The National Paediatric Diabetes Register and its Impact on Healthcare

Abstract:

In the field of management it has long been recognised that effective management of any given outcome requires knowledge and control of inputs to the system. This is also true in healthcare particularly in Type 1 diabetes (T1D), a common and serious chronic disease in childhood which is a huge health, social and economic burden. In T1D, outcome, in terms of prevention of diabetes related complications, has been clearly shown to be related to resource dependency and management. Indeed recently the Rvidore Study group demonstrated better glycemic control in those patients with more clinical contact.

Availability of robust reliable data is vital to inform effective resource allocation decisions to optimise health outcomes and appropriate planning and utilisation of resources, while minimising the opportunity cost of misplaced resources. Particularly critical as in current times when resources are scarce. Indeed one would question how it is possible to appropriately plan services in the absence of such information. Internationally the value of reliable epidemiological data to inform and appropriately plan diabetes services has been clearly demonstrated. Particularly in the European context, the Diabetes in Europe Collaboration and Epidemiology (DECEMBER) Project (1998-2003), the Danish Childhood Diabetes Registry and the EURODIABE Project (1998-2008) have all demonstrated the importance of data in informing effective resource allocation decisions.

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As a result of the establishment of the ICDNR for the first time it can be confidently confirmed that Ireland has a high incidence of T1D in the child and adolescent population and that the incidence of this disease has risen substantially since the baseline study of 1997. By comparison the increase in T1D in those aged under 15 years in the ROI. The ICDNR is a prospective incident register thus it records in a robust manner the diagnosis of new cases of T1D. It has been strongly supported by Children, families and Health Professionals nationally.

Despite T1D in childhood and adolescence being a readily identifiable disease, as it is rapidly fatal without the administration of insulin, there were limited data available regarding the number affected with this condition in Ireland. In the past Ireland was considered a country with a very low incidence of T1D and services configured accordingly. Clinicians however felt this was not the case and to address this data deficiency a baseline incidence study was undertaken in 1997 and the process to develop a national Register commenced. The Irish Childhood National Diabetes Register (ICDNR) was established in 2008 with the generous support of the National Childrens Hospital Foundation. It has been designed to comply with all statutory policies regarding data collection, storage and management within the Data Protection Acts and GDPR policies. Its role to define and monitor the epidemiology of T1D in those aged under 15 years in the ROI. The ICDNR is a prospective incident register thus it records in a robust fashion new cases of T1D. It has been strongly supported by Children, families and Health Professionals nationally.

According to the ICDNR for the first time it can be confidently confirmed that Ireland has a high incidence of T1D in the child and adolescent population and that the incidence of this disease has risen substantially since the baseline study of 1997. By comparison the increase in T1D in those aged under 15 years in the ROI. The ICDNR is a prospective incident register thus it records in a robust manner the diagnosis of new cases of T1D. It has been strongly supported by Children, families and Health Professionals nationally.

As the Register is maintained over time the annual incidence data will permit accurate determination of the total number of young people (prevalence) under 15 years with T1D in the ROI. Assessing prevalence over time using meticulously collected incidence data is the most robust and reliable method, as in the absence of a unique patient identifier, retrospective cross sectional analysis would not be feasible due to multiple counting of cases (many with diabetes attend more than one centre), uncertainty of diagnosis (increasing numbers of type 2 or monogenic diabetes units age group under-reporting). The data provided by the ICDNR is the most accurate and robust data regarding childhood diabetes in Ireland and is invaluable to support strategic developments in resource allocation and service delivery for childhood diabetes. The ICDNR has already made a significant contribution by providing data and forecasts to inform the ESRI initiative to prioritise Continuous subcutaneous insulin infusion therapy to children under 5, led by Dr Stephen O’Riordan, Clinical Lead for Paediatric Diabetes.

The ICDNR is an invaluable resource in Type 1 diabetes which provides a unique insight into the development of this disease in the Irish population and the resources required to appropriately address the needs of this large patient group, thereby optimising service delivery and enhancing patient care.

References


