Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information and Standards

Review of information management practices in the HSE Computerised Infectious Disease Reporting (CIDR) system

November 2019

Safer Better Care

About the Health Information and Quality Authority (HIQA)

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 care 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 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.

- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.

- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic 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.[(1)]

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 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*[2] — as per HIQA's remit under the Health Act 2007.[1] The standards provide a framework of best practice in the collection of health and social care data. HIQA has developed a structured review programme for assessing compliance with standards.[2,3] 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 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.

Glossary of abbreviations

Abbreviation	Explanation
AND-PH	Assistant National Director – Public Health, Health Protection and Child Health
CDC	Centers for Disease Control and Prevention
CEO	Chief Executive Officer
CHO	Community Healthcare Organisation
CIDR	Computerised Infectious Disease Reporting
DoH	Department of Health
DPH	Director of Public Health
DPIA	Data Protection Impact Assessment
DPO	Data Protection Officer
EARS-Net	European Antimicrobial Resistance Surveillance Network
ECDC	European Centre for Disease Prevention and Control
EFSA	European Food Safety Authority
ESF	Enhanced Surveillance Form
EPIS	Epidemic Intelligence Information System
EWRS	Early Warning Response System
FAQ	Frequently Asked Questions
FOI	Freedom of Information
FSAI	Food Safety Authority of Ireland
GDPR	General Data Protection Regulation
gVPN	Government Virtual Private Network
HIPE	Hospital In-Patient Inquiry
HIQA	Health Information and Quality Authority
HPSC	Health Protection Surveillance Centre
HSE	Health Service Executive
ICGP	Irish College General Practitioners
IHFD	Irish Hip Fracture Database
IHR	International Health Regulations
ILI	Influenza like illness

IMD	Invasive Meningococcal Disease
ISMS	Information Security Management System
IMSRL	Irish Meningitis and Sepsis Reference Laboratory
KPI	Key Performance Indicator
NIAC	National Immunisation Advisory Committee
NIO	National Immunisation Office
NPHLG	National Public Health Leadership Group
NVRL	National Virus Reference Laboratory
OoCIO	Office of Chief Information Officer
PHMCDG	Public Health Medicine Communicable Disease Group
PIA	Privacy Impact Assessment
PII	Personally Identifiable Information
SMO	Senior Medical Officer
SMT	Senior Management Team
SOP	Standard Operating Procedures
SPHM	Specialist in Public Health Medicine
SP&T	Strategic Planning and Transformation function
TESSy	The European Surveillance System
UCD	University College Dublin
VTEC	Verotoxigenic Escherichia coli infection
WGS	Whole Genome Sequencing
WHO	World Health Organistion

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Executive summary

The aim of this review is to assess the compliance of the Computerised Infectious Disease Reporting (CIDR) system with the *Information management standards for national health and social care data collections.*[2] 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 Health Service Executive (HSE) in Ireland. 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 recently published Sláintecare report, which outlines the priorities for the Irish health services over the next ten years, emphasises the importance of quality health data and information to drive improvements in the future of healthcare in Ireland.[4] Furthermore, there are significant changes due to take place within public health in Ireland in the coming years. A review undertaken by Crowe Horwath was published in 2018, setting out a plan to radically re-structure public health services, focusing in particular on the role, training and career structure for public health physicians in Ireland.[5] It is essential that there are 'fit for purpose' information systems in place to support the delivery of public health services into the future. CIDR would be one element of this system; it is Ireland's national system for the surveillance of notifiable infectious diseases. It is therefore essential that CIDR adapts and evolves to meet the requirements and challenges of a changing public health system.

CIDR is a shared national information system used by the CIDR partners (including the Health Protection Surveillance Centre (HPSC), public health departments, clinical laboratories, Food Safety Authority of Ireland, *safe*food and the Department of Health) for the surveillance, management and control of infectious diseases. HPSC provides national leadership on the surveillance and control of infectious diseases and is the managing organisation for CIDR.

CIDR is an extremely valuable national data collection. Over 30,000 infectious disease notifications were reported in CIDR in 2017 as required under the Infectious Diseases (Amendment) Regulation 2016.[6] Some examples of infectious diseases include influenza, salmonella infection, hepatitis, and tuberculosis (TB). The emergence of infectious diseases such as Sudden Acute Respiratory Syndrome (SARS) and recent Ebola outbreaks in Africa have highlighted the importance of early detection and timely surveillance of infectious disease. Before the implementation of CIDR in Ireland in 2004, there was no national information system for infectious diseases, which limited the ability to detect infectious disease cases early, and to prevent further illness from occurring.

Information recorded on CIDR is used for a wide variety of purposes. First of all, it is used by regional Departments of Public Health to facilitate public health action in individual cases of infectious disease, such as a case of meningitis. It is also used regionally to record, monitor and control outbreaks of disease where a number of individual cases of a disease may be linked, for example an outbreak of mumps in a school.

At a national level, CIDR allows HPSC to monitor the incidence of infectious diseases and outbreaks in Ireland in order to identify and control emerging threats, both nationally and internationally, in a timely manner. CIDR data is used to meet Ireland's international reporting requirements for specified diseases. HPSC prepares and publishes reports, based on aggregated and anonymised information from CIDR, to communicate relevant information to a wide range of stakeholders for important purposes including health service planning, determination of national vaccination programmes, evaluation of public health interventions and research purposes. One key example is that, during peak influenza season, as part of the HSE Winter Plan, HPSC prepares and publishes weekly updates on influenza incidence including summary information on the strains in circulation and the impact on morbidity and mortality. This helps to inform the public but also facilitates service providers, clinicians and policy makers in predicting the potential impact on hospitalisation rates during the influenza season.

As highlighted above, owing to the importance of the data captured in CIDR and the requirement to use this data for a wide variety of purposes, it is essential that the information held in CIDR is comprehensive and of the highest possible quality. In addition, as the information held in CIDR contains highly sensitive personal and clinical health information, it needs to be handled within strict security protocols to guarantee privacy and confidentiality for patients using the public health service. Rigorous information management practices are therefore extremely important in relation to CIDR.

The findings of this review of information management practices for CIDR will focus on three key areas: governance, leadership and management; information governance; and use of information. A summary of the findings for each of these key areas will be detailed below before outlining the summary of recommendations.

Governance, leadership and management

Strong governance, leadership and national oversight arrangements are required to ensure CIDR is meeting its objectives as Ireland's national surveillance system for infectious diseases. CIDR was developed to provide near real-time regional and national surveillance of infectious diseases, to facilitate public health action and to allow Ireland to meet its international reporting obligations.

Arising from this review HIQA has concluded that while CIDR fulfils many of its intended functions and HPSC demonstrates good practice in several aspects of information management, the system has not evolved sufficiently to meet the increasing demands of a modern infectious disease surveillance system. HIQA found that there are significant regional variations in infectious disease surveillance practices, resulting in inconsistency across regions in the level of information collected. For a national surveillance system to function effectively information collection and management should be standardised and consistent across all regions and the system should be capable of adapting to meet the information requirements of its stakeholders.

HIQA identified that the aforementioned deficiencies have arisen, at least partly, because of inadequate governance and leadership arrangements for CIDR at both national and local level. Hence, HIQA identified the need for a number of improvements in relation to the governance, leadership and management of CIDR.

CIDR was established with a national oversight structure in place, the CIDR National Steering Committee. However, HIQA concluded that this committee is not currently providing effective oversight for CIDR. Firstly, the committee only met once between October 2017 and June 2019 and, when it meets, it focusses on operational rather than strategic issues. Secondly the membership may not be appropriate as the Directors of Public Health and the Clinical Directors of the laboratories are not represented on the committee. These are the individuals who are legally responsible for reporting cases of infectious diseases and for the collection and management of information on infectious diseases within CIDR. Therefore, they need to be assured that data collection is comprehensive, secure and meeting the nation's health protection and epidemiology needs. Thirdly, HIQA identified that there is no clear upward line of reporting for the CIDR National Steering Committee within the HSE. Based on its terms of reference, HIQA concluded that the committee was established as a project management group to steer the implementation of CIDR and has not evolved sufficiently to oversee the strategic direction and future development of CIDR.

When CIDR was established, the Director of HPSC, as head of the managing organisation, held overall responsibility for information management in relation to CIDR. However, this role was vacant from May 2016 to June 2019, and was back-filled by the Assistant National Director for Public Health, Health Protection and Child Health (AND-PH) in addition to an existing broad remit of public health responsibilities. This meant that there was no senior manager dedicated to providing governance, leadership and accountability for HPSC and CIDR. In order to address this, the HSE has recently advertised a position as Clinical Director for Health Protection based at HPSC. The post holder will have direct responsibility for HPSC, the National Immunisation Office (NIO), the Departments of Public Health and the work of Medical Officers of Health appointed by the HSE. The successful candidate will also be tasked with oversight of national surveillance systems and with ensuring information governance practices are appropriate.

Publication of this HIQA report is very timely in terms of informing the current public health reform process and the future role for the Clinical Director for Health Protection. In light of this, HIQA recommends that, HPSC should enhance current national governance structures for CIDR to ensure that effective leadership, governance and management are in place across all sites where CIDR is used. Furthermore, HIQA recommends that the regional Directors of Public Health and the Clinical Directors of laboratories where CIDR is used should enhance the local governance arrangements for CIDR to ensure that surveillance information on infectious diseases is of high quality. The enhanced arrangements should provide assurance to the Clinical Director for Health Protection, the National Director for the Strategic Planning and Transformation function of the HSE, and the CIDR National Steering Committee, that CIDR is being used effectively for surveillance of infectious disease as well

as for epidemiology, infectious disease case management, health protection and policy purposes.

HIQA was informed that HPSC had no strategy in place for information management or for CIDR. Furthermore, strategic development of CIDR is not discussed at any of the higher-level groups within the HSE and there is no forum to routinely bring together all CIDR stakeholders to discuss strategic issues, including those relating to information management. Because of the imminent restructuring of public health structures and the identified need for an infectious disease case management system, a strategy is urgently required for an overarching public health information management system. HIQA has recommended that the National Director for Strategic Planning and Transformation in the HSE should ensure that a strategy is developed and implemented for an information management system which meets the current and future needs of the Irish public health system. Greater clarity is required about the future evolution of CIDR within this overall information management system.

Approximately 260 CIDR users in HPSC, laboratories and Departments of Public Health use CIDR for the surveillance, management and control of infectious diseases. During the review, HIQA identified that, currently, there is a lack of clarity among many CIDR users about their responsibilities in relation to information management. There is no scheme of delegation in place which clearly sets out the lines of accountability and responsibility for staff within HPSC, the Departments of Public Health and laboratories for information management, including information governance and data quality. HPSC should develop a detailed scheme of delegation outlining clearly defined roles and responsibilities for information management in respect of CIDR.

HIQA identified that the performance assurance system in place for CIDR is not adequate to ensure it is meeting its objectives as the national surveillance system for infectious disease. No specific key performance indicators (KPIs) have been set to measure and report on the performance and effectiveness of CIDR or the quality of the data held in the system. HPSC should develop a performance assurance framework for CIDR that generates appropriate information to assure the Director of HPSC, the Senior Management Team within the Strategic Planning and Transformation function and the CIDR National Steering Committee that CIDR is meeting the objectives set out in the strategic plan. The assurance framework should set key performance indicators (KPIs) for important aspects of information management that are carried into the annual business planning process and should include a schedule for internal and external audits.

HIQA have also recommended that HPSC should further define their risk management framework to clarify the roles of individual persons and committees for management of risks and to clarify how risks which cannot be resolved within HPSC should be mitigated or escalated.

HPSC were already aware of the need to implement formal data sharing agreements with stakeholders with whom they share data, particularly where processing falls outside of the normal statutory obligations or is not covered by the CIDR Business Rules and had commenced this work before the start of the review. HPSC should continue to prioritise the

development and implementation of such agreements to support the provision of good quality data and the legal and secure handling of data.

It is important that the enhanced governance and leadership arrangements for CIDR and the development of a strategic plan take account of the re-structuring of the public health service, the plans for a public health case management system, and should be aligned to both the Sláintecare action plan and the HSE eHealth strategy.[4,7]

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 a strong emphasis on information governance in relation to CIDR, both within HPSC and at a local level in laboratories and Departments of Public Health.

HPSC has well-developed arrangements in place to support the privacy, confidentiality and security of information within CIDR. Such measures include the development and implementation of information governance policies and procedures, as well as an audit plan to address a number of aspects of information governance. Significantly, HPSC has maintained accreditation to ISO 27001 for a number of years, demonstrating compliance with information security best practice. HIQA also recognises, as good information governance practice, HPSC's completion of a number of Privacy Impact Assessments, enabling HPSC to enhance privacy controls and mitigate potential risks relating to CIDR data.

HIQA found that, despite these positive information governance measures, there was a lack of clarity at local level (in Departments of Public Health and laboratories) in relation to the delegation of roles and responsibilities for information governance. The CIDR Business Rules set out the rules for participation in CIDR. Although they are intended to set out clear operating procedures for all CIDR users in relation to the CIDR system, further work is required to ensure that such roles and responsibilities are implemented in practice.

HPSC would benefit from implementing a more strategic approach to information governance for CIDR across all sites where CIDR is used. This should be supported by the development of a clear scheme of delegation, formally outlining roles and responsibilities in relation to information governance.

Use of Information

Considering the reliance on CIDR data for so many important purposes, as previously outlined, the quality of data held within the CIDR system is of the upmost importance. Data can be considered to be of good quality when the correct data is available to decision-makers in a timely manner and they can confidently rely on it. For example, rapid and

accurate notification of infectious diseases to local Departments of Public Health allows public health professionals to identify unusual patterns/trends in infectious diseases. The early identification of clusters or outbreaks of infectious diseases prompts further investigation and can lead to the identification of a source of infection. Public health action will be carried out in response to outbreaks and prevents the further spread of disease. Without the use of a national infectious disease notification system, early identification of national outbreaks would not be possible.

HIQA identified that, overall, there is a strong emphasis on data quality and the effective use of information generated from CIDR. The CIDR system has a number of built-in elements that drive high quality data. For the core dataset, there are mandatory fields for all events created on CIDR and drop-down options to standardise data entry and reduce data entry errors. This allows public health professions to compare infectious disease trends across regions and to get a national picture. HIQA also noted many data quality initiatives and activities led by HPSC, including the existence of detailed standard operating procedures (SOPs) for data processing, frequent data validation and de-duplication schedules. Despite these, HIQA identified variation in surveillance practice and data quality issues at local level within Departments of Public Health.

To address this, HPSC should enhance their arrangements for data quality by developing an overarching data quality framework and identifying an individual with overall responsibility for data quality within HPSC. Implementation of a data quality framework is necessary to drive a coordinated and strategic approach to data quality across regions and disease specific groups within HPSC. A schedule of data quality audits, and the effective use of KPIs, would provide assurance that the quality of the data collected and processed by CIDR is of the highest possible standard. Furthermore, a strategic approach to data quality should include effective engagement with all stakeholders, including CIDR users, to assess the usefulness and usability of the system from their perspective. The information garnered from this engagement would be invaluable in informing the development and improvement of a data quality framework and would also inform the strategic planning process.

HIQA acknowledges that HPSC disseminates information generated from CIDR through a variety of methods to ensure that infectious disease information is accessible to a wide range of stakeholders. This is done through weekly, monthly and annual publication of infectious disease surveillance reports which makes CIDR information accessible to both public and healthcare professionals.

In light of the ongoing developments and evolution of laboratory testing, HPSC needs to ensure that CIDR evolves sufficiently to capture, analyse and use the new information available. Promoting the most effective use of information, both internally and externally, is essential to harness the true potential of this data. Finally, HIQA recommends the publication of a data dictionary to enhance shared understanding, to improve data quality and to maximise the use of information.

Summary

CIDR, as the central repository for the statutory notification of infectious diseases in Ireland, is an extremely important national health data collection and has a strong level of ICT measures that support the privacy, confidentiality and security of information. When it was established fifteen years ago, it was quite an advanced system. However, HIQA has concluded that, due to inadequate governance arrangements and insufficient focus on stakeholder needs, the CIDR information management system has not evolved to meet the current needs of all its stakeholders. Clear oversight and assurance arrangements must now be provided for CIDR to provide strategic direction and instil confidence that decisions continue to be based on high-quality information, which will ultimately protect and improve public health.

The eight recommendations outlined in this report should be considered in conjunction with the findings of this review in order to improve information management practices for CIDR. The HSE are responsible for preparing and implementing quality improvement plans to ensure that the areas for improvement are prioritised and plans are implemented to improve compliance with the Information Management Standards. Once successfully appointed, the new Clinical Director for Health Protection should play a central role in ensuring that the required improvements for CIDR are implemented in a way which is consistent with the imminent restructuring of the public health system in Ireland. The HSE and HPSC should continue to assess their adherence to these standards between reviews by HIQA to ensure that they are consistently meeting the requirements of the Information Management Standards.

Summary of recommendations

Governance, leadership and management

1. Strategy for information management for public health

In light of forthcoming changes in how public health services will be delivered[5], the National Director for Strategic Planning and Transformation should, in conjunction with key stakeholders, develop and implement an information management strategy for the public health service in Ireland.

The strategy should address:

- the vision for a state-of the-art information management system spanning the full remit of public health
- the requirement for an infectious disease case management system
- the future direction and roadmap for CIDR
- clearly defined objectives, identified individuals responsible for delivery of objectives and associated business planning for all aspects of information management
- a plan for stakeholder engagement to ensure that CIDR meets the needs of all stakeholders
- alignment with Sláintecare and the HSE eHealth strategy

2. Governance Structures for CIDR

National Governance Structures for CIDR

HPSC should enhance its current governance arrangements for CIDR to:

- ensure that the CIDR National Steering Committee provides effective national oversight, leadership and strategic direction for CIDR. The membership and terms of reference for the committee should be reviewed.

- provide a detailed scheme of delegation outlining clearly defined roles and responsibilities for information management in respect of CIDR.

Local Governance Arrangements for CIDR

The Directors of Public Health and Clinical Directors of laboratories should enhance the local governance arrangements for CIDR to ensure that:

- the information held in CIDR is of high quality and used effectively for surveillance of infectious disease as well as for health protection, epidemiology and policy purposes.

- a detailed scheme of delegation is in place outlining clearly defined roles and responsibilities for information management in respect of CIDR.

3. Performance Assurance Framework

HPSC should develop a performance assurance framework which generates appropriate information to provide assurance to the HSE Strategic Planning and Transformation Senior Management Team and the CIDR National Steering Committee that CIDR is:

- meeting the objectives of a national infectious disease surveillance system
- providing high quality information to inform public health decisions

The assurance framework should include arrangements for monitoring performance against the annual HPSC business plan and CIDR workplan, measurement and reporting of key performance indicators (KPIs) for CIDR and a schedule for conducting internal and external audits against aspects of information management.

4. Risk Management Framework

HPSC should further define its risk management framework to clarify how significant risks, which cannot be resolved within HPSC, should be mitigated or escalated. The role of relevant HPSC and HSE Committees in escalating and mitigating risks should be clearly delineated.

The role of the following parties in relation to risk management and escalation, and the level of risk they should each be addressing, needs to be clarified:

- HPSC Senior Management Team
- the Director of HPSC
- the Assistant National Director for Public Health
- the National Director for Strategic Planning and Transformation
- the CIDR National Steering Committee

The revised risk management framework should be closely aligned to the enhanced arrangements for governance and leadership of CIDR.

5.	**Transparency**
	▪ HPSC should prioritise the development and implementation of data sharing agreements with those parties with whom they share CIDR data, particularly where data sharing is not covered by the CIDR Business Rules. ▪ HPSC should publish a statement of purpose that accurately describes the aims and objectives of CIDR.
	Information Governance
6.	**Enhanced arrangements for information governance**
	HPSC should further strengthen and enhance arrangements for information governance in relation to CIDR, to include data collected across all sites where CIDR is used. This includes: ▪ facilitating the standardised implementation of the CIDR Business Rules across all sites where CIDR is used, ensuring clarity for CIDR users in relation to information governance roles and responsibilities. This should also include arrangements for information security and data protection. ▪ defining roles and responsibilities for information governance within HPSC through a formal scheme of delegation. ▪ providing assurance to the CIDR National Steering Committee in relation to information governance for CIDR through reporting against KPIs, risk and the findings of audit. ▪ developing and publishing a Statement of Information Practices.
	Use of information
7.	**Data quality framework and arrangements**
	HPSC should develop and implement a data quality framework to systematically assess and improve data quality at all levels for CIDR through the use of standardised audit schedules and a comprehensive set of KPIs. This should be developed in conjunction with all CIDR partners across regions. Additional data quality arrangements to complement the framework should be implemented to include:

	▪ Assigning an individual with overall responsibility for data quality within HPSC ▪ Clearly outlining responsibilities for data quality at every level through a scheme of delegation for HPSC. ▪ A stakeholder engagement plan for data quality to incorporate a survey of CIDR users to assess the usefulness and usability of the system and their requirements of the system ▪ A formal evaluation of CIDR training to guide the development of a specific training plan to ensure the optimal use of data and information at a local and national level.
8.	**CIDR Data Dictionary**
	A data dictionary for CIDR should be developed and published to ensure consistency in data collection and to enable accurate use and interpretation of data from CIDR. This should be aligned to the plans for the National Data Dictionary being developed by the Office of the Chief Information Officer in the HSE.

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 collections*.[2]

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 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.[1] A

number of key documents have been published by HIQA in recent years in relation to national health and social care data collections (Appendix 1).

Furthermore, the *National Standards for Safer Better Healthcare,*[8] 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.*[2] 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.*[2,8] 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.*[2] 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.[3]

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 five stages involved in this review process:

1. Self-assessment tool
2. Information request
3. On-site assessments and additional evidence gathering
4. Report of findings
5. 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 of receipt.

Based on the results of the self-assessment tool and the prioritisation criteria, HIQA performed a focused review of the HSE Computerised Infectious Disease Reporting (CIDR) system.

Stage 2: Information request

Following a review of the self-assessment tool, a request for additional information was sent to the Health Protection Surveillance Centre (HPSC) and the information relevant to CIDR was returned to HIQA within 15 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 and additional evidence gathering

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

The review team conducted focus groups with representatives from Departments of Public Health and clinical diagnostic laboratories, as well as face-to-face interviews and teleconference interviews with Directors of public health, specialists in public health medicine, public health and laboratory surveillance scientists, and consultant microbiologists. An interview was also held with the National Director, Strategic Planning and Transformation within the HSE, the function in the HSE where HPSC sits, to explore aspects of governance for CIDR.

HIQA comprehensively examined data quality in two disease surveillance systems: invasive meningococcal disease (IMD) and influenza surveillance. Data quality in both systems was assessed using the data quality assessment tool outlined in *HIQA's Guidance on a data quality framework for health and social care*[9] where data sources are evaluated across 5 quality dimensions including Relevance, Accuracy and Reliability, Timeliness and Punctuality, Coherence and Comparability, Accessibility and Clarity. To facilitate this evaluation, the review team conducted interviews and focus groups with CIDR users located within HPSC, Departments of Public Health and both clinical microbiological and national reference laboratories.

Stage 4: Report of findings

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

Stage 5: Factual accuracy

HIQA provided a draft of the report of findings to the Interim Director of HPSC, the National Director Strategic Planning & Transformation, HSE and the Assistant National Director of Public Health, Health Protection and Child Health to complete a factual accuracy. All comments received from the aforementioned stakeholders were carefully considered by HIQA prior to publication of this final report.

1.4 Quality improvement plans

HPSC is responsible for preparing and implementing quality improvement plans in respect of CIDR to provide assurance that the findings relating to areas for improvement are prioritised and implemented to comply with the Information Management Standards.

HPSC 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 in respect of CIDR.

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.[(1)] 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 HSE Computerised Infectious Disease Reporting (CIDR) System's compliance with the Information Management Standards.

2. Overview

This chapter provides information on the structure of public health services in Ireland, the Health Protection Surveillance Centre (HPSC), the Computerised Infectious Disease Reporting (CIDR) system and the importance of information management for CIDR.

CIDR is a secure online national database for the notification and surveillance of infectious disease. CIDR enables clinical laboratories, Departments of Public Health and HPSC to fulfil their notification and surveillance obligations by providing a secure online resource for the mandatory reporting of infectious diseases.

Public health surveillance is generally described as *"the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know"*.[10]

The purpose of any infectious disease surveillance system is to provide information to enable timely public health action for the control and prevention of communicable disease. There are many different infectious disease surveillance strategies and systems in use around the world.[11] In a recent publication, Public Health England define a general model for health surveillance which describes the elements that should be included in a surveillance system to effectively provide and support surveillance activities (see Appendix 2 for further information).[12]

2.1 Structure of public health services

2.1.1 National structures — public health and health protection

Public health services in Ireland are divided into four pillars, as outlined in Figure 1. Leadership for the public health function lies within the HSE Strategic Planning and Transformation function. In 2018, new governance arrangements were agreed to align with the HSE leadership roles. This included the establishment of a National Public Health Leadership Group (NPHLG).

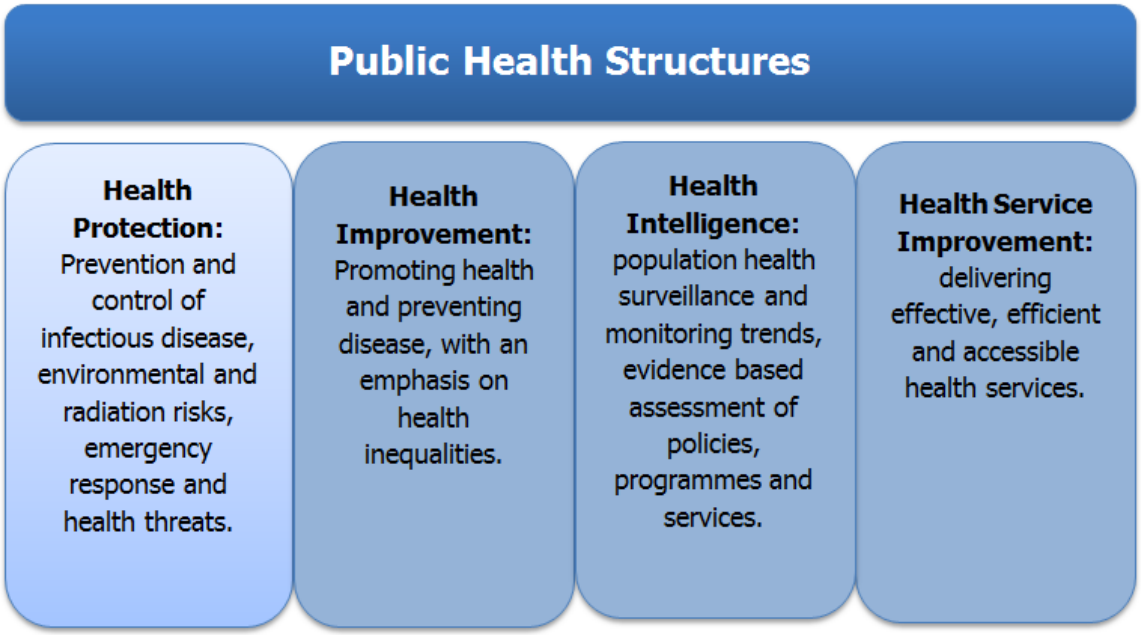

Figure 1. Public health structures in Ireland

The Assistant National Director for Public Health, Health Protection and Child Health (AND-PH) acts as the national Medical Officer of Health (MOH) and is the head of the public health function (Section 2.3.1). The AND-PH reports to the HSE National Director for Strategic Planning and Transformation.

Management of the public health function is distributed across a number of divisions and units within the HSE. The health protection pillar encompasses HPSC (Section 2.2), the National Immunisation Office (NIO) and eight regional Departments of Public Health. Other departments and units within the HSE with a public health remit include the National Health Intelligence Unit, the National Cancer Control Programme, the Quality Improvement Division, and Social Inclusion—Primary Care Division.

The Assistant National Director of Public Health, Health Protection and Child Health, as head of the public health function and Medical Officer of Health at national level, has overall responsibility for the Health Protection Surveillance Centre (HPSC), the National Immunisation Office (NIO) and eight regional Departments of Public Health. This position will be referred to as the 'AND-PH' for the remainder of this report.

2.1.2 Regional and local structures — Departments of Public Health and laboratories

There are eight Departments of Public Health in Ireland, which were established under the Health Boards in 1995 and still cover the geographical areas served by the former Health Boards rather than the current HSE geographical divisions (Figure 2).

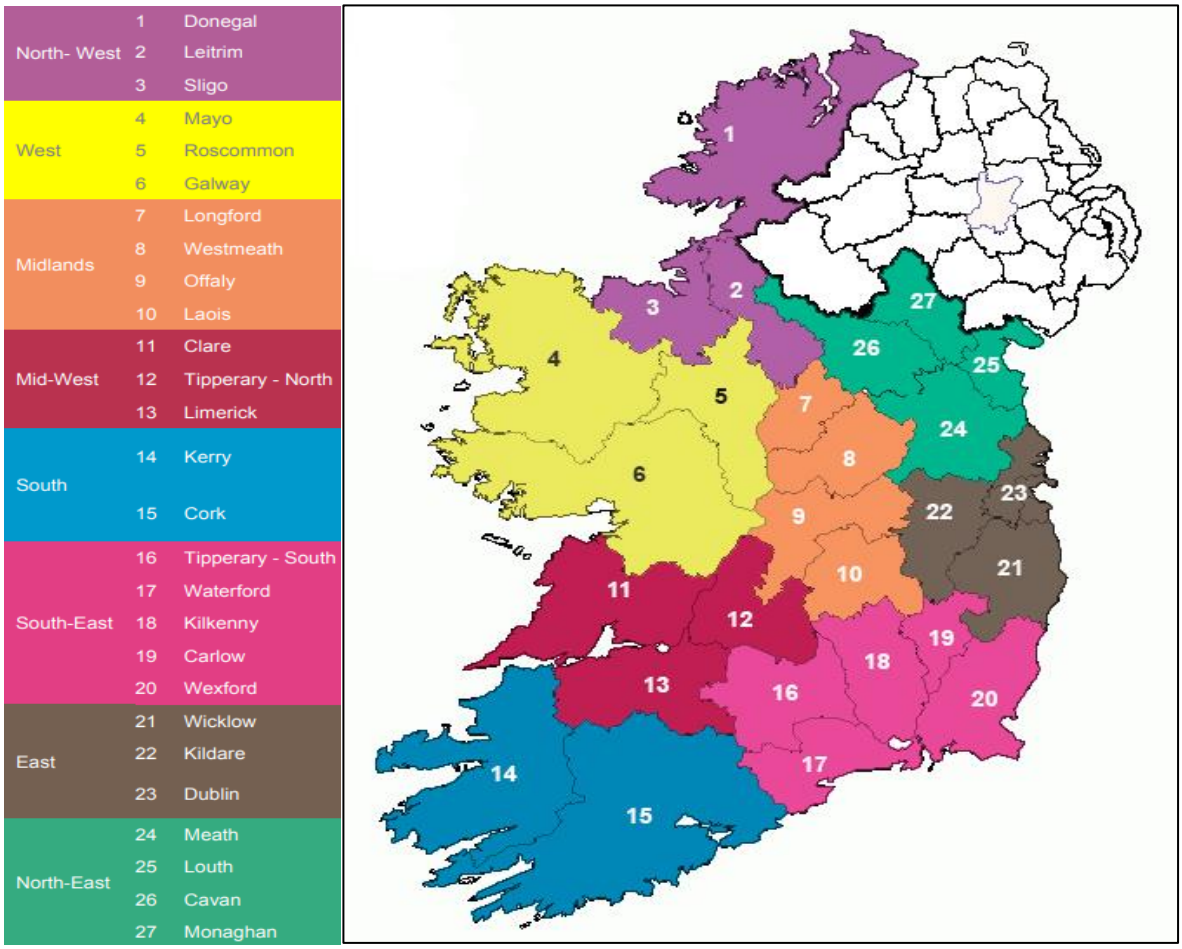

Figure 2. Regional Departments of Public Health[13]

Each department provides public health expertise and services within its own region, including health protection services, advocating and contributing to health improvement, and participating in health service development. Departments of Public Health are specifically responsible for the delivery of the following within their designated geographical areas:

- measurable health improvement
- health protection services, including actions for the prevention and control of infectious diseases, environmental hazards and response to emergencies that threaten health
- public health input to health and social care service planning and commissioning
- reduction of health inequalities.[14]

The Departments of Public Health in Ireland contribute to implementing Healthy Ireland — the Framework for Improved Health and Wellbeing.[15] They also work closely with a variety of professionals within the HSE, particularly the Health Protection Surveillance Centre; local authorities; government departments; the Environmental Protection Agency; and Public Health agencies in the UK and Europe.[16]

Clinical and reference laboratories play an important role in providing the Departments of Public Health with information on infectious disease. All laboratories are governed within the structures of the hospitals (public hospitals) or organisations (private hospitals or laboratories) in which they are located. In total, there are 29 primary hospital laboratories and five reference laboratories. The reference laboratories are:

- UCD National Virus Reference Laboratory (University College Dublin)
- VTEC Reference Laboratory (Cherry Orchard Hospital)
- National Salmonella, Shigella & Listeria Reference Laboratory (University Hospital Galway)
- Irish Meningitis and Sepsis Reference Laboratory (Temple Street Children's University Hospital)
- Irish Mycobacteria Reference Laboratory (St James's Hospital).

2.2 Health Protection Surveillance Centre (HPSC)

HPSC is part of the Health Service Executive and is Ireland's specialist agency for the surveillance of communicable diseases.

