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

Deliverable 2.1

ENGAGEMENT AND EDUCATION STRATEGIC PLAN 2024-2027

20 December 2024

Có-mhaoinithe ag an Aontas Eorpach
Co-funded by the European Union

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health

HRB
An Bord Taighde Sláinte
Health Research Board

Engagement and Education Strategic Plan 2024-2027: approach to effective engagement and education in establishing a Health Data Access Body (HDAB) for Ireland

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Work Package	2 – Dissemination, Training and Support
Deliverable / Milestone description	Deliverable 2.1 - Dissemination, training and education plan 1
Delivery Date	October 2024 (Month 12)
Dissemination Level	PU – Public

HealthData@IE: setting up health data access services in Ireland 2023-2027

Project number: 101129357 – HDAB IE

Call: EU4H-2022-DGA-MS-IBA2

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Document summary

The Department of Health was awarded grant funding from the EU to support the establishment of services of a Health Data Access Body (HDAB). The development of this infrastructure supports Ireland's commitment to the delivery of the European Health Data Space (EHDS). This project is being delivered through collaboration between the Health Information and Quality Authority (HIQA), the Department of Health and the Health Research Board (HRB). Once established, a HDAB will connect researchers and policy makers with anonymised datasets enabling them to develop insights that will improve health and social care services in Ireland.

This plan sets out a strategic approach to addressing engagement, dissemination, training and education in relation to the setting up of Health Data Access Body (HDAB) services to support the implementation of the European Health Dataspace (EHDS) in Ireland. The document aims to outline the key objectives to be delivered from 2024 to 2027 to support the establishment of HDAB services. It is recognised that there will be ongoing engagement, dissemination, education and training needs for HDAB services, beyond the lifetime of the grant. These needs will be addressed in a final report and plan, which are due in the final month of the grant agreement.

The guiding principle underlying this strategy is that engagement is based on a partnership model that is inclusive and rights-based, incorporating a wide-range of stakeholders including patients, the public, professionals and academics. The four strategic objectives, which are listed in Figure 1 below, are to be viewed in a larger context of effective engagement with the public and professionals on changes to how health information is collected, used and shared.

Figure 1 Summary of strategic objectives – Engagement and education in the establishment of Health Data Access Body (HDAB) services in Ireland

1. **Engage** with the public, health and social care professionals and relevant stakeholders on how health information is collected, used and shared for secondary use through a Health Data Access Body
2. Undertake a targeted **dissemination** campaign to raise awareness among the public, data holders and data users of the Health Data Access Body function and responsibilities
3. Identify the specific **education and training needs** of data holders, data users and Health Data Access Body staff regarding the Health Data Access Body function and responsibilities
4. Develop **education and training initiatives** to support data holders, data users and Health Data Access Body staff with regard to the Health Data Access Body function and responsibilities in Ireland

1. Introduction

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 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 EU 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, and the establishment of the EHDS was formally approved by the European Parliament in April 2024.(6)

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 health and social care 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, research and the provision of services and is being managed securely in a way that ensures their privacy and confidentiality is 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, 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; 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 set out to build a pilot version of the EHDS infrastructure for the secondary use of health data, referred to as HealthData@EU.(7) The project is developing a network infrastructure and services to support data users[*]. 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.(8)

Acknowledging that trust is fundamental to the success of the EHDS, the EU 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 Member States, there is a 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.(9)

1.2 HealthData@IE 2023-2027: setting up health data access services for Ireland

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 policymakers, with anonymised health datasets to support research and innovation, education and training, policymaking, 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 under

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[*] Data users are natural or legal persons who have lawful access to personal or non-personal electronic health data for secondary use; examples include researchers, innovators, regulators and policy makers.

the EU4Health programme to support the establishment of health data access 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 EU Commission as being core Digital Business Capabilities for HDABs.(10) 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 Secure Processing Environments (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, and training and education for data users, data holders, HDAB staff and the public.

1.3 Overview of Work Package 2: Dissemination, Training and Support

Work Package 2 is one of eight work packages within the HealthData@IE project (See Appendix 1). It comprises a programme of work centred on raising awareness of the HDAB function and responsibilities among the public, data holders and data users. An emphasis will be placed on engaging effectively with members of the public, health and social care professionals and other relevant stakeholders on changes to how health information is collected, used and shared. Engagement will also comprise training and support initiatives for HDAB staff, data holders and data users. As Ireland currently does not have a HDAB, this concept is new for all.

A well-planned strategy is required to use engagement as a tool to inform, consult, involve, collaborate with and empower the public and health and social care professionals in terms of the establishment of a HDAB. Failure to engage with the public and professionals as part of the initial phase of the establishment of a HDAB may impact on the success of this body. Previous work undertaken by HIQA and the Irish Platform for Patient Organisations, Science and Industry (IPPOSI)(11-13) highlighted that engagement on health information should be based on a partnership model. It should incorporate a wide range of stakeholders including patients, members of the public, health and social care professionals and academics.

The TEHDAS Joint Action produced recommendations for the Member States and European Commission on how to engage citizens in the EHDS. Those recommendations represented citizens’ points of view as expressed in the Health Data consultation. This consultation involved over 6,000 citizens across France, Belgium and the UK. The key aspects of the recommendations focused on the data relationship, the power balance and a citizen-powered framework. Specifically, it outlined that citizens should be treated as equal partners, with a focus on the need to be informed about the secondary use of health data.(14)

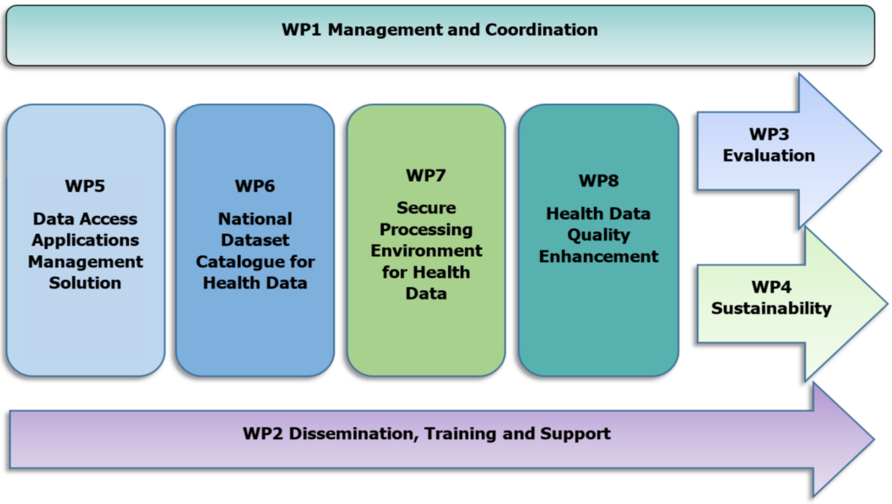
The development of education and training tools and activities for data holders, data users and HDAB staff will also be a key focus of the programme of work of this work package. Training should enable the different actors to grant or get access to data and to obtain a solid understanding of the system. This will include a training needs analysis to identify gaps in knowledge and understanding. The project team will ensure that all outputs are aligned with other relevant initiatives, including the TEHDAS2 joint action,(15) the EHDS 2 Pilot(7) and the QUANTUM(16) project. Ongoing engagement with key stakeholders will be central to the entire programme of work and help ensure that all outputs meet the needs of the public, data holders, data users and HDAB staff.

