



# Findings From a National Diabetes Survey: Highlighting Progress and Opportunities for Diabetes Prevention and Care

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## ABSTRACT

The National Diabetes Education Program (NDEP) implemented periodic deployment of the NDEP National Diabetes Survey (NNDS) in 2006 to collect data on diabetes-related knowledge, attitudes, and behaviors among U.S. adults with diabetes and on risk-reduction attitudes and behaviors among people at risk for type 2 diabetes. Because of similarities in the nationally representative samples of the past three surveys, trends between 2011 and 2016 can be assessed. We present key findings of the 2016 NNDS, focusing on areas of interest to diabetes educators. The 2016 NNDS identified both progress and gaps. Eighty-nine percent of people with diabetes are aware of the A1C test, and disparities by race and ethnicity are narrowing. Awareness of the link between cardiovascular disease and diabetes has plateaued at 75% of respondents. Most people with diabetes do not feel comfortable managing hyper- or hypoglycemia (65 and 60%, respectively), and 60–69% report some level of diabetes distress. Among people without diabetes, awareness of personal risk of type 2 diabetes has increased from 30% in 2011 to 45% in 2016. A diagnosis of prediabetes significantly increases awareness of personal risk of diabetes (65% of people with prediabetes vs. 45% of those at risk), likelihood of receiving counseling about reducing risk (45 vs. 11%), and likelihood of taking action to reduce risk (71 vs. 52%). However, 33% of people without diabetes report not planning to take action to lower their risk of type 2 diabetes. The 2016 NNDS results suggest that outreach and educational efforts have increased knowledge about diabetes and diabetes risk, but also point to the need for more education and support for people with diabetes and those at risk.

The National Diabetes Education Program (NDEP), founded in 1997, is a federally sponsored initiative of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health and the Centers for Disease Control and Prevention that involves public and private partners in efforts to improve diabetes management and outcomes, promote early diagnosis, and prevent or delay the onset of diabetes in the United States. The overall goal of the NDEP is to reduce the burden of diabetes and

prediabetes by facilitating the adoption of proven approaches to prevent or delay the onset of diabetes and its complications. In 2006, NDEP first implemented the NDEP National Diabetes Survey (NNDS) to address the lack of national data on diabetes-related knowledge, attitudes, and behaviors among U.S. adults, as well as on the management and control of diabetes by people with the disease.

The NNDS has been conducted every 2–3 years since 2006 (1–3). The NDEP has used prior NNDS results to assess program progress, guide

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strategy, and inform program initiatives (4). For example, the NDEP developed the campaign “Managing Your Diabetes Is Not Easy, But It’s Worth It” in 2009 based on NNDS findings indicating a need for messages to communicate the seriousness of diabetes and its complications and to promote making an action plan. Another NDEP campaign, “Family Health History and Diabetes” was created in 2012 based on NNDS findings that people were unaware of the importance of family health history as a risk factor for type 2 diabetes.

The full report of the 2016 NNDS survey, including a description of the methodology and all results, can be found in the survey report, available at [www.niddk.nih.gov/health-information/health-statistics](http://www.niddk.nih.gov/health-information/health-statistics). This report presents key findings from the 2016 NNDS and includes trend analyses, where comparable data are available, from earlier surveys. We focus here on findings that would be of particular interest to diabetes educators. Our findings suggest that there have been improvements in diabetes-related knowledge and behaviors among U.S. adults, but that significant gaps remain.

**Methodology**

Since 2014, the NNDS has been conducted using a national probability-based online (Web) survey. Before to 2014, the NNDS was conducted using a random digit dialing (RDD) telephone survey that was probability-based and nationwide. The change to an online format was made because of the continued decline in response to RDD landline phone surveys and to achieve more comprehensive coverage of minorities, younger adults, and cell phone-only households.

The sample for the 2016 survey was drawn from the GfK Knowledge Panel, a probability-based online panel of 42,000 households weighted to be representative of U.S. age and demographic benchmarks, including age, race/ethnicity, education levels, census region, household income, and

urban/rural residence. The 2016 target sample size was 2,500 completed interviews, with a target oversample of at least 830 Hispanics and 830 non-Hispanic blacks. These targets for the total sample size and oversampled groups were met. The survey was deployed in either English or Spanish. The survey completion rate for the 2016 NNDS total sample was 46%. The sample of respondents for the 2016 survey was weighted as in previous rounds of the survey to allow the survey sample profiles to be compared across three time periods: 2011, 2014, and 2016. In this way, each survey year’s sample is representative of the nation as a whole.

