Diabetes Registries

Enabling high quality diabetes care

European
Diabetes Forum

EXECUTIVE SUMMARY

Diabetes registries, which collect, track, and analyse patient data on parameters ranging from clinical characteristics, risk factor control indicators, diabetes complications, and treatments, can become an essential tool for improving the quality of diabetes care and securing better outcomes for people with diabetes when integrated in the diabetes care system.

Registries enable evidence-based approach to diabetes management. They ensure quality control and better adherence to guidelines; track performance across clinics or regions and help identify the sources of variation in outcomes; and inform the delivery of care and treatments, which can reduce costly complications.

Yet despite all these benefits, registries are severely underutilised across Europe, with only a handful of countries with national diabetes registries. Given the growing burden of diabetes and the mounting costs to individuals, families, societies, all stakeholders to work together to advance the integration of registries in the diabetes care systems throughout Europe.

There are many political and logistical challenges to realising this vision, but the most important thing is to get registries started –depending on the country in regional settings at first, and then – when successful – to expand nationally.

The European Diabetes Forum, a representative group comprising healthcare professionals, researchers, industry associates, and people with diabetes, have compiled recommendations on building, maintaining, and utilising registries, outlining general principles and guidance on issues related to governance, data collection, and structure and scope. As always, it takes more than just a diabetes registry to improve care. Registries must be designed and used not just for data generation, but always with the goal of improving outcomes for people with diabetes.

RECOMMENDATIONS

1. DEVELOP PROCEDURES AND GOVERNANCE MODELS FOR REGISTRIES
2. ENSURE ROBUST COVERAGE AND COMPLETE DATA FLOW
3. MAINTAIN FLEXIBLE AND ADAPTABLE REGISTRIES
4. DEVELOP IMPLEMENTATION STRATEGIES

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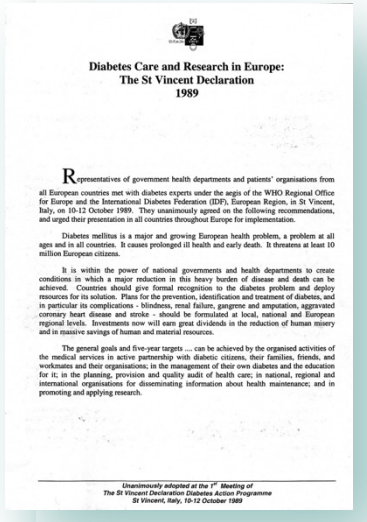
INTRODUCTION

Registries, which collect, measure, and report health data on parameters ranging from clinical characteristics, risk factor control indicators, diabetes complications, and treatments, are an increasingly vital part of the diabetes landscape.

In 1989, health officials, patient representatives, and experts from across Europe gathered in Italy to discuss joint approaches to address the growing threat of diabetes. The participants of the conference issued the landmark St. Vincent Declaration, which called for establishing better monitoring mechanisms and control systems to prevent the emergence of costly complications in diabetes.

From this declaration, several countries began to implement diabetes registries. Registries, which collect, measure, and report health data on parameters ranging from clinical characteristics, risk factor control indicators, diabetes complications, and treatments, are an increasingly vital part of the diabetes landscape. Registries have the potential to help ensure quality control and adherence to guidelines when integrated in the health care system. Registries highlight existing inequalities, and by providing useful insights into the linkages between different forms of care or treatments, can improve diabetes care delivery, and in turn reduce disabling and costly complications.

Given the complexity of diabetes, registries – when integrated in the healthcare system – promote a more evidence-based approach to disease management. As a chronic condition, diabetes is associated with serious complications resulting in high morbidity and mortality. This makes registries in diabetes care settings all the more crucial as they help track variables on metrics like glycated hemoglobin (HbA1c), blood pressure and lipid control that enable doctors and people with diabetes to more effectively manage their condition.



Diabetes Care and Research in Europe:
The St Vincent Declaration
1989

Representatives of government health departments and patients' organisations from all European countries met with diabetes experts under the aegis of the WHO Regional Office for Europe and the International Diabetes Federation (IDF), European Region, in St Vincent, Italy, on 10-12 October 1989. They unanimously agreed on the following recommendations, and urged their presentation in all countries throughout Europe for implementation.

Diabetes mellitus is a major and growing European health problem, a problem at all ages and in all countries. It causes prolonged ill health and early death. It threatens at least 10 million European citizens.

It is within the power of national governments and health departments to create conditions in which a major reduction in this heavy burden of disease and death can be achieved. Countries should give formal recognition to the diabetes problem and deploy resources for its solution. Plans for the prevention, identification and treatment of diabetes, and in particular its complications - blindness, renal failure, gangrene and amputation, aggravated coronary heart disease and stroke - should be formulated at local, national and European regional levels. Investments now will earn great dividends in the reduction of human misery and in massive savings of human and material resources.

The general goals and five-year targets ... can be achieved by the organised activities of the medical services in active partnership with diabetic citizens, their families, friends, and workmates and their organisations; in the management of their own diabetes and the education for it; in the planning, provision and quality audit of health care; in national, regional and international organisations for disseminating information about health maintenance; and in promoting and applying research.

Unanimously adopted at the 1st Meeting of The St Vincent Declaration Diabetes Action Programme St Vincent, Italy, 10-12 October 1989

St. Vincent Declaration

"Establish monitoring and control systems using state of the art information technology for quelling assurance of diabetes health care provision and for laboratory and technical procedures in diabetes diagnosis, treatment, and self-management."

