The National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD): Services for Outgoing Samples

Indiana University School of Medicine

U24AG21886

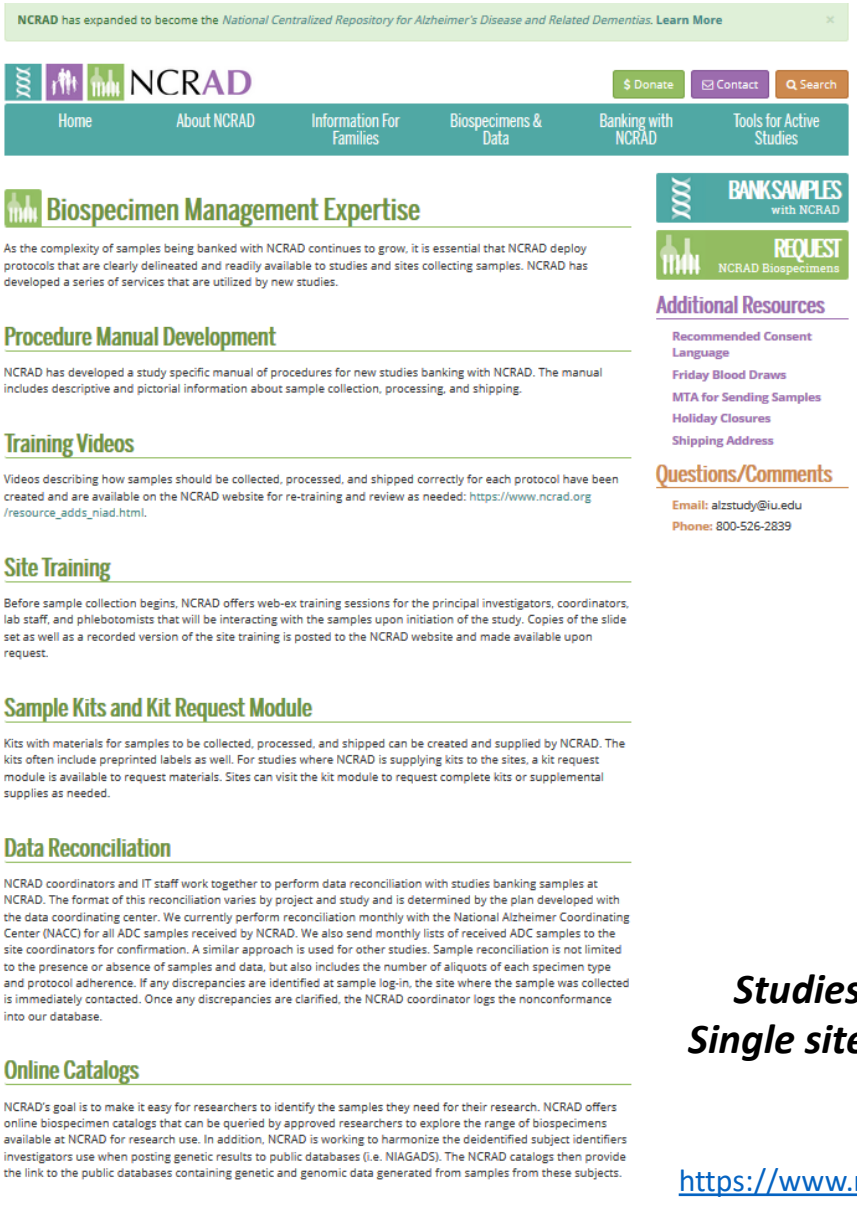
www.NCRAD.org

NCRAD

NCRAD Overview

- Established in 1990
  - NIA funded central repository for dementia-related research
- Bank samples from 40 different studies
  - > **74,000** sampled subjects
  - **~600,000** sample aliquots banked
- Broad range of biospecimens

Collect high quality specimens



NCRAD has expanded to become the *National Centralized Repository for Alzheimer's Disease and Related Dementias*. **Learn More**

NCRAD

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Home | About NCRAD | Information For Families | Biospecimens & Data | Banking with NCRAD | Tools for Active Studies

Biospecimen Management Expertise

As the complexity of samples being banked with NCRAD continues to grow, it is essential that NCRAD deploy protocols that are clearly delineated and readily available to studies and sites collecting samples. NCRAD has developed a series of services that are utilized by new studies.

