
An analysis of factors likely to impact on the interoperability required for health information exchange in the Health Service Executive as perceived by key informants

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Declaration

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

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Abstract

This dissertation examined factors which impact on the interoperability required for health information exchange in the HSE, as perceived by key informants. A review of the literature provided an overview of interoperability. Semi-structured interviews were carried out with 14 informants who held national roles in the areas of policy, quality, data, ICT and clinical programmes. The informants were chosen for their positions of influence and experience of information and ICT in the Irish Healthcare system. The sample was drawn from across a number of agencies. The data were analysed through inductive analyses. The informants identified key components required for successful system interoperability: clear organisational structures, roles and responsibilities; a single ICT strategy; effective ICT governance; IT leadership embedded in the business; a framework for the technical building blocks required; the availability of relevant standards and terminologies; financial investment; and enabling policy and legislation. This study found that there were gaps or weaknesses in all of these areas in the HSE and that these formed barriers to interoperability. Fragmentation and duplication across ICT and information management were strong themes to emerge from the interviews. Projects and initiatives underway, which touched on many of the aspects of interoperability, sat under different line management or in different agencies and were not being managed under one framework. Systems and data sets were duplicated and this constituted a corporate risk. It is recommended that an interagency group should oversee the adoption of a single strategy for ICT; that clear ICT governance arrangements are put in place in the HSE; that a project be set up to deal with duplication of systems and data sets; that the required standards be agreed among all stakeholders and responsibility for their development clarified; and that enabling policy be progressed and the required statutory basis be provided for an individual health identifier. A Chief Information Officer, who has both business and ICT competencies, is recommended to oversee the implementation of interoperability in the HSE. Ireland is undergoing a series of healthcare system reforms, including changes to the structures and to the model of care delivery, in preparation for a move to healthcare commissioning paid for through universal health insurance. This provides an opportunity to put in place the factors required for interoperability to meet the needs of the new model of health care and to enable the exchange of health data required for clinical practice and an improvement in quality, safety access and efficiency.

Contents

Abstract.....	v
Chapter 1 Introduction.....	1
1.1 Introduction.....	1
1.2 Background.....	1
1.3 Research Question.....	2
1.4 Context for Health Information Exchange and Interoperability.....	3
1.4.1 European Context.....	4
1.4.2 Irish Context.....	5
1.4.3 Conclusion.....	6
1.5 Outline of Dissertation.....	7
Chapter 2 Literature Review.....	8
2.1 Introduction.....	8
2.1.1 Health Information Exchange.....	9
2.1.2 Interoperability.....	10
2.2 Organisational factors.....	11
2.2.1 Strategy.....	11
2.2.2 Governance.....	11
2.2.3 IT Leadership.....	13
2.2.4 Stakeholder engagement.....	14

2.2.5	Quality, safety and efficiency	15
2.2.6	Finance.....	16
2.3	Technical Factors	17
2.3.1	IT Framework for Interoperability	17
2.3.2	Technical Infrastructure	19
2.3.3	Standards	21
2.3.4	Semantics and data dictionary.....	23
2.3.5	Data management	24
2.4	Policy and Legislation	25
2.4.1	Public Policy	25
2.4.2	Legislation	26
2.4.3	Unique Identifiers.....	27
2.5	Conclusion	28
Chapter 3	Methodology	29
3.1	Introduction	29
3.2	Research Design	29
3.2.1	Data Collection Technique.....	31
3.3	Selection of Participants	32
3.4	Data Analysis.....	34
3.5	Ethical Approval.....	35
3.6	Limitations.....	36

Chapter 4	Findings	37
4.1	Introduction	37
4.2	Organisational Factors.....	38
4.2.1	Reform and Reorganisation.....	38
4.2.2	Strategy	41
4.2.3	Fragmentation.....	42
4.2.4	Governance	43
4.2.5	IT Leadership.....	45
4.2.6	Stakeholder Engagement/communications	47
4.2.7	Finance.....	48
4.3	Technical Factors	50
4.3.1	IT Framework and Technical Infrastructure	50
4.3.2	Technical Infrastructure	51
4.3.3	Legacy Systems.	53
4.3.4	Standards	54
4.3.5	Semantics and Data Dictionary.....	55
4.4	Policy and Legislation	57
4.4.1	Public Policy	57
4.4.2	Individual Health Identifier	58
4.4.3	UHI and MFTP as Levers for Change.....	59
4.4.4	Data Protection.....	60

4.5	Conclusion.....	63
Chapter 5	Discussion	66
5.1	Introduction	66
5.2	Organisational Factors.....	66
5.3	Technical Factors	76
5.4	Policy and Legislation	82
5.5	Conclusion.....	84
Chapter 6	Summary and Recommendations.....	86
6.1	Summary	86
6.2	Recommendations.....	88
6.3	Limitations of the Research	89
6.4	Suggestions for Further Research	90
6.5	Conclusion.....	91
	References.....	92
	Appendix 1: Contents and Action Plan: Strategic ICT Framework for the Irish Health System, 2004.....	100
	Appendix 2: Integrated Services Framework	104
	Appendix 3: Interview Guide	110
	Appendix 4: Summary of Assessment of PPSN as a Suitable Health Identifier	111

List of Tables

Table 1: Purpose of Standards.....21

Table 2: Breakdown of Interviewees and Backgrounds33

List of Figures

Figure 1: ISF Work Streams and Collaboration.....	19
Figure 2: Steps in Data Collection and Analysis.....	35
Figure 3: ICT Information and Data Functions within HSE and DoH.....	70
Figure 4: Options for Future Organisation of ICT and Information	74
Figure 5: ISF Project Diagram showing link to Clinical Data Sets	80
Figure 6: Clinical Challenge of Dataset Duplication	81

Abbreviations

C&AG	Comptroller and Auditor General
CEO	Chief Executive Officer
CIO	Chief Information Officer
CMIO	Chief Medical Information Officer
CPCP	Corporate Planning and Corporate Performance
CTO	Chief Technology Officer
DoH	Department of Health
DPA	Data Protection Agency
ERH	Electronic Health Record
GP	General Practitioner
HeBE	Health Board Executive group
HCA	Healthcare Commissioning Agency
HIB	Health Information Bill
HIE	Health Information Exchange
HIQA	Health Information and Quality Authority
HIT	Health Information Technology
HSE	Health Service Executive
ICT	Information Communication Technology
IHI	Individual Health Identifier
ISF	Integrated Service Framework (project)
IT	Information Technology
MFTP	Money Follows the Patient
NPIO	National Pricing and Information Office
NSP	National Service Plan
PCRS	Primary Care Reimbursement Service

PPS/N	Personal Public Service/Number
ROI	Return for Investment
SDU	Special Delivery Unit
UHI	Universal Health Insurance

Chapter 1 Introduction

1.1 Introduction

There is broad consensus across health care practitioners and academics that information and communications technology (ICT) has an important role to play in improving the quality of health care. Interoperability is recognised as an essential component at the core of effective ICT systems, especially in relation to health information exchange (HIE). Prerequisites for, and barriers to, interoperability have been identified within academic research and by health care policy makers and practitioners. This study examines the factors that are relevant to HIE interoperability, as described in academic literature and it studies the current readiness for interoperability in the HSE, as perceived by key personnel involved directly or indirectly with ICT in the Irish healthcare system.

1.2 Background

The Health Services Executive (HSE) provides all public health and social services, either directly or indirectly, in Ireland. It employs 100,000 people and manages services within a budget of €13.4 billion (Health Service Executive 2013b). It operates in a context where increasing healthcare costs, reduced funding and increased need and demand mean that the cost of providing healthcare is becoming unsustainable (Department of Health 2012a).

In Ireland, since 2008, €3.3billion (22% reduction) has been removed from the budget of the health system and there has been a reduction of 11,268 workers (Health Service Executive 2013c). Costs are going up, resources are going down and waiting lists are growing. Expectations among the population of faster access to the most modern treatments are high. Health and wellbeing initiatives have been prioritised by the Minister for Health but any benefit from action in this area will take years to show results.

There is a need for a multifaceted approach to resolving the overall affordability and sustainability of the health system and within that approach there is an opportunity to improve safety and manage cost through the introduction of interoperable systems. System interoperability was named an action in 2001 in the Health Strategy '*Quality and Fairness*' (Department of Health and Children 2001); it was a core action in the '*Health Information: A National Strategy 2004*' (Department of Health and Children 2004) and it has appeared in the latest health strategy '*Future Health*' (Department of Health 2012a).

A change of government in Ireland in 2011 brought a change in direction in the structure and model of delivery of health services. This has resulted in the abolition of the HSE Board, the establishment of a HSE Directorate, a new management structure, new hospital groups which will evolve into independent 'Trusts', and a plan for integrated service areas for non-acute services. These changes are to prepare the way for a purchaser/provider split and the setting up of a healthcare commissioning agency. The current health strategy states that core parts of the health reform programme, including money follows the patient (MFTP), universal health insurance (UHI) and integrated care, will rely on fit-for-purpose information and ICT infrastructure (Department of Health 2012a). This provides the environment for change within which interoperability can be progressed if the required building blocks are put in place and an integrated approach is taken with clear direction and governance.

1.3 Research Question

This research looked at factors likely to impact on the interoperability required for health information exchange in the Health Service Executive as perceived by key informants.

The research questions, answered by literature review and interview, were:

- What factors support interoperability?

- What are the current barriers to the introduction of interoperability in the HSE, as perceived by key informants?
- What are the current opportunities for the introduction of interoperability in the HSE, as perceived by key informants?

1.4 Context for Health Information Exchange and Interoperability

Healthcare is one of the most difficult environments in which to introduce effective use of information technology. The diversity and complexity within and across health disciplines and professions creates difficulties in trying to structure knowledge (Ingram et al 2006).

Mäenpää et al (2009), in their review of regional healthcare information systems, including projects in the United States of America, Canada, South Africa and several European countries, concluded that:

“the centrepiece of a nation’s ICT vision is the implementation of health information exchanges” (p769),

while Brailer (2005) links health information exchange with interoperability and states:

“interoperability will bind together a wide network of real-time, like-critical data that not only transform but become healthcare” (pW5).

Despite the belief that health information exchange HIE has a part to play in the safe and efficient delivery of healthcare, the exchange of clinical data across providers remains low, based on details from the US, Canada, the UK, the Netherlands, Germany, Australia and New Zealand (Jha et al 2008) and it is suggested that there has been a failure to achieve widespread understanding of the benefits of health information exchange (Lluch 2011)

In the USA, the Federal focus changed from “IT adoption” to “IT interoperability” over the period 2004 - 2007. Policy and financial structures are in place to try to link interoperability and HIE with a payment structure to support it through ‘meaningful use’ legislation, the Health Information Technology for Economic & Clinical Health (HITECH) act 2009. The aim is to encourage information exchange and at the same time test the actual use of the systems and link this to financial benefits (Vest & Jaspersen 2010). HIE has been regulated so that health providers must use electronic health records (EHRs) that are:

“connected in a manner that provides for the electronic exchange of health information” (Wright et al 2010, p66).

1.4.1 European Context

Europe, like the rest of the world, is experiencing pressure in relation to providing health care in an environment in which budgets are under pressure. Healthcare worker numbers are decreasing and the prevalence of chronic disease is increasing along with consumer expectations and demands (European Commission 2012). The European Commission recognises the role of ‘eHealth initiatives’, which it links with interoperability, in supporting innovative solutions within the constraints and complexity of healthcare. Article 14 of the Directive on the Application of Patient’s Rights in Cross Border Healthcare, adopted in 2011, progressed formal cooperation on eHealth, linking interoperability to social and economic benefits. Reference is made in particular to the benefits to “*countries under adjustment programmes*” of which Ireland is one, and the need for eHealth to be used to improve efficiency and effectiveness (European Commission 2012, p15).

The European Commission Action Plan 2010–2020 identifies the lack of interoperability as a key barrier to the advance of eHealth in Europe. Consequently the action plan has, as a key objective, to achieve wider

interoperability across eHealth services. The levels of interoperability outlined in the plan include technical, organisational, semantic and legal. The plan states:

“interoperability of ICT-enabled solutions and of data exchange is the precondition for better coordination and integration across the entire chain of healthcare delivery and health data exchange” (European Commission 2012, p7).

1.4.2 Irish Context

The *Irish National Health Information Strategy* published in 2004 includes in its objectives the integration of information and data standards:

‘Adopt an integrated, national approach to the development and expansion of information sources and systems to best meet the strategic health information needs’;

and

‘Establish health information standards that ensure the quality and comparability of health information and enable appropriate sharing of health information within the health sector’ (Department of Health and Children 2004, p20).

The Health Board Executive (HeBE) group produced a comprehensive *Strategic ICT Framework for the Irish Health System* (Health Board Executive 2004) as a companion to the *National Health Information Strategy* (see Appendix 1). This framework includes the core components required for interoperability and the actions required to implement them. Subsequent changes in the health system and technology means that some of the solutions proposed in this framework may no longer be suitable but the core actions proposed around technical, semantic and organisational interoperability remain valid.

The political parties who entered Government in Ireland in 2011 proposed, in their Programme for Government (Department of the Taoiseach 2011), a fundamental reform of the public services and as part of this published *eGovernment 2012 – 2015* which has an objective to '*facilitate interoperability*' (Department of Public Expenditure and Reform, 2012, p17). In the Health sector *Future Health, the Strategic Framework for Reform of the Health Service in Ireland 2012 – 2015*, published in November 2012, set out the actions which to be taken to deliver on reform of information and ICT for health services. This was linked to improvements in healthcare capacity and performance.

The health strategy recognises that a legal framework is required to deal with such issues as health identifiers, data matching and population registers. It stated that a Health Information would be published in 2013 to deal with legal issues and facilitate:

'a standards based approach..... supporting interoperability'.
(Department of Health 2012a, p44).

The eHealth agenda in Ireland is placed within the context of the EU eHealth action Plan 2012 – 2020 (European Commission 2012)

1.4.3 Conclusion

The cost of healthcare is unsustainable therefore healthcare systems are looking for smarter and more efficient and effective ways of delivering care. Health information exchange is linked to improved patient safety and quality, and to strategies for managing healthcare cost. Effective health information exchange requires interoperability. This has been recognised and included in health strategies in Ireland for more than a decade.

This research seeks to provide insight into the state of preparedness within the HSE to achieve interoperability and the barriers to interoperability that may

exist, as perceived by senior personnel. Interviews were held with key informants who were well placed to judge the stage of preparedness for interoperability and to comment on what barriers exist and what is required to overcome these barriers. The findings of this research may be used to review current practice and deal with the barriers to interoperability in the HSE.

1.5 Outline of Dissertation

The remainder of this dissertation is organised as follows:

Chapter two provides an overview of the literature and relevant government documents on health information exchange, interoperability and the organisational, technical and policy factors known to relate to interoperability.

Chapter three describes of the research design, approach, participant selection and study analysis.

Chapter four outlines the findings which have been extracted from the detailed analysis of the interviews carried out. Quotations from the informants are provided to give the reader an insight to the themes reported.

Chapter five discusses the main findings, drawing on wider literature and putting the findings into context.

Chapter six provides a summary, recommendations and a conclusion. It outlines suggestions for further research and notes the limitations of the study.

Chapter 2 Literature Review

2.1 Introduction

The costs of healthcare are rising and, despite the level of spend on health interventions, there are global concerns that the quality and efficiency of care are far from optimal (Lluch 2011). There is also evidence that health outcomes are not equally spread within and across populations.

Health information technology has a part to play in improving quality, safety and efficiency in health care systems (Kaelber & Bates 2007, Jha et al 2008, Mäenpää et al 2009, Lluch 2011, Bélanger et al 2012, HIQA 2013a). In order to use health information technology effectively systems must be able to exchange information and use the information that has been exchanged, i.e. they must have 'interoperability' (Morris 2004, European Commission 2005, European Commission 2012).

In patient care interoperability refers to the application of technology so that the exchange of clinical data across services, institutions, agencies and borders is possible (Salzberg et al 2012).

The health system in Ireland, in common with healthcare systems around the world, is currently dealing with the challenges of reducing cost, improving quality and managing complexity, and the use of technology has been proposed to help to alleviate some of the pressures (Health Service Executive 2013b, Department of Health 2012a.)

From a policy perspective in Ireland, Future Health, the Strategic Framework for Reform of the Health Service in Ireland, states that there will be an eHealth Strategy which will:

“support and enable the delivery of integrated patient care.”
(Department of Health 2012a).

Interoperability is a complex area which involves many aspects of organisational, technical and political action. Writing in the *semanticHEALTH Report* for the European Commission, Iakovidis (2009) suggests:

“interoperability is not just a technical or standardisation issue, it goes to the heart of decisions about political, financial and legal decisions by national leaders” (p5).

Reflecting that complexity this research will be approached from the perspectives of organisation, technology and policy. These have been used in other research as a framework to view information sharing in the public sector (Dawes 1996, Zhang et al 2005, Yang & Maxwell 2011) and will be used as focal points for the research, findings and discussion in this report.

This literature review begins with an overview of health information exchange and interoperability. Organisational factors reviewed include: strategy; governance; IT leadership; stakeholder involvement; links with quality and patient safety; and finance. The technical factors which impact on interoperability are then considered including the role of conceptual frameworks; infrastructure; standards; and semantics. Finally, public policy and legislation is examined.

2.1.1 Health Information Exchange.

Health information exchange (HIE) has emerged as a term from the HIT sector in the USA. Definitions of HIE include:

“a process that links and integrates an individual patient’s information from multiple, disparate, data sources” (Vest & Jaspersen 2010 p302);

“an organisational and a technical architecture that aggregates health data from multiple data sources and facilitates the delivery of that data to clinicians and other providers” (Fu et al 2012, p773);

“formal agreements and technologies that facilitate the electronic movement of health–related information across organisations within an area or community.” (Myers et al 2012, pe22);

“the use of information technology to support the electronic transfer of clinical information across health care organisations” (Sicotte & Paré 2010, p1159).

There are common themes across these definitions: integrated processes; organisational and technical infrastructure; and standards. These underpin the success of data exchange from multiple sources across multiple sites (Yang and Maxwell 2011).

2.1.2 Interoperability

Interoperability in the context of healthcare has been defined as:

“the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged” (HIMMS 2013).

Data are often kept in ‘silos’ both within and across agencies and where this is the case shared problems may not be enough to put in place a collaborative system solution; it may require an external catalyst such as a health safety failure, to get people to cooperate (Weiss 1987, Yang and Maxwell 2011, Ferguson 2003).

Organisational interoperability requires well defined business goals and collaboration between stakeholders who work within different internal structures and processes, but who wish to exchange information (European Commission 2004). The subdivisions of interoperability include technical, semantic, organisational, political, and legal dimensions. (Miller 2000, European Commission 2004, Telemedicine Alliance 2004, Health Board Executive 2004). The *European Interoperability Framework* specifies that as

well as information and communication systems, business processes must also support the exchange of data. Miller (2000) goes further to say that the exchange and reuse of information is dependent on how the systems, procedures and culture of an organisation are managed.

2.2 Organisational factors

2.2.1 Strategy

Strategy is defined by Drucker (1999) as the translation of the purpose, objectives and defined results of an organisation into '*performance*' (p36). This is required at organisational level to set the overall policy and priorities for the health system. Equally it is required at sub-organisational level, and there should be an aligned explicit and accessible strategy for IT (Prasad et al 2010).