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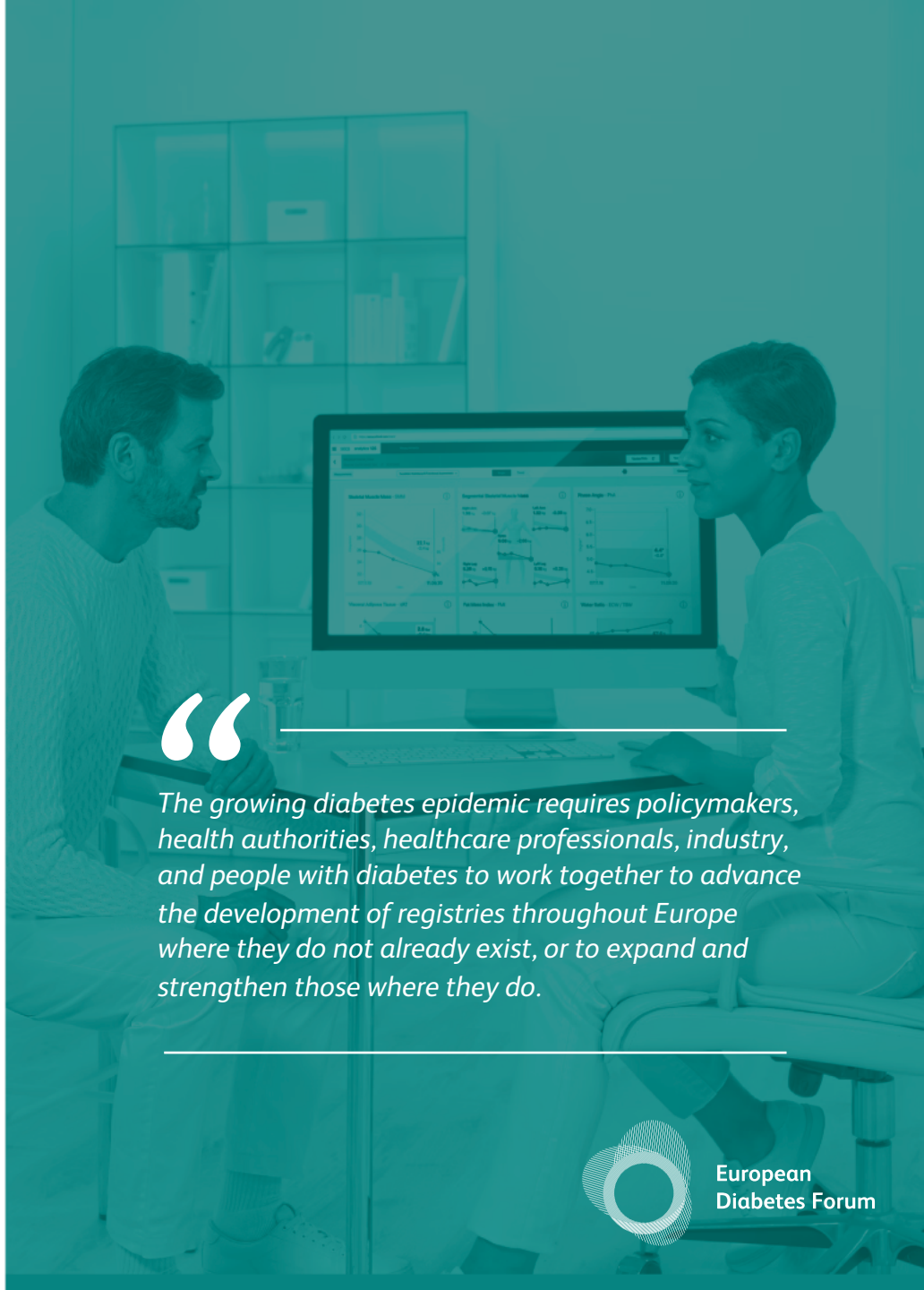
Yet for all their value, registries remain severely underutilised in health systems across Europe, and indeed across the world.

Very few countries in Europe have operational diabetes registries in place. Even among those that do, the registries are most often not integrated in the health care system, or are incomplete, whether because the data is not used effectively, or because registries are confined to certain regions rather than scaled up nationally or are primarily used for epidemiologic research purposes.

The status quo is no longer viable or acceptable. In the decades since the St. Vincent Declaration, the number of people with diabetes and the impact to health and society has only multiplied. Progress is halting. There is a widening gap between scientific advances and clinical practice. Sadly, achieved clinical outcomes haven't improved over the last decade despite regular updates of the evidence-based guidelines and enhanced access to effective medicines.

The growing diabetes epidemic requires policymakers, health authorities, healthcare professionals, industry, and people with diabetes to work together to advance the development of registries throughout Europe where they do not already exist, or to expand and strengthen those where they do. Diabetes registries are not a luxury; they should be considered an indispensable piece of the healthcare system and an integral aspect in diabetes care.



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ABOUT REGISTRIES

WHAT ARE REGISTRIES?

A patient registry is an organised database that contains information about people that share a specific health characteristic or disease, or subject to a particular procedure or therapy.

A diabetes registry is not a static entity but a living instrument. A registry only becomes meaningful if the data is properly analysed and used to inform better care standards and procedures.

For example, for diabetes, writing down blood glucose levels is of little use if the numbers are not then used to adjust medication accordingly in order to improve control.

HOW DO REGISTRIES WORK?

Well-functioning registries automatically integrate data from many different sources – primary and specialist physicians, via electronic medical records, prescription data, emergency outpatient data, pharmacy data. Each patient has a unique identifier code, which links the information across all the different points of care.

