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Registries and information systems for diabetes care in the WHO European Region: preliminary findings for consultation





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Abstract

More than 64 million people in the WHO European Region are living with diabetes, placing them at greater risk of complications and comorbidities including cardiovascular diseases and premature mortality. Strengthening health systems for diabetes care and prevention of its complications is a global and European priority towards achieving better diabetes health outcomes. Diabetes registries and diabetes information systems potentially can improve care outcomes as they promote the management of the disease course, prevent complications, ensure quality, enable trends to be estimated and research to be conducted, decrease health expenditure and inform policies. The aim of this scoping review of qualitative evidence was to generate an overview of the status of diabetes registries and similar information systems in countries of the WHO European Region. The preliminary results show seven countries with a national diabetes registry, 21 with a diabetes registry for certain age groups or types of diabetes and 13 without a national registry; the situation was unclear for remaining countries in the WHO European Region. Seven countries are developing a national registry. Six countries (all in western Europe) have subnational registries. The scope of diabetes registries varies across countries. Most countries record type 1 and 2 diabetes in children. Diabetes registries are used mainly for surveillance and over half of the countries use registries for clinical management or improving the quality of care. Diabetes registries are also used for research or to support cost estimations, governance and accountability. Where they exist, registries tend to have wide coverage, usually at over 75% of people with diabetes. Lack of standards in data collection has prevented the aggregation of data within and across countries. Challenges that stand in the way of registries' success include current regulatory frameworks, unclear ownership and privacy policies, insufficient allocation of resources, lack of international consensus on standards and ineffective technological capacity. Indirect benefits from diabetes registries include empowering patients to improve their health and well-being, fostering dialogue among people with diabetes and health professionals, informing health services and integrating care for diabetes.

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Contents

| | |
|---|-----------|
| Acknowledgments..... | vi |
| Diabetes in the WHO European Region | 1 |
| About this document..... | 3 |
| Methods | 4 |
| Sources of data | 4 |
| Keywords..... | 4 |
| Search engines, databases and websites..... | 5 |
| Selection process and criteria | 5 |
| Definitions applied..... | 6 |
| Screening process | 6 |
| Data extraction..... | 7 |
| Data analysis and validation | 8 |
| Limitations..... | 8 |
| Information systems and registries for managing diabetes | 10 |
| Status and features of national diabetes registries and information systems..... | 10 |
| Status and features of subnational diabetes registries and information systems | 11 |
| Scope of the diabetes registries | 12 |
| Uses of diabetes registries | 14 |
| Coverage of people with diabetes by diabetes registries..... | 15 |
| Sources of data for diabetes registries | 16 |
| Other health information systems and their linkages to retrieving data on diabetes..... | 17 |
| Initiatives to establish intercountry diabetes registries..... | 19 |
| Challenges to diabetes registry success | 21 |
| Regulatory frameworks..... | 21 |
| Unclear ownership and privacy policies..... | 21 |
| Insufficient allocation of resources..... | 22 |
| Lack of international consensus on standards..... | 22 |
| Ineffective technological capacity | 23 |

Disempowerment of health professionals.....23

Additional benefits from diabetes registries 24

Empowering patients to improve their health and well-being24

Fostering dialogue among people with diabetes and health professionals to increase health literacy and enhance clinical decisions24

Informing health services and integrating care for diabetes, promoting more efficient care pathways.....25

Final remarks 26

References 27

Annex 1. Keywords 1: selected languages 35

Annex 2. Keywords 2: selected languages 36

Annex 3. Data extraction fields..... 37

Annex 4. Status and features of national diabetes registries by country 39

Figures, tables and boxes

Tables

| | |
|--|----|
| Table 1. Keywords | 5 |
| Table 2. Scoping review limitations summary..... | 8 |
| Table 3. Status and features of national diabetes registries | 10 |
| Table 4. Status and features of subnational diabetes registries by country..... | 11 |
| Table 5. Scope of national and subnational diabetes registries by country | 13 |
| Table 6. Main uses of national and subnational diabetes registries | 14 |
| Table 7. Coverage of national and subnational diabetes registries, available countries only..... | 16 |
| Table 8. Diabetes registry data source | 16 |
| Table 9. Sample of countries that complement diabetes registry data with other data | 17 |
| Table 10. Sample of countries without diabetes registries that use other health information systems to retrieve diabetes data..... | 18 |

Boxes

| | |
|---|----|
| Box 1. Spain – reconciliation of data at national level..... | 12 |
| Box 2. United Kingdom, England and Wales – clinical audits to drive quality improvements..... | 15 |
| Box 3. Finland – overcoming legislative limitations | 21 |
| Box 4. Germany – advocacy for optimizing health outcomes | 22 |
| Box 5. Portugal – priority given to children | 22 |
| Box 6. Sweden – multistakeholders accessing online indicators and target time series..... | 22 |
| Box 7. France – Database: an interoperable integrated platform | 23 |
| Box 8. United Kingdom, Scotland – My Diabetes, My Way | 24 |
| Box 9. Italy – stakeholder initiatives for establishing subnational registries | 25 |
| Box 10. Bulgaria – use of the diabetes registry to reward general practice | 25 |

Figures

| | |
|--|---|
| Fig. 1 Screening and selection process visualization | 7 |
| Fig. 2 Chronological distribution of citations..... | 7 |
| Fig. 3 Number of citations per country | 8 |

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Diabetes in the WHO European Region

More than 64 million people in the WHO European Region are living with diabetes, placing them at greater risk of complications and comorbidities including cardiovascular diseases, premature mortality and loss of quality of life.

According to the International Diabetes Federation (IDF), 8.9% of adults aged 20–79 years (59.3 million people) in the European Region had diabetes in 2019 (1). A further 296 500 children and adolescents under the age of 20 live with type 1 diabetes.

Diabetes is also among the top-10 leading causes of noncommunicable disease-related deaths in the Region (2).

In 2016, diabetes mellitus accounted for 2.8% of total deaths (21.4 per 100 000 population) (3). Higher-than-optimal blood glucose is also recognized as a contributor to deaths caused by cardiovascular and other noncommunicable diseases (4).

Diabetes of all types can lead to systemic complications and can increase the overall risk of premature death. Possible complications include heart attack and heart failure, stroke, blindness, kidney failure, liver malfunction, loss of limbs and loss of life (5). During pregnancy, poorly controlled diabetes can increase the risk of many gestational complications and fetal death (4). In the context of the COVID-19 pandemic, people living with noncommunicable diseases, including diabetes, are among the most vulnerable to becoming severely ill or dying from COVID-19 and other infections (6).

The increasing prevalence of diabetes is driven by a complex interplay of genetic, socioeconomic, demographic and environmental factors. Growing urbanization and changing lifestyle habits are contributory factors to the increasing prevalence of type 2 diabetes and its related risk factors, which include rising levels of obesity, unhealthy diets and widespread physical inactivity. It has been estimated that 80% of premature heart disease, stroke and diabetes could be prevented by tackling major noncommunicable disease risk factors (7). Overweight and obesity among adults (body mass index (BMI) ≥ 25 , age-standardized) increased to 58.7% of the population of the European Region in 2016, up from 51.4% in 2000 (4). Importantly, the risk of complications can be reduced through the effective delivery of services. WHO has developed tools to support the delivery of those services (8–10).

Strengthening health systems for diabetes care and prevention of its complications is a global and European priority towards achieving better diabetes health outcomes.

Diabetes has a significant economic impact. The European Region has the third largest expenditure on diabetes of all IDF regions, with total expenditure on the advanced treatment of diabetes-related disease and its complications coming to US\$ 161.4 billion. Improved diabetes care minimizes risk factors and the incidence of complications, and decreases diabetes-related health expenditure, human suffering and the staggering economic cost (1).

WHO global and regional policies consistently have called for action to curb diabetes trends by placing emphasis on tackling risk factors and rolling-out cost-effective individual and population-based interventions to manage

diabetes and its complications. In 2013, the World Health Assembly adopted the Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013–2020 (11). The action plan is accompanied by a global monitoring framework (12) that includes indicators for monitoring the probability of dying from the four main noncommunicable diseases and following up progress made to decrease the prevalence of raised blood glucose. These measures are in line with the targets set in the United Nations Sustainable Development Goals adopted in 2015, specifically target 3.8 on achieving universal health coverage to essential health-care services and 3.4 on reducing premature mortality from noncommunicable diseases by one third by 2030 (13).

In the European context, the Action Plan for the Prevention and Control of Noncommunicable Diseases 2016–2025 (7) sets out European-specific priority areas for making progress towards better noncommunicable disease outcomes. European frameworks for strengthening integrated health services delivery (14) and health systems for better noncommunicable disease outcomes (15) offer guidance on evidence-based tools and strategies. Strategies on women's health (16) and men's health (17) have also identified evidence-based actions towards achieving gender equality in health and well-being.

Diabetes registries and diabetes information systems potentially can improve care outcomes as they promote the management of the disease course, prevent complications, ensure quality, enable trends to be estimated and research to be conducted, decrease health expenditure and inform policies.

Diabetes care requires the tracking and monitoring of many different test results and processes while simultaneously controlling risks to prevent complications. People with diabetes face complex medical regimens and often encounter numerous health professionals responsible for elements of management of the disease and prevention of its complications (18). Diabetes puts a strain on people and health systems, but the scarcity of comparable trend data makes this difficult to assess (19). Civil and vital statistics registration systems routinely collect demography and mortality data (11) but are unable to provide information useful for the management of diabetes and its complications (20). Recent studies show that the implementation of electronic health records is not sufficient to improve the quality of diabetes care (21). The use of a diabetes registry for managing diabetes and preventing its complications by tracking clinical outcomes is widely recommended (18).

Interventions using paediatric diabetes registries are associated with improved glycaemic control and complication screening rates, and reduced hospitalizations (22). Diabetes registries can improve the quality of care and of life by easing the management of the disease, tailoring treatment, preventing complications, enabling patient follow-up and empowering people for self-management (18).

