European
Diabetes Forum

ENABLING HIGH QUALITY DIABETES CARE:

Outcomes from an EUDF workshop on European diabetes registries

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ABSTRACT

The Reason

Diabetes registries collect and analyse data on parameters of diabetes health status, ranging from clinical metrics, diabetes treatment choices, type and frequency of microvascular and macrovascular complications, as well as predictive risk factors.

The Value

Over time, diabetes registries can provide clear information about changes in diabetes outcomes and the quality of care, allowing for clinical benchmarking and cost-effectiveness of different diabetes treatments to be evaluated.

The Need

Despite these proven benefits, **national diabetes registries are only established in 57% of European countries**, and there is no current mechanism for using diabetes registries at a pan-European level.

The European Diabetes Forum (EUDF) is an organisation that brings stakeholders from across the European diabetes landscape to connect governments, regulators, payers, healthcare professionals and people with diabetes, with the common goal to advocate for policy change that will meet the need to manage diabetes in the immediate and long-term European context.

In September 2024, the EUDF organised a workshop composed of leaders from across diabetes registries in Europe and Hong Kong, to discuss practical elements of creating, managing and maintaining effective diabetes registries. The workshop allowed participants to share their experiences in setting up and developing diabetes registries, the barriers and challenges that they had to overcome, and the benefits for validated treatment approaches and improved patient outcomes that are a product of a well-structured and maintained diabetes registry.

Diabetes is one of the most significant non-communicable diseases globally and in Europe, with increasing concern about the long-term costs both of treating diabetes and the health economic costs of lost workforce participation for people with diabetes and their carers.

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INTRODUCTION

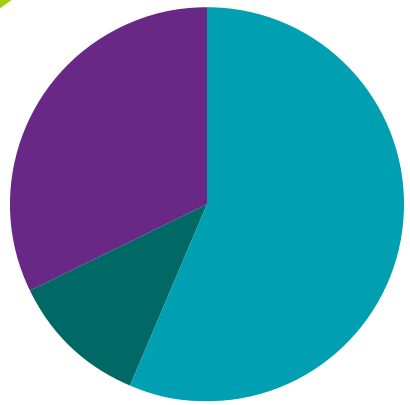
Using comparative health indicators in diabetes registries has been shown to have high value to drive improved quality of care, with improved outcomes for people with diabetes, healthcare professionals (HCPs) and payers. They typically achieve this by collecting demographic characteristics of people with diabetes alongside objective measures of diabetes health. Together, these can be monitored and audited to provide benchmarks against which the performance of diabetes care providers can be assessed at a local, regional or a national level. It is clear that diabetes registries can provide significant insights into diagnosis, treatment efficacy and treatment coverage,[1–4] yet globally and within Europe there are relatively few operational national diabetes registries.

Across Europe, the attitude and approach to diabetes care must change to reduce this disparity between the tools available to treat people with diabetes and the reality of their outcomes. This holds for all European nations and healthcare economies.

Clear treatment guidelines have been developed with diabetes best practice in mind, which are updated regularly as new evidence-based treatments and strategies are available. However, the major barrier to improved diabetes care and outcomes for people with diabetes is implementation. Consequently, the quality of care for people with diabetes is not improving at a pace that matches our understanding of the clinical science of diabetes pathophysiology and treatment responses. Ultimately, key measures of diabetes health, such as HbA1c, blood pressure and cholesterol levels, are not better managed today than they were 10-15 years ago.

Landmark studies, such as the United Kingdom Prospective Diabetes Study (UKPDS) in type 2 diabetes (T2D) and the Diabetes Control and Complications Trial (DCCT) in type 1 diabetes (T1D), make it clear that the quality of care you get as a person with diabetes in the first five years following diagnosis determines your trajectory for the rest of your life with diabetes.[5,6]

Yet we know very little about what constitutes the type and standard of care delivered in these critical first five years. This is a fundamental role for diabetes registries.



In 2023, of the 53 countries in the WHO European region:[7]

30 reported having national diabetes registries

6 reported subnational data collection structures

17 reported no registry

Registries best meeting ICHOM standards

The national registries from Sweden, Denmark, Norway, Germany, Scotland, the Netherlands and England could monitor and benchmark quality against national treatment goals. The registry from Scotland (SCI-DC) incorporated the variables recommended by ICHOM to the greatest extent. This is notable, since SCI-DC was originally developed as an electronic health record (EHR) for clinical care purposes rather than for research.

Significantly, the presence or absence of a registry does not associate with national geographical location or income level. Even when they do exist, national registries can be quite limited in terms of coverage and frequency of data collection. They are often driven by endocrinologists, such that they don't capture the full range of people with diabetes being seen in primary healthcare. Consequently, many diabetes registries are unable to consistently provide information on monitoring and managing diabetes. In addition, standardised outcome definitions and data-collection methods are essential to comparing outcomes and subsequent improvements.

To put this in context, the 2021 World Health Assembly resolution identified five global targets for diabetes,[8] as shown in **Table 1**. A 2023 survey of all 53 WHO European region countries found that none of the respondents were achieving all 5 targets.[9]

The gaps in performance were particularly large for target 3, where only a median of 33 % were estimated to have good control of blood pressure against a target of 80 %, and target 4 for which only 8 % were being treated with statins against a target of 60 %.[9] This has led to a number of initiatives to understand and rectify these trends, including the **WHO Global Diabetes Compact** launched in 2021 with a goal to reduce the risk of diabetes and ensure that all people with diabetes have access to equitable, comprehensive, affordable, and quality treatment and care. Tellingly, the **WHO Global Diabetes Compact** does not promote the value of diabetes registries.

