

BIOREPOSITORY RESOURCE CENTER

CHOP Biobanking Principles

Specimen Collection and Storage

- **All human samples collected for Biobanking as part of BioRC-supported projects must be accessioned/barcoded into the Biobank system following procedures established or reviewed by the BioRC Operational Committee (BOC).**
 - Specimens and associated data must be consented so both can be used for Future Research.
 - The investigator/study team will provide when possible, relevant specimen information such as:
 - Pathologic process and details (e.g., percent tumor, necrosis, flow data)
 - Relevant clinical data (age, gender, treatment, etc.)
 - Collection date and method, processing date and methods, deviations.
 - The BioRC will provide resources to help design the project in order to assure best practices are followed.
- **All human specimens collected for Biobanking as part of BioRC-supported projects will be stored in the BioRC repository facility.**
 - Exceptions: Investigators may request exceptions and store samples elsewhere, but this must be approved by the BOC.
 - Storage external to BioRC will follow procedures developed by the collecting investigator/team, but this will be reviewed by the BOC to ensure that all specimens are collected, processed and stored using best practices.
- **The BioRC reserves the right to refuse sample collections if for example it is discovered proper sample collection and processing guidelines were not followed during study procedures, sample quality is questionable or if the samples experienced temperature fluctuations during past storage.**
- **The BioRC reserves the right to return samples to the collecting investigator if the samples are determined to no longer be a resource for the CHOP Community or due to the investigator refusal to share the sample collection with requests of approved scientific merit.**

Specimen and Associated Data

- **Specimen, clinical, and derived data about the banked specimens will be generated and made available to CHOP investigators through a centralized portal (Arcus).**
 - The investigator/investigative team agrees to utilize the de-identification process that is made available through the Biorepository Portal - eHonest Broker system.
 - Accessioning information is automatically made available to all investigators and protected specimens will be electronically flagged.

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- Processed data (e.g. “omics” data) and other raw data (e.g., specific expression studies, response to specific drugs, etc.) will be contributed to a centralized portal (Arcus) after assessment by the Arcus Library Science Team in collaboration with the BOC. More information about Arcus data contributions is available at www.arcus.chop.edu.
- Specimen, clinical, and processed data will be made available to CHOP investigators through a centralized portal (Arcus) per data sharing terms agreed upon between the investigator/investigative team, BOC and Arcus.
- These terms include options for embargoes pending publication. More information about data sharing and Arcus is available at www.arcus.chop.edu.

Specimen Sharing and Distribution

- **The investigator agrees to entertain collaborative requests to share specimens with the CHOP research community.**
- **Specimen sharing is encouraged, however; decisions on approving requests for specimen sharing/distribution are made by the investigator/investigative team.**
 - Specimen requests will be generated through the Arcus portal.
 - The receiving investigator assumes the responsibility of confirming that the appropriate level of consent has been obtained for sharing.
 - To alleviate the burden on the investigator/investigative team, specimen requests will be facilitated/managed by the BioRC. **Specimens will not be released until final approval is obtained from the investigator/investigative team.**
 - The BOC may delegate sharing/distribution responsibilities to investigative teams that have developed infrastructure, policies, and practices that adhere to the principles established herein.
 - If samples will be available for sharing immediately after accessioning into Nautilus, the collecting study team will communicate this to BioRC.
- **The Investigator will decide prior to collection if specimens are to be made available immediately for request or should be protected for a period of time (e.g., until a primary analysis is complete).**
- **Any specimen may be distributed upon request by the original collecting investigator/investigative team.**

Institutional Specimens

- **Specimen sets classified as institutional (e.g., legacy collections that have been released for distribution or specimens collected through institutionally supported initiatives) will be made available to all CHOP researches through the BOC.**
 - The BOC will encourage distribution of specimens rather than provide obstacles to obtaining specimens.
 - Institutional specimens will be requested through the use of a short request procedure outlining scientific merit.

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- The BOC will approach proposals with the intent to distribute rather than restrict access.
- Rejection of specimen requests will require detailed reasoning, suggestions for improvement of the application, and can be appealed.