

## **CARRA Survey Policy**

### **Effective as of 3/14/2025**

#### **A. Overview**

CARRA is dedicated to supporting pediatric rheumatologists in collecting valuable research data through network-wide surveys. CARRA members are expected to participate in these surveys, to enhance the network's strength and the validity of the research results.

The policy has been updated to:

- Align with CARRA's [Strategic Plan](#) and [Research Agenda](#)
- Ensure the data collected is of the highest quality.
- Accommodate investigator survey needs.
- Reduce survey fatigue.

This policy governs surveys that are distributed through the CARRA network. All surveys distributed through this pathway should be directly related to research. Investigators are expected to publish peer-reviewed manuscripts based on their analyses of CARRA network survey responses, and to [share any resulting publications with CARRA](#). All requests to distribute surveys through CARRA must be reviewed by CARRA staff.

Details regarding the survey request process and instructions on how to apply are posted on the Surveys page of the CARRA Research Portal which you can access at <https://research.carragroup.org/en/requests/surveys>

#### **B. Process for Submitting Requests**

All requests for CARRA network surveys must be submitted online using the Survey Request Form available at (<https://research.carragroup.org/en/requests/surveys>). Instructions, application requirements, and other information that can assist in preparing applications are available on the Surveys page of the CARRA Research Portal. Additional assistance in completing applications is also available via email, phone, and online conference – please email [research@carragroup.org](mailto:research@carragroup.org) for support.

CARRA accepts requests on a rolling basis. **Applicants should submit a request at least 2 weeks in advance of the desired survey distribution date.**

The online application requests the following information:

1. Investigator contact information
2. Survey details, including:
  - i. Title
  - ii. Aims
  - iii. IRB/REB status
  - iv. Committee and workgroup affiliation
  - v. CARRA strategic plan and research agenda areas of focus
  - vi. Desired distribution date
  - vii. CARRA members to receive your survey
3. Related file uploads
  - i. Documentation of local regulatory approval or waiver for the study. This is not required at the time the application is submitted but is required prior to survey distribution.
  - ii. A word document of the survey with numbered questions, including any survey logic requirements.
  - iii. Documented confirmation of relevant committee approvals
4. Terms of use acknowledgement

### **C. Process for Reviewing Requests**

CARRA staff conducts reviews of submitted applications, ensuring the application is complete and identifying next steps based on the desired distribution method.

### **D. Process for Email Sharing**

As part of the survey request, investigators must acknowledge CARRA's terms of email use and the results sharing requirements. A copy of the terms of use acknowledgement, can be found on the [CARRA Research Portal](#).

CARRA staff will generate and share a list of the requested membership groups specified in the application. Randomized lists are available upon request.

Investigators are responsible for uploading the emails into their desired platform to distribute the survey and reminders.

## **E. Survey Distribution Conditions**

1. CARRA membership: As a benefit of CARRA membership, only active members may request to distribute a survey through the CARRA network. Visit our website to learn more about becoming a member: <https://carragroup.org/membership/become-a-member/>
2. Committee Approval: Surveys distributed to CARRA members are required to obtain approval from the relevant committees. For a list of committee chairs, please refer to the [Research Portal](#). Additionally, surveys intended for distribution to the larger CARRA membership must be approved by the Scientific Advisory Committee (SAC) chairs. Applicants will be asked to provide proof of approval (e.g. copy of email) in the survey request form. CARRA staff may reach out if there are additional approvals needed for a survey.
3. Documentation of regulatory oversight: Surveys will not be distributed until documentation of appropriate IRB/REB approval, waiver, or exemption that CARRA deems acceptable is provided to CARRA.
4. Terms of Use Acknowledgement: Investigators must acknowledge the terms of email use and the results sharing requirements via the Terms of Use Acknowledgment. This is located on the Research Portal and linked on the last page of the form when you submit your survey request. These terms include:
  - i. CARRA member emails will only be used for the approved research project and will not be shared with anyone, except those listed on the request application.
  - ii. Documentation of IRB approval or exemption must be provided before emails are shared.
  - iii. Resultant abstracts, papers, publications, posters, and presentations arising from this survey must be submitted to CARRA and are subject to the CARRA Publication and Presentation Guidelines.

5. Authorship and publication policies: The authorship plan shall appropriately recognize the contributions of others, and comply with CARRA's Authorship, Publication, and Presentation guidelines available at <https://research.carragroup.org/en/research/policies>. The Data, Sample, and Publications Committee (DSPC) must review all resulting publications, including abstracts and manuscripts, prior to submission to a conference or journal. Publications must credit CARRA and other relevant sponsors as outlined in the CARRA Publication Acknowledgements. Copies of published work must be sent to [research@carragroup.org](mailto:research@carragroup.org). Investigators are responsible for the costs of the publication.