

**Secondary Use of Clinical Data Contained in  
Optometry Electronic Patient Records to Establish  
a Population Profile of Refractive Error**

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*A dissertation to the University of Dublin, in partial fulfilment of the  
requirements for the degree of Master of Science in Health Informatics*

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## Author 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.

Signed:

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Declan Hovenden

25 June 2015

## Permission

I agree that the School of Computer Science and Statistics, Trinity College may lend or copy this dissertation upon request.

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25 June 2015

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## Abstract

Refractive error is a common problem, affecting the vision of approximately 2.3 billion people globally. However research into refractive error and its population prevalence is relatively rare, particularly in Ireland, despite some evidence that in parts of the world the prevalence of myopia, in particular, appears to have risen significantly in recent years. Large-scale studies are expensive to conduct and take long periods of time to complete.

Collecting the data contained in the electronic patient records kept by optometrists could be a means of conducting population-level research into refractive error and other aspects of eye health and primary eye care in a fashion that is efficient, inexpensive and timely. The primary aim of this study was to determine if optometry EPR data could be used to produce a population profile of refractive error in Ireland.

Following a literature review which established that data from optometry EPRs had never been used in this way previously, primary research was conducted to collect qualitative and quantitative data by carrying out a survey of practising optometrists and by designing, developing and piloting a software tool to extract appropriate anonymous data from the EPR systems of six optometry practices.

It was found that 80% of optometrists in Ireland use EPR systems and that the level of interest amongst optometrists in potentially extracting and submitting their data for secondary (research) purposes is very high despite many possible barriers being identified. These findings indicate that the potential exists to collect data relating to refractive error on up to 450,000 individuals annually.

The data extraction pilot gathered data on approximately 30,000 individuals and analysis of these data resulted in a distribution profile of refractive error for that sample population. This profile compared well with that of other conventionally-conducted studies into the prevalence of refractive error in other Western European populations. The successful data extraction pilot also demonstrated how many of the potential barriers to such a system of secondary use of EPR data could be addressed and overcome.

The study concluded that it is possible to automatically collect data from optometry EPRs in Ireland and, through analysis of these data, to produce a population profile of refractive error and facilitate future research into the field.

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## Abbreviations

AHRQ	Agency for Healthcare Research and Quality
AMIA	American Medical Informatics Association
AOA	American Optometric Association
AOI	Association of Optometrists, Ireland
ARRA	American Recovery and Reinvestment Act
BMI	Body Mass Index
BP	Blood Pressure
CDC	Centers for Disease Control and Prevention
CPR	Computerised Patient Record
CSV	Comma Separated Values
D	Dioptre
DoH	Department of Health
DPC	Data Protection Commissioner
EBM	Evidence Based Medicine
ECP	Eye Care Professional
EHR	Electronic Health Record
EMR	Electronic Medical Record
EPR	Electronic Patient Record
EUROSTAT	Statistical Office of the European Union
FODO	Federation of Ophthalmic and Dispensing Opticians
GHS	Gutenberg Health Study
GP	General Practitioner
HIE	Health Information Exchange
HIQA	Health Information and Quality Authority

HITECH	Health Information Technology for Economic and Clinical Health
HPOE	Hospitals in Pursuit of Excellence
HRB	Health Research Board
HSE	Health Service Executive
ICD	International Classification of Diseases
ICGP	Irish College of General Practitioners
ICT	Information and Communication Technology
IOM	Institute of Medicine
IPCRN	Irish Primary Care Research Network
ISO	International Organization for Standardization
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
IT	Information Technology
LOINC	Logical Observation Identifiers Names and Codes
NCRI	National Cancer Registry Ireland
NHS	National Health Service (UK)
NICER	Northern Ireland Childhood Errors of Refraction
PHI	Personal Health Information
RCT	Randomised Control Trial
RWD	Real World Data
RWE	Real World Evidence
SCSS	School of Computer Science and Statistics
SD	Standard Deviation
SNOMED	Systematized Nomenclature of Medicine
SQL	Structured Query Language
TCD	Trinity College, Dublin
WHO	World Health Organisation



# 1 Introduction

*"The material exists but it is inaccessible".....Florence Nightingale (1820-1910)*

Accessing the data and information that are captured in electronic point-of-care healthcare records and turning these data into knowledge and evidence are at the core of the discipline of health informatics.

In Ireland, primary eye care is provided to the population by optometrists. The practice of modern optometry utilises technology to a large extent, including the use of Electronic Patient Records (EPRs) to collect clinical data at the point of care. Currently these data serve no function beyond the provision of eye care.

Globally there is a relative paucity of research into refractive error<sup>1</sup> and in Ireland such research is almost non-existent. However, the evidence that exists indicates that the prevalence and incidence of refractive error are changing in many parts of the world including Western Europe. In particular, levels of myopia appear to have increased significantly in recent years. Higher degrees of myopia are associated with serious sight-threatening pathologies.

Meanwhile, new theories on the aetiology of refractive error and on possible interventions are emerging. In order to measure the impact of environmental factors or any new interventions in the future it will be important to establish the current prevalence in the population.

The data stored electronically by optometrists may be a valuable resource in meeting this challenge in a way that could be inexpensive, efficient, accurate and timely. Using these data for the secondary purpose of establishing a population profile of refractive error is the premise of the research work presented in this dissertation.

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<sup>1</sup> Refractive error is any defect of vision which can be corrected by re-focusing light entering the eye through use of, for example, an optical appliance such as spectacles.

## 1.1 Research Question

Through conducting this research, the author proposes to investigate if meaningful and useful research can be conducted into the area of refractive error by accessing and aggregating data from EPRs used in primary eye care. To this end the research question posed is:

***“Can data be collected automatically from optometry electronic patient records in Ireland in order to produce a population profile of refractive error and facilitate future research into the field?”***

In order to answer this question, the following sub-questions must be answered:

**RQ1:** Is it technically possible to extract data from optometry EPRs in order to produce a valid profile of refractive error?

**RQ2:** What is the potential quantity of data that could be gathered from optometry EPRs in Ireland?

**RQ3:** Would optometrists in Ireland be willing to be involved in a system of extraction of data from their EPRs for secondary (research) use?

## 1.2 Study Context

In the Republic of Ireland, approximately 650 registered optometrists provide primary eye care to the population. In doing so approximately 650,000 refractions (measurements of optical/refractive error) are performed annually (AOI, 2015). Globally it is estimated that 2.3 billion people have a refractive error that requires correction (Naidoo and Jaggernath, 2012) and it appears that myopia, in particular, is on the increase both in its prevalence and levels of severity.

The majority of optometrists in Ireland now use EPRs to record their patient data. For this research project, the author collaborated with the vendor (Ocuco) of the most widely used system (Acuitas) in an effort to design and develop a mechanism for extraction of data that might enable the establishing of a population profile of refractive error. This mechanism was piloted on the EPR systems of a number of optometry practices around the country.

The Association of Optometrists Ireland (AOI) is the professional body representing the interests of optometrists in Ireland. That organisation supported this research work by distributing invitations to all practising members to participate in the researcher's survey of the profession.

The researcher is himself a practising optometrist who has a particular interest in the use of advanced technology in the delivery of optometric services and eye care. He also uses an EPR system in practice.

### **1.3 Motivation for the Research**

Despite refractive error being a common disorder, affecting a large proportion of the population, there is a lack of research into its prevalence and associated health and lifestyle consequences in Ireland. Given that many parts of the world are noting significantly changing levels of myopia and that myopia has associated ocular pathologies that carry an increased risk of vision impairment, there is an increasing recognition amongst the eye care professions and healthcare systems that there is a need for greater levels of research in this area.

Through the work presented in this dissertation, the researcher hopes to lay the foundations for further epidemiological research at a population level into refractive error by demonstrating that EPR data may be a valuable and useful resource for conducting large-scale studies in a relatively efficient, inexpensive and timely fashion.

### **1.4 Study Aims and Objectives**

In order to answer the research question and its constituent components, this research project aims to:

- 1.** Demonstrate that refractive error data can be collected from optometry EPRs by:
  - a.** Establishing the willingness and ability of optometry EPR users to be involved in extraction of data from their EPRs for secondary use

- b. Designing a mechanism for extraction of these data
    - c. Performing a pilot of this data extraction
- 2. Use refractive error data collected from optometry EPRs to produce a refractive error profile by:
  - a. Gathering together the extracted EPR data
  - b. Performing statistical analysis on these data
  - c. Plotting the frequency distribution (profile) to reveal the relative rates and levels of refractive error for the pilot population
- 3. Lay the foundations for future clinical/population health research by:
  - a. Demonstrating that refractive error data can be extracted from optometry EPRs (through completion of the pilot)
  - b. Designing the extraction mechanism in such a way that it can be repeated
  - c. Establishing how much data may be available for extraction and use for research purposes

## **1.5 Terminology**

Many different terms tend to be used, sometimes interchangeably, sometimes inaccurately (even in the literature) for computerised collections of clinical/health data of individuals and/or episodes of care. Some of the common terms used are Electronic Health Record (EHR), Electronic Medical Record (EMR), Electronic Patient Record (EPR), Computerised Patient Record (CPR) (Häyrinen et al., 2008).

For the purposes of this study, the term Electronic Patient Record (EPR) will be the one that is mostly used as it most accurately and appropriately describes the type of systems employed by optometrists in providing primary eye care. It is also the best-fit term for computerised record systems currently used in many other healthcare domains and many of the findings of this study may well be relevant to these other areas. Where it has not been possible to use the term EPR (e.g. when reviewing/quoting relevant literature), the term Electronic Health Record (EHR) may be used in the interest of accuracy.

While EPRs are often considered a type or even part of the EHR (EPRs collecting a more limited amount of data in, for example, a hospital or practice), the term EHR is generally understood to mean a longitudinal, cross-institutional and person-centred digital record of the health of an individual and the healthcare provided to an individual (Kwak, 2005). See Appendix A for “Types of EHR”.

## 1.6 Dissertation Layout

The format of this dissertation is as follows:

**Chapter 1: Introduction** – introduces the reader to the study, its context, its aims and objectives, and the motivation for it.

**Chapter 2: Literature Review** – reviews scholarly literature relevant to this research project; themes explored include secondary use of data, population health, refractive error and use of EPR data for research.

**Chapter 3: Research Methodology** – outlines the approach, methods and strategy used to answer the research question.

**Chapter 4: Results** – presents the findings from both the survey of optometrists and the process of developing and piloting the data extraction software tool culminating in a refractive error profile of the studied population.

**Chapter 5: Discussion** – discusses and interprets the results of this research project including those of the survey of optometrists and the data extraction pilot.

**Chapter 6: Conclusion** – concludes the study and summarises the findings.

## **1.7 Summary**

This chapter introduced the study by presenting the background and context. The research question, study aims and objectives were outlined and an overview of the structure of this dissertation document was laid out.

In the next chapter, a literature review is conducted exploring and investigating the key areas relevant to the study.

## **2 Literature Review**

### **2.1 Introduction**

The literature review phase of the study investigates the various aspects relevant to the research question and objectives. It will look at the concept and utility of secondary use of clinical data, the population health approach to healthcare research and how the use of EPRs can facilitate this approach. Refractive error, its relevance as a motivation for this study and how it is studied will also be explored in the literature as will the current perspective on the usage of optometry EPRs for research purposes.

### **2.2 Secondary Use of Clinical Data**

#### **2.2.1 Primary and secondary clinical data**

Early medical records have been found in ancient Egyptian papyri (Frey, 1984) and in 1858 Florence Nightingale published her “Notes on Matters Affecting Health, Efficiency, and Hospital Administration of the British Army” demonstrating how the application of statistics to data gathered from the medical records of British soldiers in the Crimean War could reveal evidence that much of the mortality was due to the nature of infection in the hospitals (Aravind and Chung, 2010). Today’s health records (increasingly in electronic format) allow mining of data and sophisticated statistical analysis (Cusack et al., 2013).

Modern healthcare generates massive amounts of data in the normal course of provision of direct patient care (Safran et al., 2007, Barton et al., 2011, Teasdale et al., 2007). While the primary purpose of collecting these data is to document clinical care, there is potential for so-called “secondary use” of these data for purposes other than the delivery of healthcare (Hripcsak et al., 2014, Safran et al., 2007, Barton et al., 2011, IOM, 2003b, Heath, 2013). Collection and aggregation of these data can facilitate research, leading to improvements in the safety, quality, efficacy and efficiency of healthcare systems and increased levels of population wellbeing (Barton et al., 2011, Iakovidis, 2012, DoH, 2013a, Teasdale et al., 2007).

Secondary use can also enhance the experience of healthcare for individuals, support public health practice and assist healthcare businesses in achieving the needs of clients (Safran et al., 2007).

While there are clear benefits to this exchange of information, significant challenges exist including technical, ethical, economic and political (Safran et al., 2007, Bloomrosen and Detmer, 2008). Some of these challenges will be explored in Section 2.5.

The Institute of Medicine (IOM) in 2003 categorised the primary and secondary uses of electronically-stored health data as seen in Table 2-1 (IOM, 2003b).

**Table 2-1: Primary and secondary uses of an electronic health record system**

Primary Uses	Secondary Uses
Patient Care Delivery	Education
Patient Care Management	Regulation
Patient Care Support Processes	Research
Financial and Other Administrative Processes	Public Health and Homeland Security
Patient Self-Management	Policy Support

In 2007, the American Medical Informatics Association (AMIA) proposed the following clarification of the concept of secondary use of data: *“Reuse of health data occurs when personal health data are used for purposes other than those for which they were originally collected”* (Bloomrosen and Detmer, 2008); the AMIA further defined the secondary use of health data as *“non-direct-care use of personal health information (PHI) including, but not limited to, analysis, research, quality/safety measurement, public health, payment, provider certification or accreditation, and marketing and other business including strictly commercial activities”* (Safran et al., 2007).



There are many uses of clinical data that are categorised as secondary as outlined in Table 2-2.

**Table 2-2: Teasdale's secondary uses of clinical data**

No.	Use
1.	Support of preventative care and health
2.	Clinical audit and governance
3.	National screening and prevention campaigns
4.	Audit against national care standards
5.	National Statistics
6.	Planning services
7.	Resource allocation

*(Teasdale et al., 2007)*

### 2.2.2 Clinical record systems

EHR systems should be designed and implemented in such a way as to provide the capability of their being utilised to their full potential (Kellermann and Jones, 2013), while Cusack (2013) notes that often in response to the complex reimbursement, medico-legal and regulatory requirements, copious amounts of redundant data are collected. The AMIA has proposed a set of features that EHR systems should possess as outlined in Table 2-3.

**Table 2-3: AMIA: Proposed principles for clinical data capture and documentation**

<b>Clinical data capture and documentation should:</b>	
<b>1.</b>	Be clinically pertinent, patient-centric, and represent an individual's lifetime health and healthcare.
<b>2.</b>	Support capture of high-quality information that is accurate, relevant, confidential, reliable, valid, complete and secure.
<b>3.</b>	Be efficient and usable while enhancing the overall efficiency, effectiveness and productivity of the healthcare organisation and the care team.
<b>4.</b>	Support multiple downstream uses as a by-product of the recording of care delivery, including quality measurement, performance improvement, population health care delivery, policymaking, research, education, and reimbursement.
<b>5.</b>	Enable joint patient-provider decision-making, team collaboration, care process management, and advanced clinical decision support.
<b>6.</b>	Enable collection of data and interpretation of information from multiple sources as appropriate and necessary, including nuanced medical discourse, structured items, and data captured in other systems and devices.
<b>7.</b>	Enable automation of data capture and documentation which should be optimized whenever appropriate, allowing human beings to focus on gathering and entering data that cannot be effectively collected by automated tools (e.g. automated acquisition of data from biomedical devices).

*(Cusack et al., 2013)*

The characteristics of GP clinical record systems in the UK were identified by Teasdale et al and these are outlined in Table 2-4.

**Table 2-4: Characteristics of G.P. electronic clinical record systems in the U.K.**

Characteristic No.	Characteristics of GP EPR systems in the U.K.
1.	Used with patient at office visit –clinically focused
2.	Structured and coded records
3.	Electronic prescribing
4.	Some decision support (warnings, reminders, contraindications)
5.	Electronic lab results
6.	Half of practices are “paper-light”
7.	National registration system linked with PAP smear and mammography screening systems, and childhood vaccination system
8.	Sophisticated reporting tools

*(Teasdale et al., 2007)*

The AMIA has recommended development frameworks for secondary use of health data at a national level and has provided guidance on the components that would shape such a framework. These recommended components are listed in Table 2-5.

**Table 2-5: AMIA: Recommended components of a national framework for secondary use of health data**

Recommendation No.	Recommendation
1.	Transparent policies and practices for the secondary use of health data
2.	Focus on data control ownership rather than data ownership
3.	Consensus on privacy, policy, and security
4.	Public awareness and trust
5.	Comprehensive scope (beginning with a taxonomy)
6.	National leadership

*(Safran et al., 2007)*

### 2.2.3 Supporting secondary use

While secondary use of clinical data is still at a relatively early stage of development (Weiskopf and Weng, 2013), many countries are supporting initiatives to expand the use of health data for research purposes (Botsis et al., 2010, Cusack et al., 2013). The European Commission in 2008 issued a “*Recommendation on cross-border interoperability of electronic health record systems*” on foot of the Community e-Health Action Plan. This recommendation prioritises the interoperability of EHR systems for EU member states with a view to improving both healthcare delivery for all citizens and health information exchange (HIE) for secondary uses (Iakovidis, 2012). In Ireland, the Health Information and Quality Authority (HIQA) has conducted a review of the secondary use of health information internationally (HIQA, 2012b) and the recent Health Identifiers Act lays the legislative foundation for a framework which will enable health information exchange (DoH, 2014).

Great advances have already been made in the area of collection, organisation, retrieval analysis and application of health data. However, the full potential of the use of these data will

require the collaboration of many stakeholders including healthcare providers and clinicians, health informaticians, health information technology (HIT) vendors, researchers, regulators, funders and patients (Weiner and Embi, 2009).

#### 2.2.4 Summary

This section explored the concept of secondary use of health data by explaining the differences between primary and secondary use, by identifying how electronic records can facilitate secondary use and by pointing to some of the governmental and legislative supports that are emerging for secondary use.

The next section will investigate the population health approach to the study of health.

### 2.3 Population Health

This section explores how evidence is gathered and prevalence profiles of diseases/conditions produced as part of the population health approach to studying the health of populations.

#### 2.3.1 Population and public health

Population health has been defined as *“the health outcomes of a group of individuals including the distribution of outcomes within the group”* (HPOE, 2014, Kindig D., 2002, Friedman et al., 2013). Population health should aim to improve the quality of healthcare and its outcomes, thereby improving the health of a given population. The mechanisms for achieving these goals include:

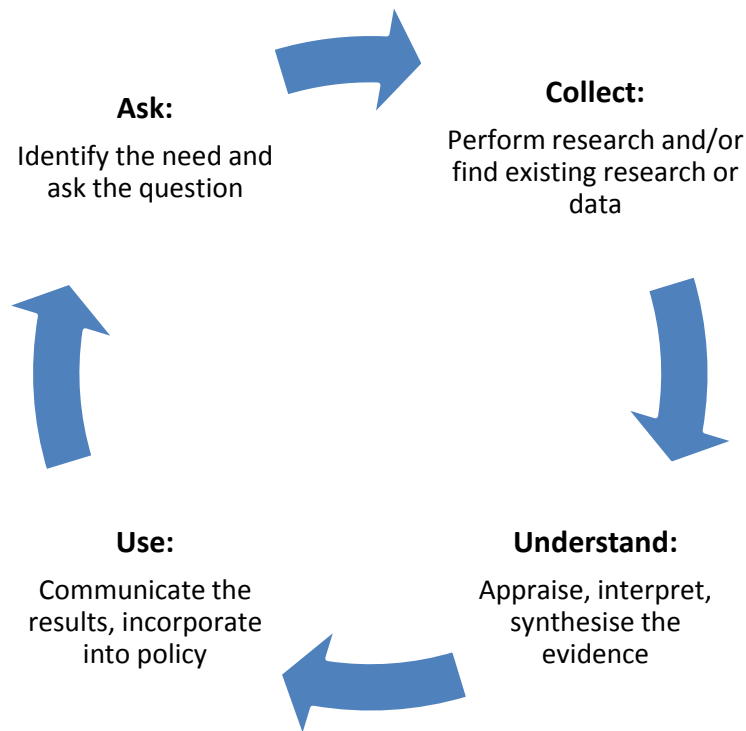
- Increasing the use of lessons learned from evidence-based medicine (EBM) in preventative healthcare services.
- Improving the quality of care and patient safety.
- Advancing the coordination of care across all healthcare providers (HPOE, 2014).

Population health relates to public health in that evidence, including that provided by the population health sciences, should inform and be the foundation for the practice of public health (Heller, 2005). Public health has been defined as the *“use of theory, experience and evidence derived through the population sciences to improve the health of the community, in a way that best meets the implicit and explicit needs of that community (the public)”* (Heller et al., 2003a) and also as *“the practices, procedures, institutions, and disciplines required to achieve the desired state of population health”* (Friedman et al., 2013, Last, 2001).

### 2.3.2 Evidence

Evidence is critical to the practice of public health and increasingly there is recognition of the use of the population sciences in gathering evidence for use in healthcare i.e. to contribute to evidence-based medicine (EBM) which is seen as *“the integration of best research evidence with clinical expertise and patient value and circumstances”* (Sackett, 2000, Straus et al., 2005). EBM arose from the discipline of clinical epidemiology which used the population sciences to research and then teach a scientific approach to clinical practice. However, epidemiological research has often been criticised for being based on identifying predictors of health outcomes among individuals rather than at the population level (Heller et al., 2003a, Heller, 2005).

The Population Health Evidence Cycle in Figure 2-1 illustrates the mechanism for gathering, appraising and using evidence to improve community (public) health (Heller et al., 2003b).



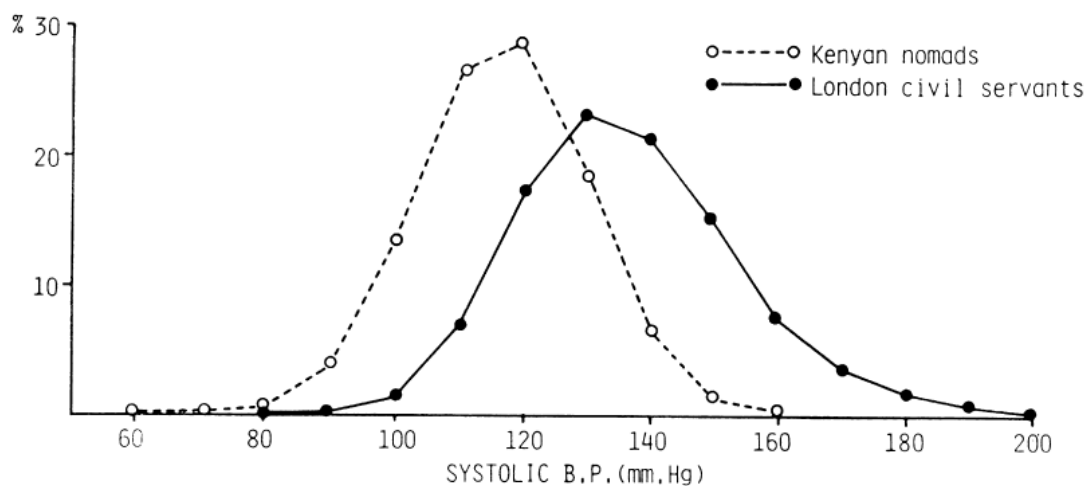
**Figure 2-1: Population health science evidence cycle**

It is accepted that there is a need to gather evidence so that an evidence base can be established and developed in order to provide for the appropriate introduction or continuation of effective treatments or interventions and inform the decision-making of policy makers.

There have been criticisms that some epidemiological research ignores the impact of populations on public and individual health (Pearce, 1996, McMichael, 2009) and Rose recognises the value in comparing populations with different disease rates in order to elicit underlying causative factors (Rose, 2001). Heller contends that it is important to think in population terms and calls for a move to “*bring the population back into epidemiology and public health*” (Heller, 2005).

### 2.3.3 Population profiles

Biological variables in a population can be represented by a distribution curve or profile – most are *normally* distributed. These profiles facilitate comparison of different populations as seen in Figure 2-2 which compares the profile of systolic blood pressure (BP) for a population of London civil servants with that of a population of Kenyan nomads. If hypertension is defined as a systolic BP of 140mmHg or higher, it is clear that a greater proportion of the London population will be defined as hypertensive than the Kenyan population (Rose, 2001). The impact of any policy or intervention should be examined according to its effect on the whole population.



**Figure 2-2: Distribution of systolic blood pressure in Kenya and London**

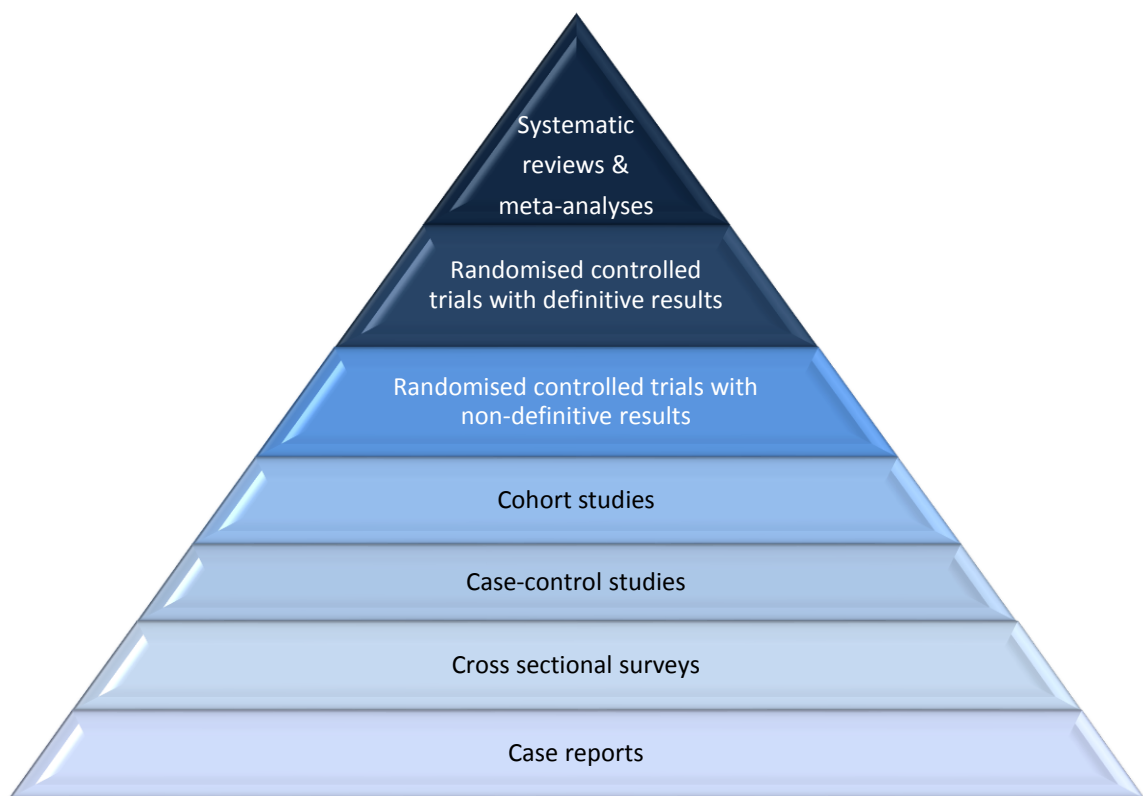
### 2.3.4 Gathering the evidence

There are several ways of measuring the potential impact of interventions on a population. Such measurements require in the first place an estimate of the proportion of the population with the particular disease or condition of interest i.e. the distribution of the factor that is to



be modified along with the proportion of those with the condition who would be eligible for the intervention (Morgenstern and Bursic, 1982, Laupacis et al., 1988). Knowing the prevalence of a disease or other health-related characteristics is also important in public health for assessing the associated burden and in planning resources (HealthKnowledge.org, 2011).

Traditionally, the sources of scientific (research) evidence are thought of in a hierarchical manner with randomised controlled trials (RCTs) and systematic reviews being considered to yield the most reliable forms of evidence as depicted in Figure 2-3 (Mhaskar et al., 2010, Greenhalgh, 2014, Aceijas, 2011).



**Figure 2-3: Pyramid of hierarchy of evidence**

More recently some argue that this traditional hierarchy is at times inadequate as study design alone is not necessarily an indicator of evidence quality in public health intervention. The hierarchy (or at least strict adherence to it) may need to be rethought and/or reconstructed in some situations (Phillips, 2014, Heller, 2005). Even Randomised Control Trials (RCTs) may be poorly performed or may be carried out on a non-representative or non-relevant population (lack external validity); much public health research does not suit the RCT design and often it is not a feasible means of studying population-level prevalence, trends and interventions.

The pragmatic approach of first identifying the research question to be answered and then identifying the most appropriate research design has been put forward (Petticrew and Roberts, 2003). As much data relating to public health and community interventions is of the non-trial type, it is important that this information not be ignored; a new hierarchy for use at population level may be needed which would judge studies on properties such as credibility, completeness and transferability (Heller, 2005). Increasingly the translation of research into clinical practice is a “*two-way street*”; scientists deliver new tools to clinicians but also clinicians’ observations can be used as evidence and may also lead to further “*scientific investigation*” (Peterson, 2006).

While challenges exist in determining how complete such evidence needs to be before basing recommendations on it and deciding how much weight should be given to it when it is to be used in decision and policy making (Rychetnik et al., 2002), research projects involving patients in primary care settings are increasingly recognised as being critical to medical research (Hummers-Pradier et al., 2008).

#### 2.3.4.1 Real world data (RWD)

While double-blind RCTs are still generally considered the most rigorous form of medical evidence, it can be difficult to extrapolate RCT data into the real life. “Real-world” studies however can assess effectiveness in large populations of patients (with comorbidities) and can help fill the knowledge gap between clinical trials and clinical practice; the need for clinical treatments to be assessed in “real-life” settings is increasingly being recognised by decision-makers in healthcare (Herland et al., 2005, New et al., 2014, Turner, 2014). The “subjects” of these studies are patients under routine care; no additional visits are required and data on

long-term outcomes that are free from interviewer or recall bias can be obtained (New et al., 2014, Garrison et al., 2007).

RWD has been defined by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) as “data used for decision-making that are not collected in conventional randomized controlled trials (RCTs)” (Garrison et al., 2007). Some of the benefits of RWD identified by ISPOR are outlined in Table 2-6 below.

**Table 2-6: Benefits of RWD studies**

No.	Benefit: RWD can provide.....
1.	Comparison of multiple alternative interventions or clinical strategies
2.	Estimates of the evolving risk-benefit profile of a new intervention, including long-term (and rare) clinical benefits and harms
3.	Examination of clinical outcomes in a diverse study population, reflecting the range of patients seen in clinical practice
4.	Data on resource use for the costing of healthcare services
5.	Data in situations where it is not possible to conduct an RCT
6.	Substantiation of data collected in more controlled settings
7.	Interim evidence – in the absence of RCT data – upon which preliminary decisions can be made
8.	More cost effective data collection

*Adapted from Garrison et al. (2007)*

The main limitation of such observational or database studies is that they typically do not meet the methodological rigor of RCTs, although the availability of sophisticated statistical

approaches to adjust for selection bias in observational data can help mitigate this problem (Garrison et al., 2007).

#### 2.3.4.2 Public health informatics

The increased use of information technology (IT) in healthcare is revolutionising the ability to collect data which can help build evidence bases for population health.

EPRs can be utilised for data collection without direct patient contact for large “real-world” population studies. EPR data has been shown to be useful in quantifying the burden of disease, identifying exacerbations and could be used to evaluate differences in clinical outcomes of novel treatments (New et al., 2011, New et al., 2014, Turner, 2014).

Public health informatics has been defined as *“the systematic application of information and computer science and technology to public health practice, research, and learning. It is the emerging discipline that integrates public health and information technology. The development of this field and the dissemination of informatics knowledge and expertise to public health professionals are critical to unlocking the potential of information systems to improve the health of the nation”* (Yasnoff et al., 2001) and also by Buchan as the *“knowledge, skills and tools for systematically creating information and managing knowledge to understand, protect and improve health in society”* (Heller, 2005).

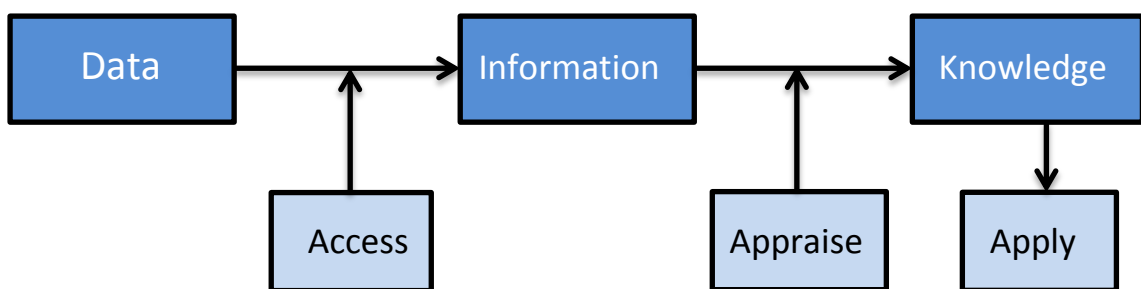
Data collected in the normal course of healthcare provision could be used to answer questions relevant to public and population health (Black and Payne, 2003). If collected regularly, these data could provide important information on trends in areas such as disease prevalence and survival rates and indicators of health and wellbeing like childhood Body Mass Index. The information collected in electronic patient/health records (EPRs/EHRs) could be harnessed to provide such valuable information and evidence. Timeliness is one important advantage of this approach, particularly if the information is to inform policy and/or intervention (Heller, 2005). The use of electronic records in this way is discussed further in Section 2.4.

### 2.3.5 Understanding and using the evidence

EBM is founded on accessing, appraising and applying evidence from healthcare. Access to research literature has been revolutionised by computerised searching technology and critical appraisal is a skill taught to many clinicians in training and is supported by evidence-synthesising methods such as those employed by the Cochrane Collaboration (Heller, 2005). However, sources other than published literature need to be considered in order to add to the evidence base for population/public health.

Evidence-based public health has been specifically defined as: *“the development, implementation, and evaluation of effective programs and policies in public health through application of principles of scientific reasoning, including systematic uses of data and information systems”* (Brownson et al., 2010).

Data which may be observations routinely collected during care provision, if assembled appropriately, can become information. When appraised, this information can be turned into valuable knowledge as illustrated in Figure 2-4 (Heller, 2005).



**Figure 2-4: The process of turning data into knowledge which can be applied**

Knowledge management has been defined as a *“structured process that enables knowledge to be created, stored, distributed and applied to decision-making”* (Sandars, 2004). It is clear that information and communication technology (ICT) now has a major role to play in this process and will be a key enabler for implementation of evidence into the practice of healthcare.

While some have argued that evidence is of only limited value when it comes to public health policy making (possibly because of the competing interests and goals of governmental policy-makers) (Black, 2001), the overwhelming consensus is that research is essential to the practice of medicine and healthcare in order to improve outcomes for individuals and for populations (Donald, 2001, Waterman et al., 2015, Orenstein and Yang, 2015).

### 2.3.6 Summary

In this section we have seen how the literature demonstrates that the adoption of a population health approach and utilisation of public health informatics methodology can produce timely and valuable information and knowledge on trends in disease/condition prevalence including the establishment of population profiles.

