
# DIABETES IN CHILDREN & ADOLESCENT REGISTRY (DiCARE)


## Presentation Outline:

- Introduction to disease registries/databases
- Understanding the DiCARE
- Objectives of DiCARE
- Conclusion


# INTRODUCTION TO DISEASE REGISTRIES/ DATABASES


## Disease Registry: Definition I

*Ongoing systematic* collection, analysis and interpretation of disease data essential to the planning, implementation & evaluation of clinical public health practice, closely integrated with dissemination of these data to those who need to know.

***(Source: CDC)***

## Disease Registry: Definition II

The final link in the chain is the *application of these data to disease treatment, prevention and control.*

A disease registration system includes a *functional capacity* for data collection, analysis & dissemination linked to clinical or public health programs.

***(Source: CDC)***

## Purpose of A Disease Registry

- **Quantify disease burden (morbidity and mortality) & its geographic and temporal trends.**
- **Early warning of rapid increase in disease incidence, eg. in infectious disease surveillance.**
- **Identify sub-groups most at risk of disease.**
- **Identify potential risk factors of disease.**
- **Evaluate treatment programme / Clinical audit**
- **Evaluate control & prevention programme.**
- **Facilitate research e.g disease aetiology, Rx effectiveness, outcomes research, prognosis**

## Uses of Registry Data

- Treatment availability & accessibility (equity)
- Outcomes research
- Technology assessment
- Clinical economics
- Clinical audit
- Support clinical trial/ clinical research

## Understanding DiCARE


## Introduction : Type 1 DM

- **Incidence : 12-14/100,000 individuals per year, with estimated frequencies from 1 in 1,430-2,500 at age 5 increasing to 1 in 300-360 by age 16 years.**
- **In Malaysia, the IDF prevalence estimates of diabetes is 8-11% in 2003 & is expected to be at 11-14% in 2025.**
- **The incidence may be rising worldwide, → increasing the major health care & economics burden to the individual, family & society.**


## Type 2 DM (T2DM)

- A retrospective diabetes clinic-based study from the greater Cincinnati, Ohio :-

  The incidence of T2DM among children & adolescents (≤19 years of age) increased 10-fold between 1982 & 1994 (0.7 vs 7.2 per 100,000/yr).


## T2DM

- **Obesity is associated with increase in the metabolic syndrome, cardiac risk factors and T2DM.**
- **85% of children with T2DM are overweight or obese at diagnosis.**
- **Studies have shown that youth with T2DM will also develop diabetes related micro & macrovascular complications, as with adults.**


## Objectives of DiCARE

- **Determine the number & the time trend of DM in the young in Malaysia.**
- **Determine the socio demographic profiles of these patients to better identify the high risk group in our Malaysian population.**
- **Determine the number, evaluate & monitor the outcomes of intervention in terms of metabolic control & complications.**
- **Stimulate & facilitate research using this database.**

## DiCARE : Scope & Coverage

**The scope & coverage of the database is to be implemented over time in phases:**

**Phase 1 of the proposed DiCARE shall be limited to meeting objectives (1), (2) & eventually (3).**

**Objective 4 can be met as the database matures & as sufficient data has been accumulated.**

## Inclusion Criteria

- Age 0 - <20 years old
- Seen in any of the participating sites.
- All types of diabetes mellitus

## DiCARE Source Data Providers (SDP)

- All paediatricians & physicians in Malaysia beginning with those currently working in the MOH and universities and later on extending it to those beyond MOH (private & armed forces).

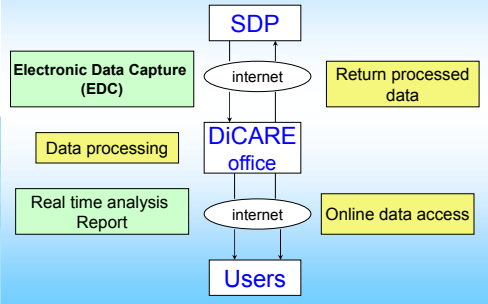
## Registries and Research

Proyer et al distinguishes 3 areas in which registries can contribute to research :-

- Descriptive studies
- Improving performance of other research designs
- For hypothesis testing as an alternative of RCT with ethical concerns.

## Data Flow

- Mix mode of web based and paper based




## Conclusion

- The WHO & several research institutions have recognized the importance of population-based registries as an essential tool in aetiological research & public health administration in the area of diabetes.
- It is timely that this study is undertaken in Malaysia so that further research on diabetes can stem out of this national database.

***THANK YOU***