Starting with the 2014 survey, additional questions were added to increase the focus on perceived risk of diabetes, diabetes prevention, and diabetes management behaviors. For these questions, time trends could only be assessed between the 2014 and 2016 surveys. Survey results are primarily reported as proportions. Analyses by subgroups of age or race/ethnicity were only conducted if cell sizes were large enough. Differences between subgroups and trends over time, when assessed, were reported as statistically significant if the *P* value for the difference was <0.05. In both the 2014 and 2016 surveys, respon-

dents who reported having diabetes were asked whether they had type 1 or type 2 diabetes. Subgroup analyses were not done for diabetes type or other demographic variables.

**Profile of Respondents**

As with each NNDS conducted since 2008, the 2016 NNDS included adults ≥35 years of age in the United States. There were 2,517 respondents in 2016. Survey results are presented for four groups of people: people with diabetes (PWD), people with prediabetes (PWP), people at risk of diabetes (PAR), and people at lower risk (All Others, or AO). Table 1 describes how these categories were defined by the survey. Self-reported demographic characteristics and diabetes status for the survey population are shown in Table 2. More detail on demographic characteristics of the survey population can be found in the full report, available at [www.niddk.nih.gov/health-information/health-statistics/diabetes-statistics/ndep-national-diabetes-survey](http://www.niddk.nih.gov/health-information/health-statistics/diabetes-statistics/ndep-national-diabetes-survey). Of the respondents with diabetes, 83% reported having type 2 diabetes, 10% reported having type 1 diabetes, and 7% were unsure of their type of diabetes or refused to answer.

**TABLE 1. Definitions for Post Hoc Classification of Diabetes Status**

Diabetes Status	Abbreviation	Definition
People with diabetes	PWD	People who had been told by a doctor or other HCP that they had diabetes or sugar diabetes
People with prediabetes	PWP	People who had been told by a doctor or other HCP that they had prediabetes, impaired fasting glucose, impaired glucose tolerance, borderline diabetes, or high blood sugar
People at risk	PAR	People whose self-reported height and weight gave them a BMI ≥25 kg/m <sup>2</sup> who had been told by a doctor or other HCP that they were at high risk for type 2 diabetes or had been told by a health care professional that they had gestational diabetes or high blood sugar during pregnancy
All others	AO	People who met none of the above criteria

**TABLE 2. Demographic Characteristics and Diabetes Status\***

	Total	PWD	PWP	PWP	AO
Total number	2,517 (100)	487 (19.3)	412 (16.3)	1,042 (41.4)	576 (22.9)
Sex					
Female	1,213 (48)	231 (47)	226 (55)	460 (44)	296 (51)
Male	1,304 (52)	256 (53)	186 (45)	582 (56)	280 (49)
Ethnicity					
Non-Hispanic white	773 (31)	107 (22)	117 (28)	351 (34)	198 (34)
Hispanic	840 (33)	165 (34)	162 (39)	324 (31)	189 (33)
Non-Hispanic black	839 (33)	206 (42)	124 (30)	348 (33)	161 (28)
Other	65 (3)	9 (2)	9 (2)	19 (2)	28 (5)
Age, years					
35–44	531 (23)	45 (9)	77 (19)	256 (25)	153 (27)
45–64	1,313 (49)	248 (51)	229 (56)	546 (52)	290 (50)
≥65	673 (27)	194 (40)	106 (26)	240 (23)	133 (23)

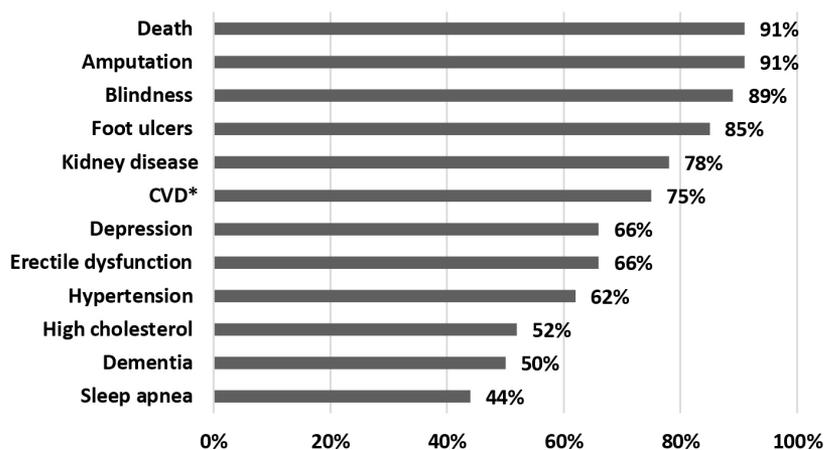
\*Unweighted counts; all data expressed as n (%).

