Towards an Integrated Health Information System in Korea



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Foreword

OECD countries need to have the right data infrastructure in place for producing health statistics and measuring health care quality and outcomes. This relates to information gathered through registries, administrative data, EHRs and other sources – and concerns data linkage between settings and levels of care, and mechanisms to generate and use timely, actionable data. Interest in strengthening health information systems has grown since the COVID-19 pandemic has brought into sharp focus the importance of reliable, up-to-date information for decision making.

The OECD launched country reviews of health information systems in January 2021 to support countries in developing health information systems for the digital age. Country reviews follow a method where OECD and national experts jointly undertake a process of uncovering the barriers and facilitators to each country's progress toward a 21st Century health information system. With a common core of content, the reviews can be compared across participating countries, furthering the value of the project to all countries.

The framework for the evaluation of each health information system is the OECD Recommendation on Health Data Governance which calls for National Health Data Governance Frameworks and sets out the key principles of such frameworks. All countries are encouraged to adhere to this Recommendation which provides guidance for building national governance frameworks that enable personal health data to be both protected and used towards public policy goals. The Recommendation:

- Encourages the availability and use of personal health data, to the extent that this enables significant improvements in health, health care quality and performance and, thereby, the development of healthy societies while, at the same time, continuing to promote and protect the fundamental values of privacy and individual liberties;
- Promotes the use of personal health data for health-related public policy objectives, while maintaining public trust and confidence that any risks to privacy and security are minimised and appropriately managed; and
- Supports greater harmonisation among the health data governance frameworks of countries that are adherents to the Recommendation so that more countries can benefit from statistical and research uses of data in which there is a public interest, and so that more countries can participate in multi-country statistical and research projects, while protecting privacy and data security.

Korea's Ministry of Health and Welfare commissioned this review to support the country in strengthening its health information system to support continuous learning, and improvement and innovation.

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Executive summary

Twenty-first century health systems will be built around data and information. The Korean Ministry of Health and Welfare commissioned the OECD to review the management and use of health data in Korea, and to recommend changes that would enable creating a health information system that supports achieving national health policy objectives.

An integrated health information system would help Korea improve its capacity to get the best performance and value out of its health system in three ways. First, it would directly improve care quality (including safety, effectiveness and efficiency). Second, it would improve patient empowerment by enabling people to access their own health information and for this information to "follow the patient" wherever they seek care. Third, it would raise the country's capacity to use health and other data for important secondary purposes, such as continuous assessment of health system performance.

A range of data assets are relevant to an integrated health information system. For Korea this includes data generated during acute- and long-term health care, data on public health and social care as well as other relevant data sources such as social, economic and environmental data.

The OECD reviewed the health information infrastructure in Korea using the OECD Recommendation on Health Data Governance as a framework. It drew information from interviews and focus groups with Korean experts from academia, business, and government and from OECD and other surveys and reports.

Building on the strengths of Korean health data infrastructure and addressing challenges

Korea has taken great strides towards creating a health data infrastructure conducive to a high-performing, modern health system. Its insurance claims data, in terms of timeliness, coverage, volume and detail, are among the best in the world. Korea reports excellent data availability, maturity and coverage of key health datasets compared to other OECD countries. Korea is also among the countries with the strongest data governance across key national datasets.

Korea implemented a unique Drug Utilisation Review system that provides a prospective, real-time review of drug prescriptions to minimise the risk of safety harms such as contraindications, drug/drug interactions or ingredient duplication. Korea is developing a comprehensive chronic disease management system by integrating patient data from multiple organisations. Korea's Benefits Information Analysis System already demonstrates many of the principles and requirements of using data to enable continuous improvement.

For research and statistics, Korea is quite advanced in creating an intermediary solution to improve health data interoperability through a Common Data Model (CDM) and has coded national health insurance claims data as well as 40 hospitals' clinical data to the Observational Medical Outcomes Partnership (OMOP) CDM.

While Korea has many advantages, a learning health system will not develop without building more trust, a fundament requirement for harmonising and sharing data while protecting privacy and data security. The

obstacles that need to be overcome are a lack of social licence and incentives toward data sharing and collaboration, the lack of a framework for research access to data, incoherent EMR systems and a lack of patient-reported data, and laws or their interpretation in practice that block progress toward a learning health system.

Towards an integrated health information system in Korea

Korea has many of the building blocks in place to develop a learning health system. The following policy actions are recommended to make this a reality:

- A central authority such as the Ministry of Health and Welfare (MoHW) or an appointed agency should lead the development of a national health information strategy for using all available data for a range of purposes.
- Legal authority will be needed to authorise and finance the national strategy and its implementation. Areas for potential legal reforms include a revision to the *Data Protection Law* to enable national agencies who are already trusted to collect and process health data to be legally permitted to link data for legitimate purposes in the public interest.
- A unifying policy framework to support a learning health system is needed. Different bureaus within the MoHW are developing policies and funding projects that will affect the health information system and this needs to be co-ordinated within the MoHW as well as greater co-ordination among national agencies who have their own health information projects.
- Data integration and exchange among Korea's national agencies responsible for national health data (HIRA, NHIS, KDCA and KOSTAT) will be essential to creating a learning health system that includes the surveillance, evaluation and improvement of health status and outcomes. It will be essential to incentivise co-operation among national agencies toward a common shared goal of improving health outcomes and the effectiveness and efficiency of health care services.
- The development of standards within Korean Health Information Service (KHIS) should include the secondary "use cases" to ensure that the data will meet the requirements of a learning health system. There should be a role for the large national agencies (HIRA, NHIS, KDCA and KOSTAT) in the development of these standards, and a mechanism for KHIS to evaluate and integrate data standards being developed by other national agencies.
- To complement laws and policies, funding and financial incentives will be needed to encourage compliance with national data standards among health care organisations and health care providers and for demonstrating (verifiable) data interoperability, and to ensure national agencies responsible for health data have the resources to support greater inter-agency collaboration to realise the strategy.
- Given the current arrangements for access to data in Korea are fragmented, the government may consider consolidating these activities into a single data hub that would simplify the process for users of Korean health data and enable secure, record-level linkage of all relevant datasets to create valuable knowledge.
- The national strategy must emphasise the importance of secure access to, linkage of and sharing of health data to serve the public interest and include the necessary changes to organisational mandates, legislations and resources so that secure exchanging of data to serve the public interest becomes the default position.

1 Key findings and recommendations

Twenty-first century health systems will be built around data and information. Data and their efficient exchange are fundamental to generating the information needed to improve and optimise health system performance. This chapter brings together the key findings of this review of how health data are managed and used in Korea and makes recommendations for creating an integrated national health information system. The chapter outlines what is meant by health data and an integrated health information system, and its role in advancing health care and it outlines the strengths and challenges of the Korean health information landscape. The review finds that Korea is well placed to build an integrated health information system that will support a high-performing health system and recommends central leadership and a national health information strategy including greater harmonisation of clinical and health data, an enabling legal and policy framework, building trust and fostering collaboration among key stakeholders, and developing a hub as a single entry point for secure data access.

In June 2021, the Korean Ministry of Health and Welfare commissioned the OECD to gather evidence and review the management and use of health data in Korea, and to recommend changes that would enable creating a health data and information system to support achieving national health policy objectives, with a special focus on using health data to improve health system performance.

To understand the strengths and weaknesses of the current arrangements in Korea and to develop recommendations, the OECD, through a series of focus groups and interviews, consulted national experts from a range of stakeholder groups (See Annex A). The discussions focused on:

- Health data interoperability (exchange and sharing): What are the challenges and what are the policy tools that can address them? i.e. regulations, incentives, standards, certification?
- Organisation and governance: What national institutions and governance mechanisms support a strong and trustworthy national health information system?

The information gathered through these consultations was complemented with information on Korea and other OECD countries collected through the OECD's regular monitoring of countries' health information systems including:

1. Survey of National Health Data Development, Use and Governance (2019-20)
2. Survey of Electronic Health Record System Development, Data Use and Governance (2021)
3. Survey of Changes to Health Data and Governance due to the COVID-19 Pandemic (2021).

This final report and recommendations from the OECD review comprises four chapters. Chapter 1 summarises the key findings and recommendations stemming from the review, beginning with a short explanation of why an integrated health information system is so critically important. The review finds that Korea is well placed to build a high-performing health system that will not only improve outcomes but create a world-leading data environment that produces cutting-edge research and innovation to advance the health and well-being of people in Korea and beyond. To create a truly 21st Century health system, Korea should focus on greater harmonisation of clinical data, an enabling legal and policy framework, and building trust and fostering collaboration among key stakeholders.

Chapter 2 describes the requirements and the benefits of a health information system where data can be accessed efficiently and securely by actors who need them and by those who can generate valuable information and knowledge by using them. It also outlines the current situation in Korea regarding health data infrastructure progress across OECD countries.

Chapter 3 describes the Korean health system in terms of how its structure, organisation and governance influence the way health data are generated, managed and used to advance health system objectives. It also examines the main strengths and shortcomings of current arrangements in Korea to manage health and social care data including legislation and policies, health information infrastructure and health data interoperability. Chapter 3 outlines the changes needed to establish an integrated health information system in Korea that supports a learning health system, setting out the requirements to take advantage of strengths and to address the problems uncovered in this study.

A 21st century health system relies on first-rate data infrastructure

Twenty-first century health systems will be built around data and information. In simple terms, an integrated health information system enables the secure exchange and movement of data to where they can be used to create information and knowledge that advances policy and health system objectives. Integrated health information systems require a strong data infrastructure made up of the relevant data assets, technology, agencies and institutions needed for the collection, storage, maintenance, distribution and (re)use of data by the different end users.

It is necessary to distinguish between data and information. Data are raw figures and facts and, in and of themselves, may not be very valuable. Information, on the other hand, is meaning and insights that are obtained from the analysis of data. While data infrastructure is a key element, an information system also includes the capacity to convert data into usable information and knowledge. A useful analogy is an integrated transportation network, which allows passengers to move safely and securely across regional boundaries around the entire country using various transport types. While the physical and technical infrastructure is an essential component, such a system also requires people and institutions to ensure it operates effectively, efficiently, safely, and predictably. Thus, this report focusses on obtaining value from health data within Korea by developing a system that yields information.

All data have several potential uses

An integrated health information system would help Korea improve its capacity to get the best performance and value out of its health system in three ways. Firstly, it would directly improve care quality (including safety, effectiveness and efficiency). Secondly, it would improve patient empowerment by enabling people to access their own health information and for this information to "follow the patient" wherever they seek care in the health system. Thirdly, it would also raise the country's capacity to use health and other data for other important secondary purposes, such as informing continuous assessment of health system performance, and enable learning and improvement cycles from the national level to the clinician's office. It would enable more effective and efficient:

- Public health monitoring and surveillance,
- Resource allocation and reimbursement to reward value,
- Biomedical research and development, and
- Innovation such as big data analytics and artificial intelligence that will enhance knowledge-based decisions for patient care and health system governance.

A range of data assets are relevant to an integrated health information system. For Korea this includes data generated during acute- and long-term health care, data on public health and social care as well as other relevant data sources such as social, economic and environmental data where necessary (Figure 1.1).

Using data to improve performance

Data and their efficient exchange to generate useful information (such as metrics and indicators) are fundamental in generating the information needed to improve and optimise health system performance. Performance can only be defined around the goals and objectives of a health system. While these may vary, the metrics and indicators needed to assess how well the system achieves its goals, and where improvement is needed, require data. Because system objectives typically cover various domains ranging from technical efficiency to equity and sustainability, a range of data from various sources will be needed to generate the necessary metrics and indices (Figure 1.1).

A '**learning health system**' leverages its data in this manner to improve performance through continuous cycles of reflection, adjustment and evaluation. Learning health systems aim to deliver health services that are of high quality and value, that improve health and well-being and, at the same time, provide innovative and rewarding workplace environments for health professionals (AHRQ, 2019[1]). Moreover, performance domains will include areas that benefit from the sharing of information (prevention and care co-ordination, for example). The importance of an infrastructure that enables the smooth exchange and sharing of high-quality data can therefore not be understated.

Figure 1.1. The main data types in a nation-wide health information system



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Interoperability and governance enable efficient and secure exchange of data

Countries making progress in this regard appreciate that data are a non-rivalrous asset (one of the hallmarks of a public good), and that each data point can and should have many uses. Data should therefore be harnessed to generate maximum social benefit. To do this, all data must be coded according to agreed technical and semantic formats. Only this way can data be meaningfully exchanged, sent to where they are needed, or analysed. Standardisation is especially important the Korean system where care provision is highly fragmented and competitive.

It is important to stress that an integrated health information system does not require all data of a certain type to be kept in a single location. It is quite possible to achieve the key objectives outlined above without central storage or even aggregation. A unified and co-ordinated approach to national data governance can enable smooth information exchange and use for a range of purposes without compromising privacy, security, and ownership of data. In fact, a federated approach to data (which is more compatible with the Korean system's supply side structure) can be more optimal.

Ensuring that data can be exchanged across national borders and beyond can amplify the benefits of data analytics and research in, for example, the context of public health, rare diseases, pharmacovigilance, and precision medicine. An information system that follows international data standards facilitates within-country and cross-border health care delivery and business opportunities for Korean research and technology sectors.

An integrated health information system requires a data governance framework that avoids the over-use of consent to authorise data exchange, in favour of legal authorisation and an approach that protects privacy and ensures data security while enabling data to be exchanged and used for legitimate purposes. The OECD Council Recommendation on Health Data Governance sets out the elements for a national health data governance framework and fosters a "privacy-by-design"[1] approach that is consistent with emerging transnational requirements such as those set out in the *EU General Data Protection Regulation* (GDPR) (See Annex B).

Clinical data play a key role

Clinical data are a key component of any health information system looking to improve care quality, optimise performance and enable research and innovation. All OECD countries that are making progress with their integrated health information systems have:

- Established a **national organisation** that is responsible for setting national clinical terminology and electronic messaging (exchange) standards
- Created a **multidisciplinary governing body** for the national organisation that represents key stakeholders
- Use **unique identification** of patients and health care providers
- Adopted **international terminology standards** for diagnoses, medications, laboratory tests and medical images
- Adopted the **HL7 FHIR standard** for data exchange (electronic messaging); and participate in **global collaborative projects** to improve international data standards.

Most countries have one **country-wide electronic health record system** and are exchanging these data at the national level including data sharing among physician offices and hospitals about patients' treatment, medication use, laboratory tests and images. Most countries also have a **Patient Internet Portal** where patients can access their own medical records from all of their current health care providers. Many countries are also utilising EHRs for other secondary purposes including **public health monitoring,** health system **performance monitoring**, patient safety **surveillance** and health and medical **research**. Some are also developing **big data analytics** including machine learning, artificial intelligence algorithms with EHRs.

OECD countries have reported in a recent OECD survey several levers to improve the spread and interoperability of their electronic clinical data.

- A **legal requirement** for health care providers to meet national standards for EHR interoperability. Thirteen countries reported to have a legal requirement for health care providers to adopt an electronic health record system (software) that conformed with national standards for both clinical terminology and electronic messaging (exchange).
- A **certification of EHR system (software) vendors** that required them to adopt national standards for both clinical terminology and electronic messaging. Again, thirteen have a certification that requires software vendors to meet requirements for national EHR interoperability.
- **Financial incentives** (or penalties) for health care providers to install an EHR system that meets national standards and requirements for national EHR interoperability. Nine countries report incentives for health care providers to keep their EHR system up to date as clinical terminology and electronic messaging standards change over time; and eight report incentives for health care providers to install and EHR system from a certified software vendor.

The Korean health system performs very well, with some room for improvement

Korea's health system is unique. On the demand side, a single payer ensures universal coverage as well as one of the richest administrative datasets in the world. Governance is shared among several agencies, including the Health Insurance Review and Assessment Agency (HIRA) and the National Health Insurance Service (NHIS), which also hold very large data assets. On the supply side, Korea is one of the most fragmented systems in the OECD. Health care providers are almost exclusively private, and acute care hospitals feature prominently in care provision. Patients have abundant freedom to choose providers, and gatekeeping to secondary and tertiary care is comparatively weak with a high degree of competition between providers and commensurately less collaboration and integration of care. From a data infrastructure perspective, the result is poorly harmonised and exchanged clinical data. There is a strong track record of key reforms, most notably the creation of the single-payer model 21 years ago. Providers and the medical professions can be very influential in policy development.

Optimising health system performance relies on good data and information

The special focus of this review was using data to optimise health system performance. Defining performance must consider the objectives of a health system. In Korea these encompass:

1. safety, efficiency and effectiveness (i.e. **quality**) of care
2. **equity** (fairness) in access to care and health outcomes
3. **sustainability**, which comprises a. ensuring the system copes with rising chronic diseases and demographic change (e.g. disease prevention and managing NCDs in non-acute settings), and b. supporting innovation and the development of cutting-edge medical technologies.

A good health data infrastructure and information system are critical to achieving these objectives in three ways. First by providing the necessary data and information on whether these objectives have been achieved or not. Metrics and indicators are needed to inform policy makers as well as providers and practitioners about performance in the domains relevant to them. Only through regular monitoring and feedback can improvement occur, and performance be optimised. Such a *learning health system* is only possible with a strong data infrastructure and health information system that covers all key performance domains. Such a system needs to go beyond answering the questions of "What went wrong (or right)?" to the more important questions of "Why did this happen?" and "What changes are needed to minimise risks and maximise value fairly across a domain or the system as a whole?"

Second, achieving all the above objectives relies on health data exchange among relevant actors ranging from patients and their providers to regulators and policy makers, to researchers and industry. These actors can then use the available data to generate information and knowledge that is relevant to them, enabling them to monitor, learn and improve on a continuous basis.

Third, it paves the way for regulatory and policy mechanisms that incentivise better performance and enable more optimal resource allocation. For example, moving from a fee-for-service remuneration model to one that rewards value for money is only possible with granular data on outputs (activity) as well as outcomes (including patient-reported outcomes) and costs across entire care cycles that span the acute, non-acute and long-term care settings. This is only possible with a fully integrated health data infrastructure.

The Korean health system can improve in areas that require better information exchange

The Korean health system compares well to other OECD countries on some metrics including avoidable mortality and treatable mortality. This is unsurprising given the strength and ubiquity of acute care in Korea. Most Koreans (71%) report being satisfied with the availability of quality health care (the figure is close to the OECD average). More recently, the health system's management of the COVID-19 pandemic achieved

case numbers and deaths that were among the lowest in the world. Notably, this was achieved through unprecedented collaboration across agencies and sectors that enabled the standardisation, integration (linkage) of data among them and the development of a secure mechanism to make these rich data accessible to a range of actors for the purpose of pandemic management and research.

There are important areas where the Korean health system compares less favourably to OECD countries. These point to where tools that enable improvement may need to be implemented. For example, Korea has a relatively high morbidity from NCDs and avoidable hospital admissions for diabetes and asthma. Rates of depression, anxiety and suicide are among the highest in the OECD, as is the proportion of people who rate their health as poor (OECD, 2021[2]).

While policy makers may point to Korea's life expectancy, which is among the highest in the OECD, longevity is a blunt indicator of health system performance (and even less useful for health *care*) due to the many non-medical factors that contribute to people's health and longevity. Insofar as life expectancy is a proxy for health, little is known in Korea about differences across social strata – and therefore about health equity (one of the main objectives of the health system).

Performance in several domains is unknown through lack of information

Although the Korean health system has abundant claims, administrative and activity data, consolidated data on outcomes (e.g. unplanned readmission) beyond where this results in a claim (e.g. admission to hospital) or an end point (e.g. death) are lacking. Clinical outcomes (e.g. test results) as well as patient-reported metrics are not reported consistently nor integrated nationally. Problems with coding and reporting present-on admission (POA) flags have been described. These and other issues mean that Korea does not provide several health statistics collected by the OECD (see Table 1.1).

This situation is problematic because it reduces the capacity of Korea to monitor, evaluate and learn and thus improve performance across the health system. It also points to key areas where Korea's health data infrastructure must be improved. This is not to say that the data do not exist – they do, typically in EMR systems of providers. It is the lack of infrastructure to harness these data for the purpose of monitoring and improvement that is missing and needs to be addressed.

Table 1.1. Selected indicators and statistics not reported to OECD by Korea

Patient safety	• Foreign body left after surgery • Postoperative PE, DVT, wound dehiscence • Obstetric trauma • Hip fracture within 2 days of admission • Anticoagulating drug in combination with oral NSAID • Inpatient suicide among people with psychiatric disorder
Care quality	• Patient experience with regular doctor • Patient experience in long-term care • Patient reported outcomes • Waiting times • Hip fracture surgery initiation
Other	• Life expectancy by education level • Diabetes prevalence

Building on the Korean system's many strengths

Korea has taken great strides towards creating a health data infrastructure conducive to a high-performing, modern health system. Its insurance claims data, in terms of coverage, volume and detail, are among the best in the world. The National Health Insurance System (NHIS) holds health care data (e.g. admission, outpatient service, emergency treatment, prescribed drugs), long-term care data (e.g. nursing, home care, prescribed drugs), public health data (e.g. birth and death, demographics, lifestyle, health checkup), social care data (e.g. Medical Aid, assisting device for the disabled, etc.), and contextual data (e.g. occupation, income level, environmental information. NHIS uses these data assets to support coverage expansion for the less-advantaged population, and to improve efficiency and sustainability through policies such as the benefit/health check-up system, finance analysis system, cost information analysis system and fraud detection system. The My Health Bank system is shared with the public based on this data-driven system.

HIRA programmes such as the Drug Utilisation Review (DUR), the Benefits Information Analysis System and the broader transition towards value-based claims review, for example, provide a strong foundation to establish a learning health system by improving the interoperability of clinical data for direct patient care, developing personal health environments, and the creation of research infrastructures for the life and the social sciences. In addition, Korea has a strong and committed academic research community that has produced some outstanding work over the years.

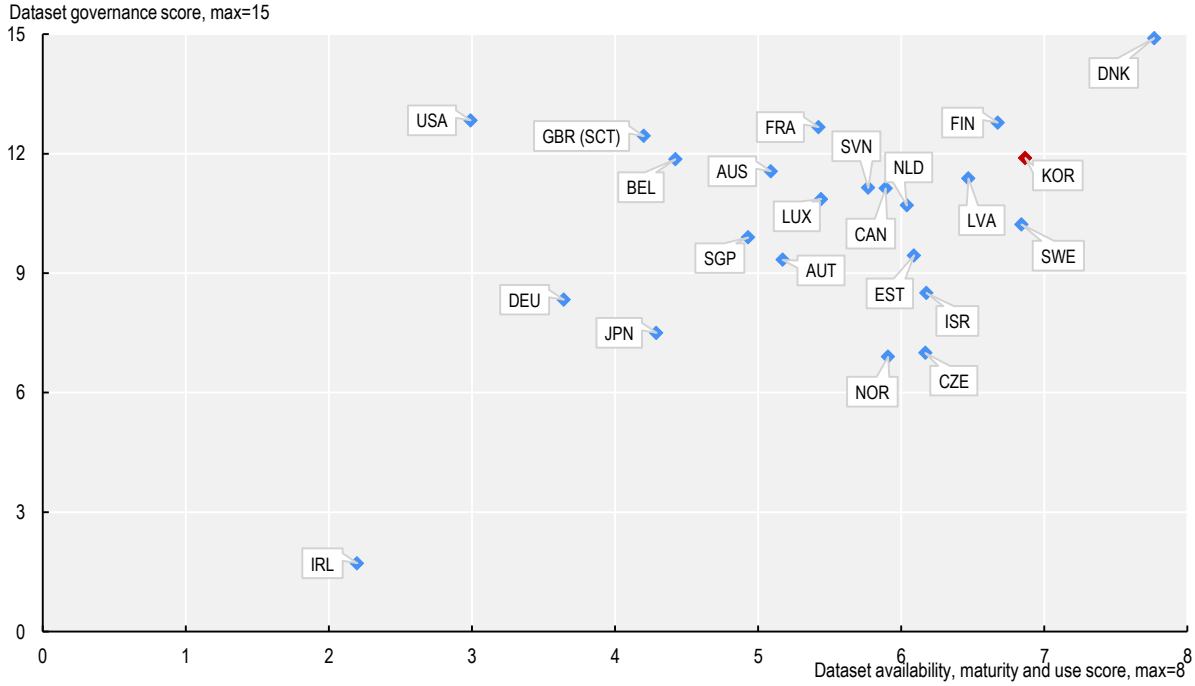
Excellent foundations for data availability and governance

Korea reports excellent data availability, maturity and coverage of key health datasets compared to other OECD countries. For much of its data, Korea also stands out for having a very short time lapse between when a data record is first created and when it is included in the national dataset used for analysis. Korea was one of only 7 countries that reported having a unique patient/person identifying number that could be used for record linkage that is included within 90% or more of their national health datasets. Korea is also among the countries with the strongest data governance across key national datasets considered (Figure 1.2).

For secondary uses of data (statistics and research etc.), Korea is already quite advanced in creating an intermediary solution to improve health data interoperability through a **Common Data Model (CDM)**. A CDM maps data from multiple organisations that use different standards to a standardised structure that makes it possible for data to be used for analytical applications, allowing for efficient data pooling and data integration for health statistics and research. Much of the data held by HIRA, as well as the EMR data of over 40 Korean hospitals have already been mapped to the Observational Medical Outcomes Partnership (OMOP) CDM as part of the global Observational Health Data Sciences and Informatics (OHDSI) Project. However, a CDM is not a practical solution for most primary uses of data such as enabling the smooth exchange of data between health care providers for direct patient care or the development of a "real time" and interactive patient Internet portal – often called a Personal Health Record.

Recent reforms demonstrate that Korea has the capability to plan and implement major structural reform of the health system, overcoming internal and external resistance. This experience will stand it in good stead to implement the necessary reforms to create a health information system for the 21st century.

Figure 1.2. Dataset availability, maturity and use, and dataset governance



Note: Dataset governance score is the sum or the proportion of health care datasets meeting 15 dataset governance elements and the dataset availability, maturity and use score is the sum of the proportion of health datasets meeting 7 elements of dataset availability maturity and use.
Source: Oderkirk (2021[3]), "Survey results: National health data infrastructure and governance", https://doi.org/10.1787/55d24b5d-en.

NHIS is ushering in integrated services for chronic disease patients by gathering scattered information

Korea is attempting to build a comprehensive chronic disease management system by integrating patient data scattered across organisations. KDCA has built health behaviour and chronic disease management status data based on the annual national nutrition survey. NHIS has benefit claim data, lifestyle data such as drinking, smoking, and exercise, and actual measurement data from health checkups. NHIS analysed its own data to produce condition management indicators including indicators about risk factors, metabolic syndrome, chronic diseases, and complications by small scale regions and workplaces. The Chronic Diseases Management Registration Program is a public data platform that collaborates with primary care providers to collect and accumulate chronic disease patient data (medical measurement and health management behaviour).

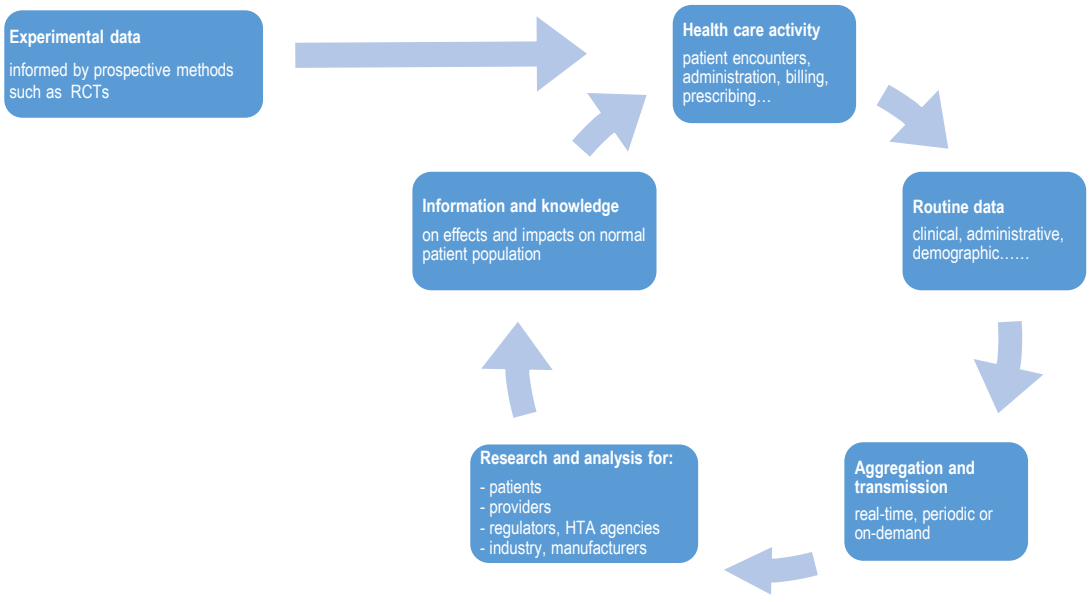
My Health Bank (a personal health record) supports individuals to manage their health risk factors, and helps policy makers set up tailored measures for their region. To build a national chronic disease management system, KDCA and NHIS are attempting to integrate the National Health Nutrition Survey and the health check-up and medical treatment system, which is expected to revolutionise the chronic disease monitoring system.

An expanded Drug Utilisation Review (DUR) as an example of what is possible

The DUR system was established in 2010 to provide a prospective, real-time review of drug prescriptions to minimise the risk of safety harms such as contraindications, drug/drug interactions or ingredient duplication. It uses data held by HIRA to provide real time advice and alerts to clinicians and pharmacists.

The DUR illustrates the current strengths of Korean data and foreshadows the possibility of an integrated data infrastructure in Korea. If expanded to include a broader range of data, it could serve as both a decision support tool as well as a world-class pharmacovigilance system. The DUR would be more useful for clinical decision making if it included information about patient-level diagnostics, pathology and test results, and if DUR advice were directly accessible within hospital and clinic EMRs – that is within the "clinical workflow". Such an expansion requires integration of EMR and claims data as well as integration of DUR data and EMR systems. This expansion could transform DUR into a full drug safety information system, able to support regulatory decision making and post-market surveillance of drugs. Such a transformation is a clear application of the learning health system paradigm (Figure 1.3).

Figure 1.3. A learning health system illustrated through medication surveillance



Source: OECD (2019[4]), *Health in the 21st Century: Putting Data to Work for Stronger Health Systems*, https://doi.org/10.1787/e3b23f8e-en.

Value-based claims review and assessment and reimbursement analysis exemplify steps in the right direction

HIRA is moving towards a more nuanced review and assessment process that aims to maximise value for patients and NHI enrolees as opposed to minimising costs. While the previous process accepted or adjusted the benefit paid based on standardised amounts on an item-by-item basis, the new approach is a more comprehensive judgement that considers the local context, quality of service and treatment outcome. It also includes expert participation by providers, academics, and policy makers, creating a "virtuous cycle" of learning development of indicators, fine-tuning standards and developing indicators that inform continuous learning.

HIRAs Benefits Information Analysis System also demonstrates many of the principles and requirements using data to promote continuous learning and improvement. The Benefits Information Analysis System draws on claims and other data held by HIRA as well as data held by Statistics Korea and the Korean weather service to analyse trends in the frequency and costs of medical interventions both within and outside the NHI coverage with the aim of preventing unnecessary medical services, preparing policy measures through medical service use analysis conducted from user and provider perspectives, and creating a more effective yet sustainable medical environment. The initiative has driven several successful

outcomes in several clinical areas including magnetic resonance imaging for stroke patients and the treatment of thyroid cancer.

Obstacles to building trust and harmonising data limit development of a learning health system

While Korea has many advantages supporting a learning health system, such a system will not develop in Korea with addressing key obstacles to building trust and, consequently, to harmonising and sharing data while protecting privacy and data security. These obstacles are a lack of trust, social licence and incentives toward data sharing and collaboration, the lack of a framework for research access to data, incoherent EMR systems and a lack of patient-reported data, and laws or their interpretation in practice that block progress toward a learning health system.

Lack of trust, social license and incentives toward data sharing and collaboration

Trust is essential to the development of an integrated health information system that will meet the needs of Korean society. Many experts consulted identified the need to rebuild public trust in the exchange of data among health care providers and between providers and national health data organisations and the government. There is a lack of trust between health care providers and the government and even a lack of trust among national health data organisations that limit the possibility of progress toward secure and privacy-protective data exchange and integration to serve the public interest.

There are several areas where a lack of trust between health care providers and the government is limiting progress in health data sharing and use for the benefit of the public. Providers voiced concerns that if they did routinely exchange data with one another that they would be responsible for data breaches/leaks and face a public backlash that would hurt their reputation and business. Providers also resist exchanging data for fear of losing patients to other health care providers, particularly large hospitals.

Health care organisations and individual providers are reluctant to share financial data with public agencies such as HIRA and NHIS. In part, this is because they view their data as a business asset, that is a private good to use to generate profit from their use and sale. Also, there are concerns that standardising and integrating EMR data with NHIS/HIRA create opportunities for unfair comparisons, and that the introduction of standards for data exchange will diminish the diversification of medical care and treatment methods that could be provided to patients (particularly privately insured services) and will harm physicians economically.

In the absence of financial incentives for data interoperability, the benefits of data interoperability and integration are perceived to mainly accrue to government, researchers and health insurers, while the costs of improving the interoperability of health information systems are mainly borne by health care providers. Government leadership and legislative and policy tools are needed to create the right environment for information exchange and collaboration that creates a “win-win” for all stakeholders in a learning health system.

Neither NHIS, nor HIRA, have a specific mandate or resources to support the improvement of health care quality and safety that permits development of a learning health system. Further, there are legal and administrative barriers to collaboration between HIRA and NHIS and between these two agencies and other key national stakeholders in the health information system, such as the Korean Health Information Service (KHIS), the Korean Disease Control Agency (KDCA) and Statistics Korea (KOSTAT) that make it very unlikely that further development of a learning system will occur over time within the existing system.

Further, the MoHW and other parts of the Korean Government, launch IT and data projects which overlap one another and lack a unifying strategy or purpose among them so that if would be possible for them to

work together efficiently to achieve common objectives that improve Korea's health system and people's health.

Lack of a framework for research access to data

There is no unifying framework for research access to health data in Korea. As a result, there are different separate initiatives underway that are each trying to fulfil a similar need resulting in unnecessary duplication of effort and expense. For example, HIRA accepts and reviews applications for access to its data holdings and provides a secure research room on its premises as well as real-time remote data access services for approved applications. The NHIS also accepts and reviews applications for access to NHIS data via dedicated terminals (remote access) within data analysis centres in multiple regions.

Researchers interviewed indicate that both HIRA and NHIS have long waiting lists for approval to access data with waiting times of several months to up to one year. Further there is no mechanism to appeal an approval decision.

Incoherent EMR systems and a lack of patient-reported data

While Korea has most of the key national health datasets that the OECD considers essential to a national health information system, there are important gaps. Although all Korean health- and long-term care providers record clinical data within EMRs, most of these data are not interoperable owing to the lack of consistent standards for terminology or exchange. Voluntary participation of health care providers in contributing to national datasets is a reason for incomplete coverage. This means that there isn't a national clinical data set, but instead there are small silos of data that are difficult to access and use.

Patient-reported data on outcomes and experiences of care can shed light on how health services perform. Collection and use of these data in Korea are still nascent. For example, paper questionnaires are used although some hospitals reportedly collect PROM data electronically. PROMS data collection could be integrated in to the clinical "work flow" as part of national EMR requirements.

KHIS provides certification for vendors and providers and carries out standardisation of data formats for the entire nation. It is anticipated that standardisation for data exchange and semantic interoperability will spread using EMR certification as a tool. MoHW is leading a pilot project of an EMR-certified fee schedule with providers and will evaluate the use of standardised EMRs. In particular, the standards will be applied to assessment items in stages, such as patient safety, treatment continuity, patient health management, and public policy support.

Regarding secondary use, KHIS plans to build a standardisation strategy for public policy support. Currently, its focus is on primary uses of data, and not on other critical uses of data for statistics, health system performance monitoring and medical research. The development of standards within KHIS excludes the development of secondary "use cases" to ensure that the data will meet the requirements of a learning health system. No role exists for the large national health data holders in the development of standards by KHIS, nor is there any mechanism for KHIS to evaluate or integrate data standards being developed by these other national organisations.

Laws and their interpretation in practice that block progress toward a learning health system

Korean laws governing the primary and secondary uses of data protect individuals' privacy but to do so in a manner that creates barriers to the privacy-protective uses of data to serve the public interest. "Privacy-by-design" mechanisms that support data sharing, linkage and accessibility should be permitted.

In Korea, it is legally possible to extract EMR data for secondary uses, but the interpretation of the laws is so strict that doing so is difficult in practice. Further, integrating health data in the custody of the main

organisations responsible for national health data (HIRA, NHIS, KDCA and KOSTAT) would seem to be legally possible to generate "official statistics" but current legislation (or its interpretation) make collaboration limited, highly bureaucratic, expensive and slow.

Best practices in "privacy-by-design", such as where organisations share a common pseudonymisation algorithm that is applied to their data so that they may be linked by pseudonymised ID, are not supported by law or policy. Further, large national organisations that are trusted to process personal health data are distrusted to undertake data linkages to serve the public interest when the linkages involve integrating their data together.

