Appendix A: **RCDI Cohort Survey**

(Adult, Telephone)

**SECTION 1:** **Pre-consent Script**

**Interviewer:** Hello, my name is []. I’m calling on behalf of [name of institution] with the CAPriCORN research group.

C.1 Is [patient name] available?

* 1Yes
* 2No [branch to C.1.1]

C.1.1 Okay, is there a better time we can call back?

* 1Yes [branch to C.1.2]
* 2No [branch to C.1.3]

C.1.2 What time works best for you?

[**Instructions**: Repeat the time back to the person who picks up, if given, and enter date

and/or time into database, along with any phone number changes requested]

**Interviewer:** Okay, thank you very much. Have a good day. [**Instructions**: Hang up.]

C.1.3 Would you like us to just try again another day?

* 1Yes
* 2No

[If 1Yes:] **Interviewer:** Okay, thank you very much. We will call back another day. Have a good day. [**Instructions**: Hang up.]

[If 2No:] **Interviewer:** Okay, thank you for your time. [**Instructions**: Hang up,

mark patient as refusal/declined in the database if the patient was the one who answered.]

**Interviewer:** My name is [\_\_\_\_\_] and I am a research assistant at [name of institution]. Along with several other Chicago area medical centers, we are working to develop the Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN). The purpose of CAPriCORN is to improve health care. As a part of this project, we are collecting data on certain clinical conditions, including *Clostridium difficile* (sometimes referred to as C diff) or diarrhea-like illness. You should have received a letter in the mail explaining the study and our plans to call you.

Have you been contacted by any other researchers from another facility in Chicago to participate in this study already?

* 1Yes [Thank you for your time and have a wonderful day]
* 2No [continue]

If you are willing, I would like to ask you to answer some questions about your illness.

C.2 Are you available to do this right now?

* 1Yes
* 2No [branch to C.2.1]

C.2.1 Okay, is there a better time we can call back?

* 1Yes [branch to C.2.2]
* 2No [branch to C.2.3]

C.2.2 What time works best for you?

[**Instructions**: Repeat the time back to the patient, if given, and enter date and/or time into database, along with any phone number changes requested]

**Interviewer:** Okay, thank you very much. Have a good day. [**Instructions**: Hang up.]

C.2.3 Would you like us to just try again another day?

* 1Yes
* 2No

[If 1Yes:] **Interviewer:** Okay, thank you very much. We will call back another day. Have a good day. [**Instructions**: Hang up.]

[If 2No:] **Interviewer:** Okay, thank you for your time. [**Instructions**: Hang up.

Mark patient as refusal in the database if the patient was the one who answered.]

**Interviewer:** Great. Participation in this project will not interfere or delay your care in any way. You may refuse to answer any questions, or stop answering questions whenever you wish. Participation in this project is voluntary. If you agree to participate, all information will be kept confidential, stored securely, and only available to researchers.

Before we begin, I need to tell you about the study. The name of this research project is: Characterizing the Effects of Recurrent Clostridium Difficile Infection on Patients. In preparation for this research XXX number (*insert number after administering query)* of medical records were reviewed and it was determined that you are eligible to participate in this research because you have had two or more episodes of an illness that causes diarrhea. We want to determine the effect of your diarrhea illness on your daily life. We will ask you questions over the phone. This will take about 30 minutes of your time. All information you give us will be kept confidential and you will not be identified in any reports of this research.

We will ask you questions about:

1. Your health and quality of life
2. The symptoms of your illness
3. How you felt about your illness
4. Your background (items such as your race, date of birth, living arrangements and household members, salary and employment status)
5. Your willingness to be contacted in the future about participation in other research projects.

All information you give us will be kept confidential. All identifying information will be replaced with a code prior to sharing information with other CAPriCORN institutions. There is a very small chance that your health information may become known to individuals who are not approved to know this information. However, the CAPriCORN network has safeguards in place that protect this from happening. Participation in this research project will not cost you any money. You will not be paid to participate in the research project.

Some of the questions we ask may cause you to feel anxious or make you feel uncomfortable. You do not have to answer any question or questions that you do not want to answer. Also, you can stop the phone survey at any time you feel that you do not want to continue. We will however use the responses that you gave in the research project before you decided to stop the survey.