## Results

### Beliefs Around Diabetes-Related Problems

In both the 2014 and 2016 NNDS, respondents were asked about a list of 13 health problems and whether they thought the problems could be caused by diabetes. Figure 1 shows the proportion who selected each of the 13 conditions.

Cardiovascular disease (CVD) is the most common cause of death in people with diabetes (5). Although 75% of 2016 NNDS respondents selected one or more of the CVD outcomes (“stroke” or “heart attack, heart condition, heart disease”) as linked to diabetes, these outcomes were cited less frequently than death, amputations, blindness, foot ulcers, and kidney disease as conditions



■ **FIGURE 1.** Reported health problems thought by respondents to be caused by diabetes: 2016. \*The CVD category was created by combining the heart disease and stroke variables. This category represents the proportion of respondents to this question who reported that heart attack, heart condition, heart disease, and/or stroke were caused by diabetes.

linked to diabetes. The survey also asked respondents to indicate which were the three most serious problems caused by diabetes. The 2016 NNDS respondents were most likely to select “death” (63%), “amputation, loss of foot or leg” (54%), and “blindness” (51%). Combining responses for “stroke” and “heart attack, heart condition, heart disease” into one category did not improve the relative ranking for CVD. The proportion of respondents selecting a CVD outcome did not increase significantly from 2014 to 2016 (73 and 75% of respondents, respectively).

Among 2016 NNDS respondents, a significantly larger proportion of PWD (83%) thought CVD could be caused by diabetes relative to people in other diabetes status groups (76% of PWP, 74% of PAR, and 70% of AO). The same proportion of PWD (83%) reported awareness of the link between diabetes and CVD in 2014.

### Insurance Coverage and Access to Care

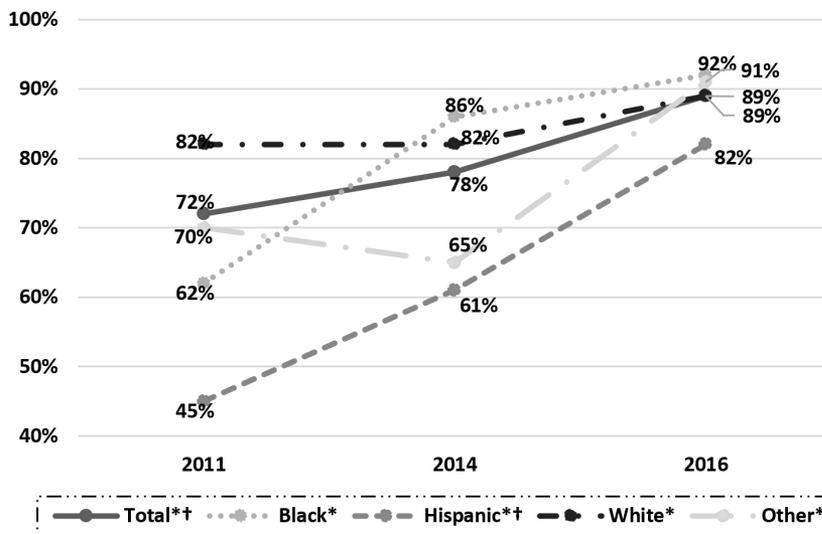
Approximately 93% of 2016 NNDS respondents reported having health insurance that paid for all or part of their medical care. This proportion represents a significant increase over the 89% of 2014 NNDS respondents who reported having health insurance.

Having a usual source of care was common; ~94% of 2016 NNDS respondents reported that they had a usual health care provider (HCP). Hispanics, at 11%, were significantly more likely to report *not* having a usual HCP than were non-Hispanic whites, at 5%, or non-Hispanic blacks, at 9%. The proportion of PWD reporting having a usual HCP increased significantly from 2014 to 2016, from 96 to 99%.