Diabetes registries and information systems strengthen institutional capacity to collect, analyse and use data on the burden and trends of diabetes and its risk factors (20). Comprehensive diabetes data inform policies and measure the scope, inclusiveness, implementation, monitoring and evaluation of policies and programmes (19). Diabetes registries and information systems can provide necessary data for the calculation of costs estimates of the disease, as demonstrated by a study conducted using the Piedmont Diabetes Registry in Italy (23).

Diabetes registries and information systems can also save money. Health-care expenditure for people with diabetes is on average twice as high than for people without diabetes (1). A large proportion of this expenditure is related to the treatment of diabetes complications (24). Diabetes registries and information systems can be used to follow-up patients and refer them to ophthalmologists, podiatrists and specialties for periodic reviews to avoid complications (21).

Diabetes registries and information systems can be used to stratify populations and target high-risk patients, send reminders to patients and provide physicians with feedback on their care – these are all critical aspects of an optimal diabetes registry that can lead to significant improvements in clinical outcomes (25). Other potential benefits include improving communication among health professionals, highlighting areas where better outcomes and efficiency gains can be achieved, facilitating (where they exist) the implementation and assessment of national diabetes programmes and informing future policy developments (25).

The development and implementation of national diabetes programmes and registries has been encouraged since the early 1990s, in alignment with the Saint Vincent Declaration (26).

Despite the potential benefits of diabetes registries and information systems, stakeholders from 23 (in 2011) and 30 (2014) of 47 countries considered their registries to be incomplete (19).

About this document

This overview is followed by the methods applied and the description of preliminary findings. Sections on challenges to ensure the success of diabetes registries and information systems and the benefits derived from their use then are presented. A final remarks chapter discusses emerging policy trends.

Brief descriptions of relevant initiatives in some countries and regions of the WHO European Region are presented throughout the text (Box 1–10).

This is a working document; you can contribute to it by submitting your insights to euncd@who.int.

Methods

The aim of this scoping review of qualitative evidence is to generate an overview of diabetes registries and similar information systems used to manage patients with diabetes and its complications in countries of the WHO European Region.

For the purpose of this review, a diabetes registry is considered as a manually or automatically generated list of people with diabetes, developed as a rule-based system based on specific inclusion criteria. The list can be updated through electronic medical records, laboratory results and/or cross-linked with other patient data panels (18). The clinical and self-management decision-support and reminder systems derived from the diabetes registry constitute a diabetes information system (27). Definitions are described further in a later section.

The potential benefits of diabetes registries and information systems in terms of outcome improvements, assurance of quality, efficiency savings and research development are well documented. Open policy questions nevertheless remain, and these need to be addressed prior to making the decision to invest (or not) in diabetes registries and information systems. These policy questions refer to the main goals of diabetes registries and information systems, type of standardized information needed, ownership, privacy and consent issues around data, data updates and use by different providers and professionals, involvement of people with diabetes, the scope (all types of diabetes), the coverage level (national or subnational population, or facility-level) and the potential linkages to other disease-specific and medical databases (28). An important feature of disease registries is patient-specificity, which allows outcomes to be linked. In many countries, providers submit the numbers of diabetes registrations to the central/national office for epidemiological purposes, but these data are not patient-specific. Providers may also collect clinical information on patients that cannot be linked to outcomes or be used in a functional way due to the lack of a unique identifier number. In addition, the lack of feedback loops and data synthesis tools, like dashboards, hinder their use by health professionals.

This work sought to identify common practices and knowledge gaps and highlight possibilities for alignments within and across the countries.

Sources of data

The sources used are: published academic articles from peer-reviewed journals; publications or official reports from WHO, other United Nations agencies, patient association websites, ministries of health, academia and national institutes of public health; abstracts, posters and presentations to international thematic events; and books or book chapters related to the topic.

Keywords

The keywords were sourced from different publications (29). A search was performed in six selected WHO European Region languages¹ using permutations of the keywords by combining one of *Keywords 1* with one or more of *Keywords 2* (Table 1).

¹ The languages were English, French, German, Italian, Spanish and Russian.

Table 1. Keywords

| Keywords 1 | Keywords 2 |
|---------------------------|--------------------------------------|
| Diabetes | Registry |
| Diabetes mellitus | Register |
| Type 1 Diabetes | Registry system |
| Diabetes mellitus, type 1 | Registry database |
| Type 2 Diabetes | Computerised (Computerized) registry |
| Diabetes mellitus, type 2 | Geographic information system(s) |
| Diabetes Registry | Medical records system(s) |
| Diabetes Register(s) | Data bank(s) |
| Diabetes Registries | Dispensary |
| | Dispensaries |
| | Disease management program(s) |
| | Chronic disease management system(s) |
| | Information (technology) system(s) |

Translation of these keywords into the other five languages are presented in Annex 1 and Annex 2.

Search engines, databases and websites

The following databases and websites were used to identify any relevant materials using the predetermined keywords and the snowballing method: PubMed; Google Scholar; Google (for grey materials from institutional and journal websites); and WHO websites.

Selection process and criteria

Relevant titles and abstracts of all articles identified through the electronic searches were imported into Covidence, and duplicates were automatically removed. All the titles and abstracts were screened for relevance using the inclusion/exclusion criteria below, and full-text articles were retrieved when the material adhered to the inclusion/exclusion criteria, or if it was unclear whether it met the selection criteria. The full text was not retrieved if at least one selection criterion was not met.

The material had to meet all the following *inclusion criteria*:

- it is a published article, report, book, book chapter, presentation or similar, including grey literature;
- the abstract and/or full text is written in any of the six selected WHO European Region languages (English, French, German, Italian, Spanish or Russian);
- the study/research/project evaluated a diabetes registry system, or similar information system, or any of its components (such as the goal of the diabetes registry system, system capabilities, data sources and data elements) rather than solely focusing on the clinical characteristics, risk factors or complications of diabetes;
- the material includes all the keywords used in the search; and
- the study/research/project was conducted in any countries of the WHO European Region.

The material was excluded if it fulfilled one or more of the following *exclusion criteria*:

- the study/research/project was on a non-diabetes disease registry system;
- the study/research/project solely addressed diabetes prevention and control, without including any information about a diabetes disease registry system;
- the study/research/project was conducted outside of countries of the WHO European Region;
- the study/research/project was any of the following types of materials: advocacy or campaign materials; infographics; newsletters; letters/statements/positions; or blog posts; or
- the article was not published in an open-access journal.

Definitions applied

Electronic health record: a standardized database used in health care. It is an automated, paperless and online medical record to which patient medical data are entered by eligible health professionals. Electronic health records contain medical information such as patient vitals, prescriptions, medical histories, diagnoses and surgical notes (30).

Diabetes registries: a diabetes registry is a specific database of people who have been affected by diabetes, including a patient list, laboratory information, disease complications and family history (31).

Information systems (health): these collect data from the health sector and other relevant sectors, analyse the data and ensure their overall quality, relevance and timeliness, and convert data into information for health-related decision-making. They also facilitate monitoring and evaluation, and provide an alert and early-warning capability (32).

Diabetes information systems: building on the above definitions, diabetes information systems are defined as information systems specific to collecting data on diabetes.

National diabetes registry: data are collected at national level, targeting the whole population.

Subnational diabetes registry: a subnational registry collects data only for a defined geographical area within the country.

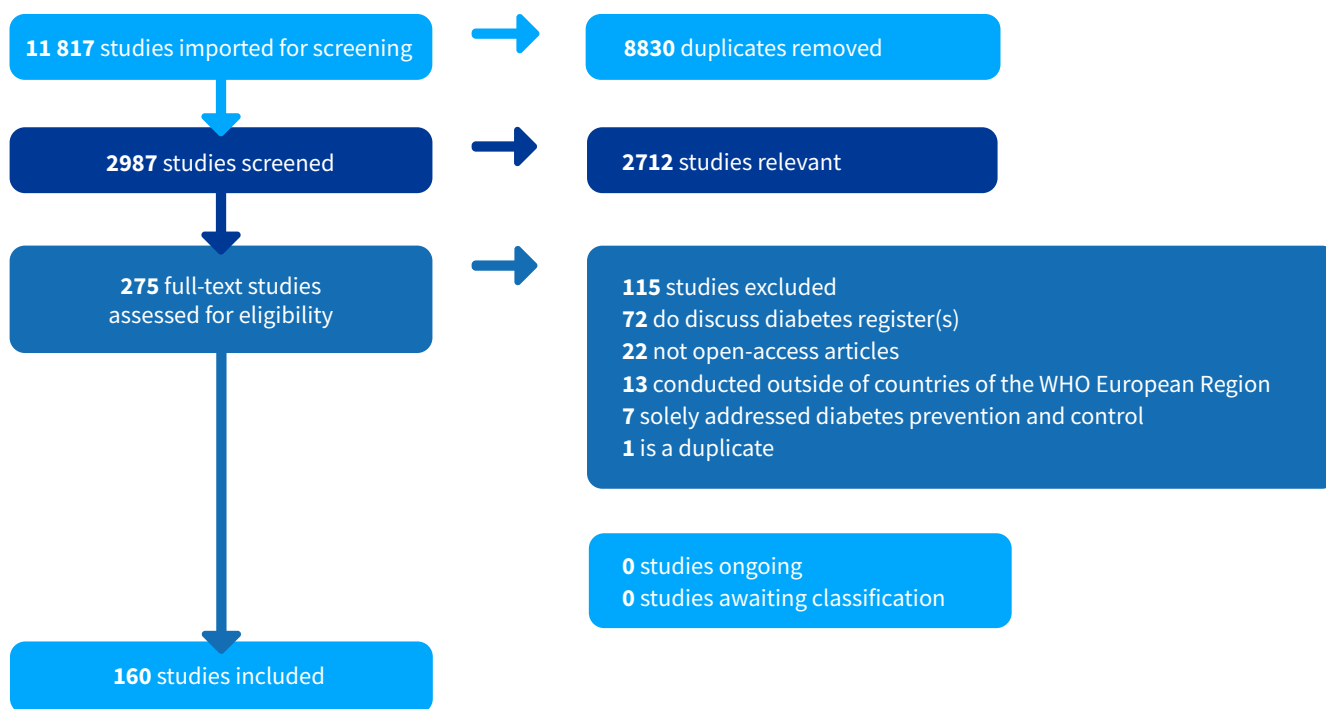
Population-level diabetes registry: population-level registries are either at national or subnational level and contain data pooled from facility-based registries or a population-wide survey.

