



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Recommendations for a Unique Health Identifier for Individuals in Ireland

25 March 2009

About the Health Information and Quality Authority

The Health Information and Quality Authority is the independent Authority which has been established to drive continuous improvement in Ireland's health and social care services. The Authority was established as part of the Government's overall Health Service Reform Programme.

The Authority's mandate extends across the quality and safety of the public, private (within its social care function) and voluntary sectors. Reporting directly to the Minister for Health and Children, the Health Information and Quality Authority has statutory responsibility for:

Setting Standards for Health and Social Services — Developing person centred standards, based on evidence and best international practice, for health and social care services in Ireland (except mental health services)

Monitoring Healthcare Quality — Monitoring standards of quality and safety in our health services and implementing continuous quality assurance programmes to promote improvements in quality and safety standards in health. As deemed necessary, undertaking investigations into suspected serious service failure in healthcare

Health Technology Assessment — Ensuring the best outcome for the service user by evaluating the clinical and economic effectiveness of drugs, equipment, diagnostic techniques and health promotion activities

Health Information — Advising on the collection and sharing of information across the services, evaluating information and publishing information about the delivery and performance of Ireland's health and social care services

Social Services Inspectorate — Registration and inspection of residential homes for children, older people and people with disabilities. Monitoring day- and pre-school facilities and children's detention centres; inspecting foster care services.

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Executive Summary

1 Background

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

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

Pursuant to the Health Act 2007, section 8 (1) (j) having regard to section 8 (2) (d), the Health Information and Quality Authority is required to provide advice to the Minister and the Health Service Executive (HSE) about deficiencies identified by the Authority in respect of health information. **The absence of a UHI for individuals is the single most important deficiency in the health information infrastructure in Ireland.**

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

A wide consultation exercise on the Bill has recently concluded. Observations made in relation to this proposal to establish a UHI will inform the detailed work on the Bill.

The purpose of this document is to examine the information available, both nationally and internationally, in order to make recommendations to the Minister for Health and Children in relation to the introduction of a UHI for individuals and to inform decision making for the forthcoming Health Information Bill.

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

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

Using the criteria agreed in stage-one (see Appendix 1), the next step was to determine the suitability of a number of potential UHIs against these criteria. The following numbers were tested against the criteria (see Appendix 2 for a summary of the findings):

- PPS Number
- Enhanced PPS Number
- A new UHI
- Medical card number
- Drug Payment Scheme number
- Birth notification number
- European Health Insurance number
- Passport number
- Driving licence number

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

The current PPS Number failed on the following criteria:

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

4. **Healthcare-focused.** A UHI should be created and used solely for the purposes of delivering health (and social) care. The PPS Number is not healthcare-focused having been created and primarily used to access various services across the Irish public sector.
5. **Legislation.** The legal framework must be in place to permit the use of the UHI in healthcare. Current legislation specifically forbids the use of the PPS Number for health and social care purposes.
6. **Standards-based.** A UHI should be based on international or industry standards. The PPS Number itself is not designed to act as a unique identifier, rather it is a personal number for use in accessing public services. It was not designed in line with international best practice for identifiers.
7. **Atomic.** A UHI should be a single data item and should not contain any elements which can be decomposed to provide any meaningful information. As noted above, approximately 200,000 of the current PPS numbers include a “w” indicating a married woman, although these are being phased out.
8. **Universal.** There should be sufficient capacity to be able to generate new numbers as required into the foreseeable future. Based on the current average issue rate, the remaining PPS Numbers available will run out by 2012, although plans are being put in place to extend the number.

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

Two of the eight remaining options passed the fundamental criteria and were deemed suitable to be assessed further. These were:

An Enhanced PPS Number

A New UHI.

Using a simplified health technology assessment (HTA) methodology, these two options were examined based on social, ethical and economic considerations.

2 The Options

2.1 Option 1: Enhancing the PPS Number

Enhancing the PPS Number involves improving or modifying the functionality and properties of the current PPS Number such that it can satisfy all of the criteria for selection of a UHI for individuals.

Thus, while the PPS Number in its present format would be both unsuitable and unsafe as a UHI, it is possible to enhance it in such a way that it could be used safely. Furthermore, its nationwide coverage and existing infrastructure make it an obvious candidate for enhancement.

2.1.1. Enhancements Required for Use of the PPS Number in Healthcare

The following enhancements to the current PPS Number and CRS are necessary in order to ensure the criteria for selection of a UHI are satisfied:

- The CRS must be upgraded such that the client search function is accessible at all times, day and night, by all authorised personnel within healthcare
- The CRS must be extended and upgraded such that an Enhanced PPS Number can be assigned immediately at any time and at any healthcare organisation via an interface with their local patient administration system (PAS) upon receipt of a properly authenticated request
- The CRS must be enhanced such that it can issue temporary health identifiers (THI) for episodes of care where the individual's identity cannot be verified
- The PPS Numbers currently in circulation with a second alpha character, a 'w' which identifies the individual as a married female, must be replaced with content-free atomic numbers
- An algorithm to generate a UHI from the original PPS Number, which is not recognisable as a PPS Number and cannot obviously be converted back to the PPS Number, must be added to the functionality of the CRS to ensure the number is healthcare-focused
- The algorithm to generate a UHI from the PPS Number must generate a new number that is based on international best practice and takes guidance from CEN* and International Standards Organisation (ISO) standards

* The European Committee for Standardisation (CEN) is a business facilitator in Europe, removing trade barriers for European industry and consumers. Its mission is to foster the European economy in global trading, the welfare of European citizens and the environment. Through its services it provides a platform for the development of European Standards and other technical specifications.

- Irish legislation must be amended to include the use of the Enhanced PPS Number for the purposes of identification of individuals in the provision of health and social care in Ireland
- The PPS Number must be extended to ensure longevity, universality and support for every living person in Ireland for the foreseeable future.

It is assumed that the Enhanced PPS Number will be permanently linked to the current CRS database which is managed by Client Identity Services (CIS) within the Department of Social and Family Affairs (DSFA). Updates will be synchronised regularly.

2.2 Option 2: A New UHI

A New UHI means introducing a new number for use in the health and social care setting. It should have the following components:

- a unique identifier
- a delimiter (a format verification technique)
- check digits
- an appropriate data set (i.e. the information associated with the UHI, such as demographics)
- an encryption scheme to support data security
- a central governing authority.

It must satisfy all 32 criteria for selection of a UHI in Ireland.

The New UHI must support positive identification of individuals, automated linkage of various computer-based records, a mechanism to support data security and the use of technology to reduce unnecessary healthcare operating costs in handling individual identification.

Encrypted UHIs are included in the criteria for hiding the identity of individuals while linking information. Separate encrypted UHIs should be allowed for different episodes of care for the same patient. The New UHI numbering system will also allow for the use of a THI controlled by individual organisations for emergency use. Any THI can be subsequently linked to the correct UHI and all information transferred.

A new central trusted authority should be responsible for processing requests for a New UHI to include the issue of UHIs, computation of check digits, choice of encryption scheme, generation of encrypted UHIs and maintenance of either a cross index between encrypted and unencrypted UHIs or an appropriate secure decryption scheme to link the two.

3 Enhanced PPS Number Versus a New UHI: Evaluation Methodology

A comprehensive, systematic and objective methodology is required in order to provide a rigorous comparison between the two candidate identifiers – the Enhanced PPS Number and the New UHI. Such a methodology is provided by using the principles of a Health Technology Assessment (HTA). HTA is concerned with the study of the medical, social, ethical and economic implications of development, diffusion and use of health technology. In this case, the 'technology' is the implementation of a UHI. The evaluation approach used is that of a so-called 'mini-health technology assessment' which takes the form of a checklist with a number of questions concerning the prerequisites for and consequences of using (new) health technology. It provides an objective and analytical model for the examination of the medical, social, ethical and economic implications of implementing a UHI based on international experience and on the information available at national and local level.

This evaluation has been developed through a review of materials from national and international sources, following guidelines for mini-health technology assessment recommended by the Danish Centre for Evaluation and Health Technology Assessment (DACEHTA) ⁽⁴⁾. Further, for purposes of information gathering and consultation, relevant individuals from a range of stakeholders were consulted as detailed in the body of this report.

4 Findings

The introduction of a UHI would deliver tangible benefits from patient safety, quality of care, efficiency, confidentiality, epidemiological and cost effectiveness perspectives. Based on the available evidence, and in the interests of patient safety and efficient use of resources, the New UHI would be cost effective, represent international best practice and would be more secure than using the Enhanced PPS Number as the UHI for Ireland.

4.1 PPS Number is Unsafe

This evaluation has shown that the use of the current PPS Number as a UHI would be unsafe.

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

4.2 Cost-effectiveness of UHI

The New UHI would be more cost-effective than an Enhanced PPS Number.

International evidence shows that the capital cost of introducing a UHI is recovered in the first few years of operation but only if the UHI is used virtually universally throughout the healthcare system. Therefore, in order to be cost-effective, the UHI must be acceptable to the public.

4.3 Public Support for a UHI

Both a RED-C poll commissioned by the Health Information and Quality Authority, and the public consultation concerning the Health Information Bill, indicate widespread support for a UHI ⁽⁵⁾.

However, the consultation process revealed serious concerns about any potential for linkage between health and financial information. Since it is intended that the Enhanced PPS Number can be linked back to, and kept in synchrony with, the PPS Number, this is likely to undermine public support and hence the willingness to provide the number in order to receive healthcare services. It is unlikely that individuals will be required to provide an identification number as a condition for receiving treatment. Therefore, unless there is full support for the UHI, the benefits will not be realised and the system would be at risk of incurring increased costs as a result.

4.4 Best Practice in Identifying Patients

The New UHI represents international best practice.

Virtually all countries that have recently introduced, or are planning to introduce, a UHI have opted for one that is healthcare-focused and confined to the healthcare sector. The main exception to this is the Scandinavian countries which have been using the social security number for many years across all sectors.

4.5 Privacy and Security

The New UHI will be more secure and provide better protection of patient privacy.

The New UHI would be confined to use within the healthcare sector and hence the potential for leakage outside healthcare is greatly diminished. The fact that the Enhanced PPS Number would have to be exported outside the health sector in order to maintain synchrony with the PPS Number represents a potential security and privacy threat.

4.6 Impact on Existing Client Identity Services (CIS)

The Enhanced PPS Number would radically impact on CIS in the DSFA, which operates the PPS Number.

A UHI based on an Enhanced PPS Number assumes that the existing CIS operated by the DSFA would act as the trusted authority and would issue and maintain the UHI. This is likely to have a negative impact on their efficiency and productivity even if further resources are allocated. Prior to establishment of the Enhanced PPS Number for health, the existing PPS Number database will have to be cleansed to remove duplicates and multiple assignments. In addition, the two-way link synchronising the PPS data with the Enhanced PPS Number will need to be established, representing a significant burden on CIS and requiring radical changes to its business processes.

5 Conclusions and Recommendations

When the Enhanced PPS Number option for a UHI is compared to the New UHI, it appears that, in each section of the assessment, the New UHI emerges as the best fit for a UHI in Ireland. While both options may facilitate the linkage of personal health information, in practice, the issues related to individual privacy concerns, data integrity, minimisation of limitations, maximum benefits realisation and best international practice indicate that the most effective and safest choice is the development of a new built-for-purpose, healthcare focused UHI.

While details of the implementation of a New UHI are beyond the scope of this document, it is important to emphasise that the introduction of the UHI cannot commence until the full infrastructure to support its safe use is in place. If this is absent, serious risks of misidentification will arise from the inability to verify identity leading to serious patient safety concerns and serious risks to privacy through inadequate governance.

Therefore, in conclusion, the Authority recommends to the Minister for Health and Children that:

1. The current PPS Number is not used as the identifier for health and social care.
2. The safest and most cost-effective option for a UHI for Ireland is a new healthcare-focused identifier, which is based on international best practice.
3. The exact nature of this new identifier should be determined through regulation.
4. The Health Information and Quality Authority establishes a broadly representative group of stakeholders, chaired by the Authority.* This group should include representatives from the Department of Health and Children, Department of Social and Family Affairs, Department of Finance, the Data Protection Commissioner and a Patient/Public representative. The group will:
 - a. *determine the exact format of the New UHI*
 - b. *establish the appropriate governance arrangements*
 - c. *provide detailed costings both for capital and recurrent budgetary requirements*
 - d. *consider the relationship between the UHI system and the proposed National Client Index (NCI)†*
 - e. *support the development of a road map for the introduction (roll out) of the identifier.*
5. Based on international best practice, it is essential that an appropriate infrastructure and governance structure are put in place prior to implementation of a UHI.
6. The new identifier should be introduced as soon as possible.

* In relation to recommendation 4, following submission of this report to the Minister for Health and Children, she has requested her Department to establish a Group, representing key stakeholders, to finalise policy in relation to the UHI. The Authority supports this development and looks forward to working with the Group.

† The National Client Index (NCI) is a HSE project. It is an index which facilitates access to patient records, which may be stored in multiple locations and systems. An NCI is established by examining existing client records and building the index using a combination of automated and manual actions using specific client-matching criteria. An enterprise master patient index (EMPI) is the common term used to describe the technology which manages this index.

1 Introduction

1.1 Background

A unique health identifier (UHI) is fundamental to ensuring patient safety. Many common causes of adverse events, such as incorrect administration of medicines or transfusing the wrong blood into a patient, can be due to poor patient identification processes caused by basic human error, incorrect filing, or to a failure in communication. Throughout the healthcare industry, the failure to correctly identify patients continues to have the potential to result in medication error, transfusion errors, wrong person procedures and the discharge of infants to the wrong families.