Experts representing civil society organisations in Korea advocated for reforming the Korean data protection law to require pseudonymisation of identifiers and the secure storage of pseudonymisation linkage keys to strengthen data protection and build trust. Further, these organisations are concerned the legal penalties for data misuse are not high enough to be a deterrent to misuse.

Creating a learning health system in Korea

Korea has many of the building blocks in place to develop a modern health data governance and information system that supports a learning health system. Policy actions are recommended to create the foundation for a world-class 21st Century health information system that serves the needs of the Korean people. These policy recommendations are summarised below (see Chapter 4).

Building trust among stakeholders and the public

Creating a learning health system will steer Korea away from the current situation of data silos toward an integrated system where secure data exchange, linkage and secondary uses are the norm. Building a learning health system will require a mindset that sees data as a public good and a resource that can be harnessed to advance the health and welfare of the Korean people. This will require a change management approach that builds trust among all stakeholders and the public.

This approach should include consulting with governmental agencies about their needs, and with non-government stakeholders especially patient groups, regions and municipalities, provider organisations, health professional groups, insurers, academia, biomedical industry and software vendors. It will require a sustained public information campaign, public consultations and other avenues for public input into the strategy, including public consultations at all stages of development, and a dialogue with the public about the benefits of data sharing and exchange, with the goal of valuing health data in Korea as a public good. This public dialogue must assuage public and stakeholder concerns about privacy risks and reassure them by clearly communicating about how privacy will be protected when data are used. Further, it must deliver on these protections in practice.

Adequate resourcing of these activities will be critically important. This means allocating sufficient time and resources to consultation with stakeholder bodies and the public at all points in the development of the strategy, so that progress from a draft strategy to a final strategy to roadmaps and implementation will feel natural, expected and safe.

Central leadership

Central leadership means that the MoHW – or any new authority or agency designated by the ministry – would oversee the development and implementation of the national strategy and its components outlined above. It would develop the campaigns and tools to build trust among stakeholders and the public, and develop and maintain analytics products and dashboards for ministerial policy making and reporting, and evaluate and publicly report on progress in the implementation of the national strategy.

It would need to facilitate progress in policy and legal reforms to support the on-going development of an integrated health information system, co-ordinate planning and funding of health information projects within the ministry to align them with the strategy. The MoHW would also need to ensure that the transition to, and maintenance of, the new arrangements across all levels of the system are adequately resourced.

Developing a national health information strategy

A central authority such as the Ministry of Health and Welfare (MoHW) or an appointed agency should lead the development of a national health information strategy for using all available data efficiently, intelligently, and securely for a range of purposes. An important part of the strategy would be to change the current institutional arrangements which are characterised by overlap, duplication, and inconsistent approaches to managing and using health data.

Internal support will be needed to build a team to take the lead. The ministry could consider creating a new unit or separate authority/agency that engages experts in health information systems, health data science and informatics and health data governance. This expertise will be essential to ensuring an effective national strategy is developed and implemented.

The national strategy should align with broader policy frameworks to build a digital society (such as the Digital New Deal or a subsequent strategy). In fact, most countries that are successfully digitalising their health systems have a national digital strategy – and data governance – that encompasses all areas of public policy including health. The advantages of a cross-sector approach are particularly strong in the health arena given the value placed on privacy and security, the key role of non-health data (which can greatly enhance knowledge-generation), and the fact that makes a country more attractive for investment of biotech capital.

A legislative framework and supportive policies

Legal authority will be needed to authorise and finance the national strategy and its implementation. Legal reforms are also needed to bring the health data governance law within Korea closer to the OECD Recommendation on Health Data Governance (OECD, 2019[5]).

The OECD Recommendation calls on countries to implement a national health data governance framework and sets out the principles for the development, content and evaluation of the framework. Implementation of this framework may require legal reforms or the publication of guidelines to ensure that all stakeholders in the health information system have a common understanding of their roles and responsibilities with respect to health data development and use and privacy and security protections. The national data governance framework should emphasise privacy-by-design and adherence to FAIR principles, that is that data are findable, accessible, interoperable and reusable.

Areas for potential legal reforms noted in this study include a revision to the *Data Protection Law* to enable national agencies who are already trusted to collect and process health data to be legally permitted to link data between them for legitimate purposes within the health-related public interest. Further revisions to privacy law should strengthen safeguards to protect data privacy and security, such as requiring data pseudonymisation and having penalties for data misuse that discourage illegal data uses that have damaged public trust.

A unifying policy framework is also necessary that will support a learning health system. Different bureaus within the MoHW are developing policies and funding projects that will affect the health information system and this needs to be co-ordinated within the MoHW as well as greater co-ordination among national agencies who have their own health information projects. Further co-ordination is needed at the whole of government level as other ministries are also funding health information projects for purposes of scientific or economic development.

Revisions may be needed to legislations authorising existing national agencies responsible for health information if their existing mandates create obstacles to collaboration or their resource allocations are insufficient to support collaboration. Revisions may also be needed to legacy legislations that pose unnecessary obstacles to a learning health system.

Enabling the National Health Insurance Institutions (NHIS&HIRA) to collaborate with each other and other agencies

HIRA was launched to be an intermediary between the National Health Insurance Service and health care providers, to protect health care providers from any potential unfairness that might have arisen from the consolidation of numerous insurers toward a single public insurance system. This role as a fair and objective intermediary (honest broker) could be strengthened by ensuring both legally and in its funding that HIRA is fully independent of NHIS and the government and focussed upon health care improvement for the benefit of all stakeholders.

To fulfil this role, and to operate at arm's length from the government, the governance of the National Health Information System would require representation of all key stakeholder groups: patients, consumers, health care providers, governmental agencies and businesses that contribute to and depend upon the health information system.

The range of data that could be linked and integrated to realise a learning health system would need to be expanded to include:

- EMR data, particularly lab results, and imaging results
- Data related to patient outcomes such as present on admission (POA) flags, Patient-reported outcomes (PROMS) and experiences (PREMS), and clinical outcomes
- Environmental, behavioural and socio-economic characteristics of patients
- Private insurance claims and uninsured health care services.
- Patient Registry

Organisational changes at HIRA would also help to both minimise the burden of reporting born by health care providers and maximise the clinical value of the quality registries HIRA would be supporting. The real-time microdata HIRA collects currently from health care providers for the purpose of adjudication of health care insurance claims must be integrated with real-time clinical data to provide real-time clinical care quality and safety monitoring that is useful for health care providers continual improvement of patient outcomes and health care workplaces.

The current process of duplicative data collection, with a separate and non-real time data collection system for the assessment side of HIRA, should be phased out because it is unnecessary and slow, with quality indicators on the assessment side lagging health care events by several years.

Instead, the collection of real-time data from health care providers should be based on the collection of clinically relevant and timely data for a full monitoring, reflection and evaluation cycle of improvement of the health system. Priority should be given to designing a data collection and reporting system that provides high quality and timely information supporting decision making of different stakeholders.

Further, data integration and exchange among HIRA, NHIS, KDCA and KOSTAT will be essential to creating a learning health system that includes the surveillance, evaluation and improvement of health outcomes of patients with infectious and chronic diseases. Such surveillance is part of the mandate of the new KDCA, but its mandate cannot be fulfilled without data exchange and integration with the data collected by the other agencies.

However, at the present time, negotiating data sharing agreements among national agencies where data linkage is necessary has been very complicated and resource consuming for all national agencies. Further,

where national agencies do not see the exchange and data linkage as a specific win-win for them, they may not engage in negotiations or may drag out work over a long period of time.

Moving forward, it will be essential to incentivise co-operation among national agencies toward a common shared goal of developing a learning health system that improves the outcomes of patients and the effectiveness and efficiency of health care services. (See also Recommendation 7 on creating a single entry point for shared data.)

Integrating the KHIS in the new Korean data infrastructure

A first-rate health data infrastructure and information system in Korea will require an expansion of the KHIS remit to cover secondary uses and, as described in the previous section, greater collaboration with other key actors. The global standards for data exchange and semantic interoperability, administered and governed by KHIS, must include "privacy-by-design" protections, particularly federated learning (distributed analytics) building forward from the recent experience of HIRA with OHDSI. Standards should include interoperability in analytics, information and knowledge and foster the broad adoption of the OMOP common data model (CDM), building from recent investments of the MoHW as well as the Ministry of Industry.

Clinical (EMR) data are an integral part of a learning health system. The KHIS has no mandate for considering secondary use of EMR data, or the contribution of the OMOP Common Data Model to realising intermediate goals for clinical data interoperability. While there is a role envisaged for KHIS in providing health information governance, it would not be possible for KHIS to fulfil such a role without working closely with the national agencies responsible for health data. KHIS should be intimately involved in developing and implementing a learning health system, as all key stakeholders should be. Revisions may be needed to the authorising legislation for KHIS.

Supporting and incentivising data quality and exchange

To complement laws and policies, funding and financial incentives will be needed to encourage compliance with national data standards, for demonstrating (verifiable) data interoperability, and to ensure national agencies responsible for health data have the resources needed to support greater inter-agency collaboration to realise the strategy.

This will require a review of government funding and financial incentives related to the exchange and use of health data, including research projects funded by government ministries. It may also require explicit financial incentives to encourage health care providers, national agencies responsible for health data and other actors to move to certified IT solutions and succeed in achieving verifiable interoperability.

Demonstrating verifiable interoperability would include incentive payments, funding or accreditation that is conditional upon passing data quality checks and passing thorough (random) data quality audits, as well as meeting national requirements for data privacy and security protection (see Chapter 4).

Korean government plans call for financial incentives to EMR software vendors to adopt national standards for data terminology and exchange and to health care providers/organisations who demonstrate they are using an EMR that conforms with national standards. These planned incentives do not include funding for the transition costs that may be faced by health care institutions as they convert from their existing system to the new standards. Concerns were raised in this study regarding the costs for infrastructure, such as upgrades to software, hardware and networking, and softer costs related to staff training and lower productivity during the transition. These up-front costs may be too high for small clinics and hospitals to self-fund and therefore they may not be able to convert, despite the attractiveness of the incentive payment.

The MoHW should also evaluate how plans for broader reforms to health care funding and remuneration that reward care co-ordination and value-based care would affect the design and functioning of the learning

health system. In short, this will include: 1. needs-based funding to hospitals and provider organisations for transitioning their local data systems and infrastructure to an agreed national format and standard; 2. incentives for verifiable interoperability and meaningful use of health data including auditing data quality, interoperability and privacy and security protections AND successful and consistent provision of data to authorised agencies (in addition to KHIS certification process); and 3. a fair and balanced method to sanction and penalise lack of compliance, comprising financial and other levers.

A single entry point for secure data access

OECD countries are increasingly providing a unique entry point for access to all public sector health data, either through an expanded mandate of an existing national organisation or through the creation of a new organisation. This unique entry point has a primary aim of improving access to health data for secondary uses that are within the public interest while protecting data privacy and security (see Chapter 2 for examples).

Given the current arrangements for access to data in Korea are fragmented, the government may consider consolidating these activities into a one-stop-shop for secure access to various health data from a variety of sources outlined in Figure 2.1. Such consolidation into a single data hub would simplify the process for researchers and other secondary users of Korean health data, and enable secure, record-level linkage of all relevant datasets to create valuable knowledge. It would make access to data for research and other secondary purposes in Korea more secure, efficient and easier. Further, it would make public sector health data collection, data use and data protection more fully transparent to the public and to the research community.

This would not require all data to be copied, transferred or held in one repository as it is now possible to perform complex analyses across a distributed or federated network. Under this approach, data always remain with their custodians. Only queries (research questions), and the aggregate results, are sent back and forth between the requestor (or hub) and the data holder. The precondition of a distributed network is that all sources of data to be accessed have already been coded to the same Common Data Model, such as the OMOP CDM which Korea has already invested in.

Moreover, the hub could support Korea in providing data linkage and access services at ‘arm’s length’ from organisations with direct involvement in the provision or assessment of health insurance, or in the provision of health care or public health services. This independence from the policy and business of health care could build greater trust among the stakeholders that the purpose of health data linkages and uses are to serve the public interest in better health, high quality health care and in privacy protection and data security.

The involvement of all key health information system stakeholders in the governance of this hub would create the opportunity to engage these stakeholders in a collaborative effort to develop and improve the quality and efficiency of standards for health data terminology, exchange and interoperability for both primary and secondary data uses.

However, a hub alone will not be sufficient to improve collaboration and data sharing among the large national organisations who are processing personal health data. The national strategy must emphasise the importance of secure access to, linkage of and sharing of health data to serve the public interest and include the necessary changes to organisational mandates, legislations and resources to ensure that exchanging data becomes the default position, where the exchange is secure and the purpose of the exchange is to serve the health-related public interest.

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Note

[1] Privacy-by-design involves designing IT systems in a way that pro-actively anticipates and addresses risks to data privacy and security so they may be mitigated. In such approaches, the privacy of all individuals whose data is within the system is protected by default. The protection of individuals' privacy and data security is embedded within the architecture and functionality of the IT system. At the same time, the IT system supports all uses and re-uses of data that are in the public interest.

2 A high-performing health system in Korea will make the most of its data

This chapter presents the characteristics and benefits of a modern health information system that supports high health system performance through a continuous cycle of learning and improvement. It describes what is meant by health data infrastructure and an integrated health information system, its key components, and how it can help countries advance policy objectives. Progress across OECD countries in the development of health data governance frameworks and in the development and governance of interoperable electronic health record (EHR) systems are presented to inform this review, and to set the scene for subsequent chapters that provide an appraisal of the Korean health data infrastructure and information system (Chapter 3) and recommend how these can be improved to help better assess and improve health system performance (Chapter 4).

Twenty-first century health systems should be built around information: the right information reaching the right place at the right time. This enables the provision of high-quality and integrated care to all people in need, as well as better public health practice, health system management, and research and innovation. While health systems will continue to be structured, funded and organised differently, success – in terms of better care, and improved public health, system management and research – will be characterised by a comprehensive, coherent, standardised and integrated approach to managing (electronic) health data. Success relies on data being harmonised and interoperable, and able to be exchanged between custodians and silos.

In this context, “health data” includes any data that contain information relevant to health policy objectives, either directly or when combined with other data. The most obvious example of health data are personal medical or health records. These data contain longitudinal information on medical interventions, medications and tests performed in health care settings as well as the results and outcomes. They may include patient-reported data on outcomes and experiences of care. Other common types of health data are administrative and insurance claims data, which typically capture medical activity and their costs/prices. Registries contain patient-level information about specific diseases or procedures (e.g. diabetes or joint replacement). Population surveys contain information for a representative sample of people and may have more detailed behavioural and environmental data, such as nutrition and physical activity, than administrative or clinical data sources. Population Census and Registry data contain detailed data that, when linked to health data, provide socio-demographic and socio-economic characteristics that are relevant to understanding health care accessibility and equity.

Data on the provision and outcomes of long-term care are increasingly relevant and important. Social care data can also provide insights into health status and needs of individuals and populations. Data on population and public health such as risk factors and behaviours are typically generated through surveys but can now be derived from more primary sources such as electronic medical records or claims data. Social and economic data such as unemployment status or income as well as environmental data on pollution, for example, can provide very valuable insights for policy makers when combined with other types of data that capture health status and health care use of individuals and populations (Figure 2.1).

Figure 2.1. The key types of data in a health information system



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It is necessary to distinguish between data and information. Data are raw figures and facts and, in and of themselves, may not be very valuable. Information, on the other hand, is meaning and insights that are obtained from the analysis of data. Thus, this report focusses on obtaining value from health data within Korea by developing a system that yields information.

Data infrastructure: The foundation of an integrated health information system

Any endeavour whose goal is social and economic advancement relies on effective infrastructure. Putting data to work successfully is no exception. **Data infrastructure** comprises data assets supported by people, processes, and technology (The Open Data Institute, n.d.[1]). Technology, including IT hardware and software, is important. But the critical aspects of a health data infrastructure in the modern era (and in technologically advanced countries like Korea) are the bodies and organisations that create, maintain and manage personal health data as well as the institutions, policies and rules (i.e. governance) that guide the use of these data. This creates an ecosystem of technology, processes and actors/organisations needed for the collection, storage, maintenance, distribution and (re)use of data by the different end users.

As an analogy, a rail infrastructure includes not only the tracks and trains but also the resources, people and equipment to maintain them, regulations and traffic control rules, as well as ticketing and other passenger services. A strong data infrastructure therefore enhances the efficiency and productivity of using data.

A data infrastructure is the foundation for a **health information system,** which not only collects, manages, compiles standardises and exchanges data but also derives meaning and information from health data through analysis and review. It is a system because the focus is on data exchange and integration of information across different stakeholders. This requires – in addition to the hardware, software, IT expertise and analytical models – the supporting laws, policies, governance, as well as public communication channels, strategic planning, implementation guidelines, and audit and evaluation mechanisms.

An integrated health information system means that electronic data are FAIR (findable, accessible, interoperable, reusable), and can be exchanged and securely used by other actors and institutions to serve the public interest. The result is that data can flow, safely and securely, to where information can be extracted to create the knowledge that advances human health and well-being.

Micro-data are needed for both primary and secondary uses

An integrated health information system can not only directly help to improve care quality, outcomes and empowerment by enabling patients and their health care providers to access important information, but it can also raise the country's capacity to use these data for other important purposes including:

- Managing health system performance from the national level to the clinical microsystem
- Public health monitoring and surveillance
- Opening new communications channels with patients to improve patient-centred care such as the active use of patient-reported metrics (PROMs and PREMs)
- Introduction of new digital services such as e-prescriptions or telehealth
- Better targeting of reimbursement for services to reward value
- Biomedical research and development
- Innovation such as big data analytics and artificial intelligence that will enhance knowledge-based decisions for patient care and health system governance.

Every data point should serve many uses, from informing a physician caring for a patient to helping patients manage their care, to health care quality monitoring indicators, value-based payments, real-world evaluation of the effectiveness of therapies and contributing to clinical decision support tools (artificial intelligence). Recent advances have also demonstrated that individuals' data are used to inform decisions about their care and the care of others. The distinction between using data for primary purposes (direct patient care) and secondary purposes (e.g. research, public health monitoring) is therefore increasingly blurred.

For this reason, health data today cannot be simply categorised as personal or non-personal when the data pertain to individuals. Simply removing personal identifying information like names, addresses, health insurance numbers and birth dates from a data set, does not render the data anonymous because it is increasingly easy to re-match the data to other datasets and re-identify individuals with some probability of success. More complex manipulations or aggregations of data to try to guarantee anonymity may reduce the quality, validity and usefulness of the data needed to produce valid information and research results.

Even the simple step of removing personal identifying information must be carefully considered, as the linkage of datasets may require this information, for example to link hospital inpatients to mortality data to find out how many patients died in the weeks following a procedure. Mechanisms that allow re-identification for approved data uses, such as investing in pseudonymisation and secure storage of re-identification keys, are recommended by the OECD (see Annex B).

The key elements of an integrated system that enables primary and secondary uses of data are: approaching health data as a public good; implementing standardised data terminologies and formats (a single "language"); a common data model and standardised analytics; and comprehensive data

governance that uses a “privacy-by-design” approach. These elements are outlined below, followed by a section on the interoperability of electronic medical records.

Using data to measure and improve performance

Data are fundamental in any effort to improve and optimise health system performance. Performance can only be defined around the goals and objectives of a health system. While these vary, the metrics and indicators needed to assess how well the system achieves its goals (and where improvement is needed) require data. Because system objectives will typically cover various domains ranging from technical efficiency to equity and sustainability, a range of data from various sources will be needed to generate the necessary metrics and indices (outlined in Figure 2.1 above). Moreover, performance domains will include areas that benefit from the sharing of information (prevention and care co-ordination, for example). The importance of an infrastructure that enables the exchange and sharing of relevant data can therefore not be understated as it not only informs on where improvement is needed but provides a key mechanism to improve performance.

As such, a ‘learning health system’ leverages its data in this manner to improve performance through continuous cycles of reflection, adjustment and evaluation. Learning health systems aim to deliver health services that are of high quality and value, that improve health and well-being and, at the same time, provide innovative and rewarding workplace environments for health professionals (AHRQ, 2019[2]). Such a system needs to go beyond answering the questions of “What went wrong (or right)?” to the more important questions of “Why did this happen?” and “What changes are needed to minimise risks and maximise value fairly across a domain or the system as a whole?” This relies on highly detailed and timely information.

As well as information to improve health service design and delivery, data informing a learning health system create new biomedical research opportunities. For example, recent studies conducted in Israel and Scotland have demonstrated the capacity to link clinical, administrative and social datasets to study the safety and effectiveness of COVID-19 vaccines in different population sub-groups in real time. The results can alert providers and policy makers to the potential risks and opportunities, as well as contribute to global efforts to control the pandemic.

Approaching data as a public good

Those countries making strides in putting their data to work have recognised that data are a valuable resource that should be used to generate public benefits. Significant public investment in health and health care – including in health care provision, health data development and health care research – are a key reason why health data should be viewed as a public good.

But there is also an economic argument in the modern era of Big Data, high performance computing and modern analytical techniques including machine learning and artificial intelligence. Data represent immense value both because of the information they potentially contain and because they can be used and re-used ad infinitum. Their use by one actor does not preclude their use by others. More importantly, like other public goods such as laws or language, data are instrumental in building social value through knowledge and information. Their exclusivity is not intrinsic, but is imposed by man-made laws, conventions, and institutions. In net terms, their commodification hampers human development.

Moreover, the social and economic value of data increases exponentially with their size. For example, a researcher looking for biomarkers that uncover a precision therapy will find a single dataset comprising 10 million records much more valuable than 100 separate datasets of 100 000 patients that cannot be linked or analysed as a whole (such as via the personal data train). In the private sector, forward-looking

firms have realised that even a small slice of analytics on a huge data pool can generate far greater returns than hoarding much smaller puddles of data for proprietary use.

But to fulfil their potential in secondary uses as well as the primary objectives of improving patients' care, experience and outcomes, data held in various places by different custodians must be coded in formats and languages that enable them to be exchanged and linked. This requires social license and trust, which can only be garnered through strong governance, political leadership, and excellent public communication.

Data must be standardised to common technical and semantic formats

The most common reason why health data are not put to work is a lack interoperability. This happens when the information systems of data holders have been developed without common standards, preventing data from being exchanged, or even when data are exchanged, making it very difficult for the data to be interpreted or integrated with other data. Without the ability to share and interpret data easily, every data exchange can become a costly and time-consuming data integration project.

The most efficient solution to maximise the value of data held in silos is to agree on and adopt common standards for data terminology and exchange (see Box 2.1). Increasingly, such standards are becoming global, enabling multi-country collaboration in the development of IT systems and tools, cross-border access to clinical information for travellers who fall ill, as well as in undertaking multi-country medical and health research. They are a fundamental component of a learning health system.

An intermediary solution is mapping data from multiple organisations that use different data standards to a **Common Data Model (CDM)**. A CDM organises data into a standard structure that makes it possible for data and the meaning of data to be shared for analytical applications, allowing for efficient data pooling and data integration for health statistics and research.

The CDM is not, however, a practical solution for all situations where interoperability is needed such as the exchange of data among health care providers for direct patient care or the development of a patient portal. This is partly because of the time lag between the data being generated and mapped (the patient may need the information before this can take place) and because the mapped data are held in a separate place on the local network (e.g. hospital) which may not be able exchange data with a portal or with the EMR system of another provider.

An integrated health information system does not require all data to be stored in a single location. It is quite possible to achieve the key objectives outlined earlier in this report without central storage or even aggregation. A unified and co-ordinated approach to national data governance can enable smooth information exchange and use for a range of purposes without compromising privacy, security and ownership of data. In fact, in some ways data protection can be enhanced under a federated data structure.

Further, ensuring that data can be exchanged across national borders can amplify the benefits of data analytics and research in, for example, the context of public health, rare diseases, pharmacovigilance, and precision medicine. An information system that follows international data standards facilitates within-country and cross-border health care delivery and business opportunities for local research and technology sectors; and is better prepared to participate in and adapt to cross-border regulations and initiatives.

Box 2.1. Data standards in health and health care

Data standards in health and health care describe the methods, protocols, terminologies, and specifications for the collection, exchange, storage, and retrieval of health data from many different sources including electronic medical records, insurance claims, laboratory test results, prescription medicine dispensing records, vaccination and public health records, population surveys and more.

Standardisation can be summarised as a three-step process. The first step is to specify and define data elements. Examples of data elements are a lab test result, a particular medicine, and a patient's name, age and allergies.

The next step is to associate data types with the data elements. Types include dates, time, counts, units (weights and measures) and codes that rely on formats and terminologies. For data to be exchanged and used for many purposes it is essential that the data types are universal and used consistently. A simple example is recording the time something occurred in a 24- or 12-hour format.

Many data elements are defined by terminologies and their associated codes. For example, SNOMED CT (Clinical Terms) is a systematically organised computer processable collection of medical terms providing codes, terms, synonyms and definitions used in clinical documentation and reporting. Standards for syntax are also required which specify how terms should be combined to be interpretable.

The third step is determining how to encode the data elements as an electronic message to exchange the data within the health information system. Message format standards include common encoding specifications, information models for defining relationships between data elements, and document architectures and clinical templates for structuring data as they are exchanged. A widely used standard for clinical record exchange is Health Level 7 (HL7).

Information models describe how elements and codes should be contextualised with additional information about data subjects. For example, the terminology and code for fever may be insufficient without also including information about the process for measuring the fever.

Document architectures are standards for classifying, capturing and revising clinical notes. Clinical templates impose constraints on an information model. For example, a message format for a laboratory test may have a clinical template that requires certain data elements to be included.

In addition to standards for data terminology and exchange, standards are also necessary for user interfaces, record linkage, and data privacy and security protections.

Standards should be accompanied by use cases.

A use case describes a particular instance of exchanging health data and includes the standardised data to be exchanged as well as the stakeholders involved and the legal framework supporting the data exchange.

Developing standards requires consideration of the data needs of all of the key stakeholders within the information system, including stakeholders requiring data for primary (direct care) and secondary (statistics and research) uses. Developing use cases alongside the development of data standards is a mechanism for ensuring that the standards will support the different uses of the data that will be needed.

Sources: Institute of Medicine (US) Committee on Data Standards for Patient Safety (2004[3]), "Health Care Data Standards", https://www.ncbi.nlm.nih.gov/books/NBK216088/; Schulz (2019[4]), "Standards in Healthcare Data", https://doi.org/10.1007/978-3-319-99713-1_3.

A concerted data governance framework, including "privacy by design" is essential

A key component of a well-functioning health information system is a data governance structure that avoids the over-use of consent to authorise data exchange in favour of legal authorisation, and adopts an approach that protects privacy and ensures data security, while still enabling data to be exchanged and used for legitimate purposes. The OECD Council Recommendation on Health Data Governance sets out the elements for a national health data governance framework and fosters a "privacy-by-design" approach that is consistent with emerging transnational requirements such as those set out in the EU General Data Protection Regulation (GDPR) (See Annex B).

Privacy-by-design involves designing IT systems in a way that pro-actively anticipates and addresses risks to data privacy and security so they may be mitigated. In such approaches, the privacy of all individuals whose data is within the system is protected by default. The protection of individuals' privacy and data security is embedded within the architecture and functionality of the IT system. At the same time, the IT system supports all uses and re-uses of data that are in the public interest (Cavoukian, 2006[5]).

Privacy-by-design is important because health data are often personal and sensitive, particularly health micro-data where there is a data record for each individual. The *EU Data Protection Regulation* (GDPR) [Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016] places personal health data in a special category with the highest standards of protection.

The OECD Recommendation on Health Data Governance responds to the growing need for a consensus about the framework conditions within which health data can be appropriately governed to enable health data processing to take place both domestically and transnationally. Such health data governance frameworks require a whole of government approach; given that the public interests served span the domains of health, justice, industry, science, innovation and finance. The OECD Council Recommendation on Health Data Governance is compliant with the EU GDPR and encourages "privacy-by-design".

The OECD Recommendation on Health Data Governance was adopted by the OECD Council on 13 December 2016 and was welcomed by OECD Health Ministers at their meeting in Paris on 17 January 2017. The Recommendation provides policy guidance to:

- Encourage the availability and use of personal health information, to the extent that this enables significant improvements in health, health care quality and performance and, thereby, the development of healthy societies while, at the same time, continuing to promote and protect the fundamental values of privacy and individual liberties;
- Promote the use of personal health data for public policy objectives, while maintaining public trust and confidence that any risks to privacy and security are minimised and appropriately managed; and
- Support greater harmonisation among the health data governance frameworks of Adherents so that more countries can benefit from statistical and research uses of data in which there is a public interest, and so that more countries can participate in multi-country statistical and research projects, while protecting privacy and data security.

Governments adhering to the Recommendation agree to establish and implement a national health data governance framework to encourage the availability and use of personal health data to serve health-related public interest purposes while promoting the protection of privacy, personal health data and data security.

The Recommendation sets out 12 key elements of the development and implementation of national health data governance frameworks. The elements encourage greater cross-country harmonisation of data governance frameworks so that more countries can use health data for research, statistics and health care quality improvement.

The 2019/20 Survey of Health Data and Governance measured implementation of national health data governance frameworks and related regulations and policies. The 23 respondents to the survey were officials of national health ministries or national health data authorities. A national health data governance framework can encourage the availability and use of personal health data to serve health-related public interest purposes while promoting the protection of privacy, personal health data and data security. Overall, 17 of 23 respondents reported that a national health data governance framework is established or is being established. Korea was one of these (Table 2.1).

Table 2.1 National health and data governance elements

Respondent	A national health data governance framework is established or is being established	Public consultation has occurred or is planned about the elements of the national health data governance framework	National law or regulation exists that speaks to the protection of health information privacy and/or to the protection and use of electronic clinical records	A central authority for the approval of requests to process personal health data is established or planned
Australia	Yes	Yes	Yes	Yes
Austria	Yes	Yes	Yes	Yes
Belgium	No	No	Yes	Yes
Canada	Yes	Yes	No	No
Czech Republic	Yes	Yes	Yes	No
Denmark	Yes	No	Yes	Yes
Estonia	No	No	Yes	Yes
Finland	Yes	No	Yes	Yes
France	Yes	No1	Yes	Yes
Germany	Yes	No	Yes	No
Ireland	Yes	Yes	Yes	Yes
Israel	Yes	Yes	Yes	Yes
Japan	No	No	Yes	No
Korea	**Yes**	**Yes**	**Yes**	**Yes**
Latvia	Yes	Yes	Yes	Yes
Luxembourg	No	Yes	Yes	Yes
Netherlands	Yes	Yes	Yes	Yes
Norway	n.r.	n.r.	Yes	Yes
Singapore (non-Adherent)	No	Yes	Yes	No
Slovenia	Yes	Yes	Yes	Yes
Sweden	Yes	No	Yes	n.r.
United Kingdom (Scotland)	Yes	Yes	n.r.	Yes
United States	Yes	Yes	Yes	Yes
Total Yes	17	14	21	17

Note: n.r.: not reported.
1. Mission of the Health Data Hub is to elaborate a citizens and patients charter in collaboration with patient associations.
Source: Oderkirk (2021[6]), "Survey Results: National Health Data Infrastructure and Governance", https://doi.org/10.1787/55d24b5d-en.

Most respondents reported health data falling under a national health data privacy legislation; other data used in health studies falling under a national privacy legislation; and certain health datasets or health data programmes falling under other legislations governing ministries, data collections or registries. Some countries have legislations at different levels of government. Overall, 21 of 23 respondents reported that a national law or regulation exists that covers the protection of health information privacy and/or to the protection and use of electronic clinical records.

Six respondents reported that their health data governance framework is set out in law (Austria, the Czech Republic, Denmark, Finland, France, Germany). In Austria, there are elements of data governance within legislation governing health telematics, documentation and research organisation. In the Czech Republic, the National Health Information System and its governance are defined in the *Act on Health Services.* Finland's health data governance framework is set out in legislation regarding digitisation and management of client and patient information as well as in regulations and guidelines of the health ministry (THL) (Box 2.2). Health data governance requirements, including GDPR requirements, are set out in federal and state laws in Germany.

In Korea, the Ministry of Health and Welfare set up the *Health care Big Data Policy Deliberation Committee* in 2018 to discuss decisions required for data related initiatives. As the importance of health care data utilisation grew, the Committee was expanded to become the *Health care Data Policy Deliberation Committee* in 2021 which oversees discussing policy and system improvement for data utilisation and personal information protection. The COVID-19 pandemic has stimulated an expansion of health data under the Digital New Deal discussed later, which allows for the expansion and linkage of national health insurance data with other relevant data and for the accessibility of data for global research.

Box 2.2. Finland: FinData

Findata is the only authority that can issue permits for the secondary use of health and social data when the data is compiled from more than one data custodian. Findata provides for the secure linkage and research access to publicly funded datasets and registries including the data holdings of the Finnish Institute for Health and Welfare (THL), the Social Insurance Institution of Finland (Kela), the Population Register Centre, the Finnish Centre for Pensions and Statistics Finland. From 2021, Findata will expand to include data within the national EHR system (Kanta).

Findata is a centralised system issuing permits and a one-stop shop for the secondary use of health and social care data in Finland. It grants data use permits when data are requested from multiple registries or from the private sector; collects, links and prepares the data; provides the data in a secure IT-environment for data users; offers electronic tools for data permit applications; offers a help desk for data users; and works in collaboration with the controllers of the data.

Findata is not a permanent data repository, but a hub in which the data flows. It exists to streamline and secure the secondary use of health and social care data for four main purposes: 1) enabling effective and safe processing and access to data; 2) enhancing data protection and security; 3) eliminating overlapping administrative burden; and 4) improving data quality.

The *Act on the Secondary Use of Health and Social Data* (enacted in May 2019) gives Findata the authority to grant secondary use for research within Finland. It is noteworthy that this is made possible due to Finland's personal identification code that remains unchanged throughout an individual's life and is the key to linking personal information from various registries.

As a rule, the data are always disclosed to Findata's secure operating environment. However, the Act empowers Findata to make the data available in another environment as well, if it is necessary for the research purpose. These other environments will be audited for compliance with the regulation.

Source: Magazanik (2022[7]), "Supporting Health Innovation With Fair Information Practice Principles: Key issues emerging from the OECD-Israel Workshop of 19-20 January 2021", https://www.oecd.org/health/OECD-Israel-Health-Data-Governance-Workshop-Report.pdf.

In France, principles of data governance are set out in an *Act on the Modernisation of the Health Care System* which unified the governance of administrative health data in the custody of three organisations and enabled dataset linkages and set out principles and procedures for data access. The 2019 *Act on the*

Organisation and Transformation of the Health System broadened the definition of the national health data system to include additional datasets and their custodians and set out data sharing principles among these custodians. The Health Data Hub, which defines the elements of shared data governance with stakeholders was launched in 2019 to support France in becoming a leader in Artificial Intelligence in health and to overcome barriers to the re-use of health data for research (Box 2.3).

Box 2.3. France: Health Data Hub

The HDH is a public interest group that was authorised by law and funded by the government to expand upon the existing national health data system (SNDS) to encompass all existing databases concerning publicly funded health activities (e.g. hospital electronic health records warehouses, cohorts, and registries). HDH was built on the infrastructure of the SNDS, the French administrative health care database that covers 99% of the population. The HDH catalogue unifies a collection of pseudonymised databases which the HDH is authorised to make available for research.

HDH's primary goal is to support research and innovation in health and health care by providing a unique entry point for secure and privacy-protective data linkage services and access to health microdata for research projects that contribute to the public interest, while respecting patient rights and ensuring transparency with civil society. The second goal was to design a state-of-the-art platform at the highest level of security, offering data storage, computing, risk mitigation and analysis capabilities. Finally, the third goal was to create a documented data catalogue built in a progressive manner to make priority data known to the scientific community.

The legal reform that launched the HDH aims to allow better visibility of common data assets for the entire ecosystem and to harmonise data access rules. Access to data is regulated and is carried out with respect for the rights of individuals. There is no obligation to process health data in France within the technological platform of the HDH and it is still possible to conduct research in other partnerships. HDH has so far launched 27 pilot projects, 9 of them COVID-19 related, after HDH received a specific mandate to accommodate COVID-19 related projects.

Permanent access to the HDH is granted to health authorities by decree of the French Ministry of Health. Other research requests for data are submitted to the "access team" that conducts a scientific and ethical assessment. If the request is found eligible, it is sent to the independent Scientific and Ethical Committee (CESREES). CESREES verifies that the purpose of the study is relevant and of public interest, that the data requested are in line with the study objective and that the proposed methodology is robust. If found positive, the project is submitted for authorisation of the French Data Protection Authority.

HDH consults with civil society by carrying out studies and consultations on the relationship that citizens have with health data and on their perceptions, needs and expectations. This knowledge is necessary to orient and adapt public communications, and to evaluate them and ensure they are clear. HDH also contributes to the implementation of a "health data culture" by providing educational tools to enable citizens to understand the data and to learn how to use them and how to carry out projects with them. (CNIL).

Source: Magazanik (2022[7]), "Supporting Health Innovation With Fair Information Practice Principles: Key issues emerging from the OECD-Israel Workshop of 19-20 January 2021", https://www.oecd.org/health/OECD-Israel-Health-Data-Governance-Workshop-Report.pdf.