The next section will further explore the use of EHR/EPR technology for population health study.

## 2.4 Using EPRs for Population Health Research

It has been contended that *“clinical research is on the threshold of a new era in which electronic health records (EHRs) are gaining an important novel supporting role”* (Coorevits et al., 2013). This section explores how the use EHRs/EPRs could support population health study.

### 2.4.1 Use of EPRs to support healthcare delivery

An ideal EHR system would capture, link, and make available all data from every healthcare encounter (Cusack et al., 2013). The landmark paper *“To Err is Human”* saw the potential for effective EHR use to improve safety in healthcare by preventing medical errors which at the time were believed to cause between 44 and 98 thousand deaths annually in U.S. hospitals (Kohn, 1999).

Widespread use of EPRs/EHRs has been estimated to have saved the U.S. approximately \$77 billion per year and in 2009 as part of the American Recovery and Reinvestment Act (ARRA), \$19 billion was provided to stimulate EHR use (Hersh, 2009).

In Ireland, the Department of Health and the HSE have recognised the importance of electronic records in its strategy document “*National Health Information Strategy*” and later in “*eHealth Strategy for Ireland*”; the HSE has acknowledged that integration of EPRs is a major innovative change required for the delivery of clinical services (DoH, 2013a, Kapur, 2011).

The use of EPRs is changing the way care is delivered by clinicians (Wasserman, 2011). Clinicians and healthcare providers generally have viewed EPRs principally as a legal record of patient encounters, used (as is the case with paper records) to record observations, share information with other professionals, justify interventions and monitor change (Reiser, 1991).

#### 2.4.2 Use of EPRs for research

However use of the clinical data from EPRs also provides an opportunity for improved clinical research capability which will lead to system-wide improvement in healthcare outcomes (Wasserman, 2011, Cusack et al., 2013, Tang et al., 2007, Curcin et al., 2010). To date research conducted in this way has been largely confined to large academic medical institutes but the more-recently-realised high levels of EPR use by primary care practitioners, improved EPR design (with greater use of structured data) and improved processing capabilities mean that there is real potential to extract valuable information and knowledge from these EPR data through epidemiological study and research (de Lusignan and van Weel, 2006, Gardner et al., 2014). Studies have shown that EPR data can be “*a useful source of population health surveillance to inform and evaluate local population health initiatives*” (Sidebottom et al., 2014). Increasingly, clinical researchers are seeking methods to enable secondary use of electronic clinical data (Barnett et al., 2012, Weiskopf and Weng, 2013).

According to the Institute of Medicine in the U.S. (IOM), one of the eight core functions that an EHR system should have is “*Reporting and Population Health*” (see Table 2-7).

**Table 2-7: The core functions of and EHR system**

No.	Core EHR function
1.	Health information and data
2.	Result management
3.	Order management
4.	Decision support
5.	Electronic communication and connectivity
6.	Patient support
7.	Administrative processes and reporting
8.	Reporting and population health

*Source: Institute of Medicine (IOM, 2003a)*

EPR systems and their databases were not initially designed for research purposes, so there are inherent limitations to their use for such purposes (Oleske et al., 2014). However, it is believed that EPRs have the potential to support improvements in population health through yielding better information on the level and distribution of disease as well as of wellbeing in populations. Observational data contained in EPRs may provide information on a wider geographic population and possibly over longer time frames than would be offered by other study types and it is predicted that EPRs will be increasingly used for population health and epidemiological research (Oleske et al., 2014). For this to be realised, and for EPRs to provide useful information on populations the following enablers are required (Friedman et al., 2013, Yasnoff et al., 2001):

- Improved population coverage of EPRs/EHRs i.e. entire populations, well-defined sub-sections of a population or representative samples of a population
- Standardised content (including coding) to give standardised measures of disease, functional status, wellbeing and factors affecting population health



- Standardised reporting methods and systems which are accessible and timely. This should allow for aggregation of data from multiple healthcare providers in multiple geographic locations i.e. Health Information Exchange (HIE)
- Linkage of data over time to provide for population health tracking over the life course
- Legislative support of EPR/EHR use and data use including the use of a unique health identifier

EPRs can allow for the collection of data just once which can then be reused for other purposes (Buck et al., 2009) leading to improved investigation and identification of conditions, diseases and events and allowing evaluation of changes in population health levels; the use of Health Information Technology (HIT) in this way can bring improvements in population health surveillance as well as in disease prevention (IOM, 2003a, Shih et al., 2011, De Leon and Shih, 2011, Calman et al., 2012). Government public health policy and financing can be informed by the estimates of disease and its distribution in populations from EPR data (Friedman et al., 2013). Table 2-8 illustrates how EPR & EHR data can contribute to population and public health.

**Table 2-8: Potential contributions of EPRs/EHRs to population and public health**

Topic and Target	Information Needed About the Target	Potential Contribution of EHRs to Information Needed About Target	Required enablers for EHRs to Provide Needed Information
<p><b>Population Health</b></p> <p><b>Primary target:</b> population or population subgroup</p>	<ul style="list-style-type: none"> <li>- Level of population’s functional status</li> <li>- Level of population’s well-being</li> <li>- Knowledge of societal factors that influence population health</li> </ul>	<ul style="list-style-type: none"> <li>- Measuring level and distribution of disease, functional status and well-being</li> <li>- Tracking health disparities</li> <li>- Building population health records</li> </ul>	<ul style="list-style-type: none"> <li>- Coverage by EHRs of population or representative population subsamples</li> <li>- Standardized EHR measures for disease, well-being, and influences on health</li> <li>- Standardized reporting to enable population aggregations and analysis</li> <li>- Unique health care identifier for individuals or effective record linkage</li> </ul>
<p><b>Public health (population-based programmes)</b></p> <p>(e.g. fluoridation of water, fortification of foods with folic acid, anti-smoking campaigns)</p> <p><b>Primary target:</b> population or population subgroup</p>	<ul style="list-style-type: none"> <li>- Level of population’s functional status</li> <li>- Level of population’s well-being</li> <li>- Presence of societal factors that influence population health and likelihood that they will affect health</li> <li>- Knowledge of safe, effective population strategies to improve health</li> </ul>	<ul style="list-style-type: none"> <li>- Improving reporting and investigation of notifiable diseases</li> <li>- Identifying sentinel diseases, injuries and events</li> <li>- Improving surveillance, programme targeting and programme interventions for chronic conditions</li> <li>- Populating disease registries</li> </ul>	<ul style="list-style-type: none"> <li>- Coverage by EHRs of population or definable subpopulations, or representative population subsamples</li> <li>- Standardized EHR measures for disease, functional status, and well-being, as needed for and specific to individual programmes</li> <li>- Standardized reporting to enable population and subpopulation aggregations and analysis</li> <li>- Timely reporting of, or access to, specific EHR information</li> </ul>
<p><b>Government public health policies and financing</b></p> <p><b>Primary target:</b> population or population subgroups</p>	<ul style="list-style-type: none"> <li>- Knowledge of safe, effective strategies to improve population health</li> <li>- Level and distribution of population health problems</li> <li>- Level and distribution of population health disparities</li> </ul>	<ul style="list-style-type: none"> <li>- Estimates of disease burden and its distribution in the population and population subgroups</li> </ul>	<ul style="list-style-type: none"> <li>- Coverage by EHRs of population or definable subpopulations, or representative subsamples</li> <li>- Standardized EHR measures for disease, functional status, and well-being as needed for and specific to individual programmes</li> <li>- Standardized reporting to enable population and subpopulation aggregations and analysis</li> <li>- Timely reporting of, or access to, specific EHR information</li> </ul>

*Adapted from Friedman et al. (2013)*

### 2.4.3 Experience to date

However, the experience to date, even in counties where EPR/EHR use is at a relatively high level, is that only very limited success in using these data for population health has been realised with poor exchange of information i.e. HIE, frequently cited as being the root cause (Friedman, 2006, Jha et al., 2008, Overhage et al., 2008, Gooch, 2014).

Where Health Information Technology (HIT) has been used in a population health approach such as in the Primary Care Information Project (PCIP) in New York City, improvements have been seen in some measures that are known to be associated with care quality. However, a significant lesson learned has been that the use of the EPR data alone is insufficient to bring improvements in the health of the population; technical assistance from the public health department to the healthcare providers is a requirement if the aims of improvement in population care delivery and health outcomes are to be reached (Kaye et al., 2014, Ryan et al., 2013).

In Ireland, a recent initiative has been the foundation of the Irish Primary Care Research Network (IPCRN) which - supported by the Irish College of General Practitioners (ICGP) and the Health Research Board (HRB) - collects data from the EPR systems of General Practitioners (G.P.s). These data are anonymised and aim to create national reports on conditions such as diabetes, atrial fibrillation and heart failure. While still in the early stages of development, the overall aim of the IPCRN project is *“to establish a national network of GP practices whose purpose is to participate in clinical research for the benefit of their patients and to enhance the discipline of general practice through research”* (IPCRN, 2015).

Providing and maintaining IT infrastructure to support EPR use for population health management is essential for the collection, secure storage and analysis of clinical and operational data and the distillation of best practices in a cost-effective manner (Block, 2014, Foldy et al., 2014, Peterson, 2006).

Providers of primary care in the community and vendors of EPR systems will need to ensure that these systems (and their workflows) are set up in a way that supports the public health agenda. This is coincident with the evolution in primary care towards community/population-based approaches (Calman et al., 2012, Gooch, 2014, Violán et al., 2013). Patient data collected along all points of care pathways will support the development of information-

powered decision-making for individuals and populations through the merging of complex data analytics and clinical care processes and initiatives (Block, 2014).

Adopting this approach is also believed to be useful in facilitating and encouraging practice-based research (Gardner et al., 2014).

#### 2.4.4 Summary

EPR data can be a powerful source of new knowledge on population health. Mining these data can identify patients at risk of developing chronic diseases or serious sequelae of existing conditions (Calman et al., 2012, Foldy et al., 2014). For example, extracting data on child gender, height, weight and age can be used to calculate body mass index (BMI) which can then be aggregated to establish the prevalence of paediatric obesity in a population (Wasserman, 2011).

Moreover, while EPRs are an excellent source of health data, augmenting these data with community level information has the potential to provide even more powerful population health information particularly if information on known associations with the condition or disease of interest is available (Roth et al., 2014). For example, in the case of studying obesity levels, knowledge of environmental factors such as the availability of recreational facilities (parks etc.) and healthy food (fruit and vegetables) as well as knowing socio-economic factors (levels of income and education) would hugely enhance the understanding of the condition and how to tackle it at a community/population level (Colls and Evans, 2014, Wang et al., 2007). When considering this type of population health study, geographic data at the finest level of granularity possible should be collected along with the EPR clinical data so that linkage to other community-level data can be made (Roth et al., 2014).

The next section will explore some of the challenges which may be preventing or limiting the use of EPR data for secondary purposes.

## **2.5 Challenges to Secondary Use of Data from EPRs**

### **2.5.1 Introduction**

To date, even in countries with relatively high rates of EPR use, only limited degrees of success in using the data from these EPR systems for population health has been realised (Friedman et al., 2013). There are many practical challenges and obstacles to the collection, aggregation and secondary use of EPR data (Diamond and Shirky, 2008).

While legal and funding issues can be significant challenges, others include EPR data content and quality, lack of data standards for broad range of population health measures, the development of techniques for generating valid estimates for populations with incomplete EPR/EHR coverage, the security and confidentiality of individuals' data and the ability to link data over time to provide for longitudinal study (Friedman et al., 2013).

In 2006, The Agency for Healthcare Research and Quality (AHRQ) provided an extensive list of challenges and divided them into six discrete topics, as detailed in Table 2-9.

**Table 2-9: AHRQ data collection challenges**

Challenge	Challenge components
<b>Inefficiency</b>	<ul style="list-style-type: none"> <li>• Collection and reporting utilise different taxonomies and data definitions leading to requirements for data validation and continuous updating</li> <li>• Documentation and data quality</li> <li>• Incomplete clinical documentation</li> <li>• Disparate electronic systems</li> <li>• Manual data abstraction</li> <li>• Inconsistent policies and practice</li> <li>• Provider staff resources: increased staffing resources in conjunction with reporting requirements</li> </ul>
<b>Variations in measurement systems</b>	<ul style="list-style-type: none"> <li>• Mandatory vs. voluntary reporting</li> <li>• Different reporting formats for different institutions, sometimes for the same disease and patient cohort</li> </ul>
<b>Organisational and cultural issues</b>	<ul style="list-style-type: none"> <li>• Health care organisations must have stakeholder acceptance, internal change organisation and a culture that allows the continuing provision of reliable data and implementation of changing requirements.</li> </ul>
<b>Technological barriers for electronic health records (EHRs)</b>	<ul style="list-style-type: none"> <li>• Uncoordinated implementation of health IT systems locally and nationally.</li> <li>• Interoperability issues.</li> <li>• Cost of technology.</li> <li>• Lack of understanding of the improvement role that EHRs can play in improving data reporting nationally.</li> <li>• Lack of minimum common data sets for population health and quality measurement.</li> <li>• Security and privacy issues.</li> <li>• Data ownership issues.</li> </ul>
<b>Economic pressures</b>	<ul style="list-style-type: none"> <li>• Costs of collecting data.</li> <li>• Cost of dissemination and interpretation of performance data within organisations</li> </ul>
<b>Competing priorities</b>	<ul style="list-style-type: none"> <li>• Variations in measure sets, data metrics and taxonomies.</li> <li>• Lack of alignment between the institutions mandating the reporting.</li> <li>• Absence of a national health care quality data set and report card.</li> <li>• Privacy of individuals versus reporting requirements.</li> <li>• Keeping up to date with the changing reporting requirements.</li> </ul>

*(AHRQ, 2006)*

For the purposes of this review, taking account of the more frequently discussed challenges in the literature and focussing on the issues pertinent to this study, the barriers identified in the following sections (2.5.1 to 2.5.4) will be explored in more detail.

## 2.5.2 Data governance (privacy, confidentiality & consent)

There are three basic options when it comes to secondary use of data for research (Lowrance, 2003):

**Option 1:** Use personal data with consent from the data-subjects

**Option 2:** Only use data that are anonymous or anonymised

**Option 3:** Use personal data without explicit consent under a public-interest mandate

Option 1 may be the approach used for patient registries (Gliklich et al., 2014, Dreyer and Garner, 2009) but obtaining informed consent for each data-extraction/research purpose will often be unduly onerous or impossible particularly for retrospective study. The case for option 3 may be made when the need to collect data is seen to outweigh the protection of identity but this will usually require specific state legislation as was enacted in Ireland in 1991 to establish the National Cancer Registry (NCRI, 2015). Option 2 is likely to be the option that is most practical approach in most cases but does present some significant challenges (Lowrance, 2003).

The collection of personal health information has a duty of confidentiality<sup>2</sup> to each person about whom information is held. There are ethical, regulatory and legislative obligations on any person or organisation processing personal health information. Thus, information governance is an essential consideration in ensuring that information is handled legally, securely, efficiently and effectively so that the that the secondary use objectives are met while

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<sup>2</sup> Confidentiality is the duty that a person owes to safeguard information that has been entrusted to them by another.

respecting every individual's right to confidentiality and privacy<sup>3</sup> (de Lusignan and van Weel, 2006).

In Ireland Data Protection legislation (Data Protection Act 1998 & 2003) enacts the European Union the EU Directive 95/46/EC on the processing and movement of personal (EU, 1995). The Directive enshrines the individual's fundamental right to privacy and confidentiality and their right to control disclosure of and access to their health information by giving, withholding or withdrawing consent. There are eight rules laid down by the Data Protection Commissioner (DPC) for upholding the rights conferred by the legislation; these are summarised in Appendix B (DPC, 2005).

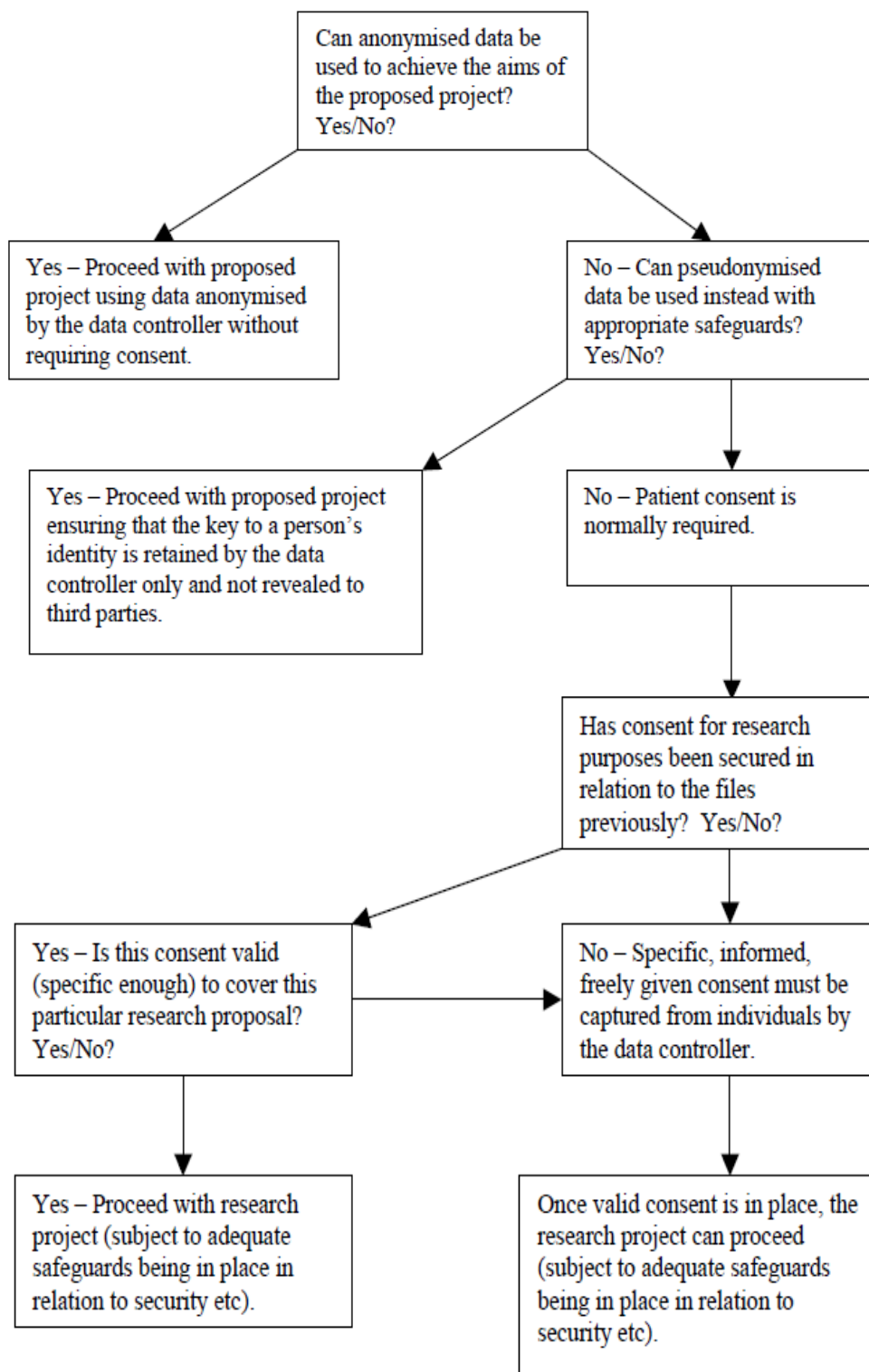
However, according to the guidance of the DPC in Ireland, healthcare data collected for secondary use that are anonymised by the data controller are outside of the regulation of the DPC and the consent of the patient is not required (DPC, 2007). This is illustrated in Figure 2-5.

Privacy and security of data must be protected during use, storage and transmission to ensure that no loss, corruption or diversion occurs. Systems that store and transmit data require ongoing capability building to stay ahead of new security threats (Foldy et al., 2014).

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<sup>3</sup> Privacy relates to the individual's right to prevent information about them being disclosed.





**Figure 2-5: Data Protection Commissioner - Best practice approach to undertaking research projects using personal data**

### 2.5.3 Data quality

It is known that EPR data can be less than optimal in terms of quality. However assessing data quality poses its own challenges. A systematic review published in 2013 into the methods and dimensions of data quality assessment in the context of EPR/EHR data reuse for research found that there is “*little consistency or potential generalizability in the methods used to assess EHR data quality*” (Weiskopf and Weng, 2013, Weiskopf et al., 2013). While HIQA has identified seven dimensions of data quality in general (see Figure 2-6), Weiskopf and Weng found that the five dimensions of completeness, correctness, concordance, plausibility and currency are the qualities relevant to secondary use of EPR data. These qualities are often referred to in other terms in the literature as illustrated in Table 2-10. Most (73%) papers reviewed by Weiskopf and Weng looked at structured data only and completeness was found to be the most-assessed data quality feature and the issue of incomplete EPR data is well recognised (Thiru et al., 2003, Chan et al., 2010, Häyrynen et al., 2008).

**Table 2-10: Terms used in the literature to describe the five common data quality features**

Completeness	Correctness	Concordance	Plausibility	Currency
Accessibility	Accuracy	Agreement	Accuracy	Recency
Accuracy	Corrections made	Consistency	Believability	Timeliness
Availability	Errors	Reliability	Trustworthiness	
Missingness	Misleading	Variation	Validity	
Omission	Positive predictive value			
Presence	Quality			
Quality	Validity			
Rate of recording				
Sensitivity				
Validity				

(Weiskopf and Weng, 2013)



**Figure 2-6: HIQA dimensions contributing to data quality**

HIQA's *"National Standards for Better Healthcare"* indicates that good quality data is essential if these data are to be used effectively as a resource for planning, delivering, monitoring, managing and improving healthcare (HIQA, 2012a).

Greater use of structured data, coding and checklists rather than narrative/free text data can help to improve data quality and facilitates data extraction for secondary use (Wasserman, 2011, de Lusignan and van Weel, 2006). While IT system tools can be utilised to minimise data inputting errors by ensuring that routine checks be performed on data items chosen, data coding and data entry, people (and their training) are the key factor in ensuring data quality.

#### 2.5.4 Interoperability

In 2007, Kalra & Blobel recognised that inter-system EPR/EHR semantic interoperability was required in order to (amongst other purposes) *"ensure the necessary data quality and consistency to enable rigorous secondary uses of longitudinal and heterogeneous data for public health, research and health service management"* (Kalra and Blobel, 2007).

Interoperability could also greatly improve the reach of EPR data mining initiatives (Kalra, 2006, Dogac, 2012).

Interoperability is defined by the International Organization for Standardization (ISO) as the ability of disparate systems to exchange information without a requirement for interpretation (ISO, 2005). Data standards are critical for interoperability and meaningful secondary use (Barton et al., 2011, Kalra, 2006, Häyrynen et al., 2008).

Some key internationally-recognised data standards include:

- Data dictionaries which clearly explain all data items gathered for a given project/purpose along with standardised definitions for each data item (Gliklich and Dreyer, 2010).
- Classification systems such as the International Classification of Diseases (ICD) and its variations, including the 9<sup>th</sup> and 10<sup>th</sup> editions (ICD-9, ICD-10) and assorted Clinical Modifications thereof (e.g., ICD-9-CM, ICD-9-AM, ICD-9-CA and ICD-10-CM) provide classifications for diseases to ensure that collected data are comparable with other systems and jurisdictions (Cimino, 2011).
- Clinical terminologies e.g. Logical Observations, Identifiers and Codes (LOINC), Systemized Nomenclature of Medicine (SNOMED); these can ensure increased accuracy and precision in the recording of clinical data and enhanced gathering of information (McDonald et al., 2003, Benson, 2012).

In 1999, the ISO Technical Committee 215 (Health Informatics) was formed to specifically support the compatibility and interoperability of ICT systems in healthcare. The ISO has also defined standard data types that can aid EHR interoperability (Kalra, 2006).

The “eHealth Ireland” project in this country should increase opportunities to gather data from EPRs by facilitating the development of integrated health technology ecosystems (Conlon, 2013, DoH, 2013b). Such interoperability will also be helped by HIQA’s standards-based approach to interoperability for the delivery of “*safer, better care*” and by the legislation to

enact the use of unique identifiers for all healthcare providers and service users in Ireland (HIQA, 2012a, McGloughlin, 2013).

While it is now well recognised that using standards such as terminologies to encode data at the point of capture in EPRs so that they can support a variety of uses and overcome the obstacles of differing clinical languages and documentation styles, it is still seen as a considerable challenge to get to the stage where these standards are universally used (Cimino, 2011, Barton et al., 2011, Coorevits et al., 2013, Rose et al., 2001). Overcoming these challenges to create interoperability will ensure that data can be used to improve individual patient care while also bringing public health benefits (McVeigh, 2008).

### 2.5.5 Clinicians and point-of-care data

If the data collected by healthcare providers and professionals in the course of their work are to be used for secondary purposes consideration must be given to how this might impact on the healthcare delivery and at the point of care. Clinicians should be involved in the discussions around why certain types of data need to be recorded consistently and completely as well as in the design and testing of any new data entry formats so that there is consensus on why it is in the best interests of both clinicians and patients. The understanding of these benefits is particularly important if changes are required in work practices (Wasserman, 2011, Hartmann et al., 2015, Curcin et al., 2010).

Structured work fields for recording clinical data can improve the quality of data extraction but these should not be imposed on clinicians without consultation and it should be made easy for healthcare providers to build any such new formats into their workflows (Gardner et al., 2014, Linder et al., 2009, Wasserman, 2011). It has been demonstrated that the greater use of structured data capture at the point-of-care may help to reduce the documentation burden on clinicians (Cusack et al., 2013, Poon et al., 2010). Given that it has been demonstrated that there are financial benefits brought by the use of EPRs through reduction or avoidance of human resource costs (Iakovidis, 2012, Silow-Carroll et al., 2012, Wang et al., 2003), any increase in resource required at the point of care to facilitate secondary use of collected data is seen as a significant barrier.

The findings from the research using the EPR data should be reported back to the clinicians. This will further strengthen the relationships and communication between clinicians and researchers and can act as enabler in (a) motivating the clinicians to ensure that they collect the data required for research purposes during their patient encounters and (b) facilitating practice-based research (Wasserman, 2011, Hartmann et al., 2015).

### 2.5.6 Summary

Currently there is only very limited successful use of data from these EPR systems for population health research purposes. This section identified the issues that may act as barriers to this secondary use. Some of these challenges - data governance, data quality, interoperability and impact on the point-of-care processes - were explored further.

The next section will introduce the topic of refractive error.

## 2.6 Refractive Error

To give context for the motivation for this study, this section will explain what refractive error is, how its prevalence is studied and why it is important to do so.

### 2.6.1 What is refractive error?

The World Health Organisation (WHO) defines refractive error as a “*very common eye disorder that occurs when the eye cannot clearly focus the images from the outside world. The result of refractive errors is blurred vision, which is sometimes so severe that it causes visual impairment*” (WHO, 2013). If uncorrected, these common disorders of vision can have severe consequences on quality of life and social and economic wellbeing (Naidoo and Jaggernath, 2012).

The most common refractive errors are:

- **myopia** (near-sightedness): difficulty in seeing distant objects clearly

- **hyperopia** (far-sightedness): difficulty in seeing close objects clearly
- **astigmatism**: distorted vision resulting from an irregularly curved cornea, the clear covering of the eyeball.
- **presbyopia**: difficulty in reading or seeing at arm's length, it is linked to ageing and occurs almost universally

Refractive errors occur when there is a mismatch between the optical power and the length of the eye (Ganesan and Wildsoet, 2010); they are diagnosed by the process of refraction during an eye examination. They are treated with corrective glasses, contact lenses or refractive surgery. It is important that refractive errors be corrected in time (particularly those occurring in childhood) by eye care professionals so as to allow for full development of good visual function (WHO, 2013, Naidoo and Jaggernath, 2012, Kempen et al., 2004). The form of correction will depend on the type of defect, age of the person and their vision requirements in terms of their work and other activities.

## 2.6.2 Prevalence

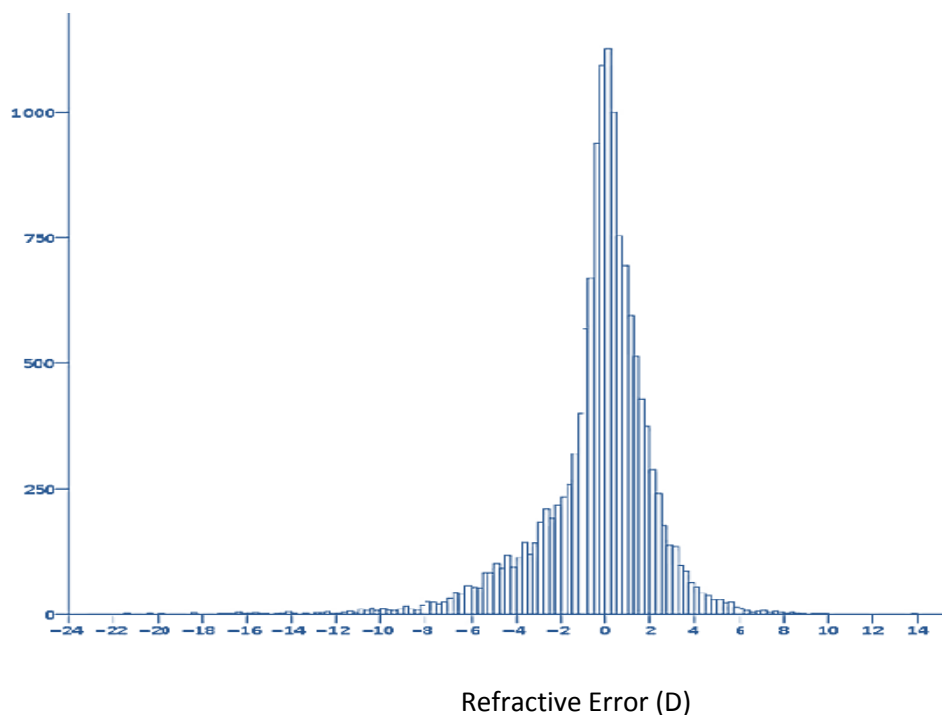
It is estimated that up to 2.3 billion people worldwide suffer from poor vision as a result of refractive error (Naidoo and Jaggernath, 2012, Thulasiraj RD, 2003). However studies of the epidemiology of refractive error are relatively rare, particularly in Europe (Dunaway and Berger, 2003). This may be because refractive errors can generally be easily corrected and the majority have no serious pathological implications (Wolfram et al., 2014). While the main refractive errors are common, they are also complex and multifactorial conditions whose rates of occurrence vary across populations with different ethnicities (Hyman, 2007). Both genetics and environment are known to play a role in the aetiology of refractive error (Wolfram et al., 2014, Morgan et al., 2012). Epidemiologic research into the distribution of refractive errors will enable more efficient planning to both improve access to care and provide a basis to evaluate changing rates and impact of remedial interventions (Dunaway and Berger, 2003).

Many of the population-based studies carried out in the world have shown that the prevalence of myopia decreases with age and that the opposite is true for hyperopia (Attebo et al., 1999,

Hyman, 2007, The Eye Diseases Prevalence Research, 2004, Kempen et al., 2004, Wang et al., 1994). Myopia has also been shown to be associated with higher levels of education (Wang et al., 1994, Attebo et al., 1999, Xu et al., 2005).

The most recent large scale population-based study in Western Europe has been the Gutenberg Health Study (GHS), a prospective cohort study carried out in the Rhine-Maine region of Germany. This study measured the refractive error of 13,959 subjects and found that the prevalence of myopia, hyperopia and astigmatism were 35.1%, 31.8% and 32.3% respectively. The prevalence of high myopia (greater than 6 dioptres<sup>4</sup>) was found to be 3.5% (Wolfram et al., 2014).

Figure 2-7 illustrates the distribution of refractive error (myopia and hyperopia) for the study population. The range is from -21.50 dioptres (myopia) to +13.88 dioptres (hyperopia). The resultant profile of refractive error does not follow a Gaussian distribution – it is skewed towards myopia ( $v = 1.457$ ).



**Figure 2-7: Distribution of refractive error (Gutenberg Health Study)**

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<sup>4</sup> Dioptre (D) = unit of measurement of refractive (optical) error



Table 2-11 presents the results of a number of studies into prevalence of refractive error from around the world.

**Table 2-11: Prevalence rates of refractive errors in population-based eye studies**

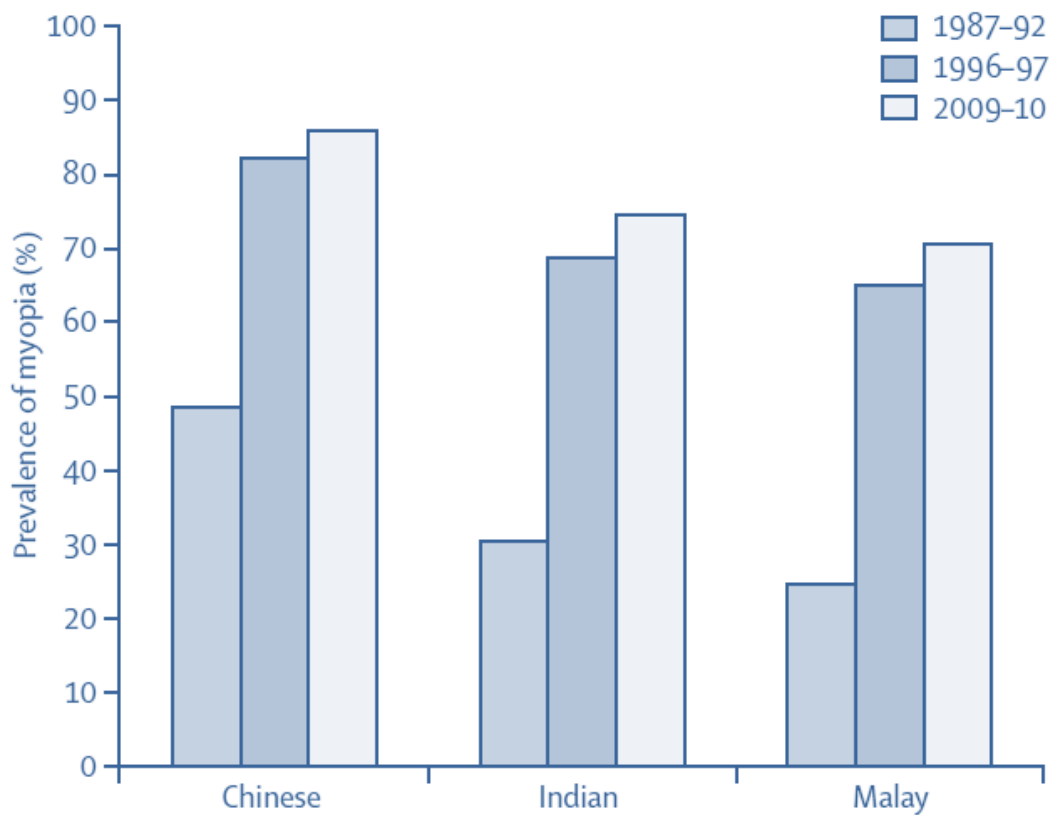
Study	Beaver Dam USA (Wang et al., 1994)	Blue Mountains Australia (Attebo et al., 1999)	Singapore Malay Population (Saw et al., 2008)	Tajimi Japan (Sawada et al., 2008)	Handan China (Liang et al., 2009)	Norfolk GB (Foster et al., 2010)	GHS Germany (Wolfram et al., 2014)
Subjects (n)	2354	3654	3400	3021	6491	2519	13959
Myopia (<-0.5 DS)	26.2%	15.5%	30.7%	41.8%	26.7%	27%	35.1%
Hyperopia (>+0.5 DS)	49.0%	56.6%	27.4%	27.9%	15.9%	52.2%	32.3%
Astigmatism >0.5 DC)	NA	NA	33.3%	54.0%	24.5%	NA	32.3%

### 2.6.3 Myopia

Myopia is of particular interest. It is the world's most prevalent eye disorder with prevalence rates of about 20 to 50% in Europe and the U.S. and higher than 80% for young adults in some parts of East Asia (Leo and Young, 2011, Si et al., 2015). It also appears that the prevalence of myopia and severe myopia have been increasing significantly in recent years while onset is occurring at younger age (Leo and Young, 2011). In Western populations the prevalence of

myopia in young children is low (less than 5%) but the prevalence amongst Asian children can be as high as 29% in 7-year-olds. In addition to the direct economic and social burdens of myopia, associated ocular pathological complications may lead to substantial vision loss (Leo and Young, 2011).