Both organisational and sub-organisational strategies must recognise the co-dependencies that exist. Successful implementation of health information exchange involves "*a process of mutual transformation*" (Berg 2001, p143) in which the technology and the organisation transform each other, a process that involves a balancing act between organisational change and health information technology as a change agent . Thus equal attention should be afforded to the technical and software aspects of health information technology and the people issues (Lorenzi et al 1997). An IT strategy should align the technology and business objectives and act as a framework to support the achievement of desired results, and in so doing avoid diversion and '*splintering of resources*' (Drucker 1999, p37).

2.2.2 Governance

One mechanism for ensuring alignment between business and IT strategies is through effective IT governance (Prasad et al 2010, Burtscher et al 2009). IT

governance involves oversight of structure, process and evaluation, described by Schwartz (2007) as:

“putting structure around how organizations align IT strategy with business strategy, ensuring that companies stay on track to achieve their strategies and goals, and implementing good ways to measure” (p1);

and by Burtscher (2009) as:

“the leadership, organisational structures and processes that ensure that the enterprise’s IT sustains and extends the organisation’s strategies and objectives” (p5).

In his article Robinson (2005) notes that Weill and Ross (2004) conclude after a study of 250 enterprises worldwide, that the single most important predictor for whether IT can deliver organisational value is the presence of an effective IT governance structure. He links IT excellence and IT governance and states the role of IT governance as:

“to create a control environment for desirable actions to drive the effective, efficient and secure use of information technology”.

Prasad et al (2010) suggested that the necessary governance controls can be managed through an IT steering group and that such a group, if constituted with the appropriate representatives, increases IT capability.

A particular focus may be required to ensure the relevant governance for supporting functions or actions within IT (Health Information and Quality Authority 2011c). Data governance is one such sub set of IT governance or other corporate governance structures, and is described as:

“the exercise of decision-making and authority for data-related matters” (Thomas 2012 p 3).

Sharing health data presumes that there is an interoperable system in place and that this is continuously being improved through innovation, in line with health system reform. The role of data governance is to oversee data ownership, data management, and data use (Meier 2013).

Other areas which may require a specific governance focus include: identity governance to avoid any misuse of identity information, intentionally or unintentionally and terminology governance which oversees the precise representation of clinical knowledge and the binding of this to agreed terminology (Hovenga and Garde 2010).

Governance and strategic consistency is dependent on strong leadership (Cresswell & Sheikh 2013) which needs to provide the vision, guidance and resources which can help build agreement within and across organisations (Rippen et al 2012).

2.2.3 IT Leadership

A systematic review by Cresswell and Sheikh (2013), looking at organisational issues in relation to health information implementation, found that the active support of senior leaders and lead professionals increased ownership of IT activities, bridged boundaries between IT, business and clinicians and facilitated process change. Salzberg et al (2012) identified two 'critical' factors needed for successful implementation of infrastructure and data standards policies: strong leadership and result focused investment.

Peppard (2010) outlined how the position of Chief Information Officers (CIO) has grown in importance over the past decade. He lists the leadership attributes of the CIO, as it pertains to IT and business processes, and sets this in the context of the senior leadership team and corporate ICT knowledge. He links success of even the most competent CIO with the understanding of IT at CEO and senior corporate team level.

Leadership is not only required at the corporate level; leaders at administration, clinical, and academic levels are required to support the conditions and factors required for health information exchange (Marchibroda 2007). Yang and Maxwell (2011) in their study of information sharing in public organisations note that leadership through formal authority assists in engaging key people and creating an environment which fosters the development of effective strategies. Informal leadership can in turn be involved in trust building, local problem solving and clarifying roles and responsibility. Physician champions can improve communications and assist clinicians to prepare for the change that using health information technology brings (Rippen et al 2012).

Cresswell and Sheikh (2013) concluded that there is a cross cutting relationship between technology, stakeholder involvement and leadership which must be managed at all stages of IT planning and implementation. The link between leadership and stakeholders is reiterated by Maenpaa et al (2009) who concluded from their systematic review of HIT and HIE that in order to translate HIE into operational reality you need leadership commitment and strong support from the stakeholders.

2.2.4 Stakeholder engagement

Health informatics improvement projects involve cooperation between many stakeholders and must cope with the complexity of the organisation and the other changes happening in parallel, for example decreases in budgets, a reducing workforce, and changing models of work (Lorenzi et al 1997, Mäenpää et al 2009, Salzberg et al 2012). Success and adoption of IT initiatives relies on the management of the concerns and interests of stakeholders (Mishra and Mishra 2011). User involvement in system development has also been identified as a critical success factor (Sicotte & Paré 2010, Lorenzi et al 1997). The involvement of different stakeholders becomes critical at different stages of the project (Mishra and Mishra 2011)

and it is recognised that incomplete or mistimed engagement with stakeholders is a barrier to the introduction of health information exchange (Salzberg et al 2012).

In looking at the viability of a regional health information organisation in the US Adler-Milstein et al (2010) suggest that a “*broad coalition*” (p61) of stakeholders supports the operations of these regional organisations. Physicians are considered integral to the introduction of interoperable health information technology and involving physicians in the design and implementation of systems can improve adoption and use (Patel et al 2011). Clinicians are more likely to engage if they can link their involvement with improvements in core service deliverables such as quality, safety and efficiency (Marchibroda 2007).

When working with stakeholders, concerns in relation to security and privacy also need to be considered (Hill and Manweiler 2010, Sicotte & Paré 2010, Salzberg et al 2012, Meier 2013) as the perceived benefits may not ‘outweigh’ the resistance these concerns create (Jha et al 2008).

While it is important to outline the benefits of IT initiatives to stakeholders to get their buy in, Zhang et al (2005) also caution against overpromising, especially in relation to organisational transformation and cost-efficiency benefits.

2.2.5 Quality, safety and efficiency

Efficiency of care, effectiveness of care, provider satisfaction and patient safety were reported as showing positive outcomes in a review of 154 articles on the benefits of health information technology (HIT) by Buntin et al (2011). The technology reviewed included electronic health records and health information exchanges, both linked to interoperability. The authors concluded that measurable benefits are now emerging from the adoption of technology in health systems. They do however caution that there may be underreporting of

negative findings. Patient safety is also reported elsewhere as a major driver for health information exchange (Kaelber & Bates 2007, Mäenpää et al 2009, Lluch 2011, Bélanger et al 2012).

Wright et al (2010) note that in clinical practice quality is underpinned by access to essential clinical information and the standardised exchange of health information is emerging as a significant contributor to assist in this. Measurement of quality is based on data linked to standardised metrics which allows comparison of clinical outcomes from new models of care (Salzberg et al 2012).

Quality is high on healthcare agendas and can be used to promote the need for interoperability policy including policy relating to the standards-based health information technology that support interoperability (Marchibroda 2007). Despite the opportunity that the quality agenda provides, Salzberg et al (2012) concluded, from their interviews with key opinion leaders in healthcare, that quality measures have not been to the fore when policies on data standards and interoperability are being promoted or developed.

There have been some safety concerns as a consequence of relying on automated exchange of patient information. Kaelber and Bates (2007) list possible risks to patient safety as being the provision of incorrect patient specific information, the risk of confusing identities, translation errors between systems and delay caused by systems.

2.2.6 Finance

Interoperable exchange of health information is linked with strategies to manage increasing healthcare cost (Machibroda 2007, Mäenpää et al 2009, Fu et al 2012, Maier 2013), but on the other hand cost and sustainable financing are listed frequently among the barriers to be overcome when implementing interoperable systems (Machibroda 2007, Hill & Mannweiler 2010, Salzberg et al 2012, Meier 2013).

Securing the initial capital required to develop and embed data exchange and the on-going capital and revenue that is required to sustain it has been identified as a barrier (Machibroda 2007, Sicotte & Paré 2010). Nevertheless it is suggested that standardised exchange of health information could yield a significant financial return. In 2005 this was estimated to be as much as 5% of the US Health budget (Walker et al 2005). However the European Commission in its report on the socio-economic impact on interoperable EHRs caution that:

“It takes at least four, and more typically, up to nine years before initiatives produce their first positive annual socio economic return (SER), and six to eleven years to realise a cumulative net benefit” (European Commission 2009 pvii).

Black et al (2011), in a systematic review of systematic reviews which looked at the impact of eHealth, report that there is a paucity of evidence on the impact in relation to patient outcomes and that the cost-effectiveness of eHealth technologies.

Overall the challenge of the appropriate level of up-front investment and the need to ensure there is a commitment to on-going financing for revenue costs in the light of any lead in time to get a return on investment are recognized as challenges in the implementation of health information exchange (Meade 2009).

2.3 Technical Factors

2.3.1 IT Framework for Interoperability

A framework for interoperability provides

“a set of policies, standards, guidelines and technical specifications” (Health Board Executive 2004).

which describes the way that services, agencies and organisations agree to interact to support the delivery of information and ultimately services.

In a clinical setting, a framework provides the building blocks to bring together existing standards, to collate clinical data from many sources, aggregate these data using a health information exchange and facilitate the use of clinical data linked to quality measurement in a standardised format. It involves a broad set of standards and semantic interoperability, to enable an exchange of data where the meaning of the data is preserved across systems. A broad strategic framework, such as this, underpins the introduction of interoperability (Fu et al 2012), and is needed to support the gradual evolution of health information exchange in an incremental manner and deal with legacy systems (Grimson et al 2000, Salzberg et al 2012).

A framework should also plan for the secondary use of data from the outset (Yang and Maxwell 2011). Examples of secondary use include data for performance measurement, quality measures, public health and research purposes (Salzberg et al 2012), outcome analysis, clinical benchmarking, quality improvement, the development of guidelines and decision making (Siddiqui et al 2012), managing disease outbreaks and public health threats, contributing to population based research (Vest and Gamm 2013), managed care, resource management, practice evaluation, research and health policy analysis (Hovenga and Garde 2010).

In Ireland an 'Information Services Framework' (ISF) project was initiated through the ICT Strategy 2008 (Department of Health and Children 2008b) with the aim of introducing a standards based approach for applications, information, communications and technical architecture in the HSE (see Appendix 2 for details of ISF).

The project is framed as an enabler for improving healthcare safety, quality and efficiency through a standards based approach. This will align information

systems in a way that enables them to communicate effectively and to join related parts in a single system (Health Service Executive 2012).

Figure 1 below demonstrates the work modules and corresponding work streams described in this project.

Integrated Service Framework Work Streams

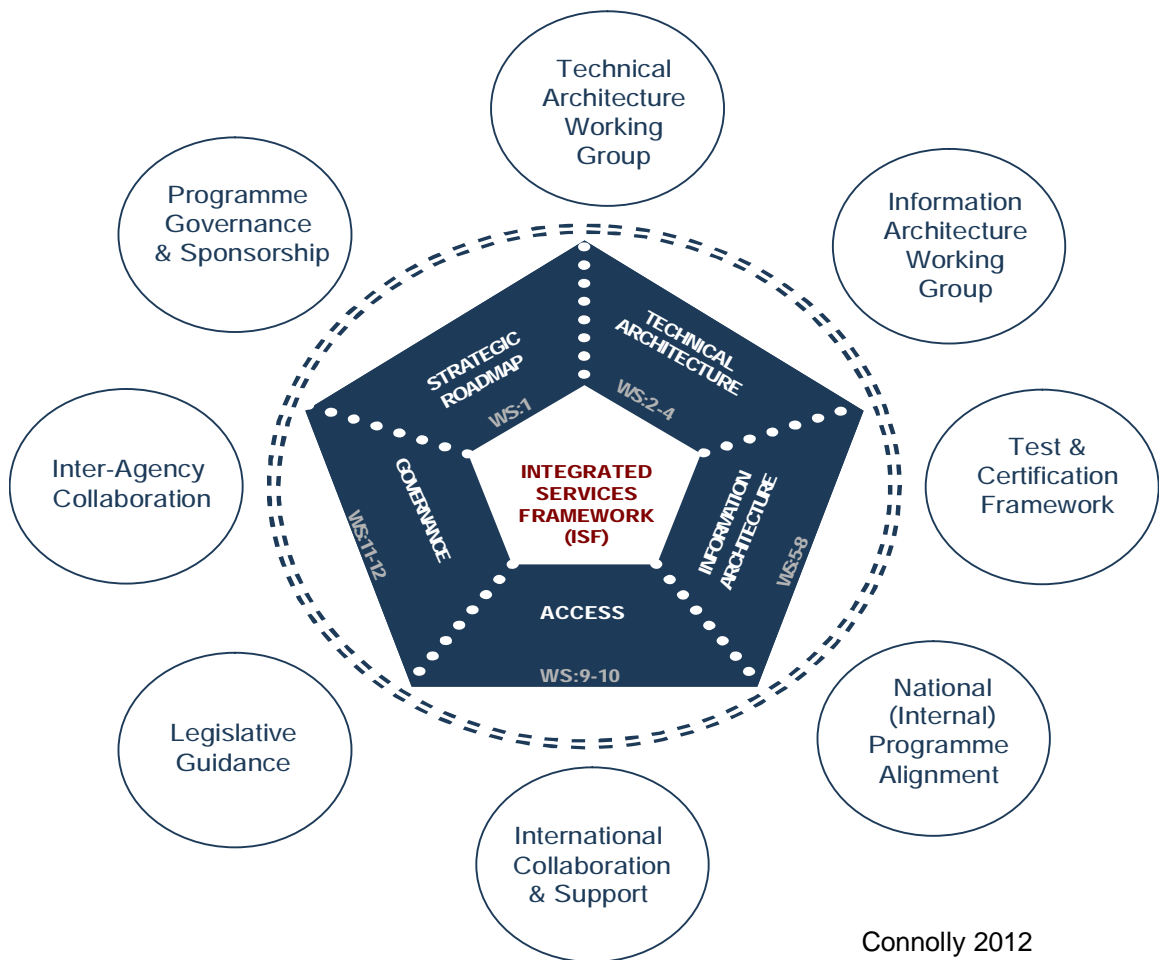


Figure 1: ISF Work Streams and Collaboration

2.3.2 Technical Infrastructure

The integrated exchange of information requires an underpinning architecture to support the sharing, storing, control and access to the information being exchanged (Vest and Jaspersen 2010).

The Commission for Patient safety and Quality Assurance in its 2008 report stated that:

“The underlying information communication technology (ICT) infrastructure, and applications within all aspects of healthcare, should be recognised as the foundation for all patient-centred systems. The infrastructure should therefore be seen as a key enabler of patient safety and quality and ICT infrastructure standards should be set at a national level to ensure good levels of reliability, performance, security and interoperability.” (Department of Health and Children 2008a, p198).

The healthcare information infrastructure to achieve this includes the computer network service, hospital administration and clinical systems, GP systems and clinical applications (Ingram et al 2006).

The strategy for the management of infrastructure must consider whether legacy systems should be used, adapted or replaced (Grimson et al 2000, Salzberg et al 2012). Walker et al suggested in a 2005 paper that the benefits of a fully standardised interoperable system outweigh any short term gain which may be made from developing interfaces between coding schemes in legacy systems. They suggest that local (patch) solutions divert resources and can delay the acceptance of national standards. There are documented difficulties in incorporating standards in legacy systems (Yang and Maxwell 2011, Bouhaddou et al 2012). However Salzberg et al (2012) acknowledges that there may be a need to leverage existing legacy investment.

The overall development of infrastructure, including the management of legacy systems, requires leadership and an investment in policy, planning and resources. (Salzberg et al 2012, Ingram et al 2006).

2.3.3 Standards

Standards provide a framework for the exchange, integration, sharing, and retrieval of electronic health information. They define how information is packaged and communicated from one party or system to another. The language, structure and data types required for seamless integration between systems is set by them. Standards support clinical practice and the management, delivery, and evaluation of health services (HL7 2013).

The purpose of standards as laid out in the strategic ICT Framework for the Irish Health System (Health Board Executive 2004) are shown in the table below.

Table 1: Purpose of Standards

Standards are required in health information to allow for the comparability of information over time or between different places and settings
Compatibility and interchangeability – standards enable easier customisation and integration of ICT solutions, making for easier more flexible and cost-effective solutions
Common understanding – having common definitions and standards helps in the efficient exchange of ideas, concepts and concrete information
Efficiency – adherence to common standards means that existing learning can readily be applied in new situations/organisations
Competitiveness – use of standards leads to competition among suppliers, thus enhancing product quality and reducing prices
Quality and Safety – enforcing standards can result in higher levels of quality and safety
Enhancing levels of competence – through better promulgation of best practice or accrediting professionals

The strategic ICT framework for the Irish health system notes that often ICT standards emerge from practice and may not be formally recognised by standards bodies. It is suggested that the lack of a mechanism for ensuring the adoption of standards in the health sector is:

“one of the biggest stumbling blocks in the provision of integrated and cohesive health information” (Health Board Executive 2004, p135).

This challenge was still being described in 2011 as the background to developing national eHealth interoperability standards for Ireland (Health Information and Quality Authority 2011a).

Bouhaddou et al (2012) in their review of the role of standards in the US Department of Veteran Affairs, note the significant obstacle to interoperability that the absence of health data standards poses. They point out that standards which deal with architecture, terminology and interoperability have been shown to reduce the time and cost of software development and contribute to the sustainability of internal and external interoperability. They also point out, however, that the implementation of standards is 20% information technology and 80% business process, integration, behaviour and social networking.

A summary of the ‘lessons learned’ from the review carried out by Bouhaddou et al (2012) are:

- The need for a clear and known pathway through the organisation which supports all actions required to complete the standards process. This is helped by management support and a dedicated resource;
- The production of standards in easily understood and readable format;
- To start with a pilot which is likely to succeed and show quick wins;
- The use of an agile development process with incremental gains;

- Collaboration with other agencies/organisations;
- The inclusion of standards as a requirement in IT acquisitions and requests for IT proposals;
- The involvement of clinical informatics experts in communication to other stakeholders to link the value of standards and improvements in patient outcomes and efficiency;
- Allowing enough time - this is slower than buying proprietary solutions.

The approach to developing standards should be practical, sensible, and iterative and allow for experimentation. This can be progressively linked to the implementation of clinical systems. A concern that innovation might be curtailed by policies, intended to facilitate the adoption of standards, is described by Salzberg et al (2012). Collaboration with academic, professional and industrial teams would be beneficial, within an organisational governance framework (Ingram et al 2006).

2.3.4 *Semantics and data dictionary*

Successful and meaningful data exchange is dependent on the introduction of standard terms and semantics (Hovenga and Garde 2010). Semantics is the ‘the study of meaning’ and focuses on words, phrases, signs and symbols and what they stand for (Wikipedia 2013). Semantic interoperability means that the information system “understands” both the semantics of the information request and the semantics of the information sources (Garde et al 2007). Veltman (2001 p167) defines this as:

“the ability of information systems to exchange information on the basis of shared, pre-established and negotiated meanings of terms and expressions.”

National adoption of semantic interoperability is an essential element in the sharing of clinical and business information. The implementation and

maintenance of semantics help users to trust data generated through an IT system. A high level of semantic interoperability is needed to support the complexity of clinical data exchange and ensure that a receiving system can understand the information received in the same context and meaning as the sender (Hovenga and Garde 2010).

2.3.5 Data management

As well as unique identifiers, building blocks for semantic interoperability include clinical data models (archetypes) (Rothenberg 2008). Commenting on the requirements of sharable guidelines for computer applications Pattison-Gordan et al (1996) point out that a data model is required for information to be shared in a way that is independent of institution and application. The achievement of this in the healthcare setting requires clinical involvement and input (Hovenga and Garde 2010).