In the Netherlands, the Information Council works on the development and sustainability of national health information and includes health care organisations and the Ministry of Health. The Council has four information system development goals: data to monitor the safety of prescription medicines; citizen access

to their own medical data and the ability to link their own health and medical data; digitisation and exchange of data between health care professionals; and that data is recorded once and reused. A sub-group of the Council is the Community of Data Experts which advises the Council about the secondary use of health data for statistics, research and health and health care policy. Several laws include rules that make it mandatory to keep a medical record, to provide patients with digital access to their medical records and regarding system quality. A new framework law that passed the parliament in 2021 requires the electronic exchange of medical records among health care providers.

Latvia developed a Health System Performance Assessment Framework in 2019 (including health care quality, patient safety and efficiency indicators). Within this framework, principles and procedures for data provision, data linkage, health data protection and access to data for research are set out.

The United States Department of Health and Human Services proposed in 2020 a new rule within the *21st Century Cures Act* to support seamless and secure access, exchange and use of electronic health records (Box 2.4). The rule aims to increase innovation and competition by giving patients and their health care providers secure access to health information; allowing more choice in care and treatment. A provision in the rule requires that patients can electronically access all their electronic health information (both structured and unstructured data) at no cost and deters blocking authorised access to and exchange of data. It calls on the health care industry to adopt standardised application programming interfaces (APIs) to allow individuals to securely and easily access structured electronic clinical data using smartphone applications.

The Department of Health and Human Services and the Office of the National Co-ordinator have also released a Trusted Exchange and Common Agreement (TEFCA) which sets out principles, terms and conditions for a common agreement to enable nationwide exchange of electronic health information across disparate health information networks. It aims to ensure that health information networks, health care providers, health plans, individuals and other stakeholders can have secure access to their electronic health information when and where it is needed.

Box 2.4. United States: New rule promoting access to data

In the United States, each state manages their own public health reporting programs and these practices are regulated by state law. Each individual hospital system may have their own network – which can include thousands of payor systems. This fragmentation impedes patients' access to their complete records, as well as the availability of health data for research. To address this, the Department of Health and Human Services (HHS) proposed a new rule within the *21st Century Cures Act* to support the seamless and secure exchange and use of electronic health records. The rule asks the health care industry to utilise Application Programming Interfaces (APIs) and to adopt the HL7 Fast Health care Interoperability Resources (FHIR) standard for health data exchange. Further, a Trusted Exchange and Common Agreement (TEFCA) sets out principles, terms and conditions to enable the nationwide exchange of electronic health information across disparate health information networks.

Standardisation of the data sources is required for health data to be exchanged across all networks, not just the major networks like Medicare. The Office of the National Co-ordinator of Health IT (ONC) plans to introduce a the United States Core Data for Interoperability Standard, that will be the content and vocabulary baseline for health data, beginning 24 months after the publication of the final rule. This standard includes new data classes and data elements, such as provenance, clinical notes, paediatric vital signs, addresses, email addresses and phone numbers. These data pieces were not universally exchanged before – but are essential for patient matching and identifying risk factors. Leveraging this data allows better demographic information to be available to health care providers so that they can evaluate patients' risks and needs.

ONC has several pathways for public engagement and input into these data interoperability standards including a federal advisory committee made up of representatives from health care, health IT, and patient advocacy organisations. It publishes proposals for public comment and conducts targeted listening sessions with different groups. Finally, on the technical aspects, it works closely with the standards organisations which include public input and consensus- based balloting processes.

Generally, there isn't financial support to all stakeholders to invest in this, but there is some support for states to implement these capabilities in their networks. For health care providers, there was previously a programme that provided incentive payments for adoption of an electronic health record system, but there has not been new funding approved by Congress to continue support. However, there are requirements for hospital systems that are paid under the Medicare (National) programme to adopt and use technology that is certified to certain standards and functionalities. ONC has added these new requirements to the existing programme requirements. There is also a programme that requires the payers (the plans that administer Medicare and Medicaid) to build Application Programming Interfaces (APIs, as well to allow the data they hold to also be accessible. And finally, ONC requires technology developers, through a certification programme, to make this technology available to their customers.

Source: Magazanik (2022[7]), "Supporting Health Innovation With Fair Information Practice Principles: Key issues emerging from the OECD-Israel Workshop of 19-20 January 2021", https://www.oecd.org/health/OECD-Israel-Health-Data-Governance-Workshop-Report.pdf.

In Australia, governmental responsibility for national health datasets is shared between Federal and State/Territorial jurisdictions. At each level of government, there are a range of agencies with responsibility for specific datasets with no overarching health data governance framework. However, all jurisdictions signed the 2020-25 National Health Reform Agreement which includes an action to scale up a national approach to data governance arrangements, structures and processes, to facilitate clear and efficient mechanisms for sharing and developing data in a sustainable, purpose-based and safe way. There is an Australian data governance framework for electronic clinical data exchanged as part of the My Health Record System. A Data Availability and Transparency Bill was introduced in 2020 to implement a scheme to authorise and regulate access to Australian Government data (Box 2.5).

Box 2.5. Australia: Data Availability and Transparency Reform including the new Dataplace

Varying legislative requirements across the Commonwealth, States and Territories, particularly for privacy and permitted uses of data, have historically made data sharing more complex. Challenges to effective and efficient sharing and use of data are not limited to legislation. Technical, data availability and data quality challenges have affected the application of data from both new and well-established data assets to respond to the needs of the health system and the different needs Commonwealth, State and Territory data users.

The Office of the National Data Commissioner (ONDC) in Australia has been tasked with developing a new data sharing and release framework, and overseeing the integrity of data sharing and release activities of Australian Government agencies. The ONDC released its first guidance in 2019 – the Best Practice Guide to Applying Data Sharing Principles – which provides general guidance to assist agencies in adopting international best practices in data sharing.

The Australian Government introduced the *Data Availability and Transparency Bill 2020* (DAT Bill) into the Commonwealth Parliament in late 2020. Once passed, the Bill will establish a new scheme to safely share Australian Government data. To support the implementation of the new data sharing scheme, ONDC is establishing digital services (known as Dataplace) to manage: the accreditation process under the scheme; the submission of data requests to data custodians; and the negotiation, registration and management of data sharing agreements.

It is intended that Dataplace will eventually support the sharing of Australian Government data both under the new data sharing scheme and through other data sharing mechanisms.

The ONDC is also preparing to implement a Data Inventories Pilot Program to develop individual data inventories for Australian Government agencies using common standards and then to aggregate these inventories into an Australian Government Data Catalogue. The Pilot will initially cover about 20 percent of Australian Government entities. The Pilot will support greater transparency of government data holdings, facilitate data sharing and assist the Australian Government to respond quickly in emergencies.

An Intergovernmental Agreement on data sharing, agreed by the National Cabinet on 9 July 2021, committed the Commonwealth, State and Territory Governments to share public sector data (including health data) as a default position, where it can be done securely, safely, lawfully and ethically. The principles-based agreement recognises data as a shared national asset and aims to maximise the value of data to deliver outstanding policies and services for Australians. National effort will also be focussed on specific time-limited national priority data areas, under the Intergovernmental Agreement's National Data Sharing Work Program.

The 2020-25 Addendum to the National Health Reform Agreement has committed to a series of national action to enhance health data to enable long term health reform and harness data and analytics to drive meaningful improvements in the health system. This includes: establishing a national approach to govern the creation, access and sharing of data from all Australian Governments and progressing mechanisms and interoperable systems for secure and comprehensive integration of data across patient journeys.

Source: OECD Questionnaire on Health data and governance changes during the COVID-19 pandemic, 2021.

Ireland's Department of Health is currently working on a national health information strategy. In this strategy, Ireland is planning a National Health Observatory which would be authorised by law and include the development of a national health data governance framework.

In Israel, responsibilities for national health data governance are shared between the Ministry of Health and the Israel Innovation Authority. Israel's government has been working on designing a policy framework for secondary use of health data for research to enable collaborative data research initiatives. This framework is not yet finalised. As a result of the COVID-19 pandemic, the government has been accelerating work toward data sharing and access (Box 2.6).

Box 2.6. Israel: COVID-19 Data Lake

The Ministry of Health is working on an initiative to form a "Data Lake" that will include Israel's digital health data from hospitals as well as HMO's and the Ministry of Health itself. On a national level, Israel has a rich and well computerised health data ecosystem consisting of 30 years of central public health care provided within HMOs serving 95% of patients. There is value in bringing all of this data together to accelerate COVID-19 related research. The "Data Lake" policy framework consists of IRB certificate mechanisms, transparency, de-identification mechanisms, secure environment, user controls, opt-out mechanisms, and data use agreements.

The public interest in making the data available for research allows for an opt-out mechanism. Israel communicated with the public about the creation of the data lake via a text message to all persons. Strengthening the argument supporting the decision to offer an opt-out mechanism were previous decisions regarding the National Patient File (summary health record). The National Patient File requires all providers in Israel to use the same central system for data management, so that they can easily communicate with each other. There were discussions in the Ministry of Health to determine if this system should have an opt-in or opt-out structure. An opt-out structure was chosen because there was strong evidence that having all of the data available for patient care provides for more accurate findings and better health care services; and allows for more effective decisions to be made, which in turn allows costs to decrease and is in the public's best interest.

The COVID-19 Data Lake is only available for pure research with no collaboration with industry. There remain concerns that providing researchers access to the data lake may diminish public trust. In order to streamline the application process to the Data Lake, Israel is preparing one formal agreement for researchers that want to access the data, since this data is needed in a timely manner due to COVID-19. Further, Israel is considering new technologies for privacy enhancement that support researchers' ability to access complete records (raw data).

Source: Magazanik (2022[7]), "Supporting Health Innovation With Fair Information Practice Principles: Key issues emerging from the OECD-Israel Workshop of 19-20 January 2021", https://www.oecd.org/health/OECD-Israel-Health-Data-Governance-Workshop-Report.pdf.

The Government of Canada, together with provinces and territories, is leading the development of a Pan-Canadian Health Data Strategy to improve Canada's collection, sharing and use of health data while protecting privacy. An Expert Advisory Group (EAG) was established in December 2020 to provide advice and guidance as work on the Pan-Canadian Health Data Strategy evolves.

Slovenia began developing a national health data governance framework in 2019. Luxembourg is planning a National Health Observatory which will be authorised by law and will support the development of a national health data governance framework. Belgium reported an intention to increase co-operation among several federal health administrations (Federal Public Service Health (FPS Health), RIZIV-INAMI, FAGG) regarding data policy.

The United Kingdom (Scotland) has an information governance framework for personal data, within which is a Public Benefit and Privacy Panel (PBPP) for health and social care data. The PBPP is a patient

advocacy panel which scrutinises applications for access to NHS Scotland health data for secondary purposes with respect to the public benefit and privacy implications of proposed projects.

Building trust in health data use through transparency and inclusion

OECD countries are fostering public trust of individuals, communities and societies in the collection, use and sharing of health data for uses within the public interest through inclusion and transparency. This includes public consultation from a wide range of stakeholders with a view to ensuring that the processing of personal health data is consistent with societal values and the reasonable expectations of individuals. This also includes transparency with the public regarding health data processing and access to data and the safeguards protecting data privacy and security.

Public consultation about health data governance

Through open and public dialogue about potential benefits, risks and risk mitigations it is possible to promote a balanced approach to the governance of personal health data within society. In response to the 2019/20 survey, 14 of 23 respondents reported that a public consultation had taken place or was planned around the elements of a national health data governance framework (Table 1.1).

Australia reported undertaking a stakeholder and public consultation as part of the steps toward developing a Framework for the Secondary Use of My Health Record system data. The My Health Record system is a nation-wide electronic health record system that contains a summary of patients' health information.

The Netherlands includes client and patient federations as members of the National Health Information Council. Further, an open public consultation takes place in the Netherlands to review documents presenting data governance concepts. The health data governance development process includes participation of civil society organisations and patients' organisations in order to reflect diverse public opinions.

Israel reported an on-going public consultation process of the Ministry of Health and the Innovation Authority using social media, public conventions and public feedback through a website.

Slovenia gathers public input to its health data governance framework through an e-Democracy portal. Latvia has undertaken in 2018 and continued in 2019 presentations and discussions with health care professionals and researchers.

Canada reported an intention to consult the public and an effort that is underway to develop the best method to do so and to determine the areas upon which the consultation should focus. France reported that a mission of the Health Data Hub is to elaborate a Citizens and Patients Charter in collaboration with patients' associations. Ireland reported that a public consultation will take place on the draft health information strategy.

The Czech Republic reported that a new law on e-health is being prepared that will include a revision of the law governing the National Health Information System (NHIS). As part of the development of this legislation, the public will be consulted. Similarly, Austria, Finland, Luxembourg and Singapore reported that public consultations take place whenever a legal reform is planned.

The United States Department of Health and Human Services provided a long open public comment period on the proposed rule within the 21st Century Cures Act to support seamless and secure access, exchange and use of electronic health records.

Fair and transparent project approval process

Fair and transparent project review processes are important to meet public expectations regarding appropriate uses of their personal health data. Review and approval procedures should involve an assessment of whether the processing is within the public interest; be robust, objective and fair; be timely; promote consistency in outcomes; be transparent while protecting legitimate interests; and be supported by an independent multi-disciplinary review.

Seventeen respondents reported in 2019/20 that a central authority for the approval of requests to process personal health data is established or planned.

In Korea, the Health care Data Policy Deliberation Committee set up a specialised sub-committee to discuss appropriate use of data.

Australia's data governance framework for the My Health Record system, as well as the legislation authorising the system, provide for a central Data Governance Board to manage requests for data from the My Health Record system. The Governance Board is not involved in requests for other national health data; and most of these requests are approved by the Australian Institute of Health and Welfare.

Finland is currently establishing a Health and Social Data Permit Authority (Findata) to approve data processing requests. Denmark has established the Danish Health Data Authority.

In Belgium, the Information Security Committee is responsible for approving requests to process personal health data; in Luxembourg, the National Commission for Data Protection grants approvals; and in France the data protection authority (CNIL) approves the creation of datasets and the processing of data. Similarly, in Estonia, the Data Protection Inspectorate approves requests to process personal health data. There are research ethics committees in Estonia that are also involved in project approvals. In Israel, the Ministry of Health's Data Delivery Committee approves requests in co-ordination with the Privacy Protection Authority of the Ministry of Justice.

In the Netherlands, organisations can create datasets and can undertake dataset linkages under the precondition that their activities meet the requirements of the GDPR and the Medical Treatment Act. The Data Protection Authority evaluates whether datasets meet GDPR requirements. Further guidelines regarding necessary elements of quality registries are also provided by the national body overseeing the electronic health record system (NICTIZ).

In Slovenia, new datasets must be authorised by law and all other cases of data processing are approved by the Information Commissioner. Likewise, the Swedish Ethical Review Authority approves requests for data processing for research projects; however, multi-purpose datasets require legal authorisation before they can be created. In Sweden, data custodians also independently approve data requests.

In Norway there are regional research ethics committees and a national centre for research data (REK) that assesses requests for health data processing in terms of research methods, an assessment of benefits/risks and data privacy safeguards.

In Canada, provinces and territories have individual processes for approval of requests to process personal health data. To support knowledge creation and help researchers, policy makers and decision-makers make more effective use of pan-Canadian data, the Heath Data Research Network's Data Access Support Hub (DASH) allows Canadian researchers requiring multi-jurisdictional data to request data from a single source.

In Germany, there are plans to open national electronic health record data for research, but it is not yet clear whether a single authority for data access management would be created or whether the organisation that is currently responsible for e-HR infrastructure would assume this task.

Current regulations in Ireland provide for a Consent Declaration Committee to adjudicate health research requests involving consent exemptions. As Ireland develops an information strategy, a national health

information office may be set up that would provide the necessary approvals for persons or organisations seeking dataset linkages and access to linked data for valid purposes.

In Latvia, the Centre for Disease Prevention and Control evaluates researchers' and research institutions' applications for the use of identifiable patient data recorded in the medical documents in specific research under Cabinet Regulation No. 446 which covers cases where it is not possible to obtain informed consent from the patient. If approved, data for research from different sources is provided/available on a person level with a direct identifier (personal ID, etc.). Requests for a data extraction from the public monitoring system for health care quality and efficiency are approved by a special project council consisting of representatives from the Centre for Disease Prevention and Control, National Health Service, State Emergency Medical Service and Health Inspectorate. In this case, approved applicants access pseudonymised data.

Information Services Scotland (ISS) sets out criteria for approval to access data within a safe haven environment. Applicants must be employed by an approved organisation and meet other requirements, such as undertaking training in information governance requirements. Applicants seeking a dataset linkage may be required to apply for approval by the NHS Scotland Public Benefit and Privacy Panel.

In the United States, most health care providers must follow the HIPAA Privacy Rule which sets a baseline protection for certain individually identifiable health information. The Rule permits, but does not require, covered health care providers to give patients a choice regarding whether their health information is disclosed or exchanged electronically with others for key purposes including treatment, payment and health care operations.

Transparency through public information

Public information mechanisms are essential to build public trust. Public information should include the purpose of the processing, the health-related public interest served, the legal basis for the processing, the procedure and criteria used to approve the processing, a summary of approval decisions taken, and information about the implementation of a national health data governance framework and how effective it has been.

Clarity and transparency supports protecting individual's privacy and autonomy while also ensuring that data processors and data users are aware of the authority under which data may be used and can plan the development of research programmes accordingly.

Twenty-one respondents reported in 2019-20 that for all or most key health care datasets there is a publicly available description of the dataset purpose and content and most provided a web-link to this public information. Singapore reported that a public description was available for two datasets; and Ireland reported this for one dataset.

Seventeen respondents reported that the description of all or most health care datasets includes the health-related public interests served by the data. Seventeen respondents reported that the description for all or most datasets includes the legal basis for the processing: Austria, Belgium, Canada, the Czech Republic, Denmark, Finland, France, Germany, Israel, Korea, Latvia, Luxembourg, the Netherlands, Norway, Slovenia, Sweden and the United Kingdom (Scotland).

The procedure to request access to the data and the criteria used to approve access to the data are publicly available for all or most health care datasets in 17 respondents: Australia, Belgium, Canada, the Czech Republic, Denmark, France, Germany, Israel, Japan, Korea, Latvia, the Netherlands, Norway, Slovenia, Sweden, United Kingdom (Scotland) and the United States.

Fourteen respondents reported that the procedure to request a record linkage or other further processing of all or most health care datasets and the criteria used to approve these requests are publicly available:

Australia, Belgium, Canada, Denmark, Finland, France, Israel, Japan, Korea, Latvia, the Netherlands, Sweden and the United Kingdom (Scotland).

When asked if there is a summary of approval decisions for the record linkage or further processing of the datasets that is publicly available, 10 respondents answered yes for all or most key health care datasets: Australia, Denmark, Finland, France, Israel, Japan, Korea, Latvia, Sweden and the United Kingdom (Scotland). When asked whether the summary describes or identifies the data recipient of an approved record linkage or further processing of the datasets, only Denmark, France, Israel, Japan, Korea, Latvia, Sweden and the United Kingdom (Scotland) said yes for all or most health care datasets.

EMR interoperability is critical with success characterised by co-ordination and leadership at the national level

Clinical data are a key component of any health information system looking to improve care quality as well as enabling research and innovation. This section outlines the current situation in OECD countries regarding the exchange and interoperability of electronic health records data, and the key elements of successful integration.

Exchange of clinical data at the national level

Most of the OECD countries (21 of 27) surveyed in 2021, are exchanging electronic clinical records among physicians, medical specialists and hospitals for the direct care of patients. Sixteen countries report that a single country-wide EHR system is in place. Thirteen countries reported that a nationally standardised patient summary is exchanged among health care providers at a national level, with a broader array of patient data exchanged among health care providers at the sub-national (state, regional) level. In three countries, Belgium, Canada and the Czech Republic, patient data is exchanged among health care providers only at the sub-national (regional, state) level.

A single authority to oversee EMR development and interoperability

Central co-ordination enhances the readiness of EMR systems to contribute to national performance monitoring and research. Twenty-three of the 27 countries reported a national organisation with the primary responsibility for national EHR infrastructure development (Table 2.2). Twenty countries reported that their national organisation is also responsible for setting national standards for both clinical terminology within EHRs and standards for data exchange (electronic messaging).

Table 2.2 National organisation responsible for EHR system and its role

Country	National organisation with primary responsibility for national EHR infrastructure development	Name of the organisation	National organisation sets standards for clinical terminology in Electronic Health Records	National organisation sets standards for electronic messaging	Other major responsibilities of this national organisation
Australia	Yes	Australian Digital Health Agency (ADHA)	Yes	No6	Coordinates and reviews Australia's National Digital Health Strategy.
Belgium	Yes	eHealth Platform & FPS Health	Yes	Yes	National eHealth services

Country	National organisation with primary responsibility for national EHR infrastructure development	Name of the organisation	National organisation sets standards for clinical terminology in Electronic Health Records	National organisation sets standards for electronic messaging	Other major responsibilities of this national organisation
Canada	Yes1	Canada Health Infoway	Yes	Yes	Accelerates the development, adoption and effective use of digital health solutions. Independent, not-for-profit organisation established in 2001 and funded by the federal government.
Costa Rica	No		n.a	n.a	
Czech Republic	Yes	Ministry of Health, Department of Informatics and Electronic Health care (ITEZ)	Yes7	Yes7	Focuses on the e-health strategy and maintenance of national information standards. Implementation of the infrastructure is provided by UZIS.
Denmark	Yes	Danish Health Data Authority	Yes	Yes	National registries, secondary use of data, statistics in health and reimbursement schemes
Estonia	Yes	Centre of Health and Welfare Information Systems	Yes	Yes	Organises and co-ordinates the administration of ICT development and management of strategies, development plans and budgets. Role includes strategic planning of information systems and e-services; advise to government; responsibility for information systems and databases; improvement of the interoperability and exchange of information of e-solutions; integrated management of the IT architecture; development and management of cross-border data exchange services; services, software and information systems procurement; implementation of best practices for the protection of personal data; implementation of the information security policy; monitors the use and security of information systems and compliance information security regulations; inspections, as necessary of information systems, data integrity and security. Responsible for ICT under the MoH including infrastructure, data communications, data security, backup, systems administration; software support for ICT, ICT governance and development, systems integration, maintenance and computer support, and user support services. data transmission formats, data control rules and data transmission systems related to information systems, development and management of classifications; management of technical data quality related to information systems; creates and manages a data warehouse which enables to fulfill the tasks assigned to the processor authorised by legislation
Finland	Yes	Social Insurance Institution (Kela)	Yes	Yes	National rules and mandatory requirements for systems
Germany	Yes	Gematik GmbH	n.r.	n.r.	
Hungary	Yes	Ministry of Health and Director General of National Hospitals (OKFO)	n.r.	n.r.	General country-wide responsibility for health care systems
Iceland	Yes	Directorate of Health, National Centre for eHealth Unit	Yes	Yes	Development and implementation of national digital solutions in health care, including the integrated electronic health record and the national patient portal, eHealth strategies, clinical terminology standards and the Icelandic HealthNet.
Israel	No2	Ministry of Health	Yes	Yes	

Country	National organisation with primary responsibility for national EHR infrastructure development	Name of the organisation	National organisation sets standards for clinical terminology in Electronic Health Records	National organisation sets standards for electronic messaging	Other major responsibilities of this national organisation
Italy	Yes	Ministry of Economy, SOGEI (in-house system integrator)	Yes	Yes	Sets strategic objectives, evaluates the ongoing activities and results, and defines the functional and technical specifications for EHR documents.
Japan	Yes	Health Insurance Claims Review and Reimbursement Services and All-Japan Federation of National Health Insurance Organisations	Yes	Yes	Payments of medical fees, system implementation supports, etc.
Korea	Yes	Korean Health Information Service (KHIS)	Yes	Yes	Department responsible for developing EHR infrastructure including standardisation, personal health records (PHR), health information data exchange, and certification (criteria development, business, education). A separate department is established for EHR data utilisation.
Lithuania	Yes	Ministry of Health and State Enterprise Centre of Registers	Yes	Yes	Formulates state policy, organises, co-ordinates and controls its implementation, including digitisation of health care sector and is the controller of the State Electronic Health Services and Co-operation Infrastructure Information System (ESPBI IS)
Luxembourg	Yes	Agence eSanté	Yes	Yes	Set up and operate a national electronic platform for the exchange and sharing of health date; promote interoperability and security in health information systems; establish and maintain roadmap for health information systems; assist regulators and authorities on strategic choices related to health information systems; and disseminate information on operational procedures and security measures.
Mexico	n.r.		n.r.	n.r.	
Netherlands	Yes	n.r.	Yes	Yes	National Health Information Council (Informatieberaad zorg). In that council both health care organisations and the Ministry of Health work on the sustainability of the information framework in health care. Four goals are: 1) safety of prescribing, 2) citizens can see their own medical data and link these to their own health data, 3) digital and standardised transfer of data between health professionals, 4) data is recorded once and then reused.
Norway	Yes	Norsk Helsenett	No8	No8	Develop, manage and operate national e-health solutions, core journal and e-prescription, as well as basic data in various registers and provide the national infrastructure for electronic communication in the health sector.

Country	National organisation with primary responsibility for national EHR infrastructure development	Name of the organisation	National organisation sets standards for clinical terminology in Electronic Health Records	National organisation sets standards for electronic messaging	Other major responsibilities of this national organisation
Portugal	Yes	SPMS (Shared Services for the Ministry of Health, EPE)	Yes	Yes	Public enterprise created in 2010 under the guardianship of the Ministries of Health and Finance. Provides shared services to health organisations: ICT, purchasing and logistics, financial services and human resources and centralises the procurement of goods and services within the NHS. SPMS is a corporate legal entity with administrative and financial autonomy and its own assets. SPMS is a Competence Centre with the main responsibility of implementation and operation of Health Information Systems to be used in the Portuguese Health System and it is the national authority for eHealth cross border co-operation. SPMS promotes the definition and use of standards, methodologies and requirements that guarantee interoperability and interconnection of health information systems with each other and with cross-sectional information systems of the Public Administration. It iworks with other EU countries to share knowledge and to align and adopt common standards (e. g. HL7 and IHE).
Russian Federation	Yes	Ministry of Health and Ministry of Digital Development, Communications and Mass Media	Yes	Yes	
Slovenia	Yes	National Institute of Public Health (NIJZ)	Yes	Yes	Public health authority
Sweden	Yes and No3	Multiple agencies involved at national and regional levels	Yes	Yes	Coordination of eHealth initiatives among regional health authorities
Switzerland	Yes	eHealth Suisse	Yes	Yes	Creation and update of the conceptual basis for the EHR certification process; creation and update of the requirements of the central components / services necessary for a running EHR (metadata index, community portal index services, HP index service and others /run by the Federal Office of Information Technology, Systems and Telecommunication FOITT; and EHR information and co-ordination
Turkey	Yes	Ministry of Health	Yes	Yes	
United States	No5		n.a.	n.a.	

Notes: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Canada Health was in a lead role for the development and implementation but it is managed by each jurisdication.
2. EHR are regulated by the Ministry of Health.
3. Some aspects are co-ordinated between a few authorities.
5. US Department of Health and Human Services adopts national standards and regulates the certification of EHR products. Governance of the exchange infrastructure is currently being defined.
6. ADHA specifies which messaging standards are required to allow other clinical systems and mobile applications to connect with the My Health Record System.
7. MoH recommends standards. Legislation is in preparation to create a legal mandate to enforce e-Health related standards.
8. Norwegian Directorate for e-health is responsible to set standards for clinical terminology and data exchange.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Fourteen countries reported that the national organisation responsible for EHR infrastructure development had a multidisciplinary governing body with representation from various stakeholder groups (Table 2.3). Multi-disciplinary governance supports the development of standards that meet the needs of different stakeholders in the health information system. The absence of an interdisciplinary body in Korea as well as the approach of establishing the KHIS to advance certification and interoperability and a separate body to address the secondary use of EMR data is discussed in Chapters 3 and 4.

Table 2.3 National organisation has a multidisciplinary governing body

Country	Governing body of the national organisation is multi-disciplinary with representation from various stakeholder groups	Stakeholder groups represented within the governing body of the national organisation
Australia	Yes	Governed by a Board and a person is eligible for appointment as a Board member only if the Health Minister is satisfied that the person has skills, experience or knowledge in at least one of the following fields: medical practice; health informatics, health technology standards and information management in large scale health settings; health care delivery; delivery of private health services; consumer health advocacy; designing, developing and delivering innovative uses of technology; developing, implementing and managing national digital health policies, strategies and services; developing, implementing and operating clinically safe work practices, methods and patient safety solutions in relation to digital health services; financial management; providing legal services and advice; managing and delivering digital health systems in State and Territory health facilities; and leadership and management in the delivery of traditional and digital health services that are managed, operated or provided by a State or Territory Government.
Belgium	Yes	Involves all health stakeholders: health care providers and organisations, patients, mutual funds, public institutions, Communities and Regions, etc.
Canada	No	Membership of Infoway is Deputy Ministers of Health for the Federal, Provincial and Territorial Governments. Infoway is responsible for engaging a wide variety of stakeholders (clinicians, patients, governments, vendors, academia, etc.)
Costa Rica	n.a	
Czech Republic	n.r.	
Denmark	No	
Estonia	No	
Finland	Yes	THL and Kela have, to some extent, a multi-disciplinary employee base and have multi-disciplinary stakeholder groups and steering mechanisms.
Germany	Yes	Shareholders are the Federal Ministry of Health (BMG), the Federal Medical Association (BÄK), the Bundeszahnärztekammer (BZÄK), the German Association of Pharmacists (DAV), the German Hospital Association (DKG), the Central Association of Statutory Health Insurance Institutions (GKV-SV), the Federal Association of Statutory Health Insurance Physicians (KBV), the Association of Statutory Dentists (KZBV) and the Private Health Insurance Association (PKV).
Hungary	No	
Iceland	Yes	Health professionals and relevant stakeholder groups are contacted to form working groups to work on different eHealth projects. Moreover, health professional surveys and citizen surveys are conducted on a regular basis.
Israel	Yes	
Italy	Yes	Representatives of the institutions (different Ministries and Regions) and stakeholders: doctors, nurses and apothecaries associations, and municipalities associations.
Japan	No	
Korea	No	
Lithuania	No	
Luxembourg	Yes	Agence eSanté GIE is established in the form of an Economic Interest Grouping which counts as members the major health care related stakeholders, namely: Luxembourg State represented by the Ministry of Health and the Ministry of Social Security; National Health Fund (Caisse Nationale de Santé); Social Security Office (Centre Commun de la Sécurité Sociale); Association of Doctors and Dentists (Association des Médecins et Médecins-Dentistes); Luxembourg Hospital Federation (Fédération des Hôpitaux Luxembourgeois); Confederation of long term and home care providers

Country	Governing body of the national organisation is multi-disciplinary with representation from various stakeholder groups	Stakeholder groups represented within the governing body of the national organisation
		(Confédération des organismes prestataires d'aides et de soins; Luxembourg federation of laboratories (Fédération Luxembourgeoise des Laboratoires d'Analyses Médicales); the association of Pharmacists (Syndicat des Pharmaciens Luxembourgeois); Association for the Defence of Patients' Interests (Patientevertriedung).
Mexico	n.r.	
Netherlands	Yes	
Norway	Yes	
Portugal	Yes	It includes several workgroups including stakeholders.
Russian Federation	No	
Slovenia	No	It is a public institution, appointed by the Ministry of Heatlh. Other stakeholders are involved indirectly.
Sweden	Yes	Coordination of eHealth initiatives among regional health authorities
Switzerland	Yes	All relevant stakeholders groups included such as political authorities (federal level and cantons), physicians, other HPs associations, hospitals, insurances and so on.
Turkey	Yes	Personnel of the health care system that is developed and managed by Ministry of Health.
United States	n.a.	

Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Convergence towards specific standards is occurring

Global consensus regarding terminology standards for key clinical terms has not been reached yet. There are, however, a few international terminology standards that are used by a significant share of countries.

In 2021, 18 respondents reported using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision **(ICD-10**) for diagnostic terms; 16 respondents reported the Anatomical Therapeutic Chemical (**ATC**) Classification System for medication terms; 13 respondents reported the Logical Observation Identifiers Names and Codes (**LOINC**) for laboratory test terms; and 10 respondents reported **DICOM** standards for medical image terms. These results for 2021 are a small improvement from 2016, as the number of respondents adopting the ICD-10 diagnostic terms and ATC medication terms has grown by a few countries.

Twelve respondents reported adopting the Systematised Nomenclature of Medicine-Clinical Terms (**SNOMED CT**) for at least one key term within their EHR. SNOMED CT is a comprehensive set of terminology standards covering key terms within EHR records. The cost of deployment; however, is a barrier to widespread adoption and the number of respondents is unchanged from 2016.

However, there remain key terms within clinical records where there is no consensus among countries about which international standard could apply. These include surgical procedures, vital signs, healthy behaviours, socio-economic status, clinically relevant cultural and psychosocial characteristics, and patient reported outcomes and experiences. Further, there are often local standards that have been adopted or, in some cases, these elements are not coded to a terminology standard but recorded as free text.

The legacy of fragmented deployment of EHRs has resulted in 11 respondents reporting clinical terminology standards are inconsistent among different networks or regions within their country. While this remains a significant problem, it has improved from 2016 when 20 respondents reported this issue.

Twenty-one respondents in 2021 reported implementing policies or projects to improve the interoperability of data within electronic health record systems (EHRs). Seventeen respondents are adopting the HL7 Fast

Health care Interoperability (Resource) standard and a further two respondents are considering adoption. The **HL7 FHIR** standard supports web-based applications in health care as they exist for other sectors such as for e-commerce, banking, and travel booking; and utilises commonly used web development tools which allow for a larger pool of developers and faster development. The KHIS is promoting FHIR as part of implementing the My Health Way initiative.

Twelve respondents are also adopting **SMART** on FHIR standards (or similar) and a further 4 respondents are considering adopting SMART on FHIR. Substitutable Medical Applications and Reusable Technologies (SMART) is a standard used on top of FHIR to develop web-browser and mobile/smartphone apps that can be connected to/interact with any EHR system. For example, an app to assist patients with managing their medications or an app for secure communication with a health care provider.

Fourteen respondents reported developing public application programming interfaces (**APIs**) and an additional respondent is considering adopting this standard. Application programming interfaces (APIs) allow data sharing among different EHR software and Health Information Technologies, overcoming blockages to data interoperability (Table 2.4).

Table 2.4 Interoperability standards

Respondent	Implementing policies or projects to improve EHR interoperability	Developing public application programming interfaces (APIs)	Adopting HL7 Fast Health care Interoperability Resource (FHIR) standard	Adopting SMART on FHIR standards
Australia	Yes	Yes	Yes	Yes
Belgium	Yes	Yes	Yes	Yes
Canada	Yes	Yes	Yes	No
Costa Rica	No	No	No	No
Czech Republic	Yes	n.r.	Yes	Yes
Denmark	Yes	Yes	Yes	No
Estonia	Yes	No	Yes	Yes
Finland	Yes	Yes1	Yes	Yes
Germany	n.r.	n.r.	n.r.	n.r.
Hungary	Yes	Yes	No	No
Iceland	Yes	Yes	Yes	No2
Israel	Yes	No	Yes	No2
Italy	Yes	No	Yes	No
Japan	Yes	No	No2	No2
Korea	**Yes**	**Yes**	**Yes2**	**No**
Lithuania	Yes	No	Yes	Yes
Luxembourg	Yes	Yes	Yes	No
Mexico	n.r.	n.r.	n.r.	n.r.
Netherlands	Yes	Yes	Yes	Yes
Norway	Yes	Yes	Yes	Yes
Portugal	No	Yes	No	n.r.
Russian Federation	n.r.	n.r.	Yes	Yes
Slovenia	Yes	n.r.	No	n.r.
Sweden	Yes	Yes	Yes	Yes
Switzerland	Yes	No2	No2	No2
Turkey	No	Yes	No	Yes
United States	Yes	No	No	No
Total Yes	21	14	17	12

Notes: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. May not be open (public).
2. In consideration for adoption.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Global collaboration towards common standards

Encouragingly, respondents reported participation in global collaborative work toward agreed international standards for clinical terminology and data exchange (electronic messaging). In 2021, 15 respondents reported participating in the Integrating the Healthcare Enterprise International collaboration and 10 respondents reported participating in the Global Digital Health Partnership (Table 2.5).

There is extensive work underway within the European Union (EU) toward improving the accessibility, sharing and use of health data that, if successful, would have an influence on the evolution of global collaboration in the sharing, use and protection of health data. A key EU project is the eHealth Digital Service Infrastructure (eHDSI) for cross-border health data exchange under the Connecting Europe Facility (CEF) that is supporting EHR data exchange at the country level and the provision of core services at the EU level. Another the Joint Action Towards the European Health Data Space (TEHDAS). TEHDAS is developing European principles for the secondary use of health data, building upon successful development of health data hubs in a few countries and aiming to develop health data governance and rules for cross-border data exchange, improve data quality and provide strong technical infrastructure and interoperability (EC, 2021[8]).

