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Personal health data systems in OECD countries: Insights into structures and solutions for public access and use

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Abstract

Personal health data (PHD) are transforming how individuals engage with health systems, creating new opportunities for trust, innovation, and improving access and quality of care. This report examines how OECD countries enable individuals to access, manage, and share their health information across digital platforms and patient portals. Drawing from in-depth interviews with national authorities in Australia, Denmark, Finland, Japan, Korea, and the United Kingdom, the paper analyses policy, technical, and governance enablers that underpin equitable access to personal health data. It identifies leading practices in interoperability, data architecture, privacy, consent, digital identity, and patient engagement. Countries with mature ecosystems demonstrated consistent public trust frameworks, integration across sectors, and strong legislative foundations balancing privacy with data interoperability and sharing. As healthcare becomes increasingly digital and the availability of patient-generated data grows, ensuring that individuals can securely access and use their own health data will be critical for future-ready, data-driven, and person-centred health systems.

Résumé

Les données personnelles de santé (DPS) transforment la manière dont les individus interagissent avec les systèmes de santé, créant de nouvelles opportunités en matière de confiance, d'innovation et d'amélioration de l'accès et de la qualité des soins. Ce rapport examine comment les pays de l'OCDE permettent aux individus d'accéder, de gérer (SPACE) et de partager leurs données de santé sur les plateformes numériques et les portails destinés aux patients. S'appuyant sur des entretiens approfondis avec les autorités nationales en Australie, au Danemark, en Finlande, au Japon, en Corée et au Royaume-Uni, le document analyse les facteurs politiques, techniques et de gouvernance qui sous-tendent l'accès équitable aux données personnelles de santé. Il identifie les pratiques de pointe en matière d'interopérabilité, d'architecture des données, de confidentialité, de consentement, d'identité numérique et d'engagement des patients. Les pays dotés d'écosystèmes matures ont démontré des cadres cohérents de confiance publique, une intégration intersectorielle et des bases législatives solides qui équilibrent la confidentialité avec l'interopérabilité et le partage des données. À mesure que les soins de santé se numérisent et que la disponibilité des données générées par les patients augmente, il sera essentiel de garantir que les individus puissent accéder et utiliser leurs propres données de santé en toute sécurité pour mettre en place des systèmes de santé tournés vers l'avenir, axés sur les données et centrés sur la personne.

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Executive Summary

The availability and use of **Personal Health Data (PHD)** is transforming how health systems deliver care, engage patients, and support system-wide improvements. PHD includes a wide array of health information—from clinical records and prescriptions to patient-generated data—used not only in direct care but also to enhance population health management, research, and digital innovation. This work explores how five countries [**Australia, Denmark, Finland, Japan**, and the **United Kingdom (England)**] have established systems to enable access to and use of PHD and identifies leading practices in the establishment and governance of this data.

The global landscape is marked by diversity in digital maturity and system design. Countries face common challenges in the implementation and use of PHD, including fragmented governance frameworks, legacy health IT systems, and inconsistent data standards. In addition, safeguarding patient privacy while facilitating meaningful access requires finely tuned consent models (or appropriate alternatives) and robust data security measures. The integration of PHD into daily healthcare practices often places additional burdens on providers, who may face workflow disruptions and concerns about liability for improper data use or practices. Meanwhile, barriers such as low digital literacy, trust deficits, and uneven connectivity limit patient engagement and the equitable use of digital tools. These challenges highlight that simply digitising health information for patients and providers is not sufficient—comprehensive governance, infrastructure, and engagement strategies are essential to realising the full potential of PHD.

This review finds important lessons in the approaches taken by peer countries. Each of the five countries studied has developed unique institutional, legal, and technical responses to PHD governance:

- **Australia** has anchored its PHD strategy in My Health Record (MHR), supported by foundational legislation and shifting toward mandatory data sharing through new laws (*Modernising My Health Record [Sharing by Default] Act 2025*), FHIR-based[1] infrastructure upgrades, and national initiatives for interoperability (e.g. Australia Clinical Data for Interoperability [AUCDI]). The aim of these foundational upgrades to personal health data governance will assist in improving the completeness and consistency of data available in MHR.
- **Denmark** offers a mature, integrated model through Sundhed.dk, built on a long-standing culture of transparency, national patient identifiers, and real-time access to structured data across care settings. It benefits from fully digitised national infrastructure, with registries dating back to 1977. Mandatory MedCom-certified standards ensures that citizens can access nearly their entire longitudinal record.
- **Finland** has established MyKanta, a centralised health data portal backed by robust legislation and governance, with strong performance in interoperability, equity, and data integration. Coverage is near-universal due to mandatory reporting to Kanta Services, and recent reforms under the 2024 Client Data Act are preparing the system for broader Personal Health Record (PHR) functionality, including the structured incorporation of wellbeing and wearable data.

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[1] Fast Healthcare Interoperability Resources or FHIR (HL7-FHIR) is a standard for the secure exchange of electronic healthcare data, developed by the Health Level Seven (HL7) healthcare standards organisation.

- **Japan** is advancing rapidly through Mynaportal, linked to national ID cards and aligned with a broader Healthcare Digital Transformation (DX) strategy that emphasises interoperability and cross-sectoral integration. New FHIR-based electronic medical chart services, currently in pilot, will enable patients to view referrals, prescriptions, and test results through Mynaportal, forming the first nationally standardised clinical dataset ahead of full rollout by 2030.
- **England** relies on the National Health Service (NHS) App as a gateway for patient access to primary and increasingly secondary care data, supported by national governance and investment in standards and digital infrastructure. The app now draws structured data from nearly all NHS Trusts and general practices, and current reforms aim to require suppliers to open data in standardised formats in support of ongoing developments for a future universal Personal Health Record.

Through interviews and research, several leading practices emerged that significantly contributed to the development, facilitation, and scalability of secure, inclusive personal health data systems. These include key governance foundations, robust legislative frameworks, prioritising interoperability, and patient and provider engagement. The leading practices include:

Governance

- **Establish a health data authority**, supported by legislation, that can enact a robust health data governance framework to promote the protection and responsible use of PHD, as well as the regulatory mandate to drive the common use of standards, data reporting and sharing, and compliance across health data offices, providers, private sector, and other key stakeholders.
- **Coordinate** with vendors, especially electronic health/medical record (EHR/EMR) system providers, and the public through public/private partnerships for requirements to share and protect information so that systems are integrated into the national data infrastructure.

Personal Health Data

- Mandate **comprehensive and standardised data contributions** to allow integration between various data sources (e.g. EHRs and EMRs) across the country, bringing them together with common definitions and standards in the patient PHD platform.
- **Enhance data timeliness and integration** by developing regulatory frameworks that mandate all healthcare providers, including private sector entities, to contribute standardised, structured data to national patient health records (PHRs) and patient-accessible portals. Encourage the use of HL7 FHIR or equivalent standards to ensure interoperability and usability of data across systems.

Data Infrastructure and Architecture

- Use **open by design systems** (where data are available and protected) which establish common standards for health information system vendors and developers, ensuring the ability to seamlessly integrate new and existing technology to create an integrated data infrastructure.
- Utilise **decentralised data storage** models where data remains in the source systems and is brought into the patient PHD platform through application programming interfaces (APIs). This allows for the data to be shared in a timely manner, ensure it remains up to date, and reduces the storage requirements for the patient PHD platform.

Provider Perspectives

- **Complete sharing of patient records** in the patient-accessible EHR (PaEHR), PHR, and/or patient portal to enable full transparency for patients into their own PHD. Be clear on exceptions, with the direction of providers, if the sharing of the data is deemed harmful and/or concerning for the patient’s care.

- **Engage and support processes for healthcare providers** to effectively use the PHD platform and to best support patients. Healthcare providers are key stakeholders, and a comprehensive approach which engages them in the decision making and requirements process, deployment, and ongoing operational use of the platform are key to ensure continued use and to establish the patient as a partner in their care.

Patient Perspectives

- **Be transparent in data access, consent, and use** by health professionals to obtain patient trust and engagement in their care. Sharing this level of information allows patients to better understand how their data is being used and for what purposes, demonstrating transparency and openness between patients and healthcare providers.
- **Enable contribution** of patient generated health data in a national PHR, allowing more usage and ongoing data collected outside of the regular clinical encounters to be incorporated into health and wellness management for patients.

The findings underscore the importance of designing an integrated system that balances coordination, accessibility, security, and trust. As health systems become increasingly digital, establishing personal health data systems that are scalable, transparent, and secure lays the foundation for person-centred healthcare. These leading practices complement the implementation priorities of ongoing international efforts, like the European Health Data Space (EHDS), and OECD country efforts, like Korea's 'My Data' and 'My HealthWay' initiatives. By learning from international experience, OECD countries can better prioritise their development of PHD systems to best fit national needs and align globally in the development of people-centred digital health systems.

1 Introduction

1. **Personal Health Data (PHD)** encompasses any information related to an individual's physical or mental health, spanning clinical records, diagnostic results, medication histories, and self-reported or device-generated health metrics (European Parliament, 2016[1]). As health systems continue to digitalise, PHD serves multiple purposes, from facilitating direct patient care and providing patients ownership over their health information and choices, to enabling population health management, research, and policy development.

2. These functionalities and organisation of health data only became possible as countries embarked on digital transformation of health systems, often with varying and even domestically diverse digital maturities. Establishing the governance and data architecture to enable PHD from existing digital health infrastructures can be complex. Korea is currently undergoing this process with its *My Healthway* initiative which seeks to generate a **Personal Health Record (PHR)** for patients to view and interact with. The Ministry of Health and Welfare (MOHW) of Korea has tasked the OECD to understand how peer countries [Australia, Denmark, Finland, Japan, and the United Kingdom (England)] have set up the capabilities for Personal Health Data use and access and draw best practices and recommendations for their implementation.

Background

3. The global digital health landscape is marked by increasing demands for accessible, integrated, and secure personal health information systems. Leading OECD countries have recognized the transformative potential of PHD in achieving better health outcomes, supporting patient engagement, patient empowerment, and advancing equity through investing in its infrastructure.

4. The evolution of health information systems has been integral to the advancement of healthcare delivery and patient management. The advent of electronic health records (EHRs) in the latter half of the 20th century from paper records marked a significant shift towards digitisation, enabling more efficient data storage and retrieval. However, OECD countries varied in their approach and coordination of digital transformation, resulting in a wide range of governance structures and health data infrastructures from which to pull information from. The introduction of open record access for patients was no exception, which has been provided through a number of different health information systems for patients (see Box 1.1 for more details).

Box 1.1. Personal Health Data and Patient Access

Personal Health Data (PHD) encompasses any information related to an individual's physical or mental health and can include:

- Allergies and adverse reactions
- Demographic information: patient statistics and clinical data
- Documents: scanned documents, shared images
- Evolution: care plan, clinical notes
- Family history
- General patient information: registration information, emergency contacts
- Home-monitored data
- Immunisations: vaccine records, immunisation history
- Insurance: coverage information, related coding for billing
- Laboratory results: lab and imaging test results
- Major illnesses
- Medications and current / previous prescriptions
- Preventive health recommendations
- Previous healthcare providers
- Scheduling: appointments, past procedures, hospitalizations
- Social history, lifestyle, and health habits
- Summaries: admissions, permanencies, and discharges
- Vital signs and key data

PHD can be made accessible to patients to view, interact with, and in some cases, contribute to, through a few different health information technologies and distinctions in ownership of the PHD by the patient or healthcare provider.

- A **Patient Portal** is an online access website which provides patients with access a defined set of their PHD, generally from one health organisation or healthcare provider. The PHD is owned by the healthcare provider and the completeness of the information in a Patient Portal varies, but can encompass documentation, medications and prescriptions, immunisation records, and lab and diagnostic results. It can also enable patients to schedule appointments and message their healthcare providers (Irizarry, DeVito Dabbs and Curran, 2015[2]).
- A **Patient-accessible Electronic Health Record (PaEHR**) is a tool which provides patients with open access to their electronic health records. The records are owned by the healthcare providers, but patients have the ability to view the records, and in some cases, contribute and/or edit their PHD (Hägglund et al., 2024[3]**).**
- A **Personal Health Record (PHR)** is a patient managed tool, allowing individuals to maintain and share their health information. PHRs bring together PHD from multiple sources, including patient input to support patient self-management and better continuity of care. PHRs have been defined by literature since at least the late 1970s, which reflects a growing recognition of the importance of patient-centred care (Roehrs et al., 2017[4]).

The goal of open record access, through a PHR, or PaEHR, is to enable patients to have access and visibility of their own health data for their own uses, to enhance continuity and prevent duplication of care, or for use by care workers or trusted persons. The data held in the source EHRs and EMRs can vary in volume and sensitivity, which impacts how much of a patients PHD is visible within their open record access system.

Source: (Sarwal and Gupta, 2024[5]; Roehrs et al., 2017[6]); (Irizarry, DeVito Dabbs and Curran, 2015[2]); (Hägglund et al., 2024[3])

5. Access to personal health information has been associated with improved health outcomes for both patients and providers. Studies have repeatedly demonstrated that when patients have access to their EHRs, there is potential for enhanced patient-provider communication and increased patient engagement in self-care leading to improvements in the quality of care. For example, one systematic review found that in 10 out of 14 studies (71.4%), providing patients with access to EHRs resulted in positive impacts on effectiveness-related outcomes. These outcomes extended to patient anxiety, symptom stability, and clinical outcomes such as LDL-cholesterol levels (although not consistently beneficial across a wider range of outcomes, due to study structure). The study also found that patients with access to their EHR data had net positive outcomes across safety and adherence as well as health system efficiency through reductions in visits (Neves et al., 2020[7]). It is clear that accessibility of PHD can support patient-centred care but countries face numerous challenges with its implementation.

6. Investing and understanding personal health data systems is a priority for OECD countries. In Europe, the EU is advancing a common legal and technical framework for the governance, access, exchange and secondary reuse of electronic health data through the European Health Data Space (EHDS) Regulation (Regulation 2025/327). By harmonising patient rights to access and contribute to their records, strengthening interoperability requirements for EHR systems, and enabling secure cross-border data use, the EHDS provides a unifying reference point for Member States. Understanding the challenges and best practices in designing and implementing personal health data systems can complement these efforts, offering practical considerations for both OECD and EU countries as they plan and implement internationally leading approaches to personal health data

Challenges

7. The establishment of PHD systems, while transformative, face a range of challenges across multiple dimensions. Due to the complex, and often fragmented, nature of digitalised health systems, countries need to manage data flows, governance processes, and consent / privacy structures across many data sources and different regions or networks. These challenges can include:

- **Governance**: Fragmented legal frameworks, unclear accountability or consistent decision making, and the necessary regulatory frameworks to support its implementation, use, and sustainability.
- **Data**: The diversity of data types and lack of standardized formats and exchanges, such as Health Level Seven (HL7) Fast Healthcare Interoperability Resources (FHIR), create interoperability challenges and limit the utility of health data for patient-centred care.
- **Data Infrastructure and Architecture**: Legacy systems struggle to support modern health data needs, with issues in scalability, cross-platform integration, and compatibility with emerging technologies.
- **Privacy and Consent**: Balancing robust privacy protections, user-friendly consent mechanisms (or alternatives to consent), and access to a wide range of health data is challenging, particularly as patients express concerns about unauthorized access and misuse of sensitive data.
- **Provider Perspectives**: Providers face integration barriers, data quality concerns, additional workload, and liability risks when managing patient-generated data, further complicated by insufficient training, engagement, and workflow misalignment.
- **Patient Perspectives**: Low digital literacy, accessibility issues, and mistrust in data security restrict patient engagement, limiting the equitable adoption and effective use of PHD systems.

8. These barriers complicate the realization of equitable, secure, and effective digital health ecosystems. These can be further exacerbated by a lack of human resources, such as IT professionals, data scientists, and clinicians with digital health expertise. However, understanding how countries have previously stood-up PHD systems and managed these issues can help identify best practices for peer countries.

