

Health Information in Ireland: A Socio-technical Analysis

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Introduction

This paper presents an analysis of the policy aspects of health information in Ireland and in a number of English-speaking countries (Australia, Canada, England and the US). This policy analysis is part of a wider study that examines, from a socio-technical perspective, the key dimensions that impact on health information. The socio-technical perspective acknowledges that there are a broad range of technical, social and organisational issues that can impact on how health information is planned for, developed and implemented. This paper addresses only one of these dimensions, that of policy and presents a cross-country analysis of policy in this area. The countries included have been strategically chosen on the basis that they provide a useful comparison with Ireland both in policy and practice terms.

Classifying Health Information Policy

While there is an acknowledged need for national health information, what this means in practice varies significantly from country to country. The Health Information and Quality Authority's (HIQA) international review of health information in six countries (HIQA, 2011a) highlights the fact that varying models operate and that differences exist between countries in how health information is organised. There are also some similarities in how countries have begun to take initiatives in this area. To understand these differences and similarities it is useful to classify the work in other countries and to see where Ireland sits *vis-à-vis* its European and international counterparts. For the purposes of the research, two key facets of policy are used to define the taxonomy of health information that exists across countries in the English-speaking world. On one axis is *clarity* of purpose or the extent to which there is clear legislative and regulatory control and strategic direction. The second is the degree to which there is *coherence* in health information systems or that there is a single point of contact for health information issues, that standards and rules apply,

and that there is investment in and support for technology and personnel. Different countries have adopted a range of approaches to these issues and these are discussed below by country and then comparatively.

Health Information Policy Internationally

Australia

Clarity of policy

Australia has had an interest in the area of health information for some time. Since 1993, national health information has been the responsibility of the National Health Information Agreement (NHIA). The Agreement was established to coordinate the strategic direction of health information, including the development, endorsement and maintenance of national data standards as well as a commitment to co-operate on agreed governance arrangements for information management. The NHIA's most recent agreement between the Australian Government and state/territory government health authorities was signed at the end of 2013 (Department of Health, Australia, 2013). Its key objectives are to: '1) ensure the availability of nationally consistent high quality health information to support policy and programme development, 2) improve the quality, efficiency, appropriateness, effectiveness and accountability of health services provided to individuals and populations and ... 3) promote the efficient, secure, confidential and timely use of information across the complete lifecycle' (Department of Health, Australia, 2013: 6). Objectives are also set out that are designed to promote and encourage consistency in the application of a standardised approach nationally.

Australia's health information legislative framework and infrastructure can best be characterised as having procedures to facilitate greater cooperation between health care data providers. In Australia, there has been greater emphasis on standard-setting and co-operation rather than on enforcement of legislation. With regard to developing strategy in this area, in 2009 Australia launched its National e-Health Strategy to develop a framework to guide national coordination and collaboration in e-health (National e-Health and Information Principal Committee (NEHIPC), 2009). Since 2006, a national approach to developing and implementing Healthcare Identifiers (HI) for individuals and providers has also been in place to 'help drive improved quality and safety of care, increase efficiency, support integration and enhanced communication between disparate health services and providers, and reduce duplication of services, assisting with the long term

sustainability of the health system in Australia' (Commonwealth of Australia, 2013: 1). As in a number of other countries, legislation for a health identifier - the Healthcare Identifiers Bill 2010 - was introduced to Parliament in 2010 and was recently independently reviewed (Commonwealth of Australia, 2013).

Coherence of policy

In Australia, there are many organisations involved in the collection and management of data and the NHIA has a co-ordination role as it acts as a single point of contact for all health information issues. The Australian Institute for Health and Welfare has been in existence since 1987 and plays a key role as a central collection point for health information. In 2005 another national agency, the National e-Health Transition Authority (NEHTA), was established to deliver Australia's National e-Health Strategy (NEHTA, 2006). As part of the development of a strategy on e-health, a number of standards-based documents have been produced (NEHTA, 2006; NEHTA, 2007). The focus across the country has been on interoperability and on work with health services to generate standardised data. The work plan for the National e-Health and Information Principal Committee (NEHIPC) identified three priorities, namely: better use of health information to improve the quality of the health system, better health information for consumers and better outcomes from targeted investment in health information through research. These priorities build on existing data collected, data linkages and better monitoring of health outcomes (NEHIPC, 2009).

With regard to the health information workforce, the Health Informatics Society of Australia (HISA) undertook a review in 2009, which recommended that health information become a national priority (Health Informatics Society of Australia, 2009). There is now a well-developed health informatics workforce in Australia, in acknowledgement by government there of the importance of having skilled staff to manage health information. In particular, investment has been made into the incorporation of informatics into undergraduate nursing programmes (see Borycki *et al.*, 2013) in recognition of the fact that nurses are frequently at the front line of health information systems. At the level of technology, much investment to date has been in improving interoperability between the federally dispersed provinces of Australia, and in 2011 a Chief Information and Knowledge Officer was appointed to continue the work of harmonising health information systems there.