This document, prepared by the Health Information and Quality Authority, examines the impact of implementing a UHI in the Irish health and social care system. It employs the framework of an evaluation following guidelines recommended by the Danish Centre for Evaluation and Health Technology Assessment (DACEHTA) ⁽⁴⁾. The purpose of this document is to present the facts and evidence available in order to obtain agreement on what the UHI should be, with a view to making recommendations to inform the forthcoming Health Information Bill which is due to be enacted early in 2010.

A UHI is defined as the designation permanently assigned to an individual for identification and should be governed by an independent central trusted authority. A UHI consists of a unique sequence of numbers and characters which provide a lifelong unique identifier for an individual and must support positive identification of an individual, automated linkage of electronic records, streamlining of records management and provision of a mechanism to strengthen security ⁽³⁾.

The National Health Information Strategy (NHIS) notes that “the use of a unique identifier should be considered as a logical extension of the use of a person’s name for identification purposes” ⁽¹⁾. Such an identifier scheme would be for all records pertaining to persons within the health and social care sector, and cover public and private sectors in Ireland throughout an individual’s lifetime.

1.2 Associated Benefits and Risks

The benefits of a UHI are wide ranging. However, it is difficult to separate the benefits attributable to the introduction of a UHI on its own from those which are associated with a UHI as a fundamental enabler of various applications such as the electronic health record (EHR). The main

benefits that can be realised through implementation of a UHI include the following⁽⁶⁾:

- Improved patient safety
- Improved quality of care
- Streamlining records management
- Reduction in repetitive and unnecessary care
- Enhanced confidentiality
- Reduced administrative costs.

The primary benefit is a reduction in adverse events thereby improving patient safety, the quality of care and a more positive patient experience. A UHI system promotes a patient-centred as opposed to the current organisation-centred view of health information. As a patient moves through the system, the potential for their information to accompany them is greatly enhanced. This increases safety, and reduces the need for unnecessary duplication and repetition.

From the healthcare professional's point of view, a UHI provides a way to identify an individual accurately thereby improving patient safety and quality. Finally, from the policy maker and planner's perspective a UHI allows data to be linked to monitor the health status of the population and to plan the necessary services and resources ⁽⁶⁾.

The benefits of a UHI scheme are well documented and the implementation of such a scheme has been on the Irish health information agenda since it was first referred to in the 2001 Health Strategy, *Quality and Fairness – A Health System for You* ⁽⁷⁾. The strategy recommends considerable investment in information and communications technology and infrastructure to support a new model of primary care. This includes an electronic patient record, based on a unique client number. Since 2001, the case for the implementation of a UHI has been further championed in the *National Health Information Strategy* (NHIS), 2004, and more recently in *Building a Culture of Patient Safety: Report of the Commission on Patient Safety and Quality Assurance*, 2008 ^(1;2).

Public opinion has also demonstrated a desire for the implementation of a UHI that would have appropriate safeguards ⁽⁵⁾. In 2008, the Authority commissioned a public opinion poll relating to the sharing of health information (see Appendix 3). It found that 96% of those surveyed thought that the same identifying number should be used across all healthcare settings. Similarly, at a consultative workshop on the proposed Health Information Bill hosted by the Department of Health and Children (DoHC) on 20 January 2009, the general consensus was in favour of the implementation of a UHI but significant concerns were raised over the suggested use of the Personal Public Service (PPS) Number as the identifier ⁽⁸⁾.

The UHI is widely praised for its benefits and the general improvements it brings to patient quality of life and its potential for cost savings, both as an intervention in its own right and also as the first step towards the development of an EHR. However, it is not without risks. Three key risks have been identified as follows:

- No legislation to support a UHI system
- Lack of resources in current economic climate
- Lack of public confidence or buy-in due to privacy concerns.

The first of these can be overcome in the near future as it is expected that the Health Information Bill will provide the legislative framework for the development and implementation of a UHI. In relation to the second point, evidence suggests that the savings that can be made from reduced administrative costs – and a reduction in adverse events – outweigh the costs of implementing and operating such a system ⁽⁹⁾. The third is perhaps the most potent risk as a lack of public confidence or buy-in will render the system ineffective if it is not used to its full potential.

The primary concerns in this regard relate to confidentiality and privacy. According to the public consultation by the DoHC in connection with the drafting of the Health Information Bill, there is some public opposition to the use of the PPS Number. If widespread, this could seriously undermine the universal use of the identifier in Ireland, with the associated reduction in the benefits realised and cost-effectiveness ⁽⁸⁾.

1.3 Criteria for Selection of a UHI

The criteria for selecting a UHI are based on those set by the American Society for Testing and Materials (ASTM) ⁽¹⁰⁾. The ASTM published the *Standard Guide for Properties of a Universal Healthcare Identifier* (UHID). Following extensive consultation with a wide range of stakeholders, necessary amendments to and groupings of the definitions were made to facilitate the application of the criteria in the Irish context.

In October 2008, the Authority hosted a round table discussion on the identification of the criteria according to which a decision on the nature of a UHI should be made. Attendees included representatives from the Authority, DoHC, Health Service Executive (HSE), Department of Social and Family Affairs (DSFA), Economic and Social Research Institute (ESRI), Institute of Public Health (IPH), National Cancer Registry of Ireland (NCR), Department of Finance, Data Protection Commissioner and the National Standards Authority of Ireland (NSAI).

There are 32 criteria in Ireland, based on the 30 criteria set by the ASTM, and these are divided into 'fundamental criteria' and 'differentiating criteria'. The fundamental criteria are the primary criteria that any potential UHI must satisfy. They allow the specification of the minimum requirements of a UHI scheme in order to be selected. Any potential

UHI that fails to satisfy any of the fundamental criteria is deemed unsuitable for use as a UHI in Ireland. The differentiating criteria are the distinguishing criteria listing the desirable properties of a potential UHI. Potential UHIs that have met the fundamental requirements were assessed against the differentiating criteria to allow for the emergence of the most suitable option for selection.

The following numbers were tested against the criteria (see Appendix 2 for a summary of the findings):

- PPS Number
- An Enhanced PPS Number
- A New UHI
- Medical card number
- Drug Payment Scheme number
- Birth notification number
- European Health Insurance number
- Passport number
- Driving licence number

Only two options, a new UHI and the Enhanced PPS Number, satisfied the 25 fundamental criteria and were deemed suitable to be tested against the differentiating criteria. As the options for a UHI were reduced to two, the next step in the process was to highlight the benefits, risks and costs of each of these two options to determine which is best for the Irish healthcare system. Although the benefits and risks are well documented, the cost of implementing such a system in addition to the costs that can be saved by doing so are somewhat more difficult to quantify. In light of this it was determined that a structured assessment on the intervention should be conducted firstly to discern if a UHI should be implemented and if so, which of the two options would be the most suitable.

1.4 Evaluation Methodology

A comprehensive, systematic and objective methodology is required in order to provide a rigorous comparison between the two candidate identifiers – the Enhanced PPS Number and the New UHI. Such a methodology is provided by the principles of health technology assessment (HTA). HTA is concerned with the study of the medical, social, ethical and economic implications of development, diffusion and use of health technology ⁽⁴⁾. In this case, the ‘technology’ is the implementation of a UHI. The evaluation approach used is that of a so-called ‘mini-health technology assessment’ which takes the form of a checklist with a number of questions concerning the prerequisites for and consequences of using (new) health technology. It examines the medical, social, ethical

and economic implications of implementing a UHI based on international experience and on the information available at national and local level.

The evaluation took the form of a checklist with a number of questions concerning the prerequisites for and consequences of using (new) health technology, in which:

- The questions are grouped according to the four perspectives: technology, individual, organisation and economy
- The answers to the questions provide a brief written basis for decisions and should take, based on experience, five to 15 hours, excluding the time spent on information retrieval and assessment, and economic calculations
- The purpose is to provide (part of) the decision-making basis for a proposal to introduce a specific new health technology or in connection with changes in the indication for the use of existing technology
- Both the preparation, and the use of the decision-making basis, may take place at local or regional level and be adapted to local or regional objectives, decision criteria and time schedules.

The use of this approach to evaluation enables the assessment to be undertaken within a short timeframe and to provide a contribution to the basis for decisions at the time when needed – in this case informing the Health Information Bill.

The evaluation explores the economic effectiveness of implementing a UHI. The basic objective of an economic analysis is to identify, measure, and value the comparative costs and effects of alternative healthcare interventions. The four most common types of economic evaluation are cost-minimisation analysis, cost-effectiveness analysis, cost-utility analysis, and cost-benefit analysis. This information informed the recommendation of the UHI as cost-effectiveness is one of the differentiating criteria for selection.

There are limitations to this approach due to the fact that costing information available is indicative and based on best estimates. In light of the limited information available, the accuracy and effectiveness of this assessment is based on a number of assumptions (Section 3) and the information used is primarily gleaned from international experience. Furthermore, the assessment does not fully reflect the cost benefits of a UHI as the improvements in patient safety and quality of life are not easily quantifiable.

2 About the Personal Public Service (PPS) Number

In recognition of the widespread use of the PPS Number throughout the health and social care sectors (see Appendix 4 for details), and the expectation that it should be significantly cheaper than a new identifier, this section provides a more detailed explanation of the implications of the failure of the current PPS Number to meet the criteria for an identifier for health. This analysis shows that, far from saving money, the use of the current PPS Number would not only fail to deliver the benefits of a UHI but could in the longer term lead to increased costs.

2.1 Introduction

As previously stated, this project adopted a two-phased approach to the selection of a UHI. In the first phase, a set of 32 criteria were agreed by a wide range of stakeholders as the basis for the selection of an appropriate identifier for Ireland. These were based on the 30 criteria set by the ASTM. Details of these criteria will be found in Appendix 1. Several numbers, including the current PPS Number were assessed against these criteria. The current PPS Number failed to meet eight of the fundamental criteria, namely accessible, assignable, content-free, healthcare-focused, legislated for, based on industry standards, atomic, and universal as detailed below, and was therefore eliminated from further evaluation.

The current PPS Number failed on the following criteria:

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

5. **Legislation.** The legal framework must be in place to permit the use of the UHI in healthcare. Current legislation specifically forbids the use of the PPS Number for health and social care purposes.
6. **Standards-based.** A UHI should be based on international or industry standards. The PPS Number itself is not designed to act as a unique identifier, rather it is a personal number for use in accessing public services; it was not designed in line with international best practice for identifiers.
7. **Atomic.** A UHI should be a single data item and should not contain any elements which can be decomposed to provide any meaningful information. As noted above, approximately 200,000 of the current PPS numbers include a “w” indicating a married woman, although these are being phased out.
8. **Universal.** There should be sufficient capacity to be able to generate new numbers as required into the foreseeable future. Based on the current average issue rate, the remaining PPS Numbers available will run out by 2012, although plans are being put in place to extend the number.

2.2 Current Use of the PPS Number in Health

Currently, the use of the PPS Number in health is for administrative purposes only and is not used to link clinical data (see Appendix 4 for details). A “live” link is needed to verify the identity of an individual at the point of care however there is no “live” link with the CRS in the DSFA for any of the sources that use the PPS Number. Some retrospective verification is carried out for the cancer screening programmes.

Public hospitals use the PPS Number for administrative purposes to record births and deaths and also when sending information to the Primary Care Reimbursement Service (PCRS) for patients claiming benefits. The NCR records information on a specific cancer in a patient for a year, and tracks the patient throughout their lifetime (that is, subsequent cancers and/or recurrences of the primary are recorded, regardless of the interval). The NCR has previously tried to extract the PPS Number or General Medical Services (GMS) number from records but these are not normally recorded in hospital systems or charts. While the Health Information Bill could remove the legal impediment to the use of the PPS Number in clinical systems, the fact remains that it is not currently used for these purposes and all existing systems would have to be modified to be able to accept the PPS Number. This would also be the case for any UHI. There is a fundamental difference between using an identifier such as the PPS Number to verify the entitlement to services or reimbursement and the use of an identifier to verify the identity of an individual at the point of care in order to link clinical data about that patient.

2.3 Issues with the PPS Number

The 32 criteria for a UHI include the requirements for the infrastructure to support the implementation of the identifier. The current infrastructure operated by the Client Identity Service in the DSFA for the PPS Number does not meet these requirements and does not conform to international best practice. There is a serious risk of misidentification arising from the inability to verify identity at the point of care leading to serious patient safety concerns. A significant overhaul of the existing infrastructure would be required.

The introduction of the PPS Number as a UHI, without first putting in place the necessary enhancements and infrastructure outlined above – a ‘bottom-up’ approach – will create many significant difficulties. Verification of the patient identity is central to the success of the UHI project and if this cannot be done in real time, misidentification is inevitable. A review of other countries that have implemented, or are in the process of implementing a UHI, has been completed ⁽⁶⁾. All these countries have taken a ‘top-down’ approach and developed a central authority to govern the UHI first. Verification of an individual’s identity as well as assignment of numbers to individuals is also done in real time.

A study carried out by Waldmann in 2002, identified the need for a UHI for cervical screening in Ireland ⁽¹¹⁾. Waldmann concluded that client demographics, such as address, that are recorded on information systems are not reliable as they change so quickly. This highlights the need for a central trusted authority to identify clients which puts effort and resources into maintaining one source rather than having multiple sources. In relation to the PPS Number, the study found for 77,451 individuals registered with the Irish Cervical Screening Programme (ICSP), 1% (768) did not have a PPS Number recorded due to a number of reasons. Three per cent (3,450) had both a primary and secondary PPS Number and 10 clients had two records where the PPS Number was different in each record. As a result the ICSP now receives a monthly import file from the DSFA for all female clients aged 25 to 60. Using the download from the DSFA, the ICSP database is updated. Verifying an individual’s identity is a key component of screening, however the current processes are time consuming, costly and also not done in real time. In addition, other organisations such as the NCR and the Mental Health Commission are specific bodies that are legislated to collect the PPS Number. However, both organisations in the past have found it difficult to collect.

