

Caregiver conversation guide

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1382.

What is the goal?

This information collection is for understanding Caregivers needs and challenges as it relates to technology, access, data sharing and privacy and making recommendations to The Centers for Medicare & Medicaid Services (CMS) for how to better serve Caregiver needs.

How long will it take?

The time required to complete this information collection is estimated to average 60 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, to review and complete the information collection.

You can leave for any reason and your privacy is important.

This information collection is voluntary, and confidential. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850.

Intro / consent 5 min (0:00 - 0:05)

1. **Who I am, role, session overview**
 - a. Thank you for participating in the session with us today.
 - b. My name is [NAME HERE], and I work for a company called Nava. Nava is a design partner working with the Center for Medicare and Medicaid Services to understand and help make recommendations on Caregivers experience around technology, access, data sharing and privacy.
 - c. We'll spend the first few minutes getting to know you a little. Then we'll jump into specific areas where we want your feedback.
2. **Who else is here**
 - a. Listening in on this session are _____. They're here to help me remember all the great things you say.
3. Please be open with your feedback to help us improve. Don't spare our feelings.
4. **Session consent**

- a. Before we begin the interview, I want to take a minute to verbally walk through the information. The consent form states what we're doing with the information we're learning, who has access to this information, and your rights during and after the interview. We will not personally quote you anywhere—your information will be anonymous.

I have your consent form pulled up.

- b. (If the participant had agreed Nava can record the session):
I want to confirm you're comfortable with us screen-recording this interview. The screen recording includes audio and video.

Audio recordings ensure we've captured the conversation accurately.

(BEGIN RECORDING)

Once recording, say, "Thank you for your permission to record this session." (This way, we can capture that we have permission)

We can stop or delete the recording at any point during or after the study upon request.

- c. (If the participant had agreed Nava can take notes):
I want to confirm you're comfortable with my colleague taking notes today.
- d. Typing up this conversation helps us accurately communicate what we're learning with our teammates. Only _____ and I will have access to raw notes from this conversation
- e. Do you have any questions?
- f. I want you to feel comfortable sharing your story. If you need to leave for any reason, you're absolutely free to go. You can also let me know if you don't want to answer a question, and we'll move on to another one.
- g. Your participation is voluntary, and you can also stop the session anytime—just let me know. Your participation won't affect your Medicare coverage in any way.

Participant background 8 min (0:05 - 0:15)

1. How did you become a Caregiver?
2. What do you enjoy about it?
3. *(if applicable based on screener survey)* You mentioned you care for more than one person — I'd love to hear a bit more about that
4. *(if applicable based on screener survey)* What are some challenges you face with managing care for multiple people?

5. I'd also like to talk about some of the harder sides of caregiving. What would make caregiving feel more manageable for you?

Caregivers use of technology 16 min (0:15 - 0:31)

6. What kind of phone do you currently use?
 - a. What sorts of things do you use your phone for?
7. Do you have a computer?
 - a. What sorts of things do you use your computer for?
 - b. Which devices do you prefer when completing Caregiving tasks?
8. Do you interact with technology on behalf of the person you are caregiving for?
 - a. And if so, what types of things are you doing for them?
9. How comfortable are you navigating portals for your care recipient?
 - a. When completing caregiving tasks, do you tend to use your phone or your computer more?
10. What apps or other tools do you use on your phone or computer for Caregiving?
 - a. What does [the app] help you with?
 - b. What do you like about [the app]?
 - c. What frustrates you about [the app]?
 - d. Do you trust the app ?
 - i. if so, what makes you trust the
11. (if applicable based on screener) You mentioned that you manage several care recipients — how do you log in to multiple online portals to access their information?
 - a. What are the challenges of managing multiple care recipient accounts?
 - b. Does your care recipient/loved one need help logging into their health portals or apps?
 - c. Was there ever a time when a health system made it necessary for you to use your recipient's direct username and password?
12. Do you currently use Medicare.gov to manage care for your Enrollee?
13. (if yes to above question) When you're stuck on a task in Medicare.gov, how do you reach out to Medicare?

Caregivers' access to Enrollee data from the Caregivers' perspective 7 minutes (:31 - :38)

1. Has your care recipient made you an Authorized Representative when it comes to Medicare?
2. How did your care recipient grant you access to be their Authorized Representative?
3. What was the last time a critical piece of missing information about your care recipient prevented you from effectively communicating with a healthcare provider?
4. On a scale of 1 to 5, where 1 means very low trust and 5 means very high trust, how much does your care recipient trust you?

- a. What made you pick [the rating]?

Enrollees' sharing of data with Caregivers 8 minutes (:38 - :46)

1. Did you discuss with your care recipient what types of health or medical information they approved sharing with you?
2. What types of medical or health information from your care recipient do you currently lack that would help you perform your caregiving tasks more effectively?
3. Do you have your own username and password to an online portal where you can access your care recipient's medical information? What do you like about it? What frustrates you about it?

Privacy languages in digital apps and Caregiver confidence in data security 8 minutes (:46 - :54)

1. When you download an application into your phone from the app store, you have to agree with their privacy policies outlining what personal data they collect, how its used and who it's shared with before being able to download the app. How thoroughly do you read the privacy policies of these apps?
 - a. If so, what do you know about how the data is being used and stored?
 - b. What would you want to know about how the data is being used and stored that you don't see today?
2. How do you feel about apps and government agencies sharing your health information with each other?
3. I'm going to give you an example before I ask you to rate your confidence level: Some Caregiving apps connect to Medicare to get certain patient data to display in their apps. When the apps receive this data, they must store it safely and protect it with strong security measures. Knowing this, how confident are you that your care recipient's data is being managed by a third-party application that connects to a government-owned entity? (Level of 1 to 5, with 1 being the lowest and 5 being the highest)
4. The next two questions are about how confident you feel that your data is being kept safe and protected, on a scale from 1 to 5, with 1 being the lowest.
 - a. The first question: what is your confidence level in how safe your data is being managed by a government-owned entity? (Level of 1 to 5, with 1 being the lowest and 5 being the highest)
5. I'm going to give you an example before I ask you to rate your confidence level: Some Caregiving apps connect to Medicare to get certain patient data to display in their apps. When the apps receive this data, they must store it safely and protect it with strong security

measures. Knowing this, how confident are you that your data is being managed by a third-party application that connects to a government-owned entity?

Future: What is an ideal Caregiver tool? 4 minutes (:54 - :58)

1. If you had a magic wand to create anything to better support you as a Caregiver, what would it be and why?

End 2 minutes (:58 - 1:00)

1. Is there anything important we didn't cover that you'd like to share?

Thanks for your input!