Canada

Clarity of Policy

Canada has a robust public health care system that is supported through its national health insurance infrastructure. Its well-developed health care system is mirrored in its approach to health data as is the case in Australia - since the early 1990s it has been developing its approach to health information. In Canada, Health Canada is the leading government department charged with the delivery of health care and with overall responsibility for health information. With regard to its legislative approach, Canada does not have a national framework for health information due to variation in legislative provision across its territories. Instead, the focus has been on developing a sound health information infrastructure, mainly through the development of an electronic medical record (EMR). One of the key policy challenges has been to devise mechanisms for linking existing data sources and for improving their quality. There is no national system of unique identification for health in Canada but this does exist at provincial level. Much of the strategic thinking in Canada has been around the EMR and developing a more integrated approach to data so as to maximize its usage.

Coherence of Policy

In Canada there is no one single organisation with responsibility for health information. Instead, there are three separate agencies - the Canadian Institute for Health Information (CIHI), Canada Health Infoway and Statistics Canada - all of which have a role to play. CIHI is the lead agency charged with the management and dissemination of all health care data. CIHI is an independent body that has been in existence since 1994. It also has a role in setting quality standards for health information and for developing an integrated approach to health data (Canadian Institute for Health Information, 2009). In this regard, its key strategic goals for the period 2012-2017 are to 'provide more complete data while integrating data across health sectors to add value and provide a patient-centred focus' (Canadian Institute for Health Information, 2012: 12). Canada's Health Infoway, which was established in 2001, has been given responsibility for developing electronic health records across the provinces with a view to providing a cross-country, interoperable structure for the maintenance and management of health data. The work to date in Canada includes the development of electronic health records, and generating health information standards that enable interoperability and systems for sharing patient health information accurately and securely. Canada's most recent strategy on health information has as its core

objective the development of a common primary health care EMR. The emphasis of much of the work has been to support the roll out of the EMR. In 2013, CIHI published its vision for use of data in the health system (Canadian Institute for Health Information, 2013), where it advocates the value and benefits of better use of data. CIHI's role in promoting good data is key to its success at getting health care settings to provide it with data.

In relation to investment in the workforce, as in Australia, Canada has focused much of its efforts on the area of nursing informatics (see Borycki *et al.*, 2013). Its investment in technology is designed to support the use of health information systems among clinicians, thereby moving the country closer to a full EMR.

England

Clarity of Policy

The National Health Service (NHS) provides health care in the United Kingdom (UK) and in England health care is managed by Strategic Health Authorities and Trusts. As with other countries, health information has been the focus of debate for some time. Within the NHS in England there have been several attempts at rationalisation and streamlining of health information governance. In 1996 an NHS number was introduced as an identification mechanism for all health care settings and the NHS's *Information for Health* document (National Health Service, 1998) set out a strategy for developing the health information infrastructure in the UK. The National Programme for Information Technology (NPfIT) initiative was established in 2003 within the NHS to deliver a national information technology infrastructure across health care settings and to provide a basis for integration and sharing of patient information. Its implementation has been problematic largely due to poor adoption rates and patchy uptake (see Waterson, 2014). In 2011, the government announced that the NPfIT was no longer fit for purpose and would be dismantled.

Following this, the UK strategy entitled *The Power of Information* (Department of Health UK, 2012) set out a ten-year strategic framework for transforming information for health and care. It aims to harness information and new technologies to achieve higher quality care and improve outcomes for patients and service users. The framework includes key recommendations on integration of health data and on connected health through 'online access to GP records in hospitals, electronic prescribing

and barcode-scanning in care homes and hospitals to reduce medication errors, and electronic access to results, X-rays and scans'(Department of Health UK, 2012: 28).

Coherence of policy

Until recently, there was no single body responsible for health information in England but in 2013 the Health and Social Care Information Centre (HSCIC) was established and replaced much of the work undertaken by the Npfit and other initiatives. Since 2013, the HSCIC has been responsible for developing, delivering and maintaining the NHS national IT infrastructure, which supports the delivery of services and the provision of healthcare in England. This includes issues such as data capture, management of identifiers and interoperability, as well as standards for information governance, information quality and secondary uses of data. The HSCIC also undertakes consultations with stakeholders and the wider public on initiatives in the health information area. In England there is a regulatory framework for health information (see HIQA, 2009a) and since 2008, there has been a Chief Information Officer for Health in place.

The UK Department of Health also established Public Health England as an executive agency with responsibility for public health issues, and part of its remit is to provide a gateway or a single point of access to data and analysis in the public health area. Public Health England was established in April 2013 to bring together public health specialists from more than 70 organisations into a single public health service. With this and the HSCIC, England has done most to support the idea of a single point of contact for health information.