Procedure Manual Development

NCRAD has developed a study specific manual of procedures for new studies banking with NCRAD. The manual includes descriptive and pictorial information about sample collection, processing, and shipping.

Training Videos

Videos describing how samples should be collected, processed, and shipped correctly for each protocol have been created and are available on the NCRAD website for re-training and review as needed: https://www.ncrad.org/resource_adds_niad.html.

Site Training

Before sample collection begins, NCRAD offers web-ex training sessions for the principal investigators, coordinators, lab staff, and phlebotomists that will be interacting with the samples upon initiation of the study. Copies of the slide set as well as a recorded version of the site training is posted to the NCRAD website and made available upon request.

Sample Kits and Kit Request Module

Kits with materials for samples to be collected, processed, and shipped can be created and supplied by NCRAD. The kits often include preprinted labels as well. For studies where NCRAD is supplying kits to the sites, a kit request module is available to request materials. Sites can visit the kit module to request complete kits or supplemental supplies as needed.

Data Reconciliation

NCRAD coordinators and IT staff work together to perform data reconciliation with studies banking samples at NCRAD. The format of this reconciliation varies by project and study and is determined by the plan developed with the data coordinating center. We currently perform reconciliation monthly with the National Alzheimer Coordinating Center (NACC) for all ADC samples received by NCRAD. We also send monthly lists of received ADC samples to the site coordinators for confirmation. A similar approach is used for other studies. Sample reconciliation is not limited to the presence or absence of samples and data, but also includes the number of aliquots of each specimen type and protocol adherence. If any discrepancies are identified at sample log-in, the site where the sample was collected is immediately contacted. Once any discrepancies are clarified, the NCRAD coordinator logs the nonconformance into our database.

Online Catalogs

NCRAD's goal is to make it easy for researchers to identify the samples they need for their research. NCRAD offers online biospecimen catalogs that can be queried by approved researchers to explore the range of biospecimens available at NCRAD for research use. In addition, NCRAD is working to harmonize the deidentified subject identifiers investigators use when posting genetic results to public databases (i.e. NIAGADS). The NCRAD catalogs then provide the link to the public databases containing genetic and genomic data generated from samples from these subjects.

BANK SAMPLES with NCRAD

REQUEST NCRAD Biospecimens

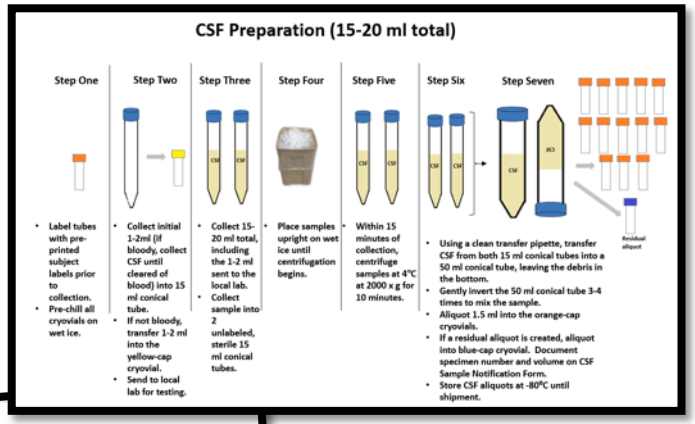
Additional Resources

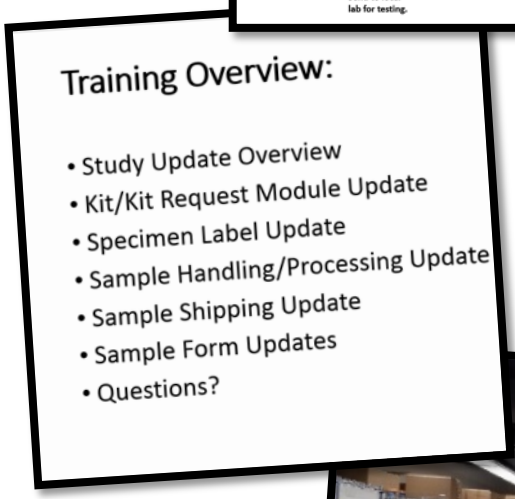
- Recommended Consent Language
- Friday Blood Draws
- MTA for Sending Samples
- Holiday Closures
- Shipping Address

