Improving the quality of information recorded in an electronic patient record in a GP out-of-hours service to facilitate health services research

Michelle Kearns

A dissertation submitted to the University of Dublin, partial fulfilment of the requirements for the degree of

Master of Science

2014
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.

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Michelle Kearns

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Michelle Kearns
Summary

With the demands of an increasingly older population and the burden of chronic disease on health care services, there is a need for evidence based research on the use of data collected for a primary care purposes utilised for the secondary function of research. It is vital to know how this data can be used to inform policy and contribute to the future development of healthcare services.

The objective of this research is to address data quality issues in the use of routinely collected health data, in this instance an out-of-hours (OOHs) GP services’ electronic patient record data, for secondary, health services research, purposes.

The first part of this research assesses if routinely collected OOHs data can contribute to a better understanding of health services usage among patients. The second part of the research uses this initial study to examine if the quality of routinely collected data can be enhanced for secondary research purposes without disrupting frontline services. An enhancement to the data collection process was then designed, implemented and evaluated.

Key findings: Routinely collected data in the Caredoc GP out-of-hours service database can be used for health services research purposes to contribute to the understanding of health care services and delivery. Enhancements to electronic patient record systems for collecting routine data that are small yet effective can be introduced to a live working environment without disrupting users or increasing their workload. The enhancements successfully improved elements of the data quality within the out-of-hours service to facilitate health services research.
Acknowledgements

I would like to thank everyone who has supported and encouraged me over the last number of years.

Thank you to my supervisor Dr Lucy Hederman for her constant support and advice.

Professor Charles Normand for his support and encouragement.

All of my work colleagues who have supported and assisted me all the way through this research.

My friends for their support and backing.

My family, Mum and Dad – Teresa and Pat, sister Audrey and brother-in-law Tom for their endless support.

Last but not least – to our beautiful daughter Abigail and to my fantastic husband John for his help, patience, relentless support and encouragement and never giving up on me.
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<td>Access Point Name</td>
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<tr>
<td>BIP</td>
<td>Business Internet Protocol</td>
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<tr>
<td>Caredoc</td>
<td>Carlow emergency doctors on call</td>
</tr>
<tr>
<td>CDSS</td>
<td>Clinical decision support software</td>
</tr>
<tr>
<td>CHF</td>
<td>Chronic heart failure</td>
</tr>
<tr>
<td>CIT</td>
<td>Community intervention team</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic obstructive pulmonary disease</td>
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<tr>
<td>CPD</td>
<td>Continuing Professional Development</td>
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<tr>
<td>D-Doc</td>
<td>Dublin Doctors on Call</td>
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<tr>
<td>DoHC</td>
<td>Department of Health and Children</td>
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<tr>
<td>DQA</td>
<td>Data Quality Assessment</td>
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<td>EPR</td>
<td>Electronic patient record</td>
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<td>GMS</td>
<td>General Medical Scheme</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>GPEL</td>
<td>General Practitioner electronic links</td>
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<td>GPRS</td>
<td>General Packet Radio Service</td>
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<td>HIQA</td>
<td>The Health Information and Quality Authority</td>
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<td>HITH</td>
<td>Hospital in the home</td>
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<td>HL7</td>
<td>Health Level Seven</td>
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<tr>
<td>HSE</td>
<td>Health Services Executive</td>
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<tr>
<td>ICGP</td>
<td>Irish College of General Practitioners</td>
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<tr>
<td>ICT</td>
<td>Information and communications technology</td>
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<td>IT</td>
<td>Information technology</td>
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<tr>
<td>MPLS</td>
<td>Multi-Protocol Label Switching</td>
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<td>Ne-Doc</td>
<td>North East Doctors on Call</td>
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<td>OOH</td>
<td>Out of hours</td>
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<tr>
<td>PHN</td>
<td>Public health nurse</td>
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<tr>
<td>SLA</td>
<td>Service Level Agreement</td>
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<tr>
<td>TIQM</td>
<td>Total Information Quality Management</td>
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<tr>
<td>TTN</td>
<td>Telephone triage nurse</td>
</tr>
<tr>
<td>VoIP</td>
<td>Voice over Internet Protocol</td>
</tr>
<tr>
<td>VPM</td>
<td>Virtual Private Network</td>
</tr>
<tr>
<td>XML</td>
<td>Extensible Mark-up Language</td>
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Chapter 1: Introduction and overview

1.1 Introduction

Internationally it is recognised that a collaborative approach to care between hospitals, general practitioners and community clinicians is essential to move healthcare successfully in to the future. Globally there is an increased onus on healthcare services to deliver more for less. The growth of healthcare needs worldwide is attributed to the rising cost of healthcare, the burden of chronic disease and the ageing populations. To address the growing requirements, it is essential to understand healthcare usage and patterns of care for patients [1-9]. Routinely collected data can contribute to the understanding of healthcare services and patterns of patient service usage.

Routinely collected data that is used for the secondary purpose of research is internationally recognised as a prized and rich source of data that can contribute to the development and improvement of healthcare services [10-13]. However to have dependable research, data quality is essential as part of the routinely collected data. If the data quality is not adequate, the data will not provide reliable information that can support research and the development of future health services.

“The need for change in the health service is unquestionable” [1]. The strategic framework for reform of the Health Service 2012 – 2015 documents the necessity for change in the health system in Ireland. The strategy identifies primary care and hospital care as two major areas requiring reform [3]. However, if healthcare spending is not tackled correctly to become more cost effective the healthcare budget of countries will “devour entire economies” [14]. Utilising and streamlining existing resources to be more efficient within health services can achieve this efficiency [2]. If routinely collected data can be utilised correctly as a secondary practice for research and to inform service deliverers, it can help in progressing health services delivery in to the future [10-12, 15-17].
Healthcare services are transforming through necessity as budgets are cut and services are expected to deliver more for less. Globally, but particularly for the population of Ireland, two of the key aspects of transforming and supporting health care are identified as:
- better management of chronic illness and
- more people treated and cared for in the community [1-3, 18].

It is recognised that to implement changes in health services, cooperation and collaboration between the main stakeholders involved is essential. This includes, but is not limited to: patients, general practitioners, hospital doctors, healthcare managers and health and social care professionals and the wider system of Government bodies and relevant statutory bodies [18, 19].

With the demands of an increasingly older population and the burden of chronic disease on health care services, there is a need for evidence based research on the use of data collected for a particular purpose utilised for the secondary function of research. It is vital to know how this data can be used to inform policy and contribute to the future development of healthcare services [10, 11, 16].

1.2 Research question and contribution to health services research

The objective of this research is to address specific data quality issues in the use of routinely collected health data, in this instance out-of-hours (OOHs) data, for secondary, health services research, purposes. There are a number of dimensions of data quality, discussed in section 2.3, but for the purpose of this research special emphasis will be placed on a subset of these dimensions.

The aims of this research were to assess:
- If routinely collected OOHs data in its current format can contribute to a better understanding of health services usage among patients
- If the quality of routinely collected data can be enhanced for secondary research purposes without disrupting frontline services
To address the research aims:

- Routinely collected data in an OOH’s database was used to analyse healthcare usage and patterns of care for patients, using chronic obstructive pulmonary disease (COPD) as an indicative case to explore the data
- Data quality issues that arose in the above study were identified as a result of using this routinely collected data
- An enhancement to the process for collection of the data was designed, implemented and evaluated

The aim of this research is to assess whether the quality of routinely collected data can be enhanced for secondary research purposes without disrupting frontline services. If routinely collected OOHs data can contribute to a better understanding of health services usage among patients it can help to inform and support policy and decision makers in implementing national health service changes.

1.3 Background and motivation for research

For the purpose of this research an OOHs service is used as an exploratory domain to facilitate understanding and investigate if routinely collected data can produce usable data for research and health service improvement as a secondary function. The primary function of the OOHs electronic record and the data collected is to support clinicians in the OOHs setting and support the patient in their journey throughout the service.

“Health is information intensive, generating huge volumes of data every day” [20]. In the OOHs service chosen for this research, the patient record is an electronic record used throughout the patient journey in the service. The call handler, telephone triage nurse and consulting doctor all document their notes as part of the electronic record in real time. Although there is no individual health identifier for patients in Ireland, the OOHs system uses demographic data to uniquely identify a caller each time they contact the service [21, 22]. As a result all the patient information is available to
consulting clinicians at each point of contact throughout the service fulfilling its primary function. The electronic record for the patient is extended each time a patient has contact with the service thus resulting in a large volume of routinely collected data that can potentially be mined for important health service research data as a secondary use. The researcher has an in depth knowledge of the OOHs system and the data collected. The motivation is that this rich seam of data could be exploited to benefit and support the development of new innovative healthcare services that will help meet the population needs as the health system changes and provide much needed understanding of what currently happens in healthcare.

1.4 Achieving the objectives of this research

To achieve the objectives of the research, routinely collected data was analysed to establish if a pattern of healthcare usage for patients can be ascertained from the information available. The quality of the data was then analysed under internationally recognised dimensions of data quality [23]. A way to improve the collection of this data was devised and an enhancement to the current method of data collection was developed, implemented and evaluated. A data quality assessment (DQA) methodology was used to carry out this research; in this instance, the total information quality management (TIQM) methodology as described by English et al was used as a framework to structure the studies [24].

As part of the DQA methodology the first study is the state reconstruction phase where contextual information on how the information is collected from an organisational processes perspective and the quality of the data is gathered[25]. This first part of the research, study one, uses descriptive statistics on patient consultations that took place in the OOHs setting. The information was documented by telephone triage nurses, doctors and call takers. The objective was to examine if the data quality of this routinely collected data in the OOHs electronic patient record (EPR) is of sufficient quality to document the patterns of healthcare usage of patients using the
OOHs service. The gaps in the data collected and documented provided a platform for the researcher to build and improve data quality for secondary use to support research.

The second study is an assessment and measurement analysis of the data quality issues that arose in study one. It is an investigation and evaluation of the current data quality of the OOHs database based on the data extracted for study one. It examines what changes could potentially be made to the current practice and workflow of the users of the OOHs service to improve the quality of the data collected, without impacting on their role within the service.

The third study is the improvement phase of the DQA methodology where a design, implementation and evaluation of an enhancement to the data collection process to improve the data collected in the OOHs service based on the knowledge gathered from study one and two was completed. A process-driven strategy was used to design and implement a solution in the live working environment of the OOHs service. A process-driven strategy has two main techniques that involves process controls; inserting checks and control procedures where data is created, and process redesign; which involves redesigning the processes that are involved in the gathering of data, to improve the quality[25]. This contributes to the knowledge of the feasibility of making changes to services and improving data quality for the secondary purpose of research.

The enhancement ran for a period of one month and the researcher examined to what extent the intervention had improved the data quality and the resulting ability to report and research based on the information gathered in the electronic records.

The evaluation took the form of quantitative and qualitative pieces of work. The quantitative aspect repeated the methodology of the first study by extracting the data from the OOHs database and analysing 1) if the process of extracting data was less time consuming and arduous and 2) if the data was of better quality and easier to navigate and understand.
The second part of the evaluation was a subjective survey of the users of the system to evaluate if the enhancement affected their workflow or had an impact on their work. This aspect of the evaluation examined if the intervention was successful and practical in the context of the users of the system.

1.5 Overview of thesis

Chapter 2: Literature Review (State-of-the-art and domain description)

Chapter 2 presents the most up-to-date literature on the data quality within healthcare services while using data for the secondary purpose of research. The chapter describes the dimensions of data quality in the literature as it pertains to secondary use of healthcare data. It introduces the state-of-the-art in OOHs services and their electronic patient records. The chapter also describes the use of OOHs data in health service research to date and the current data collections methods available in the OOHs service setting.

Chapter 3: Methodology

Chapter 3 describes the quantitative and qualitative aspects of the research including the DQA methodology for the data collection, the assessment of the data quality and how the enhancement of the data collection was developed, implemented and evaluated. The chapter is broken in to three studies that address the methodology of each research piece, the state reconstruction phase, the assessment phase and the improvement management and monitoring phase.

Chapter 4: Study one; Patterns of Healthcare usage

Chapter 4 examines the data quality of the routinely collected data and whether it is sufficient to determine patterns of care for patients in the OOHs service. This chapter examines and describes the type of data collected. It demonstrates how the information available in the OOHs setting can illuminate patterns of care and service
usage, information that can ultimately be used to inform health service delivery and decision makers.

Chapter 5: Study two; Improving data quality collection

Chapter 5 examines the data quality issues arising from the routinely collected data that were identified in study one when processing the data. This chapter discusses the aspects and dimensions of data quality this research addresses and proposes a solution to improve the quality of the data collected.

Chapter 6: Study three; Design, implementation and evaluation of an enhancement to data quality and collection

Chapter 6 describes the proposed solutions to address the issues discussed in chapter 5 and how they will be integrated into the work flow of the OOHs service to improve the data quality. The chapter also describes the implementation and the evaluations of these solutions.

Chapter 7: Summary and conclusions

Chapter 7 summarises the research conducted and the key findings. It discusses the limitations of the research and future work. It describes the key contributions made to health services research by this thesis work.
Chapter 2: Literature Review (State-of-the-art and domain description)

This chapter presents the most up-to-date literature on the data quality within healthcare services while using data for the secondary purpose of research. The chapter describes the dimensions of data quality in the literature as it pertains to secondary use of healthcare data. It introduces the state-of-the-art in OOHs services and their electronic patient records. The chapter also describes the use of OOHs data in health service research to date and the current data collections methods available in the OOHs service setting.

2.1 Introduction

“The availability of complete, accurate health data can improve healthcare experiences for individuals, expand collective knowledge about diseases and appropriate treatments, strengthen insights into the effectiveness and efficiency of healthcare systems, support public health” [11]. The OOHs databases are a rich source of data for this type of research. However the data quality within these databases has not been examined.

It is important to have accurate, valid, reliable, timely, relevant, legible and complete data for it to be trusted and utilised as a research resource [23]. This research examines the appropriate aspects of data quality and proposes an enhancement that will facilitate the secondary use of the data for research purposes without disrupting the primary function of those collecting the data. It is also important throughout this research that a balance is sought between the needs of the OOHs service and the needs of health service researchers seeking to learn from the dataset. Whatever enhancement is introduced, the aim is to gather better quality data routinely without burdening the frontline services.

The information extracted from the OOHs database for this research will also provide insight into the pattern of care for patients with chronic conditions presenting in the OOHs setting. The pattern of care is important to understand as it describes a clearer
picture of who chronic patients are and how they are currently managed in an Irish context.

### 2.2 Data quality in healthcare research

“Safe reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete” [20]. Based on international best practice, health information

- Is used to deliver and monitor safe and high quality care
- Should be of the highest quality and where appropriate collected as close as possible to the point of care
- Should be collected once and used many times
- Should be “fit for purpose” and cost effective [26].

When health information is collected and shared the information needs to be from a reliable source and understood by whoever is using the data [20]. For this research piece it is important that the information is collected once but can be used many times [16, 17, 27]. But maintaining the quality of healthcare data is widely acknowledged as problematic and is a difficult and unending process [28]. “Healthcare is a complex system that is highly political and culturally diverse, and applied health informatics research is essential to improve outcomes and performance” [27]. By applying data collection rules that enhance the data that is gathered, this information can be trusted and used by a number of sources to achieve the goals of improved outcomes and performance.

