

# Implementing an Individual Health Identifier in Ireland

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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.

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# Summary

Currently in Ireland there is no national individual health identifier (IHI) for health and social care, although it is widely accepted that there is an imperative for the introduction of an IHI. In order to uniquely identify individuals for health and social care a unique number, associated dataset and a system to manage the number and dataset are required.

In order for the benefits of an IHI to be achieved, it is vital that the infrastructure to support it is in place in terms of independent regulatory oversight, strategic oversight, business processes and technical capability.

#### **Objectives:**

- To provide an overview of the benefits of introducing an IHI and the current risks existing in the absence of an IHI.
- To carry out an international review of IHIs and assess the properties of each against an international standard.
- To propose a workable model for the IHI in Ireland based on the international review and the capabilities of current health information systems in Ireland.
- To propose a standard for electronic messages to allow interoperability between a national IHI system and local health information systems.

#### Main findings:

- The best IHI model for adaptation is the Australian model, which is a new number for exclusive use in health and social care.
- The IHI can leverage and build on existing infrastructure including the use of the Public Services Database operated by the Department of Social

Protection and the National Client Index operated by the Primary Care Reimbursement Service to initially populate the new IHI system

- HL7 v2.x is the most suitable healthcare messaging standard to facilitate information exchange between local health information systems and a national IHI system
- A Privacy Impact Assessment is required at the planning stage to inform the development of the IHI and ensure information governance controls are in place.

#### **Conclusion:**

There is a need for an in depth audit of local health information systems nationwide in order to fully ascertain the effort required in order to facilitate implementation of an integrated IHI system in Ireland. Business processes and governance rules for the operation of the IHI must be fully defined and a complete training needs analysis conducted to establish a more accurate financial estimate of the cost of the introduction of an IHI and also an appropriate timeframe for implementation.

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# **Chapter 1 – Introduction**

This chapter introduces the research topic of this dissertation, discussing the motivation, scope and process involved in order to comprehensively address the research question and arrive at a reasonable, practicable and feasible conclusion. A basic outline of the structure of the dissertation is also provided to aid readability.

#### 1.1 Introduction – Research area

The research area of this dissertation is the unique identification of individuals to facilitate the delivery of health and social care in Ireland. An Individual Health Identifier (IHI) can be defined as the designation permanently assigned to an individual for the purpose of identification to facilitate the provision of health and social care<sup>(1)</sup>. Currently in Ireland there is no national method to identify individuals for health and social care. In order to uniquely identify individuals for health and dataset are required. Throughout this dissertation, the terms healthcare, Individual Health Identifier and any discussion around the provision and delivery of healthcare refer to both health and personal social care.

The purpose of this research is to demonstrate the need for and benefits of an IHI and put forward a workable model for Irish health and social care based on knowledge gained from international sources and expertise on health identifiers. This model should be functional in the context of local systems in primary, secondary, tertiary and allied health across the continuum of public and private health and social care.

#### 1.2 Research Question

The research question is:

What type of individual health identifier would be most appropriate for health and social care in Ireland and what standard electronic messages would be required to support the use of the identifier?

## 1.3 Scope

This research focuses on the identification of individuals in the provision of personal health and social care and the elucidation and evaluation of international models to support authenticated and validated identification. The evaluation is undertaken with the needs of the Irish healthcare sector in terms of introducing an IHI so that a workable model may be proposed.

## **1.4** Motivation and value of the research

The need for and benefits that can be gained from the implementation of a robust individual health identifier (IHI) to facilitate the safe and efficient delivery of health and social care have been documented well in the past two decades. These benefits which are discussed in chapter 2 include:

- Improvements to patient safety<sup>(2)</sup>
- Reduced administrative costs<sup>(3)</sup>
- Enhanced access to epidemiological data<sup>(4)</sup>
- Reductions in unnecessary and repetitive care<sup>(5)</sup>
- Improvements to shared care initiatives<sup>(6;7)</sup>
- Facilitating development of other initiatives such as e-prescribing and electronic health records<sup>(6)</sup>.

Similarly, international evidence has shown that the absence of a unique identifier for health and social care results in preventable adverse events including:

- Medication and procedural errors made through misidentification of individuals<sup>(2)</sup>
- Duplication of testing<sup>(5;8)</sup>
- Mismatching of healthcare records and of episodes of care to individuals<sup>(2)</sup>.

It appears that almost all developed countries either have or are planning to introduce an IHI, for example, Sweden has had an IHI for several years in the form of a national identity number which is used for healthcare<sup>(9)</sup> and Australia has just recently introduced an IHI in 2010. Despite the proven benefits, it still remains for Ireland to implement an IHI in Irish health and social care services. This fact may be attributable to a number of factors such as the current economic climate, the disparity and lack of standardisation of electronic and manual systems in place across the health and social care spectrum, conflicting priorities at policy level and difficulties associated with change management at a local and national level. However, the biggest factor is probably the constant focus on front line issues such as waiting times, emergency department trolleys, major hospital enquiries and the closing of small hospitals. The IHI is not an emotive issue and has therefore not received significant attention from the media in Ireland. Given that the National Health Information Strategy (NHIS)<sup>(4)</sup>, which was one of the first major national strategies to propose the introduction of an IHI, was published in 2004 at the height of the Celtic Tiger economic boom, it is also likely that development of the IHI was delayed by disagreement over whether the Personal Public Services Number (PPS) should become the IHI. Finally, the cost of introducing an IHI in Ireland, as in other countries, is difficult to quantify given the absence of a national inventory of health information systems and their interoperability capabilities and the resultant difficulty in calculating change management requirements. This ensures that any business case for the introduction of an IHI will be complex with cost estimates likely to be imprecise.

At a national level, the introduction of an IHI formed part of the NHIS 2004<sup>(4)</sup> and is expected to be given a legislative basis in the forthcoming Health Information Bill<sup>(10)</sup>. International experience demonstrates the benefits realised by introducing an IHI and provides the opportunity for this research to utilise successful aspects of these implementations and develop these in the context of the Irish health and social care system.

### 1.5 Methodology and plan

This research requires the gathering, evaluation and analysis of qualitative data relating to IHI models in place internationally and a view of identifiers in Ireland and of local systems in health and social care. The methodology used to collect the required data for the research is an evaluative and ethnographic case study. The collected data is measured against international standard properties in order to find the most suitable model for adaptation to the Irish context. The methodology and research design is detailed in Chapter 3.

### **1.6** Data to be collected

For the international review section (Chapter 4) of this research it is necessary to select appropriate countries to inform the research. The main criterion for inclusion of a country is that there must be a national health identifier in place or planned. Furthermore, due to language constraints, it is necessary to exclude countries where English is not the primary language.

Each international case study includes:

- Documentation of the structure of the health and social care system insofar as this affects the choice and implementation of an IHI.
- Documentation of the type of identification system in place.
- Gathering of any evidence of successes and failures associated with the IHI.

For the second section of this research (Chapter 5), it is necessary to review the health information system landscape and the national identifiers currently used in Ireland. Current identification practices and systems will help to inform the development of an appropriate model for an IHI, taking into account the level of change management required for successful implementation.

This section will include:

- Documentation of current identity management practices in the health and social care setting.
- Documentation of research undertaken by the author on national identifiers currently in use in Ireland.
- Documentation of readiness of local systems in terms of ability to interoperate with a national identity management solution.

The data have been gathered through use of both peer reviewed and grey literature where available. Government organisations with involvement in the planning, implementation and management of the IHI internationally have been targeted for the majority of the international component of this research.

#### 1.7 Analysis of data and results

The data gathered is used to compare and contrast health systems internationally with the Irish health and social care system. Ability to meet international standard requirements criteria, complexity, size, ease of implementation, user acceptance and usability are all factors that will be analysed in Chapter 6 to inform the development or adaptation of a feasible IHI model. In Chapter 7, a method for local health information systems to communicate or interoperate with the IHI model is discussed based on the capabilities of local systems and best available international evidence. Finally, Chapter 8 concludes this research, summarising important points, limitations and discussing areas of work for further progression of the IHI.

## Chapter 2 – The Case for an Individual Health Identifier

#### 2.1 Introduction

This chapter provides information on the benefits that can be gained both directly and indirectly from the introduction of an IHI. Peer reviewed literature has been consulted where available to elaborate on the value of implementing an IHI. The author has found that the benefits gained directly from implementing an IHI are difficult to separate from the downstream benefits enabled by introducing an IHI, therefore the IHI as an enabler to other ehealth initiatives is discussed together with the direct benefits of the IHI. The risks and costs attributable to not implementing an IHI are also discussed. Finally, an overview of Irish national policy on the need for an IHI is provided.

#### 2.2 IHI Benefits

Introducing an IHI can enable a number of improvements in healthcare in terms of care delivery, patient safety, quality and timeliness of care. There are also a number of systematic benefits that can be gained such as access to rich data for epidemiology, streamlining of healthcare records, interoperability and opportunities to assess the health sector as a whole.

Positive, accurate identification is vital to the delivery of safe care. Mistaken identity can lead to treatment administration to the wrong individual<sup>(11)</sup>. Shared care initiatives such as General Practitioner (GP) and hospital management of chronic diseases that require long term management rely on accurate identification of individuals, where health information is regularly communicated between organisations. The IHI can greatly reduce the risk of the wrong information being associated with an individual if the same identifier is used universally across both public and private health and social care<sup>(11)</sup>. By facilitating sharing of health

information, the availability of an IHI can also reduce the number of unnecessary tests and investigations by making sure that all care providers have access to up to date and complete information about the patient<sup>(5;8)</sup>. Furthermore, health information is expensive to collect and the availability of an IHI greatly facilitates the potential for information to be reused, reducing the cost of service delivery and also facilitating planning, monitoring and control of information<sup>(3)</sup>.

In emergency situations, time is a critical factor in the success of treatment. The availability of healthcare records when they are required is essential to treatment decisions. The IHI can improve the likelihood of the correct healthcare record being available at the time it is needed by ensuring that all healthcare records that exist across different organisations for an individual are identified by the same number, the IHI<sup>(2)</sup>. In addition, the implementation of an IHI can enable healthcare records to be linked electronically by providing an associated dataset that varying health information systems can process and use<sup>(7)</sup>. Currently in Ireland, demographic information is gathered and recorded according to the structure of the data fields of any particular health information system, for example a date of birth may be recorded in a number of ways such as dd/mm/yy or dd/mm/yyyy<sup>(12)</sup>. This can make the electronic linkage of healthcare records or interoperability between health information systems very difficult. By facilitating the linkage of healthcare records electronically, the IHI provides a foundation for the development of electronic health records (EHRs) which would provide a complete account of the health of an individual across organisational boundaries<sup>(13)</sup>. From an epidemiological perspective, the linkage of healthcare records would provide a rich source of information over time, benefitting researchers in terms of data guality and thus the usefulness of epidemiological research to population health<sup>(7;10)</sup>. Research activities and trends would be greatly enhanced by linked longitudinal information about individuals. The importance of interoperability to the implementation of the IHI is discussed further in Chapter 7.

In large hospitals it is usual for an individual to have more than one identifier, each assigned by different hospital departments for example, radiology departments, laboratories and hospital pharmacies often assign their own identifier that is not the same as the main healthcare record number<sup>(10)</sup>. Manual processes allow for these records to be matched, however, these are inefficient and often require a large human effort on the part of healthcare records staff resulting in preventable delays to healthcare delivery. The IHI can enable more efficient management of healthcare records by administrative staff, ensuring all parts of a healthcare record such as blood test results and x-ray reports display the IHI<sup>(14)</sup>. This in turn can provide financial benefits for an organisation due to efficiencies gained.

The cost associated with healthcare registration staff can also be significantly reduced as each organisation would have access to a central IHI database with accurate identifying information, reducing the time and effort required for individual registration<sup>(3;15)</sup>.

The IHI is an essential foundational requirement to the realisation of many other ehealth initiatives such as the EHR and the electronic transfer of prescriptions (ETP) or eprescribing<sup>(16)</sup>. Even so, the IHI on its own can greatly enhance the timeliness, quality and safety of care by reducing adverse events due to identification errors.

#### 2.3 Summary of Benefits

While there is general agreement internationally of the benefits of an IHI, there is also recognition of the potential for increased risks to ensuring the confidentiality of patient data. It is for this reason that an essential element of any proposal for the introduction of an IHI is a robust information governance framework which establishes clearly the rules and policies governing information integration and sharing and puts in place an appropriate system for managing consent. This could

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actually serve to improve current practices around privacy and confidentiality by promoting a uniform approach to information governance across all health and social care providers. Information governance issues and the IHI are expected to form an important part of the forthcoming Health Information Bill<sup>(10;17)</sup>.

In summary, there are significant benefits of an IHI both to individual and healthcare providers in that it facilitates improvements to patient safety, quality of care, administrative efficiency and healthcare research. In the absence of an IHI, healthcare records are more likely to be incomplete or mismatched which may lead to medical error, duplicate testing, repetition of registration and unnecessary costs.

#### 2.4 Risks and costs associated with not implementing an IHI

The benefits of an IHI are well documented, however, identifying the risks or costs associated with not implementing an IHI is more difficult to isolate and measure, both from a patient safety and a financial perspective. The aim of this section is to highlight the risks and associated costs of this approach and compare these to the cost of implementing an IHI taking into account the cost savings that can result following the successful implementation of an IHI.

As mentioned previously, poor identification practices can lead to the occurrence of adverse events. This demonstrates the importance of ensuring that personal health information is available at the point of care and that it accompanies the individual at each healthcare episode, when and where it is required. Without an IHI, this is exceedingly difficult to ensure.

There are a number of risks to patient safety that have been identified across many healthcare systems worldwide that can be attributed to the absence of an IHI. Some known risks are detailed here, together with evidence from a number of countries of adverse events that have occurred as a result of misidentification of patients. It is difficult to ascertain the annual cost of patient identification errors, however, some attempts at costing these adverse events have been attempted and these examples are also detailed and discussed below.

