# Life Course Indicator: Diabetes

## The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

**Basic Indicator Information**

Name of indicator: Diabetes (LC-26)

Brief description: Percent of adults with diagnosed diabetes

Indicator category: Family Well-being

Indicator domain: Risk/Outcome

Numerator: Total diabetes cases among adults ≥ 18 years

Denominator: Total adult population

Potential modifiers: Race/ethnicity, age, income, education, gender

Data source: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Preconception Health Indicator I1; HP 2020 Focus area D-1; Chronic Disease Indicator; United Health Rankings Core Measure

## Life Course Criteria

***Introduction***

Diabetes is a chronic metabolic condition in which the body cannot adequately make (type 1) or use (type 2) the hormone, insulin. Type I diabetes is typically diagnosed in childhood or adolescence and the cause of onset remains unclear.[50] There is no known way to prevent onset of type I diabetes and management after diagnosis is critical to avoiding associated morbidity and complications.[50] Type 2 diabetes accounts for 90 to 95 percent of adult cases and is usually preventable.[22] Chronic excess energy – due to a combination of high caloric intake and low physical activity – is thought to be the primary driver for development of type 2 diabetes in susceptible individuals.[23] Due to resulting insulin resistance, individuals with diabetes accumulate high concentrations of glucose in their blood. If undiagnosed or left unmanaged, high blood glucose (also known as high blood sugar) can lead to a number of severe complications, including heart disease, blindness, kidney failure, limb amputation or death.[22] Diabetes was the seventh leading cause of death in the United States in 2010, contributing to more than 234,000 deaths annually.[22] In addition, self-reported diabetes prevalence has steadily increased in the United States over the past two decades, from 4.9 percent in 1990 to 7.3 percent in 2000 and 8.7 percent in 2010.[1,3] The Centers for Disease Control and Prevention (CDC) now estimates that 28.9 million (12.3 percent) U.S. adults aged 20 and older are currently living with diabetes, including approximately 8.1 million living with undiagnosed disease.[22] This narrative focuses mainly on the preventability of type 2 diabetes as an avenue for positively affecting this indicator, however, both type I and type 2 diabetes have implications for health over the life course and proper management of both types is crucial for improving health outcomes.

***Implications for equity***

Type 2 diabetes and its complications disproportionately affect individuals from racial and ethnic minority groups. In 2012, the rate of diagnosed diabetes was highest among American Indians and Alaska Natives, affecting an estimated 15.9 percent of this population.[22] In the same period, age-adjusted prevalence of diabetes was 13.2 percent among non-Hispanic Black adults; 12.8 percent among Hispanic adults; 9.0 percent among Asian American adults; and 7.6 percent among non-Hispanic White adults.[22,4] Significant variation exists within these populations, as well. Among Hispanic adults, Mexican Americans (13.9 percent) and Puerto Ricans (14.8 percent) displayed disproportionately high prevalence rates.[22] Likewise, high diabetes prevalence is found in American Indians in southern Arizona (24.1 percent), while Alaskan Natives have a much lower prevalence of 6 percent.[22]

Researchers have identified a number of genes associated with type 2 diabetes, and heritability is high.[23] The risk of diabetes in children is two to six times higher where one or more first-degree relatives are affected with diabetes,[7] however, not all susceptible individuals will develop the disease.[23] Susceptibility genes may be activated, or triggered, by complex social and environmental exposures, especially during critical periods of development.[5] Evidence suggests that metabolic health status is highly sensitive to epigenesis, the biochemical processes that may result from social and environmental exposures and affect which genes are expressed.[23,24] Racial health disparities may be partially attributable to epigenetic effects caused by stress and environmental conditions experienced by minorities due to discrimination and racism including inadequate housing, crowded and violent environments, and low educational attainment.[24]

Varied exposure to a complex set of risk and protective factors at critical life stages can significantly alter individuals' metabolic health trajectories, contributing to persistent disparities and increased risk of diabetes among certain groups.[5] Factors placing individuals at increased risk for diabetes include gestational diabetes, propensity toward bottle feeding for infants, poor diet, sedentary lifestyle and unhealthy sleep patterns.[23,25] Inequities in social, economic, and environmental conditions may increase these factors in racial minorities.[25,6]

To illustrate, African American women are less likely to breastfeed, a known protective factor for diabetes, than White or Hispanic women.[26] Lower breastfeeding rates in African American women may be due to cultural norms, negative perceptions about breastfeeding, lack of partner support, or unsupportive work environments.[26] In order to reduce disparities in diabetes and improve health equity, increasing protective factors such as breastfeeding in high-risk populations should be examined.