The size and complexity of the data set which is being configured can be an obstacle to interoperability and consideration should be given to starting with small data sets, which have a high impact on patient care, and to moving over time to more comprehensive sets which include the opportunity for secondary use of the data (Salzberg et al 2012). Baily and Pang (2004) concur that there is a need to manage the volume of data produced and shared and that ideally data should be pulled rather than pushed from systems. Ingram et al (2006) described features of successful international healthcare data system implementation as being small scale, with a practical focus, concentrated on the front line and supported by credible service champions.

However Salzberg et al (2012) sound a note of warning stating that while there is a case for limiting the size of the data set being proposed for interoperability, this risks excluding some stakeholders, those who perceive that they will not benefit from data exchange and therefore will not engage. Kaelber and Bates

(2007) suggest that the greater the number of people and the greater the amount of information shared the more impact there will be on patient safety.

2.4 Policy and Legislation

2.4.1 Public Policy

It is recognised that there is both cross influence and dependence between policy which enables eHealth, including interoperability, and other infrastructural and public policy areas such as telecommunications and social welfare. Relevant public policy may be in government programmes, statements of strategy, government directives, regulations or indeed judicial interpretations (Scott et al 2002). Policy should be flexible and amenable to change (Mars and Scott 2010)

In Ireland the role of the Department of Health, on behalf of the minister, is to oversee policy development, the supporting legislation and performance and evaluation of the health system (Department of Health 2012b). As with other health systems in the developed world, societal and economic conditions, patient safety, healthcare cost, consumer demands, and evolving health policy (Mäenpää et al 2009) form the background to providing healthcare against which there is a drive to seek benefits from interoperable exchange of health information.

'Future Health' (Department of Health 2012a) outlines the policy of Universal Health Insurance and its supporting concept of 'Money Follows the Patient' (MFTP). A benefit of MFTP is cited as being that the money can follow the patient out of hospital settings and support the delivery of safe, timely care in primary care and other settings. This can only be achieved with exchange of health information across care settings and the linking of performance contracts with payment and care targets. Results focused investment can be seen as a lever for health information exchange (Salzberg et al 2012). This

requires a shift in focus to align outcomes, quality and funding, i.e. a payment for outcomes model, and this in turn requires a standard way of defining and capturing and reporting quality information (Hill and Mannweiler 2010).

Policy plays an important role in successfully implementing data exchange and interoperability. For example, policy can lay out the technical infrastructure and data standards which encourage data sharing and discourage silos. Ultimately, this supports interoperability and exchange of health information. Successful policies for interoperability are a cornerstone for integrated care and can support openness through health outcome measurement. Policy to enable interoperability is essential for the evolution of health information technology and data exchange but national and organisational policies in relation to the introduction of health information technology often lag behind their intended impact and achievement (Salzberg et al 2012).

The implementation of semantically interoperable health exchange is dependent on political support in relation to standards adoption and eHealth strategies (Hovenga and Garde 2010). Four key national factors for e-readiness have been identified, national economic prosperity; technological innovativeness; institutional maturity and internet provider competition (Mishra and Mishra 2011).

2.4.2 Legislation

Legislation for eHealth is at different stages of development across the world. Areas such as data protection, telemedicine, e-health service provision, health information technology product liability and electronic health records have been legislated for in France and indicate the breadth of what needs to be considered. In many developed countries legislative development is ad hoc (Mars and Scott 2010).

In Ireland the Future Health strategy (Department of Health, 2012a) recognises the need for a legal framework to deal with such issues as health

identifiers, data matching and population registers and states the intention to bring forward a Health Information bill in 2013 to deal with the legal factors required to support interoperability.

In addition to support for direct client services, Vest and Gamm (2013) suggest that the public health benefits of health information exchange should be recognised in any legislation, regulation, and national budgetary process. This puts the collective above the individual and can be a driver managing individual or sub group objections to data sharing.

2.4.3 Unique Identifiers

It is essential that data linked to clinical information about an individual can be accurately matched and correctly assigned. To do this a method of uniquely identifying each health service user is required (Hammond et al 2010, Health Information and Quality Authority 2011b). There is also a need to uniquely identify providers of services (Health Information and Quality Authority 2011b). This can be done through a unique provider identifier. The failure to use correct identifiers to link clinical data can compromise patient safety (Hovenga and Garde, 2010).

In the absence of a unique identifier a combination of information about the patient, name, sex, date of birth, for example, may be used, but these have been found to be imperfect (Hammond et al 2010). Although there is resistance to the introduction of unique identifiers in some countries on the grounds of privacy, it is gaining acceptance. (Hammond et al 2010). It is planned that the Health Information Bill due to be published in Ireland in 2013 will introduce a a unique identifier for health services (Department of Health 2012a).

2.5 Conclusion

Health information exchange is linked to improved patient safety and quality and to strategies to reduce and/or manage healthcare costs. Health information exchange requires system interoperability which is dependent not just on the appropriate technical solutions and relevant standards being in place but also on a corporate environment which supports the action required and enabling policy and legislation at government level.

Barriers to interoperability exist in all healthcare systems and are not static and each new round of technology and reform brings its own problems (Ingram et al, 2006). Solutions to the current and future challenges that these bring are complex. There is a recognition, based on the literature, that any action to tackle current barriers must take into account the current and future environment and plan for the responsiveness required to maintain progress in line with system reform. The literature shows that the environment for interoperability, and the successful exchange of health information requires a range of interwoven factors to be in place and should be considered as an organisational change project rather than exclusively a technology problem. (Lluch 2011).

It is an objective of the Government and HSE to put in place the components of interoperability required for health information exchange. On the basis of the literature reviewed and the interviews undertaken this study aims to outline the current barriers to interoperability in the HSE and to look at changes to practice which would assist in overcoming these barriers.

Chapter 3 Methodology

3.1 Introduction

This chapter outlines the methodology used to answer the research question; it describes the qualitative approach used and the rationale for this. The selection and interview guide used with key informants will be explained and the method of analysing the data will be outlined and any limitations noted.

3.2 Research Design

This research seeks to form a judgement in relation to the current development of the factors to support interoperable systems in the HSE. This is an exploration rather than an evaluation and it is important to match this with an appropriate research design (Lee 2012b).

In considering the research philosophy the attributes of positivism and interpretivism were considered. Positivist philosophy is based on deductive theory, in which a number of propositions are generated, tested and empirical proof is sought to prove findings (Babbie 2012). It suggests that objective reality is outside the human mind and the person and the reality observed are separate (Shepard et al 1993, Weber 2004). In this approach unobservable phenomena such as meanings and intentions are not important (Burton-Jones 2009). Quantitative statistical methods are often used in positivist research to analyse information gathered as part of experiments or large scale surveys.

Interpretivism suggests that the researcher and the research world are not separable and that the research object is interpreted in light of the researcher's lived experience. Research methods include action research, case studies and ethnographic studies (Weber 2004).

The strict delineation between these philosophies has been challenged suggesting that there are many shared research experiences across both

approaches and that the understanding of the research methods, data analysis techniques and meaning of the knowledge obtained is what is important rather than any strict adherence to a philosophical approach (Weber 2004).

On the basis of the common understanding of these philosophies this research takes an interpretivist approach. Health organisations are complex operating environments and interpretivism is suited to exploring the interwoven factors which impact on their function (Hatch & Yanow 1985) and the research question requires interpretation and exploration of meaning rather than measurement.

Using this approach acknowledges the 'personal' aspect of individuals' roles and the contribution these make to overall organisational function is acknowledged (Thompson 1967). This lends itself to a qualitative approach which allowed this researcher to explore the environment, context and personal experiences of the informants and how their work and experiences relate to the sharing of data and associated interoperability of systems. The study was designed so that it might provide insight and findings which can inform practical solutions to advance interoperability (Robey and Markus 1998).

Information was gathered using a purposeful case study which aimed to explore the experience of key informants in relation to the factors, barriers, and facilitators which impact on interoperability within the public health system in Ireland. It was recognised that specialisation within a complex organisation, such as the HSE, can result in the creation of silos of knowledge. Open qualitative research facilitates cross-disciplinary knowledge gathering which takes this into consideration (Health Information and Quality Authority 2010, Lee 2012a). Using purposive sampling, informants were selected that would represent relevant but diverse perspectives inside and outside the HSE. They

were drawn from technical, operational, clinical and policy backgrounds to achieve a cross discipline response.

3.2.1 Data Collection Technique

A literature review and review of key organisational and government documents was carried out and used to inform the interview guide.

An observational data technique was used, in the form of a semi-structured interview instrument (see interview guide in appendix 3), to gather informant opinions across the main themes identified in the literature review. This captured direct personal perspectives and experiences using open ended questions and allowed the knowledge and experience of the participants to emerge as they discussed the issues.

Semi-structured interviews provide the interviewees with the opportunity to share experiences and views using their own language. This avoids the 'straightjacket' imposed by closed questions which require them to fit their narratives within a confined structure constructed by the interviewer (Lee 2012a).

The interviews provided the means to explore the informants' interpretations of current or past factors that impact on the areas under study (Walsham 1995). They were conducted in an open, non-judgemental manner and open questioning allowed the informants to use their own words to describe their experiences and perceptions and drew on their first-hand experience (Lee 2012a).

Pre-ordered topics and key questions were used to develop the areas of inquiry. Prompts were used where necessary drawing on knowledge from literature and information which was provided in preceding interviews where relevant (Lee 2012a). The intention at all times was to allow the interviewees express themselves, in order to benefit from the range of their experience and

interpretation, but at the same time to steer their input when it veered off subject to ensure that relevant questions were covered. (Walsham 1995, Lee 2012a).

3.3 Selection of Participants

This study adopted a purposive sampling method to select people, agencies and documents to aid the collection of information from multiple perspectives (Rudestam & Newton 2007).

A purposeful sample consists of a non-representative subset of a chosen population (UCD 2012). In this case the chosen population was senior healthcare personnel involved directly or indirectly in ICT in the Irish healthcare system.

Thus it is recognised that the group interviewed is not a representative sample but rather a number of people who were selected for their key roles, their knowledge of the issues under study and for the relevance of their experience (Kumar et al 1993, Rudestam & Newton 2007).

The criteria for selecting informants were:

- That informants had national responsibility in relation to an aspect of ICT, data and/or information management;
- That informants roles involved one or more of the following:
 - Quality
 - Strategy
 - Operations
 - Systems
 - Programme/project management
 - Clinical data/information management;
- That the group consisted of people who work inside and outside the HSE;

- That the backgrounds of the group interviewed were mixed, including: IT specialists; IT project managers; clinicians; and national leaders;
- That the people were available and willing to participate in interviews of approximately 45 minutes in duration.

Fifteen people were invited to participate and 14 accepted and are included. Nine of the people were employed directly by the HSE and five were employed by other relevant agencies.

Informant	National leader			Technical background	Clinical background	HSE Employee
	Policy/ Quality/ Research/ Data	ICT	Clinical programmes			
1	✓					
2	✓			✓		
3	✓					
4	✓					
5		✓		✓		
6		✓		✓		✓
7		✓		✓		✓
8		✓		✓		✓
9		✓			✓	✓
10		✓		✓	✓	✓
11			✓		✓	✓
12			✓	✓	✓	✓
13			✓		✓	✓
14			✓		✓	✓

Table 2: Breakdown of Interviewees and Backgrounds

In summary the interviewees were designated into three primary groups:

- four were national leaders drawn from the realms of data/information quality, policy, strategy and national data set management (informants 1-4);
- six were actively involved in day to day ICT strategy, operations and programme/project management (informants 6-10);
- four were clinicians (informants 11-14) who have a national role in the development and use of data and information to support clinical programmes.

The interviews were detailed and intensive lasting on average 50 minutes. The number of participants was considered adequate for the amount of relevant information generated and the level of discussion at interview (Rudestam & Newton 2007)

3.4 Data Analysis

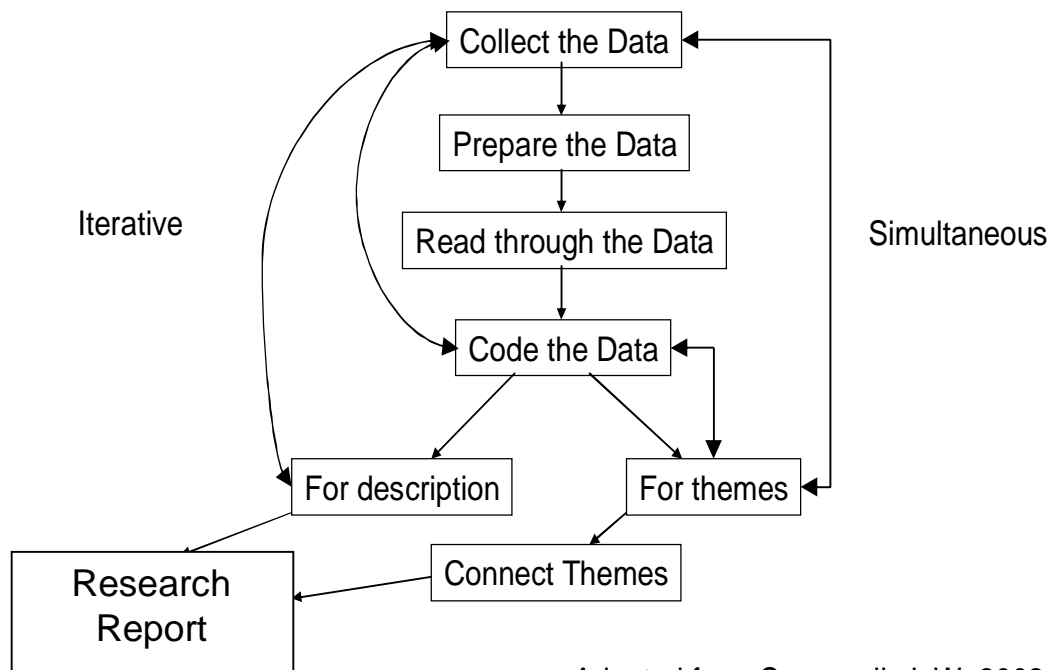
Personal interviews were conducted with each informant. The interviews were recorded with the interviewees' permission, yielding approximately 580 minutes of interviews; the transcribed audiotapes amounted to 111,000 words.

Inductive analysis was carried out through immersion in the details and specifics of the data collected. A list of themes was identified through iterative reading of the transcripts and listening to the audio files. Each interview was colour coded on the basis of the identified themes. The coding was reviewed on two occasions to check for consistency across and between interviews. The themes were placed in categories to allow for the recognition of patterns and key findings. Working papers consisted of the transcribed interviews and a paper on each category collated from relevant material across the interviews.

The analysis followed the key stages as laid out by Cresswell and presented in Bruan and Clarke (2006 p99): becoming familiar with the data; the generation

of initial codes; identification of themes; review of the themes; defining the themes and producing the report.

Steps in Data Collection and Analysis



Adapted from Cresswell, J. W. 2002, p264

Figure 2: Steps in Data Collection and Analysis

3.5 Ethical Approval

Ethics approval to carry out this study was sought and granted by the Trinity College Dublin ethics committee of the School of Computer Science and Statistics.

3.6 Limitations

This researcher is a member of the community under study and a work colleague of many of the interviewees. From a positivist point of view this may be seen to compromise the validity of the study as the researcher is considered as not being objective. This bias may threaten the validity or trustworthiness of the results as the participants may behave differently or the researcher may draw conclusions or make assumptions based on her tacit knowledge of the organisation.

On the other hand insiders have advantages which can assist the research. They have knowledge and context not available to outsiders (Walsham 1995, Rooney 2011) and interviewees may feel more comfortable and willing to talk openly because of the familiarity with the researcher. It can be argued that all qualitative research, insider and non-insider, is coloured by subjectivities and there is no guarantee of openness or honesty, as complete objectivity is not possible (Rooney 2011).

Bias may also relate to the organisational roles of the informants (Kumar et al 1993). This was recognised and considered a resource rather than a problem (Lee 2012a). The interviews were conducted in a way that sought to make explicit the assumptions the participants brought to the process and in doing so add meaning to the interpretation of the issues under study.

This study used a qualitative approach to explore the research question through semi-structured interviews with a selected number of senior participants. Although this provided an extensive and in-depth narrative it did not allow a quantification of the findings.

The number of participants included does not allow for any generalisation of the findings but their seniority, positions of influence and spread across policy, quality, ICT and clinical fields did provide a well-informed insight of direct relevant to the research topic.

Chapter 4 Findings

4.1 Introduction

The interviews were a rich source of information. Key informants (KI) interviewed, all of whom were senior personnel with a national brief directly or indirectly for information and ICT, are identified by a number and letters which indicate the primary category assigned to them: national leader for policy/ quality/ standards/ datasets (NL); national lead position within information and communication technology (ICT); or national lead position within a clinical programme (CL).

Informants were asked what interoperability meant to them and although their understanding and language varied, their responses contained many of the components outlined within the literature (Vest & Jaspersen 2010, Fu et al 2012, Myers et al 2012, HIMMS 2012) for example:

“interoperability comes under the general umbrella of setting standards for health information and fundamental to setting standards for health information is the ability to be able to share the information” (2 NL);

“interoperability is about being able to share information, but you can only share information if we can all understand it” (6 ICT);

“interoperability is around ensuring at one level that the systems can communicate with each other, but more importantly it is an end result in process terms in that the end user can interact with a number of systems seamlessly” (7 ICT);

“interoperability, in this context, is really about information crossing boundaries” (13 CL).

This chapter will outline the main themes which emerged from the interviews looking at organisational factors, technological factors, and policy. Conclusions will be drawn from the information gathered to outline the main findings.

4.2 Organisational Factors

4.2.1 Reform and Reorganisation

The organisational environment was seen as being unstable during the current stage of reform of healthcare under the Programme for Government and this influences decision making, planning and implementation. One interviewee commented that:

“until we can get some of that clarity (about reorganisation) in place we don’t know where to put problems and we don’t know where to put proposals for moving forward” (1 NL).

It was summarised by another informant, from an ICT perspective:

“The reform process isn’t mapped out yet I would say, we have a very high level to say we are going to change the access to the system, we are going to change the governance to the system, we are going to change the structure of the system, we are going to change the funding. Now once you get below that and start asking the awkward questions that ICT need to do because it is a rule driven, rule based stuff, it starts to get a bit hazy very quickly” (7 ICT).

Under the current health care delivery structures the different governance/statutory arrangements for the HSE and voluntary hospitals were stated as a factor which posed a challenge for interoperability. One interviewee remarked that this had not been resolved during the last

reorganisation of healthcare services, in the move from Health Boards to the Health Service Executive:

“We continue to have HSE hospitals and non HSE hospitals andthat that is about to continue”.....“without addressing that core issue we know that the patients systems cannot be standardised because the voluntary hospital can say ‘I won’t have that I will do it my way’ (3 NL).

The voluntary hospitals are considered separate entities and information cannot be shared across them, even with their agreement. One interviewee gave the example of the three Dublin children’s hospitals, who have requested a seamless system:

“they are happy to work together and streamline their processes because you can share waiting lists and you can book from one hospital into the other hospital” (10 ICT);

but these are ‘voluntary hospitals’ and

“under data protection we are not allowed to share information.....we have the exact same software in each hospital but totally separate databases” (10 ICT).