In addition to the fact that the PPS Number is not healthcare focused, there are serious privacy concerns associated with its use in healthcare and for the potential for leakage of health information outside the health sector. While both the Authority’s RED-C poll, and the public consultation on the Health Information Bill, demonstrated universal support for a UHI, the latter revealed universal opposition to the use of the PPS Number as the identifier for health.

The current PPS Number fails on eight of the 25 fundamental criteria for a safe health identifier. Using the PPS Number as a UHI **without** addressing these issues will give rise to serious patient safety concerns and potentially increased costs. The safety concerns arise from the potential for misidentification while the increased costs arise in the main from the need to correct identification errors and add missing ones. Examples of scenarios where problems are likely to occur if the current PPS Number is used as UHI are given below.

- For individuals **who do have a PPS Number** and are able to produce it at the point of care, without a real-time link to the central authority, the healthcare setting will only be able to verify whether the PPS Number is in the correct format. They will not be able to verify that the PPS Number belongs to that person. If the identity of the individual cannot be verified, linking records is unsafe. If the identifier cannot be verified then resources allocated to collect the identifier will be wasted and the benefits and cost savings associated with a UHI will not be realised.
- A UHI system should be available whenever and wherever required for registration and positive identification. Also, the UHI system must be able to generate temporary identifiers where the UHI is unavailable or if an individual does not have a UHI. However, this function does not currently exist with the PPS Number. The following are examples of the problems that could arise in the absence of a system to support these functions being in place.
 - If an individual arrives at a healthcare setting and **does not have a PPS Number**, for example, a person on holidays in Ireland from abroad or an asylum seeker, the healthcare setting will not be able to assign a PPS Number. And, since there is no method to assign a temporary number, this cohort of individuals will not have identifiers associated with their episode of care
 - It is essential to be able to assign an identifier to newborns immediately. Currently, the PPS Number is only assigned once the birth has been registered which can take several weeks
 - If an individual arrives at a health or social care setting and **does not know their PPS Number**, the healthcare setting will have no means of looking up and assigning the PPS Number to that individual for that episode of care. And again, there will be no means of temporarily assigning an identifier to that individual
 - The lack of a temporary identifier could also pose difficulties in major emergencies or, more generally, if an individual arrives at a health or social care setting and is unconscious and unable to provide identification .

- International evidence shows that the capital cost of introducing a UHI is recovered in the first few years of operation but only if the UHI is used virtually universally throughout the healthcare system. If only a proportion of the records in the system include the PPS Number as the unique identifier, it will be much less effective and most of the benefits will not be realised. Linkage of records where linkage can occur will be incomplete and the use of data for planning purposes will also be limited. If the benefits cannot be realised, the efforts and resources spent collecting, verifying and maintaining the data will be wasted.
- Patients accessing health services in Ireland are registered and re-registered at every individual point of service where they access care. Even when transferring between different points of service within a healthcare system, individuals are typically re-registered. In the absence of a central authority to register individuals consistently, while it may be feasible to ensure that identity is managed correctly at local level, the PPS Number could be recorded differently leading to duplicates and potential conflicts. Some records will not have a PPS Number, and it will be very difficult to identify where these duplicates exist. The resources required to implement the PPS Number as a UHI locally would provide virtually no added value while at the same time incurring additional costs.
- In the absence of a central authority with multiple points of registration, healthcare settings will probably need to develop their own 'mini index' to manage identification for individuals locally. The cost of developing such a 'mini index' within each healthcare setting will far outweigh the cost of implementing the central structure necessary to implement a UHI.

2.4 Conclusions

The safe use of the current PPS Number as a UHI requires all the infrastructural support required for the Enhanced PPS Number to be in place. Failure to put these in place before commencing the collection of PPS Numbers will result in an unsafe system leading to increased risk of misidentification. The cost of adapting existing clinical information systems to accommodate an identifier is independent of the nature of that identifier, i.e. it would be the same for the PPS Number, the Enhanced PPS Number or a New UHI. Furthermore, the work involved in adding missing PPS Numbers, or correcting ones that are incorrect, would represent a huge burden on the healthcare system. It is a fundamental principle of high quality, reliable and safe data collection systems that data is captured and verified at source. Effectively such an approach would be unworkable and the cost of cleansing the resulting data would be prohibitive.

3 Assumptions

The economic evaluation of an Enhanced PPS Number and a New UHI is based on the following assumptions:

- Personal health information is defined as information, recorded in any form or medium, which is created or communicated by an organisation or individual relating to the past, present or future, physical or mental health or social care of an individual or cohort.
- The introduction of a UHI will include, as a minimum, the following benefits:
 1. Improved patient safety
 2. Improved quality of care
 3. Streamlining records management
 4. Reduction in repetitive and unnecessary care
 5. Enhanced confidentiality
 6. Reduced administrative costs.
- The evaluation only examines the effects of a UHI in itself not the longer term costs or benefits that may be associated with, for example, the EHR.
- The Enhanced PPS Number, and a New UHI, are the only two options available for implementation as determined by the criteria for selection.
- Either option will require new or enhanced infrastructure for assignment and implementation.
- The Enhanced PPS Number will be permanently linked to the current CRS database which is managed by Client Identity Services (CIS) within the DSFA.
- The implementation of a UHI will be undertaken in a phased manner.
- Support and co-operation of the stakeholders is forthcoming.
- The skills and expertise required to manage the implementation and operation of a UHI can be successfully recruited.

3.1 Conflicts of Interest

There were no conflicts of interest declared by those individuals involved in this process.

4 Review of Options

The Enhanced PPS Number, the New UHI or the 'do nothing approach' are the options assessed in this evaluation.

4.1 Option 1: Enhanced PPS Number

Definition:

Enhancing the PPS Number involves improving or modifying the functionality and properties of the current PPS Number such that it can satisfy all of the criteria for selection of a UHI for individuals. The current PPS Number failed the following criteria: accessible, assignable, content free, healthcare focused, legislated for, based on industry standards, atomic and universal (see Appendix 2).

Therefore, while the PPS Number in its present format would be both unsuitable and unsafe as a UHI, it is possible to enhance it in such a way that it could be used safely. Furthermore, its nationwide coverage and existing infrastructure make it an obvious candidate for enhancement.

The following enhancements to the current PPS Number and CRS are necessary – a database which is managed by CIS within the DSFA – in order to ensure the criteria for selection of a UHI are satisfied:

- The CRS must be upgraded such that the client search function is accessible at all times, day and night, by all authorised personnel within healthcare
- The CRS must be extended and upgraded such that an Enhanced PPS Number can be assigned immediately at any time and at any health care organisation via an interface with their local patient administration system (PAS) upon receipt of a properly authenticated request
- The CRS must be enhanced such that it can issue temporary health identifiers (THI) for episodes of care where the individual's identity cannot be verified
- The PPS Numbers currently in circulation with a second alpha character, a 'w' which identifies the individual as a married female must be replaced with content free atomic numbers
- An algorithm to generate a UHI from the original PPS Number, which is not recognisable as a PPS Number and cannot obviously be converted back to the PPS Number, must be added to the functionality of the CRS to ensure the number is healthcare-focused

- The algorithm to generate a UHI from the PPS Number must generate a new number that is based on international best practice and takes guidance from CEN* and International Standards Organisation (ISO) standards
- Irish legislation must be amended to include the use of the Enhanced PPS Number for the purposes of identification of individuals in the provision of health and social care in Ireland
- The PPS Number must be extended to ensure longevity, universality and support for every living person in Ireland for the foreseeable future.

It is assumed that the Enhanced PPS Number will be permanently linked to the current CRS database within the DSFA. Updates will be synchronised regularly.

4.2 Option 2: A New UHI

A New UHI means introducing a new number for use in the health and social care setting. It should have the following components:

- a unique identifier
- a delimiter and check digits (both format-verification techniques)
- an appropriate data set
- an encryption scheme to support data security
- a central governing authority.

It must satisfy all 32 criteria for selection of a UHI in Ireland.

A New UHI must support positive identification of individuals, automated linkage of various computer-based records, a mechanism to support data security and the use of technology to reduce unnecessary healthcare operating costs in handling individual identification.

Encrypted UHIs are included in the criteria for hiding the identity of individuals while linking information. Separate encrypted UHIs should be allowed for different episodes of care for the same patient. A New UHI numbering system would also allow for the use of a THI controlled by individual organisations for emergency use. Any THI could be subsequently linked to the correct UHI and all information transferred.

A central trusted authority should be responsible for processing requests for a New UHI, to include the issue of UHIs, computation of check digits, choice of encryption scheme, generation of encrypted UHIs and maintenance of either a cross-index between encrypted and unencrypted UHIs or an appropriate secure decryption scheme to link the two.

* The European Committee for Standardisation (CEN) is a business facilitator in Europe, removing trade barriers for European industry and consumers. Its mission is to foster the European economy in global trading, the welfare of European citizens and the environment. Through its services it provides a platform for the development of European Standards and other technical specifications.

4.3 'Do Nothing Approach' – no Implementation of a Unique Health Identifier

If the UHI is not implemented, the current methods of identification for the provision of health and social care in Ireland will remain. On any transfer between different points of service within the healthcare system, individuals are typically re-registered and assigned new identifiers that are used only within that service setting. Apart from a national approach adopted for certain broadly administrative purposes, some regional health systems, and the systems of the private health insurance sector, client/patient identification systems are typically unique within each agency or department in the primary and secondary care domains.

None of the benefits outlined in the earlier document 'Proposal for the Introduction of a UHI for Ireland' – produced by the Health Information and Quality Authority and the HSE and which is part-one of this project to identify a UHI for Ireland – can be realised if the UHI is not implemented ⁽⁶⁾.

5 Evaluation

5.1 Introduction

The following provide the key determinants for the evaluation of the technology.

5.1.1 Who is the proposer?

The introduction of a UHI for Ireland is proposed by the Health Information and Quality Authority as per Action 16 in the NHIS, 2004 ⁽¹⁾.

5.1.2 What is the name/designation of the health technology?

UHI for individuals.

5.1.3 Who are the stakeholders?

The following are stakeholders:

- General population of Ireland
- Healthcare professionals
- Department of Health and Children
- Health Service Executive
- Health Information and Quality Authority
- Data Protection Commissioner
- Professional bodies
- Patient/client representative bodies
- Centre for Management and Organisational Development (CMOD) in the Department of Finance
- Department of Social and Family Affairs
- Private health insurers
- Private health providers
- Any other interested parties.

5.1.4 Structure of the Evaluation

The evaluation explores the following in relation to the UHI:

- **Technology** – the technical implications of implementing a UHI
- **Individual** – the impacts of the UHI on the general public of Ireland
- **Organisation** – the impacts of the UHI on the Irish healthcare sector and associated sectors
- **Economic Implications** – the financial implications of implementing a UHI in Ireland.

These are explored in more detail below.

5.2 Technology

5.2.1 What is the Indication for Use?

It is proposed that a unique number for the positive identification of individuals is introduced to facilitate the safe, effective and efficient provision of health and social care in Ireland.

5.2.2 How the Technology is New Compared to Existing Practice

Patients accessing health services in Ireland are registered and re-registered at every individual point of service where they receive care ⁽¹²⁾. This includes GP surgeries, outpatient clinics, hospitals and admissions. When transferring between different points of service within the healthcare system, patients are typically re-registered and assigned new identifiers that are used only within that service setting.

The proposed UHI would be a designation permanently assigned to an individual for identification purposes and would be unique across the entire national healthcare system.

5.2.3 Information Gathering

In the course of the project the Authority met with a number of stakeholders in order to source information. The meetings/calls that were held are detailed in Appendix 5.

A literature review was undertaken by the Authority to facilitate the development of this report. High quality research was demonstrated in the documents reviewed. However, it is noteworthy that there is a limited amount of literature available on this subject.

5.2.4 Effect of the UHI on Individuals

The main effect of both a New UHI, and an Enhanced PPS Number as a UHI, would be an improvement in the levels of patient safety by facilitating the availability of critical health information at the point of care. *Building a Culture of Patient Safety: Report of the Commission on Patient Safety and Quality Assurance (2008)* ⁽²⁾ states that the Irish health system needs to move towards a more robust and strategically managed approach to ensuring that patient outcomes can be measured and assessed at all levels of the service. The Report identifies the development and implementation of a unique identifier for every member of the population as a fundamental step towards achieving this goal. It will ensure that every time, and wherever, an individual uses the health service, the information relating to that episode of care is identifiable to that person and can be accessed by healthcare professionals, subject to appropriate information governance arrangements, in order to ensure that the information for every individual travels with them and supports the provision of safe seamless care.

A study in the United States (US) carried out by the Research and Development (RAND) Corporation in 2008 has shown that in a subset of 42,000 records taken from a database containing 80 million records, in the absence of a UHI, false positive identification errors (where the patient is matched to the incorrect record) can occur in one out of every 3,500 cases. It has also shown that false negative errors where part(s) of a patient's record are not identified can occur in 7.2% of records in a master patient index (MPI) with less than half a million records. These identification error rates can rise 39 % when MPIs are combined to form an enterprise master patient index (EMPI) ⁽⁹⁾.

A UHI, that is implemented in line with the criteria detailed in Appendix 1, will also protect patient privacy through the maintenance of secure records, centrally governed by a trusted authority. It is expected that a UHI will improve the patient's confidence in the healthcare system. However, it must be noted that individuals may have privacy concerns with an Enhanced PPS Number due to its potential to be linked back to the original PPS Number.

The individual will realise a reduction in the repetition of the same information when completing forms for identification purposes at every point of care, allowing for a more seamless journey through the various healthcare settings, thus facilitating improved efficiency and effectiveness by applying the principle of collecting information once and using it many times. As an individual moves through the system, the potential for their information to accompany them is greatly enhanced. This increases safety and reduces the need for unnecessary duplication and repetition of tests and investigations ^(9;13).

