Projections of Type 1 and Type 2 Diabetes Burden in the U.S. Population Aged <20 Years Through 2050

Dynamic modeling of incidence, mortality, and population growth

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OBJECTIVE—To forecast the number of U.S. individuals aged <20 years with type 1 diabetes mellitus (T1DM) or type 2 diabetes mellitus (T2DM) through 2050, accounting for changing demography and diabetes incidence.

RESEARCH DESIGN AND METHODS—We used Markov modeling framework to generate yearly forecasts of the number of individuals in each of three states (diabetes, no diabetes, and death). We used 2001 prevalence and 2002 incidence of T1DM and T2DM from the SEARCH for Diabetes in Youth study and U.S. Census Bureau population demographic projections. Two scenarios were considered for T1DM and T2DM incidence: *1*) constant incidence over time; *2*) for T1DM yearly percentage increases of 3.5, 2.2, 1.8, and 2.1% by age-groups 0–4 years, 5–9 years, 10–14 years, and 15–19 years, respectively, and for T2DM a yearly 2.3% increase across all ages.

RESULTS—Under scenario 1, the projected number of youth with T1DM rises from 166,018 to 203,382 and with T2DM from 20,203 to 30,111, respectively, in 2010 and 2050. Under scenario 2, the number of youth with T1DM nearly triples from 179,388 in 2010 to 587,488 in 2050 (prevalence 2.13/1,000 and 5.20/1,000 [+144% increase]), with the greatest increase in youth of minority racial/ethnic groups. The number of youth with T2DM almost quadruples from 22,820 in 2010 to 84,131 in 2050; prevalence increases from 0.27/1,000 to 0.75/1,000 (+178% increase).

CONCLUSIONS—A linear increase in diabetes incidence could result in a substantial increase in the number of youth with T1DM and T2DM over the next 40 years, especially those of minority race/ethnicity.

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See accompanying commentary, p. 2417.

Diabetes is one of the most common and costly chronic pediatric diseases (1). The SEARCH for Diabetes in Youth study (SEARCH) estimated that in 2001 about 154,000 individuals in the U.S. aged <20 years were living with diabetes and that each year approximately 15,000 youth aged <20 years are being diagnosed with type 1 diabetes mellitus (T1DM) and 3,700 with type 2 diabetes mellitus (T2DM) (2,3). Assessing the future burden of diabetes in youth by diabetes type is crucial for implementing public health primary and secondary prevention programs and planning health care delivery services.

A number of studies have estimated the burden of diagnosed diabetes through 2050 in the U.S (4,5). A limitation is that they were not able to separate the contribution of T1DM from T2DM to the projected diabetes burden. Although the majority of adults with diabetes have T2DM, the majority of youth with diabetes currently have T1DM. On the other hand, T2DM may be becoming more common in adolescents, especially among minority youth (2,3).

There is substantial variation in the incidence of T1DM and T2DM across the major racial/ethnic groups in the U.S. The incidence of T1DM is highest among non-Hispanic whites (NHWs) and lowest in American Indians (3). In contrast, T2DM disproportionally affects individuals from all racial/ethnic minority groups (3). Therefore, changes in the race/ethnicity distribution of the U.S. population will substantially impact the absolute number of individuals living with T1DM or T2DM. This makes even more compelling the need for diabetes type–specific projections.

To overcome the limitations of previous studies and provide contemporary estimates of the national type-specific burden of diabetes in youth, we constructed a system of dynamic equations that incorporate diabetes prevalence and incidence, as well as birth, migration, and mortality estimates. These equations

model the future burden of diabetes in U.S. youth aged <20 years through 2050. In addition, we perform sensitivity analyses to assess the impact of increases in the incidence and/or changes in the risk of mortality separately for T1DM and T2DM.

