

Online Supplement

Title: The Association between Mild Cognitive Impairment Diagnosis and Patient

Treatment Preferences: A Survey of Older Adults

Appendix 1. Additional Details on Methods

Appendix 2. Patient survey

Appendix 3. Surrogate survey

Appendix 1. Additional Details on Methods

Methods

Study Population

At the University of Michigan (U-M), patients with MCI and surrogates were recruited from the Cognitive Disorders Clinic, Geriatric Clinic, and active cognition studies (e.g., U-M Memory and Aging Project) in Ann Arbor and Detroit, Michigan. The study team received lists of individuals who met eligibility criteria from the Michigan Alzheimer's Disease Center's (MADC) participant registry. Each participant on the lists was given a unique, randomized identification number ordered from smallest to largest. The number of participants recruited were stratified into equivalent group sizes based on race. Additionally, recruitment for the study included volunteers who contacted the center directly to request to be referred to the study team based on their completion of the MADC's research volunteer form. The study team also used the Michigan Medicine electronic medical record system based Research Data Warehouse (DataDirect) to access potential volunteers for the study based on eligibility criteria. Lists from DataDirect were split into groups for recruitment based on randomized identification numbers. At Duke, patients with MCI and their surrogates were identified for recruitment based on medical record review. In addition to the stated eligibility criteria, patients were prioritized for contact if they lived within a reasonable distance from Duke and had a family member or friend who was involved with their medical care. We randomly selected for recruitment eligible patients with NC and their surrogates from established registries and active studies at U-M and Duke. Like the patients with MCI, patients with NC were prioritized for contact if they lived within a reasonable distance from Duke. We

excluded other race/ethnicities to focus on Black and White individuals. Survey data collection and incentive delivery differed between U-M and Duke. At U-M, we mailed the survey once with an unconditional incentive of \$50 cash included in the envelope; following a standard protocol, non-responders received reminders by telephone or email, and a second survey without cash incentive after 6 weeks of follow-up. At Duke, participants completed the survey in-person at a research office; patients and surrogates received the incentive after completing the survey.

We had procedures to ensure that patients, and not the surrogates, filled out the patient surveys. At U-M, we mailed patients and surrogates separate, individually addressed survey packets and instructed patients and surrogates to answer the survey on their own. Survey packets contained a cover letter clearly addressed to individual participants, with this language: **“Please answer the questions on the survey on your own.** Your MADC study partner will receive a different survey to complete. So please fill out the survey yourself, to the best of your ability.” At Duke, all procedures were done in the clinic and the patients and the surrogates completed the surveys in different rooms in the clinic.

Primary Outcome

The primary outcome was the Life-Support Preferences-Predictions Questionnaire (LSPQ). The LSPQ is written at the seventh grade reading level and describes different health scenarios. We used a modified version of the LSPQ that deleted four scenarios (two coma scenarios, colon cancer with constant pain, and stroke with no chance of improvement) to reduce participant fatigue and survey length

based on feedback from pilot-testing, and added an AMI scenario because cardiovascular disease (CVD) was a focus of the study. The modified LSPQ had six health scenarios: 1) the patient's current health; 2) emphysema with severe physical limitations; 3) stroke resulting in partial paralysis, language deficits, total dependence in activities of daily living, and physician opinion of slight chance of improvement; 4) colon cancer metastatic to the liver with fatigue, no pain, and a life expectancy of 6 months; 5) heart attack resulting in heart failure with partial dependence in activities of daily living, and physician opinion of slight chance of improvement; and 6) Alzheimer's disease with moderately severe cognitive impairment.

Statistical Analysis

We used stepwise procedures (hybrid method, $P > 0.10$ for removal and $P < 0.05$ for addition) to select separate sets of covariates for patients and surrogates. In the process of building final models for patients and surrogates, we considered three blocks of variables (demographics, health experience, and social support). We forced patient cognitive status and patient (or surrogate) age, race, and gender into each patient (or surrogate) model. The final parsimonious model for patient-reported LSPQ score included patient cognitive status, patient race, patient age, patient gender, patient education, surrogate gender and patient contact with stroke. The final parsimonious model for surrogate-reported LSPQ score included patient cognitive status, surrogate race, surrogate age, surrogate gender, surrogate education and surrogate stroke history.

We performed power calculations at the time of designing the study before we collected the survey data. Assuming a multivariable linear regression model with 4

predictors (two-sided $\alpha=0.05$), a sample of 100 dyads would allow us to detect a clinically meaningful difference of 10% in the LSPQ score with 88% power. However, we did not use multivariable linear regression models to analyze the collected survey data because of the distribution of LSPQ scores. A high proportion of patients and surrogates had LSPQ scores of 0, indicating they would reject zero life-sustaining treatments and want every life-sustaining treatment in every scenario. We examined associations between LSPQ score (dependent variable) and patient cognitive status using zero-inflated negative binomial (ZINB) regression, a method used to model over-dispersed count data with excessive zeros. For this reason, our originally proposed a priori power calculations were not applicable.



MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

Study ID #: _____



DukeHealth

Participant Perspectives on Medical Treatment

Conducted by: University of Michigan and Duke University

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(Postage-paid envelope included in packet)

Questions: Please call Dr. Levine at (734) 936-5216

This study is funded by a grant from the National Institutes of Health / National Institute on Aging and has been approved by the Institutional Review Board of the University of Michigan #HUM00118584.

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Decision Making for Cardiovascular Therapy in Adults with Mild Cognitive Impairment (HUM00118584)

Dr. Deborah A. Levine of the University of Michigan, invites you to take part in a research study designed to learn more about what older adults and their family members or friends think about their health risks and their preferences for treatment. We are asking you to participate because you are part of the UM Memory and Aging Project. This research is funded by the National Institutes of Health – National Institute on Aging.

Taking part in this study is completely **voluntary**.

- You do not have to participate if you don't want to.
- You may skip any survey question you feel uncomfortable answering.
- If you choose not to participate, your clinical care will not change.
- Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled.
- By completing the survey and returning it to the study team, you are agreeing to participate in this study.

All of your information will be kept **confidential** and only be viewed by researchers analyzing the data.

You may not receive any personal benefits from being in this study. We hope what we learn will help other people in the future.

To thank you for taking part in our study, we are including \$50.00 in this packet for completion of the survey.

If you have questions about your rights as a research participant, or wish to obtain information, ask questions or discuss any concerns about this study, please see the contact information below.

