HealthData@IE – setting up health data access body services in Ireland

International review of approaches to engagement, dissemination, education, training and data quality enhancement in relation to health data access body services

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1. Background

1.1. The European Health Data Space

The European data strategy, announced in February 2020, sets out to create common European Data Spaces in a number of strategic fields, including finance, agriculture and health, with the ultimate aim of creating a single market for data across all EU Member States.(1) These data spaces will facilitate the reuse of data across different sectors of the economy and society. Two crucial pieces of legislation, the Data Governance Act and the Data Act, have been put in place to provide the legislative basis and regulatory framework for achieving the objectives of the strategy.(2, 3) The European Commission has also prioritised the development of the necessary technological systems and infrastructures to optimise data use and reuse across the EU and to drive innovation. The EU's Digital Decade policy programme, launched in January 2023, sets out targets and objectives for 2030 in a number of key areas, including the digitalisation of public services and ensuring all citizens have access to their medical records online.(4)

The European Health Data Space (EHDS) is the first common data space to emerge from the European data strategy. The foundations of the EHDS were laid through the EU Joint Action, 'Towards a European Health Data Space' (TEHDAS). This Joint Action aimed to help EU Member States and the European Commission to develop concepts and proposals to promote the secondary use of health data to benefit public health and health research and innovation in Europe.(5) The recommendations from the TEHDAS project were used by the European Commission to inform the development of a proposal for a regulation on the EHDS in May 2022. The European Parliament formally approved the proposal for the establishment of the EHDS in April 2024 and the regulation to enable the EHDS is expected to enter into force in early 2025.(6-8)

The EHDS will empower individuals to take control of their own health data and make it easier to access and exchange health data across EU Member States, both to support healthcare delivery (known as primary use of data) and to facilitate other uses of the data, including research and policy-making (known as secondary use of data). In relation to the secondary use of data, in particular, the potential benefits of the EHDS include:

- For citizens and patients: Assurance that their data is being used to its full potential to drive improvements in population health and the provision of services, and assurance that it is being managed securely in a way that ensures their privacy and confidentiality are protected

- For data users, the broader workforce and the health service as a whole: Access to a wide range of data and linked datasets, through secure processing environments (SPEs), leading to greater opportunities for research and innovation; a national contact point and a more streamlined and efficient system for accessing health data via the issuing of data permits; and greater capacity for evidence-based policy and decision-making
- For data holders: Support to make their datasets more readily available and to maximise the utility and potential impact of these datasets; and training and guidance to promote the enhancement of the quality of their data.

Following on from the work of the TEHDAS Joint Action, the HealthData@EU pilot sets out to build a pilot version of the EHDS infrastructure for the secondary use of health data.(9) This HealthData@EU project is developing a network infrastructure and services to support data users, defined as persons who have lawful access to personal or non-personal data for secondary use. It will also provide guidelines for data standards, data quality, data security and data transfers to support the EHDS infrastructure. In addition, a further EU Joint Action, TEHDAS2, commenced in 2024 with the aim of developing common guidelines and technical specifications to facilitate secure access to health data and strengthen European collaboration in using data efficiently.(10)

Acknowledging that trust is fundamental to the success of the EHDS, the European Commission has prioritised ensuring secure and trustworthy platforms for facilitating access to, and processing of, health data. As such, the EHDS Regulation builds on the General Data Protection Regulation (GDPR), the Data Governance Act and the Data Act. In addition, among all EU Member States, there is need for legislative and operational preparations to ensure readiness to implement the EHDS. In Ireland, the Health Information Bill 2024 is the first piece of legislation to support its preparations for the full implementation of the EHDS.(11)

1.2. HealthData@IE 2023-2027

In respect of the secondary use of data, the EHDS Regulation places an obligation on Member States to establish one or more Health Data Access Bodies (HDABs). A HDAB service securely connects data users, such as researchers and policy-makers, with anonymised and pseudonymised health datasets to support research and innovation, education and training, policy-making, health service management and preparation of national statistics.

The Department of Health, in collaboration with the Health Information and Quality Authority (HIQA) and the Health Research Board (HRB), was awarded funding for the HealthData@IE project under the EU4Health programme to support the establishment of HDAB services in Ireland. Working with key stakeholders in the Health Service Executive (HSE) and across the health system, the HealthData@IE project will focus on the development of national infrastructures needed for data access, including data access infrastructure systems that have been identified by the European Commission as being core Digital Business Capabilities for HDABs.(12) These include a Data Access Application Management System (DAAMS) to receive, track and process applications and to issue permits, a national health metadata catalogue to facilitate data discovery and SPEs to ensure the secure processing of health data. The HealthData@IE project will also deliver important programmes of work centred on data quality enhancement, engagement and dissemination, as well as training and education for data users, data holders, HDAB staff and members of the public.

1.3. Purpose of this international review

The aim of this review is to describe approaches taken in five jurisdictions to engagement, dissemination, education, training and data quality enhancement in relation to HDAB services, or similar structures, in order to identify examples of good practice that can be adapted for an Irish context. This information will be used to support and inform programmes of work being undertaken as part of the HealthData@IE project. These programmes of work will involve various activities, including the development and implementation of strategic plans, specifying technical requirements for online platforms and the development of guidance and training materials and other tools and resources. The programmes of work will also include disseminating information as well as engagement activities with key stakeholders, such as the general public, data users, data holders and HDAB staff. The findings of this international review will help to guide the approaches taken in Ireland in preparation for the implementation of the EHDS and the establishment of HDAB services.

1.4. Methodology

Evidence relating to the approaches to engagement, dissemination, education, training and data quality was gathered from five jurisdictions:

- Finland
- Belgium
- France
- Northern Ireland
- New South Wales, Australia.

These jurisdictions were selected as they have well-established systems which facilitate the sharing and linkage of health information as well as having at least one HDAB, or similar organisation, in place. They also provide insight into practices both within, and outside, the EU.

Key organisations, including those acting as HDAB services, for each jurisdiction were identified. A grey literature search was performed, including documents from key websites. Information for each jurisdiction was verified through contacts in each organisation. Where possible, online calls were held via Microsoft Teams with the relevant individuals.

1.5. Use of terms: 'citizen' and 'members of the public'

The terms 'citizen' and 'members of the public' are both used in this review. In EU policies and legislation and in other EU Member States, the term 'citizen' is often used to describe members of the public. For consistency with those EU documents and to also describe developments in EU Member States, the term 'citizen' is used in this review to align with their work.

The term 'members of the public' is used when describing or reporting on programmes of work in the Irish context.

2. Summary of key findings

This section summarises the findings of this review of international evidence in relation to the approaches taken to engagement, dissemination, education, training and data quality enhancement regarding HDAB services in the five jurisdictions, outlined in Table 1.

