1 Key findings and recommendations

Twenty-first century health systems will be built around data and information. Their success will depend on secure exchange and movement of data to create useful information and knowledge that advance public policy objectives. This chapter brings together the key findings of this review of how health data are managed and used in the Netherlands and the recommendations for creating an integrated national health data infrastructure and 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, social care, long-term care, public health and biomedical science. It outlines the strengths and challenges of the Dutch health system in the context of using health data to advance the health and well-being of individuals and populations. It concludes with a summary of recommendations to establish a modern, integrated health information system in the Netherlands.

In January 2021, the Ministerie van Volksgezondheid, Welzijn en Sport of the Netherlands commissioned the OECD to gather evidence and recommend legal, policy and organisational reforms to support creating an integrated health information system to support four key national policy goals:

1. Strengthening integrated health care delivery across settings and sectors (so that an individual's relevant health information can be accessed by them as well as their providers ranging from first responders to general practitioners to hospitals and allied health providers)
2. Enabling comprehensive public health monitoring and management (including of the COVID-19 pandemic)
3. Capitalising on recent innovations in health information infrastructure
4. Fostering research and innovation in technologies and treatments that improve health and health care.

To understand the strengths and weaknesses of the current health information system and to develop recommendations, the OECD, through a series of focus groups and interviews, consulted national experts from academia, business, and government regarding the Netherlands' health information system in January to October of 2021 (See Annex A). The discussions focussed on three questions:

- 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?
- Personal health environment: What are the digital tools that deliver a modern health care experience, provide data access and allow interactivity?
- Organisation and governance: What national institutions and governance mechanisms support a strong and trustworthy national health information system?

The information gathered through consultations with experts was complemented with information on the Netherlands and other OECD countries collected through the OECD's regular monitoring countries' health information systems including: 1. Survey of National Health Data Development, Use and Governance (2019-20), and 2. Survey of Electronic Health Record System Development, Data Use and Governance (2021).

This is the final report and recommendations from the OECD review. The report comprises four chapters. This chapter (Chapter 1) summarises the key findings and recommendations. Chapter 2 outlines the Dutch health system with regard to how its structure, organisation and governance influence the way health and social care data are generated, managed and used to advance the four objectives listed above. It also describes the requirements and the benefits of an integrated health information system where data can be accessed efficiently and securely by actors who need them and those who can generate valuable information and knowledge by using them. It also outlines the current situation in the Netherlands in the context of progress across OECD countries. Chapter 3 examines the main strengths and shortcomings of current arrangements in the Netherlands to manage health and social care data including legislation and policies, health information infrastructure and health data interoperability. Chapter 4 outlines legal, policy and operational changes to establish an integrated health information system. It sets out the requirements to take advantage of strengths and to address the problems uncovered in this study.

An integrated health information system for the 21st century

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 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. While infrastructure is a key element, an information system also includes the capacity to convert raw 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, and predictably.

Every data point has several potential uses

An integrated health information system would help the Netherlands directly improve care quality, outcomes and patient empowerment by enabling patients and their health care providers to access health information (primary data use). The importance of this was recently highlighted in the Dutch media,[1] which reported difficulties with transferring COVID-19 patients between hospitals because their medical information cannot be exchanged electronically. This results in not only delays and inefficiencies – with busy clinicians having to manually transcribe patients' data from the local electronic record to a CD to send with the patient – but also the risk of subsequent medical errors that manual transcribing of information entails.

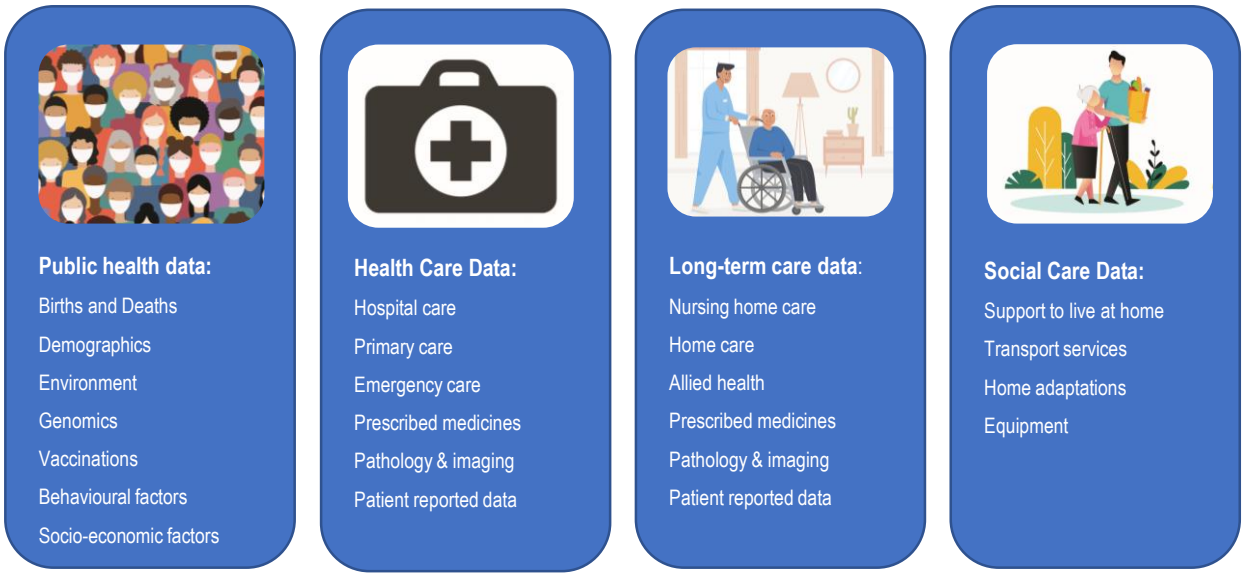
An integrated health information system would also raise the country's capacity to use these data for other important purposes (secondary data use) including:

