

INFRASTRUCTURE, SAFETY, AND ENVIRONMENT

Human Biospecimen Database

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ICORD 2007

This presentation is based on RAND Corporation research and author, s opinions. Portions of this presentation describe work-in-progress that has not undergone RAND quality assurance procedures.

A Joint Project of

RAND ISE and

NIH Office of Rare Diseases





GOAL

To facilitate research leading to treatments and cures for rare diseases, as well as more common diseases, by improving researchers' access to needed human biospecimens

OBJECTIVES

- Create a publicly available, searchable, Web-based database of biorepositories
- Facilitate researchers' access to human biospecimens by providing a system that provides access to information about repositories and their collections.
- Identify unmet needs of researchers in obtaining human biospecimens for research on rare diseases.
- Provide information to researchers, the wider research community and other interested parties about biorepositories and biospecimens

Human Biospecimen Collections

- > 307 million specimens stored in the United States*
 - Accumulating at a rate of > 20 million per year
- > 30 million specimens have been collected specifically for research purposes:
 - Stored at >300 biorepositories in the United States
- > 250 million specimens originally collected for diagnostic or therapeutic reasons
 - Stored in pathology labs

^{*} From: Eiseman, E and Haga S. *Handbook of Human Tissue Sources: A National Resource of Human Tissue Samples*. RAND MR-954-S&TPI (September 1999)

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Information in the Database

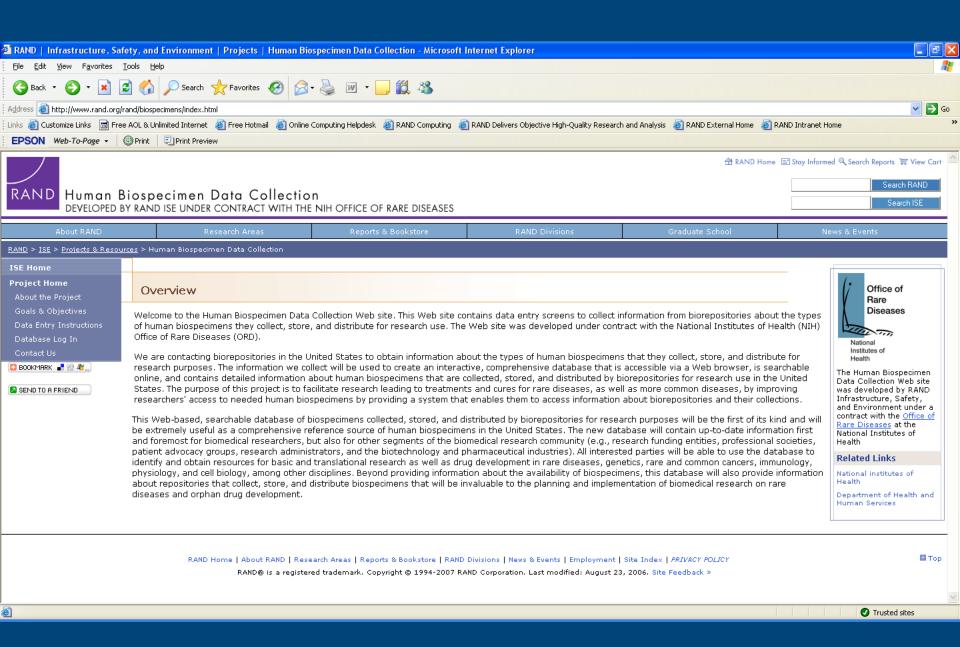
- General information about each biorepository
- Number and type(s) of biospecimens stored at each repository
- Processing methods (e.g., paraffin blocks, slides, snap frozen)
- Storage conditions (e.g., room temperature, frozen in liquid nitrogen) and length of storage
- Type of informed consent
- Limitations associated with the use of biospecimens
- Costs of obtaining biospecimens

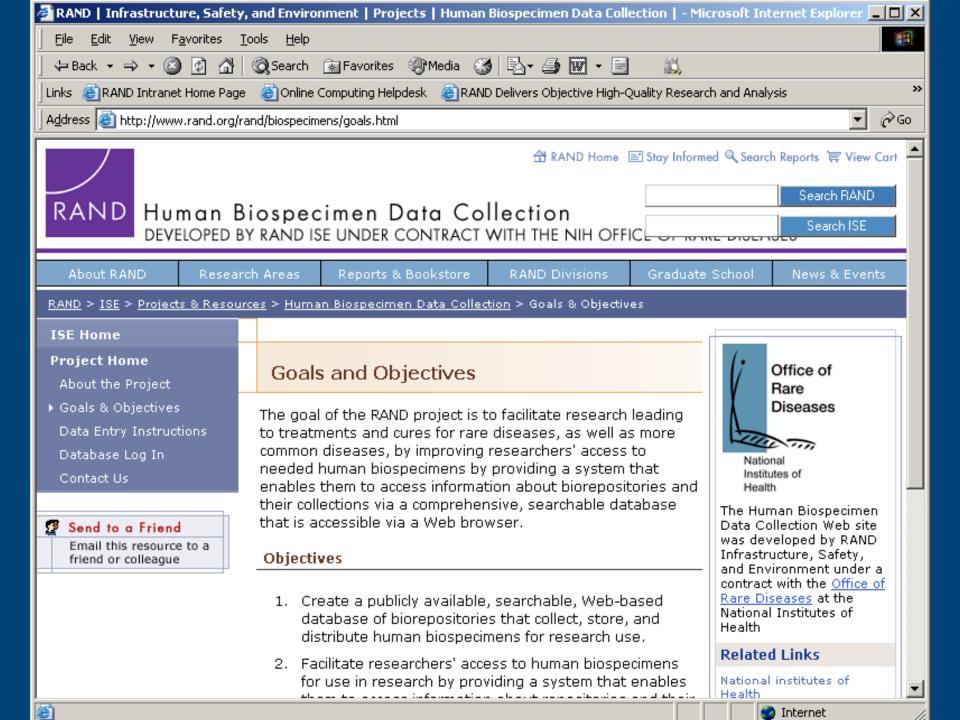
Human Biospecimen Database - Timeline -

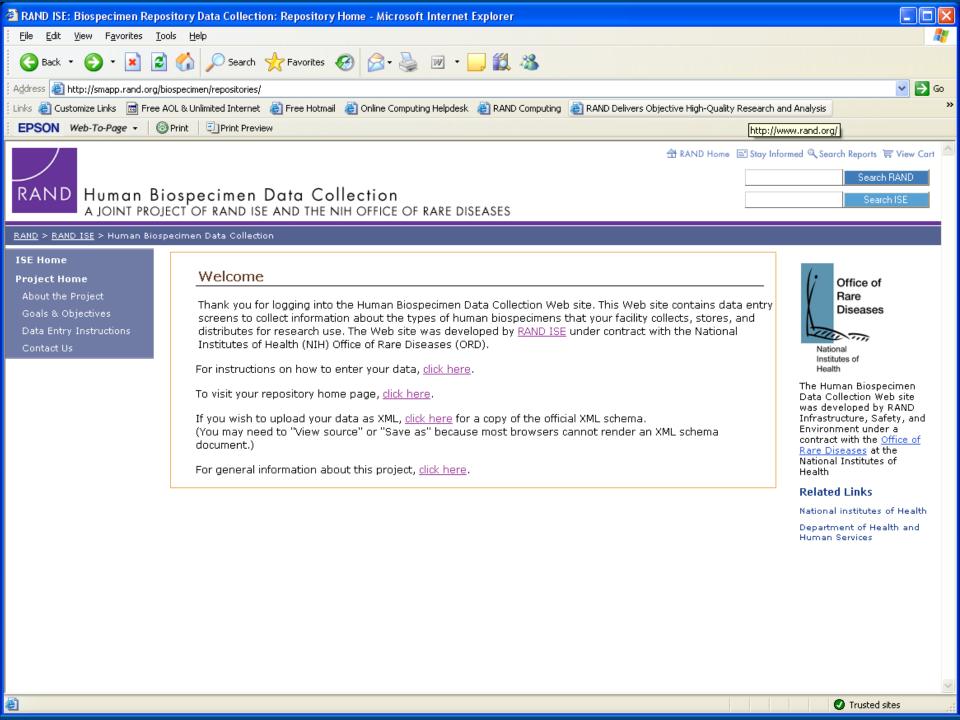
- Year 1 (completed):
 - Construct and pilot test database, data collection website, and XML schema
 - Construct search interface and website
- Years 2 & 3 (Fall 2007 Fall 2009):
 - Expand information in the Human Biospecimen Database
 - Invite biorepositories outside of U.S. to participate
 - Track unmet needs of the research community in obtaining human biospecimens for research purposes
 - Update and maintain database

