#### RESEARCH ARTICLE

# **Evaluation of the Performance and Importance of Diabetes Registries of Several Countries-calls for greater integration**

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### **Abstract**

Aims: The performance of diabetes registries in North America, Europe, and Asia, has been reviewed in the present paper.

**Methods:** The diabetes registries have been used for data storage, patient reminders, proactive care monitoring, and physician alerts, among other things, the goals primarily being improvements in quality of care and reduction in hospitalization rates. The main question is: could the high dollar investments in electronic registries be justified, and could diabetes registries lower the cost of treatment?

**Results:** Our critical data analysis of some countries North America, Europe, and Asia reveals that the quality of care has improved with the introduction of diabetes registries in these countries. At the moment, the effects of diabetes registries on healthcare policies are not clear, and more studies are needed to affirm claims about the cost-saving potential of diabetes registries. The main findings of our analysis are that medical teams would have to shift their focus from population care to individual care, use the plethora of information in the database to identify vulnerable individuals, and to preempt the emergence of complications of both type of diabetes.

**Conclusions:** The present data analyses of several countries strongly recommend that those in charge of diabetes registries should regularly engage with the various stakeholders-insurance companies, pharmaceutical companies, employers, and governments-involved, and should design healthcare policies that deliver low-cost, high value care and address the racial and ethnic biases surrounding healthcare.

#### Introduction

A disease registry contains the listing of all patients with a specific disease, laboratory data, medication history, socioeconomic indicators, and complications afflicting each patient [1]. An ideally designed diabetes registry is a computer-based searchable list that links all members of a patient's healthcare team and plays a critical role in treatment design [2]. While registries exist at the local, national, or international level for various diseases, as of 2014, about 30 diabetes registries were identified worldwide [3]. Obviously, there are many countries that lack a diabetes registry or have a newly launched registry. Fiji is one such country, where a computerized National Diabetes Registration was launched in 2017. The importance of timely notification or entry of newly diagnosed cases into databases is critical for healthcare systems due to a variety of reasons that are examined here.

In the present review, we will describe the key features of diabetes registries, such as evaluate the effectiveness of care management at existing national diabetes registries, discuss the various ways that registries can help better deliver evidence-based care and help formulate healthcare policies,

and recommend that algorithms be developed that can predict the onset of diabetes and help physicians in diagnosis [4]. We also identify steps that can be undertaken to improve the utility of diabetes registries.

#### **Key features of a successful diabetes registry.**

Diabetes registry include, but are not limited to, real-time data availability, search ability, accessibility to all providers, ability to issue timely reminders for lab and screening tests, and a capability to provide feedback to providers [1-5]. An electronic registry can provide quality of care measures that can reward physicians and clinical teams based on performance. It can also ensure adherence by provider and make certain the application of registry. Gabbay RA et. al.(2006) [5] has proposed a 'clinic champion' and a clinic leadership team with a coordinator,

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Received: July 30, 2021; Accepted: Aug 10, 2021; Published: Aug 17, 2021

preferably a non-physician with proven management skills, to achieve these goals [5]. A local clinic leadership team can use models of shared governance such as delegation of authority. For example, physicians are reluctant to typing information into the registry, so, a delegate would make a difference by overseeing the execution of strategies recommended by the registry, by tailoring clinic- specific interventions, and by marshaling appropriate resources aimed at helping clinics adapting to the challenges.

The rising costs of healthcare make a strong case for newly established registries to follow some of the strategies that have resulted in cost savings in many health systems. In countries with successful registries, doctor's offices and hospitals have access to computer-based data systems and newly diagnosed cases can easily be digitally entered into a repository that would be accessible to healthcare providers. The result is paperwork reduction and fewer office visits.