There is significant cost involved in implementing the IHI, however, the cost savings that can be made after successful implementation are arguably significantly more. It is, again, very difficult to quantify these amounts, but there are pieces of evidence from international sources which demonstrate high cost benefits of implementing an IHI:

In 2001, research was undertaken to ascertain how misidentification of individuals in healthcare most commonly occurs<sup>(11)</sup>. This research found that there are three types of adverse caused by errors in identification:

- The individual is incorrectly associated with test samples from another individual and misdiagnosis or provision of the wrong treatment can occur.
- Administration errors are made at the point of registration or identification information is communicated incorrectly resulting in the individual being associated with the wrong healthcare record.
- The wrong medication or procedure is administered to an individual due to a failure to follow robust identification procedures at the point of care<sup>(11)</sup>.

The research concluded that a reduction in adverse events caused by misidentification of individuals is vital to improving the safety of individuals receiving care from the National Health Service (NHS)<sup>(11)</sup>. In 2004, the National Patient Safety Agency (NPSA) in the United Kingdom (UK) published a report on individual identification practices across the NHS<sup>(2)</sup>. This report provides background information on the types and causes of identification errors that occur and informed the publication of subsequent safer practice notices (SPNs) released by the NPSA in an attempt to reduce the number of errors caused by misidentification. The report states that between 2006 and 2008, 1300 reports of incidents caused by identification errors were notified to the

National Reporting and Learning Service. The report also found that although it is difficult to accurately quantify the total number of adverse events that can be attributed to poor identification practice, it is likely to be high based on audits that demonstrated that up to 34% of inpatients in a large hospital did not have an identifying wristband<sup>(2)</sup>. The report also details two case studies commissioned by the NPSA on identification practices, one on manual practice and another on the use of technology to aid positive identification. The purpose of these reports was to ascertain which method is most reliable. The NPSA have concluded that the use of technology and in particular radio frequency identification (RFID) tags would greatly benefit safer identification of individuals. While it is recognised that the use of RFID would carry a significant cost, it is likely that the costs savings gained through efficiencies and a reduction in adverse events would be greater<sup>(2)</sup>.

It is estimated that an adverse event occurs in 10% of admissions cases each year in the UK equating to approximately 850,000 adverse events. The cost associated with these events is approximately £2 (€2.5) billion per annum. Of these, the Department of Health has stated that half are preventable. Given that the NPSA has found that a significant number of adverse events are caused by poor identification practices in healthcare, it is likely that implementation of a robust, secure and well governed system supporting a universally used IHI can achieve savings in this area<sup>(18)</sup>.

Furthermore, a report by the National Audit Commission found that in 2004, 180,000 NHS healthcare records were duplicated resulting in payment errors that represented a cost to the NHS of £2.7 (€3.4) million. An undertaking to remove duplicate errors from the system in 2004 following a similar audit was estimated to have saved the NHS £9.5 (€12) million by allowing the removal of 1.5 million individual registrations completed in error<sup>(8)</sup>. The exercise involved the examination of patient registrations to ascertain if any individuals had been registered more than once and were thus recorded more than once in NHS systems. Besides the

considerable cost, duplicate registrations pose a serious threat to patient safety as only parts of an individual's personal health information are associated with either healthcare record created for each registration. The project allowed for these duplicate registrations to be removed from NHS systems and associated healthcare information merged into a single healthcare record<sup>(8)</sup>. This in turn reduced risks to patient safety by allowing GP's to have access to the full medical records of their patients and by providing intelligence to National Health Applications and Infrastructure Services (NHAIS) that has led to significant improvement in the quality of patient registration data held<sup>(5;8)</sup>.

The risks and costs outlined above are all evidenced in the UK where the NHS number is currently used as an IHI. The full adoption of the NHS number nationally has only really taken place in more recent years as reports like those already mentioned highlighted to healthcare trusts, the importance of integrating the NHS number into all of their systems. It is interesting to note that the National Audit Commission carried out another exercise in 2009 and 2010 to assess the number of duplicates in the NHS systems and the numbers of duplicate registrations found were reduced by almost half to 95,000 since the 2006 report<sup>(5)</sup>. This is likely due to stronger identification practices and wider adoption of the NHS Number.

The situation in Ireland where correct patient identification relies on isolated local point of care registration in countless formats, in the absence of any standardised cross location patient identity validation, points to an even greater potential for the occurrence of duplication errors and adverse events. Consequentially, the number and cost of adverse events attributable to misidentification in Irish health and social care is probably proportionately higher. This is probably compounded by the public, private healthcare mix present in Ireland and also current Data Protection legislation, which makes the linking of personal health records across the public and private divide difficult<sup>(19-21)</sup>. Legislating for the IHI use across both sectors in

the form of the forthcoming Health Information Bill can resolve this issue to a great extent<sup>(10;17)</sup>.

The Research and Development (RAND) Corporation in the United States of America (USA) undertook two major pieces of research in 2005 and 2008 relating to the IHI<sup>(3;15)</sup>. The former research sought to establish whether the costs associated with introducing health information technology (health IT) initiatives could be justified in terms of savings enabled by those initiatives. The research concluded that savings gained following the introduction of health IT are typically five times the cost of introducing that health IT<sup>(15)</sup>. The latter research focused specifically on the introduction of the IHI and sought to examine the costs and benefits associated with introducing an IHI in the USA healthcare system<sup>(3)</sup>. This research found that the benefits that could be gained financially and in terms of patient safety are significantly higher than the cost of implementation of an IHI as the following estimates from this research illustrate:

- Estimated cost of implementing IHI in the USA = \$1.5 (€1.2) to \$11.1 (€9)
  billion
- Annual potential saving due to a reduction in duplicate testing = \$4 (3.2) billion
- Annual saving due to avoidance of adverse events from to medication errors
  = \$4.5 (€3.7) billion<sup>(3)</sup>

These estimates show that even at the highest cost estimate for implementation, the IHI is likely to pay for itself within less than 2 years of operation. The financial benefits are in addition to the improvements gained in terms of patient safety, efficiency of service and the capability of the IHI to enable other initiatives such as the EHR.

#### 2.5 National Policy

Over the past number of years, the introduction of an IHI in Ireland has been increasingly recommended in policy as vital to improvements in quality and safety of care in national strategies and reports such as "*Quality and Fairness: A Health System for You*" <sup>(22)</sup> in 2001, "Building a Culture of Patient Safety: Report of the Commission of Patient Safety and Quality Assurance"<sup>(23)</sup>, 2008 and the 1999 report, "*Building Healthier Hearts - Introduction to the Report of the Cardiovascular Health Strategy Group*<sup>424</sup>.

In 2004, "*Health Information: A National Strategy*"<sup>(4)</sup>(NHIS) mandated the introduction of an IHI and that the PPS number forms the basis of the IHI. Since then, it has become evident that the PPS number is not a suitable candidate IHI and this has been evidenced in the Health Information and Quality Authority's publication "*Recommendations for a Unique Health Identifier for Individuals in Ireland*"<sup>(1)</sup> in 2009. The author of this research was lead author of the report. The Health Information and Quality Authority found that in order for the benefits of the IHI to be realised, a healthcare focused IHI that spans all levels and domains of public and private health and social care, supporting system and robust governance arrangements are necessary. The structure and features of the IHI should be based on international standards and best available international evidence from other jurisdictions that have implemented an IHI.

The Health Information Bill due to be published before the end of 2012 will legislate for the introduction of an  $IHI^{(10;17)}$ .

# Chapter 3 – Research Design/Methodology

### 3.1 Introduction

This aim of this chapter is to outline the research methodology and tools used in order to achieve the desired outcome of the research; i.e. the proposal of a feasible IHI for health and social care in Ireland. This research required the gathering, evaluation and analysis of qualitative data relating to IHI models in place internationally and of national and local systems used in Ireland for identifying individuals. The methodology proposed to collect the required data for both parts of the research is an evaluative and ethnographic case study. Each IHI model is then measured against an appropriate international standard for identification in order to provide a robust method to evaluate each model and thus, inform the result.

## 3.2 Data to be collected

For the international section of this research it was necessary to select appropriate countries to inform the research. The main criterion for acceptance of a country as suitable for the purposes of this research is that there must be a national identifier in place which is used to identify individuals in healthcare and information about the identifier is available.

Each international case study includes:

- An overview of the structure of the health and social care system.
- Documentation of the type of health identifier in place.

For the second section of this research, it is necessary to study and gather information about local identity management practices in health and social care in Ireland.

This study includes:

- Documentation of current identity management practices in the health and social care setting.
- Documentation of readiness of local systems in terms of ability to interoperate with a national identity management solution.

#### 3.3 Data collection

Data have been gathered through use of published and unpublished information where available. Many of the government agencies responsible for implementing or managing the IHI have published detailed information on the planning, organisation and specification of the IHI. A search of government health websites and published peer reviewed literature was undertaken using terms common to identity management.

The second component of the research involved the use of vendor information on health information systems used in Ireland in primary and secondary care. Data was also collected from the Health Service Executive (HSE) Health Intelligence Unit and from research undertaken by the project team of the national Picture Archive Communication System (PACS) known as the National Integrated Medical Imaging System (NIMIS)<sup>(25)</sup>.

#### 3.4 Analysis of data

The data gathered was used to compare and contrast health systems internationally with the Irish health and social care system. Cost, complexity, size, ease of implementation, user acceptance and usability are all factors that were analysed to inform the development or adaptation of a feasible IHI model. A search has found four international standards and specifications for identification that could be applied to the selection of a suitable IHI for Ireland. These are:

 The American National Standards Institute (ANSI) approved International Standards Organisation (ISO) standard for object identifiers (OIDs)<sup>(26)</sup>.

- The *Person Identification Service Specification* (PIDS) developed by the Object Management Group (OMG)<sup>(27)</sup>.
- The ISO technical specification, ISO TS 22220 Health Informatics Identification of Subjects of Healthcare<sup>(28)</sup>.
- Standard E1714-07, the *Standard Guide for the Properties of a Unique Health Identifier* developed by the American Society for Testing and Materials (ASTM International)<sup>(29)</sup>.

# International Standards Organisation (ISO) standard for object identifiers (OIDs)

The OID consists of a numeric assigned to an object based on a hierarchical system of numbering. This means that identifiers for the issuing body, registration body and possibly organisation and provider numeric information would be included in the individual identifier, creating a potentially very lengthy number that is structured for machine readability rather than manual processing. Although the OID could be used to identify individuals, the OID standard does not specify properties for the unique identification of individuals as it is designed to identify objects rather than people<sup>(26)</sup>. For this reason and due to the complexity of this standard for identification and the fact that the IHI would become unmanageably long for manual human use, the author has discounted this standard as suitable for identification of individuals.

# The Personal Identification Service Specification (PIDS) developed by the Object Management Group (OMG)

The OMG are an international organisation with approximately 800 members including software developers, vendors and users. The PIDS was developed in order to facilitate an industry standard for developers to assist in ensuring interoperability of systems through use of standardised method of individual identification. The specification supports the continued use of local identifiers while providing a standard method for systems to interface, allowing the matching of identity data across organisational boundaries<sup>(27)</sup>. The specification does not, however, detail the format the IHI should take, therefore it is not possible to assess international identifiers already in place against the specification. Although there are aspects of this specification that may be useful to aid the development of an IHI for Ireland, for the purposes of this research in evaluating health identifiers in place internationally, this standard specification does not provide measurable properties for a national IHI and so is not suitable for this study.

# ISO technical specification, ISO TS 22220 Health Informatics – Identification of Subjects of Healthcare

The ISO are an international organisation comprising member states with responsibility for developing and approving standards across many industries, including healthcare. The ISO developed a technical specification in relation to the identification of individuals or subjects of healthcare. The specification is limited to detailing the data elements required to accurately identify an individual rather than the attributes and properties the identifier and its associated infrastructure should possess. The specification actually recommends the use of the ASTM properties detailed below, for developing an IHI<sup>(28)</sup>. ISO TS 22220 may be useful in terms of determining data elements to be associated with the IHI, however, it is not suitable for evaluation of international identifiers due to its limited scope.

# Standard E1714-07, Standard Guide for Properties of a Unique Health Identifier

ASTM International has developed an international standard indicating the properties of an individual health identifier<sup>(29)</sup>. ASTM International has developed over 12,000 standards covering almost all industries. Although this standard was developed for identifying individuals in the American health sector, ASTM International state that it is transferrable and usable for any individual health identification system and it is recommended by the ISO in ISO TS 22220 for

defining the properties of an IHI<sup>(28)</sup>. The standard lists and defines 30 properties grouped under six characteristic areas that an IHI should possess as follows:

Functional properties:

- Accessible The IHI should be available at all times. The supporting system, infrastructure and governance arrangements must be in place to support this.
- Assignable It should be possible to assign an IHI to an individual whenever it is needed. Assignment will be performed by an IHI trusted authority after receiving a properly authenticated request for a new IHI.
- Identifiable It must be possible to identify the person associated with a valid IHI. Identifying information may include such standard items as name, birthplace, sex, address, mother's maiden name. This information is not incorporated in the IHI itself, but is associated with it by linkage and where necessary this information can be updated or corrected.
- Verifiable It should be possible to determine that a candidate identifier is or is not a valid IHI without requiring additional information. This should support the ability to detect accidental information, such as typographical errors.
- Mergeable In the (theoretically infrequent) case that duplicate IHIs are issued to a single individual, it shall be possible to merge or combine the two IHIs to indicate that they both apply to the same individual.
- Splittable In the (theoretically never occurring) event that the same IHI is assigned to two individuals, there must be a mechanism to retire the IHI and assign a new IHI to both of these individuals.

Linkage of lifelong health record:

 Linkable - It should be possible to use the IHI to link various health records together in both automated and manual systems across organisational boundaries.  Mappable - During the incremental implementation of an IHI, it should be possible to create bidirectional linkages between an IHI and existing identifiers used currently by a variety of healthcare organisations.

Patient confidentiality and access security:

- Content free The structure and elements of the IHI number itself should not contain any information about the individual.
- Controllable It must be possible to ensure the confidentiality of personal information held in association with the IHI. Only trusted authorities have access to algorithms and methods used to link and de-identify individuals with the IHI.
- Healthcare focused The IHI should not be used to identify an individual for any purpose other than for the provision of health and social care.
- Secure It should be possible to encrypt and decrypt an IHI as required to ensure that individual privacy is protected. The infrastructure and governance arrangements for the IHI must ensure the security of any personal information associated with the IHI.
- Dissidentifiable It should be possible to create an arbitrary number of specialised IHIs that can be used to link health information concerning specific individuals but that cannot be used to identify the associated individual.
- Public The individual an IHI identifies should be able to reveal it publicly without revealing any personal information.

