4 Health data infrastructure and information system in Brazil

Brazil has launched an ambitious digital health strategy to leverage the potential of digital health data. Remarkably, the country already generates a large amount of digital health data within key national health datasets, but it lags behind OECD countries in data availability, reporting, governance and integration. An objective-oriented roadmap should include guidelines such as strengthening data governance and accountability, improving data collection and data comparability, and supporting evidence-based policy design with real time, linked, and inclusive health data. Health information infrastructure in Brazil could also be enhanced by fuller participation in the international benchmarking initiatives, such as the OECD's System of Health Accounts or Health Care Quality Indicators.

4.1. Introduction

Effectively producing the relevant and timely data on resources, activities, and quality across the health care sector is a major health system objective – a fact that has been exacerbated during the COVID-19 crisis, and the broad use of such data is a key factor for the improvement of health systems performance. Assessing and enhancing the health of populations and the quality and efficiency of health systems relies on the use of high-quality health data that allows measuring, monitoring, and benchmarking. The quality of these data is correlated with the strength and capacity of health information systems and infrastructure, as well as its preparedness to produce regional and national health indicators (OECD, 2013[1]).

Countries across the OECD have differences in data availability, quality, and use. Although all OECD members are investing in the enhancement of their health data infrastructure, some are falling behind due to restrictions that limit access and use of already insufficient data. Better use of data ultimately comes with more advanced and integrated information systems, throughout all service delivery sub-systems in the country (OECD, 2015[2]).

Compared to other sectors, health lags behind in exploiting the potential of data, and digital technology, which could contribute to saving lives and financial resources. Building people-centred, efficient, and sustainable health systems is an objective attainable through the intelligent use of data and digital technologies, which in turn require proper policy action and leadership (OECD, 2019[3]).

Brazil seems to share these challenges, generating the need for an in-depth revision of the health data infrastructure and information system. Some of these challenges are exacerbated due to the continental size of Brazil, with a large geography that technologies needs to reach (e.g. internet, computers), the needs for training of a large number of workers, the different climate zones, and even the highly diverse size municipalities have. Significant gains and insight could be achieved if health information system development is improved, allowing for a more digitalised health system, better comprehension of the cost and effectiveness of medical treatments leading to a reduction in wasteful spending, as well as the reduction in the gaps of intra- and inter-regional health care quality, for example.

This chapter analyses how the Brazilian health data infrastructure and information system is currently designed, together with its limitations. It describes the roles of the most important institutions within the health data infrastructure and information system, the type of data each institution handles, and the sources from which these data are collected. The chapter then compares Brazil's health data development and governance with OECD member countries, as well as data collection and availability gaps. Finally, it assesses Brazil's progress in the development of health data infrastructure and information systems, including policy recommendations oriented to moving towards a knowledge-based people-centred health system.

4.2. The Brazilian health data infrastructure and information system

4.2.1. The Ministry of Health has the steering role in the generation of health data and statistics

Intended to provide information systems and IT support to the Unified Health System-SUS, the Department of Informatics of SUS-DATASUS was created alongside the National Health Foundation-FUNASA in 1991, with staff transferred from DATAPREV, the Public Health Services Foundation-*Fundação* SESP, and the Health Campaigns Superintendence-SUCAM. The control and processing of health data fell under the competences of the Ministry of Health, through FUNASA. DATASUS being constituted as an organ of FUNASA with the objective to specify, develop, implement, and operate health information systems related to SUS.

DATASUS was then formally incorporated into the Executive Secretariat of the Ministry of Health, following a process that started in 1998 and concluded in 2002. DATASUS proposes guidelines and implements information and communication technology actions in the Ministry of Health in line with the guidelines and standards defined by the Ministry of Planning, Development and Management-MP, through its Information Technology Secretariat (Ministério da Saúde, 2020[4]). See Figure 4.1 for a more detailed view on the structure of DATASUS.

Figure 4.1.Structure of DATASUS
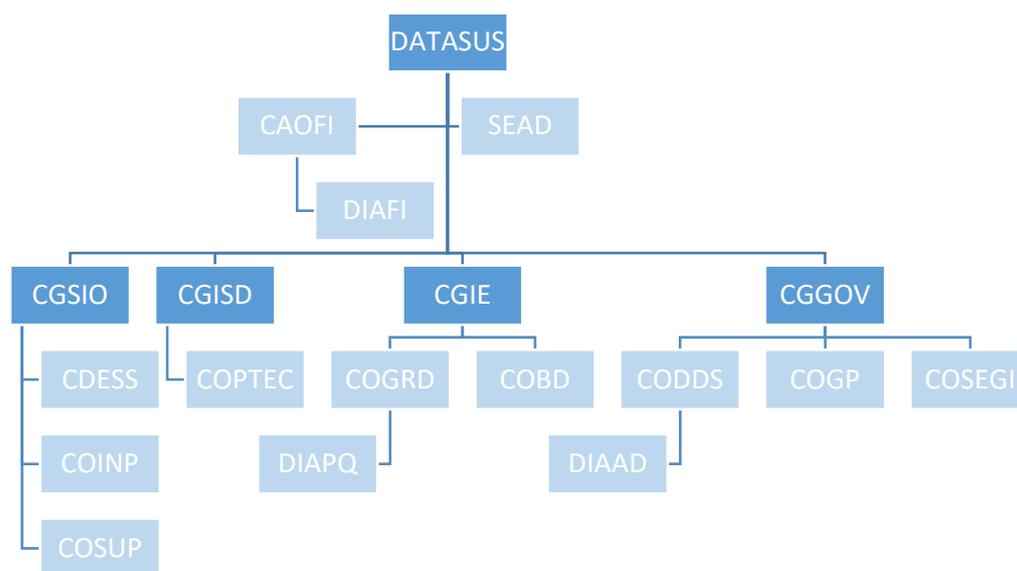
Note: Acronyms in the DATASUS organigram stand for: CAOFI – Co-ordination of Budgetary and Financial Administration; DIAFI – Financial Administration Division; SEAD – Administrative Support Service; CGSIO – General Co-ordination of Information Systems and Operation; CGISD – General Co-ordination of Innovation in Digital Systems; CGIE – General Co-ordination of Infrastructure; CGGOV – General Co-ordination of Governance and Project Management in Information and Communication Technology; CDESS – Co-ordination of Systems Development; COINP – Co-ordination of Interoperability; COSUP – Co-ordination of Users Support; COPTEC – Co-ordination of Prospecting and Innovation in Information Technology; COGRD – Co-ordination of Network and Datacentre Management; DIAPQ – Division of Technology Complex Administration; COBD – Co-ordination of Databases Management; CODDS – Co-ordination of Health Data Dissemination; DIAAD – Division of Data Analysis and Management; COGP – Co-ordination of Governance and Projects; COSEGI – Co-ordination of Information Security.
Source: Ministério da Saúde (2020[4]), "Plano Diretor de Tecnologia da Informação e Comunicação – 2019 | 2021 (1ª Revisão de 2020)", https://datasus.saude.gov.br/wp-content/uploads/2020May 22052020v5.pdf.

More recently, the Health Information and Informatics Committee-CIINFO was created in 2009 with normative, directive and supervisory functions of the activities concerning health information and informatics systems within the scope of the Ministry of Health. CIINFO co-ordinates and oversees the activities related to health data, information systems and digital governance policy in the Ministry of Health and SUS, and is part of the National Health Information System-SNIS, which is in turn organised by the Ministry of Health. In 2019, CIINFO was redefined in accordance with new national legislation that established the Digital Governance Policy within the scope of the organs and entities of the Federal Public Administration.

In line with these health data and statistics entities, the Ministry of Health is currently undertaking the Digital Health Strategy for Brazil 2020-28, which aims to improve the implementation, applications and benefits of digital health in the country progressively through 2028, having SUS as one of its main pillars. The priorities of this strategy are presented in Box 4.1.

Box 4.1. Digital Health Strategy for Brazil 2020-28

The seven priorities of the Action Plan

1. Governance and leadership for the Digital Health Strategy

Ensure that the Digital Health Strategy 2028 is developed under the leadership of the Ministry of Health and incorporating the active contribution of external actors.