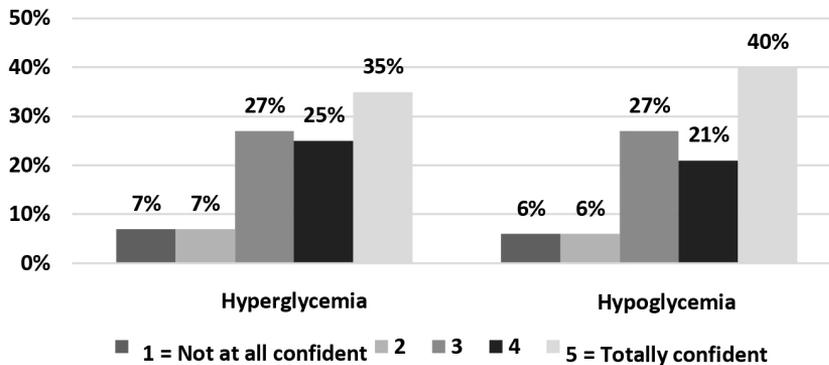
### Results Specific to PWD

#### Awareness of A1C

Among respondents to the 2016 NNDS, 89% of PWD reported that they had heard the terms “A1C,” “hemoglobin A1C,” or “glycosylated hemoglobin.” This proportion represents a significant increase over the 2014



■ FIGURE 2. PWD who had ever heard of the A1C test. \*2016 significantly different from 2011,  $P < 0.05$ . †2016 significantly different from 2014,  $P < 0.05$ .



■ FIGURE 3. PWD reporting confidence in managing hypoglycemia/hyperglycemia: 2016. Percentages might not add up to 100 because of rounding.

NNDS finding that 78% of PWD had heard of these tests. In 2016, the percentage of PWD aware of A1C was lower among Hispanic respondents (82%) than among non-Hispanic black respondents (92%) or among non-Hispanic white respondents (89%). As shown in Figure 2, trend data from 2011 to 2016 showed a significant increase overall and in each race/ethnicity subgroup, with a reduction in differences among subgroups.

Familiarity with A1C testing increased significantly among PWD who were  $\geq 65$  years of age, from 71% in 2011 to 93% in 2016. A1C awareness did not increase significantly for the two younger age-groups.

In the 2016 NNDS, the propor-

tion of PWD who reported having received at least one A1C test in the year before the survey was 87%, whereas the proportion of PWD *who did not know* whether they had the test declined from 9% in 2014 to 6% in 2016. Among those who were aware that their A1C was checked, the percentage who reported more than one A1C check in the prior year was 73%. Trends by race/ethnicity and age over the past three survey years were not significant.

### Diabetes Self-Management

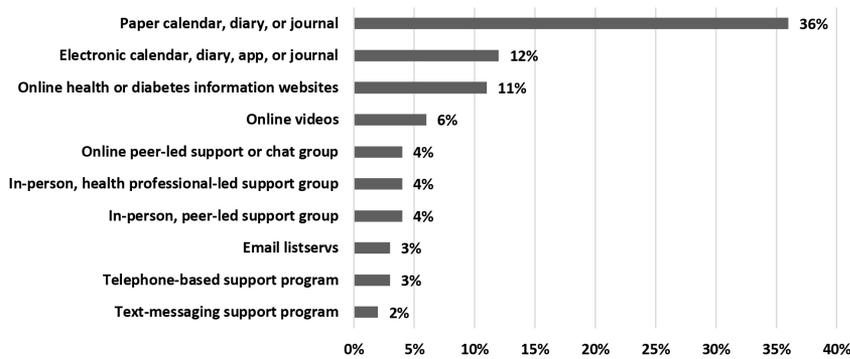
Among respondents to the 2016 NNDS, 62% of PWD reported receiving advice or counseling for diabetes management in the past 12 months. This proportion did not

change significantly compared to the 2014 survey. Among those who reported receiving advice or counseling, the reported source was most frequently a doctor (94%). Other types of HCPs reported as sources of advice or counseling for diabetes management included a nurse practitioner (41%), a diabetes educator (41%), a nurse (40%), a registered dietitian (33%), or a physician assistant (30%). A family member (42%) and friends (24%) were also listed as sources of advice or counseling.

