



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

Health Information  
and Standards

# Review of information management practices in the HSE Primary Care Reimbursement Service (PCRS)

March 2019

*Safer Better Care*

## About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory authority 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.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children and Youth Affairs, HIQA has responsibility for the following:

- **Setting Standards for Health and Social Services** – Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating Social Care Services** – The Office of the Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating Health Services** – Regulating medical exposure to ionising radiation.
- **Health Technology Assessment** – Evaluating the clinical and cost-effectiveness of health programmes and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- **Health Information** – 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.
- **National Care Experience Programme** – Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

## **Overview of the health information function of HIQA**

Health is information-intensive, generating huge volumes of data every day. Health and social care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is therefore very important that information is managed in the most effective way possible in order to ensure a high-quality safe service.

Safe, reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient is not allergic to it. Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests — if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst not given.

In addition, health information has an important role to play in healthcare planning decisions — where to locate a new service, whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision.

Under section (8)(1)(k) of the Health Act 2007, the Health Information and Quality Authority (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), HIQA is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving its quality and filling in gaps where information is needed but is not currently available.<sup>(1)</sup>

Information and communications technology (ICT) has a critical role to play in ensuring that information to promote quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient's general practitioner (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in health and social care services in Ireland is highly fragmented with major gaps and silos of information. This results in individuals being asked to provide the same information on multiple occasions.

In Ireland, information can be lost, documentation is poor, and there is over-reliance on memory. Equally those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care. Furthermore, we are all being encouraged

to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, understandable and trustworthy information on which to base our decisions.

As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice. A robust health information environment will allow all stakeholders — patients and service users, health professionals, policy makers and the general public — to make choices or decisions based on the best available information. This is a fundamental requirement for a highly reliable healthcare system.

Through its health information function, HIQA is addressing these issues and working to ensure that high-quality health and social care information is available to support the delivery, planning and monitoring of services.

HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements. In 2017, HIQA published standards in the area of health information — Information Management Standards for National Health and Social Care Data Collections<sup>(2)</sup> — as per HIQA's remit under the Health Act 2007.<sup>(1)</sup> The standards provide a framework of best practice in the collection of health and social care data. HIQA has developed a structured review programme to assess compliance with the standards.<sup>(2)</sup> The aim of this review programme is to improve the information management practices of national health and social care data collections in Ireland by assessing compliance with the standards in each national data collection. Ultimately, the review programme will drive improvements by identifying areas of good practice and areas where improvements are necessary across the range of national data collections.

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## Executive summary

The aim of this review is to assess the compliance of the Primary Care Reimbursement Service (PCRS) with the *Information Management Standards for national health and social care data collections*.<sup>(2)</sup> This review is part of an overall review programme being undertaken by HIQA to assess compliance with the Information Management Standards in all major national health and social care data collections within the HSE in Ireland. The recent Sláintecare report<sup>(3)</sup> and implementation strategy<sup>(4)</sup> on the future of healthcare identifies the importance of quality health data and information as a key enabler to drive improvements in the quality of healthcare in Ireland. It is, therefore, crucially important that information is managed in the most effective way possible in order to ensure a high-quality safe health service. Ultimately, the review programme aims to drive quality improvements by identifying areas of good practice and areas where improvements are necessary across national data collections.

The PCRS, which is part of the Health Service Executive (HSE), is responsible for reimbursing healthcare professionals for the free or reduced cost services they provide to the public under various national health schemes, including the General Medical Services (GMS) Scheme. Additionally, through its eligibility function, the PCRS processes all medical and GP visit card applications. In 2017, 3.6 million people were registered as eligible for the national health schemes, and the PCRS made payments of €2.75 billion in respect of the services provided under these schemes.<sup>(5)</sup>

### Information management

The PCRS is an extremely valuable national health data collection and holds a rich source of data in relation to eligibility and reimbursement of public health services provided under the national health schemes in Ireland. For example, the PCRS holds the most comprehensive repository of national prescription data and is the largest data source for measuring drug exposure in specific populations in Ireland.<sup>(6)</sup> For each drug dispensed in Ireland and reimbursed by the PCRS, data are available for the date of dispensing, quantity of medication provided, strength, dosage form, route of administration, ingredient cost, community drug scheme on which drug was dispensed, and dispensing fees to the pharmacist.<sup>(6)</sup> The importance of effectively using routinely collected prescribing data to inform pharmaceutical policies within countries was also highlighted in a recently published Organisation for Economic Co-operation and Development (OECD) report.<sup>(7)</sup>

These data can be used to improve the quality of the service being provided to people in Ireland and, as such, is an important source of information for the public, clinicians, policy-makers and researchers alike. It is used for guiding clinical decision-making, organising services and informing policy at both national and local levels. For example, the availability of PCRS data informs the HSE's Medicine Management Programme, which develops national initiatives to reduce overall expenditure on, and improve access to, medicines.<sup>(8)</sup> Furthermore, PCRS data is used routinely by HIQA when providing evidence to support

decision-making within the Department of Health through the conduct of health technology assessments.<sup>(9)</sup>

The availability of PCRS data has also enabled the conduct of high-quality health research in areas such as diabetes care, prevalence of chronic disease, cancer care, drug utilisation, medicine adherence and the impact of healthcare policies.<sup>(6, 10, 11)</sup> PCRS data has been linked with data from external data registries, for example, the National Cancer Registry Ireland, a population-based cancer registry. As a result, detailed information on medication use is available for those with GMS Scheme eligibility and a diagnosis of cancer.<sup>(6, 12)</sup> Additional linkages have been made with the Central Statistics Office<sup>(13)</sup>; The Irish Longitudinal Study of Ageing (TILDA), a nationally representative cohort study of over 8,000 adults aged >50 years<sup>(6, 14)</sup>; hospital data<sup>(15)</sup>; and mortality data.<sup>(16)</sup>

Given the importance of the data held within the PCRS, together with the scope and remit of the organisation, good information management practices are integral to the everyday functioning of the PCRS. Firstly, the organisation requires accurate and complete information in order to process and provide medical or GP visit cards to eligible individuals to ensure the timely access to healthcare services and medications. Secondly, it requires reliable and valid information to ensure the correct reimbursement of public expenditure. Given the complexity of steps involved in generating PCRS data, the vast quantity of sensitive financial and clinical data that is produced and stored, and the number of stakeholders involved in the process, comprehensive and high-quality information management is particularly important.

The findings of this review of information management practices within the PCRS will focus on three key areas: governance, leadership and management; information governance; and use of information. These findings are outlined below, and a summary of the recommendations is then presented.

### **Governance, leadership and management**

As previously stated, the PCRS is an extremely important health information system in relation to the eligibility and reimbursement of public health services in Ireland and, as such, requires strong governance and national oversight arrangements to ensure it is managed appropriately. The PCRS, formerly known as the General Medical Services (Payment) Board, was set up to arrange payments centrally for healthcare providers such as general practitioners (GPs), pharmacists, dentists, optometrists, ophthalmologists and clinical dental technicians who provided services or treatments to individuals on behalf of the Health Boards under the 1970 Health Act. Since then, the PCRS has reported into a number of governing structures and is currently part of the National Services Directorate within the HSE.

During the review, HIQA identified clear governance arrangements in place at an operational level in respect of the operational aspects of information management within the PCRS. These included two senior management operational teams in place: the Reimbursement Management Team and the National Medical Card Management Team. The Head of the PCRS has overall accountability for the PCRS and reports directly to the HSE National Director of National Services via monthly National Services Division meetings and one-to-one meetings. However, given the size and remit of the



PCRS, the dynamic nature of health information, including the on-going evolution of ICT in the health and social care sector, the increased risk of cyber security threats, and the changing legislative landscape (such as the General Data Protection Regulation [GDPR]), information management within the PCRS needs to have more of a strategic focus across the organisation, with key roles and responsibilities defined for information management through a scheme of delegation.

During the review, HIQA identified a less structured approach in terms of how information management is strategically discussed, planned and managed at an organisational level. Specific roles and responsibilities around aspects of information management lacked clarity, including the implementation of audit recommendations or how data generated by the PCRS is used effectively to improve the service. In the absence of a scheme of delegation in respect of information management, there may be an over-reliance on the Head of the PCRS to identify and address both strategic and operational aspects of information management across the organisation. Therefore, the PCRS should consider an oversight structure similar to that of a senior executive forum to discuss the strategic approach to be taken for information management and to address information management risks on a more regular basis.

Currently, there is no overarching strategy in place to provide direction for the PCRS organisation as a whole. During interview, the PCRS informed HIQA that an organisation-wide strategy was being developed to cover the period 2019–2021 and would define a shared vision and understanding across the PCRS, with a focus on information management as well as the efficient centralisation of schemes. While this is a positive step, given the size, budget and scope of functions of the PCRS, the development of a strategy specific to information management should be considered. This could cover aspects relating to information governance, data quality and workforce capacity, and it could outline key deliverables and indicators for the progression of strategy objectives.

### **Use of information**

The need for high-quality data cannot be overemphasised given the nature and volume of data generated, processed by and held within the PCRS. The Irish healthcare system increasingly depends on data to improve care, reduce costs and expand access. Currently, in the absence of e-prescribing, the PCRS is the richest source of national prescription data and is the largest data source for measuring drug exposure in specific populations in Ireland.<sup>(6)</sup> As a result, the data collected, processed and held within the PCRS is used for many important purposes, such as guiding clinical decision-making, monitoring diseases, organising services, informing policy making, conducting research and planning for future health and social care needs, both at a national and local level. Therefore, it is imperative that this data is of the highest possible quality.

In reviewing data quality practices, HIQA recognises an overall awareness of data quality within the PCRS and acknowledges the work being carried out to improve the quality of the

data collected, generated and disseminated. Several positive initiatives in relation to data quality have been undertaken, for example, the development of a data quality framework, ICT resources for data quality and a plan to provide access to more granular data in the future. However, the current work being undertaken would benefit from a more strategic and consolidated approach to data quality.

Given the importance of high-quality data for both the PCRS and wider stakeholder groups and the size and complexity of the system, the PCRS should develop an organisation-wide approach for strategically addressing aspects of data quality, including stakeholder training and dissemination plans. PCRS should make data and information more accessible in a timely manner to all stakeholders, including patients, clinicians, policy makers and researchers, in order to address their needs. Furthermore, it would be envisaged that a strategy for data quality is in place or, at minimum, addressed within an overall information management strategy. It should outline how the organisation is going to address data quality through the lens of the five dimensions of data and information quality, that is, relevance, accessibility and clarity, coherence and comparability, timeliness and punctuality, and accuracy and reliability,<sup>(17)</sup> and it should provide a roadmap in relation to how the organisation will manage and continuously improve the quality of its data. As part of this, the PCRS should ensure that responsibilities for data quality at every level within the organisation are clearly defined through a scheme of delegation. A data quality strategy would benefit from an overarching forum (as discussed under Governance, leadership and management) to guide and oversee its implementation, thus providing further assurances to the Head of the PCRS in relation to the quality of PCRS data.

### **Information governance**

A well-governed and managed organisation needs to develop assurance arrangements to review adherence to information governance policies and procedures as well as current and forthcoming legislation through the reporting of relevant key performance indicators (KPIs), completion of internal and external audits and the implementation of effective risk management arrangements.

During the review, HIQA identified that there is an overall awareness of the significance and importance of information governance within the PCRS, with many policies and procedures in place to support this. However, the current approach to managing information governance is somewhat disjointed, and the PCRS would benefit from an enhanced and a more consolidated approach to managing information governance, with key aspects of information governance being addressed as part of an overall organisation-wide information management strategy.

In relation to privacy risk assessment and compliance with the General Data Protection Regulation (GDPR), HIQA acknowledges that two Data Protection Impact Assessments (DPIAs) had been completed to date relating to specific aspects of the GMS Scheme. Management within the PCRS recognise the importance of conducting further DPIAs and outlined future plans for applying the HSE DPIA template to all new projects. The completion of DPIAs in relation to all of the national health schemes under the PCRS remit would highlight potential data protection risks in relation to personal information and would further

enhance privacy controls and mitigate any potential risks relating to persons engaging with the PCRS.

## **Summary**

The data held by the PCRS is an extremely rich and valuable source of health information used by the HSE and Department of Health to inform the provision, management, performance assessment, planning and funding of primary care services in Ireland. Assurance should be provided in relation to the quality of this data to instil confidence in service users, clinicians and all other stakeholders that these decisions are made based on high-quality information.

The eight recommendations outlined in this report should be considered in conjunction with the findings of this review in order to further improve information management practices for the PCRS. The PCRS should continue to assess their adherence to these standards between reviews by HIQA to ensure that they are meeting the requirements of the Information Management Standards.

## Summary of recommendations

These recommendations have been developed by HIQA following the review of compliance with the Information Management Standards for national health and social care data collections in the HSE PCRS.<sup>(2)</sup>

**Table 1.** Recommendations — Review of Information Management Practices in the PCRS

| <b>Governance, leadership and management</b> |  |
|--|--|
| <b>1.</b>                                    | <b>Governance structures in relation to information management</b>   |
|  | <p>The Primary Care Reimbursement Service (PCRS) should enhance its current governance arrangements in respect of information management to ensure that data and information is strategically addressed across the entire organisation and in relation to all the National Health Schemes. This should include:</p> <ul style="list-style-type: none"> <li>▪ a review of current governance arrangements to ensure all aspects of information management are being effectively addressed across the organisation at a strategic level within the PCRS. This could include establishment of an oversight forum to discuss strategy and risk in relation to information management and to examine previous reviews and audits of the PCRS/NMCU to ensure key recommendations in relation to information management are implemented.</li> <li>▪ a detailed scheme of delegation outlining clearly delegated responsibilities for information management across the organisation.</li> </ul> |
| <b>2.</b>                                    | <b>Strategy for information management</b>   |
|  | <p>PCRS should develop an organisation-wide strategy for information management which clearly describes how effective information management will enhance the services provided by the PCRS. This should include:</p> <ul style="list-style-type: none"> <li>▪ clearly defined objectives, enablers and deliverables and associated business planning for all aspects of information management, including data quality, information governance and use of information</li> <li>▪ clear implementation plans and identified individuals responsible for implementation of key aspects of the strategy.</li> </ul>  |
| <b>3.</b>                                    | <b>Monitoring of performance in relation to information management</b>   |
|  | <p>The PCRS should enhance current performance assurance arrangements to ensure that appropriate key performance indicators (KPIs) are in place for information management which are person-centred, outcome focused and provide assurance that</p>  |

|                               |   |
|-------------------------------|---|
|                               | information is being effectively managed to deliver on provision of services in relation to the National Health Schemes in Ireland.   |
| <b>Use of information</b>     |   |
| <b>4.</b>                     | <b>Data quality framework</b>   |
|                               | <p>To enhance ongoing work within the PCRS in relation to data quality, an enhanced data quality framework, to include a data quality strategy, should be developed and implemented for the PCRS to ensure an organisation-wide approach to data quality is in place. As part of this:</p> <ul style="list-style-type: none"> <li>▪ an individual with overall responsibility for data quality within the PCRS should be assigned</li> <li>▪ responsibilities for data quality at every level within the organisation should be clearly defined.</li> </ul> |
| <b>5.</b>                     | <b>Data dictionary</b>  |
|                               | <p>Components of a data dictionary should be made publicly available to ensure consistency and to enable accurate use and interpretation of data and information from the PCRS. This should be aligned to plans for the HSE National Data Dictionary.</p>   |
| <b>6.</b>                     | <b>Accessibility and dissemination of information</b>   |
|                               | <p>In line with legislation and government policy, the PCRS should make data and information more accessible in a timely manner to all stakeholders, including patients, clinicians, policy makers and researchers, in order to address their needs. This should be developed as part of an overall strategy for information management.</p>  |
| <b>Information governance</b> |   |
| <b>7.</b>                     | <b>Enhanced arrangements in place for information governance</b>  |
|                               | <p>The PCRS should further strengthen and enhance arrangements that are currently in place for information governance within the PCRS. This includes:</p> <ul style="list-style-type: none"> <li>▪ assigning an individual with overall responsibility for information governance within the organisation</li> <li>▪ clearly defining roles and responsibilities in respect of information governance across the organisation</li> </ul>  |

|           |  |
|-----------|--|
|           | <ul style="list-style-type: none"><li>▪ addressing key aspects of information governance as part of the overall information management strategy, such as the plans to reduce the level of manual processing of paper in the system.</li></ul>              |
| <b>8.</b> | <b>Compliance with legislation and privacy risk assessment</b>   |
|           | To ensure on-going compliance with legislation, including GDPR, the PCRS should undertake a privacy impact assessment (PIA) of all data flows in relation to the National Health Schemes to ensure that any privacy risks are being effectively addressed. |

## 1. Overview of HIQA's review programme for national data collections

This review is part of an overall programme being undertaken by HIQA to assess compliance with the Information management standards for national health and social care data.<sup>(2)</sup>

A considerable amount of data is collected on a regular basis about health and social care services in Ireland. This data is used for many important purposes such as to guide clinical decision-making, monitor diseases, organise services, inform policy making, conduct high-quality research and plan for future health and social care needs, both at national and local levels.

All stakeholders (the general public, patients and service users, health professionals, researchers and policy makers) need access to high-quality information in order to make choices and decisions. It is vital that there is confidence in this information as the delivery of safe and effective healthcare depends on access to and use of information that is accurate, valid, reliable, timely, relevant, legible and complete.

Based on international best practice, four key overarching objectives relating to health information have been identified to maximise health gain for the individual and the population:

1. Health information is used to deliver and monitor safe and high-quality care for everyone.
2. Health information should be of the highest quality and, where appropriate, collected as close as possible to the point of care.
3. Health information should be collected once and used many times.
4. Data collection should be 'fit for purpose' and cost-effective.

**National health and social care data collections** are national repositories of routinely collected health and social care data, including administrative sources, censuses, surveys and national patient registries, in the Republic of Ireland.

**Managing organisation** is defined as the organisation, agency, managing unit, institution or group with overall responsibility for the national health and social care data collection.

National health and social care data collections provide a national overview of data relating to a particular health or social care service. Examples of national data collections include BreastCheck, the Hospital In-Patient Enquiry (HIPE) scheme, the Computerised Infectious Disease Reporting (CIDR) system and the Irish Hip Fracture Database (IHFD). There is little point in investing considerable time, effort and resources into producing a high-quality data collection if the data is not used to the maximum benefit of the population it serves. Therefore, it is essential to promote, encourage and facilitate the use of data.

HIQA has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information under the Health Act 2007.<sup>(1)</sup> A number of key documents have been published by HIQA in recent years in relation to national health and social care data collections (See Appendix 1).

Furthermore, the *National Standards for Safer Better Healthcare*,<sup>(18)</sup> published in 2012, describe a vision for quality and safety in healthcare which includes the use of accurate and timely information to promote effectiveness and drive improvements. One of the eight themes, 'Use of Information', emphasises the critical importance of actively using information as a resource for planning, delivering, monitoring, managing and improving care. These nationally mandated standards apply to all healthcare services (excluding mental health) provided or funded by the Health Service Executive (HSE).

In 2017, HIQA published specific standards in the area of information management — *Information management standards for national health and social care data collections*.<sup>(2)</sup> The purpose of these standards is to improve the quality of national health information. The standards provide a framework of best practice in the collection of health and social care data. The *Information management standards for national health and social care data collections*, therefore, complement the *National Standards for Safer Better Healthcare*.<sup>(2)</sup> Together, these standards provide a roadmap to improve the quality of health information and data, which should ultimately contribute to the delivery of safe and reliable healthcare.

HIQA has developed a structured review programme to assess compliance with the *Information management standards for national health and social care data collections*.<sup>(2)</sup> Prior to commencing the review programme, the *Guide to the Health Information and Quality Authority's review of information management practices in national health and social care data collections* was published by HIQA.<sup>(2)</sup>

For the remainder of the report:

**Information Management Standards** will be used for the *Information Management Standards for National Health and Social Care Data Collections*

**Review Programme** will be used for the review programme to assess compliance of national health and social care data collections against the Information Management Standards



## **1.1 Aims of the review programme**

The aim of this review programme is to improve information management practices of national health and social care data collections in Ireland by assessing compliance with the Information Management Standards in individual national data collections. Ultimately, the review programme was developed to drive improvements by identifying areas of good practice across national data collections and areas where improvements are necessary.

## **1.2 Assessment and judgement framework**

HIQA has adopted a standard Authority Monitoring Approach (AMA) to carry out its functions. HIQA staff involved in the review programme use this approach and any associated procedures and protocols. HIQA's monitoring approach does not replace professional judgement. Instead, it provides a framework for staff to use professional judgement and supports them in reviewing compliance against the standards. The use of AMA and an assessment and judgement framework ensures:

- a consistent and timely assessment of compliance with standards
- a responsive approach to performing reviews.

## **1.3 Phase 1 of the review programme**

Due to the large number of national data collections, the review programme is being carried out using a phased approach. Phase 1 includes major national data collections within the HSE. Prioritisation criteria were developed to determine the schedule for reviews in the first phase of the review programme, which included the quality and safety impact, the policy impact and other operational factors which may impact on the review programme.

There are six stages involved in this review process:

1. Self-assessment tool
2. Information request
3. On-site assessments
4. Additional evidence gathering
5. Report of findings
6. Factual accuracy.

### **Stage 1: Self-assessment tool**

The self-assessment tool is a questionnaire which enables national health and social care data collections to determine the extent of their compliance with the Information Management Standards. The tool highlights areas where action is required and where improvements can be made. All of the national data collections in Phase 1 of the review programme were contacted and asked to complete the self-assessment tool. The designated contact person in each organisation was asked to complete and return the self-assessment tool within three weeks.

Based on the results of the self-assessment tool and the prioritisation criteria, HIQA performed a focused review of the HSE Primary Care Reimbursement Service (PCRS).

#### Stage 2: Information request

Following a review of the self-assessment tool, a request for additional information was sent to the PCRS and the relevant information was returned to HIQA within 10 working days. The information received was used to verify the findings of the self-assessment tool and to identify gaps in the evidence in order to provide clarity of focus for the on-site assessment.

#### Stage 3: On-site assessment

Two on-site assessments were conducted in the head office of the PCRS in Dublin. The aim of the on-site assessment was to gather additional evidence to assess compliance with the Information Management Standards through further documentation reviews, observations and interviews with management and staff.

