Executive Summary

Background
To measure diabetes-related knowledge, attitudes, and practices among adults in the United States, the National Diabetes Education Program (NDEP) periodically conducts the NDEP National Diabetes Survey (NNDS). Findings from this nationwide telephone survey help to assess the program’s progress and inform NDEP strategic planning.

This report presents trends and findings for three rounds of the NNDS: 2006, 2008, and 2011. Each of the surveys was nationally representative of the U.S. civilian, non-institutionalized adult population living in households that had landline telephones. All used consistent methodology and wording of questions to allow examination of trends over time. Computer-assisted telephone interviews were conducted in English or Spanish, depending on the survey respondent’s preference.

Please keep in mind:
- Questionnaire items were developed in 2006 and remained largely unchanged in 2008 and 2011 so that responses could be compared over time. Results are presented using the questionnaire language; as a result, some terminology does not reflect the most current understanding and knowledge of diabetes.
- Question responses reflect people’s perceptions at the time each survey was conducted, and there are no right or wrong answers.
- Except for those who reported that they were diagnosed by a health professional as having diabetes or prediabetes, people did not necessarily know their diabetes status at the time of the survey. They were categorized for analysis as having prediabetes or being at risk based on their responses to a series of questions.
- All percentages are weighted unless otherwise noted.

In 2006, the 1,763 respondents who completed the survey were adults ages 45 years and older. In 2008 ($n = 2,078$) and 2011 ($n = 2,234$), the age range was expanded to include adults from 35 to 44 years of age, as research showed that the rate of type 2 diabetes was growing fastest among adults in that age group. Each time the survey was administered, African Americans and Hispanics were oversampled to ensure adequate representation of these groups. Response rates were 44 percent in 2006, 54 percent in 2008, and 30 percent in 2011. Each survey’s responses were weighted to reflect unequal selection probabilities and the race/ethnicity, gender, age, education, and marital status of the U.S. population.

Respondents’ diabetes status categories used in this report were not self-reported categories. They were assigned after an interview based on information collected during the interview.

- People with diabetes (PWD) had been told by a doctor or other health professional that they had diabetes or sugar diabetes.
• **People with prediabetes** had been told by a doctor or other health professional that they had prediabetes, impaired fasting glucose, impaired glucose tolerance, borderline diabetes, or high blood sugar.

• **People at risk (PAR)** whose self-reported height and weight gave them a body mass index of 25 or greater had been told by a doctor or other health professional that they were at high risk for diabetes, or had been told by a health care professional that they had gestational diabetes or high blood sugar during pregnancy.

• **All others** met none of the above criteria.

**Key Findings**

The three surveys reveal trends in five areas that can inform future efforts to prevent and manage diabetes and its complications:

- Awareness of diabetes terminology and knowledge of diabetes facts
- Perceived risk of diabetes
- Awareness of family history as a diabetes risk factor
- Comorbidities associated with diabetes
- Diabetes management

Trends reported here are among all respondents age 45 and older (the age range included in all three surveys), unless otherwise noted.

**Awareness of diabetes terminology and knowledge of diabetes facts.** In a very short time, American adults have made significant advances in their knowledge and awareness of diabetes and prediabetes. In 2011:

- Over three-fourths of respondents (77%) were aware that type 2 diabetes is preventable (65% in 2006).
- More than half of respondents (57%) had heard the term “prediabetes” (45% in 2006).
- More than one-third (37%) of all respondents had heard of “glycosolated hemoglobin or A1C” (up from 31% in 2006).
- A growing proportion of respondents (almost two-thirds in 2011) strongly agreed that type 2 diabetes is increasing rapidly in the United States.

All of these changes represent statistically significant increases since 2006. In addition, the proportion of respondents who strongly agreed that the number of people with diabetes is rapidly increasing in the United States increased eight percentage points in 3 years—from 53 percent in 2008 to 61 percent in 2011.

Continued high levels of reported knowledge and awareness suggest that some key diabetes messages are getting through to their intended audiences.

**Perceived risk of diabetes.** While diabetes-related knowledge increased from 2006 to 2011, the NNDS did not find a corresponding increase in individuals’ perceived personal risk of developing diabetes or prediabetes. In 2006, 2008, and 2011, only about one-fourth of people with risk
factors said they felt at risk of developing diabetes or prediabetes. The overall proportions were better among people with prediabetes, with over half (60%–62%) of those surveyed at each point saying they felt at risk. However, there were no significant gains over time in perceived risk for people with prediabetes or for people at risk.