CONTACT INFORMATION

To find out more about the study, to ask a question or express a concern about the study, or to talk about any problems you may have as a study subject, please contact one of the following:

Principal Investigator: Deborah A. Levine, MD, MPH Mailing Address: 2800 Plymouth Road, Building 16, Room 430W Ann Arbor, MI 48109-2800 Telephone: 734-936-5216	Project Manager: Bailey Green, MPH Mailing Address: 2800 Plymouth Road, Building 16, Room 430W Ann Arbor, MI 48109-2800 Telephone: 734-647-3971
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You may also express a concern about a study by contacting the Institutional Review Board:

University of Michigan Medical School Institutional Review Board (IRBMED)
2800 Plymouth Road, Building 520, Room 3214
Ann Arbor, MI 48109-2800
Phone: 734-763-4768
E-mail: irbmed@umich.edu

If you are concerned about a possible violation of your privacy or concerned about a study, you may contact the University of Michigan Health System Compliance Help Line at 1-866-990-0111

Participant Perspectives on Medical Treatment

Thank you for taking time to complete this questionnaire. Your answers to these questions will help us better understand the kinds of medical treatments that adults would want if they were to become sick. **Your answers are very important to us.**

There are no right or wrong answers. We are interested in your experiences and your honest opinion.

All of your answers will be kept confidential, and we will not tell your doctor any of your answers. We will not use individual names in any notes, reports, or summaries.

Thank you for your help!

HOW TO FILL IN THIS QUESTIONNAIRE

- Please answer the questions by marking boxes this way:

Response option 1

Response option 2

- Please select your one best answer to each question, based on the information provided.
 - You may select more than one answer if the question says: (Select all that apply)

**PLEASE START THE QUESTIONNAIRE
BY READING THE INSTRUCTIONS
AT THE BEGINNING OF SECTION A.**

SECTION A.

YOUR OPINION ABOUT MEDICAL TREATMENT IF YOU WERE TO BECOME SERIOUSLY ILL

- The next questions are about **what kinds of treatments you would want to receive if you were to become seriously ill.**
- Please imagine how you would feel if you had the health condition when answering these questions.
- Think about how you would feel about receiving each treatment.

SCENARIO 1: CURRENT HEALTH

You have your current health. You feel the way you feel now.

Please mark the box which is closest to how you would feel about receiving each treatment.

Antibiotics

- Antibiotics are medicines used to treat infections.
- Without antibiotics, serious infections like pneumonia can cause life-threatening complications such as trouble breathing or death.

Imagining you have your **current health**

A1 If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

- I definitely want antibiotics.
- I probably want antibiotics.
- I am unsure.
- I probably do not want antibiotics.
- I definitely do not want antibiotics.

SECTION A. (CONTINUED)

CPR: Cardiopulmonary Resuscitation

- Doctors use CPR or cardiopulmonary resuscitation when a person's heart stops beating or a person stops breathing.
- Doctors press on the chest to help pump blood, and they use artificial breathing.
- Artificial breathing means the doctor puts a tube in the windpipe.
- Then, a machine breathes for the person through the tube.
- People usually get medicines by vein.
- People often need an electrical shock to help restart the heartbeat.
- Without CPR, the heart will not start beating again and the person will die.

Imagining you have your **current health**

A2 If your **heart stopped beating** or you stopped breathing, would **you** want to receive **CPR or cardiopulmonary resuscitation?**

- I **definitely want** CPR.
- I **probably want** CPR.
- I am unsure.
- I **probably do not want** CPR.
- I **definitely do not want** CPR.

SECTION A. (CONTINUED)

Gallbladder Surgery

- Doctors use surgery to remove the gallbladder when it is inflamed and infected.
- If untreated, an inflamed and infected gallbladder can rupture and cause life-threatening complications or death.

Imagining you have your **current health**

A3 If your gallbladder became inflamed and infected, would you want surgery to remove it?

- I definitely want surgery.
- I probably want surgery.
- I am unsure.
- I probably do not want surgery.
- I definitely do not want surgery.

SECTION A. (CONTINUED)

Artificial Feeding and Fluids

- Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive.
- The food goes through a feeding tube.
- Usually, the feeding tube goes through the skin, into the stomach.
- Without this treatment, people die within 7 to 10 days.

Imagining you have your **current health**

A4 If your condition becomes such that you lose the ability to take in food or water by mouth, would **you** want **artificial feeding and fluids?**

- I **definitely want** artificial feeding and fluids.
- I **probably want** artificial feeding and fluids.
- I am unsure.
- I **probably do not want** artificial feeding and fluids.
- I **definitely do not want** artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 2: EMPHYSEMA

Imagine that you have emphysema, a lung disease.

- You have constant shortness of breath.
- You are unable to climb stairs or walk more than a few feet.
- Your condition cannot improve.
- Your condition may get worse very quickly or slowly decline over several years.
- You can think and remember without difficulty.

Please mark the box which is closest to how you would feel about receiving each treatment.

Imagining that you have emphysema, a lung disease

A5 If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

- I definitely want antibiotics.
- I probably want antibiotics.
- I am unsure.
- I probably do not want antibiotics.
- I definitely do not want antibiotics.

SECTION A. (CONTINUED)

Imagining that you have **emphysema, a lung disease**

A6 If your **heart stopped beating** or you stopped breathing, would **you** want to receive **CPR or cardiopulmonary resuscitation?**

- I **definitely want** CPR.
- I **probably want** CPR.
- I am unsure.
- I **probably do not want** CPR.
- I **definitely do not want** CPR.

Imagining that you have **emphysema, a lung disease**

A7 If your **gallbladder** became **inflamed** and **infected**, would **you** want **surgery** to remove it?

- I **definitely want** surgery.
- I **probably want** surgery.
- I am unsure.
- I **probably do not want** surgery.
- I **definitely do not want** surgery.

Imagining that you have **emphysema, a lung disease**

A8 If your condition becomes such that you lose the ability to take in food or water by mouth, would **you** want **artificial feeding and fluids?**

- I **definitely want** artificial feeding and fluids.
- I **probably want** artificial feeding and fluids.
- I am unsure.
- I **probably do not want** artificial feeding and fluids.
- I **definitely do not want** artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 3: STROKE

Imagine that you have suffered a moderately severe stroke.

- One arm and leg are paralyzed.
- You have trouble speaking and trouble understanding when others speak.
- You rely on others for help with feeding, dressing, bathing, and toileting.
- In the opinion of your doctor, you have a slight chance of improvement.

Please mark the box which is closest to how you would feel about receiving each treatment.

Imagining that you have suffered a moderately severe stroke

A9 If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

- I definitely want antibiotics.
- I probably want antibiotics.
- I am unsure.
- I probably do not want antibiotics.
- I definitely do not want antibiotics.

Imagining that you have suffered a moderately severe stroke

A10 If your heart stopped beating or you stopped breathing, would you want to receive CPR or cardiopulmonary resuscitation?

- I definitely want CPR.
- I probably want CPR.
- I am unsure.
- I probably do not want CPR.
- I definitely do not want CPR.

SECTION A. (CONTINUED)

Imagining that you have suffered a **moderately severe stroke**

A11 If your **gallbladder** became **inflamed** and **infected**, would you want **surgery** to remove it?

- I **definitely want** surgery.
- I **probably want** surgery.
- I am unsure.
- I **probably do not want** surgery.
- I **definitely do not want** surgery.

