

ICICE Baseline Interview For Diabetes Patients



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04/26/2001

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INTRODUCTION OF STUDY TO RESPONDENT  
~~~~~

Hello, my name is [FIRST AND LAST NAME]. May I speak with [R's NAME]?

I'm calling to follow up on a letter we sent you about research [FILL SITE NAME] and RAND are conducting. The letter was mailed on [DATE] and mentioned that an interviewer from RAND would be calling to request a telephone interview and to answer any questions you have about this study.

Do you remember getting the letter?

If Yes, go to >study<

If No, go to >nolet<

>nolet< **For respondents who don't remember getting letter:**

The letter was from [FILL SITE CO-SIGNER] of [FILL SITE NAME] and Dr. Emmett Keeler, a researcher at RAND. The letter invited you to take part in research to improve the care of patients who receive care for diabetes from [fill SITE NAME]. The letter mentioned two telephone interviews and your health care records.

We are calling now to ask you to take part in the first telephone interview.

INTERVIEWER: Hit ENTER and continue

>nolet2<

Of course participation in the study is voluntary. You can stop the interview or refuse to answer a question at any time. Your decision to take part will not affect the care you get from [FILL SITE NAME] in any way. RAND will not give your doctor a copy of the answers you give in the interview. Any and all study results will be reported only at the group level. No individual person's information will be published separately in any report of results. The information we give to [FILL SITE NAME], to help them improve the care they give to people with diabetes will be limited to group summaries and statistics.

We can't pay you for your time, but we will send you \$10 as a token of our thanks for taking part in this interview. Your answers to the interview will be combined with information from your health care records from [FILL SITE NAME]. We have found that the additional information we can collect from your health care records is very valuable as it helps us to complete the picture of your health and the care you get.

>study< **All respondents get this screen:**

Our records indicate that you have diabetes. Doctors sometimes call this high blood sugar or sugar in the blood. Our study focuses on the experiences and needs of people with this condition and other conditions that can affect your health and daily activities.

Is this a good time to start the interview?

IF NEEDED: Your name and contact information was given to RAND by [SITE NAME], because you have had care for diabetes.

IF NEEDED: The goal of this study is to find out about any other health problems you may have, and the services and treatment you and others in this study receive. The interview has questions about your health and the care you got from [FILL SITE NAME] as well as questions about other health conditions, your daily activities and your feelings and emotions. It should take about 30 minutes.

IF NEEDED: The length of the interview varies depending on you and your experiences. It can take less than 30 minutes.

IF NEEDED: We don't have to do the whole interview right now, we can go for a few minutes and then I can call you back at another time to complete the interview.

USE ADVANCE LETTERS AND QUESTION AND ANSWER SHEET TO ANSWER ANY QUESTIONS.

- 1 Continue with interview
- 2 R refuses to take part in study
- 3 R requests remain of letter before deciding to take part (SET CALL BACK AND COMPLETE REMAIN REQUEST SLIP)
4. R says he/she doesn't have diabetes.
- x Schedule a call back

For all respondents, who say they don't have sampled condition:

We'll check our records again. Another interviewer may call you back in the next week or so to follow-up.

[CASE GOES TO SUPERVISOR FOR REVIEW AND VERIFICATION]

For all respondents, before any interview is started:

Before we begin, I need to tell you that for the purposes of quality control, my supervisor may monitor this call.

[Begin interview next page]

A. Type and Duration of Diabetes

First, I have some general questions about diabetes.

SOURCE DIAA1: Adapted from the *Diabetes Study Survey*, Arleen F. Brown, M.D., UCLA, 1988.

DIAA1

1. Has a doctor ever told you that you have diabetes (or sugar in your blood)?

- 1 Yes → **Skip to Question 2**
- 2 No
- 3 Don't know

DIAA1a

1a. We'll check our records again. Another interviewer may call you back in the next week or so to follow-up.

2. How long have you had diabetes?

- Enter Number of Years: _____ → **Skip to Question 3**
or, if Don't know/Don't remember → **Ask Question 2a**

SOURCE DIAA2a: Adapted from the *Diabetes Patient Survey*, California Collaborative to Improve Diabetes Management, Ann Arbor, MI: MEDSTAT Group, 1998.

DIAA2a

1a. Have you had diabetes for

- 1 Less than a year
- 2 1 to 5 years
- 3 More than 5 years

3. In the last 4 weeks did you do any of the following to keep your diabetes under control:

DIAA3a1	<u>YES</u>	<u>NO</u>
a. Take pills for diabetes?	1	2

DIAA3a2		
b. Inject insulin?	1	2

DIAA3a3		
c. Follow a special meal plan or diet?	1	2

DEFINITION: By special meal plan or diet I mean a diet or meal plan for people with diabetes that you got from your doctor, nutritionist, diabetes educator or read in any diabetes education material.

