Towards supporting community
healthcare in Ireland through the use of
information communication technology:
a cloud-based proposition

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

Author Declaration

I declare that the work described in this dissertation is, except
where otherwise stated, entirely my own work, and has not been
submitted as an exercise for a degree at this or any other
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September 2013

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Abstract

Community healthcare forms the bedrock of the Irish healthcare system since it is estimated that 90-95% of Irish health and social service needs care can be delivered in the community (Health Service Executive 2008). Thus, improving services within community healthcare has been identified as an appropriate future direction for the Irish healthcare system (Department of Health and Children 2012). Currently, there is no national architecture to support the needs of patients and healthcare professionals within this sector.

Chronic obstructive pulmonary disease (COPD) is a chronic lung disease. The COPD outreach programme, which is part of the Health Service Executive's COPD clinical care programme, is a new, evolving programme and is currently and primarily paper-based. It is thought to be a suitable candidate to investigate whether enterprise cloud service architecture (ECSA) could be utilised to support patients and healthcare professionals through the electronic delivery of that programme. ECSA is a hybrid of service-orientated architecture and cloud computing.

The qualitative research carried out investigated this proposal through a series of semi-structured interviews with stakeholders from which information technology requirements were elicited and themes obtained. From these requirements, an enterprise architecture was designed, a cloud computing platform was selected and some elements of the architecture were implemented. A small evaluation was carried out. The solution consisted of two elements: delivery of new functionality to support health record generation by healthcare professionals at point of care and creation of interfaces to allow interoperability with existing systems. The research principally

focused on the first element; namely, development of a cloud-based application to deliver new functionality. A number of themes emerged during the research study, including the provision of connected community healthcare, the importance of involving patients in their own care and the importance of data security.

The results indicated that there is potential to complete the specification and implementation of the ECSA designed for use with the COPD outreach programme. Feedback from the evaluation was generally positive, although the evaluation sample size was small. Concerns exist with respect to data security. Additionally for the solution to be fully functional, it would need to interoperate with existing systems.

Although the results of the research are specific to COPD, there is potential to apply the ideas developed as part of this research to other areas in chronic disease management within community healthcare.

Dedication

In memory of my mother

Margaret Payne

An inspirational lady

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Abbreviations

CCM Chronic Care Model

COPD Chronic Obstructive Pulmonary Disease

DoH Department of Health

ECSA Enterprise Cloud Service Architecture

CEN Comité Européen de Normalisation

XML Extensible Mark-up Language

GPMS General Practice Messaging Standard

GP General Practitioner

GOLD Global Initiative for Chronic Obstructive Lung Disease

HISA Health Informatics Service Architecture

HIQA Health Information and Quality Authority of Ireland

HL7 Health Level Seven International

HSE Health Service Executive

HaH Hospital at Home

HIPE Hospital In-Patient Enquiry

IT Information Technology

IaaS Infrastructure as a Service

ISO International Organisation for Standardization

iPRCN Irish Primary Research Care Network

MDA Model Driven Architecture

PaaS Platform as a Service

PIM Platform Independent Model

PSM Platform Specific Model

RM-ODP Reference Model - Open Distributed Processing

SOA Services Orientated Architecture

SaaS Software as a Service

UML Unified Modelling Language

WHO World Health Organisation

1 Introduction

1.1 Setting the scene

"It is change, continuing change, inevitable change, that is the dominant factor in society today. No sensible decision can be made any longer without taking account not only the world as it is, but the world as it will be... " (Asimov 1983)

The Irish healthcare system is currently in a state of flux, with care being transferred from a more traditional hospital-centric model to a community-based model (Department of Health and Children 2012). Community healthcare plays a necessary and vital role in the delivery of home-based healthcare within Ireland. encompasses such diverse services as general practice, out of hours services, public and community health nursing, mental health services and others (Health Service Executive 2012b). Further, it is estimated that 90-95% of the Irish population's health and social service needs can be delivered within the community (Health Service Executive 2008). Additionally, good quality community or primary health care provision needs to underpin the current paradigm shift within health care delivery (Compton 2011) - away from traditional hospital-centric care and towards a home-based, patient-centric care delivery model (Arnich et al. 2010). This model offers early interventions and programs that respond to a patient's changing health in a more timely way (Kvedar et al. 2011). Finally, it aims to include and collaborate with all stakeholders involved in a person's health (Accenture Health on behalf of HIMSS EU 2012).

However, health services and the associated health information systems within the community in Ireland are currently disjointed and fragmented, resulting in silos of information which cannot easily be shared (Health Information and Quality Authority

2011b). This results in the patient often being asked the same information many times (Health Information and Quality Authority 2011b). Stream-lined processes, data exchange and system interoperability all play a role in ensuring continuity of care for a patient (Coleman 2003; Bodenhiemer 2008). This is true at all transition points within the healthcare system, but especially within community healthcare given its diverse nature (Coleman 2003).

This research aims to explore how a combination of a services-orientated architecture with the cloud computing paradigm could support the information technology requirements of a specific patient cohort and their healthcare providers in the delivery of a chronic disease management initiative. Based on a literature review and requirements gathered from a cross-section of stakeholders, the author proposes an enterprise cloud services-orientated architecture. The architecture will be divided into functional modules which can be designed and implemented as required, thus attempting to meet the requirements of today, while future-proofing the solution for tomorrow. In so doing, the topics of data sharing among patients and healthcare professionals, the importance of stakeholders in patient care and system design, system interoperability, data security and privacy and issues around the use of cloud computing platforms will be explored.

1.2 Background

1.2.1 Chronic disease management in the community

The World Health Organisation (WHO) defines chronic diseases as "diseases of long duration and generally slow progression". Patients with a chronic condition require a different type of healthcare to those with an acute illness (Wagner et al. 2001). Typically, the chronically-ill patient needs education about how to manage their condition while it is stable, and effective, evidenced-based treatment plans when it exacerbates (Wagner et al. 2001). Furthermore, chronic disease management can occur within the community in collaboration with healthcare professionals (Peytremann-Bridevaux and Burnand 2009).

In Ireland, government policy supports the concept of chronic disease management initiatives in the community with the introduction of the Health Service Executive's (HSE) clinical care programmes, discussed in Section 2.5.3: Clinical care

programmes in Ireland. The recent policy decision in relation to the usage of smaller hospitals for the provision of chronic disease management in conjunction with primary care centres and general practice also provides support for chronic disease management initiatives.

Finally, the research focuses on a chronic disease management initiative, the COPD outreach programme, which is being rolled out as part of the HSE's COPD clinical care programme for patients with chronic obstructive pulmonary disease (COPD).

1.2.2 Using a cloud computing model

Cloud computing can be defined as an information technology model that offers services on demand over a network (Marston et al. 2011). Services are provisioned and accessed in real time using smartphones, tablet or desktop technology irrespective of location or time (Buyya et al. 2009). Furthermore, resource optimisation and allocation is carried out within the cloud system depending on customer usage and requirements (Marston et al. 2011). Three models have been identified: software as a service (SaaS), platform as a service (PaaS) or infrastructure as a service (IaaS) (Mell and Grance 2011). These ideas are expanded upon in Section 3.5: Cloud computing.

1.3 Research question

In conducting this research, the author wishes to examine how chronic disease management initiatives in the community could be supported through the use of information technology, specifically a cloud computing model. Thus, the over-riding research question is:

How could cloud-based enterprise architecture for community healthcare support its stakeholders?

Additionally, the author poses a number of sub-questions which shall address different dimensions of the main question. These sub-questions are:

- Who are the stakeholders and what are their information technology requirements?
- To what extent can cloud-based services offer a solution?

- What standards could be used to ensure system interoperability between legacy and new systems?
- How can the proposed infrastructure be used in practice with a specific patient cohort?

1.4 Research aims and objectives

The aims and objectives of the research are set out in Table 1-1.

Table 1-1: Research aims and objectives

Aim Objectives	
To gather requirements from stakeholders in order to design an enterprise architecture that supports their needs	 To identify stakeholders To gather requirements from stakeholders To design an architecture
To evaluate cloud-based services	 To compile a set of criteria that can be used to evaluate and cloud-based services To identify possible cloud-based services that could be used in this instance To evaluate cloud services based on criteria To identify the pre-requisites for a cloud-based service
To illustrate system interoperability between legacy and new systems	To design an interface element of the designed architecture
To implement elements of the designed infrastructure to illustrate the benefits of data sharing between different community healthcare stakeholders	 To implement an interface element of the designed architecture To link the implemented elements together to show the flow of patient data from ready at hand technology used in the community via the 'cloud' to the hospital systems for storage To evaluate the implementation
To identify what standards could be used to facilitate system interoperability	■ To discover the importance of standards in delivering high-quality, patient-centric healthcare within the community
To examine a specific patient cohort in detail	 To select a patient cohort To determine current working practices / processes to manage the selected patient cohort's illness

1.5 Research rationale

The rationale behind this research is two-fold. Firstly, there is currently no unified information technology system implemented nationally which allows community healthcare professionals communicate consistently about their patients. The prerequisites for such a system include (but are not limited to) individual health identifiers, standard message structures approved by the Health Information and Quality Authority (HIQA), Healthlink as the national messaging broker to transport these messages between systems and access control policies to ensure patient data remains secure. Incorporating patients and healthcare professionals' information technology requirements into enterprise architecture ensures that core functionality is captured which could potentially support their current and future roles in the community.

Secondly, and more specifically to the patient cohort under consideration, the COPD outreach programme is a hospital-based outreach to the community chronic disease management initiative. The outreach teams interact with various community stakeholders, including patients, general practitioners (GPs), community pharmacists, members of the primary care centres, community occupational therapists and others. Currently, this communication is by letter and telephone and is paper-based and labour intensive. It is proposed that information technology (IT), and specifically the cloud computing paradigm, could be used as an enabler to facilitate more timely communication between relevant stakeholders.

1.6 Research scope

The rationale proposes that cloud computing may enable more timely communication between stakeholders within community healthcare. Since any proposed solution is required to deliver new functionality in addition to interoperating with legacy systems (where they exist), there are two strands to developing a full solution, namely:

- Building a cloud system that enables electronic communication between stakeholders involved in the COPD outreach programme
- Building a standards- and cloud-based integration engine that interoperates with legacy systems

This study focuses primarily on designing and partially-implementing a cloud system that enables electronic communication within the COPD outreach programme as per the stakeholder's requirements. While some aspects of standards-based interoperability with legacy systems are mentioned, this strand is not investigated extensively within this study.

1.7 Dissertation layout

The dissertation is structured as follows:

Chapter 2: Literature Review - Health provides background information on aspects of the research topic, including community healthcare, stakeholder theory, chronic disease management and the importance of evaluating data quality.

Chapter 3: Literature Review - Informatics examines state of the art within the research area with specific emphasis on architectural approaches, cloud computing model, standards and interoperability and smartphone and tablet technology. Chapter 3 identifies a perceived gap in the literature which the author aims to contribute towards as a result of the primary research carried out.

Chapter 4: Research Design and Methodology presents the research paradigm. Chapter 4 explains the research framework and how the selected research methods shall be used within that research framework.

Chapter 5: Foundations of Enterprise Architecture describe the approach taken to analysis, design and implementation of the proposed solution. Chapter 5 contains a detailed specification of the proposed solution.

Chapter 6: What the Architecture Offers describes the partial implementation of the architecture. Chapter 6 discusses interoperability with legacy systems with respect to one of the designed modules.

Chapter 7: Discussion re-examines and answers the research questions, presents some additional research findings, outlines other potential approaches to answering the research question, and recommends future work in this area.

Chapter 8: Conclusion presents a summary of the research.

2 Literature Review - Health

2.1 Introduction

"You cannot open a book without learning something."

(Confucius, 551-479 BC)

The researcher is required to become familiar with their field of study as they travel through their research journey. The literature review is a vehicle to aid them in this task (O'Leary 2010). Through reading, assimilating and analysing literature from different sources, it is possible to create arguments essential to establish the worth of their research (O'Leary 2010). Also, it provides the reader with the necessary background information on the research topics (O'Leary 2010).

With that in mind, this chapter concerns itself with the non-technical topics of the research, such as how community healthcare is defined in Ireland, the relevance of stakeholder theory and the importance of evaluating data quality and infrastructure. Additionally, it focuses on the health aspects of the research, defining chronic disease management and providing material on one chronic disease, COPD. In this manner, the importance of these topics to the research is revealed. Specifically, Table 2-1 provides a list of these topics and a reason for their inclusion.

Table 2-1: Topics for inclusion in literature review - health

Topic	Reason for inclusion
Community healthcare	 Defines community healthcare and how it operates in Ireland
	 Describes the problem that shall be addressed by the primary research
Stakeholder theory	 Defines what a stakeholder is
	Describes state-of-the-art methods for rigorously

	identifying and communicating with stakeholders throughout the lifecycle of an information technology project
Chronic disease management	 Defines chronic disease management and provides background into its importance
	 Explains the Irish approach to chronic disease management through the introduction of the clinical care programmes
	 Examines one particular type of chronic disease management initiative which is relevant to the primary research
Case study: chronic obstructive pulmonary disease	 Provides background information on a particular chronic disease that shall form the basis of the primary research.
Evaluating infrastructure	 Describes an internationally accepted models of chronic care against which other models, such as that proposed in this research, could be evaluated against
Evaluating data quality	 Defines data quality Examines elements that aid data quality improvement in the context of this research

2.2 Community healthcare

Healthcare delivered within the community aims to improve an individual's quality of life by treating them in their own environment. Within Ireland, the HSE defines community in terms of their primary care strategy. The HSE view a single community region as being a geographical area with a population of between 3,000-20,000 to be served by teams of healthcare professionals working within the community (Health Service Executive 2008). These teams consist of public and community care nurses, general practitioners, community intervention teams, out-of-hours services, allied health professionals and patients working and collaborating together (Department of Health and Children 2012).

Frequently, people with chronic conditions are being cared for in the community by their families, carers and community healthcare professionals in conjunction with hospital consultants. Heretofore, this care was managed on an *ad hoc* basis with the patient frequently repeating their case history to different healthcare professionals resulting in frustration for them and in silos of information in different locations around the health system (Health Information and Quality Authority 2012a). This situation is expensive to maintain and manage - both financially and resource wise

and often results in sub-optimal healthcare for the person involved (Health Information and Quality Authority 2012a).

Integrated care pathways may provide part of the solution. While there is no universally agreed definition of what integrated care pathways are, Kinsman et al. (2010) summarised their main characteristics as supporting a multi-disciplinary team of healthcare professionals deliver structured evidence-based care for a specific patient cohort with a particular clinical condition and providing a means of communicating that care with the patient in a structured format. Furthermore, integrated care pathways provide a way of attaining continuity of care across care settings for patients (De Bleser et al. 2006). Continuity of care for the patient is essential when the care spans across hospital and community settings with a variety of healthcare professionals involved in the patient's care.

There is impetus to provide more structured care for patients with chronic conditions, with an emphasis on moving care from hospital-based to community-based settings (Department of Health and Children 2012). Consequently, integrated care pathways are required to support patients with chronic conditions. It has been established that integrated care pathways provide an effective method of care where the care is predictable (Allen et al. 2009). Further, as the Irish healthcare system evolves towards providing healthcare services in the community, the need for integrated care pathways will become more acute. Indeed, the Department of Health (DoH) have committed to implementing integrated care pathways for people with chronic conditions as part of its reform of the health system. Action 27 of the Future Health A Strategic Framework for Reform of the Health Service report states that "The Department of Health will work with the HSE to ensure that chronic disease management programmes will be introduced between 2013 and 2015" (Department of Health and Children 2012). Chronic disease management will be explored in more detail in Section 2.5: Chronic disease management.

Healthcare services delivered by healthcare professionals in the community in collaboration with the patient provide a model of healthcare that empowers patients, create dynamic, partnership relationships between healthcare professionals and patients and reduces costs in the healthcare system (Smith et al. 2013). In this

instance, patients and healthcare professionals are some of the stakeholders in community healthcare and are the focus of the next section.

2.3 Stakeholder theory

The term "stakeholder" was first seen in management literature in 1963 (Freeman, R 1984). It describes a concept whereby groups and individuals influence and are influenced by the actions of an organisation with which they interact. In this regard, Laplume, Sonpar, & Litz, (2008) establish that while there are emergent broad themes around stakeholder theory, including stakeholder definition and salience, there is continuing debate in this domain. Further examination of these theories is beyond the scope of this dissertation; of importance is that the most influential stakeholders are often those who do not have the most at stake. In the case of delivering healthcare in the community, it could be argued that those who develop the services and influence their implementation may have least to gain in terms of their delivery; they may not, after all, be suffering from the disease that the service is hoping to treat. Bearing this in mind, it is essential that all stakeholders are identified and included from project initiation through implementation to completion (Pouloudi and Whitley 1997).

However, many tools exist to ensure that stakeholders are identified correctly and included. It is essential to have background knowledge of the domain. However, more formal rigorous tools are necessary. Cadle et al. 2010 describe a useful technique in which the product or process under review is placed in the centre of a hexagon and eight stakeholder categories are placed around it, as illustrated in Figure 2-1.

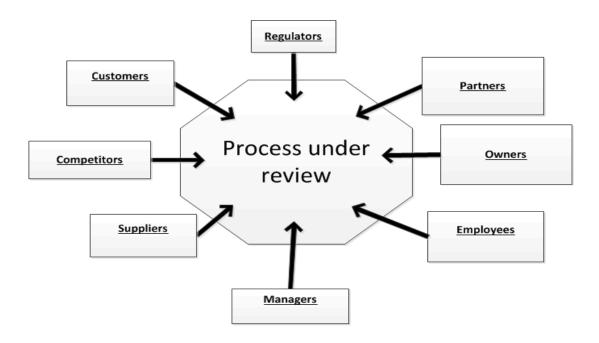


Figure 2-1: Stakeholder identification wheel template, adapted from (Cadle et al. 2010)

Each category is systematically examined to ensure inclusion of all stakeholders. Executing this technique results in the stakeholder identification wheel found in section 5.3.3.: Identifying stakeholders.

Having identified stakeholders, including them in each project stage is crucial. A means of communicating effectively with stakeholders is essential. The Object Management Group standard, known as the Unified Modelling Language (UML), is a modelling language used to describe models of systems (Fowler and Scott 1999). It uses a variety of diagrams to communicate system models to different stakeholders – more information about how it was used within this research is found in section 5.2: Approach taken to analysis, design and implementation.

Inclusion of all stakeholders at each project stage aids management of stakeholder expectations in project deliverables (Zhang et al. 2005). This is illustrated by acceptance of a patient-controlled health record for a paediatric chronic condition through an iterative, inclusive, patient-centric design process (Sox et al. 2010).

While the stakeholder theory domain is diverse, the basic message is simple: inclusion of and collaboration with all relevant stakeholders throughout a project's life-cycle will result in a better deliverable. Tools and techniques, such as involving

all stakeholders in requirements elicitation and software design evaluation, exist to enable this. Key findings in this area are discussed in more detail in section 7.2.1: Involving stakeholders in development of technology solutions.

2.4 Case study

Application of the stakeholder identification wheel described in section 2.3: Stakeholder theory to a specific patient cohort yields all possible stakeholders. One key stakeholder is the patient who has been diagnosed with the chronic condition and who is directly affected by chronic disease management initiatives aimed at treating that condition. Background material on the chronic condition selected for this research study, chronic obstructive pulmonary disease, is provided in the following section.

2.4.1 Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is a disease of the lungs that is "characterised by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious gasses or particles" (Global Initiative for Chronic Obstructive Lung Disease 2013). COPD is a chronic condition that is both preventable and treatable (Mannino and Buist 2007). COPD is caused by tobacco smoke, indoor and outdoor air pollution, infections and occupational hazards (Pauwels 2000; Mannino and Buist 2007).

Spirometry – the means of assessing lung function by measuring the amount of air expelled after inhaling a maximum amount of air – is essential in making a clinical diagnosis of COPD (Global Initiative for Chronic Obstructive Lung Disease 2013). This objective diagnostic test uses a medical device known as a spirometer to measure the airflow restriction suffered by the patient. However, while spirometry is required to diagnose COPD, other validated questionnaires are used in assessing a patient's symptoms and quality of life. These questionnaires, described in more detail in Appendix G: , include the Borg breathlessness score (Borg 1982), the modified medical research council (mMRC) score (Mahler and Wells 1988) and the COPD assessment test (CAT) (GlaxoSmithKline 2009) provide healthcare professionals a

means of assessing a patient's quality of life (Global Initiative for Chronic Obstructive Lung Disease 2013).

Management and treatment of COPD is defined by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) (Pauwels 2000). Two areas of particular interest to this study are highlighted in the latest version of the COPD GOLD guidelines. Firstly, there is an emphasis on the management of stable COPD through patient education on diet, exercise and healthy living (Global Initiative for Chronic Obstructive Lung Disease 2013). Secondly, there is an emphasis on the reduction of known risk factors such as smoking cessation in order to reduce the number of exacerbations and to prevent disease progression (Global Initiative for Chronic Obstructive Lung Disease 2013). Both of these areas can be carried out through chronic disease management initiatives within the community and require patient participation and collaboration to be fully utilised.

2.4.2 COPD exacerbations and their treatment

An exacerbation is defined as "an acute event characterized by a worsening of the patient's respiratory symptoms that is beyond normal day-to-day variations and leads to a change in medication" (Global Initiative for Chronic Obstructive Lung Disease 2013) This highlights two important points: firstly, the need to record normal day-to-day variations and secondly, the need for medical assistance when an exacerbation occurs.

Furthermore, the dangers associated with exacerbations are also noteworthy: hospital admissions are more likely with exacerbations (Global Initiative for Chronic Obstructive Lung Disease 2013). This is backed by evidence which suggests that the death rates for individuals with COPD after hospital admissions are at, on average, 15% after three months and 25% after one year (Healthcare Commission 2006). However, randomised controlled trials have shown that it is possible to treat patients with COPD exacerbations in their home environment, using the "Hospital at Home" type of care (described in Section 2.5.2: Hospital at home) provided they meet certain medical criteria, with similar results to those treated in hospital (Cotton et al. 2000; Gravil et al. 1998; Hermiz et al. 2002; Jeppesen et al. 2012).

2.4.3 Prevalence of COPD worldwide and in Ireland

The mortality and economic burden of COPD cannot be understated. Mortality rates associated with COPD are startling. In 2011, it was the fourth leading cause of death worldwide, with 5.8% of deaths attributed to it (World Health Organisation 2011). By 2020, it is projected to be ranked as the third leading cause of death (Global Initiative for Chronic Obstructive Lung Disease 2013). Furthermore, in Ireland, the disease accounted for 4.5% of deaths registered in 2011 (Central Statistics Office 2013).

In economic terms, COPD places a huge burden on the Irish health system given that there are an estimated 110,000 people who have been diagnosed with COPD and a further estimated 200,000 undiagnosed cases of COPD (McDonnell 2013). Moreover, the impact the disease has on the Irish healthcare system is immense: in 2011, it accounted for over 122,250 bed days with a mean length of stay of 9.2 days and 18,500 exacerbations in primary care per annum (National COPD Programme Working Group 2011b).

2.4.4 The patient's experience

Each patient diagnosed with COPD suffers from a myriad of symptoms, including shortness of breath, chronic cough and chronic sputum production (Global Initiative for Chronic Obstructive Lung Disease 2013). Living with COPD, and other chronic diseases, affects the patient's quality of life and the quality of life of their immediate families who are often their main carers. Consequently, strategies are required to improve a patient's quality of life, at local, national and European level. Such strategies are the focus of chronic disease management initiatives. Defining chronic disease management and exploring how initiatives in this area have been implemented in Ireland is the purpose of the next section.

2.5 Chronic disease management

2.5.1 Definition

The World Health Organisation (WHO) defines chronic diseases as "diseases of long duration and generally slow progression". Chronic diseases can be infectious or non-infectious, such as respiratory diseases, diabetes and stroke (Darker et al. 2011). Chronic diseases are often preventable (Department of Health and Children 2012).

Chronic disease management is an approach used to systematically improve the quality of care that patients with chronic conditions receive through the use of multi-disciplinary healthcare teams across the care continuum (Weingarten et al. 2002; Faxon et al. 2004). Additionally, it is maintained that patient involvement and self-care are crucial to the success of chronic disease management initiatives (Care Continuum Alliance 2013). Schrijvers (2009) recommended extending the definition of chronic disease management to include the use of information technology to enable communication between stakeholders and to support connected health initiatives in this area. In response to this recommendation, Peytremann-Bridevaux & Burnand (2009) established that disease management should also be community-based, evidence-based and that the care is systematic and structured to the needs of the individual.

Thus, chronic disease management initiatives aim to educate often, detect and diagnose early and implement effective treatment plans using evidence-based guidelines. Further, it has been shown that managing chronic conditions effectively can improve the quality of life for the individual through reduced hospital stays or improved clinical outcome (Rea et al. 2004; Pimouguet et al. 2011).

2.5.2 Hospital at home

A particular type of care known as Hospital at Home (HaH), previously mentioned in the context of COPD in Section 2.4.2: COPD exacerbations and their treatment, is one element of chronic disease management initiatives. Also known as early assisted discharge or outreach programmes, HaH care occurs when the patient is treated at home but is under the direct care of the hospital consultant for a period of time and is monitored and assessed regularly by healthcare professionals for their illness (Shepperd et al. 2011). Other variations of this type of care operating in Ireland include community intervention teams offering short-term services including completion of intravenous medications, wound dressing and early discharge support to patients for a set period of time (Gantly 2012). This type of community-based care has benefits for both the patients and the healthcare system. It allows the patient recover in the comfort of their home environment, while still being under the care of

consultant or doctor (Gravil et al. 1998). It frees up inpatient hospital beds which in turn results in cost savings for the health system (Ram et al. 2004).

2.5.3 Clinical care programmes in Ireland

In Ireland, the clinical care programmes were developed in order to improve quality of and access to care for patients in a cost-effective manner (Health Service Executive 2013b). While a total of twenty-nine programmes exist, seven programmes (asthma, acute coronary syndrome, heart failure, stroke, diabetes, COPD and mental health) focus on care of chronic conditions (Health Service Executive 2013a). The primary research examines one chronic disease management initiative that is currently being implemented as part of the COPD clinical care programme.

2.5.4 The COPD clinical care programme

Ireland has adopted a similar approach to the HaH approach, described in section 2.5.2, in its treatment of people presenting at emergency departments with exacerbations of COPD. This approach has been adopted through the HSE clinical care programme for COPD (Health Service Executive 2012a). The stated aims of the clinical care programme are to improve the early diagnosis of COPD, to provide evidence-based treatment within the community, to provide patient education to aid patient self-management initiatives and to reduce the number of hospital admissions (National COPD Programme Working Group 2011a; National COPD Programme Working Group 2011b). One element of the COPD clinical care programme is the COPD outreach programme, which is the focus of the primary research contained herein.