Investment in ICT for health has been significant. Commentators remarked that over £12 billion had been spent on health information in the last decade (Waterson, 2013). There has also been some attention given to workforce development and the promotion of health informatics as a discipline. In 2008, for example, the Department of Health published a health informatics review, which set out a framework for improving the skills of NHS workers in this area (Department of Health UK, 2008).

United States

Clarity of policy

In the US, health care provision differs significantly to the other countries already examined, as the system of care is largely based on ability to pay and on private insurance. (Woolf and Aron, 2015). In the health information context then, the need for good data is driven by the need for efficiency and effectiveness. Much of the development to date has been driven by the Health Information and Technology (HITECH) Act (2009), which came into law in 2009 as an economic stimulus package. Under the Act, every hospital is able to buy and use electronic health records with a view to creating a platform for what Bau (2011: 15) describes as 'activities that support health care quality improvement and cost reductions in the national health care reform legislation'. The HITECH Act introduced what it terms 'meaningful use' of EHR adoption in the health care system. This is regarded as a national priority. The Institute for Medicine, which has played an important role in driving the health information agenda in the US, commented that the legislation is not only about economic efficiency but also 'the establishment of a new norm around engaging patients and the population in health through the use of the digital infrastructure' (Institute of Medicine, 2010: 30). The focus in the US, therefore, is on how health data can drive improvements in health care provision as well as a greater emphasis on consumer involvement in the management of their own health information.

Coherence of policy

The US Department of Health and Human Services (DHSS) has responsibility for health information and health IT. Its Office of the National Co-ordinator for Health Information Technology (ONCfHIT) recently launched a 10-year vision to achieve an interoperable health IT infrastructure as part of its Connecting Health and Care of the Nation initiative (ONCfHIT, 2014). The document refers to the need to develop a sound health IT ecosystem, building on the existing health IT infrastructure and incorporating individual access to health data, HIT for quality and safety in delivery of care, population health management and big data and analytics. As part of its work on consumer access, it has developed the Blue Button initiative, which allows individuals to access their own health information electronically. Early in 2015, the ONCfHIT released a detailed roadmap (ONCfHIT, 2015) for digital health information and its appropriate use. It sets out a vision and path forward that will require shared action between the public and private sectors to create a health ecosystem. This roadmap builds on the ideas that the ONCfHIT raised in its 2014 document (ONCfHIT, 2014). The emphasis is firmly on the need to focus on interoperability as a priority. The ONCfHIT

acts as the single point of contact for health information issues. It recently launched its Workforce Training Program, which will provide up-to-date training materials and a roll-out of training in the use of new technologies for up to 6,000 health care workers. Within the ONCfHIT there is a National Coordinator for Health Information Technology whose role is to implement an improved health information infrastructure.

Health Policy Context in Ireland

Over the past two decades, key health policy documents and strategies in Ireland have included due consideration of the importance of health information in the broader achievement of objectives in health care. In 2001, a major governmental paper *Quality and Fairness: A Health System for You* (Department of Health and Children, 2001) recognised that a high quality information infrastructure is a fundamental necessity for achieving its objectives. The emphasis on health information in Irish policy was also captured in the Health Services Reform Plan (Department of Health and Children, 2003). One of the objectives of the plan was to ensure better patient care and safety, and one mechanism recommended for doing so was to use information – both manual patient files and electronic data – to assist with the care of the individual. Other policy documents also suggested the need for a framework for health information as an enabler for achieving the goals and objectives of key health policy initiatives (see for example, Commission on Patient Safety and Quality Assurance, 2008). This growing focus on better health information systems as a means of supporting better health care is consistent with what was happening internationally at this time, as highlighted above.

Health Information Policy in Ireland

Perhaps the most significant policy development in health information in Ireland was the publication, in 2004, of a *National Health Information Strategy* drawn up by government to set out its approach to issues in health information and how those issues relate to decisions about health care. It stated: ‘accurate, relevant and timely information is not an optional extra but is essential’ (Department of Health and Children, 2004: 15). The strategy document viewed health information as ‘a valuable resource’ (Department of Health and Children, 2004: 3) and it recognised that advances in health and health care depend - and will increasingly depend - on having useful health information. The stated aim of the *National Health Information Strategy* in Ireland was to ‘recommend the necessary actions to rectify present deficiencies in health information systems and

to put in place the frameworks to ensure optimal development and utilisation of health information' (Department of Health and Children, 2004: 7). It acknowledged that the way health information was managed, governed and regulated was insufficient when it referred to the 'fragmented, non-standard and inconsistent way in which information is collected and processed' (Department of Health and Children, 2004: 8).