Early onset of diabetes in youth, including type I diabetes, and poor glycemic control have been associated with lower educational attainment and unemployment, which may limit access to health insurance and preventive health care services, as well as impact health-seeking behaviors.[5] Underlying inequities in social, economic and environmental

conditions can also impact the ability of individuals to engage in healthy lifestyle and self-management activities that support the control of diabetes both prior to and after its onset. For example, low-income families and households with limited access to affordable produce are less likely to maintain a healthy diet than those with higher incomes and who live in close proximity to a grocery store.[27,28] Similarly, individuals who live in unsafe neighborhoods with high crime rates or that lack sidewalks, parks and other green space are less likely to maintain recommended levels of physical activity.[29,30]

***Public health impact***

Currently, 29.1 million people in the United States have diabetes, which is 9.3 percent of the population. Diabetes results in a total of $245 billion in direct medical costs ($176 billion) and indirect costs due to disability, work loss, and premature mortality ($69 billion).[22] Type 2 diabetes currently accounts for the majority of diagnosed diabetes cases in adults (90-95 percent), and an estimated 1.7 million new cases were diagnosed in 2012.[22] Onset of type 2 diabetes can be prevented by reducing risk factors such as overnutrition (taking in more calories than required for normal growth and development), physical inactivity, and overweight or obesity.[3]

An important predictor of future burden, an estimated 86 million adults in the United States are currently living with prediabetes, or impaired glucose tolerance.[22] CDC reports that 15 to 30 percent of these individuals will develop type 2 diabetes in the next five years without weight loss or changes in diet and exercise to reduce their risk.[31] This represents a substantial opportunity for impact through public health interventions. In 2010, an evaluation of clinical trials found that a modest weight loss of less than 20 pounds could substantially reduce the risk of diabetes; the study also found that moderate to intense physical activity (e.g. brisk walking for ≥150 minutes per week) could reduce diabetes risk, even without weight loss.[10]

In the absence of intervention, it is currently projected that more than 30 percent of individuals in the United States will develop diabetes in their lifetime.[32] Given the increasing prevalence of type 2 diabetes at younger ages, an increasing number of women are entering pregnancy with the disease.[37] Those who enter pregnancy with uncontrolled diabetes are more likely to experience complications, such as preeclampsia, macrosomia (birth weight >4,500 grams), congenital malformations, or perinatal death.[33] Obesity and diabetes increase risk for maternal morbidity,[35, 36] which makes prevention of these conditions a valuable preconception health opportunity. Diabetes is a risk factor for two main causes of severe maternal morbidity including cardiac conditions and preeclampsia.[36] Although screening for gestational diabetes is recommended at 24 weeks,[38] greater awareness of diabetes prevention in women of childbearing age could help to reduce the impact diabetes has on women and families.[37] Gestational diabetes is discussed in more depth in the life course indicator narrative LC-49.

