

Caregiver Survey

Supplemental File B

Start of Block: Introduction

Q1 Dartmouth College *Understanding How Information from Healthcare Visits is Shared with Informal Caregivers* Research Project Information Sheet We are conducting a short survey about how information from healthcare visits is shared with informal caregivers. This project is led by Reed Bratches MPH MALS from Dartmouth College, Hanover, New Hampshire, USA. Your participation is voluntary. In order to participate, you must be 18 years of age or older, provide health-related care for an adult, and live in the United States. Participation involves completing an approximately 10-minute survey. There are no right or wrong answers. Your responses are anonymous and no identifiable data will be collected. There are different sections to this survey: questions about you, questions about how you get information to help you provide care, questions about how caregiving impacts you, and questions about how your caregiving has been affected by COVID-19. If you have questions about this project you can contact: Reed W. R. Bratches The Dartmouth Institute for Health Policy & Clinical Practice Lebanon, NH 03756 reed.w.bratches.gr@dartmouth.edu **If you do not wish to participate in this project, or if you are under 18 years of age, please close your Internet browser.** If you wish to participate in this project, please click the "→" button below.

Q2 Are you the person who, in the past 12 months, has been most responsible for caring for the health of an adult, such as your spouse, partner, parent, relative, friend, or adult child? Providing care includes things like helping to make treatment decisions, providing medicines, assisting in medical processes, or discussing the care plan and treatment needs with the doctors or providers.

- Yes (1)
- No (2)

End of Block: Introduction

Start of Block: Age



Q3 What is your age?

End of Block: Age

Start of Block: Demographics Base/Universal

Q4 Do you live in the United States of America?

- Yes (1)
- No (2)

End of Block: Demographics Base/Universal

Start of Block: Main Questions



Q5 What is your ZIP code?

Q6 What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree (1)
- High school graduate (high school diploma or equivalent including GED) (2)
- Bachelor's or Associate's degree (4-year) (3)
- Master's degree (4)
- Doctoral degree (5)
- Professional degree (JD, MD) (6)
-

Q7 Choose one or more races that you consider yourself to be. Please select all that apply. If you choose Other, please specify in the text box.

- White (1)
- Black or African American (2)
- American Indian or Alaska Native (3)
- Asian (4)
- Native Hawaiian or Pacific Islander (5)
- Other (please specify) (6) _____
-

Q8 Do you identify as Hispanic or Latino?

- Yes, I identify as Hispanic/Latino (1)
- No, I do not identify as Hispanic/Latino (2)
-

Q9 With which gender identity do you most identify?

- Male (1)
- Female (2)
- Other (please specify) (3) _____
-

Q10 What is your household income? Select the answer that includes your entire household income from the previous year before taxes. This could include things like your job, unemployment benefits, and Social Security.

- Less than \$20,000 (1)
 - \$20,000 to \$34,999 (2)
 - \$35,000 to \$49,999 (3)
 - \$50,000 to \$74,999 (4)
 - \$75,000 to \$99,999 (5)
 - \$100,000 to \$149,999 (6)
 - \$150,000 or more (7)
-

Q11 For the next section, please answer on the adult person that you care for who requires the highest intensity level of care.

Please click the → button below.



Q12 What is your relationship to the person you care for? Please use the dropdown arrows to provide an answer.

▼ Please Select: (1) ... Other (7)



Q13 How old is the person you care for? Please use the dropdown arrows to provide an answer.

▼ Please Select: (1) ... 81 or older (8)



Q14 How long have you been providing health-related care to this person? Health-related care can range from talking over important treatment decisions to managing this person's daily care. Please use the dropdown arrows to provide an answer.

▼ Please Select: (1) ... More than 5 years (6)

Q15 What conditions do you provide care for? If you don't see a condition on the list, please write it in the "Other" text box. Please select all that apply.