Table 2.5 Global collaborations for exchange and terminology standards

Respondents	IHE (Integrating the Healthcare Enterprise) International	Global Digital Health Partnership	EU projects to facilitate sharing and utilising EHR data across EU member states
Australia	No	Yes	No
Austria	Yes	Yes	Yes
Belgium	Yes	No	Yes
Canada	n.r.	Yes	No
Costa Rica	No	No	No
Czech Republic	Yes	n.r.	Yes
Denmark	Yes	No	Yes
Estonia	Yes	Yes	Yes
Finland	Yes	No	Yes
Germany	n.r.	n.r.	Yes
Hungary	No	No	Yes
Iceland	No	No	Yes
Israel	No	No	No
Italy	No	No	Yes
Japan	Yes	Yes	No
Korea	**No**	**Yes**	**No**
Lithuania	Yes	No	Yes
Luxembourg	Yes	No	Yes
Mexico	n.r.	n.r.	n.r.
Netherlands	Yes	Yes	Yes
Norway	n.r.	n.r.	Yes
Portugal	Yes	Yes	Yes
Russian Federation	n.r.	n.r.	n.r.
Slovenia	No	No	Yes
Sweden	Yes	No	Yes
Switzerland	Yes	Yes	No
Turkey	Yes	No	Yes
United States	Yes	Yes	No
Total Yes	15	10	18

Notes: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

The 2021 survey also asked respondents about the coding of health data to CDMs which facilitate within country statistical and research projects. In 2021, five respondents reported coding data within their EHR systems to a CDM. When the common data model is international in scope, such as the OMOP (Observational Medical Outcomes Partnership) CDM, such coding efforts support internationally comparable data for a wide array of research and statistical uses. There were some applications of the OMOP CDM reported by Australia and Israel in 2021.

France is coding data within the Health Data Hub to the OMOP CDM as part of the EU EHDEN project which is affiliated with OHDSI. Notably HIRA has coded linked health data to the OMOP CDM, including national insurance claims data, for the purposes of encouraging secure access to timely data for global COVID-19 research as part of the OHDSI project. This project has produced a range of impressive outputs.

Approaches to data storage and management vary

Surprisingly, given the mounting volume of data created, only 8 of 26 respondents in 2021 reported that EHR data are stored or processed using Cloud Computing services (Australia, Israel, Japan, Korea, Luxembourg, the Netherlands, Portugal and the United States). The majority of respondents are still managing EHR data on dedicated servers.

Essential to data security, integration and patient safety are unique identifiers. In 2021, 24 of 27 countries reported that they have a unique national number that identifies patients to build and electronic health record. Further, 23 countries reported having a unique national number that identifies health care providers or other authorised persons who are entering data into an electronic health record.

Fourteen respondents reported that clinical data are encrypted when they are exchanged to protect privacy and data security. Nine respondents reported that clinical data are exchanged using a dedicated, secure network. Security measures for these networks included a digital signature for ID (Denmark), digital signature with smartcard (Luxembourg, the Netherlands), multi-factor authentication (Canada, Italy, the Netherlands, Switzerland), digital certificates for ID verification (Japan, Lithuania), virtual safeboxes for data exchange (Israel), channel encryption (Italy), and IP security and Internet key exchange (Japan). A few respondents also noted data de-identification and pseudonymisation (Italy) and even data anonymisation (Costa Rica).

Respondents reported methods they are using to secure EHR data from unauthorised access, hacking and malware. These include virus scanning, firewalls, controlled access, access logs, audit logs, automated log-out, timely software updates, network separation, auditing hardware and databases, physical security for networked hardware, staff training in data security including how to identify phishing schemes, malware and other malicious programs, penetration tests (ethical hacking), vulnerability scanning, national authorities supervising cybersecurity among data processors, and business continuity and disaster recovery planning.

Legislation requiring adoption of Electronic Health Record Systems that conform to national standards

In the 2021 survey, 17 respondents reported that there are laws or regulations requiring health care providers to meet standards for national electronic health record interoperability. Sixteen respondents reported that laws or regulations require electronic messaging standards and 16 also respondents reported that laws or regulations require terminology standards (Table 2.6).

Table 2.6 Laws or regulations require standards for EHR interoperability

Respondent	Laws or regulations require clinical terminology standards	Laws or regulations require electronic messaging standards	Laws or regulations require health care providers meet standards for national EHR interoperability
Australia	No	No	No
Austria	Yes	Yes	Yes
Belgium	No	No	No
Canada	n.r.	n.r.	n.r.
Costa Rica	Yes	Yes	Yes
Czech Republic	n.r.	n.r.	n.r.
Denmark	No	No	Yes
Estonia	Yes	Yes	Yes
Finland	Yes	Yes	Yes
Germany	n.r.	n.r.	n.r.
Hungary	Yes	Yes	Yes
Iceland	Yes	Yes[1]	Yes
Israel	Yes[2]	No	No
Italy	Yes	Yes	Yes
Japan	Yes	Yes	Yes
Korea	**Yes**	**Yes**	**Yes**
Lithuania	Yes	Yes	Yes
Luxembourg	No	Yes	Yes
Mexico	n.r.	n.r.	n.r.
Netherlands	Yes	No	No
Norway	n.r.	n.r.	Yes
Portugal	No	Yes	No
Russian Federation	Yes	Yes	Yes
Slovenia	Yes	Yes	Yes
Sweden	n.r.	n.r.	n.r.
Switzerland	Yes	Yes	Yes
Turkey	Yes	Yes	Yes
United States	n.a.	n.a.	n.a.
Total Yes	16	16	17

Notes: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Law recommends the use of EHRs.
2. For diagnosis.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Certification of Electronic Health Record System Software Vendors

In the 2021 EHR survey, 16 respondents reported that they have a certification process for the vendors of electronic health record system software that requires vendors to conform to particular health information exchange (electronic messaging) standards. Thirteen respondents reported a certification process that requires adherence to national standards for clinical terminology and 13 reported certifying vendors for adherence to requirements or standards for national EHR interoperability (Table 2.7).

While not a national certification of software vendors, reimbursement for medical expenditures requires that providers follow certain terminology and exchange requirements in Israel. In Luxembourg, there is a national labelling process for software vendors to access the national EHR system. In Italy, there are no national requirements for certification, but individual regions may impose requirements. In Slovenia, certification has been legally authorised, but it is not yet implemented due to resource constraints. However, to connect to the

national EHR system in Slovenia, vendors must use nationally standardised APIs (Application Programming Interfaces). The Korean approach to certification implemented by KHIS is discussed later.

Table 2.7 Certification requirements of vendors of EHR system software

Respondent	Conform to particular clinical terminology standards	Conform to particular electronic messaging standards	Conform to national e-HR interoperability requirements or standards
Australia	No	Yes	No
Belgium	Yes	Yes	Yes
Canada	No	Yes	Yes[1]
Costa Rica	No	No	No
Czech Republic	No	No	No
Denmark	Yes	Yes	Yes
Estonia	No	No	No
Finland	Yes	Yes	Yes
Germany	n.r.	n.r.	n.r.
Hungary	Yes	Yes	Yes
Iceland	No	No	No
Israel	No	No	No
Italy	No	No	No
Japan	Yes	Yes	Yes
Korea	**Yes**	**Yes**	**Yes**
Lithuania	No	No	No
Luxembourg	No	No	No
Mexico	n.r.	n.r.	n.r.
Netherlands	Yes	Yes	No
Norway	No	No	No
Portugal	Yes[3]	Yes[3]	Yes[3]
Russian Federation	Yes	Yes	Yes
Slovenia	yes	yes	Yes
Sweden	No	Yes	No
Switzerland	Yes[2]	Yes[2]	Yes[2]
Turkey	Yes	Yes	Yes
United States	Yes[4]	Yes[4]	Yes[4]
Total yes	12	15	12

Notes: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Optional.
2. Certification of communities using EHR software.
3. E-prescription services are certified.
4. Certification is voluntary but required for reimbursement of medical claims from national insurance programmes (Medicare, Medicaid).
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Auditing clinical records for quality

Another mechanism to verify if health data meet national expectations for data quality is to conduct audits of clinical records. In the 2021 EHR survey, 13 respondents reported that the electronic records of physicians, medical specialists and hospitals are audited to verify quality (Table 2.8). An additional three respondents indicated that at least one of these three groups are audited to verify quality. In most cases, it is a national authority that is responsible for undertaking quality audits. In Canada and Sweden, regional authorities conduct audits. In Switzerland, private sector organisations can be certified to then conduct audits as part of certifying the compliance of communities to national requirements including auditing

clinical records for quality. Under law in the United States, health care providers are responsible for generating auditing reports on the quality of their clinical records and ensuring data quality. This is an area where Korea can improve.

Table 2.8 Auditing clinical records for quality

Respondent	Physicians	Medical specialists	Hospitals	All
Australia	Yes	Yes	Yes	Yes
Belgium	No	No	Yes	Yes
Canada	Yes	Yes	Yes	Yes
Costa Rica	Yes	Yes	Yes	Yes
Czech Republic	No	No	No	No
Denmark	Yes	Yes	n.r.	Yes
Estonia	No	No	No	No
Finland	n.r.	n.r.	n.r.	n.r.
Germany	n.r.	n.r.	n.r.	n.r.
Hungary	Yes	Yes	Yes	Yes
Iceland	Yes	Yes	Yes	Yes
Israel	Yes	Yes	Yes	Yes
Italy	n.r.	n.r.	n.r.	n.r.
Japan	n.r.	n.r.	n.r.	n.r.
Korea	**No**	**No**	**No**	**No**
Lithuania	No	No	No	No
Luxembourg	No	No	No	No
Mexico	Yes	Yes	Yes	Yes
Netherlands	Yes	Yes	Yes	Yes
Norway	n.r.	n.r.	n.r.	n.r.
Portugal	Yes	n.r.	Yes	n.r.
Russian Federation	Yes	Yes	Yes	Yes
Slovenia	No	No	No	No
Sweden	Yes	Yes	Yes	Yes
Switzerland	Yes	Yes	Yes	Yes
Turkey	Yes	Yes	Yes	Yes
United States	Yes	Yes	Yes	Yes
Total yes	15	14	15	13

Note: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Policy levers used by OECD countries to increase EHR interoperability and data use

In 2021, OECD countries reported several different policy levers supporting EHR interoperability and the increased use of data from within EHR systems for direct care, patient centred services, research, statistics, applications development and other uses within the public interest. This section reviews countries use of laws or regulations requiring data standards; certification of software vendors; and incentive payments.

In 2021, 13 countries reported implementing laws or regulations that require health care providers to adopt electronic health record systems that meet national standards for both clinical terminology and electronic messaging (data exchange).

Sixteen countries, including Korea (through the KHIS), reported laws or regulations requiring health care providers to meet standards for national EHR interoperability (Table 2.9). In Iceland, regulations require

that health care providers can connect to the Icelandic HealthNet (national EHR network). In Italy, the law defines a national federated system with a mandatory, nationwide, interoperability. In Lithuania, data is structured and standardised by law and must be suitable to be forwarded smoothly to the ESPBI IS (central EHR system). In Luxembourg, connecting to the DSP (central EHR system) requires meeting legal requirements for data standardisation. In Slovenia, IHE XDS and OpenEHR standards are required with proprietary modifications that are set out in law. In Switzerland, certifying communities and software vendors are required to meet national standards including HL7 FHIR and IHE. In Portugal, by law, health care providers IT systems must conform to a catalogue of standards to exchange data.

Table 2.9 Laws or regulations requiring adoption and standardisation of electronic health records

Respondent	Laws or regulations require clinical terminology standards	Laws or regulations require electronic messaging standards	Laws or regulations require health care providers meet standards for national EHR interoperability
Australia	No	No	No
Belgium	No	No	No
Canada	n.r.	n.r.	n.r.
Costa Rica	Yes	Yes	Yes
Czech Republic	n.r.	n.r.	n.r.
Denmark	No	No	Yes
Estonia	Yes	Yes	Yes
Finland	Yes	Yes	Yes
Germany	n.r.	n.r.	n.r.
Hungary	Yes	Yes	Yes
Iceland	Yes	Yes1	Yes
Israel	Yes3	No	No
Italy	Yes	Yes	Yes
Japan	Yes	Yes	Yes
Korea	**Yes**	**Yes**	**Yes**
Lithuania	Yes	Yes	Yes
Luxembourg	No	Yes	Yes
Mexico	n.r.	n.r.	n.r.
Netherlands	Yes	No	No
Norway	n.r.	n.r.	Yes
Portugal	No	Yes	No
Russian Federation	Yes	Yes	Yes
Slovenia	Yes	Yes	Yes
Sweden	n.r.	n.r.	n.r.
Switzerland	Yes	Yes	Yes
Turkey	Yes	Yes	Yes
United States	n.a.	n.a.	n.a.
Total yes	15	15	16

Note: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Law recommends the use of EHRs.
2. Guidelines.
3. For diagnosis.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Another policy lever is requiring vendors of electronic health records systems to be certified to be in conformance with national data standards. Overall, 13 countries including Korea have a software vendor certification that requires vendors to meet national standards for both clinical terminology and electronic messaging (Table 2.10).

Table 2.10 Certification requirements of EHR software vendors

Respondent	Conform to particular clinical terminology standards	Conform to particular electronic messaging standards	Conform to standards or requirements for national e-HR interoperability	Standards or requirements vendors must meet to be certified
Australia	No	Yes	No	There is a mix of CDA and FHIR capability implemented and moving to use FHIR predominately
Belgium	Yes	Yes	Yes	https://www.ehealth.fgov.be/ehealthplatform/fr/service-enregistrement-des-logiciels
Canada	No	Yes	Yes1	https://www.infoway-inforoute.ca/en/our-partners/industry/vendor-certification-services
Costa Rica	n.r.	n.r.	n.r.	
Czech Republic	n.r.	n.r.	n.r.	
Denmark	Yes	Yes	Yes	National shared document standards with some connection to IHE and HL7 schemas
Estonia	n.r.	n.r.	n.r.	
Finland	Yes	Yes	Yes	Detailed specifications, including terminology standards and implementation guides
Germany	n.r.	n.r.	n.r.	
Hungary	Yes	Yes	Yes	EESZT API specification and EESZT-related regulations to join to the EESZT
Iceland	n.r.	n.r.	n.r.	
Israel	n.r.	n.r.	n.r.	
Italy	n.r.	n.r.	n.r.	
Japan	Yes	Yes	Yes	Japanese standard disease code and lab test code master
Korea	**Yes**	**Yes**	**Yes**	
Lithuania	n.r.	n.r.	n.r.	
Luxembourg	No	No	No	
Mexico	n.r.	n.r.	n.r.	
Netherlands	Yes	Yes	No	
Norway	n.r.	n.r.	n.r.	
Portugal	Yes	Yes	Yes	
Russian Federation	Yes	Yes	Yes	
Slovenia	Yes	Yes	Yes	National standards to participate in EHR exchange
Sweden	No	Yes	No	National agreed standards by SALAR/Inera
Switzerland	Yes	Yes	Yes	https://www.e-health-suisse.ch/technik-semantik/epd-projectathon/programmierhilfen-epd/relevante-spezifikationen.html. HL7/FHIR/IHE, partly national adaptation of IHE integration profiles. Semantics: SNOMED CT
Turkey	Yes	Yes	Yes	Dokuman Online, SKRS, VEM, all are defined by MoH, former two defining data collection standards while the latter one defines data transfer standard between products from different vendors
United States	Yes	Yes	Yes	US government's ONC Health IT Certification Program must conform to the full scope of the product's required capabilities, including regulatory/conformance expectation clarifications and interpretations set forth in Certification Companion Guides. For a full list of vendor certification criteria including conformance and standards required by criteria see: https://www.healthit.gov/topic/certification-ehrs/2015-edition-cures-update-test-method
Total yes	13	16	13	

Note: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Optional.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Finally, 8 countries have incentive payments or penalties for health care providers to install EHR systems from a certified software vendor, 9 have these payments to health care providers to keep EHR systems up-to-date regarding changes to national standards over time and 11 have incentives or penalties to meet national requirements for EHR interoperability (Table 2.11). Korea is not one of these, and KHIS reports that incentives or penalties are being currently considered (see Chapter 4).

Table 2.11 Incentives or penalties to install EHR systems from a certified vendor, to keep standards up-to-date and to meet national interoperability requirements

Respondent	Incentives or penalties to install electronic record systems from a certified vendor	Incentives or penalties to keep the EHR system up-to-date as terminology and electronic messaging standards change over time	Incentives or penalties to adopt standards or other requirements for national e-HR interoperability	Description of incentives or penalties
Australia	No	No	Yes	The Practice Incentives Program eHealth Incentive (ePIP) aims to encourage general practices to keep up to date with the latest developments in digital health. In order to meet ePIP requirements, practices are expected to adopt compliant software for secure messaging and the My Health Record system and make use of e-prescribing and nationally recognised disease classification or terminology system.
Belgium	Yes	Yes	Yes	As a general practitioner you are eligible for an integrated premium to support the practice and the use of E-services (= integrated practice premium). You must then meet a number of conditions.
Canada	No	No	No	
Costa Rica	No	No	No	
Czech Republic	No	No	No	
Denmark	No	No	No	We have incentives and penalties that are not in use, but yearly economic agreements regulate the requirements as well as the annual fiscal agreement.
Estonia	No	No	Yes	Data exchange between EHNIS and health providers is a mandatory requirement in the health service reimbursement contract between the Estonian Health Insurance Fund and health care providers..
Finland	Yes	Yes	Yes	Legislation, decrees and rules, referring to more detailed specifications, and mandates for supervisory authorities (other organisations) to enforce compliance.
Germany	n.r.	n.r.	n.r.	
Hungary	Yes	Yes	Yes	The health care provider is bound to fulfill legal rules. National Authority can audit and investigate the adherence of rules. In cases of non-compliance, consequences can be warning, penalty or withdrawal of licence.
Iceland	No	No	No and Yes2	Primary health care clinics receive a refund based on the usage of the national patient portal.
Israel	No	No	No	
Italy	No	Yes	Yes	Regions receive specific funds in order to implement the EHR according to defined objectives. Every year Regions are evaluated to verify their performance in providing health care services within the National Health Service. Among the indicators, the availability of specific EHR functionalities are included.
Japan	Yes	Yes	Yes	Health care providers that introduce a standardised e-HR system can receive a subsidy from the fund to support digitalisation of medical information. In addition, in the medical fee system, health care providers are evaluated regarding providing medical information using the standards.
Korea	**No**	**No**	**No**	
Lithuania	No	No	No	
Luxembourg	No	No1	No	

Respondent	Incentives or penalties to install electronic record systems from a certified vendor	Incentives or penalties to keep the EHR system up-to-date as terminology and electronic messaging standards change over time	Incentives or penalties to adopt standards or other requirements for national e-HR interoperability	Description of incentives or penalties
Mexico	n.r.	n.r.	n.r.	
Netherlands	Yes	Yes	No	Financial penalty; no incentives
Norway	No	No	No	
Portugal	No	No	No	
Russian Federation	n.r.	n.r.	n.r.	
Slovenia	Yes	No	n.r.	Major upgrades of hospital information systems are co-financed, e.g. via joint projects with software vendors
Sweden	No	No	No	
Switzerland	No	Yes	Yes	
Turkey	Yes	No	Yes	
United States	Yes	Yes	Yes	The US Government has programs such as the Promoting Interoperability Program which provides incentives to health care providers to adopt certified electronic health record technology. As previously noted, these incentives are voluntary for providers participating in the major US public health insurance programs who benefit from payment incentives as a result of meeting programme requirements regarding the use of certified health IT. For more information see: https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Basics. Additionally, federal laws penalise vendors that engage in information blocking practices or fail to comply with certification programme requirement. Penalities may include decertification and/or civil monetary penalties. For more information on information blocking requirements see: https://www.healthit.gov/topic/information-blocking.
Total yes	8	9	11	

Note: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. National terminology referential bases are put in place and maintained by Agence eSanté.
2. Incentive for primary health care clinics to use the national patient portal.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Patient portal to their own medical records

In most countries, patients have access to and can interact with their own medical records within a secure Internet portal. “Access” means patients can view information contained in their own record and “interact” means that patients can amend information, upload data or interact with their health care provider. Thirteen countries reported that 100% of patients have access to their own medical records through an Internet portal and 12 reported that 100% of patients can interact with their portal. Eighteen countries reported that patients can view their own records from all of their current health care providers and containing their current medications, lab tests, and imaging results (Table 2.12). The My Health Way initiative currently under development in Korea will enable patients to access their medical information in one place (Chapter 3).

Table 2.12 Patient access to and interaction with their own EHR through a secure Internet portal

Respondent	Patients can access their EHR via a secure Internet portal (Patient Portal)	Proportion of patients who can access	Patients view their own records from ALL of their current health care providers and containing their current medications, laboratory tests, imaging results within the Patient Portal	Patients can interact with the patient Internet Portal	Proportion of patients who can interact
Australia	Yes	90%	Yes4	Yes	0%
Belgium	Yes	80%	No	No	0%
Canada	Yes	27%	No	d.k.	d.k.
Costa Rica	Yes	33%	No	Yes	33%
Czech Republic	Yes	15%	No	Yes	8%
Denmark	Yes	100%	Yes	Yes	100%
Estonia	Yes	100%	Yes	No	n.a
Finland	Yes	100%	No	Yes	100%
Germany	Yes	100%	Yes	Yes	target: 100%
Hungary	Yes	40%	Yes	No	0%
Iceland	Yes	100%	No	Yes	100%
Israel	Yes	100%	Most	No	100%
Italy	Yes	100%	Yes	Yes	100%
Japan	Yes	100%	Yes	No	100%
Korea	**No**	**n.a.**	**n.a.**	**n.a.**	**n.a.**
Lithuania	Yes	100%	Yes	Yes	100%
Luxembourg	Yes	100%	Yes	Yes	n.a.
Mexico	No	n.a.	n.a	n.a	n.a
Netherlands	Yes	75%	Yes	Yes	20%
Norway	No	n.a.	n.a	n.a	n.a
Portugal	Yes	25%	No	Yes	25%
Russian Federation	Yes	100%	Yes	Yes	100%
Slovenia	Yes	5%	Yes	Yes3	None
Sweden	Yes	100%	Yes6	Yes	100%
Switzerland	Yes	n.r	Yes	Yes2	100%2
Turkey	Yes	100%	Yes	Yes	100%
United States	Yes	51%	No	Yes	n.a.
Total yes	24		16	18	

Note: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Regional (state/province) level differences.
2. All patients can upload PDF files to the portal.
3. To some extent.
4. When providers upload files to the national system.
5. Two regions and certain hospitals.
6. Some private providers not included.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Secondary use of EMR data

Most countries are regularly extracting data from the EMR systems for public health monitoring (16 countries). Such uses have been accelerating in response to the COVID-19 pandemic (Table 2.13). Further, countries have been increasingly depending upon data with EHR systems for their superior

timeliness, enabling analysis of the pandemic situation and response in near real time. Ten countries reported regularly extracting EHR data to monitor the performance of the health system including, treatments, costs and health outcomes. Twelve countries regularly rely upon EHR data to monitor patient safety, including post-market surveillance of medications. Ten countries report that EHR data are extracted for health and medical research to improve patient care, health system efficiency or population health, such as long-term follow-up studies of patients experiencing different risk factors, health conditions and treatments. Five countries are regularly relying upon EHR data to facilitate and contribute to clinical trials, such as following clinical cohorts to measure health outcomes and health care encounters over time. Five countries also enable physicians to query the data to inform themselves about previous treatments and treatment outcomes when caring for patients. Korea reports that EMR data are currently not used for any of the listed purposes.

Table 2.13 Regular secondary analysis of EHR system data

Respondent	Public health monitoring	Monitoring health system performance	Monitoring patient safety	Facilitating and contributing to clinical trials	Supporting physician treatment decisions	Research to improve patient care, health system efficiency or population health
Australia	No	No	No	No	No	No
Belgium	Yes	Yes	Yes	d.k.	No	Yes
Canada	No	No	No	No	No	No
Costa Rica	Yes	Yes	Yes	Yes	No	Yes
Czech Republic	Yes	Yes	No	No	No	No
Denmark	Yes	Yes	Yes	Yes	Yes	Yes
Estonia	Yes	No	Yes	No	No	No
Finland	Yes	Yes	Yes	No	No	Yes
Germany	n.r.	n.r.	n.r.	n.r.	n.r.	Yes
Hungary	Yes	No	No	No	No	No
Iceland	Yes	No	Yes	No	Yes, partly1	Yes
Israel	Yes	No	Yes	No	No	Yes
Italy	No	No	No	No	No	No
Japan	Yes	n.r.	Yes	Yes	n.r.	n.r.
Korea	**No**	**No**	**No**	**No**	**No**	**No**
Lithuania	Yes	Yes	Yes	No	No	No
Luxembourg	No	No	No	No	No	No
Mexico	No	No	No	No	No	No
Netherlands	Yes	Yes	Yes	No	Yes	Yes
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Portugal	Yes	Yes	d.k.	No	No	No
Russian Federation	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Slovenia	Yes	n.r.	n.r.	n.r.	n.r.	n.r.
Sweden	Yes	Yes	Yes	Yes	Yes	Yes
Switzerland	No	No	No	No	No	No
Turkey	Yes	Yes	Yes	Yes	Yes	Yes
United States	No	No	No	No	No	No
Total yes	16	10	12	5	5	10

Note: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Physicians can query their own data.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Enabling public authorities to use EMR data for secondary purposes

While many countries are extracting data from electronic clinical records to develop their key national datasets and for research (as will be discussed in the next section), 10 survey respondents in a 2019-20 survey on health data governance reported barriers to doing so.

In Korea, it is legally possible to extract data from electronic health records for secondary uses but the interpretation of the law is strict so doing so is difficult in practice (see Chapter 3).

In Luxembourg, data extraction from electronic clinical records for secondary uses is only lawful with the prior written consent of patients. Similarly, in Canada, electronic medical records in primary health care are in the custody and control of care providers who have no obligation and sometimes, depending on the jurisdiction, no legal authority to share data with public authorities, without express consent. As in Canada, the federal structure of Germany leads to different legal frameworks at the state level (state data protection laws, state hospital laws) that govern whether data may be extracted for secondary purposes. In Australia, data extraction is restricted by a number of legislative, privacy, secrecy and confidentiality requirements and medical records can be disclosed with consent, or in specified circumstances where authorised by law.

In France, extracting data from the electronic health record or DMP (dossier médical partagé) for the purposes of sharing and linking data is legally prohibited. France reports the legal prohibition came about because the national health insurance fund (CNAM) provides operational management of the linked health care administrative database and patients' associations sought a guarantee that clinical data within the DMP would not be accessible to the insurer. It is, however, legally possible to create a dataset of anonymised data from DMP records.

In Japan, there is no national electronic health record system within which data might be contributed by each medical institution. Further, medical institutions require patient consent for each research or statistical project where data would be extracted and shared from their electronic records.

In Belgium there is no real policy about the extraction of data from electronic records for secondary uses. In Latvia, there is no experience yet with data extraction as the implementation of the national e-health system has only started recently. In Ireland, most health records remain paper-based in acute care hospitals.

Concerns were further echoed by respondents to the 2021 EHR survey. In 2021, 15 respondents reported that problems with the quality of data within electronic clinical record system created a barrier to developing national health datasets from this data source. The most common concern was with unstructured (free text) data within EHRs that need to be structured following common terminology standards to be readily useable for statistics and research. Thirteen respondents also reported legal or policy barriers to public authorities extracting data from within EHRs to develop national health datasets.

Perhaps the most difficult barrier is in Switzerland, where the law which authorises the creation of electronic clinical records did not foresee the use of data from within this information system for national statistics or research and, as a result there is a total ban on utilising this information resource for any purpose within the public interest other than directly caring for an individual patient. Similarly, in Korea, the law authorising the Information Exchange Program only authorised the exchange of EHR records for direct patient care and there is no legal basis for the secondary use of EHR data.

In Sweden, whether data can be extracted from EHRs for a statistical purpose is limited to the legal authorisation of the specific use. Statistics and research uses that have not been already foreseen and legally authorised are restricted. Similarly, Finland's law authorising the EHR system did not specify that health care quality monitoring could be undertaken with data from within the EHR system and are facing restrictions to this activity which is within the public interest. In Iceland, health data registries (datasets) are each authorised by a separate legislation. If a new registry (dataset) is needed, then it is necessary to pass a new legislation to authorise it. Similarly, Portugal reports a lack of legal authorisation to extract data for statistical purposes.

Japan and Turkey report concerns that the national data privacy law restricts their ability to extract data from within their EHR systems to build national datasets that are within the public interest. Canada reports the challenge of having different data protection laws within its 13 provinces and territories.

Development of artificial intelligence algorithms, machine learning and analytics

The Netherlands, Denmark and Israel are the three countries with the most applications of machine learning, artificial intelligence algorithm development and other more advanced analytics based on EMR data that were measured in the 2021 survey. Overall, 8 countries reported data mining to find or extract data from the EMR; 8 countries are using EHRs to develop messages and alerts for patient care or managerial decision-making; and 7 countries are using EHRs to develop predictive analytics trained on EMR data for patient care or managerial decision-making. Six countries report national projects to integrate or link EMR data with genomic, environmental, behavioural, economic or other data. Three countries are also using natural language processing to convert free text to standardised (coded) data (Table 2.14). Again, Korea reports that EMR data are currently not used for any of the listed purposes.

Table 2.14 Machine learning, artificial intelligence and analytics with EHR system data

Respondent	Data mining to find or extract data from the EHR system	Natural language processing to convert text based data to coded data	Automated alerts and messages for patient care or managerial decision-making	Predictive analytics for patient care or managerial decision-making (trained on EHR data)	Other applications of machine learning/AI developed with EHR system data	National projects to integrate or link EHR data with genomic, environmental, behavioural, economic or other data
Australia	No	No	No	No	No	No
Belgium	No	No	No	No	No	Yes
Canada	No	No	No	No	No	No
Costa Rica	Yes	No	Yes	Yes	No	No
Czech Republic	No	No	No	No	No	No
Denmark	Yes	Yes	Yes	Yes	Yes	No
Estonia	No	No	Yes	No	No	Yes
Finland	Yes	No	Yes	No	n.r.	No
Germany	No	No	n.r.	No	n.r.	Yes
Hungary	No	No	No	No	No	No
Iceland	No	No	Yes	No	No	No
Israel	Yes	Yes	Yes	Yes	Yes	Yes
Italy	No	No	No	No	No	Yes
Japan	n.r.	n.r.	n.r.	n.r.	n.r.	No
Korea	**No**	**No**	**No**	**No**	**No**	**No**
Lithuania	No	No	No	No	No	No
Luxembourg	Yes2	No1	No	Yes2	No	No
Mexico	No	No	No	No	No	No
Netherlands	Yes	Yes	Yes	Yes	Yes	Yes
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Portugal	Yes	No	No	Yes	Yes	No
Russian Federation	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Slovenia	No	No	No	No	No	No
Sweden	No	No	Yes	Yes	No	No
Switzerland	No	No	No	No	No	No
Turkey	Yes	No	No	No	No	No
United States	No	No	No	No	No	No
Total yes	8	3	8	7	4	6

Note: n.r. Not Reported // n.a. Not Applicable // d.k. Unknown.
1. Physicians can query their own data.
Source: OECD 2021 Survey of Electronic Health Record System Development, Use and Governance.

Summary of the situation across the OECD regarding the interoperability of EHR systems

In 2021, most OECD countries surveyed had: 1. established a **national organisation** that was responsible for setting national clinical terminology and electronic messaging (exchange) standards; 2. Created a **multidisciplinary governing body** for the national organisation that represents key stakeholders; 3. use **unique identification** of patients and health care providers; 4. adopted **international terminology standards** for diagnoses, medications, laboratory tests and medical images; 5 adopted the **HL7 FHIR standard** for data exchange (electronic messaging); and participate in **global collaborative projects** to improve international data standards.

Most countries have one **country-wide electronic health record system** and are exchanging EHRs at the national level including data sharing among physician offices and hospitals about patients' treatment, medication use, laboratory tests and images.

Most countries have a **Patient Internet Portal** where patients can access their own medical records from all of their current health care providers. Most are extracting data from their EHR system for **public health monitoring**. Many countries are also utilising EHRs for other secondary purposes including health system **performance monitoring**, patient safety **surveillance** and health and medical **research**. Some are also developing **big data analytics** including machine learning, artificial intelligence algorithms with EHRs.

Countries reported several levers to improve the spread and interoperability of their electronic clinical data.

- Sixteen had a **legal requirement** for health care providers to meet national standards for EHR interoperability and 13 had a legal requirement for health care providers to adopt an electronic health record system (software) that conformed with national standards for both clinical terminology and electronic messaging (exchange).
- Thirteen countries had a **certification of EMT system (software) vendors** that required them to adopt national standards for both clinical terminology and electronic messaging and 13 had a certification that required software vendors to meet requirements for national EMR interoperability.
- Eleven countries had **financial incentives** (or penalties) for health care providers to install an EHR system that meets national standards and requirements for national EMR interoperability. Nine countries report incentives for health care providers to keep their EMR system up-to-date as clinical terminology and electronic messaging standards change over time; and 8 reported incentives for health care providers to install and EMR system from a certified software vendor.

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3 Appraising the Korean health data infrastructure and information system

This chapter examines the strengths of current arrangements in Korea regarding the establishment of a learning health system. These include the availability of national health datasets and their governance which is among the best in the OECD, a track record of successful health system reforms, the development of the Drug Utilisation Review system to provide “real-time” decision support and a strong and committed research community. The chapter discusses how Korea, with a learning health system, could develop better performance measurement and value-based care. A learning health system will not develop in Korea, however, unless important obstacles to harmonising and sharing data are addressed. Obstacles discussed in this chapter include a lack of trust, social licence and incentives toward data sharing and collaboration, a lack of a framework for research access to data, incoherent EMR systems and a lack of patient-reported data, and laws and policies that block progress toward a learning health system.

This chapter outlines the key features of the Korean health system, its structure and organisation, and how these influence the generation, management and use of data. A health system is defined here as the national approach to promote individual and population health through social, preventative and curative means. The scope principally includes public health, medical care, long-term care and social care. However, in terms of information relevant to health policy, data generated and stored outside the traditional health system boundaries are also relevant. As was described in Chapter 2, these include data on social and economic determinants of health *inter alia* income, employment, and education.

The structure and organisation of the Korean health system influences the national data ecosystem

This section describes the Korean health system, which is unique among OECD countries. The demand side is exclusively managed by the public sector through a national, compulsory insurance scheme (single payer model) with several government agencies responsible for managing and administering the funding and governance of the health system. The supply side, however, is highly reliant on the private sector and dominated by hospitals. It is very fragmented with limited gatekeeping functions at the primary care level and a high degree of consumer choice especially when accessing general and specialist care. As with all health systems, these structural features are important because they determine the way data are generated, managed and exchanged between relevant actors to create the information and knowledge that benefits the health and welfare of the Korean people.

Universal coverage is the cornerstone of Korean health care

The objectives of the Korean health system encompass safety, efficiency and effectiveness (i.e. **quality**) of care; **equity** (fairness) in access to care and health outcomes; and **sustainability**, which comprises a. ensuring the system copes with rising chronic diseases and demographic change (e.g. disease prevention and managing NCDs in non-acute settings), and b. supporting innovation and the development of cutting-edge medical technologies (WHO Regional Office for the Western Pacific, 2015[1]). These objectives become important when thinking about monitoring and improving system performance (building a learning health system).

The cornerstone of the Korean system, and a considerable strength, is universal access to health care. Social health insurance was introduced in 1977– first among formal sector workers in large firms, then smaller firms and finally to the self-employed – such that universal coverage was achieved in 1989. The financing system then underwent an important and major structural reform in 2000 with the merging of the three existing insurance schemes (comprising over 350 insurers) into a single payer, the National Health Insurance (NHI).

The NHI is based on a uniform contribution schedule and benefits package. For wage earners, contributions are proportional to income and shared equally between the employee and employer. For the self-employed, contributions are based on both income and the value of assets. Decisions on which health services to include in the benefit package are made centrally. Most health care services are included but cost-sharing is relatively high (20% for inpatient care). There is a ceiling on out-of-pocket (OOP) payments, with differential ceilings applied to different income groups and exemptions for the poor. The ceiling applies only to services in the benefits package and the role of voluntary health insurance is increasing.

