and economics.

(Statistics Canada, 2012)

### 3.4.2.2 Data Collection and the CCR

The primary objective for the CCR is to provide a national database of information that may be used to produce standardised and comparable statistics for incidence and survival data for each type of primary cancer. This information is used to identify risk factors for cancer; plan, monitor and evaluate a broad range of cancer control programmes and to conduct research in health services. Data for the CCR is extracted from administrative files with each territory or province supplying data on both cancers and patients in a standard format, as described in Table 3.2. It is reported that up to 180,000 new primary tumours are recorded each year. Validity and correlation edits are performed to check that the records are in an acceptable standardised format. Specialised software is used to detect for duplicate record entries and also to check death records for death clearance. Similar to the AACR, all tumours except squamous cell carcinomas and basal cell skin cancers are reported. Annual reports are published in The Daily, which is Statistics Canadas first line of communication for the media and the public. (http://www.statcan.gc.ca)

Table 3.2: Reportable Data Items for Canadian Cancer Registry. (Statistics Canada, 2014)

| | | | | | |
|---|---|---|---|---|---|
| **Patient** | Patient reporting province/territory | CCR identification number | Current surname | Second given name | Sex |
| | Province/territory or country of birth | Date of death | Death registration number | Autopsy confirming cause of death | Date of death flag |
| | Patient identification number | Type of current surname | First given name | Third given name | Date of birth |
| | Birth surname | Province/territory or country of death | Underlying cause of death | Date of birth flag | |
| **Tumour** | Tumour reporting province/territory | Tumour patient identification number | Tumour reference number | CCR identification number | Postal code |
| | Health insurance number | Method of diagnosis | ICD010 Cancer code | ICD-0-2/3 Topography | ICD-0-2 Behaviour |
| | ICD-O-3 Behaviour Grade, diffrenciation or cell indicator | Method used to establish the date of diagnosis | Diagnostic confirmation | Date of transmission | Name of place of residence |
| | Standard graphic code | Census tract | Date of diagnosis | Source classification flag | ICD-0-2 Histology |
| | ICD-O-3 Histology | Laterality | | | |

### 3.4.2.3 Website

The Canadian Cancer Registry can be accessed by the public through the Statistics Canada website (www.statcan.gc.ca). This website publishes information on the every aspect of life in Canada from commercial, industrial, financial, social, economic and general activities relating to the people of Canada (www.statcan.gc.ca). This website is offered in both English and French. The website offers to direct different types of visitors in the ‘Site Menu’. The different types of visitors are categorised into analysts and researchers, media and survey participants. One can also browse the site by subject. Upon selecting either the survey participants section or the subject of ‘Health’, one is eventually led towards the Canadian Cancer Registry (CCR) and a detailed description of the CCR is given (See Figure 3.2). One can delve further into the CCR at this point for specific reports etc. It is not an easy website to navigate, especially if you are not quite sure what you are looking for. However, one aspect of the website is Statistics Canada official release bulletin, called The Daily, which as stated previously is the agencies first line of communication with the media and the public. The Daily issues any new releases on any current social and economic conditions (including cancer) and provides a comprehensive one stop overview of new information published by Statistics Canada. Other positive aspects of the website include links to Facebook, Twitter, and a link to chat online with an expert.

Canadian Cancer Registry (CCR)

| | |
|---|---|
| **Status:** | Active |
| **Frequency:** | Annual |
| **Record number:** | 3207 |

This is an administrative database that collects information on cancer incidence from all provincial and territorial cancer registries in Canada.

Detailed information for 2010

**Data release** - October 4, 2012 (first in a series of releases. Please refer to left sidebar under the heading "The Daily")

- Variables and definitions
- Description
- Data sources and methodology
- Data accuracy
- Documentation

Description

In 1992, the person-oriented Canadian Cancer Registry (CCR) evolved from the event-oriented National

Figure 3.1: Canadian Cancer Registry website (Source: www.statcan.gc.ca)

### 3.4.3 United Kingdom Association of Cancer Registries (UKACR)

The United Kingdom Association of Cancer Registries (UKACR) is a combination of 11 registries in the United Kingdom (UK), to include England, Northern Ireland, Scotland and Wales to allow for complete coverage of the UK for the collection of population based cancer data. (See Appendix B for a list of registries) The UKACR was formed in 1992 to align with the rapid changes in technology and the increasing demands for timely and accurate information with regards cancer incidence (UKACR, 2013a).

#### 3.4.3.1 Functions of UKACR

The functions of the UKACR are:

- To work to improve the consistency and accuracy of cancer registration data, through resolution of coding and classification issues;

- To help to ensure the availability of timely, accurate cancer statistics for England by agreeing the complex interface document for transmission of data to and from the Office for National Statistics (ONS);

- To take steps to improve quality assurance through the development of national performance indicators;

- To work to improve standards in the training of registry staff through the production of a training manual, cancer specific training packs and study days;

- To take steps to ensure patient confidentiality by developing robust guidelines for data release and

- To work to increase the usefulness of cancer registration data by implementing guidelines for the standardisation of reports and the establishment of a group for sharing the latest epidemiological research.

(UKACR, 2013a)

### 3.4.3.2 Data Collection and the UKACR

As with all cancer registries, the purpose is to collect population based data on the incidence of and survival rates for cancers. As the registry collates data from several different sources, data is required to be timely, comparable and of high quality. This is achieved by collecting information on every new diagnosis of cancer occurring in their populations. Processing of data received involves checking the validity and completeness of the data. This leads to a complex process of clinical data linkage and consolidation. In the UKACR, the number of new registrations reported each year is approximately 30,000 cases on average for every 5 million people in the regions (UKACR, 2013b). The UKACR collects a similar dataset to most other registries as detailed in Table 3.3.

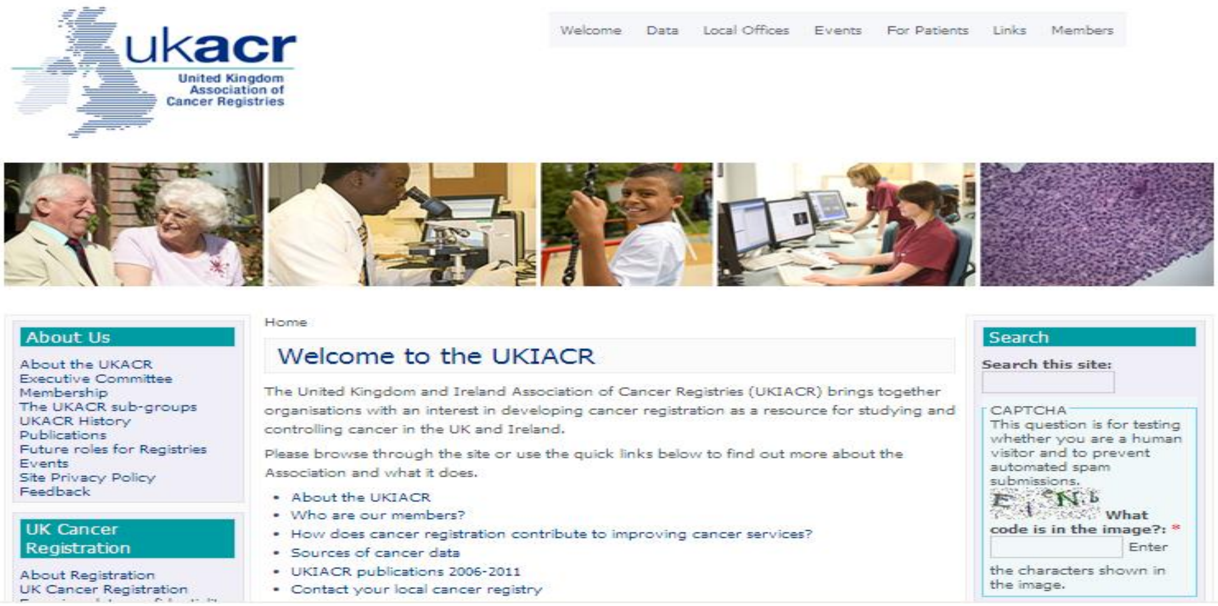
Table 3.3: UKACR Current cancer registry minimum dataset (UKACR, 2013c)

| **Core Data** | **Personal Details** | | **Diagnostic, Tumour and Treatment Details** | | **Death Details** |
|---|---|---|---|---|---|
| Hospital | NHS Number | Postcode | Site of primary neoplasm | Grade of tumour | Alive/Dead |
| Consultant (*not collected in Scotland) | Forenames | Sex | Morphology | Basis of diagnosis | Date of Death |
| Patient Unit Number | Surname | Ethnic Origin | Laterality | Date of diagnosis | Cause and place of death |
| | Name at birth(previous surname) | Date of Birth | Stage | Treatment indicators | Post mortem |
| | Address at time of diagnosis | | | | |

### 3.4.3.3 Website

Each registry that supplies information to the UKACR has its own website as does the UKACR (www.ukacr.org). The website acts a resource for studying and monitoring cancer in the UK. The homepage provides an option to browse through the website but also has collated the information into links to provide easy access around certain areas of the website (see Figure 3.3). The header of the website includes a section also for patients. This details how the UKACR has been working with patient groups in the past to ensure that patients have the appropriate information, for instance, at time of diagnosis. The UKACR have produced a leaflet that is written in Plain English and is also approved by the Centre for Health

Information Quality (CHIQ)[1] and is also accompanied by a FAQs section that may be downloaded. Further to this is suggested links and advice to contact local Registries with any further questions.



Welcome to the UKIACR

The United Kingdom and Ireland Association of Cancer Registries (UKIACR) brings together organisations with an interest in developing cancer registration as a resource for studying and controlling cancer in the UK and Ireland.

Please browse through the site or use the quick links below to find out more about the Association and what it does.

- About the UKIACR
- Who are our members?
- How does cancer registration contribute to improving cancer services?
- Sources of cancer data
- UKIACR publications 2006-2011
- Contact your local cancer registry

This question is for testing whether you are a human visitor and to prevent automated spam submissions.

