Global incidence, prevalence, and mortality of type 1 diabetes in 2021 with projection to 2040: a modelling study

Gabriel A Gregory, Thomas I G Robinson*, Sarah E Linklater, Fei Wang, Stephen Colagiuri, Carine de Beaufort, Kim C Donaghue, International Diabetes Federation Diabetes Atlas Type 1 Diabetes in Adults Special Interest Group†, Dianna J Magliano, Jayanthi Maniam, Trevor J Orchard, Priyanka Rai, Graham D Ogle*

Summary

Background Accurate data on type 1 diabetes prevalence, incidence, associated mortality and life expectancy are crucial to inform public health policy, but these data are scarce. We therefore developed a model based on available data to estimate these values for 201 countries for the year 2021 and estimate the projected prevalent cases in 2040.

Methods We fitted a discrete-time illness-death model (Markov model) to data on type 1 diabetes incidence and type 1 diabetes-associated mortality to produce type 1 diabetes prevalence, incidence, associated mortality and life expectancy in all countries. Type 1 diabetes incidence and mortality data were available from 97 and 37 countries respectively. Diagnosis rates were estimated using data from an expert survey. Mortality was modelled using random-forest regression of published type 1 diabetes mortality data, and life expectancy was calculated accordingly using life tables. Estimates were validated against observed prevalence data for 15 countries. We also estimated missing prevalence (the number of additional people who would be alive with type 1 diabetes if their mortality matched general population rates).

Findings In 2021, there were about 8·4 (95% uncertainty interval 8·1–8·8) million individuals worldwide with type 1 diabetes: of these 1·5 million (18%) were younger than 20 years, 5·4 million (64%) were aged 20–59 years, and 1·6 million (19%) were aged 60 years or older. In that year there were 0·5 million new cases diagnosed (median age of onset 29 years), about 35 000 non-diagnosed individuals died within 12 months of symptomatic onset. One fifth (1·8 million) of individuals with type 1 diabetes were in low-income and lower-middle-income countries. Remaining life expectancy of a 10-year-old diagnosed with type 1 diabetes in 2021 ranged from a mean of 13 years in low-income countries to 65 years in high-income countries. Missing prevalent cases in 2021 were estimated at 3·7 million. In 2040, we predict an increase in prevalent cases to 13·5–17·4 million (60–107% higher than in 2021) with the largest relative increase versus 2021 in low-income and lower-middle-income countries.

Interpretation The burden of type 1 diabetes in 2021 is vast and is expected to increase rapidly, especially in resource-limited countries. Most incident and prevalent cases are adults. The substantial missing prevalence highlights the premature mortality of type 1 diabetes and an opportunity to save and extend lives of people with type 1 diabetes. Our new model, which will be made publicly available as the Type 1 Diabetes Index model, will be an important tool to support health delivery, advocacy, and funding decisions for type 1 diabetes.

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Introduction

Type 1 diabetes is an autoimmune disease targeting pancreatic β-cells that results in lifelong absolute insulin deficiency. Type 1 diabetes is frequently associated with reduced quality of life, serious long-term complications, shortened life expectancy, and substantial costs for individuals and health-care systems, even in high-income countries and territories (referred to as countries herein) with access to recent advances in diabetes management.[1–4]

Evidence suggests that type 1 diabetes prevalence, incidence and associated mortality vary widely across countries and over time and that prevalence and incidence are increasing.[5–9] In low-income settings where access to or affordability of care are limited, complications and early mortality associated with type 1 diabetes are high.[3,10–13]

Only half of the world's countries, representing 76% of the world's population, have incidence data for children younger than 15 years.[7] This data includes type 1 diabetes registries[14] and longitudinal cohort studies (eg, SEARCH).[15] Of these countries, just 26 also have incidence data for adolescents aged 15–19 years.[6,7] Very few studies exist that estimate type 1 diabetes burden and mortality in low-income countries (LICs) and lower-middle-income countries (LMICs), and incidence in these settings is likely to be underestimated given that death at onset due to failure to correctly diagnose the disease (ie, non-diagnosis) is common.[10,12,16,17] Data on incidence and prevalence in adults are also particularly scarce, but suggest that geographical variation in incidence parallels that

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*Joint first authors

†Members are listed at end of the paper

Life for a Child Program, Diabetes NSW, Glebe, NSW, Australia (G A Gregory MD, J Maniam PhD, Prof G D Ogle DMedSci); **JDRF Australia, St Leonards, NSW, Australia** (T I G Robinson LLB, F Wang PhD, Priyanka Rai MSc); **Sydney Medical School** (G A Gregory, Prof K C Donaghue PhD, Prof G D Ogle) **and Charles Perkins Centre and Faculty of Medicine and Health** (Prof S Colagiuri MD), **University of Sydney, Camperdown, NSW, Australia; Royal North Shore Hospital, St Leonards, NSW, Australia** (G A Gregory); **JDRF Canada, North York, ON, Canada** (S E Linklater PhD); **DECCP, Pediatric Clinic, Centre Hospitalier de Luxembourg, Luxembourg, Luxembourg** (Prof C de Beaufort PhD); **Department of Science, Technology and Medicine, University of Luxembourg, Luxembourg** (Prof C de Beaufort); **Children's Hospital at Westmead, Westmead, NSW, Australia** (Prof K C Donaghue); **Baker Heart and Diabetes Institute, Melbourne, VIC, Australia** (Prof D J Magliano PhD); **Monash University, School of Public Health and Preventive Medicine, Melbourne, VIC, Australia** (Prof D J Magliano); **Department of Epidemiology, Graduate School of Public**

Health, University of Pittsburgh, Pittsburgh, PA, USA (Prof T J Orchard MD)

Correspondence to: Adj Prof Graham Ogle, Life for a Child Program, Diabetes NSW, Glebe, NSW 2037, Australia
grahamo@diabetesnsw.com.au

Research in context

Evidence before this study

Most countries and territories lack data on the burden of type 1 diabetes, including incidence, prevalence, and associated mortality, particularly in adults. Such estimates are critical for improving delivery of care and health outcomes for people living with type 1 diabetes. The Global Burden of Disease 2017 Disease and Injury Incidence and Prevalence Collaborators estimated that there were 13 million people living with type 1 diabetes globally in 2017, and the website for the Institute for Health Metrics and Evaluation updated this figure to 22 million in 2019. In contrast, Green and colleagues in 2021 estimated a figure of 9 million for 2017. We found no published studies that reported trends of the global burden of type 1 diabetes, nor studies that estimated the missing prevalence (the number of additional people who would be alive with type 1 diabetes if their mortality matched general population rates).

Added value of this study

We developed a new, discrete-time cohort-level Markov illness–death model to estimate type 1 diabetes prevalence, incidence, and associated mortality and life expectancy globally and at the country level. Comparison with observed data from 15 countries showed the predicted number of prevalent cases have a median relative difference of 6% from the observed prevalent cases. We also found that the projected prevalence of type 1 diabetes in 2040 will be 13·5–17·4 million people and that low-income and lower-middle income countries will experience the largest relative increases in burden. Furthermore, we also calculated missing prevalence either due to a missed diagnosis or reduced life expectancy in people with type 1 diabetes and estimated that about 35 000 (21%) of all deaths caused by the disorder globally in 2021 occurred in people younger than 25 years due to non-diagnosis.

Implications of all the available evidence

The worldwide prevalence of type 1 diabetes is substantial and growing. Improved surveillance, particularly in adults who make up most of the population living with type 1 diabetes, is essential to enable improvements to care and outcomes. There is an opportunity to save millions of lives in the coming decades by raising the standard of care (including ensuring universal access to insulin and other essential supplies) and increasing awareness of the signs and symptoms of type 1 diabetes to enable a 100% rate of diagnosis in all countries.

observed in children.[18,19] The latest published estimates of the global burden of type 1 diabetes were 13 million in 2017,[20] later revised to 22 million in 2019;[21] and 9 million in 2017.[22]

As highlighted by the *Lancet* Commission,[3] and the *International Diabetes Federation* (*IDF*) *Atlas* authors,[5,7] there is an urgent need for type 1 epidemiology data across the world, as many countries do not have any data at all, and some data is very dated. Therefore, we developed a novel, comprehensive, open-source model as part of the Type 1 Diabetes Index project to estimate the burden of type 1 diabetes in 2021 in 201 countries, and project future burden. We also aimed to assess missing prevalence due to excess mortality and non-diagnosis (ie, the number of additional people who would be alive with type 1 diabetes if their mortality matched general population rates) to provide a more complete picture of the true impact of this disease.

For the **Type 1 Diabetes Index** see https://www.t1dindex.org

Methods

Overview

Our model is used to produce estimates of type 1 diabetes prevalence, incidence (diagnosed and non-diagnosed), and associated mortality and life expectancy. It also produces scenario estimates for missing prevalence, which we define as the number of additional people who would be living with type 1 diabetes at a given time if their mortality rates matched those of the general population. We report all estimates for 2021, for the 201 countries featured in the UN World Population Prospects 2019,[6] and selected estimates for projected years 2000 and 2021–40.

These estimates are produced by a Markov model, as used previously for type 1 diabetes and other non-communicable diseases, including in the *Lancet* Commission on diabetes.[3] In brief, for any given year we start with prevalence, incorporate the estimated number of incident cases, and subtract the estimated number of deaths. We then report prevalence at the midpoint of each year. We calculate these values for a single-year birth cohort in a given country, iteratively for each year of their lifetime from age 0–99 years (figure 1). To produce country-level estimates, we then sum the values for each birth cohort living in each year, up to age 99 years. For example, our estimates for prevalence in 2021 are the sum of prevalence estimates for birth cohorts for those born in 1922 up to 2021.

To employ this approach in our model, we first estimated incidence and mortality rates with uncertainty intervals for each birth cohort in each country for each year from 1900–2040, using published data where available and a mix of statistical and machine-learning methods to fill in any gaps.

General population data for birth cohorts from 1950–2040, including population sizes, for both historical data and future projections, were taken from the UN World Population Prospects.[23] Single-year values were interpolated using the spline function.