Briefly, the COPD outreach programme aims to provide a HaH service for patients who attend an emergency department with an exacerbation of COPD. Currently, patients can be assigned to one of two programmes: an early discharge programme or an assisted early discharge programme. The criteria for entry into each of these programmes are identical; the difference between the two programmes lies in when a patient is admitted to the programme after their attendance at the emergency department. A more complete description of how the COPD outreach programme operates is found at section 5.3.2: The COPD outreach programme.

2.6 Evaluating the solution

It is crucial that any proposed and implemented solution meets the expectations of the stakeholders. Evaluation could be carried out continuously throughout the project as described by Gemert-Pijnen et al. (2011) or could follow a more formal rigorous evaluation path.

Two internationally accepted models have been developed to support patient-centric delivery of chronic care; these are the Chronic Care Model (CCM)(Wagner et al. 2001) and its extension, the Innovative Care for Chronic Conditions Framework (World Health Organisation 2002). Of further interest to this research is the CCM. A description is provided here and its relevance will be further discussed in Section 7.3.2: Evaluating chronic disease management initiatives.

Six key elements are included in the CCM: health care organisation and delivery system design refer to the personnel and patient organisational structures that the healthcare professionals operate in; decision support and clinical information systems refer to access to relevant, timely, evidence-based clinical data to support the needs of patients and information systems to control patient scheduling and other administrative task and self-management support and community resources refer to the provision of links to education, information and support elsewhere (Wagner et al. 2001). It has been shown that by structuring chronic disease managements initiative around these six elements, the quality of care that people with chronic conditions receives improves (Coleman et al. 2009). Further, Darker et al., (2011) evaluated Irish general practice activity in chronic care against the CCM in 2010. Results indicated that while some elements are embedded in GP practices, such as the use of information technology systems and the use of evidence-based guidelines for the treatment of chronic conditions including COPD, other elements are less well developed, such as health care organisation, self-management support and community resources links.

Regardless of how the solution is evaluated, the data captured must be of a sufficiently high standard that renders it useful and relevant.

2.7 Improving data quality

Data quality is an important element of healthcare service delivery (Health Information and Quality Authority 2012b). One definition of data quality is that it is "the alignment between business data requirements and the level of completeness, accuracy, and availability of the data" (Cantin 2011). Thus, an organisation does not need to have a complete data set; rather it needs a data set that is complete enough to meet its business needs. In this regard, HIQA list seven dimensions of data quality: data needs to be complete, timely, legible, relevant, reliable, accurate and valid (Health Information and Quality Authority 2012b).

Many elements aid data quality improvement; however, the one focused on in this research is the use of standardised data collection tools. Currently, standardised assessment paper-based questionnaires, reports and letters are used at each stage of the COPD outreach programme to ensure continuity of care for the patient (National COPD Programme Working Group 2011a). Modifying the underlying business processes and using smartphone or tablet technology to 'capture data once, use many times' has been shown to improve data quality dimensions (Lenz and Reichert 2007). It is suggested that this may prove to be the case also with the COPD outreach programme.

Once the data is collected and of the required quality, there is potential to aggregate and use the data for deriving and reporting key performance indicators as detailed in the COPD model of care working paper (National COPD Programme Working Group 2011a). It has been shown in other projects, such as the Minnesota Hospital Association Pilot Project, that combining data into hybrid data sets in this way drives quality improvements in clinical and administrative areas (Pine et al. 2012).

Improving data quality is the responsibility of all healthcare professionals (Health Information and Quality Authority 2012b). Understanding how information technology can be used to enable and drive data quality improvement is vital.

2.8 Conclusion

The purpose of this chapter was two-fold: firstly, to describe the non-technical aspects of the research by defining what is meant by community healthcare in Ireland, the importance of stakeholder theory and evaluating data quality and infrastructure and secondly, to investigate the health aspects of the research by defining chronic disease management and providing information on one chronic disease, COPD. Having achieved this purpose, it is time to review the technical aspects of the research in the next chapter.

3 Literature Review - Informatics

3.1 Introduction

This chapter focuses on the technical aspects of the research. Firstly, it provides background information on health and other organisations referenced in the research. Secondly, it investigates the three main technical elements of the solution: the architectural approach, the specification method and the computing paradigm in which the research is based. Thirdly, it reviews the role of standards and interoperability. In particular, Table 3-1 provides a list of the topics covered and a reason for their inclusion in this literature review. Finally, section 3.8 provides a synopsis of the literature review and offers a perceived gap that is addressed by the primary research contained in the remainder of this dissertation.

Table 3-1: Topics for inclusion in literature review - informatics

Topic	Reason for inclusion
Health informatics and other relevant organisations	 Provides background into the main organisations that are active in the domain
Dimensions of enterprise architecture	 Examines state of the art architectural approaches that shall be used in the primary research
	 Explores different models that could be used to specify enterprise architecture
Cloud computing	 Defines the cloud computing model
	 Examines state of the art applications using different cloud computing service and deployment models
	 Explores data security and privacy in the cloud
Standards and interoperability	 Defines interoperability
	 Explains the benefits of standards
Smartphone / tablet technology	Examines state of the art smartphone / tablet technology in use within the healthcare domain

3.2 Standards development organisations

3.2.1 The International Organisation for Standardization (ISO)

The International Organisation for Standardization (ISO), established in 1947, is the largest worldwide standard development body. National standard bodies form technical committees which collaborate to develop worldwide standards, with the technical committee within ISO focused on health informatics standards known as TC215 (International Standards Organization 2013a; International Standards Organization 2013b). Two published ISO standards used to specify open distributed systems are RM-ODP ISP/IEC 10746 and Health Informatics - Service Architecture (HISA) ISO 12967 are referenced later in this work (International Organization for Standardization 1998; International Organization for Standardization 2011a).

3.2.2 Health Level Seven International (HL7)

Health Level Seven International (HL7) was established in 1987 as a not-for-profit ANSI-accredited standards development organisation (Health Level Seven International 2013a). The aim of HL7 is to create standards that support interoperability between healthcare information systems in order to support clinical management (Health Level Seven International 2013a). In 2013, HL7 has announced its intention to freely licence its published standards with some restrictions in order to advance its goals of healthcare interoperability for the common good (Health Level Seven International 2013b). HL7 v2.4 is the messaging standard that is currently used in Ireland to support electronic messaging between hospital and general practice. Use of HL7 messaging is considered as part of the solution to providing interoperability between the proposed cloud system and legacy systems.

3.2.3 Comité Européen de Normalisation (CEN)

The Comité Européen de Normalisation (CEN) is an international non-profit association which was established in 1975 (Comité Européen de Normalisation 2013). Its aims are to promote innovation, competitiveness and growth through the development and promotion of consensus-based European standards (Comité Européen de Normalisation 2010). The technical committee concerned with health informatics is known as TC251 (Comité Européen de Normalisation 2009). The Health Informatics - Service Architecture (HISA) ISO 12967 standard referenced in

section 3.2.1 and used in this research was adopted as CEN standard EN ISO 12967 in 2011 (Comité Européen de Normalisation n.d.).

3.2.4 Health Information and Quality Authority (HIQA)

The Irish Health Information and Quality Authority (HIQA) were established in 2007 as an independent authority to promote improvement in the Irish health system (Health Information and Quality Authority 2013a). One of its aims in in producing health information technical standards which support system interoperability (Health Information and Quality Authority 2013c). The GP messaging standard (GPMS), which uses a modified version of HL7 v2.4, is one such standard developed by HIQA and referenced in this research (Health Information and Quality Authority 2013c).

3.3 Other relevant organisations

3.3.1 Healthlink

The National Healthlink Project was established in 1995 (The National Healthlink Project 2013a). Since then it has become the national messaging broker following the development of Healthlink online. Healthlink supports the secure transfer of patient data between general practitioners, hospitals and health care agencies (The National Healthlink Project 2013a).

3.4 Specifying enterprise architecture

The ISO 24765-2010E: system and software engineering – vocabulary standard defines architecture as the "fundamental organization of a system embodied in its components, their relationships to each other, and to the environment, and the principles guiding its design and evolution" (ISO/IEC/IEEE 2010). The operation of an enterprise or organisation requires the combination of a number of separate systems to interoperate in order to provide a seamless service to the end-user. Each of these separate systems may have different architectures. Thus, enterprise architecture is concerned with combining these systems through the use of information technology and business logic (Ross et al. 2006). Moreover other items, such as application, software and integration architecture in addition to business processes can be included within the domain of enterprise architecture (Winter and Fischer 2007).

The community healthcare sector may be considered an enterprise, comprising groups of healthcare professionals and agencies whose aim is to provide continuity of care for a patient across the different areas within the sector. So, it is suggested that the delivery of an effective service in this sector could be underpinned by well-designed standards-based enterprise architecture. Enterprise architecture consists both of bounded systems (such as the proposed cloud system that shall be designed and partially-built as part of this research) and interoperability with legacy systems. For example, the Australian's e-Health interoperability framework divides organisational, informational and technical functions into three strands allowing for separation of concerns while still maintaining an overarching view of different enterprise architecture in use across the country (National e-Health Transition Authority 2007). A similar approach has been adopted by the European Interoperability Framework (Chen et al. 2008).

With respect to the specific architectural approach used in this research project, two options became evident: model-driven architecture (MDA) or service-orientated architecture (SOA). Using a MDA approach, the model is a formal specification of the functionality, structure or behaviour of the system defined using platform independent model(s) (PIM) and at least one platform specific model (PSM) (OMG Architecture Board ORMSC 2001). The PIM represents the abstract system design which is specified using UML (OMG Architecture Board ORMSC 2001). It is mapped to one or more PSM which is the implementation platform (OMG Architecture Board ORMSC 2001). Conversely using a SOA approach, the components of the system are typically stacked as follows: a database storing the data at the back-end and middleware consisting of a combination of XML-based open standards using the internet protocol to communicate between the tiers (Welke et al. 2011). Additionally functional modules, based on user requirements, can be accessed through a service interface (Welke et al. 2011).

Using the MDA approach, it appears that there is no separation of data and functionality per se or that the approach could intuitively be mapped to a cloud computing environment. Conversely, research has been carried out in aligning the SOA approach with the cloud computing paradigm, resulting in a hybrid architectural

approach known as enterprise cloud service architecture (ECSA) (Tang et al. 2010; Wang et al. 2012). However, challenges exist with using an ECSA approach – these include data security, privacy and reliability, data interoperability and the lack of standardised guidelines for adopting cloud-based solutions (Wang et al. 2012). These challenges need to be addressed before widespread adoption is achieved.

Given the fact that community-based services are often geographically separate, and that the solution lends itself to being designed, built and deployed in a modular fashion, an enterprise cloud services architectural (ECSA) approach was selected for use within this research study.

3.4.1 Enterprise architecture models

It is necessary to find a standardised means of specifying and communicating the enterprise architecture to stakeholders. Zachman (2003) proposed a two dimensional representation with six columns representing six perspectives (what, how, where, who, when and why) and five rows representing five roles (planner, owner, designer, builder, sub-contractor), as illustrated in Table 3-2.

Table 3-2: Example of Zachman Framework

	What	How	Where	Who	When	Why
Planner						
Owner						
Designer						
Builder						
Sub-contractor						

Each cell represents an element of the system. Using this model, it is possible to define the boundaries of the system as narrowly or broadly as required. However, it appears difficult to see how dependencies between cells could be represented within the model.

The open distributed processing reference model (RM-ODP ISO/IEC 10746) is an ISO standard that provides a concise and coherent means of specifying open distributed systems (International Organization for Standardization 1998). It consists of five viewpoints: enterprise, information, computation, engineering and technology

(International Organization for Standardization 1998). Each viewpoint is aimed at a different audience and specifies distinct characteristics of the system, as outlined in Table 3-3.

Table 3-3: RM-ODP viewpoint definitions

Viewpoint	Definition	Definition adapted from
Enterprise	Concerned with specifying business objectives, rules, policies, processes and the relationships between them within the domain	(Linington et al. 2011)
Information	Concerned with specifying the shared information, their relationships and behaviours in the domain	(International Organization for Standardization 2011b; Linington et al. 2011)
Computational	Concerned with specifying the high level design of components in a platform-independent manner. The relationship between components are through formally defined interfaces	(International Organization for Standardization 2011c; Linington et al. 2011)
Engineering	Concerned with the specific platform- dependent functionality required to deploy the system in a distributed environment	(International Organization for Standardization 1998)
Technology	Concerned with the specific technology to use to implement the system	(International Organization for Standardization 1998)

These viewpoints can be specified independently but are linked together through the use of "viewpoint correspondences" – defined as "a statement that some terms or linguistic constructs in a specification from one viewpoint are associated with (e.g. describe the same entities as) terms or entities in a specification from a second viewpoint" (International Organization for Standardization 2009). Together, the five viewpoints form a full specification of a system.

The RM-ODP ISO/IEC 10746 standard forms the basis of another standard aimed specifically at systems within the healthcare domain, known as Healthcare Informatics Service Architecture (HISA) (EN ISO 12967) (International Organization for Standardization 2011a). HISA uses the three platform-independent viewpoints of the original RM-ODP standard; namely, enterprise, information and computational. In this way, the focus is on what is required, in terms of processes, policies,

information and high level design, rather than how it is delivered (Calvillo et al. 2013).

The RM-ODP ISO/IEC 10746 standard has been used successfully in many healthcare projects (Grimson et al. 1996; Bond et al. 2013). Moreover, it is an accepted standard within the sector. Indeed, Blobel (2006) advocates the use of a component-based architectural approach in the delivery of electronic health record systems. Additionally, there is a strong alignment between what the RM-ODP is designed to specify and the proposed enterprise service cloud architecture. Despite this, since the focus of the research is concentrated in two of the three platform-independent viewpoints which are included in the HISA standard, it was decided that the HISA standard be used in this research. More detail on how this was executed can be found at Section 5.2.2: Using the HISA standard.

Additionally, using the HISA standard to specify the proposed solution aligns well with the ECSA architectural approach described in the previous section, given that both offer a service-orientated approach.

Two elements of the technical solution have been explored – the architectural approach and a standard way to specify it; what remains is to describe the cloud computing paradigm, which is the focus of the next section.

3.5 Cloud computing

3.5.1 Definition of cloud computing

First referenced by Ramnath Chellappa in 1997, cloud computing is defined as an information technology model that offers services on demand over a network (Marston et al. 2011). Moreover, services are provisioned and accessed in real time using smartphone, tablet or desktop technology irrespective of location (Buyya et al. 2009). Furthermore, resource optimisation and allocation is carried out within the cloud system depending on customer usage and requirements (Marston et al. 2011). Finally, virtualisation – the process of assigning logical units of computing processing power to multiple physical devices – is a key component of any cloud computing model (Buyya et al. 2008).

The business case for using cloud computing is compelling – there is a low cost of entry and immediate access to hardware resources. Further, the model allows enterprises to scale according to their needs which in turn lower the information technology barriers to innovation. Finally, it offers the opportunity to offer new service types, such as interactive mobile applications (Marston et al. 2011). However, given the sensitivity around healthcare data, protection and security of that data are issues that need to be understood and addressed before the model will be accepted (Kuo 2011).

3.5.2 Cloud computing service models

The widely accepted National Institute of Standards and Technology (NIST) definition of cloud computing advocates three service and four deployment models (Mell and Grance 2011). Cloud computing service models offered are: Infrastructure as a Service (IaaS), Platform as a Service (PaaS) and Software as a Service (SaaS), while its deployment models are private, community, public or hybrid cloud. These service models can be viewed as a stack, with each higher level on the stack providing more services but less flexibility for the end user, as illustrated in Figure 3-1.

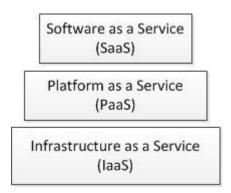


Figure 3-1: Cloud computing service model stack

IaaS: Infrastructure as a Service

At the bottom of the stack is IaaS which is a service aimed at system administrators who need access to a virtual machine and network storage (Badger et al. 2012). Typically, the end user can install any software or database they wish to on the virtual machine but they are responsible for its maintenance.

Examples of companies that provide these services include Amazon Web Services and OpenNebula (Amazon Web Services 2013; OpenNebula Project 2013). Amazon's elastic compute cloud (EC2) is Amazon's web services IasS platform. It has the ability to scale computing power up and down quickly and effortlessly. This has been successfully used in a variety of bioinformatics projects, such as a costeffective genome-genome comparison project (Kudtarkar et al. 2010) or the assembly of a full human genome which required large computing power (Bateman and Wood 2009). Both of these projects indicate the processing capacity of the IaaS platform. The OpenNebula project is an open-source project aiming to deliver and manage enterprise data centres and enterprise private clouds (OpenNebula Project 2013). OpenNebula was selected as the IaaS platform for the CloudHealth project which aimed to develop a prototype of a secure, interoperable, available and portable EHR system (Hendrick et al. 2013). Results from this project indicate that while OpenNebula is a powerful IaaS platform, detailed system administration skills are essential in order to fully utilise its potential (Hendrick et al. 2013). Typically, the bundle offered includes the IaaS if a PaaS or SaaS service is selected.

PaaS: Platform as a Service

PaaS is an application development platform whereby application developers have access to development, runtime, testing, database and other software environments in order to develop, test and deploy applications that run in the same environment (Badger et al. 2012). Companies that provide this service include Saleforce.com and Window Azure. Typically, the company provides a set of programming languages and an environment in which to develop applications with those languages. By default, the consumer gets IaaS when using PaaS.

For example, Window's Azure platform was used in conjunction with smartphone technology to provide 12-lead electrocardiography (ECG) service to rural locations in Taiwan (Hsieh and Hsu 2012). Cardiologists found the service to be medically useful since they did not need to be onsite at the hospital to view the results of the ECG (Hsieh and Hsu 2012). Moreover, Salesforce.com have developed a number of PaaS solutions for pharmaceutical and healthcare providers, including AmerisourceBergen, a pharmaceutical company who use Salesforce.com's functionality to respond to

customer queries, automate workflow and reduce paperwork (Salesforce.com 2013a) and the Schumacher Group, the largest American emergency medicines practice management company, who use Salesforce.com's integration functionality to interface with legacy systems (Salesforce.com 2013c).

SaaS: Software as a Service

SaaS is defined as "software deployed as a hosted service and accessed over the Internet" (Badger et al. 2012). The end user is provided with a web user interface into hosted software applications, such as office applications or email. Typically, there is little scope for development, although some customisation may be possible. Well-known examples of SaaS services include Gmail or Dropbox. Another company that provides SaaS service is Salesforce.com.

Section 6.2.2: Criteria for selecting the cloud computing platform provide the reasoning behind how a decision was reached on which service model to use within the research.

3.5.3 Cloud computing deployment models

A cloud can be deployed as private, public, community or hybrid (Mell and Grance 2011). It has been suggested that a cloud is the sum of the hardware and software that makes up a data centre; it is a private cloud if the data centre is owned by one organisation, otherwise it is a public cloud which is billed by subscription (Armbrust et al. 2009; Armbrust et al. 2010). However, this definition does not encompass the NIST definition of a private cloud which indicates that the "cloud infrastructure is solely for an organisation", which can be managed by the organisation or a third party.

3.5.4 Data security in the cloud

According to ISO/IEC17799:2000, the maintenance of three data characteristics defines data security: confidentiality, availability and integrity (International Standards Organization 2000). Data confidentiality is defined as "ensuring that information is accessible only to those authorized to have access" (International Standards Organization 2000). Data integrity is defined as "safeguarding the accuracy and completeness of information and processing methods" (International

Standards Organization 2000), which is linked with data quality which has previously been discussed in Section 2.7: Improving data quality. Data availability is "ensuring that authorized users have access to information and associated assets when required" (International Standards Organization 2000), which can be achieved through regular system maintenance and is beyond the scope of this research.

Data security and confidentiality within cloud healthcare systems are essential to their acceptance by patients and healthcare professionals. Implementation and management of data security have different administrative burdens depending on the service model selected, with SaaS having the least (due to the inclusion of the security model within the product), and IaaS having the most (Zhang and Liu 2010).

3.6 Standards and interoperability

The cloud computing paradigm discussed in the previous section offers a platform upon which to develop functionality that may support patients and healthcare professionals in the delivery of the COPD outreach programme. The other half of the solution, mentioned in Section 1.6: Research scope, is that new functionality should interoperate with legacy systems for the solution to be truly useful. This highlights the importance of standards to achieve the aim of interoperability between systems.

Standards provide a common language or schema which can be used regardless of what technology is implemented and which aims to allow interoperability between systems.

Car et al., 2008 establish that interoperability is "the ability of different technology systems and software applications to communicate, to exchange data accurately, effectively and consistently, and to use the information that has been exchanged". Further, HIMMS suggest that there are three levels of interoperability within healthcare: foundational, whereby data exchange is possible but the receiving system is not required to interpret the data; structural, whereby a data contract is in place between the sending and receiving systems and the receiving system is capable of syntactically decomposing the message and semantic, whereby both sending and receiving systems interpret the structure and meaning of the data in the same way (HIMSS Board of Directors 2013).

Implementing interfaces using standards is beneficial to organisations in a number of ways. Firstly, standards provide concise and agreed definitions of terms, which in turn avoid misunderstandings during design and implementation between stakeholders, as illustrated through the use of RM-ODP in healthcare specifications (Calvillo et al. 2013). Secondly, using standards reduces research risks and development costs (German Institute of Standarization (DIN) and German Federal Ministry of Economic Affairs 2000). A further study carried out in the United Kingdom illustrates that using standards both enabled innovation and facilitated technological change (Swann 2010). Finally, using standards reduces the complexity of a system through the reduction of the number of interfaces that are required to implement that system (Benson 2012).

3.7 Smartphone and tablet technology

The use of smartphone and tablet technology within healthcare is becoming ubiquitous (Boulos et al. 2011). For patients with chronic conditions, the ability to self-manage their condition using smartphone applications, such as the Asthma Coach developed by (Asthma Society of Ireland 2012) or the Migraine Monitor developed by (Irishhealth.com in association with the Migraine Association of Ireland 2009), allows them become more involved in their own care. For healthcare professionals, using such technology provides the opportunity to capture their patients' data electronically. For example an Irish company, Doctot, have developed an offline GOLD COPD evidence-based smartphone application (Doctot 2012) which allows healthcare professionals capture a patients' quality of life score based on the COPD assessment test (GlaxoSmithKline 2009). Using smartphone and tablet technology is not without its challenges, including the processing speed of mobile phones, data security if data were to be stored on the handheld device and the patient cohort's ability to use the application as designed (Boulos et al. 2011). Some of these challenges can be met through the use of the cloud computing model and are explored through the course of this research.

3.8 Conclusion

The two literature review chapters present background information on the research topic. Specifically, chapter 2: Literature Review - Health examines community healthcare in Ireland, stakeholder theory, the importance of improving data quality and provides details on chronic disease management initiatives and in particular, COPD. Chapter 3: Literature Review - Informatics describes the three main technical aspects of the research: the architectural approach, the specification method and the proposed cloud computing model. Additionally, the role of various organisations and standards and interoperability are reviewed.

In so doing, theoretical foundations were built which shall be used to develop the primary research. While much research has been carried out in the areas of enterprise architecture, cloud computing and community healthcare, it appears that there has been to date, very little overlap between the three research topics. Application of the hybrid approach of combining a service-orientated architectural approach with a cloud computing delivery model to a community healthcare 'enterprise' or organisation offers an opportunity to explore how this innovative approach may benefit the patients and healthcare professionals involved with the COPD outreach programme.

Thus having identified a perceived gap, it is necessary to select an appropriate research paradigm and research methods in which to conduct a research study. The next chapter describes the approach taken in the selection of the research paradigm and the research methods used in carrying out the research study.

4 Research Design and Methodology

4.1 Knowledge and the research process

Knowledge, and the fundamental quest for it, is a key component in research. The approach one takes towards gaining knowledge of the subject matter in question is influenced by one's belief systems. Epistemology, defined as a "theory of knowledge, especially with regard to its methods, validity and scope" (Pearsall 1999), forms the foundations of all research projects. Moreover, the epistemological assumptions influence research paradigm selection (Higgs and McAllister 2001). However, research paradigm selection is primarily dictated by the research question (Higgs and McAllister 2001).

The use of a research paradigm from which the methodologies and methods flow is essential to ensure the coherence of the research project (Ford-Gilboe et al. 1995). Both positivist and interpretative research paradigms are used within health informatics research. The positivist paradigm offers a more scientific, statistical approach to answering a research question, while the interpretative paradigm offers an opportunity to examine a phenomena from the experiences and viewpoint of the people whose reality it is (Wildermuth 1993). However, it has been argued that a pragmatic approach can be taken in what research methods are utilised in answering research questions, regardless of the paradigm chosen, provided that they fit with the underlying epistemological assumptions (Weaver and Olson 2006).

Therefore, careful consideration has been given to the choice of research paradigm and the research methods that flowed from that decision.

4.2 Research paradigm

In this instance, the research question is

How could cloud-based enterprise architecture for community healthcare support its stakeholders?

It is felt that the most appropriate research paradigm to conduct the research in is an interpretative paradigm based on the following assumptions:

- Each stakeholder has a different view on how an information technology system should and / or could work to support the COPD outreach programme.
- It is possible to capture stakeholder's requirements and design an enterprise architecture to support those requirements at this time given that the COPD outreach programme is new, evolving and primarily paper-based.
- It is possible to extrapolate from the differing stakeholder views opinions about how information technology could support community healthcare beyond the scope of the COPD outreach programme.
- It is possible to evaluate the relative influence each stakeholder feels they have on the service delivered.

4.2.1 Limitations

There are limitations to each paradigm which have to be accounted for. Using the interpretative paradigm has the following four limitations: firstly, loss of objectivity poses the risk of being unable to see emergent patterns (Weaver and Olson 2006). Secondly, potential of researcher bias which may affect the study results and should be minimised (Ford-Gilboe et al. 1995). Thirdly, the ability (or not) to confirm the validity of the data collected from the participants in the study (Ford-Gilboe et al. 1995). Finally, the ability to generalise the results of the research study (Ford-Gilboe et al. 1995).

The author has attempted to mitigate these limitations by aggregating the data captured and using the aggregated data in the solution. Thus, researcher bias has been

reduced and objectivity increased (although not completely removed). Additionally, an evaluation step has been included in an attempt to confirm the validity of the data collected. Finally, there is potential for the proposed solution to be applied to other chronic care initiatives with some modification.

4.3 Research methods

Research methods refer to the techniques used in carrying out the research (Ford-Gilboe et al. 1995). This section presents the data collection tools and research methods that were used during this research. Figure 4-1 illustrates the boundaries that the research was conducted within. The design of this framework attempts to mitigate some of the limitations of the interpretative paradigm, as outlined in section 4.2.1.

