

# A Socio-technical Review of Five National Health Information Systems in Ireland using Agreed National Standards

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Abstract: This paper presents a review of five national health information systems in Ireland using a set of guiding principles and information governance standards that have been nationally agreed by the health information regulatory body there. The review uses a socio-technical approach to examine three dimensions of these systems; policy, infrastructure and people. The review was undertaken using documentary analysis of written materials about the systems from both primary and secondary data sources. The findings show that progress has been slow in the development of health information policy in Ireland and as a result, systems like those reviewed vary in how nationally agreed standards and principles have been applied. The paper concludes the need for a more consistent approach to national health information systems like those reviewed using agreed national standards.

## 1 INTRODUCTION

This paper presents a review of five national health information systems using a set of guiding principles for health and social care collections (HIQA, 2013a) which were set by Ireland's health information regulatory body, the Health Information and Quality Authority (HIQA) and which have since become agreed information management standards (HIQA, 2017a). The research applies a socio-technical approach to the examination of the systems using the principles set out which are grouped for the purposes of the research into three dimensions; policy, infrastructure and people (Table 1).

Table 1: Dimensions and National Standards.

Policy	Legislation/Standards
Infrastructure	Governance Structures Statement of Purpose Use of Information Data Quality Information Governance
People	Use of Resources Workforce

The principles were agreed nationally through expert collaboration and public consultation and are based on robust international evidence in this area

(Canadian Institute for Health Information, 2009; Canadian Institute for Health Information, 2017).

The research question is to what extent, if at all, do the HRB's systems apply the HIQA principles and standards in their operation?

Documentary analysis was undertaken of written materials for each of the five health information systems including primary sources such as protocols for data collection and collation, data validation and reporting as well as secondary sources such as evaluations and reviews.

The paper highlights the need for standards that are nationally agreed and that are in line with international best practice.

## 2 BACKGROUND TO THE SYSTEMS

The five systems reviewed are managed by the Health Research Board (HRB) a public service body under the remit of the Department of Health in Ireland. They collect data in the areas of drugs and alcohol, disability and mental health. Data collection began as far back as the 1960s in the mental health area, followed by drug treatment and disability data systems in the 1990s and drug-related deaths in 2005. Appendix 1 presents a summary

overview of the five systems. Twenty people are employed across the five systems and the annual budget is around €1.2 million. All of the systems generate timely and accurate data at a national level to assist with service planning and monitoring of key policies in the areas identified as well as reporting at national, EU and international levels.

### 3 POLICY DIMENSION

Progress in relation to having a well-developed health information policy framework nationally in Ireland has been slow. The experience of the development of the five HRB systems reflects how developments in health information in Ireland have proceeded; information systems generally come into being on a piecemeal basis in response to a particular information need rather than as part of a nationally agreed approach. It is only very recently that there has been some recognition of the need for a more coherent framework in this area (see HIQA, 2014).

The slow pace of development of health information policy in the last ten years in particular has had an influence on the development of the HRB systems. There has been little or no progress on the legislative framework for health information nor on the necessary infrastructure outlined as part of a *National Health Information Strategy* (Department of Health and Children, 2004). As a result the 5 HRB systems have not had the benefit of an agreed policy framework but have developed as stand-alone systems with differing aims and objectives.

#### 3.1 Legislation and Standards

Forthcoming legislation for Ireland on health information was announced in 2004 (Department of Health and Children, 2004). However, it wasn't until 2014 that legislation for one part of the Irish legislative framework – a unique identifier for health - was published (Government of Ireland, 2014). As is the case in other countries, the lack of a unique system of identification hinders the HRB in its day-to-day data processing work. It also means that linking systems either in-house or with any externally-held data sources is not possible. This means that systems cannot be integrated with other health and social care data sources.

There has been a significant push in other countries for greater standardisation of health and social care data. This is largely to enable interoperability of systems and opportunities for

maximising the use of health data. In the Irish context, this drive for standardisation has been lacking. However, HIQA has taken a lead role in this area and since 2010 there has been an increasing volume of standards-based publications designed to provide guidance to organisations like the HRB (see HIQA, 2012; HIQA, 2015).

Within the HRB as the five systems developed, there was very little consideration given to interoperability and, as a result, there is now significant variation in how data are collected. Over the last few years, some attempts have been made to address this using HIQA's nationally agreed demographic dataset as a guideline (HIQA, 2013b). There is still some way to go in streamlining across systems but standards set out by HIQA, which are based on best practice, have been beneficial to the organisation in its recent work.