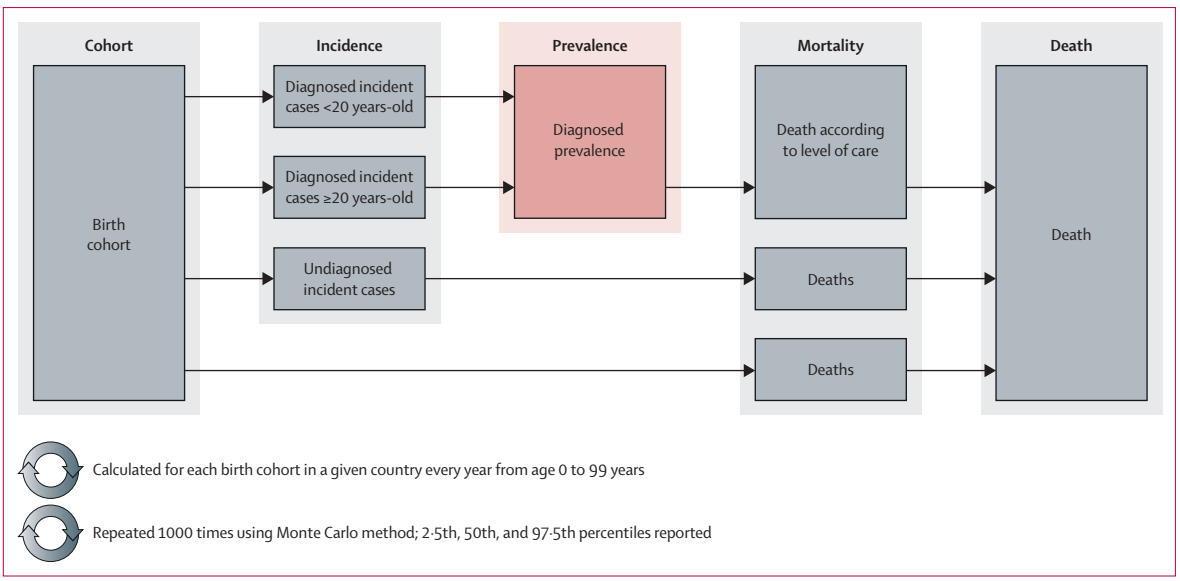

Figure 1: **Conceptual outline of core model**

Incidence

Given that type 1 diabetes incidence varies substantially by geography, age, and time,[6–8,18] our model was built to use incidence defined as a function of country, age, and year (figure 1). The model estimates the incidence of diagnosed and non-diagnosed type 1 diabetes. Incidence of diagnosed type 1 diabetes is stratified into childhood and adolescent incidence (age <20 years) and adult incidence (age ≥20 years). Incidence before and after the published data was then extrapolated using estimates of the change in incidence over time.

Diagnosed incidence

For individuals younger than 20 years, we obtained the most recent incidence for each country from data held by the *IDF Atlas*.[7] These data are stratified by age group (0–4, 5–9, 10–14, and 15–19 years) for 96 countries representing 76% of the world's population. For each of the 105 countries without incidence data, we imputed incidence using data from a similar country, based on geographical proximity, income, and ethnicity, as per the methods of the *IDF Atlas*.[6,7]

For adult incidence, our primary data source was a systematic review of the incidence of type 1 diabetes in adults by Harding and colleagues.[19] The authors identified 46 studies from 32 countries or territories that had incidence data for people aged 20 years or older (appendix p 6). Nine of these studies were excluded from our analyses as they only provided broad age-group data, and another was also excluded as it was a select population. Of the 36 remaining studies, 28 also contained data for children and adolescents younger than 20 years.

We used these 28 studies to estimate relative differences in incidence by age. To do this, we first produced an onset curve for each study population, which represents, for each age, the ratio between the incidence in that age group and the peak incidence across all age groups from 0 to 79 years. Gaps in incidence by age-groups were imputed using a ratio-based approach (appendix pp 6–8). Finally, the curves estimated for each study were averaged to develop a single global onset curve. We developed a separate onset curve for sub-Saharan Africa because peak age of type 1 diabetes onset is usually after age 15 years[10,12,17] (appendix pp 9–10). For individuals aged 20–24 years, we applied an onset curve derived using the above methodology from five studies that cover this region. Given the paucity of data on incidence for individuals aged 25 years or older from this region, the global onset curve was used thereafter.

Sensitivity analyses were conducted to assess whether year of data collection, study quality as rated by Harding and colleagues,[19] or the method used for missing data imputation, affected the shape of these curves. Although no substantial differences in shape were observed by year of data collection, only using the data from 17 higher-quality rated studies showed the presence of a second incidence peak in late adulthood, whereas 19 lower-quality rated studies on average showed incidence rates which were 25% lower from age 50 years and older (appendix pp 10–11). Therefore, our final curves were based on only the 17 higher-quality rated studies.

See Online for appendix

The global and sub-Saharan Africa onset curves were then used to develop country-specific and age-specific incidence estimates for a given year. We estimated the incidence for a given adult age group by taking childhood incidence data and multiplying it by the ratio between that adult age group and the childhood age group, as derived from the onset curve.

Non-diagnosed incidence

We sought to estimate diagnosis rates and the incidence of non-diagnosed type 1 diabetes—ie, the number of young people in lower-income settings dying of diabetic ketoacidosis soon after onset of type 1 diabetes symptoms without ever being diagnosed. We considered a set of three studies that had relevant data, and a survey of expert opinions on the rate of diagnosis (appendix p 58).

We first estimated diagnosis rates using data from studies of incidence rates over time in Rwanda,[11] Gabon,[24] and Mali.[12] If we assume the true rate of growth in incidence is no higher than 5–7% per year, we can derive an implied minimum true incidence at the start of the study period that could possibly lead to the observed incidence in the final year of the study. The ratio of this derived value to the observed value in the first year produces an estimate of the upper limit of the diagnosis rate in that year (appendix p 57).

Information about diagnosis rates was also extracted from a survey conducted by JDRF and the International Society for Pediatric and Adolescent Diabetes (ISPAD) in 2020. The question on diagnosis rates had 351 respondents from 64 countries responding for the time periods before 2000, 2000–09, and 2010–19 (appendix p 58). For high-income countries (HICs) we assumed a diagnosis rate of 100% as most respondents reported 0% and there was insufficient granularity from other respondents who reported 0–10%. For all other countries, we used the 166 responses from 32 non-HIC countries and calculated an estimated rate of diagnosis, with confidence intervals, for these three periods, for each country depending on their world region and income level.

We compared the estimates produced by these two methods for Rwanda, Gabon, and Mali. The study method produced diagnosis rates of 25–71% whereas the survey method produced rates of 64–78%. We elected to use the estimates produced by the survey method as it was more conservative about the number of deaths from non-diagnosis (appendix p 61).

Given the respondents were mostly paediatric and adolescent endocrinologists, the survey data were used to estimate diagnosis rates only in those younger than 25 years (ie, the scope of ISPAD). For a diagnosis from age 25 years onwards, the non-diagnosed mortality rate was assumed to be 0%; our survey did not cover this age group, and also the clinical onset of type 1 diabetes in adults is generally slower than in children and many of these cases are diagnosed as and treated for type 2 diabetes.[25] Thus, non-diagnosis rates of adults were not explicitly modelled.

Change in incidence over time

We also calculated incidence over time using studies with incidence data spanning at least a 5-year period, derived from all editions of the *Diabetes Atlas*, supplemented from hand-searching bibliographies of these studies. Studies were excluded if they had methodological weaknesses, very small numbers of cases, or had substantial overlap of incidence data from that in other publications. The final set comprised 146 studies from 65 countries (appendix p 21).

For each country, a single set of known incidence data was developed by pooling studies with the same methodology and geography. In cases where there was duplication of yearly incidence from several papers, data from the more recent study was used. The annual percentage change from one year to the next was calculated for the respective country.

We then calculated a global incidence over time curve, that is, a curve estimating the percentage change in incidence each year world-wide. This was achieved by fitting a line of best-fit to the year-on-year annual percentage change data described here, using data from all 65 countries across all years for which two or more countries had data (1985–2015). In addition, ten regional groups of countries (covering 54 countries) were identified that had common characteristics (economic, geographic, ethnicity and incidence; appendix pp 21–24) and we estimated a regional incidence over time curve for each of these using the same method as the global curve.

Country-specific estimates of the overall incidence in the younger than 20 years group were then estimated for 201 countries. Historical incidence data were used for all years where available, and gaps between data points were interpolated in a linear fashion. Outside of these data points, we estimated the change in incidence year-to-year from 1985–2021 using regional incidence over time curves where available and otherwise, the global incidence over time curve was used. From 2016–21 we used the final annual percentage change value from the relevant curve. Incidence was assumed to be stable before 1985 or before the earliest historical data, whichever was the earliest (appendix p 25).

Mortality

Our model required estimates of all-cause and type 1 diabetes-associated mortality for each year, country and age cohort from 0 to 99 years (figure 1).

For general population mortality, age-specific mortality rates in 5-year age brackets from 1950–2040, were obtained from the UN World Population Prospects.[23] Single-year values were interpolated using the spline function. Where mortality rates before 1950 were required, the model used data from 1950 as being the closest available.

We build on a previously published approach[9] employed by the *IDF Atlas* which uses a general linear regression model with Infant Mortality Rate as an independent variable to estimate type 1 diabetes-associated mortality. Our study updates and expands the set of studies used from 23 to 48, including more recent studies and studies of mortality in non-paediatric populations (appendix p 39). It also expands on the set of predictors used to estimate type 1 diabetes-associated mortality, using additional

predictors such as level of care, doctors per capita and gross domestic product, available from the World Bank.[26] The 48 studies cover 37 countries, include cohorts diagnosed from 1949 onwards and provide 71 data-points each representing the standardised mortality ratio (SMR) for a person with type 1 diabetes in a particular year, country, and age group.

These data were extrapolated to produce estimates of the SMR for a person with type 1 diabetes across all age-groups, years, countries, and levels of care using the following sequential imputation procedure.