Figure 2-8 documents the changes in prevalence of myopia in the three major ethnic groups in Singapore over approximately two decades (Morgan et al., 2012).



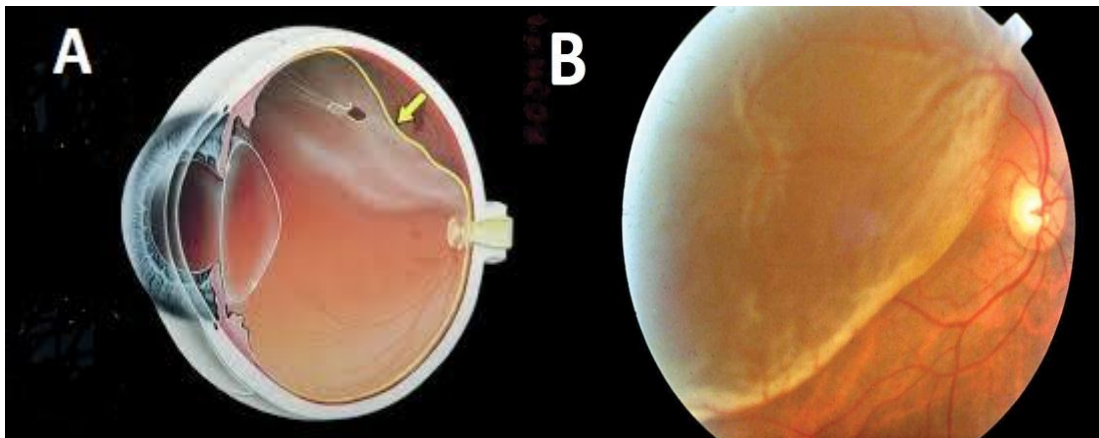
**Figure 2-8: The changing prevalence of myopia in different ethnic groups in Singapore**

### 2.6.3.1 Associated pathologies

As myopia is the refractive error that is most associated with ocular co-morbidities and it is the one whose incidence and prevalence appears to be increasing worldwide, it is worth noting the myopia-associated ocular pathologies.

In particular a higher level of myopia has been shown to be a significant risk factor for certain pathologies such as glaucoma, cataract, myopic maculopathy (myopic retinopathy), macular degeneration, choroidal neovascularisation (new blood vessels), scleral thinning, retinal detachment (Figure 2-9) and macular retinoschisis (Fujikado et al., 2014, Xu et al., 2007, Morgan et al., 2012, Khader et al., 2006, Mavracanas et al., 2000, Si et al., 2015).

While several different definitions of *high myopia* exist, studies generally have shown that the rate of presence of pathological signs increases steeply in eyes that have a level of myopia greater than -5 or -6 dioptres and that few of these signs are noted in mild-to-moderate myopic eyes (Morgan et al., 2012, Liu et al., 2010).



**Figure 2-9: Retinal detachment**

**(A: graphical representation, B: digital image of extensive retinal detachment in vivo)**

### 2.6.3.2 Strategies to prevent myopia and myopia progression (Myopia Control)

Currently and increasingly, the principal motivations for refractive error study are to establish the changing rates of occurrence of myopia, to establish the aetiological factors and to observe the impact of new “myopia control” interventions. (Si et al., 2015)

Myopia progresses as the eyeball grows. In particular, the axial length of the eye - i.e. the distance from the front of the eye (the cornea) to the posterior of the eye (the macula) - increases (Lam et al., 1999). In order to prevent progression of myopia, this elongation of axial

length must be prevented. Three main categories of methods/interventions to “control” this process have been proposed and/or used (Fujikado et al., 2014):

- Environmental
- Optical
- Pharmacological

An explanation of these different approaches is presented in Appendix C.

#### 2.6.4 Summary

This section defined and explained refractive error and explored how it and its prevalence are currently studied. As there is some evidence that rates of myopia are increasing in many parts of the world, this particular refractive error and its significance in terms of associated ocular pathologies and vision impairment was examined in more detail.

The next section of the literature review goes on to investigate the use of EPRs in optometry and how their use may contribute to population eye health research.

## 2.7 Using EPR for Refractive Error Study

This section looks at the use of EPRs in the provision of optometric eye care and how the data from these systems might be used for secondary purposes in a population health approach.

### 2.7.1 Use of ICT in optometric practice

Information technology (IT) is a prominent feature of modern optometric practice (Stolee et al., 2011, Edlow and Markus, 2008) and now influences many aspects of the delivery of optometric services including clinical assessment, patient management, dispensing, patient

education, communication, practice management and clinical record keeping (McVeigh et al., 2008). Optometry may be more proactively using technology in clinical practice than other healthcare sectors (Stolee et al., 2011).

A 2013 study by the American Optometric Association (AOA) resulted in the publication of a report providing descriptive statistics on the use of EPR systems by optometrists in the U.S. The study found that 63% of practising optometrists use a “complete” EPR system (defined as an electronic system that comprised both practice management and patient health (clinical) information systems). A further 2% used stand-alone patient health information systems, bringing the total to 65% of respondents who collect clinical data electronically. Many benefits were cited by participants including enhanced patient care, improved access to information, better outside communication and ability to e-prescribe. While 59% attest to achieving the core objectives of the so-called “*Meaningful Use*” programme<sup>5</sup>, it appears that few can verify that they are meeting the optional objectives of that programme that relate to secondary use of data for population/public health purposes (AOA, 2013). The criteria for *Meaningful Use* can be viewed in Appendix D.

As in other healthcare domains, a significant amount of data collected by eye care professionals (ECPs) is recorded in the form of free text. However, increasingly efforts are being made (e.g. through the use of checklists) to use more structured data which is more computer-readable facilitating sharing, aggregation and analysis (Lobach et al., 2005, Sanders et al., 2013). Some clinical data elements of a typical eye care encounter are inherently “structured” in nature which can even be automatically entered into an EPR from a linked digital device. For example, refractive error, visual acuity, intra-ocular pressure and keratometry (corneal curvature) are all recorded as numerical values (McVeigh et al., 2008, Chiang et al., 2011).

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<sup>5</sup> In 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act in the U.S. established an incentive programme to encourage the adoption of EHRs by hospitals and eligible professionals. Professionals who show “meaningful use” of certified EHRs are eligible for incentive payments.

### 2.7.2 Potential for use of optometry EPRs for population eye health

In 2011, a U.S. study explored how greater levels of EPR/EHR use could support public health surveillance of eye health and vision-related conditions (Elliott et al., 2012). Such eye health surveillance requires *“ongoing, systematic collection, analysis, interpretation, and dissemination of outcome specific data”* (Zambelli-Weiner and Friedman, 2012) and could be improved through *“the coordinated use of EHR data”* (Elliott et al., 2012). For example, the proportion of the population having a complete eye examination every two years could be assessed by collecting and aggregating the data from optometrists’ EPR systems. None of the systems studied by the Elliott et al. are currently used for surveillance of vision status or eye health of the populations they hold data on. However, the potential is recognised and the study identifies some of the advantages (as well as disadvantages) of using EPR data for this purpose (see Table 2-12).

In the last year, an eye health needs assessment study in the West Midlands of the U.K. has used a population health approach to identify priorities for eye health, reduce eye health inequalities and outline the development of local eye care services. However a significant challenge to this work which could have been assisted by the use of optometry EPR data had it been available, was the scarcity of good information on the prevalence and incidence of ocular conditions (Hirji, 2015).

Similarly, in an article published earlier this year, the National Expert Panel to the National Centre for Children’s Vision and Eye Health in U.S. identified the lack of a uniform and reliable approach to recording and gathering data on children’s vision care and proposed the development of an integrated data system for recording paediatric vision screening and eye care (Hartmann et al., 2015). The authors believe that the proposed system would enhance eye health at both patient and population levels.

**Table 2-12: Advantages and disadvantages of using electronic health information for vision and eye health surveillance**

Advantages	Disadvantages
Data available in real time	General EHR operating systems may not adequately document eye examinations and care
Data abstraction can be automated	Potential reluctance of eye care providers to adopt EPR technology
Obtaining EPR data is less time-consuming than traditional chart reviews	Incompatibility of different EPR systems
Data are objective	Possible limited public health value of data collected primarily for clinical purposes
Sharing EPR information facilitates comparisons across geographic regions and diverse populations	It is unclear if EPR data will contain all the types of information needed for public health surveillance of chronic conditions
Allows for incidence, prevalence, and longitudinal analysis	

*Adapted from Elliott et al. (2012)*

The total financial burden of major visual disorders (refractive error, visual impairment, blindness and the four main ocular diseases) among adults in the U.S. on the economy (direct costs and loss in productivity) has been estimated to be over \$30 billion annually (Wittenborn et al., 2013, Rein et al., 2006, CDC, 2006). In Ireland, there were an estimated 224,832 people suffering from visual impairment in 2010 and this has been projected to rise to 271,996 by 2020, the likely economic cost of which is projected to be €2.7 billion (Deloitte, 2011, Layte, 2009). Elliott proposes that the secondary use of eye care EPR data for the surveillance of eye health and vision-related conditions will support policies and programmes that improve population vision health and will reduce the associated economic burden (Elliott et al., 2012).

Refractive error is represented by numbers i.e. structured, computable data which lend themselves to collection, aggregation and analysis. Recording clinical data in structured fields also makes it easier to accommodate clinician workflow (Gardner et al., 2014).

## **2.8 Summary of Literature Review**

This chapter, through review of the literature, has explored how data collected during the process of healthcare delivery can be used for research purposes and how EPRs have the potential to facilitate this like never before; the main challenges to this secondary use of health data have also been identified. Population health study sees the value in new approaches to health research (including the use of real world data) in order to provide population-level evidence bases which can inform public health initiatives and better delivery of healthcare leading ultimately to improved levels of population health and wellbeing. While EPRs are widely used in the field of optometry, no evidence was found in the literature that the clinical data stored therein is being used for purposes other than supporting delivery of service at the point of care.



## 3 Methodology

### 3.1 Introduction

This chapter provides an insight into the processes followed by the researcher in order to address the research question. A clear framework for the work undertaken was developed and the various means of data collection and analysis are described. Limitations of the methodology are also outlined.

### 3.2 Research Question

The research question posed by this researcher is: *“Can data be collected automatically from optometry electronic patient records in Ireland in order to produce a population profile of refractive error and facilitate future research into the field?”*

In order to answer this question, the following sub-questions must be answered:

**RQ1:** Is it technically possible to extract data from optometry EPRs in order to produce a valid profile of refractive error?

**RQ2:** What is the potential quantity of data that could be gathered from optometry EPRs in Ireland?

**RQ3:** Would optometrists in Ireland be willing to be involved in a system of extraction of data from their EPRs for secondary (research) use?

### 3.3 Research Aims and Objectives

This research project aims to:

1. Demonstrate that refractive error data can be collected from optometry EPRs by:

- a. Establishing the willingness and ability of optometry EPR users to be involved in extraction of data from their EPRs
  - b. Designing a mechanism for extraction of these data
  - c. Performing a pilot of this data extraction
- 2. Use refractive error data collected from optometry EPRs to produce a refractive error profile by:
  - a. Gathering together the extracted data
  - b. Performing statistical analysis on these data
  - c. Plotting the frequency distribution (profile) to reveal the relative rates and levels of refractive error
- 3. Lay the foundations for future clinical/population health research by:
  - a. Demonstrating that refractive error data can be extracted from optometry EPRs (through completion of the pilot)
  - b. Designing the extraction mechanism in such a way that it can be repeated
  - c. Establishing how much data may be available for extraction and use for research purposes

### **3.4 Research Design**

Research design can be considered the incorporation of strategy of inquiry, philosophy and research methodology. It describes the research process from proposal of the research purpose and question(s) to analysis of collected data and/or information and provides the plan for carrying out the work (Creswell, 2013). The research design will structure the research so that the research question(s) can be addressed clearly and accurately (McGivern, 2006).

### 3.4.1 Research strategy

A framework for the strategy for the research work to be conducted for this study was developed from an initial early mind map (see Appendix E) and evolved into that which is illustrated in Figure 3-1.

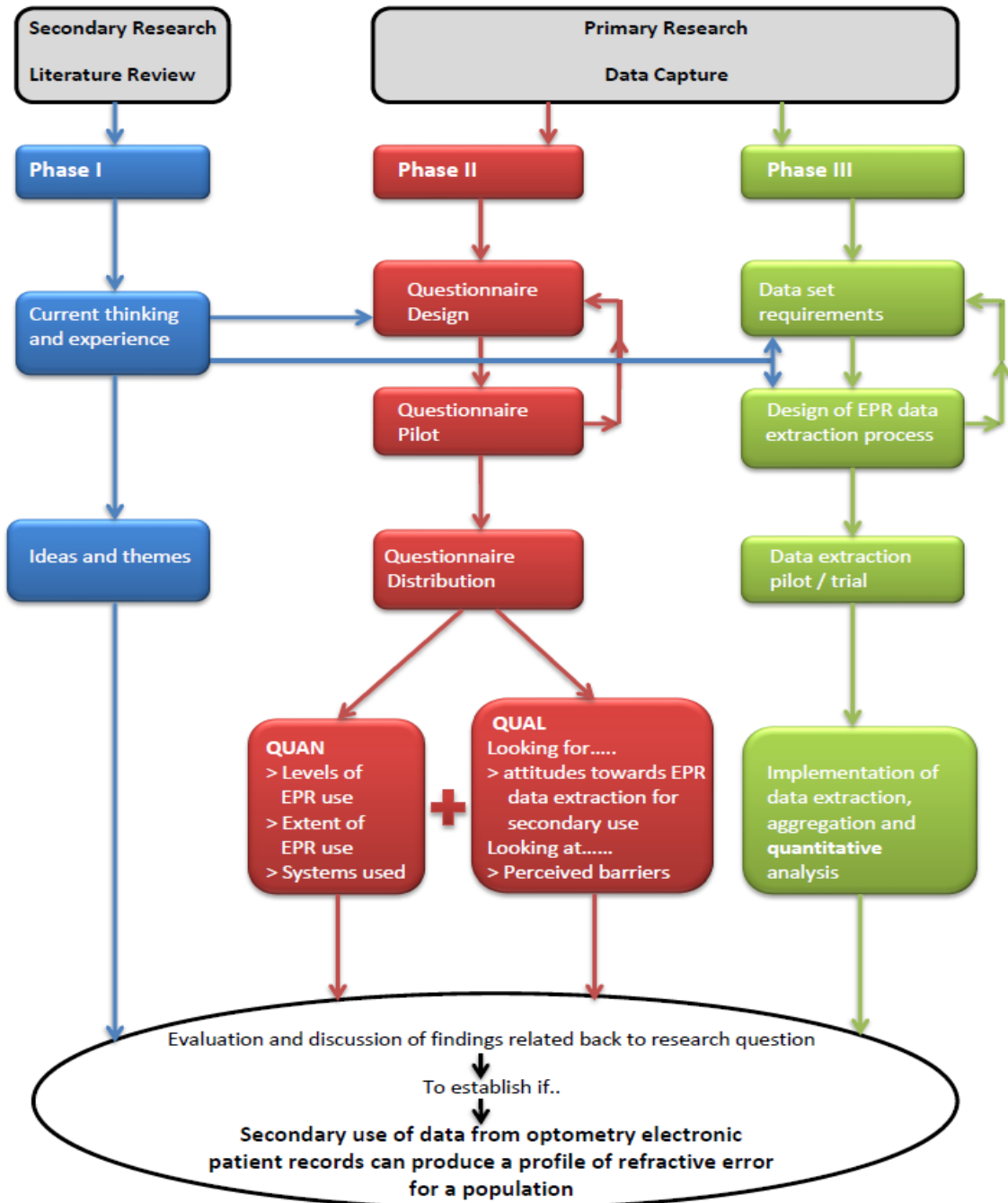


Figure 3-1: Research framework for this study

Planning the strategy for the project also included development of a timetable for the work to be carried out (see Appendix F) and maintenance of a journal to record progress notes, summaries of meetings with supervisor, and evolving to-do lists, thoughts and ideas.

### 3.4.2 Research paradigm (philosophy)

Research paradigms address the philosophical dimensions of study. A research paradigm or philosophical “*worldview*” (Creswell, 2013) is a set of assumptions and beliefs as to how the world is perceived which may influence or guide a researcher’s approach (Wahyuni, 2012). Although the philosophy is typically not explicit in most research, some believe that it is useful for researchers to address the research paradigm as a means of assisting in the design of the research framework (Creswell, 2013, Wahyuni, 2012).

While some elements of this study align with Positivist and Constructivist philosophies, the principal research paradigm is Pragmatism. The pragmatist approach usually starts with the research question in order to determine the research framework (Wahyuni, 2012, Petticrew and Roberts, 2003) and favours the use of both quantitative and qualitative data in the belief that it provides a better understanding of reality (Brannen, 2005). Therefore the research methodology typically employed by pragmatist researchers is of a mixed or multi-method design (depending on the level of integration of the different types of data and their analysis) (O’Cathain et al., 2007, Wahyuni, 2012, Creswell et al., 2004). Table 3-1 is adapted from that constructed by O’Cathain et al. (2007) and demonstrates the epistemological beliefs and research methodology usually associated with each of the three research paradigms named above.

**Table 3-1: Epistemology and methodology of research paradigms**

Characteristics	Research Paradigms		
	Positivism	Constructivism	Pragmatism
<b>Epistemology:</b> <i>the view on what constitutes acceptable knowledge</i>	Only observable phenomena can provide credible data, facts.  Focus on causality and law-like generalisations, reducing phenomena to simplest elements	Subjective meanings and social phenomena.  Focus on the details of situation, the reality behind these details, subjective meanings and motivating actions.	Either or both observable phenomena and subjective meanings can provide acceptable knowledge dependent upon the research question.  Focus on practical applied research, integrating different perspectives to help interpret the data.
<b>Methodology:</b> <i>the design/model behind the research process</i>	Quantitative	Qualitative	Quantitative and qualitative (mixed or multi-method design)

*Adapted from O’Cathain et al. (2007)*

### 3.4.3 Research methodology

Research methodology has been described as the various means of data collection, analysis and interpretation employed by a researcher in endeavouring to answer his/her research questions (Creswell, 2013). The aim of methodology is to assist understanding of not only the outcomes of the scientific study being undertaken but also the process itself (Kaplan, 1973). This researcher’s study was conducted using a mixed (or multi-) method design in several phases of data collection and analysis.

The use of mixed methods appears to have grown out of researchers’ dissatisfaction with the limitations of conventional methods (Small, 2011). While many different definitions have been proposed for mixed methodology, it broadly means combining, integrating or synthesising

both qualitative and quantitative research and data in a research study or a multiphase programme of inquiry (Creswell, 2013, Creswell et al., 2004, Johnson et al., 2007, Small, 2011). Formosa has defined such research as *“the utilization of two or more different methods to meet the aims of a research project as best as one can”* (Johnson et al., 2007). A multi-method strategy can serve particular theoretical, methodological and practical purposes (Brannen, 2005) and it is contended that *“Mixed methods studies can access knowledge or insights unavailable to a qualitative study and a quantitative study undertaken independently”* (O’Cathain et al., 2007). O’Cathain et al. go on to identify from the literature six arguments used to justify the use of mixed methods in social, health and educational research (Table 3-2).

**Table 3-2: Justifications for undertaking mixed methods studies**

No.	Justification
1.	Comprehensiveness, where using both qualitative and quantitative methods allows an issue to be addressed more widely and more completely
2.	Increased validity, when the findings from two different methods agree
3.	Development or facilitation in that one method is improved due to the existence of the other
4.	Emancipation, where the use of a variety of methods ensures that marginalized voices are given space, offering a more equitable or ethical approach to research
5.	“Satisficing” or second best because it may be impractical to undertake the single-method study ideally required
6.	“Salvaging” where one method saves another that has floundered

*(O’Cathain et al., 2007)*

For this study, having considered all of the steps and elements required to answer the research question, the particular mixed methodology that best describes the overall approach to this

work is “*Multiphase Mixed Methods Design*”. Within the overall framework, the individual phases of the study could also be described as using mixed methodology: Phase II could be considered a “*Convergent Parallel Mixed Methods Design*” and Phase III an “*Exploratory Sequential Mixed Methods Design*”. A brief explanation of the use of these different types of mixed methods is shown in Table 3-3.

**Table 3-3: Types of mixed methods design**

Mixed Method Design	Used for.....
<b>Multiphase mixed methods design</b>	Understanding the need for an impact of an intervention programme
<b>Convergent parallel mixed methods design</b>	Comparing different perspectives drawn from quantitative and qualitative data
<b>Exploratory sequential mixed methods design</b>	Developing better measurement instruments

*Adapted from Creswell (2013)*

#### 3.4.4 Phase I: Literature review

Secondary research through literature review has been defined as “*a comprehensive study and interpretation of literature that relates to a particular topic*” (Aveyard, 2010). Literature review allows the researcher to gather information on existing research and current knowledge in the area of interest. This may help to inform the researcher’s own study in aspects such as research design, methods of data collection and scope of the study (Creswell, 2013, Garrard, 2013). The review can also help to justify the requirement for the study and for further research (Creswell, 2013, Fink, 2013).

In order to target the literature review and ensure its relevance to this study and its research question, an initial high level review was conducted. From this, six primary areas of interest emerged as being relevant to meeting the objectives of the study (see Table 3-4).

**Table 3-4: Literature review primary areas of interest**

Area of Interest	Key Objectives
<b>Secondary Use of Clinical Data</b>	<ul style="list-style-type: none"> <li>• Identify what is meant by secondary use of clinical data</li> <li>• Differentiate primary and secondary uses of health data</li> <li>• Outline the potential purposes of secondary use</li> </ul>
<b>Population Health</b>	<ul style="list-style-type: none"> <li>• Define population health</li> <li>• Explore and demonstrate the usefulness of the population health approach to research</li> <li>• Explore how the use of real world data can contribute to the population health approach</li> </ul>
<b>Using EHRs for Population Health</b>	<ul style="list-style-type: none"> <li>• Demonstrate that population health should be a core function of EPR systems</li> <li>• Explore how EPRs can contribute to population and public health</li> <li>• Identify enablers for EPRs to provide useful information on populations</li> </ul>
<b>Challenges to Using EHRs for Population Health Study</b>	<ul style="list-style-type: none"> <li>• Identify the barriers to secondary use of EPR data</li> <li>• Explore the barriers relevant to this study</li> </ul>
<b>Refractive Error Study</b>	<ul style="list-style-type: none"> <li>• Explain refractive error</li> <li>• Explore how refractive error prevalence has been studied to date</li> <li>• Explore how myopia prevalence is changing and the significance of this</li> <li>• Identify proposed interventions for myopia control</li> </ul>
<b>The use of EHRs for Refractive Error Study</b>	<ul style="list-style-type: none"> <li>• Explore how extensively technology/EPRs are used in optometry</li> <li>• Identify any existing efforts to research refractive error using EPRs</li> </ul>

Based on these themes a detailed literature review was undertaken.



### 3.4.4.1 Literature search strategy

Literature searches were conducted electronically through the library service website provided by Trinity College Dublin (TCD). This ensured authorised access and availability of sources. As well as the overall catalogue search facility on the website a number of specific databases and journals were also accessed via the website. Other sources available to the researcher, particularly in the specialist areas of optometry, vision science and refractive error, were also utilised (see Table 3-5 below).

**Table 3-5: Literature search**

Databases	Journals (not available on selected databases)	Institutions/Organisations
PubMed	Optometry Today	HSE
Google Scholar	Optometry and Vision Science	AOI
Science Direct	Journal of Optometry	FODO
Cochrane Library	European Society of Cataract and Refractive Surgery – EuroTimes	NHS
JSTOR		IPCRN
Lenus		DPC
		DoH
		HIQA

To improve the focus and relevance of the review, inclusion and exclusion criteria were determined. Literature for inclusion was selected as indicated in Table 3-6 and the exclusion criteria adopted are shown in Table 3-7.

**Table 3-6: Literature review inclusion criteria**

Identified Literature	Inclusion Criteria
<b>Literature Content</b>	<ul style="list-style-type: none"> <li>• Refractive error research</li> <li>• Population health</li> <li>• Population profiles</li> <li>• Real World Evidence</li> <li>• Secondary use of clinical data</li> <li>• Use of EPRs for healthcare research</li> <li>• Use of EPRs for refractive error / primary eye care research</li> </ul>
<b>Literature Type</b>	<ul style="list-style-type: none"> <li>• Published literature</li> <li>• Government / State Agency Reports</li> <li>• Industry research and reports</li> <li>• Relevant websites</li> </ul>
<b>Language</b>	<ul style="list-style-type: none"> <li>• English language literature only</li> </ul>
<b>Date of Publication</b>	<ul style="list-style-type: none"> <li>• Later than 2000 (except for relevant legislation or key refractive error/epidemiological studies)</li> </ul>

**Table 3-7: Literature review exclusion criteria**

Identified Literature	Exclusion Criteria
<b>Literature Content</b>	<ul style="list-style-type: none"><li>• Secondary use of non-healthcare/clinical data</li><li>• Use of electronic data resources (other than EPR/EHR/health registries) for healthcare research</li><li>• Non-health-related population profiles</li></ul>
<b>Literature Type</b>	<ul style="list-style-type: none"><li>• Unpublished literature</li><li>• Website discussions</li><li>• Blogs</li><li>• Wikipedia</li></ul>
<b>Language</b>	<ul style="list-style-type: none"><li>• Non-English language literature</li></ul>
<b>Date of Publication</b>	<ul style="list-style-type: none"><li>• Earlier than 2000 (except for relevant legislation or key refractive error/epidemiological studies)</li></ul>

#### 3.4.4.2 Electronic search terms

Keywords associated with the various areas of interest were used as search terms to source the most relevant literature. The sections of the literature review and their corresponding search terms are shown in Table 3-8.

**Table 3-8: Electronic search terms**

Area of Interest	Search Keywords
<b>Secondary Use of Clinical Data</b>	Secondary use, patient data, clinical data, electronic health record, electronic patient record, clinical data research, health data research, healthcare
<b>Population Health</b>	Population health, public health, disease, prevalence, epidemiological study, electronic health record, disease profiles, cross-sectional study, registries
<b>Using EHRs for Population Health</b>	Population health, public health, public health informatics, electronic health record, electronic patient record, electronic medical record, registries, data, e-Health
<b>Challenges to Using EHRs for Population Health Study</b>	Population health, public health, electronic health records, electronic patient records, barriers, challenges, study, data, governance, quality
<b>Refractive Error Study</b>	Refractive error, study, myopia, myopia control, profile, prevalence, incidence, optometry, pathology, epidemiology, eye care
<b>The use of EHRs for Refractive Error Study</b>	Refractive error, study, data set, electronic health record, electronic patient record, optometry, eye care

The keywords and various combinations thereof elicited relevant articles and books. The most appropriate publications were selected for review (according to the inclusion/exclusion criteria) and all articles were saved electronically in categorised folders and in the EndNote® citation manager software tool (Reuters, 2011). The identified literature was appraised and all items included in the literature review were referenced appropriately.

The researcher found that while the topic of secondary use of clinical data was well covered in the literature, few articles focussed on data extraction and aggregation from point-of-care electronic records to produce real world evidence (RWE) and that none existed on this type of use of refractive error data from optometry EPRs. This pointed to the possibility of this researcher adding new knowledge, an aspiration of any research work (Creswell, 2013).

The literature review helped to inform the other phases of the study particularly in relation to design of the questionnaire in Phase II and design and development of the data extraction tool in Phase III.

### 3.4.5 Phase II: Survey of optometrists

Survey methodology was chosen to collect quantitative and qualitative data from practising optometrists in order to help answer the research questions. A survey is a system of collecting information which begins with identifying objectives and ends with analysis of the data collected (Dillman, 2000). A questionnaire to be distributed online was the data collection instrument selected.

A questionnaire offers greater anonymity to the participants particularly when conducted online. While, perhaps surprisingly, research has shown that anonymity does not consistently affect response quality or rate (McColl et al., 2001), it is considered useful when the target population is relatively small and when data that could be considered sensitive is being collected. The use of an online questionnaire also facilitates inexpensive, speedy data collection from a geographically spread target population whose email addresses are known or obtainable (Ritter and Sue, 2007, McGivern, 2006). However, the disadvantages of a questionnaire such as low response rate and self-selecting bias are also noted.

The use of the ProProfs<sup>®</sup> tool enabled the use of various question styles; it also expedited analysis of the data.

#### 3.4.5.1 Survey objectives

The purposes of the survey were to establish:

1. The prevalence of EPR use amongst optometrists in Ireland

2. How extensively optometrists use their EPR systems
3. What data is routinely recorded in optometry EPRs
4. The willingness of users (optometrists) to be involved in a system of data collection to facilitate secondary use of these data
5. Any concerns users may have associated with collection and secondary use of these data

Establishing all of the above would help inform an estimate of how much data (on how many individuals) it may be possible to collect from optometry EPRs in order to research refractive error in Ireland as well as the levels of interest amongst optometrists in Ireland in such data collection.

Table 3-9 illustrates how the objectives of the survey will help to achieve the objectives of the overall research study.

**Table 3-9: Survey and overall research objectives**

<b>Survey Objective</b>	<b>Related <u>Study</u> Aim/Objective or How this meets an aim/objective of the study</b>
To establish the prevalence of EPR use amongst optometrists	To establish how much data may be available for extraction and use for population study of refractive error
To establish how extensively optometrists use their EPR systems	To establish how much refractive error data may be available for collection as well as the potential for gathering data on other areas of eye care/health
To elicit the kinds of data that are recorded in optometry EPRs	
To measure the willingness of optometry EPR users to be involved in data extraction and aggregation for secondary use	To establish the likelihood of successfully undertaking collection of data from optometry EPRs
To identify perceived barriers on the part of optometrist users to the collection and secondary use of clinical data	To establish the ability of optometry EPR users to be involved in large scale data collection from their EPRs (by addressing barriers through designing and piloting a data extraction mechanism)

#### 3.4.5.2 Survey population

The target population was practising optometrists in the Republic of Ireland. The Association of Optometrists, Ireland represents the interests of over 90% of all practising optometrists in the state. Through the offices of this professional body, all practising members were invited by email to participate in the survey and a link to the URL for the survey questionnaire was included. Table 3-10 outlines the advantages and disadvantages of using email invitation to

online surveys. As participation in the survey is optional, the sample population will be self-selected. However, the answers to the demographics questions of the survey will help to establish representativeness of the sample by comparison with the demographics of the target population which will be established through analysis of membership data of the AOI.

**Table 3-10: Advantages and disadvantages of email invitations to survey questionnaires**

Advantages	Disadvantages
Fast response time	Email addresses of potential respondents are needed
Invitations are easy to distribute	Data are representative of only those people who use email (coverage bias)
Direct link to survey questionnaire URL can be included	Some participants may experience technological problems e.g. link to URL not working correctly
Reminders are easy to send – can be set multiple times	May be viewed as spam mail
Can easily contact people with common characteristics – e.g. members of a professional body	

*Adapted from Ritter and Sue (2007)*

The initial invitation was emailed to the membership of the AOI (Appendix G) and the survey was kept open for six week period in February and March 2015 with a reminder email being sent after two weeks and again two weeks before closing.

The number of optometrists practising in the state who received the invitation to participate was 593. The researcher set a goal of a minimum response rate of 20% i.e. approximately 120



respondents in the hope that this would yield a sufficiently representative sample. If the sample size is too small, results obtained will not be representative of the whole group (Nulty, 2008).

#### 3.4.5.3 Survey development

A novel web-based survey questionnaire was developed by the researcher using the ProProfs<sup>®</sup> tool. The questions were designed following completion of the literature review and in line with the objectives of the survey and of the overall study. In particular the questions asked by the survey of optometrists in the U.S. in 2013 (AOA, 2013), helped to inform the design of some of the questions on EPR usage in this researcher's questionnaire. The initial design was piloted on five optometry EPR users known to the researcher. Based on feedback from this process, the questionnaire was modified slightly, resulting in a set of 18 questions which were divided in to 3 sections:

**Section A:** Prevalence and extent of use of EPRs by optometrists

**Section B:** Attitudes towards potential EPR data extraction and secondary use

**Section C:** Demographics

The questionnaire was designed to take less than 10 minutes to complete and participants were introduced to the questionnaire by an information sheet at the beginning of the questionnaire (Appendix H). This provided a brief description of the research study and instructions to the survey participant. The following page contained the consent to participation (Appendix I); respondents had to indicate their consent before proceeding to the survey questions. Screenshots of the questionnaire are presented in Appendix J.

The questions in **Section A** (see Table 3-11) were chosen to elicit firstly, the prevalence of EPR use amongst the population of practising optometrists (Q1.) and secondly, (through a series of multiple-choice and checklist questions) the extent to which EPRs were utilised by those who used them, including questions on the elements of patient encounters that were recorded, linked diagnostic equipment, scanning of paper documents. The principal reason for including these extent-of-use questions was to gather quantitative data that could help to establish the

potential for the type and quantity of data that could be collected by future data extraction processes.

**Table 3-11: Survey questions - Section A**

Question No.	Topic	Format
1.	Do you use EPRs?	Multiple-choice
2.	Which EPR system used	Multiple-choice
3.	What features/functions used	Checklist
4.	Use of manual/paper records as well	Multiple-choice
5.	Diagnostic devices linked to the EPR system	Checklist
6.	Scanned paper documents	Checklist

Respondents who answered “No” to Q1 - “Do you use Electronic Patient Records?” - were taken directly to Section C of the questionnaire to answer the demographics questions. (Consideration was given to inviting them to answer the questions in Section B however it was felt that those who were familiar with the use of EPRs in practise were in a considerably better position to make valid and informed judgements on the possibility of data extraction for secondary use. The researcher acknowledges that research into the attitudes of non-EPR users in this regard may be useful for purposes beyond the scope of this study.)

**Section B** questions were introduced to the respondent with the preamble: “In this section you will be asked to consider the extraction of data from EPR systems. Please note that the mechanism being considered is that all data would be anonymised before being collected from

*your system and then gathered centrally in a way that neither patients nor practitioners can be identified*". The respondents were then asked to answer a series eight questions based on the assumption that it would be possible to extract and aggregate their EPR data (see Table 3-12). Most of the questions were multiple-choice in design but two were completely free text in nature, these two questions were designed to gather qualitative data on the potential barriers to extracting data for secondary use from EPR systems.