#### 3.2 Assessment of Policy Dimension

The Irish policy context in the health information area is characterised by fragmentation and a lack of strategic planning about how health data use can be maximised. The establishment of HIQA, in 2007 as a regulatory body for health information, however, has resulted in more recognition of the need for a standardised approach. Before this, the HRB's health information systems developed separately with little or no reference to systems already in place either in the HRB or external to it. Key areas in which robust health information policy could have had most impact on the HRB's systems include having legislation for a unique identifier and nationally agreed standards for health data.

## 4 INFRASTRUCTURE DIMENSION

Strategic developments in health information require investment in infrastructure - hence five of the eight guiding principles set out by HIQA (2013a) cover the infrastructure dimension and address issues such as governance, use of data and data quality. Each of these is described below in relation to the HRB's five systems.

#### 4.1 Governance Arrangements

Good governance arrangements are increasingly regarded as crucial to the success of health information systems (National Health Service,

2015). HIQA (2017a: 30) recommends that each health information system ought to have ‘governance arrangements to ensure that the current and future needs of the national health and social care data collection are met’. Table 2 sets out the current governance arrangements for the HRB’s national health information systems.

Table 2: Governance Arrangements for the HRB’s NHIS.

System	Governance arrangement
NDTRS	None
NDRDI	National Steering Committee comprising all stakeholders
NIDD	National Committee comprising all stakeholders
NPSDD	National Committee comprising all stakeholders
NPIRS	None

Source: Health Research Board, 2014.

Three of the five systems have formalised arrangements in place to bring together key stakeholders on a regular basis to consider the strategic direction of the system and to make decisions about any required changes. The other two systems, the NDTRS and NPIRS do not have formal structures in place for monitoring. From a governance perspective this is a weakness, and it was highlighted as such in an independent review of the HRB’s work in 2014: ‘because there is a mixed pattern of steering groups and opportunities for research user and stakeholder input to each of the five database operations, or absence of same, each database should have a suitable stakeholder group’ (Health Research Board, 2014: 13). Where information systems have national governance structures and arrangements that are active and effective this has a positive effect on the data as it allows for a process of engagement with stakeholders and contributes to the comprehensiveness and relevance of the data.

#### 4.2 Statement of Purpose

Each of the five systems managed by the HRB has a publicly available statement of purpose, setting out how the objectives of each system are achieved (see Table 3). The statement of purpose has been agreed by those involved in the governance structures that are in place to oversee the systems (where they exist). The statement is maintained by the staff responsible for managing each system and is reviewed regularly to ensure that it is fit-for-

purpose. All statements are published in HIQA’s catalogue of health and social care data collections (HIQA, 2017b).

Table 3: Statements of Purpose for the HRB’s NHIS.

<b>NIDD</b>	The NIDD is a service-planning tool designed to capture data on the usage of and need for specialist disability services among people with intellectual disability.
<b>NPSDD</b>	The NPSDD is a service-planning tool designed to capture data on the usage of and need for specialist disability services among people with physical and sensory disability.
<b>NDTRS</b>	The NDTRS was established as an epidemiological database on treated drug and alcohol misuse in Ireland. It records incidence of drug and alcohol treatment.
<b>NDRDI</b>	The NDRDI provides epidemiological monitoring of cases of drug- and alcohol-related deaths, and deaths among drug users and among alcoholics in Ireland.
<b>NPIRS</b>	The NPIRS is a psychiatric database, which provides detailed information on all admissions and discharges to in-patient psychiatric services in Ireland.

Source: HIQA, 2017b.

#### 4.3 Use of Information

Each of the five systems managed by the HRB holds a large volume of data that are used for a wide variety of reporting. Reports for each system are provided annually to the Department of Health and for two of the systems, the NDTRS and NPIRS, quarterly reports on performance indicators are produced for the health care delivery body the HSE. HIQA (2017a: 18) suggests that it is essential to ‘promote, encourage and facilitate the use of the data’. This is achieved by the HRB in three ways: first, publications from each of the systems are made available annually in hard copy and electronic format; second, analysis is undertaken on extracted data on the basis of requests received from service planners, policy makers, academics and researchers as well as the general public and third, the HRB provides data through a number of portals such as the Irish government’s Central Statistics Office ([www.StatCentral.ie](http://www.StatCentral.ie)) so that secondary analysis of data is made possible. The HRB received 313 requests for data between 2016 and 2017. Most of the requests were for service planning purposes.

