Diabetology

Extended Abstract

# Worldwide estimates of incidence, prevalence andmortality of type 1 diabetes in children andadolescents: Results from the InternationalDiabetes Federation Diabetes Atlas, 9th edition-Christopher C. Patterson- Queen's University Belfast, United Kingdom

**Christopher C. Patterson**

## Abstract

Aims:This article describes the methods, results and limitations of the International Dia-betes Federation (IDF) Diabetes Atlas 9th edition estimates of worldwide numbers of casesof type 1 diabetes in children and adolescents.Methods:Most information in the published literature is in the form of incidence ratesderived from registers of newly-diagnosed cases. After systematic review of the publishedliterature and recent conference abstracts, identified studies were quality graded. If nostudy was available, extrapolation was used to assign a country the rate from an adjacentcountry with similar characteristics. Estimates of incident cases were obtained by applyingincidence rates to United Nations 2019 population estimates. Estimates of prevalent caseswere derived from incidence rates after making allowance for higher mortality rates inless-developed countries.Results:Incidence rates were available for 45% of countries (ranging from 6% in the sub-Saharan Africa region to 77% in the European region). Worldwide annual incidence esti-mates were 98,200 (128,900) new cases in the under 15 year (under 20 year) age-groups. Cor-responding prevalence estimates were 600,900 (1,110,100) existing cases. Compared with estimates in earlier Atlas editions, numbers have increased in most IDF regions, reflectingincidence rate increases, but prevalence estimates have decreased in sub-Saharan Africabecause allowance has been made for increased mortality in those with diabetes.Conclusions:Worldwide estimates of numbers of children and adolescents with type 1 dia-betes continue to increase.

Worldwide, regional and national estimatesare produced for incidence and prevalence of type 1 diabetes(T1D) in children and adolescents. Prevalence estimates forchildren under 15 years in the 7th and previous editions ofthe Atlas have been based largely on available published inci-dence rates, with an assumption of a prevalence to incidenceratio of 6.2 made for countries with no available age-specificincidence rates[12]. However, anecdotal and published evi-dence suggests that the resulting prevalence figures wereunrealistically high in less developed countries where lackof access to insulin and facilities for T1D management resultsin high case mortality[13,14,15].Since the 8th edition IDF Diabetes Atlas[11]worldwideestimates of incidence and prevalence of T1D in the under15 year and under 20 year age-groups have been produced,and more realistic figures for prevalence have been providedthan in previous Atlas editions by making allowance for thehigher mortality rates in those with prevalent T1D.The objective of this article is to describe the methodsdeveloped for the 8th edition estimates of prevalent casesand to provide more detail and analysis of the incidenceand prevalence estimates for the 9th edition.

If more than one study was available for a country, the fol-lowing criteria were applied to select the most suitable: morerecent studies, covering a large part of the country, includingthe age ranges 0–14 and 15–19 years, providing age/sex-specific rates for 0–4, 5–9, 10–14 and 15–19 year age-groups,and quality grade A.In several countries, two or more studies were judgedequally suitable on these criteria and the results of thesestudies were combined by averaging age/sex-specific rates.All studies used in the 9th edition estimates for T1D in chil-dren and adolescents provided incidence rates rather thanprevalence rates.2.2. International Diabetes FederationThe IDF divides countries into seven Regions: Africa (AFR),Europe (EUR), Middle East and North Africa (MENA), NorthAmerica and Caribbean (NAC), South and Central America(SACA), South-East Asia (SEA) and Western Pacific (WP). Thisregional division was used throughout this

**Christopher C. Patterson**
Queen's University Belfast, United Kingdom, E-mail: c.patterson@qub.ac.uk

article.2.3. World Bank income groupCountries were assigned an income group based on grossnational income (GNI) per capita in 2018 as published in theJune 2019 World Bank Income Classification[16]:low-income country (LIC)$1025, lower-middle-income country(LMIC) $1026 to $3995, upper-middle-income country (UMIC)$3996 to $12,735; high-income country (HIC) >$12,735.2.4. Incidence rates for childrenIf age-andsex-specificincidencerateswereavailablethe directmethod of standardisation was used, with the standard popu-lation having equal populations in each 5-year age/sex sub-group. If age-specific rates were not provided separately foreach sex then the same rates were assumed for males andfemales. For countries in which no published incidence figureswere available, the 0–14 year standardised incidence rate fromsimilar countries were used instead. The choice of countryfrom which to extrapolate was based on study quality,geographical proximity, per capita income and ethnicbackground. Of the selected publications, only 19 had data on incidencerates of T1D aged 15 or older. This was too small a numberof studies for meaningful extrapolation to neighbouringcountries (the approach used in the 0–14 year age-group).Instead, 28 publications were selected to contribute towardsratio estimates for each IDF Region. Sixteen of these stud-ies were from the EUR Region, three from the AFR Region,one from SACA Region and two from each of the remainingfour Regions.Table 1shows the ratios obtained for eachRegion calculated as the average of ratios for studies fromthe Region with available data. The ratio of 7.0 for the AFRRegion was considerably larger than the ratio for any otherRegion, indicative of a markedly higher incidence in the15–19 age-group relative to the 0–14 age-group in thisRegion.

Nationwide, population-based prospective registries providethe best data on the incidence of T1D in childhood and ado-lescence, particularly if high ascertainment rates are main-tained, but such studies are typically only conducted inwell-resourced countries. Smaller studies can show large yearto year fluctuations in T1D incidence and, where available,several years of data were used to obtain more reliable esti-mates. Given the widely-reported increasing T1D incidencerates in childhood, the use of data published prior to 1990has been discontinued in the 9th edition estimates and themost up-to-date data available for each country has beenused, but many of the sources inSupplementary Table 2giverates which relate only to the 1990s. No attempt has beenmade to adjust these rates to reflect increases in incidencein intervening years, and neither have adjustments beenmade to inflate rates from registries which are known to haveincomplete ascertainment. The expense of maintaining high-quality registries is considerable, and in the future it seemslikely that alternative sources of incidence rate estimates willbe obtained from computerised clinical information systemsand prescription or health insurance databases.As well as the use of extrapolation of incidence from acountry to its neighbours, which was particularly commonin AFR Region where so few countries supplied data, the useof rates from regional studies to represent whole countriesis an obvious weakness, especially in countries with hetero-geneous and ethnically-diverse populations. Again, the avail-ability of more publications with national coverage,particularly from less developed countries, would be the mostsatisfactory solution to this concern.In the previous 8th edition of the IDF Diabetes Atlas, forthe first time, attempts were made to adjust the method ofobtaining prevalence from incidence to take account of thewell-known excess mortality in children and adolescentswith T1D. An important consequence of this is that preva-lence estimates for children and adolescents are no longercomparable with those provided in earlier editions of theAtlas, the lack of comparability affecting particularly theless-developed countries where survival of those with T1Dis poorest. The method that was used can be criticised onthe basis that it requires considerable extrapolation of a rela-tionship between excess mortality in those with T1D (as mea-sured by the SMR) and infant mortality rate that was derivedmainly from data in developed counties[4]

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**Christopher C. Patterson**
Queen's University Belfast, United Kingdom, E-mail: c.patterson@qub.ac.uk