In terms of risks, there is an unlikely risk that information about you could become known to unauthorized persons, and we have safeguards in place to prevent this from happening. There may not be an immediate benefit to participating, however we hope that the information learned from this study will improve the health care people receive in the future.

Do you have any questions or concerns at this point?

[If yes, answer the patient’s questions.

[If no, continue below.

**Instructions:** If the patient does not consent, note the reason for refusal and do not move forward with the interview.

**Instructions:** Do not ask the patient C.3. These are for the RA to fill out before beginning the survey.

C.3 Verbal Consent obtained?

* 1Yes
* A.1.1 2No; Note the reason for refusal/declination if given:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Interviewer:** Thank you for your time and consideration.

[**Instructions**: do not continue with interview, end here]

**Interviewer:** Thank you for your consent to participate in the study. Let’s get started.

**SECTION 1: RCDI-Specific Screening Questions**

**Interviewer**: Our review of your medical records indicates that you were seen by a doctor for *Clostridium difficile* infection (C. diff) or a diarrhea-like illness in the past 3 years.

1.1 Do you recall having been seen by a doctor for C. diff or diarrhea-like illness?

[If 2NO, **Interviewer**: “Thank you for your time.” terminate interview]

1YES\_\_\_ 2NO\_\_\_ 99REF\_\_\_ 98DK\_\_\_ 97Not asked\_\_\_

1.2 Have you had C. diff/diarrhea-like illness more than one time in the past 3 years?

1YES\_\_\_ 2NO\_\_\_ 99REF\_\_\_ 98DK\_\_\_ 97Not asked\_\_\_

5.2.1 If 1YES, do you remember how many times you had C diff/diarrhea-like illness in the past 3 years?

\_\_\_\_ times

* + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**SECTION 2: CMWG PROMIS Questions**

INTERVIEWER: First, I would like to ask you some questions about your health in general.

[**Instructions:** For questions 4.1 - 4.4, read aloud the answer choices after reading the first question. Repeat the answer choices as needed for the remaining questions to get the patient to answer on the scale.]

2.1 In general, would you say your health is:

* + 5Excellent
  + 4Very good
  + 3Good
  + 2Fair
  + 1Poor
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.2 In general, would you say your quality of life is:

* + 5Excellent
  + 4Very good
  + 3Good
  + 2Fair
  + 1Poor
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.3 In general, how would you rate your physical health?

* + 5Excellent
  + 4Very good
  + 3Good
  + 2Fair
  + 1Poor
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.4 In general, how would you rate your mental health including your mood and your ability to think?

* + 5Excellent
  + 4Very good
  + 3Good
  + 2Fair
  + 1Poor
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.5 To what extent are you able to carry out your everyday physical

activities such as walking, climbing stairs, carrying groceries, or moving a chair?

* + 5Completely
  + 4Mostly
  + 3Moderately
  + 2A little
  + 1Not at all
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**Interviewer:** Now I am going to read a series of statements. Please tell me how OFTEN you think they are TRUE for you.

**Instructions:** For the next three questions, read each question then prompt its respective answer choices.

2.7 In the past 7 days, I felt depressed.

* + 1Never
  + 2Rarely
  + 3Sometimes
  + 4Often
  + 5Always
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.8 In the past 7 days, I felt uneasy.

* + 1Never
  + 2Rarely
  + 3Sometimes
  + 4Often
  + 5Always
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.9 I have trouble doing all of my regular leisure activities with others.

* + 1Never
  + 2Rarely
  + 3Sometimes
  + 4Usually
  + 5Always
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**Interviewer:** Now I am going to read a couple more statements. Please tell me how MUCH you think they are TRUE for you during the past 7 days.

**Instructions:** For the next three questions, read the question and then prompt its respective answer choices.

2.10 I feel fatigued.

* + 1Not at all
  + 2A little bit
  + 3Somewhat
  + 4Quite a bit
  + 5Very much
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.11 I had a problem with my sleep.

* + 1Not at all
  + 2A little bit
  + 3Somewhat
  + 4Quite a bit
  + 5Very much
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.12 In the past 7 days, how much did pain interfere with your day to day activities?

* + 1Not at all
  + 2A little bit
  + 3Somewhat
  + 4Quite a bit
  + 5Very much
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**Interviewer:** How much do you agree with the following statement?

