Survey results: National health data infrastructure and governance

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Acknowledgements

Abstract

The strengthening of health data infrastructure and governance is a policy priority of the OECD. This report presents findings from the 2019-20 OECD survey of health data development, use and governance. Health ministries and health data authorities in twenty-three countries responded to the survey. Survey results indicate variability across countries in health data use and governance and identify a small number of countries with most of the policies and practices that protect privacy and health data security and foster the development, use, accessibility and sharing of key national health datasets for research and statistical purposes that were measured. The findings from the survey provide input for further discussion on health data development in multiple areas of work, notably in the digital community.

The report is organised in three parts. Part I presents the capacity of national health data systems to serve and protect the public interest including progress toward the development and use of 13 key national health datasets and patient-reported outcomes data. Part II focusses on country progress toward the implementation of national health data governance frameworks focussing on broad policy areas and challenges countries are facing in improving their health data systems and governance of health data. Part III delves into national health data custodians' governance of datasets and reports progress among countries for 10 health care datasets.

Résumé

Le renforcement de l'infrastructure et de la gouvernance des données sur la santé est une priorité politique de l'OCDE. Ce rapport présente les résultats de l'enquête de l'OCDE en 2019-20 sur l'élaboration, l'utilisation et la gouvernance des données sur la santé. Les ministères de la Santé et les autorités chargées des données sanitaires de 23 pays ont répondu à l'enquête. Les résultats de l'enquête indiquent une variabilité entre les pays dans l'utilisation et la gouvernance des données sur la santé et identifient un petit nombre de pays qui ont déjà mis en place la plupart des politiques et pratiques qui protègent la confidentialité et la sécurité des données de santé et favorisent le développement, l'utilisation, l'accessibilité et le partage d'ensembles de données nationales sur la santé pour la recherche et des fins statistiques. Les résultats de l'enquête peuvent servir à alimenter la discussion sur le développement des données sur la santé dans de multiples domaines de travail, notamment dans la communauté numérique.

Le rapport est organisé en trois parties. La partie I présente la capacité des systèmes nationaux de données sur la santé à servir et à protéger l'intérêt public, y compris les progrès vers l'élaboration et l'utilisation de 13 bases de données nationales sur la santé et des données sur les résultats rapportés par les patients. La partie II se concentre sur les progrès des pays vers la mise en œuvre des cadres nationaux de gouvernance des données de santé, en se concentrant sur les grands domaines de politiques en santé et les défis auxquels les pays sont confrontés pour améliorer leurs systèmes de données sanitaires et la gouvernance des données sanitaires. La partie III présente la gouvernance des bases de données de santé par les responsables nationaux et rend compte des progrès réalisés entre les pays pour 10 bases de données sur les soins de santé.

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Introduction

1.   Health data provide the means to respond to public health challenges, to manage and improve health system performance and health care quality, and to advance scientific discoveries that improve medical treatments and save lives. Health data can fuel a transformation of the health sector toward 21st century treatments and care; but they will not do so without effective health data governance that enables secure and privacy-protective data uses.

2.   While the improvement of health information infrastructure and governance has been a policy priority of the OECD for the past decade, the global COVID-19 pandemic brought into sharp focus the need for and value of high quality and timely data to identify high risk patients for testing; to track and trace individuals infected with the SARS-Cov2 virus; to allocate and manage human and physical resources in an emergency; to develop and deploy tools to support diagnosis and treatment; and to contribute to research and evaluation of treatments and vaccines.

3.   The scale, capabilities and methodologies of data gathering, aggregation, and analysis are radically evolving. Emerging technologies including Big Data analytics can, for example, utilise enhanced computing power to process broad ranges of data in real time that could support patient care and further the discovery of disease markers and disease-specific solutions. Rapid progress in information technology and processing, and associated research techniques and methodologies, may also allow for innovative solutions enabling limited access to data under secure conditions with increased opportunities for transparency, accountability and audit. Thus, there is an on-going need to evaluate the impact of new technologies on health data availability, use and the protection of health data privacy and security.

4.   Health data are sensitive in nature and fostering data sharing and use increases the risk of data loss or misuse that can bring personal, social and financial harms to individuals and can diminish public trust in health care providers and governments. Appropriate reconciliation of the risks and benefits associated with health data use is necessary if the interests of both individuals and societies are to be best served. This requires transparency, an understanding of the reasonable expectations of individuals, and the development of a shared view of how best to serve the public interest in both the protection of health data privacy and in the benefits to individuals and to societies from health data availability and use.

5.   The breadth and scale of data collection practices has also given rise to new challenges in the implementation of existing data protection standards and procedures that need to be addressed, such as consent to personal data collection and use. It has also highlighted the importance of complementing legal data protection through education and awareness raising, skills development, and the promotion of technical measures so that the potential benefits of new analytic techniques may be achieved.

6.   This report presents the results of the OECD Health Care Quality and Outcomes Working Party Survey of Health Data Development, Use and Governance that was administered in 2019/20. Twenty-three countries participated in the 2019/20 survey: Australia, Austria, Belgium, Canada, Czech Republic, Denmark, Germany, Estonia, Finland, France, Ireland, Israel, Japan, Korea, Latvia, Luxembourg, the Netherlands, Norway, Singapore, Slovenia, Sweden, United Kingdom (Scotland) and the United States.

The survey results presented in this report were provided by representatives of health ministries and national health data authorities (see Annex A).

7.   The 2019/20 survey continues a series of studies undertaken by the HCQO from 2011 to 2017 to support countries in strengthening their health information infrastructure that focussed on national data development, use and governance; and development and use of data within electronic health record systems.

8.   This report is organised in three parts. Part I presents the capacity of public sector health data systems to serve and protect the public interest. This includes presenting a review of data availability, maturity and fitness for use including national health dataset availability, coverage, automation, timeliness, unique identification, coding, data linkage and regular reporting of indicators of health care quality and system performance. This part focusses on 13 key national health datasets: hospital in-patient data, mental hospital in-patient data, emergency health care data, primary care data, prescription medicines data, cancer registry data, diabetes registry data, cardio-vascular disease registry data, mortality data, formal long-term care data, patient experiences survey data, population health survey data and population census or population registry data. This part also discusses the development of patient-reported outcomes data.

9.   Part II focusses on progress toward the implementation of national health data governance frameworks focussing on broad policy areas and challenges countries are facing in improving their health data systems and governance of health data. This includes public consultations about data governance; legal protection of personal health data; review and approval processes for data access; challenges to data use and governance; and barriers to sharing data among public authorities, to extracting data from electronic clinical records, to sharing de-identified data for research; lack of person identifiers to link data; and concerns about the quality of data that limit their usefulness.

10.   Part III delves into the health data governance policies and practices of national health data custodians and reports progress for countries across 10 key health care datasets: hospital in-patient data, mental hospital in-patient data, emergency health care data, primary care data, prescription medicines data, cancer registry data, diabetes registry data, cardio-vascular disease registry data, mortality data, and formal long-term care data. This section explores topics such as authorisation of dataset creation, staff training in data protection, data access controls, data de-identification, risk management, data sharing and authorisation to share, data sharing agreements, data transfers, remote data access, approval processes for data processing, and transparency with the public about data processing.

11.   Annex A provides details of the countries responding to the survey; Annex B provides detailed survey results in a series of tables; and Annex C provides a glossary of terms used in the survey and reflected in this report.

1 National Health Data Availability, Maturity and Use

12.   Key national health datasets are widely available across the countries surveyed and significant investments are made in health and health care monitoring and research in all countries. Overall, the countries with the strongest indicators of dataset availability, maturity and use in 2019/20 are Denmark, Korea, Sweden, Finland, and Latvia (Figure 1.1; Annex Table B.1). The top half of countries tended to report progress in dataset availability, maturity and use since 2013; while the lower half of countries tended to report a drop in capability, with the exception of Japan, which is making clear progress.

13.   Dataset availability, maturity and use includes eight elements: dataset availability, coverage, automation, timeliness, unique identification, coding, data linkage and regular reporting of indicators of health care quality and system performance (Figure 1.1). These elements are discussed in this chapter.

14.   The OECD has put a priority on supporting countries in measuring quality in health care, strengthening health data governance, developing knowledge-based health systems, and advancing health statistics. Nonetheless, cross-country variability remains significant in 2019/20 and points to challenges not yet overcome (Annex B.1).

15.   The results presented in this report reflect the health data systems in OECD countries just before the onset of the COVID-19 pandemic in March 2020. The pandemic has since heightened governments' attention upon the long-standing gaps in health data and health information systems that we describe here. When we compare the data infrastructure within the health sector to other major economic sectors, such as commerce, transportation, and banking, which integrate, standardise and manage sensitive data effectively within and across borders, the health sector stands out for being significantly behind (OECD, 2019[1]).

16.   The few countries with strong national health data systems, that include coherent, high quality, timely and linkable data across key areas of health and health care systems, were well positioned to utilise national data for critical intelligence to manage the COVID-19 pandemic. Data uses include communicating with and treating patients; identifying and testing people at higher risk of SARS-Cov2 infection; tracking and tracing the spread of the virus; managing and allocating critical human resources, health care beds and medical supplies; and conducting research to improve treatments, develop vaccines and improve health care. Examples of data driven pandemic management in Korea and Finland are presented in Box 1.1.

Figure 1.1. Key national health datasets availability, maturity and use
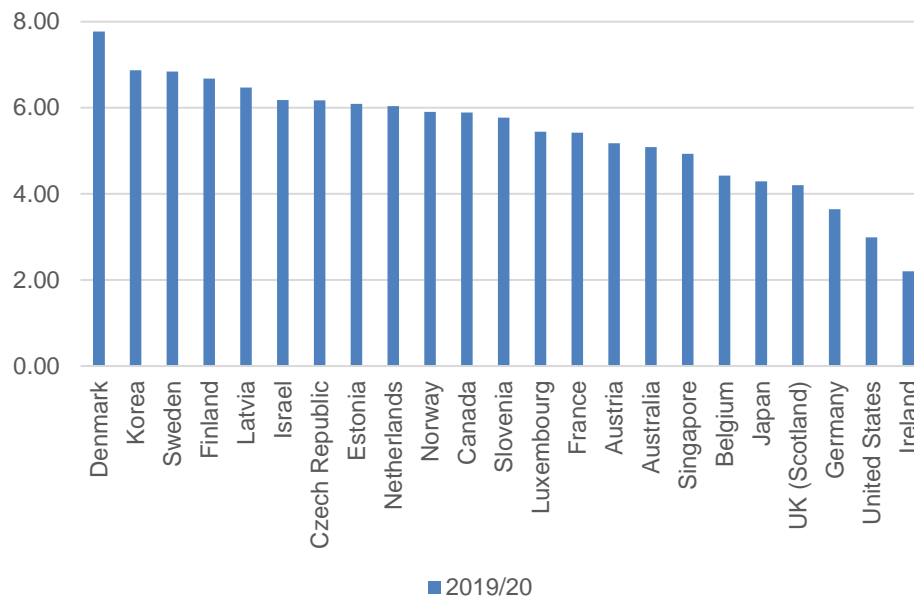
Note: Score is the sum of the proportion of health datasets meeting 8 key elements of dataset availability, maturity and use in this survey. The maximum score is 8. See Annex B.1
Source: Author.

17.   Of thirteen key national health datasets studied, eleven countries reported having all or virtually all of these datasets in 2019/20: Australia, Austria, Denmark, Estonia, France, Korea, the Netherlands, Norway, Singapore, Sweden and the United Kingdom (Scotland) (Annex B.2). Only two national datasets, however, were available in all countries: hospital in-patient data and population health survey data. The least available national dataset was a cardiovascular disease registry dataset, which is available in ten countries.

> **Box 1.1. Data driven responses to the COVID-19 pandemic in Korea and Finland**
>
> Korea and Finland have real-time, linkable data for key parts of the health care system. Finland also has an integrated national electronic health record system with capacity to extract data from that system for national statistics and a patient portal to their own e-HR records. Both countries provide examples of leveraging strong national information systems to quickly respond to and manage the pandemic at a national level.
>
> Korea has real-time data across key elements of the health care system. This data allows Korea to report the daily status of key resources and resource utilisation to best guide the health system to deliver care such as the geographic distribution of patients, the use of treatment wards (ICUs), and the current supply and allocation of key medical supplies (PPE) and medicines. Korea also developed an International Traveller Information System after the MERS outbreak and is using the system to manage Covid-19. Through this system, real-time data about travellers entering Korea from higher risk countries is shared with health care providers and pharmacies through a patient status checking system so that they may be prioritised for testing for SARS-Cov2. Patient data is also combined with databases outside of the health system to track and control disease spread, 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.[1]
>
> Finland has a well-developed national electronic health record system with a centralised architecture that allows health and social care professionals' access to their patients' electronic records and where data can be extracted from the system for statistics and research. Through a secure portal, individuals have access to their own medical records, can request a prescription renewal, can consent to disclosure of their personal data, can view well-being records and upload data from activity and heart monitoring devices and apps.[2] At the onset of the pandemic, Finland was able to quickly add to this portal a Covid-19 symptom checker questionnaire to help people to understand their risk and next steps regarding the need for testing, self-isolation and seeking health care. Within this system, questionnaire results can be linked to both testing results and results from a phone contact tracing app and sent to a health care provider and the individual can use the system to book an appointment with the provider.[3]
>
> 1. See Jongeun You (2020), Lessons from South Korea's Covid-19 Policy Response. American Review of Public Administration 50(6-7): 801-808, July 17.
> 2. See kanta.fi/en/my-kanta-pages
> 3. See omaolo.fi/palvelut/oirearviot/649.
> Source: Author.

Quality of key health care datasets

18.   This study probed elements of the quality of ten key national health care datasets including population coverage, coding of clinical terminology, extraction of data from electronic clinical records, and timeliness. The ten key national health care datasets included in this study were hospital in-patient data, mental hospital in-patient data, emergency care data, primary care data, prescription medicines data, cancer registry data, diabetes registry data, CVD registry data, mortality data and long-term care data.

19.   Most countries' datasets cover 100% of the target population (Annex B.4); however, there are important gaps in some cases. Data gaps must be closed to have a full understanding of health care

provision and outcomes. The most common reason why national datasets are not covering the full population is because they are missing records for care provided by private sector providers and institutions or that are covered by private insurance (Australia, Canada, Estonia, Finland, Germany, Ireland, Latvia, Luxembourg, and Singapore). In some cases, health care datasets are based on a representative sample of the target population, such as for primary care data in Belgium, and for patient experiences and population health data in all countries. Voluntary participation of health care providers or drawing data from a network of participants is also a reason for incomplete coverage of national data in Canada, Korea, Netherlands and Norway. Some countries also have exclusions for patients in certain regions (Canada and France) or have datasets that target a sub-set of patients or providers, particularly for disease registries (Belgium, Canada, Czech Republic, Estonia, Korea, Netherlands and Ireland). In Australia, patients living in rural or remote areas may be under-represented in some data sources[1]. Japan also indicates that where electronic records are lacking, datasets may be incomplete.

20.   Only seven countries (Czech Republic, Denmark, Israel, Netherlands, Singapore, Slovenia and Sweden) reported that all datasets rely to some extent on data extracted automatically from electronic clinical data and/or electronic insurance claims or billing data. In most countries, available key national health care datasets have some mixture of data entry from paper records and data extracted automatically from electronic records (Annex B.5). The benefits of automatic data extraction include improvements in timeliness of data capture, avoidance of costs associated with paper data capture, and minimisation of errors that occur from transcription of information.

21.   Thirteen countries reported that for all of their key health care datasets clinical terminology is coded by assigning standard codes using a classification system, such as coding diagnosis to an International Classification of Diseases (ICD) code or coding prescription medicines to an Anatomical Therapeutic Chemical Classification System (ATC) code (Annex B.6). Fifteen countries reported that the majority of their available key health care datasets included data that had been coded by a clinician, such as a physician or nurse. Thirteen countries reported that the majority of health care datasets were coded by a health care coding professional. In most countries, both coding professionals and clinicians are doing the work of data coding within national datasets. As more and more datasets are populated with data extracted automatically from electronic records the likelihood that clinical terminology has been coded by a clinical professional goes up and the need for new methodologies to verify the accuracy of the coded data rises, such as the use of audits for the quality of coded data (Oderkirk, 2017[2]).

22.   Reliance on electronic data, as well as upon clinical professionals for coding, have a positive impact upon the timeliness of data within key national datasets. Data that are available in real time or near real time open the possibility of monitoring health care quality and performance in time to detect and address issues as they are emerging, including a rapid detection and response to adverse events. Denmark, Estonia, Korea and Latvia stand 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 (Annex B.7).

23.   For the most part, however, countries are not reporting the use of national health datasets for either clinical or managerial decision-making in real time. The exceptions are Canada, where the inter-RAI tool within long-term care data has algorithms applied to it to alert clinicians in real time to areas of intervention, such as the risk of falls; Netherlands, where national diabetes registry data are included in a dashboard available to clinicians for clinical decision making; and Sweden, where regional components of the diabetes registry are used for clinical decision-making.

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[1] Patients living in rural or remote areas in Australia may be under-represented in some data sources, either because they utilise other services funded under different arrangements, or because different data collection arrangements apply.

Record linkage capabilities

24.   Record linkages enable the information value of individual datasets to grow, permitting connections between health care provided and the outcomes of that care over time; and permitting data within one dataset to be put into context with data from other sources. This study examined a set of technical factors related to capacity for record linkages including availability of a unique ID that could be used to link datasets, identifying variables that might facilitate linkages, consistency of the use of unique IDs, and the regularity of conducting dataset linkages.

25.   Only for four key national health datasets (hospital inpatient data, mental hospital inpatient data, mortality data and cancer registry data) do the majority of countries report that the dataset contains a unique patient ID that could be used for record linkage and that the data are regularly linked for research, statistics or monitoring (indicators). Opportunities to gain additional information value from other key national datasets through record linkages appear to be not pursued in many countries (Figure 1.2). In contrast, Canada, Denmark and Finland stand out for regularly linking all key national health datasets for monitoring and research (Annex B.12).

Figure 1.2. Percentage of key national health datasets available and regularly linked for monitoring and research
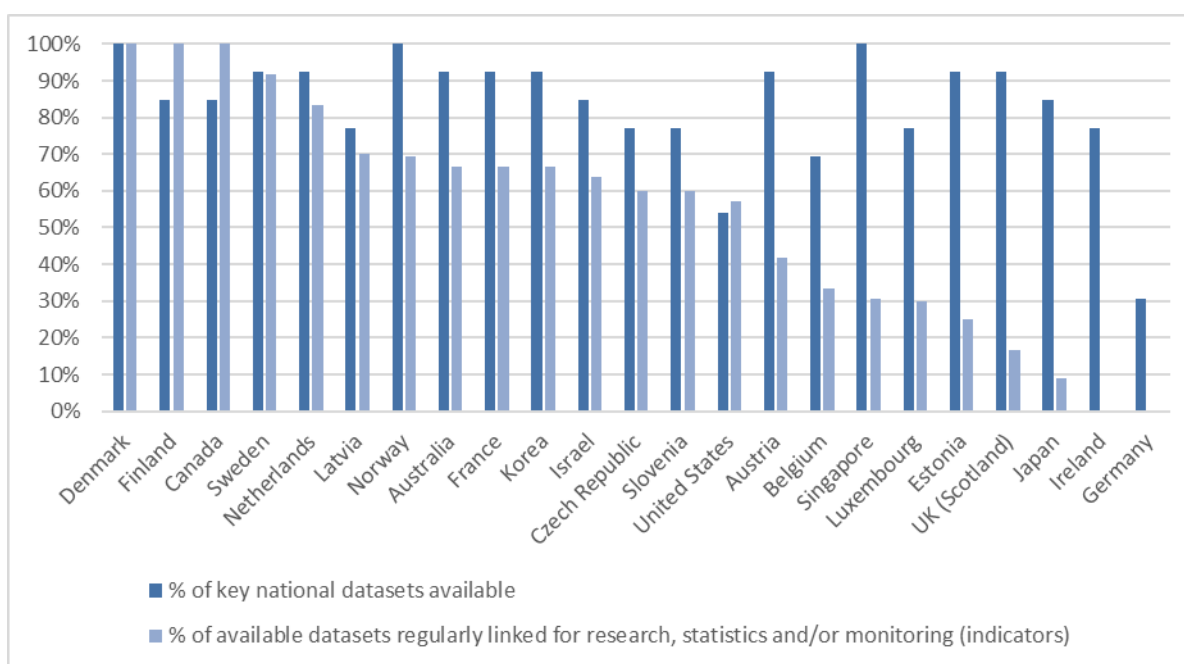
Source: Author.

26.   Seven countries (Czech Republic, Finland, Israel, Korea, Norway, Singapore, and Sweden) report 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 (Annex B.8). Fourteen countries report having the same unique ID number within 60% or more of their national health datasets (Annex B.9).

27.   Probabilistic data linkages involving matching records on other identifying variables (such as name, sex, birth date, address) could be used for the linkage of the majority of national health datasets in sixteen countries (Annex B.10). In only Australia and United States, however, it was possible to link the majority of datasets via these other identifying variables, but not via a unique patient/person ID number.

28.   Over half of countries report that dataset linkages are conducted on a regular basis with most of their national health datasets (Australia, Canada, Czech Republic, Denmark, Finland, France, Israel, Korea, Latvia, Netherlands, Norway, Slovenia, Sweden and United States) (Annex B.12). In contrast, dataset linkages are conducted on a regular basis with a minority of national datasets in Austria, Belgium, Estonia, Japan, Luxembourg, Singapore and United Kingdom (Scotland) and with no national datasets in Germany and Ireland.

29.   There are indications within this study that different unique ID's are used among national health datasets in some countries (Annex B.9). Unless there are ways to match across different ID's, then these differences will prevent the use of these ID's for dataset linkages. Countries challenged with 50% or fewer of national health datasets sharing a common unique patient/person ID number include Australia, Austria, Belgium, Germany, Ireland, Japan, United Kingdom (Scotland) and United States.

30.   Countries provided descriptions of the linkages that are conducted on a regular basis within health care settings, involving disease registries, and with survey and population registry data to provide context to interpret data (Annex B.13).

31.   A contributing factor to whether or not dataset linkages are conducted regularly is the number of custodians of key national health data sets. Most countries have 3 to 5 different organisations in custody of the thirteen key health datasets studied (Annex B.3). However, in Ireland and the Netherlands there are nine different organisations in custody of key national datasets and in France there are seven different organisations. These countries would have considerably higher challenges integrating and linking data across the pathway of care than in other countries, as laws and policies governing health data accessibility and sharing would need to be considered and applied across multiple organisations.

Information value of dataset linkages and innovative uses of health care data

32.   Countries regularly linking data also shared insights into the purpose of these linkages that include: improving the quality of national information, such as validating data and filling in information gaps; providing new information about health care quality, outcomes, performance, accessibility and equity; and advancing epidemiological and health services research (Annex B.14).

33.   Eighteen countries reported regularly linking datasets to monitor health care quality and/or health system performance (Annex B.15). Thirteen countries reported linking five or more national health datasets on a regular basis for this purpose (Austria, Canada, Czech Republic, Denmark, Finland, France, Israel, Korea, Latvia, Luxembourg, Netherlands, Slovenia, and Sweden).

34.   Thirteen countries provided examples of the types of indicators and analysis they undertake on a regular basis with linked data to monitor health care quality and/or health system performance (Annex B.16). These examples include indicators of mortality at intervals after procedures, treatments or health care episodes; indicators of readmission to hospital; indicators of rates of prescribing medicines; indicators of survival after diagnosis or treatment and more.

35.   Countries also provided examples of national projects involving record linkage of health care data; analysis of data extracted from electronic clinical records; and innovative uses of health data that have been undertaken during the past 5 years (Annex B.17).

Patient-reported health outcomes data development

36.   A new area of national health data development is the measurement of patient-reported outcomes of health care. In 2019/20, fifteen countries reported having patient-reported outcomes (PRO) data at some geographic level in their country and twelve countries reported national patient-reported outcomes data

(Annex B.18). Countries with national PRO data are Australia, Canada, Denmark, Finland, France, Ireland, Israel, Japan, the Netherlands, Norway, Sweden and United States.

37.   Twelve countries reported PROs for prostate cancer at some geographic level, and five reported national data (Annex B.19). Eleven countries reported breast cancer PROs at some geographic level, and 3 countries reported national data (Annex B.20). Eleven countries reported hip and knee PROs at some geographic level, and 4 countries reported national data (Annex B.21). Eleven countries reported cardiovascular disease PROs at some geographic level, and 4 countries reported national data (Annex B.22).

38.   Fourteen countries reported PROs data for a wide variety of other conditions or patient groups at some geographic level, with eight countries reporting national data for other conditions or patient groups (Annex B.23). These PROs ranged from very specific disease conditions and treatments to broad patient groups, such as all hospital in-patients.

39.   Denmark reported different methods to administer the questionnaires about patient outcomes. Some settings provide patients with a web-link to answer the questionnaires at home. Most regions offer patients a computer tablet or computer to provide PROs while patients are in the waiting room. One Danish region has developed a smartphone app for PROs. The app is used also in some municipalities in Denmark. Paper forms are still used in Denmark but digitisation of PROs is increasing.

40.   Like Denmark, Israel reports the use of internet surveys, smartphone apps, computer tablets and paper questionnaires. Germany reports a mixture of internet reporting, reporting using a computer tablet and paper questionnaires. Norway is using a mix of paper forms, internet surveys, telephone interviews, and computer tablets. Other countries reporting a mix of paper questionnaires and electronic reporting are Australia, Canada, Finland, France, Netherlands and Sweden. Japan and Korea reported that paper questionnaires are used. The United States collects PROs via a computer-assisted survey interview.

41.   Most countries also reported a mix of settings where the instruments are administered within their country including the patient's home and health care settings/waiting rooms. When PROs are integrated within patients' electronic medical records (EMRs) or within clinical and administrative datasets there is an increased possibility of the data being used for on-going clinical care and for health care quality and health system performance improvement.

42.   Very few countries, however, integrate PRO data into patients' EMRs. Canada reports this occurs in some provinces/territories and Denmarkreported this in some parts of the health system. In Israel and Korea, health care organisations are capturing PRO data within EMRs. A few national quality registers in Sweden capture PRO data within EMRs. In Australia, New South Wales is in the process of integrating PROs into their state-wide electronic medical record. In the Netherlands, PRO data are integrated into EMRs within mental health care organisations.

43.   PROs are recorded within other clinical or administrative datasets in eight countries. In Australia, PROs are captured within clinical quality registries at the state and national levels. In Canada, PROs administered to cancer patients are captured in regional and national databases; while PROs for hips and knees and for renal care are captured in regional databases. PROs are recorded in patient registries and in quality databases in Denmark and are integrated with quality registry software in Finland. In Germany, PROs are captured in the clinical data of health care organisations. In Israel, PROs are captured in national administrative databases, as well as within patient registries of health care organisations. PROs are also included in national quality registries in Sweden and in disease registries in Norway. PROs are captured in hospital datasets in Korea. In Sweden and Denmark, PROs are integrated within quality registries and these registries may be approved for use in research projects involving dataset linkages. In some cases, PROs are integrated within other clinical or administrative datasets in France.

44.	Denmark, France, Israel, Japan, Korea, Sweden and United States report that PROs data have been linked to other datasets. PROs data have been linked for ad hoc research projects in Australia, Austria and Norway.

45.	Few countries have been able to analyse PROs to monitor health care quality. In Australia, health care quality monitoring is a main use of PRO data at the national, regional and health care organisation levels. Similarly, PROs within quality registries are used in health care quality monitoring in Denmark and Sweden at national and regional levels and also at the health care organisation level in Denmark. In Norway, this monitoring is possible but it is not yet formalised within quality reporting requirements. The Netherlands, Japan and Israel report PRO data are used to monitor health care quality at the national level for some patient groups. The Netherlands report PROs are also used for quality monitoring at the health care organisation level and Israel reports early work toward such monitoring. In Canada, PROs administered to cancer patients are used to measure the prevalence and severity of symptoms at the regional level; and national and regional health care quality indicators based on PROs for hip and knee patients are in development. Finland, Germany, and Korea report that health care organisations are monitoring health care quality with PRO data.

46.	Countries provided examples of indicators of health care quality based on PROS used for quality monitoring including quality of life, pain, outcomes after specific interventions, and satisfaction with care (Annex B.24).

Challenges developing and analysing national health datasets

47.	Eighteen countries reported experiencing challenges developing one or more of their key national health datasets (Annex B.26). These included limitations to the quality of the data used to build the datasets, such as limits to the content and quality of insurance claims; gaps in population coverage; lack of unique patient identifiers; exclusion of non-reimbursed services; data coding problems; lack of digitised records; lack of timeliness of data; decreasing survey response rates; and breaks in time series (Annex B.27). There were also challenges related to policies and data governance, such as restrictions on analysis; high costs of data access; lack of resources for dataset development; and barriers to dataset linkages, to extraction of data from e-HRs, and to data sharing within a country.

48.	Challenges developing PROs data include inadequate resources for development, reported by thirteen countries, and insufficient interest on the part of clinical or policy communities, reported by seven countries (Annex B.25). Five countries reported challenges from having multiple item sets in use within the country for the same concepts and difficulties reaching agreement on common standards. Other challenges included the need for an IT solution to collect PROs and integrate them into patients' EMRs (Singapore); the need for an IT solution to collect and analyse PROs (Israel); challenges scaling up adoption of PROs (Finland and Netherlands); developing PROs that are useful for clinical and statistical purposes (Sweden); low response rates (Netherlands and Singapore); methodological concerns (France and Luxembourg) and data protection and other administrative barriers (Finland, Germany and Netherlands).

Plans to develop PROs over the next five years

49.	Fifteen countries have a national plan or priority to develop PROs within the next five years (Australia, Austria, Canada, Denmark, Estonia, Finland, France, Germany, Israel, Luxembourg, Netherlands, Norway, Singapore, Slovenia and Sweden). In Australia, there are priorities in the short term to develop a website to host literature and evidence on the use of PROs in Australia and internationally, including information on already established and validated PRO tools suitable for use in a range of clinical settings and levels (an item bank). The plan is also to facilitate knowledge sharing and discussion between

jurisdictions about use, learning and implementation of PROs locally and to share information and results about local, national and international implementations with the OECD and the International Consortium for Health Outcomes Measurement (ICHOM) to facilitate the development and piloting of international measures.

50.   Austria plans to include questions on patient-reported outcomes within the next intersectoral patient survey. This survey is administered every 5 years. Unfortunately, the survey planned for 2020 had to be postponed. The next survey will start after the end of the COVID-19 pandemic.

51.   Canada plans to implement a measurement and reporting cycle for validated PROs for cancer patients that will drive improvement in symptom management and programmatic interventions. Canada is also working with provinces/territories to scale up the use of standardised PROs for hip and knee surgery patients, beginning with interested provinces.

52.   Within the next five years, Denmark plans to integrate different PRO systems into its national platform where data are shared. PROs have already been developed for seven areas and four more areas will be added in 2019, and then further areas added in subsequent years. For each area, a group of clinicians from hospitals, GPs, municipalities, patients and patient organisations is established to develop national PROs and to recommend how they should be used. There is also a focus on cross-sectional use of PROs. Denmark is building a bank for all national PRO-questionnaires where hospitals and other health care organisations can collect these and use them in a local or regional setting.

53.   Progress in Finland toward national PROs datasets will depend upon the organisation and coordination of local quality registers at the national level under the THL Quality Register Project. France is providing methodological and financial support to health professions to develop and implement their own collection of PROs.

54.   Germany's Federal Joint Committee (G-BA) is legally mandated to monitor health care quality at the national level (IQTIG) including through data from patient questionnaires. IQTIG is still at an early testing stage with respect to PROs. However, in the medium term, PROs data will be used to monitor health care quality.

55.   Netherlands has set a goal of having patient reported outcome measures by 2022 for diseases accounting for one-half of the total burden of disease. Estonia is including PROs development within the National Health Plan for 2020-2030 that is in preparation and expected to be adopted by the government in 2019. Israel plans to expand monitoring of PROs for hip and knee patients. Luxembourg plans to develop PROs for chronic conditions and generic PROs. Luxembourg may also develop Cancer PROs in collaboration with the National Cancer Institute. Slovenia has a project to develop and introduce two PROs and PREMs Instruments.

56.   Singapore is planning to pilot PROs for Total Knee Replacement (TKR) and Total Hip Replacement (THR). The intent of the pilot is to incorporate PROs results into the assessment of the quality of care as part of the Value-Driven Care (VDC) initiative of the Ministry of Health, and for PROs results to be utilized by clinicians for direct patient care.

57.   The Swedish Association of Local Authorities and Regions (SALAR) is planning a national platform for patient-reported measures, including PROs and patient-reported experience measures. The platform will act both as a library for scales/items and a data collection device, with connections to EHRs and National Quality Registers. The library will also support queries for information and assistance with finding scales or items. Sweden is implementing the item bank system PROMIS. So far, all banks in the system have been translated, however, the infrastructure for national data collection remains to be created, including the computer adaptive testing function.

58.   PROs are an important development area for the Norwegian Institute of Public Health who acts as a PROMIS national centre and works to build the PROMIS item bank for Norway.

2 National Health Data Governance Framework

59.   The 2019/20 Survey of Health Data Development, Use and Governance measured elements of national health data governance including the implementation of national health data governance frameworks and related regulations and policies. Respondents to the 2019/20 survey are officials of national health ministries or national health data authorities (See Annex A). 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 countries reported that a national health data governance framework is established or is being established (Annex B.28).

60.   Six countries reported that their health data governance framework is set out in law (Austria, 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). Health data governance requirements, including *GDPR* requirements, are set out in federal and state laws in Germany.