HPSC (formerly the National Disease Surveillance Centre) was established to protect and improve the health of the Irish population by providing timely information and independent advice about the control and prevention of infectious diseases to relevant health authorities.

HPSC's responsibilities include:[17,18]

- Surveillance of communicable diseases, including the collection, collation and analysis of data and the communication of information to those who require it.
- Preparation and publication of epidemiological reports on individual infectious diseases
- Providing leadership at national level on health protection and surveillance of infectious diseases.
- Providing policy advice to government departments and other agencies in relation to the development of standards, guidelines and practices, and promoting the adoption of best practice by different agencies.
- Providing credible information to enhance decision-making capabilities in the HSE, Department of Health, Royal College of Physicians National Immunisation Advisory Committee and other agencies such as the Food Safety Authority of Ireland and *safe*food.
- Conducting and supporting research through identifying and developing best practice in relation to communicable disease surveillance and control.

- Providing information to the public and the media on infectious diseases.
- Providing an alert and response function for both national and international health protection threats.
- Serving as the Irish point of contact for the European Centre for Disease Control and the World Health Organisation for health protection threats of a national or international nature (national focal point for the Early Warning and Response system of the European Commission and national focal point for the WHO International Health Regulations).
- Liaising with other international surveillance agencies for the purposes of epidemiological intelligence gathering and dissemination of information on health protection diseases.
- Responding to, and providing advice on control measures in relation to emerging health protection threats.
- Working closely with Departments of Public Health, microbiologists, infectious disease specialists, environmental health officers, infection control nurses and many other healthcare professionals to prevent and control the spread of infections in Ireland.
- Delivering training for professionals working in communicable disease control.

HPSC hosts and is the managing organisation for the Computerised Infectious Disease Reporting system (CIDR), the national web-based information system developed to support the surveillance and control of infectious diseases in Ireland (Section 2.6). HPSC has access to all information on CIDR in a pseudonymised form and use this information to describe the epidemiology of infectious disease, to monitor emerging trends, to run regular validation and evaluation reports and to influence national policies related to infectious diseases or vaccination.

2.3 Infectious diseases legislation

2.3.1 Medical Officer of Health (MOH) role

The AND-PH, as the national MOH, has the legal responsibility and authority to investigate and control notifiable infectious diseases and outbreaks under the Health Acts 1947 and 1953 and under the Infectious Disease Regulations 1981 and subsequent amendments. As outlined in Section 2.1.1, the AND-PH is responsible for eight regional Departments of Public Health (Figure 3). The AND-PH has assigned the MOH function to Directors of Public Health. Directors of Public Health have assigned the MOH function to Specialists in Public Health Medicine based in Departments of Public Health.

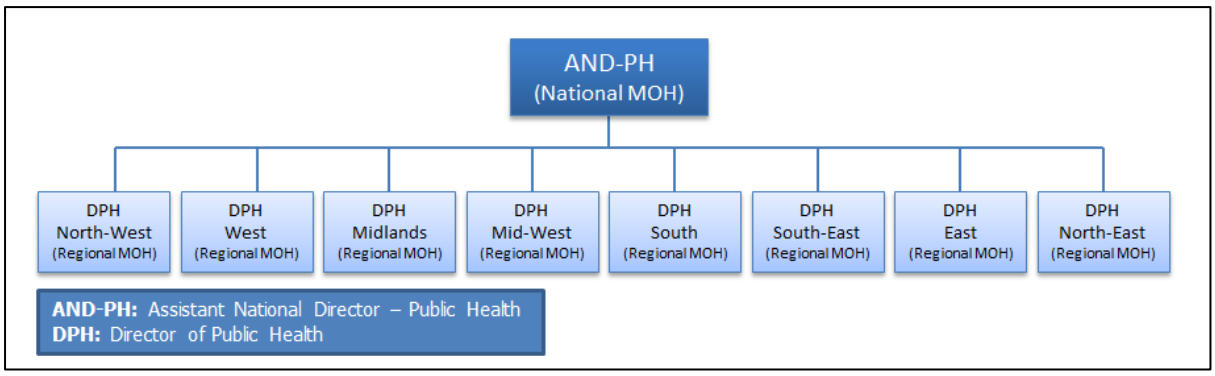

Figure 3. Delegation of MOH function

2.3.2 National Infectious Disease Regulations

All medical practitioners, including clinical directors of diagnostic laboratories, are required under legislation to notify the MOH/Director of Public Health (DPH) in the regional Department of Public Health of specific notifiable diseases. Under the Health Act 1947, the Minister for Health is entitled to specify the infectious diseases which must legally be reported. The list of notifiable diseases, and their respective causative pathogens, is contained in the Infectious Diseases Regulations 1981 and subsequent amendments.[19,20] The 1981 regulations require that medical practitioners notify the MOH "*as soon as he becomes aware or suspects that a person on whom he is in professional attendance is suffering from or is the carrier of an infectious disease*". Under the Infectious Diseases (Amendment) Regulations 2003, S.I. No 707 of 2003, the Clinical Director of a diagnostic laboratory should notify the MOH "*as soon as an infectious disease is identified in that laboratory*".[21,22] The 2003 Amendment introduces the use of case definitions for notifiable infectious diseases as well as the requirement to report unusual clusters or changing patterns of illness that may be of public health concern to the MOH. Furthermore, Regulation 18 of the 2003 Amendment states that the MOH should report cases of infectious disease to HPSC. The most recent amendment to the Regulations is the Infectious Diseases (Amendment) Regulations 2018 (S.I. No. 567 of 2018), where additional infectious diseases are categorised as notifiable.[19] The Health Act and ensuing Regulations are the legal basis for CIDR.

2.3.3. International Health Regulations

From an international regulatory perspective, Ireland is bound by the World Health Organisation (WHO) International Health Regulations (IHR) 2005, the purpose of which is to prevent, protect against, control and provide a public health response to the international spread of disease. HPSC holds the IHR National Focal Point (NFP) responsibilities. The IHR 2005 define a National IHR Focal Point as "*the national centre, designated by each State Party, which shall be accessible at all times for communications with WHO IHR Contact under these Regulations*".[23]

HPSC is also required to report at European level (to ECDC, other Member States and the European Commission) as per Decision 2119/98/EC, superseded by Decision 1082/2013/EU, in the event of outbreaks of infectious diseases extending to, or at risk of extending to, other member states.[24] HPSC is required to report into the Early Warning Response System

(EWRS), which was established under Decision 2000/57/EC (and amended July, 2009 Decision 2009/547/EC) to provide a platform for the reporting of certain communicable disease information to the European community.[25]

2.4 Proposed changes to public health — Crowe Horwath review

In 2018, a report was published which set out a plan to restructure public health services in Ireland, focusing particularly on the role, training and career structure for public health physicians in Ireland.[5] The Crowe Horwath report specifically recommends that the HSE develop an alternative organisational model for the delivery of public health services. It advocates for a 'hub and spoke' model, with a central hub fulfilling a co-ordination role, tasked with setting policies and guidelines and providing expertise. A smaller number of local areas or 'spokes' would deliver more focused services, specific to their local populations.

The Department of Health and the HSE have reviewed these recommendations and have built their implementation into the priorities set out in the National Service Plan. An Implementation Oversight Group, led by the Department of Health, has been established to address the recommendations from the Crowe Horwath report.

2.5 Importance of information management for public health and health protection

As in other countries, public health in Ireland is experiencing significant challenges. Progressive and evolving solutions are required to ensure the sustainable development of public health in Ireland. Enhanced efforts are required to protect and promote health and wellbeing, in an era where populations are aging and unhealthy lifestyles are putting huge strain on healthcare resources, leading to increased mortality and morbidity from non-communicable disease. Furthermore, antimicrobial resistance has become a significant issue, and the health impacts associated with climate change and environmental pollution are evident within society.

Protecting populations against infectious diseases requires that stakeholders accurately and effectively define diseases, measure their occurrence, and seek and implement the appropriate interventions. With the ease of global travel, viruses have the potential to spread rapidly across countries and continents. Public health emergencies such as the Influenza Pandemic in 2009 and the international Ebola Virus epidemic in 2014 have shown the value of reliable and timely data. An evolving and responsive national infectious disease surveillance system is essential to provide timely information on the incidence of suspected and confirmed cases as well as clear clinical guidance for suspected cases and public health advice. In such situations, the Department of Health in Ireland and the HSE closely monitor outbreaks, maintain regular contact with all relevant health professionals and provide extensive guidance for hospitals, GPs and laboratories.

It is essential that the information used for health protection decisions is based on good information management principles to ensure a high level of accuracy of the data and that

all stakeholders who rely on these data are assured of its quality. High-quality data can only be assured if clinicians, laboratories, Departments of Public Health, HPSC and all other relevant stakeholders implement effective arrangements to manage information appropriately. It is important to note that the validity and comparability of data on communicable diseases between Member States is a key issue for the future EU-wide surveillance system and therefore any developments need to be in line with internationally agreed standards.[26]

2.6 Computerised Infectious Disease Reporting (CIDR)

As outlined in Section 2.2, CIDR is the national web-based information system for the statutory notification of infectious diseases in Ireland (Infectious Diseases Regulations 1981 and subsequent amendments). It was developed to support health professionals to meet their obligations for notifying infectious diseases and to assist public health professionals responsible for surveillance and control of infectious diseases in Ireland. There are currently 87 notifiable diseases, covering areas such as:

- vaccine-preventable diseases
- respiratory and direct contact diseases
- infectious intestinal diseases
- vector borne and zoonotic diseases
- blood-borne and sexually transmitted infections
- healthcare associated infections.

Data on 78 of the 87 notifiable diseases are captured with CIDR. A list of notifiable diseases is available in Appendix 3, and some examples of common infectious diseases are outlined in Figure 4. CIDR is not used for the surveillance of the remaining notifiable infectious diseases*.

The core dataset contains both mandatory and non-mandatory information on the disease event. (Mandatory fields are listed below)

- Patient: surname, disease, HSE area, county
- Clinical notification: date of notification, HSE area, county
- Laboratory report: laboratory name, laboratory specimen ID, reported date, organism, patient surname, patient HSE Area, patient county, lab notifier
- Event: disease and interpreted overall lab result, HSE area, county
- Outbreak: disease, HSE area, county, outbreak type

Additional core data items include: date of birth, age, country of infection, patient type (for example, hospital inpatient, general practitioner and outcome). Disease-specific enhanced data items are collected where available, including laboratory test results, clinical presentation, risk factors, exposures and antibiotic sensitivity test.

*The following diseases are not captured on CIDR: invasive infections due to Enterococcus species, Escherichia coli, Klebsiella pneumoniae, Pseudomonas aeruginosa, Staphylococcus aureus, novel or rare antimicrobial-resistant organism, *mcr*-positive enterobacteriaceae infection or colonisation, ano-genital warts and non-specific urethritis.

Enhanced surveillance data for specific diseases can include information such as vaccination status, mode of transmission, foreign travel, treatment and patient outcomes. Some of these fields are automated 'drop down' fields; however, for many there are open text or comment boxes for CIDR users to input this information.

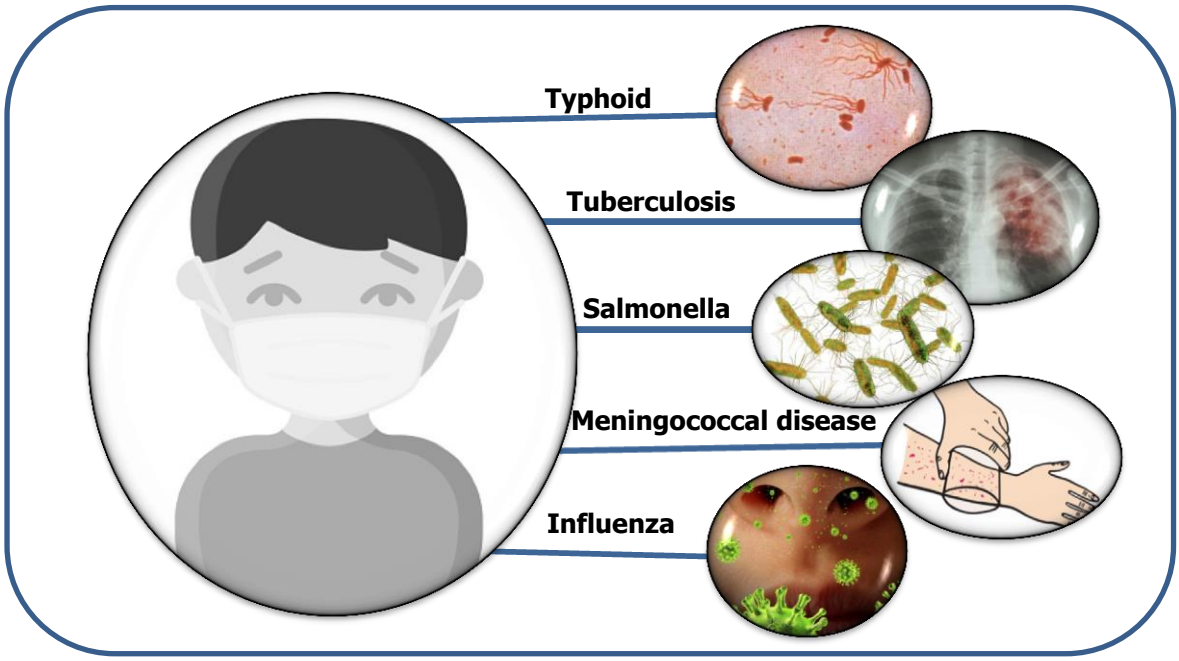

Figure 4. Examples of infectious diseases

CIDR was developed to manage the surveillance and control of infectious diseases. The system has a number of specific functions, including:

- to collect information on notifiable diseases from Departments of Public Health, clinical laboratories and reference laboratories across the country in a single shared national database
- to provide near real-time infectious disease surveillance notifications to CIDR users locally, regionally and nationally
- to provide standardised reports on the incidence and burden of infectious diseases nationally, regionally, and locally
- to allow users to build reports defined by their needs
- to facilitate the early detection of outbreaks
- to provide timely and comprehensive information to facilitate public health action in individual cases of infectious disease
- to facilitate the collection of data to evaluate the effectiveness of prevention and control programmes nationally, regionally and locally
- to enable Ireland to meet its obligations in reporting notifiable infectious disease data to international agencies such as ECDC, the European Food Safety Authority (EFSA) and WHO.[24,27]

The **Computerised Infectious Disease Reporting (CIDR)** system is the national web-based information system for the statutory notification of infectious diseases in Ireland. Microbiologists and laboratory scientists in laboratories, public health professionals and surveillance scientists use CIDR for the surveillance, management and control of infectious diseases.

Before the implementation of CIDR, there was no national electronic information system for infectious diseases in Ireland.[27] The National Disease Surveillance Centre (NDSC), which was the precursor of the current HPSC, identified the need for a new national surveillance system to deliver timely and accurate information on infectious disease.[28]

In September 1999, the NDSC, with the support of the former health board Chief Executive Officers, established a CIDR Development Committee to develop an integrated national electronic communication system to collate, analyse and disseminate laboratory-based information and clinical notification data on communicable disease in Ireland. The committee included representatives from the NDSC, laboratories, Departments of Public Health, regional IT departments, the Food Safety Authority of Ireland (FSAI), the Food Safety Promotion Board (*safe*food) and the Department of Health.

Phase 1 began in 2000 and involved consultation with partners to identify their needs for infectious disease information, the development of functional specifications for an Irish system, together with an evaluation of three systems in development elsewhere, namely, Co-Surv (England and Wales), e-COSS (Scotland) and LITS+ (USA), to examine what requirements were necessary for an Irish system.[28] Phase 2 involved the design and pilot testing of a new system. Phase 3 involved the development of a minimum necessary dataset and national roll-out of the system. The CIDR system was rolled out from 2004, and full implementation across the public health service was achieved in 2011. Historical infectious disease notification data for 1998–2004 was also migrated into CIDR. The timeline for the establishment of CIDR is presented in Figure 5.

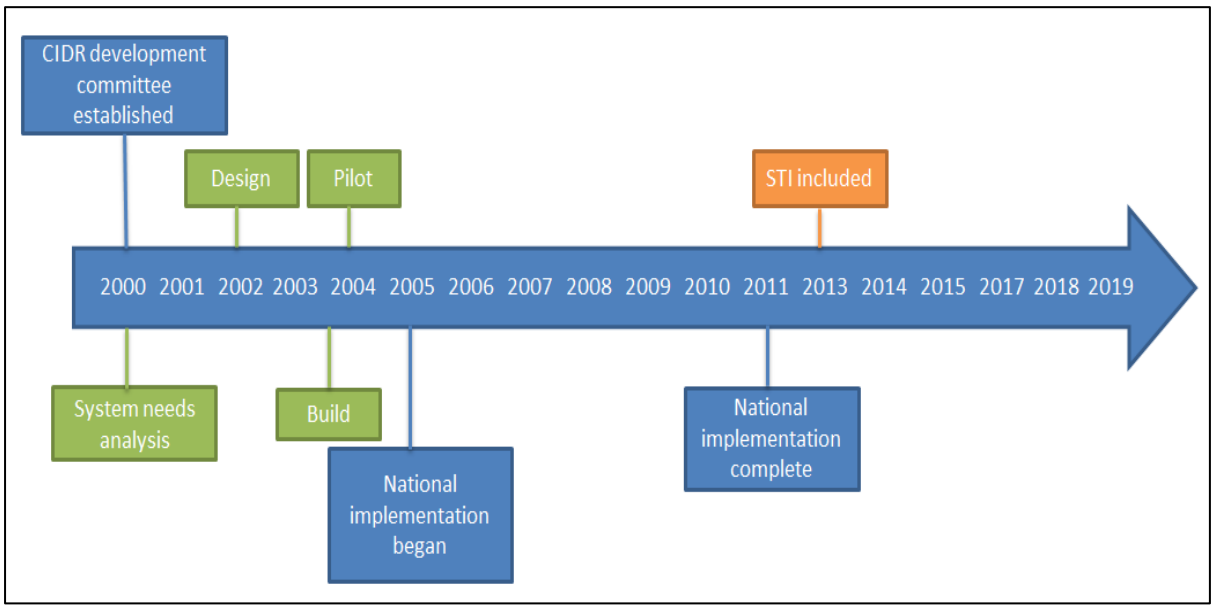

Figure 5. Timeline for the establishment of CIDR

CIDR uses a custom application, a Microsoft SQL Server database and SAP Business Objects reporting software.[29] To ensure that information within CIDR is stored and accessed appropriately, the core system is firewall-protected and access to the system is limited to authorised users. CIDR is further secured by only being accessible over the secure Government Virtual Private Network (gVPN). CIDR holds ISO 27001 certification for Information Security Management. There is also a helpdesk located in HPSC which is available to all CIDR users, covering queries in relation to both technical aspects of the system and the business process-related queries.[27]

2.6.1 Data flows on CIDR

Data collection for CIDR comes from two main sources: the Departments of Public Health and clinical laboratories/reference laboratories.

- **Departments of Public Health:** All medical practitioners are required to notify the Director of Public Health (MOH) of certain diseases outlined in the Infectious Diseases (Amendment) Regulations 2018 (S.I. No. 567 of 2018). They do this by contacting their regional Department of Public Health. These notifications are entered on CIDR by staff in the regional Department of Health.

- **Laboratories:** Most notifications of infectious disease are first notified to Departments of Public Health by microbiology laboratories through electronic upload or manual entry.

Data from CIDR is used by HPSC, Departments of Public Health and laboratories to generate reports on notifiable infectious diseases using SAP Business Objects reporting tool. A breakdown of CIDR users is provided in Figure 6.

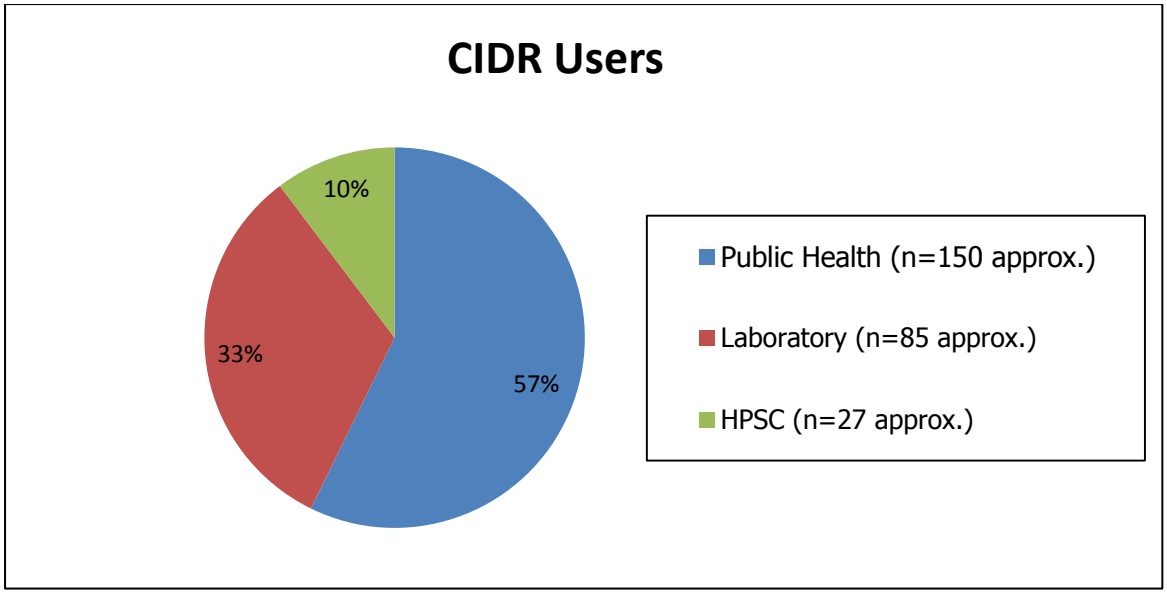

Figure 6. Breakdown of CIDR users

2.6.2 Data flow — Departments of Public Health

Notifications by medical practitioners are made using a standard notification form, which can be found in Appendix 4. This form contains the basic dataset that is applicable to all notifiable diseases. Notifications are be made by fax, by post, by encrypted email or by telephone to one of eight regional Departments of Public Health. These notifications of infectious diseases are manually added to the CIDR system as clinical records by staff in the relevant Department of Public Health and a new 'event' created if it has not already been notified by the laboratory (Section 2.6.4). Otherwise the clinical record is linked to an existing event. Any additional information provided on the notification form can be added to the existing 'event' on CIDR.

An **'event'** is a single episode of an infectious disease in an individual patient. It is the primary unit of information on CIDR.

2.6.3 Data flow — Clinical laboratories and reference laboratories

Most notifications of infectious disease are first notified to Departments of Public Health by microbiological laboratories via electronic upload or manual entry on CIDR. In total, 29 clinical microbiology laboratories in hospitals and the five reference laboratories provide notification data to CIDR either by manual entry or by uploading data extracted from their laboratory information management system (LIMS). Authorisation at local level in laboratories is required before the test result is uploaded. The result is passed to the regional Department of Public Health who link it with the patient and clinical details to create an event on CIDR.

2.6.4 Creation of 'events' in CIDR

Figure 7 represents the flow of data within CIDR. As outlined in Sections 2.6.2 and 2.6.3, Departments of Public Health collate the data from the two principal data sources. Firstly, on receiving either a clinical diagnosis from a clinician or a laboratory result from a laboratory, they carry out a search for the patient details to check if the patient is already on the database. If the patient's details are not in the existing dataset, a new patient record is created. All clinical and laboratory information relating to the disease episode can then be linked to the patient record. If details of that particular disease episode are already on the system, any additional information received is added to the event. An event is a single episode of an infectious disease in a single patient. A patient may have more than one event on CIDR, for example, they may have had a confirmed case of influenza in 2018 and have a clinical diagnosis of meningococcal disease in 2019. Each of these disease episodes are linked to the same patient and recorded as two separate events on CIDR. The team in the Department of Public Health has responsibility for adding all additional information onto the CIDR event and completing enhanced surveillance for particular diseases. Enhanced surveillance is undertaken by healthcare professionals on a subset of infectious diseases. A list of the enhanced surveillance forms available for the subset of infectious disease is included in Appendix 5. Completed enhanced surveillance forms can also be sent to Departments of Public Health from treating clinicians in hospitals or GPs and manually entered into CIDR by CIDR users in the local Departments of Public Health. CIDR can record outbreaks of notifiable diseases as well as any unusual clusters or changing patterns of any illness. Outbreaks can be created by linking together individual cases (events), for example in an outbreak of measles; while a large outbreak of norovirus may be created in CIDR to record summary data only, without each of the individual cases (events) being created for each case involved in the outbreak.[30]

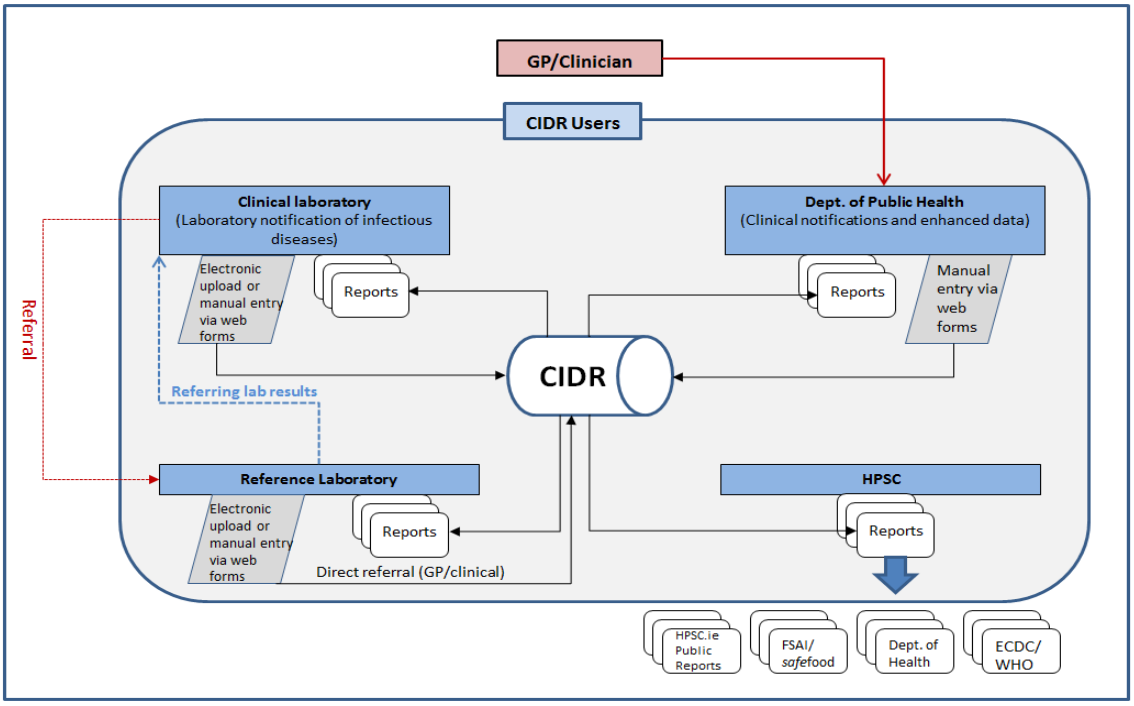

Figure 7. The flow of data on CIDR

2.7 Importance of information management for CIDR

CIDR is an extremely rich and valuable source of data used to protect and maintain public health on a national and international scale. It is the principal system to manage the surveillance and control of notifiable infectious diseases in Ireland. The availability of one central repository for notifiable infectious diseases enables public health professionals to identify trends in notifiable infectious disease, allowing for early intervention and prevention of the spread of infection. CIDR also facilitates the recording of outbreaks as well as any unusual clusters of illness. Controlling outbreaks and clusters of infectious disease is paramount in stopping the spread of disease. This is a vital source of information used by many stakeholders for surveillance, policy development, service provision and reporting purposes. Data quality is of the upmost importance so decisions are made based on accurate information that is available in a timely manner.

2.7.1 Uses of data

CIDR is a shared national information system for the surveillance of notifiable infectious disease.

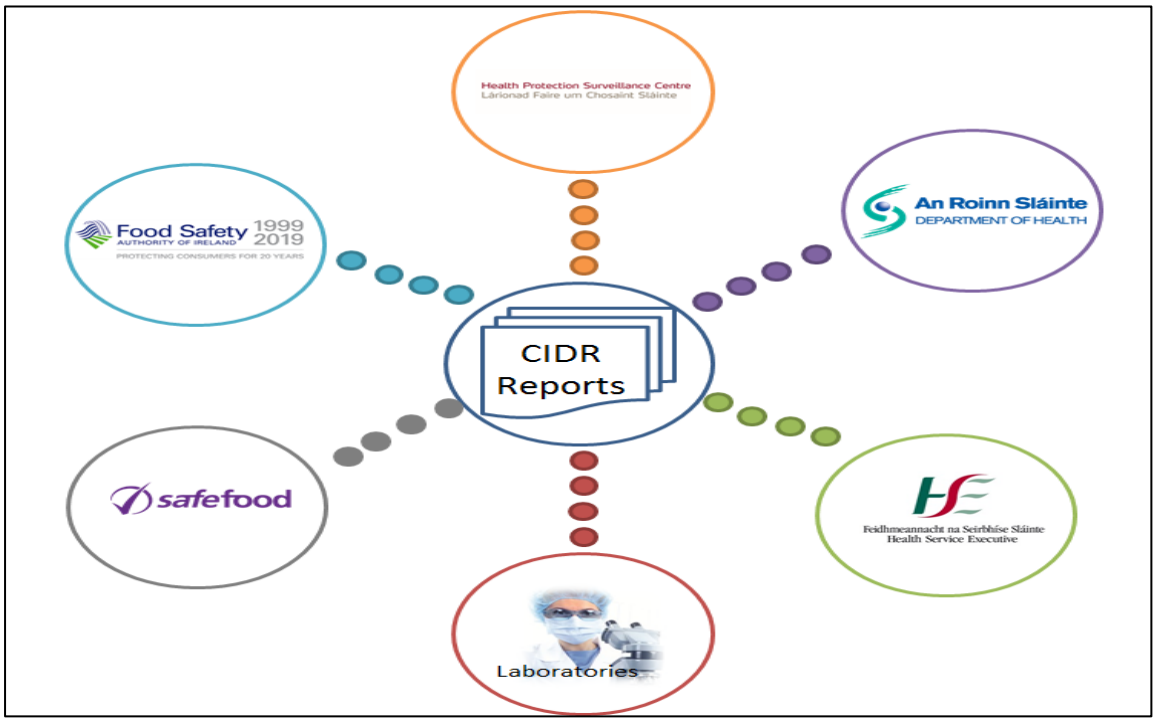

Figure 8. Users of CIDR information

As outlined in Section 2.2, HPSC uses CIDR data for a wide variety of uses. However, CIDR data is primarily used by public health professionals in Departments of Public Health to manage the prevention and control of infectious disease under the Medical Officer of Health function. Medical Officers of Health (MOH) are mandated by legislation to inform themselves of *'all influences affecting or threatening to affect injuriously the public health in the county and as respects the causes, origin and distribution of diseases in the county'.*[31] The MOH in regional Departments of Public Health relies on data captured through CIDR to undertake appropriate public health actions to ensure the population are protected, insofar as possible,

from infectious disease. This can only be achieved by capturing complete and accurate data in a timely manner. The management of information at Department of Public Health level is critical to enable the MOH to fulfil their obligations set out in legislation. The local MOH provides information to HPSC as the agent of the Minister as per the Health Act 1947 and subsequent Regulations.

CIDR data are also used for international reporting purposes, emergency preparedness, identification of emerging threats and service planning, for example, winter planning. HPSC use CIDR data for surveillance purposes and to assist in the development of guidance on infectious disease transmission for example, guidance on how to prevent the spread of healthcare-associated infections. In addition, other government departments and state agencies also have a number of responsibilities that require the use of information generated from CIDR. Some examples of uses of information generated from CIDR are listed below:

- Department of Health and Health Service Executive: The HSE develops a Winter Plan each year to prepare for and manage the anticipated service pressures that occur during the winter months. Influenza causes a considerable burden on services during the winter months and so CIDR data on influenza is used when developing the Winter Plan.[32]
- Department of Agriculture/Food Safety Authority of Ireland/*safe*food/European Food Safety Authority (Human, animal/food): CIDR data is used to meet Ireland's zoonoses reporting requirements.
- National Immunisation Office (NIO): The NIO use information generated from CIDR to assist in their remit of managing vaccine procurement and distribution, developing training and communication materials for the public and health professionals.
- National Immunisation Advisory Committee (NIAC): information generated from CIDR contributes to the evidence base that forms guidance on vaccines and immunisation in Ireland.
- International reporting: HPSC is responsible for reporting information on specified infectious diseases (a sub-set of our notifiable diseases) to ECDC (see Decision 2119/98/EC, superseded by Decision 1082/2013/EU).

Therefore, accurate data is essential in order to put in place the necessary safeguards and interventions on an international and national level to protect the health of the public.

2.7.2 Benefits of good information management for CIDR

The benefit of good information management practices within the CIDR system cannot be over-emphasised.

The benefits of appropriate management of information on CIDR at Department of Public Health level allows for:

- Prompt and appropriate response to public health threats: Accurate and timely processing of infectious disease surveillance data enables prompt response to public health threats by public health professionals. When an infectious disease notification

is received by Departments of Public Health, information on the case should be processed in an accurate and timely manner. Accurate information about a case of infectious disease assists public health professionals with their investigation and ensures the appropriate public health protection measures are implemented to control the spread of disease.