5.2.5 Risks Associated with the UHI

A key risk associated with the implementation of either option for a UHI is that at present there is no legislation to support such a system. However, as part of the Health Reform Programme, the DoHC is preparing new legislation on the collection, use, sharing, storage, disclosure and transfer of personal health information as well as ensuring that the privacy of such information is appropriately respected. It is expected that the Health Information Bill will provide the legislative framework for the development and implementation of a UHI.

Lack of public confidence, or buy-in, is another associated risk as both a New UHI and an Enhanced PPS Number would be rendered ineffective if not used in all care settings. Controversy over the development and implementation of a UHI centres primarily around confidentiality and privacy concerns. Results of an opinion poll conducted on behalf of the Authority showed that 96% of those that participated in the survey thought that the same identifying number should be used across all healthcare settings ⁽⁵⁾. The risk of threats to patient privacy and confidentiality are dramatically reduced by the implementation of a New UHI or Enhanced PPS Number. However, in the case of the Enhanced PPS Number there may still be public concern over linkage to the original PPS Number data. Additional safeguards are due to be provided for in the upcoming Health Information Bill, which aims to underpin an effective information governance structure for the health system.

A further potential risk is a lack of resources in terms of the cost of implementing and maintaining such a system, particularly given the current downturn in the Irish economy. It is vital to invest in the appropriate governance structure in advance of any UHI implementation, otherwise patient safety will be seriously compromised as a result of misplaced trust in the use of invalid identifiers.

The cost effectiveness of the implementation of the UHI cannot be fully guaranteed at this point but international evidence from New Zealand, Canada, the United States of America and the United Kingdom, in addition to evidence gleaned at hospital level in Ireland, indicate that the initial investment required to establish the UHI will be less than the savings that can be achieved in its first year of implementation ⁽¹⁴⁾. The savings that can be made from the reduction in adverse events due to correct identification of individuals alone are significant. Studies of adverse events in the United States, Australia, the United Kingdom and Canada have indicated that between 4% and 16% of patients admitted to hospital experience one or more adverse events, of which up to half are preventable ^(9;13;15;16).

Errors are not only costly in terms of human suffering and mortality; they also result in loss of trust in the healthcare system by individuals and diminished satisfaction by both patients and healthcare professionals. They are also very costly in financial terms with adverse events estimated

in 1999 to result in total costs (including the expense of additional care necessitated by the errors, lost income and household productivity, and disability) of between \$17 billion and \$29 billion (€13 billion - €22 billion approximately) per year in hospitals in the US ⁽²⁾.

In 2004 in the United Kingdom (UK), the National Patient Safety Agency published a report, *Right Patient, Right Care*, which demonstrated how patients can erroneously receive healthcare which is not intended for them or be matched with specimens other than their own. In this paper, the estimated annual cost to the National Health Service (NHS) is £2 billion (€2.15 billion approx.) in extra hospital days ⁽¹⁵⁾. Although these figures are based on significantly larger populations than Ireland it is likely that the proportionate number of errors, adverse events and, therefore, cost of misidentification in Ireland could be even higher, owing to the fact that the UK has at least in part begun the process of implementing a UHI.

5.2.6 International Studies of the Effect of the UHI

A number of studies have been completed internationally on the effects and associated benefits of the implementation of a UHI.

The National Health Index (NHI) system was implemented in New Zealand in 1992 ⁽¹⁷⁾ and since its introduction the potential to confuse patients and their information has been drastically reduced ⁽¹⁷⁾. In 2008, the RAND Corporation completed a report titled *Identity Crisis – An Examination of the Costs and Benefits of a Unique Patient Identifier (UPI) for the U.S. Health Care System* ⁽⁹⁾. RAND researchers examined the costs of creating a unique patient identification system, compared the error rates of such a system and its alternatives, and examined the operational advantages and disadvantages of the technology. The study concluded that one of the primary benefits created by broad adoption of unique patient identifiers would be to eliminate record errors, and help reduce repetitive and unnecessary care. The report draws a number of conclusions which are of relevance in the Irish context as follows:

- Broad adoption of a UPI should enhance the US healthcare system
- A hybrid system using both statistical matching and a UPI will be necessary for the foreseeable future
- The controversy surrounding the UPI and privacy is misplaced – security and privacy could in fact be strengthened with a UPI
- Costs of a UPI are significant, but probably much less than the value associated with error reduction, efficiency, and interconnectivity of the healthcare system.

The Newfoundland and Labrador Centre for Health Information implemented a provincial Unique Patient Identifier(UPI)/Client Registry(CR) in 2001. An evaluation was carried out by Canada Health Infoway and the major benefits achieved, according to this evaluation were improved

data access and data quality; revenue and cost recovery/avoidance opportunities; and capacity building, including the development of a toolkit which can be shared with other jurisdictions ⁽¹⁸⁾.

5.2.7 Has the Implementation of the UHI Previously Been Proposed?

Although the development and implementation of a UHI has been recommended in *Quality and Fairness – A Health System for You* (2001) ⁽⁷⁾, the *National Health Information Strategy* (2004) and *Building a Culture of Patient Safety: Report of the Commission on Patient Safety and Quality Assurance* (2008) ⁽²⁾, no national proposal to develop a UHI has been put forward as of yet. A UHI has also been recommended in a number of other documents, namely: *Building Healthier Hearts – Introduction to the Report of the Cardiovascular Health Strategy Group* (1999) ⁽¹⁹⁾; *A Vision for Change – Report of the Expert Group on Mental Health Policy* (2006) ⁽²⁰⁾; and *A Strategy for Cancer Control in Ireland* (2006) ⁽²¹⁾.

5.2.8 Has the UHI Been Recommended by any Authority?

The Health Information and Quality Authority has recommended a UHI as the Authority recognises the wide ranging benefits that can be realised through implementation and as a result of Action 16 in the *National Health Information Strategy*. The development of a UHI was first referred to nationally in the 2001 Health Strategy document, *Quality and Fairness – A Health System for You*, stating that the use of a unique identifier in the health field is of major importance in achieving the highest quality of care and in the delivery of patient-centred services ⁽⁷⁾. The *National Health Information Strategy* further re-inforced this stating that the effectiveness of *Quality and Fairness* will be significantly enhanced by the implementation of unique identification. Action 16 of the Strategy states that the Health Information and Quality Authority will prepare a plan for a unique identification system that meets the functional requirements of the sector ⁽¹⁾.

5.2.9 Technology: Summary and Conclusions

The current structure of health information in Ireland is extremely fragmented and as such is failing to reach its potential of ensuring safer and better care for patients. The proposed implementation of a UHI would be a designation permanently assigned to an individual for identification purposes and would be unique across the entire national healthcare system. In short this would lead to increased patient safety, improved patient privacy, a reduction in administrative costs and an overall more seamless journey for the individual. The implementation of such a system is not without risk. However, the primary concerns are that there is no legislation to support it, a lack of resources and a lack of public confidence or buy-in. These represent the high level benefits and risks of implementing a UHI, which must be examined in more detail relative to the options that are being considered.

Although the Enhanced PPS Number has satisfied the fundamental criteria for the selection of a UHI there are some concerns around its use which could result in the implementation of a UHI system not achieving the full benefits. There are concerns around the linkage to tax records and information which may result in a reduction in public buy-in and confidence in the system. These components have been identified as critical success factors. This will in turn dilute one of the primary benefits, which is enhanced patient privacy.

It has been assumed that an Enhanced PPS Number will be the more cost-effective alternative; this may not necessarily be the case as a system based on the Enhanced PPS Number will also need a new infrastructure and enhancements to the point that it will satisfy the criteria as documented in Appendix 1. An Enhanced PPS Number may also inherit any limitations of the current PPS Number system.

Furthermore, evidence shows that more recent UHI systems that have been successfully implemented or are currently undergoing implementation have not opted for a system based on the social security number, the equivalent of the PPS Number ^(9;10;13;15;22-27).

It is likely that a new UHI will not incur as many obstacles as the Enhanced PPS Number as it can be purpose built to satisfy all of the fundamental and differentiating criteria. The design of a completely new system also allows for full compliance with data protection and privacy laws. Furthermore, it is not anticipated that a completely new system will be any less cost-effective than one based on an Enhanced PPS Number.

Thus under the heading of technology in the assessment, a new UHI is likely to be more favourably received by the main stakeholders, the service users.

5.3 Individual

This section reviews the effects of the implementation of an Enhanced PPS Number or a New UHI on the individual.

5.3.1 Ethical and Psychological Considerations

There are three main areas of concern for consideration when planning implementation of a New UHI or an Enhanced PPS Number as follows:

- privacy
- identity theft
- misuse of information.

Privacy: concerns have been raised around privacy and security of health information as the debate around the implementation of a UHI has moved into the public domain. However, 96% of people questioned in a survey conducted on behalf of the Authority in 2008 thought that the same

identifying number should be used across all healthcare settings ⁽⁵⁾. This demonstrates public confidence in the security of such a system but this confidence is diminished when it is suggested that this number be linked to the PPS Number. In reality a new UHI offers greater safeguards and guarantees of privacy than the current system as the legislative and governance frameworks will allow for safeguards for the protection of such information. The legislation that is currently being developed in the form of the Health Information Bill will take account of the Data Protection and Freedom of Information Acts. Furthermore, one of the stakeholders involved in providing comments and feedback into the process of defining the criteria for the selection of a UHI, which must be satisfied, was a representative of the Office of the Data Protection Commissioner (see Appendix 1).

Identity theft: concerns have been raised in relation to potential for identity theft. The risk of this is minimised most by using a new UHI that is solely developed for healthcare purposes and has no link to any other data set. Safeguards introduced in the forthcoming Health Information Bill in addition to an information governance framework, and with a new UHI satisfying the criteria as outlined in Appendix 1, will help to diminish the risk of identity theft.

Misuse of information: within any healthcare environment there is potential for the misuse of information. Although this is an area that must be given serious consideration, it must be noted that the risk in no way increases through the implementation of a UHI. It is widely recognised that it can in fact improve security and allow for safeguards and penalties against the misuse of health information. A number of the criteria for selection of a UHI focus specifically on patient confidentiality and security issues. In addition it is expected that the forthcoming Health Information Bill will underpin an effective information governance structure, which would safeguard against the misuse of information.

5.3.2 Influence on Individual Quality of Life

The successful implementation of a New UHI, or an Enhanced PPS Number as a UHI, has the potential to improve an individual's quality of life in a number of ways:

- It is widely acknowledged that a UHI system improves patient safety thereby reducing the number of adverse events in healthcare settings
- Both UHI options allow for a more seamless experience of the healthcare system owing to time saved in providing identification information, repetition of tests that have already been conducted and an overall more efficient administrative process
- Public confidence in the system is also improved as a UHI system that is correctly implemented will have appropriate safeguards guaranteeing the individual peace of mind about the privacy and security of their health information.

For example, from May 2003 until May 2005, 10 hospital sites in Ireland agreed to report blood transfusion near miss events to the National Haemovigilance Office in order to ascertain risks associated with transfusion. There were 759 events reported and of these, 59 were categorised as high risk. Twenty-six of the high risk events related to identification errors. Had these near misses become true adverse events, the quality of life of each individual would have been adversely affected ⁽²⁸⁾. It is likely that the implementation of a UHI would reduce the risk to individual quality of life that can be associated with this type of event.

5.3.3 The Individual: Summary and Conclusions

The benefits of a UHI to the patient have been well documented primarily in terms of a more seamless journey through the healthcare system and improved levels of patient safety. A UHI which satisfies the fundamental criteria as set out in Appendix 1 can provide these benefits. It is not only the direct benefits that must be considered, however. As set out above, any evaluation of the options should also explore any potential ethical considerations that arise as the result of the intervention. It is here that significant differences come to light between the two options.

Privacy issues with regard to possible linkages between health information and financial information are of primary concern and will need to be addressed appropriately. A health identifier that is in any way linked, or indeed is perceived to be linked, to any financial information could result in public suspicion and an overall lack of confidence in such a system. A completely new UHI is likely to generate a greater level of public confidence than a number in any way linked to the PPS Number or its systems. Patient peace of mind and inherent trust in the system is paramount to the successful implementation of a UHI.

A new UHI developed solely for healthcare purposes is a more favourable option for the patient in terms of the potential success of the system. As has been highlighted at several points in this report, public buy-in is crucial to its success. The PPS Number system is recognised to be flawed and as such an Enhanced PPS Number may inherit these limitations, which may be more costly in the realm of healthcare – both to individuals in terms of safety and quality of service and at an organisation level. A new UHI will help to inspire greater levels of public confidence in the system. It is worthy of note that internationally a new UHI has been the popular choice. This is recommended to ensure the UHI remains health focused over time i.e. that the use of the health identifier will not extend into other sectors. It can also further guard against the misuse of information.

5.4 Organisation – the Irish Health System

This section outlines the impact that a UHI would have across the Irish health system from the perspective of a number of organisations within it.

5.4.1 Impact of UHI on Organisations and Staff

International research has shown that the use of a UHI will positively impact on organisations and staff ^(6;9;12;13;16;17;22;24;26). Some of these benefits include:

- Safer treatment through having the right clinical details for the right individual
- A reduction in the occurrence of adverse events due to the non-availability of up-to-date and accurate information, particularly regarding medications
- Providing better mechanisms for patient follow up and preventative care by managing routine patient events, for example, cervical screening, BreastCheck screening, eye tests
- A reduction in the number of duplicate pathology tests, radiology, prescriptions, and appointments
- Maintaining accurate personal information about an individual such as current address and contact details to ensure up-to-date patient records, and support efficient communication
- Less time wasted searching for and/or re-gathering information
- Analysing and allocating healthcare service resources in a more timely and efficient manner, and also aiding service planning
- Monitoring safety and quality of health service provision
- Areas of health inequalities would be more easily identified and the ability to perform impact assessment and demonstrate improvements in health in line with national targets would also be possible
- More complete information on which to base potentially life critical clinical decisions (ISO/TS22220*)
- The longitudinal national view of anonymised linked information facilitated by the UHI can bring many benefits to public health
- Facilitating effective epidemiological and population-based research.