Internationally, general practice and primary care electronic medical records (EMRs) are a prized resource as they are a rich source of data that have a secondary use in contributing to health services research to inform health service delivery and patterns of patient care [10-13]. They have a capacity to provide large sample sizes, generalizable findings, are a good source of data for epidemiological studies and to improve the quality of care delivered [13, 15, 17]. There is growing interest in these
resources as they can be utilised at comparatively low costs compared to setting up specific research studies and do not require extra data collection or patient recruitment [13, 15].

In line with international best practice where health information should be fit for purpose and cost effective, this research contributes to making steps towards decreasing research costs and increasing patient-centered research by utilising existing data. The problem with using these data sets for research is that the quality of the data can be highly variable, especially as research is a secondary use of the data [15]. Primary care data is recorded for the specific purpose of recording patient information that is viewable by other clinicians to support patient care. Clinical data is not recorded with the same care as research data which means it is fit for the purpose for which it is collected but there is a question about how “fit” it is to use for research [15]. If the re-use of records for health services research is to become widely accepted, the data quality must be trusted and validated. Despite the extensive use of healthcare databases there is a lack of validation [13, 15].

Large volumes of data with multiple users contributing to the data means that the terminology used is inconsistent and each individual will document their notes in the manner they are used to [12]. This makes searching this data very difficult and time consuming.

The literature indicates that there is an inherent distrust of electronic records and paper records are trusted more readily. This should not be the case as many paper records are not entirely correct or complete either [15]. Both types of records are subject to errors. Ideally databases would contain validated and accurate data that could be made available to researchers while adhering to data protection regulation and without a threat to patient confidentiality [13].

It is evident from the literature that data used for the secondary use of research is not always trusted by those using the data [28]. It is a “rich but underused source of
data”[17]. Thus, the reliability of information and the presentation is not always documented in a coherent manner [15, 28].

This research is an opportunity to validate a data collection process to ensure quality data is available for this study and also for future research.

### 2.3 Dimensions of Data Quality

A number of studies address the aspects or dimensions of data quality under a variety of headings. A study completed by Weiskopf et al [15] identified 27 unique terms for describing the dimensions of data quality. However the core dimensions emerging in a number of studies concern: correctness, timeliness, accuracy and completeness [13, 15, 27, 28].

For healthcare records, the Institute of Medicine identified four attributes of data quality as completeness, accuracy, legibility and meaning (related to comprehensibility) [29]. Meaning is described as a more abstract concept and likely to be difficult to measure which is given as a reason that assessments of this dimension are not seen in the literature [15, 29].

Throughout the literature there is an overlap on the definition on each dimension [13, 15, 23, 25, 27, 28, 30]. In some instances accuracy is used as a synonym for correctness, but in others it means both correctness and completeness [15]. An agreed definition must be laid out and clearly defined for a particular piece of research.

Completeness is the most commonly assessed dimension of data quality throughout the literature. Completeness is most commonly defined as the record containing the truth about a patient or having all the data required to measure the intended activity or event [15, 30]. However the definition of the term is relative to each study as it depends on what the specific study is.
Upon examination of the literature it became apparent that consistent definitions and explanations for dimensions of data quality are difficult to find. This is captured perfectly by Weiskopf et al [15] who reviewed 230 articles for data quality: “One of the biggest difficulties in conducting this review resulted from the inconsistent terminology used to discuss data quality. We had not expected, for example, the overlap of terms between dimensions, or the fact that the language within a single article was sometimes inconsistent”. Batini et al [25] also concluded “there are a number of discrepancies in the definition of most dimensions due to the contextual nature of quality”.

In Ireland, the Health Information and Quality Authority (HIQA) have compiled a National standard for the dimensions of data quality; accurate, valid, reliable, timely, relevant, legible and complete [23, 26]. Data quality has many dimensions and aspects contributing to the overall quality of information. The Irish Health Information and Quality Authority dimensions of data quality define specific headings under which the data quality should be addressed, see figure 2.1 and table 2.1 [30, 31].

![Figure 2.1 The Dimensions contributing to Data Quality (Health Information and Quality Authority)](image)
<table>
<thead>
<tr>
<th>Data quality dimension</th>
<th>What it is</th>
<th>Example</th>
</tr>
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<tbody>
<tr>
<td>Accurate</td>
<td>It describes or measures what it was designed to describe or measure.</td>
<td>The coding of a clinical record matches the clinical information in the written record.</td>
</tr>
<tr>
<td>Valid</td>
<td>It is collected in accordance with any rules or definitions applicable for that information. These rules check for correctness, meaningfulness, and security before the data is processed. This enables comparison and benchmarking over time.</td>
<td>When reporting the percentage of children in care that have a care plan, only care plans that comply with current child care regulations are reported.</td>
</tr>
<tr>
<td>Reliable</td>
<td>It is collected consistently over time, whether manually or electronically.</td>
<td>When reporting waiting time for elective surgery, the same point in time is used by all as the start time, such as the date the patient was placed on the waiting list by the consultant.</td>
</tr>
<tr>
<td>Timely</td>
<td>It is collected within a reasonable time period after the activity it measures and it is available when it is required and as often as it is required.</td>
<td>Notifiable diseases are reported to the Health Protection Surveillance Centre in a timely manner to facilitate the identification of an outbreak and the introduction of preventive measures to limit further spread. Accidents and incidents in nursing homes are reported to the person in charge within three days so that trends can be identified.</td>
</tr>
<tr>
<td>Relevant</td>
<td>It meets the needs of the information users.</td>
<td>When monitoring uptake of childhood vaccinations it may be necessary to record ethnicity, as future campaigns to improve vaccination uptake may need to be targeted at a particular subgroup of the population.</td>
</tr>
<tr>
<td>Legible</td>
<td>It is readable and understandable for the intended users.</td>
<td>A prescription written by a general practitioner (GP) makes clear to the dispensing pharmacist which drug is to be dispensed and in what dosage.</td>
</tr>
<tr>
<td>Complete</td>
<td>It has all those items required to describe or measure the intended activity or event.</td>
<td>When a GP refers a service user to a specialist consultant it is important that the referral letter contains all relevant medical details such as the presenting complaint, relevant medical history, findings from physical exam, results of investigations and all prescribed medications.</td>
</tr>
</tbody>
</table>
In the context of this research, the Irish national HIQA definitions of data quality dimensions will be the reference point for addressing the data quality in the OOHs service.

### 2.4 Data quality assessment methodology

Data quality assessment (DQA) methodologies are discussed comprehensively in the work carried out by Batini et al, “Methodologies for Data Quality Assessment and Improvement”. This work is a comprehensive systematic and comparative description of data quality methodologies that exist [25]. This review contains a number of methodologies that focus on different aspects of data quality assessment depending on the environment and the goals of the research.

There are a number of common phases and steps in each DQA methodology and choosing which methodology to use is guided by the type of information system in place. For the purpose of this research, a total information quality management (TIQM) methodology was used[24]. TIQM considers the relationship between the data quality, the process by which the data is collected and the organisation itself and also applies a wider range of data and process-driven techniques. This research has a strong focus on process-driven strategies where the quality of the data will be improved by redesigning the processes used to create the data.

Figure 2.2 illustrates the phases of TIQM. The assessment phase analyses the data quality by extracting random samples of the data and measuring and interpreting the quality. This phase also examines how the information is generated, by whom and the stakeholders involved. The improvement phase analyses what the cause of the data errors are and how you can design solutions and redesign processes to improve the data. The improvement management and monitoring phase describes a methodology for implementing a solution and monitoring same to improve effectiveness.
### 2.5 Out-of-hours services

The context of this research is the out of hours (OOHs) setting. In Ireland, healthcare is delivered to patients in a number of settings and is provided by a range of clinicians and healthcare workers. As a result a patient may not always be in the correct place or with the most appropriate care giver for a particular illness to be treated or a disease to be managed. Many episodes of illness are treated within the hospital setting where patients present as alternatives to their GP or community services [2].

This is reflected in the unscheduled care setting in Ireland where patients have fewer points of contact than throughout the day and access to only the OOHs service or hospital services after normal GP surgery hours. GPs treat a wide variety of patient conditions in the OOHs setting. Understanding the users of the OOHs service will provide a substantial picture of the patterns of care for patients and how healthcare services are utilised.

OOH services in Ireland provide urgent primary care services to patients who need medical attention after their own doctors’ surgery close. OOH services are considered by the HSE as highly significant quality initiatives for patient care, general practice and health services as a whole, with the national review of OOH services concluding that OOH services should be extended to cover the total population of Ireland[32]. In
Ireland OOH services have been developed and work successfully in conjunction with local general practitioners (GPs) to provide unscheduled care for their patients. Around 65% of the Irish population is currently covered by OOH services and this is to increase over the coming years to 100% cover in line with the National Review of GP OOH services [32]. The repository of data collected by these services should be utilised to help inform and understand patients and how health services are currently delivered.

OOHs are valuable sources of research data as best practice OOH services are data and information driven and use electronic protocols and guidelines and clinical decision support software (CDSS) as part of the patient management [32].

Eleven of Irelands OOHs services use the Adastra call management system [32]. Adastra is an electronic patient record system that provides multiple users with information pertaining to a patient episode of illness in a timely and efficient manner while providing access to previous patient encounters and any special notes or patient care plans that a GP may have put in place [33]. This includes the electronic, faxed and verbal data that is shared between services [32]. The users (clinical and non-clinical) are provided with varying degrees of pertinent information that is required for the treatment of the patient. This data infrastructure can be leveraged to support health services research.

2.6 Research domain description: Caredoc

In order to give a coherent understanding of where the data for this research comes from and where the data quality is being enhanced and evaluated; this section is a description of the OOHs service and the workflow. It is necessary to understand the people and the software elements in the collection of the data as both of these factors will have an effect on data quality.

Caredoc is a not-for-profit company limited by guarantee and governed by a board of directors comprising of nineteen voluntary member doctors. Caredoc holds a service
level agreement (SLA) with the HSE for the provision of services to HSE South, HSE DML, HSE NE in accordance with the Health Act 2004. There are 400 general practitioners members of the Caredoc service [34, 35].

Caredoc commenced operation on the 8th June 1999 providing cover for Carlow town, Carlow county and neighbouring areas. Between 2000 and 2005 the service was extended to the counties of Kilkenny, South Tipperary, Wexford, South Wicklow and Waterford[35]. Caredoc has handled over 1.9 million patient contacts to date. The average number of cases dealt with weekly by the Caredoc service is between 7,500 to 9,500 calls, depending on the time of year. The highest amount of activity was in December 2011 with 19,000 calls assessed within 1 week. 390,000 patient contacts were assessed for the year 2013 [34, 36]. As a result the Caredoc database contains a massive amount of data on a scale that most health services researchers in Ireland have never had access to.

2.5.1 Patient pathway through the OOHs service

Throughout the patient journey through the service, data is documented at different points by different users. An overview of the pathway is presented here to understand how the data is documented and by whom. This section also describes the fields where the data is collected, and how they are used in this research. When a patient contacts the service their case is logged on to the system by a call taker. The call is then passed to a telephone triage nurse for assessment. Based on the nurse assessment the case is transferred to a duty doctor for a consultation, referred to hospital or the case is completed by the nurse giving evidence based advice.

A non-clinical trained call taker logs the patient’s demographic details and the patient’s symptoms. The telephone number is always taken first to ensure that if the caller is disconnected the patient is contactable. The call taker uses the telephone number provided by the patient as the main search criteria for finding an existing record for this caller as there is no individual health identifier for patients in Ireland. If
no patient record is returned, the call taker will search using the date of birth or can use name or address fields.

The fields documented by the caller taker are; telephone number, first name, surname, date of birth, additional contact telephone number, address, current location (if the patient is not at home), name of person making the call (if the caller is not the patient), relationship of the person making the call to the patient, name of patients own GP and the presenting symptoms (what is wrong with the patient today) as in figure 2.2.

Figure 2.3 Case Entry Screen - Adastra System

When the call taker has logged the patient demographic details and recorded the presenting symptoms, the case is prioritised as routine, urgent or emergency. The priority of the case is determined by the call taker based on guidelines developed by the Caredoc clinical governance team and the medical director of Caredoc. The medical director and clinical staff hold training sessions with the call takers throughout the year where the guidelines are discussed and revised [37].
Within the Adastra call management EPR system, when the call takers’ interaction with the electronic record is concluded and designated a priority, the call is transferred to the “telephone triage nursing pool”. Here the nurse is presented with a screen where the calls are displayed by priority and by the time they were recorded within the call management system. This ensures that calls with the highest priority are dealt with immediately. As a visual aide for the nurses, the calls are colour coded; red for emergency, yellow for urgent and white for routine. The cases can also have case tag descriptions to identify calls for the nurses e.g. Deaf / Hard of hearing case, figure 2.3.

<table>
<thead>
<tr>
<th>Case #</th>
<th>Priority</th>
<th>Time</th>
<th>Case Tag Description</th>
<th>Fullname</th>
<th>Address</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>78182</td>
<td>Emergency</td>
<td>13:44</td>
<td></td>
<td>Test Patient3</td>
<td>Main Street</td>
<td>71 years</td>
</tr>
<tr>
<td>78103</td>
<td>Urgent</td>
<td>13:45</td>
<td></td>
<td>Test Patient4</td>
<td>Main Street</td>
<td>7 years</td>
</tr>
<tr>
<td>78181</td>
<td>Routine</td>
<td>13:44</td>
<td></td>
<td>Test Patient</td>
<td>Test Address Main Street</td>
<td>32 years</td>
</tr>
<tr>
<td>78104</td>
<td>Routine</td>
<td>13:46</td>
<td></td>
<td>Test Patient</td>
<td>Main Street</td>
<td>Unknown</td>
</tr>
<tr>
<td>78105</td>
<td>Routine</td>
<td>13:47</td>
<td></td>
<td>Test Patient5</td>
<td>Main Street</td>
<td>5 years</td>
</tr>
<tr>
<td>78188</td>
<td>Routine</td>
<td>13:50</td>
<td></td>
<td>Test Patient5</td>
<td>Main Street</td>
<td>5 years</td>
</tr>
<tr>
<td>78189</td>
<td>Routine</td>
<td>13:51</td>
<td>Deaf / Hard of Hearing</td>
<td>Test Patient4</td>
<td>Main Street</td>
<td>7 years</td>
</tr>
</tbody>
</table>

Figure 2.4 Telephone Nurse Triage Screen

The nurse opens the call and is presented with the patient’s demographic details. The “current consultation” screen is where the nurse documents the triage assessment for the current episode of care. The nurse uses the Nightingale Teleguides clinical decision support software (CDSS) when assessing a patient. The Nightingale Teleguides are a trinary logic set of algorithms for symptom specific problems. The algorithms rule out the most emergent conditions first and support the nurse in reaching an appropriate level of care for the patient [38-40].

