Request for Approval under the "Generic Clearance for the Collection of Routine Customer Feedback" (NCI) (OMB Control Number: 0925-0642-16, Expiration Date 9/30/2014)

TITLE OF INFORMATION COLLECTION: International Focus Group to Inform Economic Barriers and Challenges to Biobankers

PURPOSE: A lack of sufficient public and private funding is a significant challenge facing human specimen biobanking in support of translational research. This is essential for implementation of good laboratory practice and quality management programs to optimize specimen and data quality along the biobanking supply chain. Adequate funding is also required to ensure the long-term sustainability of the resource, which in turn promotes sharing of materials and data among the researchers studying the same or similar diseases. However, in economically challenging times, biobanks must increasingly rely on cost efficiency and cost effectiveness measures to stay operational relevant with respect to improvements in biomedical technology.

The National Cancer Institute's (NCI) Biorepositories and Biospecimen Research Branch (BBRB) is involved in on-going studies of the economics of biobanking, which include costrecovery modeling and the qualification and quantification of the economic impact of standardization of practice and centralization of resources. The first step in accomplishing this goal is to gain a clearer understanding of the specific challenges being faced, from the point of view of those directly impacted, through techniques such as this focus group. The focus group will provide impressions and comments regarding a survey to occur in the future (a separate request will be submitted to OMB when the survey is finalized).

DESCRIPTION OF RESPONDENTS: The respondents for this collection will be participants at the European, Middle Eastern, and African Society for Biopreservation and Biobanking in Granada, Spain on November 7-10, 2012 who have direct experience regarding economic challenges and barriers for biobanking.

TYPE OF COLLECTION: (Check one)

- [] Customer Comment Card/Complaint Form
- [] Usability Testing (e.g., Website or Software
- [x] Focus Group

CERTIFICATION:

I certify the following to be true:

- 1. The collection is voluntary.
- 2. The collection is low-burden for respondents and low-cost for the Federal Government.
- 3. The collection is non-controversial and does <u>not</u> raise issues of concern to other federal agencies.
- 4. The results are <u>not</u> intended to be disseminated to the public.
- 5. Information gathered will not be used for the purpose of <u>substantially</u> informing <u>influential</u> policy decisions.
- 6. The collection is targeted to the solicitation of opinions from respondents who have experience with the program or may have experience with the program in the future.

Name: _____Chana A. Rabiner, PhD, Program Director, CDP/BBRB_____

- [] Customer Satisfaction Survey
- [] Small Discussion Group

[] Other:_____

To assist review, please provide answers to the following question:

Personally Identifiable Information:

- 1. Is personally identifiable information (PII) collected? [] Yes [X] No
- 2. If Yes, will any information that is collected be included in records that are subject to the Privacy Act of 1974? [] Yes [] No
- 3. If Yes, has an up-to-date System of Records Notice (SORN) been published? [] Yes [] No

Gifts or Payments:

Is an incentive (e.g., money or reimbursement of expenses, token of appreciation) provided to participants? [] Yes [x] No

BURDEN HOURS

Category of Respondent	No. of Respondents	Participation Time	Burden
Private Sector	25	1.5 hr	38

Total Burden Hours used for IC's to date:888Total Burden Hours Approved for IC's under 0925-0642:8750Total Burden Hours currently requested:38

FEDERAL COST: The estimated annual cost to the Federal government is _____\$3,000_____

If you are conducting a focus group, survey, or plan to employ statistical methods, please provide answers to the following questions:

The selection of your targeted respondents

1. Do you have a customer list or something similar that defines the universe of potential respondents and do you have a sampling plan for selecting from this universe?

[X] Yes [] No

There are 500 participants at this conference. Participants will be made aware of this focus group through a list serve, along with other meetings at the time, and will have the opportunity to respond as to whether they wish to join this focus group.

Administration of the Instrument

- 1. How will you collect the information? (Check all that apply)
 - [] Web-based or other forms of Social Media
 - [] Telephone
 - [x] In-person
 - [] Mail
 - [] Other, Explain

2. Will interviewers or facilitators be used? [x] Yes [] No Two focus groups, each consisting of approximately 10-12 individuals each, will be held at different times during the 4 day conference in November.

List of instruments, instructions, and scripts submitted with this request:

Attachment #1: Questions for BBRB Study Focus Group/ESBB Conference

Attachment #2: Focus Group Moderator's Guide