# Registries aid in formulating healthcare policies.

While the influence of diabetic registries on health policies is yet to be ascertained [3]. It is not too far-fetched to imagine that health practitioners can tap into the vast amount of information available in registries to identify patients at risk as well as barriers to treatment. Moreover, identification of barriers to treatment can then help inform national and even international policy making. For example, the Diabetes Registry Outcomes Project for HbA1c Reduction (DROPR) was successfully used in Canada to identify patients from a registry with more than ten thousand patients. These patients had persistently high HbA1c levels (> 9%) and faced barriers in achieving glycemic control. Some of the barriers that these patients identified included lack of psychological support, challenging socioeconomic circumstances, lack of accessibility (not having transportation and poor communication), and comorbidity. Next, a barrier-specific care path was implemented. The care path included reducing the barriers by training diabetes educators about the barriers faced by the patients, by providing social support and translation services, by arranging transportation, by using phone or email consultation, and by utilizing flexible scheduling [6]. The results, at 12 months of intervention, showed that 60 % of the patients (n = 136) could achieve a 1.5 % reduction in their HbA1c through structured diabetes program. Whereas, HbA1c had declined about 0.5 % in patients (n = 966) receiving standard care [6]. While other studies are needed to further ascertain the effectiveness of registries in promoting glycemic control, the results of the DROPR of HbA1c trial can be illustrative of how a diabetes registry could be used to identify at-risk patients, to locate barriers to treatment, and to design intervention strategies that can lead to better glycemic control. Taken a few steps further, these lessons can lead to the formulation of policies that would allocate resources to alleviate the socio-economic disadvantages patients' face, to offer telephonic and video

consultations to patients, to offer nutritional counseling, and to design preventive care.

# Effectiveness of Care management at existing registries.

Care management is defined as an array of activities and services delivered by a healthcare team that reduces the need for medical services and helps patients and caregivers better manage the disease ([7], Robert Wood Johnson Foundation). An ideal diabetes registry would lead to improved quality of care for patients and come national diabetes registries have already succeeded in improving quality of care. In Singapore, the Chronic Disease Management System, built in 2005, resulted in greater number of patients with target level LDLcholesterol and fewer patients with poorly controlled HbA1c [8]. An ideal diabetes registry will also be expected to result in cost savings since the annual global cost of diabetes care excess USA \$ one trillion [9]. Even though several studies and computer models purporting to address cost-effectiveness of Internet-based disease management (IBDM) have been put forth in recent years, conclusive evidence about savings emanating from the use of diabetes registries is lacking.

A recent study has shown that individual with type 2 diabetes that participate in registries are 15 % less likely to use unnecessary hospitalization and 20 % less likely to visit emergency rooms [10]. Bu et al. [11] conducted a modeling study to compare benefits from three categories of diabetes care management technologies: technologies used by providers; technology used by payers; technology used by individual with diabetes [11]. A simulated model was produced that reflected the demographic and epidemiological characteristics of the broader USA population. This model utilized data from major clinical trials and epidemiological studies to estimate the effect of Internet-based diabetes management on major parameters such as HbA1c, retinopathy, neuropathy, blood pressure, total cholesterol, and compliance with foot, eye, and micro albuminuria examinations [11]. Their findings conclude that provider centered technologies, i.e., diabetes registries had saved nearly 14 billion dollars in the USA over a ten-year period of 2004-2014 [11]. Although, cost-benefit analysis of the long-term use of diabetes registries is expensive, difficult to design, and takes a long time, but it is indubitable that registries allow long-term storage of data, reduce the search time, afford prompt data retrieval, and enable centralized data sharing [11]. Although, cloud storage is expensive, it allows long term storage. So, it can be concluded that a broader utilization of diabetes registries can possibly result in substantial cost savings.

Diabetes registries remove the emergence of comorbidities and delay the onset of later complications of the diabetes mellitus disease in individuals.

Registries, if properly used, can reduce hospitalization by preventing the emergence of co-morbidities and delaying the onset of later complications of the disease. Entering information about newly emerging complications in patients into an interconnected and searchable database will allow physicians to be preemptive and help prevent a diabetic patient from developing problems down the road. For example, diabetes predisposes patients to diabetic retinopathy. Any physician treating these patients can easily access these results and find patients that were diagnosed with retinopathy, those individuals with diabetes that missed laser therapy and also keep an eye on any untoward changes in visual acuity and eye health of the individuals with diabetes [12].