Questions/Comments

Email: alzstudy@iu.edu

Phone: 800-526-2839



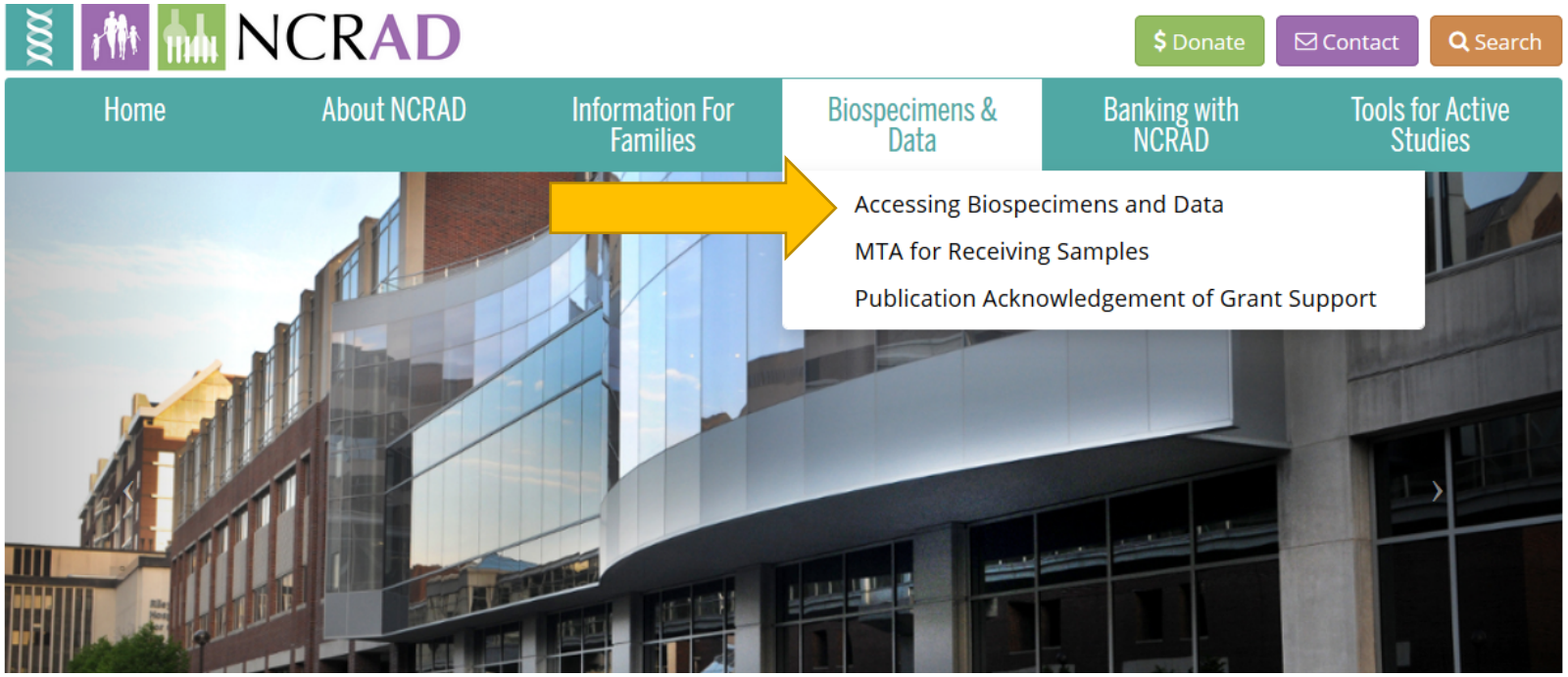


Studies of varying size:
Single site or Multisite (60+)

https://www.ncrad.org/expertise.html

Visit NCRAD website to review available cohorts

www.ncrad.org



Cohorts publicly available for request can be found on the "Accessing Biospecimens and Data" page

