

## The need to establish local Diabetes Mellitus registries

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The epidemiologists look at the distribution, determinants and health related states of diseases which will assist in the control of the disease as well as its survival pattern. Disease registries provide information regarding the components of the epidemiology of that particular disease.

Disease registries provide the list (electronic or manual) of all patients with a specific chronic disease or condition, the socio demographic details, laboratory investigation data, complications, medication history etc. Registries play a critical and important role in the Chronic Care Model (CCM). The aim of the CCM is to improve chronic care at the individual as well as the population level of management [1]. Registries can provide support in different ways to the CCM. The registries are usually sponsored by the government, not-for-profit organizations or private agencies. Data collection should follow ethical principles such as confidentiality, privacy, anonymity, and voluntary participation. It is the patients' voluntary decision to provide data to the disease registry. Registries also help to improve the adherence of physicians to the current treatment guidelines [2].

In many countries cancer registries (hospital based and population based) are established and are providing relevant data which assists in prevention, control and treatment modalities. These include district, state and national registries. Well-established cancer registries around the world report how the registry data is assisting in the quality management

initiatives in the health settings by providing feed back to the healthcare providers [1]. Many other disease registries have been established in some developed countries [3] such as cardiovascular disease registries.

The International Diabetes Federation (IDF) atlas published in the year 2015 reported that diabetes is one the largest health problems in this century. As per the statistics, the global prevalence among people aged 20-79 years is about 8.8% (7.2-11.4%) in 2015 and the estimates showed it will be 10.4% (8.5-13.5%) in 2040. This shows that diabetes mellitus is a major public health problem. Therefore there is a need to revamp the preventive, promotive and appropriate curative modalities for it. Usually an ideal disease for establishing the registry is a disease with sufficient public health importance. Hence diabetes mellitus can be considered as an ideal disease to establish such a registry [4].

Data collected by local diabetes registries can assist in understanding the burden of the disease better because the data coming from registries are complete with respect to all aspects of the disease including the different types of treatment. Hence these data can be used for many sustainable public health and preventive activities which will also help the clinicians to take decisions on the modality of treatment and also to get the incidence rate of diabetes mellitus. The incidence rate of diabetes mellitus is not available from many countries. A recent publication in United Arab Emirates

reported the incidence of diabetes among Emiratis as 4.8/1000 Person Years using a retrospective cohort approach [5].

Few established diabetes registries that have published their data have demonstrated how the registries are helping in improving the effectiveness of diabetes care. The Hong Kong Diabetes Registry was established in Prince of Wales Hospital (PWH) in 1994. One of the main aims of the registry was “to improve quality of diabetes care through innovative research and development of human resources and to study the disease pattern and derive risk equations to estimate 5-year probability of major diabetes complications including cardiovascular disease, end-stage renal disease and death in our locality” [6]. Childhood Type 1 Diabetes Mellitus registry was established in Italy in 1997 to coordinate the existing registries and to set up more local registries. Since then seven regional registries and five provincial registries have been established<sup>7</sup>. The National Danish Diabetes Register was established in 2006. The aim was to monitor the patients and to find the distribution of cases and death in relation to various socio-demographic variables [8]. The National Diabetes Registry (NDR) of Malaysia was established in 2008 under the Ministry of Health which helps in providing clinical and treatment information including co-morbidities [9]. This information is utilized for the quality of care and management of diabetes mellitus [6-9].

Most of the established diabetes registries are at the National or State level. If diabetes registries can be organized at the local level, the quality of the data may be more reliable and can be used in the local situation and this data can also be used by the national and state registries. Registries on diabetes mellitus is an urgent need at both local and national level.

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