Enter the characters shown in the image.

Figure 3.2: United Kingdom Association of Cancer Registries (Source: www.ukacr.org)

### 3.4.5.1 Functions of NCRI

The legislative functions, as reported by the NCRI include:

- The identification, collection, classification, storage and analysis of information relating to the incidence and prevalence of cancers in Ireland.
- The collection, classification, recording and storage of information in relation to each newly diagnosed individual cancer patient and each tumour that occurs.

---

[1] **The Centre for Health Information Quality (CHIQ) was established in 1997 by the UK government's Department of Health. CHIQ acts as a clearing house for all aspects of patient information, providing practical advice to the UK National Health Service (NHS) and others about the production of good quality information for patients.**

- The promotion and facilitation of the use of data that is collected for research for the planning and management of services.
- The publication of an annual report.

(NCRI, 2013b)

### 3.4.5.2 Data Collection and the NCRI

Data collection within the NCRI is a manual process carried out by trained Tumour Registration Officers (TRO), who work in hospitals around Ireland to access local data sources to obtain and register all relevant patient, tumour and treatment details. Approximately 85% of notifications are from pathology reports and are registered manually by the TRO's. Information is also obtained through the Hospital Inpatient Enquiry System (HIPE), radiology/oncology departments, medical charts and hospital databases. These account in total for approx 95% of all registrations. Death certificate data accounts for the remaining 5% and this is supplied by the Central Statistics Office (CSO). Figure 3.4 represents the registration process that takes place within the NCRI. TROs will continue to check and update data sources for further data to ensure completeness of data that is reported. This includes patient data, treatments, staging and other tumour data. This is termed as the 'Local Processing' Stage. It is at this stage that merging and checking for quality assurance takes place to ensure completeness in reporting of data and once this is assured, reporting and analysis can take place.

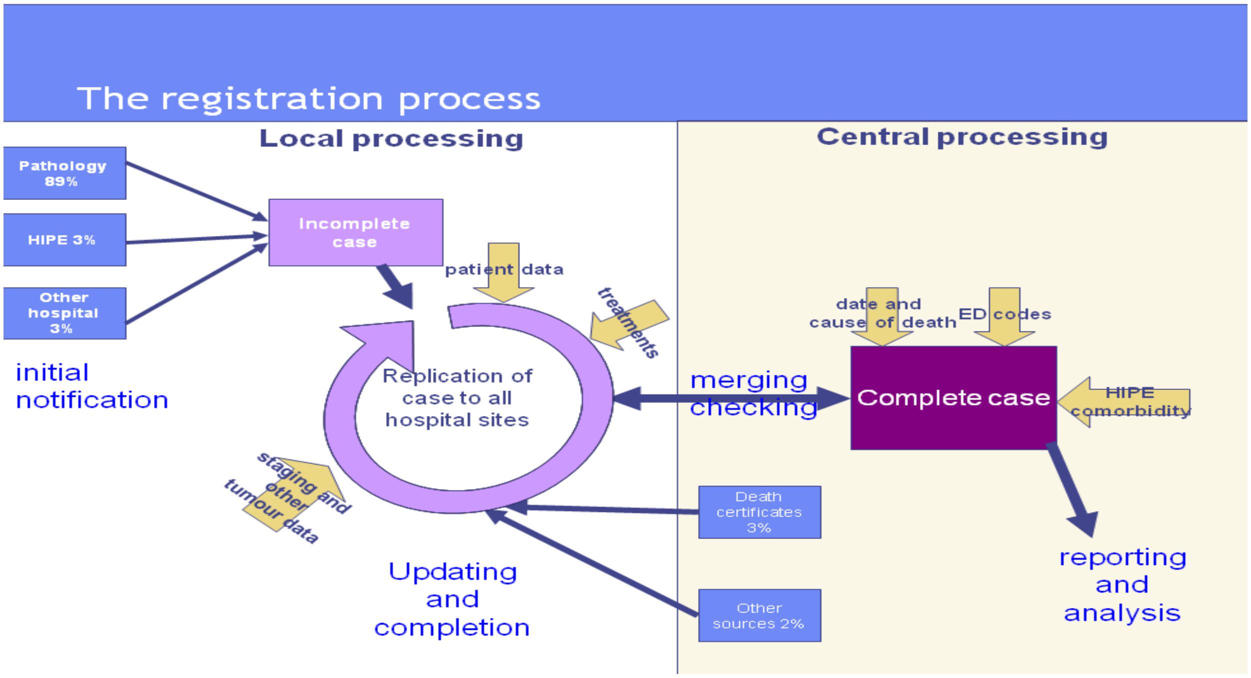


Figure 3.3: NCRI Data Collection (Comber, 2010)

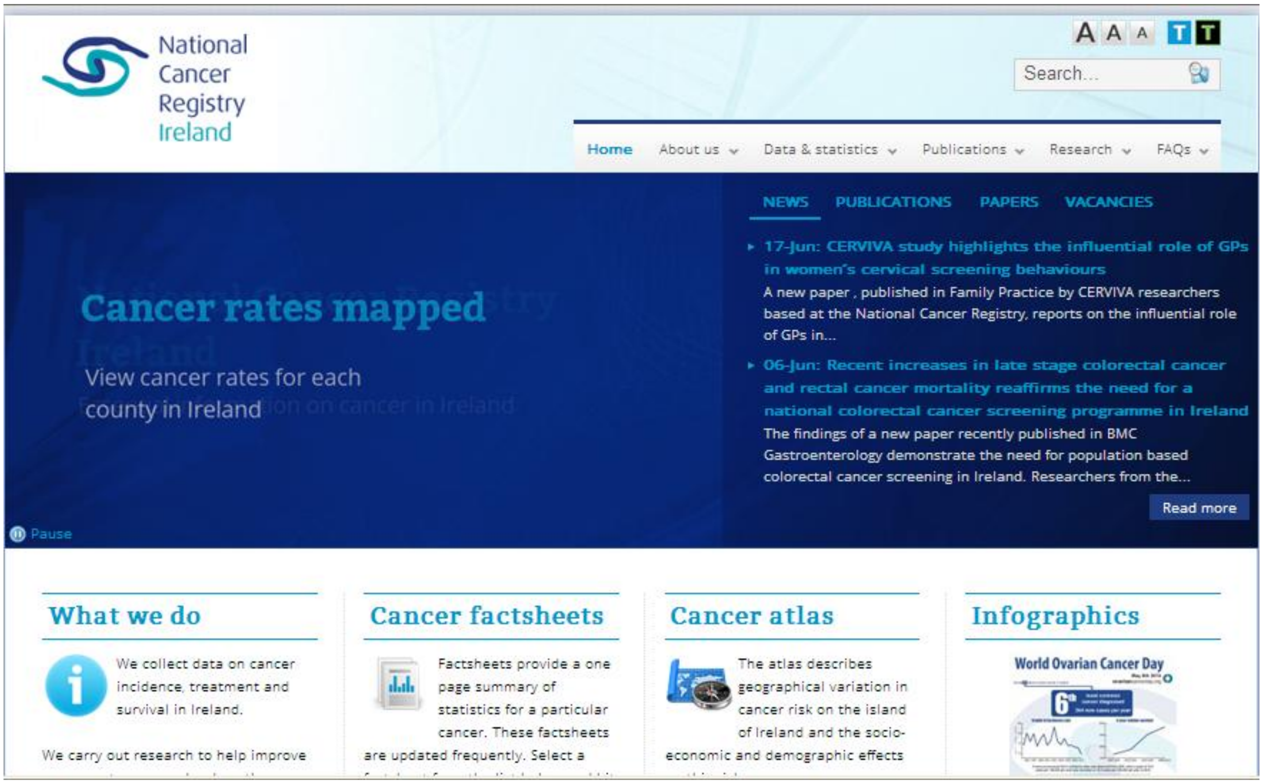
As case checking and quality assurance along with obtaining data from other sources can take some time, the NCRI normally produces definitive statistics 2-3 years following the end of year of diagnosis. This indicates that data reported in 2014 is relevant to 2011-2012. Cases are coded as per the International Classification of Diseases for Oncology (ICD-O3) and case data is recoded according to the International Classification of Diseases Version 10 (ICD10). Table 3.4 shows a selection of the data that is recorded by the NCRI in their dataset. (NCRI, 2012)

Table 3.4: Selection of data recorded by the NCRI (NCRI, 2013)

| **Fieldname** | **Description** |
|---|---|
| ID | Randomly generated number for each data request |
| MARITAL | Marital status |
| SMOKER_ID | Current (c), Never smoked (n), Ex smoker (x), Unknown Z) |
| GEOGRAPHICAL UNIT | County |
| DEAD | Dead (d), Unknown (z), Alive (a) |
| TOPOG | Site of primary tumour; ICD-O-3 code |
| MORPH | Histological type of tumour; ICD-O-3 code |
| MDESC | Morphology description |
| BEHAVE | Benign (0), Uncertain (1), In situ (2), Invasive (3) |
| GRADE | Histological grade |
| ICD10 | ICD10 code |
| SUMSTAGE0 | Summary stage based on AJCC version 5 |
| YOI | Year of incidence |
| AGE_GROUP | 0-14; 5-9; 10-14; 15-19; up to 85+ |
| SEX | Sex of patient |
| MTDPRES | Symptoms (s), Screening (c), Incidental (i), Unknown (z), Autopsy (a) |
| MICROVER | Microscopic verification Yes (y), No (n), Unknown (z) |

### 3.4.5.3 Website

The NCRI is accessed through www.ncri.ie. The website is available with different text lettering and visual impairment themes for those who require it. The website provides information in what they do, and advises that they collect data on cancer incidence, treatment and survival in Ireland. It also states that they carry out research to help improve cancer outcomes and reduce the cancer burden. They publish an annual report along with cancer factsheets and recent publications. There is a link provided to various different cancer factsheets where a member of the public can choose the type of cancer they wish to learn about and this includes key facts, profiling, trends and survival rates. They also advertise their links to social media including Twitter and LinkedIn (See Figure 3.5). The site is easy to navigate and is includes several dropdown menus for information about the NCRI, Data and Statistics, Publications, Research and FAQs. There is no resource identified for patients or members of the public to access information about the data available on the NCRI. However, the FAQ section covers any information to do with the website.