The Strategy, although announced by the then Minister for Health, Micheál Martin in 2000, didn't come to fruition until 2004 following an information-gathering process by the National Health Information Strategy Steering Committee, which was established by the Department of Health. In the lead up to the Strategy, a conference - jointly sponsored by the Department of Health and the Faculty of Public Health Medicine of the Royal College of Physicians of Ireland (RCPI) - was held to identify the issues considered central to a successful strategy. The main issues that emerged were 'strong leadership, political will and adequate resources to ensure it comes about, a strategy that is realistic with short, medium and long-term goals, clear objectives and a patient/client-centred basis for development' (Royal College of Physicians of Ireland, 2000: 3-4). These comments indicated a recognised need to champion the strategy at policy level and to provide supports - both in terms of funding and personnel - to enable its implementation.

The objectives of the Strategy focused on a legislative and information governance framework, an integrated national approach to health information, standards for better health information and the identification of opportunities to exploit enabling technologies. Fundamental to the Strategy was the intention to develop an electronic healthcare record to link patients' details across health care settings in order to provide a fuller picture of their health needs. Reference to an electronic healthcare record in the strategy document was significant as it would ultimately require stakeholder buy-in, changes to information management in a range of health care settings, and significant investment in infrastructure. A background paper on the Electronic Health Record (HIQA, 2009d), which was drafted for a workshop on this theme, raised considerable questions about the type of record envisaged and the most appropriate implementation model.

The *National Health Information Strategy* proposed the development of the EHR on a phased basis in recognition that it was an evolving and complex concept (Department of Health and Children, 2004). Research on user attitudes to the implementation of an EHR in the Irish Health Services

concluded that there are a number of significant barriers to the adoption of an EHR; some of the main barriers identified include the need for a high-level implementation strategy driven by and funded by government, fear by ICT managers within the Irish health care sector of EHR becoming another high profile e-government failure, fragmentation of the health care sector, and difficulties in justifying back-office ICT investment at a time when front-line health care resources were under considerable strain (Lang and Melia, 2009).

Clarity of Irish Health Information Policy

The *National Health Information Strategy* proposed two key institutional developments: the enactment of legislation on health information, and the establishment of HIQA. Both of these developments are important, as they constitute the two main policy mechanisms to support health information in other countries. Yasnoff *et al.* (2004) presented a similar overview of health information in the US, with the same institutional enablers highlighted.

Legislation and Regulation

The *National Health Information Strategy* outlined the intention for health information legislation to give legal status to the electronic health record and to a unique identifier for health, which would enable data to be shared across institutions. The implementation of an individual health identifier represents potentially one of the most significant departures for health care data ever in Ireland, as it allows for the possibility of data linkage, thereby leading to a more integrated approach to the use of health information. In 2006, a Health Information Bill was published (Government of Ireland, 2006) with the following specified objectives: 'to establish a legislative framework to enable information in whatever form to be used to best effect to enhance medical care and patient safety throughout the health system; to facilitate the greater use of information technologies for better delivery of patient services and to underpin an effective information governance structure for the health system generally.' A detailed consultation with key stakeholders took place, a report on which observed that there was widespread support for the underlying principles and objectives of the legislation (Department of Health and Children, 2008). A discussion paper by the Department of Health argued that using health information requires 'an examination of how information is used, the areas where it could be better used and the safeguards needed to ensure appropriate protection' (Department of Health and Children, 2008: 2). To facilitate this, a Health Information Inter-Agency Group was established in the Department of Health in 2008 and had as its terms of

reference to agree a common vision and set of principles for health information and ICT and to bring clarity to the roles of the three organisations – the Department, the Health Service Executive and HIQA – in this area. In practice, this group did not achieve its stated aims due in large part to delays in the drafting and finalisation of the legislation and a lack of agreement on the respective responsibilities of the participating agencies.

One of the recognised key requirements for good health information is ‘a system of unique identification to promote the quality and safety of client/patient care’ (Department of Health and Children, 2004: 61; HIQA, 2009a). This has also been described as ‘the single most important deficiency in the health information infrastructure in Ireland’ (HIQA, 2009a: v). A consultation process revealed serious concerns about any potential for linkage between health and financial information. The debate about the appropriate identifier involved agencies such as the Data Protection Office, which did not favour use of PPS numbers, and HIQA, which found that as per international best practice, virtually all countries that had recently introduced, or were planning to introduce, a Unique Health Identifier (UHI) had opted for one that was healthcare-focused and confined to the health care sector (HIQA, 2009b).

