Using a Self-Assessment Tool (SAT) to Review National Health Information Systems in Ireland

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Abstract: This paper presents a review of four national health information systems in Ireland using a nationally agreed self-assessment tool (SAT) developed in Ireland by the health information regulatory body there. The review was undertaken using documentary analysis of written materials about the systems from both primary and secondary data sources. The findings show high levels of compliance with the standards identified but that there is still some work to do to ensure that all aspects of the standards are met.

1 INTRODUCTION

This paper presents a review of four national health information systems using a self-assessment tool (SAT) which was developed by Ireland's health information regulatory body, the Health Information and Quality Authority (HIQA, 2017a) and which have since become an agreed set of information management standards for evaluating national health and social care data collections (HIQA, 2017b).

The value of having key standards for monitoring data quality is well-recognised internationally (see Canadian Institute for Health Information, 2009; Australian Institute of Health Welfare, 2014) and several tools have been developed to assist the managers of health information systems to ensure good information governance is at the heart of their processes (e.g. American Health Information Management Association, 2011; Health and Social Care Information Centre, 2015) in their work. Building on the international evidence, HIQA developed a self-assessment tool (SAT) for use on national health information systems and this is in process of being applied to the major Irish health and social care data collections currently (e.g HIQA, 2019).

The research questions for the study were:

a) To what extent, if at all, do the Health Research Board's (HRB) systems comply with the HIQA standards?
b) What does the HRB need to do to ensure full compliance with the standards?

The paper highlights the value of having standards that are informed by international best practice and that create targets for national bodies in achievement of this best practice. The overall benefits are better quality data which in turn results in better service planning at the national and local level, safer, better care for patients and service users and improved population health (HIQA, 2017b).

2 BACKGROUND

The Health Information and Quality Authority (HIQA) is an independent statutory authority in Ireland that was established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public in Ireland. Its role in health information is focused on advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services. In recent years HIQA's health information function has been particularly focused on producing resources for the managers of health information systems that are designed to support the implementation of common standards in relation to information governance and data quality.

The SAT devised by HIQA is based on six broad themes which are then broken down into ten standards (see Table 1).

Table 1: Themes and National Standards.

Theme	Standard
Person-centred	1. Arrangements to protect privacy of people
Governance, leadership and management	2. Effective governance 3. Publicly available statement of purpose 4. Compliance with relevant legislation
Use of data	5. Compliance with health information standards 6. Monitors quality of data 7. Effective and appropriate dissemination strategies
Information governance	8. Effective information governance
Workforce	9. Workforce to deliver objectives
Use of resources	10. Effective allocation of resources

The themes and standards were agreed nationally through expert collaboration and public consultation and are based on robust international evidence in this area (see American Health Information Management Association, 2011, Australian Institute of Health Welfare, 2014). The themes, standards and metrics for measuring compliance are all set out in the self-assessment tool (HIQA, 2017a) which is available on the HIQA website (www.hiqa.ie).

Following the publication of the self-assessment tool for health and social care data collections in 2017, the HRB committed to undertaking an evaluation of its four national systems using the tool. The HRB is a public service body under the remit of the Department of Health in Ireland. It collects data in the areas of drugs and alcohol (the National Drug Treatment Reporting System (NDTRS) and the National Drug-related Deaths Index (NDRDI)); in relation to disability (the National Ability Supports System (NASS)) and mental health (the National Psychiatric In-patient Reporting System (NPIRS)).

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 four systems. Twenty-five people are employed across the four 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 METHODS

During 2018, a project team was formed in the HRB consisting of staff members working in each of the four systems along with the HRB's Head of National Health Information Systems. The project team was chaired by a HIQA representative. The method adopted was largely documentary where key protocols for each of the systems were reviewed and the SAT was completed based on this written evidence as well as staff knowledge about practices within each system. Staff worked in pairs so as to ensure peer-review of the completed SAT which improved the quality of the information recorded.

Analysis was undertaken of written materials for each of the Health Research Board's (HRB) four national 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 work took place over a period of 3 months.