#### 4.4 Data Quality: Audit and Evaluation

To ensure data quality, a process of audit and evaluation needs to be included as an integral part of any information system (see Canadian Institute for Health Information, 2017). Over the last number of years, the HRB has given some attention to this area of its work and the organisation's latest strategy proposed that there would be investment in evaluation and audit of health information systems within the HRB during the strategy period (see Health Research Board, 2016). Previously, the level of activity overall in evaluation and audit has, however, not been high. In the last five-year period, only one of the five systems was formally evaluated and in the last ten-year period, only one other was audited.

#### 4.5 Information Governance

Information governance is defined as effective arrangements that will protect the rights of people about whom information is held (HIQA, 2017a). With regard to information governance in the HRB's five information systems, there is no one-size-fits-all model. Across the five systems, the nature of relationships between those that are providing services and the HRB to whom they return data is complex. Staff from the HRB facilitate data providers in three ways; 1) the provision of detailed protocols that set out how data should be recorded; 2) ongoing training and refresher training and 3) contact with senior staff within the HSE about the return of data. Work is underway to put in place formalised agreements with data providers to support the supply of quality data. Key aspects of governance centre on the information being treated securely and confidentially and ensuring that those registered can access their own data. Consent is sought from individuals for three of the five systems; two of these seek explicit consent and the other involves implied consent.

All of the systems' protocols address the issue of confidentiality. This is to ensure that the data are provided only to those stated and only for the purposes stated. These protocols are reviewed annually. Individuals seeking access to their own data are referred to the local HSE office, as the HRB does not hold personal details and so identification is not possible. Over time, the HRB systems have been guided by data protection legislation as well as the views of service users and those providing services in terms of dealing with sensitive data. Changes will

come into effect in 2018 as the EU General Data Protection Regulation becomes law.

#### 4.6 Assessment of Infrastructure Dimension

The key aspects of infrastructure that have been set out in the HIQA guiding principles and standards vary across the HRB's five systems. There is no consistent approach to governance and accountability. Processes and procedures are reviewed regularly to improve data processes but only two of the systems have been evaluated to assess the quality of their data. More effective use of data has developed over time, as demonstrated by the many requests for information from those involved in day-to-day service planning. Secondary analysis of data has been developing as a key area of the HRB's work in information systems but more effort is needed to address the structural issues that prevail in relation to data access and linkage. All of the HRB's systems have made changes to address the issue of information governance with a view to protecting the confidentiality of the individuals about whom data are held, and security is an important aspect of the day-to-day work within the HRB.

### 5 PEOPLE DIMENSION

#### 5.1 Workforce, Skills and Investment

One of the factors recognised in the literature as key to successful health information systems is the staff that work on and continually evaluate such systems (Yusof *et al.*, 2008; Kushniruk and Turner, 2011; Cresswell and Sheik, 2014). Much of the day-to-day work on the HRB systems is done by research staff supported by database administrators/analysts. Staff members are drawn from a range of backgrounds and disciplines and have been recruited largely for their expertise in the four specialist areas in which the HRB carries out this function.

For the most part, within the HRB, teams work on individual systems rather than across systems. Over time, what has resulted is a silo-ed approach to the work and limited opportunities for movement of staffing resources between systems. This has led to the development of a workforce that is specialised in one area of the HRB's work rather than a more flexible health informatics workforce.

## 5.2 Use of Resources

On foot of a review of internal processes three years ago, the HRB made significant changes to how staffing resources are utilised in relation to its health information systems. The emphasis of the review was the move from a system of organisation where staff work on only one information system to one in which they could use their skills across all five of the information systems; and 2) the development of an ICT solution within the HRB that would provide a single technological platform for the five systems to enable staff working in this area to develop a core set of computer and analytical skills that are more widely applicable within the organisation.

These two factors represent the critical success factors needed for the ongoing operation of the HRB's health information work and by implication, better use of its existing resources. Both of these objectives were identified as core to the integration and streamlining of the health information systems work, which is consistent with the overall framework for health information here in Ireland (HIQA, 2017a) and internationally (OECD, 2013).