- Cancer (1)
 - Dementia-type Illness (e.g., Alzheimer's) (2)
 - Developmental Disabilities (e.g., autism, Down's Syndrome) (3)
 - Traumatic Brain or Spinal Cord Injuries (4)
 - Infectious Disease, (e.g., HIV/AIDS, Hepatitis) (5)
 - Heart or Cardiovascular Disease (6)
 - Other (Please specify) (7)
-
- Diabetes or other Metabolic Disorder (8)
 - Arthritis (9)
 - Mental Health or Psychiatric Disorders (e.g., depression) (10)
 - Parkinson's (11)
 - Stroke (12)
 - Mobility Problems (14)
-

Q16 When the person you care for goes to the see a healthcare provider, how do you normally receive information about what happened during the visit? Please select one bubble per row

	Never (1)	Sometimes (2)	Often (3)	Always (4)
Going to the healthcare provider with the person I provide care for (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Printed paper summary from the healthcare provider's office (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telephone call to the healthcare provider's office (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Audio recording of the visit (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Video recording of the visit (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient Portal or Patient Profile through a website (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speaking with the person I provide care for (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
From a source not listed above (Please specify) (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q17 About how many hours per day do you spend providing care? Please use the dropdown arrows to select an answer

▼ Please Select: (1) ... More than 9 hours (6)

Q18 What best describes your level of comfort with the following technologies? Please select one bubble per row.

	Not Very Comfortable (1)	Comfortable (2)	Very Comfortable (3)	Don't Use (4)
Computers (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smartphones (like an iPhone, Android, or other internet-connected phones) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tablets (like an iPad, Microsoft Surface, Kindle, or other tablet) (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Main Questions

Start of Block: Recording Questions

Q19

Patients and their doctors have recently started to record some of their visits so they can listen to them later.

For the next few questions, we are going to ask you about recordings. It is OK if you don't have any experience with recording; we just want to ask you some questions about your thoughts and feelings towards recordings.

Please click the → to continue

Q20

Would you feel comfortable if the person you provide care for had their clinic visit recorded?

Yes (1)

No (2)

Q21 If the person you care for had an audio or video recording of their clinic visit, how might you use it? Please select all the apply

- To remember or recall what was said in the visit (1)
 - To prepare for the next clinic visit (2)
 - To help me prepare for my caregiving responsibilities (3)
 - To find out what the doctor told the patient in the visit (4)
 - To listen back to the recording (5)
 - To monitor the health of the person I care for (6)
 - To listen for changes in the treatment of the person I care for (7)
 - To view how the condition has changed since the recording (8)
 - To share with others that were not present during the visit (9)
 - Other (please describe how else you might use an audio or video recording) (10)
-
- I wouldn't use an audio or video recording of the visit (11)
-

Q22 Do you have any concerns about recording or receiving a recording of a clinic visit?

	Doesn't Concern Me At All (1)	Concerns Me A Little (2)	Concerns Me A Lot (3)
That the recording will remain confidential (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That the recording will remain private (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
That the recording will be stored securely (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Could affect the doctor/patient relationship (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q23 Do you have any other concerns about recording or receiving a recording of a clinic visit that were not mentioned?

- Yes (Please specify) (1) _____
- No (2)



Q24 If the person you care for had an audio or video recording of their clinic visit, would you like to have access to it?

- Yes (Optional: add your reason why) (1)

- No (Optional: add your reason why not) (2)

Q25

For the next section, we are going to ask you to respond to some statements about how caregiving makes you feel, and how you feel about caregiving.

Please click the → to continue

Q26 Now we would like to ask you about whether you agree or disagree with some statements about how you feel when you provide care.

For this question, please select one bubble per row.