According to the CDC, strong correlation also exists between diabetes and the presence of comorbidities, such as heart disease and stroke.[8] A review of 2004 death certificates revealed that heart disease was reported in 68 percent of diabetes-related deaths.[8] Screening for type 2 diabetes is now recommended for adults with high blood pressure and other cardiovascular risk factors in order to identify and manage undiagnosed cases.[9]

The consequences of uncontrolled diabetes can be devastating for individuals, their families, and their communities. In 2011, diabetes was the leading cause of blindness among adults age 20 to 74 years.[8] Diabetes also accounted for an estimated 60 percent of non trauma-related lower-limb amputations and 44 percent of end-stage renal failure in adults.[8] A number of other morbidities have been linked to diabetes including gum disease, hearing loss, non-alcoholic fatty liver disease, erectile dysfunction, depression, polycystic ovarian disease, complications of pregnancy, and some cancers.[17-20,23] As a result of their higher risk for comorbid conditions, individuals with diabetes, on average, incur more than twice the medical costs as those who do not have diabetes.[8]

***Leverage or realign resources***

Given the complex set of social, economic, and environmental factors associated with the onset of type 2 diabetes, investment in a multi-sector approach offers the most promising route to its prevention and management. A wide range of possible diabetes prevention partners exist for maternal and child health (MCH) programs including other state or local level programs (e.g. transportation, parks and recreation), community or faith-based organizations (e.g. churches), community recreation facilities, universities, private companies (e.g. sporting goods, restaurants, corner stores), and health care organizations. A number of groups at the national level have been addressing diabetes through web-based resources and community integration programs including:

- The National Diabetes Prevention Program by CDC[43]
- CheckUp America by the American Diabetes Association[44]
- Community Health Workers/Promotores de Salud: Critical Connections in Communities by CDC[45]

Overweight and obesity are associated with risk for type 2 diabetes, making prevention strategies for type 2 diabetes similar to those employed in overweight and obesity prevention. State or local level policies such as the New York City local government's requirement for posting nutrition information on menus and limiting the size of beverage cups make healthy nutrition choices easier and may make consumers more aware of nutrition.[42] Other interventions that are shown to be effective in reducing incidence and effectively managing type 2 diabetes include combined diet and physical activity promotion programs in clinical or community settings, case management to monitor and improve glycemic control, and type 2 diabetes self-management education in community gathering locations.[39]

Medicare and Medicaid have a significant interest in diabetes prevention due to health care costs. The Medicaid Incentives for the Prevention of Chronic Disease (MIPCD) grant program currently funds state programs designed to address chronic disease prevention goals including controlling or reducing weight, preventing diabetes onset, and improving management of diabetes.[40] In Minnesota, the state health department and local YMCAs partner to enroll Medicaid beneficiaries in a weight loss and control program funded by MIPCD designed to reduce diabetes and improve cardiovascular health.[40] In Hawaii an MIPCD grant funds the Hawaii Patient Rewards and Incentive for Supporting Empowerment Project (HI-PRAISE), which focuses on prevention of diabetes and managing the disease through incentives for activities such as blood tests, eye exams, behavioral health counseling and education.[40] Currently, Medicare covers diabetes screening tests and tools needed for diabetes self-management such as insulin and other medications.[16] Also, through the Affordable Care Act, preventive services such as type 2 diabetes screening, diet counseling, and blood pressure screening are covered without cost sharing.[16]

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) works with low-income women and children who are at risk for developing type 2 diabetes and may mitigate risk factors through provision of nutrition education and healthy foods.[41] WIC not only provides families with healthy food options such as fruits, vegetables, and whole grains, but also promotes breastfeeding among participants,[41] which is a protective factor against diabetes for children.[26]

Type 2 diabetes is increasingly being diagnosed among children and adolescents,[22] making schools a key partner in prevention. Beyond nutrition and physical problems, diabetes in school-age children increases risk for academic disadvantage (i.e., poor student attendance, impaired cognitive ability, or reduced academic achievement).[11] A study done by Datar, et. al. found an association between overweight children and lower standardized test scores in math and reading.[12] In addition, adolescents ages 15-17 who are overweight tend to show signs of depression, shame,[13] and being victims and perpetrators of bullying.[14] Many schools already have interventions in place that promote physical activity and behavioral changes. Some have been successful in diet modification and increasing physical activity, but more research is needed about long-term effects of school interventions, and whether or not the interventions are being followed through outside of the school environment.[15]