2. Digitalisation of the three levels of health care

Induce the implementation of digitalisation policies for health systems, accelerating the adoption of Electronic Health Records-EHR and hospital management systems as an integral part of health services and processes.

3. Support for improving health care

Make the National Health Data Network-RNDS support the best clinical practices, through services, such as telemedicine and mobile phone applications.

4. The user as the protagonist

Engagement of patients and citizens, to promote the adoption of healthy habits and the management of their health, their family, and their community, in addition to assisting in the construction of the health information systems they will use.

5. Training and capacity building of human resources

Train health professionals in Health Informatics and ensure the recognition of Health Informatics as a research area.

6. Interconnected environment

Allow the National Health Data Network-RNDS to enhance collaborative work in all health sectors so that technologies, concepts, standards, service models, policies and regulations are put into practice.

7. Innovative ecosystem

Ensure that there is an innovative ecosystem, which makes the most out of the health interconnected environment.

Source: Ministério da Saúde (2020[5]), "Estratégia de Saúde Digital para o Brasil 2020-28", http://bvsms.saude.gov.br/bvs/publicacoes/estrategia_saude_digital_Brasil.pdf.

Based on the guidelines of the Digital Health Strategy for Brazil 2020-28, the National Health Data Network-RNDS was enacted as the national health data interoperability platform. Established in 2020 as a DATASUS initiative, it is part of *ConecteSUS*, a programme from the federal government that promotes the exchange of information between the actors of the health care network in Brazil, aiming to allow the transition and continuity of care in the public and private sectors. It is expected that the RNDS will be connected to all 27 states by 2023, through the implementation of virtual cloud containers provided to each state. The General Co-ordination of Information Systems and Operation-CGSIO from DATASUS is responsible for the acquisition, installation and maintenance of these virtual cloud containers (DATASUS, 2020[6]).

4.2.2. Several public entities participate in health data and statistics processes

Linked to the Ministry of Health, and created to regulate the private market of supplementary health insurance, the National Supplementary Health Agency-ANS was enacted in 2000. The Agency is the dedicated public entity that periodically collects and publishes figures on the users, providers, and use of private supplementary health insurance plans, and the different plans that are offered in Brazil. Data on the number and characteristics of users, geographic coverage, incomes and expenses of providers, types of private supplementary health plans offered, and the number of claims and disputes made by the users are amongst the statistics regularly published by the ANS.

Also linked to the Ministry of Health, the National Health Surveillance Agency-ANVISA protects the Brazilian population health through the sanitary control of the production, marketing and use of products and services subject to health regulation. ANVISA is part of SUS as the co-ordinator of the National Health Surveillance System-SNVS. ANVISA regularly collects and publishes data on the receipt and registration of documents related to its scope; import licenses and customs enclosures; budget execution panels; and the price list of medicines. The Agency also envisages to openly publish data that they already collect on pharmacovigilance and food and medicines registries, for example.

Outside the Ministry of Health, other institutions contribute with the collection, publication and analysis of health data in Brazil. One of these entities is the Brazilian Institute of Geography and Statistics-IBGE, which is tied to the Ministry of Economics and is the main provider of data and information in the country, aiming to fulfil the needs of civil society, as well as federal, state, and municipal government agencies. Box 4.2 contains in more detail the different surveys on the health of the Brazilian population performed by the IBGE.

States and municipalities also participate in the process of health data collection. DATASUS has the mission to assist states and municipalities in the digitalisation of activities related to SUS in accordance to the Decree 9795 of 2019 from the Presidency of Brazil.

Box 4.2. Brazilian Institute of Geography and Statistics-IBGE main health-related surveys

Pesquisa Nacional de Saúde – PNS

The National Health Survey-PNS collects information on the performance of the national health system. Access and use of available services and continuity of care is taken into consideration, as well as the health conditions of the population, surveillance of chronic non-communicable diseases, and risk factors.

The most recent version of this survey was performed in 2019 and featured four main topics: perception of own health, risk factors, chronic diseases, and dental health. The survey shows data disaggregated by the following age groups: population aged 18 to 29; 30 to 59; 60 to 64; 65 to 74; aged 75 and over; and total population.

Pesquisa Nacional de Saúde do Escolar – PeNSE

The National School Health Survey-PeNSE determines and measures risk factors on the health of adolescents. There are two target populations: the first sample focuses on elementary school students attending 9th grade; and the second sample on schoolchildren aged 13 to 17 (attending 6th to 9th grade of elementary school and 1st to 3rd grade of high school).

Last performed in 2015, this survey provides information on the basic characteristics of the study population, including topics such as socio-economic aspects, behavioural risk factors, exposure to

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Pesquisa de Orçamentos Familiares – POF

The Family Budget Survey-POF provides information on the composition of household budgets and the living conditions of the Brazilian population. Factors such as their perception of quality of life and their nutritional profile are measured and analysed.

The latest edition of this survey was performed in 2017-18, and in addition to information on expenditure and its components, other dimensions were analysed: income, housing, access to public services, health, and education.

Pesquisa Nacional por Amostra de Domicílios Contínua – PNAD Contínua

The Continuous National Household Sample Survey-PNAD *Contínua* monitors quarterly fluctuations and the evolution of the workforce, and other information necessary for the study of the Brazilian socio-economic development.

On November 2020, the most recent edition of this survey was released; it includes indicators such as the unemployment rate and the average monthly income of the population aged 14 and over.

Sources: OECD (2019[3]), *Health in the 21st Century: Putting Data to Work for Stronger Health Systems*, https://dx.doi.org/10.1787/e3b23f8e-en.

4.2.3. Internet and EHR access is lacking in some parts of Brazil

In 2019, 18% of the Primary Care Centres (*Unidades Basicas de Saude* – UBS) did not report having access to the internet, and 9% reported not having used a computer during the last 12 months (OECD, 2019[3]). Remote locations, indigenous communities and localities with limited access to information and communication technologies-ICT are excluded as a result from health data collection processes in Brazil.

Availability of EHR is also hindered due to the lack of connectivity. Patients require access to the internet and the *ConecteSUS* platform in order to visualise their EHR. As mentioned in Chapter 4 on Digital technology of the Primary Health Care Review for Brazil, an estimated 82% of all health care facilities and 78% of primary health care units had EHR systems in 2019 (CGI.br, 2020[7]). Around 18 000 health care facilities – corresponding to 18% of all facilities and including 12 000 public facilities- did not have an EHR system in place. Of the 50 202 family health teams in the National Register of Health Establishments-CNES, only 62% of its registries were digitalised (Ministério da Saúde, 2020[8]). Adoption of EHR systems was highest in the southern and south-eastern regions at 90% and 83%, respectively, compared to the north-eastern and northern regions at 77% and 74%, respectively. Digitalisation is least advanced in the north-eastern and northern regions, where Brazil's indigenous communities are more commonly based (Ministério da Saúde, 2020[9]). See Box 4.3 on the importance of connecting and digitalising primary care practices.

Box 4.3. A digital transformation can help realise the full potential of primary health care

Digital primary health care is the use of digital technologies to support primary health care (it is a subfield of digital health focusing specifically on primary health care). Digital technologies (or information and communication technologies) are electronic tools, systems, devices and resources that generate, store, process and/or transmit data. Digital technologies include devices such as smartphones and computers, as well as intangible products such as software, platforms and algorithms, and can support primary health care in a variety of ways.

At the centre of digital primary health care is the electronic health record or EHR. The EHR is a longitudinal digital record of an individual patient that contains or virtually links together multiple electronic medical records from different institutions and health care settings. As it contains a history of contact with health care providers from any organisation at any level of care, the EHR plays an essential role in helping primary health care providers co-ordinate care for individual patients.