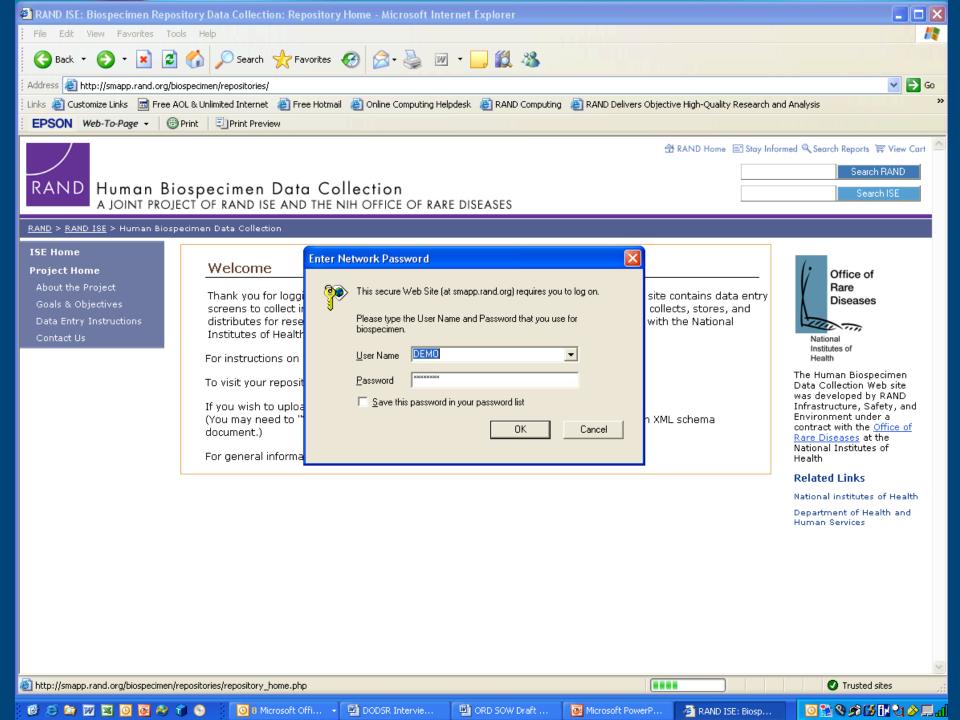
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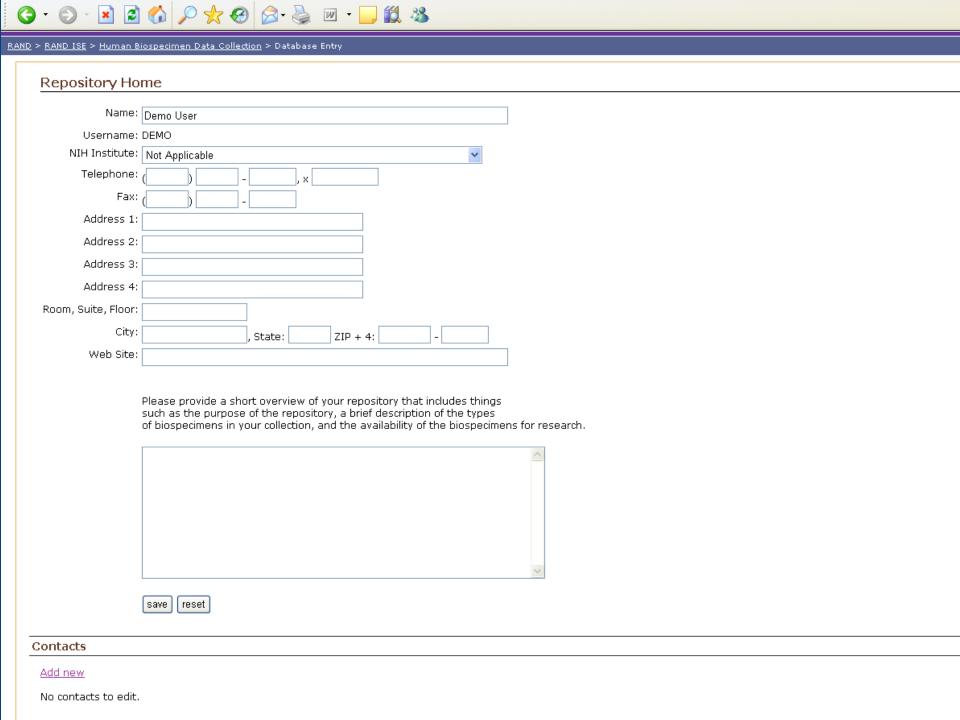
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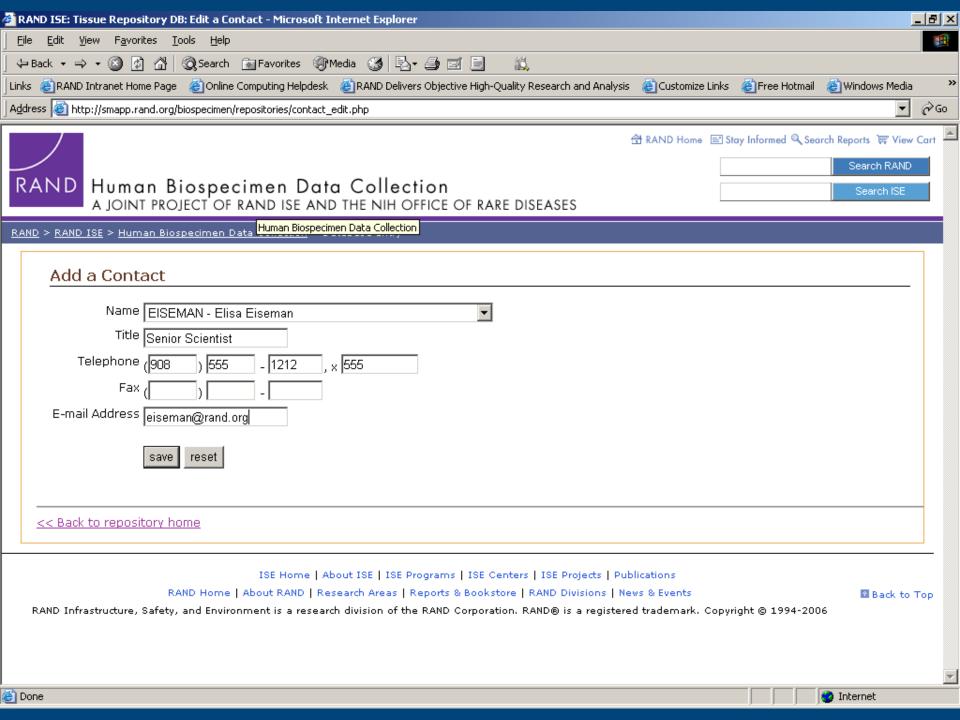