Compatibility with standards and technology:

 Based on industry standards - The IHI and its supporting infrastructure should be based on international best practice and take guidance from international standards.

- Deployable The IHI should be implementable using a variety of technologies, including magnetic cards, bar code readers, optical cards, smart cards, audio, voice, computer data files, and paper.
- Usable The IHI should be processable by both manual and automated means. While manual methods for such functions as verifying the validity of an IHI may require considerably more time, there should be no technical or policy inhibitions to manual operation.

Design properties:

- Unique A valid IHI should identify one and only one individual.
- Repository based A secure, permanent repository should exist in support of the IHI system. The repository should contain the IHI and other relevant information to support the function of the IHI system.
- Atomic An IHI should be a single data item. It should not contain sub elements that have meaning outside the context of the entire IHI. Nor should the IHI consist of multiple items that must be taken together to constitute an identifier. The IHI must have no elements that can be analysed into any type of coherent structure.
- Concise The IHI should be as short as possible to minimise errors, the time required for use, and the storage needed.
- Unambiguous Whether represented in automated or handwritten form, an IHI should minimise the risk of misinterpretation (for example confusing the letter 'o' with a zero).
- Permanent Once assigned, an IHI should remain with the individual. It should never be reassigned to another person, even after the individual's death.
- Centrally governed A management organisation should exist that is responsible for overseeing the IHI system. This agency will determine the policies that govern the IHI system, manage the trusted authority, and take

such actions to ensure that the IHI can be used properly and effectively to support the delivery of healthcare.

- Networked The IHI should be supported by a secure network that makes IHI services universally available where needed.
- Longevity The IHI system should be designed to function for the foreseeable future. It should not contain known limitations that will force the system to be restricted or revised radically.
- Retroactive It should be possible to assign an IHI to all currently existing individuals at the time that the IHI system is implemented.
- Universal The IHI should be able to support every living person for the foreseeable future. This includes all areas and levels of health and social care across the public and private sectors.
- Incremental implementation The IHI system should be capable of being implemented in a phased-in-manner. This may include incremental implementation for a specific institution for the information on a specific patient, and for a geographical area.

Reduction of cost and enhanced health status:

 Cost effective - The IHI system should achieve maximum functionality while minimising the investment required creating and maintaining it<sup>(29)</sup>.

The properties listed above and taken directly from the standard, cover the important aspects of the IHI including the number itself and its functions, the infrastructure supporting the IHI, interoperability, security and governance of the IHI and cost effectiveness<sup>(29)</sup>. Therefore, the ASTM International standard E1714 - 07 has been selected for this research as a robust and detailed standard focused specifically on health. The data about the IHI gathered from the international component of this research is assessed against the properties of this standard.

# **Chapter 4 – International Review**

#### 4.1 Introduction

The aim of this chapter is to assess the IHI in the following countries with a specific focus on the ASTM properties:

- England
- Newfoundland and Labrador
- Australia
- New Zealand

The information contained in this chapter is based on the authors previous research paper, "*International Review of Unique Health Identifiers for Individuals*" published by the Health Information and Quality Authority<sup>(30)</sup>. Where relevant, details of the review have been updated. All four countries have introduced an IHI using varying approaches at different times. The diverse experience of each of these countries provides this research with a rich source of information and informs the proposal of a potentially successful adaptation for Ireland.

This chapter describes and reviews each of the individual health identifiers for the above countries under the following headings:

- Purpose of the IHI
- Format of the IHI
- Validation of the IHI
- Dataset associated with the IHI
- Technical design
- Governance
- Features of the IHI
- Privacy

Finally, at the end of this chapter, relevant information about each IHI is tabulated with the ASTM properties to ascertain the most suitable model for adaptation to Ireland.

## 4.2 England

#### 4.2.1 Introduction

Established in 1948, the National Health Service (NHS) is the largest public health system in the world. The NHS in England is funded by taxation and employs 1.3 million people who provide health and social care to approximately 50 million individuals. The NHS is governed by the Department of Health in England and care is delivered via ten strategic health authorities (SHAs), each responsible for a number of healthcare trusts<sup>(31)</sup>.

NHS Connecting for Health, launched in 2005, is an NHS directorate with responsibility for delivering the National Programme for IT (NPfIT) with the major goal of achieving an EHR across health and social care in England. The NPfIT project, once described as the largest information technology project ever undertaken outside of the military, has ceased prior to completion due to spiraling costs and a lack of value for money. However, the NHS Number Programme remains as a successful and vital component of the project. The NHS Number is the name given to the IHI in England and it predates the NPfIT project by a number of years having been developed in 1996<sup>(32;33)</sup>. The NPfIT role with regard to the NHS Number was to ensure widespread adoption across all sectors of health and social care in England by providing the infrastructure necessary to allow access to the NHS Number system known as the Personal Demographics Service (PDS).

Prior to development of the current NHS Number in 1996, many different formats of NHS Numbers existed throughout the NHS<sup>(34)</sup>.

The NHS Operating Framework 2008/9<sup>(35)</sup> mandated the NHS Number as the IHI to be used across all NHS services. In order to help health and social care organisations in achieving full adoption of the NHS Number, the NHS Number programme was established with NHS Connecting for Health providing guidance on implementing the NHS Number<sup>(3)</sup>.

Organisations are required to assess their usage of the NHS Number and consult the guidance to ascertain the necessary steps to achieving full coverage. It was anticipated that the NHS number would be universally used by 2010 and this was largely achieved, however, the NHS Number does not yet extend to some areas such as dentistry and prisoners healthcare<sup>(36)</sup>.

The guidelines for implementation state that strong communication with staff, intensive training and clear definition of staff roles together with detailed assessment of current systems and their compatibility with the use of the NHS Number are key to efficient successful implementation of the programme<sup>(37)</sup>.

#### 4.2.2 Purpose of the Identifier

In September 2009, the National Patient Safety Agency (NPSA) published an updated Safer Practice Notice (SPN) for the use of the NHS Number. The SPN was developed based upon the NPSA's evidence that use of the NHS Number will significantly improve patient safety. It states that the NHS Number should be known and used by NHS staff and patients in order to reduce the clinical risk to the patient<sup>(2)</sup>.

According to the SPN, the NHS Number:
- Minimises the potential risk of duplication of healthcare records
- Ensures that healthcare records are unique to each individual
- Enhances security and safety of sharing health information across organisational boundaries
- Facilitates clinical audit<sup>(2)</sup>

The document *The NHS Plan, a plan for investment, a plan for reform* requires that the patient is central to the NHS<sup>(38)</sup>. It is recognised by NHS Connecting for Health that in order to support the plan, it is essential that each patient can be identified accurately at every encounter with the health and social care system. Universal use of the NHS Number supports this by identifying various healthcare records associated with an individual across healthcare organisations, which provides a means of ensuring that health information about the right individual is available when needed<sup>(38)</sup>.

#### 4.2.3 NHS Number Format

The NHS Number consists of ten digits – the first nine digits constitute the identifier and the tenth is a check digit that ensures its validity. In order to reduce the risk of inaccurate reading or transposition of digits, it is recommended that the NHS Number is always displayed in 3-3-4, for example 123-456-7891. The NHS number is content free and therefore the number itself contains no information about the individual it is used to identify. The NHS Number is atomic, unambiguous, can be made public and is supported by a secure network<sup>(37)</sup>.

#### 4.2.4 NHS Number Validation Method

The last digit of the NHS Number is known as a "check-digit". This is used to confirm the validity of the NHS Number electronically. The number is validated

using a Modulus 11 algorithm, the use of which is mandatory in all NHS systems. This validation method does not verify the identity of an individual; it simply assures that the number is a valid NHS Number<sup>(18)</sup>.

## 4.2.5 Dataset Associated with the NHS Number

The Personal Demographics Service (PDS) implemented by NHS Connecting for Health is the system associated with the NHS Number and its associated dataset of demographic information. It enables NHS providers to access the NHS Number and the personal demographic dataset and to assign an NHS Number at the point of care <sup>(34)</sup>.

The demographic information associated with the NHS Number is detailed in full in Appendix 1. This information includes a summary identifying dataset that can be used when trying to locate an individual on the PDS system, or when verifying the identity of an individual in possession of an NHS Number (e.g. name, place of birth, date of birth). It does not contain any clinical information about the individual<sup>(34)</sup>.

## 4.2.6 Technical Architecture

The PDS database is part of a national network of NHS systems known collectively as the NHS Care Record Spine<sup>(39;40)</sup>. These systems allow for electronic referrals and appointment booking, communications between health and social care providers and electronic prescribing. Members of the public can also access part of the Spine in order to gain information about providers, view their personal summary care record or to view the demographic information held about them on the PDS. Central to the Spine system is the Transaction and Messaging Service (TMS). This system links and routes all information between the various Spine systems using Health Level 7 (HL7) healthcare messaging standards, for example PDS demographic information and the NHS Number can be accessed by the appointment booking system known as 'Choose and Book' via the TMS. This increases efficiency and reduces possible transcription errors that could lead to misidentification<sup>(40)</sup>. A basic graphical overview of the Spine system is illustrated in Figure 1 below<sup>(41)</sup>:



*Figure 1: NHS Spine architecture* Source: NHS Connecting for Health<sup>(41)</sup>

## 4.2.7 NHS Number Governance

The use of the NHS Number and access to the PDS service is governed by the National Information Governance Board for Health and Social Care (NIGB) which was established as a statutory body under the Health and Social Care Act 2008<sup>(7)</sup>. All access to and sharing of personal health information in the UK is governed by the Data Protection Act UK<sup>(42)</sup> and specifically by the *NHS Code of Practice for* 

*Healthcare Professionals 2006* <sup>(14)</sup>. All NHS staff who are authorised to access the Spine can access the PDS service at the appropriate security level which is assigned locally.

The NHS Number was developed with individual security and privacy in mind. Information cannot be ascertained about an individual through their number alone and it is unlikely that staff will associate a number with an individual in the same way that they would a name. There is no mechanism for a member of the public to access information about an individual from their NHS Number. All NHS staff have a duty to treat information as confidential and security procedures are in place to ensure that access to health information is limited by passwords, smartcards and role based access controls. Role based access controls allow for different levels of access to various staff according to the information required to carry out their duties. In order to gain access to the PDS, NHS staff must individually as a provider and organisationally as an employee, sign and agree to use the PDS in accordance with the NHS standards of security and confidentiality<sup>(43)</sup>. The PDS is capable of sending alerts to designated privacy officers in the event that confidentiality may have been compromised so that these may be investigated further and any necessary action taken<sup>(39)</sup>.

There is no option for individuals to "opt-out" of having their information stored on the PDS as anyone receiving an NHS Service is registered on the PDS. However, individuals can opt for their NHS Number not to be attached to certain clinical records which may be of a sensitive nature, for example in relation to sexual health. In particular, contact details must be held to satisfy legal requirements for maintenance of General Practitioner (GP) registers, to ensure that each individual presenting for care is an English resident and therefore eligible for free care, to help ensure that the right information is associated with the right individual and to allow healthcare providers to contact individuals when necessary. Sensitive records such as adoption files are limited to certain staff using role based access controls and are managed by the National Back Office, a department of Connecting for Health with responsibility for ensuring the confidentiality of sensitive records<sup>(43)</sup>.

The NHS Number Implementation Guide lists the permitted uses of the NHS Number<sup>(37)</sup>. These uses were defined by alignment to the benefits that can be gained from each use; for example, the number can be used as the identifier on electronic referrals and prescriptions, to support correct and accurate identification of individuals and their medical records, thereby reducing duplication of records and clinical risk. The NHS Number can also be used to enable multi-agency involvement within health and social care, streamlining the patient experience and underpinning the strategic aim of a patient centered NHS.

#### 4.2.8 Features of the NHS Number

Individuals are allocated an NHS Number either at birth, in the primary care setting or at the first point of contact with the NHS. In the primary and secondary care settings, the decision is made locally as to which members of staff have the authority to assign new NHS Numbers in cases where the individual does not have one. The NHS Number Implementation Guidance document provides information and guidance on role-based access levels for various staff to aid local decision making about staff authority to assign NHS Numbers<sup>(37)</sup>.

Entitlement to free healthcare does not affect the assignment of an NHS Number and a new NHS Number can be assigned at the point of care in real time by those authorised to register new patients on the PDS. As possession of an NHS Number does not entitle the bearer to free or subsidised care, new NHS Numbers are routinely assigned to overseas visitors who require health or social care<sup>(37)</sup>. The NHS Number can be traced, accessed or verified in real time by approved NHS staff at the point of primary or secondary care through the PDS system. The PDS is accessed by NHS Staff via a secure N3 connection using the NHS staff identity smartcard. It allows staff to search for an individual's NHS Number by inputting name and date of birth and it also allows staff to verify who an NHS Number identifies. The NHS Connecting for Health Website provides instructions for NHS staff in how to trace NHS Numbers on the PDS; however, such detailed information about accessing and using the PDS is only available on a secure network to NHS staff<sup>(37;44)</sup>.

## 4.2.9 NHS Number and Privacy

It is of fundamental importance that the IHI is secure in order to protect the privacy of the bearer. There are a number of the ASTM criteria which related to this; for example, the number should be healthcare focused, content-free and it should be possible to make the number public without revealing any information about the individual it identifies. The NHS Number satisfies these criteria in relation to privacy<sup>(45)</sup>.

Any individual accessing NHS Services will be allocated an NHS Number as its use as an IHI for NHS Services has been mandated; therefore, individual consent is not required in order to allocate a new number. The dataset associated with the NHS number includes a consent field stating whether the individual consents to being contacted by NHS staff, for example to communicate laboratory results.

Strict and robust safeguards are in place to protect the security and confidentiality of every patient's NHS Healthcare record, including the demographics information stored in the PDS. These include:

- The use of 'smart cards' with a Personal Identification Number (PIN). These are individually issued to staff that will be using the NHS Care Records Service and accessing the PDS, following training.
- The level of access to the PDS and associated health information is determined by the role of the staff member
  – for example, a consultant will see more detail than a receptionist who will only see the information necessary to process an appointment.
- NHS Care Records are accessible in a de-identified form to healthcare researchers and the health information may be used in an anonymised format. This is achievable due to the content-free nature of the NHS Number.
- Audit trails are maintained so that access history can be recorded. The patient has a right to request information about who has accessed their records<sup>(39)</sup>.