An EHR that is complete, accurate, up-to-date, comprehensive, and that can be shared, enables a plethora of digital applications in primary health care. An EHR that contains clinical (e.g. medications prescribed), sociodemographic (e.g. employment) and administrative (e.g. insurance) information allows supports many applications, including among many others:

- Targeted alerts and reminders to patients (e.g. for screenings or vaccinations).
- Electronic referrals, ePrescribing and certifications (e.g. for sick leave).
- Clinical decision making (e.g. medications to avoid given patient allergies).
- Telemedicine applications (e.g. video consultations and remote monitoring).
- Mobile health or mHealth applications (e.g. smoking cessation and mental health apps).
- Population-level statistics on the prevalence and incidence of diseases and risks.
- Research studies taking into account real-world data (e.g. pharmacovigilance).

It is possible to implement some of these applications without a complete EHR system (e.g. telemedicine), however without the EHR, digital technologies will fall short of their potential and will not fully assist primary health care.

Source: World Health Organization (2018[10]), "Digital technologies: shaping the future of primary health care", https://apps.who.int/iris/bitstream/handle/10665/326573/WHO-HIS-SDS-2018.55-eng.pdf; OECD (2019[3]), *Health in the 21st Century: Putting Data to Work for Stronger Health Systems*, https://dx.doi.org/10.1787/e3b23f8e-en.

4.3. Comparing Brazil's health data development and governance with OECD countries

4.3.1. Health data governance performance in Brazil is around OECD average, but there are gaps in the development and use of health datasets

Health data governance refers to the regulations, policies, and practices that foster the development and use of health data for research, statistics, and other uses within the health-related public interest while protecting health data privacy and data security.

In 2020, Brazil participated in the OECD Survey of Health Data Use and Governance which provides a foundation for understanding the current situation in Brazil and permits comparison of health data governance policies and practices in Brazil to those of 23 OECD countries who responded to this survey

in 2019-20. The survey contributes to monitoring countries' progress toward adopting the 2017 OECD Council Recommendation on Health Data Governance (OECD, 2019[11]). This Recommendation asks countries to develop a national health data governance framework and sets out the principles for doing so (see Box 4.4 and Table 4.1).

Box 4.4. OECD Council Recommendation on Health Data Governance

The 2017 OECD Council Recommendation on Health Data Governance asks all adhering countries to implement a national health data governance framework and sets out 12 high-level principles for the development, content and evaluation of national frameworks:

1. Engagement of stakeholders in the development of a national health data governance framework.
2. Co-ordination within government and co-operation amongst personal health data processors to encourage common data-related policies and standards.
3. Review of the capacity of public sector health data systems to serve the public interests.
4. Clear communication to individuals about the processing of their personal health data.
5. Processing of personal health data by informed consent and appropriate lawful alternatives.
6. Implement review and approval procedures to process personal health data.
7. Achieve transparency through public information about the processing of personal health data.
8. Maximise the development and use of technology for data processing and data protection.
9. Have mechanisms to monitor and evaluate the impact of the national health data governance framework.
10. Provide training and skills development of personal health data processors.
11. Have controls and safeguards within personal health data processors.
12. Require personal health data processors to meet the expectations set out in the national health data governance framework.

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

Implementing the Recommendations helps to address barriers to using data and to developing digital technologies and provides health system leaders with a tool for clear communication about the benefits of a digital transformation of the health sector. The framework enables informed public discourse about opportunities and risks of data uses, including the benefits foregone from not putting health data to work.

Source: OECD (2019[11]), Recommendation of the Council on Health Data Governance.

In Brazil, a new law protecting personal data privacy, the General Data Protection Law-LGPD, entered into force in August 2018 and, one year later, the National Data Protection Agency-ANPD was launched. The Agency is responsible for approving the creation of personal health datasets and approving requests for the processing of personal health data, such as dataset linkages.

It is challenging to implement new data governance legislation. Brazil is developing a national framework for health data governance via CIINFO. Brazil reports experiencing delays in the introduction of the new data protection law and in the new National Data Protection Agency and there is work remaining to develop regulations governing data sharing and access. The country is also challenged to develop sufficient qualified technical staff to process data and support making data more accessible for research.

Table 4.1. 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 health records	A central authority for the approval of requests to process personal health data is established or planned
Australia	No	Yes	Yes	Yes
Austria	Yes	Yes	Yes	Yes
Belgium	No	No	Yes	Yes
Brazil	**Yes**	**Yes**	**No**	**No**
Canada	Yes	Yes	No	No
Czech Republic	Yes	Yes	Yes	No
Denmark	Yes	No	Yes	No
Estonia	No	No	Yes	Yes
Finland	Yes	No	Yes	Yes
France	Yes	No[1]	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**	**15**	**21**	**16**

1. Mission of the Health Data Hub is to elaborate a citizens and patients charter in collaboration with patients associations.
Source: OECD Survey of Health Data Development, Use and Governance 2019-20.

Results of the survey indicate that Brazil compares favourably to other countries in terms of the development and use of data within key national health datasets and has elements of good governance of these datasets. Figure 4.2 provides a summary of the survey results.

Figure 4.2. Distribution of countries overall performance in health data development, maturity and use and in governance of health datasets
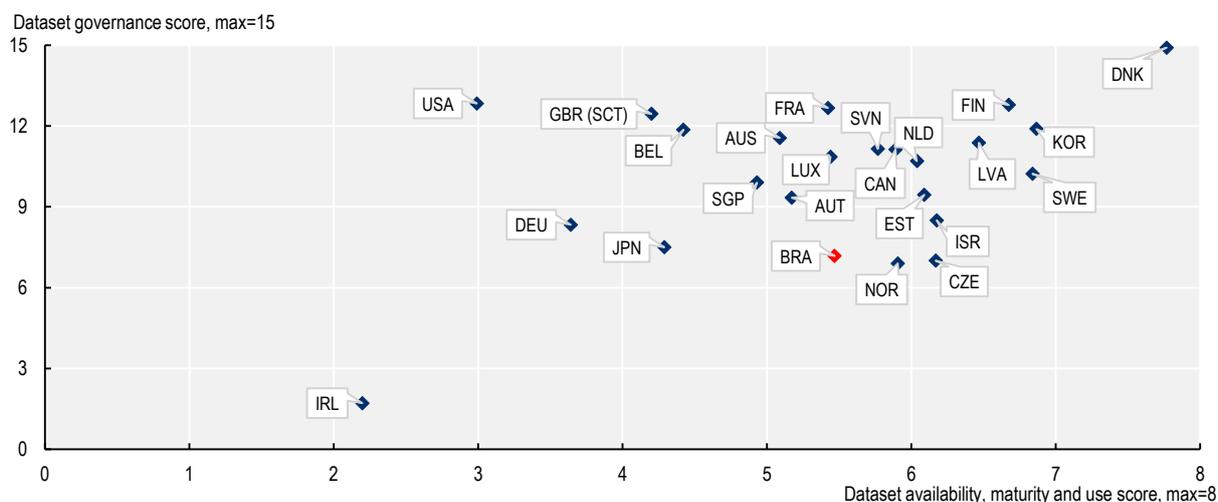
Source: OECD Survey of Health Data Development, Use and Governance 2019-20.

Dataset availability, maturity and use is calculated through a series of parameters that measure how developed each country is on these aspects. According to the responses sent to the OECD Survey of Health Data Development, Use and Governance, Brazil has reported to perform very well in some of these parameters, such as the percentage of available datasets sharing the same unique patient identifier; and health care datasets where standard codes are used for clinical terminology. For other parameters Brazil performs closely to the OECD members average, such as the percentage of available key national health datasets; health care datasets with coverage of 80% or more of the population; health care datasets where data is extracted automatically from electronic clinical or administrative records; datasets used to regularly report on health care quality or health system performance; and datasets regularly linked for research, statistics and/or monitoring. Finally, Brazil's performance is of 0% on the percentage of available datasets where the time between record creation and its inclusion in the dataset is one week or less, compared to 16% for OECD members.

On Dataset governance, another set of parameters is taken into account to evaluate the performance of each country. Brazil has reported to perform very well on having legislation that authorises datasets, and having a data privacy/data protection officer, as well as a public description of datasets. Brazil's performance is close to OECD average on having staff that are trained in data protection, and sharing data within the public sector, academic/non-profit sector, for-profit sector, and across borders. The performance of Brazil is considered low compared to the OECD average on having staff data access controls; de-identifying data prior to analysis; testing re-identification attack risk; having standard data sharing agreements and remote data access service or research data centres; having descriptions that include legal basis for the dataset; and having procedures to request and approval criteria for data linkages; with scores for Brazil that go as low as 0%.