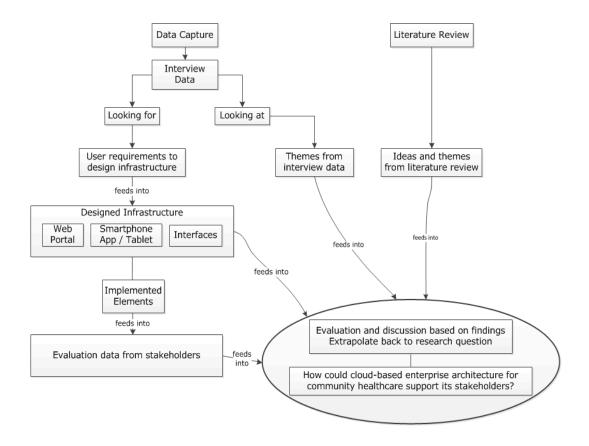


Figure 4-1: Research framework used in this work

4.3.1 Literature review

The purpose of this section is two-fold: to connect the literature review with the stated research objectives and to describe the literature search strategy. More detail has

been previously provided on why each topic was included in the literature review in Table 2-1: Topics for inclusion in literature review - health and Table 3-1: Topics for inclusion in literature review - informatics on pages 7 and 20 respectively.

Initially, a narrative literature review in the areas of community healthcare, enterprise architecture, cloud computing and stakeholder theory was carried out in order to obtain a broad level of knowledge in the research area.

Following that, a systematic literature review was carried out in order to answer the research sub-questions as defined in Section 1.3: Research question and set out in Table 4-1.

Table 4-1: Connecting literature review topics to research sub-questions

Topics	Research sub-question
Community healthcareStakeholder theoryChronic disease management	Who are the stakeholders and what are their information technology requirements?
 Enterprise architecture Cloud computing Smartphone / tablet technology 	To what extent can cloud-based services offer a solution?
Standards and interoperabilityHealth informatics organisations	What standards could be used to ensure system interoperability between legacy and new systems?
Case study: chronic obstructive pulmonary disease	How can the proposed infrastructure be used in practice with a specific patient cohort?

Information was initially obtained from the following sources: British Standards Online, IEEE Digital Library, PubMed, Science Direct, Springer and Google Scholar (The British Standards Institution 2013; IEEE 2013; National Center for Biotechnology Information 2013; Elsevier B.V. 2013; Springer 2013; Google 2013). Material referenced included both published and grey literature. In the case of published literature, the reference lists of these articles were examined to locate additional relevant articles. Grey literature was searched to obtain working papers, reports, industry writing and technical notes on the topics as required in Table 4-1 (O'Leary 2010).

The literature search was limited to English language articles.

4.3.2 Information gathering

Information was gathered from stakeholders through a series of semi-structured interviews. The purpose of these interviews was three-fold: firstly, to elicit how the COPD outreach programme is currently run; secondly, to obtain a set of user requirements that would inform the architecture design and finally, to determine any emergent themes amongst stakeholders in community healthcare.

Each stakeholder category had a different interview protocol developed specifically to meet the needs of each category with a core set of questions, as documented in Appendix A: Interview Protocols. The semi-structured interview format allowed provision for additional questioning around those core questions. This was to ensure that user requirements were obtained but also provided scope for themes to emerge as per the interests of the interviewees.

The sample group selected was non-random because a specific set of healthcare professionals work with the outreach service and a specific set of patients are associated with it. Consequently, two sampling techniques were used to select the participants: handpicked sampling to ensure domain expertise and snowball sampling to ensure enough representation within each stakeholder group (O'Leary 2010). Using the snowball sampling technique required asking the initial interviewees for the names of other people who they felt may be interested in participating. Each participant was contacted by email or post with an invitation to participate in a semi-structured interview on the research. An interview appointment was set up following agreement by the participant to be included in the research study.

There was an option to record the interview if the participant was agreeable and the researcher had a recording device available to do this. In these instances, the interview was transcribed; in the remaining cases, the researcher took notes during the interview which were written up. In all cases, data was aggregated to carry out the analysis which is described in the next section.

4.3.3 Data analysis

A set of seven data analysis tasks were defined in order to attempt to answer the research questions in two categories:

- Laying the foundations of enterprise architecture
- Understanding what the architecture can offer different stakeholder groups

Laying the foundations of enterprise architecture

Four data analysis and design tasks were identified and carried out in this category. Table 4-2 provides a description of each task and links it back to the appropriate research sub-question.

Table 4-2: Task List - laying the foundations of enterprise architecture

Task number	Task description	Research sub-question
1	Understand the stakeholders and their information technology requirements	Who are the stakeholders and what are their ICT requirements?
2	Define a set of user requirements	Who are the stakeholders and what are their ICT requirements?
3	Define a data model	Who are the stakeholders and what are their ICT requirements?
4	Design an enterprise architecture	Who are the stakeholders and what are their ICT requirements?
		To what extent can cloud-based services offer a solution?

Understanding what the architecture can offer different stakeholder groups

Three data analysis, design and implementation tasks were identified and carried out in this category. Three elements of the design were implemented based on the user requirements obtained in the first set of tasks. A third set of requirements was selected in order to illustrate interoperability between systems in the architecture. Table 4-3 provides a description of each task and links it back to the appropriate research sub-question.

Table 4-3: Task List - what the architecture offers to different stakeholder groups

Task number	Task description	Research sub-question
5	Implement an application that can be used on a handheld device to capture patient details, upload this data and	How can the proposed infrastructure be used in practice with a specific patient

	view it via the cloud portal.	cohort?
	It should be possible to view data through the application by a variety of different community healthcare professionals and patients in a variety of different locations.	To what extent can cloud-based services offer a solution?
6	Implement a reporting module that can be accessed via the cloud portal.	How can the proposed infrastructure be used in practice with a specific patient cohort?
7	Describe the transfer of clinical data between a community-based information technology system and the cloud portal using health informatics standards.	What standards could be used to ensure system interoperability between legacy and new systems?

4.3.4 Design and software evaluation

An evaluation of the architecture designed and the software elements implemented was carried out on a subset of the original stakeholders. The selected subset of participants was recruited based on continuing interest in the research from the different stakeholder groups. Each participant was contacted by email or post with an invitation to participate in the design and software evaluation. Each appointment was set up following agreement by the participant to be included in the research study.

Given time limitations, the author deemed the initial evaluation questionnaire (Appendix B: Original Evaluation Questionnaire) too large to execute with the selected participants. The initial questionnaire had three sections: the first section containing seven questions requested feedback on the solution's architectural design, the second section containing three questions requested feedback on the implemented elements and the final section gathered demographic information.

A more concise questionnaire (Appendix C: Evaluation Questionnaire Used) was developed based on the initial one. It consisted of ten questions and focused on obtaining the participants' impression on whether the proposed designed solution and implemented software elements would address their requirements in relation to the following areas: perceived potential for improvement in service delivery to patients and the perceived potential for improvement in data quality. In addition, it queried

the importance of patient involvement in chronic disease management and the extent to which the proposed solution may address such involvement.

Each evaluation followed a structured format as follows: the author provided a short presentation and demonstration on the proposed solution, followed by the participant using the software for a short period of time and asking any questions that they had. Finally, the participant was asked to complete the evaluation questionnaire. Data was aggregated and included in the research findings, as per Figure 4-1: Research framework used in this work.

4.3.5 Thematic coding

The final data analysis task that was identified and executed was a thematic analysis of the interview data. The interview data was coded to identify emergent themes. The identified themes were included in the research findings, as per Figure 4-1: Research framework used in this work.

4.4 Ethical considerations

A requirement of any research study that involves human participation is that ethics approval is sought and obtained from the Research Ethics Committee of the School of Computer Science and Statistics (Research Ethics Committee 2013). Thus, an application was made comprising a research proposal, the proposed participant information sheets and consent forms for both the planned semi-structured interview and the evaluation. Ethics approval was granted in January 2013 to carry out this research study.

The data collected during the research study was treated in accordance with the Data Protection Acts (& Amendments). Specifically to ensure participant anonymity, each participant was given a code. The participant-code combination was stored in a password protected Excel spread sheet to which only the author had access. Additionally, once the data was analysed and aggregated, it was not possible to attribute any particular requirement or opinion to a specific person. No direct quotes were used.

The prototype system was populated with a small amount of manufactured (dummy) patient data. During the evaluation stage, this data was shown to the participants to illustrate the feasibility of the solution. Real patient data was never used during the course of the research study. A copy of the ethics application is provided in Appendix D: Ethics Application.

4.5 Conclusion

This chapter explored the reasoning behind the research paradigm selected to carry out the primary research and listed the limitations of the selected paradigm. It described the research methods that shall be used in terms of a research framework. Finally, it outlined the process followed in order to obtain ethical approval to carry out the proposed research study.

The following chapters describe the primary research, beginning with defining the foundations of enterprise architecture in the context of the research study conducted and from there, considering what the designed architecture offers its stakeholders.

5 Foundations of Enterprise Architecture

5.1 Introduction

The community healthcare sector consists of groups of healthcare professionals and agencies whose aim is to provide care for their patients across the different areas within the sector. Their work may be more effectively supported by well-designed standards-based enterprise architecture.

As stated previously in Section 4.3.3: Data analysis, seven data analysis tasks were defined in order to attempt to answer the research sub-questions in two categories:

• Laying foundations of enterprise architecture

• Understanding what the architecture can offer different stakeholder groups

The next two chapters shall explain the execution of the seven tasks listed in section 4.3.3 on page 37. Firstly, Section 5.2 shall outline the methodological approach taken to analysis, design and implementation of these tasks. Specifically, this chapter is concerned with the first four tasks, listed in Table 5-1, that fall under the category of laying foundations of enterprise architecture.

Table 5-1: Laying the foundations of enterprise architecture

Task number	Task description
1	Understand the stakeholders and their information technology requirements
2	Define a set of user requirements
3	Define a data model
4	Design an enterprise architecture

The first task explores the role of stakeholders and their information technology requirements. The final three tasks in this chapter propose a solution underpinned by the principles that lie at the heart of the HISA standard; namely its focus on the development of "a unified open architecture based on middleware independent from specific applications and capable of integrating common data and business logic and of making them available to diverse, multi-vendor applications through many types of deployment" (International Organization for Standardization 2011a).

5.2 Approach taken to analysis, design and implementation

The software development life-cycle followed a simple waterfall model whereby each stage in the life-cycle – requirements gathering, design, implementation and evaluation – follow sequentially (Boehm and TRW Defense Systems Group 1987). This approach allowed for input from patients and healthcare professionals at the requirements gathering and evaluation stages in the software development life-cycle. Thus, those stakeholders that benefit directly from the service influence its evolution and implementation, as highlighted in Section 2.3: Stakeholder theory.

5.2.1 Design principles

The architecture design was based on a number of design principles and methodologies: an architectural design pattern, known as Model-View-Controller (Gamma et al. 1995), allowed loose coupling between the data model (model) and the user interface (view) with the controller (referred to as middleware in the HISA standard) providing the business logic. The business logic can be as simple or as complex as required. Furthermore, for each element that required further analysis, the following UML diagram types aided that analysis: the class diagram aided understanding of the domain, the use case described how the system should act in a specific situation and the activity diagram provided flowcharts to describe business logic within specific scenario. Not all of the UML diagrams types described above are used in every scenario; they are used where appropriate.

Jensen (2013) suggested five design principles for an infrastructure integration project in Denmark. While the architectures of the author's proposal and the Danish case study are different, the design principles upon which they are based are pragmatic and similar: start small with targeted solution that is useful to the stakeholder, expand by

building modularly using appropriate standards, obtain and maintain stakeholder buyin through collaboration and keep the information technology as simple as possible
(Jensen 2013). The final design principle is to use existing infrastructure and systems
(Jensen 2013). Using existing infrastructure and systems implies designing a solution
that creates a system with the newly defined functionality in addition to being
interoperable with legacy systems. While both elements are required for a full
solution, the research focus is on the provision of new functionality rather than on
ensuring interoperability with legacy systems.

5.2.2 Using the HISA standard

The principles underpinning the HISA standard have been used to specify the proposed solution. The enterprise viewpoint is used to specify the requirements and high level design of the proposed architecture and its effect on the business processes of the COPD outreach service. The information viewpoint is used to partially specify the data elements that support the proposed architecture. If used, the computational viewpoint would provide a model comprising a set of actions that can be carried out on the information objects specified as part of the information viewpoint (International Organization for Standardization 2011c). However, the platform selected has its own internal computational model which is deemed adequate for the purposes of this research.

The HISA standard recommends that the UML is used in specification (International Organization for Standardization 2011a). Consequently, the UML is used extensively in the specification in the form of class diagrams, use case diagrams and activity diagrams, as described previously. Finally, the two viewpoints offer different perspectives of the same architecture. The combination of the enterprise and information viewpoints offers a fuller picture of the solution specification, through the use of viewpoint correspondences as defined in Section 3.4.1: Enterprise architecture models.

5.2.3 User requirements gathering

Information technology requirements were extracted from the aggregated interview data. These requirements aimed to support more electronic communication between

patients, hospital- and community-based healthcare professionals involved with the COPD outreach programme.

5.3 System specification - enterprise viewpoint

5.3.1 Domain description

Both hospital- and community-based healthcare professionals care for patients with COPD. Hospital-based staff include hospital consultants, clinical nurse specialists and physiotherapists. Community-based staff include general practitioners, practice nurses, pharmacists, out-of-hours GP services, members of primary care teams and others. Patients have been diagnosed with COPD and attend services provided in both hospital and community locations.

Information about the patient is stored in a variety of locations. Typically in hospitals, information about the patient is currently stored in both the hospital information systems and in paper medical charts. Typically in GP surgeries, information about the patient is currently stored in the GP's patient management system. A patient's medication and prescription information is stored in the pharmacies' dispensing software.

Currently, communication between hospital and community-based healthcare professionals about a patient is generally via posted letter or telephone contact. There is no way of ensuring that the communication has been received or that any actions communicated have been executed.

5.3.2 The COPD outreach programme

The COPD outreach programme is a HaH programme, as described in Section 2.5.2: Hospital at home. It is a hospital-based outreach service which treats patients within the community. Its aim is to reduce hospital admissions for patients with COPD exacerbations. Paper-based, standardised quality of life questionnaires, reports and letters are used at each stage and aim to ensure continuity of care for the patient.

When a patient attends an emergency department with a COPD exacerbation, they are assessed for eligibility into the early discharge programme of the COPD outreach programme. Provided they meet a defined set of medical criteria, the patient is

discharged under the care of the COPD outreach team within 72 hours of presentation to an emergency department. An outreach team member (either a clinical nurse specialist or a senior physiotherapist) visits and assesses the patient in their own home on days 1, 2, 3 and 14. The patient remains under the care of the hospital consultant until day 14. On day 14, care is transferred back to the patient's own GP. The final visit from the outreach team takes place after week 6. The patient is discharged from the service at this point. The underlying assumption of this process, which is diagrammed in Figure 5-1 overleaf, is that the patient recovers throughout; should complications arise, the patient may be admitted into hospital.

During the initial visit, which lasts between 45 and 90 minutes, the outreach team member takes a full assessment of the patient. This includes a set of objective observations (blood pressure, temperature etc.) and a set of subjective evidence-based quality of life questionnaires (Borg breathless score, COPD assessment score etc.) which aim to ascertain how a patient's quality of life. Additionally, the outreach team member verifies the medication that the patient is on, which often involves communication with the patient's pharmacist and GP. Finally, the outreach team member discusses what other community-based resources that the patient may require. Such resources include occupational therapy or access to smoking cessation services. Notes are taken during the consultation. Upon returning to the COPD outreach office, the outreach team member documents the medical notes, writes referrals letters to appropriate services, writes to the patient's GP and uploads required information to the Hospital In-Patient Enquiry (HIPE) system. More information on uploading required information to HIPE is documented in Appendix F: F.7: High level design for Mod 009: share administrative data.

On subsequent visits, the outreach team member records a set of patient observations and quality of life questionnaire scores. The outreach team member provides COPD education and support to the patient about COPD during these visits.

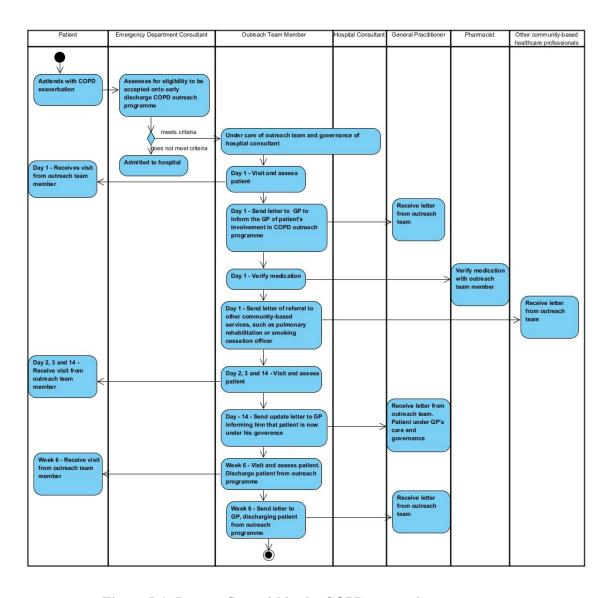


Figure 5-1: Process flow within the COPD outreach programme

5.3.3 Identifying stakeholders

Creation of the stakeholder identification wheel, described in section 2.3: Stakeholder theory produced the wheel illustrated in Figure 5-2.

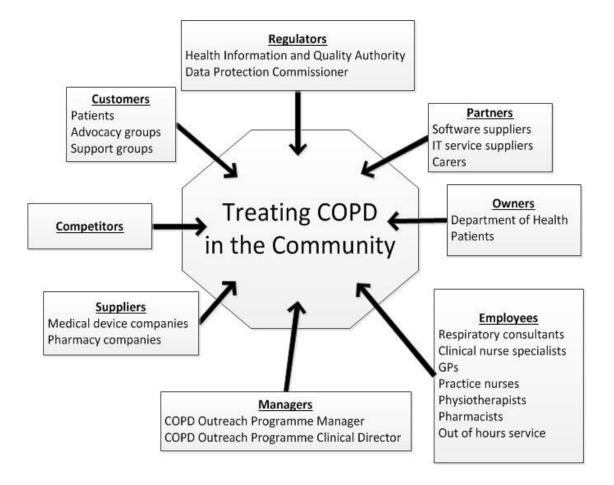


Figure 5-2: Completed stakeholder identification wheel

Using this stakeholder identification method ensured that no stakeholder was accidently excluded. However for the purposes of this research, a subset of five stakeholder categories were identified from the full set listed in Figure 5-2. Table 5-2 provides this mapping.

Table 5-2: Stakeholder categories and number interviewed in each category

Stakeholder category	Identified in stakeholder wheel as	Description	Number interviewed
Category 1	Employees	Stakeholders who treat patients directly within the COPD outreach programme, such as physiotherapists and clinical nurse specialists	9
Category 2	Employees	Stakeholders who treat COPD patients within the community, such as GPs, practice nurses, out-of-hours services and pharmacists	9
Category 3	Customers	Interest and support groups leaders	2
Category 4	Managers Owners	Stakeholders who manage the outreach programme	2
Category 5	Competitors Regulators Suppliers Partners	Industry stakeholders	1

5.3.4 Describing stakeholders

Information was obtained from a cross-section of stakeholders through a series of semi-structured interviews, as described in Section 4.3.2: Information gathering. The information obtained from stakeholders during the interviews was divided into requirements which were used to inform the enterprise architecture design presented herein and themes which were included in chapter 7: Discussion. A total of twenty three participants took part in the study. Their characteristics are described in the following sections.

5.3.4.1 Category 1: Stakeholders who treat patients in outreach programme

Category 1 stakeholders are a subset of the employee group in the stakeholder identification wheel. The COPD outreach programme model of care indicates that a team consists of a respiratory consultant, a respiratory nurse specialist and a respiratory physiotherapist (National COPD Programme Working Group 2011a).

The role of the pulmonary physiotherapist and the clinical nurse specialist is to provide the day to day service that the COPD outreach programme offers; namely, to visit patients in their homes and to provide care for their COPD in the community.

Consequently, three physiotherapists and four clinical nurse specialists were interviewed.

The role of the respiratory consultant is to provide clinical support for patients enrolled in the COPD outreach programme during the first 14 days prior to the patient's transition back to care under general practice, should it be required. One respiratory consultant was interviewed.

The role of the physiotherapy manager is to provide management and guidance for the physiotherapists under their supervision. One physiotherapist manager was interviewed.

5.3.4.2 Category 2: Stakeholders who treat patients in the community

Category 2 stakeholders are a subset of the employees group in the stakeholder identification wheel. A diverse set of healthcare professionals treat COPD patients within the community; these include GPs, pharmacists, practice nurses, out-of-hours services and others.

The role of a GP within the context of the COPD outreach programme is to provide medical care after the initial 14 day period. Five GPs were interviewed for this study; four were in urban general practice, one was in rural general practice. Respiratory clinics are held in some general practices. The practice nurse interviewed for this study ran one such clinic in an urban general practice.

Medication is vital to control symptoms in COPD patients. Two pharmacists were interviewed for this study; both worked in busy suburban pharmacies.

The out-of-hours general practice service offers acute episodic care for patients. In some cases, a patient may choose to attend such a service in preference to an emergency department if they are aware of their COPD exacerbations and feel it can be managed best in that way. One medical director of a rural out-of-hours service was interviewed. Finally, one of the GPs interviewed was also a medical director of a Dublin-based out-of-hours service and, where appropriate, he answered on behalf of the out-of-hours service.

A known limitation in the study was the lack of input from public health nurses and members of community intervention teams. Attempts were made to interview both groups since it was felt that both would offer a different perspective; however, it was not possible to recruit participants.

5.3.4.3 Category 3: Support group leaders

Category 3 stakeholders are from the customers group in the stakeholder identification wheel. Both support group leaders interviewed have been diagnosed with COPD. They both have high levels of COPD knowledge and its many implications and are interested in self-management strategies.

One support group leader represented a large rural support group, where the local hospital does not currently have a COPD outreach programme in place. Consequently, some of the questions and answers were theoretical.

The other support group leader represented a smaller urban support group, where the local hospital does have a COPD outreach programme running for a number of years. This outreach programme has been and is currently used by a number of the group members.

In hindsight, it would have been interesting to obtain more views from patients, especially in light of the relative influence that patients may have on the development of a healthcare service, as highlighted in 2.3: Stakeholder theory.

5.3.4.4 Category 4: Stakeholders who manage the outreach programme

Category 4 stakeholders are a subset of the managers group in the stakeholder identification wheel. Both people interviewed in this category are members of the HSE's national COPD clinical programme working group.

They are both involved in the roll-out of the COPD clinical care programme with an aim to ensuring that there is an even spread of COPD outreach programmes around the country.

They are both interested in obtaining data from the programme with respect to patient outcomes and programme cost-effectiveness as efficiently as possible.

5.3.4.5 Category 5: Industry stakeholders

Category 5 stakeholders are in the partners group in the stakeholder identification wheel. The interviewee worked in a company that develop medical smartphone applications. As such, the interviewee provided background and perspective into how to develop smartphone applications for the medical sector.

Consequently, the interviewee did not provide any specific requirements that could be used in the architecture design. However, the interviewee's opinions are included in discussion chapter.

A known limitation within the study was the small number of participants interviewed from this category; obtaining the requirements and views of regulators, competitors and suppliers would have provided a more rounded perspective on the research topic.

5.3.5 Functional user requirements

The functional user requirements form the basis of the solution. Fifty requirements were gathered from stakeholders. These were divided into four categories, one for each stakeholder category. Table 5-3 provides an overview of the number of requirements gathered per stakeholder category.

Table 5-3: Number of user requirements by stakeholder category

Stakeholder category	Number of user requirements
Category 1: Treat as part of outreach programme	21
Category 2: Treat in community	14
Category 3: Interest and support groups	4
Category 4: Management	11
Total	50

Each group of stakeholders have a different perspective on the problem and on what is required in information technology architecture to support their needs.

Table 5-4 provides a flavour of the requirements, which contain a combination of new functionality and integration with legacy systems, as they were suggested by the

different stakeholder groups. A full listing of requirements is provided in Appendix E: Complete Set of User Requirements.

Table 5-4: Some of the requirements suggested by stakeholders

Stakeholder category	Requirement description	Requirement type
Category 1: treat as part of outreach programme	Capturing patient information, such as demographics, observations, quality of life scores and medication on a handheld device in the patient's home	New functionality
Category 1: treat as part of outreach programme	Providing an electronic referral system to community-based healthcare professionals including the patient's GP and pharmacist	Integrate with legacy system
Category 1: treat as part of outreach programme	Providing direct input of relevant data into the HIPE portal	Integrate with legacy system
Category 2: treat within community (primarily GPs)	Obtaining access to and integrating data held by COPD outreach service into patient management software, perhaps using Healthlink as the messaging broker	Integrate with legacy system
Category 2: treat within community (primarily pharmacists)	Obtaining additional information in the form of care plans in addition to prescriptions would help them understand the medication needs of their patients better	New functionality
Category 3: Support group leaders	Obtaining access to education about COPD	New functionality
Category 3: Support group leaders	Providing functionality that provides more support and help for the patient to self-manage their condition	New functionality
Category 4: Management	Reporting functionality	New functionality
Category 4: Management	Capturing patient data on a hand-held device	New functionality
Category 4: Management	Providing the ability to allow the patient to self-manage their chronic condition	New functionality

In addition to functional requirements suggested by the stakeholder groups, there are also non-functional requirements that apply to computer systems generally, which are discussed next.

5.3.6 Non-functional requirements

The non-functional requirements apply to the entire system and are reasonably general in nature. While many non-functional requirements exist, this research focussed on data security and privacy.

Firstly, data security has previously been defined in Section 3.5.4: Data security in the cloud as consisting of the maintenance of three data characteristics: confidentiality, availability and integrity. With regard to the non-functional requirements for this research project, access control refers to controlling access to the application using login credentials, which is a key requirement to support data confidentiality as defined in Section 3.5.4. In order to support data integrity, audit trail provision refers to the ability to maintain a log of data changes and dates associated with those changes. Audit trails are often necessary for medico-legal reasons. For reasons of scope, data availability (as defined in Section 3.5.4) was not examined within this research.

Secondly, data privacy refers to ensuring that viewing a patient's data is restricted to the minimum set of people who require it. Data privacy is supported by both access control and the provision of audit trails measures.

Together, the functional and non-functional requirements were used to inform design of the enterprise architecture, which is expanded upon in the next section.