The nurse assesses the patient and determines how quickly the patient needs to be seen, and by whom. Telephone triage is not face-to-face and therefore is not diagnostic. The nurse documents contemporaneous free text notes while speaking with the patient within the “current consultation” screen of the EPR system. These are the notes that are extracted for the research.
When a face-to-face consultation with the duty doctor is required, this can be an emergency, urgent or routine case. The consultation can take place at a treatment centre or in the patient’s home or place of residence (e.g. nursing home).

Whether the patient is consulted in the treatment centre or in the patients’ place of residence, the doctor has access to the Caredoc EPR as seen by the nurse; this includes the full triage assessment from the nurse for this episode of care. The doctor enters their own consultation details in a separate “current consultation” screen. In this screen, the doctor documents the notes under four separate fields “history”, “examination”, “diagnosis” and “treatment”. When the doctor is finished the consultation, the consultation is set to complete. The doctor may not be required to attend to see the patient, but only to give advice. Doctors advise patients, and in some cases pharmacists that have queries on prescriptions and medications. All this is documented in the patient OOHs EPR under “current consultation” and was extracted for this research. Doctors are encouraged to complete all the fields in the current consultation screen however they are not mandatory and are unstructured free text fields which as a result affect data quality.

2.7 Previous research using out-of-hours service data

The rich seam of data available from the OOHs database in its current format is used by researchers and clinicians already. Similar data has been used in a number of research projects for medical students completing GP training schemes, students completing MSc & PhDs, hospital doctors and national and international researchers across the board for example: alcohol consumption, palliative care, gastroenteritis, prescribing in the community, clinical decision support software, asthma[41, 42]. The data is also utilised by doctors who use the data for auditing their consultations for continuing professional development (CPD) which is required by the Irish College of General Practitioners (ICGP) [43].

It is important to have a complete data set when investigating or researching a specific disease. OOHs services have been used for research on a number of topics however
the data set on any specific disease is not complete. Consequently there is currently no complete COPD data set available in the OOHs, information commonly missing for example is the classification of the severity of the COPD. However it is important to understand what can be achieved with the information that is available in the OOHs. This research explores the information available and examines what can be achieved with it. This is the first study of its kind that uses the OOHs data to investigate the pattern of care for COPD patients. OOHs data has not been used in a COPD study like this before. The data has been used in other studies.

Research completed by Brabazon et al in 2006 showed how OOHs data can be utilised successfully in the area of syndromic surveillance for influenza like illness (ILI) [44]. As evidenced by this study, the data routinely collected is being utilised as an early alert system for the increase in ILI throughout Ireland.

Routinely collected data is reported at a national level on a monthly basis and key performance indicators are fed back to relevant statutory bodies as required.

While there is a wealth of information available, searching this data is time consuming and difficult. Data quality has not been addressed by researchers in previous studies, as the data given to researchers had to be anonymised and extracted from the database by users within the OOHs service. Therefore a certain amount of data quality issues were addressed by OOHs staff before exporting data to the researchers. For example, if a researcher was looking for records for patients who abused alcohol, the data was extracted based on specific search terms. However, before the researcher received the data, no records could be given that did not adhere to the specific criteria of “patients who abused alcohol”. A thorough search of the fields had to be completed to ensure those patients who did not match the criteria were not given in error.

2.8 Chronic conditions and Chronic Obstructive Pulmonary Disease

This section introduces chronic illness and chronic obstructive pulmonary disease (COPD). The first part of this MSc research, study one, uses COPD as an indicative case
to extract information from the OOHs database and to determine what information could be utilised for research purposes. COPD was chosen due to the nature of the disease and the fact that it is expensive and costly to the health services and is a good disease to target for improvement to prevent wasteful uses of resources.

A chronic disease is an illness that is recurrent or long lasting [2]. Chronic illnesses can present in many forms and are considered under several definitions; diseases that require on-going surveillance, illnesses that have an acute onset followed by relative periods of stability but acute exacerbations, or diseases that are slowly progressive but have chronic on-going dysfunction [45].

Internationally, chronic diseases are identified as a burden on the health care system considering that they account for high hospital admissions and a high proportion of the health budget each year. The older population has increasing demands for services with increases in incidences of chronic illness. The 65+ age group continues to increase and the death rate in Ireland continues to fall steadily with a consequential growth in chronic disease [2]. Chronic conditions are identified as key areas that need to be addressed in order to help improve the current health service in Ireland [19]. To understand how services to support this healthcare environment can be developed and implemented, evidenced based research is required.

The HSE national service plan also emphasises the need for integration of services, cost reductions, value for money and improvement of the current health services infrastructure to improve the quality and timeliness of care received by patients [19]. Study one of this MSc research will help to inform this by understanding the needs of patients. Study one will examine their patterns of care and what is currently happening to the patients using data that is currently documented and available. This is a valuable resource to the development of these future services.
COPD is as a serious, preventable and costly disease that affects approximately 440,000 people in Ireland. It is estimated that the disease will increase in line with Ireland’s ageing population. 50% of people over 70 currently suffer from the condition. COPD is the third most common cause of acute hospital admission in Ireland and the average cost of a COPD in-patient case is 39% higher than the average cost of other in-patient cases. COPD was responsible for over half a million lost work days in 2004 in Ireland [46]. It is an ideal area of inquiry for assessing the use of OOHs data. COPD will escalate in the coming years in Ireland unless a national integrated and structured approach based on evidence-based prevention and care is implemented.

Unscheduled health care in Ireland is limited to accident and emergency (A&E) or out of hours’ (OOH) services. The only option for patients with COPD who suffer from an episode of illness after the GP surgery closes is to contact an OOHs service or go to hospital [32]. It is also a disease that could benefit more from a timely intervention [8, 47-50].

If Ireland’s high quality, information and data driven services are utilised correctly for research and planning the benefits would not only be for the patient, but for the health system as a whole.

2.9 Summary

Data quality is essential for primary uses of data. But if the data is to be used for secondary use of research, it must also be of high quality. Any enhancements made to the data quality within a service to facilitate secondary usage must not impact on the primary function of the service or on the users documenting the data.

The large volume and variety of data collected in an OOHs service by the call taker, the telephone triage nurse and the doctor are a valuable resource for researchers to understand what is happening to patients and to document their pattern of care.
“There is very limited data available from the primary and community care sectors”[26]. Choosing COPD as an indicative case provides an opportunity to study a costly disease to the health service that can benefit from a more complete picture of the patterns and pathways of care for COPD patients. If you can utilise the COPD data collected to determine patterns of care, this can be transferred to other chronic conditions and implemented throughout OOHs services in Ireland. This can contribute to the national health and social care data collection in Ireland.

HIQA is charged with making recommendations in improving the quality of health information and filling in gaps where information is needed and not available [20]. This research contributes to filling this gap.
Chapter 3: Methodology

3.1 Introduction

There are three interlinked studies that address the research question using both quantitative and qualitative methods. The methodology used in the TIQM data quality assessment as discussed in section 2.4 provides focused steps to assess the quality of data and to implement and monitor improvements. The phases outlined in section 2.4 supports the structure of this research, in particular the final phase of improvement management and monitoring. TIQM provides guidelines to manage and monitor and redesign processes.

The aims of this research are to assess:

- If routinely collected OOHs data can contribute to a better understanding of health services usage among patients
- If the quality of routinely collected data can be enhanced for secondary research purposes without disrupting frontline services.

To address these aims the research was carried out in three phases:

- Study one was the first part of the assessment phase which extracted samples of the routinely collected data in an OOHs database to analyse healthcare usage and patterns of care for patients using chronic obstructive pulmonary disease (COPD) as an indicative case
- Study two was part of the assessment phase that identified data quality issues that arose in study one as a result of using routinely collected data
- Study three was the improvement management and monitoring phase by designing, implementing and evaluating an enhancement to address the quality of the routinely collected data.

The first part of this research examined if the data quality within the database was sufficient to describe the pattern of healthcare usage of patients in the OOHs setting
using COPD as an indicative case. The information gathered provided a snapshot of the healthcare resource utilisation of COPD patients and the setting it is provided in e.g. was the patient treated in the community OOHs setting or was the patient referred to hospital. The quantitative aspect of this study is detailed using descriptive statistics to analyse the data, structured and unstructured, that is documented in the database.

Based on the data from study one, study two described the data quality in the OOHs service database and the difficulty in using the data for research. The study describes the problems with identifying the required data and extracting the correct information from the system. From this, specific data quality dimensions were identified that could be improved to ensure the routinely collected data has a secondary use to inform research.

Study three was the design, implementation and evaluation of an enhancement based on the findings of study two. The objective of the enhancement was to improve the collection of the data in a more streamlined manner to support health services research. The design of the enhancement was based on the knowledge gathered from study one and two. Both a quantitative and qualitative approach was taken to evaluate this study. Similar to study one, quantitative descriptive statistics were used to examine if in fact the targeted data quality dimensions had improved the data. The qualitative aspect was a subjective survey that the users of the system completed to evaluate if the enhancement complemented their work and did not impact on their primary function to facilitate the secondary function of research.

### 3.2 Study One

The purpose of study one, the assessment phase, was to examine if the data quality of routinely collected data in the OOHs database could sufficiently describe the pattern of healthcare usage of patients in the OOHs setting using COPD as an indicative case to uncover the data quality issues. The results and findings are presented in chapter 4.
The data were extracted from the Carlow emergency doctors on call GP OOHs service database. The information was contained within the Adastra Call Centre Management System which contains the patients OOHs electronic record.

Data for the year 2009 were anonymously extracted using a report and export of the system. The data was extracted to a Microsoft Excel file. Due to the large volume of data available (210,828 patient episodes of care), the data were extracted on a month by month basis.

The aim of the study was to give a detailed picture of the healthcare usage and the needs of patients with the chronic disease COPD. COPD was chosen as the disease to explore for this research. When patients present with COPD OOHs in the primary care setting the only option available for the patient may be acute admission to hospital. This coupled with a lack of services and supports in the community can result in unnecessary lengths of hospital stay. Understanding more about COPD patterns of care is a valuable resource for health service delivers and policy makers. This detailed description of patients in an Irish context does not currently exist. The data collected and the subsequent findings are discussed in chapter 4.

The OOHs data is collected and documented by the call taker, the triage nurse and the doctor. The data is not exhaustive and the patient may not always be identified as having COPD. The nature of OOH services is to deal with a particular symptom occurring at the time. If the patient does not volunteer the information, and the information is not extracted by the nurse or doctor as relevant to the current consultation taking place then the information will not be recorded. If the patient is ringing in with a potential broken arm, COPD may not be relevant as it is not a COPD episode of care. As a result, the information may not include all patients with COPD, but does include the patients ringing with a problem relating to their COPD. This is the exact information that is required for the study. This is important from a data quality perspective that the researcher understands clearly what exact information they are dealing with.
After the data were extracted, each month was analysed individually to identify the records relevant for this particular study. The data was analysed using STATA 11 and Microsoft Excel. STATA 11 is a statistical software package that analyses large set of data. The extracted data contained 18 different fields. Not all of the fields were required for the study. The fields contained both structured (specific items to choose from) and non-structured (free text) data. Only the required data fields were kept, the rest were deleted, see table 3.1.

Table 3.1 Data fields extracted for research purposes

<table>
<thead>
<tr>
<th>Field Name</th>
<th>Explanation of field</th>
<th>Used in this research</th>
</tr>
</thead>
<tbody>
<tr>
<td>From</td>
<td>Date information extracted from</td>
<td>No</td>
</tr>
<tr>
<td>To</td>
<td>Date information extracted to</td>
<td>No</td>
</tr>
<tr>
<td>SITENAME</td>
<td>Name of site (CAREDOC)</td>
<td>No</td>
</tr>
<tr>
<td>CaseNo</td>
<td>Individual case number</td>
<td>No</td>
</tr>
<tr>
<td>Gender</td>
<td>Gender of patient</td>
<td>Yes</td>
</tr>
<tr>
<td>Age</td>
<td>Age of patient</td>
<td>Yes</td>
</tr>
<tr>
<td>CaseStatus</td>
<td>Not recorded</td>
<td>No</td>
</tr>
<tr>
<td>ActiveDate</td>
<td>Actual date of individual case</td>
<td>No</td>
</tr>
<tr>
<td>CaseType</td>
<td>How the call was completed in the OOHs service</td>
<td>Yes</td>
</tr>
<tr>
<td>CallOrigin</td>
<td>Where the call originated from / who was calling on behalf of the patient</td>
<td>Yes</td>
</tr>
<tr>
<td>PriorityOnReception</td>
<td>Priority assigned by call taker</td>
<td>Yes</td>
</tr>
<tr>
<td>PriorityAfterAssessment</td>
<td>Priority assigned by nurse</td>
<td>Yes</td>
</tr>
<tr>
<td>PriorityOnCompletion</td>
<td>Priority assigned by doctor</td>
<td>No</td>
</tr>
<tr>
<td>ReceivedSymptoms</td>
<td>Symptoms of patient documented by the call taker</td>
<td>Yes</td>
</tr>
<tr>
<td>Diagnosis_Outcome</td>
<td>Outcome of the case as recorded by the consulting doctor</td>
<td>Yes</td>
</tr>
<tr>
<td>Diagnosis_OutcomeClinician</td>
<td>Consulting doctor name</td>
<td>No</td>
</tr>
<tr>
<td>TriageNotes</td>
<td>Triage assessment recorded by the nurse</td>
<td>Yes</td>
</tr>
<tr>
<td>TriageProvider</td>
<td>Triage nurse name</td>
<td>No</td>
</tr>
</tbody>
</table>

Of the fields used for the research, the three fields containing the free text information, ReceivedSymptoms, Diagnosis_Outcome, and TriageNotes, were searched for key words to identify the required records.
The relevant OOHs data was identified within the database using an “if statement” to search the key terms for COPD. The original terms used were: chronic obstructive pulmonary disease, chronic obstructive airway disease, COPD, COAD. However, this is when the first problem with the data quality was identified. Through searching this data it was discovered that not all records were being returned, this was due to the quality of the documentation of the data. After extensive searching through the data, other search terms were identified to compensate and try to address the data quality issues, see table 3.2. The punctuation made a difference to the search terms.

Table 3.2 COPD Search Terms

<table>
<thead>
<tr>
<th>Search Terms for COPDS</th>
<th>COPD</th>
<th>chronic obstructive pulmonary disease</th>
<th>respiratory disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD</td>
<td>chronic obstructive pulmonary disease</td>
<td>respiratory disease</td>
<td></td>
</tr>
<tr>
<td>COAD</td>
<td>chronic obstructive airway disease</td>
<td>lung disease</td>
<td></td>
</tr>
<tr>
<td>c.o.p.d</td>
<td>Emphysema</td>
<td>c.o.a.d</td>
<td></td>
</tr>
<tr>
<td>c.o.a.d</td>
<td>C.O.A.D</td>
<td>C.O.P.D</td>
<td></td>
</tr>
</tbody>
</table>

3.3 Study Two

Study two is part of the assessment phase and is a qualitative analysis of data quality issues arising in study one. Using the HIQA dimensions of data quality discussed in section 2.3, the relevant dimensions appropriate to study one were identified. A qualitative analysis of the quality of the OOHs COPD data on the designated dimensions was carried out. The findings are presented in chapter 5.