#### Stage 4: Additional evidence gathering

The review team gathered additional evidence from a sample of healthcare providers currently contracted by the PCRS, including community pharmacists and general practitioners, to identify how these groups interact with the PCRS from an information management perspective. The team also reviewed examples of information management practices in other jurisdictions, including Northern Ireland, the UK and Australia. International Examples of Information Management Practices is presented in Appendix 2 of this report.

#### Stage 5: Report of findings

The findings of the assessment of compliance with the Information Management Standards in the PCRS are outlined in this report.

#### Stage 6: Factual accuracy

HIQA provided a draft of the report of findings to the Head of the PCRS to complete a factual accuracy review in January 2019. All comments received from the PCRS were carefully considered by HIQA prior to publication of this final report.

Developments or changes implemented by the PCRS after the draft report was sent to the Head of the PCRS for factual accuracy are not included in this report. The implementation of these changes will be assessed in any follow-up review of information management practices in the PCRS.

## **1.4 Quality improvement plans**

Managing organisations are responsible for preparing and implementing quality improvement plans to provide assurance that the findings relating to areas for improvement are prioritised and implemented to comply with the Information Management Standards.

The PCRS should continue to assess their adherence to the standards in between reviews by HIQA to provide assurance that they are meeting the requirements of the Information Management Standards.

Where opportunities for improvement have been identified by the review team during the review, checks will be carried out during future reviews to ensure that the necessary improvements have been implemented.

## 1.5 HIQA's legislative remit

HIQA has a specific remit in relation to health information as laid out in the Health Act 2007.<sup>(1)</sup> The review programme falls within this legislative remit. The relevant sections of the Act are as follows:

- **Section 8(1)(k)** — to set standards as the Authority considers appropriate for the Health Service Executive, the Child and Family Agency and service providers respecting data and information in their possession in relation to services and the health and welfare of the population
- **Section 8(1)(l)** — to advise the Minister, the Minister for Children and Youth Affairs, the Executive and the Agency as to the level of compliance by the Executive and service providers with the standards referred to in paragraph (k)
- **Section 12** — the Authority may require the Executive, the Agency or a service provider to provide it with any information or statistics the Authority needs in order to determine the level of compliance by the Executive, the Agency or by service providers with the standards set by the Authority in accordance with section 8.

## 1.6 Scope of this review

The aim of this review is to examine the findings of the Primary Care Reimbursement Service's compliance with the Information Management Standards in relation to the national community health schemes, with a particular focus on the General Medical Services (GMS) Scheme. It should be noted that information management practices in relation to national health schemes managed by HSE Local Health Offices and also information management practices in respect of the High Tech Drug scheme\* were beyond the scope of this review.

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\* The High Tech Drug Scheme provides access to high-tech medicines, for example, anti-rejection drugs for transplant patients dispensed through community pharmacies.

## **2. Overview of the Primary Care Reimbursement Service**

This chapter provides background information on the Primary Care Reimbursement Service (PCRS). In particular, the chapter presents an overview of the history of the PCRS; a summary of two of its core functions (reimbursement and eligibility); information on the various national health schemes it operates; a description of the information systems and data flows within the PCRS; and details of the significance of information management practices in the PCRS to support the delivery of primary care services in Ireland.

### **2.1 Establishment of the PCRS**

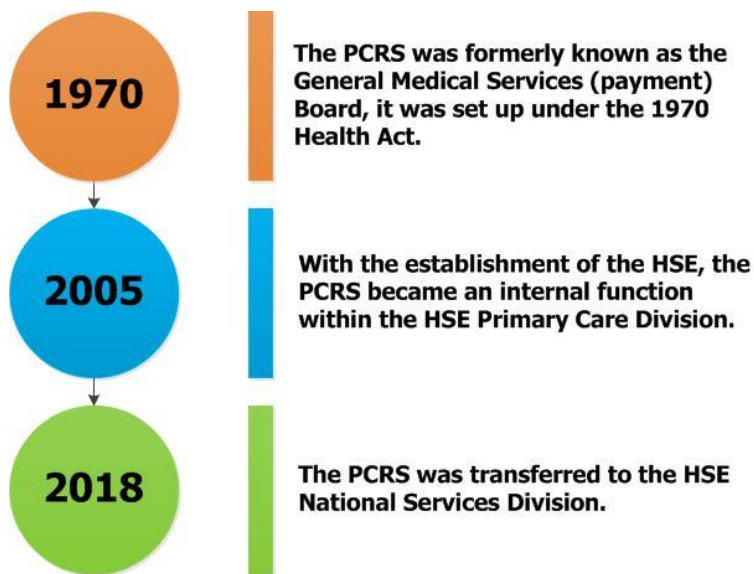
The PCRS, which is part of the Health Service Executive (HSE), is responsible for making payments to healthcare professionals for the free or reduced cost services they provide to the public. In the past, the PCRS reported into a number of governing structures, most recently the HSE Primary Care Division, before moving to the National Services Directorate within the HSE in 2018, as outlined in Figure 1.

The PCRS was formerly the General Medical Services (Payment) Board, which was set up to arrange payments centrally for healthcare providers such as general practitioners (GPs), pharmacists, dentists, optometrists, ophthalmologists and clinical dental technicians who provided services or treatments to individuals on behalf of the Health Boards under the 1970 Health Act.

With the establishment of the HSE on 1 January 2005, under the 2004 Health Amendment Act, the General Medical Service (Payments) Board became the PCRS. With this move, the PCRS became an internal function of the HSE,<sup>(19)</sup> led by the National Director of Primary Care within the HSE Primary Care Division. In 2018, the PCRS was transferred from the HSE Primary Care Division to the HSE National Services Division.<sup>†</sup> Overall responsibility and accountability for this Division lies with the HSE National Director of National Services.

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<sup>†</sup> The HSE National Services Division comprises of seven units; the PCRS, environmental health, emergency management, the special delivery unit, the national performance oversight group (NPOG), the compliance unit and the north south unit.



**Figure 1.** Timeline for establishment of the PCRS

## 2.2 Role of the PCRS

The PCRS is responsible for making payments/reimbursement services to healthcare providers including GPs, dentists, pharmacists, optometrists/ophthalmologists and clinical dental technicians for the free or reduced costs services they provide to the public.<sup>(20)</sup> Almost all payments for services provided in the community by these contracted healthcare providers are made by the PCRS<sup>(21)</sup> under various national health schemes/payment arrangements, which are outlined in the following section. Additionally, the National Medical Card Unit (NMCU), within the PCRS, is responsible for processing all medical and GP visit card applications.

The PCRS also provides additional services to the wider health service through, for example, the function of the High Tech Arrangement, which provides payments to suppliers and manufacturers of high-tech drugs (HTD).<sup>(20)</sup> Such HTD, which include anti-rejection drugs for transplant patients, are purchased by the HSE and supplied through community pharmacies. The PCRS also facilitates direct payment to hospitals involved in the provision of national treatment programmes such as the National Cancer Control Programme, the National Hepatitis C Treatment Programme and the National Drugs Management Scheme implemented for multiple sclerosis.<sup>(22)</sup>

In addition to providing these services, the PCRS also publishes annual reports of payments and claims along with data on the range of primary care services supported by the PCRS, which are available for download on its website.<sup>(23)</sup>

**The Primary Care Reimbursement Service (PCRS)** is the national service responsible for making payments to healthcare professionals — GPs, dentists, pharmacists, optometrists/ophthalmologists and clinical dental technicians — for the free or reduced costs services they provide to the public across a range of national health schemes.

The PCRS is divided into the following two core functions:

- reimbursement
- eligibility, which is carried out by the NMCU.

Within the PCRS, there are a number of additional business areas, including the ICT Unit, the Customer Relations Management Unit, the Facilities Unit, the HR Unit and or the Finance Unit, that are shared by both the reimbursement function and the NMCU.

## 2.3 Reimbursement

Under the reimbursement function, the PCRS is responsible for making payments to almost 7,000 healthcare providers who are contracted by the HSE to provide free or reduced cost services to members of the public across a range of community health schemes. The number of healthcare providers reimbursed by the PCRS is outlined in Table 2.

**Table 2.** Number of healthcare providers reimbursed by the PCRS as of April 2018

| Healthcare Provider           | Number       |
|-------------------------------|--------------|
| General practitioners         | 2,904        |
| Pharmacists                   | 1,855        |
| Dentists                      | 1,605        |
| Optometrists/ophthalmologists | 597          |
| <b>Total</b>                  | <b>6,961</b> |

### 2.3.1 National health schemes

Currently, there are a number of national health schemes/payment arrangements administered by the PCRS, as outlined in Table 3. These make up a large part of the way in which the HSE delivers a significant proportion of primary care to the general public. In 2017, 3.6 million people were registered as eligible for the national health schemes and the PCRS made payments of €2.75 billion in respect of services provided under these schemes.<sup>(5)</sup>

**Table 3.** Description of national health schemes operated by the PCRS

| <b>Scheme</b>                                      | <b>Description</b>   |
|--|--|
| General Medical Services (GMS) Scheme              | Provides access to free or reduced cost GP medical and surgical services for persons who are unable without undue hardship to arrange these services for themselves or their dependents.   |
| Drugs Payment Scheme (DPS)                         | Provides for payment to the pharmacist for the supply of medicines to individuals and families where the threshold of €134 has been exceeded in a calendar month. From 1 April 2019, the threshold will be €124.   |
| Long-Term Illness (LTI) Scheme                     | Provides individuals with certain illnesses or disabilities free access to medicines and surgical appliances that are directly related to the treatment of their illness. This scheme is due for modernisation within the PCRS in 2019.  |
| Dental Treatment Services Scheme (DTSS)            | Provides access to certain dental treatment for adult medical card holders (aged 16 or over) free of charge.   |
| HSE Community Ophthalmic Services Scheme (HSE-COS) | Adult medical cardholders and their dependents are entitled, free of charge, to eye examinations and necessary spectacles/appliances.  |
| High Tech Drug (HTD) Arrangement                   | Provides access to high-tech medicines, for example, anti-rejection drugs for transplant patients dispensed through community pharmacies.  |
| Methadone Treatment Scheme                         | Methadone is prescribed by GPs and dispensed by pharmacists, free of charge, for approved patients.  |
| Immunisations for certain GMS Eligible Persons     | Provides certain immunisations, free of charge, to GMS cardholders.  |
| Primary Childhood Immunisation Scheme              | Provides free immunisation for certain conditions such as measles, mumps and rubella. This scheme is administered by community health organisations and the PCRS makes payments to 50% of GP providers located in four former health boards. The PSCS plan to centralise payments for this scheme in 2020. |
| Health (Amendment) Act 1996                        | Provides certain healthcare services free of charge to persons who have contracted Hepatitis C directly or indirectly from the use of Human Immunoglobulin – Anti D or the receipt within the State of another blood product or blood transfusion.   |
| European Economic Area (EEA) entitlements          | Provides free emergency medical treatment to European citizens while they are on a temporary visit to Ireland.   |
| Discretionary Hardship Arrangements                | Provides certain medicines to GMS patients for whom non-GMS reimbursable items have been prescribed.   |

|  |   |
|--|---|
| Centralised reimbursement of Outpatient Parenteral Antimicrobial Therapy (OPAT)                          | Provides centralised reimbursement of OPAT drugs, medicines and appliances.   |
| Centralised reimbursement of selected high cost drugs administered or dispensed to patients in hospitals | Facilitates centralised reimbursement and data capture of selected high-cost oncology drugs.  |
| Redress for Women Resident in Certain Institutions   | Women eligible for the Magdalen Restorative Justice Ex-Gratia Scheme are provided with access to certain medical services free of charge. |

The largest of these national health schemes is the General Medical Services (GMS) Scheme, which was established in 1970 to provide individuals with the means to access healthcare services without which it would not be financially possible. There are two main types of entitlement under the GMS Scheme: Medical Card coverage and GP visit card coverage. Medical card holders are entitled to GP visitation, prescription services (that is, the cost of regular and high-tech drugs and dispensing fees), and dental and ophthalmic care. GP visit card holders are entitled to primary GP care.<sup>(24)</sup> There are also a number of other benefits operating, including the provision of GP visit cards to children under six year of age and those aged over 70 years. In 2018, there were over 1.5 million medical card holders and almost half a million GP visit cardholders.

### **2.3.2 Probity and assurance**

The PCRS is obliged to ensure the accuracy and reasonableness of claims submitted by the healthcare providers contracted to deliver the free or reduced cost services outlined above. Therefore, the PCRS has a probity function dedicated to:

- preventing, detecting and deterring invalid, inappropriate or fraudulent claiming
- ensuring healthcare provider compliance with the claiming terms of their contract
- identifying and monitoring healthcare provider claiming patterns.

Furthermore, the PCRS also manages any probity cases which require referrals under the provisions of the various contracts; referrals to An Garda Síochána; referrals to professional bodies; and referrals as part of civil proceedings. The recommendation on the appropriate route is made at the Probity Governance Group of the HSE, which is chaired by the PCRS and whose membership comes from various professionals and experts across the HSE and externally.

## **2.4 National Medical Card Unit**

Determining eligibility for medical and GP visit cards is the second core function within the PCRS and this is carried out by the NMCU. The NMCU was established in 2011 to process GMS Scheme applications, administer medical cards and GP visit cards, review eligibility and make any necessary amendments to card holder information.<sup>(25)</sup> In 2017, the NMCU



processed 440,000 GMS Scheme applications and issued 94,658 new medical cards and 86,738 GP visit cards.

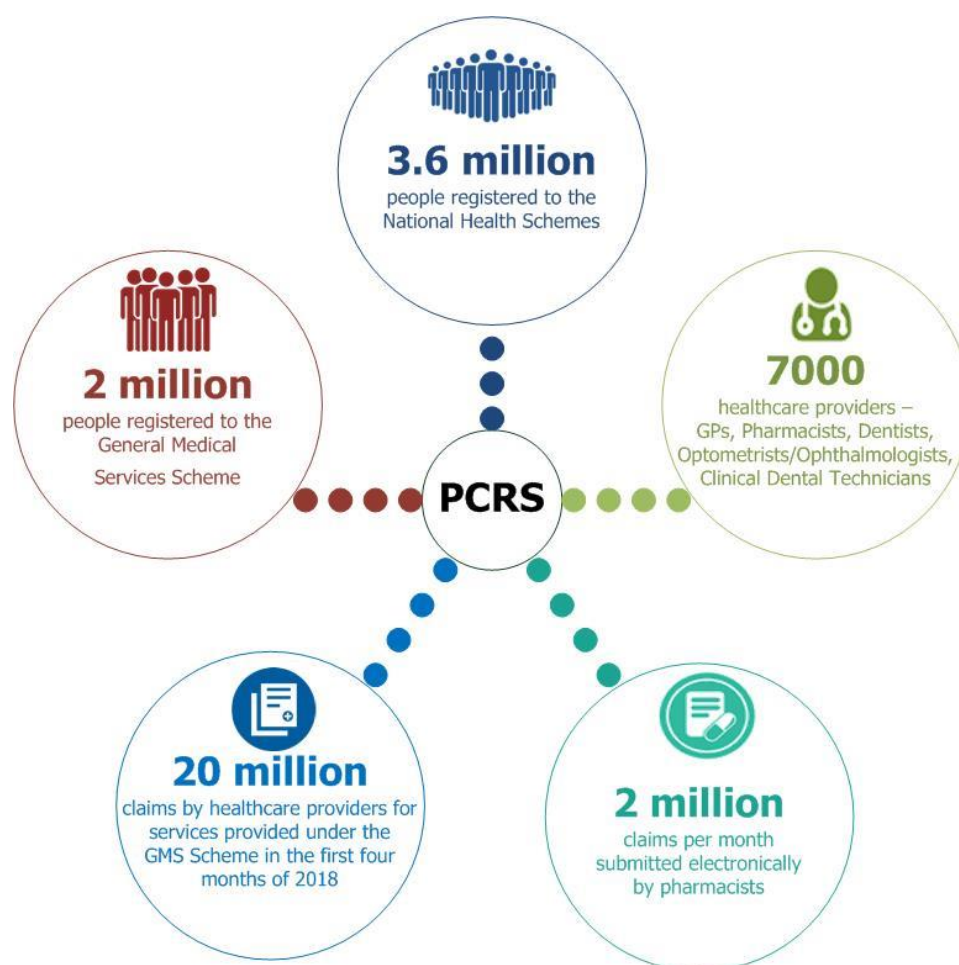
Prior to the establishment of the NMCU in 2011, the processing and approval of GMS applications was the responsibility of Local Health Offices based in more than 100 locations across Ireland.<sup>(26)</sup> In 2007, an independent report conducted for the HSE identified significant issues with the processes in operation at the time. These included a lack of single governance of the GMS Scheme, lack of transparency and delayed and unstandardised processing of applications.<sup>(26)</sup> To resolve these issues, the NMCU was established within the PCRS to centralise the GMS Scheme application process by providing a single, uniform system for applications and renewals to replace the systems previously used in the local health offices.<sup>(25)</sup> Other key objectives of centralising the service were to:

- improve customer services
- streamline work processes and implement process improvements
- reduce the number of staff required to process applications and renewals
- ensure a more accountable and better managed medical card processing service.

## **2.5 PCRS — data flows**

Under the Health Act 2004, the PCRS has a lawful basis for processing personal data, for example, name, date of birth and Personal Public Service (PPS) number.<sup>(27)</sup> This legislation allows for the PCRS to receive this data from individuals for the purpose of determining eligibility and entitlement under the GMS Scheme. In addition, the PCRS has a legal basis under the Health (Alteration of Criteria for Eligibility) Act 2013 to share this data with the Office of the Revenue Commissioner and the Department of Employment Affairs and Social Protection (DEASP).<sup>(28)</sup> The Social Welfare Consolidation Act 2005 also provides a legal basis for exchange of data between specified public bodies.<sup>(29)</sup>

As outlined in Figure 2, large volumes of data are collected by the PCRS and there are significant interactions between the PCRS and various stakeholders, including the public and contracted healthcare providers as well as external stakeholders such as the Irish Prison Service, pension suppliers and union organisations. With a focus on the GMS Scheme, this section describes the flow of data from the processing of medical card applications within the NMCU, to the issuing of contracted healthcare provider payments by the reimbursement function.



**Figure 2.** Data held within the PCRS with respect to the GMS Scheme

### 2.5.1 GMS Scheme application process — journey through the NMCU

Figure 3 outlines the journey of a medical card application through the NMCU. In summary, when an individual applies to the GMS Scheme for a medical card or a GP visit card, they must submit either a paper-based or electronic application to the NMCU. All GMS Scheme applications were paper based until January 2018, when the HSE launched its new National Medical Card Online service. This service enables individuals to apply for a medical card online, and to renew their eligibility online, via their desktop/laptop, tablets or mobile devices.<sup>(30)</sup> It also allows for the electronic upload and transfer of supporting evidence, therefore minimising the potential risk of lost documents. A significant amount of personal data relating to an individual's income and living arrangements must be included in a GMS Scheme application (for both paper-based and electronic applications).<sup>(31)</sup> As well as the standard set of personal data requested such as name, address, date of birth and PPS number, the following documentation may also be required to assess eligibility:

- details of income
- details of savings and investments
- rent/mortgage payments
- mortgage protection/house insurance payments

- childcare costs
- travel costs
- maintenance payments
- nursing home care payments
- medical expenses (including details of illness).<sup>(32)</sup>

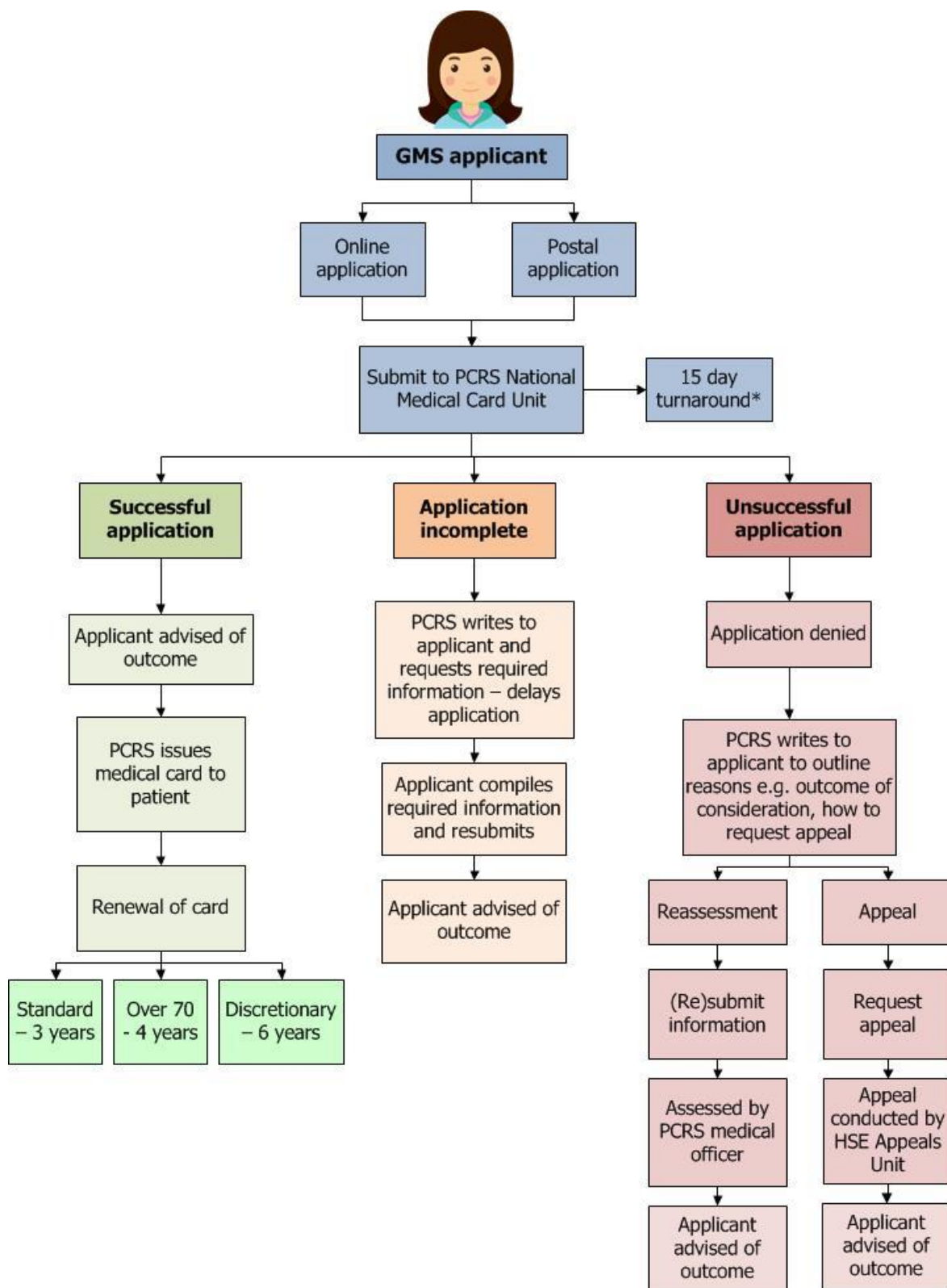
Paper-based applications must be stamped by a GP and all necessary documentation sent to the PCRS by post. In contrast, the online application service allows individuals to scan and upload documents and no longer requires a GP stamp.<sup>(30)</sup> GPs do, however, retain the ability to accept (or otherwise) patients through this online facility.