5.3.7 Enterprise architecture design

Following on from requirements elicitation and analysis, an enterprise architecture, shown in Figure 5-3, was designed. The requirements have been modularised in keeping with the service-orientated architectural approach used and as described by the HISA standard (International Organization for Standardization 2011a). Further, the requirements are specified under three workflows: subject of care, activity management and clinical information workflows, again as described in the HISA standard (International Organization for Standardization 1998). Appendix F: Additional Design Information specifies the full list of modules, while the following sections focus on the elements that were designed and / or implemented as part of the research study.

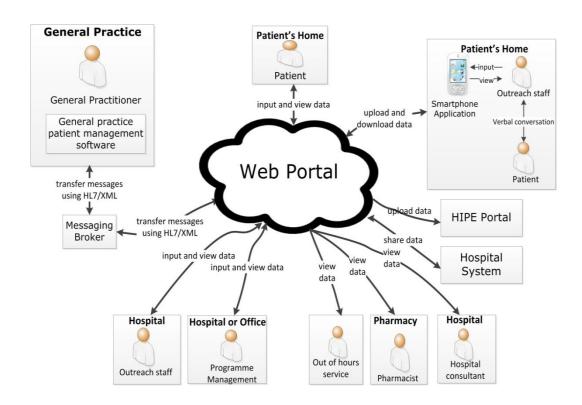


Figure 5-3: Enterprise architecture to support COPD outreach programme

As presented, the core of the architecture is a web portal, hosted in the cloud, which contains the business logic, stores the data and can be integrated with legacy systems. Thus the web portal could be viewed as the middleware that provides interoperability with legacy systems as described in HISA. However, the focus of this research is on provision of new functionality within the cloud portal. It is proposed that legacy systems interfacing with the web portal are standards-based.

5.3.7.1 Subject of care workflow

The subject of care workflow deals with the patient-centric business processes, which includes management of patient encounters with the healthcare organisation and the management of the patient's personal and statistical information (International Organization for Standardization 2011a). Table 5-5 lists the modules relevant to the research study and provides a description of each module. A full listing can be found in Appendix F: Additional Design Information.

Table 5-5: Subject of care functional modules

Module number	Module name	Description
Mod_001	Capture patient data in the home	Provides functionality to allow capture of a patient's data, such as demographics, observation sets and medication, on a handheld device in the patient's home.
Mod_002	View patient data using a web portal	Provides functionality to allow patients and healthcare professionals view patient data from different locations through a web portal. The view of the data should be restricted to the minimum data set required.
Mod_003	Share clinical data	Provides functionality that allows a patient to self-manage through the daily application of an appropriate evidence-based assessment with the results being saved each day. If a clinically significant change occurs an event is triggered which sends a message to either a GP or outreach team.

5.3.7.2 Activity management workflow

The activity management workflow deals with the carer-centric business processes that the healthcare professional is required to carry out on behalf of the patient, such as requesting, scheduling and executing appointments on behalf of the subject of care in addition to reporting of these events within the organisation (International Organization for Standardization 2011a). Table 5-6 provides a description of the module relevant to the research study. A full listing can be found in Appendix F: Additional Design Information.

Table 5-6: Activity management functional module

Module number	Module name	Description
Mod_004	Generate reports	 Provide report functionality: To improve service delivery in a timely fashion To ensure that the service is cost-effective To verify that the service is meeting its key performance indicators

5.3.7.3 Clinical information workflow

The clinical information workflow deals with the information-centric business processes that deal with clinical data management (International Organization for Standardization 2011a). With regard to this, the collection of the patient's observation set, medication list and quality of life scores could potentially be documented under the clinical information workflow. However, for simplicity of documentation these three items are contained in Mod_001 and Mod_002 in the subject of care workflow since they also fall under that workflow.

5.3.8 Detailed requirements analysis

The four modules specified in this section offer a selection of functionality across the subject of care and activity management workflows. Additionally, it was felt that these modules represent the core functionality required in the electronic delivery of the COPD outreach programme. Finally, Mod_003: share clinical data offers the potential to explore interoperability between new and legacy systems.

5.3.8.1 Subject of care workflow – capture patient data in the home

Stakeholders who treat patients as part of the outreach programme and management requested an application that would allow capture of patient data in the home. Indicators from the interviews were that these stakeholders would benefit from an application that captured patient data, such as demographics, clinical observations and medication on a hand-held device. Figure 5-4 illustrates the use case.

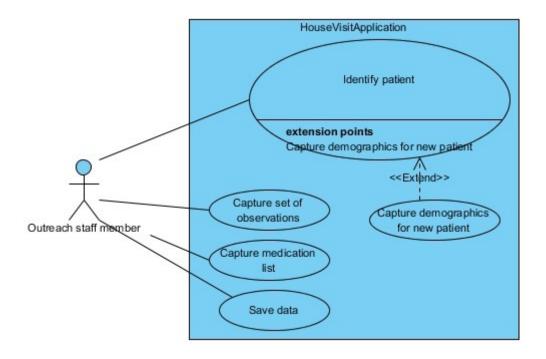


Figure 5-4: Use case diagram – capture patient data in the home

As illustrated, the outreach staff member locates a patient's details (either by searching for a patient's details or by creating a new record), captures the patient's observation set and medication details and saves the information. Appendix F: F.3: Use case description for Mod_001 – capture patient data in the home provides a formal requirement definition.

5.3.8.2 Subject of care workflow – view patient data using a web portal

All stakeholders proposed that access to patient data through a centralised portal accessible from different locations would be beneficial. The patient support group leaders viewed it as essential since they believe access to information is critical to aiding them in self-management of their chronic condition. However, concerns were expressed in relation to data security and privacy, which will be addressed in Section 7.3.3: Significance of data security and protection. Figure 5-5 illustrates the use case.

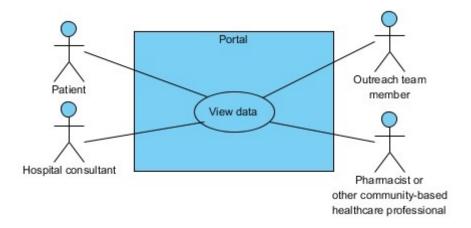


Figure 5-5: Use case diagram – view patient data using a web portal

As shown, different people can view data from different locations using a web portal. Appendix F: F.4: Use case description for Mod_002 – view patient data provides a formal requirement definition.

5.3.8.3 Subject of care workflow – share clinical data

Both support group leaders requested functionality that allowed for self-management of their COPD through a daily assessment, with results being shared their healthcare professionals. Stakeholders in other categories were broadly in favour of this although barriers were cited: the health literacy of the patient cohort given their demographics, the selection of which assessment to use, the potentially subjective nature of the assessment results, the possibility of data overload for clinicians and the possibility of missing a critical test result due to the amount of data generated.

The selection of the patient assessment is fundamental to the success of this functionality. With respect to that, many participants indicated that sputum colour and quantity were indicators of the potential of a COPD exacerbation, which suggests that the breathlessness, cough and sputum scale (BCSS) quality of life score might be a useful assessment (Leidy et al. 2003). However, the COPD GOLD guidelines have included a new assessment tool, known as the clinical COPD questionnaire (CCQ), aimed specifically at COPD self-management (van der Molen et al. 2003; Global Initiative for Chronic Obstructive Lung Disease 2013). A more objective approach which aligns with what healthcare professionals have indicated as their preference is to predict the likelihood of an exacerbation based on physiological data such as blood

pressure, heart rate, weight, lung function and oxygen level – research by M. H. Jensen et al. (2012) showed that it is possible to discriminate between stable and exacerbated COPD with a sensitivity level of 70%. Thus, there is potential in using physiological data as a predictor of COPD exacerbations when recorded daily. However, having a patient take a set of observations each day may prove problematic given the patient cohort demographics. As a result, no specific patient assessment has been selected since the variables are broad and careful consideration is required prior to any decision being made.

In addressing some of these barriers, the following solution is proposed: the patient would perform an evidence-based assessment each day, the results of which would be stored in the cloud. When a clinically significant change occurs, an event would be triggered in the cloud portal, which sends a HL7 message to the patient's general practitioner's patient management software and / or the COPD outreach team that the patient is associated with via a messaging broker. This solution is illustrated in Figure 5-6.

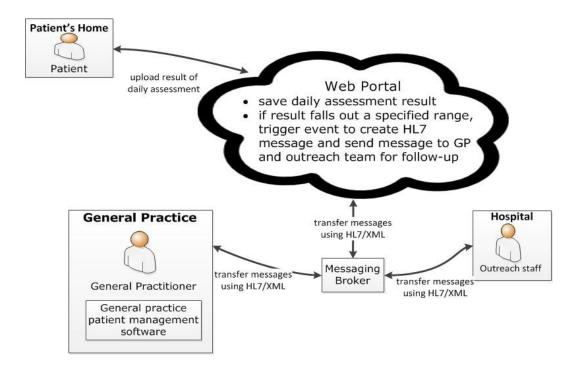


Figure 5-6: Sharing clinical data between patient and healthcare provider

As presented, the solution uses health informatics standards to promote interoperability between legacy and new systems, and in so doing, perhaps improve timely communication between patients and their healthcare providers. While this module was not implemented and remains at the high level design stage presented here, a suggested implementation is provided in Section 6.4: Interoperability explored – sharing clinical data. Appendix F: F.3: Use case description for Mod_001 – capture patient data in the home provides a formal requirement definition.

5.3.8.4 Activity management workflow – generate reports

Management indicated that they require reporting functionality that would allow them speedier access to data in order to generate reports, such as the number of patients admitted to the COPD outreach programme from the emergency department in a given date range. Figure 5-7 illustrates the use case.

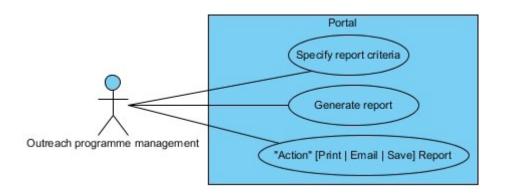


Figure 5-7: Use case diagram – generate reports

As shown, it is possible for the outreach programme manager to specify report criteria and generate reports and then perform certain actions, such as printing, emailing or saving the report. Appendix F: F.6: Use case description for Mod_007 – generate reports provides a formal requirement description.

5.4 System specification - information viewpoint

The information viewpoint of the system provides a view of the information shared within the COPD outreach programme and the relationships and behaviours that exist between the information elements. Thus, a single integrated logical information model is required to underpin the business processes described in section 5.3: System

specification - enterprise viewpoint. Evolution of the information model presented here began with the design of an entity-relationship diagram and an associated data dictionary, documented in Appendix G: Evolution of the Information Model, based on the standardised paper chart used by the COPD outreach programme. Each data element has been given a data element number. Traceability between the two different models is by way of the data element number, as can be seen in the tables presented later in this section.

Within HISA, the information model is divided into seven information object groups which relate back to the corresponding activity in the enterprise viewpoint. The general purpose of each of these seven information object groups is described in Table 5-7.

Table 5-7: Description of HISA's information objects

Information Object Groups	Description, adapted from (International Organization for Standardization 2011b)		
Subject of care	Acts as a container for information pertaining to patient identification and demographic information		
Activity management	Acts as a container to store information elements that deal with the management of integrated care pathways and the management of health information life-cycles		
Clinical and health information	Used to store clinical and health information elements on behalf of the subject of care		
Users and authorisation	Used to store information needed to deal with access control of users and enterprise organisation		
Resource management	Acts as a container for information needed to support the management of resources, including staff, location, equipment and so on		
Classification	Acts as a container for information pertaining to coding sets for use within the application		
Messaging	Acts as a container for information to support activities to communicate with other systems, including message structuring		

Figure 5-8 illustrates how these information objects relate to the data used within the COPD outreach programme. This information model represents a high level logical view of the information contained within the proposed system.

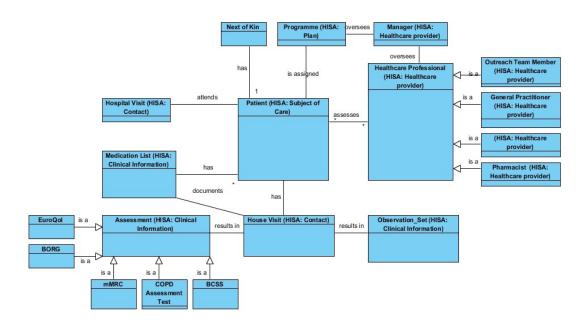


Figure 5-8: Model of information objects used by COPD outreach programme

As shown, both HISA class names and the application class names are provided. The data elements used were based on the standardised paper chart currently in use within the national COPD outreach programme.

5.4.1 Subject of care information object group

The subject of care information object group acts as container for data elements that deal with patient identification and demographic information. Table 5-8 provides a description and the attributes of each information element contained in this group. A mapping to the class name used in Figure 5-8 is also provided.

Table 5-8: Information elements in subject of care information object group

HISA class name	Mapped to class name in Figure 5-8	Description	Attributes and data types in the format [attribute: data type (length) – data element number]
Subject of care	Patient	Person who has been admitted into the COPD outreach programme	hospitalMRN:integer(10) – DEM_001 firstName:varchar(32) – DEM_002 surname:varchar(32) – DEM_003 dateOfBirth:date – DEM_004 addressLine1:varchar(45) – DEM_005 addressLine2:varchar(45) – DEM_006 addressLine3:varchar(45) – DEM_007

			addressLine4:varchar(45) – DEM_008 addressLine5:varchar(45) – DEM_009 telNumAreaCode:integer(3) – DEM_010 telNum:integer(7) – DEM_011 mobileNum:integer(10) – DEM_012 livesWith:varchar(32) – DEM_013 homeHelp:varchar(32) – DEM_014 mealsOnWheels:varchar(32) – DEM_015 mobility:varchar(32) – DEM_016 occupation:varchar(32) – DEM_017 programmeID:integer(10) – DEM_018
Period of care	Episode	Patient has experienced an event where they need to attend hospital or been attended in their home	episodeNum:integer(10) - ADM_019 hospitalMRN:integer(10) - DEM_001 date:date - ADM_021 nationalProgrammeDay:varchar(32) - ADM_022 visitId:integer(10) - ADM_023
Contact	House Visit	Visit by an healthcare professional to the patient's home as part of the COPD outreach programme	visitId:integer(10) – ADM_011 hospitalMRN:integer(10) – DEM_001 episodeNum:integer(10) – ADM_013 staffNum:integer(10) – ADM_014 Date:date – ADM_015 Time:integer(10) – ADM_016 startTime:timestamp – ADM_017 endTime:timestamp – ADM_018
Contact	Hospital Visit	Visit by the patient to an emergency department as a result of a suspected COPD exacerbation	episodeNum:integer(10) – ADM_003 hospitalMRN:integer(10) – DEM_001 referralPlace:varchar(255) –ADM_005 dateofAdmission:date – ADM_006 dateOfDischarge:date – ADM_007 programmeType:varchar(255) – ADM_008 lengthOfStay:integer(10) – ADM_009 reasonAdmission:varchar(255) – ADM_010

5.4.2 Activity management information object group

The activity management information object group acts as a container for data elements that deal with the management of integrated care pathways, as described in Section 2.2: Community healthcare. Table 5-9 provides a description and the attributes of each information element contained in this group.

Table 5-9: Information elements in the activity management object group

HISA class name	Mapped to class name in Figure 5-8	Description	Attributes and data types in the format [attribute: data type (length) — data element number]
Plan	Programme	COPD programme to which the patient can be admitted. It is one of "early discharge programme" or "assisted early discharge programme"	programmeID:integer(10) – ADM_001 name:varchar(70) – ADM_002

5.4.3 Clinical and health information object group

The clinical and health information object group is used to record clinical and health information elements on behalf of the subject of care. Table 5-10 provides a description and the attributes of each information element contained in this group.

Table 5-10: Information elements in the clinical and health information object group

HISA class name	Mapped to class name in Figure 5-8	Description	Attributes and data types in the format [attribute: data type (length) – data element number]
Clinical information	Assessment	Set of quality of life scores that the healthcare professional carries out each time they visit the patient	AssessmentID:integer(10) – CLIN_001 visitId:integer(10) – CLIN_002
Clinical information	Observation set	Set of observations that the healthcare professional takes each time they visit the patient	observationID:integer(10) – CLIN_003 visitId:integer(10) – CLIN_004 weight:integer(10) – CLIN_005 height:integer(10) – CLIN_006 BMI:integer(10) – CLIN_007 bpSystolic:integer(10) – CLIN_008 bpDiastolic:integer(10) – CLIN_009 heartRate:integer(10) – CLIN_010 respiratoryRate:integer(10) – CLIN_011 temperature:integer(10) – CLIN_012

			o2Saturation:integer(10) - CLIN_013 sputumColour:varchar(32) - CLIN_014 sputumAmount:varchar(32) - CLIN_015 sputumConsistency:varchar(32) - CLIN_016 chestAuscultation:varchar(32) - CLIN_17
Clinical information	Medication list	Medication list that the patient has been prescribed	medicationID:integer(10) – CLIN_018 visitId:integer(10) – CLIN_019 hospitalMRN:integer(10) – DEM_001 drug:varchar(70) – CLIN_021 dose:varchar(70) – CLIN_022 route:varchar(32) – CLIN_023 frequency:varchar(32) – CLIN_024 inhalerDevice:varchar(32) – CLIN_025 episodeNum:integer(10) – CLIN_026

5.4.4 Resource management information object group

The resource management information object group is used to store information required to support the management of resources, including staff, location and equipment. Table 5-11 provides a description and the attributes of each information element contained in this group.

Table 5-11: Information element in the resource management information object group

HISA class name	Mapped to class name in Figure 5-8	Description	Attributes and data types in the format [attribute: data type (length) – data element number]
Healthcare provider	Healthcare professional	Person who treats the patient. The outreach team member is the actual healthcare professional whose attributes are defined.	staffNum:integer(10) – ADM_024 firstName:varchar(32) – ADM_025 Surname:varchar(32) – ADM_026 Role:varchar(32) – ADM_027 telNumAreaCode:integer(3) – ADM_028 telNum:integer(7) – ADM_029 mobileNum:integer(10) – ADM_030

5.4.5 Other information object groups

Currently, there are no classes specified within the information model for the final three information object groups: users and authorisation, classification and messaging. All these elements would be required for a full production system. Specifying these information objects was beyond the scope of the research.

5.4.6 Additional comments on information model

As described, the proposed systems' information viewpoint has been partially specified using HISA. What has been presented is a high level design; for a full specification, it would be necessary to drill down to a much lower level of detail into each use case specified in each business process within the enterprise viewpoint to ensure that all data elements have been accounted for within the information model.

Additionally, within the HISA – information viewpoint standard, attributes are associated with each class (International Organization for Standardization 2011b). There are differences between these attributes and the attributes that were used within the application. It was not possible to do a full analysis of the differences between the two due to time constraints.

Furthermore, differences exist between the logical and physical information models, which are outlined in Section 6.2.5: Physical data model.

This section partially specified the necessary data elements to support functionality required by the proposed cloud system. These data elements need to be shared with legacy systems in order to provide continuity of care for the patient.

5.4.7 Information shared between systems

In addition to information contained within the proposed cloud system, information should be shared between the new and legacy systems in order to provide a degree of interoperability. While detailed analysis of the data shared between legacy systems and the proposed cloud middleware is beyond the research scope, it is appropriate to highlight relevant data that could potentially be shared. Two important message types that may be shared are referral and discharge messages.

With regard to referral messages, work has been carried out to develop a national standard referral dataset consisting of six sections: patient details, referral details, referrer details, patient's usual GP, clinical information and a hospital-use section (Health Information and Quality Authority 2011c; MacCarthy 2011). One of the aims of the COPD clinical care programme is that GP refer patients to it, rather than all referrals coming from the emergency department as is currently the case. Using the national referral dataset and electronic messaging within the proposed architecture may provide a timely method of achieving that aim.

With regard to discharge messages, HIQA have recently published a national standard for patient discharge summary information (Health Information and Quality Authority 2013e), which could potentially be incorporated into the architecture. Currently, a standardised discharge letter is sent by the COPD outreach team to the patient's GP following the 6 week review. The author suggests that this letter could be modified to ensure it complies with HIQA's patient discharge summary information and that it could be integrated into the proposed architecture. Further work is required to investigate exactly how this could be executed.

5.5 Viewpoint correspondence

The specification presented here uses the core principles from the HISA standard; namely, that shared business logic and a single integrated information model underpin an open architecture that is capable of interacting with many different vendors deployed in many different ways. Thus, the enterprise viewpoint described the various business processes in terms of subject of care, activity management and clinical information workflow while the information viewpoint partially-specified the information model in terms of the subject of care, activity management, clinical and health information and resource management information object groups. Use of similar linguistic terms indicated the "viewpoint correspondences" between the two viewpoints, suggesting an association between the different elements in the two viewpoints as seen from different perspectives, as described in Section 3.4.1: Enterprise architecture models. In combination, they form a more complete specification of the system.

5.6 Conclusion

This chapter explained the execution of the first four tasks of the research study. Specifically, identifying stakeholders and capturing their requirements. Then, proposing a data model and an enterprise architecture that could meet those requirements.

The next chapter focuses on what the designed architecture may offer patients and community healthcare professionals; through a description of what was implemented and evaluated from the proposed solution. Additionally, issues surrounding interoperability between the proposed cloud system and legacy systems shall be explored at a high level.

6 What the Architecture Offers

6.1 Introduction

Once specified, the enterprise architecture should be beneficial to stakeholders within community healthcare. These benefits include a reduction in data entry for healthcare professionals working in the outreach service, more timely access to data for healthcare professionals working in the community and online access to education and information for COPD patients. It is practical to illustrate some of these benefits through a partial implementation and evaluation of the proposed solution.

As stated previously, a set of seven data analysis tasks were defined in order to attempt to answer the research questions under two categories:

- Laying the foundations of enterprise architecture
- Understanding what the architecture can offer different stakeholder groups

The previous chapter described the first four tasks while this chapter focuses on the final three tasks listed in Table 6-1. This chapter explores how the system specified in the previous chapter can be used in practice with the COPD outreach service, what and how standards can be used to ensure system interoperability between legacy and new systems and to what extent can cloud-based services offer a solution.

Table 6-1: Understanding what the architecture can offer different stakeholder groups

Task number	Task description
Implement an application that can be used on a handheld device to capture patient details, upload this data and view it via the cloud portal.	
It should be possible to view data contained in the application by variety of different community healthcare professionals and pati	

	a variety of different locations.
6	Implement a reporting module that can be accessed via the cloud portal.
7	Describe the transfer of clinical data between a community-based information technology system and the cloud portal using health informatics standards.

It should be noted that this chapter was not written using the principles underpinning the HISA standard for reasons of simplicity and clarity of explanation.

6.2 Implementing architectural elements

Three modules were implemented to illustrate that the proposed solution was feasible. The modules selected for implementation were:

- Mod_001: capture patient data in the home
- Mod_002: view patient data via a portal
- Mod_004: generate reports

An additional module, Mod_006: provide patient information and education resources, was partially implemented in conjunction with implementing Mod_002.

Figure 6-1 indicates implementation scope and identifies the selected platforms within the proposed architecture.

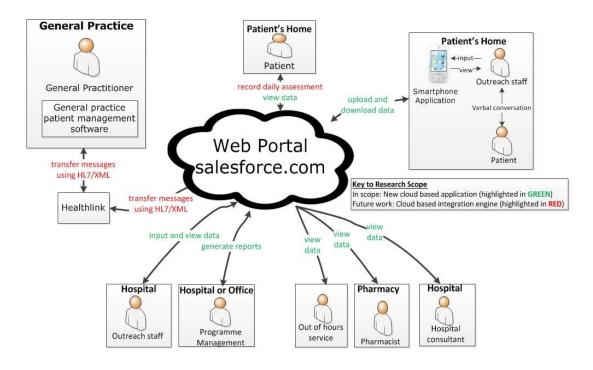


Figure 6-1: Enterprise architecture of implemented elements

6.2.1 Development and hosting platforms

Decision tables were drawn up to discover the most appropriate cloud computing platform, smartphone technology and messaging broker to use in the implementation.

6.2.2 Criteria for selecting the cloud computing platform

Table 6-2 lists the criteria used in determining which cloud computing platform to use for developing and hosting the application.

Table 6-2: Decision table for selecting cloud computing platform

Criteria	Amazon Web Services	OpenNebula	Salesforceplatform (force.com)	Windows Azure
Where does it fit in the cloud computing application stack?	IaaS	IaaS	Saas and PaaS ¹	PaaS ²
Case Study	Mobile healthcare information management utilizing cloud computing and android OS	CloudHealth: Developing a reliable cloud platform for healthcare applications	http://www.salesforce.com/c ustomers/stories/amerisource -bergen.jsp	A cloud-computing based 12-lead ECG telemedicine service
Reference	(Doukas et al. 2010)	(Hendrick et al. 2013)		(Hsieh and Hsu 2012)
Ease of configuration	Requires system administration skills	Requires system administration skills	Very simple, provided that the business rules and processes are understood in advance. 'Out of the box' point and click functionality	Requires system administration skills
Different views for different people	Requires development	Requires development	Available out of the box with minimal configuration	Requires development
REST API available	Yes	Yes	Yes	Yes
HL7 API available	Yes, but requires installation, administration and development	Yes, but requires installation, administration and development	No – but it is possible to implement a SOAP interface to middleware (one open	No – but it is possible to use Microsoft Biztalk as middleware translates the

¹The SaaS and PaaS automatically uses IaaS as described in section 3.5.2.

²The PaaS automatically uses IaaS as described in section 3.5.2.

			source option is JITTERBIT) which translates the SOAP message into a HL7 message	message into a HL7 message
Programming languages provided	Possible to install any programming language you require	Possible to install any programming language you require	Markup language: VisualForce	Any language – including Java, .NET, Ruby, Python
			Programming language: Apex	
Licensing	Not investigated	Not investigated	Certain number of free licences in developer mode provided they are not used for commercial purposes	Free 90 day trial after which everything is billed

The three layers (IaaS, PaaS and SaaS) in the cloud computing stack were compared to determine which had the best fit for the implementation. While the IaaS offers more in terms of flexibility, it takes longer to install and configure. Given the author's skill set and the research project's time constraints, it was immediately excluded.

Consequently, the choice remained between the two PaaS / SaaS platforms: Windows Azure and Salesforce.com. Development with Windows Azure requires installation of the Eclipse software development kit while Salesforce.com's development platform is in the cloud (for what is implemented in this project). Windows Azure supports many programming languages while Salesforce.com supports Apex and VisualForce for business logic and user interface development respectively. Underpinning both platforms is a relational database management system.

There is a free Salesforce.com development edition which offers the capability for integration with legacy systems through a web services application programming interface, enterprise reporting, two licences for the full applications and five portal licences (thus making it possible to view data from different locations using a web portal) provided that the application is not used commercially (Salesforce.com 2013e). Conversely, the much less transparent licencing and costs for Windows Azure suggested that after a free trial, there were a number of plans that could be purchased depending on requirements (Microsoft 2013a; Microsoft 2013b).