**Table 3-12: Survey questions - Section B**

Question No.	Topic	Format
7.	Would you be interested in submitting your EPR data to such a system?	Multiple-choice
8.	Who should gather and store the data	Multiple-choice
9.	Method of actioning the data extraction (manual or automatic)	Multiple-choice
10.	Interest in receiving analysis of their data comparing it with the national picture	Multiple-choice
11.	Interest in using the system to carry out practice-based research	Multiple-choice
12.	Identification of disadvantages of such a system	Free text
13.	Issues/problems that would prevent participation (barriers)	Free text
14.	Willingness to pay for the service	Multiple-choice

Although the majority of the questions in Section B were of a structured, multiple-choice nature, some of these (Q9 & Q10) ask *how-type* questions that will yield data that is qualitative in nature; they ask about attitudes to future possibilities rather than to quantifiable existing realities. Qualitative data is often used when trying to develop suggestions and recommendations (Berg et al., 2004).

Questions 12 and 13 of the instrument were also designed to obtain qualitative data, this time by gathering unstructured, free-text answers; these data were planned to be systematically analysed through dividing responses into emergent category themes then interpreting the overall messages.

Open-ended questions are particularly useful when exploring new topics and offer the chance to learn unanticipated information and can give a richer insight into respondents' attitudes. However they should be used sparingly in self-administered questionnaires so as not to "turn off" the respondent due to greater effort involved in answering such questions (Ritter and Sue, 2007).

**Section C** contained the demographic questions. These questions were presented to all respondents (both those who do and do not use EPRs). The questions on employment category, gender and age were multiple-choice and the answer to the final question on geographic location was to be selected from a drop-down list.

One of the purposes of collecting the demographic data of the respondent sample was to establish the sample's representativeness of the total population of optometrists in the country by comparing these data with those of the membership of the AOI.

#### 3.4.5.4 Data collection and management

The data were collected using the ProProfs® tool and were stored securely in a password-protected area. Additionally, the data were extracted regularly to an Excel® file which was securely stored on the researcher's laptop and backed up to a secure cloud-based location.

#### 3.4.5.5 Data analysis

The ProProfs® tool provided some basic analysis of each question. All data collected were also exported to Excel® for further analysis by the researcher. Analysis of the demographic data collected was compared with that of the AOI membership data in order to establish the representativeness of the survey sample.

#### 3.4.6 Phase III: Design, development & piloting of EPR data extraction tool

This phase of the study involved identifying the data elements to be extracted from the EPRs, communicating these and all requirements of the data extraction process to the provider of the main optometry EPR software (Ocuco), coding and testing the data extraction software tool and implementing a pilot of the data extraction process yielding demographic and clinical data to be analysed. Analysis of these data would produce a profile of refractive error for the pilot population.

##### 3.4.6.1 Dataset

The set of data required to produce meaningful information regarding distribution of refractive error was considered by the researcher and informed by the literature review. It was decided to use anonymous data (see section 2.5.2). While the need for individual anonymity must be preserved, in the interest of providing the opportunity for valuable and meaningful research, some quasi-identifiers were included (gender, year of birth and county of residence). The researcher took into account the guidance of the DPC on using personal data for research projects, the guidelines of WHO on “*proportional or reasonable anonymity*” and the ISO/EN 13606 norm on “*partial anonymization*” when deciding on the level of granularity of the demographic data to be collected (DPC, 2007, Somolinos et al., 2014). While it may be beyond the scope of this study, collection of geographic data maximises the potential to study refractive error epidemiology using a population health approach (Roth et al., 2014). Data sets used in conventional refractive error studies were also taken into account (Hartmann et al., 2015, O'Donoghue, 2010, Wolfram et al., 2014). The data set ultimately decided upon for this study is outlined in Table 3-13.

**Table 3-13: Dataset to be extracted from EPR**

Data Category	Data Elements
<b>Demographic Data</b>	<ul style="list-style-type: none"> <li>• Gender</li> <li>• Year of birth / Age at exam date</li> <li>• County of residence</li> </ul>
<b>Visit Data</b>	<ul style="list-style-type: none"> <li>• Date of eye examination</li> </ul>
<b>Clinical data</b>	<ul style="list-style-type: none"> <li>• Subjective refraction (sphere, cyl, axis, prism, near addition) for Right + Left eyes (R+L)</li> <li>• Prescribed refractive correction i.e. Rx Given (only if subjective refraction not available) R+L</li> <li>• Refraction Spherical Equivalent R+L (calculated during extraction)</li> <li>• Unaided vision R+L</li> <li>• Corrected visual Acuity R+L</li> </ul>

### 3.4.6.2 Software development

While the providers of two optometry EPR systems were approached, only Ocuco Limited (see Appendix K), the developers and suppliers of the Acuitas optometry EPR system were in a position to support this study at this time. (The other system was about to start a process of re-design and re-build). Ocuco agreed to help by coding a piece of software that would enable the extraction of the required dataset. The researcher liaised with a senior developer in Ocuco to discuss the software requirements. The software solution was designed and written so that a Structured Query Language (SQL) program contained the code to action the data extraction process (see Appendix L) and a batch (.bat) file was created to launch this SQL program when required. The data extracted from the Acuitas database by running this software were export to a Comma Separated Values (CSV) file. These data could then be accessed and saved in an Excel® spreadsheet and used for analysis by the researcher.

### 3.4.6.3 Software testing

The researcher is the data controller for the optometry practice in which he works and was therefore in a position to test the new data extraction software tool on the Acuitas database for that practice.

While the initial version of the tool worked well, some minor changes were discussed and decided upon through two further iterations ultimately yielding an enhanced final version. Table 3-14 below outlines the changes/enhancements that were introduced through the iterative design/testing process.

**Table 3-14: Changes/enhancements to data extraction software tool**

Change No.	Change made
1.1.	Step introduced to calculate the spherical equivalent of the refractive error and include this in the data output
1.2.	Elimination of duplicates (i.e. each patient will only appear once – only the refractive error data from the most recent visit will be included)
2.1.	If the “Subjective Refraction (Rx)” is not recorded for a patient, the “Rx Given” will be shown instead and every refraction output will have an indication of whether it is “Subjective” or “Given” in an adjacent column of the data spreadsheet.
3.1.	A practice code will be included for each entry – the key for this code will only be known to the EPR vendor (not the researcher)

### 3.4.6.4 Data extraction pilot

A number of optometrists known to the researcher were approached regarding their potential interest in providing anonymous data from their Acuitas EPR systems for the purposes of the

study. The reason for using a number of different practices and optometrists was to demonstrate that the data extraction process could be performed in numerous locations for the same defined time period and that the data collected could then be aggregated and analysed to produce information on refractive error for a population spread across several optometric practices in different locations.

In total six optometry practices took part in the data extraction pilot. It was decided that data would be extracted for a two-year period from 1 April 2013 to 31 March 2015. The data extraction process was performed on 2 April 2015 and yielded data on almost 30,000 individual patients.

#### 3.4.6.5 Data aggregation and storage

The extracted data were exported to Excel® spreadsheets. This allowed aggregation of all data collected from the various optometry practices into one Excel® file for analysis. The file size was determined to be approximately 140 KB per thousand patients so for the purposes of this study all data were easily stored on the researcher's own computer (and back up storage).

The data for each individual patient were represented on a single row in the Excel® spreadsheet. As Excel® (2010) spreadsheets can handle 1,048,576 rows of data, this file type was more than adequate for the purposes of storage and analysis of the data for this study. Should larger-scale data extraction be conducted in the future other data base storage and analysis methods may have to be considered. While Excel® would be capable of storing the data from all 650,000 eye examinations carried out in a given 12 month period in the Republic of Ireland, it would not handle the data for all eye examinations carried out over a longer period of time in one file.

#### 3.4.6.6 Data analysis

Excel® was used to analyse the aggregated data of almost 30,000 individuals. The principal analysis was to produce a frequency distribution curve (profile) of refractive error for that population.



## **3.5 Ethical Considerations**

### **3.5.1 Ethics approval**

As human participation was a feature of this study, ethical approval was required. Application for this approval was submitted to the research ethics committee of the School of Computer Science and Statistics (SCSS) at Trinity College, Dublin (see Appendix M – Application & Research Proposal). Ethical approval was granted by the committee following some minor revisions to the initial application and was communicated by email in January 2015 (Appendix N). As the participation of patients was not a requirement of the research, no further ethical approval was needed.

### **3.5.2 Survey**

Survey participants were provided with a description of the study and the role of the survey questionnaire. To proceed with the survey they were required to indicate their consent prior to answering any questions. Information was given that there was no obligation to answer any of the questions and that participants were free to withdraw from the survey at any time without submitting their response. Participants were also provided with the telephone and email contact details of the researcher should they have any queries or concerns that they wished to have addressed.

The survey was conducted online and while some demographic questions were asked, each submission was anonymous. (An I.P. address and a date and time stamp were recorded for each submitted response in order to distinguish individual responses). The data collected were not disclosed to any third parties and were legitimately used for the purpose of this research study.

### **3.5.3 Clinical data**

Patient data (from EPR) were to be provided for this research study. The researcher followed the best practice guidelines on research in the health sector of the Data Protection Commissioner (DPC, 2007). As the data could be reasonably considered as anonymous, patient consent was not required.

In order to extract the data from the EPR systems of a number of optometric practices for this study, written consent of the data controller in each case was sought and obtained. The consent form detailed the specific and limited dataset to be extracted (Appendix O).

#### **3.5.4 The role of the researcher**

There is potential for a researcher's personal values, biases and background to influence the direction of their work particularly in qualitative research (Johnson and Onwuegbuzie, 2004, Creswell, 2013). This researcher's perception that a missed opportunity currently exists in not using clinical data collected in optometry EPRs for additional purposes may also have potentially influenced the approach to the study. However, being aware of this, the researcher endeavoured to ensure that the research methods and instruments employed were reliable and valid and designed in such a way as to control biases.

### **3.6 Limitations of the methodology**

#### **3.6.1 Survey limitations**

The participants in the survey of optometrists were given very little information on how a system of EPR data extraction would work. Therefore their perceptions of such a system were based on a somewhat intangible concept rather than on real experience. This may have affected the responses e.g. an over- or under-estimation of barriers.

There was also the potential risk of selection bias in using an online questionnaire in that this may have excluded practitioners not so comfortable with computer use. However, representativeness of the sample will be tested by comparing it with the total membership of the AOI.

Ideally more use would be made of open-ended questions providing for free-text answers which may give 'richer' information and greater insight. However in the interest of keeping the questionnaire short and maintaining high response rates to all questions, the majority of questions were of the multiple-choice or checklist type.

### 3.6.2 Data extraction tool limitations

The prototype data extraction tool developed and piloted in this study was built for one EPR system only (albeit the most commonly used system). To conduct valid larger population studies, software capable of extracting data from all EPRs in use (or at least the one other major system – Socrates) would have to be developed.

### 3.6.3 Overall study limitations

The proposed system of data extraction from optometry EPRs for research purposes means that such research would be limited to the cohort of people who attend optometrists rather than a census or a cross-sectional population study. This bias may lead to a distortion of the refractive error profile i.e. it may not be representative of the whole population. This will be discussed further in the Discussion chapter (Sections 5.2.2 and 5.7).

## 3.7 Summary

This chapter outlined the research methodology to be utilised to answer the research question. The questionnaire design, survey participants, data extraction tool, its piloting and data analysis were specified. Ethical considerations were also discussed.

The next chapter will present the results of the analysis of the data collected from Phases II and III of the study.

## 4 Results

### 4.1 Introduction

In order to answer the research question: *“Can data be collected automatically from optometry electronic patient records in Ireland in order to produce a population profile of refractive error and facilitate future research into the field?”*, primary research was conducted as described in the previous chapter. Phase II of this research used a questionnaire instrument to yield survey data and Phase III garnered data from optometry EPRs on approximately 30,000 patients. These data were analysed and the results of these analyses are presented in this chapter.

### 4.2 Survey Results

The data collected by the survey questionnaire instrument were analysed in part by the Proprofs® tool itself. All data were also exported to Excel® spreadsheet format which allowed for further analysis.

#### 4.2.1 Response level

The questionnaire received 163 responses. This represented a response rate of almost 30%.

All respondents answered the opening screening question (Q1: *“Do you use Electronic Patient Records (EPRs)?”*) with 130 (80%) answering *“Yes”* and the remaining 20% answering *“No”*. Of the 33 respondents answering *“No”*, only one did not go on to answer the demographic questions in Section 3 before submitting their response. The completion rates of the demographic questions are shown in Table 4-1 below.

**Table 4-1: Completion of demographics questions in Section C**

Question No.	Subject/topic	Number of respondents	Rate of response (%)
Q15.	Employment status	162	99%
Q16.	Gender	162	99%
Q17.	Age	162	99%
Q18.	Location (county)	159	97.5%

Only respondents who indicated in Q1 that they use EPRs (N=130) were invited to answer all of the questions in Sections A and B and the rates of completion of these questions is laid out in Table 4-2 and Table 4-3.

**Table 4-2: Completion of questions in Section A by those using EPRs**

Question No.	Topic	Number of responses	Response rate (%)
Q2.	EPR system used	129	99%
Q3.	Features/functions used	130	100%
Q4.	Use of additional manual/paper records	130	100%
Q5.	Linked equipment	75	58%
Q6.	Scanning of paper documents	90	69%

**Table 4-3: Completion of questions in Section B by those using EPRs**

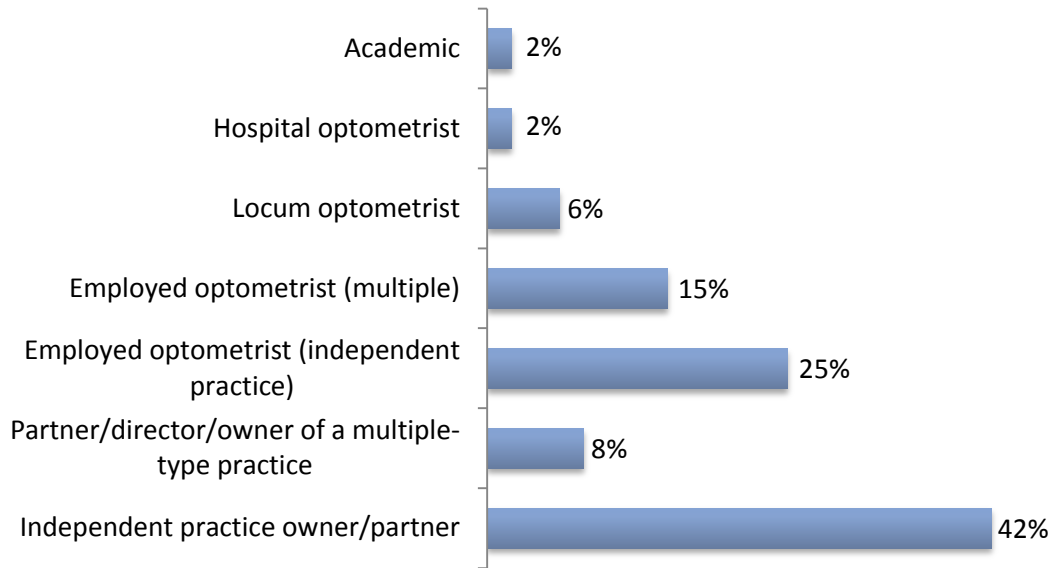
<b>Question No.</b>	<b>Topic</b>	<b>Number of responses</b>	<b>Response rate (%)</b>
<b>Q7.</b>	Interest in EPR data extraction for secondary use	129	99%
<b>Q8.</b>	Opinion on who should gather/store the data	122	94%
<b>Q9.</b>	Preferred means of actioning data extraction	121	93%
<b>Q10.</b>	Interest in analysis of own data for comparison with national aggregated data	123	95%
<b>Q11.</b>	Interest in using the process for practice-based research	126	97%
<b>Q12.</b>	Disadvantages of EPR data extraction for secondary use	53	41%
<b>Q13.</b>	Barriers to EPR data extraction for secondary use	66	51%
<b>Q14.</b>	Willingness to pay for such a process	126	97%

## 4.2.2 Respondent demographics

The responses to the demographics questions were analysed and the results are presented below.

### 4.2.2.1 Employment status

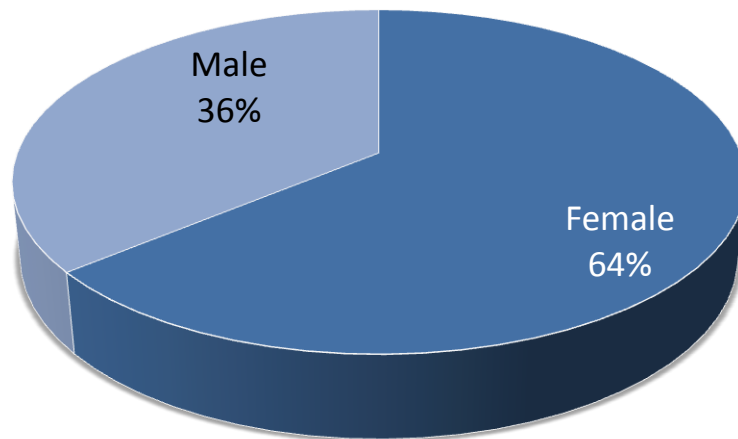
Respondents were asked to choose the employment category that best described their situation



**Figure 4-1: Employment status of survey participants**

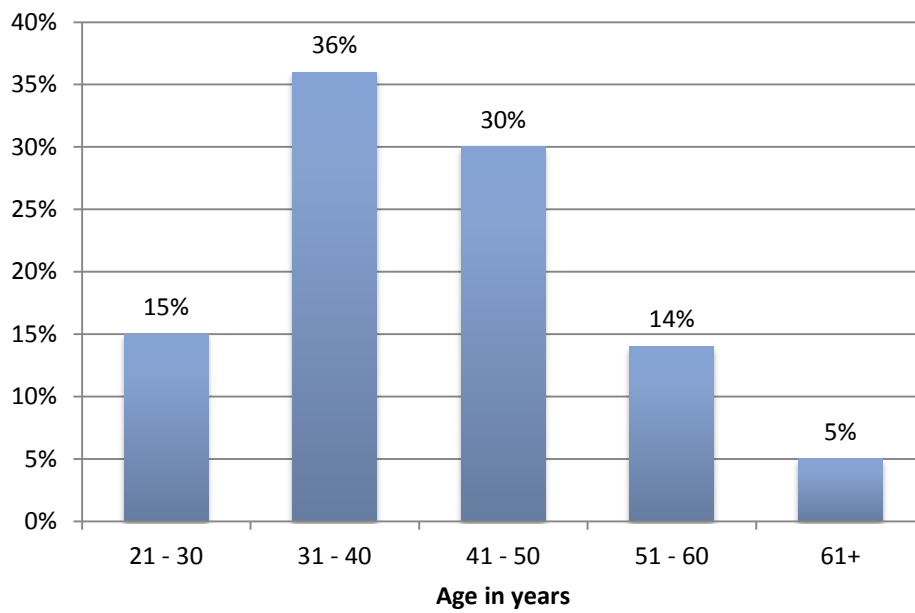
#### 4.2.2.2 Gender

The female to male ratio was approximately two-thirds to one-third.



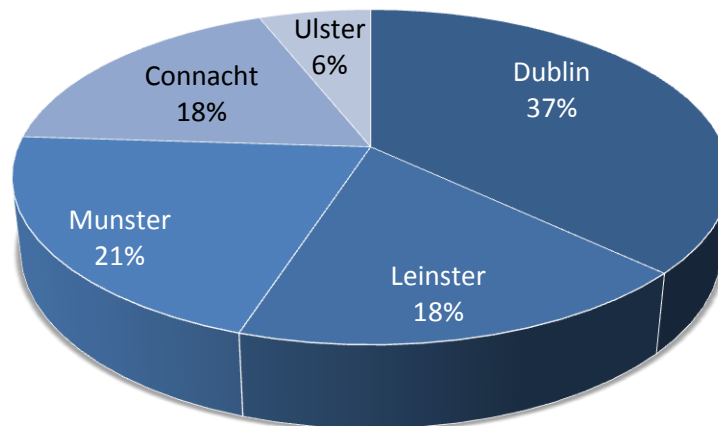
**Figure 4-2: Gender of survey respondents**

#### 4.2.2.3 Age



**Figure 4-3: Age distribution of survey respondents**

#### 4.2.2.4 Location



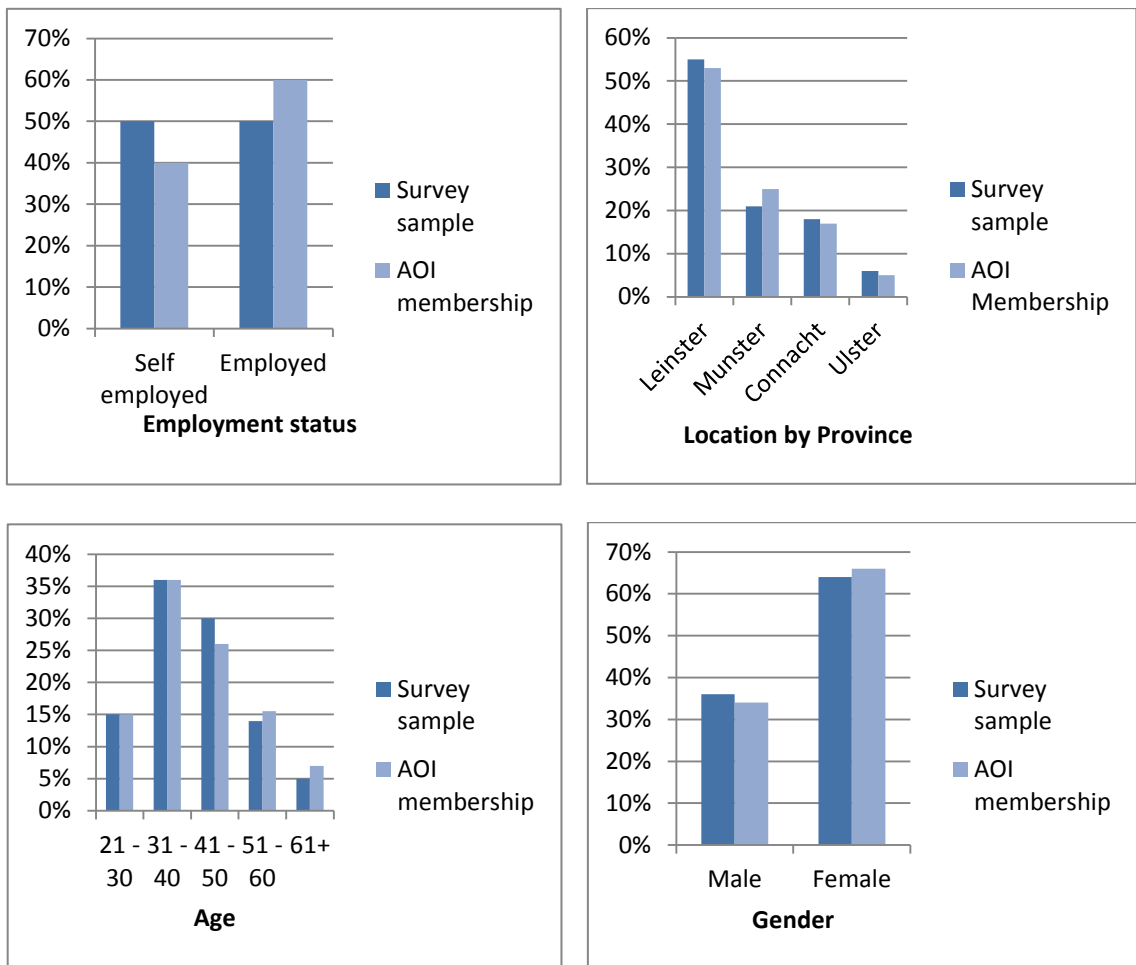
**Figure 4-4: Location of survey respondents**



To test the representative nature of the survey, the demographics of the survey participants were compared with those of the membership of the AOI (only those who currently practise in the Republic of Ireland were included). Age, gender, employment status and geographic location were all compared as shown in Table 4-4 and Figure 4-5.

**Table 4-4: Comparison of demographics of survey sample and AOI membership**

Demographic	Category	Survey Sample	AOI Membership
<b>Gender</b>	Female	64%	66%
	Male	36%	34%
<b>Age</b>	21-30 years	15%	15%
	31-40 years	36%	36%
	41-50 years	30%	26%
	51-60 years	14%	16%
	61+ years	5%	7%
<b>Employment Status</b>	Self-Employed	50%	40%
	Employed	50%	60%
<b>Location</b>	Leinster	55%	53%
	Munster	21%	25%
	Connacht	18%	17%
	Ulster	6%	5%

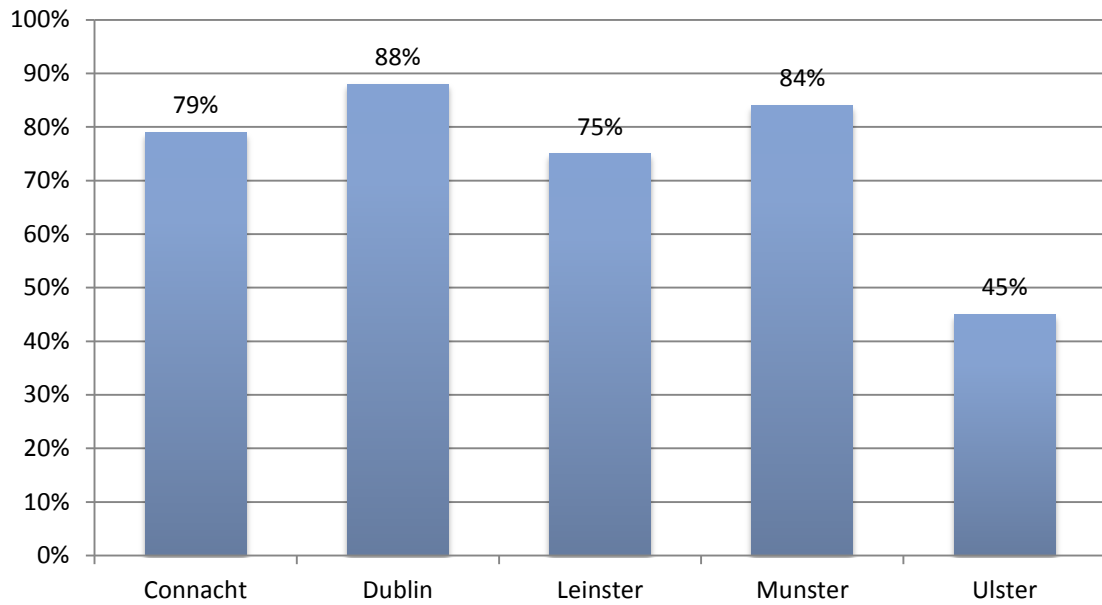


**Figure 4-5: Comparison of demographics of survey respondents and AOI membership**

### 4.2.3 EPR use

As indicated above the level of EPR use amongst the survey participants was shown to be 80%. This was further analysed according to age and while there was no significant difference in usage levels between those under 40 years of age and those over 40 (both approximately 80% usage), perhaps not unexpectedly, there was a marked difference between the youngest cohort and the oldest: 96% of the 21-30 age group reported using EPRs while only 25% of the 61+ year olds use them.

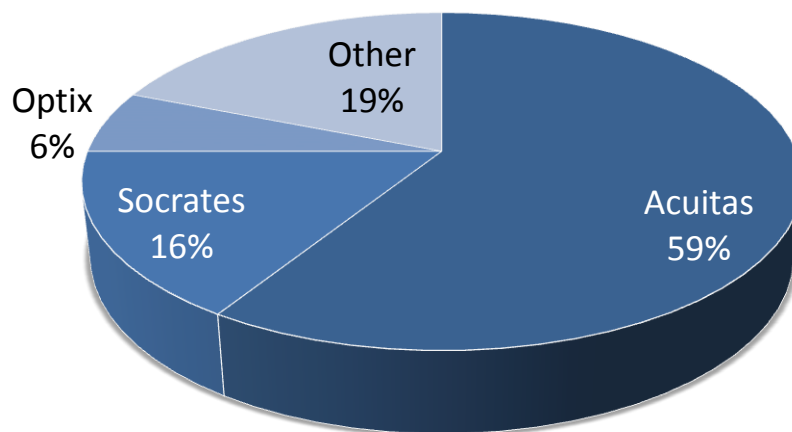
EPR usage by geographic location was also analysed. The highest levels of EPR use were found to be in Dublin at 88% while the lowest were in Ulster at only 45% (see Figure 4-6).



**Figure 4-6: EPR use by location**

#### 4.2.4 EPR systems used

**Question 2** of the survey questionnaire asked those who responded affirmatively to the initial screening question (Q1) what EPR system they used. The results are shown in Figure 4-7.



**Figure 4-7: Optometry EPR systems used**

In the “Other” category numerous different systems were identified by these 25 respondents. These are outlined in Table 4-5.

**Table 4-5: Other EPR systems used**

Other EPR Systems in use	No. of users	Other EPR Systems in use	No. of users
Skalpell	4	Optisoft	1
In-house/personal system	4	Synergy	1
Unspecified	3	Optinet	1
FOCUS	2	Ocellus	1
See2020	2	Red Green	1
iBall	1	Opticabase	1
Outlook	1	Icareweb	1
Customised CRN	1		

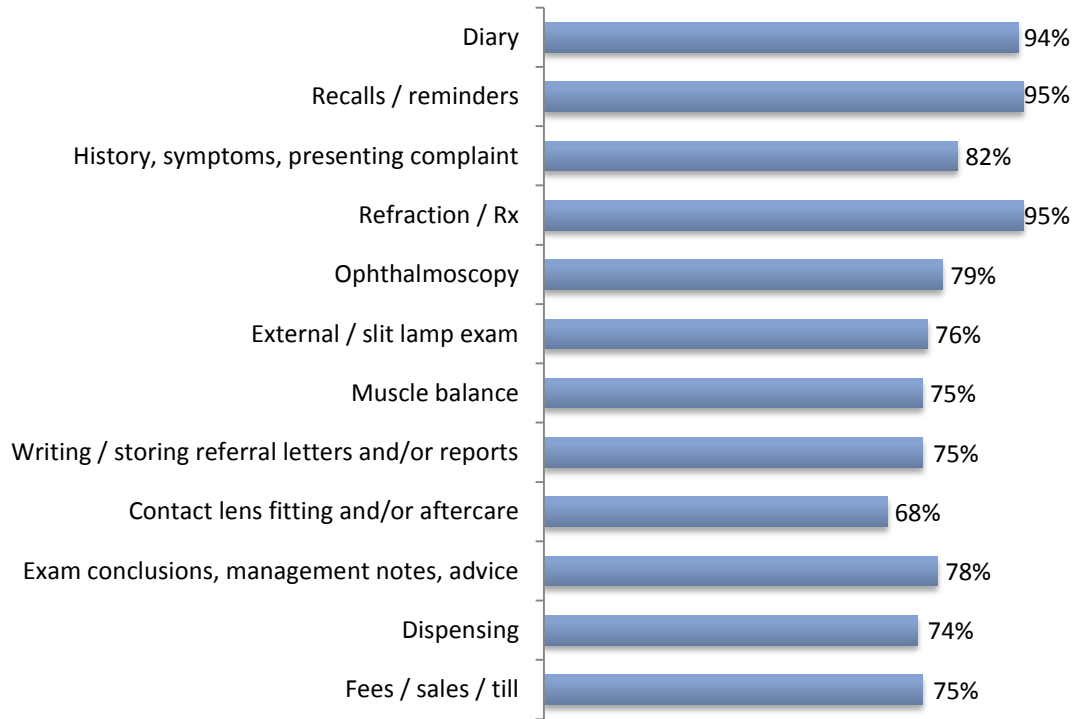
#### 4.2.5 Extent of EPR use

The remainder of the questions in Section A of the survey questionnaire were concerned with how and to what extent EPRs are used in optometric practice.

**Question 3** asked respondents to choose all features/elements of their EPR system that they use (

Figure 4-8). Given that refractive error is the focus of this study, it is noteworthy that 95% of users of electronic record systems in practice use them to record refractive error data.

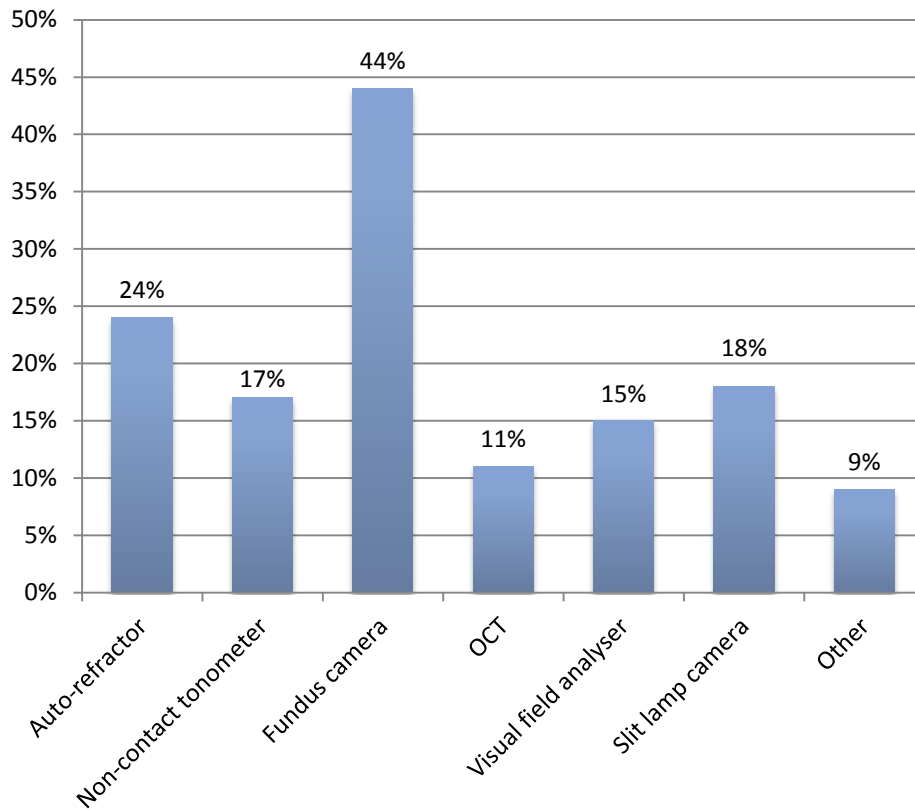
Furthermore, 100% of those using the Acuitas system indicated that they use it to record refractive error results.



**Figure 4-8: EPR functions used by respondents**

**Question 4** asked EPR users about their extent of EPR use in terms of whether or not they continued to use manual/paper for some elements of their patient encounters. 64% indicated that they do, while the remainder appear to run totally paperless operations.

