

Cognitive Testing of the 2016 NHIS Diabetes Primary Prevention Questions
Center for Questionnaire Design and Evaluation Research
National Center for Health Statistics

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1. Introduction:

This report summarizes findings from cognitive testing of the 2016 National Health Interview Survey (NHIS) Diabetes Primary Prevention Questions. The main objective of the NHIS is to monitor the health of the United States population through the collection and analysis of data on a broad range of health topics. The 2016 Diabetes Primary Prevention questions are designed to address the following objectives:

- Assess the levels of screening, testing, and detection of prediabetes and diabetes currently underway in the U.S.
- Examine levels of selected diabetes risk factors
- Examine levels of referral, uptake, and participation in structured diabetes prevention programs, community weight loss and exercise programs
- Identify adults with Type 1 diabetes among those with diagnosed diabetes

Cognitive testing was conducted to ascertain how the diabetes questions are able to meet these objectives. This evaluation is based on 45 cognitive interviews that were conducted by the Center for Question Design and Evaluation Research (CQDER) at the National Center for Health Statistics (NCHS), between February and April of 2015. Cognitive interviewing is a qualitative question evaluation method used to assess the construct validity of survey questions (Willis 2005; Miller 2011). The following sections of this report include an overview of cognitive interviewing methodology, a summary of key findings, and a question by question analysis.

2. Methodology:

Sampling and Respondent Characteristics:

As a qualitative method, the sample selection for a cognitive testing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute, such as diabetes diagnosis, that is relevant to the type of questions being examined. The goal of a purposive sample is not to obtain a statistically representative sample. Instead, emphasis is on coverage of the survey questions and topics, not the survey population. As a result, recruitment included individuals who have diabetes, have been told they might have diabetes, think they might have diabetes, or do not have diabetes.

Forty-five respondents were included in this study and were recruited through newspaper advertisements, flyers, word-of-mouth, and by contacting respondents from past CQDER projects who expressed interest in participating in upcoming projects. Twenty respondents were interviewed in round 1 (February, 2015) and 25 in round 2 (April, 2015). Prior to the interview, respondents filled out

several forms, including a consent form to allow video-recording of the interview. Once paperwork was completed, the interviewer described the mission of NCHS, the purpose of the current study, and how the interview would take place. Interviews lasted up to one hour, and a \$40 token of appreciation was given to each respondent. The demographic breakdown of respondents appears in Table 1.

Table 1: Demographic summary of respondents

	Round 1 (n=20)	Round 2 (n=25)	Total (n=45)
Gender			
Female	12	17	29
Male	8	8	16
Age			
18-29	3	4	7
30-49	9	7	16
50-64	5	14	19
65 and over	3	0	3
Hispanic/ Non-Hispanic			
Hispanic	2	2	4
Non-Hispanic	18	23	41
Race/Ethnicity			
Black	10	19	29
White	7	5	12
Asian/ American Indian or Alaskan Native	2	0	2
Don't know	1	1	2
Education			
Less than HS	2	3	5
HS Diploma or Some college/ no degree	6	11	17
Associate Degree	4	5	9
College Degree	6	4	10
Master's Degree	2	2	4
Reported Diabetes			
Type 1	3	2	5
Type 2	8	11	19
Other (don't know and other)*	0	2	2
Prediabetes/borderline*	4	4	8
No diabetes	5	6	11

**These categories came from how respondents answered the diabetes diagnosis questions, but also from information that emerged during probing that may not be represented in the survey questions. See Question by Question analysis below for further explanation.*

Data Collection:

Questions were evaluated using cognitive interviewing methodology. This is a qualitative method of question evaluation that can be used to uncover potential response errors and as a means of assessing construct validity (Willis 2005; Miller et al., 2014). The aim of cognitive interviewing is to investigate how well survey questions perform when asked of respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it impacts the research objective.

Different types of cognitive interviewing techniques exist. Respondent narrative and intensive follow-up verbal probing techniques were the primary cognitive interviewing method used for the project. With these techniques, interviewers administer the survey question, obtain an answer, and then probe the respondent for information relevant to his or her responses. This technique yields rich and detailed information on how respondents answered the question, what they were thinking when answering, and how they interpreted the meaning of the question. Probes included questions such as: Why did you answer the way that you did? How did you arrive at your response? Can you tell me more about that? Can you clarify what you mean?

Questions were revised and tested in an iterative fashion. In the analysis of round 1 interviews, problems were identified, revisions were made, and questions were re-tested in round 2. All data were entered into and are currently stored on Q-Notes, a software application developed and maintained by NCHS. This software was designed specifically for cognitive interview methods to facilitate data organization and analysis.

Data Analysis:

Data analysis was guided by the grounded theory approach which does not aim to test existing hypotheses, but instead generates explanations of response error and various interpretive patterns that are closely tied to the empirical data. This includes the constant comparative method of analysis, in which analysts continually compare data findings to original data (Lincoln and Guba 1985; Strauss and Corbin 1990; Creswell 1998), resulting in data synthesis and reduction (Strauss and Corbin 1990; Suter 2012).

Analysis was conducted from interviewer notes and video recordings. The texts of the interviews were collated by question so that comparisons could be made systematically across all respondents. Several levels of analysis were performed. First analysts synthesized interview data into summaries, detailing how and why each respondent interpreted the question and formulated their answers. Next, analysts compared summaries across respondents, identifying common themes. Once themes were identified, analysts compared themes across subgroups, revealing ways in which different groups of respondents processed questions differently depending on their differing experiences and socio-cultural backgrounds. Finally, analysts made conclusions, determining and explaining how a question

performed as it functioned within the context of respondents' various experiences and socio-cultural locations. With each analytic step in this process, data was reduced and systematically extracted in order to produce a theoretical summary detailing a question's performance. As such, these different analytic steps represent both data reduction and a movement toward larger conceptual themes.

The next section presents a summary of key findings, followed by a question-by-question analysis.

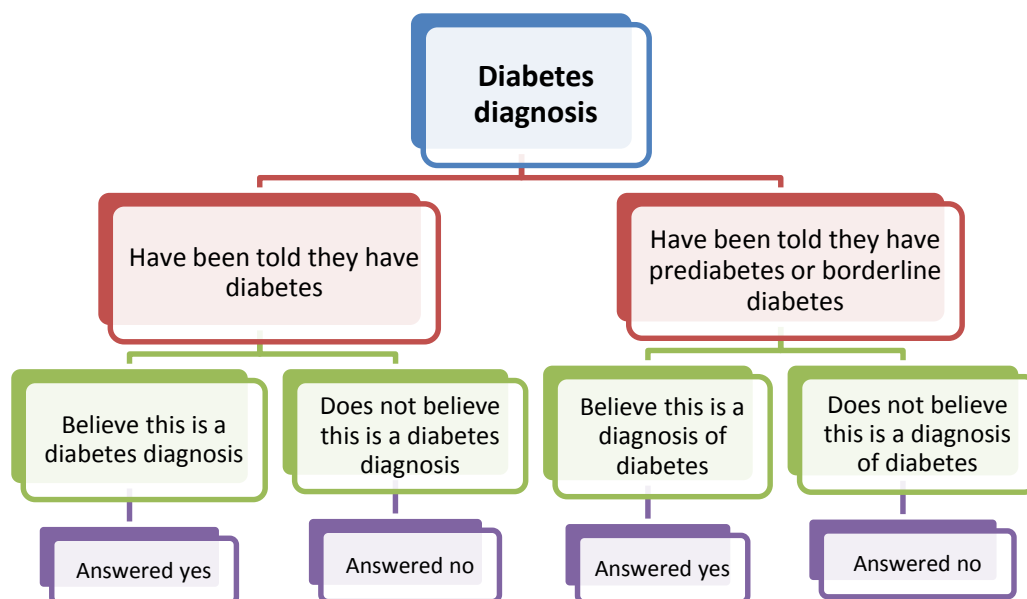
3. Results:

Summary of Key Findings:

1. Categorization Difficulties for Prediabetes and Borderline Diabetes

Many of the questions tested for this project were contingent on respondents being able to classify themselves as having diabetes. Respondents' ability to correctly classify themselves, however, varied depending on the diagnosis conversation with their doctor and their understanding of that conversation. For example, when answering the initial diagnosis question ("Have you ever been told by a doctor or health professional that you have diabetes?"), respondents who understood and trusted their doctor's diagnosis, had no difficulty answering the question. On the other hand, respondents who did not understand the conversation as a clear diagnosis tended to experience difficulty. This was particularly true for respondents who were told that they had 'prediabetes' or 'borderline diabetes'; respondents did not always understand these conditions to be diabetes. In general, respondents' answers are based on their interpretation of what the doctor said. Figure 1 illustrates respondents' thought processes in forming a response to the question.