Project scope

9. The Ministry of Health and Welfare of the Republic of Korea is launching *My Data* – an ambitious initiative so individuals and patients can have access to their comprehensive, personal health information. The supporting data flows and infrastructure will be known as the *Health Data Highway*. With *My Data* and *Health Data Highway*, data will be available for both healthcare (primary use) and health system innovations, management, and improvements (secondary use).

10. For this paper, the Republic of Korea has asked the OECD Secretariat to conduct a comparative analysis of international practices, projects, and platforms for the **personal access and use of health data**. Specifically, this analysis will examine the underlying governance, infrastructure, data flows, and key barriers and challenges that peer countries faced when developing their own PHD and platforms. Countries included in this international scan were selected based on the readiness and comparability of their digital health infrastructures and capabilities. The interviewed OECD countries are: **Australia, Denmark, Finland, Japan,** and the **United Kingdom (England)**.

11. This international analysis explores structural pillars, including policy readiness (e.g. legislation, accountability, incentives), technical infrastructure (e.g. architecture, standards, access), health data management (e.g. data collection, linkability, and quality), and health equity (e.g. privacy, security, accessibility). This paper will also consider wider academic literature and current trends in digital transformation. The analysis organised country findings across five main areas:

- Governance
- Personal Health Data
- Data infrastructure and architecture
- Provider perspectives
- Patient perspectives

12. Following the research findings, best practices will be identified and detailed into recommendations for the Korean context.

2 Governance

Overview

13. Governance of PHD encompasses the policies, legal frameworks, institutional arrangements, and processes that oversee the collection, storage, sharing, and use of health information. Effective governance ensures that PHD is managed in a way that upholds privacy, security, and equity while enabling innovation, interoperability, and value-driven healthcare. As digital transformation accelerates, governance frameworks must adapt to address ethical considerations, public trust, and the complexities of integrating diverse stakeholders.

14. In 2016, the OECD Council adopted the *Recommendation on Health Data Governance* which outlines 12 key principles to encourage the availability and use of PHD to serve health-related public interest purposes while promoting the protection of privacy and data security. When considering the governance structures underlying the capability of PHD use and access, all 12 principles are needed, as seen in Box 2.1.

15. When developing these governance frameworks, enacting legislation are the key building blocks to support the accessibility and protection of key information needed to populate PHD. Countries varied in their timelines of policy development, as well as cultural approaches to the understanding of health data sharing. All the countries interviewed have a central authority that oversees data-related regulations, such as data standards, however they differ in their ability to coordinate nationally and incentivise data sharing and consolidation. Furthermore, each country explores relationships and regulations of EHR vendors and public/private partnerships differently, usually in relation to the strength of their governance frameworks.

Box 2.1. OECD Recommendation on Health Data Governance (2016)

12 principles for a national health data governance framework for the use and availability of personal health data

1. **Engagement and participation of stakeholders**: involve all relevant parties, including the public, in developing health data governance frameworks to ensure diverse perspectives and trust.
2. **Co-ordination within government and co-operation among organisations:** promote collaboration across governmental bodies and organisations to establish consistent data-related policies and standards.
3. **Review of the capacity of public sector health data systems:** assess and enhance public health data systems to ensure they effectively serve and protect public interests.
4. **Clear provision of information to individuals**: provide individuals with transparent information about how their personal health data is processed, including notifications of significant breaches or misuse.
5. **Processing of personal health data by informed consent and appropriate alternatives:** obtain informed consent for data processing when feasible, and establish lawful alternatives when consent isn't practical, ensuring data protection.
6. **Implementation of review and approval procedures**: establish transparent procedures for approving the processing of personal health data for research and other public interest purposes.
7. **Transparency through public information**: maintain openness about the purposes of health data processing and the criteria for approval to build public trust.
8. **Maximising the development and use of technology**: leverage advanced technologies to enhance both data processing capabilities and the protection of personal health data.
9. **Monitoring and evaluation of the health data governance framework**: continuously monitor and assess the effectiveness of data governance policies, adapting to new data and emerging risks.
10. **Training and skills development of personal health data processors**: ensure that individuals handling personal health data receive proper training to uphold data protection standards.
11. **Implementation of controls and safeguards within organisations**: enforce organisational measures, including technological and physical safeguards, to protect privacy and ensure data security.
12. **Demonstration of meeting expectations set out in the health data governance framework**: require organisations to demonstrate compliance with national health data governance expectations through audits and assessments.

Source: (OECD, 2016[8])

Table 2.1. Data standards related to personal health records

Adapted from Roerhs et. al (2017), a systematic review of personal health record data standards

Group or standard	Description	Comments
Nomenclature and terminology		
HNA/NIC	Classifications of nursing activities and interventions	
ICDx	Family of international classification of diseases	ICD-11 is the latest (since 2022)
LOINC	Code names for identifying medical observations	
SNOMED CT	Terminology collection of medical terms	Still expanding (311,000+ terms)
UMLS	System of medical vocabularies	
Privacy		
HIPAA	USA legislation for medical information	Updated in 2024 for reproductive health
GDPR	EU privacy framework for data protection	
Country Specific	Other country specific privacy frameworks relevant to each context	
Structural and semantic		
ASC X12N	Accredited standards committee X12-INS	
CCD	Specification for exchange clinical documents	
CCR	Specification for sharing continuity of care content	
CDA	Specification for clinical notes	
DICOM	Standard for medical digital imaging	
EN 13606	EHR standards in Europe	
HL7/FHIR/SMART	Family of standards and platforms based on the HL7 reference model	
ISO[d]	TR (Technical Report) 14292 (PHR) and ISO/IEEE 11073 PHD	
openEHR	Open standards specification in eHealth	
xDT	German family of data exchange formats	
IHE	Framework for interoperability between health IT systems	
OMOP	Observational Medical Outcomes Partnership common data model	
Templates and technology platforms (Examples)		
OpenMRS	Platform and reference application named Open Medical Record System	
OSCAR	EHR system named Open Source Clinical Application and Resource	

Note: Authors updated changes since 2017
Source: (Roehrs et al., 2017[6])

Country Findings

Australia

16. Australia's governance framework for PHD is grounded in a robust legislative and institutional foundation, with the **My Health Record (MHR)** system as its centrepiece. Launched in 2012 under the *My Health Records Act* (2012), the system transitioned to an opt-out model in 2019, significantly increasing its coverage to now over 90% of Australians. This legislation establishes the rights of individuals to access their key health information while mandating secure and lawful data handling by providers and the Australian Digital Health Agency (ADHA) as the system operator of My Health Record.

17. The *Australian Privacy Act* (1988) provides the overarching framework for data protection and privacy, setting obligations for organisations to handle personal information securely and transparently.

The *Healthcare Identifiers Act* (2010) introduced unique identifiers for patients, providers, and organisations, streamlining data integration across systems. These key legislative steps laid the foundation for the *My Health Records Act* in 2012. Since their implementation, both the *My Health Records Act* (2012) and the *Healthcare Identifiers Act* (2010) have been regularly updated with amendments to further refine the specifications for specific users or use cases, clarify operational details, and expand the scope of legislation. Australia utilises cycles of reviews and consultations to continually assess if health data policies, including those relating to PHD and MHR, are fit-for-purpose. This promotes transparency and trust with users and administrators (Australian Digital Health Agency, 2024[9]; Australian Institute of Health and Welfare (AIHW), 2022[10]).

18. The Australian Digital Health Agency directly oversees the governance of MHR, as well as operating Australia's digital health infrastructure, collaborating with standards organisations, and more. The Agency is both the national implementation partner and system operator of the MHR and My Health App (user interface).

19. Coordination with providers to populate MHR with key health information and comply with data requests and standards is currently limited. The Agency monitors information uploads and views and encourages healthcare providers to use the system and upload information, but fundamentally, it is still voluntary. Specific health services and professionals are required to upload certain documents (e.g. public hospital discharge summaries, pharmacist dispensing records), and some sector-specific incentives were used to encourage adoption. For example, conditional incentives are issued for the upload of a set percentage of patient cohort summaries; however, many providers consequently aim to only reach the target percentage and large, private providers, will not change standard practice until required. It should be noted that the recent *Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Act 2025* (introduced in November 2024, passed in February 2025) has established a legal framework for the **mandated sharing by healthcare providers** of key health information to MHR by default, starting with pathology and diagnostic imaging sectors. Furthermore, the national Medicare Benefits Scheme (MBS) will conditionally reimburse upon uploading of the required information, establishing strong financial incentives for data sharing. This 'sharing by default' arrangement is already increasing the volume of information available in the MHR, and will be a key driver in the governance and use of platforms (Conn, 2024[11]).

20. Coordination with EHR vendors remains a challenge. Often, there are only a few, big vendors with their own priorities over the adoption of standards and an embedded culture of expectation for incentives. Consultation and engagement are seen as critical to finding a solution. For example, the *Sparked* initiative is a roundtable approach to develop and adopt HL7 / FHIR standards with input from public sector, technology vendors, providers, domain experts, and more. This initiative is actively developing foundational data models (Australian Clinical Data for Interoperability (AUCDI), AU Core Data Standards) and implementation guides which, once adopted, might alleviate coordination issues, and facilitate easier sharing of PHD into MHR.

Denmark

21. Denmark's governance of PHD is rooted in a decades-long commitment to digitalisation and strategic policymaking, starting with the Civil Registration Number (unique identifier – still used today) in 1967, development of a National Patient Registry in 1977, and the first national digitalisation strategies in the 1990s for the activities of the **Danish Health Data Authority**. A key legislative milestone was the *Health Act* (2005) which codified the rights of patients to access their health data and established obligations for healthcare providers to document and share information through interoperable systems. These legislative developments culminated in the launch of **Sundhed.dk** in 2003, the **national e-health portal** that integrates data from primary and secondary care providers. This portal serves as a central platform for citizens to access their health information and manage healthcare interactions. Through

legislative changes in the development and use of Sundhed.dk, Denmark benefitted from a strong, cultural foundation embedded in *Health Act* (2005) legislation – a patient's rights for transparency and access to their health information (Ministry of the Interior and Health, 2005[12]).

22. The governance framework emphasises interoperability and technical standardisation, which are facilitated by **MedCom**. This agency works to develop and define standards to ensure the secure and efficient exchange of health information between healthcare providers and to define protocols for data sharing and certifying EHR systems. The **Danish Health Data Network**, a secure national infrastructure, supports real-time data exchange while ensuring data accuracy and integrity. Additionally, the Danish Health Data Authority oversees these frameworks, ensuring compliance and driving innovation in data governance. In relation to the national data infrastructure and Sundhed.dk, these agencies and the Ministry essentially mandate (via protected access, not data requests) the real-time availability of information for patient access (primary use). When specific datasets are not fully available in the Sundhed.dk portal, for example GP clinical notes, the Ministry will hold consultations until this is able to meet specifications for inclusion in the national data infrastructure. The driving cultural and legislative reasoning is that all health and service information should be transparent and available to the public.

23. Transparency and public trust are central to Denmark's approach to governance. Tools such as *MyLog* allow citizens to monitor who has accessed their data, fostering accountability among providers. The use of *MitID*, a secure national digital identification system, ensures authenticated access for patients and providers, which is integrated directly into Sundhed.dk. These measures reflect Denmark's commitment to balancing privacy with usability, enabling the secure sharing of PHD while maintaining public confidence in the system.

24. Denmark employs a mix of regulatory mandates and voluntary measures to ensure compliance with its governance standards. For example, public hospitals and general practitioners (GPs) are required to use certified EHR systems that adhere to MedCom standards or meet conformity assessments, ensuring interoperability. Regions and municipalities can tender their own EHR systems if they meet national MedCom requirements – a policy that has been in place since 2011. Denmark's ability to mandate certification criteria and continued collaboration with EHR vendors has proven beneficial to supporting interoperability and secure access to PHD.

Finland

25. Finland's governance of PHD is built on a robust legislative framework that prioritises citizen rights and data interoperability. Health data governance has long been a part of Finland's health information system starting in 1992 with the *Patient Rights Act*, which guarantees patients the right to access their medical records and established a culture of transparency in healthcare. The *Act on the Electronic Processing of Customer Data in Social and Health Care* (2007) which mandated the adoption of interoperable digital systems across public and private providers, enabled the development of national e-health solutions. These laws laid the groundwork for the launch of **MyKanta** in 2010, a centralised platform that integrates health records, e-prescriptions, and other critical data, ensuring accessibility for both citizens and healthcare professionals.

26. The overarching governance structure is split by technical and strategic capabilities. **The Ministry of Health and Social Affairs** oversees national strategies and the coordination of the national information services, or **Kanta Services**. The national health authority (**THL**) operates the health service providers (public and private), including instituting mandatory standards, classifications, terminologies, and code sets. **Kela**, manages the technical implementation of MyKanta, including support and coordinating technical standards with regional EHR systems. Furthermore, **Valvira** oversees the authentication service and Health IT surveillance, and **Fimea** oversee medication data and medical devices surveillance. All of these agencies work closely with healthcare providers and municipal authorities to ensure compliance with national standards. The system's design ensures that structured data from local EHR systems are

integrated into Kanta Services, providing a unified and secure repository of PHD. Regular updates to technical requirements and user guidelines reflect Finland's commitment to continuous improvement and system scalability.

27. Interoperability is a cornerstone of Finland's governance framework, supported by the mandatory adoption of HL7 FHIR standards and semantic harmonisation practices. **HL7 V3** remains in use for core backend data exchange within Kanta Services, while **HL7 FHIR** is being adopted for newer interfaces and external interoperability, including patient-facing services and portals such as MyKanta.

28. Finland relies on legislative mandates to drive compliance with its governance standards. Providers are legally required to use interoperable systems and report specific data sets to Kanta Services. Legislation, including the recent *Customer Data Act* (2024), specify organisational arrangements and data sharing protocols to support the central coordination of the Kanta PHR. These mandates are complemented by funding mechanisms that support digital infrastructure development, particularly for smaller providers. Policy reviews are conducted regularly to ensure that the governance framework remains fit for purpose, aligning with evolving healthcare needs and technological advancements.

Japan

29. Japan has made significant progress in developing legislative frameworks to facilitate the sharing and utilisation of PHD. The *Act on the Protection of Personal Information* (APPI) (2003) serves as the cornerstone for personal data governance, providing detailed rules for handling sensitive personal information, including health data. A broad, ongoing initiative, known as the *Healthcare DX Roadmap* outlines specific goals for the digital transformation of healthcare. This includes the establishment of a standardised electronic medical chart system to be operational by 2030 and the integration of health insurance and medical information into **Mynaportal**, a centralised digital access platform for patients to view and manage personal information, including health information. The capabilities for Mynaportal have developed quickly, spurred by the *Healthcare DX Roadmap*. In December 2024, the Individual Number Card or My Number Card (unique patient identifier for the national health insurance) and Health Insurance Card have been integrated into Mynaportal, where patients can use their Individual Number Card to securely access their medical information. A subset of the PHR known as the **standardised electronic medical chart** allows patients to view basic medical information (allergies, laboratory tests, prescriptions, diagnoses, etc.) and is currently being tested before fully deployed. The electronic medical chart will be available in Mynaportal and both platforms will utilise HL7 FHIR APIs to reference the information, noting this development is still in progress.

30. Japan lacks a centralised health data authority equivalent to models in Denmark or Finland. However, multiple agencies play critical roles in oversight:

- The **Ministry of Health, Labour and Welfare (MHLW)** oversees the implementation of digital healthcare initiatives and regulatory compliance.
- The **Personal Information Protection Commission (PPC)** enforces compliance with APPI regulations. Collaboration among government agencies, healthcare providers, and private stakeholders is fostered through working groups such as the Product Working Group (PWG), which focuses on developing interoperable systems like the standardised electronic medical chart.