Protracted negotiations on the UHI led to significant delay in the passage of the health information legislation. In December 2013, a *Health Identifiers Bill* was finally published (Government of Ireland, 2013a). This represented only one part of the legislation that was promised in this area. The Bill provides for a unique number – the Individual Health Identifier - to be assigned to each individual to whom a health service is provided; it provides for a unique number for the person who provides a health service; and it provides for the association of identifiers with medical records and related communications. In this respect, the legislation, once implemented, will allow for greater degrees of linkage and integration across health information sources which, heretofore, have not been possible in the Irish context. A further piece of legislation is awaited in relation to health information, which, it is anticipated, will provide greater detail on issues such as data access, linkage and sharing. This Bill was expected in 2014 but at the time of writing it still had not been published. In 2015, HIQA published its standards for governance and management of unique identifiers (HIQA, 2015).

Regulatory Control: HIQA

The second key policy initiative set out in the *National Health Information Strategy* was the setting up of HIQA as the central driving force behind the implementation of the Strategy. As stated on its website, HIQA is the independent Authority established in May 2007 to drive continuous improvement in Ireland's health and social care services function. Its role as defined in the *Health Act 2007* (Government of Ireland, 2007) includes 'the setting of standards for health information and health information systems and monitoring their compliance in a growing portfolio of information-related areas, provision of advice and guidance to the sector, evaluation of available information about the health and welfare of the population, identification of gaps in the health information landscape across the sector and making recommendations to the Minister for Health in respect of filling these gaps' (HIQA, 2011a: 9). Reporting directly to the Minister for Health, HIQA's role is to promote quality and safety in the provision of health and personal social services in order to benefit the health and welfare of the public. One of its key strategic roles relates to health information governance: 'advising on the efficient and secure collection and sharing of information ... about the delivery and performance of Ireland's health and social care services' (HIQA, 2012b: 1).

HIQA was established as an interim body in 2006 and was formally launched as an agency in 2007. In its initial stages, the work of its Social Services Inspectorate came to prominence. The Inspectorate has responsibility for the registration and inspection of residential homes for older people - and more recently for children and people with disabilities. Early on, HIQA came to be associated with inspections of nursing homes for older people, and high-profile cases in the media contributed to this emphasis. As a result, its focus on health information was somewhat overshadowed in its early years of operation. Since that time, its work on health information governance has gained momentum; it has carried out two international reviews of health information, one on governance (HIQA, 2009a) and one on health information sources (HIQA, 2011a). On foot of the publication of the *National Health Information Strategy*, it carried out work on the development of a unique health identifier (HIQA, 2009b; HIQA, 2009c). It also examined the existing health information landscape in Ireland with an 'as is' analysis of Irish health information sources (HIQA, 2009e) and published a detailed catalogue of all sources (HIQA, 2010a; HIQA, 2014a).

HIQA's role in supporting the delivery of good health information and its governance, although slow to take off, has developed in the last few years through: 1) provision of practical advice for those working in the health care and health information settings; 2) developing standards and guidelines to improve health information; and 3) policy input to government on key aspects of health information. It has published a range of reports aimed at providing guidance in relation to governance in this area (see for example, HIQA, 2009a; HIQA, 2009e; HIQA, 2011c; HIQA, 2011d).

HIQA's general operational style is largely consensus driven, aimed at achieving agreement from a broad range of stakeholders. Much of its work is done through advisory bodies consisting of key stakeholders. For example, an Advisory Committee was established in 2011 to draft and agree the wording of standards for health information sources (HIQA, 2011b) and a process of consultation was undertaken with the wider public before final publication. Similarly, a working group came together to agree the standards for safer, better health care (HIQA, 2012c), which also had as one of its core principles better health information. This method of working has moved HIQA into the realm of soft regulation, where good practice is promoted and acknowledged but there is little or no sanction for non-compliance.

The long delay in the finalisation of the *Health Information Bill* (Government of Ireland, 2006) has hampered the role given to HIQA to fulfil its statutory obligations in relation to health information and in the development and promotion of better integration of health information and systems. The Authority's key responsibilities in health information governance and the setting of standards have been its most visible contributions to date (see HIQA, 2012b; HIQA 2011c) but it has had less success in monitoring or enforcing compliance with the standards. It has also played an important role to date in raising awareness of the need for investment in ICT with a view to addressing problems of interoperability (HIQA, 2011d). Prior to HIQA's establishment, governance in the area of health information was shaped by a range of national and international directives, which include international data protection initiatives; EU initiatives; and national law, including the *Data Protection Acts 1988 and 2003* (Government of Ireland 1988; Government of Ireland 2003a), the *Freedom of Information Acts 1997 and 2003* (Government of Ireland 1997; Government of Ireland 2003b), and professional ethical codes. In addition, an updated EU Directive on data protection is due in 2016 and will mean that new legislation in Member States will be further strengthened. The combination of this wider legislative basis and the good practice approach promoted by HIQA is

likely to influence the overall health information infrastructure in Ireland. However, the delay in putting a legislative framework in place has meant that HIQA has been somewhat stymied in its regulatory function, as the framework for the standards for health information are not yet underpinned by powerful sanctions. Indeed, in the process of drafting the standards, the final publication removes the word 'standards' and replaces it with 'guiding principles' in recognition of the fact that there is no authority attached to HIQA's role in setting standards in this area.