The benefits of appropriate management of information on CIDR at HPSC level allows for:

- Evaluation of public health interventions: Accurate monitoring of incidence of disease and disease trends, at a national and international level, can be used to evaluate the effectiveness of control and preventative public health measures such as the introduction of the rotavirus vaccine in 2016.

- Confidence in the public health system: Good information management provides assurance to the public that infectious disease surveillance data and information is held securely and the necessary precautions to maintain individuals' privacy and confidentiality are in place. Surveillance systems hold sensitive personal health information, the content of which needs to be handled within strict security protocols to guarantee privacy and confidentiality for those using the service. This is essential to promote enhanced engagement with services. CIDR has a number of security features that ensure the protection of personal health information.

- Knowledge sharing: Good information management practices facilitate greater empowerment and involvement by communicating accurate information effectively with all stakeholders, including the public. Ultimately, the aim is to create a culture in which information will be used more effectively for public health, audit, research and quality improvement.[33] HPSC does this by publishing surveillance reports on their website. Information on different diseases is published frequently; weekly, quarterly and annual reports.

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. 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.

- A well-governed managing organisation is clear about what it does, how it does it and is accountable to its stakeholders. The managing 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 to ensure compliance with relevant legislation.

- Managing 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. These plans should be aligned with the broader health information strategies in Ireland.[4,7,34] The strategy should set out how the organisation aims to improve the management of information in order to achieve its overall strategic objectives. This should include consideration of the information technology, information governance, data quality and the use of information.

- A well-governed and managed service can only be achieved if the managing organisation has robust processes in place to monitor its performance. Senior management are responsible for delivery of the objectives set out in the strategic plan. They require information on performance to be assured that the objectives are being met and that practices are consistently of a high standard within the national data collection. This involves using key performance indicators to measure and report on performance and undertaking regular audits to assess practice and performance.

- Managing organisations should have a comprehensive risk management framework in place to ensure that information-related risks are identified, managed and effectively controlled on an ongoing basis.

- Data sharing agreements are necessary to support the provision of good quality data, and the legal and secure handling of data. The agreements outline the responsibilities of both parties and the associated timelines for the completion of tasks.

- Managing organisations with robust governance structures promote transparency by informing those individuals about whom data is being shared about any data sharing

agreements in place. 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 for CIDR against Standards 2, 3 and 4 of the Information Management Standards.

The findings on governance, leadership and management will be presented in the following Sections:

- Overview of governance structures for CIDR within the HSE
- National oversight arrangements for the governance of CIDR
- Lines of reporting and responsibility within the HSE
- Strategic vision, planning and direction for CIDR
- Risk and performance management
- Transparency

3.1 Findings — Overview of governance structures for CIDR within the HSE

Good governance of an organisation requires formalised structures with clear lines of responsibility and reporting for executive and management teams. Governance arrangements should bring together key decision-makers to discuss issues such as strategic planning, performance and information risk management. HIQA examined governance structures for information management within the HSE at the time of the review. As CIDR was developed within a partnership model, with information being input and shared by several stakeholders, HIQA looked at the governance arrangements in place for CIDR in the Health Protection Surveillance Centre (HPSC), the Departments of Public Health, the clinical laboratories and reference laboratories. The way in which each of these CIDR users was embedded within the wider HSE structure was also examined.

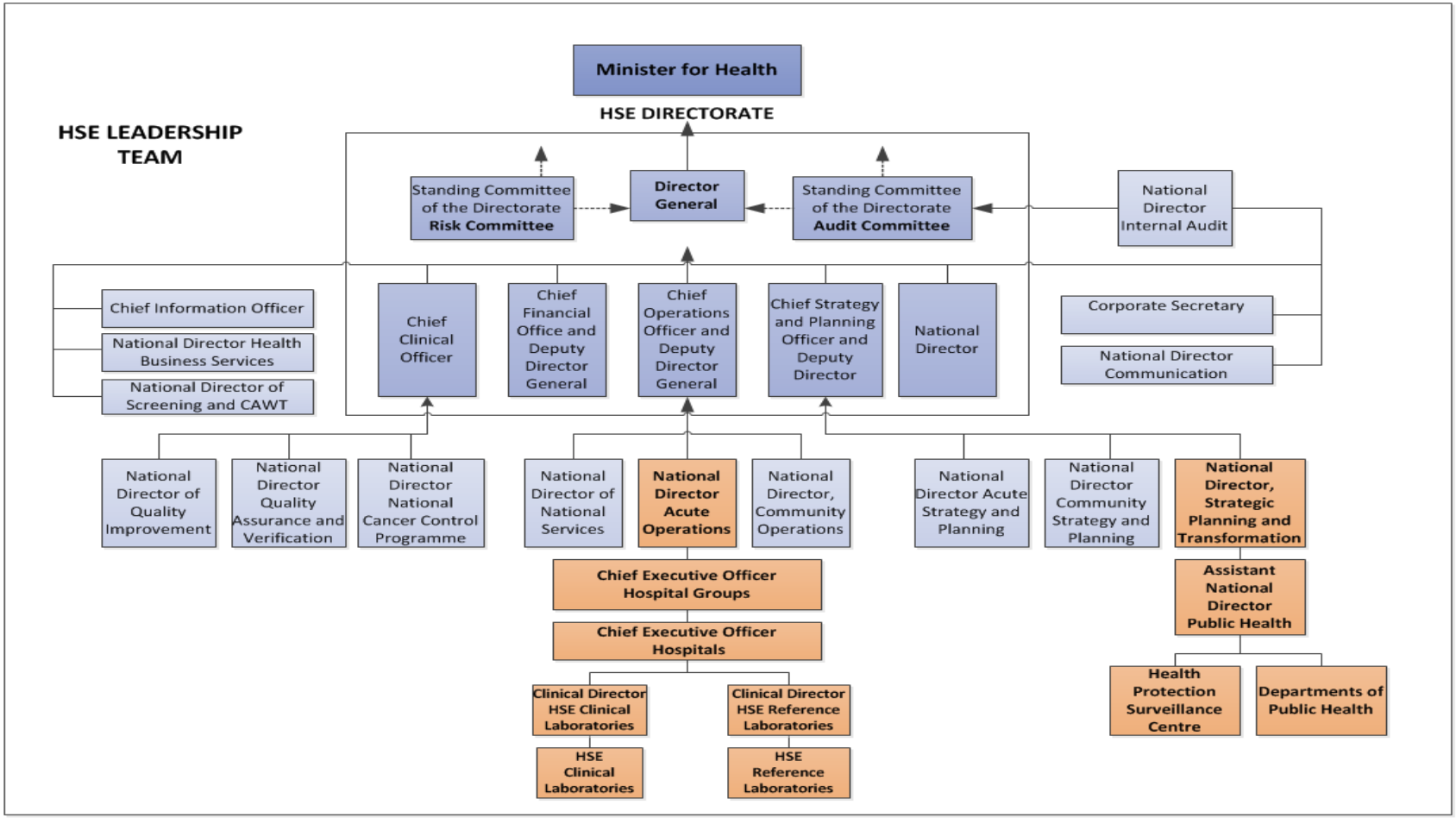

Figure 9. Organisational Structure of the Health Service Executive (HSE)

3.1.1 Overview of governance structures

Figure 9 identifies the key structures within the HSE that are relevant to CIDR. The Departments of Public Health and HPSC are part of the public health system which reports into the Strategic Planning and Transformation (SP&T) function which in turn reports to the Chief Strategy and Planning Officer. The clinical laboratories are primarily based in public hospitals and report through their Clinical Directors and the hospital CEO and, where relevant the hospital group CEO, to the National Director for Acute Operations. Most of the reference laboratories are also based in hospitals and report to the Acute Operations division in the same way as clinical laboratories, although the National Virus Reference laboratory lies under the governance structure of University College Dublin.

3.1.1.1 Strategic Planning and Transformation function, HSE

The organogram for this function is included in Appendix 6. Strategic Planning and Transformation was established in January 2018 arising from new governance arrangements for the health services that provide three new functional areas – Strategy & Planning, Operations and Clinical Management. The work of the Strategic Planning and Transformation function is focused on long-term, multi-annual planning to develop a more sustainable health service, improve efficiencies and value and improve the health and wellbeing of the population. The function works closely with community and acute planning teams and with operational and clinical functions to support transformational change in the health service. The National Director for Strategic Planning and Transformation has overall responsibility for this function and was previously the National Director for the Health and Wellbeing Division. A number of sub-functions that were in the former Health and Wellbeing Division transferred to the new Strategic Planning and Transformation function in January 2018, including Public Health, Health Promotion and Improvement and Research and Development, amongst others.

HPSC, eight regional Departments of Public Health and the National Immunisation Office (NIO) report through the Assistant National Director of Public Health, Health Protection and Child Health (AND-PH) to the National Director, Strategic Planning and Transformation.

The duties of the AND-PH role include compliance with statutory instruments; delivery and development of the public health system including the health surveillance and immunisation services; and advising local government on issues such as housing and sanitation. HIQA was informed that the AND-PH has overall accountability for the CIDR system.

Through interviews, HIQA was informed that the National Director for Strategic Planning and Transformation (SP&T) and AND-PH meet twice a month. The National Director receives a monthly update from the AND-PH and the National Public Health Leadership Group (NPHLG), which covers all areas of their work including the work of HPSC. The National Director also receives various surveillance reports from HPSC, for example during the flu season the National Director receives weekly updates on flu surveillance.

The Strategic Planning and Transformation Senior Management Team meet on a monthly basis. Based on an agenda for one of these meetings (April 2019), HIQA noted that they discuss a range of issues, including updates from each function within the division, performance management reports, resourcing issues and financial updates. Risk

management is a standing item on the agenda and service-level risk registers for each sub-function within the Strategic Planning and Transformation function are reviewed every two months at Senior Management Team meetings (see 3.5.1).

Despite this, when interviewed towards the end of this review process, the National Director for Strategic Planning and Transformation was unaware of some of the key risks identified by HIQA as the review progressed. These included the fact that the CIDR National Steering Committee is not meeting regularly and that there is variation in infectious disease surveillance practice across regional Departments of Public Health. These issues are outlined in greater detail in Sections 3.2 and 3.3 below.

3.1.1.2 National Public Health Leadership Group (NPHLG), HSE

The National Public Health Leadership Group is a senior management team for the public health service. It consists of the AND-PH, the regional Directors of Public Health, the Director of the National Immunisation Office (NIO) and the Director of HPSC. The Public Health Medicine Communicable Disease Group (PHMCDG) is a sub-group of the NPHLG. The purpose of these groups, and their role in relation to public health and surveillance of infectious diseases is outlined in Table 1.

Table 1. The National Public Health Leadership Group and the Public Health Medicine Communicable Disease Group

Group	Purpose	Details	Role in relation to public health and surveillance of infectious diseases
National Public Health Leadership Group (NPHLG)	Public health management team established in 2018 to provide leadership for public health function at national level Aims and objectives outlined in Appendix 7 of this report	**Frequency:** Weekly Health Protection teleconference and formal monthly meeting **Chair:** AND-PH **Membership:** Directors of Public Health, Director of HPSC, Director of NIO **Line of reporting:** AND-PH and National Director for SP&T **Documentation:** TOR developed Sept 2018. Monthly meetings have formal minutes. Monthly report to National Director for SP&T	Agenda for monthly meeting includes review of health protection and risk management Responsible for development of public health strategy and standardising operational matters across the eight regional Departments of Public Health.
Public Health Medicine Communicable Disease Group (PHMCDG)	Sub-group of NPHLG	**Frequency:** Every 2 months **Chair:** Director of Public Health (SE) **Membership:** Representatives from each regional Department of Public Health, HPSC and NIO **Line of reporting:** NPHLG **Documentation:** (TOR/minutes/agenda)	Develop and amend policy and guidelines in relation to surveillance of infectious diseases Develop protocols for individual infectious diseases Develop and approve changes to enhanced surveillance forms Detect and resolve regional differences in surveillance activities. Significant variations referred to NPHLG for resolution.

The NPHLG is scheduled to meet on a monthly basis and, through interview HIQA was advised that health protection is a standing item on the agenda for their meetings. HIQA was not provided with the agenda or minutes of these meetings due to the sensitive nature of the discussions and cannot provide direct evidence on the frequency or the scope of the discussions that take place.

The NPHLG provide a monthly report to the National Director, Strategic Planning and Transformation. HIQA reviewed three of these reports which provide the National Director with a high-level update on the very broad range of public health responsibilities that lie within the remit of the AND-PH and the Directors of Public Health. These include budgeting, recruitment and resourcing of HPSC and eight Departments of Public Health, national immunisation and vaccination schemes, national health promotion programmes, and environmental and water quality issues. The Health Protection update provides the number of notified cases for specific infectious diseases in that period as well as an update on vaccination uptake. These reports are too high-level for any aspect of CIDR to be specifically addressed.

According to their terms of reference (included in Appendix 7), the NPHLG is tasked with developing a long-term public health strategy. Through interviews, HIQA established that the NPHLG have strongly supported the need for a new infectious disease case management system and recommended the introduction of a system similar to the Welsh *Tarian* system in Ireland. Despite this, from evidence provided through interview, HIQA established that CIDR has not been discussed in any detail at the NPHLG.

HIQA identified from interviews with staff from Departments of Public Health that there is a lack of consistency in approach in relation to the collection of enhanced surveillance information. HIQA were advised that all requests for enhanced surveillance are considered by both the NPHLG and the PHMCDG. However, HIQA found evidence of variations in practice in relation to enhanced surveillance for particular diseases. Because enhanced surveillance is considered to be optional rather than mandatory, Departments of Public Health agree to enhanced surveillance requirements, often in the knowledge that they will not have the resources to routinely complete them. There is an acceptance that individual Departments of Public Health can discontinue the enhanced surveillance of particular diseases based on local priorities. HIQA was informed that the NPHLG have begun the process of standardising practice across regional departments and it was acknowledged that there is still a significant amount of work to be done in this area.

There is clear potential for the NPHLG to be better utilised to address issues and risks related to surveillance of infectious disease and the role of CIDR therein. The group has capacity to drive improvements in data quality and the use of data to inform case management and policy decisions. The Directors of Public Health within the group hold the overall responsibility for management of information on infectious diseases, including CIDR data, within their region. However, it must be recognised that the breadth of public health activities covered by the Directors of Public Health is such that they will only ever have a limited amount of time to focus on CIDR. In addition, this group does not have oversight of the roles or requirements of clinical or reference laboratories.

3.1.1.3 Health Protection Surveillance Centre (HPSC), HSE

As outlined in Section 2.3, HPSC is Ireland's specialist agency for the surveillance of communicable diseases and the managing organisation for CIDR. An overview of the functions of HPSC has been previously outlined in Section 2.3.

HPSC is staffed by a multidisciplinary team including specialists in public health medicine (SPHMs), medical officers, surveillance scientists, infection control nurses, research officers and surveillance assistants. As set out in Figure 10 below, the staff of HPSC are assigned to the following specialised teams:

- Gastroenteric, Zoonotic and Vector-borne diseases (GZV)
- Hepatitis
- Respiratory
- Vaccine-Preventable
- HIV and STIs
- Microbiology/HCAI/ SARI/EARS-Net/Maternal Sepsis
- Emergency Planning

Each specialist team is headed by a SPHM or a consultant microbiologist, who reports to the Director of HPSC. They are supported by a number of cross-functional units (Administration, IT and IT Surveillance Systems) and the Senior Surveillance Scientist. The IT Surveillance System team is responsible for the IT and technical aspects of CIDR. The staffing allocation in HPSC is 48 FTE posts; at the start of the review five of these positions were vacant.

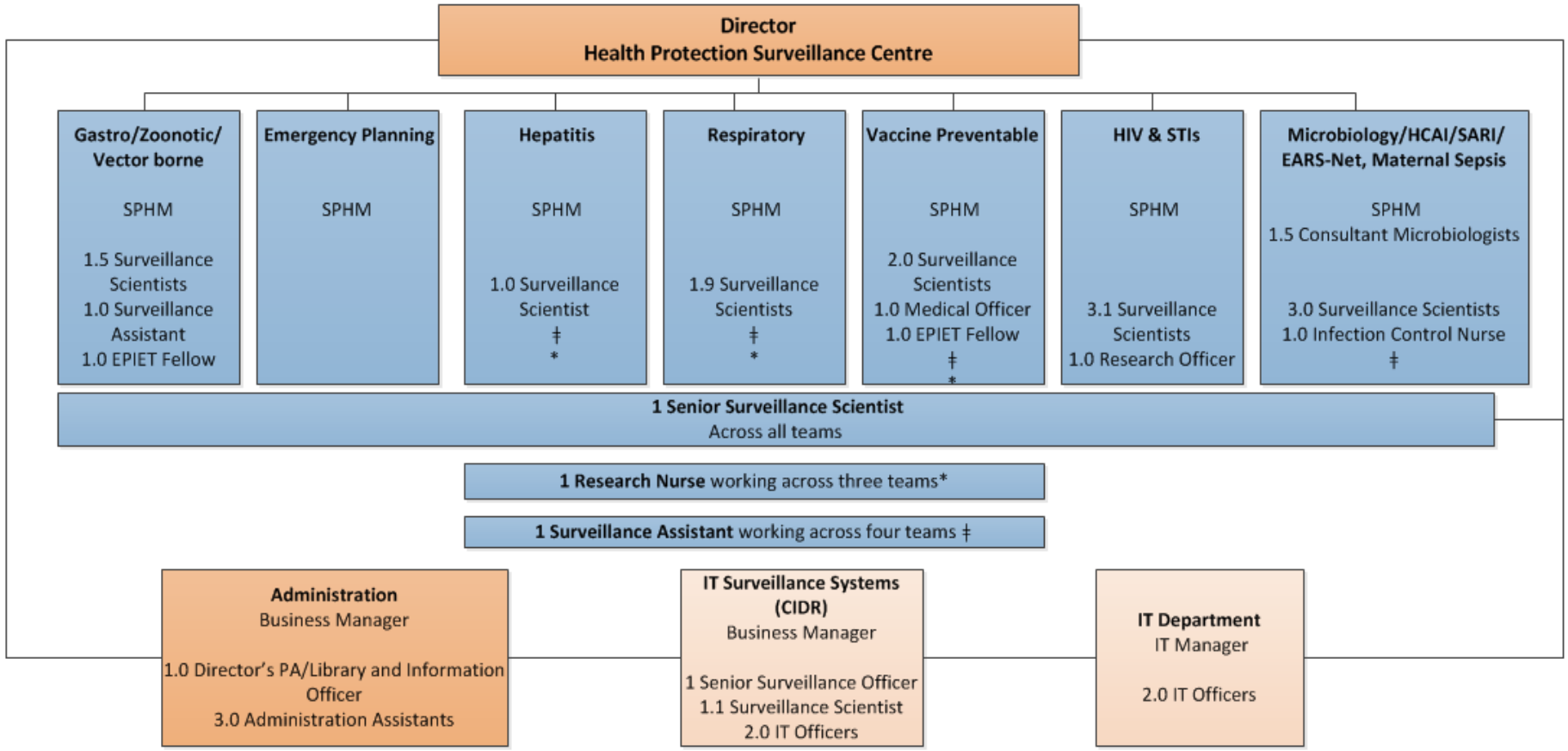

Figure 10. Organisation Chart for the HSE Health Protection Surveillance Centre (HPSC)

3.1.1.3.1 Director of HPSC

The Director of HPSC reports to the AND–PH and is a member of the NPHLG. The Director post in HPSC was vacant for a period of three years following the retirement of the previous Director in May 2016. The position was back-filled for this period of time by the AND-PH, in addition to two existing roles as AND-PH and Acting Director of Public Health North East.

HIQA was advised that the Director post had not been filled for the previous three years because, although the position had been advertised on three occasions, it had not been possible to attract suitable candidates. While the difficulty in recruitment is acknowledged, HIQA believe that the consequence was that CIDR did not have the appropriate level of oversight and leadership during this period. HIQA established that for this three-year period there was too great a reliance on one individual to deliver governance and leadership at three different levels within the public health function. The evidence presented in this report indicates that this had a negative impact on effective delegation of responsibilities and escalation of issues and risks in respect of CIDR.

As the evidence-gathering stage of this review was being concluded, HIQA was advised of the appointment of an Interim Director for HPSC on 8 July 2019. HIQA was informed that this interim post was being put in place to support initial reorganisation in HPSC as part of the process to develop a new model for delivery of public health services in Ireland, resulting from the Crowe Horwath report.[(5)]

In line with this, the HSE advertised a new position of 'Clinical Director for Health Protection' in August 2019. HIQA were provided with the job specification for this role. It is envisaged that a successful appointee will report to the National Director for Strategic Planning and Transformation and have direct responsibility for providing leadership for HPSC, the NIO, the Departments of Public Health and the work of the Medical Officers of Health appointed by the HSE. They will also be tasked with ensuring that effective governance arrangements are in place across HPSC, the NIO and the Departments of Public Health and with providing 'best-in-class' health protection intelligence.

3.1.1.3.2 HPSC Senior Management Team

The Director of HPSC is supported by a Senior Management Team (SMT). This group comprises specialists in public health medicine from the individual disease teams, consultant microbiologists, a senior surveillance scientist, the Business Manager, the IT Manager and the IT Surveillance Systems Business Manager. Meetings are chaired by the Director of HPSC and have been chaired by the AND-PH while this position was vacant. Clear terms of reference have been set, including a requirement that meetings are scheduled at least quarterly. The terms of reference are broad and typical of an organisational management team, including strategic decision-making, setting out strategic business plans, monitoring the performance of HPSC and oversight of audits. HIQA noted that the terms of reference of this team do not refer to CIDR specifically.

HIQA was advised that the HPSC Senior Management Team is scheduled to meet every 4 to 6 weeks and was provided with evidence that the management team met six times between Jan 2018 and February 2019. There were gaps of several months between some meetings

because of the lack of availability of the Acting Director, who up to July 2019, was responsible for chairing these meetings.

HIQA reviewed the minutes from three SMT meetings held between late 2018 and February 2019. The meetings addressed operational issues around CIDR including the need for up-dating of equipment but there is no evidence that they addressed issues such as strategic development or risk management in relation to CIDR in any detail.

3.1.1.3.3 HPSC CIDR Team

The CIDR team at HPSC have formal responsibilities for elements of CIDR and their roles and job descriptions reflect these. The CIDR Business Rules set the rules for use of CIDR at all locations, although these are not formally delegated or accepted.

HIQA identified that there was no formal scheme of delegation in place to further assign responsibilities for CIDR.

3.1.1.4 Departments of Public Health

As outlined in Chapter 2, each regional Department of Public Health is led by a Director of Public Health who reports to the AND-PH. The AND-PH has assigned the MOH function, as outlined in Section 2.2.1, to the Directors of Public Health in each region. HIQA identified that CIDR users in Departments of Public Health have the highest level of access to surveillance data because, as well as being able to enter and see patient-specific details on CIDR, they hold paper notifications of infectious disease submitted by clinicians and follow-up case management information. As the Director of Public Health is legally mandated under the MOH function to collect regional data, they are the person at regional level who is accountable for the data. The Director of Public Health is generally supported by a senior management team and a range of staff including SPHMs, surveillance scientists, infection control nurses, research officers and administrative staff. At the time of the Crowe Horwath review in 2018, there were 7.5 Directors of Public Health, 34.7 specialists in public health medicine and 144 multi-disciplinary support staff working across the eight regional Departments of Public Health.[(5)]

3.1.1.5 Diagnostic and reference laboratories

The clinical laboratories which input data to CIDR are under the governance of the Acute Operations Division of the HSE. As outlined in Section 2.6.3, HIQA was informed that thirty four clinical laboratories (both local microbiology and reference laboratories) input laboratory results on CIDR. Under the Infectious Disease (Amendment) (No.3) Regulations 2003, the clinical director of a laboratory is responsible for notifying the MOH of suspected cases, clusters or unusual patterns of infectious disease. Although the governance arrangements in laboratories were not entirely clear to CIDR users, the general consensus at focus groups was that the Clinical Director has overall responsibility for governance of CIDR in the laboratory.

3.2 Findings — National oversight arrangements for the governance of CIDR

3.2.1 CIDR National Steering Committee

CIDR was established with a national oversight structure, the CIDR National Steering Committee. The CIDR National Business Rules Committee is a sub-group of this Committee. The roles of the CIDR National Steering Committee and the CIDR National Business Rules Committee in relation to CIDR are outlined in Table 2.

Table 2. Key National Committees for CIDR Governance

Committee	Purpose	Details	Role in relation to CIDR
CIDR National Steering Committee	According to the CIDR Business Rules, to provide overall governance for CIDR	**Frequency:** Not specified in TOR or CIDR Business Rules **Chair:** AND-PH(to July 2019) Director HPSC (from July 2019) **Membership:** Consultant PHM, HSE Clinical Microbiologist, ISCM ICT Delivery Director, OoCIO IT Surveillance Systems Manager, HPSC Senior Surveillance Scientist, HPSC Scientific Officer, *safe*food **Line of reporting:** Unclear **Documentation:** (TOR/minutes/agenda)	Terms of Reference: (1) Manage the project, ensuring it achieves its business objectives given the budget, resources and timescales allocated to it (2)To ensure co-operation and ownership of the project within the wider organisations (3)To ensure resources are made available as required (4)To ensure human resources are managed properly (5)To ensure appropriate information governance is in place for CIDR
CIDR National Business Rules Committee	To update the CIDR Business Rules as required	**Frequency:** As required **Chair:** SPHM, Dept PH S **Membership:** Representatives from HPSC, laboratories and Departments of Public Health **Line of reporting:** Sub-committee of CIDR National Steering Committee **Documentation:** CIDR Business Rules	Re-convened whenever an update of the CIDR Business Rules is considered necessary Role is to update CIDR Business Rules Last reconvened Oct 2018 to update the CIDR Business Rules in line with General Data Protection Regulation

Section 1.3 of the draft revised CIDR Business Rules states that the CIDR National Steering Committee is intended to provide overall governance for CIDR, although this role is not reflected in the current terms of reference for this committee or in the current CIDR Business Rules. Figure 11, taken from the draft revised CIDR Business Rules, illustrates HPSC's view of the governance arrangements for CIDR. However, HIQA has concluded that this figure does not clearly outline the actual governance arrangements for CIDR as it doesn't address the roles of the HPSC Senior Management Team and several HPSC internal staff and committees that play a role in governance of CIDR. It also does not clarify the relationships with the NPHLG, the Strategic Planning and Transformation function, individual Departments of Public Health or the laboratories.

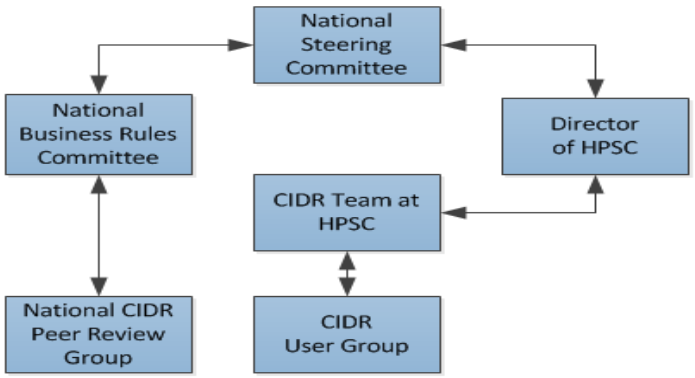

Figure 11. Governance of CIDR, taken from Version 3.6 of the CIDR Business Rules

To achieve compliance with the Information Management Standards, the managing organisation of a national data collection must have effective management, leadership and management structures in place and should be able to demonstrate that they have a detailed strategy in place for information management. Best practice for national surveillance systems similar to CIDR is to have an oversight board or committee involved in deciding the strategic direction for the surveillance system as well as decision-making, audit and risk management (see more detail in Appendix 8).[12,35,36,37,38] In order to be able to do this, the oversight committee needs to have appropriate membership, reporting relationships and terms of reference.

Membership: HIQA identified that the CIDR National Steering Committee is currently the only governance committee for CIDR with representation from all of the CIDR partners including the Departments of Public Health, HPSC and the laboratories. Having reviewed the membership of this Committee, HIQA consider that the membership and the level of representation may not be appropriate. Over the past three years, this Committee was chaired by the AND-PH in the absence of a Director for HPSC. HIQA has now been informed that, since the appointment of an interim Director, the Committee will be chaired by the Director of HPSC. The Directors of Public Health and the Clinical Directors of the laboratories are not currently represented on the group. The Departments of Public Health have a single representative but not at Director level. All of the clinical laboratories and reference laboratories are represented by a single delegate from their professional body, the Irish

Society of Clinical Microbiologists. If this is the Committee which is intended to provide leadership and accountability for CIDR, it is important that the representation is at a level which can drive improvements and which can ensure that decisions taken by the group are fully implemented at all sites where CIDR is used.

Reporting Arrangements: HIQA identified that there is no clear reporting line or support structure for the CIDR National Steering Committee. There is no direct link between the committee and the NPHLG, the National Director for Strategic Planning and Transformation, the Directors of Public Health or the laboratories.

Terms of reference: HIQA reviewed the terms of reference for this committee. A document entitled 'National Steering Group –Terms of Reference' was submitted to HIQA but there was no date or version details for the document. The document outlines five functions for the CIDR National Steering Committee (see Table 2). Four of the five functions refer to 'the project' but there is no definition of the project involved. Based on these terms of reference, HIQA concluded that the committee was established as a project management group to steer the implementation of CIDR and did not evolve, or was not sufficiently reconfigured, to take responsibility for the strategic direction, sustainability or further development of CIDR once it had been fully implemented.

Meetings: There is no specified schedule for meetings of the CIDR National Steering Committee in either its terms of reference or the CIDR Business Rules. HIQA was informed that the CIDR National Steering Committee had not met at all during 2018 due to difficulty in getting a quorum of members together. This arose because of the need to replace three Committee members. HIQA was provided with the agenda and minutes for three teleconference meetings held in 2017, the last of these in October 2017. The minutes indicate that the CIDR National Steering Committee, when it was meeting, focused largely on operational issues. The agenda and minutes for the teleconference meetings make no reference to strategic planning for CIDR. In January 2019 the membership of this committee was restored and an introductory teleconference took place on 25 February 2019. Through interviews HIQA learned that, prior to the renewal of membership in 2019, the Departments of Public Health had not been represented on the committee but they were included at this stage. HIQA reviewed minutes from the meeting of 25 February which highlight that a CIDR Roadmap or Strategic Plan 'would be useful'. An additional meeting was held in July 2019 but, as this meeting took place after the evidence-gathering phase of this review, HIQA have not reviewed the minutes of this meeting.

Even if it was meeting more regularly, it is difficult to see how the CIDR National Steering Committee, with its current membership and reporting arrangements, could provide effective governance and leadership of CIDR or ensure that decisions taken at the level of the committee are implemented by CIDR partners on the ground. If this committee is to provide leadership and governance for CIDR, its role needs to be significantly enhanced and the findings set out below need to be addressed.

A review of other international surveillance systems (Appendix 8), indicates that best governance practice for surveillance systems similar to CIDR involves having a governance structure which provides oversight and strategic direction but also facilitates stakeholder

engagement.[12,35,36,37,38] This oversight arrangement could take the form of an oversight committee, a management board, an advisory forum, a board sub-committee or an appropriate combination of these models.

Findings in relation to the National Oversight of CIDR

- The CIDR National Steering Committee is not currently providing effective oversight of CIDR. The Committee was originally established as a project steering group to facilitate the design and implementation of CIDR. However, it has not evolved or been reconfigured sufficiently in the past fifteen years to allow it to take responsibility for the strategic direction, sustainability and future development of CIDR.
- The terms of reference for the committee are not what would be expected for a committee responsible for the strategic oversight and development of a national surveillance information management system.
- The reporting, influencing and decision-making powers of the committee are not defined.
- The link between the CIDR National Steering Committee and other key CIDR stakeholders is unclear. It does not have an appropriate support structure to inform decision-making or ensure decisions taken by the Committee are implemented.
- The committee is not meeting regularly and did not meet at all from October 2017 to February 2019. Furthermore, meetings focus on operational rather than strategic issues.
- The committee's membership is not fully representative of all stakeholders. Clinical laboratories, reference laboratories and Departments of Public Health are not adequately represented.
- The National Public Health Leadership Group (NPHLG) is being used as an alternative forum to discuss infectious disease surveillance and associated information systems, but not with the focus and in the level of detail that is required. The diagnostic and reference laboratories are not represented on the NPHLG.

3.2.2 CIDR National Business Rules Committee

The CIDR National Business Rules Committee, a sub-group of the CIDR National Steering Committee, was first established in 1999 to plan the levels of access and resources required for the CIDR system which was then under development. Its role then evolved to draft the first set of CIDR Business Rules for participation in pilot-testing of CIDR in 2002. Currently, the committee is re-convened whenever an update of the CIDR Business Rules is considered necessary. It is chaired by an SPHM from one of the Departments of Public Health and has representatives from laboratories, HPSC and the Departments of Public Health. The CIDR Business Rules are important from a governance perspective in that they set out the principles of participation in CIDR, to which all CIDR partners are expected to adhere. The CIDR Business Rules which are currently in operation are Version 3 which was adopted in

2014. The CIDR Business Rules Committee re-convened in 2018 to revise the CIDR Business Rules to take account of the General Data Protection Regulation[†] (GDPR). The draft revised CIDR Business Rules made available to HIQA for the purposes of this review was Version 3.6, dated February 2019. HIQA was informed that this draft is almost complete and ready for circulation later this year. Once the draft revised CIDR Business Rules are signed off by the Business Rules Committee, they will be approved by the CIDR National Steering Committee and circulated to the CIDR Manager at each site where CIDR is used. HIQA has also been advised by HPSC that this will be followed by an 'all user' phase of the roll-out process which will involve communicating a summary of the key revisions, FAQs and provision of a point of contact for queries to all CIDR users.

