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Building a population-based diabetes register: An Italian experience



Paola Ballotari^a, Sofia Chiatamone Ranieri^{b,*}, Massimo Vicentini^a,
Stefania Caroli^a, Andrea Gardini^c, Rossella Rodolfi^d, Roberto Crucco^e,
Marina Greci^f, Valeria Manicardi^g, Paolo Giorgi Rossi^a

^a Servizio Interaziendale di Epidemiologia, Local Health Authority of Reggio Emilia, Italy

^b Clinical Chemistry, Laboratory and Endocrinology Unit, Department of Laboratory Medicine, Azienda Ospedaliera ASMN, Istituto di Ricovero e Cura a Carattere Scientifico, Italy

^c Pharmaceutical Department, Local Health Authority of Reggio Emilia, Italy

^d Planning and Control Staff, Local Health Authority of Reggio Emilia, Italy

^e Information Technology Unit, Local Health Authority of Reggio Emilia, Italy

^f Primary Care Department, Local Health Authority of Reggio Emilia, Italy

^g Department of Internal Medicine, Hospital of Montecchio, Local Health Authority of Reggio Emilia, Italy

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ABSTRACT

Aims: To describe the methodology used to set up the Reggio Emilia (northern Italy) Diabetes Register. The prevalence estimates on December 31st, 2009 are also provided.

Methods: The Diabetes Register covers all residents in the Reggio Emilia province. The register was created by deterministic linkage of six routinely collected data sources through a definite algorithm able to ascertain cases and to distinguish type of diabetes and model of care: Hospital Discharge, Drug Dispensation, Biochemistry Laboratory, Disease-specific Exemption, Diabetes Outpatient Clinics, and Mortality databases. Using these data, we estimated crude prevalence on December 31st, 2009 by sex, age groups, and type of diabetes. **Results:** There were 25,425 ascertained prevalent cases on December 31st, 2009. Drug Dispensation and Exemption databases made the greatest contribution to prevalence. Analyzing overlapping sources, more than 80% of cases were reported by at least two sources. Crude prevalence was 4.8% and 5.9% for the whole population and for people aged 18 years and over, respectively. Males accounted for 53.6%. Type 1 diabetes accounted for 3.8% of cases, while people with Type 2 diabetes were the overriding majority (91.2%), and Diabetes Outpatient Clinics treated 75.4% of people with Type 2 diabetes.

Conclusion: The Register is able to quantify the burden of disease, the first step in planning, implementing, and monitoring appropriate interventions. All data sources contributed to completeness and/or accuracy of the Register. Although all cases are identified by deterministic record linkage, manual revision and General Practitioner involvement are still necessary when information is insufficient or conflicting.

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* Corresponding author at: Clinical Chemistry, Laboratory and Endocrinology Unit, Department of Laboratory Medicine, Azienda Ospedaliera ASMN, Istituto di Ricovero e Cura a Carattere Scientifico, Viale Risorgimento 80, Reggio Emilia, Italy. Tel.: +39 0522 295730; fax: +39 0522 296052.

E-mail address: sofia.chiatamoneranieri@asmn.re.it (S. Chiatamone Ranieri).
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1. Introduction

Diabetes is a major public health concern worldwide. In 2013, 392 million people had diabetes; by 2035 there will be 592 million [1]. Type 2 diabetes accounts for 95% of diagnosed cases and Type 1 diabetes for the remaining 5% [2]. The estimated prevalence for Italy was 7.9% in adults (20–79 years) in 2013, forecasted to increase to 9.8% for 2035 [1].

Diabetes is a chronic disease with a high impact on health systems. A study conducted in Emilia-Romagna region [3] found a per capita expenditure for diabetic patient 2.5 times higher than that for a non-diabetic citizen.

The impact is also relevant on individual health conditions due to possible long-term complications, such as retinopathy, nephropathy, peripheral and autonomic neuropathy, and increased incidence of atherosclerotic cardiovascular, peripheral arterial, and cerebrovascular disease [4–7].