Cancer rates mapped

View cancer rates for each county in Ireland

- 17-Jun: CERVIVA study highlights the influential role of GPs in women's cervical screening behaviours
  A new paper , published in Family Practice by CERVIVA researchers based at the National Cancer Registry, reports on the influential role of GPs in...
- 06-Jun: Recent increases in late stage colorectal cancer and rectal cancer mortality reaffirms the need for a national colorectal cancer screening programme in Ireland
  The findings of a new paper recently published in BMC Gastroenterology demonstrate the need for population based colorectal cancer screening in Ireland. Researchers from the...

We collect data on cancer incidence, treatment and survival in Ireland.

We carry out research to help improve

Factsheets provide a one page summary of statistics for a particular cancer. These factsheets are updated frequently. Select a

The atlas describes geographical variation in cancer risk on the island of Ireland and the socio-economic and demographic effects

Figure 3.4: National Cancer Registry Ireland (Source: www.ncri.ie)

## 3.5 Conclusion

It was necessary to establish the information that was available surrounding registries in a separate chapter to the literature review as this chapter focused on what not only the 4 different registries but also the raison d'être for their existence, which is the prevalence of cancer worldwide. It was shown that Ireland is comparable in its financial impact on families when receiving cancer treatment and as a result the public require to be informed as to how they can deal financially with the burden of cancer.

There were 4 different registries analysed under 4 headings which were background, function, data collection and their website content. Similarities were apparent in all 4 registries in their background and dataset required. As the NCRI carries out a manual process of collecting data, it is evident that there could be a more efficient way to collecting such vast amounts of information and this became apparent in the analysis. As Ireland has released its eHealth Strategy, now is time to consider ways in which the resource-intensive manual process of data collection in the NCRI with more automated processes.

Further to this, the registries that were includes in the review (Australia, UK, Canada and the NCRI), have no specific plans to integrate the public into their work. The information that is released and reported on is, in general, to inform for service planning, financial planning etc. Attempts by the UKACR are notable in their website with valuable information and easy access offered to all information.

To summarise, both the literature review and the registries chapter together are important as they provide the motivation for increasing the relevance of patient registries for the public. Patient empowerment through use of information is key to the success of health system reform in Ireland. The literature review highlighted data collections and its governance structure in Ireland, patient registries and the EU PARENT project as a means of joining a European wide registry of registries to ensure cross border secondary use of data. Further to this, the significance of the eHealth Strategy being published was discussed and what this will mean for Ireland going forward in a system reform for healthcare and ICT. Health literacy is central to tying together the strands of involving the public in being enabled to take responsibility for their own health through the use of information. This is shown by the central role that it is taking in implementing the Healthy Ireland framework to help improve the health and wellbeing of the population of Ireland over the course of the coming generations.

In order to bring change to any system, the essential area of data quality must be addressed. If the quality of the data is not of a high standard, then failure to progress can only be assumed. This is why the NCRI, as a registry, can be used as an excellent example of a data collection system that has its functions and systems at a high standard that will allow for data to be collected and used again. It is hoped that by augmenting the literature review with the review of the registries, that it is clear to see that there is justification to the argument of using the NCRI as an example for involving the public through the use of high quality health information in a meaningful and sustainable way.

The literature review has highlighted that by not involving the public, registries are missing an important opportunity to enhance the use of the information, and governments are missing the opportunity which these valuable data collections offer for patient empowerment and health promotion. With the review of literature having taken place, it was necessary to construct a methodology of research that would allow for further examination of the knowledge gap in data collections but also to augment the argument for increasing the relevance of health information for the public. Chapter 4 will discuss the research methodology that was undertaken for the final part of the dissertation.

# Chapter 4 Research Methodology

## 4.1 Introduction

*"Research is to see what everybody else has seen and to think what nobody else has thought"*

*Albert Szent-Gyorgyi (1893-1986)*

This chapter outlines the methodology that was used to answer the research question outlined in Chapter 1. The research entailed exploring the potential further uses of a national information source such as the NCRI and to recognise the increased relevance such information can have for the public and how this might happen. The logic for choosing the qualitative approach to the research undertaken is examined and explained following the definition of the objectives of the research carried out. The rationale also underpins the philosophy behind the research methodology which is to merely question a valuable commodity already in existence.

Following the analysis over the type of data collection used, there will be a discussion on the decision to carry out a thematic analysis on the data. The ethical and legal implications of using people for interviews are discussed and the procedure for obtaining ethical approval will be explained. It is necessary when discussing the research and types of research that have taken place, that the limitations of undertaking this method of research must also be acknowledged.

## 4.2 Research Methodology

For the purposes of the completion of the dissertation, research commenced once the subject matter was chosen. Background research was required at the beginning to determine if carrying out an investigation into a named national information source was a worthwhile topic. The initial assessment of what was required to be achieved and how it could be solved determined the methodology that would be used. The research involved several different stages that were mapped out for clarity that allowed the researcher maintain a degree of control over the project. The stages are identified in Figure 4.1.

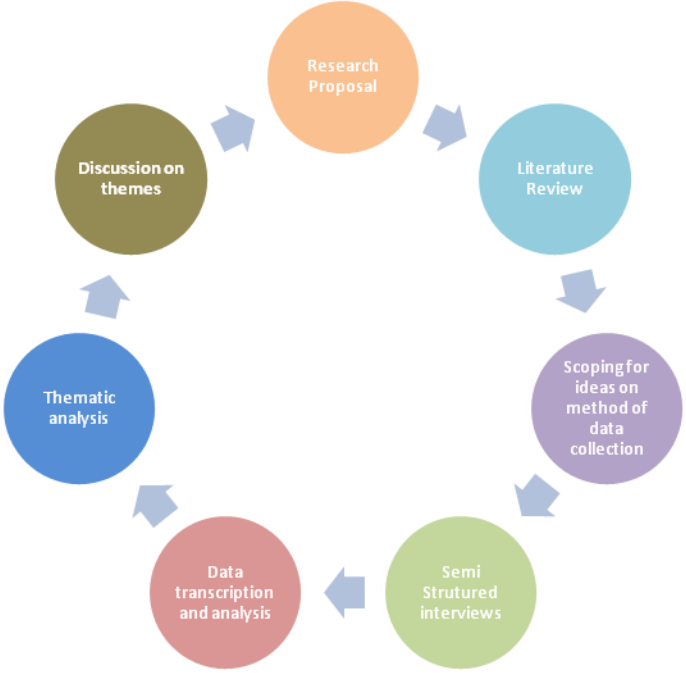


Figure 4.1: Stages of Research Methodology

The research question that is posed in Chapter 1 was: *How can the public relevance and use of a data collection, such as the NCRI, be increased?* This question prompted the questioning of the motivation behind the research. The research question poses a philosophical stance as to what the question actually infers? By looking at keywords such as ‘relevance’ and ‘data collection’, this determined that rather than analysing data in a quantitative manner, it was more appropriate to capture the thoughts of identified relevant stakeholders in a qualitative approach. The qualitative approach is appropriate as the aim of the dissertation is to use international registries, similar to the NCRI, to provide for a set of recommendations and this will be based on the experiences and thoughts of others which cannot be evaluated numerically.

### 4.2.1 Qualitative Research

For the purposes of the dissertation, it was decided to approach the research from a qualitative perspective. Qualitative research is defined as:

"*… any research that uses data that do not indicate ordinal values"* (Nkwi, et al, 2001).

Other interpretations offered on what qualitative research is, include: "*…is aimed at gaining a deep understanding of a specific organisation or event, rather than a surface description of a large sample of a population. It aims to provide an explicit rendering of the structure, order, and broad patterns found among a group of participants. It is also called ethnomethodology or field research."*(California State University, 2014) The advantages of carrying out this type of research included allowing the researcher the freedom to carry out interpretative semi - structured interviews. It also allows for the assimilation of not only the results of the field studies but also the interpretation of what was researched in the literature review carried out for the purposes of the dissertation. Academics have documented the advantages of qualitative data which are listed in Table 1 (University of South Alabama, 2014). It was found that the qualitative approach allowed for diversion in carrying out the research; for example, if during an interview a valuable point was made, the qualitative process allowed for further secondary research to take place for the purposes of the literature review and therefore a degree of flexibility enhanced the overall output of the dissertation

Table 4.1: Advantages of Qualitative Research (Source: University of South Alabama, 2014)

| **Advantages of Qualitative Research** | |
|---|---|
| Data based on the participants' own categories of meaning | Data are usually collected in naturalistic settings in qualitative research |
| Provides individual case information | Qualitative approaches are especially responsive to local situations, conditions, and stakeholders' needs |
| Can conduct cross-case comparisons and analysis | Qualitative date in the words and categories of participants lend themselves to exploring how and why phenomena occur |
| Provides understanding and description of peoples personal experiences of phenomena i.e. the emic or insider's viewpoint) | |

## *4.3 Role of literature review and analysis of Registries*

The literature review (Chapter 2) and registry analysis (Chapter 3) serve to function as a foundation to the primary piece of the research, which is the interview process and analysis of the data collected from the interviews. It frames the discussion and provides context to questions. Yin (2009) describes how a literature review is not only concerned with finding out what is already known on a topic but it also serves to allow the researcher to use the literature to develop more worthwhile and insightful questions. The importance of national information sources, data collection, health literacy and patient empowerment are an example of some of the keywords that were used in the formation of the literature review as discussed in Chapter 2. Chapter 3 analysed 4 different registries including the NCRI by looking at their background, functions, data collection methods and also their website. The vast amount of information that was gained from these 2 chapters was necessary to provide a clear direction for the primary research and thus shows the reasoning why it necessitated taking such a large section of the dissertation.