As outlined in the HealthData@IE grant agreement, the specific objectives of Work Package 2 are to:

- raise awareness among the public, data holders and data users of the Health Data Access Body function and responsibilities
- conduct training initiatives and orchestrate support initiatives for Health Data Access Body staff, data holders and data users.

The milestones and deliverables associated with Work Package 2 are listed in Appendix 2. A significant feature of Work Package 2 is that it is a horizontal work package linked to activities across all work packages in the HealthData@IE grant (see Figure 2). Therefore, stakeholders of Work Package 2 include those involved in other work packages. This strategic Engagement and Education plan is to be submitted to the EU in October 2024 (month 12 of the grant) and a final plan along with a final report are due to be submitted in October 2027 (month 48).

Figure 2 Overview of the work packages of the HealthData@IE grant



1.4 Stakeholder analysis and target audience

In order to gain an understanding of the needs of the public and professional groups, a stakeholder analysis was completed to identify the target audience for engagement, dissemination, education and training methods and materials. A stakeholder is any individual, organisation or community with a direct interest in the delivery of the objectives of the work package. The stakeholders have an identifiable interest in different aspects of the work, such as the project's governance, the engagement and dissemination methods and materials used, the content of the training and educational resources being developed or the project's outputs and outcomes. For Work Package 2, the contributions of stakeholders are crucial and necessary for the successful development, implementation and embedding of engagement, dissemination and training tools, resources and activities.

The target audience for the engagement and dissemination methods and materials include the general public, patients, health and social care professionals and other relevant stakeholders such as researchers, government organisations and service providers.

The target audience for the education and training methods and materials include relevant professional groups, with a specific focus on data users, data holders and staff of a HDAB.

1.4.1 The public and patients

Widespread engagement campaigns will be conducted with the general public and patients. This includes engagement and dissemination campaigns with groups including:

- advocacy groups
- patient representative groups
- voluntary and community groups
- ethnic minorities
- the traveller community
- the disability community
- patients
- the LGBTQIA+ community.

1.4.2 Health and social care professionals

Widespread engagement and awareness campaigns will be conducted across a wide range of professionals within the health and social care sector. In addition, there will be targeted awareness and training campaigns aimed at specific groups of professionals. The establishment of HDAB services will directly impact data holders, data users and HDAB staff and they will be the focus of targeted campaigns.

While specific engagement activities with data users, data holders and HDAB staff are a key priority, other professional groups referenced in the HealthData@IE grant agreement will also be addressed. These include service providers, policy makers, public bodies, government organisations, researchers, industry and technical experts. As Work Package 2 operates in a horizontal manner across the larger project, stakeholders of this work package include the professionals involved in the other work packages associated with this project.

Professional needs are centred on the different stakeholder groups obtaining a solid understanding of the system, including the functions and responsibilities of the HDAB. The need for training in data management is also highlighted in the *National Engagement on Digital Health and Social Care*.(11) Guidance is required to ensure better information management to enhance the generation of good quality data and standardised information governance practices to support HDAB services.

2. Evidence that informed development of this plan

This strategic plan was informed by the HealthData@IE grant agreement, national and international evidence, other associated EU projects, information from EU Communities of Practice associated with the HealthData@EU project and through consultation with the Work Package 2 Working Group, which included key stakeholders.

2.1 National evidence

Engagement with the public, health and social care professionals and other stakeholders in relation to health information, is an essential element of building trust and ensuring that new developments in this area progress successfully. As such, a key feature of Work Package 2 is effective public engagement. Failure to undertake effective engagement will undermine public trust, impacting on the successful implementation of health information initiatives.(10)

In an Irish context, this is supported by key findings and learnings from two HIQA reports, *National Public Engagement on Health Information* (2020-2021)(12) and the *National Engagement on Digital Health and Social Care* (2024); (11) a citizens' jury, conducted in 2021 by the Irish Platform for Patient Organisations, Science, and Industry (IPPOSI), in relation to health information; (17) and a report by EIT Health Ireland-UK's Think Tank, *Implementing the European Health Data Space*.(18) This research provides us with an evidence base to support both policy development and implementation. Findings have indicated that the public in Ireland have a desire for better engagement, enhanced transparency and control regarding how health information is used and shared.(11, 12) Respondents to HIQA's *National Public Engagement on Health Information (2020-2021)* viewed genuine engagement as an essential first step and noted that the focus must be realistic in terms of where change is possible.(12) This Irish research is outlined in more detail in the following sections.

2.1.1 National Public Engagement on Health Information (2020-2021)

HIQA, in partnership with the Department of Health and the Health Service Executive (HSE), published the results of the first *National Public Engagement on Health Information* in 2021.(12) Through a national telephone survey and focus groups, the public were asked to share their views on how their health information should be collected, used and shared and their opinions on the use of digital technologies in health and social care. The focus groups provided a deeper understanding of the survey findings and of some of the key issues and challenges faced by people who have specific health and social care needs.

In relation to the use of health information for direct patient care, some of the key findings were that respondents want to be able to access their own health information. People also want to be informed about who their health information will be shared with and for what purpose, and they want assurance that they will not be discriminated against as a result of sensitive information contained in their health records. In relation to the use of health information beyond the direct care of the patient, the findings indicated that people want to be informed about how their information will be used for purposes beyond their direct care.

In relation to digital records, people need assurances that appropriate safeguards are in place to keep their health information safe and secure and protect their right to privacy. People want to be able to access their own information via a patient portal, as they feel this would empower them to play a role in their own care. Many people would also like to be able to control who can see certain types of information that are considered more sensitive, such as information about mental health.