For the remainder of this report we will distinguish between two versions of the CIDR Business Rules:

- Current CIDR Business Rules refers to Version 3.0 which came into effect in 2014
- Draft revised CIDR Business Rules refers to Version 3.6, dated February 2019, which was made available to HIQA for the purpose of this review.

3.3 Findings — Lines of reporting and responsibility for CIDR within the HSE

A well-defined governance structure should clearly set out lines of accountability and responsibilities which are communicated throughout the organisation to ensure a shared understanding of roles.

3.3.1 Lines of reporting and responsibility for CIDR within HPSC

The deficiencies in governance and leadership as a result of the Director role in HPSC being vacant for an extended period have already been highlighted in Section 3.1.1.3.1.

Under the current CIDR Business Rules there is a requirement for a local CIDR Manager at each location where CIDR is used but no-one is assigned overall responsibility at these sites for data protection or control. The draft revised CIDR Business Rules introduce a new requirement for a Data Controller at each site and the Director of HPSC will carry out the this role for HPSC. This carries with it significant legal obligations and responsibilities for data collection, quality, access and protection. HPSC should ensure it has a system to provide the Director with assurance in relation to each of these. Interviews with staff in HPSC identified that while they run regular validation reports and request Departments of Public Health to complete data fields on CIDR to drive improvements in data quality, they have no mechanism in place to compel the collection of the data even where this is necessary for monitoring of national disease trends or for submission to ECDC, WHO or other international surveillance projects.

[†] EU General Data Protection Regulation, EU Regulation 2016/679

Further delineation of the respective roles of the Director of HPSC and the AND-PH for information management is required, particularly in light of the recently advertised position of Clinical Director for Health Protection, the imminent reform of the public health system and the roll-out of the draft revised CIDR Business Rules.

3.3.2 Lines of reporting and responsibility for CIDR within the Departments of Public Health

As highlighted in Section 3.1.1.4, the Directors of Public Health have the overall responsibility for collection and management of information on infectious diseases within the eight regional Departments of Public Health. They are generally supported by a senior management team and a range of staff, including SPHMs, surveillance scientists, infection control nurses, research officers and administrative staff.

Under the current CIDR Business Rules it is stipulated that there should be a local CIDR Manager at each site where CIDR is used and they are assigned a wide range of responsibilities including compliance with the business rules, information governance, timeliness of data entry and event creation and access arrangements for local CIDR uses.

The draft revised CIDR Business Rules indicate that:

- there should be a CIDR Data Controller and a designated CIDR Manager in place at each location where CIDR is used
- it is appropriate that the CIDR Data Controller functions in Departments of Public Health are carried out by Medical Officers of Health.

This reflects a key revision of the roles within the CIDR Business Rules. As well as modifying the role of the local CIDR Manager it introduces a new role for a CIDR Data Controller at each site where CIDR is used. It also indicates that the CIDR Data Controller within Departments of Public Health should be the Medical Officer of Health or Director. This is consistent with their existing role as Medical Officer of Health.

From interviews and focus groups conducted with public health staff, HIQA learned that, currently, the Director of Public Health holds responsibility as the regional CIDR Data Controller but, in practice, they informally delegate some of these responsibilities to SPHMs or surveillance scientists on their team. Delegated responsibilities often include data quality and CIDR training. In many cases there seemed to be a lack of clarity about who is fulfilling the local CIDR Manager role, with no one individual having overall responsibility.

During the review, HIQA identified significant differences in the completion of enhanced surveillance information for individual diseases between regional Departments of Public Health. Evidence from interviews with public health staff indicated that some regions have a capacity to collect almost all enhanced surveillance information based on the guidance and forms prepared by HPSC and approved by the PHMCDG. However, some Departments of Public Health have taken independent decisions not to collect particular enhanced surveillance information for a variety of reasons. These include prioritization of other public health requirements linked to resourcing issues or a view that some data fields are not

required for public health management purposes. Also, there can be very significant regional differences in the time taken to complete enhanced surveillance information, as highlighted in a recent evaluation of the syphilis surveillance system in Ireland.[39] In this study, the enhanced surveillance form was completed for only 65% of syphilis cases and the time taken to complete the form ranged from 1 day in some regions to a median value of 26 days in other regions, and, on occasion, up to 15 months. The consequences of this are that there is incomplete national epidemiology for syphilis. Some of the enhanced surveillance fields, such as mode of transmission, country of birth, HIV status and re-infection status are important in terms of public policy decisions, so incomplete or delayed information means that decisions about national health policy and health protection measures are not based on timely, complete data.

Evidence from focus groups indicated that decisions not to collect enhanced surveillance information are generally taken by the Director of Public Health and communicated to the AND-PH and HPSC. They do not have to be discussed at the NPHLG, may not be formally recorded and the implications of these decisions are not addressed through the risk management process.

A key issue identified during interviews with staff from Departments of Public Health is that CIDR is not discussed in any detail at any of the forums where Directors of Public Health meet, including their meetings with the AND-PH or the NPHLG teleconferences. The role of the Directors of Public Health is critically important in that they are the individuals with overall legal responsibility for the collection, protection and use of the data in CIDR. They make decisions about what public health and enhanced surveillance activities are prioritised and how resources within their department are allocated. They review performance of their departments against prioritised objectives at departmental management meetings and this review process determines the focus of departmental staff. The Directors of Public Health are therefore central to achieving improved and consistent surveillance on infectious disease and ensuring that data is used to deliver maximum impact for epidemiology, case management and health protection purposes. This will continue to be the case as the new, more devolved, public health model is implemented. It is important that a system is put in place to ensure that Directors of Public Health have a clear overview of any issues arising with CIDR and any future health information system and that they have sufficient opportunities to discuss and implement solutions, to fulfill their responsibilities to improve data collection and use.

3.3.3 Lines of reporting and responsibility for CIDR within clinical laboratories

As outlined in 3.3.2 above, under the current CIDR Business Rules, a local CIDR Manager within laboratories is allocated a range of responsibilities for CIDR data.

The draft revised CIDR Business Rules indicate that the Clinical Director should fulfil the CIDR Data Controller role which has overall responsibility for data collection, quality and protection in laboratories.

As with the Departments of Public Health, HIQA identified through interviews and focus groups, that there was a lack of clarity about the governance of CIDR within the laboratories. Most laboratory staff believed that the Clinical Director was ultimately responsible for the overall governance of CIDR. Some members of laboratory staff appeared to have been effectively assigned the existing role of local CIDR Manager without formally accepting it or being clear about the responsibilities involved. In other laboratories, the role seemed to be shared by two or more surveillance scientists. As the revised CIDR Business Rules are rolled out, these roles need to be clearly defined and formally delegated.

3.4 Findings — Strategic vision, planning and direction for CIDR

Strategic plans are the foundation on which all businesses operate. A strategy should outline the vision for the national data collection, its current and future aims and objectives, its legal responsibilities and future needs. 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 business 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.

The HSE National Service Plan is the annual business plan which sets out the services against which the HSE's performance is measured.[40] The HSE National Service Plan 2019 sets a number of key priorities and actions for the public health service. Two of these development priorities are important in relation to CIDR:

- develop a case and incident management system for health protection to support more efficient and robust reporting and management of infectious disease outbreaks
- develop a new operating model for public health in Ireland, in conjunction with the Department of Health.

These are also reflected in the Business Plan for Health & Wellbeing, Strategic Planning and Transformation 2019, an electronic copy of which was supplied to HIQA by the National Director for Strategic Planning and Transformation. This is effectively the annual business plan for the Strategic Planning and Transformation function and is aligned to the HSE National Service Plan 2019.

While the key priorities referred to above are not the subject of this review, they define the context within which the HSE and HPSC are currently operating. They outline high-level strategic objectives which would have a clear impact on CIDR but the consequences for HPSC or CIDR are not addressed.

3.4.1 Strategy for CIDR

HIQA was informed through the information request, and during interviews that, at the time of the review, there was no strategy in place for CIDR or for the future public health

information management system. HIQA also identified that strategic developments for CIDR are not discussed at any of the higher-level groups within HPSC or HSE.

CIDR was originally intended to be a near real-time surveillance system. However, the data flows are complex and require many stakeholders to input data at different stages, particularly enhanced surveillance information. This means that CIDR data is often delayed or incomplete. At focus groups, many stakeholders expressed concern that CIDR had not developed any significant increase in functionality since its introduction 14 years ago. A new CIDR module to facilitate electronic surveillance of HIV and sexually transmitted diseases has been in development since 2016. It was foreseen at the outset that CIDR might be extended to provide an infectious disease case management system but this development never occurred.

Interviews and focus groups with staff from public health, clinical laboratories and HPSC all indicated that CIDR data entry is time-consuming and that the system itself was largely in 'maintenance' mode while technology, laboratory methods and the quantity of available information have all evolved significantly. The need for CIDR to be up-graded in terms of operability, agility, future-proofing and alignment with a potential future case management system were highlighted.

The above issues, as well as those outlined below, indicate the urgent need for a strategy for an information management system to support Ireland's future public health needs with full integration of CIDR into that system. Countries such as Wales, England and Canada have all recently developed long-term strategies for their infectious disease surveillance systems, as has ECDC.[26,36,41,42,43,44,45,46] Further details are outlined in Appendix 8.

3.4.1.1 Crowe Horwath Report implementation

As outlined in Section 2.4 of this report, it is envisaged that the delivery of public health services within the HSE will undergo a significant re-organisation in the coming years. Crowe Horwath implementation is regarded by the Strategic Planning and Transformation function as a 'once in a lifetime' opportunity to streamline public health services and to avoid much of the duplication of work in the present system. Implementation of the recommendations in the Crowe Horwath report will have significant consequences for CIDR and it is important that the Implementation Oversight Group incorporate CIDR as they plan for this. HIQA was advised that HPSC provided a submission to the Health Protection module of the implementation project in June 2019 to inform the development of a Health Protection Design Options paper.

3.4.1.2 Interface between CIDR and the proposed Case Management System

As CIDR was not designed to be an infectious disease case management system, many of the case management activities carried out by Departments of Public Health are not currently recorded on CIDR, leading to the emergence of parallel case management databases at regional level. Hence, the Departments of Public Health have identified the need for a case management system which will capture the details for follow-up on cases of infectious disease including interactions with clinicians at local level, tracing of contacts, vaccination, antibiotic administration and chemoprophylaxis. The NPHLG has reviewed

alternative case management systems and recommended that a system analogous to the Welsh *Tarian* system be introduced in Ireland. This project is being progressed by the Departments of Public Health and the HSE's Office of the Chief Information Officer. HIQA was advised that the Public Health Case Management system is still at the scoping/project request stage and that, if approval is granted, a formal project team will be established including a CIDR representative. While there is agreement in principle that a Public Health Case Management system and CIDR should not result in duplication of data entry, no work has yet been done on the interaction of this new system with CIDR. This is of concern given that the two systems, if both are required, should be fully integrated. A new public health information management system should streamline work and avoid duplication of data entry while ensuring that it provides a surveillance system which meets the needs of all stakeholders into the future. As previously indicated, HIQA believe that planning for effective information systems should be a core element of the new proposed model for our public health system.

3.4.1.3 Evolving Laboratory Methodologies and Information Requirements

The methodologies employed to allow laboratories to detect and type microorganisms are becoming more sophisticated with the emergence of molecular typing methods including the advent of whole-genome sequencing (WGS). The European Centre for Disease Control (ECDC) has outlined a priority list of diseases for which WGS data will be gradually integrated into EU-level surveillance systems and multi-country investigations of cross-border outbreaks.[47]

From interviews with two reference laboratories, HIQA identified that CIDR has not evolved to enable capture of such molecular typing data, including WGS-based typing, either at all, or in a format which can be readily searched or retrieved. This has limitations in terms of CIDR as the national repository for molecular epidemiology and public health surveillance of important infectious diseases and pathogens. These requirements should be considered when the strategic plan for CIDR is being developed.

In addition, HIQA was advised that reference laboratories currently have limited access to CIDR data. This presents difficulties in terms of they having a real-time national picture of the incidence of the infectious disease for which they are responsible and for their ability to provide comprehensive and timely submissions to ECDC and WHO. Currently, laboratories cannot access CIDR events. There may now be a need to review CIDR business rules arrangements for reference laboratories in light of the experience gained over the past fifteen years.

3.4.2 Business planning for CIDR

A well-governed and managed organisation monitors its performance against its objectives and key performance indicators (KPIs) which are outlined through the process of business planning.

HPSC produces an annual business plan which sets out key priorities for the year. HIQA was also provided with a more detailed CIDR work plan for 2019.

Both of these documents have a focus on maintenance of CIDR for surveillance purposes, rather than any strategic improvements to the system. The CIDR work plan outlined a schedule of planned works in relation to improving server security and performance as well updating of the CIDR Business Rules. One new initiative noted for 2019 was to plan for the implementation of the CIDR module for sexually transmitted infections (STIs) by putting in place a project team to carry out user acceptance training and pilot implementation at one or more clinic sites. The absence of strategic performance targets in the business plan is directly linked to the absence of an overall strategy for information management systems.

3.5 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 a national data collection is being managed efficiently at an operational level. Effective performance management can be achieved by identifying and reviewing key performance indicators (KPIs), commissioning internal and external audits to assess compliance with relevant policies and legislation and reviewing the risk register.

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

3.5.1 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.

The HSE Integrated Risk Management Policy (2017) outlines the HSE's process for risk assessment and the organisation's commitment to proactive management of risk.[48] It states that risk management is a line management responsibility and must be a focus of management teams at all levels in the HSE. Each division is required to clearly outline their arrangements for risk management and the process for notification and communication of identified risks/actions.

Within the Strategic Planning and Transformation (SP&T) function, risks are reviewed every two months at the Senior Management Team meeting. The process for up-dating the risk register was further revised in February 2019 and training was provided to representatives from the Departments of Public Health and HPSC on the process of identifying and

escalating risks. The service level risk registers for each sub-function within SP&T are reviewed every two months at Senior Management Team meetings. Each sub-function has the opportunity to raise risks that they wish to escalate to the overall Strategic Planning and Transformation risk register. This informs any decisions in relation to risks being put forward to the Corporate Risk Register, which is managed centrally in the HSE by the Quality Assurance and Verification function.

The NPHLG is responsible for updating the Public Health Risk Register.

HPSC provided HIQA with an outline of their risk management process which is included in Appendix 9. The Information Governance Committee, whose role is described in Section 4.2, hold a register of information governance risks and many CIDR risks, that can be managed within HPSC, are actioned at this level. The main committee responsible for management of higher- level HPSC risks is the Risk Management Committee, whose role is summarised in Table 3.

Table 3. Role of HPSC Risk Management Committee

Committee	Details	Focus on risk	Risk register
HPSC Risk Management Committee	**Frequency:** Every 2-3 months **Chair:** HPSC Business Manager **Line of reporting:** Senior Management Team (not formal)	Addresses risks that have been escalated from the Information Governance Committee or risks that are not related to information governance. Significant cross-over of membership with the Information Governance Committee. Line of reporting upwards not clearly defined.	Maintains HPSC Risk Register. Risks that HPSC cannot manage in-house should be highlighted in HPSC risk register and notified for inclusion on the HSE Public Health risk register.

3.5.1.1 CIDR risk registers

There are a number of risk registers in place within HPSC and the wider HSE where CIDR risks should be recorded. These include:

- the IG Risk Register managed by the Information Governance Committee in HPSC
- HPSC Risk Register managed by the Risk Management Committee in HPSC
- the Departmental Risk Register held by individual regional Departments of Public Health
- the National Public Health Risk Register held by the AND-PH
- the Strategic Planning and Transformation function Risk Register
- the HSE Corporate Risk Register

HIQA was provided with copies of the Information Governance Risk Register (dated 30 January 2019) and HPSC Risk Register (dated 10 April 2019). Most of the CIDR risks included on the Information Governance Risk Register were related to IT infrastructure, procurement and security or compliance with GDPR requirements and were being actively managed by the Information Governance Committee.

The HPSC Risk Register contains a number of higher level risks which might have national or international implications. These include:

- failure to recruit a Director for HPSC, which is considered to be a critical post
- supplier inability to deliver contracted services critical to the operation of CIDR
- difficulty replacing key staff leading to risks with the provision of expert advice and delayed response to queries, carrying a risk of reputational damage for HPSC
- threat to HSPC's ability to deliver its services due to a failure to plan strategically at local level
- risks associated with the provision, timeliness and quality of data provided to HPSC due to resourcing issues in hospital laboratories
- inability to deliver essential functions in the event of a major national public health outbreak
- lack of resources to keep guidelines and frequently asked questions (FAQs) on HPSC website updated

The risk describing the failure to plan strategically was added to the risk register initially on 02 Feb 2012. The risk rating was increased on 14 Dec 2016 and it remained open as a high risk on 10 April 2019, seven years after the risk was first identified.

HIQA was also provided with an extract of the HSE Strategic Planning and Transformation function risk register (dated 30 April 2019) highlighting the following risks which relate to CIDR:

- The risk of suboptimal corporate and clinical governance at HPSC due to the vacant Director post (since May 2016) and the inability to recruit a suitably qualified replacement. Despite the existing controls (AND-PH back-filling post, notification of issue to HSE and Department of Health) the risk was still rated as high. This pre-dated the appointment of an interim Director of HPSC on 8 July 2019.
- Inability to maintain a high-quality, efficient, effective and consistent public health response to notifications, incidents and outbreaks and associated risk to population health due to lack of national health protection standard operating procedures and a case and incident management system.

Overall, the evidence suggests that both the Information Governance Committee and the Risk Management Committee within HPSC are well-established and have been active in identifying and mitigating risks. Both of these committees hold a risk register, address the risks at regular intervals and mitigate and close-off risks within their control. Up to recently, risks have been largely managed within HPSC in so far as this was possible. During the site visits, HIQA was informed that CIDR-specific risks have never been escalated to the HSE Risk Register. While Issue/Risk Management is a standing item on the agenda for the CIDR National Steering Committee, the minutes reviewed by HIQA reflect no evidence of risks being discussed.

This review has highlighted some significant risks related to CIDR which were not placed on the Public Health or HSE Corporate Risk Register. These include failure of the CIDR National Steering Committee to meet on a regular basis and regional variation in enhanced surveillance information. As the laboratories are in a different division of the HSE than public health and HPSC, some of the cross-functional issues would need to be raised at the level of the CIDR National Steering Committee or the Strategic Planning and Transformation function in order to be comprehensively resolved.

While HIQA recognises that the Strategic Planning and Transformation function has made significant progress in clarifying their risk management process earlier this year, there is still scope for further clarification on the roles of the HPSC Senior Management Team, the Director of HPSC, the AND-PH, the NPHLG and the CIDR National Steering Committee in relation to risk management and the process for escalating risks in respect of CIDR which cannot be managed within HPSC.

3.5.2 Internal and external audit

Audit is a key feature of performance management. It is necessary to evaluate whether current practices are in line with legislation, best practice guidelines or standards. Audit should also be used to evaluate performance, to understand why particular risks or issues are arising, to identify specific training needs and to implement improvements to information management practices based on the findings. Senior management need to regularly review the findings to recognise areas of good practice and to identify areas for improvement.

It is necessary to undertake both internal and external audits in order to obtain a complete, unbiased view of an organisation.

3.5.2.1 Internal audits

HPSC has implemented an Information Security Management System (ISMS) to help safeguard its information. This system includes a review of all of its information security policies and procedures on an annual basis and regular internal audits. Any recommendations from these audits are closed out by the Information Governance Committee. This is outlined in greater detail in Section 4.2.3.

3.5.2.2 External audits

HPSC is accredited to the ISO 27001 Standard and subjected to certification audits which take place at least annually. Any recommendations made are compiled in an action plan which is reviewed by the Information Governance Committee until all actions have been closed out. The annual reports prepared by the Information Governance Committee for the Acting Director of HPSC provide evidence that this committee is very proactive in terms of scheduling, carrying out and following up on audits. Further detail on their auditing of information governance is outlined in detail in Section 4.2.3.

There have been a number of evaluations of individual infectious disease surveillance systems, as outlined in Section 5.1.2.4, and each of these have made a number of recommendations. While some of the recommendations have been actioned, many of them have not. Further detail will be provided in Chapter 5 in relation to this.

HIQA acknowledge that HPSC demonstrates good practice in audit and review of information governance. However, while surveillance scientists actively audit and validate data quality as outlined in Section 5.1.2.1, it is not subjected to the same rigorous assessment and close-out procedures as information governance.

HIQA have concluded that senior management within the HSE has not placed sufficient emphasis on auditing and resolving data quality issues associated with CIDR. A more effective system is required for addressing the findings from CIDR data validations and evaluations across the public health function.

3.5.3 Key performance indicators

Relevant key performance indicators (KPIs) are essential for good governance so that senior management within HPSC have assurance that CIDR is functioning effectively as our national surveillance system for infectious disease. KPIs should be carefully identified and linked to strategic and business plan objectives as this enables senior management to regularly review whether the organisation is on target to achieve what it set out to achieve for that period. 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.

While individual teams within HPSC review data from CIDR on a regular basis, no specific KPIs have been developed for the CIDR system, and there has not been sufficient focus at a senior management level within HPSC or the wider HSE on reviewing the performance or effectiveness of CIDR in meeting its overall objectives and the needs of its stakeholders. The only measures of performance that are actively monitored within HPSC are the availability of CIDR (< 10% downtime) and CIDR helpdesk activity levels. The absence of specific KPIs for CIDR was confirmed by the AND-PH and the National Director, Strategic Planning and Transformation at interview. The HPSC Business Plan and the CIDR Work Plan for 2019 include no specific performance measures for CIDR. The only KPI which HIQA identified was

the 75% target for completeness of the enhanced surveillance information for some diseases as outlined in Section 5.1.2.1, but this is largely reviewed by individual disease teams within HPSC and there is no mechanism in place for ensuring that the target is met. The absence of specific targets for performance means that there is no real incentive or driver for improving elements of CIDR performance such as data completeness and quality, use of the Outbreak module, use of information for case management or health protection purposes. It also means that achievements or good practice in any of these areas is not recognised and reinforced.

HIQA recommend the development of performance metrics for information management for CIDR and any other health protection information systems which might be developed into the future. The KPIs developed should have a focus on the key features of data quality including relevance, reliability, timeliness, comparability, accessibility and clarity among other performance measurements. It is important that the KPIs are set so that they encourage collection of the information which is most useful to key stakeholders, with a particular focus on those measurements which deliver real improvements in public health. A representative group of stakeholders should be involved in the development of KPIs. Once the KPIs have been developed, a performance report detailing the KPIs should be compiled and reviewed by senior management on a regular basis. Because of the partnership approach for CIDR and the need for a focus on quality at each stage of the data flow process, it is important that review of KPIs should take place within a cross-functional leadership group, for example through the NPHLG, the CIDR National Steering Committee and/or the Strategic Planning and Transformation function.

3.6 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 public health and in line with legislation and best practice guidelines. 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. The use of data sharing agreements is recognised as good practice in this area.

3.6.1 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. HPSC currently has no publicly available statement of purpose which succinctly captures why CIDR exists and outlines its overall function and objectives. HPSC has information in a variety of locations, including its website and the Business Plan for 2019, that will assist in compiling a statement of purpose which complies with Standard 3 of the *Information Management Standards for National Health and Social Care Data Collections.*[(2)]

3.6.2 Data sharing agreements

Data sharing agreements define a common set of rules to be adopted by the organisations involved in a data sharing operation.

As referred to in Section 4.2.3, the Irish Computer Society conducted an audit of HPSC's compliance with data protection legislation in 2018. This audit recommended that HPSC should engage with each stakeholder and agree roles and responsibilities in line with statutory obligations. It also recommended that HPSC consider adopting formal data sharing agreements with stakeholders, particularly where processing falls outside of the normal statutory obligations. HIQA acknowledge that at the time of the review, HPSC had spent over a year developing a draft data sharing agreement with the National Virus Reference Laboratory in UCD. HIQA was advised that the document was nearly complete and would then be subject to review by UCD before finalisation. HPSC will use this template as the basis for further data sharing agreements with other stakeholders. HIQA recommend that HPSC prioritise this work to provide clarity for other parties in relation to the governance arrangements for sharing information, ensuring that data is handled legally and securely and that the shared data is of the highest possible quality. Once the data sharing agreements have been agreed, there is also a need to have an audit arrangement to ensure that all parties are implementing the agreed measures.

3.7 Findings — Significance of findings — Governance, leadership and management

Strategy for information management for public health in Ireland in the context of public health service reform and changing health protection needs

- CIDR is the national information system for surveillance of notifiable infectious diseases in Ireland and, as such, is a very important national data collection. CIDR has been in place since 2004, with HPSC as its managing organisation. It was established to provide timely and comprehensive information to facilitate regional and national surveillance of infectious diseases. In addition, information derived from CIDR is used to facilitate public health action, to evaluate the effectiveness of prevention and control programmes and to allow Ireland to meet its international reporting obligations to agencies such as the European Centre for Disease Control and WHO. HIQA has concluded that, while fulfilling many of these functions, CIDR has not evolved to meet the increasing demands of an effective infectious disease surveillance system, including the requirements for an infectious disease case management system or the ability to capture the increasing complexity of available laboratory data.

- At present, there is a major change and reform process underway to completely reconfigure and re-structure the public health system in Ireland. This will result in a new management and organisational approach to the delivery of public health functions including the surveillance, management and prevention of infectious disease. Despite this, at present, there is no strategy or vision in place for developing an effective information management system to meet these health protection needs.

- The National Public Health Leadership Group has identified the need for an infectious disease case management system which is currently being progressed by this group in co-operation with the Office of the Chief Information Officer. HPSC have not been actively involved in developing or planning for this system. The interface and connectivity between CIDR and the new proposed case management system has not been explored.

- HIQA identified during the review that the implementation plan for the new public health model should include, at the earliest possible stage, a consideration of the information management systems which will support the new model and should clarify how CIDR can best contribute. This provides a real opportunity to review the needs for information management across the public health service, to develop a vision of what a state-of-the art public health information system would include and to implement a strategy to move towards this. Consultation with key CIDR partners and stakeholders is essential in identifying the requirements and potential benefits of a state-of-the-art information management system.

Leadership and governance arrangements for CIDR

CIDR is the primary surveillance system for infectious disease in Ireland so it is important that it operates as effectively as possible to capture incidence of disease, both locally and nationally, to detect emerging health threats at regional and national level and to provide reliable data to facilitate international monitoring of infectious disease trends.

HIQA have concluded that the current governance and leadership arrangements in place for CIDR are inadequate and should be enhanced.

- The National Director for Strategic Planning and Transformation and the AND-PH, who have responsibility for a wide range of public health areas and initiatives, do not have the appropriate systems in place to provide assurance on the effectiveness of CIDR in fulfilling its role as the national system for surveillance of infectious disease. They have not had sufficient awareness or focus on risks arising with CIDR including the fact that the CIDR National Steering Committee have not been meeting regularly and that there are significant variations in surveillance activities between regional Departments of Public Health.

- The CIDR National Steering Committee is not providing effective oversight of CIDR. This committee did not meet between October 2017 and February 2019. Its terms of reference, membership and relationship with key CIDR stakeholders need to be revised if it is to provide effective governance and leadership for CIDR. At present, it is not playing an active role in developing a strategy for CIDR, in monitoring its performance or in assessing and managing risks to the system.

- The Director of HPSC, as head of the managing organisation, has overall responsibility for information management in relation to national surveillance for infectious diseases. The Director post in HPSC was vacant from May 2016 to June 2019 and was being back-filled by the AND-PH in addition to a broad remit of other public health duties. This gap in the chain of accountability placed an over-reliance on the AND-PH to provide governance, leadership and accountability for CIDR. In addition to assuming a role as Acting Director of HPSC for over three years, the AND-PH was already filling two roles as AND-PH and Acting Director of Public Health, North East.

- KPIs have not been developed for CIDR and there is no review of its performance at senior management level within the HSE.

- HPSC strives to achieve consistent data collection through standardised protocols and enhanced surveillance forms and drives data quality by requesting all Departments of Public Health to complete the required information. HPSC do not have the control systems to ensure surveillance information is collected and entered on CIDR.

- For a surveillance system to function effectively, information collection and management should be standardised and consistent across all regions and sites where data is input and used. Due to an inadequate governance structure, practice across the regions has diverged over time. Decisions not to collect some enhanced surveillance information are taken at the level of individual Departments of Public Health and are not taken in any consistent manner. This has led to significant regional variation in data completeness, timeliness and accuracy for some infectious diseases. It also reduces the quality of information that HPSC submits to international bodies such as ECDC and WHO. HIQA believes this represents poor practice because it leads to regional variations in enhanced surveillance and to incomplete national surveillance for some diseases. It would be better practice to agree a level of overall enhanced surveillance which is matched with the resources available and which can be committed to and applied consistently across all regions.

- There is no scheme of delegation in place to clearly set out the lines of accountability and responsibilities for staff of the HPSC, the Departments of Public Health and the laboratories. The newly drafted revised CIDR Business Rules will be a very useful mechanism of communicating roles to all stakeholders but the roles of CIDR Data Controller and CIDR Manager need to be more clearly defined and formally delegated. Currently, there is a lack of clarity among those who are involved in managing information on surveillance of infectious disease about their responsibilities for information management.

Strategy & business planning for CIDR

- HIQA was informed that, at the time of the review, there was no strategic plan in place for CIDR. This means that there is currently no vision for what the national surveillance system can deliver or a strategy to implement this. There has not been sufficient focus on review of the CIDR system or pulling together key parties to review what is working well, what improvements are required and how the national surveillance system can be used to maximum effect to improve the health of the Irish public and our national preparedness for public health threats. HIQA believes that this has largely arisen due to gaps in the governance and leadership arrangements which are outlined above.

- Strategic development of CIDR is not discussed at any of the higher-level groups within HPSC or HSE. There is currently no cross-functional forum in place to routinely bring together all CIDR stakeholders to discuss strategic issues, including those relating to information management.

- While CIDR was novel for Ireland when it was designed in 2002, it has evolved very little in the interim period, despite very significant developments and changes in emerging infectious diseases, new laboratory methodologies and new requirements for surveillance systems. Feedback from a range of CIDR users indicated that it is in

'maintenance' mode and that it is not fully meeting the needs of its stakeholders. It has not evolved to meet the needs of the public health system for a case management system or to capture valuable laboratory data in a format which is readily retrievable.

- The use of CIDR within Departments of Public Health, HPSC and laboratories is currently disjointed in that each stakeholder is using it for their own purposes and attempting to work around whatever limitations it poses for them. This is evidenced by discrepancies in the data being collected in different regions, the inability of HPSC to ensure completeness of enhanced surveillance information, different approaches to information management in different locations and the number of parallel databases which have emerged at individual sites to store or analyse data which cannot be efficiently handled within CIDR.

There are also a range of other issues which should be part of a strategic planning process. These include:

- Monitoring whether CIDR is fit for purpose as a national surveillance system or if it should be extended to provide a more comprehensive surveillance system of health risks beyond communicable diseases with greater case management capabilities. This is of particular importance in terms of the changing approach to healthcare at national level including the recommendations of the Crowe Horwath report, the review of the public health model in Ireland and the Sláintecare Implementation Strategy 2018.
- Evaluating if CIDR is fulfilling its role in terms of predicting national and international health threats.
- Planning the resources (human, physical and ICT) to ensure continued sustainability of the national data collection.

Performance assurance in relation to information management

Performance management

The performance assurance systems in place for CIDR are not adequate to appropriately govern and manage CIDR and to ensure it is meeting its objectives as the national surveillance system for infectious disease. No specific key performance indicators (KPIs) have been set to measure and report on the performance and effectiveness of CIDR or the quality of the data held in the system. The use of KPIs for CIDR are not incorporated into a strategic plan or annual business plans, and there is no system in place at senior management level for monitoring CIDR's performance relative to pre-set KPIs.

Audit

Overall, HIQA found that HPSC demonstrates good practice in relation to internal and external audits. HPSC has implemented an Information Security Management System which

is accredited to ISO 27001 and undergoes external audit against this standard at least annually. The HPSC Information Governance Committee co-ordinates these audits and follows up on any recommendations that come out of them. In 2018, it commissioned a GDPR readiness audit and is in the process of implementing the recommendations.

Risk management

- Within HPSC, the Information Governance Committee and Risk Management Committee meet regularly, keep risk registers and mitigate risks which lie within their capacity to resolve.
- Despite this, some risks which should have been raised at the level of the National Public Health Leadership Group or the Strategic Planning and Transformation Senior Management Team appear to have been retained within HPSC. These include risks around regional variations in data collection and quality and the fact that the CIDR National Steering Committee was not meeting for a prolonged period.
- The process for escalating risks identified by the Information Governance or Risk Management Committees to higher levels within HPSC or HSE not clear.

Statement of purpose

- HPSC has not published a statement of purpose for CIDR. A statement of purpose is a publicly available document which succinctly explains why the national data collection exists and clearly outlines its overall function and objectives. This document would provide the public with an understanding of the service HPSC provides in terms of national surveillance for infectious disease and the role of CIDR as the information management system to facilitate this. Preparing this document would also help to provide clarity about the priorities for CIDR.

