EIT HEALTH BELGIUM–NETHERLANDS

IMPLEMENTING THE EUROPEAN HEALTH DATA SPACE IN THE BENELUX REGION

CONTENTS

INTRODUCTION

The European Commission's proposed regulation for a European Health Data Space (EHDS) that will allow access to health data across the EU and facilitate the secondary use of health data for research and policy making. It defines for data holders—hospitals and other healthcare providers, research institutions, pharmaceutical and medical technology companies—obligations to register their data in a national catalogue, describe it using a quality label, and make it available upon request by health data access bodies. Health data access bodies will be entrusted with a wide range of responsibilities, including evaluating access requests and delivering data permits, supporting data holders with data characterisation and providing the national data catalogue, linking and pseudonymising datasets, providing access to data through secure processing environments and ensuring the confidentiality of these processes, among others.

The European Commission has set out to issue technical specifications for the implementation of the EHDS through implementing acts and is equally expected to provide central access forms, contracts, an EU-wide data catalogue connected to the national catalogues, and the cross-border communication infrastructure HealthData@EU. It may also perform the role of a health data access body with secure processing capabilities for EU institutions and agencies.

There is broad political consensus on the need to increase the availability of health data for secondary use in research and innovation, policy development, healthcare, quality management, training and AI development, beyond regional and national borders. Yet there remain areas of uncertainty regarding the impacts and implications of implementing the EHDS in practice.

To assess the feasibility of implementing the EHDS in different EU regions and member states, EIT Health is conducting a pan-European, multi-stakeholder public affairs initiative to gather experiences and real-world insights of EIT Health's partners and other relevant agents of the EU healthcare innovation ecosystem. Its aim is to shed light on what the realities and needs are in the individual countries in relation to adopting the EHDS, and to distil lessons learnt and best practices from previous experiences of sharing health data beyond the setting of care delivery, for use in academic or commercial research and evidence-based policymaking.

A series of 10 national and regional roundtable discussions were staged throughout Europe in 2023 to compare and contrast the ability across sectors and borders to put the regulation as it currently stands into practice. A European steering committee made up of experts from different countries and chaired by Dr. Andrzej Rys, Director of Health Systems, Medical Products, and Innovation at the European Commission's Directorate-General for Health and Food Safety is overseeing the initiative.

On 11th October 2023 in Brussels, EIT Health Belgium-Netherlands hosted a regional roundtable discussion bringing together nine panellists from Belgium, the Netherlands and Luxembourg and spanning the fields of EU public policy, healthcare, health data, med tech, patient advocacy, and public health. Complementary insights and background were obtained through individual interviews.

Underlining the importance of this consultation effort, Dr. Rys highlighted that the EHDS proposal, incubated during the COVID-19 pandemic, reflects a new legislative approach that has never been attempted before. "I strongly believe that the difficult implementation work ahead of us will also create many opportunities to move our health systems, our research and development ecosystems, as well as our regional, national and European health governance towards a brighter common future," he added.

The following report summarises the key challenges, enablers and recommendations identified to inform the implementation process in the Benelux region and beyond.

PRIMARY USE

The primary use of data is the individual health record for a patient generated and recorded as part of their diagnosis and treatment during an episode of care.

SECONDARY USE

The secondary use of health data means using health data for purposes other than the primary reason for which they were originally collected. The secondary use can be, for example, research, decision-making, development and innovation, and education.

CURRENT LANDSCAPE

Belgium

Political recognition of the importance of health data and efforts to make it more FAIR (findable, accessible, interoperable and reusable) go back several years in Belgium. As to date, difficulties in accessing data have hindered epidemiological research and limited the ability to develop targeted public health policies in the country. There is no unified patient record in Belgium, and electronic health records in individual healthcare institutions are not interoperable. However, a process has been established for structuring requests and facilitating access to data from the various sources in healthcare, which does not amount to a fully-fledged data permit as foreseen by the EHDS proposal, but nonetheless defines a pathway for data requests to receive legal and privacy clearance.