Separately, the **International Consortium on Health Outcome Measurement (ICHOM)** has been engaging with clinical experts and patient advocate groups to develop consensus on registry outcomes that are meaningful to people with diabetes.[10] The **ICHOM** Standard Set for Adults with T1D or T2D consists of 13 health outcomes, which can be subdivided in 6 domains (**See Box 1**). Overall, European registries corresponded fairly well with the **ICHOM** set.[11] Most registries were able to monitor and improve the quality of diabetes care using guidelines as a benchmark.

The EUDF has been taking a lead role in initiatives to promote the value of diabetes registries within the European healthcare landscape.[12,13]

These efforts have centred on raising the profile of diabetes registries and identifying unmet needs for development and maintenance of diabetes registries, including governance, data collection and structures. Currently, Norway, Sweden and Scotland are examples of well-established national diabetes registries, with high-quality information that covers the large majority of people with diabetes in those countries.

EASD European Association for the Study of Diabetes

In September 2024, as an adjunct activity to the European Association for the Study of Diabetes (EASD) 60th Annual Meeting, the EUDF organised a workshop bringing key stakeholders from diabetes registries from across Europe and Hong Kong, to discuss practical elements of creating, managing and maintaining effective diabetes registries.

OBJECTIVES

- Share best practices and optimise the clinical use of existing registries to improve outcomes for people with diabetes
- Discuss experience with diabetes registries and explore current thinking in regard of patient registries
- Identify opportunities for additional initiatives in optimising the use of diabetes registries
- Inspire countries planning to set up a diabetes registry and provide advice on the implementation
- Identify additional potential candidates for initiating diabetes registries and develop relationships that can motivate and support these countries

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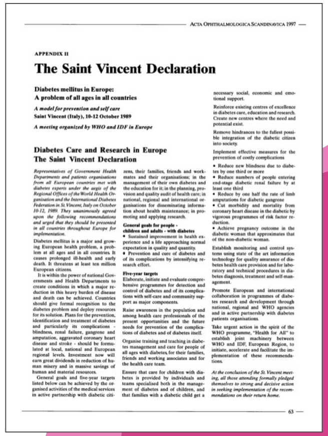
DEFINING THE PURPOSE OF A DIABETES REGISTRY AND THE DATA COLLECTED

The Saint Vincent Declaration in 1989, established the clear goal of improving the care and outcomes for people with diabetes across Europe.[14] One of its key recommendations was to create monitoring and control systems, using state-of-the-art information technology, for quality assurance in diabetes care. This included the development of national diabetes registries to track and improve the quality of care provided to people with diabetes.



Acta Ophthalmologica Scandinavica 1997

APPENDIX II

The Saint Vincent Declaration

Diabetes mellitus in Europe:
A problem of all ages in all countries

A model for prevention and self care
Saint Vincent (Italy), 10-12 October 1989

A meeting organized by WHO and IDF in Europe

Diabetes Care and Research in Europe
The Saint Vincent Declaration

Representatives of Government Health Departments and patients organisations from all European countries met with diabetes experts under the aegis of the Regional Offices of the World Health Organisation and the International Diabetes Federation in St. Vincent, Italy on October 10-12, 1989. They unanimously agreed upon the following recommendations and urged that they should be presented 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 ten 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 particularly its complications - blindness, renal failure, gangrene and amputation, aggravated coronary heart disease and stroke - should be formulated at local, national and European regional levels. Investment now will earn great dividends in reduction of human misery and in massive savings of human and material resources.

General goals and five-year targets listed below 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; in promoting and applying research.

General goals for people - children and adults - with diabetes

- Sustained improvement in health experience and a life approaching normal expectation in quality and quantity.
- Prevention and cure of diabetes and of its complications by intensifying research effort.

Five-year targets

Elaborate, initiate and evaluate comprehensive programmes for detection and control of diabetes and of its complications with self-care and community support as major components.

Raise awareness in the population and among health care professionals of the present opportunities and the future needs for prevention of the complications of diabetes and of diabetes itself.

Organise training and teaching in diabetes management and care for people of all ages with diabetes, for their families, friends and working associates and for the health care team.

Ensure that care for children with diabetes is provided by individuals and teams specialised both in the management of diabetes and of children, and that families with a diabetic child get a necessary social, economic and emotional support.

Reinforce existing centres of excellence in diabetes care, education and research. Create new centres where the need and potential exist.

Remove hindrances to the fullest possible integration of the diabetic citizen into society.

Implement effective measures for the prevention of costly complications

- Reduce new blindness due to diabetes by one third or more
- Reduce numbers of people entering end-stage diabetic renal failure by at least one third
- Reduce by one half the rate of limb amputations for diabetic gangrene
- Cut morbidity and mortality from coronary heart disease in the diabetic by vigorous programmes of risk factor reduction.
- Achieve pregnancy outcome in the diabetic woman that approximates that of the non-diabetic woman.

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

Promote European and international collaboration in programmes of diabetes research and development through national, regional and WHO agencies and in active partnership with diabetes patients organisations.

Take urgent action in the spirit of the WHO programme, "Health for All" to establish joint machinery between WHO and IDF, European Region, to initiate, accelerate and facilitate the implementation of these recommendations.

At the conclusion of the St. Vincent meeting, all those attending formally pledged themselves to strong and decisive action in seeking implementation of the recommendations on their return home.

