

**RESEARCH SUBJECT CONSENT FORM**

**Title:** Amyloidosis Research Consortium Patient Experience Survey:  
2025 Community Survey for Patients with Amyloidosis and Their  
Caregivers

**Protocol No.:** ARC007

**Sponsor:** Amyloidosis Research Consortium

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**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 2027. Once published, study findings will be available at [arci.org](http://arci.org).

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

If you take part in this research, you will be responsible to answer 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 psychologic 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.

## **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.

You can also contact the North Star Review Board, the Institutional Review Board (IRB) that reviewed the project, at 877-673-8439 (toll free) or [info@northstarreviewboard.org](mailto:info@northstarreviewboard.org). The IRB is an independent committee that helps protect research participants' rights.

## **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 be 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.

## **Statement of Consent:**

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