It was suggested by one informant:

“you want the ability to coordinate, you want simpler organisational structures, you want simpler governance structures you want to be able to promote, cross organisational interface, difficult to see how you do that with completely different organisations” (5 ICT).

It is hoped that this barrier will be removed in the setting up of new hospital groups, which was announced in May 2013, and the evolution of these groups to independent Trusts (Department of Health 2013b). While this move may

remove the barrier presently posed by some hospitals being set up as independent entities under statute, it poses another challenge in that these Trusts will have the option to choose and implement their own ICT systems. Already there is evidence of hospitals choosing to specify and purchase IT systems which are outside the national solution offered. Informants' views on the risk that this created varied.

Some informants expressed concern that independent system development at Trust level would result in the national and local getting "*further and further apart*" (7 ICT) and that over a short period of time there is a risk that

"we will end up with totally separate and different disparate systems" (7 ICT).

On the other hand one informant stated:

"I don't worry about allowing Trusts to do their own thing, however that places an absolute imperative of having standards in place and getting them in place in a timely fashion" (2 NL).

Which would require that the system:

"Support Trusts and give guidance to them from a standards perspective and from an interoperability perspective" (8 ICT).

There is a gap in the national standards and standard operating procedures required to ensure that any future variation from national systems by Hospital Trusts will not compromise interoperability. This needs to be considered as part of the impact analysis of the reorganisation on ICT.

Finding: The final shape of the reorganisation is still emerging and the impact or implications of this reorganisation for ICT and interoperability are unknown.

4.2.2 Strategy

An operating environment which is undergoing organisational change requires a robust strategy to support ICT work at a strategic and operations level (Drucker 1999). The absence of such an agreed strategy was a theme in the interviews

“there is no coherent overall strategy” (5 ICT);

“we are an enormous organisation with an enormous budget and we have no IT strategy” (10 ICT).

It was recognised that it was impossible to plan, develop and implement systems to meet business needs without the framework of a strategy,

“in the absence of any strategy we are all just speculating” (9 ICT).

An IT strategy document was produced by the HSE in 2010 and submitted to the Department of Health for agreement but it

“never got approved in the DoH” (7 ICT).

Although this is not approved it forms the basis for current decision making around proposed ICT projects (7 ICT).

Two of the people interviewed for this study, from different parts of the health system stated that they were involved in the development of separate ICT strategies. Action in more than one place to provide an IT strategy is an indication of a lack of coordination between the HSE and the DoH.

One informant reflected that:

“the DoH and the HSE, at the moment, I don’t think have got the common space to stand on to make a decision for an information strategy” (1 NL).

Finding: There is no single ICT strategy to guide the ICT work plan or coordinate inputs from different actors.

4.2.3 Fragmentation

Informants recognised disconnect in ICT at planning, development and implementation stages. Words used include:

Fragmented:

“I would characterise it (ICT) as being extremely fragmented” (2 NL);

“it is incredibly fragmented and it is by luck and good grace that you trip across things”(5 ICT).

Disparate:

“information tends to be seen as disparate, there is an information system here; there is an information system there” (4 NL);

“it is as disparate and as confused as I could imagine” (5 ICT).

Chaotic

“discovering somebody else has done this already but they have a slightly different version of it, that is chaos” (12 CL),

“the HSE ICT is telling us this, SDU¹ ICT is telling something different, never the twain shall meet and we are the meat in the sandwich! To be honest with you it was chaotic” (11 CL).

¹ The Special Delivery Unit (SDU) was set up by the Minister for Health within the Department of Health in 2011 to improve acute care waiting times and eliminate trolley waits. It was transferred under the HSE in January 2013.

Other words used to describe the situation include “*tribalism*” (1 NL), “*duplication*” (2 NL), ICT projects that “*don’t hang together*” (7 ICT), projects that are “*wandering all around the place*” (9 ICT).

Fragmentation and duplication is described in the interviews at data level and at system level. Fragmentation is known to result in risks to patient safety and inefficiencies and in an environment such as this the requirement to achieve interoperability is critical (Brailer, 2005).

Finding: ICT corporate structures and functions are fragmented and duplication of systems and data sets poses a corporate risk.

4.2.4 Governance

The Comptroller and Auditor General (C&AG) reviewed ICT governance in the HSE as part of his report on the accounts of the Public Service 2009 (Comptroller and Auditor General 2010). He based his assessment on the rules set out by the Department of Finance (DoF) in guidance issued in 2005 (Department of Finance, 2005). His enquiries were in relation to:

“the extent to which ICT governance arrangement and project management processes specified by the Department of Finance were in place in the HSE” (Comptroller and Auditor General 2010, p525).

He found that at the end of 2009 there was no formally adopted ICT strategy and that the ICT Steering Committee, which under the Department of Finance guidelines was responsible for “*making priority and activation (ICT) decisions*” had ceased to function. He was informed that the steering committee was to be reinstated in September 2010, and he concluded in this report, published in September 2010, that:

“It is important that the HSE develops a clear ICT strategy that is fully aligned with its transformation and reconfiguration objectives and puts appropriate ICT governance arrangements in place” (Comptroller and Auditor General 2010).

Governance and its link with decision making was a recurring theme across the interviews suggesting that there was at the time of this research, in 2013, no ICT steering group or other decision making body which met the requirements of the Department of Finance guidelines or the Comptroller and Auditor General. The gap in governance arrangements was an issue for many informants:

“there is nobody helping us or there is no kind of background governance group” (9 ICT);

“the governance structure never properly existed” (10 ICT).

One informant remarked that:

“the governance and the coordination might exist in peoples’ heads, there are some really strong good people in ICT and it exists in their heads, however what flows down and gets communicated and gets socialised and gets accepted is another question” (5 ICT).

Reflecting this position governance was named as a key priority for action:

“set up governance so that we have the appropriate conversations but have a decision making process in the heart” (1 NL);

“from an ICT perspective there needs to be an appropriate governance structure that can look for the realisation of maximum value from our strategic, core, very costly investment” (8 ICT);

the first thing you need is a top governance group” (11 CL).

Finding: there is a lack of formal ICT governance arrangements in the HSE

4.2.5 IT Leadership

“There has never been a strong commitment and leadership in the ‘IT in Health’ area in Ireland, never, not at a political or a policy level” (2 NL).

There were varying opinions on the type of leadership required. Some people opted for a *‘command and control’* (4 NL) approach and emphasised the importance of a *“master/slave”* relationship where responsibility for pieces of work is clear and then everyone follows *“the pied piper”* (10 ICT). On the other hand there was one opinion that success depended on a *“coalition”* approach which was explained as a collection of people who have a shared interest drawn from key stakeholders (13 CL).

Leadership was linked to the perceived value given to ICT and the understanding that ICT is a key enabler of the health system, a point borne out by the literature (Cresswell and Sheikh 2013):

“health IT is not seen as significant in the delivery of healthcare in Ireland” (6 ICT);

and

“there is a failure on behalf of government and the delivery system to recognise the fact that health is a completely information intensive industry” (6 ICT).

It was suggested that:

“the management of the health service is now totally reliant on ICT without anyone actually understanding that” (7 ICT);

and in spite of this it may be that:

*“a cross section of the senior teams are not comfortable with ICT”
(5 ICT).*

The representation and influence of ICT at senior level was a cross cutting theme:

“You have HSE ICT at the moment and it is not clear to me that they have a straight line up to where decisions are being made” (12 CL);

“ICT is not recognised at the management team ... that is virtually unique in any high performing health systems where ICT is often not only on the management team but the next senior position....every other high performing health system in the world,they put ICT at the heart of it” (6 ICT).

There was a recurring suggestion that there is a need for

“strong leaders to take ownership of what needs to be done” (10 ICT).

One informant posed the question:

“how do we get the leadership of some elements of the system committed to the very deep changes to institute 21st century healthcare information systems, and institute them in such a way that they can talk to the other bits of the system” (1 NL).

The fragmentation and lack of leadership emerged as a key issue for informants. It was suggested in interviews that a clear decision making structure, with a lead person who sits on the senior management team and has access to the Director General, is required. There are different opinions as to whether this should be one person, who would be the lead for both Information and Technology, or whether there is a need for a role called a

Chief Information Officer who would in turn have a lead person or an equal colleague on the technology side. This will be discussed further in the next chapter.

Finding: Informants identified a gap in leadership and a lack of understanding and appreciation of the value of ICT.

4.2.6 Stakeholder Engagement/communications

It has been shown from reviews of implementation of health information projects that involvement of stakeholders increases the success and adoption of the project (Mishra and Mishra 2011) and the more complex the organisation the greater the need for cooperation (Lorenzi et al 1997, Mäenpää et al 2009, Salzberg et al 2012). In this study informants suggested that internal stakeholders, not directly working within ICT, had little understanding about how ICT was organised as a unit, how ICT decisions got made and implemented or what the communication protocol was. Communication was raised as an issue by informants, even those who were acting as project managers for IT projects but were not directly employed in ICT. Examples of comments include:

“there is very poor communication around a lot of the current ICT initiatives” (5 ICT);

“we never sit down in one room” (9 ICT);

“(ICT) communication is extremely poor” (10 ICT).

There were varying opinions in relation to the need to work with system users in the development of systems. One informant speaking as if directly to a stakeholder commented:

“you are the one who is going to use it and if you don’t understand how you use it, why you use it and where and how it supports you

doing what you do, you are not going to get the benefit out of it” (6 ICT).

Another, however, felt that there was “too much democracy” involved and suggested:

“clinicians are all independent, they all feel that they are the most important, they all feel that their view is the most weighty, so they all want to do it their way” (9 ICT).

This informant felt that if an IT project was implemented effectively it would provide a system that is fit for purpose and this, at the end of the day, is what the clinicians want, they do not need to be involved every step of the way.

Some authors have suggested that clinicians are integral to the process (Patel et al 2011) but it is also suggested that if clinicians are to be involved it is important to link their involvement with improvements in service delivery (Marchibroda 2007). In the opinion of one clinical informant:

“Unless you can guarantee them something will actually happen you lose the interest of the clinicians and you can’t do that because you can’t develop anything unless you have their input” (11 CL).

Finding: there is a need for enhanced communication between ICT and its stakeholders.

4.2.7 Finance

Informants suggested areas which could be considered in relation to driving costs down. An example given was that systems could share common back ends to manage the elaborate, and expensive, security required for managing

sensitive health information (3 NL). It was however acknowledged that this would not “*save money overnight*” (2 NL) and would be more of a medium to long term gain. This is borne out in literature which looked at the economic return for investment in HIT (European Commission 2009)

Cost avoidance was discussed and it was suggested that it was not desirable to see “*a proliferation of separate information systems*” (4 NL) and that savings were possible by rationalising information systems. It was pointed out that if you standardise on systems you standardise on the number of interfaces and this is less costly. If on the other hand, as may be the case in the newly structured health organisations, Trusts design and implement their own systems:

“that invariably ends up being very costly, developing new interfaces ranges typically from €50,000 to €150,000”(4 NL).

Value could also be derived from current systems if we invested in the people and time to:

“fully vet them and challenge the companies to amend them slightly to make them more usable” (9 ICT)

Upfront investment required to progress the work required to upgrade systems (Meade 2009) was dealt with in the interviews. One informant put the cost of upgrading all of the hospital systems at “*a quarter of a billion euros*” (4 NL). He suggested that some of the investment could be aimed at driving down costs but this would be in the longer term, for example investment in HR and Finance systems would be more efficient and “*drive out a huge amount of money*” (4 NL).

A point made strongly by one informant was that money provided for IT projects needs to cover more than just capital costs. Currently in the HSE IT project funding covers the cost of the technical infrastructure and licensing,

considered the 'capital', but new finance is not made available for project staff, training, communications, change management, process change, and 'go live' support. As one informant put it this is based on:

“a philosophy that says we will sweat the business to release all the non-capital costs because if they can't release it, the project doesn't matter to them!” (4 NL).

This informant estimated that in any project the tangible hardware, software and licensing costs accounts for 25% of funding and the remaining 75% of funding goes on all the other costs, which are not factored in the capital allocation provided.

Finding: There is a need for substantial up-front investment and a commitment to on-going finance before any potential savings can be realised.

4.3 Technical Factors

4.3.1 IT Framework and Technical Infrastructure

It is recognised that there is a need for a framework to bring together the components required for interoperability (Health Board Executive 2004, Fu et al 2012). Within the HSE this requirement resulted in the initiation of the National Integrated Services Framework (ISF) project by the ICT Directorate to develop a framework for ICT applications, information, communications and technical architecture in the HSE. The objective of the project is to define how ICT components interact through standards applied to the structure, functionality, operation, implementation and maintenance of each component. It will also integrate relevant governance and legislative requirements. The supporting documentation states that the framework will ensure that ICT solutions are aligned with HSE strategy and business objectives and it will, if implemented, lay the foundation for a future Electronic Health Record (EHR)

and National Patient/Client/Healthcare Professional Portal (Health Service Executive 2012, see appendix 2 for detail).

The ISF provides a framework and details the work streams necessary to introduce the core elements required for interoperability. However, it was mentioned by very few of the informants and those who did suggested that it was not being used or understood outside the core ICT team:

“none of the projects that I would be talking to would be looking to it (the ISF) to provide anything..... I have never heard it mentioned once” (5 ICT)

I think it (the ISF) is trying to achieve standards where everything becomes generic and links in together. The (ISF) presentation I wasn't sure what it was about (9 ICT).

Finding: The Integrated Services Framework project has a part to play in promoting and supporting system interoperability but it is not fully understood or used as a resource outside the core ICT team.

4.3.2 Technical Infrastructure

The Commission for Patient Safety and Quality Assurance (2008) specified that ICT infrastructure is the foundation for all patient systems. While this was acknowledged in the interviews, informants felt that the ‘wires’ piece was less problematic than the ‘execution’ (1 NL) of the technology. A senior ICT manager stated that:

“The (physical) infrastructure is now in place to deliver large scale technology programmes” (7 ICT);

and this informant went on to explain that interoperability could be delivered through:

“a portal technology sitting above a standards based set of data dictionaries, communication tools and protocols, and a set of more open systems than we have today sitting underneath.... So in an ideal world in a hospital I should be able to go along to a web browser and get all the information that I require presented to me in a web browser that is sucked out of the systems below in real time.” (7 ICT).

Current HSE policy is to put in place national solutions to meet key hospital needs. Current systems under development include: the Patient Administration System (PAS); Order Communications; Laboratory; Radiology; ePrescribing; and document management. One informant suggested that the rationale for this may be linked to interoperability but advises some caution in relation to this:

“There was a rationale for the decision to have a single solution because it does overcome potentially a lot of the interoperability problems that you might have at a certain level. It only solves some of them. It doesn’t solve all of them because you are never going to have a single piece of software that is going to meet all the requirements right across the acute, primary, community, so you are always going to have multiple vendors and multiple solutions out there. Probably it helps at the easier end of interoperability than at the more difficult end” (2 NL).

Even though the delivery of these systems is national policy it was pointed out by one informant that :

“the HSE does not have the organisational skills or resources to deliver these” (7 ICT).

and another that not all hospitals are happy with this approach:

“you have a particular cohort of your major stakeholders who don’t believe it is fit for purpose (5 ICT).

Finding: progress has been made on IT infrastructure but there are gaps in implementation and there are differing views on the effectiveness of the major national system implementation programme

4.3.3 Legacy Systems.

The treatment of legacy systems is one which has been debated over time in the literature (Grimson 2000, Salzberg et al 2012). In the interviews opinions about how to deal with legacy systems varied. It was acknowledged as an issue:

“how the hell are we are going to retrofit all the existing stuff back in” (5 ICT).

The position is that there are:

“Legacy systems that are older than some of the people supporting them.A lot of legacy systems are very good, they do what they say on the tin”“we are using the business intelligence tools to mine those systems to bring the data out. but the difficulty is that as they don’t have the unique numbers running across the whole system the data is coming out as a blob.” (7 ICT).

There is a decision required on whether to create the process and information maps required to relate legacy systems to new agreed definitions on new systems (6 ICT) or, as one informant suggested

“It would depend on what the legacy system could and couldn’t do, it may be much more effective simply to say it worked very well but we are a new world now and we have agreed this so let’s just move on” (6 ICT).

Finding: a review of legacy systems is required to inform decisions on whether to map them on to new systems or replace them.

4.3.4 Standards

It was agreed by informants that standards for the exchange of information is a prerequisite for interoperability and it was understood that the development of standards for information fall under HIQA's remit, as set out under legislation (Department of Health and Children 2007). There were however varying opinions among the informants about how HIQA implements this role:

"HIQA would see themselves, as consumers of standards as opposed to a developer of standards"..... "we need an agency which would be associated more so with the development and implementation of standards" (8 ICT);

"you could argue that setting standards is maybe HIQA's role. And I think in the past I probably have done so, but HIQA are not particularly proactive in that sort of environment" (6 ICT);

"From our point of view HIQA are still only beginning to start to get to grips with information standards" (9 ICT).

One informant suggested that at times HIQA's approach seemed to be based on an *"idealised world view"* (3 NL).

There were also comments about the need for enforcement of standards and the lack of clarity as to who holds that responsibility:

"the view tends to be .. (that HIQA) ... put up the guidelines, and ... the standards without any responsibility for enforcing them" (3 NL);

and another commented that in relation to HIQA and interoperability standards:

“they don’t have the same sort of enforcement role. They can’t mandate that these standards be used in the same way they can with Nursing Homes standards and others” (4 NL).

The responsibility that HIQA holds in relation to the development of standards seemed to be understood, but key informants questioned whether the process through which standards are agreed, prioritised and enforced is clear or adequate.

Finding: there is a gap in the development of standards to support interoperability and a need for clarity in relation to HIQA’s role

There was specific mention of the need for the adoption of a national standard for clinical terminologies, for example SNOMEDCT and LOINC, to support current project implementation and future planning. Key informants from ICT stated that the absence of a definitive position on the adoption of an agreed clinical terminology standard was a barrier in their work.

Finding: the implementation of national systems is being adversely affected by the absence of an agreed national medical terminology.

4.3.5 Semantics and Data Dictionary

Data exchange which is useful and used is dependent on having standard terms and meanings (Hovenga and Garde 2010). Informants understood the need for information to mean the same to those sending it and receiving it for example:

“the particular standards are applied to the data (so that) it will have the same understanding in an alternate setting” (8 ICT);

“to determine this is what a piece of data means and when it goes from one system to another it (the meaning) remains the same” (9 ICT).

One clinician expressed the need for common meaning, and the complexity that can be involved, by giving an example:

“The one that has caused the most problem is the definition of a DNA (‘did not attend’). How do you define a DNA? That is very straight forward until you start sitting down and defining it. What if you ring up before hand, is that a DNA?” (14 CL).

There are examples of clinical work where the same data requirements are described, specified and coded for different clinical programmes and inevitably this results in some differences across the data sets which then render them incompatible (2 NL). This duplicates work and results in a lack of interoperability because there is a difference in meaning.

Finding: Collaborative work is required, including across clinical programmes, to remove data duplicates and develop semantic interoperability.

Data dictionaries were specifically mentioned by key informants who recognised the need to put a dictionary in place:

“We haven’t been as rigorous as we should have been about definitions and data and so on which leads to misinterpretation, confusion and duplication ” (2 NL).

It was not clear where responsibility for the development of a data dictionary lies. Two informants, from different agencies, specifically stated that the development of a dictionary was within their role. One informant reported that a process is in place to provide a dictionary for use across the health system. Most recently the DoH policy paper on Money Follows the Patient (MFTP) (Department of Health 2013a) stated that the data dictionary will be developed as part of the work of the National Pricing and Information Office, a structure and function that is still in the process of being described and implemented.