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The Saint Vincent Declaration in 1989

The Swedish National Diabetes Register (NDR) was established in 1996 as a direct response to the Saint Vincent Declaration.[15] Ultimately, the **NDR** has delivered major contributions in clinical epidemiology of diabetes and has improved clinical care by providing benchmarking data for healthcare providers, with actionable real-time insights into the management and progression of diabetes. The **NDR** has evolved to provide information that can be used to drive everything from staff recruitment to drug selection and access.

This clinical imperative is a stated purpose for most diabetes registries. With experience, this imperative has been further adapted, such that diabetes registries have also become continuous quality improvement initiatives, able to benchmark the care provided by physicians and clinics at a local, regional and national level.

The primary purpose of the NDR was to collect objective information on measures of diabetes health, including HbA1c, blood pressure, lipid levels, markers of macrovascular and microvascular disease, to assess the association between diabetes complications and changes in the pathophysiological parameters identified in the registry.

As well as supporting best practice, part of this benchmarking is directed to reducing inequalities and creating a level playing field for every person with diabetes, independent of ethnicity, age, gender, education or income level.

Secondary aims are focused on diabetes epidemiology, aiming to understand the incidence, prevalence, patient and diabetes disease characteristics for research purposes. In the era of precision medicine, having person-level data with long term follow-up, is critical for developing models to optimise the value of advances in diabetes diagnostics, therapeutics and technologies.

Additionally, the **SWEET** registry has a stated mission to reduce inequalities in paediatric and adolescent diabetes care on the basis of agreed standards of care, criteria for certification, international guidelines, benchmarking and quality control.[16]

Despite their clear value in this context, it is not typically a stated purpose of most diabetes registries to actively inform regional or national policies on diabetes care, although this may ultimately be a consequence. Policy-directed objectives are more likely to be a stated aim of more-recently created diabetes registries, building on the experience of established registries. For example, the **Initiative for Quality improvement and Epidemiology in Diabetes (IQED) Sciensano** registry was established by the **National Public Health institute (NIHDI)** in Belgium in 2001. Part of its active delivery is to provide biennial global and national reports for governmental stakeholders, payers, health insurers and healthcare institutes. After the **IQED** registry of adults living with diabetes and followed in the convention, registries were set up for children and adolescents (**IQECAD**, since 2008) and diabetes foot problems requiring specialised care (**IQED-foot**, 2005).

DIABETES REGISTRY DEVELOPMENT AND SUPPORT

Many diabetes registries were driven by clinical endocrinologists and diabetologists, either as dedicated individuals or as part of a professional association. This is true for the Swedish NDR, the AMD Annals (Italy), Société Francophone du Diabète–Cohorte Diabète de Type 1 (SFDT1) registry, SWEET (Germany), the Dutch Paediatric and Adult Registry of Diabetes (DPARD), Hong Kong Diabetes Registry (HKDR). In contrast, IQED Sciensano (Belgium) was set up and is funded by the NIHDI, and is a quality initiative in the context of a formal contract (convention) between people living with diabetes, specialised diabetes centres and the NIHDI aiming to improve diabetes self-management.

The critical role of clinical champions: A fundamental component of long-standing and effective diabetes registries is a clinical champion. This is an individual with the instinct and vision for a diabetes registry to change the way diabetes care is delivered and the associated improvements in outcomes for people with diabetes. This was true for early diabetes registries such as the **HKDR** and the **NDR**, but it remains just as important today. Starting a diabetes registry will always face challenges in getting HCPs and administrators to buy in (**See Box. 2**). Resistance and scepticism are common with new healthcare initiatives, even when there are examples that demonstrate the value of such registries. There are always competing priorities for resources and manpower. A clinical champion will have the persistence and perseverance to overcome these barriers.

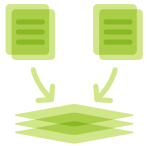
Funding for diabetes registries: A range of models are used to fund diabetes registries and these tend to reflect pragmatic needs and relationships. Public funding is often available to established registries, for example the **NDR** is supported by the Swedish government and the individual healthcare regions that pay for healthcare. Similarly, the Belgian **NIHDI** provides funding as part of a social contract that recognises the value of registry data as a holistic part of healthcare services. **SWEET** was initiated in 2008 as a project funded by the EU Public Health Program, but since 2011, **SWEET** has functioned as an independent legal entity and has developed into a global initiative. Participating diabetes centres/clinics who submit data to the **SWEET** registry can pay a membership fee for which they can participate in clinical benchmarking and auditing activities. Funding can also come from professional medical associations (**AMD Annals**, **SFDT1**), from consortia of physicians and people with diabetes, or combinations of these sources (**DPARD**). **Breakthrough T1D** is also a supporter for some T1D registries (**SFDT1**). Commercial organisations are also common providers of funds, via partnership fees (**SWEET**, **SFDT1**). Initially supported by university, the **HKDR** later evolved to become a territory-wide registry funded by the government (**Risk Assessment and Management Program**, **RAMP**) and a platform-based registry (**Joint Asia Diabetes Evaluation (JADE)** Program) supported by a non-government organisation.

Role of people with diabetes and patient advocacy groups: An early step during the development of many national diabetes registries has been to involve patient organisations (**NDR**, **SFDT1**, **DPARD**). This group of stakeholders can provide valuable input on the purpose of the registry and variables it is set up to collect. In the case of the **SFDT1** registry, which is designed to identify new factors and markers associated with cardiovascular complications in T1D, the scope of the registry includes both clinical data and psychosocial data, with patient-reported outcome measures (PROMs) being added in monthly updates. The **IQED Sciensano** registry is supported by a steering committee of endocrinologists and academics, and has a close collaboration with the two national diabetes patient organisations in Belgium, **Diabetes Liga** and **Association Diabète**, with whom they work to communicate outcomes internationally and to broader public stakeholders in diabetes.