4.3.2. Brazil has conducted several dataset linkages, but unique identification of patients is still insufficient

Dataset linkages are regularly conducted amongst the following datasets in Brazil: hospital in-patient data, mental hospital in-patient data, emergency care data and mortality data. Birth data is also linked regularly to these datasets. Most dataset linkages in Brazil are for research purposes, however, primary care data

linkages also support health care financing and mortality data linkages can be done to audit records for quality.

A strength in Brazil is the use of a patient identifying number across all of the key national health care datasets, the *Cartão Nacional de Saúde*-CNS. However, it is possible that more than a single number has been assigned to the same patient, creating a duplicated identity issue that could be solved through the ongoing migration towards the use of the *Cadastro de Pessoas Física*-CPF some databases have recently started. Other identifying variables are also available within these health care datasets that could support approved dataset linkages. Identifying variables were not available; however, within Brazil's population health and patient experiences survey data or within population census data. Thus it is not technically possible to link survey or census data with health care data so that the richness within these datasets regarding demographic and socio-economic characteristics and health behaviours, for example, can be used to better understand health care utilisation and outcomes of care.

A caution, however, is that Brazil also reports that the requirement to include a personal identifier within national health datasets is relatively new and problems identifying individuals in the health datasets is an important data quality problem.

Most national health datasets in Brazil are used to regularly report indicators of health care quality or health system performance. However, only primary care data are regularly linked to provide indicators to monitor quality or performance and the main purpose of the linkage is limited to produce indicators monitoring immunisation of children aged 0-1. As indicated in the survey, many datasets are regularly linked for research purposes, although Brazil is not linking the datasets regularly to report on health care quality or health system performance, which would represent an improvement for the outputs of the national health data infrastructure and information system.

In other countries, indicators based on dataset linkages provide a wider range of information to monitor health care quality and performance such as indicators of readmission to hospital and death following key events, like acute myocardial infarction or following key hospital procedures, for instance hip replacement surgery. With Brazil's timely health data and capacity to conduct dataset linkages, there is a missed opportunity to utilise these data to monitor how the health system is performing and to detect problems. See Table 4.2 for examples of the indicators based on record linkage that are used to regularly monitor health care quality or health system performance in OECD member countries.

Of course, the datasets themselves must be of sufficient quality to support research and indicator development and Brazil has raised a number of concerns. These include that hospital in-patient, mental hospital in-patient, and emergency care data are populated from insurance claims and this information source is limited in terms of key clinical information. These data also have problems with the quality of health terminology coding and with underreporting of data elements. For primary care data, where the source of data are clinical records, concerns relate to the need to improve electronic clinical record systems by improving the adoption of standardised clinical terminologies, expanding the maturity of clinical information models and adopting a standard for clinical information exchange, such as HL7-FHIR. Mortality data in Brazil is challenged by the need to investigate unidentified causes of death.

Brazil is not alone in confronting data quality challenges within national datasets. Indeed, 18 of 23 countries identified challenges developing several and often most national health datasets. As with Brazil, data quality problems related to availability of terminology standards and coding to these standards are common. The OECD has been surveying countries' development of electronic health record systems and the use and governance of data within these systems, including progress toward and barriers to data interoperability, and Brazil is encouraged to participate in these efforts.

Table 4.2. Indicators based on record linkage that are used to regularly monitor health care quality or health system performance

Country	Indicators
Australia	Unplanned hospital readmissions for selected surgical procedures; annual reporting of cancer survival.
Austria	Hospital readmission rates after surgery, mortality rates following hospitalisation, 30-day mortality for heart attack patients.
Belgium	Monitoring Antibiotic prophylaxis in hospital; 30- and 90-day mortality for pancreas, oesophageal and rectal cancer.
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; 5-year cancer survival rate with lung cancer, breast cancer, et al.; 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-hypertensive, 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	191 indicators of process, outcome and structure domains. Different indicators included from Eurostat (healthy life years at birth; amenable mortality; life expectancy at birth), EU-SILC survey (inhabitants aged 16 year and over 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 (immunisation 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, 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.
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: OECD Survey of Health Data Development, Use and Governance 2019-20.

Estonia provides a good example of how beneficial health data linkages can be for patients, facilitating the access to their own electronic health records-EHR, which can also be securely accessed by their health care providers. This was achieved through the unique patient identifier – the national personal identification number- Estonians have. See Box 4.5 for a more in-depth view of the Estonian patient portal.

Box 4.5. The Estonian patient portal

In Estonia, all citizens who are insured by the Estonian Health Insurance Fund have access to their health data through a web-based patient portal. The portal provides access to the national health database, which unifies data from various health care providers in EHR. People can view their medical data, including data entered by health care providers on diagnoses, test results and their interpretations, and treatments received as well as data on medicines prescribed and dispensed.

In addition to providing access to data stored in their EHR, the portal allows people to create summary documents (such as case summaries and dental care charts), set up reminders, book appointments, inform all medical institutions simultaneously about changes in their contact details, make declarations of intent (such as registering for organ donation) and initiate administrative processes. For example, instead of seeing a health care provider for such purposes, they can apply for health certificates through virtual medical checks that use existing medical data in their EHR and make such documents available for administrative purposes, for instance for getting a driving license.

By default, all citizens can access their own data and health care providers can access data of their patients. Parents also have access to data of their underage children. However, users are their own access administrators and can restrict data access selectively or opt out of the system entirely at any time. Adult users can authorise other persons to access their data and appoint representatives for the performance of certain activities (for instance for buying prescription medicines) so that, for example, people can support the care of their parents or grandparents. A function to give consent for use of data for research purposes is currently under development.

For data security, the system relies on digital authentication for access, digital signing of all data, encryption and decentralised data storage, and logging of all activity backed by blockchain technology. People access the portal using their digital identity card tied to a citizen ID, which is identical for all public services, including health care. Every data query results in an unalterable log so that any potential abuse remains fully traceable. Data access logs are monitored centrally and by users themselves, who can check by whom and when data were viewed. In the past, health care providers who accessed data without appropriate authorisation already faced severe disciplinary measures, including loss of their license to practice.

As per 2018, the portal has been actively used by approximately 480 000 people, representing 37% of the Estonian population. Just under 700 people have opted out of the system, which represents less than 1% of users.

Source: OECD (2019[3]), *Health in the 21st Century: Putting Data to Work for Stronger Health Systems*, https://dx.doi.org/10.1787/e3b23f8e-en.

4.4. Data collection and availability gaps between Brazil and OECD member countries

4.4.1. Substantial gaps in data availability and reporting exist between Brazil and OECD member countries

Brazil lags behind in the regular collection and reporting of some health indicators, which might limit the potential for national health-related analysis and hinders the comparability of the country with OECD members in multi-countries reports. When contrasting the health data indicators and years available in the

OECD Health Statistics 2020 update, Brazil data availability is below the OECD average for all the group of indicators, and in most cases it is less or equal than the minimum value amongst OECD member countries (see Table 4.3).

Table 4.3. OECD Health Statistics data availability for member countries and Brazil, 2020

Group of indicators	Brazil	OECD	Maximum value	Minimum value	Number of indicators
Health status	0.12	0.67	0.85	0.48	25
Risk factors	0.19	0.37	0.85	0.06	12
Remuneration	0.00	0.43	1.00	0.00	5
Waiting times	0.00	0.32	1.00	0.00	7
Employment	0.00	0.61	0.93	0.11	80
Health care resources	0.00	0.60	1.00	0.14	40
Health care utilisation	0.00	0.56	0.77	0.11	35
Long-term care	0.00	0.41	0.97	0.00	9
Pharmaceutical market	0.00	0.64	0.98	0.00	62
Social protection	0.08	0.64	1.00	0.19	9

Note: Values are averages per group of indicators that range from 0 to 1, with 1 point assigned to each indicator if data is available up to t-1 (2019), 0.75 if data is available up to t-2 (2018), 0.5 if up to t-3 (2017), and 0 if data is older or not available.
Source: OECD Health Statistics 2020.