Developing a Strategic Approach

Following a period of policy inertia due to a significant delay in the legislation for health information, there has been a recent resurgence of interest in this area, fuelled in part by EU policy and in part by the need to drive efficiency within the health sector. In 2013, the Government published its *e-Health Strategy* (Department of Health, 2013a: 5), which specifically refers to 'the integration of all information and knowledge sources involved in the delivery of health care via information technology-based systems'. E-health is part of a broader attempt by government to develop a national data infrastructure and develop e-government options for making administrative data available within the Irish public sector in a planned, rational and coordinated way (see Department of Public Expenditure and Reform, 2011; MacFeely and Dunne, 2014). Indeed a recent National Statistics Board (2011) publication calls for a national data infrastructure and identifies a number of key actions that include: 1) development of the infrastructure to maximise all available data sources; 2) a need to address data protection concerns that serve as constraints on secondary or further processing (including data linkage, integration and matching) for statistical purposes; and 3) engagement with policy-makers. These actions represent the key challenges to the successful implementation of the Department of Health's *National Health Information Strategy*. Of particular relevance to this research is that one of the fundamental enablers for the successful execution of the e-Health Strategy is 'a standards-based, multi-layered information and technical infrastructure' as well as 'the development of appropriate health informatics skills and/or staff training' (Department of Health, 2013a: 8).

The e-Health Strategy in Ireland originated largely as a result of an EU *Task Force Report* (European Union, 2012), which was compiled to examine how technology can assist in delivering greater efficiency, lower costs and better health outcomes (European Union, 2012). It acknowledges that individuals are the owners and controllers of their own health data but that shared ownership with

the health system should be promoted to lead to use of anonymised data for epidemiological purposes. It recommends that as a lever for change, data should be liberated: 'large amounts of data currently sit in different silos within health and social care systems' (European Union, 2012: 10). The main precondition for this lever for change is 'robust data, gathered in a standardised way, integrated with care services and made available to researchers' (European Union, 2012: 11). The primary aim of the EU's Task Force report was to call for a legal framework and safeguards for the integration of health data as well as using 'the power of data' (European Union, 2012: 16) to drive improvements in health care and to, ultimately, improve outcomes for patients.

As a result of the EU *Task Force Report* and the European Commission's *eHealth Action Plan 2012-2020* (European Commission, 2012), all countries including Ireland began to develop an e-health strategy. The initiatives that are captured in Ireland's e-Health Strategy includes EHRs, e-prescribing telecare and telemedicine. Key to the deployment of this approach within the e-Health Strategy is the existence of a national health identification number. It is not, therefore, surprising that the *Individual Health Identifier Bill, 2013* and the *e-Health Strategy* were launched on the same day in December 2013.

The Strategy acknowledges that the process of adapting technology systems within the health care area has been slow, due to factors such as a lack of technology standards, organisational factors such as an unwillingness to change processes, and legacy underinvestment in general healthcare ICT systems. The benefits of e-health are set out in detail (Department of Health, 2013a), but perhaps the benefit that relates most to health information is the focus on health monitoring and reporting, which provides for improved ability in supporting surveillance and management of public health interventions, and improved ability in analysing and reporting on population health outcomes.

In other recent health strategies, health information is also regarded as key to their successful implementation. A 2012 health care strategy *Future Health* (Department of Health, 2012a) highlighted the need for enactment of the Health Information Bill and for reform in relation to information and ICT capacity. The report characterised the health information environment in Ireland as '... a patchwork of information systems, some national and some local [that] have varying degrees of quality and comprehensiveness but do not currently support delivery of the efficient, integrated and timely information required ...' (Department of Health, 2012a: 43). The

report acknowledged the progress made by HIQA in addressing information deficits and in information standards. Its key recommendation, however, is the legal framework for better governance of health information.

Other health policy documents have also identified the need for improvements in the information and ICT infrastructure in order to successfully implement change in health care. *Healthy Ireland*, a recent public health strategy aimed at promoting health and well-being (Department of Health, 2013b), advocated the need for high quality and accurate data to monitor lifestyle and health. A recent report to the Department of Health on the implementation of *Healthy Ireland* (Hanafin, 2014) recommends that existing health information systems and administrative data sources need to be incorporated in the knowledge management plan developed for the strategy. Other reforms such as those advocated in *Money Follows the Patient* (Department of Health, 2013c) and the paper on universal health insurance (Department of Health, 2013d) will also be reliant on good information systems - so much so that the Hospital In-Patient Enquiry (HIPE) information system is now located in the recently established National Pricing Office of the HSE so that data on hospital procedures, waiting lists and length of stay can be part of an overall approach to costing and paying for health care.