**Family history.** From the 2006 and 2008 NNDS, the NDEP learned that people not diagnosed with diabetes believed family history was a principal factor that increased their personal risk for diabetes. The 2008 results also showed a significant increase from 2006 in respondents who had a history of diabetes in their immediate family. These results prompted the NDEP to revise its prevention materials, adding family history to the messages to engage its target audiences in this topic. In 2011, family history was a perceived risk factor reported by about half of undiagnosed people overall, and was the reason mentioned most often. The proportion of people not diagnosed with diabetes who thought family history was a major risk factor dropped 10 percentage points from the 2006 level, although the change was not statistically significant. Among people with prediabetes and Hispanics, there were significant declines in the proportion citing family history as a reason for their perceived risk.

**Comorbidities associated with diabetes.** Perceptions of the most serious health problems caused by diabetes changed significantly from 2006 to 2011 for some problems but not for others. At all three points in time, blindness and amputation were mentioned most often as the most serious health problems. Across the time periods, the proportion of people naming blindness, foot ulcers, or stroke as serious diabetes-related problems significantly decreased, while those mentioning kidney disease or death significantly increased. There were no significant changes in awareness with respect to conditions related to heart disease and diabetes. Cardiovascular disease, high blood pressure/hypertension, and heart attack were infrequently reported as the most serious health problems associated with diabetes.

**Diabetes management.** Management and control of their disease for people with diabetes is modestly better than in 2006, but still shows room for improvement, especially in education for self-management.

In 2011, even though over three-fourths of people with diabetes (77%) said they checked their own blood sugar, this was a statistically significant drop from the 90 percent who reported doing so in 2008.

A modest but significant increase was noted in the understanding of people with diabetes as to how to use the results of monitoring their own blood sugar. In 2006, 89 percent rated their understanding as good or excellent, and by 2011, 95 percent did so. There was no significant change over time in the percentage of people with diabetes who said they had received instruction on up to nine common diabetes management topics, and who rated their understanding of these topics (other than monitoring their blood sugar) as good or excellent. Understanding of management of their low blood sugar continued to lag, with no significant change among people with diabetes surveyed who rated their understanding as poor (12%).

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1 Topics included: 1) the role of diet in blood-sugar control, 2) the role of exercise in diabetes care, 3) the medications the respondent is taking, 4) how to use the results of blood-sugar monitoring, 5) the prevention and treatment of high blood sugar, 6) the prevention and treatment of low blood sugar, 7) the prevention of long-term complications of diabetes, 8) proper foot care, and 9) the benefits of improving blood-sugar control.
Implications for the NDEP

Findings from the NNDS can help identify education, information, and messaging opportunities for the NDEP. Over the three rounds of the survey, there has been substantial progress in knowledge and awareness of diabetes, including primary and secondary prevention. This is good news for the NDEP, and suggests that future program efforts can concentrate on increasing awareness of personal risk for diabetes and on the behavioral aspects of diabetes prevention and management.

The findings on perceived risk of diabetes showed that limited progress has been made among those undiagnosed with the disease (e.g., people at risk of diabetes and people with prediabetes). Developing a more thorough understanding of factors that influence individuals’ perceptions of personal risk and their willingness to take action to reduce risk may help the NDEP craft interventions that reduce the burden of diabetes. Family history is one area where messaging could be reevaluated to more effectively communicate its role as a risk factor for type 2 diabetes. More emphasis on the family history message may be necessary to ensure that the risks associated with a family history of the disease are well understood.

Messages to indicate kidney disease as a serious health problem caused by diabetes appear to have been effective. However, heart-related conditions are not frequently mentioned as some of the most serious health problems associated with diabetes, suggesting a need for additional targeted messages related to cardiovascular disease and diabetes.

NNDS data show that there is still a lot of work to do to increase the understanding of people with diabetes as to how they can better manage their diabetes. In particular, they need help learning how to manage low blood sugar.

In summary, the NNDS provides insight into what the NDEP might focus on to motivate people at risk, people with prediabetes, and people with diabetes to take action to prevent diabetes and improve their management of the disease. In addition, the NNDS provides information on how to engage people to improve behaviors associated with diabetes prevention and management.