First, any SMR reported for a particular age, year, and country was converted to an age-standardised SMR (aSMR) for that year and country. To do this we averaged the studies that reported SMRs in every age group to produce a single curve of SMR by age. This curve was then scaled down so that the average value across all ages was one, thereby producing a global relative SMR curve. An aSMR was then calculated for that year and country by taking the ratio between the observed SMR and the corresponding value for that age on the global relative SMR curve. Next, for each of the 37 countries with an observed aSMR in a given year, aSMR values for the non-observed years were imputed. This imputation was achieved by training and cross-validating a random forest model (model 1) on the available data to estimate aSMR based on year as well as a number of country characteristics representing the economy, health-care system, and level of care. Model 1 was then used to predict and impute aSMR for the years with missing values thereby producing an expanded dataset containing values for each year for the 37 countries with SMR observations. Another random forest model (model 2) was then trained on the expanded dataset to estimate aSMR based on year and country characteristics. Model 2 was used to predict and impute aSMRs across all years for the 164 countries for which no SMR values were available in the original dataset. These estimates of aSMR for each country and year were multiplied by the corresponding values on the global relative SMR curve, and the background mortality rates from the UN, to estimate all-cause and type 1 diabetes-associated mortality and life expectancy for each age group, country, year, and level of care (appendix pp 40–49). Mortality for non-diagnosed type 1 diabetes populations is assumed to be 100% within 1 year.[27]

Prevalence

Using the estimates of cohort, incidence, and mortality as inputs, we then used the Markov model (figure 1) to estimate prevalence for each year of age for each country and by income level or world region.[26]

Life expectancy

Life expectancy for new-onset symptomatic diagnosed type 1 diabetes was calculated by deriving survivorship data from the time series generated by the Markov model for each birth cohort, and then translating it into a series of standard life tables for each year. Life expectancy was then estimated as the average number of person-years lived by the cohort at age x until all members of the cohort have died.

For countries and ages where the type 1 diabetes diagnosis rate was less than 100%, the remaining life expectancy for the undiagnosed population was assumed to be 6 months.[27]

These values were then combined to estimate an overall life expectancy. For example, if a diagnosed and then treated 10-year-old could ordinarily expect to live another 11·7 years, but the diagnosis rate in the country was only 50%, then the overall remaining life expectancy is calculated as 50% multiplied by 11·7 years plus 50% multiplied by 0·5 years, that is 6·1 years in total.

Missing prevalence and projections

We used the model to estimate two scenarios regarding missing prevalence.

The first scenario estimated missing prevalence due to non-diagnosis. The model was run with the diagnosis rates set to 100% (ie, effectively with an increased incidence rate), with an unchanged mortality rate. We then compared the prevalence estimates of the two models to estimate how many people would have been alive if everyone had been diagnosed.

The second scenario estimated an additional missing prevalence due to the reduced life expectancy of diagnosed people living with type 1 diabetes. The model was run again with all-cause mortality rates set to those of the general population. The prevalence values for the first and second scenarios were compared.

To estimate the global type 1 diabetes population between 2021 and 2040, we developed two scenarios. The first (conservative estimate) held incidence, mortality, and diagnosis rates constant from 2020 onwards. The second (momentum estimate) continues to change these inputs at the same annual rate of change as for 2012–21.

Uncertainty intervals

To develop uncertainty intervals for the estimates, we used a Monte Carlo simulation: running the entire model end-to-end to estimate both inputs (incidence, mortality) and then outputs (prevalence, missing prevalence, life expectancy) 1000 times. Each time, for each year of a country, the Monte Carlo simulation selected a series of random draws from the input data, using the most relevant measure of error from the published studies from which these data had been sourced.[28]

We then report the median, 2·5th and 97·5th percentile values for each country. For global, regional, or income summary groups we use the median, 2·5th and 97·5th percentile for each of the component countries and then take their straight sum for incidence, deaths, and prevalence or their weighted average (weighted by sum of prevalence and missing prevalence) for life expectancy (appendix pp 3–5).

Model validation

We tested our modelled estimates against prevalence in three age groups (0–14, 0–17, and 0–19 years) in 15 countries, using the most recent prevalence estimates available from those countries (appendix p 62). For each country we calculated the percentage variation between observation and estimate, and then used the median of these values as a proxy for the overall accuracy of the estimates.

We also compared our estimates with previously published estimates of type 1 diabetes prevalence, an *IDF Atlas* 2021,[5] Green and colleagues 2021,[22] and the Institute for Health Metrics and Evaluation estimate for 2017,[21] and calculate the percentage variation between our estimate and published estimates.

Finally, we assessed how sensitive the model was to its inputs by varying those inputs and measuring the corresponding change in global prevalence and missing prevalence in 2021 under multiple scenarios (appendix pp 69–70).

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

Our model estimates that there were 8·42 (95% uncertainty interval [UI] 8·10–8·75) million people aged 0–99 years worldwide living with type 1 diabetes in 2021 (figure 2), 1·48 (18% [1·41–1·54]) million of whom were aged 0–19 years, 5·37 (64% [5·18–5·56]) million of whom were aged 20–59 years, and 1·58 (19% [1·47–1·70]) million of whom were aged 60 years or older; with a median age of 39 years (IQR 27·3; table, appendix pp 14, 71). The ten countries with the highest type 1 diabetes prevalence (USA, India, Brazil, China, Germany, UK, Russia, Canada, Saudi Arabia, and Spain) account for 5·08 (60% [4·89–5·27]) million of global cases of type 1 diabetes.

These modelled estimates were compared to published prevalences for three age groups (0–14, 0–17, and 0–19 years) in 15 countries, with a median per-country variation of 6% (9% in non-high-income countries; appendix p 63).

They were also compared with other published global estimates (appendix p 63–66). Our model estimates prevalence in individuals younger than 20 years as 1·48 million (95% UI 1·41–1·54) in 2021 compared with 1·2 million in the *IDF Atlas* 2021 estimate.[5] It also estimates all-ages prevalence in 2017 of 7·22 million (6·97–7·47; appendix p 65) compared with the Green and colleagues[22] estimate of 9·0 million and the most recent GBD estimate 20·5 million for 2017.[21] There is a systemic trend towards other published estimates having lower paediatric prevalence and higher adult prevalence than in our model.

Key sensitivities tested produced a change of not more than 12% for global prevalence across all scenarios (appendix pp 69–70).

Regarding incidence, we estimate that there were almost 510 000 incident cases of type 1 diabetes globally in 2021 (appendix p 71). The mean age of type 1 diabetes diagnosis was estimated at 32 years (SD 21) whereas the median was 29 years (IQR 34; appendix p 14). We estimated that 316 000 (62%) of 510 000 new diagnoses worldwide in 2021 occurred in people aged 20 years and older (figure 3A). We also identified a peak in global incidence at age 10–14 years, with a second rise also occurring in older age, around 70 years (figure 3B), a rise that is more pronounced in global averages due to the higher representation of North America (Canada and the USA) and Europe in older populations. We identified wide variation in type 1 diabetes incidence by geographic region (figure 3B) and country (appendix p 71), ranging in 2021 from 2·51 (1·90–3·12) per 100 000 population in east Asia and the Pacific to 25·06 (21·96–28·48) per 100 000 population in North America for individuals younger than 20 years. Analysis of published data indicated the annual percentage change of incidence reached its peak in the late 1990s, before tapering off in 2000–15 (appendix p 24).

Regarding mortality, we estimate that there were about 175 000 (134 000–218 000) deaths due to type 1 diabetes worldwide in 2021, of which about 40 000 were in sub-Saharan Africa and 42 000 in south Asia (appendix p 51). Of these 35 000 (20% [30 000–41 000) were attributed to non-diagnosis (which we estimated in people aged <25 years only), with 14 500 in sub-Saharan Africa and 8700 in south Asia. Thus, for individuals younger than 25 years only, we estimate that non-diagnosis accounts for 65–68% of the 44 000–63 000 type 1 diabetes deaths in this age group (appendix p 51).

The model was also used to estimate remaining life expectancy for a 10-year-old who develops new-onset type 1 diabetes in 2021 as well as for a 10-year-old without type 1 diabetes (table). Globally there is a 24-year gap in the remaining life expectancy with and without type 1 diabetes (40 years *vs* 64 years). This gap varies substantially by income group, with a 46-year gap in LICs (13 years *vs* 60 years), 36-year gap in LMICs (26 years *vs* 62 years), 25-year gap in upper-middle income countries (UMICs; 43 years *vs* 67 years), and 11-year gap in HICs (61 years *vs* 72 years).

In addition, we quantify missing prevalence in 2021 as 3·75 million (3·53–3·98), of which 84% (3·15 million [2·93–3·39]), were due to early mortality and a further 16% (0·60 million [0·57–0·63]) due to non-diagnosis. The proportion of estimated missing prevalence varies widely by region (figure 2) and by country (appendix p 71). In North America, there are 5·1 prevalent cases of type 1 diabetes for every missing prevalent case (none due to non-diagnosis), versus in sub-Saharan Africa 0·5 prevalent cases for every missing prevalent case (128 000 cases or 17% of missing prevalence being due to

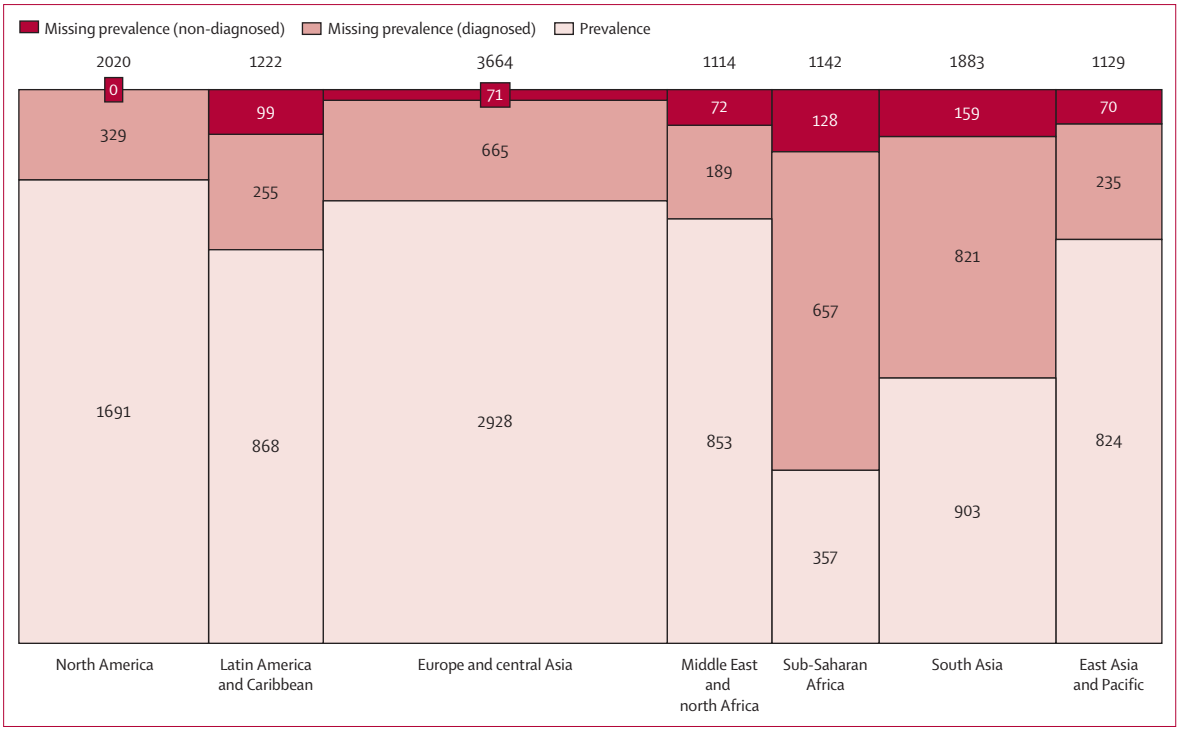

Figure 2: **Estimated size of global type 1 diabetes population 2021 (thousands) by region (depicted in variwide graph where area is proportional to numerical value)**

non-diagnosis). Estimates of missing prevalence vary more widely than those for prevalence, with a range of –27% to 66%, driven mostly by uncertainty in non-diagnosis rates (appendix p 69).