* This is a standard set by the International Standards Organisation. ISO/TS 22220:2009 indicates the data elements and structure suited to accurate and procedurally appropriate and sensitive identification of individuals in a face-to-face healthcare setting is supported by computer technology, or through interactions between computer systems. It provides guidelines for improving the positive identification of subjects of care within and between healthcare organisations.

5.4.2 Can the UHI be Implemented within Present Physical Settings?

A central trusted authority and secure central repository will be required for the management of the Enhanced PPS Number or the New UHI. In either case, present organisational and provider physical settings will be unaffected by implementation of the UHI, that is, it is assumed that current hardware in place in organisations is sufficient for the management of the UHI.

5.4.3 Will the UHI Affect other Service Functions?

A number of meetings were held with various stakeholders (see Appendix 5) to discuss the impacts of the UHI. The following key areas were identified during these information gathering sessions which demonstrate how the UHI for individuals will address core issues raised:

- The NCR in Ireland has stated that the implementation of a UHI would solve a number of difficulties experienced in gathering complete information for the Registry. The Registry provides a life-long record of the care pathway for each cancer patient diagnosed in Ireland. This requires linkage of the initial cancer notification, from whatever source, to information on a large number of relevant episodes, the most important being medical and other care in different hospitals, pathology records, death certificates, Hospital In-Patient Enquiry Scheme (HIPE) records and Healthlink (a messaging system between hospitals and GPs) records. Linkage is currently by name, address and date of birth, none of which is consistently available, totally reliable or recorded in any standard format, and name and address are not fixed throughout one's life. This has the following major consequences for cancer registration:
 - The process of linkage, using probabilistic matching software and subsequent manual review of borderline matches, uses a considerable part of their data-processing resource
 - Linkage is never exact, as names and addresses are not unique or consistently spelled, and dates of birth may be incorrect or absent. This inevitably leads to duplication of records and loss of some data from each duplicate. The NCR now has a significant number of patients who are assumed from their clinical data to have died, but for whom they have no matching death certificate. Linkage problems are increasing due to higher proportion of misspelled non-Irish names, and of names (for example, Arabic or Chinese) for which the format does not follow standard European conventions and which are recorded quite differently at different hospitals
 - Duplication of medical records is still widespread within hospitals, leading to incomplete recording of clinical information, as only one medical chart out of every two or three may be known to the NCR or retrieved by them

- The Registry must use names and addresses of cancer patients for all phases of data processing and store these until death. This gives rise to major data security concerns.
- The National Haemovigilance Office at the Irish Blood Transfusion Service has detailed the areas of blood transfusion practice which would benefit from the introduction of a UHI ⁽²⁸⁻³³⁾. It is the remit of the National Haemovigilance Office to collect information on adverse events which occur as a result of errors related to the transfusion of blood and blood products. Representatives from the National Haemovigilance Office have stated that the introduction of a UHI would:
 - Improve patient identification procedures associated with blood transfusion practice. Errors around patient identification can lead to patients receiving incorrect or wrong blood, or inappropriate blood components. Should a UHI be implemented, this risk would be reduced
 - Minimise potential for haemolytic transfusion reactions with the introduction of a national register of patients' antibodies, populated with a UHI. Reports from the National Haemovigilance Office have sought this since 2000 and the introduction of a national register of antibodies has been recommended in its 2007 Annual Report. The implementation of a UHI is essential to the realization of this national register
 - Facilitate follow up of women who are sensitised following delay in administration or omission of Anti D. The National Haemovigilance Office has recommended that clinical follow up and subsequent reporting is necessary to identify the level of sensitisation. The implementation of a UHI in Ireland can facilitate this longitudinal tracking of each individual over time, thereby improving safety for both mother and baby.
- The Authority held a meeting with representatives of the Irish College of General Practitioners (ICGP) to discuss the benefits of a UHI and it has stated, "GPs, and their patients, derive huge benefits from electronic messaging. A UHI would help in matching requests and results to the correct patient. This would decrease the risk of incorrect matching and save time in the practice and the laboratory or radiology department with manual matching of requests and results to the correct patient". The ICGP would welcome the implementation of a UHI recognising that it would improve administrative efficiencies by reducing the need to duplicate effort in capturing the same data numerous times.
- Representatives from the Population Health Directorate of the HSE acknowledge that the implementation of a UHI would provide better information for research in population health, planning and policy purposes and optimising the uptake and use of e-health initiatives nationally.

- Meetings with private health insurance companies have demonstrated that the implementation of a UHI will positively impact their organisations by providing them with a 'source of truth' identifier to facilitate efficient processing of health insurance claims.
- The ESRI, which manages the HIPE and the National Perinatal Reporting System (NPRS), have reported that the introduction of a UHI would enable longitudinal tracking of individuals within each of the systems as well as between the two. This would provide detailed information on population health and health outcomes.

5.4.4 Impact on Cooperation with Other Sectors

As outlined in the criteria for selection of a UHI document, the UHI will be health focused and will not be used to identify an individual for any purpose other than the provision of health and social care in Ireland. As such the implementation of a UHI will not impact on other sectors. *Health Online: A Health Information Action Plan for Australia* (second edition, 2001) stresses the need to ensure that the use of a health identifier does not extend to other sectors (i.e. that there is no "function creep" over time). Therefore before any identifier is implemented, adequate safeguards need to be in place to ensure appropriate usage ⁽²³⁾.

It is recommended that a UHI be implemented incrementally on a phased basis. A number of factors need to be in place before implementation can begin including a legislative framework for the system, the establishment of a trusted central authority to govern the UHI and the appropriate information governance structures. The timeline for the implementation of the UHI will depend on which option is adopted – a new UHI or an enhanced version of the PPS Number.

In either case, it is recommended that the implementation be undertaken on a phased basis - international experience demonstrating that such a project could be implemented within two years ⁽¹⁸⁾. The NHS Information Standards Board for Health and Social Care anticipate conformance with a standard relating to the use of the NHS Number as the National Unique Patient Identifier to be achieved within 12 months of its publication ⁽¹⁸⁾. The Newfoundland and Labrador Centre for Health Information began planning the implementation of the unique patient identifier in 1999 with actual implementation beginning in early 2000. By 2001, the UPI had been successfully implemented province-wide ⁽¹⁸⁾. A similar timescale could be anticipated in Ireland in the context of the assumptions outlined earlier in this document.

5.4.5 Has the UHI been Implemented in Other Countries?

The UHI has been successfully implemented in a number of countries and many more are currently in the process of implementation. In most countries where the UHI has been implemented, the decision has been made not to base the UHI on the social security number equivalent with the exception of the Scandinavian countries where the UHI was implemented many years ago ⁽³⁴⁾. The UHI which has been implemented, or planned, in some of these countries are described below.

UK

The UK's NHS is in the process of full implementation of the new NHS number as a UHI, which will enable the unique and unambiguous identification of a patient. This number is healthcare focused and not based on the UK equivalent of the social security number. The old number had 22 formats, was liable to transcription errors and was not suitable for extensive use within computerised environments. The new number is 10 digits in length with the last digit being a validation digit designed to prevent errors when entering the number in electronic databases ⁽³⁵⁾. The new NHS number is perceived as an important advance towards improved accuracy of identification, enhanced accessibility and responsiveness of services, improved linkage capability, increased patient confidentiality and improved data quality. A phased approach is being used, initially focused on primary care, then secondary care, then community care. The complete adoption of the NHS number has been included as a key priority as part of the NHS Operating Framework. To facilitate this, the Information Standards Board for Health and Social Care has developed standard guidelines for organisation and staff to meet this priority.

Denmark

The Danish EHR Strategy identified a national unique citizen's identifier as an essential precondition to the successful implementation of a national EHR ⁽⁶⁾. Denmark uses the 'Personnummer' (personal number) for unique health identification and every Danish citizen can be accounted for through this number. The Civil Registration System stores the Personnummer and lists individuals that are born in Denmark of a mother already registered or individuals that reside legally in Denmark. The architecture for the Personnummer consists of a central database called the Master Client Index that in turn populates the regional and local health centre databases.

Finland

Finland introduced a personal identification number system in 1964, and since then practically all administrative registers, including health, have used this unique identification code ⁽³⁴⁾.

New Zealand

New Zealand's use of a UHI dates back to 1977. This number is healthcare focused and cannot be used for any other purpose. Initially this took the form of the National Master Patient Index which was held on a single mainframe computer system ⁽²²⁾. The organisations responsible for maintaining this system were privatised and sold in the 1980s and 1990s. The move to a funder/provider split in the health sector and the associated break-up of Area Health Boards into competing Crown Health Enterprises meant that information would be held in separate independent repositories. The New Zealand Health service was established in 1992 to act as a centralised repository for key national standards and minimum data sets ⁽¹⁷⁾. To help it carry out this function the New Zealand Health Information Service (NZHIS) established a National Health Index (NHI), which stores NHI unique numbers. In 1994, New Zealand's Privacy Commissioner produced the first version of the Health Information Privacy Code. As the legislation underlying the Code was primarily concerned with unique identifiers in all sectors of society, one of the 12 rules in the code is devoted to the regulation of the NHI. The NHI number is assigned to each person using health or disability support services in New Zealand and approximately 95% of New Zealanders have their own unique NHI number. The NZHIS is a group within the Ministry of Health responsible for the collection and dissemination of health-related data and is responsible for the NHI. The Privacy Act of 1993 provides parameters for the national client identifier and prohibits the use of NHI numbers for any purpose other than the provision of healthcare services, and of information relating to those services.

Australia

Currently in Australia there is no national system for unique identification of its citizens or residents. However the requirement for a UHI was identified in *Health online: A Health Information Action Plan for Australia* (first edition, 1999) and was incorporated in a national plan of action. This was also endorsed by the National Health Management Advisory Council as an issue of high priority on its agenda. The National Electronic Health Transition Authority (NEHTA) is developing the requirements for a unique, nationally applicable individual healthcare identifier (IHI). In February 2006, the Council of Australian Governments approved \$98 million (€49.6 million) in joint funding to NEHTA to deliver two fundamental elements of reliable electronic communication within healthcare: the IHI and the healthcare provider identifier (HPI Together, these initiatives are referred to as the UHI Program) ⁽²⁵⁾. NEHTA have published *Privacy Blueprint – Unique Health Identifiers*, which sets out a systematic framework to consider the privacy issue raised by the collection and use of information involved with the UHI service. The IHI will consist of two parts – a number and a record of information. It is not planned for the Australian UHI to be based on the Australian equivalent to the social security number. The records of information associated with the UHI will be divided into three sections:

summary record, identification record and demographic record. It is anticipated that similar records of information will be associated with the Irish UHI to help ensure positive identification.

Canada

In 1997, extensive work on the issue of unique identifiers was undertaken by the Canadian Institute for Health Information Working Group on Health Identification Systems as part of its work on developing standards for data linkage in Canada. A survey was conducted which explored the current state and future plans for UHIs. This revealed that a wide variety of unique identifiers were found to be in use in the Canadian healthcare system with varying levels of sophistication ⁽³⁶⁾. In order to link individual province-wide UHIs in various formats, Canada Health Infoway has focused on client registries as its solution to unique identification of patients for EHR purposes. Canada does not currently have a universal UHI, however, some jurisdictions are in the process of or have fully implemented client registries. The client registries will be developed in jurisdictions and include a range of identifying data about all people who have received healthcare. The client registries will allow the linkage of provincial UHIs currently planned and in place, thereby facilitating the ability for positive identification nationwide. Some jurisdictions such as Newfoundland and Labrador have successfully implemented a UPI/ client registry using an EMPI system solution. The EMPI is the enabling system which holds the dataset associated with individuals and allows the identification and linkage of individuals across jurisdictions. The unique patient identifier in use in Newfoundland and Labrador is healthcare focused and not used for any other purpose ⁽¹⁸⁾.

United States

A UHI has not been implemented in the United States as of yet. The use of the UHI has been mandated under the 1996 Health Insurance Portability and Accountability Act. This law requires the adoption of standards to support the electronic exchange of a variety of administrative and financial healthcare transactions. It specifically requires unique identifiers for individuals availing of healthcare services. Five implementation teams were set up to identify and analyse options and propose policies to implement the statutory requirements. Considerable consensus has been achieved in the US on most of the standards, except that of the individual identifier. The level of controversy (in relation to privacy issues) surrounding this standard has caused much national debate and a delay in its implementation. The initiative came to a halt when Congress put a moratorium on Federal funding for the UHIs in the US by passing legislation prohibiting the use of any funds in 1999 to address the need for a unique client identifier. The National Committee on Vital and Health Statistics has recommended that a standard for a unique identifier for individuals should not be adopted until privacy legislation has been adopted. The US Department for Health and Human Service

published a White Paper on *Unique Health Identifier for Individuals* reviewing both the positive and negative aspects of six UHI options (social security number, biometrics, public key-private cryptography method) using the *Standard Guide for the Properties of a Universal Healthcare Identifier* ⁽¹⁰⁾. In this paper it was found that the current social security number was not suitable as a UHI.

In 2008, the RAND Corporation conducted a study based on the use of UHIs in various states and groups of providers in the US which concluded that creating a new unique patient identification number for every person in the US would facilitate a reduction in medical errors, simplify the use of electronic medical records, increase overall efficiency and help protect patient privacy. Researchers from RAND Health estimated that creating such an identification system could cost between \$1.5 billion and \$11 billion but that the effort would likely return even more in benefits to the nation's healthcare system ⁽⁹⁾. Based on the population of the US compared to the population of Ireland, this cost estimate can be scaled down to costing between approximately €16 million and €114 million in Ireland. Further analysis is needed to determine the applicability of these figures in the Irish context.