- Managing health system performance on national, regional and network levels,
- 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, and
- Innovation such as big data analytics and artificial intelligence that will enhance knowledge-based decisions for patient care and health system governance.

This would enable better public health policies and interventions, and health system management. It would enable biotechnology innovation and enable the Netherlands to participate in global health efforts and make the country an attractive destination for capital investment.

A range of data assets is relevant for these purposes. For the Netherlands, this implies data generated during acute- and long-term health care as well as data on public health (publieke gezondheid) and social care (sociale domein) (Figure 1.1). The integrated health information system should cover the health system as a whole as well as drawing on other relevant data sources such as social, economic and environmental data where necessary.

Figure 1.1. Four main types of data in the Netherlands



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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 and that each data point can and should have many uses. Data have many of the features of a public good, and should be harnessed to generated 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 in a highly fragmented and disaggregated health system like the Netherlands.

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 Dutch health system's structure and governance) can be more secure.

Ensuring that data can be exchanged across national borders into Europe 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 the Netherland's research and technology sectors; and is better prepared to participate in and adapt to European regulations and initiatives.

For secondary uses of data (statistics and research etc.) an intermediary solution to improve health data interoperability is 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. 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 patient portal.

A well-designed, 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'[2] 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 as well as enable research and innovation. 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 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. 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, 13 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 8 report incentives for health care providers to install and EHR system from a certified software vendor.

Building on strengths while addressing existing barriers

The Dutch health system has many strengths that can be harnessed to develop a world-class health data infrastructure and information system: strong patient engagement and leadership of patient groups toward data interoperability; progress in developing data exchange standards; Dutch universities and institutions are leading good practice in common data models and technologies enabling large-scale research on distributed data; and a unique 'can-do' culture. In the Centraal Bureau voor de Statistiek (CBS), the country has an agency with the capacity and experience in a privacy-by-design approach to data development, linkage, sharing and accessibility that is secure and privacy-protective (see Box 1.1).

However, the Dutch system also has several fundamental barriers that need to be overcome. One of these is the fragmentation – a design feature that enables competition and market mechanisms to work but that also presents an institutional block to data sharing and exchange. The current Dutch health data landscape is characterised by the highest number of data custodians reported in the OECD. This fragmented structure does not preclude being able to leverage available data to achieve the objectives listed earlier. It does, however, create greater challenges to data sharing and integration than in other countries.

Laws and regulations need to be aligned with policy objectives

Lack of alignment and a common interpretation of legislation and regulations also present a challenge. Data custodians have varying interpretations of laws and regulations such as the *EU General Data Protection Regulation* (GDPR) for example. A fragmented approach to health data management creates (a) missed opportunities to generate improvements in health and other desirable outcomes, and (b) heightened risk of personal health data being compromised. Both a national health data governance framework and guidance on the implementation of the GDPR would help to overcome different legal interpretations that are limiting data sharing in the Netherlands.

A further issue raised by experts in the Netherlands are legacy legislations that precede the GDPR and that may create unnecessary obstacles to the exchange and use of health data. In particular, the *Medical Treatment Contracts Act* (Wgbo) requires doctors to obtain patient consent to share data with third parties. Third parties include quality standards/registers. Under Wgbo, patients are required to provide explicit consent for their records to be included within the Landelijk Schakel Punt (LSP). As a result, the exchange is missing data on non-consenting patients and for patients whose health care provider did not ask them to provide consent. This limits the reliability of the data for direct care or secondary uses.