# 4.3 Newfoundland and Labrador (Canada)

## 4.3.1 Introduction

The Department of Health and Community Services govern health and social care services in Newfoundland and Labrador. The Canadian federal government sets standards and assists with funding for health and social care while there is provincial responsibility for the administration and delivery of services. All residents of Newfoundland and Labrador are entitled to public health insurance coverage by Medical Care Plan (MCP), the publicly funded organisation which operates under the Department of Health and Community Services<sup>(46)</sup>. As a result of this, public health insurance system, there are very few private health insurance options, with policies available only to cover healthcare not provided for by the MCP for example, some types of dental work.

The Newfoundland and Labrador Centre for Health Information (NLCHI) was established in 1996 and is directly accountable to the Department of Health and Community Services<sup>(47)</sup>. The role of the NLCHI is to provide health information to health professionals, health services managers and the public. Collaborating with stakeholders, NLCHI has a provincial mandate to develop and manage a Health Information Network (HIN) as a means of achieving the best possible health care for the province. The cornerstone of the HIN is the Unique Person Identifier (UPI)/Client Registry (CR)<sup>(48)</sup>.

The NLCHI implemented a provincial UPI/CR in 2001. This system was upgraded by 2005 with funding from Canada Health Infoway and is known as the CR1 project. Canada Health Infoway is an independent pan-Canadian organisation established by the provincial first ministers of Canada in 2001. Canada Health Infoway's purpose is to drive healthcare transformation through the use of information technology initiatives. Funded centrally by the Canadian federal government, Canada Health Infoway provides both financial and expertise investment at provincial level to progress health information technology initiatives that have potential for re-use in other provinces and territories. Canada Health Infoway defined the components for enhancing the original UPI/CR system by looking at client registries throughout Canada in order to identify best practice. These enhancements were designed to create a reusable client registry solution, which can be shared with other jurisdictions across Canada<sup>(49;50)</sup>.

#### 4.3.2 Purpose of the Identifier

The UPI/CR is a provincial index, which contains the most current demographic information on clients of the provincial health and community services system, and facilitates the appropriate linkage of client records across source systems. The Canadian UPI/CR differs from the other IHI models reviewed in that it is based on

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a client index (CI) model. The fundamental difference between the CI and IHI models is that the CI is used to match an individual's information held on different systems across different locations and verify which records of information correspond to each individual. The main function of an IHI system on the other hand, is to record and store a dataset of information about each individual, and to assign a unique identifier to each dataset that should be used in all health and social care organisations as the main identifier for each individual. The CI solution is suited to Newfoundland and Labrador as the vast majority of its population already carry a Medical Care Plan (MCP) number that can be used as an identifier at present.

The UPI/CR enables an individual's clinical information to be consolidated from multiple regions and sources as the HIN is further developed<sup>(49)</sup>.

The purpose of the UPI/CR is to:

- provide a central database of clients of the health and community services system
- identify accurately an individual during an encounter with the health system
- confirm an individual's eligibility for free medical care coverage
- maintain the accuracy of demographic information in local systems
- identify newborns for metabolic screening
- provide for the linking of health information in the proposed Electronic Health Record (EHR)<sup>(49;51)</sup>

## 4.3.3 UPI / Client Registry Number Format

The UPI/CR automatically assigns a nine digit unique identification "shadow" number to each individual registered; however, this number is not used as an IHI. The registry system uses this number for the purposes of indexing the records it holds and is not visible to users of the system<sup>(20)</sup>. Individuals will continue to use their MCP number as an IHI province wide, unless there is a demonstrated need to

use the "shadow" number. NLCHI recognise that there may be a requirement to develop the shadow number generated by their CI for use as an IHI at some point in the future should the MCP number or registry become obsolete. Individuals are also registered with local identification numbers in healthcare facilities using Meditech, the information system used in hospitals, and the Client Referral Management System (CRMS), used in primary care. These systems all communicate with the UPI/CR system which facilitates the linking and cross-referencing of various identifiers for an individual<sup>(49;52)</sup>.

## 4.3.4 UPI Client Registry Number Validation Method

As the unique identification number is generated in the background and used as a shadow identifier by the UPI/CR system, there is currently no validation method for the number itself. The demographic information collected at registration points throughout the health system is stored on local registration systems and shared with the UPI/Client Registry. Responsibility for data accuracy lies with the local system managers<sup>(51;52)</sup>.

## 4.3.5 Dataset Associated with the Registry

The dataset associated with the UPI/Client registry is accessed and can be updated by authorised individuals in health and social care organisations. The full dataset is tabulated in Appendix 1. It is interesting to note that the dataset includes details of public health insurance eligibility and also any private health insurance information<sup>(51)</sup>.

## 4.3.6 UPI / Client Registry Architecture

When a client presents to receive health services, registration staff use one of a number of information systems to access and/or update the client's demographic and administrative information. These systems are:

- Meditech
- Client Referral Management System (CRMS)
- Medical Care Plan (MCP)

This means information for a client receiving health services can exist in more than one location. To ensure a client's record is up-to-date and consistent across each of the information systems, the UPI/CR interacts with the various information systems to assist in identifying duplicate records and communicating updates. The UPI/CR integrates the information systems and helps tie the various sources of client information together. The UPI/CR and information systems interact by exchanging client information as shown in figure 2 on the next page<sup>(51;52)</sup>.



*Figure 2: Newfoundland and Labrador Client registry* Source: Newfoundland and Labrador Centre for Health Information<sup>(51;52)</sup>.

## 4.3.7 UPI / Client Registry Governance

As the lead organisation in the development of the UPI/Client Registry, the NLCHI is responsible for ensuring the personal information that is collected, used, disclosed, stored, or disposed of is subject to the highest level of confidentiality and security available through best practices in the health system and through the protection of legislation. Within the NLCHI, the Registry Integrity Unit (RIU) is responsible for the file maintenance of the UPI/Client Registry<sup>(50)</sup>. In order to promote transparency and enhance accountability the NLCHI has carried out a privacy impact assessment (PIA) of the UPI/CR to ensure that the registry does not allow breaches of individual privacy<sup>(51)</sup>.

The UPI/CR is a provincial information system of demographic registration information collected by the Regional Integrated Health Authorities and the Department of Health and Community Services, Medical Care Plan (MCP). Each public body is the custodian for the personal information they hold. The NLCHI is the custodian of the provincial database of demographic information, the UPI/CR<sup>(50)</sup>.

The UPI/CR was approved by the Minister of Health and Community Services under the authority of the *Hospitals Act*, the *Health and Community Services Act*, and the *Medical Care Insurance Act*<sup>(51)</sup>.

Any individual, whether resident in Newfoundland and Labrador or a visitor to the province, will be registered on a system that is linked with the UPI/CR. The UPI/CR will then assign a shadow unique identifier to the individual. There is no option to opt out of registration and individuals accessing both public and private health facilities are registered. The collection, use and disclosure of health information is governed by the *Access to Information and Protection of Privacy Act* (ATIPPA) of Newfoundland and Labrador and more specifically by the Personal Health Information Act, enacted in 2011<sup>(53;54)</sup>.

#### 4.3.8 Features of the UPI / Client Registry

The unique identification number created by the UPI/Client registry system is assigned automatically when an individual is registered at any healthcare facility using a local system. This usually occurs at the point of registration of a new birth on a hospital system, but any individual who has never accessed health services in Newfoundland and Labrador can be registered at the point of care. This includes visitors who may not be resident in the province. At the point of registration, the local system queries the UPI/Client registry with the basic demographic details of the individual. The UPI/Client Registry then returns the individuals full demographic details if the individual has been previously registered on any other system. If the individual's details are not found, the authorised user then registers the individual locally and assigns a local identification number. This information is communicated to the UPI/Client Registry where a new record is created automatically<sup>(49;50)</sup>.

Access to the UPI/Client Registry is granted to authorised registration and medical record personnel by their Regional Health Board. Authorisation and access management (e.g., user ID/password assignment) is coordinated between NLCHI and a designate registration manager or IT security-coordinating contact at Regional Health Board level. The UPI/CR front-end database access tool is accessible by authorised users through Meditech, and as such, users are not required to undergo a separate log-on process to the Client Registry<sup>(51)</sup>.

#### 4.3.9 Privacy Concerns and Consent Process

All initiatives that collect, use, store or disclose personal information run some risk of a breach of the privacy of personal information. The NLCHI have made efforts to design an information system, develop policies and procedures, and establish ongoing processes that will protect the UPI/Client Registry data.

The UPI/Client Registry was not designed as a privacy enhancing technology for the health system; however, some of the features of the information system support the protection of personal information. By using an index of identifiers, rather than a single identifier for the full provincial health system, a record can be identified by a number or alphanumeric code and still easily retrieved for the correct individual. Re-identification of such records is still possible but requires several steps including authorised access to a registration database. The role of the Registry Integrity Unit ensures accuracy and integrity of demographic information that was not previously possible in a health system with disparate registration systems. Additionally, the design of the database limits the collection of personal information only to standardised data fields.

Before every encounter with the health system, a person is registered on a system that is linked to the UPI/CR therefore there is no option to opt out. Consent is considered implied for the primary purposes of registration. As the UPI/CR is not directly accessed by users, role based access levels are approved locally for users to access the system they connect to the UPI/CR with. The users who collect the registration information do not seek consent from the individual for its use or disclosure. The individual will be unable to receive care or services without providing demographic information to the stakeholder, which is why an individual accessing the health service is considered to have given (implied) consent.

Demographic information for people receiving emergency care may be collected after the care according to each hospital's policies and procedures. Detailed access management procedural documentation, including UPI/Client Registry access application forms are held by the authorising managers at Regional Health Board level. Application access to the UPI/Client Registry system contains entities and attributes to implement security, audit requirements, and to establish functions per user. Users are assigned user ID's, passwords, and a set of functions that they are eligible to execute based on their organisation's requirements e.g. some users will only be able to perform client searches (read access) while others will have access to update Client Registry data via the source system they use<sup>(51)</sup>.

## 4.4 Australia

### 4.4.1 Introduction

The health service in Australia is governed centrally by the Department of Health and Ageing. The department has responsibility for providing leadership in policy making, public health, research and national health information management. Each state and territory has individual responsibility for the management and delivery of public health services and the regulation of healthcare practitioners within their state or territory boundary. Public health services are delivered by Medicare Australia, an organisation which is funded by revenue from taxation. All Australian citizens are entitled to receive healthcare with Medicare Australia. Private healthcare is also an option for those who wish to avail of private health insurance and the Australian government subsidises the cost of this by providing for 30 percent of the cost<sup>(55)</sup>.

The health identifier for individuals in Australia is referred to as the Individual Healthcare Identifier (IHI). Australia implemented the IHI in June 2010 and much work has been done to develop structures and governance to support the new IHI. The National E-Health Transition Authority Limited (NEHTA) was established by the Australian territorial governments with the purpose of enhancing the management of health information by development of e-health initiatives<sup>(56)</sup>. Part of their strategy to achieve this was to develop a Healthcare Identifiers (HI) service, which was completed by NEHTA and launched in mid 2010<sup>(57)</sup>.

### 4.4.2 Purpose of the Identifier

The intended primary purpose of the IHI is the accurate identification of individuals in health and social care.

According to NEHTA, the main reasons for implementing an IHI are to ensure that:

- The right health information is matched with the right individual at the point of care.
- Shared health information between healthcare providers is matched with the right individual<sup>(58)</sup>.

## 4.4.3 IHI Number Format

The IHI is a content-free 16 digit identifier that is assigned to all individuals accessing healthcare services in Australia. Each number identifies only one individual and their health and social care records<sup>(58)</sup>. There are three component parts of the number<sup>(59)</sup>:

- the first five digits correspond to the issuer and will be the same for all IHIs issued. This number is 80036 and is assigned by ISO to describe that the number is used for health and that it has been issued in Australia. The sixth digit denotes whether the number identifies an individual, a healthcare practitioner or a healthcare organisation
- the next nine digits identify the individual and corresponds to ISO standard ISO-7811-3
- the sixteenth and final digit is a check digit for verification that the IHI is valid

The IHI format complies with International Standards Organisation (ISO) standards ISO-7812, ISO-7811-3 requirements and the Australian standard for healthcare identification AS-5017, 2006<sup>(57;59)</sup>.

### 4.4.4 IHI Validation Method

The method of validation of the IHI number is by use of a check digit at the end of the number. This digit electronically verifies that the number is a valid IHI and uses the Luhn formula modulus 10 in accordance with ISO standard ISO-7812 in validating the number<sup>(59)</sup>. Validating the IHI in this way does not verify the identity of the individual possessing the number.

## 4.4.5 Dataset Associated with the IHI

The IHI consists of the number itself and an associated record comprising three sub-categories of record that are used for different purposes<sup>(60)</sup>. These are (in order):

- a summary record whose purpose is to facilitate searching for and locating the right identifier for the individual. It contains the minimum set of personal attributes that are required for healthcare professionals to confirm they have located the right individual's IHI. This summary record could be viewed during the process of retrieving the individual's record for an appointment with their healthcare provider.
- an identification record which contains a list of attributes in addition to the summary record (acquired information) which describes an individual; for example, address and traits (inherent features) of the individual which normally do not change such as gender and date of birth that are used for identification.
- a demographic record, which contains additional information about the individual, that is not mandatory for identification but is essential for healthcare and healthcare related communication. This may include attributes such as home phone number, mobile phone number and email<sup>(60)</sup>.

The minimum dataset required to uniquely assign an IHI is: name, date of birth, date of birth accuracy indicator, gender<sup>(59)</sup>. Date of birth accuracy indicator is a code used by healthcare practitioners in Australia to show whether a date of birth is partially or fully estimated. The full dataset associated with the IHI is detailed in Appendix 1.

## 4.4.6 IHI Architecture

The conceptual operating model outlined below in Figure 3 is the basic blueprint for the Healthcare Identification Services<sup>(59)</sup>.



*Figure 3: Health Identifier Service Conceptual Model* Source: National eHealth Transition Authority<sup>(59)</sup>.