Data sharing agreements

- HPSC has conducted a GDPR Readiness Audit which recommended that HPSC should engage with each stakeholder and agree roles and responsibilities in line with statutory obligations. It also recommended that HPSC adopt formal data sharing agreements with stakeholders, particularly where processing falls outside of the normal statutory obligations. HIQA acknowledge that HPSC have been developing a draft Data Sharing Agreement with the National Virus Reference Laboratory in UCD and that they plan to use this as a template for data sharing agreements with other stakeholders.

3.8 Recommendations - Governance, leadership and management

Governance, leadership and management	
	Strategy for information management for public health
	In light of forthcoming changes in how public health services will be delivered[5], the National Director for Strategic Planning and Transformation should, in conjunction with key stakeholders, develop and implement an information management strategy for the public health service in Ireland. The strategy should address: ▪ the vision for a state-of the-art information management system spanning the full remit of public health ▪ the requirement for an infectious disease case management system ▪ the future direction and roadmap for CIDR ▪ clearly defined objectives, identified individuals responsible for delivery of objectives and associated business planning for all aspects of information management ▪ a plan for stakeholder engagement to ensure that CIDR meets the needs of all stakeholders ▪ alignment with Sláintecare and the HSE eHealth strategy
	Governance Structures for CIDR
	National Governance Structures for CIDR HPSC should enhance its current governance arrangements for CIDR to: ▪ ensure that the CIDR National Steering Committee provides effective national oversight, leadership and strategic direction for CIDR. The membership and terms of reference for the committee should be reviewed. ▪ provide a detailed scheme of delegation outlining clearly defined roles and responsibilities for information management in respect of CIDR. Local Governance Arrangements for CIDR The Directors of Public Health and Clinical Directors of laboratories should enhance the local governance arrangements for CIDR to ensure that:

- the information held in CIDR is of high quality and used effectively for surveillance of infectious disease as well as for health protection, epidemiology and policy purposes.

- a detailed scheme of delegation is in place outlining clearly defined roles and responsibilities for information management in respect of CIDR.

Performance Assurance Framework

HPSC should develop a performance assurance framework which generates appropriate information to provide assurance to the HSE Strategic Planning and Transformation Senior Management Team and the CIDR National Steering Committee that CIDR is:

- meeting the objectives of a national infectious disease surveillance system
- providing high quality information to inform public health decisions

The assurance framework should include arrangements for monitoring performance against the annual HPSC business plan and CIDR workplan, measurement and reporting of key performance indicators (KPIs) for CIDR and a schedule for conducting internal and external audits against aspects of information management.

Risk Management Framework

HPSC should further define its risk management framework to clarify how significant risks, which cannot be resolved within HPSC, should be mitigated or escalated. The role of relevant HPSC and HSE Committees in escalating and mitigating risks should be clearly delineated.

The role of the following parties in relation to risk management and escalation, and the level of risk they should each be addressing, needs to be clarified:

- HPSC Senior Management Team
- the Director of HPSC
- the Assistant National Director for Public Health
- the National Director for Strategic Planning and Transformation
- the CIDR National Steering Committee

The revised risk management framework should be closely aligned to the enhanced arrangements for governance and leadership of CIDR.

	Transparency
	▪ HPSC should prioritise the development and implementation of data sharing agreements with those parties with whom they share CIDR data, particularly where data sharing is not covered by the CIDR Business Rules. ▪ HPSC should publish a statement of purpose that accurately describes the aims and objectives of CIDR.

4. Information governance

National data collections, such as the Computerised Infectious Disease Reporting (CIDR) System, 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 confidentially 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 individual's data; 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 5, the use of information and the generation of high-quality data will be discussed in detail. The focus in this chapter will be on the development of good information governance practices.[49,50]

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 achieve the appropriate balance between protecting an individual's personal information and confidentiality while allowing information to be used and shared effectively and legally for the benefit of the individual, the service provider, the clinician, the wider health service and the public. 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 should be 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 improvement. 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 arrangements in place to protect the privacy of individuals and to ensure that personal information is handled legally and securely, to achieve compliance with Standards 1 and 8 of the Information Management Standards.

The findings will be presented in the following Sections:

- Information governance structures for CIDR
- Effective arrangements to assess and manage information governance.

4.1 Findings — Information governance structures for CIDR

4.1.1 Information governance responsibilities for CIDR

4.1.1.1 Information governance structures within HPSC

HIQA identified that there were a number of arrangements in place in relation to information governance for CIDR within HPSC. As the managing organisation for CIDR, HPSC is responsible for information governance and security relating to the system, and is also responsible for the use of the system by HPSC staff.

The current CIDR Business Rules stipulate the information governance responsibilities for all CIDR users, including HPSC, Departments of Public Health and laboratories. During interview, HIQA was informed that the Director of HPSC has overall responsibility for information governance within HPSC and is supported in delivering on this responsibility by members of the HPSC CIDR team, the Information Systems Manager, the HPSC IT Manager and the HPSC Information Governance Committee. HIQA was also informed, through interview, that all HPSC staff members have responsibility for aspects of information governance in relation to their particular area of work. However, HIQA did not receive evidence of any formal scheme of delegation to outline how these arrangements are managed in practice.

In relation to specific responsibilities for data protection (including responding to potential data security breaches or incidents), HIQA was informed that the Director of HPSC has overall responsibility for ensuring that the organisation complies with legislative requirements. HIQA was informed that HPSC is under the remit of the HSE Data Protection Officer (DPO) and Deputy DPOs in relation to reporting of potential data breaches. An internal DPO role is also in place in the HPSC and HIQA was informed that this role had been informally assigned to the IT Manager. However, during the review it emerged that there was a lack of clarity in relation to what the role of the 'HPSC DPO' specifically entails.

Furthermore, it was noted by HIQA that the HPSC Security Incident & Data Breach Management Procedure, for example, does not make reference to the role of the HPSC DPO.

The CIDR team within HPSC has a role in relation to management of operational and technical aspects of the CIDR system. Their roles and responsibilities in respect of information governance are outlined in Table 4 below.

Table 4. HPSC CIDR Team

Purpose	**Membership of Team**	**Responsibilities in relation to CIDR, including information governance**
Responsible for operational aspects of CIDR	**Membership:** HPSC Business Manager Information Surveillance Systems CIDR Operations Manager (n=1) CIDR surveillance scientists (n=1) Surveillance assistants (n=0.1) CIDR IT Officer (n=2)	Ensures that the CIDR system remains operational by: • Providing CIDR helpdesk technical and business support • Monitoring information security of CIDR • Resolving potential information security breaches • Maintaining back-up and disaster recovery systems • Controlling access rights to CIDR • Facilitating the National CIDR user Group.

A number of committees have varying levels of responsibility for aspects of information governance for CIDR. The main committee with responsibility for aspects of information governance is the HPSC Information Governance Committee, with the HPSC Risk Committee and, to a lesser extent, the HPSC Quality and Safety Committee, also having a role in relation to information governance. The role of the HPSC Information Governance Committee will be discussed in more detail in Section 4.2.

4.1.1.2 CIDR information governance arrangements at user locations outside of HPSC

It is imperative that the security and confidentiality of the information held within CIDR is appropriately protected and that the correct governance structures are in place in order to facilitate this. The current CIDR Business Rules, as referred to in Section 3.2.2, sets out the operating rules for the CIDR system.[‡] The Rules outline the general principles for

[‡] This includes rules in relation to the information governance of the system such as the legal framework within which information is shared in CIDR, the arrangements for role-based access to the database, the processing of data requests and the responsibilities of CIDR users and managers.

participation in CIDR by all partners. The development and implementation of the CIDR Business Rules are facilitated by the CIDR National Business Rules Committee.

HIQA identified through focus groups and interviews with representatives from Departments of Public Health and laboratories, that there is a lack of clarity at local level in relation to the assigned roles and responsibilities for information governance of CIDR, as defined within the current CIDR Business Rules. HIQA also found varying levels of implementation of these rules across sites where CIDR is used.

A revision to the CIDR Business Rules document is being developed to take account of the General Data Protection Regulation (GDPR) and other relevant data protection regulations[§]. The draft revised CIDR Business Rules includes a new CIDR Data Controller role, which is not present in the current CIDR Business Rules. According to the draft revised CIDR Business Rules, overall responsibility for CIDR data protection locally remains with the CIDR Data Controller, who determines the purposes and means for the processing of personal data for CIDR. The CIDR Data Controller may formally assign certain administrative and user management tasks to a nominated local CIDR user.

HIQA has concluded that where there is a lack of clarity in relation to governance and oversight for CIDR at a national level, it may be difficult for the CIDR National Business Rules Committee to be assured that the CIDR Business Rules are being implemented in practice. Therefore, when the draft revised CIDR Business Rules are published, the Committee should ensure that clarity is provided for CIDR users in relation to their roles and responsibilities for information governance. This will help to ensure that the CIDR Business Rules are strategically implemented across all Departments of Public Health and laboratories that use CIDR.

4.2 Findings — Effective arrangements to assess and manage information governance

HIQA reviewed the arrangements within HPSC which are used to assess and manage information governance in relation to CIDR. In doing so, the team observed that there was a good overall awareness of the importance of information governance for CIDR. HIQA recognises good practice in the fact that HPSC has a specific committee in place to address information governance for HPSC, including CIDR, namely the Information Governance Committee. Details of this committee are included in Table 5.

Table 5. HPSC Information Governance Committee

[§] HIQA was advised that the draft revised CIDR Business Rules (Version 3.6) is to be finalised by the end of 2019, and it will be formally rolled out to all CIDR users at that time.

Purpose	Details	Role in relation to information governance
Set up to establish a framework to ensure the privacy, confidentiality, security and availability of information within HPSC and to ensure that the related policies are implemented and complied with. Responsible for making operational decisions relating to information governance matters for HPSC, including CIDR.	**Frequency:** Monthly **Chair:** Business Manager— IT Surveillance Systems (interim basis) **Membership:** Maximum of eight members from the following groups - public health doctors, surveillance scientists, administrative staff, and information technology **Line of reporting:** Director of HPSC (sign-off of decisions and receipt of annual report) and Senior Management team monthly updates	• Establish information security plans and policies. • Ensure compliance with information governance legislation. • Ensure appropriate security roles and responsibilities are assigned. • Maintains the Information Governance and Information Security Management System (ISMS) Risk Registers. • Escalates risk to Risk Committee, where necessary. • Oversee the development of Data Sharing Agreements. • Review implementation of the ISMS.

The HPSC Information Governance Committee holds a risk register for HPSC information governance risks, in which there are two risks recorded in relation to CIDR. Where information governance risks cannot be dealt with by the Information Governance Committee, they are escalated to the HPSC Risk Management Committee to address. Risk will be discussed in more detail in Section 4.2.2.2. According to the terms of reference provided to HIQA, another internal committee called the HPSC Quality and Safety Committee also has some role in relation to information governance, but to a much lesser extent than the aforementioned committees. Furthermore, the CIDR National Steering Committee, as detailed in Section 3.2.1, notes in its terms of reference that its responsibilities include ensuring that appropriate information governance is in place for CIDR. As previously noted by HIQA, the CIDR National Steering Committee did not meet between October 2017 and February 2019. In the absence of such meetings, it would be difficult for this committee to be assured that appropriate information governance practices are in place in relation to CIDR.

4.2.1 Legislation, policies and procedures

4.2.1.1 Compliance with legislation for information governance

A significant volume of personal information is held within the CIDR system. As previously outlined in Section 4.1.1.1, HIQA was informed that the Director of HPSC had responsibility for information governance within HPSC. The current CIDR Business Rules also stipulates that the CIDR Operations Manager (supported by the HPSC IT Security Officer, the HPSC Data Protection Compliance Officer, and the HPSC Information Governance Committee) is responsible and accountable for the protection of health information on infectious diseases/organisms and antimicrobial susceptibility in the organisation. However, in light of GDPR, the need to review and clarify roles and responsibilities in relation to information governance for CIDR was noted and will be addressed within the revised CIDR Business Rules. At each site where CIDR is used, CIDR Data Controllers will be assigned responsibility for ensuring that information governance policies and procedures are up to date and accessible and are being implemented in order to facilitate good information governance practices.

HIQA was informed that HPSC's policies and procedures for information governance are aligned to the equivalent HSE policies and procedures. With respect to demonstrating compliance with relevant legislation, HPSC identified that there are a number of key pieces of legislation governing CIDR, including the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (DPA), the Freedom of Information Act 2014, the Infectious Disease Regulations 1981 and subsequent amendments (Section 2.3.2) and the ECDC founding regulations (Regulation (EC) 851/2004).[19,20,51] As noted in the CIDR Business Rules, the Infectious Disease Regulations oblige and provide authorisation for clinical laboratories, Departments of Public Health (Medical Officer of Health) and HPSC, to collect and process personal data relating to notifiable diseases, specified in the regulations for the purposes of protecting public health.

As previously noted in Section 4.2, and according to the current CIDR Business Rules, the HPSC Information Governance Committee is responsible for ensuring that HPSC remains compliant with legislation that relates to information collection, storage, analysis and dissemination. The HPSC Information Governance Committee is also responsible for the implementation of HPSC's information security policies, of which HIQA was provided with a comprehensive list, as detailed in Appendix 10. These policies and procedures are regularly reviewed to maintain compliance with ISO 27001, and HIQA acknowledges HPSC's efforts in demonstrating such compliance with information security best practice.

These policies and procedures provide clarity in relation to how HPSC addresses information governance internally in relation to CIDR. However, HIQA identified a lack of clarity regarding roles and responsibilities specific to information governance for CIDR within Departments of Public Health and laboratories. Hence, it may be difficult for the CIDR National Steering Committee to be assured that policies and procedures are being effectively implemented where CIDR is accessed at a local level. This concern is further highlighted by

the fact that, as outlined in Section 3.2.1, the CIDR National Steering Committee has not met regularly since 2017.

4.2.1.2 Record retention and destruction

HIQA was informed that data retention was noted as a risk on the HPSC risk register and is being addressed by the HPSC Records Management Group. Circumstances for the retention and destruction of data and information within HPSC are clearly defined within the HPSC Record Retention and Destruction Policy and Record Retention and Destruction Standard Operating Procedure. HIQA recognises as good practice that the HPSC Records Management Group reviews pseudonymised data on an annual basis to determine if the data can be further anonymised or destroyed in a confidential manner.

At the time of the review, a sub-group of the Public Health Medicine Communicable Disease Group (PHMCDG) was exploring the circumstances under which data and information should be retained or destroyed in line with legislation. HIQA was informed that these discussions will have implications for defining policy and procedures in relation to CIDR-related data, held outside of the secure CIDR system, by Departments of Public Health and laboratories. HPSC informed HIQA that some of the challenges in defining data retention and destruction policy relate to the need to achieve a balance between data minimisation requirements under legislation and retention of public health records in the interest of public health.

HIQA was informed through interview that the implementation of existing policies and procedures varies significantly at a local level, with some laboratories and Departments of Public Health developing and implementing their own policies and procedures, while others do not. Of note is that some Departments of Public Health informed HIQA that they have been unable to destroy paper records which have passed their destruction date, as defined under legislation, due to resourcing issues. While HIQA acknowledge the challenges involved in reviewing and agreeing timelines for data retention and destruction of hard and soft copy data pertaining to CIDR within Departments of Public Health and laboratories, there is a need to collaboratively address this challenge in order to reduce information governance risks for CIDR.

4.2.1.3 Data breaches

HIQA was informed that HPSC adheres to the HSE requirements for the management of data breaches, engaging with the HSE Data Protection Officer (DPO) in the event of a suspected data breach. HIQA recognises as good practice that, in line with ISO 27001, HPSC has developed a tailored Security Incident and Data Breach Management Procedure document which provides guidance on the procedure to be undertaken in the event of an information security incident. The 2019 Information Governance Committee Management Review Report notes that in 2018, one data breach occurred. This breach took place when CIDR data was mistakenly sent to points of contact beyond those originally intended whilst fulfilling international reporting requirements. A further data breach, of a similar nature, occurred at the beginning of 2019. HIQA was advised that these breaches were appropriately addressed, in line with HPSC's Security Incident and Data Breach Management Procedure and in accordance with HPSC's legislative requirements.

Furthermore, the current and draft revised CIDR Business Rules stipulate that CIDR users must report breaches of confidentiality or security immediately, using an incident report procedure, to the local CIDR Manager. However, as discussed in Section 4.2.1.1, where there is a lack of clarity at a local level in relation to the assigned roles and responsibilities for information governance for CIDR, this may potentially impact on the management and reporting of data breaches in relation to CIDR. Furthermore, HIQA was informed, through focus group discussions, that a number of CIDR users within Departments of Public Health and laboratories were unclear as to what constituted a data breach. HIQA deems it necessary that a standardised approach to the management of data breaches is implemented, and associated training for staff is rolled out, across all sites where CIDR users are operating, to ensure that any breaches specific to CIDR are managed appropriately.

4.2.1.4 Access to CIDR

HIQA acknowledges as good information governance practice the presence of strict policies and procedures for granting and removal of access to CIDR. Procedures for all CIDR users are defined within the current and draft revised CIDR Business Rules and access is based on the individual's role, location and the infectious disease/organism on which information is being sought. HPSC has a number of internal policies and procedures in place, including CIDR Access Control Procedure, RSA Token Management and Confirmation of User Access, as well as CIDR Business Rules. As well as completing data protection and CIDR training, potential CIDR users must fill in a CIDR User Access Request Form, stipulating the level of access required, before consideration is given to granting access to CIDR. Once granted, CIDR can only be accessed by two-point authentication. The CIDR Business Rules also stipulate that the CIDR Operations Manager must be notified immediately when a CIDR user no longer requires access to CIDR, so access can be revoked. Through interview, HIQA was informed of further best practice whereby audits are undertaken in relation to user access rights, at minimum, on an annual basis.

4.2.2 Information governance practices

4.2.2.1 Privacy Impact Assessment

HIQA recognises the substantial effort that HPSC has undergone in assessing and identifying privacy risks in relation to CIDR by conducting a number of privacy impact assessments (PIAs). PIAs have been completed for each specific disease type inputted onto CIDR as well as for the CIDR system, CIDR extracts and the CIDR helpdesk. At the time of the review, 24 PIAs had been completed, three were awaiting sign-off and two had not yet been finalised. HIQA reviewed a sample of these PIAs as part of the review. Aligned to this, a data protection audit, which will be discussed in more detail in Section 4.2.3, was undertaken to evaluate HPSC's current data protection environment and degree of compliance with both the DPA 2018 and the GDPR. The audit recommended that HPSC should 'habitually adopt and cultivate Data Protection Impact Assessments (DPIAs) particularly on project initiatives that involve the use of sensitive personal data e.g. health research'. HIQA acknowledges

HPSC's work in addressing the aforementioned recommendation in relation to PIAs in light of legislative requirements.

4.2.2.2 Risk management in relation to information governance

Through interview, HIQA was informed that, earlier this year, the Strategic Planning and Transformation function refined its risk management process, which is aligned to the HSE Integrated Risk Management Policy. HIQA was provided with the HPSC risk management scheme which outlined the roles and responsibilities for escalating risk from the HPSC Risk Committee to the HSE corporate risk register (see Appendix 9). It details the parties involved in the management of risk within HPSC, including the HPSC Risk Committee, the Senior Management Team and the Director of HPSC.

As outlined in Section 3.5.1.1, HIQA received two risk registers for HPSC, an information governance specific risk register and a HPSC corporate risk register. HIQA was informed that CIDR related risks are typically managed at the CIDR team level or addressed by the HPSC Information Governance Committee where necessary. Information governance risks are discussed as a standing item at the HPSC Information Governance Committee meetings and information governance updates are also provided at Senior Management Team meetings. CIDR risks noted on the information governance risk register include '*unauthorised access or disclosure of HPSC confidential records'* and *'Failure to correctly manage information security at HPSC and loss of accreditation of ISO27001.'*

The HPSC Information Governance Committee also maintains a risk register associated with the Information Security Management System (ISMS). This risk register is a subsidiary to and co-ordinated with, the HPSC corporate risk register. It was noted that there are no CIDR specific risks on the corporate risk register. Furthermore, CIDR specific risks have never been escalated to the HSE risk register. Although HIQA recognises that extensive work is being undertaken by HPSC in order to minimise risk, as evidenced during the review, HIQA became aware of a number of additional information governance risks which are not included in a risk register, for example, the absence of data sharing agreements for all stakeholders with whom HPSC shares data and the lack of a formalised process for retention and destruction of hard and soft copy CIDR data. In the interest of ensuring that HPSC can adequately monitor and mitigate against all potential risks pertaining to CIDR, such risks should be formally recorded on a risk register and all relevant parties should be informed of the emergence of new risks or any changes to the status of current risks.

As noted in Section 4.2.2.1, HPSC conducted PIAs in relation to CIDR, through which a number of information governance risks were identified. One such risk, identified from the PIA completed for the CIDR system, concerned the absence of a procedure for data subjects to access their personal information and to have the opportunity to correct their personal information where necessary. As HPSC is not the primary data collector or source of this information, this responsibility does not lie with HPSC. However, HPSC has proposed to mitigate this risk by ensuring that a clear procedure and governance structure is in place in relation to data protection and freedom of information requests, should such requests be received by HPSC. In line with this, HIQA observed that the draft revised CIDR Business

Rules outline the process for addressing data subject access requests received by HPSC in relation to CIDR. The PIA for CIDR Extracts, which relates to data which is extracted from CIDR into other program types or databases, was completed in September 2018. It identified two privacy risks requiring mitigation by HPSC. These included a risk relating to CIDR data extracts being saved to less restricted and multiple areas on HPSC server and CIDR data extracts containing identifiers being retained for time periods longer than is justifiably required. HPSC proposed to develop a standard operating procedure (SOP) on managing CIDR data extracts at HPSC to mitigate this risk, which at the time of review, had not yet been finalised. A PIA has been conducted in relation to the CIDR helpdesk, with a number of risks identified pertaining to the inappropriate use or communication of personally identifiable information (PII). Actions to mitigate identified risks include the development of clear SOPs that prevent inappropriate release of PII and SOPs to ensure that PII is not inappropriately recorded during the logging of support calls. HIQA recognises HPSC's ongoing work in drafting SOPs to help mitigate these risks.

4.2.2.3 Statement of Information Practices

A method that can be simply employed by organisations to comply with the principle of transparency is to publish a Statement of Information Practices which outlines what information the service collects, how it is used, with whom it is shared and for what purpose, the safeguards that are in place to protect it and how people can assess information held about them.

HIQA acknowledges as good practice the availability of information on the HPSC website pertaining to how HPSC handles personal information. However, best practice would indicate that HPSC should publish a Statement of Information Practices, which would formally outline such detail. The publication of a Statement of Information Practices would ensure also that the public would be provided with information on the process for having information about them corrected, should they be aware of any inaccuracies. Additionally, when reviewing the complaints management process in relation to CIDR, HIQA observed that HPSC had not published detail in relation to a complaints procedure for issues pertaining to CIDR. Through interview, HIQA was informed that the complaints process is guided by the HSE's *'Your Service Your Say'* policy.[52] Furthermore, all issues pertaining to the CIDR system are raised through the CIDR helpdesk, in accordance with HPSC's 'Support Call Procedure'. HPSC informed HIQA that no complaints were received in 2018. A Statement of Information Practices would provide suitable opportunity for HPSC to formally publish details of the complaints process for CIDR.

4.2.2.4 Data subject access requests

The current and draft revised CIDR Business Rules outline the process for processing CIDR data subject access requests and FOIs in line with data protection and FOI legislation. The draft revised CIDR Business Rules state that, in accordance with the Data Protection Act 2018 and GDPR, local data controllers within the Departments of Public Health and laboratories are responsible for processing such requests. HIQA was informed that a number of policies and procedures are in place in relation to accessing personal information, the details of which are available through HPSC website. In 2018 there were 14 FOI requests

and no data subject access requests; all FOI requests were processed in line with agreed HSE policy and procedures. As described in Chapter 5, data requests for research purposes are handled through the CIDR National Peer Review Group, and applications undergo a strict review process to ensure that information is protected and only disclosed where appropriate.

4.2.3 Audit

HPSC regularly carry out information governance audits, both internal and external. Table 6 outlines the audits which took place in 2018.

Table 6. HPSC information governance audits 2018

Audit type	Details
Internal audit	
Information governance audits (6 monthly)	Audits include a review of security polices, access to CIDR, compliance with legislation, information security incidents, business continuity and disaster recovery, Freedom of Information (FOI) activity, and monitoring of information governance risk. • Activities undertaken as part of the internal audit process contribute to the retention of ISO 27001 accreditation standard. • The 2018 report indicated that over 40 information security issues or potential information security risks were identified and addressed as part of an action plan. • This report provides a summary of information security incidents between 2014- 2018, FOI activity in 2018, findings from the review of ISMS policies, as well as an overview of changes to the risk register from 2016-2018. • All corrective actions which arose from these internal audits have been addressed and signed off by the auditors.
External audit	
ISO 27001 accreditation maintenance audit (annually)	Audit of information security practices within HPSC, including CIDR. • Compliance with ISO 27001 demonstrates compliance with information security best practice. • As part of ISO27001 accreditation, HPSC are required to ensure that all policies and procedures relating to information security are updated in line with legislation. • HIQA was informed that the 2019 accreditation audit was due to take place during the period of HIQA's review. • Attaining ISO27001 accreditation highlights HPSC's strong commitment to implementing information security in line with best practice.
Irish Computer Society audit in relation to GDPR Readiness (once-off)	Evaluation of HPSC's current data protection environment and its degree of compliance with the Data Protection Act 2018 and GDPR.

	• The audit report presents 25 recommendations, some of which relate specifically to CIDR.
	• In line with these recommendations, work is ongoing to:
	  • Define the role of data controller and data processor in all future agreements and arrangements relating to CIDR data (data sharing agreements and the CIDR Business Rules).
	  • Clarify the retention and storage of data and audit of same within HPSC and across the wider HSE.
	  • Develop PIAs for all existing and future projects within HPSC, including CIDR.
	
	HIQA was informed through interview that implementation of the recommendations are on track.
	Note: HIQA was informed that implementation of these audit recommendations are not mandatory and therefore the recommendations have not been incorporated onto the corporate or information governance risk registers.

In addition to the audits detailed in Table 6, HIQA was informed that an external CIDR Technical Infrastructure Review also took place during 2018. HIQA positively recognises the strong emphasis that HPSC has placed on conducting information governance audits and in actively addressing recommendations which have arisen from these audits.

4.2.4 Information governance training

The Business Plan 2018 details the role of the Information Governance Committee and includes a list of KPIs that the HPSC Information Governance Committee must meet in order to deliver on its objectives. One such KPI is to 'ensure that 95% of staff complete an Information Security training event'.

Different levels of training are provided to staff within HPSC, depending on their role within the organisation. Currently, all HPSC staff receive information governance training on induction. In addition to this, since the beginning of 2018, HPSC has rolled out the following information governance training and initiatives, for all HPSC staff:

- Information Security Seminar—January 2018 (participation rate 58%)
- Data Protection Training for GDPR— April/May 2018 (participation rate 85%)
- Information Security Crossword— December 2018 and January 2019 (participation rate 58%)

While HIQA acknowledges that HPSC places a strong emphasis on information governance training and initiatives, it was observed from the evidence provided that 15% of staff had not completed data protection training for GDPR in 2018. Best practice would indicate that appropriate organisational measures are put in place to ensure that all staff complete data protection training, in light of the sensitive nature of infectious disease data which they handle.

HIQA was informed that a new information governance training module will be rolled out shortly, which has a greater focus on GDPR, following the introduction of this regulation in May 2018. Furthermore, as part of the Performance Management and Development System (PMDS) annual review process, HIQA was informed that training requirements are identified for each staff member and training logs are reviewed to ensure that the required training has taken place.

Additionally, all CIDR users receive training on data protection and information governance. As previously mentioned, this is a prerequisite to being provided with a CIDR account.

During the review, HIQA was informed that the post responsible for ensuring continued compliance with GDPR and the DPA 2018, including the roll out of training and assessment in relation to information governance, became vacant. This role is being covered on an interim basis by another staff member. It is imperative that the commitment given to information governance training for HPSC staff is continued, in light of the revised responsibilities.

4.3 Significance of findings — Information governance

Overall, HIQA found through the review, that since the establishment of CIDR, HPSC has strived to adhere to information governance best practice, ensuring that well-structured measures are in place to support the privacy, confidentiality and security of the information within CIDR. There is a well-established Information Governance Committee that meets regularly to consider information governance issues. HPSC has an audit plan in place to address a number of aspects of information governance, and has maintained accreditation to ISO 27001 (Information Security Standard). Furthermore, HIQA acknowledges HPSC's work in completing a significant number of PIAs to date, including a PIA on CIDR.

Information governance arrangements

- HIQA was informed that the Director of HPSC has overall accountability for information governance in relation to CIDR. The terms of reference of the CIDR National Steering Committee indicated that they are tasked with ensuring that appropriate information governance is in place for CIDR. However, as identified in Chapter 3, the CIDR National Steering Committee has not been meeting regularly and has not been providing effective oversight of CIDR at national level and this extends to their information governance responsibilities also. While there are identified individuals with responsibility for aspects of information governance, it was noted that there is no formal scheme of delegation in place in relation to information governance within HPSC to provide clarity in relation to roles and responsibilities. For example, there was a lack of clarity in relation to the role of the HPSC Data Protection Officer.

- HIQA identified a good overall awareness of the significance and importance of information governance within HPSC, public health departments and laboratories. HIQA recognises as good practice the development of CIDR Business Rules. However, HIQA found that there was a lack of clarity among CIDR users regarding the assignment of roles and responsibilities for information governance in relation to CIDR, as outlined in the current CIDR Business Rules. HIQA acknowledges the development of the draft revised CIDR Business Rules, outlining revised roles and responsibilities for information governance in light of GDPR. HPSC would benefit from providing clarity for all CIDR users regarding roles and responsibilities for information governance within the draft revised CIDR Business Rules and putting in place plans to communicate such information to all CIDR users, when the draft revised CIDR Business Rules are formally rolled out. This would help to facilitate a strategic approach to their implementation across all sites where CIDR is used.

Information security

- HIQA recognises as good information governance practice, HPSC's efforts in undertaking a number of internal and external information governance audits annually. HIQA acknowledges, in particular, the work that HPSC undertakes to improve information governance practices whilst maintaining accreditation to ISO 27001. Furthermore, HIQA acknowledges the work that HPSC are doing in addressing the recommendations of the GDPR Readiness Audit.

- Currently policies and procedures in relation to retention and destruction of data relating to CIDR vary significantly, at sites where CIDR is used. HIQA was made aware that discussions are taking place at HSE level in relation to the circumstances under which data and information should be retained or destroyed. There is a need to collaboratively address such information governance risks in order to protect the privacy and security of personal information within HPSC and in Departments of Public Health and laboratories supplying data to CIDR.

- HIQA recognises the security measures that HPSC has in place in relation to access to the CIDR system, ensuring that access is granted based on an individual's role, location and the specific disease area that individual is working on. HIQA further recognises the internal procedures that are in place to ensure that CIDR can only be accessed by two-point authentication.

- It emerged during the review that there is a lack of clarity among CIDR users in Departments of Public Health and laboratories as to what constitutes a data breach in relation to CIDR. Such lack of clarity may potentially lead to variability in how a data breach is managed. In the absence of such clarity it may be difficult to determine whether or not a breach had occurred. This could lead to HPSC being unaware of potential data breaches that may have occurred in relation to CIDR and data breaches not being appropriately identified and reported.

Privacy and confidentiality

- HIQA acknowledges the work that HPSC has undertaken in conducting 24 privacy impact assessments, including a PIA on the CIDR system, as required under GDPR. These PIAs highlight any potential data protection risks in relation to personal information and enable HPSC to mitigate potential risks relating to persons engaging with CIDR. HPSC should continue to undertake PIAs where personal information is used in all future projects pertaining to CIDR.

- A Statement of Information Practices has not been published by HPSC including procedures to allow members of the public to raise queries or complaints relating to their personal information held within CIDR.

Training

- HIQA positively recognises the training programmes that HPSC has in place in relation to information governance and the work that is ongoing in relation to developing a new training module focusing on GDPR requirements.

4.4 Recommendations – Information Governance

Information Governance	
	Enhanced arrangements for information governance
	HPSC should further strengthen and enhance arrangements for information governance in relation to CIDR, to include data collected across all sites where CIDR is used. This includes: ▪ facilitating the standardised implementation of the CIDR Business Rules across all sites where CIDR is used, ensuring clarity for CIDR users in relation to information governance roles and responsibilities. This should also include arrangements for information security and data protection. ▪ defining roles and responsibilities for information governance within HPSC through a formal scheme of delegation. ▪ providing assurance to the CIDR National Steering Committee in relation to information governance for CIDR through reporting against KPIs, risk and the findings of audit. ▪ developing and publishing a Statement of Information Practices.

5. Use of information

Over 30,000 events and 500 outbreaks were reported to CIDR in 2017**.[6,30] CIDR is an extremely rich and valuable source of data used to protect and maintain public health on a national and international scale. The availability of one central repository for notifiable infectious diseases enables public health professionals to identify trends in these diseases, allowing for early intervention and prevention of the spread of infectious disease. Controlling outbreaks and clusters is paramount in stopping the spread of disease. CIDR is a vital source of information used by many stakeholders, including public, clinicians, policy-makers and researchers. CIDR data is used for surveillance, policy development, service provision and reporting purposes. Data quality is of the upmost importance so decisions are made based on accurate information that is available in a timely manner.

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.[53,54] In the healthcare sector, effectively using information is 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.[53,54]

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 use the information confidently to inform decisions and the data should be aligned with health information standards and nationally agreed definitions to enable comparability and support interoperability.