Finding: Responsibility for developing, implementing and maintaining a national data dictionary needs to be clarified and a plan and timeline agreed.

4.4 Policy and Legislation

4.4.1 Public Policy

There are several policy areas which were cited by informants as current or future levers for progressing the required components of interoperability.

The Health Reform programme is recognised as an opportunity to capitalise on the political and organisational appetite for change. One informant stated that :

“the key driver is looking at how it supports the Government’s reform programme” (5 ICT);

and another looked at the area of reform which intends to rebalance the delivery of care between acute and primary and noted :

“the talk about integrated care, shared care, it is the whole basis of the shift from secondary to primary care, reducing hospital outpatients, reducing unnecessary visits and so on. In order to do that the shared care model, whether it is in obstetrics or diabetes, involves literally the sharing of the information” (12 CL).

Fiscal policy is driving austerity and creating an environment where value for money and return for investment is under scrutiny. At a time like this areas which can increase value for money or drive return for investment are scrutinised. Informants commented that:

“We have an opportunity now because we have no money, and our resources are so tight, there is more pressure to actually do things smarter, and things better “(10 ICT.)

another informant expanded on the opportunity as follows::

“I think there is a real opportunity now particularly given the financial constraints.....You cannot run an efficient system if you don’t have the information part of it sorted out. That would deliver your efficiencies, that will allow you to analyse your methods of care and your processes of care to see what can be improved and see what is working well. Increasingly I think people recognise that in order for that to happen you need integrated systems, interoperable systems. So I think there is an opportunity with this new health reform programme to ensure that you have the structures in place to do that” (4 NL).

4.4.2 Individual Health Identifier

The need for an individual health identifier is seen as a prerequisite for interoperability in the literature (Hammond et al 2010, Health Information and Quality Authority 2011b) and the IHI was a recurring theme across the interviews.

While it was acknowledged by all that an individual health identifier is required, many felt that this was not a “*show stopper*” (8 ICT, 12 CL). Given the length of time this has been planned, projects are progressing with their own solutions and providing the means to map onto the nationally agreed Individual Health Identifier (IHI) once it is available. One informant said:

“because we have delayed for so long in this we should do it properly and do it right, even if it takes a bit longer, we should do it right” (2 NL).

There were different views on whether the IHI should be linked to the PPS number. It was stated by an informant that:

“the PPS number is used for entitlement to services and that is fine but you still need a separate number for the clinical side of things” (2 NL).

and was of the view that the IHI should not be linked to the PPSN.

Another view was that what is important is that there is a link between them:

“I don’t think that it would make sense to introduce for use a unique health identifier that is not linked with the PPS number” (4 NL).

And another implied that even among senior leaders there may be a difference of opinion about the use of the PPSN:

“Now for many, many years I have been saying why can’t we collect (and use) the PPS Number? Just what is the downside?” (3 NL)

It was recognised that, whichever number is used, the resources involved with the application and maintenance of the number will be considerable,

“the most important thing is not what the number is but who actually manages the number, how that number is issued, how that number is deleted, at what point is it deleted, and how do you prevent duplicates occurring” (10 ICT).

Finding: the absence of a unique way of identifying users and providers of health services needs to be addressed urgently.

4.4.3 UHI and MFTP as Levers for Change.

There was an acknowledgement that payment for services had often acted as a lever in the past:

“Where there is payment methods involved, for example immunisation, the data suddenly becomes very, very structured and uniform because to submit it in a particular format entails having it in a particular form” (12 CL);

“There is a primary reason for doing it, it may be funding driven, usually a need for payment or something similar” (13 CL).

The stated policy intention to move to a system of Universal Health Insurance (UHI) and the current supporting preparation underway to introduce money follows the patient (MFTP) (Department of Health 2013a) will have the effect of concentrating minds to provide the information required to bill insurers for services provided. This was articulated by one informant as follows:

“The biggest lever to move us on will be the health insurance market, because it will drive us to do it” (7 ICT);

“It will drive a requirement to be able to understand costing which in some ways will be better at driving than the patient safety piece because the patient safety piece is, in some ways, a bit more nebulous, in some ways it is a bit harder to say what is the ROI” (7 ICT).

Finding: Current health policy, including UHI and MFTP, is a lever which has the potential to accelerate the changes required for interoperability.

4.4.4 Data Protection

Data protection was raised by all informants as having an impact on the ability to share patient information between services and health service providers.

There was a variety of views about the current legal situation under the data Protection Act and overall the situation was perceived to be confused and

open to interpretation. One suggestion was that difficulties in interpreting and using data protection law arose because:

“IT systems are all geared to support the professionals and the organisations not the patients” (2 NL).

If an approach was taken which put the patient at the centre then:

“that unlocks a lot of this (data protection) because you put them in charge of decisions about what should happen” (2 NL).

Overall it was suggested that the intent of data protection law, and the data protection commissioners, was not:

“to thwart logical practical business being carried out” (10 ICT).

but it doesn't help that people have had experiences of:

“different data commissioners where the same law has applied but has been interpreted very differently” (10 ICT).

Across current IT project teams it was also noted that

“they are all researching, going off on courses on data protection and sometimes they come to completely different conclusions” (5 ICT).

Particular data protection issues were mentioned in relation to “voluntary” hospitals as each one of them is considered a separate reporting entity under data protection. These hospitals cannot, under data protection rules, have a single index of patients and they must have partitioned data bases. It emerged in one interview that advice is being sought currently on whether patient safety and wellbeing supersedes any protection for data in law (9 ICT). This may clarify the ambiguity in this area.

Many of the informants commented that while people value privacy and the confidentiality in relation to information there is also an underlying assumption that data on their health status is available and accessible when appropriate and required:

“if you talk to most people in the public, they assume that the HSE has a joined up system. They assume that you are actually going to keep their information, that you are going to keep it safe, its secure, it is somewhere where people that need to access it can access it immediately” (10 ICT);

“I think people presume and expect that people who are supposedly looking after them and their best interests have access to the particular vital information that they need” (12 CL).

One informant felt that the HSE, for its size and complexity, should have a data protection unit which would be the one stop shop for all projects and would provide one view of the data protection parameters within which the Health service must work (5 ICT). If the law is being interpreted correctly now and this means that health data cannot be shared appropriately across boundaries and settings then the view of another informant is that the law needs to be changed:

“For years we have been trying to manoeuvre around data protection get over it get under it whatever and I am of the opinion now that we need to step back, if the law isn’t working we actually need to change the law” (10 ICT).

The possibility of data protection being a lever for change was mentioned by one informant giving the example of the investment in blood spot screening IT systems to respond to a data risk identified by the data commissioner.

“That had to go ahead because there was a clinical risk identified, the data protection commissioner insisted on the changes” (13 CL).

Finding: the current application of the Data Protection law is perceived as a barrier. There is a need for clarification of the law and, if required for interoperability, an amendment to the law to support the sharing of data where appropriate.

4.5 Conclusion

This chapter drew together and summarised the main themes which emerged from the interviews. These provide an overview of the factors and barriers to interoperability in the HSE as perceived by the key informants.

Organisational

- The final shape of the reorganisation of healthcare in Ireland is still emerging and the impact or implications of this reorganisation for ICT and interoperability are unknown.
- There is no single ICT strategy to guide the ICT work plan or coordinate inputs from different actors,
- ICT corporate structures and functions are fragmented and duplication of systems and data sets poses a corporate risk.
- There is a lack of formal ICT governance arrangements in the HSE.
- Informants identified a gap in leadership and a lack of understanding and appreciation of the value of ICT.
- There is a need for enhanced communication between ICT and its stakeholders.
- There is a need for substantial up-front investment and a commitment to on-going finance before any potential savings can be realised.

Technical

- The Integrated Services Framework project has a part to play in promoting and supporting system interoperability but it is not fully understood or used as a resource outside the core ICT team.
- Progress has been made on IT infrastructure but there are gaps in implementation and there are differing views on the effectiveness of the major national system implementation programme
- A review of legacy systems is required to inform decisions on whether to map them on to new systems or replace them.
- There is a gap in the development of standards to support interoperability and a need for clarity in relation to HIQA's role
- The implementation of national systems is being adversely affected by the absence of an agreed national medical terminology.
- Collaborative work is required, including across clinical programmes, to remove data duplicates and develop semantic interoperability.
- Responsibility for developing, implementing and maintaining a national data dictionary needs to be clarified and a plan and timeline agreed.

Policy and legislation

- The absence of a unique way of identifying users and providers of health services needs to be addressed urgently..
- Current health policy, including proposed health reforms, is a lever which has the potential to accelerate the changes required for interoperability.
- The current application of the Data Protection law is perceived as a barrier. There is a need for clarification of the law and, if required for interoperability, an amendment to the law to support the sharing of data where appropriate.

Interoperability is a complex area which has at its heart a series of required actions. These actions require plans, owners and organisational support but

importantly it also needs to be understood that they are interwoven and success requires a coordinated approach which can progress all of the elements in a way that supports the whole.

The next chapter will consider the key findings and discuss the implications of on current practice.

Chapter 5 Discussion

5.1 Introduction

This research shows that there has been a delay in putting in place required building blocks for interoperability, and there is evidence of a level of fragmentation structurally and operationally which is impacting on the introduction of standards and an agreed approach to new system development.

These findings are not unusual and reflect similar difficulties experienced in other health systems in trying to manage information technology across a diverse and complex system (Ingram et al, 2006)

In this chapter the key findings under the headings organisational factors, technical factors, and policy will be discussed to elucidate the findings of the research and to draw conclusions.

5.2 Organisational Factors

There is significant reform underway in the HSE, and the final shape of the planned reorganisation is still emerging and the impact for ICT is unknown. Even though interviewees for this research were senior personnel who all hold national roles there was a recurring theme of uncertainty regarding the organisational changes. When asked if the current reorganisation offered an opportunity for advancing interoperability, responses from informants included:

“I find that difficult to answer. Because to be honest it is potentially a bit confusing” (2 NL),

“I have no idea what way the new structures are going to work” (6 ICT),

“to be honest I don’t know enough about it” (8 ICT),

“nobody has a clue what is being planned” (10 ICT).

There was a sense that the detail of future reorganisation was “undetermined”, (1 NL) and therefore it was difficult to know what effect it would have. In the light of this uncertainty the need for a clear strategy and governance was emphasised by the informants.

Strategy is what converts assumptions, objectives and business goals into performance (Drucker 1999). This research found that informants believed that there was no agreed strategy in place to guide the planning and implementation of ICT operations and, by extension, interoperability. The recognition by informants of the need for such a strategy is outlined in the findings and the recognition of action to implement such an agreed approach was also expressed:

“we have to have a clear strategy, but it is not enough to have a strategy,... we have to have a hard implementation plan” (2 NL).

The absence of a strategy was acknowledged by the Minister for Health and he stated at the eHealth conference in Dublin in May 2013:

“I plan to publish an eHealth strategy for Ireland in the coming months“ (Reilly, 2013).

While it is important to have this political focus and support, it is equally important that the main stakeholders in the IT, information and business areas are clear about the authorship and ownership of this strategy and how they can contribute. At the time of this research there was a lack of clarity among informants about who was responsible for developing a strategy and what work was underway.

In May 2013 the Director General designate of the HSE announced the setting up of a “*system reform ICT Strategy Team*” with a brief to advise on the ICT aspects of Future Health (Department of Health 2012a) and review and advise the changes required to provide ‘sign off’ on the ICT strategy in this context (Health Service Executive 2013a). This may eliminate the duplication of effort that was reported through the interviews in relation to strategic planning. The ICT strategy team will be linked into a System Reform office (Health Service Executive 2013a).

An aspect of the reform underway involves the restructuring of the ICT function within the HSE and this provides an opportunity to promote the full value and remit of ICT, to improve ICT processes to deal with identified weaknesses and to put in place a communication strategy. It should also deal with the high degree of fragmentation which has been identified within the HSE and across other agencies, in relation to aspects of ICT.

As one informant pointed out:

“there is so much work for us all to do, we just have to agree who is going to do what and we will just get on with it” (2 NL).

Given the range of people and roles involved in the area of information and ICT Robinson (2005) suggests that good governance is dependent on the need to ensure,

“effective, efficient and secure use of information technology” (p45).

Despite the findings and recommendation from the Comptroller and Auditor General (2010) that the HSE:

“put appropriate ICT governance arrangements in place” (p530),

this research found that there was still a lack of formal governance arrangements in relation to ICT and information.

Informants linked the lack of governance with a lack of decision making, leadership and authority. There is currently no ICT governance structure in the HSE, therefore people felt they didn't know where to go to get decisions made. One person commented as follows:

“Until we can get some of that clarity in place we don't know where to put problems and we don't know where to put proposals for moving forward. And as a result of that I think it is a universally felt angst at the moment that we are just going around in circles, we are in a holding pattern” (1 NL).

One issue that emerged was the fragmented nature of the structure and operational responsibility of ICT in relation to data and information. It is evident from the chart below that elements of data, information and ICT were being managed in different lines and that links were not always made between core functions, for example: responsibility for ICT strategy and operations sat under different line management within the HSE; responsibility for elements of data and analytics sat with both the Corporate Planning and Corporate Performance (CPCP) Directorate and the SDU; and some core national data sets were not linked into core business units.

The following organisational chart depicts the structure within the HSE and the DoH in May 2013.

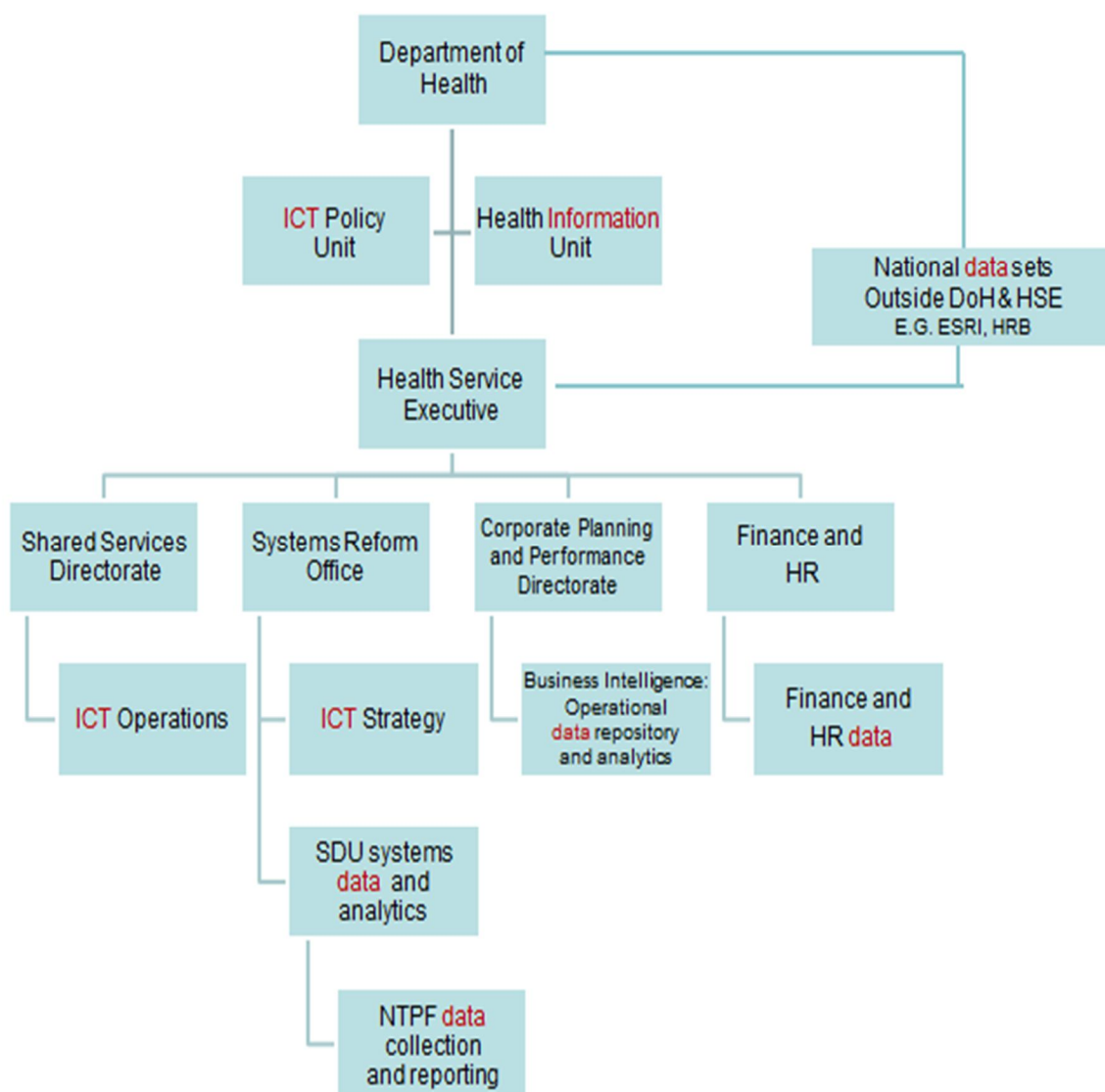


Figure 3: ICT Information and Data Functions within HSE and DoH

This organisational structure contributes to the weaknesses observed by informants in terms of fragmentation and lack of clear strategy and governance.

One informant commented:

“information (is) chucked into about 6 different agencies none of which are in control” (1 NL).

Another remarked in relation to ICT:

“If we take the ICT area there seem to be a number of different groups who are engaged and involved in different aspects of it and that is not helpful in terms of having a clear strategy” (2 NL).

The requirement for a governance group which would oversee the “*appropriate conversations*” and “*decision making*” (1 NL) came up explicitly or implicitly in all of the interviews. Governance crosses ICT and day to day business and informants suggested that this interlinked work needs to be managed under a strong national lead.

The need to combine business and technology actions in order to succeed in implementing the necessary factors for interoperability generated varying comments from informants on whether technology and information roles are separate or whether both could be managed by one person.

Some informants queried whether ‘information’ is well serviced by being bundled with other areas such as technology. One informant said:

“(it) concerns me is that the distinction between the technical or if you like the IT side, the technology side of it and the information side, they’re continuously being confounded with one another” (4 NL).

The question of whether a Chief Technology officer can meet both the technical and information needs of the organisation was raised by some informants. An example of this is the comment by one informant who recommended the establishment of a “*chief technology officer*” and goes on to say that equally there is a need for a “*chief information officer*” to deal with the overall business around the use of information (8 ICT).

Future Health suggests that a Chief Information Officer (CIO) would be put in place along with a Chief Medical Information Officer (CMIO), and a Chief Technology Officer (CTO) (Department of Health, 2012a).

It would seem that the core question being considered is whether the elements of 'information' that need to be managed for interoperability can be adequately looked after if it is part of a wider ICT/information remit. As fragmentation emerged as a significant issue in the interviews it is worth considering whether this problem of equal emphasis and attention for the 'information', including clinical information, and the 'technology' part of ICT could be solved by introducing a role such as a Chief Information Officer who would be a business leader responsible for both information and technology.

Peppard in his paper "Unlocking the Performance of the Chief Information Officer (CIO)" (2010) looks at the role of the CIO and proposes a model which links the CIO role with organisational performance enabled by IT. He notes that his findings suggest that CIOs need the same leadership qualities as any other high functioning senior manager:

"leadership, being a visionary, a strategic thinker, a relationship architect, a deliverer"

and he goes on to list some personal attributes:

"communication, influencing skills, commercial acumen, networking skills, people management skills" (Peppard 2010, p74&75).