Facility-based diabetes registry: a registry based within a clinical facility that contains data only on patients of that facility.

Screening process

There were 11 817 citations identified, and after duplicate removal, 2987 citations were assessed. A total of 275 citations was considered relevant to this work. Following a careful analysis and based on the inclusion criteria, 160 citations were included in the scoping review. Fig. 1 provides a visualization of the review process.

Fig. 1. Screening and selection process visualization

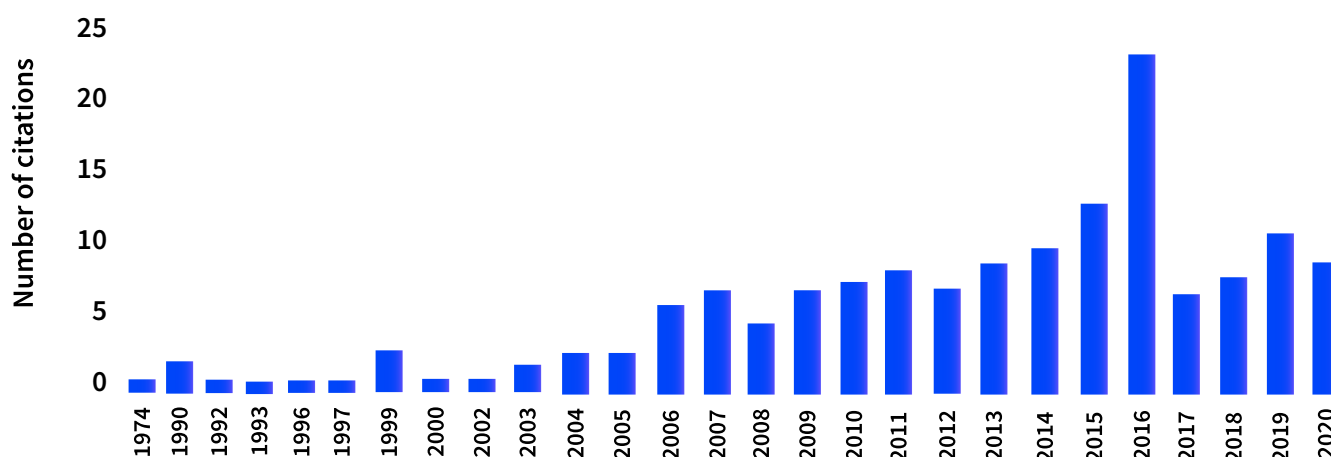


Data extraction

Materials that met the criteria were organized in Covidence. Data were extracted using a predefined form developed in Covidence and an Excel sheet (Annex 3).

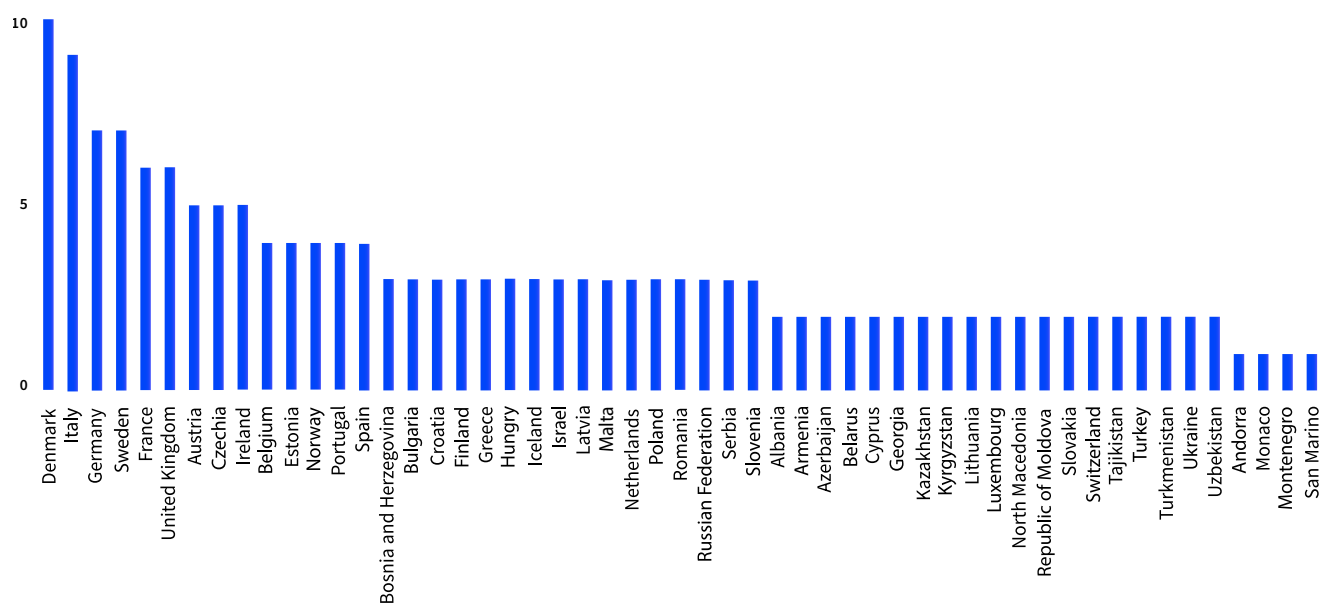
The online search was conducted in June 2020 and yielded 160 citations, which were included in this scoping review. The chronological and geographical distribution of these selected citations are depicted in Fig. 2 and 3.

Fig. 2. Chronological distribution of citations



Data gathered in the extraction step were integrated into an Excel-based file that includes the 53 Member States of the WHO European Region. The file allows for comparisons among national and subnational registries identified in the review. Data about national or subnational registries were identified for all countries included in the study.

Fig. 3. Number of citations per country



Data analysis and validation

Many types of data were captured in the review, including peer-reviewed articles, surveys from institutions, grey literature, proceedings and registrations from meetings and country assessments. For about one quarter (24.5%) of the countries, data collected from different sources did not match and, in most cases, were conflicting. To validate the data, references were cross-checked in a time dimension, with more recent data being considered valid; data were checked against relevant websites and the WHO 2019 Noncommunicable Disease Country Capacity Survey results (33). Once synthesized, findings were reviewed by an expert on diabetes. Information regarding Kyrgyzstan and Uzbekistan were validated by WHO country office national professionals.

Limitations

Limitations are presented in Table 2.

Table 2. Scoping review limitations summary

| Limitation | Comment |
|--------------------|---|
| Timeline | The scoping review was conducted in a short time span. The scoping review process focused on balancing a comprehensive approach and the goals of the review. |
| Representativeness | The data search cannot be considered representative of all national and subnational diabetes information systems in countries of the WHO European Region. |
| Definition | The study considered diabetes registries and related health information systems as defined in the section above. Apart from the diabetes register, the diabetes-specific information system includes dispensary records, the medical records system for diabetes patients (including electronic records) and the chronic disease management system. |
| Language | The search mainly was conducted in English. The other five selected languages were used to uncover details about a registry in a specific country. The abstract and selected text was translated using Google Translate online software. |
| Accessibility | The scoping review utilized only full-text versions from open-access articles. |

Table 2 contd

| Limitation | Comment |
|-------------------|--|
| Disease registers | The scoping review did not consider diabetes registers within the broader context of disease-specific registers, specifically those for cancer, to consider comparability and common issues. |

The limitations described in Table 2 may have resulted in missing registries, particularly at subnational level.

The preliminary findings of this scoping review have not yet been validated by ministries of health.

Information systems and registries for managing diabetes

The characteristics of diabetes registries and information systems uncovered in this scoping review suggest that countries design their registries based on the features of their health systems, which leads to similarities and dissimilarities across countries (34).

Status and features of national diabetes registries and information systems

The results of this review show that out of the 53 countries of the WHO European Region, seven have a national diabetes registry, 21 have a dedicated diabetes registry for certain patient ages or type of diabetes, and 13 do not have a national registry; status is unclear for the remaining 12 countries. Some countries, including France, Greece and Iceland, currently are developing a national registry, while Georgia is developing a subnational registry. Table 3 and Annex 4 provide an overview and details by country.

Table 3. Status and features of national diabetes registries

| National diabetes registry | National diabetes registry for selected age, type or benefits | No national diabetes registry | Not classified ^a |
|----------------------------|---|-------------------------------|-----------------------------|
| Belarus | Austria | Albania | Armenia ^b |
| Croatia | Belgium | Andorra | Azerbaijan |
| Denmark | Czechia | Estonia | Bosnia and Herzegovina |
| Kyrgyzstan | Georgia | Cyprus | Bulgaria ^b |
| Latvia | Hungary | Finland | Greece ^b |
| Sweden | Iceland ^b | France | Kazakhstan |
| Uzbekistan | Ireland | Germany | Malta ^b |
| – | Israel | Lithuania | San Marino |
| – | Italy | Monaco | Serbia ^b |
| – | Luxembourg | Netherlands | Turkey |
| – | Montenegro | Republic of Moldova | Turkmenistan |
| – | North Macedonia | Switzerland | Ukraine ^b |

Table 3 contd

| National diabetes registry | National diabetes registry for selected age, type or benefits | No national diabetes registry | Not classified ^a |
|----------------------------|---|-------------------------------|-----------------------------|
| – | Norway | United Kingdom | |
| – | Poland ^b | – | – |
| – | Portugal | – | – |
| – | Romania | – | – |
| – | Russian Federation | – | – |
| – | Slovakia | – | – |
| – | Slovenia | – | – |
| – | Spain | – | – |
| – | Tajikistan | – | – |

^a Not classified refers to those cases in which, based on the literature reviewed, it has not been possible to attribute the country to one of the other categories. For most of these countries, the information is contradictory, and for others outdated.