Several organisations and agencies feature in the governance of the health system

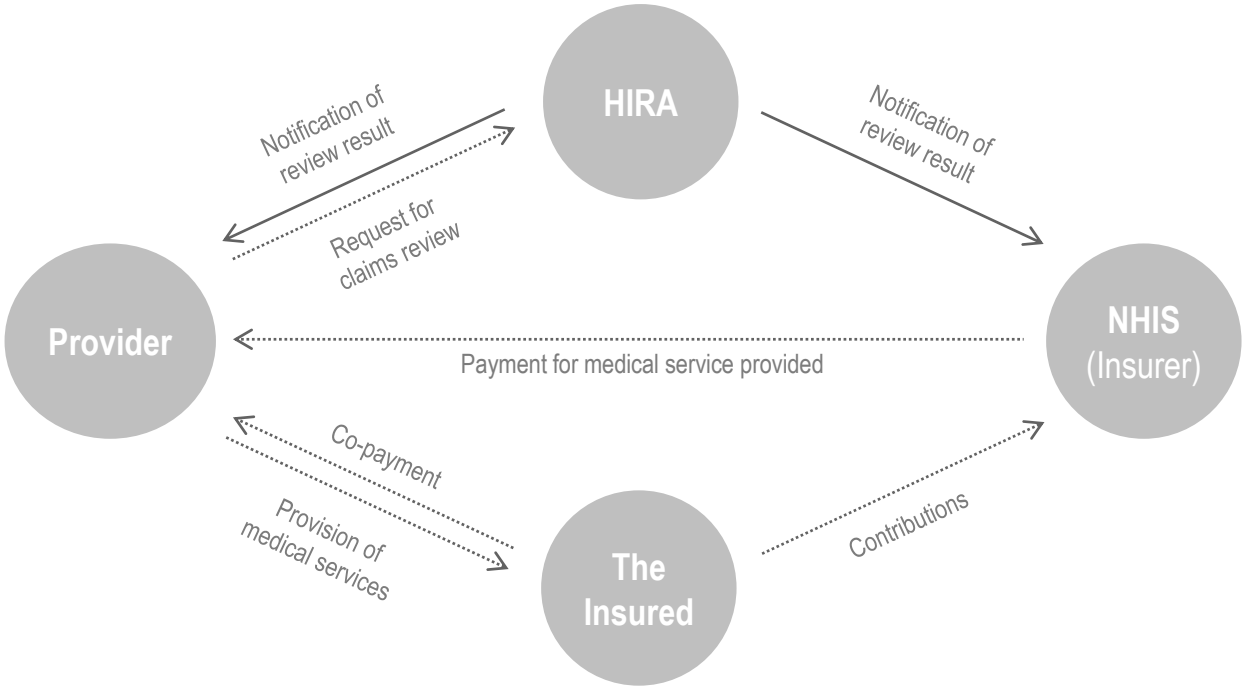
The Ministry of Health and Welfare

The Ministry of Health and Welfare (MoHW) is responsible for promoting health across the entire population. It plays a central role in health policy implementation at the national level. It implements various public health policies through collaborating with medical and health centres at the regional and municipal level. It also directly manages several national hospitals in areas the private sector fails to meet medical needs (e.g. psychiatric hospitals, tuberculosis). Governance of the Korean National Insurance (NHI) funding scheme is summarised in Figure 3.1. The MoHW has delegated the task of managing the NHI to two quasi-independent agencies: Health Insurance Review and Assessment Service (HIRA) and the National Health Insurance Service (NHIS).

Health Insurance Review and Assessment Service (HIRA)

HIRA is a de-facto regulator of health care provided through the NHI. Its stated mission is to address health burden, ensure patient safety and provide the best quality of medical service to the people of Korea. Its strategic direction is built around four pillars: 1. transitioning from volume to value in service provision; 2. Expanding coverage based on what people and populations need; 3. Promoting value through deployment of digital technologies; and 4. Building social value through innovation at all levels of the health system. HIRAs responsibilities concern managing the medical services included under the NHI, assess the quality of health services, as well as reviewing service claims (billing) filed by providers, then sent to the NHIS which reimburses providers.

Figure 3.1. Interaction between HIRA, NHIS, providers and the insured population under the NHI scheme



Source: Material provided to the OECD Secretariat from HIRA.

HIRA manages the benefits and services included in (and excluded from) the NHI as well as the fee schedule. It carries out evaluation of cost-effectiveness of medicinal drugs for health insurance reimbursement. The Drug Reimbursement Evaluation Committee (DREC), appointed by the president of HIRA, assesses the cost-effectiveness of drugs and recommends their inclusion or exclusion in the NHI benefit package. The value of these assessments could be greatly enhanced in the future by real-world data from electronic medical records as well as claims data.

HIRA's claims review function promotes sustainability in health funding by monitoring use of services against expected trends through its Benefits Information Analysis System and a transition towards a value-based review and assessment framework (see later in this chapter). It analyses health care activity to identify variation and assess quality of care, working with providers to promote quality improvement based on th collaboration with providers to adjust clinical guidelines to promote better care. these efforts have yielded impressive results across several aspects of health care (these are provided in a later section in this Chapter).

Other functions include managing the provider payment system, including Diagnosis-Related Groups (DRGs) for casemix payment, per-diem payments for long-term care hospitals (see below) and consultation fees for public health care centres (see below). HIRA also develops and manages the Korean disease classification system – the KCD, which is based on ICD with additional information to provide a richer source of data. These activities have enabled successful adoption of new classification system like ICD-11.

In 2010, HIRA established a drug utilisation review (DUR) system, which uses HIRA's real-time data on Korean patients to provide real-time alerts to clinicians and pharmacists regarding counter-indicated drug prescriptions due to pregnancy, drug-drug interactions, and counter-indications due to age. The DUR is a prospective, real-time review of each prescription before the medication is prescribed and dispensed to the individual patient to minimise the risk of harm such as drug/drug interactions or ingredient duplication. The DUR is enabled electronically by HIRA and is a good demonstration of the possibilities of using a combination of existing and new data to improve health outcomes using administrative health ese analyses. The mechanisms include a transition to an incentive programme and data (see below).

NHIS is the custodian of data on treatments, procedures and tests (although not results) as well as some socio-economic data to enable risk-adjustment. HIRA therefore has a lot of expertise and experience in collecting, managing, processing and analysing big datasets (including claims, drug prescription/utilisation, disease classification, and hospital activity data) as well as using the information derived from these analyses to promote quality and sustainability of the Korean health system.

However, while certainly more granular and detailed than many national administrative data sets, Korean claims data still lack information on health outcomes including clinical lab and image results, and patient-reported data. While HIRA publishes information on, for example, antibiotic prescription rates, the number of medicines per prescription, and Caesarean-section rate, these indicators could be enhanced by including data on their health outcomes.

National Health Insurance Service (NHIS)

NHIS is the single insurer of the NHI scheme and National Long-term Care Insurance providing health insurance coverage for the public. Roles and responsibilities of NHIS include eligibility management, premium imposition and collection, benefit reimbursement, disease prevention and health promotion as well as the Medical Aid Program, Long-term Care Insurance and integrated premium collection of social insurance programs. With its universal coverage, NHIS is committed to improving public well-being and contributing to the stability of the national health insurance fund by securing additional financial sources and a stable premium collection system. It has an upgraded benefit system to expand coverage and strengthen the social safety net to improve public health and quality of life.

NHIS exchanges national data (person-level data, from birth to death) with 42 organisations including the Ministry of Public Administration and Security, National Tax Service, National Pension Service, and HIRA. Based on these data, NHIS provides various health services, including PHR, management of metabolic syndrome and chronic diseases, and appropriate medication. The socio-economic variables present in the data enable the NHIS to conduct equity assessment based on tracking observed health service use (treatment) and health outcomes by income level or region. Diverse monitoring services are developed and offered based on the research database, which include infectious disease monitoring, chronic disease monitoring, health service use monitoring by region, financial status monitoring and K-ATLAS (health map). The public can access data through the Big Data Open System. This online platform helps alleviate information inequality and facilitate equal access. Sustainable development of health sector is supported by evidence for policy and industrial development.

Regional and municipal governments

Regional governments manage regional medical centres. They also have the authority to build new hospitals for their residents. Municipalities manage smaller, local health centres, subcentres and primary care clinics. Each municipality has one health centre that provides basic medical care as well as population health services such as antenatal care and vaccination. There might also be health sub-centres and primary care clinics to ensure residents' access to basic health services in areas with limited access.

Funding flows from local taxes and national revenue sharing. Regional governments and municipalities do not have the authority to raise additional revenue for public health or health care. However, they do control resources and revenue is allocated within their catchment.

Ministry of Food and Drug Safety (MFDS)

The MFDS is the Korean regulator for medicinal drug safety and effectiveness, like the Food and Drug Administration (FDA) in the United States, the European Medicines Agency (EMA) and Japan Pharmaceuticals and Medical Devices Agency (PMDA). While HIRA carries out cost-effectiveness analysis (see above), the MFDS is responsible for post-market surveillance of medicines – monitoring approved drugs for hitherto unnoticed adverse events, reactions, and other safety concerns. As has been demonstrated by the FDA, real-world data can greatly enhance pharmacovigilance efforts, as well as providing valuable information on how medical technologies perform in post-trial, routine clinical situations (see later section in this chapter).

National Evidence-based Healthcare Collaborating Agency (NECA)

Established in 2009, NECA is a relatively new quasi-public agency that is in charge of carrying out health technology assessment. It generates evidence on the clinical effectiveness and cost-effectiveness of various health services, technologies and health products, and informs consumers, health care providers and health policy decision-makers including the payer.

NECA's Center for New Health Technology Assessment (CnHTA) focuses on evaluating safety, efficacy, and cost-effectiveness of medical procedures and diagnostics. Its Committee for New Health Technology Assessment, overseen by the Ministry of Health and Welfare, consists of 20 health professionals. There are five assessment committees by specialty area: internal, surgical, dental, traditional medicine and other procedures, which prepare review reports for deliberation by the Committee. This work would also be greatly enhanced by access to real-world clinical data from EMRs.

Korean Disease Control Agency (KDCA)

Management of NCDs and their well-known risk factors, such as cigarette smoking, overconsumption of alcohol, lack of physical exercise and obesity have become a major target of Korean public health policy.

The main legal framework for public health activities includes the *Regional Public Health Act* and *National Health Promotion Act*.

The KDCA – formerly Korean Centers for Disease Control and Prevention (KCDC) – is responsible for conducting the Korea National Health and Nutrition Examination Survey (KNHANES) which provides various data on health behaviours and risk factors. KDCA also conducts a community health survey and an ambulatory care survey focussing on particular disease conditions including circulatory diseases. It is the custodian of a national disease registry for diabetes. Provision of public health services is shared between the public and private sectors, due to the dominance of the private sector in the provision of health care (see below). Taking account of the social determinants of health, health in all policies has recently been promoted along with health impact assessments, making the data collected and held by the KDCA a very important resource.

The Korean Health Information Service (KHIS)

Health care providers are predominantly paid through fee-for-service. All licensed providers are guaranteed a contract with NHIS unless they have committed serious misconduct. Almost all private health facilities have EMRs, principally because this enables electronic submission of claims for care. However, there is little harmonisation and concordance between these two systems in terms of interoperability and potential exchange of data. (Proposals to introduce personal electronic health cards, which enable individual's health data to follow them wherever they seek care (a de facto national EHR) were resisted by providers due to privacy concerns).

The Korean Health Information Service (KHIS) was established in September 2019. Its main function is to certify EMR software, following the example of the US Office of the National Co-ordinator (ONC) for Health IT. For an EMR vendor to become certified they must satisfy 86 certification criteria that ensure that patient data are in an electronic format that satisfies government standards for clinical terminology and exchange (electronic messaging). The system of certification of software vendors aims to expand the use of standards and the interoperability of clinical records. KHIS will also have a usage certification for health care institutions (hospitals and clinics) to ensure their EMR software meets government standards.

The KHIS EMR standardisation roadmap (2021-2025) consists of 5 core actions: Standardization of terminology; Adoption of HL7 FHIR; preparation of future oriented data standards; validation and expansion of best practices of standardisation; strengthening the basis for implementation of standardisation.

Key among these is adopting the HL7 FHIR standard for data exchange. As noted in Chapter 2, Korea is among 17 OECD countries that have adopted or are considering the adoption of this standard which supports interoperability and mobile app development. Work is under way between HL7 FHIR and OHDSI to integrate the OMOP CDM into HL7 FHIR, which would perfectly position Korea for global research given Korea's investments in OMOP CDM.

Korea has also purchased SNOMED-CT licences for clinical terminology and is using other global standards such as ATC and LOINC. These global standards will position Korea to more easily code data to the OMOP CDM and to participate in research with other countries.

KHIS is also establishing the "My Health Way" platform where individuals can efficiently view and share their own personal health data which is otherwise scattered across the systems of each of their health care providers. Currently, patients wanting to share their own health data must visit and request data from each of their health care providers. The My Health Way platform project has been pursued by a Presidential Committee on the Fourth Industrial Revolution (see "Digital New Deal" below). A "My Health Record" App (Android) was launched in February 2021 that allows search, saving, and utilisation of public health data on a smart phone (such as HIRA records). An expansion to also include patients clinical data from private sector EMRs such as health care records and life log is planned (See below).

However, KHIS does not have a mandate to involve health information stakeholders in its work, nor the legal authorisation to support secondary uses of health data. This is addressed further later in this chapter and in Chapter 4.

Care provision is highly fragmented and hospital-centric

Except for a small number of national hospitals, special public hospitals and regional/municipal health care facilities, health care delivery in Korea relies heavily on the private sector. Almost all clinics and about 94% of hospitals are privately owned.

The legal framework for health care provision comprises the *Health Care Law* and the *NHI Law*. The role and function of health providers is not well differentiated, particularly between clinics and hospitals. Some clinics have inpatient beds while all general hospitals provide outpatient services. There is no gatekeeper role in the Korean health care system. Individuals are not required to register with any health care provider and have the freedom to choose health care provider at any level according to their preference, as long as they can afford to pay the necessary out-of-pocket (OOP) costs. With nearly unlimited access and patients' preference for high-tech medical care, patients are increasingly using large general or tertiary hospitals.[1]

The dominance of the private sector in health care delivery goes back to the early years of the Republic. The Health Insurance Law was enacted in December 1963 by the military government soon after its coup d'état. But the law did not include the requirement of mandatory coverage. Full social insurance was implemented in 1977 as part of a national economic reform programme. Until then, meeting the health needs of the population had been left to market forces.

An incremental approach to extending coverage followed, achieving universal population coverage in 1989. This resulted in a steep increase in health care use over a short time. The private sector expanded rapidly to meet the increased demand.

Concentration of patients in the large metropolitan hospitals has been identified as an issue. Experts interviewed have suggested that retaining market share is a strong disincentive for smaller hospitals to exchange patient data with other providers.

The Korean Government tried introducing a primary care gatekeeping scheme in 1996. This was resisted by the medical professions and failed to gather sufficient support (Sung NJ, 2013[2]). In 2011, the MoHW proposed voluntary registration of hypertensive and diabetic patients with a primary care provider, with incentives to both provider and patient in order to promote care integration for these chronic diseases. The proposal was opposed by the Korean Medical Association and was later rejected.

In 2008, a pilot project for telemedicine dubbed "Ubiquitous health care" (U-health) was implemented in four remote Korean municipalities. The pilot aimed to evaluate the safety, effectiveness and cost-effectiveness of U-health. The government has since tried to extend U-health to the elderly and to patients with chronic diseases. This was criticised by the public for being too business friendly. The KMA also opposed the policy, saying that the extension of U-health would enable the large, metropolitan hospitals to attract even more patients.

Remarkably, much ambulatory care in Korea is provided by hospitals. Even tertiary and specialised hospitals are offering these services, sometimes in competition with primary care providers and community hospitals.

Long-term care is covered by a mix of funding and governance

An amendment of the Medical Service Act provided criteria for long-term care (LTC) hospitals. These hospitals treat chronic illness, and care for patients at a post-acute stage, for example with dementia and disabilities. LTC hospitals are financed by the NHI, in contrast to LTC facilities, which are reimbursed by LTC insurance. LTC hospitals are paid on a modified per diem model compared with LTC facilities which

are paid on a fee-for-service basis. The distinction is significant because data generated by per diem payments lack the granularity of fee-for-service data.

Residential care or nursing home care is provided by LTC facilities, licensed nursing homes, retirement homes, and licensed residential establishments. Home care or community care includes ADL-supporting care at home, portable bath services, nursing care at home, and day care services. Cash benefits are given to eligible people in remote areas or islands where no regular support is available.

The Korean health system performs well but there is room for improvement

The focus of this report is on using health data to improve the performance of the health system based on its objectives. This section briefly outlines how the Korean system performs on indicators compared to other OECD countries, although it should be noted that Korea does not supply data for several indicators and statistics collected by the OECD (these gaps are discussed in the following section).

Managing chronic diseases, mental health and perceptions of quality can be improved

Korean life expectancy at birth is among the highest in the OECD at 83.3 years compared to the OECD average of 81 years (OECD, 2021[3]). However, life expectancy is a blunt indicator of health system performance (and an even less useful metric for health *care*) due to the many non-medical factors that contribute to people's health and longevity. Insofar as life expectancy is a proxy for health, little is known about differences across social strata – therefore about the equity of health and health care – in Korea.

Looking at more granular indicators of health system performance (OECD, 2021[3]):

- Avoidable mortality (a more useful metric for how the health care system treats health problems) is lower than the OECD average (97 vs 126 per 100 000 population).
- Treatable mortality is among the lowest, second only to Switzerland, at 42 (OECD average is 73 per 100 000 population).
- Morbidity from chronic diseases, however, is slightly worse than the OECD average.
- Hospital admission rates for diabetes and asthma are among the highest in the OECD (both close to double the OECD average), but among the lowest for congestive heart failure. They are just below average for COPD.
- Despite universal health insurance coverage and the freedom to choose their provider, only 71% of Koreans report being satisfied with the availability of quality health care (similar to the OECD average).
- The proportion of people who rate their health as "poor" is among the highest in the OECD (15.2% versus an OECD average of 8.5%).
- Depression, anxiety and suicide rates in Korea are among the highest in the OECD.
- At the time of writing, Korea has excelled at containing COVID-19, with the number of cases and deaths is among the lowest of all OECD countries.

A good health data infrastructure and information system are critical to improving health system performance in three ways. First by providing the necessary data and information on whether objectives are achieved or not. Metrics and indicators are needed to inform policy makers, as well as providers and practitioners, about performance in the domains that are relevant to them. Only through regular monitoring and feedback can improvement occur, and performance be optimised. As was outlined in Chapter 2, a *learning health system* relies on a solid data infrastructure and health information system that covers all key performance domains.

Second, achieving objectives concerning health care quality and management of NCDs directly relies on health data exchange among relevant actors ranging from patients and their providers to regulators and policy makers, to researchers and industry. These actors can then use the available data to generate information and knowledge that is relevant to them, enabling them to monitor, learn and improve on a continuous basis.

Third, it paves the way for regulatory and policy mechanisms that incentivise better performance and enable more optimal resource allocation. For example, moving from a fee-for-service remuneration model to one that rewards value for money is only possible with a granular data on outputs (activity) as well as outcomes (including patient-reported outcomes) and costs across entire care cycles that span the acute, non-acute and long-term care settings. These themes are explored later in the report.

Creating a learning health system requires addressing data gaps

A learning health system utilises health data effectively to create a continuous cycle of improvement through reflection, adjustment and evaluation. They are characterised by using all available data to generate metrics that measure performance against its objectives, and feed this information back to relevant actors in a continuous cycle of quality improvement. This is impossible without comprehensive, high-quality data.

Although the Korean system is awash with administrative and activity data, consolidated data on outcomes (e.g. unplanned readmission) beyond where this results in a claim (e.g. admission to hospital) or an end point (e.g. death) are lacking. More subtle clinical outcomes (e.g. test results) as well as patient-reported metrics are not reported consistently. Problems with coding and reporting present-on admission (POA) flags – an important tool to identify patient safety lapses in hospitals – have been described. These and other challenges mean that Korea does not provide several health statistics collected by the OECD (see Table 3.1).

Table 3.1. Selected indicators and statistics not reported to the OECD by Korea

Patient safety	• Foreign body left after surgery • Postoperative PE, DVT, wound dehiscence • Obstetric trauma • Hip fracture within 2 days of admission • Anticoagulating drug in combination with oral NSAID • Inpatient suicide among people with psychiatric disorder
Care quality	• Patient experience with regular doctor • Patient experiences in long-term care • Patient reported outcomes • Waiting times • Hip fracture surgery initiation
Other	• Life expectancy by education level • Diabetes prevalence

These gaps make it difficult, perhaps even impossible, to truly assess how the system performs against the goals of safety, efficiency and effectiveness (i.e. **quality**) of care; **equity** (fairness) in access to care and health outcomes; and **sustainability**. For example, not knowing life expectancy by education level makes it difficult to gauge how equitably health outcomes (some of which will manifest in longevity) are distributed across the Korean population regardless of their socio-economic status.

Meaningful performance monitoring and improvement

The performance of a health system against relevant domains depends on a variety of factors covering policy and organisational structures, institutional management, workflows and supplies, working conditions and environments, training and patient experiences, values and behaviours. A continuous loop of quality and safety monitoring, reflection, evaluation and improvement must be inclusive of and be relevant to all of the stakeholders involved – from the clinical microsystem to regulators, to high-level decision makers. Some examples are provided in the box below.

A learning health system, by definition, measures and evaluates all relevant domains, acting on the steady flow of information by putting in the necessary structures and capacities to continually improve its performance. The two fundamental steps of creating a high performing, learning health system are:

1. Develop routine monitoring and evaluation of domains relevant to health system objectives.
2. Ensure that the data to allow examination of the important questions are available, and can lead to a continuous loop of evaluation, reflection and adjustment.

In areas where HIRA has a direct mandate, Korea participates fully in OECD data collection and statistics, especially quality and safety. However, the health care quality assessment work of HIRA is limited predominantly to claims data for services reimbursed by the NHI scheme. While these data cover the entire population, they exclude certain outcomes and aspects of health care and quality domains, as is evidenced by Korea's reduced participation in the OECD reporting of safety indicators. This limits Korea's capacity to understand and improve health care quality and performance. Some examples of other countries using their data to drive learning are presented in Box 3.1 below.

Box 3.1. Other countries are using data assets to enable continuous learning and improvement

Clinical care quality registries in Sweden have been developed for several chronic diseases. These registries collect data about individual patients including medical interventions, procedures and outcomes where data are integrated into clinical workflows and are available to health care providers in real time. The registries are used by patients, health care providers, and health care institutions in a continuous loop of health care improvement and are considered by Sweden as a reason for the country's high level of care quality when compared with other OECD countries (Quality Registries, 2021[4]; Oderkirk, 2021[5]).

An additional consideration of the learning health system paradigm (beyond the scope of this report) is that stakeholders must be empowered to act on data/information on their performance. At the Veteran's hospitals in the United States, a dashboard of relevant quality metrics is provided to clinical teams but, importantly, those teams were integral leaders in the continuous improvement loop who were developing organisational and work process changes. Key outcomes of the process were improvements in both patient health care outcomes as well as in workplace culture and the morale of the health care providers involved (Meredith LS, 2018[6]).

Lastly, Finland's ministry of health and welfare (THL) has been developing clinical care quality registries over the past five years and serves as a useful example for Korea because, like HIRA, the THL collects health data covering the full population and has a sophisticated programme of national health care quality reporting and is, therefore, planning registries that are national in scope. THL's aim is to improve patient outcomes by improving care quality, treatment effectiveness and patient safety through services that are patient-centred, timely and equitable regardless of ethnicity, location or socio-economic status (Peltola, 2020[7]).

The inclusion of patient reported experiences and outcomes (PREMS and PROMS) in Finland are key to measuring patient-centredness. The aim of the new registries is to improve health care by

streamlining patients' treatment paths, comparing, and developing treatment practices, examining effectiveness and safety of different treatments, communicating treatment results openly to patients and other citizens, and steering the service system and service production towards high-quality and effective care (THL, 2021[8]).

The foundation of the information system in Finland is the integration and linkage of high quality and timely real-world data (RWD) from insurance records, clinical records, patient-reported data and contextual data regarding socio-economic and environmental factors that influence patient outcomes.

Value in health care is typically defined as the ratio between health care outcomes and costs. It can be achieved by improving outcomes, reducing costs, or both. People-centred and value-based care models change the orientation of health care systems from paying for sickness care to rewarding a cycle of continuous improvement toward care that delivers value for patients and society. A pre-requisite to achieve a health care system that delivers value for patients and citizens is a modern, interoperable health data infrastructure that can deliver information on short- and long-term outcomes from a patient and population perspective (the other is to measure the costs of producing not just outputs but outcomes).

For example, under the current Korean fee-for-service payment system claims data of patients with non-communicable diseases include treatment continuity information (number of visits and number of prescription dates), but does not collect patient treatment outcomes (e.g. HbA1C levels in diabetic patients). In treatment of AMI and acute stroke, 30-day mortality rate after admission is collected, but pre-hospital or between hospital data are insufficient.

At the core of making health systems more people-centred is the ability to systematically collect data on what matters most to patients through patient-reported outcome (PROMs) and experience (PREMs) data collections. Such patient-reported data are among the key elements proposed by Porter and Lee as part of a value agenda to measure and reward value-based care. Other key elements include multi-disciplinary care teams providing person-centred care, measurement of each patient's health care outcomes and costs, and the IT infrastructure and data standards necessary to measure and reward value (Porter, 2013[9]). Of course, traditional outcomes are still critical to patient safety, such as measurement of survival after treatment, avoidable hospital admissions and adverse events, but these traditional measurements alone do not give insight on whether the patients' needs have met and their functioning improved. For example, if the treatment has allowed the patient to re-join the workforce.

National patient-reported outcomes measurement is still relatively new among OECD countries. However, Norway and the Netherlands, as well as the United Kingdom have national PROMs measurement in place for several conditions and procedures. Denmark is also developing a comprehensive national PROMs monitoring programme (see Box 3.2). Based on the recent OECD survey of health data governance and use as well as interviews with local experts, this is a new area in Korea and needs national-level discussion. In 2019-20, Korea reported to the OECD that there was no national measurement or regional measurement of PROMs for any disease condition, but there were some initiatives within individual hospitals for hip and knee, breast cancer and prostate cancer patients. Since 2020, HIRA is using symptom and behaviour evaluations in dementia patients (PHQ-9, Clinical Dementia Rating (CDR), Global Deterioration Scale (GDS)) as outcome measures. PREMs are partially, but gradually expanding from individual hospital units to national units.

Box 3.2. Patient-reported outcomes measurement is still relative limited in many countries

An OECD 2019-20 survey indicated that PROMs are still relatively uncommon among OECD countries. Overall, 12 countries out of 23 reported having national PROMs data collections for at least one disease area or patient group.

Australia reported that Australia and New Zealand had a Prostate Cancer Outcome Registry using the SF-12 and EPIC-26 PROMs (general health/quality of life and disease-specific items). Canada reported the ESAS-r as the national standard PROM tool recommended by Canadian Partnership Against Cancer as well as the EQ-5D quality of life tool. National standards were also developed for PROMS for hip and knee replacement including the EQ-5D-5L, Oxford Hip Score, and Oxford Knee Score. France reported utilising the PROMIS-29 (quality of life PROMS) at the national level. The United States reported using PHQ and GAD measures for severity of depression and anxiety.

Norway has an advanced programme of PROMs monitoring at the national level. Norway reported national PROMs using the following generic instruments: RAND-12, WHO-5, EQ-5D-3L, and SF-36; and the following disease specific instruments: COPD Assessment test, Epworth Sleepiness Scale (ESS), Problem Area in Diabetes Scale (PAID), the Gold Scale, Perceived Competence in Diabetes Scale (PCDS), Strengths and Difficulties Questionnaire (SDQ), Fatigue Severity Scale (FSS), Multiple Sclerosis Impact Scale-29 (MSIS-29), Mini Mental Status Evaluation (MMSA-NR3), Montgomery-Åsberg Depression Rating Scale (MADRS), I-ADL, P-ADL, Informant Questionnaire for Cognitive Decline (IQCODE), Neuropsychiatric Inventory Questionnaire (NPI-Q), Cornell Scale for depression in dementia (CSDD), Mayo sleep form, VAS smerte, Knee injury and Osteoarthritis Outcome Score questionnaire (KOOS), Owestry Disability Index (ODI), Neck Disability Index, ISCoS International SCI Quality of Life data set, AddiQoL, m-HAG, DAS28-CRP, BASDAI, DLQI, Eating Disorder Examination Questionnaire (EDE-Q), Clinical Impairment Assessment (CIA), and Sullivans Catasthopizing Scale.

The Netherlands also has an advanced programme of PROMs monitoring at the national level including under the umbrella of the Dutch Institute for Clinical Auditing (DICA): PROMS for colorectal cancer, oesophagus cancer, gynaecological cancers, low back pain, morbid obesity, head neck cancer, skin cancer (melanoma), and breast cancer. Cataract surgery PROMs are also collected nationally. The National Health Care Institute collects national PROMS for hip and knee osteoarthritis patients and there is a national heart registry collecting PROMS for CVD patients. Under the Netherlands patient federation, every person with a disease or disability is invited to fill in a questionnaire about health and participation.

Denmark has a national PRO Secretariat under the Danish Health Data Authority. Work includes national PROMS for apoplexy, knee/hip osteoarthritis, depression, diabetes, heart rehabilitation, pregnancy/maternity, psoriasis and palliative care.

Source: Oderkirk (2021[5]), "Survey results: National health data infrastructure and governance", https://doi.org/10.1787/55d24b5d-en; Pro Secretariat (2019[10]), "The Danish National Work on Patient Reported Outcomes, Danish Health Data Authority", https://pro-danmark.dk/da/pro-english.

A recent example of value-based health care measurement and improvement can be seen in Massachusetts for breast cancer surgery patients. Longitudinal collection of PROMs at various points along the care pathway is undertaken and the results are made available to patients and integrated within the clinical workflow to support clinicians and patients to make treatment decisions. The purpose is to detect and monitor changes in physical and psychosocial function. Brigham and Women's Hospital (BWH) and Dana Farber Cancer Institute (DFCI) have launched an app for breast cancer oncology patients that has an interface to both clinical and administrative systems and gathers PROMs from patients throughout

the cycle of care (Brigham Health, 2021[11]). This work has been expanded to develop measures of time and activity-based costing that could support value-based payments.

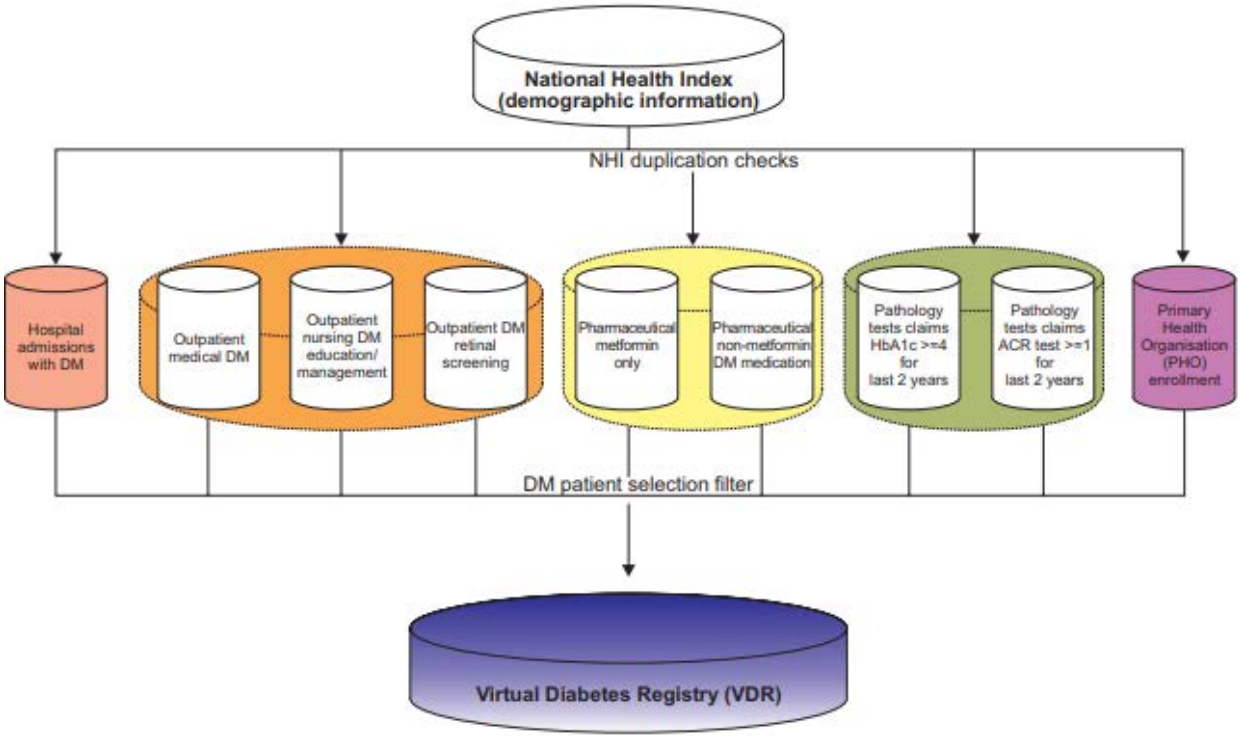
In Korea, HIRA is collecting PROMs data for research purposes, examining health outcomes associated with high-cost medications among cancer patients treated in hospitals, in particular pain and impacts on quality of life. The pilot began in 2020 and the results will be used to evaluate the potential usefulness of PROMs data in value-based payment. Initial plans are that PROMS could be expanded to other health care settings and a broader range of health conditions. The data collection method is expected to be electronic, such as a Web-based (Internet) survey.

Building 'virtual' disease registries from existing data: less costly, more accurate

Disease registries contain data that can yield important information and enable value-based services and a learning health system. However, registries are often developed and maintained manually and separate to existing data infrastructure, This duplication is costly inefficient. Modern data science and analytics can help. Linking existing datasets to build registries is an economical way to create an information repository that can inform a range of policy and practice decisions. Models based on EMR data have been demonstrated to deliver high predictive accuracy in identifying people with undiagnosed type 2 diabetes (Anderson, 2016[12]).

Health authorities in New Zealand are developing virtual registries for chronic diseases by extracting relevant data from a range of existing sources including EMRs, hospital admissions, primary care and pharmaceutical dispensing (Figure 3.2). The virtual diabetes registry allows for disaggregating prevalence estimates to the level of District Health Boards (local holders of health care budgets in New Zealand) and primary care practices. The information can be used to monitor quality of care and its outcomes across regions. Also, data from the registry allows for predicting who may be at risk of developing diabetes so that health care providers can act accordingly. If Korean health data (especially clinical data) are standardised and/or mapped to a CDM, there is little standing in the way of creating similar registries covering the entire population for all relevant diseases.

Figure 3.2. Databases for a virtual diabetes registry in New Zealand



Source: Jo (2015[13]), "Development of a Virtual Diabetes Register using Information Technology in New Zealand", https://doi.org/10.4258/hir.2015.21.1.49.

Better payment methods and resource allocation rely on integrated data

An assessment by the Economist Intelligence Unit in 2016 found that interest in value-based care and adoption of bundled payment systems was highest among countries spending over 10% of GDP on health care and was motivated by the need to control rising health care costs. However, if found that there was little implementation of value-based care models in practice (Economist Intelligence Unit, 2016[14]).

One way to reward value (rather than volume) is to replace a fee-for-service payment model with a method that provides a bundled payment for an entire care pathway. Bundled payments are a risk-adjusted contract with all providers and services over a full cycle of care (or period of time). Outcome measures are used to reward care cycles that meet or exceed objectives through an incentive payment.

The major impediment to developing value-based incentive payments in Korea is the lack of health data exchange and interoperability because methods such as bundled payments, for example, require accurate tracking of patients' progress across multiple settings and providers over a lengthy period of time (see Box 3.3).

Box 3.3. Value based payments: Examples from OECD countries

A recent paper provides an assessment of the extent to which value-based care models have been implemented in the United Kingdom (England), Norway, the Netherlands and the US state of Massachusetts (Mjåset, 2020[15]). The study found that both England and Norway were developing a bottom-up approach to costing that would allow measurement of the costs of a full patient treatment pathway that could then be used to reward value.

In the United Kingdom (England) the approach is called the Patient Level Information and Costing System (PLICS) and was first proposed in 2016 and is being implemented now across the health care system. The motivation for PLICS is that other costing methods are unable to answer the most important questions such as:

- Which health care pathways produce the highest value and for which patients?
- How do you set limits on variation in clinical care practices when you don't know what variation in costs and patient outcomes results from them?
- How could you assess the benefits of new models of health care delivery without knowing the value each is delivering? (HFMA, 2022[16]).

PLICS data are collected from many different streams of patient-level and service-level data throughout the health care system and require an IT system and common data standards that are integrated with the local systems of health care providers (NHS, 2022[17]). NHS England has already collected pilot statistics of PLICS in several care areas including acute care and mental health care and intends to move fully to PLICS for all areas of care in 2022.

Norway has introduced bundled payments recently but has not yet tied them to outcomes directly although this is part of a long-term plan. In the United Kingdom (England), a system of best practice tariffs had been introduced several years ago to incentivise health care quality, although they were not tied to patient reported outcomes. The best practice tariff was typically a base rate with additional incentive payment conditional upon performance. The tariff incentives were not significant enough, in light of the complex reimbursement system in the United Kingdom, to have a significant impact on performance (Gershlick, 2016[18]). It will be interesting to see how the PLICS system will contribute to the value-based payment system in the coming years.