However he also suggests that his research has identified a set of leadership challenges as being specific to the CIO. These are:

- Securing the engagement and active involvement of business colleagues in IT issues;
- Demonstrating and proving value from IT spend;

- Overcoming the IT stereotype;
- Creating a vision for IT;
- Building the IT leadership team (Peppard, 2010).

Peppard stresses that even with all of these competencies and attributes present there is another factor which influences the likelihood of success and that is “*the environment within which he operates*”.

Issues outlined by Peppard in his paper and also named by the informants in this study include: confusion between the role of a CIO and IT head of service; lack of involvement in strategic decision making at senior level; lack of IT literacy or “IT savvyness” among the Senior Team; senior team expectations; the relationship between the CEO and the CIO; the need to have an integrated, clear decision making process; change management; meaningful performance measures.

The appointment of a CIO, with the competencies and attributes outlined above, who is placed within a supporting structure with a mandate to transform ICT would be well placed to deal with the issues raised by the informants and progress interoperability.

A structure which might reflect the management and governance needs in relation to ICT and information within the HSE and the DoH, taking into account the factors raised by informants and the knowledge of requirements to meet Government policy, could be shaped along the following lines:

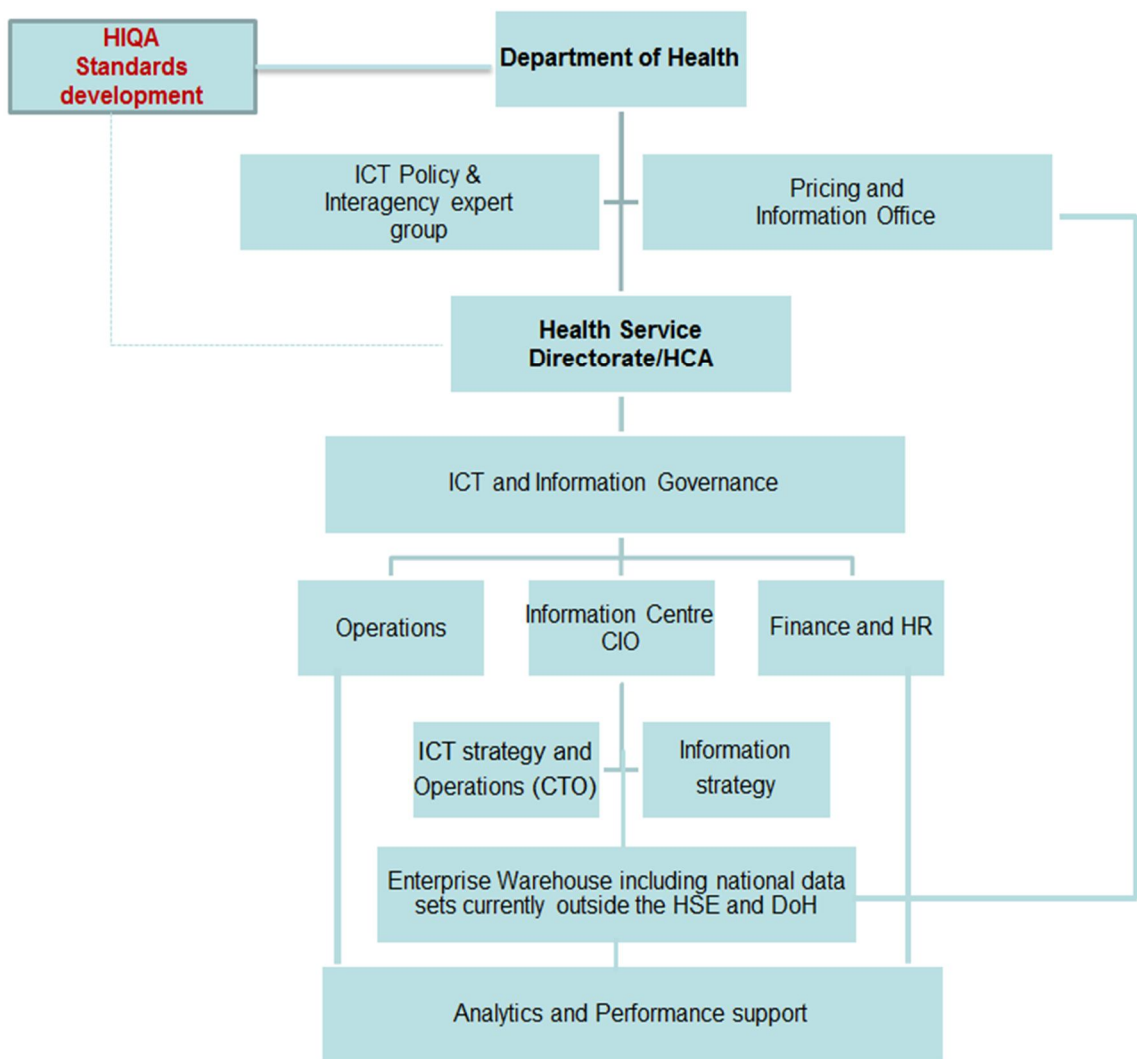


Figure 4: Options for Future Organisation of ICT and Information

This organisational structure includes an overarching governance role and has an ‘information centre’ through which all other aspects of ICT and Information can be managed.

This deals with some specific suggestions and/or concerns which arose in the interviews for example:

- An interagency expert/advisory group is set up in the DoH to allow all parties a say in policy and strategy and to clarify overlapping roles. It would bring together:

“the Department with its responsibility for policy and legislation, (HIQA) with the responsibility for standards and monitoring compliance and the HSE for the implementation and delivery” (2 NL).

- A cross cutting information/ICT governance body sits above the business and ICT/Information arm of the current HSE which will evolve into the Healthcare Commissioning Agency.
- An Information Unit provides leadership and focus for ICT, data warehousing, management of external national data sets and the analytics required to support the business.
- Operations are key players and provide a route to engage with clinicians and business users.
- The business is linked in at the stage of data development and they will use the data for performance management.
- HIQA fulfil the role of standards development on behalf of the DoH but linked into the HSE/HCA.

Reform of function or structures is dependent on appropriate investment and while it is suggested in the literature that technology, and particularly integrated technology, can reduce costs (Machibroda 2007, Mäenpää et al 2009, Fu et al 2012, Maier 2013) it is also recognised that this however needs to be balanced with the investment of money required for IT development, implementation and maintenance (Machibroda 2007, Sicotte & Paré 2010).

While the informants suggested that systems which are interoperable could potentially reduce costs, it was evident that they recognised that any savings would be long term and would not contribute to current cost cutting initiatives.

The reality is that there has been reducing investment in IT systems for the health system in Ireland over the past number of years and the process of

getting investment has become very bureaucratic. This means that there is now a 'catch-up' investment requirement before any benefits can be realised. One informant suggested that hospital systems alone may require an investment of €25 billion. Systems outside the hospitals are much less developed so there is likely to be a matching figure required.

Alongside the system investment, a budget is also required for a medical terminology licence and for implementing the unique identifier for health. Both of these require extensive back up and on-going maintenance.

Under the 'capital' rules in the HSE, budget allocated only covers the hardware, software and licences, a budget is not allocated for communications, change management, process change, and go live support. This is a substantial proportion on the overall costs it is often too much for the service to contribute and therefore can be a significant barrier to progressing system development.

ICT investment is often seen as 'back office' and removed from front line services. Informants stressed the importance of communicating the fact that ICT is embedded in health system delivery, it is part of every health contact and procedure. It is important that the investment required to build health systems and ensure that they are interoperable be provided and that the link is made between this investment and patient outcomes.

5.3 Technical Factors

The practical challenge in relation to interoperability involves putting in place the key technological factors required. A selection of these are outlined in this section.

The need for an IT framework is described in the literature (Fu et al 2012) and recognised by the ICT Directorate who put in place the Integrated Services Framework (ISF) project in 2011, as outlined in the findings section and

detailed in appendix 2. This framework deals with the development of standards at several levels and recognises the need to integrate governance and legislative requirements. However this research found that the ISF was not adequately known or understood or used as a resource outside the core ICT team. A review of the ISF project is required to see how it lines up with current and planned system development and to clarify the role of this project in the area of the development and implementation of standards for interoperability.

Within this framework the need for standards to support the exchange, integration, sharing and retrieval of electronic health information is recognised. The role of HIQA in this area was outlined by several informants. However there was a perceived gap in the development of standards to support interoperability and there a stated need for clarity in relation to the role HIQA plays in this.

HIQA has responsibility for setting standards for health information and monitoring compliance with those standards under section (8) (1) (k) of the Health act 2007 (HIQA, 2011a). The standards under HIQAs remit include those required for data definitions, clinical concepts and terminologies/coding and classifications (HIQA, 2013a). A specific programme of HIQA work covers interoperability standards, *“to support the sharing of patient information between healthcare professionals and across healthcare organisations”* (HIQA, 2013b). A consultation on interoperability standards was sent out by HIQA in December 2011 (HIQA, 2011a) and an overview of standards for interoperability published in July 2013 (HIQA, 2013a).

Despite the legal basis for HIQA’s role in standard setting, as stated in the Health Act 2007, and the reports published by HIQA at the time of the research, there were concerns expressed by some informants regarding the range of standards being developed, the timeliness of their availability and the

link between standards development and the reality of service delivery on the ground.

It was suggested, however, that HIQA have a strong brand and are trusted by the public (2 NL). The development of standards for health care information is part of their remit and any perceived gap in relation to standard development and any confusion about roles and responsibilities needs to be clarified between the agencies involved.

When discussing standards a particular issue raised by informants was the absence of an agreed national medical terminology and it was stated that the implementation of national systems is being adversely affected by the absence of specified meanings of terms and an agreed national medical terminology. HIQA stated in 2011:

“there was unanimous support that Ireland should adopt SNOMED CT as the national terminology standard, but it was agreed it was not cost-effective to purchase a national SMOMED CT licence at this time” (HIQA, 2011a).

The fiscal context in which this decision is being made is an influencing factor. The cost of the licence and the level of investment and commitment its application would require in terms of set up costs, training costs and maintenance costs has been a barrier to its adoption. In the current environment of constricting budgets and reducing workforce within the HSE a decision is required to prioritise investment needed to set up and maintain this terminology system for Ireland.

“why haven’t we said SNOMED is the standard? What is stopping us doing that?I think what is probably stopping us is that there is a recognition, realisation, that there is an enormous training, an enormous cost, an enormous implementation of that which the system can’t deliver” (7 ICT).

Overall there does not seem to be the confidence that the level of investment required would get organisational or political support during any debate on the relative value of investing in what is perceived to be 'technology' rather than front line services.

HIQA have indicated that they will publish guidance on medical terminologies for Ireland later in 2013 and suggested that:

"SMODED CT is likely to continue to gather momentum (internationally) as the de facto terminology standard for semantic interoperability and it is likely that Ireland will follow suit at a time when purchase of a national licence is a cost-effect option" (HIQA 2013a).

As well as the need for standard terminologies other supports for 'semantic interoperability', was understood among informants but it was suggested that there is a need for collaborative work to progress this, especially across clinical programmes. One clinical informant commented:

"We got as far as defining the clinical data set, in so far as these were the items as understood by clinicians, and that was quite a tortuous process as you can imagine, getting the GPs and consultants to agree on that! But it was only when we got help from an ICT analyst, who was excellent, that she actually made it clear to us that there was more to it than that, and it was through the process of specification that a lot of the painful detail got sorted" (11 CL).

It would seem that working through the process of specifying data and applying a data model would help clinicians to understand the level of detail required and how it is managed. A suggestion from one clinical informant was:

“what is needed is a pathway of (data) development for clinical systems to be set out by the HSE and then we (clinicians) need to be taught what it is” (11 CL).

The Integrated Services Framework (ISF) project describes a “HSE Health Data Model” (Connolly, 2012) which will support the extraction of data in a way that can be aggregated and consolidated. This is subjected to a series of tests in relation to patient identity, access rules and provider identity before being available for inclusion in a shared business or patient record.

The ISF project lays out in its project documentation the link from the project to clinicians (Connolly 2012) and their data needs (see figure 6 below).

Integrated Clinical data sets within the ISF

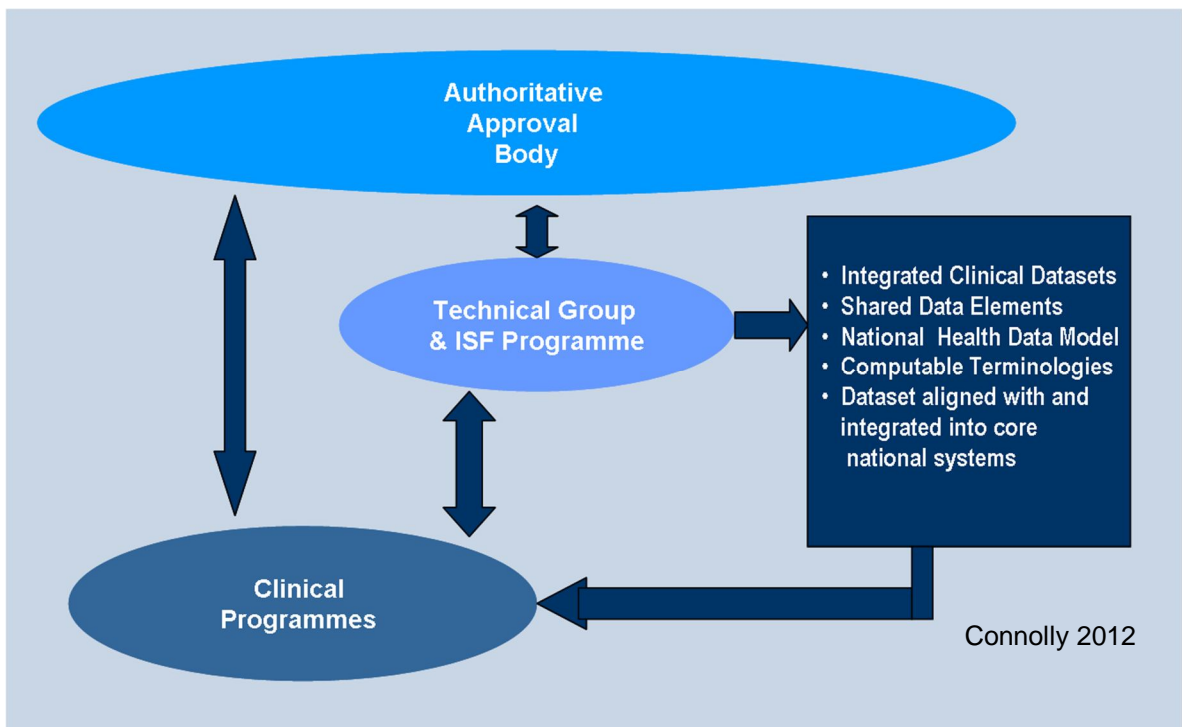


Figure 5: ISF Project Diagram showing link to Clinical Data Sets

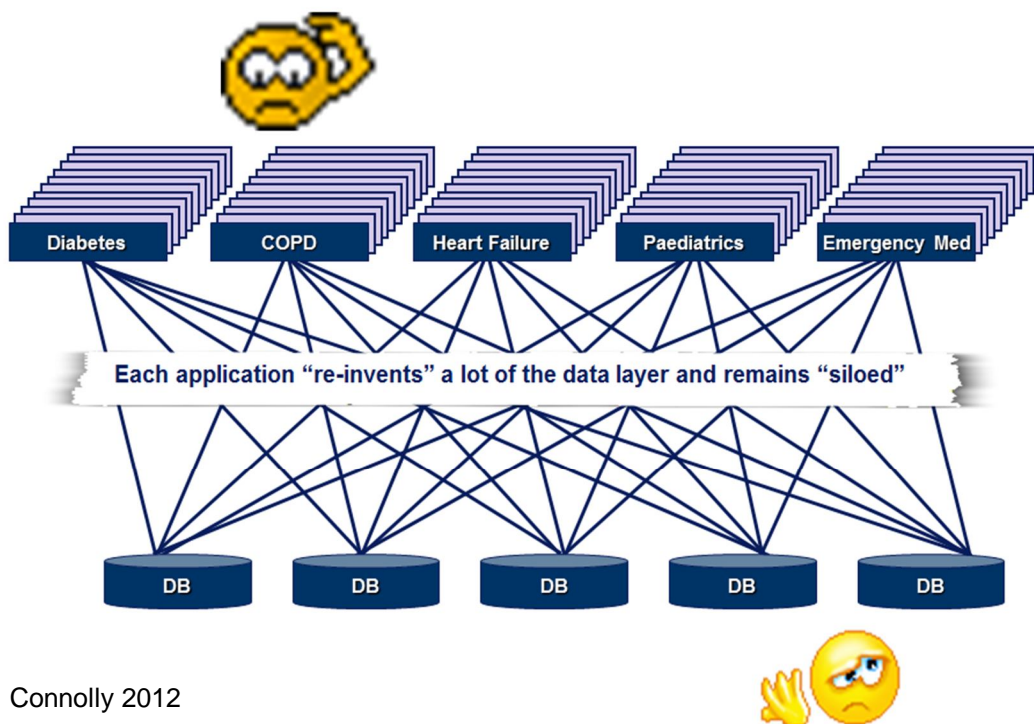
Although these components and linkages have been set out it is suggested in some interviews that clinicians do not understand what is required or their role in this.

One of the clinicians interviewed stated:

“there was no method offered by HSE in general to ‘how does this get done?’ (11 CL).

It is evident that guidance and support is required to support clinicians’ data development. The duplication of data sets across clinical programmes poses a corporate risk to clinical safety as well as being inefficient. This was highlighted during presentations at the Health Information Society Ireland (HISI) conference in Dublin in 2012. There is a need for focused attention in this area to eliminate duplication and risk.

DATA CHALLENGE



Connolly 2012

Figure 6: Clinical Challenge of Dataset Duplication

Overall information from informants suggested that progress has been made on the physical technical infrastructure but here isn't an agreed position in relation to a major national system implementation programme.

Despite this, one informant suggested:

“when the system as a whole is ready to embrace interoperability there won’t be any particular technical impediments” (4 NL);

another said:

“the technology side is not the complex side,the real complex side in all organisations is around changing the business processes to make the most of the ICT and knowing where you want to end up” (7 ICT).

5.4 Policy and Legislation

Government policy as set out in the Future Health strategy (Department of Health 2012a) describes a reorganisation of the structure, model and operation of the health system in Ireland. This provides opportunities to resolve some of the structural barriers described by informants in relation to ICT and to clarify roles and responsibilities. The level of information that will be required to plan, deliver and manage universal health insurance far surpasses anything currently available and this presents an opportunity to ensure that any new information systems meet the standards required for interoperability.

The absence of a unique identifier was identified as a barrier to interoperability by all of the informants. The link between the Health Information Bill and the ability to introduce a unique way of identifying users of health service was felt by some to be not useful and it was suggested that progress should be made on the individual health identifier (IHI) outside the bill.