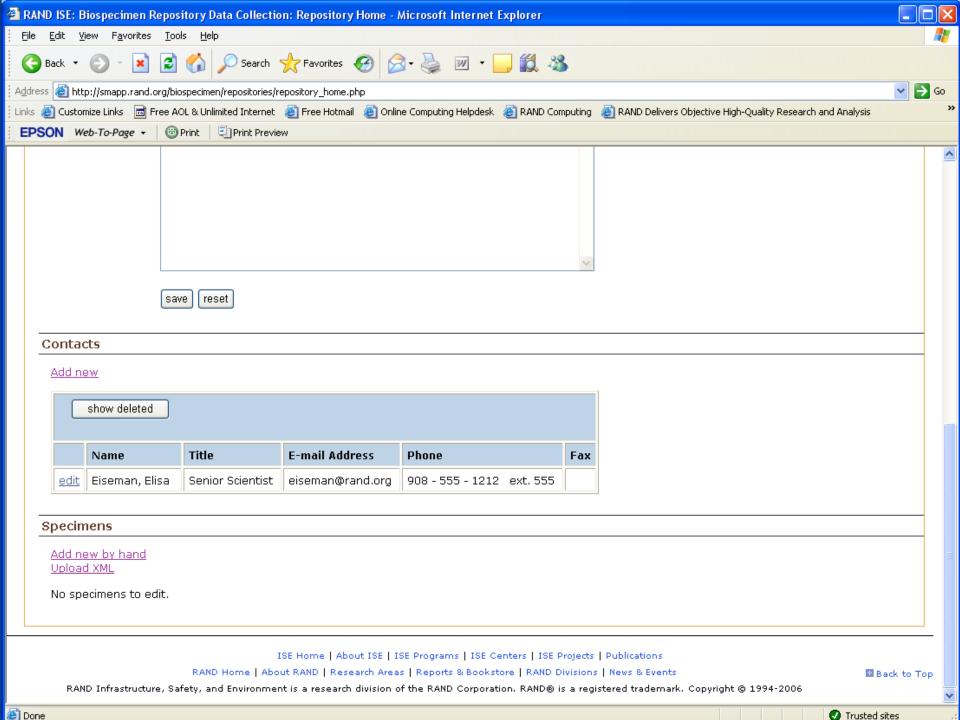


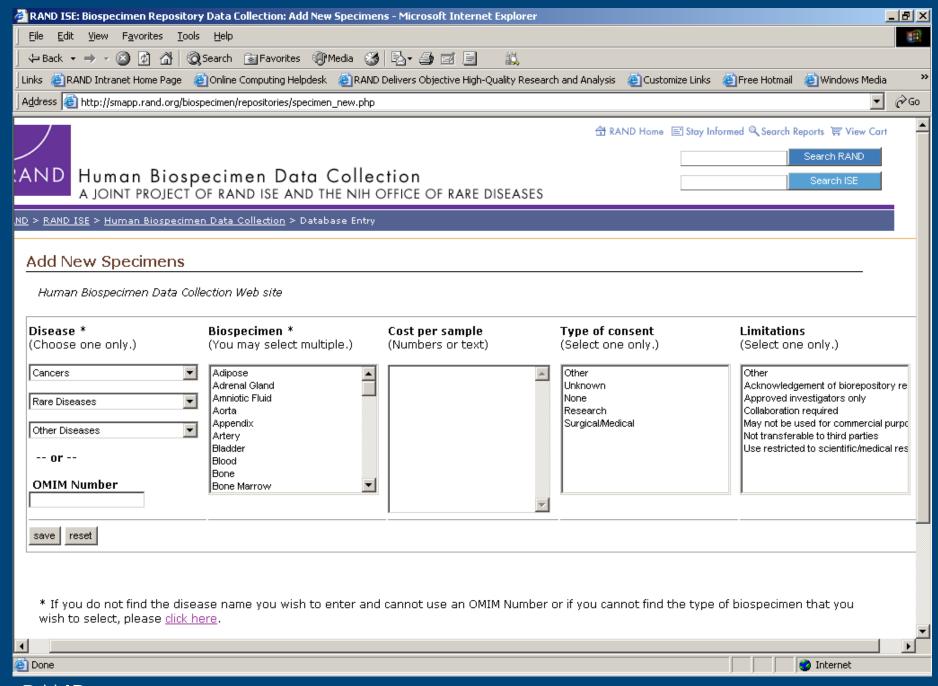


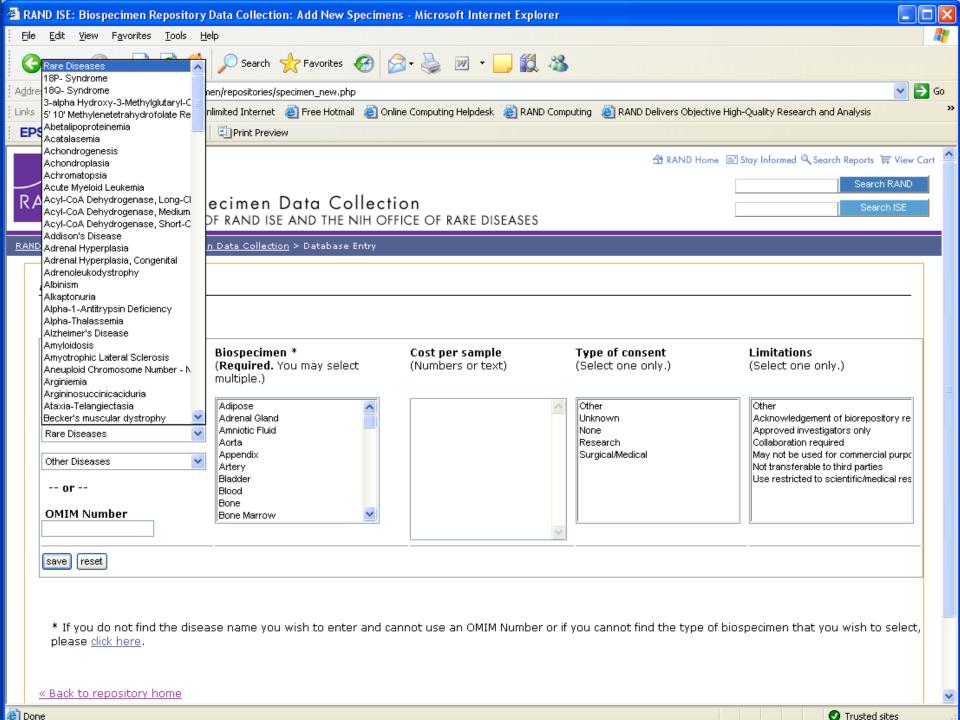


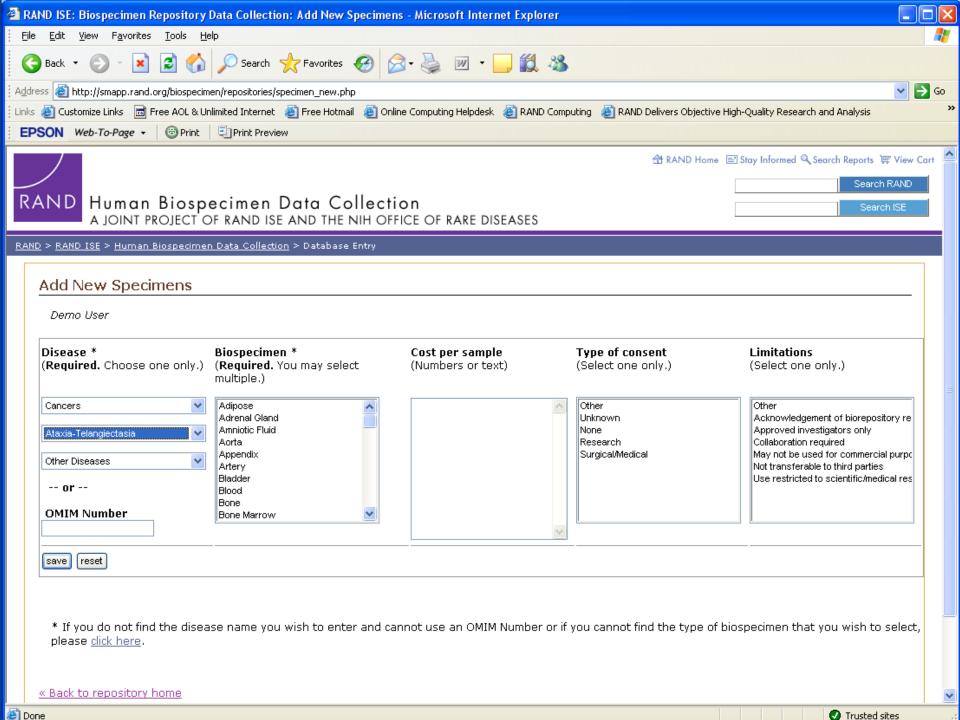


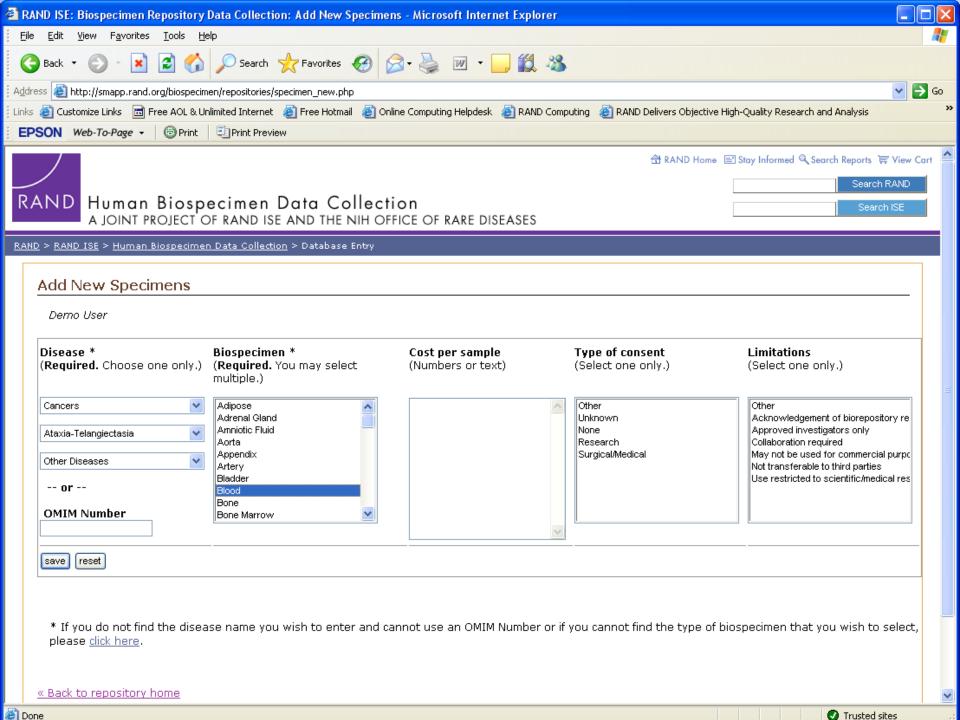