31. Policy instruments in Japan include both financial incentives and legal mandates. The APPI outlines conditions under which health data can be shared without explicit patient consent, particularly in scenarios involving public interest or emergencies. The government also promotes the adoption of integration and data standards, with subsidies for providers implementing standardised electronic medical records. These mechanisms aim to encourage voluntary compliance while gradually embedding mandatory requirements.

32. Japan's healthcare digitalisation relies on a collaborative ecosystem of public and private stakeholders. The PWG, comprising of experienced EHR vendors and government representatives, works to ensure that new systems meet national standards. Initiatives like the Mynaportal API enable private health data solutions to integrate seamlessly with public health records, fostering innovation while ensuring compliance. Challenges include the fragmented nature of Japan's healthcare system and the diverse technological maturity of providers, which the government addresses through technical assistance and financial support for compliance.

United Kingdom (England)

33. England's approach to enabling interoperable and accessible health information is rooted in its central organisational structure of the National Health Service (NHS) and with iterative legislative and policy frameworks. The foundation lies in the **Health and Social Care Act 2012**, which established the Health and Social Care Information Centre (now **NHS Digital**) to oversee data collection, analysis, and sharing. Additionally, the **Data Protection Act 2018** (aligned with GDPR) provided robust provisions for data privacy and security, enabling safe information sharing across the NHS. Recent legislation has contributed greatly to data availability in the NHS. These include the revision of a National Opt-Out Policy as well as the *SMART Data and Information Bill* which standardises data sharing and enforce compliance with EHR suppliers. **NHS England** serves as the central authority overseeing health data governance, following the absorption of NHS Digital in 2023. This body sets and enforces data-sharing standards, promotes interoperability, and manages national digital initiatives. It oversees the development and operation of key digital tools, including the **NHS App**, and works with regional Integrated Care Systems (ICSs) to ensure alignment of local efforts with national objectives.

34. The NHS App is the main PHD platform for patients. It was first initiated by the Health Secretary in 2017 but did not grow substantially until the COVID-19 pandemic, with a growth of approximately 9 million users per month during this time. The NHS App enables users to access GP records, book appointments, and manage prescriptions. NHS England has worked closely with GP IT system suppliers, such as TPP and EMIS, which cover over 99% of the market, to ensure seamless integration. The NHS App now connects to secondary care systems, expanding its functionality to include hospital appointments and laboratory test results. Public-private partnerships have also facilitated the incorporation of advanced features, such as wearable integration and digital triage tools, enhancing the app's utility for both patients and providers.

35. England employs several policy instruments to ensure the widespread adoption of data-sharing practices. The *NHS Digital, Data and Technology Standards Framework* mandates compliance with interoperability and cybersecurity standards for NHS organisations and their suppliers. Programmes such as the Global Digital Exemplar (GDE) initiative provide funding and recognition to trusts that demonstrate leadership in digital innovation, thereby encouraging adherence to national standards. The introduction and promotion of HL7 FHIR-based APIs further mandates the integration of standardised data-sharing protocols among service providers.

Policy considerations

36. Across all OECD countries, legislation is used to set in motion the ownership of PHD, sharing of PHD, standards, and implementation of a PHD system. Countries have demonstrated that policy levers are valuable tools to support standardisation and common practice in a technology space that is quite fragmented. With a wide variety of vendors, health information standards, and data architectures in place, a consistent trend is to set core data for interoperability, as done in **Australia**, or to require vendors to meet common standards for their products to be eligible for procurement, as in **Denmark**. Legislation can also be a proactive measure to notify health organisations and system developers of changing

requirements and new functionality, such as in **Finland** which is setting the stage for a Kanta PHR and more active patient contribution in their record with the Customer Data Act.

37. Health data authorities are used to oversee the use of digital health technologies and ensure that compliance to standards is met. Additionally, legislation is in place in all OECD countries to extrapolate on the patients right to their data, the healthcare providers role, and data privacy rules and regulations. These are key building blocks on which a PHD system can be built.

Table 2.2. Summary of country findings – governance of personal health data

	Australia	Denmark	Finland	Japan	UK (England)
Key legislative steps to enable interoperable and accessible health information	Privacy Act (1988); Healthcare Identifiers Act (2010); My Health Records Act (2012) transitioned to opt-out in 2019; Health Legislation Amendment (Modernising My Health Record Sharing by Default) Act (2025)	Health Act (2005) ensures patient access; Sundhed.dk integrates primary and secondary care data.	Patient Rights Act (1992); Customer Data Act (2024); MyKanta launched with e-prescriptions in 2010.	Act on the Protection of Personal Information (2003); Healthcare DX Roadmap (ongoing); Mynaportal launched.	Health and Social Care Act (2012); Data Protection Act (2018); SMART Data Bill enforces compliance.
Health data authority that oversees and can impose standards regulations (or others)	Australian Digital Health Agency (ADHA) oversees MHR and digital health infrastructure.	Danish Health Data Authority ensures compliance; MedCom defines data-sharing standards.	Multiple agencies: THL (standards), Kela (technical operations), Valvira (authentication), Fimea (medication data).	No central authority; Ministry of Health and PPC enforce regulations, PWG ensures standards development.	NHS England oversees data governance post-NHS Digital merger; manages standards and NHS App development.
What policy levers are used to mandate sharing of information	'Sharing by default' policy incentivised via Medicare Benefits Scheme; some mandatory uploads (starting with diagnostic imaging and pathology).	Mandatory certified EHR use; consultation for including new datasets like GP notes.	Mandatory HL7 FHIR adoption; funding mechanisms for smaller providers to ensure compliance.	FHIR standards incentivised with subsidies; mandatory sharing in emergencies per APPI.	Digital, Data, and Technology Standards Framework mandates compliance; GDE incentives for innovation.
Coordination with vendors (E.g. EHR/EMR systems) and public/private partnerships	Consultation with vendors via Sparked initiative for HL7/FHIR; AU Core standards under development.	MedCom-certified systems ensure interoperability; municipalities choose systems meeting MedCom standards.	National EHR integration coordinated by Kela; semantic harmonisation practices ensure interoperability.	PWG ensures standards; Mynaportal API enables private sector integration; fragmented system addressed with support.	NHS App integrated with TPP, EMIS, and secondary care systems; partnerships for wearable integration.

Note: Summarised from text in Governance – Country Findings
Source: OECD Authors; Interviews and information requests from involved countries

38. While governance structures for PHD vary among the countries interviewed according to political context, health system organisation, and legislative histories, two **leading practices** emerged:

- Health data authority supported by legislation enacting a robust health data governance framework to promote the protection and responsible use of PHD, as well as the regulatory mandate to drive the common use of standards, data reporting and sharing, and compliance across health data offices, providers, private sector, and other key stakeholders.

- Coordination with vendors (E.g. EHR/EMR systems), public/private partnerships, and continued engagement on requirements to share information, to enable the existing and net new systems developed to be integrated into the national data infrastructure.

Table 2.3. Summary of leading practices in the Governance of PHD

Recommendation	Australia (My Health Record)	Denmark (Sundhed.dk)	Finland (My Kanta)	Japan (Mynaportal)	United Kingdom (England, NHS App)
Health data authority with legislative and regulatory mandate for PHD standards and integration	Yes	Yes	Yes	In Development	Yes
Coordination and engagement with vendors to incorporate data into national infrastructure	In Development	Yes	Yes	In Development	In Development

Source: OECD Authors; Interviews and information requests from involved countries

3 Personal Health Data

Overview

39. The range of information available in PHRs can vary widely by how that information is captured, where it is stored, the level of standardisation, the ability for that information to be pulled by an API or sent by providers via data requests, etc. The one thing that remains true is the importance of patients having access to this information. Of the information available in PHRs, they can include:

- **Clinical Data**: Includes diagnoses, treatment plans, and lab test results, which are critical for clinical decision-making.
- **Medication and Immunisation Records**: Providing comprehensive lists of prescribed medications and vaccinations to ensure accuracy and avoid adverse drug interactions
- **Patient-Generated Health Data (PGHD)**: Such as wearable device outputs and wellness data, which offer insights into chronic condition management
- **Administrative Data**: Appointment schedules and billing information that enhance patient engagement and health system efficiency.

40. A systematic review of 48 studies on PHR examined the most common data points included in personal health datasets, as seen in Table 3.1.

Table 3.1. Personal Health Record Data Types

Type	Description	Number of studies where data is included
Allergies	Allergies and adverse reactions	13
Demographic	Patient statistics and clinical data	6
Documents	Attached files (photos, scanned documents)	3
Evolution	Progress and clinic notes, care plan	4
Family history	Family medical history	8
General	Patient registration information, emergency contact	5
Genetic	Genetic information	2
Home monitor	Home-monitored data	3
Immunisations	Immunization records (vaccine), tracking immunizations	12
Insurance	Insurance plan information, coding for billing	3
Laboratory results	Laboratory and imaging test results (laboratory tests)	12
Major illnesses	List of major diseases	5
Medications	Medication list prescribed, past medicines taken	11
Prescriptions	Medical prescription refills (renewing)	7
Prevention	Preventive health recommendations	5
Providers	Previous health care provider list	5
Scheduling	Appointments, past procedures, hospitalizations	9
Social history	Social history, lifestyle (health habits)	5
Summaries	Admissions, permanencies, and discharges	3
Vital signs	Status of bodily functions	5

Note: Total number (of 48 articles) where the data type is mentioned in a study on PHR systems
Source: (Roehrs et al., 2017[6])

41. Allergies, immunisations, laboratory results, and medications are the most cited as data included in PHRs. More functional, service-based information is also included, such as appointments and prescriptions for refills. The range of information is wide, which can pose a problem for the data architecture behind PHRs and patient portals. However, the benefit for patients accessing this range of information is clear. Patients who can access their health data benefit from:

- **Enhanced Patient Safety**: Access to medication records and shared health summaries reduces errors and duplication of tests.
- **Support for Self-Management**: Patients equipped with knowledge about their conditions can better adhere to lifestyle changes and treatment regimens
- **System Efficiency**: Streamlining administrative workflows through digital tools reduces provider burden, enabling more focused care delivery

42. This section will outline what information interviewed OECD countries are able to report in PHRs, how they are able to prepare and present information, and any considerations taken when choosing the PHD generated.

Country Findings

Australia

43. In Australia, the My Health Record (MHR) system provides patients access to an array of PHD types aimed at empowering patient-centric care. The system collects clinical information such as diagnostic reports, pathology results, immunisation records, shared health summaries, medication prescriptions, and hospital discharge summaries. This is complemented by administrative data, including Medicare Benefits Schedule (MBS) claims and Pharmaceutical Benefits Scheme (PBS) records. However, the inclusion of specific health information remains contingent on healthcare provider compliance and laws in certain jurisdictions. Currently, the Sharing by Default initiative has mandated the sharing of diagnostic imaging and pathology reports, however participation remains voluntary for all other information types. Patients can also add personal health notes, allergies, and advanced care plans.

44. The coverage of the data within the MHR is substantial but uneven. Over 90% of Australians have a record in the MHR system due to the shift to an opt-out model in 2019. However, the quality and completeness of these records vary, as not all healthcare providers consistently upload data. Clinical information, for instance, often lacks the detail and consistency found in broader linked datasets, as the system currently relies on providers' willingness to curate and upload information. Furthermore, private sector contributions to MHR remain limited compared to public healthcare data inputs, leaving gaps in comprehensiveness.

45. The granularity of data within MHR varies. While structured data formats like discharge summaries and vaccination records offer detailed and interoperable insights, many contributions remain in less granular formats, such as unstructured PDFs or narrative-style entries. This affects the usability of data for advanced purposes like analytics or secondary research. Australia is transitioning towards greater adoption of HL7 FHIR standards to improve structure and accessibility.

46. In terms of timeliness, MHR data is frequently updated in near-real time for automated systems like pathology and diagnostic imaging uploads. However, delays can occur in other areas, such as manually uploaded clinical summaries or discharge notes, depending on healthcare provider workflows

and system integrations. Legislative and incentive measures are being introduced to improve the timeliness of uploads across sectors.

47. Data storage and processing are mixed. Key health information is shared from the original data custodians (i.e. healthcare providers) and stored in a centralised MHR repository, accessible for providers through conforming Clinical Information Software or read-only through a national provider portal[2]. Other data are stored with the original custodians and accessed through the MHR portal. A secure national infrastructure underpins this system to ensure data security and patient privacy compliance. This decentralised architecture supports real-time queries and automated updates but has gaps where standards or reporting requirements have not been agreed.

48. Finally, while structured data is increasingly centralised for availability in MHR, much work remains to fully standardise all data sources across providers and datatypes. Plans to transition towards interoperable standards like FHIR (with the Australia accelerator, *Sparked*) and the ongoing AUCDI aim to address these challenges, with ongoing efforts to incentivise healthcare providers for more structured and comprehensive data uploads (See Figure 7.1 and Figure 7.2 for more details).

Denmark

49. In Denmark, the Sundhed.dk portal enables access to a wide range of data types, including medical histories, diagnostic imaging, laboratory results (including blood tests and biological materials), shared medication records (SMR), hospital discharge summaries, and immunisation records. The SMR provides a unified overview of all medications prescribed to citizens across care settings. Furthermore, the system integrates administrative data, such as appointment overviews and care plans, enhancing both patient engagement and care continuity.

50. The coverage of data is comprehensive and built on Denmark's unique Civil Registration Number (CPR), which allows for the linkage of health data across the primary, secondary, and municipal healthcare sectors. This national infrastructure supports complete data capture for all Danish residents from their first interaction with the healthcare system (birth) through to death. Coverage includes both public and private care data, although private sector contributions may vary slightly in completeness. Data from hospitals, GPs, and municipalities are fully integrated into the system.

51. Granularity of data in Denmark is notable for its detail and standardisation. Structured data formats are employed across health records, including HL7-based messages for laboratory results, diagnostic imaging reports, and clinical summaries. For example, the SMR includes granular information such as medication names, dosages, and prescribing details. Efforts to standardise, enforce, and increase interoperability have been successful, ensuring that health professionals and patients can access precise and actionable data. Furthermore, data are very timely, with most systems operating in near-real time, with minor exceptions like discharge summaries, depending on local workflows.

52. The storage and processing of data are underpinned by Denmark's robust digital infrastructure, which integrates local systems (e.g., EHRs at hospitals and GPs) with national platforms like Sundhed.dk and the National Service Platform. Data is decentralised, with primary responsibility for data storage residing with the originating institutions (e.g., hospitals, GPs). The system employs secure data-sharing mechanisms, ensuring compliance with privacy and security standards, while the CPR enables seamless linkage across multiple datasets. The data available through Denmark's health system is predominantly structured and centrally accessible via Sundhed.dk. The platform aggregates data from multiple sources, providing citizens and healthcare professionals with a unified view of health records. Structured formats,

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[2] My Health Record | Digital Health Developer Portal

such as the SMR, diagnostic results, and care plans, ensure that data is easily searchable, interoperable, and actionable for both primary and secondary uses.

Finland

53. In Finland, the My Kanta (OmaKanta) system provides citizens with a comprehensive view of their personal health data, facilitating access to essential clinical and administrative information. Patients can view structured summaries of diagnostic and laboratory test results, e-prescriptions, vaccination records, discharge summaries, and care plans. The system also offers detailed lists of medications, diagnoses, procedures, and vaccinations, ensuring clarity and accessibility for both patients and healthcare providers. Additionally, patients can access encounter-specific data in a standardised HL7 format, which includes referral information, appointment records, and procedural details. Beyond clinical records, My Kanta enables the integration of patient-generated health data from approved well-being applications, allowing citizens to contribute metrics such as blood pressure or glucose levels to their health records. This capability, while currently limited, represents a growing focus on patient participation in health data management.