^b Some sources report diabetes registries in development.

Cyprus and the Netherlands have policies on privacy and protection of personal data that are preventing the creation of a diabetes registry. Similarly, Finland and Switzerland reported that their current legislation prohibits the creation of disease-specific registries. Czechia, Germany and Italy had project-based registries that possibly are no longer active.

Around 14 countries are reported to have unclear status regarding the existence of a national diabetes registry, because the data collected and/or the follow-up showed conflicting findings.

Status and features of subnational diabetes registries and information systems

Six countries in western Europe – Germany, Italy, the Netherlands, Spain, Sweden and the United Kingdom – have subnational registries (Table 4).

Table 4. Status and features of subnational diabetes registries by country

| Countries | Feature | Comment |
|-----------|---------|---|
| Austria | | Tyrol Diabetes Registry is a project-based registry aimed at improving the quality of care for diabetes patients and obtaining epidemiological information (35). |
| Cyprus | | According to the 2016 and 2019 CCS, there is a subnational registry (19,32,36). |
| Czechia | | The Prague Diabetes Registry is a project-based registry founded in 1989 that includes patients above 18 years with type 1 diabetes. The registry has not been cited since 1993 so it possibly is no longer active (37,38). |

Table 4 contd

| Countries | Feature | Comment |
|----------------|---------|--|
| France | | There is a subnational registry with children under 16 years who had been hospitalized in the Languedoc-Roussillon region from 2003 to 2006. There is also a proposal for the establishment of a registry of diabetes in children and adolescents in three regions of western France (39,40). |
| Georgia | | Some subnational registers for type 2 diabetes in children are also being developed (19). |
| Germany | | There are two subnational registries: the Baden-Württemberg Diabetes Incidence Registry and the North Rhine-Westphalian Diabetes Registry. There is also one registry for children in a particular region, the Childhood Diabetes Registry Saxony (41,42). |
| Italy | | The subnational registries recorded are the Tuscany Diabetes Registry and the Piedmont Diabetes Registry. Italy has two defined registries, the Pavia Type 1 Diabetes Registry and the Regional Registry of Childhood-onset Diabetes (19,23,31,43–45). |
| Romania | | Local lists are kept for adults with diabetes. This is confirmed by the 2019 CCS, which indicates that Romania has a subnational diabetes registry (19,33,46,47). |
| Slovenia | | This study identified two subnational registries: the Diabetes Registry of Slovenia for type 1 diabetes; and a diabetes register for children with diabetes. |
| Spain | | Data on diabetes patients are collected at regional level. There is evidence on the Madrid registry (48,49). |
| Sweden | | The Skaraborg Diabetes Registry for all diabetes patients was identified (45,50–52). |
| Ukraine | | Regional diabetes registries do exist (19,53), but no further information was found. |
| United Kingdom | | There are registries in Wales, Northern Ireland, England and Scotland: the Yorkshire Registry of Diabetes in Children and Young Adults (England); the Scottish Care Information – Diabetes Collaboration database; and the National Diabetes Audit/central diabetes register (Wales) (31,54–57). |

CCS: (Noncommunicable Disease) Country Capacity Survey (WHO (33)).

- Registry for all diabetes patients in a defined geographical unit (subnational registry).
- Subnational registry for defined ages and/or type of diabetes (such as children, type 1 diabetes). It includes databases for patients with dedicated benefits (social, insulin).
- Unclear status.

Box 1. Spain – reconciliation of data at national level

Although there is no national diabetes registry, diabetes data can be retrieved from health surveys conducted nationally every three years, as data are collected at regional level (through the autonomous regions). For instance, the registry of type 1 diabetes mellitus (DM1) aims to analyse the epidemiological characteristics of DM1 and its evolution since 1991 in Aragón. The data are collected through annual notification by primary and secondary sources (49).

Scope of the diabetes registries

The scope of diabetes registries varies across countries. Most countries record type 1 and 2 diabetes in children and adolescents. The registries of diabetes in adults are less consistent: while most countries record type 1 diabetes, fewer record type 2, and only a few record gestational diabetes. Table 5 depicts the specificities by country.

Table 5. Scope of national and subnational diabetes registries by country

| Country | Children and adolescents | | No national diabetes registry | | Complications (32) |
|------------------------|--------------------------|-----------|-------------------------------|-----------|--------------------|
| | Type 1 | Type 2 | Type 1 | Type 2 | |
| Armenia | Not found | Not found | Not found | Not found | No |
| Austria | X | X | X | X | Not available |
| Azerbaijan | X | X | X | X | No |
| Belarus | X | X | X | X | Yes |
| Belgium | X | – | X | – | Not available |
| Bosnia and Herzegovina | Not found | Not found | Not found | Not found | No |
| Bulgaria | Not found | Not found | Not found | Not found | Yes |
| Croatia | X | X | X | X | Yes |
| Czechia | X | X | X | – | Yes |
| Cyprus | Not found | Not found | Not found | Not found | Yes |
| Denmark | X | X | X | X | Yes |
| France | X | X | – | – | Not available |
| Germany | X | X | X | – | Yes |
| Hungary | X | – | – | – | Not available |
| Ireland | X | – | – | – | Not available |
| Israel | X | X | – | – | Yes |
| Italy | X | – | X | X | Not available |
| Kazakhstan | X | X | X | X | Yes |
| Kyrgyzstan | X | X | X | X | Yes |
| Latvia | X | X | X | X | Yes |
| Luxembourg | X | X | – | – | Not available |
| Montenegro | X | – | – | – | Yes |
| North Macedonia | X | – | X | – | Yes |
| Norway | X | X | – | – | Not available |
| Poland | X | X | – | – | Not available |
| Portugal | X | X | – | – | Yes |
| Romania | X | X | X | X | Yes |
| Russian Federation | X | X | X | X | Yes |
| San Marino | Not found | Not found | Not found | Not found | Yes |
| Serbia | X | X | X | X | Yes |
| Slovakia | X | – | – | – | Not available |

Table 5 contd

| Country | Children and adolescents | | No national diabetes registry | | Complications (32) |
|----------------|--------------------------|-----------|-------------------------------|-----------|--------------------|
| | Type 1 | Type 2 | Type 1 | Type 2 | |
| Slovenia | X | X | X | – | No |
| Spain | X | – | X | – | Not available |
| Sweden | X | X | X | X | Not available |
| Tajikistan | Not found | Not found | Not found | Not found | No |
| Turkmenistan | Not found | Not found | Not found | Not found | Yes |
| United Kingdom | X | X | X | X | Yes |
| Uzbekistan | X | X | X | X | No |

Note: no data were found regarding the scope of registries for Ukraine.

Data about the scope of national or subnational registries were identified for 31 countries. All these countries register children and adolescents with type 1 diabetes and 21 record data in adults. Five countries register only children and adolescents with type 1 diabetes.

Uses of diabetes registries

Data about the use of national and subnational registries were identified for 22 countries. Table 6 illustrates the main uses of diabetes registries uncovered by this review.

Table 6. Main uses of national and subnational diabetes registries

| Countries with diabetes registry | Surveillance | Clinical use for patient management ^a | Improving the quality of care | Research | Governance, accountability ^b | Resource/cost estimation |
|----------------------------------|--------------|--|-------------------------------|----------|---|--------------------------|
| Austria | – | – | X | – | – | – |
| Belgium | – | – | – | X | X | – |
| Bulgaria | – | X | – | X | X | – |
| Croatia | X | X | X | X | – | – |
| Czechia | – | – | – | – | X | – |
| Denmark | X | X | X | X | X | – |
| France | X | X | X | X | – | – |
| Germany | X | – | – | X | – | – |
| Hungary | – | – | – | X | – | – |
| Ireland | X | – | – | – | – | – |
| Italy | X | X | X | X | – | – |
| Latvia | – | – | – | – | – | – |
| Luxembourg | X | X | – | X | – | – |

Table 6 contd

| Countries with diabetes registry | Surveillance | Clinical use for patient management ^a | Improving the quality of care | Research | Governance, accountability ^b | Resource/ cost estimation |
|----------------------------------|--------------|--|-------------------------------|----------|---|---------------------------|
| North Macedonia | – | – | – | – | – | – |
| Norway | X | X | X | – | – | – |
| Russian Federation | X | – | X | – | – | – |
| Serbia | X | – | – | – | – | – |
| Spain | | – | – | X | – | – |
| Sweden | X | – | – | – | – | X |
| Tajikistan | – | X | – | – | – | – |
| Turkmenistan | – | X | – | – | – | – |
| United Kingdom | X | X | X | X | – | – |

^a Regarding the generation of lists of patients or registers to support diabetic retinopathy screening, it seems to fall under two columns: (mostly) clinical use for patient management; and (less commonly) improving the quality of care (it is not possible to determine precisely).

^b Governance and accountability include policy development around diabetes, encouraging accountability (such as incentivizing good practice) and the generation of facility-specific annual reports.

Diabetes registries mainly are used for surveillance purposes and over half of the countries use registries for clinical management or for improving the quality of care. Diabetes registries are also used for clinical or epidemiological research.

Some countries use diabetes registries to perform cost estimations and undertake governance and accountability functions.