### **2.5.1.1 Medical card assessment process**

Once documents are received by the NMCU, they are first entered into the 'Oracle' database.<sup>(32)</sup> The application is then financially assessed by the NMCU. To facilitate this process, the PCRS validates data with Revenue and the DEASP. If all relevant information is received and the applicant fulfils the eligibility criteria, a medical card is issued. This card contains the applicant's name, medical card number and other information embossed thereon. All cards are valid for a particular period of time and contain a 'Valid To' date.<sup>(31)</sup> The HSE reserves the right to review and modify an individual's medical/GP visit card eligibility status, at any time, and this notification is documented on the correspondence when cards are issued.

If the NMCU require further information to process the application, they will send correspondence to the applicant explaining so. If the application was made online, this correspondence will be sent directly to the applicant's online account and via email. When the applicant has returned further information to support their application, the Additional Information team within the NMCU will update this information and run the application to completion.

Finally, if the applicant is over the income threshold, the application is unsuccessful, and a medical card will not be issued. In this instance, the PCRS will write to the applicant to outline the reasons for denial and how to request an appeal. If an appeal is requested, a Medical Officer within the NMCU and or a Deciding Officer will re-evaluate the application and make a decision in relation to their eligibility. In some cases, if an applicant is over the threshold, and there is evidence of a medical condition which may incur additional expenditure, the application will be considered for the award of discretion on the basis of undue hardship. The application with the medical report will be considered by the Medical Officer team at the PCRS, where a recommendation will be made and then referred to the Deciding Officer team for final decision. The Medical Officers may request the applicant to complete a 'Burden of Illness' Questionnaire, which was introduced in 2017 following its consideration, design and agreement at the Clinical Advisory Group established by the Director General.



**Figure 3.** Journey of a medical card application through the NMCU

\*15 day turnaround relates to fully complete applications

## **2.5.2 Reimbursement process — data flow**

When a service is provided to an individual under the GMS Scheme, the healthcare provider (that is, the GP, pharmacist, dentist, optometrist/ophthalmologist or clinical dental technician) who provided the service will submit a claim to the PCRS to request financial reimbursement. In the first four months of 2018, the PCRS processed almost 20 million claims submitted by healthcare providers for the services they provided to individuals on the GMS Scheme.<sup>(33)</sup>

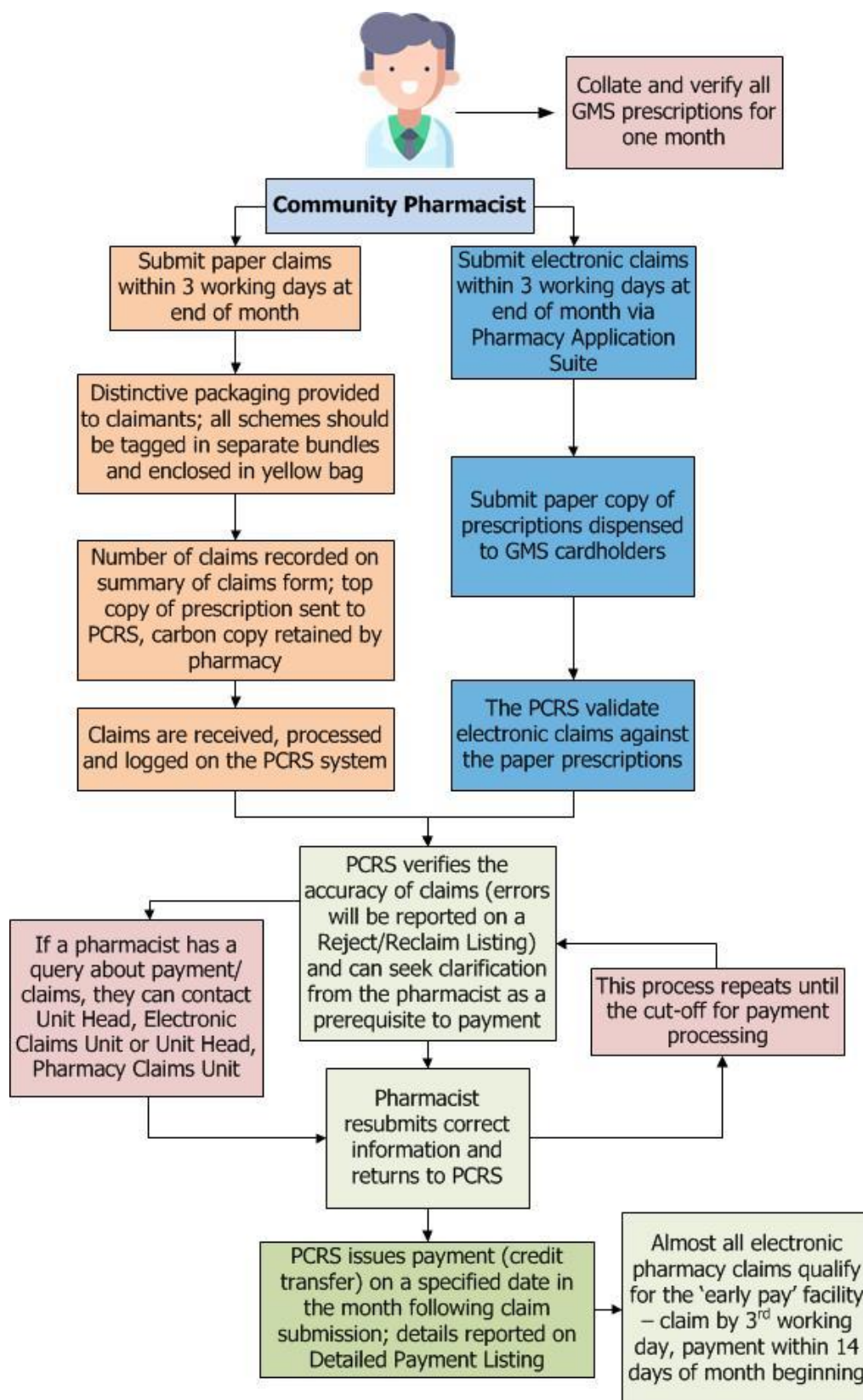
The reimbursement process for the GMS Scheme is a structured formal process managed by the reimbursement unit of the PCRS. On a specified date in each month, the PCRS receives claims from each healthcare provider group (there is a different date for each group) for the GMS Scheme. The claims contain details of the individual and the treatment they received from the healthcare provider. This information is required by the PCRS to process the reimbursement payment.

Contracted healthcare providers can submit GMS Scheme claims manually using paper-based claims sent through the post or electronically via an online IT platform known as a 'contractor suite'. The majority of contracted healthcare providers submit claims electronically and each has a dedicated suite designed to provide a range of services specifically for them. For example, pharmacists have access to the PCRS Pharmacy Application Suite for some functions. However, most of the claims are reimbursed through the pharmacists own local dispensary system which is integrated with the PCRS system. Currently 99.6% of community pharmacists submit their monthly claims electronically through this integrated method. This translates to about 2 million claims per month involving 6.4 million items. In addition to submitting electronic claims, each month pharmacists must also send the PCRS a paper copy of the prescriptions they dispensed to GMS Scheme cardholders. The PCRS then validate the electronic claims against the paper prescriptions.

If the PCRS identifies errors in the claim or has a question regarding the validity of the claim, the healthcare provider is asked for clarification. If the claim was submitted electronically, as is the case for the majority of claims, the healthcare professional is informed of any issues with claims electronically. For those who submit their claims manually, they are informed in writing. Likewise, if the healthcare provider has a query about their reimbursement, they can raise it with the PCRS. Once the claim has been verified, payment is issued on a specified date in the following month. Payment is made by credit transfer to the healthcare provider's bank account. Details of claims paid are reported on a detailed payment listing, which the PCRS issues within a week of payment to each healthcare provider paid in that month. Figure 4 outlines the GMS Scheme reimbursement data flow for pharmacists.

Under the GMS Scheme, GPs are paid a standard capitation fee for services they provide to GMS Scheme cardholders. In addition to this fee, GPs can claim payments for special items

of service such as the flu vaccination through the GP Suite or through manual claims sent to the PCRS.



**Figure 4.** GMS Scheme reimbursement data flow for contracted healthcare providers, using the example of community pharmacists

## **2.6 PCRS customer relations**

The eligibility and application process for the GMS Scheme, which was outlined in detail in the previous section, involves significant stakeholder interaction. Therefore, in order to appropriately support the volume of information received and processed by the PCRS, a dedicated Customer Relations Management (CRM) Unit is in place.

### **2.6.1 Queries from the public**

In the context of person-centred care and safety, it is important that the GMS Scheme application process is handled in an efficient and timely manner to ensure individuals are provided with the appropriate means to access healthcare. Therefore, a dedicated customer service facility, provided by an external third-party contact centre, is staffed by 92 full-time and 19 part-time staff. The contact centre provides dedicated support lines to members of the public, GPs, members of the Oireachtas and the Regional Health Forums in relation to applications for the GMS Scheme. In addition to this, there is a corresponding dedicated email address for these stakeholders.

The contact centre acts as the primary point of contact for the public for all matters relating to the GMS scheme. It has the ability to view the status of a GMS applications being processed by the NMCU, in terms of when it was received and logged, and can advise of any outstanding supporting documents required to complete the application. From time to time, queries and complaints are escalated from the external contact centre to the PCRS CRM Unit. In many cases, these queries relate to additional information required and requests which need more specialist input by the CRM Unit. This process is described in detail in Section 3.3.3 of this review.

### **2.6.2 Queries from healthcare providers**

Contracted healthcare provider queries either go to the CRM unit or are dealt with directly by the dedicated units, for example, the pharmacy unit. Since 2017, each day a daily query handling report for the reimbursement function is made available online via a reports drive. This report is also shared automatically by email to a specified distribution list. It provides statistical data pertaining to the healthcare provider queries received and processed by that particular unit. The report also contains data on the volume, status and type of queries processed as well as the average turnaround time for processing these queries.

## **2.7 Information systems used by PCRS**

In the PCRS, data received and generated through the reimbursement service and the NMCU are stored on an internal database management system. This database processes and stores applications for the national health schemes, tracks the provision and uptake of these schemes and documents the reimbursement payments made by the PCRS to contracted healthcare providers.

The PCRS reimbursement function is undertaken by the bespoke PCRS Claims and Payments System (CPS). CPS is comprised of a large number of software components and infrastructure. Within this internal IT system daily dashboards are generated to show activity statistics and the number of claims, items processed, costs to date and the number of unique patients. A query handling tool gives details of the known status of a query and the turnaround time. The details provided within this tool allow the PCRS to update their frequently asked questions section for contracted healthcare providers online.

In addition, a National Schemes Viewer (NSV) is available as a web-based tool that provides access to personal information (that is, demographic and eligibility details for schemes that members of the public are registered on) and can be used for searching applicants, card number and GP details. This system is for use by authorised staff working on an internal basis within the HSE, for example, PCRS staff, hospital staff and CHO staff. Contracted healthcare providers have access to a slimmer view of eligibility data based on the card number, that is, in the context of providing a service to the person concerned. Each user will have been individually authorised to use the NSV by senior management.

## **2.8 Significance of information management for PCRS**

The benefit of good information management practices is to instil confidence in service users, clinicians and all other stakeholders that decisions are made based on high-quality information, the availability of which will ultimately improve patient outcomes.<sup>(2)</sup> It is widely recognised that effective information management improves quality through enhanced knowledge and understanding for all involved in generating and using the data. Furthermore, good information management promotes assurance that information will be held securely; puts in place the necessary precautions to maintain individuals' privacy and confidentiality; facilitates greater empowerment and involvement by communicating effectively with stakeholders including the public, and, ultimately, creates a culture in which information will be used more effectively.<sup>(34)</sup>

In the absence of e-prescribing, the PCRS is the richest source of national prescription data and the largest data source for measuring drug exposure in specific populations in Ireland.<sup>(6)</sup> For each drug dispensed in Ireland and reimbursed by the PCRS, data are available for the date of dispensing, quantity of medication provided, strength, dosage form, route of administration, ingredient cost, community drug scheme on which drug was dispensed and dispensing fees to the pharmacist.<sup>(6)</sup>

This data can be used to improve the quality of the healthcare service being provided to people in Ireland, thus making the PCRS a rich source of information for the public, clinicians, policy-makers and researchers alike. It is used for guiding clinical decision-making, organising services and informing policy at both at national and local levels. For example, the availability of PCRS data informs the HSE's Medicine Management Programme, which develops national initiatives to reduce overall expenditure on, and improve access to, medicines.<sup>(8)</sup> Furthermore, PCRS data is used routinely by HIQA when conducting health technology assessments in order to provide accurate and reliable evidence to support decision-making within the Department of Health.<sup>(9)</sup>



The availability of PCRS data has also enabled the conduct of high-quality health research in areas such as diabetes care, prevalence of chronic disease, cancer care, drug utilisation, medicine adherence and the impact of healthcare policies.<sup>(6, 10, 11)</sup> PCRS data has been linked with data from external data registries, for example, the National Cancer Registry Ireland, a population-based cancer registry. As a result, detailed information on medication use is available for those with GMS Scheme eligibility and a diagnosis of cancer.<sup>(6, 12)</sup> PCRS data has been linked with The Irish Longitudinal Study of Ageing (TILDA), a nationally representative cohort study of over 8,000 adults aged >50 years.<sup>(6, 14)</sup> This linkage has allowed the conduct of high-quality research, in particular, of potentially inappropriate prescribing in older individuals.<sup>(6, 11)</sup> Finally, linkages have also been established between PCRS and hospital<sup>(15)</sup> and mortality data,<sup>(16)</sup> as well as the Central Statistics Office.<sup>(13)</sup>

Given the importance of the data held within the PCRS, together with its size and remit, good information management is integral to the everyday functioning of the organisation. Firstly, the PCRS requires accurate and complete information in order to process and provide medical or GP visit cards to eligible individuals to ensure the timely access to healthcare services and medications. Secondly, it requires reliable and valid information to ensure the correct reimbursement of public money.

Given the complexity of steps involved in generating PCRS data, the vast quantity of sensitive financial and clinical data that is produced and stored, and the number of stakeholders involved in the process, comprehensive and high-quality data collection can only be assured if the PCRS has appropriate arrangements in place to manage information appropriately. The process of collecting, processing, validating and storing eligibility and reimbursement data requires the contribution from a range of stakeholders, including members of the public, healthcare providers and PCRS staff. Like other resources within an organisation, information is a resource that must be strategically and effectively managed.

### **3. Governance, leadership and management**

To achieve compliance with the Information Management Standards, the managing organisation of a national data collection must have effective governance, leadership and management structures in place. These structures should promote good information management practices throughout the organisation. It is not necessary to have separate governance structures for information management; instead, these practices should be an intrinsic part of the existing governance structures of the managing organisation and national data collection. Effective governance arrangements for information management are necessary to ensure that processes, policies and procedures are developed, implemented and adhered to in respect to information management.

Features of good governance, leadership and management include:

- A well-governed organisation is clear about what it does, how it does it and is accountable to its stakeholders. Formalised governance arrangements ensure that there are clear lines of accountability for individuals and teams so that everyone is aware of their responsibilities in respect to information management. The organisation should be unambiguous about who has overall executive accountability for the national data collection, and there should be identified individuals with responsibility for information governance and data quality. There is also an onus on senior management to develop the required knowledge, skills and competencies within the organisation to manage information effectively and to ensure compliance with relevant legislation.
- Organisations should demonstrate strong leadership by strategically planning and organising resources to achieve their objectives. Strategic and business planning need to specifically address the area of information management given the ever evolving health information landscape in the wider health service, which should be aligned with the broader health information strategies in Ireland.<sup>(35, 36)</sup> Organisations often outline the information management strategy within the overall strategic plan.<sup>(37)</sup> However, increasingly, organisations with a core data and information function are choosing to develop a specific information management strategy. An information management strategy should set out how the organisation aims to improve the management of information in order to achieve its overall strategic objectives. It should include the technological infrastructure requirements, information governance, data quality and the use of information.<sup>(34)</sup>
- A well-governed and managed service can only be achieved if the organisation has robust processes in place to monitor its performance for information management. Senior management require information on performance to be assured that practices are consistently of a high standard within the organisation. This involves using key performance indicators to measure and report on performance, undertaking regular audits to assess practice and having a comprehensive risk management framework in place throughout the entire organisation to help identify, manage and control information-related risks.

- Formalised data sharing agreements are in place with external organisations. These agreements outline the responsibilities of both parties and the associated timelines for the completion of tasks. Data sharing agreements are necessary to support the provision of good quality data, and the legal and secure handling of data.
- Organisations with robust governance structures promote transparency by informing individuals about whom data is being shared about any data sharing agreements in place, and they accurately describe the aims and objectives of the national data collection in a published statement of purpose.

The HIQA review team assessed the governance, leadership and management arrangements at the Primary Care Reimbursement Service (PCRS) against Standard 2, 3 and 4 of the Information Management Standards.

The findings of governance, leadership and management will be presented in the following sections:

- Governance structures of PCRS within the HSE
- Strategic vision, planning and direction
- Risk and performance management
- Formalised governance structures for data sharing agreements
- Transparency.

## **3.1 Findings — Governance structures of PCRS within the HSE**

This section outlines the governance structures in the PCRS at the time of the review, including the positioning of the PCRS within the Health Service Executive (HSE), governance arrangements in the PCRS with respect to information management, and a summary of the significance of findings for this chapter.

### **3.1.1 Overview of governance structures**

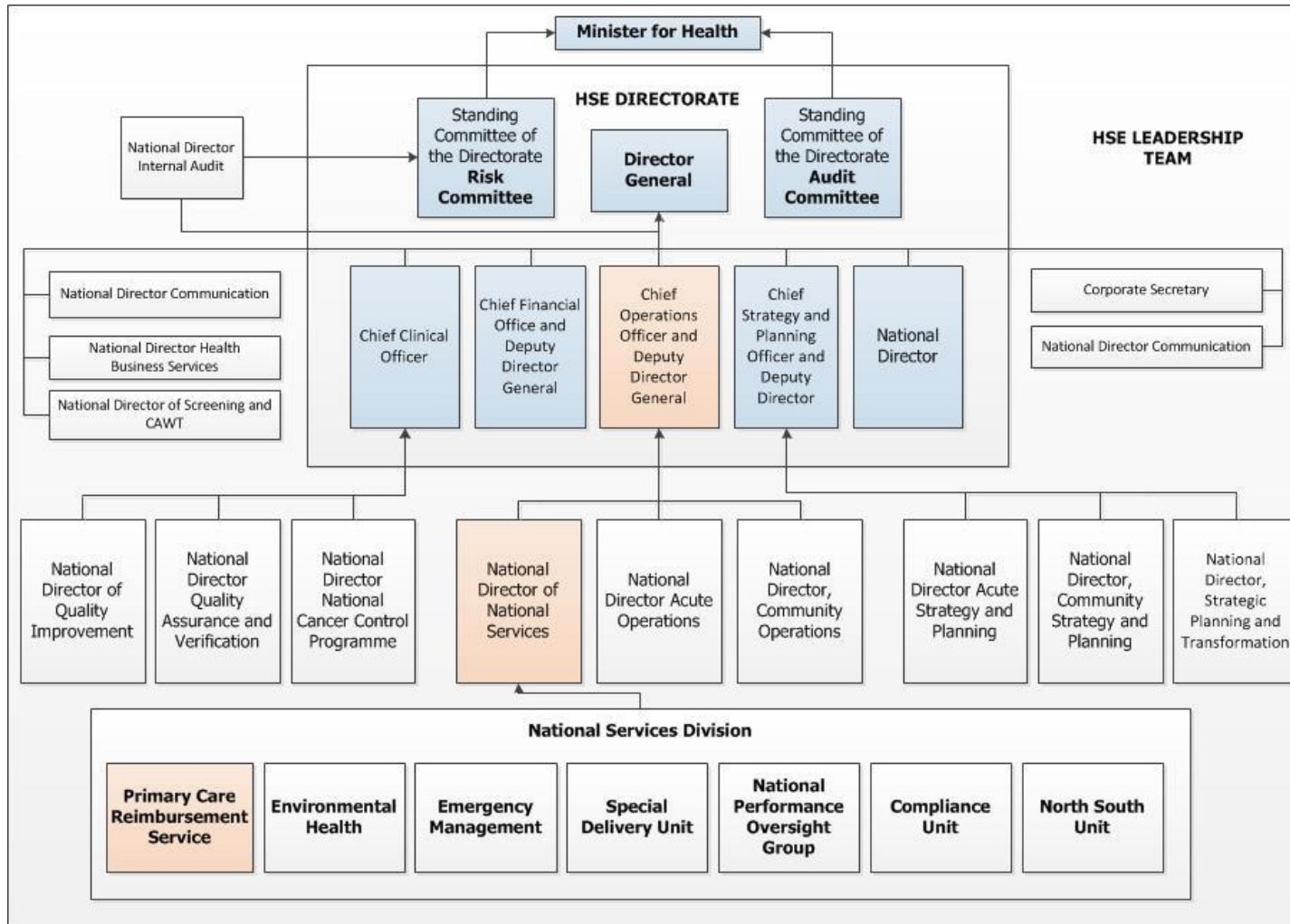
#### **3.1.1.1 National Services Division, HSE**

At the time of this review, the PCRS was under the remit of the HSE National Services Division, led by the National Director of National Services who has overall executive responsibility and accountability for the division. The National Director of National Services reports to the Deputy Director General/Chief Operating Officer of the HSE and sits on the HSE National Leadership Team. The positioning of the PCRS within the HSE is outlined in Figure 5.