The precursor to value-based payments were systems of pay-for-performance (P4P) which arose in the early 2000s across many OECD countries. These P4P methods were appealing in concept but were hampered in practice by inadequate inputs, particularly inadequately available and integrated patient-level health data including outcomes of care. As a result, many were unable to demonstrate significant improvements in health care quality (OECD/WHO, 2014[19]). Nonetheless, broader positive impacts from the development of P4P occurred including improved dialogue and agreement among payers and providers regarding the shared goal of health care quality improvement.

Korea is in a strong position to begin working toward measuring valued-based care because of its existing data infrastructure and the potential evolution toward an integrated health information system. The Korean single-payer model provides an established basis for calculating patient-level costs of care. HIRA could build partnerships with health care providers interested in value-based care to develop measurement systems and then, in collaboration with the NHIS, pilot test bundled payments with financial incentive bonuses for higher value health care pathways. Such pilot tests should be accompanied by the design of comprehensive evaluation frameworks to ensure that if the payments are tied to improvements in outcomes of care that these improvements can be clearly detected.

A solid data infrastructure can supply multiple purposes, it could for example enable prospective resource allocation that is based on, and adjusted to, health and social need. An enhanced, needs-based resource allocation model covering the entire population has been implemented in Spain. The model is based on Morbidity-Adjusted Groups (Grupos de Morbilidad Ajustados – GMAs). The goal was to transition from a disease-centred to a patient-centred model of health care delivery, by identifying individual health needs and implementing needs-based models of care and resource allocation (see Box 3.4).

Box 3.4. Grupos de Morbilidad Ajustados – GMAs

The GMA system stratifies the entire population into 31 distinct GMAs. A complexity index is calculated for each person based on analysis of past resource use variables. Each morbidity group except the healthy population is stratified into 5 complexity subgroups. In addition, a label is assigned to each person with information on the most relevant diseases, from a list of 80 prioritised health problems. Data come from EMRs of primary care providers and hospitals and from claims. Every insured person (about 99% of the population) has a unique ID, which allows for data linkage and inclusion of the entire population of each autonomous region.

GMAs serve a variety of purposes. These include designing specific models of care and supporting clinical decision-making in primary care. At the system-level, GMAs are used to predict demand and to set needs-based budgets, determine payments for medicines, health workforce planning, as well as public health monitoring and identifying people to include in epidemiological and clinical studies.

GMAs have been found to accurately predict parameters that are relevant for needs-based planning and resource allocation, such as primary care visits, unplanned hospitalisations and pharmaceutical spending per patient. Policy makers report satisfaction with the ease of use, the versatility of the system for multiple purposes, and in some cases the indirect effect the implementation has had on coding practices by health professionals and data quality.

Source: OECD (2019[20]), *Health in the 21st Century: Putting Data to Work for Stronger Health Systems*, https://doi.org/10.1787/e3b23f8e-en.

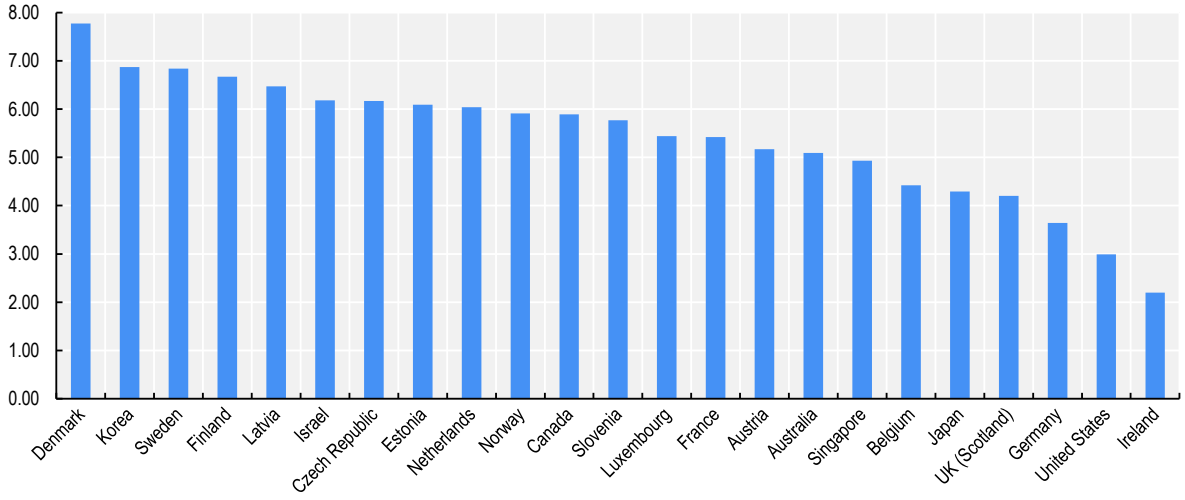
Korea can build on its unique strengths

This section outlines the many strengths and advantages of the current Korean health system. These strengths can be built upon to develop a world-leading, modern health information system. Korea performed well compared with OECD countries in many aspects of health data maturity, use and governance in the 2019-20 OECD survey discussed in Chapter 2. In most cases, the data needed to achieve an integrated health information system and fulfil the government's policy objectives exist. All that is needed are a set of consistent rules to connect actors in the information system together and to enable access to the right data by the right people at the right time. The strengths of the Korean system are technical, regulatory as well as political, with a solid track record of major health system reforms.

Korea has good health data availability, coverage, and governance

For example, Korea reported all but 1 of 13 important datasets in 2019/20 (inpatient data, mental health inpatient data, emergency care data, primary care data, prescribed medicines data, cancer registry data, diabetes registry data, cardiovascular disease registry data, mortality data, long-term care data, patient experience survey data, population health survey data, and population census or registry data). Korea performed well on the maturity and use of these data assets based on their availability, coverage, automation, timeliness, unique identification, coding, data linkage and regular reporting of indicators of health care quality and system performance (Figure 3.3).

Figure 3.3. Korea ranks highly on health dataset availability, maturity and use, 2019-20

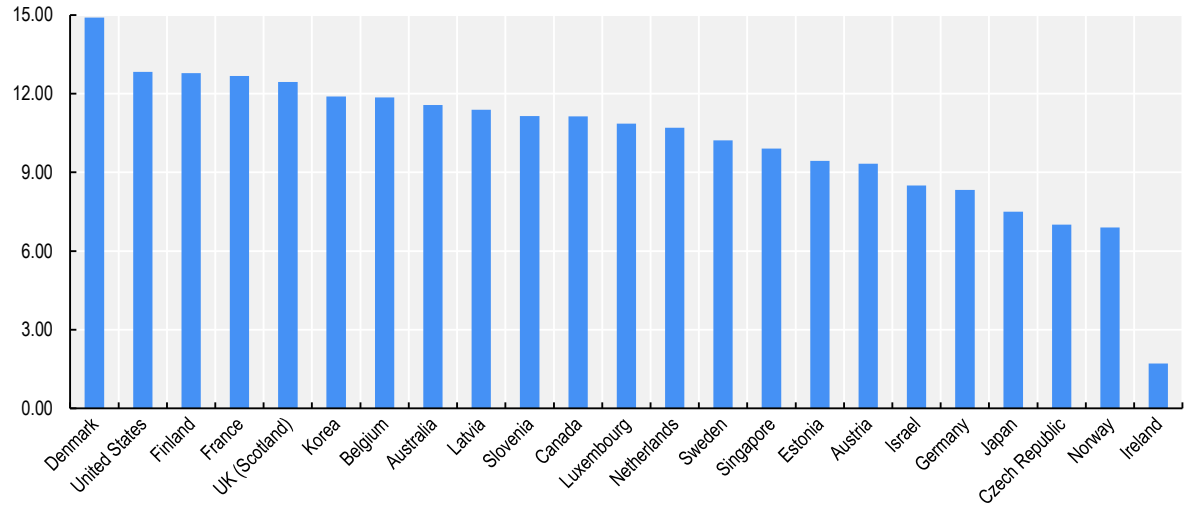


Note: Score is the sum of the proportion of health datasets meeting 8 key elements of dataset availability, maturity and use in this survey. The maximum score is 8.
Source: Oderkirk (2021[5]), "Survey results: National health data infrastructure and governance", https://doi.org/10.1787/55d24b5d-en.

Korea stands out for having a very short time lapse, of one week or less, between when a data record is first created and when it is included in the national dataset used for analysis for most key national datasets. Korea also was 1 of only 7 countries that reported having a unique patient/person identifying number that could be used for record linkage within 90% or more of their national health datasets.

Korea is also among the countries with the strongest data governance across 10 key national health care datasets considered in the 2019-20 survey based on the following elements: legal authorisation dataset creation, privacy/data protection officers, staff training in data protection, data access controls, data de-identification, testing for re-identification attack risks, data sharing within the public sector, data sharing with academia, data sharing with for-profit sector, data sharing across national borders for multi-country research, standardised data sharing agreements, remote data access or research data centre services, and public communication regarding health datasets and their legal basis and requirements to request access to data and to be approved access to data (Figure 3.4).

Figure 3.4. Korea compares well on national health care data governance



Note: The score is the sum of the proportion of national health care datasets meeting 15 governance elements. The maximum score is 15.
Source: Oderkirk (2021[5]), "Survey results: National health data infrastructure and governance", https://doi.org/10.1787/55d24b5d-en.

Korea has a strong track record of health reform and adaptation

Recent reforms demonstrate that Korea has the capability to plan and implement major structural reforms in the health system, overcoming internal and external resistance. This is perhaps the biggest strength to draw on when creating a data infrastructure for the 21st century.

Creating a single payer system

Prior to 2000, the Republic of Korea's national health insurance system consisted of more than 350 quasi-public health insurers. There were three types of health insurance schemes that were subject to strict regulation by the Ministry of Health and Welfare: health insurers for employees and their dependents, numbering more than 100; a single health insurance society for civil servants, teachers, and their dependents; and over 200 health insurers for the self-employed.

There was little competition among health insurers with enrolees assigned to insurers based on workplace or residential area. Despite identical statutory benefits, contribution rates differed across insurers raising concerns about equity (enrolees in poor or rural areas paid a greater proportion of their income). Risk-pooling/sharing mechanisms across insurers based on demographics and catastrophic medical expenses were introduced, and insurers with a higher proportion of the elderly and greater burden of catastrophic expenditures were cross-subsidised by others. Nevertheless, many insurers continued to face insolvency through structural inequities and inefficiencies that government interventions could not address.

The reform to merge all health insurers into a single payer in 2000 increased efficiency, improved equity, and reduced administrative costs in the system.

But it was not an easy journey. The National Assembly passed legislation to merge all insurance funds in the early 1990s, but the President vetoed the law mainly due to budgetary concerns that a single payer could increase the government responsibility for financing health care. It wasn't until 2000 that a new government successfully implemented this major policy reform. Civil society were instrumental in the reform process.

Separation of drug prescribing and dispensing

Prior to 2000, physicians and pharmacists both prescribed and dispensed medicines. This system provided strong financial incentives for over-prescribing drugs with higher profit margins. As medical service fees were strictly regulated, dispensing was a sought-after revenue stream. As a result, Korea had comparatively high proportion of total expenditures on pharmaceuticals.

Physicians and pharmacists favoured the status quo as they wanted to keep the right to prescribe and lobbied successfully to block reform. With the active support of civil society, the government successfully separated separating prescribing from dispensing in 2000.

This resulted in a series of nationwide strikes by physicians, leading to weakening some of the elements of the reform package. The government agreed to increase medical fees to compensate for foregone medicines-related revenues resulting from the reform. The dramatic increase in physician fees, as much as 40%, contributed to a fiscal crisis in the national health insurance system when its accumulated financial reserve was exhausted in 2001 (Kwon, 2007[21]).

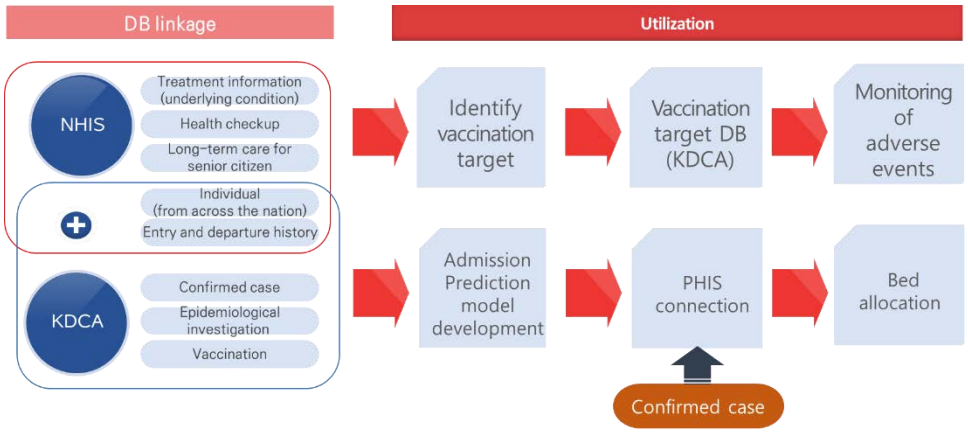
Responding to pandemics (MERS and COVID-19)

As part of its response to the COVID-19 pandemic, the Korean Government has approved temporary projects that promote using real-time data across key elements of the health care system. Although strictly for pandemic management and population health and separate to the Korean Digital New Deal (see below), these initiatives further illustrate what is possible in Korea with sufficient political will and social license. For example, daily reports are produced on the status of key resources and resource use to guide the health system to deliver care (geographic distribution of patients, the use of treatment wards (ICUs), and the current supply and allocation of key medical supplies (PPE) and medicines).

NHIS provides priority vaccination targets using the NHI eligibility and treatment data. NHIS also developed prediction scores for severity level of COVID-19 confirmed cases by linking COVID-19 data (confirmed cases, epidemiological investigation, and vaccination) of KDCA with the National Health Insurance Big Data (underlying condition, health checkup, Long-term Care data, etc.). The severity prediction score is added to the Public Health Information System (PHIS) and used for epidemiological investigation and bed assignment. Regarding COVID-19 oral antiviral Paxlovid, NHIS identified those who requires caution when prescribing the medicine (see Figure 3.5).

Korea also developed an International Traveller Information System (ITS) after the MERS outbreak and is using the system to manage COVID-19. The ITS is part of the Drug Utilisation Review (DUR) platform, which was outlined previously (and is discussed later in this chapter). The ITS provides real-time data about travellers entering Korea from higher risk countries to health care providers and pharmacies through a patient status checking system so that they may be prioritised for testing for SARS-Cov-2. Patient data are also linked with databases outside of the health system to track and control disease spread by tracking the movements of individuals who test positive for the virus through credit card usage records and mobile phone GPS, and publicly sharing information about travel routes and locations visited. While this poses privacy concerns, Korea has maintained public support for its pandemic response and has avoided lockdowns, strict stay at home orders and entry bans for foreigners (You, 2020[22]).

Figure 3.5. NHIS data efforts to manage COVID-19



Source: Material provided to the OECD Secretariat from NHIS.

Not all reforms succeeded

In 1997, the government began the pilot programme for case-mix funding based on Diagnosis Related Groups (DRGs) for five disease categories for voluntarily participating providers. The government planned to extend the payment model system to all health care providers in 2000, alongside the above financing and pharmaceutical reforms. However, following doctors' strikes against the pharmaceutical reform, the government decided to give up on nationwide implementation of the DRG-based payment system. Nevertheless, continued efforts with phased-approach resulted in full implementation of DRG at all providers across the nation.

The Korean Digital New Deal

The Digital New Deal is one of the four components of the Korean New Deal initiative aiming to accelerate the digital economy and this initiative highlighted the importance of citizen-friendly data including data gathering, processing, exchange and use. Under the Digital New Deal, real-time insurance claims data should be linked with real-time clinical data. For example, Korea is developing the capability to monitor adverse events from the COVID-19 vaccination in real time. In response to COVID-19, the Ministry of Health and Welfare and HIRA have been working together with the international community in sharing COVID-19 data (see Box 3.5).

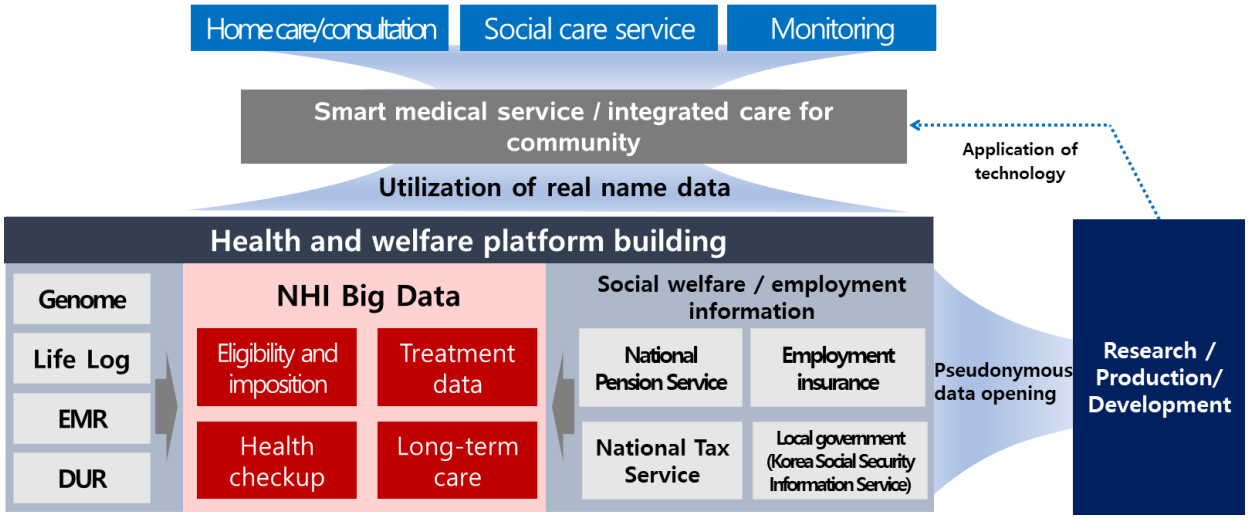
As a first step, the government is collecting scattered health sector data into a data lake, which the government plans to use to 1) provide lifestyle-related guidance to the public using personal information and community care, 2) pseudonymise the data and proactively open the data for researchers in the private and public sectors, to lead the transition to a digital economy. Legislation has been prepared to allow public bodies and private companies to have access to the data lake. Korea aims to link additional repositories to this national initiative. Korea plans to maintain the data lake after the pandemic ends so it may continue to support international researchers' access to updated COVID-19 patient data. De-identification techniques such as pseudonymisation are being used as a safeguard, and qualified organisations will perform data preparation. Engagement with the data lake is by application to qualified agencies (Magazanik, 2022[23]).

The objectives of the New Deal include creating "smart medical services and caring service infrastructure and opening and using data in the fields closely related to people's lives." To build smart medical service and community care infrastructure, MoHW is establishing smart medical service infrastructure at hospitals

and promoting smart health management and a virtual community care project. The My Healthway platform will consolidating and connecting genome, treatment history (clinical data), health insurance data.

NHIS is consolidating data from 42 organisations for operation of the National Health Insurance and the National Long-term Care Insurance, along with data shared by KDCA, Ministry of Environment, and Ministry of Labour. The data lake consisting of the consolidated data is not only open to the public but also providing services for the public. To realise the digital New Deal and support economic activity, NHIS is opening access to the data lake to the private-sector. Previously, access was only granted for policy and academic purposes. However, access to data for private insurance companies is still under discussion due to different opinions. Data are increasingly accessible to health service industries, including AI, precision medicine, disease prediction model development, health index development, etc. Private-sector applicants may be approved access to heterogenous linked data that have been pseudonymised (Figure 3.6).

Figure 3.6. MyHealthway platform



Source: Material provided to the OECD Secretariat from NHIS.

Box 3.5. The "H New Deal" Project

HIRA has taken on the responsibility to implement the digital new deal in the health system (the H-New Deal). The key areas of focus will be creating a digital health ecosystem that promotes an integrated patient health record (My Health Way), enables Artificial Intelligence (AI) tools development, co-ordination of medical services at a glance, practical assistance for Korea Government's response (COVID-19) and (importantly) industry-academia and government collaboration. The centrepiece of the scheme will be the HIRA data platform.

The H-New Deal is expected to benefit society, government, academia and industry. The benefits for patients and citizens will include:

- Secure access to personal medical information for individuals and for sharing with their health care professionals, i.e. My Health Way,
- Quick response to national health crisis by digital health care resources co-ordination,
- Prevention of patient harms/better safety,
- Value through reduction of medical expenses and improvement of health care quality,
- Expanding medical access for vulnerable people, and
- More convenience through providing digital health care services in real-time.

The project began in 2021 and implementation of all components is expected to show results in 2023.

Source: Material provided to OECD Secretariat by HIRA.

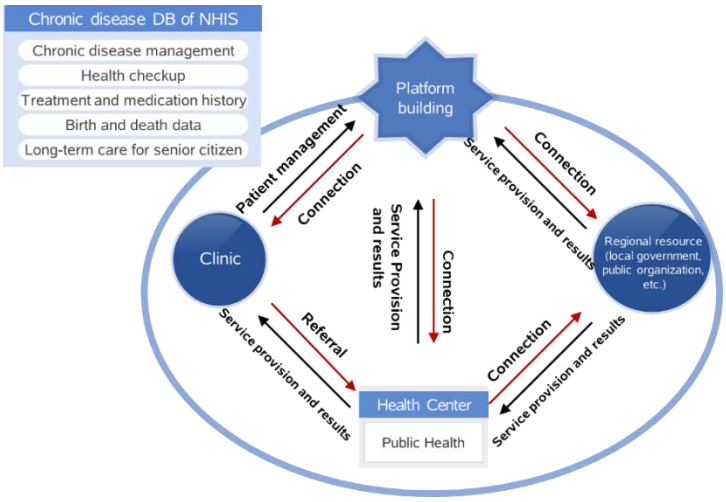
National health insurance agencies should play a central role in these advances. NHIS is the custodian of patient-level data, including the National Health Insurance, medical resources, health checkup, Long-term cares service, etc. In particular, NHIS is building a state-of-the-art data platform, which facilitates a favorable environment for data collection, utilisation, and access. In addition to the elements outlined in the Box above, HIRA is well placed to play a fundamental role in the Digital New Deal by providing hub or platform for secure and efficient data exchange. The experience of the DUR and ITS, as well as the pilot PROMs data collection and the value-based review and assessment project (see next section) gives HIRA a solid grounding to perform fundamental functions.

NHIS is building integrated services for chronic disease patients

Korea is attempting to build a comprehensive chronic disease management system by integrating personal health data scattered data across organisations. KDCA has built health behaviour and chronic disease management status data based on the annual national nutrition survey. NHIS has benefit claim data, lifestyle data such as drinking, smoking, and exercise, and actual measurement data from health check-ups.

NHIS analysed its own data to produce condition management indicators including indicators of risk factors, metabolic syndrome, and chronic diseases and complications by small scale region and workplace. The Chronic Diseases Management Registration Program (Figure 3.7) is a public data platform that collaborates with primary care providers to collect and accumulate chronic disease patient data (medical measurement and health management behaviour). My Health Bank contains medical consultation results (personal information, disease history, and complications), physical examination (blood pressure, etc.) clinical tests (blood sugar, etc.), and self-tested data (blood pressure, blood sugar, number of steps, etc.). It supports individuals to manage their health risk factors, and helps policy makers set up tailored measures for their region.

Figure 3.7. NHIS chronic diseases management registration programme

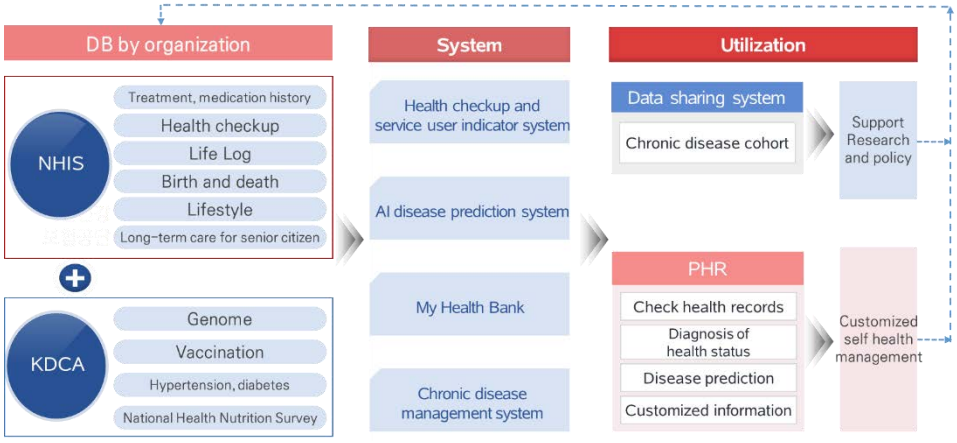


Source: Material provided to the OECD Secretariat from NHIS.

Using the Patient Management System, NHIS provides feedback on chronic disease patients' health management status and supports patient management and outcome improvement activities by sharing monitoring results (structure, process, outcome) by regions. The system helps improve chronic disease management indicators, supports individuals to manage risk factors by themselves based on customised diagnosis information, and supports policy makers to come up with the right solutions for the region. About 460 000 patients are receiving chronic disease management services from this system. Over 5 years, the "diabetes medication adherence rate in 1 year" rose by 5.02% to reach 63.11%.

KDCA and NHIS are attempting to build a national chronic disease management system by connecting the National Health Nutrition Survey and the health check-up and medical treatment system, which is expected to revolutionise the chronic disease monitoring system (Figure 3.8). Previously, NHIS and KDCA have exchanged and connected data for one-off policy analysis and research projects.

Figure 3.8. National chronic disease management system



Source: Material provided to the OECD Secretariat from NHIS.

HIRA is transitioning towards a value-based assessment and monitoring framework

Through its role in quality assessment and monitoring, HIRA has been able to achieve improvements in several important medical activity. For example, rates of antimicrobial prescribing for viral upper respiratory infections reduced from 73% in 2002 to 38% in 2019. The number of drugs per prescription have reduced from 4.3 to 3.7 over the same period. Meanwhile, antibiotic administered within 1 hour of surgery has increased from 24% to 90%.

More specifically, HIRAs deliberate transition towards a value-based claims assessments, as well as its Benefits Information Analysis System and the Drug Utilisation Review (DUR) illustrate the possibilities of using routine data to promote continuous learning and performance improvement in Korean health care.

Towards a value-based claims review and assessment

The current transition by HIRA towards a more nuanced way to assess and review claims that aims to maximise value (as opposed to minimise costs) is also encouraging. This is part of broader reforms to make services covered by the NHI more patient-centric and evidence-based. Whereas in the past, claim assessments were normalised based on average costs, the new approach builds in the distinct characteristics individual providers and their patients, based on a more detailed assessment of data.

The review process is also being made more transparent. Previously, claims were finalised by an internal committee. Now, clinical experts and academic groups participate in the process through a Professional Review Committee (PRC). A Special Review Committee (SRC) works with HIRA to develop clinical guidelines, standards, and indicators to monitor performance. A broader Review System Operation Committee was established to include providers, experts, and citizens/patients in how the process is designed and overseen.

In short, the previous process accepted or adjusted the benefit paid based on standardised amounts on an item-by-item basis. The new approach is a more comprehensive judgement that considers the local context, quality of service and treatment outcome. It also includes expert participation by providers and academics, creating a “virtuous cycle” of learning development of indicators, fine-tuning standards and developing indicators that inform continuous learning.

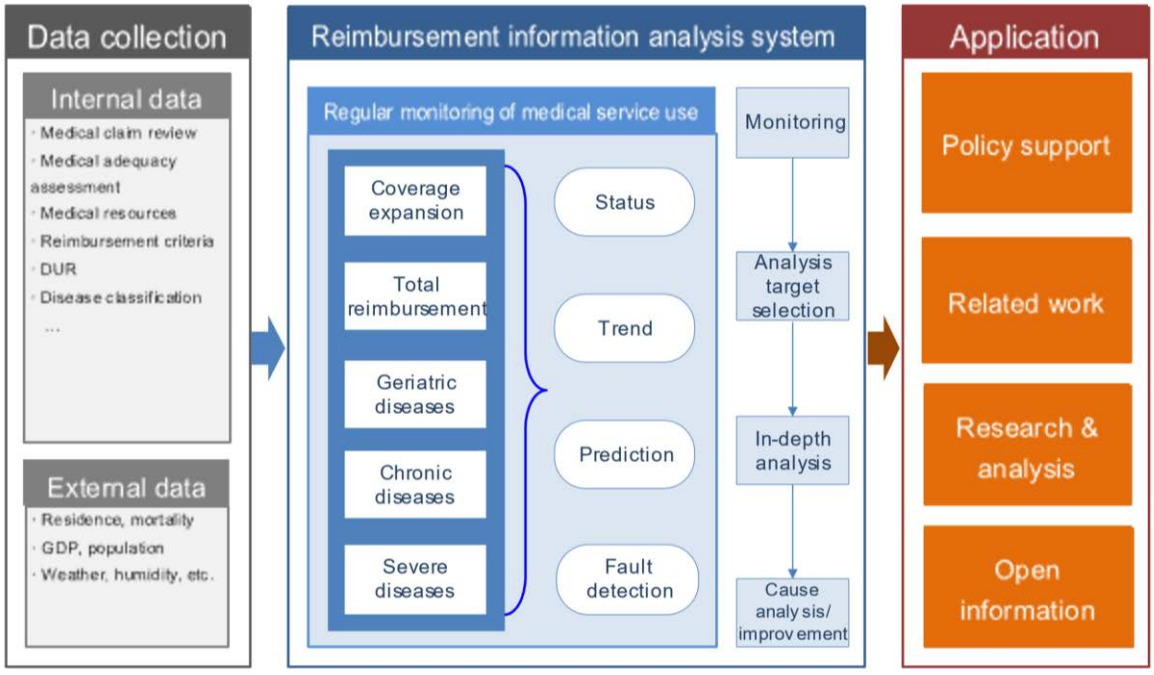
HIRA links health data with other data to provide information for policy, practice and patients

The Benefits Information Analysis System already demonstrates many of the principles and requirements described in the previous chapter of using existing data to promote continuous learning and improvement. The Benefits Information Analysis System draws on claims and other data held by HIRA as well as data held by Statistics Korea and the Korean weather service to analyse trends in the frequency and costs of medical interventions both within and outside the NHI coverage (Figure 3.9). According to HIRA, the aim is to:

- prevent unnecessary medical service use by identifying causes and preparing policy measures through medical service use analysis conducted from user and provider perspectives, and
- ensure the provision of essential medical treatments and prevent unnecessary financial expenditure to create a sustainable medical environment.

The Benefits Information Analysis System monitors actual use of services and resources against modelled, expected trends for a range of specific diseases (e.g. thyroid cancer), interventions (e.g. MRI scans), and populations groups (e.g. over 75s). The analyses are used to detect of abnormal trends in service provision, generate statistics to promote public health (e.g. heat-related illnesses in summer, fractures/falls in winter), and inform policies (and their evaluation) to guide sustainable coverage expansion. The initiative has driven several successful outcomes.

Figure 3.9. The Benefits Information Analysis System uses various data to support policy, research and public information

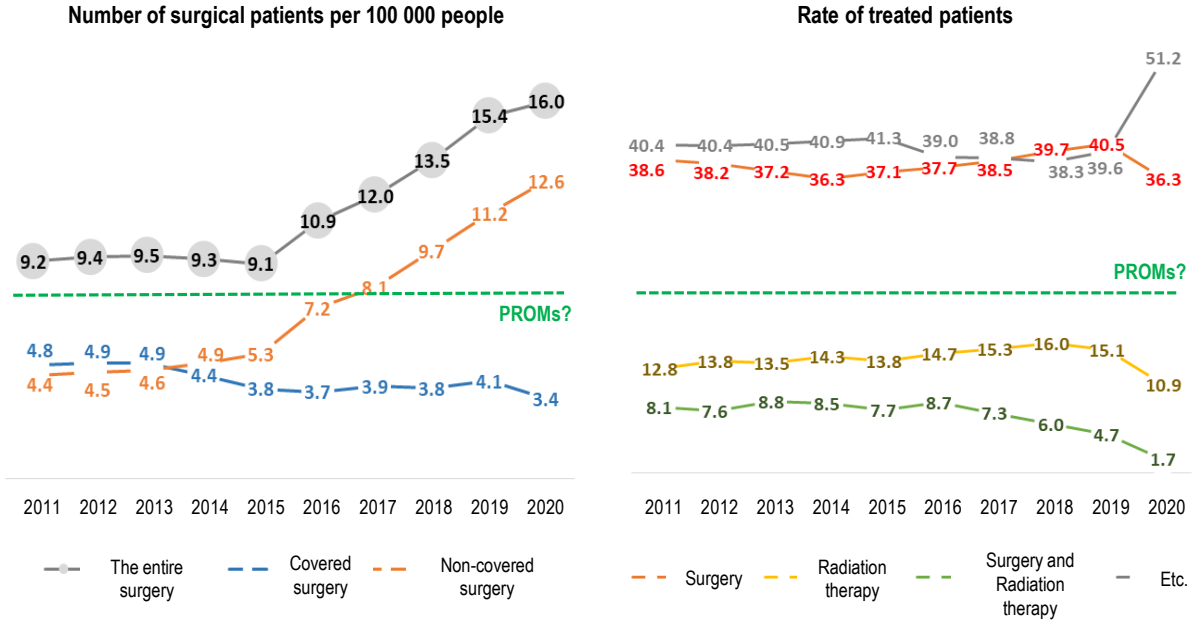


Source: Material provided to the OECD Secretariat from HIRA.

For example, data collected during suggested that MRI was over-used in stroke patients over 2019. Corrective action included meetings with providers and specialist groups where the clinical standards were updated. This resulted in a reduction in MRI use in line with expected rates based on population and cerebrovascular disease trends. In another example, monitoring on thyroid cancer treatment from 2011 to 2020 confirmed the change in treatment pattern, as total thyroidectomy fell, and partial removal and nonsurgical treatment increased.

Analysis of prostate cancer intervention rates over the same period showed a rise in non-covered items (robotic surgery) with a parallel reduction in covered services including radiation and surgery. Rates of non-covered items could be inferred because they generate a hospital admission, which *is* covered and therefore generates a NHI claim (the NHIS plans to begin collecting data on non-covered items beginning in late 2022 – see below). This may require policy intervention because it is not clear if robotic surgery, which is more expensive, produces superior outcomes. In fact, collecting patient-reported outcome metrics (PROMs) would enable policy makers, providers and patients to ascertain the relative value of these procedures, and provide feedback on performance (if patient-level data could be shared with providers) (Figure 3.10).

Figure 3.10. Data on prostate cancer intervention rates can be complement with PROMs data



Source: Material provided to the OECD Secretariat from HIRA.

The DUR can be expanded to provide real-world evidence on safety and performance of technologies

The DUR is a prospective, real-time review of drug prescriptions to minimise the risk of harm such as contraindications, drug/drug interactions or ingredient duplication. It uses data held by HIRA to provide the advice and alerts. A review of the DUR found that it has lowered the prescription of counter-indicated drugs and lowered pharmaceutical expenditures by reducing over-utilisation of drugs (Lee, 2019[24]).

HIRA hopes to add the another utilisation of DUR to alarm each person's side-effects based on patient's allergy records. To proceed, the information accumulated by only hospitals needs to be integrated with DUR. The system would be even more useful for clinical decision making if it included information about patient-level diagnostics, pathology, and test results and if this was accessible within hospital and clinic EMRs. For example, for patients with renal failure it would be helpful for clinicians to have guidance from DUR regarding the dosage and how it corresponds to patients' creatinine levels from their lab test results. But for the DUR to be expanded to include dosage and pathology results, the data collection of HIRA must be expanded to include clinical, pathology and prescription data. If this expansion occurred, then the DUR could offer more nuanced recommendations.

For medical professionals and pharmacists to use DUR to its fullest potential the DUR advice should be integrated into the clinical workflow to support clinical decision-making. This would require DUR to use global clinical terminology standards that align with the national standards recommended by the Korean Health Information Services (KHIS), including clinical terminology standards, for example SNOMED-CT and LOINC, and data exchange standards (HL7 FHIR).

A world-class post-market surveillance system

Moreover, Expanding the DUR to include the following data sources could transform it to serve as a full drug safety information system, able to support regulatory decision making and post-market surveillance of drugs, assisting agencies such as the Ministry of Food and Drug Safety (MFDS):

- Patient-level diagnostics, pathology and test results,
- Drug allergy information
- Patient-level health care utilisation (claims),
- Health outcomes including PROMs and mortality, and
- Demographic, social and environmental data.

An example of such a system is the Sentinel Surveillance System of the US Food and Drug Administration (FDA) where routinely collected data, particularly data from electronic medical records (EMRs) and insurance claims are used to support drug approval and post-approval surveillance and research (see Box 3.6). Further the FDA Sentinel is expanding to include surveillance of medical devices.

The FDA Sentinel System uses a distributed federated network and a CDM to query data of health care providers while preserving the data within the custody of health care providers, thereby enhancing the protection of health data privacy. Korea has recently invested in the coding of both hospital data and health insurance claims data to the OMOP CDM as part of the OHDSI project, a distributed federated research partnership, which constitutes the groundwork for moving to a privacy-protective sentinel surveillance system.