5.4.6 Organisation: Summary and Conclusions

The evidence outlined above indicates the anticipated impact of a UHI on the Irish health system and its staff, primarily documented from international experience. Increased organisational efficiency, a reduction in administrative costs and the use of a UHI in the collection of data from a wide range of sources for research purposes, are the clear benefits to be derived at this level. Both UHI options will have the same impact on present organisational and provider physical settings in that they will be unaffected by the implementation of a UHI. However, varying outcomes are anticipated depending on which of the two potential options are selected.

The impact of the UHI on cooperation with other sectors was explored in the course of this evaluation. A UHI based on an Enhanced PPS Number assumes that CIS in the DSFA would act as the trusted authority and would issue and maintain the UHI. This is likely to impact on the resources of the DSFA and potentially have a negative impact on its efficiency and productivity. Furthermore, an Enhanced PPS Number system operating from the CIS might not be as timely as is recommended, thereby diluting the benefit of efficiency at organisational level. There are a number of enhancements that are required of the current system in addition to a clean up of existing duplications and multiple assignments. In addition, a two-way link synchronising the PPS data with the Enhanced PPS Number will need to be established. As this is work that will need to be undertaken by the DSFA it will possibly impact on the timeliness of the implementation of the system and could take longer than a fit-for-purpose UHI. It is clear from the international evidence above that most countries

have deemed that a UHI based on the equivalent of the PPS Number would be unsuitable for use in healthcare ^(13;17;23;24).

There are inherent risks in the implementation of a new UHI in that there is no current infrastructure to support a new UHI – a New UHI requires the development of a plan for the establishment of a central trusted authority, the definition of its power, organisational structure and operating procedures. However, this can also be interpreted as a benefit as it allows for the development of a completely fit-for-purpose system representing a fresh start without any known defects or limitations. A new UHI avoids crossover problems from an existing system that needs to be corrected or a system that cannot be corrected retrospectively. Concerns have been raised around the cost of developing a completely new system. The fact that the cost is difficult to quantify justifies these concerns but must be examined in the context of the savings that are to be made if the system is allowed to operate to its full potential – with complete public confidence and buy-in, which is more probable with a new UHI.

From the evidence outlined in this section, it is clear that a new UHI would incur the maximum achievable benefits at an organisational level, that being the Irish health system as a whole.

5.5 Economic Implications

5.5.1 What is the Start-up Cost?

There are a number of start-up cost components that are common to both a New UHI and an Enhanced PPS Number. These components are:

- New or expanded central trusted authority
- Governance structure which will include resources to develop processes, standards, policies to manage the implementation and operation of a UHI
- An information governance framework
- Unique health identification cards
- Enactment of legislation.

The exact costs of these components are difficult to quantify. However, estimates from other projects both here and in the UK can provide an overview of the estimate of likely costs.

The cost of issuing unique health identity cards is likely to be the same in both the case of implementation of a New UHI or an Enhanced PPS Number. Based on cost estimates in the UK of £3.50 sterling per smart card for use as national ID cards, the cost of issuing a similar card in Ireland to a population of 4,234,925 (Central Statistics Office (CSO) Census 2006) people can be estimated at just under €16 million ⁽³⁷⁾.

The cost of establishing a central trusted authority, repository and software solution for a UHI is comparable to the estimated cost of implementing a central operational unit for a National Client Index* (NCI) in Ireland. The capital cost of implementing the NCI identified in the HSE's *National Client Index Study* document ⁽¹²⁾ including adopter projects over a 5 year period is estimated to be in the region of €17 - €30 million. This is dependent on the implementation approach selected. This does not include the cost of issuing cards to individuals.

The recommended work packages for implementation of an NCI are also recommended for implementation of a UHI given that the same infrastructure, expertise and incremental adoption are required. The *National Client Index Study* document has stated that, "Any UPI project should leverage synergies in the areas of process, organisation and technology which the NCI project will have developed and implemented solutions"⁽¹²⁾. Therefore, it would appear that there is the potential for cost savings to be achieved if the two projects – the UHI and the NCI – were to be progressed together if not fully integrated.

New UHI

The start-up costs for a New UHI will include the following component in addition to the costs outlined above:

- New technical infrastructure.

Enhanced PPS Number

The start-up costs for an Enhanced PPS Number would include the following components in addition to the costs outlined above:

- Improved accessibility (live links to the central trusted authority for healthcare providers)
- Enhanced assignability (this means a change from three to five days to real time assignment of numbers at birth and at the point of care)
- PPS Number data cleansing exercise
- Enhanced longevity and universality
- Enhancement of technical infrastructure to allow:
 - Programme development to encrypt/decrypt Enhanced PPS Number in real time
 - Programme development to synchronise Enhanced PPS Numbers with PPS Numbers in real time.

At the time of writing it is not possible to cost the enhancements that are necessary to the PPS Number exactly.

* The National Client Index (NCI) is a project run by the HSE. It is an index which facilitates access to patient records, which may be stored in multiple locations and systems. An NCI is established by examining existing client records and building the index using a combination of automated and manual actions using specific client-matching criteria. An enterprise master patient index (EMPI) is the common term used to describe the technology which manages this index.

5.5.2 Consequences in Terms of Efficiency and Resources for the Next Five Years

One of the well documented benefits of the implementation of a UHI is an increase in efficiency and a reduction in administration costs in healthcare settings. Although it is not possible to determine the exact cost of implementing such a system, research suggests that the system will pay for itself within the first years of implementation and continue to accrue savings in the years that follow owing to a reduction in adverse events and making the best use of information by applying the principle 'collect once, use many times'.

New UHI

A suggested staffing model for the NCI organisation has been developed based on experience from other jurisdictions and would need to be confirmed during the more detailed design process. It is anticipated that the central organisation would have in the region of 20 to 25 whole time equivalents (WTEs) with an annual operating cost of approximately €1.1 million – €1.7 million per annum (2007 estimate) ⁽¹²⁾.

Enhanced PPS Number

It is likely that the cost of extra staff to expand CIS within the DSFA such that the Enhanced PPS Number can be supported operationally will be similar to the estimates for the NCI project. The DSFA would be required to increase staffing levels to allow 24-hour real-time access to the Enhanced PPS Number system, maintain quality and synchronisation of data and also to implement and oversee the information governance framework required to operate the Enhanced PPS Number as a UHI.

5.5.3 What is the Additional or Saved Annual Cost? (Cost of UHI versus cost of no UHI)

There is very little information available in Ireland to demonstrate additional and saved annual costs due to implementation of a UHI. However, a literature review has identified the following from national and international sources. These additional and saved costs have been grouped by theme as follows:

- Preventable adverse events
- Records duplication
- Repeat laboratory testing
- Effect of health information technology (HIT) implementation in financial terms.

Preventable adverse events:

- *The British Medical Journal* published in 2001 an article entitled, *Adverse Events in British Hospitals: preliminary retrospective record review*, which sought to categorize the types of patient identification errors that occur. The article stated that central to improving patient safety in the NHS was the elimination of errors in the matching of patients with their care ⁽¹⁵⁾.
- The Department of Health in the UK estimates that there are over 850,000 (10% of admissions) adverse events occurring each year, half of which could be prevented. These errors result in an estimated cost to the NHS of £2 billion sterling each year in extra hospital days ⁽³⁸⁾.
- In October 2008, the RAND Corporation published up to date research on the costs and benefits of a UHI, *IDENTITY CRISIS An Examination of the Costs and Benefits of a Unique Patient Identifier for the U.S. Health Care System*. It was found in the study that avoiding adverse drug events, which are often the result of incomplete linking of information about a patient's medications or allergies, could save an additional US \$4.5 billion per year which equates to €58.5 million in terms of the size of the Irish population ⁽⁹⁾.

Records duplication:

- In the United Kingdom, it was found that there is a significant cost involved in resolving preventable issues related to duplicate records and confusions of identity. The cost of creating a single record from duplicate records is estimated to be in the region of £20 sterling (€22.47) per record ⁽³⁸⁾
- In addition, the 2006 National Audit Commission Report (UK), *National Duplicate Registration Initiative*, identified approximately 180,000 duplicate records that year which resulted in incorrect payment which equated to an unnecessary cost of £2.7 million sterling per annum. This equates to approximately €206,000 in Ireland based the size of the population. Furthermore, the data matching exercise undertaken in 2004 following the audit for that year found 1.5 million matches and was estimated to have generated savings in excess of £9.5 million sterling (approximately €725,000 in Irish terms) by enabling 0.3% of patient registrations, which were done in error, to be cancelled ⁽¹³⁾.

Repeat laboratory testing:

- A significant reduction in duplicate testing and imaging that could result from more-complete retrieval of medical records could potentially save US \$4 billion per year in the United States which equates to almost €44 million in terms of the Irish population ⁽⁹⁾.

Effect of HIT implementation in financial terms:

- Global Standards Ireland (GS1) has implemented its Global Service Relationship Number system in the National Centre for Haemophilia and Coagulation Disorders at St James's Hospital in Dublin. This involves using unique identifiers for individuals, healthcare professionals, products and locations. Within one year of implementation, the cost savings surpassed the cost of implementation. The main benefits, cited by GS1, realised in the first year are ⁽¹⁴⁾.
 - Annual savings now running in excess of €1 million
 - Product wastage reduced from €90,216 to zero in the year post-service implementation
 - Documentation errors have reduced from 12 to zero in the year post-service implementation
 - 40% more patient treatments with same level of staff
 - Surveys show 99% client satisfaction level.
- In *Extrapolating Evidence of Health Information Technology Savings and Costs*, 2005, published by the RAND Corporation in the United States, the authors compared the efficiency savings with the costs the nation had to incur in order to be able to realise those savings. They found that savings outweigh costs by a factor of five, which implies that, even if a large portion of savings is not realized, the ratio of benefit to cost is still larger than one ⁽³⁹⁾.
- Based on 1998 insured services program costs in Canada, it has been calculated that the introduction of a UHI would allow for more up to date eligibility information to be available across provinces representing a 10% reduction in cost of claims ⁽¹⁸⁾.
- The Benefits Driven Business Case estimated the total one-time cost of the UPI/Client Registry for Newfoundland and Labrador in a range of \$2,908,000 (€1.8 million) to \$3,344,000 (€2.07 million) in up-front professional and capital costs, with ongoing operations and maintenance costs of \$343,000 (€212,000) to \$394,000 (€244,000) ⁽¹⁶⁾.
- Combining potential revenues not captured for both inpatient and outpatient events, the total lost revenues in 2000 is estimated at \$3.95 million (€2.44 million), or 0.48% of the total Health Board's budget (2000). Based on these estimates, the investment in the Client Registry in Newfoundland and Labrador would be recouped in approximately 2.3 years ⁽¹⁸⁾.
- In Finland, a study from the 1990s showed that it is possible to get identification numbers retrospectively in cases where these numbers are missing from the original data that predates the personal identification numbers. In that study, consisting of a cohort of 4,431 women who were pregnant in 1954-1963, only 0.6% of the cohort

remained unidentified, but the process was very complicated, time consuming and expensive. The total costs to allocate retrospectively the identification numbers were estimated to be €23,000, while had the identification numbers already been available, then the validation of their correctness would have only cost €925⁽³⁴⁾.

5.5.4 Additional or Saved Costs in Other Sectors

Other sectors can be defined as organisations associated, but not directly responsible for, the delivery of healthcare in Ireland, for example, research institutes and insurance companies. This information was gathered during stakeholder meetings about UHIs (see Appendix 5).

An Irish health insurance company carried out a study in 2007 of the cost to them of misidentification of clients due to incorrect or out-of-date contact details. This cost was estimated to be in the region of €10,000 per annum. A representative of the company has stated that this additional cost could be avoided if a UHI were implemented in Ireland as a 'source of truth' identifier. As outlined in the criteria for selection of a UHI document, the UHI will be health focused and will not be used to identify an individual for any purpose other than the provision of health and social care in Ireland.

An Irish research institute has stated that implementation of a UHI in Ireland would allow it a means to link much of its research data providing much improved information on population health and outcomes.

5.5.5 Uncertainties Where Evidence is Limited

It is not possible to provide exact cost estimates and cost savings that can be achieved by implementation of a UHI in the Irish context as there is currently no basis nationally for comparison. However, overwhelming international evidence suggests that the implementation of a UHI has many benefits while being at the very least, cost neutral and more likely to be cost-saving.

Canada Health Infoway, and the National E-Health Transition Authority in Australia, have confirmed to the Authority that their UHI implementation organisations never undertook any kind of cost-benefit analysis of the UHI. It was regarded as unnecessary due to the fact that implementation of a UHI was deemed to be an imperative and fundamental enabler from a safety and efficiency perspective. This has contributed to the uncertainties around providing accurate cost estimates of the savings that can be accrued through UHI adoption.

There is also an uncertainty in attempting to estimate the cost involved in enhancing the PPS Number such that it satisfies all fundamental criteria for selection of a UHI. This type of exercise has not been undertaken in other countries for the purpose of enhancing the PPS Number equivalent for use as a UHI as the option has always been discounted prior to the costing stage of the project.

5.5.6 Economic Implications: Summary and Conclusions

The costs of a nationwide UHI – both in terms of its implementation and its potential savings – have proved difficult to quantify as this information is not available in the Irish context. International evidence suggests that savings that are made in the first years of implementation will cover the costs of the development of such a system. A similar result is anticipated in the Irish context and as such the implementation of a UHI is deemed to be a cost-effective intervention.

Having satisfied the fundamental criteria, both options need to be assessed against the differentiating criteria, one of which is cost-effectiveness. Research has shown that both options would be cost-effective in terms of the savings that would be made if implemented successfully, but a more detailed comparison is required as to which would be the most cost effective.