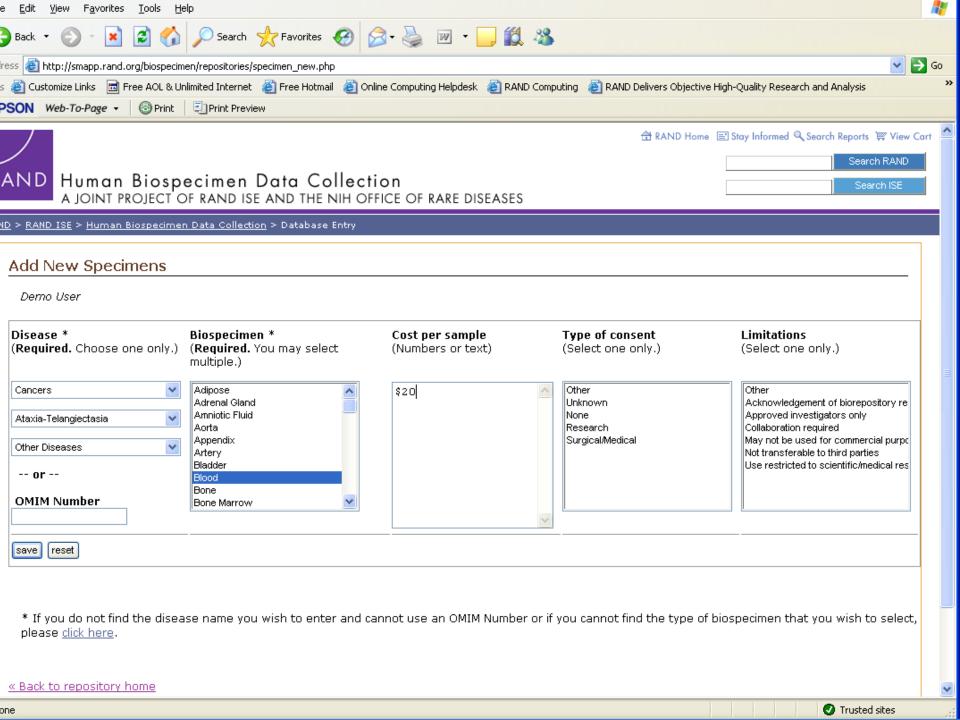


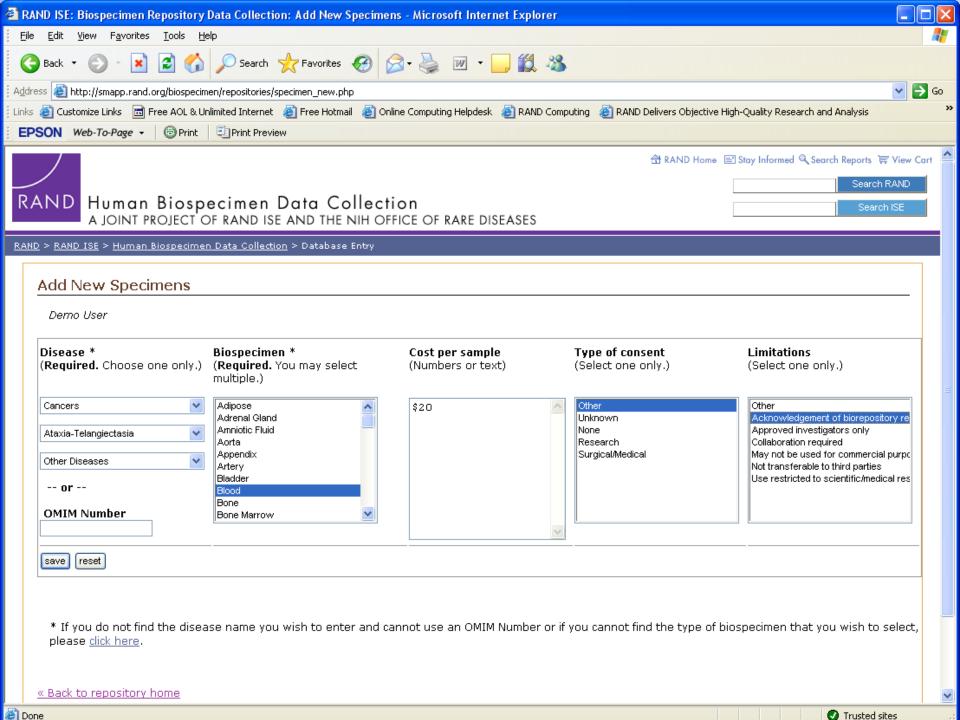


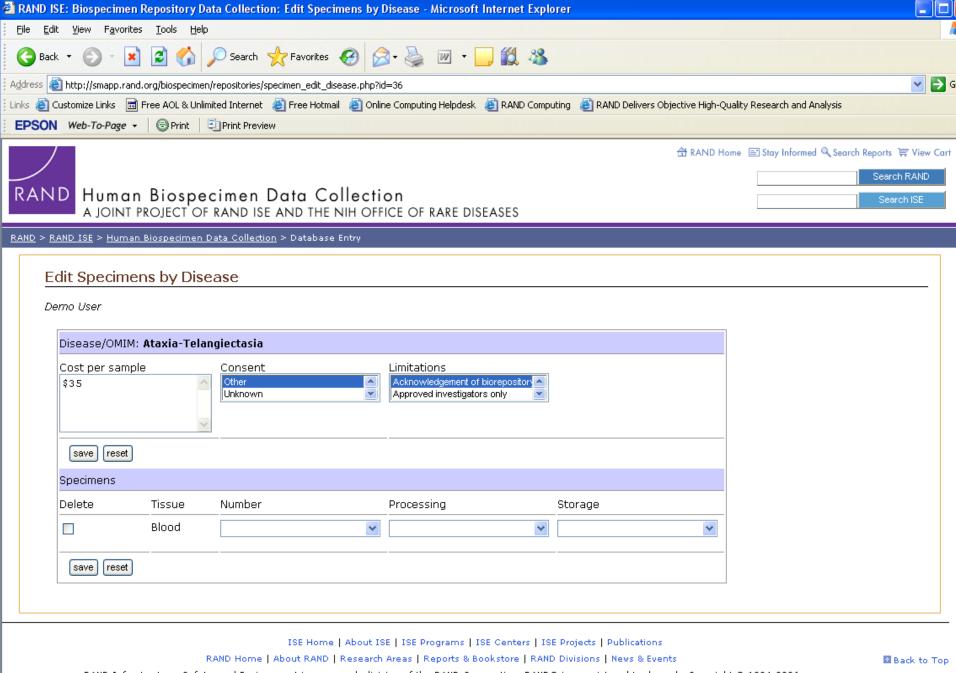






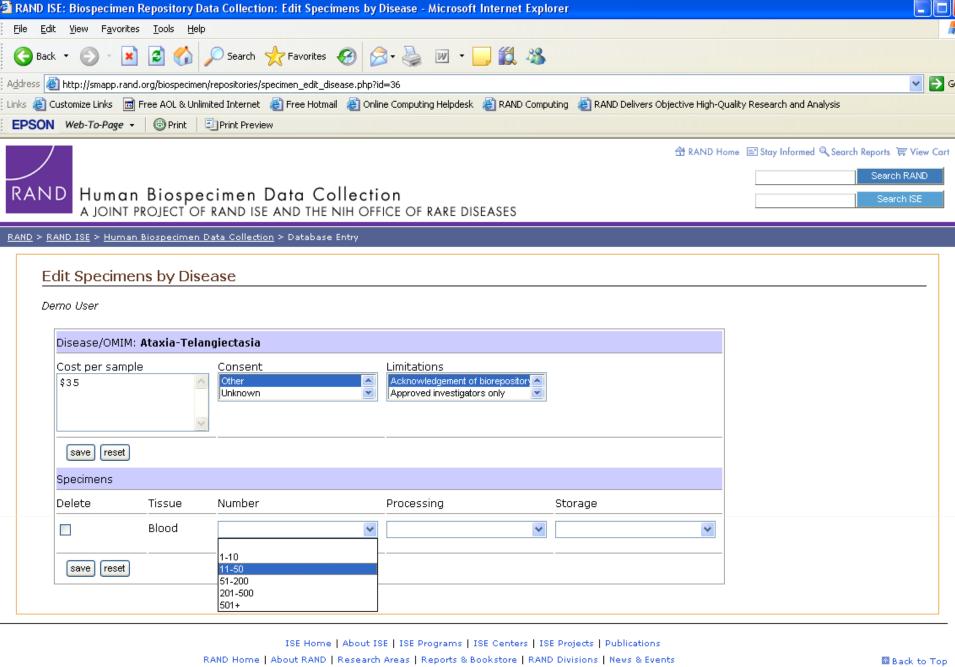






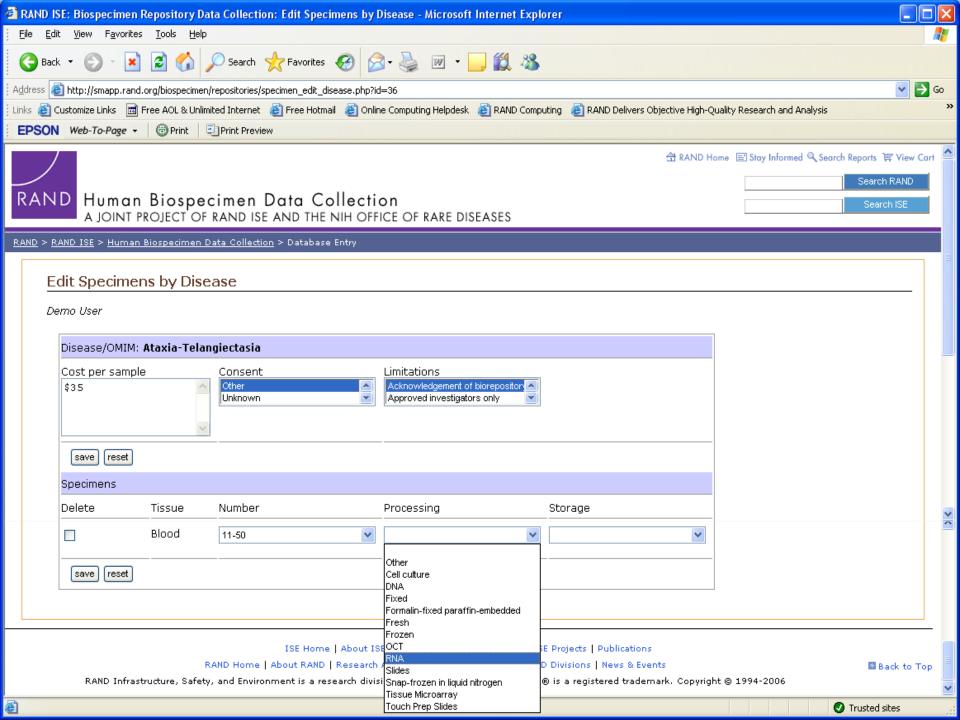