Increasing the number of health data indicators for Brazil in OECD health databases represents an opportunity to allow for more evidence-based policy recommendations and the inclusion of Brazil in multi-country studies. Some indicators can also improve its utility with more recent data, such as the density of nurses which is available only up to 2012 in the OECD Health Statistics database.

Amongst the group of indicators we can find topics that widely encompass the functioning of health systems. The first group in Table 4.1 is Health status, which includes indicators such as life expectancy, maternal and infant mortality, infant health, and communicable diseases; Chile, Israel, and the Slovak Republic were the OECD members with the highest completeness in this group of indicators with values around 0.80, while Belgium, New Zealand, and the United States were amongst the lowest ones with values around 0.50. On Risk factors we have indicators on tobacco, alcohol, fruits and vegetables consumption, as well as overweight and obese population; countries like Belgium, France, and New Zealand have the highest completeness, while Chile, Hungary, Slovenia, and the Slovak Republic have the lowest values on completeness.

Then, on Remuneration we observe indicators on the annual income of salaried and self-employed general practitioners, specialists, and nurses; with Chile, Estonia, Iceland, Turkey, and the United Kingdom having a full completeness, while Austria, Denmark, France, Korea, Latvia, and Lithuania had a completeness value of zero like Brazil. On Waiting times we can observe indicators on the number of days that passed between assessment and treatment for procedures like cataract surgeries, hip and knee replacements, and coronary bypasses; with a similar story showing OECD member countries like Hungary, Italy, and the Netherlands with a full completeness of data availability, and a few other members having a completeness value of zero like Brazil. This is also the group of indicators with the lowest number of respondents, only 16 of the 38 OECD member countries have sent information on waiting times.

For Employment, indicators on practicing physicians, nurses, specialists, dentists, pharmacists, and medical graduates are taken into account; and member countries like Iceland, Israel, and Norway exhibit the highest values on data completeness, while Finland, Mexico, and the Slovak Republic are amongst the countries with the lowest data completeness, although higher than Brazil.

On Health care resources, there are indicators on number of hospital by ownership, number of hospital beds, and medical technological units; member countries like Iceland, Israel, and Slovenia have a full or nearly full data completeness, while Australia, Norway, and the United Kingdom have the lowest data completeness, although once again these lower values are still higher than Brazil. Then, for Health care utilisation, the OECD Health Statistics databases handle data on consultations, immunisations, hospital aggregates, screening, diagnostic exams, and surgical procedures; Estonia, Lithuania, and Slovenia are the member countries with the highest data completeness, while Greece, Japan, and Portugal are those with the lowest data completeness. Brazil has fully completed data available on diphtheria, tetanus and pertussis-DTP, measles, and hepatitis B immunisations up to 2018, although for the methodological approach of this data completeness figure only considers data on influenza immunisation, which is not available for Brazil in the OECD Health Statistics databases.

For long-term care, the group contains selected indicators on workers, recipients, and number of beds; Israel, New Zealand, and Portugal are the OECD member countries with the highest data completeness values, while Belgium, Chile, and Mexico are those with the lowest availability of data, Brazil also exhibits a lack of data for this group of indicators. Pharmaceutical markets include a wide set of indicators on consumptions, sales, and generic market; on one side we find Estonia, Italy, and Portugal that have a nearly complete availability of data for these indicators, while France, Poland, and the United States are on the opposite side with a major part of pharmaceutical indicators not available, similarly to Brazil. Lastly, on Social protection there are indicators on public and private health insurance coverage; Australia, Canada, and New Zealand are the OECD member countries with a fully complete data availability on these indicators, while Japan, Latvia, and Lithuania exhibit the lowest data completeness, although it is still higher than the data completeness value for Brazil.

Areas in the OECD Health Statistics like health care resources and utilisation, both crucial for a correct assessment of the strengths and weak points of national health systems, are lacking data for Brazil as aforementioned. Having a proper data collection for these indicators, and its subsequent transmission to the OECD, could be a key component for evidence-based policy recommendations that benefit from the past experiences of member countries that provided a similar set of comparable indicators. This could contribute to building a more resilient and inclusive health system, people centred, and with an improved understanding of Brazil's population health, health care outcomes and health system financial aspects. See Box 4.6 for examples on how OECD member countries use data to improve the quality of their health systems.

Box 4.6. Using data to drive quality improvements in Sweden

In Sweden, the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions (SALAR) regularly publish counties' performance across more than 150 indicators of health care quality and efficiency, drawn from Sweden's extensive set of national patient registers. The National Board also conducts in-depth assessments of defined areas of care.

These reports typically examine 20 to 60 relevant indicators, presented on different levels (national, regional, county council and unit for instance hospital) as well as being disaggregated by age, gender and socio-economic status (such as educational level). In an appendix to the main report the county councils' and units' results are presented as profile graphs showing their achievements relative to the national mean value per indicator.

For each county council a summary of what areas need to be improved is compiled and measures to be taken in order to increase the quality of care are recommended. The assessment also results in national recommendations to the care providers focusing on indicators where performance appears poor (OECD, 2013[1]).

4.4.2. Gaps exist between Brazil and OECD member countries on health care quality outcomes indicators and other health surveys and questionnaires

Other OECD Health Statistics databases such as those on Health Care Quality Outcomes-HCQO are also lacking figures from Brazil. The aim of HCQO database is to collect, analyse, and monitor variations in health care quality across countries over time, instead of a descriptive assessment of health-related topics which is undertaken in the aforementioned health data collections. Every two years, questionnaires on avoidable admissions, acute care, cancer care, mental health, patient experience, prescribing in primary care, and patient safety are sent to countries. Brazil currently has no data on these HCQO indicators even if the questionnaires are being periodically sent to national contact points, although some countries that are not OECD members either did provide the Organisation with figures on these indicators during the 2020-21 data collection round. These data are subsequently used in multi-country analyses and publications (see Figure 4.3).

Figure 4.3. Distribution of countries responding to the Health Care Quality Outcomes questionnaires, 2020-21
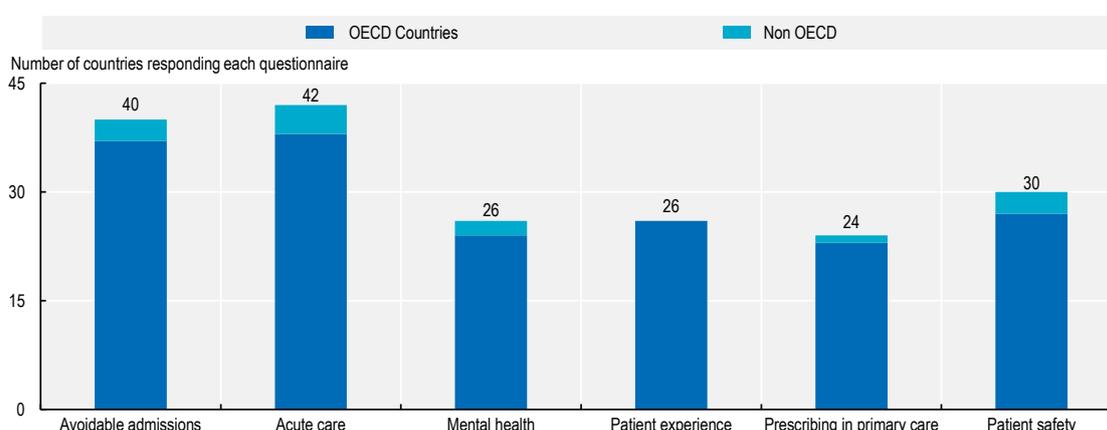
Source: OECD Health Statistics 2021.

Having indicators on HCQO for Brazil would represent another major improvement for data comparability with OECD member countries and key partners, allowing as well for more tailor-made policy recommendations based on the outcomes of the Brazilian health care system.

