

**Title of proposed program:** A Virtual Biorepository

**Submitting IC:** NIH

**What is the major obstacle/challenge/opportunity that the Common Fund should address?**

The NIH reports to Congress every year on the numbers, types and locations of biospecimens that have been obtained from research subjects. Yet, beyond general characteristics of the samples (tissue type) and condition under study in the relevant protocol, very few data are available for retrieving specimens from subjects with specific phenotypes and genotypes. As a result, researchers often find that they must recruit new subjects and obtain new specimens in order to ask new questions that could otherwise be answered by materials and data already on hand. A database that links data about current specimens and the information about the subjects from which they were drawn, would be an invaluable resource to both intramural and extramural researchers.

**What would the goals of the program be?**

The overall goal is to obtain data about specimen types and locations from diverse NIH data sources and integrate them into a single Information System that will allow investigators to perform queries on data from their own protocols or across all NIH protocols. An Information System like this exists within the NIH intramural program already, which contains phenotypic data on hundreds of thousands of NIH subjects, including problem lists, laboratory results, radiology and pathology reports, medication administration, clinical notes and discharge summaries, with work under way to add genomic data as well. The goal of the program would be to allow all investigators to identify the availability and location of specimens from subjects that meet specific clinical and genetic criteria.

**Why is a trans-NIH strategy needed to achieve these goals?**

No trans-NIH program currently provides comprehensive information about all research specimens. Coordination across the NIH will be required to generate this information system.

**What initiatives might form the strategic plan for this topic?**

The first initiative would be to establish a policy for specimen sharing, including a uniform approach to Institutional Review Board concerns. The second initiative would be to adopt (or establish) a standard for reporting specimen data. The third initiative would be the transfer of specimen data to the Information System for community-wide access.

**If a Common Fund program on this topic achieved its objectives, what would be the impact?**

The impact of a Virtual Biorepository would be to realize the vision of maximal reuse of specimens collected and stored at great expense to answer new research questions without requiring the effort, risk and cost of collecting new biomaterials.