RESEARCH DESIGN AND METHODS

Data sources

The data sources for this study include the U.S. Census Bureau (6) and the SEARCH study (2,3,7–11). Census data include estimates of the 2001 U.S. population by ages (0, 1, 2,. . .,19 years), race/ethnicity (NHW, non-Hispanic black [NHB], Hispanic, Asian and Pacific Islander [API], American Indian/Alaska Native [AIAN]), and sex, as well as projection estimates of births, deaths, and net migration by the same dimensions for the years 2002–2050. For each of these components of population change—fertility, mortality and net migration—the census applied three different assumptions to forecast the future population size. We used the series using the middle assumption for each of these components, also designated as the middle series. SEARCH data include diabetes prevalence in 2001 and incidence from 2002 to 2007 collected from geographically defined populations in Ohio, Colorado, South Carolina, and Washington, as well as Indian Health Service beneficiaries from four American Indian populations, and enrollees in managed health care plans in California and Hawaii. SEARCH is a multicenter study that began in 2001 and is conducting population-based ascertainment of youth aged <20 years with clinically diagnosed, nongestational diabetes. Institutional review board(s) for each site approved the study protocol. A detailed description of the SEARCH study has been published elsewhere (2,3).

Statistical analysis

2001 prevalence estimation. We used Poisson regression to estimate T1DM and T2DM prevalence as a function of age (0,1,. . .,19 years), race/ethnicity (NHW, NHB, Hispanic, API, AIAN), and sex. The Bayesian information criterion was used to select the best fitting models (12). The Bayesian information criterion selects a model from a collection of possible nonnested models by maximizing the likelihood but with a penalty for higher dimensional models. Posterior predictive checking was used to assess model consistency with the data (13). We used the deviance function as a test measure and calculated the "Bayesian *P* value." Bayesian *P* values do not work like the more common frequentist *P* values; values between 0.1 and 0.9 indicate good model fit (14). Models were fit using Bayesian methods in WinBUGS (15). The final models included a cubic spline for age (knots at 0, 9, and 19 years), race/ethnicity, and sex. Posterior predictive checking yielded Bayesian *P* values equal to 0.39 and 0.22, indicating good model fit for T1DM and T2DM, respectively. Our estimates of the 2001 T1DM and T2DM prevalence were the means of the posterior distributions obtained from fitting the final models.

2002 incidence rate estimation. From a population size of 30,549,412 person-years in 2002 through 2007, SEARCH identified 6,164 incident cases of T1DM and 1,534 incident cases of T2DM. We used Poisson regression to estimate T1DM and T2DM incidence as a function of age (0,1,. . .,19 years), race/ethnicity (NHW, NHB, Hispanic, API, AIAN), sex, and calendar year. We were primarily interested in incidence estimates for the year 2002. Including 6 years of data with random effects by year improved the year 2002 estimates by "borrowing strength" from the other years. The final models included a cubic spline for age (knots at 0, 9, and 19 years), race, sex, age by sex interactions, and random effects of calendar year. Posterior predictive checking yielded Bayesian *P* values equal to 0.29 and 0.12, indicating good model fit for T1DM and T2DM, respectively. Our estimates of the 2002 T1DM and T2DM incidence rates were the means of the posterior distributions obtained from fitting the final models.

Projection model. We constructed dynamic models consisting of systems of difference equations similar to models described previously (16,17). In these models, the U.S. population aged 0 to 19 years is modeled at 1-year intervals starting at year 2001 and ending at year 2050. Specifically, we defined numbers of individuals in various disease states (diabetes, no diabetes, and death). The mathematical details are presented in Supplementary Appendix 1.