Table 1 Jurisdictions and key organisations included in this international review

Jurisdiction	Organisation
Finland	Findata
Belgium	Health Data Agency (HDA)
France	Health Data Hub Directorate of Research, Studies, Evaluation and Statistics (DREES)
Northern Ireland	Honest Broker Service (HBS) Digital Health and Care Northern Ireland (DHCNI)
New South Wales	Centre for Health Record Linkage (CHeReL) The Population Health Research Network (PHRN)

2.1. Stakeholder engagement and dissemination

There were multiple examples of public engagement across the jurisdictions included in this international review. Engagement included online public engagement and consultation, public representation on committees and councils, public consultation in policy development, and surveys to gather public attitudes towards the secondary use of health data.(13-17) Although various approaches to, and levels of, engagement were observed across jurisdictions, it was evident that engagement was considered important in all cases. The differences between jurisdictions were often due to structures, such as legislation or policies, as well as the overall general levels of trust in public systems.

There are a range of dissemination methods and materials used across the jurisdictions. Dissemination in this context refers to informing the public about HDAB services and the secondary uses of their heath data. Dissemination also refers to raising awareness and demand among data users and data holders of HDAB services and how they enable access to health datasets. All of the organisations reviewed utilise websites that offer information to the public, as well as data users and data holders, on the secondary use of health and social care data. The dissemination materials include short introductory videos, infographics, information leaflets and webinars.(18-23) The dissemination materials aimed at data users and data holders across all reviewed jurisdictions commonly include guides and resources offering information on how to access, manage and store data safely and securely.

2.2. Training and education

The organisations in this international review adopt various approaches to education and training and have implemented a range of guidance and support tools. These include generic information resources published online, webinars, general online training modules and more targeted and advanced online modules.(22, 24-28) At a minimum, such training and resources usually include training in relation to privacy, information governance, GDPR and how to navigate the relevant health data access system.(26, 29-32)

In addition to providing training and education resources, all reviewed jurisdictions facilitate ongoing support for data users and data holders. Examples of these initiatives include one-to-one support for both data holders and data users, information sessions, data access application clinics to support data users in making data access applications, output checking and support with de-identifying and sharing data.(33-35)

2.3. Data quality

While data quality assurance checks are generally carried out on data submitted to HDAB services, the responsibility for data quality remains largely with the data holders. For example, some jurisdictions have legislation and regulations in place which underpin requirements for data holders to provide descriptions of the content of individual data collections to enable assessment of the data suitability.(36) A number of the HDAB services reviewed utilise a labelling system, or similar, to enable data users to explore the quality of available datasets. This review demonstrated instances where jurisdictions made data collections available using a data utility framework which allows data users to search the data in accordance with various data utility parameters.(37)

Many established HDAB services included in this international review have implemented guidance and support tools to promote data quality among data holders. These range from technical specifications setting out interoperability standards for health data to online peer support forums which facilitate communication on a range of health data topics.(26, 38) Other examples of these supports and resources included online platforms to host learning courses and additional materials.

With regard to data quality and information management, the review has shown that a maturity framework can provide a structured path for continuous improvement, enabling an organisation to self-assess their current strengths and weaknesses and guide improvement and the adoption of best practices.

3. Overview of the jurisdictions included in this review

3.1. Finland

Findata, Finland's Social and Health Data Permit Authority, was established in 2019 under the Act on the Secondary Use of Health and Social Care Data.(39, 40) The aim of the Act is to support the efficient and secure processing of personal data collected from health and social care provision.(41)

Findata operates under the guidance of the Ministry of Social Affairs and Health as an independent unit within the National Institute for Health and Welfare.(42) The Director of Findata, as well as the organisation's Steering Committee, are appointed by the Ministry of Social Affairs and Health.(43)

As the Data Permit Authority, Findata functions as a one-stop-shop which processes applications from, and grants permits to, data users to use secondary social and healthcare data.(43) Findata's other responsibilities include collecting data from data holders; improving the security of data materials; enabling more efficient utilisation of data materials; operating a secure data processing environment and providing guidance to all stakeholders, including the general public, data users and data holders, on the secondary use of data.(43)

Data permit requests are made through the Findata website.(44) Datasets are available from a number of data holders and via Findata's 'ready-made datasets'. Once a request is submitted, it is reviewed by Findata and a decision is made on whether to grant the permit or not. If the permit is granted, Findata will provide information on costs for extracting, processing and delivering the data.(45)

3.2. Belgium

Belgium's Health Data Agency (HDA) is a statutory agency established in 2023 under the Act on the Establishment and Organisation of the Health (care) Data Agency.(46) Before becoming a legally established organisation, the HDA had existed as a programme structure financed by European and public funds.(47) The HDA's operational framework is purposefully designed to align with the EHDS and similar future initiatives.(48) As such, the HDA aims to facilitate the availability of healthcare and related data, to develop secure and reliable methods for the exchange of health data and to develop and implement a health data policy strategy. A further objective of the HDA is to contribute to affordable, preventative and targeted healthcare by stimulating innovation, scientific research and evidence-based policy support.(19) The HDA also aims to ensure the trust of citizens and patients by placing significant emphasis on the importance of transparency and security.(19)

In order to access data for secondary use, data users can make an application through the HDA website.(49) The available data is documented in the Data Catalogue, which data users can browse on the HDA website.(50) Data users can submit a request for data using a data request form. The HDA operates under the FAIR principles, aiming to ensure that data is findable, accessible, interoperable and reusable.(51) As such, the HDA aims to handle requests for data free of charge, although fees are charged in some cases.(52)

The Health Data Enabled for Re-use Across Belgium (HeDERA) project coordinated by the Belgian Federal Public Service (FPS), in partnership with Sciensano (the federal institute for health and public policy) supports the HDA to facilitate secondary use of health, healthcare and wellbeing data in a safe, uniform and transparent environment.(53) The project aims to increase the capacity of the HDA, ensuring its connection, alignment and technical interoperability with the EHDS and HealthData@EU infrastructure.

3.3. France

In France, the Health Data Hub (HDH) is the public body tasked with facilitating access to health data for projects in the public interest. Established in 2019 by ministerial decree, the organisation was founded as a public body to provide access to anonymised and pseudonymised health data in a secure manner.(35) Prior to its establishment, the HDH was a project operated within the Ministry of Solidarity and Health, Directorate of Research, Studies, Evaluation and Statistics (DREES).(54) The HDH provides a single point of application for access to health data in France, and its collection contains a range of national healthcare datasets. The HDH is actively involved in the EU-funded projects TEHDAS2 and QUANTUM (an EU-funded project that aims to create a common label system that can be used across Europe to report on the quality and utility of datasets), and acts as coordinator of the HealthData@EU pilot project.

Applications to access data are made through the HDH. These are then forwarded to two independent committees for validation. Firstly, the Ethics and Scientific Committee for Research, Studies and Evaluations in the Health Sector (CESREES) must verify that the project is ethically relevant and in the public interest.(55) Next, the request is forwarded to the National Commission for Data Protection and Liberties (CNIL).(56) This second committee considers whether the request is acceptable, given data protection and individuals' rights. Once final approval is received, the HDH facilitates access to the data in a dedicated workspace within the HDH platform. Key details about approved projects are listed on the HDH website.