The HIQA review team assessed the use of information in CIDR against Standards 5, 6 and 7 of the Information Management Standards.

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.

** Each event relates to an episode of illness; therefore, a single event may have a clinical record and multiple laboratory records linked to it.

5.1 Findings — Data quality

5.1.1 Data quality responsibilities

Data quality is a key component of information management. It is essential that data is accurate, valid, reliable, timely, relevant, legible and complete. CIDR is an extremely valuable national repository of health information and, therefore, it is important that there is confidence in the quality of the data it collects and processes.

As described in Chapter 2, CIDR is a shared system where data is accessed by HPSC, the regional Departments of Public Health and the diagnostic and reference laboratories. Data quality needs to be assured at all levels to meet the needs of infectious disease surveillance locally, regionally and nationally and to allow HPSC to meet international reporting obligations. Currently, there is no identified person with overall responsibility for data quality within HPSC. Instead, it is managed within the individual disease-specific teams, primarily by surveillance scientists. HIQA was informed that the need for a HPSC data quality manager had been raised at senior management team meetings and in 2019 a business case was made to have such a post authorised. However, during the course of the review, no further developments had been made in relation to securing such a post.

At regional level, as per the CIDR Business Rules, responsibility for data quality ultimately lies at a local level within Departments of Public Health and laboratories where CIDR managers and CIDR users are responsible for the management and use of the CIDR system and infectious disease surveillance data for their area. Findings from focus groups confirmed that public health surveillance scientists have responsibility for data quality; however, this is not formalised and arrangements are not standardised across Departments of Public Health and laboratories. Furthermore, as stated previously in Section 3.3, it became evident during the review that, for some CIDR users, the role and responsibilities of a CIDR manager are not fully explicit and require further clarification.

5.1.2 Data quality arrangements

5.1.2.1 Data quality arrangements at national level (HPSC)

During the review, HIQA identified examples of data quality initiatives and activities within HPSC including the development of detailed data processing standard operating procedures (SOPs), frequent data validation and de-duplication schedules, and to a lesser extent, the use of key performance indicators which relate to the timely publication of reports of notifiable diseases. However, HIQA was informed that there is no overarching data quality framework[††] for CIDR.

In relation to policies and procedures, HIQA was provided with evidence of SOPs in place for each specific infectious disease group. Such SOPs provide detailed information for CIDR users on the case definition, the collection of core and enhanced data, data validation and patient de-duplication, creating outbreaks and reporting data.

[††] A document which outlines the approaches to systematically assess, document and improve data quality. It includes a data quality strategy, data quality assessment methodology, reporting on data quality and data quality improvement cycle.

In addition to these SOPs, HIQA acknowledges that surveillance scientists in HPSC conduct data validation on a weekly, quarterly and annual basis to identify obvious errors and inconsistencies in CIDR data. In the first instance, data pertaining to the weekly outbreak and weekly infectious disease reports are reviewed and validated by the surveillance assistant responsible for producing these reports. Where information is missing, contact is made with the relevant Department of Public Health to complete missing fields. More detailed validation checks are conducted on a quarterly basis whereby surveillance scientists in HPSC request that surveillance scientists in Departments of Public Health and laboratories run routine core validations for the previous quarter for all diseases. HIQA was informed that there is frequent contact between the surveillance scientists in HPSC and Departments of Public Health and laboratories in relation to gaps in CIDR data or with regard to any unusual events created on CIDR. This helps to ensure that any outstanding data discrepancies are identified and resolved as appropriate, thus reducing the data quality validation workload at the end of each quarter or year. Further data validations are carried out by external subgroups. For example, for hepatitis, data variables and reports are reviewed on an ongoing basis by the hepatitis subgroup of the Public Health Medicine Communicable Disease Group (PHMCDG).

In terms of the use of key performance indicators (KPIs) to monitor data quality across the dimensions,[‡‡] HIQA was informed that HPSC has a 75% target for the completion of risk factor data for certain diseases. HIQA did not identify how this target is monitored and whether it is achieved in practice. In addition to this target, although not a KPI, HPSC provide a 'completeness assessment' broken down by region. This is useful to identify different practices across regions and to promote improvements by providing feedback on performance. This report is circulated to all CIDR users in that region together with national figures. This puts a specific focus on achieving a high level of completeness for core data. From evidence provided through information requests, HIQA learned that CIDR users in Departments of Public Health are encouraged to correct any errors and are the end-point for rectifying any data quality issues that exist. However, HIQA identified areas where there were concerns regarding the completeness of data. These will be examined in further detail using two case studies (Section 5.4).

Although, the use of this target to drive completeness of data is a positive step in monitoring and driving improvements in data quality, HIQA identified a need to identify and implement the use of a comprehensive set of KPIs to assess data quality for disease-specific areas within CIDR that captures the range of data quality dimensions.[(9)] Taking the quality dimension of timeliness as an example. CIDR was established to capture real-time data on infectious disease notifications. However, evidence from interviews with laboratories identified that, the timely upload of data to CIDR does not always happen in practice. This is often due to local practices and resourcing issues. HIQA was assured that the clinical management of the case is not affected, as the laboratories will inform the Departments of Public Health of a new notification once laboratory confirmation has occurred. However,

[‡‡] Quality of data can be defined and assessed using the following internationally accepted dimensions: relevance, accuracy and reliability, timeliness and punctuality, coherence and comparability, and accessibility and clarity.

there are situations when, due to circumstances like annual leave or busy periods, there can be a backlog of laboratory notifications that need to be uploaded to CIDR. When uploaded, this data can skew national trends as it leads to an artificially high number of cases during the upload timeframe. HIQA did not identify the use of any KPIs to enable senior management to monitor this, or other data quality issues, at a local level.

5.1.2.2 Groups that focus on data quality and use of information

There is a strong emphasis on data quality and data validation in HPSC. Each disease-specific team within HPSC considers data quality on an ongoing basis. Within HSPC, there is a cross-functional team group that focuses on some aspects of data quality, namely, the HPSC Surveillance Scientists and Assistants Group and also a weekly forum where data issues can be addressed, the HPSC Weekly Scientific Meeting. Additionally, the HPSC Scientific Advisory Committee and its various sub-committees for the specific disease areas may also address some aspects of data quality for CIDR in relation to particular infectious diseases.

At a national level, the CIDR User Group provides a forum for users to report data quality issues. However, although data quality issues are discussed at meetings, this forum tends to focus on the clinical management of events such as weekly trends, unusual cases and outbreaks. In addition, there is a CIDR National Peer Review Group, which reviews data access requests from third parties and thereby aims to ensure the appropriate use of CIDR data by applicants (Table 7).

Although aspects of data quality are addressed at a number of levels, HIQA identified that there is no committee or forum with specific responsibility to drive consistency of practices and data quality across all disease areas and across all regions. HIQA also recognises that a lot of quality improvement work is occurring across sub-committees for disease specific areas. However, as there is no specific committee or person responsible for the oversight of an organisational strategy for data quality, this activity is occurring in silos and at times in an ad-hoc manner. Given the importance of data quality for CIDR, it is essential to systematically assess, document and improve data quality in a strategic way through the most appropriate forum.

Table 7. Groups — data quality and use of information

Group	Purpose	Details	Quality focus
HPSC Weekly Scientific Meeting	To review the numbers of infectious diseases and outbreaks notified during the previous week, to update ongoing outbreak investigations and to discuss operational support issues including EPIS, EWRS and IHR alerts and content for communications (social media, website and Epi-insight).	**Frequency:** Weekly **Chair:** Rotating Chair (weekly rota for Surveillance Scientists) **Lines of reporting:** Director HPSC **Documentation:** Agenda recorded but minutes are not taken.	• Data quality issues can be flagged and discussed at these meetings.
HPSC Surveillance Scientists and Assistants Group	To discuss issues relevant to Surveillance Scientists and Surveillance Assistants, which may include surveillance, research, training, continued professional development, resourcing and staff welfare.	**Frequency:** Ad-hoc **Chair:** Senior Surveillance Scientist **Lines of reporting:** SMT **Documentation:** Agenda and minutes recorded	• Data quality issues can be flagged and discussed at these meetings.
National CIDR User Group	To provide a forum for all CIDR users to communicate their needs and learn of recent developments.	**Frequency:** Quarterly **Chair:** Public Health HSE-S **Lines of reporting:** CIDR National Steering Committee **Documentation:** Agenda and minutes recorded	• Discuss updates on CIDR operations including CIDR availability, helpdesk queries, user training and CIDR reporting. • Data quality issues can be flagged and discussed at these meetings.
National CIDR Peer Review Group	To facilitate the collaborative use of CIDR data.	**Frequency:** A teleconference convened to discuss request/s as required. **Chair:** Chair rotates every 2-3 years. **Lines of reporting:** Decisions recorded and response sent to the applicant. **Documentation:** Group assesses	• To review the purpose for which data is requested. • To ensure that publications or communications arising from data provided from CIDR are in line with the CIDR Publication guidelines. • To ensure that, if

		application using set principles. Decisions recorded.	CIDR data is provided, there are formal processes for the maintenance of confidentiality and a clear understanding of what data protection obligations need to be addressed.

5.1.2.3 Data quality arrangements at regional level

At Department of Public Health level, depending on the disease group, there are weekly, monthly, quarterly and annual data validation schedules. However, due to time and resourcing constraints, this is not standardised across the country. Each disease area is prioritised by resources at a local level and, whereas some areas validate weekly or monthly, others validate data on a quarterly basis. Findings from focus groups confirmed that data quality initiatives and audits are carried out in an ad-hoc manner, that is, not all teams audit on a regular basis and there is no audit schedule for the different teams. Thus, practice is not standardised across the country and may be in response to issues flagged at HPSC level. Furthermore, HIQA was informed that during an outbreak or, for example, flu season, the public health management of the disease becomes priority as expected. This may have implications for the quality of CIDR data, particularly around the timeliness and completeness of enhanced surveillance information. In the absence of a strategy for CIDR, this needs to be taken into consideration when prioritising and planning resources.

In addition, in relation to data quality within laboratories, all data is validated and authorised before it is passed to the Department of Public Health to allow them to create an event which provides a level of assurance at this level.

5.1.2.4 Evaluations

In addition to the above initiatives, some infectious disease surveillance systems have been formally evaluated in terms of completeness, accuracy, timeliness and usefulness. These evaluations make practical recommendations for improving aspects of infectious disease surveillance in relation to the CIDR system (Table 8). HIQA was informed that these are usually conducted on an ad-hoc basis by EPIET[§§] Fellows or specialist registrars in public health medicine as part of academic projects. HIQA acknowledges that some improvements have been made in relation to, for example, the HIV enhanced surveillance form following an evaluation of the completeness of HIV surveillance in 2015.[(55)] In this example, the team at HPSC requested feedback on proposed changes to the HIV surveillance form, including the removal of multiple poorly populated fields, which has resulted in a shorter version of the form. However, for more complex recommendations, such as those suggesting the need

[§§] The European Programme for Intervention Epidemiology Training (EPIET) Fellowship provides training and practical experience in intervention epidemiology at the national centres for surveillance and control of communicable diseases in the European Union.

for more training or to improve stakeholder engagement and communication between CIDR partners, there is little evidence of their implementation.

It is very clear that a lot of time and effort has been dedicated to undertaking 13 evaluations, which have presented many recommendations for improvement. Unfortunately, however, the recommendations emerging from these reviews have not been systematically implemented and formalised implementation plans are not routinely prepared. In reviewing the recommendations for all evaluations, HIQA found common findings in relation to a need to explore the user satisfaction with the CIDR system, to examine methods to improve completeness and timeliness, and to further engage with internal and external stakeholders (Appendix 11). However, despite similar findings over the course of 10 years, a strategic approach to implementing change has not being developed. For example, the lack a standardised approach to data collection across regions was identified in the first evaluation of Salmonella in 2008, and 11 years later, HIQA has found that this issue is still a significant problem in relation to data quality. This presents a missed opportunity as understanding and addressing the issues identified through these evaluations in a coordinated and strategic way would lead to improved data quality. This finding is also linked to the fact that there is currently no forum for strategically addressing data quality within CIDR as discussed in Section 5.1.2.2.

Table 8. List of evaluations undertaken by HPSC

Disease	Year	Report name
Salmonella	2008	Completeness and timeliness of Salmonella notifications in Ireland[56]
Measles	2012	Evaluation of the Measles surveillance system Ireland[57]
Viral Encephalitis and Viral Meningitis	2013	Underreporting of viral encephalitis and viral meningitis, Ireland, 2005-2008[58]
Measles	2013	A gap analysis of the surveillance information required to measure progress towards measles and rubella elimination in Ireland[59]
HIV	2015	Evaluation of the HIV surveillance system in Ireland[55]
Influenza ICU surveillance system evaluation	2016	An evaluation of the Irish national surveillance system for monitoring confirmed cases of influenza admitted to ICU, 2010-2015[60]
Influenza —Paediatric enhanced surveillance system evaluation	2017	Evaluation of the paediatric hospitalised influenza surveillance system in Ireland[61]
Syphilis	2017	An evaluation of case based syphilis surveillance in Ireland[39]
TB	2018	Evaluation and comparison of the National Tuberculosis (TB) surveillance system in Ireland before and after the introduction of the Computerised Electronic Reporting System (CIDR)[62]

Meningococcal disease	2018	A retrospective assessment of the completeness and timeliness of meningococcal disease notifications in the Republic of Ireland over a 16-year period, 1999-2015 (63)
HIV	2018	An evaluation of HIV case-based surveillance and change in the national surveillance case definition(64)
Haemophilus influenzae	2018	Determining the level of agreeance between the General Register Office and CIDR reporting of mortality in relation to Haemophilus influenzae in Ireland(65)
Invasive meningococcal disease	2018	Evaluation of the invasive meningococcal disease surveillance system(66)

5.1.3 Data Quality — training and education

Up to 2013, CIDR training was conducted centrally by surveillance scientists at HPSC. It has since moved to a localised model where each Department of Public Health or laboratory has a designated 'super-user', usually a surveillance scientist, to provide training at a local level using a CIDR test/training module. CIDR training sessions are arranged, configured and monitored by the CIDR team. The CIDR team verify that training was completed by reviewing the access logs on the training system. The CIDR training module uses the test system which is a copy of the CIDR system containing 'dummy' data'. CIDR training sessions are not supported on the live CIDR system. Through interview, HIQA was informed that the type of training users receive depends on their role, region and the disease area they will be working on.

HIQA was informed that access to the test environment for training purposes is by arrangement so training is released on demand. This means a Department of Public Health or laboratory must wait until HPSC release the training module. Although it was reported to HIQA that this has improved in the past year, some users may still have to wait a number of weeks before they receive training, during which time they do not have access to the system. The reason for this delay is because the training is done on the test system so they need to ensure that they are not using the test environment while training is occurring, as it can cause instability. If these arrangements are not satisfactory, there may be a need for alternative arrangement to ensure training can be provided in a timely manner. In addition, it was reported that there is difficulty in accessing and using the 'dummy' data. Some CIDR users have described this data as being out-of-date and believe it is not a true reflection of the live system. As a result, HIQA was informed during focus groups that some public health regions have resorted to using the live CIDR system for training purposes.

In terms of advanced training, particularly the use and creation of customised CIDR reports, HPSC previously offered a one day advanced training course but this has not been provided since 2013. It was reported by HPSC that this training is now included in the standard local core training module. Information gathered during focus groups suggests that CIDR users also work on it themselves and 'self-learn'. For others, they extract CIDR data to other

programmes such as Microsoft Word or Access for manipulation. During the review, CIDR users have been unanimous in their views that additional training, particularly around the use of business objects (report and business intelligence software), which is detailed in Section 5.2.1, is required to enable them to analyse data and run reports from the CIDR system more effectively. Refresher training is not routinely provided, however it is possible to provide this on the live system at a local level as the person has already received core training on the system and has been granted access.

A formal evaluation of CIDR training was delivered as part of the pilot implementation of CIDR in 2004. It was agreed at that stage that delivery of CIDR training would be centralised at HPSC. Between 2005 and 2012, participants and trainers completed a feedback form at the end of each training session. Since CIDR training was decentralised in 2013, feedback on CIDR training is received via the CIDR Users Group. There has been no formal evaluation of CIDR training since 2013. HPSC reported that they routinely review the number and nature of calls to the helpdesk, which helps to identify and address any current issues.

5.1.4 Stakeholder engagement to inform data quality

Effective stakeholder engagement is vital given the complexity of CIDR as a partnership model between HPSC, the Departments of Public Health, diagnostic and reference laboratories, the Food Safety Authority of Ireland, and *safe*food. HIQA acknowledges the work that HPSC have undertaken to engage with CIDR partners to inform them of changes aimed at improving data quality through direct email or the CIDR User group. However, HIQA was informed that there is no strategic approach to engagement.

HIQA recognises the CIDR User Group as an important forum for all CIDR users to communicate their needs and learn of recent developments. Furthermore, the CIDR helpdesk is also available to assist users. The helpdesk supports queries that relate to both the business process and the technical side of CIDR. Queries are usually logged via email; however, HIQA was informed that any urgent queries are dealt with directly via telephone if possible. From feedback at focus groups, HIQA identified that CIDR users were satisfied with the assistance provided by the CIDR helpdesk. Through information request, HIQA learned that the information gathered through this helpdesk is used to inform the re-development of SOPs and information sheets and included on the HPSC website in the form of frequently asked questions.

Although HPSC has many good practice examples of engagement with stakeholders, through interview, HIQA learned that HPSC identified a need to further understand engagement opportunities. As a consequence, the Quality and Safety Committee recently completed a mapping exercise to identify the level of engagement among stakeholders for the HPSC. One objective of this exercise was to tailor communication towards the needs of different stakeholders, which is being accelerated through a review of website content and social media feeds. However, HIQA also identified a need to improve stakeholder engagement in relation to CIDR. In interview it was noted that HPSC has not undertaken a comprehensive survey of all CIDR users to assess the usefulness and usability of CIDR following the full

implementation of the system. This would be a simple and effective way to systematically engage with all CIDR users. For example, HIQA learned through focus groups that usability and user acceptance would increase if automatic updates to existing CIDR events were possible. A significant duplication of work, time and effort, goes into manually adding laboratory records to existing CIDR events. The information garnered from stakeholder engagement would be invaluable to inform a data quality strategy.

In reviewing the approach to engagement, it is important to create a two-way communication process whereby feedback is sought and follow-up communication is provided back to the stakeholders. This should explain actions taken as a result of the feedback but also, when there is a genuine reason for not implementing change, it is equally important to clearly communicate these reasons to stakeholders. HIQA identified a level of dissatisfaction in this regard with CIDR users. Through focus groups, CIDR users expressed frustration with the fact that enhanced surveillance fields on CIDR may not correspond with the latest version of the enhanced surveillance form. CIDR users stated that they have discussed the issue at the CIDR User Group meetings on various occasions, without appropriate resolution in their view. HPSC provided evidence that this arises because there can be a delay between receiving a request for changes to the enhanced surveillance form from HPSC disease team and the CIDR team being able to make the changes to CIDR. From a stakeholder's point of view, it is difficult when feedback is provided to highlight quality issues but change does not occur as a result.

5.2 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 the information is made accessible to those who make decisions or conduct research in a timely manner.

Primarily, CIDR is used for local control, management and prevention of infectious diseases and then subsequently for national control, management and prevention of infectious disease. The data held in CIDR is also used by the HSE and Department of Health to inform the provision, management, performance assessment, planning and funding of health and social care services in Ireland. It is used by the general public, the media, healthcare professionals and national and international academic researchers. For example, the National Immunisation Advisory Committee uses information from CIDR to inform decisions on changes to the immunisation schedule in Ireland and the proposed introduction of new vaccinations. Some of the users of CIDR data and information are represented in Figure 12.

Figure 12. Examples of users of CIDR data and information

5.2.1 Information management functions to support the use of CIDR data

CIDR reports can be generated using Business Objects, a reporting tool that can analyse information based on age group, gender, risk category, HSE area, disease classification and outcome. During the review, CIDR users indicated that Business Objects is adequate in terms of running standard reports. However, HIQA was informed of some difficulties in using this tool particularly when customised disease reports are required. In this instance, specific training and support is required to use this reporting tool to its full potential. As a result, CIDR users create parallel programmes in Microsoft Access or Excel to facilitate report production and statistical analysis. This results in significant duplication of work and effort, and potentially compromises data security.

Furthermore, there is an outbreak module on CIDR which should be used to manage the surveillance of infectious disease outbreaks. Outbreaks of notifiable diseases as well as any unusual clusters or changing patterns of any illness can be created by linking together individual cases (events), for example, in an outbreak of measles. In addition, notification of an outbreak can be directly inputted into CIDR. All outbreaks are recorded on CIDR and this information is used to generate the weekly and other Outbreak reports. During focus groups, HIQA was informed that many CIDR users are using the outbreak module to a limited extent, particularly to capture enhanced surveillance information. Some are capturing enhanced outbreak surveillance data within separate databases in Departments of Public Health. CIDR users reported using Excel or other programmes, raising potential concerns in

respect of data quality and information governance. This signals that a review of the usefulness and usability of this module is necessary. This could be addressed by means of a user survey as suggested in Section 5.1.4 and as part of a strategy for data quality.

As discussed in Chapter 3, the requirements and methodologies as well as information requirement of laboratories is rapidly evolving. However, the ability for the laboratories and reference laboratories to capture, extract and send this data to CIDR to be used effectively is limited. This should be addressed through strategic planning at the level of the CIDR National Steering Committee.

5.2.2 Dissemination and use of CIDR data

HIQA acknowledges that HPSC disseminates information and data from CIDR through a wide variety of methods to ensure that infectious disease data and information is accessible to a wide range of stakeholders. For example, weekly, monthly, quarterly and annual reports are published online on HPSC website. Other outputs and feedback include frequent social media posts, articles published in 'Epi-Insight' (the monthly HPSC bulletin), monthly reports on notifications for certain diseases, and through lectures, presentations, scientific paper publications and conference abstracts.

HPSC have a number of national KPIs in relation to the dissemination of CIDR data which ensures the timely publication of key infectious disease data on a weekly basis:

- To publish 95% of the Weekly Infectious Disease Reports by the scheduled day (Wednesday) of each week
- To publish 95% of the Weekly Outbreak Reports by the scheduled day (Wednesday) of each week
- To publish 95% of the influenza surveillance reports by Friday of the weeks when flu activity is above baseline (Note: this report is usually produced on a weekly basis from October, that is, Week 40, until flu activity is below baseline for two consecutive weeks and thereafter on a fortnightly basis until the end of flu season, that is, Week 20).

At a local level, CIDR data is used by Departments of Public Health to facilitate public health action on individual cases of infectious disease as well as identifying and managing infectious disease outbreaks. Within hospitals, medical staff and management can use surveillance data for audit and research purposes. At a national level, the data held in CIDR are used by HPSC to provide reports on the incidence and burden of infectious disease regionally and nationally. Furthermore, this trend data is also used by the HSE and Department of Health to co-ordinate and oversee the development of key organisational planning processes at national level including corporate and national service planning across all divisions. In addition, CIDR data is used to enable Ireland to meet its obligations in reporting notifiable infectious disease data to international agencies, as outlined in Section 2.3.3, such as the European Centre for Disease Control (ECDC), the European Food Safety Authority (EFSA) and the World Health Organisation (WHO). For example, in accordance with the ECDC founding regulation (Regulation (EC) 851/2004), EU Member States are required to notify ECDC "In a timely manner with the available scientific and technical data

relevant to its mission".[51] This data is captured within the European Surveillance System (TESSy) held within ECDC, in order to collect, analyse and disseminate surveillance data on infectious diseases in Europe. Finally, CIDR data is also used by journalists and politicians, often through parliamentary questions, to report public health issues at a regional and national level. Each request is dealt with individually, and much of this information is publically available on HPSC website.

5.2.3 Publicly available data from CIDR

On the HPSC website, the publications page is dedicated to disseminating a variety of reports which provide website visitors with access to summary statistical data on the range of disease topic areas monitored on CIDR, including:

- HPSC Annual Epidemiological Reports — available as a series of individual epidemiological disease reports
- weekly reports on infectious disease, outbreaks, influenza surveillance and STI/HIV
- scientific publications
- articles published in EPI-Insight, which is primarily targeted at those with an interest in the diagnosis, surveillance, control and prevention of infectious diseases
- information leaflets for the general public such as immunisation and vaccine leaflets
- information and guidance for GPs and primary care such as *Hepatitis C Screening: National Clinical Guideline*

Through information requests, HIQA learned that the use of information is monitored by HPSC's Information Officer and the use of data is reported in a monthly and annual report on the impact assessment of outputs. This demonstrates a positive and proactive method to reviewing the use of CIDR data.

5.2.4 Formal data requests

The CIDR Business rules states that CIDR users are encouraged to use and disseminate CIDR data. At a local level, Departments of Public Health and laboratories are free to use and publish information collected for their own HSE area and laboratory, respectively. However, there is a transparent process in place for assessing and processing external data requests at a national level.

The protection and disclosure of CIDR data is subject to the legal remit of the Health Act 2007 and data protection legislation. The CIDR National Peer Review Group reviews requests for data from CIDR and the purpose for which it is requested. This purpose needs to be in line with the reason that the information was originally collected, that is, the surveillance, management, prevention and control of the notifiable infectious diseases and their causative organisms. This group is also responsible for advising applicants that any publications or communications arising from data provided from CIDR must be in line with the CIDR publication guidelines. To ensure that this information is protected and only disclosed appropriately, application to the CIDR National Peer Review Group is required for CIDR data requests from third parties and from CIDR partners seeking access to CIDR data beyond their current access level.

The CIDR National Peer Review Group provides a clear procedure regarding the application and assessment process for accessing and using CIDR data. However, information relating to this group or the formal data request procedure is not available online on the HPSC website.

5.3 Findings — Use of health information standards and terminologies

HIQA reviewed practices in CIDR to assess the use of health information standards and nationally agreed definitions to enable comparability and sharing of information. The 2003 Amendment to the 1981 Infectious Diseases Regulations require that a medical practitioner and a Clinical Director of a diagnostic laboratory, in notifying infectious diseases, have a thorough understanding of the case definitions for infectious diseases circulated by HPSC. A case definition means the set of clinical characteristics including the common and relevant signs and symptoms of the disease, or microbiological characteristics confirmed by laboratory tests, by which a case of infectious disease is defined.

HPSC is responsible for maintaining, updating and circulating the case definitions, which are based mainly on standardised European case definitions (Commission Decision 2008/426/EC). Where European definitions are not available, definitions from other sources are used or adapted. These other sources include Centers for Disease Control and Prevention (CDC), WHO and the European Antimicrobial Resistance Surveillance Network (EARS-Net). These are used by many EU/EEA countries and allow some comparisons between countries. However, it is important to note that testing criteria, data quality and surveillance systems do vary between countries.

Through information request, HPSC provided HIQA with information on the core dataset as well as enhanced data by disease. The core dataset includes both mandatory and non-mandatory information on the disease event (these are outlined in Section 2.6).

Enhanced data for specific diseases can include information such as vaccination status, mode of transmission, foreign travel, treatment and patient outcomes. Some of these fields are automated 'drop down' fields; however, for many there are open text or comment boxes for CIDR users to input this information. This information is, therefore, not always captured in a standardised fashion, which makes it difficult to analyse and use. Collecting this data is time consuming and some CIDR users have expressed uncertainty about how some of this information is used to improve public health. Furthermore, there are cases where the information collected through enhanced surveillance forms does not match the fields present in the CIDR system. As a result, there is no facility for CIDR users to record some information they have taken the time to collect and hence this information is not being used effectively. In the interest of efficiency and to improve completion rates, it would be beneficial to update CIDR to match all infectious disease notification forms and where possible to rationalise forms. The information collected through enhanced surveillance is vital in helping to compile a complete understanding of the epidemiology of each infectious disease, and to enable the review of risk factors and outcome data. HIQA was informed through interviews and focus groups that there are issues with the completeness of enhanced data.

In line with this, HPSC informed HIQA that it does not publish a formal data dictionary. The publication of a data dictionary is recognised as good practice for enhancing data quality and maximising the use of information as it contains a descriptive list of names, definitions and attributes of data elements collected in an information system or database. It also improves communication and understanding for those collecting and using the data as it supports a shared understanding of the definitions. The development of a data dictionary will also help to give a clear description of exactly what data is being collected and the format in which the data is collected. This would be particularly useful given the issues with enhanced data described above, as a data dictionary would help to establish why each field is being collected and how the data is being used. Further engagement with CIDR users to outline the purpose of collecting each data field may improve the completion of enhanced data, as this is not always apparent to those entering the data.

5.4 Findings — Case studies on data quality

To further review aspects of data quality, HIQA undertook a comprehensive look at two surveillance systems: invasive meningococcal disease (IMD) and paediatric hospitalised influenza surveillance system. These case studies involved a detailed review of the systems through the lens of the five dimensions of data quality: relevance; accuracy and reliability; timeliness and punctuality; coherence and comparability; accessibility and clarity.[9]

5.4.1 Case Study 1 — Invasive meningococcal disease (IMD) surveillance

5.4.1.1 Context — IMD surveillance in Ireland

Invasive meningococcal disease (IMD), caused by *Neisseria meningitidis*, is a major cause of bacterial meningitis and septicaemia, associated with high fatality rates and significant long-term morbidity. Clinical presentations of IMD include meningitis, severe sepsis, septic shock and, less commonly, pneumonia and arthritis.(63) Accurate and detailed surveillance, combining clinical, epidemiological and laboratory data, is critical for the diagnosis and management of suspected IMD in the clinical setting as well as informing national policy for the introduction of preventative measures such as vaccination and monitoring the impact of such interventions in the population.(63)

In Ireland, in 1981, bacterial meningitis (including meningococcal septicaemia) was made a notifiable disease and, in 1994, a National Laboratory Surveillance System for IMD was introduced. As a result of a significant rise in notifications, the Irish Meningitis and Sepsis Reference Laboratory (IMSRL) was established in 1996. National surveillance of IMD is now co-ordinated by the vaccine-preventable disease group within HPSC with the assistance of Departments of Public Health, microbiology laboratories and the IMSRL. A full timeline for the IMD surveillance system is presented below in Figure 13. At European level, the surveillance of IMD is coordinated by the European Centre for Disease Prevention and Control (ECDC), having been transferred from the European Union Invasive Bacterial Infections Surveillance Network (EU-IBIS) in 2007.(67)

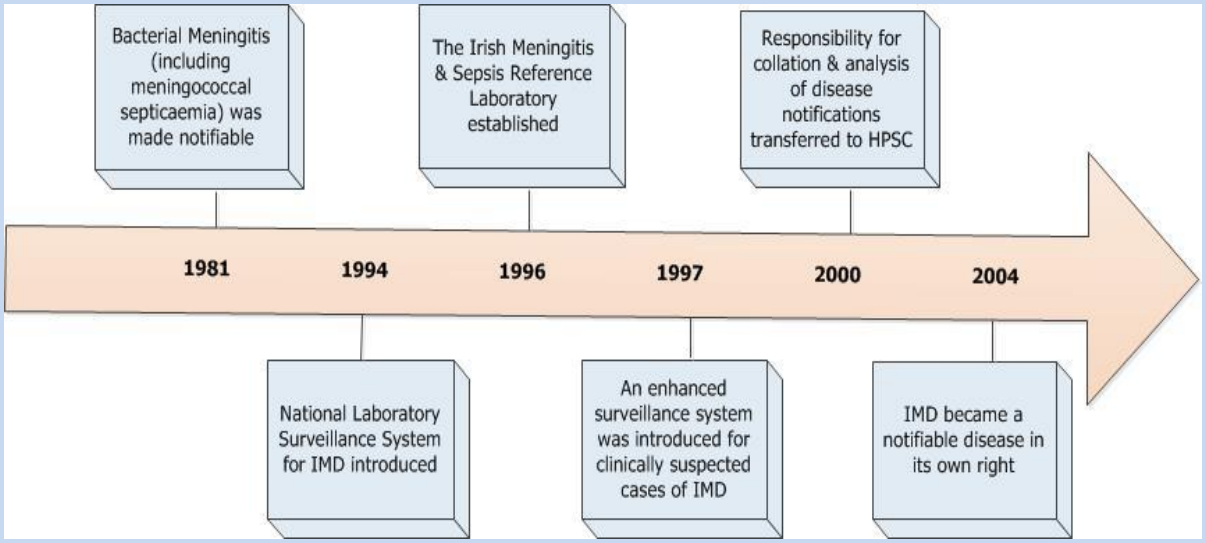

Figure 13. Timeline for IMD surveillance system

5.4.1.2 Relevance

Relevant data meets the needs of users and potential future users.

The aim of the IMD surveillance system in Ireland is fourfold:

1. to enable prompt identification and appropriate management of IMD cases
2. to enable prompt identification of clusters/outbreaks

3. to detect changes in the incidence and distribution over time
4. to monitor the impact of the vaccination programme.

In 2017, with 77 reported cases and 71 confirmed cases, Ireland had the second highest notification rate observed in Europe (1.5 per 100 000 population).[(63)] These rates coupled with the severe consequences outlined above led to IMD becoming a high-priority disease for population health in Ireland. To ensure prompt public health action it is essential that the information collected on CIDR is of the highest quality and fit for purpose, that is, it provides sufficient information to allow public health practitioners to detect and manage cases in a timely manner. Evidence from focus groups suggests that CIDR IMD data performs adequately in this regard.