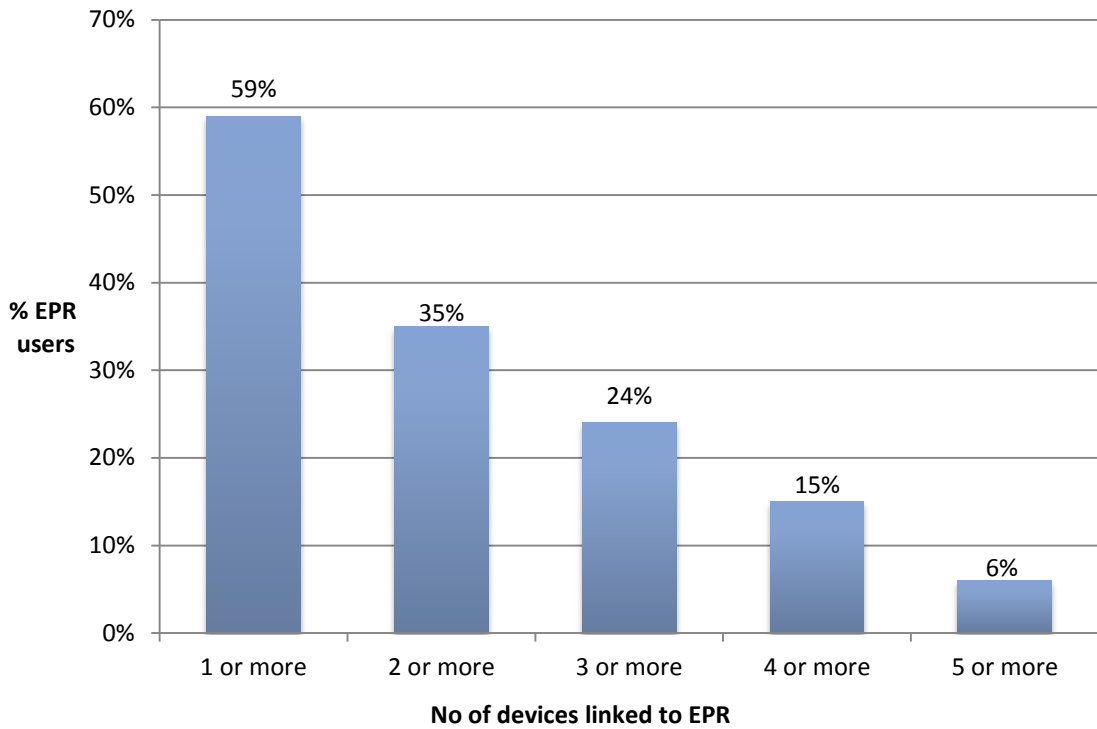
**Question 5** asked the EPR-user respondents to indicate what diagnostic devices are linked directly to their EPR systems. Figure 4-9 illustrates the responses showing the percentage of EPR users who have linked their systems to certain diagnostic devices that may be found in use by eye care practitioners today.



**Figure 4-9: Diagnostic devices linked to EPR systems**

There were three devices identified by the 9% of respondents who have “other” pieces of equipment linked to their EPR systems namely Pentacam® (corneal tomographer), digital phoropter and digital lensmeter.

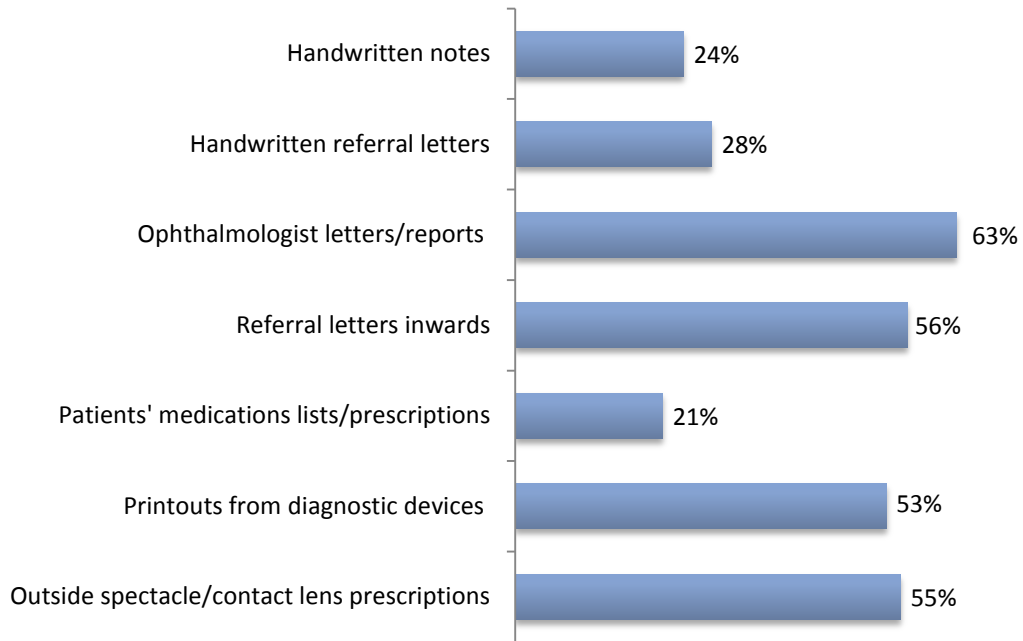
Overall, 59% of the EPR users (N = 130) indicated that they have at least one diagnostic device linked to their EPR system while 35% indicated that they have 2 or more linked devices. These results along with the percentage of EPR users who have even greater numbers of linked devices are shown in Figure 4-10.



**Figure 4-10: Proportion of the EPRs users with diagnostic devices linked to EPR**

Amongst the users of the Acuitas EPR system an even higher proportion (73%) have at least one diagnostic device linked directly with the EPR system.

**Question 6** asked the EPR-using respondents to identify from a list of options what, if any, paper documents are regularly scanned into a patient’s EPR. These results are illustrated in Figure 4-11.



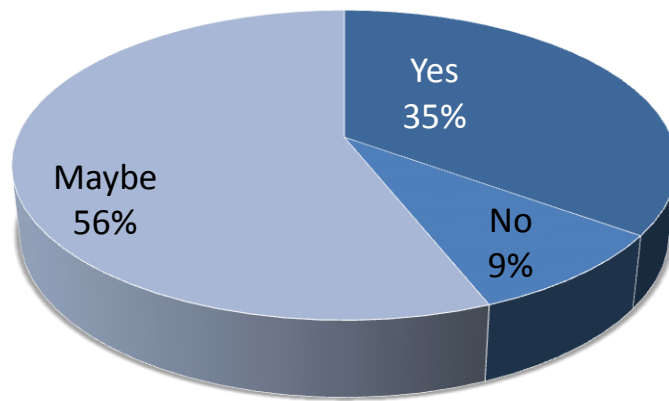
**Figure 4-11: Documents regularly scanned to EPR**

#### 4.2.6 Attitudes to EPR data extraction for secondary use

The questions in Section B were designed to gather respondents' views on whether or not they would be interested in being involved in a system of EPR data extraction for research purposes, how aspects of this might be conducted and what, if any, disadvantages and/or barriers they perceived.

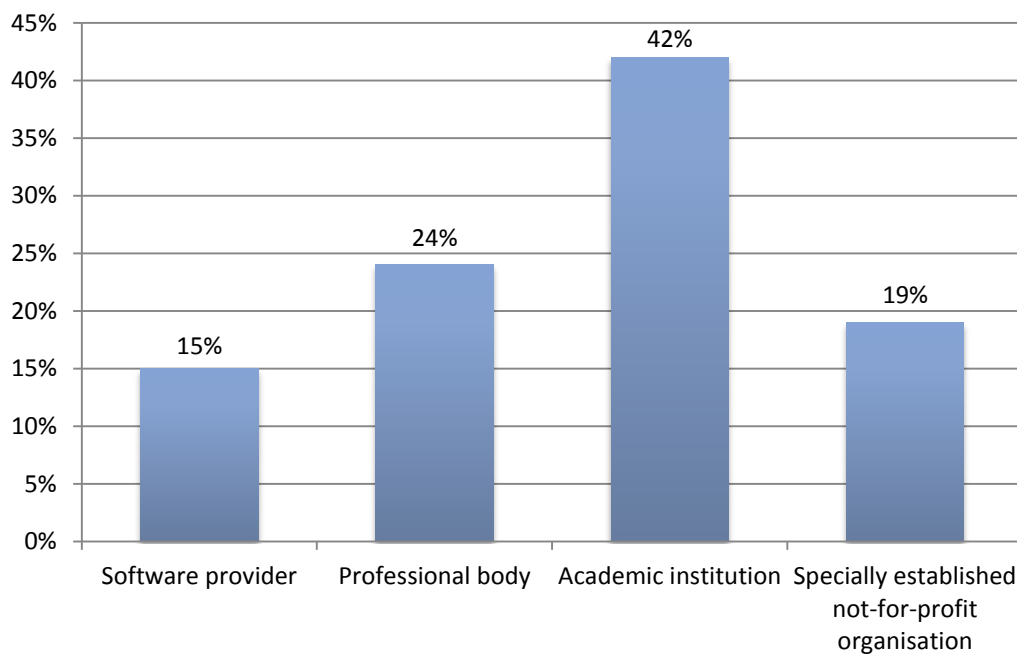
The first question (**Question 7**) in a series of eight questions asked if they would be interested in participating in such research initiatives by extracting and submitting data from their own EPR databases. 91% of EPR users stated either that they would or may be interested in being involved in such a system (Figure 4-12). Further analysis showed that the 9% who stated they would not be interested in such an initiative were evenly split between employers and employees.





**Figure 4-12: Interest in EPR data extraction**

**Question 8** asked the respondents to identify what entity they would prefer to gather and store the extracted anonymous clinical data. The most favoured option was a relevant academic institution (42%) while EPR provider was the least preferred at 15%.



**Figure 4-13: Who should store and manage the extracted data**

**Question 9** aimed to establish how automated the EPR users would like the extraction process to be. The options and the percentage respondents choosing each one are outlined in Table 4-6. A clear majority of respondents favour the maximum level of automation.

**Table 4-6: level of automation of data extraction preferred**

Option	% respondents
<i>"I would prefer to action the data anonymisation and extraction process myself at any time I choose"</i>	19%
<i>"I would prefer to action the data anonymisation and extraction process myself when requested to by the system"</i>	21%
<i>"I would prefer to have the data anonymisation and extraction process performed automatically as required by the system without any action on my part"</i>	60%

Respondents who use EPRs were asked in **Question 10** if they would like to have the opportunity to compare their clinical data with that of a much larger population (e.g. national) and **Question 11** enquired about respondents' interest in using such a data extraction tool to carry out practice-based research. An overwhelming majority (98%) answered "Yes" to Q10 and similarly 97% answered either "Yes" or "Maybe" to Q11. Also 97% of these respondents (answering "Yes" or "Maybe" to Q10 & Q11) had indicated a willingness to be involved in a system of EPR data extraction in Q7.

The next two questions collected free text responses (no choices were presented). **Question 12** asked respondents to identify any disadvantages they saw in participating in extracting data from their EPR database for secondary (research) use and **Question 13** asked them if they could anticipate any issue(s) that would prevent their participation in such an initiative i.e. barriers.

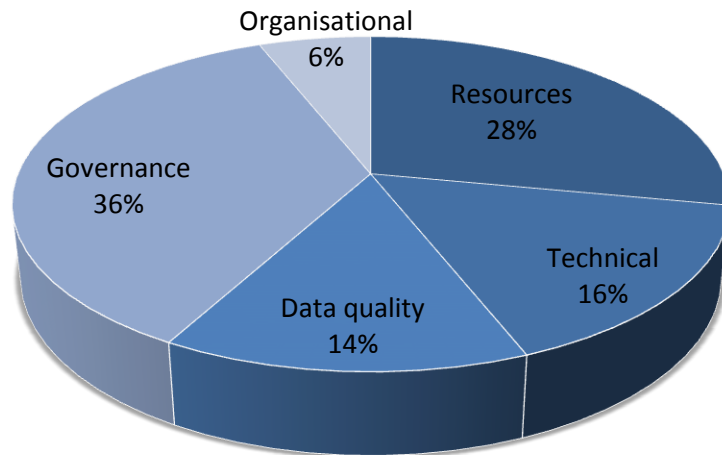
For Q12, of the 130 EPR-using respondents, 92 either did not identify any disadvantages or actively indicated "None" in the response box. The disadvantages identified by the remaining

40 users were grouped into themes which were further grouped into five categories; these are listed along with the frequency of their occurrence in Table 4-7. (Note that some respondents listed more than one disadvantage.)

**Table 4-7: Perceived disadvantages of EPR data extraction for secondary use**

<b>Category</b>	<b>Disadvantage identified</b>	<b>No. of respondents</b>
<b>Resource Implications</b>	Time	9
	Workload/effort	4
	Cost	1
<b>Technical Issues</b>	Interference/conflict with the EPR system	5
	Different/incompatible EPR systems (i.e. interoperability)	3
<b>Data Quality</b>	Incomplete data	2
	Data accuracy	2
	Inconsistent terminology	1
	Rx modification (adjustment of optical correction to be prescribed)	2
<b>Data Governance</b>	Data protection	5
	Confidentiality	3
	Improper/unintended use (misuse) of data by third parties	6
	Patient consent	4
<b>Organisational</b>	Employer interest/willingness	3

Figure 4-14 illustrates the relative levels of the five categories



**Figure 4-14: Overview of perceived disadvantages of EPR data extraction**

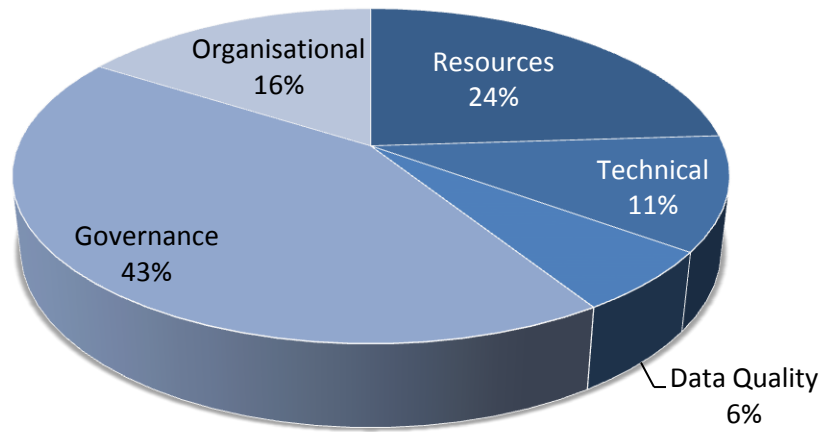
For Q13, 75 of the 130 respondents either did not identify any issues that would prevent them from participating in a data extraction initiative or actively indicated that there were “None” in the response box. The remaining 55 EPR-using respondents listed 74 perceived barriers which grouped into sixteen themes and these were further aggregated into five categories; these are listed along with the frequency of their occurrence in Table 4-8.

The responses that were given to Q13 (barriers) aligned with the themes and categories as those for the previous question (disadvantages).

**Table 4-8: Perceived barriers to EPR data extraction for secondary use**

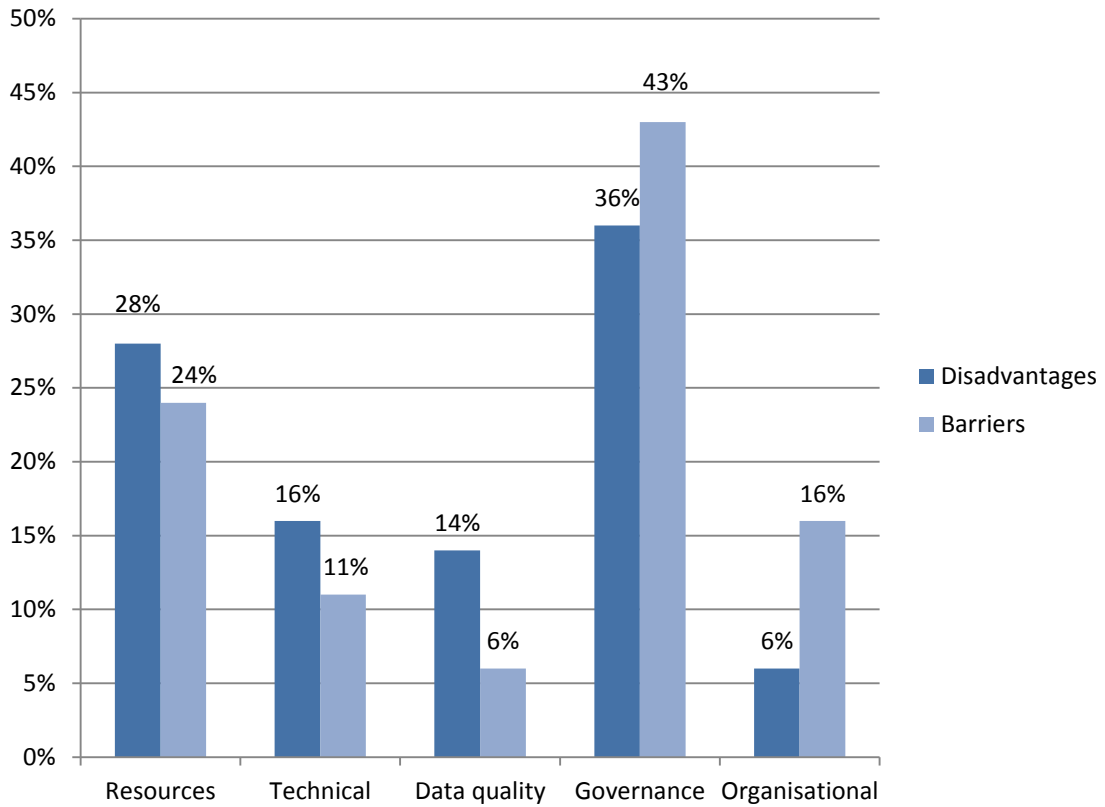
<b>Category</b>	<b>Barrier</b>	<b>No. of respondents</b>
<b>Resource implications</b>	Time	12
	Cost	1
	Workload/workflow interruption	3
	Lack of I.T. skills	1
	Negative impact on business	1
<b>Technical issues</b>	Different/incompatible EPR systems (i.e. interoperability)	7
	Interference/conflict with the EPR system	1
<b>Data quality</b>	Incomplete data	1
	Inconsistent terminology	1
	Data accuracy	2
<b>Data governance</b>	Data protection	11
	Confidentiality	5
	Security	5
	Patient consent	5
	Improper/unintended use (misuse) of data by third parties	6
<b>Organisational</b>	Employer interest/willingness	12

Figure 4-15 illustrates the relative levels of the five categories



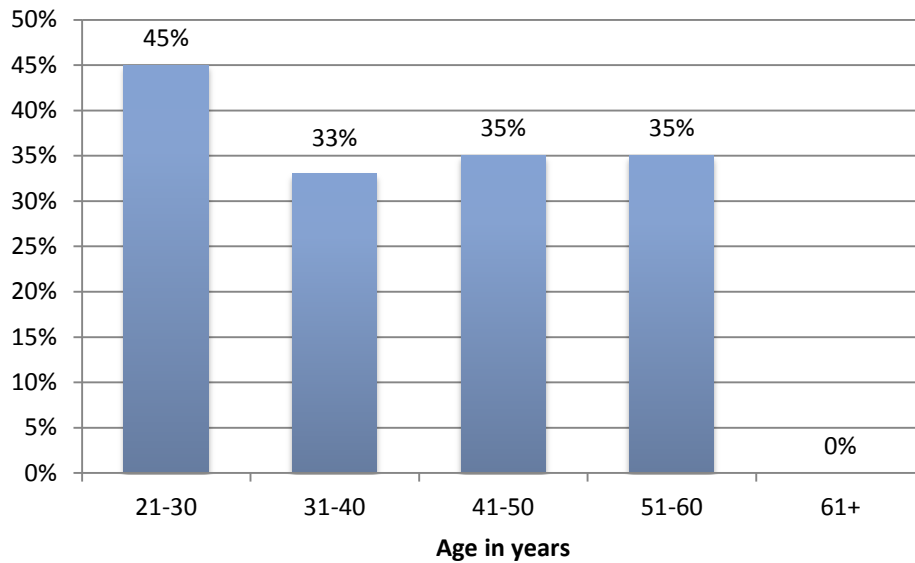
**Figure 4-15: Overview of perceived barriers to EPR data extraction**

Given that the same five categories emerged in the responses to both Question 12 and Question 13, a comparison of the distribution of these categories for each question was carried out. This comparison is illustrated in Figure 4-16 below.



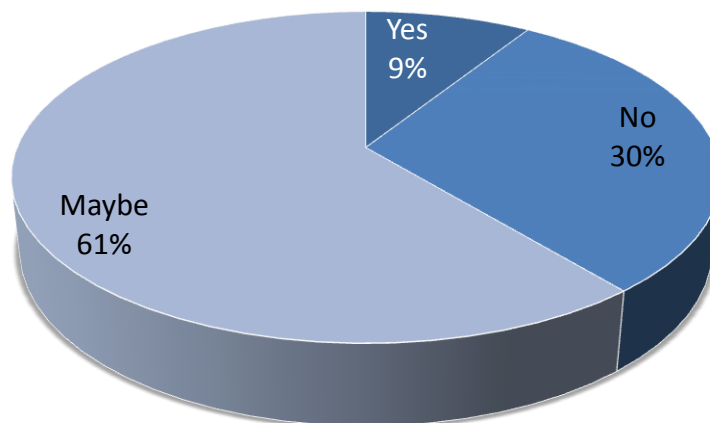
**Figure 4-16: Comparison of perceived disadvantages and barriers**

The levels of identification of barriers to EPR data extraction for secondary use were also analysed according to age group. It was found that the three middle cohorts had very similar levels of identifying barriers while potential barriers were identified by significantly more respondents in the youngest group (21 to 30 years) and by none at all in the 61+ years group. These results are illustrated in Figure 4-17.



**Figure 4-17: Percentage of respondents who identified potential barriers by age group**

Finally **Question 14** asked if the EPR user respondents would be willing to pay a fee to be involved in a research process/initiative that used anonymous data extracted from their EPR systems. As shown in Figure 4-18, 70% indicated that they either would or might be prepared to pay for such a service.



**Figure 4-18: Willingness to pay for data extraction and feedback service**



### 4.3 EPR Data Extraction Results

The data extraction tool was developed in Phase III of this study and was piloted to yield anonymous EPR data on almost 30,000 individuals.

#### 4.3.1 Extraction tool software development process

The process of designing and developing the software tool to extract data from the Acuitas optometry EPR system was an iterative collaborative process between the researcher and a senior developer in Ocuco Limited. While it proved to be a relatively straightforward and speedy process, as outlined in the methodology chapter, some enhancements were made at each iterative stage (see Table 3-14).

The development process resulted in an SQL software program (see Appendix L) which was initiated by a batch file as required. This actioned the extraction of the required data the Acuitas database of the given optometry practice; these data were saved in a CSV file which could be converted to Excel® spreadsheet by the researcher for analysis. The resulting file size was 140 KB per thousand patients.

#### 4.3.2 Pilot population

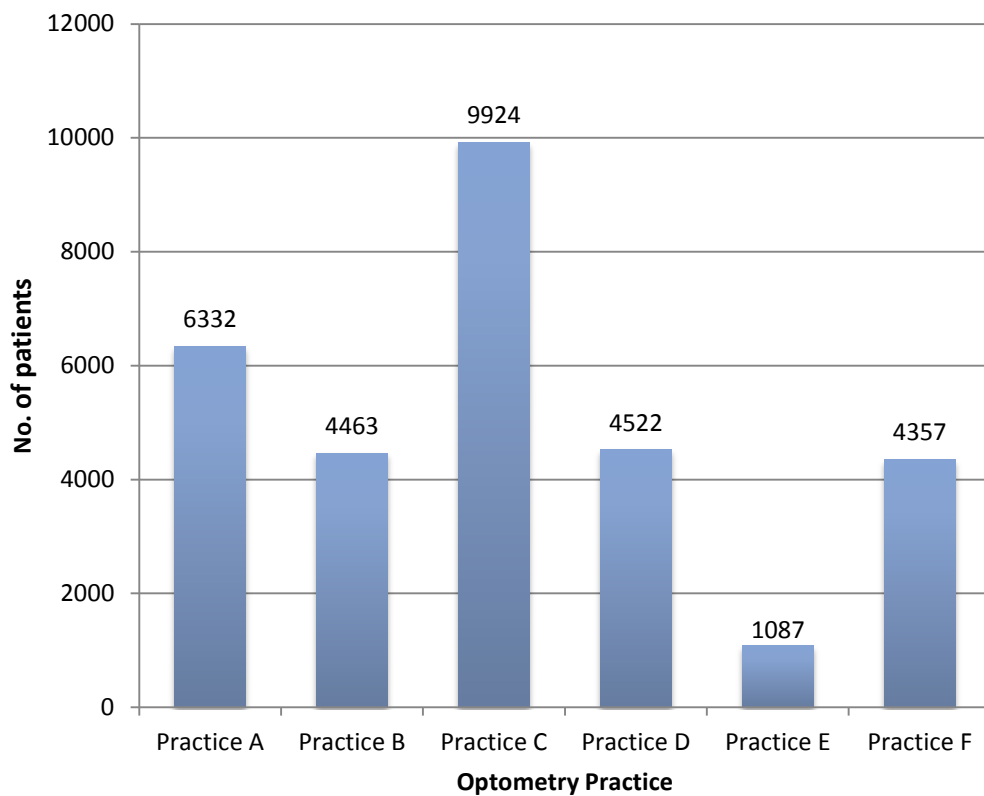
Six optometry practices (all known to the researcher) were invited to participate in the data extraction exercise by contributing anonymous data from their EPR systems. These participating practices were from a variety of locations around the country as listed below:

- Dublin 8
- Dublin 15
- Co. Wicklow
- Co. Tipperary
- Co. Clare
- Co. Galway

All practices were independently owned and operated and they ranged from a small part-time practice in a small town to a busy shopping-centre-based practice in suburban Dublin. The data

extraction tool was designed so that only patients for whom refractive error data existed were included in the data extraction exercise.

The period for which data was extracted from each of the EPR systems was a two-year span from 1 April 2013 to 31 March 2015. This yielded refractive error data on a total number of 28,574 patients. The mean no. of patients per practice for the two year period was 5,114 with a range from 1,087 to 9,924 (see Figure 4-19).



**Figure 4-19: No. of patients with refractive error data per optometry practice**

### 4.3.3 Data quality

The main data quality issue encountered in the extracted data was completeness. In particular, age, gender and county of residence were not always present in the extracted dataset for each individual patient. In the case of age and gender this is most likely due to these pieces of data

simply not being recorded. (As a result of feedback from this study, practices involved in the pilot have “switched on” a pre-existing Acuitas feature that makes recording of gender mandatory). In the case of the county of residence, the cause may be due to either (a) non-recording or – as is more likely - (b) recoding in a different line (field) of the address than the one dedicated to “county”. In order to best preserve anonymity, the data extraction pilot only took data from the “county” field.

The rates of availability of these data items in are illustrated in Table 4-9.

**Table 4-9: Completeness of data in extraction pilot**

Data item	% of cases where this data item was available to the researcher
Age	98%
Gender	80%
County of residence	56%

The core clinical data collected by the pilot data extraction i.e. refractive error did not suffer significantly from a data incompleteness issue. Only 84 cases (0.29%) did not have a refractive error recorded for the right eye. However every one of these cases had a refraction recorded for the left eye. Therefore the most likely reason for no data being available for the right eye is that these cases were uni-ocular i.e. had only one (functioning) eye. Future researchers could decide to overcome this in the data analysis stage by using the left eye data in this small number of cases.

As far as could be determined, data accuracy was not an issue in this pilot data extraction. The only data accuracy issue that was detected was that 3 patients had incorrect years of birth recorded giving impossible ages of 1,828, 1034 & 833 years.

#### 4.3.4 Patient age

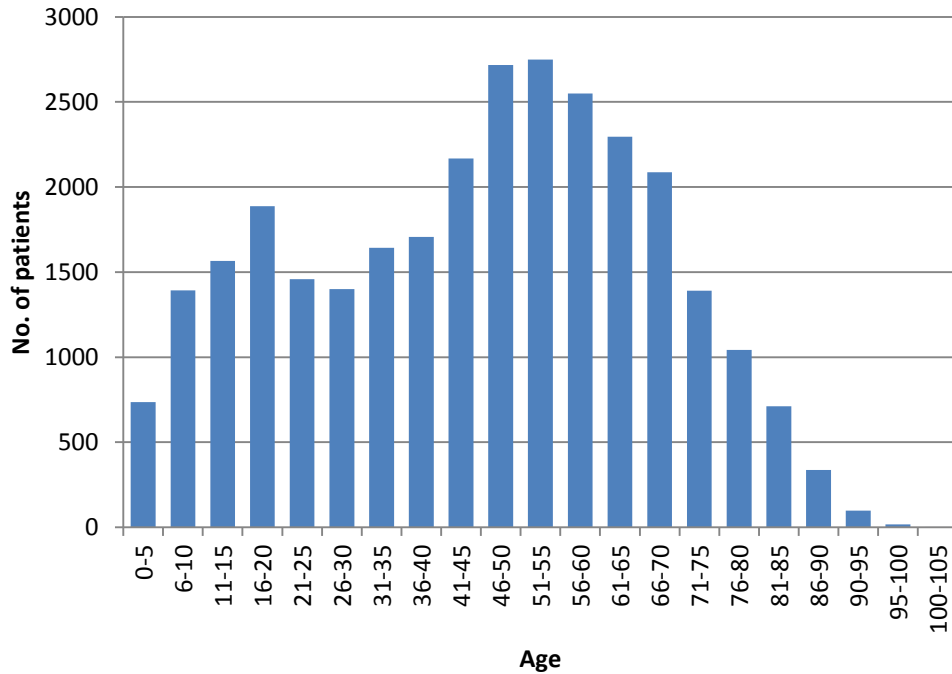
The age at the time of the eye examination was extracted for each patient. However approximately 2% of individuals had no age recorded. The mean age of the 27,806 patients for whom age was recorded was 44.9 years (SD 21.8 years) ranging from a minimum value of less than 1 year to a maximum of 105 years.

The mean age of the patients of each practice was calculated for comparison and the results are presented in Table 4-10. While the majority of the practices had similar mean age for their patient base, two (Practice B and E) had significantly lower mean patient age. Each practice had a broadly similar diversity of patient age as indicated by the similar standard deviations.

**Table 4-10: Patient age profile per optometry practice**

Practice	Location	Mean Patient Age (years)	Standard Deviation
A.	Co. Tipperary	47.18	22.88
B.	Galway City	37.46	19.60
C.	Dublin 15	44.32	20.29
D.	Dublin 8	47.75	22.50
E.	Co. Wicklow	40.79	20.10
F.	Co. Clare	48.50	23.03

The age distribution for aggregated patient cohort from all six practices is shown in Figure 4-20.



**Figure 4-20: Age distribution of patients from six sample optometry practices**

#### 4.3.5 Patient gender

Of the 24,575 patients whose gender was recorded 58% were female and 42% male. The inclusion of gender in the dataset allows for analysis and comparison of refractive error distribution for each gender if desired.

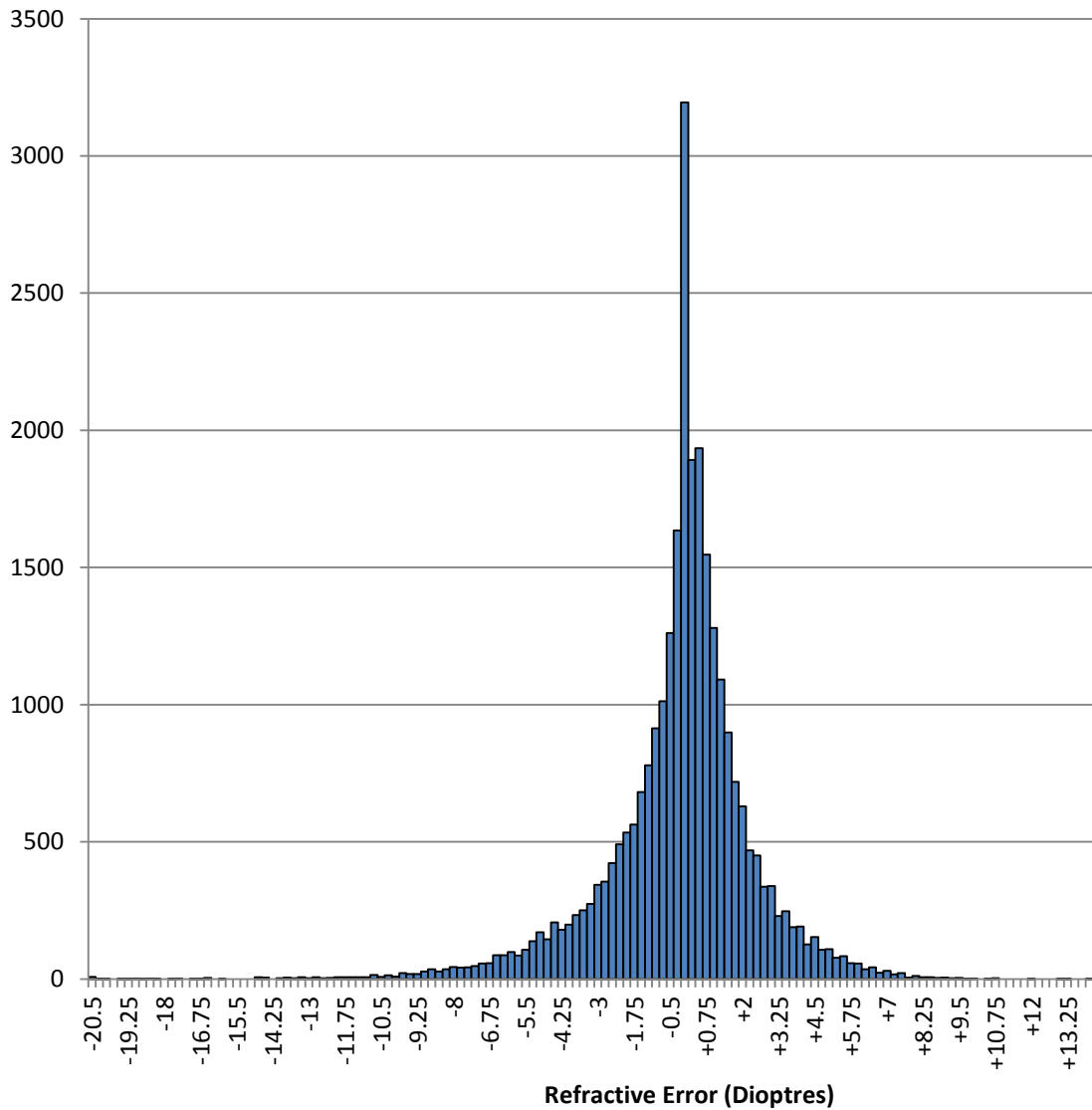
#### 4.3.6 Refractive error

The distribution of refractive error (myopia and hyperopia<sup>6</sup>) for the patient population of the pilot (n = 28,490) i.e. the population refractive error profile is illustrated in Figure 4-21.

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<sup>6</sup> Myopia is indicated by a minus value (< 0) and hyperopia by a positive value (> 0).

Following the convention of refractive error studies in the literature, refractive error was plotted using the spherical equivalent<sup>7</sup> value for the right eye of each patient.