Include a manageable range of diabetes measures: One of the guiding principles that shaped the **Swedish NDR** was that it has included a relatively narrow set of indicators, which simplifies collection, analysis and dissemination of registry outcomes. Other established healthcare registers are perceived to include too many parameters, making them harder to use and provide effective reporting. Currently, in the case of the **NDR**, clinicians can lobby for additional parameters to be included if they have clinical value, but healthcare and epidemiological researchers cannot, although these latter groups can access and use the data included in the **NDR**.

BASIC REQUIREMENTS FOR INITIATING A DIABETES REGISTRY

A diabetes registry has several core requirements that must be met by all registries. The first of these is a sponsor, an organisation or an institution that embodies the goals and capabilities of the registry. The sponsor organisation can also provide the governance structure, with a board that represents all relevant stakeholders. Funding is a basic requirement, as is the scope of the core dataset, as indicated above. A co-ordinator is also a necessity, which may be an individual or a co-ordinating office.



A fundamental requirement is that of data collection, and a key need is to persuade HCPs and healthcare centres to participate and submit data. Early in the process of starting the **Swedish NDR**, a big effort was made to involve and encourage primary healthcare units, who would have responsibility for gathering and submitting much of the data. Good relationships with primary care providers continue to be important for many registries. The **IQED registry** is able to avoid these requirements, since participation of all specialised centres is mandated by the **NIHDI** in Belgium.

In the 21st century, data privacy regulations mandate that people with diabetes must agree that their data can be used as part of a registry. A number of strategies are in place to solicit people with diabetes to opt-in or opt-out to having their data included in a registry. The EU is pushing for a default 'opt-out' strategy in which there is an assumed opt-in, unless a person with diabetes actively chooses to opt-out when prompted. In Belgium, people with diabetes are informed of their participation in the **IQED** registry using a General Data Protection Regulation (GDPR) information letter and a privacy statement of the project, explaining their rights and options to opt-out. For children and adolescents, their parents must provide informed consent for their child's data to be included in the registry.

WHAT ARE THE MOST IMPORTANT BARRIERS FACED IN BUILDING A REGISTRY?

Possibly the biggest challenge is getting sceptical physicians, administrators, institutional or commercial funding organisations and policymakers to buy in.

In the case study provided by the **Irish NDR** (**Box 2**), politicians with influence may have little interest in a (long-term) healthcare initiative with limited (short-term) voter appeal. Similarly, persuading healthcare centres and clinics to collect and submit data may not be straightforward. This emphasises the need to work hard with professional medical societies and patient advocate groups to maintain momentum.

Funding is an important barrier, since setting up a registry takes time and space, with tasks that need to be managed by real people. Early diabetes registries benefited from their association with professional medical societies, and some were able to get limited early funding from universities, governmental bodies, including the EU.

Data and technology issues: Even within a single healthcare service, new registries can face a lack of standardised data structure, with multiple EHR versions and formats from different software providers. Each hospital may require individual connection, which demands considerable time and effort from local Information and Communication Technology (ICT) departments adding to the burden of data collection when automatised extraction of data is not possible.

Finding a vendor able to build the technical architecture and manage technical aspects of data flows can be a major barrier, with a requirement for pseudonymisation or anonymisation of patient data, in alignment with GDPR regulations and upcoming European Health Data Space (EHDS) regulations.

Two European diabetes registries have considerably mitigated these constraints. From its start, the **SCI-DC** registry was built around a diabetes specific EHR for clinical management purposes that secondarily forms an effective diabetes register. In Italy, more-than 90 % of diabetes clinics use the same EHR, allowing for straightforward extraction of standardised data regarding clinical practice and outcome measures. In particular, the **AMD Annals** initiative involves 300 diabetes clinics (one-third of all diabetes clinics nationally; >500,000 people with T2D and 40,000 people with T1D), all using the same EHR and software for data extraction.[17] Furthermore, data extracted in the **AMD Annals** initiative are anonymous by design and are analysed centrally such that the diabetes centres are also anonymous. Each patient is assigned a unique numerical code, allowing longitudinal analysis of data from the same individual.

Data collection should ideally be real-time and 'living' allowing adaptations in response to novel technologies and/or therapies.

Although transferring electronic health data between different EHR systems and for different purposes has traditionally been accomplished by allowing multiple data standards and formats, this is now changing.

Health information management is increasingly using a common format for exchange of data, termed Fast Healthcare Interoperability Resources (FHIR) created by the Health Level Seven (HL7) standards organisation.[18] FHIR is enabling better data extraction and interoperability between different EHRs and other health information systems, particularly in the US Department of Health and Human Services (DHSS), but there continues to be a need for better standardisation and interoperability in a European context.

Notably, payers may believe that the availability of EHRs may make the need for non-communicable disease registries less important, but the register guarantees the quality of the data and provides tools that are established for real-time data visualisation and analysis, such as dashboards and on-demand reporting.

OVERCOMING EARLY BARRIERS

The simple answer to dealing with early challenges in building a registry is hard work. Creating a core team to manage this phase of registry development is important, one that is resilient to early setbacks and problems. Often the solution can be to work with the agency or vendor that is the roadblock. Collaboration with EHR vendors can overcome issues with multiple systems and formats. In the case of the **IQED**, **DPARD** and the **NHS NDA**, the fact that the registry was or became mandatory allowed hospitals to allocate time and staff for data deliveries to the registry. Likewise, the setup of diabetes centres in Hong Kong has enabled the evolution of the university-funded **HKDR** at one hospital to become a territory-wide registry.