Type 1 diabetes prevalence and missing prevalence vary markedly by country income level, as shown by representative countries in figure 4. For example, in the USA, missing prevalence is greatest in older people and non-diagnosis deaths are zero. By contrast, in the Democratic Republic of the Congo, most type 1 diabetes deaths occur earlier in life, with the result that missing prevalence outweighs the number of people living with type 1 diabetes in the working age population.

Finally, the model was used to estimate the global burden of type 1 diabetes in the future under two scenarios (appendix p 85). In scenario one, the conservative estimate, the number of people living with type 1 diabetes will increase by 66% globally between 2020 and 2040, from 8·11 (7·82–8·42) million to 13·51 (12·65–14·42) million. The largest change would occur in people aged 20 years and older (figure 5). World regions that will see the largest relative increases in prevalence are those with predominantly non-White populations, for example a 141% increase in sub-Saharan Africa, 131% in Middle East and north Africa, and 78% in south Asia. In scenario two, the momentum estimate, prevalence will increase by 116% globally between 2020 and 2040, from 8·11 (7·82–8·42) million to 17·43 (15·63–19·39) million (appendix pp 81–82).

In conclusion, our findings indicate that 8·42 (8·10–8·75) million people were living with type 1 diabetes worldwide in 2021, but that the overall footprint of type 1 diabetes, including missing prevalence due to excess mortality, is much greater, totalling 12·17 (11·64–12·73) million.

Discussion

Our findings show that estimating the global burden of type 1 diabetes by accounting only for prevalent cases, as is typically the focus in HICs, grossly underestimates the true impact. This is particularly true for regions such as sub-Saharan Africa, which accounts for 4% (357 000 [331 000–383 000]) of global prevalence but 23% (40 000 [34 000–47 000]) of lives lost each year. Given that prevalence is projected to increase in all countries over the next two decades, particularly in world regions with a high proportion of LICs and LMICs, our results herald substantial negative implications for individuals, families, societies, and health-care systems. In addition, our novel findings that 63–70% of deaths due to type 1 diabetes in individuals younger than 25 years are estimated to be due to non-diagnosis, and that these deaths represent up to a fifth of all-age deaths due to type 1 diabetes, highlight an urgent need to increase awareness of the signs and symptoms of type 1 diabetes in LICs and LMICs.

Most previous epidemiological studies of type 1 diabetes incidence, prevalence, and mortality are based on European and North American data, with estimates for most LICs and LMICs derived by extrapolation.[7,9,22]

	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
Global	8 423 530 (8 103 139–8 749 702)	1 476 030 (1 412 988–1 542 713)	6 947 403 (6 670 019–7 228 108)	40 (37–43)	64
High-income countries	4 584 200 (4 435 431–4 742 083)	525 174 (504 759–547 223)	4 059 734 (3 920 799–4 203 710)	61 (57–65)	72
Upper-middle income countries	2 049 417 (1 968 012–2 128 509)	375 345 (356 088–394 971)	1 673 363 (1 606 286–1 740 203)	43 (40–46)	67
Lower-middle income countries	1 574 314 (1 500 333–1 647 053)	499 991 (481 241–519 961)	1 074 211 (1 015 460–1 132 039)	26 (23–28)	62
Low-income countries	215 599 (199 363–232 056)	75 521 (70 901–80 558)	140 096 (127 473–152 156)	13 (12–15)	60
North America	1 690 726 (1 638 926–1 749 197)	199 751 (192 435–208 482)	1 491 369 (1 441 606–1 544 571)	58 (55–61)	70
Canada	276 284 (267 612–285 679)	31 601 (30 182–32 979)	244 671 (236 711–253 080)	63 (60–66)	74
USA	1 414 441 (1 371 314–1 463 518)	168 150 (162 253–175 503)	1 246 698 (1 204 895–1 291 491)	57 (53–60)	70
Latin America and the Caribbean	868 281 (832 566–903 470)	164 693 (156 626–172 852)	703 238 (673 581–733 072)	43 (40–46)	68
Antigua and Barbuda	121 (116–127)	25 (24–27)	96 (92–101)	45 (42–49)	68
Argentina	82 015 (79 663–84 487)	16 608 (15 966–17 337)	65 395 (63 463–67 402)	51 (48–54)	68
Aruba	5·2 (5·0–5·4)	0·9 (0·9–1·0)	4·3 (4·1–4·4)	48 (46–51)	68
The Bahamas	844 (806–885)	187 (177–199)	657 (627–687)	44 (41–46)	65
Barbados	605 (576–633)	106 (101–112)	498 (474–523)	47 (44–50)	71
Belize	149 (144–154)	39 (37–40)	111 (107–114)	34 (31–37)	66
Bolivia	2636 (2457–2805)	1023 (968–1083)	1614 (1483–1736)	21 (18–24)	66
Brazil	564 249 (538 458–589 365)	109 827 (103 978–115 582)	454 070 (432 867–475 444)	42 (40–46)	68
Chile	35 243 (33 920–36 540)	6117 (5834–6410)	29 121 (28 050–30 232)	57 (54–61)	71
Colombia	17 374 (16 845–17 934)	3519 (3387–3666)	13 860 (13 428–14 318)	41 (38–44)	69
Costa Rica	2196 (2138–2253)	380 (366–395)	1816 (1767–1865)	49 (46–52)	72
Cuba	9063 (8773–9373)	1136 (1094–1179)	7925 (7655–8206)	50 (47–55)	70
Curaçao	8·4 (8·1–8·7)	1·5 (1·4–1·6)	6·9 (6·6–7·1)	51 (48–54)	70
Dominican Republic	1361 (1318–1409)	376 (362–393)	985 (951–1021)	36 (34–39)	67
Ecuador	5742 (5556–5914)	1400 (1340–1456)	4340 (4196–4467)	40 (37–43)	69
El Salvador	1743 (1639–1837)	550 (526–573)	1193 (1103–1275)	21 (18–24)	66
French Guiana	740 (706–773)	210 (197–223)	530 (508–553)	46 (44–49)	72
Grenada	223 (212–233)	51 (49–54)	171 (163–179)	35 (33–38)	64

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	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
Guadeloupe	781 (743–816)	154 (145–162)	626 (596–656)	44 (42–47)	73
Guatemala	6348 (6121–6554)	1911 (1831–1997)	4438 (4279–4595)	33 (31–36)	67
Guyana	29 (28–30)	10 (9·5–10)	19 (18–20)	23 (20–26)	63
Haiti	799 (745–854)	377 (359–398)	422 (383–459)	13 (11–15)	61
Honduras	3008 (2861–3143)	977 (933–1022)	2032 (1919–2139)	24 (21–27)	68
Jamaica	2026 (1962–2095)	421 (404–438)	1605 (1551–1660)	39 (36–42)	66
Martinique	758 (723–792)	124 (117–131)	634 (604–664)	46 (43–49)	74
Mexico	89 408 (86 764–92 059)	11 414 (11 031–11 835)	78 002 (75 507–80 364)	39 (37–42)	67
Nicaragua	1941 (1847–2033)	600 (573–628)	1340 (1263–1419)	24 (21–27)	67
Panama	1673 (1625–1721)	391 (377–407)	1282 (1244–1318)	47 (44–50)	71
Paraguay	1550 (1503–1596)	398 (383–414)	1150 (1115–1188)	37 (34–40)	66
Peru	5553 (5398–5718)	1115 (1072–1161)	4438 (4305–4565)	42 (39–45)	69
Puerto Rico	14 837 (14 218–15 487)	2593 (2468–2731)	12 249 (11 714–12 802)	50 (47–54)	71
Saint Lucia	361 (343–379)	71 (67–75)	289 (274–305)	34 (31–38)	68
Saint Vincent and the Grenadines	221 (211–232)	52 (49–55)	169 (161–178)	36 (33–39)	64
Suriname	27 (26–28)	7·3 (7·0–7·6)	19 (19–20)	41 (32–44)	64
Trinidad and Tobago	2859 (2732–2994)	573 (544–607)	2286 (2185–2395)	43 (40–46)	66
US Virgin Islands	289 (256–324)	49 (42–57)	240 (214–268)	60 (57–63)	72
Uruguay	10 179 (9847–10 516)	1547 (1471–1623)	8635 (8354–8923)	52 (49–56)	69
Venezuela	1318 (1276–1361)	350 (337–364)	968 (934–1000)	36 (34–39)	65
Europe and central Asia	2 927 826 (2 823 691–3 034 192)	364 641 (352 295–377 337)	2 563 451 (2 466 259–2 662 208)	53 (50–57)	69
Albania	4200 (3936–4469)	704 (641–772)	3496 (3287–3714)	51 (48–54)	70
Armenia	3443 (3346–3538)	721 (707–736)	2722 (2631–2810)	44 (42–47)	67
Austria	31 631 (30 566–32 734)	3418 (3339–3501)	28 222 (27 185–29 258)	63 (59–68)	73
Azerbaijan	8590 (8170–9001)	2041 (1920–2168)	6547 (6234–6861)	41 (39–43)	65
Belarus	15 421 (14 604–16 209)	2684 (2525–2840)	12 744 (12 052–13 401)	45 (42–49)	66
Belgium	41 713 (40 461–43 119)	4499 (4347–4671)	37 210 (36 096–38 524)	63 (59–67)	73