## *4.4 Semi – Structured Interviews*

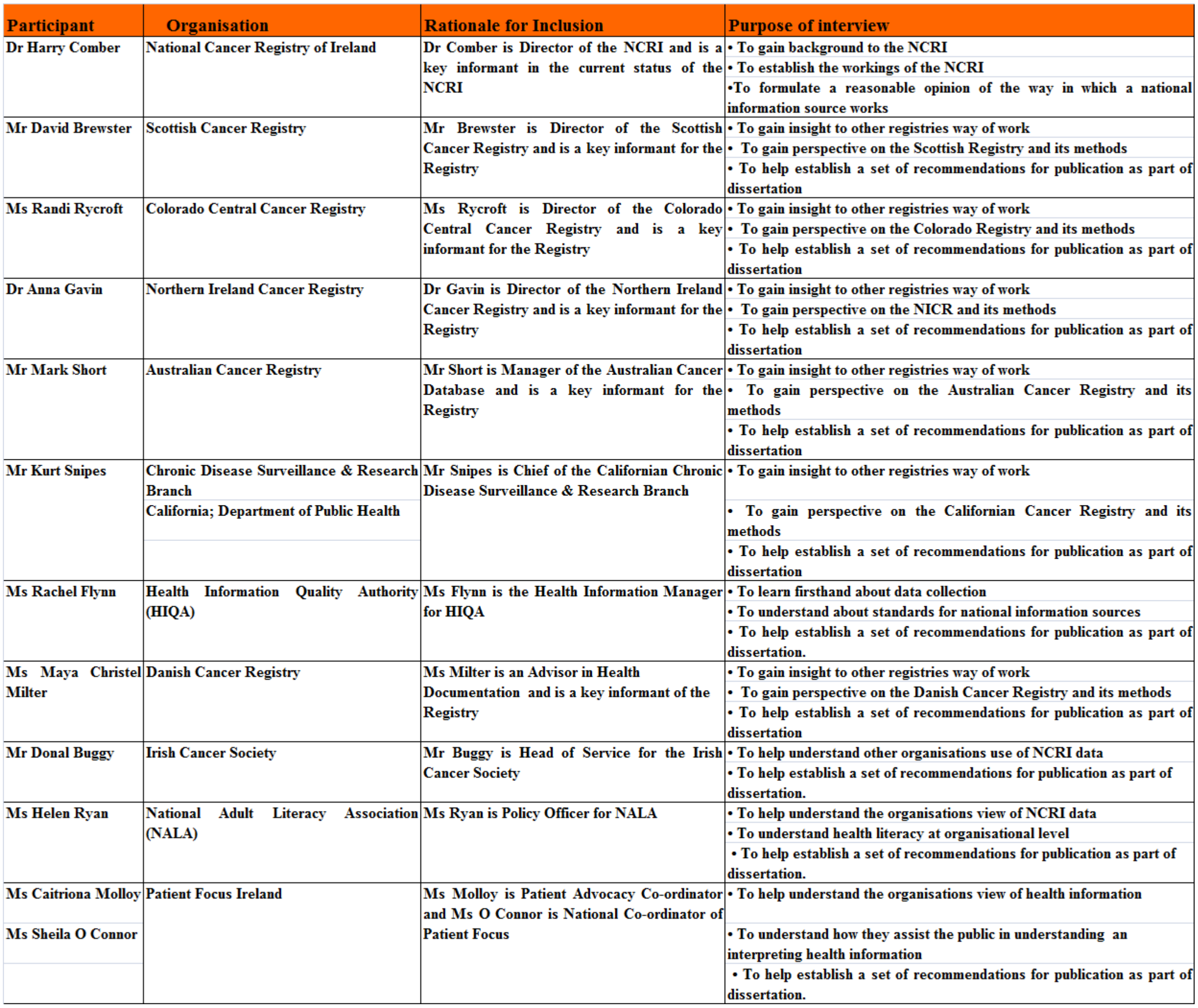
### 4.4.1 Selection of interview participants

Table 4.2 identifies the participants who were contacted for interview either in person, by phone or by email. The justification for choosing to contact each participant is identified and the rationale for the interview is explained. It is worth noting that the outcome of the interview quite often differed from the initial intended interview outline.

### 4.4.2 Interview Process

Kvale (1996) described a qualitative research interview as seeking to describe what is in place and to discover the meanings of the central themes in the world surrounding the subject or interviewee. Interviews are common practice in data collection and especially for collecting qualitative data. The main objective of the interviewer is to determine the meaning of what the interviewee has said. The type of interview technique that was chosen to interview participants was the semi - structured interview.

Table 4.2: Interview Participant Table



| Participant | Organisation | Rationale for Inclusion | Purpose of interview |
|---|---|---|---|
| **Dr Harry Comber** | **National Cancer Registry of Ireland** | **Dr Comber is Director of the NCRI and is a key informant in the current status of the NCRI** | **• To gain background to the NCRI<br>• To establish the workings of the NCRI<br>•To formulate a reasonable opinion of the way in which a national information source works** |
| **Mr David Brewster** | **Scottish Cancer Registry** | **Mr Brewster is Director of the Scottish Cancer Registry and is a key informant for the Registry** | **• To gain insight to other registries way of work<br>• To gain perspective on the Scottish Registry and its methods<br>• To help establish a set of recommendations for publication as part of dissertation** |
| **Ms Randi Rycroft** | **Colorado Central Cancer Registry** | **Ms Rycroft is Director of the Colorado Central Cancer Registry and is a key informant for the Registry** | **• To gain insight to other registries way of work<br>• To gain perspective on the Colorado Registry and its methods<br>• To help establish a set of recommendations for publication as part of dissertation** |
| **Dr Anna Gavin** | **Northern Ireland Cancer Registry** | **Dr Gavin is Director of the Northern Ireland Cancer Registry and is a key informant for the Registry** | **• To gain insight to other registries way of work<br>• To gain perspective on the NICR and its methods<br>• To help establish a set of recommendations for publication as part of dissertation** |
| **Mr Mark Short** | **Australian Cancer Registry** | **Mr Short is Manager of the Australian Cancer Database and is a key informant for the Registry** | **• To gain insight to other registries way of work<br>• To gain perspective on the Australian Cancer Registry and its methods<br>• To help establish a set of recommendations for publication as part of dissertation** |
| **Mr Kurt Snipes** | **Chronic Disease Surveillance & Research Branch<br>California; Department of Public Health** | **Mr Snipes is Chief of the Californian Chronic Disease Surveillance & Research Branch** | **• To gain insight to other registries way of work<br>• To gain perspective on the Californian Cancer Registry and its methods<br>• To help establish a set of recommendations for publication as part of dissertation** |
| **Ms Rachel Flynn** | **Health Information Quality Authority (HIQA)** | **Ms Flynn is the Health Information Manager for HIQA** | **• To learn firsthand about data collection<br>• To understand about standards for national information sources<br>• To help establish a set of recommendations for publication as part of dissertation.** |
| **Ms Maya Christel Milter** | **Danish Cancer Registry** | **Ms Milter is an Advisor in Health Documentation and is a key informant of the Registry** | **• To gain insight to other registries way of work<br>• To gain perspective on the Danish Cancer Registry and its methods<br>• To help establish a set of recommendations for publication as part of dissertation** |
| **Mr Donal Buggy** | **Irish Cancer Society** | **Mr Buggy is Head of Service for the Irish Cancer Society** | **• To help understand other organisations use of NCRI data<br>• To help establish a set of recommendations for publication as part of dissertation.** |
| **Ms Helen Ryan** | **National Adult Literacy Association (NALA)** | **Ms Ryan is Policy Officer for NALA** | **• To help understand the organisations view of NCRI data<br>• To understand health literacy at organisational level<br>• To help establish a set of recommendations for publication as part of dissertation.** |
| **Ms Caitriona Molloy<br>Ms Sheila O Connor** | **Patient Focus Ireland** | **Ms Molloy is Patient Advocacy Co-ordinator and Ms O Connor is National Co-ordinator of Patient Focus** | **• To help understand the organisations view of health information<br>• To understand how they assist the public in understanding an interpreting health information<br>• To help establish a set of recommendations for publication as part of dissertation.** |

Semi - structured interviews are usually pre-organised with the interviewer listing a set of pre-determined questions that will allow for other questions to emerge naturally as a result of an answer given by the participant. They are the most widely used interview format for qualitative research (Britten, 1995 & Dicicco-Bloom et al 2006). The main advantage for using the semi - structured interview method for completion of this dissertation was due to the fact that the interviewer was not an expert in the field of national information sources (i.e. cancer registries) or data collection. As the participants were all experts in their own areas, this allowed for variations in questions asked and this maintained the fluidity of the interviews. This provided a more relaxed environment for all participants thus ultimately gaining a more robust and candid script for examination at analysis stage.

The candidates were identified for interviewing at the time of the literature review stage and initial contact was sought with some participants to gain an informal perspective of a national information source and cancer registries. Prior to contacting any of the international registries or other participants, websites were consulted to gain a broad overview of their work while avoiding possible bias prior to interviewing. Interviews were carried out in stages either in person, on the phone or via email. It was decided to interview 2 participants first and review the questions posed post same and then all interviewees were contacted and interviews were set up over a period of approximately 2 months. Interviews that were carried out in person were recorded on a Dictaphone and were transcribed *verbatim.* The transcripts were sent to the participants for review, commentary and sign off.

## *4.5 Ethical and Legal Consideration*

Ethical approval was sought and obtained from Trinity College Dublin as part of course requirements for completion of the dissertation. This was obtained following one change to the application submitted. Participants were each given an information sheet, informed consent form and a list of intended questions that were all approved in advance (see Appendices C, D and E, respectively). The list of questions helped to the interviewees to prepare for the interviews which in turn led to a more constructive dialogue. The semi - structured nature of the interviews allowed for the conversation to flow and to be contained or redirected where necessary. This also proved beneficial in the openness and transparency aspect of the interviews.