The Healthcare Identification Services conceptual model is underpinned by appropriate identity, security and access methods, and is accessible to individuals using the Internet via a secure web portal. For non-internet users alternate access channels to the HI Service are provided, for example, contact centres are available to allow authorised users to access information held on the system. This allows the individual to view their IHI and associated dataset. The data held and the ability to access that data is primarily private in nature. This means the right to access that information must be established through verifying credentials prior to gaining access. Not having access to the internet does not prevent access to services by any individual<sup>(60)</sup>.

#### 4.4.7 IHI Governance

The use of the IHI and its information record is healthcare focused as defined by the Governance Authority, currently part of NEHTA. A Ministerial Council comprising the Territorial Health Ministers has strategic responsibility for the HI Service. Key responsibilities are the strategy for the HI Service and the assignment of authorities levels for use of the HI Service<sup>(57)</sup>. Medicare Ausralia are responsible for the day to day operation of the HI Service and an independent regulator oversees the HI Service to ensure compliance with privacy legislation and regulations<sup>(61)</sup>.

The full set of data items contained in the IHI record are subject to legal and privacy assessment. A look-up capability allows the IHI to be linked to existing local, private, and public health identifiers so that health information can be associated across healthcare sites. The IHI services privacy framework defines suitable role based access levels to the information stored in the repository. Specific Commonwealth legislation was drafted to detail the governance, privacy and approved uses for the Individual Healthcare Identifiers. As well as this, access to the IHI and the limited information it contains, is protected by state and national privacy laws. Penalties apply if any of these laws are breached<sup>(62)</sup>.

#### 4.4.8 Features of the IHI

Medicare Australia has responsibility for provision and administration of health related programmes. They are the initial operator of the healthcare identifiers service using the current infrastructure in place. The HI service is operated separately to the Medicare entitlements functions<sup>(62)</sup>.

The IHI service database was initially populated by demographic data from Medicare Australia's Consumer Directory Maintenance System (CDMS). The CDMS captures demographic information for approximately 98 per cent of the Australian population. This means that when the HI service was launched, the majority of the population were already assigned an IHI<sup>(62)</sup>. The Department of Veteran Affairs database was also used as a trusted data source (TDS) to populate the initial HI service database and capture the individuals who were not registered on the CDMS<sup>(59)</sup>. The IHI is not issued directly to individuals as the major trusted data sources which populated the IHI database cover the vast majority of the population and individuals are issued with identifying numbers for these trusted data sources already. These numbers although not required, in addition to personal demographic information, can aid healthcare practitioners to ascertain each individual's IHI securely online.

Collection of personal information to assign a new IHI to an individual only occurs in limited circumstances. Where an individual is not registered on the Medicare Australia CDMS or the Department of Veteran Affairs database such as a visitor to Australia, only information required for the identification of healthcare individuals is collected by the HI service<sup>(57;59)</sup>. Where an individual is not registered and does not present at a TDS centre for full enrolment, an unverified temporary IHI can be

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assigned at the point of care at any time. This unverified IHI can later be verified at such time as the individual presents for full registration.

The IHI and the IHI record are available via a single source. Access to the system is controlled, and constantly audited and monitored. Those wishing to access the system must be appropriately authenticated and authorised. Authenticated healthcare providers and healthcare administrators are able to search for or view the IHI record of individuals for whom they provide healthcare. An identifier for healthcare providers (HPI-I) and organisations (HPI-O) was implemented at the same time as the IHI and all healthcare providers, including healthcare administrators were assigned a HPI-I following authentication.

Individuals have the right to access their IHI record and the record of those for whom they act in an authorised representative capacity. This includes access to audit trails detailing who has accessed their IHI record and when. The system allows individuals to access their IHI record using a number of different options; for example, over the counter, over the phone or through a web portal<sup>(60)</sup>.

#### 4.4.9 IHI Privacy Concerns and Consent Process

The Australian Health Ministers' Advisory Council published a consultation document on proposed legislation about the privacy of individuals in July 2009. In 2010, the Australian government enacted the Health Identifiers Act, which outlines legislation on the governance, assignment and permitted uses of the IHI. Three separate privacy impact assessments (PIAs) were also undertaken on the IHI implementation project to ensure the privacy and confidentiality of individuals<sup>(57)</sup>. PIA is an assessment process that facilitates the identification of potential privacy risks to a project prior to implementation. This improves the protection of the privacy of individuals. Usually, the PIA process begins at the project planning stage and is revisited throughout the duration of the project. This allows for the identification and mitigation of potential risks to privacy before any significant investment has been made<sup>(63)</sup>. For example, in one of the Australian PIA reports on the IHI project, it was noted that the original proposed dataset to be associated with the IHI contained more personal information than was strictly necessary for identification purposes. As a result, the dataset was shortened representing an enhancement to individual privacy, but also a cost saving in that less information was required to be collected and stored in order to assign an IHI<sup>(64)</sup>.

## 4.5 New Zealand

## 4.5.1 Introduction

The Minister of Health is responsible for the health and disability system in New Zealand. The health service is funded and delivered by 21 district health boards (DHBs) who report directly to the Minster of Health<sup>(65)</sup>. The DHBs govern both the public and private health sectors with approximately 30 per cent of the population of New Zealand availing of private healthcare insurance. The New Zealand Health Information Service (NZHIS), reporting directly to the Minister of Health, was established in the early 1990's to develop a national method for identification of individuals in healthcare known as the National Health Index (NHI). The primary driver for development of the NHI was a need to reduce fragmentation of health information in New Zealand<sup>(66)</sup>.

New Zealand is one of the earliest adopters of an IHI having had some form of health identifier in place since the late 1970s. The current NHI was implemented in 1992. The NHI is a database of demographic information associated with an IHI known as the NHI number that is assigned to all individuals accessing health and social care in New Zealand. A major upgrade of the NHI is currently approaching completion following a review of efficiency and effectiveness in 2001. This review recommended a programme to remove duplicate record entries, upgrade of the technology used by the NHI in order to increase efficiency and the expansion of the NHI such that it is accessible outside of hospitals in other parts of the health sector<sup>(66;67)</sup>.

Although the NHI number has been in existence for over 30 years, it is only in more recent years that its implementation and use are spreading nationally across the various health sectors to the population of just under four million people<sup>(66)</sup>.

## 4.5.2 Purpose of the Identifier

As the benefits of using an IHI became apparent over time and following a comprehensive review of the NHI<sup>(67)</sup>, the NHI system is currently undergoing expansion to include primary care as part of the upgrade<sup>(66)</sup>. Comprehensive, universal use of the NHI number is intended to enable:

- Accurate identification of individuals.
- The linkage of health information across organisational boundaries.
- Access to longitudinal healthcare records for individuals<sup>(66)</sup>.

## 4.5.3 NHI Number Format

The NHI number is seven alphanumeric digits in length and is content-free. The number appears in the format ABC 1234 with the alpha digits always displayed in uppercase letters to aid accurate transposition of the number and facilitate a reduction in data entry errors<sup>(68)</sup>. The number is generated randomly and is content free and therefore contains no information about the individual it identifies<sup>(66)</sup>.

### 4.5.4 NHI Validation Method

The seventh digit of the NHI number acts as a check digit to verify that the number is a valid NHI number. This digit validates the number using a modulus 11 calculation similar to the validation method used by the NHS number in England and Wales. This method of validation does not verify the identity of an individual; rather it verifies the validity of the number itself and is therefore only useful for electronic transactions on systems equipped with the algorithm to run the modulus 11 calculations<sup>(66)</sup>.

### 4.5.5 Dataset Associated with the NHI

The NHI does not record any clinical information<sup>(69)</sup>. The full demographic dataset associated with the NHI is detailed in Appendix 1. Further attributes will be added to the dataset as part of the ongoing NHI upgrade including geo-spatial fields and the storage of previous addresses <sup>(38)</sup>.

All the information associated with the NHI number is designed to accurately identify individuals receiving healthcare services and to allow them to be associated with the correct medical records. The NHI number and its associated demographics are held centrally on the NHI Online Access for Health (NOAH) system<sup>(69)</sup>.

## 4.5.6 NHI Architecture

There is no visual representation of the technical structure of the NHI available at the time of this research due to the fact that the legacy NHI system supporting the NHI is currently being replaced by a newer system<sup>(13;67)</sup>. The NHI itself will not change as part of this process to upgrade the NHI system (NOAH). Permitted health information systems in hospitals access the NHI through application programming interfaces which control authorisation and level of access to the NHI

such as the ability to create a new record or simply view existing records. Authorisation is granted and certified by the NZHIS as the governing body for the operation of the NHI<sup>(66)</sup>.

### 4.5.7 NHI Governance

The NZHIS, a division of the Ministry of Health, act as the central trusted authority for the NHI number and the NOAH system. The NZHIS hold responsibility for ensuring that all users who access the NHI number system and its dataset are fully authorised and that the NHI number is only used in compliance with the Privacy Act 1993 and the Health Information Privacy Code 1994<sup>(70)</sup>. Authorised healthcare providers are authenticated by the Health Practitioner Index Common Person Number (HPI-CPN), a unique identifier for healthcare providers. All users who have access to the NHI are required to sign an access agreement, binding them to the regulations of the Health Information Privacy Code<sup>(70)</sup>.

The purposes for which the NHI Number can be used are governed by the Health Information Privacy Code 1994<sup>(71;72)</sup>. The allowed uses include:

- Identification of individuals for referrals hospital visits, clinical tests and patient related correspondence.
- The linkage of health information across different specialties and various authorised health providers
- Communication with patients
- Reporting of patient events to national data collections and for screening programmes.

The NHI number can be encrypted to allow linkage of anonymised health information, benefitting health research initiatives without compromising confidentiality<sup>(71)</sup>.

### 4.5.8 Features of the NHI Number

Most NHI numbers are issued at birth and it is estimated that the NHI number has achieved coverage of 98% of the population<sup>(70)</sup>. Anyone without an NHI number who presents at a healthcare organisation is assigned a number following a search of the index by an authorised user. New numbers can be assigned electronically by request directly to the NZHIS or to the relevant DHB in close to real time. It is recognised real time assignment of the NHI number at the point of care is necessary and this is being addressed as part of the current NHI upgrade programme<sup>(70)</sup>. Individuals are not provided with NHI number cards, however, an individual can find out their NHI number through their general practitioner if they wish.

The NHI was initially designed for use solely in public hospitals. It is accessed via the NOAH system, which was made available in all public hospitals directly linked to the hospital information system in the 1990's. As part of the upgrade of the NHI, the NOAH system has recently become available to primary care via a webbased portal with the majority of users gaining read only access initially. Following sufficient training, write access will be rolled out incrementally in the primary care sector<sup>(70)</sup>.

### 4.5.9 NHI Privacy Concerns and Consent Process

The Health Information Privacy Code 1994 allows for the assignment of the NHI number without the express consent of the individual as it is deemed necessary to facilitate the provision of safe and secure care<sup>(72)</sup>.

Prior to the ongoing upgrade of the NHI, there were serious concerns about the accuracy of data held on the NHI due to large numbers of duplicate records; however, a dedicated team within the NZHIS are actively working to remove duplicates and improve the data integrity of the index for the NHI Training

Package<sup>(73)</sup>. This initiative, together with intensive training for users is helping to significantly address the issue of duplicates in the index.

Another initiative implemented as part of the NHI upgrade programme in order to protect the privacy of the individual is the NHI audit. Auditing is a useful means of ensuring that authorised users do not abuse the trust that has been placed with them. The audit project was implemented to audit all of the users of the NHI and verify that the NHI is only accessed for legitimate reasons<sup>(70)</sup>.

## 4.6 Summary

The aim of this chapter was to explore the international experience of implementing an IHI to inform best practice for implementation in Ireland. Structures, formats, governance and current status in a number of countries were documented.

Table 1 below summarises and compares each IHI reviewed against the ASTM properties. This information helps to determine the most suitable model for adoption in Ireland.

In the table below, the following abbreviations are used:

Eng = England

N & L = Newfoundland and Labrador

NZ = New Zealand

Aus = Australia

- Y = The IHI satisfies this property
- N = The IHI does not satisfy this property
- U = It is not known if the IHI satisfies this property
- P = The IHI partially satisfies this property.