WHAT INFORMATION IS COLLECTED IN DIABETES REGISTRIES?

While different diabetes registries may differ on the details, there is a certain data set that is generally agreed as the minimum standard. The data collected in diabetes registries can be divided in three categories: demographics, process- and outcome indicators.

Process indicators track treatments or examinations specific to diabetes. Examples are the number of HbA1c measurements, or foot and eye examinations. Outcome indicators include clinical data (body weight,HbA1c, blood pressure and lipids) and the presence of complications (i.e. retinopathy, or cardiovascular disease). Demographic data involves non-diabetes specific metrics like age, gender and ethnicity.

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THE VALUE OF REGISTRIES

Registries provide many benefits for many different stakeholders in the diabetes landscape. The most important goal and the rationale for registries is to improve outcomes and reduce the risk of complications for people with diabetes.

Registries accomplish this objective in several ways, by monitoring performance, tracking the extent with which clinics or hospitals are adhering to guidelines, identifying sources of variation in outcomes, and informing processes and decision-making.

- Benchmarking
- Monitoring, surveillance, & health-care planning:
- Patient Empowerment
- Real World Evidence
- Research

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THE VALUE OF REGISTRIES

MONITORING, SURVEILLANCE, AND HEALTHCARE PLANNING

Registries can facilitate the implementation of guidelines in diabetes care and help ensure high quality standards are being followed.

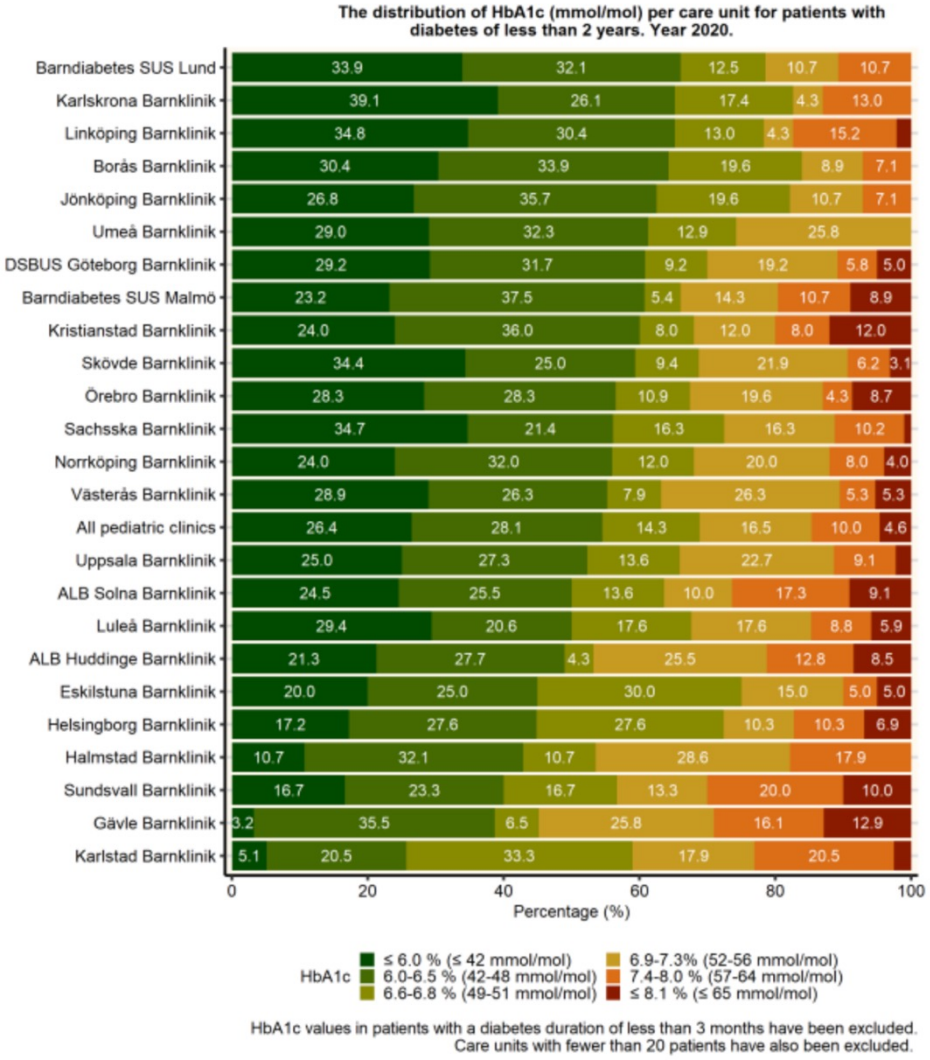
Registries provide useful information for policymakers and public health authorities – by shedding light on the larger trends in quality criteria of diabetes care, and revealing whether targets are being reached over time.

Registries can be used to formulate strategic objectives. Registries enable policymakers to more effectively allocate resources by offering insights into which innovations or treatments have a positive impact. Over time, registries make it easier to monitor the effects of these investments and modify these accordingly.

BENCHMARKING

Registries can sort information geographically. That means they enable performance comparisons between different clinics, hospitals, and/or regions. These comparisons can trigger assessments of what is either going right or wrong. Adjustments can be made, and resources and attention reallocated, accordingly. Registries can therefore play an important role in reducing inequalities between different regions.

Benchmarking can also unleash a healthy competitive spirit among healthcare providers and between different clinics and regions. Peer comparison feedback has been shown to lead to improvements in care by tapping into a professional desire to perform well and maintain standards. Comparison can inspire discussions how to improve.