54. The platform achieves near-universal coverage by mandating participation from public healthcare providers and encouraging contributions from private organisations. Over 92% of public health organisations actively upload data, complemented by approximately 70% of private entities. Encounter data from both primary and secondary care is uploaded systematically, ensuring that patients receive timely updates after clinical visits. However, independent practitioners and smaller private providers contribute less consistently, leaving minor gaps in the overall dataset. Patients accessing their records via My Kanta benefit from real-time updates for critical information, such as prescriptions and laboratory results, while older or less frequently updated records can be requested manually through regional or local systems.

55. Data timeliness in My Kanta depends on the type of information. Diagnostic results and prescriptions are generally updated in near real-time, ensuring patients and providers can access the latest information promptly. Some delays occur for data requiring professional review, such as health check-up results or summaries intended for secondary care. Efforts to improve the speed of updates are supported by Finland’s legislative framework and ongoing technical enhancements. Structured data formats dominate My Kanta’s design, ensuring central availability and usability through the portal. These formats align with national interoperability standards, allowing seamless integration across providers and regions, further strengthening the utility of My Kanta for patients and healthcare providers alike.

Japan

56. In Japan, Mynaportal serves as a secure gateway for accessing personal health information as part of the country’s healthcare digital transformation (Healthcare DX). Citizens can view vaccination records, municipal health check-up results, insurance qualification details, prescriptions, allergies, and diagnostic test results through the platform. Patients also have access to referral letters and discharge summaries from participating medical facilities. This integration is aimed at empowering citizens by centralising their health information in a user-friendly portal.

57. Coverage of health data through Mynaportal is extensive, linked to the national health insurance system and the integration of Individual Number Cards (My Number Cards). This ensures nearly universal access for insured individuals. However, efforts are ongoing to incorporate data from smaller clinics and private healthcare providers, expanding the reach and utility of the portal. Recent developments include electronic medical chart information sharing, which allows patients to view referral and discharge documents, prescription histories, and test results. The standardisation of data formats, including HL7 FHIR, is expected to enhance this integration.

58. Data is granular and meant to support patient information and activity. Vaccination records include detailed timelines and doses, while municipal health check-up results provide key health metrics, such as cholesterol levels, blood pressure, and BMI. The electronic medical chart initiative focuses on structuring and sharing clinical data, such as summaries of consultations, prescriptions, and diagnostic outcomes, ensuring that both patients and healthcare providers can access actionable and reliable information. Strict authentication via My Number Cards ensures compliance with the Act on the Protection of Personal Information (APPI). Structured data formats, such as those employed in electronic medical charts, enable seamless sharing and integration, supporting Japan's vision for a unified and efficient digital health system.

United Kingdom (England)

59. In England, the NHS App serves as a gateway for patients to access their personal health data, facilitating informed decision-making and engagement with their healthcare. The app provides access to a wide range of data, including general practitioner (GP) health records, vaccination histories, prescription details, test results, and appointment information. Additional features allow patients to book GP appointments, request repeat prescriptions, and access organ donation registration details. Patients can also view their NHS number and other administrative information. Recent updates have focused on expanding data availability to include hospital and specialist care records, enabling patients to track referrals and follow-ups with secondary care providers.

60. The coverage of data available through the NHS App is steadily expanding. GP data, which forms the backbone of the app, is near-universal, as over 65,000 GP practices contribute data through centralised IT systems. However, the integration of secondary and community care records is still in progress. Currently, 95 out of 130 NHS Trusts share outpatient appointment data through the app, with plans to include more Trusts and additional record types, such as inpatient care and mental health services. The app's coverage reflects England's fragmented approach to secondary care, where not all providers are connected to the central system.

61. The granularity of data collected and displayed in the NHS App is variable. For GP records, structured data includes medications, allergies, immunisations, and test results, often formatted for interoperability using FHIR (Fast Healthcare Interoperability Resources) standards. Secondary care data, however, may be less granular or provided in non-standardised formats due to the varying levels of digital maturity among NHS Trusts. Free-text notes from GPs are generally not visible to patients due to concerns about misinterpretation, but structured summaries ensure critical health information is readily accessible.

62. Timeliness of data in the NHS App depends on the source. GP data, including prescriptions and immunisations, is updated in near real-time due to established centralised systems. However, data from secondary care, such as outpatient appointments and test results, may experience delays depending on provider workflows and integration maturity. Future updates aim to reduce these delays by mandating standardised data sharing across all NHS providers.

63. Data storage and processing within the NHS App follow a decentralised model. Health data is not stored directly in the app but remains with the originating providers, such as GP practices and NHS Trusts. The app functions as a portal, accessing data from these systems via secure APIs. This approach maintains data security while enabling real-time access to records. Strong encryption, NHS login authentication, and audit trails ensure compliance with stringent UK data protection regulations.

64. Finally, structured data is a priority for the NHS App, with FHIR standards used to enable interoperability and improve data accessibility. While GP data is predominantly structured and easily integrated, secondary care data remains less consistent, with ongoing efforts to harmonise standards across providers. These efforts aim to create a unified health record, as outlined in the NHS's Long Term Plan, enhancing the app's utility for both patients and healthcare professionals.

Table 3.2. Data types by patient PHD system

Data Type	Australia (My Health Record)	Denmark (Sundhed.dk)	Finland (My Kanta)	Japan (Mynaportal)	UK (England, NHS App)
Allergies	Yes	Yes	Yes	Yes	Yes
Medicines	Yes	Yes	Yes	Yes	Yes
Adverse Reactions	Yes	Yes	Yes	Yes	Yes
Diagnostic Imaging Reports	Yes	Yes	Yes	Yes	Yes (expanding across Trusts)
Discharge Summaries (Shared by the Provider)	Yes	Yes	Yes	Yes	Yes
e-Referrals	Yes	Yes	Yes	No	Yes
Event Summaries	Yes	Yes	No	No	No
Goals of Care Document	No	Yes (part of care plans)	Yes (via patient-uploaded plans)	No	Yes (future state planned)
Immunisations	Yes	Yes	Yes	Yes	Yes
Pathology Reports	Yes (automatically uploaded)	Yes	Yes	Yes	Yes
Pharmacist Shared Medicines List	Yes	Yes	No	No	No
Prescription and Dispense Records	Yes	Yes	Yes	Yes	Yes
Shared Health Summaries	Yes	Yes	Yes	No	Yes
Specialist Letters	Yes	Yes	Yes	Yes (as referral letters)	Yes

Source: OECD Authors; Interviews and information requests from involved countries

Policy considerations

65. Across **Australia, Denmark, Finland, Japan,** and the **United Kingdom (England)**, a shared policy priority is achieving comprehensive data coverage, granularity, and timeliness. While most countries offer core data types such as allergies, prescriptions, diagnostic results, and immunisation records, the scope of data available remains inconsistent. Gaps are evident in incorporating patient-generated data and ensuring the inclusion of all private sector contributions. Policies must also address the interoperability and standardisation of data, leveraging international frameworks like HL7 FHIR to ensure structured and actionable health records.

66. Data storage and processing are central to trust and usability. Decentralised models, as seen in **Denmark** and **England**, require robust encryption and clear governance to protect patient privacy while enabling seamless data sharing across providers. Ensuring real-time or near-real-time updates is another critical policy area, as delays in data availability can undermine care outcomes. Policymakers must also balance inclusivity and accessibility, ensuring digital tools are intuitive and cater to varying levels of digital literacy across populations. Two leading practices identified through interviews include the ability to:

- **Mandate comprehensive and standardised data contributions**: Develop regulatory frameworks that mandate all healthcare providers, including private sector entities, to contribute standardised, structured data to national PHRs and patient-accessible portals. Encourage the use of HL7 FHIR or equivalent standards to ensure interoperability and usability of data across systems.

- **Enhance data timeliness and integration**: Invest in infrastructure and governance models that support near-real-time updates of health records across care settings. Prioritise seamless integration of patient-generated health data from wearables and other devices to create holistic and actionable PHRs.

Table 3.3. Leading practices for Personal Health Data availability by country

Recommendation	**Australia (My Health Record)**	**Denmark (Sundhed.dk)**	**Finland (My Kanta)**	**Japan (Mynaportal)**	**UK (England, NHS App)**
Mandate comprehensive, standardised data contributions	In Development	Yes	Yes	In Development	In Development
Enhance data timeliness and integration (incl. patient-generated data)	In Development	Yes	In Development	In Development	In Development

Source: OECD Authors; Interviews and information requests from involved countries

4 Data Infrastructure and Architecture

Overview

67. Of the OECD countries interviewed, PHD is stored across diverse systems and with various approaches to ensure accessible and available health data. PHD can be utilised to support the ongoing care of a patient, also known as primary use. OECD countries aim to make this data as readily available as possible for clinical decision makers and to allow patients to have open access to this information to better engage them into their care. Another purpose for this data is for secondary purposes, such as research, innovation, and population health management. To enable access to PHD a robust data infrastructure and architecture is needed for the collection and sharing of the PHD.

68. Across the five OECD countries, different health system structures are present, which introduce potential regional or national barriers to the establishment of an integrated health data infrastructure. For example, in federated countries, such as Australia, data is not easily shared between regions and currently, the MHR is utilising a manual push of health data summaries from healthcare providers. However, in Denmark, the data infrastructure has been long established with a culture of trust and transparency, enabling a comprehensive record of the patient being shared across the different regions and systems.

Country Findings

Denmark

69. In Denmark, health data foundations are established, connected through a national personal number which connects citizens to the health and social services. The national patient registry is a key component of this data foundation, and the data collected enable patients to access their cross sectoral health record in the Sundhed.dk portal and see any clinical encounters and health information as far back as 1977 (Sundhed.dk, 2024[13]). Data in Denmark is stored from birth to grave, and is not deleted, with over 30 million records within the current health data infrastructure (See Box 4.1). All data is connected through the National Service Platform (NSP) which utilises an integration platform to connect local systems to the portal from various EHRs in hospitals and GP practices. This data is sent to the national patient registries which then distribute data into the sundhed.dk porta (See Figure 4.2). Currently, Sundhed.dk provides only a view into the data for citizens with limited ability for citizens to update their record.

Box 4.1. The Danish National Infrastructure

The Danish Health Data Authority, which holds responsibilities for managing the national health registries and ensuring that the health of Danish citizen's is improved through the use of data. Denmark has a long history of collecting health related data with a foundation laid in trust and transparency between healthcare providers and citizen's, along with the national personal identifier, the CRP number (see Figure 4.1 and Figure 4.3).

The national patient registry dates back to 1977, and when accessing their health information through the sundhed.dk portal, citizens can find their health information as far back as this date. Currently all health-related data of a citizen, with the exclusion of general practice notes, is included in the national data infrastructure. A new agreement is being made with GPs currently who work as private enterprises to share their data to the national registries. With this change, all data related to each Danish Citizen will be viable through the sundhed.dk patient portal.

To enable this timely and complete sharing of health data, Denmark's infrastructure utilises APIs between the various EHR systems in use (See Figure 4.2). The infrastructure operates on a closed Health Data Network, the SDN and utilises legacy standards of EDIfact (international format) and OIOXML (Danish format) standards. Work is underway by MedCom, an organisation responsible for developing and maintaining the Danish health IT infrastructure, to convert all standards to the HL7 FHIR standard which will further enhance the existing data infrastructure.