Think about the following statements. How much do you agree or disagree? Providing help to the person I care for:

	Disagree a Lot (1)	Disagree a Little (2)	Neither Agree nor Disagree (3)	Agree a Little (4)	Agree a Lot (5)
Providing care made me feel more useful (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care made me feel good about myself (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care made me feel needed (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care made me feel appreciated (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care made me feel important (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care made me feel strong and confident (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care enabled me to appreciate life more (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care enabled me to develop a more positive attitude toward life (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Providing
care
strengthened
my
relationship
with others
(9)



Q27 Now we have some questions about how well prepared you feel for providing different aspects of care.

Think about the following statements and mark your level of preparedness for each. Please select one bubble per row.

	Not at all prepared (1)	Not too well prepared (2)	Somewhat well prepared (3)	Pretty well prepared (4)	Very well prepared (5)
How well prepared do you think you are to take care of your family member/loved one's physical needs? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well prepared do you think you are to take care of his or her emotional needs? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well prepared do you think you are to find out about and set up services for him or her? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well prepared do you think you are for the stress of caregiving? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well prepared do you think you are to make caregiving activities pleasant for both you and your family member? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How well prepared do you think you are to respond to and handle emergencies that involve him or her? (6)

How well prepared do you think you are to get the help and information you need from the health care system? (7)

Overall, how well prepared do you think you are to care for them? (8)

Q28 Now we are going to ask you about whether you agree or disagree with some statements about how you feel your life has been affected by being a caregiver.

Think about whether you agree or disagree with the following statements. Please select one bubble per row.

	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
My life satisfaction has suffered because of the care I provide (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I often feel physically exhausted (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
From time to time I wish I could "run away" from the situation I am in (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sometimes I don't really feel like "myself" as before (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Since I have become a caregiver, my financial situation has decreased (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is affected by the care situation (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The care takes a lot of my own strength (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel torn between the demands of my environment (such as family) and the demands of care (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about my future because of the care I give (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

My relationships with other family members, relatives, friends, and acquaintances are suffering as a result of the care. (10)



End of Block: Recording Questions

Start of Block: COVID Questions

Q29 Almost done!

For the final section, we are going to ask you about how your caregiving has been impacted by the COVID-19 pandemic.

We are going to ask about telemedicine visits. These visits can be done through a phone call, a video call, or a video conferencing service.

It is OK if you have no experience with telemedicine visits, we would still like to get your thoughts.

Please click the → to continue

Q30 Have you participated in a telemedicine clinic visit with the person you care for during the COVID-19 pandemic?

Yes (1)

No (2)

Skip To: Q34 If Have you participated in a telemedicine clinic visit with the person you care for during the COVI... = No

Q31 How did you talk with the doctor during the telemedicine visit? Please select all that apply

Video call (1)

Audio Call (2)

Q32 Was it difficult to connect to the telemedicine visit?

Yes (1)

No (2)

Q33 How was the quality of the communication in the telemedicine visit?

Good (Please explain) (1) _____

Poor (Please explain) (2) _____

Q34 For the following statements, please think about how your caregiving is affected by the COVID-19 pandemic.

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
The hospital/clinic team have made an effort to involve me in telemedicine visits (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The person I care for has made an effort to involve me in telemedicine visits (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel up-to-date about the health information for the person I care for (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel more isolated from the person I care for (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel more anxious about providing care (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel encouraged to be involved in treatment decisions (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like I contributed to the discussion of next steps of care (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I feel like my questions about caregiving were answered (8)

I am spending less time providing care (9)

I feel it is easier to attend the clinic visit of person I provide care for (10)

Q35 Will you use telemedicine after the COVID-19 pandemic restrictions are eased?

Yes (Please explain) (1) _____

No (Please explain) (2) _____



Q36 Thank you so much for taking part in our survey! One thing that is very important to us is understanding the experiences of caregivers like you. We would like to connect with interested caregivers and ask them some follow-up questions. Caregivers who complete an interview will receive a \$30 gift card.

If you would not like to be contacted, please click the → button below.

If you would like to be contacted for an interview, please leave your email in the following text box, and then click the → below.

End of Block: COVID Questions