Sensitivity analyses. We conducted sensitivity analyses by varying both relative risks of death in youth with diabetes versus nondiabetic youth and incidence rate projections for T1DM and T2DM. Two scenarios were considered for relative risks of death: *1*) the relative risks of death for youth in the age-group <20 years with T1DM or T2DM are equal to one, i.e., death rates by age, race/ethnicity, and sex for persons with and without diabetes are equal to the census projected death rates; *2*) death rates of youth with diabetes are higher than those without diabetes with a relative risk equal to 1.5. Two scenarios for T1DM incidence rates were considered: *1*) constant incidence over time at 2002 levels (baseline scenario); *2*) yearly percentage increases of 3.5, 2.2, 1.8, and 2.1% by age-groups 0–4 years, 5–9 years, 10–14 years, and 15–19 years (as seen in a previous study from Colorado [18]), respectively, were applied to all 10 race-sex combinations. Correspondingly, two scenarios for T2DM incidence rates were considered: *1*) constant incidence over time at 2002 levels (baseline scenario); *2*) a yearly 2.3% increase applied uniformly to all ages (0–19 years) for each of the 10 race-sex combinations. This increase represents the overall increase of T1DM registered in the Colorado youth population (18).

RESULTS—Our estimates of the 2002 T1DM and T2DM incidence rates by age and race/ethnicity from fitting the final models are presented in Fig. 1. The incidence of T1DM peaks around the age of 10 years and is highest among NHWs followed by NHBs, Hispanics, APIs, and AIANs (Fig. 1*A*). The incidence of T2DM peaks around 14 years of age. AIAN youth have the highest incidence rate, followed by NHBs, Hispanics, APIs, and NHWs (Fig. 1*B*).

We used these incidence rates in the projection model for each year from 2002 through 2050 in the baseline scenario, where we assume constant incidence rates over time.

Baseline scenario

Table 1 shows the projected number of youth with T1DM and T2DM by race/ethnicity for selected years. The model forecasts that the number of youth with T1DM will increase by 23%, from 166,018 in 2010 to 203,385 in 2050. Due to the absolute increases in the numbers of minority youths in the population as projected by the U.S. Census, this increase is primarily driven by these youths. In 2010, NHWs represented 71% of all youth with T1DM, but by 2050 this proportion will decrease to 55%. Over the 40-year period, the number of Hispanic youth with T1DM is projected to increase 2.5-fold. The overall prevalence