Figure 1:



As shown in the figure above, some respondents who were told that they had borderline or prediabetes answered 'yes' while others answered 'no.' Many borderline respondents answering 'yes' explained that their doctor told them that borderline diabetes was close enough to diabetes to be considered serious and treated in the same manner as diabetes. Other borderline respondents did not have such a clear understanding of their condition and expressed outright confusion over whether prediabetes was a true form of diabetes. For example, one respondent answered 'no' to having diabetes, but was also unsure about the borderline category. She said, "I would choose 'no' only because 'borderline' confuses me as far as what you're asking when you say 'borderline'. Borderline to me signifies 'are you unsure'." But she also saw how it could mean "you're on the cusp of developing the actual disease."

2. Some Questions Elicit Multiple Interpretations

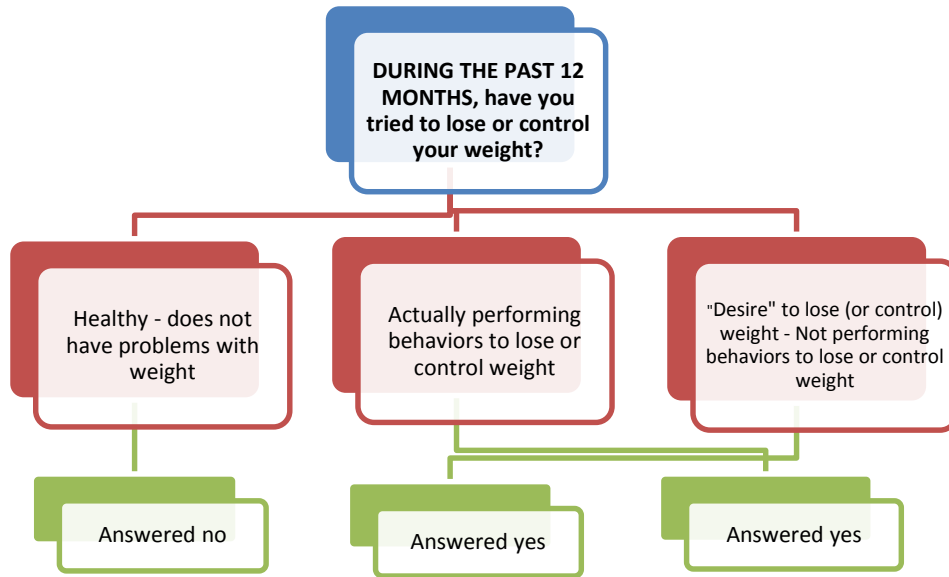
Some of the questions captured a range of interpretations and, therefore, measured multiple constructs. This was especially true for questions pertaining to losing and controlling weight, diabetes screening, and diabetes prevention program questions.

a. Losing and controlling weight:

The first series of questions asked respondents about weight loss and management. The first was, "During the past 12 months, have you tried to lose or control your weight?" For the most part, this question captured the concept of desire to lose weight as opposed to actions taken to lose or control weight. That is, most respondents answered 'yes' even when actual efforts of weight loss or weight management were unclear. Several respondents explained their answers of 'yes' by revealing that they had been trying, unsuccessfully, to lose weight for quite some time. For example, one respondent said she has been trying lose about 10 pounds for the past eight years and another similarly said for the past four years she had been trying to lose five or 10 pounds. Another respondent said she had been trying to lose weight "on and off for a while." The question captures varying degrees of effort and commitment to weight loss or control.

As shown in Figure 2 below, those who felt they were healthy or did not have weight problems, tended to answer 'no' because they have not tried to lose or control weight. On the other hand, those who answered 'yes' to this question did so because they were actually performing behaviors to lose or control weight, or they had a desire to lose or control weight, and may not be performing behaviors to do lose or control weight.

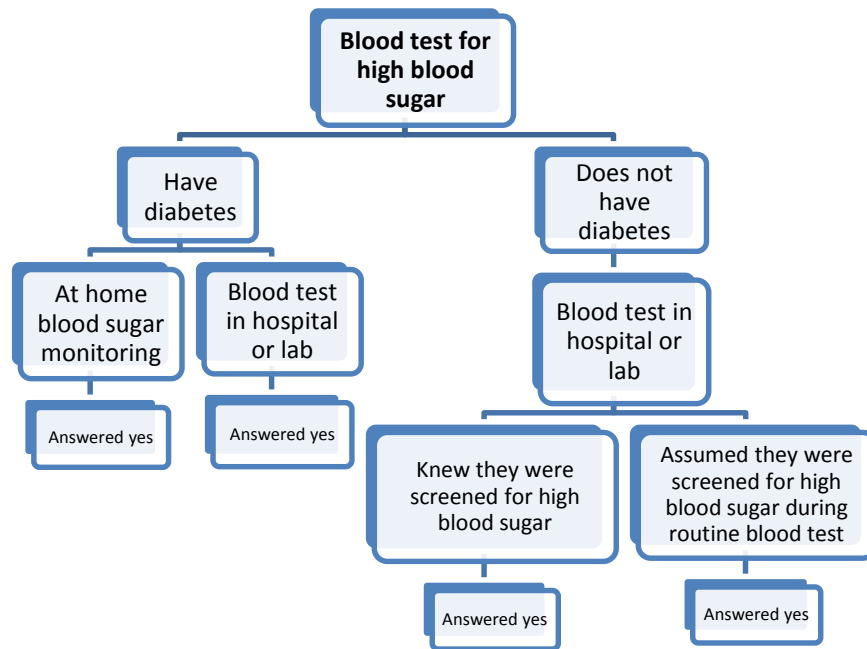
Figure 2:



b. Blood tests and diabetes screening:

The question about diabetes screening asked respondents, "About how long has it been since you last had a blood test for high blood sugar or diabetes?" Generally, respondents answered this question based on two interpretations: 1) the daily monitoring of diabetes or 2) blood tests performed in a doctor's office or hospital during a clinical exam. Further complicating respondents' understanding of this question is that when thinking about recent blood tests in a hospital or doctor's office, many respondents (mainly those without diabetes) did not know if they were screened for diabetes or blood sugar. They knew when they had blood tests, but were unsure whether the tests specifically checked for diabetes. These respondents usually answered 'yes' (as opposed to 'don't know') to receiving a blood test for diabetes, often assuming that diabetes screening is a standard part of blood work. The Figure 3 below shows these patterns of interpretation.

Figure 3:

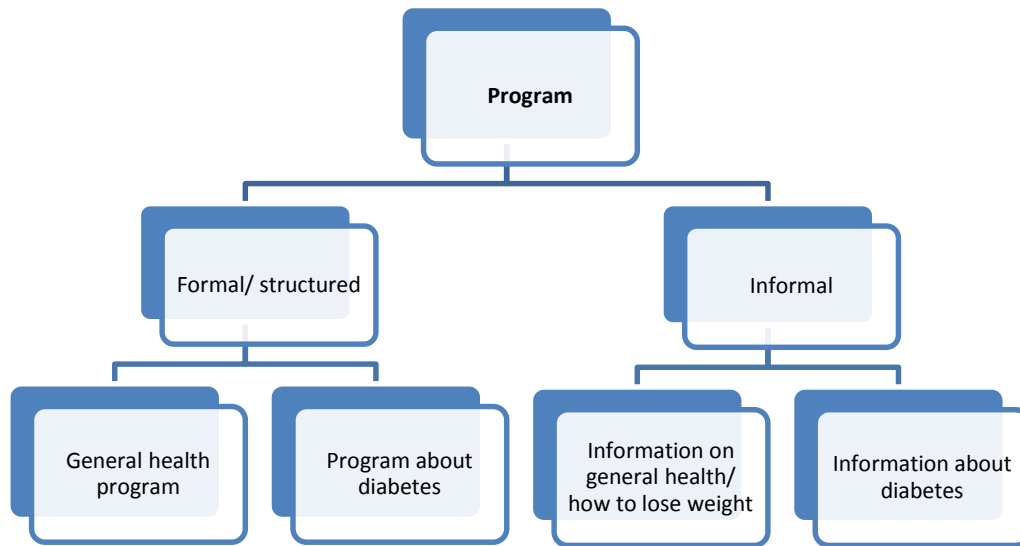


For example, one respondent who answered yes (she had a blood test that tested for blood sugar) said, “It’s been less than a year since I’ve had blood drawn, and I’m not sure what they were testing it for. But I think it’s the same things every year, so if they ever tested it, then they did it.” Since this respondent was not told she had problems with her blood sugar, she reported that everything “is well on the blood front” as her doctor said.

c. Diabetes prevention program:

Several questions asked respondents about participation in a program to prevent Type 2 diabetes. Because the program does not have a consistent name across geographical regions, it was described in a preamble. Nevertheless, respondents had a wide range of interpretations regarding what the program entailed. Two main patterns of interpretation emerged. Respondents either interpreted the program as an informal or formal/ structured program. Some also differentiated between a formal (or informal) health program, and a formal (or informal) program about diabetes. Figure 4 below shows these different patterns of interpretation.