Imagining that you have suffered a **moderately severe stroke**

A12 If your condition becomes such that you lose the ability to take in food or water by mouth, would **you** want **artificial feeding and fluids**?

- I **definitely want** artificial feeding and fluids.
- I **probably want** artificial feeding and fluids.
- I am unsure.
- I **probably do not want** artificial feeding and fluids.
- I **definitely do not want** artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 4: COLON CANCER

Imagine that you have colon cancer, which has spread to your liver.

- You are tired and weak, requiring some help with household chores.
- You can think and remember without difficulty.
- You have pain that requires the constant use of medication.
- In the opinion of your doctor, you have a slight chance of recovery.
- Your doctor estimates that you have about six months to live.

Please mark the box which is closest to how you would feel about receiving each treatment.

Imagining that you have **colon cancer**

A13 If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

- I definitely want antibiotics.
- I probably want antibiotics.
- I am unsure.
- I probably do not want antibiotics.
- I definitely do not want antibiotics.

Imagining that you have **colon cancer**

A14 If your heart stopped beating or you stopped breathing, would you want to receive CPR or cardiopulmonary resuscitation?

- I definitely want CPR.
- I probably want CPR.
- I am unsure.
- I probably do not want CPR.
- I definitely do not want CPR.

SECTION A. (CONTINUED)

Imagining that you have **colon cancer**

A15 If your **gallbladder** became **inflamed** and **infected**, would **you** want **surgery** to remove it?

- I **definitely want** surgery.
- I **probably want** surgery.
- I am unsure.
- I **probably do not want** surgery.
- I **definitely do not want** surgery.

Imagining that you have **colon cancer**

A16 If your condition becomes such that you lose the ability to take in food or water by mouth, would **you** want **artificial feeding and fluids**?

- I **definitely want** artificial feeding and fluids.
- I **probably want** artificial feeding and fluids.
- I am unsure.
- I **probably do not want** artificial feeding and fluids.
- I **definitely do not want** artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 5: HEART ATTACK

Imagine that you have had a severe heart attack, which weakened your heart.

- You feel short of breath doing activities and get tired easily.
- Your ankles and feet are swollen.
- You require help with household chores.
- Your condition may get worse very quickly or slowly decline over several years.
- You can think and remember without difficulty.
- In the opinion of your doctor, you have a slight chance of improvement.

Please mark the box which is closest to how you would feel about receiving each treatment.

Imagining that you have had a severe heart attack

A17 If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

- I definitely want antibiotics.
- I probably want antibiotics.
- I am unsure.
- I probably do not want antibiotics.
- I definitely do not want antibiotics.

SECTION A. (CONTINUED)

Imagining that you have had a **severe heart attack**

A18 If your **heart stopped beating** or you stopped breathing, would **you** want to receive **CPR or cardiopulmonary resuscitation?**

- I **definitely want** CPR.
- I **probably want** CPR.
- I am unsure.
- I **probably do not want** CPR.
- I **definitely do not want** CPR.

Imagining that you have had a **severe heart attack**

A19 If your **gallbladder** became **inflamed** and **infected**, would **you** want **surgery** to remove it?

- I **definitely want** surgery.
- I **probably want** surgery.
- I am unsure.
- I **probably do not want** surgery.
- I **definitely do not want** surgery.

Imagining that you have had a **severe heart attack**

A20 If your condition becomes such that you lose the ability to take in food or water by mouth, would **you** want **artificial feeding and fluids?**

- I **definitely want** artificial feeding and fluids.
- I **probably want** artificial feeding and fluids.
- I am unsure.
- I **probably do not want** artificial feeding and fluids.
- I **definitely do not want** artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 6: ALZHEIMER'S DISEASE

Imagine you have Alzheimer's disease or dementia.

- You have trouble remembering things and thinking clearly.
- You cannot always recognize people you know.
- You have no chance of recovery.
- Your mental abilities may get worse quickly or slowly.
- You can do physical activities without difficulty.

Please mark the box which is closest to how you would feel about receiving each treatment.

Imagining you have Alzheimer's disease or dementia

A21 If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

- I definitely want antibiotics.
- I probably want antibiotics.
- I am unsure.
- I probably do not want antibiotics.
- I definitely do not want antibiotics.

Imagining you have Alzheimer's disease or dementia

A22 If your heart stopped beating or you stopped breathing, would you want to receive CPR or cardiopulmonary resuscitation?

- I definitely want CPR.
- I probably want CPR.
- I am unsure.
- I probably do not want CPR.
- I definitely do not want CPR.

SECTION A. (CONTINUED)

Imagining you have **Alzheimer's disease or dementia**

A23 If your **gallbladder** became **inflamed** and **infected**, would you want **surgery** to remove it?

- I **definitely want** surgery.
- I **probably want** surgery.
- I am unsure.
- I **probably do not want** surgery.
- I **definitely do not want** surgery.

Imagining you have **Alzheimer's disease or dementia**

A24 If your condition becomes such that you lose the ability to take in food or water by mouth, would **you** want **artificial feeding and fluids**?

- I **definitely want** artificial feeding and fluids.
- I **probably want** artificial feeding and fluids.
- I am unsure.
- I **probably do not want** artificial feeding and fluids.
- I **definitely do not want** artificial feeding and fluids.

SECTION B.

DECISIONS ABOUT MEDICAL TREATMENT

- People can make decisions about what medical treatments to receive in many different ways.
- Family or friends may help make decisions about treatment too.
- The next questions are about **how you like to make decisions about medical treatments for a health problem.**

B1 Please **check the one statement** that best describes what you believe would be ideal:

- I prefer to **make the decision** about which treatment I will receive.
- I prefer to **make the final decision** about my treatment **after seriously considering my doctor's opinion.**
- I prefer that **my doctor and I share responsibility** for deciding which treatment is best for me.
- I prefer that **my doctor makes the final decision** about which treatment will be used but **seriously considers my opinion.**
- I prefer to **leave all decisions** regarding treatment to **my doctor.**

SECTION C.

DECISIONS ABOUT TREATMENTS FOR HEART ATTACK AND STROKE

- Some people like to be very involved in making medical decisions, while others want their doctor or a loved one to help them in making these decisions.
- The next questions are about **how involved you would want to be in making medical decisions, specifically if you had a heart attack or a stroke.**
- Please think through **how you would want to make the decision** rather than whether you would want the treatment.

HEART ATTACK

- A heart attack happens when the flow of blood to a part of your heart suddenly becomes blocked and the heart can't get oxygen.
- If blood flow isn't restored quickly, part of the heart muscle begins to die.
- The most common reason for a blockage is a blood clot.

Imagining that you had a heart attack

Please **mark the one statement** which is closest to **how involved you** would want to be in **making the decisions** for the following **treatments**.