Managing the relevance of data also requires that organisations remain aligned with the information needs of data users as they evolve. Engaging with stakeholders on an ongoing basis will allow organisations to remain aware of the changing needs and priorities of data users. HIQA acknowledge that HPSC are active in relation to communicating any changes and updates to IMD surveillance in Ireland. For example, revisions have been made to update and streamline the IMD enhanced surveillance form and all changes have been circulated to CIDR users. Through focus groups, HIQA learned that while some CIDR users believe the IMD enhanced surveillance form to be fit for purpose, they believe that there is room for rationalisation as some of the fields may be unnecessary.

Furthermore, considerations have to be made in terms of future anticipated data requirements, both domestically and internationally (for example, TESSy). However, technology in relation to laboratory diagnostics is changing rapidly, both in terms of how and where infectious diseases are detected and reference typed. Therefore, increasingly complex sub-typing data is becoming available, particularly in relation to molecular typing and genomics. Through additional evidence gathered during focus groups, HIQA has learned that the CIDR system has not evolved to keep up with this, for example, there is limited ability to enter enhanced molecular typing data in relation to IMD on CIDR. Therefore, much of the valuable reference laboratory data available in relation to IMD has to be manually entered into open-text fields and therefore is not captured in a standard way, limiting the ability to undertake routine analysis of these data, or in some cases it is not entered at all.

5.4.1.3 Accuracy and reliability

How closely the data accurately describes what it was designed to measure. Completeness is a core component.

HIQA was informed that HPSC policy is to review IMD data quality through data validation prior to publication of scheduled reports and on an ad-hoc basis as required. Quarterly reminders are issued to each Department of Public Health when validation is due as per the agreed schedule prior to report production. Normally a reminder is circulated to public health one month after the quarter has ended. HIQA was informed of a number of validation check reports that are available on CIDR for this purpose. Each year, a HPSC surveillance scientist runs these same reports to ensure that the validation checks have been completed, and that

any outstanding issues have been circulated to the relevant Department of Public Health. In addition to these validations, during focus groups, HIQA was informed that audits on completeness may also be conducted within Departments of Public Health but on an ad-hoc basis.

In general, because IMD is a high priority for population health in Ireland, there is a high level of completeness of CIDR data for confirmed cases. This includes the enhanced surveillance information. In 2018, an evaluation of the completeness and timeliness of IMD notifications and reference laboratory records for the period between 01 July 1999 and 30 June 2015 was conducted.[63] The authors found that data quality, especially relating to demographic data items, was relatively high at >95%.[63]

5.4.1.4 Timeliness and punctuality

Timely data is collected within a reasonable agreed time period. Punctuality refers to whether reports were published on time.

Timely and appropriate interventions in relation to antibiotic therapy can significantly improve patient outcomes in relation to cases of IMD. Moreover, the timely detection of cases is important to limit spread of disease by offering prophylaxis to close contacts of cases. However, the prompt identification and management of IMD contacts is dependent on the completeness and timeliness of notification of suspected cases. HIQA was informed that, because IMD is a high priority disease in Ireland, all relevant surveillance data is collected and input to CIDR as soon as possible.

Appendix 12 illustrates the data flow for the IMD surveillance system in Ireland. In summary, once a patient presents with suspected IMD, clinicians usually call the relevant Department of Public Health directly. Core information is recorded on a standardised form. The information from the form is manually entered on CIDR to create an event and is then visible to the senior medical officer (SMO) in that area. The SMO is responsible for updating the event and the enhanced surveillance form with details on clinical symptoms and case management. This information is generally completed within a number of days. In the meantime, specimens are sent to the primary laboratory and the IMSRL for classification and serotyping, respectively. There may be a delay in receiving confirmation from labs. HIQA was informed that this does not have an impact on the timeliness of public health response. The 2018 evaluation concluded that the timeliness of the IMD surveillance system compared favourably with similar investigations conducted elsewhere.[63]

5.4.1.5 Coherence and comparability

Consistent over time and across providers and can be easily combined with other sources.

As previously mentioned, case definitions allow standardisation and comparisons both within, and between, countries. The case definition for IMD changed in 2012, which has had a minor impact on the degree of consistency or reporting of details since 1999. Through information request, HIQA learned that in 2015 enhanced surveillance reporting for IMD was updated; however, this has not yet been reflected on the CIDR system. Consequently, not all data recorded by Departments of Public Health has been or can be entered on to CIDR in a standardised way.

5.4.1.6 Accessibility and clarity

Data are easily obtainable and clearly presented in a way that is understood.

In terms of publishing and disseminating data — HIQA identified that HPSC are effective in publishing regular updates on a weekly basis, as well as publishing quarterly and yearly reports.

However, in focus groups and interviews, when asked what improvements they would like to see occur as result of this review, there was a high level of agreement that advanced CIDR training needs to be addressed to ensure CIDR users can generate their own reports to meet their needs.

In addition, through focus groups HIQA learned that reference laboratories currently have limited access to CIDR data which presents difficulties in terms of having a real time national picture of the incidence of the infectious disease for which they are responsible. This highlights a need to review CIDR business rules arrangements for reference laboratories.

5.4.2 Case study 2 — Influenza surveillance with specific focus on paediatric (0–14 years) hospitalised influenza surveillance system

5.4.2.1 Context — Influenza surveillance in Ireland

Influenza is a highly contagious viral infection, readily spread person-to-person by respiratory droplets. There are three different types of influenza: A, B and C. Influenza poses a public health concern due to its high seasonal morbidity and mortality, the burden it places on the health services and society and its on-going pandemic potential. Each year, influenza is responsible for between three and five million cases of severe illness and 250,000 to 500,000 deaths worldwide.(61) Influenza in children is particularly problematic. The paediatric population have the highest influenza attack rates, with an annual incidence rate of up to 30% due to hygiene issues and limited pre-existing immunity.(68) Annual influenza vaccination is recommended by WHO for pregnant women, the elderly, children aged between two months and five years, those with chronic medical conditions and health care workers.(69) However, at present universal childhood influenza vaccination is not part of the national immunisation schedule.

Influenza viruses are notifiable diseases in Ireland under the Infectious Disease Regulations.*** Figure 14 describes the multifaceted data flows that constitute Ireland's national influenza surveillance system and denotes the contribution of CIDR data within the broad surveillance system. While CIDR data is an important component of the influenza surveillance system, there are several other sources of information that are used in influenza surveillance. The national influenza surveillance system was established in 2000 and involves collection of both clinical and virological data. Clinical surveillance in primary care contributes to monitoring the impact of the illness on the health service and the community. HPSC work with the Irish College of General Practitioners (ICGP) and the National Virus Reference Laboratory to operate a network of 61 sentinel general practices that monitor influenza and influenza-like illness (ILI)††† in patients presenting to their practices. ILI rates indicate when ILI symptoms are in circulation in the community and virological surveillance confirms that influenza is circulating and also identifies the current strain. Monitoring of calls to GP out-of-hours is undertaken by the Department of Public Health in HSE North-East and aggregated data reported to HPSC. These calls are monitored for self-reported influenza. Vaccination uptake rates in at-risk populations and excess mortality rates are also monitored. Enhanced surveillance on confirmed paediatric hospitalised influenza cases and ICU admissions from influenza is undertaken. Notifications of influenza cases (including hospitalisation status and outcome) and influenza outbreaks are reported on CIDR.

Steps in the notification process are as follows:

1. A notification of influenza is made to the regional Department of Public Health by clinician or laboratory. Hospital laboratories upload initial information such as name, date of birth, address, testing clinician, where test was ordered (inpatient, GP) onto CIDR. Laboratories can also send a paper notification to the regional Department of

*** Infectious Disease Regulations 1981 and Infectious Disease (Amendment) Regulations 2003

††† Influenza-like illness (ILI) is characterised by: the sudden onset of symptoms with a temperature of 38°C or more, in the absence of any other disease; at least two of the following: dry cough, headache, sore muscles and a sore throat.

Public Health. The regional Department of Public Health then creates a CIDR event.

2. In six of the eight Departments of Public Health, enhanced surveillance of hospitalised paediatric influenza cases are collected using the enhanced surveillance form and uploaded to CIDR. Surveillance data are obtained from patients, the treating paediatric team or in some instances the GP.
3. Notifications are then collated and analysed in HPSC. Information is disseminated by HPSC in the form of season and weekly influenza updates every Thursday throughout the influenza season (October–May).[61]

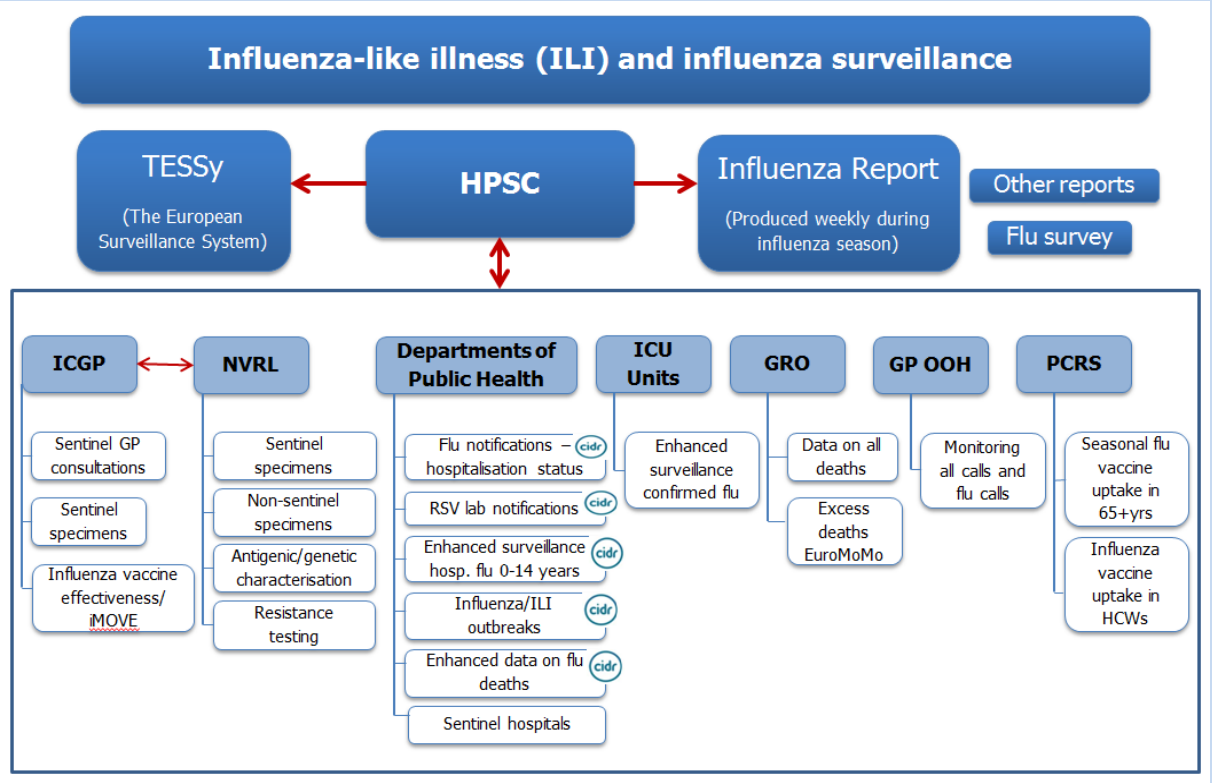

Figure 14 The overall national influenza surveillance system

To further investigate the quality of CIDR Influenza data, HIQA undertook a detailed review of one aspect of the multifaceted surveillance system: enhanced surveillance for paediatric hospitalised influenza. Hospitalised paediatric influenza surveillance is undertaken for children aged 14 years and younger hospitalised with confirmed influenza. In 2017, an evaluation of the paediatric hospitalised influenza enhanced surveillance system was undertaken as there were concerns from the regional Departments of Public Health who advised HPSC that the system was cumbersome, time consuming and labour intensive.[61]

5.4.2.2 Relevance

Data that is relevant meets the needs of users and potential future users.

For the influenza season 2017/2018, a total of 2,573 confirmed influenza cases aged between 0 and 14 years were notified on CIDR, 1,104 (42.9%) of these cases were reported as hospital inpatients.[70] To ensure prompt public health action, it is essential that the

information collected on CIDR is fit for purpose, that is, it provides relevant, accurate and timely information to allow public health practitioners to detect when influenza is circulating, identify the strains, detect changes in the virus and monitor morbidity and mortality. Relevant information is necessary to determine which age and risk groups are affected so that targeted public health interventions can be implemented. Ultimately, good quality data should help to manage cases and prevention in a timely manner.

Firstly, an evaluation conducted in 2017 on the paediatric surveillance system identified that there were no specific objectives set for this paediatric influenza surveillance system. A recommendation emerged from the evaluation that further clarification was required on this matter.[61] HIQA recognises that the system was set up initially in 2003 when there was a drifted strain of influenza A (H3N2) which affected children adversely i.e. severe morbidity and mortality. Subsequently, the paediatric surveillance system was maintained as it was felt that the information collated would help in decisions relating to the implementation of a universal influenza vaccination programme for children. HIQA did not find evidence that work to address this recommendation has been progressed.

Currently, the basic requirement for influenza data is to supply trend data to national and international stakeholders such as WHO and ECDC. This requires a lot of work from Departments of Public Health, clinicians and policy makers. Also WHO and ECDC recommend that all member states undertake surveillance on severe influenza so that systems are well established in the event of a pandemic and can be operated promptly in this scenario. In line with the specific objectives of this surveillance system, it is necessary to assess the relevance of the data collected for current and potential users to establish whether the data is fit for purpose.

A clear finding from the review undertaken by HIQA, as well as the findings presented in the 2017 evaluation, is that a streamlined approach to the collection and use of data is necessary in order to improve the quality of data.[61] Minimal information (lab confirmation and hospitalisation status) is required to establish that an event has occurred. Departments of Public Health use the enhanced surveillance form when undertaking enhanced surveillance for confirmed hospitalised influenza cases aged 0-14 years. However, a significant amount of detail is required to complete the paediatric enhanced influenza surveillance. Through interviews and focus groups, HIQA learned that many CIDR users did not accept that all data collected in the enhanced surveillance forms was necessary for surveillance purposes. Obtaining the enhanced data is complex and presents various obstacles when collecting the information, such as acquiring the information from different sources at multiple time points. It is essential that further attempts are made to ensure those inputting the data are aware of the reason why each data field is being collected and the importance of complete, accurate and timely data.

5.4.2.3 Accuracy and reliability

Accuracy and reliability is the degree to which data correctly and consistently reflects the situation it was designed to measure.

In the 2017 evaluation of this surveillance system, the results highlighted a great variation in the completeness of data. As expected it found that the core data had almost 100%

completion as this is mandatory data.[61] The evaluation reported that this data can be easily obtained from the laboratory systems, and hence the problem with completeness lies with enhanced surveillance data which is more difficult to obtain. For example, it found the completion of symptomatology ranged from 24.4% to 65.6%. This poor completion rate is linked to the difficulty in gathering some data elements and a lack of understanding that all data fields need to be completed.[61] Through interviews, HIQA was informed that there is a need to rationalise the number and scope of questions in the enhanced surveillance form to encourage greater participation in completing enhanced data fields and to improve the quality of data collected. Although changes were made to the form two years ago, issues remain with the number and scope of questions collected on the enhanced surveillance forms.

Furthermore, HIQA learned through the evaluation and through interviews that the enhanced data fields are not representative nationally.[61] Firstly, only six out of eight regions collect the enhanced data. Furthermore, as influenza surveillance does not require immediate public health action, it is deprioritised when outbreaks requiring immediate action occur. The poor completion rates are an indication that the detail required in the enhanced surveillance form is not well accepted by those collecting the data. In interview with HPSC, it was acknowledged that they had to rationalise the form two years ago, however issues remain with acceptance of the enhanced surveillance data. HIQA identified some inefficiencies in the data collection process, which would impact on data quality.

A list of issues identified include (some of these issues are linked to CIDR data in general and others relate specifically to influenza surveillance):

- data needs to be first completed on the enhanced surveillance form and then entered onto CIDR
- there is a duplication of a sub-set of data which appears on the paediatric surveillance form and the ICU influenza form which can lead to completeness issues as there may be an assumption that the data is being captured elsewhere. However, this only occurs for a small number of cases
- some laboratory information management systems are not easily matched to CIDR fields so often laboratories have to enter data onto their laboratory system and then manually enter information onto CIDR
- there is a complex data collection process which involves waiting for data from numerous stakeholders at different time points
- an extensive enhanced surveillance form which is not entirely entered onto CIDR.

Because of these issues, there are concerns with the quality of this data. HPSC reported that the paediatric influenza surveillance system was introduced in 2003 and since then, the workload pertaining to routine influenza surveillance, both at HPSC and Department of Public Health level, has increased. This is due to the development of rapid tests and increased awareness of influenza as a diagnosis. Despite the fact that there is an increased workload and increased public health concern, staffing levels have not been maintained or increased to meet demand. HIQA was informed that plans to include the ICU influenza surveillance dataset on CIDR, thereby integrating the surveillance of paediatric influenza and

ICU influenza on the one system, have not advanced due to resourcing issues.

5.4.2.4 Timeliness and punctuality

Timely data is collected within a reasonable agreed time period. Punctuality refers to whether reports were published on time.

The evaluation undertaken in 2017 identified that the time between symptom onset and completion of the enhanced surveillance took a median of 13 days. Typically, two days elapsed between symptom onset and admission to hospital and a further day before a specimen was sent to the laboratory for testing. Usually, only one day elapsed between event creation and completion of the enhanced surveillance form, indicating no delay in obtaining enhanced surveillance data after the event was created. The longest delay occurred between the date the laboratory result became available and the date when the case was notified to the Departments of Public Health; however, these dates were not consistently recorded.[(61)] HPSC reported that because the event is already created on CIDR and updated once the results are available, this step in the process was not always fully completed in a timely manner. However, public health action would have been taken. In interview with a Department of Public Health, HIQA learned that often the result is communicated verbally and action is taken prior to the event being updated electronically. The result of this is that the national data can be skewed because the data are not being reported in the period which it occurred.

As influenza is a priority disease, the punctuality of reporting is good: during the flu season, reports are published and data is uploaded on TESSy on a weekly basis.

5.4.2.5 Coherence and comparability

Consistent over time and across providers and can be easily combined with other sources.

Case definitions are used to collect data for Influenza A and B virus using the Case Definitions for Notifiable Diseases 2012 Version 1.8. This creates consistency over time and across providers which can be easily combined with other sources. However, due to the great variation in completion rates of enhanced data across regions and over time due to competing resources at different times of the year, the enhanced data fields cannot be reliably compared. Firstly, it is not possible to compare across all regions, as two regions do not collect enhanced data. Secondly, through interview, HIQA was informed that in busy periods or as case numbers increase, Departments of Public Health are sometimes unable to collect the enhanced surveillance data. There have been situations when HPSC has taken the decision to stop enhanced surveillance for a period due to an inability to record all cases in each region. The consequence of this is that data may not be accurately compared over time. However, in this situation, although the enhanced surveillance is stopped, surveillance of paediatric cases continues with recording of core data and hospitalisation status.

5.4.2.6 Accessibility and clarity

This dimension refers to data that are easily obtainable and clearly presented in a way that is understood.

Influenza surveillance reports are produced every Thursday throughout the influenza season providing prompt information that is accessible to the public, clinicians and policy

makers. Graphs and tables are used effectively to display complex clinical and virological data from CIDR, sentinel practices and the National Virus Reference Laboratory in an easy to understand format. News articles are also published on HPSC's website throughout the influenza season. These news articles summarise influenza activity and are written in plain English so that they are easily understood by the public. In addition, season summaries are also available on the HPSC website. All hospitalised influenza cases, GP ILI rates and NVRL virological data are reported directly to ECDC on a weekly basis via TESSy. While weekly reports do not contain details on enhanced paediatric surveillance, annual influenza reports have a comprehensive section on enhanced pediatric surveillance.

Overall, accessibility and clarity of influenza surveillance data is of a high standard; reports are produced weekly through the influenza season and are presented in a way that is easily understood. Although, reports include an assessment of data quality, data quality statements are not published to support the appropriate interpretation of data.

5.5 Significance of findings — Use of information

Data quality governance arrangements

- HIQA identified during the review that overall there is a strong emphasis on data quality and the use of information in CIDR, led by HPSC. For the core dataset, there are mandatory fields for all events created and drop-down options to standardise data entry and reduce data entry errors. This allows public health professionals to compare infectious disease trends both nationally and between regions. HIQA also identified many examples of data quality initiatives and activities within the organisation, including the development of detailed data processing standard operating procedures (SOPs), frequent data validation schedules and de-duplication schedules. However, HIQA identified that there is a need to standardise data quality practices across all Departments of Public Health to ensure the quality of all CIDR data within the system.

- Due to the complexity of data flows and number of stakeholders, as part of an overall strategy, CIDR would benefit from developing an overarching data quality framework and assigning an individual with specific responsibility for data quality within HPSC for CIDR.

- The main issues identified by HIQA in relation to governing data quality are the following:
    - Currently, there is no identified person with overall responsibility for data quality within HPSC. Individuals within the disease-specific teams manage data quality.
    - Although, there are a number of groups and committees that deal with aspects of data quality for CIDR in HPSC, HIQA identified that there is no forum with specific oversight for data quality or the responsibility to develop a data quality strategy.
    - At local level, within laboratories and Departments of Public Health, surveillance scientists are delegated responsibility for data quality; however, this is not formalised and arrangements are not standardised across regions.
    - To date, there have been 13 evaluations of surveillance systems for individual infectious diseases undertaken by HPSC with CIDR partners. These evaluations make practical recommendations for improving the quality of data in CIDR. However, this work has also occurred in silos across disease specific areas as opposed to being coordinated in a strategic manner. The review team did not see evidence of an implementation plan for any of these recommendations, which could potentially improve the quality of the data held within CIDR by prioritising and planning improvements across disease specific areas, and spreading this learning across the teams.
    - There is no process in place to identify and implement the use of a comprehensive set of KPIs to assess data quality for disease specific areas within CIDR, which captures the range of data quality dimensions.

- These findings add further weight to Chapter 3 on governance, leadership and management as it emphasises the need for strong governance structures for CIDR and highlights the consequences of not having effective oversight in place nationally. Currently, there is no forum to systematically assess, document and improve data quality in a strategic way. The data quality governance arrangements are indicative of a national data collection that lacks a strong strategic approach. Given the importance of good quality data for the prompt surveillance and public health management of infectious disease in Ireland, it is important that aspects of data quality be addressed within an overall strategy for CIDR that consolidates the approach across regions. It should outline roles and responsibilities for how HPSC, together with CIDR partners, are 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. This strategy would help to provide assurance, through audit and the effective use of KPIs, that the quality of the data collected and processed by CIDR is of the highest possible standard.

Data quality arrangements

- In respect to data quality, there is a consensus that the system has not evolved sufficiently alongside the progressions over the past 15 years. The following is a summary of some key issues identified:
    - Departments of Public Health are responsible for data quality within their regions. However, processes are not standardised and each disease type is prioritised according to resources at a local level. Therefore, data validation schedules are determined at a local level for each disease and data quality initiatives and audits are carried out in an ad-hoc manner.
    - Another issue emerging regarding data quality was the poor integration of systems linking some of the laboratory systems to CIDR. This results in double entry of data onto two systems, which leads to a greater chance for entry errors and increases workload for a small number of laboratories.
    - Furthermore, there are ongoing issues with enhanced surveillance forms as changes in the forms are not advanced in a timely way on CIDR. As a result, there is either no facility for CIDR users to record some data or the data is entered in open-text fields, which makes it difficult to search and analyse some of the information they have taken the time to collect.
    - There is also the added issue that the fields on the enhanced surveillance forms do not always match the fields on CIDR which leads to confusion as to what information is required. It is often unclear to those entering the data if and how the data is used, resulting in data completion issues. The collection of enhanced data needs to be reviewed in line with a data quality framework.
    - Limited access to, and use of, CIDR data for key partners such as the reference laboratories and laboratories. Improved access, without

compromising privacy, to national data for key stakeholders would help to promote data quality and stakeholder relationships. Furthermore, through a CIDR user's survey it would be beneficial to examine how CIDR data could be more effectively used at a local level.

- There are many opportunities for improving data quality by addressing these areas. Improving the integration of systems and coordination of data collection, both in the short and long term, should be addressed within a broader strategy for CIDR and also within a data quality framework.

Engagement with stakeholders

- HIQA acknowledges the work that the CIDR team in HPSC have undertaken to engage with CIDR partners to inform them of changes aimed at improving data quality including through the CIDR users helpdesk and the CIDR User Group.

- Positively, the Quality and Safety Committee recently completed a mapping exercise to identify and understand current engagement. Ongoing reflection on engagement practices specifically for CIDR would help to drive further improvements. CIDR would benefit from a strategy for effective and comprehensive stakeholder engagement. The information garnered through this process should identify continuous improvements and promote meaningful change.

- Interviews with CIDR users identified the need for a comprehensive survey of all CIDR users to assess the usefulness and usability of the system. This would be a simple and effective way to systematically engage with all CIDR users. The information garnered from this approach would be invaluable to inform a data quality framework and strategic planning.

Training

- In 2013, CIDR began to provide training at a local level by using a designated 'super user', usually a surveillance scientist, who provides training using a module released by HPSC. Although users report that access to training has improved in recent years, some issues still exist. New users may have to wait a number of weeks before they receive training, in which time they do not have access to CIDR. Furthermore, advanced training was discontinued by HPSC and, therefore, some users have limited capability to use Business Objects for data analysis and manipulation.

- Since the initial evaluation of CIDR training in 2004, HPSC has not conducted a formal evaluation of training. HIQA were informed that CIDR users have the opportunity to complete a feedback form after training is given. However a formal evaluation, including a survey of CIDR users, may help to identify the strengths and

weaknesses of the current approach.

Accessibility and dissemination of data

- HIQA acknowledges that HPSC disseminates CIDR data through a wide variety of methods to ensure that infectious disease data and information is accessible to a wide range of stakeholders.

- CIDR users indicated that Business Objects is adequate in terms of running standard reports. However, HIQA was informed of some difficulties in using this tool particularly when customised disease reports are required. Enhancing capacity to develop individualise reports would improve the use of CIDR data locally. In this instance, specific training and support is required to use this reporting tool to its full potential.

- The CIDR National Peer Review Group provides a clear procedure regarding the application and assessment process for accessing and using CIDR data. However, information relating to this group or the formal data request procedure is not available online on HPSC website.

Use of health information standards and terminologies

- HPSC is responsible for maintaining, updating and circulating the case definitions which are based mainly on standardised European case definitions (Commission Decision 2008/426/EC). Where European definitions are not available, definitions from other sources are used or adapted.

- To date HPSC has not developed a data dictionary for CIDR. The publication of a data dictionary is recognised as good practice for enhancing data quality and maximising the use of information as it contains a descriptive list of names, definitions and attributes of data elements collected in an information system or database. It also improves communication and understanding for those collecting and using the data as it supports a shared understanding of the definitions. The development of a data dictionary will also help to give a clear description of exactly what data is being collected, the format in which the data is collected, why the data is being collected and how the data is being used. This would be particularly useful given the issues described above with enhanced surveillance data.

5.6 Recommendations – Use of Information

Use of information	
	Data quality framework and arrangements
	HPSC should develop and implement a data quality framework to systematically assess and improve data quality at all levels for CIDR through the use of standardised audit schedules and a comprehensive set of KPIs. This should be developed in conjunction with all CIDR partners across regions. Additional data quality arrangements to complement the framework should be implemented to include: ▪ Assigning an individual with overall responsibility for data quality within HPSC ▪ Clearly outlining responsibilities for data quality at every level through a scheme of delegation for HPSC. ▪ A stakeholder engagement plan for data quality to incorporate a survey of CIDR users to assess the usefulness and usability of the system and their requirements of the system ▪ A formal evaluation of CIDR training to guide the development of a specific training plan to ensure the optimal use of data and information at a local and national level.
	CIDR Data Dictionary
	A data dictionary for CIDR should be developed and published to ensure consistency in data collection and to enable accurate use and interpretation of data from CIDR. This should be aligned to the plans for the National Data Dictionary being developed by the Office of the Chief Information Officer in the HSE.

6. Conclusion

The aim of this review was to assess the compliance of the Computerised Infectious Disease Reporting (CIDR) system 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. It is essential that health information is managed in the most effective way possible in order to protect public health. The recently published Sláintecare report, which outlines the priorities for the Irish health services over the next ten years, emphasises the importance of quality health data and information to drive improvements in the future of healthcare in Ireland.[4]

CIDR is the national web-based information system for the statutory surveillance of notifiable infectious diseases in Ireland. Currently, there are 87 diseases listed as notifiable under the Infectious Diseases Regulations 1981 (and subsequent amendments) and data on 78 of these are entered on CIDR. Once the occurrence of a notifiable infectious disease is confirmed, either through clinical diagnosis or laboratory confirmation, the case details are reported to local Departments of Public Health and entered on CIDR. This information is used for a variety of purposes but primarily for regional and national surveillance of infectious disease. Approximately 260 CIDR users in laboratories, Departments of Public Health and the Health Protection Surveillance Centre (HPSC) now use CIDR for the surveillance, management and control of infectious diseases.

CIDR data enables public health professionals to identify trends in infectious disease, and facilitates timely detection of clusters and outbreaks, allowing for early intervention and prevention of the spread of infection. Without a national infectious disease notification system early identification of outbreaks to prevent the further spread of disease would not be possible. CIDR is also a central component in Ireland's emergency response system. Information derived from CIDR is used by the HSE, the Department of Health, the National Immunisation Office, the National Immunisation Advisory Committee and other agencies such as the Food Safety Authority and safefood for a variety of health protection purposes including health service planning, national vaccination programmes, for the evaluation of public health interventions and for research purposes. In addition, CIDR is used to support Ireland's obligations to report specified infectious diseases to the European Centre for Disease Prevention and Control (ECDC), the European Commission and the World Health Organisation (WHO). International surveillance assists in preventing, controlling and providing a public health response to the international spread of communicable diseases.

Effective information management for CIDR is vital as the system holds highly sensitive and confidential personal health information and it is an extremely valuable source of data and information for the protection of public health. Good information management practices instil confidence in the public, healthcare professionals and all other stakeholders that high quality information is securely held and shared effectively to inform decisions about patient care and protection of the health of the public. Furthermore, good information management promotes assurances and 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, it creates a culture in which information will be used more effectively.

Overall HIQA identified that HPSC demonstrated good practice in many aspects of information management and these are referenced in this report. However, as a result of the review, HIQA have recommended improvements in a number of areas. The eight recommendations outlined in this report should be considered in conjunction with the findings of this review in order to improve information management practices in CIDR.

HPSC 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. HPSC 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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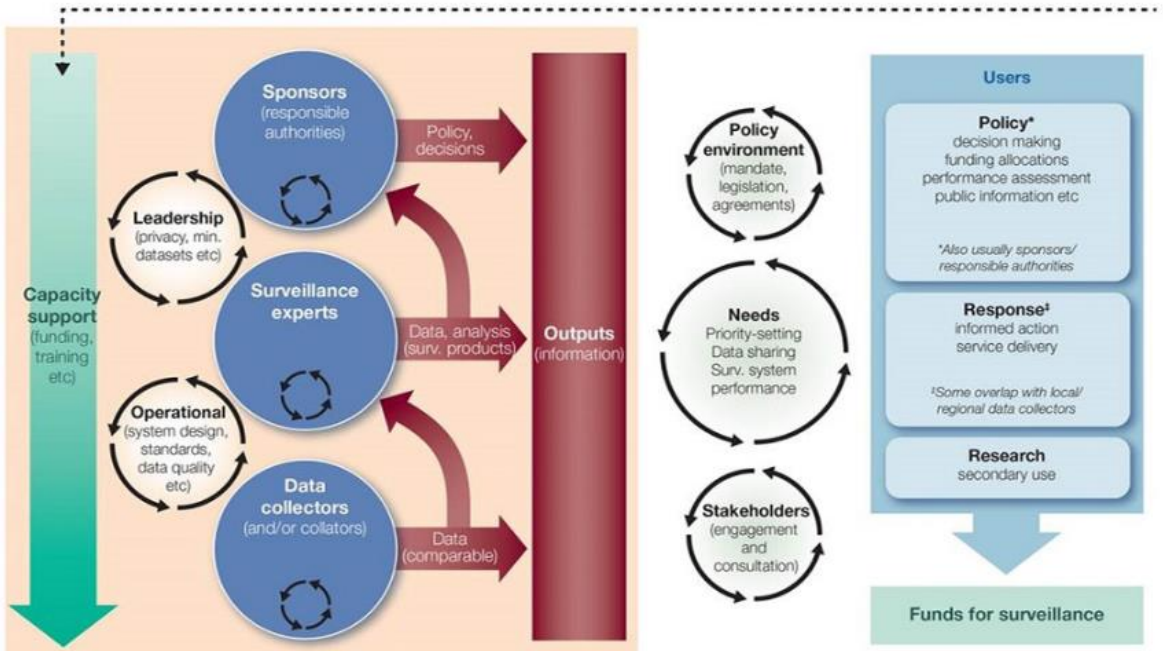
77. Health Information and Quality Authority. *Privacy Impact Assessment toolkit for health and social care*. 2017. Available from: https://www.hiqa.ie/sites/default/files/2017-10/Privacy-Impact-Assessment-toolkit-A5.pdf. Accessed on: 27 March 2018.