DIAA3a4		
d. Exercise?	1	2

DIAA3a5		
e. Something else?	1	2

B. Adherence

DIAB1

1. In the last 4 weeks how often were you able to take care of your diabetes the way you should? Was it:

- 1 None of the time
- 2 A little of the time
- 3 Some of the time
- 4 Most of the time
- 5 All of the time

SOURCE Q2-5: "Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease," Williams MV, Baker DW, Parker RM, *Archives of Internal Medicine*, 1998; 158:166-172.

DIAB2

2. Do you check your blood sugar level at home?
- 1 Yes
 - 2 No → **Skip to Q4**

DIAB3

3. During the last 4 weeks, how often did you check your blood sugar at home? Would you say:
- 1 Never
 - 2 Less than once a week
 - 3 A few times per week
 - 4 Once a day
 - 5 Twice a day or more

DIAB4

4. Many people with diabetes watch what they eat closely to help keep their diabetes under control. For example, they avoid eating foods with lots of sugar or fat.
- Over the last month, how much of the time did you only eat the foods that you should? Would you say:
- 1 None of the time
 - 2 A little of the time
 - 3 Some of the time
 - 4 Most of the time
 - 5 All of the time

DIAB5

5. Over the last month, how often did you eat foods that you knew you were not supposed to? Was it:
- 1 Never
 - 2 Only once or twice a month
 - 3 At least once a week
 - 4 3 or 4 times each week
 - 5 Every day or almost every day

DIAB6

6. About how many hours a week do you usually do the following activities:

	0	1-2	3-5	6-9	10 or More
	<u>Hours</u>	<u>Hours</u>	<u>Hours</u>	<u>Hours</u>	<u>Hours</u>

DIAB6a1

6. Jobs or household tasks that require a moderate amount of physical activity (for example, lifting or carrying light loads, ironing, cleaning windows, light gardening)? Is it: (READ RESPONSES).....
- | | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

DIAB6a2

7. Jobs or household tasks that involve heavy or vigorous physical activity (for example, construction, heavy gardening, scrubbing things, carrying heavy loads)? Is it:
- | | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

DIAB6a3

8. Recreation or leisure activities that require a moderate amount of physical activity (for example, hiking, golf, dancing)? (Is it).....
- | | | | | | |
|--|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|

DIAB6a4

9. Recreation or leisure activities that involve heavy or vigorous physical activity (for example, aerobics, swimming laps, skiing, jogging)? (Is it).....1 2 3 4 5

SOURCE DIAB10: "Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease," Williams MV, Baker DW, Parker RM, *Archives of Internal Medicine*, 1998; 158:166-172.]

DIAB10

10. How often during the last month, did you check your feet for blisters or sore spots. Was it:
- | | |
|------------------------------|---------------------------------|
| 1 Never | 4 3 or 4 times each week |
| 2 Only once or twice a month | 5 Every day or Almost every day |
| 3 At least once a week | |

C. Self-Efficacy

I'm going to read you some statements about you and your diabetes. For each one, I'll ask you how much you disagree or agree with the statement.

DIAC1

1. I know the right way to take my diabetes medications. Do you:
- | | |
|------------------------------|--|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | n I DON'T TAKE MEDICATION FOR DIABETES |

DIAC2

2. I know what to do if I have symptoms of low blood sugar. Do you:
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D. Knowledge

SOURCE: "Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease," Williams MV, Baker DW, Parker RM, *Archives of Internal Medicine*, 1998; 158:166-172.

DIADINT

I'd like to find out about how much you know about diabetes and treatment of diabetes. I'm going to read a question and some possible answers. Tell me which answer you think is correct. If you don't know the answer, don't worry, you can just say "I Don't Know".

DIAD1

1. What is a healthy or OK fasting blood sugar for someone with diabetes? Is it:
- DEFINITION: Fasting blood sugar is your first blood sugar in the morning before you eat. Fasting blood sugar can also be blood sugar after not eating for 12 hours.
- | | |
|-----------------------|--------------------|
| 1 Between 80 and 125 | 3 Greater than 200 |
| 2 Between 126 and 200 | d DON'T KNOW |

DIAD2

2. If you feel thirsty and urinate frequently it usually means your blood sugar is:
- | |
|--------------|
| 1 High |
| 2 Low |
| d DON'T KNOW |

DIAD3

3. Exercise causes your blood sugar to:

- | | |
|-----------------|--------------|
| 1 Go up | 3 Go down |
| 2 Stay the same | d DON'T KNOW |

DIAD4

4. Insulin and diabetes pills make your blood sugar:

- | | |
|-----------------|--------------|
| 1 Go up | 3 Go down |
| 2 Stay the same | d DON'T KNOW |

DIAD5

5. How often should a person with diabetes check their feet for sore or red spots? Would you say:

- | | |
|----------------|--------------------------------|
| 1 Once a month | 4 Only if there is a sore spot |
| 2 Once a week | d DON'T KNOW |
| 3 Every day | |

DIAD6

6. If you suddenly feel shaky, sweaty, nervous, or hungry, should you:

- | | |
|---------------------------------------|--------------------------|
| 1 Lie down and rest, | 3 Eat some form of sugar |
| 2 Take more insulin or diabetes pills | d DON'T KNOW |

DIAD7

7. How often should you get your eyes checked? Would you say:

- | | |
|----------------------------|-------------------------|
| 1 Every 6 months or sooner | 4 Every 3 or more years |
| 2 Every year | d DON'T KNOW |
| 3 Every 2 years | |

E. Health Related Quality of Life

SOURCE: "Empirically Defined Health States for Depression from the Short Form (SF)-12," C.A. Sugar, R. Sturm, T.T. Lee, and C.D. Sherbourne, *Health Services Research*, 33(4), 1998, pp. 911-928.