Funding issues can be overcome once the registry starts to generate outcomes. Once the **HKDR** was able to show an impact on diabetes practice and outcomes, support from government, industry, grant bodies, and other partners became accessible. Similarly, the **SWEET** registry was initiated in 2008 as an EU funded 3-year project, but by 2011 it was able to sustain itself through the **SWEET** membership programme (clinic membership fee and corporate partnership fee).

DO REGISTRIES MEET THE ORIGINAL PURPOSE THAT DEFINED THEIR MISSION?

In all cases, the answer is yes. The **IQED Sciensano** registry is able to show to policymakers that the diabetes convention is efficient and worthwhile. Since the start of **IQED**, quality of care has improved for people living with T1D in Belgium.[19] Since its initiation in 2017, the **DPARD** registry has created a solid governance structure, a dependable data infrastructure and well-defined quality indicators.

With **89%** of all outpatient treatment centres in the Netherlands participating, the **DPARD** registry is close to achieving its goal to be a fully national registry for outpatient care.

The Italian AMD Annals initiative was launched 20 years ago for the monitoring and continuous improvement of the quality of diabetes care.

2006 2007 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021 2022 2023 2024 2025

Over this period, tangible improvements in all indicators of diabetes care have been documented, including longitudinal improvements in HbA1c and reductions in low-density lipoprotein (LDL) cholesterol and hypertension,[20,21] as well as increased prescribing of cardioprotective drugs, such as SGLT2-inhibitors and GLP-1 receptor agonists, and reduced risks for cardiovascular disease.[22]

The **SWEET** diabetes registry is founded differently, with a focus on paediatric T1D and with a purpose to establish a global network of certified diabetes centres to improve quality of care and reduce inequalities for children and adolescents with T1D.

Significantly, the number of SWEET centres now includes:

131 active centres

In **60** countries

Covering **113,000** children and adolescents with T1D

The **SWEET** network aims to be a centre of reference for agreed standards of care, criteria for certification, international guidelines, benchmarking and quality control. In all of these areas, it is a prominent driver of change. It is active in education and clinical decision making, and regularly publishes real-world outcomes from its dataset.[23]

Importantly, it can show improvements in quality of care and outcomes, with a doubling of **SWEET** registrants achieving HbA1c targets of <7.0% (<53 mmol/mol) between 2013-2022, and significant reductions in acute diabetes events such as severe hypoglycaemia or DKA.[24]

Along with driving quality improvement in diabetes care, a purpose stated for the **HKDR** was to understand the causes, trajectories and consequences of diabetes. In this context it has published regularly on these topics.[25]

This success measure is also met by the **Swedish NDR**, with high coverage of people with diabetes and long-term data that has high value for understanding the impact of evolving diabetes care treatments.[2]

HOW DO REGISTRIES IMPACT DIABETES CARE AND THE OUTCOMES FOR PEOPLE WITH DIABETES?

Diabetes registries allow healthcare organisations to benchmark outcomes for the people in their care against similar organisations. This can be done at a local level (treatment centres), regional level (local healthcare economy) or national level. This information can be used to identify and target quality improvement initiatives.

For example, the **IQED** provides biennial reports for policymakers and clinical leaders, with an overview of the epidemiology and the quality of diabetes care across Belgium. Individual benchmarking feedback is made available to each participating centre, through which they can anonymously compare their own performance with other centres. Where necessary, each centre can identify ways to improve care. After each audit, several initiatives are organised where expertise can be shared and barriers to improve care in daily practice are identified and discussed.

The **SWEET** registry generates scientific analyses and publications that reflect improvement or gaps regarding the treatment and outcomes for children and adolescents with T1D. These can inform and improve care at national and international levels. The active publication of registry-based insights is common to other diabetes registries, including the **HKDR**, the **Swedish NDR**, the **UK NHS NDA**, and the **German DPV**.

Italy's **AMD Annals** initiative produces a standardised set of quality indicators at a local (diabetes centres), regional and national level. This allows yearly evaluation and critical revision of patterns of diabetes care across Italy.[26]

A clear improvement in T2D care overtime has been documented,[20–22] with a tangible impact on clinical outcomes and related healthcare costs.[27] Recently, the **AMD Annals** initiative has been recognised by WHO European Region as a case study for measuring the global diabetes targets in the WHO European Region.

In the UK, the **NHS NDA** has made the delivery of good care more uniform, such that lower-ranked treatment centres and healthcare authorities can identify gaps in care. Care delivery in high-performing centres and regions may not see gains from the audit specifically, but overall the standard of diabetes care improves.[28]

NHS NDA data is used routinely in epidemiological and clinical research, leading to publications that highlight gaps in care for attention and remedy. The **SCI-DC** registry is used as the basis of an annual report to NHS Scotland health boards, summarising the levels of achievement of key processes of care, and it also has a clinical dashboard that can be used to obtain clinic level summaries of key metrics at any point, including patient level summaries. Achievement of clinic level and regional level targets can be compared with national averages, which drive performance improvement.

An additional benefit that diabetes registries provide is to set examples that can be followed by other regional stakeholders. Through publications and visible projects, the **HKDR** has driven the development of the web-based **JADE** Register and the territory-wide **RAMP** and **Hong Kong Diabetes Surveillance Database (HKDSD)**. Together, these raise public and professional awareness with many stakeholders, including policy makers.