To counteract the increase of Type 2 diabetes burden, WHO promotes a change in model of care, recommending the application of a patient-oriented chronic care model able to integrate management of disease into primary health care whenever feasible [8].

In light of this recommendation, the Italian Ministry of Health published guidelines in 2008 for shared care management of Type 2 diabetes [9], mainly directed to non-insulin-dependent diabetes patients and defined as the joint participation of primary care and specialised care (diabetes clinic), where the general practitioner (GP) is in charge of routine metabolic check-ups, if the blood glucose level is on target and no complications arise. The Emilia-Romagna region Health Authority updated its guidelines in 2009 [10]. In this framework, an information system is needed in order to evaluate the performance of the new model of care (i.e. shared care involving the GP) compared to specialised care (i.e. directly diabetes clinic care). Emilia-Romagna region guidelines encourage local health authorities to set up a diabetes register based on routinely collected health data. The advantages of this approach to setting up a disease-specific register include feasibility, accessibility, and low cost [11–17].

The aim of this paper is to describe the methodology used to set up the Reggio Emilia Diabetes Register, measuring the contribution of each source of information and estimating the diabetes prevalence on December 31st, 2009 in order to evaluate the algorithm reliability.

2. Materials and methods

2.1. Setting

Reggio Emilia is a province situated in Emilia-Romagna region, northern Italy. The health system is administered by the local health authorities; the province is divided into five health districts. The Diabetes Register covers the whole province population, i.e. the 525,267 residents on December 31st, 2009 [18].

The Diabetes Register uses WHO diabetes classification [19]: Type 1 diabetes; Type 2 diabetes; others specific types (i.e. genetic, drug- or chemical-induced, unknown), and no

diabetes (i.e. gestational diabetes, IGT – impaired glucose tolerance, IFG – impaired fasting glycaemia).

In the Reggio Emilia province there are 7 Diabetes Outpatient Clinics able to provide specialised care for diabetes patients. Patients are referred to specialised centres by the GP, but the patient can choose to be seen only by GP. When the patient with Type 2 diabetes accepts specialised care, diabetologist and GP decide together whether he needs to be followed directly by Diabetes Clinic or if he is eligible for shared care management. Thus three models of care are possible: GP only, Diabetes Clinic directly, and shared care management. The patients with Type 1 diabetes are in charge of Diabetes Outpatient Clinics.

In the northern district of the Reggio Emilia province the shared care model of managing Type 2 diabetes has been in place since 1999. In 2005, the whole province adopted the first edition of the regional guidelines [20], which were updated in 2009 [10].

2.2. Sources

Data sources and criteria used to ascertain cases of diabetes and to assign type of diabetes and model of care are reported in Table 1.

2.2.1. Disease-specific Exemption database

This file contains the patients exempted to co-payment (d.m. 329/99 and subsequent amendments) [22]. The Italian National Health System provides universal health insurance to all the citizens. The implementation of the health system is through the regional health authorities which are organised into local health authorities. A small co-payment is made by subjects for outpatient care (diagnostic tests and specialised visits) and drugs, although exemption can be granted in case of specific diseases, including diabetes. In order to obtain the exemption, the diabetes patient must present to the local health authority a certificate issued by a diabetologist or other established documentation.

Exemption database uses the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM).

2.2.2. Hospital Discharge database

This file includes all resident discharges from any Italian hospital. There is one primary discharge diagnosis and up to fourteen secondary diagnoses, coded using ICD-9-CM.

2.2.3. Biochemistry Laboratory database

This file includes laboratory results of tests carried out in the provincial public health network, coded using internal classification.

2.2.4. Drug Dispensation databases

The files are two: the first is the Pharmacy Drug Dispensation database which contains information on drugs dispensed by pharmacies located in the province; the second one is the Direct Drug Dispensation database collecting information on drugs directly distributed by the health services (e.g. Diabetes Outpatient Clinic, hospitalisation Unit). Drugs are coded using anatomic therapeutic chemical (ATC) classification.

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