SOURCE Q1-12: Medical Outcomes Study (MOS) Short-Form 12: *How to Score the SF-12 Physical and Mental Health Summary Scales*, J.E. Ware, M.A. Kosinski, and S.D. Keller, The Health Institute, New England Medical Center, 2nd Ed., 1995.

DIAE1

1. In general, would you say your health is:

- 5 Poor
- 4 Fair
- 3 Good
- 2 Very good
- 1 Excellent

DIAE2

2. Now I'm going to read a list of activities that you might do during a typical day. As I read each item, please tell me if your health now limits you a lot, limits you a little, does not limit you in these activities.

First, moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. Does your health now limit you a lot, limit you a little, or not limit you at all?

IF R SAYS "I DON'T DO ACTIVITY," PROBE: Is that because of your health?

- 1 Yes, Limits a lot
- 2 Yes, Limits a little
- 3 No, Not limited at all

DIAE3

3. Climbing several flights of stairs. Does your health now limit you a lot, limit you a little, or not limit you at all?

IF R SAYS "I DON'T DO ACTIVITY," PROBE: Is that because of your health?

- 1 Yes, Limits a lot
- 2 Yes, Limits a little
- 3 No, Not limited at all

DIAE4

4 The following two questions ask you about your physical health and your daily activities.

During the past 4 weeks, have you accomplished less than you would like as a result of your physical health?

- 5 Yes
- 1 No

DIAE5

5. During the past 4 weeks, were you limited in the kind of work or other regular daily activities you do as a result of your physical health?

- 5 Yes
- 1 No

DIAE6

6. The following two questions ask about your emotions and your daily activities.

During the past 4 weeks, have you accomplished less than you would like as a result of any emotional problems, such as feeling depressed or anxious?

- 5 Yes
- 1 No

DIAE7

7. During the past 4 weeks, did you not do work or other regular daily activities as carefully as usual as a result of any emotional problems, such as feeling depressed or anxious?

- 5 Yes
- 1 No

DIAE8

8. During the past 4 weeks, how much did pain interfere with your normal work, including both work outside the home and housework. Did it interfere:

- 1 Not at all
- 2 A little bit
- 3 Moderately
- 4 Quite a bit
- 5 Extremely

DIAE9

9. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends or relatives? Has it interfered:

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

DIAE10

10. These next questions are about how you feel and how things have been with you in the past 4 weeks. As I read each statement, please give me the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks have you felt calm and peaceful? Was it:

- | | |
|--------------------------|------------------------|
| 1 All of the time | 4 Some of the time |
| 2 Most of the time | 5 A little of the time |
| 3 A good bit of the time | 6 None of the time |

DIAE11

11. How much of the time during the past 4 weeks did you have a lot of energy? (Was it:)

- | | |
|--------------------------|------------------------|
| 1 All of the time | 4 Some of the time |
| 2 Most of the time | 5 A little of the time |
| 3 A good bit of the time | 6 None of the time |

DIAE12

12. How much of the time during the past 4 weeks have you felt downhearted and depressed? (Was it:)

- | | |
|--------------------------|------------------------|
| 1 All of the time | 4 Some of the time |
| 2 Most of the time | 5 A little of the time |
| 3 A good bit of the time | 6 None of the time |

Diabetes-Related Symptoms

SOURCE DIAE13: Adapted from the *Diabetes Patient Survey, California Collaborative to Improve Diabetes Management, Ann Arbor, MI: MEDSTAT Group, 1998*

DIAE13

13. These next questions ask about the past 6 months.

Overall, how much have your diabetes symptoms changed in the past 6 months? Would you say:

- 1 They are much better
- 2 They are somewhat better
- 3 They have stayed about the same
- 4 They are somewhat worse, or
- 5 They are much worse

SOURCE: Q14-16: Adapted from the *Diabetes Patient Survey—California Collaborative to Improve Diabetes Management, MEDSTAT Group, 1988*

DIAE14

14. I'm going to read you some symptoms that people with diabetes sometimes have. Please tell me how often you had each one in the past 6 months.