**Instructions**: Read question 4.13, then read aloud the answer choices.

2.13 I have a good life.

* + 1Strongly disagree
  + 2Disagree
  + 3Neither agree nor disagree
  + 4Agree
  + 5Strongly agree
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.14 People often miss a dose of their medicines from time to time. How many days in the past week did

you miss taking one or more of your medications?

\_\_\_\_\_\_\_\_ days [range of acceptable answers: 0-7]

* + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

2.15 Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care

possible, what number would you use to rate all your health care in the

past 12 months?

\_\_\_\_\_\_\_\_ [range of acceptable answers: 0-10]

* + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**SECTION 3:** **Disease Characteristics**

3.1 Were you hospitalized with C. diff or diarrhea-like illness any time in the past 3 years?

* + 1Yes
  + 2No
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

3.2 Please estimate how many days you were unable to participate in your

normal activities because of C. diff or diarrhea-like illness in the past 3 years.

\_\_\_\_\_ days

* + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

3.3 Prior to first being diagnosed with C. diff or diarrhea-like illness, were you taking any of

the following medications?

[**Instructions**: Read answer options 1 and 2 to the interviewee, select all answers that apply.]

* + 1Antibiotic for another illness or infection
  + 2Medication for heartburn or gastric reflux disease
  + 99Prefer not to answer
  + 98Don’t know/don’t remember
  + 97Not asked

**SECTION 4:** **Symptoms and Severity**

4.1 When was your most recent/last episode of C. diff or diarrhea-like illness?

* + 1More than 6 weeks ago
  + 21 to 6 weeks ago
  + 3I still have symptoms/am still sick
  + 4I am not sure/don’t know
  + 99Prefer not to answer
  + 98Don’t know/don’t remember
  + 97Not asked

4.2 Thinking about your most recent or last episode of C. diff or diarrhea-like illness, please

rate how severe each of these symptoms were on a scale of 1 being “mild” to 5 being “severe” while

you were sick, or let me know if you did not have the symptom.

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Symptoms | Mild |  |  |  | Severe | Did not have | REF | DK | Not asked |
| 4.21 Diarrhea (watery or liquid stools, more than 3 bowel movements/day) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 4.22 Abdominal pain | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 4.23 Nausea or unsettled stomach | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 4.24 Fever (temp of 100.4 degrees or higher) | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 4.25 Headache | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 4.26 Physical exhaustion or weakness | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 4.27 Unplanned weight loss | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |

**SECTION 5:** **Social Isolation (PROMIS items)**

**Interviewer**: I am now going to read several statements about how you felt when you were sick. Please let me know how often these statements were true for you during your most recent episode of C. diff or diarrhea-like illness using the choices of: never, rarely, sometimes, usually, or always.

[**Instructions**: Repeat the scale after each of the first few statements, and continue doing so if the interviewee is having difficulty remembering.]

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | NEVER | RARELY | SOMETIMES | USUALLY | ALWAYS | REF | DK | Not asked |
| 5.1 I felt left out | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 5.2 I felt that people barely knew me | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 5.3 I felt isolated from others | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 5.4 I felt that people were around me but not with me | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 5.5 I felt that people avoided talking to me | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 5.6 I felt detached from other people | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 5.7 I felt like a stranger to those around me | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |

5.8 Where were you living or staying when you were sick the last time with C.

diff or diarrhea-like illness?

* + 1At my house
  + 2At a relative or friend’s house
  + 3In the hospital
  + 4In a nursing home
  + 5In an assisted living facility
  + 6In a shelter
  + 7I was homeless
  + 99Prefer not to answer
  + 98Don’t know/don’t remember
  + 97Not asked

**SECTION 6:** **Emotional Distress**

**Interviewer**: Now I am going to read you a list of worries people often have when they have C. diff or diarrhea-like illness. Thinking back to the most recent time you/ had C. diff or diarrhea-like illness, please rate how worried or distressed you were about each item on a scale of 1 to 5, where 1 is “a little worried or distressed” and 5 is “very worried or distressed”. If you were not worried, let me know.