## *4.6 Conclusion*

Chapter 4 covered the methodology that was employed in the primary research that took place for this dissertation. The benefit of qualitative research was examined along with the importance of the literature review and the analysis of registries. The value of semi - structured interviews was discussed and a rational process was employed for all of the participants involved. The interview process that took place was described in detail as the final part of the research process.

It is important to acknowledge the challenges faced when employing a triangulation method of research which involved the literature review, analysis of registries and an interview process with 11 participants. However, it is encouraging to note that this method of research is found to increase the strength and validity of the data and findings (Creswell, 2009). The results that arose from this research are presented in Chapter 5.

# Chapter 5 Results and Evaluation

## *5.1 Introduction*

In this chapter, the results from the semi structured interviews carried out over the course of the research study are presented and analysed. The recommendations from the qualitative study are then explored and the steps taken to describe the findings are presented. The study involved identifying individuals from varying professional organisations that included national and international registries, regulatory bodies and advocacy groups. Semi structured interviews were carried out with these individuals to allow for a more complete capture of information and to enhance the quality of data that could be obtained by the researcher alone.

## *5.2 Conducting a Thematic Analysis*

For the purpose of this dissertation, the approach of conducting a thematic analysis was considered necessary to gain the desired results. Joffe (2011) describes how thematic analysis can be viewed as a process for encoding qualitative information. Themes can be sensed through, in this case, the answers given in the semi structured interviews. This is the first step in conducting the process of a thematic analysis.

### 5.2.1 Semi-structured interviews

Over a period of two and a half months, from late February 2014 to early May 2014, a total of 11 stakeholders were interviewed, either face to face or by email. Due to the international context of some of the interviews, it was felt that the interview would be more appropriately carried out by sending a list of questions to be answered. This decision was made to accommodate time constraints of both the researcher and the international participants but also to increase the quality and content of the data being provided. This resulted in almost a 50/50 breakdown of face to face and email interviews. See Table 5.1 for the breakdown of type of interview environment for each participant.

Table 5.1: Types of interviews carried out

| Face to face Interviews | Email Interviews |
|---|---|
| Dr Harry Comber, National Cancer Registry Ireland (HC) | Mr Randi Rycroft, Colorado Cancer Registry (RR) |
| Ms Rachel Flynn, Health Information Quality Authority (RF) | Mr Mark Shortt, Australian Cancer Registry (MS) |
| Ms Helen Ryan, National Adult Literacy Agency (HR) | Mr David Brewster, Scottish Cancer Registry (DB) |
| Mr Donal Buggy, Irish Cancer Society (DB) | Ms. Maya Christel Milter, Danish Cancer Registry (MCM) |
| Ms Sheila O Connor, Patient Focus (SOC) | Dr Anna Gavin, Northern Ireland Cancer Registry (AG) |
|  | Mr Kurt Snipes, Californian Cancer Registry (KS) |

### 5.2.2 Data Analysis

In preparation for each interview, research was carried out into each organisation to tailor the questions appropriately in order to gain as much relevant information as possible to inform the recommendations but also in order to identify further research and analysis where required. Questions were emailed in advance to the interviewees to allow them to prepare for the interview in order to increase the quality of the answers but also for reassurance that there were no conflicting or vested interests on the researchers behalf that may conflict with their own organisations ethos.

For each interview, the researcher also sent an information sheet (see Appendix C) to inform the participant of the nature of the dissertation. Each participant was also asked to sign a consent form to acknowledge that they had agreed to participate but also to ensure that the information received in the course of the interview would be treated as identified in the consent form and as approved by the Ethics Committee of Trinity College Dublin. As the scripts from the 6 emailed interviews were received, they were catalogued with their consent forms for thematic analysis at a later stage. The 5 face to face interviews took place over a period of time to allow for the researcher to travel and meet each participant individually. The researcher recorded each interview, with the participant's permission, on a Dictaphone. The interview was then transcribed *verbatim* onto an MS Word® document and sent to each participant for review and amendment as appropriate. This allowed the participants to maintain a degree of control over their contribution and to ensure validity of the work being carried out.

Once all interviews were received, they were compiled into one large document for ease of reading for the researcher. There were several stages involved in conducting the thematic analysis. First, a read though of all interviews was carried out to gain a general sense of what was being asked and also what was being answered in the interviews. Figure 5.1 describes the questions or subjects that were asked or covered in the interviews.

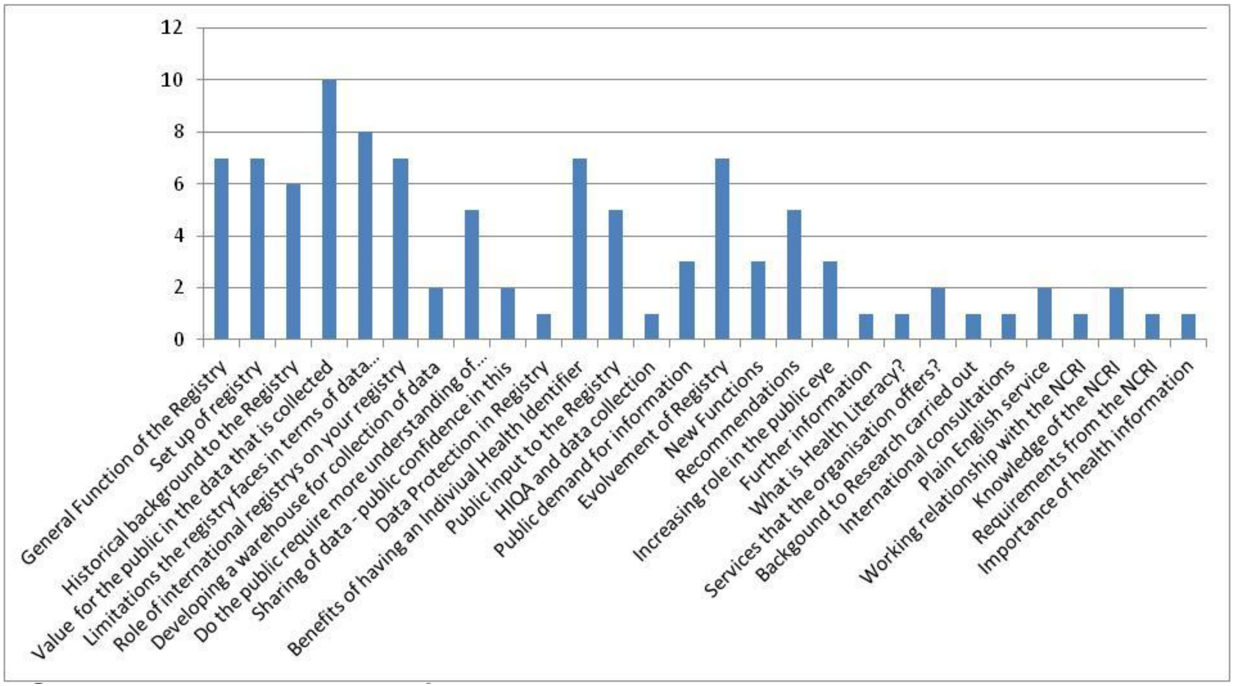


Figure 5.1: Questions/Subjects covered in interviews

As the numbers of participants were limited to 11, the data that was captured was small enough to be analysed manually using MS Excel® and MS Word®. As above, the questions were categorised by the subject matter covered and it is evident that some participants did not answer questions that may have not been relevant to them. Details are to be found in Appendix F.

It was then necessary to re-read the interviews to identify possible recommendations and highlight them as appropriate. If a rationale or some explanatory commentary was given then this was also highlighted for future reference. At this stage, recommendations were emerging from the interviews and these needed to be categorised along with the commentary and the source. Details are given in Appendix G. Table 5.3 shows the final set of recommendations that are proposed from the interviews that were carried out. There are 7 recommendations contained within Table 5.3, however it is apparent that some of the recommendations are not relevant to the research question. For example, Recommendation No 6: To secure public funding to support the procurement of a public health genomics coordinator. However, as it was a finding from one of the interviews with one of the international participants, it was decided to include in the provisional list as detailed below. Following an analysis of the recommendations, it was decided that the first 3 recommendations would be taken forward as they were deemed by the researcher as the most relevant to answering the research question.

Table 5.2: List of Recommendations arising from interviews

| **Recommendations for Evolvement of the NCRI** | |
|---|---|
| **Recommendation No 1** | Patient engagement through inviting members of the public to represent patients on an advisory council. |
| **Recommendation No 2** | Run an information campaign about a national information source using the NCRI as an example |
| **Recommendation No 3** | Work with a national information source to make it more health literacy friendly e.g. through the Plain English service |
| **Recommendation No 4** | Train staff in Cancer centres of Excellence in data collection for the a cancer registry |
| **Recommendation No 5** | Move all National Information Systems under one roof i.e. to a data warehouse by sharing the IT infrastructure |
| **Recommendation No 6** | Secure public funding to support the procurement of a public health genomics coordinator |
| **Recommendation No 7** | Ireland should have an Individual Health Identifier |

## *5.3 Discussion of Results*

### 5.3.1 Recommendation Number 1

**Patient engagement through inviting members of the public to represent patients on an advisory council.**

*"Patients would be better informed to respond to consultations about legislation in relation to cancer registries."(AG)*

The Northern Ireland Cancer Registry (NICR) provided valuable commentary to advise of the inclusion of patient representation on the NCRI council. Currently, the governance of the NCRI comprises of NCRI staff members, representation from another registry and the Department of Health. The statutory functions of the NCRI, as previously identified in Chapter 3, relate to collation and reporting of information, promoting the use of data and planning and management of services. These are functions that greatly affect the public in how they are controlled and enforced.

The NICR has created strong links with the public. They have highlighted through their website that they involve patients in various sectors of the work in the registry and one area is through having "lay" representation on the Council of the NICR. The Council is appointed by the steering group and they advise the Director and the steering group on any matters arising within the NICR, particularly the outputs. It provides a mechanism for the Registry to link with key stakeholders annually.