April 2023 saw the official creation and funding by law of the federal Health Data Agency, a public body tasked with facilitating the collection, standardisation and responsible secondary use of health data for the benefit of Belgian citizens and the European community. All stakeholders, including healthcare providers, health insurers and patients, are represented within its governance structure. One of its first important activities is the compilation of a national data catalogue, to provide data users with a central point of information and access for their research needs. In the future, it will also pursue the development of federated analytics as an alternative to transferring datasets to further facilitate access and use. As Hans Constandt, who oversaw the agency's initial development, reported, ongoing staffing of the new agency has been a critical aspect of ensuring operational success in a context where multidisciplinary medical, data and legal skillsets are needed. However, it remains unclear whether the Health Data Agency will become Belgium's national health data access body as it is still being debated whether the latter's responsibilities could or should be concentrated within a single organisation. For example, the new agency currently has no mandate to issue data permits or host secure processing environments for secondary use.

In a national health system characterised by its regional organisation and complex processes, Constandt expected that winning public trust through transparency and implementing a streamlined system operated with simple, user-friendly tools would be some of the main challenges for Belgium in adopting the EHDS. While he was optimistic about the widespread willingness to collaborate on driving implementation among key national stakeholders, Constandt also hoped to see faster and more agile decision-making in this area.

The Netherlands

The healthcare sector in the Netherlands is fragmented, with the electronic data systems of different actors most often isolated from one another and collaboration between healthcare providers and academic institutions not well established. Early steps have been taken by some large hospitals to improve patients' access to their own health data, but so far remain limited to providing information and fall short of ensuring true data portability, including between different healthcare providers for primary use purposes. Improving the interoperability of data and data systems will thus be a critical task for the Netherlands as for many other EU countries in realising the EHDS.

Margo Van Mol, ICU nurse at Erasmus MC in Rotterdam, reported that awareness of the EHDS and topics related to the secondary use of data currently remains low among healthcare professionals. Van Mol therefore saw a further success factor in engaging with and involving doctors and nurses early on in the development of use cases that could make the purpose of the framework tangible for them and facilitate the emergence of viable solutions for standardised data collection in healthcare. This engagement could be mediated by the chief nursing information officers who have recently begun to be appointed in Dutch hospitals as actors with an interest in digital innovation and data, and who could mobilise their colleagues to facilitate implementation. Van Mol was optimistic about Dutch healthcare professionals' willingness to adopt data-driven innovation that integrates seamlessly into the process of care delivery but cautioned that the heterogeneity of digital skills especially within the nursing workforce should not be underestimated.

One illustrative initiative to enable the secondary use of data from healthcare in the Netherlands is the Dutch ICUdata Warehouse, which is working to gather all data from the country's intensive care units into a single database to develop prediction models for the optimisation of acute care delivery. The experience from this project, including the background legal, technical and conceptual work to make it possible, could inform the Dutch approach to integrating primary data for secondary use within the EHDS on a larger scale. Another noteworthy initiative that is jointly driven by several Dutch research organisations, including all academic medical centers, is Health-RI, whose aim is to build an integrated health data infrastructure for research and innovation.

Luxembourg

Luxembourg is a small member state with just 600,000 inhabitants and a limited health ecosystem dominated by public healthcare provision and centred around four large hospitals. As many as 200,000 people enter the country for work each day. With the national health system dependent on the systems of neighbouring countries and vice versa, cross-border healthcare is a particularly relevant topic for Luxembourg's citizens and workers. While this creates favourable conditions for implementing the EHDS in terms of the motivation of different stakeholders to engage in data-sharing on a European level, according to Bert Verdonck, CEO of the Luxembourg National Data Service (LNDS), it also makes the task of fostering understanding of and trust in both the primary and secondary use facets of the EHDS all the more important.

In terms of digital infrastructure, a project to introduce a unified patient record has been initiated but the current landscape remains fragmented and modern upgrades to existing health information systems are needed. The impending adoption of the EHDS has made decision-makers in Luxembourg hesitant to commit to large investments in IT solutions that may need to be adapted once the framework is implemented. The interaction with healthcare professionals and citizens on the way to making these digital transformations has also yet to mature, according to Verdonck.

Benelux countries encounter significant digital infrastructure challenges for EHDS implementation. Belgium lacks a unified patient record and interoperable electronic health records. The Netherlands faces fragmentation, with isolated data systems and limited collaboration. Luxembourg's efforts for a unified patient record are impeded by a fragmented landscape requiring modern system upgrades. Addressing these issues is vital for successful EHDS implementation in the region.