Throughout study one, the quality of the data emerged as an issue. When reviewing the COPD cases a problem with the documentation of the condition was identified, but also other conditions and important data pertinent to the patient. This does not affect the day-to-day operation as the data is still identifiable when reading it, but it causes problems if the data is to be used for a secondary use, in this instance, research. Clinicians type and do not always review what they type leading to simple spelling
errors e.g. chronic obstructive pulmonary disease. This can lead to a problem when identifying cases, as the researcher must be cognisant of the potential errors and cases that will not be identified.

As discussed in section 2.2 and 2.3, data quality has many dimensions and aspects contributing to the overall quality of information. The definitions for these dimensions can vary from study to study and in some instances even within the same study. For the purpose of this research the Irish Health Information and Quality Authority definitions for the dimensions of data quality are used to define the headings under which the data quality will be addressed.

Based on the data extracted from study 1, when all the records were identified that would be included for COPD patients, a thorough qualitative analysis of the three fields containing the free text information, ReceivedSymptoms, Diagnosis_Outcome, and TriageNotes, as described in section 2.5, was carried out. This involved analysing and documenting how the data was currently presented for research purposes and the problems arising. Based on this information, study two identifies two possible enhancements to enrich the data captured with the result of improving the data quality within the OOHs database.

3.4 Study Three

The purpose of study three, combining the improvement phase and the improvement management and monitoring phase, was to design, implement and evaluate an enhancement to the information collected in the OOHs database to improve the data quality for research purposes, based on the findings from study one and two. A solution was designed by the researcher and implemented in conjunction with the appropriate stakeholders – clinical and nursing management and ICT personnel.

The development and implementation of the enhancement is based on the knowledge gained in studies one and two. As this research was part of a live working environment, it had to be facilitated seamlessly with minimal impact and change to
the current working pattern. The design of the implementation was based on what suited the organisation and staff and could be implemented from a technical perspective without undue cost and development time.

Three aspects of the enhancement were evaluated. One assessed the quantitative aspect of the solution to measure if the enhancement had improved the extraction of the information required for research purposes. COPD cases were extracted for a period of time and compared to the extraction process required for study one.

The second was a quantitative and qualitative evaluation to examine the data quality of the collection. The extracted COPD cases were evaluated qualitatively to examine if the data quality had improved. Quantitatively, the number of cases extracted were compared using the extraction method of study 1 compared to the new enhancement.

The third aspect involved a qualitative subjective survey of the users of the system to determine the success of the solution and the impact on their work, if any. The tool Survey Monkey was used to facilitate the survey and aggregate the results. All appropriate users of the EPR were invited to take part in the survey.

### 3.5 Summary

The three separate studies and the TIQM methodology were utilised to address the research question and the aims and objectives of this thesis. Descriptive statistics were used to analyse the data in the database as it pertained to COPD patients. Study one determined if there is relevant information that can be utilised to inform health services and policies.

Study two used qualitative analysis to examine data quality aspects of the free text fields. It examined if the data quality of the information documented currently and if it could be used more frequently for the secondary purpose of health services research.
The final qualitative and quantitative evaluation in study three examined if it is possible to make small changes to electronic patient systems and working environments, without disrupting users and work flow patterns greatly to facilitate improvements in dimensions of data quality to improve secondary use of data for research purposes.
Chapter 4: Patterns of healthcare usage

This chapter describes study one which uses OOHs data to understand patterns of care for patients. It presents the findings of the patterns of healthcare usage of COPD patients using the OOHs service database. This is part of phase one of the TIQM model as described in section 2.4, figure 2.2.

4.1 Introduction

Routinely collected data in the OOHs service is a rich seam of data. To expose data quality issues and exploit this data for secondary research use, the researcher examined the data to answer; what is the pattern of care for patients in the primary care setting using out of-hours data with COPD as a chronic disease to explore the data?

Firstly the study identified the data quality problems in identifying COPD patients within the database. The extraction process was time consuming and ultimately not exhaustive due to the number of records in the service.

Secondly, despite the data quality problems, the study identified the healthcare usage of patients’ in the OOHs service and their transition through primary and secondary care. It provides a valuable source of information especially as there is a lack of primary research on how patients use services. It is important to know what services patients are utilising and how these services can be developed for future service users to benefit patients and health service deliverers.

COPD was chosen as it is a chronic disease that is information intensive and requires frequent consultations with GPs and hospitalisation of patients, especially when they suffer an exacerbation of their COPD[8, 48, 50-53]. It is a condition that can be supported by information and managed in the community but patients frequently end
up in hospital for long stays[49, 54, 55]. Knowing more about the types of patients and care delivered to the patients is an invaluable source of information for planning future healthcare services for patients.

### 4.2 Data collected

Descriptive statistics were used to analyse data extracted from an OOHs service to summarise and describe the pattern of care of patients with COPD in the OOHs setting. This data was extracted from the Carlow Emergency Doctors on Call GP OOHs service database from the 1\textsuperscript{st} of January 2009 – 31\textsuperscript{st} December 2009. A total of 1,681 records were identified. This extracted data facilitated the formulation of a detailed description of the pattern of care for COPD patients when they required unscheduled care.

An OOHs setting is the hours between 6.00pm – 9.00am when the patients’ own GP is closed. In Ireland, patients have access to an OOHs service, ambulance or A&E departments for unscheduled care. OOHs services are an extension to the primary care services delivered by general practitioners (GP) and are available to patients who require a GP when their own doctors’ surgery is closed [32].

There is little known about the number of COPD patients who attend OOHs services and their healthcare usage and in general “the care of COPD patients in Ireland has received limited study”[51]. The aim of this study is to describe healthcare usage of COPD patients in the OOHs setting while exploring the data quality issues within the OOHs database.

Data was anonymously extracted from the Carlow Emergency Doctors on Call (Caredoc) general practitioners (GP) OOH service electronic database [35]. The Caredoc service covers the areas of Carlow, Kilkenny, South Tipperary, Wexford, Waterford and South Wicklow, a population of approximately 525,000 patients. The data extracted are representative of the population covered by Caredoc. All the COPD episodes for one year (January 1\textsuperscript{st} – December 31\textsuperscript{st} 2009) were extracted from all the
data collected by the Caredoc service. All patients identified in the data as seeking a medical intervention for a problem with their COPD were included in the study.

The study population was the total population of callers to the Caredoc GP OOHs service as identified from the “IF Statement” (table 4.1) with symptoms relating to their COPD as their main complaint for one full year.

Table 4.1 IF Statement

| =IF(SUM(COUNTIF(N2:P2,{"*COPD*","*COAD*","*coad*","*copd*","*C.O.P.D.*","*C.O.P.D.*","*C.O.A.D.*","*C.O.A.D.*","*chronic obstructive pulmonary disease*","*chronic obstructive airway disease*","*lung disease*","*respiratory disease*","*emphysema*"}))>0,"COPD","None") |

This is described in more detail in section 4.3. Patients with COPD were identified from:

1) The presenting complaint documented by the call taker
   Or
2) The history and assessment completed by the triage nurse
   Or
3) The doctor consultation notes.

The search terms used were:

- “COPD”, “COAD” and variations of same with alternative punctuation
- Chronic obstructive pulmonary disease
- Chronic obstructive airway disease
- Respiratory disease
- Lung disease
- Emphysema.

As discussed in section 2.5.1, once contact is made with the service, the call is passed from the call taker to the telephone triage nurse who carries out a comprehensive
assessment and assigns an appropriate level of care to the patient. This determines the urgency of the patients’ complaint, i.e. emergency, urgent or routine. The patient may require evidenced based nurse advice, consultation with duty doctor or referral onward to hospital. If a doctor consultation is required, the nurse determines how soon and if the patient should be treated at a local treatment centre or in their place of residency which could be their own home or care of elderly facility. The levels of care available to the telephone triage nurse include:

- 999 (ambulance referral to hospital)
- A&E and Hospital Referral (patient referred to hospital but does not require ambulance)
- Calls passed to Duty Doctor (doctor advice, treatment centre or home visit)
  - Emergency Consultation
  - Urgent Consultation
  - Routine Appointment
  - Doctor Advice
- Patient to make appointment within own GP within 4 hours (routine call when patient telephone OOHs service early on a weekday morning and own GP is open with the hour)
- Patient to make appointment with own GP within 1 to 3 days
- Nurse Advice according to documented home care treatment

A COPD case may include a patient receiving a doctor consultation at a treatment centre or in their place of residence and a referral onward to hospital. This is documented in free text in the “Triage Nurse Assessment” or the “Doctor Consultation” notes.

The extracted data was analysed for descriptive statistics using STATA version 11 and Microsoft Excel. A detailed analysis of all the data fields was completed on a case by case basis particularly the free text fields of “Received Symptoms”, “Triage Nurse Assessment” and “Doctor Consultation”. These fields contain any extra notes.
pertaining to previous GP consultations or hospital discharge relating to the patient’s condition which may have occurred within the preceding days.

The analysis and findings are described in the rest of this chapter. First however, in section 4.3 the issues of data quality that arose are discussed.

### 4.3 Quality of the Extracted Data

To extract the correct data, the “IF statement” as described in section 3.2, table 4.1, was used to identify as many records as possible that could potentially be COPD patients. To ensure the correct records only were chosen, the researcher had to manually check the returned records of the consultations to see what related to COPD, and what was not a COPD case. In some instances, patients who were identified as having emphysema were not diagnosed with COPD, whereas some patients were. This means to ensure that only COPD cases were correctly identified a thorough search of all the free text information had to be conducted. This means that the data was not complete in terms of data quality.

In the free text information, a great deal of information was documented about previous and future referral to hospital and to visits to the patient’s own GP in the preceding days. In order to collect this information in a standardised manner, a template or a redesign of how data is documented is required.

One of the difficulties in identifying what happened to the patient was to understand the record in the context of the OOHs EHR system. The system has a number of structured fields to choose from on how the call was dealt with within the system e.g. if it was finished as nurse advice. However the call may have been finished as nurse advice but the patient was also referred on to A&E. There is also the possibility that the information was documented in free text by the consulting doctor or the triage nurse, and therefore to get the complete picture you must thoroughly examine all the free text fields.
The reliability of the data extracted in 2009 was poor due to the consistency of how each user documented the data at the time. There was no set way to identify a case as a COPD case, and no designated spelling or consistent way of identifying COPD from the free text due to the number of variations of spelling.

Due to the volume of cases extracted for 2009, (210,829), examining each case was impossible. Subsets of cases were examined for a weekend period in January 2009. This helped to identify what sort of language was used to describe COPD cases and if the COPD spelling was incorrect or had different punctuation. It was clear from this exercise that not all COPD cases could be identified simply. There was too much variation in spelling, punctuation and description of the disease. The cases that were missed by the initial "if statement" search were included in to the overall study. However it was not practical to search through every case for 2009 in the OOHs database.

Within the cases identified, in some instances the notes were "patient does not have COPD". These patients had to be taken out of the study, but this was only possible by reading through all of the free text notes. The search terms as described in section 4.2 were sometimes used in a different context for specific cases that were not COPD cases. These cases were also eliminated.

In some instances, a diagnosis of COPD had not been established by the patient’s own GP previously and the consulting GP may have referred the patient back to their own GP for further investigation e.g. “Patient to attend own GP to determine if COPD is present”. There was a clear requirement for a more focused and reliable method for collecting specific data on patients with COPD. These issues are the subject of study two and are discussed in chapter 5.
4.4 Results of the 2009 COPD Data

The data yielded a total number of 1,681 COPD cases over a year period. Table 4.2 provides a demographic summary of the cases.

Table 4.2 Summary of Patient Characteristics

<table>
<thead>
<tr>
<th>Summary of Patient Characteristics</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>859</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>822</td>
<td></td>
</tr>
<tr>
<td>Median Age</td>
<td>74</td>
<td></td>
</tr>
<tr>
<td>Average Age</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Age Range</td>
<td>23 – 101</td>
<td></td>
</tr>
<tr>
<td>0-45 years of age</td>
<td>45</td>
<td>2.70%</td>
</tr>
<tr>
<td>45-65 years of age</td>
<td>400</td>
<td>23.80%</td>
</tr>
<tr>
<td>65+</td>
<td>1236</td>
<td>73.50%</td>
</tr>
</tbody>
</table>

Calls to the service

For the same period of time, 76% of all calls made to the OOHs service were made up of self-referrals or a parent or guardian calling on behalf of a child (42% & 34% respectively) the other 24% were made up of district nurses, ambulance services, friends and neighbours of patients. It is an indication of the dependency of COPD patients on others to assist in managing their care that self-referrals make up only 32.4% of the calls and the other 67.6% come from family members, neighbours or district nurses as seen in table 4.3. Daughters (18%) are the most common category of caller on behalf of COPD patients. The evidence throughout the consultations is that patients are depending on family members when they call. For example, as documented by the telephone triage nurse: “Daughter visiting patient, as per daughter, patient is “in bad shape and has gone downhill” since last visit”.


Table 4.3 COPD patients contacting the OOHs service

<table>
<thead>
<tr>
<th>COPD Patients Contacting the OOHs Service</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact made by the patients themselves</td>
<td>544</td>
<td>32.4%</td>
</tr>
<tr>
<td>Contact made by another person on behalf of the patient</td>
<td>1137</td>
<td>67.6%</td>
</tr>
</tbody>
</table>

The calls are assigned an initial priority by call handlers before the full telephone triage assessment by the nurse. After the nurse assessment, calls are prioritised by the telephone triage nurse as requiring an emergency, urgent or routine consultation by the doctor on duty, table 4.4. For COPD cases 62.2% were prioritised as urgent or emergency cases. For the COPD patients who receive a home visit, 83% of the initial contacts were made by someone who is not the patient; this may reflect the severity of the case.

Table 4.4 Priority after nurse assessment

<table>
<thead>
<tr>
<th>Priority After Nurse Assessment</th>
<th>Emergency</th>
<th>Urgent</th>
<th>Routine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor Advice</td>
<td>1</td>
<td>0.1%</td>
<td>47</td>
</tr>
<tr>
<td>Home Visit</td>
<td>109</td>
<td>7.3%</td>
<td>548</td>
</tr>
<tr>
<td>Treatment Centre</td>
<td>19</td>
<td>1.3%</td>
<td>209</td>
</tr>
</tbody>
</table>

Case outcomes
As seen in table 4.5 The type of intervention received by patients indicates that most COPD patients require a face-to-face consultation (home visit or treatment centre visit) with a doctor (87.1%), with most of these consultations taking place where the patient resides (home visits 56.9%). This is an indication of how ill patients are that telephone the service with COPD as their main complaint. Although these patients receive a home visit consultation from a doctor, 23% (220 patients) still required additional referral to hospital.