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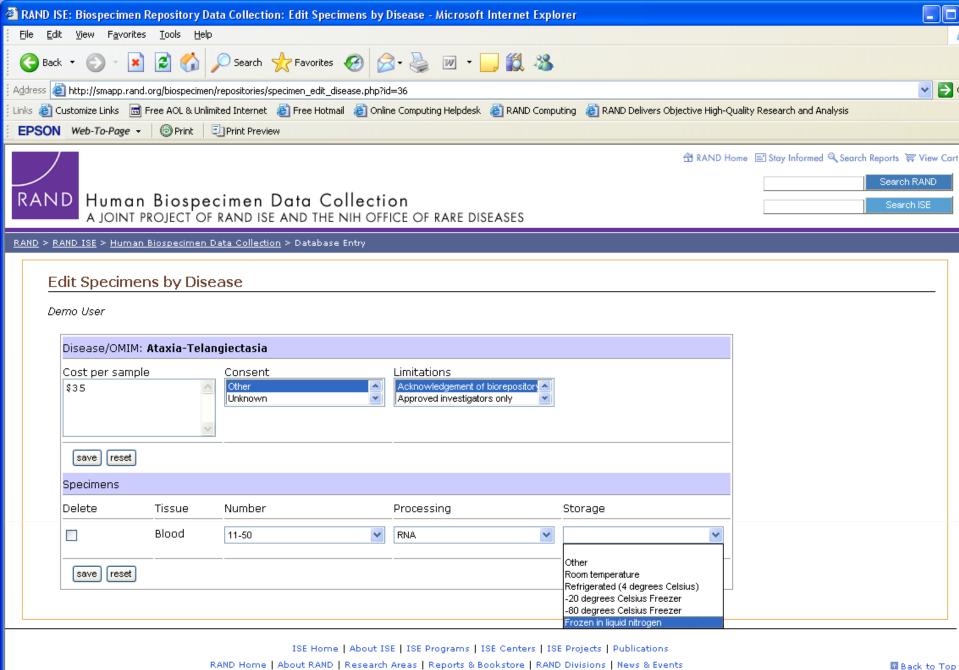
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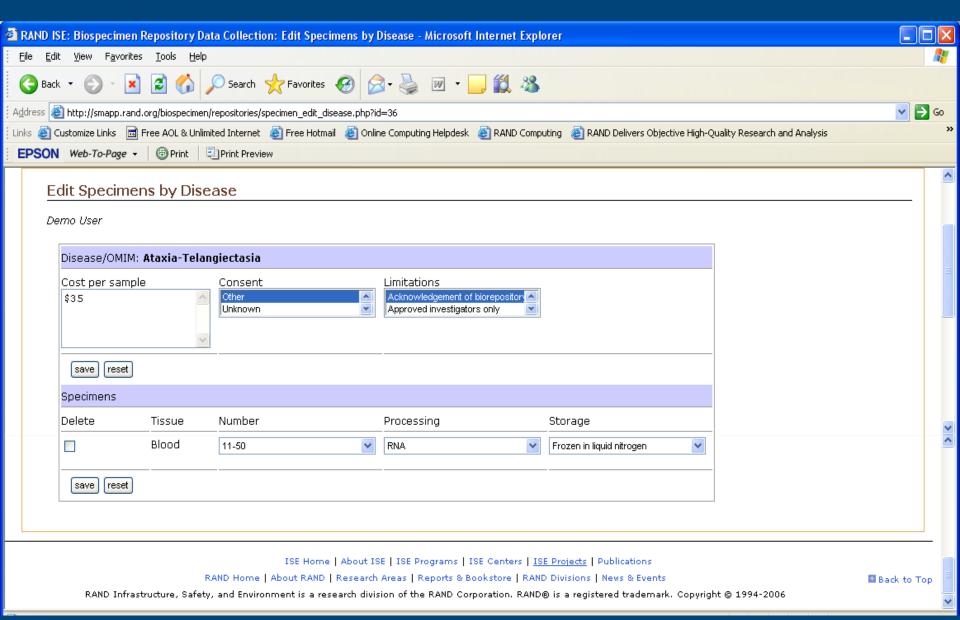


