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DCCPS Biorepository Information Gathering Questionnaire

This questionnaire was designed to better understand the value of NCI supporting a central Biorepository/biospecimen archive where extramural researchers could store their remaining biospecimens after the main aims of their NCI-funded study have been completed. The goal would be to make these biospecimens available to other researchers for ancillary studies. An NCI biorepository would assume custodianship of the biospecimens, which would involve maintaining and providing access to the specimens.

Thanks in advance for your cooperation.

1. Do you possess, or are you currently collecting, biospecimens that were collected through a currently- or historically-funded NCI grant and are human in origin?

Yes

No

2. Do you have any of the following information on the biospecimens that were collected through a currently- or historically-funded NCI grant and are human in origin (check all that apply)

Usage stats (e.g. volume remaining)

Processing stats (e.g. freeze/thaw cycles)

Storage stats (e.g. storage duration)

I have not collected any of the information listed

Additional comments:

3. Will any data associated with the biospecimens be deposited into dbGaP or another NIH repository?

Yes, associated data has already been deposited

Yes, there are plans to deposit associated data into one of these repositories in the future

No

4. Regarding the biospecimens that you identified above, please describe the type of biospecimens that you anticipate having by the time that your main study aims are completed (in other words, the leftover or legacy samples you will have). Please specify their required storage condition and the number of samples (e.g. total vials) you expect to have remaining.

	Storage condition	Approximate number of samples remaining (e.g. total vials)
Buccal/Saliva/Oral Swab for DNA	▼	▼
Cell Lines	▼	▼
Cervical Swab	▼	▼
Cryopreserved Whole Blood	▼	▼
DNA	▼	▼
Feces	▼	▼
Fingernails	▼	▼
Guthrie Cards/Blood Spot	▼	▼
Leukocytes/Buffy Coat	▼	▼
Packed Red Blood Cells	▼	▼
Peripheral Blood Lymphocytes	▼	▼
RNA	▼	▼
Saliva for Biomarkers	▼	▼
Serum or Plasma	▼	▼
Tissue - FFPE block	▼	▼
Tissue - FFPE core or section	▼	▼
Tissue - Fresh Frozen block	▼	▼
Tissue - Fresh Frozen core or section	▼	▼
Tissue Microarray	▼	▼
Tissue - slide	▼	▼
Urine	▼	▼

5. What is your long-term plan for the storage of your biospecimens?

- You plan on storing all samples indefinitely at a centralized location within your university/organization.
- You plan on storing all samples indefinitely within your individual research space (i.e. lab/freezer).
- You plan on storing all samples indefinitely at a commercial biorepository.
- You plan on dividing your samples and storing them indefinitely in different locations within your university/organization.
- You plan on destroying all remaining samples.
- You plan on transferring all samples to another investigator for use in their research.
- You are not yet sure.
- Other (please specify)

[Redacted text box]

6. What are your future plans for obtaining funding to support the continued storage of your biospecimens?

- Your institution will likely provide support
- You will likely need to find other sources of support
- You will likely need additional funding and plan to seek that from NIH/NCI
- Other (please specify)

[Redacted text box]

7. If you could not obtain financial support for the storage of your biospecimens, what options would you consider?

- Destroying the biospecimens

Alternate storage options (specify):

[Redacted text box]

8. Do you have an established process to allow investigators outside of your research group to request access to your biospecimen collections?

- Yes
- No
- Other (please specify)

9. If you are able to share your established biospecimen request process, you may provide the link to published document here:

10. What criterion do you use to provide access?

11. Approximately how many requests for biospecimens from your collection do you receive annually?

12. Would you consider allowing the NCI biorepository to assume custodianship of your NCI-funded study's biospecimens (leftover or legacy)? Assume that NCI would have the rights to maintain and provide access to the specimens consistent with the usage rights outlined by the participant's consent and that moving and storing these samples would be free of cost.

- Yes
- No
- It depends

Other or additional information

13. If you answered "No" or "It depends" to the previous question, what specific reasons contributed to this?

14. Would any of the following be considerations for you when deciding whether to move your NCI-funded study's specimens (leftover or legacy) to an NCI central biorepository? (check all that apply)

- You already have access to a centralized biorepository with the same goal of specimen and data sharing.
- Privacy issues related to sending accompanying demographic and clinical information would restrict you from doing so
- The logistical and organizational effort needed to identify, gather, and send biospecimens to new biorepository is anticipated to be too much work
- The approvals needed from your own institution to move the biospecimens will be difficult to obtain
- Biospecimens were gathered in a collaborative effort, and you are not sole decision-maker in terms of their storage & use
- The paperwork needed to finalize process (IRB, MTA) might be too burdensome
- You are opposed to allowing NCI to provide others with access to your biospecimens
- You are not opposed to allowing NCI to provide others with access to your biospecimens but wish to be involved in the approval process
- You are not opposed to allowing NCI to provide others with access to your biospecimens but wish to ensure that material remains for your research purposes
- Other (please specify)

15. Would you like to elaborate on any of the perceived challenges to move your study's specimens to an NCI central biorepository?

16. Are there additional concerns/factors that you would like NCI to be made aware of when considering the feasibility of such a biorepository?

17. Thank you for participating in this survey - your input will be helpful! If you would be interested in sharing your insights further with us, we would appreciate it if you left your contact information below.

We welcome you to reach out to us with any comments or questions at NCIEpiCommunications@mail.nih.gov.

Name	<input type="text"/>
Title	<input type="text"/>
Organization	<input type="text"/>
City/Town	<input type="text"/>
State/Province	<input type="text"/>
Email Address	<input type="text"/>
Phone Number	<input type="text"/>