Related to HCQO, the OECD Secretariat jointly with country representatives are continuously exploring new sources to analyse quality of health care. For instance, a new generation of indicators presented in 2020 will allow international benchmarking on performance of integrated care delivery with the development of quality measurement. These indicators are part of the HCQO Integrated Care-IC data collection, and take a patient care pathway perspective by using country-wide EHR systems and data linkage across existing data sets. Linked data, for instance, would allow monitoring the disease progression of a given patient throughout long episodes of care involving various services and data sourced by hospital in-patient care, primary health care and outpatient specialist care, as well as drug prescribing and death registries, so to follow key events on a journey across the system for a person, for example, suffering a first stroke. This will allow to measure how care delivered before and after hospitalisation prevents hospital re-admissions or death. The OECD Framework for Health System Performance is being used to assess performance of integrated care delivery to start HCQO IC indicator development by piloting 19 new indicators in 2021 for patients admitted in the hospital with congestive heart failure-CHF or stroke.

In addition, HCQO has also included a pilot data collection in 2020 of new indicators related to end-of-life care in OECD countries. Indicators around people's last year of life such as place of death, hospital admissions, 30-day hospital readmissions, utilisation and length of stay in palliative care services, medications used, ICU admission and emergency department visits in the last 30-days of life are being explore to be collected on a more regular basis in the future.

4.4.3. Brazil has started to implement the System of Health Accounts and should consider participating regularly in the OECD health spending data collection

The OECD has been collecting data on health spending based on a common definition and framework for more than 20 years. The purposes of the "System of Health Accounts 2011" (know by the acronym SHA) (OECD/Eurostat/WHO, 2017[12]) are manifold: (i) to provide a framework of the main aggregates relevant to international comparisons of health expenditures and health systems analysis; (ii) to provide a tool, which can produce useful data in the monitoring and analysis of the health system; (iii) to define internationally harmonised boundaries of health care for tracking expenditure on consumption.

The SHA 2011 framework is structured around a tri-axial accounting approach where health spending should be categorised along the dimension of financing schemes ("who pays for services?"), health providers ("who provides the services?") and health functions ("what types of health services are consumed?"), defining health expenditure as the final consumption of health care goods and services.

At the moment, more than 40 countries are submitting annually health spending data for year t-2 along the three core dimensions as part of the Joint Health Accounts Questionnaire (JHAQ) data collection.

Brazil has started to implement the System of Health Accounts building on their long experience with their Health Satellite Account, an exercise that is carried out on in regular intervals by the IBGE, together with other stakeholders such as the *Fundação Oswaldo Cruz*-Fiocruz, the Ministry of Health and others (IBGE, 2019[13]). Work to map those result into the international SHA framework are ongoing. For the years 2010-14, a mapping exercise for the three dimensions of SHA was successful for SUS spending (Ministério da Saúde/Fundação Oswaldo Cruz, 2018[14]). In 2021, Brazil has participated in the JHAQ data collection submitting for the first time internationally comparable date for health care functions. To improve the international comparability of its health spending data, Brazil has become an active member of the OECD Working Party of Health Statistics, which provides a platform to exchange country experiences with the implementation of the System of Health Accounts and discuss methodological challenges and possibilities to solve them.

Brazil should continue the implementation efforts for the System of Health Account and consider to regularly participate in the annual OECD data collection for health spending data for year t-2 for all three core dimensions. This would benefit health system analysis in Brazil by providing a clearer picture how the country compares internationally.

4.5. Moving towards a knowledge-based health system for stronger sustainability

Brazil has been able to start developing their health data infrastructure and information system through a digitally oriented approach that has increased the importance and visibility of relevant health data for a more resilient and inclusive health system. Although important advances have been achieved, Brazil can highly benefit from a well-defined strategy towards a knowledge-based health system, enhancing the Digital Health Strategy for Brazil 2020-28 (Ministério da Saúde, 2020[5]). An objective-oriented roadmap should include guidelines such as strengthening data governance and accountability through integration, transparency, and interoperability; improving data collection procedures with a better prepared, connected and equipped staff; increasing data comparability and coverage through the standardisation of definitions and methodologies; supporting evidence-based policy design with real time, linked, and inclusive health

data; and increasing Brazil's capacity for international benchmarking and its national coverage of health data by adopting OECD standards.

4.5.1. Integration of different levels of government and use of a unique patient identifier would strengthen data governance and accountability

Promotion of tripartite integration and regionalisation

Given the political structure of Brazil as a Federal Republic, a key component for an efficient functioning of data governance and accountability is the integration and co-ordination at federal, state, and municipal levels. Organs such as CONASS and CONASEMS are key for the achievement of this tripartite partnership between the different levels of government, and including them in the elaboration of a roadmap aimed at this objective would facilitate a seamless integration. State and municipal levels require continuous and institutionalised mechanisms of feedback, and for retrieving information useful for planning and management. On this aspect, regionalisation can also be decisive for better structuring tripartite integration, as well as to improve the capacity for planning and management of the health system, and the dissemination of health data.

In addition, silos are in place between health data producers and final users in Brazil, especially at the state and municipal levels. Improving synergies between these two groups would increase the impact and collection of health data, by better co-ordinating the needs of health data users, and the range of data collected by data producers. In this sense, enhancing the skills and data literacy of health workers that collect and report health data can facilitate the reduction of these gaps. Regionalisation would also ease co-ordination on health data collection and use, by better planning these needs between different states and municipalities.

The national coverage of data in Brazil is another aspect that could be improved through regionalisation, in order to allow for comparisons between regions, states or municipalities in Brazil, as well as having health data that more accurately reflect the needs and requirements of the Brazilian population as a whole. Having in mind the difficulties that exist in a geographically extent country like Brazil, and the many differences the territory englobes, this is a hard-to-achieve but certainly worthy objective.

Use of a unique patient identifier and moving from probabilistic to deterministic health data linkages

An effective way of strengthening data governance and accountability is facilitating the identification of patients to improve the linkage of their information across the different areas of SUS. In this sense, it is key to continue the migration from probabilistic methods for identifying and linking patient data in *VinculaSUS* – such as using the patient's name, place and date of birth, or parents' personal information – towards deterministic methods like those applied in *ConecteSUS* using unique patient identifiers such as the *Cadastro de Pessoas Físicas*-CPF. The CPF is the taxpayer identification number, which is unique at a federal level, unlike other identification numbers that are issued at a state level or the *Cartão Nacional de Saúde*-CNS from SUS that in some cases identifies the same patient with various numbers instead of a single identifier. This process should receive special attention and be boosted trough the enhancement of related efforts such as the recently established RNDS.

Italy, for example, uses the *Codice Fiscale*-taxpayer identification number as a unique patient identifier, it is therefore the single identification number printed on the national health card to identify patients (see Box 4.7).

Box 4.7. Italian taxpayer identification number as a unique patient identifier

The *Tessera Sanitaria*-health card is the personal identification document that includes the taxpayer identification number as the unique patient identifier. All Italian citizens entitled to the services provided by the National Health Service-SSN have access to a national health card.

Municipalities assign taxpayer identification numbers to the newborns after the presentation of the birth declaration, this process is performed in co-ordination with the tax registry. Alternatively, the taxpayer identification numbers can be issued by offices of the *Agenzia delle entrate*-Italian revenue agency.

Once the taxpayer identification number has been assigned, the health card is issued and delivered to the address of the newborn citizen. This national health card for newborns is valid for one year, while the health cards issued after are valid for six years -just like those issued to citizens that request them for the first time (Agenzia delle entrate, 2021[15]).

Through this unique patient identifier, datasets can be linked more effectively and allow for impactful health research. For example, analyses on topics such as the administrative data of acute ischemic stroke events and thrombolysis treatments were performed through databases that were linked using the Italian taxpayer identification number as a unique patient identifier, showing the benefits that researchers, and not only policy makers, can obtain from the availability of linked health data (Baldereschi et al., 2018[16]).

Protect personal data privacy of patients

Having this integration in mind, the personal data privacy of patients needs to be protected with an appropriate legal framework. Brazil has recently moved forward in this aspect through LGPD, which entered into force in August 2018, and ANPD that was launched one year after, nevertheless both are experiencing delays in introduction, and there is work remaining to develop regulations governing data sharing and access as mentioned in Section 4.3.