4 FINDINGS OF THE SELF-ASSESSMENT

Overall, the HRB's health information systems displayed high levels of compliance with the themes and standards set out by HIQA. The specific findings in relation to each of the themes and standards are set out below.

4.1 Person-centredness

A person-centred approach focuses on the need to protect the privacy of the individuals about whom the data are collected (HIQA, 2017b). One of the fundamental principles in this regard is that the data subject is aware of how their data is being used. Ways in which this can be achieved include having a statement of information practice and undertaking privacy impact assessments on a regular basis.

In relation to how the HRB's information systems rate on effective arrangements in to protect the privacy of people about whom it holds information, compliance is high as there are privacy policies implemented for each system. However, there is a need to make statements of information practice publicly available on the organisation's website to ensure greater transparency.

4.2 Governance, Leadership and Management

This theme requires bodies that manage health information to have good governance, leadership and management arrangements in at the level of the organization. Ways in which this can be achieved is through clarity in relation to the objectives of the data collection, having an identified individual with overall responsibility for the data collection, a statement of purpose and a well-documented organizational chart and an identified governance group consisting of key stakeholders.

In relation to the standards captured in this theme the HRB's national health information systems rate highly but there is variability in the practices across systems. Two of the four systems have formalised arrangements in place (Table 2) 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.

Table 2: Governance Arrangements for the HRB's health information systems.

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

Source: Health Research Board, 2014.

However, the HRB does not currently publish reports on the effectiveness of the national data collections it holds although all publications from these systems refer to the quality of the data contained within. The assessment also found that there should be more key performance indicators in place to measure and report on the effectiveness of the HRB's information systems.

Within the HRB, some policies are in place on privacy and confidentiality but more transparency is needed on how and how often statements of purpose are reviewed.

The assessment also showed high levels of compliance with legislation, particularly data protection legislation but proactive identification of risks and issues in upcoming legislation was seen to be needed.

4.3 Use of Data

HIQA recommends in its information management standards (HIQA, 2017b) that all organisations involved in the collection of health information should ensure that the use of the information is optimized to achieve the best value for money and to maximize social gain. This includes ensuring accuracy, completeness, legibility, relevance, reliability and timeliness of the data. It also includes having published data dictionaries for each data collection and a framework for data quality that is agreed at the level of all stakeholders as well as the incorporation of international classifications.

In relation to this theme, all but one of the HRB's systems have incorporated international classifications. Whilst a data dictionary has been developed for each system it is not currently made publicly available.

Similarly, within the HRB, there is a recognition of the need for quality data in all the information systems and considerable time and effort go in to ensuring the quality of the data. However, there is no formalized data quality framework in place. Some work has been undertaken on audit internally and two of the systems have invested in external audit and evaluation, but these are outdated, and further work is required in this regard. The SAT findings suggest that the HRB needs to plan for further internal and external audit of the data and consider the use of the data quality framework dimensions as an audit framework.

With regard to dissemination of data there is a high level of compliance in the HRB's information systems. The assessment found that more could be done to support users of the data, data quality statements and notifying, in advance, on an annual basis what publications will be available. In particular, the findings suggested that more efforts were needed to provide training to data users around the use of the data and greater regard needed to be given to recording metrics in relation to the timeliness of responding to requests for the data. The SAT also found that a simple calendar of when publications from the information systems, if disseminated to stakeholder, would improve timeliness and raise awareness about when reports would come on stream.

4.4 Information Governance

This theme is about ensuring that those involved in the collection of health data build in processes to promote security and privacy in the collection and reporting of data. It includes reliable information governance practices in areas such as ensuring consent is obtained from the data subject where it is necessary, having statements of information

practices, arrangements around the appropriate sharing of information and ongoing audit on information governance practice.

There are high levels of compliance in the HRB with the standard on information governance but the assessment found that more work is required on information governance audits and training for staff on information governance issues.

Each of the four 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, 2017c).

Table 3: Statements of Purpose for the HRB's health information systems.