61.   In France, principles of 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. A Health Data Hub will define the elements of shared data governance with stakeholders.

62.   In Korea, the Ministry of Health established health data governance in 2018 and set up a Health care Big Data Policy Deliberation Committee which is responsible for data development, use and dataset linkages.

63.   Latvia developed a Health System Performance Assessment Framework (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.

64.   In the Netherlands, a National Health 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. It's expected that a new law will be

passed by parliament in 2021 to require the electronic exchange of medical records among health care providers.

65. The United States Department of Health and Human Services proposed a new rule within the *21st Century Cures Act* to support seamless and secure access, exchange and use of electronic health records. 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 of 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 Coordinator 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.

66. In Israel, responsibilities for national health data governance are shared between the Ministry of Health and the Israel Innovation Authority.

67. Ireland's Department of Health is currently working on a national health information strategy to be published in early 2020. 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.

68. Canada is starting work to establish a pan-Canadian health data governance framework. Slovenia is 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 cooperation among several federal health administrations (Federal Public Service Health (FPS Health), RIZIV-INAMI, FAGG) regarding data policy.

69. The Scottish Government 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.

70. 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 and there is no overarching health data governance framework. However, all jurisdictions have 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.

Public consultation on National Health Data Governance

71. In 2019/20, 14 of 23 countries reported that a public consultation had taken place or was planned about the elements of a national health data governance framework (Annex B.28).

72.   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 (Oderkirk, 2017[2]).

73.   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. Health data governance development in Korea includes participation of civil society organisations and patients' organisations in order to reflect diverse public opinions.

74.   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.

75.   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.

76.   Canada reported an intention to consult the public and that 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.

77.   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.

78.   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.

Legal protection of the privacy of personal health data

79.   The 2019/20 survey asked about legislations protecting health data privacy. Survey respondents are health ministry or health data authority officials (see Annex A). Most 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 (Annex B.29). Some countries have legislations at different levels of government. Overall, 21 of 23 countries reported that a 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.

80.   European countries report adherence to the *EU Data Protection Regulation (GDPR) [Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016]*. The *GDPR* places personal health data in a special category with the highest standards of protection. Compliance requires that personal health data are very well organised and portable. For example, organisations must have data systems that allow them to fulfil individuals' rights to access their own personal data, to rectify or restrict their processing and to request data portability from one organisation to another; as well as to assure data are correctly categorised and demonstrate compliance with the regulation. In addition to national privacy laws compliant with the *GDPR*, most EU countries reported other national legislations with provisions specific to the protection of health data; such as laws regarding patient rights, the collection and

management of health information, the provision of medical care and health care organisations, electronic clinical record systems and health research (Annex B.29).

81.   Canada has a national privacy law (*PIPEDA*) that is not specific to health information, but governs personal information in commercial contexts and certain other situations. All 13 provincial/territorial jurisdictions in Canada have specific legislation related to the privacy of personal information and, where that legislation has been deemed substantially similar to *PIPEDA*, the provincial/territorial legislation will govern. Most provinces/territories have legislation specific to the protection of health information, but there is no such legislation at the national level.

82.   National legislation protecting personal data privacy are reported in Israel, Japan, Korea and Singapore. Japan also has legislation specific to the protection of personal information held by administrative bodies and incorporated administrative agencies. Israel also reported regulations protecting personal health data security. Singapore also reports health sector specific legislations that speak to health data privacy protection.

83.   The United States has a sectoral approach to health data governance and privacy law. In the traditional health care industry, where care is provided by a health care professional or hospital and paid for by health insurance, the information related to patients' care is protected in three ways. First, the *Health Insurance Portability and Accountability Act of 1996 (HIPPA)* provides protections through privacy, security and data breach protection rules. Entities covered by *HIPAA* regulations include health insurance companies, HMOs, company health plans, most health care providers (those with certain electronic business transactions), health care clearinghouses (who code data to data standards) and business associates of covered entities.

84.   The *HIPPA* rules are enforced by the Office for Civil Rights of the US DHHS and criminal penalties for certain disclosures are enforced by the Department of Justice. Second, the Federal Trade Commission enforces legislation protecting consumers from unfair or deceptive acts or practices, such as organisations who fail to respect their own privacy policies or who fail to disclose uses of personal data. Third, about half of US States have enacted privacy and data security rules that apply in addition to *HIPPA* to strengthen data privacy protection for certain clinical conditions or circumstances (HIV/AIDS status, mental or reproductive health conditions or protections of the health information of teenagers).

Review and approval processes for personal health data processing

85.   Seventeen countries reported in 2019/20 that a central authority for the approval of requests to process personal health data is established or planned (Annex B.28).

86.   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.

87.   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.

88.   In Korea, the Health care Big Data Policy Deliberation Committee supervises and manages the Korea Health Industry Development Institute, which is responsible for information strategy planning, and the National Evidence-based Health care Collaboration Agency, which is responsible for undertaking dataset linkages.

89.   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 coordination with the Privacy Protection Authority of the Ministry of Justice.

90.   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).

91.   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.

92.   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.

93.   In Canada, provinces and territories have individual processes for approval of requests to process personal health data. There is early consideration being given now for some coordination among them for pan-Canadian data requests. In Denmark there are sub-national authorities that approve requests.

94.   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.

95.   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.

96.   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.

97.   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.

98.   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.

Challenges to national health data use and governance

99.   The 2019/20 survey asked about challenges and difficulties countries were experiencing in the development of health data governance. These included legal or policy barriers to sharing data among public authorities; to public authorities undertaking data linkages; to public authorities extracting data from electronic clinical records; to sharing de-identified data with university or non-profit research organisations within the country; and to sharing de-identified data with a foreign government or a foreign researcher. Other challenges were a lack of person identifiers to link data; concerns with the quality of data that limit their usefulness; and lack of resources or technical capacity to process data or make data accessible for research and statistics. Survey respondents are health ministry or health data authority officials (see Annex A).

100.   Virtually all respondents reported that their country is experiencing one or more data governance or technical challenges at the national level (Annex B.30). The most commonly experienced challenges to developing health data infrastructure were legal or policy barriers to public authorities undertaking data linkages (16 countries); concerns with the quality of data that limit their usefulness (15 countries); and legal or policy barriers to sharing data among public health authorities (13 countries). A group of countries reported experiencing a high number of health data governance and technical challenges: Belgium, Australia, Ireland, Luxembourg, Germany and the Netherlands.

Legal or policy barriers to sharing data among public authorities

101.   Respondents in 13 countries reported a legal or policy barrier to sharing data among public authorities (Annex B.30). In Australia, there was an inquiry in 2012 by the Productivity Commission into data availability and use. The Inquiry identified barriers to data sharing and release; and unnecessarily complex processes for data access. Belgium reported difficulties sharing data among federal public authorities; between public authorities at the federal and regional levels; and between public authorities and semi-public actors, such as health insurance providers. In Canada, there are legal barriers to the disclosure of personal health information among provincial/territorial public authorities and between provincial authorities and federal authorities. In the Czech Republic there are legal barriers to data digitisation that present barriers to data sharing among public authorities.

102.   Estonia reports that data protection legislation makes linking and accessing different data sources a complicated and time consuming process that has become bureaucratic. In Israel, the committee evaluating proposals for the sharing of data among public authorities decline proposals of public authorities that are determined to insufficiently protect privacy. In Luxembourg, each occasion of data sharing among public authorities requires a specific confidentially agreement. In Latvia and Slovenia, data sharing among public authorities can only take place if there is a legal basis for it and laws are developed on a case-by-case basis. In Ireland there is a *Data Sharing Act* that applies to public bodies, however it excludes sensitive personal data, including health data. The Netherlands reports that sharing data for the purpose of calculating indicators of health care outcomes by health care institution is often prohibited.

103.   Japan reports that the *Act on the Protection of Personal Information* requires that sharing of individuals' health data only take place with the consent of the individual or after the data have been de-identified according to a rule set out in the Act. However, personal data may be shared without consent subject to a legal authorisation for the sharing.

Legal or policy barriers to public authorities undertaking dataset linkages

104.   Respondents in 16 countries reported legal or policy barriers to public authorities undertaking dataset linkages (Annex B.30). In Norway, there is no legal basis for dataset linkages. Similarly, there is no legislation in Japan that explicitly regulates the linkage of datasets of public authorities.

105.   The United States *HIPAA* required the creation of national identifiers for patients, providers, hospitals and payers; however, subsequent legislation prohibited the Department of Health and Human Services from funding the promulgation or adoption of a unique national patient identifier. Consequently, data matching is less accurate, poses patient safety risks and raises concerns regarding data integrity and compliance with any restrictions on data use authorised by individuals. Belgium also reports a lack of identifiers to track patients through care processes in different settings or levels of care.

106.   In Canada, there are some provincial/territorial jurisdictions with legal or policy barriers to dataset linkages, particularly for the linkage of health and non-health data. Similarly, in the Czech Republic it isn't possible to link data within the National Health Information System to external data.

107.   In Korea, data set linkages among public authorities are legally possible but the interpretation of the law is strict. The new Big Data Platform Project aims to enable data linkage for health care research.

108.   In Latvia, there must be a specific legal basis for a dataset linkage among public authorities to take place. In 2017, an agreement was signed among four public authorities (Centre for Disease Prevention and Control, National Health Service, State Emergency Medical Service and Health Inspectorate) to establish a linked health database to be used to fulfil a new framework for transparent indicators of health care quality, patient safety and efficiency. In Luxembourg, linkages among public authorities are difficult due to the provision of pseudonymisation services. In Slovenia difficulties arise when the data to be linked are held in more than one public authority.

109.   Public authorities in Australia must be accredited as an Integrating Authority before they can undertake high risk data integration projects, such as the record linkage of national (Commonwealth) datasets. Accreditation assures that the data integration will take place in a safe and secure manner. In Israel, the committee evaluating proposals for the linkage of data among public authorities declines proposals determined to insufficiently protect privacy.

110.   In France, a new legislation in 2019 removed legal barriers to the linkage of the administrative health care (SNDS) dataset and other datasets governed by public authorities and set out conditions under which linked datasets can be created for multiple purposes.

Legal or policy barriers to public authorities extracting data from electronic health records

111.   While many countries are extracting data from electronic clinical records to develop their key national datasets and for research, survey respondents in ten countries reported barriers to doing so (Annex B.30).

112.   In the Netherlands, there are barriers that have arisen following the introduction of the *EU GDPR*. In the Netherlands, health datasets are in the custody of various public sector organisations (such as the Dutch Hospital Data institute, and the Perined (child birth data) institute). Among the custodians of health data, there are different interpretations of the *EU GDPR* and some have determined that past data exchange arrangements are no longer legally permitted. To clarify that data exchange is lawful, some organisations and institutes are asking government for legislation authorising the exchange of electronic clinical data.

113.   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 or not 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.

114.   In France, there is a legal prohibition against extracting data from the electronic health record or DMP (dossier médical partagé) for the purposes of sharing and linking data as part of the health care information system modernisation effort. 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.

115.   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.

116.   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. 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.

Legal or policy barriers to sharing de-identified data for research

117.   The survey asked about sharing de-identified data with researchers for statistical and research projects within the public interest; such as academic and non-profit researchers within the country, and foreign academic, non-profit and government researchers. Respondents in 4 countries (Belgium, Germany, Israel and the Netherlands) reported barriers to sharing de-identified data for research purposes within the country and seven countries (Canada, Denmark, Germany, Ireland, Japan, Korea and Sweden) reported barriers to such sharing with a foreign academic, non-profit or public sector researcher (Annex B.30). Sharing de-identified health data for research purposes with academic and non-profit researchers in the European Economic Area is governed by the provisions of the *EU General Data Protection Regulation (GDPR)* that came into force in May 2018. Under this regulation, de-identified data may be considered personal data and subject to the regulation.

118.   In Germany, sharing of de-identified data (data that are not considered anonymous) falls under data protection legislations at the federal and state levels as well as under state hospital laws. With respect to foreign researchers, approval depends on the regulation governing the data involved. A solution can be to form a research collaboration with a German institution.

119.   In the Netherlands it is not clear how to interpret *EU GDPR* requirements as they relate to sharing data as was discussed in the previous section and, as a result, sharing de-identified data has become more restricted. As many datasets in the Netherlands are owned by health care providers, they are not always willing to share data. As in Germany, a solution for foreign researchers to access data in the Netherlands is to become part of a research team with Netherlands researchers. In Sweden, the sharing of data with foreign researchers depends upon whether the data protection legislation of the receiving

country is considered adequate vis-à-vis the national legislation. As a result, in practice, it is easier for researchers within the EU to be approved access to data.

120.   In Estonia, sharing data can be a lengthy and bureaucratic process, however, it is possible for both foreign and domestic applicants to be approved. Belgium follows the *EU GDPR* and does not distinguish between national use and foreign research, but applicants must fulfil all of the conditions of the Information Security Committee and be approved by the data owners. Approval may be granted for scientific studies but not for commercial purposes. In Belgium there is no policy with respect to sharing data. In Ireland, provisions of the *Data Protection Act* deal with the transfer of data to a third country; however, concerns of individual organisations whose data would be involved may preclude data sharing with foreign researchers.

121.   In Australia, researchers who demonstrate that their work has been approved by the appropriate ethics committee should be able to access de-identified data securely. However, approval processes can be complex and lengthy. If the researcher is in a foreign country then the difficulty is in ensuring that the data could not be re-identified. The *Privacy Act* 1988 requires that an entity that releases an individual's personal health data is accountable if the foreign researcher mishandles the data. Further, the regulatory framework for the MyHealth Record (electronic health records) prohibits data within the MHR from being shared or stored outside Australia.

122.   In Canada, some provinces and territories prohibit, by law or policy, the disclosure of de-identified record level data outside of Canada. There is no legal basis to share data with a foreign researcher in Korea.

Lack of person identifiers to link the data

123.   Respondents in 8 countries reported a lack of person identifiers needed to link data for research and statistical purposes in the public interest (Annex B.30). As was discussed earlier, federal authorities in the United States are prohibited from funding the promulgation or adoption of a national unique patient identifier and, as a result, record linkage is probabilistic. In Japan, there is no unique person identifier that could be used to link health datasets. In Australia there is no universally used health care recipient identifier and dataset linkages are probabilistic and based on combinations of personal information such as date of birth and address. Belgium has a national register number (INSZ or NISS) that could be used as a unique patient identifier, but there is no legislation that authorises its use for this purpose, so it is not applicable.. Canada has a unique health care number within each province and territory but linkage across provinces and territories is difficult and it is challenging to link to non-health care datasets. There is no unique person identifier in Germany that works across all datasets. In Norway, a legislation introduced in 2014 enabled the creation of unique health identifiers, however the identifiers have not yet been rolled out to the public making any potential attempt to link data technically difficult. In the Netherlands, there are still some datasets lacking person identifiers but the number of such datasets has been decreasing. In France, research teams require the approval of the National Data Authority to link health databases using a general identifier. While the process to request approval was made easier since 2016, few research teams have sought this approval.

Concerns about the quality of data that limit their usefulness

124.   Overall, respondents in 15 countries reported that there are concerns about the quality of national data that limit their usefulness (Annex B.30). More detail about these concerns was expressed in Part 1 regarding each of the key national health datasets.

125.   Overall, countries stated that there may be concerns with the quality of administrative data when they are used for purposes beyond their original intent (Latvia, Australia); as well as with the quality of data

entered/coded by health care practitioners in electronic records, which has not yet been widely assessed (Australia, Estonia). There is a problem with the usability of data within medical records in France due to multiple software providers and a lack of data standards; there is also a problem of lack of structured data and use of free text data capture in health records (Austria, France). The lack of common data standards across provinces and territories in Canada and inconsistent application of standards are emerging issues. Inadequate digital capture of data is another challenge (Singapore).

126.   In the United States, lack of data standards, inconsistent data formats and inaccuracies in demographic data across different data sets diminish the accuracy of dataset linkages. Patient identity matching across datasets is usually reliant on patient demographic data as record linkage uses technologies such as a master or community patient indices and deterministic and probabilistic linkage methods. Studies have found that errors in data matching often result from the quality of patient demographic data, where the quality issues arose when the data were first collected during the patient registration process.

127.   Timeliness is an issue, as are a lack of quality control mechanisms and sanctions for poor quality data (Belgium). In the Netherlands, medical care data from medical specialists in hospitals and ambulatory settings is not timely due to a long delay in billing data and the coding system used by these providers is difficult to analyse. There are health care sectors (including general mental health care, long term care and health care for children and youth) where datasets are not available, are incomplete or are missing diagnosis. Coverage of diagnosis in the registry of primary health care visit and the coverage of secondary diagnosis in hospital data are data quality concerns in Finland. There are concerns in Germany about the quality of cause of death information in mortality data.

128.   In Ireland, there are more concerns about dataset governance than quality. The Health Information and Quality Authority (HIQA) has written several reviews of information practices in key health datasets and has found several issues of governance.[2]

Lack of resources or technical capacity to process data or make data accessible

129.   Respondents in 9 countries reported a lack of resources or technical capacity to process data and make data accessible (Annex B.30). Australia noted that maintaining and maximising a dataset's usefulness requires specialised skills and understanding of potential data users and that these skills are in short supply, particularly in the public sector. In Australia, skill development has been identified as a priority by government's seeking to increase the use of their data.

130.   In Belgium, technical capacities are fragmented because of a large number of dataset custodians within and outside of public administration and there is a lack of specialised competencies. Further the high number of data custodians results in the need to address differing dataset governance requirements to undertake research and statistical projects. Ireland is lacking a central body to process and make data available in an efficient manner. These tasks are done in individual organisations to varying degrees.

131.   Latvia does not yet have a technical infrastructure to provide researchers with direct access to data. In the Netherlands, data access is expensive and datasets are sometimes incomplete which make them difficult to link with other datasets. Data accessibility is a challenge in Singapore due to a limited headcount within the research data centre. In Sweden, large volumes of research requests to national authorities challenge capacity to manage them. Similarly, in Finland the quantity of data access requests exceeds the human IT resources to process them within a reasonable time limit.

132.   The United States reports investments in technical resources for projects related to data interoperability for research and health outcomes as a solution to improve capacity to process and make

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[2] See https://www.hiqa.ie/reports-and-publications/health-information.

data accessible. A share of a trust fund for Patient Centred Outcomes Research goes to the Office of the Secretary of Health and Human Services to build data capacity for patient-centred outcomes research. The US National Institutes of Health is also investing in the All of Us Research Program that provides researchers with access to diverse and accessible data resources, subject to safeguards protecting data privacy and data security.

3 Governance of key national health care datasets

133.   While Part II outlined key aspects of national data governance and challenges to data development and governance, this section delves deeper into how these national governance frameworks are applied in practice within 10 key national health care datasets. In this way, variability in data governance practices within countries are clarified, as well as variability across countries. Countries overall performance regarding health care dataset governance is summarised in Annex B.31. Considering 15 key dataset governance elements measured in this survey and presented in this section, the countries with the strongest dataset governance were Denmark, United States, Finland, France, UK (Scotland), Korea and Belgium (Figure 3.1)

Figure 3.1. Key national health care datasets governance elements
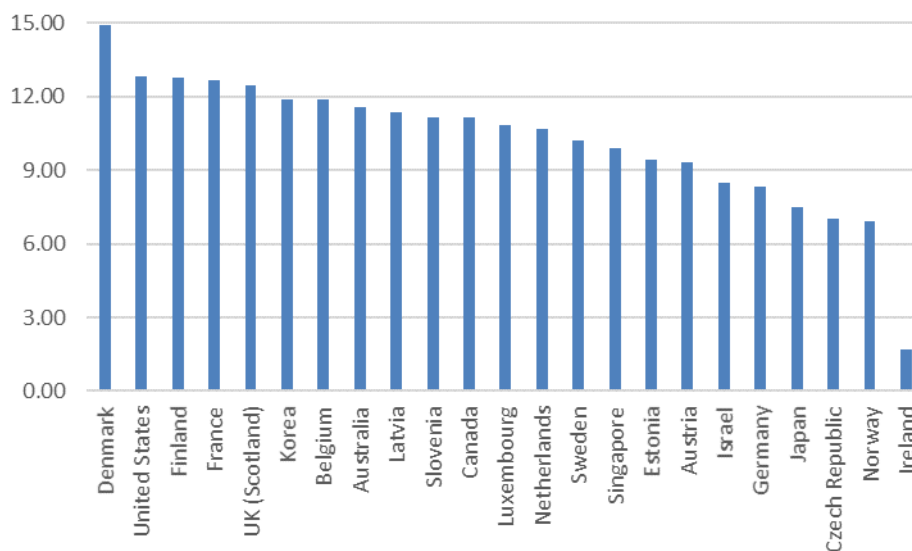
Note: The score is the sum of the proportion of national health care datasets meeting 15 governance elements. The maximum score is 15. See Annex B.31.
Source: Author.

Authorisation of dataset creation

134.   In most countries all, or nearly all, of the 10 key national health care datasets included in this study are authorised by law. Thirteen countries reported that 100% of their key national health care datasets were authorised by law and another four countries reported that 85% or more of these datasets were legally authorised (Annex B.32). Patient consent is rarely the legal authorisation for national dataset creation in health care. In three countries, Norway, Korea and Australia, the national diabetes registry is authorised by patient consent. National emergency care data are authorised by consent in Germany and

the United States; prescriptions medicines data are authorised by consent in the United States; and long-term care data are authorised by consent in Australia and the United States. In the Netherlands, prescription medicines and cardiovascular disease registry data are authorised by consent and legislation. In the United States, primary care data are authorised by consent. In Korea, it is possible for next of kin to consent to inclusion of a record in the mortality database.

135.   In more countries, patients can opt-out of having their information included in a national health care dataset. Patients can opt-out of the majority of national health care datasets in four countries (France, the Netherlands, Singapore and United States). In France, the opt-out does not apply to data processing by public bodies. In the Netherlands, opt-out only applies to research uses of in-patient hospitalisation data and for mental hospital in-patient data, opt-out is offered for diagnosis. In United States, the *HIPPA* law provides for an opt-out, however, most patients sign a *HIPPA* disclosure form which allows data sharing for research purposes. Other countries offering opt-out of health care datasets include Australia (diabetes registry), Belgium (cancer and diabetes registries), Germany (emergency care), and Norway (diabetes and cardiovascular disease registries). In Norway, patients can also opt-out of research uses of cancer registry and formal long-term care data. In Sweden, patients can opt-out of quality registries for CVD conditions, but not from the national dataset. In Korea, it is possible for next of kin to opt-out of inclusion of a record in the mortality database.

136.   In seven countries, all or nearly all datasets are authorised by a privacy regulatory body or a research ethics committee often in addition to legislative authorisation (Australia, Belgium, Denmark, France, Korea, Netherlands and United States). In three countries, a privacy regulatory body or research ethics committee authorised one national health care dataset: the diabetes registry in Norway, the prescription medicines dataset in Canada, and the cancer registry in Luxembourg.

137.   In Canada and Australia, the authority for the creation of some datasets is a contractual or agreed relationship between national authorities and data suppliers. In Australia, data for hospital and mental hospital in-patients and emergency care are provided for the national datasets under the National Health Information Agreement with data suppliers. The diabetes registry in Australia is developed under a contract between the Department of Health and Diabetes Australia. In Canada, the Canadian Institute for Health Information is a secondary collector of health data, specifically for the planning and management of the health system, including statistical analysis and reporting. Data providers are responsible for meeting the legislative requirements in their respective jurisdictions, where applicable, at the time the data are collected.

138.   In Australia, for the formal long-term care dataset, there is a legal authorisation for data suppliers to provide data to the Australian Institute of Health and Welfare.

139.   In the United States, U.S. state laws and regulations authorise the collection of mortality data that is then provided to the federal government for national statistics.

Data protection/privacy officers within national dataset custodians

140.   Most countries have a data protection or privacy official within the data custodian's offices for all of their national health care datasets (Annex B.33). In countries within the European Economic Area, the requirements of data protection officers within data processors are set out in the *General Data Protection Regulation*.

141.   In Germany and the United Kingdom (Scotland) there was an officer reported for the majority of national health care datasets. In Ireland, the custodian of national hospital in-patient data has a data protection official. In Norway, a national data protection or privacy official was not reported within the organisations responsible for health care datasets.

142.   The main responsibilities of the data protection/privacy officer within organisations processing health care data are similar across countries. Principally, these officers ensure that all aspects of the processing of personal health data are done in conformity with legal requirements for data protection, which often involves developing internal policies and guidelines, and providing education and advisory services to staff. In some countries they may have additional responsibilities, such as the ethical use of data in Singapore and United States; data de-identification/pseudonymisation and disclosure mitigation in Belgium, Israel, Czech Republic and United States; and for cyber security in the Czech Republic.

Staff processing personal health data are trained in data privacy and security protection

143.   The 2019/20 survey asked countries if the organisations responsible for 10 key national health care datasets provide regular training to staff regarding their responsibilities to protect privacy and data security.

144.   Sixteen countries reported that regular training was provided to staff across all of the organisations responsible for all key health care datasets (Annex B.34). The United Kingdom (Scotland) reported that this was the case for the majority of key health care datasets. Six countries did not confirm that regular staff training is provided for most key national health care datasets (Norway, Japan, Israel, Ireland, Germany, and Estonia).

145.   In Belgium, Canada, Czech Republic, Korea, and Latvia training is provided when staff start a new job and then annually afterward. Training is provided annually in Denmark and United States. United Kingdom (Scotland) provides training when staff start a new job and then every 2 years afterward. Slovenia provides training when staff start a new job and then every 3-4 years afterward. In Luxembourg, training is provided when staff start a new job and then on an ad hoc basis afterward. Singapore provides training when staff start a new job or gain access to a new dataset. Sweden provides training when staff start a new job involving the health registries. In Australia, training in data privacy and security protection is provided for new staff or when there are changes in legislation and at other regular intervals. Similarly, training is provided in Finland at the start of employment and when necessary afterward, such as when there are changes in legislation.

146.   Training is provided to new staff and to all staff annually for some health care datasets in Estonia (cancer registry, cardiovascular disease registry and mortality data) and for the cancer registry in Japan. Training is provided in Germany for staff processing hospital in-patient data at 1-2 year intervals.

147.   In Austria and the Netherlands, the frequency of staff training depends on each organisation's internal rules and practices. Most organisations in the Netherlands, however, reported training staff who were starting a new job.

Controlling access to personal health data

148.   Identities of staff accessing all key national health care datasets are controlled and tracked in 14 countries and for most national health care datasets in 4 countries (Annex B.35). In Sweden, employees are authorised to access datasets, as required, and usage is not tracked; with the exception of the cancer registry where usage is logged. The control and tracking of the identities of staff accessing the majority of national personal health care datasets in Germany, Ireland, Israel, and Norway was not reported.

149.   Slovenia uses personal digital certificates to track the identities of individuals accessing personal health data. Singapore uses data request forms for data access and tracks and audits system access. Luxembourg restricts access to authorised persons and every dataset access is logged. In Latvia, authorisation is only possible with internet bank access details, electronic ID or electronic signature (for E-health system) or username and password (for other health data systems). Further, all access to personal

health data is audited. In Finland, staff must have permission to access data, the access is password protected and usage is logged.

150.   Staff approved to access SNDS data in France, access the data via a secure portal that authenticates users and tracks usage. In the United States, staff must complete a data user access request form detailing the folders and files they will be accessing. Access to data is provided through a Research Data Centre.

151.   In Korea, only authorized personnel are allowed access and the data cannot be stored on a storage device, such as USB. Estonia also restricts access to authorized personnel and, for some datasets, logs activity. In Canada, some datasets require a user-id and a password to access while other datasets maintain access and activity logs. Australia and Czech Republic restrict access to authorized personnel. In Belgium there is a data access management process.

152.   Denmark is revising its practices in response to changes to regulations and to a re-organisation of health data processors.

Data de-identification

153.   Seventeen countries report that all of their key health care datasets are de-identified prior to analysis (Annex B.36). This is also the case for the majority of health care datasets in four countries. Norway and Ireland did not report that data are de-identified prior to analysis.

154.   Fifteen countries reported that pseudonyms are created for direct identifiers on all of their health care datasets and four countries reported this was the case for most of their health care datasets (Annex B.37). Reversible pseudonyms facilitate re-identification to conduct future approved data linkages and analysis or to inform an individual of a specific condition or research outcome, where appropriate.

Risk Management

155.   Thirteen countries reported that there is a process for the assessment of the risk of data re-identification for all or the majority of their health care datasets (Annex B.38). In contrast, in 10 countries, assessment of data re-identification risk is not done or is done for only one or two health care datasets.

156.   Nine countries reported that there are practices for the treatment of variables that pose a re-identification risk (such as rare diseases, exact dates, locations, or ethnic origins) for all of their key health care datasets (Annex B.39). Another 10 countries reported that this was the case for most of their key health care datasets. Four countries did not report these practices (Austria, Ireland, Norway and Slovenia).

157.   The United Kingdom (Scotland) reported techniques to protect against data re-identification including table redesign, supressing values and swapping records. Singapore reported using data suppression, grouping values and randomising shifts in values. Canada reported using data suppression, truncation of values and grouping, and for mortality data rounding to a base of 5. Japan and Australia reported grouping values and supressing values. Czech Republic, Israel, Luxembourg and Latvia reported grouping values. Estonia reported supressing values, including where variables represent less than 5 cases. Denmark reported rounding values and supressing variables representing less than 5 cases. Belgium and United States reported grouping, suppression and data masking, as well as restricting some data in Belgium to aggregated data only and, in the US, creating restricted data files. Korea reported grouping values and supressing values. Most data custodians in the Netherlands reported grouping values and some reporting supressing values. Germany reported not using exact dates within cancer registry data and Japan reported grouping and supressing values in the cancer registry.

158.   Few countries reported conducting testing on all or the majority of datasets to ensure that realistic re-identification attacks will have a very small probability of success: Denmark, France, Korea, Singapore,

United Kingdom (Scotland) and United States (Annex B.40). Belgium, Germany, Luxembourg, the Netherlands and Sweden reported conducting this testing on some of their health care datasets.

159.   In Sweden, the main effort is prevention of data intruders. All data at the National Board of Health and Welfare are managed and placed in a separate network/servers. The lock to access the network is supervised and logged. This is handled in a similar way at the diabetes register. A few years ago, ethical hackers were engaged to test the strength of the protection against intrusion. France reported testing re-identification by using external information. Both France and Sweden indicated that their main effort is directed toward preventing data intruders, such as secure storage and access to data and access controls.

160.   Korea reported using an encryption technique where data are made unintelligible to all except holders of the decryption key and testing the risk of unauthorised decryption. Denmark uses a method similar to that of Korea when data are to be shared with external researchers. Luxembourg reported using data security auditing for the cancer registry. The Netherlands reported using software developed to detect reidentification risk for mortality data. Belgium reported disclosure risk assessment to ensure that released data has 5 or more cases per cell. Singapore reported testing the data anonymization process. Denmark reported that the testing methods are under development.

Data sharing within government

161.   This survey asked if key national health care datasets are ever shared with any other public data custodian or government entity.

162.   Eight countries indicate that all of their key health care data sets are shared with other pubic data custodians or government agencies and nine more countries indicated this sharing with the majority of key health care datasets (Annex B.41). Some countries reported sharing was possible with one dataset only, which is the cancer registry in Slovenia, long-term care data in Singapore and hospital in-patient data in Germany. In Japan, Ireland and Czech Republic, key national health data sets were not reported as ever shared with other data custodians or public entities.

163.   Countries were asked if data shared with other data custodians or public entities contains direct identifiers or variables that are used for dataset linkages (Annex B.42). Such sharing usually occurs because it is necessary for dataset linkages for dataset creation for public administration or monitoring or for particular research projects. This sharing is possible in Denmark for all health care datasets and for most health care datasets in Korea and Canada. This sharing occurs for cancer registry, cardiovascular disease registry and mortality data in Estonia. It occurs only for prescription medicines data in Belgium, only for long-term care data in Singapore and only for diabetes registry data in Sweden.

164.   Far more common was sharing data containing pseudonymised identifiers with other data custodians and government entities. Fourteen countries share all or most health care datasets with pseudonymised identifiers (Annex B.43).

Sharing de-identified data for research and statistics

165.   This survey asked countries about whether key national health care datasets, after data de-identification, can be shared for research, statistics or other uses in the public interest and with whom. Analysts employed by a government ministry or department may apply for and be approved access to all key de-identified personal health care datasets in 11 countries (Annex B.44). In eight countries this was possible for the majority of health care datasets. In four countries, this sharing occurred for one dataset or no sharing was reported.

166.   Analysts employed by a university or non-profit research centre may apply for and be approved access to all de-identified personal health care datasets in 11 countries (Annex B.45). In another nine countries, this was true for the majority of health care datasets. In Austria this was true for hospital in-

patient, cancer registry, long-term care and mortality data. In the Czech Republic and Ireland, no sharing with university or non-profit researchers was reported.

167.   Analysts employed by a health care provider can apply for and be approved access to all de-identified personal health care datasets in 8 countries (Annex B.46). In another 10 countries, this is possible for the majority of health care datasets and in 2 countries for a few datasets. Such sharing was reported in Sweden for the diabetes registry. In Czech Republic and Ireland such sharing was not reported.

168.   Analysts employed by a for-profit business could apply for and be approved access to all key de-identified personal health care datasets in Denmark, Finland, Norway, Singapore and United States (Annex B.47). Access to the majority of key de-identified personal health care datasets for this group was possible in United Kingdom (Scotland), France, Estonia, Canada and Australia. In Austria, de-identified hospital in-patient, cancer registry and mortality data can be shared with analysts employed by a for-profit business. In the Netherlands, de-identified prescription medicines and cardio-vascular disease registry data can be shared with analysts in this group. In Japan and Germany, cancer registry data could be shared with this group. In contrast, 9 countries have no sharing of de-identified personal health care datasets with analysts employed by a for-profit business.

