

Privacy Policy

Cooperative Human Tissue Network (CHTN)

1. Purpose and Commitment

The Cooperative Human Tissue Network (CHTN), a National Cancer Institute (NCI)-supported biospecimen resource, is dedicated to protecting the privacy and confidentiality of all individuals whose tissue specimens and associated data are entrusted to us. This Privacy Policy governs the collection, use, and disclosure of information within the CHTN and explains how we use and protect information.

2. Scope

This policy applies to:

- All biospecimens (malignant, benign, diseased, normal tissues, and biofluids such as urine, serum, plasma, and buffy coat) collected and distributed by the CHTN.
- All associated clinical, research, and operational data maintained by the CHTN.
- All investigators, institutions, and staff participating in CHTN activities.

3. Information Collected

The CHTN collects and maintains:

- **Biospecimen data:** Tissue samples from surgeries, autopsies, and routine procedures, processed prospectively to meet investigator requirements.
- **Clinical metadata:** Limited, de-identified information necessary for research use.
- **Administrative data:** Investigator contact details, project requests, and distribution records.
- **Operational data:** Records of specimen acquisition, processing, and delivery. Information received in Investigator applications and correspondence. Queries about sample feasibility and CHTN services.

4. Use of Information

Information is used exclusively for:

- Facilitating biomedical research in compliance with ethical and legal standards.
- Supporting investigator projects without asserting intellectual property claims over research outcomes.
- Ensuring proper tracking and accountability of biospecimen distribution.
- Maintaining communication with investigators and institutions.

5. Data Protection and Security

The CHTN employs safeguards, including:

- Secure electronic systems with restricted access.
- Encryption of sensitive data where applicable.
- Compliance audits and IRB oversight.
- Mandatory training for staff on biospecimen handling and confidentiality.
- The use of reasonable organizational, technical, and administrative measures to protect information within our organization. If you have reason to believe that your interaction with us is no longer secure, please immediately notify us in accordance with the “*Contact Information*” section below.

6. Data Sharing and Restrictions

- Biospecimens and associated data are shared only with approved investigators under executed agreements.
- Recipients must not attempt to re-identify donors, sell tissues, or transfer specimens to third parties without prior written permission.
- All tissues must be handled as potentially infectious, in accordance with biosafety standards.
- The CHTN does not require the return of research data generated from biospecimens.

7. Regulatory Compliance

The CHTN complies with:

- Department of Health and Human Services regulations (45 CFR Part 46) for the protection of human subjects.
- Applicable state and local privacy laws.
- Institutional Review Board (IRB) requirements across all participating divisions.
- HIPAA regulations, where applicable.

8. Rights of Individuals

Individuals whose specimens are collected retain rights under applicable law to:

- Assurance that specimens are de-identified before distribution.
- Protection from unauthorized use or disclosure.
- Oversight by IRBs to safeguard human subjects.

9. Policy Updates

- This Privacy Policy may be updated periodically to reflect changes in regulations, technology, or operational practices. Updates will be communicated through official CHTN channels.

10. Contact Information

- For questions or concerns regarding this Privacy Policy, please contact:

Cooperative Human Tissue Network (CHTN)

Your primary division contact or Kiley Radin, CHTN Central Coordinator
(kradin@chtn.org or 317-620-1026).