***Predict an individual's health and wellness and/or that of their offspring***

As noted above, improperly managed diabetes can lead to damage to the heart, blood vessels, eyes, kidneys, mouth, gums, teeth, and nerves leading to multiple serious health problems including cardiovascular disease, blindness, kidney failure, and lower limb amputations. [46,47] Diabetes causes damage to small blood vessels in the kidneys creating high risk for chronic kidney disease, which presents in 35 percent of adult diabetics.[48] Multiple risk factors for cardiovascular disease are common in individuals with diabetes, particularly type 2 diabetes.[46] Type 2 diabetics also have a higher risk for high blood pressure, high cholesterol, obesity, and/or high triglyceride levels.[46] A clustering of three or more of these cardiovascular disease risk factors in an individual is known as metabolic syndrome.[46] In an estimated 50 percent of diabetics, some form of diabetic neuropathy (nerve damage) will occur, with risk increasing with the duration of diabetes.[46] Neuropathy results in numbness, pain and weakness in limbs, hands, and feet.[46] Lastly, there is also evidence that people with diabetes are at double the risk of depression compared to people without diabetes.[5,46] Elevated risk for depression may be due to stress related to having diabetes or could be linked to the effect diabetes has on brain function.[46]

The 'developmental origins of adult disease' hypothesis, also known as the 'Barker hypothesis' states changes in physiology and metabolism occur due to early developmental experiences, particularly intrauterine experiences, creating

an increased risk for disease in adulthood.[49] Increased health risks for infants born to diabetic mothers may illustrate this hypothesis. Infants born to diabetic mothers are at a high risk for spontaneous abortion, congenital malformations, stillbirth, and perinatal morbidity and mortality.[18] Maternal diabetes may cause infants to produce excess insulin, leading to increased growth rates and macrosomia (birthweight > 4,000 to 4,500 grams). Maternal diabetes also leads to a higher risk for breathing problems and low blood glucose levels in infants.[19] In childhood and adolescence children born to diabetic mothers are at a higher risk for obesity and development of type 2 diabetes.[20] The elevated risk of diabetes in children and adolescents born to mothers with diabetes during pregnancy creates a cycle of diabetes that persists across generations.[37] Greater awareness, prevention and management of diabetes across the lifespan will reduce the impact diabetes has on women, children, and families.[37]

## Data Criteria

***Data availability***

The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam for adults 18 years and older. CDC provides state and national level prevalence data on their web site.

The CDC develops approximately 80 questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There are also CDC supported modules that address specific topics that states can use. States may also develop additional questions to supplement the core questions. Modules used by states are noted on the CDC websites

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents.

Data on self-reported physician diagnosis of adult diabetes is available in all 50 states and the District of Columbia through the CDC BRFSS.[1] Included within the core BRFSS module of questions used by all states, diabetes data also are available annually for select MMSAs. In many states, BRFSS may be the only source of timely data on adult diabetes.

BRFSS was selected as the primary data source because adults have a higher incidence and burden of diabetes than children or adolescents. Juvenile diabetes is also a major public health issue; however, analysts may have insufficient cases and statistical power to make meaningful interpretations of the data.

***Data quality***

Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for over 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response

rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.72 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level. The child prevalence data are reliant on proxy report from the adult respondent to the BRFSS and may be subject to misclassification related to this method.

Data on adult diabetes is based on self-reported information, without provider confirmation of diagnosis. Survey participants are asked to respond to the question, "Have you ever been told by a doctor that you have diabetes?" However, past studies have found that BRFSS data on diabetes is reliable. Prior to this study, Brownson and colleagues (1994) conducted a test-retest study of the Missouri BRFSS. The authors examined self-reported, diagnosed diabetes, among several chronic disease survey questions. In this study, the prevalence of diabetes was 7 percent among 222 respondents. Percent agreement was 98 percent and Kappa was 0.86, indicating excellent agreement after accounting for chance.[2]

***Simplicity of indicator***

The numerator and denominator for this indicator is simple, therefore the level of complexity for diabetes as an indicator is low. The data do not require linkage, and BRFSS provides pre-calculated rates for every state and for several counties and cities. Data weighting and adjustments are calculated by state health departments and the CDC prior to posting on their website.

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