In comparison to the COPD cases, only 10.7% of all other patients using the OOHs
As described in the triage nurse assessment or doctor consultation data fields, when a patient has been assessed and consulted by a doctor, a recommendation of referral to hospital by ambulance or by their own transport is reached. In some instances the patient refuses the ambulance and admission to hospital, as seen in table 4.6, of the

<table>
<thead>
<tr>
<th>Case Type</th>
<th>Gender</th>
<th>Total for COPD Cases</th>
<th>Overall Cases for same time period</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F</td>
<td>M</td>
<td></td>
</tr>
<tr>
<td>Doctor Advice</td>
<td>50 (6.1%)</td>
<td>46 (5.4%)</td>
<td>96 (5.7%)</td>
</tr>
<tr>
<td>Home Visit</td>
<td>442 (53.8%)</td>
<td>515 (60.0%)</td>
<td>957 (56.9%)</td>
</tr>
<tr>
<td>Nurse Advice</td>
<td>50 (6.1%)</td>
<td>71 (8.3%)</td>
<td>121 (7.2%)</td>
</tr>
<tr>
<td>Treatment Centre</td>
<td>280 (34.1%)</td>
<td>227 (26.4%)</td>
<td>507 (30.2%)</td>
</tr>
<tr>
<td></td>
<td>822</td>
<td>859</td>
<td>1681</td>
</tr>
</tbody>
</table>

The male and female patterns of care are very similar, however the percentage of females seen at a treatment centre is higher than males, and males are more likely to receive a home visit.

**Referral onward to hospital**

As described in the triage nurse assessment or doctor consultation data fields, when a patient has been assessed and consulted by a doctor, a recommendation of referral to hospital by ambulance or by their own transport is reached. In some instances the patient refuses the ambulance and admission to hospital, as seen in table 4.6, of the
370 patients referred to hospital, 77 refused to attend with a further 21 refusing to go but there was no other alternative for the GP or nurse but to send them on to hospital. Specifically within the home visit category, of the 957 people that received a home visit, 274 were referred onwards to hospital. Of those patients who refused, 54 stayed in their own home while 17 were referred onwards to hospital as there was no alternative treatment option available for the patient or the GP to consider.

Table 4.6 COPD Cases referred to hospital but refusing to attend

<table>
<thead>
<tr>
<th>Case Type</th>
<th>Patients who stayed at home</th>
<th>Patients who attended hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not referred to hospital</td>
<td>Referred but refused to attend</td>
</tr>
<tr>
<td>Doctor Advice</td>
<td>81</td>
<td>3</td>
</tr>
<tr>
<td>Home Visit</td>
<td>683</td>
<td>54</td>
</tr>
<tr>
<td>Nurse Advice</td>
<td>48</td>
<td>1</td>
</tr>
<tr>
<td>Treatment Centre</td>
<td>422</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>1234</td>
<td>77</td>
</tr>
</tbody>
</table>

**Exacerbations of COPD**

In the data the numbers of male and female COPD patients are very similar. However male COPD callers were more likely than females to be identified and documented by the triage nurse or doctor as suffering from an exacerbation. Of the exacerbations 60.3% of males were referred onward to hospital for further treatment compared to 39.7% of females, as demonstrated in tables 4.7 and 4.8.
Table 4.7 Exacerbations of COPD

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number of COPD Patients without Exacerbations</th>
<th>Number of COPD Patients with Exacerbations</th>
</tr>
</thead>
<tbody>
<tr>
<td>F (48.9%)</td>
<td>685</td>
<td>137 (44.3%)</td>
</tr>
<tr>
<td>M (51.1%)</td>
<td>687</td>
<td>172 (55.7%)</td>
</tr>
</tbody>
</table>

Table 4.8 Patients' referred to hospital with Exacerbation of COPD

<table>
<thead>
<tr>
<th></th>
<th>Exacerbation not referred to Hospital</th>
<th>Exacerbation referred to Hospital</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>108 (45.8%)</td>
<td>29 (39.7%)</td>
<td>137</td>
</tr>
<tr>
<td>Male</td>
<td>128 (54.2%)</td>
<td>44 (60.3%)</td>
<td>172</td>
</tr>
<tr>
<td>Total</td>
<td>236</td>
<td>73</td>
<td></td>
</tr>
</tbody>
</table>

Contacts with other Healthcare services

124 of COPD cases had been discharged from hospital within the previous one week with a problem relating to their COPD condition. 187 patients had a consultation with a GP for their COPD with 9 patients having been in hospital and had a consultation with a GP in the previous week.

Comorbid Conditions

1,098 (65.3%) of the COPD cases had co-morbid conditions documented in the OOHs database. The real percentage is undoubtedly higher. The pie chart documents the number of additional comorbid conditions; i.e. COPD + 1 extra.
The comorbid conditions ranged across a broad number of illnesses including various heart problems, diabetes, epilepsy, anxiety, depression, Alzheimer’s, various cancers, kidney problems and on a smaller scale, Parkinson’s, blood disorders and special needs. Of the 65.3% of patients with comorbid conditions, figure 4.1 demonstrates the percentage breakdown of these patients and the number of additional comorbid conditions they have e.g. 2% of patients have COPD and 5 or more additional comorbid conditions.

**Figure 4.1 Breakdown of patients with COPD and additional comorbid conditions**

There were 46% more ambulances ordered and 137% greater number of COPD patients readmitted to hospital for those with documented comorbid conditions compared to those without as seen in tables 4.9 and 4.10.

The patients documented with comorbid conditions are undoubtedly higher than documented for this study as the nature of an OOHs service means that the presenting symptoms of the patient are dealt with as they arise, and so comorbid conditions may not be mentioned during OOHs consultations.
Table 4.9 Ambulance ordered for patients

<table>
<thead>
<tr>
<th></th>
<th>Co-morbid documented</th>
<th>Co-morbid not documented</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Ambulance ordered</td>
<td>1,009</td>
<td>522</td>
</tr>
<tr>
<td>Ambulance Ordered</td>
<td>89</td>
<td>61</td>
</tr>
</tbody>
</table>

Table 4.10 Patient readmission to hospital

<table>
<thead>
<tr>
<th></th>
<th>Co-morbid documented</th>
<th>Co-morbid not documented</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Readmission to Hospital</td>
<td>1,079</td>
<td>575</td>
</tr>
<tr>
<td>Readmission to Hospital</td>
<td>19</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 4.11 is a complete summary of the COPD cases and statistics.

Table 4.11 Summary of COPD statistics

<table>
<thead>
<tr>
<th>Summary of Statistics</th>
<th>Total</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Number of Ambulances Ordered</td>
<td>151</td>
<td>9.0%</td>
</tr>
<tr>
<td>Total Cases sent to A&amp;E</td>
<td>377</td>
<td>22.4%</td>
</tr>
<tr>
<td>Readmission to Hospital</td>
<td>27</td>
<td>1.6%</td>
</tr>
<tr>
<td>Declined Ambulance</td>
<td>59</td>
<td>3.5%</td>
</tr>
<tr>
<td>Declined Hospital</td>
<td>130</td>
<td>7.7%</td>
</tr>
<tr>
<td>Home from hospital within previous week</td>
<td>133</td>
<td>7.9%</td>
</tr>
<tr>
<td>For A&amp;E if no improvement</td>
<td>46</td>
<td>2.7%</td>
</tr>
<tr>
<td>Exacerbations</td>
<td>308</td>
<td>18.3%</td>
</tr>
<tr>
<td>Exacerbation and with own GP previous week</td>
<td>30</td>
<td>1.8%</td>
</tr>
<tr>
<td>With own GP previous week</td>
<td>196</td>
<td>11.7%</td>
</tr>
<tr>
<td>Follow up with own GP next 2-3 days</td>
<td>316</td>
<td>18.8%</td>
</tr>
<tr>
<td>Documented Co-morbid conditions</td>
<td>1098</td>
<td>65.3%</td>
</tr>
<tr>
<td>Total Number of COPD Cases</td>
<td>1681</td>
<td>100%</td>
</tr>
</tbody>
</table>
Alternative healthcare setting to hospitals

At the time the data was extracted for the study, there was no alternative to hospital if a patient had deteriorated to a certain stage. With the innovation of community intervention teams, there is now an option for suitable patients to be cared for in their own home, while receiving the treatment that usually would have required hospitalisation[56-58].

An investigation of the records of a subset of the COPD cases that required referral to hospital found that 43% of the random calls analysed would have been suitable for an intervention and support within the community setting and could have avoided hospital admission. The criteria for selection are determined by a set of clinical exclusion and inclusion criteria that are applied to a patient by the referring clinician to ensure they are clinically suitable for treatment in the community.

Discussion

The COPD patients contacting the OOHs service are generally very sick patients who require resource intensive episodes of care. There are patients, who refuse hospital when advised by the nurse that they require treatment in hospital, which go on to have a home visit consultation with the duty doctor and still require hospitalisation. In these instances, some patients still refuse to go to hospital and the GP leaves an admission letter with the patient or their carer for A&E at a later date if required. In one instance the patient stated “does not want to go to hospital, has been there 17 times in the last 2 years”. Also patients who have seen their own GP within the previous week still require OOHs care. This can be attributed to the nature of the illness as patients can deteriorate quickly.

When patients do make contact with the OOHs service, 62.2% of cases have already reached an urgent or emergent status and require immediate intervention from a nurse or doctor. There is a case for patients with COPD to be managed through
preventative programs when a deterioration in their condition is identified before the patient requires emergency doctor intervention or hospitalisation.

Patients lose independence when in hospital and with the average for COPD patients of around 8.3 days per hospital stay, the focus on patient empowerment and education in their own home and the community setting cannot be underestimated.

The number of COPD patients contacting the service for themselves is only 32.4%. There are a large number of patients that rely on family and carers to support them. The patient does not seek medical attention for themselves which can lead to an exacerbation of their condition as they do not realise how that have deteriorated because they are living with the COPD.

In some instances, patients move from one healthcare setting to another without resolving the problem – e.g. stay in hospital, consultation with own GP, consultation with OOHs doctor and referral back in to hospital.

The percentage of patients over 65 (75.3%) is in line with global trends and the rise of chronic disease. A more suitable setting than hospital is required to treat patients with COPD and to educate, empower and motivate patients to engage and manage their own medical conditions. With the advent of community intervention teams this is now possible, as the focus is caring for patients in the community setting and away from the hospital setting; there is now an option to keep COPD patients in their own home and not refer them onward to hospital. As there are patients refusing ambulances and admission / readmission to hospital, this would provide a more suitable care setting for these patients, while also reducing hospital admission rates.

The evidence from this study suggests that patients with COPD are resource intensive users of OOHs services and require support from family members and carers. There is the potential for community intervention teams and preventative monitoring to impact these patients and increase their overall health and wellbeing as their symptoms would be identified before exacerbation or before they required an emergent or urgent consultation.
4.5 Findings

The aim of study one was to investigate if the data quality within the OOHs service database was sufficient to describe the pattern of healthcare usage of patients in the OOHs setting using COPD to explore the data. This is part of the assessment phase of the TIQM methodology where samples of data were extracted to measure and interpret data quality while also successfully demonstrating that routinely collected data could contribute to the patterns of care and understanding of patients with specific healthcare needs. As described in section 2.7, although there is not a complete data set available for COPD, there was enough information to analyse and produce substantial information based on the OOHs data. This is a large contribution to health services research as this information was not previously known. Consequently there is more known about COPD and also it is now known that OOHs data can be used to investigate patterns of care for chronic diseases.

This research successfully explores the current pathway of care for patients with the chronic condition COPD, and discovers how patients with COPD currently use health care services. One of the most important aspects to delivering quality healthcare is the availability of correct patient information at the correct time. If clinicians have up-to-date patient information to hand, they can have a more complete picture of the patient needs and a more in-depth understanding of the patient’s condition[59].

The information provides valuable data on how patients are treated and how they move through services. The information can be used to inform policy and decision makers who are charged with delivering healthcare services for patients. It has a massive potential to contribute to health services research and the future design of services.

Although the preceding information gives a unique view of the patient journey through an OOHs service, the extraction of the data was problematic and time
consuming. It was labour intensive and exposed the poor data quality within the database.

**Chapter 5: Improving data quality collection**

This chapter is the improvement management and monitoring phase of the research. It examines the issues arising from the routinely collected data that were identified in chapter 4 when examining the data. This chapter discusses the aspects and dimensions of data quality this research addresses and proposes a solution to improve the quality of the data collected. This is part of the assessment phase of TIQM as discussed in section 2.4, figure 2.2. The chapter firstly describes the data used and the context of the data quality dimensions. It then discusses the data documented within the OOHs database and the specific analysis carried out on this data.

### 5.1 Research Data and Data Quality

The data from study one presented in chapter 4 was extracted from the Caredoc OOHs database. Study one successfully addresses the aim “if routinely collected OOHs data in its current format can contribute to a better understanding of health services usage among patients”. Study two examines the quality of the data collected. The data captured is both specific data items and free text. Specific items are patient demographic details and information relating to the patient’s own GP. The information is in a structured, pre-populated defined format or unstructured, free text boxes.

The OOHs data used for this research is fit for its intended purpose in the OOHs setting and the data quality is adequate for the purpose for which it is gathered. Clinicians are reading the data and can interpret spelling mistakes; however when searching for research purposes, identifying this data is difficult.

As discussed in section 4.3, while there is a wealth of information available, searching this data is time consuming and difficult. The data must first be searched, filtered and
streamlined by someone working within the service who understands the data before it is suitable for external researchers.

However, with significant data cleaning and effort, even in its current format the data from study one has provided an insight into patient’s patterns of care which did not exist before. In some instances, patients have recently been discharged from hospital, have had a GP consultation the same day, then require treatment in the out-of-hours setting and are referred back in to hospital as described in section 4.4. This type of information was not known before.

Doctors and nurses record the information that is pertinent to their current consultation. In some instances that may include recording specific chronic diseases or allergies or relevant past medical history. However, if it is not relevant to the current patient complaint, it may not be documented. The database is a very rich source of data, but it is not always easy to navigate or identify the data required.

The documentation of diseases and symptoms is also unique to each doctor and nurse. When documenting a condition like an exacerbation of chronic obstructive pulmonary disease (COPD) for example, clinicians may document it as: “exac. COPD”, “exacerbation COAD” or “exac chronic obstructive pulmonary disease” where punctuation can make a difference to the search terms. There is also a problem with the spelling of certain conditions, where clinicians are typing and not reviewing what they type leading to simple spelling errors e.g. chonic obstrctuve pulmonary diease or exacerbabation. A researcher must always be aware of these potential problems.

There is a need to understand the patterns of care for patients with chronic diseases in the primary care setting. In the absence of a unique identifier, out-of-hours services data can provide a piece of that research puzzle. Between the telephone triage nurse assessment and doctor consultation, the movement of patients between healthcare services is documented.
Searching for the data and identifying cases is complex. The descriptors used for the fields collected need to be understood. The field names need to be dealt with in context and in line with national guidelines[23]. This is only one of the problems of interpreting the data collected within the databases. As discussed in section 2.2 and 2.3 data quality is interpreted specific to particular studies by each individual. A clear description and interpretation of what dimensions of data quality are being examined are essential to give context and understanding to a study.

“Guiding Principles for National Health and Social Care Data Collections” published by the Health Information and Quality Authority identify that it is difficult to follow the pathway of an individual patient in the absence of a unique identifier since data gathered in Ireland is gathered in silos and is not shared between healthcare services. By designing a more reliable and valid way of collecting data, the research can contribute to National health and social care data[26].