C1 How involved would you want to be in the decision on whether or not to have a **medical procedure** (called an angioplasty) to treat the heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION C. (CONTINUED)

Imagining that you had a **heart attack**

C2 How involved would you want to be in the decision on whether or not to have **open-heart surgery** (called bypass surgery) to improve blood flow to the heart after you had a heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C3 How involved would you want to be in the decision on whether or not to do a **heart rehabilitation program in a clinic** to improve your health and well-being after you had a heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C4 How involved would you want to be in the decision on whether or not to start a **cholesterol medicine** to reduce the chance of having another heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION C. (CONTINUED)

STROKE

- A stroke happens when the flow of blood to a part of your brain suddenly becomes blocked and the brain can't get oxygen.
- If blood flow isn't restored quickly, part of the brain begins to die.
- The most common reason for a blockage is a blood clot.
- A stroke can cause a person to have difficulties with walking, balance, and speech.

Imagining that you had a **stroke**

Please **mark the one statement** which is closest to **how involved you** would want to be in **making the decisions** for the following **treatments**.

C5 How involved would you want to be in the decision on whether or not to have **clot-busting medicine** injected into a vein to treat the stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C6 How involved would you want to be in the decision on whether or not to have **surgery on a neck artery** to improve blood flow to the brain after you had a stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION C. (CONTINUED)

Imagining that you had a **stroke**

C7 How involved would you want to be in the decision on whether or not to do **stroke rehabilitation in a hospital or facility** to improve your walking and balance after you had a stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C8 How involved would you want to be in the decision on whether or not to start **blood-thinning medicine** to reduce the chance of having another stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION D.

YOUR THOUGHTS ABOUT FUTURE HEALTH RISKS

The next questions are about **your health risks in the future**. Please mark the box that describes **the chance** that this will happen to you.

D1 I feel that I'm going to have **a fall** in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

D2 I feel that I'm going to have **a heart attack** in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

SECTION D. (CONTINUED)

D3 I feel that I'm going to have a stroke in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

D4 I feel that I'm going to develop dementia in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

SECTION E. YOUR HEALTH

The next questions are about your health. Your answers are confidential.

E1 In general, how is your health?

- Excellent
- Very good
- Good
- Fair
- Poor

E2 Has a doctor ever told you that you had a stroke?

- Yes
- No

E3 Has a doctor ever told you that you had a heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems?

- Yes
- No

E4 Has a doctor ever told you that you have chronic lung disease such as chronic bronchitis, COPD, or emphysema?

- Yes
- No

SECTION E. (CONTINUED)

E5 Has a doctor ever told you that you have cancer or a malignant tumor, excluding minor skin cancer?

Yes

No

E6 Has a doctor ever told you that you have arthritis or rheumatism?

Yes

No

E7 Over the past 2 weeks, how often have you been bothered by little interest or pleasure in doing things?

Not at all

Several days

More than half the days

Nearly every day

E8 Over the past 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless?

Not at all

Several days

More than half the days

Nearly every day

SECTION E. (CONTINUED)

Because of a health or memory problem, do you have difficulty with any of the following activities?

	Yes	No
E9. Walking several blocks	<input type="checkbox"/>	<input type="checkbox"/>
E10. Dressing, including putting on shoes and socks	<input type="checkbox"/>	<input type="checkbox"/>
E11. Bathing or showering	<input type="checkbox"/>	<input type="checkbox"/>
E12. Eating, such as cutting up food	<input type="checkbox"/>	<input type="checkbox"/>
E13. Getting in or out of bed	<input type="checkbox"/>	<input type="checkbox"/>
E14. Using the toilet, including getting up and down	<input type="checkbox"/>	<input type="checkbox"/>

SECTION F. ABOUT YOURSELF

The next questions are about you. We want to make sure this study represents different people's views. Please remember your answers are confidential.

F1 What is your age?

YEARS

F2 What is your gender?

- Male
 Female

F3 Are you Hispanic or Latino(a)?

- Yes
 No

F4 What is your race? (Select all that apply.)

- American Indian or Alaska Native
 Asian
 Black or African American
 Native Hawaiian or Other Pacific Islander
 White
 Other [Please specify:]

SECTION F. (CONTINUED)

F5 What is your current marital status? (Mark one box.)

- Married
- Living with someone as a couple, but not married
- Divorced or separated
- Widowed
- Never married

F6 Do you have any children – please include biological, stepchildren, and adopted children?

- Yes
- No

F7 Do you have at least one adult child that lives with you?

- Yes
- No

F8 Do any of your adult children who do not live with you live within 30 miles of you?

- Yes
- No

SECTION F. (CONTINUED)

F9 What is the highest grade of school that you completed? (Mark one box.)

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

F10 Has a close family member or friend had dementia?

- Yes
- No

F11 Has a close family member or friend had a stroke?

- Yes
- No

F12 Has a close family member or friend had a heart attack?

- Yes
- No

Thank you for your help!

Your answers will allow us to better help people with heart attack and stroke.

If you completed the questionnaire in the clinic or research center, please put the questionnaire into the brown envelope and give it to the interviewer.

If you completed the questionnaire in your home, please send the questionnaire back in the postage-paid white envelope.

Study ID #:

Study Partner Perspectives on Medical Treatment

Conducted by: University of Michigan and Duke University

Return to: Dr. Deborah Levine
University of Michigan
Department of Medicine
2800 Plymouth Road
Building 16-430W
Ann Arbor, Michigan 48109-2800

(Postage-paid envelope included in packet)

Questions: Please call Dr. Levine at (734) 936-5216

This study is funded by a grant from the National Institutes of Health / National Institute on Aging and has been approved by the Institutional Review Board of the University of Michigan (# HUM00118584).

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Decision Making for Cardiovascular Therapy in Adults with Mild Cognitive Impairment (HUM00118584)

Dr. Deborah A. Levine of the University of Michigan, invites you to take part in a research study designed to learn more about what older adults and their family members or friends think about their health risks and their preferences for treatment. We are asking you to participate because you are part of the UM Memory and Aging Project. This research is funded by the National Institutes of Health – National Institute on Aging.

Taking part in this study is completely **voluntary**.

- You do not have to participate if you don't want to.
- You may skip any survey question you feel uncomfortable answering.
- If you choose not to participate, your clinical care will not change.
- Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled.
- By completing the survey and returning it to the study team, you are agreeing to participate in this study.

All of your information will be kept **confidential** and only be viewed by researchers analyzing the data.

You may not receive any personal benefits from being in this study. We hope what we learn will help other people in the future.

To thank you for taking part in our study, we are including \$50.00 in this packet for completion of the survey.

If you have questions about your rights as a research participant, or wish to obtain information, ask questions or discuss any concerns about this study, please see the contact information below.