Authority for sharing data within government and with external researchers

169.   The 2019/20 survey asked under what authority data could be shared with other government entities or external researchers. Survey respondents are officials from health ministries and health data authorities (see Annex A). Respondents reported that in Slovenia, Norway, Korea, Germany, Finland and Denmark, the sharing of health care datasets is authorised by law for all key health care datasets. In the United States, the Netherlands, Luxembourg, Japan, France, Canada, Austria and Australia, legislation authorises the data sharing for most key health care datasets that are shared. Legislation authorities the sharing of a minority of datasets in Singapore, Latvia, Estonia, Belgium and United Kingdom (Scotland). In Israel, legislation allows the Central Bureau of Statistics to receive datasets from the health ministry. No sharing of the key health care datasets with other government entities or external researchers is authorised by legislation in Sweden, Ireland, and Czech Republic.

170.   Far less common is authorising the sharing of health care datasets within government or with external researchers by patient consent. Only in Latvia (8 datasets), United States (5 datasets) and Canada (5 datasets) did respondents report that patient consent is an authorisation for the sharing of a majority of health care datasets. Three key health care datasets in the Netherlands, two in Korea and Estonia, and one in Australia, Austria, Germany, Norway and United Kingdom (Scotland) were authorised to be shared by patient consent.

171.   Data subjects were rarely given an opportunity to opt-out of the sharing of key health care datasets. Only respondents in France, the Netherlands and United States reported that one-half or more of key health care datasets had an opt-out of data sharing with government entities or external researchers. Opt-out to data sharing with government entities or external researchers was reported for the sharing of diabetes registry and/or cancer registry data in Sweden, Norway, Luxembourg and Australia. Norway also offers an opt-out to the sharing of long-term care data.

172.   A data privacy protection authority or a research ethics committee authorises the sharing of data with government entities or external researchers for all health care datasets in 9 countries and for the majority of health care datasets in 7 countries. In the United Kingdom (Scotland), Luxembourg and Austria, this was reported as a requirement for sharing one health care dataset. This type of approval was not reported for sharing health care datasets in Czech Republic, Denmark, Germany and Ireland.

Cross-border data exchange and collaboration

173.   In this survey, many countries report recent policy relevant projects involving multiple countries in the linkage of their datasets or in the extraction of data from clinical record systems (Annex B.54). These projects include parallel studies, where researchers in each country follow a common study protocol, and studies where data were shared across borders. Examples included studies of prescription drug use and harms between Australia and Canada; between United States and Canada; among Denmark, Finland, Norway and Sweden; and among Australia, United States, Denmark, Finland, Iceland, Norway and Sweden. There are examples of indicator development and research to improve health system performance including projects between Latvia and Slovenia; among Japan, Singapore, China and Hong Kong; and among Finland, Hungary, Italy, the Netherlands, Norway, UK (Scotland) and Sweden. There are multiple examples of global and European projects examining cancer incidence and survival; and multiple examples of European projects involving indicator development and research.

174.   In some OECD countries, data localisation regimes either explicitly forbid health data processors from approving the sharing of data with an organisation located outside of their country or create obstacles such as a lack of clarity about how data sharing outside of the border might be approved (Svantesson, 2020[3]). Existing regimes can also result in processes to obtain approval that would be prohibitive in terms of time and resources. In federated countries, laws and policies within states, provinces or regions may entrench data localisation at a national level.

175.   In this survey, countries were asked if de-identified data from key national health datasets may be shared with approved researchers working in a foreign academic or non-profit research organisation (Annex B.48). 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 reported sharing data outside of their country was possible with the majority of health care datasets. A minority of de-identified health care datasets could be shared cross-border in Austria and Latvia.

176.   Australia noted that while such sharing is possible, it would only be permitted for data that cannot be re-identified and no instances of such sharing are known in practice. Australian researchers who demonstrate that their work has been approved by the appropriate ethics committee should be able to access de-identified data securely. However, approval processes can be complex and lengthy in order to ensure that the use of the data would be secure and appropriate. This may be a barrier to accessing and using these data.

177.   Canada reported that such sharing is possible at the national level but only if it is not prohibited by provincial law or by the terms of data sharing agreements with data suppliers. Germany also indicated that due to a federal structure, state data protection laws and laws governing hospitals may prohibit data sharing with foreign entities within, and outside of, national borders. This illustrates how the harmonisation of policy frameworks within countries is critical.

178.   Cancer registry data are the national data that are the most likely to be shared internationally. Fourteen countries reported that they could share de-identified national cancer registry data with approved foreign researchers in academic and non-profit organisations. Along with the rich history of international cancer research collaboration, this reflects the success of creating a policy and legislative environment that enables relevant data to be available for research. It also illustrates that it is eminently possible to free up personal health data for secondary uses with the requisite political will and coordination of effort.

179.   In some countries, however, no key national de-identified health care data can be shared with foreign researchers. Eight countries, Czech Republic, Ireland, Israel, Japan, Korea, Sweden, United Kingdom (Scotland) and United States, would not approve sharing de-identified data from any of the thirteen key national health datasets with a foreign researcher in the academic or non-profit sectors. United States reported that while there is no access to de-identified national health care datasets (restricted

datasets) for foreign researchers, foreign researchers can access public-use microdata files, which are datasets where variables have been treated to ensure a very low re-identification risk. Privacy policies in Israel limit approval of data sharing outside of the country, but mechanisms exist to permit sharing under agreed conditions. The preference, however, is to provide access to information/research results.

180.   Under the *European General Data Protection Regulation* (*GDPR*), de-identified microdata may still be considered personal data and be subject to protection. Ensuring that *GDPR* requirements are met was noted in the 2019/20 survey as a barrier to data sharing by Germany and the Netherlands.

Data sharing agreements

181.   Eighteen countries reported that they have a standard data sharing agreement for disclosing data from all or the majority of their health care datasets (Annex B.49). A standard data sharing agreement was reported for one dataset in Ireland. The use of standard data sharing agreements was not reported in Austria, Czech Republic, Estonia, and Norway.

182.   Standard data sharing agreements include requirements for certain data privacy and security practices at the data recipient's site for all or the majority of health care datasets shared by sixteen countries (Australia, Belgium, Canada, Denmark, Finland, France, Israel, Japan, Korea, Luxembourg, Netherlands, Singapore, Slovenia, Sweden, United Kingdom (Scotland) and United States).

183.   Examples of the requirements for data privacy and security practices in standard data sharing agreements include:

- Qualified personnel,
- Secure data storage,
- Data use is in accordance with applicable laws,
- Data is used only for approved purposes,
- Secure physical site where data is held,
- Data access is restricted via a secure server (remote access),
- Data access is restricted to authorised staff,
- Data destruction date is respected,
- No unauthorised data linkages,
- No unauthorised data sharing,
- No attempt at data re-identification,
- Disclosure rules applied to published statistics and research findings,
- Training in data privacy and security protection, and
- Adherence to national or international standards for IT security.

184.   Seven countries reported providing training to data recipients regarding data privacy and security practices when all or the majority of health care datasets are shared (Austria, Demark, Finland, France, Korea, United Kingdom (Scotland) and United States). Estonia provides training when cancer registry and mortality data are shared, the Netherlands provides training when mental hospital in-patient data and mortality data are shared, and Ireland provides training when hospital in-patient data are shared.

185.   The United States offers on-line training. In-person instruction is provided in Estonia. One-on-one meetings or trainings are reported in the Netherlands and Finland. France requires training take place before data access can be approved. United Kingdom (Scotland) trains on the Medical Research Council requirements for research, *GDPR* requirements and data confidentiality protection.

186.   The survey asked whether data sharing agreements include penalties that would occur if the required data privacy and security practices were not respected. Penalties were reported as included in standard data sharing agreements in Australia, Canada, Estonia, Finland, Germany, Japan, Korea, Latvia, Luxembourg, Netherlands, Singapore, Sweden, United Kingdom (Scotland) and United States.

Data transfers to approved applicants

187.   Countries were asked if they transfer data to approved applicants, such as by sending a copy of a dataset. This method is used for transferring all health care datasets to approved applicants in eleven countries and for transferring some key health care datasets in another nine countries (Annex B.50). Fourteen countries described secure portals/file transfer protocols to transfer data over the internet (Australia, Belgium, Canada, Denmark, Finland, Germany, Ireland, Israel, Korea, Luxembourg, Netherlands, Singapore, United Kingdom (Scotland) and United States).

188.   A few countries were encrypting the data and sending it to the recipient on a USB stick or CD: Sweden, Slovenia, Latvia, and Japan, In Estonia, the encrypted data may be sent by e-mail, by using a cloud transfer mechanism and by USB stick. In Canada data is sometimes encrypted and sent on a CD and in Korea it is sometimes sent on a USB stick.

Alternatives to transfers – remote data access and research data centres

189.   Alternatives to data transfers to third parties include secure research data access centres and remote data access facilities. Overall, 11 countries out of 23 provided secure access to all or most de-identified national health datasets via remote data access, a research data centre or both (Austria, Denmark, France, Israel, Korea, Luxembourg, the Netherlands, Singapore, Slovenia, United Kingdom (Scotland) and United States).

190.   Remote data access is a service providing access to data stored on a computer or network from a remote distance. Remote data access services are often secured to ensure that users can only access data to which they have been approved and that users can not alter or withdraw/copy the data from the system without permission.

191.   Six countries provide access to all or most key health care datasets to external approved applicants via a remote data access facility: United Kingdom (Scotland), Luxembourg, Korea, France, Denmark and Austria (Annex B.51). Sweden and Belgium offer remote data access to the diabetes registry. Germany and the Netherlands provide remote access to in-patient hospital data. The Netherlands also has this service for access to mental hospital in-patient data, CVD registry and mortality data. Finland has this service for mortality data. Australia offers remote data access to primary care and prescription medicines data via an enterprise data warehouse.

192.   A research data centre is a secure physical setting, such as a secure room, where access is provided to data. Research data centres may have physical security, such as supervision and locked doors, as well as computer and data security, such as computer systems that ensure users can only access data to which they have been approved and that users can not alter or withdraw/copy data from the system without permission.

193.   A research data centre is provided for all or most health care datasets in seven countries: Denmark, Israel, Korea, Singapore, Slovenia, United Kingdom (Scotland) and United States (Annex B.52). Australia offers a research data centre for primary care data, prescription medicines data, and long-term care data; Austria offers this service for hospital in-patient, cancer registry and mortality data; the Netherlands offers this service for CVD registry, long-term care and mortality data; and Canada offers this service for cancer registry and mortality data. A few more countries offer a research data centre for one

dataset: Sweden for diabetes registry data, Germany for hospital inpatient data, Finland for mortality data and Belgium and Luxembourg for cancer registry data.

194.   Australian national authorities use remote access data laboratories for analysing routinely collected data, allowing researchers to log in remotely and securely analyse data. For the diabetes registry in Belgium, remote data access is provided via virtual desktops with SAS Enterprise Guide, connected to a SAS server and a DB2 database. In Luxembourg, a government cloud environment is used to create one virtual office per project where approved applicants access the data by state internal network or VPN with strong user authentication. In Sweden for the diabetes registry data, the remote access service is called SODA - Secure Online Data Access. SODA users cannot download or copy data and can only perform data analysis.

195.   In the Netherlands, hospital in-patient and mental hospital in-patient data are accessible through a remote data access service of Statistics Netherlands. A remote data access service for long-term care data is provided within the Vektis Institute. Research data centres are provided for CVD registry and mortality data.

196.   In France, the law restricts the processing of data to secure environments that conform with security requirements. Access to national de-identified health care data is via secure remote data access platforms provided by organisations meeting these security requirements. The linked health care administrative data in France (SNDS) are accessible via a platform operated by CNAM. Other platforms also provide remote access to health data, such as a platform for accessing hospital data managed by ATIH, and a platform offering access to a broad range of economic and social data via a Centre for Secure Data Access (CASD) on behalf of several public organisations.

197.   In Austria, the secure research data centre is called SafeCentre and is provided by Statistics Austria. In Korea, the Remote Analysis System is managed by the Health Insurance Review and Assessment Service (HIRA).

198.   In the United States, access to de-identified personal health data (restricted data) is provided within research data centres of the National Centre for Health Statistics, which has four locations on the east coast, and also via a network of statistical research data centres managed by the US Census Bureau, which has sites across the country.

199.   In the research data centre for the cancer registry in Belgium, data users access a computer that is part of a system that limits data access to only approved datasets and prevents users from downloading or copying data without permission. In Slovenia, there is a special room within a secured building that is without internet connection and provides users with access to several standard software packages (SPSS, SAS, MS).

200.   Finland has launched a new Health and Social Data Permit Authority (Findata) to promote the secondary use of health and social data, facilitate the process to authorise data access and protect data privacy and security. As part of this effort, Finland is developing a remote data access service that will provide access to the majority of national health datasets.

201.   In Canada, the Canadian Institute for Health Information is developing a secure analytic environment for data access to national health care datasets. Some health datasets are accessible in Canada via Statistics Canada's Research Data Centres which are located across the country.

202.   The number of analysts accessing health care datasets in research data centres or via remote data access services varies a lot by dataset in many countries. The highest number of annual external data users was reported by Korea and France. Korea reported 1,500 external analysts accessing the national health care data of HIRA per year. Since 2017, France has received 450 applications for access to the national linked health administrative data (SNDS). Australia reported over 1000 external analysts accessing long-term care data each year, but relatively fewer accessing hospital in-patient data (100) and

emergency care data (50). The United States reported over 1000 external analysts accessing mortality data. The number of external data users varied by health care dataset from 1 to 500 in the Netherlands; 33 to 300 in Sweden; 10 to100 in Finland; from 5 to 83 per year in Canada; about 40 in Germany; from 4 to 20 in Estonia; under 100 in Singapore; and 2 to 20 in Slovenia.

203.   Eleven countries reported a financial charge for access to all or most key health care datasets: United States, United Kingdom (Scotland), Sweden, the Netherlands, Latvia, Korea, Japan, Finland, Denmark, Canada, and Australia (Annex B.53). France has a financial charge for access to in-patient hospital and mental hospital data and is planning a financial charge for other health care datasets. Statistics Austria has financial charges to access hospital in-patient, cancer registry and mortality data. Germany has a financial charge for access to inpatient hospital data and Belgium has charges to access primary care data and the cancer and diabetes registries.

204.   Seven countries charge for dataset linkages among all or most health care datasets (Australia, Canada, Denmark, Finland, Sweden, United Kingdom (Scotland) and United States). Japan and Korea have charges for linkages involving cancer registry data and Belgium for linkages involving cancer and diabetes registry data. The Netherlands has charges for linkages involving primary care data, long-term care data and mortality data.

Approval processes for access to data and dataset linkages

205.   The survey asked countries which body or bodies would approve a dataset linkage or further processing of key health care datasets. Only in a few countries was it clear that the approval to further process health care data was a decision taken by an independent body. Many countries have internal committees within data custodians that approve further data processing.

206.   In Australia, research ethics committees approve projects as do the custodians of the datasets involved. In France, the national data protection authority approves health dataset linkages and further processing of health data. In Denmark, both the Danish Health Data Authority and the data protection agency approve further health data processing. Research ethics committees approve processing of health care data in Estonia. The Swedish Ethical Review Authority approves processing of health care datasets in Sweden. The Public Benefit and Privacy Panel approve processing of health care data in United Kingdom (Scotland). In Finland, when dataset linkages involve datasets in the custody of two or more organisations, the Health and Social Data Permit Authority approves the processing.

207.   In Belgium, a consultative committee and the data protection authority approve further processing of cancer registry data; an evaluation committee with expertise in prescribing approves further processing of prescription medicines data; a board of experts approves further processing of primary care data; and an information security system approves further processing of hospital inpatient, mental hospital inpatient and emergency care data.

208.   In the Netherlands, some dataset custodians have internal bodies to approve dataset linkages or further processing of health data including for primary care data where a committee of GPs and a privacy committee approves; CVD registry data where a board of directors approves; long-term care data where health care insurers approve; mortality data where the bureau of statistics approves; and emergency care data where the knowledge centre injury prevention approves.

209.   In Latvia, applications for identifiable patient data recorded in medical documents for a specific research project are approved by the Centre for Disease Prevention and Control under Cabinet Regulation No. 446 (4 August 2015) "Procedures for Using the Patient Data in a Specific Research". Applications for data from the public monitoring system for health care quality and efficiency are approved by a special project Council. The Council consists of representatives from Centre for Disease Prevention and Control, National Health Service, State Emergency Medical Service and Health Inspectorate.

210.	Internal committees of data custodians approve further processing of health care data in Canada (Canadian Institute for Health Information and Statistics Canada); Denmark (Danish Health Authority); Luxembourg (General Inspection of Social Security, Cancer Registry and Ministry of Health) and Slovenia.

211.	Data custodians approve further processing of health care data in Korea (Health Insurance Review and Assessment Service, National Cancer Centre, and Korea Centre for Disease Control and Prevention), Singapore (Ministry of Health) and Ireland (Healthcare Pricing Office). In the United States, approval for dataset linkages and further processing of data in the custody of the National Centre for Health Statistics (NCHS) are approved by the director of the NCHS, the head of the NCHS division responsible for the dataset(s) and the NCHS Confidentiality Officer.

Transparency through public information

212.	Twenty-one countries reported 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 (Annex B.55 and B.57). Singapore reported that a public description was available for two datasets; and Ireland reported this for one dataset.

213.	Seventeen countries reported that the description of all or most health care datasets includes the health-related public interests served by the data. Seventeen countries reported that the description for all or most datasets includes the legal basis for the processing: Austria, Belgium, Canada, Czech Republic, Denmark, Finland, France, Germany, Israel, Korea, Latvia, Luxembourg, the Netherlands, Norway, Slovenia, Sweden and United Kingdom (Scotland) (Annex B.56).

214.	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 seventeen countries: Australia, Belgium, Canada, Czech Republic, Denmark, France, Germany, Israel, Japan, Korea, Latvia, Netherlands, Norway, Slovenia, Sweden, United Kingdom (Scotland) and United States.

215.	Fourteen countries 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 United Kingdom (Scotland).

216.	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 countries answered yes for all or most key health care datasets: Australia, Denmark, Finland, France, Israel, Japan, Korea, Latvia, Sweden, and 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 United Kingdom (Scotland) said yes for all or most health care datasets.

4 Next steps

217.   The 2019/20 survey results indicate that there remains variability across countries in health data use and governance. There is a small cluster of countries reporting high agreement with the policies, regulations and practices that foster the development, use, accessibility and sharing of key national health datasets for research and statistical purposes that were measured in this survey; while also reporting high agreement with the health data governance policies and practices that were measured. Countries reporting the strongest national health data availability, maturity and use and health dataset governance policies and practices were Denmark, Finland and Korea. These countries were followed by Australia, Canada, France, Latvia, Netherlands, Slovenia, Sweden and United Kingdom (Scotland) (Figure 4.1).

Figure 4.1. Three countries score highly on both dataset availability, maturity and use and dataset governance
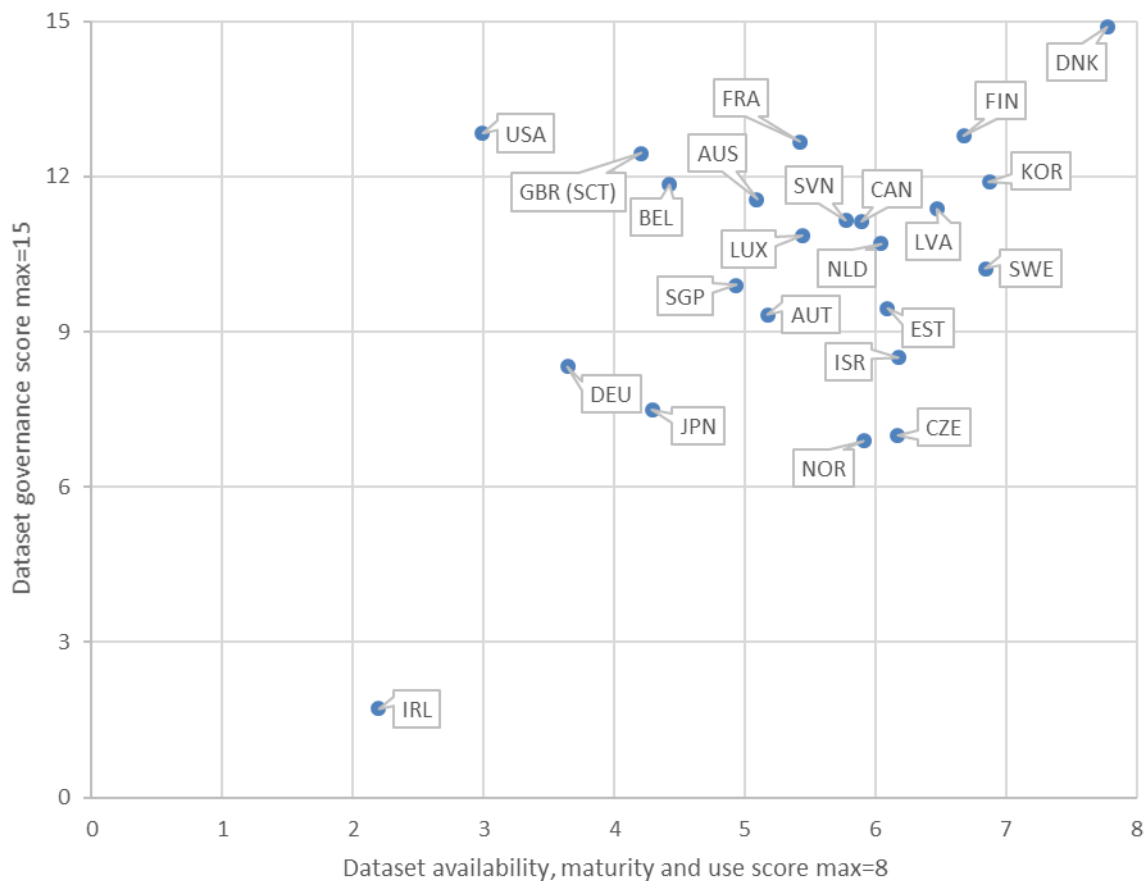
Note: Dataset governance score is the sum or the proportion of health care datasets meeting 15 dataset governance elements and the dataset availability, maturity and use score is the sum of the proportion of health datasets meeting 7 elements of dataset availability maturity and use. See Annex B.1 and B.31.
Source: Author.

218.   The OECD Health Committee, with the cooperation of the Committee on Digital Economy Policy, will report to OECD Council in 2022 on progress toward the adoption of the *OECD Recommendation on Health Data Governance* (see Box 4.2). The results of the 2019/20 survey presented in this report will provide an important input to the report to Council. Another input to the report to Council will be the 2021 OECD Survey of Electronic Health Record System Development, Data Use and Governance that will investigate developments toward and barriers to standardised and interoperable electronic clinical records and the use of data within records for statistics and research.

219.   Further input to the report to the OECD Council in 2022 will be progress and recommendations toward strengthening data privacy and security protections for personal data undertaken by the Working Party on Data Security and Privacy of the OECD Committee on Digital Economy Policy.

Box 4.2. *OECD Recommendation on Health Data Governance*

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 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 minimized 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* will 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 twelve 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.

Source: OECD (2019), Recommendation of the Council on Health Data Governance, OECD Legal Instruments, Paris, http://legalinstruments.oecd.org.

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Annex A. Questionnaire on Health Data Use and Governance

220.   The HCQO Survey on Health Data Use and Governance was developed and reviewed by the OECD Working Party on Health Care Quality and Outcomes. Members of the Working Party who coordinate the completion of the questionnaire in their countries in 2019/20 are provided in Table A.1

Table A A.1. Countries responding to the 2019/20 HCQO Survey of Health Data Use and Governance

Country	Name	Position	Organisation
Australia	Australian OECD Co-ordination team		Australian Government Department of Health
Austria	Clemens Martin Auer	Special Envoy for Health	Federal Ministry of Social Affairs, Health, Care and Consumer Protection
Belgium			
Canada	Brent Diverty	Vice President, Programs	Canadian Institute for Health Information
Czech Republic	Ondrej Majek	Head of Department of International Affairs	Institute of Health Information and Statistics of the Czech Republic
Denmark	Pernille Christensen, Mathilde Barington and Mette Bjerrum Koch	Section Head and colleagues	Danish Health Data Authority
Estonia			
Finland	Jutta Järvelin, Päivi Hämäläinen	Chief Physician and Leading Expert	Finnish Institute of Health and Welfare
France	Dominque Polton	Scientific Advisor	Ministry of Solidarity and Health - Directorate for Research, Studies, Evaluation and Statistics (Direction de la recherche, des études, de l'évaluation et des statistiques)
Germany	Judith Haugwitz	OECD Coordinator	Federal Ministry of Health
Ireland	Sheona Gilsenan	Senior Data analyst	Dept of Health
Israel	Ziona Haklai	Head of Information Division	Israel Health Ministry
Japan	Tomohiro Murakami	Section chief, International Affairs Division	Ministry of Health, Labour and Welfare
Korea	Kyoung-Hoon Kim	Director of Review and Assessment Research Department	Health Insurance Review and Assessment Service
Latvia	Jana Lepiksone	Head of Research and Health Statistics Department	The Centre for Disease Prevention and Control Of Latvia
Luxembourg	Anne-Charlotte Lorcy	Scientific collaborator	Ministry of Health - Directorate of Health
Netherlands	Ronald Gijsen	Health Care Researcher	National Institute for Public Health and the Environment (RIVM)
Norway	Katrine Skyrud	Researcher	Norwegian Institute of Public Health
Singapore	Karen Ng	Deputy Director	Ministry of Health, Singapore
Slovenia	Metka Zaletel	Head of Health Data Centre	National Institute of Public Health / Nacionalni inštitut za javno zdravje
Sweden	Max Köster	Special Adviser	National Board of Health and Welfare (NBHW)
UK Scotland	Jade Carruthers	Principal Information Analyst	ISD Scotland
United States	Lisa Wagner	Health Policy Analyst	National Center for Health Statistics (NCHS), U.S. Centers for Disease Control and Prevention

Annex B. Tables

Table A B.1. Key national health dataset availability, maturity and use

Country	% of key national health datasets available[1]	% of available health care datasets with coverage of 80% or more of the population	% of available health care datasets where data extracted automatically from electronic clinical or administrative records	% of available health datasets where the time between record creation and inclusion in the dataset is one week or less	% of available health datasets sharing the same unique patient ID	% of available health care datasets where standard codes are used for clinical terminology	% of available health datasets used to regularly report on health care quality or health system performance (published indicators)	% of available health datasets regularly linked for research, statistics and/or monitoring (indicators)	Sum
Australia	92%	100%	56%	17%	17%	78%	83%	67%	5.09
Austria	92%	100%	78%	0%	33%	89%	75%	42%	5.17
Belgium	69%	71%	86%	11%	22%	71%	78%	33%	4.42
Canada	85%	75%	75%	0%	64%	100%	91%	100%	5.89
Czech Republic	77%	100%	100%	0%	90%	100%	90%	60%	6.17
Denmark	100%	100%	100%	77%	100%	100%	100%	100%	7.77
Estonia	92%	89%	78%	50%	83%	100%	92%	25%	6.09
Finland	85%	100%	56%	36%	100%	100%	91%	100%	6.67
France	92%	78%	56%	8%	58%	100%	83%	67%	5.42
Germany	31%	100%	33%	0%	0%	100%	100%	0%	3.64
Ireland	77%	86%	29%	0%	0%	29%	0%	0%	2.20
Israel	85%	88%	100%	18%	64%	100%	100%	64%	6.18
Japan	85%	100%	75%	0%	45%	88%	27%	9%	4.29
Korea	92%	89%	89%	58%	100%	100%	92%	67%	6.87
Latvia	77%	88%	63%	80%	80%	100%	90%	70%	6.47
Luxembourg	77%	100%	71%	10%	70%	86%	100%	30%	5.44
Netherlands	92%	70%	100%	0%	75%	100%	83%	83%	6.04
Norway	100%	80%	90%	0%	77%	90%	85%	69%	5.91
Singapore	100%	80%	100%	0%	62%	90%	31%	31%	4.93
Slovenia	77%	100%	100%	0%	70%	100%	70%	60%	5.77
Sweden	92%	100%	100%	8%	92%	100%	100%	92%	6.84
UK (Scotland)	92%	100%	67%	0%	0%	78%	67%	17%	4.20
United States	54%	33%	17%	0%	14%	67%	57%	57%	2.99

Note: The sum column is the sum of the preceding columns and the maximum is 8. Percentages in this table are from tables A B.2 to A B.15. n.a: not applicable (countries not surveyed in 2013).
1.Thirteen national datasets including 10 health care datasets (hospital in-patient, mental hospital in-patient, emergency health care, primary care, prescription medicines, cancer, diabetes, cardiovascular disease, mortality and formal long-term care); patient experiences survey, population health survey and population census/registry.
Source: Author.

Table A B.2. Data available at a national level

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data	% of key national datasets available
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	92%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes[5]	Yes	Yes	Yes	Yes	Yes	92%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	n.r.	69%
Canada	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	85%
Czech Republic	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	77%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	92%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	85%
France	Yes	Yes	Yes	Yes[1]	Yes	Yes	No	Yes[2]	Yes	Yes[3]	Yes	Yes	Yes	92%
Germany	Yes	No	No	No	Yes	Yes	n.r.	n.r.	n.r.	n.r.	n.r.	Yes	n.r.	31%
Ireland	Yes	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	77%
Israel	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	85%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	85%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	92%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	77%
Luxembourg	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	77%
Netherlands	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	92%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	Yes	Yes	77%
Sweden	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	92%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	92%
United States	Yes[4]	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	n.r.	Yes	n.r.	54%

Note: Data custodian is a national authority and dataset is included even if it doesn't cover 100% of the population. n.r.: not reported.
Source: Author.

1. Primary care data are derived from insurance claims and exclude clinical information, such as diagnosis and laboratory tests.
2. Registry is of ischemic heart disease and stroke.
3. New database of long term care for people with disabilities only including applications for benefits (in kind or in cash) and benefits provided.
4. Not enough hospitals participate to produce reliable national estimates.
5. Data refer to heart surgery and stroke unit only.