Box 3.6. United States FDA Sentinel Initiative

Sentinel is the FDA's national electronic system for monitoring the safety of FDA-regulated medical products, including drugs, vaccines, biologics, and medical devices. It was launched in 2008 following the passage of legislation requiring the development of a system for active post-marketing risk assessment and analysis for medical products. Development took place in collaboration with public, academic, and private entities, to establish procedures for obtaining access to disparate data sources and validated methods for the creation of a system to link and analyse data from multiple sources. The project harnesses information from multiple EHR systems, administrative data and insurance claim records – these data include demographics, enrolment history, drug dispensing, encounters, vital signs, lab results, diagnoses, procedures, and mortality.

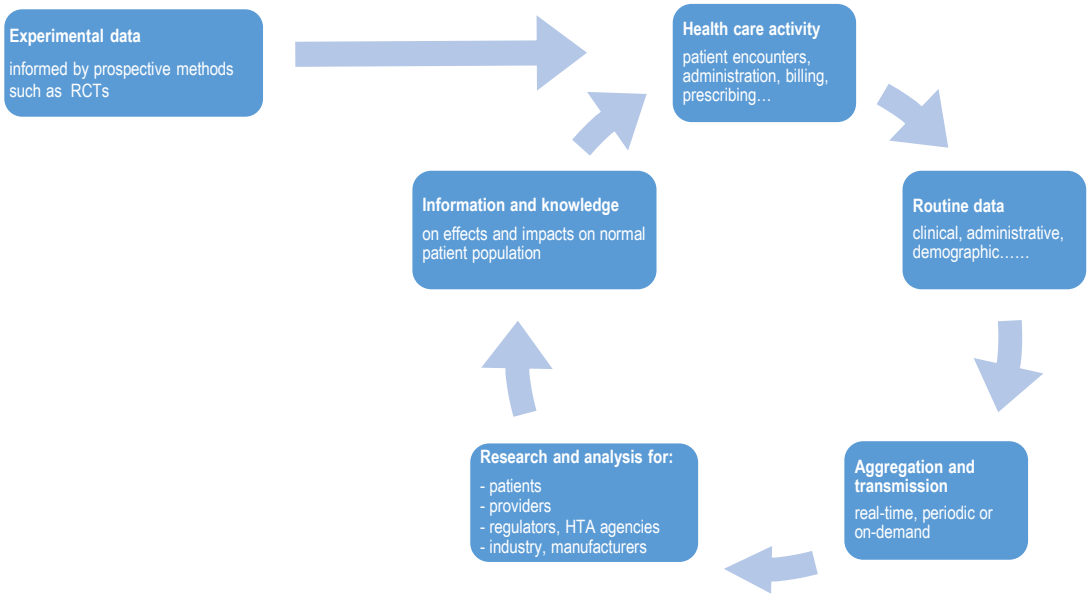
For many years, various parts of FDA have gathered risk information about drugs and other medical products through programs that rely on external sources (such as product manufacturers, consumers, patients, and health care professionals) to report suspected adverse reactions, such as its Adverse Event Reporting System. This type of safety monitoring is known as "passive surveillance." In contrast, the Sentinel System has been designed as an "active surveillance" system, because the FDA can initiate its own safety evaluations that use available electronic health care data to investigate the safety of medical products.

The Sentinel infrastructure is expanding to purposes beyond drug safety surveillance, such as to studying the effects of switching between branded and generic medicines and to the surveillance of the safety of medical devices. For medical devices, the same principles used to select data sources and study designs for medicines would be used for devices, but the scope of routinely collected data and evidence from clinical practice may need to be wider. Plans for uses of medical device sentinel data include routine post-market surveillance to understand the benefits and risks and identify safety signals, post-approval studies required at the time of device approval, prospective clinical studies, control groups for clinical studies, and product safety labelling.

Source: OECD (2019[25]), "Using Routinely Collected Data to Inform Pharmaceutical Policies: Analytical Report for OECD and EU countries", https://www.oecd.org/health/health-systems/Using-Routinely-Collected-Data-to-Inform-Pharmaceutical-Policies-Analytical-Report-2019; FDA (2019[26]), "FDA Sentinel Initiative", https://www.fda.gov/safety/fdas-sentinel-initiative.

Building such a system in Korea is eminently possible and would realise the concept of a learning health system in drug safety and HTA where experimental evidence is subsequently complemented with evidence from real-world data harnessed from routine health care activity (see Figure 3.11). This would greatly enhance the pharmacovigilance work of MFDS. It would also benefit the cost-effectiveness work of HIRA, and NECAs work on HTA. In addition, HIRA would be a good candidate to host the data platform for this expanded DUR as well as other aspects of the Korean health data infrastructure.

Figure 3.11. A learning health system illustrated through medication surveillance



Source: OECD (2019[20]), *Health in the 21st Century: Putting Data to Work for Stronger Health Systems*, https://doi.org/10.1787/e3b23f8e-en.

My Health Way – the launch of an integrated personal health record

The My Health Way project to develop a national personal health record (PHR) began in February 2021 and the planning phase will continue until 2023. The MoHW is considering the plans for personal care records applied in other countries such as the Blue Button in the United States and the NHIS PHR in the United Kingdom. Other considerations include secure data storage. The EMR records are stored by health care institutions, but an intermediary data storage is needed that integrates and standardises the data to provide patients with secure access to their own data. Participation in the PHR is voluntary for institutions.

Four types of data are envisaged to be shared with patients:

- Medical records, laboratory test and medical image results,
- Insurance claims,
- Patient contributed data, and
- Genetic data.

The hospitals and clinics participating in My Health Way are doing so voluntarily and they have different EMR systems using different terminology standards. Through the PHR, patients will not be given access to their complete medical records but will be given views of data that are determined to be the most important for them. The platform will be a simple media that connects patients with their relevant data within different institutions who have treated them. As a result, it is the responsibility of the hospitals and

clinics that join the PHR to map their data to the terminology standards required for the PHR (or to adopt an EMR system that conforms to PHR standards).

The My Health Way PHR has been partially established and patients can use a smartphone app and a Website to check their public health insurance record (NHIS) and their public sector medical check-up data.

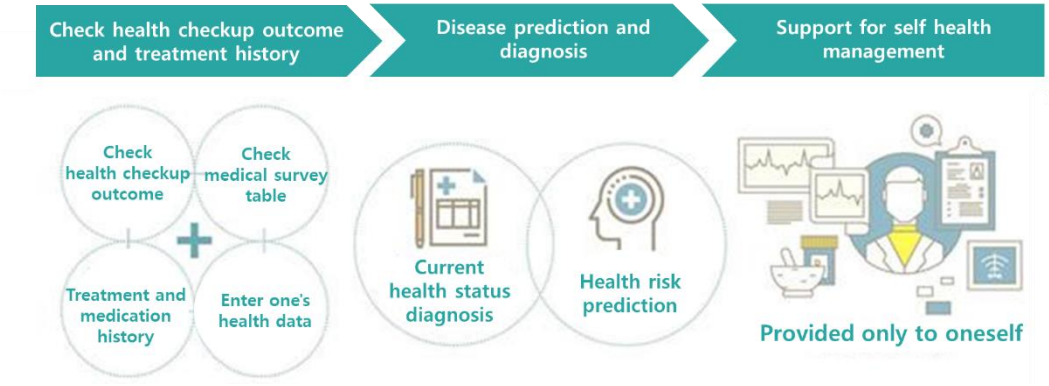
The PHR development decision-making committee (My Healthway Promotion Committee) is led by MoHW, with participation from relevant departments, the medical society, industry, an academic circle, a legal circle, other relevant organisations and patient-group representatives. In addition, it runs a consultative group to facilitate more active utilisation of health data by public organisations, including HIRA, NHIS, National Cancer Centre, Korea Social Security Information Service, KHIS, and the Korea Health Industry Development Institute.

NHIS "My Health Bank"

In 2012, NHIS launched My Health Bank PHR service and began providing access to personal health data (Figure 3.12). The service includes:

- Personal health record check: 5-year medical treatment and 1-year prescription records of the subscriber and his/her children (14 years and younger), health check-up history and 10-year health check-up results and lifestyle information, etc.
- Diagnosis and prediction: Healthy-age check based on health check-up results and a personalised disease-risk prediction service for 5 diseases (stroke, heart diseases, diabetes, etc.)
- Health self-management support: Based on health check-up results and medical treatment records, personalised health information is provided including a smoking cessation programme, an obesity reduction programme, and management of metabolic syndrome and chronic disease. The programs are connected to the government's health management programs, such as the health improvement centre.

Figure 3.12. My Health Bank services



Source: Material provided to the OECD Secretariat from NHIS.

My Health Bank is provided with the individual's consent. The service is available on the Web and via an App, and individuals can check only their own information. The information is not shared with medical professionals even in the case of an emergency. Another limitation is that various types of data are not organically connected and are scattered across programs.

To overcome these limitations, an informatisation project is being promoted to integrate and link health information provided by public agencies and local governments. In addition, based on a digital prescription, health information could be shared between patients, doctors, and pharmacists, thereby establishing a process to efficiently respond to chronic disease management, medication management, and emergency patient response.

HIRA is also creating a platform for individuals to access to their personal data

HIRA is also initiating the provision of a comprehensive health information service including personal medical records and medical expenses. The agency is working to reconstruct the existing dataset (including claim data, DUR data etc.) in the same way as the patient-unit dataset (life-cycle) database. Re-organising individuals' medical information in this way will enable linkage with the national PHR or other platforms. The provision of information by HIRA based on the patient-level database is expected to enable the public to access their medical information and to secure continuity of care for medical institutions.

HIRA already provides detailed medication information based on the information from DUR system. It is currently also building a patient-level database using HIRA's data: personal medical history, treatment information, and medication history. As part of this project, HIRA's current mobile application is being expanded into "Health E-UM" to be completed in 2022. This new application will enable:

- people to check their personal medical history, treatment information and medication history
- enquiries about medical information only by a simple authentication process and without a submission document.
- service linkage between relevant public institutions.

In is unclear to what extent the development of personal medical and health information apps by the MoHW, NHIS and HIRA as outlined above are being developed in a co-ordinated fashion. Doing this development in silos, with little collaboration across agencies, creates a high risk of duplication, inefficiency and suboptimal outcomes for patients who then need to consult with multiple PHRs. The recommendation is to consolidate these activities as much as possible to maximise benefit to Korean patients and the public (see Chapter 4).

A committed research community and a common data model (CDM)

The number of analysts accessing health care datasets in research data centres or via remote data access services varies by dataset in many countries. The highest number of annual external data users in the 2020-21 OECD survey were reported by Korea and France. In Korea, the number of external analysts for the health sector is reported to be around 3 000 a year (1 500 through NHIS and 1 500 through HIRA).

A pleasing result of the dedicated researchers is the implementation of a common data model (CDM) across the country's health data. While Korean hospitals use different EMR systems and data formats, the EMR data of approximately 40 large hospitals have been mapped to the global Observational Medical Outcomes Partnership (OMOP) CDM by a group of dedicated academic researchers.

These hospitals are participating in the global Observational Health Data Science and Informatics (OHDSI) project where participating organisations are part of a federated network with a "privacy-by-design" approach where data remain at all times in the custody of the organisations holding them and network researchers submit queries and programs (distributed analytics) without accessing or visualising the personal data records. Code is shared through GitHub, supporting interoperability of data analytics as well as of data. Researchers can access only the data schema (structure and variables) to prepare statistical programmes (coding) or submit queries through a tool (ATLAS).

HIRA has also mapped much of its claims data to this model, creating the foundation of a rich and valuable data asset for health and medical research. HIRA coded linked health data to the OMOP CDM, including

HIRA's national insurance claims data, for the purposes of encouraging secure access to timely data for global COVID-19 research as part of the OHDSI project. The project opened data for a large group of domestic and international researchers to collaborate on COVID-19 research while protecting data privacy and security within HIRA. Further, the Public Institutional Bioethics Review Board (IRB) of Korea's National Institute for Bioethics Policy supported the timeliness of this international research by deciding to exempt this COVID-19 research from IRB review.

The use of the OMOP CDM is also growing across multiple countries. France is coding data within the Health Data Hub to the OMOP common data model as part of the EU EHDEN project, which is part of OHDSI. In 2021, Australia and Israel reported projects to code EHR data to the OMOP CDM.

The EU EHDEN (European Health Data and Evidence Network) project is particularly advanced with 98 data partners from 23 different countries which are mapping their data to the OMOP CDM (EHDEN, 2022[27]). EHDEN is a public-private project funded by the European Union and the European Federation of Pharmaceutical Industries and Associations. The coding of health data in the EU to OMOP CDM is expected to be further accelerated when the new European Medicines Agency (EMA) Darwin project begins which will be a co-ordination centre to provide timely and reliable evidence on the use, safety and effectiveness of medicines for human use, including vaccines, from real world health care databases across the European Union (EU) coded to a CDM (EMA, 2021[28]).

A world-class R&D environment to attract talent and support innovation

Korea can build a digital society where data, including health data, can be (1) more available to support research and innovation and (2) where health care can be smarter by using real-time data for health care monitoring and better use of digital devices and tools. This review has revealed both progress toward and obstacles to realising a world class R&D environment for research and innovation in Korea. The data needed to develop a learning health care system are the same data needed for medical and health R&D.

If there was a goal of investing in "Big Data" and digital technologies in the health sector, it would be to produce reliable, actionable evidence about prevention and treatment pathways and the health outcomes that result from them (Colombo, 2020[29]).

Academic researchers interviewed for this study identified several key areas where the health data holdings of HIRA and NHIS could be improved to support research. For example, the administrative claims data of HIRA and NHIS are based on crude time points (week or month) which don't allow to determine whether activities or health status are pre- and post- a health event or medical service provided. HIRA and NHIS data would be more valuable to research if the full timeline that is captured within the electronic medical records of hospitals and medical institutions could be integrated into the HIRA/NHIS data. In a second example, which was raised earlier, research into the safety of prescription medicines necessitates the integration of clinical data on dosage with existing claims data. Research into treatment pathways and outcomes requires information on lab values and medical imaging results. Lastly, as was mentioned earlier, to understand the whole health care system it is necessary to also have data on non-insured health care services.

It is equally important that hospital EMR data on its own, even if the data were standardised and interoperable, would be insufficient for health and medical research because they only include events within their facility. Outcomes of hospital care frequently occur in the community, such as in primary care, home care or long-term care. Further, integrated care delivery is an increasingly important policy and research focus and requires integrated data across the full patient care pathway.

A key challenge concerns the coherence and exchange of clinical data

While the timeliness, consistency and quality of Korean administrative/claims data are second-to-none, as has been outlined several times in this report, a key challenge is the lack of coherence and exchange of EMR data. These data are critical to cover inherent gaps of claims and other administrative data, and complement data on population health, demographics and other important contextual factors. Improving the coherence and exchange of EMR data is necessary to create a learning health system.

EMR data interoperability is needed for direct care and system learning

While Korea has most of the key health datasets covering close to 100% of the target population, there are gaps. Voluntary participation of health care providers in contributing to national datasets is a reason for incomplete clinical data coverage in Korea and is a reason why Korean disease registries target only a sub-set of patients or providers.

Korean claims data are granular and detailed, but they only contain services covered by the NHI benefit package. Non-benefit services, paid for out-of-pocket or through voluntary insurance, do not appear in claims data held by HIRA or NHIS. The proportion of uninsured services and voluntary health insurance has been growing (WHO Regional Office for the Western Pacific, 2015[1]). Data on the provision and outcomes of uninsured services are needed to provide a complete picture of health system activity and therefore performance. The NHIS has collected non-covered service data from some hospitals and medical expense surveys and use them for cost analysis and is encouraging to learn that the NHIS plans to begin collecting these data from the entire health care institutions in late 2022.

Although Korea launched patient referral pilot programme using e-forms to exchange data digitally, experts acknowledge that while Korea is one of the more digitalised societies, when it comes to health care data exchange the old ways of working are still being used, such as sending patients to a new provider with a paper copy or CD of their own records. Also, patient-reported data on outcomes and experiences of care can shed light on how health services perform. Collection and use of these data in Korea are still nascent. For example, paper questionnaires are used although some hospital reportedly collect PROM data electronically.

As described in Chapter 2, a well-designed, longitudinal (interoperable) electronic health record (EHR) system can greatly enhance care quality – especially co-ordination and integration – as well as supply valuable information for research, innovation and public health. For example, an individual with multiple health problems can manage their health much better if they have access to their own medical information, and if all their health care providers – GPs, specialists, hospitals, emergency rooms, pharmacists, dieticians and physiotherapists – also have access to the same information. Patient Internet Portals to their own current medical records from multiple health care providers exist now in most OECD countries.

Moreover, EHR data are integral for creating “a learning health system” that monitors performance on a range of domains to enable continuous improvement. The data within the EHR system can be linked to other datasets to, for example, develop machine learning algorithms to predict the mortality risk in sub-strata of patients thereby improving the safety and effectiveness of care in close to real-time.

A longitudinal EHR system does not mean a single, centralised electronic medical record (EMR). It can equally comprise a distributed network of EMRs belonging to hospitals, specialists’ rooms, GPs and pharmacies if the technical and operational infrastructure exists for data to be standardised and exchanged between them, and where people can access all their own health information in one place. The lack of EMR interoperability means that patients and the public are missing out on better care and knowledge to improve care co-ordination and integration, public health, and research and innovation.

Although virtually all Korean health- and long-term care providers record clinical data on EMRs, most of these data are not interoperable owing to the lack of consistent standards. This means that there isn’t

actually a national clinical dataset but instead there are multiple small silos of data that are difficult to access for primary or secondary purposes.

Lack of data exchange for direct patient care is inconvenient and costly

Several inefficiencies in health care delivery and overall performance were emphasised by experts because they relate directly to the current management of health data in Korea.

Certification for hospital EMR systems can be obtained if hospitals are sharing data with patients electronically. Civil society experts consulted expressed concerns of consumers regarding the cost of repetition of these tests and images and the inconvenience of having to carry their paper records (or CDs) themselves when they receive care from more than one provider (or change provider).

Further, health care providers recommend treatments and diagnostic services that are not covered by the NHIS and the costs for this care is higher and is particularly concerning for patients when medical images and laboratory tests are repeated unnecessarily because of a lack of data exchange among providers. The My Health Way App does not include plans for the inclusion of clinical data from health care providers and therefore isn't a vehicle to solve this problem. Some hospitals provide patients with access to some of their own data within that hospital, however, civil society advocates indicate that this data is seldom sufficiently detailed so that new health care providers still require a CD or print-out of the medical records.

The KHIS mandate excludes secondary use of data

KHIS is tasked with certifying manufacturers and providers, and national data format standardisation. While its current focus is on primary uses of data, the long-term goal of KHIS is to invest in data standardisation to support secondary uses of clinical data and R&D in the medical field. KHIS is working towards building a legal basis that would enable the organisation to collaborate with all stakeholders in health information system. This will facilitate meeting the requirements of a learning health system (monitoring performance, quality and safety monitoring, public health surveillance and value-based care).

Past experience within OECD countries indicates that when the focus of standards development is exclusively upon primary data uses, sub-optimal decisions may be taken because data standards supporting national public health and health care objectives for monitoring and research are not considered and the evolution of the standards don't provide for necessary life-cycle data interoperability, so that the data within the IT system will be comparable data over time and therefore suitable for statistical and analytical uses.

Conversely, there is the opposing risk that the data standards and collection methods developed by other national organisations responsible for health data will be incompatible with the plans and priorities of KHIS and impose a needless financial and human resource burden on health care providers because they are not integrated within the HIS, do not use the same standards for clinical terms and are stand-alone electronic or paper-based systems outside of the clinical workflow. To avoid this risk, unified standards under the Ministry of Health and Welfare should be applied.

The mapping of Korean EMR data to the global OMOP CDM (outlined previously) can be an intermediate step to enable analytics of these data as the country moves to full interoperability. However, a CDM is not really suited to enabling exchange of data for direct care (primary purposes) and is therefore not preferred to standardised coding and semantics across all EMRs (see Chapter 2).

Access to data for secondary uses can be made more efficient

It is difficult for Korean researchers to access health data for medical and health research. The two main reasons for problems accessing health data are legislation and its interpretation, and the lack of a unifying framework for data access.

Legislation and its interpretation can hinder data exchange especially for research and analytics

Four main laws govern the protection of health data privacy in Korea:

1. The *Personal Information Protection Act (PIPA)* is a general law that was enacted in 2011 to regulate the protection of privacy in all aspects of society including health.
2. The *Act on Promotion of Information and Communications Network Utilisation and Information Protection* (DREE) was enacted in 2016 to facilitate the use of ICTs and to protect the privacy and security of data of consumers utilising ICTs (Telecommunications and Internet).
3. The *Use and Protection of Credit Information Act* was enacted in 2009 to regulate the management of credit information and protect individuals' credit data from loss or misuse (1-3 are collectively called the "data privacy laws").
4. The *Medical Services Act* was enacted in 2016 to regulate providers of health care services (hospitals) including the data they collect about patients (including EMRs) and the conditions under which patient data may be shared.

There are amendments to the *Medical Services Act* that were submitted to the legislative assembly in March 2021 to enable patients to request (consent to) the electronic transmission of their medical record from one health care provider to another (currently this is only permitted in emergency situations). This exchange of data would be via a medical record support system. The role of this support system is still vague in terms of the services they would provide. The amendments also would allow sharing data with patients via an electronic Internet portal to their own data. The amendments may not have been passed yet.

The law in Korea is strict regarding the need for informed consent of patients to share data. The DREE law was amended in 2020 to allow for the sharing of de-identified or pseudonymised data with industry. In addition, the Ministry of Health and Welfare established the Guidelines for the Health Data, which includes the procedure of pseudonymising health data.

Pseudonymised health data can be shared for research in Korea. However, large national organisations that are trusted to manage personal health data are prevented from utilising a common pseudonymisation algorithm to enable a high-quality direct dataset linkage using a pseudonymised ID for projects within the public interest.

Korean law reflects the culture and priorities of the Korean people who are highly sensitive regarding the protection of personal health data. There is a concern among NGOs that lobby the government that the RRN is a powerful weapon that the government could use to track the movement of people.

There are legislative penalties that punish those who attempt to re-identify data that has been de-identified.

While *PIPA* requires consent of patients for data to be collected, these data may be re-used for purposes that are reasonably related to the purpose the patient consented to. An amendment to PIPA that entered into force in August 2020 also involved amendments to other laws related to data privacy and created a central role for a Personal Data Protection Commission for Korea and legislated that pseudonymised data could be shared for research without consent. This amendment may make it easier to undertake dataset linkages in Korea. However, there may be other reasons for not allowing data sharing such as professional rivalries, lack of trust and concerns about accidental data breaches.

Strict interpretation of laws regarding medical data

In Korea, it is legally possible to extract data from electronic health records for secondary uses but the interpretation of the laws is strict so doing so is difficult in practice. Further the law authorising the Korean Health Information Service (KHIS) does not provide a legal mandate to extract data from EHR records to create datasets for government statistics and monitoring or for approved medical or health research (OECD, forthcoming). As a result, KHIS work does not include consultation with stakeholders in the national health information system or development of standards and certification processes that ensure these stakeholders information needs will be met.

Achieving an integrated personal health record with My Health Way (an App designed to give people access to their personal medical information) will require legal authorisation to overcome restrictions on data exchange and integrations under the *PIPA* and the *Medical Services Act*. My Healthway is currently attempting to enact and revise laws and regulations on health data transmission rights to enable individuals to send and use their own data as they wish. It is also working towards adoption of a protection and use system for My Data, using the My Healthway platform.

There is also no legal basis to share de-identified data with a foreign researcher in Korea, even if the data sharing is within the health-related public interest and the data protections in the foreign country are adequate when compared with Korean legislative requirements. This contrasts with other OECD countries where, in 2019-20, seven countries (Australia, Belgium, Denmark, Finland, Norway, Singapore and Slovenia) reported that de-identified data from all health care datasets could be shared for approved research to take place outside of their country. Another six countries (Canada, Estonia, France, Germany, Luxembourg and the Netherlands) reported sharing de-identified health data outside of their country was possible with the majority of health care datasets. Many of these countries are under the *EU General Data Protection Regulation (GDPR)* which is explicit regarding the safeguards enabling the exchange of personal health data across borders.

Integrating health data in the custody of the main national organisations responsible for national health data (HIRA, NHIS, KDCA and KOSTAT) would seem to be legally possible to generate “official statistics”. Further all of these organisations are authorised by the Korean Government as trusted organisations to undertake record linkages.

However, experts interviewed identified obstacles to direct record linkage using the Resident Registration Number or other personal IDs. Within a single organisation, such as HIRA, the RRN is used for direct and high-quality data linkages to produce health data and information to fulfil its mandate. However, there is a concern that privacy laws prevent the use of the RRN for data linkages involving data from different organisations. Other identifiers, such as birth date, may be used for probabilistic linkages but are subject to a high degree of error that can compromise research results and patient safety. Hospitals each create their own unique IDs but these cannot be used to link data among different hospitals or between a hospital and a large national organisation responsible for health data, such as NHIS.

Further, while the recent amendment to DREE in 2020 allows for the sharing of de-identified or pseudonymised data with industry, the large national organisations responsible for health data reported being prevented from integrating data among them by utilising a common pseudonymisation algorithm to enable a high-quality direct dataset linkage (using a pseudonymised RRN ID) for an approved project within the health-related public interest. There is also a further obstacle where they are required to find a trusted third party to conduct a data linkage that is different from the trusted organisations wishing to integrate data.

Experts representing civil society organisations in Korea advocated for reforming the Korean data protection law to require pseudonymisation of identifiers and the secure storage of pseudonymisation linkage keys to strengthen data protection and build trust. Further, these organisations are concerned the legal penalties for data misuse are not high enough to be a deterrent.

Mechanisms to access data for research needs to improve

There is no unifying framework for research access to health data in Korea and, as a result, there are different separate initiatives underway that are each trying to fulfil a similar need resulting in unnecessary duplication of effort and expense. For example, HIRA accepts and reviews applications for access to its data holdings and provides a secure research room on its premises as well as real-time remote data access services for approved applications. When NHIS receives a data access application, it reviews and takes security actions, and provides access services through an intranet Cloud at a secure health insurance analysis centre at NHIS, a participating university, or health data-centric hospital.

Researchers interviewed indicate that both HIRA and NHIS have long waiting lists for approval to access data with waiting times of several months to one year. Regarding project approval, experts interviewed indicated that the approval process for access to HIRA data is unclear, particularly the criteria for approval and why data requested are denied or only a portion of requested data are approved. Further there is no mechanism to appeal an approval decision.

Because of limited access to data, some experts revealed that researchers launch digital start-ups to gain access to data either through a special arrangement with a particular hospital or by setting themselves up as an intermediary or software vendor between health care providers and insurance companies to facilitate claims submission and reimbursement and, consequently, gain access to the data that has been exchanged.

Both HIRA and NHIS orient staffing toward their primary functions which include policy analysis and statistics; however, both would like to develop capacity for more sophisticated applications, such as machine learning and artificial intelligence. At the same time, in both the non-profit and for-profit research community there is a greater pool of talent available to undertake software development work, thus there is a need and an opportunity to build public-private partnerships for fair, transparent and secure access to data that provides a win-win. But such a result would depend upon both reducing duplication of services within HIRA and NHIS and then strengthening the resourcing needed to improve access to data.

Using the OHDSI project as a catalyst to expand secure medical and health research

A key strength outlined above is Korea's research community and infrastructure. This was exemplified when the Ministry of Health and Welfare and HIRA established and securely shared de-identified COVID-19 personal health datasets for international research that yielded over 40 scientific papers improving the global understanding of this new disease and possible treatments. This project relied on the global OHDSI project and all data were re-coded to the aforementioned OMOP Common Data Model (CDM) and the federated distributed analytics platform of HIRA provided secure and privacy protective access to data. Included in the initiative were HIRA benefit claim of COVID-19 cases, DUR data and confirmed case data from the KDCA.

The OHDSI platform, with the data from HIRA within it already, has a great potential to improve research and monitoring of health care quality and health system performance. For example, through OHDSI, the Korean data at HIRA and American EHR data have been used to understand that a new drug which was more expensive and increasingly being prescribed was no more effective in real world patients than an older drug (Ticagrelor vs Clopidogrel) for patients with acute coronary syndrome (You, 2020[30]). HIRA alone, and in partnership with OHDSI, could conduct a wide variety of similar studies and the results could support revising care guidelines, rewarding better care paths and reducing costs in the system.

With such world-class data and research opportunities, it would be possible to attract talented people to HIRA and NHIS, who will engage in big data analytics and software development. Appropriate career paths for these data scientists, perhaps among all of Korea's large health data organisations would need to be developed to retain these data scientists. Further, it is important to consider that within a partnership such as OHDSI, Korean national organisations (HIRA, NHIS and KDCA) can work with talented researchers in

hospitals and in academic and for-profit organisations in Korea and around the world, and the opportunity for building research collaborations should be more fully exploited to benefit Korean society.

Further, Korean hospitals are partners in OHDSI and the number of participants has reached 40 tertiary hospitals in 2021. For HIRA to act as full partners in OHDSI who can access Korean and foreign hospital data, it will be essential build trust between HIRA and Korean health care providers.

There is a further technical issue that is limiting access to data in Korea through OHDSI. Internal computer system of HIRA has to deal with massive data collected from nation-wide, which could cause server performance degradation. Initially, server upgrade and data optimisation could enhance access. Another alternative could be building a Cloud system. As was discussed in Chapter 2, eight OECD countries are planning to process and store EHR data within a secure national cloud, including Korea (KHIS).

Lack of trust and social license are barriers to an integrated health information system in Korea

Trust is essential to the development of an integrated health information system that will meet the needs of Korean society. Concerns were raised by experts consulted that there is a need to rebuild public trust in the exchange of data among health care providers and between providers and national health data organisations and the government. Further, there is a lack of trust between health care providers and the government and even a lack of trust among national health data organisations that limit the possibility of progress toward secure and privacy-protective data exchange and integration to serve the public interest.

Concerns of civil society

There are concerns of civil society that the development of medical innovation and research would be at the expense of personal data privacy and would lead to an expansion in for-profit health care. There is a general feeling among civil society groups that government policy prioritises the needs of businesses and industries ahead of the needs of people to have their privacy rights protected and to have health data used to serve the public interest. Further, civil society is concerned their personal health data are being commercialised and that the government has not been proactive in the development of data uses that produce a direct public benefit. Technically the infrastructure for data exchange and telemedicine is ready but social concerns must be addressed first. Social license to expand the exchange and use of health data is needed. The creation of a national health data governance framework following the OECD recommendation on health data governance will be very important to begin rebuilding public trust.

Before COVID-19, telemedicine was not legally permitted in Korea. Telemedicine was temporarily allowed during COVID-19. Society (patients) are not objecting to telemedicine. However, there is a general concern in Korea that the private sector will use telemedicine to take over the provision of health care. There is a distrust of large corporations. The Digital New Deal raises furth concerns among civil society groups that the medical sector will be absorbed into large corporations.

Civil society is concerned that private health insurance will take over public insurance and there will be further privatisation of the health sector and profit seeking. This is strongly opposed. There is a concern that for digitalisation and telemedicine to grow and have a positive impact, the government must concede to greater privatisation and involvement of industry. Civil society also is concerned that private insurers will use the data against them regarding client selection and underwriting.

Civil society groups further oppose the exchange of clinical data due to concerns that data governance is inadequate and there will be data breaches and misuse. In particular, patients are concerned that their health data that has been de-identified may be re-identified through statistical matching and that because

the Resident Registration Number (RRN) is in widespread use, once the number has been re-matched to the data then there is the potential for a wide array of data to be linked to health data.

Civil society groups indicated that the public would support the safe exchange of data among health care providers through enabling patients a choice to consent or not consent to the exchange of their own data; and where there are safeguards and security to protect data that are exchanged. Consumers also want transparency through public information about the exchange of medical and health data and about the safeguards and protections for patients and their data when data are exchanged. Patients are concerned that they have no voice in the utilisation of their own health data for research and are excluded from participation in the creation of treatment data for research. Patients with chronic conditions are interested in new data-driven technologies, such as AI algorithms and e-consultations but some are concerned to share their data for research because of the concerns summarised in this section.

A particularly troubling concern of civil society is that when national health data organisations and health insurance companies engage software vendors to support data exchange, these vendors harvest the personal data exchanged and may use or sell these personal data without consent or legal authorisation to do so. There is no compensation for the victims and only minor fines for the corporations who have violated the law which don't create a disincentive to the illegal use or sale of the data. Cases where software vendors have sold patient data have created public mistrust in public institutions.

Concerns of health care providers that restrict data sharing

There are several areas where a lack of trust between health care providers and the government is limiting progress in health data sharing and use for the benefit of the public. These tension points need to be discussed and productively lessened for health care providers and national organisations responsible for health data, such as HIRA and NHIS, to work together to reduce inefficiencies/overlaps in care provision within public and private insurance and to develop and communicate about a framework for health data governance that meets the needs of all stakeholders within the health information system.

Providers indicated they do need to modernise their IT architecture and adopt common global standards for data exchange and terminology. There is a concern in the short-run that the IT system upgrade costs will not be affordable for them unless there is support from the government. There are highly customised and unique EMR systems that may require a significant upgrade to be able to exchange standardised data.

Health care providers are interested in AI tools and digitalisation to improve patient care and health outcomes but they also are concerned that data are safe and secure when they are exchanged for treatment or research uses. In particular, providers are concerned that if they did routinely exchange data with one another that they would be responsible for data breaches/leaks and face a public backlash that would hurt their reputation and business.

Providers cite concerns over loss of autonomy and income

Providers have concerns about the scope of data sharing envisaged within the My Health Data PHR project. If data from private health insurers are standardised and integrated with NHIS/HIRA data then there will be greater opportunity to measure and compare the performance and outcomes of private and public health care services. There is a concern that the introduction of standards and mechanisms of data exchange that are proposed by the government will diminish the diversification of medical care and treatment methods that could be provided to patients (particularly privately insured services) and will harm physicians economically. For this reason, private sector health care organisations/providers are reluctant to share financial data with public agencies such as HIRA and NHIS, particularly financial data within the records of private health insurance providers.

Further, health care providers and private health insurers resist the disclosure of the prices that are being charged for uncovered services (services outside of national health insurance). Health care providers may

also be reluctant to share data because they view their data as a business asset, that is a private good to generate profit from its use and sale. Providers also resist exchanging data for fear of losing patients and thus market share to other, larger hospitals.

To build trust, dialogue is needed between the MoHW, NHIS, HIRA and health care providers regarding the scope of NHIS/HIRA's work and the governance and protection of the data. Discussion among all stakeholders in the health information system regarding the benefits of digitalisation and data use and appropriate governance and data protection would further support building trust of health care providers that health data development and use will serve the public benefit, improving health care quality and outcomes. Such dialogue has been made more difficult recently due to a government policy to place CCTV cameras in surgical rooms to monitor surgeons. This policy disrupted discussions between the Korean Medical Association and the government regarding reforms, particularly the adoption of telemedicine and remains an obstacle to productive dialogue.

Limitations in mandates and misaligned incentives also limit collaboration and data integration

The mix of policies, laws, and mandates within the Korean health system, overall, act as a barrier to creating the data infrastructure needed for a learning health system. This concerns the way the national agencies operate, as well as the policy framework for health care delivery.

Fostering more collaboration among national agencies

Korea has rich public sector health data thatx could be linked and integrated to realise the benefits of a digitalised and timely data to improve patient experiences, health care quality and outcomes and provide timely and relevant information for clinical, managerial and policy decision-making. To move forward, it will be essential to examine the mandates, incentives, resourcing and cultures of the key national organisations responsible for health data in Korea that limit collaboration and create inefficiencies and duplication of effort regarding data processing and data governance.

However, some authorities and resources are insufficient. Further, there are legal and administrative barriers to collaboration between HIRA and NIHS and between these two agencies and other key national agencies and organisations that are stakeholders in the health information system, such as KHIS, KDCA and KOSTAT that make it very unlikely that further development of a learning system will occur over time within the existing system. Further, legitimate concerns of the public and health care providers that are unaddressed by government action, foster distrust in the intensions of government and national agencies that will make progress unlikely.

Current health care funding and governance model does little to promote data exchange and efficiency

The current health care remuneration model encourages more activity and service volume. Funding based on fee-for-service further disincentivises collaboration and integration of care across sectors and settings because the provider is rewarded simply for their input item in the broader care cycle. Not only can this result in sub-optimal patient experiences and health outcomes, but it is also often more expensive. The situation in Korea is exacerbated by the relative lack of gatekeeping mechanisms (as described earlier).

Because care integration also relies on sharing information about patients and processes, financially rewarding joined-up care and outcomes will de facto also encourage the sharing of information about patients' health and their care. Funding reforms are therefore an integral part of creating an environment

where data linkage and exchange makes financial sense. The business case will strengthen if collaboration is rewarded.

Experts interviewed also raised concern about incentives. In the absence of financial incentives for data interoperability, the benefits of data interoperability and integration mainly accrue to government, researchers and health insurers; while the costs of improving the interoperability of health information systems are mainly borne by health care providers. Government leadership and legislative and policy tools are needed to create the right environment for information exchange and collaboration.

