



DATE: August 25, 2014

TO: Daniela Seminara, Ph.D., M.P.H.
Division of Cancer Control and Population Sciences
National Cancer Institute

FROM: NIH Privacy Act Officer

SUBJECT: Applicability of the Privacy Act: "Data Collection for Public Cancer Epidemiology Descriptive Cohort Database"

I have reviewed the NCI submission to OMB referenced above. The project involves the development of the publicly accessible and sortable web-based, Cancer Epidemiology Descriptive Cohort Database (CEDCD). The CEDCD will contain descriptive information about existing cancer epidemiology cohorts (e.g. study design, eligibility criteria, enrollment numbers, scope of content domains collected, numbers of biospecimens, number of cancer and other health outcomes) to enable the research community to locate information about the existence of data and to find potential collaborators to further important research aims. It will not contain any participant-level data.

The CEDCD will be populated with information collected from the cohort Principal Investigators (PIs) via a collection form and biospecimen information spreadsheet. The PIs will provide their name, phone number and email address, affiliation or institution, the contact information of staff affiliated with their study, the overall number of participants, and the race and ethnicity of the participants. The email address is collected for the purpose of registering users and responding to inquiries. Due to the fact that there are several PIs for each project, the PI names will not be included in the cohort table within the CEDCD. The PIs and Business Officials will be requested to sign an Approval Form and denote what data and supporting documentation can be publicly posted on the CEDCD website. The PIs will then email the forms and any other supporting documents they agree to make public to an NCI contractor to be entered into an electronic format. The CEDCD can be sorted by cohort name, acronym and the date the data was last updated.

I have determined the Privacy Act will apply to this information collection due to the fact that information about individuals will be stored in an electronic record system designed to be retrieved by a personal identifier. 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 questions, please contact me at (301) 402-6201.

Karen M. Plá

cc: Karla Bailey, NCI PRA Liaison