5.1.1 Data documented and captured within the OOHs database

Below, table 5.1, is an extract of the “received symptoms” as documented by the call taker, the “triage consultation” as documented by the triage nurse and the “doctor consultation” as documented by the consulting GP. The cases are extracted from the 2009 Caredoc OOHs database. This extract demonstrates the information documented by the call takers, nurses and doctors. Any information contained in the record is articulated by the patient and is not a comprehensive record of the patient’s medical history.

Table 5.1 Sample data captured from the OOHs database

<table>
<thead>
<tr>
<th>Information Documented by the Call Taker Details</th>
<th>Information Documented by the Telephone Triage Nurse</th>
<th>Information Documented by the Consulting Doctor</th>
</tr>
</thead>
</table>

51
<table>
<thead>
<tr>
<th>dose of flu, cough.</th>
<th>as per pt pt has flu with cough not sleeping at night no illness no meds nkda app carlow base @ 13.50</th>
<th>Cough for week, dry No sore throat or fever Cough getting him up T 37 ENT pharyngitis BP 138/80 CHEST hyperinflation heavy smoker, no rhonchi or creps ABD non tender CNS nad URTI -- COPD Alupent Singulair Vibramycin 1000 bd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pt has chest infection</td>
<td>cough, productive, no temp, hx asthma, no breathing problems, no rash, no chest pain, NKA, appt Waterford</td>
<td>Diag: Exacerbation of COPD TX: Hydrocortisone 100mg Ipramol 5mg neb given Clorom 500mg bd x 1/52</td>
</tr>
<tr>
<td>Said he had visit from Dr. ** this a.m. Advice re. warfarin. Very breathless and said Dr. ** know his condition.</td>
<td>hx copd, a fib Dr *** was just with pt, says he changed his Warfarin dose, but pt cannot remember what he said, last INR 2.4 alternating 4/5mg. contacted Dr ***. he will contact pt himself.</td>
<td></td>
</tr>
<tr>
<td>asthmatic, bad cough - came into chemist and they told him to see the caredoc</td>
<td>as per pt. c/o cough/ wheezy x 2 days. no temp. pmhx: asthma. copd. appt 15.50</td>
<td>COAD with bronchitis and spasm Combivent nebulizer pt</td>
</tr>
<tr>
<td>Emphysema - in bed</td>
<td>Past history: C.O.P.D., on nebs and home oxygen, nkda, on a lot of meds, now c/o unwell since xmass, weak, SOB, foamy white sputum, home vist arklow</td>
<td>COPD LRTI. Deltacortril 30mg Augmentin Duo Pulmicort respules Follow up own gp</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Suffering with chest, on nebuliser which does not seem to be working, a lot of phlegm</td>
<td>Speaking with daughter in law. 68 yr- coughing. pmx-breathing. meds- inhalers/aspirin. nkda. appt waterford.</td>
<td>Diag: Exac of C.O.P.D. TX: pred 30mg 3/7. Clavamel tid. Review with own gp</td>
</tr>
<tr>
<td>Spoke to *** earlier and would now like for the doctor to call out to ****</td>
<td>As per dtr ’ confused talking to himself all day seen yesterday, advised A/E but would ’nt go exhausted ’ might go to hospital if Dr*** sees him Home Viist PLease Gorey</td>
<td>Patient extremely sob, sianotic on o2. very stubborn to go to hospital, convinced him in end worsening copd referral to hospital</td>
</tr>
<tr>
<td>Chest infection, breathing difficulty</td>
<td>As per wife, HX: Cancer prostate and bone, also heart problems, recent hospital admission for chest infection, breathing seems laboured, Nka, urgent home visit please</td>
<td>Chronic obstructive pulmonary disease and CLF augmentin duo 1000 Uniphyllin ? for A&amp;E if not improvement</td>
</tr>
</tbody>
</table>

Table 5.2 displays an extract of the structured fields from the same database, captured at the call taking stage; they are
- gender
- date of birth
- call origin – who placed the call (the patient or someone on behalf of the patient)
- case type (what type of consultation took place)
- priority on reception (the priority of the case assigned by the call taker)
- priority after assessment (the priority of the case after assessment by the triage nurse)
- informational outcome (indicates if the call was completed or if the patient was referred on for further consultation).

When a case is completed, the case type is set to nurse advice, doctor advice, treatment centre or home visit. An “informational call” type is also available and this reflects approximately 2% of the calls to the service. This call type is allocated to patients who ring looking for a service in a different area or directions to a treatment centre.

The priority of the episode of care is attached to each case. This includes the priority given to the case by the call taker, and the priority given after a complete nurse triage assessment.

The clinician (telephone triage nurse (TTN) or doctor) must add an “informational outcome” to each case type. This is used for key performance indicators and general statistics. The “informational outcomes” the clinicians have available are; consultation completed, patient deceased, ambulance arranged, patient referred to A&E and Non A&E – Direct hospital referral.

Table 5.2 Sample extract of the structured fields

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Case Type</th>
<th>Call Origin</th>
<th>Priority On Reception</th>
<th>Priority After Assessment</th>
<th>Informational Outcome</th>
</tr>
</thead>
</table>
Within the Adastra call management system, there is a colour scheme to not only alert users to the urgency of the call, but also to the different types of calls. For example, notification of patients who are deaf or hard of hearing (figure 5.1) or notification when a call is a home visit or doctor advice (figure 5.2). This alerts the nurse, doctor, receptionist or drivers to the type of each call.
5.1.2 Interpreting the data in the OOHs databases

Searching for the data and identifying cases is complex as discussed above. The descriptors used for the fields collected within the software system need to be understood. The field names need to be dealt with in context. This is only one of the problems of interpreting the data collected within the databases.

For example, within the OOHs database, all calls are assessed by a nurse and are given some amount of nurse advice. These cases can be completed by nurse advice or sent for further consultation with a duty doctor, or referred on to hospital. However within the system the “case type” descriptions of completed calls are: nurse advice, doctor advice, home visit or treatment centre.

The “informational outcomes” (consultation completed, patient deceased, ambulance arranged, patient referred to A&E and Non A&E – Direct hospital referral) indicate if the case was completed or referred on for further consultation. The case could be ended as nurse advice and consultation complete, or nurse advice and patient referred to A&E.
As seen in table 5.3 below, the case completed as nurse advice may also have a follow up informational outcome as ambulance arranged. The possibilities are tabulated below.

Table 5.3 Possible combinations of outcomes for cases completed in Adastra System

<table>
<thead>
<tr>
<th>Informational Outcome</th>
<th>Nurse Advice</th>
<th>Doctor Advice</th>
<th>Home Visit</th>
<th>Treatment Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation complete</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Patient deceased</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Ambulance arranged</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Patient referred to A&amp;E</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Non A&amp;E – Direct hospital referral</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

5.1.3 Using the Data for Research purposes

While the data can currently be used for research, it is incredibly time consuming and requires an intimate knowledge of how the OOHs service works and how the data is interpreted. This does not lend itself well to widespread research or using the data within the system for easy extraction or expedient learning for specific patient groups or diseases.

5.2 Analysing the Data Quality Dimensions

As discussed in section 2.2, 2.3 and 2.4, specific dimensions of data quality can be considered and improved to enhance a database for secondary use of research. However, there are a number of dimensions and each offer different meanings to the context of certain studies. For the purpose of this research, the national Irish Health Information and Quality Authority dimensions of data quality are used as a reference point to ensure consistency of measurement.

As referenced in section 2.3 these dimensions are
Addressing each of the dimensions in reference to the findings of study one, there are clear dimensions that are appropriate to assess and some that are not relevant to the data held in the OOHs service database.

The information is documented in an electronic patient record, therefore legibility from a reading what was written perspective was not a problem. However legibility, as shown in 5.1, was a problem from an abbreviations and spelling perspective. There is no duplication in the documenting of the record i.e. written on paper and then transcribed to electronic record, so there is no valid way of testing accuracy without access to another source of information e.g. in-hours GP record or interview with a patient. However as the primary use of the data requires a high level of accuracy there is no reason to believe that the accuracy should be an issue for the secondary use of research. All information is documented at the time of interaction with the patient in an electronic format. The validity of the data was not examined as any validation checks in the software are completed at the time of documentation. As the data is being used for research, the timeliness was not a factor; the data required was already collected.

Relevant data “meets the needs of the information users”[31]. This is harder to determine from a research perspective as the information documented in the OOHs service is relevant to the current consultation taking place and the primary focus of the data. The data is relevant for the primary function, but may not be relevant for research. Taking this in to account, it is not practical to try and improve or measure this as it would require a substantial change to the service and the information
gathered and held which has consequences in terms of data protection, i.e. why are you gathering and storing this information?, and as a result is not a goal of this research.

The two most appropriate dimensions to examine for this study based on the results of study one are reliability and completeness, see table 5.4. These could be addressed with a view to improving the data quality for the secondary use of research without comprising or impacting on the service or the users of the electronic patient record system that document the data. As the research aspect is an ancillary use of the data, it is important that any quality improvement be smoothly introduced and not impact work practices [10, 11].

Table 5.4 Dimensions of Data Quality for this research

<table>
<thead>
<tr>
<th>Dimension of Data Quality</th>
<th>Appropriate for assessment based on findings of study 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete</td>
<td>Yes</td>
</tr>
<tr>
<td>Legible</td>
<td>No</td>
</tr>
<tr>
<td>Relevant</td>
<td>No</td>
</tr>
<tr>
<td>Reliable</td>
<td>Yes</td>
</tr>
<tr>
<td>Timely</td>
<td>No</td>
</tr>
<tr>
<td>Valid</td>
<td>No</td>
</tr>
<tr>
<td>Accurate</td>
<td>No</td>
</tr>
</tbody>
</table>

As discussed in section 2.3, Reliable data is “collected consistently over time, whether manually or electronically” [31]. Given the nature of OOHs services and the number of users working within the system, consistently collecting data when it is free text relies on each user conforming to a particular set of guidelines or a template. This is currently missing in the OOHs setting. Users may document the same medical condition in a number of abbreviations, formats or spellings.

Complete data “has all those items required to describe or measure the intended activity or event” [31]. All the relevant information pertaining to a patients’ episode of care should be contained within the electronic record. This study investigated how complete the data was within the current electronic record pertaining to COPD cases.
Under the dimension of reliability, the data was analysed to find trends between the users and how notes are documented. The main problem with the OOHs data is that each user documents patient conditions, diseases, medication, treatment, diagnosis etc in different ways. Approximately 400-500 cases are recorded on a Monday – Friday, with approximately 1,200 – 1,500 cases recorded every Saturday and another 1,200 – 1,700 cases each Sunday, Bank Holiday Mondays or busy periods throughout the year i.e. Christmas, New Years and Easter.

On a given evening shift or weekend shift there are approximately 45 – 65 different users per shift[36]. As a result there is absolute no consistency of documenting free text.

5.3 Assessing the Data under specific Data Quality Dimensions

To assess the reliability and completeness of the data a qualitative approach was taken. Based on the data extracted from study one, when all the records were identified that would be included for COPD patients, a thorough analysis of the three fields containing the free text information, ReceivedSymptoms, Diagnosis_Outcome, and TriageNotes, as described in section 3.3.1, was carried out. This involved analysing and documenting how the data was currently presented for research purposes and the problems arising from this.

After reviewing the 1,681 COPD cases to identify the trends in the data, it was clear that a number of chronic conditions are documented in the patients’ record along with the main symptom or problem that they are looking for assistance with at a particular time.

In the free text fields from the data, 80 documented conditions were identified that ranged from frequently used to rarely used. This is not the only instance of reliability throughout this data, put for the purpose of this study the medical conditions of patients were focussed on for this study. Other spelling mistakes exist for medications
and general spellings but medical conditions were chosen as for future studies if a medical condition can be identified more easily, it will enhance the research data. Each of these conditions had spelling problems throughout the records. Even though some appear straight forward and simple to spell, when they are being documented on a busy day, they are misspelled.

Although this list in table 5.5 is not exhaustive, it gave a starting point to address how the data quality could be improved. An exhaustive list was impractical due to the large number of conditions and abbreviations.

**Table 5.5 List of medical conditions**

<table>
<thead>
<tr>
<th>Abdominal Aneurysm</th>
<th>Cellulitis</th>
<th>Gastric Problems</th>
<th>Osteoarthritis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>Cholesterol</td>
<td>Glaucoma</td>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>Choleystitis</td>
<td>Guilliene Barrie Syndrome</td>
<td>Padgets Disease</td>
</tr>
<tr>
<td>Amputee</td>
<td>Cirrhosis</td>
<td>Hemochromatosis</td>
<td>Pancreatitis</td>
</tr>
<tr>
<td>Anaemia</td>
<td>Coeliac</td>
<td>Hip Operation</td>
<td>Parkinson’s</td>
</tr>
<tr>
<td>Angina</td>
<td>Cognitive Impairments</td>
<td>Hypertension</td>
<td>Peg feeding</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Confusion</td>
<td>Hypothyroidism</td>
<td>Peripheral neuropathy</td>
</tr>
<tr>
<td>Aortic Stenosis</td>
<td>COPD</td>
<td>Hysterectomy</td>
<td>Psychiatric Problems</td>
</tr>
<tr>
<td>Arthritis</td>
<td>Deaf</td>
<td>IG deficiency</td>
<td>PVD</td>
</tr>
<tr>
<td>Asthma</td>
<td>Delirium</td>
<td>IHD</td>
<td>Renal Failure</td>
</tr>
<tr>
<td>Atrial Fibrillation</td>
<td>Dementia</td>
<td>Kidney Failure</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>Bi polar</td>
<td>Depression</td>
<td>Korsakoff’s syndrome</td>
<td>Sheehan’s</td>
</tr>
<tr>
<td>Bilateral leg ulcers</td>
<td>Diabetes</td>
<td>Lupus</td>
<td>Special Needs</td>
</tr>
<tr>
<td>Blind</td>
<td>Diverticulosis</td>
<td>Lymphedema</td>
<td>Spine Bifida</td>
</tr>
<tr>
<td>Blood Disorder</td>
<td>DVT</td>
<td>Ménière's</td>
<td>Splenectomy</td>
</tr>
<tr>
<td>Brain atrophy</td>
<td>Dysphagia</td>
<td>MI</td>
<td>Stroke (CVA)</td>
</tr>
<tr>
<td>CABG</td>
<td>Emphysema</td>
<td>MRSA</td>
<td>Thyroid</td>
</tr>
<tr>
<td>Cancer</td>
<td>Epilepsy</td>
<td>MS</td>
<td>Umbilical hernia</td>
</tr>
<tr>
<td>Cardiomyopathy</td>
<td>Falls</td>
<td>Musco-skeletal</td>
<td>Vertigo</td>
</tr>
<tr>
<td>CCF</td>
<td>Gallstones</td>
<td>Oesophageal</td>
<td>Womb Prolapse</td>
</tr>
</tbody>
</table>
All of these conditions had numerous spellings and abbreviations. This final list was agreed upon with the clinical and nursing team as the most common way to document the condition.

If a common dictionary was available to all users to select these options from a list it would ensure that future searching of the data would be uniform and eliminating spelling errors would reduce the potential to miss records that could be included for research on specific conditions. This would contribute to improving one aspect of the reliability of the data.