You had low blood sugar readings or symptoms of low blood sugar such as sweating, weakness, trembling or an insulin reaction. (In the past 6 months) did this happen:

- | | |
|-----------------------|-----------------|
| 1 More than 5 times | 3 Once or twice |
| 2 Three to five times | 4 Not at all |

DIAE15

15. You had high blood sugar readings or symptoms of high blood sugar such as thirst or frequent urination. (In the past 6 months) did this happen:

- | | |
|-----------------------|-----------------|
| 1 More than 5 times | 3 Once or twice |
| 2 Three to five times | 4 Not at all |

DIAE16

16. Your vision was more blurry than usual. (In the past 6 months) did this happen:

- | | |
|-----------------------|-----------------|
| 1 More than 5 times | 3 Once or twice |
| 2 Three to five times | 4 Not at all |

SOURCE DIAE17: Adapted from the *PacifiCare of California Diabetes Survey, PacifiCare Health Systems, 1998.*

DIAE17

17. In the past 6 months, did you have any numbness or tingling in your hands or feet that lasted more than an hour?

PROBE: Include numbness and tingling from any cause, whether it's related to your diabetes or not.

- | | |
|-------|--------------|
| 1 Yes | d DON'T KNOW |
| 2 No | |

SOURCE DIAE18: Adapted from the *Diabetes Study Survey, Arleen F. Brown, M.D., UCLA, 1998*

DIAE18

18. In the past 6 months, did you have any new foot ulcers or foot infections that took more than a month to heal?

- | | |
|-------|--------------|
| 1 Yes | d DON'T KNOW |
| 2 No | |

F. Patient Satisfaction

SOURCE: Adapted from "CAHPS™ 2.0 Survey and Reporting Kit," U.S. Department of Health and Human Services, Public Health Services. Agency for Healthcare Research and Quality. AHRQ Publication Number 99-0039, October 1999.

DIAF1

1. A personal doctor or nurse is the health provider who knows you best. This can be a general doctor, a specialist doctor (including your diabetes doctor), a physician assistant, a nurse, or other health provider. Do you have one person you think of as your personal doctor or nurse?

- | |
|----------------------------------|
| 1 Yes |
| 2 No → Skip to Question 6 |

DIAF2

2. Is your personal doctor or nurse:

- | |
|--|
| 1 A general internist or a family medicine doctor |
| 2 A diabetes specialist or endocrinologist → Skip to Question 4 |
| 3 A nurse or physician assistant → Skip to Question 4 |
| 4 Or something else → Skip to Question 4
(SPECIFY) _____ |

DIAF3

3. Does your personal doctor or nurse specialize in diabetes care?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAF4

4. In the past 6 months, did you see your personal doctor or nurse?

- | | |
|-------|--|
| 1 Yes | 2 No → Skip to Programming Note before Question 6 |
|-------|--|

DIAF5

5. We want to know your overall rating of your personal doctor or nurse.

Use any number from 0 to 10 where 0 is the worst personal doctor or nurse possible and 10 is the best personal doctor or nurse possible. How would you rate your personal doctor or nurse in the past 6 months?

ENTER NUMBER: _____ → **Skip to Question 7**

PROGRAMMING NOTE: Question 6 is only asked if there is no personal doctor or nurse (Question 1 in this section coded No, d, or r).

DIAF6

6. These next questions are about your diabetes care provider. This is the doctor or other health provider you see most often for care related to your diabetes.

Do you have one doctor or other health provider you go to for care related to your diabetes?

1 Yes 2 NO → **Skip to Question 12**

DIAF7

7. Is the person you go to most for care related to your diabetes the same person as your personal doctor or nurse?

1 Yes → **Skip to Question 9** 2 No

DIAF8

8. Is your diabetes care provider:

- 1 A general internist or a family medicine doctor,
- 2 A diabetes specialist or endocrinologist,
- 3 A nurse or physician assistant,
- 4 Or something else (SPECIFY) _____

DIAF9

9. How long have you been seeing your diabetes care provider? Is it:

DEFINITION: Your diabetes care provider is the doctor you see most often for care related to your diabetes.

- 1 Less than 6 months 4 2 up to 5 years
- 2 6 up to 12 months 5 5 years or more
- 3 12 up to 24 months

PROGRAMMING NOTE: Questions 10 and 11 are skipped if Question 7 is coded 1 (Yes) (Diabetes care provider and personal doctor or nurse are the same person)

DIAF10

10. In the past 6 months, did you see your diabetes care provider?

1 Yes 2 No → **Skip to Question 12**

DIAF11

11. We want to know your overall rating of the health provider you see most often for your diabetes care.

Use any number from 0 to 10 where 0 is the worst diabetes care provider possible and 10 is the best diabetes care provider possible. How would you rate your diabetes care provider in the past 6 months? (If you saw more than one provider for your diabetes please rate the provider you saw most often)

ENTER NUMBER: _____

DIAF12

12. In the past 6 months, how much of a problem, if any, was getting a referral to a specialist that you needed to see for your diabetes? Was it:

- 1 A big problem,
- 2 A small problem, or
- 3 Not a problem?