Benchmarking is a key pillar of Sweden's diabetes registry – sharing data, comparing performance, learning from one another, and making changes to improve care (see more in best practices, page 11, below).

Source: www.ndr.nu/pdfs/Annual_Report_Swediabkids_2020.pdf

BENEFITS TO PEOPLE WITH DIABETES

People with diabetes benefit from registries through improved health system performance and disease management. But registries can also engage people with diabetes to play a more active role in their own care.

Diabetes is a very complex disease, and despite the best efforts of countless health professionals – largely a self-managed one. Patients with access to registries can see their own data and more importantly compare their results with others. This can enable a more informed exchange with clinicians.

REAL WORLD EVIDENCE

Registries can also play an important role in real world evidence generation; this is of special interest following the introduction of novel medicines or technologies where the question is whether the benefits and risks observed in registration trials can be replicated in a real-world setting. The long-term follow-up from data in the clinical setting provide information about the effectiveness and safety of novel interventions.

RESEARCH

Registries can be a rich source for diabetes research. Researchers can glean insights into incidence, prevalence, or the epidemiology of diabetes and related complications, and draw inferences from this these data in ways that can inform feedback into better treatments or care delivery.

Registries can make it simpler and more cost-effective to find representative cross-section of patients to participate in clinical trials by providing a platform for recruitment.

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CHALLENGES IN CREATING REGISTRIES

POLITICAL WILL

It takes time, effort, and expense to get diabetes registries off the ground. Moreover, their benefits are not always readily visible to decision-makers at the outset. Registries need to have buy-in from all stakeholders, and this requires sustained advocacy.

Establishing registries is not just act of political will, it is also an organizational and logistical challenge, given all the parties involved, and the technical specifications required.

REAL-TIME DATA

For a registry to function effectively, data must be continuously updated in real time, and it must reflect the latest information. This process should be as simple as possible for overburdened healthcare providers, and, unfortunately, this is not usually the case. Complex processes for manually adding data in a registry have a negative impact both on the maintenance of an up-to-date registry and, eventually, the quality of the data added to it. Therefore, where data input is still manual, the collection of data, and in particular the real-time data, will be challenging.

REGULATORY

From the regulatory standpoint, the GDPR (general data protection regulation) poses challenges in terms of data exchange and collaboration. The correct systems and rules need to be in place to leverage data from registries.

DATA QUALITY

The quality of measurements, and the comprehensiveness of the information, rely on local standards and procedures, which can differ according to local contexts. Lack of standardised methodologies challenges the quality of the collected data, and by extension their usability and usefulness.

EDUCATION AND TRUST

In general, there is a lack of awareness on the benefits and the possibilities of registries. Moreover, in the digital age, citizens have grown increasingly weary of sharing their data.
Data registries raise important issues about ensuring proper handling of data in due in respect for data privacy and security. Therefore, an important part of establishing a registry is a mechanism to ensure data privacy compliance.

DIGITAL INFRASTRUCTURE

In some countries, the digital infrastructure for registries needs to be improved.

INCENTIVES

Physicians have a personal and professional incentive to do what is best for their patients and are interested in their level of performance relative to others. But time is also finite and to ensure the sustainability of registries, additional incentives are needed.

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PUTTING THE DATA TO GOOD USE

Setting up a registry and collecting data is only one part of the challenge.

The most important step is what you do with this information. Collecting data just for recording's sake them does not produce any tangible outcomes for people with diabetes. Processes must be put in place to ensure data is regularly reviewed and changes in clinical practice are implemented based on key findings.

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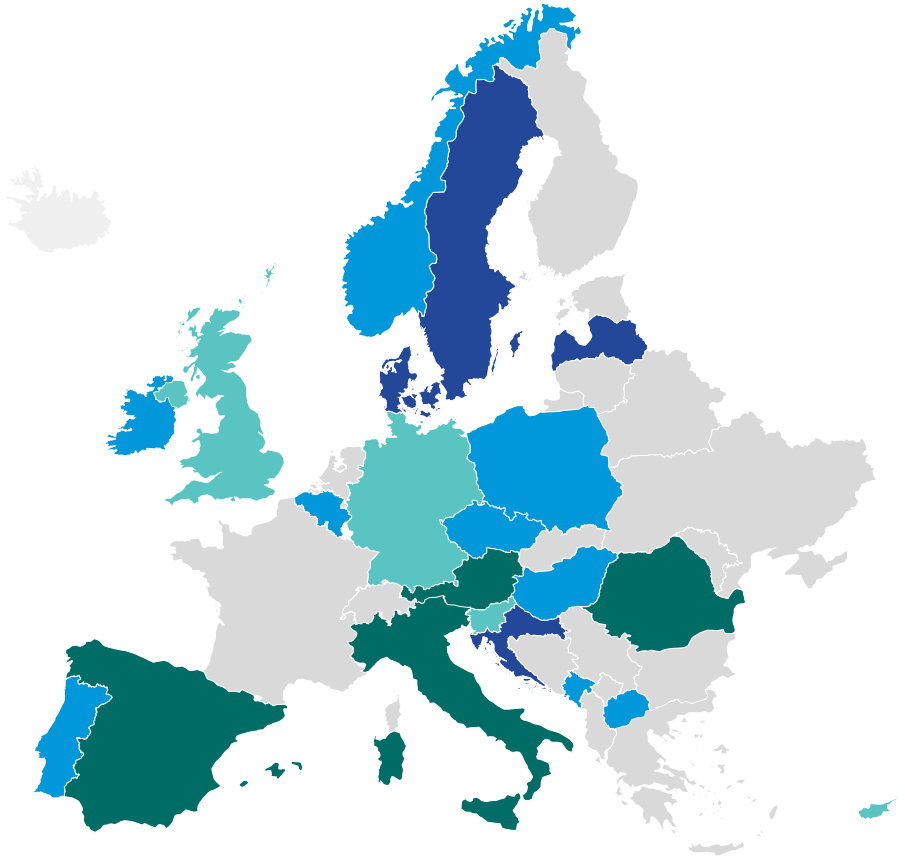
Despite their numerous benefits, there are very few national diabetes registries in Europe which cover all or the majority of people with diabetes. Some countries have subnational registries at the regional or state level.