Figure 4:



As shown in the figure, regarding the informal program interpretation, some respondents thought of a discussion with a clinician who provided information or pamphlets. Among the three respondents who said their doctor referred them to such a program, one explained that his doctor suggested he make an appointment to receive education about diabetes, while another said his doctor simply wanted him to see a dietician to lose weight.

On the other hand, some respondents saw the program as a formal/structured program that teaches participants about diabetes or how to live a healthy lifestyle. For example, some respondents thought the program was designed to focus on general health such as “learning how to live a healthy lifestyle,” “controlling weight,” “receiving nutritional information” about food choices or being put on an “exercise plan.” Other respondents were thinking specifically of diabetes and mentioned program goals such as “monitoring diabetes” or attending “classes for awareness” that “educate people about diabetes.”

3. Respondents knowledge (or lack thereof) about diabetes:

Respondents often had limited knowledge regarding diabetes type and treatment (pills and insulin).

a. Diabetes type

Not all respondents with diabetes knew the difference between the types of diabetes. For example, one respondent admitted, “All I know is that there is Type 1, Type 2 and sugar.” Another respondent mentioned Type 3 and Type 4. A few described diabetes as a spectrum, where prediabetes, borderline or Type 1 is the least severe, and Type 2, 3, or 4 is the most severe. Sometimes respondents inferred the type they had based on their situation, such as age of diagnosis, the need for insulin in particular or the need for medication in general.

This lack of knowledge impacted the ways in which respondents answered questions pertaining to diabetes type. For example, in the question “What type of diabetes do you have?” respondents based their answers on their knowledge (or lack thereof) of diabetes type. This question was difficult for respondents who were unclear about their condition. However, rather than answer ‘don’t know,’ several answered based on their personal understanding of the difference between Type 1 and Type 2 – which may or may not be correct. This knowledge often came from respondents doing their own internet research or from talking with family and friends. For example, one respondent who answered Type 2 said, “its insulin dependent.” He did not remember a specific conversation about his type with his doctor, but he said he is “insulin dependent” and Type 2 is “insulin dependent” so, therefore, he must have Type 2. When asked, he said he did not remember how he acquired this information.

On the other hand, when respondents remembered receiving a clear diagnosis, they easily answered the question – even if they did not know the difference between Type 1 and Type 2. They simply reported what they were told by their doctor. For example, one respondent said, “The only reason why I know is because of what the doctor said.”

b. Diabetes medication (pills and insulin)

Respondents who reported having diabetes or prediabetes were asked if they take diabetes pills and if they take insulin. Generally, respondents knew whether or not they were taking pills or insulin to control their diabetes. However, one respondent confused his pills and insulin. Insulin is a medication that is administered through a shot or pump, and does not come in a pill form. This respondent considered his diabetes pills insulin, and referred to them as “insulin pills” and his insulin as “injectable insulin.” He answered the medication and insulin questions based on this information and, therefore, this led to response error because of his lack of knowledge of the difference between the two treatments.

Several respondents who took pills did not know the name of the pill they took and many did not know the dosage. Respondents who did not take pills were not always aware that pills existed. One respondent said “I didn’t even know you can take a pill, I always thought it was something with the needle.” Respondents who knew what insulin was did not appear to have trouble answering the insulin question, but for those that did not, the question was more difficult.

Question by Question Analysis:

1. *[Round 1: Doctors and other health professionals often advise patients on ways they can lower their risk for health problems and/or certain diseases]*

DURING THE PAST 12 MONTHS, have you tried to lose or control your weight?

Round 2: DURING THE PAST 12 MONTHS, have you tried to lose or control your weight?

01 Yes

02 No

- 07 Refused
- 09 Don't know

Answer choice	Round 1	Round 2	Total
Yes	18	21	39
No	2	4	6

Round 1:

In round 1, all but two of twenty respondents answered ‘yes’ to this question. Most respondents answered the question simply on the basis of their desire to lose weight, irrespective of what a doctor told them. This question seems to capture the concept of “wanting” to lose weight, as oppose to actually performing actions to “lose or control weight. Most respondents answered ‘yes’ even when actual efforts at exercise or weight management were unclear. For example, one respondent who answered yes explained, “It is not my main focus, but I am eating differently.” After further probing she said “...Ideally I would say yes.” The question captures varying degrees of effort and commitment to weight loss or control.

When asked why, most people cited personal reasons for trying to lose or control weight. These included general health reasons, ability to engage in activities, and physical appearance. Only five people linked their answer to the preamble that originally preceded this question: *Doctors and other health professionals often advise patients on ways they can lower their risk for health problems and/or certain diseases.* In other words, only five people answered ‘yes’ to the question specifically because their doctor advised them to lose or control their weight.

The respondents who answered ‘No,’ either did not have a problem with weight or were not told to lose weight by their doctor. One respondent explained he feels he walks more often “than people his age, and faster than many people half his age.” In addition, several respondents explained their desire or efforts to control their weight in order to control or prevent diabetes or other health issues. One respondent mentioned that maintaining his weight is a “constant concern” because when one is diabetic, "it's much harder to lose weight."

Round 2:

In round 2, the preamble was dropped, because there was no particular interest in determining if respondents perform these behaviors due to a doctor’s recommendation. In addition, in round 1, only five people answered ‘yes’ to the question specifically because their doctor advised them to lose or control their weight. As mentioned previously, most respondents answered the question simply on the basis of their desire to lose weight, irrespective of what a doctor told them.

In round 2, 21 respondents answered ‘yes’, and four respondents answered ‘no’ to this question. Similar to round 1, some respondents answered based on their desire to lose weight, while others answered based on behaviors and actions they are taking to lose or control their weight. Those who answered ‘no’ mentioned they did not think about their weight. Overall, most respondents answered

‘yes’ to this question, even when actual efforts at exercise or weight management were unclear. For example, several respondents explained their answers of ‘yes’ by revealing that they had been trying – unsuccessfully – to lose weight for quite some time. One respondent said she has been trying lose about 10 pounds for the past eight years and another similarly said for the past 4 years she had been trying to lose five or 10 pounds. Another said she had been trying to lose weight “on and off for a while.” It is clear that the question captures varying degrees of effort and commitment to weight loss or control.

As shown in Figure 2 on page 6, those who felt they were healthy or did not have weight problems, tended to answer no because they have not tried to lose or control weight. On the other hand, those who answered yes to this question did so because they were actually conducting behaviors to lose or control weight, or they had a desire to lose or control weight, and may not be performing behaviors to do lose or control weight.

Those who answered ‘yes’ referred to specific dietary changes (clean eating, cutting down on sweets, eating vegetables and salads) and exercise to characterize efforts to lose weight. For example, one respondent said, “Yes and I’m still trying...and it’s coming off slowly. I’ve been watching my calorie intake and trying to eat the right foods...and I know weight gain contributes to diabetes.” Similarly, one respondent said, “well, I watch what I eat...mostly [not eating as many] sweets.” This respondent did not worry about “regular food” but typically tried to reduce the amount of sweets she eats. Similar to round 1, respondents with diabetes or concerned about diabetes, mentioned this as a reason to lose or control weight. For example, one respondent mentioned that his doctor told him he should lose some weight because he has diabetes. Among the respondents who answered ‘No,’ two mentioned they do not worry about their weight because they have never had a problem with this and do not think much about their eating or physical activity routines.

2. Are you NOW doing any of the following?

[Interviewer Instruction: Enter all that apply.]

- 01 Increasing your physical activity or exercise
- 02 Reducing the amount of fat or calories in your diet
- 03 Participating in a weight loss program

Answer choice	Cases
Increasing your physical activity or exercise	30
Reducing the amount of fat or calories in your diet	32
Participating in a weight loss program	6
None	6

The analysis summaries for rounds 1 and 2 are combined, because no change was made to this question between rounds. Of the 45 respondents in the study, 30 chose ‘Increasing your physical activity or exercise,’ 32 chose ‘Reducing the amount of fat or calories in your diet,’ six reported ‘Participating in a weight loss program,’ and six said they were not doing any of these things.