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	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
Bosnia and Herzegovina	5960 (5739–6168)	829 (794–866)	5128 (4936–5320)	49 (46–51)	69
Bulgaria	22 538 (21 712–23 351)	2986 (2875–3104)	19 540 (18 792–20 335)	50 (46–53)	66
Channel Islands	941 (911–974)	96 (91–101)	845 (817–875)	58 (55–61)	74
Croatia	13 503 (13 101–13 873)	1906 (1857–1957)	11 596 (11 216–11 945)	60 (57–64)	70
Cyprus	3 967 (3 819–4 114)	399 (384–415)	3 567 (3 426–3 704)	64 (60–68)	72
Czechia	42 307 (40 843–43 598)	5235 (5038–5445)	37 077 (35 739–38 244)	60 (56–65)	70
Denmark	32 229 (31 191–33 289)	3197 (3080–3312)	29 032 (28 079–30 043)	65 (61–68)	72
Estonia	6144 (5844–6429)	916 (864–973)	5222 (4961–5473)	60 (54–66)	70
Finland	68 562 (66 437–70 749)	6239 (6073–6401)	62 362 (60 209–64 476)	66 (61–71)	73
France	196 153 (189 558–203 856)	24 483 (23 529–25 490)	171 762 (165 602–178 624)	68 (65–72)	74
Georgia	4209 (3957–4484)	1151 (1091–1223)	3060 (2854–3277)	30 (27–33)	65
Germany	422 087 (408 062–436 936)	40 153 (38 793–41 577)	382 070 (368 779–396 013)	64 (60–69)	72
Greece	26 731 (25 376–28 309)	2444 (2248–2696)	24 272 (23 062–25 611)	64 (61–68)	73
Hungary	35 595 (33 217–38 499)	4419 (3939–4915)	31 177 (29 165–33 661)	60 (57–64)	68
Iceland	1370 (1299–1437)	148 (136–162)	1222 (1160–1282)	68 (64–73)	74
Ireland	25 646 (24 692–26 680)	3493 (3371–3619)	22 156 (21 267–23 119)	63 (60–67)	73
Italy	184 476 (177 333–190 335)	12 138 (11 734–12 561)	172 335 (165 165–178 207)	69 (64–74)	74
Kazakhstan	4967 (4696–5238)	1163 (1033–1303)	3802 (3620–3976)	42 (40–45)	65
Kyrgyzstan	1401 (1305–1494)	454 (398–508)	948 (886–1002)	27 (25–29)	64
Latvia	4689 (4494–4860)	674 (639–709)	4017 (3841–4174)	53 (49–57)	66
Lithuania	8494 (8132–8831)	1137 (1082–1194)	7361 (7029–7667)	55 (50–61)	67
Luxembourg	2371 (2307–2431)	237 (229–245)	2134 (2075–2193)	63 (60–68)	73
North Macedonia	3040 (2851–3234)	468 (429–509)	2572 (2414–2729)	49 (46–52)	67
Moldova	6409 (6123–6723)	1389 (1357–1418)	5024 (4748–5310)	29 (27–32)	64
Montenegro	2098 (2033–2169)	364 (353–377)	1733 (1673–1795)	50 (47–53)	68
Netherlands	78 588 (76 644–80 313)	7738 (7544–7915)	70 829 (69 013–72 510)	65 (62–69)	73
Norway	40 301 (38 198–43 872)	4004 (3852–4155)	36 286 (34 287–39 901)	66 (62–71)	73

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	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
Poland	115 158 (110 938–119 477)	14 557 (13 801–15 287)	100 640 (96 898–104 573)	58 (55–62)	70
Portugal	38 009 (36 744–39 107)	3350 (3236–3474)	34 647 (33 407–35 722)	63 (59–67)	73
Romania	41 159 (39 781–42 538)	6706 (6561–6848)	34 472 (33 147–35 752)	46 (44–49)	67
Russia	321 460 (309 930–333 042)	54 034 (53 013–55 110)	267 370 (256 375–278 466)	41 (38–45)	64
Serbia	22 407 (21 695–23 102)	3259 (3156–3371)	19 148 (18 471–19 789)	48 (45–51)	67
Slovakia	20 549 (19 514–21 585)	2940 (2743–3156)	17 615 (16 745–18 464)	55 (52–58)	69
Slovenia	6283 (6069–6473)	766 (737–797)	5515 (5312–5700)	60 (56–64)	72
Spain	203 865 (195 216–211 870)	17 142 (16 293–18 026)	186 645 (178 571–193 921)	68 (63–74)	74
Sweden	97 024 (93 501–100 843)	10 040 (9563–10 547)	86 995 (83 674–90 522)	67 (63–72)	74
Switzerland	26 022 (25 419–26 600)	2193 (2128–2264)	23 829 (23 250–24 370)	68 (65–72)	75
Tajikistan	3292 (3177–3409)	1410 (1378–1447)	1881 (1791–1971)	25 (23–27)	64
Türkiye	137 072 (134 746–139 297)	28 454 (28 134–28 800)	108 615 (106 551–110 647)	49 (47–53)	70
Turkmenistan	8366 (8172–8570)	2298 (2269–2327)	6069 (5889–6253)	34 (32–37)	62
Ukraine	121 481 (114 932–128 214)	29 927 (29 446–30 463)	91 582 (85 229–97 937)	27 (24–30)	63
UK	403 608 (391 064–416 028)	41 591 (39 593–43 434)	362 114 (350 803–373 483)	66 (63–70)	72
Uzbekistan	12 296 (11 839–12 725)	4047 (3955–4147)	8246 (7845–8603)	30 (27–32)	64
Middle East and north Africa	853 387 (827 891–879 324)	204 338 (196 804–212 130)	649 039 (629 381–668 764)	42 (40–45)	66
Algeria	151 824 (148 280–155 660)	42 536 (41 515–43 568)	109 289 (106 630–112 189)	43 (41–46)	70
Bahrain	2116 (2060–2171)	306 (293–319)	1810 (1764–1854)	58 (56–61)	69
Djibouti	1979 (1852–2117)	396 (367–425)	1584 (1474–1695)	19 (17–21)	62
Egypt	36 997 (35 064–39 046)	13 309 (12 532–14 090)	23 676 (22 377–25 105)	29 (26–31)	64
Iraq	37 602 (36 469–38 755)	11 834 (11 359–12 340)	25 742 (25 017–26 540)	36 (34–38)	63
Iran	99 327 (96 736–101 953)	18 893 (18 199–19 697)	80 414 (78 341–82 439)	47 (45–50)	69
Israel	22 902 (22 193–23 565)	4095 (3957–4242)	18 811 (18 155–19 383)	70 (66–74)	74
Jordan	6239 (6043–6432)	1297 (1234–1367)	4945 (4790–5089)	42 (40–44)	67
Kuwait	32 463 (31 675–33 366)	5408 (5194–5658)	27 063 (26 433–27 737)	56 (54–59)	67
Lebanon	4884 (4733–5032)	664 (630–699)	4221 (4087–4347)	51 (48–54)	70

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	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
Libya	23 135 (22 380–23 876)	5083 (4791–5366)	18 055 (17 520–18 577)	41 (38–44)	65
Malta	2469 (2259–2722)	192 (182–203)	2277 (2070–2529)	64 (62–67)	74
Morocco	116 097 (112 299–119 685)	34 904 (34 053–35 809)	81 193 (78 126–84 203)	35 (32–38)	69
Oman	5923 (5758–6070)	936 (894–978)	4986 (4860–5100)	55 (53–58)	69
Qatar	19 766 (19 255–20 314)	1457 (1400–1525)	18 307 (17 840–18 818)	61 (58–64)	71
Saudi Arabia	224 636 (218 500–230 734)	45 348 (43 316–47 319)	179 279 (174 724–183 644)	55 (52–58)	67
Palestine	2396 (2301–2496)	676 (641–713)	1722 (1648–1795)	31 (28–34)	66
Syria	6736 (6385–7144)	1967 (1866–2078)	4778 (4461–5123)	28 (25–30)	68
Tunisia	28 012 (26 917–29 142)	6800 (6520–7099)	21 223 (20 311–22 116)	34 (32–37)	69
United Arab Emirates	12 439 (12 118–12 742)	1416 (1358–1478)	11 022 (10 747–11 277)	59 (57–62)	69
Yemen	15 445 (14 615–16 303)	6821 (6503–7158)	8642 (8007–9206)	16 (14–18)	61
Sub-Saharan Africa	357 155 (330 726–383 483)	111 435 (104 384–118 867)	245 696 (224 736–265 817)	12 (11–14)	58
Angola	11 339 (10 523–12 051)	3698 (3459–3918)	7638 (7032–8184)	14 (13–16)	58
Benin	3439 (3155–3718)	1043 (980–1112)	2394 (2172–2618)	11 (9–12)	60
Botswana	892 (858–927)	142 (135–150)	750 (721–781)	26 (25–28)	63
Burkina Faso	1065 (976–1155)	330 (310–351)	734 (663–804)	10 (9–12)	59
Burundi	1994 (1789–2193)	669 (621–717)	1325 (1154–1481)	7 (6–8)	58
Cameroon	7671 (7096–8249)	2406 (2251–2559)	5259 (4819–5730)	12 (11–14)	56
Cabo Verde	277 (265–290)	42 (40–45)	235 (224–247)	25 (22–27)	65
Central African Republic	198 (180–217)	78 (74–83)	120 (106–135)	8 (7–9)	52
Chad	647 (579–712)	240 (223–257)	406 (352–455)	7 (6–8)	54
Comoros	298 (279–318)	107 (101–113)	191 (176–207)	13 (11–14)	60
Côte d'Ivoire	7317 (6710–7818)	2380 (2233–2517)	4932 (4456–5325)	12 (10–13)	55
Democratic Republic of the Congo	17 259 (15 743–18 792)	5451 (5139–5826)	11 798 (10 525–13 050)	9 (8–11)	59
Equatorial Guinea	582 (550–616)	118 (111–124)	464 (438–494)	18 (17–20)	56
Eritrea	6073 (5634–6505)	1872 (1744–2018)	4203 (3852–4526)	14 (13–16)	61
Eswatini	392 (367–421)	125 (118–132)	268 (247–292)	14 (13–15)	55

