



Additional ADRC Guidelines for Requests of Finite/Depletable Biospecimens

- 1) Requester is strongly encouraged to discuss the request with and to collaborate with a member of the ADRC executive committee with similar research interests, prior to submission of the formal request. There are several reasons for this:
 - A) There will often be thematic overlap between work already being done by Duke-UNC ADRC investigators and that which investigators outside of the ADRC may be interested in pursuing. Thus, to avoid unnecessary or duplicative work, and to promote synergistic/ collaborative scientific approaches, we strongly suggest that requesters discuss their project with a member of the ADRC with similar interests prior to submitting a formal resource request. Per ICJME criteria, it will thus often be appropriate to include the relevant collaborating member of the ADRC executive committee on grants and papers that stem from this work. If you are unsure who within the ADRC might have similar research interests, please feel free to contact Center Co-Directors, Drs. Garden (gagarden@email.unc.edu) or Whitson (heather.whitson@duke.edu).
 - B) Having a collaborator within the Duke-UNC ADRC helps ensure that the Duke-UNC ADRC remains updated on the progress of the project, and can help link up this project with other relevant resources/projects/investigators within the Duke/UNC ADRC.
 - C) It is especially helpful to have a collaborator within the Duke/UNC ADRC whenever requesting a large amount of non-renewable/depletable biospecimens, since it is particularly important for the ADRC to be actively involved in projects that use a significant amount of non-renewable ADRC resources.
- 2) Up to 50% of finite/depletable aliquots obtained from any ADRC participant at any time point may be used for pilot studies (i.e. for studies that will not measure biomarkers in all ADRC samples). Once 50% of these aliquots have been used up, additional aliquots will be provided for projects only when the project has sufficient funding to measure the indicated biomarker(s) on all ADRC participant samples. This serves to balance the needs of investigators who may need a small number of aliquots to obtain preliminary data for grant applications, while also ensuring that the ADRC will be able to maximize the sample size of biomarker data (across all ADRC participants) in order to achieve the greatest statistical power for finding associations with phenotypes, genotypes, etc.
- 3) When a request is granted, the requester is asked to provide progress updates (using the attached template) every 6 months on results/data obtained from the biospecimen request, and on any meeting abstracts/posters/presentations, papers and grants that have resulted from this request. Timely submission of these progress updates may be considered as a factor when considering future resource requests from a given investigator.
- 4) Biospecimens will be provided to investigators only in blinded fashion, to ensure scientific integrity of any data obtained on these samples. Complete assay data (on de-identified/blinded ADRC samples) must be returned to the ADRC, before the ADRC will release sample identification information (i.e. on which samples come from patients with which genotypes, phenotypes, or other characteristics).
- 5) At the time that data is returned back to the ADRC, it must also be made publically available to the scientific community on an appropriate public repository/website