Additionally, the Agence du Numérique en Santé (Digital Health Agency) was established in 2009 to support digital health initiatives in France.(38) This joint initiative across the Ministry of Health, the National Health Insurance Fund and the National Solidarity Fund for Autonomy develops frameworks and best practice initiatives in the area of health data sharing and exchange, standards, cybersecurity support and establishing an interoperability framework for health information systems.

3.4. Northern Ireland

In Northern Ireland, the Honest Broker Service (HBS) brings together routinely collected data from health and social care services and facilitates its use for research purposes.(57) The relevant legislation governing the service includes both the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. The HBS is the Trusted Research Environment for Health and Social Care Northern Ireland (HSCNI) and is hosted within the HSCNI Regional Business Services Organisation (RBSO/BSO). The HBS is part of the Health Data Research UK (HDRUK) Alliance and makes information about its data available through the HDRUK Innovation Gateway.(58, 59) Through this portal, researchers can review available datasets and apply for access. Approved researchers can access the data remotely through the secure e-research platform (SeRP).(60) SeRP was developed as a solution for remote access by the Secure Anonymised Information Linkage (SAIL) databank, based at the University of Swansea.

Digital Health and Care Northern Ireland (DHCNI) is the public body lead on data and technology for health and social care services in Northern Ireland.(61) Overseen by the Department of Health, the DHCNI is an amalgamation of the former eHealth and Care Directorate and the Public Health Agency’s Centre for Connected Health and Social Care. In 2022, DHCNI published a range of strategies, including a Data Strategy which sets out a plan to establish a Data Institute within its organisation structure. Currently in development, the institute will include the Health and Social Care Northern Ireland Trusted Research Environment (NITRE), which is an expansion of the HBS.(62) It will also support the development of strong information governance and advise Health and Social Care Trusts on the collection and submission of their information centrally to the Northern Ireland Department of Health. Finally, it will facilitate data analysis through outreach support to two platforms, the Northern Ireland Health Analytics Platform (NIHAP), which was developed in response to the COVID-19 pandemic, and the General Practitioner Intelligence Platform (GPIP), a system used to transfer GP data to a data warehouse.

3.5. New South Wales, Australia

The Centre for Health Record Linkage (CHeReL) was established in 2006 as the health and human services data linkage body for both the state of New South Wales (NSW) and the Australian Capital Territory.(63) The CHeReL is a statutory organisation operating under the Health Records Information and Privacy Act 2002 for personal health information and the Privacy and Personal Information Protection Act 1998 for personal information.(64, 65) Its function is to make linked administrative and health data available to researchers and public bodies in accordance with relevant regulatory frameworks.

The CHeReL is operated and funded by the NSW Ministry of Health. Its collection contains over 200 distinct datasets and it undertakes data linkage using its core record linkage system, the Master Linkage Key. Researchers wishing to access data must apply directly to the CHeReL. The application process consists of a number of stages, including a technical review of the proposed study, which is carried out by a dedicated internal research team. If deemed technically viable, the CHeReL seeks approval from the data holder for the use of their data in the proposed project. After successfully completing this stage, the researcher then separately submits the complete proposal, including the approvals received, to the NSW Population and Health Services Research Ethics Committee.(66) On receipt of the committee’s approval, the researcher then engages with the CHeReL to gain access to the data. There are pricing rules for accessing datasets, with larger studies and those accessing multiple datasets accruing increased costs.

The Population Health Research Network (PHRN), which is funded through the National Collaborative Research Infrastructure Strategy programme, was established in 2009 as a network of data linkage centres across Australia.(67) As an initiative of the Australian government, it ensures that data can be shared appropriately and accessed by researchers across Australian states and territories. The PHRN hosts a searchable metadata platform in which researchers can identify available collections across the states and territories.

4. Stakeholder engagement and dissemination

4.1. Importance of stakeholder engagement and dissemination

In the context of establishing HDAB services, engagement refers to the practice of involving members of the public, data holders and data users in development and decision-making processes in relation to the establishment of a HDAB and the secondary use of data. Dissemination, on the other hand, refers to informing the public about the services of a HDAB and the secondary uses of their health data. Dissemination also refers to raising awareness and demand among data users and data holders of the services provided by the HDAB regarding the provision of access to health data.

Raising awareness of the secondary use of health data and the establishment of HDAB services in Ireland is a central element of the HealthData@IE project. There is strong evidence on the need to engage effectively with members of the public and health and social care professionals on changes to how health information is collected, used and shared.(68) As Ireland does not currently have a HDAB service, this concept is new for all. Failure to engage the public appropriately during the initial stages of the establishment of the new services may result in changes not being welcomed, which could affect the success of the project. The engagement strategy for the establishment of HDAB services in Ireland must set out to build trust amongst the public, data users and data holders. It must also educate them on how the secondary use of information can be used to drive improvements across the health and social care system.(69)

4.2. European initiatives relating to stakeholder engagement for health data access body services

4.2.1. TEHDAS (2020-2023)

The TEHDAS Joint Action produced 12 recommendations in relation to citizen engagement on the secondary use of health data. These recommendations are based on an analysis of almost 6,000 contributions gathered through the public Healthy Data Consultation, as well as a literature review of citizens' values and opinions of the secondary use of health data. Stakeholder interviews and workshops were conducted at EU and national levels in Belgium, France and the UK.(69, 70) The recommendations fall under three themes: the data relationship, the power balance and a citizen-powered framework. These are outlined below.

The data relationship

1. Citizens should be able to access information about the secondary use of health data in an understandable way.
2. Citizens should have access to their data and knowledge about how it is used for secondary purposes. However, they want to choose how and when they are informed about the uses of their data.
3. Citizens' values should inform what is beneficial to individuals and what constitutes the common good.
4. Decision-making processes should rely on a plurality of views and actors to increase their trustworthiness.
5. Citizens should be given the opportunity to be involved in the lifecycle of health data as they need to be engaged on a continuous basis. Otherwise, their relationship with data custodians and users can deteriorate.

The power balance

6. Citizens should be provided with the opportunity for meaningful and active decision-making in the secondary use of health data as they value the ability to exercise control.
7. The protection of individuals' identity should be ensured. Citizens perceive this as one of the best ways to balance the harms and benefits of the secondary use of health data.
8. Data users' intentions should be transparent and in line with purposes that citizens support.
9. Accountability could be enhanced through transparent and stronger mechanisms.
10. Good IT solutions to protect citizens' data are required, beyond having a strong legal framework in place.

A citizen-powered framework

11. Stakeholders should respect principles that align with citizens' ethical values.
12. Citizens recommend having a framework that facilitates the secondary use of health data for purposes and benefits that they support, while minimising the potential risks they identify.(69)

4.2.2. TEHDAS2 (2024-2026)

The goal of TEHDAS2 is to develop common guidelines and technical specifications to facilitate smooth access to health data and strengthen European collaboration in using data efficiently.(10) These guidelines and specifications will guide EU Member States in developing solutions and operationalising cross-border collaboration on the secondary use of health data. The importance of stakeholder engagement in TEHDAS2 is clearly demonstrated as two work packages of the project are dedicated to communicating with, and involving, citizens and other stakeholders throughout the project.(71)

4.3. Findings from each jurisdiction included in this review

The following section provides an overview of the approaches to engagement and dissemination, particularly with the general public, taken in the reviewed jurisdictions in relation to HDAB services and the secondary use of health data.