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	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
Ethiopia	18 454 (17 019–19 863)	4057 (3805–4302)	14 409 (13 183–15 634)	12 (10–14)	62
Gabon	919 (872–965)	181 (170–194)	738 (700–773)	25 (23–27)	61
The Gambia	128 (118–138)	37 (35–39)	91 (83–99)	11 (9–12)	58
Ghana	10 261 (9572–10 939)	2636 (2482–2801)	7625 (7059–8170)	15 (13–17)	59
Guinea	697 (638–751)	211 (199–224)	486 (437–530)	10 (9–12)	58
Guinea-Bissau	91 (82–99)	29 (27–31)	62 (54–69)	9 (8–10)	55
Kenya	21 602 (20 261–22 815)	5971 (5650–6312)	15 642 (14 541–16 594)	17 (15–18)	61
Lesotho	614 (567–664)	189 (179–201)	425 (385–466)	11 (10–12)	51
Liberia	282 (261–303)	80 (76–84)	202 (184–220)	12 (10–13)	60
Madagascar	10 003 (9264–10 673)	2853 (2674–3037)	7150 (6554–7677)	13 (11–14)	61
Malawi	6054 (5595–6512)	2116 (1990–2252)	3934 (3554–4292)	11 (10–13)	59
Mali	775 (712–841)	277 (255–297)	498 (451–546)	10 (8–12)	58
Mauritania	1726 (1629–1824)	422 (398–448)	1304 (1226–1387)	18 (16–20)	61
Mauritius	776 (746–807)	101 (96–105)	676 (648–705)	31 (29–33)	67
Mayotte	125 (118–132)	39 (37–41)	86 (80–92)	23 (20–26)	70
Mozambique	9599 (8831–10334)	3460 (3265–3683)	6126 (5537–6701)	11 (10–12)	57
Namibia	1222 (1165–1280)	262 (247–277)	961 (913–1008)	22 (20–23)	58
Niger	1087 (993–1169)	384 (360–407)	702 (630–769)	10 (9–11)	59
Nigeria	47 807 (43 881–51 859)	16 689 (15 571–17 829)	31 092 (27 931–34 259)	9 (8–10)	53
Congo (Brazzaville)	1792 (1678–1910)	527 (495–557)	1267 (1173–1362)	16 (14–18)	59
Reunion	398 (370–425)	82 (78–86)	317 (290–341)	25 (22–29)	72
Rwanda	3402 (3177–3609)	829 (786–874)	2574 (2369–2750)	15 (13–17)	63
São Tomé and Príncipe	88 (83–92)	23 (22–24)	65 (61–68)	22 (20–24)	64
Senegal	5826 (5441–6198)	1613 (1518–1707)	4211 (3894–4514)	15 (13–17)	62
Seychelles	58 (56–60)	8·5 (8·1–8·9)	49 (47–51)	39 (37–42)	65
Sierra Leone	315 (280–344)	112 (104–120)	202 (176–227)	7 (6–8)	53
Somalia	19 812 (17 924–21 811)	7433 (6828–8074)	12 406 (11 003–13 769)	8 (7–9)	56

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	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
South Africa	30 075 (28 698–31 504)	5125 (4866–5404)	24 950 (23 754–26 155)	22 (20–23)	58
South Sudan	7803 (7065–8463)	3760 (3510–4000)	4036 (3561–4483)	8 (7–9)	56
Sudan	48 369 (44 667–52 124)	17 501 (16 318–18 834)	30 843 (28 139–33 345)	15 (13–17)	61
Tanzania	20 664 (19 283–22 131)	6517 (6132–6918)	14 155 (13 039–15 269)	13 (11–14)	60
Togo	414 (378–448)	124 (117–132)	290 (261–318)	10 (8–11)	58
Uganda	14 931 (13 830–16 086)	5254 (4933–5592)	9688 (8775–10544)	12 (10–13)	59
Western Sahara	51 (47–54)	7·2 (6·8–7·6)	44 (40–46)	21 (19–24)	64
Zambia	6784 (6392–7210)	2166 (2042–2288)	4621 (4320–4938)	16 (14–17)	59
Zimbabwe	4706 (4326–5064)	1659 (1566–1758)	3052 (2748–3318)	12 (10–13)	56
South Asia	902 541 (859 980–943 633)	305 565 (294 068–318 045)	596 846 (564 026–628 809)	24 (21–26)	64
Afghanistan	9358 (8740–10091)	5244 (4947–5605)	4110 (3749–4481)	14 (12–16)	61
Bangladesh	24 338 (22 636–25 924)	5780 (5334–6248)	18 562 (17 194–19 835)	26 (23–29)	66
Bhutan	454 (430–474)	148 (142–154)	306 (286–322)	22 (20–24)	65
India	818 620 (780 950–854 953)	276 294 (266 378–287 049)	542 208 (512 955–570 766)	24 (21–26)	63
Maldives	429 (414–446)	81 (77–85)	348 (336–362)	46 (44–49)	71
Nepal	17 045 (16 201–17 781)	6539 (6278–6822)	10 503 (9 886–11 060)	20 (18–23)	64
Pakistan	18 754 (17 658–19 827)	7601 (7172–8045)	11 144 (10 457–11 840)	23 (21–26)	63
Sri Lanka	13 544 (12 951–14 136)	3877 (3740–4036)	9665 (9162–10 143)	29 (26–32)	69
East Asia and Pacific	823 615 (789 357–856 404)	125 607 (116 376–135 000)	697 763 (670 430–724 868)	43 (41–46)	68
Australia	122 139 (120 052–124 192)	13 941 (13 845–14 043)	108 190 (106 147–110 166)	67 (64–70)	74
Brunei	94 (91–98)	19 (18–20)	75 (73–78)	50 (48–53)	67
Cambodia	2148 (2012–2278)	838 (786–889)	1312 (1223–1401)	21 (18–23)	63
China	430 647 (409 404–450 012)	64 224 (57 279–71 202)	366 193 (350 194–381 597)	46 (44–48)	69
Fiji	116 (110–122)	36 (33–38)	80 (76–84)	30 (28–32)	60
French Polynesia	44 (42–46)	9·4 (8·8–10)	34 (33–36)	49 (47–52)	69
Guam	4·3 (4·1–4·5)	0·9 (0·9–1·0)	3·4 (3·2–3·5)	56 (54–58)	72
Hong Kong	4770 (4628–4910)	512 (496–528)	4260 (4124–4385)	61 (58–64)	75

(Table continues on next page)

	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
Indonesia	39 919 (37 659–42 281)	12 942 (12 208–13 666)	26 959 (25 349–28 768)	26 (23–28)	64
Japan	77 874 (75 506–80 338)	5380 (5239–5524)	72 518 (70 142–74 973)	69 (64–73)	75
Kiribati	12 (12–13)	5·2 (4·9–5·5)	7·1 (6·6–7·6)	20 (17–22)	63
Laos	982 (923–1040)	397 (374–420)	585 (545–624)	23 (20–25)	62
Macau	423 (410–436)	48 (46–49)	375 (364–387)	60 (58–63)	75
Malaysia	6772 (6463–7047)	1458 (1373–1538)	5314 (5079–5523)	43 (40–45)	67
Micronesia	2 (1·9–2·1)	0·8 (0·7–0·8)	1·2 (1·1–1·3)	27 (25–30)	61
Mongolia	663 (606–725)	208 (180–239)	455 (422–491)	26 (24–28)	62
Myanmar	6659 (6261–7105)	2513 (2377–2669)	4148 (3843–4462)	20 (18–22)	61
New Caledonia	46 (44–48)	9·5 (8·9–10)	37 (35–39)	52 (50–54)	69
New Zealand	17 600 (17 063–18 143)	2207 (2102–2317)	15 389 (14 918–15 868)	63 (60–66)	73
North Korea	10 391 (9845–10 982)	2503 (2418–2600)	7891 (7398–8399)	22 (19–25)	65
Papua New Guinea	134 (125–144)	63 (58–67)	71 (66–77)	18 (16–20)	59
Philippines	15 710 (14 752–16 654)	5 918 (5 601–6 283)	9 784 (9 112–10 438)	22 (20–25)	64
Samoa	26 (25–28)	10 (9·2–10)	17 (16–18)	36 (33–38)	65
Singapore	5947 (5810–6089)	552 (531–572)	5395 (5269–5521)	64 (61–68)	74
Solomon Islands	12 (11–13)	5·5 (5·2–5·8)	6·7 (6·2–7·0)	23 (20–26)	65
South Korea	33 684 (32 510–34 981)	3597 (3479–3732)	30 081 (28 975–31 327)	63 (60–66)	74
Taiwan	21461 (20885–22048)	2031 (1991–2076)	19428 (18877–19990)	52 (49–55)	72
Thailand	10 906 (10 509–11 316)	2171 (2108–2236)	8734 (8372–9095)	39 (37–42)	69
Timor-Leste	188 (177–198)	83 (79–88)	104 (98–110)	24 (22–27)	64
Tonga	14 (13–14)	5·2 (4·9–5·5)	8·4 (8·0–8·9)	29 (25–38)	63
Vanuatu	37 (35–39)	15 (14–16)	21 (20–23)	27 (24–30)	63

(Table continues on next page)

Therefore our model, which provides country-level estimates that are highly comparable to observed data in our systematic comparison, fills an important gap in the literature and provides a basis for meaningful change in type 1 diabetes care and policy.

Although type 1 diabetes and type 2 diabetes are markedly different in their aetiology, pathology, age of onset, lived experience, and management, most existing reports of diabetes prevalence provide data on both types combined, hindering efforts to effectively address

	Prevalence			Remaining life expectancy if diagnosed at age 10 years in 2021	
	Total*	Age <20 years	Age ≥20 years	Type 1 diabetes, years	Non type 1 diabetes, years†
(Continued from previous page)					
Viet Nam	14 190 (13 369–15 058)	3904 (3697–4138)	10 283 (9636–10 959)	26 (23–28)	68

Data are n (95% uncertainty interval). *The total number is not necessarily the exact sum of [age <20 years] + [age ≥20 years] because each value reported is a median of that value across 1000 Monte Carlo simulations. As these medians are not all from the same simulation, they do not consistently total as expected. †There is no uncertainty range for the background population number, which are sourced from the UN population projections.