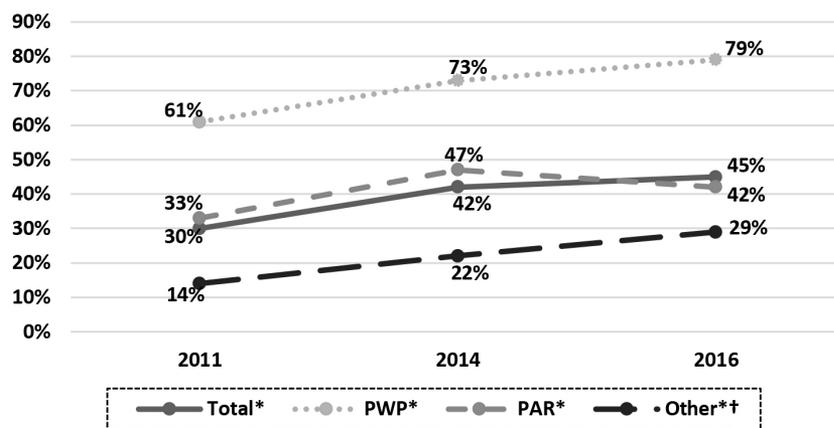
Beginning in 2014, the NNDS asked new questions to elicit a measure of PWD’s confidence in knowing what to do with problems with their blood glucose such as hypoglycemia or hyperglycemia. In 2016, 40% felt “totally confident” in knowing how to handle hypoglycemia, and 35% of PWD felt “totally confident” in their knowledge of what to do if they had hyperglycemia. At the other extreme of the scale, 6% reported feeling “not at all confident” in managing hypoglycemia, and 7% reported feeling “not at all confident” in managing hyperglycemia. A majority of PWD reported intermediate levels of confidence (54% for hypoglycemia and 59% for hyperglycemia), as shown in Figure 3. These proportions did not change significantly between 2014 and 2016.

Levels of confidence in handling hypoglycemia (but not hyperglycemia) differed significantly by age-group, with PWD  $\geq 65$  years of age reporting significantly higher confidence in handling hypoglycemia (53% felt totally confident) compared to 30% of PWD who were 45–64 years of age and 33% of those who were 35–44 years of age.

In terms of overall self-management, the majority of PWD (62%) reported that their way of managing their diabetes had “usually been effective,” whereas 35% reported that their diabetes management was “sometimes effective,” and 3% reported it was “not effective.” These proportions



■ **FIGURE 4.** Tools and resources PWD reported using to help manage diabetes in the 4 weeks before taking the survey: 2016.



■ **FIGURE 5.** Respondents reporting that they feel at risk of diabetes. \*2016 significantly higher than 2011,  $P < 0.05$ . †2016 significantly higher than 2014,  $P < 0.05$ .

did not change significantly between 2014 and 2016.

The 2016 NNDS asked about the use of diabetes self-management tools in the 4 weeks before survey participation. As shown in Figure 4, paper calendars, diaries, or journals to track diabetes-related activities were most frequently used, by 36% of PWD. Electronic tools such as apps were used by 12% of PWD, health or diabetes websites by 11%, and videos by 6%. Other self-management tools were listed by fewer than 5% of PWD. When asked specifically about use of social media (e.g., Facebook and Twitter) to help learn about or manage diabetes, 3% of PWD reported using it “often” and 15% reported using it “only once in a while.”

### Diabetes-Related Distress

The 2014 NNDS and 2016 NNDS asked PWD to rate their level of distress in the past 4 weeks resulting from 1) “the demands of living with diabetes,” 2) “my diabetes routine,” and 3) “possible serious long-term complications, no matter what I do.” Respondents indicated their level of distress on a 5-point scale ranging from 1 = no distress to 5 = serious distress. The 2016 NNDS indicated that the majority of PWD reported some level of distress (rating of 2–5), with 62% reporting at least some distress resulting from demands of living with diabetes, 60% from their diabetes routine, and 69% from possible long-term complications. Distress ratings in each of the three areas did not change significantly from 2014 to 2016.

## Results Specific to People Without Diabetes

### Perceptions of Type 2 Diabetes Risk

The proportion of survey respondents without diabetes (PWP, PAR, and AO) who felt they had a chance of developing type 2 diabetes increased significantly from 2011 (30%) to 2014 (42%), as shown in Figure 5. The increase in risk awareness continued from 2014 (42%) to 2016 (45%) but was not statistically significant. The most commonly cited reasons for feeling at risk for diabetes were weight (67%), family history (57%), and level of physical activity/exercise (51%).