4.3.1. Finland – stakeholder engagement and dissemination activities

A survey carried out in 2016 by Sitra, the Finnish Innovation Fund, examined citizens' attitudes towards secondary use of data for the wellbeing of the Finnish population. The survey confirmed that citizens of Finland have a high level of trust in their healthcare system authorities.(17) However, it was also found that citizens want to have the power to influence how their data is collected and used. The findings also made clear that citizens want their data shared for specific purposes only.(72)

Findata engaged with the public through press releases prior to the enactment of the Act on the Secondary Use of Health and Social Care Data (2019) governing the secondary use of health data.(73) The communications strategy focused on ensuring transparency by providing clarity on how citizens' health data would be used by Findata. News articles were published to demonstrate how data was being used in research and to highlight the benefits of secondary uses of health data.

Continuous engagement occurs between Findata and key stakeholders to develop good working relationships with data holders, data users and the general public. Information aimed at the general public can be found under a dedicated 'information for citizens' section of the Findata website.(74) These resources include information on how data is collected and shared, Frequently Asked Questions (FAQs) and a short animated video explaining general concepts about the secondary use of data. Much of the content aimed at the general public focuses on the rights of individuals in relation to the secondary use of their data.

4.3.2. Belgium – stakeholder engagement and dissemination activities

As part of the TEHDAS initiative, a public consultation was held online, followed by virtual workshops in 2021 and 2022 to explain the process of setting up the Belgian Health Data Agency (HDA).(13, 70) The objective of the consultation was to provide an opportunity for the public to voice their opinions on the ethical, legal and societal framework for the secondary use of health data and to translate their insights into recommendations and to inform the development of an online health data platform. Information materials, including educational tools, case studies and interactive comic books were provided to participants in non-technical language. The online Health Data Platform also included an educational toolkit for teachers at secondary school level and monthly newsletters to familiarise participants with the concept of health data and the Belgian health information system. The consultation was disseminated among policy makers, patient organisations, schools, academics, researchers, the general public and health institutions. Between December 2021 and May 2022, the Health Data Platform recorded 25,000 visits and collected up to 6,000 contributions regarding the secondary use of health data.(13)

The HDA website offers general information to the public on the secondary use of data and provides links to a series of online courses and videos on the purpose and function of the HDA and the EHDS. This includes a short information video outlining the HDA's key functions in managing health-related data within Belgium, its commitment to privacy, security and transparency and its collaboration with European entities.(19) There is also an 'I am a Citizen' section on the website. This provides information on privacy rights, legal protections, ethical considerations and information on how the HDA operates within these to facilitate the secure reuse of health data.(75) This section of the website also provides updates on news and events related to the secondary use of health data in Belgium.

4.3.3. France – stakeholder engagement and dissemination activities

The Health Data Hub (HDH) has formed a specific team dedicated to listening, informing, training and establishing partnerships with citizens and non-governmental organisations (NGOs). In addition, its public directory of projects shows where anonymised and pseudonymised health data has been used for research. The HDH has also created a computerised system which allows citizens to exercise their rights in relation to GDPR and secondary use health data.

A partnership between France's HDH and France Assos Santé (FAS) was established to increase public engagement with users of the French health system. FAS is a rights-based union of several hundred national and regional patient associations that advocate for quality, universal access to health.(76) This partnership identified the need to consider citizens' experiences and to increase public representation on their scientific and ethical committees.

The HDH has also held community events to engage with the public, such as the 2023 Secondary School Engagement Project, which involved a debate with fifty high school students in Paris on the topic of AI and health data for research.(14) Two workshops were facilitated by experts to help young people understand the subject of secondary data. In April 2023, the HDH, in collaboration with FAS and PariSanté Campus, hosted a Consensus Conference in which 70 members of the public gathered for a weekend to discuss how to raise awareness of the sharing of health data. The conference involved opportunities for the public to engage with health data experts; to reflect, in groups, on the topic of the secondary use of data; and to co-develop proposals for tools and materials for communicating about the benefits of sharing health data. The participants opted for communication strategies that targeted the entire population, indicating that the sharing of health data was perceived to be a topic that is relevant to everyone.(77)

The HDH has developed a suite of educational resources for the general public, data users and data holders which are available on the HDH website. For example, recorded webinars from their Health Data Tuesday webinar series are organised as themed modules on the website, which the learner is guided through.(26) The HDH has also developed infographics and guides on topics such as citizens' rights in relation to health data.(78)

4.3.4. Northern Ireland – stakeholder engagement and dissemination activities

In Northern Ireland, much emphasis has been placed on engagement with the public in relation to HDAB services. For example, the governance board of the HBS includes a member of the general public and a representative from the Patient Client Council. The Patient Client Council was created as part of the reform of health and social care in Northern Ireland and has a number of functions including representing the interests, and promoting the involvement, of the public in health and social care services. In addition, in all HBS applications for data access, public and patient involvement (PPI) and engagement are key criteria that applicants must address.(79)

Furthermore, across the UK, since the COVID-19 pandemic, a number of public engagement activities have been conducted in relation to the use of health data. For example, the Data Saves Lives strategy is specifically aimed at emphasising transparency and building public trust.(80) Additionally, the National Health Service (NHS) Transformation Directorate has undertaken large-scale public meetings over two weekends on topics related to health data.(81) The outcomes are summarised in reports with recommendations that have been developed with the public. The National Data Guardian has also gathered insights from the public to develop guidance on data access for research and innovation to ensure that health data is used in ways that benefit both individuals and society.(82)

Northern Ireland's Public Data Panel (NIPDP) is a pilot partnership initiative from the Administrative Data Research Centre (ADRC) and the NITRE.(15) The panel was set up to facilitate conversation with the public on the topic of data use in research, innovation, service delivery and decision-making. The panel members co-develop their outputs and provide advice on how to garner public trust, create transparency and build acceptance with regards to the use of data.

