



## EDITORIAL

## Is the Spanish type 1 diabetes mellitus registry really necessary?

### Registro español de diabetes mellitus tipo 1. ¿Es realmente necesario?

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Type 1 Diabetes mellitus (T1DM) is currently a chronic autoimmune disease with a major socioeconomic and health impact. It accounts for between 5% and 10% of all cases of diabetes and its incidence seems to have been increasing all around the world. The current estimated incidence of T1DM in children under 15 years of age in Spain is between 11 and 15 cases per 100,000 inhabitants per year.<sup>1</sup> However, there is no national registry, and the data currently available on T1DM in Spain, which derive from studies in the different autonomous communities using different methodologies, reflect a significant regional heterogeneity and information limited to incidence and prevalence over a specific period.

It is essential to have the most accurate information possible on the epidemiology of T1DM in Spain to identify the aetiopathogenic mechanisms of the disease and its complications, as well as to develop strategies geared towards prevention, improving the quality of life of people with the disease and harnessing the available health resources appropriately. If we look around us, it is evident that many countries have diabetes registries that were launched in response to the recommendations of the Saint Vincent Declaration to ensure quality in diabetes care. Data from the International Diabetes Federation show that there has been an absolute increase in the number of countries

with some kind of diabetes registry—from 23 in 2011 to 30 in 2014 (out of 47 countries)—, although more than 83% were considered to be incomplete,<sup>2</sup> and a recent publication<sup>3</sup> has analysed the status of national diabetes mellitus registries globally, quantifying their data and assessing their influence on diabetes care. The study identified 12 national clinical diabetes registries spread across four different continents, mostly concentrated in northern Europe. More specifically, the registries of Sweden, Finland, Denmark, Norway, the Netherlands, Germany, Latvia, Scotland, England, the United States, Australia and Saudi Arabia were analysed, and their databases globally comprised a total of 7,181,356 people with diabetes, although it should be noted that they all included people with T1DM or type 2 diabetes. Nevertheless, the conclusion drawn is important, because most of the registries were shown to improve the quality of diabetes care using the guidelines as a reference point. The effects on national health policy-making were more variable and often less clear; however, the data collected should help to optimise healthcare system performance and to assign resources and interventions to where they are most needed. The global implementation of a set of variables would improve the comparison and sharing of outcomes and treatments in clinical diabetes care.

In this context, the Spanish Society of Endocrinology and Nutrition (SEEN), the Spanish Diabetes Society (SED) and the Spanish Society of Paediatric Endocrinology (SEEP) recently decided to jointly launch a national T1DM registry in Spain, the National T1DM patient registry; with a view to gathering

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accurate epidemiological data and generating high-quality scientific information about T1DM. A national registry would enable researchers, healthcare professionals, managers and policy-makers to identify trends and patterns in the incidence and prevalence of T1DM, assess the impact of existing and future therapies and improve the care and quality of life of T1DM patients. It could also provide a solid foundation for clinical and epidemiological research and identify potential risk factors and patients for clinical studies, which could lead to new discoveries and more effective therapies. Furthermore, as the registries have the potential to collect large data sets that can aid decision-making, it could be of great economic benefit and also act as a tool for local quality control and comparison with national treatment targets, as well as assess which therapies and treatment models work in clinical practice, in addition to randomised controlled trials.<sup>4</sup>

This Spanish T1DM registry will include at least clinical, demographic, analytical and socio-environmental data at diagnosis and throughout follow-up. The longitudinal analysis of the epidemiology of T1DM, as we have already indicated, will make it possible to define global and partial incidences (by age, gender, ethnicity or geographical area), data related to aetiopathogenesis, to evaluate the efficacy and safety of different treatments, to develop new therapies and establish clinical phenotypes and genotypes that will be key to developing and applying precision medicine in the T1DM population. The project will be implemented progressively in all centres in the different regions of Spain, and is supported by the Juvenile Diabetes Research Foundation, the International Diabetes Federation and the Instituto de Salud Carlos III [Carlos III Health Institute].

The SEEN, SED and SEEP believe that the registry is necessary. We hope that this time it will work and that the national

T1DM registry will become a reality and bear its fruit in the coming years (and that we will see this).

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## Conflicts of interest

We have no conflicts of interest to declare in relation to the subject matter.

## References

1. Gómez-Peralta F, Menéndez E, Conde S, Conget I, Novials A, SED and investigators of the SED1 study. Clinical characteristics and management of type 1 diabetes in Spain. The SED1 study. *Endocrinol Diabetes Nutr (Engl Ed)*. 2021;68:642–53, <http://dx.doi.org/10.1016/j.endien.2021.11.020>.
2. International Diabetes Federation Europe, p. 34. Available from: <https://idf.org/our-activities/advocacy-awareness/resources-and-tools/140-integrating-diabetes-evidence-into-practice.html>, 2017.
3. Bak JCG, Serné EH, Kramer MHH, Nieuwdorp M, Verheugt CL. National diabetes registries: do they make a difference? *Acta Diabetol*. 2021;58:267–78, <http://dx.doi.org/10.1007/s00592-020-01576-8>.
4. Hoque DME, Kumari V, Hoque M, Ruseckaite R, Romero L, Evans SM. Impact of clinical registries on quality of patient care and clinical outcomes: a systematic review. *PLoS One*. 2017;12:e0183667, <http://dx.doi.org/10.1371/journal.pone.0183667>.