More countries have national registries for selected age, type or benefits, but these tend to be selective. For example, many countries record Type 1 diabetes. Others tend to record type 1 and 2 diabetes nationally, but only for children and adolescents.



NATIONAL REGISTRIES

Croatia
Denmark
Latvia
Sweden

SUBNATIONAL REGISTRIES

Austria
Germany
Italy
Spain
Romania
United Kingdom

NATIONAL DIABETES REGISTRY FOR SELECTED AGE, TYPE OR BENEFITS

Austria
Belgium
Czech Republic
Hungary
Ireland
Italy
Luxembourg
Montenegro
North Macedonia
Portugal
Romania
Slovenia
Norway
Slovakia
Poland
Spain

National registries

Subnational registries

Selective national registries
(For example, children or Type 1 diabetes)

Subnational registries and a selective national registry

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

www.euro.who.int/__data/assets/pdf_file/0003/505371/registries-information-systems-diabetes-consultation-eng.pdf

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BEST PRACTICE EXAMPLES

SCOTLAND

Scotland has an electronic health platform called SCI Diabetes that is used for general management of care for people with diabetes. Data is collected and recorded in a standardised fashion.

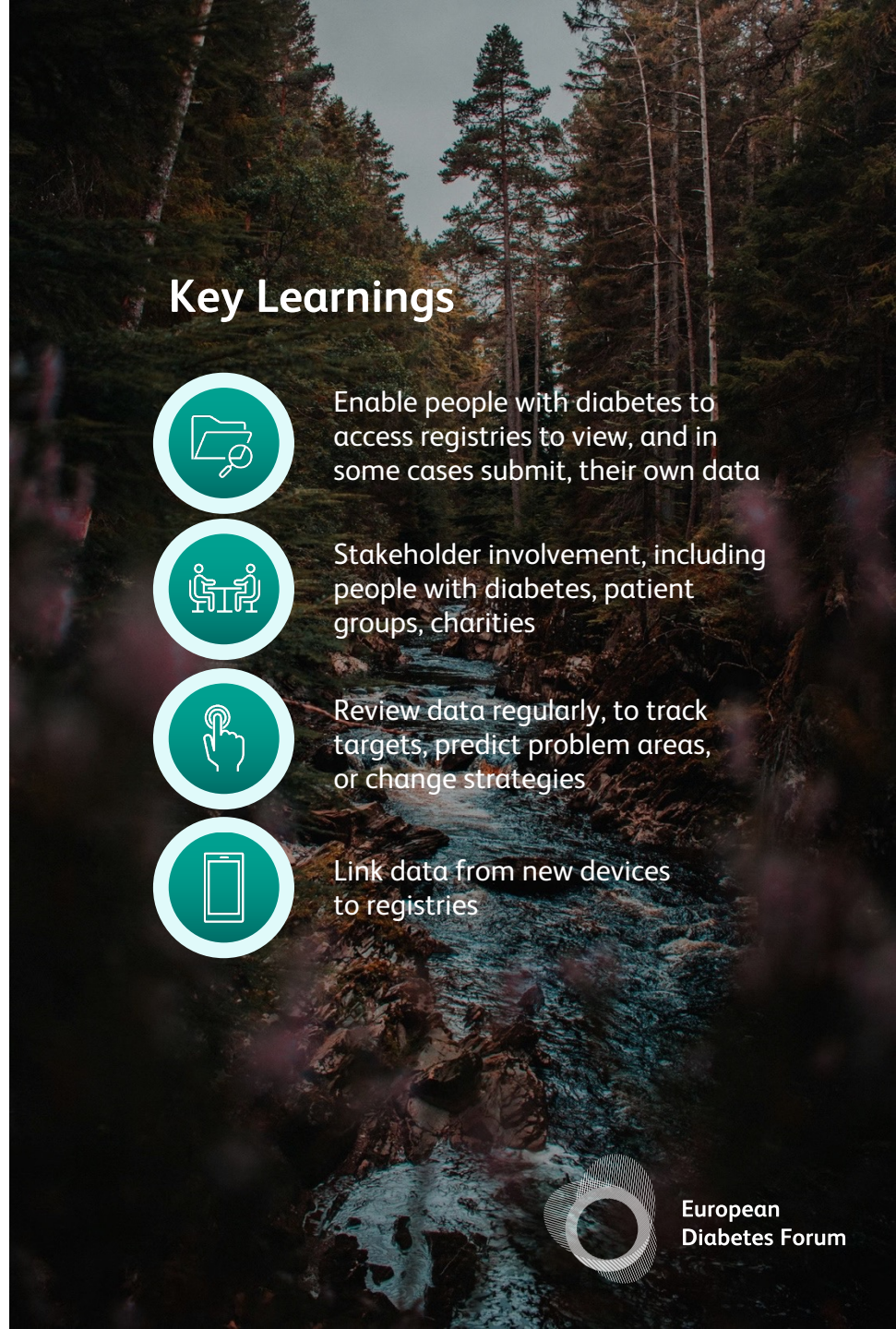
The data is registered automatically when a diagnostic code is generated in primary care. The data is held at a centralised Health Board level, but is federated to allow for queries across all of the boards simultaneously.