Table: **Type 1 diabetes prevalence and remaining life expectancy for a 10-year-old newly diagnosed in 2021**

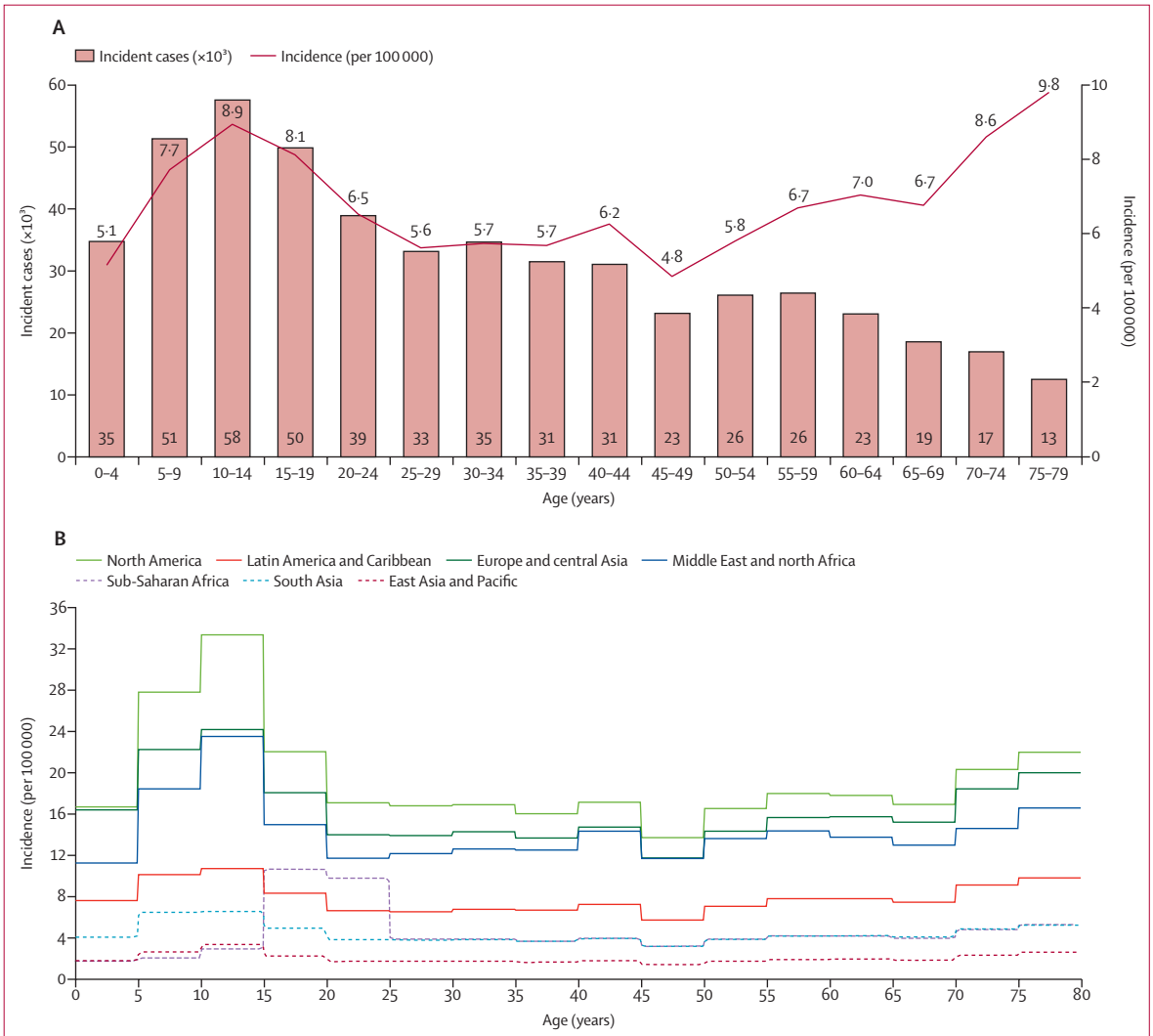

Figure 3: **Type 1 diabetes incidence, 2021**
(A) Global incident cases and incidence, by age. (B) Incidence by age group and region.

gaps in knowledge and care. Previous estimates suggest that type 2 diabetes represents more than 90% of the entire population living with diabetes in HICs, with type 1 diabetes cases constituting most of the remainder.[29,30] However, this ratio will be different in many LICs and LMICs where type 1 diabetes prevalence

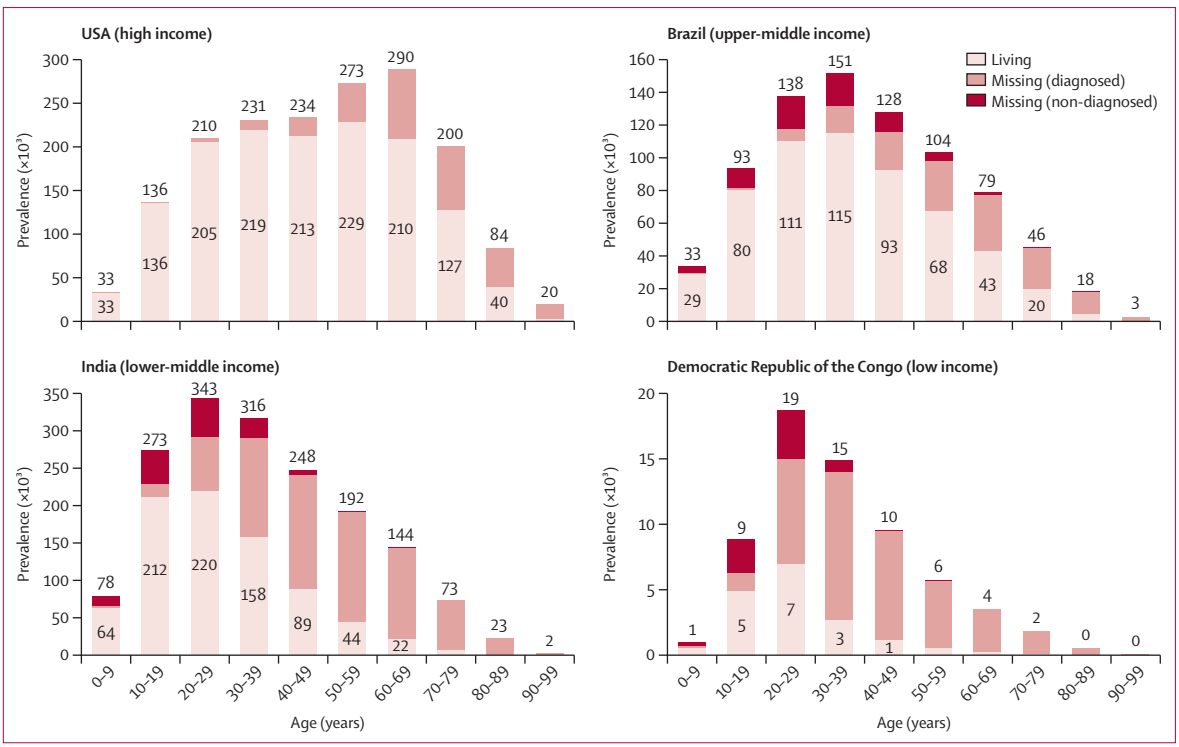

Figure 4: **Prevalence and missing prevalence due to type 1 diabetes in four example countries by age group (2021)**

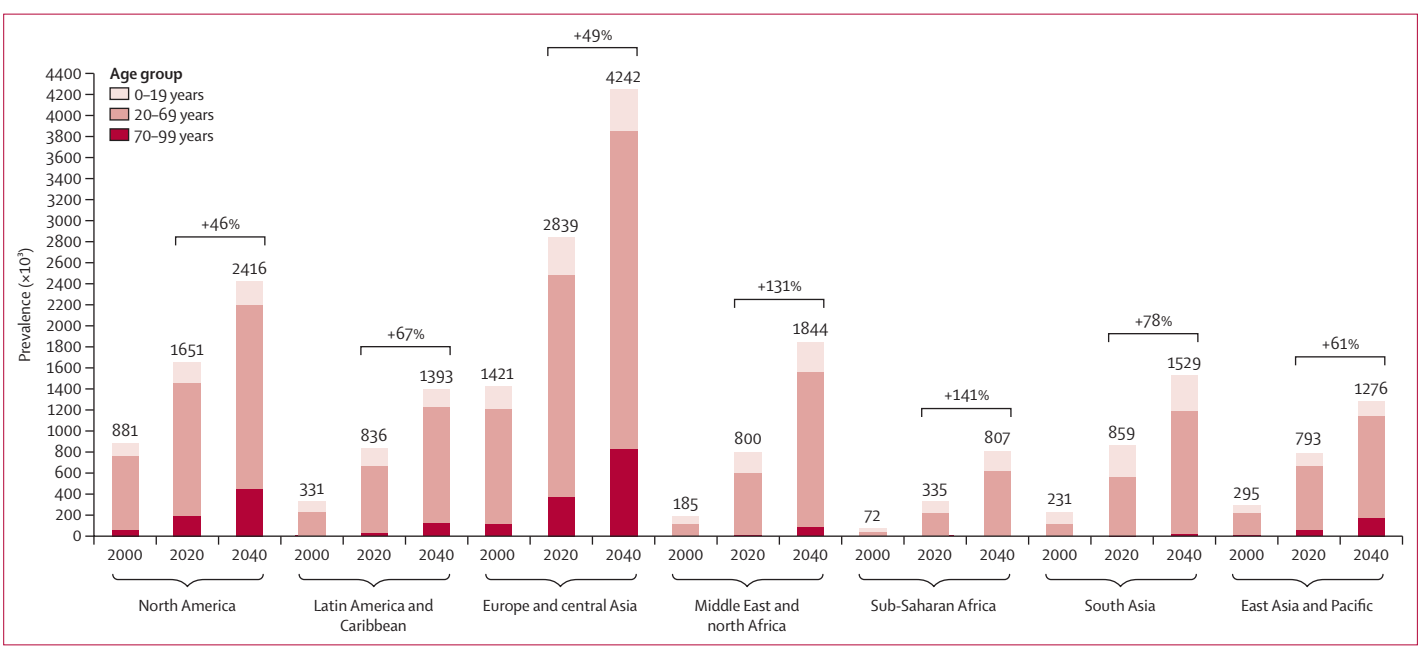

Figure 5: **Prevalence of type 1 diabetes in people aged 0–99 years by world region in 2000, 2020, and 2040**
Data are (×10³) based on conservative scenario.