Among non-PWD respondents who felt they had a chance of getting diabetes, the degree to which they felt at risk differed significantly by diabetes status, with 65% of PWP, 45% of PAR, and 15% of AO indicating that their chance of getting diabetes was very or somewhat high. Responses to the question about degree of risk did not significantly differ by age or race/ethnicity.

Among non-PWD, the proportion reporting that they received advice or counseling in the past 12 months about how to prevent type 2 diabetes was 16% overall, 45% for PWP, and significantly lower (11%) for PAR. Among those reporting advice and counseling about diabetes prevention, the main sources reported were doctors (82%) and family members (42%). The proportion who reported receiving diabetes prevention advice and counseling from diabetes educators increased significantly from 13% in 2014 to 21% in 2016.

Among those who reported receiving diabetes prevention advice or counseling in the 2016 NNDS, similar proportions of respondents reported advice to control or lose weight (87%), to reduce calories (86%) or to increase physical activity/exercise (89%). It was much less common, at 23% of respondents, to report

receiving advice to take medication to prevent diabetes.

### Preventive Actions

People with prediabetes were significantly more likely to report having taken action in the past 12 months to reduce their risk of developing type 2 diabetes (71%) than PAR (52%) or AO (43%). The three most commonly reported activities were weight loss or weight management, reducing calories or portions, and walking for exercise. Reported preventive activities related to lifestyle did not change significantly from 2014 to 2016. The proportion who reported taking prescribed medication to reduce their diabetes risk, however, decreased significantly from 44% in 2014 to 35% in 2016.

In 2016, 67% of people without diabetes reported that they were “somewhat likely” or “very likely” to become more active in the next 6 months, and 71% reported that they were “somewhat likely” or “very likely” to lose weight to reduce their chance of getting diabetes. These proportions did not change significantly between 2014 and 2016.

However, 33% of non-PWD indicated they were “not at all” likely to become more active or lose weight in the next 6 months to reduce their diabetes risk. The most common reasons were “I have not thought about it before” (45%), “I do not know what else to do” (28%), and “Other things are more important to me right now” (21%).

### Discussion

The results of the 2016 NNDS survey and available comparisons with prior surveys have important implications for diabetes educators, other HCPs, NDEP, and policymakers. Survey results indicate that awareness campaigns and education have led to some successes (3). Awareness that diabetes is associated with complications such as blindness and amputations, and with premature mortality, is very high. However, despite the fact that the risks of CVD events and CVD death are very high in people with diabetes,

25% of people (17% of PWD) remain unaware of the link between diabetes and CVD. This may hinder acceptance of counseling and interventions aimed at lowering risk of CVD, such as smoking cessation, statin use, and blood pressure management.

Another success in awareness and education is that people with diabetes are highly likely to know about the A1C test. Such awareness has increased markedly in recent years, especially among black and Hispanic individuals. However, other findings of the 2016 NNDS highlight ongoing needs for more diabetes self-management support and education (DSMES). Most PWD reported not feeling totally self-confident in managing hyper- and hypoglycemia (65% and 60%, respectively), and 60–69% reported at least some diabetes-related distress. Only 62% of PWD reported receiving “advice or counseling about diabetes management” in the past year. Of these, 41% reported the source of this counseling as a diabetes educator. The “glass half-full” conclusion might be that 25% of the NNDS respondents with diabetes reported having seen a diabetes educator within the past year, which is significantly higher than published rates of DSMES program utilization (6–8). Whether NNDS respondents have higher rates of seeing a diabetes educator than the general population with diabetes or whether respondents had a broad definition of a diabetes educator is unclear, but the fact remains that 75% of PWD did not report receiving advice or counseling from a diabetes educator in the past year.

One interesting finding of the 2016 NNDS is that people with diabetes were more likely to report using paper tools (diaries, calendars, and logbooks) for diabetes self-management and tracking than electronic, telephone-based, or text-based tools. With the rapid proliferation of and zeal for apps, Web tools, and other high-tech forms of education, tracking, and support, one should not lose sight of patients’ preferences regarding

what is most helpful and comfortable for them.