In terms of the start-up cost it is anticipated that there will be little difference between the two options as enhancing the PPS Number will require many adjustments both to the actual number and the system of issuing and maintaining it before it would satisfy the criteria for selection. The necessary enhancements may cost more than implementing a new fit-for-purpose UHI. A UHI based or any way linked to the PPS Number is likely to be a drain on the resources of the DSFA and CIS and have a negative impact on their efficiency thereby reducing the overall efficiency of the system before it has even been implemented.

Furthermore, as has been documented earlier in the report, a new UHI has the potential to be more successful in any case owing to increased public buy-in and as such has the potential for greater savings and a greater return on investment. Unless the UHI is virtually used universally throughout the healthcare system, the expected benefits cannot be realised and the cost-effectiveness undermined. In essence, the greater the use of the UHI, the greater the return on the investment.

The cost of implementing a new UHI has proved extremely difficult to quantify resulting in the use of international evidence and an examination of figures taken from the HSE's *NCI Business Case* forming the basis for this analysis. The evidence indicates that a successfully implemented UHI is a cost-saving intervention and there is no reason why this would not translate to the Irish context. In light of the evidence documented above under the headings of the technology, the individual and the organisation it is clear that the potential for a successful, efficient and effective UHI is greatly enhanced if that UHI is a completely new built-for-purpose identifier. As such a new UHI can be distinguished as the more cost-effective option and the better choice economically as a whole.

6 Findings

The introduction of a UHI would deliver tangible benefits from patient safety, quality of care, efficiency, confidentiality, epidemiological and cost effectiveness perspectives. Based on the available evidence, and in the interests of patient safety and efficient use of resources, the New UHI would be cost effective, represent international best practice and would be more secure than using the Enhanced PPS Number as the UHI for Ireland.

Detailed below are the findings of this evaluation, along with conclusions and recommendations.

6.1 PPS Number is Unsafe

This evaluation has shown that the use of the current PPS Number as a UHI would be unsafe.

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

6.2 Cost-effectiveness of UHI

The New UHI would be more cost-effective than an Enhanced PPS Number.

International evidence shows that the capital cost of introducing a UHI is recovered in the first few years of operation but only if the UHI is used virtually universally throughout the healthcare system. Therefore, in order to be cost-effective, the UHI must be acceptable to the public.

6.3 Public Support for a UHI

Both a RED-C poll commissioned by the Health Information and Quality Authority, and the public consultation concerning the Health Information Bill, indicate widespread support for a UHI ⁽⁵⁾.

However, the consultation process revealed serious concerns about any potential for linkage between health and financial information. Since it is intended that the Enhanced PPS Number can be linked back to, and kept in synchrony with, the PPS Number, this is likely to undermine public support and hence the willingness to provide the number in order to receive healthcare services. It is unlikely that individuals will be required to provide an identification number as a condition for receiving treatment. Therefore, unless there is full support for the UHI, the benefits will not be realised and the system would be at risk of incurring increased costs as a result.

6.4 Best Practice in Identifying Patients

The New UHI represents international best practice.

Virtually all countries that have recently introduced, or are planning to introduce, a UHI have opted for one that is healthcare-focused and confined to the healthcare sector. The main exception to this is the Scandinavian countries which have been using the social security number for many years across all sectors.

6.5 Privacy and Security

The New UHI will be more secure and provide better protection of patient privacy.

The New UHI would be confined to use within the healthcare sector and hence the potential for leakage outside healthcare is greatly diminished. The fact that the Enhanced PPS Number would have to be exported outside the health sector in order to maintain synchrony with the PPS Number represents a potential security and privacy threat.

6.6 Impact on Existing Client Identity Services (CIS)

The Enhanced PPS Number would radically impact on CIS in the DSFA, which operates the PPS Number.

A UHI based on an Enhanced PPS Number assumes that the existing CIS operated by the DSFA would act as the trusted authority and would issue and maintain the UHI. This is likely to have a negative impact on their efficiency and productivity. Prior to establishment of the Enhanced PPS Number for health, the existing PPS Number database will have to be cleansed to remove duplicates and multiple assignments. In addition, the two-way link synchronising the PPS data with the Enhanced PPS Number will need to be established, representing a significant burden on CIS and requiring radical changes to its business processes.

6.7 Conclusions and Recommendations

When the Enhanced PPS Number option for a UHI is compared to the New UHI, it appears that, in each section of the assessment, the New UHI emerges as the best fit for a UHI in Ireland. While both options may facilitate the linkage of personal health information, in practice, the issues related to individual privacy concerns, data integrity, minimisation of limitations, maximum benefits realisation and best international practice indicate that the most effective and safest choice is the development of a new built-for-purpose, healthcare focused UHI.

While details of the implementation of a New UHI are beyond the scope of this document, it is important to emphasise that the introduction of

the UHI cannot commence until the full infrastructure to support its safe use is in place. If this is absent, serious risks of misidentification will arise from the inability to verify identity leading to serious patient safety concerns and serious risks to privacy through inadequate governance.

Therefore, in conclusion, the Authority recommends to the Minister for Health and Children that:

1. The current PPS Number is not used as the identifier for health and social care.
2. The safest and most cost-effective option for a UHI for Ireland is a new healthcare-focused identifier, which is based on international best practice.
3. The exact nature of this new identifier should be determined through regulation.
4. The Health Information and Quality Authority establishes a broadly representative group of stakeholders, chaired by the Authority.* This group should include representatives from the Department of Health and Children, Department of Social and Family Affairs, Department of Finance, the Data Protection Commissioner and a Patient/Public representative. The group will:
 - a. *determine the exact format of the New UHI*
 - b. *establish the appropriate governance arrangements*
 - c. *provide detailed costings both for capital and recurrent budgetary requirements*
 - d. *consider the relationship between the UHI system and the proposed National Client Index (NCI)†*
 - e. *support the development of a road map for the introduction (roll out) of the identifier.*
5. Based on international best practice, it is essential that an appropriate infrastructure and governance structure are put in place prior to implementation of a UHI.
6. The new identifier should be introduced as soon as possible.

* In relation to recommendation 4, following submission of this report to the Minister for Health and Children, she has requested her Department to establish a Group, representing key stakeholders, to finalise policy in relation to the UHI. The Authority supports this development and looks forward to working with the Group.

† The National Client Index (NCI) is a HSE project. It is an index which facilitates access to patient records, which may be stored in multiple locations and systems. An NCI is established by examining existing client records and building the index using a combination of automated and manual actions using specific client-matching criteria. An enterprise master patient index (EMPI) is the common term used to describe the technology which manages this index.

Appendix 1

Selection Criteria for a UHI

In 1995, the American Society for Testing and Materials (ASTM) published the *Standard Guide for Properties of Universal Healthcare Identifier (UHID)*. It covers a set of criteria outlining the properties of a UHI. It includes altogether 30 characteristics required of a UHI candidate.

To facilitate Irish requirements, two further criteria have been added, legislation and Deactivation. The criteria have been grouped firstly according to the following characteristics types:

- 3.1 Functional characteristics
- 3.2 Linkage of life-long health record
- 3.3 Patient Confidentiality and Access Security
- 3.4 Compatibility with standards and technology
- 3.5 Design characteristics
- 3.6 Reduction of cost and enhanced health status

Any potential UHI that fails to satisfy any of the fundamental criteria is deemed unsuitable for use as a UHI in Ireland. Potential UHIs that satisfy these criteria will be assessed and compared against the differentiating criteria.

Table 3.1 – Functional characteristics

Criteria	Definition	Testing against criteria
Accessible – <i>fundamental</i>	The UHI system should be available whenever and wherever they are required for registration/positive identification purposes. Any UHI should be available in an efficient and timely manner 24 hours a day.	What is the process or what will be the process of accessing the UHI System? Can you access an existing UHI in an efficient and timely manner 24 hours a day?
Assignable – <i>fundamental</i>	It should be possible to assign a UHI to an individual whenever it is needed. Assignment will be performed by a UHI trusted authority after receiving a properly authenticated request for a new UHI.	How long will it/does it take to assign a UHI to an individual? Is there a trusted authority? Does the UHI System support the registration of temporary and new UHI numbers?
Identifiable – <i>fundamental</i>	It shall be possible to identify the person associated with a valid UHI. Identifying information may include such standard items as name, birthplace, sex, address, mother’s maiden name. This information is not incorporated in the UHI itself, but is associated with it by linkage and where necessary this information can be updated or corrected.	Is there a standard set of information held on the individual for identification purposes? If so, what information is held in this standard set? Answer: Yes/No
Mergeable – <i>fundamental</i>	In the (theoretically infrequent) case that duplicate UHIs are issued to a single individual, it shall be possible to merge the two UHIs to indicate that they both apply to the same individual. In such cases, the invalid UHI must remain linked to the valid UHI.	Can the UHI be merged with a duplicate UHI without any loss of linked information? Answer: Yes/No If a process already exists please indicate what this process is?
Splittable – <i>fundamental</i>	In the (theoretically never occurring) event that the same UHI is assigned to two individuals, there must be a mechanism to retire the UHI and assign a new UHI to both of these individuals.	Can the UHI be split to generate multiple new numbers without the loss of any linked information? Answer: Yes/No If a process already exists please indicate what this process is?

Criteria	Definition	Testing against criteria
Verifiable – <i>fundamental</i>	A user should be able to determine that a candidate identifier is or is not a valid UHI without requiring additional information. This should support the ability to detect accidental information, such as typographical errors. It is not meant to be able to preclude intentional misinformation or misuse of an identifier.	Does the UHI support a check digit to verify its validity? Does the UHI system support a process of individual authentication? Answer: Yes/No

Table 3.2 - Linkage of life-long health record

Criteria	Definition	Testing against criteria
Linkable – <i>fundamental</i>	It shall be possible to use the UHI to link various health records together in both automated and manual systems.	Is the UHI used already in large healthcare systems? Can the UHI be used to support linkage of healthcare records in both a manual and automated environment? Answer: Yes/No
Mappable – <i>differentiating</i>	During the incremental implementation of a UHI, it shall be possible to create bidirectional linkages between a UHI and existing identifiers used currently by a variety of healthcare institutions.	Is the UHI used as a secondary identifier by healthcare organisations? Could existing identifiers be mapped to the newer UHI system.

Table 3.3 – Patient confidentiality and access security

Criteria	Definition	Testing against criteria
Content-free – <i>fundamental</i>	The structure and elements of the UHI number itself should not contain any information about the individual.	Does the number component of UHI have information contained as part of the number? Are any alpha elements in the UHI relative to the individual it is used to identify? E.g. : the SSN in the US contains the location and time of issue information Answer: Yes/No
Controllable – <i>fundamental</i>	It must be possible to ensure the confidentiality of personal information held in association with the UHI. Only trusted authorities have access to algorithms and methods used to link and disidentify individuals with the UHI.	Are the necessary administrative and technical infrastructures in place to control the UHI? Are there any barriers to sufficient control with the current infrastructure?
Healthcare focused – <i>fundamental</i>	Was the number created for healthcare purposes? The UHI should not be used to identify an individual for any purpose other than for the provision of health and social care in Ireland.	Was the UHI created for healthcare purposes? Is the UHI currently being used for anything other than healthcare purposes? Answer: Yes/No
Public – <i>fundamental</i>	The individual a UHI identifies should be able to reveal it.	Does possession of the number by any individual allow access to personal information associated with that number without authentication? Answer: Yes/No
Secure – <i>fundamental</i>	It should be possible to encrypt and decrypt a UHI as required to ensure that individual privacy is protected.	Is it possible to securely encrypt and decrypt the number? Answer: Yes/No
Legislation – <i>fundamental</i>	Legislation should allow that the UHI can be used for health and social care purposes while stipulating severe penalties for misuse of the UHI.	Is there current or forthcoming legislation to allow the use of the number for health and social care purposes? Answer: Yes/No
Disidentifiable – <i>differentiating</i>	It should be possible to create an arbitrary number of specialised UHIs that can be used to link health information concerning specific individuals but that cannot be used to identify the associated individual.	Does the UHI system support the generation and assignment of other random numbers to de-identify and dissociate an individual from the UHI, e.g. for use in research and/or clinical trials? Answer: Yes/No

Table 3.4 – Compatibility with standards and technology

Criteria	Definition	Testing against criteria
Deployable – <i>fundamental</i>	The UHI 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.	Is it compatible with the following technologies – barcode scanning, optical scanning, smart card technology, biometric authentication, audio/voice recognition, data storage and manual paper storage? Does the structure of the UHI prohibit or inhibit the use of any of the technologies currently used in the Irish health and social care system? Answer: Yes/No
Standard/based on industry standards – <i>fundamental</i>	The identifier scheme should be based on international best practice and take guidance from CEN and ISO standards.	Is the UHI numbering system in line with international best practice?
Usable – <i>fundamental</i>	A UHI should be processable by both manual and automated means. While manual methods for such functions as verifying the validity of a UHI may require considerably more time, there should be no technical or policy inhibitions to manual operation.	Does the system work efficiently and effectively in both manual and automated modes? Can the processes of issuing and using a UHI be maintained manually, e.g. in the event of technology or power failure? Answer: Yes/No