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.*[71] The current catalogue features 120 data collections.
- In 2013, HIQA published *Guiding Principles for National Health and Social Care Data Collections,*[72] 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.*[73] 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*[50]
    - *Guidance on information governance for health and social care services in Ireland*[49]
    - *What you should know about data quality- a guide for health and social care staff*[74]
    - *Five quality improvement tools for national data collections, 2017*[75]
    - *Guidance on privacy impact assessment (PIA) in health and social care*[76]
    - *Privacy impact assessment (PIA) toolkit for health and social care*[77]
    - *Guidance on a data quality framework for health and social care 2018*[9]

Appendix 2 – Public Health England – A general model for health surveillance[12]



Data collectors; ensure that comparable data are provided to, and available for, the surveillance experts.

Surveillance experts; ensure that data are analysed and interpreted so that the findings can be translated to support an informed response and improved service delivery. This also informs policy development and the role of the sponsor, and should be collaborative with knowledge experts.

Sponsors are the authorities responsible for making sure that the correct systems are in place to prevent gaps and identify issues relevant to population health and wellbeing at an early stage. They set out what conditions are important for surveillance, such as:

- objectives for surveillance
- what to do with signals or indicators
- how to use data for longer-term planning[12]

Appendix 3 – Notifiable Diseases and their respective causative pathogens

Notifiable Diseases and their respective causative pathogens

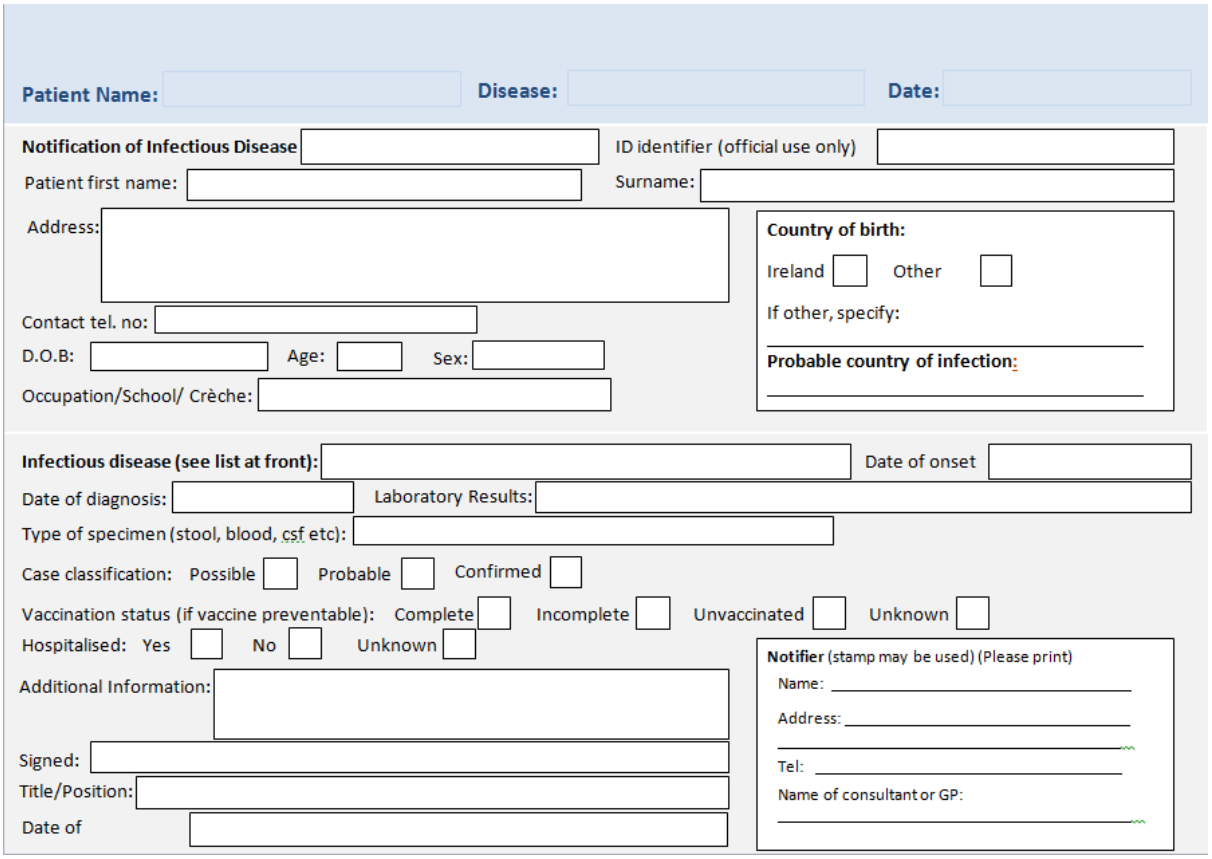
specified to be Infectious Diseases under Infectious Diseases (Amendment) Regulations 2018 (S.I. No. 567 of 2018) (December 2018)

Disease	Causative Pathogen
Acute anterior poliomyelitis	Polio virus
Ano-genital warts	Human papilloma virus
Anthrax	*Bacillus anthracis*
***Bacillus cereus* food-borne infection/intoxication**	*Bacillus cereus*
Bacterial meningitis (not otherwise specified)	
Botulism	*Clostridium botulinum*
Brucellosis	*Brucella* spp.
***Campylobacter* infection**	*Campylobacter* spp.
Carbapenemase producing *Enterobacteriaceae*, infection or colonisation	Carbapenemase producing *Enterobacteriaceae*, infection or colonisation
Chancroid	*Haemophilus ducreyi*
Chickenpox – hospitalised cases	Varicella-zoster virus
Chikungunya disease	Chikungunya virus
***Chlamydia trachomatis* infection (genital)**	*Chlamydia trachomatis*
Cholera	*Vibrio cholerae*
***Clostridium difficile* infection**	*Clostridium difficile*
***Clostridium perfringens* (type A) food-borne disease**	*Clostridium perfringens*
Creutzfeldt Jakob disease variant Creutzfeldt Jakob disease	
Cryptosporidiosis	*Cryptosporidium parvum, hominis*
Cytomegalovirus infection (congenital)	Cytomegalovirus
Dengue fever	Dengue virus
Diphtheria	*Corynebacterium diphtheriae* or *ulcerans* (toxin producing)
Echinococcosis	*Echinococcus* spp.
Enterococcal bacteraemia	*Enterococcus* spp. (blood)
***Escherichia coli* infection (invasive)**	*Escherichia coli* (blood, CSF)
Giardiasis	*Giardia lamblia*
Gonorrhoea	*Neisseria gonorrhoeae*
Granuloma inguinale	*Klebsiella granulomatis*
***Haemophilus influenzae* disease (invasive)**	*Haemophilus influenzae* (blood, CSF or other normally sterile site)
Hepatitis A (acute) infection	Hepatitis A virus
Hepatitis B (acute and chronic) infection	Hepatitis B virus
Hepatitis C infection	Hepatitis C virus
Hepatitis E infection	Hepatitis E virus
Herpes simplex (genital)	Herpes simplex virus
Herpes simplex (neonatal)	Herpes simplex virus
Human immunodeficiency virus infection	Human immunodeficiency virus
Influenza	Influenza A and B virus
***Klebsiella pneumoniae* infection (invasive)**	*Klebsiella pneumoniae* (blood or CSF)
Legionellosis	*Legionella* spp.
Leprosy	*Mycobacterium leprae*
Leptospirosis	*Leptospira* spp.
Listeriosis	*Listeria monocytogenes*
Lyme disease (neuroborreliosis)	*Borrelia burgdorferi*
Lymphogranuloma venereum	*Chlamydia trachomatis*
Malaria	*Plasmodium falciparum, vivax, knowlesi, ovale, malariae*
***mcr*-positive *Enterobacteriaceae* infection or colonisation**	*mcr*-positive *Enterobacteriaceae* infection or colonisation

Disease	Causative Pathogen
Measles	Measles virus
Meningococcal disease	*Neisseria meningitidis*
Mumps	Mumps virus
Non-specific urethritis	
Novel or Rare Antimicrobial-resistant Organism (NRAO)	
Noroviral infection	Norovirus
Paratyphoid	*Salmonella* Paratyphi
Pertussis	*Bordetella pertussis*
Plague	*Yersinia pestis*
***Pseudomonas aeruginosa* infection (invasive)**	*Pseudomonas aeruginosa* (blood or CSF)
Q Fever	*Coxiella burnetii*
Rabies	Rabies virus
Respiratory syncytial virus infection	Respiratory syncytial virus
Rotavirus infection	Rotavirus
Rubella	Rubella virus
Salmonellosis	*Salmonella* spp. other than S. Typhi and S. Paratyphi
Severe Acute Respiratory Syndrome (SARS)	SARS-associated coronavirus
Shigellosis	*Shigella* spp.
Smallpox	Variola virus
Staphylococcal food poisoning	Enterotoxigenic *Staphylococcus aureus*
***Staphylococcus aureus* bacteraemia**	*Staphylococcus aureus* (blood)
***Streptococcus* group A infection (invasive)**	*Streptococcus pyogenes* (blood, CSF or other normally sterile site)
***Streptococcus* group B infection (invasive)**	*Streptococcus agalactiae* (blood, CSF or other normally sterile site)
***Streptococcus pneumoniae* infection (invasive)**	*Streptococcus pneumoniae* (blood, CSF or other normally sterile site)
Syphilis	*Treponema pallidum*
Tetanus	*Clostridium tetani*
Toxoplasmosis	*Toxoplasma gondii*
Trichinosis	*Trichinella* spp.
Trichomoniasis	*Trichomonas vaginalis*
Tuberculosis	*Mycobacterium tuberculosis* complex
Tularemia	*Francisella tularensis*
Typhoid	*Salmonella* Typhi
Typhus	*Rickettsia prowazekii*
Verotoxigenic *Escherichia coli* infection	Verotoxin producing *Escherichia coli*
Viral encephalitis	
Viral haemorrhagic fevers	
Viral meningitis	
West Nile fever	West Nile virus
Yellow fever	Yellow fever virus
Yersiniosis	*Yersinia enterocolitica, Yersinia pseudotuberculosis*
Zika virus infection	Zika virus

Please refer to the case definitions for the above diseases. The up-to-date list of diseases and case definitions are available on the HPSC website at www.hpsc.ie/notifiablediseases

Appendix 4 – Infectious disease notification form



Patient Name: **Disease:** **Date:**

Notification of Infectious Disease ID identifier (official use only)

Patient first name: Surname:

Address:

Contact tel. no:

D.O.B: Age: Sex:

Occupation/School/ Crèche:

Country of birth:

Ireland Other

If other, specify:

Probable country of infection:

Infectious disease (see list at front): Date of onset

Date of diagnosis: Laboratory Results:

Type of specimen (stool, blood, csf etc):

Case classification: Possible Probable Confirmed

Vaccination status (if vaccine preventable): Complete Incomplete Unvaccinated Unknown

Hospitalised: Yes No Unknown

Additional Information:

Signed:

Title/Position:

Date of

Notifier (stamp may be used) (Please print)

Name:

Address:

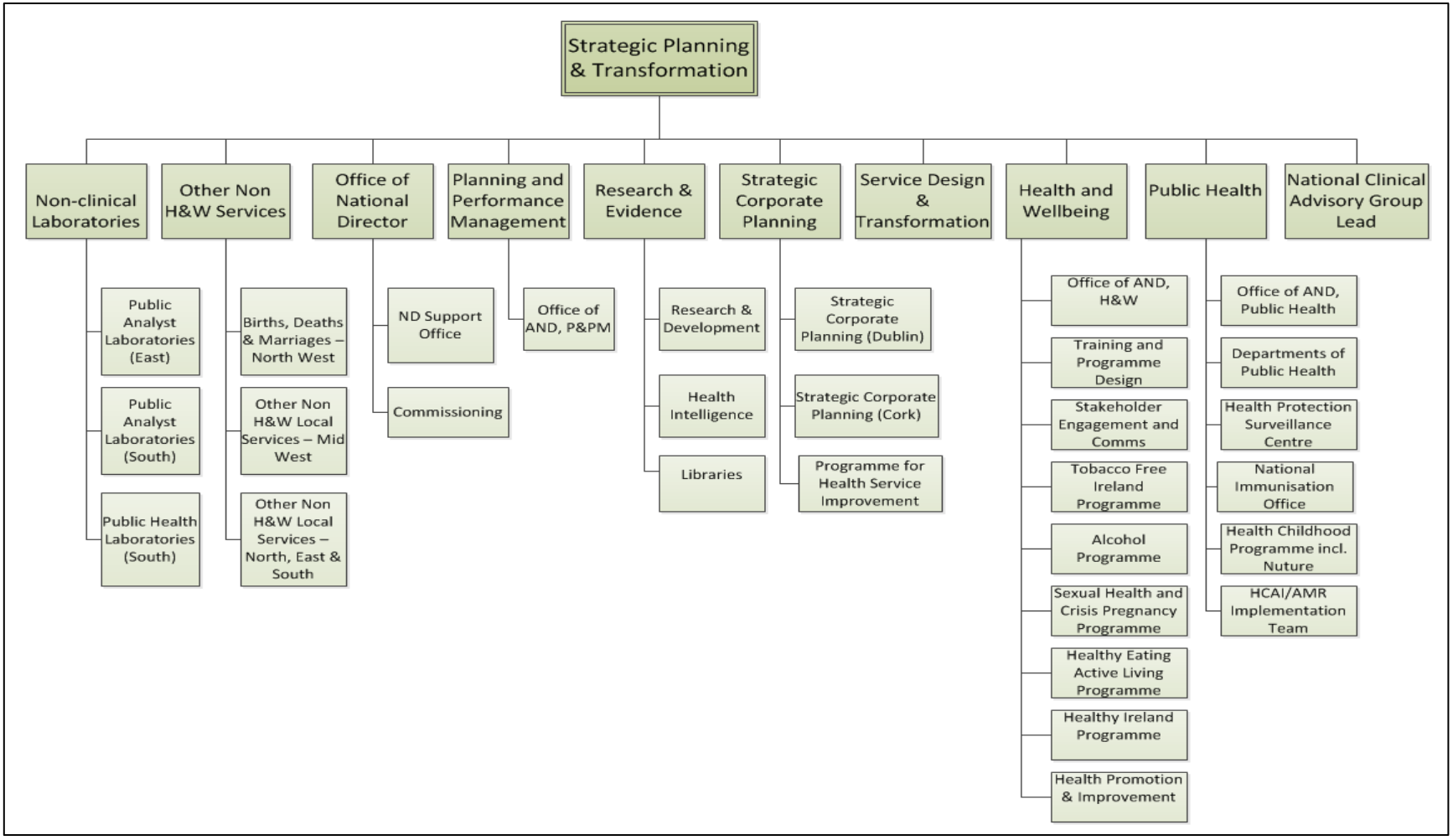
Tel:

Name of consultant or GP:

Appendix 5 – List of enhanced surveillance forms available on HPSC website

- Acute Flaccid Paralysis (AFP)
- Hepatitis B
- Malaria
- Streptococcus group A (invasive)
- Avian Influenza
- Hepatitis C
- Measles
- Syphilis
- Bacterial Meningitis / Meningococcal Disease
- Hepatitis E
- MERS-CoV
- Tetanus
- Chickenpox (Varicella)
- HIV
- Mumps
- Tuberculosis
- Cryptosporidiosis
- Infectious intestinal disease (IID)
- Outbreaks
- Varicella (Chickenpox)
- EARSS Enhanced Bacteraemia Surveillance
- Influenza
- Pertussis
- Verotoxigenic Escherichia coli (VTEC)
- Gastroenteritis
- Legionellosis
- Plague
- Zika virus infection
- Gonorrhoea
- Leptospirosis
- Pneumococcal Disease (invasive)
- Haemophilus influenzae
- Listeriosis
- Rubella
- Hepatitis A
- Lymphogranuloma Venereum
- Salmonellosis

Appendix 6 – Organogram for the Strategic Planning and Transformation function provided by National Director, Strategic Planning and Transformation on 19th July 2019



Appendix 7 – National Public Health Leadership Group (NPHLG) Terms of Reference

Aims of the NPHLG

- To strengthen and continually improve the role of the HSE public health function in improving the health and wellbeing of the people of Ireland;
- To share learning in leading the work of individual departments to carry out the responsibilities of the Medical Officer of Health function, protecting the health of the people of Ireland;
- To work across health and social care systems regionally & nationally providing a vital system leadership role, promoting & advocating evidence based practice; and
- To promote and enable the above three aims through encouraging the establishment of collaborative partnerships regionally & nationally.

Objectives

- To lead the public health function on behalf of the HSE;
- To provide leadership in the continued development and strengthening of governance arrangements, including clinical governance arrangements, across the public health function (AND, Departments of Public Health, NIO and HPSC);
- To lead the planning and implementation of the public health aspects of the HSE's National Service Plan and Operational Plans on an annual basis to improve the health of the population;
- To develop a strategy for the public health service with a long term vision;
- To provide a mechanism for collective decision making and peer support to enable a unified public health voice and influence on public health matters locally, regionally and nationally;
- To lead ongoing review of workforce capacity, training and development requirements, so as to ensure implementation, monitoring and evaluation of the operational plans are not compromised and where patient care is prioritised;
- To support the review of the national Specialist Registrar training, recruitment & assessments and ensure the Departments of Public Health are able to provide good learning environments for public health registrars at all stages of their training;
- To lead the research and development priorities and agree a Research Strategy for public health;
- To be visible influential strategic public health system leaders in Ireland and advise HSE on changes needed from time to time to respond to emerging threats and changing population need;
- To support the function of public health by aiming to standardise operational matters within the eight Departments of Public Health across the country;
- To guide and provide oversight including endorsement/approval for the development and implementation of public health guidelines, guidance and protocols; and
- To guide, direct and provide oversight of the work of other sub groups that act in an advisory role to the NPHLG.

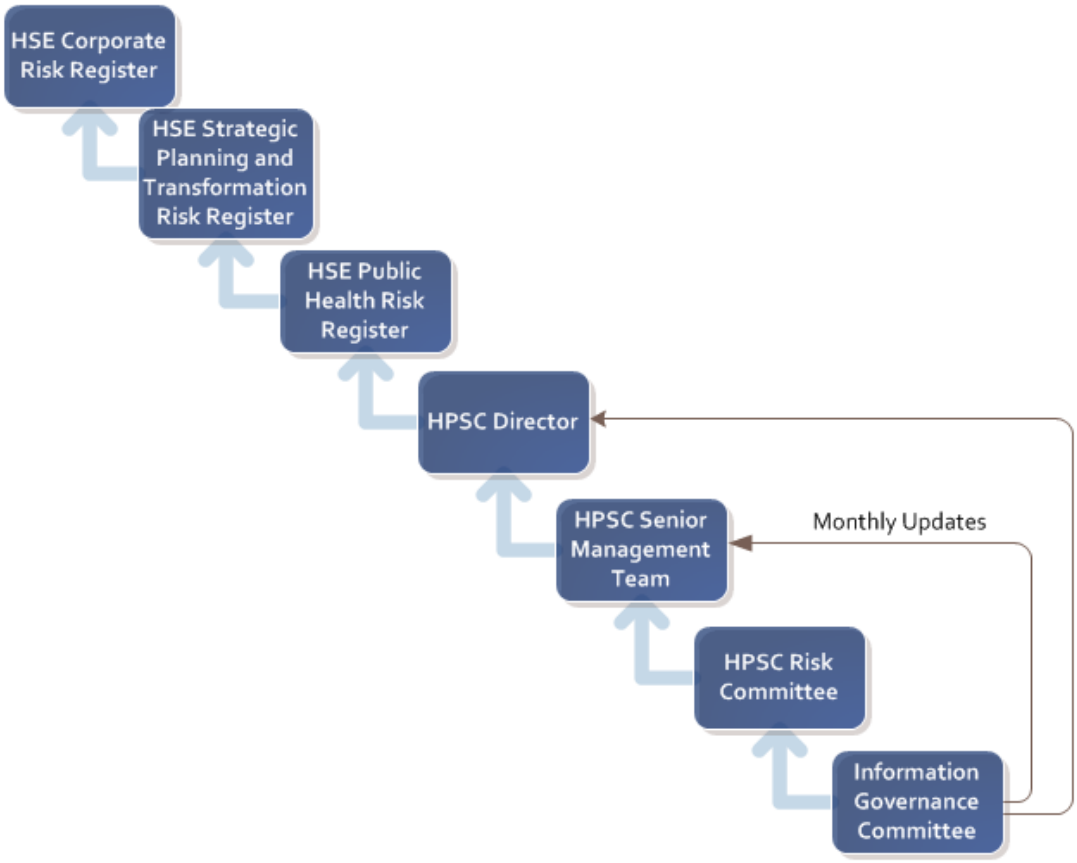
Appendix 8 – Governance Arrangements for International Infectious Disease Surveillance Systems

National Surveillance System	Public Health System Structure	Governance Arrangements	Roles for Governance Body	Strategy Documents
Public Health England (PHE)	Wide health protection role, delivering a range of services including surveillance and emergency response to communicable and non-communicable disease and environmental hazards	PHE Surveillance Strategy Group chaired by the Director of Health Improvement accountable to the PHE Strategy Group[12]	Oversee existing and new surveillance activities Strategic direction Audit and Risk Management Committee Promote stakeholder engagement	5 Year Infectious Diseases Strategy (2020-25) sets out 10 strategic priorities published Sept 2019[42]
Public Health Wales (PHW)	Overall health protection and promotion role including protection of the public from infection and environmental threats	Board functions as a corporate decision – making body for all aspects of public health[37] 4 Board Sub-Committees with specific responsibilities	Quality, Safety & Improvement Committee looks after clinical risk management, information governance and data protection Audit and Corporate Governance Committee oversee corporate governance, regulatory compliance, risk management, the Board assurance framework and internal audit.	Long Term Strategy 2018-2030[44] Strategic Plan for 2019-2022[43] Have published their Decision Making Framework and Joint Working Framework

European Centre for Disease Preventions and Control (ECDC)	ECDC is an independent EU Agency which collects, analyses and disseminates surveillance data on 56 communicable diseases and related special health issues from all 28 EU Member States and two of the three remaining European Economic Area (EEA) countries (Iceland and Norway).	Management Board, comprised of nominees from the 28 Member States, the European Commission and the European Parliament[35] Advisory Forum made up of experts from Member States, a European Commission official and representatives from scientific associations and civil society, advise on the quality of scientific work.	Management Board acts as a governing body for the Agency and holds Director of ECDC responsible for leadership and management of the centre. Audit Committee assists the Management Board in its oversight responsibilities for financial reporting, internal control systems and the auditing process.	Long-term Surveillance Strategy 2014-2020 sets out longer-term priorities and targeted actions for European surveillance[41] Single Programming Document 2019-2020 sets out ECDC work programme for 2019[46] ECDC strategic framework for the integration of molecular and genomic typing into European surveillance and multi-country outbreak investigations 2019–2021[47]

Appendix 9 – HPSC Risk Management Scheme

Provided by HPSC as part of Document Request



Appendix 10 – Documents and procedures used within the CIDR Information Security Management System

Category	Document Title	Description and purpose
ISO27001	CIDR File Index	To document the various documents and procedures used within the CIDR Information Security Management System.
Access Control & Incidents	Access Control Procedure	To document the procedures for granting and removing access to CIDR.
Audit	Auditing Procedure	To document the configuration of CIDR audit logs and the procedure for their review.
User Support	Support Call Procedure	To document the procedure for handling end user queries to HPSC CIDR helpdesk.
Access Control & Incidents	RSA Token Management Procedure	To outline the procedure for managing the CIDR RSA tokens.
Change Management	Change Management Procedure	To outline CIDR change control procedures.
Policies & ISO27001	Business Continuity Policy	To outline the Business Continuity policy for CIDR.
Access Control & Incidents	Access Controls	To summarise CIDR access controls.
Access Control & Incidents	Third Party Access To CIDR	To outline access granted to Fujitsu and PFH personnel.
Access Control & Incidents	Incident Management Procedure	To outline the approach to be taken when investigating a suspected information security incident within CIDR.
Policies & ISO2700101	Risk Assessment Policy	This policy outlines the approach to ongoing risk assessment in relation to CIDR.
Policies & ISO27001	Security Access Control & Activity Logging Policy	This policy defines HPSC's position on Access Control, relating to HPSC use and maintenance of the CIDR application. The CIDR application contains confidential information. The CIDR access control policy specifies the users' responsibilities to maintain confidentiality and how access is managed within CIDR. The use of CIDR by staff outside HPSC is governed by the CIDR National Business Rules and is the responsibility of the region /agency in question via their local CIDR Manager.
Business Continuity Disaster Recovery	Disaster Recovery Invocation Procedure	To document the high-level decision making process surrounding the Disaster Recovery invocation procedure.
Change Management	Functional Check	To identify a series of checks that can be applied to CIDR to functionally test the application pre & post software upgrades.
Operations	Tasklist	To schedule all of the tasks in CIDR001.doc and link to other documentation where necessary.

Business Continuity Disaster Recovery	CIDR Topology	To illustrate the configuration and Topology of the CIDR Production and DR environments
Audit	Confirmation Of User Access Procedure	To outline the procedure for managing the CIDR RSA tokens and confirming user access to CIDR
Policies & ISO27001	Data Handling Policy	This policy defines HPSC's position on the management and control of data retrieved from CIDR.
Policies & ISO27001	CIDR VMWare System Security And Access Control Policy	This policy defines HPSC's position on the system security and access control policy of the CIDR VMWare System
Audit	CIDR VMWare System Capacity Monitoring	To outline what should be monitored within the CIDR VMWare system to ensure reliable operation.
Access Control & Incidents	Server Password Management Procedure	To outline password management / change control for CIDR servers.
Policies & ISO27001	Change Management Policy	This policy defines HPSC's position on CIDR change management and control.
Business Continuity Disaster Recovery	CIDR046 - Production External Drive Backup Strategy.Xls	Description of External backup system
Information Governance	PII Data Extraction Procedure	Procedure for the Extraction from CIDR of Personally-identifiable Information, its distribution, and its subsequent storage and deletion.
Policies & ISO27001	CIDR Business Rules	This document outlines general principles for participation in CIDR by all partners. It has been revised after discussion and regional feedback at National Business Rules Committee meetings from July 2001 to date. It has also been revised in light of experience gained during pilot implementation. This version is the agreed document for use in CIDR national implementation/operation.
Access Control and Incidents		
Access Control & Incidents	Access Control Procedure	To document the procedures for granting and removing access to CIDR.
Access Control & Incidents	RSA Token Management Procedure	To outline the procedure for managing the CIDR RSA tokens.
Access Control & Incidents	Access Controls	To summarise CIDR access controls.
Access Control & Incidents	Third Party Access To CIDR	To outline access granted to Fujitsu personnel.
Access Control & Incidents	Incident Management Procedure	To outline the approach to be taken when investigating a suspected information security incident within CIDR.
Access Control & Incidents	Server Password Management Procedure	To outline password management / change control for CIDR servers.

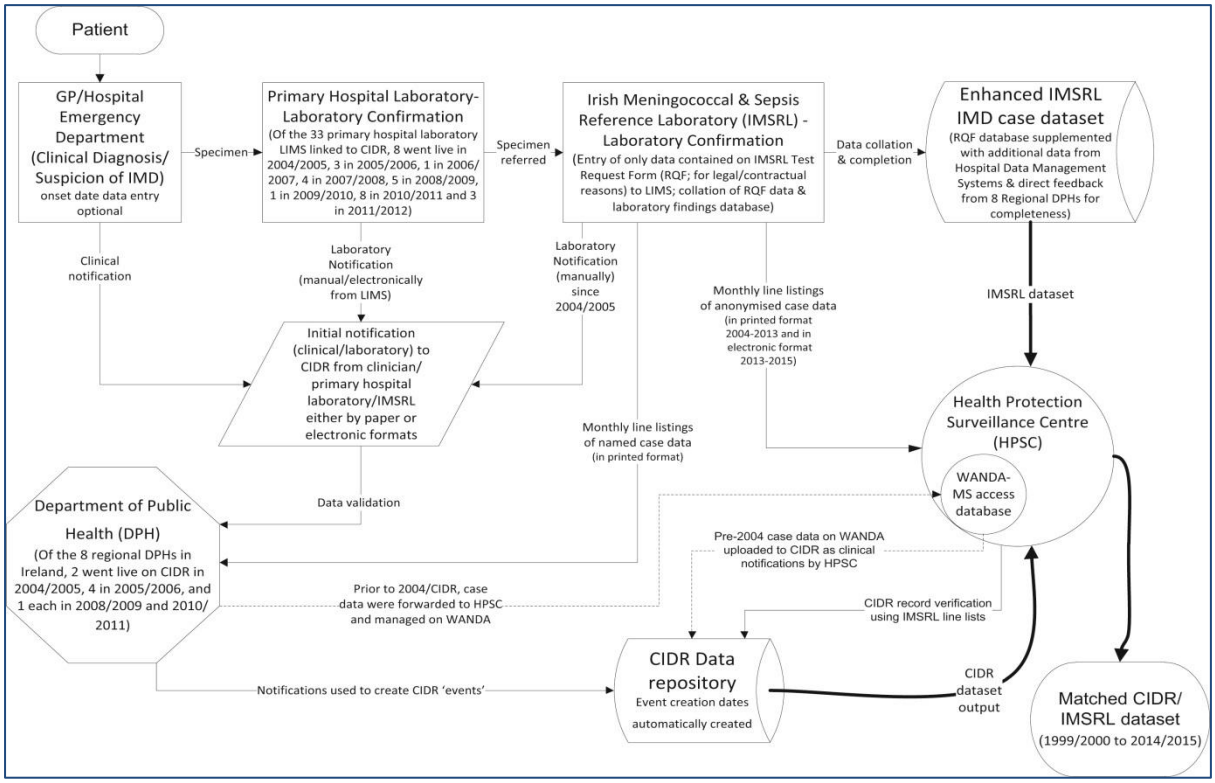
Audit		
Audit	Auditing Procedure	To document the configuration of CIDR audit logs and the procedure for their review.
Audit	Confirmation Of CIDR User Access Procedure	To outline the procedure for managing the CIDR RSA tokens and confirming user access to CIDR.
Audit	CIDR VMWare System Capacity Monitoring	To outline what should be monitored within the CIDR VMWare system to ensure reliable operation.
Business Continuity and Disaster Recovery		
Business Continuity Disaster Recovery	Disaster Recovery Invocation Procedure	To document the high-level decision making process surrounding the Disaster Recovery invocation procedure.
Business Continuity Disaster Recovery	CIDR Topology	To illustrate the configuration and Topology of the CIDR Production and DR environments
Business Continuity Disaste**r Recovery**	CIDR046 - Production External Drive Backup Strategy.Xls	Description of External drive backup system
Change Management		
Change Management	Change Management Procedure	To outline CIDR change control procedures.
Change Management	CIDR Functional Check	To identify a series of checks that can be applied to CIDR to functionally test the application pre & post software upgrades.
Information Governance		
Information Governance	PII Data Extraction Procedure	Procedure for the Extraction from CIDR of Personally-identifiable Information, its distribution, and its subsequent storage and deletion.
Operations		
Operations	Tasklist	To schedule all of the Tasks in CIDR001.doc and link to other documentation where necessary.
Policies & ISO27001		
Policies & ISO27001	Business Continuity Policy	To outline the Business Continuity policy for CIDR.
Policies & ISO27001	Risk Assessment Policy	This policy outlines the approach to on-going risk assessment in relation to CIDR.
Policies & ISO27001	Security Access Control & Activity Logging Policy	This policy defines HPSC's position on Access Control, relating to HPSC use and maintenance of the CIDR application. The CIDR application contains confidential information. The CIDR access control policy specifies the user's responsibilities to maintain confidentiality and how that access is managed within CIDR. The use of CIDR by staff outside HPSC is governed by POLICIES & ISO27001the CIDR Business Rules and is the responsibility of the region /agency

		in question via their local CIDR Manager.
Policies & ISO27001	Data Handling Policy	This policy defines HPSC's position on the management and control of data retrieved from CIDR.
Policies & ISO27001	Change Management Policy	This policy defines HPSC's position on CIDR change management and control.
Policies & ISO27001	CIDR Business Rules	This document outlines general principles for participation in CIDR by all partners. CIDR Business Rules v3 approved by CIDR Business Rules Committee on 31/07/2014
Policies & ISO27001	CIDR VMWare System Security And Access Control Policy	This policy defines HPSC's position on the system security and access control policy of the CIDR VMWare System
Risk Assessment		
Policies & ISO27001	Risk Assessment Policy	This policy outlines the approach to on-going risk assessment in relation to CIDR.
User Support		
User Support	Support Call Procedure	To document the procedure for handling end user queries to HPSC CIDR helpdesk.

Appendix 11 – Examples of recommendations from evaluations

Common recommendations from evaluations	Examples of recommendations
Explore user satisfaction with the CIDR system in terms of usability, flexibility and simplicity	• Match CIDR fields to Enhanced Surveillance Forms
Examine methods to improve completeness and timeliness of CIDR data in consultation with CIDR users	• Investigate regional differences in completeness of data and standardise if possible • Set targets for timeliness e.g. times between event creation date and enhanced surveillance form completion date • Provide refresher training to CIDR users to ensure optimal use of the system • Examine if missing data is disease specific or common to multiple diseases e.g. cause of death • Monitor data quality on a regular basis • Explore automatic rules to increase efficiency
Engage with internal and external stakeholders	• Further investigate approaches to effective communication that promote a collaborative approach to enable early identification of infectious disease • Engage with clinical staff to promote timely completion of Enhanced Surveillance Forms • Promote the purpose and importance of infectious disease data

Appendix 12 – Data flow for IMD surveillance in Ireland[66]



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