Respondents who chose a category gave fairly generic explanations of exercise or fat/calorie reduction. One respondent said, “I am trying to eat better, and I am increasing exercise...now that the weather is better.” Another respondent mentioned, “Well, I am more cautious of what I purchase in the store, I buy more sugar-free items, less fat in foods, sticking to fish and chicken, less fried foods.” Similar to the previous question, this question also seemed to capture respondents’ “desire” to lose weight, even when actual efforts to lose weight were unclear. For example, a respondent considered leaving the house and attending a day program (that does not include specific fitness activities) as “increasing physical activity or exercise.” Another respondent chose ‘reducing the amount of calories in your diet’ and explained that he tries to eat more fruit and vegetables, but this happens “off and on.” However, he also mentioned that for the most part “I eat what I want.”

The respondents who expressed they were not increasing physical activity or exercise attributed this to being busy, injury, or not “increasing” physical activity because physical activity levels have remained the same. One respondent mentioned that although he has a gym in his building, he doesn’t have time to go due to his busy work schedule and long commute. In addition, one respondent who reported that she has not increased physical activity or exercise explained she is already physically active and therefore is not “increasing.”

3. Has your mother, father, brother, or sister EVER been told by a doctor or other health professional that they have diabetes or sugar diabetes?

- 01 Yes
- 02 No

Answer choice	Cases
Yes	33
No	12

The analysis summaries for rounds 1 and 2 are combined, because no change was made to this question between rounds. All 45 respondents were asked this question. Thirty-three answered ‘yes’ and 12 answered ‘no.’

Respondents understood and answered the question by thinking about their biological family members specified in the question. For example, one respondent answered ‘yes’ to this question thinking about her biological mother who has diabetes as opposed to her step-mother who does not have it. She said, “Yes, my mom has sugar diabetes, [but] I was raised with my step-mom, so I don’t know her too well.” There was no evidence that respondents based their answers on family members not included in the question.

Respondents were asked how they knew if a family member had diabetes. Many said they knew their family member had diabetes because he or she had told them or because they saw their family take pills or injecting insulin. Furthermore, all respondents reported that their family members learned about their diagnosis from a doctor. Some respondents included family members who had died if they

had been told they had diabetes prior to their deaths. Moreover, some respondents were able to estimate how long their family members had diabetes.

4. [Females: Other than during pregnancy, have you EVER been told by a doctor or other health professional that you have diabetes or sugar diabetes?]/[Males: Have you EVER been told by a doctor or other health professional that you have diabetes or sugar diabetes?]

Round 1: Interviewers read answer categories to respondents

- 01 Yes (Go to Q7)
- 02 No (Go to Q5)
- 03 Borderline (Go to Q9)

Round 2: Interviewers were instructed “Do NOT read answer categories to the respondent.”

- 01 Yes (Go to Q7)
- 02 No (Go to Q5)
- 03 Borderline (Go to Q5)

Answer choice	Round 1	Round 2	Total
Yes	12	16	28
No	7	7	14
Borderline	1	2	3

Round 1:

Twelve respondents answered ‘yes’ to this question, seven answered ‘no’ and one answered ‘borderline.’ Respondents were generally able to report whether or not they had been told they have diabetes. However, the ‘borderline’ category is potentially confusing when the categories are read aloud to the respondent (as they were in round 1). Two respondents who answered ‘yes’ to this question and one who answered ‘no’ actually fall into the ‘borderline’ category. For example, one respondent answered ‘no’ to this question, but was somewhat unsure of her answer because she was diagnosed with prediabetes. When asked why she chose ‘no,’ she said “I would choose ‘no’ only because ‘borderline’ confuses me.... Borderline to me signifies ‘are you unsure’.” But she saw how it could also mean “you’re on the cusp of developing the actual disease.” Another person who answered ‘yes’ explained, “I was told that I was borderline. But to me, ‘yes’ and ‘borderline’ would be the same answer.” Because of the confusion generated by the ‘borderline’ category, the question was modified for round 2.

Round 2:

In round 2, interviewers did not read the answer categories in order to minimize respondent confusion over the ‘borderline’ category. This is consistent with NHIS survey format where the answer choices are not read aloud for this question. In addition, this item moved up one spot in the question ordering. Asking the diabetes question earlier allowed those who answer ‘yes’ to this question (i.e., that they have diabetes or borderline) to skip directly to the follow up questions on diagnosis, type and medication.

In round 2, all 25 respondents were asked this question; 16 said 'yes,' seven said 'no,' one volunteered 'borderline' and one chose 'borderline' after being read the answer categories after expressing much confusion.

Of importance to note, all diagnoses occurred in a doctor's office, hospital or in an Emergency Room. All respondents considered information told to them by a doctor or other health professional when answering this question. The answer to this question was based on their interpretation of what a doctor told them, as well as whether or not they *think* they have diabetes, despite what a doctor told them. As shown in Figure 1 on page 4, those who were told by a doctor or health professional that they had diabetes, and believed they had diabetes, had little difficulty answering the question. On the other hand, those who did not interpret what the doctor told them as a diabetes diagnosis, did not believe they had diabetes, and therefore answered 'no.' This was especially true for those respondents who were told they were "borderline" or had "prediabetes."

If respondents were told by a doctor or health professional that they had borderline diabetes or prediabetes, their answer depended on whether they considered prediabetes or borderline diabetes to be an actual diagnosis. Some respondents believed that a prediabetes classification meant they essentially have diabetes (e.g., in a mild form), while others understood the classification as meaning they do not have diabetes. Respondents' understanding of these diagnoses determined how they interpreted and answered the question. Figure 1 on page 4 illustrates how respondents' interpretation of their diagnoses impacted the response process. Respondents who said they were told by their doctor that they had prediabetes or borderline diabetes and believed this was an actual diagnosis, answered 'yes.' Those who did not believe this was a formal diagnosis of diabetes, answered 'no.' For some respondents answering 'yes', the decision to categorize themselves as having diabetes, was often tied to information given to them by a physician. They explained that their doctor told them that borderline diabetes was close enough to diabetes to be considered serious and treated in the same manner as diabetes. However, other respondents who reported having prediabetes but answered 'yes' to having diabetes were not told by a doctor that they have "diabetes" but were told they have "prediabetes" or "borderline diabetes" and assumed for themselves that this was essentially equivalent to diabetes.

Four respondents with prediabetes or borderline diabetes answered 'yes' they have diabetes. One respondent answered 'yes' to this question because her doctor said, "I'm borderline, or something like that...at the borderline." The doctor prescribed her medication. For others, the decision to categorize themselves as having diabetes was more decisive. They explained that they or their doctor thought borderline diabetes was close enough to diabetes to be considered serious and treated in the same manner as diabetes. For example, one respondent with borderline diabetes said her doctor told her "basically you're diabetic" and another explained "the doctor said I was borderline, but then the endocrinologist said we were just going to go ahead and say I was diabetic." A third respondent assumed for herself (i.e., a physician did not suggest) that borderline was nearly equivalent to diabetes. She noted "to me 'borderline' and 'yes' would be the same answer...borderline you may as well consider yourself a diabetic because you have increased sugar, it's not where it should be."

Lastly, the "other than during pregnancy" phrase caused some confusion. For example, one respondent in round 1 and a second respondent in round 2 stated that they were unsure of whether the question meant during pregnancy or not. One woman said 'no' because when she was pregnant

she did not have diabetes, but was diagnosed with diabetes many years later. She said, “I’m thinking you mean during my pregnancy have I ever been told...”

5. Have you EVER been told by a doctor or other health professional that you have any of the following: prediabetes, impaired fasting glucose, impaired glucose tolerance, borderline diabetes, or high blood sugar?

- 01 Yes (Go to Q9)
- 02 No (Male Go to Q16; Female Go to Q14)

Answer choice	Cases
Yes	7
No	12

The analysis summaries for rounds 1 and 2 are combined because no change was made to this question between rounds. Only respondents who said they do not have diabetes or had borderline diabetes in the previous question (Q4), were asked this question. A total of 19 respondents were asked this question. Seven said ‘yes,’ and 12 said ‘no.’

Respondents’ perception on whether or not these conditions (mainly prediabetes and borderline) constitute diabetes, determined how they answered this question (similar Q4 above - the figure illustrates this response pattern). If they have been told by a doctor or health professional that they have one of these conditions, and they do not think it is diabetes, they answer ‘no’ to Q4 and will be asked this question. Then, because prediabetes and border is mentioned, they typically (not always) say ‘yes.’ However, if they believe these conditions (mainly prediabetes and borderline) are diabetes, they will say ‘yes’ to Q4 and will be skipped out of this question, therefore inaccurately capturing their diagnosis, and possibly leading to response error. In essence, you can miss people who believe that prediabetes and borderline is a diagnosis of diabetes, because they are screened out of this question. For example, one respondent who answered ‘yes’ to Q4 (diabetes diagnosis) was skipped out of this question, but through probing she said she was diagnosed with borderline diabetes. This similar situation occurred with 3 other respondents.