In addition to engagement activities, the HBS has developed a number of resources for the public to increase knowledge and awareness of the secondary use of data.(18, 83) These resources include a video and booklet outlining the purpose and role of the HBS, as well as a number of case studies to illustrate the benefits of the secondary use of data.(84) There are also several webpages dedicated to explaining various aspects of the secondary use of data such as secure processing environments, the need for health data research and analysis and the de-identification of data.(18)

4.3.5. New South Wales, Australia – stakeholder engagement and dissemination activities

In 2018, Australia's Department of Health held a public consultation as part of the development of a framework to guide the secondary use of data in the pre-existing My Health Record (MHR) system. The MHR is an electronic system which collects patient health information and works to inform and improve clinical decision-making across Australia. This work was carried out, in part, to build public trust in the process of sharing secondary data on the MHR platform. Over 700 people engaged with the consultation process through webinars, workshops, interviews, surveys and written submissions. The main findings of the consultation were that there was a need for stronger engagement with Indigenous communities and that citizens should be offered the opportunity to consent to, or opt-out of, the use of their MHR data for secondary purposes.(16)

In New South Wales, the CHeReL has a Community Advisory Committee that aims to provide advice on issues of community interest.(85) The committee responds to concerns or complaints from the community as well as reviewing proposed projects in relation to the public interest. Through the CHeReL website, the general public can access information resources which describe what the CHeReL is, what it does, how privacy is protected and the benefits of data linkage.(85)

At a national level, the Population Health Research Network's website provides information on privacy, data linkage and case studies about the impact of secondary use of health data on health services.(86) Additionally, the Australian Digital Health Agency's website provides information on the benefits of data sharing and a Frequently Asked Questions (FAQ) section which focuses on data protection. It also offers information and instructions on how to change secondary data sharing settings on the MHR application.

5. Training and education

5.1. Importance of training and education when establishing health data access body services

To prepare for the implementation of the EHDS Regulation, it is essential that resources are allocated to capacity building and increasing knowledge of all stakeholders involved, particularly data users, data holders and future HDAB services staff. Education and training are required so that the relevant stakeholders are equipped with the necessary skills and knowledge to meet the obligations set out under the EHDS. Education and training will also help to ensure that the right steps are taken by all stakeholders to mitigate against risks, such as data breaches. Training, education and support — such as peer support networks, training modules, information materials, and support services — should allow the different actors to grant or get access to data and to obtain a solid understanding of the new system.

5.2. Findings from each jurisdiction included in this review

The following section provides an overview of the approaches to education and training for data users and data holders taken in the reviewed jurisdictions.

5.2.1. Finland – approaches to training and education for data users and data holders

Findata offers a range of training and support resources for data users and data holders on its website.(39) Working groups and sub-groups were involved in the development and implementation of education and training for the different stakeholders.

Data users

Findata offers a number of support and training initiatives to data users. One such initiative is an online one-to-one consultation service.(23) Through this service, appointments are available three days a week and last for 20 minutes. These appointments offer support in relation to general Findata services, data permit applications, application amendments, completing forms such as data extraction description forms and using Kapseli, which is Findata's secure processing environment and data storage service.(33, 41) In addition, Findata offers bi-monthly Application Clinics in the form of online information sessions.

At these sessions, experts offer practical support to those who are currently submitting, or planning to submit, a data permit application. Findata also offers a Help Desk service through which general queries can be submitted by email.

In addition to these interactive services, there are numerous resources and guides available on the Findata website. These include information about what data is available and how to request it, general tips, a user guide for Findata's secure processing environment and FAQs. There is also a web Application Assistant, where users can select from which data controller they wish to retrieve data.

Data holders

Findata offers a one-to-one counselling service to data holders where it provides advice and guidance on topics like the submission of data, data descriptions, general questions concerning the Act on the Secondary Use of Health and Social Data and how to securely submit extracted data to Findata using the Nextcloud transfer service.(27) Nextcloud is a cloud-based transfer system with instructions for controllers on the submission process. Findata provides tools, support and training for creating data descriptions, such as the Data editor, as well as a Data Catalogue, where data descriptions are published.(27)

Findata also provides various guides and information resources for data holders on different topics. The section of the website called 'Instructions for holders' includes links to further resources on topics such as data transfers to Findata, invoicing and regulations on user environments, data descriptions and data permit applications.(27) Other resources include guidance on how data descriptions should be applied and guidance around ensuring the anonymity of data.(32, 36, 87) The Findata website also provides information to ensure that each authority involved processes data permit applications in a consistent and lawful manner.(88)

5.2.2. Belgium – approaches to training and education for data users and data holders

The HDA in Belgium offers a range of training and education resources aimed at data users and data holders. The majority of courses on offer are available in English, French and Flemish.

Data users

Data users can navigate directly to the 'I am a data user' section of the HDA website where they will find resources and information.(21) This includes information and guides in relation to how data should be requested, the processes involved, legal insights and regulations and a list of FAQs. The HDA also hosts a Data Academy, which aims to increase data literacy and related skills and practices among stakeholders such as data providers, data users and the general public.(24) The academy has a range of resources on various topics that are openly available. Some of these resources are recordings of webinars, some are short information videos and others are training modules. Topics include introductions to the EHDS, the HDA and the surrounding legal context, Open Data,[*] and Artificial Intelligence in health data. The HDH continuously adds to the catalogue of online courses available through the Data Academy. Users have the option to create an account so that they can track the courses they have completed, certificates acquired as well as forum and discussion posts.

Data holders

Data holders can navigate directly to the "I am a data provider" section of the website, which provides links to the Health Data Academy. Many of the available courses are particularly relevant to data holders, for example, the course on the FAIR data principles. Also on this section of the website, there is information on how data holders can become HDA partners and how they can share data with the HDA.(51, 89)

5.2.3. France – approaches to training and education for data users and data holders

In France, the HDH website has specific sections for data users and data holders.(90) The HDH offers training courses and related resources aimed at the various stakeholders and it hosts a monthly webinar series called Health Data Tuesdays on various topics related to the secondary use of health data.(25, 26, 91) The answers to high-interest queries asked during the webinar are published on the HDH website as a perpetual resource.

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[*] Open data is data which is accessible, usable and shareable by all, including citizens, government and businesses.

Data users

There are a number of training resources aimed specifically at data users available through the HDH website. Training mainly takes the form of webinars, both live and recorded, and slide decks.(26) Many of these training resources are labelled as suitable for all audiences, including citizens and students, but some are more advanced and require some pre-requisite knowledge. Courses for data users include accessing and using the National Health Data System's (SNDS)[†] databases and procedures for accessing health data.

Other training and support resources that are offered to data users include toolkits and guides to help data users get started.(29) These toolkits provide information on anonymous and pseudonymised data, regulatory procedures, how to access health data in France and how to inform people about the processing of their personal data. As part of its open approach, the HDH also offers a support forum for new health data users and is actively involved in a Meetup community, which is a type of peer support network. The HDH is also a member of a consortium in partnership with Sorbonne Université that aims to develop educational resources to train healthcare professionals in digital health.

Data holders

A range of resources and training specifically for data holders is available on the HDH website. These include information on the data catalogue and how data holders can have their data included within the HDH.(92) A Data Controller Charter has also been published which includes background information on the roles, purpose and function of the HDH.(93) The HDH holds weekly webinar training and education sessions on various themes which may be attended by data controllers and data users.

The HDH provides an array of additional supports to data holders. These include supporting data holders in the collection, standardisation and documentation of data, financial contributions, providing expertise to data managers for carrying out the various actions required to transfer and make data available, providing secure

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[†] The SNDS are rich datasets comprising three major pre-existing databases encompassing the French population as a whole. These databases focus mainly on health insurance reimbursements, healthcare use, medical cause of death and hospital stays.

hosting and support for GDPR compliance. The HDH also works to strengthen the network of hospital health data warehouses by organising group training and experience-sharing sessions.

