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The International Diabetes Federation's Guide for Diabetes Epidemiological Studies

Running head

Diabetes epidemiological studies

Authors

Pablo Aschner¹, Suvi Karuranga², Steven James³, David Simmons⁴, Abdul Basit⁵, Jonathan Shaw⁶, Sarah H Wild⁷, Katherine Ogurtsova⁸ and Pouya Saeedi², **on behalf of the International Diabetes Federation's Diabetes Epidemiological Guide Writing Group**

Institutions

¹Javeriana University School of Medicine and San Ignacio University Hospital, Bogotá, Colombia

²International Diabetes Federation, Brussels, Belgium

³School of Nursing, Midwifery and Paramedicine, University of the Sunshine Coast, Petrie, Australia

⁴Macarthur Clinical School, Western Sydney University, Campbelltown, Australia

⁵Baqai Institute of Diabetology and Endocrinology Medical Unit IV, Baqai Medical University, Karachi, Pakistan

⁶Baker Heart and Diabetes Institute, Melbourne, Australia

⁷Usher Institute of Population Health Sciences and Informatics, University of Edinburgh, Edinburgh, Scotland

⁸Institute for Health Services Research and Health Economics, Heinrich Heine University Düsseldorf, Düsseldorf, Germany

Corresponding author

Pouya Saeedi: International Diabetes Federation, 166 Chaussee de La Hulpe, B-1170 Brussels, Belgium; Telephone: +32-2-538 55 11; Email: Pouya.saeedi@idf.org; Atlas@idf.org

Authors contributions

The paper was conceived by members of the International Diabetes Federation's Diabetes Epidemiology Guide Writing Group. All authors wrote, read and approved the final manuscript.

Potential conflicts of interest

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The global prevalence of diabetes mellitus has been increasing steadily for over 50 years and has now reached pandemic proportions. The prevalence of both diagnosed and undiagnosed diabetes was estimated to be 9.3% (463 million people) in 2019, and is projected to rise to 10.2% (578 million) by 2030 and 10.9% (700 million) by 2045 [1]. The rising prevalence of diabetes is related to aging populations and wider adoption of unhealthy life-styles, resulting in higher prevalence of obesity [2]. In 2006, the United Nations Resolution 61/225 encouraged all nations to develop national policies for the prevention, care and treatment of diabetes to reduce the growing threat from the pandemic [3]. A pre-requisite to achieving this common goal, and to be able to demonstrate the impact of new policies, is the capability to measure the distribution of diabetes (prevalence and incidence) and its determinants (risk factors), as well as its consequences including complications, premature mortality, reduced quality of life and increased health expenditure.

For the last two decades, the First through Ninth Editions of the International Diabetes Federation (IDF) Diabetes Atlas have provided worldwide diabetes epidemiological data. The IDF Diabetes Atlas rates the quality of the identified data sources for each edition by using an analytical hierarchy process, based on defined characteristics. Preference is given to data sources that are nationally representative, conducted in the previous five years, published in peer-reviewed journals and are based on objective measurement of diabetes status. Studies are excluded if they are not population-based, only include people in a specific age group or do not include age-stratified data, or if they use unconventional glucose thresholds to define diabetes.

The availability of data is improving, but unfortunately not all countries have high-quality data on diabetes prevalence and even fewer countries have data on incidence of diabetes. In the past decade, the number of countries with data on diabetes prevalence, for example, has increased

from 91 in 2009 [4] to 138 in 2019 [5]. However, one third (57 out of 195 countries worldwide) remain without high-quality data. On the other hand, some of the data are becoming out-of-date. In countries without in-country or updated data, diabetes prevalence estimates and standardized incidence rates are generated by extrapolation using diabetes prevalence data from countries deemed to be similar in terms of ethnicity, language, World Bank income classification and geographical proximity. While necessary to provide global coverage, extrapolated estimates cannot be a substitute for well executed and high quality in-country data.

The high number of countries without high-quality data sources has motivated the IDF Diabetes Atlas Committee to produce a guide for diabetes epidemiological studies, with the intention of stimulating and supporting clinicians, epidemiologists and any other researchers to generate basic local diabetes epidemiological data using standardized criteria. Studies, from low and middle-income countries are particularly encouraged. The expectation is that quality studies will be designed, conducted, analyzed and published, to address gaps in diabetes epidemiological data, thereby providing a better global picture of the diabetes situation.

The *IDF guide for diabetes epidemiological studies* contains 10 chapters. In summary, the guide firstly presents the principles of prevalence studies which emphasise the rigor needed for having an unbiased sampling frame, and includes discussion on methodology such as the advantages of different choices of the sample population, case identification, as well as the inclusion of aspects such as ethnicity, sociodemographic and anthropometric factors. Subsequent chapters focus on survey organisation and conduct (including the study team, protocol, budget preparation, and data collection), and the principles of data handling and statistical analysis (including data validation, data weighting, statistical methods of prevalence calculation, bias in estimates, adjustment for confounding and validity of analysis). A chapter

on incidence highlights the importance of this metric in both type 1 and type 2 diabetes, and advises how to assign diabetes type in registries and administrative datasets. This is followed by a chapter on the principles of studies involving mortality, survival and life expectancy in people with diabetes. A chapter on assembling diabetes registries using routine data and their application for diabetes epidemiology considers the difficulties of maintaining complete and accurate records, and gives recommendations on how to plan and implement a registry. A special chapter is dedicated to the particularities of studies on pregnant women, children and adolescents. Issues related to elderly populations are also discussed throughout the document. Finally, the guide provides practical recommendations on how to publish the results, and use of data for advocacy to engage stakeholders in the prevention and management of diabetes and its complications, and to establish national diabetes plans that are appropriate to local contexts.

The *IDF guide for diabetes epidemiological studies* represents a major effort to improve data quality in diabetes surveillance and to support those with limited resources in establishing studies that will inform and evaluate approaches to preventing diabetes, and health service planning. It will be launched in November 2021 and can be found on the IDF website [6]. An online course of the guide will also be launched in early 2021 at the IDF's School for Diabetes [7].

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