Coherence of Irish Health Information Policy

One of the key facets of health information policy in other countries is having a single point of contact for health information issues. In Ireland, HIQA, while not a single point of contact, has begun to develop a leadership role in relation to health information policy and practice. In 2014, for example, HIQA published a set of recommendations for the Minister for Health on developing a more integrated approach to health information (HIQA, 2014d). The report reviewed international best practice and concluded with a series of recommendations for health information in Ireland. Within the report are key recommendations in relation to 'the development of a strategic framework for national health and social care data collections in Ireland ... setting out a roadmap and informing policy development' (HIQA, 2014d: 7). The report acknowledged that the implementation of such a roadmap is likely to take a number of years but that it will result in reduced fragmentation and duplication of health information. This is moving the Irish situation closer to that of the countries described earlier. Other key areas in which HIQA has made recommendations include the secondary use of information for national purposes when major ICT

projects are being developed, compliance with legislative and regulatory requirements, development of a framework for data quality and the optimal use of and access to data. It has also played a key role in standard-setting (HIQA, 2013c).

Investment in ICT and the Workforce

The ICT infrastructure for health was also seen within the *National Health Information Strategy* as a necessary prerequisite for the programme of health care reform. The Strategy recognised that there was considerable variation in the usage of ICT in the Irish health system; in some areas there has been ‘sophisticated support for complex processes’ (Department of Health and Children, 2004: 81) while in others ICT is very limited. The strategy also acknowledged that financial support was a significant issue: ‘the legacy of under-investment in ICT is an inadequate infrastructure to support the complex requirements of a modern health service’ (Department of Health and Children, 2004: 81). To address this, the Strategy proposed a national ICT framework to develop a ‘cohesive and integrated approach’ (Department of Health and Children, 2004: 82). HIQA was to develop a multi-annual information and ICT action plan as a matter of priority. A key pillar of the ICT plan was the personnel, payroll and related systems (PPARS) project, which was designed to develop an information system to integrate human resources and pay within the health services. The project experienced major implementation difficulties due to spiralling costs and lack of accountability (see Loonam, 2008; Sammon and Adams, 2010 for discussion). The outcome of this has been delays in other large-scale ICT projects in the health sector. The HSE has spent the last number of years developing a national ICT framework for health, and this only came to fruition in 2014 following protracted negotiation. Recent moves include the increase of the HSE budget for ICT from €40 million in 2014 to €55 million for 2015 (Breslin, 2014) and the appointment of a Chief Information Officer for Health who took up office in December 2014. This appointment is consistent with what some of the countries reviewed above have done. His role is to drive the implementation of the e-Health Strategy.

With regard to developing appropriate skills for those working in health information, the strategy states: ‘issues such as skills and training of staff, therefore, are as important as pure technical competency when it comes to integrating e-health technologies’ (Department of Health, 2013a: 24). Again, this is consistent with moves in the US and Canada, for example, to promote health informatics as a key aspect of training for those working in the health sector. The *National Health*

Information Strategy stated: ‘the availability of appropriately skilled and trained staff to support the potential of information within health agencies, together with providing the skills-base and training programmes to support the roll-out and full use of major ICT solutions throughout the sector, are critical for the implementation of the strategy’ (Department of Health and Children, 2004: 86).

With regard to human resources, the *National Health Information Strategy* stated that there would be ‘integrated workforce planning’ and ‘assignment of an appropriate number of knowledge workers’ to support the implementation of the Strategy (Department of Health and Children, 2004: 90). In the intervening period between its publication and the publication of the e-Health Strategy there has been no significant progress in this area. One likely contributing factor was that the health services underwent a major shake-up and restructuring; in 2004, just as the Strategy was agreed, major reform of the health services saw the introduction of the HSE and the abolition of the Health Boards. This led to a period of significant upheaval; staff within the health services experienced major changes in their lines of reporting and levels of responsibility, which created an environment that was unlikely to support significant informatics training and upskilling for staff and so the necessary environment for the implementation of the elements of the Strategy relating to the workforce were not put in place.

Comparing Countries

From a policy perspective, there are a number of key differences in how health information is managed and operated in different countries and some of this has already been documented in reviews of international practice undertaken by HIQA (HIQA, 2009a; HIQA, 2011a) and others (Greenhalgh *et al.*, 2013, Kusniruk *et al.*, 2013). An examination of the two dimensions outlined above, along with the Irish experience, suggests that where there is strong policy underpinning the health information area – either by way of a legislative base or a clear national strategy - the health information landscape tends to be better. Countries also differ in the extent to which they enforce regulation of health information and health information technology through legislation. England has a well-developed regulatory framework based on national legislation mainly focused in the area of governance. By comparison, Canada and Australia do not have overall legislative frameworks but rely instead on principles, which drive the attitudes and behaviour of those working in the health and social care sector. In the US, ICT for health has had a legislative basis since 2009.