5.2.4. Northern Ireland – approaches to training and education for data users and data holders

In Northern Ireland, the HBS offers a range of general resources for members of the public, data users and data holders.

Data users

For data users, the HBS shares information on how to apply for health data, how to complete application forms as well as various guidance documents covering topics such as output checking procedures, dos and don'ts when making an application and various service policies.(34) All of these guides are available to download in a Researcher Pack.(34) The HBS also offers ongoing support to data users throughout their research project. For example, it offers guidance and advice on the application process, output checking and de-identifying data.(34)

In terms of specific training, data users are directed towards the Office of National Statistics (ONS) to undergo training to become an accredited researcher.(94) Data users must become accredited researchers in order to access health data through the HBS.(28) Data users are directed towards Learn HCSNI, which is a training portal used within the health and social care sector in Northern Ireland.(95)

Data holders

The HBS does not provide any training for data holders directly. However, relevant training courses are available through Learn HSCI and the ONS.(94-96) Examples of available training on these platforms include Data Privacy in Machine Learning and Artificial Intelligence, Quality Assurance of Administrative Data and Awareness in Data Linkage.(97-99)

5.2.5. New South Wales, Australia – approaches to training and education for data users and data holders

A small number of education and information resources aimed at the general public, data users and data holders are made available through the CHeReL website. However, in general, training tends to be accessed or delivered at a national level.

Data users

The CheReL has developed guidance documents for data users, focusing on the processes of accessing, linking and using data.(22, 100) These guidance documents include information on the application process, general information on data linkage, as well as tips and templates for data users to follow when developing their applications to access secondary health data. Additional information is provided in relation to quality assurance and data security.(101) The CHeReL also offers a webinar series for researchers on Clinical Trials and Data Linkage which provides guidance on navigating the access and approval processes. For researchers using Biolink data, a service which links biospecimens with a broad range of health data, the Biolink Research Project Manager provides ongoing advice and support in relation to accessing the service and on ethical and data custodian processes.(100) The CHeReL staff members provide university lectures on their data linkage methods.

Data holders

No training or resources were identified specifically for data holders on the CHeReL website. The CHeReL has established ongoing partnerships with data holders to help identify knowledge or skills gaps and as a result, develop informal training for data holders so that they can upload data to the CHeReL's systems correctly.

6. Data quality

6.1. Importance of data quality in the context of health data access body services

High-quality data is data which is fit-for-purpose; that is, it meets the needs of data users.(102) When high-quality data is available, individuals receive better care and support, effective and strategic decision-making is supported, improved patient health outcomes are delivered and essential public policy development and research are facilitated.(102) Within the context of the EHDS, assurances with regard to the quality of available data are essential to facilitate the reliable secondary use of health data in research, regulation and policy-making. In order to achieve high-quality data, all of the different actors in the data quality process have roles and responsibilities relating to various activities and services which include:

- the use of data management and data quality assurance procedures
- the semantic mapping of datasets using international standards
- the linkage of datasets and the application of privacy enhancement technologies
- the publication and cataloguing of metadata
- the enrichment of datasets and procedures
- data minimisation and purpose limitation activities.

The assessment of health data quality is commonly undertaken through consideration of a number of dimensions, including: relevance; accuracy and reliability; timeliness and punctuality; coherence and comparability; accessibility and clarity.(102) As set out in HIQA's *National Standards for Information Management in Health and Social Care*, organisations striving to ensure data quality should develop a data quality framework.(103) Essential elements of a data framework include a data quality strategy, a data quality assessment tool, data quality reports and a data quality improvement cycle.(102)

6.2. European initiatives relating to data quality

6.2.1. TEHDAS (2020 - 2023)

The TEHDAS Recommendations on a Data Quality Framework, published in 2023, also utilise the fit-for-purpose definition of data quality. This sets out a two-fold perspective, whereby both data quality and utility at a dataset level and the maturity of the data quality process at data holder level are considered. TEHDAS sets out the following dimensions of data quality: relevance; accuracy and reliability coherence;

coverage; completeness; and timeliness.(104) The TEHDAS data quality framework also defines what activities are relevant for each phase of the data use: discovering the data, applying for permits to use the health data, using the data effectively and publishing results.

TEHDAS produced a number of recommendations relating to data quality which centred on ensuring the use of technical standards, the need to assess and report on the maturity of data and the importance of publishing data descriptions and addressing issues of data security and privacy.(105)

Specific TEHDAS recommendations on data quality included:

- the need for data holders to use a data quality and utility label to inform data users about the quality and utility characteristics of the datasets, enabling users to select datasets that best fit their needs
- the importance of applying a data quality framework at all phases of the data use cycle
- the need for data holders to self-assess levels of data management maturity according to an EU-wide model
- the need for data holders to implement widely adopted standards of semantic interoperability
- the need for data holders to publish a description of their datasets using EU-adopted publication standards
- the need for HDABs to publish and maintain a metadata catalogue of all datasets made public by the data holders under their remit
- the need to implement data management procedures that allow dataset linkage and identification while protecting personal information
- the importance of publishing information on data provenance, relevance and coverage to ensure the highest possible degree of transparency
- the promotion of the development of a benchmarking process which facilitates a Europe-wide approach to measuring data quality in the medium to longer term.(104, 106-108)

With regard to regulating data quality and assessing compliance with data quality standards and regulations, TEHDAS recommendations included the following:

- Data quality should be assessed at institutional level, and the EHDS nodes (entry points for stakeholders to the EHDS) should be responsible for ensuring transparency, as well as the implementation of data quality assessment procedures.
- The regulation of data quality should include a focus on guidance.

- Processes for benchmarking and continuous improvement should be developed to assist with the measurement of data quality.
- Governing health data in Europe should be based on clearly defined roles for organisations that will process health data.(107, 109)

6.2.2. TEHDAS2 (2024 – 2026)

The TEHDAS2 Joint Action is continuing preparations to enable the secondary use of health data in the EHDS. This includes addressing the gaps in infrastructure and HDAB services by developing necessary guidelines, technical specifications and tools for data users, data holders and HDAB staff.(110) Guidelines are on topics such as making data available and data enrichment capabilities, establishing harmonised procedures for granting data permits, creating specifications for secure processing environments and technical specifications for national metadata catalogues.(71)

6.2.3. QUANTUM (2024 – 2026)

QUANTUM is an EU-funded project that aims to create a common label system that can be used across Europe to report on the quality and utility of datasets. The data quality and utility label will enable data users to identify high-quality data for research and decision-making.(111) QUANTUM sets out to address the requirement of the EHDS Regulation which mandates for health datasets to use a labelling system to demonstrate the quality and usefulness of the data being used for secondary purposes.

As well as the data quality and utility label, other relevant project outputs are:

- the findings of a stakeholder learning needs assessment designed to identify the educational needs of the project's stakeholders
- online training courses and workshops for data holders and other stakeholder groups
- guidelines and specifications for the implementation of the QUANTUM label
- a Community of Practice repository containing guidelines, templates, checklists and initial QUANTUM labelling experiences
- a QUANTUM exchange platform and academy to facilitate capacity building.