In Scotland it is understood that registries alone do not suffice. Rather, it is the extent the data in registries is analysed, and the key findings translated, in ways that influence patient care.

Each year, Scotland produces a diabetes report assessing whether it has been successful reaching its targets. Every care unit gets fed back its data, and there is a direct dashboard for each unit to compare their performance with another. For example, it is possible to identify units where glycaemic controls are an outlier in relation to other units.

While the primary goal is improving outcomes and care, the Scottish registry also has procedures in place to use registries for research purposes. Anonymised data is regularly transferred to a local safe haven for such research purposes, where all personalised identifiers have been stripped away to assure privacy.

Another key element of the Scottish system is the way in which there is constant interaction between the clinical epidemiologists who understand the provenance of the data, the software developers who can array it properly, and the analysts who crunch the data for data reports.



Key Learnings

- Enable people with diabetes to access registries to view, and in some cases submit, their own data
- Stakeholder involvement, including people with diabetes, patient groups, charities
- Review data regularly, to track targets, predict problem areas, or change strategies
- Link data from new devices to registries

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SWEDEN

Sweden's National Diabetes Register (NDR) was launched in 1996 and has since become a very rich source of high quality, representative data which has been used to drive improvements in care and reduce complications for people with diabetes.

The Swedish registry covers 90 % of all people with both Type I and Type II diabetes. All information is transferred from hospital records, outpatient files, and primary care clinics. 70 % of the information is automatically transferred into the registries, while 30 % is entered manually. The registry includes all clinically relevant variables, in line with national guidelines. The goal of the registry is high coverage and high acceptance of requested variables, rather than including all the possible variables that might be of any clinical interest.

Clinics in Sweden run quality circles, benchmarking the performance of centres against other centres. Registries often inspire discussions among diabetes teams on how to improve the quality of care.

Since 2017, pilot units in Sweden have begun to use patient-reported experience measures (PREMS) and patient-reported outcome measures (PROMS) data to more fully assess quality of care from a patient's perspective.

The NDR is online and fully accessible to clinics to monitor their results and compare their statistics to the national average in real time. The data allows different clinics to contrast their outcome indicators to the national average. Data from this population based registry has been used to publish seminal scientific papers describing the natural course of the disease and the occurrence of complications in Sweden.

Key Learnings

- Focus on clinically relevant variables, which are easy to input and access
- Discuss results from registries local, regional, & national diabetes meetings
- Interactive statistical reports make for easier benchmarking
- Ensure access and involvement for people with diabetes

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SWEET REGISTRY

SWEET (Better control in Pediatric and Adolescent diabetes: Working to create centers of reference), a large international multicentered pediatric diabetes registry for children with diabetes, was launched in 2008. Presently it contains data from 90,000 participants and one million visits from 120 centers on all continents, with 60 % of them located in Europe.

The aim of SWEET was to improve secondary prevention, diagnosis and control of all types of diabetes in children and adolescents, by supporting the development of centres of reference for paediatric and adolescent diabetes services across the European Union based on agreed standards of care, international guidelines and quality control. 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 (ISPAD).

The use of a unified electronic data-reporting system, easy-to- analyse, customisable benchmarking dashboards combined with peer-review visits have been identified as success factors. This approach demonstrated a sustained improvement of several outcome measures over the last decade, evenly distributed throughout all paediatric age-groups.

Challenges include the sustainability of these quality control measures as their reimbursement is not an integral part financed on center or patient level in most countries.

In addition the network allows analyzing the impact of general health threats like the COVID-19 pandemic or the introduction of new therapeutic options for the treatment and care of children and adolescents with type 1 diabetes.

Key Learnings

- Ensure financial sustainability of registries, as a long-term solution
- Translate data into health interventions, with the involvement of people with diabetes
- Use easy-to-analyse, customisable benchmarking dashboard

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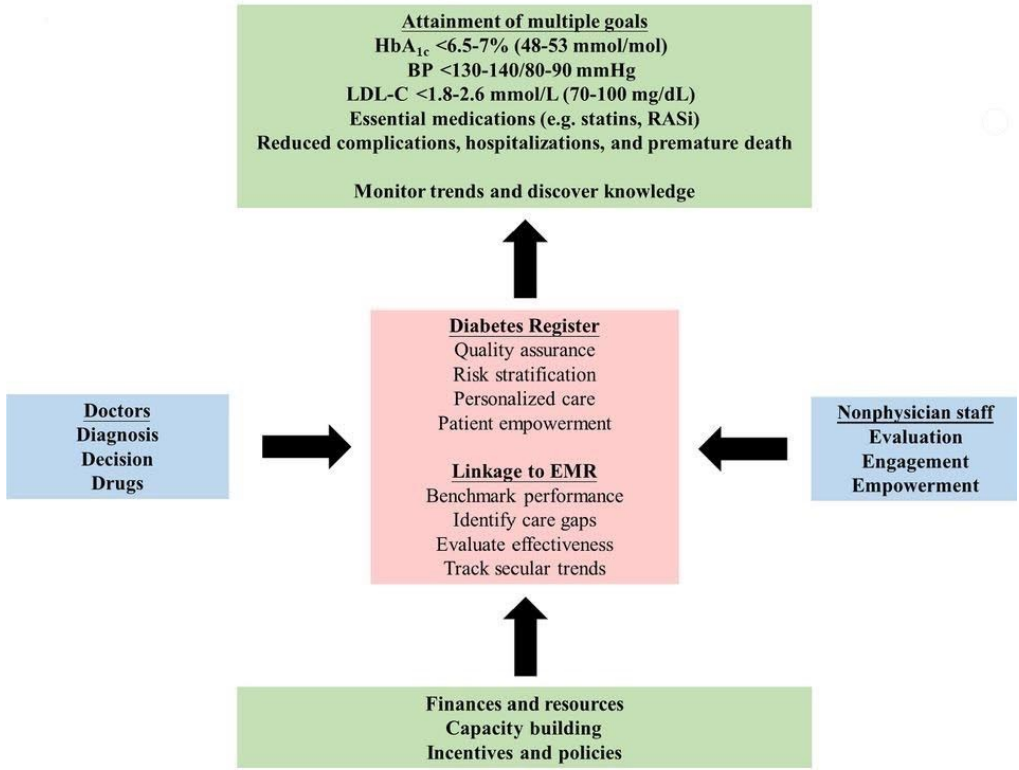
HONG KONG