The Access to Information Law-LAI, enacted in 2011 and which allows citizens to ask the three different levels of government for access to public information, is another way of enforcing transparency in health data use and governance. Although, a national law or regulation that aims to ensure the protection of health information privacy and/or to the protection and use of EHR should be enacted following the OECD Council Recommendation on Health Data Governance, as has been the case in 21 member countries to date (see Table 4.1).

Granting patients access to personal health records

Another aspect in which Brazil has moved forward is in allowing patients to access their personal health records. This has started to be implemented through the *ConecteSUS* system, which allows patients to access their personal health records and information on other aspects such as exams, immunisations and treatments using the CPF unique identifier. These personal health records can also be accessed by medical personnel in order to provide better health care. The *ConecteSUS* also facilitates the delivery of prescribed medicines to patients in pharmacies that are part of the SUS partnership network *Aqui tem Farmácia Popular*, allowing also for a better control of medicines delivered by these pharmacies under the scope of their partnership with SUS. See Box 4.8 on the Swedish eHealth strategy which enables people to access their personal health information.

ConecteSUS should be expanded to allow for as many as possible patients in the country to access this platform. A key component of this access is the CPF as a unique patient identifier, ensuring that more

citizens have one can strengthen and expand access to *ConecteSUS* and, therefore, personal health records.

The integration and interoperability, through a unique patient identifier, of these databases at a national level could also result in performance indicators available to health care managers, health workers and the general public, which would facilitate the progressive improvement of health systems through the transparent identification of existing issues and bottlenecks.

Box 4.8. Enabling patient access to electronic health records: The Swedish eHealth Strategy

Since 2017, electronic health records for patients have been accessible in all 22 counties in Sweden. Through their EHR, Swedish residents have access to information from medical and dental services, including physician's notes, test results, vaccination histories, medications, referrals, and a history of who has accessed their online medical record. While residents cannot change the information in their patient record, they are able to add comments to flag where information may be incorrect (Armstrong, 2017[17]). Throughout Sweden, multiple electronic health records systems have been implemented. From the patient's perspective, however, the development of a national Health Information Exchange platform has allowed the multiple EHR systems to be consolidated, allowing a single record to be viewed by the user (Hägglund, 2017[18]).

Efforts to roll out access to electronic health records have come as part of Sweden's national e-health strategy, which has been developed to promote patient empowerment through involvement in their health and social care, as well as strengthen quality of care and decision-making among health and social care professionals. In addition to facilitating access to residents' health and social care information, the eHealth Strategy has also made it a priority to provide information important to health and social care systems users, such as quality and accessibility issues, in a user-friendly format. To strengthen the quality of long-term care for older persons, the platform also allows residents to authorise access to information related to their care, contained in a Care Diary, to family and friends who wish to monitor the care they receive on a regular basis (Swedish Ministry of Health and Social Affairs, 2011[19])

Sweden has further monitored user response to the rollout of electronic patient records, to ensure the system is meeting the needs of its users. A national patient survey of users of the patient-accessible electronic health records (PAEHR) system, Journalen, found that overwhelming majority of users felt positively towards the system (Moll et al., 2018[20]).

4.5.2. Data collection procedures and reliability can be improved through the training of staff, and provision of necessary IT equipment and connectivity

Providing staff with infrastructure tools, training and monetary incentives to municipalities

The Ministry of Health is promoting the collection and use of health data through the training of staff and monetary incentives provided to municipalities that comply with the submissions of health data in a timely manner. The continuation and enhancement of such support from the federal government is necessary for the accurate inclusion of data from more municipalities in Brazil, especially those located in remote areas, and the reduction of inequalities. Ensuring access to the internet, as well as infrastructure tools -such as computers and EHR platforms- and training for data collection and transmission, need to be taken into consideration as well. See Chapter 4 on Digital technologies of the Primary Health Care Review for Brazil for a more in-depth discussion on these aspects.

Strengthening staff who are programmers and IT specialist is another key component for the improvement of data collection procedures and the reliability of these indicators. In order to satisfy the needs and

requirements of data collection and handling, Brazil should count with sufficiently skilled staff in these areas. DATASUS and other bodies that handle health data are in an optimal position to foster programming and IT skills of health workers, especially in areas that have less access to these technologies.

Implementing a national repository of EHR

Based on the improvement of data collection procedures and the programming and IT skills of Brazilian health workers, a more sophisticated data collection and linkage could be developed. Through the migration from probabilistic to deterministic data linkage methods that rely on unique identification numbers, Brazil could connect primary care centres and hospitals in an effort towards implementing a national repository of EHR. See Box 4.9 for an example from Denmark on the successful implementation of EHR, and the consolidation of governance over health data infrastructure and information system.

Box 4.9. Development and use of Electronic Health Records-EHR in Denmark

The majority of OECD health systems have implemented or are starting to implement a national electronic health record system that contains or virtually links together records from multiple electronic medical and patient record systems which can then be shared (interoperable) across health care settings.

Denmark provides a good example of successful implementation of electronic health records that facilitate portability of care (Protti and Johansen, 2010[21]). Nearly all primary care physicians in Denmark use electronic health records, which are linked through a national network that allows physicians to communicate directly with other health care providers. All individuals have unique person identification numbers linked to their health records which are also linked to other areas including taxation, making it easy to follow individuals, regardless of where they receive care.

Electronic health records were phased in gradually in Denmark. In the 1980s, doctors began to be paid a small amount for electronically sending medical claims. This incentivised greater use of computers in medical practices, and spawned a later programme that allowed doctors to send clinical messages to other providers and to eventually electronically send prescriptions to pharmacies. With support from the Ministry of Health, this endeavour grew; in the 1990s, national standard templates for frequently used communications were developed and a health care data network was established. An independent non-profit organisation, MedCom, was tasked with overseeing and expanding the electronic health records programme. Throughout, there has been a strong focus on maintaining homogeneity across the system. For example, while there are over 50 different electronic medical record platforms, there is a single electronic form that is used for all communications from primary care physicians. This has helped to deter parallel, incompatible information systems from being created.

At the same time, Denmark has consolidated governance of its health care information systems. The National Institute for Health Data and Disease Control functions as a public enterprise under the Danish Ministry of Health, and is responsible for collecting all health documentation within the Danish health care system and steering a strategic approach to development of the information infrastructure. This includes co-ordinating agreements between the central authorities on common goals for better data use, co-ordinating activities across central and regional authorities and liaising with Denmark's extensive set of national patient registers (OECD, 2013[22]).

Consolidating and expand the work on population health surveys

Another benefit from improving data collection procedures and having more skilled health workers could be the expansion of the work on population health surveys. As discussed in Section 4.2, the Brazilian

Institute of Geography and Statistics-IBGE currently works on different population health surveys (see Box 4.2) which could benefit from these advances, both in terms of data collection and analysis, as well as in terms of the amount of population covered, therefore contributing to the reduction of inequalities in health amongst Brazilians.

IBGE health surveys such as the PNS and the PeNSE should be fully published with regular periodicity at least every five years, allowing for a more organised funding and planning while also improving the timeliness and relevancy of these surveys and the health indicators they collect. To obtain a more accurate picture of children and adolescents health in Brazil, the PeNSE survey could be expanded to account for a broader age group than only Brazilians aged 13 to 17, or through the creation of a new national children and adolescents health survey again with a more regular periodicity of at least very five years. See Box 4.10 for examples from Australia and the United States on national children and adolescents health surveys.

Box 4.10. National children and adolescents health surveys in Australia and the United States

Australia's children report

Australia's children report provides an overview of the well-being of children in the country. Latest available data is brought together on a wide range of topics, and builds on previous Australian Institute for Health and Welfare-AIHW reporting about children.

The publication includes information on health, education, social support, household income and finance, parental employment, housing and justice and safety. Children aged 0 to 12 are taken into account for this report, covering infancy through to the end of primary school. The report was launched in 2020 and is expected to be updated periodically as more data becomes available.

National Survey of Children's Health

Designed to produce nationally and state-representative estimates, the National Survey of Children's Health-NSCH examines the health of children aged 0 to 17 in the United States.