Box 2. United Kingdom, England and Wales – clinical audits to drive quality improvements

The National Diabetes Audit programme is one of the most extensive annual clinical audits in the world, integrating data from general practice and specialized care sources (58). It measures the effectiveness of diabetes care against the clinical guidelines and quality standards of the National Institute for Health and Care Excellence (NICE). The National Diabetes Audit holds providers accountable for improving outcomes while supporting them through initiatives like RightCare, which supports systems to concentrate improvement efforts where there is the greatest opportunity to improve population health (59).

Coverage of people with diabetes by diabetes registries

Data on the coverage of people with diabetes by the 12 national or subnational diabetes registries are presented in Table 7.

Table 7. Coverage of national and subnational diabetes registries, available countries only

| Country/region | Registry name | Coverage of patients with diabetes |
|----------------|--|--|
| Croatia | Croatian National Diabetes Registry | 20% of all patients with diabetes (46) |
| Czechia | Czech National Childhood Diabetes Registry | 85% of Czech paediatric patients (60) |
| Czechia | Czech National Registry of patients treated with continuous subcutaneous insulin infusion (CSII) | 80–90% of all patients with diabetes (46) |
| Denmark | Danish National Diabetes Registry | Over 90% (61) |
| Denmark | Danish Adult Diabetes Registry | 97% (62) |
| Denmark | Danish Adult Diabetes Database Registry | About 90% (63) |
| Germany | Baden-Württemberg Diabetes Incidence Registry | 90% (41) |
| Germany | Rhine-Westphalian Diabetes Registry | Type 1 diabetes: 72.5% of 18–34-year olds; 24.4% of 17 years or younger Type 2 diabetes: 72% or 77% of 11–18-year-olds (41) |
| Latvia | Registry of Diabetes | 90% (64) |
| Spain | Madrid Registry | 90% (48) |
| Sweden | Swedish National Diabetes Registry | 75% (65) |
| United Kingdom | Scottish Care Information – Diabetes Collaboration database (SCI-DC) | 99.5% of the Scottish population with diabetes (55) |

For those countries listed in Table 7, there is large coverage (over 75%) in most registries.

Sources of data for diabetes registries

Diabetes registries data are gathered using two methods: a *facility-based approach*, which includes people with diabetes treated in a certain facility or by a certain provider; and a *population-based approach*, which includes records for people diagnosed with diabetes who reside within a defined geographic region, allowing the potential to link health information from multiple providers through a unique identifier number (Table 8).

Table 8. Diabetes registry data source

| Population-based | Facility-based |
|------------------------|----------------|
| Azerbaijan | Armenia |
| Bosnia and Herzegovina | Belarus |
| Croatia | Bulgaria |
| Czechia | Cyprus |
| Denmark | Denmark |
| Germany | Germany |
| Israel | Kazakhstan |
| Italy | Kyrgyzstan |
| Latvia | Poland |
| Montenegro | Portugal |

Table 8 contd

| Population-based | Facility-based |
|--------------------------|----------------|
| North Macedonia | Romania |
| Norway | Slovenia |
| Russian Federation | Tajikistan |
| San Marino | Turkey |
| Serbia | Ukraine |
| Spain | |
| Turkmenistan | |
| United Kingdom (England) | |

Source: authors, based on WHO (33).

Other health information systems and their linkages to retrieving data on diabetes

In addition to the registries, countries also retrieve and/or complement diabetes data from other sources such as health information systems, individual health records or other disease or programmatic registries. Table 9 provides some examples.

Table 9. Sample of countries that complement diabetes registry data with other data

| Country | Health information systems used for diabetes |
|---------------------|--|
| Bulgaria | The Bulgarian National Diabetes Registry is linked to outpatient records collected by the Bulgarian National Health Insurance Fund and an existing system of patient registration (19,46). |
| Czechia | The Czech National Registry collects data on patients who receive CSII treatment, which can be used to treat patients with type 1 diabetes (66). The Czech National Childhood Diabetes Registry, ČENDA, is linked to the Czech childhood diabetes incidence registry (60). The registry is also directly connected and synchronized with the electronic health-care system (48). Czechia also has a system for recording patient information that includes noncommunicable disease status, including hypertension, diabetes and tobacco-use status, that has national coverage (33). |
| Croatia | The Croatian National Diabetes Registry (CroDiab) is connected via the CroDiab NET System, which integrates electronic patient records. CroDiab is also linked to CEZIH, a central Croatian electronic public health information system (46). |
| Denmark | Linkage of person-specific data between the registries is possible using the personalized identification number. The Danish National Diabetes Registry is linked to the Danish National Patient Registry and the Danish National Health Service Registry. It builds on data from Danish health registries (63,67). The Danish Adult Diabetes Database (DADD) is linked to the Danish Registry of Causes of Death and the Danish National Patient Registry (68). For the Faroe Islands, data on diabetes are included in the health information system. |
| Latvia | The Registry of Diabetes is part of the united registry of patients with specific diseases. Since 2009, information in the Registry of Diabetes has been compared to the reimbursed medicine database of the National Health Service (19,64). |
| Norway ^a | The Norwegian Diabetes Registry and the Norwegian Childhood Diabetes and Quality project merged and ceased to exist as independent research registries/projects. They are now embedded in the Norwegian Diabetes Registry (69). |

Table 9 contd

| Country | Health information systems used for diabetes |
|---------------------|---|
| Poland ^a | The diabetes registry is linked and synchronized to e-health-care systems, although no single nationwide system exists (46). |
| Serbia | The diabetes registry that is under development is connected and synchronized with the electronic health-care system (46). |
| Sweden | The Swedish system of a personalized identifying number allows cross-linkage with quality registries to other official Swedish statistical platforms (31, 70). |
| United Kingdom | In England and Wales, general practices and specialist services are required to participate in the Core National Diabetes Audit, which measures the effectiveness of diabetes health care against NICE clinical guidelines and NICE quality standards. It is delivered by NHS Digital in partnership with Diabetes UK. It collects and analyses data and produces reports to improve the quality of services and health outcomes for people with diabetes (58). |

^a Classified as “unclear status” given the contradictory information retrieved.

Some countries without diabetes registries gather data on diabetes through generic health information systems. Table 10 provides some examples.

Table 10. Sample of countries without diabetes registries that use other health information systems to retrieve diabetes data

| Country | Health information systems used for diabetes |
|------------------------|--|
| Bosnia and Herzegovina | The Renal Registry of Bosnia and Herzegovina was established in 2002, with the aim of following up the trends of renal replacement therapy in the country. This registry is increasing its inclusion of patients with diabetes, as diabetes is a major cause of end-stage renal disease (71). |
| Estonia | National guidelines exist only for type 2 and gestational diabetes, and there are prevention policies covering all major risk factors (19). Estonia also has a system for recording patient information that includes noncommunicable disease status (including hypertension, diabetes and tobacco-use status) that has national coverage (33). |
| Finland | There are ad hoc initiatives for collection of diabetes data from national and local health information systems and health-care registers: <ol style="list-style-type: none"> 1. the Diabetes in Finland (FinDM) project, which aimed to identify all potential persons with diabetes from national registries in Finland between 1964 and 2017 (72); and 2. the Prospective Childhood Diabetes Registry for 1987–1996, which collected data combining local health-care registers (73). |
| Georgia | Georgia has a system for recording patient information that includes noncommunicable disease status (including hypertension, diabetes and tobacco-use status) that has national coverage. |
| Iceland | Registration of diabetes patients is conducted at local paediatric diabetes centres (19). Iceland also uses standardized registration at the onset of diabetes and at every follow-up visit (74). |
| Portugal | Data on adults are collected via the National Health Service information system, so not all are registered. Portugal also has a national electronic health records system for recording patient information that includes noncommunicable disease status (including hypertension, diabetes and tobacco-use status) that has national coverage (33). |
| Spain | National diabetes data are retrieved from health interviews conducted nationally every three years. Spain also has a national electronic health records system for recording patient information that includes noncommunicable disease status (including hypertension, diabetes and tobacco-use status) that has national coverage (32). |

Table 10 contd

| Country | Health information systems used for diabetes |
|-------------|--|
| Switzerland | Various initiatives exist to collect health data on certain population groups living with diabetes (19), but further details about these initiatives could not be found. Switzerland does not have a system for recording patient information that includes NCD status (including hypertension, diabetes and tobacco-use status) (33). |
| Turkey | Data on diabetes patients are collected via the health information system (19). Turkey also has a national system of electronic health records with patient information including noncommunicable disease status (including hypertension, diabetes and tobacco-use status) (33). |

Initiatives to establish intercountry diabetes registries

The diversity of the data collected for diabetes registries, alongside variations in collection methodologies and definitions, have prevented the collation of data across countries and the Region. The integration of registries with electronic health record functions and aggregation of regional registry data for national or international analysis and benchmarking require, among other things, the use of standards and interoperability across technologies. Data standards can also support the development of new registries by allowing reuse of elements, definitions and systems that often take months or years to develop (21). Understanding of the sources and flows of data and how the sponsors overcome structural, institutional and financial barriers would provide useful lessons for initiatives aimed at aggregating databases. Despite these challenges, this review identified a number of intercountry initiatives.

SWEET – Better control in Paediatric and Adolescent diabetes: Working to create CENTers of Reference

SWEET (Better control in Paediatric and Adolescent diabetes: Working to create CENTers of Reference), a large international multicentred paediatric diabetes registry for children with diabetes, was launched in 2008 (75). The aim of SWEET was to improve secondary prevention, diagnosis and control of all types of diabetes in children and adolescents, including those of rare form, by supporting the development of centres of reference for paediatric and adolescent diabetes services across the European Union. The project, initially funded by the European Union, ended in 2011, though the network (SWEET e.V.) became a registered charity with close ties to scientific organizations such as the International Society for Paediatric and Adolescent Diabetes and nongovernmental organizations like the IDF. This network continues to work to sustain and expand the current high-quality professional network for the treatment and care of children and adolescents with type 1 diabetes, based on agreed standards of care, international guidelines and quality control (76).