Leveraging registry data for clinical purposes

The scale and scope of many registries, especially those with many years or decades of data, can play an important role in providing objective, evidence-based retrospective analysis of diabetes care, with conclusions that can inform both national and international standards of care. If a register has a well-defined structure and purpose, it may also be used for prospective evaluation of risk factors, treatment modalities and other outcomes. As mentioned, many European diabetes registries are able to provide clinically actionable insights.

However, this must be done in a manner that does not compromise the fundamental purpose of the registry, particularly for patient privacy, for example:

- Anonymity or pseudonymity – for clinical purposes, patient-level information must be protected at all levels and no link between the identity of a person and their data can exist for clinical reporting. Where necessary, an identifier (a random number, for example) may be applied that collects the data from an individual in one package for consistent analysis (pseudonymity) but the real person behind the data is always shielded. The same principle can apply to individual treatment centres, such that in a benchmarking exercise a specific centre is not identifiable.
- Treatment centres with access to diabetes registers may not have access to data being collected from their own electronic patients files, for example PROMs and patient-reported experience measures (PREMs) collected from their patients.
- Summary statistics and outcomes are legitimate clinical outputs, whereas raw data is not.
- No commercial exploitation. Commercial partnerships can be accommodated within the scope and purpose of the diabetes registry, with benefits for both partners, but registry data cannot be handed over to commercial organisations for them to use outside the governance of the registry.

HOW CAN DIABETES REGISTRIES ACROSS EUROPE STANDARDISE AND COLLABORATE?

The Collaborative Health Information European Framework (CHIEF) is a pilot initiative that aims to implement a sustainable system for the periodic collection of diabetes indicators from across the European Best Information through Regional Outcomes in Diabetes (EUBIROD) network, using software that automates the delivery of local statistical reports and aggregates data for comparisons across Europe, without requiring changes to local operations.

The data in each national diabetes registry has been acquired after considerable work persuading the healthcare providers to collect and submit the data. This hard work can be leveraged to provide pan-European diabetes registry capability. This must be guided by a fundamental principle – don't reinvent the wheel. Accepting that regional and national registries differ in many aspects (**See Box 3**), it seems a daunting prospect to generate an overarching tool that can manage this. Each of these registries has a different approach and collects data on different populations. Although the landscape of health information management is evolving rapidly, with registry platform proposals using google Survey of Health and Patient Experience (SHAPE)[29] and FHIR record management,[30] the goal of a European diabetes registry is the fundamental aim of only a small number of active projects.

The Joint Action on Cardiovascular Diseases and Diabetes (JACARDI) initiative is part of the European Commission's Healthier Together program (as is **CHIEF**), aimed at reducing the burden of cardiovascular diseases (CVD) and diabetes across Europe. It involves 21 European countries and focuses on both individual and health system levels. JACARDI is not a research project, it is an implementation initiative, fostering pilot projects designed to improve the prevention, diagnosis, and management of these chronic diseases. A key technical work package within JACARDI is focused on data availability, quality and sharing. It highlights the need for standardised and high-quality data to accurately monitor risk factors and disease prevalence. The first key task in this context is mapping and understanding the information that is available across European diabetes registries and how it is collected in each country. Fundamentally, the level of information collected is similar across countries but there is a need to understand the framework that defines the information, because the same information often has different labels and definitions. For example, the term 'denominator' is important for tracking a disease but often has a different meaning in primary care versus secondary care, even within one healthcare region.