Hong Kong established its diabetes registry in 1995 and it has since become an essential and integral element of its diabetes care.

Hong Kong's registry again shows the importance of this link between measuring and registering variables, and then using this data to introduce necessary changes in the delivery of diabetes care. Hong Kong's experience is evidence that the introduction of an integrated registry results in substantial improvements in long term outcomes.

In Hong Kong, this works as a continuous feedback loop. Variables included in the registries are informed by the guidelines, and targets are set for clinics as a way of measuring success. The guidelines are updated regularly to take into considerations the most recent and relevant variables and patient outcomes.

Another key lesson of the Hong Kong registry is the importance of identifying medical champions, to spread the word to a broad base of nurses and physicians, both to get registries off the ground, and cement them as part of the functioning of the system. Once the registries are operational, these champions can play a role in governance, whether it be supervising and interpreting the data, influencing payers, and more.



The concept of the multicomponent integrated care model

Hong Kong Diabetes Register to JADE Program to RAMP-DM for Data-Driven Actions. Diabetes Care 2019;42(11):2022–2031; https://doi.org/10.2337/dci19-0003

Key Learnings

- Continuous feedback loops between variables collected in the registry and guidelines
- Identify medical champions to spearhead registries

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KEY PRINCIPLES OF REGISTRIES

Best practice examples like Sweden, Scotland, Hong Kong, or SWEET already serve as a guidepost for registries. While each country will have to adapt to fit local habits and cultures, there are a series of general principles which widely apply.

1. BUILDING A REGISTRY

All relevant stakeholders should be involved in a registry to mobilise the political will and achieve the necessary buy-in.

Registries should start small, in a select number of clinics, and with a select number of variables, and then expand. Avoid the tendency to try to gather all possible information, and focus on that which is most relevant. Risk factors that are linked to outcomes – Hb1c, blood pressure, lipids, statin use, smoking – are the priority. Over time, indicators can be added, as needed.

Registries may decide to include quality of life metrics and the patient view by incorporating PREMS and PROMS data, as part of a more holistic approach to understanding diabetes, but that something to consider over the medium to long-term, and is not immediately essential.

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2. MAINTAINING A REGISTRY:

Data entry must be as easy as possible and simple to navigate. Data must also link up different parts of the healthcare system. **Moreover, registries must be sustainable**, which usually requires putting long-term funding and incentives in place to ensure active participation.

A registry should be operated by an institutional, not private, authority. Patients should own their data.

Patients organisations should be closely involved.

3. USING A REGISTRY:

Registries need to be part of the integrated care process and multifunctional (i.e. not just for research or benchmarking purposes).

Data should be transparent and registries act as quality measurement standards to compare clinical performance between clinics, with a regular publication of data per unit (e.g. yearly). There should be ongoing reviews and data should be pored over in regular local, regional, and national meetings.

Registries should be equally accessible to patients, scientists, interested HCPs and payers.

Patients should own their data, and the data must be secure. While people with diabetes are usually then eager to participate, ultimately, there should be an opt-out clause if necessary.

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RECOMMENDATIONS

1 DEVELOP THE RIGHT PROCEDURES AND GOVERNANCE MODELS FOR REGISTRIES

Create a governance structure, a body that will ensure data is handled properly, carefully, and in adherence to legal requirements

Create an inclusive, multi-disciplinary Executive Committee, comprised of the main stakeholders, including people with diabetes and representatives from multi-disciplinary teams

- The Committee will be involved both in creating the registry (establishing minimum data set, research questions, procedures) and in its continued maintenance and execution. The Committee will ensure the involvement and buy-in from all stakeholder groups. More critically the Committee will ensure that any registry will be integral part of a well-designed healthcare system. The Committee would recommend needed changes in care/ guidelines, based on the results/insights that emerge from the registry. They could also add/subtract parameters as necessary.

Link quality output to allocated funds

There must be economic and non-economic incentives to maintain a high-quality registry.

Results and key indicators on the registry should be accessible

This is important to translate data on the registry to improvements in care, by tracking the performance of care centres and clinics and answering important research questions.