2.1.2 IPPOSI Citizens’ Jury on Access to Health Information (2021)

In April 2021, the Irish Platform for Patient Organisations, Science, and Industry (IPPOSI) undertook a citizens’ jury on the topic of access to health information in Ireland.(17) Overall, the jurors concluded that the sharing of health data for the improvement of patient care is a collective responsibility and ‘the right thing to do’. However, the importance of adopting a partnership approach with the public in all initiatives around the sharing of health data was emphasised as crucial to successful implementation. Further, the need for partnership with the public when developing any future legislation, regulation, policy or practice that informs how health information is to be managed was also stressed. Jurors also underlined the need for increased public awareness around health information access issues. They emphasised, in particular, that transparency and trust in everything from technology to processes to the reasons for collecting health information was essential.

2.1.3 National Engagement on Digital Health and Social Care (2024)

In 2024, HIQA, in partnership with the Department of Health and the HSE, published the findings from the *National Engagement on Digital Health and Social Care*.(19) Like the previous *National Public Engagement on Health Information*, the digital engagement was also a partnership with the Department of Health and the HSE. The aim of the project was to understand the opinions and attitudes of both the Irish public and professionals working in health and social care to the digitalisation of services.

The study was conducted in the context of EU targets and the Health Information Bill 2024, which pave the way for people having access to and control over their digital health records. The project comprised of a telephone survey with members of the public and a separate online survey with professionals working in health and social care. A number of focus groups were also held with members of the public, including representatives from minority groups, people who use disability services, as well as professionals working in health and social care.

The results showed that the public are ready to engage digitally to help manage their health and want to use their online health record for practical tasks to manage their health. Professionals think digital care is important to empower patients as partners on their health and social care journey but are concerned that some members of the public may not be ready to interact with them digitally. Professionals also highlighted areas that need to be addressed to support the provision of services and communicating digitally. The findings of this project provide evidence to inform the development and provision of digital health systems and services in Ireland. In particular, people want to see education, training and supports rolled out with any online health system. People also want assurances regarding data security which reinforces the importance of upholding people's rights regarding the collection, use and sharing of their information. IT skills and infrastructure were identified as potential challenges by both the public and professionals.

2.1.4 Implementing the European Health Data Space across Europe (2024)

A 2024 report by EIT Health's Think Tank, *Implementing the European Health Data Space Across Europe,* put forward a number of recommendations for the successful implementation of the EHDS.(18) The recommendations, which were informed by a series of 11 national roundtable discussions and one-to-one stakeholder interviews involving European and national leaders from healthcare, industry and academia, span six broad themes: Governance; Capacity and Skills; Resources and Funding; Data Quality; Awareness, Education and Communication. A number of recommendations emphasise the need for engagement with stakeholders. For example, one of the key recommendations under governance is the need for patient and citizen representation in EHDS governance bodies, including Ireland's Health Data Access Body, once established. The importance of transparency across secondary use for data subjects was also highlighted. Further recommendations include the need to empower citizens with digital tools to manage their own health and health data; and the need to adopt measures to enhance digital literacy among citizens.

2.2 European initiatives

The EU Joint Action, TEHDAS (2020-2023), produced 12 recommendations relating 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, a literature review of citizens' values and opinions on the secondary use of health data and stakeholder interviews and workshops conducted at EU and national levels in Belgium, France and the UK.(14) The recommendations fall under three themes: the data relationship, the power balance and a citizen-powered framework. Please refer to Appendix 3 for more detail.

The second Joint Action, TEHDAS2 (2024-2026),(15) is continuing preparations to enable the secondary use of health data in the EHDS. This includes addressing the gaps in infrastructure and data access services by developing necessary guidelines, technical specifications and tools. Stakeholder engagement in TEHDAS2 is centred on two work packages dedicated to communicating with and involving citizens and other stakeholders throughout the project.

The QUANTUM project,(16) which is underway until 2026, aims to create a common label system that can be used across Europe to report on the quality and utility of datasets. QUANTUM also places a strong emphasis on stakeholder engagement as two work packages focus on engagement and dissemination with the public and professionals regarding data quality. These examples of engagement and dissemination are relevant to this strategic plan in the context of the provision of HDAB services.

2.3 Review of international HDABs

An international review was completed to identify examples of good practice and key learnings from jurisdictions with established HDABs, or similar organisations, in place. The purpose of this review was to identify how to engage successfully with the public and professionals, which informed the strategic objectives of this plan. This included a desktop review as well as semi-structured interviews with key individuals from each of the jurisdictions reviewed. The five jurisdictions were: Finland, Belgium, France, Northern Ireland and New South Wales, Australia. Details of the relevant organisations in each jurisdiction are provided in the table below.

Table 1 Details of jurisdictions included in the international review

Jurisdiction	Relevant organisations
Finland	Findata
Belgium	Health Data Agency
France	Health Data Hub Directorate of Research, Studies, Evaluation and Statistics
Northern Ireland	Honest Broker Service Digital Health and Social Care Northern Ireland
New South Wales, Australia	Centre for Health Record Linkage (CHeReL) The Population Health Research Network

2.3.1 Summary of international review findings relating to engagement, dissemination, education and training

A summary of the key findings relating to engagement, dissemination, education and training is provided below. This includes other relevant projects and initiatives and examples of available guidance and educational resources.

Engagement

There were good 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 and public consultation in framework development. Examples of engagement included:

- Belgium: an online public consultation (2021-2022) under TEHDAS, on the ethical, legal and societal framework for the secondary use of health data.(20)
- Finland: the Finnish Innovation Fund examined citizens' attitudes towards secondary use of data for the wellbeing of the Finnish population. The findings indicated that citizens have a high level of trust in their healthcare system authorities(21) but want to have the power to influence how their data is collected and used.(22)
- France: the Health Data Hub held community events including the 2023 Secondary School Engagement Project, which aimed to help young people understand the subject of secondary data.(23)
- Northern Ireland: the Northern Ireland Public Data Panel (NIPDP)(24) facilitated conversations with the public on data use in research, innovation, service delivery and decision making. The panel members co-develop their outputs, with advice on how to garner public trust, create transparency and build acceptance.
- Australia: in 2018, the Department of Health held a public consultation on developing a framework to guide the secondary use of data in the pre-existing My Health Record (MHR) system.(25) Recommendations included stronger engagement with Indigenous communities and citizen opportunity to consent to, or opt-out of, the use of their MHR data for secondary purposes.

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 countries were often due to structures within the specific country as well as the overall general level of trust in public systems.