AG suggested that having patient representation on the registries council would be beneficial to the NCRI and are already engaging well with the public as the NCRI already has an excellent website and the quality of the material they produce is very high. AG commented on some of the ways the patient involvement in the NCRI council could work would be through "*including patients in specific steering group projects or involving patients in the development of their reports and launches*".

In Chapter 2, the case for empowering the patient through information was discussed. This can be the perfect opportunity to support this. WHO (2009) confirmed that if the public can understand the information that they are being presented with, then it is possible that involving the public in the NCRI could help change health behaviours. Coulter et al (2008) wrote how health systems across Europe are searching for ways to making the services more responsive to the patients through patient engagement. The positive effects this can have include: understanding the cause of diseases and the factors that influence health and also adopting healthy behaviours to prevent the outcome or occurrence of a disease. The Healthy Ireland 2013 framework has reiterated this as it established one of its high level goals to be achieved "*To create an environment where every individual and sector of society can play their part in achieving a Healthy Ireland". (Dept of Health, 2013c)*

It is necessary as part of the engagement process with the public to understand the fears of the public about data collections. Most likely, it is that they do not know what data is being passed to whom and to where and then what is done with this data. This is why direct involvement by the public could allow for understanding as to why data is collected and that it is only collected for the reason which is stated in a data collections objectives. This is due to the requirements of data protection. Haymon (2014) wrote that understanding data collections adds context to an argument and that it allows people accessing the data collection to make decisions thus improving the overall system. Through the interview process, this recommendation arose with KS who stated that *"Limitations of data collections are not well understood by the public and this would be a good opportunity for the public to engage in a data collection".* HIQA have used the Guiding Principles for National and Social Care Data Collections to address this issue (HIQA, 2013). The document defined under its principles that any data collection should have a clear statement of purpose and a clear set of objectives to govern the collection. This document provides an avenue in which the public can have confidence in the transparency and validity of health data collections reported in Ireland.

The NCRI have a well established system in place since the early 90s to run the registry and produce reports as required. There is now a requirement to understand that the public are not willing to accept being given edited versions of data. There is now an expectation to show where the information was received from and why it was obtained in the first place. In an unprecedented move by the European Court of Justice, a decision was passed that members of the public can have any mention of themselves removed from the internet and this may have repercussions on data collections. (European Court of Justice, 2014)

### 5.3.2 Recommendation Number 2

**Run an information campaign to inform the public about the NCRI**

*"Public education is a good strategy because it may demystify what a cancer registry is and what it does for the public good." (RR)*

The above recommendation is particularly interesting because there was some disagreement amongst the interviewees as to the benefits of an information campaign solely for informing the public about the workings of a national information source like the NCRI. HC conveyed his thoughts stating "*We have such regular exposure in the media and we are also quoted a lot in the newspapers, therefore I don't see a requirement for a public campaign".* However, it is important for the public to understand what a registry is and why data is collected on cancers for the whole population of Ireland, where the data comes from and how it is used. MS agreed with HC stating that "*As cancer is a notifiable disease...therefore data collection is legally required and there is no opt out mechanism...greater engagement of the public would not help to improve the quality of cancer incidence data collected in Australia".* It is perhaps surprising that as cancer is a notifiable disease, there ought to be a general awareness among the public as to why data must be collected on the disease. It is not acceptable to work on the presumption that as there is no opt out clause then there is no need to tell people what you are doing. HIQAs Guiding Principles document provides evidence to this effect under Principle 2 which states that *"The managing organisation of the national health and social care data collection maintains a publicly available statement of purpose, setting out how it will achieve its stated objectives".* Principle 5 states that *"The information produced by the national health* *and social care data collection is accessible to data users in line with legislation and disseminated to optimise its benefit.”*

KS commented that *“It will lead to increased trust by the public when registry is responding to community cancer concerns. Within our ageing population that is living longer there will be more public concerns about cancer in the communities and the workplace”.* The NCRI carry out research on cancer clusters in certain areas and report as appropriate. Comber (2012) indicated that possible clusters are identified when someone notices that there may be an abnormal rate of cancer occurrence in one area. This is a reactionary method of responding to the public requests for information. There is a need to use the high quality source of information that the NCRI obtains to inform the patient of cancer incidence per area.

Communication is an integral part of ensuring public confidence in data collection and is necessary to gain trust to support the use of data. This was emphasised by DB who commented that “*To explain how data is collected, looked after and used in the public interest to help engender trust) and support for the legitimate uses of the data”* and that *“it helps patients understand the flow of information”.* There is valuable and high quality information being collected by the NCRI and it is being reported on very effectively. The NCRI produces report on 5 year survival rates from cancer and if this information was to be presented to the public alongside information about a prevention campaign, for example, this may act as a combined force to encourage people to partake in their own health and wellbeing. This means using the data to prove why the public should take control of their health by being aware of the information that is in place.

Bouchardy et al (2014) carried out a study on the Geneva Cancer Registry to identify how data collected for the purposes of a cancer registry may be used to improve the quality of care for patients in the community. They acknowledged that the purpose of cancer registries has shifted from the original function of describing the burden of disease to providing survival data to assess the overall efficacy of the health care system. This also includes using clinical variables to respond to the growing need for information to assess standardisation of best practice, variances in care and also the long term effects of treatment. This study serves to show that there are countless possibilities for the use of the data collected by the NCRI. The value in the data can be greatly enhanced by helping the public to understand what the data means. The researcher believes that these are tangible areas for communicating to the public as it is data that is already available and ready to be used to inform the public. Using evidence based information to supplement a campaign will strengthen the impact of the NCRI. (HIQA, 2013)

### 5.3.3 Recommendation Number 3

**Work with the NCRI to make it more health literacy friendly e.g. through the Plain English service**

*"The contents of a data collection are not a normal part of everyday language so incorporating a literacy friendly environment will allow people to understand the information that the NCRI produce."(HR)*

Chapter 2 documented the importance of health literacy. It was explained that as we are now in an era where we are expected to look after our own health in conjunction with the clinicians; therefore being able to understand health information is vital. NALA as an independent charity was set up to assist people with literacy and numeracy difficulties and fulfils a valuable function which can help to ensure that the public become more health literate. The Healthy Ireland framework has dictated that they are to engage with NALA and the public to ensure that health literacy is a key component in the future development of any policies, educational and information interventions that take place. It was also discussed that Ireland came second in the European Health Literacy Survey (Doyle et al, 2012). It is important that this momentum should be kept up to continue in creating the vision of Healthy Ireland that health literacy is a priority for all organisations.

Rudd et al (2012) stated that there is a growing mismatch between existing literacy skills and the expectations of the health sector and this mismatch may play a part in poor health outcomes. They carried out a study that cited various authors who all reached a joint consensus that health materials require sophisticated reading skills and that many materials that are made available to the public are inappropriate for the intended audience. (Clayton, 2010; Muir & Lee, 2010; Herdon et al 2010 cited in Rudd et al, 2012).

HR commented that *"If people are not health literate, this may result in people getting sicker and ultimately costing the state more money ".* An obvious development for NALA to assist in this issue is the promotion of the Plain English mark. They have taken instruction from the National Literacy and Health Programme of the Canadian Public Health Association (CPHA). This programme commenced in 1998 and promoted awareness of the links between literacy levels and health. The focus was primarily on the use of plain language in health information (CPHA, 2014). Dr Rima Rudd, a recognised world leader in health literacy, advised that not only does health information need to be written in plain language; it also needs to be written with the user in mind. Dr Rudd commented that "*Materials designed from the perspective of the user, based on clear understandings of the purpose the materials serve and the tasks adults need to undertake, could lessen the burden on the user"* (Rudd, 2007).

NALA has been at the fore in developing a Plain English service and in 2009, NALA with the HSE published its Literacy Audit for Healthcare settings providing a manual to assist healthcare professionals as to how they can lead this development within their organisations (NALA, 2009). During the interview process, the researcher asked if NALA has worked with the NCRI and they indicated that they have not as of yet. A search of the NCRI website to search for a Plain English mark did not yield any results. Examples of where the Plain English mark has been used that would be useful as a starting point for the NCRI is the Patient Information leaflet produced by the NICR, which was referenced in Recommendation No 2.

In order to obtain the Plain English mark, organisations must contact NALA with a request. If an organisation wishes to get their website approved, it is usually advised that they choose the most popular pages to be checked such as the home page and the FAQ section as an entire website could be in excess of 1000 pages. These pages are reviewed by NALA and they look at inconsistencies and minor errors contained within the pages and make recommendations based on this. The Plain English mark is awarded once the final layout and content has been approved by NALA. *"The Plain English mark shows that the group have been though a quality process to ensure clear communications. This could be done by picking out the most frequently visited pages such as the FAQ's and the homepage to start"(HR).*

The research question in Chapter 1 indicated that the purpose of this research was to look at ways in which to increase the relevance of a national information source to the public. The ideal solution, subject of course to any privacy and confidentiality issues, is to make health information accessible to all by using the Plain English mark, or equivalent. This in term will contribute to increasing health literacy levels among the general public.

## *5.4 Conclusion*

This chapter outlined the process of evaluating the information that was taken from the qualitative research that was carried out. A list of 7 recommendations was produced. Following an analysis of these recommendations with respect to the research question and the literature review, the researcher decided to use the top 3 recommendations as the most relevant to the research question and to evaluate how they may be progressed within the NCRI. The researcher combined the information that was garnered from the literature review and from the interviews to produce a solid and robust evidence base to assist in further increasing the relevance of data collections in Ireland.

# Chapter 6 Conclusions

## 6.1 Introduction

The primary objective of this dissertation was to provide recommendations that would increase the relevance of patient registries by the public through the lens of the National Cancer Registry of Ireland (NCRI). At the outset, a literature review was carried out to inform the qualitative research which was to follow. A project management approach was adopted with a timeline of events put in place at the beginning of the academic year. Empowerment of the patient was a central theme of the research and this is consistent with standards and guidance documents presented throughout the dissertation.