Consequently, it was decided to use Salesforce.com as the development and hosting environment for the application because it offered the functionality that was required to illustrate solution feasibility in the time allowed using a freely available development edition.

However, the selection criteria would be far more precise and stringent if an enterprise production system were to be deployed. Specifically, it would be essential that the cloud platform selected adequately supported data security considerations. With regard to that, Salesforce.com offers a security model based on profiles and roles that supports data security and privacy (Salesforce.com 2013d). Each user type is assigned a profile and role. The profile defines field and table access (read / write

and read-only). The role defines data record visibility (hidden, read only or read/write). The role can be defined as coarsely or finely as required. Furthermore, there is a concept of territory-based roles (or as the author views it, "hospital / site-specific" roles) where it is possible to only access data from a specific sites, thus restricting data to only the person who is entitled to view it.

But for the purposes of this research, this criterion was not paramount. Firstly, only dummy data was used. Secondly, the purpose of the implementation was to illustrate that it was possible to use the proposed architecture with a specific patient cohort. Consequently, the implementation serves as a proof of concept rather than as a functioning system.

6.2.3 Criteria for selecting the handheld technology

Table 6-3 lists the criteria for selecting which handheld technology to use to develop and host the application for capturing patient data at point of care.

Table 6-3: Decision table for selecting smartphone technology

Criteria	Android	Apple	Salesforce.com mobile app	Use Salesforce.com portal within the smartphone's built-in browser
Open platform for development	Yes	No	Not applicable	Not applicable
Access to development platform and tools	Yes	No	Yes	Yes
Integrate with salesforce.com developed portal	Yes, with development effort	No	Yes	No integration required
User requirement	Not specifically mentioned	Yes	Not specifically mentioned	Not specifically mentioned

The aims of implementing a solution - illustrating the benefits of data sharing between stakeholders and the principle of capture data once and re-using it many times where appropriate – can be fulfilled by any of the smartphone technologies listed. The following outlines how the selection was made.

Firstly, some stakeholders suggested a preference for Apple technology. However, it was not feasible to obtain the hardware and software necessary to develop in that environment, so that option was rejected.

Secondly, some time was spent researching how smartphone applications are developed using the Android software development kit; the software development kit was installed and a small application developed. Even with development experience, initial indications were that it would take a considerable amount of time to develop a mobile application. Consequently, developing an Android application was also excluded.

Thirdly, the Salesforce.com mobiles application was downloaded onto both an Android and Apple iTouch device. It was possible to use 'out-of-the-box' functionality immediately but customisation was required to access the custom-built application. So, this option was eliminated.

Finally, using a smartphone's native browser to log into Salesforce.com's web portal allowed full access to standard and custom-built applications without further customisation and provided instant cross-platform support without any development effort. Consequently, the author focussed implementing the web portal. The smartphone's native browser is used as the access point to the web portal application.

6.2.4 Criteria for selecting the messaging broker

There were two criteria used in selecting the messaging broker: input from stakeholders and use of existing national infrastructure. Both of these pointed towards using Healthlink which is, as previously described in Section 3.3.1: Healthlink, Ireland's national messaging broker.

6.2.5 Physical data model

Figure 6-2 presents the data model that was implemented. The diagram was generated from the schema builder tool within the Salesforce.com development environment. The physical data model was originally derived from the entity-relationship diagram illustrated in Appendix G: Evolution of the Information Model.

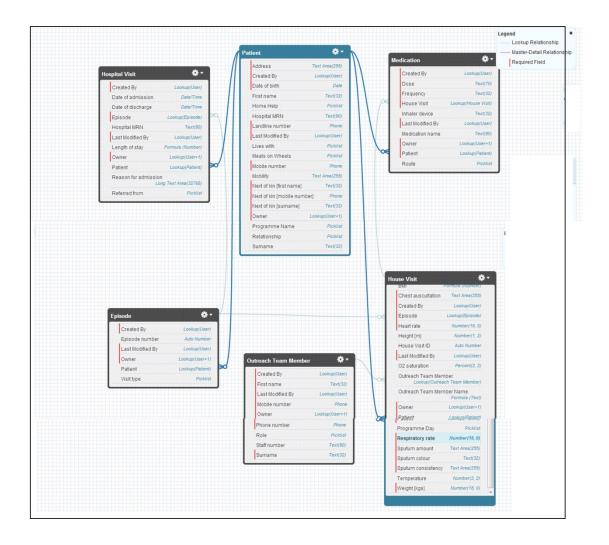


Figure 6-2: Physical data model

Differences exist between the physical data model and the logical information model presented in Section 5.4: System specification - information viewpoint. The main difference between the two models is that six tables were created as part of the implementation, while ten entities are presented in the logical information model. This reduction in table number is the result of two factors. Firstly, some functionality was not implemented – an example is the "Assessment" entity in the logical information model, which does not exist in the implementation. Secondly, for ease of implementation, entities were merged into larger tables, which contain the attributes of both entities – an example of this is the merging of the "House visit" and "Observation set" entities in the logical information model into one table called "House Visit" in the implementation.

Nonetheless, it is possible to show traceability from the data elements specified in the logical information model at the database level. Table 6-4 provides an example of where the data element number is used to illustrate this traceability between the two models for the more pertinent attributes associated with the patient entity.

Table 6-4: Traceability between logical and physical data elements

Physical database table name (taken from Figure 6-2)	Data element number	Field name in database	HISA class name	Mapped to class name in Figure 5-8
Patient				
	DEM_001	Hosptial_MRN	Subject of care	Patient
	DEM_002	First name	Subject of care	Patient
	DEM_003	Surname	Subject of care	Patient
	DEM_004	Date of Birth	Subject of care	Patient
	DEM_005 through DEM_009	Address	Subject of care	Patient
	DEM 010 and DEM_011	Landline number	Subject of care	Patient
	DEM_012	Mobile number	Subject of care	Patient
	ADM_002	Programme name	Plan	Programme

6.2.6 Non-functional requirements

The two non-functional requirements identified during requirements elicitation were data security and data privacy. Both of these could be supported through the provision of audit trial and access control measures.

Data security and privacy is underpinned by Salesforce.com's security model, which has been described in Section 6.2.2: Criteria for selecting the cloud computing platform. As stated, it consists of roles and profiles. Within the implementation, the security model was partially implemented – in that a number of profiles were created to support the development and deployment of customised web portals for different stakeholders. However, each role was not defined which meant that all data was

displayed in all web portals. Obviously, both elements of the security model need to be fully defined and implemented for a production system.

Access control refers to controlling access to the data through the use of login credentials. It is possible to create users and assign them appropriate profiles and roles based on the data security model underlying Salesforce.com. Additionally, it is possible to easily customise the amount of idle time before automatic logout occurs.

Audit trail provision refers to the ability to record key changes with dates. Salesforce.com supports four different audit tracking mechanisms (Salesforce.com 2013b), as listed in Table 6-5.

Table 6-5: Audit trail mechanisms provided by Salesforce.com

Mechanism	Description
Basic audit functions	User responsible for and the date of additions and modifications to each field are recorded
Login history tracking	Login attempts are stored for a set period of time
Setup audit tracking	Changes made to the configuration of the application are tracked
Object field tracking	Changes on specific fields within an object are stored

All these mechanisms ensure that actions taken within the system are recorded and can be audited. Of particular interest is the object field tracking since the data captured can be viewed either on the page where the tracking has occurred or can be used within the reporting module. It is possible to track twenty fields in any object. The downside is that field tracking is expensive in terms of database storage. This functionality was implemented on the "Next of Kin [first name]" field in the patient object: Figure 6-3 illustrates that a date-stamp, the user who made the change and the action taken is recorded.



Figure 6-3: Screenshot - field tracking data

6.2.7 Business logic

The three modules were developed in the cloud using the Salesforce.com developer edition. The author created a Salesforce.com application called "COPD Outreach Programme" which contained the functionality for the three modules. The data model underlying the application is as described in section 5.4: System specification - information viewpoint.

The business logic takes the form of simple validation rules to ensure required fields have been completed with the correct data types. Additionally, some fields are populated automatically using a formula. An example of this is the body mass index (BMI), which is calculated from the patient's weight and height.

Of interest is the implementation of Mod_001: capture patient data in the home since that module provides the data capture functionality for the application. The activity diagram, presented in Figure 6-4 overleaf, shows the actions taken by the application. However, implementing the module in this way is rather contrived since it should not be necessary to specify whether the visit is a hospital or house visit; ideally, the hospital number should be imported from an existing hospital system and linked with the episode number created by the Salesforce.com application. It was implemented in this way to support the creation of reports which required data (in particular, how many patients were referred from the emergency department to the outreach programme) which would normally be stored in an existing hospital system. This illustrates the need for interoperability between the new cloud system and existing hospital systems, which was beyond the research scope.

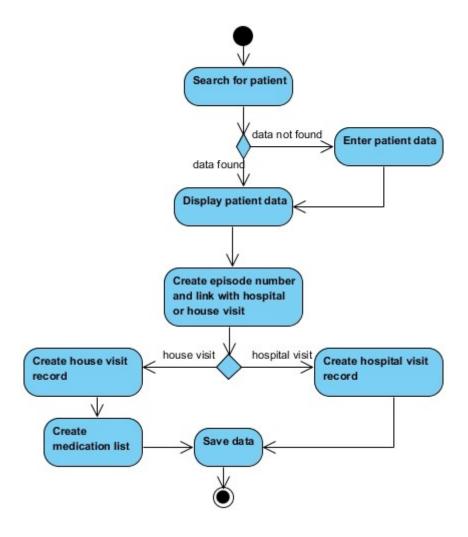


Figure 6-4: Activity diagram - capture patient data in the home

6.2.8 User interface

There are two different user interfaces within the application. Firstly, the user interfaces for Mod_001: capture patient data in the home and Mod_007: generate reports can be accessed via the web, smartphone or tablet computer. This user interface provides read and write access of data to the end-user. Figure 6-5 shows an example screenshot of viewing patient's details and functionality options from that page.

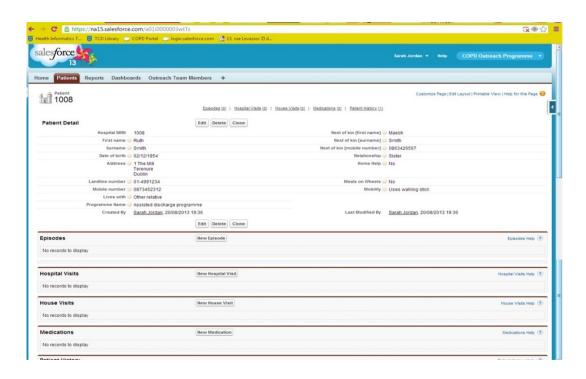


Figure 6-5: Screenshot – view patient's details and access other functionality

Once a user has logged into the application, using the tabs at the top of the screen, they can navigate through the application to search, view, create or capture health data for a patient at point of care or generate reports about COPD programme activity, as per the functionality specified. Figure 6-6 diagrams the relationship between the screens in the web portal.

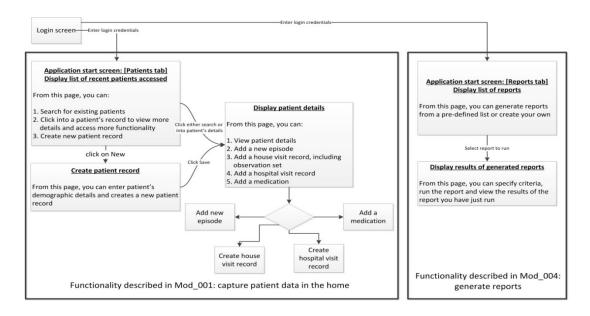


Figure 6-6: Relationship between screens in web portal

With respect to Mod_002, web portals (shown in Figure 6-7) used to view patient data from different locations by stakeholders. Four such web portals were configured through Salesforce.com: one for each of patient, GP, pharmacist and hospital consultant.

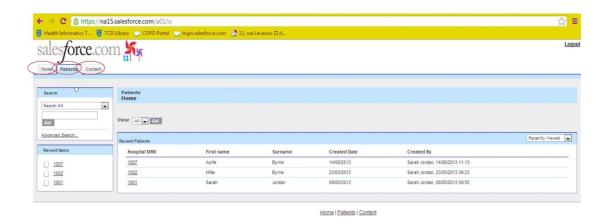


Figure 6-7: Screenshot - web portal

The portal consists of three screens, navigated by using the three tabs (circled in red in Figure 6-7) and described in Table 6-6.

Table 6-6: Tabs in the web portal

Tab	Description		
Home	Lists open tasks. This functionality is standard but is not used within this implementation.		
Patients	Contains a patient list and provides search functionality. It is possible to click into each patient to access more data.		
Content	Contains a list of education and information resources available to the enduser. It represents a partial implementation of Mod 006: provide patient information and education resources because Salesforce.com was configured to allow end-users to view the information but currently they are unable to upload documents themselves.		

While the web portals provide a view of patient data, a better solution would be to integrate a data view within the end-user's existing IT system if it exists. It would be possible to develop an integration engine on the Salesforce.com platform using its programming language, Apex, which could generate and send the appropriate HL7 messages to the end-user's existing system using Healthlink as the messaging broker. Thus, a combination of web portals and integration with legacy systems would allow

different stakeholders view data in the environment they require. As stated previously, implementing this integration was beyond the research scope and is noted here for completeness.

Appendix H: contains the implementations' main screenshots.

6.3 Software design and implementation evaluation

A software design and implementation evaluation was carried out in June. From the original stakeholder group, twelve stakeholders were invited to take part in the evaluation. Four stakeholders agreed to participate. These were selected to ensure a cross-section of opinions was obtained from the various stakeholder categories. Table 6-7 provides a breakdown of the participants.

Table 6-7: Evaluator categorisation

Stakeholder Category	Number	Healthcare Professional
Category 1: Treat as part of outreach programme	0	No participant
Category 2: Treat in community	2	General practitioner
		Pharmacist
Category 3: Interest and support groups	1	Support group leader
Category 4: Management	1	Manager

The author used the enterprise architecture diagram (Figure 5-3: Enterprise architecture on page 55) and the class diagram (Figure 5-8: Model of information objects used by COPD outreach programme on page 63) to explain the solution to each participant. Following that there was a demonstration. Finally, each participant was asked to complete a paper-based questionnaire (Appendix C: Evaluation Questionnaire Used). The participants' input has been included in the contents of the discussion chapter.

6.4 Interoperability explored – sharing clinical data

The module designed to support the support group leaders' requirement to self-manage their condition through a daily assessment, with critical results being shared with their healthcare professionals is Mod_003: share clinical data. This module, previously described and discussed in Section 5.3.8.3 on page 59, affords the

opportunity to investigate how the new web portal could interoperate with legacy systems used in general practice and hospitals systems, highlighted in red in Figure 6-8.

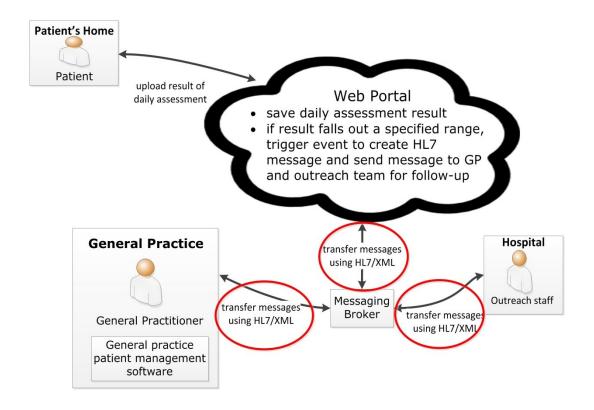


Figure 6-8: Interface between portal and legacy systems

With regard to the highlighted interface, the General Practice Messaging Standard (GPMS) Version 2.0, developed by HIQA, was explored at a high level to verify its suitability to meet this requirement. The GPMS promotes standardised interfaces in order to share electronic information between GPs and other healthcare services within Ireland (Health Information and Quality Authority 2011a). The GPMS currently supports exchange of health messages between GPs and a number of healthcare services, including GP cooperatives, referral services, laboratories, emergency departments and others (Health Information and Quality Authority 2011a). The GPMS uses a modified form of HL7 v2.4 to define a specific set of messages that cover a range of scenarios including (but not limited to) laboratory order and results, outpatient department summary, online referral and response and admission notification (Health Information and Quality Authority 2011a). As currently defined, it appears that the GPMS could not be used to implement this

requirement since message flows are not defined to support a self-management of chronic condition scenario. However, it may be possible to define standard message flows using HL7 v2.4 to support self-management of chronic conditions which could be included in a future version of the GPMS. Definition of these message flows are beyond the scope of this work and further research would be required to examine if this is possible.

Thus, the following solution assumes that such a scenario could be supported within the GPMS in the future. Figure 6-9 illustrates the data flow between the patient and the four systems identified within this requirement.

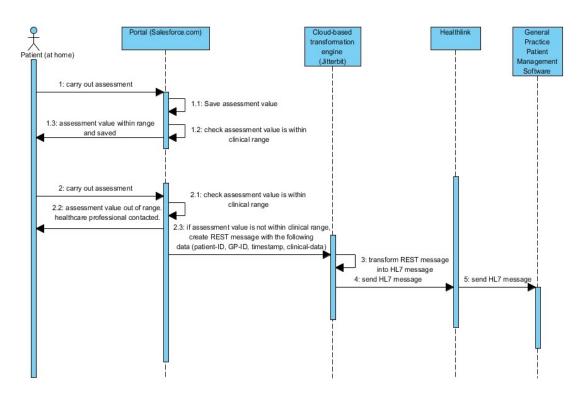


Figure 6-9: Sequence diagram – data flow between portal and legacy systems

As illustrated, the patient carries out an assessment each day which is verified and stored by the web portal. Each assessment has a clinically acceptable range. Clinical decision support software, developed using the portal's programming language, identify whether the assessment value entered by the patient is within that acceptable range. If it is, the value is stored and the patient is notified via a message on the portal that the assessment is completed successfully. If the value is not within the acceptable clinical range, the portal generates a REST message that is sent to a cloud-

based transformation engine, such as Jitterbit (Jitterbit 2013), which transforms the REST message into a HL7 message. The HL7 message is then sent to Healthlink and routed to the patient's GP software. At this point, a manual process is invoked and the GP should contact the patient.

The solution presented does not address many technical design issues, such as whether the data should be pushed or pulled from the web portal to the transformation engine, how messages are routed to the correct general practice or outreach service, and the timeliness of the message transfer. Nor does the solution address the many social issues, such as whether this approach is appropriate for the specific patient cohort and whether patients or healthcare professionals would support such a system. However, it does address the barrier cited by healthcare professionals of data overload since only critical test results are sent for review.

Although implementing this module was beyond the scope of this research, the design presented here highlights the feasibility of interoperability with legacy systems using health informatics standards and cloud-based services.

6.5 Conclusion

The previous two chapters detailed the research study in terms of seven data analysis tasks. A solution, based on enterprise cloud services architecture, was proposed and specified using the principles underlying the HISA standard. The proposed solution allows healthcare professionals capture patient data at point of care for patients enrolled in the COPD outreach programme. Moreover, it illustrates how patients and other stakeholders can view data stored centrally via a portal. Finally, it suggests one way of allowing patients to self-monitor their COPD, with distance support from their healthcare professionals as needed using health informatics standards.

The next chapter examines whether the proposed solution answers the research questions and examines other relevant themes that emerged during the course of the study.

7.1 Introduction

It is widely acknowledged that a paradigm shift towards community-based healthcare is occurring (Department of Health and Children 2012; Compton 2011). Government policy on the use of smaller hospitals advocates building stronger links between these hospitals and primary care for the provision of chronic disease management (Department of Health and Children 2013). The combination of the shift towards community-based healthcare and recent government policy announcements raises the question:

How could cloud-based enterprise architecture for community healthcare support its stakeholders?

In attempting to answer this research question, the author wished to examine the role of IT in community healthcare. Specifically, a perceived gap was identified whereby applying enterprise cloud service architecture to a community healthcare 'enterprise' offered an opportunity to explore the benefits of this approach to stakeholders involved with the COPD outreach programme. Furthermore, the solution designed aimed to account for integration with and re-use of existing infrastructure in addition to provision of new functionality identified by stakeholders while being cognisant of the varying levels of IT currently in use within the community healthcare sector.

This chapter is structured as follows: section 7.2 reviews the research findings in the context of the research questions, aims and objectives as presented in Section 1.4: Research aims and objectives on page 4. Section 7.3 provides commentary on themes resulting from the literature review, analysis of the interviews, partial implementation and software evaluation of the proposed solution. These themes were mapped onto

the research framework used in this research, as illustrated in Figure 7-1: Findings applied to research framework on page 96. Section 7.4 itemises the limitations of the research study. Section 7.5 lists other potential approaches to researching this topic while section 7.6 recommends future areas of research work.

7.2 Re-examining the research questions

In addition to the primary research question, four sub-questions, listed below, were asked to examine different aspects of the research area.

- Who are the stakeholders and what are their information technology requirements? (Section 7.2.1)
- To what extent can cloud-based services offer a solution? (Section 7.2.2)
- What standards could be used to ensure system interoperability between legacy and new systems? (Section 7.2.3)
- How can the proposed architecture be used in practice with a specific patient cohort? (Section 7.2.4)

7.2.1 Involving stakeholders in development of technology solutions

There are many advantages to including stakeholders in the development of information technology solutions, including providing them with an IT system that supports their needs, helping them understand the solution and how to use it to their best advantage and reducing fears about the technology, especially if the technology is new to the stakeholder. Consequently, one research aim was to gather requirements from stakeholders in order to design an enterprise architecture that supports their needs. The three objectives associated with this aim are listed in Table 7-1.

Table 7-1: Objectives of involving stakeholders in ICT solution development

Objectives

- To identify stakeholders
- To gather requirements from stakeholders
- To design an architecture

The author feels that these objectives were accomplished in the following manner. Firstly, through rigorous stakeholder identification which ensured that no stakeholder was accidently excluded, described in sections 2.3: Stakeholder theory, 5.3.3: Identifying stakeholders and 5.3.4: Describing stakeholders. Secondly, through inclusion of a cross-section of stakeholders in both requirements elicitation and evaluation which ensured that the requirements were multi-dimensional, described in sections 4.3.2: Information gathering and 4.3.4: Design and software evaluation. This was further illustrated by the resultant list of requirements, itemised in Appendix E: Complete Set of User Requirements and by the execution of the evaluation described in section 6.3. Finally, through the design of enterprise architecture that supports a number of requirements specified by the stakeholders including data capture in the home, data sharing through a number of web portals, report generation and sharing clinical data using health informatics standards, all of which have been previously described in Chapter 5: Foundations of Enterprise Architecture and Chapter 6: What the Architecture Offers.

In hindsight, it would have been interesting to obtain more views and requirements from patients since they are the people affected most by COPD and would benefit most from a properly connected community healthcare sector, as remarked upon in Section 2.3: Stakeholder theory.

7.2.2 Using cloud-based services

The author proposed that cloud-based services could support the community healthcare stakeholder requirements since cloud-based services are accessible from many platforms, have low capital investment and can be expanded as requirement expands. Accordingly, another research aim was to evaluate cloud-based services. The objectives associated with this aim are listed in Table 7-2.

Table 7-2: Objectives of using cloud-based services

Objectives

- To compile a set of criteria that can be used to evaluate cloud-based services
- To identify possible cloud-based services that could be used in this instance
- To evaluate software cloud services based on criteria
- To identify the pre-requisites for a cloud-based service

The author feels that this aim was partially achieved. Firstly, the means by which the objectives were achieved was through a literature review and the author's reasoning. Thus, Section 3.5: Cloud computing provides an overview of cloud-computing, with an emphasis on the service model stack. Table 6-2: Decision table for selecting cloud computing platform on page 73 provided the author's reasoning in the selection of which platform to use through a comparison of the service model stack. However, there are many other cloud computing platforms that were not included in the decision making, which may also be suitable candidates. Finally, while some of the prerequisites of a cloud-based solution, such as health identifiers, potential to interoperate with other systems, standard message structures approved by HIQA and so on, were identified, it was beyond the research scope to fully investigate their importance or how to incorporate them into the designed enterprise architecture.

7.2.3 Significance of standards and interoperability

Using health informatics standards to underpin a connected community healthcare sector is crucial in providing continuity of care for the patient. Two research aims related to examining the significance of standards and interoperability: to identify what standards could be used to facilitate system interoperability and to illustrate system interoperability between legacy and the new system. So, Table 7-3 lists the objectives associated with these two aims.

Table 7-3: Objectives of standards and interoperability

Objectives

- To design an interface element of the designed architecture
- To discover the importance of standards in delivering high-quality, patient-centric healthcare within the community

Again, the author feels that this aim was partially achieved. Firstly, the proposed system was specified using the principles of the HISA standard. The enterprise viewpoint provided a perspective of the solution in terms of business processes in each of the subject of care and activity management workflows. The information viewpoint partially specified the data elements that supported these business processes using similar language. Using viewpoint correspondences, it was possible to link the two perspectives together; thereby giving a fuller overview of the proposed

solution. The result was a modularised solution which aligned well with the ECSA approach utilised in the design and implementation phase of the project.

However, while a description and the importance of interoperability and standards were included in section 3.6 and a high level design of one module (Mod_004: share clinical data) that illustrated how interoperability between the new system and legacy systems could potentially be implemented in sections 5.3.8.3 and 6.4, it was beyond the research scope to implement this and to fully understand the benefits and challenges associated with interoperability between health information systems.

7.2.4 Using the architecture with a patient cohort

Two aims were identified to demonstrate the feasibility of the solution for patients enrolled in the COPD outreach programme. These aims, with their associated objectives, are listed in Table 7-4.

Table 7-4: Aims and objectives of using the architecture with a patient cohort

Aim	Objectives				
To examine a specific patient cohort in detail	 To select a patient cohort To determine current working practices / processes to manage the selected patient cohort's illness 				
To implement elements of the designed infrastructure to illustrate the benefits of data sharing between different community healthcare stakeholders	 To implement an interface element of the designed architecture To link the implemented elements together to show the flow of patient data from smartphone technology used in the community to the cloud To evaluate the implementation 				

The author feels that these aims and objectives were achieved as stated. Firstly, a case study of the patient cohort and the challenges that they live with in terms of disease progression was presented in Section 2.4: Case study. Secondly, sections 5.3.1 and 5.3.2 provided a detailed description of the business processes used by the COPD outreach programme. Thirdly, two modules were implemented to illustrate data sharing. One module (Mod_001) used a smartphone application to capture and save patient data to the cloud at point of care while the other (Mod_002) allowed patients and healthcare professionals in disparate locations to access data through a web portal. These two modules were described in sections 5.3.8.1 and 5.3.8.2

respectively. Finally, section 6.3 detailed the software design and implementation that was executed.