Dissemination

There were a variety of dissemination methods and materials used across the reviewed jurisdictions. Dissemination in this context refers to informing the public about the services of a HDAB and the secondary uses of their heath 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 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 included short introductory videos on secondary use of data and HDAB services. The videos from the Northern Ireland Honest Broker Service(26) and the Belgian Health Data Agency(27) also focus on promoting public trust by emphasising how data is kept safe and secure. Other common materials aimed at the general public include infographics, information leaflets and webinars. 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 safety and securely.

Education and training

The organisations included in this international review have implemented a range of guidance and support tools. These include generic information resources published online, webinars, one-to-one consultation services and more targeted and advanced online modules. At a minimum, such training and resources usually include training in relation to privacy, information governance and GDPR. In Belgium, for example, the Health Data Academy(28) is an online platform which acts as a central location for hosting learning materials and initiatives for data holders, data users and citizens. The available courses aim to increase data literacy and related skills and practices. The French Health Data Hub(29) hosts a 'Meetup' online forum with over 3000 members. Through this forum, the Health Data Hub organises regular meetings to discuss current projects. There are also toolkits providing information on anonymisation and pseudonymisation of data, regulatory procedures, accessing health data in France and how to inform the public about the processing of their personal data. The Northern Irish Honest Broker Services (HBS) website also offers general resources and training.(26) To access data through the HBS, researchers are first required to complete Safe Researcher Training through the Office for National Statistics.(30)

Provision of support

In addition to providing training and support resources, all reviewed jurisdictions facilitate ongoing support for data users and data holders. In Finland, Findata provides one-to-one support(31) for both data holders and data users. It also hosts regular information sessions and application clinics(32) to support data users in making data access applications. The French Health Data Hub also offers a number of supports to data holders and data users, including monthly webinars on various topics where data users and data holders can pose questions to experts.(33) The Northern Ireland Honest Broker Service supports data users and data holders on issues such as the application process, output checking and de-identifying data throughout their research project.(34) The CHeReL in New South Wales, Australia also offers a webinar series for researchers on Clinical Trials and Data Linkage which provides guidance on navigating its access and approval processes.(35)

2.3.2 Key findings

The key finding from this international review that we have brought forward into this strategy is that meaningful engagement is central to the success of HDAB services, particularly in relation to building public trust. In addition, the dissemination, education and training methods used are broad and varied, reflecting both widespread and targeted engagement practices. Many jurisdictions provide a range of services, supports and tools that reflect the varying needs of the public and professionals involved. While engagement with, and dissemination to, stakeholders were common across all jurisdictions, the timing, level and topics of engagement and dissemination have varied. There were also differences in how education and training were approached. Some jurisdictions have developed more training and education training materials than others. The desktop review did not indicate one best practice model for establishing a HDAB or best practice approaches to dissemination, engagement, training and education in relation to HDABs and the secondary use of health data. However, good examples were observed across jurisdictions which, together with stakeholder feedback, will inform the execution of this strategic plan.

3. Strategic objectives

3.1 Strategic objective 1: Engagement framework

Engage with the public, health and social care professionals and relevant stakeholders on how health information is collected, used and shared for secondary use through a Health Data Access Body

Definition of engagement

In this context, 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.

Purpose

The purpose of this strategic objective is to engage effectively and meaningfully with the public and professionals on changes to how health information is collected, used and shared. This will be achieved by involving the public in a number of ways as detailed in Table 2 below. As noted previously, Ireland does not currently have a HDAB and so this concept is new for all. Therefore, a well-planned strategy is required to use engagement as a tool to inform, educate, consult, involve, collaborate with and empower the public and professional groups in terms of the governance and operation of a HDAB. Coordinated and ongoing public and professional engagement is a critical factor in building trust. In addition, transparency, confidence and integrity must be at the centre of any decisions around the use and sharing of health and social care data.(12) The work of this objective in relation to strategic public engagement will underpin the outputs of all work packages within this grant. This work will also be informed by the establishment and ongoing engagement with the Public and Patient Involvement (PPI) panel, which has been established to ensure that the public voice is central to the process of engaging and disseminating information and raising awareness about the functions of the HDAB to the public.

Engagement activities

The engagement activities will be co-created based on evidence-based methods, including the Gunning Principles(13) and Universal Design.(36) There will be a strong emphasis on engagement with the public throughout the lifetime of the grant. To ensure regular and consistent interaction between data users, data holders and

HDAB staff, the services offered by the HDAB will be promoted through proper training, promotion and communication activities. This will include promotion and communication activities of the project work to support full engagement by key professional groups.

Table 2 Strategic Objective 1 - Actions and proposed activities

Item	Action	Proposed activities	Timeline
1	Develop a targeted stakeholder engagement plan	▪ Identify and prioritise key stakeholders including the public, patients, health and social care professionals, health and social care management, academics, and industry. ▪ Collaborate with relevant organisations and convene a Working Group to provide expert advice and input on the development of engagement, dissemination, training and education activities.	April 2024 – October 2024
2	Establish, and work in partnership with, a PPI panel to inform engagement and education activities	▪ Undertake an evidence review of best practice in PPI panel establishment ▪ Recruit members of the PPI panel ▪ Co-create a work plan for the PPI panel, aligning with grant objectives and outputs, to identify what is required for the public in terms of engagement, dissemination, education and training in relation to the establishment of HDAB services ▪ Evaluate the impact of the PPI panel ▪ Publish an academic paper on the establishment of a PPI panel to support the evidence base on protocols and evaluation of such panels.	October 2024 (panel established) October 2024 - October 2027
3	Engage with the general public and patients	▪ Undertake a widespread engagement campaign to: - determine what the current level of public knowledge and trust is in relation to the secondary use of health data and the functions and benefits of a HDAB for Ireland - ensure that the public are central to the transformational change in the collection, use and sharing of health data in Ireland ▪ The engagement campaign will be achieved through:	October 2024 - October 2027