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | A little worried or distressed |  |  |  | Very worried or distressed | Not worried | REF | DK | Not asked |
| 6.1 Fear of getting sick again | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.2 Fear of needing surgery | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.3 Fear of getting others sick | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.4 Felt dirty/unclean | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.5 Felt like a prisoner in my house or hospital room | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.6 Was scared of dying | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.7 Was depressed | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.8 Was unable to sleep | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.9 Was unable or unwilling to eat | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.10 Fear of leaving my home | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.11 Felt Shame/Embarrassment | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.12 Felt Anger | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |
| 6.13 Was worried about loss of intimacy/sexual relationships | 1 | 2 | 3 | 4 | 5 | 6 | 99 | 98 | 97 |

**SECTION 7:** **Attitudes toward Hygiene/Infection/Prevention**

Sometimes people change what they do or how they act after they have been sick. I am going to read you a series of statements about activities related to cleaning and prevention of illness. Please rate how true you think these statements are for you after having had C. diff or diarrhea-like illness on a scale of 1 to 5, where 1 is “Not at all” and 5 is “Very much”.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Activity | Not at all |  |  |  | Very much | REF | DK | Not asked |
| 7.1  I increased my cleaning around my home | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.2  I increased my use of bleach to clean things | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.3  I changed what I eat (by avoiding and/or adding certain foods) | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.4  I wash my hands more frequently | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.5  I increased use of antibacterial gels/wipes | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.6  I increased use of soap and water for washing/bathing | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.7  I eat out less | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.7  I avoid certain medications (like antibiotics, heartburn medications) | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.8  I avoid shared places like public bathrooms or buffets in restaurants | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |
| 7.9  I increased my use of probiotic supplements | 1 | 2 | 3 | 4 | 5 | 99 | 98 | 97 |

**PATIENT DEMOGRAPHICS SECTION 8:**

INTERVIEWER: For this next set of questions, I would like to ask you a few questions about yourself. I also would like to remind you at this time that you can choose to not answer any questions that you are uncomfortable with or do not wish to answer. Doing so will not affect your health care services or delivery.

8.5 What is your date of birth?[[1]](#footnote-1)

* + Format: YYYY/MM/DD
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8.6 What is your sex?[[2]](#footnote-2)

* + 1Male
  + 2Female
  + 2.6.1 3Comment: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8A.7 What is your race?

[**Instructions:** allow patient to self-identify (or proxy on their behalf), do not read choices unless asked

to by interviewee. Mark down more than one choice if applicable.] [[3]](#footnote-3)

* + 1Asian (i.e. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.)
  + 2Black, African American, African, or Afro-Caribbean (i.e. African American, Haitian, Nigerian, etc.)
  + 3Hispanic, Latino, or Spanish origin (i.e. Mexican, Mexican American, Puerto Rican, Cuban, Argentinian, Colombian, Dominican, Nicaraguan, Salvadorian, Spaniard, etc.)
  + 4Middle Eastern/North African
  + 5Native American, American Indian or Alaskan Native (i.e. Navajo, Mayan, Tingt, etc.)
  + 6Native Hawaiian or Other Pacific Islander (i.e. Native Hawaiian, Guamanian or Chamorro, Samoan, Fijian, Tongan, etc.)
  + 7White (i.e. German, Irish, Italian, Lebanese, Egyptian, etc.)
  + 8A.7.1 8Some other race or origin *(please specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8.8 (Over 18 only) What is the highest degree or level of school you have completed?[[4]](#footnote-4)

* + 18th grade or less
  + 2Some high school, but did not graduate
  + 3High school graduate or GED
  + 4Some college or 2-year degree
  + 5College graduate
  + 6More than a college degree
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8.9 Including you, how many people live in your household most of the

time? [[5]](#footnote-5)

8.9.1 \_\_\_\_\_\_ persons

* + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8.10 How many persons less than 18 years of age usually live in your home? [[6]](#footnote-6)

2.10.1 \_\_\_\_\_\_ persons

* + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8.11 What is your marital status?[[7]](#footnote-7)

* + 1Now married
  + 2Unmarried, but living with a partner / significant other
  + 3Widowed
  + 4Divorced
  + 5Separated
  + 6Never married
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8.12 What language do you mainly speak at home?[[8]](#footnote-8)