- n I didn't need to see a specialist for my diabetes in the past 6 months

PROGRAMMING NOTE: Question 13 is skipped if Question 10 is coded 1 (Yes) (Respondent visited diabetes care provider in past 6 months)

DIAF13

13. In the past 6 months, did you see a doctor or other health provider for care related to your diabetes?
- 1 Yes
 - 2 No → **Skip to Question 20**

DIAF14

14. These next questions are about all of the doctors and other health providers who treated your diabetes in the past 6 months, not just the person you saw most often. Include all of the general doctors, specialists (like eye doctors, foot doctors, etc.), nurses, nutritionists, and any other health provider who helped you take care of your diabetes in your answers to these questions.

In the past 6 months, how often did the doctors and other health providers who treated your diabetes listen carefully to you? Was it:

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

DIAF15

15. In the past 6 months, how much of a problem, if any, was getting the care you, your doctor or other health provider believed necessary for your diabetes? Was it:
- 1 A big problem
 - 2 A small problem
 - 3 Not a problem

DIAF16

16. In the past 6 months, how often did the doctors and other health providers who treated your diabetes explain things in a way you could understand? Was it:
- 1 Never
 - 2 Sometimes
 - 3 Usually
 - 4 Always

DIAF17

17. In the past 6 months, how often did the doctors and other health providers who treated your diabetes show respect for what you had to say? Was it:
- 1 Never
 - 2 Sometimes
 - 3 Usually
 - 4 Always

DIAF18

18. In the past 6 months, how often did the doctors and other health providers who treated your diabetes spend enough time with you? Was it:
- 1 Never
 - 2 Sometimes
 - 3 Usually
 - 4 Always

DIAF19

19. We want to know your overall rating of all your diabetes care in the past 6 months from all general doctors, specialists (like eye doctors, foot doctors, etc.), nurses, nutritionists, and all other health providers who helped you take care of your diabetes.

Use any number from 0 to 10 where 0 is the worst diabetes care possible and 10 is the best diabetes care possible. How would you rate all your diabetes care in the past 6 months?

ENTER NUMBER: _____

SOURCE Q20-26: Adapted from set from the Sandi MacColl Institute for Healthcare Innovation, Group Health Coop., Puget Sound, Seattle, WA.

DIAF20

20. Please tell me how much you disagree or agree in general with the following statements about the doctors and nurses who treated your diabetes.

I feel my diabetes doctors and nurses have given me choices and options about my diabetes treatment. Do you:

- | | |
|-----------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree or agree | |

DIAF21

21. I feel my diabetes doctors and nurses have given me confidence that I can make changes in my life to control my diabetes:

- | | |
|-----------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree or agree | |

DIAF22

22. My diabetes doctors and nurses are interested in my questions . Do you:

IF NEEDED: Give me the answer that comes closest to your experience most of the time.

- | | |
|-----------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree or agree | |

DIAF23

23. My diabetes doctors or nurses regularly review with me how I am doing in managing all aspects of my diabetes. Do you:

- | | |
|-----------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree or agree | |

DIAF24

24. Have your diabetes doctors or nurses worked with you to develop a plan so that you know how to take care of your diabetes ?

- | | |
|-------|----------------------------|
| 1 Yes | 2 No → Skip to Question 27 |
|-------|----------------------------|

DIAF25

25. Do you have a copy of this plan in writing?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAF26

26. Did you work with your diabetes doctors or nurses to set personal goals for your diabetes treatment?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAG1f

- f. Did you see a nutritionist, or dietitian (in the past 6 months)?
- | | | | |
|---|-----|---|------------|
| 1 | Yes | d | DON'T KNOW |
| 2 | No | | |

H. Education

SOURCE: Adapted from the *Diabetes Patient Survey, California Collaborative to Improve Diabetes Management*, Ann Arbor, MI: MEDSTAT Group, 1998

SOURCE Q1-13: (Charlson Co-Morbidity) Katz JN, Chang LC, Sangha O, Fossel AH, Bates DW, "Can Comorbidity Be Measured by Questionnaire Rather than Medical Record Review?" *Med Care* 1996 Jan;34:73-84.

DIAH1

1. You might get information about diabetes and your health from different sources, such as your doctor, another health provider, or from some other source. I'm going to read you a list of topics, please tell me if you got information on any topic in the past 6 months.

(In the past 6 months), did you get information on blood sugar control?

- | | | | |
|---|--|--|--|
| 1 | Yes | | |
| 2 | No | | |
| d | Don't know/Not sure | | |
| n | R Volunteers: I've had diabetes for years and know all about how to take care of myself/I've had diabetes for years and my doctor told me all this long ago. | | |

DIAH2

2. (In the past 6 months, did you get) information on the use of insulin or pills for diabetes?