Table 3.5 – Design characteristics

Criteria	Definition	Testing against criteria
Atomic – <i>fundamental</i>	A UHI should be a single data item. It should not contain sub-elements that have meaning outside the context of the entire UHI. Nor should the UHI consist of multiple items that must be taken together to constitute an identifier. The UHI must have no elements that can be analysed into any type of coherent structure.	Is the UHI a single data item? Can any part of the identifier be analysed in isolation to display any kind of pattern? Answer: Yes/No
Governed Centrally – <i>fundamental</i>	A management organisation shall exist that is responsible for overseeing the UHI system. This agency will determine the policies that govern the UHI system, manage the trusted authority, and take such actions to ensure that the UHI can be used properly and effectively to support healthcare.	Is there/will there be a central authority with local offices to govern the UHI system? Are there policies and procedures in place that govern the use of the UHI? Answer: Yes/No
Networked – <i>fundamental</i>	The UHI should be supported by a secure network that makes UHI services universally available where needed.	Is there a secure network in place that can support the issue and use of the UHI? Answer: Yes/No
Permanent – <i>fundamental</i>	Once assigned, a UHI should remain with the individual. It should never be reassigned to another person, even after the individual's death.	Is the number ever re-used for another individual? Answer: Yes/No
Repository- based – <i>fundamental</i>	A secure, permanent repository shall exist in support of the UHI system. The repository should contain the UHI and other relevant information to support the function of the UHI system.	Is there or could there be a permanent, secure repository that does/could support this number? Answer: Yes/No
Retroactive – <i>fundamental</i>	It should be possible to assign a UHI to all currently existing individuals at the time that the UHI system is implemented.	Is there a process in place or planned to facilitate the issue this number to the existing general population? Answer: Yes/No

Criteria	Definition	Testing against criteria
Unambiguous – <i>fundamental</i>	Whether represented in automated or handwritten form, a UHI should minimise the risk of misinterpretation (for example confusing o with a zero)	Does the number include safeguards to minimise misinterpretation? Answer: Yes/No
Unique – <i>fundamental</i>	A valid UHI should identify one and only one individual	Is there a trusted method of issuing the number? Does the central UHI system prevent the issue of duplicate numbers in the event of multiple registrations simultaneously? Answer: Yes/No
Universal – <i>fundamental</i>	A UHI should be able to support every living person for the foreseeable future. This may include the future expansion of the UHI system to include individuals from outside of Ireland.	Does the number allow for future linkage with UHI from other countries? Does the number have a finite capacity for generation? Answer: Yes/No
Incremental – <i>differentiating</i>	The UHI 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.	Will the incremental implementation of this number have an adverse effect on systems and processes currently in place in the health and social care environments?
Longevity – <i>differentiating</i>	The UHI 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.	Does the number have any limitations in relation to longevity, e.g. finite capacity, known inability to function with future standards and technologies?
Concise – <i>differentiating</i>	The UHI should be as short as possible to minimise errors, the time required for use, and the storage needed.	Is the structure or size of the number inhibitive to efficient and effective use and storage? How long is the number?
Deactivation – <i>differentiating</i>	The UHI numbering system should allow for the deactivation of a UHI.	Does the UHI numbering system allow for the deactivation of a UHI?

Table 3.6 – Reduction of cost and enhanced health status

Criteria	Definition	Testing against criteria
Cost effective – <i>differentiating</i>	The UHI system chosen should achieve maximum functionality while minimizing the investment required to create and maintain it.	In general is this approach cost effective?

Appendix 2 – Summary of run through of options

	PPSN	Enhanced PPSN	New UHI Number	Medical card number	Drug Payment Scheme number	Birth notification number	European Health Insurance number	Passport number	Driving licence number
Functional Characteristics									
Accessible	X	✓	✓	✓	X	X	X	X	X
Assignable	X	✓	✓	✓	X	X	X	X	X
Identifiable	✓	✓	✓	✓	✓	✓	✓	X	X
Mergeable	✓	✓	✓	✓	X	X	Pending	Pending	✓
Splittable	✓	✓	✓	✓	*	✓	Pending	Pending	✓
Verifiable	✓	✓	✓	X	*	X	X	✓	X
Linkage of life-long health record									
Linkable	✓	✓	✓	✓	*	✓	Pending	X	X
Patient confidentiality and access security									
Content-free	X	✓	✓	X	X	X	Pending	Pending	X
Controllable	✓	✓	✓	✓	*	✓	Pending	Pending	Pending
Healthcare focused	X	✓	✓	✓	X	X	✓	X	X

	PPSN	Enhanced PPSN	New UHI Number	Medical card number	Drug Payment Scheme number	Birth notification number	European Health Insurance number	Passport number	Driving licence number
Public	✓	✓	✓	✓	✓	✓	✓	✓	✓
Secure	✓	✓	✓	✓	*	✓	Pending	Pending	✗
Legislation	✗	✓	✓	✗	✗	✗	✗	✗	✗
Compatibility with standards and technology									
Deployable	✓	✓	✓	✗	*	✗	✓	Pending	✗
Standard/Based on Industry Standard	✗	✓	✓	✗	✗	✗	✓	Pending	✗
Usable	✓	✓	✓	✓	*	✓	Pending	Pending	✓
Design characteristics									
Atomic	✗	✓	✓	✗	✗	✗	Pending	Pending	✗
Governed centrally	✓	✓	✓	✓	✗	✓	✓	✓	✓
Networked	✓	✓	✓	✓	*	✓	Pending	Pending	✓
Permanent	✓	✓	✓	✓	✗	✓	Pending	Pending	✓
Repository-based	✓	✓	✓	✓	✗	✓	Pending	Pending	✓
Retroactive	✓	✓	✓	✗	✓	✗	Pending	Pending	✓

	PPSN	Enhanced PPSN	New UHI Number	Medical card number	Drug Payment Scheme number	Birth notification number	European Health Insurance number	Passport number	Driving licence number
Unambiguous	✓	✓	✓	✓	✓	X	✓	✓	✓
Unique	✓	✓	✓	✓	✓	X	X	Pending	✓
Universal	X	✓	✓	X	X	X	Pending	Pending	✓

* Dependent on the functionality of the PPS Number, the CRS and CIS

Appendix 3

Summary of RED C Public Opinion Poll on the sharing of health information

- In general, the public feel comfortable with the use of their health information in a number of different situations
- 96% of those surveyed felt that they had a right to be informed of who has access to their health information
- 86% thought that health information should be linked up across healthcare settings
- 96% thought that GPs and hospitals should use the same number to identify individuals
- All user-types of health services are comfortable with the sharing of health information, with no significant differences between frequent and infrequent users
- The poll clearly demonstrates high levels of acceptance and agreement that more should be done to link health information across healthcare settings
- In general, the public are very comfortable with the use of their information for a variety of different reasons. Even when there is no obvious direct health benefit, the percentage that are comfortable is over 75%
- Almost all adults (94%) feel that their personal medical records should be accessed by medical professionals if picked up by an ambulance in a life threatening situation. The percentage remains the same across each of the demographic groups and shows a universal desire for this to be the case
- A slight variation in the level of belief among each of the demographics as to whether the linkage of health information currently happens was seen. When asked whether people felt that currently the hospital contacts their GP after people come out of hospital to update them on important information, nearly three-quarters (71%) felt that this was the case

The majority of people (86%) feel that medical information from different sources should be linked up to improve patient safety and care, with those in older age groups most likely to agree (91%) while frequent users of health services show similar levels of agreement.

Appendix 4

Use of PPS Number in the health sector

HSE Areas	Use of the PPS Number
Midlands Area	<ul style="list-style-type: none"> ■ All Supplementary Welfare Allowance payments are made under the PPS Number ■ Registration of clients under the Drug Payment Scheme ■ Checking of applicants for Nursing Home Scheme
Mid-West Area	<ul style="list-style-type: none"> ■ The Cervical Screening Section uses the PPS Number to register each client ■ The Drug Refund Section uses the PPS Number as an identifier ■ The Long Term Illness Section uses the PPS Number as an identifier ■ Administration of Supplementary Welfare Allowance ■ Medical Card Section use the PPS Number to register each client
Northern Area	<ul style="list-style-type: none"> ■ Administration of the Drugs Payment Scheme (used as an identifier) ■ Administration of the Supplementary Welfare Allowance (used as an identifier) ■ Used to confirm income details for the Nursing Home Subvention Scheme, Medical Card Scheme, Blind Welfare Allowance Scheme and the Mobility Allowance Scheme
North East Area	<p>Used to support the administration of the following:</p> <ul style="list-style-type: none"> ■ The Medical Card Scheme ■ Drugs Payment Scheme ■ Child Immunisation Scheme ■ Hi-Tech Scheme ■ Hep C Scheme
North West Area	<ul style="list-style-type: none"> ■ PPS Number used on a limited scale for employees' contributions and income tax affairs
South East Area	<ul style="list-style-type: none"> ■ Administration of Supplementary Welfare Allowance payments ■ Registration and verification of clients under the Drug payment Scheme ■ Verification of clients on the Medical Card Scheme
South Area	<ul style="list-style-type: none"> ■ Used as a unique identifier for Supplementary Welfare Allowance payments ■ Used as a unique identifier for the Drugs Payment Scheme ■ Used for validating eligibility for the Medical Card Scheme

HSE Areas	Use of the PPS Number
South West Area	■ Used for the administration of the Drugs Payment Scheme
West Area	■ Used for the administration of the Drugs Payment Scheme
Other Areas	
BreastCheck and Irish Cervical Screening Programme	Currently, BreastCheck and ICSP have their own registries and manage each registry and duplicates independently. There is a review currently underway to determine the best way forward in relation to these registers and whether a national Cancer Screening Register is required. Both BreastCheck and ICSP are established under legislation to allow access to an individual's data to communicate the screening programmes and call for appointments. In relation to the ICSP register, as the DSFA provide the source data on women eligible for cervical screening, almost all records have a PPS Number (app. 0.19% do not have a PPSN)
Primary Care Reimbursement Scheme	The PCRS also collect the PPS Number when processing applications for the European Health Insurance Card ⁽⁶⁾ .
HSE Dental Services	The HSE dental services take a feed from DSFA each summer and get a school list from the Department of Education. These are cross-referenced to identify target children based on their age and/or school year. Primary school children must be checked every two years. Currently the PPS Number is used as the main identifier. However, the service also uses telephone number as an identifier as children tend to remember this number" ⁽⁶⁾ .
Mental Health Commission	The Mental Health Commissions are one of the specified bodies that can collect the PPS Number.

Appendix 5

Meetings with stakeholders

Date of meeting	Organisation	Purpose of the meeting/call
13 Oct 2008	Various stakeholders: DoHC, Health Information and Quality Authority, HSE, DSFA, Department of Finance, ESRI, IPH, NCR, NSAI, and Gwen Malone Stenography Ltd	Round table discussion on the agreement of the criteria according to which a decision on the nature of a UHI should be made
10 Nov 2008	Health Information and Quality Authority	Proposal for HTA discussed
11 Nov 2008	Europa Donna Ireland	Comments and feedback on UHI proposal
14 Nov 2008	Health Information and Quality Authority	Advice sought from Patricia Harrington, Acting Director of HTA regarding HTA process
14 Nov 2008	HSE	Information gathering on PPS Number
24 Nov 2008	Irish College of General Practitioners	Comments and feedback on UHI proposal
24 Nov 2008	VHI	Comments and feedback on UHI proposal
25 Nov 2008	GS1 Ireland	Comments and feedback on UHI proposal
25 Nov 2008	CIS	Information gathering on PPS Number
26 Nov 2008	DoHC, HSE	Comments and feedback on UHI proposal
28 Nov 2008	Irish Patients Association	Comments and feedback on UHI proposal
13 Jan 2009	NCHCD, St James's Hospital, Dublin	Overview of NCHCD unique identification system with discussion on costs and cost savings
13 Jan 2009	Hibernian Aviva	Comments and feedback on UHI proposal

Date of meeting	Organisation	Purpose of the meeting/call
3 Feb 2009	PCRS	Overview of PCRS system, use of identifiers and discussion on costs
11 Feb 2009	DoHC, HSE	Discussion on Draft Health Information Bill with regard to UHI
24 Feb 2009	DoHC	Discussion on Draft Health Information Bill with regard to UHI
19 Mar 2009	Alberta Health and Wellness	Discussion on Alberta Province, Canada development, cost and use of UHI
19 Mar 2009	Irish Blood Transfusion Service	Discussion on benefits of UHI

Appendix 6

Glossary of Terms

ASTM	American Society for Testing and Materials
BDBC	Benefits-driven business case
CEN	European Committee for Standardisation
CIS	Client Identity Service
CMOD	Centre for Management and Organisational Development
CMA	Cost minimisation analysis
COAG	Council of Australian Governments
CR	Client registry
CRS	Central Records System
CSO	Central Statistics Office
DACEHTA	Danish Centre for Evaluation and Health Technology Assessment
DoHC	Department of Health and Children
DPC	Data Protection Commissioner
DSFA	Department of Social and Family Affairs
EHR	Electronic health record
EMPI	Enterprise master patient index
ESRI	Economic and Social Research Institute
GP	General practitioner
GS1	Global Standards Ireland
GSRN	Global Service Relationship Number
HIPE	Hospital In-Patient Enquiry Scheme
HIPPA	Health Insurance Portability and Accountability Act
HIT	Health information technology
HPI	Healthcare provider identifier
HSE	Health Service Executive
HTA	Health technology assessment
ICGP	Irish College of General Practitioners

ICSP	Irish Cervical Screening Programme
IHI	Individual health identifier
IPH	Institute of Public Health
ISO	International Standards Organisation
MPI	Master patient index
MRN	Medical record number
NCHD	National Centre for Haemophilia and Coagulation Disorders
NCI	National Client Index
NCR	National Cancer Registry
NEHTA	National Electronic Health Transition Authority
NHI	National Health Index
NHIS	National Health Information Strategy
NHS	National Health Service (UK)
NLCHI	Newfoundland and Labrador Centre for Health Information
NPRS	National Perinatal Reporting System
NPSA	National Patient Safety Authority
NSAI	National Standards Authority of Ireland
NZHS	New Zealand Health Information Service
PAS	Patient administration system
PCCC	Primary, Community and Continuing Care (of the HSE)
PCRS	Primary Care Reimbursement Scheme
PPS	Personal Public Service
RAND	Research and Development (Corporation)
THI	Temporary health identifier
UHI	Unique health identifier
UK	United Kingdom
UPI	Unique patient identifier
US	United States
WTE	Whole time equivalent

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