The range of topics analysed in the NSCH includes physical and emotional health, access to quality health care, and the child's family, neighbourhood, school, and social context. The NSCH is a yearly survey that begun in 2016, with data collected by the Census Bureau. Data can be refined to assess differences by states, income, race/ethnicity, type of health insurance, amongst other demographic and health status characteristics.

Sources: Australian Institute of Health and Welfare (2020[23]), "Australian's Children", https://doi.org/10.25816/5ebca4d0fa7dd; Census Bureau (2019[24]), https://www.census.gov/programs-surveys/nsch.html.

4.5.3. Towards more data comparability and coverage through expansion and enforcement of data standardisation

Standardising data definitions and methodologies

Brazil has been conducting a standardisation of definitions and compilation methodology with the Health Ministry Ordinance 2073 of 2011, which regulates the use of health interoperability and information standards for health information systems within the scope of SUS, at all government levels, and for private and supplementary health sector systems.

In this sense, the terminology SNOMED-CT is being applied for coding clinical terms and mapping terminologies used in Brazil, the Exchange of Information on Supplementary Health- TISS standard for the interoperability with supplementary health systems, and the Health Level 7-HL7 standard for the integration of exams requests and results, supporting semantic interoperability between systems. Ordinance 2073 of 2011 also contemplates the application of standardised EHR in Brazil through the OpenEHR terminology. Following international guidelines and best practices for EHR can be beneficial for Brazil in this task, as aforementioned in this section and in Box 4.9.

Brazil's standardisation of definitions and compilation methodology conducted through the Ordinance 2073 of 2011 is an important step forward, although it has not been done as timely and efficiently as expected. Organs like CONASS are asking to increase the frequency of the meetings that discuss the application of this Ordinance in order to accelerate the harmonisation of health data standards and methodologies. In addition, monetary incentives for compliance would represent a powerful catalyser for improving the standardisation process.

4.5.4. Supporting evidence-based decision making and impactful health research in Brazil with real time, linked and inclusive health data

Improving timeliness of data

Brazil should promote a health data infrastructure system with an enhanced timing of data, improved data linkages, and that includes data from the private sector. Progress in these three areas would yield more relevant, up-to-date, and comprehensive data that could serve as building blocks for evidence-based policy design. Research centres and universities would also benefit from this innovative and cutting-edge data. See Box 4.11 for examples on how Portugal has been using data to optimise their health system.

Having real time data is a necessary tool for evaluating the continuous impact of health policies, as well as to make better informed and accurate decision. This is true not only for exceptional scenarios as pandemics and other health crises, but also in less contingent times.

Box 4.11. Portugal's use of data to inform smarter purchasing

Portugal has implemented, and continues to develop, a number of initiatives that seek to optimise both cost and quality. A particularly successful area of reform has been the reduction in spending on pharmaceuticals through the promotion of generic drugs. Generic prescribing became mandatory in 2012. The Ministry of Health already exercises its monopsony powers by setting an annual limit on total pharmaceutical spend (as a percentage of GDP), and uses countries with the lowest purchase prices for each drug (such as Spain, France or the Slovak Republic) as the reference point from which to begin negotiations. In addition, the ministry is currently negotiating a new tax on pharmaceutical sales – in effect, a fiscal claw back. Initiatives have also been directed toward pharmacists. They are required to have available three of the five cheapest formulations for each drug and be able to sell the cheapest. If not, they are heavily fined. This comprehensive and sophisticated set of measures has led to Portugal exhibiting one of the sharpest declines in pharmaceutical expenditure over the past decade.

It is important to note that this reduction in pharmaceutical spend was not achieved simply through imposition of budget cuts, product withdrawals and sanctions. Initiatives to encourage higher quality prescribing were also introduced. A shift to electronic prescribing has allowed better monitoring of individuals' medication history, compliance and potentially unsafe drug interactions.

A key advance has been to integrate these initiatives together – guidelines and the formulary are now embedded in the electronic prescribing system, allowing the issue of alerts if doctors prescribe beyond these guidelines. Doctors also receive monthly feedback on their prescribing patterns, alerting them, for example, to the extent to which they prescribe outside the national formulary.

Making health data in Brazil more inclusive

There is a need to include remote locations, indigenous communities and localities with limited access to ICT into health data collection processes in Brazil. Fostering the inclusion of parts of the country most excluded by these factors can help prevent the widening in inequality gaps between states and municipalities that have different levels of financial resources, number of inhabitants and development.

Finally, the inclusion of the private sector would also be beneficial in order to have a more complete picture of the Brazilian health system. Partnerships between the ANS and SUS under the umbrella of the Ministry of Health, as well as the inclusion of ANS data in the RNDS of *ConecteSUS* could be favourable for all stakeholders, and yield more relevant data to policy makers, researchers and analysts.

4.5.5. International benchmarking capacity and national coverage of health data through adoption of OECD standards

Adopting OECD standards for use of data and adhering to Council recommendations

Brazil is invited to adopt OECD standards for national and international use of data and statistics, attending as well the different health statistics and expert meetings in which best practices are discussed, and participating in the different data collection processes for OECD member countries and key partners. This closer participation can also allow Brazil to improve their data collection, availability and comparability, which can in turn be used in multi-national studies and analyses performed by the OECD and others.

Brazil's adherence to the Recommendation of the OECD Council on Health Data Governance is also encouraged. This recommendation promotes the implementation of a national health data governance framework and sets out 12 high-level principles for the development, content, and evaluation of national frameworks on areas such as patient's privacy, transparency, monitoring and independent research, training and skills development, amongst others (OECD, 2019[11]). See Box 4.4 for a detailed view of the OECD Council Recommendation on Health Data Governance, and Table 4.1 for a list of countries that have implemented or are implementing a national health data governance framework which is a principle aspect of adhering to the OECD Council Recommendation, as well as other elements that are also part of the adherence.

Participation in international expert meetings and data collections

Brazil is encouraged to attend the different health data expert meetings in which best practices are discussed, and participate in related data collection processes such as HCQO, Health Statistics, economics of public health, and pharmaceutical and medical devices.

Brazil could also to take part in ad hoc expert groups that have been recently created such as mental health performance, integrated care, end-of-life care and the Patient-reported Indicator Surveys-PaRIS, along with any other that can be created in the future.

4.6. Conclusion

The Brazilian Health Data Infrastructure and Information System, highly reliant on DATASUS, has recently started an ambitious Digital Health Strategy for the period 2020-28, based on the RNDS, and even if the Ministry of Health has the steering role in the generation of health data and statistics, other public entities also participate in health data and statistics processes. Bodies such as the ANS, ANVISA and the IBGE are key players for health data production in Brazil, which could be even more impactful when further data linkages are undertaken. Although, one of the most restrictive issues is the lack of access to the internet, and digital health resources such as EHR, in some parts of the country, especially in remote and indigenous communities.

Based on the results of the 2019-20 OECD Survey of Health Data Development, Use and Governance, Brazil compares favourably to other countries in terms of the development and use of data within key national health datasets, although improvements could be made on the governance of these datasets to approach the average score of OECD members. In addition, even if Brazil has conducted several dataset linkages, more efforts are required to uniquely identify patients.

Another aspect to be improved by Brazil is the availability and reporting of health data, as substantial gaps exist between the country and OECD members. These gaps exist not only for the OECD Health Statistics main indicators, for which Brazil collected and reported data only for two out of ten groups of indicators, but also for health care quality outcomes indicators and other health surveys and questionnaires. Brazil is invited to participate in upcoming data collection rounds for projects such as HCQO and the Integrated Care indicators.

Brazil can strengthen data governance and accountability by integrating different levels of government and using a unique patient identifier; and improve data collection procedures and reliability in the country through the training of staff, and providing them with the necessary IT equipment and connectivity. Brazil can also increase comparability and coverage through expanding and enforcing data standardisation; and support evidence-based decision making and impactful health research with real time, linked and inclusive health data. Lastly, Brazil can promote their international benchmarking capacity and national coverage of health data by adopting OECD standards.

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