Furthermore, some respondents focused on the origin of the diagnosis of prediabetes as being the essential construct of this question. In other words, the question can be perceived as asking *who told them* this diagnosis, not that they *obtained* the diagnosis. For example, one respondent had not been told by her primary care doctor that she had prediabetes, but had blood work done for a clinical trial in which she participated. This blood work indicated her blood sugar was in the prediabetes range. When asked, this woman identified as having prediabetes but answered ‘no’ to this question because she did not consider this information to be a diagnosis from a “doctor or other health professional”. In essence, when answering this question, she focused on the fact that she was not officially diagnosed by a health professional, even though she had blood work that indicated her blood sugar was in the prediabetes range.

In addition, this question does not specify if respondents have ever been told they have any of these conditions during pregnancy. One respondent who was in this situation, answered ‘yes.’ She explained

that she had a test that indicated borderline diabetes while she was pregnant but she did not have borderline diabetes at any time outside of her pregnancy. It is not clear if this is intended to be within the scope of the question or not.

Also, most respondents did not recognize many of the other terms in this question (i.e. impaired fasting glucose, impaired glucose tolerance...). Many recognized only the terms “prediabetes,” “borderline,” and/or “high blood sugar. Respondents tended to base their answers on the familiar term.

Lastly, some respondents thought prediabetes and borderline diabetes were the same thing, while others thought they were different. One respondent who identified as having prediabetes thought the conditions were different and seemed to believe prediabetes was a progression of borderline, saying, “a long time ago, [about 5 years before I was diagnosed with prediabetes], I was diagnosed with borderline high blood sugar, but I have no idea what it meant and the doctor didn’t tell me what it meant.” She considered prediabetes and borderline diabetes to be different conditions. Furthermore, some respondents believed that borderline was worse than prediabetes. For example, when one respondent was asked the difference between prediabetes and borderline, he said, “Borderline diabetes is probably worse than prediabetes, it’s like right before you open the door versus actually being in the doorway.”

6. About how long has it been since you last had a blood test for high blood sugar or diabetes?

- 01 Less than 1 year
- 02 More than 1 year, but not more than 2 years ago
- 03 More than 2 years, but not more than 3 years ago
- 04 More than 3 years ago
- 05 Never

If Q5 = Yes then Go to Q9; If No and Male, go to Q16, if no and Female go to Q14

Answer choice	Round 1	Round 2	Total
Less than 1 year	19	7	26
More than 1 year, but not more than 2 years ago	0	2	2
More than 2 years, but not more than 3 years ago	0	0	0
More than 3 years ago	0	0	0
Never	1	1	2

Round 1:

In round 1, this question was asked of all 20 respondents. Nineteen respondents answered ‘less than 1 year.’ Only one answered ‘never.’ Respondents were thinking of blood tests in two ways. Some respondents were thinking of general blood work they had done within the past year, usually in association with a yearly checkup. In these cases, some respondents knew that diabetes (or blood sugar level) was specifically included in the test, but others simply assumed it was. Other respondents thought of blood work that was done to monitor their diabetes. In this group, some respondents were

thinking of the laboratory blood test conducted by their doctor and others thought of the tests they do to self-monitor their own blood sugar levels at home. Figure 3 on page 7 illustrates these patterns of interpretation.

Round 2:

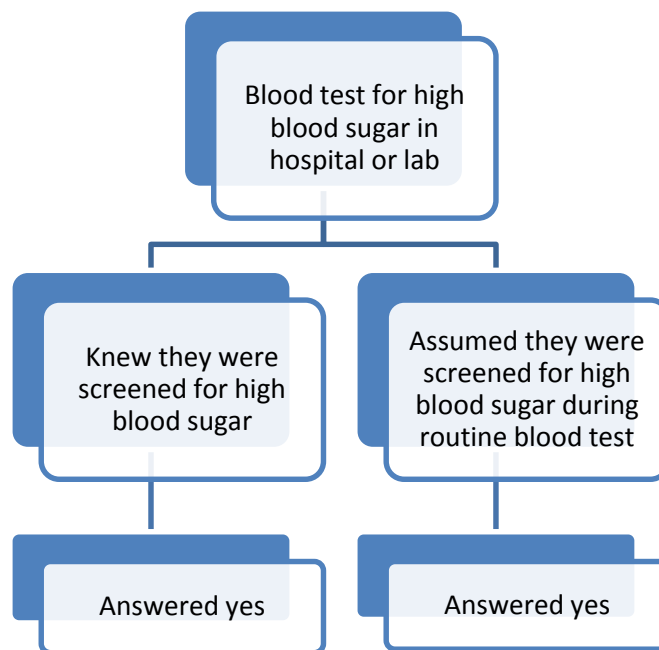
In round 1, respondents interpreted this question as either a formal blood test conducted in a doctor’s office (or hospital) that may or may not be specific to diabetes or as an at-home daily blood sugar monitoring that those with diabetes conduct. This question was meant to capture diabetes screening performed by a doctor or in a hospital. In round 2, if respondents had diabetes or prediabetes, they skipped out of this question, i.e., only those without diabetes or prediabetes answered this question in round 2.

In round 2, ten respondents were asked this question. Seven answered ‘Less than 1 year,’ two responded ‘More than 1 year, but not more than 2 years ago’, and one answered ‘Never.’ No respondent answered ‘More than 2 years, but no more than 3 years ago’, or ‘More than 3 years ago.’

Because respondents with diabetes were screened out of this question in round 2, the self-monitoring interpretation from respondents with diabetes was eliminated. But the question still captured two types of blood tests, those initiated specifically as a check for diabetes (as intended by the question) and those initiated as part of an annual physical or check-up.

As figure 5 below shows, the response patterns of those with diabetes (shown in Figure 3 on Page 7) was removed because they were screened out of the question. Therefore, this question accurately captured blood tests for high blood sugar in a hospital or lab. However, 2 response patterns remained; those who knew they were screened for high blood sugar, and those who assumed they were.

Figure 5:



Of the respondents who answered ‘Less than 1 year,’ five said they received a blood test from a doctor as part of a routine physical examination. These respondents did not recall their doctors specifically saying that they were being tested for diabetes or blood sugar levels. Most respondents mentioned they were unaware of what they were tested for but included this experience in their answer because they assumed that if the blood results tested positive for problems (including diabetes), their doctors would have told them. For example, one respondent said: “It’s been less than a year since I’ve had blood drawn, and I’m not sure what they were testing it for. But I think it’s the same things every year, so if they ever tested it, then they did it.” Since this respondent was not told she had problems with her blood sugar, she assumed that everything “is well on the blood front.” Another respondent answered ‘never’ to this question but had a similar rationale. She said, "I've had blood tests, but I didn't get them because my doctor thought I had diabetes. I'm not even sure if they ever tested [me] for diabetes."

In sum, respondents answered this question based on whether or not they had blood drawn to test for diabetes (blood sugar levels) or whether they had blood drawn as part of a physical/check-up in the last year, irrespective of whether they knew the test was specifically for diabetes.

7. How old were you when a doctor or other health professional FIRST told you that you had diabetes or sugar diabetes?

_____ age in years

Age range	Total
Under 20	2
21-30	5
31-40	2
41-50	8
51-60	10
61-70	0

The analysis summaries for rounds 1 and 2 are combined, because no change was made to this question between rounds. Many respondents were able to give an exact age of diagnosis because they had specific recollections of the time in their life when they were diagnosed. Other respondents struggled to find an exact year and provided an estimate as to their age. Recall was not a problem for respondents who were diagnosed in the past year because their diagnosis was a recent or salient event, such as a diagnosis during a hospital stay.

For some respondents, the ability to think about the “first” time they were told they had diabetes was difficult. One respondent said he had been told he had diabetes but “didn’t pay it no mind” until four or five years later when he started having symptoms. For other respondents, recall was somewhat difficult (that is, they had to think it through before arriving at an answer), but they were still able to do so. Some respondents have multiple points in time at which they are told they have diabetes, and

these respondents found the question more challenging. For example, one man was diagnosed with diabetes several years before his condition worsened. When he first answered the question, he reported that he was 44 years old, but when the interviewer asked during probing, he remembered he had been told he had diabetes before that, but did not worry about it until he became symptomatic years later. He changed his answer to say he was 40 when he was first diagnosed. Another respondent who was diagnosed with diabetes as an adult was initially told she had Type 2 diabetes, but was later told she had Type 1 diabetes when she switched doctors. She reported her first diagnosis of Type 2 diabetes.