Does the use of a diabetes registry enhance the quality of life in individuals with diabetes? With the advancements in medical care and technology, albeit in the presence of rising healthcare costs, we have witnessed some improvements in the quality of life in individuals with type 1 diabetes. In a recent study, about 800 patients that have lived with type 1 diabetes for 40 plus years, across 5 regions in **France**, were questioned about their quality of life. The answers were reassuringly positive and indicated that more than two thirds of these individuals had an active life: 55 % of these had been employed, 38% had continued to play sports; and 66 % had been traveling [13]. When it comes to quality of life for individuals with T2DM, there is no denying the fact that lifestyle modifications can delay the onset of complications and afford a quality of life not much different from that enjoyed by people with enviable health. How much of the improvement in the quality of life enjoyed by individuals with T1DM or T2DM can be attributed to the successful implementation of a diabetes registry is still being investigated.

#### Algorithms and Predictive Clinical Analyses.

The future of any health registry with the impending popularization of telemedicine and automation lies in its capacity to transform to a predictive and interfacing platform. Data, reports, and medical charts in any National Disease Registry can be fed into software that can be taught to make predictions on patients that are most likely to develop future complications of the disease. Periodic alerts can then be issued to medical teams that can take appropriate steps at intervention. (Figure 1)

# How many national diabetes databases exist and how do these databases affect daily practice?

National diabetes databases exist in 12 countries, namely, **Sweden**, **Norway**, **Denmark**, **Holland**, **Germany**, **Scotland**, **England**., **Latvia**, **USA**, **Saudi Arabia**, **and and Finland**(Jessica C et.al 2020). The former Minister of health, Fiji, Rosy Akbar launched National diabetes registry of **Fiji** in 2017 (Fiji Times 9.9.17) to record all diabetes patients' data in database.

While Australia boasts the distinction of having started the national registry in 1987, England's registry includes the

highest number of individuals, and Scotland covers almost all its diabetes individuals [3]. Strikingly, USA and England have registries that don't cover children with either type 1 or 2 diabetes mellitus. Impressively, the Australian registry is designed to improve self-management in diabetes individuals and to help them to obtain diabetes products at lower cost [3]. While both manual and automated data collection are used by these registries, there is a growing tendency for electronic health records to be transmitted into the database. The source of the data collected is different: hospitals provide clinical and laboratory data; data on mortality and time trends is fed into the system by national sources [3]. In the USA, the Diabetes Collaborative Registry (DCR) was started in 2014 as the culmination of joint efforts by the American College of Cardiology, American Diabetic Association American College of Physicians, American Association of Endocrinologists, and Joslin Diabetes Center [14]. Primary care physicians, specialists, endocrinologists, and cardiologists have access A to the DCR via the website (www.thediabetesregistry.org). Using a system that extracts relevant, standardized data, the DCR tracks data on seven metrics: HbA1C; retinopathy score, nephropathy score, neuropathy score, blood pressure control, ACE or ARB therapy patients, and tobacco use history. A fragmentation of care occurs when patients receive treatment from different specialists- an individual with T2DM admitted to a cardiac hospital with cellulitis and poor glycemic control evokes a nightmarish scenario for any diabetes registry. Any data entered at cardiology might miss any measures taken to improve glycemic control.

One of the most ambitious registries of diabetes has been launched in **Saudi Arabia** with a stated goal of serving as an electronic sink of clinical, investigational and medical information [12]. The most intriguing feature of the Saudi National Diabetes Registry (SNDR) is the integration of a Geographic Information System that provides interactive mapping and economic assessment of the disease across the country [12]. Inclusion of cost analysis of disease expenditures and consideration of socio-economic factors impacting the burden of the disease enable the SNDR to act as an advisory body that helps in planning prevention programs.

### How can Diabetes Registries be improved?

Improvements in the performance of diabetes registries will require standardization of parameters, congruity in the definition of standards, and agreement with regards to outcome measures. Moreover, psychosocial well-being should be considered as a variable and improvements in social isolation and emotional distress as global outcomes.