A new framework law (Wegiz) introduced in 2021 aiming to improve health data interoperability takes a cautious and incremental approach, raising concerns among experts interviewed that full health data interoperability would not be achieved in the medium term. The framework law will likely require additional follow-on administrative orders to authorise the new standards called for by professional groups. Experts interviewed are concerned that the process could be slow and potentially result in conflicting and incomplete sets of standards. However, a recent letter from Minister De Jonge to parliament (15 October 2021) outlines ways in which implementation of the Wegiz is being expedited.

The Wegiz requires that apart from the technical information standards, (addressing the how) a complementary set of clinical content oriented quality standards (addressing the what) are developed and included in the National Quality Standards Register held by Zorginstituut Nederland (ZiN). To evaluate and adopt these different types of standards seems a complex undertaking. Before recommending standards, it will be necessary to evaluate whether health care providers and organisations could conform to new requirements and the evaluation will necessitate acquiring knowledge about the various IT architectures and software in current use including the different structured terminology standards and uses of free text (unstructured data).

Box 1.1. Dutch health information infrastructures with beneficial features

While there are many health data custodians in the Netherlands, three research infrastructures have emerged whose aims and purpose align with those envisaged for the developing EU Health Data Spaces.

The Health Research Infrastructure initiative (**Health-RI**) aims to establish an interconnected data infrastructure for Dutch personalised medicine and health research. Experts interviewed indicate that Health-RI would like to access data within hospital and GP electronic health record systems for approved research projects in real time and use distributed analytics to protect privacy and data security (personal health train).

ODISSEI (Open Data Infrastructure for Social Science and Economic Innovations) provides researchers with access to the data holdings of the CBS, including the micro-data in-flowing to CBS from Dutch Hospitals, GPs, health insurers and research institutes as well as health survey data and information on the health care industry and follows 'privacy-by-design' practices to offer secure data linkage and access to data as well as advanced computing and analytics.

Netherlands leads the **EU EHDEN** (European Health Data and Evidence Network) project. Participating organisations re-code their health and clinical data to the OMOP Common Data Model. 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 health data. Code is shared through GitHub, supporting interoperability of data analytics as well as of data.

Source: Dutch Tech Centre for Life Sciences (2021[1]), "Health-RI", https://www.dtls.nl/large-scale-research-infrastructures/health-ri/; ODISSEI (2021[2]), https://odissei-data.nl/en/; EHDEN (2021[3]), https://www.ehden.eu/.

Many data assets are fragmented and not easily exchanged

The Dutch approach to electronic medical data is perhaps the most striking example of fragmentation. While notable initiatives such as MedMij and LSP are trying to address this, the lack of co-ordination and steering is evident. Experts interviewed described that most health care organisations have engaged software vendors to develop bespoke EHR platforms to specifications that suit their requirements and priorities. In most cases, and in the absence of an overarching national data strategy and governance framework, little attention has been paid to exchanging data. Experts described that many providers are locked into agreements with their vendors, who either limit or charge large sums to retrofit interoperability and exchange capability into their systems.

The situation is likely to continue without legislation, certification and financial incentives to prevent information blocking by software vendors and to encourage software vendors to provide modern IT architectures that support data exchange and analytical uses of data that are in the public interest. This can, in fact, create a level playing field for competition and the market to thrive while advancing public policy objectives.

Meanwhile, information standards developed by either the Nationaal ICT Instituut in de Zorg (Nictiz) or MedMij are voluntary and participation in a data exchange is voluntary. Moreover, multiple institutes are funded by the government to collect data on aspects of health or parts of the health care system. However, funding is not contingent upon collaboration among them and data interoperability among them is not required. Similarly, 'hoofdlijnakkoorden' (outline agreements) between the government and specific sectors such as medical specialists, include agreements on finances and quality but not on data

interoperability. As a result, sectors continue to operate in silos. While the government provides financial incentives to physicians and hospitals to become MedMij certified; certification does not include verification that the data within MedMiJ are interoperable, nor verification that the user experience for patients would meet reasonable expectations. For example, verification of how well health information is integrated and presented to the patient is not included.

In the near term, standardisation of health data could support health care quality measurement and information by mapping/re-coding data from the diverse array of information systems in the Netherlands to a common data model (CDM). While this may not be feasible for health organisations with the most customised and irregular IT systems, it may be possible for most health care providers and organisations holding health data to have their existing data mapped/re-coded to a CDM.

Experts 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.

While many countries are gearing up to use data, including health data, as the fuel to power research and innovation, the Netherlands risks being left behind in this regard unless current deficiencies in data governance, interoperability and exchange are addressed. A recent Open Data Institute report put the Netherlands in the 'limited vision' category for advancing the secondary use of health data when compared with other EU countries (Boyd M, 2021[4]).