- | | | | |
|---|-----|---|--|
| 1 | Yes | d | Don't know/Not sure |
| 2 | No | n | R Volunteers: I've had diabetes for years and know all about how to take care of myself/I've had diabetes for years and my doctor told me all this long ago. |

PROGRAMMING NOTE: If 1 and 2 both coded n, then skip to Question 11

DIAH3

3. (In the past 6 months, did you get) information on exercise?

- | | | | |
|---|-----|---|---------------------|
| 1 | Yes | d | Don't know/Not sure |
| 2 | No | | |

DIAH4

4. (In the past 6 months, did you get) information on nutrition?

- | | | | |
|---|-----|---|---------------------|
| 1 | Yes | d | Don't know/Not sure |
| 2 | No | | |

DIAH5

5. In the past 6 months, did you get information on monitoring blood sugar?

- | | | | |
|---|-----|---|---------------------|
| 1 | Yes | d | Don't know/Not sure |
| 2 | No | | |

DIAH6

6. (In the past 6 months, did you get) information on foot care?

- | | | | |
|---|-----|---|---------------------|
| 1 | Yes | d | Don't know/Not sure |
| 2 | No | | |

DIAH7

7. (In the past 6 months, did you get) information on how often you should see the eye doctor?

- | | |
|-------|-----------------------|
| 1 Yes | d Don't know/Not sure |
| 2 No | |

DIAH8

8. (In the past 6 months, did you get) information on alcohol use?

- | | |
|-------|-----------------------|
| 1 Yes | d Don't know/Not sure |
| 2 No | n Don't use alcohol |

DIAH9

9. (In the past 6 months, did you get) information about stopping smoking?

- | | |
|-------|-----------------------|
| 1 Yes | d Don't know/Not sure |
| 2 No | n Don't smoke |

DIAH10

10. (In the past 6 months, did you get) information on how to lower your cholesterol?

- | | |
|-------|---|
| 1 Yes | d Don't know/Not sure |
| 2 No | n Cholesterol is not high/R not sure if cholesterol is high |

These next questions are about materials or programs you may have received or taken part in during the past 6 months.

DIAH11

11. (In the past 6 months) did you get any materials, like a newsletter, magazine, pamphlet, or videotape on caring for diabetes?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAH12

12. (In the past 6 months) did you get any one-on-one educational or counseling session(s) on caring for diabetes?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAH13

13. (In the past 6 months) did you attend any group classes to learn more about diabetes?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAH14

14. (In the past 6 months) did you use a book to record your blood sugar test results?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAH15

15. (In the past 6 months) did you attend any support group meetings with others who have diabetes?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

DIAH16

16. (In the past 6 months) were you given a health advice telephone line you can call if you have questions about your diabetes?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

- DIAI4a
4a. Do you receive treatment for it?
1 Yes 2 No
- DIAI4b
4b. Does it limit your activities?
1 Yes 2 No
- DIAI5
5. Have you had a heart attack?
PROBE: Has a doctor ever told you that you had a heart attack?
1 Yes 2 No → **Skip to Question 6**
- DIAI5a
5a. Did you receive treatment for it?
1 Yes 2 No
- DIAI5b
5b. Does it limit your activities?
1 Yes 2 No
- DIAI6
6. Do you have heart failure?
PROBE: Has a doctor ever told you that you have heart failure or that your heart was not pumping strongly enough?
1 Yes 2 No → **Skip to Question 7**
- DIAI6a
6a. Do you receive treatment for it?
1 Yes 2 No
- DIAI6b
6b. Does it limit your activities?
1 Yes 2 No
- DIAI7
7. Do you have cancer?
INTERVIEWER: Include skin cancer only if malignant melanoma.
1 Yes 2 No → **Skip to Question 8**
- DIAI7a
7a. Do you receive treatment for it?
1 Yes 2 No
- DIAI7b
7b. Does it limit your activities?
1 Yes 2 No
- DIAI8
8. Do you have depression?
1 Yes 2 No → **Skip to Question 9**

DIAI8a
8a. Do you receive treatment for it?
1 Yes 2 No

DIAI8b
8b. Does it limit your activities?
1 Yes 2 No

DIAI9
9. Do you have degenerative arthritis?
PROBE: The usual arthritis of older age, and is sometimes called osteoarthritis
INTERVIEWER: Do not code rheumatoid arthritis here.

1 Yes 2 No → **Skip to Question 10**

DIAI9a
9a. Do you receive treatment for it?
1 Yes 2 No

DIAI9b
9b. Does it limit your activities?
1 Yes 2 No

DIAI10
10. Do you have rheumatoid arthritis?
1 Yes 2 No → **Skip to Question 11**

DIAI10a
10a. Do you receive treatment for it?
1 Yes 2 No

DIAI10b
10b. Does it limit your activities?
1 Yes 2 No

DIAI11
11. Have you had a stroke?
1 Yes 2 No → **Skip to Question 12**

DIAI11a
11a. Did you receive treatment for it?