Based on our thorough examination of the literature, we found that diabetes registries do not record the same Based on our thorough examination of the literature, we found that diabetes registries do not record the same parameters and

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some measures were missing in all registries. Surprisingly, the single most important parameter of glycemic control, HbA1c was not recorded in all registries. Neither was blood pressure even though the comorbidity of hypertension can significantly raise the risks of vascular complications in diabetes [3]. We also found that almost all diabetes registries lacked any measure of the psychosocial status of the patients. Furthermore, while diabetes registries give good indications about the socioeconomic conditions of patients, at present, diabetes registries are unable to provide clinical teams with any information about the emotional well-being of the individuals. It has been noticed by both the general public and researchers that social isolation and emotional disturbances can likely worsen the outcomes mortality and hospitalization in individuals with type 1 and type 2 diabetes [15]. In a recent study, for example, a psychometric analysis of emotional regulation in diabetes patients led to the conclusion that diabetes-related distress is linked with negative emotional states and adeptness [16].

We also found that most free clinical laboratories in the **USA** don't use a diabetes registry, a primary reason being that currently the federal government doesn't disburse them for adopting electronic health records [17]. It will be highly desirable to petition Health and Human Services to reconsider its existing policy and entice free health clinics to begin using diabetes registry.

In the future, it will be helpful if a global set of standard parameters or variables could be entered into all or most diabetes registries. For example, the International Diabetes Foundation could seek inputs from medical professionals and recommend that a certain number of variables, such a HbA1c, diabetic foot exam score, uric acid levels, retinopathy exam results, GFR, and blood pressure, be adopted by all registries, and yet give them options to include variables that might be necessary due to geographic or socio-economic constraints. Across the board, most diabetes registries include similar variables, yet the definitions of these variables vary [3]. It is important to facilitate global data sharing, outcome measures ought to be standardized as well throughout all diabetes registries.

#### Fiji Diabetes Register.

Located in the Pacific Ocean, the prevalence rate of diabetes higher in Fiji (12-13%). It is also high in other pacific countries. In the case of Fiji, one of the earliest published reports dates the establishment of a national register in 1970, mentioning inaccurate case reporting and double notification [19]. The latest Diabetes Registration is an initiative of Diabetes Fiji Inc. with the support of LDS Charities in Fiji and health information unit of Ministry of Health & Medical services (MHMS). A computerized National Diabetes Registration was launched in 2017 with the stated goal of

giving health professionals nationwide access to registration records. The former Head of Wellness and National Adviser of NCD Ministry of Health Fiji endorsed the diabetes registration working group to facilitate and strengthen the diabetes registration. Teams from Health information unit of Ministry of Health (MHMS) and Diabetes Fiji mobilized diabetes registration. The purpose was to identify and address the gap in the total number of people living with diabetes registered versus the actual number of people with diabetes according to survey data and other systems that capture diabetes information such as Diabetes Notification System, PATISplus, Consolidated Monthly Return Information System (COMRIS), Mortality database and Hospital Return Monthly Tearoffs. The data on these systems need to be explored and triangulated to understand the facility data on diabetes. There is also anecdotal evidence of incompleteness and poor quality data mostly due to incomplete notifications and diabetes cases not being notified. There is also screening application founded through DFAT, Aus, facility called the Tamanu Screening app which captures NCD screening data and is in the Pilot phase.

Additionally, the country uses PATISplus (Patients administration and Information system) which has morbidity data and SOPD data that can be used to strengthen the registry and vice versa. Other system that capture diabetes data in Fiji is mortality database and this will need to be fed into the registry for precise prevalence. All systems that capture patient's data in Fiji need to be integrated with diabetes registry for the added benefit of continuation of care, including linkages with private sectors health care.

The importance of timely notification of newly diagnosed cases can't be overemphasized in the Asia Pacific Island region, where 3 out of 4 cases remained undiagnosed about ten years ago [20].

### Aim and Objectives of Fiji Diabetes Registry

- evidence based high quality health information of patients to improve health status of all Fijians.
- Improve policy decision making by having accurate data for Procurement of drugs, lab reagents and consumable.
- Better access to the patient's minimum medical history and continuum of care. Share information to other health worker who are treating diabetes patients allowing the medical community to better track patient and give continuity of care.
- Increase awareness of general population towards diabetes.
- Decrease risk of long term complications
- Measure the outcome of quality of care and diabetes related campaign.