CONTACT INFORMATION

To find out more about the study, to ask a question or express a concern about the study, or to talk about any problems you may have as a study subject, please contact one of the following:

Principal Investigator: Deborah A. Levine, MD, MPH Mailing Address: 2800 Plymouth Road, Building 16, Room 430W Ann Arbor, MI 48109-2800 Telephone: 734-936-5216	Project Manager: Bailey Green, MPH Mailing Address: 2800 Plymouth Road, Building 16, Room 430W Ann Arbor, MI 48109-2800 Telephone: 734-647-3971
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You may also express a concern about a study by contacting the Institutional Review Board:

University of Michigan Medical School Institutional Review Board (IRBMED)
2800 Plymouth Road, Building 520, Room 3214
Ann Arbor, MI 48109-2800
Phone: 734-763-4768
E-mail: irbmed@umich.edu

If you are concerned about a possible violation of your privacy or concerned about a study, you may contact the University of Michigan Health System Compliance Help Line at 1-866-990-0111

Study Partner Perspectives on Medical Treatment

Thank you for taking time to complete this questionnaire. Your answers to these questions will help us better understand the kinds of medical treatments that adults would want if they were to become sick. **Your answers are very important to us.**

There are no right or wrong answers. We are interested in your experiences and your honest opinion.

All of your answers will be kept confidential, and we will not tell your doctor any of your answers. We will not use individual names in any notes, reports, or summaries.

Thank you for your help!

HOW TO FILL IN THIS QUESTIONNAIRE

- Please answer the questions by marking boxes this way:

Response option 1

Response option 2

- Please select your one best answer to each question, based on the information provided.
 - You may select more than one answer if the question says: (Select all that apply)

**PLEASE START THE QUESTIONNAIRE
BY READING THE INSTRUCTIONS
AT THE BEGINNING OF SECTION A.**

SECTION A.

YOUR OPINION ABOUT MEDICAL TREATMENT IF YOUR STUDY PARTNER WERE TO BECOME SERIOUSLY ILL

- The next questions are about **what kinds of treatments you would want your study partner to receive if they were to become seriously ill.**
- Please imagine how you would feel if your study partner had the health condition when answering these questions.
- Think about how you would feel about your study partner receiving each treatment.

SCENARIO 1: CURRENT HEALTH

Your study partner has their current health; the way they feel now.

Please **mark the box** which is closest to how you would feel about **your study partner** receiving each treatment.

Antibiotics

- Antibiotics are medicines used to treat infections.
- Without antibiotics, serious infections like pneumonia can cause life-threatening complications such as trouble breathing or death.

Imagining that your study partner has their **current health**

A1 If your study partner developed a **serious infection**, like **pneumonia**, would you want them to use **antibiotics** to treat the infection?

- I **definitely would want** them to use antibiotics.
- I **probably would want** them to use antibiotics.
- I am unsure.
- I **probably would not want** them to use antibiotics.
- I **definitely would not want** them to use antibiotics.

SECTION A. (CONTINUED)

CPR: Cardiopulmonary Resuscitation

- Doctors use CPR or cardiopulmonary resuscitation when a person's heart stops beating or a person stops breathing.
- Doctors press on the chest to help pump blood, and they use artificial breathing.
- Artificial breathing means the doctor puts a tube in the windpipe.
- Then, a machine breathes for the person through the tube.
- People usually get medicines by vein.
- People often need an electrical shock to help restart the heartbeat.
- Without CPR, the heart will not start beating again and the person will die.

Imagining that your study partner has their **current health**

A2 If your study partner's heart stopped beating or they stopped breathing, would you want them to receive CPR or cardiopulmonary resuscitation?

- I definitely would want them to receive CPR.
- I probably would want them to receive CPR.
- I am unsure.
- I probably would not want them to receive CPR.
- I definitely would not want them to receive CPR.

SECTION A. (CONTINUED)

Gallbladder Surgery

- Doctors use surgery to remove the gallbladder when it is inflamed and infected.
- If untreated, an inflamed and infected gallbladder can rupture and cause life-threatening complications or death.

Imagining that your study partner has their **current health**

A3 If your study partner's **gallbladder** became **inflamed** and **infected**, would you want them to have **surgery** to remove it?

- I **definitely would want** them to have surgery.
- I **probably would want** them to have surgery.
- I am unsure.
- I **probably would not want** them to have surgery.
- I **definitely would not want** them to have surgery.

SECTION A. (CONTINUED)

Artificial Feeding and Fluids

- Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive.
- The food goes through a feeding tube.
- Usually, the feeding tube goes through the skin, into the stomach.
- Without this treatment, people die within 7 to 10 days.

Imagining that your study partner has their **current health**

A4 If your study partner's condition becomes such that they lose the ability to take in food or water by mouth, would you want them to get **artificial feeding and fluids?**

- I **definitely would want** them to get artificial feeding and fluids.
- I **probably would want** them to get artificial feeding and fluids.
- I am unsure.
- I **probably would not want** them to get artificial feeding and fluids.
- I **definitely would not want** them to get artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 2: EMPHYSEMA

Imagine that your study partner has emphysema, a lung disease.

- They have constant shortness of breath.
- They are unable to climb stairs or walk more than a few feet.
- Their condition cannot improve.
- Their condition may get worse very quickly or slowly decline over several years.
- They can think and remember without difficulty.

Please mark the box which is closest to how you would feel about your study partner receiving each treatment.

Imagining that your study partner has emphysema, a lung disease

A5 If your study partner developed a serious infection, like pneumonia, would you want them to use antibiotics to treat the infection?

- I definitely would want them to use antibiotics.
- I probably would want them to use antibiotics.
- I am unsure.
- I probably would not want them to use antibiotics.
- I definitely would not want them to use antibiotics.

SECTION A. (CONTINUED)

Imagining that your study partner has **emphysema, a lung disease**

A6 If your study partner's **heart stopped beating** or they stopped breathing, would you want them to receive **CPR or cardiopulmonary resuscitation?**

- I **definitely would want** them to receive CPR.
- I **probably would want** them to receive CPR.
- I am unsure.
- I **probably would not want** them to receive CPR.
- I **definitely would not want** them to receive CPR.

Imagining that your study partner has **emphysema, a lung disease**

A7 If your study partner's **gallbladder** became **inflamed** and **infected**, would you want them to have **surgery** to remove it?

- I **definitely would want** them to have surgery.
- I **probably would want** them to have surgery.
- I am unsure.
- I **probably would not want** them to have surgery.
- I **definitely would not want** them to have surgery.

SECTION A. (CONTINUED)

Imagining that your study partner has **emphysema, a lung disease**

A8 If your study partner's condition becomes such that they lose the ability to take in food or water by mouth, would you want them to get **artificial feeding and fluids?**

- I **definitely would want** them to get artificial feeding and fluids.
- I **probably would want** them to get artificial feeding and fluids.
- I am unsure.
- I **probably would not want** them to get artificial feeding and fluids.
- I **definitely would not want** them to get artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 3: STROKE

Imagine that your study partner has suffered a moderately severe stroke.