The National Services Division is comprised of:

1. Primary Care Reimbursement Service
2. Environmental Health
3. Emergency Management
4. Special Delivery Unit
5. National Performance Oversight Group (NPOG)
6. Compliance Unit
7. North South Unit

Senior management within these service areas report to the National Director of National Services and meet as a senior management team. HIQA was provided with evidence in relation to clear agendas and minutes from these meetings. It was noted that this team met frequently (six times between March and October 2018) and attendance at these meetings was high. These senior management meetings, chaired by the National Director for National Services, cover aspects in relation to the operational functioning of each service area, including human resources and finance.



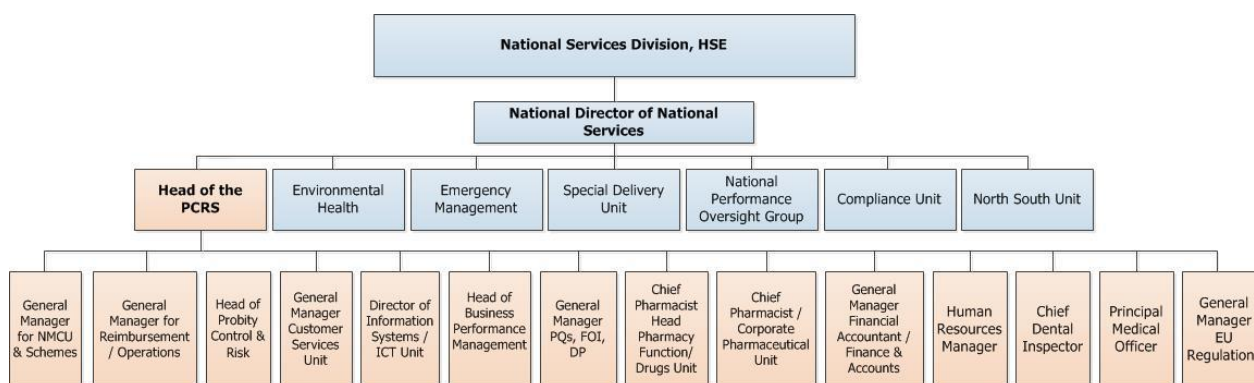
**Figure 5.** Current governance structures of the positioning of the PCRS within the HSE (adapted from <https://www.hse.ie/eng/about/who/>)

### 3.1.1.2 The Primary Care Reimbursement Service

The PCRS is led by an Assistant National Director (the Head of the PCRS) within the National Services Division of the HSE. Under the HSE Performance and Accountability Framework <sup>(38)</sup> the Head of the PCRS is defined as an Accountable Officer,<sup>‡</sup> who is responsible and accountable for the performance of the PCRS.

The Assistant National Director for National Services, with overall accountability and responsibility for PCRS, will be referred to as the Head of the PCRS for the remainder of this report.

Within the PCRS there are 14 business units, each of which is assigned specific responsibilities. HIQA was provided with a comprehensive organisational chart which illustrates the lines of reporting within each of these units. The manager of each reports directly to the Head of the PCRS. Figure 6 depicts these units as well as the lines of reporting from the Head of the PCRS to the National Director of National Services.



**Figure 6.** Governance structures of the PCRS within the National Services Division, HSE<sup>§</sup>

### 3.1.2 Governance arrangements for information management

Good governance of an organisation requires formalised structures with clear lines of responsibility and reporting for executive and management teams. HIQA examined the structure and composition of senior management teams within the PCRS to assess what governance arrangements were in place to bring together key decision makers to discuss areas, including performance, risk and strategy in relation to information management.

<sup>‡</sup>An Accountable Officer is fully responsible and accountable for the services they lead and deliver; they are required to have formal performance management arrangements in place with the individual services they are responsible for, to ensure delivery against performance expectations and targets.

<sup>§</sup> PQs – Parliamentary Questions, FOI – Freedom of Information, DP – Data Protection

### **3.1.2.1 Oversight arrangements for the governance of PCRS**

The Head of the PCRS has overall accountability and responsibility for the PCRS and reports directly to the HSE National Director of National Services via the aforementioned monthly National Services Division senior management meetings. In addition to these meetings, HIQA was also informed that the Head of the PCRS meets with the National Director of National Services on a one-to-one basis. A new National Director for National Services was appointed in mid-2018, and HIQA was informed that at the time of the review two meetings had been held between the Head of the PCRS and this newly-appointed National Director of National Services (in September and October 2018).

### **3.1.2.2 PCRS management teams**

HIQA was informed that there are two senior management teams in place within the PCRS:

- the Reimbursement Management Team
- the National Medical Card Management Team.

The lines of reporting, the responsibilities, the composition and the functioning of these teams are outlined in Table 4. HIQA noted that they meet separately, but on a frequent basis (that is, fortnightly and weekly for the Reimbursement and National Medical Card teams, respectively) and attendance at these meetings is high. After reviewing the agendas and detailed minutes from these meetings, HIQA acknowledged that the PCRS are effective in managing operational issues relating to both functions.

HIQA identified other groups and committees operating within the PCRS. For example, the PCRS informed HIQA that two specific planning meetings are held with members of both senior management teams, jointly, on a bi-annual basis. Furthermore, a Risk Committee also meets bi-annually to discuss organisational risks. Finally, it was noted that individual managers meet on an ad hoc basis should issues arise in relation to specific projects. However, through the review it was unclear as to which forum strategic planning for information management issues and the management of information-related risks are routinely discussed, at an organisational level. Aspects of information management, such as data quality and information governance, are organisation-wide issues and so it is vital that there is a strategic approach to the management of these issues, that is consistent across the organisation.

In order to ensure a more strategic approach to information management across the PCRS, an oversight structure similar to that of a senior executive forum should be considered. It is possible that the composition of such a team would be similar to that of the current Risk Committee and, therefore, it could be the case that this committee meet on a more frequent basis to provide a more strategic approach across the different elements of information management.

**Table 4.** Details of the PCRS Reimbursement and National Medical Card Management Teams

|                         | <b>Reimbursement Management Team</b>   | <b>National Medical Card Management Team</b>  |
|-------------------------|--|---|
| <b>Chair</b>            | Head of the PCRS   | Head of the PCRS  |
| <b>Membership</b>       | <ul style="list-style-type: none"> <li>▪ Head of Customer Relations Management Unit</li> <li>▪ Head of Information Services (ICT)</li> <li>▪ Head of PCRS Reimbursement</li> <li>▪ Head of Pharmacy Function</li> <li>▪ General Manager, Finance</li> <li>▪ Chief I Pharmacist.</li> <li>▪ Head of Probity</li> <li>▪ Head of Corporate Pharmaceutical Unit Chief 1</li> </ul>   | <ul style="list-style-type: none"> <li>▪ Head of Customer Relations Management Unit</li> <li>▪ IT Development Representatives</li> <li>▪ General Manager, NMCU</li> <li>▪ Quality Manager, NMCU</li> <li>▪ Lead Medical Advisor</li> <li>▪ Business Manager</li> <li>▪ HR Manager.</li> </ul>   |
| <b>Purpose</b>          | The management, processing, review and reporting of payments to GPs, pharmacists, dentists and optometrists/ ophthalmologists who have entered into an agreement with the HSE to provide services to eligible persons under national health schemes.   | The management of, processing, review and reporting of medical card and GP visit card applications.   |
| <b>Responsibilities</b> | <ul style="list-style-type: none"> <li>▪ Ensuring payments are made to primary care contractors, in line with contracts, policy, legislation and guidelines</li> <li>▪ Governance of reimbursement-related services</li> <li>▪ Ensure appropriate systems of quality, safety and risk management</li> <li>▪ Contribute to and assure implementation of the Service Plan and Operational Plans</li> <li>▪ Measure, monitor, control and manage performance against key targets</li> <li>▪ Ensure appropriate links with contractors and bodies</li> <li>▪ Establish and develop effective collaborative relationships with key stakeholders and manage effective communications</li> <li>▪ Implement all corporate policies, procedures and standards.</li> </ul> | <ul style="list-style-type: none"> <li>▪ Responsible and accountable for the delivery of Medical Card services within legislation, standards, policies and resources</li> <li>▪ Ensure governance in the delivery of service provision</li> <li>▪ Ensure appropriate systems of quality, safety and risk management are in place</li> <li>▪ Contribute to, and assure implementation, of the Annual Service and Operational Plans</li> <li>▪ Develop and implement an appropriate operational management structure</li> <li>▪ Measure, monitor, control and manage performance against key targets</li> <li>▪ Ensure timely access for clients and ensure a patient-centred service</li> <li>▪ Establish and develop effective collaborative relationships with stakeholders, ensuring effective communications</li> <li>▪ Implement all corporate policies, procedures and standards.</li> </ul> |
| <b>Frequency</b>        | Fortnightly  | Weekly  |



## **3.2 Findings – Strategic vision, planning and direction**

Strategic and corporate plans are the foundation on which all business activities can be connected and aligned. In order to effectively deliver a strategy, it is necessary to specify how the national data collection is going to achieve their strategic objectives by producing regularly updated plans. Developing and implementing business plans is an essential process to translate strategies into realistic work targets, and this process also provides a basis to monitor progress to ensure that key outcomes are achieved within the specified timelines.

### **3.2.1 Strategy for the PCRS**

As a result of a review of the National Medical Card Unit conducted by Prospectus and Deloitte in 2014, a strategic plan was developed for the NMCU to cover the period 2016–2018.<sup>(25)</sup> While this plan was aligned with the goals outlined in the current HSE Corporate Plan,<sup>(39)</sup> HIQA noted that information management was not identified as a strategic priority for the NMCU in order for it to deliver on the five priorities outlined in this plan. Presently, there is no strategic plan outlining key priorities for, or objectives of, the Reimbursement Unit.

HIQA was informed that, at the time of the review, the PCRS did not have an overarching strategy to define a shared vision and understanding across the organisation. During interview, the PCRS informed HIQA that such a strategy was being developed to cover the period 2019–2021 and would have a focus on information management as well as the efficient centralisation of schemes. The Head of the PCRS informed HIQA that a stakeholder consultation would be held prior to its publication. HIQA was unable to assess the content of this strategy as it is still in development and has not, at the time of publication of this review, been published.

The importance of information management for PCRS has been identified in a number of key reviews of the PCRS in recent years,<sup>(40, 41)</sup> and, therefore, a key feature of an organisation-wide strategy should be to outline how the PCRS is going to achieve effective information management in order to deliver on the overall strategy. For example, in the UK, the National Health Service Business Services Authority (NHS BSA) has outlined how it is planning to deal with issues relating to the General Data Protection Regulation (GDPR) as well as risks relating to information security within its Business Strategy 2018–2021.<sup>(42)</sup> However, given the volume of information held within the PCRS as well as the importance of this information to healthcare professionals and policy makers alike, the development of a strategy specific to information management should also be considered.

While this move towards the development of an overarching strategic plan is a positive step for the PCRS, it further strengthens the need for an oversight structure similar to that of a senior executive forum to oversee and ensure its implementation.

### **3.2.2 Business planning for the PCRS**

A well-governed and managed organisation monitors its performance to ensure it meets its objectives, which are outlined through the process of business planning. The PCRS publishes an operational plan each year which outlines the priority actions to be delivered by the organisation for that specific year, key project areas, budget allocation and potential risks. At the time of the review, the PCRS Operational Plan 2018<sup>(22)</sup> was aligned with the HSE National Service Plan 2018<sup>(43)</sup> and the Primary Care Division Operational Plan 2017.<sup>(44)</sup> The key priorities set out in the PCRS Operational Plan 2018 were to:

- ensure equitable access to services in line with policy, regulations and service level arrangements governing administration of health schemes through reimbursement of contractors
- implement the provisions of the *Framework Agreement on the Supply and Pricing of Medicines*
- strengthen accountability and compliance.<sup>(22)</sup>

The plan makes a number of references to the improvement of information management practices across the organisation, including risk, governance and transparency. It is important that the development of objectives within the proposed PCRS Strategy 2019–2021 align with the associated annual operational plans to enable and ensure the review and monitoring of performance and management within that period.

## **3.3 Findings – Risk and performance management**

Robust risk and performance management promotes accountability to all stakeholders by facilitating informed decision-making and improvements through continuous and rigorous self-assessment.

Risk and performance management involves using the appropriate tools to produce the necessary information to assure senior management that the PCRS is being managed efficiently at an operational level. Effective performance management can be achieved by employing a number of key tools, including identifying and reviewing key performance indicators (KPIs) and metrics, commissioning internal and external audits to assess compliance with relevant legislation and the organisation's policies and procedures, and reviewing the risk management policy and risk register.

Risk and performance management are closely aligned, with clear governance structures where explicit lines of reporting and clarity regarding specific accountabilities are essential. Under the previously mentioned Performance and Accountability Framework,<sup>(38)</sup> the Head of the PCRS is defined as an Accountable Officer<sup>(38)</sup> and as such is required to sign a Performance Agreement. This Performance Agreement is held between the Head of the PCRS and the National Director of National Services and confirms that the Head of the PCRS

accepts responsibility and accountability for producing and delivering their operational and functional plans and acceptance of the regime of supports, interventions and sanctions set out under the Performance and Accountability Framework.<sup>(38)</sup> In line with this framework, the PCRS submit quarterly operational updates to the HSE.

Risk management, audit and the use of KPIs for the PCRS will be detailed in the following sections.

### **3.3.1 Risk management**

Senior management need regular assurance that the risk management policy is being implemented within the organisation by regularly reviewing the risk register at senior management meetings and assessing whether risks are being managed appropriately within the organisation.

Risk management is a key component of effective performance management. The PCRS is required to comply with the HSE Integrated Risk Management Policy.<sup>(45)</sup> This policy encourages management to adopt a proactive approach to risk management by identifying risks that threaten the achievement of objectives and compliance with governance requirements. An example of such risks is the failure to comply with legal and regulatory requirements. The policy clearly outlines that it is the responsibility of all staff members to identify and manage risk within the context of their own work.

Through the presence of a Risk Committee and Risk Register, which are both outlined in more detail in the following section, HIQA identified good practice in relation to risk management at an operational level. HIQA noted, however, that a strategic review of risk needs to occur at an organisational level, particularly in relation to information management-related risks.

#### **3.3.1.1 Risk Committee**

HIQA was informed that a Risk Committee, comprising of senior management (n=17) across each of the functions within the PCRS, is responsible for performing in-depth risk assessments on a biannual basis. This committee serves as a forum for senior management to discuss organisational risk in detail and update the PCRS risk register accordingly. Membership of the Risk Committee is presented in Table 5.

In addition to this committee, each of the two core functions within the PCRS assigns risk management as a standing item on meeting agendas which facilitates the appropriate rating, assessment, mitigation and control of risks at that functional level; if a risk cannot be managed at that level, it is escalated and brought to the Risk Committee for discussion. In the NMCU, managers meet monthly to review risk and rate accordingly. Where necessary, risk is then escalated further to the HSE for incorporation on its register.

A gap analysis was recently conducted by an external consultant to identify and assess risk in the context of GDPR legislation. An implementation group has been convened in order to progress the recommendations and mitigate the identified risks — further detail on this analysis as well as further risks relating to information governance are outlined in Chapter 5 of this report.

**Table 5.** Recent internal and external audits conducted within the PCRS

|                   | <b>Risk Committee</b>  |
|-------------------|--|
| <b>Chair</b>      | Head of the PCRS   |
| <b>Membership</b> | <ul style="list-style-type: none"> <li>▪ General Manager Financial Accountant</li> <li>▪ General Manager Reimbursement/Operations Function</li> <li>▪ General Manager for NMCU &amp; Schemes</li> <li>▪ Director of Information Systems</li> <li>▪ HR Manager</li> <li>▪ Business Performance Management Unit – Community Schemes Control Officer</li> <li>▪ Head of Probity</li> <li>▪ Business Manager Hi-Tech Co-Ordination Unit / Operations</li> <li>▪ Lead Medical Officer</li> <li>▪ Head Pharmacy Function/Drugs Unit</li> <li>▪ Chief Pharmacist/Head of Corporate Pharmaceutical Unit</li> <li>▪ General Manager Customer Relations Management Unit</li> <li>▪ Facilities Manager</li> <li>▪ Quality Assurance Manager NMCU</li> <li>▪ Head of Customer Service Schemes &amp; Eligibility</li> <li>▪ Analysis &amp; Reporting Unit Business Manager</li> </ul> |
| <b>Agenda</b>     | The agenda for each meeting is essentially a review of the Risk Register and any updates to the register that arise from the meetings are essentially the minutes of the meetings. Any escalation of risk that may arise will be notified to the HSE for incorporation on its Register.  |
| <b>Frequency</b>  | Biannually   |

### 3.3.1.2 PCRS risk register

PCRS provided HIQA with a copy of the PCRS risk register, which is a composite register of risks from both of the core PCRS functions (that is, the reimbursement function and the eligibility function) as well as shared services (for example, ICT) and covers various day-to-day operational risks, such as the risk of fraudulent claiming.

### 3.3.2 Internal and external audit

The use of audit is also a key feature of performance management. Audit is necessary to evaluate whether current practices are in line with best practice guidelines or standards and to provide the necessary information to assure senior management that the PCRS is being managed efficiently. Audit should be used to assess compliance with legislation, and policies and procedures or to undertake an in-depth assessment to understand why particular risks or issues are arising. Senior management within PCRS need to regularly review the findings to recognise areas of good practice and to identify areas needing further improvement. Audits are necessary to identify specific training needs and to ultimately identify and implement improvements to information management practices based on the findings.

It is necessary to undertake both internal and external audits in order to obtain a complete, unbiased view of an organisation. HIQA was informed that there are a number of auditing processes in place for the PCRS, which take place on a continuous, monthly, quarterly and biannual basis. These audits, which are outlined in Table 6, address aspects of information management including data quality and information governance.

**Table 6.** Recent internal and external audits conducted within the PCRS

| <b>Name and type of audit</b>  |
|--|
| <b>Internal Audits</b>   |
| Data Protection – IT Controls Audit (2016)<br>Conducted by the HSE Internal Audit Division and external consultancy firm |
| ICT Vulnerability Assessments (2016)<br>Conducted by the HSE Internal Audit Division and external consultancy firm       |
| Internal process reviews / Internal Audit<br>Conducted by ISO Project Group in NMCU and CRM                              |
| Monthly Verification and Compliance Reports<br>Conducted by Business Performance Unit                                    |
| National HSE Internal Audits   |
| <b>External Audits</b>   |
| Annual Comptroller & Audit (C&AG) Audit<br>Conducted by the Comptroller and Auditor General                              |
| ISO 9001:2015 Gap Analysis (2018)<br>(Stage 1 & 2 audits have occurred since then)                                       |
| National Medical Card Unit Inspection (2017)<br>Conducted by the Data Protection Commissioner                            |
| GDPR Gap Analysis (2017)<br>Conducted by external consultancy firm   |
| Technical Infrastructure Security Assessment (2014)<br>Conducted by external consultancy firm                            |
| PCRS Medical Card Process Review (2014)<br>Conducted by external consultancy firm  |

### **3.3.2.1 Internal audits**

Internal audits within the PCRS are normally conducted by the HSE Internal Audit Division. These audits serve to provide assurance that PCRS is operating efficiently, in accordance with best practice and in line with the appropriate regulations. Where required, recommendations are developed to improve existing controls and procedures within the organisation.

HIQA received evidence of a number of internal audit reports from the PCRS, which were conducted in 2016. These audits were carried out by an external consultancy firm, contracted by the HSE Internal Audit Division to identify and test targeted areas of the PCRS ICT infrastructure and determine the existence and adequacy of IT controls within the PCRS.

The most recent internal audit report provided to the review team related to data protection IT controls. While it recognised that efforts are on-going within the PCRS to implement previous recommendations, it identified potential areas for improvement. Specifically, it made six medium priority recommendations and one low priority recommendation; these related mainly to database security, for example, password controls and user access. The PCRS informed HIQA that these recommendations are addressed through dialogue and actions assigned at the respective senior management team meetings. HIQA was also informed of an audit report recommendation implementation status tracker. However, after reviewing this document, a lack of clarity remains in relation to the specific timelines and roles and responsibilities around the implementation of these recommendations.

### **3.3.2.2 External audits**

External audits can be commissioned when a specific area of expertise, which may not be available in-house, is required or when an extra level of independence is considered necessary. Such audits are normally conducted by external agencies. PCRS provided HIQA with the reports of a sample of external audits that had been carried out in 2017.

#### **GDPR gap-analysis**

In preparation for GDPR, the PCRS proactively commissioned an external consultancy firm to conduct a comprehensive gap analysis to assess data protection processes and controls within the PCRS, and the NMCU, in the context of GDPR legislation. The report, compiled by the consultancy firm in 2017, acknowledged the efforts made by the PCRS prior to the review to ensure compliance with existing legislation and successful progress towards improving and optimising its business processes. Overall, the report indicated preparedness for continued compliance under GDPR. However, it also outlined 16 recommendations to further strengthen compliance with the legislation. The PCRS is working to implement many of these recommendations through the establishment of an implementation group, which is outlined in Table 7.

HIQA noted that in light of the above audit recommendations, an information management strategy could help to provide strategic direction and focus in terms of implementing these recommendations. Such a strategy would further benefit from an overall PCRS executive management forum that could drive and monitor its implementation at an organisational level.

**Table 7.** GDPR gap analysis 2017 recommendations — implementation group

|                              |  |
|------------------------------|--|
| <b>Chair</b>                 | General Manager of Customer Services (with responsibility for GDPR and freedom of information)   |
| <b>Membership</b>            | Head of Information Services (ICT)<br>Head of Operations/Reimbursement<br>Head of Pharmacy Function<br>Data Protection Advisor (in attendance) |
| <b>Purpose</b>               | To address the recommendations outlined in the GDPR Gap Analysis report  |
| <b>Responsibilities</b>      | Individual responsibilities for the implementation of recommendations are related to the specific functional remit                             |
| <b>Frequency of meetings</b> | Monthly basis (March–August 2018)  |

### 3.3.2.3 Review by the Office of the Data Protection Commissioner

In 2017, the Office of the Data Protection Commissioner conducted a review of the PCRS to identify areas within the PCRS which required improvement in the context of data protection and GDPR legislation and found that, in general, there was very high organisational awareness of data protection principles in evidence. The review compiled three recommendations which, if implemented, would help to drive the quality and safety of health and social care services. These recommendations related to data breaches, data protection training and the legislative basis for making checks with other government agencies.