EUBIROD – European Best Information through Regional Outcomes in Diabetes

The European Union, under the Health Information Strand of the Public Health Programme of DG-SANCO, ran the EUBIROD project from 2008 to 2012. It was built upon the information system realized by the Best Information through Regional Outcomes (BIRO) project. BIRO – building a shared European diabetes information system – worked on the principle of privacy by design for cross-border flow of diabetes information between 19 European countries (77). The objective of the project was to build a common European infrastructure for standardized information exchange in diabetes care, and monitoring, updating and disseminating evidence on the application and clinical effectiveness of best practice guidelines regularly. A plan was developed based on the adoption of a system approach to make the best use of different sources of information, the promotion of efficient use of available resources using systems already in place at regional level, and implementation of technical solutions

to build comprehensive reports on a range of outcomes (78). EUBIROD was later transformed into a non-profit network that includes 15 countries and other associated registries.

REal World INformation for Diabetes and Associated Complex condITions (REWIND&ACT)

The European Parliament Resolution of 14 March 2012 (2011/2911 RSP) (79), addressing the European Union diabetes epidemic, called for:

the [European] Commission to draw up common, standardised criteria and methods for the data collection on diabetes, and, in collaboration with the Member States, to coordinate, collect, register, monitor and manage comprehensive epidemiological data on diabetes, and economic data on the direct and indirect costs of diabetes prevention and management.

In response to this call, IDF is leading a coalition to develop and submit a proposal regarding the establishment of a European diabetes register.

CoviDiab project

It is still unclear how SARS-Co-2, the virus that causes COVID-19, impacts diabetes. A news release from King's College London, United Kingdom, in June 2020 (80) stated:

Clinical observations so far show a bi-directional relationship between COVID-19 and diabetes. On the one hand, diabetes is associated with increased risk of COVID-19 severity and mortality. Between 20 and 30% of patients who died with COVID-19 have been reported to have diabetes. On the other hand, new-onset diabetes and atypical metabolic complications of pre-existing diabetes, including life-threatening ones, have been observed in people with COVID-19.

Also in June 2020, The CoviDiab project, a collaborative international research initiative, announced the establishment of a global registry of new cases of diabetes in patients with COVID-19. The registry is designed specifically to establish the extent and characteristics of new-onset COVID-19-related diabetes and investigate its pathogenesis, management and outcomes (81). By establishing this global registry, the research initiative is calling on the international medical community to rapidly share relevant clinical observations that can help answer the most pressing questions about the bi-directional relationship between diabetes and COVID-19 (80).

The European Reference Networks

Launched in 2017, the European Reference Networks (ERNs) are virtual networks involving health-care providers across Europe. They aim to facilitate discussion on complex or rare diseases, including rare forms of diabetes, and conditions that require highly specialized treatment, concentrated knowledge and resources. The ERN on rare forms of diabetes serves epidemiological purposes, such as establishing the number and types diagnosed per year, and gathers professionals from different countries through discussion fora on diagnostic tools, treatment and results (82).

The following are potential challenges or barriers countries face in developing, implementing and utilizing diabetes registries.

Challenges to diabetes registry success

Regulatory frameworks

Regulatory frameworks can halt the creation of diabetes registries (19); for example, legislation prohibits the creation of disease-specific registers in Finland and Switzerland. Political will, strategic vision and the involvement of stakeholder representatives from patient groups, providers and industry can be utilized to develop new policies for disease-specific registries to ensure their success (83).

Unclear ownership and privacy policies

Box 3. Finland – overcoming legislative limitations

Finland's current legislation prohibits the creation of disease-specific registries. Data on diabetes were collected via studies combining local health-care registries. The one instance when a diabetes-specific registry was created and used was from 1987 to 1996, collecting data on 3613 childhood diabetes cases (84). Today, Finland uses a Finnish population-based registry to track type 1 diabetes cases and evaluate mortality rates. This registry was established by linking the Finnish Hospital Discharge Registry with the Social Insurance Institution Central Drug Registry using the unique personal identification numbers recorded in both registers. Data on hospitalizations were obtained from the Finnish Hospital Discharge Registry (84).

The insufficient use of medical records can be attributed to increasing concerns over privacy and the lack of standardized approaches to secure data transmission. There is a pressing need to secure trust in how data are collected and used (69). The growing number of sources of diabetes data increases concerns over ownership and privacy. Legal arrangements on ownership and protection of personal data prevent the creation of countrywide registers, transnational registries and cross-border data-transfer. Disease registries require a posted privacy policy. The privacy policy should include pertinent details such as the purpose of the registry, who will have access to data, how the data will be used and how the potential registrant can withdraw from the registry (83). Patients' consent to inclusion on the registry should be obtained unless there is a good reason not to do so (85). Ultimately, people with diabetes will value data collection when they see that their data are secure and their use translates into better outcomes (83). Clear links of data to the information chief authority, research ethics committees and arrangements for accessing data, security, accountability, reporting and publication should be elicited to ensure trust (85).

Box 4. Germany – advocacy for optimizing health outcomes

Germany has multiple subnational registries in North-Rhine-Westphalia, Baden-Wuerttemberg and Saxony. These registries include children and adolescents with type 2 diabetes and adults with type 1 diabetes. Overall, coordination between primary and specialist care is ensured by disease management programmes that offer people with diabetes tailored treatments and ensure close monitoring by specialists. A vast majority of people with diabetes who participate in disease management programmes assess the quality of the programmes and their output positively (83). Currently, people with diabetes are advocating for more information concerning their health outcomes and the use of tools that enable the tracking of the effectiveness of their treatment to optimize health outcomes.

Insufficient allocation of resources

Many countries have limited resources allocated for disease-specific registries, or activities related to diabetes screening, education and training. For this reason, some countries have prioritized the development of child and adolescent registries, usually associated with type 1 diabetes. Many countries have invested in dedicated projects to create registries based on sunset funding. Other countries need to address silos in funding to successfully develop and implement diabetes registries (83).

Box 5. Portugal – priority given to children

Portugal has a national diabetes registry for children. Data on adults are collected through the national health service information system, but not all are registered. Private health providers are not required to share patient information.

Lack of international consensus on standards

The absence of consensus on definitions, data-collection methods and data reporting across countries makes it difficult to determine a country-specific diabetes registry. Countries need to move towards generating and implementing standardization of registry data, and put in place appropriate data-sharing platforms and governance structures (20), including standardization of case definitions and clinical diagnostic criteria (21). This kind of approach can be more effective than conducting pilot projects based on different standards (86).

Box 6. Sweden – multistakeholders accessing online indicators and target time series

The Swedish National Diabetes Registry has been using indicators, including HbA1c, blood pressure, blood lipids, statin treatment, use of glucose sensors and insulin pumps, that can be consulted through its online platform since 2002 (83). The personal identifying number enables cross-linking of registries with other official statistical platforms, adding significant value. The use of a simple and clear feature, known as the button, makes it easy to access data for all interested stakeholders, including clinicians and patients, and allows clinicians quickly to follow up on targets over time and compare patients against their peers (83).

Ineffective technological capacity

The analysis of immense volumes of data is key to the success of a diabetes registry, and integrated online systems can encourage the exchange of data in real time. In reality, diabetes registries are often appended to existing clinical systems or are not integrated into existing workflows (18), often aggravated by outdated software in public services and limited access to technology in remote areas. The interoperability between registries and electronic health records and vice versa and the transfer of data to new health providers raise governance challenges in the establishment and management of registries (21). The National Health Service in the United Kingdom currently has inadequate interoperability across digital systems (19,31,57). In Spain, data are collected at regional level (through autonomous regions) and periodically collated via health surveys. France is developing a health data hub as a platform for making health data available to health providers (87).

Box 7. France – Diatabase: an interoperable integrated platform

The French health system has a large amount of data on diabetes. These data currently are used mainly to target the at-risk population with prevention and education campaigns on diabetes. With this kind of data, the French health system could go further and propose personalized health assistance. In 2018, the Médecine de Santé: Prédicative, Préventive, Personnalisée, Participative (M4P) Consortium, supported by the Ministry of Economy and Finance, launched a clinical database on diabetes called Diatabase, which aimed to improve care, knowledge, information sharing and research on diabetes (88). The database is populated by information from several sources, including hospitals, community medicine and research centres, has connected objects and is cross-referenced with data from the National Health Data System and economic databases. The success of the initiative depends on the ability to make the data collected interoperable, and M4P has given itself three years to build Diatabase and to make it available for use to serve health professionals and patients (89).

Disempowerment of health professionals

The lack of timely patient data increases the workload of health professionals, who consequently have to repeat the recording of information. Diabetes registries and information systems, rather than providing a solution, can pose an overwhelming task. This can be overcome by, for example, designing and implementing feedback systems (such as dashboards) that synthesize data and signpost critical patients. The use of data for clinical management and quality improvement generates learning loops and increases the quality of data.

Additional benefits from diabetes registries

Empowering patients to improve their health and well-being

A well functioning diabetes registry can support physician adherence to standards of care and promote patient compliance with medications and behavioural changes (21). Linking registries to mHealth interventions can optimize self-management in people living with diabetes by enabling them to have access to information and experts from their homes, schools and workplaces. A recent study on mobile phone messaging applications, including short- and multimedia-message services, suggests that these interventions present convenient, cost-effective ways of supporting self-management and improving patients' self-efficacy skills. Their knowledge of diabetes did not increase, but patients receiving text messaging improved their self-management (90).