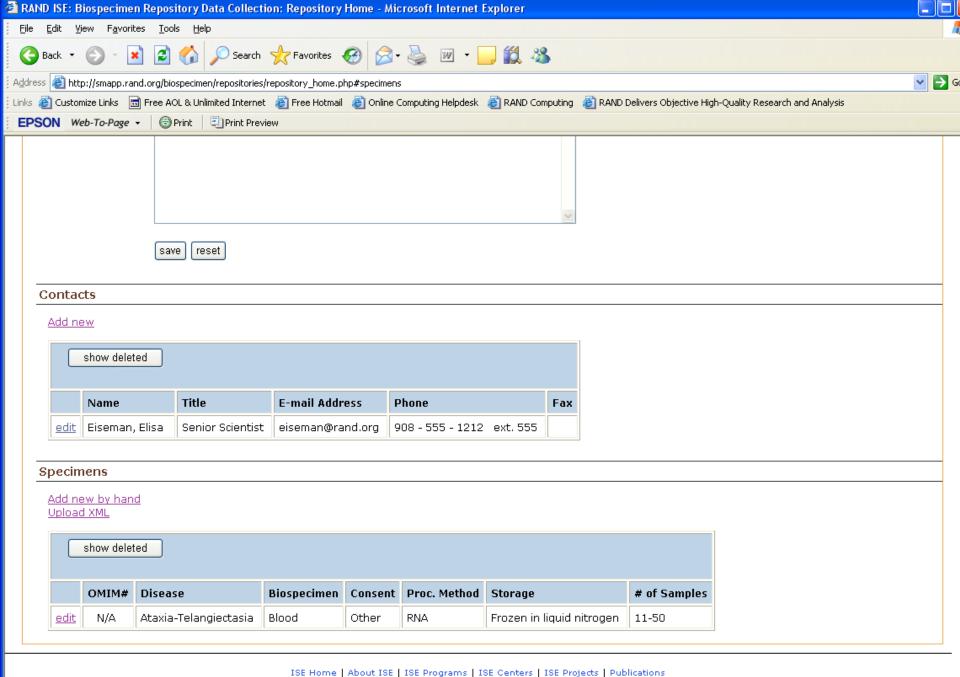
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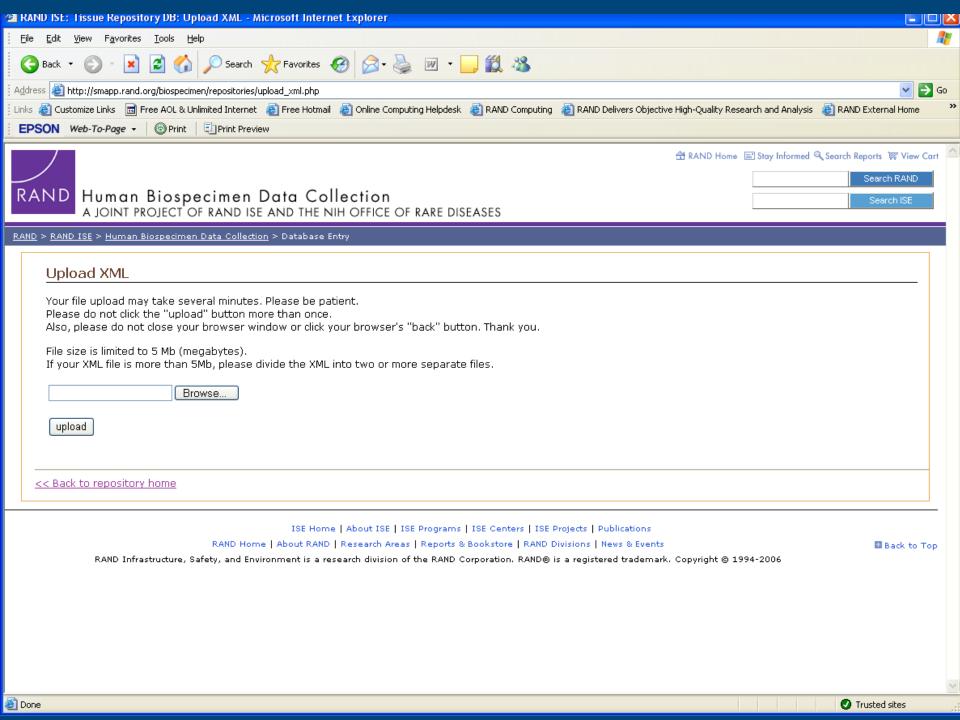
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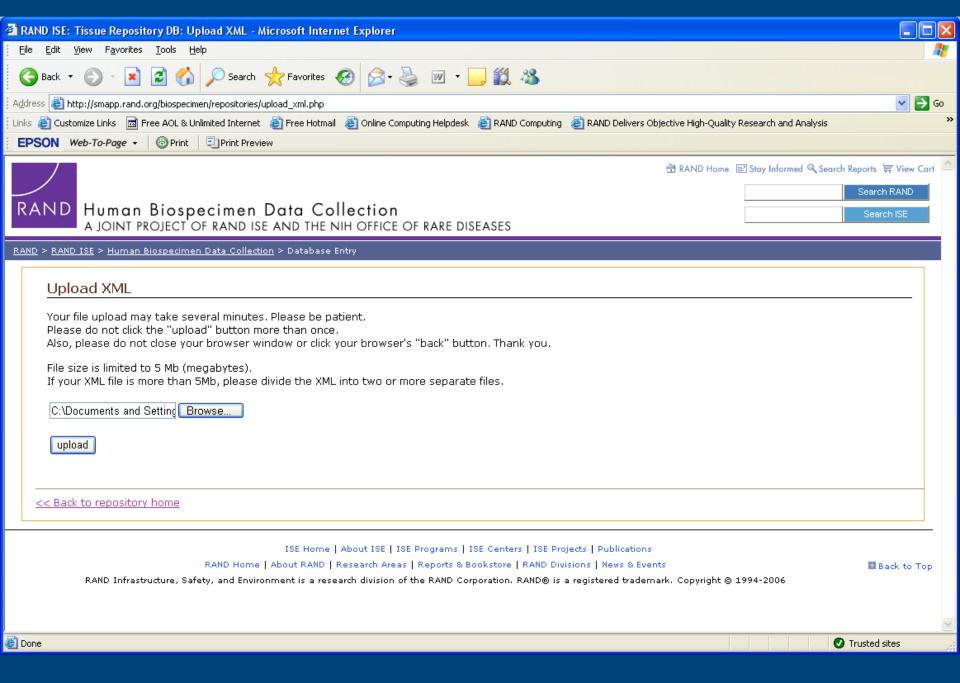
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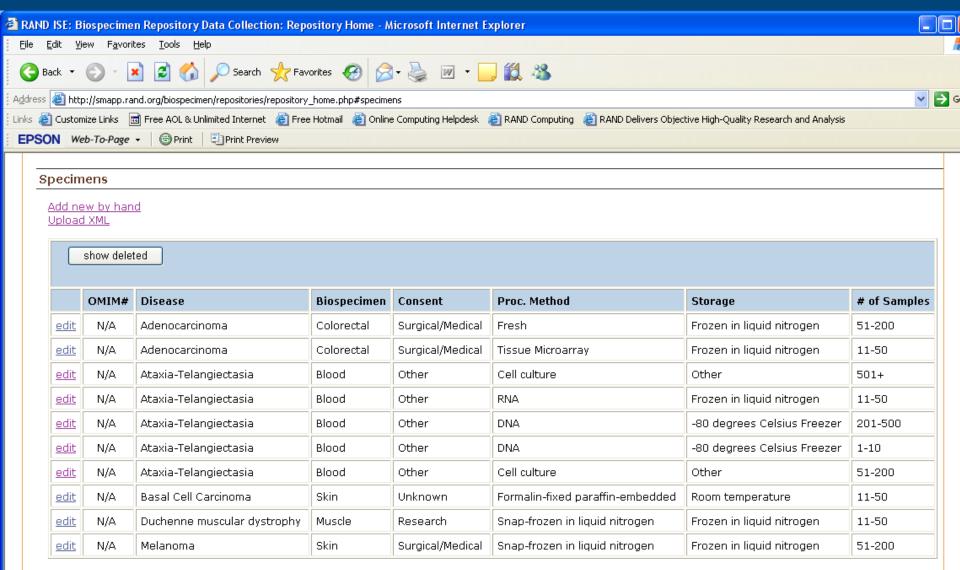
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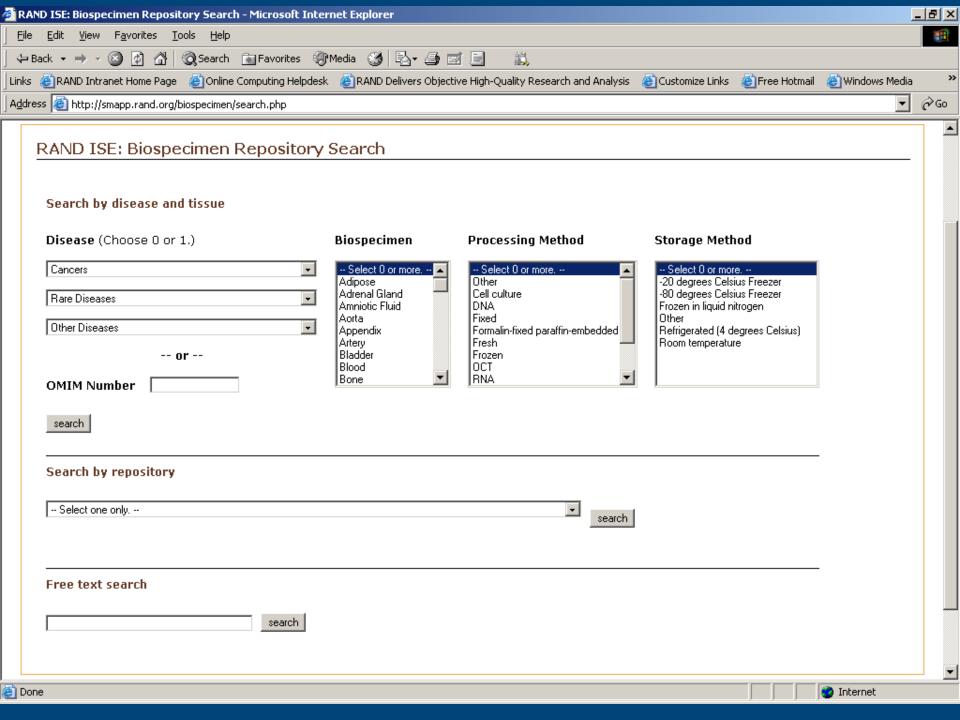
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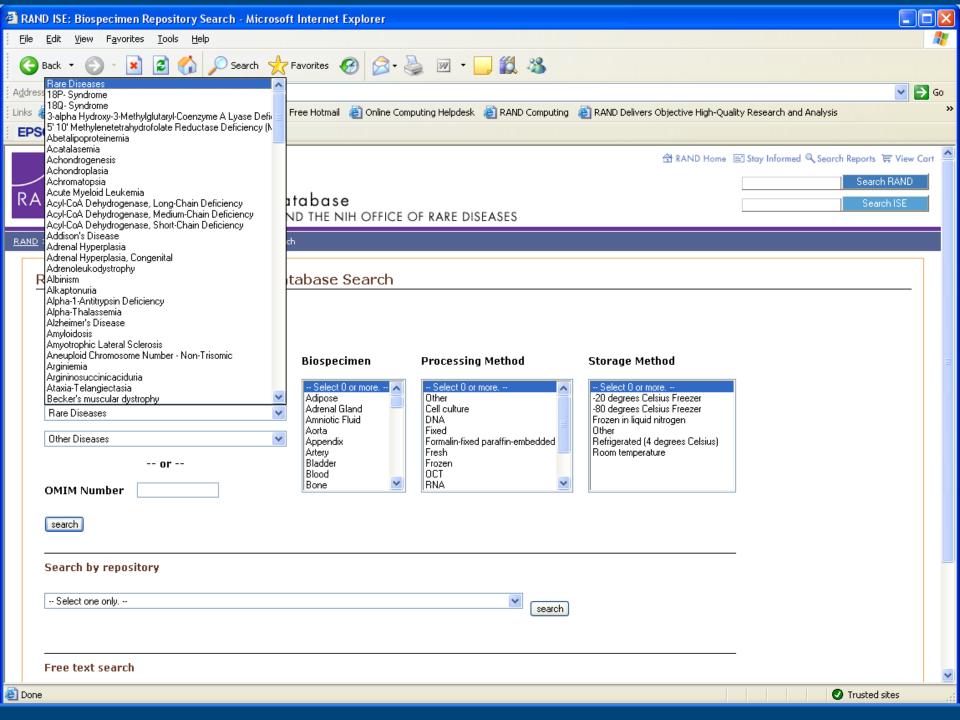
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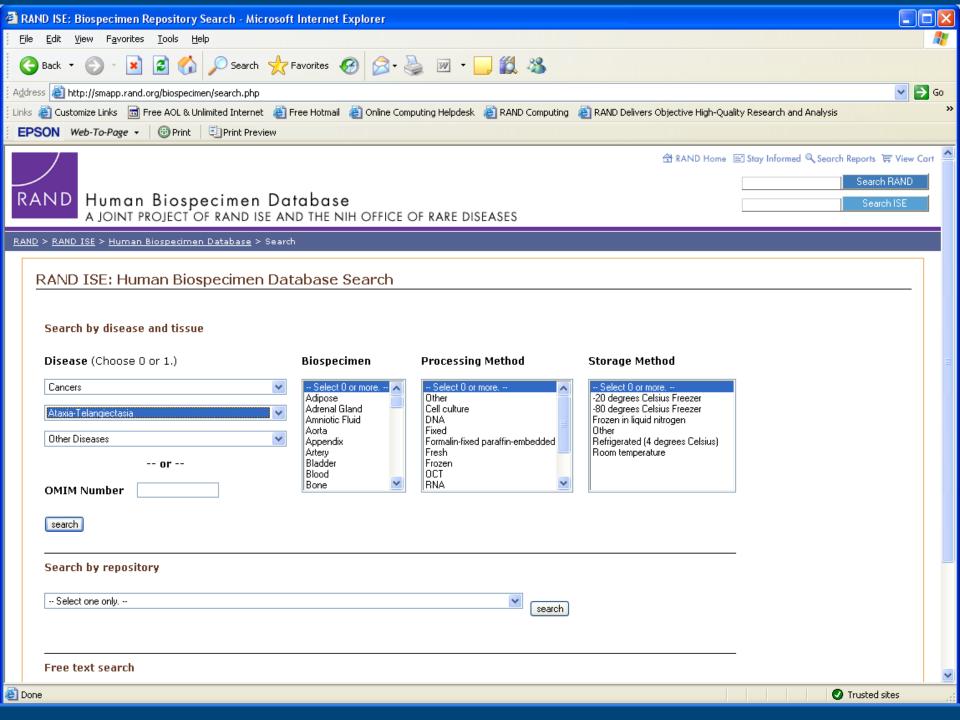