Related to this, respondents who were first told they had prediabetes and later that they had diabetes often had difficulty recalling their exact age. Several respondents gave the age at which a doctor told them they had prediabetes. This was not a problem for them – they expressed no confusion, but one respondent did express recall issues. She had to figure out how old she was when she was diagnosed with prediabetes and then how old she was when she was diagnosed with diabetes, which she determined were approximately one year apart. Other respondents also considered an initial diagnosis of prediabetes to be a first diagnosis and a diagnosis of diabetes to be a second diagnosis.

In addition, several respondents were diagnosed in the past year or two and could easily give an age. Others connected it to another major event such as a graduation or a diagnosis during childhood, which was the case for two respondents. However, other respondents expressed hesitation at providing an exact age. For example, one respondent said she was in her “mid-fifties” and when pushed to give an age, she did not know, so she said “55.” Other respondents noted the initial calculation of their age at diagnosis did not align with the amount of time they believed had elapsed since diagnosis. For example one respondent mentioned, “When you asked me how long ago, I said 2007, but when I counted 8 years, I didn’t see it as that long, so it’s been about 6 or 7 years.” Another noted, “Well I'm 60 now, so I think it was like 54 or something when I was told. But, I probably could go to my doctor and find out...and I'd probably be all wrong. It might be more, it might longer. I'm just be saying 5 or 6 [years ago], but it might be 7 or 8.”

In sum, this question effectively captures the age of respondents who were diagnosed within the past two years and those whose diagnoses was tied to a particular life event (such as a during childhood, a graduation or a medical emergency). However, when the event occurred many years ago, respondents found it difficult to remember the date of diagnosis without a marker to assist their memory. In addition, if a respondent was diagnosed multiple times, whether with diabetes, prediabetes, or borderline diabetes, the age of initial diagnosis can be unclear.

8. What type of diabetes do you have?

***Read answer categories below.**

- 01 Type 1
- 02 Type 2
- 03 Other

Answer choice	Cases
Type 1	6
Type 2	20

Answer choice	Cases
Other	1
Don't know	2

No change was made to this question between round 1 and round 2, so the analysis summaries for both rounds are combined. A total of 29 respondents, all of those who reported having been told they have diabetes (i.e. answered 'yes' to Q4), were asked this question. Twenty answered 'Type 2' and six answered 'Type 1,' two said 'don't know' and one said 'other' explaining she thinks she has "borderline diabetes." Respondents either reported the type they were told by a doctor or health professional, or reported the type they think they have based on other information (personal research or treatment type).

Respondents who reported that a doctor or health professional diagnosed them with diabetes had little difficulty answering the question – even if they did not know the difference between Type 1 and Type 2. They reported what they were told by their doctor. For example, one respondent who said he found out he had Type 1 as a child said, "The only reason why I know is because of what the doctor said." Another person reported Type 2 because that is what the doctor told her. But she was less sure of the difference between the two. She said, "When you say Type 1, I feel like it's controlled by pills. Type 2 is when you have the insulin and the pills. That's my knowledge of it."

However, some respondents did not remember a doctor telling them which type they had. But rather than answer 'don't know,' they answered the question based on their understanding of the difference between Type 1 and Type 2 – which may or may not be correct. This knowledge often comes from respondents doing their own Internet research or from talking with family and friends. For example, one respondent who answered Type 2 said, "its insulin dependent." He did not remember a specific conversation about his type with a doctor, but he said he is "insulin dependent" and Type 2 is "insulin dependent," and therefore he must have Type 2. He did not remember where he heard this information.

Respondents used a variety of strategies to determine their type of diabetes. Most individuals reported what their doctor told them, but expressed some level of uncertainty about the different types. Respondents generally held one or more beliefs about the difference between types. The most common belief was that diabetes is a progressive disease that develops from one type to another. Many respondents believed that it starts with borderline or Type 1 diabetes and progresses to Type 2. For example one respondent with diabetes said he didn't have a good understanding of the different types but "Type 2 is the worst of diabetes, there's Type 1 and Type 2 and Type 2 being the later stages...it's a progressive stage." Three respondents mentioned higher levels of diabetes, like Type 3 or Type 4 diabetes.

In sum, respondents answered first based on what they recalled their doctor telling them and if they could not recall this information, answered based on their understanding of the different types which was not necessarily correct.

9. Are you NOW taking diabetic pills to lower your blood sugar? These are sometimes called oral agents or oral hypoglycemic agents.

- 01 Yes
- 02 No

Answer choice	Round 1	Round 2	Total
Yes	4	14	18
No	11	5	16

Round 1:

Respondents who reported having diabetes or prediabetes (i.e. answered ‘yes’ to Q4) were then asked if they take diabetes pills. Four respondents said ‘yes’ and eleven said ‘no.’ Generally, respondents knew whether or not they were taking pills to control their diabetes. Most had heard of diabetes pills before but one respondent said, “I didn’t even know you can take a pill, I always thought it was something with the needle.”

Three of the four respondents who said they took diabetes pills also reported using insulin to control their blood sugar. Three of them clearly distinguished between insulin and pills, whereas one respondent differentiated “insulin pills” from “intravenous insulin.” All respondents knew how many pills they took (and when) in the day, though some did not remember the names of the pills or dosage level. Overall, respondents who took pills and those who did not seemed to be able to answer this question easily and accurately.

Round 2:

In round 2, the order of the questions about diabetes pills and insulin were switched putting this question before the series about insulin (Q10-13). In round 2, 19 respondents said they had diabetes or prediabetes and 14 said they took pills. As in round 1, respondents knew whether or not they were taking pills to control their diabetes. However, respondents were not always aware of the names or dosage of their oral medication. Many reported using metformin, others used Januvia and a few reported other drugs. Respondents generally said they took their pills either once a day in the morning or the evening, or they took them both in morning and the evening and that they took them around meals. A few respondents believed pills to be a form of insulin.

Overall, all respondents who took pills, and those who did not, seemed to be able to answer this question easily and accurately. In other words, even respondents who confused diabetes pills with intravenous insulin were able to identify whether it was something they took.

10. Insulin can be taken by shot or pump. Are you NOW taking insulin?

- 01 Yes (Go to Q11)
- 02 No (If Male Go to Q16; If Female Go to Q14)

Answer choice	Round 1	Round 2	Total
Yes	9	1	10
No	6	18	24

Round 1:

In round 1, this question did not have a preamble “Insulin is taken by shot or pump” and read, “Are you NOW taking insulin?” It was asked to the 15 respondents who reported having diabetes or borderline/prediabetes. Nine respondents said ‘yes’ and six said ‘no.’ Most respondents interpreted this question to be asking if they took insulin through injection. Respondents who said ‘yes’ reported taking insulin from two times per week, to once a day, to multiple times per day, to 24 hours a day via pump.

Most respondents knew whether or not they were taking insulin, so this question presented little difficulty. However, one respondent answered ‘yes’ not because she was actually taking insulin, but because she should be taking it. She said, “Yes, but no. I should be taking insulin and I have a prescription for it.” She had recently been diagnosed with Type 2 diabetes and said she had to get over the “mental block” of taking insulin. She answered ‘yes’ because it’s something she should be taking.

In addition, there was some confusion regarding the difference between pills and insulin. Insulin is a medication that is administered through a shot or pump, and does not come in a pill form. Not all respondents understood the difference between insulin and pills to control diabetes. For example, one respondent, who took insulin for diabetes, distinguished between “intravenous insulin” that he now takes and “insulin pills” that he used to take. Likewise, another respondent who did not have diabetes said, “I’ve heard of diabetes pills, I don’t know what they are, I’m not sure if they’re just a dissolvable form of insulin.” This confusion may lead to response error, specifically false positives for insulin use.

All respondents knew insulin was somehow connected to diabetes. Most seemed to think of it as an injectable drug, but a few did not distinguish between insulin shots and pills. Respondents who knew what insulin was did not appear to have trouble answering this question, but not all respondents knew this information, and for them the question was more difficult.

Round 2:

As some respondents in round 1 illustrated confusion regarding the difference between diabetes pills and insulin, the preface “Insulin can be taken by shot or pump” was added to this question for clarification. Additionally, the question was moved after the question about taking diabetes pills (Q9) to reduce the confusion between insulin and pills.

In round 2, only one person reported using insulin. This respondent had been diagnosed with Type 1 diabetes at age 2 and took injections multiple times a day. Since only one respondent reported insulin use, this allowed us to test for false positives among those who were asked this question and did not take insulin.

All respondents specifically knew they were not taking insulin. It seems as if switching the order of the insulin and diabetes pills questions, as well as adding the preface, may have helped ease confusion.