Box 8. United Kingdom, Scotland – My Diabetes, My Way

The Scottish Care Information Diabetes Collaboration (SCI Diabetes) provides a national online database of people with diabetes to streamline patients' journeys between primary and secondary care. SCI Diabetes is considered one of the most comprehensive databases in the world. Since its inception, it has provided 99.5% coverage of the Scottish population with diabetes. Another long-standing programme, My Diabetes, My Way, is an award-winning national electronic personal health record and self-management platform for diabetes patients in Scotland launched by National Health Service Scotland and the University of Dundee. It provides information on diabetes, medication and broader effects. It also provides access to medical records to help facilitate more personalized care (91,92). Collecting diabetes data has helped highlight critical issues, such as differences in outcomes between specialty services, and between younger and older people with diabetes, and people with different types of diabetes. It has also revealed the effectiveness of specific policies, including the rising number of people being checked for HbA1C, and areas in need of improvement, such as fewer than 10% of people with diabetes attending a structured education course in 2016/2017 (93).

Fostering dialogue among people with diabetes and health professionals to increase health literacy and enhance clinical decisions

The dialogue between health professionals and people with diabetes is facilitated by data provided by registries and other diabetes information systems that support patient management. At policy level, this can translate into overviews of clinical parameters and patient-reported outcomes that provide a more comprehensive picture of the efficacy and effectiveness of diabetes care (91). For example, a programme of data- and experience-sharing in Ipswich, England (United Kingdom) allowed participants to map treatments to the most appropriate professionals and settings and, ultimately, improved outcomes (94).

Box 9. Italy – stakeholder initiatives for establishing subnational registries

The national registry for type 1 diabetes mellitus was established in 1996 to coordinate existing registries for incidence and promote the establishment of new registries in regions that lacked one. The project included the Italian Society of Diabetes and the Paediatric Italian Society of Endocrinology and Diabetes (95).

Informing health services and integrating care for diabetes, promoting more efficient care pathways

Improved data collection on diabetes will help policy-makers understand the extent of the problem and health professionals to take steps towards early detection, treatment and resource allocation (19). A national database of patient data can be used to streamline decision-making and facilitate collaborative working between general practice and specialized care. Using health-outcomes data has been shown to improve the prevention of complications through a reduction in diabetes amputation and retinopathy requiring laser treatment rates throughout informatics implementation and data usage (55).

Box 10. Bulgaria – the use of the diabetes registry to reward general practice

The national diabetes registry was generated in 2015 from outpatient records collected by the Bulgarian National Health Insurance Fund. It is based on an existing system of patient registration, which avoids putting an extra burden on health professionals (83). The registry captures epidemiological and complications data and supports the study of diabetes and cardiovascular complications, as well as life expectancy. The Ministry of Health uses the registry to reward general practitioners for performance (83).

Final remarks

Strengthening health systems for diabetes care and prevention of its complications is a global and European priority in the pursuit of better diabetes health outcomes. A strategy to tackle diabetes and its consequences should provide specific epidemiological data and useful differential reporting to all stakeholders, including policy-makers, community authorities, people with diabetes and health professionals. Diabetes registries may contribute to addressing these needs.

Diabetes registries and diabetes information systems potentially can improve care outcomes as they promote the management of the disease course, prevent complications, ensure quality, enable trends to be estimated and research to be conducted, decrease health expenditure and inform policies.

The aim of this scoping review of qualitative evidence was to generate an overview of diabetes registries and similar information systems used in countries of the WHO European Region. The registries and information systems vary across the Region due to historical reasons, purposeful design, data sources, and technological and regulatory differences. Most countries record type 1 and 2 diabetes in children. Diabetes registries are used mainly for surveillance and over half of the countries use registries for clinical management or for improving the quality of care. Diabetes registries are also used for research. Some countries use diabetes registries to perform cost estimations and strengthen governance. The lack of agreed standards for data collection has prevented the aggregation of data within and across countries. In the absence of diabetes registries per se, countries use information systems creatively in supporting diabetes care and preventing complications.

Challenges that stand in the way of registries' success include current regulatory frameworks, unclear ownership and privacy policies, insufficient allocation of resources, lack of international consensus on standards and ineffective technological capacity. Indirect benefits from diabetes registries include empowering patients to improve their health and well-being, fostering dialogue among people with diabetes and health professionals, informing health services and integrating care for diabetes.

Diabetes registries require strong links with broader health information platforms and systems to be sustainable over time. In this way, they benefit from information technology advances using dynamic data integration, such as linkage to other registries (renal, vascular and dialysis registries), electronic health records, electronic patient registration systems, patient management systems and personal health records (96). Recognizing that benchmarking is a useful resource for quality improvements and focusing on diabetes health outcomes would accelerate the adoption of shared indicators by different stakeholders. Despite the potential advantages, diabetes registries are not found as commonly as registries for other conditions, such as cancer.

Consultation with national authorities to confirm findings is needed, as is further analysis to understand the upstream causes in national contexts.

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Annex 1. Keywords 1: selected languages

| English | Italian | Spanish | French | Russian | German |
|--------------------------|----------------------------------|--------------------------|-------------------------|------------------------|--|
| Diabetes | Diabete | Diabetes | Diabète | диабет | Diabetes |
| Diabetes mellitus | <i>Diabete mellito</i> | Diabetes mellitus | Diabète mellitus | Сахарный диабет | Mellitus Diabetes |
| Diabetes mellitus type 1 | Diabete mellito di tipo 1 | Diabetes mellitus tipo 1 | Diabète mellitus type 1 | Сахарный диабет 1 типа | Diabetes mellitus Typ 1 |
| Type 1 diabetes | Diabete di tipo 1 | Diabetes tipo 1 | Diabète de type 1 | Диабет типа 1 | Diabetes Typ 1 |
| Diabetes mellitus type 2 | <i>Diabete mellito di tipo 2</i> | Diabetes mellitus tipo 2 | Diabète mellitus type 2 | Сахарный диабет 2 типа | Diabetes mellitus Typ 2 |
| Type 2 diabetes | <i>Diabete di tipo 2</i> | Diabetes tipo 2 | Diabète de type 2 | Диабет типа 2 | Typ 2 Diabetes |
| Diabetes registry | Registro Diabete | Registro de diabetes | Registre du diabète | Реестр диабета | Diabetes-register |
| Diabetes registries | Registri del diabete | Registros de diabetes | Registres du diabète | Реестры диабета | Diabetesregister |
| Diabetes register(s) | <i>Registro(i) del diabete</i> | Registro(s) de diabetes | Registre(s) du diabète | Регистр(ы) диабета | Diabetes Register <i>Diabetesregister</i> |
| AND | e | Y | et | и | Und |

Annex 2. Keywords 2: selected languages

| English | Italian | Spanish | French | Russian | German |
|----------------------------------|--|--|---------------------------------------|---|---|
| Registry | <i>Registro</i> | Registro | Enregistrement | реестр | Registrierung |
| Register | Registriati | Registrarse | Registre | регистр | Registrieren |
| Registry system(s) | Sistema(sistemi) di registro | Sistema(s) de registro | Système(s) d'enregistrement | Система регистрации Системы регистрации | Registrierungs- system(e) |
| Registry database(s) | <i>Database di registro</i> | Base(s) de datos de registro | Base(s) de données du registre | База данных реестра Реестр баз данных | Registrierungs- datenbank(en) |
| Computerized registry | <i>Registro informatico</i> | Registro informatizado | Registre informatisé | Компьютеризированный реестр | Computergestützte Registrierung |
| Geographic information system(s) | Sistema d'informazione geografica <i>Sistemi di informazione geografica</i> | Sistema(s) de Información Geográfica | Système(s) d'information géographique | Географическая информационная система Геоинформационные системы | Geographisches Informationssystem Geografisches Informationssystem |
| Medical records system(s) | Sistema (sistemi) di cartelle cliniche | Sistema(s) de registros médicos | Système(s) de dossiers médicaux | Система медицинских карт Системы медицинской документации | Krankenakten-System(e) |
| Data bank(s) | Banca dati Banche dati | Banco(s) de datos | Banque(s) de données | Банк(и) данных | Datenbank(en) |
| Dispensary | Dispensario | Dispensario | Dispensaire | диспансер | Apotheke |
| Dispensaries | dispensari | Dispensarios | Dispensaires | Диспансеры | Apotheken |
| Disease management program(s) | Programma di gestione delle malattie Programmi di gestione delle malattie | Programma(s) de manejo de enfermedades | Programme(s) de gestion des maladies | Программа управления заболеваниями Программы по борьбе с болезнями | Disease- Management- Programm(e) |

Annex 3. Data extraction fields

The Covidence form includes the following fields.

*The material's title and full-text link will automatically be included.

- Type of material
- Abstract language
- Full-text language
- Brief description (aims and objectives)
- Study setting
- Name of the lead author
- Institution of the primary author
- Publication year
- Publisher

The Excel sheet includes the following fields.

Per country, please answer the following when possible.

- Is there an official national or regional diabetes registry in the country?
- Current status of the diabetes registry or potential diabetes registry? (For example, active, inactive, in preparation, etc.?)
- Are there any known barriers to the preparation and introduction of a diabetes registry?
- Reference(s)
- Publication year(s)

*If yes or being prepared.

- The registry title/name
- Aim of the registry
- Location
- Registry data source(s)
- Data collection process
- Who started the registry and/or when?
- Who is the registry administrator?
- Who is paying for the maintenance of the registry?
- Who is authorised to input the data into the registry?
- Is data input obligatory?

If obligatory, what are the measures if the authorised person(s) does not use input data?

- Any data collection or reporting standards?
- Are there any quality control measures for the registry?
- If yes, what are the quality control measures?
- How is personal data safety secured?
- What kind of data is included in the registry system?