- One arm and leg are paralyzed.
- They have trouble speaking and trouble understanding when others speak.
- They rely on others for help with feeding, dressing, bathing, and toileting.
- In the opinion of their doctor, they have a slight chance of improvement.

Please mark the box which is closest to how you would feel about your study partner receiving each treatment.

Imagining that your study partner has suffered a moderately severe stroke

A9 If your study partner developed a serious infection, like pneumonia, would you want them to use antibiotics to treat the infection?

- I definitely would want them to use antibiotics.
- I probably would want them to use antibiotics.
- I am unsure.
- I probably would not want them to use antibiotics.
- I definitely would not want them to use antibiotics.

SECTION A. (CONTINUED)

Imagining that your study partner has suffered a **moderately severe stroke**

A10 If your study partner's heart stopped beating or they stopped breathing, would you want them to receive CPR or cardiopulmonary resuscitation?

- I definitely would want them to receive CPR.
- I probably would want them to receive CPR.
- I am unsure.
- I probably would not want them to receive CPR.
- I definitely would not want them to receive CPR.

Imagining that your study partner has suffered a **moderately severe stroke**

A11 If your study partner's gallbladder became inflamed and infected, would you want them to have surgery to remove it?

- I definitely would want them to have surgery.
- I probably would want them to have surgery.
- I am unsure.
- I probably would not want them to have surgery.
- I definitely would not want them to have surgery.

SECTION A. (CONTINUED)

Imagining that your study partner has suffered a **moderately severe stroke**

A12 If your study partner's condition becomes such that they lose the ability to take in food or water by mouth, would you want them to get **artificial feeding and fluids**?

- I **definitely would want** them to get artificial feeding and fluids.
- I **probably would want** them to get artificial feeding and fluids.
- I am unsure.
- I **probably would not want** them to get artificial feeding and fluids.
- I **definitely would not want** them to get artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 4: COLON CANCER

Imagine that your study partner has colon cancer, which has spread to their liver.

- They are tired and weak, requiring some help with household chores.
- They can think and remember without difficulty.
- They have pain that requires the constant use of medication.
- In the opinion of your study partner's doctor, they have a slight chance of recovery.
- Their doctor estimates that they have about six months to live.

Please mark the box which is closest to how you would feel about your study partner receiving each treatment.

Imagining that your study partner has colon cancer

A13 If your study partner developed a serious infection, like pneumonia, would you want them to use antibiotics to treat the infection?

- I definitely would want them to use antibiotics.
- I probably would want them to use antibiotics.
- I am unsure.
- I probably would not want them to use antibiotics.
- I definitely would not want them to use antibiotics.

SECTION A. (CONTINUED)

Imagining that your study partner has **colon cancer**

A14 If your study partner's **heart stopped beating** or they stopped breathing, would you want them to receive **CPR or cardiopulmonary resuscitation?**

- I **definitely would want** them to receive CPR.
- I **probably would want** them to receive CPR.
- I am unsure.
- I **probably would not want** them to receive CPR.
- I **definitely would not want** them to receive CPR.

Imagining that your study partner has **colon cancer**

A15 If your study partner's **gallbladder** became **inflamed** and **infected**, would you want them to have **surgery** to remove it?

- I **definitely would want** them to have surgery.
- I **probably would want** them to have surgery.
- I am unsure.
- I **probably would not want** them to have surgery.
- I **definitely would not want** them to have surgery.

SECTION A. (CONTINUED)

Imagining that your study partner has **colon cancer**

A16 If your study partner's condition becomes such that they lose the ability to take in food or water by mouth, would you want them to get **artificial feeding and fluids?**

- I **definitely would want** them to get artificial feeding and fluids.
- I **probably would want** them to get artificial feeding and fluids.
- I am unsure.
- I **probably would not want** them to get artificial feeding and fluids.
- I **definitely would not want** them to get artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 5: HEART ATTACK

Imagine that your study partner has suffered a severe heart attack, which weakened their heart.

- They feel short of breath doing activities and get tired easily.
- Their ankles and feet are swollen.
- They require help with household chores.
- Their condition may get worse very quickly or slowly decline over several years.
- They can think and remember without difficulty.
- In the opinion of their doctor, they have a slight chance of improvement.

Please mark the box which is closest to how you would feel about your study partner receiving each treatment.

Imagining that your study partner has had a severe heart attack

A17 If your study partner developed a serious infection, like pneumonia, would you want them to use antibiotics to treat the infection?

- I definitely would want them to use antibiotics.
- I probably would want them to use antibiotics.
- I am unsure.
- I probably would not want them to use antibiotics.
- I definitely would not want them to use antibiotics.

SECTION A. (CONTINUED)

Imagining that your study partner has had a **severe heart attack**

A18 If your study partner's heart stopped beating or they stopped breathing, would you want them to receive CPR or cardiopulmonary resuscitation?

- I definitely would want them to receive CPR.
- I probably would want them to receive CPR.
- I am unsure.
- I probably would not want them to receive CPR.
- I definitely would not want them to receive CPR.

Imagining that your study partner has had a **severe heart attack**

A19 If your study partner's gallbladder became inflamed and infected, would you want them to have surgery to remove it?

- I definitely would want them to have surgery.
- I probably would want them to have surgery.
- I am unsure.
- I probably would not want them to have surgery.
- I definitely would not want them to have surgery.

SECTION A. (CONTINUED)

Imagining that your study partner has had a **severe heart attack**

A20 If your study partner's condition becomes such that they lose the ability to take in food or water by mouth, would you want them to get **artificial feeding and fluids?**

- I **definitely would want** them to get artificial feeding and fluids.
- I **probably would want** them to get artificial feeding and fluids.
- I am unsure.
- I **probably would not want** them to get artificial feeding and fluids.
- I **definitely would not want** them to get artificial feeding and fluids.

SECTION A. (CONTINUED)

SCENARIO 6: ALZHEIMER'S DISEASE

Imagine that your study partner has Alzheimer's disease or dementia.

- They have trouble remembering things and thinking clearly.
- They cannot always recognize people they know.
- They have no chance of recovery.
- Their mental abilities may get worse quickly or slowly.
- They can do physical activities without difficulty.

Please mark the box which is closest to how you would feel about your study partner receiving each treatment.

Imagining that your study partner has Alzheimer's disease or dementia

A21 If your study partner developed a serious infection, like pneumonia, would you want them to use antibiotics to treat the infection?

- I definitely would want them to use antibiotics.
- I probably would want them to use antibiotics.
- I am unsure.
- I probably would not want them to use antibiotics.
- I definitely would not want them to use antibiotics.

SECTION A. (CONTINUED)

Imagining that your study partner has **Alzheimer's disease or dementia**

A22 If your study partner's heart stopped beating or they stopped breathing, would you want them to receive CPR or cardiopulmonary resuscitation?

- I definitely would want them to receive CPR.
- I probably would want them to receive CPR.
- I am unsure.
- I probably would not want them to receive CPR.
- I definitely would not want them to receive CPR.