## 5.3 Assessment of People Dimension

The research shows that ICT redevelopment and staff reorganisation were two key change areas for the HRB health information systems. The socio-technical approach suggests that both of these changes are inextricably linked; staff need to be part of the early consultation about a new ICT system and have to be involved in all stages of its design and development. While this takes considerable time, it is supported by much of the literature on socio-technical theory around the importance of people in the development and implementation of new ICT systems (see Goldberg *et al.*, 2011; Cresswell and Sheik, 2014).

The focus on a shared ICT platform for the HRB's five health information systems, combined with a sharing of staff resources across the systems is important not only for its emphasis on better use of resources but also as a move towards an integrated approach, which is part of the national agenda (HIQA, 2014). As noted earlier, HIQA identified the HRB's work in this area as an example of good practice (HIQA, 2014). Work is ongoing in the roll-out of the new ICT platform training of all HRB staff and system users is under way.

## 6 CONCLUSIONS

This review of the HRB's health information systems shows that there is a broad range of processes at play within and between the 5 systems in achieving their goals and objectives in the delivery of key national health data. The five systems vary significantly in how they collect, organise, manage and disseminate data. Each system developed in response to a particular information need and without reference to the other systems in the HRB. This mirrors what happened nationally in relation to decisions about the establishment of health information systems. Over the last two to three years, however, there has been increased recognition of the need to develop a greater coherence within and between the five systems. This is in line with the need to develop integrated approaches to health information, which is consistent with views nationally and internationally.

In relation to policy, there is some evidence to suggest that over the last decade, the implementation of policy in relation to health information in Ireland has been slow largely because it has not been afforded any priority at national level. As a result, the 5 HRB systems reviewed developed in a piecemeal fashion without reference to any national standard.

With regard to infrastructure, the HRB systems also exhibit patchiness in how they have addressed issues such as governance and accountability, quality, evaluation and audit and standardisation. An examination of the systems showed that very little attention was given until recently to measures designed to achieve integration within the HRB. In this respect, the HRB's systems can be viewed as examples of how health information systems in Ireland have grown up over time. The findings of the research suggest, however, that slow progress is being made towards a more coherent approach to the data held by the HRB.

In relation to people, the analysis acknowledges that changes in the use of staff resources in the HRB, combined with the development of a new ICT solution, have been important to the organisation's work in recent years. At a broader level, efforts are in train to skill up a more generic health informatics workforce which will be able to work across systems and apply a generic set of skills and expertise.

This documentary analysis was organised based on national guiding principles and standards set out by HIQA. The experience of the HRB's systems suggests that there is still some way to go to develop

best practice in relation to these principles. Their examination in the context of one organisation highlighted the important role they can play in ensuring standardisation of health information systems in the future.

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## APPENDIX 1: OVERVIEW OF HRB SYSTEMS

	Objectives	Activity
<b>National Drug Treatment Reporting System (NDTRS)</b>	To gather data on treated drug and alcohol misuse in Ireland that can be used by policy makers and service providers	<ul style="list-style-type: none"> <li>• 30,000 records annually</li> <li>• Data items: 64</li> </ul>
<b>National Drug-related Deaths Index (NDRDI)</b>	To collect information on drug and alcohol-related deaths and deaths among drug and alcohol users in Ireland	<ul style="list-style-type: none"> <li>• 600 deaths annually</li> <li>• Data items: 70</li> <li>• 15,000 coroners files consulted each year</li> </ul>
<b>National Intellectual Disability Database (NIDD)</b>	To capture details of current service provision and the future service requirements of individuals with an intellectual disability	<ul style="list-style-type: none"> <li>• 27,300 records</li> <li>• Data items: 108</li> </ul>
<b>National Physical and Sensory Disability Database (NPSDD)</b>	To capture and provide the Department of Health and HSE with details of current service provision and the future service requirements of individuals with a physical and/or sensory disability to assist in service planning.	<ul style="list-style-type: none"> <li>• Number of records/returns: 29,600</li> <li>• Data items: 198</li> </ul>
<b>National Psychiatric In-patient Reporting System (NPIRS)</b>	To collect and report on all admissions and discharges to inpatient psychiatric units both public and private. A regular psychiatric census is carried out.	<ul style="list-style-type: none"> <li>• 38,000 records annually - 19,000 admissions and 19,000 discharges</li> <li>• 67 sites</li> <li>• Number of data items: 28</li> </ul>