



National Institutes of Health
Bethesda, Maryland 20892

DATE: May 12, 2010

TO: Glennwood E. Trivers, Ph.D.
Biologist, LHC, CCR, NCI

FROM: NIH Privacy Act Officer

SUBJECT: Applicability of the Privacy Act: NCI – Resource for the Collection and Evaluation of Human Tissues and Cells from Donors with an Epidemiology Profile

I have reviewed the National Cancer Institute submission to OMB entitled “Resource for the Collection and Evaluation of Human Tissues and Cells from Donors with an Epidemiology Profile.” The project involves the collection of personally identifiable information to conduct and support research programs to study the cause, detection, diagnosis, prevention and treatment of cancer resulting from occupational and environmental exposure to carcinogens. Additionally, NCI plans to collect, identify, analyze and disseminate information on methods for the prevention and early detection of cancer and the identification of individuals with a high risk of developing cancer.

I have determined that the Privacy Act will apply to this data collection, which includes the collection of personally identifiable information such as name, Motor Vehicle ID, mailing address, phone number, SSN, DOB, race, sex and age.

The information provided will be kept confidential and will not be disclosed to anyone but the researchers conducting the study. Online data will be maintained on a secure server for the duration of the research, after which it will be deleted. Updated contact information may have to be added to the collected data at a later date, in the event a study design change is made. Upon notification to the participants, the data may have to be tagged with the restraints imposed by a participant to limit accessibility in the contractor’s permanent database.

The data collection is covered by NIH Privacy Act Systems of Record 09-25-0200, “Clinical, Basic and Population-based Research Studies of the National Institutes of Health (NIH), HHS/NIH/OD.”

If you have any questions, please contact my office at (301) 496-2832.

Karen M. Plá

Attachment: NIH Privacy Act Systems of Record 09-25-0200

CC: Vivian Horovitch-Kelly, PCL, NCI