- How is the registry used?
- Is the registry directly connected or synchronized with an electronic health record in the country or other registries? If yes, which system(s)?
- What percentage of all patients with diabetes are already included in the national registry?
- Is it a population-based or clinical system?
- What are the relevant diabetes societies or association(s)?
- Comments

Annex 4. Status and features of national diabetes registries by country

| Countries | Feature | Comment |
|------------------------|---------|---|
| Albania | | A national diabetes registry was planned for 2012 but no further progress has been reported. In 2014, it was reported that stakeholders were discussing this possibility with national authorities (1–3). |
| Andorra | | (2,4). |
| Armenia | | Stakeholders reported that a national diabetes registry exists but it is incomplete (1,2,5). |
| Austria | | The Austrian Diabetes Registry is a national registry for children with diabetes. The 2019 CCS indicates that there is no national diabetes registry (1,2,6,7). |
| Azerbaijan | | Stakeholders reported that the registry might be incomplete (1,2,8). |
| Belarus | | The national diabetes registry includes people with type 1 and type 2 diabetes. Stakeholders reported that the registry might be incomplete (1,2,9). |
| Belgium | | The Belgian Diabetes Registry includes newly diagnosed people with diabetes aged under 40 years, mainly with type 1 diabetes. According to the 2019 CCS, there is no national diabetes registry (1,2,10,11). |
| Bosnia and Herzegovina | | The 2016 WHO DCP indicates that a diabetes registry exists but no further details have been found (2,12,13). |
| Bulgaria | | A national working group was established to develop a registry, but stakeholders reported no further activity since 2014. The 2016 DCP indicates there is no registry while the 2019 CCS indicates that there is one (1,2,14,15). |
| Croatia | | The Croatian National Diabetes Registry was founded in 2000 with the aim of improving the health care of people with diabetes, including its complications (14,16–20) (see further details in Table 3, main text). |
| Cyprus | | According to the 2016 DCP there is a national registry but it is incomplete because the participation of private providers is voluntary and some groups contest the collection of patient data (1,21) (see further details for subnational registries in Table 2, main text). |
| Czechia | | The Czech National Childhood Diabetes Registry (ČENDA) focuses on treatment and outcome data of children and adolescents (0–19 years) with any type of diabetes treated at one of the participating outpatient clinics (6,14,22–24) (see further details for subnational registries in Table 2, main text). |

| Countries | Feature | Comment |
|------------|---------|--|
| Denmark | | Seven diabetes registries were identified: the Danish National Diabetes Registry (NDR), the Danish Adult Diabetes Registry (DADR), the National Ophthalmological Diabetes Database, the Paediatric Diabetes Database, the Danish Childhood Diabetes Registry (DIA-REG B&U), the Danish Registry of Childhood and Adolescent Diabetes (DanDiabKids), and the Danish Adult Diabetes Database (DADD) (1,6,25–32). |
| Estonia | | See further details in Table 3, main text (1,33,34). |
| Finland | | The country does not allow disease-specific registries. In 2014, it was reported that stakeholders were discussing the possibility of establishing a national registry with national authorities (1,35,36) (see further details in Table 3, main text). |
| France | | A multi-source diabetes database called Diabase is expected to be operational by 2021. It will comprise data from hospitals, practices and research centres and be cross-referenced with the medical–economic databases of the National Health Data System. A type 1 diabetes registry was maintained from 1988 until 1997 (1,37–39) (see further details for subnational registries in Table 2, main text). |
| Georgia | | A national diabetes registry was designed to include people with diabetes who are on insulin, supporting the procurement and provision of medications by the state. According to the 2016 DCP and 2019 CCS, there no national diabetes registries (1,2,40). A registry for type 2 diabetes in children is being developed (1). |
| Germany | | The DiaRegis was a project-based registry that included adults with type 2 diabetes from 2009 to 2010. It is likely this is no longer active. The 2016 DCP and 2019 CCS indicate that there is no national diabetes registry (2,6,41–44) (see further details for subnational registries in Table 2, main text). |
| Greece | | A national diabetes registry for diabetes patients under 18 years is being developed. This diabetes registry was piloted from January to December 2017 to test its validity (1,45,46). |
| Hungary | | The Hungarian Childhood Diabetes Registry is designed to include children under 15 years with newly diagnosed type 1 diabetes. The 2016 DCP and 2019 CCS indicate that there is no diabetes registry (2,14,47). |
| Iceland | | According to the 2014 IDF report, there is a national registry for type 1 diabetes, based on the records of the national reference hospital. According to the 2016 DCP and 2019 CCS, there is no diabetes registry (1,2,48,49) (see further details in Table 3, main text). |
| Ireland | | The Irish Childhood Diabetes National Registry (ICDNR) includes patients under 15 years who have type 1 diabetes. According to the 2016 DCP and 2019 CCS, there is no diabetes registry (1,2,50–53). |
| Israel | | The national diabetes registry includes children with diabetes. The Ministry of Health indicates that this registry had been extended to include adults, but stakeholders could not confirm (1,14,54). |
| Italy | | There was a project-based national type 1 diabetes registry – the Registry for Insulin-dependent Diabetes Mellitus (RIDM) – which included data from seven Italian regions and five provincial registries. The aim was to coordinate existing registries for the incidence of type 1 diabetes and promote the establishment of new registries in uncovered areas (1,6,55–58) (see further details for subnational registries in Table 2, main text). |
| Kazakhstan | | A national registry is designed to include people diagnosed with diabetes but is reported to be incomplete. According to the 2016 DCP, there is a diabetes registry, but further details have not been found (1,59). |

| Countries | Feature | Comment |
|---------------------|---------|---|
| Kyrgyzstan | | The national registry has been established and is designed to include people diagnosed with diabetes, but it is reported to be incomplete (1,60). There have been several attempts to integrate the diabetes registry into the e-health national system. Currently, all outpatient visits are recorded in the clinical information system. |
| Latvia | | The registry was established in 1997 by the Latvian Association of Endocrinologists. According to regulations, family doctors must report newly diagnosed diabetes patients annually, except for those with gestational diabetes, and provide updated information on previous cases. Although formal validation studies have not been performed, the completeness of the Diabetes Registry has been examined regularly since 2007 by comparing records with the database of reimbursed medication prescriptions and questioning prescribing physicians if unregistered patients are found. Its primary focus is clinical parameters, and the registration includes neither socioeconomic nor lifestyle factors (1,61,62). |
| Lithuania | | (1,2,63). |
| Luxembourg | | A registry is available for children with diabetes. It is based in the national children's hospital, Luxembourg City, the national reference hospital. According to the 2019 CCS, there is no diabetes registry (1,2). |
| Malta | | According to 2014 IDF report and 2016 DCP, there is a national diabetes registry but it is incomplete. According to the 2019 CCS, there no registry (1,2,64,65). |
| Monaco | | (2) |
| Montenegro | | The Montenegro Childhood Diabetes Registry has included children with type 1 diabetes since 1982 (66,67). |
| Netherlands | | Efforts for a national registry for type 1 diabetes were made in 2015 but legal frameworks on privacy and protection of personal data prevent the creation of disease-specific national registries (64,68) (see further details for subnational registries in Table 2, main text). |
| North Macedonia | | The national registry covers people on insulin therapy, mainly to monitor the cost of insulin therapy (type 1) (1,69). |
| Norway | | The Norwegian Childhood Diabetes Registry is for all types of diabetes, children and adolescents. This is confirmed by the 2016 DCP. The 2019 CCS reports that the country does not a registry (1,2,64,70,71). |
| Poland | | As of 2014, there has been a diabetes registry for children and for existing and gestational diabetes in pregnancy. According to the 2016 DCP and 2019 CCS, there is no diabetes registry in the country (1,2,14,72). |
| Portugal | | The registry tracks the prevalence of type 1 diabetes in children and young people (1,73,74) (see further details in Table 3, main text). |
| Republic of Moldova | | (1,2,75) |
| Romania | | There is a national diabetes registry for children that is updated every year (1,14,76) (see details for subnational registries in Table 2 and Table 3 for other types of information systems (main text). |
| Russian Federation | | The federal diabetes registry includes children and adolescents with diabetes (6,77–79). |
| San Marino | | Data indicate that there is a diabetes registry, but no further details can be found (80). |

| Countries | Feature | Comment |
|----------------|---------|--|
| Serbia | ■ | A diabetes registry has been designed but has not been introduced into practice (1,14,81) (see further details in Table 3, main text). |
| Slovakia | ■ | There is a national registry for children with type 1 diabetes (1,82). |
| Slovenia | ■ | There are two registries: diabetes registry for type 1 diabetes; and diabetes registry for children with diabetes (1,83,84). |
| Spain | ■ | There is a registry of type 1 diabetes (1,85) (see details for subnational registries in Table 2 and Table 3 for other types of information systems (main text)). |
| Sweden | ■ | Two national registries were identified: the Childhood Diabetes Registry; and the National Diabetes Registry (NDR). The NDR, initially designed for patients with type 1 diabetes, has included patients with type 2 diabetes since 2000 (6,48,86–89). |
| Switzerland | ■ | Current legislation prohibits the creation of disease-specific registries (1,90) (see further details in Table 3, main text). |
| Tajikistan | ■ | A national diabetes registry ensures the provision of social support and pharmaceuticals such as free insulin (91,92). |
| Turkey | ■ | Data indicate that there is a diabetes registry, but no further details can be found (1,93). |
| Turkmenistan | ■ | All data indicate that there is a diabetes registry, but no further details can be found (94,95). |
| Ukraine | ■ | There is a national diabetes registry, but it is incomplete. The registry has not been endorsed by the Ministry of Health (1,96). |
| United Kingdom | ■ | According to the 2016 DCP and 2019 CCS, there is a central (national) diabetes registry, hospital-based (2,97). The United Kingdom also has local (subnational) registries (see further details for local registries in Table 2, main text). |
| Uzbekistan | ■ | There is a national registry (1,2,98). |

CCS: WHO (Noncommunicable Disease) Country Capacity Survey, 2019 (2).

DCP: WHO diabetes country profiles, 2016 (99).

IDF: International Diabetes Federation (1).

- National registry for all ages and types of diabetes.
- National registry for defined ages and/or type of diabetes (such as children, type 1 diabetes). It includes databases for patients with dedicated benefits (such as social, insulin).
- No national registry.
- Unclear status.

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The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health.

The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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