It was noted that the PCRS is actively working to implement these recommendations, for example, in relation to data breaches. In addition to the HSE’s Data Protection Breach Management Policy, a cross-functional working group in the NMCU was set up to discuss cases where a breach has occurred and identify possible mechanisms to minimise breach reoccurrence. HIQA was also informed that another group involving the General Manager of the NMCU was established and had met in October 2018 to discuss the system and policy changes needed in relation to key data breach themes. The PCRS management of breaches will be discussed further in Chapter 5.

### 3.3.3 Key performance indicators

Key performance indicators (KPIs) can be a valuable tool to assess performance if used effectively; they can be used to monitor how effectively an organisation is reaching targets. KPIs should be linked to strategic and business plan objectives as this enables senior management to regularly review whether the organisation is on-target to achieving what it set out to achieve for that period. It is important that organisations have a systematic process in place to identify, develop, collect and review KPIs.

Relevant, reliable and accurate indicators are essential for good governance and so senior management within the PCRS need assurance that there is a carefully planned process in

place to derive the appropriate KPIs. A performance report, detailing KPIs, should be reviewed at management meetings and actions decided upon if performance drops below the pre-specified target at any point. PCRS provided HIQA with the agenda and detailed minutes from six management team meetings held between February and April 2018 (three Reimbursement Unit Management Team meetings and three National Medical Card Management Team meetings). From these documents, HIQA has noted that issues relating to performance management are routinely discussed as a specific standing item at Reimbursement Management Team meetings and under 'Business Management' at National Medical Card Management Team meetings and that attendance at these meetings is high.

### **3.3.3.1 Performance of the PCRS core functions**

The HSE National Service Plan and the PCRS Operational Plan 2018 include a number of national KPIs in relation to assessing the performance of the PCRS, specifically in terms of the National Medical Card Unit of the PCRS. These KPIs are outlined in Table 8. KPIs relating to reimbursement include the number of GMS Scheme prescriptions, the number of LTI scheme claims, as well as the number of DPS scheme claims.

**Table 8.** NMCU Key Performance Indicators

| <b>Indicator</b>  |
|---|
| Percentage of completed medical card/GP visit card applications processed within 15 days  |
| Percentage of medical card/GP visit card applications, assigned for medical officer review, processed within five days                                |
| Percentage of medical card/GP visit card applications which are accurately processed from a financial perspective by National Medical Card Unit staff |
| Percentage of medical card/GP visit card applications that are processed from end to end without the need for additional information                  |

HIQA noted that the KPI in relation to a 15 day turnaround for medical card applications begins at the point of receipt of a fully complete application. It does not capture the extensive amount of work that is involved prior to this point, including correspondence between the PCRS and the applicant in cases where additional information is required, thus potentially not reflecting the true experience of applicants to the scheme. Evidence provided to HIQA indicated that some applications are taking in excess of 65 days to process. In addition, HIQA identified through interview and document request that metrics capturing the length of time it takes to complete an application when information is missing or inadequately provided, as is the case for 20% of applications received, are not publicly available.

The Head of the PCRS acknowledged the need for additional KPIs in certain areas, particularly in relation to assurance relating to the quality of claims submitted by contracted healthcare providers, rather than placing a focus specifically on probity. Such insights would provide additional assurance around the quality of data submitted by external stakeholders. HIQA was informed through interview that additional KPIs will be developed and added to the previously mentioned organisational strategy to be published in 2019. With this in mind, HIQA would welcome the addition of performance metrics that have an increased focus on



service user outcomes rather than those primarily process-driven. To do so, PCRS should consider engaging with and requesting feedback from external stakeholders, including contracted healthcare providers and people using the services of the PCRS.

The use of KPIs in areas of information management such as data quality and information governance are of particular significance to the work of the PCRS given the volume and nature of information collected. The review team was informed, through documentation and interview, that such indicators are not routinely collected within the organisation. As a result, HIQA is unclear as to which forum, if any, these issues are reviewed. This indicates the need to introduce more robust performance measures in order to provide assurance to the Head of the PCRS and the broader National Services Division with respect to information management.

### **3.3.3.2 Customer service contact centre**

As described in Chapter 2, the PCRS has contracted the services of an external customer service contact centre which is staffed by 92 full-time and 19 part-time contact centre staff. Through interview, HIQA was informed that in May 2018 the contact centre received over 71,000 calls from service users, GPs, members of the Oireachtas and members of the Regional Health Forum, primarily in relation to the GMS Scheme application process.

HIQA was informed that a monthly business review meeting is held between the PCRS and the contact centre. A number of representatives from the PCRS attend this meeting, including the Head of the CRM Unit, the Head of the NMCU, along with Operations Managers and Team Leaders from the contact centre. Following this meeting, the Head of the CRM Unit provides a report to the Head of PCRS. These reports provide details in relation to a number of performance standards and metrics which are in place to enable the PCRS to monitor and evaluate the performance and efficiency of the contact centre. These standards relate to areas such as the average call handling time, answer rate and escalation rates from the contact centre to the PCRS. HIQA noted that these metrics do not capture the number of repeat callers or the nature of their queries. Such information could indicate areas for improvement within the PCRS system, for example, the usability of the GMS Scheme online application system, and should be considered for inclusion in the report provided to the Head of the PCRS. While HIQA was informed that these metrics are used to monitor operational aspects of the application process, it was unclear to the review team how this data is strategically used to drive improvements within the GMS application system.

HIQA reviewed, in detail, the breakdown of calls received by the contact centre in a particular month during 2018 and noted that a number of themes have emerged in relation to the types and context of calls received through the centre. Most calls related to the status of GMS Scheme applications, online application support (19% of calls), confirmation that the client's receipt of application was received, and enquiries in relation to requests for additional information to complete an application. While HIQA acknowledges that the high volume of calls received by the PCRS is indicative of the complexity of the eligibility and application

process, a detailed strategic review of the nature and outcome of these calls should be undertaken by the PCRS; this may uncover potential areas of information management that could be improved upon in relation to the GMS Scheme application process.

### **3.3.3.3 Customer Charter**

During the review, HIQA identified actions the PCRS are taking to improve the delivery of a high-quality customer service that is consistent with the Principles of Quality Customer Service developed for the public service.<sup>(46)</sup> In 2018, the PCRS published a Customer Charter<sup>(21)</sup> which provides information on how customer input can contribute to the continuous improvement of services provided by the PCRS / NMCU and outlines how to address queries and complaints.

A well-governed organisation is one that has a process in place for capturing positive and negative feedback, including a formal complaints procedure for reviewing and investigating complaints.<sup>(2)</sup> HIQA was informed that upon receipt of a query requiring escalation to the CRM Unit, the contact centre logs it on the database, includes information on the nature of the query and clarification required, and categorises it as either low, medium, high or urgent. From 1 January to 31 December 2017, 55,584 queries were escalated from the contact centre to the CRM Unit for resolution. In compliance with the HSE Complaints Management Policy, the PCRS investigates and reports on all complaints within 30 days. At the time of the review, HIQA was informed that 134 complaints had been created on the system for 2018. The PCRS stated that all shortcomings are reported on and lessons are identified for future learning across the organisation. HIQA identified through document request that aspects relating to queries and complaints are discussed as a standing item at both senior management team meetings. However, during the review, HIQA was unclear as to the specific mechanisms by which the PCRS use this information in a strategic manner to drive improvements within the service.

### **3.3.3.4 Customer Satisfaction Survey**

In order to monitor and improve on customer service, a customer satisfaction survey is conducted on an annual basis. Two surveys have been conducted to date, with the most recent one completed in November 2017. Survey results were reviewed by HIQA. The surveys include similar questions for each cycle to enable the PCRS to make comparisons between service delivery on an annual basis. Questions cover various aspects of an individual's interaction with the PCRS, including ease of correspondence, methods used to contact the PCRS and use of the online application process. They also requested participants to assign a rating for their interactions with the PCRS. To ensure the process is accurate and unbiased, a random sample of successful and unsuccessful medical card applicants (of different age profiles) are invited to participate.

Following analysis of findings, the results of the survey are discussed during the business management review meeting held between the PCRS and the dedicated contact centre and used to guide areas for improvement within the PCRS, for example, staff training and data entry. It was explained to HIQA that a number of improvements have been made to systems and processes as a result, for example, the development of a new application form.

While HIQA acknowledges that the PCRS are capturing feedback through various mechanisms including stakeholder meetings with Citizens Information Bureau, patient/advocacy group forums as well as Regional Health Forums, it was identified during the review that more could be done to use this information more effectively to drive service improvement. In Northern Ireland, as outlined in their Customer Relations Strategy 2017–21,<sup>(47)</sup> the Health and Social Care Business Service Organisation (HSC BSO) has developed a well-established network of customer partnership forums which typically meet on a quarterly basis. These forums are structured meetings between service providers and customers working in partnership to deliver changes and improvements, including the co-creation of new services and products.<sup>(47)</sup>

### **3.3.3.5 ISO 9001:2015 Quality Management System (QMS)**

HIQA acknowledges that the PCRS are currently in the process of seeking certification to the ISO 9001:2015 Quality Management System (QMS) and recognises this as a positive step towards service improvement. Internationally, organisations use the standard to demonstrate their ability to consistently provide products and services that meet customer and regulatory requirements. In June 2018, PCRS started phase 1 of the application process by performing a gap analysis.

## **3.4 Findings — Transparency**

Organisations with robust governance structures promote transparency by publicly reporting a statement of purpose which clearly outlines the aims and objectives of the national data collection. Furthermore, data sharing between organisations is encouraged if it is for the benefit of the service user and public health and in line with legislation and best practice guidelines. The use of data sharing agreements is recognised as good practice in this area. The governance of data sharing should ensure personal information is shared in a way that is fair, transparent and in line with the rights and expectations of the individuals whose information is being shared.

### **3.4.1 Statement of purpose**

A statement of purpose provides specific detail on why the national data collection exists and clearly outlines its overall function and objectives. This outlines the purpose and function of the national data collection.

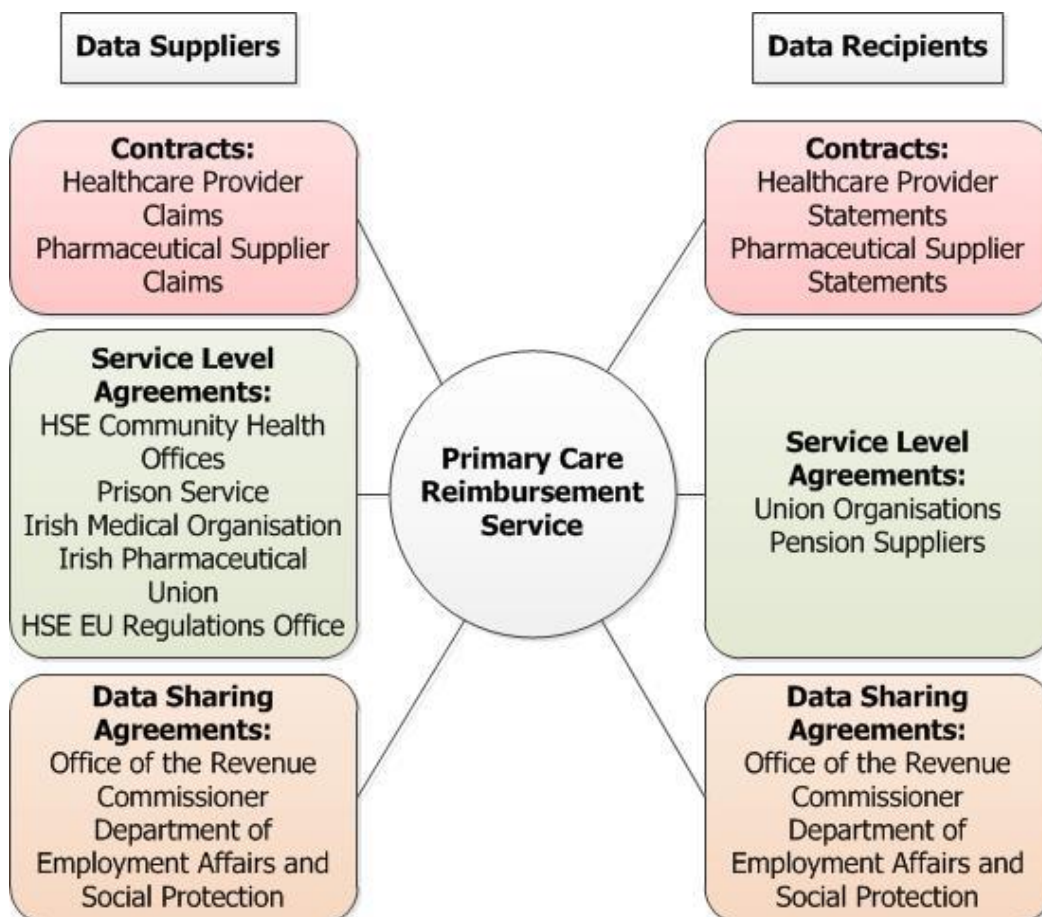
HIQA recognises that the PCRS has published its Statement of Purpose on the PCRS website. It is a comprehensive document which outlines important information in terms of overall function and purpose, aims and objectives, governance structures, funding arrangements, adherence to national legislation and contact details. It is approved by the Head of the PCRS and is reviewed by the organisation on an annual basis. A statement of purpose promotes transparency by informing the public and people who use the data about the PCRS, outlining

the objectives and purpose of the national data collection in a clear and unambiguous manner. See Appendix 3 for a Statement of Purpose template.

### 3.4.2 Data sharing agreements

The sharing of PCRS data with key agencies is important in order to facilitate the efficient and appropriate use of data across and beyond the health and social care setting. HIQA identified that the PCRS routinely shares data with the wider HSE, the Department of Health and other external organisations such as the Central Statistics Office and the Department of Public Expenditure and Reform. Improving the data flow between the PCRS and these agencies could reduce the likelihood of duplicate payments, improve service user experience and reduce delays in waiting times for those eligible for a medical card.

Robust governance structures are essential to enable the appropriate sharing of data, providing oversight, assurance and transparency for all data leaving and entering the organisation. A standardised and official approach to data sharing reduces privacy risks from occurring when sharing personal information and promotes data quality across organisations. Therefore, the use of data sharing agreements is recognised as good practice. They define a common set of rules to be adopted by organisations involved in sharing data.



**Figure 7.** Key data flows within the PCRS

PCRS provided evidence to the review team of the existence of a number of types of agreements through a data flow diagram, which is shown in Figure 7. Furthermore, it provided an example of a data exchange agreement between the PCRS NMCU and the Department of Employment Affairs and Social Protection (DEASP). This document constitutes an agreement to transfer specified data to the NMCU in accordance with the law and in a manner which satisfies security and data protection standards. HIQA was also provided with a copy of a clear data sharing agreement between the National Cancer Registry Ireland and the NMCU. This document sets out the framework for sharing data, including personal data and sensitive personal data or special category of personal data, between the parties as data controllers. It defines the principles and procedures that all parties shall adhere to and the responsibilities the parties owe to each other.

HIQA acknowledges that in many instances the PCRS have data sharing agreements in place. The PCRS should continue to endeavour that relevant data sharing agreements are in place with all key data providers and are reviewed and updated on a regular basis. Further details on data sharing agreements can be found in Appendix 4.

## **3.5 Significance of findings — Governance, leadership and management**

### **Governance structures in relation to information management**

- During the review, HIQA identified clear governance arrangements in place at an operational level in respect of the operational aspects of information management within the PCRS. The Head of the PCRS has overall accountability for the PCRS and reports directly to the HSE National Director of National Services via monthly National Services Division meetings and one-to-one meetings. There are also two senior management operational teams in place: the Reimbursement Management team and the National Medical Card Management Team.
- During the review, HIQA identified a less structured approach in terms of how information management is strategically discussed, planned and managed at an organisational level. Specific roles and responsibilities around aspects of information management lacked clarity, including the implementation of audit recommendations or how data generated by the PCRS is used effectively to improve the service. In the absence of a scheme of delegation for information management, there may be an over-reliance on the Head of the PCRS to identify and address both strategic and operational aspects of information management across the organisation. Therefore, the PCRS should consider an oversight structure similar to that of a senior executive forum to discuss the strategic approach to be taken for information management and to address information management risks, on a more regular basis.
- Given the size and remit of the PCRS, the dynamic nature of health information, including the on-going evolution of ICT in the health and social care sector, the increased risk of cyber security threats, and the changing legislative landscape (such as GDPR); PCRS would benefit from an oversight structure similar to that of a senior executive forum to determine strategy and discuss issues and risks in relation to information management, on a more regular basis.

### **Strategy and business planning**

- Currently there is no overarching strategy providing direction for the PCRS organisation as a whole. During interview, the PCRS informed HIQA that an organisation-wide strategy was being developed to cover the period 2019–2021 and would define a shared vision and understanding across the PCRS, with a focus on information management as well as the efficient centralisation of schemes. However, HIQA was unable to assess the content of this strategy as it is still in development and has not, at the time of publication of this review, been publicly shared.
- The importance of information management for PCRS has been identified in a number of key reviews of the PCRS in recent years<sup>(40, 41)</sup> and, therefore, should be a key component of this strategy. However, given the size, budget and scope of functions of the PCRS, the development of a strategy specific to information

management should be considered. This could cover aspects relating to information governance, data quality and workforce capacity, and it could outline key deliverables and indicators for the progression of strategy objectives.

- While the development of an organisation-wide strategic plan is a positive step for the PCRS, it further strengthens the need for an oversight structure similar to that of a senior executive forum to oversee its implementation and ensure issues relating to information management are being addressed in a strategic manner.

## **Risk, audit and performance management**

### **Risk management**

- HIQA identified evidence that the PCRS is effective at managing risk at an operational level. However, at an organisational level, HIQA noted that the PCRS could benefit from a more strategic review of organisation-wide or corporate risks, particularly in relation to information management risks. Some information management risks, such as those relating to information governance and compliance with GDPR, are organisation-wide issues and as such should be discussed and managed in a consistent manner across the organisation. A corporate risk register could be reviewed and tracked by an overall executive management forum, thus providing further assurances to the Head of PCRS in relation to management of information-related risks.

### **Audit**

- The PCRS undertakes a comprehensive set of internal and external audits in order to provide assurance on performance which is positive. These audits address aspects of information management, including data quality and information governance. HIQA acknowledges that the PCRS is actively working to implement recommendations made by various audits through, for example, the development of an implementation group for GDPR readiness. However, it is unsure whether or how, in the absence of an overall information management strategy, these audit recommendations are being strategically addressed in order to be implemented in the future. The organisation would benefit from a more coordinated and consolidated approach to ensure that audit recommendations are driving improvement in information management across the organisation. An information management strategy would help to provide strategic direction and focus in terms of implementing these recommendations. Additionally, such a strategy would benefit from an overall executive management forum that could drive and monitor its implementation at an organisational level.

### **Performance Management**

- While HIQA acknowledges that KPIs and metrics are in place at a number of levels internally within the PCRS, it noted that these are primarily process-based indicators. For example, the indicator relating to a 15 day turnaround for applications begins at

the point of receipt of a fully completed application and does not reflect the experience of all medical card applicants. HIQA would welcome the addition of performance metrics that have an increased focus on service user outcomes. To do so, the PCRS should consider consultation and engagement with key stakeholders, including those contracted healthcare providers and individuals using the system.

- Similarly, HIQA was informed of performance metrics generated by an external contact centre that include average call handling time, answer and escalation rate and that these are used to monitor operational aspects of the application process. Information on the number of repeat callers or the nature of their queries, which could potentially be used for improving service user experience, is not captured. In addition to information gathered through consultation with wider external stakeholders, this data should be captured and used to improve the operability of the PCRS and reduce the demand on third party users, thus improving overall service user experience.
- During the review, it was unclear to the review team how the information gathered through KPIs and metrics is strategically used to drive improvements across the organisation in respect of information management. Therefore, how the PCRS collect and use such data should be addressed as part of an overall information management strategy for the PCRS.

#### **Formalised data sharing agreements**

- The PCRS provided HIQA with data sharing and service-level agreements with key agencies such as the Office of the Revenue Commissioner and the Department of Employment Affairs and Social Protection (DEASP). The PCRS should continue to ensure that relevant data sharing agreements are in place with all key data providers and are reviewed and updated on a regular basis.



### **3.6 Recommendations – Governance, leadership and management**

| <b>Governance, leadership and management</b> |   |
|--|---|
| <b>1.</b>                                    | <p><b>Governance structures in relation to information management</b></p> <p>The Primary Care Reimbursement Service (PCRS) should enhance its current governance arrangements in respect of information management to ensure that data and information is strategically addressed across the entire organisation and in relation to all the National Health Schemes.</p> <p>This should include:</p> <ul style="list-style-type: none"> <li>▪ a review of current governance arrangements to ensure all aspects of information management are being effectively addressed across the organisation at a strategic level within the PCRS. This could include establishment of an oversight forum to discuss strategy and risk in relation to information management and to examine previous reviews and audits of the PCRS/NMCU to ensure key recommendations in relation to information management are implemented.</li> <li>▪ a detailed scheme of delegation outlining clearly delegated responsibilities for information management across the organisation.</li> </ul> |
| <b>2.</b>                                    | <p><b>Strategy for information management</b></p> <p>PCRS should develop an organisation-wide strategy for information management which clearly describes how effective information management will enhance the services provided by the PCRS.</p> <p>This should include:</p> <ul style="list-style-type: none"> <li>▪ clearly defined objectives, enablers and deliverables and associated business planning for all aspects of information management including data quality, information governance and use of information</li> <li>▪ clear implementation plans and identified individuals responsible for implementation of key aspects of the strategy</li> </ul>  |
| <b>3.</b>                                    | <p><b>Monitoring of performance in relation to information management</b></p> <p>The PCRS should enhance current performance assurance arrangements to ensure that appropriate key performance indicators (KPIs) are in place for information</p>   |

|  |   |
|--|---|
|  | management which are person-centred and outcome focused, and provide assurance that information is being effectively managed to deliver on provision of services in relation to the National Health Schemes in Ireland. |
|--|---|

## 4. Use of information

Health information is a valuable resource – wherever possible, it should be collected once and used many times – provided the appropriate protections and safeguards are in place. It is now widely recognised that the appropriate sharing and effective use of information can bring enormous benefits.<sup>(48, 49)</sup> In the healthcare sector, effectively using information is the key to driving quality improvements, leading to safer, more integrated care and greater prevention of ill health. Timely access to good quality information benefits a range of stakeholders by enabling individuals to make informed choices about their health; professionals to make better and safer decisions; managers to effectively deliver a high-quality service; policy-makers to strategically plan services; and researchers to establish best practice. In essence, there is a growing expectation that the information held by national data collections will be shared and used optimally for the benefit of the service user and public health.<sup>(48, 49)</sup>

For organisations that aim to maximise the use of information, there are two important considerations: the underlying data must be of good quality so that all stakeholders can confidently use the information to inform decisions and the data should be aligned with health information standards and nationally agreed definitions to enable comparability and support interoperability.