Property	Eng	N & L	NZ	Aus	Comments
Accessible Assignable	Y	Y	N	Y	The NHI in NZ has been available to all public hospitals since 1992. Developments since the Wave report has increased availability to primary care, however the NHI is still not accessible at all points of care. The NHI is specifically designed to meet this criteria; however,
					assignment is not currently undertaken in real time across the entire healthcare service
Identifiable	Y	Y	Y	Y	
Mergeable	Y	Y	Y	Y	
Splittable	Y	Y	Y	Y	
Verifiable	Y	Ν	Y	Y	The UPI/Client registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. Therefore the number itself is not manually verifiable.
Linkable	Y	Y	Y	Y	
Mappable	Y	Y	N	Y	NHI numbers in NZ can be linked one to another to eliminate duplicates, but there is no specific mapping facility
Content-free	Y	U	Y	Y	The UPI/Client registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. Therefore it is not known if the number is content-free.
Controllable	Y	Y	N	Y	One-way encryption algorithms have been developed in NZ; however it is possible that this encryption could be

					cracked using the power of modern
					computers, therefore this is under
					review currently and cannot be
					deemed controllable at present
Healthcare	Y	Y	Y	Y	
Focused					
Public	Y	U	Y	Y	The UPI/Client registry in N & L
					utilises a "shadow identifier" which is
					not seen by the provider or
					individual. Therefore it is not known
					if the number can be made public
					without revealing any personal
					information.
Secure	Y	Y	Р	Y	Encryption facilities exist for the NHI
					Number in NZ. These facilities are
					currently under review as they are
					not in line with modern capabilities
Dis-identifiable	Y	Y	Y	Y	not in line with modern capabilities
Dis-identifiable Deployable	Y Y	Y Y	Y Y	Y Y	not in line with modern capabilities
Dis-identifiable Deployable Standard /	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most
Dis-identifiable Deployable Standard / Based on	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is
Dis-identifiable Deployable Standard / Based on Industry	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard.
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is not seen by the provider or
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. It is not known if this
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. It is not known if this number is based on any standard.
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. It is not known if this number is based on any standard. The NHI as a legacy system was not
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. It is not known if this number is based on any standard. The NHI as a legacy system was not designed based on international
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. It is not known if this number is based on any standard. The NHI as a legacy system was not designed based on international standards, however, upgrades
Dis-identifiable Deployable Standard / Based on Industry Standards	Y Y N	Y Y U	Y Y N	Y Y Y	not in line with modern capabilities The NHS Number predates most international standards and it is unlikely that the number itself is based on any standard. The UPI/Client Registry in N & L utilises a "shadow identifier" which is not seen by the provider or individual. It is not known if this number is based on any standard. The NHI as a legacy system was not designed based on international standards, however, upgrades underway bring the system in line

Usable	Y	Y	Y	Y	
Atomic	Y	Y	Y	Y	
Governed	Y	Y	Y	Y	
Centrally					
Networked	Y	Y	Y	Y	
Permanent	Y	Y	Y	Y	
Repository-	Y	Y	Y	Y	
based					
Retroactive	Y	Y	Р	Y	NHI numbers are estimated to have
					been issued for 95% of the New
					Zealand population
Unambiguous	Y	N	Y	Y	The UPI/Client registry in N & L
					utilises a "shadow identifier" which is
					not seen by the provider or
					individual. This number designed for
					computer use as opposed to human
					use so it is unlikely to employ
					methods to avoid ambiguity.
Unique	V	V	V	V	
Unique	I	I	I	•	
Universal	Y	Y	N	Y	The number of NHI identifiers that
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are
Universal	Y	Y	N	Ŷ	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to accommodate assignment to more
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to accommodate assignment to more individuals
Universal	Y	Y	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to accommodate assignment to more individuals
Universal	Y N/A	Y N/A	N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to accommodate assignment to more individuals Both the NHS Number and the
Universal	Y N/A	Y N/A	Y	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to accommodate assignment to more individuals Both the NHS Number and the UPI/Client Registry has been fully
Universal	Y N/A	Y N/A	Y	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to accommodate assignment to more individuals Both the NHS Number and the UPI/Client Registry has been fully implemented to all individuals.
Universal Incremental Longevity	Y N/A P	Y N/A P	N Y N	Y	The number of NHI identifiers that can be generated is finite. There are sufficient unused numbers to serve the needs of the New Zealand population for at least another decade, however, following this, the NHI will need to be amended to accommodate assignment to more individuals Both the NHS Number and the UPI/Client Registry has been fully implemented to all individuals. The identification part of the NHS

					allows a finite number of possible
					lengthening at some point in the
					more distant future.
					The NHI system has functioned in its
					current form without major changes
					since 1992; however, there are a
					finite number of NHI Numbers that
					can be generated. NZHIS are
					currently working to increase
					longevity
Concise	Y	Y	Y	Y	
Cost effective	N	Y	Р	Y	The NHS number cannot be said to
Cost effective	N	Y	Р	Y	The NHS number cannot be said to be cost effective mainly due to the
Cost effective	N	Y	Р	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to
Cost effective	N	Y	Р	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger
Cost effective	Ν	Y	Р	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English
Cost effective	Ν	Y	Ρ	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English NHS.
Cost effective	Ν	Y	Ρ	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English NHS. The cost of operating the NHI in NZ
Cost effective	Ν	Y	Ρ	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English NHS. The cost of operating the NHI in NZ has become progressively lower over
Cost effective	Ν	Y	Ρ	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English NHS. The cost of operating the NHI in NZ has become progressively lower over time, however, the cost of upgrading
Cost effective	Ν	Y	Ρ	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English NHS. The cost of operating the NHI in NZ has become progressively lower over time, however, the cost of upgrading the system and number are
Cost effective	Ν	Y	Ρ	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English NHS. The cost of operating the NHI in NZ has become progressively lower over time, however, the cost of upgrading the system and number are additional to original implementation
Cost effective	Ν	Y	Ρ	Y	The NHS number cannot be said to be cost effective mainly due to the fact that it has taken many years to fully implement as part as a larger programme for IT across the English NHS. The cost of operating the NHI in NZ has become progressively lower over time, however, the cost of upgrading the system and number are additional to original implementation costs and therefore, the NHI cannot

Table 1: International IHI comparison with ASTM properties

Of the information that was sourced in the course of this research the following are the key points:

 Privacy and the protection of individual confidentiality is important to the success of an IHI with all countries reviewed developing legislation or policies governing the IHI such as the Health Information Privacy Code in New Zealand and Health Identifiers Act in Australia. Strong governance controls must be in place with clear lines of accountability prior to any implementation of an IHI. Undertaking a Privacy Impact Assessment is beneficial to mitigating privacy risks and informing the content of the dataset to be associated with the IHI.

- A central trusted authority with responsibility for assignment and access rules to the IHI, such as Medicare in Australia and the Registry Integrity Unit in Newfoundland and Labrador, is necessary in order to ensure consistency of usage and ensure the integrity of the data held through identity verification.
- The IHI number should include security features to reduce the possibility of fraudulent use and error of transcription such as the check digit used to verify the validity of the IHI in Australia, New Zealand and England.

# **Chapter 5 – The Irish Context**

## 5.1 Introduction

The aim of this chapter is to briefly introduce and provide a summary of the national identifiers currently in use in Ireland and their usefulness (if any) to healthcare as an IHI. This work was previously undertaken by the author for the Health Information and Quality Authority in 2009, whereby the national identifiers in Ireland were measured against the ASTM properties<sup>(29)</sup>. The work is summarised below and helps to inform this research in terms of whether a current Irish national identifier or an international model should be adapted for use as the IHI. Current initiatives by the Department of Social Protection to improve the Personal Public Service (PPS) Number and its infrastructure are discussed relative to its potential impact on the introduction of the IHI. This chapter also provides a broad overview of the health landscape in Ireland in terms of information systems used at primary and secondary care levels and readiness for a national IHI.

## 5.2 Summary of national identifiers and the IHI

In 2009, the author undertook to assess national identifiers currently in use in Ireland to ascertain their suitability for adoption as an IHI. The following identifiers were measured against the ASTM properties for a unique health identifier:

- The Personal Public Service (PPS) Number
- An enhanced PPS Number
- A new identifier not based on any currently used in Ireland
- The Medical Card Number
- The Drug Payment Scheme Number
- The Birth Notification Number
- The European Health Insurance Number

- The Passport Number
- The Driver's Licence Number<sup>(1)</sup>

Only the options of a new identifier and the enhanced PPS Number possessed the properties outlined in the ASTM properties, therefore the author deemed all other identifiers as unsuitable for adaptation as an IHI. Enhancing the Personal Public Service (PPS) Number involves improving or modifying the functionality and properties of the current PPS Number such that it possesses the properties in the ASTM standard.

Both options were then compared and evaluated using a health technology assessment (HTA) approach to assess which option provides a best fit. HTA involves the assessment of the implications of a new health technology. The approach used was that of a mini-HTA which involves analysis of responses to a number of questions concerning the consequences of implementing a new technology<sup>(74)</sup>. The medical, social, ethical and economic implications of implementing either a new IHI or an enhanced PPS Number were assessed based on national and international evidence. The results concluded that a new IHI based on international experience is likely the most suitable candidate identifier. Based on these results, this research focuses on information gathered on international identifiers in order to propose a candidate model that is most adaptable to Ireland and possesses the ASTM properties.

Although it was found that there is no existing identifier in Ireland that is suitable for use as an IHI, there are some national infrastructures associated with other identifiers for other purposes that could be utilised to support the establishment of a healthcare focused identifier. The use of existing national infrastructure, expertise and databases to populate a new IHI database represent one such possibility. The potential to use any existing infrastructure could reduce the cost of introducing the IHI and also facilitate the expediency of the implementation. There are two national databases that have been identified by the author that could be used for this purpose, namely the PPS Number database and the National Client Index as they both achieve coverage of the vast majority of the Irish population. These databases and their potential to facilitate the IHI project are discussed in the following sections.

### 5.2.1 Improvements to the PPS Number infrastructure

In 2011, Client Identity Services (CIS), a division of the Department of Social Protection, began enhancing the PPS Number and its infrastructure to improve accuracy, validation of the PPS and verification of identity. This project is ongoing at the time this research, however, there are a number of identification initiatives underway as part of this work that could support and benefit the introduction of the IHI in terms of expediency and cost reduction of implementation<sup>(75)</sup>. The improvements to the PPS Number and its infrastructure include:

- Adoption of the the Standard Authentication Framework Environment (SAFE) levels for authentication of identity. Safe level 0 assumes no assurance of identity, while safe level 1 has minimum authentication and allows identification with limited information such as name and address alone. Safe level 2 provides a much greater level of assurance and safe level 3 provides assurance of identity beyond any reasonable doubt, for example, through use of a biometric. Safe level 2 has been deemed sufficient at this time for the purposes of public service provision in Ireland. It involves the use of a photograph and signature of the individual, face to face registration with fully trained registration personnel and the requirement that identity and address are proven at the point of registration<sup>(75)</sup>.
- The PPS Number currently incorporates a "w" added to end of any male's PPS Number who is married. This PPS Number with the added "w" indicates the spouse of the male. CIS are currently isolating these numbers and
reverting them back to the original PPS Numbers allocated to each individual woman prior to her marriage. The practice of assigning the "w" PPS Numbers has ceased, however, there are still many of these numbers in the system<sup>(76)</sup>.

- The system supporting the PPS Number is undergoing cleansing to eradicate duplicate records and correct erroneous information. Currently there are approximately eight million individual records on the PPS database representing the Irish population over the age of sixteen. In order to verify identity to Safe Level 2 and to facilitate the cleansing of the database, all individuals over the age of sixteen will be required to attend a designated registration centre to verify their details so that they are correct and up to date on the PPS database<sup>(75)</sup>.
- The CIS is issuing a Public Services Card (PSC) to each individual who has had their identity verified. The PSC is a smartcard which displays the PPS Number, a unique PSC card number, card expiry date, the name and a photograph of the individual. An RFID chip, readable at designated registration centres and at authorised centres is used to store the demographic information of the individual in accordance with the public services dataset. This card can be presented at authorised centres for access to public entitlements such as the collection of the jobseekers allowance or child benefit payments<sup>(75)</sup>.

Although the PPS Number is not suitable for use as an IHI even with the improvements underway<sup>(1)</sup>, there is potential opportunity for the expertise on identity verification within CIS to benefit the IHI implementation. It is possible that the chip on the new PSC could potentially store the new IHI in a secure segment, only accessible to authorised health providers. The clean Public Services database could also be used as a source database and TDS, similar to Australia, to populate a new healthcare focused IHI database. The PSC will not be distributed to

individuals under the age of sixteen. For this reason, it is prudent to locate another national database that could be used in conjunction with the PPS database to populate the new IHI database and to ensure the entire Irish population is captured.

#### 5.2.2 The National Client Index

The National Client Index (NCI) is operated by the Primary Care Reimbursement Service (PCRS) and uses Enterprise Master Patient Index (EMPI) technology to match records of individuals from a number of other databases associated with public entitlements such as the drug payments scheme and the medical card numbers database. This index contains 3.8 million unique records<sup>(77)</sup>. The records held on the NCI are regularly updated by the databases feeding into it such as the drug refund scheme and medical card databases; therefore, the data is likely to be up to date in many cases. However, the records are unverified in terms of identity authentication, equivalent to Safe level 1. The NCI could be used to assist in populating a new IHI database, particularly to capture the cohort of the population under the age of sixteen. These records would remain unverified until such time as the individual presents to an authorised health provider with proof of identity to Safe level 2.

#### 5.3 Health Information Systems in Ireland

There are currently thousands of identifiers in use in Ireland in health and social care. Typically, each healthcare provider uses a proprietary identifier and set of demographic data (dataset) that is unique and meaningful only to that organisation. In hospitals, different departments assign their own identifiers such as laboratory numbers and radiology numbers. This can represent a significant issue when attempting to implement a national system in that various fields within the dataset at local level will differ to those specified in the national system, for

example, the date of birth of an individual can be recorded in many ways using six or eight digits and varying symbols between date, month and year of birth. This is in addition to the fact that there is always potential for incorrect recording of personal information, often leading to the existence of more than one record for a single individual within an organisation. In order for the benefits of a national IHI system to be realised, it is vital that all healthcare providers can seamlessly access the national IHI database without adding significant administrative effort to documenting and verifying the identity of individuals. This means that health information systems must be able to communicate with a national IHI system in real time and function using the IHI as the identifier for each individual across primary, secondary, tertiary, public and private healthcare systems. However, it is not feasible to suggest that all health information systems should be replaced with a new system that supports the national IHI. Therefore, it is necessary to find a way that the various local systems can communicate or interoperate with the national IHI system. In order to arrive at the most suitable solution, the capability of local systems to interoperate with other systems must be ascertained. There is no single source of information available about all types of health information system currently used in Ireland across both public and private health sectors, however, preparatory work undertaken prior to the implementation of the National Integrated Medical Imaging System (NIMIS) on the readiness for local patient administration systems (PAS) to integrate with a central registry can inform this research with regard to the readiness of local systems to integrate with a national IHI database.

#### 5.3.1 National Integrated Medical Imaging System

The NIMIS project involved the introduction of a national Picture Archive and Communication System (PACS) to facilitate electronic reporting and storage of radiology and imaging services. The ultimate goal of the project is to allow for paperless and filmless reporting of medical images at any site the individual may

attend, with images from one site accessible at another provided consent has been given<sup>(25)</sup>. This is achieved by local radiology systems linking to the NCI run by PCRS, which matches the identity of an individual with the correct record stored on the central NIMIS repository<sup>(78)</sup>. The NCI has the ability to use matching technology based on agreed parameters to recognise similar information stored in differing formats such as the date of birth example above. Once this matching has occurred, the required image is then viewable at the site where it was requested. At the planning stage of the NIMIS project, it was recognised that the ability of PAS and radiology systems to communicate with the NCI had to be ascertained. A site readiness survey was undertaken and the survey information can inform this research in terms of how local PAS systems can interoperate with a national IHI system<sup>(79)</sup>. The part of this survey relevant to this research is what type of interoperability capability local systems possess. The national IHI system must be able to interface functionally with local systems and it is prudent in terms of cost effectiveness to select the type of functional interoperability standard most local systems are compliant with (if any) across the Irish health sector already. Interoperability and its importance are discussed in further depth in chapter 7 of this dissertation. The survey found that very few of 32 local hospital systems are not capable of interfacing with other systems and that the majority are Health Level 7 (HL7) Version 2.x compliant<sup>(79)</sup>. Therefore, HL7 standards for functional interoperability will be applied to this research in proposing a national IHI model for Ireland. HL7 is internationally recognised as a robust and secure functional messaging standard which facilitates secure messaging between health information systems with HL7 capability $^{(79)}$ .

