

Executive summary

Twenty-first century health systems have to be built around data and information. An integrated health information system enables the secure exchange and flow of data to where they can be used to create information and knowledge that advances policy objectives. In the Netherlands, an integrated health information system is needed to support developing, delivering and monitoring integrated health care delivery; offering integrated public health monitoring and management, including of the COVID-19 pandemic; capitalising on recent innovations in health information; and fostering research and innovation in technologies and treatments that improve health and health care.

A range of data assets is relevant for these policy objectives. This includes data generated during acute- and long-term health care and data on public health and social care. The integrated health information system should cover the health system as a whole, as well as on other relevant data sources such as social, economic and environmental data.

Countries making progress toward an integrated health information system 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 generate maximum social benefit. To do this, all data must be coded according to agreed technical and semantic formats. It is only in this way that data can be meaningfully exchanged, sent to where they are needed, or analysed.

The OECD reviewed the health information infrastructure in the Netherlands using the [OECD Council Recommendation on Health Data Governance](#) as the analytical framework. It drew information from interviews and focus groups with Dutch experts from academia, business, and government and from OECD and other surveys and reports monitoring health data development, use and governance.

This report describes the requirements and the benefits of an integrated health information system; outlines the current situation in the Netherlands in the context of progress across OECD countries; and recommends legal, policy and operational changes to overcome barriers to the efficient exchange and sharing of health data and to establish an integrated health information system.

Challenges and opportunities of the 21st Century require a new approach

The Dutch health system has many strengths that can be harnessed to develop a world-class health data infrastructure and information system, including strong patient engagement and leadership of patient groups toward data interoperability; progress in developing data exchange standards; universities and institutions that are leading good practice in common data models and technologies enabling large-scale research on distributed data; and a unique ‘can-do’ culture.

However, the Dutch system also has several fundamental barriers that need to be overcome. One of these is health system fragmentation, a design feature that enables competition and market mechanisms to work but also presents an institutional barrier to data sharing and exchange. Fragmentation has particularly affected electronic medical data, where despite efforts toward data exchange, the data remain underdeveloped, siloed and underused. Lack of alignment and a common interpretation of legislation and

regulations also present a challenge to advancing secure health data sharing, accessibility and use. Overall, this review found that while there are many strong organisations developing data in silos, there are few incentives from government or from the private sector to integrate the silos into a whole health information system.

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 call for a political choice, legislative guidance and fitting strategic action in order to facilitate ethical and optimal use of this rapidly expanding resource.

Creating an integrated health information system that meets the needs and opportunities of the 21st century will require a unified national strategy and a new set of institutional functions to develop, implement and oversee a health data infrastructure and integrated information system. Successful implementation will require good governance that builds trust among all stakeholders.

Development of a national strategy toward 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. 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 in order to include inputs from the public into the strategy and provide a website to share information about the development process and its outcome.
- Considers developing a broad digital strategy encompassing the health data strategy and ensuring full alignment.
- 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.

It is also recommended that the ministry 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, support '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 ministry and to oversee and maintain the resulting integrated health information system. This could be done by 'strengthening' or combining expertise of existing organisations or creating a new agency.

It is recommended that the ministry 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.

It is recommended that the national agency take responsibility for four key activities that are essential for an integrated health information system:

- 1) 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.
- 2) **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.
- 3) 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.
- 4) **Stakeholder engagement and public consultation** about the national strategy and its implementation; and **public transparency** through clear communication about the national strategy and the development, exchange, uses and data privacy and security protections of health data.



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