Little incentive for patients to demand co-ordinated care

Stakeholder interviews suggest that patients often do not mind repeating tests or investigative procedures (necessary because of the lack of interoperability) if the co-payment is low. This creates a lot of unnecessary activity that is not only inefficient and wasteful, but also introduces unnecessary risks to patient safety.

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Note

[1] Anecdotal evidence suggests that this trend has been accelerated by the introduction of fast trains that have eased access to metropolitan centres where these hospitals are mainly located.

4 Towards an integrated health information system in Korea

Korea has many of the building blocks in place to develop a health information system that supports a learning health system that meets the needs of the 21st Century, however the current health information landscape remains fragmented. This chapter recommends seven requirements that can support Korea in the transition to becoming one of the highest performing health systems in the world. Central leadership and a national health information strategy are necessary and should include greater harmonisation of clinical and health data, an enabling legal and policy framework, building trust and fostering collaboration among key stakeholders, and developing a hub as a single entry point for secure data access.

A modern, learning health system utilises health data effectively to create a continuous cycle of improvement through reflection, adjustment and evaluation. The same real-world evidence (RWE) that supports a learning health system and the provision of value-based care, also supports medical and health innovation, including the development of drugs, medical devices, tools and apps. Thus, investments in a learning health system yield benefits for society and the economy.

Korea has many of the building blocks in place to develop a health information system that supports a learning health system that meets the needs of the 21st Century. This report has described how personal health data, as well as other data relevant to health and well-being, are managed, exchanged, and deployed to advance policy objectives in Korea including service improvement, better public health, research outputs and innovation. Despite some considerable strengths and advantages, the current health information landscape in Korea remains fragmented is some aspects such that further reforms and developments are deemed necessary to enable Korea to create a learning health system. These are related to the legacy of past regulations, policies and organisational structures, as well as to current approaches to health data project planning and investment. Further there is a need to strengthen public trust in a learning health system through investment in a trustworthy system that meets reasonable expectations for data protection and security.

This chapter recommends seven requirements that can support Korea in the transition to becoming one of the most successful and high-performing health systems in the world. The requirements are based on two pre-requisites: 1. a mindset that sees data as a public good and a resource that can be harnessed to advance the health and welfare of the Korean people; 2. Establishing trust among all stakeholders, and including public transparency about the availability, uses and benefits, and protections of health data. This needs to be embodied in a national health information strategy that must be developed inclusively and be trusted by all stakeholders.

There was a clear consensus from the interviews conducted for this study that there is not yet such a strategy or roadmap in place for Korea to achieve the integrated health information system that is needed to support a learning health system and fulfil other policy objectives. A range of policies, regulations and enabling legislation will be needed to implement the national strategy. Technical infrastructure and standards will need to be implemented. An overarching governance framework will be required, including greater harmonisation of data privacy and security policies and practices.

The requirements include a new or existing national organisation to act as a hub for efficient and fair access to, and uses of, health data for the public benefit. This would greatly simplify the convoluted arrangements currently in place, enabling medical and health research and innovation as well as the development of information to advance public health, health care quality and health system performance. A single hub would also foster greater co-operation among stakeholders in the health information system and ensure that health data uses are trustworthy.

Experts and stakeholders expressed a high level of interest in improving health data standards, and secure data sharing and uses but those interviewed faced constraints from their existing mandates, legislations and resources. This suggests that that the data integration Korea will need for the 21st Century will not occur without the leadership of the Ministry of Health and Welfare.

Building trust among stakeholders and the public

The national strategy for a learning health system will steer Korea away from the current situation of data silos toward an integrated system where secure data exchange, linkage and secondary uses are the norm. The strategy should modernise data development, exchange, management, and governance and it will require a change management approach that builds trust among all stakeholders and the public. Some examples of the activities involved include the following:

- Consult with governmental agencies about their needs for information, analytics and information products.
- Consult with non-government stakeholders especially patient groups, regions and municipalities, provider organisations, health professional groups, insurers, academia, biomedical industry and software vendors.
- Develop and implement a public information campaign, public consultations and other avenues for public input into the strategy.
- Conduct public consultations at all stages of development of the national health data governance framework and provide public information, such as a website, to disseminate information about the development process and its outcome, as part of the national strategy.
- Launch a campaign with communication experts to promote a dialogue with the public about the benefits of data sharing and exchange, with the goal of valuing health data in Korea as a public good (see below).
    - This public dialogue must assuage public and stakeholder concerns about privacy risks and reassure them by clearly communicating about how privacy will be protected when data are used.

Adequate resourcing of these activities will be critically important. This means allocating sufficient time and resources to consultation with stakeholder bodies and the public at all points in the development of the strategy, so that progress from a draft strategy to a final strategy to roadmaps and implementation will feel natural, expected and safe. It will be essential to build trust with the public and with health care providers by ensuring that obstacles to constructive dialogue are addressed first or, at least, there is a public commitment to address them. These include tension points discussed in this report (perception of privatisation of the health system, health care professionals' mistrust of government, weak data privacy protections, and illegal uses of personal data that are not adequately penalised). The following Box 4.1 contains some additional information on building trust.

Box 4.1. Building trust

Building trust among stakeholders and the public is an important aspect of health data governance and an effective data infrastructure. A lack of trust will undermine efforts to exchange data for primary and secondary purposes.

First and foremost, trust is achieved through actions not words. Rhetoric must be matched by visible acts and changes to the status quo. It is a challenging process. While trust is established over a long time (years not months), it can be lost very quickly.

Any campaign to establish trust (and it should be approached as a campaign) should be based on transparency and inclusion. All stakeholders need to be part of developing and designing the change – in this case the strategy – from the beginning. Consultation on the finished product, developed by experts, will not achieve this. An iterative consultation process on the national strategy comprising 2 to 3 steps may take longer but will ensure people trust the finished product because *inter alia* they will have a sense of ownership and are invested in its success.

Transparency is key for establishing trust and for maintaining it. Key decisions, challenges, problems and resolutions should be communicated, and lines of accountability made clear. Successful countries have created public websites where people can access information about the strategy and everything concerning health data, its use, how it is managed and secured, how privacy is protected as well as the outputs of various programmes and projects that use personal health data.

Using health data to serve the public interest should be framed as an opportunity, not a risk. The long list of benefits should be explained in detail, using real-world examples. Every stakeholder group should be made aware how the changes will benefit them. For example: patients stand to receive modern health services, higher quality care and access to better, safe treatments; providers will have better data and information to improve practice and deliver high quality care; public health officials will have timely and complete information about infectious disease outbreaks, real-time data on vaccine safety and effectiveness, granular data to guide policies for managing NCDs; payers stand to access more detailed information on health care activity, costs and outcomes; policy makers will be better able to assess how the system performs and regulate it more intelligently; industry will have a tremendous resource to spur invention and technology; and society will benefit from an innovative and agile health sector that not only delivers the best possible outcomes but attracts investment and contributes to economic growth.

This way, the conversation can shift to a more complete view where NOT using data is a risk health and prosperity, and the discussion becomes how this can be done safely and securely. It is therefore crucial to be upfront about privacy, how it is secured, and how problems or failures are resolved. In fact, transparency is critically important when things don't go to plan. Nothing destroys trust faster than bad news being hidden. Equally, timely and clear communication about how past problems have been resolved can have a reassuring effect.

Finally, public education and PR campaigns need to be intelligently planned and rolled out. Engagement of professional expertise from advertising and communications are advised. Prominent "champions" and thought-leaders from various walks of life should be co-opted to be part of the campaign promote the strategy. Alongside health and data science experts, it can be helpful to employ public figures (actors, musicians, footballers) to communicate the message. Getting the PR campaign wrong can have consequences. In 2014, the United Kingdom mailed out paper pamphlets to inform the public about health data governance under the care.data project. The campaign failed to get the public's attention and when public concerns about care.data arose later on they included the reaction that public consultation and communication about care.data were inadequate.

Source: OECD (2015[1]), *Health Data Governance: Privacy, Monitoring and Research*, https://dx.doi.org/10.1787/9789264244566-en.

Central leadership will be needed

Central leadership means that a central ministry, such as the MoHW or a new authority or agency designated by it, would oversee the development and implementation of the national strategy and its components outlined above. It would develop campaigns and tools to improve public transparency about health information, information governance and public benefits from improvements in health information. It would also develop and maintain analytics products and dashboards for ministerial policy making and reporting, and evaluate and publicly report on progress in the implementation of the national strategy.

It would need to facilitate progress in policy and legal reforms to support the on-going development of an integrated health information system, and co-ordinate planning and funding of health information projects within the ministry to align them with the strategy. This would include continuous or periodic review of planning and funding of health information projects within the ministry to ensure they align with and contribute to the strategy and do not detract from or create disincentives to advance the strategy.

Perhaps most importantly, the MoHW would need to ensure that the transition to, and maintenance of, the new arrangements across all levels of the system are adequately and intelligently resourced.

Several key competencies would be required to achieve this:

- Strategic planning of health information projects,
- Evidence-based indicator development and policy analysis,
- Informatics (IT architecture, data exchange standards, semantic interoperability),
- Health data science (statistical and software development competencies, interoperability of analytics),
- Legislative frameworks,
- Privacy-by-design (privacy protection, data security and related information technology competencies), and
- Public consultation and communications/public relations.

Developing a national health information strategy

A central authority such as the Ministry of Health and Welfare (MoHW) or an appointed authority should lead the development of a national health information strategy. The ministry must be supported in developing the strategy by experts, particularly external experts in health data informatics, data interoperability and health data science, as well as external experts in “privacy-by-design” approaches to health data governance.

MoHW has already laid out several important initiatives including the first Comprehensive Health Insurance plan, adoption measures for My Healthway (February 2021), a road map for health data standardisation (April 2021), and innovative strategies for health data and AI (June 2021). A national health information strategy could tie these and other initiatives together into a coherent framework.

An important part of the strategy (and the need for central leadership) is to rationalise the functions, and improve collaboration among, the relevant agencies: HIRA and NHIS as well as KDCA, KOSTAT and KHIS. This report has identified that the current institutional arrangements are characterised by overlap, duplication, and inconsistent approaches to managing and using health data. This is not only wasteful and inefficient but creates a major barrier to a learning, high-performing health system that uses its data efficiently, intelligently and securely for a range of purposes.

Internal support will be needed to build a team to take the lead. The ministry could consider creating a new unit or separate authority/agency that engages or seconds experts in health information systems, health

data science and informatics and health data governance. This expertise will be essential to ensuring an effective national strategy is developed and implemented.

Another key issue will be to have the right input in terms of technical, IT, policy, and legal expertise to develop a worthwhile and trustworthy strategy. Stakeholders will then be more at ease and comfortable to share their needs, their constraints, and their hopes for the strategy.

Alignment with a national digital and data strategy

The national strategy for a learning health system should align with the broader policy frameworks to build a digital society (such as the Digital New Deal or subsequent strategy). In fact, most countries that are successfully digitalising their health systems have a national digital strategy – and data governance – that encompasses all areas of public policy including health. Estonia, for example, decided over two decades ago to become a "digital society" meaning that 99% of public services, including health care are accessible virtually.[1] This has paid not only immense dividends during the COVID-19 pandemic, enabling the country's health, education and welfare systems to continue to function as normal, it has also promoted technological and policy advances in privacy and digital identity, made Estonia into Europe's top entrepreneurial hotspot according the World Economic Forum.[2]

The advantages of a cross-sector approach are particularly strong in the health arena given the value placed on privacy and security, the key role of non-health data (which can greatly enhance knowledge-generation), and the fact that health data infrastructure make a country more attractive for investment of biotech capital.

A legislative framework and supportive policies

Legal authority will be needed to authorise and finance the national strategy and its implementation. Legal reforms are also needed to bring the health data governance law within Korea closer to the OECD Recommendation on Health Data Governance which aligns with the *EU General Data Protection Regulation* (GDPR) (OECD, 2019[2]).

The OECD Recommendation calls on countries to implement a national health data governance framework and sets out the principles for the development, content and evaluation of the framework. Implementation of this framework may require legal reforms or the publication of guidelines to ensure that all stakeholders in the health information system have a common understanding of their roles and responsibilities with respect to health data development and use and privacy and security protections. The national data governance framework should emphasise privacy-by-design and adherence to FAIR principles, that is that data are findable, accessible, interoperable and reusable.

Areas for potential legal reforms noted in this study include a revision to the *Data Protection Law* to enable national agencies who are already trusted to collect and process health data to be legally permitted to link data between them for legitimate purposes within the health-related public interest. Further revisions to privacy law should strengthen safeguards to protect data privacy and security, such as requiring data pseudonymisation and having penalties for data misuse that discourage illegal data uses that have damaged public trust.

A unifying policy framework is also necessary that will support a learning health system. Different bureaus within the MoHW are developing policies and funding projects that will affect the health information system and this needs to be co-ordinated within the MoHW; as well as the need to establish greater co-ordination among national agencies who have their own health information projects. Further co-ordination is needed at the whole of government level as other ministries are also funding health information projects for purposes of scientific or economic development.

Enabling the National Health Insurance Institutions (NHIS and HIRA) to collaborate with each other and other agencies

HIRA was launched to be an intermediary between the National Health Insurance Service and health care providers, to protect health care providers from any potential unfairness that might have arisen from the consolidation of numerous insurers toward a single public insurance system. This role as a fair and objective intermediary (honest broker) could be strengthened by ensuring both legally and in its funding that HIRA is fully independent of NHIS and the government and focussed upon health care improvement for the benefit of all of the stakeholders in the health information system.

To fulfil this role, and to operate at arm's length from the government, the governance of the National Health Information System would require representation of all key stakeholder groups in the health information system, especially patients, consumers, health care providers, health care institutions, governmental agencies and businesses that contribute to and depend upon the health information system. It is critical that a learning health care system is jointly developed with patient groups and providers.

Reporting of data on quality and safety developed from enhanced data collection and information systems should be shared with the public and with the NHIS and the government only after development, testing and evaluation conducted by the HIRA governing board. Testing would build trust and confidence in the value, usefulness and accuracy of reporting tools among patients, the public and health care providers.

The range of data that could be linked and integrated to realise a learning health system would need to be expanded to include:

- EMR data, particularly lab results, and imaging results
- Data related to patient outcomes such as present on admission (POA) flags, Patient-reported outcomes (PROMS) and experience (PREMS), and clinical outcomes
- Environmental, behavioural and socio-economic characteristics of patients
- Private insurance claims and uninsured health care services.
- Patient Registry

Where such data are already available within other national governmental organisations, such as the data held by the NHIS on medical check-ups, long-term care and home-care benefit claims, and social care data, they should be securely shared with HIRA to be linked to HIRA data holdings for the purpose of improving the Korean health system for the benefit of the Korean people.

Organisational changes at HIRA would also help to both minimise the burden of reporting born by health care providers and maximise the clinical value of the quality registries HIRA would be supporting. The real-time microdata HIRA collects currently from health care providers for the purpose of adjudication of health care insurance claims must be integrated with real-time clinical data to provide real-time clinical care quality and safety monitoring that is useful for health care providers and supports the continual improvement of patient outcomes and health care workplaces.

The current process of duplicative data collection, with a separate and non-real time data collection system for the assessment side of HIRA, should be phased out to improve the current process with quality indicators on the assessment side lagging health care events by several years.

Instead, the collection of real-time data from health care providers should be based on the collection of clinically relevant and timely data for a full monitoring, reflection and evaluation cycle of improvement of the health system. Priority should be given to designing a data collection and reporting system that provides high quality and timely information supporting decision making of different stakeholders including clear provision of information to consumers about the quality of health care services, useful and valuable information within clinical workflows to support clinical decision-making, and useful and timely dashboards

for health care organisations and for the government to support continuous improvement, organisational planning, policy planning and evaluation.

Promoting a "win-win" mentality on cross-agency collaboration

The importance of data to support public health policy decisions in real time has been made clear to all OECD countries because of combatting the COVID-19 pandemic. The focus of planning within the OECD, the WHO and the European Union has turned to examining the data flows needed to be resilient to future public health emergencies from multiple sources including environmental, radiological, biological and other threats. The integration of patient-level health care data within HIRA with NHIS data on medical check-ups, KDCA data on COVID-19 cases and international travellers (ITS), and KOSTAT data on mortality provided a powerful tool for policy planning and management of the pandemic. It also provided a basis for global research into the pandemic and potential treatments.

Such data integration and timely exchange among HIRA, NHIS, KDCA and KOSTAT will be essential to creating a learning health system that includes the surveillance, evaluation and improvement of health outcomes of patients with infectious and chronic diseases. Such surveillance is part of the mandate of the new KDCA, but its mandate cannot be fulfilled without data exchange and integration with the data collected by the other agencies.

However, at the present time, negotiating data sharing agreements among national agencies where data linkage is necessary has been very complicated and resource consuming for all national agencies. Further, where national agencies do not see the exchange and data linkage as a specific win-win for them, they may not engage in negotiations or may drag out work over a long period of time.

Moving forward, it will be essential to incentivise co-operation among national agencies toward a common shared goal of developing a learning health system that improves the outcomes of patients and the effectiveness and efficiency of health care services. Data held by NHIS and HIRA could be linked so that HIRA data on prescribed medications, for example, integrates in real-time with data within NHIS on patients' socio-economic characteristics; or HIRA data on health care pathways could be linked with NHIS data on long-term care patients.

Reforms are needed to encourage the large health data custodians (HIRA, NHIS, KOSTAT and KDCA) to collaborate and to link and integrate data in a secure manner to advance the health-related public interest and to improve the coherence and usability of personal health records for the public. These changes must ensure that data linkages among agencies the government has deemed trustworthy can be undertaken in a privacy protective and efficient manner. In this context, a single entry point (or health data hub) for accessing linked data would benefit all stakeholders and is proposed later in this chapter.

Integrating the KHIS within the Korean health data infrastructure

A first-rate health data infrastructure and information system in Korea will require change of the KHIS remit to cover secondary uses and, as described in the previous section, greater collaboration with other key actors.

Global standards for data exchange and semantic interoperability, administered and governed by KHIS, must include privacy-by-design protections, particularly federated learning (distributed analytics) building on the recent experience of HIRA with OHDSI. Standards should include interoperability in analytics, information and knowledge and foster the broad adoption of the OMOP common data model (CDM), building from recent investment of the MoHW to code some data holdings within HIRA, NHIS, the National Cancer Centre and KDCA to OMOP CDM and recent investments of the Ministry of Industry to code data within private hospitals to OMOP CDM. The standards should Include lifecycle interoperability to ensure

analytical uses of historical data as the information system evolves (i.e. ensure health trajectories and longitudinal data analysis are supported).

As has been discussed throughout this report, clinical data are an integral part of a learning health system and make a fundamental contribution both directly and indirectly to health care quality and safety, value-based health care, public health surveillance and to biotechnology, medical and life-sciences research and innovation. These objective encompass primary and secondary uses of EMR data. The KHIS, however, has no mandate for considering secondary use of these data, or the contribution of the OMOP Common Data Model to realising intermediate goals for clinical data interoperability, nor how it might be used to, for example, realise a personal health record years before all health care institutions are conforming to national clinical data terminology and exchange standards. Further there is a role envisaged for KHIS in providing health information governance, but it would not be possible for KHIS to fulfil such a role without close collaboration with the other national agencies responsible for health data. The KHIS should therefore be involved in developing and implementing a learning health system, as all key stakeholders should be.

KHIS should be supported to achieve its long-term goal of supporting secondary use of clinical data and R&D in the medical field, and to build a legal basis which would enable KHIS to collaborate with all stakeholders in health information system.

Supporting and incentivising data quality and exchange

To complement laws and policies, funding and financial incentives will be needed to encourage compliance with national data standards, for demonstrating (verifiable) data interoperability, for launching a modern health data hub (see below) and to ensure national agencies responsible for health data have the resources needed to support greater inter-agency collaboration to realise the strategy.

This will require a review of government funding and financial incentives related to the exchange and use of health data, including research projects funded by government ministries. It may also require explicit financial incentives to encourage health care providers, national agencies responsible for health data and other actors to move to certified IT solutions and succeed in achieving verifiable interoperability.

Currently, the Korean Government plans call for financial incentives to EMR software vendors to adopt national standards for data terminology and exchange and to health care providers/organisations who demonstrate they are using an EMR that conforms with national standards.

Current plans for financial incentives to adopt standards for clinical data content and exchange have not included funding for the transition costs that may be faced by health care institutions as they convert from their existing system to the new standards. Concerns were raised in this study regarding the costs for infrastructure, such as upgrades to software, hardware and networking, and softer costs related to staff training and lower productivity during the transition. These up-front costs may be too high for small clinics and hospitals to self-fund and therefore they may not be able to convert, despite the attractiveness of the incentive payment.

The MoHW should also evaluate how plans for broader reforms to health care funding and remuneration that reward care co-ordination and value-based care would affect the design and functioning of the learning health system.

In short, this will include the following requirements:

- Provide needs-based funding to hospitals and provider organisations for transitioning their local data systems and infrastructure to an agreed national format and standard.

- Institute incentives for verifiable interoperability and meaningful use of health data including auditing data quality, interoperability and privacy and security protections AND successful and consistent provision of data to authorised agencies (in addition to KHIS certification process).
- Together with stakeholders, develop a fair and balanced method to sanction and penalise lack of compliance, comprising financial and other levers.

"Pay-for-data" schemes can have negative unintended consequences

Paying organisations such as hospitals an explicit financial reward to provide data to agencies such as HIRA has outward appeal. Learning from experiences in other OECD countries, financial incentives for data exchange are insufficient because they do not incentivise data quality, completeness and usability. Demonstrating verifiable interoperability would include incentive payments, funding or accreditation that is conditional upon passing data quality checks and passing thorough (random) data quality audits, as well as meeting national requirements for data privacy and security protection (see also the next section). As was reported in Chapter 2, 13 countries reported in 2021 that the electronic clinical records of physicians, medical specialists and hospitals are audited to verify quality.

Pay-for-data schemes can be problematic. For one, it frames the exchange of data in transactional terms as opposed to a collaboration that is not only mutually beneficial but also extends benefits to patients and to society. Second, paying for data implies ownership and signals to providers that they could be paid for a data point every time it is used. This not only goes against the concept of health data as a public good and a resource to increase public welfare (see Chapter 2) but could end up being costly for agencies such as HIRA (while profitable for providers). Unconditional payment does not incentivise providers to ensure data quality, completeness, useability and privacy and security protection, nor does it create a "win-win" where data providers invest in health data quality because the data help them in a cycle of continuous improvement of their patients' outcomes, the quality of their services and their own workplace environment. If the data are viewed by providers as only useful for HIRA, there is no incentive to invest in data quality.

Investing in, and rewarding, verifiable interoperability is preferred. This includes earmarked funding to ensure data that are exchanged are of high-quality (complete, timely, formatted and coded to required standards, and ready for key primary and secondary uses), that the data exchanged are secure and patients' privacy has been protected. Metadata (the who, what, where, when and why of data without the actual data content) plays a critical here because it provides the contextual information needed to put data to use. It makes data findable and verifiable, and is one of the elementsof common a standard format to enable interoperability. Developing data quality metrics based on can support verifiable interoperability, along with an auditing process to provide a detailed review of data quality, interoperability and privacy and security protections.

Legal and policy reforms (outlined above) would ensure that providers and other actors are legally obligated to share and exchange their data with agreed agencies as part of their contractual obligations under the NHI system, with a failure to comply attracting sanction and/or penalties. These penalties can be financial or other, such as exerting social or cultural pressure (e.g. publicly naming organisations that do not contribute data for the benefit of the Korean public).

While financial penalties may appear the equivalent to pay-for-data, a key difference is that they frame data exchange in contractual, not transactional, terms. This is an important distinction because it removes implication of data ownership as well as reducing the temptation to sell data, which could create privacy risks.

"Meaningful use" incentives are a better option

Verifiable interoperability should also include measures of the meaningful use of electronic patient data by health care providers for direct patient care and for the efficient management of their clinic or hospital.

Meaningful use incentives – like those implemented by the US Centers for Medicare & Medicaid Services – could be considered. This US programme provides financial rewards to health care providers who use appropriate EHR technologies in demonstrated, meaningful ways (as opposed to simply paying for provision of data to a third party). Meaningful uses could include, for example, providing contributing towards a public reporting initiative on health care quality or outcomes throughout Korea.

A single entry point for secure data access

OECD countries are increasingly providing a unique entry point for access to all public sector health data. The unique entry point could be through an expanded mandate of an existing national organisation or through the creation of a new organisation. This "health data hub" has a primary aim of improving access to health data for uses that are within the public interest while protecting data privacy and security. Consider the examples of such access points presented in Chapter 2 such as the French Health Data Hub, Findata in Finland, the Australian Health Dataplace and the new European initiative to encourage Health Dataspaces in all EU countries.

The current arrangements in Korea for accessing data for secondary uses are fragmented. To create a world-leading data infrastructure as a basis for a learning health system, this must be consolidated into a one-stop-shop for secure access to various health data from a variety of sources outlined in Chapter 1, Figure 1.1. Such consolidation would simplify the process for researchers and other secondary users of Korean health data, and enable secure, record-level linkage of all relevant datasets to create valuable knowledge. It would make access to data for research and other secondary purposes in Korea more secure, more efficient and easier. Further, it would make public sector health data collection, data use and data protection more fully transparent to the public and to the research community.

Data do not need to leave their location to be useful

Importantly, this would not require all data to be copied, transferred, or held in one place or repository because it is now possible to perform complex analyses across a distributed or federated network. Under this approach, data always remain with their custodians. Only queries (research questions), and the aggregate results or results of statistical modelling are sent back to the researcher (via the "hub") who submitted the query.

Recent advances in analytics have meant that, in terms of statistical power, there is virtually no disadvantage in this approach. Modern data science has ensured that this approach is equivalent to analyses of data as if they were aggregated in one place. For example, the OHDSI initiative applied Cox Proportional Hazard regression across a federated structure without accessing the patient-level data in a Korean study comparing two drugs used to treat acute coronary syndrome (You, 2020[3]).

However, the precondition of a distributed network is that all data sources have already been coded to the same Common Data Model (such as the OMOP CDM which Korea has already invested in) – again underscoring the importance of data harmonisation and standardisation in a learning health system.

A single hub or entry point would serve as a portal where authorised agencies, organisations or individuals can securely access the data held by participants in the federated network. Obviously, the inclusion of EMR data would be a major advantage in such a federated structure, and (as discussed above) incentives will be required for private providers and hospitals to not only standardise and map their data to common formats, but make their data available and participate actively in initiatives.

The data hub can also securely integrate, link and standardise data to a Common Data Model for analytical applications where integrated data are required, such as the linkage of clinical data, medical check-ups, claims data, and cause of death information. The data within the hub can then be securely accessed by researchers using a distributed/federated network.

The functions of the data hub would include:

- Creation of a national catalogue of all public sector health data
- Support for organisations coding data to the Common Data Model (OMOP CDM)
- Support for researchers applying for data linkages and access to data
- Regular feedback to organisations processing health data regarding data useability, standardisation and quality
- Regular feedback to organisations development standards for health data terminology, exchange and interoperability regarding the data needs of the research community
- Approval (permitting) of applications for access to microdata from multiple national organisations
- Data linkage of microdata from multiple national organisations
- Secure access to microdata through real time remote services, including requests through the OHDSI distributed network
- Data de-identification and pseudonymisation and secure storage of linkage keys
- Public transparency regarding data collection, data linkages and approved projects
- Public transparency regarding the process to apply for and be approved access to data and mechanisms to appeal a decision.

Governance would need to include regular consultation with all of the key stakeholders in the health information system including the key national organisations (HIRA, NHIS, KDCA, KHIS and KOSTAT), health care providers and health care organisations and patients/consumers. The hub would also need to be resourced to provide a timely service with qualified staff and appropriate computing facilities to support research work including software development, machine learning and development of AI algorithms.

There are many benefits of consolidating access to health data under the roof of an existing institution, such as HIRA, NHIS or KHIS. However, one potential drawback is that data linkage and access would not be at “arm’s length” from organisations with direct involvement in the provision or assessment of health insurance or other services. It would therefore be important to ringfence this function from other activities to build trust among the stakeholders (especially provider organisations) and clarify that the purpose of health data linkages and uses are to serve the public interest in better health, high quality health care and in privacy protection and data security.

Inclusion, engagement and leadership will determine success

More important than who is responsible for this hub is that it benefits national organisations as well as health care providers and hospitals, including the provision of data linkage services that meet their needs and provide them with support to grow the research uses of health data without each developing its own full suite of data access services. Again, the involvement of all key stakeholders in its governance would also create the opportunity to engage these stakeholders in a collaborative effort to develop and improve the quality and efficiency of standards for health data terminology, exchange and interoperability for both primary and secondary data uses.

However, a hub alone will not be sufficient to improve collaboration and data sharing among the large national organisations who are processing personal health data. The national strategy must emphasise the importance of secure access to, linkage of and sharing of health data to serve the public interest and include the necessary changes to organisational mandates, legislations and resources to ensure that exchanging data becomes the default position, where the exchange is secure and the purpose of the exchange is to serve the public interest.

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Notes

[1] https://e-estonia.com/.

[2] https://www.weforum.org/agenda/2020/07/estonia-advanced-digital-society-here-s-how-that-helped-it-during-covid-19/.

Annex A. Consultation with experts

The recommendations presented in this report were supported by a series of interviews and focus group discussions conducted by the OECD team with Korean exerts throughout 2021. Initial interview subjects were identified by HIRA personnel. These interview subjects recommended other experts for the OECD to consult. The OECD continued interviews until the information gathered from key informants began to share similar messages expanding our understanding of the data landscape and recent innovations in Korea.

The OECD thanks and appreciates the contributions of the following experts whose insights, experiences and aspirations informed the development of these recommendations.

Table A A.1. Experts interviewed either individually or in a focus group

Name	Position	Organisation
Jang, Yong Myung	Director of Benefits Management	HIRA
Kim, Nam Hee	Director of Review and Assessment	HIRA
Kim, Min Sun	Department Director, ICT Strategy Department	HIRA
Park, Han Jun	Department Director, Big Data Department	HIRA
Park, Young Hee	Department Director, Review and Assessment Innovation Department	HIRA
Jang, In Sook	Department Director, Benefits Strategy Department	HIRA
Shin, Yun Gy	Division Director, Review Information Standardization Division	HIRA
Kim, Kyoung Hoon	Division Director Director, Review and Assessment Research Division	HIRA
Kwon, Ah Young	Division Director, Quality Assessment Department Division	HIRA
Lee, Mi Jung	Deputy Director, Quality Assessment Information Division	HIRA
Jung, Yeun Joo	Deputy Director, Medical System Improvement Division	HIRA
Han, Mi Soon	Deputy Director, Review Information Standardization Division	HIRA
Kang, Ra Won	Division Director, Benefits Information Analysis Division	HIRA
Seo, Moon Min	Division Director, Benefits Information Development Division	HIRA
Chung, Seol Hee	Department Director and Research Fellow, International Co-operation Department	HIRA
Koo, Jung Hoe	Deputy Director, International Co-operation Division	HIRA
Oh, Young Won	Deputy Director, International Co-operation Division	HIRA
Son, Mi-jung	Senior Manager, International Co-operation Division	HIRA
Lee, Soo Wan	Senior Deputy director/Division of Health Insurance Policy	MoHW
Kim, Hee Su	Deputy Director/Division of Health Insurance Assessment	MoHW
Cho, Young Dae	Deputy Director/Division of Health Insurance Benefits	MoHW
Lee, Gil Won	Deputy Director/ Division of Healthcare Information Policy	MoHW
Kim, Hyo Jung	Deputy Director Division of Healthcare Data Promotion	MoHW
Kim, Su Jeoung	Professional Advisor Division of Healthcare Data Promotion	MoHW
Nam, Ji Hee	Assistant Director/Division of Health Insurance Policy	MoHW
Kwon, Jeong Nam	Assistant Director/Division of Healthcare Information Policy	MoHW
Jeong, Zip Min	General Manager, Healthcare Standardization Department	Korea Health Information Service (KHIS)
Kim, Yoo Mi	General Manager, Certification Criteria Development Department	Korea Health Information Service (KHIS)
Lee, Ji Young	Deputy Director Statistical Data Planning Division	Statistics Korea
An, Jae Yong	Assistant Director Vital Statistics Division	Statistics Korea
Hong, Su Min	Assistant Director Vital Statistics Division	Statistics Korea

Lee, Won Seog	Assistant Director International Co-operation Division	Statistics Korea
Park, Joon Il	Executive Board Member	Korean Hospital Association (KMA)
Lee, Kye Hwa	Research Associate Professor	Asan Medical Center; The Korean Society of Medical Informatics (KOSMI)
Yoon, Duk Yong	Associate Professor	Yonsei University, The Korean Society of Health Informatics and Statistics (KOSHIS)
Yum, Ho Kee	Professor, President of KoSQua	Paik Hospital, Korean Society for Quality in Health Care (KosQua)
Kim, Soon Seok	Professor	Halla University, Korea Institute of Information Security & Cryptology (KIISC)
Choi, Jung In	Manager	Korea Pharmaceutical and Bio-Pharma Manufacturers Association (KPBMA)
Baek, Young Jae	Expert advisor	Korea Medical Devices Industry Association (KMDIA)
Kim, Mun Gu	General Manager	Korea Smart Health care Association (SHA)
Yoon, Myung	Secretary General	Consumers Korea
Nam, Eun Kyung	Director for Social Policy	Citizen's Coalition for Economic Justice (CCEJ)
Choi, Sung Chul	Executive Director	Alliance for cancer patients
Jeong, Hyoung Sun	Professor	Yonsei University
Kim, Yoon	Professor	Seoul National University
Lee, Sang Il	Executive Director	National Health Insurance Service (NHIS)
Heo, Yun Jung	Professor	Ajou University School of Medicine
Kim, Chong Jai	Chief Research Officer	Asan Medical Center
Kim, Chi Weon	CEO	Seoul Wise Hospital
Lee, Seon Kui	Director of the Division of Risk Assessment and International Co-operation	KDCA
Park, Jae Hee	Employee	Korean Hospital Association (KMA)
Park, Rae Woong	Professor & Director, Department of Biomedical Informatics	Ajou University
Rho, Yeon Sook	Director, Big Data Unit	National Health Insurance Service (NHIS)
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Annex B. OECD Recommendation on Health Data Governance

The work of the OECD to support strengthening health data infrastructure and governance and to protect privacy and data security culminated in the OECD Recommendation on Health Data Governance [OECD/LEGAL/0433], which provides guidance for building national governance frameworks that enable personal health data to be both protected and used towards public policy goals.

The Recommendation applies to the access to, and the processing of, personal health data for health-related public interest purposes, such as improving health care quality, safety and responsiveness; reducing public health risks; discovering and evaluating new diagnostic tools and treatments to improve health outcomes; managing health care resources efficiently; contributing to the progress of science and medicine; improving public policy planning and evaluation; and improving patients' participation in and experiences of health care.

The Recommendation recommends that Adherents establish and implement a national health data governance framework to encourage the availability and use of personal health data to serve health-related public interest purposes while promoting the protection of privacy, personal health data and data security.

National health data governance frameworks should provide for:

- Engagement and participation of stakeholders in the development of a national health data governance framework;
- Co-ordination within government and co-operation among organisations processing personal health data to encourage common data-related policies and standards;
- Reviews of the capacity of public sector health data systems to serve and protect public interests;
- Clear provision of information to individuals about the processing of their personal health data including notification of any significant data breach or misuse;
- The processing of personal health data by informed consent and appropriate alternatives;
- The implementation of review and approval procedures to process personal health data for research and other health-related public interest purposes;
- Transparency through public information about the purposes for processing of personal health data and approval criteria;
- Maximising the development and use of technology for data processing and data protection;
- Mechanisms to monitor and evaluate the impact of the national health data governance framework, including health data availability, policies and practices to manage privacy, protection of personal health data and digital security risks;
- Training and skills development of personal health data processors;
- Implementation of controls and safeguards within organisations processing personal health data including technological, physical and organisational measures designed to protect privacy and digital security; and
- Requiring that organisations processing personal health data demonstrate that they meet the expectations set out in the national health data governance framework.

These 12 principles set the parameters to encourage greater cross-country harmonisation of data governance frameworks so that more countries can use health data for research, statistics and health care quality improvement.

The Recommendation also recommends that Adherents support trans-border co-operation in the processing of health data for purposes that serve the public interest. It further recommends that Adherents engage with relevant experts and organisations to develop mechanisms that enable the efficient exchange and interoperability of health data.

Finally, it encourages non-governmental organisations to follow the Recommendation when processing personal health data for health-related purposes that serve the public interest and invites non-Adherents to take account and to adhere to the Recommendation.

Towards an Integrated Health Information System in Korea

Twenty-first-century health systems will be built around data and information. An integrated health information system enables the secure flow of data to where they can be used to create information and knowledge to advance policy and health system objectives. This report describes the requirements and the benefits of an integrated health information system; outlines the current situation in Korea in the context of progress across OECD countries; and recommends policy and operational changes to overcome barriers to the efficient exchange and sharing of health data and establish an integrated health information system that supports continuous learning, improvement and innovation.

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