## 6.2 Research Summary

A comprehensive literature review was carried out to inform the researcher of the information surrounding cancer registries. This identified a wealth of material from the Health Information and Quality Authority (HIQA), who have produced many guidance documents for national data collections such as registries. Also, the literature review was heavily influenced by the literature on patient empowerment and health literacy. This provided for a literature review that not only focused on the relevant polices and guidance documents but also sought to understand why the NCRI should increase the relevance of their patient registry for the benefit of the public. Cancer registries were discussed in Chapter 3 to provide for background to understand how the NCRI is placed in terms of how they function in comparison to other cancer registries.

The practical section of research entailed a qualitative approach to assimilating information for developing recommendations as part of the dissertation. It was decided to carry out a series of semi-structured interviews with key stakeholders who agreed to be interviewed. These included representatives from international registries, NALA, Patient Focus Ireland and HIQA. Once the data was gathered and transcribed, a thematic analysis was carried out to identify themes that could inform the final set of recommendations.

## 6.3 Summary of Findings

There were 7 recommendations identified in total. Of these, three were identified has being directly relevant to this research, namely creating a public awareness campaign of the NCRI, make the NCRI more literacy friendly, and to invite members of the public to sit on an advisory council as part of a patient engagement process. The other recommendations, whilst important, were not included as they were either irrelevant to the topic of the dissertation or else they were recommendations that were already being implemented.

## 6.4 Reflections on the Research

The research question that was posed in Chapter One was: How can the relevance of the NRCI be increased for the public's benefit? The researcher believes the aims of the research were achieved through the set of recommendations presented in Chapter 5. The aims included to explore the area of data collections, to identify key pieces of literature relevant to the research, to carry out a thematic analysis and to develop recommendations for increasing the relevance of the NCRI for the public's benefit. The researcher believes that these aims were achieved with a strong and valid argument presented for each recommendation that was discussed.

However, given the importance of public involvement identified in this research, it would be preferable if public engagement is built in at the start rather than added subsequently as an afterthought when it can be difficult to ensure that it is fully embedded.

## 6.5 Limitations of the Research

The NCRI was chosen by the researcher to develop recommendations to increase the relevance of data collections for the public. The NCRI is a well established and mature dataset and perhaps this may have put limitations on the results that were obtained. If a different patient registry had been chosen, then the results may have been different. Nevertheless the recommendations represent an important contribution which has relevance to all registries, including new ones which are in the process of being established.

The researcher, due to time constraints of the academic year and working fulltime, would have liked more time to carry out many more interviews and conducted a broader literature review.

A larger sample of people that could have been interviewed could have changed the shape of the results for 2 reasons. Larger numbers would have increased the validity of the recommendations that were presented. Also, due to the fact that there were 11 participants, it was decided that it was justified to carry out a manual analysis of the data. If there were more interviewees, then it would have been necessary to employ a statistical tool to analyse the results. This may have allowed for a more scientific approach to analysing the results and may have strengthened the overall design of the research undertaken.

The researcher would also like to acknowledge any perceived bias that there may be due to a professional background in healthcare. It is also important to realise the generalisability that could be applied to the recommendations but they can act in a comparable fashion for other patient registries and also national data collections more broadly, as similar challenges in terms of increasing public relevance are likely to be present.

## *6.6 Conclusion*

Without bias, this piece of research can prove to be a very valuable piece of work if taken as intended by any patient registry and also national data collections in general. It is imperative that data collections seek to evolve from where they stand, to allow for a dynamic source of information that can be accessed and used by all, thereby representing better value for money. But even more important is the contribution which this research has made to the potential contribution which these data collections can make to patient empowerment and supporting the public to maintain a healthy lifestyle. The need to place much greater emphasis on health living as stated in Healthy Ireland is critical to the future economic survival of the healthcare system in Ireland and elsewhere. The gap between the demand for health services from an increasingly knowledgeable and demanding public and the ability to meet that demand especially in the context of publicly funded healthcare systems is growing wider every year. This research has examined the contribution which patient registries and national data collections could potentially play in helping to bridge that gap using the NCRI as an example. The NCRI was chosen as it is a mature registry with high quality data.

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# Appendices

## *Appendix A: Summary of International Guidelines on Patient Registries*

| | **UK** | **US** | **Australia** | **Sweden** |
|---|---|---|---|---|
| **Ethics & Privacy** | Freely given fully informed consent can be waived disproportionate effort/methodological problems involved. Separate storage for identifiable and Cixl data, or anonymised data. Research ethics approval if register is involved in research | Freely given fully informed consent unless the register has been given a waiver. Anonymisation or separation of identifiable data and use of crosswalk files to link to clinical file with access restricted to management. Must have ethical approval. | Consent best practice, but can be waived under certain circumstances. Require ethical approval for data collection at each site unless covered by legislation | Generally consent required for data processing, but the quality registers are exempt from this obligation (Section 18 Personal Data Act) Must have ethical approval |
| **Standards** | Written data standards Multiple sources cases ascertainment Validation to ensure correctness of data Case definition essential | Using existing data standards, or develop standards and use data dictionary and data map. Documented data validation/ cleaning Staff training & supervision Defined target pop clear inclusion and exclusion criteria | Use existing standards or develop standards and use data dictionary. Data validation Training and supervision of staff Published eligibility criteria | Written agreed data elements In built data validation. Meet end users to ensure data validity and completeness Defined system cases lost to follow up |
| **Evaluation** | Regular evaluation to ensure aims and objectives still valid and being met. If this is | Regular evaluation to assess quality including | Regular evaluation to ensure that it is meeting its key | Registers must complete evaluation when applying |

| | | | | |
|---|---|---|---|---|
| | not the case, close/ revamp the register. | purpose and context , data validity , resources and cost | functions in order to receive funding | for continued funding |
| **Governance** | Compliance with data protection, security and ethical requirements. Oversight and accountability of staff. Publication and wide use of register data. | Governance functions incl. executive , scientific , liaison, adjudification, data access, use and publication should be established | Formal governance structure which must be legal entity to include executive and management functions | Compliance with data protection, public record regulations and encryption standards Accountability of staff and management |
| **Resources & Funding** | Appropriate multidisciplinary team Robust and secure funding allocation system, with 3-5 yearly funding for approved registers. | Multidisciplinary team incl. clinical, registry science, data collection and database management, legal, QA, project management. Mixed funding methods | Mix of disciplines including clinical, epidemiologists and health informaticists. Secure funding subject to review of relevance and quality | Central allocation of funding based on transparent criteria with deadline for applications in October and decisions in December |
| **Co-ordination** | Central co-ordination of policy and practice for registers National register of registries | Not covered | These guidelines to act as a national resource for registers National registry of registries | National body for funding registers and provide support to registries |

Excerpt from Dr. Fionnuala Donohues presentation at the meeting ‘Towards a National Strategy for Patient Registries in Ireland’ in May 2011

## *Appendix B: List of Members of UKACR*

Eastern Cancer Registration and Information Centre

North West Cancer Intelligence Service

Northern and Yorkshire Cancer Registry and Information Service

Oxford Cancer Intelligence Unit

South West Cancer Intelligence Service

Thames Cancer Registry

Trent Cancer Registry

West Midlands Cancer Intelligence Unit

Northern Ireland Cancer Registry

Scottish Cancer Registry

Welsh Cancer Intelligence and Surveillance Unit

## *Appendix C: INFORMATION SHEET FOR PARTICPANTS*

- Information collection and reporting has become an integral part of the structure of the Irish health system and defines the capabilities of each sector of society as to how the existence, performance and achievements of various sectors of healthcare are acknowledged. With the increasing technology in healthcare, the opportunity exists to improve and educate the wider community with available data. Patients have a sense of empowerment with the increased access to healthcare knowledge and as a result, are in a greater position to question the way in which services are provided.
  Large amounts of data mining and collection take place every day. Reports were examined along with graphical representations from the National Cancer Registry of Ireland (NCRI) and whilst statistics and graphs are in abundance to inform policy makers, financial planners and health professionals, the value of data will be questioned from the publics perspective. The purpose of this piece of research is to allow for a clearer understanding of the public perceptions of data collection from a national source, like the NCRI and to see if there is a potential for evolvement in the use of this data to further empower the public in understanding their own health.
- There is no conflict of interest from the interviewer.
- Participation in the interviews is voluntary and interviewees have the right to withdraw at any stage of the process and may review the transcribed interview prior to completion of analysis of results.
- Participants will be required to attend or participate in the interview process for approximately 1 hour and will be contacted by the interviewer to review transcribed document. A commitment of 2-3 hours maximum is required from participants.
- There are no anticipated risks/benefits for the participants.
- Anonymity is not assured as participants will be identified by their name and role within the organisation.
- Please be advised that any discovery of illegal or illicit activities will be notified to the relevant authorities.
- The interviewer may return to participants to verify and sign off direct quotations within their contextual appropriateness.
- Ethical approval has been sought and approved from Trinity College Dublin. Consideration was given to participants being asked for their opinion as a person representing their organisation and not for personal opinions. This will also be made explicit in the written consent. Data that will be analysed in the dissertation will not identify a member of the public in any way.
- The interviews will be audio recorded and will be used for the sole purpose of assisting the interviewer in transcribing the interview for analysis. They will not be used in any public forum or for any presentation purposes , in accordance with the Data Protection Act, 1998 (amended 2003)

## *Appendix D: INFORMED CONSENT FORM*

**LEAD RESEARCHER:** Fionnuala O Connor

**BACKGROUND OF RESEARCH:**

Information collection and reporting has become an integral part of the structure of the Irish health system and defines the capabilities of each sector of society as to how the existence, performance and achievements of various sectors of healthcare are acknowledged. With the increasing technology in healthcare, the opportunity exists to improve and educate the wider community with available data. Patients have a sense of empowerment with the increased access to healthcare knowledge and as a result, are in a greater position to question the way in which services are provided.

Large amounts of data mining and collection take place every day. Reports were examined along with graphical representations from the National Cancer Registry of Ireland (NCRI) and whilst statistics and graphs are in abundance to inform policy makers, financial planners and health professionals, the value of data will be questioned from the publics perspective. The purpose of this piece of research is to allow for a clearer understanding of the public perceptions of data collection from a national source, like the NCRI and to see if there is a potential for evolvement in the use of this data to further empower the public in understanding their own health.

