

## CARRA Survey Policy

**Overview:** CARRA is committed to assisting pediatric rheumatologists in gathering important data through the use of surveys of members of the network. The following policy has been adopted to be sensitive to the work these surveys place on CARRA members, and to help assure that surveys sent to the members are both relevant to CARRA goals and that the data collected through questionnaires is of the highest quality. The CARRA steering committee will also consider sending surveys to CARRA members if the survey results are of critical importance to pediatric rheumatology, even when they may not be specifically one of the goals of CARRA. CARRA members are expected to participate in these surveys, as greater participation will strengthen the network, and the science it produces.

### **Process:**

1. All surveys submitted for completion by the full CARRA membership (or subsets of the members) will be reviewed by the relevant Disease Specific Committee. Surveys not fitting into any committee purview will be reviewed by the Steering Committee or the Executive Committee.
2. Questionnaires/surveys will be reviewed by the relevant committee for match of the goals and content of the questionnaire with CARRA network goals. If the questionnaire is relevant and will be circulated to CARRA members, then feedback concerning questionnaire format and content will be relayed to the author, if the committee has recommendations to strengthen the document. Once the submitter and the committee come to an agreement relating to the questionnaire, then it will be beta tested and then submitted to the CARRA membership. If the questionnaire is not relevant to CARRA-related issues and does not address an issue of critical importance to the field of pediatric rheumatology, then the committee will recommend not utilizing the CARRA network to complete the questionnaire.
3. Before circulation to CARRA members, the submitter must obtain IRB approval or exemption from their institution. Exemption or need for full application will depend on the specific survey and the individual institutional IRB.
4. Summary results of any survey sent to CARRA members will be reported to those CARRA members who responded to the survey.
5. Any publication that includes the results of a survey of CARRA members should acknowledge CARRA in at least one of the following locations: publication title, title page information or methods section.