Figure 4.1. Timeline of Data Storage in Denmark

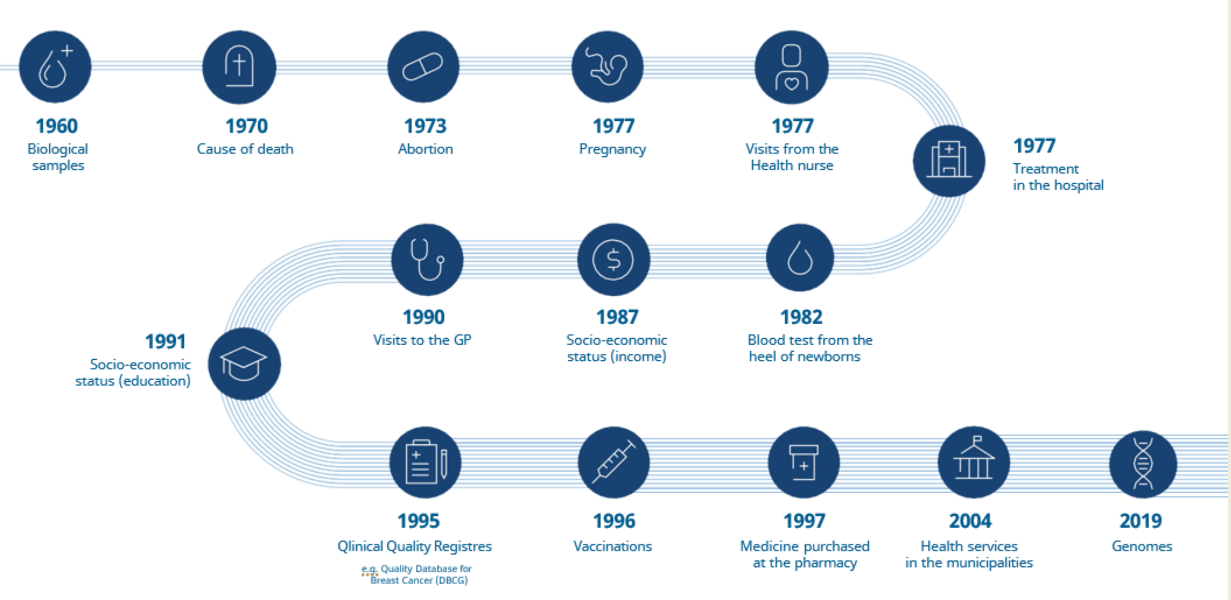


Figure 4.2. The Danish National Infrastructure

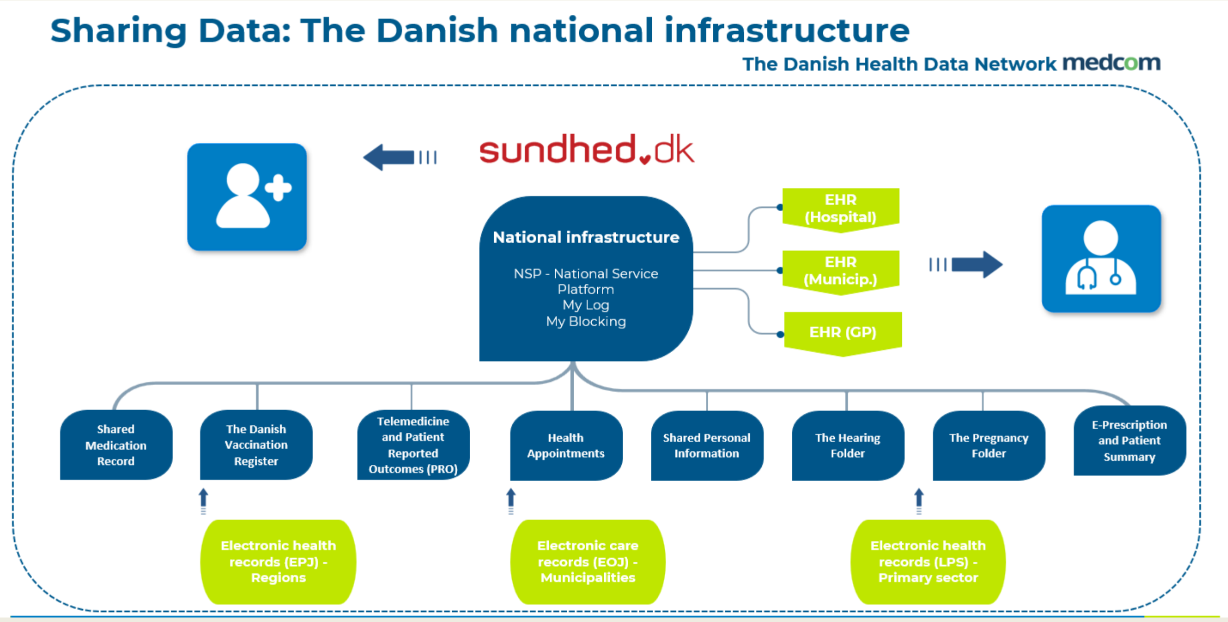
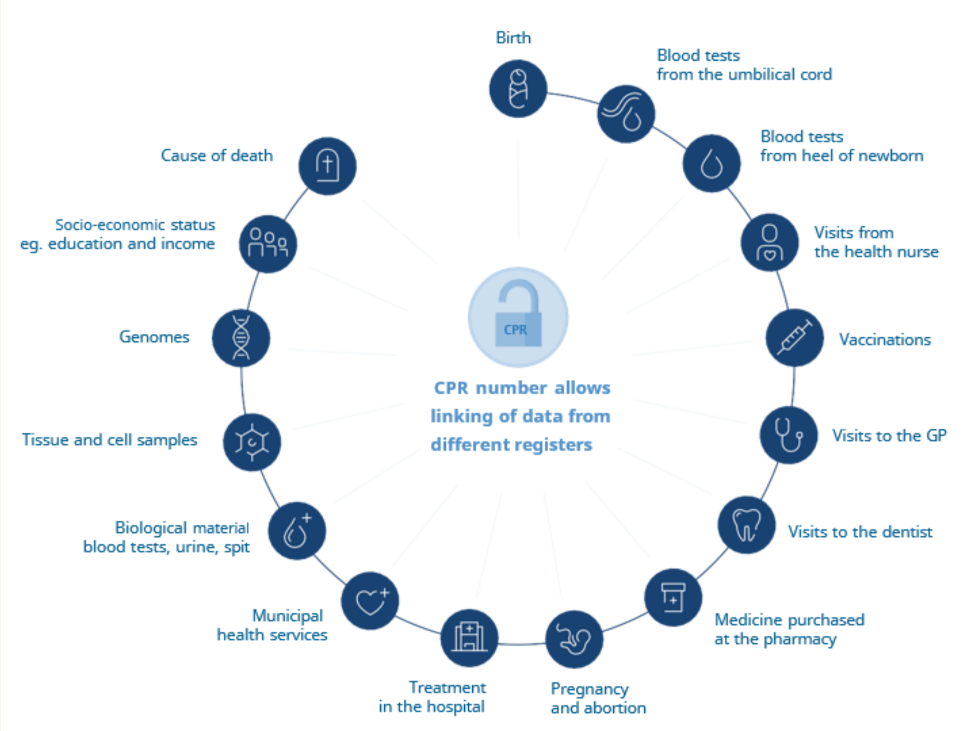


Figure 4.3. Linkable data in Denmark

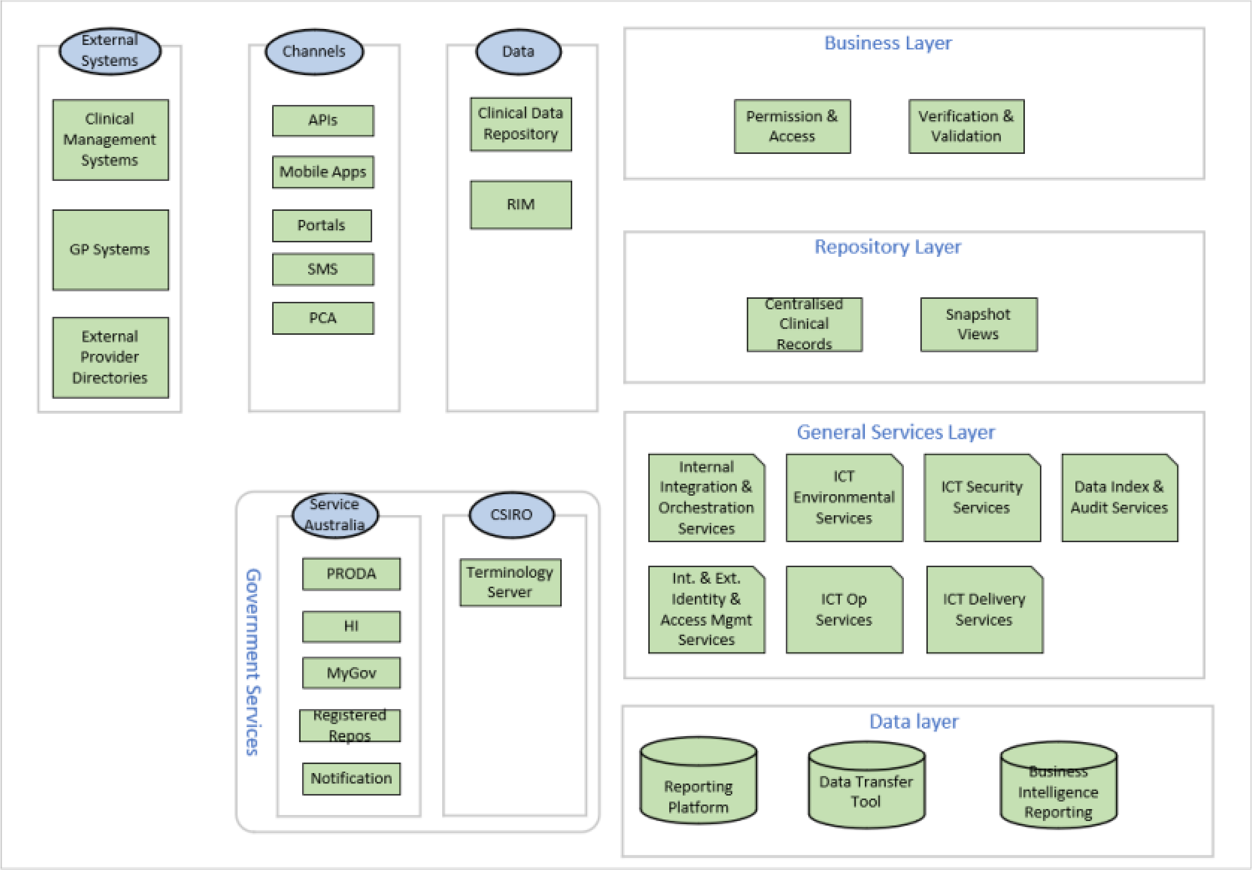


Source: (medcom, 2023[14]) (Medcom, 2024[15])

Australia

70. In Australia, the national MHR system enables patients and healthcare providers across the country to have access to a core set of health information. This information is curated by clinicians in their own EMR and EHR systems in a Clinical Document Architecture as point-in-time information. This information is stored within the MHR data repository and is only updated as more data is pushed into the data repository by the healthcare providers in their own EMRs and EHRs. Due to the storage model utilised by the MHR, when patients choose to remove their record from the MHR, all data is deleted, and it is permanently lost. Any data which is stored on the source health information systems would still be maintained and not modified by the inclusion in the MHR. The health data infrastructure of Australia uses a Business-to-Business gateway and FHIR APIs (See Figure 4.4 for more information).

Figure 4.4. Australia Current State Architecture



Source: (Australian Digital Health Agency, 2024[16])

Finland

71. In Finland, Kanta is the national repository for social care and patient data which utilising HL7 V3 and HL7 FHIR (for the PHR) standards to enable semantic interoperability between various health information system sources, such as EHRs and EMRs systems. Primary use health data is pulled in from various user groups into the Kanta applications, such as the Kelain for web-based prescriptions, MyKanta, and the national service bus. This data goes through the Kanta messaging layer to distribute the data into specific data repositories, including the prescription centre and pharmaceutical database, the patient data

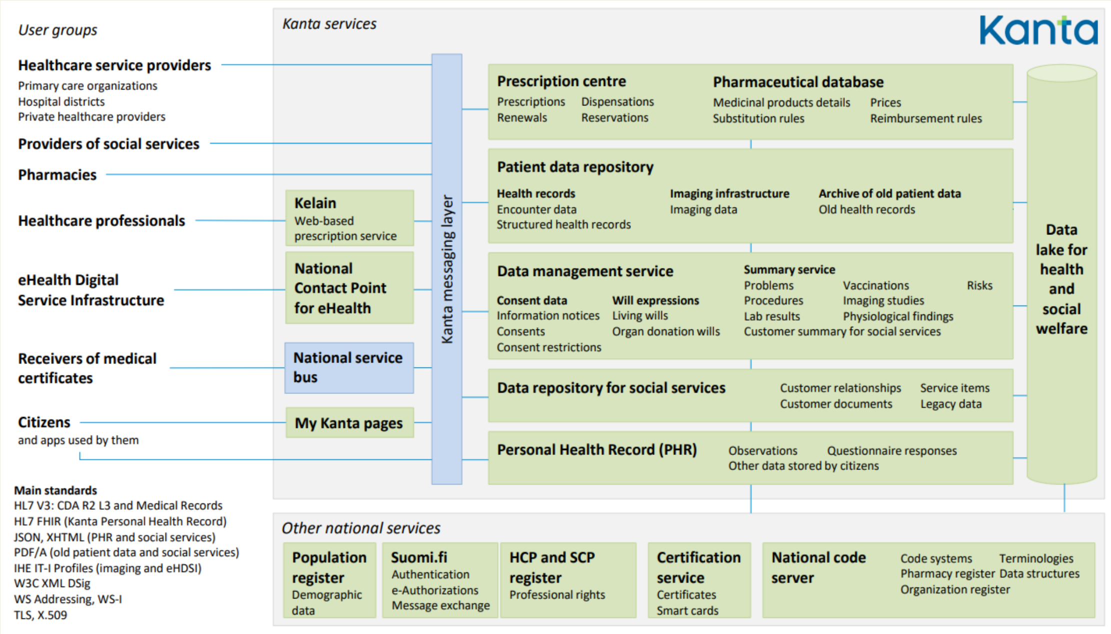
repository, data management services, data repository for social services, and the PHR (See Figure 4.5). Under the *Act on Secondary Use of Health and Social Data* in 2019, a data lake was developed for health and social welfare data to enable the efficient and secure processing of personal data (Ministry of Social Affairs and Health, 2019[17]). This data is combined with that of social insurance institutions in Finland, Digital and Population Data Service Agency, Statistics Finland, and the Finnish Centre for Pensions. Additionally, the Kanta Personal Health Record is a national data repository where citizens have the ability to enter information on their health and wellbeing, with plans in the future for patients to contribute lifestyle and fitness data in Kanta PHR with healthcare and social welfare professionals under the Client Data Act to come into effect in 2026 (Finlex, 2023[18]).

Box 4.2. API Based Infrastructure – Kanta Services

In Finland, the Kanta services serve as a key backbone for both health and social services and is unique in the storing of both types of data. With this data foundation, Kanta offers a single platform for its citizens to access their health data, MyKanta, and to continue to their own PHR, the Kanta PHR.

The Kanta service infrastructure utilises common semantic interoperability standards and the Kanta messaging layer to integrate information between the health data sources into the specific Kanta services. Data is then stored within a data lake for health and social welfare. Common standards are used to support the Kanta data infrastructure and the use of open APIs allow developers to easily integrate.

Figure 4.5. Kanta Services Infrastructure



Source: (Kanta, 2024[19])

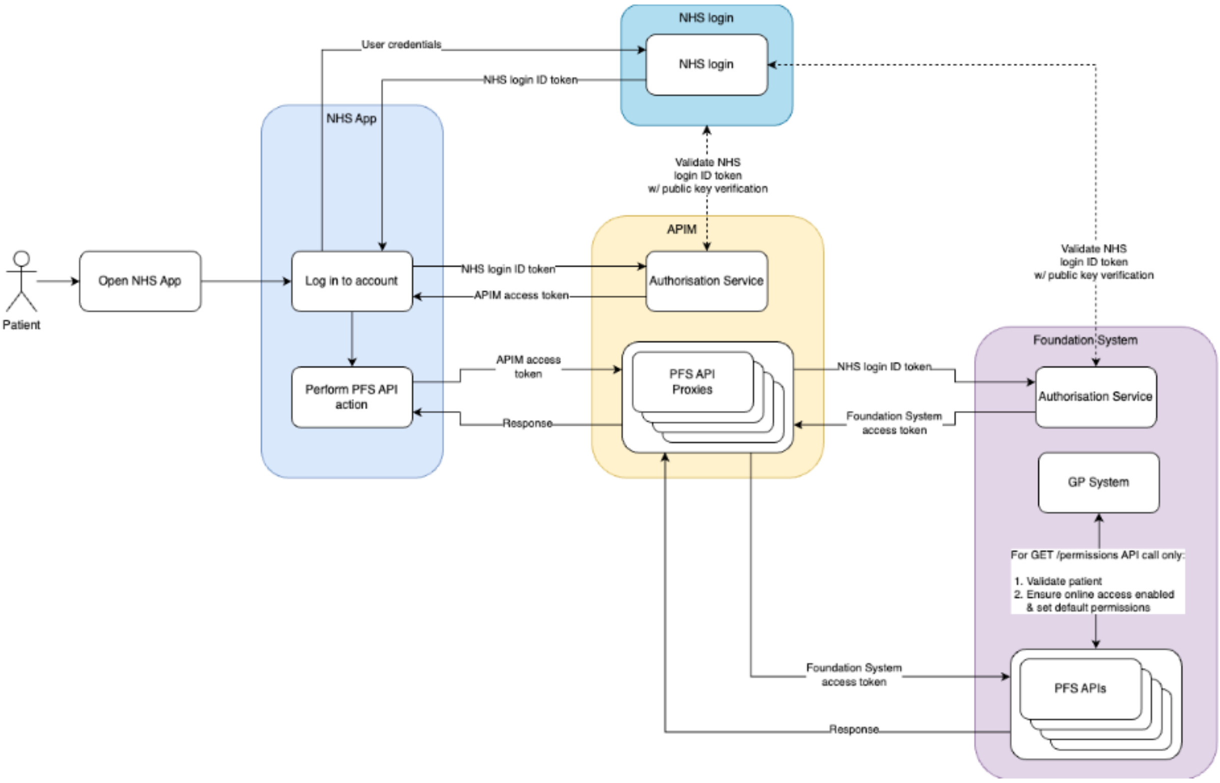
Japan

72. In Japan, patients can access their PHD through the Mynaportal PHR system. A key component of this is the *My Number Card* and its unique personal identifier, which all citizens are required to have in order to access the Mynaportal. To account for the private and public sector data holders within Japan, APIs are publicly available for integration into the Mynaportal PHR. Data is transmitted utilising semantic interoperability standards, including HL7 FHIR. Some example data sources include electronic medical charts containing patient medical information (such as allergies, tests, prescriptions, diagnoses) and medical institutions which can share referral letters and discharge summaries. The foundation for the Mynaportal PHR system is evolving, and to align with the Japanese roadmap for the Promotion of Healthcare DX, a Nationwide Healthcare Information Platform is being developed (Ministry of Health, 2022[20]). This platform will allow for the sharing of information on healthcare, medical care, and nursing care (Ministry of Health, 2022[20]).

United Kingdom (England)

73. In England, the NHS App is available to all citizens with a comprehensive view into their primary care data from general practice offices and a subset of information from secondary care in hospitals. This data is brought together through a network of open APIs which maintain the data in the source system but point to the NHS App to the appropriate local database to present the information to the citizen in their NHS App interface (see Figure 7.3 for more details). The NHS App has many points of integration that bring data into the same space using both HL7 FHIR and older interface standards based on the timing of integration. The primary health identifier, the NHS number, is utilized to connect all data sources. The NHS app data infrastructure leveraged existing requirements for suppliers of EMR systems to develop online solutions for GP practices. One example of this interface is found the use of the API management platform (APIM) to provide source information from the GP system to the patient through the NHS App (See Figure 4.6 for detailed data flow diagram). The NHS is currently developing a future PHR which will have a broader view into the patients' health data and enable patients to contribute wellness information into the record.