However, while a module (Mod_003) that illustrated interoperability between the proposed cloud system and legacy systems was designed and a solution proposed, as detailed in sections 5.3.8.3 and 6.4, it was not possible to implement it due to time constraints.

7.2.5 Using ECSA to support community healthcare stakeholders

The primary research questioned whether cloud-based enterprise architecture could be used as an enabler to support stakeholders within community healthcare. Specifically, the research examined whether a Salesforce.com application could be used to transform the current paper-based COPD outreach service to an electronic system where data is captured once in the patient's home and propagated to other relevant systems and stakeholders, including patients, in a seamless way. As stated in Section 1.6: Research scope there are two elements to the research: creating new functionality to build the cloud service as per the stakeholder's requirements and integrating the new system with the existing mix of legacy systems currently in hospitals and community-based practices. This research focussed on building a new cloud system, rather than on integrating with legacy systems.

Previous sections have detailed the process by which the new cloud system was built. The author believes that once the enterprise architecture has been designed, it is possible to modularise the different elements into blocks of functionality or services, which can then be implemented in a piece-meal fashion as resources become available. The author believes that she has demonstrated the feasibility of this approach by specifying twelve modules (documented in Appendix F: using the principles underlying the HISA standard, providing a high level design and appropriate discussion around four of those modules (documented in chapter 5) and implementing three of the modules (documented in chapter 6).

Additionally, given the current economic conditions that exist in Ireland, this approach could be utilised since the modules could be prioritised and implemented as resources become available. Furthermore, it is possible to scale the solution as

additional modules are specified, designed, developed and deployed. Using standards to underpin the architecture development using a modular approach ensures system interoperability. An example of this is in the high level design of Mod_003: share clinical data which utilises HL7 messaging to share critical events between patients and healthcare professionals. Indeed, one stakeholder who participated in the evaluation step indicated that this approach would be beneficial to delivery of the self-management element of the COPD outreach service.

With respect to interoperability between the new system and legacy systems, and mindful that this area was not researched extensively, the author offers some design options. Specifically, the author suggests using Healthlink, the national messaging broker, to support standards-based messaging between the patient, community and hospital when implementing "Mod_003: Share clinical data", due to its widespread use in Ireland. As of 29th July 2013, there are 33 live hospitals, 1279 practices, 3028 GPs and 1800 practice staff using Healthlink (The National Healthlink Project 2013b). Finally, the author suggests integrating messages received into general practice patient management software where they are in use so that data may be viewed in the context of the patient's medical history.

These suggestions may help alleviate the frustration voiced by the participants during the initial interviews at the lack of collaboration between the hospital, community healthcare professionals and patients. The majority of stakeholders – be they working within the COPD outreach programme, working in the community with COPD patients or patient support groups – indicated that information is not always shared in an expedient fashion between the key players. In particular, currently all referrals from the outreach programme to community healthcare professionals are paper-based, with no acknowledgement that they have been received or acted upon. Additionally, much time is spent by outreach staff attempting to contact community healthcare professionals in relation to their patient's care and medication. Moreover, there is little knowledge of the COPD outreach programme within the community, with patients often informing their GPs of its existence and their participation in it. The author believes that a solution using enterprise cloud services architecture, integrated with existing infrastructure using a standards-based approach may enable a more

connected community healthcare sector and may aid communication between the different players involved in community healthcare.

7.3 Other research findings

A number of research findings emerged as a result of the literature review, analysis of the interviews and software evaluation and partial implementation of the proposed solution. These findings are illustrated on the research framework in Figure 7-1.

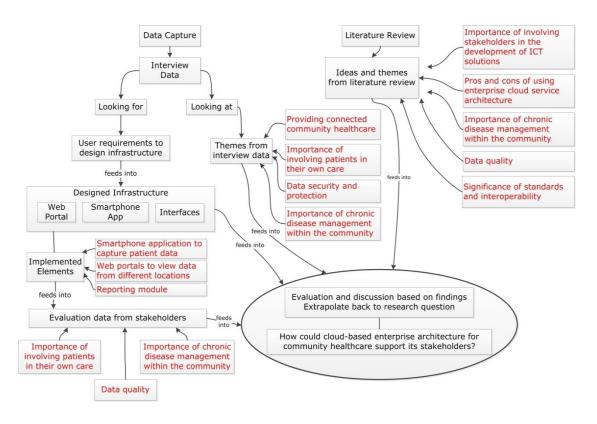


Figure 7-1: Findings applied to research framework

While all these findings complement the following discussion, four topics, listed in Table 7-5, are highlighted as interesting.

Table 7-5: Discussion topics

Topic for discussion				
Importance of stakeholder involvement in their own care				
Evaluating chronic disease management initiatives				
Significance of data security and protection				
Improving data quality				

7.3.1 Importance of stakeholder involvement in their own care

Research indicates that patients wish to be involved at some level with their own healthcare (Bensinga et al. 2013). For example, a survey of elderly patients in 11 European countries concluded that that patient cohort preferred a person-centric approach to their care where they had a good relationship with their clinicians who provided them with relevant information (Bastiaens et al. 2007). This person-centric approach can be facilitated to some extent through the innovative use of IT solutions, such as that described herein. This promotes collaboration between the various stakeholders in a patient's care, and aims to put the patient at the centre of the care process.

The two support group leaders that the author interviewed who spoke on behalf of the patients in their respective groups both indicated that the patient is entitled to, and more importantly, wants access to their data and to education and information about COPD. This gives rise to the concept of participatory medicine, where patients are equal stakeholders in their own care. While exploring this theme during the interviews, the author asked healthcare professionals: "How useful would you find it if your patient tracked their condition using an online tool between visits?" and "What level of trust would you put on that data?" There was cautious approval for the idea of patient self-management with many caveats and concerns. The main concerns were that the COPD patient cohort is often more elderly, less literate and possibly not technically knowledgeable. Additionally, the choice of assessment is critical to the success of using such a tool with an objective test being preferred. Finally, stakeholders indicated that only critical test results should be reported to reduce the possibility of data overload. A suggested way of achieving this functionality has been outlined in section 6.4: Interoperability explored – sharing clinical data. With respect to the level of trust assigned to the data provided by the patient, more trust would be put on the data where the patient is known to the healthcare professional and where the self-administered test is objective. Interestingly, one respondent noted that clinical information can be obtained from a phone-call with a COPD patient in terms of how breathless they are while speaking which would be lost in an online assessment.

Furthermore, a broader question was asked of the small number of people who evaluated the solution: "To what extent is patient involvement in chronic disease management important and to what extent does the solution address that?" The participants indicated that patient involvement is crucial to the success of initiatives in this area. While more work is required, the author suspects that while patient self-management of chronic conditions in the way described may be suitable for a subset of COPD patients, it is more suitable for other chronic conditions and perhaps a younger patient cohort who are more familiar with technology. Indeed, the Asthma Society of Ireland have developed a mobile application that allows asthma suffers record their peak flow measurements each day (Asthma Society of Ireland 2012).

There are other more general perspectives from which one can examine the topic of patient involvement in their own care: two of which shall be mentioned here. Firstly, allowing patients access to data to ensure its quality with an appropriate feedback loop should the data be incorrect. With respect to this, there needs to be a sensible information governance structure in place to ensure the patient's data is maintained and used appropriately (Health Information and Quality Authority 2013b). Secondly, allowing access to anonymised data to allow innovation to occur – access to and analysis of previously un-accessible data may provide access to new insights and technologies (Byrne 2013). Finally, access to anonymised data for research purposes, which is a topic covered in the next section.

7.3.2 Evaluating chronic disease management initiatives

Having the capability to evaluate the performance of chronic disease management initiatives, preferably against international best practice, in terms of patient clinical outcome and healthcare service delivery is necessary. The chronic care model (CCM), mentioned in Section 2.6: Evaluating the solution, offers an internationally-accepted means of evaluating the delivery of patient-centric chronic care. A survey conducted in 2010 evaluated chronic care management in Irish general practice against the CCM (Darker et al. 2011). It concluded that while GPs were supportive of shared chronic disease management initiatives with local hospitals, they felt that chronic disease management should primarily be led by GPs or practice nurses in a community setting. It is heartening that GPs are broadly supportive of the current

paradigm shift in the health system. However, there was concern that there were not enough resources in place to fully support a community-based delivery model.

The GPs interviewed suggested that one research resource currently used and beneficial to them is the Irish Primary Research Care Network (iPRCN) (ICGP et al. 2013). The iPRCN provides tools that allow GPs code data within their patient management software using ICPC-2 (a subset of ICD-10) for specific chronic illnesses and create local registers of patients with that chronic disease. Additionally, it allows GPs upload anonymised data to a central server for additional analysis. Currently, the iPRCN tools searches for and codes patients with the following conditions: diabetes, chronic kidney disease, possibility of heart failure or atrial fibrillation and eligibility for flu vaccination. It is the author's opinion that this clinical research tool should be expanded to include other chronic diseases, such as COPD, since it offers the potential to provide data that could aid the delivery of chronic disease management initiatives at both local and national level.

It was not possible to evaluate the proposed solution against the CCM. Instead, participants in the evaluation step of this research were asked two questions in relation to chronic disease management. The first question posed was "To what extent is patient involvement in chronic disease management important and to what extent does the solution address that?" While it is acknowledged that the sample size was small and possibly not representative of a large population, all respondents felt that patient involvement was critical in chronic disease treatment. Moreover, it was indicated that the designed solution would provide assistance in achieving patient involvement; particular reference was made to "Mod_003: share clinical data" which allows patients to self-manage their condition and if difficulties arise, send automatic notification to the healthcare professional.

The second question was "If the solution were fully implemented, to what extent would it support chronic disease management initiatives, such as the COPD clinical care programme?" Participants felt that the solution would allow greater collaboration between healthcare professionals, that data would be more accessible in a timely manner and that it would be useful for patient case management and data

collection. Indeed, one participant felt that this model could be extended to other chronic diseases.

Given the ageing demographics of the Irish population, chronic disease management initiatives are essential to support their needs. The author feels that the proposed solution is a feasible mechanism to support chronic disease management initiatives, provided that data security and data protection issues raised by stakeholders during the interview process are addressed adequately.

7.3.3 Significance of data security and protection

The technology proposed within this research is a cloud solution where the data is stored 'in the cloud'. Essentially, this means the data is stored in a remote server. As previously noted, there are two types of cloud: public and private.

7.3.3.1 Right data, right person, right view

Given the sensitivity of healthcare data, it is essential that the view of the data is limited to the minimum set of people who need to see it. With respect to this, three non-functional requirements were highlighted throughout: a security model to protect patient's data, access control and a mechanism to maintain an audit trail.

The proposed solution has a number of web-based portals to which a variety of different community and hospital based healthcare professionals and patients would have access to large amounts of data if it were to be implemented. This poses challenges in terms of restricting access to data. It would be essential to ensure that access to data was restricted on a per-patient basis, especially where the data is not anonymous.

Firstly, Saleforce.com's security and audit model, as described in section 6.2.2, provides a suitable model that would support the concept of right data, right person, right time (Salesforce.com 2013d). The security model supports a tight-coupling of data between the user and their data. Furthermore, it is possible to restrict access to data based on location, by including a specific location in a user's role. This would ensure that, for example, any particular GP can view only their patient's data.

Secondly access control (described in section 6.2.6), restricts access to the data by using login credentials and enabling automatic logout functionality on the cloud platform. Both of these functions are available with minimal configuration in Salesforce.com.

Thirdly, the ability to maintain an audit trail of changes made to specific fields within the database would be crucial for medico-legal reasons. Again, this functionality (described in section 6.2.6) is available with minimal configuration in Salesforce.com.

Implementing measures to ensure that data is protected and only visible to the right person at the right time is essential to the success of any application that spans the continuum of care. Ensuring that it is possible to audit who has viewed what data when is also required. The author proposes that Saleforce.com offers a solid data security and audit model.

7.3.3.2 Legislative

The protection of healthcare data is enshrined in Irish law through the data protection acts, which were the transposition into law of EU directive 95/46. Article 25 of EU directive 95/46 states that personal data cannot be stored in a "third country" – defined as a non-European Union country – unless the country provides adequate protection for personal data (European Parliment 1995). This would suggest that healthcare data stored in a cloud solution, such as that proposed herein, must be stored within the EU. However, development of the EU-US safe harbour privacy principles ensures that adequate levels of data protection are provided when these principles are implemented in "third countries" (European Commission 2000). For private companies, the EU-US safe harbour principle is a self-certification process whereby companies must comply with the standards laid out and self-certify that they are doing so. In theory, the existence of the EU-US safe harbour principle suggests that it is possible to store healthcare data outside the EU without violating EU directive 95/46. Indeed, Salesforce.com has current certification indicating that the company complies with EU-US safe harbour principles (www.export.gov 2013).

However, while interviewing participants, the author posed the question: "To what extent would you be concerned about data privacy or data security issues?" if a cloud solution were to be used to store patient data. The answers generally fell into two categories: either the participant was prepared to accept that the IT solution would provide appropriate and sufficient data privacy and security protection or that the data must be stored in a private cloud owned by the HSE, with the data stored in Ireland.

Two points of interest are highlighted: firstly, under the EU directive data can be stored anywhere in the EU and does not necessarily have to be stored in Ireland. Secondly, the cloud computing paradigm is not well understood by non-technical people. This results in a perception that the multi-tenant public cloud is somehow unsafe and insecure. The reality is that many healthcare providers in the United States of America use public clouds to store and access patient data. Examples include Blue Shield of California, who provide a platform for patients and doctors to collaborate to develop health management plans, and Zimmer, who use social networking functionality to connect with surgeons, patients and hospitals. Both companies use Salesforce.com's public cloud to store patient data. Additionally, the Croatian e-health strategy uses an innovative cloud-based product, known as medicus.net, to provide access to data across a variety of healthcare sites in conjunction with other industry leaders ("e-Health Croatia" 2013).

In many respects, the decision to deploy a cloud application to support business processes and store healthcare data remotely is based on many criteria – an important criterion being data security and protection. Due diligence is required in the selection of which cloud computing partner is most suitable. With innovation, there is always risk which needs to be weighed up against public perception, cost and the potential benefits of the solution.

7.3.4 Improving data quality

Improving data quality is the responsibility of all healthcare professionals (Health Information and Quality Authority 2012b). In the context of the COPD outreach programme, the potential impact for improvement to three data quality dimensions, defined in Table 7-6 should the designed architecture be fully implemented was queried as part of the evaluation step in the research study.

Table 7-6: Definition of data quality dimensions, taken from (Health Information and Quality Authority 2012b)

Data Quality Dimension	Description
Completeness	Complete data is data that has all those items required to measure the intended activity or event
Timeliness	Timely data is collected within a reasonable agreed time period after the activity that it measures and it is available when it is required and as often as it is required
Accuracy	Accurate data refers to how closely the data correctly captures what it was designed to capture

Specifically, two questions were asked in relation to the potential for data quality improvement, based on a short demonstration of "Mod_001: capture patient data in the home" and "Mod_007: generate reports" to participants. It is acknowledged that the sample size was small and results provided are preliminary and indicative. However, all participants felt that the potential for improvements in the timeliness, completeness and accuracy of data was likely should the solution be fully implemented based on a demonstration of the implemented modules. These results support the concept that IT can enable improvements in data quality.

Additionally, the use of a data dictionary and standard terminological systems are other data quality improvement measures (Health Information and Quality Authority 2013b). Consequently, the information model presented herein was based on a data dictionary format recommended by HIQA and documented in Appendix G: Evolution of the Information Model.

Moreover, while standard terminological systems were not considered extensively within this research, there is potential to code the data captured at point of care using a classification system such as ICD-10 or ACHI (Australian Classification of Health Interventions). One module (Mod_009: share administrative data) designed and documented in Appendix F: describes a requirement that automatically sends data from a central store to HIPE. HIPE data is coded using ICD-10 or ACHI (Health Information and Quality Authority 2013d). Coding data at point of care using these terminological systems would aid implementation of this module. This approach

supports the principle of capturing data once and re-using it many times where appropriate.

However, lack of an individual health identifier impedes data quality improvements and reduces the ability of healthcare professionals to track a patient's journey across the different community healthcare providers they attend as part of their treatment. The publication and passing into law of the forthcoming Health Information Bill could help to remedy this.

7.4 Limitations to this research

Four limitations were highlighted in section 4.2.1 as a result of the interpretative research paradigm used; these were loss of objectivity, potential of researcher bias, ability to confirm the validity of the results and the potential to generalise the results. Attempts were made to reduce the possibility of these limitations throughout the course of the study through data aggregation, inclusion of an evaluation step and the use of a research framework.

Another limitation included a lack of input from certain stakeholders identified in the stakeholder identification wheel, such as patients, public health nurses, members of community intervention teams, regulators and suppliers.

Finally, delivery of the fully implemented solution incorporating both strands of the solution – a new cloud-based application containing new functionality and a cloud-based integration engine that interoperated with existing systems - would have been ideal; however, it was not possible to achieve this in the given timeframe.

7.5 Other approaches to this research

There are many ways to answer a broad research question such as that posed herein. Some alternative approaches that could have been taken include:

- Selection of a clinical scenario based solely in the community (rather than across the community-hospital continuum of care as is the case in the research)
- Analysis, design, implementation of a cloud-based integration engine which examines interoperability between systems

• Requirements elicitation from patients who wish to use IT to support chronic disease self-management within the community across a broad spectrum of conditions (rather than a focus on a specific chronic condition)

Nonetheless, each approach is as valid as that actually carried out and could potentially be another research study in its own right.

7.6 Recommendations for future work

Knowledge, and the fundamental quest for it, is a key component in research. Searching for answers to specific questions normally leads to more questions and this was indeed the case with this research. Thus, there are a number of strands for future work that could be carried out; both specific to the solution proposed and more generally in the area of using health informatics to support community healthcare stakeholders.

With respect to the solution proposed to enable stakeholders involved with the COPD outreach programme, the author notes that two strands are required to develop a full solution: a new cloud system and a cloud-based integration engine that interoperates with legacy systems. The author recommends that a standards- and cloud-based integration engine is specified and implemented, which would result in a far more useful solution to the many and varied stakeholders involved in the COPD outreach programme.

More generally, the author proposes research into whether enterprise cloud service architecture and smartphone / tablet technology could be used to support patients with other chronic conditions who wish to become more involved in self-management of their condition. Research into this could further work made in relation to stakeholder influence mentioned in section 2.3: Stakeholder theory. Specifically, given the current paradigm shift towards disease prevention and early diagnosis (Department of Health and Children 2012), it would be interesting to investigate perceptions around use of such technology with different patient cohorts.

Also, the author suggests research into how health informatics standards could support chronic disease self-management initiatives, such as that described in section

6.4: Interoperability explored – sharing clinical data. Extending the GPMS to include scenarios that support electronic messaging between a patient and a healthcare organisation using the cloud (or other middleware) as a portal is a potential area of interest.

Finally, the author recommends that work be carried out in the area of data quality improvement given that within community healthcare, there are many originating data sources from many locations – some electronic, some paper-based – but, it appears, no national unified way of ensuring the quality of that data is sufficiently high to meet the needs of patients and healthcare professionals.

7.7 Conclusion

The purpose of this chapter was to discuss the research findings: in terms of the research questions and additional commentary that resulted from the study carried out. Other potential areas of research interest were identified. The next chapter provides a summary of the research.

8.1 Introduction

This research examined how cloud-based enterprise architecture for community healthcare could support its stakeholders. Specifically, it investigated how the currently paper-based COPD outreach programme would benefit from using enterprise cloud service architecture. Having set out the research's aims and objectives, carried out the research study and presented and discussed the findings from that study in previous chapters, it is time to present the conclusion.

Thus, this chapter has the following structure: section 8.2: Key findings of the study presents the research's main results while section 8.3: Contribution to research provides the research's contribution to the subject field. Finally, section 8.4: In conclusion offers the authors' concluding remarks on the topic.

8.2 Key findings of the study

Community healthcare includes a diverse set of stakeholders. Patients, healthcare professionals, service managers, suppliers and partners all contribute to services delivered within the community. Each stakeholder has a different perspective on their IT requirements. The stakeholder identification wheel proved to be a useful tool to ensure that no stakeholder was accidently excluded.

With regard to the specific requirements gathered for the COPD outreach programme, key IT requirements included the following: capturing patient data in the home, providing more electronic communication pathways within the community, providing access to data to patients for disease self-management and allowing access to data to managers for reporting and programme management.

Moreover, the solution proposed using enterprise cloud service architecture to provide a framework in which functional modules could be designed, implemented and deployed in a piecemeal fashion as resources allowed. The enterprise architecture designed allowed for both new functionality and interfaces with existing systems, although the focus of the research was on the former.

Additionally, the solution was partially-specified using the enterprise and information viewpoints of the HISA standard which allows for a domain-specific, platform-independent specification. While the viewpoints were aimed at different audiences, linking them together linguistically through the use of viewpoint correspondences demonstrated a fuller specification of the system.

Finally, the importance of patients' involvement in their own disease management was emphasised by both patients and healthcare professionals, which could potentially be facilitated through the implementation of solutions such as that proposed in this research.

8.3 Contribution to research

This research has shown that there is a requirement for information technology to support patients and healthcare professionals working in the community healthcare sector within Ireland. The author proposes that it is feasible to use enterprise cloud service architecture to support the information technology requirements of the COPD outreach programme and in this way support the needs of a subset of the community healthcare sector. Further, the author believes that it may be possible, with modifications, to apply the concepts contained in this research to other chronic disease management initiatives within community healthcare.

However there are barriers to adopting this approach, including concerns relating to data security and protection, data interoperability (particularly between the proposed system, general practice and hospital systems) and stakeholder fears about new technology. These barriers would need to be addressed before this approach could be adopted.

8.4 In conclusion

The Department of Health has stated that one of their aims is, where appropriate, to move hospital-based services into the community (Department of Health and Children 2012). The COPD outreach programme is a prime example of this approach. However, health information systems are required to support and enable this initiative. While alternative methods to support community healthcare stakeholder IT requirements currently exist, the author feels the solution proposed in this dissertation is a feasible and viable strategy.

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Appendix A: Interview Protocols

A.1: Introduction

This appendix contains the core set of questions that were asked of each participant in each stakeholder category. The questions asked of participants in each category were slightly different because each category of stakeholder has a different perspective on the area under research.

A.2: Category 1: Stakeholders who treat patients in outreach programme

- How much time do you spend with patients in their homes as part of the COPD outreach programme?
- What I.T tools, if any, would facilitate you spending more time with your patients?
- For example, would you find using a smartphone application to capture assessment data useful when you are visiting a patient? If so, what functionality would you like to see in such an application?
- What data would you like to capture?
- To what extent would you find it useful for data to be captured electronically in the patient's home and transferred to their hospital chart automatically?
- To what extent would you be concerned about data security or data privacy issues?
- How useful would you find it if your patient tracked their condition using an online tool between visits? What level of trust would you put on that data?

• Would you be willing for me to contact you again to evaluate my research?

A.3: Category 2: Stakeholders who treat patients in the community

- When a patient attends a COPD clinic at your practice, what assessments are carried out? Where is the data stored? Who is it shared with? If it is shared, how is it shared?
- Would you be aware if patients presenting to you with COPD are enrolled in a COPD hospital outreach programme? If so, how is this communicated to you?
- To what extent would you find it useful to have access to data that has been obtained on a patient as part of that hospital outreach programme?
- What is your opinion on using a web-based tool to provide you with access to data collected as part of a hospital outreach programme?
- What sort of data would you like to capture?
- In what format (integrated / stand-alone) would you like to view that data?
- To what extent would you be concerned about data security or data privacy issues?
- What other functionality would you like to see in such a tool?
- Would you be willing for me to contact you again to evaluate my research?

A.4: Category 3: Support group leaders

Note that these questions were answered on behalf of the members of the interest group.

- To what extent would your members find it useful to track their own well-being while at home using an online tool?
- Which technology (mobile app or web tool) would you or they prefer?
- Are you or they aware of outreach programmes from hospitals?

- What issues, if any, would you or they have if the data collected were shared with healthcare professionals such as members of an outreach team or general practice?
- To what extent would you or they be concerned about data security or data privacy issues?
- What other functionality would you or they like to see in such a tool?
- Would you be willing for me to contact you again to evaluate my research?

A.5: Category 4: Stakeholders who manage the outreach programme

- What role do you play in the clinical care programme?
- What I.T tools, if any, would facilitate your role within the programme?
- For example, would you find using a smartphone application to capture assessment data useful when you are visiting a patient? If so, what functionality would you like to see in such an application?
- What I.T. tools, if any, would facilitate management of the outreach programme more efficiently?
- To what extent would you find it useful for data to be captured electronically in the patient's home and transferred to their hospital chart automatically?
- What data would you like to be captured?
- To what extent would you be concerned about data security or data privacy issues?
- What is your opinion on using a web-based tool that would provide you with access to data collected as part of a hospital outreach programme?
- What other functionality would you like to see in such a tool?
- Would you be willing for me to contact you again to evaluate my research?

A.6: Category 5: Industry stakeholders

- How is your product used currently? Is it in use in any integrated care pathways that you are aware of? If so, what are they?
- Can you keep track of metrics once downloaded, can you see how often the app is used?
- What approach did you use to ensure stakeholder buy-in in your applications? Who are the stakeholders?
- What approach did you use when designing your application?
- What approach / techniques / tools did you use when evaluating your application?
- Where is the data stored? Can it be downloaded onto desktop from the app?
- To what extent would you or your customers be concerned about data security or data privacy issues?
- What other functionality would you or your customers like to see in an app for COPD?
- Would you be willing for me to contact you again to evaluate my research?

Appendix B: Original Evaluation Questionnaire

B.1: Introduction

This appendix contains the original evaluation questionnaire. Upon reflection, it was deemed to be too long and complex to ask participants to complete, so a more concise questionnaire was developed based on the original. It is included here for completeness.

B.2: The questionnaire

Section 1: High Level Infrastructure Design

- If fully implemented, what impact, if any, do you think this infrastructure would have on your day-to-day process?
- Which aspects of it would you view as more or less important
 - (provide list of various aspects of infrastructure and request interviewee to rank them in order of importance)
- Why do you rank them in that order?
- If fully implemented, to what extent do you think this infrastructure would support the quality of the data that you collect?
- What dimensions of data quality, if any, do you think it would address?
 - (provide list and definitions as per HIQA of data quality dimensions and request interviewee to select or rank them in order or importance)
- Does it address any of the data security or privacy issues that may have been raised in the user requirements gathering interviews?
- Do you have any other comments?

Section 2: Implemented Elements

The interviewee will have had an opportunity to examine the implemented elements of the infrastructure prior to answering these questions.