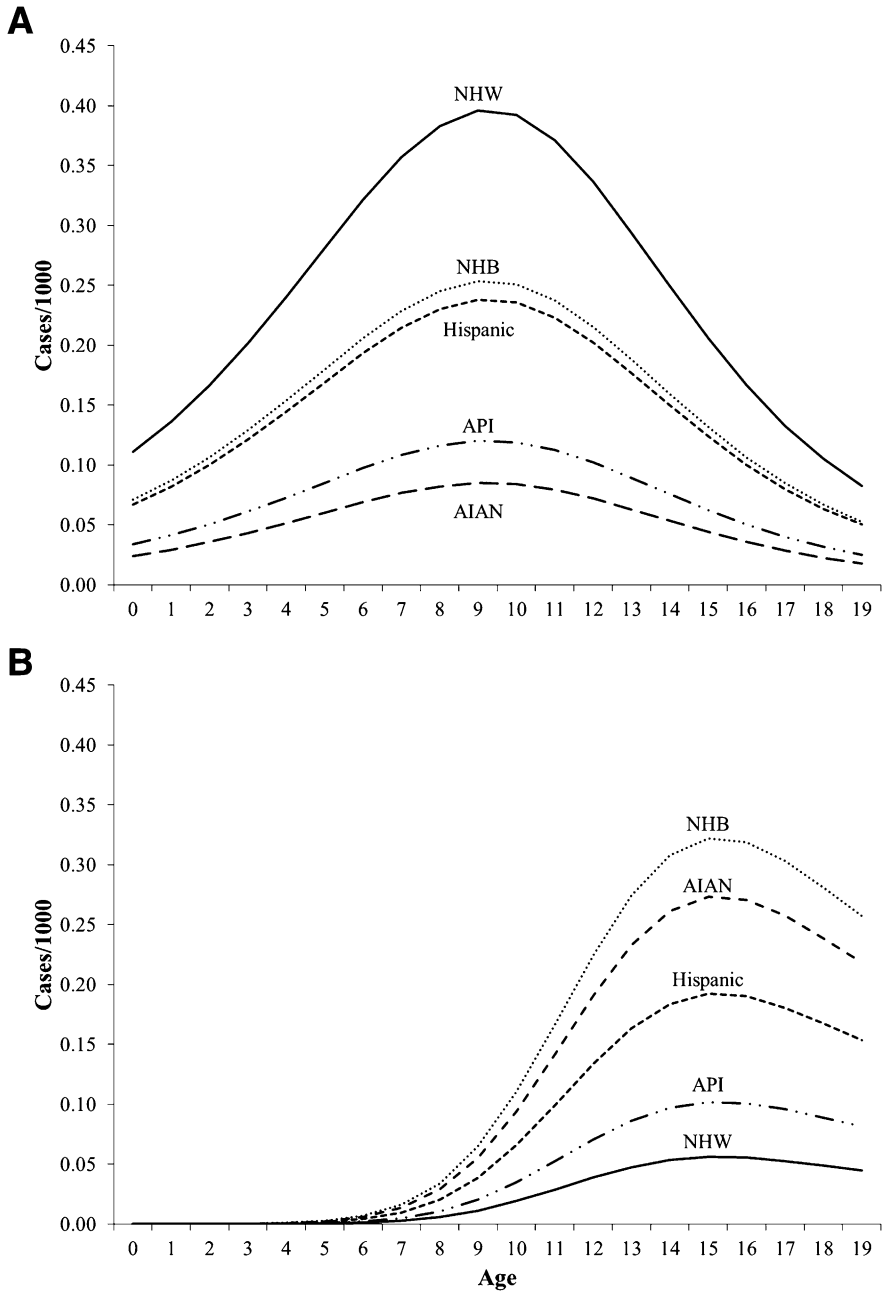

Figure 1—*Estimated 2002 incidence of T1DM* (A) *and T2DM* (B) *among U.S. individuals aged <20 years by age and race/ethnicity.*

of T1DM remains largely unchanged from 1.97/1,000 in 2010 to 1.80/1,000 in 2050, a decrease of 9%, reflecting the lower incidence of T1DM among youth from minority groups compared with NHW youth.

The model estimated that in 2010 20,203 youth in the U.S. had T2DM. Youth of minority groups represented the majority of T2DM cases, while 25% were NHW. The number of youth with T2DM is projected to increase to 30,111 by 2050. As for T1DM, this increase is driven largely by the increase in the population of youth of minority groups. By 2050 Hispanics are estimated to represent 50% of U.S. youth aged <20 years with T2DM. Between 2010 and 2050, the overall prevalence of T2DM may increase by 13%, from 0.24/1,000 to 0.27/1,000.

Increased incidence scenario

Table 2 presents the results of the sensitivity analyses in which the incidence rates of T1DM and T2DM increase while the relative risk of death is equal to 1.0. Under this scenario, the model projects the number of youth with T1DM will increase 3.3-fold, from 179,388 in 2010 to 587,488 in 2050. The number of youth with T1DM will increase 6.6-fold in Hispanics, 5.4-fold in APIs, 4.4-fold in AIANs, 3.0-fold in NHBs, and 2.5-fold in NHWs. The prevalence will increase by 144%, from 2.13/1,000 to 5.20/1,000, with the highest estimate still among NHW youth (7.04/1,000).

Under the scenario of an annual increase of 2.3% in the incidence of T2DM, the model indicates that, in the U.S., in 2010 there were 22,820 youth aged <20 years with T2DM. By 2050, our model predicts that this number will almost quadruple, to 84,131, with Hispanics representing 50% and NHBs 27% of all youth with T2DM. On the basis of our projections, the prevalence will rise from 0.27/1,000 in 2010 to 0.75/1,000 in 2050, an increase of 178%. The prevalence will be highest in NHBs (1.63/1,000) and lowest in NHWs (0.28/1,000).