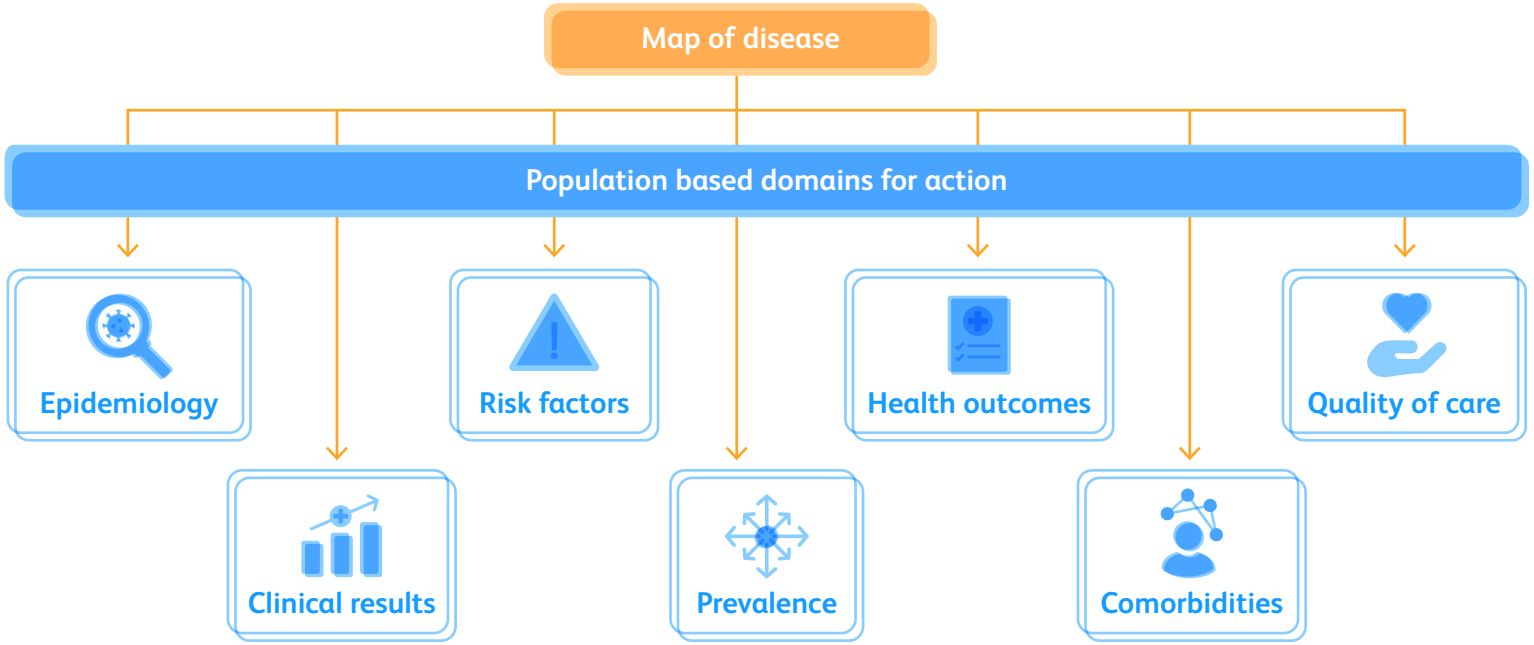
Taking a systematic approach,

01 define the data architecture

02 define the data standards

03 define the items themselves

In this way it may be possible to create a map of the disease, the features of the disease and the disease modifiers, which can be applied across separate diabetes registries.



When mapping diabetes healthcare data within and between countries, the task of assigning definitions that allow for better comparisons between countries, with benchmarking, is critically important. This need for clear, agreed 'gold standard' definitions for many terms is currently unmet.

These can be rendered from a framework of inpatient or outpatient clinical care, including primary care. In this way, the JACARDI initiative can enable the identification of European-wide opportunities for improving quality of care from the patient perspective. Significantly, 56 % of JACARDI pilot projects on data availability, quality, accessibility and sharing are focused on diabetes.

In providing hope that the goal of connecting distinct and different registries to improve care can be achieved, it may be productive to use Sweden as a case study, where there are at least 100 quality registers for different diseases (cancer, arthropathy, other chronic diseases). Each of these individual registries can be linked using the national registry ID at the patient identifier level, to show regulators and payers the value of registries and registry data for improved clinical outcomes. This can also translate into cost-effectiveness data for different treatment modalities between clinics and regions.

Just as importantly, use of registries in this way can also identify and pinpoint healthcare inequalities, for example the SCI-DC registry in Scotland has been used to map poorer outcomes for people with diabetes to areas with multiple indices of deprivation.[31]

Costing a European diabetes registry capability

A fundamental requirement of any European diabetes registry initiative is that it has low costs to maintain and manage. Most of the overall cost of data collection, structuring and storage, is provided at the national level, for national decisions and outcomes. The main costs from a European perspective are to support harmonisation of registry data from the national databases and to provide European-level analysis for policy makers.

The European commission and non-EU policy makers will need to engage with this initiative and understand the health outcomes benefits and financial gains from having European-wide diabetes healthcare information and quality improvement programs at their fingertips. This also includes what governance and oversight is in place from a European perspective.

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CONCLUSIONS

The goal of ensuring that national diabetes registries in Europe are able to drive quality improvements in diabetes care, with consequent improvements in outcomes for people with diabetes, is a work in progress with encouraging successes.

Initiatives are ongoing that need to lower these barriers to success, but the will amongst national clinical stakeholders within Europe is building, as is evident from the outcomes of this EUDF workshop.

The allied objective of creating a diabetes registry capability at a pan-European level faces challenges that are founded in the overall scope, structure and management of national and regional diabetes registries.

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Author contributions

The authors collectively developed the concept and content of this document, interpreted data and critically revised and completed this document.

Authorship

All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published.

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GLOSSARY

CHIEF	Collaborative Health Information European Framework
CVD	Cardiovascular disease
DCCT	Diabetes Control and Complications Trial
DKA	Diabetic ketoacidosis
DPARD	Dutch Paediatric and Adult Registry of Diabetes
DPV	German Diabetes Prospective Follow-up Registry
EASD	European Association for the Study of Diabetes
EHDS	European Health Data Space
EHR	Electronic health record
EUDF	European Diabetes Forum
FHIR	Fast Healthcare Interoperability Resource
GDPR	General Data Protection Regulation
HCPs	Healthcare Professionals
HKDR	Hong Kong Diabetes Registry
HKDSD	Hong Kong Diabetes Surveillance Database
HSE	Health Service Executive
ICHOM	International Consortium on Health Outcome Measurement
ICT	Information and Communication Technology
IQECAD	Initiative for Quality improvement and Epidemiology in Children and Adolescents with Diabetes
IQED-foot	Initiative for Quality improvement and Epidemiology in foot problems in Diabetes
IQED	Initiative for Quality improvement and Epidemiology in Diabetes Sciensano
JACARDI	Joint Action on Cardiovascular Diseases and Diabetes
JADE	Joint Asia Diabetes Evaluation Program
NDA	National Diabetes Audit
NDR	National Diabetes Register
NHS	National Health Service UK
NIHDI	National Public Health Institute in Belgium
NOCA	National Office of Clinical Audit
NPDA	National Paediatric Diabetes Audit
PREMs	Patient-reported experience measures
PROMs	Patient-reported outcome measures
RAMP	Risk Assessment and Management Program
SCI-DC	Scottish Care Information – Diabetes Collaboration
SFDT1	Société Francophone du Diabète–Cohorte Diabète de Type 1
SHAPE	Survey of Health and Patient Experience
SWEET	International paediatric T1D diabetes registry based in Germany
WHO	World Health Organisation