2.a: Data capture using ready at hand technology³

- How comfortable would you be in capturing patient data using ready at hand technology?
 - Very comfortable
 - Comfortable
 - Neither comfortable or uncomfortable
 - Uncomfortable
 - Very uncomfortable
- For each of the data quality dimensions listed, indicate how likely or unlikely you feel that using the implemented ready at hand technology would improve the quality of the data captured⁴:

	Very Likely	Likely	Neither likely or unlikely	Unlikely	Very unlikely
Completeness					
Legibility					
Relevance					
Reliability					
Timeliness					
Validity					
Accuracy					

³ The ready at hand technology referred to is what will be implemented as part of the research.

⁴ This question will be asked for each ready at hand application designed and / or implemented as appropriate

2.b: System interface

• For each of the data quality dimensions listed, indicate how likely or unlikely you feel that using the implemented system interface to transfer the captured data from the home environment to the cloud would improve the quality of the data captured:

	Very Likely	Likely	Neither likely or unlikely	Unlikely	Very unlikely
Completeness					
Legibility					
Relevance					
Reliability					
Timeliness					
Validity					
Accuracy					

Section 3: Demographic Information

- Geographical region
- Stakeholder group

Appendix C: Evaluation Questionnaire Used

C.1: Introduction

This appendix contains a copy of the questionnaire that was completed by the participants as part of the evaluation. Its design was based on the original questionnaire presented in Appendix B: Original Evaluation Questionnaire.

C.2: The questionnaire

- 1. What is your overall impression of the solution?
- 2. How does it address your requirements, in particular data capture, sharing, security and privacy requirements, as discussed in the initial interview?
- 3. In terms of the software implemented and in particular, the capturing of patient data using a hand-held device, how comfortable would you be in capturing patient data using this application? *Please circle the most appropriate answer*.

Very comfortable Comfortable Neither comfortable uncomfortable	Uncomfortable	Very uncomfortable	Question not relevant
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4. The Health Information and Quality Authority define three data quality dimensions as follows:

"Completeness: "Complete data is data that has all those items required to measure the intended activity or event" (Health Information and Quality Authority 2012b)"

"Timeliness: "Timely data is collected within a reasonable agreed time period after the activity that it measures and it is available when it is required and as often as it is required" (Health Information and Quality Authority 2012b)

"Accuracy: "Accurate data refers to how closely the data correctly captures what it was designed to capture" (Health Information and Quality Authority 2012b)

For each of these data quality dimensions listed, indicate how likely or unlikely you feel the application to capture patient data in the home would improve the quality of the data captured:

	Very Likely	Likely	Neither likely or unlikely	Unlikely	Very unlikely	
Completeness						Question not relevant
Timeliness						Question not relevant
Accuracy						Question not relevant

- 5. What impact would the data sharing elements of the designed solution have on service delivery for patients?
- 6. If the solution were fully implemented, to what extent would it support chronic disease management initiatives, such as the COPD clinical care programme or others?
- 7. To what extent is patient involvement in chronic disease management important and to what extent does the solution address that?
- 8. In terms of the implementation of the *reporting module*, can you indicate how likely or unlikely you feel the information gained from reports generated would potentially improve the delivery of the COPD clinical care programme in terms of the data quality dimensions listed:

	Very Likely	Likely	Neither likely or unlikely	Unlikely	Very unlikely	
Completeness						Question not relevant
Timeliness						Question not relevant
Accuracy						Question not relevant

9. In terms of the implementation of the *web portals* for the different stakeholders, can you indicate how likely or unlikely you feel that communication between those stakeholders would be improved, should it be fully implemented? *Please circle the most relevant answer*.

Very likely	Likely	Neither likely or	Unlikely	Very unlikely	Question not relevant
пкегу		unlikely			

10. Do you have any additional comments?

Appendix D: Ethics Application

D.1: Introduction

This appendix contains copies of the following documents that were submitted to the Research Ethics Committee of the School of Computer Science and Statistics as part of ethics application process:

- Participant interview information sheet
- Participant evaluation information sheet
- Participant consent form

D.2: Participant interview information sheet

Project Title: Towards supporting community healthcare in Ireland through

the use of ICT: A cloud-based proposition

Project Duration: February to June 2013

Lead Researcher: Sarah Jordan

Research Project Background

The purpose of this research is to design an information communication technology infrastructure to support the needs of community healthcare professionals and their patients. It is thought that this infrastructure will utilize a cloud computing model. This model of computing allows immediate access to hardware resources for little initial capital investment scales well and provides the opportunity to develop innovative solutions (for example, interactive mobile applications) (Marston et al. 2011).

Community healthcare plays a necessary and vital role in the delivery of home-based healthcare within Ireland. In particular, chronic diseases, which account for 86% mortality and 77% of overall disease burden within Ireland, should be managed and treated with the community, with the provision of timely, community-based care (Department of Health and Children 2012). A number of national clinical care programmes have been implemented to treat various chronic diseases. They aim to engage patients, align stakeholders and provide a better quality, easier to access healthcare.

The focus of this study is on how the national clinical care programme for chronic obstructive pulmonary disease could be delivered electronically through the use of ready-at-head technology in a cloud computing environment. In particular, an examination will be made of how patient assessment data that is captured within the home environment could be captured, stored and transferred electronically.

Participant Selection

You have been invited to participate in this research project because you are a stakeholder in the community healthcare sector. Your opinions and input into this research will inform the design of an infrastructure that aims to share data

electronically within the community care setting for the treatment and management of patients with chronic obstructive pulmonary disease.

Voluntary Participation

You have the option to decline to answer any questions that are posed. You have the option to withdraw from the research study at any stage.

You will be asked if this interview can be recorded. If you do not want it recorded, no recording will take place. Instead, the researcher will transcribe your answers.

Regardless of whether the interview is recorded or written, the information you supply will be treated with the strictest confidentiality. Its contents will only be available to the researcher and will only be used for the purposes outlined below.

Duration of Participation

This interview will take between 10-30 minutes to complete.

Following on from the interview, the researcher will design the infrastructure and implement some elements of it. You may be asked to validate or test that implementation and provide feedback on it at a later stage in the research project. If you decide that you no longer wish to participate in the research study, that decision will be honoured.

Data Storage, Usage and Confidentiality

The information you provide will be stored in Word documents. As part as the data storage process, each stakeholder will be coded. The stakeholder name-code combination will be stored in a password protected Word document and only known to the researcher. This ensures your anonymity.

The information you provide during this interview will be aggregated. It will be used to inform the design of the proposed infrastructure. Additionally, it will aid the researcher's aim of understanding of current processes within the defined area.

It will be used to produce a dissertation in part-fulfilment of the requirements of Masters of Science in Health Informatics. Additionally, it may be used to write article(s) that are publishable in relevant journals or for relevant conferences.

Data Confidentiality

Any information you provide will be treated with the strictest confidentiality. Data will be aggregated and analysed. Results will be derived from the aggregated data. I do not intend quoting people directly in my thesis or in other publications.

Personal data – such as the consent form – will be treated as per the Data Protection (& Amendment) Act. It will be stored in a safe location that is not accessible to anyone other than the researcher.

Conflict of Interests

The researcher has no conflict of interest in carrying out this study.

Benefits for You

Upon completion of the research, you may have access to the results of this study.

Risks to You

There are no anticipated risks to you should you decide to participate in this study.

Research Ethical Approval

Ethical approval to carry out this research was sought from the Research Ethics Committee of the School of Computer Science & Statistics, University of Dublin, Trinity College. It was granted on 24th January 2013.

D.3: Participant evaluation information sheet

The participant evaluation information sheet is identical to the participant interview information sheet except where noted below.

Participant Selection

You have been invited to participate in this research project because you are a stakeholder in the community healthcare sector. You have already contributed to this research by providing input which informed the architecture and implementation that are currently under evaluation. You are now invited to comment on the design of the architecture based on your previous input and the implementation of some elements of that architecture. Your opinions and input into this evaluation will provide data on the potential improvement of data quality within the community care setting for the treatment and management of patients with chronic obstructive pulmonary disease. It will also provide data on the potential support solutions such as that proposed may have for chronic disease management initiatives within the community care setting.

Evaluation Format

The evaluation has the following format:

- The researcher will present the architecture and demonstrate the elements that have been implemented. It is expected that this should take between 5-10 minutes.
- You have an opportunity to examine the implementation(s) and ask any
 questions you may have. It is expected that this should take between 10-15
 minutes.
- You will be requested to complete a questionnaire. It is expected that this should take 10-20 minutes.

Duration of Participation

This interview will take between 25-40 minutes to complete.

D.4: Participant consent form

Project Title: Towards supporting community healthcare in Ireland through

the use of ICT: A cloud-based proposition

Project Duration: February to June 2013

Lead Researcher: Sarah Jordan

Declaration:

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

- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.
- I agree that my data is used for scientific purposes and I have no objection that
 my data is published in scientific publications in a way that does not reveal my
 identity.
- I understand that if I make illicit activities known, these will be reported to appropriate authorities.
- I understand that I may stop electronic recordings at any time, and that I may at any time, even subsequent to my participation have such recordings destroyed (except in situations such as above).
- I understand that, subject to the constraints above, no recordings will be replayed in any public forum or made available to any audience other than the current researchers.
- 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 that if I or anyone in my family has a history of epilepsy then I am proceeding at my own risk.
- I have received a copy of this agreement.

Participant's Name (block letters):
Participant's Signature:
Date:
Statement of Researcher's Responsibility:
I have explained the nature and purpose of this research study, the procedures to be
undertaken and any risks that may be involved. I have offered to answer any
questions and fully answered such questions. I believe that the participant
understands my explanation and has freely given informed consent.
Researcher's Contact Details:
Name: Sarah Jordan
Email: scjordan@tcd.ie
Phone:
Researcher's Signature:
Date:

Appendix E: Complete Set of User Requirements

E.1: Category 1: Stakeholders who treat patients in outreach programme

Requirement Number	Description	New functionality or integration with legacy system?	Number requesting [Total = 9]
C1_01	Capture patient's demographics on a handheld device. The patient's demographics that must be captured are first name, surname, date of birth, address, telephone number, mobile number, next of kin and hospital MRN.	New functionality	7
C1_02	Capture patient observations on a handheld device. A patient's observations that must be captured are weight, height, BMI, blood pressure, heart rate, respiratory rate, temperature, O2 saturation, sputum colour, amount and consistency and chest auscultations. This data must be captured and stored each time the outreach team member visits the patient in their home.	New functionality	8
C1_03	Capture patient's current medication list on a handheld device. The medication details that must be captured are drug, dosage, route, frequency and the inhaler device used (if applicable). This data must be captured by the outreach team member the first time they visit the patient in their home.	New functionality	6

C1_04	Capture patient's treatments and investigations on a handheld device.	New functionality	1
C1_05	Capture the Borg breathlessness score on a handheld device. Borg's breathlessness scale is a subjective assessment tool used to measure breathlessness in COPD patients (Borg 1982). It consists of a scale from 0 to 10, where 0 is "Nothing at All" and 10 is "Maximal" (Borg 1982). The National COPD programme stipulates that this quality of life score is carried out at each visit to the patient.	New functionality	7
C1_06	Capture the modified MRC score on a handheld device. The mMRC dyspnoea scale is a quality of life score that is used to rate a person's subjective feeling of breathlessness (Mahler and Wells 1988). It is comprised of five statements. The patient is required to select one. The National COPD programme stipulates that this quality of life score is carried out at each visit to the patient.	New functionality	7
C1_07	Capture the COPD assessment test (CAT) on a handheld device. The COPD assessment test (CAT) is a quality of life test. It consists of 8 questions relating to subjective quality of life issues, which are answered using a 5-point likert scale (GlaxoSmithKline 2009). The National COPD programme stipulates that this quality of life score is carried out at each visit to the patient.	New functionality	7
C1_08	Capture the EuroQol – Health Status Questionnaire (EQ-5D-3L) on a handheld device. The EuroQol – Health Status Questionnaire (EQ-5D-3L) is a two-part assessment tool that measures the patient's health state at time of questioning. The first part of the assessment is comprised of five	New functionality	7

			
	sections, each of which has three options. The second part of the tool is a scale from 0 to 100 where the patient must indicate how they are feeling at time of questioning where 0 is feeling the worst and 100 is feeling the best. (The EuroQol Group 1990). The National COPD programme stipulates that this quality of life score is taken three times while the patient is with the outreach service: on Day 1, Day 14 and at Week 6.		
C1_09	Provide electronic referral to community services on a handheld device that can be sent from the patient's home. In this case, community services include pulmonary rehabilitation, community occupational therapy and smoking cessation services. If the receiving community service does not allow for electronic referral, provide functionality to create a letter that can be printed or faxed upon return to the outreach office.	Integration with legacy system(s)	3
C1_10	Provide an electronic link to the hospital system	Integration with legacy system(s)	7
C1_11	Provide an electronic link to the primary care team	Integration with legacy system(s)	4
C1_12	Provide an electronic link to general practitioner	Integration with legacy system(s)	2
C1_13	Reconcile medication list with what is contained in hospital chart	Integration with legacy system(s)	1
C1_14	Provide direct input of relevant data into HIPE. The relevant data that must be input into HIPE is defined as follows: Set of patient's observations on days 1, 14 and 42 of programme Set of patient's subjective quality of life scores on day 1, 14 and 42 of programme Indication if patient has been	Integration with legacy system(s)	1

	referred to pulmonary rehabilitation Indication if patient has been referred to smoking cessation Patient's inhaler technique This data is specific to the outreach programme and is additional to the standard HIPE data required.		
C1_15	Provide access to medication list. The data that must be provided are drug, dosage, route, frequency and the inhaler device used (if applicable).	New functionality	3
C1_16	Provide access to test results that are available on existing hospital systems	Integration with legacy system(s)	4
C1_17	Provide access to other healthcare professional's contact details, such as the patient's GP, pharmacist or public health nurse	New functionality	1
C1_18	Provide access to evidence-based guidelines, such as the COPD GOLD guidelines, in the patient's home	New functionality	1
C1_19	Capture a patient's public health nurse contact information. The data that must be captured is name, health centre and telephone number.	New functionality	Derived from requirement number C1_17
C1_20	Capture a patient's general practitioner's contact information. The data that must be captured is name, address, telephone number and fax number.	New functionality	Derived from requirement number C1_17
C1_21	Capture a patient's community pharmacist's contact details. The data that must be captured is name, address, telephone number and fax number.	New functionality	Derived from requirement number C1_17

E.2: Category 2: Stakeholders who treat patients in the community

Requirement Number	Description	New functionality or integration with legacy system?	Number requesting [Total = 9]
C2_01	Data to be integrated into GP patient management software with bidirectional data flows.	Integration with legacy system(s)	6
C2_02	Data to be integrated into GP patient management software with bidirectional data flows, using Healthlink.	Integration with legacy system(s)	2
C2_03	Provide access to the fact that the patient is in the COPD outreach programme.	Integration with legacy system(s)	6
C2_04	Provide access to a patient's baseline statistics. This data must contain the following: weight, height, BMI, blood pressure, heart rate, respiratory rate, temperature, O2 saturation, sputum colour, amount and consistency and chest auscultations.	New functionality	6
C2_05	Provide access to medication list or medication changes. The data that must be provided are drug, dosage, route, frequency and the inhaler device used (if applicable).	New functionality	6
C2_06	Provide access to data and functionality through a web portal	New functionality	4
C2_07	Provide information and help for patients with COPD through a web portal. This information shall include the following: Access to how to obtain oxygen if required Access to smoking cessation help Access to information about COPD in plain English	New functionality	2
C2_08	Provide information and education for healthcare professionals through a web portal, including:	New functionality	2

	 Information on advances in the care and management of COPD Guided pathways in the treatment of COPD 		
C2_09	Provide access to data that may exist on hospital systems. This data can be broadly categorised into three main areas, as follows: Objective data, such as date of diagnosis, blood test results and spirometry results Subjective data, such as quality of life scores and symptoms	Integration with legacy system(s)	6
	 Miscellaneous, such as investigations, treatment plans, dates of next review and access to agreed guidelines 		
C2_10	Provide functionality to refer patient back to outreach team	Integration with legacy system(s)	1
C2_11	Provide central repository for medication, which has the following high level functionality: Who has prescribed the medication When the medication was prescribed Why the medication was prescribed	New functionality which requires integration with legacy system(s)	1
C2_12	Provide functionality to input when and how often a prescription has been filled	New functionality	1
C2_13	Provide functionality to mark what medication a patient is using from the prescription given to them from their doctor	New functionality	1
C2_14	Provide functionality to send a reminder to call to pharmacist for an informal check-up	New functionality	1

E.3: Category 3: Support group leaders

Requirement Number	Description	New functionality or integration with legacy system?	Number requesting [Total = 2]
C3_01	Provide functionality to perform a daily assessment as part of the patient's self-management plan. The daily assessment should be carefully selected to suit the COPD patient cohort. Because of this, it has not be specified which assessment to carry out at this time, although the BCSS may be a suitable candidate, as suggested by C4_11. If the result of the patient assessment is within normal ranges, the result should be stored. If the result of the patient assessment is not within normal ranges, a Healthlink message should be generated and sent to either (or both?) the GP or the outreach team for follow-up.	New functionality that requires integration with legacy system(s)	Informed by requirement numbers C4 10 and C4_11
C3_02	Provide functionality to keep track of medication changes. The data that must be provided are drug, dosage, route, frequency and the inhaler device used (if applicable).	New functionality	2
C3_03	Provide access to an exercise plan	New functionality	1
C3_04	Provide chat forum	New functionality	1

E.4: Category 4: Stakeholders who manage the outreach programme

Requirement Number	Description	New functionality or integration with legacy system?	Number requesting [Total = 2]
C4_01	Develop a reporting module that can report on the following key	New functionality	2

	 performance indexes: Patient's hospital length of stay Number of outreach patients seen in a given time frame Number of patients admitted from emergency department 		
C4_02	Develop a reporting module that can report on how long each outreach visit takes.	New functionality	2
C4_03	Send reminders to staff that they have carried out required tasks as listed in the 10-point COPD bundle.	New functionality	1
C4_04	Send reminders to staff to ensure they inform patients about smoking cessation and pulmonary rehabilitation.	New functionality	1
C4_05	Develop functionality to provide GPS location to support lone worker protocol.		1
C4_06	Capture patient observations on Day 1, 2, 3, 14 and Week 6 on a handheld device.	New functionality	1 Same as C1_02
C4_07	Capture quality of life scoring on Day 1, 2, 3, 14 and Week 6 on a handheld device.	New functionality	Same as C1 05, 1 06, C1 07 and C1_08
C4_08	Provide functionality to run reports on captured observations. These reports should be generated as graphs and / or tables.	New functionality	1
C4_09	Provide functionality to run reports on captured quality of life scores. These reports should be generated as graphs and / or tables.	New functionality	1
C4_10	Send alerts to outreach team member if observations are not with acceptable ranges.	New functionality	1
C4_11	Provide the ability for the patient to track their own condition. The most important symptom is sputum colour and quantity, which can be checked daily using the BCSS scale.	New functionality	1

Appendix F: Additional Design Information

F.1: Introduction

This appendix contains additional design information. The full module list specified for the proposed solution (section F.2:), use case descriptions for the modules described in the main body of the text (sections F.3: through F.6:) and a high level design for Mod 009: share administrative data (section F.7:).

F.2: Full modules list

This section lists the modules that were specified as part of the enterprise viewpoint for the proposed solution. Due to time constraints, it was not possible to develop use case diagrams and descriptions for each of them; hence, only those which were deemed relevant to the research question were included in the main body of the text.

The proposed system contains twelve modules, currently listed under the subject of care and activity management workflows, as defined by the HISA standard and itemised below.

Subject of care workflow modules

Module number	Module name	Description
Mod_001	Capture patient data in the home	Provides functionality to allow capture of a patient's data, such as demographics, observations and medication, on a handheld device in the patient's home.
Mod_002	View patient data using a web portal	Provides functionality to allow patients and healthcare professionals view patient data from different locations through a web portal. The view of the data should be

		restricted to the minimum data set required.
Mod_003	Share clinical data	Provides functionality that allows a patient to self-manage through the daily application of an appropriate evidence-based assessment tool with the results being saved each day. An event is triggered, which sends a message to either a GP or outreach team when a clinically significant change occurs.
Mod_004	Capture patient quality of life scores in the home	Provides functionality to allow capture of a patient's quality of life scores on a handheld device in the patient's home.
Mod_005	Provide centralised medication database	Provides functionality that allows patients and healthcare professionals view the most recent list of a patient's prescribed medication. Changes to the patient's medication are updated and reflected in a centralised database.
Mod_006	Provide patient information and education resources	Provides functionality to upload information and education resources about COPD to the patient's web portal.

Activity management workflow modules

Module number	Module name	Description
Mod_007	Generate reports	Provide functionality to report on the COPD outreach programme:
		 To improve service delivery in a timely fashion
		 To ensure that the service is cost- effective
		 To verify that the service is meeting its key performance indicators
Mod_008	Schedule patient appointments	Provide functionality to schedule patient appointments and send reminders to patients about the appointments.
Mod_009	Share administrative data	Provide functionality to allow direct, automatic input to HIPE of the relevant patient data in a timely way.
Mod_010	Provide bi-directional electronic referral pathway between COPD outreach service and other community-based services	Provide functionality to allow for electronic referral by the outreach team member to community-based services, such as community occupational therapy, pulmonary rehabilitation, smoking cessation services and other community-

		based services as necessary.
Mod_011	Provide bi-directional electronic referral pathway between COPD outreach service and GPs	Provide functionality to allow GPs refer patients back to the outreach service.
Mod_012	Develop functionality to provide global positioning system (GPS) location to support lone worker protocol	Provide functionality to allow the handheld device act as a GPS locator in order to protect the outreach team member when they are working alone in the community.

F.3: Use case description for Mod_001 – capture patient data in the home

The following table provides a formal description of the capture patient data in the home scenario, which is a module contained in the subject of care workflow.

Use Case Name	Capture patient data in the home
Module number	Mod_001
Use case ID	UC_001
Linked to requirements number(s) – see Appendix E: for a full listing	C1_01, C1_02, C1_03, C1_05, C1_06, C1_07, C_08 C4_06, C4_07
Primary business actor	Outreach team member
Other participating actors	Hospital system
Other interested stakeholders	Patient Hospital consultant Pharmacist
Pre-condition	 The outreach team member is at the patient's home. The outreach team member has access to the smartphone application The outreach team member has logged into the application using their login credentials
Typical scenario of events	The outreach team member uses the search facility to identify the patient (use case: "identify patient"). This returns the patient's details if the patient is already enrolled in the outreach programme. Otherwise, the outreach team member captures the new patient's demographics (use case: "capture demographics for new patient") as described in Extensions. The outreach team member records a set of patient observations

	(use case: "capture set of observations").	
	The outreach team member records what medication the patient is currently on (use case: "captures medication list").	
	The outreach team member saves the information within the application (use case: "save data").	
Extension	If the patient data is not returned after using the search facility (as a result of use case: "identify patient"), the outreach team member is required to capture the patient's demographics and save them to the portal.	
Post-condition	The patient's data has been captured	
	■ The patient's data has been saved	
	The patient's data can be viewed via the cloud portal	
	 The outreach team member has logged out of the smartphone application 	
Business rules	N/A	
Assumptions	N/A	

F.4: Use case description for Mod_002 – view patient data

The following table provides a formal description of the view patient data using a web portal scenario, which is a module contained in the subject of care workflow.

Use Case Name	View patient data	
Module number	Mod_002	
Use case ID	UC_002	
Linked to requirements number(s) – see Appendix E: for a full listing	C1_15, C1_17 C2_03, C2_04, C2_05 C3_02	
Primary business actor	Outreach team member Patient Hospital consultant Pharmacist or other community-based healthcare professional	
Other participating actors	N/A	
Other interested stakeholders	General practitioner	
Pre-condition	 The actor has access to the portal. The actor has logged into the portal using their user login and password 	
Typical scenario of events	The actor can view data on the patient's as per the business rules listed below.	
Alternative scenarios	In the case where there is more than one patient's	

	data listed, it shall be possible to click into each patient and view the data in full.
Extension	N/A
Post-condition	 The patient's data has been viewed via the portal The actor has logged out of the portal (either by themselves or automatically after a short time lapse)
Business rules	Restrictions apply on what data each actor is allowed view: A hospital consultant is only allowed view patients that are currently under their care An outreach team member is only view patients that are currently enrolled in the outreach programme and under their care A patient is only allowed view their own data A pharmacist is only allowed view prescription data related to patients under their care
Assumptions	

$F.5: \ Use \ case \ description \ for \ Mod_003-share \ clinical \ data$

The following table provides a formal description of the generate reports scenario, which is a module contained in the subject of care workflow.

Use Case Name	Share clinical data
Module number	Mod_003
Use case ID	UC_003
Linked to requirements	C2_01, C2_02
number(s) – see Appendix E: for a full listing	C3_01
Primary business actor	Outreach team member
	Patient
	General practitioner
Other participating actors	N/A
Other interested stakeholders	Hospital consultant
Pre-condition	The patient has access to the portal.
	The patient has logged into the portal using their user login and password
Typical scenario of events	The patient performs an evidence-based assessment and uploads it to the portal.
	The portal saves the assessment value. The portal verifies whether the assessment value is within an

	acceptable range.
	If it is not within the range, an event would be triggered in the cloud portal, which sends a HL7 message to the patient's general practitioner's patient management software and / or the COPD outreach team that the patient is associated with via a messaging broker.
Alternative scenarios	N/A
Extension	N/A
Post-condition	The patient has logged out of the portal
Business rules	N/A
Assumptions	An appropriate assessment has been selected

F.6: Use case description for Mod_007 – generate reports

The following table provides a formal description of the generate reports scenario, which is a module contained in the activity management workflow.

Use Case Name	Create reports on outreach service			
Module number	Mod_007			
Use case ID	UC_003			
Linked to requirements number(s) – see Appendix E: for a full listing	C4_01, C4_02			
Primary business actor	Outreach programme manager			
Other participating actors	N/A			
Other interested stakeholders	Outreach team member			
Pre-condition	 The outreach programme manager has access to the portal. The outreach programme manager logs into the portal using their login credentials. 			
Typical scenario of events	The outreach programme manager specifies the report parameters, as defined in C4 01 (use case: "specify report criteria"). The following report have been defined:			
	 Report 1: Patient hospital length of stay within a user-input date range 			
	 Report 2: Number of patients admitted from emergency department within a user-defined input date range 			
	The outreach programme manager generates the report (use case: "generate report").			
	The outreach programme manager selects which			

	action to perform on the report that has been generated. The following options are available: print, save or email report (use case: "action [print save email] report").			
Alternative scenarios	N/A			
Extension	N/A			
Post-condition	 The required reports have been generated. The outreach programme manager has logged out of the portal. 			
Business rules	N/A			
Assumptions	The outreach programme manager has the required permissions to generate reports			

F.7: High level design for Mod 009: share administrative data

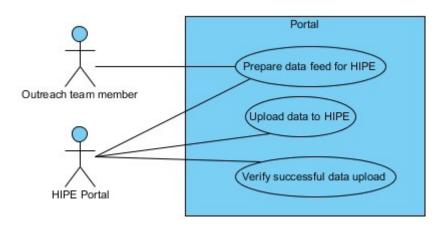
As stated in Section 5.3.5: Functional user requirements, one requirement that stakeholders working within the outreach programme suggested would be beneficial is direct input of relevant data from a centralised database into the Hospital In-Patient Enquiry (HIPE) system, which would reduce data entry for them.