In the field of secondary data use, meanwhile, Luxembourg has taken a major step in the run-up to adopting the EHDS by establishing the LNDS in 2022 as a national organisation providing services for access to and value creation from various categories of public sector data, including health data. Similar initiatives are beign developed in the Netherlands and Belgium. The LNDS enables controlled sharing and reuse of data for public and private actors, offers know-how, technology and data services including secure processing environments, and develops and supports solutions for responsible secondary use for research and policymaking purposes. The organisation is involved in the national implementation of the EU Data Governance Act and will collaborate with the Ministry of Health on designing the health data access body for Luxembourg as part of the EHDS implementation. It is also contributing actively to the Data Spaces Support Centre, which is coordinating the development of the nine planned European data spaces and working towards common standards and interoperability between them.

CHALLENGES AND ENABLERS ON THE PATH TO IMPLEMENTATION

During the roundtable discussion, participants highlighted some of the key challenges associated with establishing effective data governance structures for the EHDS, ensuring the quality of the data that is made available for secondary use, and accelerating the application of insights and adoption of innovation generated through the EHDS in healthcare. Enablers of implementation were also proposed to foster an integrated data-sharing environment of linking patients, healthcare providers, payers and policymakers in a cycle of continuous improvement and co-development of solutions that can transform healthcare delivery for the better.

Governance

Challenges

Data ownership and consent

Various voices were raised against establishing consent requirements for secondary use of health data that would burden healthcare professionals, patients and citizens with repeated forms and procedures, and which could hinder the development of data-driven innovation that relies on accumulating historical data. "An algorithm is nothing without the data that trained it. If you want to retrain it, you cannot just use the mathematical formula, you need that initial dataset and often this cannot be completely anonymised without losing relevant information," said David Van Laere, Founder and CEO of Innocens, a Belgian company developing AI software to better detect and prevent sepsis in newborn infants.

Legal uncertainty

Heterogeneous and sometimes overly strict interpretations of the EU General Data Protection Regulation (GDPR) were found during country visits conducted by the Joint Action Towards a European Health Data Space (TEHDAS) to be a common barrier to the reuse of health data for research, as was reported by Nienke Schutte, a scientist at Sciensano, Belgium's national public health research institute involved in the TEHDAS project.

In this context, Verdonck called for more articulated guidance on how to fulfil GDPR requirements for data anonymisation and pseudonymisation in a way that strikes a sensible balance between risk and benefit, to remove the legal uncertainty and resulting fear of litigation for secondary users of data.

Poor health literacy and low awareness of health data among citizens

Lack of awareness among the majority of EU citizens of what health data they actually have, where it is located, and what rights they have with respect to it was considered a significant obstacle to conveying to the general public the rationale for and benefits of gaining better access and control over one's health data. With as much as half of the EU population also considered to have poor health literacy, significant investment in educational measures will be required to achieve widespread public engagement with the secondary use facet of the EHDS and prevent it from becoming a vector of further health inequities.

One participant saw a potential role for pharmacists here, whom a survey of European citizens found to be the second most trusted actors after healthcare professionals for providing guidance on health applications, the use of which will be key to empowered participation in data-sharing within the EHDS. Currently an underutilised resource, pharmacists could help vulnerable groups or people with low digital literacy to engage appropriately with digital health applications, share their data and benefit equally from the EHDS—similar to their recognised role in ensuring patient safety and adherence in medication use.

Enablers

Public trust in data governance

Several participants reported from national and international surveys, including a public consultation by TEHDAS of 6,000 EU citizens about the secondary use of their medical data for research and policymaking, that citizens are generally open to sharing their personal data if this is done in a manner that is transparent, secure and matches their ethical values. Van Mol confirmed that openness to the reuse of medical data both for research and quality management is also widespread among patients, whose preferences are indiscriminate across these two use purposes despite them being subject to very different legal requirements. "Patients see it as being in their interest to contribute to innovation that will result in better quality of care," she explained.

In this context, there was agreement that winning the public's trust in the EHDS and in the ability of health data access bodies to ensure the correct use of data should be considered a priority. Constandt called for an approach to data governance similar to blood donation: "I don't give blood for money, and I don't need to know who it was given to exactly, but I do want to be sure it's being used appropriately for specific purposes," he said. One suggestion was to establish transparent reporting and timely, easily understandable communication to the public about which datasets are actually used, for what purposes, and with what results. The staffing of access bodies with trustworthy, socially motivated individuals was also considered important in this setting.