6.3. Findings from each jurisdiction included in this review

The following section provides an overview of the approaches to data quality taken in each of the jurisdictions included in this review.

6.3.1. Finland – approach to data quality

Findata processes applications and grants permits for access to health and social care data for secondary use. After granting a permit, Findata facilitates access to the data by compiling and processing it. While some general checks are carried out by Findata on the datasets, responsibility for the quality of data lies primarily with the data holders. Findata has issued a regulation on data contents, concepts and data structures of data descriptions.(36) This outlines requirements for data holders to prepare descriptions of the contents of their data collections. This is so the suitability of the data for the uses referred to in the Act on the Secondary Use of Health and Social Data can be assessed.(41) The purposes of the regulation are outlined as follows:

- to ensure uniform and high-quality descriptions of the data resources of the organisations referred to in section 6 of the Act on the Secondary Use of Health and Social Data
- to allow safe and effective use of health and social data resources
- to ensure that Findata can perform its tasks and provide its customers with services in an effective and high-quality manner in accordance with the principles of good governance
- to promote the interoperability of data collections held by different organisations.

Under this regulation, data holders are required to describe and submit information to Findata on all their data collections that fall within the scope of the Act. Findata provides data holders with advice and training in the production of data descriptions and disseminates information on matters concerning data descriptions. The ultimate aim for Findata is to produce a comprehensive national catalogue of health and social care data resources.

In 2024, Findata launched FinHITS – Strengthening Finnish Health Data ICT for Secondary Use, an EU-funded project to support Finland’s preparations for the EHDS.(112) This four-year project comprises of nine work packages with one focussed on evaluating the quality of health data. The project aims to support the data quality agenda through the development of national guidelines.

6.3.2. Belgium – approach to data quality

The Belgian HDA facilitates access to quality health, healthcare and welfare data for secondary use. In relation to data quality, the HDA provides resources and courses through the Health Data Academy covering topics such as:

- How to analyse your organisation's data maturity
- What is the EHDS? A basic introduction
- Proposed Regulation on the EHDS
- The Journey of Requesting Access to Data through the HDA
- An introduction to metadata
- Data Maturity Analysis (DMA).(24)

One online learning course covers DMA for those working with health data. One dimension of the DMA course is data quality. In this section of the course, the HDA provide a description of data quality and metrics to ensure quality, such as data quality controls and data quality process and standards. The HDA provides supports to organisations during their data maturity analysis. Three options for support include end-to-end support, advice and assistance through the DMA process.

The HDA sets out clearly that the responsibility for data quality and the enhancement of data quality lies with the data holders, and the HDA provides advice and support where required.(113)

6.3.3. France – approach to data quality

The French HDH has developed a 'Data Controller Charter' which sets out the respective roles and responsibilities of data holders and the HDH. The charter details that the responsibility for enhancing data quality sits with the data holders.(93) The HDH does carry out certain quality assurance checks on datasets that are submitted and provides support to data managers in the process of transferring and making data available. Additionally, as part of its health data warehouse initiative, the HDH hosts group training and information sharing sessions for data holders on the secondary use of health data.

The Agence du Numérique en Santé (Digital Health Agency) has published a range of resources to support the enhancement of data quality across digital health data in France. This includes a technical doctrine document which sets out the interoperability standards for health data. In addition, a Convergence platform has been designed so that data holders can self-assess their compliance with its interoperability standards.(114) The results of these assessments can be made available to the public. The agency also supports data holders to develop improvement plans to improve their compliance.

6.3.4. Northern Ireland – approach to data quality

In Northern Ireland, the Honest Broker Service (HBS) facilitates access to available datasets and ensures all projects comply with the Five Safes framework.(18) While the HBS performs certain quality checks on data it receives, in general, data quality is the responsibility of the data holder. For example, for all health datasets, specific technical guidance is issued to data holders from the Department of Health on the collection, submission and validation of datasets. In addition, quality reports are undertaken by the Department of Health on datasets under its remit. These cover the following quality dimensions: relevance, accuracy, reliability, timeliness, punctuality, accessibility, clarity, coherence and comparability. These guidance documents and quality reports are published on the website of the Department of Health.(115)

Researchers can view data collections available through the HBS on the HDRUK Innovation Gateway webpage.(59) The gateway lists information about each dataset (such as description, size of the population contained within that dataset and the legal basis for access) that can help data users decide which datasets are most suitable for their requirements. In establishing this facility, HDRUK developed a data utility framework so that researchers can search the collections according to various data utility parameters. The framework contains five categories, separated across a range of dimensions, each of which is qualitatively evaluated to describe the characteristics of a dataset. Scores are assigned progressively along a four-level rating scale from Bronze to Platinum, with a definition for each level across the five categories. The use of the framework enables:

- data holders to communicate the utility of their dataset and any improvements made to it
- users to identify datasets that meet the minimum requirements for their specific purpose
- system leaders and funders to identify where to invest in data quality improvements and to evaluate what improvements have happened as a result of their investments.(37)

6.3.5. New South Wales, Australia – approach to data quality

In New South Wales, the CHeReL holds a Master Linkage Key (MLK), which consists of a number of linked data collections. It regularly links other datasets to the MLK on a project-by-project basis. The CHeReL carries out initial data quality assurance checks on datasets submitted. These checks are centred on ensuring that required data is available to facilitate linkage with other datasets. Ultimately, data quality is the responsibility of the data holders. The CHeReL carries out an annual comprehensive quality assurance exercise on the MLK with the aim of detecting and correcting false positive and false negative links.(101)

The CHeReL website outlines details of each dataset included in its MLK, including a data dictionary and relevant metadata where available.(116) In addition, the website provides resources for data users, including information on edit checks for linked data, reporting guidelines, data linkage flow charts and training on the process of data linkage.(22)

At a national level, the PHRN hosts a Metadata Platform where all data collections that are routinely linked in each state and territory can be searched by data users to establish exactly what data is available. This also enables them to determine the characteristics of the available collections, including details on whether a data dictionary and data quality statement have been provided.(117)

7. Conclusion

Meaningful engagement and, in particular, building trust amongst members of the public, is key to the successful establishment of HDAB services. To support this approach, both widespread and targeted engagement is required where the needs of members of the public and professionals are identified and addressed. Appropriate and accessible information and education materials need to be developed which meet the needs of all stakeholders. Because Ireland does not have HDAB services and the concept is new to all, it is important that any engagement and dissemination activities involve consultation and education of members of the public. It is necessary that the public are assured that their health data will be used appropriately.

In preparing for the implementation of the EHDS and the establishment of HDAB services, it is also important that training and supports are provided to data holders and data users. The evidence in this review indicates that varying levels of guidance and training are provided by HDAB services to these key groups. However, in order to facilitate the successful establishment of HDAB services in Ireland, and to ensure adequate preparation, it is essential that a planned and coordinated approach is taken to the provision of training and guidance for data holders and data users. This includes specific training and guidance for data holders on their data quality obligations once the EHDS is implemented. Adapting and adopting key resources and outputs from QUANTUM, TEHDAS2 and the EHDS2 Pilot for the Irish context will be essential.