While the goal of diabetes therapy in Fiji happens to be a reduction in HbA1c, the fact that the process of using the registry is cumbersome and participation in the registry entails no incentives combine to make its implementation difficult. In almost every hospital, there is a full team that includes doctor, nurse, educator, foot care nurses, dietitian, physiotherapist, and counselors. For example, if any individual's HbA1c level is high due to poor compliance with the recommended diabetic diet, the counselor and dietitian deal with this patient. If the HbA1c level is high due to stress, then counselors will teach the patient about stress management. If the HBA1c is out of control due to other factors such as drug therapy or co-morbidity, a doctor will look after this to control patient diabetes.

Some healthcare workers are reluctant to use the registry because it is too large and lots of information need to be filled. Moreover, information, e.g. all lab reports, that are required to to be entered into the registry is not available at the initial diagnosis of the patients. The Fiji Diabetes registry could be improved by integrating all patients' data collecting systems with diabetes registry. Healthcare workers need to use Diabetes Apps for data collection that support all networks (DG cell, Voda phone, TFL) because some islands have only DG cell networks. These networks and data systems need to be integrated with the private hospitals, clinics and GPs because most of them are not maintaining Diabetes Registry. There has to be a follow- up on the data in the registry and intervention if needed. Furthermore, medical teams could be rewarded for achieving their primary goal of HbA1c reduction. We suggest that other goals be added on to the existing one and a graded reward system put in place to further incentivize the use of the registry across the country

# Pathophysiology and diagnosis of individual with type 2 diabetes mellitus in Fiji.

Diabetes mellitus (DM) is a metabolic disorder of multiple etiology, characterized by chronic hyperglycemia with disturbance of carbohydrate, protein and fat metabolism resulting from impaired in insulin secretion, insulin resistance or both [21,22]. The major three types of individuals with type 1 and type 2 and gestational diabetes. New diagnosis of individuals with T2DM is based on a Fasting plasma glucose >7.0 mmol/L (126 mg/dl) or a random plasma glucose >11 mmol/L (200 mg/dl) in individual with classic symptoms of hyperglycemia or hyperglycemic crisis or a 2 hour plasma glucose level of >11 mmol/L (200 mg/dl) during a 75 gm oral glucose tolerance test (OGTT)) or HbA1c level 6.5% (48 mmol/mol) or higher (ADA). Diagnosis of Gestational diabetes based on the performing 75 gm OGTT after overnight fast at least 8 hours. The diagnosis of GDM is made when any of the following criteria are met fasting blood glucose 92 mg/dl (5.1 mmol/L) or higher., 1 hours, 180 mg/ dl (10.0 mmol/L) or higher 2 hours 153 mg/dl (8.5 mmol/L) or higher.

In **Fiji**, the guidelines for diagnosis of DM call for testing overnight fasting blood sugar level even though random blood sugar can also be used. Two positive results on two different days are recommended. A single positive result is significant if there is unequivocal hyperglycemia with metabolic decompensating or if accompanied by symptoms of diabetes. HbA1c level is used in Fiji for monitoring the control of DM. A person, not known to have diabetes, presenting with the following symptoms: weight loss, polyuria, polydipsia, lethargy, pruritus vulvae, and banalities needs to have blood glucose tests done to establish the diagnosis. Since diabetes is a notifiable disease in **Fiji**, all newly diagnosed cases need to be notified.

# Metrics Used in Fiji.

Diagnosis of diabetes is based on the following blood result: The normal venous blood sugar level of fasting blood sugar (FBS), random blood sugar (RBS) < 6.1 mmol/L to < 6.5 mmol/L, impaired fasting glucose (IFG) 6.1 to 7.0 mmol /L, impaired glucose tolerance (IGT) 6.5 to 11.0 mmol/L, diabetes mellitus (DM) >7.0 mmol /L > 11.0 mmol/L (*The values above do not apply to the pregnant mothers*). The HbA1c result of 6.5 % or more is now considered to be useful in the initial diagnosis of diabetes. However, its greatest value in Fiji at present is for monitoring and control of blood sugar levels.