11. Thinking back to when you were first diagnosed with diabetes, how long was it before you started taking insulin?

01 Less than 1 month

- 02 1 month to less than 6 months
- 03 6 months to less than 1 year
- 04 More than 1 year

Answer choice	Cases
Less than 1 month	5
1 month to less than 6 months	1
6 months to less than 1 year	1
More than 1 year	3

The analysis summaries for rounds 1 and 2 are combined, because no change was made to this question between rounds. This question was asked to all respondents who reported using insulin. In total, 10 respondents were asked this question. Most respondents had no difficulty answering the question because they were put on insulin immediately after being diagnosed, either during a routine exam or during hospitalization for severe symptoms and complications arising from undiagnosed diabetes. However, recall was an issue for some respondents and again, distinguishing between insulin and pills, continued to be an issue for one respondent in this question.

Regarding the issue of recall, one person said, “I think it was less than one year...but I’m not sure.” This question also relies on respondents having a certain level of knowledge about their medication. One respondent had trouble answering and said, “I have to understand what you mean. My doctor immediately started me on pills that I believe were insulin pills, so that would’ve been less than a month. If you mean the injectable insulin, then it’s more than a year after being diagnosed.” He decided to report when he first went on pills (less than one month). Insulin is a medication that is administered through a shot or pump, and does not come in a pill form. This indicates not all respondents understand the difference between insulin and pills to control diabetes. This confusion may lead to response error, specifically false positives for insulin use, as it did in this respondent’s case.

Overall, respondents who started taking insulin immediately upon diagnosis were able to answer this question correctly. However, as mentioned above, when there was some confusion as to the difference intravenous insulin and “insulin pills,” it becomes more difficult.

12. Since you started taking insulin, have you ever stopped taking it for more than 6 months?

Round 1:

- 01 Yes (If Q11=1, 2, or 3, Go to Q13; If Q11=4, R, D, Go to Q 13)
- 02 No (Go to Q9) **In round 1, insulin questions (Q10-13) preceded the pills question (Q9)**

Round 2:

- 01 Yes (If Q11=1, 2, or 3, Go to Q13; If Q10=4, R, D, Go to Q 13)
- 02 No (If Male Go to Q16; If Female Go to Q14)

Answer choice	Cases
Yes	1
No	8

As no changes were made to this question, the analysis for rounds 1 and 2 are combined. This question was asked to 9 respondents, all of those who reported taking insulin. One said yes and 8 said no. Most respondents had no difficulty with this question and answered ‘no.’ The respondents who were taking insulin knew it was an integral part of their wellbeing. One person said, “People always ask me that. You know, have you ever missed a day or something like that. Well. Do you want to feel like [expletive]? No!” Even when not strictly adhering to a schedule, respondents knew the six month timeframe. One respondent said, “Sometimes I may come in tired and go straight to bed and forget to take insulin. So that’s about it.” Another respondent brushed it off altogether as a “stupid” question explaining that a person with Type 1 diabetes needs insulin and would die without taking it for six months.

However, like the previous question, some respondents were confused about the insulin form. For example, one person was not sure whether to report for pills or insulin injections. He reported ‘yes’ because he had stopped taking pills for about eight months (which he believed to be insulin pills). Again, the misunderstanding between pills and insulin can lead to response error, as it did in this case.

13. Was this only during the first year after you were diagnosed with diabetes?

- 01 Yes
- 02 No

This question was only asked to respondents who answered ‘yes’ to Q12, reporting that they had stopped using insulin for at least 6 months at some point in their past. Only one respondent was asked this question, so it could not be thoroughly evaluated. This respondent said he first took “insulin pills” when he was diagnosed in April and stopped taking them in September (5 months later) because he ran out of pills. He said he later went on to “intravenous insulin.” It appeared challenging for him to remember how long he was off medication in general, however but felt confident it was more than 6 months. Once this respondent started taking “intravenous insulin” he remained on it. This indicates that this respondent does not understand the difference between insulin (an injectable medication) and pills to control diabetes. This could lead to response error. This particular respondent answered ‘yes’ he had stopped taking insulin during the first year of diagnosis, when he had in fact stopped taking his pills during the first year of diagnosis.

14. [If Female] During pregnancy, were you ever told by a doctor or other health professional that you had diabetes, sugar diabetes, or gestational diabetes? Please do NOT include diabetes that you may have known about before pregnancy.

- 01 Yes
- 02 No
- 03 Never been pregnant (If Q4=Y, End Interview; If Q4=N, R, D, Go to Q16)

Answer choice	Cases
Yes	3
No	16
Never been pregnant	9

No change made to this question between round 1 and round 2, so the analysis summaries are combined. A total of 28 respondents were asked this question. Three answered 'yes,' 16 answered 'no' and 9 answered 'never been pregnant.'

Respondents often answered this question with a rationale that was couched in the absence, not the presence, of a specific memory. For example, respondents who answered 'no' often could not recall being tested for diabetes during their pregnancy, but simply remembered having a "healthy" pregnancy, without any complications. Respondents also mentioned that the doctor never told them they had diabetes during their pregnancy, or gestational diabetes specifically. For example, one respondent explained, "They drew blood for everything they would normally do for pregnancy and there was nothing mentioned of diabetes." Another remarked, "It was not something that was mentioned or told to me and my child wasn't that big."

A couple respondents who answered 'never been pregnant' expressed irritation when asked the question because it begins with "During pregnancy..." For example, one respondent explained, "What if you were talking to someone who tried to get pregnant... couldn't get pregnant...I think that's a really terrible question...you really need to take that question out..."

The three respondents who answered 'yes' were able to explain that gestational diabetes is diabetes that occurs during pregnancy. One recalled being tested during pregnancy and was told her "sugar was high" and that she had "gestational diabetes." Another respondent remembered that she was surprised and her doctor told her "sometimes you get it with pregnancy" and "it may go away when you have the baby."

Lastly, this question is long and several problems emerged as a result. First, some respondents had difficulty understanding what was being asked and requested that the question be repeated. Second, respondents often answered the question before the interviewer finished reading it (specifically the second sentence, "**Please do NOT include diabetes that you may have known about before pregnancy.**" Third, the interviewer typically did not read the answer choices (yes, no, never been pregnant) because respondents would answer before the interviewer completed the question. Two respondents answered incorrectly as a result, answering 'no' when the better answer was 'never been pregnant.' If the respondents heard the answer choices, they may have answered differently.

15. [If Female] Have you EVER had a baby that weighed 9 pounds (4 kg) or more at birth?

01 Yes (If Q4=Y, End Interview; If Q4=N, R, D, Go to Intro before Q16)

02 No (If Q4=Y, End Interview; If Q4=N, R, D, Go to Intro before Q16)

Answer choice	Cases
Yes	2
No	17

No change was made to this question between round 1 and round 2, therefore the analysis summaries are combined. Women who reported a past pregnancy in Q14 were asked this question. This resulted in a total of 19 respondents who were asked this question. Seventeen answered ‘no’ and 2 answered ‘yes.’

Most respondents had no difficulty answering this question. All respondents who had children remembered their child’s exact birthweight, even with multiple pregnancies. For example, one respondent explained that knowing the weight of your child is “something you never forget” and “it’s on the birth certificate.” One respondent answered ‘no,’ but mentioned that the combined weight of her twins was over nine pounds. She said she thought the question was asking about the birth of an individual baby rather than multiple babies born at the same birth session. Also, some respondents who answered ‘no’ mentioned that they had a “regular” or “normal” pregnancy or delivery, suggesting that children under nine pounds is a normal birthweight.

16. These next questions are about a year-long program that can help people prevent Type 2 diabetes. This program has weekly sessions during the first 6 months and monthly sessions over the last 6 months. People in the program receive support from a lifestyle coach on achieving and maintaining a healthy lifestyle.

The following figure is relevant in Q16 and Q17. It depicts the different interpretations of the meaning of the program described in this preamble. Two main patterns of interpretation emerged. Respondents either interpreted the program as an informal or formal/structured program. Some also differentiated between a formal (or informal) health program, and a formal (or informal) program about diabetes. Figure 4 on page 8 shows the different patterns of interpretation.

Have you EVER participated in this type of year-long program to prevent Type 2 diabetes?

- 01 Yes
- 02 No

Answer choice	Round 1	Round 2	Total
Yes	0	1	1
No	12	12	24

Round 1:

In round 1, all respondents answered ‘no’ to this question. The preamble was long and, therefore, difficult for many respondents to understand, regarding the timeline as well as the aspects of the program. Most respondents answered based on the general concept of overall health programs and programs that would help prevent diabetes.

No one had heard of this specific program, but some were aware of other programs that may have similar goals. Responses varied on what the program was intended to do, from including “changing what you eat and getting more exercise...and to lose weight,” “getting a lifestyle coach and talking to a diabetes specialist,” “gaining further education about the illness,” “a program aimed at communities,

certain ethnic communities, to help them with diabetes,” and to “prevent going on medication to control diabetes.” Respondents either interpreted the program as an informal or formal/structured program. Further, some also differentiated between a formal (or informal) health program, and a formal (or informal) program about diabetes. It was unclear to some respondents whether the question was asking about a specific program or about programs in general. Please see Figure 4 on page 8.