Figure 4.6. NHS App Patient Authentication with GP Connect and the API Management Platform



Note: Diagram representing the patient authentication data flow and how the NHS App interacts with the GP patient record.
Source: (NHS England, 2024[21]) Data Flow Diagram - NHS England Digital

Table 4.1. Leading Practices for Data Infrastructure for PHD by Country

Country	**Australia**	**Denmark**	**Finland**	**Japan**	**UK (England)**
Use of standard APIs for integration with PHR/Patient Portal	Limited	Yes	Yes	Yes	Yes
Real time data integration to the PHR/Patient Portal	No	Yes	Yes	Yes	Yes
Existence and utilization of a primary health identifier	Yes	Yes	Yes	Yes	Yes
Open by design systems with common standards for developers	Yes	Yes	Yes	Limited	Yes
Decentralized data storage models, where data remains at the source	No	Yes	Yes	Yes	Yes

Note: Summarised from text in Data Infrastructure and Architecture – Country Findings
Source: OECD Authors; Interviews and information requests from involved countries

Policy considerations

74. Across the five OECD countries, a number of consistent practices were found to contribute to timely and comprehensive access to health information for patients in PHRs. **Denmark** represents a leading practice for the establishment of an integrated data infrastructure across the country with the foundation in the national personal identifier and integration to all EHRs across hospitals, municipalities,

and general practice officers. All countries have made developer tools and architecture available, with the **United Kingdom (England)** and **Finland** leading in the use of open by design products with clear developer tools to connect to the API infrastructure standards for the PHR. Developers can easily access the recommended standards to support the integration of various health data sources and enable data to flow seamlessly from source systems to the PHD platforms for patient viewing, without requiring the copying of the data into the desired architecture.

75. When countries are considering the development of national PHD platform, the foundation lies in open by design systems with common semantic interoperability standards and the ability to integrate between EHR and PHD source systems to enable the viewing of data by patients. Legislative and governance support are also key to enable the timely sharing of PHD.

5 Provider Perspectives

Overview

76. A key perspective to consider regarding personal health data (PHD), patient portals, and personal health records (PHR) are those of the healthcare providers. Healthcare providers hold significant ownership over the quality of health records and continuum of patient care, however they face many challenges in doing so, such as integration barriers, increased workload, and liability concerns when new PGHD is introduced. Additionally, providing patients with more access to their health information and potentially the ability to be a more active contributor to their health record changes the long-standing patient-provider dynamic. With this in mind, understanding the healthcare provider perspective on the access to PHD, the means at which they understand how the data is accessed and shared, and how they foresee their role with the patient changing are crucial to any patient portal and PHR deployment.

77. Across the OECD countries interviewed, healthcare provider perspectives were central to considerations for the development of a national patient portal and PHR, with varied degrees of adoption and support for the tools. The governance structure and decision-making authority within each country, such as a federated or centralised system, also played a role in the legislation and use of incentives for uptake of the tool by healthcare providers. These structures can also impact the amount of PHD which is freely shared with a patient varies, with different takes on the timeliness of data sharing and the inclusion of sensitive information in a patient portal. For example, in Denmark, trust and transparency of information has been ingrained in practices for over 30 years, while in the United Kingdom (England), the culture still veers towards a patriarchal relationship between the patient and their healthcare provider. In Australia, incentives have been used to increase update and quality of the documentation in the MHR, which aims to provide a unique national record to patients within its federated country.

Country Perspective

Australia

78. Australia takes an active approach to healthcare provider engagement, with ongoing support and education offered through the Australian Digital Health Agency, along with supportive legislation. At present, healthcare providers are not mandated to upload information or data from clinical systems into the MHR. However, the implementation of the Sharing by Default framework will contribute significantly to nationally consistent information sharing to MHR by introducing mandatory sharing of key health information, beginning with diagnostic imaging and pathology reports. Providers receive incentives to more actively share information through government programs, such as the Practice Incentives Program eHealth Incentive (ePIP) (Australian Digital Health Agency, 2025[22]). While these incentives do aid in adoption, there is some reluctance from healthcare providers in Australia to contribute to the MHR as it adds additional work into their daily practice, and it not easily integrated into their current workflows. It was also noted that high usage rate by patients would build up the urgency for healthcare providers to contribute information to the MHR. As more patients begin to use the tool, healthcare providers are more encouraged to actively upload and share data to the MHR.

79. The uptake of MHR uploads by healthcare providers is also impacted by the industry adoption of the integration mechanisms for distribution to MHR. Australia is working with technology vendors to adopt common APIs and functionality to allow for integration with the MHR, but the actual implementation of this differs across jurisdictions and vendors. There is a perception that improved quality and consistency in vendor implementation of MHR API could occur if the consumers of the tools, such as the healthcare providers, were more actively requesting it. Australia's healthcare providers could benefit from more integrated means of sharing their patient data with the national MHR system in a way which streamlines workflows and limits healthcare provider burden.

Denmark

80. In Denmark, the transparent sharing of electronic health information has been an ingrained practice since the 1970's. Currently, any citizen can see their comprehensive health record with the exception of GP notes which should be added to the sundhed.dk by 2026 as per a new collective agreement with GPs in September 2024 (Danske Regioner, 2024[23]). Healthcare practitioners are supportive of the sharing of health information and the infrastructure is in place to make this sharing of information seamless.

81. When it comes to PGHD, healthcare providers in Denmark are concerned about the responsibility, potential liability, and additional workload that would be added to have to review this data as part of their everyday practice. Additionally, there is some scepticism regarding how real and reputable the data is in healthcare. Healthcare providers seek to have control of the data and the equipment used to produce the data if applicable, rather than patients own devices.

Finland

82. In Finland, the sharing of health records with patients has been a long-standing, self-evident, and engrained practice which healthcare providers support. Additionally, this support is backed by legislative provisions. *The Act on the Processing of Client Data in Healthcare and Social Welfare*, which came into force in January 2024, specified that each service provider has an obligation to utilise the national Kanta services and with this ensure their health information systems can share data and integrated with Kanta functionalities (Finlex, 2023[18]). All data requirements regarding the primary use of core health records data are clearly specified for healthcare providers. In the context of PGHD, healthcare providers are seeking clear guidance and direction, with some concerns about the variety of health data generated which may impact liability and burden of this rapid expansion of data.

Japan

83. In Japan, the healthcare provider has the autonomy to choose what information is appropriate to be shared with the patient through the Mynaportal. Additionally, Japan is working to support increased implementation of standardised and interoperable EMR systems through subsidies by the Health Insurance Claims Review and Reimbursement Service (Health Insurance Claims Review & Reimbursement Service, 2025[24]). These subsidies will incentivise the input of quality data by healthcare providers and consequently, a rise in quality and consistent PHD in the Mynaportal for Japanese patients. To ensure the success of the Mynaportal and active sharing of health information, the Japanese Medical Association is being engaged in the project.

United Kingdom (England)

84. In England, a number of legislations support the sharing of patient data including the *Data Protection Act* of 2018 and the *Health and Care Act* of 2022 (NHS England, 2018[25]) (NHS England, 2022[26]). The *Health and Care Act* of 2022 also supports a more integrated sharing of health records while

maintaining data protection (NHS England, 2022[26]). While this legislation is in place, a culture shift is still needed from healthcare providers and the system to change the patient's role to being more of a partner in their care. For the health information systems that are already integrated with the NHS app, such as those from the general practice offices and some of the secondary health services, data is less structured and there are regional disparities on the adoption and availability of data in the NHS App. For the systems which do not have integration set up with the NHS app, manual entry may be required to share information with the patient if necessary (NHS England, 2024[27]). The healthcare providers in England do have the ability to exclude specific information from being shared with the NHS app, usually in rare cases where there is a need to safeguard information or prevent harm to a patient (e.g. mental health data) (NHS England, 2024[27]). To support the adoption and use of the NHS App by healthcare providers, England offers comprehensive training sources for integrating the NHS into clinical practice, including how to guide patients on the use of the service (NHS England, 2025[28]).

Leading Practices

85. Across the five OECD countries, common leading practices emerged regarding the roles and sharing of PHD between healthcare providers and patients. Countries are moving towards integrated data flows and the automated sharing of health records through a PHR and/or patient portal. In this, the healthcare provider experiences limited impact to their existing workflows but retains the ability to exclude information on a case-by-case basis as applicable. Some countries, such as **Australia** and **Japan**, are using incentives to enable the more proactive sharing of select PHD with the national patient portal/PHR, however a more efficient and effective approach is to not add additional work to the healthcare providers workflow. The feasibility of this integration is influenced by the structure of the health system. Additionally, countries are taking different approaches to engaging healthcare providers in the design, deployment, and adoption of the national PHR and/or patient portal. Active and ongoing engagement are crucial to ensuring healthcare providers buy in to the new technology and are active participants, ensuring standardised and high-quality data is available to patients. The use of a PHR and/or patient portal introduces a new dynamic in the patient healthcare provider relationship, designing the systems, the timeliness, and completeness of the health data which is shared with a patient with key healthcare provider groups is key.

86. With PHR, the patient owns and can modify their own health record which introduces a new data type, PGHD. Healthcare providers are interested in gaining access to more timely and accurate data about their patients care, but considerations are needed regarding the liability on healthcare providers to review the data, the quality and reliability of the data, and how it will be brought into a healthcare providers everyday practice. **Finland** is taking an active approach in this space to legislate that this data will be brought into MyKanta in 2026 and are actively engaging healthcare providers in the work to support this.

Table 5.1. Leading Practices for Provider Perspective in PHD

	Australia	Denmark	Finland	Japan	UK (England)
Use of incentives to enable sharing of information to the patient portal and/or PHR	Yes – Vendor and Provider	No	No	Partial	Yes - Vendors
Provider control over the information to be shared in the patient portal and/or PHR	Yes	Partial	Partial	Yes	Partial
Complete sharing of patient record in the patient portal and/or PHR	Partial	Yes*	Yes*	Partial	Partial
Provider support for the integration of patient generated health information into the patient portal and/or PHR	In Development	In Development	In Development	In Development	In Development
Automated sharing of patient data to the patient portal and/or PHR	No	Yes	Yes	Yes	Yes
Engagement process for healthcare providers regarding the use of PHR/Patient Portal	Yes	Minimal	Minimal	Yes	Yes

Note: Summarised from text in Provider Perspective – Country Findings, *Small exceptions are not included in the patient portal and/or PHR (e.g. GP notes in Denmark and some private practice notes in Finland. Additionally, healthcare providers can exclude data if deemed necessary for patient care and/or patient privacy concerns)
Source: OECD Authors; Interviews and information requests from involved countries

Box 5.1. Australia's Provider Embedded Engagement in My Health Record

In Australia, concentrated efforts have been made to embed healthcare provider engagement in the work to expand the scale and use of the MHR system. Regular engagement and discussion with providers are a key step to build trust, buy in, and desire to promote and advocate for the use of the MHR by patients. With more healthcare provider input in the design and implementation of the tool, the associated usefulness and usability also improves.

This embedded engagement was essential due to the fragmented nature of health services across the federated states and territories. The work of developing the MHR system set in place health data standards at a national level. Healthcare provider stakeholder engagement and active participation are a key component of maximising the amount and quality of information in the patient portal.

One example of this active engagement is the comprehensive support services is from the Australian Digital Health Agency which provides educational eLearning, training, and individual support on request. The Australia Government has also introduced the Practice Incentives Program eHealth Incentive (ePIP). This program supports healthcare providers to meet the data quality standards and supports the ongoing use of the MHR.

Source: (Australian Digital Health Agency, 2025[22])

6 Patient Perspectives

Overview

87. Patients are at the core of any Patient Portal or PHR solution, with a primary objective of providing open access to health records is to empower patients to be more empowered in their own care. Some key considerations for patients when accessing their own health information electronically are the consent over their information, transparency into how the information is being collected and used, the accessibility, usability, and equitability of the digital technologies, and the ability to be a more active member in their care through contributing to the health record and/or correcting errors and omissions. It has been demonstrated that access to personal health information is beneficial to patient engagement and ongoing management of care, especially in chronic disease management (Carini et al., 2021[29]).

88. Legislation is starting to move countries towards more open access to health data for patients, including the European Health Data Space, which includes stipulations for 5 key principles: the right to access, proxy access, rectifying errors and omissions, patients input of their own health data, and access control (Hägglund et al., 2024[30]). These legislative steps are working towards putting the patient at the centre of their care and their data.

89. Another consideration is the patients trust in how their data is being used, both with the use and lack of use of health data (Wawrzyniak, 2024[31]). For a long time, the health industry has focused on the harm of data being breached and patients personally identifiable information is no longer secure. In these instances, there is a potential harm to the patient and associated loss of potential trust. However, there is also a challenge related to trust and not utilizing health data. If a patient is trusting their healthcare provider and/or organisation to have access to their health information, they want it to be used (Wawrzyniak, 2024[31]). If the data is not being looked at, acknowledged, or appreciated, the trust a patient has in the process and value of sharing their information will be minimized.

90. Each of the interviewed OECD countries have made patient engagement and empowerment in their care a key priority with the introduction of patient portal and/or PHR solutions. In their implementation, different approaches to consent, equity, accessibility, and engagement have been taken based on the country context.

Country Perspectives

Australia

91. In Australia, a key focus is to integrate the health record and provide patients with one place where they can see their health journey. This vision is still in progress, as work is underway to better integrate vendor solutions with MHR and increase use of MHR by both patients and healthcare providers. MHR was initially implemented with an opt in model but due to low uptake of the tool, a transition was made towards an opt out model in 2018. To support patients' privacy concerns, there is the ability to delete an MHR, and once deleted the whole record is permanently deleted. If a patient wishes to re-open a MHR in the future, it is started from scratch and any data uploaded by their healthcare providers is lost within the MHR system. Patients are also granted access controls to protect their information, including choosing

what their healthcare providers can view and choosing a nominated representative (e.g. family member) to access, view, and manage their record. Transparency is built into MHR by allowing patients to know which healthcare providers have accessed their record. To support the literacy and equitability of MHR, Australia has provided its consumers with comprehensive online learning modules and educational videos.

92. In terms of the ability for patients to interact with their health record more actively, MHR offers a national view of their health information and the ability to share that information with their healthcare providers. Additionally, patients are able to update some of their information including: contact numbers and emergency contact details, current medicines, allergy information (including previous reactions), personal health notes (for their own use rather than sharing with the clinician), child's development and health information, Indigenous status, Veterans' or Australian Defence Force status, advance care plan or contact details of custodian, preferred language, country of birth (Australian Digital Health Agency, 2024[32]). Managing care (e.g. appointments, communication with healthcare provider) is technically done via separate applications, such as 'My Health App', not directly within MHR. One unique attribute MHR provides Australian citizen's is the ability to record wellness data and other personal health notes in MHR, but that information is not currently distributed anywhere for further use.

Denmark

93. In Denmark, which has a longstanding history of open record access, transparency, and citizen trust in the health system, work is just starting for enabling patient access to alter and update their own record. Patients are provided with full transparency of what interactions have occurred with their PHD, who has accessed it, and what the healthcare providers charged for the associated health encounters to prevent fraud. This is accessible through the MyLog where patients can see which healthcare providers have access their record and when.

94. In Denmark, privacy is done by design and consent is assumed. Patient consent to sharing their PHD is implied and patients have the right to deny access to their health records if they do not wish particular data to be seen by other health professionals (sundhed.dk, 2024[33]). In the case where a medical emergency is occurring, any data blocking can be circumvented to allow the necessary healthcare professionals to access the information.

