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 severe chronic disease in childhood which is a huge health, social and economic burden[1,2]. In T1D the outcome, in terms of prevention of diabetes related complications, has been clearly shown to be related to resource dependent disease management[3] and more recently the Hvidore Study group demonstrated better glycaemic control in those patients with more clinical contact[4].

Availability of robust reliable data is vital to inform effective resource allocation decisions to optimise health outcomes and ensure effective 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 regarding Type 1 diabetes has long been recognised with the establishment of the DIAMOND project by the World Health Organisation in 1990[5] and the Euroodiab collaborations, which have monitored the epidemiology of this important disease since the late 1980s[6,7]. These studies have shown annual increases in incidence of T1D ranging from 0.6 â 9.3% in most European populations, the average increase being 3.9%[6] 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[8,9] 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[10] 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[11]. The increase has been of the order of 5% per annum (although it must be recognised that incidence rates in T1D are not linear over time[7]). Data on almost 1500 children and adolescents with T1D is currently maintained in the Register. The benefits of 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 consideration, 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 populations with T1D can be forecast. The period of transition from child to adult services for those with diabetes is an area of particular risk where young people may fall out of care and re-engage only with life-threatening crises. 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 provision for childhood diabetes. The ICDNR has already made a significant contribution by providing data and forecasts to inform the HSEs initiative to prioritise Continuous subcutaneous insulin infusion therapy to children under 5, led by Dr Stephen Oâ Riordan, Clinical Lead for Paediatric Diabetes.

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 self-reported cross-sectional analysis of centres would be unreliable 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 in this age group)and under-reporting (most paediatric T1D centres do not have a computerised database). The ICDNR enables monitoring of changes in disease epidemiology in the population over time and the pattern and frequency of serious disease complications at diagnosis. A vital function of the ICDNR is that it will enable the assessment of completeness of audit through provision of reliable accurate denominator data, thereby enhancing patient care and improving disease outcomes. In the absence of accurate denominator data it is possible that a significant proportion of the audit population could be missed due to non-attendance etc thus yielding misleading results. As a national disease register the ICDNR participates with the Eurodiab collaboration to aid further insight into the causation of this common complex disease.

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.

EF Roche

Department of Paediatrics, The National Children’s Hospital, Tallaght, Dublin 24

Email: rocheef@tcd.ie

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