		- ongoing engagement with the PPI panel - co-development of resources that help the public and patients understand these changes to the secondary use of health data and the establishment of HDAB services - engagement with targeted stakeholder groups, including people who use services and special interest groups, through focus groups and interviews to understand how their needs and preferences can be recognised and integrated into all decisions around the secondary use of health data - opportunities for the public and patients to discuss the changes to how health information will be collected, used and shared and how they may contribute to how HDAB services are developed - social media channels - attending and or hosting events, such as conferences or seminars, to create opportunities to engage with members of the public.	
4	Engage with data holders, data users and HDAB staff	▪ Carry out specific engagement campaigns with target audiences including data users, data holders and potential HDAB staff to determine the current level of knowledge and trust in relation to the secondary use of health data and the role and function of a HDAB. This will include: - one-to-one meetings - focus groups - engagement through social media channels - attending and or hosting events, such as conferences or seminars, to create opportunities to engage with data users, data holders and HDAB staff.	October 2024 - October 2027
5	Engage with health and social care professionals	▪ Carry out specific engagement campaigns with target audiences including health and social care professionals, academic institutions and professional bodies to determine	October 2024-October 2027

		the current level of knowledge and trust in relation to the secondary use of health data and on the role and function of a HDAB including: - one-to-one meetings - focus groups - engagement through social media channels - attending and or hosting events, such as conferences or seminars, to create opportunities to engage with health and social care professionals.	
6	Engage with key international experts to inform and support Ireland's engagement activities and the establishment of a HDAB in Ireland	▪ Consult and actively collaborate with international partners through the EHDS Communities of Practice ▪ Conduct a desktop review of international HDABs ▪ Carry out semi-structured interviews with partners in international HDABs ▪ Publish an international review of HDABs ▪ Apply the TEHDAS Joint Action citizen engagement recommendations to materials produced ▪ Consult international peers working on TEHDAS2 for guidance and recommendations on engagement activities.	April 2024 – October 2027
7	Publish a report to inform future engagement activities that will be required of a HDAB, once established	▪ Use the learnings from engagement activities conducted as part of the project to develop a guidance report that will inform how the future HDAB should engage with stakeholders on an ongoing basis, once established ▪ Conduct specific workshops with the public to help co-develop the guidance report on future meaningful engagement including how the public and patients may be represented at institutional, regional and national level in HDAB services and policy development.	October 2027

3.2 Strategic objective 2: Dissemination

Undertake a targeted dissemination campaign to raise awareness amongst the public, data holders and data users of the HDAB function and responsibilities

Definition of dissemination

Dissemination refers to informing the public about the services of a HDAB and the secondary uses of their heath 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 sets.

Purpose

The purpose of the targeted dissemination campaign is to raise awareness of the secondary use of health-related data and the establishment of HDAB services in Ireland. This will be achieved through the co-creation of materials, with the PPI panel, that clearly communicate the functions and responsibilities of a HDAB; and the dissemination of these materials to relevant stakeholder groups.

Dissemination activities

The development of dissemination materials, in conjunction with the PPI panel, will be an important piece of work in ensuring early and ongoing engagement with the public. It will also help ensure that dissemination methods will take into consideration the needs of the different stakeholder groups. Information may be distributed using a variety of avenues. These include use of media (for example, websites, news outlets, newsletters, social media and so on), materials (for example, leaflets, posters, reports, articles, press releases and so on), digital platforms such as portals, and events such as conferences or workshops.

In the context of the EHDS, Ireland is required to develop HDABs whose responsibilities include facilitating the secondary use of health data for research, innovation and policy-making. The EHDS legislation also addresses primary use of health data to empower patients to access their health data in an electronic format, via electronic health records (EHRs). To meet this 2030 target, Ireland is also actively developing EHRs as set out in the Department of Health's *Digital for Care: A Digital Health Framework for Ireland 2024-2030*. (37) Given that health data shared for secondary use will largely be collected by personal health records, it will be important to consider synergy in information dissemination campaigns related to the primary and secondary use of health data.

Table 3 Strategic Objective 2 - Actions and proposed activities

Item	Action	Proposed activities	Timeline
1	Develop dissemination activities and materials for the general public and patients	▪ Engage in dissemination activities to raise awareness amongst the public of the secondary use of health data and the services and responsibilities of the HDAB. These activities include the development of dissemination materials such as a website that has a landing page with general information on what the secondary use of health data means for the general public and patients, as well as the role of the HDAB services. This website will also include audio-visual materials, newsletters, press releases and information leaflets that will be freely accessible. ▪ The dissemination activities will also consider the use of various social media platforms in order to communicate with a broad range of people on the secondary use of health data and the role of HDAB services in their lives. ▪ All materials will be adapted to meet the health data literacy needs of the target audience.	October 2024 – October 2027
2	Develop dissemination activities and materials for health and social care professionals and other stakeholders	▪ The focus of dissemination activities and materials for health and social care professionals and other stakeholders including academic institutions and professional bodies will be to raise awareness and demand of the services provided by the HDAB. ▪ These activities and materials will include:	October 2024 – October 2027

		- guides and resources on accessing, managing and sharing data safely and securely, targeted at data users, data holders and potential HDAB staff - content on good information management in relation to the HDAB, the generation of good quality data and standardised information governance practices - the use of a website, videos, news outlets, newsletters, press releases, academic articles, leaflets, posters and reports focusing on the secondary use of health data and the role of HDAB services in an Irish context - the development of materials for dissemination to professional bodies and service providers such as the HSE and general practitioners (GPs) - hosting and recording webinars for data users and holders on how they may use a HDAB service - dissemination of materials and information through social media channels - presenting at conferences such as: ○ Future Health Summit ○ National Office for Clinical Audit (NOCA) annual conference ○ National Patient Safety Office (NPSO) annual conference ○ Smart Health Summit ○ Relevant international conferences.	
3	Develop and implement a national Dissemination, Education and Training Portal	▪ Complete a tendering process for sub-contractors to design an online portal ▪ Together with the PPI Panel and Work Package 2 Working Group, collaborate with software developers to design the online portal	October 2024 – October 2027

		- Incorporate lessons learned from the development of HDAB portals in other countries ▪ Undertake user testing ▪ Share feedback with software developers to incorporate revisions ▪ Commence the upload of dissemination, training and education materials to the portal ▪ Incorporate a Data Quality online peer-to-peer support network ▪ Launch online portal ▪ Incorporate lessons learned from the development of the portal into all output reports.	

3.3 Strategic objective 3: Education and training needs

Identify the specific education and training needs of data holders, data users and Health Data Access Body staff regarding the HDAB function and responsibilities

Definition of education and training

In this context, education and training refers to all targeted capacity building and resources involved to increase knowledge and awareness of HDAB services in Ireland for different audiences, particularly data users, data holders and future HDAB staff.

Purpose

The purpose of identifying the specific education and training needs of various stakeholder groups is to identify the gaps in knowledge and expertise relating to HDABs. It will also help prioritise the training needs of different stakeholder groups. The identified gaps in knowledge and expertise will inform the development of relevant guidance and training materials.

Training Needs Analysis

The specific education and training needs of data holders, data users and HDAB staff will be identified through a detailed training needs analysis programme of work.