Imagining that your study partner has **Alzheimer's disease or dementia**

A23 If your study partner's gallbladder became inflamed and infected, would you want them to have surgery to remove it?

- I definitely would want them to have surgery.
- I probably would want them to have surgery.
- I am unsure.
- I probably would not want them to have surgery.
- I definitely would not want them to have surgery.

SECTION A. (CONTINUED)

Imagining that your study partner has **Alzheimer's disease or dementia**

A24 If your study partner's condition becomes such that they lose the ability to take in food or water by mouth, would you want them to get **artificial feeding and fluids?**

- I **definitely would want** them to get artificial feeding and fluids.
- I **probably would want** them to get artificial feeding and fluids.
- I am unsure.
- I **probably would not want** them to get artificial feeding and fluids.
- I **definitely would not want** them to get artificial feeding and fluids.

SECTION B.

DECISIONS ABOUT MEDICAL TREATMENT

- People can make decisions about what medical treatments to receive in many different ways.
- Family or friends may help make decisions about treatment too.
- The next questions are about **how you like to make decisions about medical treatments for a health problem.**

B1 Please **check the one statement** that best describes what you believe would be ideal:

- I prefer to **make the decision** about which treatment I will receive.
- I prefer to **make the final decision** about my treatment **after seriously considering my doctor's opinion.**
- I prefer that **my doctor and I share responsibility** for deciding which treatment is best for me.
- I prefer that **my doctor makes the final decision** about which treatment will be used but **seriously considers my opinion.**
- I prefer to **leave all decisions** regarding treatment to **my doctor.**

SECTION C.

DECISIONS ABOUT TREATMENTS FOR HEART ATTACK AND STROKE

- Some people like to be very involved in making medical decisions, while others want their doctor or a loved one to help them in making these decisions.
- The next questions are about **how involved you would want to be in making medical decisions, specifically if your study partner had a heart attack or a stroke.**
- Please think through **how you would want to make the decision** rather than whether you would want the treatment for them.

HEART ATTACK

- A heart attack happens when the flow of blood to a part of the heart suddenly becomes blocked and the heart can't get oxygen.
- If blood flow isn't restored quickly, part of the heart muscle begins to die.
- The most common reason for a blockage is a blood clot.

Imagining that your study partner had a heart attack

Please **mark the one statement** which is closest to **how involved you** would want to be in **making the decisions for your study partner** for the following **treatments**.

C1 How involved would you want to be in the decision on whether or not they have a **medical procedure** (called an angioplasty) to treat the heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION C. (CONTINUED)

Imagining that your study partner had a **heart attack**

C2 How involved would you want to be in the decision on whether or not they have **open-heart surgery** (called bypass surgery) to improve blood flow to the heart after they had a heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C3 How involved would you want to be in the decision on whether or not they do a **heart rehabilitation program in a clinic** to improve their health and well-being after a heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C4 How involved would you want to be in the decision on whether or not they start a **cholesterol medicine** to reduce the chance of them having another heart attack?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION C. (CONTINUED)

STROKE

- A stroke happens when the flow of blood to a part of the brain suddenly becomes blocked and the brain can't get oxygen.
- If blood flow isn't restored quickly, part of the brain begins to die.
- The most common reason for a blockage is a blood clot.
- A stroke can cause a person to have difficulties with walking, balance, and speech.

Imagining that your study partner had a **stroke**

Please **mark the one statement** which is closest to **how involved you** would want to be in **making the decisions for your study partner** for the following **treatments**.

C5 How involved would you want to be in the decision on whether or not they have **clot-busting medicine** injected into a vein to treat the stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C6 How involved would you want to be in the decision on whether or not they have **surgery on a neck artery** to improve blood flow to the brain after they had a stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION C. (CONTINUED)

Imagining that your study partner had a **stroke**

C7 How involved would you want to be in the decision on whether or not they do **stroke rehabilitation in a hospital or facility** to improve their walking and balance after they had a stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

C8 How involved would you want to be in the decision on whether or not they start **blood-thinning medicine** to reduce their chance of having another stroke?

- I **definitely want** to be involved in making the decision.
- I **probably want** to be involved in making the decision.
- I am unsure.
- I **probably do not want** to be involved in making the decision.
- I **definitely do not want** to be involved in making the decision.

SECTION D.

YOUR THOUGHTS ABOUT YOUR STUDY PARTNER'S FUTURE HEALTH RISKS

The next questions are about **your study partner's health risks in the future**. Please mark the box that describes **the chance** that this will happen to your study partner.

D1 I feel that my study partner is going to have **a fall** in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

D2 I feel that my study partner is going to have **a heart attack** in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

SECTION D. (CONTINUED)

D3 I feel that my study partner is going to have **a stroke** in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

D4 I feel that my study partner is going to develop **dementia** in the next 2 years.

- Disagree strongly
- Disagree
- Neither agree nor disagree
- Agree
- Agree strongly

SECTION E.

YOUR STUDY PARTNER'S CURRENT HEALTH

The next questions are about your study partner's current health. Please **mark the one description** that most closely applies to your study partner. If no description is exactly right, mark the description that seems to apply most of the time.

E1 Memory

- Normal memory.
- Occasionally forgets things that they were told recently. Does not cause many problems.
- Mild consistent forgetfulness. Remembers recent events but often forgets parts.
- Moderate memory loss. Worse for recent events. May not remember something they were just told. Causes problems with everyday activities.
- Substantial memory loss. Quickly forgets recent or newly learned things. Can only remember things that they have known for a long time.
- Does not remember basic facts like the day of the week, when last meal was eaten, or what the next meal will be.
- Does not remember even the most basic things.

SECTION E. (CONTINUED)

E2 Speech and Language

- Normal ability to talk and to understand others.
- Sometimes cannot find a word but able to carry on conversations.
- Often forgets words. May use the wrong word in its place. Some trouble expressing thoughts and giving answers.
- Usually answers questions using sentences but rarely starts a conversation.
- Answers questions but responses are often hard to understand or don't make sense. Usually able to follow simple instructions.
- Speech often does not make sense. Cannot answer questions or follow instructions.
- Does not respond most of the time.

E3 Recognition of Family Members

- Normal. Recognizes people and generally knows who they are.
- Usually recognizes grandchildren, cousins, or relatives who are not seen frequently but may not recall how they are related.
- Usually does not recognize family members who are not seen frequently. Is often confused about how family members such as grandchildren, nieces, or nephews are related to them.
- Sometimes does not recognize close family members or others whom they frequently see. May not recognize their children, brothers, or sisters who are not seen on a regular basis.
- Frequently does not recognize spouse or caregiver.
- No recognition or awareness of the presence of others.

SECTION E. (CONTINUED)

E4 Orientation to Time

- Normal awareness of time of day and day of week.
- Some confusion about what time it is or what day of the week but not severe enough to interfere with everyday activities.
- Frequently confused about time of day.
- Almost always confused about time of day.
- Seems completely unaware of time.