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Table 1. World Health Assembly resolution identified five global targets for diabetes

Description of target	Achievement in Europe†
1. 80 % of people living with diabetes are diagnosed, the total number with diabetes is defined by either self-reported prior diagnosis, taking diabetes medications, or having elevated HbA1c or fasting glucose	63.7 %
2. 80 % have good control of glycaemia, defined as less than 8 % (64 mmol/mol)	70.5 %
3. 80 % of people with diagnosed diabetes have good control of blood pressure, defined as less than 140/90 mmHg	33.3 %
4. 60 % of people with diabetes of 40 years or older receive statins	7.7 %
5. 100 % of people with type 1 diabetes have access to affordable insulin and blood glucose self-monitoring	N/A*

† Figures indicate median percentage achieved for each target in 2023 compared to the percentage indicated in the 2021 World Health Assembly resolution

* Not estimated as achievement varies based on national reimbursement policies and processes

Box 1. The International Consortium for Health Outcome Measurement (ICHOM) standard set for adults with type 1 diabetes or type 2 diabetes

Diabetes control

- glycaemic control
- body weight
- blood pressure
- lipid profiles

Acute events

- diabetic ketoacidosis
- hyperglycaemic hyperosmolar syndrome
- hypoglycaemia

Survival

- cardiovascular mortality
- all-cause mortality

Patient-reported outcomes

- psychological well-being
- diabetes distress
- depression

Chronic complications

- micro- and macrovascular complications
- nervous system complications
- treatment complications

Health services

- financial barriers to treatment
- healthcare utilisation

Box 2. Starting a national diabetes registry in 2024 – a case study

The Health Service Executive (HSE) and the National Office of Clinical Audit (NOCA) in Ireland are proposing to launch a National Diabetes Registry (NDR) for adults with diabetes (to be hosted by the HSE) and a National Paediatric Diabetes Audit (NPDA) to be hosted by NOCA.

Purpose	Development and support	Basic requirements	Important barriers	How will these barriers be overcome?
The Irish NDR will provide national data on prevalence and incidence of diabetes through the merging of existing national datasets. The NDR project team will also explore ways of providing dashboard data to clinicians relevant to their practice. The NPDA aims to develop an audit that will capture data from existing sources in paediatric hospitals and use performance indicators in diabetes and outcomes against clinical standards to provide benchmarking data. The vision is to improve outcomes nationally for children with diabetes.	The National Clinical Programmes for Adult and Paediatric Diabetes (clinicians), Diabetes Ireland (not-for-profit advocacy) and some members of the national parliament have been championing a NDR for many years. The Department of Health released funding to HSE and NOCA for Adult NDR and NPDA in 2023. A NDR Consortium was established and led by Dr Claire Buckley, Consultant in Public Health Medicine and National Lead for Chronic Disease.	With funding in place the Irish NDR is able to focus on creating a data architecture, explore available diabetes datasets and specify a minimum dataset. In this they will work with Integrated Information Systems (a section of the HSE ICT Division).	(a) Lack of a tradition in Ireland of sharing/merging datasets for the common good, (b) Lack of digital data at the point of care in hospitals, (c) Lack of a unique health identifier for data linkages, (d) a disconnect between the healthcare funding cycle (typically annual) and the longer term perspective necessary for a project like a Diabetes NDR to be successful.	(a) A Chronic Disease Data System Framework is being developed and will address Legal, Governance, Data Protection and IT infrastructure issues, (b) A new paediatric hospital will have a compatible Electronic Health Record format, (c) Existing adult and paediatric hospitals will be encouraged to move to electronic data capture, (d) the HSE has implemented an Individual health identifier project which is being rolled out across services, (e) continue to build clinician and patient advocacy for an NDR.

Box 3. The challenge of creating a European diabetes registry capability

Lack of data standardisation: Different national registries have varying standards for data collection and reporting, even within their own healthcare settings.	**Privacy concerns:** Data privacy laws, such as the General Data Protection Regulation (GDPR) and the European Health Data Space (EHDS) initiative, impose strict regulations on how personal health data can be collected, stored, and shared across borders.	**Resource allocation:** Establishing and maintaining a comprehensive registry requires significant financial and human resources, which may not be uniformly available across all European countries.
Political and administrative barriers: Coordinating efforts across multiple national health systems and governments can be complex and slow-moving. The European landscape comprises more nations than the European Union, so European Commission involvement has limitations.	**Coverage:** There are few national diabetes registries that cover the majority of people living with diabetes, often focusing on children and adolescents with T1D. Equally, people with diabetes are often treated in different healthcare settings, such as outpatient clinics or primary care practices, which may not all provide data to the registry.	**Regulation:** Regulatory frameworks differ between national healthcare services, creating a landscape of ownership, oversight and allocation of resources that make overall governance complex.

RECOMMENDATIONS

01

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 an 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 into improvements in diabetes care, by tracking the performance of treatment centres and clinics and answering important research questions.
- Identify stakeholders who will be accountable for the implementation of registries.

02

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 input only once. For example, lab data should be linked to physician dossiers. Ensure all medicines, medical devices, hospitalisation 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 HbA1c, blood pressure, lipids, statin use and 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.

03

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 utilising 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.

04

Develop implementation strategies

- Mobilise patient advocate 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 stakeholders in the health ecosystem.
- 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 registries are used to improve care.