Data quality

Challenges

Insufficient understanding of data requirements

For Verdonck, there is a gap in knowledge among many stakeholders about data ontology and coding systems, as well as about the types of data that are relevant and necessary for each secondary use purpose. "There are too many standards in the health domain, we need to make choices about which ones are instrumental to conduct the types of research we want to enable. Then the primary data capture systems will need to be structured to record data according to those standards from the start," he argued.

Recognising that, even if standards improve, raw data from primary use will still require processing work to be done to make it reusable for secondary purposes, Verdonck also called for guidance regarding the data requirements and appropriate tools to fulfil them. "Attention should be given to how these processed datasets can be preserved or stored semi-permanently should they be needed again in the future, as currently, nothing in the regulation prevents data holders from deleting them after use unless they need them for their own purposes," he said.

Ensuring the credibility of health insights and solutions generated from healthcare data

Healthcare professionals have a key role in contributing data in the primary use setting that will be reusable for secondary purposes and generate credible research results. "When we read about a new study in a journal, we as doctors are trained not to trust the overall message but to look at the patient characteristics and details to understand how and why a particular result was achieved," said Sabine Tejpar, an oncologist at Leuven University Hospital in Belgium. "If you tell doctors, this device can predict why someone's blood pressure is high, they will not believe it unless they have proof that the manufacturer is in control of the model and has fed it with all those characteristics and explanatory variables that we like to see in a clinical trial." According to Tejpar, however, disparate EHR (Electronic Health Record) systems as well as clinicians' variable capacity and willingness to collect data beyond the information needed for patient care will make this type of data enrichment challenging to achieve, thus limiting the research applications for which electronic health records can be used.

Van Laere agreed that doctors and nurses do not have time to record data that is not immediately relevant to their care provision, calling for developers of data-driven health solutions to take this into account in their products' development and implementation phases. Both participants nonetheless advocated that efforts be made to enable the collection of the relevant data points in the healthcare setting by providing high-quality data definitions and defining specific requirements as needed for different use cases.

Enablers

A role for patients in data collection

It was suggested by several discussants that patients themselves could be empowered to collect and share their own data for reuse. The quality aspects, in this scenario, would need to be balanced against the usefulness of the datasets that can be obtained in this way. "Maybe the patient's weight scale is inaccurate, but the fact that you have a daily measurement compensates for that inaccuracy," said Verdonck, calling for efforts to improve data custodians' and data users' knowledge of how to deal with and use data of varying quality levels.

A quality label for wellness applications

The Label2Enable project, funded by Horizon Europe, is creating an ISO 17000 series-compliant certification scheme for the ISO Technical Specification 82304-2 (health and wellness apps quality and reliability). According to project coordinator Petra Hoogendoorn, under the EHDS this could become the voluntary label for wellness applications that claim to be interoperable with electronic health records as introduced in Article 31 of the EHDS. However, Hoogendoorn cautioned that like any voluntary scheme, it would likely not be taken up by the majority of developers, raising the question of whether integration of this type of data into the EHDS should be conditioned upon obtaining the quality label. "What are the pass-fail criteria for health data? When is the quality sufficient and how can you tell?" she said, raising some of the important questions to be resolved in this area.

CLOSING THE LOOP: THE RELATION BETWEEN PRIMARY AND SECONDARY USE

Challenges

Reconciling different interests in the transformation of healthcare

As data flows from primary to secondary use environments and then back into healthcare when new insights and solutions are generated, the resulting transformations in care delivery could be immensely beneficial to patients, healthcare providers and public health systems, but could also be met with significant resistance if they are not well understood and accepted by the relevant parties. In this area, van Mol anticipated in particular that the benefits of new processes and pathways in the patient journey would need to be clearly defined and communicated to patients and their caregivers in a way that is meaningful to them, which may be different from the rationale for the changes from the doctor or system perspective.

Van Mol highlighted an example from her field of expertise as an intensive care nurse: "When we conduct focus groups on the possibilities for developing e-health interventions and AI-based tools to reduce the time patients spend in the ICU or optimise the use of staff resources in follow-up care, patients and their relatives always say that what they want is in-person interaction with their doctors and that they don't mind spending an extra day in the ICU if that means getting the best quality of care." Rather than the potential to improve the cost-effectiveness of healthcare services, Van Laere, therefore, advocated for the bigger picture to be painted for patients and the wider public, illustrating how the EHDS and data-driven healthcare could contribute to protecting Europe's unique social security systems and keeping high-quality care accessible to all citizens in the future.