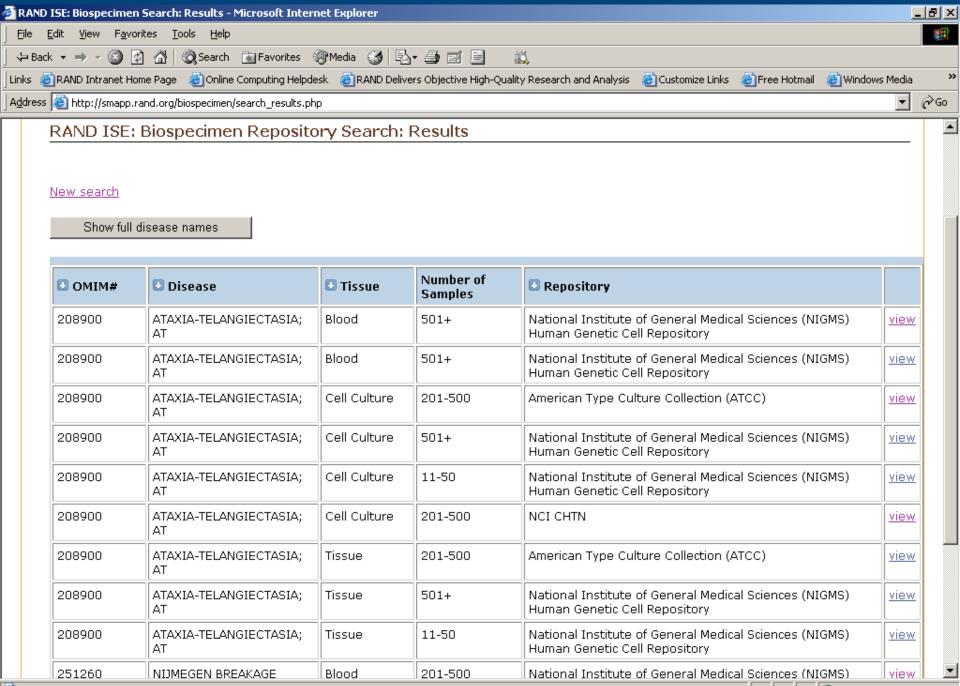
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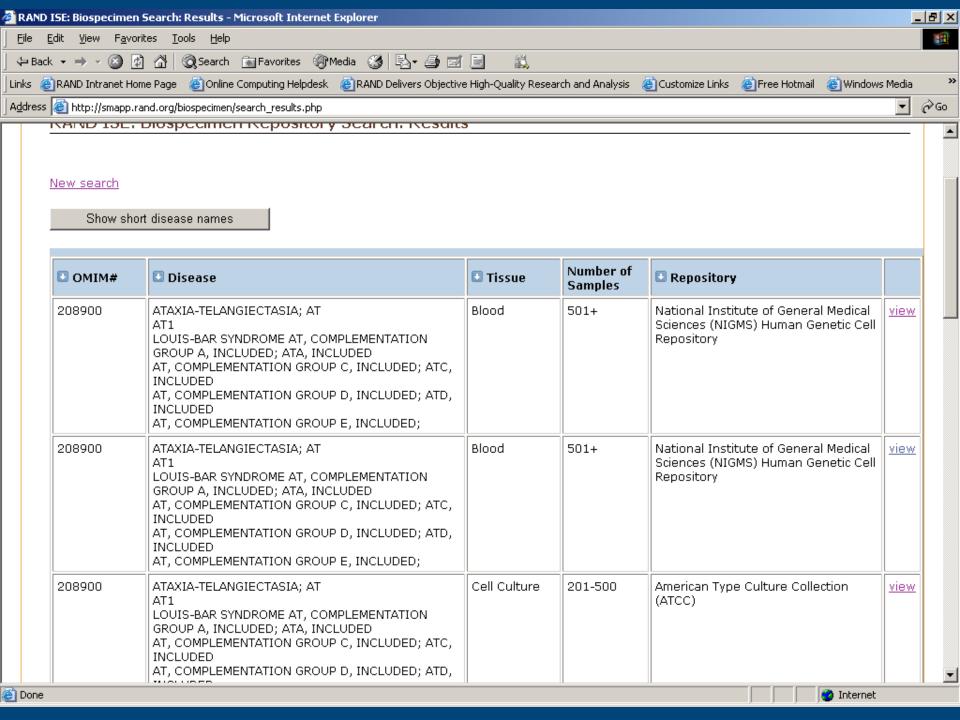
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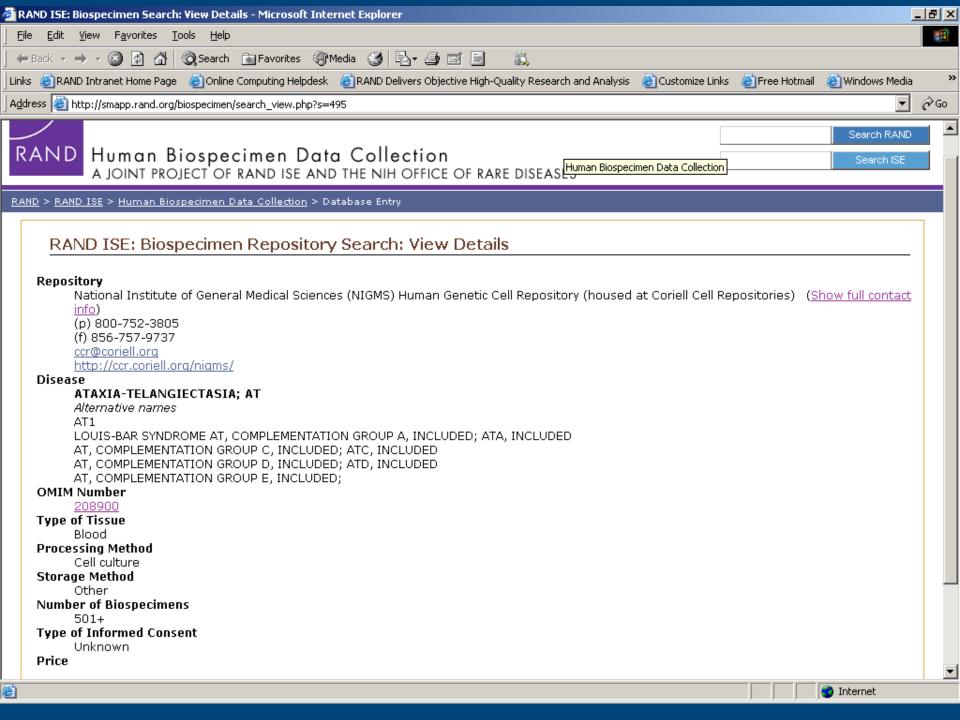


