



*This policy applies to research collaboration with other scientists and institutions, and to sharing Registries' data and materials with others.*

### **Collaboration with other institutions is encouraged**

To maximize the scientific worth and output of the unique materials and data under its purview, the Registries encourages and actively seeks collaboration with other investigators and institutions. Collaboration is sought to compliment rather than duplicate the capabilities of the Registries, and to facilitate the efforts of the Registries in achieving its primary goal. Collaboration may take the form of joint evaluations of data, tissues, or other Registries materials, preparation of articles for peer-reviewed literature, or preparation of joint research proposals to a potential sponsor.

### **Confidentiality**

USTUR data shall be held in the highest confidence and every possible precaution will be taken to protect Registrants. These data include, but are not limited to: worksite medical, radiation dosimetry, and industrial hygiene histories; correspondence; and autopsy findings.

### **Definition of collaborative researchers**

Data, tissues, and other unique materials collected or generated by the Registries may be made available to other scientists under the following conditions:

1. Potential research collaborators must submit to the Registries a written proposal that describes the specific materials requested, and includes a clear scientific hypothesis for the proposed usage of the requested materials.

2. Research collaborators must provide written assurance that the Registries' policies with respect to human subjects and privacy of the Registrants and their next-of-kin will be followed as agreed in Form 106.
3. Research collaborators who will receive biological samples from deceased Registrant(s) must provide assurance that they are authorized to handle human samples.

Materials from the National Human Radiobiological Tissue Repository are available only to those researchers who qualify as collaborative researchers, as described above.

### **Dissemination of Registries' data and tissue materials**

The USTUR director must approve each individual who will have access to USTUR data and/or tissue materials by signing the administrative portion of F106 (USTUR Statement of Confidentiality).

Registries' data are classified into three levels, based on the potential for identification of the donors and dissemination of the data to other researchers. Access to the data will be restricted as follows:

Level 1: Data include direct personal identifiers and specific dates of events with specific sites of employment. These data are available, by written request, to medical and radiation protection groups from the worksites of the Registrants. Access to these

data is restricted by site. For example, medical and radiation protection personnel at a work site may access data of Registrants only from that site. Signed confidentiality statements (Form 106) must be received from the responsible person(s) at the sites requesting data.

Level 2: Data include no direct personal identifiers; however, specific dates of events and general descriptions of the sites of employment are included. These data are available to collaborative researchers as defined above.

Level 3: Data include no direct personal identifiers, only general times of employment and radiologic events, and general information regarding worksites.

Registrant data shall be sent to collaborators as PDFs, Excel spreadsheets, or other files that have been redacted of direct personal identifiers (name, SSN, address, phone number, fax number, email address, worker identification numbers, medical record numbers), encrypted using 256AES technology (password protected), and copied to a removable storage device (e.g. CD/DVD, USB drive, etc.). The removable storage device shall be shipped overnight, signature required, for receipt to the researcher, and the password will be sent to the researcher by a different means (e.g. email). Correspondence regarding Registrants shall be limited to their unique four-digit case number. As an alternative, unencrypted files that contain Registrant data may be shared with collaborators using Washington State University's Microsoft Office 365 OneDrive cloud service.

Tissues shall be shipped, for overnight delivery, in compliance with all applicable shipping regulations.

### **Data Storage**

Paper and electronic files containing Registrant information must be kept in a secure location. Computers or servers that have Registrant

information must have a firewall and be password protected. Registrant data may not be stored on web-based storage or backup systems, e.g. the cloud. The only exception is that a USTUR staff member may create a folder on Washington State University's Microsoft Office 365 OneDrive and share it with collaborators, provided that separate folders are created for each collaborative team to prevent comingling of data. Collaborators may upload files to this folder; however, they shall not share the folder with anyone else.

### **Additional Researchers or Collaborators**

USTUR data and tissue materials are shared with approved collaborators for specific research purposes. Tissue materials may not be analyzed for purposes beyond the scope of research agreed upon prior to receipt of specimens. Data recipients may not share the materials with other researchers or perform research outside the agreed upon scope without prior approval from the Registries.

Each individual who will have access to Registries data must:

1. read USTUR procedures P106 (USTUR Scientific Collaboration and Data Access Policy) and P107 (USTUR Publications Policy); and
2. sign USTUR form F106 (USTUR Statement of Confidentiality).

### **Return or Disposal of Registries' data and tissue materials**

All original printed and/or electronic files sent by the USTUR, as well as any secondary files created by the recipient that contain potentially identifiable information, must be destroyed or returned to the USTUR within 1 year of publication, or within 5 years of receipt, whichever comes first. Extensions may be requested in 1-year increments if additional time is needed.

Tissue materials that are not destroyed during analysis must be returned to the USTUR within 1 year of analysis or 3 years of receipt, whichever comes first. Extensions can be requested in 1-year increments if additional time is needed.

**Publication of data and results from collaborative research**

No publicly available or open-literature publication, or presentation, shall be made in which Registrants are identified without the prior consent of the Registrant, or the legally responsible party, unless legally required by law, regulation, or court order.

Scientific manuscripts and technical reports based on collaborative research involving previously unpublished Registries' data, tissue samples, or other materials, or which involve collaborative effort by Registries staff, shall include, as appropriate, one or more Registries staff members as co-authors. If the Registries' involvement has been limited to a loan or provision of tissues or other materials, and the resulting manuscript or technical report has been prepared exclusively by other investigators without consultation with the Registries staff, or inclusion of unpublished Registries' data or evaluation, no Registries staff need be included as co-authors. Instead, a written acknowledgement of the Registries as the source of the tissue or other materials shall be included.