Table A B.3. National Authority in Custody of National Health Data

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Australia	Australian Institute of Health and Welfare (AIHW)	Australian Institute of Health and Welfare (AIHW)	Australian Institute of Health and Welfare (AIHW)	Department of Health	Department of Health	Australian Institute of Health and Welfare (AIHW)	Australian Institute of Health and Welfare (AIHW)	n.a.	Australian Institute of Health and Welfare (AIHW)	Australian Institute of Health and Welfare (AIHW)	Australian Bureau of Statistics	Australian Bureau of Statistics	Australian Bureau of Statistics
Austria	Ministry of Health	Ministry of Health	Ministry of Health	Sick funds	Sick funds	Statistics Austria	n.a.	Austrian National Public Health Institute (GÖG)	Statistics Austria	sick funds	Austrian National Public Health Institute (GÖG)	Statistics Austria	Statistics Austria
Belgium	FPS Public Health	FPS Public Health	FPS Public Health	Sciensano	National Institute for Health and Disability Insurance (NIHDI)	Belgian Cancer Registry	Sciensano	n.a.	n.a.	n.a.	Sciensano	Sciensano	n.a.
Canada	Canadian Institute for Health Information (CIHI)	Canadian Institute for Health Information (CIHI)	Canadian Institute for Health Information (CIHI)	Canadian Primary Care Sentinel Surveillance Network	Canadian Institute for Health Information (CIHI)	Statistics Canada	n.a.	n.a.	Statistics Canada	Canadian Institute for Health Information (CIHI)	Canadian Institute for Health Information (CIHI)	Statistics Canada	Statistics Canada
Czech Republic	Institute of Health Information and Statistics (IHIS)	Institute of Health Information and Statistics (IHIS)	Institute of Health Information and Statistics (IHIS)	n.a.	Institute of Health Information and Statistics (IHIS)	Institute of Health Information and Statistics (IHIS)	Institute of Health Information and Statistics (IHIS)	Institute of Health Information and Statistics (IHIS)	Institute of Health Information and Statistics (IHIS)	n.a.	n.a.	Institute of Health Information and Statistics (IHIS)	Czech Statistical Office (CZSO)

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Denmark	The Danish Health Data Authority	The Danish Health Data Authority	The Danish Health Data Authority	The Danish Health Data Authority	The Danish Health Data Authority	The Danish Health Data Authority	The Danish Health Data Authority	The Danish Health Data Authority	The Danish Health Data Authority	Municipalities	Regions	National Institute of Public Health	National CPR administration
Estonia	Estonian Health Insurance Fund (EHIF)	Estonian Health Insurance Fund (EHIF)	Estonian Health Insurance Fund (EHIF)	Estonian Health Insurance Fund (EHIF)	Estonian Health Insurance Fund (EHIF)	National Institute for Health Development (NIHD)	n.a.	Tartu University Hospital	National Institute for Health Development (NIHD)	Estonian Health Insurance Fund (EHIF)	Estonian Health Insurance Fund (EHIF), Ministry of Social Affairs, Hospitals	Statistics Estonia, National Institute for Health Development (NIHD)	Ministry of the Interior
Finland	Finnish Institute for Health and Welfare (THL)	Finnish Institute for Health and Welfare (THL)	Finnish Institute for Health and Welfare (THL)	Finnish Institute for Health and Welfare (THL)	Kela	Finnish Institute for Health and Welfare (THL)[2]		Finnish Institute for Health and Welfare (THL)	Statistics Finland	Finnish Institute for Health and Welfare (THL)		Finnish Institute for Health and Welfare (THL)	National population registry
France	ATIH (Agence technique d'information hospitalière) + CNAM (Caisse nationale d'assurance maladie)	ATIH (Agence technique d'information hospitalière) + CNAM (Caisse nationale d'assurance maladie)	ATIH (Agence technique d'information hospitalière) + CNAM (Caisse nationale d'assurance maladie)	CNAM (Caisse nationale d'assurance maladie)	CNAM (Caisse nationale d'assurance maladie)	Adults: INCa, SPF, FRANCIM, HCL		Santé publique France / INSERM (Institut national de la santé et de la recherche médicale	INSERM (Institut national de la santé et de la recherche médicale)	CNSA (Caisse nationale de solidarité pour l'autonomie)	"ATIH (Agence technique d'information hospitalière) / Haute autorité de santé (HAS)"	Ministry of Health and IRDES (Institut de recherche et de documentation en économie de la santé)	INSEE (Institut national de la statistique et de l'administration économique)

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Germany	Federal Statistical Office	n.a.	n.a.	n.a.	AOK Research Institute (WIdO)	Robert Koch Institute (RKI)	n.a.	n.a.	n.a.	n.a.	n.a.	Robert Koch Institute (RKI) + Federal Statistical Office	n.a.
Ireland	Healthcare Pricing Office	Health Research Board	Health Services Executive (BIU)	n.a.	Primary Care Reimbursement Service (PCRS HSE)	National Cancer Registry Ireland - HSE.ie	n.a.	n.a.	Central Statistics Office (CSO) + General Register Office (GRO)	Nursing Homes Support Scheme (NHSS)	Health Information and Quality Authority (HIQA)	Dept of Health	Central Statistics Office (CSO)
Israel	Israel Health Ministry	Israel Health Ministry	Israel Health Ministry	Hebrew university Jerusalem	n.a.	CDC	CDC	n.a.	Central Bureau of Statistics	Israel Health Ministry	Israel Health Ministry	Central Bureau of Statistics	Central Bureau of Statistics
Japan	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	n.a.	n.a.	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	Ministry of Health, Labour and Welfare (MHLW)	Statistic Bureau, Ministry of Internal Affairs and Communications

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Korea	Health Insurance Review and Assessment Service	Health Insurance Review and Assessment Service	Health Insurance Review and Assessment Service	Health Insurance Review and Assessment Service	Health Insurance Review and Assessment Service	National Cancer Center(NCC) and Ministry of Health and Welfare	Korea Center for Disease Control & Prevention		Korea National Statistics Office, Ministry of the Interior and Safety	Health Insurance Review and Assessment Service	Health Insurance Review and Assessment Service, Ministry of Health and Welfare and Korea Institute for Health and Social Affairs	Korea Center for Disease Control and Prevention	Korea National Statistics Office
Latvia	National Health Service	National Health Service	National Health Service	National Health Service	National Health Service	Centre for Disease Prevention and Control	Centre for Disease Prevention and Control	n.a.	Centre for Disease Prevention and Control	n.a.	n.a.	Centre for Disease Prevention and Control Central Statistical Bureau	Central Statistical Bureau
Luxembourg	National Health Insurance + Directorate of Health[1]	National Health Insurance + Directorate of Health[1]	n.a.	National Health Insurance	National Health Insurance	Luxembourg Institute of Health (LIH)	n.a.	n.a.	Ministry of Health	National Health Insurance	Ministry of Health / Directorate of Health	Ministry of Health / Directorate of Health	Ministry of Digitalisation

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Netherlands	Dutch Hospital Data (DHD) + Statistics Netherlands (CBS)	NZa (National Health Care Authority)	Veiligheid NL (Consumer and Safety Institute)	Nivel (Netherlands institute for Health Services Research)	Zorginstituut Nederland (National Health Care Institute)	Netherlands Comprehensive Cancer Organisation (IKNL)	DPARD (Dutch Pediatric and Adult Registry of Diabetes)	Nederlande Hart Registratie (Dutch Heart Registration)	Statistics Netherlands (Centraal Bureau voor de Statistiek)	Several organisations (CIZ, Het CAK, NZa, ZIN, SVB, Bureau Jeugdzorg, Vektis)	n.a.	Statistics Netherlands (Centraal Bureau voor de Statistiek)	Statistics Netherlands (Centraal Bureau voor de Statistiek)
Norway	Norwegian Directorate of Health	Norwegian Directorate of Health	Norwegian Directorate of Health	Norwegian Directorate of Health	Norwegian Institute of Public Health	Cancer Registry of Norway	Oslo University hospital / Haukeland university hospital	Norwegian Institute of Public Health	Norwegian Institute of Public Health	d.k	Norwegian Institute of Public Health	Norwegian Institute of Public Health	Norwegian Tax Registry
Singapore	Ministry of Health (MOH)	Ministry of Health (MOH)	Ministry of Health (MOH)	Ministry of Health (MOH)	Ministry of Health (MOH)	Ministry of Health (MOH)	Ministry of Health (MOH)	Ministry of Health (MOH)	Immigration and Checkpoints Authority (ICA)	Ministry of Health (MOH)	Ministry of Health (MOH)	Ministry of Health (MOH)	Department of Statistics
Slovenia	National Institute of Public Health	National Institute of Public Health	National Institute of Public Health	National Institute of Public Health	National Institute of Public Health	Institute of Oncology	n.a.	n.a.	National Institute of Public Health	n.a.	National Institute of Public Health	National Institute of Public Health	Statistical Office of the Republic of Slovenia.

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Sweden	National Board of Health and Welfare	National Board of Health and Welfare	National Board of Health and Welfare	n.a.	National Board of Health and Welfare	National Board of Health and Welfare	County Council of Västra Götaland Region	National Board of Health and Welfare + national quality registers in several county councils	National Board of Health and Welfare	National Board of Health and Welfare	Swedish Association of Local Authorities and Regions	The Public Health Agency of Sweden	Statistics Sweden
UK (Scotland)	Public Health and Intelligence (PHI) National Services Scotland (NSS)	Public Health and Intelligence (PHI) National Services Scotland (NSS)	Public Health and Intelligence (PHI) National Services Scotland (NSS)	Public Health and Intelligence (PHI) National Services Scotland (NSS)	Public Health and Intelligence (PHI) National Services Scotland (NSS)	Public Health and Intelligence (PHI) National Services Scotland (NSS)	SCI-Diabetes Scotland - Scottish Government	n.a.	National Records of Scotland (NRS)	National Services Scotland (NSS) + Scottish Government	Scottish Government	Scottish Government	Scottish Government
United States	National Center for Health Statistics (NCHS)	Substance Abuse and Mental Health Services (SAMHSA)	National Center for Health Statistics (NCHS)	National Center for Health Statistics (NCHS)	National Center for Health Statistics (NCHS)	National Institutes of Health (NIH)/National Cancer Institute (NCI)	n.r.	n.r.	National Center for Health Statistics (NCHS)	National Center for Health Statistics (NCHS)	Agency for Healthcare Research and Quality (AHRQ)	National Center for Health Statistics (NCHS)	Census Bureau

Note: n.a.: not applicable; n.r.: not reported.

Source: Author.

[1]Two national datasets: dataset of National Health Insurance (CNS), and dataset of the Ministry of Health and National Health Insurance (CNS).

[2]The practical maintenance of the cancer registry is done by the Finnish Cancer Registry.

Table A B.4. Proportion of national population covered by national dataset

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of available datasets with 80% coverage or greater
Australia	100%	100%	100%	100%	100%	100%	99.7%[2]	n.a.	100%	100%	100%
Austria	100%	100%	100%	100%	100%	100%	n.a.	≈100%	100%	100%	100%
Belgium	100%	100%	100%	1.0-1.5%	100	100%	≈20%	n.a.	n.a.	n.a.	71%
Canada	100%	100%	85%	5%	37%	100%	n.a.	n.a.	100%	80%	75%
Czech Republic	100%	100%	100%	n.a.	100%	100%	100%	100%	100%	n.a.	100%
Denmark	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
Estonia	94%	94%	100%	94%	100%	100%	n.a.	100%	100%	n.r.	89%
Finland	100%	100%	100%	100%[3]	100%	100%	n.a.	100%	100%	100%	100%
France	100%	100%	100%	100%	100%	20% adults, 100% children	n.a.	3% for IHD and <1% for stroke	100%	100%[4]	78%
Germany	≈98%	n.a.	n.a.	n.a.	≈80%	100%	n.a.	n.a.	n.a.	n.a.	100%
Ireland	≈80%	100%	95%	n.a.	50%	100%	n.a.	n.a.	100%	80%	86%
Israel	100%	100%	100%	100%	n.a.	100%	100%	n.a.	100%	75%	88%
Japan	100%	100%	100%	94%	100%	100%	n.a.	n.a.	100%	100%	100%
Korea	100%	100%	100%	100%	100%	100%	d.k.	n.a.	100%	100%	89%
Latvia	88%	88%	60%	82%	90%	90-95%	95%	n.a.	100%	n.a.	88%
Luxembourg	≈95%[1]	≈95%[1]	n.a.	≈95%	≈95%	100%	n.a.	n.a.	99.90%	≈95%	100%
Netherlands	100%[5]	80%	13%	10%	98%	100%	11.3%[6]	100%[7]	100%	100%	70%
Norway	100%	100%	100%	100%	100%	100%	n.r.	100%	100%	n.r.	80%
Singapore	100%	80%	100%	40%	80%	100%	80%	100%	100%	50%	80%
Slovenia	100%	100%	100%	100%	100%	100%	n.a.	n.a.	100%	n.a.	100%
Sweden	100%	100%	100%	n.a.	100%	100%	100%	100%	100%	100%	100%
United Kingdom (Scotland)	100%	100%	100%	100%	100%	100%	100%	n.a.	100%	100%	100%
United States	n.r.	n.r.	n.r.	n.r.	≈97%	n.r.	n.r.	n.r.	100%	n.r.	33%

Note: n.a.: not applicable; n.r.: not reported.
1. Data from CNS (National Health Insurance).
2. National Diabetes Register (NDR) has 99.7% capture of individuals with type 1 diabetes.
3. Includes public primary care and excludes privately provided outpatient care.

4. Target is to reach 100% coverage by the end of 2021.
5. A diagnosis is known for 100% of inpatients and 83% of daycases (2016).
6. Diabetic patients treated in secondary and tertiary care (1.7% of all diabetic patients).
7. 100% of heart interventions.

Source: Author.

Table A B.5. Percentage of available national health care datasets populated by source

Country	Data entry from paper clinical records	Data extracted automatically from electronic clinical records	Data entry from paper claim or billing records	Data extracted automatically from electronic claim or billing records	A survey questionnaire	Data extracted from an electronic source (clinical and/or claim-billing records)
Australia	33%	33%	11%	44%	0%	56%
Austria	11%	78%	0%	33%	0%	78%
Belgium	71%	86%	0%	14%	29%	86%
Canada	38%	63%	0%	13%	0%	75%
Czech Republic	0%	100%	0%	38%	0%	100%
Denmark	0%	100%	0%	0%	0%	100%
Estonia	0%	11%	0%	67%	0%	78%
Finland	0%	44%	0%	0%	0%	56%[1]
France	56%	33%	0%	22%	0%	56%
Germany	0%	33%	33%	0%	0%	33%
Ireland	29%	29%	29%	0%	29%	29%
Israel	25%	100%	0%	100%	0%	100%
Japan	0%	0%	0%	75%	13%	75%
Korea	11%	22%	0%	78%	0%	89%
Latvia	38%	13%	0%	50%	0%	63%
Luxembourg	14%	0%	43%	71%	0%	71%
Netherlands	40%	80%	0%	30%	20%	100%
Norway	30%	90%	0%	0%	0%	90%
Singapore	30%	100%	0%	10%	0%	100%
Slovenia	14%	100%	0%	14%	0%	100%
Sweden	11%	89%	0%	11%	11%	100%
UK(Scotland)	0%	67%	11%	0%	0%	67%
United States	0%	17%	0%	17%	67%	17%

Source: Author.

1. Pharmaceutical data are automatically extracted from Finland's national e-prescription depository.

Table A B.6. Percentage of available national health care datasets coded to a terminology standard

Country	Clinical terminology is coded by assigning standard codes using a classification system	Data is entered by a health care coding professional	Data is entered by a clinical care professional
Australia	78%	33%	22%
Austria	89%	0%	67%
Belgium	71%	57%	57%
Canada	100%	63%	38%
Czech Republic	100%	88%	100%
Denmark	100%	100%	100%
Estonia	100%	22%	78%
Finland	100%	0%	89%
France	100%	56%	22%
Germany	100%	67%	33%
Ireland	29%	14%	29%
Israel	100%	63%	63%
Japan	88%	13%	63%
Korea	100%	100%	100%
Latvia	100%	0%	100%
Luxembourg	86%	57%	43%
Netherlands	100%	30%	80%
Norway	90%	90%	90%
Singapore	90%	60%	20%
Slovenia	100%	14%	86%
Sweden	100%	22%	67%
UK(Scotland)	78%	78%	78%
United States	67%	67%	33%

Source: Author.

Table A B.7. Timeliness of national health datasets

Country	Number of key national health datasets where data is available:		% of key national datasets where data is available:	
	Within one week or less	Within 3 months or less	Within one week or less	Within 3 months or less
Australia	2	2	17%	17%
Austria	0	7	0%	58%
Belgium	1	4	11%	44%
Canada	0	0	0%	0%
Czech Republic	0	0	0%	0%
Denmark	10	10	77%	77%
Estonia	6	6	50%	50%
Finland	4	4	36%	36%
France	1	6	8%	50%
Germany	0	0	0%	0%
Ireland	0	0	0%	0%
Israel	2	2	18%	18%
Japan	0	2	0%	18%
Korea	7	7	58%	58%
Latvia	8	9	80%	90%
Luxembourg	1	1	10%	10%
Netherlands	0	4	0%	33%
Norway	0	0	0%	0%
Singapore	0	6	0%	46%
Slovenia	0	4	0%	40%
Sweden	1	4	8%	33%
United Kingdom (Scotland)	0	2	0%	17%
United States	0	0	0%	0%

Source: Author.

Table A B.8. National dataset contains a patient/person identifying number that could be used for dataset linkages

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data	% of national datasets
Australia	No	No	No	Yes[5]	Yes[5]	No	No	n.a.	Yes	Yes	No	No	No	33%
Austria	No	No	No	No	No	Yes	n.a.	Yes	Yes	n.r.	No	Yes	Yes	42%
Belgium	No	No	No	No	No	Yes	Yes	n.a.	n.a.	n.a.	Yes[1]	Yes[1]	n.a.	44%
Canada	Yes	Yes	Yes	Yes.	Yes	No	n.a.	n.a.	No	Yes	Yes	No	No	64%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No	Yes	90%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.r.	Yes	85%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	No	No	Yes	83%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	No	Yes	No	Yes	No	58%
Germany	No	n.a.	n.a.	n.a.	No	No	n.a.	n.a.	n.a.	n.a.	n.a.	No	n.a.	0%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	No	n.a.	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	91%
Japan	Yes[2]	Yes[2]	Yes[2]	Yes[2]	Yes[2]	No	n.a.	n.a.	No	No	No	No	Yes	55%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	n.a.	No	No	80%
Luxembourg	Yes[3]	Yes[3]	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	No	No	Yes	80%
Netherlands	Yes[4]	Yes[4]	No	Yes	Yes	No	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	83%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	Yes	Yes	Yes	92%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	No	Yes	Yes	n.a.	n.a.	Yes	n.a.	No	No	Yes	70%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	92%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	d.k.	n.a.	Yes	Yes	n.r.	n.r.	Yes	75%
United States	Yes	n.r.	No	No	No	n.r.	n.r.	n.r.	No	No	n.r.	No	n.r.	14%
Sum	18	17	15	14	17	15	10	9	16	13	6	10	15	

Note: n.a.: not applicable; n.r.: not reported; d.k.: unknown.
1. Yes but not directly.
2. Encrypted ID.
3. Yes applies to data from National Health Insurance (CNS)
4. From 2012 onward.
5. Pseudonymised identifiers (i.e. PIN) can only be disclosed where authorised by law.
Source: Author.

Table A B.9. Name of the identifying number that could be used for record linkage

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data	Highest number of data-sets with same ID#	% of national datasets with same ID#
Australia	n.a.	n.a.	n.a.	Patient ID PIN	Patient ID PIN	n.a.	n.a.	n.a.	Mortality identifier	Recipient ID, Assessment ID	n.a.	n.a.	n.a.	2	17%
Austria	n.a.	n.a.	n.a.	n.a.	n.a.	bPK AS	n.a.	bPK GH area-specific personal identification	bPK AS	n.a.	n.a..	bPK AS	bPK AS	4	33%
Belgium	n.a.	n.a.	n.a.	n.a.	n.a.	National Number for Social Security	National registry number	n.a.	n.a.	n.a.	HIS ID	HIS ID	n.a.	2	22%
Canada	Health information number (provincial/territorial)	Health information number (provincial/territorial)	Health information number (provincial/territorial)	Health information number (provincial/territorial)	Health information number (provincial/territorial)	n.a.	n.a.	n.a.	n.a.	Health information number (provincial/territorial)	Health information number (provincial/territorial)	n.a.	n.a.	7	64%
Czech Republic	personal ID	personal ID	personal ID	n.a.	personal ID	personal ID	personal ID	personal ID	personal ID	n.a.	n.a.	n.a.	personal ID	9	90%
Denmark	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	CPR number (UPI)	13	100%
Estonia	ID-code	ID-code	ID-code	ID-code	ID-code	ID-code	n.a.	ID-code	ID-code	ID-code	n.a.	n.a.	ID-code	10	83%

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data	Highest number of data-sets with same ID#	% of national datasets with same ID#
Finland	Personal Identification Number	Personal Identification Number	Personal Identification Number	Personal Identification Number	Personal Identification Number	Personal Identification Number	n.a.	Personal Identification Number	Personal Identification Number	Personal Identification Number	n.a.	Personal Identification Number	Personal Identification Number	11	100%
France	National health identifier	National health identifier	National health identifier	National health identifier	National health identifier					National health identifier		Civil status / National health identifier		7	58%
Germany	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	0	0%
Ireland	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	0	0%
Israel	encrypted ID	ID	encrypted ID	n.a.	n.a.	ID	encrypted ID	n.a.	ID	ID	ID	ID	ID	7	64%
Japan	encrypted ID	encrypted ID	encrypted ID	encrypted ID	encrypted ID	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	NAME, DOB, SEX	5	45%
Korea	Resident Registration Number	Resident Registration Number	Resident Registration Number	Resident Registration Number	Resident Registration Number	Resident Registration Number	Resident Registration Number		Resident Registration Number	Resident Registration Number	Resident Registration Number	Resident Registration Number	Resident Registration Number	12	100%
Latvia	Personal ID	Personal ID	Personal ID	Personal ID	Personal ID	Personal ID	Personal ID	Enter the name	Personal ID	Enter the name	Enter the name	Enter the name	Enter the name	8	80%

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data	Highest number of data-sets with same ID#	% of national datasets with same ID#
Luxembourg	Matricule[1], Pseudonymised ID2	Matricule[1], Pseudonymised ID2	n.a.	Matricule	Matricule	Pseudonymised ID	n.a.	n.a.	Matricule	Matricule	n.a.	n.a.	Matricule	7	70%
Netherlands	BSN (citizen service number) pseudonym	BSN (citizen service number) pseudonym	n.a.	BSN (citizen service number) pseudonym	BSN (citizen service number) pseudonym	n.a.	BSN (citizen service number) pseudonym	Internal identification number	A number converted to a BSN pseudonym	BSN (citizen service number) pseudonym	n.a.	BSN (citizen service number) pseudonym	A number converted to a BSN pseudonym	9	75%
Norway	PIN	PIN	PIN	PIN	PIN	PIN	PIN	PIN	PIN	n.a.	n.r.	n.r.	PIN	10	77%
Singapore	Surrogate ID	Surrogate ID	Surrogate ID	Surrogate ID	NRIC	NRIC	NRIC	NRIC	Surrogate ID	NRIC	NRIC	NRIC	NRIC	8	62%
Slovenia	PIN = EMŠO	PIN = EMŠO	PIN = EMŠO	n.a.	PIN = EMŠO	PIN = EMŠO	n.a.	n.a.	PIN = EMŠO	n.a.	n.a.	n.a.	PIN = EMŠO	7	70%
Sweden	Personnummer	Personnummer	Personnummer	n.a.	Personnummer	Personnummer	Personnummer	Personnummer	Personnummer	Personnummer	n.a.	Personnummer	Personnummer	11	92%
United Kingdom (Scotland)	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	0	0%
United States	PATIENT_ID	n.r.	n.a.	n.a.	n.a.	n.r.	n.r.	n.r.	n.a.	n.a.	n.r.	n.a.	n.r.	1	14%

Note: n.a.: not applicable; n.r.: not reported.
1. Matricule ID is used on the National Insurance Data (CNS) dataset and a pseudonymised ID will be used on the Directorate of Health dataset.
Source: Author.

Table A B.10. Dataset contains identifying variables that could be used for record linkage

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Australia	No	No	No	Yes	Yes	Yes	Yes	n.a.	Yes	Yes[1]	Yes	Yes	Yes
Austria	No	No	No	No	No	Yes	n.a.	No	Yes	n.r.	No	n.r.	n.r.
Belgium	Yes[2]	Yes[2]	Yes[2]	No	Yes	Yes	No[3]	n.a.	n.a.	n.a.	No	No	n.a.
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	Yes	Yes	Yes
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.r.	Yes
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	No	No	Yes
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	Yes	Yes
France	No	No	No	No	No	No	n.a.	Yes	Yes	n.r.	No	No	Yes
Germany	No	n.a.	n.a.	n.a.	No	No[3]	n.a.	n.a.	n.a.	n.a.	n.a.	No	n.a.
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.
Israel	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes
Japan	No	No	No	No	No	Yes	n.a.	n.a.	No	No	No	No	No
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	n.a.	No	No
Luxembourg	Yes[4]	Yes[4]	n.a.	Yes	Yes	No	n.a.	n.a.	Yes	Yes	No	No	Yes
Netherlands	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	Yes	Yes	Yes
Sweden[5]	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	No	No	n.r.
UK(Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	n.r.	n.r.	Yes
United States	Yes	n.r.	No	No	Yes[6]	n.r.	n.r.	n.r.	Yes	No	n.r.	Yes[6]	n.r.

Note: n.a.: not applicable; n.r.: not reported.
1. Available for some LTC datasets.
2. A pseudonymised number (unique per hospital), birth year, sex and postal code.
3. Some information available but it is insufficient for record linkage.

4. Yes applies to data from National Health Insurance (CNS)
5. Dataset linkage is based on a Unique ID number only.
6. In confidential files only.
Source: Author.

Table A B.11. Data used regularly to report on health care quality or health system performance

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data	% of national datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	No	Yes	Yes	Yes	83%
Austria	Yes	Yes	Yes	No	No	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	83%
Belgium	Yes	Yes	Yes	No	Yes	Yes	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	78%
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	No	Yes	Yes	91%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	No	90%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	92%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	n.a.	Yes	Yes	91%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	No[2]	Yes	Yes	No	83%
Germany	Yes	n.a.	n.a.	n.a.	Yes	Yes	n.a.	n.a.	n.a.	n.a.	n.a.	Yes	n.a.	100%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	100%
Japan	n.r.	n.r.	n.r.	n.r.	n.r.	No	n.a.	n.a.	Yes	Yes	Yes	No	No	27%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	No	92%
Latvia	Yes	Yes	No	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	n.a.	Yes	Yes	90%
Luxembourg	Yes	Yes[1]	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	Yes	Yes	Yes	100%
Netherlands	Yes	Yes[4]	Yes[5]	Yes	Yes	Yes	Yes	Yes	No	Yes	n.a.	Yes	No	83%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	85%
Singapore	Yes	No	Yes	No	No	No	No	Yes	Yes	No	No	No	No	31%
Slovenia	Yes	Yes	No	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	No[2]	Yes	No	70%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes[3]	Yes	100%
UK(Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	n.r.	n.r.	n.r.	67%
United States	No	n.r.	Yes	Yes	No	n.r.	n.r.	n.r.	No	Yes	n.r.	Yes	n.r.	57%

Note: n.a.: not applicable; n.r.: not reported.
1. Yes for dataset of the Ministry of Health and National Health Insurance (CNS)
2. Not yet.
3. Indicators of public health.
4. Tariff calculations and monitoring.
5. Effectiveness of prevention.
Source: Author.

Table A B.12. Record linkage projects using this dataset are conducted on a regular basis

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data	% of national health datasets
Australia	Yes	Yes	No	Yes	Yes	Yes	No	n.a.	Yes	Yes	No	No	Yes	67%
Austria	Yes1	No	No	No	No	Yes	n.a.	Yes	Yes	n.r.	n.r.	No	Yes	42%
Belgium	Yes	No	No	No	No	Yes	No	n.a.	n.a.	n.a.	No	Yes	n.a.	33%
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	Yes	Yes	Yes	100%
Czech Republic	Yes	Yes	No	n.a.	No	Yes	Yes	Yes	Yes	n.a.	n.a.	No	No	60%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	n.r.	n.r.	n.r.	n.r.	b.r.	Yes	n.a.	Yes	Yes	n.r.	No	No	No	25%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.r.	Yes	No	No	Yes	No	67%
Germany	No	n.a.	n.a.	n.a.	No	No	n.a.	n.a.	n.a.	n.a.	n.a.	No	n.a.	0%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	No	n.a.	Yes	Yes	n.a.	Yes	Yes	No	No	No	64%
Japan	No	No	No	No	No	No	n.a.	n.a.	Yes	No	No	No	No	9%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	No	No	No	67%
Latvia	Yes	Yes	No	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	n.a.	No	No	70%
Luxembourg	No	No	n.a.	No	No	Yes	n.a.	n.a.	Yes	No	No	No	Yes	30%
Netherlands	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	n.a.	Yes	Yes	83%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	69%
Singapore	Yes	No	Yes	No	No	No	No	Yes	Yes	No	No	No	No	31%
Slovenia	Yes	Yes	No	No	Yes	Yes	n.a.	n.a.	Yes	n.a.	No	No	Yes	60%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	92%
UK (Scotland)	Yes1	Yes2	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	17%
United States	Yes	n.r.	No	No	Yes	n.r.	n.r.	n.r.	Yes	No	n.r.	Yes	n.r.	57%

Note: n.a.: not applicable; n.r.: not reported
1.ACaDMe (Acute, Cancer, Deaths and Mental Health) datamart contains linked inpatient and daycase (SMR01), mental health (SMR04), cancer registration (SMR06) and death (NRS) records from 1981 to present day and is updated monthly.
2.Partly yes.
Source: Author.

Table A B.13. Datasets linked on a regular basis

Country	Health Care Settings Linked	Disease Registries Linked	Population registry, surveys and contextual data linkages
Australia	Primary care and prescription medicine data are linked to hospital inpatient and mortality data.	Cancer registry data are linked to mortality data	Multi-Agency Data Integration Project (MADIP) to develop a secure approach for linkages of health care, education, government payments, personal income tax, and population demographics (including the Census) to create a comprehensive picture of Australia over time.
Austria	Hospital inpatient data is linked to mortality data.	Cardiovascular disease and cancer registry data are linked to mortality data.	
Belgium	Health insurance claims data (primary care and prescription medicines) linked to hospital inpatient data	Cancer registry data are linked with Social Security (vital status) and insurance claims (medical acts and medications).	Population health survey data are linked to health expenditures data.
Canada	Hospital inpatient, mental hospital inpatient, emergency care and long-term care data are linked to each other. Prescription medication data are linked to hospital inpatient data.	Cancer registry data are linked with mortality data	Patient experiences survey data are linked to hospital inpatient data. Population health survey data are linked to tax data. Population Census data are linked to hospital inpatient, mortality and cancer registry data.
Czech Republic	Hospital inpatient data are linked to mortality data	Cardiovascular disease and cancer registry data are linked to hospital inpatient and mortality data	
Denmark	All Danish Health care data can be linked using the personal identifier (CPR)	All Danish Health care data can be linked using the personal identifier (CPR)	All Danish Health care data can be linked using the personal identifier (CPR)
Estonia		Cardiovascular disease and cancer registry data are linked with mortality data	Population registry data are linked to cardiovascular disease registry, cancer registry data and mortality data.
Finland	Hospital inpatient, mental hospital inaptient, emergency care data and long-term care data are linked to each other and to prescription medicines data, mortality data and other data.	Cancer registry data are linked with mortality data and cardiovascular disease registry data comprise data from many other registries.	Population health survey data are linked to hospital and prescription medicines data; population registry data (socio-demographic characteristics) are linked to other data.
Germany			
Ireland			
Israel	Hospital inpatient, mental hospital inpatient, emergency care and long-term care data are linked to mortality data.	Diabetes and cancer registry data are linked to mortality data.	
Japan		Cancer registry data are linked to mortality data.	
Korea	Hospital in-patient data is linked to mortality data, prescription medicines data and emergency care data. Mental hospital in-patient data are linked to hospital inpatient data and prescription medicines data. Primary care data are linked to prescription medicines data.	Cancer registry data are linked to mortality data.	Long-term care data are linked to survey data on activities on daily living.

Country	Health Care Settings Linked	Disease Registries Linked	Population registry, surveys and contextual data linkages
Latvia	Hospital inpatient data and mental hospital in-patient data are linked with newborn registry, primary care, prescription medicines, mortality, and emergency care data.	Cancer registry, diabetes registry, cardiovascular disease registry and other disease registry data are linked to each other and to hospital inpatient, mental hospital in-patient, emergency care, prescription medicines, primary care, long-term care, newborn and mortality data.	Population registry data are linked to disease registry data including cancer, cardiovascular and diabetes registries.
Luxembourg		Cancer registry data are linked with mortality data and national cancer screening program data (breast & colorectal cancer).	
Netherlands	Hospital inpatient and mental hospital inpatient data are linked to primary care data and mortality data. Primary care data are linked to hospital in-patient, prescription medicines, medical specialist (inpatient and outpatient), and mortality data.	Cancer registry data are linked to pathology, hospital in-patient, and prescription medicines. Future plan to link diabetes registry data with diagnosis-treatment data.	Population registry (demographic) data are linked with hospital inpatient, mental hospital inpatient, primary care, cancer registry, long-term care, mortality and population health survey data. Tax data (income) are linked to hospital inpatient, long-term care and population health survey data. Quality of life questionnaire data are linked to cancer registry data.
Norway			
Singapore	Hospital inpatient data are linked to emergency care data.	Cardiovascular disease data are linked to mortality data.	
Slovenia	Hospital inpatient data are linked with prescription medicines, mortality and perinatal data. Mental health inpatient data are linked with prescription medicines and mortality data.	Cancer registry data are linked to mortality data and screening program data (cervical, breast and colorectal cancer).	Population registry data are linked to hospital inpatient and cancer registry data.
Sweden	Hospital inpatient, mental hospital inpatient and emergency care data are linked to prescription medicines and mortality data. Long-term care data are linked to data from other care settings, prescription medicines data and mortality data.	Cancer and diabetes registry data are linked to mortality data. Cardiovascular disease registry data are linked to mortality and prescription medicines data.	Population registry data are linked to hospital inpatient, mental hospital inpatient, emergency care and disease registry data. Population health survey data are linked to data from all health care settings, social insurance data and to the population registry.
United Kingdom (Scotland)			
United States	Hospital inpatient data are linked to Centers for Medicare & Medicaid Services (CMS) data, Medicare Beneficiaries Summary File (MBSF) and the National Death Index (NDI). Prescription medicines data are linked to Centers for Medicare & Medicaid Services (CMS) data, the National Death Index (NDI), Housing and Urban Development (HUD) data, Social Security Administration (SSA) data and United States Renal Data System (USRDS) data.		Population Health Survey is linked to Centers for Medicare & Medicaid Services (CMS) data, the National Death Index (NDI), Housing and Urban Development (HUD) data, Social Security Administration (SSA) data and United States Renal Data System (USRDS) data.

Source: Author.

Table A B.14. Purpose of regular dataset linkages

Dataset creation and quality	Meeting information needs
Create a comprehensive picture of the population	Estimate readmissions, complications, and mortality after treatment/surgical procedures
Reduce respondent burden	Analysis of the continuum of care/clinical care pathway
Dataset validation and validation of key indicators	Measuring outcomes of care
Add key dates (diagnosis, death)	Estimate survival rates and relative survival rates
Create health statistics by income, education and ethnic group	Estimate disease prevalence
Associate cases, stays, events and prescriptions to persons	Estimate length of stay
	Measure waiting time for care
	Measure outcomes for sub-populations (ethnic groups, education levels, occupations, income)
	Measure shifts in care from primary to secondary care levels
	Treatment quality, health care quality, patient safety and efficiency indicators
	Create process indicators
	Monitor activity in emergency care
	Inform health care financing decisions
	Epidemiological research projects
	Health services research projects
	Measure inequality in health care access and outcomes

Source: Author.