Table 4 Strategic Objective 3 - Actions and proposed activities

Item	Action	Proposed activities	Timeline
1	Design training needs analysis for data holders, data users and HDAB staff	▪ Create training needs analyses for each stakeholder group, including data holders, data users and HDAB staff, guided by the: - TEHDAS2 common guidelines and technical specifications - advice of the Working Group and PPI panel.	October 2024 - April 2025
2	Conduct training needs analysis for data holders, data users and HDAB staff	▪ Carry out the training needs analyses based on topics including: - understanding the HDAB system - identifying gaps in knowledge and awareness of the secondary use of data and functions of the services provided by a HDAB - granting or gaining access to data - identifying gaps in knowledge and expertise related to data quality - other specialist training requirements identified by data holders, data users and potential HDAB staff.	April 2025 – October 2025
3	Report on results of training needs analyses	▪ Develop a report on the results of the training needs analyses ▪ Use the results of the training needs analyses to inform education and training initiatives ▪ Incorporate lessons learned from the development, implementation and results of the training needs analyses into the Dissemination, Education and Training Monitoring Report on completion of the project.	October 2025 – December 2025

3.4 Strategic objective 4: Education and training initiatives

Develop education and training initiatives to support data holders, data users and Health Data Access Body staff with regard to the HDAB function and responsibilities in Ireland

Definition of education and training

In this context, education and training refers to all targeted capacity building and resources involved to increase knowledge and awareness of HDAB services in Ireland for different audiences, particularly data users, data holders and future HDAB staff.

Purpose

The purpose of education and training initiatives is to support HDAB staff, data holders and data users to grant or gain access to data and to obtain a solid understanding of the HDAB system.

Education and training initiatives

A standardised approach to education and training will be employed to ensure a consistent approach is followed. The project team will build on HIQA's experience in developing guidance and education materials in the area of health information, including *Guidance on a data quality framework for health and social care,*(38) *Guidance on information governance,*(39) and eLearning modules such as *Introduction to Data Quality*(40) and *Developing a data quality framework.*(41) An online portal will be developed in conjunction with other work packages to support the dissemination of education and training materials.

Implementation support tools

The development of implementation support tools will be informed by the findings of the training needs analysis. These implementation support tools will take into consideration media requirements and materials and resources such as e-learning modules, webinars, videos, as well as conferences and workshops. An online portal will be developed to host such guidance and training materials.

Table 5 Strategic Objective 4 - Actions and proposed activities

Item	Action	Proposed activities	Timeline
1	Develop general training and education materials for data holders, data users and HDAB staff, informed by training needs analyses	▪ Develop general materials, guidance and resources including eLearning modules, webinars, manuals, videos, conferences and workshops with a focus on secondary use of health data and the services provided by a HDAB, including: - good information management practices in key areas such as privacy and confidentiality - compliance with relevant legislation and codes of practice - data security and cyber awareness in relation to HDABs ▪ Review and pilot materials and resources by engaging with target audiences, the PPI panel and the Working Group - Conduct these reviews through video conferencing, email or in-person meetings ▪ Incorporate feedback into materials.	October 2025 – October 2027
2	Develop specialised training modules for data holders, data users and HDAB staff, informed by training needs analyses	▪ Develop specialised toolkits and topics in relation to the HDAB, such as: - informing the public about the processing of their personal data - data literacy, anonymisation and pseudonymisation - data access procedures - data linkage - data quality	October 2025 – October 2027

		▪ Align outputs with initiatives including the TEHDAS2 Joint Action, the EHDS Pilot and the QUANTUM project ▪ Review and pilot materials and resources by engaging with target audiences, the PPI panel and the Working Group - Conduct reviews through video conferencing, email or in-person meetings ▪ Incorporate feedback into materials.	
3	Develop and implement a national Dissemination, Education and Training Portal	▪ In line with Strategic Objective 2, item 3, complete a tendering process for sub-contractors to design an online portal ▪ Together with the PPI panel and Work Package 2 Working Group, collaborate with software developers to design the online portal - Incorporate lessons learned from international HDAB portal development ▪ Commence the upload of dissemination, training, and education materials ▪ Incorporate a Data Quality online peer-to-peer network ▪ Undertake user testing ▪ Share feedback with software developers to incorporate revisions ▪ Launch the online portal ▪ Incorporate lessons learned from the development of the portal into all output reports.	October 2024 – October 2027
4	Develop accessible materials and activities	▪ Develop dissemination, engagement, education and training materials and activities in line with the: - EU Web Accessibility Directive - European Accessibility Act 2025.	October 2025 – October 2027

5	Report on the development of education and training resources	▪ Incorporate lessons learned from the development of the education and training resources into the Dissemination, Education and Training Monitoring Report on completion of the project ▪ Develop a final Dissemination, Education and Training Plan to describe the follow-on strategic objectives to this initial plan.	October 2027

4. Methodology for implementation of the plan

To ensure they are evidence-based, the context and format of the engagement, dissemination, training and educational tools and materials being developed will be informed by an international review of practices and available resources in other jurisdictions (as outlined in Chapter 2). They will also be informed by extensive stakeholder engagement, which will include the convening of a Working Group, the establishment of a PPI panel, public consultation with key stakeholders and engagement with international experts.

4.1 Principles of effective engagement

In order to engage meaningfully with the public while achieving the strategic objectives of this plan, the principles of effective engagement will be informed by the International Association for Public Participation (IAP2) Spectrum of Public Participation model,(42) the Gunning principles,(13) Universal Design(36) and a human rights-based approach.(43, 44) A human rights-based approach can be defined as a conceptual framework for the promotion and protection of human rights based on international standards. The approach is underpinned by five key human rights principles: participation, accountability, non-discrimination and equality, empowerment and legality. Implementing a human rights-based approach ensures that the needs, voices, rights and protection of people are central to all engagement activities and outcomes.(43,44)

A HIQA report published in 2022 entitled '*Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland'*(13) outlines crucial elements required to be put in place to ensure effective engagement for Ireland's health information system. This includes ensuring that public engagement is informed by evidenced-based methods and frameworks such the IAP2 Spectrum of Public Participation,(42) which details the different approaches to engagement and participation and reflects the organisation's Code of Ethics and Core Values for the Practice of Public Participation. This includes that those who are affected by a decision have a right to be involved in the decision making process. The Spectrum of Public Participation describes five general modes of participation that fall on a progressive continuum of increasing public influence over decision-making in a civic engagement process. The five modes, which demonstrate increasing levels of shared decision-making authority, include to inform, to consult, to involve, to collaborate with and to empower.