**Figure 4-21: Distribution (profile) of refractive error for pilot population (n = 28,490)**

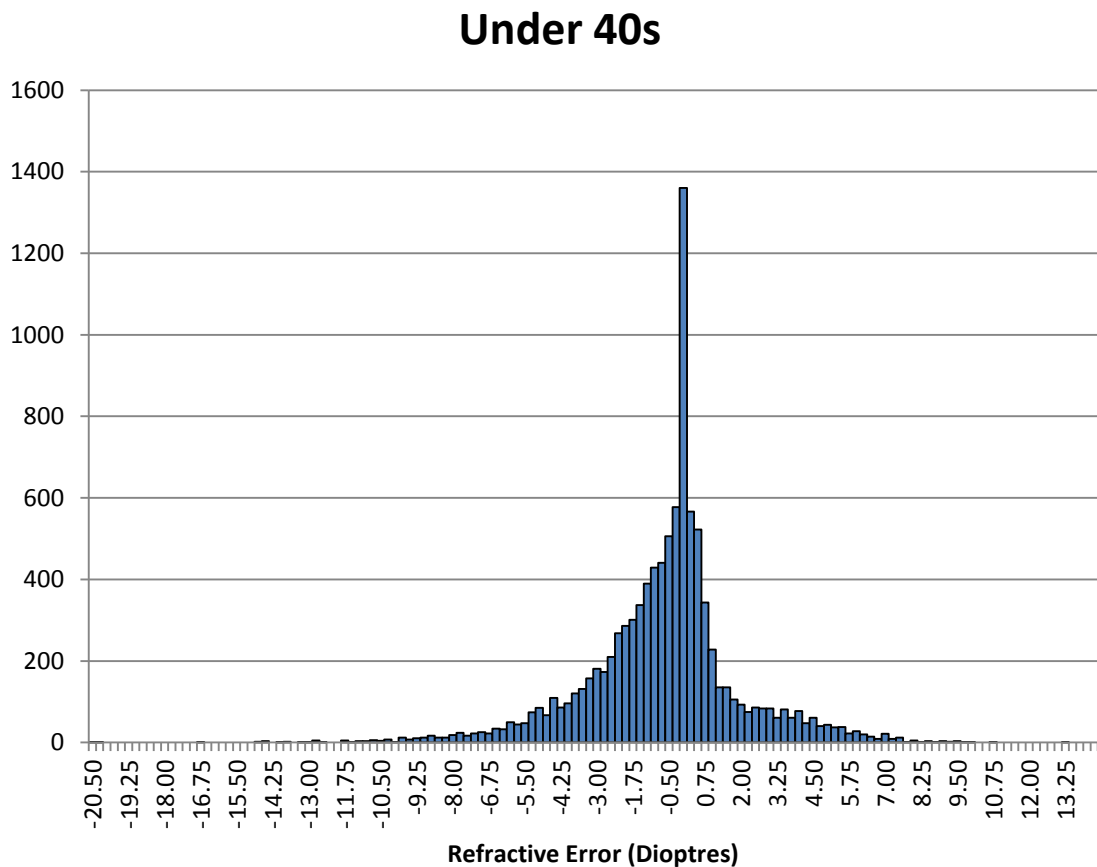
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<sup>7</sup> Spherical Equivalent is the calculated 'average' refractive error for an individual; it is calculated by adding half of the dioptre value for any astigmatism present to the dioptre value for the eye's myopia or hyperopia.

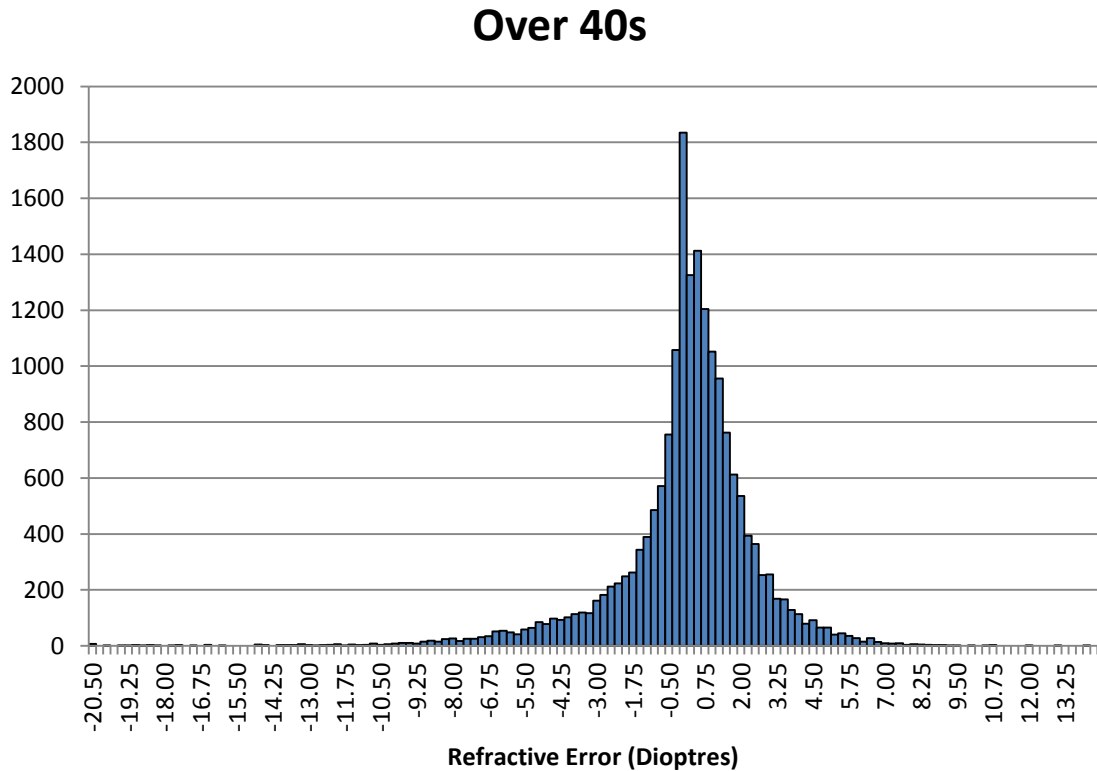
The mean refractive error for the sample was -0.224 Dioptres with a range of -30.00 Dioptres (myopia) to +14.00 Dioptres (hyperopia) and standard deviation of 2.58. The distribution is not normal (Gaussian): asymmetry is demonstrated by the skewness value of -1.19 (i.e. towards myopic side of the spectrum) and there is a positive kurtosis of 6.65 (clearly illustrated by the high and sharp central peak of the histogram above).

The percentage of the population with myopia, hyperopia and astigmatism were 33.15%, 32.90% and 37.80% respectively.

For further analysis, the proportion of the population for whom age was available (27,806) was divided into two age groups – those under 40 years and those aged 40 and above. The distribution for each group is shown in Figure 4-22 and Figure 4-23 respectively.



**Figure 4-22: Distribution (profile) of refractive error for under 40s (n = 10,008)**



**Figure 4-23: Distribution (profile) of refractive error for over 40s (n = 17,798)**

As is the case for the total pilot population, the two age cohorts (under and over 40 years) also show a non-Gaussian distribution (asymmetrical and positive kurtosis). However the mean refractive error for the younger group is more myopic (-0.73 D) than that of the older group which is slightly on the hyperopic side of the refractive error spectrum (+0.05 D).

Further analysis (beyond the scope of this study) based on different age categories, gender, geographic location, different time frames, individual practices/practice groups etc. would be possible using the data set and data extraction tool developed by this project.



## **4.4 Summary**

This chapter presented the results of Phase II and III of the study. Phase II results were those of the survey of optometrists regarding EPR use and attitudes towards extraction of data from their EPR systems for research purposes. Phase III results included the findings of the process of development and implementation of the data extraction tool as well as the results of the produced from analysis of the pilot EPR data extraction ultimately providing a distribution profile of refractive error for the pilot population.

The next chapter will discuss and interpret the results of this research work.

## 5 Discussion

### 5.1 Introduction

The primary objective of this study was to determine whether clinical data could be collected automatically from EPRs used in the field of optometry so that these data could be further used for meaningful research purposes, specifically the establishment of a population profile of refractive error. The key elements to establishing an answer to this question were:

**RQ1:** Determining that it is possible from a technical ICT perspective to develop a process of data extraction from optometry EPRs that will yield a valid profile of refractive error.

**RQ2:** Estimating the potential quantity of refractive error data that could be gathered from optometry EPRs in Ireland.

**RQ3:** Establishing the attitudes of optometry EPR users (optometrists) towards extraction of data from their EPR systems for secondary (research) use.

Clinical data are collected by optometrists on over 650,000 patients annually in Ireland particularly in relation to refractive error, the measurement and treatment of which is the core function of optometric practice. Yet there is a distinct lack of research into this area globally and especially so in Ireland. Given that so much of this type of data is now collected and stored by optometrists in electronic format, this researcher's ambition was to demonstrate that these silos of data could be tapped into and their potential to provide valuable information unlocked. Secondary use of clinical data in this way is at the core of the discipline of health informatics, enabling meaningful and useful research through the collection of Real World Data (RWD) to provide Real World Evidence (RWE) in healthcare domains.

This chapter will discuss how the results of the various aspects of the work conducted address the research objectives and provide an answer to the research question.

## 5.2 Technical Solution (RQ1)

The first research sub-question (RQ1) of this study asked: *“Is it technically possible to extract data from optometry EPRs in order to produce a valid profile of refractive error?”*

In order to establish that the necessary clinical data could be extracted from optometry EPRs to produce a refractive error profile for a population, Phase III of this study involved the researcher in working with the principal supplier of optometry EPR systems in Ireland (and a leader in the field globally), Ocuco Limited. A software tool to extract the data was developed through a short iterative process and was implemented on a pilot basis in cooperation with six optometry practices resulting in the relevant data on approximately 30,000 patients being successfully extracted and gathered into a format to facilitate analysis. For the purposes of this study, data from a time span of two years (1 April 2013 to 31 March 2015) were collected from each practice. This time interval could be easily adjusted through a simple setting in the data extraction software tool so that data from anything to one day to several years could be extracted and analysed as required. The tool also provided for elimination of duplicates so that only the most recent data for a given patient were included, ensuring that no individual was “counted” more than once.

Once the data extraction tool was installed remotely on the server of the participating optometry practices, it could be run very simply and it took no more than a few seconds to perform its task. In order to retain anonymity of the individual practice submitting the data for analysis, the data files were sent to the researcher via Ocuco Ltd., the only identifier being a practice code known only to Ocuco Ltd.

The total amount of work involved in discussing requirements, planning, coding, testing, general management and ultimately deployment of the data extraction software has been quantified by Ocuco as no more than 12 hours. It was viewed by Ocuco as a *“relatively simple requirement”* needing *“simple code”*. (The code for the software tool can be viewed in Appendix L.)

This proof-of-concept pilot demonstrated that the extraction of required data could be easily achieved technically through the development and implementation of a simple software tool, providing anonymous analysable data in a manageable format.

In terms of data quality, the only significant issue was data completeness; this is in-keeping with the experiences cited in the literature in this area (Weiskopf and Weng, 2013). This mainly affected two data elements in this study – patient gender and county of residence. In 20% of cases in the pilot population, gender was not recorded. This was fed back to Ocuco and it was revealed that the Acuitas system already had an option to make completion of the “Gender” field mandatory; practices participating in the pilot have since “switched on” this feature. For the county of residence data, it is likely that in most cases where the information is not appear in the data extraction pilot, it was due to the “County” part of the address being recorded in a different line (field) of the address section rather than not being recorded at the point of care. This could be resolved in future by either making the “County” field mandatory or by designing the data extraction tool to take information from more lines of the patient address however care would have to be exercised with the latter option lest there be a risk of compromising patient confidentiality.

The refractive error data did not suffer any data quality or completeness issues, so the lack of some gender and county of residence information did not affect the ability to produce a profile of refractive for the total pilot population – it only affected the ability to further analyse refractive error on the basis of gender and geographic location.

### 5.2.1 Refractive error data collected

The data collected by the pilot of the data extraction mechanism in Phase III of the study were analysed by the researcher with a view to establishing the distribution of refractive error (refractive error profile) for the population studied. Analysis of the data provided results from which a refractive error profile was produced. In Table 5-2, these results are compared with those of the largest study of refractive error found in the literature i.e. the Gutenberg Health Study (see Section 2.6.2). This was a population-based, prospective, observational cohort study in Germany with approximately 15,000 randomly selected participants and it took 7 years to collect the data (Wolfram et al., 2014). That study found a mean refractive error of -0.401 Dioptres and the frequency distribution skew value was -1.457. Table 5-2 compares the main statistical findings of the GHS with those of this study (EPR Study). For the purposes of direct comparison, the definitions of myopia, hyperopia, astigmatism and high myopia used in the GHS were applied to this study (see Table 5-1).

**Table 5-1: Study definitions of refractive error**

Refractive Error	Study Definition
<b>Myopia</b>	< -0.50 D Sph (i.e. more than 0.5 dioptres myopia)
<b>Hyperopia</b>	> +0.5 D Sph (i.e. more than 0.5 dioptres hyperopia)
<b>Astigmatism</b>	> 0.5 D Cyl (i.e. more than 0.5 dioptres astigmatism)
<b>High Myopia</b>	< -6.00 D Sph (i.e. more than 6 dioptres myopia)

**Table 5-2: Comparison of results with Gutenberg Health Study**

Result	GHS	EPR Study
<b>Subjects (n)</b>	13,959	28,490
<b>Mean Refractive Error (D)</b>	-0.401	-0.224
<b>Distribution Skew (D)</b>	-1.457	-1.200
<b>Myopia %</b>	35.10%	33.15%
<b>Hyperopia %</b>	31.80%	32.90%
<b>Astigmatism %</b>	32.30%	37.80%
<b>High Myopia %</b>	3.50%	2.90%

The results from the two studies compare well, although the mean refractive error in the GHS study is slightly more myopic (short-sighted) than that of this EPR study.

To further help establish the meaningfulness of the data collected in this pilot, results were compared with those from a study on a similar population - the Northern Ireland Childhood Errors of Refraction (NICER) Study. That study was a population-based cross-sectional epidemiological study of refractive error among school-aged children in Northern Ireland conducted over a two-year period between 2006 and 2008 (O'Donoghue et al., 2010). It found that the prevalence of myopia in the 661 children studied increased six-fold from younger childhood (6-7 years) to older childhood (12-13 years). The refractive error data from this researcher's EPR-based pilot study found the same six-fold increase in the rate of myopia from the 6 year old cohort to the 12 year old cohort (N = 613).

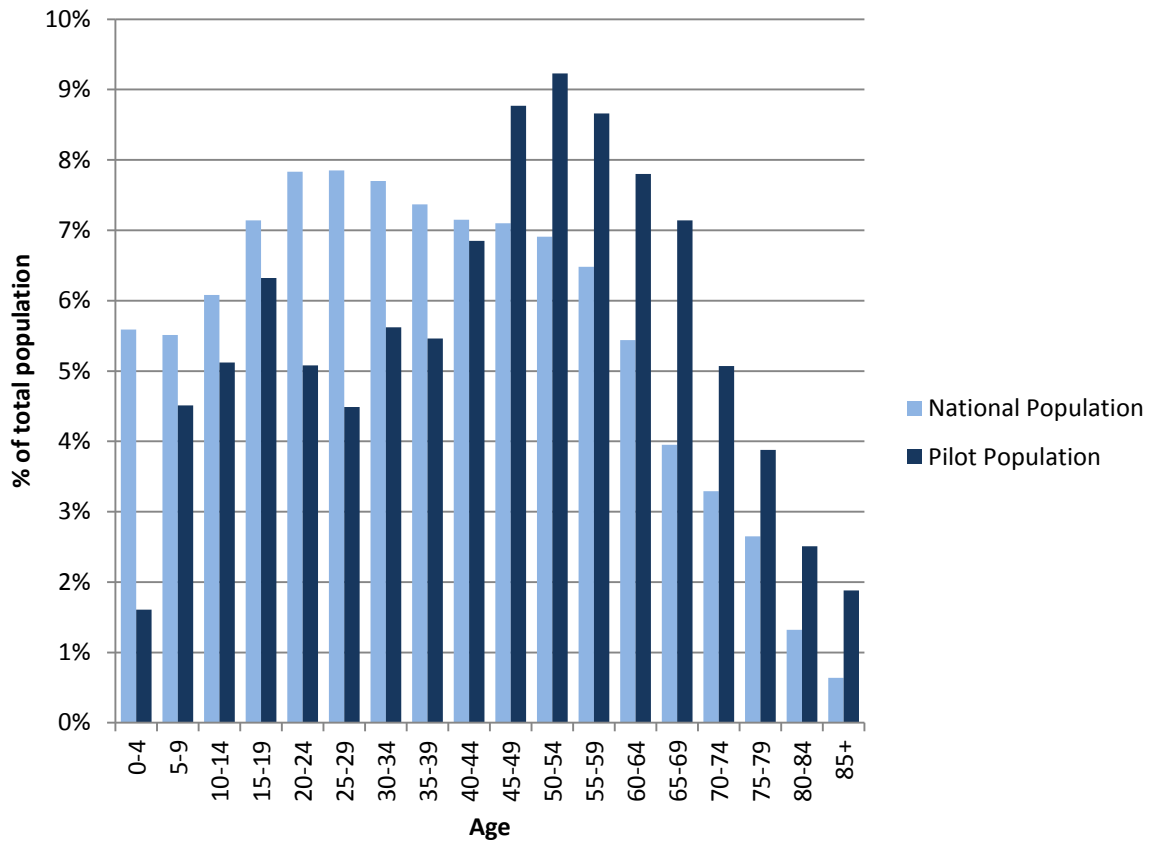
The researcher also looked at the distribution profiles for the age cohorts under and over 40 years and found that the mean refractive error was on the myopic side for the younger group and hyperopic for the older cohort. This is in keeping with the findings of all previous studies on refractive error.

These comparisons with rigorously conducted clinical studies can be considered a reasonable indicator of the validity of the results of the EPR study – validity and reliability could be further improved by collecting data from a larger number of optometric practices in future larger-scale studies.

### 5.2.2 Study bias

However, the researcher acknowledges that there is a selection bias inherent in using data only about individuals who access care from optometrists and optical practices (using EPRs) as opposed to conducting a whole-population census or cross-sectional study. This challenge to generating valid estimates for populations with incomplete EPR coverage has previously been identified in the literature; though the availability of sophisticated statistical analysis tools to adjust for selection bias in such observational data can help in addressing this issue (Garrison et al., 2007, Friedman et al., 2013). Sources of bias must be identified so that they can be adjusted for.

In order to employ such high-end statistical approaches and accurately calculate population prevalence of refractive error, the difference between the optometry-visiting population and the whole population of the country would have to be taken into account. Figure 5-1 compares the national population (EUROSTAT, 2013) with that of the cohort of individuals studied in the pilot data extraction of this study.



**Figure 5-1: Comparison of age distributions of pilot population and national population**

*Source of national population statistics: EUROSTAT*

It can be seen from Figure 5-1 that this bias is most pronounced for the cohort between the ages of 20 to 40 years. This contributes an apparent relative under-representation of under 20s and over-representation of the over 45s in the optometry-visiting population of this pilot

study. This is consistent with the general experience of optometric practice in that people between the ages of 20 and 40 (young healthy individuals) are less likely to visit an optometrist unless they already have a diagnosed refractive error and an established need for optical correction. However, after the age of 40/45 almost everyone will require the services of optometrists (due to the onset of presbyopia i.e. difficulty with focussing up close). If the data from optometry EPRs are to be used to calculate population prevalence, this bias would have to be accounted for.

Despite this, the EPR data (even for the younger population cohort) is likely to be accurate in terms of absolute numbers requiring optical correction; this is especially true for myopia, given how symptomatic and problematic this issue is even at mild levels of the condition. One of the principal drivers for studying refractive error now and in the future is the change in incidence and prevalence of myopia and how new interventions may impact on this. Even with the population bias outlined above, use of optometry EPR data has the ability to yield valuable and valid indicators of these trends.

### **5.3 Potential Quantity of Collectable Data**

The research sub-question RQ2 asked: *“What is the potential quantity of data that could be gathered from optometry EPRs in Ireland?”*

The survey of optometrists in practice conducted as part of Phase II of this study helps to inform the potential for the amount of data that could be collected on refractive error in Ireland. Approximately 650,000 primary eye care examinations (involving measurement of refractive error) are performed each year in the Republic of Ireland. This service is provided by about 350 optometry practices (AOI, 2015).

The survey indicated that 80% of optometrists use electronic record systems of some kind and 95% of those using electronic systems indicated that they use them to record refractive error data. Given that the survey sample has been shown to be representative of the total population of optometrists, it can therefore be reasonably extrapolated that at least 76% (i.e. 95% of the 80%) of eye examination (refraction) results are recorded electronically. In reality, the figure is likely to be greater than this as practices/practitioners not using EPRs are likely to



be smaller in size (performing relatively fewer eye examinations) while larger practices/practice groups seeing greater volumes of patients are more likely to be using electronic systems. Using the conservative estimate of 76% and applying the percentage of practitioners who indicated an interest in potentially being involved in data extraction from their systems (91%), there is a theoretical availability of data on at least 70% of eye examinations performed (i.e. approximately 450,000 refractive error measurements annually). Even if the system of data extraction were applied only to users of the three most popular EPR systems (Acuitas, Socrates & Optix), the refractive error data on almost 400,000 people could potentially be collected per annum.

As it is relatively unusual for most people to visit an optometrist more frequently than every two years, this should equate to approximately the same number of individual patients. If a data extraction exercise were to collect data for a two year period (as was done in this study), the refractive error data for close to 1 million people could potentially be available for analysis at any given time. Of course, data could be collected for periods greater than two years and given that this study's data extraction tool eliminates duplicate visits by any individual (within the same practice) which would yield data on even greater numbers. Even if only 50% of optometrists ultimately agreed to be involved, the potential exists to conduct research on very large numbers of patients, yielding meaningful and useful information on the rates of refractive error.

Furthermore, data extraction could be performed for different retrospective periods of time in the past and the resultant population profiles compared, instantly yielding a picture of how refractive error distribution has changed over time. Similarly, data extraction can be performed repeatedly at points in time in the future (even on a daily/weekly basis if desired) to produce a dynamic profile of refractive error for the population - providing valuable and timely insight into contemporaneous changing trends. Given the apparently increasing prevalence and incidence of myopia in particular (as evidenced in the literature review) and the clinical implications of this, such information gleaned at a population level and in a timely fashion will be important for the provision of eye care services. Should clinical interventions for control of myopia become a feature of optometric practice, the gathering and analysis of RWD will be valuable in monitoring the impact of such treatments and establishing evidence their efficacy at a population level.

While data completeness was found to be an issue in this study, it only affected availability of data on gender and county of residence and not on refractive error itself. So while this data quality issue would not have any significant effect on the potential amount of refractive error data available, it would compromise the number of individuals available for analysis of refractive error based on gender or location.

## **5.4 Willingness of Optometrists**

Research sub-question RQ3 asked: *“Would optometrists in Ireland be willing to be involved in a system of extraction of data from their EPRs for secondary (research) use?”*

As well as the technical ability to perform data extraction from optometry EPRs, the other key element is the willingness to participate on the part of those collecting the clinical data at the point of care i.e. optometrists in practice who use EPRs. Section B of the survey of optometrists was designed to gain an insight into this aspect of the data extraction for secondary use.

An overwhelming majority of responding optometrists indicated an interest in an on-going system of data extraction for research purposes (only 9% said they would not be interested). An even greater proportion (98%) demonstrated an interest in receiving reports comparing the information on their patient base with that of a larger population (potentially national) and a similar percentage showed an interest in the ability to carry out practice-based research using such a system.

### **5.4.1 Perceived barriers**

Several possible barriers to participation in a data extraction scheme were identified by approximately 40% of EPR-using respondents to the survey. The concerns that were raised were not particularly surprising to anyone with knowledge of health informatics. Also, almost all of the challenges to such schemes of data collection identified by the AHRQ (see Section 2.5.1 above) are represented in the barriers perceived by the participants of this study’s survey (albeit in different terminology); of the 24 AHRQ challenge components the only one not

identified in this survey was “*Absence of a national health care quality data set and report card*”. Thus a very good level of appreciation of the type of issues that can arise in the implementation of such systems was demonstrated by the survey respondents.

The most frequently cited issue was that of “*time*” i.e. the time that the clinician would potentially have to spend extracting and submitting the data. It is not surprising therefore that when presented with a set of options for how this process would be carried out in terms of level of the clinician’s involvement/effort, a large majority (60%) chose to have the process performed completely automatically without any action on their part (beyond consent), as a means of overcoming the “*time*” concern. This approach was followed in the pilot data extraction in Phase III.

Issues around data governance (data protection, confidentiality, security, patient consent and misuse of data) were also cited as disadvantages and over 40% of those respondents who identified potential barriers to the implementation of such a system, perceived these data governance issues as a possible threat. The word “*trust*” appeared several times in the free-text responses to the question on barriers. In this light, it is interesting to note that two-thirds of the EPR-using respondents would prefer either an appropriate academic institution or professional body to gather and store the extracted data possibly indicating a greater level of “*trust*” in these bodies rather than in the alternatives (EPR software providers/vendors or a new entity specifically set-up for the purpose). For a research system to successfully recruit optometrists to submit their data a significant amount of effort would have to be expended in reassuring them about data governance and gaining their trust.

#### 5.4.2 How this project addressed barriers

Phase III of this research project developed a data extraction tool and piloted it to extract data from the EPR systems of six optometry practices; one of the objectives of this exercise was to demonstrate how barriers (real and perceived) to the performance of data extraction from optometry EPRs could be addressed and overcome. Through the completion of this research project and the implementation of the pilot (or prototype) data extraction all of the potential barriers pointed to by the survey participants were addressed.

Table 5-3 outlines how these barriers were addressed and shown to be dealt with by the data extraction pilot.

**Table 5-3: How this project addressed potential barriers to EPR data extraction for secondary use**

<b>Category</b>	<b>Barrier</b>	<b>How this project demonstrated overcoming these</b>
<b>Resource implications</b>	Time	The pilot demonstrated that the data extraction could be performed entirely automatically without any time/effort of the part of the EPR user
	Cost	Once the data extraction software tool is developed, there are no direct costs to the EPR user
	Workload/workflow interruption	There was no interruption of workflow or additional workload involved in carrying out the data extraction pilot
	Lack of I.T. skills	As the extraction process can be fully automated and actioned remotely, no IT skills are required by the EPR user
<b>Technical issues</b>	Interference/conflict with the EPR system	No conflict was caused by the data extraction pilot. The process involved is not complex or processor-demanding and file sizes for the extracted data are not onerously big
<b>Data quality</b>	Incomplete data	The pilot identified some demographic data elements that were missing in a number of cases (date of birth, gender, county of residence) – the pilot demonstrated how this can be addressed through feedback to clinicians and EPR developers e.g. gender now mandatorily recorded

	Inconsistent terminology	Due to the nature of the data collected in this project – this was shown not to be an issue.
	Data accuracy	As far as could be ascertained by this pilot, accuracy of clinical (refractive error) data was not a problem. (There were 3 cases where impossible (i.e. inaccurate) dates of birth were recorded).
<b>Data governance</b>	Data protection	The data could be extracted in compliance with the guidance from the Data Protection Commissioner
	Confidentiality	Given the data set used, it would not be possible to identify any individuals
	Security	The data files were securely stored. The in-built anonymity meant that even if a security breach were to occur, no optometrist or patient would be identifiable
	Patient consent	Patient consent was not necessary because of the anonymous nature of the data (in line with the guidance from the Data Protection Commissioner)
	Improper/unintended use (misuse) of data by third parties	Commitments regarding the limitations of the use of the data were given and adhered to by the researcher. The EPR system provider was keenly aware of data protection rules and gave similar commitments regarding data usage
<b>Organisational</b>	Employer interest/willingness	Only 9% of EPR using respondents indicated no interest in a data extraction system – this was almost evenly split between employer and employed optometrists (5% employer, 4% employee). Also, the optometrists who participated in pilot data extraction were employers.

### 5.4.3 Possible enablers

As seen earlier, conducting research through the secondary use of EPR data has already been shown in the literature to facilitate practice-based research (Wasserman, 2011, Hartmann et al., 2015). The optometrists responding to this study's survey demonstrated extremely high levels of interest in the possibility of receiving reports comparing their data with a "*national picture*" and in the potential to conduct practice-based research (97% and 98% respectively); these could be used as incentives to participation and act as enablers for the implementation of a system of EPR data collection.

## 5.5 Potential Use (within and beyond optometry)

The survey of optometrists established that those who use EPR systems in the practice of their service provision use these systems extensively to support their work both administratively and clinically. It is clear that as well as capturing data on the refractive error element of eye examination encounters, EPRs are used to record other relevant clinical information including eye pressure, medical history, ocular health clinical findings, diagnoses, referral, management and advice to patients. The survey also demonstrated that many optometrists have diagnostic devices linked directly to their EPRs and as greater access to such diagnostic technology and improvements in the capability of EPR systems to link to and record results from these devices over time, the amount of clinical data accessible in this way is set to increase further in coming years.

Therefore, beyond gathering and analysing data on refractive error, the potential exists for secondary use of other useful clinical data from optometry EPRs for future research purposes.

This concept of data extraction for secondary use can also be extended to other healthcare domains where there are already high (and increasing) levels of EPR use. In Ireland, this is already happening to a certain extent for data recording by GPs through the Irish Primary Care Research Network (IPCRN). The methodology of that on-going research initiative and that of this project with optometry EPRs could be drawn on by other healthcare areas such as dentistry, physiotherapy and medical/surgical specialities (dermatology, paediatrics,

orthopaedics, gerontology etc.) to provide for powerful and timely analysis of real world data on large populations and thus contribute to clinical knowledge and evidence bases.

## **5.6 Research Question**

The research question asked *“Can data be collected automatically from optometry electronic patient records in Ireland in order to produce a population profile of refractive error and facilitate future research into the field?”*

Based on the evaluation of the survey of optometrists, the development of a prototype software tool to extract the necessary data from EPR systems and the successful pilot use of this tool which did indeed produce a profile of refractive error which compared well with that from a rigorous and lengthy population-based study, it is possible to deduce that meaningful and valid research on refractive error (and potentially other aspects of eye health) could be conducted by extracting data from optometry EPRs in this way. The ease with which this can be achieved technically and the levels of willingness indicated by optometrists mean that the potential also exists to conduct such work on a repeated/on-going basis, allowing for the production of dynamic population profiles over time.

## **5.7 Limitations of the Study**

The researcher recognises that there were some limitations to the research conducted in this study. These include:

1. The participants in the survey of optometrists were given very little information on how a system of EPR data extraction would work. Therefore their perceptions of such a system were based on a somewhat intangible concept rather than on real experience. This may have affected the responses e.g. an over- or under-estimation of barriers.

2. The proposed system of data extraction for research purposes means that such research would be limited to the cohort of people who attend optometrists rather than a census or a cross-sectional population study. This bias may lead to a distortion of the refractive error profile i.e. it may not be representative of the whole population. Specifically, this bias may be more of a factor when studying younger portions of the population. Depending on the purpose of such study, this factor may have to be considered and adjusted for using sophisticated statistical analysis.
3. The prototype data extraction tool developed and piloted in this study was built for one EPR system only (albeit the most commonly used system). To conduct (near-to) whole- population studies, software capable of extracting data from all EPRs in use (or at least the one other major system – Socrates) would have to be developed. A level of interoperability in the gathering and/or aggregation of the data would be required.
4. Because of the requirement for anonymity in this study (in compliance with the guidance of the DPC), it would not be possible to track the progression of refractive error in individuals. In the future the introduction of unique patient identifiers may facilitate such research if use of these identifies were to be permitted by legislation for such EPR studies.
5. This EPR data extraction conducted in this study was done on a pilot basis only – using the data from only six optometry practices known to the researcher. The resultant refractive error profile therefore should not be considered statistically representative or generalizable.

The reader may also wish to consider the potential personal biases of the researcher including the author's self-declared pragmatic approach (see Section 3.2.1.). These may well have influenced the direction of this research. Additionally, the author had a clear self-interest in endeavouring to earn an MSc in Health Informatics through completion of this dissertation.



## **5.8 Future Work**

One of the objectives of this work was to lay the foundations upon which future research into refractive error could be built. This study provides scope for future research in a number of areas.

### **5.8.1 Larger scale study of refractive error**

The mechanism developed to extract refractive error data from optometry EPRs as part of the work of this project could be expanded to include data from a much greater number of optometry practices. This study used the data from only six practices. Even if only those practices using the Acuitas EPR system were to be involved this would yield data from a large number of optometry practices. If it were possible to carry out similar data extraction with the users of the other leading optometry EPR systems in Ireland the potential to gather and analyse these data on hundreds of thousands of individual patients annually.

Such studies could be performed on an on-going basis to provide an insight into changing prevalence and incidence of refractive error over time and aetiological influences at a population level or to evaluate the impact of new interventions which may become widely practised such as in the area of myopia control. Comparisons of the relative frequencies of the different refractive errors in different geographical regions would be novel and insightful.

### **5.8.2 Other eye health studies**

The model of EPR data extraction developed and implemented in this study could be used to gather other clinical data recorded in optometry systems thus providing the basis for large scale study of other eye health issues.

### **5.8.3 Data quality study**

Although not an objective of this study, information of data quality (particularly data completeness) emerged as a by-product of the data extraction pilot. Studies with the specific purpose of assessing data quality in optometry EPRs would have the potential to inform

clinicians on improving clinical record keeping and developers on optimising design and usability of EPR systems.

## **5.9 Summary**

This chapter demonstrated and discussed how the analysis of the results from the different phases of the research conducted showed that research question could be answered affirmatively. Limitations to the research were identified and potential future work relevant to the study was considered.

The next chapter will discuss key findings of the study as well as its contribution to the research.

## **6 Conclusion**

Having recognised a lack of research and evidence in the area of refractive error prevalence, the researcher explored the potential for implementing a means of automatically extracting clinical data (specifically refractive error data) from EPRs used in the practice of optometry in Ireland with a view to using these data for research purposes in order to establish a population profile of refractive error.

To achieve the aims of the study, following a review of relevant literature, practising optometrists were surveyed and an EPR data extraction tool was designed, developed and piloted. A profile of refractive error for the pilot population was produced.

### **6.1 Key Findings**

From the literature it is clear that while there is now a high level of use of EPRs amongst many healthcare providers and it is well recognised that one of the key purposes of EPRs and EHRs is to facilitate research which should inform clinical practice, in reality there is very little secondary use of data from EPRs for this purpose. This is particularly true in the domain of optometry where no example of such a system of secondary use was found in the literature. The use of optometry EPR data could provide a valuable means of filling the gap that exists in refractive error research at a time when refractive error prevalence is changing and new aetiological theories and interventions are emerging. Traditional research methodology for larger-scale population studies in this field has been shown to be costly and very time consuming.

By developing and successfully piloting a software tool, this study has shown that it is technically possible and relatively straightforward to extract the real world EPR data necessary to conduct research into refractive error and produce valuable information on the levels of refractive error in a population. Once implemented, extraction of data from the EPR systems could be readily and frequently repeated to facilitate on-going epidemiological research into refractive error and trends in its prevalence and incidence.

This study found that in Ireland 80% of optometrists routinely use EPR systems in the provision of primary eye care services. These systems are used extensively, gathering data on refractive error and many other aspects of eye and vision health. Almost 60% of these optometrists use one particular EPR system (Acuitas) and over 80% use one or other of the three most popular systems (Acuitas, Socrates and Optix). Extraction of data from these three systems could potentially yield refractive error data on almost 400,000 individuals per annum.

In order to access these data, the cooperation of optometrists in practice is required. This study demonstrated a very high level of willingness amongst these practitioners in Ireland; they indicated an interest in secondary use of data from their EPR systems for research purposes and in the potential to use such a system to facilitate practice-based research. This interest could be leveraged to facilitate implementation of a large-scale data collection and aggregation scheme.

Several potential barriers to participation in a system of data extraction were identified by optometrists. These barriers were typical of those encountered by many ICT implementations and could be categorised into resource, technical, data quality, data governance and organisational concerns. However, it was possible through the running of the proof-of-concept pilot conducted as part of this research to demonstrate how these barriers could be addressed and overcome.