95. Denmark is also leading with efforts in digital and health literacy, with an active partnership with France, and a conscious approach of enabling patients who do not feel comfortable utilising technology to still receive their health information via analogue means (e.g. paper referral letters in the mail or phone appointment booking). There is also an accepted practice that patients can contact their healthcare provider to understand the implication of their PHD viewed in sundhed.dk and to ensure the information is written in a way that is understandable. For complex situations, more attention is paid to the understanding of and communication with the patient, especially to help those who may struggle more with the provided digital tools. For Denmark, supporting patients who may encounter challenges with seeing their full health record in sundhed.dk are a larger challenge than those facing literacy barriers, though both items are prioritised. Some approaches to reduce equity barriers include communication campaigns on sundhed.dk to locate their health data and to provide information on the website in English.

96. Denmark acknowledges that patient generated health data (PGHD) is an area which requires additional investigation. There is currently no infrastructure, website, or tool for patients to share their data with their health providers outside of the clinical encounter. Additionally, there are concerns raised by the healthcare providers, specifically physician unions, about the responsibility they would have related to PGHD. The current impression is that PGHD from wearables devices and other sources, is not real health data. With this in mind, Denmark is looking into means to support patients to contribute to their own hospital records to align with the EHDS legislation.

Finland

97. In Finland, trust has been paramount in the development of Kanta services and MyKanta, with citizens given the ability to define the use of their PHD within the stipulations of the law. For example, patients do have the ability to restrict the use of their data partially or by a particular service provider. Patients also are able to see who has accessed their information and for what purposes. When collecting PHD, patient consent is defaulted and given unless explicitly denied. By receiving treatment, the consent to use of their data is implied. To support patient literacy about their health information, physicians and nurses can explain the contents of their health information during the visit. Additionally, patients can contact their healthcare provider for clarification.

98. In Finland, it was acknowledged that the PGHD space is a bit tattered, as activities are happening on a number of various levels from national, local, regional, and privately. A lot of clarification is needed regarding the specifications of PGHD. Currently in the MyKanta portal, the patient can contribute certain information, but it is not shared back to the healthcare provider (Kanta, 2024[34]). In general Kanta service does not transfer any citizen's health app data to or from the national health service applications and health and wellness applications are not currently connected to the personal information database. There is future development work planned to enable patients to have a more interactive experience with their health data through a PHR (Kanta, 2024[35]). This work aligns with the new *Act on the Electronic Processing of Client Data in Health Care and Social Welfare* which is set to be in force in January 2026 and by that time, for Kanta services to enable wellbeing data from the Kanta PHR to be available to healthcare providers (See Box 6.1. Finland and Setting Standards for the Kanta PHR) (Kanta, 2024[36]).

99. A national level discussion is occurring in Finland on the Kanta and what the requirements are for PGHD to be used in healthcare, with some initial examples including blood pressure and blood glucose data (see Box 6.1). It was mentioned that new SNOMED-CT standards have been defined for PGHD, but it is not yet clear on what data is reliable enough to be utilized in the healthcare setting. There is a need to develop the data standards in a uniform way and to validate the quality of the data, as patients can produce data in a variety of ways. PGHD is an area of focus for Finland, but there are a number of issues which need to be solved around the citizen producing the data themselves, such as how to prioritize the information, how it will be viewed, and interoperability standards.

United Kingdom (England)

100. In England, two levels of consent are used for the NHS App. By default, PHD is shared with the appropriate healthcare providers by receiving care at the NHS. To enable patients to have control over the use of their data for secondary data use, there is a national data opt-out process (NHS, 2024[37]). An addition feature included in the NHS App is the ability to opt in or out of organ donation. The NHS has also taken a clear approach to digital and health literacy of its citizen's, with an inclusive digital healthcare framework (NHS England, 2024[38]). This framework provides guidelines on how to address inherent disparities and has set forth initiatives to improve the digital literacy, accessibility, and equity of service.

101. The NHS App team is working towards utilising the application for more preventative medicine, including vaccinations, screening programs, and health promotion. Currently, the NHS app does not allow patients to directly input or update their own health information but does allow them to communicate with their healthcare providers through messaging (NHS, 2023[39]). One key initiative underway is the development of a PHR system, which is still being specified and the requirements being established; it is envisioned that patients will be able to contribute their own health data, including those from wearable devices.

Japan

102. In Japan, the Mynaportal is Japan's national citizen portal, enables citizens to view their medical records, health insurance details, test results, and medical expense information but does not yet support patient entry or updating of PHD (Mynaportal, 2017[40]) Some information is visualized to aid in the understanding for patients, such as test results. The government aims to expand these digital health capabilities, eventually enabling patients to actively contribute to their health records in a standardized format. This will be in the form of a PHR system that would allow citizens to access their health information and contribute PGHD, including daily activity data, to support illness prevention and promote health maintenance (総務省、厚生労働省、経済産業省, 2021[41]).

103. Privacy provisions around the use of the Mynaportal and PHD are outlined in the *Act on the Protection of Personal Information*, including the clear rules regarding data use (Japanese Government, 2003[42]). Consent for the use of PHD is required through the My Number Cards, and when used, consent is valid for 24 hours. With consent, PHD that is stored within online verification systems of the insurance providers and is shared with medical institutions and pharmacies.

Leading Practices

104. Across the five OECD countries, a number of leading practices emerged from the patient's perspective regarding PHD. Patients are looking to gain more access to their health information and have a central place to be able to interact with the system. Countries are responding to these needs by developing patient portals and PHR systems which allow the management of appointments, communication with their healthcare professionals, immunisation records, electronic prescription management, referral management, and supporting digital and health literacy resources.

105. Consent is often implied to the use of PHD, with additional provisions in place regarding the use of that data in a patient portal or PHR application. Countries are transitioning to the use of an opt-out model for these applications to ensure more equitable access while also enabling patients who are not comfortable with their data being shared in this platform to restrict its use. Other considerations are made for the blocking of certain PHD or for certain healthcare practitioners to provide patients with more power over their own PHD.

106. To respond to the growing amount of PGHD that patients have access to through wearable devices and wellness applications, OECD countries, such as the **United Kingdom (England)** and **Finland** are in the process of developing PHRs which allow patients to contribute their own health information and have ownership of their health record. Currently, the information stored in the PHRs are not shared back to healthcare professionals, but **Finland** is actively working to provide this functionality, and it will be required of other European countries with the enactment of the EHDS legislation. The future path for patients is to be able to interact with their health information, with the ability to contribute to their own PHD and correct errors and omissions.

107. While greater access and contribution to personal health data strengthens patient empowerment and engagement, it must be accompanied by robust rights and privacy protections to maintain public trust. Across OECD countries, legal frameworks such as the EU General Data Protection Regulation (GDPR), **Japan's** *Act on the Protection of Personal Information*, and **Korea's** *Personal Information Protection Act*, establish transparency, accountability, and individual control over data use while ensuring that data access and sharing respect clear consent mechanisms and safeguards against misuse. Strengthening these rights-based approaches will be essential to ensure that expanding coverage and usage of personal health data supports patient privacy and trust.

Table 6.1. Leading Practices for Patient Perspective in PHD

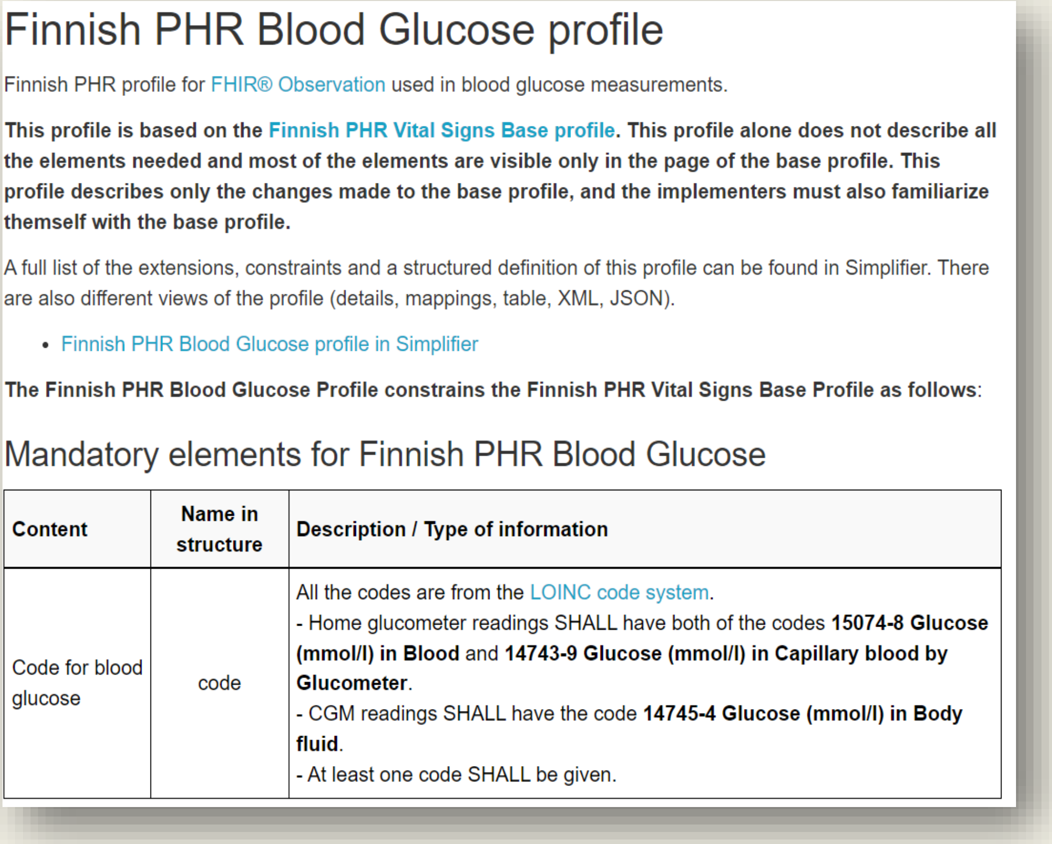
	Australia	**Denmark**	**Finland**	**Japan**	**UK (England)**
Use of opt-out model for national patient portal access	Yes	Yes	Yes	No	Yes
Transparency in data access and use by health professionals	Limited	Yes	Yes	Limited	Limited
Ability to contribute patient generated health data in a national PHR	Limited	No	In Development	Limited	In Development
Available education and strategy to support digital literacy associated with PHR and patient portal use	Yes	Yes	Limited	Limited	Yes
Ability to correct errors and omissions through patient portal or PHR	No – Can be requested through healthcare provider	No – Can be requested through healthcare provider	No – Can be requested through healthcare provider	No – Can be requested through healthcare provider	No – Can be requested through healthcare provider
Ability to manage care through a patient portal or PHR (e.g. appointments, communicate with health professional)	Yes (through separate app)	Yes (through separate app)	Yes	Limited	Yes

Note: Summarised from text in Patient Perspective – Country Findings
Source: OECD Authors; Interviews and information requests from involved countries

Box 6.1. Finland and Setting Standards for the Kanta PHR

Finland's Kanta service has demonstrated a leading practice in their preparation for the inclusion of PGHD into the health record, which is based in data standards and HL7 FHIR. It provides a strong example of how to build transparent public private sector partnerships and enable higher quality PGHD.

The Kanta PHR system is still in development, but information is publicly available on the standards, specification, integration criteria and overall developer guidelines for the PHR. Included in this specification are links to the FHIR profiles and key elements for all relevant data which could be incorporated into the PHR, including vital signs like blood glucose, body weight, and blood pressure. The approach sets the stage for Finland to enable data interoperability, higher levels of PGHD data quality, and easier integration of PGHD. It is proactively preparing for the updates to the Finnish Client Data Act, which will come into force on January 1, 2026, and requires Kanta services to share patient wellbeing data from the Kanta PHR to healthcare and social service providers.



Finnish PHR Blood Glucose profile

Finnish PHR profile for FHIR® Observation used in blood glucose measurements.

This profile is based on the Finnish PHR Vital Signs Base profile. This profile alone does not describe all the elements needed and most of the elements are visible only in the page of the base profile. This profile describes only the changes made to the base profile, and the implementers must also familiarize themself with the base profile.

A full list of the extensions, constraints and a structured definition of this profile can be found in Simplifier. There are also different views of the profile (details, mappings, table, XML, JSON).

- Finnish PHR Blood Glucose profile in Simplifier

The Finnish PHR Blood Glucose Profile constrains the Finnish PHR Vital Signs Base Profile as follows:

Mandatory elements for Finnish PHR Blood Glucose

Content	**Name in structure**	**Description / Type of information**
Code for blood glucose	code	All the codes are from the LOINC code system. - Home glucometer readings SHALL have both of the codes **15074-8 Glucose (mmol/l) in Blood** and **14743-9 Glucose (mmol/l) in Capillary blood by Glucometer**. - CGM readings SHALL have the code **14745-4 Glucose (mmol/l) in Body fluid**. - At least one code SHALL be given.

Source: (Kanta, 2024[35]) (Kanta, 2023[43])

7 Discussion

Key Findings

108. The healthcare system is in the process of providing patients with greater transparency, ownership, and engagement into their PHD and care. A big enabler of this change is the use of Patient Portals, PHR and PaEHRs systems to share a patient's health record with them in a timely and transparent way (See Box 1.1 for more details). In this report, the governance, policies, technical infrastructure, data, standards, and key stakeholder perspectives related to PHD were explored to identify leading practices to facilitate this new care dynamic. While there is evidence to support patients having more access and ownership of their PHD, implementing the necessary technologies can face a number of challenges (Neves et al., 2020[7]). These challenges include the integration of health information systems, timeliness and accuracy of the data, collaboration in private public sector partnerships, equitable access, and supporting the adoption by patients and healthcare providers. Experts related to the PHD systems for each of the five OECD countries were interviewed to understand how these challenges are being addressed and what type of access patients currently have to their PHD. It was found that the structure of the health system, from federated to centralised, have an impact on the countries adaptability and capacity to counteract each challenge. Each country approached the goal of providing more open PHD access to their patients with different tools and technologies (see Table 7.1).

Table 7.1. Country Approach to Open Personal Health Data Access for Patients

Platform	Patient Portal	PaEHR	PHR
Australia (My Health Record)	Yes	Developing	Yes
Denmark (Sundhed.dk)	Yes	Yes	No
Finland (MyKanta)	Yes	Yes	Developing
Japan (MynaPortal)	Yes	No	Yes
United Kingdom (England - NHS App)	Yes	Developing	Developing

Source: OECD Authors; Interviews and information requests from involved countries

109. Interviews revealed key leading practices to enable a national PHR and/or PaEHR system, with a foundation of legislative direction, data standards and integration, and active engagement with key stakeholder groups. One key legislative action which is driving the way patient's role in their care is the European Health Data Space (EHDS). This legislation sets the precedence for member states to provide patients with the ability to view, share and manage their own PHD, ultimately enabling them to be a more active participant in their care (See Box 7.1 for more information). Findings from this analysis show that several OECD countries are already advancing many of the EHDS's core ambitions, such as mandating common data standards, improving data portability and strengthening consent frameworks. These align closely to the leading practices identified in this analysis, which indicates complementary practical pathways for the implementation of personal health data systems compatible with initiatives like the EHDS.

Box 7.1. European Health Data Space

The European Health Data Space (EHDS) is setting the stage for patient empowerment and engagement with the mandate to incorporate PGHD into EHRs. This framework requires healthcare systems to allow individuals to contribute their own health data, a first step to information such as patient surveys, wellness tracking, self-reported symptoms, and lifestyle data being reflected in the health. Additionally, the EHDS is enabling patients to be able to update their records when errors or omissions are noticed, allowing for a more comprehensive and accurate health record. These principles support a more participatory model of healthcare, where patients have both transparency about their health data and agency over their health information.

The EHDS regulation was adopted by the European Parliament on April 24, 2024. Member States are required to implement the EHDS provisions within 24 months from the date of entry into force, aiming for full compliance by the second half of 2026.

