

# Scleroderma Research Foundation

## Privacy Notice for Survey Respondents

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**Effective on: June 1, 2026 Last Modified on: June 1, 2026**

### 1. Introduction

Scleroderma Research Foundation (“SRF”, “we”, “us”, “our”) would like to thank you for responding to this Research Utilization Questionnaire (“Survey”) conducted by SRF. We are committed to safeguarding the privacy and confidentiality of all individuals who participate in the Survey. This notice sets forth the measures adopted to protect the information collected. Please note that this Survey is completely voluntary.

### 2. What data is collected?

We collect certain demographic information, including date of birth, gender, race and ethnicity, and country of residence. Health-related information may be collected as part of the Survey responses. However, all such data is fully anonymized and will not be linked to any you in any way. In addition, IP addresses are anonymized to ensure that technical data cannot be traced back to respondents.

We do not request or record any personal identifiers such as your name, contact details, or other information that could be used to identify you. Should you provide personal data in response to any of our questions, please consider whether your responses reveal information which may identify you and whether you wish to include them. Any disclosure of personal data is at your own discretion, but such data will be safeguarded in accordance with our [Privacy Notice](#). You should restrict your answers to the question at hand and avoid disclosing the personal data of others.

### 3. How do we use the data?

All data collected through the Survey will be analyzed and reported exclusively in aggregate form. Demographic and health-related data will be used solely for research purposes and will not be disclosed, published, or shared. The anonymization of responses, combined with aggregate reporting, provides strong protection against the identification of yourself and other respondents.

### 4. How do we protect the data?

The data we collect through the Survey is stored securely in compliance with applicable data protection standards. We ensure that all access to stored data is restricted to authorized personnel only, and access permissions are reviewed periodically to maintain strict oversight and control.

## 5. For how long do we keep the data?

The data collected from the Survey will be retained only for the period necessary to achieve the research objectives. Upon completion of the analysis, the data will be securely deleted in accordance with applicable regulations.

## 6. Contact Information

If you have any questions about this notice or our processing of your data, please send an email to [info@srfcure.org](mailto:info@srfcure.org) or call 800-441-CURE. You may also contact VeraSafe, our Data Protection Officer (“DPO”) directly using the contact details listed below. We will respond to your request within one month of receipt.

### **VeraSafe**

100 M Street S.E., Suite 600

Washington, D.C. 20003

Email: <https://www.verasafe.com/about-verasafe/contact-us/>

Web: <https://www.verasafe.com/about-verasafe/contact-us/>

Tell: +1-617-398-7067