The refractive error profile that was produced by this study for the sample population of almost 30,000 individuals demonstrated a level of validity in that it compared closely with that produced by the largest cross-sectional study of refractive error conducted in Western Europe (GHS) which took seven years to complete.

The EPR data collection mechanism developed by this study could be utilised for larger-scale and repeated studies which could potentially produce profiles of refractive error for the national population on an on-going basis.

## **6.2 Main Limitations**

The pilot EPR data extraction conducted in this study was limited to collecting data from only one EPR system (Acuitas). To maximise the reach and reliability of national research using EPR data, the data from other systems (or at least the second most popular system) should be included. (Given the ease with which the software tool for extracting the data from Acuitas was developed, it is unlikely that there would be a significant technical barrier to performing the same task on the Socrates system.)

A selection bias exists in using data only from individuals who access care from optometrists and optical practices (further limited to those practices using EPRs) as opposed to conducting whole-population census or cross-sectional studies. In order to accurately calculate a national population prevalence of refractive error, the difference between the optometry-visiting population and the whole population of the country would have to be identified and sophisticated statistical analysis applied to appropriately adjust for this.

## **6.3 Contribution to Research**

This study has identified a high level of willingness amongst optometrists in Ireland to contribute anonymous clinical data from their EPR systems for secondary (research) use. Given the high levels of EPR use by these eye care professionals, the potential to gather large amounts of data on refractive error and other eye health issues has been demonstrated.

The successful piloting of an effective and inexpensive data extraction mechanism has shown that this potential can be realised with relative ease from a technical point of view.

These findings provide for an approach to conducting large-scale population epidemiological study into refractive error and eye health (in Ireland and beyond) in a timely and cost efficient manner through accessing the valuable clinical data that exists in optometry EPRs. To the best of the author's knowledge, this approach to refractive error study has not previously been explored anywhere in the world and given the dearth of research into the field at a time when refractive error rates and levels of severity are increasing it represents a valuable opportunity to contribute to knowledge and ultimately to clinical practice.

## **6.4 Next Steps**

The logical next step leading from this research work is the conducting of a larger-scale study which would aim to extract the data from the EPR systems of as many optometry practices as possible around the country in order to get nearer to a national population profile of refractive error.

Once this has been achieved, the aim should be to conduct these data extractions on a repeated and on-going basis in order to produce (possibly changing) profiles over time. Further analysis, particularly based on age and geographic location could also be performed to add further information using a population health approach.

## **6.5 Recommendations**

The results of this research indicate that, while the technological means to extract useful clinical data from optometry EPRs can be relatively easily put in place, users of these EPR systems perceive numerous barriers to such a system. Through the successful implementation of a pilot data extraction exercise, the author demonstrated how these barriers can be addressed and overcome. However, while the self-employed optometrists who participated in the survey indicated a willingness to be involved in data extraction and the optometrists who participated in the pilot were self-employed (some being employers of other optometrists), the pilot did not involve any of the large multiple-outlet optometry providers. If this work is to be continued in trying to establish a national profile of refractive error, the leaders of these larger providers of optometry services would have to be engaged by convincing them of the benefits of participation and the negligible disruption to workflows and efficiencies at the point of care. Involving these stakeholders in the project development and implementation would be a crucial step. A well-managed change management process is necessary to ensure successful implementation in line with the objectives of such a project.

Similarly, providers/vendors of EPR systems should be involved in understanding the needs of a system of data extraction for secondary use so that consideration can be given to this when EPR systems are being designed and developed. Collection of health data should be integrated

into the process of documentation of care provision with minimal disruption if it is to remain sustainable.

EPR data collections should conform to HIQA's guidelines on healthcare and interoperability standards in order to ensure standardisation of data collection thus facilitating sharing and adaptation of collected data both at local and national level.

## **6.6 Dissemination of this work**

Part of the work of this research (the survey of optometrists) was presented at a meeting of the Royal Academy of Medicine in Ireland (Health Informatics Section) on 20<sup>th</sup> May 2015 and the abstract of that presentation will be published in the Irish Journal of Medical Science (see Appendix P).

The researcher intends to submit applications to present the completed work of the project presented in this dissertation at upcoming national and international conferences in the health informatics and optometry domains.

## **6.7 New Developments**

At the time of finalising the writing of this dissertation, the American Optometric Association (AOA) at its annual meeting in Seattle (24-28 June 2015) formally launched a plan to develop a system that will collect anonymous patient data from optometrists' EPRs. The AOA represents 39,000 optometrists in the U.S. and this new initiative ("Measures and Outcomes Registry for Eyecare – MORE") will initially involve six of the optometry EPR systems used there in "*an effort to improve primary eye care in the United States*" (AOA, 2015).

## **6.8 Reflections & Final Thoughts**

Navigating my way through the process of conducting this research project and learning how to structure the work using research strategies, philosophies and methodologies has been a valuable and enjoyable experience. Given my own pragmatic nature, it was particularly interesting to discover that Pragmatism is a recognised philosophical approach to research and to realise how my own approach to this work aligned comfortably with that philosophy.

It was encouraging to discover the high levels of interest by optometrists in the potential to conduct and contribute to research through secondary use of their EPR data. I found it interesting that optometrists in Ireland identified all of the literature-described barriers to implementation of such a system of secondary use and was pleased to be able to demonstrate how these could be addressed. I look forward to disseminating the findings of my research to the optometry profession.

Producing a profile of refractive error for the studied population was a rewarding and satisfying output of my work, particularly as it compared well with other respected scientific studies in the field.

I hope that the foundations laid by this work will be built upon and act as a significant enabler to conducting large-scale research into refractive error and other aspects of primary eye care. It is very interesting to note that the optometry profession in the U.S. has just recognised the potential of collecting EPR data for such research purposes and I will watch with interest as their proposed system develops over the coming years.

This research project would have benefitted from having more than one EPR system involved, the opportunity to do so remains for future work.

I feel that this work has made a significant contribution to the future of research into primary eye care by demonstrating how a health informatics approach to secondary use of electronic data can access existing information and turn it into valuable knowledge. With changing eye health needs, new interventions and expanding scope of optometric practice, my hope is that the value of this opportunity will be appreciated by the optometry profession and developers of optometry EPR systems and that both will facilitate the turning of this opportunity into reality.



## **6.9 Summary**

This study developed a relatively simple technical mechanism to perform extraction of refractive error data from optometry EPRs. The research conducted identified that there is a potential to collect data on 400,000 to 450,000 individuals in any one year period and that there is a very high level of willingness on the part of optometrists to be involved in a system of data extraction.

This researcher concludes that a population health approach to researching refractive error and establishing population profiles of refractive error on an on-going basis is possible in Ireland through the secondary use of automatically extracted optometry EPR data.

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## Appendix A: Types of EHR

<b>Table 2 – Types of EHR</b>	
Type of EHR (ISO)	Definition
Electronic medical record (EMR) Departmental EMR (n = 29)	Generally focused on medical care Contains information entered by a single hospital department Picture archiving and communication system (PACS) Anaesthesia records Intensive care records Ambulatory records Emergency department systems Pathology laboratory system Oncology records Cardiology records Operation theatre records Gynaecology records Internal medicine records Pharmacy systems Geriatric centre records Diabetes clinic records Radiology reporting system
Inter-departmental EMR (n = 2)	Contains information from two or more hospital departments Obstetric records for inpatient and outpatient clinics Prescribing system
Hospital EMR (n = 8)	Contains all or most of patient's clinical information from a particular hospital
Inter-hospital EMR	Contains patient's medical information from two or more hospitals
Electronic patient record (EPR) (n = 13)	Contains all or most of patient's clinical information from a particular hospital
Computerized patient record (CPR) (n = 13)	Contains all or most of patient's clinical information from a particular hospital
Electronic health care record (EHCR) (n = 1)	Contains all patient health information
Personal health record (n = 8)	Controlled by the patient and contains information at least partly entered by the patient
Computerized medical record	Created by image scanning of a paper-based health record
Digital medical record	A web-based record maintained by a health care provider
Clinical data repository	An operational data store that holds and manages clinical data collected from health service providers
Electronic client record	Scope is defined by health care professionals other than physicians, e.g. by physiotherapists or social workers
Virtual EHR	No authoritative definition
Population health record	Contains aggregated and usually de-identified data

(Friedman et al., 2013)

## Appendix B: Data Protection Rules

### The Data Protection Rules

Data controllers have certain key responsibilities in relation to the information which they keep on computer or in a structured manual file about individuals. These may be summarised in terms of eight "Rules" which must be followed, and which are listed below:

- **Obtain** and process the information fairly
- **Keep** it only for one or more specified and lawful purposes
- **Process** it only in ways compatible with the purposes for which it was given to you initially
- Keep it **safe and secure**
- Keep it **accurate and up-to-date**
- Ensure that it is **adequate, relevant and not excessive**
- Retain it **no longer than is necessary** for the specified purpose or purposes.
- **Give a copy of his/her personal data** to any individual, on request.

(DPC, 2005)



## **Appendix C: Strategies for Myopia Control**

### **Environmental intervention**

While genetics appear to play a small role in the development of myopia, environmental change appears to be a much more important factor in increasing the prevalence of myopia around the world (Morgan and Rose, 2005). Environmental factors affecting myopia is strongly supported by animal experimentation. Such experiments are not possible on humans but the association between years of schooling and educational achievement has been consistently demonstrated (Attebo et al., 1999, Wang et al., 1994). Some striking examples of this are the high prevalence of myopia in boys compared with that of girls attending Orthodox schools in Israel (Zylbermann et al., 1993) and the concurrent rises in myopia prevalence and intensity of education in urban east Asia (Morgan et al., 2012).

Recent studies have shown increasing the total amount of time that children spend outdoors protects against the development and/or progression of myopia (Rose et al., 2008, Sherwin et al., 2012, Guo et al., 2013). While the mechanisms for this effect are not fully understood, it has been replicated in animal experiments (Smith et al., 2012).

Therefore proposed environmental interventions include those where time spent by children and adolescents performing near visual tasks is reduced and/or time spent outdoors is increased. Some school- and community-based trials are currently underway in China and Singapore.

### **Optical Intervention**

Several optical interventions have been trialled and reviewed (Walline, 2011). The earliest approach was to prescribe spectacles providing under-correction of the myopia or bifocal correction; RCTs of these methods have proved them to be ineffective at slowing myopic progression (Morgan et al., 2012, Leo and Young, 2011, Fulk et al., 2000).

More recently, more complex lens designs have been used to provide correction for distance , intermediate and near visual tasks, typically progressive power lenses (PALs). The efficacy of this type of correction in retarding myopia is thus-far inconclusive; some studies have shown

small (clinically insignificant) initial effects but continued use did not afford any further protection (Morgan et al., 2012, Berntsen et al., 2012).

The most recent and the most promising optical devices designed to tackle the myopic progression challenge are lenses even more complex lens designs which provide accurate correction of central vision but provide a different correction for the peripheral retina. Some early trials have shown both statistically and clinically significant results (Sankaridurg et al., 2010) and other trials are on-going. However, because it is important for the success of this technique that the centration of the corrective lens is consistent no matter what direction the eye is looking in, contact lenses incorporating these designs may prove more successful than those provided in spectacles (Sankaridurg et al., 2011, Fujikado et al., 2014).

### **Pharmacological Intervention**

Trials on the use of the topical (eye drop) drug Atropine have been studied for many years (Ganesan and Wildsoet, 2010, Leo and Young, 2011). RCTs have shown that the progression rate of myopia is slower in children given these eye drops compared with those given a placebo (Song et al., 2011, Chua et al., 2006). However the effectiveness appears to decrease over time and on cessation an initial increase in the rate of myopia has been observed (Tong et al., 2009).

The treatment however is associated with some significant side effects most notably photophobia (light-sensitivity) – due to the effect of pupil dilation – and decreased near vision – due to the effect on the eye’s focussing muscles. Other possible side effects are dry eye, dry mouth, dry throat, flushed skin and constipation (Leo and Young, 2011, Morgan et al., 2012). These issues along with the fact that there would be increased exposure to the damaging effects of ultra-violet light to the eye’s internal structures for prolonged periods have meant that the technique has not been widely practised clinically. However, more recently the success of newer alternative drugs with lower concentrations and reduced side effects in animal studies may represent new opportunities for pharmacological control of myopia in humans (McBrien et al., 2011).

## Appendix D: Criteria for “Meaningful Use”

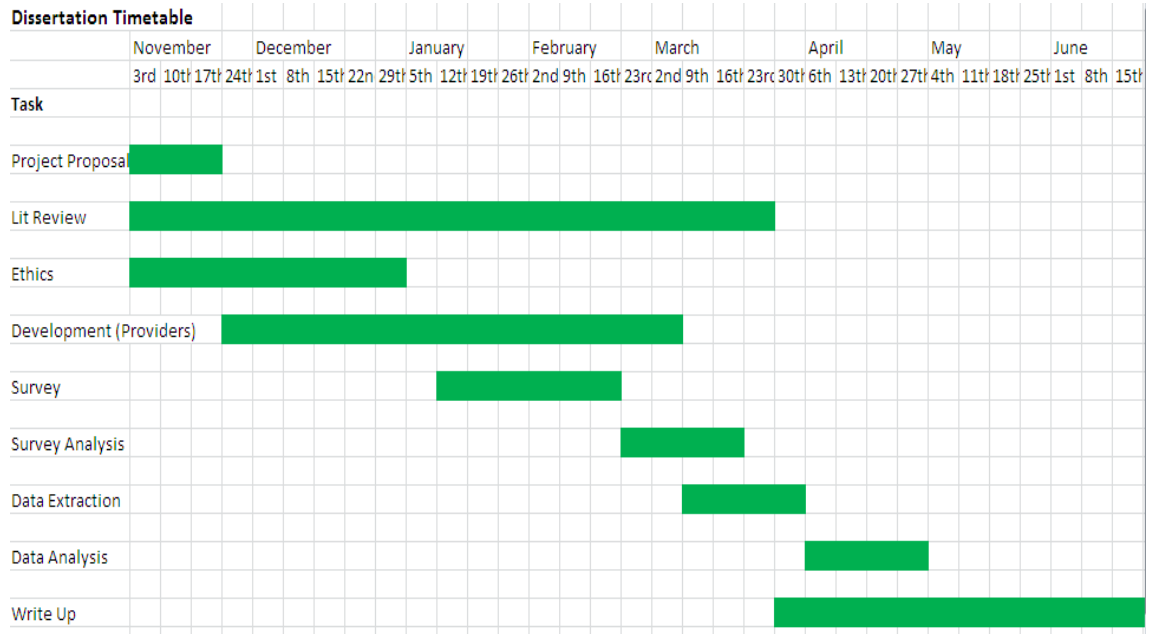
Core set of objectives to be achieved by all eligible professionals, hospitals	Set of additional optional objectives (any five of these must be achieved to reach the Meaningful Use Standard)
1. Record patient demographics (sex, race, ethnicity, date of birth, preferred language, and in the case of hospitals, date and preliminary cause in the event of death)	1. Implement drug formulary checks
2. Record vital signs and chart changes (height, weight, blood pressure, body-mass index, growth charts for children)	2. Incorporate clinical laboratory test results into EHRs as structured data
3. Maintain up-to-date problem list of current and active diagnoses	3. Generate lists of patients by specific conditions to use for quality improvement, reduction of disparities, research, or outreach
4. Maintain active medication list	4. Use EHR technology to identify patient-specific education resources and provide those to the patient as appropriate
5. Maintain active medication allergy list	5. Perform medication reconciliation between care settings
6. Record smoking status for patients 13 years of age or older	6. Provide summary of care record for patients referred or transitioned to another provider or setting
7. For individual professionals, provide patients with clinical summaries for each office visit; for hospitals, provide an electronic copy of hospital discharge instructions on request	7. Submit electronic immunization data to immunization registries or immunization information systems
8. On request, provide patients with an electronic copy of their health information (including diagnostic-test results, problem list, medication lists, medication allergies, and for hospitals, discharge summary and procedures)	8. Submit electronic syndromic surveillance data to public health agencies
9. Generate and transmit permissible prescriptions electronically	<b>Additional Choices for Professionals</b>
10. Computer provider order entry (CPOE) for medication orders	9. Send reminders to patients (per patient preference) for preventive and follow-up care
11. Implement drug–drug and drug–allergy interaction checks	10. Provide patients with timely electronic access to their health information (including laboratory results, problem list, medication lists, medication allergies)
12. Implement capability to electronically exchange key clinical information among providers and patient-authorized entities	<b>Additional Choices for Hospitals</b>
13. Implement one clinical decision support rule and ability to track compliance with the rule	9. Record advance directives for patients 65 years of age or older
14. Implement systems to protect privacy and security of patient data in the EHR	10. Submit electronic data on reportable laboratory results to public health agencies
15. Report clinical quality measures	

(Blumenthal and Tavenner, 2010)

## Appendix E: Research Project Mind Map



## Appendix F: Research Project Timetable



## Appendix G: Email invitation to participate in survey

Dear Optometrist,

I am currently undertaking a master's degree at Trinity College Dublin in the area of Health Informatics and am conducting research for my dissertation titled: "***Secondary Use of Data from Optometry Electronic Patient Records to Produce a Population Profile of Refractive Error***".

Part of this research is to establish (by means of survey questionnaire) the levels of use of electronic patient records amongst optometrists in Ireland and your potential interest in being involved in a system whereby anonymised data from your records would be collected and aggregated to produce information that would be of interest to the profession, the public and the healthcare system. I am also hoping to pilot a data gathering exercise in order to provide information on the prevalence and distribution of refractive error in Ireland. Should this prove to be possible, there may be potential to apply this method of data aggregation to other aspects of eye care as a means of providing greater levels of understanding about eye health and eye care provision at a population level.

I would be extremely grateful if you would take approximately 5-10 minutes to participate in my survey (link below); this will be of major assistance to me in completing my dissertation but I hope that it will also help to establish the foundations for future research that could bring benefits for our profession and our patients in the future.

Even if you do not currently use computerised patient records, please take the (shorter) survey by answering 'NO' to Q1.

The first two pages contain a description of the study and consent for participation. At the end of each page simply click the '**NEXT**' button to proceed. Should you wish to contact me about the survey, my email address is [hovended@tcd.ie](mailto:hovended@tcd.ie) and my mobile number is 086-6010510.

Again, I really appreciate your time in assisting me by participating in this study. The link to the survey is:

<http://www.proprofs.com/survey/t/?title=optometry-electronic-patient-records>

Thank you,

**Declan Hovenden**

## Appendix H: Survey Participants' Information Sheet

Dear Participant,

I would like to invite you to take part in a research study entitled "***Secondary Use of Data from Optometry Electronic Patient Records to Produce a Population Profile of Refractive Error***". This research study is being undertaken in part fulfilment of an MSc in Health Informatics in conjunction with the University of Dublin, Trinity College, Ireland.

### **Voluntary Participation**

Your participation in this survey is voluntary and you are free to withdraw at any time without providing a reason. If you do not wish to answer any specific questions, these wishes will be respected by the researcher.

### **Conflict of interest**

The researcher has no conflict of interest to declare.

**Name of Researcher:** Declan Hovenden

**Timeframe & duration of research:** January – May 2015

### **What is the purpose of the research study?**

The purpose of the study is to establish if anonymised data can be extracted from optometry electronic patient record systems for secondary use – specifically with a view to producing a population profile of refractive error for Ireland. Part of this research is to identify the levels of use of electronic patient records amongst optometrists in Ireland and their degree of willingness to be involved in potential data collection from electronic patient record systems for research purposes.

Research into refractive error has been extremely rare in Ireland and the possibility of secondary use of electronic patient data for this purpose has never been investigated. Should this method of research into refractive error prove possible it will produce information on refractive error in Ireland that should be valuable to optometrists, the optometry profession and researchers in the field.

### **Why have you been chosen?**

You have been chosen to participate in this study because of your role as a practising optometrist in Ireland.

### **Who is organising the research study?**

This study is being organised by the lead researcher, Declan Hovenden, and is being supervised by a Trinity College lecturer. The study will be completed between January 2015 and June 2015.

### **What will happen to me if I take part?**

If you choose to take part in this study please continue to complete the questionnaire. You will be required to give informed consent and the time taken to complete the questionnaire is anticipated to be less than 10 minutes.

### **Confidentiality - who will know I am taking part in the research study?**

The survey questionnaire is completely anonymous – no personal data will be collected so there is no possibility that you can be identified through your participation.

**Research Ethics Approval:**

The Research Ethics Committee of the School of Computer Science & Statistics, University of Dublin, Trinity College granted ethical approval for this study in January 2015.

**What will happen to the results of the research study?**

The results of the study will be presented in my dissertation for submission to the University of Dublin, Trinity College, and may be used by others for academic research. In addition the research outcomes may be presented at selected conferences, seminars or workshops.

**Identifying third parties:**

Please do not name third parties in any of the open text questions of the questionnaire. Any such replies will be anonymised.

**Procedure to be used if assistance or advice is needed**

In the event that you require further information, assistance or advice about this study please contact me by email: [hovended@tcd.ie](mailto:hovended@tcd.ie) or by phone: 086 6010510 and I will be happy to answer your questions.

Thank you for taking the time to read this information and for considering taking part in the survey as part of this research study.

Yours sincerely,  
Declan Hovenden



## Appendix I: Survey Participants' Consent Form

**Title of research:** *Secondary Use of Data from Optometry Electronic Patient Records to Produce a Population Profile of Refractive Error*

**Timeframe & duration of research:** January – May 2015

### **DECLARATION:**

- 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 I understand the description of the research that is being provided to me
- I understand that my participation is fully anonymous and that no personal details about me will be recorded
- I agree that the data I provide may be used for scientific purposes and I have no objection the data being published in scientific publications or presentations given that my identity cannot be revealed.
- I understand that if I make illicit activities known, these will be reported, to appropriate authorities
- 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 am 18 years or older and am competent to provide consent

**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 and believe that the participant understands my explanation and is freely giving informed consent.

### **RESEARCHER'S CONTACT DETAILS:**

Declan Hovenden  
hovended@tcd.ie  
Tel: 086 6010510

# Appendix J: Survey Questionnaire Screenshots



## Optometry Electronic Patient Records

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### Dear Participant,

I would like to invite you to take part in a research study entitled "**Secondary Use of Data from Optometry Electronic Patient Records to Produce a Population Profile of Refractive Error**". This research study is being undertaken in part fulfilment of an MSc in Health Informatics in conjunction with the University of Dublin, Trinity College, Ireland.

### Voluntary Participation

Your participation in this survey is voluntary and you are free to withdraw at any time without providing a reason. If you do not wish to answer any specific questions, these wishes will be respected by the researcher.

### Conflict of interest

The researcher has no conflict of interest to declare.

**Name of Researcher:** Declan Hovenden

**Timeframe & duration of research:** January – May 2015

### What is the purpose of the research study?

The purpose of the study is to establish if anonymised data can be extracted from optometry electronic patient record systems for secondary use – specifically with a view to producing a population profile of refractive error for Ireland. Part of this research is to identify the levels of use of electronic patient records amongst optometrists in Ireland and their degree of willingness to be involved in potential data collection from electronic patient record systems for research purposes.

Research into refractive error has been extremely rare in Ireland and the possibility of secondary use of electronic patient data for this purpose has never been investigated. Should this method of research into refractive error prove possible it will produce information on refractive error in Ireland that should be valuable to optometrists, the optometry profession and researchers in the field.

### Why have you been chosen?

You have been chosen to participate in this study because of your role as a practising optometrist in Ireland.

### Who is organising the research study?

This study is being organised by the lead researcher, Declan Hovenden, and is being supervised by a Trinity College lecturer. The study will be completed between January 2015 and June 2015.

### What will happen to me if I take part?

If you choose to take part in this study please continue to complete the questionnaire. You will be required to give informed consent and the time taken to complete the questionnaire is anticipated to be less than 10 minutes.

### Confidentiality - who will know I am taking part in the research study?

The survey questionnaire is completely anonymous – no personal data will be collected so there is no possibility that you can be identified through your participation.

### Research Ethics Approval:

The Research Ethics Committee of the School of Computer Science & Statistics, University of Dublin, Trinity College granted ethical approval for this study in January 2015.

### What will happen to the results of the research study?

The results of the study will be presented in my dissertation for submission to the University of Dublin, Trinity College, and may be used by others for academic research.

In addition the research outcomes may be presented at selected conferences, seminars or workshops.

### Identifying third parties:

Please do not name third parties in any of the open text questions of the questionnaire. Any such replies will be anonymised.

### Procedure to be used if assistance or advice is needed

In the event that you require further information, assistance or advice about this study please contact me by email: [hovended@tcd.ie](mailto:hovended@tcd.ie) or by phone: 086 6010510 and I will be happy to answer your questions.

Thank you for taking the time to read this information and for considering taking part in the survey as part of this research study.

Yours sincerely,  
Declan Hovenden

Next



## Optometry Electronic Patient Records

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**Title of research:** *Secondary Use of Data from Optometry Electronic Patient Records to Produce a Population Profile of Refractive Error*

**Timeframe & duration of research:** January – May 2015

**DECLARATION:**

- 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 I understand the description of the research that is being provided to me
- I understand that my participation is fully anonymous and that no personal details about me will be recorded
- I agree that the data I provide may be used for scientific purposes and I have no objection the data being published in scientific publications or presentations given that my identity cannot be revealed.
- I understand that if I make illicit activities known, these will be reported, to appropriate authorities
- 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 am 18 years or older and am competent to provide consent

**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 and believe that the participant understands my explanation and is freely giving informed consent.

**RESEARCHER'S CONTACT DETAILS:**

Declan Hovenden  
hovended@tcd.ie  
Tel: 086 6010510

*[By clicking on the **Next** button below, you agree with the declaration above and consent to participate in the survey]*

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Next



**Section A**

This section of the questionnaire deals with the extent to which you use electronic patient records in practice. Even if you don't use electronic records, please answer 'no' to Q1 and proceed to section C.

**1. Do you use Electronic Patient Records (EPRs)?**

- Yes
- No

**2. Which software system/package do you use?**

- Acuitas
- Socrates (Specsavers)
- Optix
- Other (Please specify)

**3. What elements/functions is your system used for? (Choose as many as are applicable)**

- Diary
- Recalls / reminders
- History, symptoms, presenting complaint
- Refraction / Rx
- Ophthalmoscopy
- External / slit lamp exam
- Muscle balance
- Writing / storing referral letters and/or reports
- Contact lens fitting and/or aftercare
- Overall management notes, conclusions and patient advice
- Dispensing
- Fees / sales / till

**4. Do you continue to use manual/paper records for some elements of patient examinations/encounters?**

- Yes
- No

**5. Do you have any of the following diagnostic equipment linked directly to Patient Record System?**

- Auto-refractor
- Non-contact tonometer
- Fundus camera
- OCT
- Visual field analyser
- Slit lamp camera
- Other (Please specify)

**6. Are any of the following paper documents regularly scanned into the patients file in the system?**

- My handwritten notes
- My handwritten referral letters
- Ophthalmologist letters/reports received in response to referrals
- Referral letters inwards (e.g. GP's referring patients to you)
- Patients' medications lists or copies of medication prescriptions
- Printouts from diagnostic devices e.g. visual field plots
- Copies of outside spectacle or contact lens prescriptions

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## Optometry Electronic Patient Records

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### Section B

In this section you will be asked to consider the extraction of data from EPR systems. Please note that the mechanism being considered is that all data would be anonymised before being collected from your system and then gathered centrally in a way that neither patients nor practitioners can be identified.

7. If it were possible to collect anonymous data (e.g. on refractive error) from electronic patient record systems, would you be interested in participating in such on-going research by submitting data from your system?

- Yes
- No
- Maybe

8. If such a data collection system existed who do you think should gather and store the data?

- Software Provider (e.g. Ocucio, Socrates)
- Professional body (e.g. AOI, FODO)
- Academic Institution (e.g. DIT / National Optometry Centre)
- A specially established independent not-for-profit organisation

9. If you were to participate in such a scheme and assuming you have given consent which of the following data extraction methods would you prefer?

- I would prefer to action the data anonymisation and extraction process myself at any time I choose to
- I would prefer to action the data anonymisation and extraction process myself when requested to by the system
- I would prefer to have the data anonymisation and extraction process performed automatically as required by the system without any action on my part

10. If you were to participate in such a system, would you like to receive reports which demonstrate how your data compares with the overall (national) picture e.g. a profile of refractive error for your practice compared with the national profile?

- Yes
- No

11. Would you like to have the ability to use this service to carry out practice-based research?

- Yes
- No
- Maybe

12. Please identify any disadvantages you would see in participating in a system that would collect anonymised data (e.g. refractive error data) from your electronic patient record system?

13. Are there any problems/issues that you think would prevent you from participating in such a data collection initiative?

14. If such a system existed in the future would you be prepared to a fee to be part of this research process in order to cover the cost of running the system?

- Yes
- No
- Maybe

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## Optometry Electronic Patient Records

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### Section C

These final questions are designed to gather information about you and how you practise. However the survey is completely anonymous - you will not be identified.

**15. Which of the following categories best describes you?**

- Independent practice owner/partner
- Partner/director/owner of a multiple-type practice
- Employed optometrist (independent practice)
- Employed optometrist (multiple)
- Locum optometrist
- Hospital optometrist
- Academic

**16. What is your gender?**

- Female
- Male

**17. In which age category are you?**

- 21 - 30 years
- 31 - 40 years
- 41 - 50 years
- 51 - 60 years
- 61+ years

**18. In which county do you (mainly) practice?**

Select an option ▾

- Should you wish to exit the survey **without** submitting your answers you should close the window now. Otherwise please submit your responses by clicking the **SUBMIT** button below.

Thank you!

← Prev

Submit

## **Appendix K: Ocuco & Acuitas**

Ocuco was founded in 1993. With its head office in Ireland, Ocuco initially targeted Independent opticians/optometrists in Ireland and the UK. Acuitas, its flagship product, gathered swift momentum as the first paperless practice management system with full integration of electronic medical records links to various types of diagnostic equipment.

In 2005, after successfully tendering for the practice management system contract for the 200 Vision Express stores, Ocuco completed a management buyout and restructured itself as a global company, with a departmental structure which could scale for growth across the world.

Ocuco later (2007) acquired Relcon, its main rival in the UK market, giving it the dominant market position in the UK. In parallel, Ocuco made international acquisitions: Innovations in the US, ASPE in France and Luna IT in Italy. These acquisitions were strategic in nature, both in gaining immediate market share in the countries, and also in obtaining a market presence and local optical market experts to generate sales to large chains in the regions.

Ocuco has two flagship products. The Acuitas Practice Management System, is now localized for Ireland, UK, France, Italy, Sweden, Spain, Canada and Mexico, with customers including Salmoiraghi & Vigano (500 stores, Italy), Vision Express (385 stores, UK) and FYiDoctors (100 stores, Canada). The Innovations optical Lab Management System is installed across over 3,500 labs worldwide and is installed in Lenscrafters and Eyecare Centres of America (ECCA) stores across the US.

### **March 2015: Ocuco's Acuitas activEHR now Drummond Certified**

Acuitas activEHR 2.0, a new Ocuco product being tailored specifically for the US optometry market, has achieved Certification as a 2014 Edition Complete EHR. Certification has been granted by Drummond Group, an ONC-ATCB with whom the organization has worked since 2011. This is an exciting development in Ocuco's objective to deliver a complete practice management/Certified EHR offering to the North American Optometry market. Acuitas activEHR 2.0 will allow Eligible Professionals to meet all necessary obligations and qualify for stimulus funds as per current requirements for either Stage 1 or Stage 2 Meaningful Use, as

directed by the ONC and CMS. Certification of Acuitas activeEHR 2.0 included use of the DrFirst e-Prescribing platform, as well as Secure Exchange Solutions (SES) technology to demonstrate compliance with all current Meaningful Use requirements. DrFirst provides necessary tools for electronic prescribing of medications and interaction with pharmacies across the US. Secure Exchange Solutions technology is used to share health information and facilitate secure communications between providers, as well as between doctor and patient by way of individualized Patient Portals. Ocuco anticipates that Acuitas activeEHR 2.0 will become available to the North American market in the summer of 2015.



## Appendix L: Data Extraction Tool

```
-----  
--  
-- The below code does an extract of refraction information from an --  
-- Acuitas database and produces a resultant CSV file containing the --  
-- basic refraction data, along with some general information about --  
-- the patient to which the refraction belongs. --  
--  
-----  
  
-- First, we create an Oracle directory object. This is used by the extract  
-- process to know where the CSV file is being created. The directory can  
-- be anywhere on the disk, but we typically keep all Acuitas related files  
-- in the already existing "Acuity" folder, which is typically on the D: drive  
  
CREATE OR REPLACE DIRECTORY EXTRACTDIR AS 'D:\Acuity\Extract'  
/  
  
-- This procedure then does the actual extract  
-- 1. Declares the variables needed  
-- 2. Defines the query that we are running on the database  
-- 3. Creates an empty CSV file  
-- 4. Writes a header row into the CSV  
-- 5. Runs the query  
-- 6. Loops the results  
-- 7. Output each record in the query to the CSV  
-- 8. Close the CSV file  
  
-- There is no error handling required because this process would be run  
-- manually by Ocuco personnel, so any errors encountered would be seen  
-- on screen and dealt with at the time, corrected and the process re-executed.  
  
DECLARE  
  
    FromDate DATE;  
    ToDate DATE;  
    ExamAge NUMBER;  
    HasRx BOOLEAN;  
    PracticeNumber NUMBER;  
  
    OutputFile UTL_FILE.FILE_TYPE;  
    OutputLine VARCHAR2(2000);  
  
    RAcuity PRES_SUBJECTIVE.R_DIST_ACUITY%TYPE;  
    RSphere PRES_MODIFIED.R_DIST_SPHERE%TYPE;  
    RCylinder PRES_MODIFIED.R_DIST_CYLINDER%TYPE;  
    RAxis PRES_MODIFIED.R_DIST_AXIS%TYPE;  
    RPrism1 PRES_MODIFIED.R_DIST_PRISM1%TYPE;  
    RPrism2 PRES_MODIFIED.R_DIST_PRISM2%TYPE;
```

```

RBase1 PRES_MODIFIED.R_DIST_BASE1%TYPE;
RBase2 PRES_MODIFIED.R_DIST_BASE2%TYPE;
RInterAdd PRES_MODIFIED.R_INTER_ADD%TYPE;
RNearAdd PRES_MODIFIED.R_NEAR_ADD%TYPE;
RAidedVA PRES_MODIFIED.R_DIST_ACUITYAIDED%TYPE;

```

```

LAcuity PRES_SUBJECTIVE.L_DIST_ACUITY%TYPE;
LSphere PRES_MODIFIED.L_DIST_SPHERE%TYPE;
LCylinder PRES_MODIFIED.L_DIST_CYLINDER%TYPE;
LAxis PRES_MODIFIED.L_DIST_AXIS%TYPE;
LPrism1 PRES_MODIFIED.L_DIST_PRISM1%TYPE;
LPrism2 PRES_MODIFIED.L_DIST_PRISM2%TYPE;
LBase1 PRES_MODIFIED.L_DIST_BASE1%TYPE;
LBase2 PRES_MODIFIED.L_DIST_BASE2%TYPE;
LInterAdd PRES_MODIFIED.L_INTER_ADD%TYPE;
LNearAdd PRES_MODIFIED.L_NEAR_ADD%TYPE;
LAidedVA PRES_MODIFIED.L_DIST_ACUITYAIDED%TYPE;

```

```

LSphericalEquivalent PRES_MODIFIED.R_DIST_SPHERE%TYPE;
RSphericalEquivalent PRES_MODIFIED.L_DIST_SPHERE%TYPE;

```

```

RxType VARCHAR2(30);
BirthYear VARCHAR2(10);
PrescriptionDate DATE;

```

```

-- The below is the query to extract the prescriptions. It has to allow
-- for there being two separate prescription data tables, one for the
-- subjective and the other for the given rx. And either can exist or not
-- but we only want one to be output in the CSV. So we have two sub-queries
-- one each to retrieve from each prescription table, and then these are
-- grouped together by the patient so as to have one record per patient
-- per prescription date.