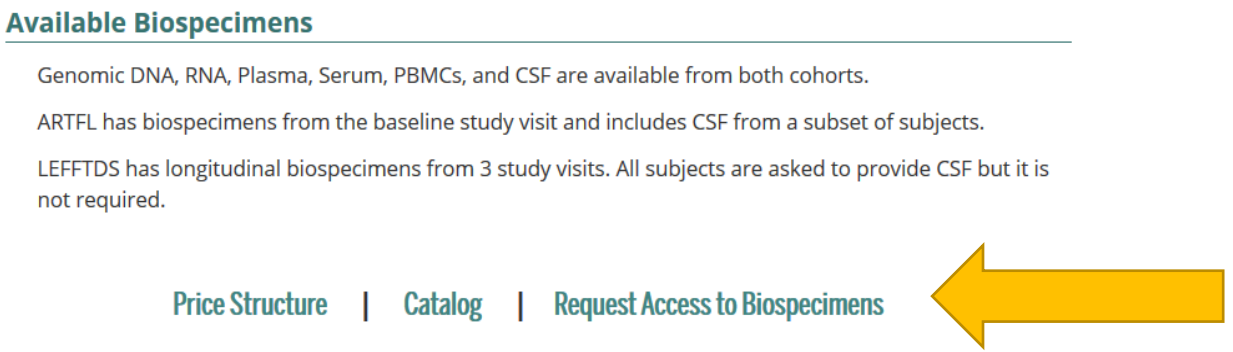
Tour the Catalog

https://www.ncrad.org/accessing_data.html

Data at NCRAD

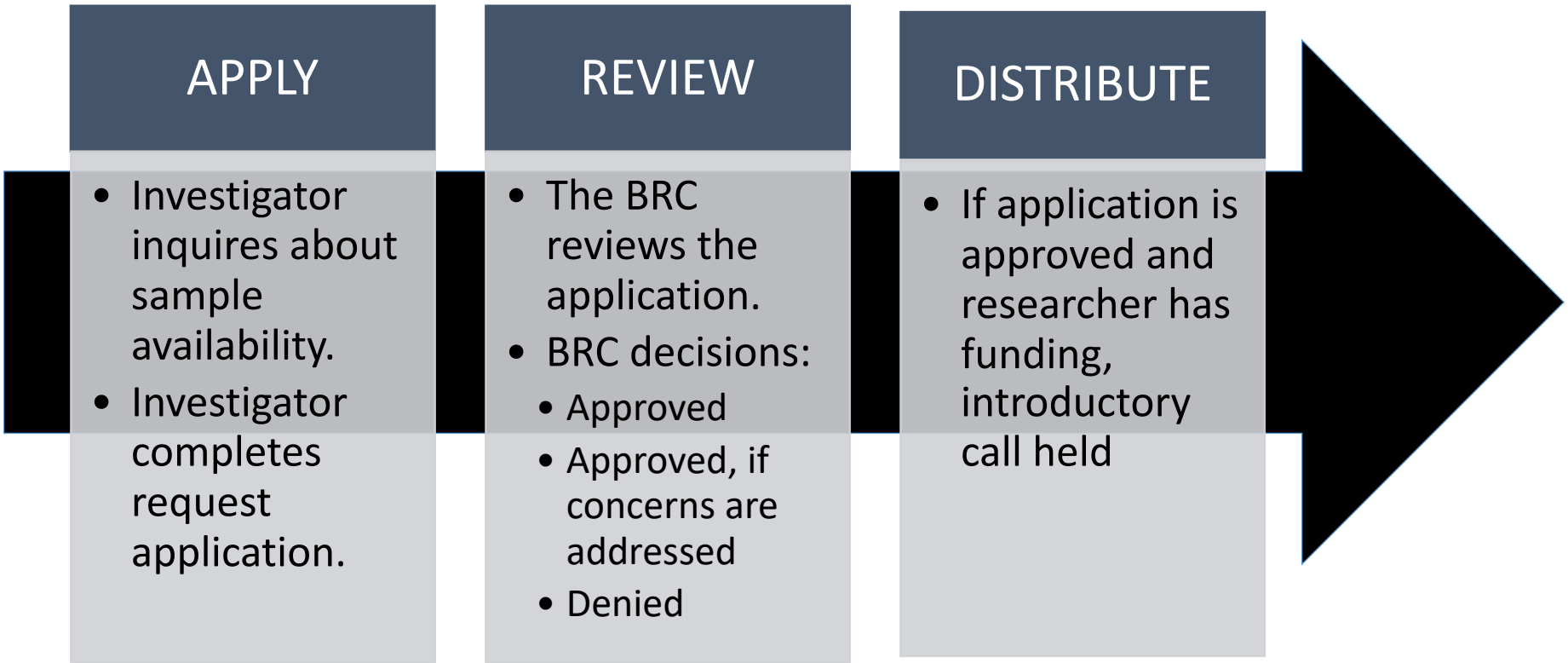
- For many samples banked at NCRAD, a more detailed dataset is located elsewhere
  - NACC: UDS for ADC samples
  - LONI: ADNI (clinical, imaging, biomarker)
  - NIAGADS: genetic data
- For some studies, NCRAD hosts a minimal dataset within our catalogs
  - NCRAD developed methods to easily link external data to NCRAD specimen catalogs
- Imaging data (MRI, PET, etc) are not stored at NCRAD
  - Files are typically located at NACC, LONI or another resource