E5 Orientation to Place

- Normal awareness of where they are, even in new places.
- Sometimes disoriented in new places.
- Frequently disoriented in new places.
- Usually disoriented, even in familiar places. May forget that they are already at home.
- Almost always confused about place.

E6 Ability to Make Decisions

- Normal. As able to make decisions as before.
- Only some difficulty making decisions that arise in day-to-day life.
- Moderate difficulty. Gets confused when things get complicated or plans change.
- Rarely makes any important decisions. Gets confused easily.
- Not able to understand what is happening most of the time.

SECTION E. (CONTINUED)

E7 Social and Community Activities

- Normal. Acts the same as before with people.
- Only mild problems that are not really important but clearly acts differently from previous years.
- Can still take part in community activities without help. May appear normal to people who don't know them.
- Often has trouble dealing with people outside the home without help from caregiver. Usually can participate in quiet home activities with friends. The problem is clear to anyone who sees them.
- No longer takes part in any real way in activities at home involving other people. Can only deal with the primary caregiver.
- Little or no response even to primary caregiver.

E8 Home Activities and Responsibilities

- Normal. No decline in ability to do things around the house.
- Some problems with home activities. May have more trouble with money management (paying bills) and fixing things. Can still go to a store, cook, or clean. Still watches TV or reads a newspaper with interest and understanding.
- Makes mistakes with easy tasks like going to a store, cooking, or cleaning. Losing interest in the newspaper, TV, or radio. Often can't follow a long conversation on a single topic.
- Not able to shop, cook, or clean without a lot of help. Does not understand the newspaper or the TV. Cannot follow a conversation.
- No longer does any home-based activities.

SECTION E. (CONTINUED)

E9 Personal Care – Cleanliness

- Normal. Takes care of self as well as they used to.
- Sometimes forgets to wash, shave, comb hair, or may dress in wrong type of clothes. Not as neat as they used to be.
- Requires help with dressing, washing, and personal grooming.
- Totally dependent on help for personal care.

E10 Eating

- Normal. Does not need help in eating food that is served to them.
- May need help cutting food or have trouble with some foods but basically able to eat by themselves.
- Generally able to feed themselves but may require some help. May lose interest during the meal.
- Needs to be fed. May have trouble swallowing.

E11 Control of Urination and Bowels

- Normal. Does not have problems controlling urination or bowels except for physical problems.
- Rarely fails to control urination (generally less than one accident per month).
- Occasional failure to control urination (about once a week or less).
- Frequently fails to control urination (more than once a week).
- Generally fails to control urination and frequently cannot control bowels.

SECTION E. (CONTINUED)

E12 Ability to Get from Place to Place

- Normal. Able to get around on their own. (May have physical problems that require a cane or walker.)
- Sometimes gets confused when driving or taking public transportation, especially in new places. Able to walk places alone.
- Cannot drive or take public transportation alone, even in familiar places. Can walk alone outside for short distances. Might get lost if walking too far from home.
- Cannot be left outside alone. Can get around the house without getting lost or confused.
- Gets confused and needs help finding their way around the house.
- Almost always in a bed or a chair. May be able to walk a few steps with help but lacks sense of direction.
- Always in bed. Unable to sit or stand.

SECTION F. YOUR HEALTH

The next questions are about **your health**. Your answers are confidential.

F1 In general, how is your health?

- Excellent
- Very good
- Good
- Fair
- Poor

F2 Has a doctor ever told you that you had a stroke?

- Yes
- No

F3 Has a doctor ever told you that you had a heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems?

- Yes
- No

F4 Has a doctor ever told you that you have chronic lung disease such as chronic bronchitis, COPD, or emphysema?

- Yes
- No

SECTION F. (CONTINUED)

F5 Has a doctor ever told you that you have cancer or a malignant tumor, excluding minor skin cancer?

Yes

No

F6 Has a doctor ever told you that you have arthritis or rheumatism?

Yes

No

F7 Over the past 2 weeks, how often have you been bothered by little interest or pleasure in doing things?

Not at all

Several days

More than half the days

Nearly every day

F8 Over the past 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless?

Not at all

Several days

More than half the days

Nearly every day

SECTION F. (CONTINUED)

Because of a health or memory problem, do you have difficulty with any of the following activities?

	Yes	No
F9. Walking several blocks	<input type="checkbox"/>	<input type="checkbox"/>
F10. Dressing, including putting on shoes and socks	<input type="checkbox"/>	<input type="checkbox"/>
F11. Bathing or showering	<input type="checkbox"/>	<input type="checkbox"/>
F12. Eating, such as cutting up food	<input type="checkbox"/>	<input type="checkbox"/>
F13. Getting in or out of bed	<input type="checkbox"/>	<input type="checkbox"/>
F14. Using the toilet, including getting up and down	<input type="checkbox"/>	<input type="checkbox"/>

SECTION G.
ABOUT YOURSELF

The next questions are about **you**. We want to make sure this study represents different people's views. Please remember your answers are confidential.

G1 What is your age?

YEARS

G2 What is your gender?

Male

Female

G3 Are you Hispanic or Latino(a)?

Yes

No

G4 What is your race? (Select all that apply.)

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or Other Pacific Islander

White

Other [Please specify:]

SECTION G. (CONTINUED)

G5 What is your current marital status? (Mark one box.)

- Married
- Living with someone as a couple, but not married
- Divorced or separated
- Widowed
- Never married

G6 What is your relationship to the study partner? (Mark one box.)

- Spouse
- Child
- Sibling
- Parent
- Friend
- Guardian
- Neighbor
- Live-in companion
- Other (Specify): _____

G7 How long have you known the study partner? (Write the number of years.)

Years: _____

SECTION G. (CONTINUED)

G8 On average, in the past year, how often did you see the study partner? (Mark one box.)

- I live with the person
- Daily
- Several times a week
- Once a week
- One to three times a month
- Less than once a month
- Never
- Other (Specify): _____

G9 If you see the study partner less than once a week, how often do you speak with them? (Mark one box.)

- Daily
- Several times a week
- Once a week
- One to three times a month
- Less than once a month
- Never
- Other (Specify): _____
- Not applicable. I see them once a week or more

SECTION G. (CONTINUED)

G10 What is the highest grade of school that you completed? (Mark one box.)

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

G11 Has a close family member or friend had dementia?

- Yes
- No

G12 Has a close family member or friend had a stroke?

- Yes
- No

G13 Has a close family member or friend had a heart attack?

- Yes
- No

Thank you for your help!

Your answers will allow us to better help people with heart attack and stroke.

If you completed the questionnaire in the clinic or research center, please put the questionnaire into the brown envelope and give it to the interviewer.

If you completed the questionnaire in your home, please send the questionnaire back in the postage-paid white envelope.