is lower due to lower incidence and higher mortality, and type 2 diabetes prevalence could be higher. Our results indicate that type 1 diabetes accounts for 1·6% of the estimated 538 million global prevalence of diabetes.[5]

Historically, type 1 diabetes is typically considered to be a disease with onset in childhood. Our results show that numerically more adults than children and adolescents are diagnosed each year (316 000 *vs* 194 000 incident cases worldwide in 2021), and that the median

age for a person living with type 1 diabetes is 37 years. Additionally, analysis of pooled high-quality studies suggests a moderate rise in incidence in older adults, with incidence for individuals aged 50 years and older being higher in higher versus lower-quality studies. This rise has been commented on in Thundander and colleagues[31] and also highlighted by a systematic review.[19] These findings have important implications for diagnosis, models of care, and peer support programmes. Such programmes, in countries where they exist, are almost exclusively designed and delivered for children and youth with type 1 diabetes. In addition, our findings emphasise the urgent need for enhanced surveillance and data collection on type 1 diabetes incidence, prevalence, and mortality in adult populations—an area where data are especially scarce. The challenge of recognising adult-onset type 1 diabetes, and differentiating it from type 2 diabetes, was highlighted by a report from a JDRF workshop.[25]

Evidence has accumulated from other studies that death from diabetic ketoacidosis from non-diagnosis of new-onset type 1 diabetes in children and youth is likely to be common in some LICs and LMICs, and could be the commonest cause of death for young people with type 1 diabetes globally. This includes publications on near-miss diagnoses,[16,32] high rates of diabetic ketoacidosis in LMICs,[33] marked differences between urban and rural incidence[34] and prevalence,[13,35] and rapid increases in new case numbers when a type 1 diabetes programme is established.[12,17,24] Our study provides the first data quantifying this problem, estimating 35 000 (20% [30 000–41 000] people younger than 25 years dying from non-diagnosis in 2021. In 2021, this cause of death was responsible for 16% of the global missing prevalence, and 65–68% of the total type 1 diabetes deaths in people younger than 25 years. Estimated diagnosis rates in 2021 were sometimes quite low with the analysis of published studies suggesting this rate could be even lower in some countries.

These results also show the marked disparity in remaining life-expectancy for a 10-year-old with new-onset symptomatic type 1 diabetes, which varied from 7–70 years by income group. This disparity could be due to a multitude of reasons; however, it reinforces the need for national and international efforts to improve access to insulin, and, just as importantly, blood glucose monitoring, diabetes education, and skilled health care.[3,10,36–38] Universal health coverage programmes must be encouraged and fostered, so that type 1 diabetes care is available and affordable to all. These efforts should emphasise cost-effective approaches to selections of insulins and other components of care, which have been shown to improve outcomes and reduce mortality.[37–39] Such efforts have resulted in increasing life expectancy and sharp increases in prevalence in children and youth, as observed with nation-wide programmes in Uzbekistan,[40] Rwanda,[10] Tanzania,[41] and Mali.[12] These programmes all involved a combination of non-government organisation support and ministry of health efforts. Such initiatives should include awareness programmes of the signs and symptoms of type 1 diabetes to improve diagnosis rates, such as the poster campaign used in Mali.[12]

Our model improves upon these previous estimates in multiple ways. First, our estimates include all known incidence data for individuals aged 15–19 year and those 20 years and older. Second, our model integrates all published information on incidence over time, and updates current incidence estimates in all countries, some of which have not had incidence measured since the 1990s.[7] Third, our model takes account of all available type 1 diabetes-associated mortality studies to estimate both higher type 1 diabetes-associated mortality overall, especially in the decades before 1980. This leads to our relatively lower prevalence estimates for adult populations. Despite these differences, the total prevalence estimated by our model for 2017 is similar to (20% lower) that of Green and colleagues,[22] and markedly lower than GBD estimates. Fourth, our model accounts for elements of the burden of type 1 diabetes not reflected in traditional prevalence figures—ie, non-diagnosis and missing prevalence. Finally, our model is capable of making projections of future burden.

However, this study has various limitations. The first set includes the limitations of known type 1 diabetes incidence information. Half of the world's countries, including some populous nations, do not have data for children and adolescents,[7] thus rates are extrapolated from nearby countries and might be more or less accurate depending on genetic and environmental factors. Few countries have any data before 1975. Data are even more limited for adult populations, and studies vary in the method of diagnosis of type 1 diabetes. Furthermore, most countries do not have data about type 1 diabetes incidence over time. These data are particularly limited from south Asia, sub-Saharan Africa, and parts of central and South America, and the mean incidence changes in known populations might not reflect the true changes in incidence in these countries.

The second set of limitations concerns mortality. Given its nature as a so-called known unknown, the estimate of the rate of death from non-diagnosis and its change over time is based on clinician impressions that are broadly consistent with the limited published information; however, it is possible that the estimated rates are lower or higher than the actual situation. For mortality rates in diagnosed cases, information is scarce before 1980. Recent studies are more frequent, but predominantly report on childhood-onset cohorts followed into early adulthood. The estimate of the percentage receiving minimal rather than intermediate or comprehensive care is based on clinical impression. Also, the model is not stratified for gender, which might affect both incidence and mortality rates.

The third set of limitations concerns uncertainty. In our modelling we have quantified the statistical uncertainty in the underlying data, but not the structural

uncertainty in our modelling methods. Therefore, the reported uncertainty intervals understate the true level of uncertainty in our estimates.

This work is the basis for a publicly available, open-source model that will be updated as further incidence, prevalence, and mortality data become available, as part of the Type 1 Diabetes Index project. This standardised and accessible platform can facilitate further studies on topics such as the burden and cost of complications from type 1 diabetes in any given country.

Affiliations
Department of Surgery (J L Harding), Department of Medicine, School of Medicine (J L Harding), and Department of Epidemiology, Rollins School of Public Health, (J L Harding) Emory University, Atlanta, GA, USA; Veterans Affairs Puget Sound Healthcare System, Seattle, WA, USA (P L Wander); Department of Medicine, University of Washington, Seattle, WA, USA (P L Wander); Department of Medicine and Therapeutics (X Zhang, R C W Ma), Hong Kong Institute of Diabetes and Obesity (R CW Ma), and Li Ka Shing Institute of Health Sciences (R CW Ma), The Chinese University of Hong Kong, Hong Kong Special Administrative Region, China; National Clinical Research Center for Metabolic Diseases, Department of Metabolism and Endocrinology, The Second Xiangya Hospital of Central South University, Changsha, Hunan, China (X Li, H Chen, Y Xie, Z Zhou); International Diabetes Federation, Brussels, Belgium (S Karuranga, H Sun); Institute of Biomedical and Clinical Sciences, College of Medicine and Health, University of Exeter, UK (R A Oram); Exeter Academic Kidney Unit, Royal Devon and Exeter NHS Foundation Trust, Exeter, UK (R A Oram); Baker Heart and Diabetes Institute, Melbourne, VIC, Australia (D J Magliano); NHMRC Clinical Trials Centre, University of Sydney, Sydney, NSW, Australia (A J Jenkins); Insulin for Life Global, Sydney, NSW, Australia (A J Jenkins)

Contributors
GAG designed and built the original mathematical model and contributed to analysis and writing of the paper. TIGR co-conceived the work, contributed to the methods and analysis, contributed to writing of the paper, verifies the data, and was responsible for the decision to submit the manuscript. SEL and PR contributed to the analysis and writing of the paper. FW developed the model and contributed to analysis and writing of the paper and verified the data. KD developed and facilitated distribution of the survey of experts globally through the International Society for Pediatric and Adolescent Diabetes (ISPAD) and contributed to the interpretation of the data and writing of the paper. CdB contributed to the interpretation of the data and the writing of the paper. SC contributed to methods, interpretation of data and writing of the paper. DM provided data to validate the model, interpretation of data and contributed to the editing of manuscript. JM and TJO contributed to the methods, data analysis, and reviewed the manuscript. GDO co-conceived the work, contributed to the methods and analysis, and contributed to writing of the paper, verifies the data, and was responsible for the decision to submit the manuscript. All authors had full access to all the data in the study and accept responsibility to submit for publication.

Declaration of interests
TIGR, SEL, FW, and PR are employees of JDRF, a funder of the study. All other authors declare no competing interests. International Diabetes Federation Diabetes Atlas Type 1 Diabetes in Adults Special Interest Group members: RCWM has received research grants for clinical trials from AstraZeneca, Bayer, MSD, Novo Nordisk, Sanofi, and Tricida; and honoraria for consultancy or lectures from AstraZeneca and Boehringer Ingelheim. All proceeds were donated to the Chinese University of Hong Kong to support diabetes research. AJJ has served on advisory boards for Medtronic Australia, Abbott Diabetes Australia and Sanofi-Aventis and received research grants Abbott Europe, Mylan and Sanofi, JDRF, and the NHMRC and has received speaker honorarium from Amgen. RAO has received consulting fees from Janssen, and funding from Janssen as a Co-Investigator on the CASCADE type 1 diabetes screening study. RAO has received UK Medical Research Council Funding to develop a type 1 diabetes genetic risk score diagnostic test in collaboration with Randox. The 10th edition of the *IDF Diabetes Atlas* was supported by an educational grant from the Pfizer-MSD Alliance, with additional support from Sanofi and Novo Nordisk. All remaining authors do not have any conflicts of interest. All other members declare no competing interests.

Data sharing
An interactive dashboard showing incidence, prevalence, mortality, and other data will be made available upon publication at www.t1dindex.org. The underlying code and data used or collected to create the model will also be made publicly available at www.t1dindex.org or can be requested at hello@t1dindex.org. Both the code and data are made available under creative commons public license number 4.0. Where we have used data made available to us in confidence to build the model, these data will be made publicly available only once that work is published. Survey data will be made available with redactions to de-identify participants.

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