Table A B.15. Record linkage projects used to regularly monitor health care quality or health system performance

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Australia	Yes	No	No	No	No	Yes	No	n.a.	No	No	No	No	No
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.r.	n.r.	n.r.	n.r.
Belgium	Yes	No	No	No	No	Yes	No	n.a.	n.a.	n.a.	n.r.	No	n.a.
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	Yes	Yes	Yes
Czech Republic	Yes	No	No	n.a.	No	Yes	Yes	Yes	Yes	n.a.	n.a.	No	No
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Estonia	No	Yes	No	No	No	No	n.a.	Yes	Yes	n.r.	No	No	No
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	n.a.	No	Yes
France	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	No	Yes	No	No	Yes	No
Germany	No	n.a.	n.a.	n.a.	No	No	n.a.	n.a.	n.a.	n.a.	n.a.	No	n.a.
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.
Israel	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	n.a.	Yes	Yes	n.r.	n.r.	n.r.
Japan	No	No	No	No	No	No	n.a.	n.a.	No	No	No	No	No
Korea	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	n.r.	n.r.	n.r.
Latvia	Yes	Yes	No	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	n.a.	No	No
Luxembourg	Yes	Yes	n.a.	No	No	Yes	n.a.	n.a.	Yes	n.r.	No	No	Yes
Netherlands	Yes	Yes	No	No[1]	Yes	Yes	No	No	Yes	No	N/A	No	Yes
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Singapore	Yes	No	Yes	No	No	No	No	Yes	Yes	No	No	No	No
Slovenia	Yes	Yes	No	No	Yes	Yes	n.a.	n.a.	Yes	n.a.	No	No	No
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	No	Yes
United Kingdom (Scotland)	Yes	Yes	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.
United States	No	n.r.	No	No	No	n.r.	n.r.	n.r.	No	No	n.r.	No	n.r.

Note: n.a.: not applicable; n.r.: not reported.
Source: Author
1.Dataset linkages not undertaken regularly.

Table A B.16. Examples of indicators of health care quality or health system performance based on record linkage

Country	Indicators
Australia	Unplanned hospital readmissions for selected surgical procedures; annual reporting of cancer survival
Austria	Hospital readmission rates; mortality rates following hospitalization; 30-day mortality for heart attack patients; 5-year relative cumulative survival after cancer diagnosis
Belgium	Monitoring Antibiotic prophylaxis in hospital; 30- and 90-day mortality for pancreas, oesophageal and rectal cancer
Canada	Urgent hospital readmissions for mental illness, and for medical, surgical, obstetric and pediatric patients; high user hospital beds; self-harm; hospitalisations entirely caused by alcohol; and predicted net cancer survival.
Czech Republic	30-day mortality indicators for hospital and cardiovascular disease patients; survival estimates for patients with cancer, diabetes, and other diagnoses.
Estonia	30-day and 1-year mortality for patients with acute myocardial infarction; suicide among schizophrenic patients
Finland	Mortality following AMI, stroke, hip fracture; prescriptions of antibiotics for acute respiratory infections; vaccination coverage; survival from breast, colorectal and uterus cancer (and other cancers); number of days that hip fracture patients spend at home in the year following the fracture; and risk-adjustment of performance indicators
Korea	Mortality (at hospital, within 7 days after discharge, within 30 days after surgery) for coronary artery bypass grafting; injection rate of antibiotics within 8 hours after hospital arrival for pneumonia; readmission of mental hospital inpatients within 30 days after discharge; MRI or CT rate within 1 hour after arrival to emergency room; antibiotics prescription rate; number of drugs per prescription; relative cancer survival; cancer mortality; mortality following coronary artery bypass graft; and indicators for patients in long-term care including: percentages of patients with a reduced activities on daily living; prescription rate of atypical anti-psychotics for schizophrenia; 30-day readmission to hospital after discharge from hospital for schizophrenia; Rate of overlapping prescription, prescriptions of 4-or-more component anti-hypertensives, parallel administration of diuretics, prescription of not-recommended parallel therapies, prescription days, and continued prescription group for hypertension; and medication cost per administration day.
Latvia	List is extensive: 191 indicators of process, outcome and structure domains. In it different indicators from Eurostat (healthy life years at birth; amenable mortality; life expectancy at birth), EU-SILC survey (inhabitants (16+) very good or good self-perceived health; self-reported unmet need for medical care; the main reasons for unmet need for medical care (except dentist) during last 12 months: too expensive, waiting list, too far to travel; financial reason for unmet need for medical care (except dentist) during last 12 months: too expensive), OECD (AMI, ischemic/haemorrhagic stroke 30 day mortality (patient based); death from suicide within 30 days/1 year after discharge among patients diagnosed with mental disorder; health expenditure; remuneration of doctors; etc.) , ECDC (alcohol hand rub consumption; number of blood cultures per year/patient days) and nationally developed indicators (immunization coverage; incidence of different malignant tumours; share of practicing doctors and nurses aged 55 years and over, etc.) are combined.
Luxembourg	HCQO indicators; 30 and 90-day mortality rates following initial treatment for cancer; annual indicators of cancer mortality and survival
Netherlands	Readmission, unexpected length of hospital stay, HSMR, generic prescribing, HCQO indicators (mortality after AMI or stroke, hip fracture, avoidable admissions, patient safety, prescribing); suicide rates and excess mortality rates; survival rates; cholesterol levels and eye exams among diabetic patients; and spirometry measures for lung patients.
Singapore	30-day readmission for hospital patients; return to emergency department within 72 hours; 30-day mortality for cardiovascular patients
Slovenia	HCQO indicators; cancer incidence, prevalence, mortality, survival, and geographical distribution
Sweden	Appropriate prescribing of drugs among persons with heart failure; deaths and prescribing in mental health populations; mortality following hip fractures; benzodiazepine prescriptions; cancer survival; AMI and stroke case fatalities; suicides in various populations; and prescription rates for long-term care patients.

Source: Author.

Table A B.17. Examples of projects involving dataset linkages, extraction of data from electronic clinical records or other innovative uses of health data

Australia	Project title:	Linking data from three national cancer screening programs
	Purpose of the project:	The project has three aims: 1) To determine key cancer outcomes in screening and non-screening individuals; 2) To gain an understanding of the screening behaviour of participants, such as who screens, in which programs, and whether this is influenced by any common factors such as socioeconomic status, history of positive test results, or other events; and 3) To use linked data to enhance currently available screening data, such as analysis of linked cervical screening and human papillomavirus (HPV) vaccination data to look at the effect of HPV vaccination on cervical abnormalities, cancers and participation in cervical screening.
	Project description:	Australia has three national cancer screening programs—the National Bowel Cancer Screening Program, Breast Screen Australia and the National Cervical Screening Program. Data from the three programs were linked together and to the Australian Cancer Database, the National Death Index and the National HPV Vaccination Register.
	Publication:	Analysis of cancer outcomes and screening behaviour for national cancer screening programs in Australia; Analysis of breast cancer outcomes and screening behaviour for Breast Screen Australia
	Author:	AIHW
	Publisher:	AIHW
	Date:	September 2018; November 2018
	Web-link:	https://www.aihw.gov.au/reports/cancer-screening/breastcancer-outcomes-screening-behaviour-programs/contents/table-of-contents
		https://www.aihw.gov.au/reports/cancer-screening/cancer-outcomes-screening-behaviour-programs/contents/table-of-contents
Australia	Project title:	Enhancing patient safety through identification of adverse events from pharmaceutical use
	Purpose of the project:	To identify adverse events associated with medicines.
	Project description:	The pilot analysed 684 medicines looking for an association with heart failure as an adverse event. One hundred and twenty-two medicines already known to be associated with heart failure as an adverse event were successfully identified. Five new medicines were shown to be potentially associated with heart failure.
	Publication:	Preventing harm from medicines
	Author:	Australian Government Department of Health
	Publisher:	Australian Government Department of Health
	Web-link:	http://www.health.gov.au/internet/main/publishing.nsf/Content/Data-Integration-Partnership-Australia
		http://www.health.gov.au/internet/main/publishing.nsf/Content/3BA1C2301604E8F6CA25836700821D68/$File/Adverse-effects-one-pager-V9.pdf
Australia	Project title:	Variation in Opioid Use
	Purpose of the project:	The project is using linked data to investigate variation in opioid use in Australia.
	Project description:	This project will investigate the variations in prescription opioid dispensing patterns and service utilisation between different groups of patients and the factors that are likely to be best targeted through interventions. In determining population and patient groups that are within scope, analysis is expected to include, for example, break down by field of employment, income level, education status, level of geographical remoteness, age groups, and the types of health services being accessed.
Australia	Project title:	Use of Government Services by Older Australians
	Purpose of the project:	Expenditure on older Australians makes up a substantial proportion of the social security, welfare and health portfolio budgets and is projected to grow. To ensure the sustainability of the system for older Australians, insights are needed into how older Australians interact with government services.

	Project description:	This project aims to analyse the use of government-funded services by Australians aged 65 and over (50 years and over for the Indigenous population) using linked, cross-portfolio, people-centred data to: • Better understand government service use by older Australians • Support current reforms in services for older Australians • Effectively engage policy areas in developing analytic insights to inform policy development.
Australia	Project title:	General Practice insights report
	Purpose of the project:	To explore how MedicineInsight data can help inform policy, research and health systems to improve health outcomes for all Australians.
	Project description:	The General Practice Insights Report 2016–17 is the first time clinical data collected from participating MedicineInsight practices have been used to provide insights into general practice at a national level. It includes key findings including the most frequent reasons recorded as to why patients go to a doctor, the top chronic conditions with which patients present to GPs, and the most frequently prescribed medicines and medical tests.
	Publication:	General practice insights report July 2016 to June 2017: A Working paper
	Author:	NPS MedicineWise
	Publisher:	NPS MedicineWise
	Date:	2018
	Web-link:	https://www.nps.org.au/medicine-insight#general-practice-insights-report-2016-17
Austria	Project title:	A-IQI (Austrian Inpatient Quality Indicators)
	Purpose of the project:	Quality assessment
	Project description:	Analysis of DRG data
	Publication:	Austrian Inpatient Quality Indicators (A-IQI) - Report 2019
	Author:	This report was prepared within the framework of A-IQI: "Nationwide uniform result quality measurement from routine data", Austrian Inpatient Quality Indicators. Members of the A-IQI Steering Group: Regional Health Fund, Private Hospital Financing Fund, Main Association of Austrian Social Insurance Institutions, Federal Ministry of Labour, Social Affairs, Health and Consumer Protection
	Publisher:	Austrian Federal Ministry of Labour, Social Affairs, Health and Consumer Protection, Stubenring 1, 1010 Vienna
	Date:	October 2019
	Web-link:	https://www.sozialministerium.at/Themen/Gesundheit/Gesundheitssystem/Gesundheitssystem-und-Qualitaetssicherung/Ergebnisqualitaetsmessung.html and www.kliniksuche.at
Austria	Project title:	A-OQI (Austrian Outpatient Quality Indicators)
	Purpose of the project:	Outpatient quality assessment.
	Project description:	Pilot project.
Belgium	Project title:	Quality indicators for the management of cancer
	Purpose of the project:	To develop a set of quality indicators (process and outcome) for the diagnosis and treatment of different cancer types; To calculate quality indicators at the national level and to (anonymously) benchmark at the hospital level; and To assess the volume-outcome association.

	Project description:	Based on literature search and expert opinion quality indicators are identified and selected, e.g. for head and neck squamous cell carcinoma, for lung cancer. If measurable based on a linkage between the cancer registration database and health insurance data, The Belgian Cancer Registry calculates the quality indicators (national + benchmarking of hospitals). Individual feedback reports are provided to all Belgian hospitals, to benchmark their results with other (anonymized) hospitals.
	Publication:	Quality indicators for the management of head and neck squamous cell carcinoma
	Author:	Leroy R, De Gendt C, Stordeur S, Silversmit G, Verleye L, Schillemans V, Savaye I, Vanschoenbeek K, Vlaeyen J, Van Eycken L, Beguin C, Dubois C, Carp L, Casselman J, Daisne JF, Deron P, Hamoir M, Hauben E, Lenssen O, Nuyts S, Van Laer C, Vermorken J, Grégoire V
	Publisher:	Belgian Health Care Knowledge Centre (KCE)
	Date:	January, 2019
	Web-link:	https://www.kce.fgov.be/en/quality-indicators-for-the-management-of-head-and-neck-squamous-cell-carcinoma
	Publication:	Quality indicators for the management of lung cancer
	Author:	Vrijens F, Verleye L, De Gendt C, Schillemans V, Robays J, Camberlin C, Dubois C, Stordeur S, Jegou D, Silversmit G, Van Eycken E, Wauters I, Van Meerbeeck J
	Publisher:	Belgian Health Care Knowledge Centre (KCE)
	Date:	April, 2016
	Web-link:	https://kce.fgov.be/en/quality-indicators-for-the-management-of-lung-cancer
Belgium	Project title:	Medicomut Working Party 'Complex surgery'
	Purpose of the project:	Estimate and compare postop-mortality in Belgian hospitals involved in the surgical treatment of (peri) pancreatic and oesophageal cancer. The final goal was to decide on a minimum surgical volume for these treatments by a multidisciplinary panel of experts of all stakeholders involved.
	Project description:	Coupling of the Belgian Cancer Registry data with vital status and health insurance data allowed to combine information on treatment and survival for patients diagnosed with (peri)pancreatic or oesophageal cancer. Odds ratios for postop-mortality at 30 and 90-day since surgery were adjusted for tumour and patient baseline characteristics.
Belgium	Project title:	Impact of different attitudes towards breast cancer screening on breast cancer stage distribution and diagnosis of benign lesions.
	Purpose of the project:	To map different screening attitudes in the Flemish and Walloon eligible population for breast cancer screening; To assess breast cancer rate and stage distribution in women with different screening attitudes; To compare cost-effectiveness between opportunistic and organized mammographic screening; To analyse the amount of benign lesions diagnosed in the opportunistic and organized mammographic screening.
	Project description:	Screening history for Flemish and Walloon eligible population cohorts (from 2002-2015) were identified to assign a screening attitude to each individual woman based on screening program data and reimbursement data for opportunistic screening. Afterwards, linking with the BCR databases allows to determine breast cancer stage distribution in each different screening attitude group as well as benign/malignant detection ratios for organized versus opportunistic screening. Further linkage with reimbursement data for diagnostic procedures allows to estimate cost-effectiveness.
Canada	Project title:	Surrey Project
	Purpose of the project:	To assess the socio-economic determinants of the drug overdose crisis by leveraging and integrating various administrative databases.
	Project description:	In 2016, British Columbia's provincial health officer declared a public health emergency in response to a rise in illicit drug overdoses and related deaths. Between 2011 and 2016 there were 2,362 confirmed illicit drug overdose deaths in British Columbia and 332 in Surrey alone. The project is a partnership between Statistics Canada, the BC Coroners Service, City of Surrey, Surrey Fire Service, Surrey RCMP Detachment, Fraser Health Authority, BC Stats, BC Centre for Disease Control, BC Ministry of Health and Public Safety Canada. The first focus of analysis involves the integration of illicit drug overdose deaths with employment and social assistance data, health and hospitalization records, and criminal justice system contacts.
	Publication:	Illicit drug overdose deaths, 2011 to 2016, British Columbia and Surrey

	Author:	Statistics Canada
	Publisher:	Statistics Canada
	Date:	November, 2018
	Web-link:	https://www150.statcan.gc.ca/n1/daily-quotidien/181113/dq181113a-eng.htm
Canada	Project title:	Quality of Stroke Care in Canada - Stroke Report 2017
	Purpose of the project:	1) To identify patterns of occurrence of stroke and locations of where care is delivered 2) to monitor changing trends in stroke disease across age groups and geographic regions over the past years and anticipate future volumes 3) to explore specific clinical research questions related to patterns of care and outcomes for patients with stroke 4) identify elements of quality stroke care that can be used to compare to existing Canadian stroke benchmarks and best practice recommendations, and guide quality improvement at regional and provincial levels
	Project description:	This is primarily a quality improvement/research initiative. Descriptive analysis will look at each key stroke performance indicator as described above. Inferential stats and regression modelling will be calculated to compare stroke types, peer groups, age groups or changes in care across years. The project will have direct benefit on the scope and quality of stroke services in Canada, ensure patients in the high volume areas have appropriate survivor support mechanisms available, and influence access to services in the future
	Publication:	Stroke Report, 2018
	Author:	Heart and stroke foundation of Canada
	Publisher:	Heart and stroke foundation of Canada
	Date:	June 2019
	Web-link:	https://www.heartandstroke.ca/what-we-do/media-centre/stroke-report
Canada	Project title:	Quality Mental Health Services in Canada: A Comparison of Performance Indicators Across 5 Provinces.
	Purpose of the project:	The purpose of the project is to test the feasibility of creating and reporting on a small number of mental health and addictions services performance indicators that could be compared across provinces.
	Project description:	A team of mental health and addictions scientists from five provinces (British Columbia, Alberta, Manitoba, Ontario and Québec) developed and generated the measures, where possible for ages 10 years and up, using data already available from the health care systems. These measures were chosen in part because of availability of reasonably comparable cross-province data and are not intended to be representative of the mental health system in its entirety. The six performance indicators are: • Access to the same family physician for people diagnosed with a mental disorder or addiction. • First treatment contact for a mental disorder or addiction is in an emergency department. • Physician follow-up after hospital discharge for a mental disorder or addiction. • Rates of suicide attempts among people diagnosed with a mental disorder or addiction. • Suicide rates among people diagnosed with a mental disorder or addiction. • Mortality of people diagnosed with a mental disorder or addiction The project demonstrates that the process is feasible.
	Publication:	Quality Mental Health Services in Canada: A Comparison of Performance Indicators Across 5 Provinces.
	Author:	Centre for Applied Research in Mental Health & Addiction
	Publisher:	Centre for Applied Research in Mental Health & Addiction
	Date:	July, 2017
	Web-link:	https://www.sfu.ca/content/dam/sfu/carmha/resources/2017-toward-quality-mh/CARMHA%20REPORT_29%20Aug_Final.pdf

Czech Republic	Project title:	Pressure Injuries in Inpatient Care Facilities in the Czech Republic: Analysis of a National Electronic Database
	Purpose of the project:	The purpose of this study was to analyse pressure injury (PI) occurrence upon admission and at any time during the hospital course for inpatients in care facilities in the Czech Republic. Secondary aims were to evaluate demographic and clinical data of patients with PI and the impact of a PI on length of stay (LOS) in the hospital
	Publication:	Pressure Injuries in Inpatient Care Facilities in the Czech Republic: Analysis of a National Electronic Database.
	Author:	Pokorná A, Benešová K, Jarkovský J, Mužík J, Beeckman D.
	Web-link:	https://www.ncbi.nlm.nih.gov/pubmed/28549051
Czech Republic	Project title:	Analysis of data sources from NHIS for the national project focused on evidence based guidelines development. The data were used for epidemiological analyses for 4 different clinical conditions
	Purpose of the project:	The data were used for epidemiological analyses for 4 different clinical conditions: Epidemiological analyses for preparation of Clinical Practice Guidelines related to Acute Coronary Syndromes in the Czech Republic Epidemiological analyses to inform Stroke Clinical Practice Guideline Development in the Czech Republic Epidemiological analyses for Clinical Practice Guideline focused on the diabetic patients treated with insulin Epidemiological analyses to inform an early stage of Colorectal Carcinoma Clinical Practice Guideline development in the Czech Republic
	Web-link:	https://kdp.uzis.cz/res/file/konference/jbi-symposium-2018-collection.pdf
Czech Republic	Project title:	Data Sources for Monitoring of Non-healing Wounds in a National Health Information System – Epidemiology of Non-healing Wounds – Analysis of the National Register of Hospitalized Patients in 2007– 2015
	Purpose of the project:	The aim of this study is to analyse possibilities for using data from the National Health Information system to monitor the epidemiology of non-healing wounds. Hospital stays related to non-healing wounds (according to ICD-10) in acute and long-term care facilities in the Czech Republic (2007–2015), medical interventions and causes of death in patients with monitored diagnosis related to non-healing wounds were analysed
	Publication:	Data Sources for Monitoring of Non-healing Wounds in a National Health Information System – Epidemiology of Non-healing Wounds – Analysis of the National Register of Hospitalized Patients in 2007– 2015
	Author:	Pokorná A, Benešová K, Jarkovský J, Mužík J, Dušek, L.
	Publisher:	Cesk Slov Neurol N 2017; 80/113 (Suppl 1)
	Date:	July 2017
	Web-link:	http://www.csnn.eu/pdf?id=62200
Finland	Project title:	Perfect project
	Purpose of the project:	Performance measurement
	Project description:	Investigates the performance, effectiveness and costs of treatment episodes
	Publication:	The PERFECT project: measuring performance of health care episodes
	Author:	Häkkinen, Unto, Malmivaara, Antti (Guest Editors)
	Publisher:	Annals of Medicine
	Date:	2011
	Web-link:	doi.org/10.3109/07853890.2011.586901
Finland	Project title:	Diabetes in Finland (FinDM)

	Purpose of the project:	Ultimate purpose is to improve the care of diabetic patients.
	Project description:	Studies the incidence and prevalence of diabetes; complications from diabetes; use, outcomes and costs of health services among diabetic patients
	Publication:	Regional trends in avoidable hospitalisations due to complication among population with diabetes in 2 Finland in 1996-2011 – A register based cohort study
	Author:	Manderbacka K, Arffman M, Lumme S, Lehikoinen M, Winell K, Keskimäki I. Regional trends in avoidable hospitalisations due to complication among population with diabetes in 2 Finland in 1996-2011 – A register based cohort study. BMJ Open 2016;6:e011620
	Publisher:	BMJ Open
	Date:	2016
	Web-link:	doi:10.1136/bmjopen-2016-011620
Finland	Project title:	Drugs and pregnancy
	Purpose of the project:	Medication safety during pregnancy
	Project description:	Analyzes the use of medicines during pregnancy, the effects of medicine use on maternal and child health, and on the occurrence of malformations.
	Publication:	Selective serotonin-reuptake inhibitors and venlafaxine in early pregnancy and risk of birth defects
	Author:	Furu K et al.
	Publisher:	BMJ
	Date:	2015
	Web-link:	doi: https://doi.org/10.1136/bmj.h1798
France	Project title:	SNDS (National Health data system)
	Purpose of the project:	Links databases regarding health information collected primarily for administrative purposes (claims, invoices, reporting, death certificates, disability benefits) and organises large-scale access to these linked databases.
	Project description:	Legal framework to define the content of the unique database (SNDS), the responsibilities to manage it, the rights of access and the procedures to access the data.
	Publication:	Projects using SNDS are undertaken by public institutions (permanent access) and by various stakeholders (access to data approved for specific projects). Information on specific projects is available on the website of INDS (Institut national des données de santé)
France	Project title:	Health Data Hub
	Purpose of the project:	Promote and facilitate the linkage between all available health databases and promote innovation in the use of health data.
	Project description:	Legal framework to enlarge the definition of the SNDS and encompass all existing databases concerning publicly funded health activities (e.g. hospital electronic health records warehouses, cohorts, and registries).
France	Project title:	EDP Santé - Echantillon démographique permanent santé
	Purpose of the project:	Database linkage.
	Project description:	EDP is a permanent demographic sample (3 million people) with data from 5 sources including Census, fiscal data and labour data.

Germany	Project title:	Data Box
	Web-link:	https://www.dkfz.de/de/databox/index.html
Germany	Project title:	Medical Informatics Initiative
	Web-link:	https://www.medizininformatik-initiative.de/en/start
Germany	Project title:	BIDA-SE
	Web-link:	https://tu-dresden.de/med/mf/imb/forschung/forschungsprojekte/bida-se
Israel	Project title:	Acute care hospitalization and causes of death
	Purpose of the project:	Evaluate outcomes for specific diseases
	Project description:	Data merging on encrypted unique identifier
Israel	Project title:	Psychiatric hospitalization and suicide
	Purpose of the project:	Evaluate danger levels among inpatients and discharged patients
	Project description:	Data merging on encrypted unique identifier
	Publication:	The mortality risk among persons with psychiatric hospitalizations.
	Author:	Haklai Z1, Goldberger N, Stein N, Pugachova I, Levav I.
	Publisher:	Isr J Psychiatry Relat Sci.
	Web-link:	https://www.ncbi.nlm.nih.gov/pubmed/22572086
Israel	Project title:	Livebirth registry and cause of death database
	Purpose of the project:	Evaluate risk factors for infant mortality
	Project description:	Data merging on encrypted unique identifier
	Publication:	Health in Israel
	Web-link:	https://www.health.gov.il/UnitsOffice/HD/MTI/info/Pages/HealthInIsrael.aspx
Japan	Project title:	Health Data Project
	Purpose of the project:	To extend healthy life expectancy; To reduce the growth of future medical expenditure
	Project description:	The government will promote the health insurers to use and analyse health data such as health insurance claims and health check-up to implement efficient and effective health services for their subscribers using the PDCA cycle. The services includes population approaches to maintain and enrich health and approaches for high-risk cases to prevent occurrence and progression of non-communicable diseases.
Korea	Project title:	HIRA Quality Assessment
	Purpose of the project:	Improvement of health care quality is pursued by assessing the adequacy of medical services and by steadily improving care found to be inadequate based on the assessment outcome.

	Project description:	The Quality Assessment of National Health Insurance benefits was conducted by HIRA under the National Health Insurance Act. In Quality Assessment items, AMI, CABG, colorectal cancer, hypertension care, diabetes mellitus care, long-term care hospital and mental hospital within medical aid were assessed using the data linkage. In the AMI and CABG assessment, we selected populations primarily from the Medical Claims Data Warehouse, then sent lists of patients to medical care institutions. The medical care institutions entered information of patients based on the health medical registry through a web-based quality assessment data collection system. Data for hypertension care, and diabetes mellitus care extracted from primary care data were linked to the prescribing data. Fatality was one of the outcome indicators for AMI, CABG, and colorectal cancer, and was calculated from hospital in-patient data linked to computerized resident registration data maintained by the MOPAS. Prescription rates of atypical anti-psychotics and rates of readmission within 30 days of discharge from hospital for schizophrenia were calculated from mental hospital in-patient data linked to prescribing data and hospital in-patient data.
	Web-link:	http://www.hira.or.kr/bbsDummy.do?pgmid=HIRAJ030000002000
Korea	Project title:	Annual cancer statistics
	Purpose of the project:	To accurately and consistently report the nationwide cancer statistics via collecting cancer incidence data, controlling data quality, and analyse. To systematically provide cancer incidence data that serves as an important basis material in National Cancer Control Programs and National R&D program for Cancer Control.
	Project description:	The National Cancer Centre is carrying out the National Cancer Registration Program under the Cancer Control Act. The centre established a National Cancer Incidence Database by having the following incorporated into one: the database for the Korea Central Cancer Registry, the data from additional medical review survey, the database of the 11 population-based regional cancer registries, and the database of site specific cancer registries. The centre reports the nationwide cancer statistics, including incidence, mortality and survival rates, and their trends. To estimate survival and prevalence by age, sex and region, NCID is linked to the death registry at the Korea National Statistics Office and the computerized resident registration data (address) maintained by the MOPAS.
	Web-link:	https://www.e-crt.org/journal/view.php?number=2850
Latvia	Project title:	Public monitoring system for health care quality and efficiency development
	Purpose of the project:	To develop transparent health care quality, patient safety and efficiency indicators framework; to foster data analysis and research activities using administrative data
	Project description:	This project was started in 2017 by Centre for Disease Prevention and Control in cooperation with University of Latvia. It aims to provide publicly available pseudonymised patient-level data by pooling health data from several public authorities (National Health Service, Centre for Disease Prevention and Control, State Emergency Medical Service, Health Inspectorate). Expected long term outcomes of the project are: -data usage for policy making; -national benchmarking; -transparency of health care providers; -inside competition between health care facilities to improve their services.
Luxembourg	Project title:	Data exchange between National Cancer Registry and Causes of Deaths registry
	Purpose of the project:	Calculation of cancer survival
	Project description:	National Causes of Deaths registry send all information from deaths certificate to the National Cancer Registry in electronic form with national pseudonym in order to calculate cancer survival.
Luxembourg	Project title:	Data exchange between National Cancer Registry and National cancer screening programs (Breast & colorectal cancer)
	Purpose of the project:	Identification of interval cancers and use for quality audit for cancer screening program
	Project description:	National cancer screening programs (Breast & colorectal cancer) send information regarding participants to the National Cancer Registry in electronic form with national pseudonym in order to identify interval cancers.

Luxembourg	Project title:	Data exchange between Causes of Deaths registry and National Health Laboratory (autopsies)
	Purpose of the project:	Improve the quality of mortality data
Netherlands	Project title:	Improving morbidity estimates
	Purpose of the project:	Improving morbidity estimates by record linkage of data from several different health care sectors (primary and secondary care)
	Project description:	Linking of several databases to get a better estimate of prevalence and incidence rates. Used databases: GP registration, in-hospital registration, Diagnosis Treatment Combination (DBC) Information System for medical specialities (in and out of hospital), cause of death registration and database of prescribed medicines. The follow-up of this project includes also the DBC Information System for mental health care and the registration of CIZ (CIZ evaluates the indication for long term care, issued by health professionals).
	Publication:	Eenduidige cijfers over morbiditeit. Morbiditeitscijfers op basis van in de zorg geregistreerde gegevens. [Unified figures on morbidity. Morbidity figures based on data documented in the process of care]
	Authors:	Mark Nielen, René Poos, Laura Voorrips, Floor van Oers, Miriam de Roos, Agnes de Bruin
	Publisher:	NIVEL
	Date:	2019
Netherlands	Project title:	Oncoguide
	Purpose of the project:	Improving accessibility, reliability, validity, and transparency of prediction models in oncology.
	Project description:	The project joins information from literature and databases into a decision support tool. Data from the cancer registration are linked to the data from the in-hospital registration.
	Publication:	Facilitating validation of prediction models: a comparison of manual and semi-automated validation using registry-based data of breast cancer patients in the Netherlands.
	Authors:	Steenbeek, C.D., Maaren, M.C., Siesling, S. et al.
	Publisher:	BMC Med Res Methodol
	Date:	2019
	Web-link:	https://doi.org/10.1186/s12874-019-0761-5
Netherlands	Project title:	Safety of vaccination against influenza A (H1N1) during pregnancy in the Netherlands
	Purpose of the project:	This study aims to assess the safety of Influenza A(H1N1), vaccination administered during the second and third trimester and containing MF59 and thiomersal, measured by pregnancy outcomes and infant's health.
	Project description:	Questionnaire data were linked with the Netherlands Perinatal Registry and data from general practitioners.
	Publication:	Safety of vaccination against influenza A (H1N1) during pregnancy in the Netherlands: results on pregnancy outcomes and infant's health: cross-sectional linkage study.
	Authors:	N van der Maas, J Dijs-Elsinga, J Kemmeren, A van Lier, M Knol, H de Melker
	Publisher:	BJOG: an international Journal of Obstetrics & Gynaecology
	Date:	2016
	Web-link:	https://doi.org/10.1111/1471-0528.13329
Netherlands	Project title:	Perinatal health and health care

	Purpose of the project:	Improving the quality of perinatal care.
	Project description:	Several registries are linked. One woman or one child can be included in several registries. Those registries are: LVR1, LVRh, LVR2, LNR, respectively National Obstetric Registration of Midwifery Care, General Practice, Obstetrics, and Pediatrics.
	Publication:	Jaarboek Zorg 2019 (Annual Report 2019)
	Authors:	Perined
	Publisher:	Perined
	Date:	December 2020
	Web-link:	https://assets.perined.nl/docs/aeb10614-08b4-4a1c-9045-8af8a2df5c16.pdf
Singapore	Project title:	National Population Health Survey (NPHS)
	Purpose of the project:	Population health surveillance
	Project description:	Track health (.e. prevalence of non-communicable diseases like diabetes and hypertension) and risk factors (e.g. obesity and smoking) of Singapore residents.
	Publication:	Executive Summary on National Population Health Survey 2016/17
	Date:	August, 2018
	Web-link:	http://www.moh.gov.sg/resources-statistics/reports/national-population-health-survey-2016-17
Singapore	Project title:	Analysis of Health Care Expenditure Growth
	Purpose of the project:	To study the drivers of growth in health care expenditure
Singapore	Project title:	Cost Drivers for Cost Per Episode
	Purpose of the project:	To study the cost drivers for rising cost per inpatient/day surgery episodes
Slovenia	Project title:	Labour Market and Health
	Purpose of the project:	The purpose is to study the impact of labour market events on health / chronic diseases. To provide the necessary input for informed policy decisions studies examining the following questions: How do unemployment, precarious work and retirement affect the risk of mental diseases, cardiovascular diseases, and diabetes? Do such effects vary between men and women and across socioeconomic variables?
Slovenia	Project title:	National Financial Analyses
	Purpose of the project:	The purpose of this analyses was to link the financial and HR data from hospitals with in-patient health data (DRG) to re-assess the financial situation of the hospitals and to define national DRG weights.
Slovenia	Project title:	To study the drivers for rising costs per inpatient/day surgery episodes
	Purpose of the project:	Monitoring of Management of Diabetes in Slovenia
	Project description:	An important part of this project is to extract information of diabetes patients and their complications from various health care databases and link them to sociodemographic data - prepare epidemiological data on diabetes.
	Publication:	The economic burden of diabetes in Slovenia 2012
	Author:	Sonja Paulin et. al.