7.1. Next steps

The findings of this international review have informed the development of three plans which set out how key HealthData@IE project milestones and deliverables will be achieved:

- Engagement and Education Strategic Plan 2024 – 2027
- Data Quality Guidance and Education Plan 2024 – 2027
- Work Package 8 Programme Plan 2024 – 2027.

The development of tools, resources and materials within these programmes of work will be largely informed by the key findings of this review as well as by extensive stakeholder engagement over the duration of the HealthData@IE project.

In relation to engagement and dissemination, the findings of this review will inform engagement and dissemination activities with various stakeholders, including members of the public, data holders and data users regarding the establishment of HDAB services in Ireland. The findings will also be used to inform training and education initiatives for relevant stakeholders in relation to the implementation of the EHDS and HDAB services. All activities, which will aim to create awareness, build trust and develop the knowledge and skills required to successfully implement the EHDS once enacted, will be evidence based and will build on learnings from other jurisdictions.

In relation to health data quality enhancement, the findings of this review will be used to inform the development of data quality guidance and training materials, a national interoperability framework, a digital self-assessment tool, a compliance assessment framework and a benchmarking tool. The overall aim is to enhance the quality of electronic health data made available through HDAB services and support data holders in enhancing the quality of their data.

The development and implementation of these programmes of work will contribute to the successful establishment of HDAB services in Ireland and will enable it to meet its obligations under the EHDS. This will be associated with benefits for the general public, data holders and data users in relation to the secondary use of health data in Ireland.

8. Glossary of Abbreviations

Abbreviation	Definition
BSO	Business Services Organisation
CESREES	Ethics and Scientific Committee for Health Research, Studies & Evaluations
CHeReL	Centre for Health Record Linkage
CNIL	National Commission for Data Protection and Liberties
DHCNI	Digital Health and Care Northern Ireland
DMA	Data Maturity Analysis
DREES	Directorate of Research, Studies, Evaluation and Statistics
EHDS	European Health Data Space
FAS	France Assos Santé
FAQ	Frequently Asked Questions
GDPR	General Data Protection Regulation
GPIP	General Practitioner Intelligence Platform
HBS	Honest Broker Service
HDA	Health Data Agency
HDAB	Health Data Access Body
HDH	Health Data Hub
HDRUK	Health Data Research UK
HSCNI	Health and Social Care Northern Ireland
MHR	My Health Record

Abbreviation	Definition
MLK	Master Linkage Key
NHS	National Health Service
NI	Northern Ireland
NIHAP	Northern Ireland Health Analytics Platform
NITRE	Northern Ireland Trusted Research Environment
NSW	New South Wales
PHRN	Population Health Research Network
PPI	Public and Patient Involvement
TEHDAS	Towards the European Health Data Space
RBSO	Regional Business Services Organisation
SeRP	Secure e-Research Platform
SNDS	National Health Data Systems

9. Glossary of Terms

Term	Definition
Dataset	Dataset means a structured collection of electronic health data.(7)
Data Act	The Data Act entered into force on 11 January 2024. The Act clarifies who can create value from data and under which conditions. The Data Act aims to enable a fair distribution of the value of data by establishing clear and fair rules for accessing and using data within the European data economy, while ensuring the protection of personal data.(2)
Data catalogue	A data catalogue is a collection of datasets descriptions, which is arranged in a systematic manner and consists of a user-oriented public part, where information concerning individual dataset parameters is accessible by electronic means through an online portal.(7)
Data controller	A data controller determines the purposes for which personal data is processed and the means by which it is processed.(7)
Data Governance Act	The Data Governance Act was the first deliverable under the European strategy for data and became applicable in September 2023. The Data Governance Act regulates processes and structures that facilitate voluntary data sharing. The Act is a cross-sectoral instrument that aims to regulate the reuse of publicly held, protected data.(3)
Data holders	A data holder is a person or organisation who has the right or obligation (through control of the technical design of a product and related services, and the ability to make data available), to register, provide, restrict access or exchange certain data.(7)
Data maturity	Data maturity represents an organisation's proficiency and sophistication in managing and leveraging its data assets. The data maturity level is an indication of how well an organisation understands, values, and utilises its data throughout various processes and functions.(118)

Term	Definition
Data maturity analysis	A data maturity analysis is a systematic review of an organisation's existing capabilities and practices related to different data dimensions including, but not limited to, data governance, data management, data usage and data quality.(118)
Data permit	A data permit is an administrative decision issued to a data user by a health data access body or data holder to process the electronic health data specified in the data permit for the secondary use purposes specified in the data permit based on conditions laid down in EHDS Regulation.(7)
Data quality	Data quality refers to the degree to which characteristics of electronic health data are suitable for secondary use.(7)
Data quality and utility label	A data quality and utility label is a graphic diagram, including a scale, describing the data quality and conditions of use of a dataset.(7)
Data users	A natural or legal person who has lawful access to personal or non-personal electronic health data for secondary use.(7)
European Health Data Space	The EHDS is an initiative by the European Union that aims to create a unified framework for health data across EU Member States.(7)
FAIR data	FAIR data refers to data that adheres to the FAIR principles of Findability, Accessibility, Interoperability and Reusability. The FAIR principles were established in 2016 to improve the efficiency and effectiveness of data usage.(51)
Health Data Access Body (HDAB)	A HDAB is a service that allows data users, such as researchers and policy-makers, to apply for access to health datasets to support research and innovation, education and training, policy-making, health service management and preparing national statistics. Under the EHDS, each EU Member State will be required to establish one or more HDABs.(7)

Term	Definition
HealthData@EU	HealthData@EU is the infrastructure connecting national contact points for secondary use of electronic health data and the central EU platform.(7)
HealthData@EU Pilot project	The HealthData@EU Pilot project is a two-year long European project that aims to build a pilot version of the EHDS infrastructure, HealthData@EU.(7)
HealthData@IE	The Department of Health has been awarded EU funding under the EU4Health programme to support the establishment of health data access body services in Ireland. The grant-funded project, known as HealthData@IE, is being delivered in collaboration between the Department of Health, the Health Information and Quality Authority (HIQA) and the Health Research Board (HRB).(12)
Interoperability	Interoperability is the ability of organisations, as well as software applications or devices from the same manufacturer or different manufacturers, to interact towards mutually beneficial goals. It involves the exchange of information and knowledge without changing the content of the data.(7)
Metadata	Metadata is information that describes other data. It helps to explain what the data is, how it can be used and where to find it.(119)
Open data	Open data is data that is openly accessible, exploitable, editable and shareable by anyone for any purpose.(120)
Public and Patient Involvement (PPI)	Public and Patient Involvement refers to research that is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.(121)
Secondary use of health data	Secondary use of health data means the processing of health data for purposes such as research, innovation, training and policy-making. The data used may include personal electronic health data initially collected in the context of primary use, but

Term	Definition
	also electronic health data collected for the purpose of the secondary use.(7)

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