Under the dimension of completeness, the data was analysed for completeness in relation to what was documented by the users for the patients’ specific episode of care. This one aspect of completeness was chosen based on study one and the ability to correctly identify all COPD cases. In most instances, if a patient was identified with COPD, it may have only been documented in one of the free text fields. If this was the call taking field, the nurse and doctor can read the free text. If it is not documented by the call taker or the nurse, the doctor may deal with the case and document it in the consultation notes. The data is incomplete when COPD is not documented in any of the fields through error or omission or is documented incorrectly e.g. spelling.

From a research perspective, a thorough search of all the documented free text must be completed and as previously mentioned, the volume of cases does not lend itself to extensive searching without being extremely time consuming. Each field must be searched to ensure a complete and thorough exploration has been accomplished.

To eliminate this tedious and time consuming process, a way of identifying COPD cases from the outset would be preferable. This would ensure that all COPD cases were identified immediately without the requirement of extracting all records for a particular time period, and then searching those records for COPD cases. If the COPD cases were identified from the outset, this would ensure only the relevant cases were exported for research purposes. Quantitative data on the extent of incompleteness and unreliability in data extracted for study one are presented in section 6.4.2.
5.4 Findings

The data quality for the secondary use of the OOHs data for research purposes in its current format is poor as it contains incomplete and unreliable data. Based on this incomplete and unreliable data, it is time consuming and requires a thorough knowledge of the OOHs service and an understanding of how the information is documented before it is usable for research purposes.

This study is part of the assessment phase of the TIQM methodology where the extracted data is analysed for quality.

Notwithstanding, this can be improved by designing and implementing enhancements to the data collection process to facilitate a more user friendly way of exporting and reporting on the required data for specific research purposes.
Chapter 6: Implementation and evaluation of an enhancement to data quality and collection

This chapter describes the proposed enhancements to address the issues discussed in chapter 5 and how it will be integrated into the work flow of the OOHs service to improve the data quality. The chapter also describes the implementation and the evaluations of these enhancements. This is part of the improvement phase and the improvement management and monitoring phase of TIQM as discussed in section 2.4, figure 2.2.

6.1 Introduction

Chapter 5 identified two enhancements to improve the data quality and collection of OOHs data in this research setting. To improve the reliability of the data, an enhancement to create a single dictionary of 80 identified medical conditions is proposed. To improve the completeness of the data an enhancement to ensure COPD cases are complete within the OOHs data is proposed.

6.2 Design of solution to improve data quality

Two enhancements are proposed to address components of the reliability and completeness dimensions of data quality. After thorough research in to the electronic patient record system in its current format, there were a limited number of options available that would benefit the users without disrupting their workflow completely. Solutions were identified that had the least impact on the users of the system, were the most cost effective and least time consuming i.e. did not require development work on behalf of the applications supplier or an investment by the OOHs service.
The enhancements were presented to, discussed in detail and agreed with the clinical and nursing management team in the OOHs service.

6.2.1 Enhancing the reliability of data quality

In the first instance, 80 identified medical conditions were included as options for users to select from a list thus improving the consistency of spelling and terminology used. This enhancement was created by using a drop down list in alphabetical order of the 80 words that were selectable by the user when using the free text fields.

There were 4 identified fields within the electronic patient record system where the free text drop down list would be utilised. The fields identified were:

1) Call taking: Received Symptoms
2) Online Clinician – Nurse Telephone Triage – Notes
3) Nightingale Teleguides – Nurse Telephone Triage – Current consultation – History
4) Doctor Consultation – Current Consultation – History

as shown in figure 6.1 below.

This enhancement allows the nurses to select the correct spelling and abbreviations for medical conditions thus improving the search ability when looking for specific conditions. This should improve the reliability of searching for particular diseases within the EPR. This could benefit future research as diseases should be correctly identifiable from the patients EPR.
6.2.2 Enhancing the completeness of data quality

To address the issue of completeness in the data when trying to identify a specific condition, a “COPD” button was introduced to the workflow. The aim of the COPD button was to ensure that all the appropriate cases are identified as a COPD case without having to rely on searching through free text fields to ensure all cases are identified. When a patient telephones the service with a complaint about COPD the call handler, the telephone triage nurse or the consulting doctor can indicate that this is a COPD cases by clicking on this button, see figure 6.2.

Four screens within the electronic patient record system were identified

1) Call Taking – Case Entry Screen
2) Nurse Telephone Triage – Online Clinician Screen
3) Nurse Telephone Triage – Nightingale Teleguides Screen
4) Doctor Consultation – Current Consultation Screen
This identifies a COPD case immediately in the database and eliminates the need to extract all the cases for a time period and then search through those cases to identify the required COPD cases. If this button works for COPD, it can be used for other research and identifying other cases.

**6.3 Implementation**

After the enhancements were agreed with the clinical and nursing management teams, the process to embed them into the users’ workflow began. The complete list of 80 medical conditions was added in to the free text boxes identified. The COPD identifier was added in to 4 screens identified.

All relevant users of the system were informed of the change via email and hand outs were made available to staff members as they arrived on duty. The instructions explained the purpose of both the COPD button and the drop-down list and how to use both. Training was not provided to each user. The researcher was on site for the initial roll out of the enhancement to answer questions and introduce staff to the change. To target all the staff members was difficult as the staff work shift patterns and are not necessarily working for a number of days.

**6.4 Evaluation**

Three aspects of the enhancement were evaluated.
1) From a quantitative perspective: Is the information easier to extract and report on?
2) From both a quantitative and qualitative perspective: Has the data quality improved?
3) From a qualitative perspective: Did the enhancement affect the workflow of those collecting and documenting the data?

6.4.1 Evaluation One

The researcher extracted all the relevant COPD cases that had been identified with the new COPD button. To ensure the method worked, the researcher compared this to the old method of extracting all the cases for a three week post-intervention time period and searching through the free text fields using if statements and qualitative methods to ensure that no cases had been missed as described in section 3.3.1.

The COPD button was successful at extracting the relevant COPD cases. The new method of extracting the cases involved running a report to successfully identify that the COPD button was clicked and assigned to a COPD case. To run the report took approximately 1 minute. To analyse the results of the report took approximately another 1 to 2 minutes to get a tally for COPD cases identified in the OOHs service.

This was compared to the old method used in study 1 to identify the cases. For the same time period the extraction of these cases took approximately 10 minutes. All the cases for the three week time period had to be extracted. There were a total of 10,741 cases. The “IF statement”, in table 6.1, was used to identify the COPD cases from the total.

Table 6.1 IF Statement

| =IF(SUM(COUNTIF(N2:P2,{"*COPD*","*COAD*","*coad*","*copd*","*C.O.P.D.*","*C.O.P.D.*","*C.O.A.D.*","*C.O.A.D.*","*chronic obstructive pulmonary disease*","*chronic obstructive airway disease*","*lung disease*","*respiratory disease*","*emphysema*"}))>0,"COPD","None") |
Among the post-intervention 3 week data set, 239 cases were identified with this method. A thorough search of the EPR notes then took place. This took approximately an hour and a half. Of the initial cases identified, 131 cases were COPD cases. The other 108 had been incorrectly retrieved. The reasons for incorrect identification were some of the same problems as identified in study one:

- Documented as “no medical history of COPD”
- Documented as “please follow up with own GP to test for COPD”
- Documented as “past medical history of COPD”, however patient was ringing with “fall” or “pain in right hand” or “leaking catheter”.

The COPD cases were much easier to extract and were correctly identified with the COPD button. A correct COPD case is where a patient called the service with a complaint in relation to their COPD and this case was identified. When compared to the old method, this method was much faster. However they did not yield the same results (table 6.2).

<table>
<thead>
<tr>
<th></th>
<th>Old Method</th>
<th>New Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of COPD cases identified</td>
<td>239</td>
<td>50</td>
</tr>
<tr>
<td>No of correct COPD cases identified</td>
<td>131</td>
<td>50</td>
</tr>
<tr>
<td>No of incorrect COPD cases identified</td>
<td>108</td>
<td>0</td>
</tr>
</tbody>
</table>

The initial reaction was that the COPD button, while it did identify the cases, was not used successfully and did not identify all of the cases. The new method had perfect precision whereas the old method had identified a larger number of cases. This was disappointing but the reasons behind this low number became apparent when evaluation 3, the survey of the staff members, was completed. See section 6.4.3

6.4.2 Evaluation Two
When the post-intervention 3 week COPD records were extracted, the quality of the data contained in the free text boxes was quantitatively and qualitatively evaluated. Based on the information extracted from evaluation one, a second if statement, table 6.3, was used on the 131 COPD cases correctly identified to see if there had been any improvement, compared to the original COPD records extracted for study one, in the documenting of COPD (by spelling only) based on the implementation of the drop down list.

**Table 6.3 Updated "IF Statement"**

<table>
<thead>
<tr>
<th>IF Statement</th>
<th>New COPD Records</th>
<th>Original COPD Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of COPD cases identified</td>
<td>131</td>
<td>1681</td>
</tr>
<tr>
<td>No of spelling errors identified</td>
<td>4 (3.1%)</td>
<td>965 (57.4%)</td>
</tr>
<tr>
<td>No of correct COPD spellings</td>
<td>127 (96.9%)</td>
<td>716 (42.6%)</td>
</tr>
</tbody>
</table>

The data quality for free text documenting of COPD had improved immensely and all but 4 cases had used the correct notation of COPD within the record.

The data was further assessed to determine the use of the drop down list. The spellings of the 80 diseases, as identified in study two, were analysed for the 131 records. It was clear that the drop down list had been utilised and was successful. The other 74 diseases that were included in study two either did not appear in the new extracted data or were spelled correctly if they did appear.

**Table 6.5 Comparison of spelling for free text boxes**

<table>
<thead>
<tr>
<th>New Data Quality</th>
<th>Old Data Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spelling errors</td>
<td>Correct Spelling</td>
</tr>
<tr>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Diabetees</td>
<td>Diabetes</td>
</tr>
<tr>
<td>Alzheimers</td>
<td>Alzheimer's</td>
</tr>
<tr>
<td>Chol/cholesrol</td>
<td>Cholesterol</td>
</tr>
<tr>
<td>Cellutitis</td>
<td>Cellulitis</td>
</tr>
<tr>
<td>Esophogeal</td>
<td>Oesophageal</td>
</tr>
</tbody>
</table>

The quality of the data has improved significantly. The data has improved from an error margin of 82.4% - 85.3% to an error margin of between 6.3% - 25%. While this is not a 100% capture of all the data and all other spellings, it is a significant improvement on previous data sets extracted and demonstrates the potential of improving data quality by utilising simple processes.

6.4.3 Evaluation Three

The users of the system were surveyed to examine if they had experienced any change to their workflow when the enhancement had been introduced. The survey questions were designed to examine

- If the users had used the new enhancements?
- How often had they used the new enhancements?
- Did the enhancements integrate with their working environment?
- Had their work load changed?
- Did the users have any additional suggestions for the enhancements?

Ethics approval was sought from the Caredoc OOHs service to carry out the questionnaire. When approval was granted, an application was also submitted to Trinity College Dublin for the study. This application was also granted approval. Each participant was made fully aware of the study; see appendices 1 & 2. As the researcher was a work colleague, it had to be very clear to participants that this was not part of
their normal work and that they were under no obligation to complete the survey, see appendices 3 & 4.

Table 6.6 Survey for Users of the EPR

<table>
<thead>
<tr>
<th>Survey for Users of the Electronic Patient Record system after the enhancement was introduced</th>
</tr>
</thead>
<tbody>
<tr>
<td>An evaluation of an enhancement to improve data quality for research purposes using data collected in the OOHs service</td>
</tr>
</tbody>
</table>

1. Did you make use of the new COPD button to identify COPD cases?
   - Yes
   - No
   - N/A
   - Comments

2. Did you make use of the drop down list when recording details?
   - Yes
   - No
   - N/A
   - Comments

3. How often did you use the COPD button to identify COPD cases?
   - Always
   - Frequently
   - Occasionally
   - Not at all
   - When I remembered it
   - None of the above: Please specify

4. How often did you use the drop down list when documenting details?
   - Always
   - Frequently
   - Occasionally
   - Not at all
   - When I remembered it
   - None of the above: Please specify

5. Do you feel the COPD button integrates with your working environment?
   - Yes
   - No
   - N/A
   - Why?

6. Do you feel the drop down list integrates with your working environment?
   - Yes
   - No
   - N/A
   - Why?

7. Has your workload changed since the introduction of the COPD button?
   - Increased workload
   - Decreased workload
   - No change in workload
   - Comments

8. Has your workload changed since the introduction of the drop down list?
   - Increased workload
   - Decreased workload
   - No change in workload
   - Comments:

9. What suggestions do you wish to make that would improve the identification of COPD?
   - Comments

10. What suggestions do you wish to make that could improve the spelling and quality of data documented?
    - Comments

Call handlers and Telephone triage nurses working in the OOHs service were asked to participate in a survey to determine if the enhancement was a success from a user perspective. There were approximately 80 users, 55 triage nurse and 25 call takers,
who were asked to participate. However not all would have been on duty in the period of time for the survey when it was available to staff members. In total there were 41 participants.

The survey results were interesting as the survey captured both people who had used the button and those who had not. However it was evident from the comments that not all were aware on the correct use of the buttons or the list and decided not to use it as a result.

A longer period of time would have been preferable to allow users to train correctly on how to use the COPD button and the drop down list. The instructions given to users from the outset were not sufficient and users were only getting used to the button when they were surveyed about it. As a result, the button was not utilised fully. This is reflected in the findings from evaluation one.

A number of users reported separately that when they arrived for their shift (night duty, or weekends) they were not aware of the COPD button until after they had completed their shift or read their emails. As a result they did not use the button to identify cases.

Due to the fact a drop down list was already available with limited spellings and words users were familiar with the list, this did not seem to cause any problems for most users. This is reflected in evaluation two in the significant decrease of spelling errors.