#### **5.3.2 General Practice Information Systems**

Currently in Ireland there are three major primary care software suppliers who provide systems used by the majority of General Practitioners (GPs). These are Helix Health<sup>(80)</sup>, Socrates<sup>(81)</sup> and Complete GP<sup>(82)</sup>. All support HL7 Standard

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messaging functionality, further adding to the reasoning for utilising HL7 Messaging standards to facilitate interoperability between local primary care systems and a central IHI system<sup>(80-82)</sup>.

#### 5.3.3 The National Healthlink Project

The National Healthlink Project (Healthlink) is a Health Service Executive funded project operating in the Mater Hospital since 1995 and as a national project since the launch of Healthlink Online in 2003<sup>(83)</sup>. The project provides a healthcare messaging service which allows for the exchange of health information between the primary and secondary healthcare sectors. Healthlink uses the HL7 v2.4 messaging standard to facilitate the exchange of health information between GPs and hospitals and acts as a broker, allowing GPs to access health information generated by a hospital via a web portal<sup>(84)</sup>. The most current information available from Healthlink on August 28<sup>th</sup> 2012 states that Healthlink provides this service to 32 hospitals and 2732 GPs in Ireland<sup>(83)</sup>. This widespread use and compliance of local health information software systems with the HL7 v2 messaging standard, together with availability of expertise on implementation supports the proposal to use this messaging standard to allow health information systems to communicate with the IHI system.

# **Chapter 6 – Evaluation and Analysis of Results**

#### 6.1 Introduction

The aim of this chapter is to evaluate and discuss the individual health identifiers reviewed and assessed against the ASTM properties in Chapter 4. These results together with the information about local systems inform the selection of the most suitable international IHI model that could be adapted to the Irish health sector.

## 6.2 Results

The international section of this research has demonstrated that the Australian model for an IHI is most likely the suitable model to adapt to the Irish health sector. It is the only country of those reviewed that possesses all 30 of the ASTM properties of an individual health identifier. Figure 4 on the next page illustrates a summary of the outcome of the assessment of the IHI from each of the reviewed countries against the properties. Although each IHI model reviewed has strong attributes, often based on many years of experience post implementation, the Australian model, being very recently designed, has the benefit of having learned from international experiences both successful and not, prior to implementation. This is likely why the Australian model possesses the attributes put forth in the ASTM properties.



Figure 4: Summary of Assessment

## 6.3 Proposed Model for adaptation

The results of this assessment point to the Australian model of the IHI as most suitable for adaptation to the Irish health and social care sector. Below is a proposed outline of how the Australian IHI could be adapted such that it could be implemented in Ireland. Current infrastructures in Ireland detailed in Chapter 5 are taken into account when adapting the Australian IHI model.

The operation of the IHI proposed is discussed in terms of:

- The identifier database setup Approach, data sources and populating the new IHI database
- Operation of the IHI Registration, issue and access
- Dataset Minimum required, dataset from other IHI databases
- Governance of the IHI

## 6.4 Adapting the Australian model to Ireland

Learning from the current Australian experience, it is prudent to utilise a clean national database repository in order to initially populate the new IHI database. This is known as seeding of the new database. This repository should have wide and up to date coverage of the population and a unidirectional link from the national repository to the IHI database and should be maintained in order to allow the automatic updating of datasets.

A trusted data source (TDS) in the context of the IHI is an external repository of demographic information that is trusted as a source of data that can be used to populate a new system. This TDS, such as the Medicare database in Australia, automatically updates the content of the IHI database at regular intervals to ensure it is up to date.

In the Irish context of the proposed IHI system, the database maintained by the Primary Care Reimbursement Scheme (PCRS) and/or the database maintained by Client Identity Services (CIS) in the Department of Social Protection (DSP), may be suitable to act as a TDS for the IHI database, subject to data quality and completeness review. Any updates to either TDS could automatically be reflected in the IHI database. The IHI system would require the ability to match records from each of these systems in order to avoid duplications. A graphical representation of this adaptation is illustrated in Figure 5 on the next page.



Figure 5: Graphical overview of IHI system

The Single Customer View currently under development by the Department of Finance could be assessed for suitability as a TDS to aid the automatic updating of the data held on the IHI database. The Request for Tender (RFT) documents<sup>(85)</sup> which detail the expected functionality of the Single Customer View mention that any national datasets not included in the Single Customer View may still have their datasets checked for accuracy without actually being included in the integrated view. This use of the Single Customer View by the IHI system could aid the verification and accuracy of the IHI dataset without compromising the privacy of individuals.

Use of the TDS sources as aids to identity verification will require that the IHI system has some client index (CI) capabilities in that it has the ability to match

datasets across different systems. In order for this start up solution to be effective, it is important that an exercise is undertaken to ensure that the data in the TDS database(s) are clean. There are many data cleansing software solutions available which can detect incomplete data and which apply 'fuzzy logic' to identify duplicate records. However, it would be essential to set the threshold for automatic matching very high and to allow for manual intervention in cases where there is any doubt.

The current plan to require all holders of a PPS Number to physically attend a registration office to verify their identity to Safe Level 2 and receive the new PSC will greatly enhance the likelihood that a new IHI system populated by the PSC database will contain verified, valid and up to date data for the cohort of individuals entitled to a PSC. A web portal, similar to that in Australia, whereby individuals could register to be able to view their IHI and associated dataset would also be helpful in maintaining an up to date dataset and would have the added benefit of a transparent IHI service provision.

#### 6.5 Operation of the IHI

This section will discuss how the IHI system could operate with or without IHI identity cards, and the alternatives for health and social care practitioners to interface with and access the IHI database. Examples of day to day operations of an IHI system are detailed to further explain how it is envisaged the system could be run.

The issue of IHI wallet cards to individuals is not essential to the operation of the IHI service as individuals would not be required to produce their IHI in order to receive health or social care. However, a smartcard which could be used to verify the identity of an individual as well as display the IHI number could be useful at the point of care to improve efficiency. There is a significant cost associated with

the issue of identity cards, the level of which depends on the complexity of the card itself. The added efficiencies gained by issuing cards should be assessed against the cost of issue and replacement of lost cards. It is possible to include the IHI and associated dataset securely on a segment of the chip on the new PSC currently being rolled out to all individuals who are in possession of a PPS Number. This solution is logical given that the PSC cards can accommodate the IHI without incurring the cost of producing separate health identity cards.

Ideally, local patient administration systems (PAS) and practice management systems will be able to seamlessly access the IHI database and retrieve the IHI number of an individual. This is discussed further in Chapter 7, whereby interoperability of systems is explored. Alternatively, in the absence of a direct interface, access could be achieved via a web portal which allows the health and social care practitioners access to search the IHI database and retrieve an IHI number. This alternative would be less efficient and would have a significant impact on the time needed to locate the IHI of each individual attending for health and social care. The requirements of local systems to interface with a central IHI database are discussed further in the next chapter.

#### 6.6 Use Cases

The following use cases are detailed as examples in order to illustrate the types of process the adapted IHI should support:

#### 6.6.1 Process for receipt of a new IHI for newborns

All newborns in Ireland are currently registered on local systems almost immediately following birth. Newborns will be allocated an unverified IHI at this time and this number will be used as the identifier on all health and social care records. The IHI will become verified via automated processes at the time the newborn is registered on a TDS database or if the parents of the newborn wish to verify the demographic details at the time of registration. A delay in verifying the number can be useful as name changes are common shortly following the birth of a child. An unverified IHI is processed and used in the same way as the verified IHI with the exception that the information contained in the dataset can be corrected/updated by authorised local health and social care providers at any time.

#### 6.6.2 Process for receipt of a new IHI for non residents

Non-resident individuals such as holiday-makers, asylum seekers and visitors who require any health or social care intervention in Ireland can be registered on local systems as per current practice. As the individual will not be registered on a TDS, the IHI service will assign an unverified IHI to the individual. This number will remain unverified unless the individual establishes residency in the country and becomes enrolled with a TDS.

# 6.6.3 Process for provisional IHI assignment for unconscious or incapacitated individual

Individuals who require health care and are not identifiable through being unconscious or incapacitated and are not carrying any identification can be assigned a provisional IHI with the name recorded as "Unknown". This provisional number can be used to identify the individual and their health records for the episode of health until such time as identification of the individual is possible. When the individual is able to provide their identity, the provisional IHI can be merged with the correct IHI or can be verified if that individual did not have an IHI yet.

## 6.6.4 Process for creation of a pseudonymous IHI

Individuals who wish to protect their identity for certain aspects of health and social care received may require creation of an IHI separate to their standard IHI used. This could be required for such instances as episodes of care of a sensitive nature where the individual does not wish for a particular episode of care to be associated with their health record. In each health and social care provider, a nominated user of the IHI system should have the authority to create a pseudonymous IHI. The individual may request to meet with the nominated user to discuss the need for protected identity for an episode of care. If the individual is eligible, the nominated user will create the pseudonymous IHI for the individual. This will be linked confidentially to the original IHI; however, its existence will not be visible to IHI system users. The individual can request at any time that the pseudonymous IHI is retired or merged with their original IHI record.

This highlights the importance of a successful public campaign promoting the benefits of using the IHI. In most cases it should not be necessary to create a pseudonymous IHI as the privacy of the individual is safeguarded by the governance structures around IHI use.

Figure 6 on the next page illustrates the above processes:



Figure 6: IHI System Sample Processes

#### 6.7 Dataset Associated with the IHI

The Social Welfare Act 2002 defined a dataset appropriate to allocating the personal public service (PPS) number<sup>(86)</sup>. This dataset is referred to as the public

service identity (PSI) dataset and is sufficient to facilitate positive identification of an individual. The components of the dataset are:

- Surname
- Forename
- Date of birth
- Place of birth
- Sex
- All former surnames (if any)
- All former surnames (if any) of his/her mother
- Address
- Nationality
- Date of death
- Such other information as may be prescribed which, in the opinion of the minister is relevant to and necessary for the allocation of a personal public service number

The International Standards Organisation published a technical specification for identification of subjects of healthcare in 2009<sup>(28)</sup>. This specification does not recommend the addition of any clinical information to the subject of care identifier dataset. The final decision on the exact dataset should follow a full privacy impact assessment (PIA) of the project. In Australia, the agreed dataset was amended and shortened following a PIA which was undertaken during their individual health identifier implementation planning<sup>(64)</sup>. This helped to create a balance between benefits gained and the protection of the privacy of the individual.

Given that the primary purpose of the IHI is to facilitate positive identification of an individual, the minimum dataset of personal information requirements, similar to the Australian dataset, are:

Surname

- Forename
- Date of Birth
- Sex
- Address

This dataset can be collected from the databases that could seed the IHI database, e.g. PCRS and PSC databases. Any further fields to be added require justification by statement of additional or secondary purposes for the data to be held on the IHI database.

## 6.8 Governance of the IHI

In line with the Australian model, there are three broad governance functions required in order to ensure robust governance arrangements are in place to manage the IHI service:

- Strategic oversight will determine national policies and strategic direction of the IHI service. Key responsibilities include defining the scope of the service and the required regulatory and legislative arrangements. The Minister and Department of Health could assume responsibility for strategic oversight of the IHI service
- Management and operation oversight the central trusted authority will have responsibility for managing and assigning the IHI. It will also manage access to and use of the IHI service database in accordance with the policies and strategic direction set by the strategic oversight body. The central trusted authority will be responsible for the conduct of PIAs to ensure operation of the IHI service does not pose any undue threat to individual's privacy. The central trusted authority will have responsibility for the education and training of health and social care providers in the

operation of the IHI service. The central trusted authority should be an organisation that will be trusted by the public and by both public and private health and social care providers

 Independent regulatory oversight – the independent regulatory body will have responsibility for monitoring the management and operation of the IHI service, responding to and investigating significant complaints about the handling of information and providing guidelines to the central trusted authority in line with the policies of the strategic oversight group

# Chapter 7 – Interoperability and Messaging

## 7.1 Introduction

The aim of this chapter is to describe the terms 'interoperability' and 'messaging' in context with health and social care and to discuss the importance of these to the introduction of the IHI. Messaging specifications are explained and the method used in the Australian model is discussed in terms of feasibility for adaptation to Ireland. Finally, an example scenario is presented and this is developed and encoded into a healthcare message, demonstrating how the IHI can be progressed from a technical perspective.

## 7.2 Interoperability and messaging

Interoperability can be defined as the ability of a system to communicate and exchange information with one or more systems in a manner such that the exchanged information is usable<sup>(87)</sup>. In terms of healthcare, the ability of health information systems to exchange health information is important in enabling initiatives such as shared care and the IHI. Standards for healthcare interoperability exist and there are two main types of standard specifying differing levels of interoperability as follows<sup>(87)</sup> :

- Technical interoperability is the exchange of data between one or more systems. The systems do not have any understanding about the meaning of what is exchanged.
- Semantic interoperability guarantees that systems exchanging information understand the meaning of the information in the same way. Semantic interoperability is central to healthcare interoperability as it facilitates a standard way for health information systems to interpret exchanged information.<sup>(87)</sup>

Currently an individual's medical records can be recorded on paper, electronically or a combination of both, typically held in different locations making it difficult to get a complete picture of the patient's healthcare journey. Additionally, fragmentation of services, locally within hospitals and between primary, secondary and tertiary care settings, alongside the use of different health information systems in different care settings can make it difficult to safely communicate health information. This may lead to miscommunication or missing patient information ultimately adversely affecting patient safety. While the introduction of an IHI can address this fragmentation to an extent, it is vital that ICT is used in conjunction with the IHI to facilitate the safe and timely exchange of health information.