Some informants felt that it would be useful to reopen the debate on using the PPSN number to uniquely identify people for health services as the distribution and infrastructure for security and maintenance for this is already in place. It has been proposed that a separate identifier is required for health interactions and that this should be put in place over the coming years. This stems from a

review carried out by HIQA in 2009 which concluded that, at that time, the PPSN was deemed to be unfit for the following reasons: it was not accessible 24 hours a day; there was a delay in assigning numbers; some number content had a marker for married women; legislation barred the use of the number for health and social care; it did not meet international standards; there was limited access to numbers (HIQA 2011b) See appendix 3 for an extract of the report outlining the rationale for this decision.

In this study one informant held the view that while the PPS could be used for entitlement to health services a separate number would be required for the clinical services. This informant was not in favour of any link between the PPSN and a number which would be used for clinical services (2 NL).

Other informants, however, felt that had the legal authority been in place to collect and use the PPSN for health services in recent years it would have advanced interoperability. There were some opinions that the PPS number is still an option that should be considered (3 NL, 4 NL).

Because of the delay in a national unique number for health services system developers have put in place solutions to meet the immediate need for identifiers within new systems with the understanding that these identifiers will have to map to the national unique identifier system when it is in place.

The introduction of a unique way of identifying people who receive health services requires absolute clarity around data protection rules. Informants, who have had to deal with data protection law and officials, described varying experiences and interpretation. It is important that clarity emerges which fulfils the intention of data protection law to protect the right of individuals to privacy and to have their data treated securely, while ensuring that required health data is available when needed.

One informant felt that the HSE, for its size and complexity, should have a data protection unit which would be the one stop shop for all projects and

would provide one view of the data protection parameters within which the Health service must work (5 ICT). If the law is being interpreted correctly now and this means that health data cannot be shared appropriately across boundaries and settings, the view of another informant is that the law needs to be changed:

“For years we have been trying to manoeuvre around data protection get over it get under it whatever and I am of the opinion now that we need to step back, if the law isn’t working we actually need to change the law” (10 ICT).

5.5 Conclusion

Overall a strong message across informants was that we should and not “reinvent the wheel” (9 ICT, 14 CL, 10 ICT) and that we “can learn some very important lessons from other countries” (2 NL).

Although there were statements from informants which implied a lack of clarity about the healthcare reform underway there was also an acknowledgement that this creates an opportunity. The change in management structures presents an opportunity to tackle the fragmentation described, embed ICT, develop a strong ICT strategy, and establish the required governance arrangements.

The intended move to an insurance model may be a strong lever for putting in place the building blocks for interoperability. The need for sharable data for payment purposes under the money follows the patient (MFTP) policy will drive the system to put in place all of the necessary supports to allow this to happen. While this may not be the ideal motivation for sharing patients’ data it may provide the opportunity for “purposeful opportunism” (Drucker 1999) and to build the foundations which will allow those who wish to share data to improve patient quality, safety, access and the efficiency of the system to do so.

HIE and interoperability are linked with strategies to drive down cost it but it is evident that this is not a quick win and may take many years to realise any return on investment. In the meantime there is a need for financial investment in terms of up-front capital funds, project support funds and a realistic budget for sustaining and maintaining systems.

The Integrated Services Project provides a framework within which elements of interoperability such as standards, medical terminologies, data dictionary, data models and identifiers can be progressed. There is some confusion in relation to roles and action in some of these areas and it would be useful to carry out a review of the ISF to decide if it is fit for purpose or if an alternative approach to coordinate all of these actions is required.

Supportive and enabling policy and legislation in particular in respect of the individual identifier and data protection is required. As stated by the European Commission (2009b).

“interoperability is not just a technical or standardisation issue, it goes to the heart of decisions about political, financial and legal decisions by national leaders” (p5).

A Chief Information Officer, with responsibility for both IT and information, who has the required leadership competencies and attributes and is a member of the senior leadership could provide one point of responsibility to coordinate all of the actions required. Structural changes to support clear accountability would be desirable.

Chapter 6 Summary and Recommendations

6.1 Summary

This study set out to examine factors likely to impact on the interoperability requirements for health information exchange in the Health Service Executive (HSE), as perceived by key informants. The themes of organisation, technology and policy were used as a framework to review the information gathered through literature review and from interviews.

The study was carried out in a context where health care costs are increasing, demand is going up, new technologies are expensive and the amount of money available for health services is reducing. Health information exchange (HIE) has been proposed as one element of a multifaceted approach to the containment of cost, while also improving safety and providing a better experience for those who receive healthcare services. Interoperability is a prerequisite for HIE.

The Irish health care system is undergoing reorganisation and there is an ambitious reform programme laid out over the next 3-8 years, which presents opportunities and challenges for progressing interoperability. The exchange of information relies on technical building blocks, underpinned by standards and supported by business processes.

The findings of this study indicate that among the key people interviewed there was an awareness of factors required to support interoperability and problems that exist which may create barriers to its introduction. Indications of organisational fragmentation, uneven progress in technical development and an absence of enabling policy and legislation emerged in the interviews.

Factors which create barriers to interoperability as identified by the informants included:

- The fragmentation of ICT at a strategic and operational level, and deficient ICT coordination within the HSE and between the HSE, DoH and HIQA.
- The absence of a single adopted ICT strategy.
- The absence of a formal ICT governance mechanism within the HSE.
- The development of data sets in silos within the HSE resulting in duplication and posing a corporate risk to interoperability.
- A gap in required standards for interoperability.
- The delay in mainstreaming the ICT sponsored project, the Integrated Services Framework, which has as its objective the achievement of interoperability.
- Continuing restraints on financial investment in ICT systems, programmes and licences and a lack of investment in the support, education and maintenance infrastructures for ICT.
- The absence of enabling policy and legislation to put in place essential building blocks for interoperability such as the unique health identifier.
- Conflicting interpretations of data protection law and the effect of the Data Protection Agency (DPA) which restricts the sharing of data even where this is deemed appropriate from clinical and customer service perspectives.
- The lack of clarity about the reorganisation of the healthcare system, which was underway at the time of the study, and the impact of this on the ICT structure and function.

Although the topic of technical infrastructure was dealt with in the interviews informants stressed that, in their opinion, it was not the 'wires' and technical ability which were the main barriers to sharing data, but rather the lack of organisational coherence in strategy, leadership and governance, the

fragmentation of roles and responsibilities, and a lack of investment and enabling policy and legislation.

6.2 Recommendations

This study provided an opportunity to review the current status of the implementation of interoperability in the HSE, to look at the barriers which key informants have identified and to suggest actions which could contribute to overcoming these barriers. The findings have implications for management practice and change management during this time of reorganisation.

Based on the findings from the interviews and knowledge gleaned from the literature, the following recommendations are made:

- A high level, interagency action group should be put in place including representatives from the DoH, HSE and HIQA with a mandate to adopt a single strategy for interoperability and to oversee the delivery of an implementation plan within an agreed timeframe.
- A project to implement effective governance of ICT throughout the HSE should be established. The objectives of this project should include assigning clear responsibilities for different components of ICT management, in particular ICT strategy development, standards development and implementation.
- Once a single ICT strategy is agreed a multi-year ICT investment programme should be agreed across HSE and Department of Health, linked with the Government Strategy Future Health
- A review of the Integrated Services Framework (ISF) project should be completed. This should assess whether the ISF provides the framework required to implement interoperability within the HSE. The outcome of this

assessment should dictate whether the ISF is mainstreamed or replaced with a framework considered more appropriate.

- A project team should be established to deal with the problem of duplication of data sets within the HSE. This should have two terms of reference: to identify and document duplication of data throughout the HSE and to develop a plan to eliminate such duplication where possible and where this is not possible to recommend procedures to reduce or eliminate the risks from such duplication.
- A review of the interoperability standards available and those still required should be carried out and development plan agreed. This would fall under HIQA's remit.
- The guidance from HIQA on a preferred medical terminology standard, (due in late 2013) should be acted on immediately and the necessary licences and support structures put in place.
- Implementation of the legislation and supporting infrastructure for an individual health identifier should be prioritised. If the current review of the options for an individual health identifier confirm that this will not be the PPSN number, a plan for an alternative number is required urgently.
- A Chief Information Officer with responsibility for the information, technical and clinical data aspects of progressing interoperability throughout the HSE should be appointed and included in the leadership team of the organisation.

6.3 Limitations of the Research

This study used a qualitative approach to explore the research question through semi-structured interviews with a selected number of senior participants. Although this provided an extensive and in-depth narrative it did

not allow a quantification of the findings which might have given an insight to the degree of agreement and difference among the group.

The number of participants included does not allow for any generalisation of the findings but their seniority, positions of influence and spread across policy, quality, ICT and clinical fields did provide a well-informed insight of direct relevant to the research topic.

Had time allowed, the inclusion of data protection and legal experts and a review of experience in other large public organisations who have introduced interoperability would have been useful and added value to the research.

6.4 Suggestions for Further Research

Some questions arose in the course of this research which might usefully form the basis of further research. These questions include:

- What is the cost of not implementing a national medical terminology?
- Independent hospital Trusts will have the right to choose ICT systems which they believe best meet their needs. What impact will this have on the national policy to provide single national ICT solutions for core systems in the acute hospitals?
- How much of a barrier to system development in the HSE is the practice that only hardware, software and licences are funded under the capital allocation for ICT, leaving services to fund the resources required for project staff, training, communications, change management, process change, and go live support from day to day budgets?

6.5 Conclusion

This study set out to describe factors likely to impact on the interoperability required for health information exchange in the Health Service Executive, (HSE) and to assess barriers to interoperability, as perceived by key informants. The study achieved its objective and presented are the findings and conclusions. Unsurprisingly organisational factors such as strategy, leadership and governance were perceived as significant levers for interoperability and where they are absent, as significant barriers.

The contribution of this study is to provide an outline of the barriers to interoperability which exist, as perceived by senior leaders, and provide a focus on the actions required to overcome these barriers. Given the extent of healthcare system reform underway it is an ideal time to take action.

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Appendix 1: Contents and Action Plan: Strategic ICT Framework for the Irish Health System, 2004

Source HeBE 2004

TABLE OF CONTENTS

Introduction	6
Methodology	6
Strategic ICT Framework – Phases and Outputs	7
The Single Over-Riding Theme – Obtaining Value from ICT	9
Why is there a need for a Strategic ICT Framework?	10
Making the Agenda Happen	11
The Implementation Timeframe	11
Part A – ICT Vision	12
Introduction	13
A-1 The Strategic ‘Business’ Context	13
A-1.1 Supporting a Modernised Health System	14
A-1.2 The Changing Health System Landscape	14
A-2 The ICT Vision	16
A-3 The ICT-Enabled Health System in 2011	17
A-3.1 The Health System from the Public’s Perspective	18
A-3.2 The Health System from the Provider’s Perspective	23
Part B – ICT Strategy	28
Introduction	29
B-1 Strategy in a Changing Environment	29
B-1.1 The Moving Target – Being Purposefully Opportunistic	29
B-1.2 Meeting Challenges from a Fast-Paced World	30
B-1.3 Harnessing Opportunities that Arise	31
B-2 Review of the Current ICT Environment	31
B-2.1 Summary of Current Enterprise Systems Policy	31
B-2.2 Summary of Current ICT Environment	33
B-2.3 Health Systems Reviews – ICT- Related Findings	35
B-2.4 ICT Uptake Rates in Healthcare Internationally	38
B-3 The ICT Strategy - Components and Purpose	40
B-3.1 The ICT Strategy’s Components	40
B-3.2 The Business Objectives that need to be Supported	42
B-3.3 Achieving the ICT Strategy’s Purpose	44

B4	The ICT Strategy - Strategic Goals Informing ICT Applications	45
B-4.1	Strategic Goal 1 – Enabling Integrated, Person –Centric Service Delivery	45
B-4.2	Strategic Goal 2 – Increasing Effectiveness, Efficiency and Economy of Operation	57
B-4.3	Strategic Goal 3 – Supporting System-Wide Business Intelligence (Working Smarter rather than Harder)	67
B-4.4	Strategic Goal 4 – Supporting eGovernment and eEurope	72
B-4.5	Satisfying the Strategic Goals through the Enterprise ICT Services Domains	76
B5	The ICT Strategy - ICT Operations	85
B-5.1	Ensuring Strategic Intent Translates into Practical Applications on the Ground	85
B-5.2	Developing Capacity to Deliver	86
B-5.3	Operating on an Enterprise-Wide Basis	86
B-5.4	Co-Ordinating and Consolidating ICT Services	87
B-5.5	Ensuring Resilience in The ICT Environment	91
B-5.6	Phasing Major ICT Programmes	91
B-5.7	Procurement	92
B-5.8	Linking with Other Public Sector Efforts with Similar Objectives	93
B-6	The ICT Strategy - Investment	94
B-6.1	Improving Investment Levels	94
B-6.2	Identifying Alternative Financing Models	97
B-6.3	Improving Investment Appraisal and Benefits Realisation	98
B-7	The ICT Strategy - Technology	102
B-7.1	Enterprise Architecture	102
B-7.2	Migrating To Enterprise ICT Services	103
B-7.3	Technology Components	104
B-7.4	Scoping Out the Required ICT Policies and Standards	114
B-7.5	Logical Architectural Views to Facilitate Ongoing Discussion	115
B-8	The ICT Strategy - People	116
B-8.1	People as Members of the Public and as Patients	116
B-8.2	People Involved In Health System Delivery	116
B-8.3	People Involved In ICT Service Delivery	118
B-9	The ICT Strategy - Governance	121
B-9.1	Overview	121
B-9.2	Objectives of Governance	121
B-9.3	A Layered Governance Model	121
B-9.4	Current Models	122
B-9.5	The Governance Model Required	122
B-10	The ICT Strategy - Required Migration Arrangements	123

Part C – ICT Action Plan	124
Introduction	125
C-1 Summary Action Plan	126
C-1.1 Foundation Programmes	126
C-1.2 Development programmes	128
C-1.3 Operational Programmes	130
Summary Gantt Chart	133
Part D – ICT Policies and Standards	134
Introduction	135
Background	135
What are the Policies?	135
Why do we need Policies?	135
Why do we need Standards?	136
Initial Scope of Policies and Standards Efforts	137
Next Steps	137
Appendices	140
Appendix 1 – Membership and Terms of Reference	141
Appendix 2 – Project Phases	142
Appendix 3 – Targeted Consultations	143
Appendix 4 – The Changing Health Landscape	144
Appendix 5 – Logical Architectural Views	146
Bibliography	153

	Start	Finish
D-2.1 Foundation Programmes		
D-2.1.1 Governance & Structures		
Agree Governance mechanism	Dec-03	Dec-04
Establish Programme Management Office	Jan-04	Dec-04
D-2.1.2 Strategic Enables		
Communicate ICTS Strategy	Jan-04	Mar-04
Obtain Investment commitment	Jan-04	Dec-04
Develop Enterprise Architecture	Jan-04	Dec-05
Develop Structured Approaches	Jan-04	Dec-05
D-2.1.3 Policies & Standards		
Develop & Implement Policies & Standards	Jan-04	Dec-11
D-2.1.4 Infrastructure Development		
Design & Built ICT Infrastructure	Jan-04	Dec-07
D-2.2 Development Programmes		
D-2.2.1 Care Delivery Supports		
Define Electronic Care Records Services	Apr-04	Dec-05
Implement Patient Management Systems	Jan-04	Dec-07
Acquire & Implement Enterprise Lab System	Apr-04	Dec-06
Implement Health Identity Service	Apr-04	Dec-08
Implement Electronic Care Records Services	Apr-04	Dec-11
Define Acquire & Implement PCCC ICT Services	Oct-04	Dec-11
Define & Implement Health Support Agencies ICT Services	Oct-04	Dec-11
Define & Implement Communications Toolset	Jul-04	Dec-06
Define additional ICT Services for Hospitals	Jan-04	Dec-06
Design & Implement Clinical Decision Support Systems	Jan-04	Dec-09
Acquire & Implement additional Hospital ICT Services	Jan-04	Dec-11
D-2.2.2 Enterprise resource Planning		
Implement Human Resources Systems (PPARS)	Jan-04	Dec-07
Implement Financial & Materials Management Systems (FIS)	Mar-04	Dec-07
D-2.2.3 Business Intelligence		
Design & Implement Business Intelligence Systems	Jan-05	Dec-11
D-2.3 Operational Programmes		
D-2.3.1 ICT Operations		
Set up National Shared Services Centre	Jan-04	Dec-05
Develop ICT Contingency Plans	Jan-04	Dec-04
Develop & Implement Migration Strategy	Jan-04	Dec-07
ICT Staff Development Programme	Jan-04	Dec-11
Develop & Implement ICT Support Arrangements	Jan-04	Dec-11
D-2.3.2 Research and Monitoring		
Monitor the Implementation of "Quality & Fairness"	Jan-04	Dec-04
Develop set of investment related performance indicators	Jan-04	Dec-11
Establish ICT Research & development Framework	Jan-04	Dec-11
Research Enterprise Products and Services	Jan-05	Dec-11
Review project/programme funding each year	Jan-04	Dec-11
Monitor/review ICT Strategy implementation	Jan-04	Dec-11
D-2.3.3 Government		
Implement health-related e-Government Systems	Jan-04	Dec-07

Appendix 2: Integrated Services Framework

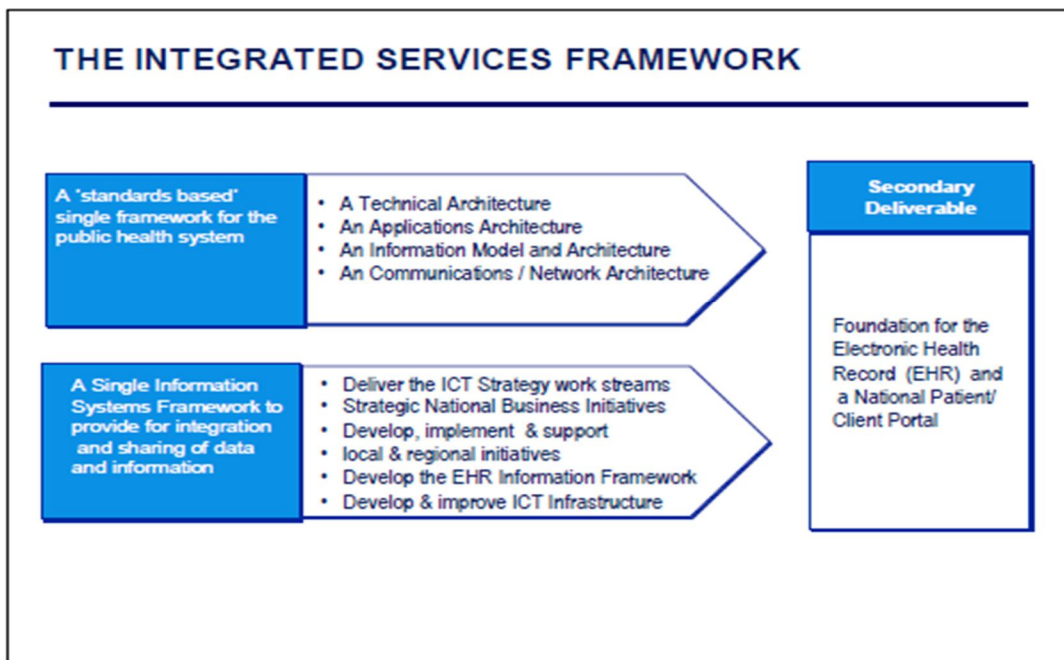
Source Connolly 2012

National Integrated Services Framework

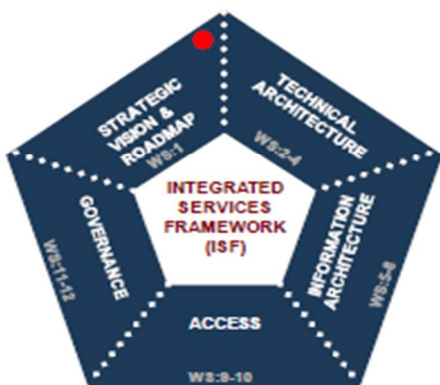
The Foundation for Future e-Health Connectivity



Peter Connolly Nov 2012



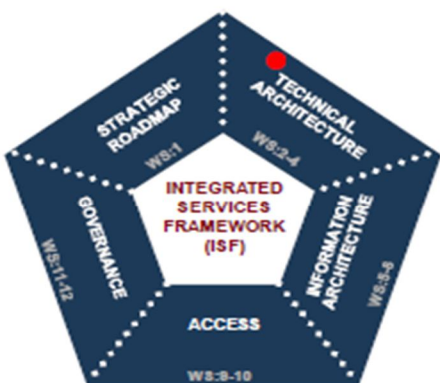
WORKSTREAM 1: VISION & STRATEGIC ROADMAP



□ Work-stream 1: ISF Vision & Roadmap

The conceptual and logical visualisation of the Integrated Services Framework. Sets the direction, purpose and rationale for the National ICT Integrated Services Framework (ISF). Articulates the principles and elements of standards based delivery platform. States the principles and best practices that should be applied. Outlines the approach, building on the shoulders of giants (ie the early adopters). Outlines the approach to collaboration and ongoing maintenance of the Integrated Services Framework.