* + 1English
  + 2Spanish
  + 3Chinese
  + 2.12.1 4Some other language (please print) \_\_\_\_\_\_\_\_\_\_\_\_\_
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8A.13 In what country were you born? [[9]](#footnote-9)

* + 1USA [branch to 2.A13.1]
  + 2Other Country [branch to 2.A13.2]
  + 99Prefer not to answer [skip to 2A.14]
  + 98Don’t know [skip to 2A.14]
  + 97Not asked

8A.13.1 Please specify the US State: [Use a dropdown box for selection. Then skip to 2A.14.][[10]](#footnote-10)

8A.13.2 Please specify the country you were born in: [Use textbox with a

dropdown of Census choices for selection][[11]](#footnote-11)

[**Instructions:** Let the interviewee give a response, look for the best fit, then clarify.]

8A.14 This next question is about your employment situation. You can choose multiple

answers. Are (you/the PATIENT) currently: [[12]](#footnote-12)

[**Instructions**: Read all choices aloud to interviewee, mark all choices selected.]

* + 1Employed for wages (full-time or part-time)
  + 2Self-employed
  + 3Out of work for more than 1 year
  + 4Out of work for less than 1 year
  + 5A homemaker
  + 6A student
  + 7Retired
  + 8Unable to work (disabled)
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

8B.15 What is your household’s annual total income?[[13]](#footnote-13)

[**Instructions**: For telephone interviews, the interviewer must read ranges aloud.]

* + 1Less than $10,000 (USD)
  + 2$10,000 – $24,999
  + 3$25,000 - $49,999
  + 4$50,000 – $74,000
  + 5$75,000 - $99,999
  + 6$100,000 - $149,999
  + 7$150,000 - $199,999
  + 8$200,000 - $249,999
  + 9$250,000 and above
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**Interviewer:** Please tell me if you are covered by any of the following types of health insurance:[[14]](#footnote-14)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Insurance Type** | **Yes** | **No** | **Prefer not to answer** | **Don’t Know** | **Not asked** |
| 8A.16 Insurance through a current or  former employer or union | 1 | 2 | 99 | 98 | 97 |
| 8A.17 Insurance purchased directly from  an insurance company | 1 | 2 | 99 | 98 | 97 |
| 8A.18 Medicare, for people 65 and older  or people with certain disabilities | 1 | 2 | 99 | 98 | 97 |
| 8A.19 Medicaid, Medical Assistance, or  any kind of government  -assistance plan for those with low  incomes or a disability | 1 | 2 | 99 | 98 | 97 |
| 8A.20 TRICARE or other military health  care | 1 | 2 | 99 | 98 | 97 |
| 8A.21 Veterans Administration (including  those who have ever used or  enrolled for VA health care) | 1 | 2 | 99 | 98 | 97 |
| 8A.22 Indian Health Service | 1 | 2 | 99 | 98 | 97 |
| 8A.23 Another type of insurance | 1 | 2 | 99 | 98 | 97 |
| 8A.24 No Insurance | 1 | 2 | 99 | 98 | 97 |

**SECTION 9: Level of Willingness to Take Part in Research as a Research Subject/Interest in Potential Research Studies**

**Interviewer:** For the final section, I will ask about your willingness to take part in future research studies. These questions help us get a sense of the best way to collect information for the purposes of research.

9.1 Have you ever taken part in research projects related to (your/the PATIENT’S) health or

the health of a family member?[[15]](#footnote-15)

* + 1Yes
  + 2No
  + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**Interviewer:** How would you prefer to be contacted to learn about potential research studies? I am going to read you a list of ways a research study could contact (you/the PATIENT). Please tell me if any of them are ways you would prefer to be contacted.[[16]](#footnote-16)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Type of Contact** | **Okay** | **Not okay** | **Prefer not to answer** | **Don’t Know** | **Not asked** |
| 9A.2 E-mail | 1 | 2 | 99 | 98 | 97 |
| 9A.3 Cell phone text messaging | 1 | 2 | 99 | 98 | 97 |
| 9A.4 Social media (such as Facebook,  Twitter, or Pinterest) | 1 | 2 | 99 | 98 | 97 |
| 9A.5 Letter or post card in the mail | 1 | 2 | 99 | 98 | 97 |
| 9A.6 A computer created phone  message | 1 | 2 | 99 | 98 | 97 |
| 9A.7 Personal phone call from  research staff or my doctor | 1 | 2 | 99 | 98 | 97 |
| 9A.8 Talking face-to-face with  research staff or my doctor when  I am visiting the clinic | 1 | 2 | 99 | 98 | 97 |
| 9A.9 Other  [If 1Okay, proceed to 3.9.1.  Otherwise skip to 3.10] | 1 | 2 | 99 | 98 | 97 |