Three of the countries examined have had a strong focus on the development of an EHR - one of the recent policy developments in health information that was identified in the literature. The other strategic aspect of policy that is noted most in the literature is e-health and this is also an important feature of the strategies employed by three of the countries reviewed.

In terms of the dimensions associated with policy coherence, there appears to be a move towards a central point of authority or reference on information issues, hence developments such as the establishment of the HSCIC in England. In the US and Canada respectively, the ONCfHIT and CIHI also but not exclusively provide this central role. HIQA is unique in the role that it has developed in Ireland in that it is not the single point of contact for health information but provides a degree of leadership in this area. In all of the countries reviewed there is a Chief Information Officer for Health – or its equivalent – to provide direction at national strategic levels.

Countries differ in the extent to which they have and implement national standards and codes of practice for health information and whether the standards are based on legislation. The emphasis in Australia is on standards and guidelines rather than on legislation. In both Australia and the US, efforts to improve the state of health information have focused on information sharing, interoperability and co-ordination. In Canada, the development of an integrated approach to EMRs is a dominant aspect of its efforts to improve health information.

There is patchy evidence about the level of investment by the countries reviewed in the development of ICT for health and in developing a health information workforce. There is evidence that in the UK and in the US, in particular, there has been substantial investment in this area. Not all of this investment has been viewed as effective, however (see Waterson, 2013; Kushniruk *et al.*, 2013). It has been shown that efforts to ensure health informatics become a recognised part of training for health care professionals are well advanced in both Australia and Canada.

The situation in Ireland is best characterised by slowness in the implementation of top-down initiatives set out in a national strategy designed to improve the state of health information. However, very recent developments suggest that there are a number of interventions that are likely to improve this area. HIQA's establishment as an organisation with some responsibility for health information issues is positive as it has provided a spotlight on issues to be addressed as well as lessons to be learned from international best practice. The passage of the *Individual Health*

Identifiers Act in 2014 is also likely to improve health data once it is implemented. The increase of the HSE's ICT budget for 2015 is also likely to be of benefit to new health information projects going forward. These combined with the publication of an e-health strategy and the appointment of a Chief Information Officer for Health point to a renewed interest in developing and improving health information in Ireland.

On the basis of the review of policy in four countries and in Ireland, a summary of features relevant to each country is set out in Figure 1. The aspects identified in the literature as important to a country's health information policy process are set out and grouped into the two broad areas of clarity and coherence. The table shows that both Canada and Australia appear to be ahead of other countries in relation to how they manage and deliver in the area of health information.

	Canada	Australia	England	US	Ireland
Clarity of Policy					
- Legislative framework	X	X	√	√	X
- Regulatory control	√	√	√	X	√
- Strategic approach	√	√	X	√	√
Coherence of policy					
- Single point of contact	X	X	√	√	X
- Standards/guidelines	√	√	√	√	√
- Investment in health ICT	√	√	√	X	X
- Health informatics personnel	√	√	X	X	X
- Integration of systems	√	√	X	X	X

Figure 1: Overview of Health Information Policy Aspects in Five Countries

Conclusion

This paper presents a policy overview for health information both in Ireland and in other countries. The findings of the review indicate that different countries are employing different strategies in relation to their legislative and regulatory infrastructure; in countries where there is well-defined strategy in relation to health information and an organised approach to the overall management of health data, progress towards a nationally agreed perspective on health information would appear to be better. Ireland fares poorly on these characteristics at present. Having a single point of contact for health information also seems to assist countries in the delivery of their objectives in

this area; the most recent establishment of the HSCIC in England provides an example of an initiative designed to address the poor implementation of the NPfIT programme there. In countries like Canada and Australia, a focus on developing standards and the health informatics workforce provides a good basis on which to build. In particular, all of those countries examined have focused on the two core strategies of EMR development and e-health, which were identified in the literature as important policy drivers in the health information context.

In relation to the state of Ireland's policy on health information, this review suggests that it is developing but that progress has been slow in two areas. First, in relation to legislation; a Bill promised in 2004 only partially emerged in 2013. Surprisingly, Ireland has fared better in relation to regulation of this area through the establishment of HIQA and its work in encouraging good practice through the development of standards and guiding principles for health information.

Second, Ireland has not fared well in its development of the necessary infrastructure for health information; investment in ICT promised as part of the *National Health Information Strategy* in 2004 did not materialise until 2015 nor did the allocation of staff to the health information area. In addition, there was evidence of a lack of leadership in the area of health information between the Department of Health, the HSE and HIQA.

Recent policy developments, such as the publication of the E-Health Strategy and the appointment of a Chief Information Officer for Health point to a renewed interest in developing the health information landscape in Ireland so that it can be used more effectively in the planning and delivery of health services.

30 September 2015

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