**Results of the Survey**

<table>
<thead>
<tr>
<th>1. Did you make use of the new COPD button to identify COPD cases?</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>60.0%</td>
<td>21</td>
</tr>
<tr>
<td>No</td>
<td>31.4%</td>
<td>11</td>
</tr>
<tr>
<td>N/A</td>
<td>8.6%</td>
<td>3</td>
</tr>
</tbody>
</table>

answered question 35
skipped question 6
For those who responded No or N/A the reasons given were:

- had no call which required this to be used yet
- I had no calls from patients stating that they were suffering from COPD
- have not had any calls from patients with COPD
- call already logged drom call takers* (call identified by call taker)

### 2. Did you make use of the drop down list when recording details?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>68.6%</td>
<td>24</td>
</tr>
<tr>
<td>No</td>
<td>22.9%</td>
<td>8</td>
</tr>
<tr>
<td>N/A</td>
<td>8.6%</td>
<td>3</td>
</tr>
</tbody>
</table>

*answered question 35

*skipped question 6

Comments on question 2:

- Drop down list good for confirmation of spelling

### 3. How often did you use the COPD button to identify COPD cases?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>21.9%</td>
<td>7</td>
</tr>
<tr>
<td>Frequently</td>
<td>15.6%</td>
<td>5</td>
</tr>
<tr>
<td>Occasionally</td>
<td>21.9%</td>
<td>7</td>
</tr>
<tr>
<td>Not at all</td>
<td>21.9%</td>
<td>7</td>
</tr>
<tr>
<td>When I remembered it</td>
<td>18.8%</td>
<td>6</td>
</tr>
<tr>
<td>None of the above: Please Specify</td>
<td></td>
<td>7</td>
</tr>
</tbody>
</table>

*answered question 32

*skipped question 9

Specified reasons:

- had no call that required it
- No patients suffering from COPD
- no calls received as yet with COPD
- Did not use as no COPD cases since set up
- not on caredoc often enough only on nights
- new button and hasn’t been used yet
- as and when patient was identified during my assessment

### 4. How often did you use the drop down list when documenting patient details?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>12.1%</td>
<td>4</td>
</tr>
<tr>
<td>Frequently</td>
<td>24.2%</td>
<td>8</td>
</tr>
</tbody>
</table>
Occasionally 33.3% 11
Not at all 27.3% 9
When I remembered it 3.0% 1
None of the above: Please Specify 4

| answered question | 33 |
| skipped question  | 8 |

Comments on question 4:
- had no call that required it
- No patient suffering from COPD on my shift
- no calls received as yet with COPD
- Did not need to use since set up, but very good to have available

5. Do you feel the COPD button integrates with your working environment?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>82.4%</td>
<td>28</td>
</tr>
<tr>
<td>No</td>
<td>2.9%</td>
<td>1</td>
</tr>
<tr>
<td>N/A</td>
<td>14.7%</td>
<td>5</td>
</tr>
<tr>
<td>Why?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| answered question | 34 |
| skipped question  | 7  |

Comments on question 5:
- i havent used it yest
- will have to get used to this when I receive COPD calls
- I was not sure how to use it. So i didn't try it.
- I always felt it was left out and i felt it needed special attention. My father died of COPD so i empathise
- type of business we are in

6. Do you feel the drop down list integrates with your working environment?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>71.4%</td>
<td>25</td>
</tr>
<tr>
<td>No</td>
<td>5.7%</td>
<td>2</td>
</tr>
<tr>
<td>N/A</td>
<td>22.9%</td>
<td>8</td>
</tr>
<tr>
<td>Why?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| answered question | 35 |
| skipped question  | 6  |
Comments on question 6:
- as above (*I was not sure how to use it. So i didn't try it.*)
- it an aid to help pt.
- bit cumbersome to use in a hurry
- was helpful with spelling
- helps to confirm medical spelling
- am happy to type rather than look for words phrases that either nay not be there or not phrased as i would want them - time consuming

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased workload</td>
<td>0.0%</td>
<td>0</td>
</tr>
<tr>
<td>Decreased workload</td>
<td>0.0%</td>
<td>0</td>
</tr>
<tr>
<td>No change in workload</td>
<td>100.0%</td>
<td>35</td>
</tr>
</tbody>
</table>

answered question 35
skipped question 6

Comments on question 7:
- no difference
- only the click of a button
- only workload was remembering to use the button

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased workload</td>
<td>0.0%</td>
<td>0</td>
</tr>
<tr>
<td>Decreased workload</td>
<td>14.3%</td>
<td>5</td>
</tr>
<tr>
<td>No change in workload</td>
<td>85.7%</td>
<td>30</td>
</tr>
</tbody>
</table>

answered question 35
skipped question 6

Comments on question 8:
- helps to speed things up when typing as I am not thinking of how to spell the word
9. What suggestions do you wish to make that would improve the identification of COPD?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>answered question</td>
<td>7</td>
</tr>
<tr>
<td>skipped question</td>
<td>34</td>
</tr>
</tbody>
</table>

Comments on question 9:
- none
- none at present
- nil
- a colour on nurses clinition list. something like we are doing for palliative care nurse
- Not all patients are aware of their dx.... only noted in database hx
- None
- during the teleguides, i can not click COPD button until the very end of the triage assessment. usually COPD is identified in the first 1-2 mins of the assessment, if i could press button then there would be no chance of forgetting it. When using OLC, i can press the button at any time.

10. What suggestions do you wish to make that could improve the spelling and quality of data documented?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>answered question</td>
<td>11</td>
</tr>
<tr>
<td>skipped question</td>
<td>30</td>
</tr>
</tbody>
</table>

Comments:
- none
- List of spellings for medications
- none at present as i have no used this yet
- nil
- we have dictionary drop down box. it could be more comprehensive especially for bad spellers like me
- see if a medical / english dictionary can be inserted into spell check
- drop down box needs to be split for conditions and medications as it is too long at the moment and causes delays - this seems to be worse since the box was updated recently.
- more words added
- i find spell check brilliant, maybe this could be updated regularly or request sent when words need to be included
- if you had the whole collection of Collins Dictionary words that would be great
more choices in drop down list

6.5 Findings and Discussion

Study three successfully addresses the aim “if the quality of routinely collected data can be enhanced for secondary research purposes without disrupting frontline services”. While both the drop down list and the COPD button achieved their aims for each evaluation, the COPD button was 100% successful at identifying the correct COPD cases which reflected excellent precision. But unfortunately was not used by all users through lack of understanding and lack of awareness. This meant that there was poor recall as all COPD cases in the database were not identified. This can be attributed to the short time period of implementation and the comments documented in evaluation three.

The drop down list was successful in improving the data quality of the spellings for the 80 identified conditions from study two. The addition of this list was a relatively uncomplicated addition to the workflow of the users but increased the data quality dramatically. This is very positive for any future use of the data for research purposes.

Overall, the two enhancements were not perceived to have impacted or increased the workload of the users of the system. The workload either stayed the same (85.7% of respondents) or decreased (14.3% of respondents). In its current format the users are happy with both enhancements. This work was all completed in a live healthcare services environment which suggests that small enhancements to routinely collected data can improve data quality for the purposes of research without impacting on users on their workflow. This work as part of the improvement phase and the improvement management and monitoring phase of TIQM followed outline of the methodology to assess and monitor the changed to the workflow.
Chapter 7: Summary and conclusions

This chapter summarises the research conducted and the key findings. It discusses the limitations of the research and future work. It describes the key contributions made to health services research by this thesis work.

7.1 Introduction

The objective of this research was to address data quality issues in the use of routinely collected health data, OOHs data, for the secondary purpose of health services research.

The aims of this research were to assess:
- If routinely collected OOHs data in its current format can contribute to a better understanding of health services usage among patients
- If the quality of routinely collected data can be enhanced for secondary research purposes without disrupting frontline services.

To address the research aims:
- Routinely collected data in an OOHs database was used to analyse healthcare usage and patterns of care for patients, using chronic obstructive pulmonary disease (COPD) as an indicative case to explore the data
- Data quality issues that arose in the above study were identified as a result of using this routinely collected data
- An enhancement to the routinely collected data was designed, implemented and evaluated

The aims of this research were achieved through three interlinked studies supported by a data quality assessment methodology, in this instance TIQM. In the assessment phase, using routinely collected OOHs data gave a detailed picture of COPD patients
and their journey through the OOHs setting. It also gave a snapshot view into the usage of other services including hospital, ambulance and GP surgeries. It highlighted the intense resource usage for COPD patients, and the possibility of treating these patients in the community setting by using alternative services. It contributes to a better understanding of how patients are using services and how changes in healthcare delivery for the future can support patients in their own home or in the community without the need for referral to hospital.

The data routinely collected for the primary use of case consultation in the OOHs service can be used sufficiently for the secondary use of research. Although problems were identified with the quality of the data and the time consuming extraction and identification process, these issues were addressed in study two and three, the improvement phase and the improvement management and monitoring phase.

The data quality issues highlighted by the extraction and searching of the data for study one, gave a starting point for study two to begin looking at data quality in more detail. Due to the nature of the data, the two most appropriate data quality dimensions for this study to examine were reliability and completeness. When the data was analysed in the context of completeness, it was found that the data was not complete for the purpose of documenting COPD correctly within a patient’s EPR.

From the perspective of reliability, the data quality was poor due to the number of spelling errors and the various different ways diseases were documented. This is a problem due to the number of users within the system documenting their own way.

To address these identified data quality issues two enhancements to the collection of the data were implemented. This was completed in the live working environment of the OOHs service and therefore had to integrate seamlessly with the users workflow while also being cost effective to develop and implement.
The enhancements were a success as they did not affect the work of the users and improved the data quality and the prospect of using it for research purposes. This was a big success factor, as it means that there is a potential to mine data in similar services by introducing cost effective, undisruptive data collection enhancements that do not affect staff working on the ground.

7.2 Key findings of research

1) Routinely collected data can be used for research purposes to contribute to the understanding of health care services and delivery.

From study one, it was possible to use the routinely collected data in the OOHs service to provide a snap shot of a COPD patient and their use of healthcare services in the OOHs setting and in some instances through GP surgeries in-hours and hospitals (table 4.4). There was also an insight into the mind set of patients with COPD; for example, although they often required referral in to hospital, they were unwilling to go (table 4.6).

The COPD patients presenting in the OOHs setting require resource intensive care i.e. a home visit with the duty doctor as they are too unwell to attend at a treatment centre. While the overall cases for the time period are not directly comparable, they do give an indication of the use of home visits for COPD patients: 56.9% compared to other service users at 10.7% (table 4.5).

Although the data did have data quality problems and was not easy to extract for research purposes, by introducing small yet effective solutions to the collection of the data, this improved the research capabilities.

Introducing two small yet effective enhancements to the data collected in the OOHs setting improved the completeness of the data and the reliability of the data. The
enhancements were not costly or complicated, but improved the data collected for research purposes. The solutions did not need to be widespread big changes that changed or affected how the staff members carried out their work. The enhancements did not affect the primary use of the data.

2) This research was completed in a live working environment that did not affect any users of the system or staff members, or most importantly have any impact on how patients were treated or how the service was delivered.

The results of the survey were very positive with 100% of participants claiming no change in workload or a decreased workload for both the introduction of the COPD button and the use of the drop down list. The enhancement integrated seamlessly as part of the live working environment.

7.3 Limitations of research

Study one is based only on OOHs patient records. Information for this study was gathered from the free text of the nurse and doctor consultations and what they deemed important to document. It is not a complete medical record for the patient.

In study one there is no direct comparison possible with the other patients attending OOHs services as their conditions and demographics vary greatly. If a comparable set of patients were identified, based on age and gender, this could lead to a better understanding of the COPD patients and their requirement for care; is it disease specific, age specific or are there other factors impacting on their healthcare service usage?

The enhancement in study three for identifying COPD patients only applies to one condition. It would be beneficial to expand this enhancement to include more conditions.
The two enhancements that were implemented were only implemented for a short period of time. It would have been more beneficial to run the enhancements for a longer period of time to ensure that all users were aware of them and how to use them. As reflected in the survey a number of users did not know about the enhancements until they completed their work for the day. Communicating the changes to large numbers of staff members who work out of normal hours and shift work is difficult. As the enhancements only ran for a month, it was not adequate enough time to ensure all users were aware of the changes and understood them correctly.

For the survey in evaluation 3 there is a potential for response bias as the researcher is a work colleague of the system users.

7.4 Future work and recommendations

Based on the findings from study one and evaluations, it would have been beneficial to run more statistics on the initial COPD dataset for more comparisons with the post-enhancement COPD data.

With the introduction of the drop down list for spellings it would be important to re-examine this at a later date to ensure the quality was still intact. The initial use of the drop down list could have been short lived as people were more aware of the spellings and the problems for that short period of time.

It is important to identify the needs of the OOHs service and the needs of a researcher. As they both differ, it’s important that a thorough consultation process takes places to understand exactly what is required of a system before there are any improvements or changes to be made. It is beneficial to have someone who understands both perspectives.

For future studies, the template for the COPD button to identify cases for other types of research is an excellent option. The button correctly identifies the cases required
and without input from the OOHs user the data could go straight to the researcher. The button could also be duplicated to include more chronic conditions.

When collecting the information for the OOHs EPR, it would be important to design a template or more restrictive fields where possible to collect the information. There will always be a requirement for free text, but this should be limited as much as possible without affecting the primary function of the system.

Using the TIQM as outlined in section 2.4 gave the research a structured data quality assessment to follow. Due to the scope and aims of this research, it did not concentrate on the cost analysis or benefits that were included in the TIQM methodology. This aspect of the methodology should be included in future research as it would bring an extra dimension to the overall research and examine the economics of improving data quality.

7.5 Conclusion

The objectives of the research were successfully achieved through each of the three studies and validated in the evaluations. It is possible to use routinely collected health services data for the secondary purpose of research. Implementing changes to a live working environment to improve data quality is also possible without disrupting the normal workflow of users or their primary function within a service.
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Appendices

Appendix 1 – Ethics approval from Caredoc

28th November 2013

Re: Research for MSc

Dear Michelle,

Thank you for your application to the Caredoc Ethics Committee. Your application to:

1) Complete research using anonymous data from the Caredoc database
   and

2) To interview nurses working within the Caredoc service to evaluate a data quality enhancement
   has been reviewed by the Committee and I wish to inform you that you have been granted approval.

We would like to take this opportunity to wish you every success in your endeavours.

Kind Regards,

Dorcas Collier
Clinical Manager
Caredoc
Appendix 2 – Ethics approval from Trinity College Dublin

RE: Ethics Application for Michelle Kearns - 135/14

Tricia Fowler <Tricia.Fowler@scss.tcd.ie>
to me, Research ()

Hi Michelle

Thank you for your application. As you have received External Ethical Approval you may now proceed with this study.

We wish you success in your research.

Kind Regards
Tricia

Tricia Fowler
Executive Officer – Research Unit
School of Computer Science & Statistics
O’Beirne Institute
Trinity College
Dublin 2

Tel: +353 1 896 1445
Appendix 3 – Participant Information Sheet

Trinity College Dublin - Information Sheet for Participants

Researcher: Michelle Kearns

Institute: Trinity College Dublin

This research is being carried out as part of an MSc. The research is assessing if an enhancement to your work practice will improve the quality of data collected for research purposes.

You are being asked to answer this survey or short interview as part of a research thesis; it does not form part of your daily work and you are under no obligation to participate.

You may withdraw you responses at any time or omit particular responses for the survey or interview.

The time expected to complete the survey is approximately 5 minutes.

The benefits of this research is to improve the data collection process of your work flow to contribute to future research

I am available for any questions you may have regarding the information by email, telephone or in person.

All results are anonymous and the findings will not be presented in a person specific manner unless a direct quote is taken from your survey or interview. In the event this happens, all quotes will be anonymous and described in context.
Appendix 4 – Informed consent form

Trinity College Dublin - Informed Consent Form

Lead Researcher: Michelle Kearns

Background of Research: Improving data quality of information recorded on an electronic patient record in a GP out-of-hours service to facilitate research and progress health service delivery by understanding patient patterns of care and healthcare usage.

Declaration:

• I am 18 years or older and am competent to provide consent.

• I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.

• I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity.

• I understand that if I make illicit activities known, these will be reported to appropriate authorities.

• I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

• I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.

• I understand that my participation is fully anonymous and that no personal details about me will be recorded.

I understand and agree to participate

I do not agree to participate