For both T1DM and T2DM, the differences in the numbers of youth with diabetes from the baseline scenario are due to the increasing incidence rates over baseline.

Under the increasing incidence scenario and the baseline scenario, when we set the relative risk of death at 1.5 for youth with either T1DM or T2DM diabetes, results were virtually identical (data not shown).

CONCLUSIONS—We have estimated the future burden of diabetes in youth by type in the major race/ethnic groups in the U.S., using the most recent population-based estimates of diabetes incidence and prevalence and taking into account demographic changes over time. Our model projected that over the next 40 years, at the current incidence rates, the number of youth with T1DM and T2DM may increase by 23% and 49%, respectively. However, if the incidence of T1DM or T2DM increases, there may be more than a threefold increase in the number of youth with T1DM and about a fourfold increase in the number of youth with T2DM, especially among minority youth.

Very little is known about effective prevention of T1DM, and more research is needed. However, T2DM can be prevented in high risk adults. Additional research is needed to examine the most effective methods for T2DM prevention in youth and should address strategies applicable to obesity prevention and control, as well as strategies for youth at high risk for T2DM. The projected increase in the

Table 1—*Projections of the number of individuals aged <20 years with T1DM or T2DM and prevalence estimates* for selected years, by race/ethnicity under baseline scenario†*

	Race/ethnicity					
Year	NHW	NHB	Hispanic	API	AIAN	Total
T1DM						
2010	117,523 (2.45)	19,640 (1.60)	25,572 (1.35)	2,814 (0.70)	469 (0.46)	166,018 (1.97)
2020	115,989 (2.43)	19,373 (1.54)	35,139 (1.44)	3,661 (0.75)	570 (0.49)	174,732 (1.93)
2030	116,735 (2.46)	20,631 (1.57)	43,206 (1.43)	4,195 (0.74)	656 (0.51)	185,423 (1.90)
2040	113,405 (2.46)	21,051 (1.56)	53,063 (1.44)	4,905 (0.74)	693 (0.50)	193,117 (1.85)
2050	111,576 (2.44)	21,869 (1.55)	63,413 (1.45)	5,765 (0.74)	762 (0.50)	203,385 (1.80)
T2DM						
2010	5,095 (0.11)	7,686 (0.63)	6,162 (0.33)	757 (0.19)	503 (0.50)	20,203 (0.24)
2020	4,792 (0.10)	7,179 (0.57)	8,251 (0.34)	932 (0.19)	509 (0.44)	21,663 (0.24)
2030	4,891 (0.10)	7,769 (0.59)	10,203 (0.34)	1,080 (0.19)	608 (0.47)	24,551 (0.25)
2040	4,788 (0.10)	7,971 (0.59)	12,524 (0.34)	1,248 (0.19)	645 (0.47)	27,176 (0.26)
2050	4,659 (0.10)	8,209 (0.58)	15,074 (0.34)	1,473 (0.19)	696 (0.46)	30,111 (0.27)

*Numbers in parentheses are the estimated prevalence of T1DM or T2DM per 1,000. †Assumes constant incidence of T1DM and T2DM over time and relative risk of death equal to 1.0.

prevalence of T2DM should serve as a call to action so that by 2050 the actual number of affected youth will fall markedly short of our projections.

Because of the early age of onset and longer diabetes duration, children and adolescents are at risk for developing diabetes-related complications at a younger age. As these youth age, this profoundly affects their productivity, quality of life, and life expectancy and increases health care costs. Even in childhood, the medical expenditures of youth with diabetes are approximately 6.2 times of those without diabetes (19). The health care system and society as a whole will need to plan and prepare for the delivery of quality health care to meet the needs of the growing number of youth with diabetes. This may need to include the training of additional health care professionals to treat and manage children and adolescents with T1DM and T2DM.