Fears surrounding AI

Hoogendoorn also reported that patients, when asked about their preferences for future digital health and care, in addition to a desire for continued personal contact with their medical team commonly expressed a fear of AI and a need for a trustworthy authority to tell them which solutions they can safely adopt. "In healthcare, we need to move stepwise with these technologies in order to build that trust," Hoogendoorn emphasised.

Bringing patients and their relatives on board in the development of concrete practical applications in this field was recommended as an important step to foster acceptance by making the advantages tangible. Efforts to include the wider population, not just the highly engaged and often highly educated patients that tend to be involved in collaborative initiatives with healthcare, were also deemed necessary to prevent inequities in access to health innovation.

Enablers

A European tender for large-scale standardised data collection and use

As an example of successful capture and reuse of primary data to generate directly applicable insights in the clinic, it was reported that electronic data systems exist in the USA that intelligently define what information is needed and collect only data of the highest quality from different sources, enabling the creation of avatars that allow doctors to visualise patients' characteristics as they compare to others. In situations not covered by existing clinical practice guidelines, physicians can then recommend treatment strategies with the highest chances of benefit based on similarities with historical patient profiles in the database. However, the relevant providers' financial and privacy terms were deemed inapplicable in the European context, as was the prospect of a few monolithic commercial parties owning the market to achieve the required scale for their solutions to work.

A European solution, Tejpar proposed, could be an approach similar to the OncNGS initiative, in which a consortium of European cancer centres, supported by EU funding, collaborated to define the needs and specifications for cancer diagnostic tools based on next-generation sequencing (NGS) technology and launched a public call for tenders to foster the development of more competitive offerings in a market dominated by a few large corporations.

Value-based health and healthcare models

Value-based healthcare (VBHC) has been gaining traction in recent years as an approach to channelling public health systems' scarce human and financial resources towards interventions that improve the health outcomes which matter most to patients. For roundtable participants, adopting new value-based models of healthcare financing would be pivotal in enabling the adoption in practice of predictive and preventive models of care that data-driven innovation could make possible on a much larger scale under the future EHDS, and which could have far-reaching benefits throughout society.

As Van Laere highlighted, "In intensive care, the current fee-for-service model means that the best patients are the ones who experience many complications and die quickly because they use up little bed capacity and rack up a lot of billable actions. Paying per result rather than per service could incentivise keeping people healthy over treating the sick."

In addition to improving public health systems' understanding of what outcomes are truly important to an individual patient, such as being able to return to work, care for their family, or do the activities they love, participants saw a need to extend value-based approaches to health in general, where prevention through health-promoting lifestyle choices could increase wellness and healthy ageing on a population level. In this setting, several discussants argued that notwithstanding the common preconception that 'apps should be free', a health application that measurably improves a lever of prevention such as healthy eating could have an immense impact on total health costs and, as such, should legitimately be funded by public payers.

"The value of secondary use of data for public health is difficult to quantify, but this exercise must be done to demonstrate the benefits to society," Schutte emphasised.

Use cases around which all stakeholders can coalesce to scale up implementation

Finally, a consensus emerged around the table that in adopting a framework as complex as the EHDS, developing approaches to implementation based on concrete use cases that answer real unmet needs would be essential to ensuring its viability and acceptance in healthcare and in society. As one of the major expectations surrounding the EHDS is that it will accelerate the development of artificial intelligence in the health sector, Van Laere further highlighted that the common pitfall should be avoided of using data to develop solutions without first identifying a problem and defining the need. "The focus has to be on what we want artificial intelligence to solve: that is where breakthroughs will come from," said Van Laere.

Getting projects involving all stakeholders off the ground quickly and learning by doing was unanimously heralded as a way to identify best practices on the way to full-scale implementation. Menno Kok, Managing Director of EIT Health Belgium-Netherlands, emphasised that bringing stakeholders together will be crucial to understanding not just what each group expects and needs, but also the inner workings of the interactions between them, which could make or break a particular approach to implementing the regulation.

"In the course of the TEHDAS project, we found that countries really need concrete examples of how problems have been solved elsewhere and how they can apply these solutions at home. Every EU member state needs their own roadmap that considers the investments necessary to get ready for the EHDS," said Schutte.

In a sector characterised by significant fragmentation such as healthcare, Verdonck additionally saw value in defining a moonshot project—a truly ambitious target for EHDS stakeholders to coalesce around, similar to the lofty goals defined in Europe's Beating Cancer Plan, which can then be broken down into a programme of individual measures and projects that pay into the greater purpose.