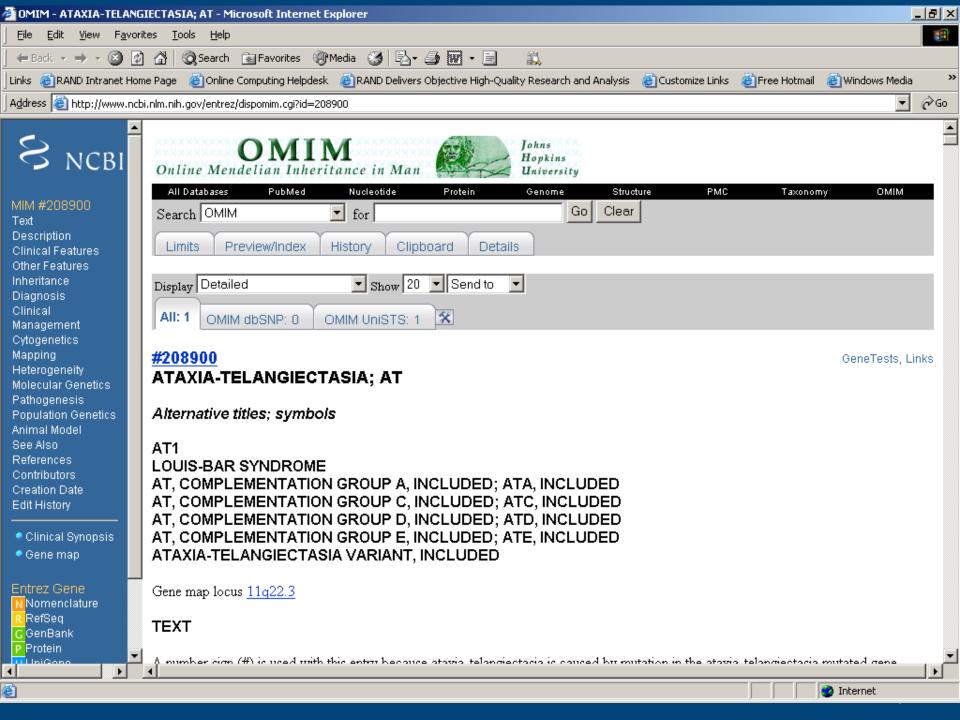


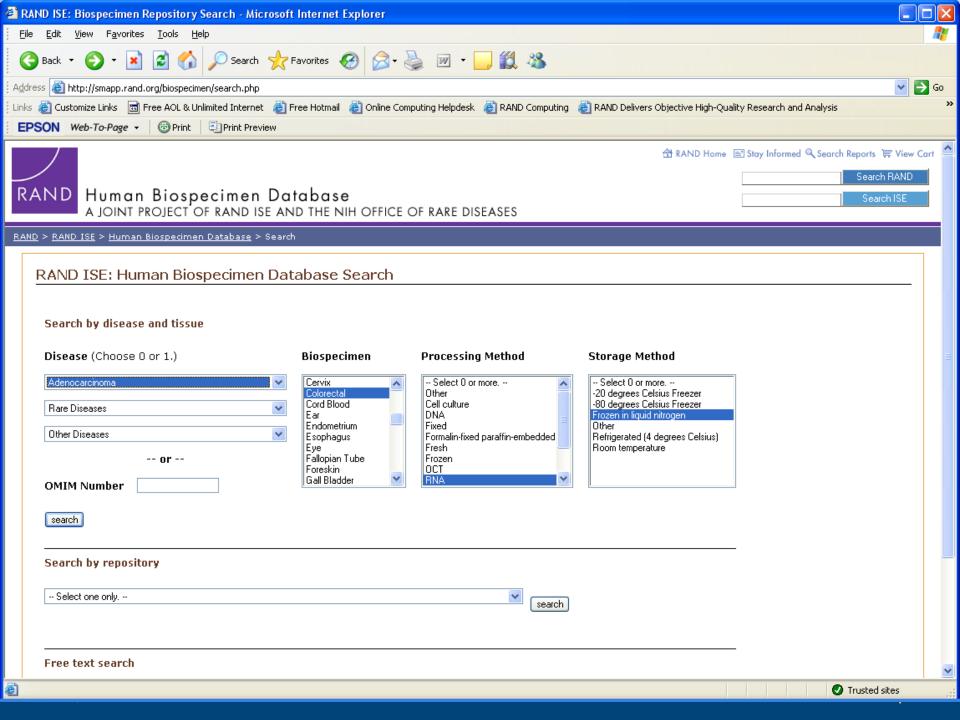


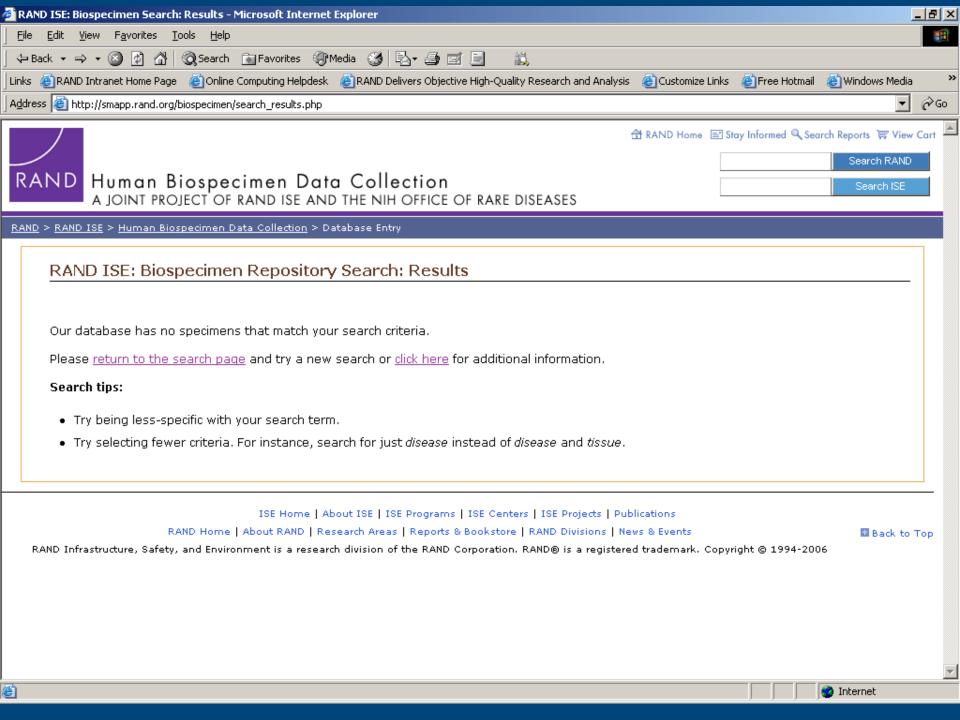


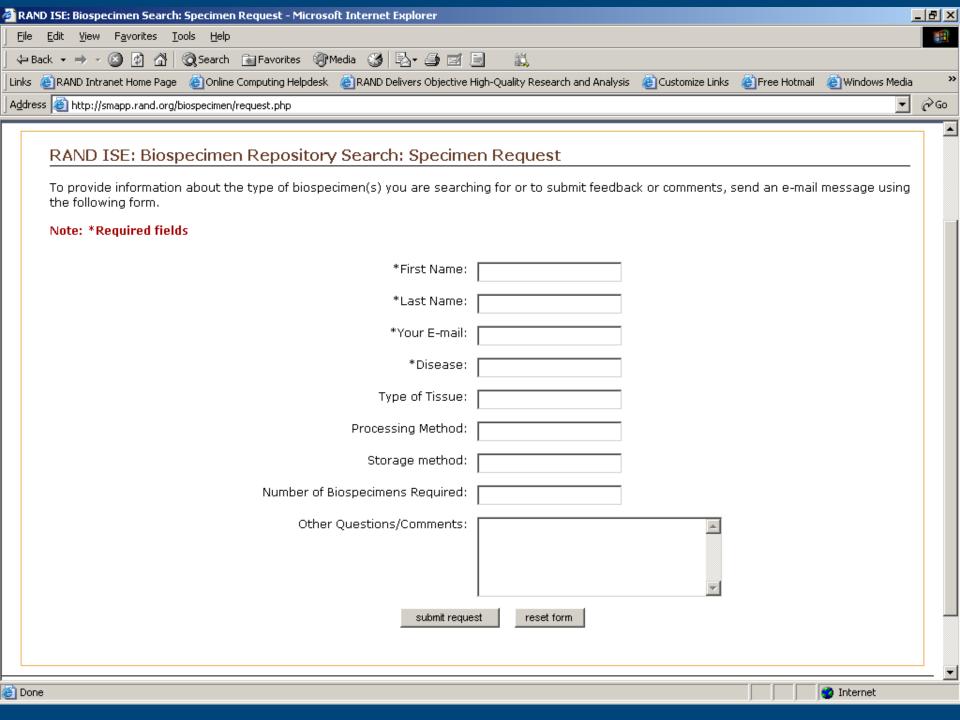












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- AIDS Cancer Specimen Resource



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