Messaging standards exist to define a standard structure and content of electronic messages to enable the effective and accurate sharing of information. Technical and semantic interoperability, mentioned above, can be achieved using messaging standards where systems exchange information using the defined structure of a standard such as that of Health Level Seven (HL7)<sup>(88)</sup> and where the content is defined using agreed semantic terms such as those contained in the Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT)<sup>(89)</sup>. This ensures that the information sent from one system is received and understood by the receiving system. A "message" can be defined as a unit of data exchanged between one or more software systems, such as between a laboratory information system and a general practice management system. Messaging standards are vital in ensuring that information can be shared across healthcare organisations and between healthcare organisations. The use of messaging standards will allow local health information systems to communicate or interoperate with the IHI system. For example, when a local PAS system requests the retrieval of demographic information from the IHI system, messaging standards will be used to send the request message from the PAS system and the IHI system will return a message with the requested information which will populate the relevant demographic data fields on the PAS system<sup>(90)</sup>.

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There are two main types of healthcare messaging standard, one which defines the technical structure, elements and order of elements a message should contain (syntax) and one which defines a common meaning for each element of the message (semantics). Health information standards are intended to remove ambiguity and ensure that systems can process and understand health information messages exchanged<sup>(91)</sup>.

#### 7.3 Healthcare messaging standards

A number of healthcare messaging standards exist worldwide including Health Level Seven (HL7)<sup>(92)</sup>, the Electronic Data Interchange for Administration, Commerce and Transport (EDIFACT)<sup>(88)</sup> standard, the openEHR<sup>(93)</sup> specifications and the EN13606<sup>(93)</sup> standard. These messaging standards define which elements are required and/or optional in a message in a structured format (syntax). Coding standards such as the International Classification of Diseases revision 10 (ICD-10)<sup>(94)</sup>, Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT)<sup>(89)</sup> and Logical Observation Identifiers Names and Codes (LOINC)<sup>(95)</sup> assign meaning to the elements contained in the message (the semantics).

As documented in Chapter 5, the most common type of healthcare messaging standard used in Ireland is known as Health Level 7 version 2.x (HL7 v2.x). It is logical from a cost effectiveness viewpoint that the capability of current health information systems is utilised where possible. Internationally, HL7 v2.x messaging standards are widely used as a robust and secure method for technical exchange of health information. In Australia, as part of the development of their interoperability strategy, NEHTA conducted an audit of the existing use of healthcare messaging standards. It was found, similar to Ireland, that HL7 v2.x was the most widely used standard for healthcare interoperability. NEHTA concluded that the continued use of this standard is most practical and beneficial

until such time as it may be superseded by HL7 v3 and CDA and there is clarity in relation to the standards for electronic health  $records^{(96)}$ .

## 7.4 Health Level Seven

The Health Level Seven (HL7) organisation are an ANSI accredited standards development organisation with the purpose of developing and publishing healthcare specific standards. They publish messaging standards for healthcare interoperability that aim to enhance care delivery, knowledge transfer and optimise workflow<sup>(95)</sup>.

The HL7 organisation has developed the following standards:

- HL7 version 2.x messaging standards (v2.x). The v2.x suite of standards is one of the most widely used standards for communicating clinical data among clinical information systems in hospitals and general practice across the United States of America (USA) and Europe<sup>(97)</sup>. V2.x standards provide specifications for messages to support the sharing of information upon referral, appointment booking, admission, transfer and discharge from hospital. The ordering of laboratory and radiology tests and pharmaceutical products for patients and reporting test results are also supported by v2.x standards. HL7 v2.x is the most commonly used standard for health information exchange and supports individual identification between systems. This means that it is suitable for application to the IHI project and can support the transfer of the IHI and its associated dataset between a national IHI database and most local health information systems. The use of v2.x is logical given that capability widely exists in Ireland in current health information systems.
- HL7 version 3 messaging standard (v3). The v3 standard uses an information model called the Reference Information Model (RIM) and a formal methodology called the HL7 Development Framework (HDF) to

increase the detail, clarity and precision of the message specification<sup>(97)</sup>. V3 was developed in response to a need to reduce the level of optionality available in messages that is prevalent in v2.x. Although v3 messaging is not currently used in Ireland, v3 messages are compatible with v2.x messages, however migration from v2.x to v3 would represent a very complex task from an implementation perspective<sup>(98)</sup>.

 HL7 Clinical Document Architecture standard (CDA). CDA is a suite of standards for representing clinical documents such as a referral form or a discharge summary<sup>(99)</sup>. The development of CDA has been driven by the need for health information to be both human and computer readable.

#### 7.5 HL7 v2.x message structure and the IHI

The HL7 v2.x standard is organised into chapters, each of which contains the required information to create a v2.x message relevant to each chapter domain. For example, Chapter 11 of HL7 v2.x contains the required information to create messages supporting patient referral. In order to define a v2.x message, HL7 specifies a set of building blocks for messages known as segments. These segments can be re-used when defining messages for different purposes<sup>(97)</sup>. Each segment is contains groups of related data fields which can be defined as required or optional and also occurring only once or repeatable. Each segment contains attributes that are defined in the corresponding chapter of the HL7v2.x standard. Each field within a segment is a string of characters that are defined by a HL7 data type. A list of all fields is contained in Appendix A of the HL7v2.x standard. Each field can contain one or more components and/or sub-components depending on the data type of the field<sup>(97)</sup>. The structure of a HL7 v2.x message is illustrated in Figure 7 on the next page:



Figure 7 - HL7 v2.x structure<sup>(97)</sup>

HL7 messages are encoded as ASCII text strings which allow the usage of HL7 recommended delimiters in constructing a message:

- Segment terminator <</li>
- Field separator
- Component separator
   ^
- Sub-component separator &
- Repetition separator ~
- Escape separator \

These delimiters allow for the construction of messages that are both machine readable and understandable to implementers<sup>(97)</sup>.

It is possible to incorporate the proposed IHI into HL7 v2.x messages so that one or more systems could send and receive identifying information using the IHI as the individual identifier.

#### 7.6 IHI Use case and sample message

Using HL7 v2.x, a sample message can be created to illustrate how a national IHI system and a local system would interoperate in order to satisfy the conditions of a scenario. Consider the following scenario:

## Retrieve the demographic record associated with a given IHI

## Example scenario:

John Johnson attends the emergency department (ED) of the St. Elsewhere Hospital with a suspected broken ankle. He arrives at the reception desk with his PSC and gives it to the clerk. The clerk scans the PSC which contains John's IHI stored securely on a segment of the chip on the card. The IHI, 123456789, appears on the PAS system on the clerk's computer screen and the clerk promptly requests John's demographic information from the national IHI system. The IHI system returns John's information and the clerk can register John locally.

In order to request John's information from the IHI system, the PAS system sends a HL7 v2.x query message, QRY^A19, to the IHI system. This message requests patient demographic information using a unique identifier. The IHI system then acknowledges that it has received the query message and returns a response message, ADR^A19, to the PAS system.

These messages can be encoded using ASCII text strings as follows:

## QRY^A19:

MSH|^~\&|StElsewhereHospitalPAS||IHISystem||201206071200||QRY^A19||P|2.4| QRD|201206071200|R|I|GetPatient|||1^RD|123456789|DEM|||

#### ADR^A19:

```
MSH|^~\&|IHISystem||StElsewhereHospitalPAS||201206071200||ADR^A19||2.4
MSA|AA
QRD|201206071200|R|I|GetPatient|||1^RD|123456789|DEM
PID|||123456789||Johnson^John^^^||19770209|M|||23
AnyStreet^AnyArea^Dublin^^D8|||0861234567||||
```

Below in Figure 8 is a visual representation of the messages sent and received by the PAS and IHI systems.



Figure 8: Sample message

## 7.7 Summary

The aim of this chapter was to highlight the importance of interoperability to the introduction of an IHI. The use of a healthcare messaging standard is vital to allow the IHI system to integrate with local systems so that an individual's identifying information is available at the point of care. In line with the Australian model, it has been shown that HL7 v2.x is the most suitable standard for adoption due to its widespread use in Ireland in existing health information systems. It is logical to use a standard which is widely supported to minimise the cost of introducing the IHI and ensuring that local systems can process and use the IHI. A sample scenario, developed and encoded into a HL7 v2.x message is provided to illustrate how the

use of a messaging standard facilitates the exchange of the information associated with the IHI.

## **Chapter 8 – Conclusion and Future Work**

#### 8.1 Main findings

There have been many calls for the introduction of an IHI in Ireland over the past decade or more and it is government policy to introduce an IHI. An IHI will also be essential for the introduction of universal health insurance as proposed under the Programme for Government. However, in spite of universal agreement on the imperative to introduce an IHI, progress has been very slow. This is most likely due to the fact that the IHI is not an emotive issue and funds tend to be directed towards frontline areas such as creating new healthcare facilities. Disagreement about whether or not to use the Personal Public Services Number have probably also contributed to the delay. The downturn in the economy has also adversely affected the availability of government funding for the IHI.

This research aimed to answer the following question:

What type of individual health identifier would be most appropriate for health and social care in Ireland and what standard electronic messages would be required to support the use of the identifier?

The research question was addressed by the gathering of information on international health identifiers and also on the broad Irish health landscape with regard to identifying individuals. Previous research by the author in this area, particularly on identifiers used nationally outside of the health sector such as the PPS Number and the Passport number, also influenced the direction of this research. Following assessment of the international information against a recognised international standard, the most suitable international model for adaptation to the Irish health sector was arrived at, namely that of Australia. The information gathered about national databases such as the Public Services database currently in place in Ireland informed a proposal on how the Australian model could be adapted to the Irish context. This involves the creation of a new IHI number that is healthcare focused and based on international standards. Expertise on identity verification and healthcare messaging that already exist in Ireland in Client Identity Services and Healthlink respectively can be leveraged to support the introduction of the IHI, ensuring a cost effective approach.

Currently, there are systems in place in Ireland, specifically the Public Services database operated by Client Identity Services within the Department of Social Protection and the National Client Index operated by the Primary Care Reimbursement Service that could act as trusted data sources in order to populate a new IHI database. The capability of some local systems such has Patient Administration Systems in hospitals, radiology information systems and General Practitioner Practice Management systems to exchange information with a national IHI system exists already with the wide use of the HL7 v2.x messaging standard in many systems. Healthcare messaging is vital to allow health information systems to communicate with each other, for example, when updating demographic details or requesting an IHI number. Thousands of authorised users will have a legitimate need to access and update the IHI database from a wide variety of different health information systems. This could not be achieved without the use of a healthcare messaging standard such as HL7 v2.x which is widely used internationally. It is therefore recommended that this standard is adopted when implementing the IHI.

#### 8.2 Limitations of this research

This research is limited by the availability of current information on local health information systems in Ireland. Ideally, a national audit of all health information systems would better inform this research in terms of ascertaining fully, the capability and any enhancements required in order to introduce an integrated IHI in Ireland. This will aid the more precise cost estimations for the implementation of the IHI. The necessary steps and processes involved in populating a new IHI database with data from the Public Services database and the National Client Index have not been analysed. The suitability of these databases as trusted data sources in terms of integrity, governance, availability and technical viability must be ascertained before any plan to adopt this proposal is made.

The decision to recommend the use of HL7 v2.x as the standard for interfacing with the IHI database was largely a pragmatic one based on the fact that it is by far the most widely used messaging standard internationally and hence is more likely to be supported by health information systems such as PAS and RIS systems. While its use in Ireland is not universal, it has been adopted by Healthlink which is a key national project facilitating the exchange of health information between GPs and hospitals. Therefore, there are many people in Ireland with expertise in HL7 v2.x unlike, for example HL7 v3 or CDA. However, a more rigorous analysis of the pros and cons and alternatives to the adoption of HL7 v2.x is necessary to ensure that this is the logical standard to adopt for the implementation of an IHI in Ireland.

Finally, the international review section of this research is limited to four countries. These countries were selected as they have all implemented an IHI in various forms and information is available on these in English. Many other countries have introduced an IHI and there may be lessons that could be learned from a wider review examining the IHI in other locations.

#### 8.3 Future Work

As mentioned, a national audit of health information systems in Ireland would be beneficial to the progression of the IHI in terms of ascertaining the level of effort required to integrate a national IHI system with local systems. In addition, the level of staff training and the cost of changes to current identification and registration practices are likely to be significant. Research in establishing change management requirements would allow for cost estimations and also a realistic timeframe for introduction of the IHI. The limitations previously mentioned above should be addressed together with a detailed cost analysis to ascertain the feasibility of the proposed model.

It is also recommended that a Privacy Impact Assessment (PIA) is conducted at the project planning stage of the introduction of the IHI and that the results of the PIA are updated as the project progresses. PIA is an assessment process that facilitates the identification of potential privacy risks to a project prior to implementation. Usually, the PIA process begins at the project planning stage and is revisited throughout the duration of the project. This allows for the identification and mitigation of potential risks to privacy before any significant investment has been made.

	Australia	New Zealand	England	Newfoundlan d & Labrador
Field				
Other national identifier				×
Local healthcare identifier				×
Surname	<ul> <li>V</li> </ul>	<b>v</b>	×	×
Forename	<ul> <li>V</li> </ul>	<b>v</b>	×	×
Aliases			×	×
DOB	×	×	×	×
DOB accuracy indicator	~			
Sex	×	×	×	<b>v</b>
Address	~	×	×	<b>v</b>
Date of birth registration				1
Place of birth	>	>	1	
Residency status		1		
Birth order			>	
Delivery time			>	
Date of death		1	>	1
Death notification status			~	1
Mothers first name				1
Alternative contacts			>	
Telephone number	1		>	1
Email address	1		>	
Ethnicity		1		
Domicile code		1		
Geo spatial information		1		
Public health eligibility				>
Health insurance				>
Preferred contact times			A	
Preferred contact method			V	
Preferred written comm.			A	
Format				
Preferred language			V	
Interpreter required			<b>V</b>	
Consent to share record			×	
status				
Nominated dispensing			×	
contractor				
Reason for removal (from			×	
a GP register)				
Previous public health			×	
Patient contact consent			×	
Status			4	
Snared secret			V	
Sensitive record indicator			× .	
Primary care practice			✓	
Date of registration with			×	
טר			1	I

# Appendix 1 – Datasets associated with IHI internationally

Back office location		×	
Serial change number		>	
Web portal status		>	
Primary care system		>	
information			



Appendix 2 – HL7 E-Learning Certificate attained by the author

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