WORKSTREAMS 2-4: TECHNICAL ARCHITECTURE



Work-stream 2: Technical Infrastructure

□ An overview and developmental roadmap for the standards based referential technology framework. It will provide overarching guidance on the identification and selection of compatible technical platforms and focuses on higher level standardisation and integration parameters of the model.

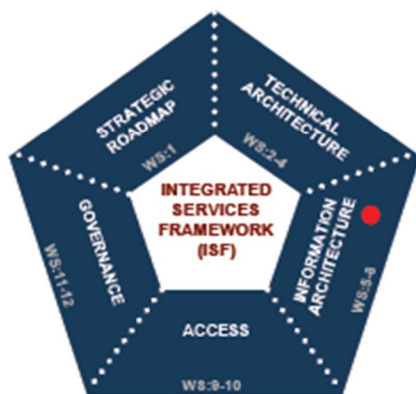
□ Work-stream 3: Applications reference Base

A referential portfolio of software applications and the associated standards for enabling integration of services. It will embrace both commercial and in-house software applications within its scope along with specification for maintenance standards.

□ Work-stream 4: Integrated Systems Management Framework

The portfolio management arrangements for components and their associations within the Framework. It will provide governance over Framework components which may be affected by the revision or modification to adopted assets or standards.

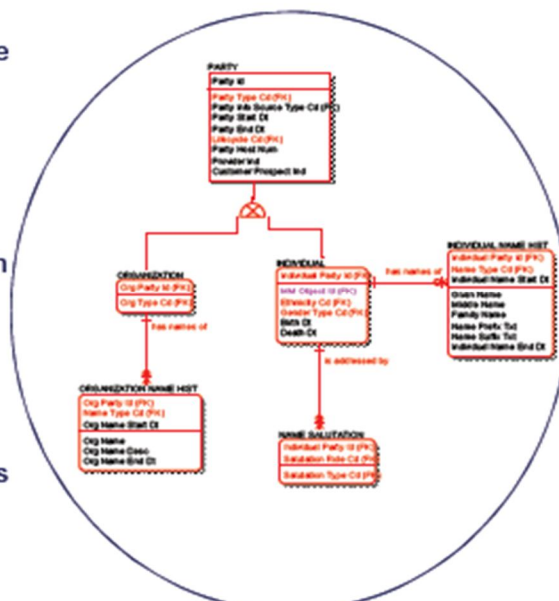
WS:5-8 INFORMATION ARCHITECTURE



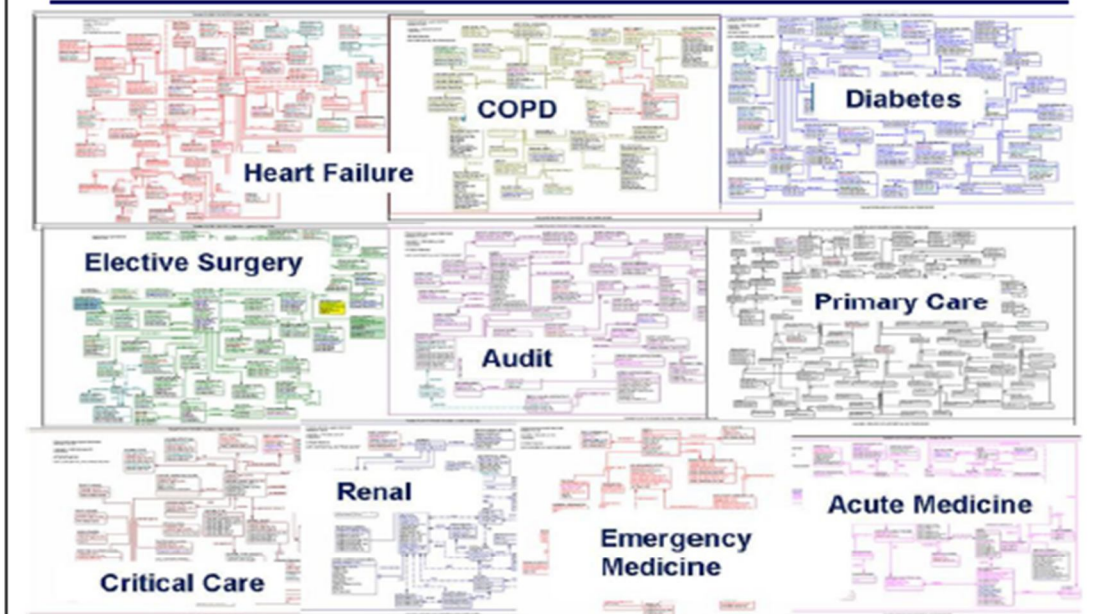
- **Work-stream 5: High Level Business Process Specification** A consolidated 'high-level' oversight of core business processes, architecture and associated data. Its outputs will include specification of data file types, data mapping and exchange formats.
- **Work-stream 6: Information Architecture Model** Specification of a best practice 'Information Architectural Model'. It will take into consideration current information constructs, along with the assimilation of best practices and models from other healthcare jurisdictions.
- **Work-stream 7: Data & Information Repository** The objective of this work stream is to define the current data and information repository assets and to establish an aligned 'standards based' data repository structure.
- **Work-stream 8: Transformation, Interfacing & Sourcing** To define the data transformation mapping and communication services required for linking source data applications to user interfaces. This will be done in harmony with the roadmap of E-HR components specified in workstream-1.

DATA MODEL

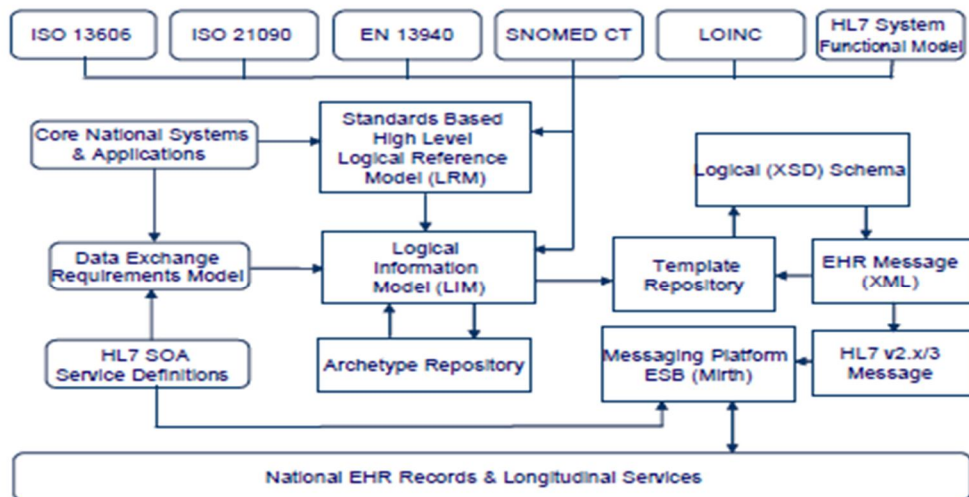
- A visual business representation of how data is organised within the enterprise
- It facilitates communication within the business (e.g. within ICT and the business)
- Identifies those things about which it is important to track information (entities)
- Facts about those things (attributes)
- Associations between those things (relationships)



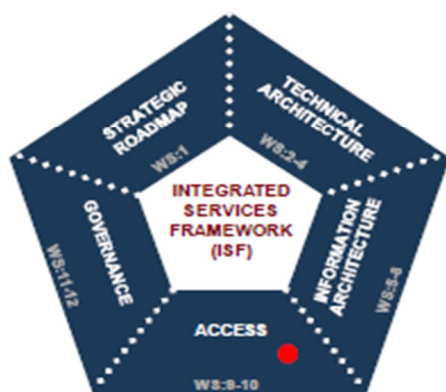
DATA MODEL FOR CLINICAL PROGRAMMES



LOGICAL INFORMATION REFERENCE MODEL

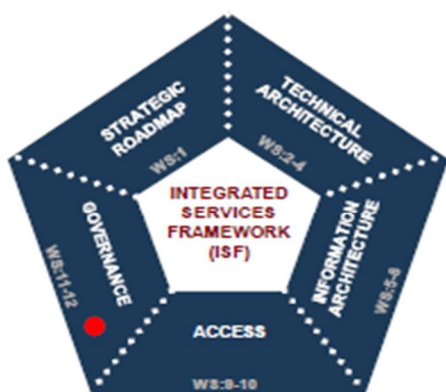


WS:9-10 ACCESS



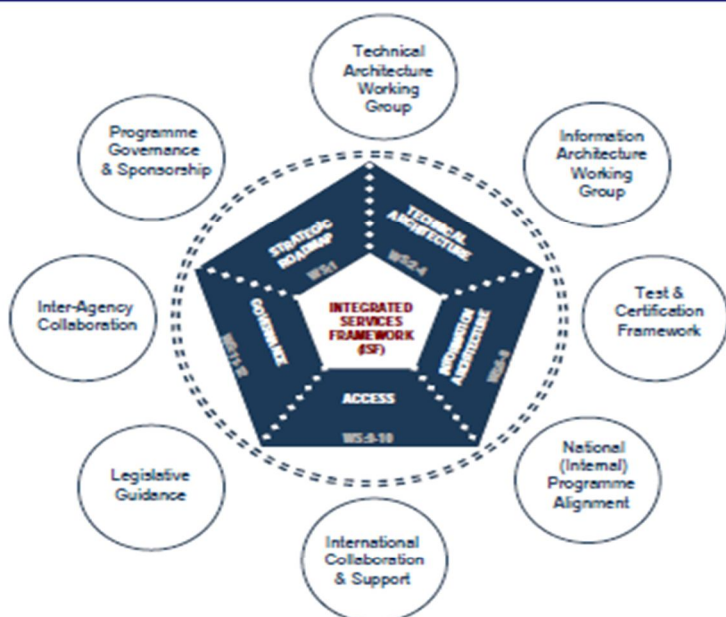
- Work-stream 9: , Access & Consent Management**
To establish a standards base for the Identity & Access Management (IAM) component of the Framework, including the baseline orchestration and conformance parameters to accommodate the capture and management of consent within the Integrated Services Framework.
- Work-stream 10: EHR Portal & Presentation**
The objective of this work-stream is the high level specification of the architecture and integration standards required for the portal and presentation domains for a future EHR, within the construct of the ISF Framework.

WS:11-12 GOVERNANCE

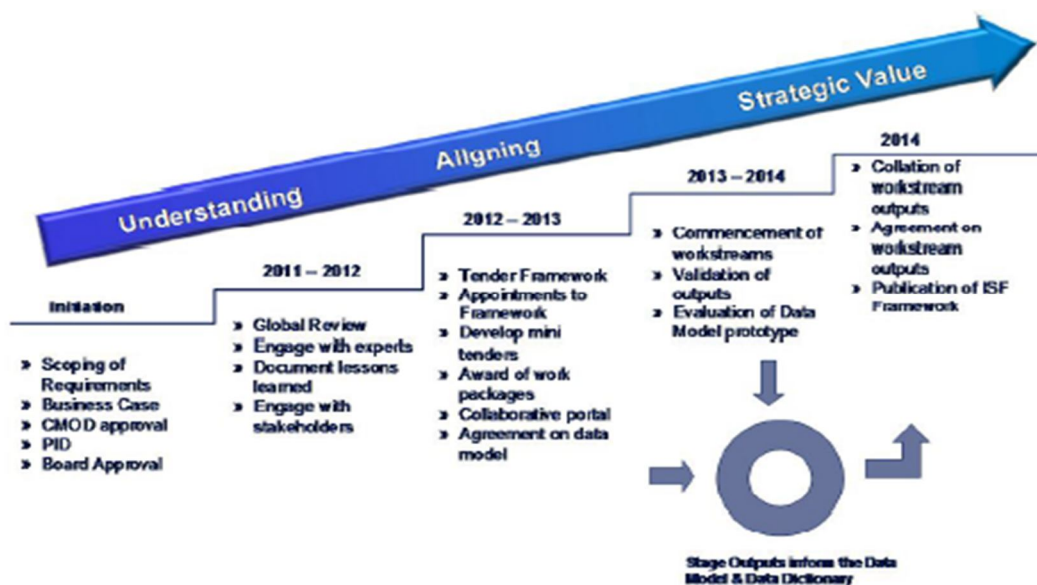


- Work-stream 11: Architecture Documentation**
To establish the criteria and architectural specification for the Integrated Services Framework's document repository, and also its associated management system. This includes storage, indexing, versioning, search, and retrieval of the inventory of material associated with the Framework.
- Work-stream 12: Governance Model**
Being a dynamic platform, this workstream will define the appropriate oversight and direction to ensure all stakeholders have representation and can contribute both to the delivery and maintenance of integrated service value, and to its long term strategic road map.

COLLABORATION



PROGRAMME



Appendix 3: Interview Guide

The following are the questions that were used as a guide during the interviews.

I would like you to think about the collection, handling and use of data and information as it impacts on your role.

- Please describe what this means to you.
- What has been your experience in relation to data /information sharing?
- From your own work point of view how do you engage in or influence data/information sharing?
- What does the term interoperability mean to you?
- What factors do you think need to be in place to progress interoperability?
- What, in your opinion, are the current barriers to interoperability in the HSE?
- Does the reorganisation of the health services which is underway present an opportunity to progress factors that are required for interoperability?
- If you were in charge in the morning what steps would you take to progress interoperability?

Appendix 4: Summary of Assessment of PPSN as a Suitable Health Identifier

Extract from 'Recommendations for a Unique Identifier for Individuals in Ireland' (HIQA 2011)

Being able to identify an individual uniquely is essential for patient safety in the provision and management of high quality healthcare.

The National Health Information Strategy (NHIS) states that a system for unique identification within the health sector is required to promote the quality and safety of client/patient care. The NHIS proposed that unique identification within the health sector be based on the Personal Public Service (PPS) Number⁽¹⁾. *Building a Culture of Patient Safety: Report of the Commission of Patient Safety and Quality Assurance* (2008) also recommends the introduction of a unique health identifier (UHI) highlighting the contribution it could make to improved patient safety and quality⁽²⁾. The forthcoming Health Information Bill will allow for the introduction of a UHI⁽³⁾.

A method for unique identification, as well as a governance framework to support unique identification, is needed. The approach adopted must be able to bridge the primary, secondary and tertiary care domains, including the public, private and voluntary sectors, and must be able to support the shared care of clients/patients irrespective of the locations of service. This deficit required public debate, which was addressed substantially through the consultation processes of the forthcoming Health Information Bill. The challenge is to select an identifier scheme that achieves an appropriate balance in relation to practicality, cost and privacy.

The purpose of this document is to examine the information available, both nationally and internationally, in order to make recommendations to the Minister for Health and Children in relation to the introduction of a UHI for

individuals and to inform decision making for the forthcoming Health Information Bill.

The work has been undertaken in two stages. The first stage explored the advantages of a UHI, covering the public, private and voluntary sectors, and the identification of the criteria according to which a decision on the nature of a UHI should be made. The second stage presents a set of alternative proposals for the UHI and its introduction, evaluated according to the agreed criteria, with a view to making a set of recommendations.

There are 32 criteria which are based on the 30 criteria set by the American Society for Testing and Materials. These were agreed following consultation with a broad range of stakeholders. They are divided into 'fundamental criteria' and 'differentiating criteria'. The fundamental criteria are the primary criteria that any potential UHI must satisfy. Any potential UHI that fails to satisfy any of the fundamental criteria is deemed unsuitable for use as a UHI in Ireland. The potential UHIs that met the fundamental requirements were then assessed against the differentiating criteria to allow for the emergence of the most suitable option for selection.

Using the criteria agreed in stage-one (see Appendix 1), the next step was to determine the suitability of a number of potential UHIs against these criteria. The following numbers were tested against the criteria

- PPS Number

- Enhanced PPS Number

- A new UHI

- Medical card number

- Drug Payment Scheme number

- Birth notification number
- European Health Insurance number
- Passport number
- Driving licence number

The current PPS Number was assessed against these criteria and failed to meet eight of the fundamental criteria as listed below. Therefore, the PPS Number was eliminated from further evaluation.

The current PPS Number failed on the following criteria:

1. Accessible. A UHI system should be available at all times to all healthcare providers for the purposes of registration and positive identification of individuals. The Central Records System (CRS) which operates the current PPS Number system is not available 24 hours a day.
2. Assignable. It should be possible to assign a UHI to an individual whenever it is needed. It takes three to five days to assign a new PPS Number and this can only be done by one of the 53 social welfare offices, and this function will soon be restricted to just one office per county.
3. Content-free. The structure and elements of the UHI should not contain any information about the individual. Currently there are approximately 200,000 older PPS numbers in which husband and wife share the same number with the letter “w” appended to the number in the case of the woman.
4. Healthcare-focused. A UHI should be created and used solely for the purposes of delivering health (and social) care. The PPS Number is not healthcare-focused having been created and primarily used to access various services across the Irish public sector.

5. Legislation. The legal framework must be in place to permit the use of the UHI in healthcare. Current legislation specifically forbids the use of the PPS Number for health and social care purposes.

6. Standards-based. A UHI should be based on international or industry standards. The PPS Number itself is not designed to act as a unique identifier, rather it is a personal number for use in accessing public services. It was not designed in line with international best practice for identifiers.

7. Atomic. A UHI should be a single data item and should not contain any elements which can be decomposed to provide any meaningful information. As noted above, approximately 200,000 of the current PPS numbers include a “w” indicating a married woman, although these are being phased out.

8. Universal. There should be sufficient capacity to be able to generate new numbers as required into the foreseeable future. Based on the current average issue rate, the remaining PPS Numbers available will run out by 2012, although plans are being put in place to extend the number.

The analysis presented in this document shows that, far from saving money, the use of the current PPS Number would not only fail to deliver the benefits of a UHI but could, in the longer term, lead to increased costs. Also, the use of the PPS Number without the appropriate infrastructure will result in an unsafe system leading to increased risk of misidentification which will impact negatively on patient safety.