**PROCEDURES OF THIS STUDY:**

Participants will be contacted to arrange a face to face interview. The interview is expected to last up to 1 hour maximum. Participants may/will be asked to take part in a debriefing session (via phone or email) to ensure contextual appropriateness of results and information obtained following the interview. There is no perceived risk identified for participants.

**ETHICAL CONSIDERATIONS:**

For the interview, both verbal and written permission to carry out interviews will be sought. Interviews will not be anonymous. Participants will be asked for their opinion as a person representing their organisation and not for personal opinions. This will also be made explicit in the written consent. Data that will be analysed in the dissertation will not identify a member of the public in any way.

**PUBLICATION:**

The results obtained from interviews and any other research carried out is for the publication of the dissertation for the MSc in Health Informatics, Trinity College Dublin.

**DECLARATION:**

- I am 18 years or older and am competent to provide consent.
- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions

have been answered to my satisfaction and understand the description of the research that is being provided to me.

- I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity.
- I understand that if I make illicit activities known, these will be reported to appropriate authorities.
- I understand that I may stop electronic recordings at any time, and that I may at any time, even subsequent to my participation have such recordings destroyed (except in situations such as above).
- I understand that, subject to the constraints above, no recordings will be replayed in any public forum or made available to any audience other than the current researchers/research team.
- I understand that audio recordings will be made and stored at the researchers place of residence for transcribing purposes.
- I understand that audio recordings will be permanently deleted by the researcher following submission of dissertation to Trinity College Dublin.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.
- I understand that my participation will not be anonymous and will be named as the interviewee in the researchers study.
- I have received a copy of this agreement.

**PARTICIPANT'S NAME:**

**PARTICIPANT'S SIGNATURE:**

**Date:**

**Statement of investigator's responsibility:** I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

**RESEARCHERS CONTACT DETAILS**: Fionnuala O Connor 0870518085

**INVESTIGATOR'S SIGNATURE:**

**Date:**

## *Appendix E: SAMPLE INTERVIEW QUESTIONS*

1. Can you tell me the background to the set up of the cancer registry in your country?
2. Data collection is a large part of the work carried out by the National Cancer Registry of Ireland (NCRI) in Ireland and its value is noted in service planning, budget planning etc. What is the perceived value for the public in the data that you collect for your countries registry?
3. What limitations does your countries cancer registry face with regards data collection?
4. How has your registry evolved since it began?
5. What further functions did it take on?
6. What other countries do you consult with to maintain best practice and guidelines?
7. The NCRI, which is the National Cancer Registry of Ireland have some limitations in that we don't have an individual health identifier – does your registry operate with one and if so, what are the advantages of it
8. Is there engagement with the public at any stage of the process of cancer registration?
9. If you were to further include the public, either by a consultative process or even through media campaigns, what are the perceived benefits of doing this, if it has not happened already?
10. Do you see cancer registries having an increased role in the public eye in the future? If so, what context?
11. Do you think the public require more understanding of health information and data collection?
12. What recommendations would you make to the NCRI for evolvement for the publics perception of the registry?
13. Can you provide me with any other further information you think may be relevant to my research?

# *Appendix F: Subjects covered per interview*

| | NCRI | HIQA | Scotland | Northern Ireland | Australia | Colorado | NALA | Denmark | Irish Cancer Society | California | Patient Focus |
|---|---|---|---|---|---|---|---|---|---|---|---|
| General Function of the Registry | ✔ | | ✔ | ✔ | ✔ | ✔ | | | ✔ | ✔ | |
| Set up of registry | ✔ | | ✔ | ✔ | ✔ | ✔ | | ✔ | | ✔ | |
| Historical background to the Registry | ✔ | | ✔ | ✔ | ✔ | ✔ | | | | ✔ | |
| Value for the public in the data that is collected | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | ✔ | ✔ | ✔ | ✔ |
| Limitations the registry faces in terms of data collection | ✔ | | ✔ | ✔ | ✔ | ✔ | | ✔ | ✔ | ✔ | |
| Role of international registrys on your registry | ✔ | | ✔ | ✔ | ✔ | ✔ | | ✔ | | ✔ | |
| Developing a warehouse for collection of data | ✔ | ✔ | | | | | | | | | |
| Do the public require more understanding of data collection? | ✔ | ✔ | ✔ | | | ✔ | | | | ✔ | |
| Sharing of data - public confidence in this | ✔ | ✔ | | | | | | | | | |
| Data Protection in Registry | ✔ | | | | | | | | | | |
| Benefits of having an Indiviual Health Identifier | ✔ | ✔ | ✔ | ✔ | | ✔ | | ✔ | | ✔ | |
| Public input to the Registry | ✔ | | ✔ | ✔ | | ✔ | | | | ✔ | |
| HIQA and data collection | | ✔ | | | | | | | | | |
| Public demand for information | | ✔ | | | | | | | ✔ | | ✔ |
| Evolvement of Registry | | | ✔ | ✔ | ✔ | ✔ | | ✔ | ✔ | ✔ | |
| New Functions | | | ✔ | | | ✔ | | | | ✔ | |
| Recommendation | | | ✔ | | ✔ | ✔ | | | | ✔ | ✔ |
| Increasing role in the public eye | | | | | | ✔ | | | ✔ | ✔ | |
| Further information | | | | | | | | ✔ | | | |
| What is Health Literacy? | | | | | | | ✔ | | | | |
| Services that the organisation offers? | | | | | | | ✔ | | | | ✔ |
| Backgound to Research carried out | | | | | | | ✔ | | | | |
| International consultations | | | | | | | ✔ | | | | |
| Plain English service | | | | | | | ✔ | | | | ✔ |
| Working relationship with the NCRI | | | | | | | | | ✔ | | |
| Knowledge of the NCRI | | | | | | | | | ✔ | | ✔ |
| Requirements from the NCRI | | | | | | | | | ✔ | | |
| Importance of health information | | | | | | | | | | | ✔ |

## *Appendix G: Recommendations from interviews*

| **Recommendation** | **By Whom** | **Commentary or Rationale** |
|---|---|---|
| **Patient representation on NCRI by setting up a council of the registry with patient involvement** | Anna Gavin (NIreland) | To involve patients in the development of the reports and their launches<br>To include patients in specific project steering groups<br>“Patients would be better informed to respond to consultations about legislation in relation to cancer registries.” |
|  | Kurt Snipes (California) | Limitations of data collections are not well understood by the public and this would be good opportunity for the public to engage in a data collection |
| **NCRI should have an Individual Health Identifier (IHI)** | Anna Gavin (NIreland) | “It has increased the efficiency of the data capture and matching of data” |
|  | Harry Comber (NCRI) | “If we had an IHI, we could operate without knowing who anyone else, as long as we could uniquely identify the patient”<br>“It will be of benefit in linking data sources” |

| | | |
|---|---|---|
| | Donal Buggy (Irish Cancer Society) | “We are always looking at historical data and that is a challenge as it’s always going to be behind what is currently happening. Without a IHI, people will not be able to look at Real Time information” |
| | Randi Rycroft (Colorado) | “It aids in record linkage among multiple source records” |
| | Maya Christel Milter (Denmark) | Huge advantage in linkage to other registries for data qualification, research and correction of errors |
| | Kurt Snipes (California) | It will allow for automation of manual processes<br>It will increase functionality to accept information from electronic medical records and electronic pathology reports |
| **Run an information campaign about NCRI or national information sources with NCRI as an example** | David Brewster (Scotland) | To explain how data is collected, looked after and used in the publics interest to help engender trust and support for the legitimate uses of the data.<br>It is arguably more efficient to run a |

| | | |
|---|---|---|
| | | campaign covering all health information and data collections and could be government sponsored.<br>To help patients understand the flow of information |
| | Anna Gavin (NIreland) | To provide information about cancer registration |
| | Harry Comber (NCRI) | “We have such regular exposure in the media and we are also quoted a lot in the newspapers, therefore I don’t see a requirement for a public campaign” |
| | Randi Rycroft (Colorado) | “Public education is a good strategy because it may demystify what a cancer registry is and what it does for the public good.” |
| | Kurt Snipes (California) | It will lead to increased trust by the public when registry is responding to community cancer concerns. Within our ageing population that is living longer there will be more public concerns about cancer in the communities and the workplace. |
| **Train staff in Cancer centres of Excellence in data collection** | Harry Comber (NCRI) | There is not enough staff or flexibility of the staff |

|  |  |  |
|---|---|---|
| **for the NCRI** |  | to cover the approx 300000 cases of cancer in Ireland each year.<br>"NCRI discovered that people who don't work in the NCRI have difficulty understanding our data" |
|  | Donal Buggy (Irish Cancer Society) | "If a member of the Irish Cancer Society was trained in the data collection methods of the NCRI, this staff member could work on the information and carry out research on our behalf. It would have to be done in a managed way and it would be an efficient use of public resources and money." |
| **Move all National Information Systems under one roof i.e. to a data warehouse by sharing the IT infrastructure** | Rachel Flynn (HIQA) | Looking at international practice, Canada and New Zealand are moving towards this model |
| **Secure public funding to support the procurement of a public health genomics coordinator** | Randi Rycroft (Colorado) | It is designed to educate providers and patients regarding genetic risk for patients diagnosed with cancer and their family members.<br>It is an opportunity to empower patients to help their family members achieve better outcomes through increased screening and earlier |

| | | |
|---|---|---|
| | | detection. |
| **Work with the NCRI to make it more health literacy friendly e.g. through the Plain English service** | Helen Ryan (NALA) | To allow people to understand the information that the NCRI produce.<br>“If people are not health literate, this may result in people getting sicker and ultimately costing the state more money. “<br>The Plain English mark shows that the group have been though a quality process to ensure clear communications. This could be done by picking out the most frequently visited pages such as the FAQ’s and the homepage to start. |