

**Investigator:**  
**Project Title:**



## **CARRA Registry Data and Biospecimen Release and Use Conditions**

1. Progress reports will be submitted every six months to the CARRA Registry Data and Biospecimen Share Committee for review of progress (abstracts, papers, publications, presentations, project status). The CARRA Registry Data and Biospecimen Share Committee will review the progress reports for adherence to the timeline. If investigators do not keep to their stated timeline and a request is made for similar data by another investigator(s), the data use permission will be withdrawn from the original investigator and issued to the next investigator in line.
2. The investigator agrees to use the data and biospecimens only for the approved research project as proposed in the application. Any portions of biospecimens remaining after the approved research project is complete will be stored at his/her laboratory facility as part of the CARRA Tissue Repository. Once biospecimen analysis is complete, an inventory of remaining biospecimens will be sent to the CARRA Tissue Repository Core Lab at Cincinnati Children's Medical Center, attention Susan Thompson, PhD. These biospecimens are available to be used only in projects approved by the CARRA Registry Data and Biospecimen Share Committee. If the investigator is unable to store the leftover biospecimens at his/her facility, he/she will ship the biospecimens to the CARRA Tissue Repository Core Lab at Cincinnati Children's Medical Center. If the investigator desires additional data or biospecimens or wants to use the data and biospecimens for any use other than the study focus/question, a new application must be submitted. Publication of data for purposes not expressly authorized by the approved research project constitutes a breach of agreement and may result in denial of access to data and biological samples in the future for all authors listed on the publication.
3. Data and biospecimens will not be shared with other individuals except those on the application for use of the data and biospecimens.
4. Use of data and biospecimens must follow HIPAA (Health Insurance Portability and Accountability Act) rules and local research compliance rules and be approved by the investigator's local IRB. IRB documentation of review (approval or exemption) will be provided to the CARRA Registry Data and Biospecimen Share Committee prior to release of any data and/or biospecimens.
5. Investigators are responsible for the costs related to shipment of biospecimens to his/her laboratory facility for study analyses. Investigators are responsible for costs of shipment of remaining biospecimens back to the CARRA Tissue Repository Core Lab (if he/she is not storing at own facility).
6. Investigators are responsible for the costs of publications. CARRA has no funds to pay for costs related to investigator publications.
7. All publications will credit CARRA, NIAMS, the Arthritis Foundation, Friends of CARRA and the Duke Clinical Research Institute. The CARRA Registry Publications Committee may require the investigator to list additional organizations based on the funder of the data and biospecimens used for this project.

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8. Resultant abstracts, papers, publications, and presentations arising from these collaborations are subject to CARRA Registry Publication and Presentation Guidelines, including listing “for the CARRA Registry Investigators” as the final author and including a paragraph listing all the CARRA Registry Investigators in an acknowledgement.
9. Prior to submission for publication, the paper will be submitted to the CARRA Registry Publications Committee for review of authorship and to ensure that CARRA is credited. The paper will be maintained in confidence by CARRA prior to its publication.
10. Copies of all abstracts, papers, presentations, published manuscripts and any other publications arising from the project will be sent to the CARRA Registry Data and Biospecimen Share Committee for listing on the CARRA Registry’s [www.clinicaltrials.gov](http://www.clinicaltrials.gov) record and on the CARRA website.
11. Investigator will arrange for all published manuscripts to be made publicly available via PubMed Central® (PMC): <http://www.ncbi.nlm.nih.gov/pmc/>

***I have read and agree to all conditions listed above:***

Name (printed): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_