The PCRS collects large volumes of data from individuals who use primary care services and from GPs, pharmacists, opticians, dentists, hospitals, and other external stakeholders such as Revenue and the prison service. This data is a rich source of health information collected from primary and community care within the Irish health service. The PCRS should systematically assess the quality of its data to ensure its objectives are met. The quality of PCRS data can be determined through assessment against a number of quality dimensions — relevance; accuracy and reliability; timeliness and punctuality; coherence and comparability; and accessibility and clarity.

The data held by the PCRS is a valuable repository of health information for the public, clinicians, policy-makers and researchers, and all who may be interested in using the data to improve the quality of healthcare services being provided to people in Ireland.<sup>(50)</sup> To enable optimal use of PCRS data, the PCRS should have a strategy in place to ensure its data and information is appropriately disseminated and that its data users have access to the data and information in a timely manner to meet their needs. The HIQA review team assessed the use of information at the PCRS against Standards 5, 6 and 7 of the Standards for Information Management.

The findings on the use of information are presented in the following sections:

- Data quality
- Accessibility and dissemination of information
- Use of health information standards and terminologies.

## **4.1 Findings — Data quality**

### **4.1.1 Data quality responsibilities**

Data quality is a key component of information management, and it is essential that data is accurate, valid, reliable, timely, relevant, legible and complete. As previously mentioned, the PCRS is an extremely valuable national repository of health information, and as such it is essential that there is confidence in the quality of the data its collected and processed in relation to the national health schemes it manages. Data quality is important at every stage of the data flow pathway, which includes steps from the collection of data submitted as part of the eligibility process for GMS Scheme applications, where data entry errors could lead to the incorrect processing of an individual's application, to the reimbursement of payments provided to contracted healthcare providers – where the data is required to be accurate, valid and timely.

HIQA was informed that the Head of the PCRS has overall accountability for data quality within the PCRS. Within the NMCU, there is a dedicated focus on data quality, with a Quality Assurance (QA) Manager in place to regularly assess the quality and accuracy of data being processed. Within Reimbursement, as part of the probity function, HIQA was informed that the Business Performance Management team and inspectors may identify data quality issues in the course of their work. HIQA observed, from agendas and minutes provided by the PCRS, that aspects of data quality are discussed at both Reimbursement and NMCU senior management team meetings. In addition to this, the PCRS informed HIQA that all staff are assigned aspects of data management duties, which include maintaining, correcting, collating, interrogating, validating and processing data. It was not clear, however, how this assignment of duties is coordinated in a strategic manner across the organisation.

Quality Control is a standing item on the agenda of the weekly National Medical Card Management Team meeting. At this meeting, the QA Manager discusses the results of the weekly internal QA process in relation to GMS applications in order to monitor the accuracy of data entry. Case studies are also presented in relation to individual applications. In relation to the Reimbursement Management Team, Quality and Risk is a standing item on the agenda of the fortnightly meeting. HIQA was informed in interview that data quality issues in relation to the accuracy of healthcare provider claims are raised at this meeting. There was, however, no detail provided in the minutes supplied to HIQA in relation to this.

Given the importance of good quality data for both the PCRS and its wider stakeholders and the size and complexity of the system, it would be envisaged that a strategy and framework for data quality is in place or, at minimum, addressed within an overall information management strategy. It should outline how the organisation is going to address data quality through the lens of the five dimensions of data and information quality, that is, relevance, accessibility and clarity, coherence and comparability, timeliness and punctuality, and accuracy and reliability.<sup>(17)</sup> Such a strategy would benefit from an overarching forum to guide and oversee its implementation thus providing further assurances to the Head of PCRS that the quality of the data collected and processed is to the highest possible standard.

#### **4.1.2 Data quality arrangements**

HIQA identified examples of data quality initiatives and activities underway within the organisation. In relation to policies and procedures, HIQA was provided with evidence of data processing standard operating procedures (SOPs) in place within individual units of the organisation.

As noted in Section 4.1.1., there is a dedicated emphasis on data quality and quality assurance within the NMCU function of the PCRS. The QA Manager is responsible for the quality assurance programme for applications logged and processed within the NMCU. This involves random sampling of 5–10% of all applications processed by the unit. A standard template is used to assess the quality of the application from an accuracy perspective. Aspects such as inaccurate entry of a person's dependent details, income details, and discretionary details are scored using this QA check system. Approximately 1,000 quality checks are conducted on a weekly basis. It was noted in interview that a 25% reduction in QA scoring, where key information was incorrectly entered, may impact on the assessment of eligibility for that individual. An internal KPI of 90% accuracy for quality checks on NMCU applications is in place. There is also a 95% KPI for medical card/GP visit card applications accurately processed from a financial perspective by NMCU. The findings of this QA assessment are reported to the NMCU at the weekly senior management team meeting. HIQA acknowledge the approach of learning from individual case studies as an important quality improvement step. However, in the absence of an overall information management strategy for the PCRS, it was unclear how these learnings are addressed in a strategic way across the organisation.

Within the Reimbursement Unit, the emphasis on data quality is directed at the point of entry for electronic claims. Members of the Reimbursement Unit review the quality of the claims received by verifying their accuracy and reasonableness. If an issue is identified in relation to data quality, it can be referred to the Business Performance Management (BPM) unit for review or to the Inspectorate Unit for investigation. Monthly reviews in relation to a sample of reimbursement claims are routinely checked. Individual cases are referred to the Probity Governance Group in respect to probity cases concerning individual healthcare providers that are suspected of submitting invalid claims or where specific concerns arise. HIQA was informed that the Reimbursement Unit is also audited by the Comptroller and Auditor General on an annual basis.

In 2018, the PCRS developed a data quality framework, which is a positive development. This framework outlines the overall approach that the organisation is taking in relation to developing data quality policies and procedures, KPIs, data quality audits and data quality improvement initiatives. In relation to data quality policies and procedures, the review team was informed that all PCRS units have data processing SOPs in place which must be adhered to by all staff. HIQA also noted that the PCRS has published handbooks for each contracted healthcare provider group which explain how each should submit paper-based claims to the PCRS. However, these handbooks are not regularly updated and some do not include

guidance on how to submit claims electronically. For example, the GP handbook was last updated in 2006.<sup>(51)\*\*</sup>

In the absence of a data quality strategy and a fully implemented data quality framework that address all dimensions of data quality, the current approach to addressing data quality issues is somewhat disjointed across the organisation. While HIQA acknowledges the work the PCRS has done to date in developing and implementing components of a data quality framework, a strategic approach to addressing all dimensions of data quality could further enhance and build the quality function within the PCRS. To progress and enhance the data quality framework, the PCRS should consider developing the previously mentioned overarching data quality strategy, as outlined in HIQA's recently published data quality framework guidance.<sup>(17)</sup> The strategy should include a coordinated approach to data quality throughout the data flow pathway for all the national community health schemes administered by the PCRS. The strategy should address aspects of data quality in relation to the processing and storage of paper-based applications in the NMCU and paper-based claims in the reimbursement function.

#### **4.1.3 Training and education**

HIQA was informed that the PCRS has a quality assurance training programme for staff members. In interview, HIQA was informed that the PCRS provides structured training to all staff, facilitated by its Training Officer. This includes a four-week induction programme for new staff, followed by a supervised shadowing period where the quality of their work is extensively reviewed.

In the NMCU, the QA Manager is responsible for staff training. The work of new staff undergoes a 100% QA check until it reaches a required quality level that is a 90% quality assurance result to pass the probation phase. Specific training is also provided to staff moving to a supervisory role within the PCRS. In addition to structured training, supervisors also conduct QA checks on the work of data processors working in their function. The results of these checks are fed back to the quality assurance section in the PCRS and inform staff training needs.

The PCRS further informed HIQA that in the Reimbursement Unit, data quality training and guidance are provided to contracted healthcare providers through handbooks, circulars, and onsite training. However, during the review, the need for more data quality training and guidance initiatives was identified based on evidence gathered from a sample of contracted healthcare providers. Therefore, it is important that the PCRS consider engaging with contracted healthcare providers and develop additional training as required. This would ensure that these healthcare providers have the skills and knowledge required to submit valid and accurate claims to the PCRS in a timely manner.

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\*\*At the time of the review, GP and Pharmacists handbooks were being updated and at an advanced stage of development.

#### **4.1.4 Stakeholder engagement**

HIQA acknowledges the work the PCRS has undertaken to engage with key stakeholders to inform changes aimed at improving data quality. For example, the PCRS has created a live link with the Department of Employment Affairs and Social Protection (DEASP) to improve information management and data entry for the NMCU's GMS application process.

In relation to engagement with the contracted healthcare providers that administer the national community health schemes, HIQA was informed that the Head of the PCRS meets with various external stakeholders, including the Irish Medical Organisation (IMO), the Irish Pharmaceutical Union (IPU) and Community Healthcare Organisations (CHO) senior officers at the CHO/PCRS Forum. These meetings provide an ideal opportunity for the PCRS to discuss and address data quality issues with those stakeholders who provide large volumes of data to the PCRS, at a strategic level.

In addition to these meetings, HIQA is aware of other methods used to provide support to contracted healthcare providers, such as circulars, videos and contractor suites. HIQA was informed, however, through additional evidence gathered from a sample of contracted healthcare providers, that some felt their level of engagement with the PCRS was insufficient. It was suggested that more two-way communication with them and their patients in relation to changes being made to the national healthcare schemes was required. This further strengthens the need for the PCRS to work in collaboration with all contracted healthcare providers to develop initiatives to improve the quality of data the PCRS receives from these key stakeholders and the quality of data the PCRS sends to them.

#### **4.1.5 Information and communication technology (ICT) resources**

Through document request and interview, HIQA noted a number of ways the PCRS are using their ICT infrastructure to manage, improve and assure data quality. HIQA noted that the PCRS use information technology to support data quality initiatives such as leveraging online functionality to mitigate risk in data entry. They also use data analytics to report and present data, to highlight data anomalies in probity reporting and reimbursement payments, to validate data received by the PCRS at the point of entry and to identify data quality issues. For example, the NMCU has an inbuilt validation check on the PCRS database which validates an applicant's information with the DEASP's database. The PCRS has also started to use ICT to improve the GMS application process, and make it more timely, by sending text messages to GMS applicants to ask them to send additional documents to support their GMS application if required.

During the review, HIQA was informed of a number of ICT resources that are available to support the production of high-quality reimbursement data. For example, in the reimbursement function, the Oracle Discoverer has a daily dashboard which generates activity statistics for the system. It shows the number of claims, items processed and payments issued by the PCRS to contractors. This information is automatically collated into

daily progress reports that are sent to specific PCRS staff that analyse the data. As outlined in Chapter 2, each contracted healthcare provider group has a dedicated application suite which allows them to submit claims electronically to the PCRS. In each suite there is a facility that allows contractors to validate their claims before they are submitted to the PCRS and check the status of any claim. HIQA was informed that the purpose of these facilities is to reduce the number of queries the PCRS receives from contracted healthcare providers in relation to the processing status of their claims.

## 4.2 Findings — Accessibility and dissemination of data

The use of routinely collected healthcare data to generate evidence requires first, that reliable and accurate quality data are collected, and second, that they are made accessible to those who conduct research or make decisions in a timely manner.<sup>(7)</sup> The data held by the PCRS is used by the HSE and Department of Health to inform the provision, management, performance assessment, planning and funding of primary care services in Ireland. It is also used by the general public, the media, healthcare professionals and their representative organisations, national and international academic researchers as well as other national data collections such as the Central Statistics Office and the National Cancer Registry Ireland. Some users of data generated by the PCRS are outlined in Figure 8.



**Figure 8.** Examples of users of PCRS data



HIQA acknowledges that the PCRS disseminate data through a variety of methods to ensure that information is accessible to a wide range of stakeholders. For example, the PCRS publish annual reports of payments and claims along with summary data on the range of primary care services supported by the PCRS, and these are available for download on its website.<sup>(23)</sup> HIQA was also informed of other methods used by the PCRS to promote and disseminate their data, including circulars, letters, information leaflets and conference presentations.

While this is positive, evidence suggests that the data generated by the PCRS may not be maximised or used to their full potential. In 2019, the Organisation for Economic Co-operation and Development (OECD) published an overview report of patient-level data on medicines routinely collected in health systems across 26 OECD and EU member countries from sources including the PCRS in Ireland. Findings suggest that while this routine data is collected, they are not optimally used to inform pharmaceutical policies or assess the performance of medicines in clinical practice.<sup>(7)</sup>

#### **4.2.1 Publicly available data from the PCRS**

On the PCRS website, the PCRS Publications area is dedicated to disseminating a variety of PCRS reports on medical card eligibility and reimbursements.<sup>(23)</sup> Website visitors have access to these reports as well as summary statistical data on the range of primary care services supported by the PCRS. Such data includes:

- monthly reports on GP expenditure and claims by community health organisation
- monthly reports on optical expenditure at national and local health office level
- routine pharmacy reports detailing claiming patterns, claims rates and payments by scheme and product dispensed
- reports on payments to wholesalers of high-tech drugs by month
- expenditure reports for the Dental Treatment Service Scheme by age group and cost for medical card holders over 16 years.<sup>(52)</sup>

HIQA acknowledges that this data is also available on Ireland's Open Data Portal,<sup>(53)</sup> and the PCRS provide web-based tools to enable data analysis.

The PCRS informed HIQA that Google analytics is one method used by the PCRS to monitor and ensure the needs of its data users are being met. However, through additional evidence gathering, HIQA was informed that some healthcare providers require access to more granular level data, for example, prescribing trends, to inform patient treatment. This already takes place in other jurisdictions, such as Northern Ireland and the UK.<sup>(54)</sup> HIQA was informed that the PCRS is currently engaging with the Royal College of Surgeons in Ireland (RCSI) to develop and provide access to such granular data. While this is a positive development that aligns with other jurisdictions, it has not yet been implemented, and, therefore, HIQA are unable to review such progress.

## **4.2.2 Formal data requests**

Like other organisations, the PCRS receives information requests through parliamentary questions and Freedom of Information requests. The review team were informed that performance indicators are in place to ensure that these data requests are responded to in a timely manner and are subject to formal monitoring. In addition to these formal data requests, the PCRS is also asked for data from other stakeholders, including the media, academia or healthcare providers. The review team were informed that these requests are submitted through a dedicated email that is managed by the PCRS Analysis and Reporting Unit.<sup>(23)</sup> While HIQA acknowledges that this service is available, it is unclear how these emails are managed or whether there are performance indicators in place for responding to such requests. Furthermore, HIQA noted that the PCRS did not have a clear and transparent policy outlining the terms and conditions for these requests even though such policies are in place in similar organizations.<sup>(55)</sup> Therefore, the review team was unable to identify the type and volume of information required by the PCRS to process these ad hoc data requests.

## **4.3 Findings — Use of health information standards and terminologies**

HIQA reviewed practices at the PCRS to assess the use of health information standards and nationally agreed definitions to enable comparability and sharing of information. The PCRS informed HIQA that they use a number of messaging and other related standards where they are available and applicable. For example, the PCRS uses the Health Level 7 standard for the transfer of clinical and administrative data between software applications used by various healthcare providers. The PCRS also use the Anatomical Therapeutic Chemical Classification System for the classification of active ingredients of all drugs and medicines provided to individuals through the national community health schemes.

### **4.3.1 Data dictionary**

Through a document request, the PCRS provided HIQA with a sample of their data dictionary, which included a partial overview of 1,500 data structures in operation on the PCRS database. While an internal database structures document is in place within the PCRS, describing the details of the complex relational database management system, the organisation does not currently publish a data dictionary, which may prevent lack of consistency in interpretation of the data held by the PCRS. The PCRS should consider publication of components of a data dictionary to ensure consistency and to enable accurate use and interpretation of data and information produced by the PCRS. The PCRS should continue to engage with the Office of the CIO in the HSE to ensure this work is aligned to the on-going development of the HSE National Data Dictionary.

## 4.4 Significance of findings — Use of Information

### Data quality

- The Irish healthcare system increasingly depends on data to improve care, reduce costs, and expand access. Currently, in the absence of e-prescribing, the PCRS is the richest source of national prescription data and the largest data source for measuring drug exposure in specific populations in Ireland.<sup>(6)</sup> As a result, the data collected, processed and held within the PCRS is used for many important purposes, such as guiding clinical decision-making, monitoring diseases, organising services, informing policy making, conducting research and planning for future health and social care needs, both at a national and local level. Therefore, it is imperative that this data is of the highest possible quality.
- In reviewing data quality practices, HIQA recognise an overall awareness of data quality within the PCRS and acknowledge the work being carried out to improve the quality of the data collected, generated and disseminated. Several positive initiatives in relation to data quality have been undertaken, for example, the development of a data quality framework and ICT resources for data quality as well as a plan to provide access to more granular data in the future. However, this work would benefit from a more strategic and consolidated approach to data quality.
- Given the importance of high-quality data for both the PCRS and wider stakeholder groups and the size and complexity of the system, the PCRS should develop an organisation-wide approach for strategically addressing aspects of data quality, including stakeholder training and dissemination plans. Furthermore, it would be envisaged that a strategy for data quality is in place or, at minimum, addressed within an overall information management strategy. It should outline how the organisation is going to address data quality through the lens of the five dimensions of data quality, that is, relevance, accessibility, coherence, timeliness and accuracy,<sup>(17)</sup> and provide a strategic roadmap in relation to how the organisation will manage and continuously improve the quality of its data. As part of this, the PCRS should ensure that responsibilities for data quality at every level within the organisation are clearly defined. Such a strategy would benefit from an overarching forum (as previously mentioned under Governance, Leadership and Management) to guide and oversee its implementation, thus providing further assurances to the Head of the PCRS in relation to the quality of PCRS data.
- High-quality data is contingent on staff with a wide range of skills in data entry, processing and cleaning, and archiving. In the absence of such, data quality may be compromised. The PCRS also relies on contracted healthcare providers to accurately input data onto the PCRS system in a timely manner. HIQA recognises the emphasis on training for PCRS staff in relation to aspects of data quality, particularly within the

NMCU function. In contrast, however, it was found that contracted healthcare providers may require additional support. Efforts should be made by the PCRS to engage further with healthcare providers to identify their needs in relation to the quality of data they submit to the PCRS. It is important that the PCRS continues to work in collaboration with all its data providers to develop initiatives to improve the quality of data collected and produced by the organisation.

### **Accessibility and dissemination of data**

- As already mentioned, the data held by the PCRS is an extremely rich source of information used by many key stakeholders within the Irish health system, including the HSE and Department of Health. HIQA recognises that the PCRS currently disseminates its data through a number of methods to ensure that information is accessible to a wide range of stakeholders. The potential of routine data sources, such as the PCRS, to be maximised to provide key information relating to pharmaceutical policies or prescribing patterns was highlighted in a recent OECD report.<sup>(7)</sup>
- HIQA noted that the dissemination and use of the PCRS data could be improved and enhanced further through, for example, the publication of more granular level prescription data as is done in other jurisdictions such as Northern Ireland and the UK.<sup>(54)</sup> Such data could be used to explore trends in prescribing to help indicate the factors for growth in volume and cost of prescribing in Ireland.
- As part of an overall information management strategy, an accessibility and dissemination plan, which includes the steps for easily accessing such data, would help to ensure that PCRS data could be used to its full potential and meet the needs of a wide range of data users.

### **Compliance with health information standards**

#### **Data dictionary**

- While an internal database structures document is in place within the PCRS, describing the details of the complex relational database management system, the organisation does not currently publish a data dictionary, which may prevent consistency in interpretation of the data held by the PCRS. The PCRS should consider publication of components of a data dictionary to ensure consistency and to enable accurate use and interpretation of data and information produced by the PCRS. The PCRS should continue to engage with the Office of the CIO in the HSE to ensure this work is aligned to the on-going development of the HSE National Data Dictionary.

## 4.5 Recommendations – Use of information

| <b>Use of information</b> |   |
|---------------------------|---|
| <b>4.</b>                 | <b>Data quality framework</b>   |
|                           | <p>To enhance ongoing work within the PCRS in relation to data quality, an enhanced Data Quality Framework, to include a data quality strategy, should be developed and implemented for the PCRS to ensure an organisation-wide approach to data quality is in place. As part of this,</p> <ul style="list-style-type: none"> <li>▪ an individual with overall responsibility for data quality within the PCRS should be assigned</li> <li>▪ responsibilities for data quality at every level within the organisation should be clearly defined.</li> </ul> |
| <b>5.</b>                 | <b>Data dictionary</b>  |
|                           | <p>Components of a data dictionary should be made publicly available to ensure consistency and to enable accurate use and interpretation of data and information from the PCRS. This should be aligned to plans for the HSE National Data Dictionary.</p>   |
| <b>6.</b>                 | <b>Accessibility and dissemination of information</b>   |
|                           | <p>In line with legislation and government policy, the PCRS should make data and information more accessible in a timely manner to all stakeholders, including patients, clinicians, policy makers and researchers in order to address their needs. This should be developed as part of an overall strategy for information management.</p>   |

## 5. Information governance

National data collections, such as the Primary Care Reimbursement Service (PCRS), are repositories for large volumes of sensitive and important health information. Health information is considered to be the most sensitive form of information and, therefore, extra precautions need to be taken to protect privacy. The process of collecting, using, storing and disclosing personal health information can present a risk to the privacy and confidentiality of service users. National data collections have an obligation, under legislation, to protect personal health information. Information governance provides a means of bringing together all the relevant legislation, guidance and evidence-based practice that apply to the handling of information.