#### **Discussion**

Several advantages accrue from a properly functioning diabetes registry. These include notification of newly diagnosed cases of DM and the ability to predict incidence rate of DM from prevalence rates. A diabetes registry can help policymakers formulate health care policy. Health departments can use data from the diabetes registry in planning the procurement of drugs and realize cost savings. Physicians can monitor individuals with diabetes compliance, measure glycemic control and more importantly, a diabetes registry can help to eliminate the emergence of comorbidities in the future. It can also delay the onset of late complications. Epidemiologists can monitor the diabetes registry to gain a better picture about the prevalence and incidence of the disease, about patient adherence and compliance, and about the effectiveness of therapeutic regimens. Data in the registry can identify any surges in the incidence of type 2 diabetes in a particular region, thereby enabling the recruitment of diabetes educators and nutritionists to push for prevention efforts. In addition, examination of laboratory results can quickly pinpoint how faithfully individuals with diabetes follow therapeutic instructions and dietary regimens. Moreover, healthcare teams with instant access to results of kidney

function test results that have been entered into the registry can gain valuable insights into developing trends in particular regions with respect to the emergence of later complications of diabetes such as nephropathy. The same would be true for eye exams and foot exams in cases of diabetic retinopathy, and neuropathy, respectively.

What are the disadvantages that might result from the use of a national registry? Can it be hacked? Can it be abused? Yes. Any computer-based system with huge data will be vulnerable to hackers that can steal confidential medical records that must be protected. At the same time, there exists the potential for misuse of personal medical information by employers and insurance companies. The potential for misuse is magnified in countries lacking laws that deter misuse of personal medical information and mandate stiff penalties for abuse.

National diabetes registries serve crucial roles in the prevention and management of hyperglycemia and its attendant complications. In many countries, searchable, interconnected databases have utilized GPS technology employed to identify and target regions that have displayed poor glycemic control [12]. Existent reports confirm that measures undertaken after following the metrics provided by the registries helped physicians, caregivers, and educators elicit better patient compliance. Economically, when it comes to cost savings to budgetary allocation of resources and procurement of medical equipment, a registry with timely notification can help achieve economies of scale as well.

#### **Conclusions**

In the future, diabetes registry needs considerable improvements especially in the face of an expanding population of individuals with type 2 diabetes mellitus. Moreover, there are needs for global harmonization in the way different parameters are used by different diabetes registries. Most importantly, software algorithms and predictive analysis values can be improved to the extent that diabetic registries can help diagnose cases and alert physicians to those individuals that are vulnerable to the debilitating complications of diabetes. Therefore, for national diabetes registry to work best, it will be important to require healthcare teams to enter data in a timely fashion, raise societal awareness of the confidentiality of medical information, install adequate layers of IT security to protect databases, and establish a legal framework that can prevent the misuse of confidential, private information. Diabetes registries have been effective in most countries that have utilized them. These registries began with different goals but now there is a greater need to align their goals to some degree. Since national registries use different parameters, there needs to be further standardization of outcome measures that can be recommended by the International Diabetes Foundation. In short, the present data analyses of North America, Europe and Asia indicate that those in charge of diabetes registries should regularly engage with the various stakeholders-insurance companies, pharmaceutical companies, employers, and governments-involved, and should design healthcare policies that deliver low-cost, high value care and address the racial and ethnic biases surrounding healthcare [23,24]. Moreover, during these times of a pandemic, there have been calls for a global diabetes registry that will track the development of diabetes in corona patients. While there is a need for an integrated global diabetes registry, it will be more prudent to have more national registries first. Once we have enough countries with diabetes registries, an international registry will be the icing on the cake.

#### **Abbreviation:**

DM = diabetes mellitus, T1DM or T2DM = type 1 or type 2 diabetes mellitus, IT = inform Tech.

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**Citation:** Ahmed M, Ismail A, Nand D, Jamal SA (2021) Evaluation of the Performance and Importance of Diabetes Registries of Several Countries-calls for greater integration. J Diab Clin Stud 5(1): 001-008.

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