Strengths of the current study include the use of contemporary population-based estimates of the prevalence and incidence of T1DM and T2DM from the SEARCH study for the major race/ethnic groups in the U.S. This enabled us to quantify race/ethnicity–specific future diabetes burden. Prevalence and incidence estimates were based on physician's diagnosis of T1DM or T2DM, and case definitions met consistent eligibility criteria (2,3). Moreover, physician's diagnosis of diabetes type was in good agreement with the etiologic biochemical and clinical characteristics of the two major types of diabetes (20).

The projections have some limitations. First, the recent estimated increase in the incidence of T1DM is limited and only available in one U.S. study conducted in Colorado (18). The Colorado study found a slightly lower annual increase in T1DM incidence among youth than a large registry-based study conducted in 17 European countries (EURODIAB; overall yearly average increase 2.3% in Colorado vs. 3.9% in Europe) (18,21). However, the pattern of the increase in Colorado was similar to that observed in Europe, with children younger than 5 years old experiencing the greatest relative increase. If the actual rate of increase in the

Table 2—*Projections of the number of individuals aged <20 years with T1DM or T2DM and prevalence estimates* for selected years, by race/ethnicity under increased incidence rate scenario†*

	Race/ethnicity					
Year	NHW	NHB	Hispanic	API	AIAN	Total
T1DM						
2010	126,910 (2.65)	21,174 (1.72)	27,745 (1.47)	3,048 (0.76)	511 (0.50)	179,388 (2.13)
2020	156,537 (3.28)	26,164 (2.08)	47,336 (1.94)	4,915 (1.01)	775 (0.67)	235,727 (2.60)
2030	201,914 (4.26)	35,705 (2.71)	74,840 (2.48)	7,232 (1.28)	1,141 (0.89)	320,832 (3.28)
2040	252,478 (5.47)	46,928 (3.48)	118,527 (3.21)	10,922 (1.64)	1,558 (1.13)	430,413 (4.11)
2050	322,214 (7.04)	63,232 (4.48)	183,212 (4.18)	16,598 (2.14)	2,232 (1.46)	587,488 (5.20)
T2DM						
2010	5,756 (0.12)	8,680 (0.71)	6,965 (0.37)	853 (0.21)	566 (0.56)	22,820 (0.27)
2020	6,798 (0.14)	10,179 (0.81)	11,693 (0.48)	1,320 (0.27)	723 (0.62)	30,713 (0.34)
2030	8,698 (0.18)	13,816 (1.05)	18,135 (0.60)	1,918 (0.34)	1,083 (0.84)	43,650 (0.45)
2040	10,670 (0.23)	17,766 (1.32)	27,919 (0.76)	2,782 (0.42)	1,441 (1.04)	60,578 (0.58)
2050	13,009 (0.28)	22,932 (1.63)	42,121 (0.96)	4,118 (0.53)	1,951 (1.28)	84,131 (0.75)

*Numbers in parentheses are the estimated prevalence of T1DM or T2DM per 1,000. †The incidence of T1DM and T2DM increase (see RESEARCH DESIGN AND METHODS) and relative risk of death equal to 1.0.

U.S. is more similar to that observed in Europe, then our projections may underestimate the future burden of T1DM in the U.S. However, it should be noted that EURODIAB included only children aged 0–15 years and the greatest relative increase in the incidence rate was observed in countries with low baseline incidence. Second, in our study we applied the same rate of increase across all race/ethnic groups. The Colorado study population included only NHWs and Hispanics, and the overall rate of increase in Hispanics was slightly lower than that of NHWs (1.6 vs. 2.7% per year, respectively). The U.S. Census projections indicate that the proportion of the youth population of NHW race/ethnicity will diminish from 62% in 2001 to 41% in 2050 (22). Because of this demographic shift and the possibility that youth of other races/ethnicities than NHW may experience a lower increase in the incidence, it is possible that the number of youth with T1DM could be lower than that estimated by our study under the increasing incidence scenario. Third, we assumed constant increases in T1DM incidence over time and did not account for the possible effect of yet to be identified primary prevention strategies that may influence our predicted number of youth with T1DM. Given our current knowledge, the increased incidence scenario should be taken with caution. However, we would like to point out that recent findings from Europe indicated a constant linear trend over a 15-year period (21) or, starting in the early 1990s, even a steeper increase (23).