1 Yes 2 No

DIAI11b
11b. Does it limit your activities?
1 Yes 2 No

DIAI12
12. Do you have any other medical problems?
1 Yes (Specify): _____
2 No → **Skip to Section J**

DIAI12a
12a. Do you receive treatment for [INSERT]?
1 Yes 2 No

DIAI12b

12b. Does it limit your activities?

1 Yes

2 No

DIAI13

13. Do you have any other medical problems?

1 Yes (Specify): _____

2 No → **Skip to Section J**

DIAI13a

13a. Do you receive treatment for [INSERT]?

1 Yes

2 No

DIAI13b

13b. Does it limit your activities?

1 Yes

2 No

J. Demographics

These next questions are about you and will help us to describe all the diabetes patients who take part in this study.

Age and Gender

SOURCE Q1-2: Adapted from the "CAHPS™ 2.0 Survey and Reporting Kit," U.S. Department of Health and Human Services, Public Health Services. Agency for Healthcare Research and Quality. AHRQ Publication Number 99-0039, October 1999.

DIAJ1

1. What is your age now? Stop me when I get to the right category.

1 18 to 24

4 45 to 54

7 75 or older

2 25 to 34

5 55 to 64

3 35 to 44

6 65 to 74

DIAJ2

2. INTERVIEWER, ASK ONLY IF NECESSARY: Just so I can be sure, are you male or female?

1 Male

2 Female

Race, Ethnicity

DIAJ3

3. How would you describe your race or ethnicity? Are you:

1 Latino or Hispanic,

2 White,

3 Black or African-American,

4 Asian or Pacific Islander, or

5 Another race or multiracial.

Education

SOURCE: Adapted from the "CAHPS™ 2.0 Survey and Reporting Kit," U.S. Department of Health and Human Services, Public Health Services. Agency for Healthcare Research and Quality. AHRQ Publication Number 99-0039, October 1999.

DIAJ4

4. What is the highest grade or level of school that you have completed?

PROBE: Did you graduate with a diploma or degree?

INTERVIEWER: Code Trade School or Technical School as "Some college or 2-year degree."

- 1 8th grade or less
- 2 Some high school, but did not graduate
- 3 High school graduate or GED
- 4 Some college or 2-year degree
- 5 4-year college graduate
- 6 More than 4-year college degree

Health Insurance

SOURCE Q5: Adapted from the 2000 Consumer Survey for the California Health Care Foundation, Santa Monica, Calif: RAND, forthcoming.

DIAJ5

5. Do you have any kind of health insurance, or are you enrolled in any kind of program that helps to pay for your health care?

- 1 Yes
- 2 No → Skip to Question 9

SOURCE Q6: HIV Cost and Service Utilization Study (HCSUS) Baseline Technical Report, Santa Monica, Calif: RAND, MR-1090, forthcoming.

DIAJ6

6. Do you belong to a health maintenance organization or HMO?

- 1 Yes
- 2 No

SOURCE Q7: HIV Cost and Service Utilization Study (HCSUS) Baseline Technical Report, Santa Monica, Calif: RAND, MR-1090, forthcoming.

DIAJ7

7. Does your insurance plan or program allow you to go to any doctor you want or does it require you to choose from a group or list of doctors?

- 1 Any Doctor
- 2 Select from group or list
- d DON'T KNOW

SOURCE Q8-9: Adapted from the "Diabetes Study Survey," Arleen F. Brown, M.D., UCLA, 1998

DIAJ8

8. Does your insurance plan or program pay all, part or none of the cost for:

	<u>ALL</u>	<u>PART</u>	<u>NONE</u>	<u>DON'T KNOW</u>
a. Prescription medicine?.....	1	2	3	d
b. Glucose monitors?.....	1	2	3	d
DEFINITION: A glucose monitor is a machine you use at home to check your blood sugar levels.				
c. Glucose strips?	1	2	3	d

DIAJ9

9. On average, how much do you spend out of your own pocket each month on prescription medicines? Is it:

- 0 Nothing
- 1 Less than \$20
- 2 \$20 to \$50 dollars
- 3 \$51 to \$100 dollars
- 4. More than \$100

DIAJ15b

15b. In the past 6 months, how many times did you go spend one night or more in the hospital? (Your best estimate is fine).

PROBE: Include all of your health care in your answer, not just care related to your diabetes.

Enter Number: _____ (acceptable range is 0-15 times)

DIAJ15c

15c. Think about all the doctor's offices and clinics you've visited for health care in the last 6 months. In total, about how many visits have you made to get care for yourself? (Your best estimate is fine.) Was it:

PROBE: Include all of your health care in your answer, not just care related to your diabetes.