Identify actors that will be accountable for the implementation of registries

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2 ENSURE ROBUST COVERAGE AND COMPLETE DATA FLOW

Ensure all data is uploaded only once, and all systems communicate with each other

- All data must be inputted only once. For example, lab data should be linked to physician dossiers. Ensure all medicines, medical devices, hospitalization data is either on the registry or linked to the registry. Preferably all data should be uploaded automatically.
- The focus of data gathering should be on parameters that are linked to outcomes for people living with diabetes, such as Hb1c, blood pressure, lipids, statin use, smoking.

Develop incentive schemes to ensure participation for all diabetes care teams

- This is to ensure data is regularly updated and registries remain a sustainable and integral part of the diabetes care system.

Create a validation mechanism for these databases to ensure they are capturing all the data correctly

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3 MAINTAIN FLEXIBLE AND ADAPTABLE REGISTRIES

Keep the possibility open that diabetes registries will eventually link to registries of other chronic and non-communicable disease

Establish a unique identifier for patients

- One way of doing this is linking the unique identifier to payment/credit/bank account/national ID/etc. (as in US, for example, with Social Security code).
- Over time, this will enable diabetes registries to link to registries from other disease areas. This also opens up possibilities in terms of utilizing new technologies to analyse public health problems; for example – using geo-mapping to identify areas suffering from diabetes inefficiencies or shortages.

Ensure registries remain adaptable and can be updated with new insights and innovations

- Variables should be able to be updated when clinically relevant. Registries should be sufficiently flexible that their methods can continually be improved.

Develop a European forum to exchange best practices

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4 DEVELOP IMPLEMENTATION STRATEGIES

Mobilise patient organisations and involve people with diabetes in the establishment of registries

Develop communications strategies to convey the value of registries for diabetes care

- Ensure there are clear and transparent educational materials on registries.
- Appeal to the interests of different actors in the health ecosystem.
  Tailor messages to different stakeholder groups, including among people with diabetes.

Design registries so the data is clear and intuitive to interpret, and ensure people with diabetes have access to their own data

- People with diabetes should be able to understand how and why registries function. They should be able to see that the registries are used to improve care

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Recommended Literature EUDF Forum: Data & Registries

- The St Vincent Declaration on diabetes care and research in Europe. Acta diabetologia. 1989, 10 (Suppl) 143-144.
- Define, track, measure and improve - How health data and registries can help improve health outcomes for people with diabetes - EFPIA Round Table in Sweden - June 2019
  efpia.eu/publications/downloads/efpia/define-track-measure-and-improve-how-health-data-and-registries-can-help-improve-health-outcomes-for-people-with-diabetes
- The Lancet Commission on diabetes: using data to transform diabetes care and patient lives Lancet 2020; 396: 2019–82
  https://linkinghub.elsevier.com/retrieve/pii/S0140673620323746
- National diabetes registries: do they make a difference? Acta Diabetologica
  https://link.springer.com/article/10.1007/s00592-020-01576-8
- Cohort profile: National Diabetes Audit for England and Wales
  https://onlinelibrary.wiley.com/doi/10.1111/dme.14616
- Registries and information systems for diabetes care in the WHO European Region: preliminary findings for consultation
  https://www.euro.who.int/__data/assets/pdf_file/0003/505371/registries-information-systems-diabetes-consultation-eng.pdf
- Design and rationale of DISCOVER global registry in type 2 diabetes: Real-world insights of treatment patterns and its relationship with cardiovascular, renal, and metabolic multimorbidities, Kamlesh Khunti, Journal of Diabetes and Its Complications
  https://www.sciencedirect.com/science/article/pii/S1056872721002968?via%3Dihub
- Cunningham SG, Carinci F, Brillante M, Leese GP, McAlpine RR, Azzopardi J, Beck P, Bratina N, Boucquet V, Doggen K, Jarosz-Chobot PK, Jecht M, Lindblad U, Moulton T, Metelko Ž, Nagy A, Olympios G, Pruna S, Skeie S, Storms F, Di Iorio CT and Massi Benedetti M, Defining a European diabetes data dictionary for clinical audit and healthcare delivery: core standards of the EUBIROD project, Methods of Information in Medicine, 2015 Dec 15;55(2)
  https://doi.org/10.3414/me15-01-0016
- Chan, J.C.N., So, W., Ma, R.C.W. et al. The Complexity of Vascular and Non-Vascular Complications of Diabetes: The Hong Kong Diabetes Registry. Curr Cardiovasc Risk Rep 5, 230–239 (2011).
  https://link.springer.com/article/10.1007/s12170-011-0172-6
- From Hong Kong Diabetes Register to JADE Program to RAMP-DM for Data-Driven Actions. Diabetes Care 2019;42(11):2022–2031
  https://doi.org/10.2337/dci19-0003
- Considerably decreased risk of cardiovascular disease with combined reductions in HbA1c, blood pressure and blood lipids in type 2 diabetes: Report from the Swedish National Diabetes Register
  https://journals.sagepub.com/doi/10.1177/1479164116637311
- Read, S.H., Kerssens, J.J., McAllister, D.A. et al. Trends in type 2 diabetes incidence and mortality in Scotland between 2004 and 2013. Diabetologia 59, 2106–2113 (2016).
  https://link.springer.com/article/10.1007/s00125-016-4054-9
- Gerhardsson P, Schwandt A, Witsch M, Kordonouri O, Svensson J, Forsander G, Battelino T, Veeze H, Danne T on behalf of the SWEET study group. The SWEET project: benchmarking over 10 years is associated with improved HbA1c and increased use of diabetes technology in youth with type 1 di abe tes from 19 countries worldwide. Diabetes Technol Ther . 2021 Feb 26.
  https://doi.org/10.1089/dia.2020.0618