NCRAD Request Process



Study specific request forms and price structure can be found in the detailed boxes

Biospecimen Review Committee: Review Sample Requests



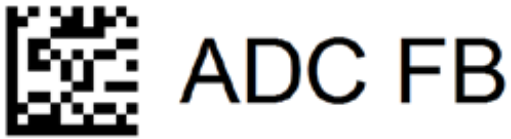
NCRAD MTA Out

- Material Transfer Agreement (MTA)
  - Must be completed prior to receiving samples from NCRAD
  - Describes terms and conditions for receiving samples from NCRAD
    - Same terms for all investigators and institutions
    - Also includes requirement for investigators to return results to data warehouse (i.e. NIAGADS, dbGaP, LONI)
  - Includes language for investigators to acknowledge parent studies that collected samples in publications
  - Master Agreement has Institutional signature, Appendices need investigator signature only
- https://www.ncrad.org/mta_out.html

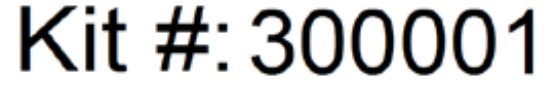
Blinded Sample Distributions

Distribution Label

Specimen number unique to each aliquot



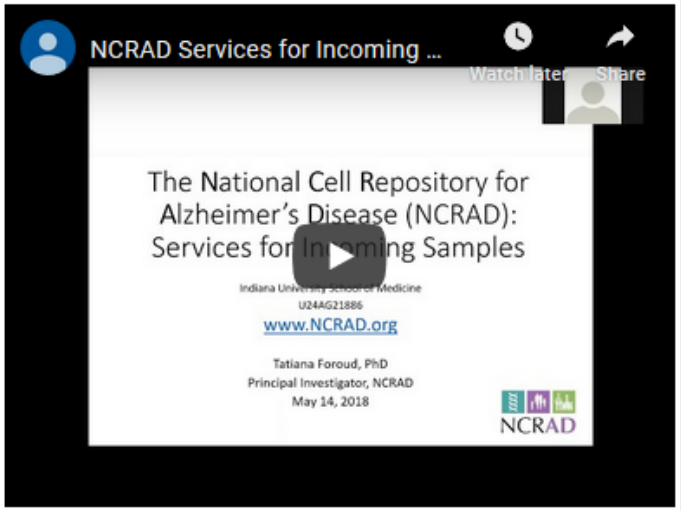
Kit number unique to each visit



Samples are distributed under a unique Biorepository Kit and Specimen number only.

Assay data is returned by researchers with Biorepository Kit and Specimen and unblinded to link with clinical dataset for analysis

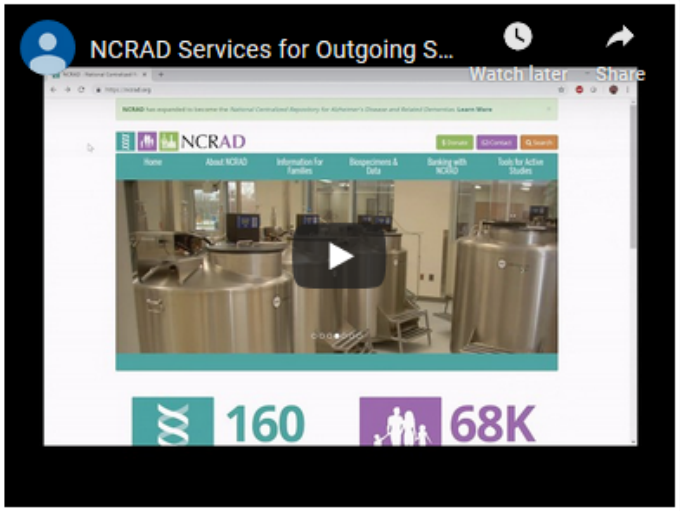
NCRAD Past Webinars



Services for Incoming Samples

Watch this video to learn more about the services offered to studies banking samples with NCRAD.

Go To Video | Learn More



Services for Outgoing Samples

Watch this video to learn more about the process of obtaining samples banked at NCRAD.

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For more information, contact NCRAD at:

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