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

4.5 Workforce

HIQA defines the workforce standard to include all of those who work in or for the national health information system and recommends that staff with specialist skills and qualifications are needed to ensure that aspects of quality are factored in to the work and that there is good workforce planning to deal with expected and unexpected events. It is about

having the 'right people with the right knowledge' (HIQA, 2017b: 41).

In relation to the HRB's workforce there are high levels of compliance with the organisation of its workforce and its ongoing development. Workforce planning is undertaken regularly to anticipate any likely changes in staffing levels.

4.6 Use of Resources

HIQA defines resources as including human, physical, financial and ICT resources and recommends that organisations involved in the collection and reporting of health data should strive to ensure that its resources are adequate to ensure the sustainability, continual relevance and maximum impact of the data for which they are responsible.

The SAT exercise showed that in relation to the allocation and use of resources within the HRB, there are high levels of compliance with planning and management of the necessary resources. This is particularly the case in relation to skills audit, succession planning and the organisation's training and development fund.

5 DISCUSSION

Following the completion of the SAT, the HRB reviewed its findings with HIQA and devised a set of actions which were then presented to senior management in the organisation as an improvement plan. Overall, the review of the HRB's health information systems shows that there is a broad range of processes at play within and between the four systems in achieving their goals and objectives in the delivery of key national health data. The systems vary significantly in how they collect, organise, manage and disseminate data but, for the most part, there is good practice in a number of the standards and themes that constituted the SAT. Areas for improvement are as follows:

- Publish statements of information practice on the HRB website.
- Set up oversight committees for the remaining two systems, the NPIRS and the NDTRS.
- Put in place formalised agreements with data providers.
- Consider adding more detail on performance/effectiveness of HRB systems in publications.
- Develop an annual process to review statements of purpose.

+ Put in place a process for reviewing upcoming legislation relevant to the HRB data collections.
+ Publish data dictionaries for each system.
+ Formalise a data quality framework for the information systems that incorporates the elements of good practice already applied to the data.
+ Plan for further internal and external audit of the data and consider the use of the data quality framework dimensions as an audit framework.
+ Use the organisation's website monitoring to record access to health information publications
+ Add more metrics to monitor the use of the data such as tracking the number of times data are accessed on the HRB's website.
+ Provide training to data users around the value of the HRB's data.
+ Add some performance metrics to the existing log of data requests to include timeliness of response to these requests.
+ Develop an annual calendar on publication of reports from the HRB's systems.
+ Include more detailed data quality statements in each HRB publication.
+ Devise a schedule for internal and external audit of the HRB systems.
+ Devise a training programme for staff on information governance.

6 CONCLUSION

The study set out to address two research questions:

a) To what extent, if at all, do the Health Research Board's (HRB) systems comply with the HIQA standards?
b) What does the HRB need to do to ensure full compliance with the standards?

The findings indicate that there are high levels of compliance with the standards across all four systems but that there is variability in the level of this compliance. The areas for improvement identified as part of the study show a pathway towards full compliance. A follow-up review will be undertaken to track progress in this regard.

Overall, the study highlights the value of having agreed national standards for health information systems such as those managed by the HRB.

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APPENDICE

Appendix 1: Overview of HRB Systems.

	Objectives	Activity
National Drug Treatment Reporting System (NDTRS)	To gather data on treated drug and alcohol misuse in Ireland that can be used by policy makers and service providers	• 30,000 records annually • Data items: 64
National Drug-related Deaths Index (NDRDI)	To collect information on drug and alcohol-related deaths and deaths among drug and alcohol users in Ireland	• 600 deaths annually • Data items: 70 • 15,000 coroners files consulted each year
National Ability Supports System (NASS)	To capture details of current service provision and the future service requirements of individuals with a disability	• 30,000 records • Data items: 200
National Psychiatric In-patient Reporting System (NPIRS)	To collect and report on all admissions and discharges to inpatient psychiatric units both public and private. A regular psychiatric census is carried out.	• 38,000 records annually - 19,000 admissions and 19,000 discharges • 67 sites • Number of data items: 28