The 2016 NNDS also provides evidence for successes and opportunities related to risk of type 2 diabetes and prevention of type 2 diabetes in those at risk. NNDS trends show that awareness of diabetes risk continues to rise in the population, and known strong risk factors of body weight and family history are cited as the most common reasons for people to feel at personal risk. A diagnosis of prediabetes significantly increases awareness of personal risk of diabetes (65% awareness in PWP vs. 45% in PAR and 11% in AO), the likelihood of receiving counseling about how to reduce risk (45% of PWP vs. 11% of PAR), and the likelihood of taking action to reduce one’s risk (71% of PWP vs. 52% of PAR and 43% of AO). These findings suggest that guidelines and policies encouraging screening high-risk individuals for prediabetes (9) are making a difference and should continue to expand. The prevention counseling that people are receiving, which emphasizes lifestyle more so than medications, is consistent with evidence that lifestyle interventions have greater efficacy than medications such as metformin (9). The reasons given by the 33% of people who reported not planning to make lifestyle changes to prevent diabetes (lack of knowledge about effect, not knowing what to do, and competing priorities) suggest the need for education and support for people with prediabetes, which can be provided by National Diabetes Prevention Program (National DPP) sites and by diabetes educators.

As with previous installments, findings from the latest NNDS will help inform strategic planning and assist in identifying program improvements such as which messages, audiences, and activities should be emphasized. This reflection includes examining the NDEP’s use of communication channels and platforms to reach intended audiences. For example, the most recent NNDS results continue to

demonstrate the important role that HCPs play in providing advice or counseling on diabetes prevention and management. In an effort to encourage the timely sharing of insights and practical tips to foster a team care approach to diabetes care, the NDEP and NIDDK launched a new blog for HCPs called, Diabetes Discoveries & Practice ([www.niddk.nih.gov/health-information/professionals/diabetes-discoveries-practice](http://www.niddk.nih.gov/health-information/professionals/diabetes-discoveries-practice)). The goal of the NDEP blog is to create an online community to facilitate the dissemination and adoption of research-proven approaches and to leverage technology to keep up with the pace of change and discovery in research. Thought leaders and people in the field representing a variety of disciplines are invited to share their insights and best practices on topics ranging from general diabetes care and prevention to shared decision-making, motivational interviewing, medication adherence, and digital tools and technology for optimizing diabetes care. NNDS findings will be shared through the NDEP blog, and individual topics can be explored more deeply to encourage conversations and facilitate the speed through which new, research-proven approaches can be shared.

### Strengths and Limitations

A key strength of the NNDS is that the sample is nationally representative in terms of age, race, and ethnicity and includes people with and without diabetes and at different levels of diabetes risk. In addition, for some areas, the NNDS can identify trends over time. However, the survey has known or potential limitations. Changes to how the survey is administered (i.e., from telephone to Web survey) do not appear to have affected data trends but may have had some unobserved effects. Because the survey data are self-reported, they may reflect personal influences and subjective information. For most questions, the survey is unable to determine the reasons behind an individual's answer (for example, why they have not seen

a diabetes educator in the past year). In addition to sampling error, other factors may have introduced error or bias into the findings, such as the way questions were worded or the practicalities of administering the surveys. The survey does not include people <35 years of age, those whose primary language is other than English or Spanish, and those with low literacy.

### Conclusion

Findings of the 2016 NNDS, and trends from prior surveys where available, point to significant successes of both public campaigns and individual-level education and support for people with diabetes and those at risk. However, many gaps remain. More people with diabetes need to become aware of the strong link between the disease and CVD events or death so that they will be receptive to messages and interventions to reduce these risks. DSMES remains underutilized, and many people with diabetes lack confidence in their ability to deal with hyper- and hypoglycemia and suffer diabetes-related distress. On the prevention side, population awareness of risk of type 2 diabetes continues to rise. However, more of the estimated 33.9% of the adult population with prediabetes needs to become aware of this condition through screening and education (10). Awareness of prediabetes greatly increases personal awareness of risk and advice and intention to take action to reduce risk. Continued deployment of the National DPP and other methods of education and support will be crucial to our efforts to improve the health of those at risk for type 2 diabetes.

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### Duality of Interest

No potential conflicts of interest relevant to this article were reported.

### Author Contributions

M.S.K., D.T., and C.E.B., each researched data, contributed to discussion, wrote the manuscript, and reviewed/edited the manuscript. M.S.K. 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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