RESEARCH SUBJECT CONSENT FORM

Title:	Amyloidosis Research Consortium Patient Experience Survey: 2024 Community Survey for Patients with Amyloidosis and Their Caregivers
Protocol No.:	ARC006
Sponsor:	Amyloidosis Research Consortium
Investigator:	Sabrina Rebello 320 Nevada Street, Suite 210 Newton, MA 02460 United States
Study-Related Phone Number(s):	617-467-5170

DETAILED RESEARCH CONSENT

You are being invited to take part in a research study. A person who takes part in a research study is called a research participant.

What should I know about this research?

- This form explains this research to you.
- Taking part in this research is voluntary. Whether you take part is up to you.
- You can choose not to take part. There will be no penalty or loss of benefits to which you are otherwise entitled.
- You can agree to take part and later change your mind. There will be no penalty or loss of benefits to which you are otherwise entitled.
- If you don't understand, ask questions.
- Ask all the questions you want before you decide.

Why is this research being done?

The purpose of this research is to gather information on the experiences with diagnosis, treatment, and the journey of living with amyloidosis of amyloidosis patients and their families. The data generated from this survey will be used to inform our ongoing efforts to improve awareness, science, and treatment for amyloidosis, ultimately benefiting the entire community.

Who and how many people are being asked to participate in this research?

Individuals or caregivers of individuals with amyloidosis are invited to take part in this research. About 1000 participants will take part in this research.

How long will I be in this research?

We expect that your taking part in this research will last 30 minutes.

What happens to me if I agree to take part in this research?

This research relies on an online survey. Therefore, your participation is limited to answering the survey questions online and you will not have direct contact with the research team.

The survey consists of approximately 60 questions. There are unique surveys for patients and caregivers to complete. While you can leave in the middle of the survey and return to the same page you left off, we encourage completing the survey in one sitting.

Data collected via this one-time online survey will be aggregated and analyzed by the research team at ARC. Quotes from the text fields may be used in reporting but will not be attributed to

you. You may choose not to provide any quotes. The report and manuscript that will summarize the results of this study will report only aggregate numbers and is slated to be completed by the end of 2026. Once published, study findings will be available at arci.org.

What are my responsibilities if I take part in this research?

If you take part in this research, you will be responsible for answering the one-time online survey. There will be no follow-up survey or additional responsibilities. You will not be contacted or asked to provide any additional information.

Could being in this research hurt me?

Participation in an online survey is voluntary and has minimal risk to you. It does not include physical risks, legal risks, social risks, or economic risks. However, you may experience discomfort answering questions about experiences you or your family have related to amyloidosis, which may be associated with psychological risks (such as embarrassment).

Your answers are confidential. We are committed to protecting your privacy and ensuring the confidentiality of your information. Patient privacy is secured because all responses are de-identified and caregiver comments cannot be traced back to the patient. All data collected during this study will be handled with the utmost care and stored securely. Your personal information will be anonymized, meaning that your identity will not be linked to any data or results shared outside of this study.

Only authorized research team members will have access to your information, and it will be used solely for the purposes of this research. We will not share your data with any third parties without your explicit consent.

If you have any questions or concerns about how your information will be used or protected, please feel free to reach out to us at any time. Your participation in this study is voluntary, and you may withdraw at any point without any impact to you. Thank you for your trust in us.

Will it cost me money to take part in this research?

Taking part in this research may lead to added costs to you, such as: costs of internet access or a device to access the internet.

Will being in this research benefit me?

There are no benefits to you from your taking part in this research. We cannot promise any benefits to others from your taking part in this research. However, possible benefits to others include learning more about the patient and caregiver experience with diagnosis and treatment of amyloidosis and how this experience has changed over time.

What other choices do I have besides taking part in this research?

This research is not designed to diagnose, treat or prevent any disease. Your alternative is to not take part in the research.

What happens to the information collected for this research?

The information collected during this research study will be used exclusively for research purposes. Here's how we will handle your data:

1. **Data Collection**: We will gather information through surveys as outlined in this study.
2. **Data Anonymization**: Your personal information will be anonymized to ensure that your identity cannot be linked to your responses. This means that any identifying details will be removed or altered. Patient privacy is secured because all responses are de-identified and caregiver comments cannot be traced back to the patient.
3. **Data Storage**: All data will be stored securely in password-protected files and will only be accessible to authorized research team members.
4. **Data Analysis**: The anonymized data will be analyzed to understand the study's objectives and will contribute to advancing knowledge in this field.
5. **Publication of Results**: Findings from this research may be published in scientific journals or presented at conferences. However, any published material will not contain any information that could identify you.
6. **Retention of Data**: The deidentified data collected in this research might be used for future research or distributed to another investigator for future research without your consent.

If you have any questions about the handling of your information, please feel free to ask. Your participation is vital, and we appreciate your trust in this research.

The deidentified data collected in this research might be used for future research or distributed to another investigator for future research without your consent.

Who can answer my questions about this research?

If you have questions, concerns, or complaints, or think this research has hurt you or made you sick, talk to the research team at the phone number listed above on the first page.

What if I am injured because of taking part in this research?

There is no risk of injury or sickness because of taking part in this research.

Can I be removed from this research without my approval?

The person in charge of this research can remove you from this research without your approval. Possible reasons for removal include: not completing the entire survey, or answers you provide

which are outside a reasonable range or highly improbable. To limit the possibility of out of reasonable range responses, the survey has some logical validation rules in place. For example, in a question asking in the past 30 days, how many days have you experienced an event; only a response between 0-30 will accepted. The vast majority of questions are multiple choice and this minimizes the risk of removal from the research.

What happens if I agree to be in this research, but I change my mind later?

If you decide to leave the research early by exiting the survey before the last question, there are no risks with this decision. Any responses you answered prior to leaving the survey may be used as part of the aggregated data. No contact or notification to the research team is required.

Will I be paid for taking part in this research?

You will not be paid for taking part in this research. For US residents only, you have the option of entering a drawing to win one of thirty gift cards worth $50 each at the end of the survey.

Whom to Contact with Questions

If you have questions later or if you have a research-related problem, you can call Sabrina Rebello at (617) 467-5170 or email at srebello@acri.org

This research is being overseen by North Star Review Board, an Institutional Review Board ("IRB"). An IRB is a group of people who perform independent reviews of research studies to make sure the rights of participants are adequately protected. You may talk to them at 1-877-673-8439 or email info@northstarreviewboard.org if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research participant.

Statement of Consent:

By clicking on the survey link and continuing to the online survey, you provide your consent to participate in this study.