	Publisher:	National institute of public health
	Web-link:	http://www.mz.gov.si/fileadmin/mz.gov.si/pageuploads/javno_zdravje_2015/breme_sladkorne.docxEnter text
Sweden	Project title:	National Performance Assessments - Stroke
	Purpose of the project:	To evaluate the stroke and TIA health care in Sweden. Furthermore to analyse to what degree there is compliance with the national guidelines of stroke and TIA health care. Also to point out areas of improvement for the regions and municipalities that are responsible for health care. Data are from the Causes of Death Register, Prescribed Drug Register, the National Patient Register and the Health Care Quality Register for Stroke.
	Project description:	Comment: Personal data are requested by the NBHW for the purpose of producing statistics.
	Publication:	National Performance Assessments - Stroke
	Author:	Anastasia Simi and others
	Publisher:	NBHW
	Date:	December, 2018
	Web-link:	https://www.socialstyrelsen.se/publikationer2018/2018-12-57
Sweden	Project title:	"Does compulsory care save lives?"
	Purpose of the project:	A follow up of individuals in compulsory addiction treatment. This comprises follow up in several registers and different data custodians: the National Patient Register, Prescribed Drug Register, The Cause of Death Register, The Population Register, Register on Correctional Treatment, and Register for Institutional Care
	Project description:	Comment: Data are requested for research purposes
United Kingdom (Scotland)	Project description:	Approved dataset linkage projects are described on the information governance website.
	Web-link:	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/
United States	Project title:	Assessing Children's Health in Public and Assisted Housing
	Purpose of the project:	This analysis was summarized in a chapter for a book by the Bipartisan Policy Committee to illustrate how evidence can be used for public policy making.
	Project description:	The project uses NCHS household survey data linked to administrative data from the Department of Housing and Urban Development to examine lead exposure in public housing.
	Publication:	Evidence Works: Cases Where Evidence Meaningfully Informed Pollicy
	Authors:	Lisa Mirel, Irma Arispe, Veronica Helms, Christine Cox
	Publisher:	Bipartisan Polilcy Committee
	Date:	June 2019
	Web-link:	https://bipartisanpolicy.org/wp-content/uploads/2019/06/Evidence-Works-Cases-Where-Evidence-Meaningfully-Informed-Policy.pdf
United States	Project title:	Evaluating Survey Report of Social Security Disability Benefit Receipt Using Linked National Health Interview Survey and Social Security Administration Data
	Purpose of the project:	To assess agreement between benefit receipt based on Social Security Administration administrative records and report of benefits in a national household survey and to examine characteristics associated with misclassification.

	Project description:	The project uses NCHS household survey data linked with administrative data from the Social Security Administration to examine receipt of Social Security Disability Insurance and Supplemental Security Income as well as characteristics of beneficiaries and their health care utilisation.
	Publication:	Evaluating Survey Report of Social Security Disability
	Authors:	Benefit Receipt Using Linked National Health Interview
	Publisher:	Survey and Social Security Administration Data
	Date:	4 November 2019
	Web-link:	https://www.cdc.gov/nchs/data/nhsr/nhsr131-508.pdf
United States	Project title:	National Hospital Care Survey Demonstration Projects
	Purpose of the project:	To demonstrate use of linked data from the National Hospital Care Survey to the National Death Index for patient centred outcomes research.
	Project description:	The project uses files created through a Patient Centered Outcomes Research Trust Fund funded project that links claims and electronic health record data from the NHCS to the National Death Index and separately to administrative data from the Medicare Chronic Conditions Warehouse. The project demonstrates the feasibility of using these data for post hospitalization mortality for stroke.
	Publication:	National Hospital Care Survey Demonstration Projects
	Authors:	Geoffrey Jackson and Karishma Chari
	Publisher:	NCHS National Health Statistics Report
	Date:	13 November 2019
	Web-link:	https://www.cdc.gov/nchs/data/nhsr/nhsr132-508.pdf

Source: Author.

Table A B.18. Patient outcomes data are available by geographic level

	National	Region or State	Health Care organisation	Other level
Australia	Yes	Yes	Yes	Yes[1]
Austria	No	n.r.	n.r.	n.r.
Belgium	n.r.	n.r.	n.r.	n.r.
Canada	Yes	Yes	Yes	n.r.
Czech Republic	No	No	No	No
Denmark	Yes	Yes	Yes	Yes
Estonia	No	No	No	No
Finland	Yes[6]	No	Yes	No
France	Yes[6]	No	Yes[2]	n.r.
Germany	No	No	Yes	Yes[2]
Ireland	Yes	n.r.	n.r.	n.r.
Israel	Yes	No	Yes	n.r.
Japan	Yes3	No	No	No
Korea	No	No	Yes	n.r.
Latvia	No	No	No	n.r.
Luxembourg	No	No	No	No
Netherlands	Yes	No	Yes	Yes[4]
Norway	Yes	n.r.	n.r.	n.r.
Singapore	No	No	No	No
Slovenia	No	No	Yes	No
Sweden	Yes	No	No	Yes[5]
United Kingdom (Scotland)	No	n.r.	n.r.	n.r.
United States	Yes	Yes	No	n.r.

Note: n.r.: not reported.
1. Quality registries (some of which are available at state and national levels).
2. Hospital level.
3. Sampling survey conducted every 3 years.
4. Quality registries and registries for research aims.
5. Quality registries (which are available at the national level).
6. In development.
Source: Author.

Table A B.19. Prostate cancer patient-reported outcomes data, by level

Country	National	Region or State	Health Care Organisation	Other level
Australia	No	No	No	Yes
Austria	No	n.r.	n.r.	n.a.
Belgium	n.a.	n.a.	n.a.	n.a.
Canada	Yes	Yes	No	n.a.
Czech Republic	n.a.	n.a.	n.a.	n.a.
Denmark	n.a.	Yes	Yes	No
Finland	n.a.	n.a.	n.a.	n.a.
France	n.r.	n.a.	Yes	n.a.
Estonia	No	No	d.k.	n.a.
Germany	n.a.	n.a.	Yes	Yes
Ireland	Yes	n.a.	n.a.	n.a.
Israel	No	No	Yes	n.a.
Japan	No	n.a.	n.a.	n.a.
Korea	n.a.	n.a.	Yes	n.a.
Latvia	n.a.	n.a.	n.a.	n.a.
Luxembourg	n.a.	n.a.	n.a.	n.a.
Netherlands	No	No	Yes	Yes
Norway	Yes	n.a.	n.a.	n.a.
Singapore	n.a.	n.a.	n.a.	n.a.
Slovenia	n.a.	n.a.	No	n.a.
Sweden	Yes	n.a.	n.a.	n.r.
United Kingdom (Scotland)	n.a.	n.a.	n.a.	n.a.
United States	Yes	Yes	n.a.	n.a.

Note: n.a.: not applicable; n.r.: not reported
1. Nantes and Lyon Comprehensive Cancer Centres.
Source: Author.

Table A B.20. Breast cancer patient-reported outcomes data, by level

Country	National	Region or State	Health Care Organisation	Other level
Australia	No	Yes	No	No
Austria	No	n.r.	n.r.	n.r.
Belgium	n.a.	n.a.	n.a.	n.a.
Canada	Yes	Yes	No	n.a.
Czech Republic	n.a.	n.a.	n.a.	n.a.
Denmark	n.a.	Yes	Yes	No
Finland	n.r.	n.a.	Yes	n.a.
France	No	No	Yes1	n.a.
Germany	n.a.	n.a.	Yes	Yes
Ireland	Yes	n.a.	n.a.	n.a.
Israel	No	n.a.	Yes	n.a.
Japan	No	n.a.	n.a.	n.a.
Korea	n.a.	n.a.	Yes	n.a.
Latvia	n.a.	n.a.	n.a.	n.a.
Luxembourg	n.a.	n.a.	n.a.	n.a.
Netherlands	No	No	Yes	Yes
Norway	No	n.a.	n.a.	n.a.
Singapore	n.a.	n.a.	n.r.	n.a.
Slovenia	n.a.	n.a.	No	n.a.
Sweden	No	n.a.	n.a.	n.r.
United Kingdom (Scotland)	n.a.	n.a.	n.a.	n.a.
United States	Yes	Yes	n.a.	n.a.

Note: n.a.: not applicable; n.r.: not reported
Source: Author.

Table A B.21. Hip and Knee patient-reported outcomes data, by level

Country	National	Region or State	Health Care Organisation	Other level
Australia	No	No	Yes	No
Austria	No	n.r.	n.r.	n.r.
Belgium	n.a.	n.a.	n.a.	n.a.
Canada	Yes	Yes	Yes	n.a.
Czech Republic	n.a.	n.a.	n.a.	n.a.
Denmark	n.a.	No	Yes	No
Estonia	n.a.	n.a.	n.a.	n.a.
Finland	n.r.	n.a.	Yes	n.a.
France	No	No	Yes	n.a.
Germany	n.a.	n.a.	Yes	No
Ireland	d.k.	n.a.	n.a.	n.a.
Israel	No	n.a.	Yes	n.a.
Japan	No	n.a.	n.a.	n.a.
Korea	n.a.	n.a.	Yes	n.a.
Latvia	n.a.	n.a.	n.a.	n.a.
Luxembourg	n.a.	n.a.	n.a.	n.a.
Netherlands	Yes	No	Yes	Yes
Norway	No	n.a.	n.a.	n.a.
Singapore	n.a.	n.a.	n.a.	n.a.
Slovenia	n.a.	n.a.	No	n.a.
Sweden	Yes	n.a.	n.a.	n.r.
United Kingdom (Scotland)	n.a.	n.a.	n.a.	n.a.
United States	Yes	Yes	n.a.	n.a.

Note: n.a.: not applicable; n.r.: not reported; d.k.: unknown.
Source: Author.

Table A B.22. Cardiovascular disease patient-reported outcomes data, by level

Country	National	Region or State	Health Care Organisation	Other level
Australia	No	No	No	Yes
Austria	No	n.r.	n.r.	n.r.
Belgium	n.a.	n.a.	n.a.	n.a.
Canada	No	Yes	No	n.a.
Czech Republic	n.a.	n.a.	n.a.	n.a.
Denmark	n.a.	Yes	Yes	Yes
Estonia	n.a.	n.a.	n.a.	n.a.
Finland	n.r.	n.a.	Yes[1]	n.a.
France	No	No	d.k.	n.a.
Germany	n.a.	n.a.	Yes	Yes
Ireland	d.k.	n.a.	n.a.	n.a.
Israel	No	n.a.	Yes	n.a.
Japan	No	n.a.	n.a.	n.a.
Korea	n.a.	n.a.	Yes	n.a.
Latvia	n.a.	n.a.	n.a.	n.a.
Luxembourg	n.a.	n.a.	n.a.	n.a.
Netherlands	Yes	No	Yes	Yes
Norway	Yes	n.a.	n.a.	n.a.
Singapore	n.a.	n.a.	n.a.	n.a.
Slovenia	n.a.	n.a.	No	n.a.
Sweden	Yes	n.a.	n.a.	n.r.
United Kingdom (Scotland)	n.a.	n.a.	n.a.	n.a.
United States	Yes	Yes	n.a.	n.a.

Note: n.a.: not applicable; n.r.: not reported

1. Ischaemic heart disease.

Source: Author.

Table A B.23. Other patient-reported outcomes data, by level

Country	National	Region or State	Health Care Organisation	Other level	Explanatory note
Australia	Yes	Yes	Yes	Yes	Quality registries, hospitals and other organisations are collecting PROs from rheumatology and mental health patients, patients with other cancers and other patients.
Austria	No	n.r.	n.r.	n.r.	
Belgium	n.a.	n.a.	n.a.	n.a.	
Canada	No	Yes	No	n.a.	Alberta collects PROs in primary care, chronic disease management, renal care, bariatrics, palliative care, and community rehab sectors. British Columbia collects PROs in hospital inpatient, emergency department and renal care sectors.
Czech Republic	n.a.	n.a.	n.a.	n.a.	
Denmark	n.a.	Yes	Yes	Yes	PROs are collected from asthma, diabetes type 1, gestational diabetes, hydrocephalus, COPD, narcolepsy, kidney failure, prostate cancer, epilepsy, HIV, arthritis, neuromuscular disease, and sclerosis patients.
Estonia	n.a.	n.a.	n.a.	n.a.	
Finland	n.r.	n.a.	Yes	n.a.	Spine surgery, diabetes, rheumatoid arthritis, HIV (being launched), possibly others
France	Yes	No	Yes	n.a.	Chronic kidney disease (national) and Cataract in health care organisations
Germany	n.a.	n.a.	Yes	Yes	Pros are collected from Bowel cancer patients.
Ireland	n.r.	n.a.	n.a.	n.a.	
Israel	Yes	n.a.	Yes	n.a.	PROS are collected from patients in psychiatric rehabilitation (national level) and a medical centre collects PROs from patients with 30 conditions.
Japan	Yes	n.a.	n.a.	n.a.	PROs are collected from general hospital inpatients and outpatients through a national survey.
Korea	n.a.	n.a.	Yes	n.a.	PROs are collected in some hospitals from ophthalmology, mental health and other patients.
Latvia	n.a.	n.a.	n.a.	n.a.	
Luxembourg	n.a.	n.a.	n.a.	n.a.	
Netherlands	Yes	No	Yes	Yes	PROs are collected from cataract patients (national level) and from patients within colon cancer, oesophagus cancer, gyn oncology, low back pain, morbid obesity, pancreatic cancer, Parkinson's disease, prostate cancer, head and neck cancer, lung cancer, pancreas cancer, inflammatory arthritis, skin cancer (melanoma), peripheral arthrosis, hip fracture, and peripheral arterial disease registries. The national patient federation collects PROs for patients with a (chronic) disease or disability. In mental health care routine outcome monitoring is done on the level of the individual patient and on the level of healthcare organisations.
Norway	Yes	n.a.	n.a.	n.a.	PROs are collected from patients with chronic obstructive pulmonary disease, diabetes, cerebral palsy, multiple sclerosis, cognitive symptoms, ACL injury, hip fracture, back surgery, joint prostheses, neck- and back pain, anal incontinence, endoscopically operated for gynaecological conditions, female incontinence, spinal cord injury, autoimmune diseases, vasculitis, arthritis, tonsil surgery, hidradenitis suppurativa, eating disorders, and porphyria.
Singapore	n.a.	n.a.	n.a.	n.a.	
Slovenia	n.a.	n.a.	Yes	n.a.	PROs are collected in some medical centres from patients following spine and abdominal hernia surgeries, in procedures of elective hip and knee arthroplasty,patients in rehabilitation and haemophilia patients.
Sweden	Yes	n.a.	n.a.	Yes	PROs are collected from a wide range of patients through Quality Registries.
UK(Scotland)	n.a.	n.a.	n.a.	n.a.	
United States	Yes	Yes	n.a.	n.a.	All conditions asked of all sample adults to include mental health outcomes, pain, other selected conditions, etc.

Note: n.a.: not applicable; n.r.: not reported..
Source: Author.

Table A B.24. Examples of indicators based on PROs that are used to monitor health care quality

Country	Examples of health care quality indicators based on PROs
Australia	Clinical quality registries frequently collect patient-reported quality of life.
Denmark	Physical functioning, pain, quality of life, disease activity index (BASDAI), frequency of urinary incontinence after surgery, prolapse symptoms after surgery, adipose surgery outcomes, and depression after rehabilititation for heart conditions.
Finland	Physical functioning following hip, knee, and spine surgery.
Germany	PROs are used for health care organisation certification and for internal quality management.
Israel	Functioning, social adaptation and medical care quality measures.
Japan	Satisfaction with health care.
Korea	Change of physical functioning after surgery such as hip and cancer surgery.
Netherlands	Items: pain, sleeping problems, performing daily activities, quality of life, autonomy, fear, worries, physical functioning, perceived health, disease-specific symptoms, tiredness, social roles, social activities, cognition, depressive symptoms. In addition, we use response indicators (e.g. the number of patients recording the PROM compared to the number of patients who are in the registry). For example skin cancer: the percentage of patients in the Dutch Melanoma Treatment Registry (DMTR) who filled out a PROM questionnaire at inclusion in the DMTR registry.
Sweden	Proportion of patients who report that they are satisfied at 1, 6 and 10 years after hip arthroplasty.

Source: Author.

Table A B.25. Challenges developing PROs

Challenges developing PROs
Resources to develop and collect these data (Australia, Canada, Czech Republic, Denmark, Estonia, Finland, France, Germany, Korea, Latvia, Luxembourg, Norway, Slovenia)
Multiple measures for the same concepts/Agreeing and adopting standards for PROs (Canada, Denmark, Finland, Germany, Sweden)
Clinical and policy maker interest (Austria, Czech Republic, France, Germany, Korea, Norway, Slovenia)
Data protection (Germany and Netherlands)
Administrative/governance barriers (Finland and Germany)
Methodological issues (France and Luxembourg)
Scaling up adoption of PROMS (Finland and Netherlands)
Patient response rates (Netherlands and Singapore)
Making PROM data useable for clinical and statistical purposes (Sweden)
ICT issues (Netherlands)
Integration with Electronic Clinical Record (Singapore)
Unified electronic system to collect data and share results (Israel, Singapore)

Source: Author.

Table A B.26. Challenges developing national health datasets

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	Patient experiences survey data	Population health survey data	Population census or population registry data
Australia	No	No	No	No	No	No	Yes	n.r.	n.r.	Yes	No	No	No
Austria	No	No	No	No	No	No	n.a.	No	No	No	No	No	No
Belgium	No	No	No	Yes	Yes	No	Yes	n.r.	n.r.	n.r.	No	No	n.r.
Canada	No	No	No	Yes	No	No	n.r.	n.r.	No	No	No	No	No
Czech Republic	Yes	No	Yes	n.r.	Yes	Yes	Yes	Yes	Yes	n.r.	n.r.	Yes	n.r.
Denmark	No	No	No	No	No	No	No	No	No	No	No	No	No
Estonia	Yes	Yes	Yes	Yes	Yes	No	n.r.	Yes	No	Yes	Yes	Yes	No
Finland	Yes	Yes	Yes	Yes	No	Yes	n.a.	n.r.	No	Yes	n.a.	Yes	No
France	No	No	No	No	No	Yes	Yes	Yes	No	Yes	Yes	No	No
Germany	n.r.	n.r.	n.r.	n.r.	Yes	No	n.r.	n.r.	n.r.	n.r.	n.r.	Yes	n.r.
Ireland	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Israel	No	No	No	No	Yes	No	No	n.r.	No	No	No	No	No
Japan	n.r.	n.r.	n.r.	n.r.	n.r.	Yes	n.r.	n.r.	No	No	No	No	Yes
Korea	Yes	Yes	Yes	Yes	Yes	No	No	n.a.	No	Yes	No	No	No
Latvia	No	No	No	No	No	Yes	Yes	n.r.	No	n.r.	n.r.	No	No
Luxembourg	Yes	Yes	n.r.	Yes	n.r.	Yes	n.r.	n.r.	Yes	No	Yes	Yes	No
Netherlands	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	No
Norway	No	No	No	No	No	No	No	No	No	Yes	No	No	No
Singapore	Yes	Yes	Yes	Yes	Yes	No	No	No	No	Yes	No	No	No
Slovenia	No	No	No	No	No	No	Yes	Yes	No	Yes	No	No	No
Sweden	No	No	No	n.r.	No	No	No	No	No	No	n.r.	n.r.	No
UK(Scotland)	No	No	No	No	No	No	No	n.r.	No	No	No	No	No
United States	Yes	n.r.	No	Yes	No	n.r.	n.r.	n.r.	No	No	n.r.	No	n.r.

Note: n.a.: not applicable; n.r.: not reported.
Source: Author.

Table A B.27. Description of challenges to national dataset creation

Hospital in-patient data	Mental hospital in-patient data	Emergency care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	CVD Registry data	Mortality data	Formal long-term care data	Patient reported experiences data	Population health survey data	Population Census or Registry	General
Lack of SES data (Czech Republic)	Registration of diagnoses on DSM-5 level has been discontinued (Netherlands)	Communicating with insurance companies and providers is complex (Czech Republic)	Barriers to data linkage and extraction of data from clinical records (Belgium)	Non-reimbursed drugs are not covered (Belgium)	Break in the time series due to a change in dataset custodians (Czech Republic, Latvia)	Break in the time series due to a change in dataset custodian (Latvia)	Difficulties with data annonymisation and linkage to other datasets (Czech Republic)	Lack of SES data (Czech Republic)	Incomplete data and other quality issues (Australia, France, Netherlands)	Not implemented on a recurrent basis (Luxembourg)	Coverage excludes migrants and very old people (Germany)	"not reported" records are higher for some population groups (Japan)	Coding problems within health insurance data (Estonia)
Difficult to uniquely identify foreigners (Czech Republic)		Difficulties with data management and validation (Czech Republic)	Patient registry does not include primary care (Sweden)	No information on diagnosis (Belgium)	Break in the timeseries due to a change in methodology with new datasets for specific diseases (Czech Republic)	Data sources are limited to insulin-treated diabetes cases and exclude those caring for their diabetes with lifestyle modification.(Australia)	Difficult to uniquely identify foreigners (Czech Republic)	Difficult to link to administrative data (Czech Republic)	Issues with ability to link the data (Australia)	Incomplete coverage of the patient population (France and Netherlands)	Decreasing response rates (Luxembourg, Netherlands and Sweden)		Digitalisation of paper records and data quality could be improved (Singapore)
Original purpose of the data is claim reimbursement which limits dataset content and quality. (Czech Republic, Luxembourg)		Data are not at the national level (Netherlands)	Primary care physician response rates (United States)	Communication with insurance companies and providers is challenging (Czech Republic).	Lack of a unique patient identifying number for linkages (Japan)	Technical barriers to dataset linkages and extraction from electronic health records (Belgium)	Lack of resources to develop a Myocardial Infarction Register (EMIR) (Estonia)	Issues with certification and data coding (Czech Republic)	Legal barriers to sharing data within the country (Australia)	Data are not linkable (Netherlands)			Improving timeliness/developing local information systems that allow real-time data collection (Finland)

Hospital in-patient data	Mental hospital in-patient data	Emergency care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	CVD Registry data	Mortality data	Formal long-term care data	Patient reported experiences data	Population health survey data	Population Census or Registry	General
Gaps in population coverage (Luxembourg)		Data are not linkable (Netherlands)	Completeness of records from medical specialists is uncertain (Netherlands)	Difficulties with data management and validation (Czech Republic)	Lack of resources to develop the dataset (Japan)	Communicating with insurance companies and providers is complex (Czech Republic)	Registry is limited to heart patients that had invasive procedures (Netherlands).	Data covers deaths in the territory only, so residents who die abroad are excluded (Luxembourg)	Lack of resources and will to develop the data (Slovenia)				Data quality within all registries is a continuous challenge (Finland).
Lack of resources (Luxembourg)		Procedures, medications and waiting times are not registered (Netherlands)	Coding problems including superficially high diagnostic codes and uncoded (free text) in records (Netherlands)	Detailed data at the regional level including variables to allow dataset linkages are not provided (Germany)	Legal or policy barriers to sharing the data within the country (Japan)	Difficulties with data management and validation (Czech Republic)			Multiple insurers/reimbursement organisations increases the challenge to amalgamate and link data (Netherlands).				Legal barriers to the linkage of datasets limits dataset development (Korea)
Completeness and timeliness of the data (Netherlands)		Funding for national data on emergency care provided outside hospitals is needed (Finland).		Small health insurers do not participate (Netherlands)		Primary care data not yet linked (Netherlands)							Technical challenges linking administrative (claims) data and clinical data (France)

Hospital in-patient data	Mental hospital in-patient data	Emergency care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	CVD Registry data	Mortality data	Formal long-term care data	Patient reported experiences data	Population health survey data	Population Census or Registry	General
Diagnosis information is sometimes recorded before all diagnostics are completed (Netherlands)													Cost and human resources to develop morbidity registries (France).
Hospital participation rates (United States)													

Source: Author.

Table A B.28. National health data governance elements

Country	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	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: Author.

Table A B.29. National law or regulation that speaks to health data protection and/or extraction of data from electronic clinical records

Country	National Law or Regulation
Australia	*Privacy Act 1988*, *My Health Records Act 2012*, *Healthcare Identifiers Act 2010*, *Health Insurance Act 1973*, and *National Health Act 1953*
Austria	*Health Telematics Law* https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111, *Documentation Law*: https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=10011011, and *Research organisation law*: https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=10009514
Belgium	*Loi du 30 juillet 2018 relative à la protection des personnes physiques à l'égard des traitements de données à caractère personnel* (Moniteur belge du 5 septembre 2018)
Canada	Canada has a national privacy law (PIPEDA) that is not specific to health information. All 13 provincial/territorial jurisdictions in Canada have specific legislation related to the privacy of personal information and most have legislation specific to the protection of health information.
Czech Republic	Act no. 101/2000 Coll., on personal data protection, and Act no. 372/2011 Coll., on health services and conditions of their provision
Denmark	The regulation for the protection of health data in Denmark is broad. The most significant laws are the *Data Protection Act (Databeskyttesesloven)*, which is a supplement to the *GDPR*[1] applicable in Denmark and then we have a special regulations in the *Health Act (Sundhedsloven)*.
Estonia	Collection, management and analysis of all kinds of personal health data in Estonia are regulated by the *Personal Data Protection Act*. Estonia has 14 national health-related registries or databases. All of them have statutes describing: the purpose; owner or authorized processor; main data providers; datasets; rules of procedures for data modification, access, extraction and dissemination; security measures; security levels; etc.
Finland	*Data Protection Act*, *Act on Patient's Status and Rights*, and several other Acts and Decrees including the *Decree on Patient Records* and *EU General Data Protection Regulation*[1]. See https://stm.fi/en/social-and-health-services/information-management.
France	France was one of the first countries to have such legislation, it dates back to 1978 (*Data Protection Act of 6 January 1978*). It was updated recently to be consistent with the *Act of 28 January 2016 on the modernisation of the health care system* and with the EU *GDPR*[1]. See https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000886460
Germany	Several laws and regulations govern the protection of health data, depending on the processing operations (i.e. *Social Code,law on human genetic diagnostics*, data protection and hospital laws on federal and state level etc.)
Ireland	While there is no specific law dealing exclusively with health information or electronic clinical records, regulations made under the *Data Protection Act 2018* speak to the provision of health data for research purposes, in particular the need for an application to the consent declaration committee to seek consent exemptions. The *Data Protection Act* itself also activates the relevant sections of *GDPR*[1] in the area of health.
Israel	*Protection of Privacy Law*, 5741-1981on; protection of privacy regulations (information security) 2017
Japan	*Act on the Protection of Personal Information*, *Act on the Protection of Personal Information Held by Administrative Organs* and *Act on the Protection of Personal Information Held by Incorporated Administrative Agencies*, etc.
Korea	*Personal Information Protection Act*
Latvia	*Law On the Rights of Patients*; *Medical Treatment Law*; Cabinet Regulation No. 134 (11 March 2014) Regulations Regarding Unified Electronic Information System of the Health Sector; Cabinet Regulation No. 746 (15 September 2008) Procedures for Developing, Supplementing and Maintaining Register of Patients who are Ill with Certain Diseases; and Cabinet Regulation No. 446 (4 August 2015) Procedures for Using the Patient Data in a Specific Research
Luxembourg	*Act of 1 August 2018 on the organisation of the National Data Protection Commission and the general data protection framework* : http://legilux.public.lu/eli/etat/leg/loi/2018/08/01/a686/jo; and law regarding e-clinical records that is in the legislative process
Netherlands	*GDPR*[1] (in Dutch: *AVG (Algemene verordening gegevensbescherming)* and UAVG (implementation act of the AVG)), but medical confidentiality is also anchored in legislation through the *Medical Treatment Agreement Act* (*Wet op de geneeskundige behandelingsovereenkomst*; WGBO)
Norway	There are several legislations. A summary is given by REC here; https://helseforskning.etikkom.no/reglerogrutiner/loverogregler?p_dim=34770&_ikbLanguageCode=us

Singapore	*Personal Data Protection Act* (PDPA) and various MOH specific legislation
Slovenia	*Health Database Act*, national *Law on Personal Data Protection*
Sweden	*GDPR*[1], *Patient Data Act*, *Health Data Register Act* and *Public Access to Information and Secrecy Act*
UK (Scotland)	*GDPR*[1]
United States	*Health Insurance Portability and Accountability Act* (HIPAA) that was passed by the US Congress in 1996. *HIPAA* provides security provisions and data privacy in order to keep patients' medical information safe. Under the *HIPAA* Privacy Rule, patients have the rights over their health information regardless of the form of that health information (electronic, oral, and written). The Privacy Rule sets rules and limits on who can look at and receive patients' health information. Also, under *HIPAA*, individuals have a right to access their personal health information in a designated record set. The U.S. has a sectoral approach to health data governance/privacy law. In the traditional health care industry, where care is provided by a provider or hospital and paid for through health insurance, an individual's health information is protected in three main ways: First, *Health Insurance Portability and Accountability Act of 1996* (HIPAA), also known as Public Law 104-191, is a federal law that establishes a nationwide floor of privacy and security standards, imposes protections through its implementing Privacy, Security, and Breach Notification Rules, at 45 Code of Federal Regulation Parts 160 and 164. Those rules are enforced by the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR), while criminal penalties for certain disclosures are enforced by the U.S. Department of Justice. Second, the Federal Trade Commission (FTC) enforces the FTC Act's consumer protection prohibition against acts or practices that are unfair or deceptive. These could include, for example, failing to comply with an entity's own privacy policy, deceptively failing to disclose material information about the use of personally identifiable information, or failing to reasonably secure this information. Third, approximately half the states in the U.S. have enacted health privacy rules that apply in addition to, and are more protective of patient privacy than, *HIPAA* but which concern specific clinical conditions or circumstances (e.g., HIV/AIDS status, mental or reproductive health conditions, or the health information of teenagers). Rules serve as the foundation for federal protection of the privacy and security of identifiable health information (referred to as protected health information (PHI)) and apply in conjunction with state laws that impose more stringent privacy and security protections

Source: Author.

Table A B.30. National data governance difficulties

	Legal or policy barriers to sharing data among public authorities	Legal or policy barriers to public authorities undertaking data linkages.	Legal or policy barriers to public authorities extracting data from electronic clinical records?	Legal or policy barriers to sharing de-identified data with university or non-profit research organisations in your country.	Legal or policy barriers to sharing de-identified data with a foreign government or a foreign researcher	Lack of person identifiers to link the data	Concerns with the quality of the data that limit their usefulness	Lack of resources or technical capacity to process data or make data accessible for research and statistics	Other challenges
Australia	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No
Austria	No	No	No	No	n.r.	No	Yes	No	n.r.
Belgium	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Canada	Yes	Yes	Yes	No	Yes	No	No	No	No
Czech Republic	Yes	Yes	No	No	No	No	Yes	No	No
Denmark	Yes	Yes	No	No	Yes	No	No	No	No
Estonia	No	No	No	No	No	No	Yes	Yes	n.r.
Finland	No	No	No	No	No	No	Yes	Yes	n.r.
France	No	Yes[1]	Yes	No	No	Yes	Yes	No	n.r.
Germany	n.r.	n.r.	Yes	Yes	Yes	Yes	Yes	No	No
Ireland	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No
Israel	Yes	Yes	Yes	Yes	No	No	No	No	No
Japan	Yes	Yes	Yes	No	Yes	Yes	No	No	No
Korea	No	Yes	Yes	No	Yes	No	No	No	n.r.
Latvia	Yes	Yes	No	No	No	No	Yes	Yes	n.r.
Luxembourg	Yes	Yes	Yes	No	No	Yes	Yes	Yes	n.r.
Netherlands	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Singapore	No	No	No	No	No	No	Yes	Yes	No
Slovenia	Yes	Yes	No	No	No	No	No	No	No
Sweden	No	No	No	No	Yes	No	Yes	n.r.	n.r.
UK (Scotland)	Yes	Yes	No	No	No	No	No	No	No
United States	No	Yes	No	No	No	No	Yes	No	n.r.

Note: n.r. not reported.
1. Legal barriers to dataset linkages were eased through legislation introduced in 2019.
Source: Author.

Table A B.31. Proportion of key national health care datasets with recommended governance elements

Country	Legislation authorises datasets	Data privacy/data protection officer	Staff are trained in data protection	Staff data access controls	Data de-identified prior to analysis	Testing re-identification attack risk	Data shared within public sector	Data shared with academic/non-profit sector	Data shared with for-profit sector	Data shared cross-border	Standard data sharing agreement	Either remote data access service or research data centre	Public description of dataset	Description includes legal basis for the dataset	Procedure to request and approval criteria for data linkage are publically available	sum
Australia	67%	100%	100%	100%	100%	0%	78%	89%	89%	100%	78%	33%	100%	22%	100%	11.56
Austria	100%	100%	100%	100%	100%	0%	89%	44%	33%	33%	0%	78%	78%	78%	0%	9.33
Belgium	100%	100%	100%	100%	100%	43%	57%	100%	0%	100%	100%	29%	100%	100%	57%	11.86
Canada	25%	100%	100%	100%	100%	0%	88%	88%	75%	75%	88%	25%	88%	75%	88%	11.13
Czech Republic	100%	100%	100%	100%	100%	0%	0%	0%	0%	0%	0%	0%	100%	100%	0%	7.00
Denmark	100%	100%	100%	100%	100%	90%	100%	100%	100%	100%	100%	100%	100%	100%	100%	14.90
Estonia	100%	100%	33%	100%	100%	0%	100%	89%	89%	89%	0%	0%	100%	33%	11%	9.44
Finland	100%	100%	100%	67%	100%	0%	100%	100%	100%	100%	100%	11%	100%	100%	100%	12.78
France	78%	100%	100%	100%	100%	78%	100%	100%	78%	78%	67%	67%	89%	67%	67%	12.67
Germany	67%	67%	33%	33%	67%	33%	33%	67%	33%	67%	67%	33%	100%	100%	33%	8.33
Ireland	100%	14%	14%	0%	0%	0%	0%	0%	0%	0%	14%	0%	14%	0%	14%	1.71
Israel	88%	100%	0%	0%	100%	0%	88%	88%	0%	0%	100%	63%	63%	63%	100%	8.50
Japan	100%	100%	13%	75%	88%	0%	0%	88%	13%	0%	75%	0%	100%	13%	88%	7.50
Korea	100%	100%	100%	100%	100%	89%	89%	89%	0%	0%	78%	78%	89%	89%	89%	11.89
Latvia	100%	100%	100%	100%	100%	0%	100%	100%	0%	38%	100%	0%	100%	100%	100%	11.38
Luxembourg	100%	100%	100%	100%	100%	14%	100%	100%	0%	57%	100%	86%	57%	57%	14%	10.86
Netherlands	80%	100%	100%	60%	100%	20%	70%	80%	20%	60%	100%	50%	100%	70%	60%	10.70
Norway	90%	0%	0%	0%	0%	0%	100%	100%	100%	100%	0%	0%	100%	100%	0%	6.90
Singapore	40%	100%	100%	100%	70%	80%	10%	100%	100%	100%	50%	100%	20%	20%	0%	9.90
Slovenia	100%	100%	100%	100%	100%	0%	14%	100%	0%	100%	100%	100%	100%	100%	0%	11.14
Sweden	89%	100%	100%	11%	100%	11%	100%	100%	0%	0%	100%	11%	100%	100%	100%	10.22
UK (Scotland)	89%	89%	89%	89%	89%	89%	89%	89%	89%	0%	89%	89%	89%	89%	89%	12.44
United States	100%	100%	100%	100%	100%	100%	83%	100%	100%	0%	100%	100%	100%	17%	83%	12.83

Note: The sum is the addition of the preceding columns and the maximum sum is 15. The percentages in this table are from the tables that follow (B.32 to B.58).
Source: Author

Table A B.32. Legislation authorises dataset creation

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	No	No	No	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	67%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	No[1]	No[1]	No[1]	n.r.	Yes	n.r.	n.a.	n.a.	Yes	No[1]	25%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes	78%
Germany	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Israel	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	n.a.	Yes	Yes	88%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes*	Yes	100%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes[2]	80%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	90%
Singapore	No	No	No	No	No	Yes	No	Yes	Yes	Yes	40%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	No	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	No	Yes	Yes	Yes	89%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.