The '*Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland'*(13) report also noted that respondents wished for public engagement to be based on the Gunning Principles(13) which are designed to make consultation fair and worthwhile. These include:

- consultation taking place when the proposal is still at a formative stage
- sufficient reasons being forwarded for the proposal to allow for intelligent considerations and response
- adequate time being given for consideration and response
- conscientiously taking into account the product of consultation.

In addition, respondents also noted that all groups of society must be included and that focus should be placed on improving basic digital and health literacy skills, where relevant, using a Universal Design approach.† This will ensure that all elements of the engagement are accessible to different groups and tailored to their needs.(45)

The evidence on engagement demonstrates the need to consult meaningfully with the public around digital developments in health.(11-13, 17) The development of a HDAB provides an opportunity to engage successfully and to apply the learnings from national public consultations.(11-13, 17) It is clear that evidence-based engagement, with transparent communication, is a key facilitator in successfully achieving the objectives of this project. When key stakeholder groups understand the HDAB developments, they are likely to be more accepting of change and the time involved to implement that change. Therefore, engagement must be undertaken in a meaningful and authentic way to build trust and confidence. This will ensure that new technologies and initiatives are implemented in a way that is socially acceptable. It is important to engage early and on an ongoing basis to ensure expectations are met and to support successful implementation of initiatives. Equally, it is important to learn from the challenges encountered by other countries.

4.2 Stakeholder engagement

To deliver on this strategic plan, a Stakeholder Engagement Plan has been developed in which a stakeholder has been identified as any individual, organisation, or community with a direct interest in the delivery of the objectives of the Work Package‡. With regard to the engagement, dissemination, education and training methods and materials developed, there are four main engagement strategies being utilised:

- Close collaboration with a Working Group
- Undertaking public consultation and involvement through a PPI panel
- Widespread and targeted engagement with key stakeholder groups
- Engagement with international experts.

[†] Universal Design involves the design of products, services, buildings and information and communications technology (ICT) so they are accessible to everybody regardless of age, size, ability, or disability.

[‡] Identified stakeholders are listed in Chapter 1.

4.2.1 Working Group

A Working Group has been convened to actively contribute to the successful and timely completion of key project milestones and deliverables through providing expert advice, reviewing and providing feedback on all project outputs and supporting stakeholder engagement at key stages. The group comprises representatives from the Health Service Executive (HSE), Department of Health, Central Statistics Office, Health Research Board (HRB), Child and Family Agency (Tusla), Irish Platform for Patients Organisations, Science & Industry (IPPOSI), EIT Health Ireland - UK and representatives from academia, as well as a representative of the HSE's National Patient and Service User Forum.

With regard to the development of engagement, dissemination, education and training methods and materials, the Working Group will:

- review and contribute to this Engagement and Education Strategic Plan
- input to proposals on the engagement and dissemination campaigns and targeted communication needed to raise awareness among identified stakeholders
- input to proposals on training and education requirements of identified stakeholders
- inform other Working Group members of research, programmes, activities, policies or other developments that may be relevant at a national and international level
- engage with stakeholders through identifying and recruiting relevant experts in the area to assist in the development and implementation of resources
- review and provide feedback on draft versions of the resources at key stages of the project
- assist in revising resources and developing an ongoing evaluation process ready for full implementation by the HDAB
- advise on further steps, including awareness and update of the tools
- contribute, where relevant, to peer-reviewed research in the area of health information, academic partnerships and international collaborations.

4.2.2 Patient and Public Involvement (PPI) Panel

The project team has established a Patient and Public Involvement (PPI) panel to ensure that the public voice is central to the process of engaging and disseminating information and raising awareness about the functions of the HDAB to the public. The project team underwent PPI training and undertook an evidence review to identify best practice in relation to establishing a PPI panel. This included extensive stakeholder mapping to help ensure a diversity of perspectives. The panel members were identified following an open call on the PPI Ignite Network Opportunities Noticeboard,(46) as well as promotion via Working Group members' networks. A draft Terms of Reference will be co-developed with the PPI panel. It is planned that the PPI panel will meet four times a year throughout the lifetime of this grant and will actively contribute to key engagement, dissemination, education and training methods and materials. This process will be evaluated and impact measures will be considered, as appropriate.

4.2.3 Widespread engagement and dissemination campaigns

A widespread awareness and engagement campaign, aimed at the general public and other stakeholders will be undertaken. The aim of the campaign is to increase awareness of the functions and wider benefits of a HDAB for Ireland. The widespread campaign will be evidence based and will be informed through consultation with the PPI panel and the Working Group. The campaign will involve developing materials such as websites, video, infographics, information leaflets and webinars.

4.2.4 Targeted engagement

Over the lifetime of the project, there will be additional opportunities to engage with stakeholders who have relevant experience and expertise. This will help inform the implementation of the Engagement and Education Strategic Plan. Such targeted forms of engagement will include one-to-one meetings or focus groups and other events, conferences or seminars. In addition, many advocacy bodies, national service providers, special interest groups and academic institutions host forums that may be relevant for the project team to attend or present at to raise awareness and create additional opportunities for engagement.

4.2.5 International engagement

Engagement with relevant international stakeholders will also take place to learn from their experiences and identify best practice. Engagement will take place through various routes such as the European Communities of Practice associated with the HealthData@EU project,(7) and stakeholders under the TEHDAS2(15) and QUANTUM(16) projects. Other groups may be identified over time as the project progresses. Engagement will also be determined based on the countries identified for inclusion in the international review.

4.3 Accessibility considerations

As part of the implementation of this strategic plan, materials will be developed to support engagement and training on the services of a HDAB. The development of these materials will take account of accessibility considerations and responsibilities under the EU Web Accessibility Directive.(47)

In addition, the European Accessibility Act will come into force in June 2025. It seeks to ensure equal access to digital products and services throughout Europe by harmonising accessibility standards for certain products and services. It will bring benefits to businesses, people with disabilities and older people. There will be specific accessibility requirements which will apply to all products and services covered by the legislation. This includes websites and other forms of archived content that are updated and edited after 28 June 2025.(48) The requirements of this European Accessibility Act will also be considered in the development and implementation of dissemination, education and training materials.

4.4 Monitoring

This strategic plan will be evaluated through meeting milestone and delivery deadlines as outlined in the grant agreement. It will be monitored during updates on the activities of Work Package 2 at the HIQA Grant Group monthly meetings. The overarching HealthData@IE project is overseen by the Grant Consortium Steering Committee. Updates on the activities of Work Package 2 will be provided to the Grant Consortium Steering Committee at the Committee's monthly meetings. The Working Group and PPI panel will also provide feedback and evaluation at key points throughout the lifetime of the grant.