The way forward: A cohesive strategy, concerted governance, and strong leadership

The Dutch health system has served the country very well in the 20th century. But the challenges and opportunities of the 21st century are different, and the increasing quantity of generated health data calls for a political choice, legislative guidance and fitting strategic action in order to facilitate ethical and optimal use of this rapidly expanding resource.

The first thing to say is that radical overhaul of the entire health system is not required. However, creating an integrated health information system that meets the needs and opportunities of the 21st century will require a unified national strategy (preferably aligned with a broader national digital / data strategy). It will require a new set of institutional functions to develop, implement and oversee a health data infrastructure and integrated information system, either through a new national agency or by consolidating and strengthening the remit, function, and competencies of existing agencies. Successful implementation will require good governance, policy, and trust among all stakeholders.

The following is a summary of recommended actions to develop an integrated health information system in the Netherlands that are set out more fully in Chapter 4.

Develop a national strategy for an integrated health information system

The Ministerie van Volksgezondheid, Welzijn en Sport **would lead the development of a National Strategy** in the form of a **strategic plan** that considers the data assets and information infrastructure already in place and builds forward from them to develop the tracks and signals that are missing. Developing the plan requires working with stakeholders to determine the objectives of the strategy and the values that the stakeholders want to uphold.

It is essential that the strategy is sufficiently broad and deep. Breadth refers to **incorporating the four main data types: health care, public health, social care and long-term care data**. Depth ensures that

all data are included, and that they can be linked at the individual level to enable better care integration as well as more precision and scope in secondary uses. An important accompaniment to the digital strategy is a set of **roadmaps for each strategic objective**, particularly those that will be challenging to achieve, such as data interoperability.

To lead the development of the national strategy it is recommended that the Ministry:

- Builds trust and support for the strategy through **consultation with governmental and non-governmental stakeholders** on needs for information, analytics and information products
- Builds public trust through a **public information** campaign, public consultations and other avenues for **public input** into the strategy and provide a website to share information about the development process and its outcome.
- Considers developments in the Netherlands toward a **broader digital strategy** and ensure that the strategy for health data will be in alignment with them.
- Develops the **draft high-level IT architecture/infrastructure** for an integrated health information system that meets the information needs of key stakeholders including global standards for data exchange and semantic interoperability, privacy-by-design protections and interoperability in analytics, information and knowledge.
- Develops the **policy tools and financial incentives** to realise the strategy.

The ministry is recommended to further develop and **strengthen the national health data governance legislative framework** to support the national strategy. The framework should specify how to ensure uniform data and interoperability standards, enable the exchange, access to and use of data to serve the health-related public interest, protect privacy by design and align with EU regulations.

A national agency to implement and oversee the health information system

A single agency will be needed to **co-develop and implement the national strategy** with the Ministerie van Volksgezondheid, Welzijn en Sport (VWS) and oversee and maintain the resulting health information system. This could be done by 'strengthening' or combining expertise of existing organisations or creating a new agency.

The ministry is recommended to develop the **role and legal mandate** to launch the agency and to ensure that the governance of the agency provides a **formal involvement of key stakeholders** in the health information system.

1) It is recommended that the national agency take responsibility for four key activities that are essential to an integrated health information system:
2) Agreeing (or developing) and maintaining consistent **national standards** for terminology (semantics), data exchange (electronic messaging), analytics, data accessibility and sharing and harmonisation of data privacy and security policies and practices.
3) **Certification** including for vendors of IT solutions and digital tools for compliance with national standards; and verifying through quality checks and audits that health care providers and other information system actors have achieved interoperability standards and are exchanging useable (quality) data and are not blocking data flow.
4) Building and maintaining a **national public data platform** for public data exchange, acting as a hub through which the data flows. The platform should enable effective and secure processing of personal health data including data integration/linkage; foster adoption of a common health data model (CDM); manage the approval process for data integration and access requests involving data from multiple organisations; enable effective and secure mechanisms for access to personal health data for approved purposes, such as approved research; improving data quality, including

conducting data quality auditing; and reducing overlapping and duplicative administrative and data processing activities among key stakeholders within the health information system.

5) **Stakeholder engagement and public consultation** about the national strategy and its implementation; and **public transparency** about the national strategy and the development, exchange, uses and data privacy and security protections of health data.

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Notes

[1] https://eenvandaag.avrotros.nl/item/gegevens-op-de-fax-of-een-dvd-bij-verplaatsing-van-coronapatienten-wordt-gemis-van-elektronisch-patientendossier-wel-heel-duidelijk/.

[2] 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.