9A.9.1 Please Specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_

* + 99Prefer not to answer
  + 98Don’t know
  + 97Not asked

**Interviewer:** I’m going to read you a list of different activities research studies can involve. Please tell me how interested you would be, on a scale of “Not interested”, “Somewhat interested”, or “Very interested”. If a researcher was studying a condition or health problem that you care about, would you participate if it required:[[17]](#footnote-17)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **What Type of Project Would You Consider Taking Part In?** | **Not interested** | **Somewhat interested** | **Very interested** | **REF** | **DK** | **Not asked** |
| 9A.10 Completing a survey two or  more times | 1 | 2 | 3 | 99 | 98 | 97 |
| 9A.11 Giving a blood sample | 1 | 2 | 3 | 99 | 98 | 97 |
| 9A.12 Taking part in a study that  involves talking by phone or  over the internet (for example,  to get advice about your  health) | 1 | 2 | 3 | 99 | 98 | 97 |
| 9A.13 Taking part in a study where  you have to  take a medication | 1 | 2 | 3 | 99 | 98 | 97 |
| 9A.14 Taking part in a study that  involves meeting at a local  community center or school | 1 | 2 | 3 | 99 | 98 | 97 |
| 9A.15 Taking part in a study that  involves you  and other people in your  family | 1 | 2 | 3 | 99 | 98 | 97 |
| 9A.16 Taking part in a study in which  you would stay  in the hospital for 1 or more  days | 1 | 2 | 3 | 99 | 98 | 97 |

**SECTION 10 FINAL:** **Thank You and Conclusion**

**Interviewer:** This concludes our interview. Thank you for participating in our study. We appreciate you taking the time to help us with our research. At this point, do you have any questions for me?

10. I have two final questions about research.

a. – would you agree to being contacted about any future research opportunities related to C diff or diarrhea-like illnesses?

* + 1YES
  + 2NO

b. would you agree to being contacted about any future research opportunities to learn more about how to prevent, detect, or treat other health conditions?

* + 1YES
  + 2NO

If YES**, INTERVIEWER:** Thank you. We will send you in the mail a form to complete and sign with a postage-paid, addressed envelope to return that indicates your willingness to be contacted, along with a place to provide your signature. We will include a postage-paid envelope for your convenience. Thank you for your interest. [NOTE to RAs: mail letter and envelope right after completing the interview]

**Instructions:**Answer any questions the patient may have. After all questions have been answered, hang up and answer the following questions pertaining to the interview:

F.1 Rate the quality of the interview:

* + 1Excellent
  + 2Good
  + 3Fair
  + 4Poor

F.2 Was the interview conducted in English or Spanish?

* + 1English
  + 2Spanish
  + 8.2.1 3Other (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

The interview is now complete.

1. TIER 1 [↑](#footnote-ref-1)
2. TIER 1 [↑](#footnote-ref-2)
3. TIER 1 *Q3 is using the updated US Census combined race and ethnicity question* [↑](#footnote-ref-3)
4. TIER 1 [↑](#footnote-ref-4)
5. TIER 1 [↑](#footnote-ref-5)
6. TIER 1 [↑](#footnote-ref-6)
7. TIER 1 [↑](#footnote-ref-7)
8. TIER 3 [↑](#footnote-ref-8)
9. TIER 3 [↑](#footnote-ref-9)
10. TIER 3 [↑](#footnote-ref-10)
11. TIER 3 [↑](#footnote-ref-11)
12. TIER 3 [↑](#footnote-ref-12)
13. TIER 3 [↑](#footnote-ref-13)
14. TIER 3 [↑](#footnote-ref-14)
15. TIER 1 [↑](#footnote-ref-15)
16. TIER 1 [↑](#footnote-ref-16)
17. TIER 1 [↑](#footnote-ref-17)