5. Next Steps

The purpose of this strategic plan is to outline how the key milestones and deliverables set out under Work Package 2 of the grant will be met. In the current plan, Strategic Objectives 1 and 2 relate to the engagement and dissemination of information and materials to the general public, data users and data holders on the secondary use of health data and HDAB functions; while Strategic Objectives 3 and 4 relate to the training and education of data users, data holders and HDAB staff.

This strategic plan, which will be submitted to the EU in October 2024, is the first of three related deliverables on engagement, dissemination, education and training for key stakeholder groups, on the function and responsibilities of a Health Data Access Body (HDAB) in an Irish context. The final plan and report, both due at the end of this grant (October 2027), will provide details on how the priority tasks were achieved. The final plan and report will also provide recommendations on the future engagement, dissemination, education and training needs of key stakeholders. This will help to ensure the ongoing sustainability of the services of a HDAB and will enable Ireland to meet its obligations under the EHDS for the benefit of the general public, health professionals, researchers, regulators and policy-makers in relation to health and health care in Ireland.

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7. Appendices

Appendix 1 – HealthData@IE Project Work Packages

Work Package Number	**Work Package Name**	**Lead**
WP1	Management and Coordination	Department of Health
WP2	**Dissemination, Training and Support**	**HIQA**
WP3	Evaluation	Department of Health
WP4	Sustainability	Department of Health
WP5	Data Access Applications Management Solution (DAAMS)	Department of Health
WP6	**National Dataset Catalogue for Health Data**	**HIQA**
WP7	Secure Processing Environment	Department of Health
WP8	**Health Data Quality Enhancement**	**HIQA**

Appendix 2 – WP2 Milestones and Deliverables

No	**Milestones**	**No**	**Deliverables**
MS 4	Dissemination Campaign 1: Establish PPI panel (Month 12 – Oct 24)	**D2.1**	Dissemination, Training and Education Plan 1 (Month 12 – Oct 24)
MS 5	Dissemination Campaign 2: Execute engagement plan (Month 24 – Oct 25)	**D2.2**	Dissemination, Training and Education Plan 2 (Month 48 – Oct 27)
MS 6	Dissemination Campaign 3: Publish guidance on effective engagement (Month 48 – Oct 27)	**D2.3**	Dissemination, Education and Training Portal 1 (Month 18 – Apr 25)
MS 7	Training and Education Material: Availability of the training material and courses in the form of guidelines, instructions, manuals (Month 48 – Oct 27)	**D2.4**	Dissemination, Education and Training Portal 2 (Month 33 – June 26)
		D2.5	Dissemination, Education and Training Portal 3 (Month 39 – Dec 26)
		D2.6	Dissemination, Education and Training Portal 4 (Month 48 – Oct 27)
		D2.7	Dissemination, Education and Training Monitoring Report (Month 48 – Oct 27)

Appendix 3 – TEHDAS Recommendations relating to citizen engagement

TEHDAS (2020-2023)

The EU Joint Action, TEHDAS (2020-2023), produced 12 recommendations relating 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, a literature review of citizens' values and opinions on the secondary use of health data and stakeholder interviews and workshops conducted at EU and national levels in Belgium, France and the UK.(14) The recommendations fall under three themes: the data relationship, the power balance and a citizen-powered framework.

The data relationship

1. Citizens recommend being able to access information about the secondary use of health data in an understandable way.
2. Citizens recommend having access to their data and knowledge about how it is used for secondary purposes. However, citizens want to choose how and when they are informed about the uses of their data.
3. Citizens recommend that their values should inform what is beneficial to individuals and what constitutes the common good.
4. Citizens recommend that decision-making processes rely on a plurality of views and actors to increase the trustworthiness of those processes.
5. Citizens recommend being 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 recommend being 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. Citizens recommend ensuring the protection of individuals' identity, which they perceive as one of the best ways to balance the harms and benefits of the secondary use of health data.
8. Citizens recommend that data users' intentions should be transparent and in line with purposed citizens' support.
9. Citizens recommend that accountability could be enhanced through transparent and stronger mechanisms.
10. Citizens recommend fostering good IT solutions to protect their data, beyond having a strong legal framework in place.

A citizen-powered framework

11. Citizen recommend that stakeholders respect principles that align with citizens’ ethical values.
12. Citizen 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.

Appendix 4 – Work Package 2 Working Group Membership

Name	**Organisation - Title**
Barbara Foley (Chair)	Health Information and Quality Authority (HIQA) - *Deputy Director – Health Information Quality & Assurance*
Bernard Barrett	Child and Family Agency (Tusla) - *National Research and Information Specialist*
Billy McCann	Health Service Executive (HSE) National Patient Forum - *Patient Representative*
Brendan Brady	Department of Health, Health Information Policy Unit - *Data Officer & Health Literacy Policy Lead*
Ciara Coveney	HSE – *Advanced Midwife Practitioner*
Denise Manton	EMPOWER Data Governance (Maynooth University) – *Executive Director*
Derick Mitchell	Irish Platform for Patients Organisations, Science and Industry (IPPOSI) - *CEO*
Elaine Murray	European Institute of Innovation and Technology (EIT) Health, Ireland-UK - *Public Affairs Lead*
Gavin Lawler	Health Research Board (HRB), Research and Innovation Infrastructures Research Strategy and Funding Directorate *- Programme Manager*
Ken Moore	Central Statistics Office (CSO), Quality Management, Support & Assurance Division *- Senior Statistician*
Leah Dowdall	Department of Health, Health Information Policy Unit - *Assistant Principal Officer*
Marie Higgins	HIQA - *Acting Programme Manager, Health Information Quality & Assurance*
Tina Bedenik	Royal College of Surgeons in Ireland (RCSI), Data Science Centre, School of Population Health - *Postdoctoral fellow*
Thelma Pentony	HSE - *Training Manager, Business Operations*
Sheila Fitzgerald	IPPOSI - *Patient Representative*

Appendix 5 – HIQA internal project oversight group members

Name	Role
Rachel Flynn (Chair)	Director – Health Information & Standards
Barbara Foley	Deputy Director – Health Information Quality & Assurance
Deirdre Connolly	Acting Deputy Director – Health Information Standards
Elaine Meehan	Acting Programme Manager (Work Package 8)
Kevin O'Carroll	Standards and Technology Manager
Marie Higgins	Acting Programme Manager (Work Package 2)
Suzanne Barror	Health Information Quality Manager (Work Package 6)

Appendix 6 – HIQA Project Team

Name	Role
Chloe Walsh	Research Officer
Joanne Fallon	Senior Business Analyst
Marie Higgins	Acting Programme Manager

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