Robust information governance arrangements focus on the following areas: the maintenance of privacy and confidentiality of individuals; the protection of information security; the generation of high-quality data; and the implementation of appropriate safeguards for the secondary use of information. In Chapter 4, the use of information and the generation of high-quality data will be discussed in detail due to the significance of enhancing the appropriate use of good-quality data for a wide range of stakeholders. However, data quality will be further considered in this chapter in the context of developing good information governance practices.<sup>(56, 57)</sup>

Good information governance enables personal health information to be handled legally, securely, efficiently and effectively in order to deliver the best possible service. The main aim of information governance is to create a balance between effectively using information and meeting the needs of the service user while also respecting an individual's privacy. To develop good information governance practices, it is necessary for an organisation to have the structures and processes in place to provide clear direction to staff:

- Responsibility and accountability for information governance must be clearly defined, and the appropriate governance and management structures should be outlined. These arrangements should align to, and integrate with, the organisation's overall governance structure. Formalised arrangements are essential to ensure that there are clear lines of accountability for information governance. All staff should be aware of their responsibilities for information governance, and management should assign specific tasks to named staff members.
- A culture of information governance is embedded within the organisation through the development of policies and procedures to help all staff comply with legislation and information governance requirements as well as identifying training requirements on a routine basis. Employees should be promoted and supported by management to engage in good information governance practices as part of their routine working schedule.
- Organisations need to perform information governance assessments to identify good practice and to highlight areas that need improvements. Self-assessments — in the form of internal and external audits, monitoring of key performance indicators (KPIs)

and assessing risk — are necessary to examine compliance with policies and procedures, to identify specific training needs of employees and to ultimately identify and implement improvements to information governance practices based on the findings.

The HIQA review team assessed the information governance and person-centred arrangements at the PCRS against standard 8 of the Information Management Standards.

The findings will be presented in the following sections:

- Information governance structures in the PCRS
- Effective arrangements to assess and manage information governance.

## **5.1 Findings — Information governance structures in the PCRS**

### **5.1.1 Information governance responsibilities within the PCRS**

HIQA was informed that the Head of the PCRS has overall accountability for information governance within the organisation. The PCRS informed HIQA that information governance is a responsibility which is delivered at an operational level within the organisation, with all staff having responsibility. During the review, however, HIQA identified a lack of clarity in relation to the scheme of delegation for information governance within the PCRS. This resulted in a level of uncertainty around particular roles and responsibilities specific to information governance across the organisation and how assurance in relation to information governance practices is provided to the Head of the PCRS.

HIQA was informed that the Head of ICT has specific responsibility for the information security aspects of information governance. HIQA was further informed that the PCRS has a Data Protection Advisor in place who deals with queries in relation to data protection issues and is responsible for escalating these issues, including data breaches, to the HSE Data Protection Officer (DPO). This Data Protection Advisor reports to the General Manager within the Customer Relations Unit who has lead responsibility for data protection, Freedom of Information (FOI), parliamentary questions, representation management and liaison with statutory bodies, for example, the Ombudsman.

A recent audit relating to compliance with the General Data Protection Regulation (GDPR) requirements recommended that the PCRS appoint a dedicated DPO, who would be assisted by data protection champion roles. HIQA was informed that the appointment of a dedicated DPO is being considered in the context of the PCRS organisational structural review to ensure that internal procedures are in place to address data protection issues as they arise. In the meantime, given the size and remit of the organisation, the PCRS should ensure that the role of the current Data Protection Advisor is aligned to the requirements of the role of a

DPO. Furthermore, while the PCRS noted that managers and supervisory staff are considered data protection champions for their respective areas of work, HIQA did not find evidence that data protection champion roles were formally assigned within the PCRS.

A number of internal groups are in place within the PCRS which address various aspects of information governance. For example, an internal Security and Data Protection Governance group meets on a quarterly basis and is chaired by the Head of ICT. Representatives from the two core functions of the PCRS, the Reimbursement Unit and the NMCU, attend. HIQA was further informed that a Cross Functional Working Group for Data Breaches is also in place since 2016. Details of these groups are outlined in Table 9. Although HIQA was provided with agendas and minutes, which indicate that aspects of information governance are discussed at a number of these meetings, HIQA did not find evidence of an overarching forum which routinely brings together all senior executives to discuss high-level information governance issues which are likely to be common across the organisation.

**Table 9** Security and Data Protection governance group / Cross Functional Working Group for Data Breaches

| Name   | Chair                                      | Purpose  | Frequency of meetings |
|--|--|--|-----------------------|
| Security and Data Protection meeting             | Director of Information Systems / ICT Unit | The meeting will deal with the following set of items: <ol style="list-style-type: none"> <li>1. Review the monthly security reports published in the period and ensure that all items arising are making progress to resolution.</li> <li>2. Review available IT audit reports and ensure that all items arising are making progress to resolution. Example reports include;                             <ol style="list-style-type: none"> <li>a. The National Schemes Viewer usage report</li> <li>b. Anomaly Email Usage report</li> <li>c. Anomaly Logon report.</li> </ol> </li> <li>3. Review the PCRS user base by system and resolve any issues arising. User bases include                             <ol style="list-style-type: none"> <li>a. remote access users</li> <li>b. email users</li> <li>c. National Schemes Viewer users</li> <li>d. PCRS Systems Users</li> <li>e. CHO Users of PCRS Systems</li> </ol> </li> <li>4. Review the status of the PCRS Annual Data Protection Certification process.</li> </ol> | Quarterly             |
| Cross Functional Working Group for Data Breaches | Data Protection Advisor                    | The purpose of the Cross Functional Working Group is to: <ol style="list-style-type: none"> <li>1. Establish and review the factual circumstances leading to the incident of data breaches</li> <li>2. Identify any key causal factors that may have occurred</li> <li>3. Identify the contributory factors that caused the key causal factors</li> </ol>  | Weekly                |



|  |  |  |  |
|--|--|--|--|
|  |  | <ol style="list-style-type: none"> <li>4. Recommend actions that will address the contributory factors so that the risk of future breaches arising from these factors is eliminated, or if this is impossible, is reduced as far as is reasonably practicable</li> <li>5. Analyse other relevant complaints or queries received from our customers that alert us to a system or business concern which could lead to an incident arising. In this regard, the group will establish if sufficient controls exist to mitigate against such an incident occurring.</li> </ol> |  |
|--|--|--|--|

In terms of risk management, currently all risks, including those relating to information governance with a particular focus on ICT, are formally discussed at the biannual Risk Committee meetings. Other aspects of information governance are discussed on an ad-hoc basis at the individual senior management team meetings of the Reimbursement Unit and NMCU. However, information governance is not a standing item on the agendas of these senior management team meetings and is not discussed in a strategic manner at this level.

HIQA noted that compliance with GDPR legislation, which is a potential information governance risk, is not currently noted as an overarching risk for the organisation. This is surprising given the size and complexity of the organisation and the volume and nature of the personal information it processes. HIQA identified further risks in relation to information governance which are not noted on the risk registers provided to the review team. HIQA was informed of one such example at interview, whereby contracted healthcare providers, through an informal agreement, use pharmaceutical suppliers to deliver claim forms to the PCRS on a monthly basis. Although the PCRS reported that the number of healthcare providers submitting paperwork in this manner is small, the information governance risks associated with such practices can be significant and increases the opportunity for a breach to occur. HIQA acknowledges that any information governance issues that arise as a result of the current arrangements regarding how healthcare providers submit claim forms to the PCRS are the responsibility of the healthcare provider and not the PCRS, in line with current legislation. However, as the PCRS require this information from contracted healthcare providers, the means by which this information is submitted to the PCRS should be considered as part of an overall information management strategy.

The current arrangements for information governance, as outlined above, may result in a disjointed approach to how information governance is managed across the PCRS. In the absence of a scheme of delegation defining key roles and responsibilities, there may be an over-reliance on the Head of the PCRS to address information governance issues across the organisation. In order to provide assurance to the Head of the PCRS, it would be expected that organisation-wide information governance-related risks are discussed in a more strategic manner and on a more regular basis and that there is a clear scheme of delegation in relation to information governance across the organisation.

## 5.2 Findings – Effective arrangements to assess and manage information governance

HIQA reviewed the arrangements within the PCRS which are used to assess and manage information governance. Through interview and document request, the review team identified that there is an awareness of the importance of information governance within the organisation, with many policies and procedures in place to support information governance practices. However, the PCRS does not currently have an overall information governance framework in place, which would support the organisation by providing guidance on an approach and outline its responsibilities in relation to information governance.<sup>(58, 59)</sup>

### 5.2.1 Legislation, policies and procedures

With respect to demonstrating compliance with relevant legislation, the PCRS identified that there are key pieces of legislation governing the PCRS. These include the Health Act and Health Amendments Acts 1947–2017, the Data Protection Acts and Amendments 1988–2018, the ePrivacy Regulation 2011 and the General Data Protection Regulation 2018. PCRS provided a comprehensive list of all legislation relating to work carried out by the organisation, which is included in Appendix 4.

In order to ensure the privacy and security of their information, organisations must have robust policies and procedures in place. The PCRS handles a significant volume of personal information every day, and, therefore, there is a need for the organisation to ensure that internal policies and procedures are up to date and accessible. The PCRS provided a list of codes of practice, policies and procedures that it adheres to in relation to information governance. Within this list, the PCRS makes reference to a more complete list which is maintained on the HSE’s intranet. These codes of practice, policies and procedures are detailed in Table 10.

**Table 10.** Information governance codes of practice, policies and procedures

| <b>HSE ICT codes of practice, policies and procedures</b>  |
|--|
| HSE policy documents in relation to information security, computer systems, data management etc. including the following list of policies. |
| HSE Information Technology Acceptable Use Policy.  |
| HSE Electronic Communications Policy.  |
| HSE Password Standards Policy.   |
| HSE Encryption Policy.   |
| HSE Access Control Policy.   |
| HSE Remote Access Policy.  |
| HSE Mobile Phone Device Policy.  |
| HSE Data Classification & Handling Policy.   |
| HSE Data Protection Breach Management Policy.  |
| HSE Internet Content Filter Standard.  |
| HSE Service Provider Confidentiality Agreement.  |
| HSE Third Party Network Access Agreement.  |
| HSE Risk Management Policy and Procedures  |

## HSE Annual Controls Assurance Process

Included in the list provided to HIQA's review team were policies which have been developed specifically for the PCRS:

- Information Classification Handling and Data Retention Policy 2016
- Primary Care Reimbursement Service Remote Access Policy
- Policy on Record Retention National Medical Card Unit 2018.

These policies provide greater clarity for PCRS staff in relation to how the organisation addresses information governance internally; however, as previously mentioned, where a lack of clarity exists in relation to roles and responsibilities specific to information governance, it may be difficult for the Head of the PCRS to be assured that policies and procedures are being effectively implemented.

Furthermore, HIQA noted that, in some instances where policies are available, the policies only relate to one function of the PCRS rather than the organisation as a whole. For example, the PCRS provided HIQA with a copy of a policy on record retention for the NMCU, which focuses on data retention practices within the NMCU only. While the review team acknowledges that the PCRS operates under the HSE policy in relation to the handling and retention of hard copy documents, the development of an up-to-date data retention policy which reflects the storage and retention requirements of all data handled by the PCRS would be beneficial at an organisation level.

In relation to the management of data breaches, HIQA was informed that the PCRS also adheres to the HSE Data Breach Process Guidance, which provides guidance on the process that must take place should an incident or breach occur. The assessment of whether or not this guidance has been effectively implemented was beyond the scope of this review.

With respect to the HSE Access Control Policy, HIQA was made aware that the PCRS operates role-based access to the PCRS systems. Only those who require access to personal information to fulfil the duties of their role are granted access to such information. Furthermore, some roles may have read-only access. HIQA recognises as good information governance practice the conduct of audits of access to the PCRS systems by the ICT team, which ensure, for example, that when a staff member leaves the PCRS, they are removed from the system so that they can no longer gain access to any information held within the PCRS.

Finally, in relation to reviewing compliance with relevant legislation and policies in the area of information governance, the review team did not find evidence of key performance indicators (KPIs)/metrics in place. Such KPIs are essential in reporting and providing assurance to senior management in relation to information governance practices across the organisation. Therefore, the development of KPIs/metrics should be considered in line with

the development of an information management strategy which clearly addresses information governance risks.

### **5.2.2 Information governance practices**

The review team acknowledges that during 2018 the PCRS published a Privacy Statement outlining the procedure for data subject access requests. This document is publicly available on the PCRS website.<sup>(19)</sup> This Privacy Statement promotes transparency and supports the PCRS in complying with requirements under GDPR. The PCRS informed the review team that the PCRS Privacy Statement is now being incorporated in all paper application forms as new batches are produced and also on selected correspondence to clients.

HIQA identified areas in relation to privacy risk assessment which would further enhance privacy controls and mitigate potential information governance risk to persons engaging with the PCRS. The PCRS informed the review team that a number of audits and assessments have been completed which together have served as privacy impact assessments (PIAs) since they measured the performance of the PCRS regarding the provisions of the data protection legislation and subsequent safeguards in place to protect data subject's privacy. The review team recognise the completion of two data protection impact assessments (DPIAs) relating to the GMS Scheme and acknowledge that a number of other DPIAs are currently being conducted. A previous external review recommended that the PCRS embed DPIAs in IT projects. The PCRS highlighted that a DPIA template has now been adopted by the HSE and is being applied to all new projects. At the time of the review, the PCRS had not completed PIA for all national health schemes under their remit. Given the nature of the information being collected, the PCRS should consider conducting PIAs for all aspects of its work.

The current structure of the PCRS involves the handling of significant volumes of paper within the system. Currently, the PCRS estimates that the NMCU receives in the region of 15,000 physical documents each week. This number is substantially higher for the Reimbursement Unit, which handles two million claims every month with paper copies to verify these claims.

During the review, HIQA identified a number of potential information governance risks associated with the level of paper within the system and acknowledge that the PCRS recognises these risks. HIQA further acknowledges that due to the nature of the PCRS business activities, the requirement for paper within the system will remain, for example, paper-based forms are required by the Comptroller and Auditor General for audit purposes. Furthermore, a large volume of personal information is submitted to the PCRS by post from individuals applying for schemes. Submitting information in this manner, rather than by electronic means, increases the opportunity for a breach to occur. In light of this, consideration should be given to the development of a detailed information management strategy, which clearly sets out a plan to reduce, as much as possible, the volume of physical paper within the system. HIQA acknowledges the efforts of the PCRS to date, including the transfer of the GMS and drug payment

schemes to online systems and future plans to move the Long-Term Illness scheme to an online system.

Additional evidence, gathered from a sample of contracted healthcare providers during the review, highlighted examples where information sent by them, at the request of the PCRS, was mislaid. Such examples include physical copies of prescriptions required by the PCRS for claim validation purposes under the GMS Scheme and information in relation to staff providing services under various schemes, including new starters, study leave, annual leave and P60 forms. This poses a risk to the privacy and security of personal information and results in individuals and contracted healthcare providers having to resubmit the same information a number of times. As is best practice, where the PCRS are made aware by a contracted healthcare provider or service user that information has been mislaid or is missing, the PCRS should maintain a record of such instances. As outlined in Chapter 3, in the absence of a formal strategy to address information management, which includes detail in relation to the communication of information between the PCRS and healthcare providers, it may be difficult for the PCRS to address such issues.<sup>(60)</sup>

During the review, HIQA identified that the PCRS recognises the importance of information security within the organisation. The risk register includes details of a number of risks in relation to aspects of information security. Of note is recognition of risks relating to unauthorised access to the PCRS systems as a result of hacking and risk of failure to maintain a robust disaster recovery/business continuity plan. HIQA acknowledges that the PCRS has a number of IT security controls in place and have performed third-party security reviews and audits. The PCRS inability to implement various IT controls onto contracted healthcare providers' software due to the PCRS not being the direct customer of the software supplier was also acknowledged as part of this review. HIQA recognises the security measures that the PCRS have put in place to minimise information governance risks.

### **5.2.3 Training**

HIQA was informed through interview that training is provided to staff in relation to information governance at various stages throughout their term of employment with the PCRS. All staff receive data protection training and are issued with policies in relation to data protection during induction. All staff members also receive refresher training on all HSE policies on an annual basis and any changes or amendments to policies are communicated to all staff on an ongoing basis. Formal training, conducted by the HSE Consumer Affairs Unit, is mandatory every two years and covers data protection, Freedom of Information and the complaints procedure. The Customer Relationship Management Unit within the PCRS has facilitated four data protection briefing sessions to date in 2018. This training incorporates examples of specific incidents which have occurred in relation to data protection. Training is certified annually by managers for staff within their teams.

#### **5.2.4 Third-party arrangements**

In relation to the information governance responsibilities of contracted healthcare providers, HIQA was informed that, in preparation for the introduction of GDPR, the PCRS issued a circular to contracted healthcare providers outlining the PCRS and healthcare provider obligations in relation to the role of data controller and data processor. The circular details that patient records that are created and maintained by a healthcare provider do not fall within the remit of the PCRS. Therefore, for such records, the primary care contractor is the Data Controller. The PCRS considers this circular and the national health scheme contracts in combination to be sufficient data processor agreements. Best practice would be to ensure that future contract arrangements include details in relation to the clarification of roles and responsibilities of data controllers and data processors in order to ensure the privacy and security of personal information.

## **5.3 Significance of findings – Information governance**

### **Information governance arrangements**

- HIQA found that while there was an overall awareness of the significance and importance of information governance within the PCRS, the organisation would benefit from an enhanced and more consolidated approach to managing information governance.
- It was noted that the Head of the PCRS has overall accountability for information governance and identified individuals have responsibilities for some aspects of information governance, such as ICT security. However, the governance arrangements, including reporting structures in relation to information governance, should be enhanced for all teams across the organisation to ensure that information governance-related risks are identified, reported and managed appropriately within the PCRS. In addition, delegation of specific responsibilities in relation to all aspects of information governance, including privacy and confidentiality, data quality, and use of information, should be enhanced through a clearly defined scheme of delegation.
- In relation to current governance arrangements, aspects of information governance are addressed, on an ad-hoc basis, at the two individual senior management meetings, chaired by the Head of the PCRS. A Security and Data Protection Governance Group is in place and meets quarterly, chaired by the Director of ICT Unit. Furthermore, information governance risks are formally discussed at the Risk Committee, which meets bi-annually. This current approach to managing information governance is somewhat disjointed, and the PCRS would benefit from an organisation-wide strategic focus, with key aspects of information governance being addressed as part of an overall organisation-wide information management strategy.
- In relation to compliance with GDPR, HIQA noted that the roles of data controller and data processor have been clarified in a circular issued by the PCRS to contracted healthcare providers, detailing the obligations of PCRS and healthcare providers in this regard. Future contractual arrangements, as negotiated by Community Strategy and Planning, should include specific details in relation to the clarification of roles and responsibilities of data controllers and data processors in order to ensure the privacy and security of personal information.

### **Privacy and confidentiality**

- In relation to privacy risk assessment and compliance with the GDPR, the PCRS informed HIQA that two DPIAs had been completed to date relating to specific

aspects of the GMS Scheme. Management within the PCRS recognised the importance of conducting further DPIAs and informed HIQA that the HSE DPIA template was being applied to all new projects. The completion of PIAs in relation to all of the national health schemes under the PCRS remit would highlight potential data protection risks in relation to personal information and would further enhance privacy controls and mitigate any potential risks relating to persons engaging with the PCRS.

- The current structure of the PCRS schemes involves the handling of significant volumes of paper across both the reimbursement and eligibility functions. HIQA acknowledges the progress made in relation to reducing the volume of paper handled by the PCRS by moving a number of schemes to online application systems. The PCRS should review the information governance risks associated with this volume of paper as part of an organisations-wide information management strategy. Furthermore, the means by which healthcare providers submit paper-based forms to the PCRS should also be addressed as part of an information management strategy.
- HIQA acknowledges the publication of a Privacy Statement for the PCRS in 2018. The publication of a Privacy Statement promotes transparency by outlining the procedure for data subjects' access requests.

### **Training**

- HIQA received evidence in relation to a structured training programme in place for staff in relation to information governance. All staff receive policies and training in relation to data protection at induction and, subsequently, staff receive refresher training annually on all HSE policies, including a number of information governance policies. The PCRS should continue to review its training in the area of information governance on an ongoing basis to ensure it meets the needs of the organisation and is compliant with relevant policies and legislation.



## 5.4 Recommendations – Information governance

| <b>Information governance</b> |   |
|-------------------------------|---|
| <b>7.</b>                     | <b>Enhanced arrangements in place for information governance</b>  |
|                               | <p>The PCRS should further strengthen and enhance arrangements that are currently in place for information governance within the PCRS. This includes:</p> <ul style="list-style-type: none"> <li>▪ assigning an individual with overall responsibility for information governance within the organisation</li> <li>▪ clearly defining roles and responsibilities in respect of information governance across the organisation</li> <li>▪ addressing key aspects of information governance as part of the overall information management strategy, such as the plans to reduce the level of manual processing of paper in the system.</li> </ul> |
| <b>8.</b>                     | <b>Compliance with legislation and privacy risk assessment</b>  |
|                               | <p>To ensure on-going compliance with legislation, including GDPR, the PCRS should undertake to conduct a privacy impact assessment (PIA) of all data flows in relation to the National Health Schemes to ensure that any privacy risks are being effectively addressed.</p>  |

## 6. Conclusion

The aim of this review was to assess the compliance of the Primary Care Reimbursement Service (PCRS) with the Information Management Standards. Ultimately, the overall review programme of national data collections in Ireland aims to drive improvements by identifying areas of good practice and areas where improvements are necessary across national data collections.

Through its reimbursement function, the PCRS is responsible for making payments/reimbursement services to healthcare providers, including GPs, dentists, pharmacists, optometrists/ophthalmologists and clinical dental technicians, for the free or reduced costs services they provide to the public.<sup>(20)</sup> Additionally, the National Medical Card Unit (NMCU), within the PCRS, processes all medical and GP visit card applications. The data held by the PCRS, which includes sensitive GMS applicant information as well as detailed healthcare provider claims, is a rich source of information for the public, clinicians, policy-makers and researchers. This data can be used to improve the quality of the service being provided to people in Ireland.