1.Not authorised by national legislation.

 2.Long-term care data consist of several linked datasets. The answers are for the health care claims portion of the data.

Source: Author.

Table A B.33. Data privacy/data protection official within organisation in custody of the dataset

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	Yes	Yes	Yes[1]	n.a.	n.a.	Yes[1]	Yes	100%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Germany	Yes	n.a.	n.a.	n.a.	no	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	Yes	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	14%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes[2]	Yes	100%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK(Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported

1. Information management division.

2. Several officers.

Source: Author.

Table A B.34. Staff are trained in data privacy and security protection

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Czech Republic	Yes	Yes	Yes	n.r.	Yes	Yes	Yes	Yes	Yes	n.r.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	No	No	No	No	No	Yes	n.r.	Yes	Yes	No	33%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes[1]	100%
Germany	Yes	n.a.	n.a.	n.a.	No	No	n.r.	n.r.	n.r.	n.r.	33%
Ireland	Yes	n.r.	No	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	14%
Israel	n.r.	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.r.	n.r.	0%
Japan	n.r.	n.r.	n.r.	n.r.	n.r.	Yes	n.a.	n.a.	No	No	13%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.
1. The database is in the testing phase.
Source: Author.

Table A B.35. Identities of staff accessing personal health data are controlled and tracked

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	67%
France	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	n.r.	Yes	n.r.	100%
Germany	Yes	n.a.	n.a.	n.a.	No	No	n.r.	n.r.	n.r.	n.r.	33%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	n.r.	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.r.	n.r.	0%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No*	No	75%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes	No	No	No	Yes	Yes	No	Yes	Yes	60%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	Yes	n.r.	n.r.	n.r.	11%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported
Source: Author.

Table A B.36. Data is de-identified prior to analysis

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Germany	No	n.a.	n.a.	n.a.	Yes	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No	Yes	88%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes[1]	Yes[1]	Yes[3]	Yes	Yes	Yes	Yes[4]	Yes	Yes	Yes	100%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.r.	Yes	n.r.	70%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK(Scotland)	Yes[2]	Yes[2]	Yes[2]	Yes[2]	Yes[2]	Yes[2]	n.r.	n.a.	Yes2	Yes2	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.
1. Unique identifier is replaced by an anonymous number.
2. Sometimes.
3. Only health care providers can link the data using an annonymous emergency care number.
4. Linkage is by pseudonymised ID.
Source: Author.

Table A B.37. Pseudonyms created from direct identifiers

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	No	No	No	Yes	Yes	No	No	n.a.	No	n.a.	22%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes	78%
Germany	n.r.	n.a.	n.a.	n.a.	No	Yes[1]	n.a.	n.a.	n.a.	n.a.	33%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	No	n.a.	n.a.	No	Yes	75%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	90%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK(Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.
1. This is done at the federal state level.
Source: Author.

Table A B.38. Process for the assessment of the risk of data re-identification

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Belgium	Yes	Yes	Yes	No	Yes[1]	Yes	Yes	n.a.	n.a.	n.a.	86%
Canada	No[2]	No[2]	No[2]	Yes	Yes	No	n.a.	n.a.	No2	No[2]	25%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	90%
Estonia	No	No	No	No	No	No	n.a.	No	No	No	0%
Finland	No[5]	No[5]	No[5]	No[5]	n.r.	n.r.	n.a.	No[5]	n.r.	No[5]	0%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes	78%
Germany	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	No	No	No	No	n.a.	No	No	n.a.	No	No	0%
Japan	n.r.	n.r.	n.r.	n.r.	n.r.	No	n.a.	n.a.	No	Yes	13%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	89%
Latvia	No	No	No	No	No	No	No	n.a.	No	n.a.	0%
Luxembourg	Yes[3,4]	Yes[3,4]	n.a.	Yes[3]	Yes[3]	No	n.a.	n.a.	No	Yes[3]	71%
Netherlands	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	70%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	No	No	No	No	No	No	n.a.	n.a.	No	n.a.	0%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK(Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.

1. Yes for data communication.

2. Not currently, but under development.

3. Only if data are transferred to external bodies.

4. Yes for the dataset of National Health Insurance (CNS).

5. Assessment occurs in different ways in various contexts, but an explicit process does not exist.

Source: Author.

Table A B.39. Practices for the treatment of variables that pose a re-identification risk

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	No	No	No	No	No	No	n.a.	No	No	No	0%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	57%
Canada	Yes	Yes	Yes	Yes	Yes	No	n.a.	n.a.	Yes	Yes	88%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	90%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Germany	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No[1]	Yes	88%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	89%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	No	Yes	86%
Netherlands	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	80%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	90%
Slovenia	No	No	No	No	No	No	n.a.	n.a.	No	n.a.	0%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported; d.k.: unknown.
1. Demographic survey does not collect directly identifying information.
Source: Author.

Table A B.40. Testing to ensure re-identification attacks will have a small probability of success

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	No	No	No	No	No	No	No	n.a.	No	No	0%
Austria	No	No	No	No	No	No	n.a.	No	No	No	0%
Belgium	No	No	No	No	Yes	Yes	Yes	n.a.	n.a.	n.a.	43%
Canada	No[1]	No[1]	No[1]	No[1]	No[1]	No	n.a.	n.a.	No[1]	No[1]	0%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	90%
Estonia	No	No	No	No	No	No	n.a.	No	No	No	0%
Finland	No	No	No	No	d.k.	No	n.a.	No	d.k.	No	0%
France	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	n.r.	Yes	Yes	78%
Germany	Yes	n.a.	n.a.	n.a.	No	No	n.a.	n.a.	n.a.	n.a.	33%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	No	No	No	No	n.a.	No	No	n.a.	No	No	0%
Japan	No	No	No	No	No	No	n.a.	n.a.	No	No	0%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	89%
Latvia	No	No	No	No	No	No	No	n.a.	No	n.a.	0%
Luxembourg	No[2]	No[2]	n.a.	No	No	Yes	n.a.	n.a.	No	No	14%
Netherlands	Yes	No	No	n.r.	No	No	No	No	Yes	No	20%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	80%
Slovenia	No	No	No	No	No	No	n.a.	n.a.	No	n.a.	0%
Sweden	No	No	No	n.a.	No	No	Yes	No	No	No	11%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.
1. Not currently, but under development.
2. Work in progress for the dataset of National Health Insurance and Directorate of Health.
Source: Author.
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Table A B.41. Data shared with any other data custodian or government entity

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	No	Yes	n.a.	No	Yes	78%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	89%
Belgium	Yes	Yes	No	No	Yes	Yes	No	n.a.	n.a.	n.a.	57%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Germany	Yes	n.a.	n.a.	n.a.	No	No	n.a.	n.a.	n.a.	n.a.	33%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	No	n.a.	Yes	Yes	n.a.	Yes	Yes	88%
Japan	No	No	No	No	No	No	n.a.	n.a.	No	No	0%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	89%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes[1]	Yes	Yes	Yes	Yes	No	No	No	Yes[2]	70%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	No	No	No	No	No	No	No	No	No	Yes	10%
Slovenia	No	No	No	No	No	Yes	n.a.	n.a.	No	n.a.	14%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	No	83%

Note: n.a.: not applicable; n.r.: not reported.

1. Shared with Statistics Netherlands for statistical purposes.

2. Shared the Dutch Health Care Authority, the National Health Care Institute and Statistics Netherlands.

Source: Author.

Table A B.42. Data shared with other public data custodians contains direct identifiers

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Australia	No	No	No	No	No	n.a.	No	n.a.	n.a.	No
Austria	No	No	No	No	No	No	n.a.	No	No	No
Belgium	No	No	n.a.	n.a.	Yes	No	n.a.	n.a.	n.a.	n.a.
Canada	Yes[1]	Yes[1]	Yes[1]	No	No	Yes	n.a.	n.a.	No	Yes[1]
Czech Republic	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Estonia	No	No	No	No	No	Yes	n.a.	Yes	Yes	No
Finland	No[4]	No[4]	No[4]	No[4]	No[4]	No[4]	n.a.	No[4]	No[4]	No[4]
France	No	No	No	No	No	No	n.a.	No	No	No
Germany	No	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Ireland	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Israel	No	No	No	n.a.	n.a.	No	No	n.a.	No	No
Japan	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Korea	Yes	Yes	Yes	Yes	Yes	Yes[3]	n.r.	n.a.	No	Yes
Latvia	No	No	No	No	No	No	No	n.a.	No	n.a.
Luxembourg	No	No	n.a.	No	No	No	n.a.	n.a.	No	No
Netherlands	No	No	No	No	No	No	n.a.	No	n.a.	No
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Singapore	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	Yes
Slovenia	n.a.	n.a.	n.a.	n.a.	n.a.	n.r.	n.a.	n.a.	n.a.	n.a.
Sweden	No	No	No	n.a.	No	No	Yes[2]	No	No	No
UK (Scotland)	No	No	No	No	No	No	n.a.	n.a.	No	No
United States	No	n.r.	No	No	No	n.r.	n.r.	n.r.	No	n.a.

Note: n.a.: not applicable; n.r.: not reported.

1. Where legal authority to disclose exists.

2. Direct identifiers may only be used when absolutely necessary for the research or when data is delivered to a national government agency for linkages (and in the following step pseudonymised).

3. Only if legally authoritised, such as reporting to National Statistical Office.

4. Only in exceptional cases would direct identifiers be shared.

Source: Author.

Table A B.43. Data shared with other public data custodians contains pseudonymised identifiers

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Australia	No	No	No	Yes[3]	Yes[3]	n.a.	No	n.a.	n.a.	Yes
Austria	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes
Belgium	Yes	Yes	n.a.	n.a.	Yes	Yes	n.a.	n.a.	n.a.	n.a.
Canada	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	n.a.	Yes	Yes
Czech Republic	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Denmark	No	No	No	No	Yes	No	No	No	No	No
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes
Germany	Yes	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Ireland	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Israel	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	n.a.	Yes	Yes
Japan	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Korea	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes
Netherlands	Yes	Yes[2]	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	Yes
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Singapore	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.r.
Slovenia	n.a.	n.a.	n.a.	n.a.	n.a.	n.r.	n.a.	n.a.	n.a.	n.a.
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes
UK (Scotland)	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	n.a.	n.a.	Yes[1]	Yes[1]
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	n.a.

Note: n.a.: not applicable; n.r.: not reported.
1. Sometimes.
2. Pseudonomised BSN is re-pseudonomised by a trusted third party before transfer to Statistics Netherlands.
3. Pseudonymised identifiers (i.e. PIN) can only be disclosed where authorised by law.
Source: Author.

Table A B.44. Analysts employed by a government ministry may apply for and be approved access to de-identified personal health data

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	89%
Austria	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes[1]	Yes	89%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes[2]	Yes[2]	Yes[2]	Yes[2]	Yes[2]	Yes[2]	n.a.	Yes[2]	Yes[2]	Yes[2]	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	89%
Germany	No	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	33%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No	Yes	88%
Korea	Yes	Yes	Yes	Yes	Yes	No	Yes	n.a.	Yes	Yes	89%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	80%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	No	No	No	No	No	No	n.a.	n.a.	No	n.a.	0%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes[3]	n.r.	Yes[3]	Yes[3]	Yes[3]	n.r.	n.r.	n.r.	Yes[3]	Yes[3]	100%

Note: n.a.: not applicable; n.r.: not reported; d.k.: unknown.
1. Limited to regional government entities having access to own regional data.
2. Subject to permission.
3. Subject to approval to access the data in the National Center for Health Statistics or Federal Research Data Center.
Source: Author.

Table A B.45. University or non-profit researchers may apply for and be approved access to de-identified personal health data

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	89%
Austria	Yes	No	No	No	No	Yes	n.a.	No	Yes	Yes	44%
Belgium	Yes	Yes	Yes	Yes	Yes[1]	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	89%
Finland	Yes[3]	Yes[3]	Yes[3]	Yes[3]	Yes[3]	Yes[3]	n.a.	Yes[3]	Yes[3]	Yes[3]	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Germany	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	No	88%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No	Yes	88%
Korea	Yes	Yes	Yes	Yes	Yes	No	Yes	n.a.	Yes	Yes	89%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes	Yes	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	80%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes[2]	n.r.	Yes[2]	Yes[2]	Yes[2]	n.r.	n.r.	n.r.	Yes[2]	Yes[2]	100%

Note: n.a.: not applicable; n.r.: not reported.
1. Data without risk of re-identification.
2. Subject to approval to access the data in the National Center for Health Statistics or Federal Research Data Center.
3. Subject to permission.
Source: Author.

Table A B.46. Analysts employed by a health care provider in your country may apply for and be approved access to de-identified personal health data

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	89%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	No	89%
Belgium	Yes	Yes	Yes	Yes	Yes[1]	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	89%
Finland	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	n.a.	Yes[4]	Yes[4]	Yes[4]	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes	78%
Germany	No	n.a.	n.a.	n.a.	Yes	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No	Yes	88%
Korea	Yes	Yes	Yes	Yes	Yes	No	No	n.a.	Yes	Yes	78%
Latvia	No	No	No	No	No	Yes	Yes	n.a.	Yes	n.a.	38%
Luxembourg	Yes[2]	Yes[2]	n.a.	No	No	Yes	n.a.	n.a.	No	No	43%
Netherlands	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	70%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	No	No	No	n.a.	No	No	Yes	No	No	No	11%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes[3]	n.r.	Yes[3]	Yes[3]	Yes[3]	n.r.	n.r.	n.r.	Yes[3]	Yes[3]	100%

Note: n.a.: not applicable; n.r.: not reported.

1. Data without risk of re-identification.

2. Yes for the dataset of National Health Insurance and Directorate of Health

3. Subject to approval to access the data in the National Center for Health Statistics or Federal Research Data Center.

4. Subject to permission.

Source: Author.

Table A B.47. Analysts employed by a for-profit business in your country may apply for and be approved access to de-identified personal health data

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	89%
Austria	Yes	No	No	No	No	Yes	n.a.	No	Yes	No	33%
Belgium	No[1]	No[1]	No[1]	No[1]	No[2]	No	No[1]	n.a.	n.a.	n.a.	0%
Canada	Yes	Yes	Yes	n.r.	No	Yes	n.a.	n.a.	Yes	Yes	75%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	89%
Finland	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	n.a.	Yes[4]	Yes[4]	Yes[4]	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes	78%
Germany	No	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n..a	n.a.	33%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	No	No	No	No	n.a.	No	No	n.a.	No	No	0%
Japan	No	No	No	No	No	Yes	n.a.	n.a.	No*	No	13%
Korea	No	No	No	No	No	No	No	n.a.	No	No	0%
Latvia	No	No	No	No	No	No	No	n.a.	No	n.a.	0%
Luxembourg	No	No	n.a.	No	No	No	n.a.	n.a.	No	No	0%
Netherlands	No	No	No	No	Yes	No	No	Yes	No	No	20%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	No	No	No	No	No	No	n.a.	n.a.	No	n.a.	0%
Sweden	No	No	No	n.a.	No	No	No	No	No	No	0%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes[3]	n.r.	Yes[3]	Yes[3]	Yes[3]	n.r.	n.r.	n.r.	Yes[3]	Yes[3]	100%

Note: n.a.: not applicable; n.r.: not reported

1. The only aim of the project is scientific or statistical.
2. They may receive aggregated data.
3. Subject to approval to access the data in the National Center for Health Statistics or Federal Research Data Center.
4. Subject to permission.

Source: Author.

Table A B.48. Analysts employed by a foreign university or non-profit research centre may apply for and be approved access to de-identified personal health data

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	n.a.	Yes[1]	Yes[1]	100%
Austria	Yes	No	No	No	No	Yes	n.a.	No	Yes	No	33%
Belgium	Yes	Yes	Yes	Yes	Yes[3]	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes[2]	Yes[2]	Yes[2]	n.r.	No	Yes	n.a.	n.a.	Yes[4]	Yes[2]	75%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	Yes	89%
Finland	Yes[7]	Yes[7]	Yes[7]	Yes[7]	Yes[7]	Yes[7]	n.a.	Yes[7]	Yes[7]	Yes[7]	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	Yes	Yes	78%
Germany	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	No	No	No	No	n.a.	No	No	n.a.	No	No	0%
Japan	No	No	No	No	No	No	n.a.	n.a.	No	No	0%
Korea	No	No	No	No	No	No	No	n.a.	No	No	0%
Latvia	No	No	No	No	No	Yes	Yes	n.a.	Yes	n.a.	38%
Luxembourg	Yes[5]	Yes[5]	n.a.	No	No	Yes	n.a.	n.a.	Yes[6]	No	57%
Netherlands	No	No	Yes	Yes	Yes	Yes	No	Yes	Yes	No	60%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	No	No	No	n.a.	No	No	No	No	No	No	0%
UK (Scotland)	No	No	No	No	No	No	No	No	No	No	0%
United States	No	n.r.	No	No	No	n.r.	n.r.	n.r.	No	No	0%

Note: n.a.: not applicable; n.r.: not reported; d.k.: unknown
1. Potentially yes, but only if the data cannot be re-identified and we are unaware of any arrangements to date.
2. Except where prohibited by law or agreement.
3. Data withough risk of re-identification.
4. Data is shared with WHO.
5. Yes for the dataset of National Health Insurance and the Directorate of Health
6. Data is shared with Eurostat.
7. Subject to permission.
Source: Author.

Table A B.49. A standard data sharing agreement is used for disclosing data

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	No	No	Yes	Yes	n.a.	Yes	Yes	78%
Austria	No	No	No	No	No	No	n.a.	n.r.	No	n.r.	0%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	No	No	No	No	No	No	n.a.	No	No	No	0%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	n.r.	Yes	Yes	n.r.	n.a.	n.r.	Yes	Yes	67%
Germany	Yes	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	67%
Ireland	Yes	n.r.	n.r.	n.a.	n.a.	n.a.	n.r.	n.r.	n.a.	n.a.	14%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.r.	n.r.	75%
Korea	Yes	Yes	Yes	Yes	Yes	No	No	n.a.	Yes	Yes	78%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes[1]	Yes[1]	n.a.	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Netherlands	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No	50%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.; not reported.
1. Yes for the dataset of National Health Insurance (CNS).
Source: Author.

Table A B.50. Data is transferred to approved applicants

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	n.r.	78%
Belgium	Yes	Yes	No	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	86%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[1]	Yes[2]	n.a.	Yes[3]	Yes	Yes[1]	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	No[6]	No[6]	No[6]	No[6]	No[6]	n.r.	n.a.	n.r.	No[6]	No[6]	0%
Germany	No	n.a.	n.a.	n.a.	No	Yes	n.a.	n.a.	n.a.	n.a.	33%
Ireland	Yes	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	14%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.r.	n.r.	75%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes[4]	Yes[4]	n.a.	Yes[4]	Yes[4]	Yes	n.a.	n.a.	Yes[5]	Yes[4]	100%
Netherlands	Yes	Yes[7]	Yes	Yes	Yes	Yes	No	No	No	Yes	70%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	No	No	No	No	No	Yes	No	Yes	No	No	20%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.
1. Share a copy of the data needed for analysis.
2. Sending data to the approved applicant.
3. University of Tartu Institute of Genomics according to Human Genes Research Act
4. Dataset of the National Health Insurance (CNS) will allow in rare cases.

5. A reduced dataset.
6. In most cases.
7. To Statistics Netherlands.
Source: Author.

Table A B.51. Remote data access service is provided for approved applicants

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of health care datasets
Australia	No	No	No	Yes	Yes	No	No	n.a.	No	No	22%
Austria	Yes	Yes	Yes	Yes	Yes	No	n.a.	No	No	n.r.	56%
Belgium	No	No	No	No	no	No	Yes	n.a.	n.a.	n.a.	14%
Canada	No[1]	No[1]	No[1]	n.r.	No[1]	No	n.a.	n.a.	No[1]	No[1]	0%
Czech Republic	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	No	No	No	No	No	No	n.a.	No	No	No	0%
Finland	No[1]	No[1]	No[1]	No[1]	d.k.	No[1]	n.a.	No1	Yes	No[1]	11%
France	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	n.r.	Yes	n.r.	67%
Germany	Yes	n.a.	n.a.	n.a.	no	No	n.a.	n.a.	n.a.	n.a.	33%
Ireland	No	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	no	no	no	no	n.a.	no	no	n.a.	no	no	0%
Japan	No	No	No	No	No	No	n.a.	n.a.	n.r.	n.r.	0%
Korea	Yes	Yes	Yes	Yes	Yes	No	No	n.a.	Yes	Yes	78%
Latvia	No	No	No	No	No	No	No	n.a.	No	n.a.	0%
Luxembourg	yes	yes	n.a.	Yes	Yes	No	n.a.	n.a.	No	Yes	71%
Netherlands	Yes	Yes[2]	No	No	No	No	No	Yes	Yes	No	40%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	No	No	No	No	No	No	No	No	No	No	0%
Slovenia	no	no	no	no	no	no	n.a.	n.a.	no	n.a.	0%
Sweden	no	no	no	n.a.	no	no	yes	no	no	no	11%
United Kingdom (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	No	n.r.	No	No	No	n.a.	n.a.	n.a.	No	No	0%

Note: n.a.: not applicable; n.r.: not reported; d.k.: don't know.

1. Under development.

2. Provided by Statistics Netherlands.

Source: Author.

Table A B.52. Research data centre (supervised data access centre) is provided for approved applicants

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of health care datasets
Australia	No	No	No	Yes	Yes	No	No	n.a.	No	Yes	33%
Austria	Yes	No	No	No	No	Yes	n.a.	No	Yes	n.r.	33%
Belgium	No	No	No	No	No	Yes	No	n.a.	n.a.	n.a.	14%
Canada	No	No	No	n.r.	No	Yes	n.a.	n.a.	Yes	No	25%
Czech Republic	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	No	No	No	No	No	No	n.a.	No	No	No	0%
Finland	No	No	No	No	d.k.	No	n.a.	No	Yes	No	11%
France	No	No	No	No	No	n.r.	n.a.	n.r.	No	n.r.	0%
Germany	Yes	n.a.	n.a.	n.a.	No	No	n.a.	n.a.	n.a.	n.a.	33%
Ireland	No	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes	No	Yes	No	n.a.	Yes	Yes	n.a.	Yes	No	63%
Japan	No	No	No	No	No	No	n.a.	n.a.	n.r.	n.r.	0%
Korea	Yes	Yes	Yes	Yes	Yes	No	No	n.a.	Yes	Yes	78%
Latvia	No	No	No	No	No	No	No	n.a.	No	n.a.	0%
Luxembourg	No	No	n.a.	No	No	Yes	n.a.	n.a.	No	No	14%
Netherlands	No	No	No	No	No	No	No	Yes	Yes	Yes	30%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	No	No	No	n.a.	No	No	Yes[1]	No	No	No	11%
United Kingdom (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported; d.k.: don't know.
1. Yes but still using the remote data access service.
Source: Author.

Table A B.53. Financial charge for access to de-identified data

Country	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes[1]	n.a.	Yes	No	89%
Austria	Yes	No	No	No	No	Yes	n.a.	n.a.	Yes	n.r.	33%
Belgium	No	No	No	Yes	No	Yes	Yes	n.a.	n.a.	n.a.	43%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	0%
Denmark	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	Yes[4]	100%
Estonia	No	No	No	No	No	No	n.a.	No	No	No	0%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes[5]	Yes[5]	No[6]	No[6]	No[6]	n.r.	n.a.	n.r.	No	n.r.	22%
Germany	Yes	n.a.	n.a.	n.a.	No	No	n.a.	n.a.	n.a.	n.a.	33%
Ireland	n.a.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	n.r.	n.r.	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.r.	n.r.	0%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.r.	n.r.	75%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	n.r.	Yes	78%
Latvia	Yes[2]	Yes[2]	Yes[2]	Yes[2]	Yes[2]	No	No	n.a.	No	n.a.	63%
Luxembourg	No	No	n.a.	No	No	No	n.a.	n.a.	No	No	0%
Netherlands	Yes	Yes[7]	Yes	Yes	No	n.a.	Yes	No	Yes	Yes[8]	70%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	No	No	No	No	No	No	No	No	No	No	0%
Slovenia	No	No	No	No	No	No	n.a.	n.a.	No	n.a.	0%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK(Scotland)	Yes[3]	Yes[3]	Yes3	Yes[3]	Yes[3]	Yes[3]	n.r.	n.a.	Yes[3]	Yes[3]	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.
1. Sometimes.
2. There is financial charge for external analysts for National Health Service's databases only.
3. Depending on the request.
4. Financial charge for researchers only.

5. Yes for private users for access to hospital databases through ATIH; No through SNDS.
6. A payment is foreseen but is not yet in place.
7. There are charges only for the data access service (not for the data).
8. Charges apply except where a legislation authorises otherwise.
Source: Author.

Table A B.54. Multi-country projects involving analysis of personal health data

Includes recent parallel studies, where analysts in each country follow a common study protocol, and projects involving data sharing across borders

Project	Geography	Purpose	Description	Publication	Authors	Publisher	Date	Web-link
Opioid use and harms	Australia and Canada	Collaboration between the Australian Institute of Health and Welfare and the Canadian Institute for Health Information. Presented high-level comparisons of prescription opioids; emergency department presentations and hospitalisations for opioid harm; and documented the issues explored and overcome and the usefulness of international comparisons. Explored5 different types of opioid harm: accidental and intentional poisoning, opioid dependence, adverse reaction to opioids and other types of harm.	The project was a parallel study, with analysts in each country aiming to follow common methods where possible and share findings. Parallel reports were published by the Australian Institute of Health and Welfare and the Canadian Institute for Health Information on 09 November 2018.	1)Opioid harm in Australia: and comparisons between Australia and Canada	Australian Institute of Health and Welfare	Australian Institute of Health and Welfare	09-11-2018	https://www.aihw.gov.au/reports/illicit-use-of-drugs/opioid-harm-in-australia/contents/table-of-contents
				2)Types of Opioid Harms in Canadian Hospitals: Comparing Canada and Australia	Canadian Institute for Health Information	Canadian Institute for Health Information	10-07-1905	https://www.cihi.ca/sites/default/files/document/types-opioids-harm-report-can-aus-nov2018-en-web.pdf
US and Canadian Measurement Surveys Joint Analysis of Prescription Drug Use	Canada and United States	To compare prescription drug use between the US and Canada	Descriptive analysis of data from national measurement surveys from the US and Canada	Prescription Drug Use Among Adults Aged 4079 in the United States and Canada	Hales CM et al.	HEALTH & HUMAN SERVICES, Centers for Disease Control and Prevention National Center for Health Statistics	01-08-2019	https://www.cdc.gov/nchs/data/databriefs/db347-h.pdf

Project	Geography	Purpose	Description	Publication	Authors	Publisher	Date	Web-link
CONCORD Programme	Global	Global programme for world-wide surveillance of cancer survival	The CONCORD-3 programme updates the world-wide surveillance of cancer survival to 2014, for patients diagnosed with cancer during the 15-year period 2000-2014 and includes 18 cancers or groups of cancers. The CONCORD programme is led by the London School of Hygiene & Tropical Medicine and is endorsed by 40 national and international agencies, including WHO EURO, the Organisation for Economic Co-operation & Development (OECD) and the World Bank.	Global surveillance of trends in cancer survival: analysis of individual records for 37,513,025 patients diagnosed with one of 18 cancers during 2000-2014 from 322 population-based registries in 71 countries (CONCORD-3)	Allemania C et al	Lancet 2018; 391: 1023-1075 doi:10.1016/S0140-6736(17)33326-3	17-03-2018	https://doi.org/10.1016/S0140-6736(17)33326-3
Eurocare	Europe	European cancer registry based study on survival and care of cancer patients	EUROCARE is the widest collaborative research project on cancer survival in Europe that began in 1989. Aims of the study are: to provide an updated description of cancer survival time trends and differences across European countries, to measure cancer prevalence, and to study patterns of care of cancer patients. The fifth and current edition, EUROCARE-5, includes data on more than 21 million cancer diagnoses provided by 116 Cancer Registries in 30 European countries.	Quality analysis of population-based information on cancer stage at diagnosis across Europe, with presentation of stage-specific cancer survival estimates: A EUROCARE-5 study.	Minicozzi P1, Innos K2, Snchez MJ3, Trama A4, Walsh PM5, Marcos-Gragera R6, Dimitrova N7, Botta L4, Visser O8, Rossi S9, Tavilla A10, Sant M11; EUROCARE-5 Working Group.	Eur J Cancer. 2017 Oct;84:335-353. doi: 10.1016/j.ejca.2017.07.015. Epub 2017 Sep 1.	Oct 2017	https://www.ejcancer.com/article/S0959-8049(17)31125-5/fulltext

Project	Geography	Purpose	Description	Publication	Authors	Publisher	Date	Web-link
Scandinavian multi-registry study of antiepileptic drug teratogenicity: the SCAN-AED study	Denmark, Finland, Norway, Sweden	Drug utilization and safety during pregnancy	Study aims to examine the risk of major congenital malformations, somatic and neuropsychiatric disease and survival in the children after exposure to mothers epilepsy and antiepileptic drugs during pregnancy.					
Nordic and International Pregnancy Drug Safety Studies (NorPress and InPreSS)	Australia, Denmark, Finland, Iceland, Norway, Sweden and United States	Drug utilization and safety during pregnancy	The objective is to better understand the potential consequences of in-utero drug exposure for fetal development, birth and longer-term outcomes in the child, as well as maternal social and health consequences of discontinued treatment.	Antidiabetic Medication Use during Pregnancy: An International Utilization Study. BMJ Open Diabetes Res Care 2019	Cesta CE et al.	BMJ Open Diabetes Res Care	02-11-2019	https://drc.bmj.com/content/7/1/e000759
Risk of childhood cancer after prenatal exposure to medications a Nordic registry based study	Nordic countries	Late effects of drug use in pregnancy	The aim is to study thethe risk of childhood cancer associated with maternal drug use (antibiotics, antidiabetics, cardiovascular medications, immunosuppressive agents, sex hormones, thyroid medications) during pregnancy.	Maternal Diabetes and Risk of Childhood Cancer in the Offspring	Seppl LK et al.	Int J Cancer	28-10-2019	
ConcePTION	Europe	Building an ecosystem for better monitoring and communicating safety of medicines use in pregnancy and breastfeeding: validated and regulatory endorsed workflows for fast, optimised evidence generation.	Project aims to establish a trusted ecosystem that can efficiently, systematically and in a ethically responsible manner, generate and disseminate reliable evidence-based information regarding effects of medications used during pregnancy and breastfeeding to women and their health care providers.					

Project	Geography	Purpose	Description	Publication	Authors	Publisher	Date	Web-link
EURO-PERISTAT	Europe	Goal is to produce data and analysis on a regular basis for use by national, European and international stakeholders who make decisions about the health and health care of pregnant women and newborns.	The EURO-PERISTAT projects goal has been to develop valid and reliable indicators that can be used for monitoring and evaluating perinatal health in the EU. The project began in 1999 as part of the Health Monitoring Programme. In November 2018 the third European Perinatal Health Report was published (fouth measurement, because the results of the first one were published as journal papers). In this report, data of 10 core indicators and 20 recommended indicators were presented, from 31 European countries. Many outcomes were calculated by using databases linked on personal identifier.	EUROPEAN PERINATAL HEALTH REPORT. Core indicators of the health and care of pregnant women and babies in Europe in 2015	Jennifer Zeitlin et al.	Euro-Peristat	2015	https://www.europeristat.com/images/EPHR2015_web_hyperlinked_Euro-Peristat.pdf
EURO-PERISTAT	Europe	Assessing the extent to which data are linked routinely for perinatal health research and reporting.	Inventarisation of perinatal studies based on linkage of routine data.	Linking databases on perinatal health: a review of the literature and current practices in Europe	Delnord M et al.	Eur J Public Health	2016	https://www.ncbi.nlm.nih.gov/pubmed/26891058
EuroHOPE	Finland, Hungary, Italy, Netherlands, Norway, Scotland and Sweden	Health care system performance assessment	EuroHOPE - European Health Care Outcomes, Performance and Efficiency - evaluates the performance of European health care systems in terms of outcomes, quality, use of resources and costs.	A number of papers have been published, please see web page for complete list of references				http://www.eurohope.info/publ.html
Developing Health System Performance Assessment for Slovenia and Latvia (Grant Nr. SRSS/S2017/019)	Latvia and Slovenia	Improve Latvian Health System performance, in terms of quality of care, equity, and financial sustainability	Project has 3 goals: (1) Health System Performance Assessment framework development; (2) Capacity building to support future health system performance assessment without external support; (3) Development of an action plan for the implementation of the health system performance assessment system.					