- 0 None
- 1 1 to 3 visits
- 2 4 to 6
- 3 More than 6 visits

SOURCE: *HIV Cost and Service Utilization Study (HCSUS) Baseline Technical Report*, Santa Monica, Calif: RAND, MR-1090, forthcoming; and

R.D. Hays, C.D. Sherbourne, and R.M. Mazel, *The RAND 36-Item Health Survey 1.0: Santa Monica, Calif: RAND, RP 247, 1993.*

DIAJ16

16. During the last month, how many days did your health keep you in bed all day or most of the day?

Enter Days _____ (0-31)

Language

SOURCE Q17-18: Adapted from set from David Baker, M.D., Case Western Reserve University, Cleveland, OH, 2000.

DIAJ17

17. What language do you usually speak at home?

- 1 English → **Skip to Q19**
- 2 Spanish
- 3 Other (Specify) _____

DIAJ18

18. In the last 6 months, how often did you have a problem communicating with your doctor or nurse because of language differences? Was it:

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

Marital Status and Household Composition

SOURCE Q19-20: *HIV Cost and Service Utilization Study (HCSUS) Baseline Technical Report*, Santa Monica, Calif.: RAND, MR-1090, forthcoming.

DIAJ19

19. At this time, are you married or living with a partner?

- 1 Yes
- 2 No

DIAJ20

20. What is your current living arrangement? Right now, are you living . . .

(Code all that apply)

0 Alone

1 With your spouse or partner

2 With others who are related to you

3 With others who are not related to you

Employment

SOURCE Q21-23: HIV Cost and Service Utilization Study (HCSUS) Baseline Technical Report, RAND, MR-1090, forthcoming

DIAJ21

21. Right now, are you working for pay?

1 Yes → **Skip to Q23**

2 No

DIAJ22

22. Is that because of your health?

1 Yes → **Skip to Q24**

2 No → **Skip to Q24**

DIAJ23

23. During the last month, about how many days of work did you miss because of illness?

Enter Days _____ (0-31)

Income

SOURCE Q24-26: Adapted from the "Diabetes Study Survey," Arleen F. Brown, M.D., UCLA, 1998

DIAJ24

24. Now I have a question about total income for you and your spouse or partner. Income can come from a number of sources: like salaries, wages, social security, welfare, dividends, interest, and any other income. Think about your total household income in 1998. Would it amount to \$30,000 or more?

1 Yes → **Skip to Q26**

2 No

DIAJ25

25. Would it amount to \$15,000 or more?

1 Yes → **Skip to Q27**

2 No → **Skip to Q27**

DIAJ26

26. Would it amount to \$50,000 or more?

1 Yes

2 No

Home Ownership

DIAJ27

27. Do you own or rent your home?

INTERVIEWER: If R'S parents or family own the home, code it as "own."

1 Own

2 Rent

3 Exchange work for rent or some other rent-free arrangement

K: STUDY ENROLLMENT AND FOLLOW-UP

We will send you a \$10 check for completing this interview. I want to be sure we have your correct address and phone number.

The address I have for you is:

[fill STREET] _____

[fill CITY] [fill STATE], [fill ZIP] _____

Is this correct?

1 No

5 Yes

What is your correct address? ENTER CORRECTIONS OR NEW ADDRESS

STREET ADDRESS: _____

CITY: _____ STATE _____ ZIP _____

The phone number I have for you is _____

Is this correct?

1 No

5 Yes

What is your correct phone number? _____

We would like to interview you again by phone about 12 months from now in order to find out about changes in your health and to ask about the care you receive over the next 12 months.

Even if you agree to a follow-up interview now, you can change your mind when we call you next year.

Do we have your permission to call you back about 12 months from now?

5 Yes

1 No

In case we have trouble reaching you next year when we do our follow-up interview we'd like you to give us information we can use to locate you.

Do you expect to move any time between now and [MONTH 12 MONTHS FROM NOW]?

1 No

5 Yes

Do you know the address you will be moving to?

INTERVIEWER: Enter as much information as R can give you now.

STREET ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

We'd like to have the name of a friend or relative who always knows how to reach you. We would only contact this person if we are unable to reach you by mail or phone next year for the follow-up interview. Is there a friend or relative that you always keep in close contact with (other than your husband/wife)?

1 No

5 Yes

What is his or her name and address?

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

PHONE: _____

What is your relationship to [Person Named Above]?

1 Friend

2 Daughter/Son

3 Sister/Brother

4 Grandchild

5 Other Relative

6 Other

We respect your decision. To help the researchers in this study, would you mind telling me the main reason you don't want to do the follow-up interview?
(ENTER MAIN REASON VERBATIM)

That's all of the questions I have for you today. You should receive your \$10 check in the next 4 weeks. Thank you for your help.

That's all of the questions I have for you today. You should receive your \$10 check in the next 4 weeks. We'll send you a letter to remind you about the follow-up interview.

Thank you for your help.

[Goodby]