A comprehensive and high-quality national data collection can only be assured if the organisation manages its information appropriately.<sup>(2)</sup> To achieve good information management practices, organisations need to implement a sequence of robust arrangements, including devising formalised governance structures and clearly outlining responsibilities throughout the organisation in respect of information management; developing an information management strategy; preparing detailed plans to outline how the organisation will successfully achieve this vision; developing a system to effectively assess the delivery of the plans by monitoring information-related performance indicators and undertaking necessary audits to provide assurance of good practice; and identifying and controlling information-related risks by implementing an integrated risk management policy. Like all other resources within an organisation, information is a resource that must be strategically and effectively managed.

Effective information management leads to enhanced knowledge and understanding for all involved in providing and using the service as it instils confidence in service users, clinicians and all other stakeholders that decisions are made based on high-quality information, the availability of which will ultimately improve outcomes.<sup>(2)</sup> Furthermore, good information management promotes assurance that information will be held securely, puts in place the necessary precautions to maintain individuals' privacy and confidentiality, facilitates greater empowerment and involvement by communicating effectively with the public and, ultimately, creates a culture in which information will be used more effectively.<sup>(34)</sup>

The eight recommendations outlined in this report should be considered in conjunction with the findings of the review in order to improve information management practices in the PCRS. The PCRS is responsible for preparing and implementing quality improvement plans to ensure that the areas for improvement are prioritised and implemented in order to comply with the Information Management Standards.<sup>(2)</sup> The PCRS should continue to assess the adherence to the standards in between reviews by HIQA to ensure that they are meeting the requirements of the Information Management Standards.

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## Appendices

### Appendix 1 — Key publications by HIQA in relation to national health and social care data collections

- A catalogue of all national health and social care data collections in Ireland was first published in 2010 and was most recently updated in 2017 — *Catalogue of National Health and Social Care Data Collections in Ireland*.<sup>(61)</sup> The current catalogue features 120 data collections.
- In 2013, HIQA published *Guiding Principles for National Health and Social Care Data Collections*,<sup>(62)</sup> which provide current and new national health and social care data collections with advice and guidance on best practice.
- In 2014, HIQA published and submitted to the Minister for Health *Recommendations on a More Integrated Approach for National Health and Social Care Data Collections*.<sup>(63)</sup> These recommendations emphasise the need for a strategic framework to inform policy development in this area. The implementation of these recommendations has the potential to reduce fragmentation and duplication and ensure a more consistent approach to improving the quality of data collected.
- HIQA has published a number of detailed guidance documents on best practice for information management:
  - *What you should know about information governance: a guide for health and social care staff*<sup>(57)</sup>
  - *Guidance on information governance for health and social care services in Ireland*<sup>(56)</sup>
  - *What you should know about data quality- a guide for health and social care staff*<sup>(64)</sup>
  - *Five quality improvement tools for national data collections, 2017*<sup>(65)</sup>
  - *Guidance on privacy impact assessment (PIA) in health and social care*<sup>(66)</sup>
  - *Privacy impact assessment (PIA) toolkit for health and social care*<sup>(67)</sup>
  - *Guidance on a data quality framework for health and social care*.<sup>(17)</sup>



## Appendix 2 — International examples of information management practices

| Type of initiative                           | International examples of initiatives in practice  |
|--|--|
| <p><b>Strategy and business planning</b></p> | <p>A key feature of an organisation-wide strategy should be to outline how an organisation is going to achieve effective information management in order to deliver on the overall strategy. In the UK, the National Health Service Business Services Authority (NHS BSA) has outlined how they are planning to deal with issues relating to GDPR as well as risks relating to information security within their Business Strategy 2018–2021.<sup>(42, 68)</sup> This strategy is aligned to their annual business plan, which covers issues relating to information security including audit and risk management, data sharing and GDPR.<sup>(69)</sup></p> <p>In Northern Ireland (NI), the Health and Social Care Business Services Organisation (HSC BSO) publishes annual business plans that are also aligned to three year corporate strategies. Their most recent strategy (BSO Corporate Strategy 2015–18) outlines plans for information governance, customer care and risk management.<sup>(70)</sup> The BSO Business Plan 2017/18 outlines the HSC vision for a digital record-in-common for every citizen in NI which will be known as an Electronic Health and Care Record (EHCR), service-level agreements and the use of data to improve services.<sup>(71)</sup></p> |
| <p><b>Risk and audit management</b></p>      | <p>In the UK, the NHS BSA operates an organisation wide Audit and Risk Management Committee with meetings held as required and not less than four times each financial year.<sup>(72)</sup> Similarly, within their information governance policy, the HSC BSO in NI outlines how all information assets and information flows should be risk assessed to determine appropriate, effective and affordable information governance controls are in place. Risk assessment in conjunction with overall priority planning of organisational activity is undertaken to determine appropriate, cost-effective information governance controls are in place.<sup>(59)</sup> Furthermore, they undertake or commission regular assessments and audits of information governance policies and arrangements.<sup>(59)</sup> In addition to the above policy, the HSC BSO have an Information Risk Policy and an Information Security Policy outlining specific roles and responsibilities in relation to information risk and security, respectively.<sup>(73)</sup></p>   |
| <p><b>Data sharing agreements</b></p>        | <p>Within their Data Protection and Confidentiality Policy, the NHS BSA outline how they assure all contracts, data sharing agreements and memorandums of understanding comply with GDPR principles before sign off. This includes ensuring that up-to-date best practice templates are available to staff for such agreements.<sup>(74)</sup> These are the responsibility for the in-house Data Protection Officer (DPO).<sup>(74)</sup></p>   |

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| <p><b>Information governance arrangements</b></p> | <p>The NHS BSA has an information governance policy which applies to all employees, non-executive directors as well as non-NHS BSA employees, including contractors, agents, representatives and temporary staff working on behalf of the organisation. Within this policy, reporting structures within the NHSBSA are clearly outlined.<sup>(75)</sup></p> <p>Similarly, in NI, the HSC BSO carries a legal responsibility for the appropriate processing and protecting of information of many types. This includes information which contains personal details of patients/clients, their families or staff. The information governance requirements set out within the BSO Information Governance Policy as well as subsequent policies and procedures are intended to ensure there is a robust framework concerning the obtaining, recording, holding, using, sharing and destruction of all data, personal information and records held or used and ensuring that relevant information is available where and when it is needed.<sup>(59)</sup> Within this policy<sup>(59)</sup> and a Data Protection and Confidentiality Policy,<sup>(74)</sup> the BSO clearly outlines the roles and responsibilities of staff in relation to data protection. The BSO operates an internal information governance management group to ensure the development of an information governance culture within BSO and ensure compliance within the organisation of all aspects of information governance policy. The effectiveness of the BSO information governance policy is assessed via a number of factors:</p> <ul style="list-style-type: none"> <li>• compliance with the legislation</li> <li>• the management (including frequency) of data breaches, including inappropriate release of information and near misses</li> <li>• the retention, disposal and destruction of records in accordance with the Department of Health Good management, good records guidelines<sup>(76)</sup></li> <li>• staff training records.</li> </ul> <p>In addition to a formal information governance policy, the BSO have developed an effective communications strategy to ensure all staff and the public are kept accurately informed of the key messages in information governance. It outlines the steps to be taken to maintain and improve communication of the strategic information governance agenda in the Business Services Organisation (BSO).<sup>(60)</sup></p> |
| <p><b>Data protection officer</b></p>             | <p>Within its Data Protection Policy,<sup>(74)</sup> the HSC BSO outline the role of the data protection officer (DPO), who is responsible for overseeing the data protection strategy and implementation to ensure compliance with GDPR requirements. The DPO is also involved in data protection impact assessments as outlined in their Policy and Procedure for conducting a Data Protection Impact Assessment (DPIA).<sup>(77)</sup> Amongst other responsibilities, the DPO ensures that DPIAs are carried out at an early stage of any change in compliance with GDPR requirements to effectively manage privacy risks relating to the NHS BSA processing of personal data. They also liaise with the Caldicott guardian regarding disclosures of patient identifiable data or the processing of that data outside England. A Caldicott Guardian also has a number of responsibilities relating to data quality. In the UK, the NHS BSA also have a DPO who is the designated</p>  |

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|   | <p>Information Governance Lead and is responsible for ensuring there is senior level awareness and support for information governance, overseeing data protection strategy and implementation to ensure compliance with GDPR requirements.<sup>(75)</sup></p>   |
| <p><b>Use of information policy</b></p> | <p>The NHS BSA have an Acceptable Use Policy<sup>(78)</sup> which is publicly available online to ensure that staff are given the relevant support to ensure they are aware of what is acceptable to use of any computer system owned or operated by NHSBSA and therefore can apply procedures accordingly. In addition to this policy the NHS BSA also promote the effective management and use of information, recognising its value and importance as a resource for delivering NHSBSA objectives through a dedicated Records Management Policy.</p>   |
| <p><b>Data quality strategy</b></p>     | <p>In 2017, the Canadian Institute for Health Information (CIHI) published an Information Quality Framework which provides a structure for CIHI's data and information quality management practices.<sup>(79)</sup> This document outlines the dimensions of data and information quality, describes the information life cycle and provides guidance on specific activates and outputs in relation to information quality.<sup>(79)</sup> Recently, numerous NHS trusts have published data quality strategies describing how data quality will be improved in their respective areas.<sup>(80-83)</sup> These strategies outline the importance of good quality data, the characteristics of data quality, issues surrounding good quality data, strategic priorities, roles and responsibilities, training and key performance indicators.</p> |
| <p><b>Data request policies</b></p>     | <p>The NHS BSA recognises the importance of using data to benefit public health. However, it also recognises the importance of using data in an ethical, controlled and consensual way. NHS BSA policies ensure data used for public health research remains confidential. All requests for data are subject to the provisions outlined in the following:</p> <ul style="list-style-type: none"> <li>• common law duty of confidentiality</li> <li>• data protection legislation</li> <li>• the Caldicott principles</li> <li>• the Information Commissioner's statutory data sharing code of practice</li> <li>• the national data opt-out programme.</li> </ul> <p>The NHS BSA also has detailed information on how to apply for access to data as well as how it reviews requests on its website.<sup>(55)</sup></p>                           |

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|                        | <p>NHS digital also have a Data Access Request Service (DARS) which offers clinicians, researchers and commissioners the data required to help improve NHS services.<sup>(84)</sup> Organisations and individuals wanting to use certain kinds of data need to show they meet strict data governance standards by completing the NHS Digital DARS application process. The DARS team ensure they only supply sensitive patient-level data to organisations that look after it according to information governance requirements and use it to improve health and care services.<sup>(84)</sup></p>   |
| <b>Data dictionary</b> | <p>The New Zealand Ministry of Health operates a number of data dictionaries, including the Pharmaceutical Claims Data Mart data dictionary.<sup>(85)</sup> The Pharmaceutical Claims Data Mart (Pharms DM) is a data mart that supports the management of pharmaceutical subsidies. Pharms DM contains claim and payment information from pharmacists for subsidised dispensings that have been processed by the General Transaction Processing System (GTPS). There is also a data dictionary for the Primary Health Organisation Enrolment Collection Data Mart.<sup>(86)</sup> The Primary Health Organisation Enrolment Collection is a national collection that holds primary healthcare patient enrolment data.</p> <p>In the UK, the NHS Data Model and Dictionary provides a reference point for approved Information Standards Notices to support healthcare activities within the NHS in England. It has been developed for everyone who is actively involved in the collection of data and the management of information in the NHS.<sup>(87)</sup></p> |

## **Appendix 3 — Statement of purpose**

The statement of purpose<sup>(65)</sup> should contain the following information about the national data collection:

- full legal name
- the year it commenced operation
- contact details, including website information
- name of the managing organisation
- target population
- overall function and purpose
- aims and objectives
- list of data providers
- legal basis
- source of funding
- governance and managing structure
- national legislation and standards that it must adhere to
- international legislation and standards it must adhere to
- document version number
- date it is effective from
- signatures of all parties responsible.

## **Appendix 4 — Data sharing agreement**

Data sharing agreements should document, at a minimum, the following:

- the purpose(s) of sharing
- legal basis for sharing (if applicable)
- the potential recipients or types of recipients and the circumstances in which they will have access
- the data to be shared
- data quality — relevant data quality dimensions
- data security
- retention of shared data
- individuals' rights — procedures for dealing with access requests, queries and complaints
- review of effectiveness/termination of the sharing agreement
- sanctions for failure to comply with the agreement or breaches by individual staff.

## Appendix 5 – Legislation governing the PCRS

| <b>LEGISLATION GOVERNING PCRS</b> |  |
|-----------------------------------|--|
| <b>Health Act</b>                 | <b>Description</b>   |
| <b>2017</b>                       |  |
| SI 577                            | Health Services (Drug Payment Scheme) Regulations 2017 - Reduction of Co-Payment to €134 and calculation based on Reference Price or price as defined in Health (Pricing and Supply of Medical Goods) Act 2013 |
| SI 553                            | Health Services (Prescription Charges) Regulations 2017 - Reduction from €2.50 to €2.00  |
| SI 155                            | Health (Amendment) Act 2017 (Commencement) Order 2017 - Prescription Charges (Over 70s) and DCA Allowance  |
| SI 272                            | Health Professionals (Reduction of Payments to Community Pharmacy Contractors) (Amendment) Regulations 2017 - Emergency Hormonal Contraception   |
| <b>2016</b>                       |  |
| SI 635                            | Health Act 1970 (Section 59(4) Regulations 2016 - Prescription Charges Refugees  |
| SI 576                            | Health (Reimbursement List) (Application Fees) Regulations 2016 - New Medicines Application Fees   |
| SI 233                            | Health Professional (Variation of Payments to General Practitioners) Regulations 2016 - GP Payments, Rural Practice Support and Special Items of Service   |
| <b>2015</b>                       |  |
| SI 382                            | Health Act 1970 (Section 59 (4) Regulations 2015 - Direct Provision Asylum Seekers   |
| SI 348                            | Health (General Practitioner Service) Act 2015 (Commencement) Order 2015 - Universal GP Services over 70's   |
| SI 284                            | Health Act 1970 (Section 58C) (Payments to Relevant Medical Practitioners) Regulations 2015 - Under 6's  |
| SI 278                            | Health Act 1970 (Section 58A) (8) (Classes of Payments) Regulations 2015 – Redress   |
| SI 277                            | Health Act 1970 (Section 45A (7)) (Classes of Payments) Regulations 2015 - Redress   |
| SI 267                            | Health (General Practitioner Service) Act 2014 (Certain Provisions) (Commencement) Order 2015 - Universal GP Service for under 6's   |
| SI 235                            | Redress for Women Resident in Certain Institutions Act 2015 (Commencement) Order 2015  |
| Health Act                        | Redress for Women Resident in Certain Institutions Act, 2015   |
| Health Act 19                     | Health (General Practitioner Service) Act 2015 - Universal GP Services over 70's   |
| <b>2014</b>                       |  |
| Health Act                        | Health (General Practitioner Service) Act 2014   |
| SI 504                            | Medical Products (Prescription and Control of Supply (Amendment) No. 2 Regulations 2014  |
| SI 382                            | Full Eligibility for Certain Persons taking up employment (Section 45 (3) of the Health Act 1970   |
| Health                            | Assignment of individual health identifier & establishment and maintenance of  |

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|--------------------|--|
| Identifiers Act 15 | National Register  |
| SI 203             | European Union (Application of Patient's rights in Cross Border Healthcare) Regulations 2014                               |
| SI 28              | Health (General Practitioner Service) Act 2014 - free GP care for Under 6's  |
| SI 196             | European Communities (Late Payment in Commercial Transactions) (Amendment) Regulations 2014                                |
| SI 124             | Public Service Management (Sick Leave) Regulations 2014  |
| <b>2013</b>        |  |
| SI 546             | Protection of Life During Pregnancy Act 2013   |
| SI 133             | Health (Alteration of Criteria for Eligibility) Act 2013 (Certain Provisions) (Commencement) Order 2013                    |
| SI 279             | Health Professionals (Reduction of Payments to Community Pharmacy Contractors) Regulations 2013                            |
| SI 278             | Health Professionals (Reduction of Payments to General Practitioners) (National Immunisation Programmes) Regulations 2013  |
| SI 277             | Health Professionals (Reduction of Payments to General Practitioners) Regulations 2013                                     |
| SI 274             | Health Professionals (Reduction of Payments to Ophthalmologists, Optometrists and Dispensing Opticians) Regulations 2013   |
| SI 275             | Health Service Executive (Governance) Act 2013 (Commencement) Order 2013   |
| SI 437             | Health Services (Prescription Charges) Regulations 2013  |
| SI 202             | Health (Pricing and supply of Medical Goods) Act 2013 (Commencement) Order 2013  |
| Health Act 14      | Health (Pricing and supply of medical Goods) Act 2013  |
| Health Act 23      | Health Service Executive (Governance) Act 2013   |
| Health Act 10      | Health (Alteration of Criteria for Eligibility) Act 2013   |
| <b>2012</b>        |  |
| SI 548             | Health Professionals (Reduction of Payments to Registered Dentists) Regulations 2012                                       |
| SI 545             | Health Services (Prescription Charges) Regulations 2012  |
| SI 526             | Health Services (Drugs Payment Scheme) Regulations 2012  |
| SI 580             | European Communities (late Payment in Commercial Transactions) Regulations 2012  |
| <b>2011</b>        |  |
| SI 135             | Health Professionals (Reduction of Payments to Registered Dentists) Regulations 2011                                       |
| SI 261             | Health Professionals (Reduction of Payments to Optometrists for certain services) Regulations 2011                         |
| SI 300             | Health Professionals (Reduction of Payments to Community Pharmacy Contractors) Regulations 2011                            |
| SI 525             | Medicinal Products (Prescription and Control of Supply) Regulations 2011   |
| SI 556             | Health Professionals (Reduction of Payments to General Practitioners) (National Immunisation Programmes ) Regulations 2011 |
| SI 648             | Health Services (Drugs Payment Scheme) Regulations 2011  |
| <b>2010</b>        |  |
| SI 638             | Health Professionals (Reduction of Payments to General Practitioners) Regulation 2010                                      |
| Health Act 20      | Health (Amendment) (No. 2) Act 2010  |
| <b>2009</b>        |  |
| SI 195             | Health Professionals (Reduction of Payments to Ophthalmologists,   |



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|                          | Optometrists and Dispensing Opticians) Regulation 2009  |
| SI 171                   | Health Professionals (Reduction of Payments to Registered Dentists) Regulation 2009   |
| SI 246                   | Health Professionals (Reduction of Payments to Pharmacy Contractors) Regulation 2009  |
| SI 262                   | Health Professionals (Reduction of Payments to General Practitioners) Regulation 2009   |
| SI 536                   | Health Service (Drugs Payment Scheme) Regulations 2009  |
| Health Act Section 9 (3) | FEMPI Act 2009 - Reduction of Payments to Community Pharmacy Contractors  |
| Health Act Section 9 (8) | Financial Emergency Measures in the Public Interest Act, 2009 - Community Pharmacy can withdraw services  |
| Health Act Section 9 (9) | Financial Emergency Measures in the Public Interest Act, 2009 - HSE can engage services of another professional to ensure services continue to be available |
| <b>2007</b>              |   |
| SI 99                    | Medicinal Products (Revocation of the Medicinal Preparations(Control of Amphetamine) Regulations, 2007  |
| SI 201                   | Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations, 2007   |
| SI 200                   | Misuse of Drugs ( Amendment) Regulations, 2007  |
| SI 543                   | Irish Medicine Board (Miscellaneous Provisions) Act 2006 (Commencement) (No.2) Order 2007   |
| SI 541                   | Medicinal Products (Control of Advertising) Regulations, 2007   |
| SI 540                   | Medicinal Products (Control of Placing on the Market) Regulations, 2007   |
| SI 539                   | Medicinal Products (Control of Manufacture) Regulations, 2007   |
| SI 538                   | Medicinal Products (Control of Wholesale Distribution) Regulations, 2007  |
| <b>2004</b>              |   |
| SI 832                   | Health Service Regulations, 2005  |
| SI 885                   | Health Service Act 2004 (Establishment Day) Order 2004  |
| SI 886                   | Health Service Act 2004 (Commencement) Order 2004   |
| SI 90                    | Interim Health Service Executive (Establishment) Order, 2004  |
| SI 378                   | Health (Amendment) Act 2004 (Commencement) Order2004  |
| SI 887                   | Health Service Act 2004 (Commencement) (No.2) Order 2004  |
| <b>2003</b>              |   |
| SI 658                   | Health Service Regulations, 2004  |
| <b>2002</b>              |   |
| SI 28                    | Health (Community Pharmacy Contract Agreement) Regulations, 1996 (Revocation) Regulations, 2002   |
| SI 603                   | Health Service Regulations, 2003  |
| SI 627                   | Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations, 2002   |
| <b>2000</b>              |   |
| SI 75                    | GMS payments Board (Establishment) (Amendment) Order, 2000  |
| <b>1999</b>              |   |
| SI 222                   | Local Authorities (Officers and Employees) Act, 1926, Local Authorities (Declaration of Offices) Oder, 1999   |
| SI 34                    | Parental leave (Maximum Compensation) Regulations, 1999   |

|             |  |
|-------------|--|
| <b>1998</b> |  |
| SI 504      | Safety, Health and Welfare at Work ( Children and Young Persons) Regulation, 1998                                  |
| SI 225      | Misuse of Drugs (Supervision of Prescription and Supply of Methadone) Regulation, 1998                             |
| SI 44       | Organisation of Working Time (Code of Practice on Compensatory Rest and Related Matters) (Declaration) Order, 1998 |
| <b>1996</b> |  |
| SI 152      | Health (Community Pharmacy Contract Agreement) Regulations, 1996   |
| <b>1994</b> |  |
| SI 442      | GMS Payments Board Order, 1972 (Amendment) Order, 1994   |
| <b>1990</b> |  |
| SI 223      | GMS Payments Board Order, 1972 (Amendment) Order, 1990   |
| <b>1973</b> |  |
| SI 184      | Health Service Regulations 1973  |
| <b>1972</b> |  |
| SI 88       | Health Service Regulations 1972  |
| <b>1970</b> |  |
| Health Act  | Health Act 1970  |