```

```

CURSOR CurPatients IS
  SELECT PID, SEX, COUNTY, DATE_OF_BIRTH, PRESCRIPTION_DATE
  FROM
  (
    SELECT PID, SEX, COUNTY, DATE_OF_BIRTH, GREATEST( NVL(PS_RX_ID,'01-JAN-1899'),
    NVL(PM_RX_ID,'01-JAN-1899' )) "PRESCRIPTION_DATE"
    FROM
    (
      SELECT PID, SEX, COUNTY, DATE_OF_BIRTH, MAX(PS_RX_ID) "PS_RX_ID", MAX(PM_RX_ID)
      "PM_RX_ID"
      FROM
      (
        SELECT P.PID, P.SEX, P.COUNTY, P.DATE_OF_BIRTH,
        MAX( RX.PRESCRIPTION_DATE ) "PS_RX_ID", NULL "PM_RX_ID"
        FROM PATIENTS P,
        PRES_SUBJECTIVE RX
        WHERE P.RECORD_DELETED = 0
        AND RX.PID = P.PID
        AND RX.RECORD_DELETED = 0
        AND ( RX.R_DIST_TEXT IS NOT NULL OR RX.L_DIST_TEXT IS NOT NULL )

```

```

AND RX.PRESCRIPTION_DATE >= FromDate
AND RX.PRESCRIPTION_DATE <= ToDate
GROUP BY P.PID, P.SEX, P.COUNTY, P.DATE_OF_BIRTH
UNION ALL
SELECT P.PID, P.SEX, P.COUNTY, P.DATE_OF_BIRTH,
      NULL, MAX( RX.PRESCRIPTION_DATE )
FROM PATIENTS P,
      PRES_MODIFIED RX
WHERE P.RECORD_DELETED = 0
AND RX.PID = P.PID
AND RX.RECORD_DELETED = 0
AND ( RX.R_DIST_TEXT IS NOT NULL OR RX.L_DIST_TEXT IS NOT NULL )
AND RX.PRESCRIPTION_DATE >= FromDate
AND RX.PRESCRIPTION_DATE <= ToDate
GROUP BY P.PID, P.SEX, P.COUNTY, P.DATE_OF_BIRTH
)
GROUP BY PID, SEX, COUNTY, DATE_OF_BIRTH
)
)
ORDER BY PRESCRIPTION_DATE, PID;

```

BEGIN

```

-- The query runs within a date range supplied by Declan and then manually
-- altered by the Ocuco person running the extract

```

```

FromDate := '01-APR-2013';
ToDate   := '31-MAR-2015';

```

```

-- Because the CSV files will all be grouped up by Declan in the end,
-- he needed a unique reference number to distinguish each Acuitas
-- customer's extract. Ocuco have a unique customer number, so the
-- Ocuco person running the extract substitutes that customer number
-- here before execution.

```

```

PracticeNumber := <OPOSNumber>;

```

```

-- Create the output file

```

```

OutputFile := UTL_FILE.FOPEN( 'EXTRACTDIR', 'AcuitasExtract.csv', 'W', 32767 );

```

```

-- Add the headings

```

```

UTL_FILE.PUT_LINE( OutputFile,
  'Practice' || ';' ||
  'Gender'   || ';' ||
  'County'  || ';' ||
  'Year Of Birth' || ';' ||
  'Exam Date' || ';' ||
  'Age at Exam' || ';' ||
  'Rx Type'  || ';' ||
  'Right Unaided VA' || ';' ||
  'Right Sphere' || ';' ||

```

```

'Right Cylinder' || ',' ||
'Right Axis' || ',' ||
'Right H Prism/Base' || ',' ||
'Right V Prism/Base' || ',' ||
'Right Aided VA' || ',' ||
'Right Inter Add' || ',' ||
'Right Near Add' || ',' ||
'Right Equivalence' || ',' ||
'Left Unaided VA' || ',' ||
'Left Sphere' || ',' ||
'Left Cylinder' || ',' ||
'Left Axis' || ',' ||
'Left H Prism/Base' || ',' ||
'Left V Prism/Base' || ',' ||
'Left Aided VA' || ',' ||
'Left Inter Add' || ',' ||
'Left Near Add' || ',' ||
'Left Equivalence');

```

-- Open the query and loop the results

FOR PatientRec IN CurPatients LOOP

HasRx := FALSE;

-- First, try and retrieve a subjective prescription for the  
-- prescription date returned by the query. If that succeeds then  
-- we set an Rx Type variable as being 'subjective' and that gets  
-- included in the output file.

BEGIN

```

SELECT R_DIST_ACUITY, R_DIST_SPHERE, R_DIST_CYLINDER, R_DIST_AXIS,
R_DIST_PRISM1, R_DIST_PRISM2, R_DIST_BASE1, R_DIST_BASE2,
R_INTER_ADD, R_NEAR_ADD, R_DIST_ACUITYAIDED,
L_DIST_ACUITY, L_DIST_SPHERE, L_DIST_CYLINDER, L_DIST_AXIS,
L_DIST_PRISM1, L_DIST_PRISM2, L_DIST_BASE1, L_DIST_BASE2,
L_INTER_ADD, L_NEAR_ADD, L_DIST_ACUITYAIDED, PRESCRIPTION_DATE
INTO RAcuity, RSphere, RCylinder, RAxis,
RPrism1, RPrism2, RBase1, RBase2,
RInterAdd, RNearAdd, RAidedVA,
LAcuity, LSphere, LCylinder, LAxis,
LPrism1, LPrism2, LBase1, LBase2,
LInterAdd, LNearAdd, LAidedVA,
PrescriptionDate
FROM PRES_SUBJECTIVE
WHERE RX_ID =
(
SELECT RX_ID
FROM
(
SELECT RX_ID
FROM PRES_SUBJECTIVE

```

```

WHERE PID = PatientRec.PID
AND PRESCRIPTION_DATE = PatientRec.PRESCRIPTION_DATE
AND RECORD_DELETED = 0
ORDER BY PRESCRIPTION_DATE DESC, RX_ID ASC
)
WHERE ROWNUM = 1
);

```

```

HasRx := TRUE;
RxType := 'Subjective';

```

#### EXCEPTION

```

-- If there is no subjective record then this exception handler
-- will be invoked and we switch to trying to look for an Rx Given.
-- Again, if that succeeds then we set the Rx Type variable to
-- 'Given'.

```

#### WHEN NO\_DATA\_FOUND THEN

```
BEGIN
```

```

SELECT R_DIST_SPHERE, R_DIST_CYLINDER, R_DIST_AXIS,
       R_DIST_PRISM1, R_DIST_PRISM2, R_DIST_BASE1, R_DIST_BASE2,
       R_INTER_ADD, R_NEAR_ADD, R_DIST_ACUITYAIDED,
       L_DIST_SPHERE, L_DIST_CYLINDER, L_DIST_AXIS,
       L_DIST_PRISM1, L_DIST_PRISM2, L_DIST_BASE1, L_DIST_BASE2,
       L_INTER_ADD, L_NEAR_ADD, L_DIST_ACUITYAIDED,
       PRESCRIPTION_DATE
INTO  RSphere, RCylinder, RAxis,
      RPrism1, RPrism2, RBase1, RBase2,
      RInterAdd, RNearAdd, RAidedVA,
      LSphere, LCylinder, LAxis,
      LPrism1, LPrism2, LBase1, LBase2,
      LInterAdd, LNearAdd, LAidedVA,
      PrescriptionDate
FROM  PRES_MODIFIED
WHERE RX_ID =
(
  SELECT RX_ID
  FROM
  (
    SELECT RX_ID
    FROM PRES_MODIFIED
    WHERE PID = PatientRec.PID
    AND PRESCRIPTION_DATE = PatientRec.PRESCRIPTION_DATE
    AND RECORD_DELETED = 0
    ORDER BY PRESCRIPTION_DATE DESC, RX_ID ASC
  )
  WHERE ROWNUM = 1
);

```

```
HasRx := TRUE;
```

```

RxType := 'Given';

EXCEPTION

-- There is a belt-and-braces exception handler here too,
-- but this condition cannot be reached. There must be either
-- a subjective or given prescription for this patient's
-- record to have been retrieved in the SQL query at all.

WHEN NO_DATA_FOUND THEN
  RAcuity := NULL;
  LAcuity := NULL;

END;

END;

-- Now we come to outputting the data to the CSV file
-- We have to do some calculations

IF HasRx = TRUE THEN

-- We need to calculate the patient's age

IF PatientRec.DATE_OF_BIRTH IS NULL THEN
  ExamAge := NULL;
  BirthYear := NULL;
ELSE
  ExamAge := TRUNC(( PatientRec.PRESCRIPTION_DATE - PatientRec.DATE_OF_BIRTH )/365.25);
  BirthYear := TO_CHAR( PatientRec.DATE_OF_BIRTH, 'YYYY' );
END IF;

-- We have to calculate the spherical equivalent for both eyes

IF ( NVL(RSphere,0) IS NULL ) AND ( NVL(RCylinder,0) IS NULL ) THEN
  RSphericalEquivalent := NULL;
ELSIF NVL(RCylinder,0) = 0 THEN
  RSphericalEquivalent := RSphere;
ELSE
  RSphericalEquivalent := RSphere + ( RCylinder / 2 );
END IF;

IF ( NVL(LSphere,0) IS NULL ) AND ( NVL(LCylinder,0) IS NULL ) THEN
  LSphericalEquivalent := NULL;
ELSIF NVL(LCylinder,0) = 0 THEN
  LSphericalEquivalent := LSphere;
ELSE
  LSphericalEquivalent := LSphere + ( LCylinder / 2 );
END IF;

-- And now we output the data to the file

UTL_FILE.PUT_LINE( OutputFile,

```

```

TO_CHAR( PracticeNumber ) || ',' ||
PatientRec.SEX || ',' ||
PatientRec.County || ',' ||
BirthYear || ',' ||
TO_CHAR( PrescriptionDate, 'DD/MM/YYYY' ) || ',' ||
TO_CHAR( ExamAge ) || ',' ||
RxType || ',' ||
'=' || RAcuity || ',' ||
TO_CHAR( RSphere ) || ',' ||
TO_CHAR( RCylinder ) || ',' ||
TO_CHAR( RAxis ) || ',' ||
TO_CHAR( RPrism1 ) || ',' ||
RBase1 || ',' ||
RPrism2 || ',' ||
RBase2 || ',' ||
'=' || RAidedVA || ',' ||
TO_CHAR( RInterAdd ) || ',' ||
TO_CHAR( RNearAdd ) || ',' ||
TO_CHAR( RSphericalEquivalent ) || ',' ||
'=' || LAcuity || ',' ||
TO_CHAR( LSphere ) || ',' ||
TO_CHAR( LCylinder ) || ',' ||
TO_CHAR( LAxis ) || ',' ||
TO_CHAR( LPrism1 ) || ',' ||
LBase1 || ',' ||
LPrism2 || ',' ||
LBase2 || ',' ||
'=' || LAidedVA || ',' ||
TO_CHAR( LInterAdd ) || ',' ||
TO_CHAR( LNearAdd ) || ',' ||
TO_CHAR( LSphericalEquivalent )
);

END IF;

END LOOP;

-- Close the file

UTL_FILE.FCLOSE( OutputFile );
END;
/

```

# Appendix M: Ethics Application and Research Proposal

## School of Computer Science & Statistics Research Ethics Application

### School of Computer Science and Statistics Research Ethical Application Form

#### Part A

Project Title: **Secondary Use of Clinical Data Contained in Optometry Electronic Patient Records to Establish a Population Profile of Refractive Error for Ireland**

Name of Lead Researcher (student in case of project work): .....**Declan Hovenden**.....

Name of Supervisor: .....**Dr. Lucy Hederman**.....

TCD E-mail: ...**hovended@tcd.ie**..... Contact Tel No.: ....**086-6010510**.....

Course Name and Code (if applicable): ...**MSc Health Informatics**.....

Estimated start date of survey/research: .....**12/01/2015**.....

I confirm that I will (where relevant):

- Familiarize myself with the Data Protection Act and the College Good Research Practice guidelines [http://www.tcd.ie/info\\_compliance/dp/legislation.php](http://www.tcd.ie/info_compliance/dp/legislation.php);
- Tell participants that any recordings, e.g. audio/video/photographs, will not be identifiable unless prior written permission has been given. I will obtain permission for specific reuse (in papers, talks, etc.)
- Provide participants with an information sheet (or web-page for web-based experiments) that describes the main procedures (a copy of the information sheet must be included with this application)
- Obtain informed consent for participation (a copy of the informed consent form must be included with this application)
- Should the research be observational, ask participants for their consent to be observed
- Tell participants that their participation is voluntary
- Tell participants that they may withdraw at any time and for any reason without penalty
- Give participants the option of omitting questions they do not wish to answer if a questionnaire is used
- Tell participants that their data will be treated with full confidentiality and that, if published, it will not be identified as theirs
- On request, debrief participants at the end of their participation (i.e. give them a brief explanation of the study)
- Verify that participants are 18 years or older and competent to supply consent.
- If the study involves participants viewing video displays then I will verify that they understand that if they or anyone in their family has a history of epilepsy then the participant is proceeding at their own risk
- Declare any potential conflict of interest to participants.
- Inform participants that in the extremely unlikely event that illicit activity is reported to me during the study I will be obliged to report it to appropriate authorities.
- Act in accordance with the information provided (i.e. if I tell participants I will not do something, then I will not do it).

Signed: .....  
Lead Researcher/student in case of project work

Date: **17/12/14**.....



**Part B**

<i>Please answer the following questions.</i>		<i>Yes/No</i>
Has this research application or any application of a similar nature connected to this research project been refused ethical approval by another review committee of the College (or at the institutions of any collaborators)?		No
Will your project involve photographing participants or electronic audio or video recordings?		No
Will your project deliberately involve misleading participants in any way?		No
Does this study contain commercially sensitive material?		No
Is there a risk of participants experiencing either physical or psychological distress or discomfort? If yes, give details on a separate sheet and state what you will tell them to do if they should experience any such problems (e.g. who they can contact for help).		No
Does your study involve any of the following?	Children (under 18 years of age)	No
	People with intellectual or communication difficulties	No
	Patients	No

**School of Computer Science and Statistics  
Research Ethical Application Form**

Details of the Research Project Proposal must be submitted as a separate document to include the following information:

1. Title of project
2. Purpose of project including academic rationale
3. Brief description of methods and measurements to be used
4. Participants - recruitment methods, number, age, gender, exclusion/inclusion criteria, including statistical justification for numbers of participants
5. Debriefing arrangements
6. A clear concise statement of the ethical considerations raised by the project and how you intend to deal with them
7. Cite any relevant legislation relevant to the project with the method of compliance e.g. Data Protection Act etc.

**Part C**

I confirm that the materials I have submitted provided a complete and accurate account of the research I propose to conduct in this context, including my assessment of the ethical ramifications.

Signed:  .....  
Lead Researcher/student in case of project work

Date: 17/12/14 .....

*There is an obligation on the lead researcher to bring to the attention of the SCSS Research Ethics Committee any issues with ethical implications not clearly covered above.*

**Part D**

If external or other TCD Ethics Committee approval has been received, please complete below.

External/TCD ethical approval has been received and no further ethical approval is required from the School's Research Ethical Committee. I have attached a copy of the external ethical approval for the School's Research Unit.

Signed: .....  
Lead Researcher/student in case of project work

Date: .....

**Part E**

If the research is proposed by an undergraduate or postgraduate student, please have the below section completed.

I confirm, as an academic supervisor of this proposed research that the documents at hand are complete (i.e. each item on the submission checklist is accounted for) and are in a form that is suitable for review by the SCSS Research Ethics Committee

Signed: Lucy Hederman Date: 17 Dec 2014  
Supervisor

Completed application forms together with supporting documentation should be submitted electronically to [research-ethics@scss.tcd.ie](mailto:research-ethics@scss.tcd.ie). Please use TCD e-mail addresses only. When your application has been reviewed and approved by the Ethics committee hardcopies with original signatures should be submitted to the School of Computer Science & Statistics, Room F37, O'Reilly Institute, Trinity College, Dublin 2.

## RESEARCH PROPOSAL FOR ETHICS APPLICATION

### **Secondary Use of Clinical Data Contained in Optometry Electronic Patient Records to Establish a Population Profile of Refractive Error in Ireland.**

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Supervisor: Dr. Lucy Hederman

Student: Declan Hovenden

School of Computer Science and Statistics, Trinity College Dublin

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## Project Overview

**Research Question:** Can refractive error data be collected from optometry electronic patient records repeatedly in order to produce a dynamic refractive error profile for Ireland and facilitate future research into the field of primary eye care?

Refractive error (the need for optical correction) is commonplace and the vast majority of people in Ireland have relatively easy access to primary eye care professionals (mainly optometrists) for the purposes of eye examination, management of various eye conditions and provision of appropriate optical correction where required.

One of the main refractive errors encountered is myopia. Evidence from many countries around the world is that the prevalence, incidence and severity of myopia have been increasing significantly in recent decades. As well as the increased need for optical correction that this brings about, myopia is also associated with a number of ocular complications and diseases. Significant research has recently been and continues to be carried out (particularly in Australia) into the aetiology of myopia and the factors that influence it; recent discoveries suggest some new interventions that may reduce the rates and levels of the condition.

In Ireland, epidemiological studies into refractive error and myopia in particular have been extremely rare. However, as most optometry practices now use electronic patient record (EPR) systems to record the optical and clinical data of their patients, there is a potential opportunity for secondary use of these data in order to produce a national profile of refractive error. Should it prove possible to do this, it could be envisaged that the data could be collected repeatedly at intervals to characterise the refractive error profile over time and identify changes in it. This would provide the opportunity to establish, through a population health approach, trends in refractive error, for example, increased rates and severity of myopia over time and the impact on interventions on these.

A theoretical example of a population refractive error profile is seen in Fig 1

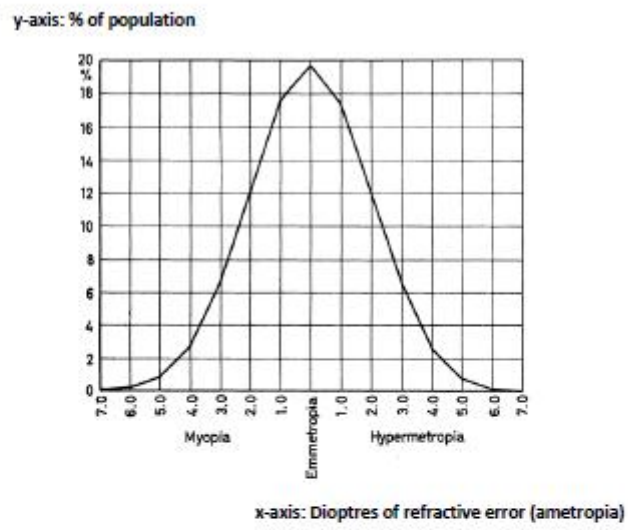


Figure 1: Theoretical curve of range and distribution of refractive error

## Research Objectives

This research project proposes to:

1. Demonstrate that refractive error data can be collected from optometry EPRs by:
  - a. Designing a mechanism for extraction of these data
  - b. Establishing the willingness and ability of optometry EPR users to be involved in this data extraction for secondary use
  - c. Performing a pilot of this data extraction exercise
  
2. Use refractive error data collected from optometry EPRs to produce a refractive error profile by:
  - a. Gathering together the extracted data
  - b. Performing statistical analysis on the data
  - c. Producing a curve (profile) to reveal the relative rates and levels of refractive error
  
3. Lay the foundations for future clinical/population health research by:
  - a. Building in the ability to expand the data extraction to all optometry EPR users
  - b. Designing the mechanism in such a way that it can be repeated
  - c. Discussing how this mechanism could be used for collection of other clinical data from optometry records

## Research participants

The research participants for this study will be optometrists in practice who will be surveyed regarding their use of EPR systems and their willingness to participate in collection of anonymised data from those systems for secondary use.

## Survey Method

The survey questionnaire will be distributed online. A link to the survey URL will be emailed to all members of the two professional bodies in Ireland who represent optometrists i.e. the Association of Optometrists, Ireland and the Federation of Ophthalmic and Dispensing Opticians (FODO), Ireland. This method should ensure that almost all optometrists practising in the Republic of Ireland will be invited to participate.

## Survey Objectives

The purposes of the survey will be to establish:

- a. The prevalence of EPR use amongst optometrists in Ireland
- b. How extensively optometrists use their EPR systems
- c. What data is routinely collected in optometric practice
- d. The willingness of users (optometrists) to be involved in a system of data collection to facilitate secondary use of these data
- e. Any concerns users may have associated with collection and secondary use of these data

The main sections of the survey questionnaire will be:

- A: What the EPR systems are used for
- B: Barriers to gathering data for secondary use
- C: Demographics

Table 1 illustrates how the objectives of the survey will help to achieve the objectives of the overall research study.



Table 1: Survey and Overall Research Objectives

Survey Objective	Related Study Objective or How this meets an objective of the study
To establish the prevalence of EPR use amongst optometrists	To establish the potential for whole population study of refractive error
To establish how extensively optometrists use their EPR	To establish what the potential is for gathering data on refractive error and on other areas of eye care
To elicit what kinds of data are recorded by optometry EPRs	To establish what the potential is for gathering data on refractive error and on other areas of eye care
To measure the willingness of optometry EPR users to be involved in data extraction and aggregation for secondary use	To establish the likelihood of successfully undertaking collection of data from optometry EPRs
To identify perceived barriers on the part of optometrist users to the collection and secondary use of clinical data	To predict the barriers to the operation of large scale data collection from optometry EPRs

### Confidentiality

Participation in the survey will be completely anonymous – it will not be possible in any way to identify any of the respondents. The data will only be viewed by the researcher and will be stored and retained by him.

### Other data

The research project aims to pilot the proposed collection of data from optometry EPR systems by carrying out the exercise on a small number of such systems. The data collected for this pilot will be patient data that has been anonymised by the relevant data controller(s) in such a way that patients cannot possibly be identified. Similarly, no practitioner or user identifiers will be collected. This is in keeping with the best practice approach to Undertaking Research Projects using Personal Data as set out by the Data Protection Commissioner (see Fig 1) in their document “Guidelines on research in the Health Sector”. Therefore, in keeping this with this guidance and the Data Protection Acts 1998 & 2003, as the data collected will be fully anonymised, the consent of the patients is not required.

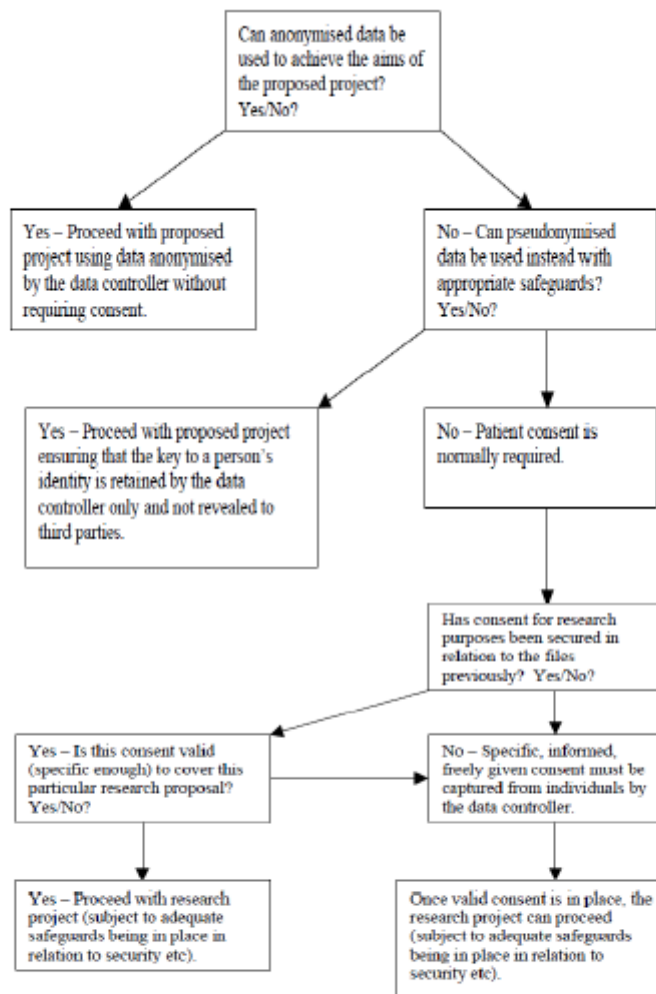


Figure 2: Data Protection Commission best practice approach to undertaking research projects using personal data

## Why this research will be useful

1. Refractive error data has never been collected in any large-scale or meaningful way before in Ireland.
2. It will provide the means to establish the rates of different refractive errors and their levels of severity in Ireland.
3. The resultant refractive error information can be compared with that from other countries and contribute to international research
4. Research into refractive error in Ireland will be enabled; this will be especially in the context of new emerging techniques of reducing the rates and levels of myopia – myopia control.
5. Practice-based research could be enabled
6. The mechanism could be used to extract other data from optometry EPRs in order to research and inform other aspects of eye care
7. Prediction of future incidences of associated eye-disease would be facilitated – disease modelling.
8. The cost of providing optical correction and treatment of associated eye-disease (incl. by the state) could be better predicted
9. Application of this method of data collection and secondary use could be applied to other domains/disciplines

## Indicative Project Timetable

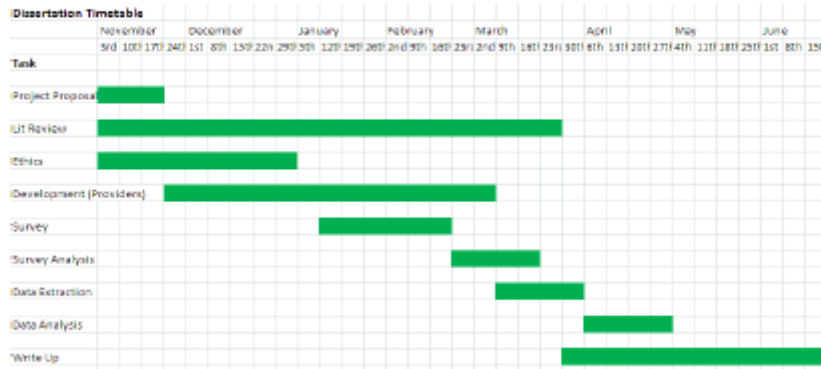








Figure 3: Project Timetable

## Appendix N: Ethics Approval

### Email Confirmation of Ethics Approval

Fwd: FW: Research Ethics Application  Inbox x  

 **Declan Hovenden**  11:15 AM (6 minutes ago)     
to me 

----- Forwarded message -----

From: **Sara Gutierrez Llaneza** <[Sara.Gutierrez@scss.tcd.ie](mailto:Sara.Gutierrez@scss.tcd.ie)>  
Date: 12 January 2015 at 10:24  
Subject: FW: Research Ethics Application  
To: Declan Hovenden <[hovended@tcd.ie](mailto:hovended@tcd.ie)>  
Cc: Research Ethics <[research-ethics@scss.tcd.ie](mailto:research-ethics@scss.tcd.ie)>

Dear Declan,

Many thanks for this revision. It has been reviewed by the Research Ethics Committee who has approved your application. You may proceed with this study.

We wish you success in your research.

Kind regards,

Sara

# Appendix O: Consent to EPR data extraction and secondary use

## Consent to Extraction and Secondary Use of Data from Acuitas

I, \_\_\_\_\_ (Print Name) confirm that I am the data controller for \_\_\_\_\_ (Practice/Company Name). I consent to the use of data from my electronic patient record system (Acuitas) by Declan Hovenden for research purposes in accordance with:

1. the best practice guidelines on research in the health sector from the Data Protection Commissioner<sup>1</sup>
2. the approval of the research ethics committee in the School of Computer Science and Statistics, Trinity College Dublin.

The purpose of the use of the extracted data has been explained to me.

I understand that the data extracted will be limited to the data set indicated in the table below and will exclude patient names and identification numbers.

I also hereby authorise Ocuco to access my system remotely for the purposes of installing the data extraction software and running the data extraction process when and as required for the purposes of the Declan Hovenden's research.

Table: Data Set

Data Category	Data Elements
Demographic Data	<ul style="list-style-type: none"><li>• Gender</li><li>• Year of birth / Age at exam date</li><li>• County of residence</li></ul>
Visit Data	<ul style="list-style-type: none"><li>• Date of exam</li></ul>
Clinical data	<ul style="list-style-type: none"><li>• Subjective refraction (sphere, cyl, axis, prism, near addition) for Right + Left eyes (R+L)</li><li>• Prescribed refractive correction i.e. Rx Given (only if subjective refraction not available) R+L</li><li>• Refraction Spherical Equivalent R+L (calculated during extraction)</li><li>• Unaided vision R+L</li><li>• Corrected visual Acuity R+L</li></ul>

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

<sup>1</sup> [http://www.dataprotection.ie/documents/guidance/Health\\_research.pdf](http://www.dataprotection.ie/documents/guidance/Health_research.pdf)

## **Appendix P: Royal Academy of Medicine in Ireland (RAMI) Meeting, 20<sup>th</sup> May 2015**

### **Abstract:**

**Are clinicians interested in using data from their Electronic Patient Records (EPRs) to contribute to national research? - A survey of primary eye care practitioners in Ireland.**

**Author:** Declan Hovenden

School of Computer Science and Statistics, Trinity College Dublin

National Optometry Centre, Dublin Institute of Technology.

Email: [declan.hovenden@dit.ie](mailto:declan.hovenden@dit.ie)

### **Introduction:**

Approximately 650,000 primary eye examinations are carried out by optometrists in Ireland annually but there is a distinct lack of research into refractive error. Much of the data is collected electronically; this may present an opportunity to conduct large scale, timely population study into the field.

This study aimed to establish the extent of use of EPRs by optometrists in Ireland, to determine the level of interest by EPR-using optometrists in secondary use of their collected clinical data, and to identify perceived barriers to such a system of EPR data use.

### **Method:**

A survey of practising optometrists using a novel online questionnaire was conducted in early 2015.

### **Results:**


A representative 163 survey responses were received. 80% of respondents use EPR systems (59% of those use one system). 91% of the EPR users indicated a potential interest in being involved in extraction of data from their EPR systems for research purposes. However 42% of users identified issues that could potentially act as barriers to their involvement in such a scheme.

### **Conclusions:**

There is a very high level of EPR use by optometrists in Ireland and the vast majority of these practitioners would be interested in secondary use of their clinical data for research purposes. However, for such a system to be successfully implemented, the perceived barriers would have to be addressed.

This study formed part of the work for an MSc dissertation and ethical approval was granted by the Ethics Committee of the School of Computer Science and Statistics, Trinity College Dublin.

## Programme:



**Royal Academy of Medicine  
in Ireland**

**Section of Healthcare Informatics  
Students Meeting**

Geoffrey Bourke Room,  
1<sup>st</sup> Floor, Setanta House,  
Setanta Place, Dublin

Wednesday 20<sup>th</sup> May 2015

Programme

**13:00 Registration**

**13:15 Opening Address**

**13:30**  
**Can recorded data from elite athlete monitoring systems be used to improve athlete abilities during training and create injury prevention regimes?**  
Middleton, L  
School of Medicine, School of Computer Science and Statistics, Trinity College Dublin

**13:45**  
**Designing and publishing indoor maps in an academic teaching hospital**  
Ryder, K  
ICT Department, Tallaght Hospital, Dublin 24

**14:00**  
**Designing anatomically realistic 3D-printable prostheses: Connecting the dots with Health Informatics**  
Thangaramanujam, M<sup>1,2</sup>, Jones, J<sup>1</sup>, O'Ceirbhail, E<sup>1</sup>, Felle, P<sup>1</sup>  
Biomedical Section<sup>1</sup>, UCD School of Medicine and Medical Science; UCD School of Mechanical and Materials Engineering<sup>2</sup>, University College Dublin

**14:15**  
**Healthcare professionals' perceptions of the facilitators and barriers to implementing electronic systems for prescribing, dispensing and administration of medicines in hospitals: a systematic review**  
Hogan-Murphy, D<sup>1,2</sup>, Tonna, AP<sup>2</sup>, Strath, A<sup>2</sup>, Cunningham, ITS<sup>2</sup>  
Health Service Executive<sup>1</sup>, Robert Gordon University<sup>2</sup>, Aberdeen

**14:30**  
**How to provide high quality information for health decision makers: a pre-design analysis model**  
Mousavinejad, SMA<sup>1</sup>, Neville, K<sup>2</sup>, Adam, F<sup>3</sup>  
Dept. of Business Information Systems<sup>1</sup>, Business Information Systems<sup>2</sup>, Business Information Systems<sup>3</sup>, University College Cork

**14:45**  
**The transformative potential of ICT is currently underutilised in the provision of healthcare to people with intellectual disabilities**  
Molloy, R  
Dublin City University

**15:00 Refreshment Break**

**15:30**  
**Monitoring the Movement of infection in hospital: Is there potential for RFID**  
Impey, S<sup>\*</sup>, Kane, B  
Department of Computer Science, Trinity College Dublin

**15:45**  
**The Code To Traceability For Organ Transplantation**  
Cooney, A<sup>\*</sup>, Felle, P  
Dept. of Healthcare Informatics,  
School of Medicine and Medical Science,  
UCD, Belfield, Dublin 4

**16:00**  
**A study of an infant tagging system in a Maternity Hospital in practice**  
Pius, A<sup>1</sup>, Vinu, M<sup>1</sup>, Middleton L<sup>2</sup>, Ahmad, S<sup>2</sup>, Kane, B<sup>2</sup>  
Department of Nursing & Midwifery<sup>1</sup>, National Maternity Hospital, Dublin 2, School of Computer Science & Statistics<sup>2</sup>, Trinity College Dublin

**16:15**  
**Health Information Delivery for Teens/Adolescents; Systematic Review: Usability of Children's Hospital Websites for Teens**  
Francois-Beehan J<sup>1</sup>, Connolly C<sup>2</sup>, Gaule P<sup>3,\*</sup>  
IT Department<sup>1</sup>, Biochemistry Laboratory<sup>2</sup>, National Children's Research Centre<sup>3</sup>, OLCHC, Dublin 12

**16:30**  
**Facilitating the melanoma multidisciplinary team meeting with technology, such as a mobile dashboard - what is required?**  
Wall, D<sup>\*</sup>, Lawson, R, Hyland, D, Hovenden, D  
School of Computer Science and Statistics, Trinity College Dublin, Ireland

**16:45**  
**Are clinicians interested in using data from their Electronic Patient Records (EPRs) to contribute to national research? - A survey of primary eye care practitioners in Ireland**  
Hovenden, D  
School of Computer Science and Statistics, Trinity College Dublin. National Optometry Centre, Dublin Institute of Technology

**17:00**  
**Discussion  
Awarding of Medal  
Networking/ Refreshment Break**

Register for RAMI Meetings on the following link:  
<http://rami.ie/?q=node/202>

**Certificate:**

