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 (T1), a chronic and severe chronic disease in childhood which is a huge health, social and economic burden. In T1, the outcome, in terms of prevention of diabetes related complications, has been clearly shown to be related to resource dependent disease management and more recently the Rvidrove Study group demonstrated better glycaemic 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 to appropriately plan services in the absence of such information. Internationally the value of reliable epidemiological data concerning disease prevalence has been recognised since the establishment of the International Diabetes of Childhood in 1999 and the Eurodiab collaborations, which have monitored the epidemiology of this important disease in children. The first five shown annual increases in incidence of T1D ranging from 9.6 to 9.3% in most European populations, the average increase being 3.9% Many countries have established National Diabetes Registries to monitor T1D in their populations.

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 maintenance within the Data Protection Acts and HIQA 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.

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.

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.

The ICDNR includes provision of comprehensive and accurate data regarding annual incidence of Type 1 diabetes in children and adolescents in Ireland since 2008. It provides accurate demographic data, allowing identification of areas of higher disease density and evaluation of sub populations with diabetes who require special considerations e.g. those aged under 5 or adolescent cohorts. These data permit the design of healthcare services to support the National Model of Care. Such data enables reconfiguration of healthcare services to meet specific needs, such as, prioritising the development of transition services in areas where large growth in the adolescent population will take place.

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References