Also, when probed about the program timeline, some respondents expressed confusion. One respondent explained how she understood the timeline and said, “Something about 6 months and 16 weeks, so over a year? ...When you said months, I was thinking weeks. I have no idea what is 16 weeks...There is too much information.”

Round 2:

The preamble was shortened in round 2 to make it less confusing for respondents. Also, because this question was intended to capture information on a program to *prevent* Type 2 diabetes, it was only asked to respondents who reported they DO NOT have diabetes.

Original preamble: These next questions are about a year-long program that can help people prevent Type 2 diabetes. This program has 16 weekly sessions during the first 6 months and 6 monthly sessions over the following 6 months. People in the program receive support from a lifestyle coach on achieving and maintaining a healthy lifestyle.

New preamble: These next questions are about a year-long program that can help people prevent Type 2 diabetes. This program has weekly sessions during the first 6 months and monthly sessions over the last 6 months. People in the program receive support from a lifestyle coach on achieving and maintaining a healthy lifestyle.

In round 2, this question was asked to 13 respondents and all but one respondent answered ‘no’ to this question. Similar to round 1, respondents either interpreted the program as an informal or formal/structured program. Further, some also differentiated between a formal (or informal) health program, and a formal (or informal) program about diabetes. It was unclear to some respondents whether the question was asking about a specific program or about programs in general. Please see Figure 4 on page 8.

Respondents answered based on the general concept of programs that would help either “maintain” or “prevent” Type 2 diabetes. Respondents primarily understood the program as part of a health regimen, such as “learn how to live a healthy lifestyle,” “control weight,” “receive nutritional information” about food choices, including an “exercise plan,” to “monitor diabetes,” or attend “classes for awareness” that “educates people about diabetes.”

Several respondents referred to the program as specifically for Type 2 diabetes, but not all of them understood it to be focused on prevention. This may have had to do with the amount of information in the preamble. For example, one respondent asked for the question to be repeated because she felt that there was a lot of information in the question. She said, “Sorry, it’s a long question.” This same respondent at first thought this was a program for people with Type 2 diabetes, not a program to *prevent* Type 2 diabetes. She asked, “It’s for those who don’t have?”

Once the preamble was shortened from round 1 to round 2, respondents seemed to have better understood the timeline overall. The few respondents who referred to the timeline in their responses understood the program as being year-long and monthly. Conveyed in the words of one respondent, “Well when you first mentioned year long program, I thought a long time, then broke it down 6 months and 6 months and then I felt I would be assisted in reducing Type 2 diabetes.” Clearly, this respondent understood the program timeline. In general it was easier for respondents to follow the shortened preamble.

17. Has a doctor or other health care professional ever referred you to such a program to prevent Type 2 diabetes?

01 Yes (If Q16=Y, End Interview)

02 No

Answer choice	Round 1	Round 2	Total
Yes	0	3	3
No	15	10	25

Round 1:

The same respondents who answered the previous question, Q16, were asked this question. All 15 respondents answered ‘no’ to this question.

The majority of respondents (particularly those who have not been diagnosed with diabetes) made reference to their “doctor” and one respondent to a “health care professional” as never mentioning such a program to them when answering this question. When thinking about the program, they were thinking more in terms of a formal health program as opposed to general information about diabetes. In other words, several respondents noted that their doctors suggested to “change eating patterns” and “keep an eye on sugar” or gave a “print-out and recommendations to control eating habits, but never an official program.”

Of the respondents who have already been diagnosed with Type 2 diabetes, they mentioned that the program would not be relevant to them because they have already been diagnosed, suggesting that they understood the question as specifically asking about prevention of diabetes. However, they too could not recall their doctors or health care professionals ever referring them to such a program.

Round 2:

This question was asked to 13 respondents and all but three respondents answered ‘no’ to this question. In round 1, this question was asked to all respondents, in round 2 they were only asked to those who reported they DO NOT have diabetes. When formulating their response, the majority of respondents made reference to their “doctor” and one respondent to a “health care professional” as never mentioning such a program to them.

As seen in the previous question, two main patterns of interpretation emerged. Respondents either interpreted the program as an informal or formal/structured program. Some also differentiated between a formal (or informal) health program, and a formal (or informal) program about diabetes. Again, Figure 4 on page 8 clearly shows these different patterns of interpretation.

Some respondents, who answered ‘yes’ to this question, were thinking more in terms of an “informal” program or information. In other words, several respondents noted that their doctors suggested that they should see a dietician to lose weight, or to “change eating patterns,” “keep an eye on sugar” or gave a “print-out and recommendations to control eating habits, but never an official program.”

On the other hand, some respondents thought of the program as being more formal than just receiving information about diabetes. Some respondents saw the program as a formal program that teaches participants about diabetes or how to live a healthy lifestyle. For example, some respondents thought the program was designed to focus on general health such as “support groups” to help with diet or a program to get more information about diabetes.

Similar to round 1, some respondents who answered ‘no’ did not consider general information about diabetes when thinking about this question. As one respondent, who answered ‘no,’ explained, “They may have given me a pamphlet. I read through it. It didn’t say anything more explicit than what I clearly know. It was just information.” This further shows that some respondents interpreted this program as formal.

Among the three respondents who answered ‘yes,’ only one explained that his doctor suggested he make an appointment to receive education about diabetes while another said his doctor simply wanted him to see a dietician to lose weight. The third respondent made it clear that her doctor wanted her to lose weight prior to having gastric bypass surgery, and she needed to participate in a “prep” program that teaches participants how to lose weight and eat better. Her response further suggests, similar to question 16, that some respondents thought of this program as a general program that may be related to other health programs, and not a program specifically to prevent diabetes.

18. How interested are you in beginning such a year-long program to prevent Type 2 diabetes?

Would you say...

- 01 Very interested
- 02 Somewhat interested
- 03 Not interested

Answer choice	Cases
Very interested	11
Somewhat interested	4
Not interested	12

No change was made to this question between round 1 and round 2, therefore the analysis summaries are combined. The same respondents who answered question 16 were asked this question. Eleven

respondents answered they were ‘very interested,’ four answered they were ‘somewhat interested,’ and twelve answered they were ‘not interested.’

Respondents often thought of investments of time or money when deciding on an answer. However, this did not necessarily lead respondents to the same answer category. Several respondents explained they were interested, but chose only ‘somewhat interested’ (over ‘very interested’) because they did not have the time or money to fully invest in this type of program. Other respondents chose ‘not interested’ using the same rationale.

A person’s diabetes status influenced how they interpreted the question (This only occurred during Round 1, respondents with diabetes were not asked questions 16-18 in round 2). Some respondents who did not have diabetes understood the question as asking about people who already have diabetes, even though the question states “to *prevent* Type 2 diabetes.” This shows that not all respondents understood the program is to prevent diabetes. They answered ‘not interested’ as a way of indicating the question was not applicable to them. For example, one respondent who had not been diagnosed with diabetes stated, “I think its useful information, but I don't think that right now, it would be useful to myself.” On the other hand, another respondent made note that she would not be interested because she does not have diabetes. Neither interpreted this as a prevention question.

19. Imagine that this type of year-long program to prevent Type 2 diabetes is available to you free of charge at a convenient location OR, if you prefer, through your television or the internet. Which of the following reasons is MOST LIKELY to keep you from participating?

* Read answer choices if necessary.

- 01 Not worried about diabetes
- 02 Doctor hasn’t recommended
- 03 Other programs haven’t helped
- 04 Transportation issues
- 05 Child care issues
- 06 Caring for an elderly or disabled person
- 07 Other

Answer choice	Cases
Not worried about diabetes	0
Doctor hasn’t recommended	3
Other programs haven’t helped	0
Transportation issues	2
Child care issues	1
Caring for an elderly or disabled person	0
Other	5

This question was only asked in round 1; 14 respondents were asked this question. The hypothetical nature of this question and multiple answer categories were problematic to respondents. Not only must respondents consider the possibility of participating in such an imaginary program, they must think about why they would NOT participate. One person said, “Do you mean if I were at risk for

diabetes that I would be given a free pass to be in a program to help me manage it? What would prevent me from doing that? Is that what the question means?" Another person got right to the point by explaining that it was too hard to try to imagine reasons that are not happening right now in her life. So reasons today could be different from reasons tomorrow as to why she would not participate. Another person also couldn't answer hypothetically for herself, so she answered based on what she thinks other people might do. This question was dropped for round 2.

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