KEY RECOMMENDATIONS

Design a one-time consent mechanism for the secondary use of health data that allows the accumulation of historical data and minimises the administrative burden on citizens and healthcare professionals

Provide detailed guidance at EU level for fulfilling data anonymisation and pseudonymisation requirements

Develop the tools needed to make the EHDS work in practice: information portals, access request portals, all with an appropriate user experience for both citizens and professionals involved

Warrant open, understandable, and timely communication by health data access bodies through information and access request portals about how data is used, why, and with what outcomes to earn and retain trust of citizens in the system and its outputs

Explore ways to foster inclusion and empower populations with low digital and health literacy to engage in data-sharing through trusted health system actors such as primary care physicians and pharmacists

Establish robust data traceability, especially with regard to where, how and by whom data was collected to help data users better understand and manage variability in data quality within the EHDS and ensure appropriate use of different datasets

Develop educational resources for all stakeholder groups (citizens, healthcare professionals, healthcare institutions, insurance providers, public health and political actors) to improve knowledge of the new technologies being developed and deployed in the health sector

Adopt value-based models of healthcare financing informed by systematic collection of patient-reported outcome measures (PROMs) to enable the adoption of data-driven predictive and preventive solutions in healthcare

Explore the value of data to improve population health and funding mechanisms for wellness and prevention solutions

Develop national roadmaps considering the investments required to implement the EHDS in a phased approach

Next to the European health data catalogue, develop a European catalogue of secondary use projects to enable cross-border synergies and collaborations at scale

Define ambitious goals and concrete projects for stakeholders to coalesce around and solve through the implementation of EHDS

Get projects involving all stakeholders off the ground quickly and deliver open-source solutions that reflect real practice and can be reused by others

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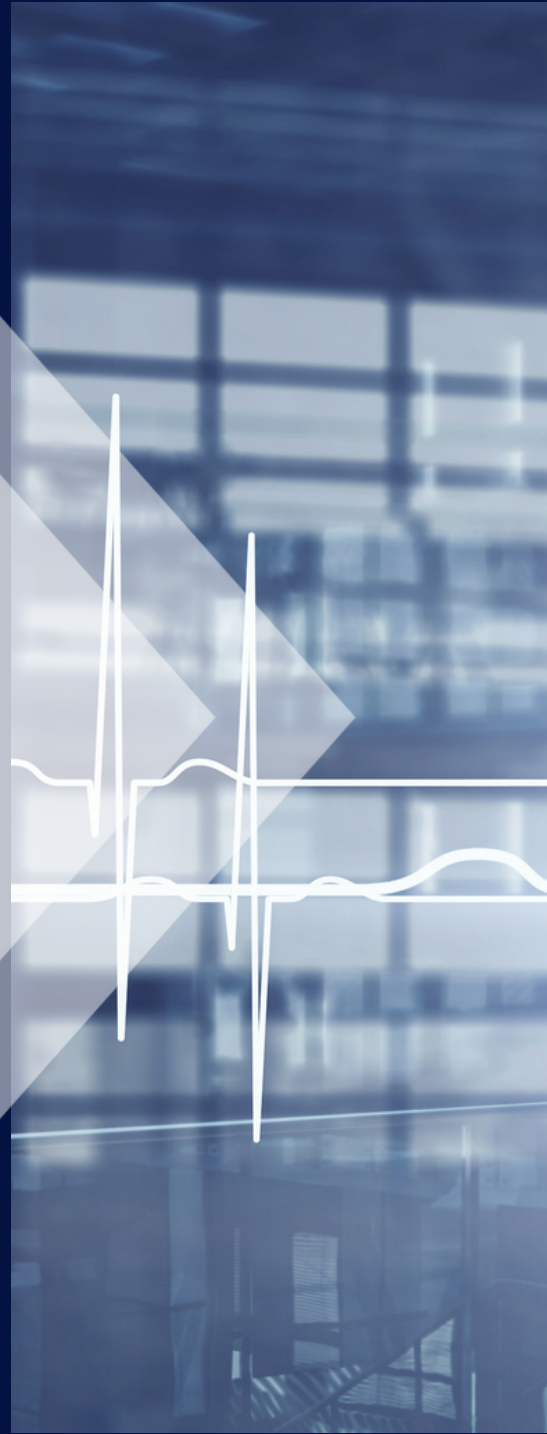The Netherlands
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