The Economic and Social Research Institute (ESRI) is contracted by the Department of Health to manage the HIPE system (Health Information and Quality Authority 2013d). The HIPE system is a computer-based system used in all Irish public acute hospitals to gather demographic, clinical and administrative data on patient discharges and deaths (The Economic and Social Research Institute 2013). The HIPE portal is a web-based application that is used to capture HIPE data (The Economic and Social Research Institute 2010). Currently within the COPD clinical care programme, a pilot is running in three hospitals whereby the COPD outreach staff must upload a certain subset of data to HIPE using the HIPE portal. This process is currently paper-based but there is scope to automate it.

While this module is not core functionality, it does present an opportunity to explore interoperability between the new cloud portal and legacy systems and is included here for that reason. It is suggested that web services, such as REST or SOAP be used to implement this module, although its implementation was beyond the scope of this

research project and it is presented as a high level design of a possible solution to the requirements specified by the stakeholders.

Outreach team members are required to input data into HIPE. These stakeholders have requested that this labour intensive data entry activity is automated by uploading the required data from the centralised data storage to HIPE, as illustrated in the following use case diagram.



As presented, there are three steps involved in this process: the outreach team member prepares the data feed, then the data is uploaded and finally a verification step is executed to ensure the data quality. The process by which this occurs is formally defined in the table below.

Use Case Name	Transfer data to HIPE
Module number	Mod_009
Use case ID	UC_004
Linked to requirements number(s) – see Appendix E: for a full listing	C1_14
Primary business actor	Outreach team member HIPE portal (web-based portal)
Other participating actors	N/A
Other interested stakeholders	Outreach programme management
Pre-condition	The actor has access to the portal.

	The actor has logged into the nortal using their user login					
	The actor has logged into the portal using their user login and password					
	The data to transfer has been previously saved to the portal					
	1 7 1					
Typical scenario of events	The portal prepares the data (use case: "Prepare data feed for HIPE"), as per the agreed data contract described in C1 14; in addition to the standard data required by HIPE (which is outside the scope of this use case), the following data must be collated on behalf of the COPD outreach programme and sent to HIPE: patient's objective and subjective measurements on days 1, 14 and 42 of the programme, the patient's inhaler technique and an indication of whether the patient has been referred to pulmonary rehabilitation and smoking cessation. The data contract specifies the format for each field, how the transfer takes place and how often it takes place. The transfer could be completely automatic. The portal logs onto the HIPE portal using an agreed protocol. Once logged in, the portal transfers the data. The portal logs out once the transfer is complete. This functionality is					
	contained in use case: "Upload data to HIPE".					
	Verification that the correct number of records was transferred can be carried out as per an agreed schedule. Information regarding this is contained in use case: "Verify successful data upload".					
Alternative scenarios	The following alternative scenarios are listed:					
	 There is an error generating the data feed. In this scenario, a message is sent to the administrator to investigate the issue. There is an error transferring the data to the HIPE portal. Errors could include problems logging into HIPE portal, or transmission problems. Again, a message is sent to the 					
	administrator to investigate the issue. The entire data feed is stopped until the issue is rectified to ensure data integrity.					
	 The verification algorithm indicates that there an incorrect number of data records. In this scenario, the entire data feed is rolled-back (to preserve data integrity) and the issue investigated. 					
Extension	N/A					
Post-condition	■ The data has been successfully uploaded to the HIPE portal					
	<u> </u>					

Appendix G: Evolution of the Information Model

G.1: Introduction

Creation of the logical information model began with identifying data elements necessary to capture key patient demographic, clinical and administrative data from the standardised paper chart currently in use by the COPD outreach team. Additional contextual information was added based on interview data with key stakeholders and by further analysis by the author.

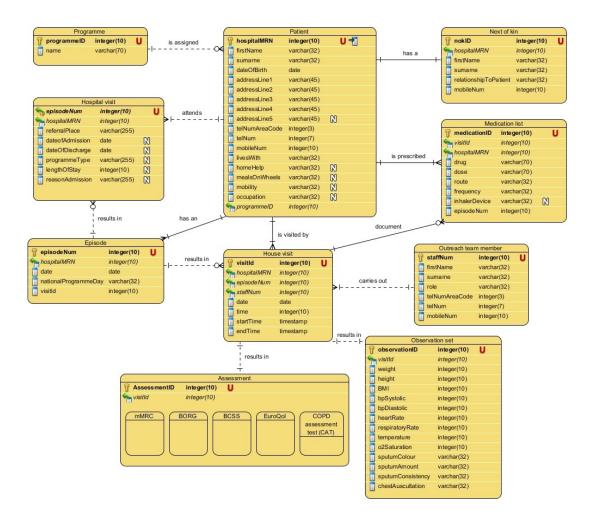
Initially, the logical data model was represented as an entity-relationship diagram with an associated data dictionary. This was done in order to understand the key data elements and the relationships that existed between them. These are explored in more detail in G.2: Logical data model and G.3: Data dictionary.

As stated previously, a decision was made to specify the system using the principles underlying the HISA standard as much as possible. With respect to that, the final information model presented in the main body of the text has been partially specified using the principles of the information viewpoint of the HISA standard (International Organization for Standardization 2011b). The entity-relationship diagram was reexamined to develop the class diagram (Figure 5-8: Model of information objects used by COPD outreach programme on page 63) used in the main body of the text. Both contain the same data elements, which are simply specified using different notations and linked together via a data element number.

The physical data model (section 6.2.5: Physical data model on page 77 of the main text) was originally derived from the logical data model as depicted in the entity-relationship diagram in this appendix. The initial logical data model is illustrated in the next section.

G.2: Logical data model

The logical data model was initially represented as an entity-relationship diagram, shown below.



It has ten entities, each of which have a number of attributes and associated data types which were defined in a data dictionary and described in the next section.

G.3: Data dictionary

The entities contained in the diagram can be divided into datasets, as per guidelines set out by HIQA in Appendix 4 of their publication "Guiding Principles for National Health and Social Care Data Collections" (Health Information and Quality Authority 2013b). Table A: lists the datasets and their associated logical entities.

Table A: Datasets and their associated logical entities

Dataset	Entity
Demographic	Patient
	Next of kin
Clinical information	Assessment
	Observation set
	Medication list
Programme administration	Programme
	Hospital visit
	House visit
	Episode
	Outreach team member

G.4: Demographic dataset

The demographic dataset contains the two entities that deal with patient's demographic details, such as name, date of birth, address and so on. In particular, Table B: lists details in relation to the patient while Table C: provides details about the patient's next of kin.

Table B: Data elements contained within "Patient" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
DEM_001	hospitalMRN	integer(10)	PKUnique. Medical record number for the patient	No	Included following analysis
DEM_002	firstName	varchar(32)	Patient's first name	No	Paper chart used in COPD outreach programme
DEM_003	Surname	varchar(32)	Patient's surname	No	Paper chart used in COPD outreach programme
DEM_004	dateOfBirth	Date	Patient's date of birth	No	Paper chart used in COPD outreach programme
DEM_005	addressLine1	varchar(45)	First line of patient's address	No	Paper chart used in COPD outreach programme
DEM_006	addressLine2	varchar(45)	Second line of patient's address	No	Paper chart used in COPD outreach programme
DEM_007	addressLine3	varchar(45)	Third line of patient's address	No	Paper chart used in COPD outreach programme
DEM_008	addressLine4	varchar(45)	Fourth line of patient's address	No	Paper chart used in COPD outreach programme
DEM_009	addressLine5	varchar(45)	Last line of patient's address	Yes	Paper chart used in COPD outreach programme
DEM_010	telNumAreaCode	integer(3)	Phone number area code	No	Paper chart used in COPD outreach programme
DEM_011	telNum	integer(7)	Phone number	No	Paper chart used in COPD outreach programme

DEM_012	mobileNum	integer(10)	Mobile number, including prefix	No	Paper chart used in COPD outreach programme
DEM_013	livesWith	varchar(32)	Who the patient lives with	No	Paper chart used in COPD outreach programme
DEM_014	homeHelp	varchar(32)	Whether the patient currently has home help	Yes	Paper chart used in COPD outreach programme
DEM_015	mealsOnWheels	varchar(32)	Whether the patient currently has meals on wheels	Yes	Paper chart used in COPD outreach programme
DEM_016	Mobility	varchar(32)	Details about how mobile the patient is	Yes	Paper chart used in COPD outreach programme
DEM_017	Occupation	varchar(32)	What the patient's occupation is	Yes	Paper chart used in COPD outreach programme
DEM_018	programmeID	integer(10)	FK (programme.programmeID) Link to programme entity	No	Included following analysis

Table C: Data elements contained within "Next of Kin" entity

Data element ID	Name	DataType(MaxLength)	Description (including constraints)	Nullable	Source
DEM_001	hospitalMRN	integer(10)	FK (Patient.hospitalMRN) Medical record number for the patient	No	Included following analysis
DEM_020	firstName	varchar(32)	First name of next of kin	No	Paper chart used in COPD outreach programme
DEM_021	Surname	varchar(32)	Surname of next of kin	No	Paper chart used in COPD outreach programme
DEM_022	relationshipT	varchar(32)	Relationship that named next of kin	No	Paper chart used in COPD

	oPatient		has to patient		outreach programme
DEM_023	mobileNum	integer(10)	Contact details of next of kin	No	Paper chart used in COPD outreach programme

G.5: Clinical information dataset

The clinical information dataset contains the three entities that deal with the patient's clinical information. In particular, the assessment entity acts as a container for the standardised quality of life assessment questionnaires, listed in Table D:. Table F:lists the data elements associated with taking a patient's observation set while Table G: lists data elements associated with a patient's medication list.

Table D: Data elements contained within the "Assessment" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
CLIN_001	AssessmentID	integer(10)	PKUnique Unique identifier for the assessment carried out	No	Included following analysis
CLIN_002	visitId	integer(10)	FK (houseVisit.visitId) Link to the house visit record	No	Included following analysis

Five additional entities were identified as inheriting the properties of the assessment entity. Each of these child entities captures the data for a specific quality of life assessment that is carried out on the patient. Defining the attributes of each of these entities was beyond the scope of this research. However, had they been defined, the data source would have been based information contained in 0.

Table E: Quality of life assessment questionnaires used by the COPD outreach programme

Quality of Life Measurement Questionnaires	Description
BORG Breathlessness Score	Borg's breathlessness scale is a subjective assessment tool used to measure breathlessness in COPD patients. It consists of a scale from 0 to 10, where 0 is "Nothing at All" and 10 is "Maximal" (Borg 1982).
Modified MRC Score (mMRC)	The mMRC dyspnoea scale is a quality of life score that is used to rate a person's subjective feeling of breathlessness (Mahler and Wells 1988). It is comprised of five statements. The patient is required to select one.
COPD Assessment Test (CAT)	The COPD assessment test (CAT) is a quality of life test. It consists of 8 questions relating to subjective quality of life issues, which are answered using a 5-point likert scale (GlaxoSmithKline 2009)
EuroQol – Health Status Questionnaire (EQ-5D-3L)	The EuroQol – Health Status Questionnaire (EQ-5D-3L) is a two-part assessment tool that measures the patient's health state at time of questioning. The first part of the assessment is comprised of five sections, each of which has three options. The second part of the tool is a scale from 0 to 100 where the patient must indicate how they are feeling at time of questioning where 0 is feeling the worst and 100 is feeling the best. (The EuroQol Group 1990).
BCSS Assessment Tool	The Breathlessness, Cough and Sputum Scale (BCSS) is a quality of life score that is used to rate the severity of the three symptoms listed in its title. The patient is required to rate each symptom separately on a 5-point scale with higher numbers indicating more severe more symptoms (Leidy et al. 2003)

Table F: Data elements contained within the "Observation Set" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
CLIN_003	observationID	integer(10)	PKUnique Unique identifier for this set of	No	Included following analysis

			patient observations		
CLIN_004	visitId	integer(10)	FK (houseVisit.visitId) Link to house visit	No	Included following analysis
CLIN_005	weight	integer(10)	Patient's weight	No	Paper chart used in COPD outreach programme
CLIN_006	height	integer(10)	Patient's height	No	Paper chart used in COPD outreach programme
CLIN_007	BMI	integer(10)	Patient's BMI	No	Paper chart used in COPD outreach programme
CLIN_008	bpSystolic	integer(10)	Patient's blood pressure - systolic rate	No	Paper chart used in COPD outreach programme
CLIN_009	bpDiastolic	integer(10)	Patient's blood pressure - diastolic rate	No	Paper chart used in COPD outreach programme
CLIN_010	heartRate	integer(10)	Patient's heart rate	No	Paper chart used in COPD outreach programme
CLIN_011	respiratoryRate	integer(10)	Patient's respiratory rate	No	Paper chart used in COPD outreach programme
CLIN_012	temperature	integer(10)	Patient's temperature	No	Paper chart used in COPD outreach programme
CLIN_013	o2Saturation	integer(10)	Patient's O2 saturation	No	Paper chart used in COPD outreach programme
CLIN_014	sputumColour	varchar(32)	Description of the colour of the patient's sputum	No	Paper chart used in COPD outreach programme
CLIN_015	sputumAmount	varchar(32)	Description of the amount of sputum that the patient is producing	No	Paper chart used in COPD outreach programme

CLIN_016	sputumConsistency	varchar(32)	Description of the consistency of the sputum that the patient is producing	No	Paper chart used in COPD outreach programme
CLIN_017	chestAuscultation	varchar(32)	Description of listening to a patient's chests by the outreach team member	No	Paper chart used in COPD outreach programme

Table G: Data elements contained within the "Medication List" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
CLIN_018	MedicationID	integer(10)	PKUnique Unique identifier for this set of medication list entries	No	Included following analysis
CLIN_019	VisitId	integer(10)	FK (houseVisit.visitId) Link to house visit entity	No	Included following analysis
DEM_001	HospitalMRN	integer(10)	FK (Patient.hospitalMRN) Link to medical record number for the patient	No	Included following analysis
CLIN_021	Drug	varchar(70)	Medication name	No	Paper chart used in COPD outreach programme
CLIN_022	Dose	varchar(70)	Medication dose that has been prescribed	No	Paper chart used in COPD outreach programme
CLIN_023	Route	varchar(32)	How the patient is taking the medication – for example, it could be orally or through an inhaler	No	Paper chart used in COPD outreach programme
CLIN_024	Frequency	varchar(32)	How often the patient is taking the	No	Paper chart used in COPD

			medication		outreach programme
CLIN_025	inhalerDevice	varchar(32)	If the medication is inhaled, what device is being used	Yes	Paper chart used in COPD outreach programme
CLIN_026	episodeNum	integer(10)	Link to the specific house visit	No	Included following analysis

G.6: Programme administration dataset

The programme administration dataset contains the five entities that deal with running the COPD programme. These five entities are: programme, hospital visit, house visit, episode and outreach team member. The "Programme" entity is a look-up table that contains a list of programmes contained within the COPD programme (see Table H:). The "Hospital Visit" entity contains data elements about a patient's hospital visit when they suspect that they have a COPD exacerbation (see Table I:). The "House Visit" entity contains contextual details about an outreach team member's visit to a patient (see Table J:). Each visit by a patient to the hospital or from an outreach team member to a patient's home is referred to as an episode – the "Episode" entity is tightly coupled with the house / hospital visit and contains extra contextual data elements (see Table K:). The "Outreach Team Member" data entity contains staff member details (see Table L:).

Table H: Data elements contained within the "Programme" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
ADM_001	programmeID	integer(10)	PKUnique Unique identifier for each programme	No	Included following analysis
ADM_002	Name	varchar(70)	Programme name. Currently, it is either early discharge programme or assisted early discharge programme	No	Paper chart used in COPD outreach programme

Table I: Data elements contained within the "Hospital Visit" entity

Data element ID	Data element	DataType(MaxLength)	Description (containing constraints)	Nullable	Source
ADM_003	EpisodeNum	integer(10)	PK/FK (episode.episodeNum) Unique identifier of this event or episode	No	Included following analysis
DEM_001	HospitalMRN	integer(10)	FK (Patient.hospitalMRN) Link to medical record number for the patient	No	Included following analysis
ADM_005	ReferralPlace	varchar(255)	Location from which the patient has been referred. Currently, it is the emergency department, but there is potential to expand this to general practice, self-referral or referral from primary care centres and so on	No	Included following analysis
ADM_006	dateofAdmission	Date	Date patient was admitted to hospital	Yes	Paper chart used in COPD outreach programme
ADM_007	dateOfDischarge	Date	Date patient was discharged from hospital	Yes	Paper chart used in COPD outreach programme
ADM_008	programmeType	varchar(255)	Programme name (possibly a redundant field)	Yes	Paper chart used in COPD outreach programme
ADM_009	lengthOfStay	integer(10)	Length of stay that patient had in hospital	Yes	Paper chart used in COPD outreach programme
ADM_010	reasonAdmission	varchar(255)	Reason why patient was admitted to hospital	Yes	Paper chart used in COPD outreach programme

Table J: Data elements contained within the "House Visit" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
ADM_011	visitId	integer(10)	PKUnique	No	Included following analysis
			Unique identifier for this visit by the outreach team member to the patient		
DEM_001	hospitalMRN	integer(10)	FK (Patient.hospitalMRN)	No	Included following analysis
			Link to medical record number for the patient		
ADM_013	episodeNum	integer(10)	FK (episode.episodeNum)	No	Included following analysis
			Link to episode number		
ADM_014	staffNum	integer(10)	FK (Outreach Team Member.staffNum)	No	Included following analysis
			Link to outreach team member's staff details		
ADM_015	Date	Date	Date that visit occurred	No	Included following analysis
ADM_016	Time	integer(10)	Time that visit occurred	No	Included following analysis
ADM_017	startTime	Timestamp	Start time of visit. Potential to use for reporting and resource management	No	Included following analysis
ADM_018	endTime	Timestamp	End time of visit. Potential to use for reporting and resource management	No	Included following analysis

Table K: Data elements contained within the "Episode" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
ADM_019	episodeNum	integer(10)	PKUnique	No	Included following analysis
DEM_001	hospitalMRN	integer(10)	FK (Patient.hospitalMRN) Link to medical record number for the patient	No	Included following analysis
ADM_021	Date	Date	Date that the episode or event occurred	No	Included following analysis
ADM_022	nationalProgrammeDay	varchar(32)	Which day of the programme that the episode refers to; it can be Day 1, 2, 3, 14 or Week 6. This field is used for reporting on national key performance indicators	No	Paper chart used in COPD outreach programme
ADM_023	visitId	integer(10)	Link to house visit	No	Included following analysis

Table L: Data elements contained within the "Outreach Team Member" entity

Data element ID	Data element	DataType(MaxLength)	Description (including constraints)	Nullable	Source
ADM_024	staffNum	integer(10)	PKUnique Unique staff identifier	No	Included following analysis
ADM_025	firstName	varchar(32)	First name of staff member	No	Included following analysis
ADM_026	Surname	varchar(32)	Surname of staff member	No	Included following analysis
ADM_027	Role	varchar(32)	Role of staff member	No	Included following analysis
ADM_028	telNumAreaCode	integer(3)	Phone number area code	No	Included following analysis
ADM_029	telNum	integer(7)	Phone number	No	Included following analysis
ADM_030	mobileNum	integer(10)	Mobile number	No	Included following analysis

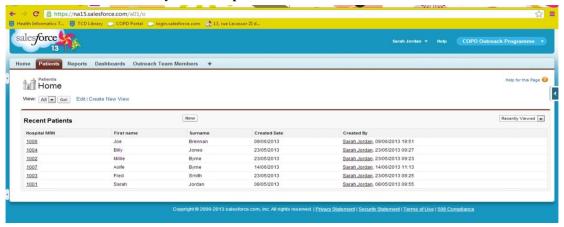
Appendix H: Application Screenshots

H.1: Introduction

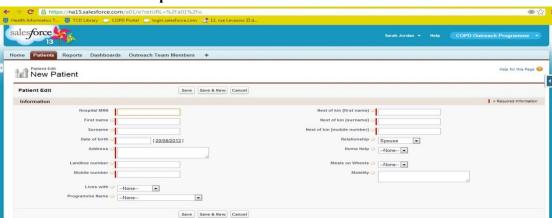
This appendix contains screenshots of the application that was implemented as part of this research. The relationship between the various screens has previously been described in section 6.2.8.

H.2: Screenshots for Mod_001: capture patient data in the home

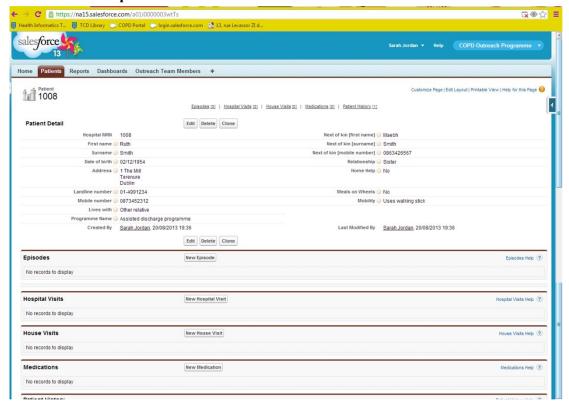
Patient tab: list of recently accessed patients



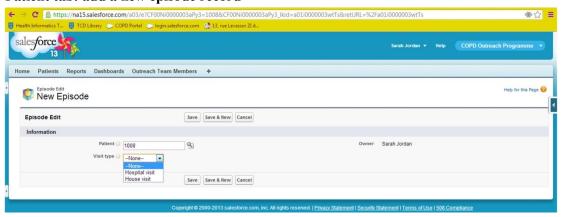
Patient tab: create a new patient record



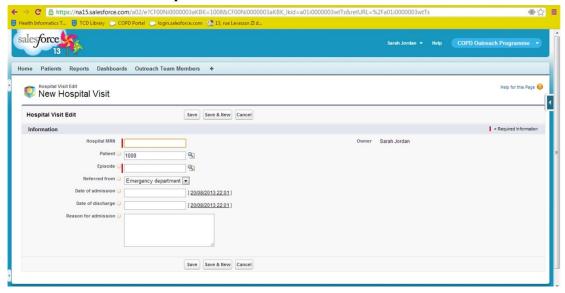
Patient tab: view patient details



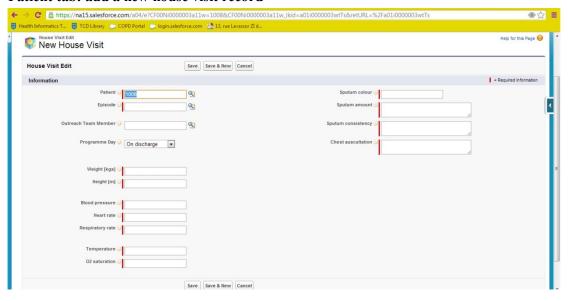
Patient tab: add a new episode record



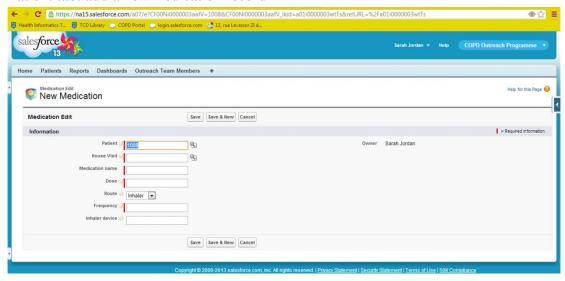
Patient tab: add a new hospital visit record



Patient tab: add a new house visit record

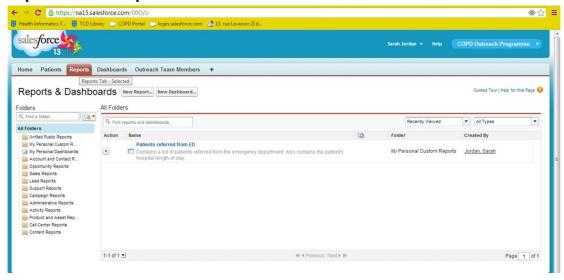


Patient tab: add a new medication record

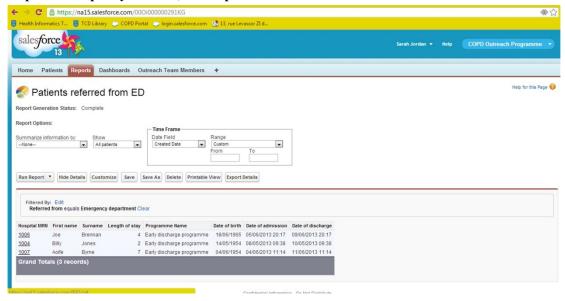


H.3: Screenshots for Mod_004: generate reports

Report tab: select report to run

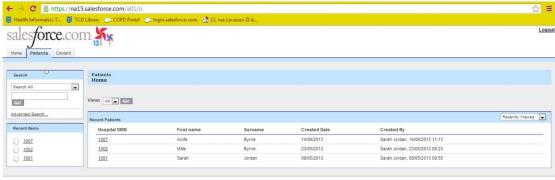


Report tab: specify criteria, run report and view results



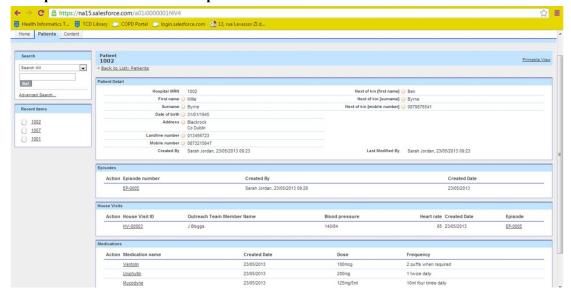
H.4: Screenshots for Mod_002: view patient data

Web portal interface - Patient tab: list of recently accessed patients



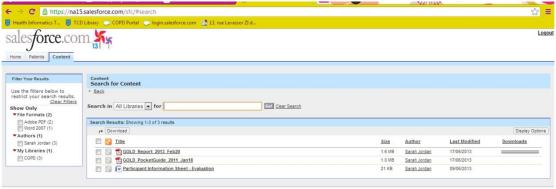
Home | Patients | Conter

Web portal – Patient tab: view patient detail



H.5: Screenshots for Mod 006: provide patient information and education

Web portal – Content tab



Home | Patients | Content