Finally, because of the lack of population-based estimates of T2DM incidence trends in youth aged <20 years, we used a yearly increase of 2.3% in our increasing incidence scenario, based on the overall increase of T1DM in the Colorado study (18). In the Pima Indians, a population at very high risk of developing T2DM (24), among youth aged 5–14 years, between 1965 and 2003 the incidence of T2DM increased almost sixfold (25). In Finnish adolescents and young adults (aged 15–39 years) during a 10-year period from 1992 to 2002, the incidence of T2DM increased on average by 4.3% per year, while that of T1DM increased by 3.9% per year (26). Obesity is a major risk factor for the development of T2DM. Since the 1980s, obesity prevalence among U.S. children and adolescents tripled; however, recent national data indicate that during the last decade obesity prevalence may be leveling off at 17% (27). If obesity remains stable for the next 40 years, it is plausible that the current T2DM incidence rate will remain steady. However, even under this scenario, the number of youth with T2DM may increase by 49%. On the other hand, implementation of interventions for the prevention of childhood obesity at the individual or population level may result in decreasing T2DM incidence over time (28,29).

In both scenarios in our study, increasing the relative risk of death to 1.5 did not affect our estimates. This might be partially explained by the very low number of diabetes-related deaths in this age-group (1.15 per million youths) (30).

Our projections suggest a shift in the proportional distribution of racial/ethnic groups among youth with T1DM. By 2050, about half of T1DM youths will be of minority race/ethnic groups. This change may influence potential trends in clinical presentation, treatment patterns, and quality of care. Minority youth are more likely to be overweight or obese (27) and this may lead to a misdiagnosis of T2DM. Among SEARCH study participants, minority youth with T1DM were significantly more likely to have poor glucose control (glycated hemoglobin >9%) than NHW youth (31). Minority youth with T1DM are also more likely to live in households with low income and parental education (7–11). This in turn may affect their access to and quality of health care (32,33). Because of the changing demographics of the youth population with T1DM, health care policies and delivery systems need to assure that less advantaged youth receive appropriate care.

Our projections indicate a serious picture of the future national diabetes burden in youth. Even if the incidence remains at 2002 levels, because of the population growth projected by the U.S. Census the future numbers of youth with diabetes is projected to increase, resulting in increased health care needs and costs. Future planning should include strategies for implementing childhood obesity prevention programs and primary prevention programs for youth at risk for developing T2DM. Likewise, to prevent future human suffering and health care costs, effective interventions for the prevention of diabetes-related complications should be available to all youth with diabetes (34). At the same time, it is crucial to continuously monitor diabetes trends at the population level, as well as complications and quality of care among youth.

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G.I. conceived the study, participated in study design and coordination, and wrote a first draft of the manuscript. J.P.B. developed and programmed the multistate dynamic models, participated in study design and coordination, and helped draft the manuscript. T.J.T. developed and programmed the incidence projection model, participated in study design and coordination, and helped draft the manuscript. D.C. participated in study design and coordination, assembled the SEARCH prevalence and incidence data for analysis, and commented on drafts of the manuscript. D.D., R.F.H., J.M.L., A.D.L., L.L.L., E.J.M.-D., and D.S. reviewed and edited the manuscript and contributed to discussion. B.L.R. reviewed the manuscript and contributed to discussion. G.I. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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