Source: (European Commission, 2024[44]) (European Parliment, 2024[45]) (European Union, 2022[46])

EHDS Regulation:

Article 8b, "Natural persons or their representatives as referred to in Article 8aa(2) shall have the right to insert information in their own EHR through electronic health data access services or applications linked to these services as referred to in Article 8aa. That information shall in such cases be clearly distinguishable as inserted by the natural person or by his or her representative. Natural persons shall not have the possibility to directly alter the electronic health data and related information inserted by health professionals."

Article 8c, "Electronic health data services referred to in Article 8aa shall provide a possibility for natural persons to easily request rectification of their personal data online as a way to exercise their right to rectification under Article 16 of Regulation (EU) 2016/679. Where appropriate, the data controller shall validate the accuracy of the information provided in the request with a relevant health professional."

110. The **10 key leading practices** for the implementation of PHD systems are:

Governance

- Health data authority supported by legislation enacting a robust health data governance framework to promote the protection and responsible use of PHD, as well as the regulatory mandate to drive the common use of standards, data reporting and sharing, and compliance across health data offices, providers, private sector, and other key stakeholders.
- Coordination with vendors (E.g. EHR/EMR systems), public/private partnerships, and continued engagement on requirements to share information, to enable the existing and net new systems developed to be integrated into the national data infrastructure.

Personal Health Data

- Mandate comprehensive and standardised data contributions to allow integration between various data sources (e.g. EHRs and EMRs) across the country, bringing them together with common definitions and standards in the PHD platform.
- Enhance data timeliness and integration by developing regulatory frameworks that mandate all healthcare providers, including private sector entities, to contribute standardised, structured data to national PHRs and patient-accessible portals. Encourage the use of HL7 FHIR or equivalent standards to ensure interoperability and usability of data across systems.

Data Infrastructure and Architecture

- Use open by design systems which establish common standards for health information system vendors and developers to use, ensuring the ability to seamlessly integrate new and existing technology to create an integrated data infrastructure.
- Utilise decentralised data storage models where data remains in the source systems and is brought into the patient PHD platform through APIs. This allows for the data to be shared in a timely manner, ensuring it remains up to date, and reduces the storage requirements for the patient PHD platform.

Provider Perspectives

- Complete sharing of patient records in the patient-accessible EHR (PaEHR), PHR, and/or patient portal to enable full transparency for patients into their own PHD. Be clear on exceptions, with the direction of providers, if the sharing of the data is deemed harmful and/or concerning for the patients care.
- Engagement and supportive process for healthcare providers regarding the use of the PHD platform and how to best support patients. Healthcare providers are key stakeholders, and a comprehensive approach that engages them in the decision-making and requirements process, deployment, and ongoing operational use of the platform are key to ensure continued use and to establish the patient as a partner in their care.

Patient Perspectives

- Transparency in data access, consent, and use by health professionals are key components to obtain patient trust and engagement in their care. Sharing this level of information allows patients to better understand how their data is being used and for what purposes, demonstrating transparency and openness between patients and healthcare providers.
- Ability to contribute patient generated health data in a national PHR is an important next step for PHD platforms, allowing more ongoing data which is collected outside of the regular clinical encounters to be incorporated into the ongoing health and wellness data available to healthcare providers about their patients.

111. The interviewed OECD countries alignment to the leading practices is summarised in Table 7.2 below.

Table 7.2. Summary of leading practices in PHR and PaEHR systems across five OECD member countries

Section	Leading Practice	Australia	Denmark	Finland	Japan	United Kingdom (England)
Governance	Health data authority that oversees and can impose standards regulations (or others)	🟩	🟩	🟩	▨	🟩
	Coordination with vendors (E.g. EHR/EMR systems) and public/private partnerships	▨	🟩	🟩	▨	▨
Personal Health Data	Mandate comprehensive, standardised data contributions	▨	🟩	🟩	▨	▨
	Enhance data timeliness and integration (incl. patient-generated data)	▨	🟩	▨	▨	▨
Data Infrastructure and Architecture	Decentralised data storage models, where data remains at the source	⬜	🟩	🟩	🟩	🟩
	Open by design systems with common standards for developers	🟩	🟩	🟩	▨	🟩
Provider Perspective	Engagement process for healthcare providers regarding the use of PHR/PaEHR	🟩	▨	▨	🟩	🟩
	Complete sharing of patient record in the PHR/PaEHR	▨	🟩	🟩	▨	▨
Patient Perspective	Transparency in data access and use by health professionals	▨	🟩	🟩	▨	▨
	Ability to contribute patient generated health data in a national PHR/PaEHR	▨	⬜	▨	▨	▨

Yes	🟩	No	⬜	Partial	▨

Source: OECD Authors; Interviews and information requests from involved countries

Considerations for Korea

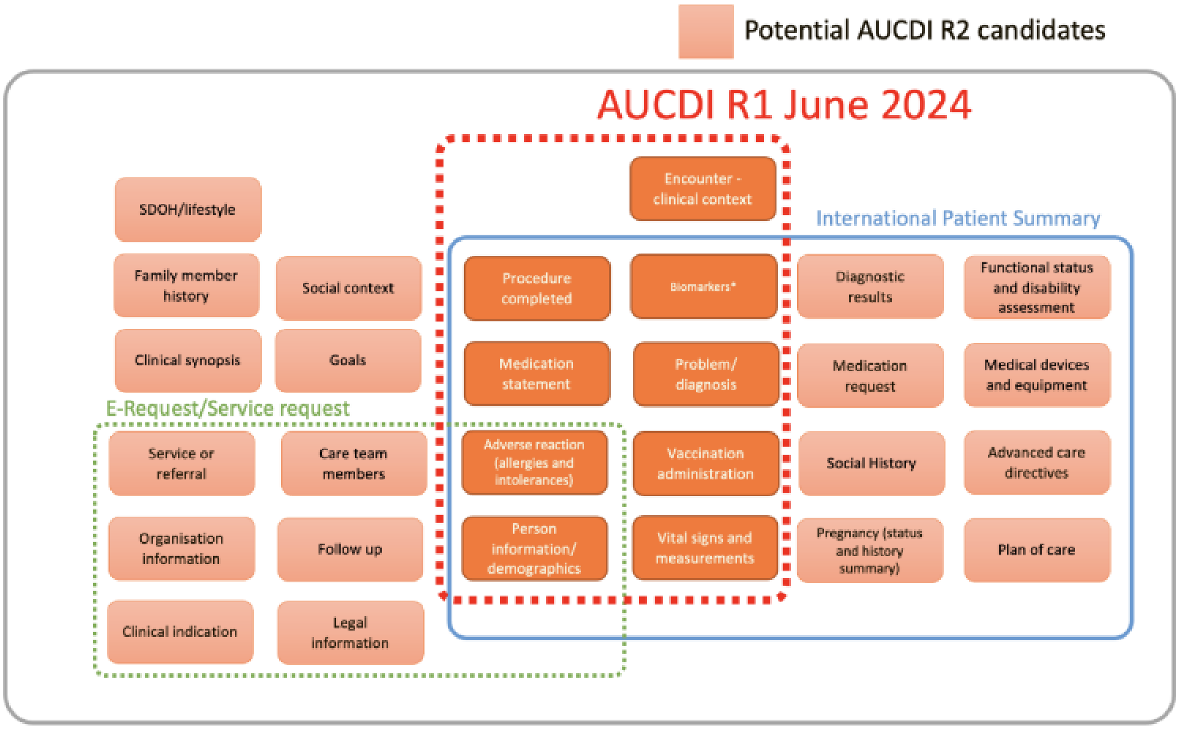
112. In Korea, the My Healthway platform serve as a key component of a national digital health initiative that provides patients with centralized access to their personal health information, including vaccination records, health checkup results, treatment histories, surgery reports, and pathology test results (Ang, 2023[47]). Managed by the Ministry of Health and Welfare, the My Healthway platform aims to streamline healthcare access and improve continuity of care. Currently, patients can view and share their health information with authorized healthcare providers, although they are not yet able to directly input or update their own health data within the platform. The government is working toward integrating PGHD in future updates, with the potential for including data from wearable devices and home monitoring tools to support more proactive and preventive healthcare (OECD, 2022[48]). Key challenges remain, such as ensuring data security, improving interoperability across healthcare systems, and addressing patient digital literacy to enhance engagement and the effective use of My HealthWay (Lee et al., 2022[49]).

113. As Korea works to support the My Healthway platform, the lessons from the five OECD countries can be used to address the key challenges facing the country. This report identified that a key to success is to have a history of legislation establishing the transparent sharing of health records with patients, patient ownership of their health information, privacy by design and opt-out models to gaining access to a PHD

platform, and to use legislation and an established health data authority to set and enforce data standards. Healthcare providers are key stakeholders in the active implementation of a PHD platform and it is key to engage them throughout the planning, development, and implementation. Additionally, healthcare vendors are key stakeholders as they develop the applications with which the PHD platform should be integrated with. It is key to establish open by design systems and clear development standards for seamless integration into the existing healthcare data infrastructure through APIs.

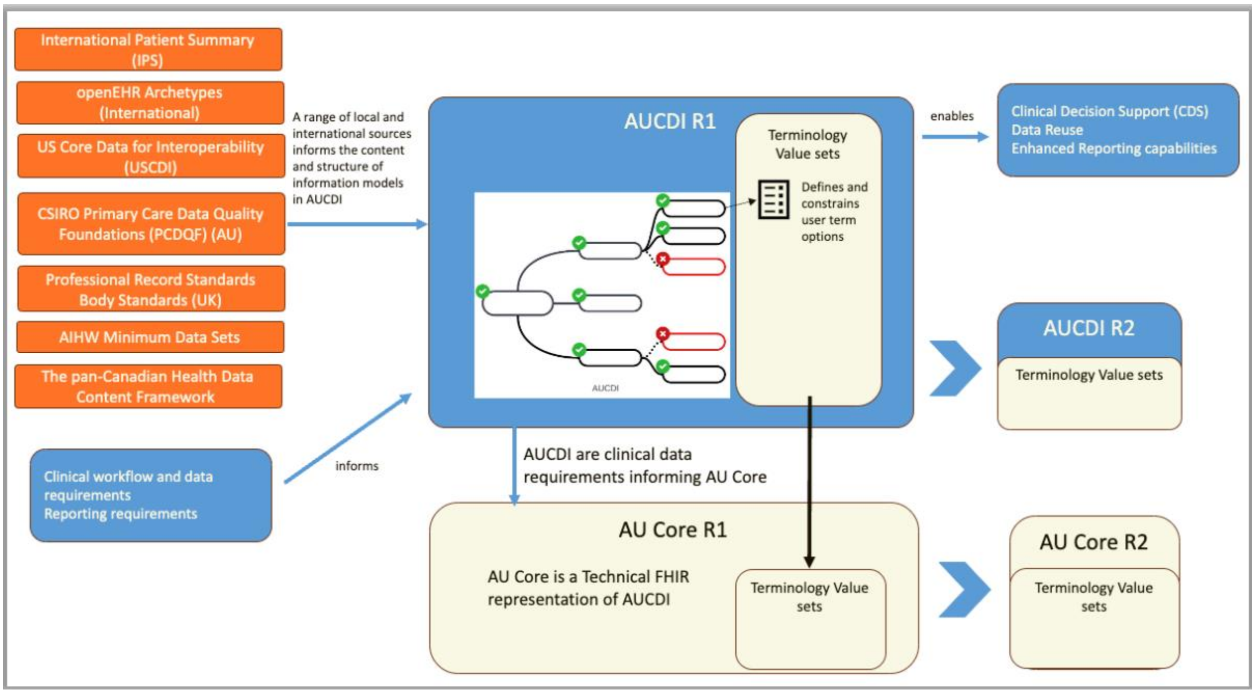
8. Appendix:

Figure 7.1. Australian Clinical Data for Interoperability (AUCDI) – Release 1 (R1)



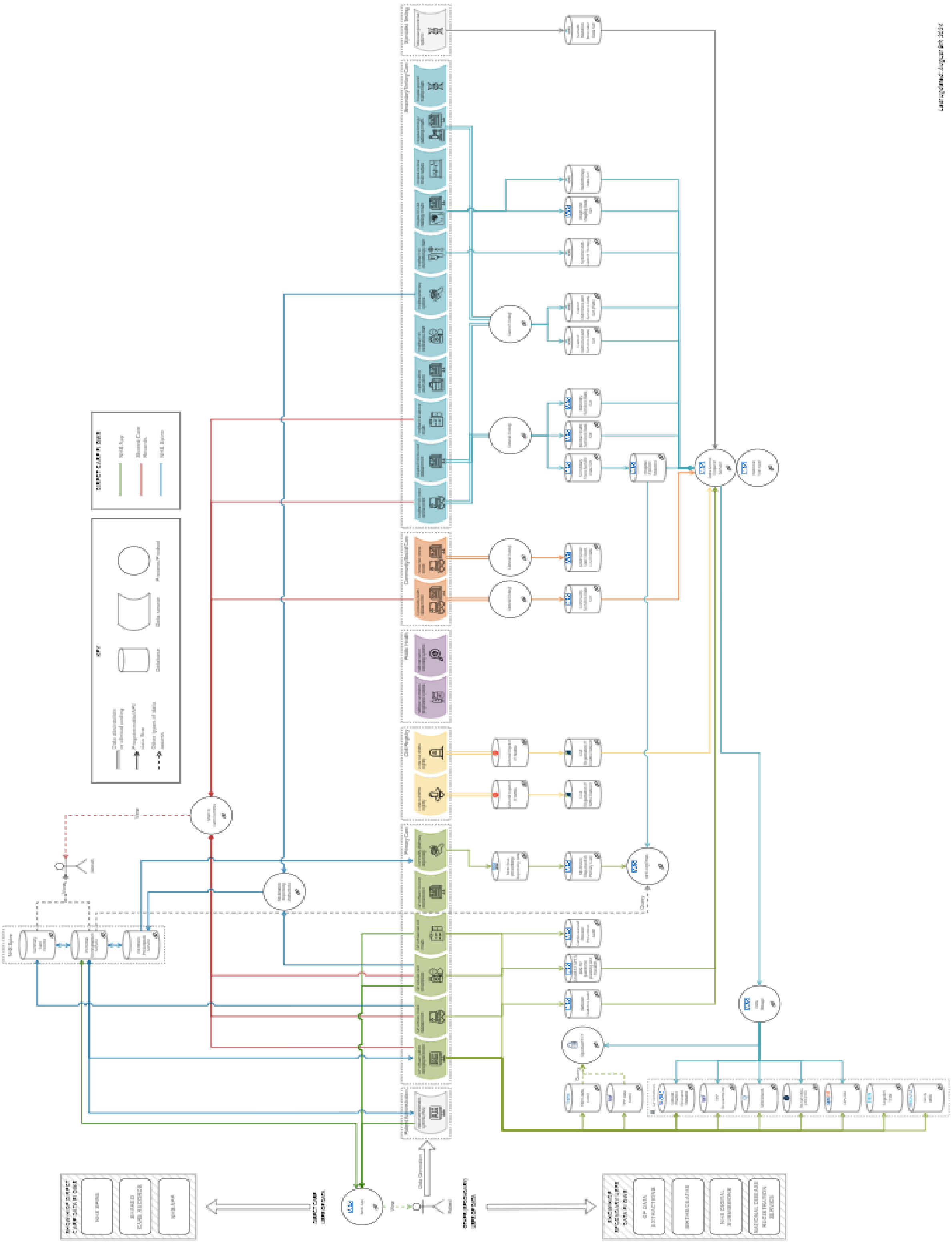
Source: (Sparked, 2024[50]); Design of the AUCDI – Sparked

Figure 7.2. Australian AUCDI and Partnerships



Source: (Sparked, 2024[50]); Design of the AUCDI – Sparked

Figure 7.3. NHS Data Architecture and Data Flows



Source: (NHS, 2024[51]); [National Schematic – NHS Data Architecture & Data Flows]

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