

## Unlocking the potential of the European Health Data Space to improve diabetes management in crises and beyond

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“In the small amount of time it takes to complete this introduction, more than 40 people will die of diabetes.” **Maurizio Guidi, Co-Chair of the EFPIA Diabetes Platform**, opened the first webinar of a two-part series co-hosted by the **EFPIA Diabetes Platform** and the **European Diabetes Forum (EUDF)**, investigating the syndemic threat of COVID-19 and chronic diseases by using diabetes as a case study.

An estimated 9% of total health expenditure goes towards diabetes, but 75% of these costs are ‘preventable’ – that is, they are due to avoidable complications of the disease. It is a disease that does not work in isolation. Comorbidities interact with one another, and risk factors aggravate outcomes. The COVID-19 pandemic in particular has revealed the extent with which diabetes is intertwined with other social determinants, creating a multidimensional, syndemic threat.

A syndemic – or synergistic epidemic – is the aggregation of two or more concurrent diseases on a background of social and economic disparity, which exacerbates the adverse effects of each separate disease. During this pandemic, 1/3 of people who died from COVID-19 had diabetes.

This concept illustrates that managing a public health crisis effectively is not simply about controlling the spread of a virus. For people living with one or multiple chronic diseases, pandemics such as COVID-19 bring severe synergistic impacts, which require a more nuanced and comprehensive approach to how we manage diseases, particularly in times of crises.

Keynote speaker **Dr. Tammy Boyce, Senior Research Associate at UCL Institute of Health Equity** drew attention to the fact that data can help us better understand the impact of diseases. COVID-19 has been a prime example of this. But diabetes would benefit from a similar preoccupation with data. Data enables one to understand the roots and mechanisms of the disease – to share best practices, understand when things have gone wrong, and improve the quality and quantity of research studies to accelerate advances in all fields. Now with registries and data we have some of the real-time evidence that can improve outcomes. Data also enables a better understanding that there are communities of special need where additional efforts are required.

**Jaivir Pall, advisor to the International Diabetes Federation European Region (IDF Europe)**, and **Adrian Sanders, Secretary General, Parliamentarians for Diabetes Global Network (PDGN)**, pointed out that diabetes care has in some cases become more coordinated during the pandemic. The fact that hospitals were compelled to go digital forced much overdue changes. But experience across Europe is still very variable, with the gap between rich and poor countries widening.

As **MEP Cristian-Silviu Buşoi (EPP, Romania)** highlighted: managing non-communicable diseases, such as diabetes, is a prerequisite for successful containment of COVID. With the number of people living with chronic diseases growing, public policy needs to strengthen its efforts in this area. Fortunately, the EU4Health programme aims to strengthen e-health systems, by raising awareness and increasing uptake of digital tools and services across the continuity of care to make health systems more resilient.

#### **Recommendations:**

How can we improve the quality of data in diabetes care? First, standardised data is needed for meaningful comparisons. Registries have high quality information, but they are heterogenous and fragmented, and are difficult to compare at the international level. "It is more difficult to compare apples to oranges rather than apples to apples", said **Dr. Jeannette Söderberg, European Research Director at JDRF**, "we have a wealth of good quality data in Europe, but it is difficult to use them. Collaboration is key to get over this hump and ensure data can help us improve patient outcomes. The European Health Data Space provides an opportunity to make access, use and sharing of data easier".

It is also vital to make sure the data that is collected is data we can trust. It is not about collecting data for data's sake, but applying it in a scientifically rigorous way that can positively impact outcomes for people with diabetes. Maurizio Guidi commented during the event that "data registries should not be used only for cost-containment measures, but should really drive investments in health for better outcomes". That is why researchers must consider ways of incorporating patient-reported outcomes like pain, distress, fatigue that cannot be measured in a lab but are nonetheless central to the patient experience. Involving the patient also improves the reliability of the data.

Europe has a role to play, including in highlighting best practices. At the same time, as **Prof. Dr. Chantal Mathieu, Chair of the European Diabetes Forum (EUDF)** pointed out, with "different healthcare systems across countries, pushing top-down approaches will not work." European data collection must be supplemented with regional translations that are appropriate for each of the systems in the different regions.

Rewatch the event [here](#)