



DATE: April 15, 2013

TO: Chana Rabiner, Ph.D.  
Division of Cancer Treatment and Diagnosis  
National Cancer Institute

FROM: NIH Privacy Act Officer

SUBJECT: Applicability of the Privacy Act: "Financial Sustainability of Human Tissue Biobanking"

I have reviewed the submission to OMB which requests the approval of the Biobanking Survey Site sponsored by the NCI Biorepositories and Biospecimen Research Branch (BBRB) to help formulate strategies for program planning efforts to support national and international biobanks.

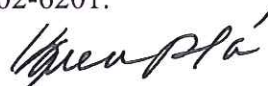
NCI will use a commercial solution constructed by their contractor, HealthCare IT, Inc. for data collection and analysis. The caCURE survey tool will be hosted at the contractor data center facility. It will collect a combination of structured, quantitative, and free-text descriptive data that characterize the type and maturity of biobanks, their sources of funding, and their usage of funding in conducting operations.

The purpose of the survey is to collect information regarding the challenges that human tissue biobanks encounter in achieving financially sustainable operations. Through invitation emails, interested respondents will be directed to a website (<http://healthcit.com>), asked to create an account, provide company contact information through a secure online registration form, complete the survey sections and submit data on the full range of costs that are incurred along the biospecimen collection, processing, storage, and distribution continuum.

No personally identifiable information will be asked in the survey. Participants will respond on behalf of their company. They will indicate only broad, general characteristics of their company biobank (i.e., demographics and background information, funding sources, major direct and indirect costs, technical/operational challenges, techniques used to overcome challenges, economic information or tools to increase funding and the format in which information or tools would be useful). HealthCare IT, Inc. will monitor and track registrations and the status of responses.

I have determined the Privacy Act does not apply to this information collection.

If you have questions, contact me at (301) 402-6201.

  
Karen M. Plá

cc: V. Horovitch-Kelley, NCI OMB Project Clearance Liaison Office