Project	Geography	Purpose	Description	Publication	Authors	Publisher	Date	Web-link
Avoidable Hospital Admissions from Diabetes Complications in Japan, Singapore, Hong Kong and Communities outside Beijing	China, Hong Kong, Japan, Singapore	Avoidable Hospital Admissions from Diabetes Complications in Japan, Singapore, Hong Kong and Communities outside Beijing	We estimated the avoidable admission rates among diabetic patients in each country and medical spending associated with avoidable admissions, before we conducted an empirical analysis of the correlation between outpatient visits and inpatient avoidable admissions.	Avoidable Hospital Admissions from Diabetes Complications in Japan, Singapore, Hong Kong and Communities outside Beijing	Quan J, Zhang H, Pang D, Chen BK, Johnston JM, Jian W, Lau ZY, Iizuka T, Leung GM, Fang H, Tan KB, Eggleston K	Health Affairs	Nov-17	https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2017.0479?rfr_dat=cr_pub%3Dpubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&journalCode=hlthaff
CEPHOS-LINK	Austria, Finland, Italy, Norway, Romania and Slovenia	The overall objective of the CEPHOS-LINK project was to establish psychiatric rehospitalisation rates and their predictors by applying a common protocol to administrative data from large national electronic health care registries in six European countries (Austria, Finland, Italy, Norway, Romania, Slovenia), all with different health care systems and different data collection routines.	CEPHOS-LINK aims to compare different types of health service interventions in terms of differences in rehospitalisation outcomes in adult patients, who have been discharged with a psychiatric diagnosis from hospital.	Comparative Effectiveness Research on Psychiatric HOSpitalisationby record LINKage of large administrative data sets in six European countries - Final Scientific Report for Objectives 1, 2 and 3	Heinz Katschnig & Christa Stramayr	IMEHPS.research, Austria	31-03-2017	https://thl.fi/en/web/thlfi-en/research-and-expertwork/projects-and-programmes/comparative-effectiveness-research-on-psychiatric-hospitalisation/publications-and-presentations
Eurostat Morbidity Statistics	Europe	The aim of this pilot data collection is to study the feasability of obtaining internationally comparable diagnosis-based data on prevalence and incidence of diseases on the revised Eurostat Prioritised Short List.	Diagnostic and health contact information of several medical registries is linked on personal level to obtain the best possible estimates of the number of persons with a (new) disease. In the Netherlands, data are used from hospital discharges, dispensed drugs, Diagnosis Treatment Combinations of mental health care and somatic specialised care, causes of death and other registries, linked to the primary care database.					

Project	Geography	Purpose	Description	Publication	Authors	Publisher	Date	Web-link
EPIMS	Europe	Aim of this inventory was to identify existing (or planned) sources and methods in view of producing best national estimates for the morbidity indicators included in the Eurostat Prioritised Short List (version November 2013)	Each participating member state made an inventory of sources and methods to produce the best national estimate for morbidity data. No actual data collection was performed, but the conclusion was that in most countries linking of databases on personal level would lead to best estimates. In NL, linkage of other medical registries (hospital discharges, perscriptions, Diagnosis Treatment Combinations of mental health care and somatic specialised care etc) to the Nivel Primary Care Database was assessed to give the best estimate for most diseases on the shortlist.	Inventory on morbidity statistics in The Netherlands. Final report	Laura Voorrips et al.	CBS	2016	https://ec.europa.eu/eurostat/en/web/products-statistical-working-papers/-/KS-TC-14-003
One million *genome*	Europe	Enable access to at least 1 million sequenced genomes in the European Union by 2022	The goal is to improve personalised medicine research and more personalised treatments, in particular for rare diseases, cancer and prevention/population health on a European level via collaborations of the different signatory countries. This European project will allow and enable further developments in Luxembourg concerning IT and sequencing infrastructure as well as the development of specific competences. A secondary effect of the project will be a better integration and use of genomics data in hospitals and the entire healthcare system.					

Source: Author.

Table A B.55. Publicly available description of the dataset purpose and content

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	No	Yes	n.r.	78%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.r.	Yes	Yes	89%
Germany	Yes	n.a.	n.a.	n.a.	Yes	Yes	n.a.	n.a.	n.a.	n.a.	100%
Ireland	Yes	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	14%
Israel	Yes	No	No	No	n.a.	Yes	Yes	n.a.	Yes	Yes	63%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	Yes	100%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	89%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes[1]	Yes[1]	n.a.	No	No	Yes	n.a.	n.a.	Yes	No	57%
Netherlands	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	No	No	No	No	No	Yes	No	Yes	No	No	20%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes[2]	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	Yes	100%

Note: n.a.: not applicable; n.r.: not reported.
1. Yes for the dataset of National Health Insurance and the Directorate of Health.
2. Yes for the patients.
Source: Author.

Table A B.56. Publicly available description of the dataset includes the legal basis for the data processing

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	No	No	No	No	No	Yes	No	n.a.	Yes	n.r.	22%
Austria	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.r.	Yes	n.r.	78%
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	n.a.	100%
Canada	Yes	Yes	Yes	n.r.	Yes	No	n.a.	n.a.	Yes	Yes	75%
Czech Republic	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	n.a.	100%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	n.r.	n.r.	n.r.	n.r.	n.r.	Yes	n.a.	Yes	Yes	n.r.	33%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	n.r.	Yes	n.r.	67%
Germany	Yes	n.a.	n.a.	n.a.	Yes	Yes	n.a.	n.a.	n.a.	n.a.	100%
Ireland	No	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	0%
Israel	Yes.	n.r.	n.r.	n.r.	n.a.	Yes	Yes	n.a.	Yes	Yes	63%
Japan	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.a.	n.a.	No	Yes	13%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	Yes[1]	Yes[1]	n.a.	n.r.	n.r.	Yes	n.a.	n.a.	Yes	n.r.	57%
Netherlands	Yes	No	Yes	Yes	Yes	n.r.	Yes	Yes	Yes	No	70%
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Singapore	n.r.	n.r.	n.r.	n.r.	n.r.	Yes	n.r.	Yes	n.r.	n.r.	20%
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	Yes	n.a.	100%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes[2]	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.a.	Yes	Yes	89%
United States	No	n.r.	No	No	No	n.r.	n.r.	n.r.	Yes	No	17%

Note: n.a.: not applicable; n.r.: not reported.

1. Yes for the dataset of National Health Insurance and the Directorate of Health.

Source: Author.

Table A B.57. Web-links to the public information provided about the dataset.

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Australia	https://www.aihw.gov.au/about-our-data/our-data-collections/national-hospitals	https://www.aihw.gov.au/about-our-data/our-data-collections/national-hospitals	https://www.aihw.gov.au/about-our-data/our-data-collections/national-hospitals	https://www.aihw.gov.au/about-our-data/our-data-collections/medicare-benefits-schedule-mbs	https://www.aihw.gov.au/about-our-data/our-data-collections/pharmaceutical-benefits-scheme	https://www.aihw.gov.au/about-our-data/our-data-collections/australian-cancer-database	https://www.aihw.gov.au/about-our-data/our-data-collections/national-insulin-treated-diabetes-register	N/A	https://www.aihw.gov.au/about-our-data/our-data-collections/national-mortality-database	https://www.gen-agedcaredata.gov.au/Resources/Reports-and-publications/2016/Oct/National-Aged-Care-Data-Clearinghouse-Data-Diction
Austria	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentummer=ERV_2012_1_111	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111 http://pic.statistik.at/web_de/frageboegen/gesundheitseinrichtungen/krebsregistermeldung/index.html http://pic.statistik.at/web_de/statistiken/menschen_und_gesellschaft/gesundheit/krebserkrankungen/index.html	n.a.	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111	regulated in the health telematics law: https://www.ris.bka.gv.at/Dokument.wxe?Abfrage=Erv&Dokumentnummer=ERV_2012_1_111

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Belgium	https://www.health.belgium.be/nl/gezondheid/organisatie-van-de-gezondheidszorg/ziekenhuizen/registratiesystemen/mzg	https://www.health.belgium.be/nl/gezondheid/organisatie-van-de-gezondheidszorg/ziekenhuizen/registratiesystemen/mpg	https://www.health.belgium.be/nl/gezondheid/organisatie-van-de-gezondheidszorg/ziekenhuizen/registratiesystemen/mug	https://fair.healthdata.be/dataset/9976f4c4-3fd1-4cc6-b0aa-9107eccec137	https://www.inami.fgov.be/fr/statistiques/medicament/Pages/statistiques-medicaments-pharmacies-pharmanet.aspx	https://kankerregister.org/	https://fair.healthdata.be/dataset/2e2adc57-1922-48f5-9d18-4a87ad7a8933			
Canada	https://www.cihi.ca/en/acute-care https://www.cihi.ca/en/cad_pia_jan_2013_en.pdf https://www.cihi.ca/en/discharge-abstract-database-metadata	https://www.cihi.ca/en/hospital-mental-health-database-metadata-hmhdb https://www.cihi.ca/en/cad_pia_jan_2013_en.pdf https://www.cihi.ca/en/ontario-mental-health-reporting-system-metadata	https://www.cihi.ca/en/cad_pia_jan_2013_en.pdf https://www.cihi.ca/en/emergency-and-ambulatory-care https://www.cihi.ca/en/national-ambulatory-care-reporting-system-metadata		https://www.cihi.ca/en/cad_pia_jan_2013_en.pdf https://www.cihi.ca/en/national-prescription-drug-utilization-information-system https://www.cihi.ca/en/national-prescription-drug-utilization-information-system-metadata	http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=440378&dis=1 https://www.statcan.gc.ca/eng/record/summ https://www.statcan.gc.ca/eng/rdc/rdc			http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3233 https://www.statcan.gc.ca/eng/record/summ https://www.statcan.gc.ca/eng/rdc/rdc	https://www.cihi.ca/en/cad_pia_jan_2013_en.pdf https://www.cihi.ca/en/continuing-care-metadata https://www.cihi.ca/en/residential-care
Czech Republic	http://www.uzis.cz/en/national-register-hospitalised-patients-nrhosp	http://www.uzis.cz/en/national-register-hospitalised-patients-nrhosp	http://www.uzis.cz/registry/narodni-zdravotni-registry/narodni-diabetologicky-registr		http://www.uzis.cz/registry/narodni-zdravotni-registry/narodni-diabetologicky-registr	http://www.uzis.cz/en/czech-national-cancer-registry-cncr	http://www.uzis.cz/registry/narodni-zdravotni-registry/narodni-diabetologicky-registr	http://www.uzis.cz/en/registers/national-health-registers/nr-cardiovascular-surgery-and-interventions	http://www.uzis.cz/registry-nzis/list-prohlidce-zemreleho	
Denmark	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk	https://www.sum.dk/ and www.esundhed.dk

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Estonia	Health Insurance Fund Database regulation	Estonia		Health Insurance Fund Database regulation	Estonia		Health Insurance Fund Database regulation	Estonia		Health Insurance Fund Database regulation
Finland	https://thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/care-register-for-health-care	https://thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/care-register-for-health-care	https://thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/care-register-for-health-care	https://thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/register-of-primary-health-care-visits	https://www.kanta.fi/en/web/guest/data-protection-and-data-security	https://cancerregistry.fi/		https://thl.fi/web/kansantaudit/sydan-ja-verisuonitaudit/sydan-ja-verisuonitautirekisteri	http://tilastokeskus.fi/meta/tietosuojaselosteet/tietosuojaseloste_kuolintodistusarkisto.html	https://thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/care-register-for-health-care
France	https://portail-acces-securise.atih.sante.fr/ https://www.indsante.fr/fr/ce-quil-faut-savoir-pour-acceder-aux-donnees-de-sante More generally: https://www.indsante.fr (in the near future: www.healthdatahub.fr)	https://portail-acces-securise.atih.sante.fr/ https://www.indsante.fr/fr/ce-quil-faut-savoir-pour-acceder-aux-donnees-de-sante More generally: https://www.indsante.fr (in the near future: www.healthdatahub.fr)	https://portail-acces-securise.atih.sante.fr/ https://www.ameli.fr/l-assurance-maladie/statistiques-et-publications/sniiram/finalites-du-sniiram.php More generally: https://www.indsante.fr (in the near future: www.healthdatahub.fr)	https://www.ameli.fr/l-assurance-maladie/statistiques-et-publications/sniiram/finalites-du-sniiram.php https://www.indsante.fr/fr/ce-quil-faut-savoir-pour-acceder-aux-donnees-de-sante More generally: https://www.indsante.fr (in the near future: www.healthdatahub.fr)	https://www.ameli.fr/l-assurance-maladie/statistiques-et-publications/sniiram/finalites-du-sniiram.php https://www.indsante.fr/fr/ce-quil-faut-savoir-pour-acceder-aux-donnees-de-sante More generally: https://www.indsante.fr (in the near future: www.healthdatahub.fr)	https://lesdonnees.e-cancer.fr/Informations/Sources/Base-commune-des-registres-de-cancers			https://www.cepidc.inserm.fr/causes-medicales-de-deces/la-base-des-causes-medicales-de-deces https://www.indsante.fr/fr/ce-quil-faut-savoir-pour-acceder-aux-donnees-de-sante More generally: https://www.indsante.fr (in the near future: www.healthdatahub.fr)	
Germany					https://arzneimittel.wido.de/PharMaAnalyst	www.krebsdaten.de				
Ireland	http://www.hpo.ie/HIPE_Accessing_HIPE_Data.htm									

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Israel	https://www.health.gov.il/hozer/comp01_2012.pdf					http://www.israelhpr.org.il/1054/524.htm	http://www.israelhpr.org.il/1054/524.htm		https://www.health.gov.il/hozer/comp01_2012.pdf	https://www.health.gov.il/hozer/comp01_2012.pdf
Japan	https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/iryouhoken/reseputo/index.htmlb-link	https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/iryouhoken/reseputo/index.htmlb-link	https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/iryouhoken/reseputo/index.htmlb-link	https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/iryouhoken/reseputo/index.htmlb-link	https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/iryouhoken/reseputo/index.htmlb-link	https://ganjoho.jp/reg_stat/can_reg/index.html			https://www.e-stat.go.jp/stat-search/database?page=1&toukei=00450011&tstat=000001028897	https://www.mhlw.go.jp/stf/shingi2/0000198094_00002.html
Korea	https://opendata.hira.or.kr/or/orb/useGdInfo.do	https://opendata.hira.or.kr/or/orb/useGdInfo.do	https://opendata.hira.or.kr/or/orb/useGdInfo.do	https://opendata.hira.or.kr/or/orb/useGdInfo.do	https://opendata.hira.or.kr/or/orb/useGdInfo.do			https://opendata.hira.or.kr/or/orb/useGdInfo.do		https://opendata.hira.or.kr/or/orb/useGdInfo.do
Latvia	http://med.oranzais.lumii.lv/index.html https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research	http://med.oranzais.lumii.lv/index.html https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research	http://med.oranzais.lumii.lv/index.html https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research	http://med.oranzais.lumii.lv/index.html https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research	http://med.oranzais.lumii.lv/index.html https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research	http://med.oranzais.lumii.lv/index.html https://visr.eps.gov.lv/visr/default.aspx?action=2&rid=138 https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research	http://med.oranzais.lumii.lv/index.html https://visr.eps.gov.lv/visr/default.aspx?action=2&rid=138 https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research		http://med.oranzais.lumii.lv/index.html https://visr.eps.gov.lv/visr/default.aspx?action=2&rid=28 https://www.spkc.gov.lv/lv/profesionali/atlauja-izmantot-pacienta-datu https://likumi.lv/ta/en/en/id/275747-procedures-for-using-the-patient-data-in-a-specific-research	

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Luxem-bourg	Dataset of National Health Insurance and Directorate of Health https://www.dcsh.lu/	Dataset of National Health Insurance and Directorate of Health https://www.dcsh.lu/				www.rnc.lu			1. https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32011R0328&from=FR 2. http://legilux.public.lu/eli/etat/leg/rgd/1963/06/20/n1/jo 3. http://legilux.public.lu/eli/etat/leg/rgd/2013/04/18/n2/jo 4. http://sante.public.lu/fr/publications/m/mortalite-lux-evolution-historique/index.html	
Netherlands[1]	https://www.dhd.nl/producten-diensten/lbz/Paginas/dataverzameling-lbz.aspx	https://www.cbs.nl/-/media/cbs%20op%20maat/zelf%20onderzoek%20doen/projecten_met_bestanden.xlsx	www.veiligheid.nl/letselregistratie	https://www.nivel.nl/en/nivel-primary-care-database	www.gipdatabank.nl/toelichting	www.iknl.nl	https://dica.nl/dpard/home	https://nederlandsehartregistratie.nl/	https://www.cbs.nl/en-gb/our-services/customised-services-microdata	https://www.vektis.nl/inzichten-op-maat/voorwaarden-maatwerkverzoek
Norway	https://helsedirektoratet.no/english/norwegian-patient-registry	https://helsedirektoratet.no/english/norwegian-patient-registry	https://helsedirektoratet.no/english/norwegian-patient-registry	https://helsedirektoratet.no/kommunalt-pasient-og-brukerregister	https://www.fhi.no/en/op/data-access-from-health-registries-health-studies-and-biobanks/norwegian-prescription-database/Access-data-norpd/	https://www.kreftregisteret.no/en/General/About-the-Cancer-Registry/	https://www.noklus.no/en/Home.aspx	https://www.fhi.no/en/hn/health-registries/cardiovascular-disease-registry/about-the-norwegian-cardiovascular-disease-registry/	https://www.fhi.no/en/about/about-niph/	https://helsedirektoratet.no/kommunalt-pasient-og-brukerregister

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
Slovenia	http://www.nijz.si/sl/podatki/podatkovne-zbirke-in-raziskave	http://www.nijz.si/sl/podatki/podatkovne-zbirke-in-raziskave	http://www.nijz.si/sl/podatki/podatkovne-zbirke-in-raziskave	http://www.nijz.si/sl/podatki/podatkovne-zbirke-in-raziskave	http://www.nijz.si/sl/podatki/podatkovne-zbirke-in-raziskave	https://www.onko-i.si/eng/crs/			http://www.nijz.si/sl/podatki/podatkovne-zbirke-in-raziskave	
Sweden	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag		General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/omwebbplatsen/personuppgifter Information on how to get a copy of everything that is registered about you (according to *GDPR*): http://www.socialstyrelsen.se/register/begararegisterutdrag	General information for the public about the registers and what they are used for at the NBHW http://www.socialstyrelsen.se/omwebbplatsen/halsodata-ochsocialtjanstregister and http://www.socialstyrelsen.se/register/begararegisterutdrag

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data
United Kingdom (Scotland)	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/			https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/	https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/
United States	https://www.cdc.gov/rdc/b1datatype/Dt1224h.htmeb-link		https://www.cdc.gov/nchs/ahcd/ahcd_questionnaires.htm	https://www.cdc.gov/nchs/ahcd/ahcd_questionnaires.htm	Survey Description documents provided annually with the release of the public use data via https://www.cdc.gov/nchs/nhis/index.htm. A breif description of the dataset is also available on the NCHS dataset RDC page.				https://www.cdc.gov/nchs/nvss/index.htm	https://www.cdc.gov/nchs/nsltcp/nsltcp_questionnaires.htm

1.Information about all Dutch health and health care datasets is included in https://bronnen.zorggegevens.nl/Bron/Zoek.

Source: Author.

Table A B.58. Procedure to request a record linkage or other further processing of this dataset and the criteria used to approve this request are publicly available

	Hospital in-patient data	Mental hospital in-patient data	Emergency health care data	Primary care data	Prescription medicines data	Cancer registry data	Diabetes registry data	Cardio-vascular disease registry data	Mortality data	Formal long-term care data	% of national health care datasets
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	100%
Austria	No	No	No	No	No	No	n.a.	No	No	n.r.	0%
Belgium	Yes	Yes	Yes	NA	n.a.	No	Yes	n.a.	n.a.	n.a.	57%
Canada	Yes	Yes	Yes	n.r.	Yes	Yes	n.a.	n.a.	Yes	Yes	88%
Czech Republic	No	No	No	n.a.	No	No	No	No	No	n.a.	0%
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Estonia	No	No	No	No	No	No	n.a.	Yes	No	No	11%
Finland	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	100%
France	Yes	Yes	Yes	Yes	Yes	No	n.a.	n.r.	Yes	n.r.	67%
Germany	Yes	n.a.	n.a.	n.a.	No	n.a.	n.a.	n.a.	n.a.	n.a.	33%
Ireland	Yes	n.r.	n.r.	n.a.	n.r.	n.r.	n.a.	n.a.	n.r.	n.r.	14%
Israel	Yes	Yes	Yes	Yes	n.a.	Yes	Yes	n.a.	Yes	Yes	100%
Japan	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	n.a.	No	Yes	88%
Korea	Yes	Yes	Yes	Yes	Yes	Yes	No	n.a.	Yes	Yes	89%
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n.a.	Yes	n.a.	100%
Luxembourg	No	No	n.a.	No	No	Yes	n.a.	n.a.	No	No	14%
Netherlands	n.r.	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	60%
Norway	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	0%
Singapore	No	No	No	No	No	No	No	No	No	No	0%
Slovenia	no	no	no	no	no	no	n.a.	n.a.	no	n.a.	0%
Sweden	Yes	Yes	Yes	n.a.	Yes	Yes	Yes	Yes	Yes	Yes	100%
UK (Scotland)	Yes	Yes	Yes	Yes	Yes	Yes	n.r.	n.r.	n.a.	Yes	89%
United States	Yes	n.r.	Yes	Yes	Yes	n.r.	n.r.	n.r.	Yes	No	83%

Note: n.a.: not applicable; n.r.: not reported.

Source: Author.

Glossary of Terms

The following is a glossary of terms used in the 2019-20 HCQO Survey of Health Data Use and Governance and reflected in the text of this report.

Table A B.59. Glossary of Terms used in this Report

Term	Definition used in the 2019-20 HCQO Survey of Health Data Use and Governance
Cancer registry	A cancer registry is a type of patient registry defined by patients having a diagnosis of cancer. It is an organised system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for this population that serves a predetermined scientific, clinical, or policy purpose. The registry database is the file (or files) derived from the registry. (ARHQ, Registries for Evaluating Patient Outcomes: A User Guide, 2007)
Cancer registry dataset	This dataset typically includes variables such as age, sex, location, date of diagnosis, method of diagnosis, site of neoplasm, type of neoplasm, stage and treatment.
Cardiovascular disease (CVD) registry	A cardiovascular disease registry is a type of patient registry defined by patients having a diagnosis of one or more types of cardiovascular disease, such as heart disease, acute myocardial infarction or stroke. It is an organised system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for this population that serves a predetermined scientific, clinical, or policy purpose(s). The registry database is the file (or files) derived from the registry. (ARHQ, Registries for Evaluating Patient Outcomes: A User Guide, 2007)
Cardiovascular disease (CVD) registry dataset	A CVD registry dataset may refer to only some cardiovascular disease conditions or to some procedures. For example, the European Society of Cardiology has developed a set of registries to assess cardiovascular risk factors, epidemiology and prevention measures; to monitor the application of clinical practice guidelines (Heart Failure, Atrial Fibrillation General, Implantable cardioverter-defibrillation); and to assess the impact of interventional procedures and imaging techniques (Atrial Fibrillation Ablation, Transcatheter Valve Treatment) (ESC, www.escardio.org). Variables in such registries may include age, sex, risk factors, dates of diagnosis and treatment, method of diagnosis, procedures and treatment details and outcomes.
Consent	Consent is an expression of will, with which the data subject authorizes the processing of data.
Data protection	Data protection refers to the set of privacy-motivated laws, policies and procedures that aim to minimize intrusion into respondents' privacy caused by the collection, storage and dissemination of personal data.
Dataset record	A dataset record is a row of data in a dataset table consisting of a single value from each column of data in the table. The data in the columns of the dataset are all of the same type of data, such as birth date or address, whereas the rows represent a given instance, such as a single patient or person or a group of patients or persons.
De-identified data	This is data that has been altered so that the resulting data cannot be readily associated with particular individuals, that is the data does not identify individuals directly. De-identification requires the removal of name and exact address; and can also involve the removal of any other detail or combination of details that might support identification.
Deterministic record linkage	In this approach, often referred to as exact matching, a unique identifier or set of identifiers is used to merge two or more sources of data. In health linkages, the identifier used is often a unique patient identifying number or UPI.
Diabetes registry	A diabetes registry is a type of patient registry defined by patients having a diagnosis of diabetes. It is an organised system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for this population that serves a predetermined scientific, clinical, or policy purpose(s). The registry database is the file (or files) derived from the registry. (ARHQ, Registries for Evaluating Patient Outcomes: A User Guide, 2007)
Diabetes registry dataset	A diabetes registry dataset typically includes age, sex, risk factors, date of diagnosis, type of diabetes, lab tests, procedures, treatments and complications.
Direct identifier	A direct identifier is a means to identify a specific individual and can include their name, full address or unique patient identifying number (health insurance number, social security number).
Electronic Clinical Record	For this OECD study, an electronic clinical record includes clinical information about individual patients within electronic medical, patient or health records. See definitions of electronic health record and electronic medical record/electronic patient record.

Electronic Health Record	For this OECD study, an electronic health record (EHR) refers to the longitudinal electronic record of an individual patient that contains or virtually links records together from multiple Electronic Medical Records (EMRs) which can then be shared across health care settings (interoperable). It aims to contain a history of contact with the health care system for individual patients from multiple organisations that deliver care.
Electronic Medical Record/Electronic Patient Record	For this OECD study, an electronic medical record (EMR) or Electronic Patient Record (EPR) is a computerised medical record created in an organisation that delivers care, such as a hospital or physician's office, for patients of that organisation. EMR/EPR is provider or organisation centric and allows storage, retrieval and modification of clinical patient records.
Emergency care	Acute care of patients who present without prior appointment, either by their own means or by ambulance. Emergency care is usually found in a hospital (emergency department (ED), also known as accident & emergency (A&E), emergency room (ER), or casualty department) or other primary health care centre.
Emergency care dataset	This dataset will typically include information on the dates of attendance and discharge, reason for attendance, the diagnosis, treatments or procedures provided, medications at discharge, and discharge destination. It may also include information on waiting times and whether or not an ambulance was used.
Formal long-term care	Long-term care is the care for people needing support in many facets of living over a prolonged period. Formal long-term care can be provided in home, institutional or day-care settings, from public, not-for-profit and for-profit providers, with services varying from alarm systems to daily personal care.
Formal long-term care dataset	This data set typically includes information on patient age and gender, main diagnosis, dates of care, care type and care provider. It may also contain information on the patient's functional health status and mental health status.
Health care coding	The process of assigning a standard code to a description of a clinical diagnosis, procedure or treatment using a standardised clinical terminology classification system. (See definition of medical coding.)
Hospitals	Hospitals comprise licensed establishments primarily engaged in providing medical, diagnostic, and treatment services that include physician, nursing, and other health services to in-patients and the specialised accommodation services required by in-patients. Hospitals may also provide out-patient services as a secondary activity.
Hospital in-patient dataset	This dataset will typically include information on the age and gender of in-patients, their dates of admission to hospital and discharge from hospital, their main diagnosis, the procedures administered to them and medications prescribed at discharge.
In-patient care	In-patient care refers to care for a patient who is formally admitted (or 'hospitalised') to an institution for treatment and/or care and stays for a minimum of one night in the hospital or other institution providing in-patient care. In-patient care includes accommodation provided in combination with medical treatment when the latter is the predominant activity provided during the stay as an in-patient.
Medical coding	The process of assigning a standard medical code to a description of a clinical diagnosis, procedure or treatment using a standardised medical classification. Commonly used standardised classifications for medical coding including the WHO ICD9 or ICD10 codes for diagnosis and ATC codes for medications.
Mental hospital	Mental hospitals comprise licensed establishments primarily engaged in providing medical, diagnostic and treatment services that include physician, nursing and other health services to in-patients requiring care for mental health, psychiatric or substance-abuse related health conditions.
Mental hospital inpatient dataset	This dataset will typically include information on the age and gender of in-patients, their dates of admission to hospital and discharge from hospital, their main diagnosis, the procedures administered to them, and medications prescribed at discharge.
Mortality dataset	A census of all deaths by cause of death and demographic characteristics of the deceased within a defined population.
Opt-out	Opt-out is an expression of will, with which the data subject objects to the processing of their data under certain circumstances and the objections are honoured.
Patient experiences survey dataset	This dataset contains the results of a survey to measure patient experience of health care services. Content domains can include accessibility of care, coordination of care, communication quality, adherence to clinical guidelines, and patient satisfaction. It includes both surveys of patients or of service users, including surveys of the general population.
Patient-reported outcomes (PROs)	Patient-reported outcomes (PROs) are reports coming directly from patients about how they feel or function in relation to a health condition and its therapy without interpretation by healthcare professionals or anyone else. PROs can relate to symptoms, signs, functional status, perceptions, or other aspects such as convenience and tolerability. (Cochrane Handbook for Systematic Reviews of Interventions, 2008). Questionnaires are often used to collect PROS both before and after a treatment is given.
Patient-reported outcomes (PROs) dataset	PROs may be collected from patients at the point of care or collected from patients via a telephone, mail or other survey. Thus PROs data may exist as a stand-alone dataset or PROs data may be included within other datasets, such as within hospital datasets, primary care datasets, patient survey datasets or population health survey datasets.
Personal health data	Personal health data are any information relating to an identified or identifiable individual that concerns their health, and includes any other associated personal data.
Population census or registry	A population census is the total process of collecting, compiling, evaluating, analysing and publishing or otherwise disseminating demographic, economic and social data pertaining, at a specified time, to all persons in a country or in a well delimited part of a country.

Population census or registry dataset	This dataset typically includes variables such as age, sex, location, household members, education, employment, income, ethnicity, and immigration status. When integrated with or linked to health data it provides a powerful means to understand differences in health and health outcomes within a population, such as socio-economic disparities in health outcomes or access to care.
Population health survey dataset	This dataset contains the results of a survey of the general population regarding health status and presence of diseases, socio-demographic characteristics and, in most cases, exposure to health-related risk factors.
Prescription medicines	Prescription medicines are medicines exclusively sold to customers with a medical voucher, irrespective of whether it is covered by public or private funding and include branded and generic products.
Prescription medicines dataset	This dataset will typically include information on prescription medicines dispensed over the counter (community pharmacies) by their name or by code, as well as the date of dispensing.
Primary care	Provision of continuing and comprehensive medical care to individuals and families in an ambulatory setting. It may be provided by general practitioners (or "family doctors") and their teams. The critical elements are a focus on the part of the providers on generalism rather than specialism; the provision of patient-centred rather than disease-centred, coordinated, and accessible services; and the integration of biomedical, psychological, and social dimensions of the presentation and management of presenting problems.
Primary care dataset	This dataset will typically include information on the age and gender of patients, the dates of visits, the main diagnosis, medications prescribed, and lab and imaging test results.
Privacy	Privacy is not being observed or disturbed by others. Privacy is a concept that applies to data subjects, while confidentiality is a concept that applies to data.
Processing data	Processing data means all data-related operations involving personal health data such as data collection, use, disclosure, storage, recording, editing, retrieval, transfer, sharing, linkage or combining, analysis and erasure.
Probabilistic record linkage	In this approach, a set of possible matches among the data sources to be linked are identified. For example, identifying information such as names, dates of birth, and postal codes, may be used to assess potential matches. Then statistics are calculated to assign weights describing the likelihood the records match. A combined score represents the probability that the records refer to the same entity. Often there is one threshold above which a pair is considered a match, and another threshold below which it is considered not to be a match. This technique is used when an exact match between records across databases is not possible, or when data capture errors have caused deterministic matches to fail.
Pseudonymisation	This is a technique where identifying information about individuals, such as names, complete addresses and patient numbers, are converted to a meaningless name or number in a consistent manner. The consistency of the application of the pseudonymisation algorithm permits record linkage among databases. The assignment of a pseudonym may be done it a way that permits it to be reversible or not.
Record linkage	Record linkage refers to a merging that brings together identifiable records from two or more sources of data with the object of consolidating facts concerning an individual or an event that are not available in any separate record. (Handbook of Vital Statistics Systems and Methods, Volume 1: Legal, Organizational and Technical Aspects, United Nations Studies in Methods, Glossary, Series F, No. 35, United Nations, New York 1991.) An example would be linking patient records in a hospital database to any death records for the same persons in a mortality database in order to identify patients who died following treatment.
Re-identification	Re-identification means a process by which information is attributed to de-identified data in order to identify the individual to whom the de-identified data relate. Re-identification requires information about the individual obtained from personal knowledge or from data stored in other datasets about the same individual. For example, a dataset with a reversible pseudonymised identifier may be re-identified with the pseudonymisation key. In another example, a person who is listed in a non-health dataset with their name and address included might be matched, with some probability, to a health dataset that has no names or addresses included. Using probabilistic record linkage, the two databases are linked to the same individual on the basis of similar variables available in both datasets. Examples of similar variables might be city, sex, age, marital status, birth date, etc.
Remote data access service	Remote data access service is a service providing access to data stored on a computer or network from a remote distance. Remote data access services are often secured to ensure that users can only access data to which they have been approved and that users cannot alter or withdraw/copy the data from the system without permission.
Research data centre	Research data centre is a secure physical setting, such as a secure room, where access is provided to data. Research data centres may have physical security, such as supervision and locked doors, as well as computer and data security, such as computer systems that ensure users can only access data to which they have been approved and that users cannot alter or withdraw/copy data from the system without permission.

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