



National Cancer Institute Survey of Human Biospecimen Needs and Challenges for the Biomedical Research Enterprise

Thank you for assisting the National Cancer Institute (NCI) Office of Biorepositories and Biospecimen Research (OBBR) with this survey.

Before you begin, please note:

- Completing this survey will take about 15 minutes of your time. If you don't believe you can respond about these issues, please feel free to forward your invitation email to someone else (note however, that the login ID will only work for one person).
- As you go through the survey, if you want to return to an earlier section you can use your browser's back button to do so.
- After you click the "save and continue" button (at the bottom right hand-side of your screen), your data will be saved for that page. If for some reason you exit the survey before completion, you may log in again using the same ID; you will see your saved answers up through the last page you completed.

To continue and begin the survey, click the "next" button below.

We appreciate your interest and look forward to receiving your input on this important survey. If you have any questions about the survey, please do not hesitate to contact the NCI OBBR at biospecimens@mail.nih.gov.

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Privacy Statement

Your participation in this survey is completely voluntary. Please be assured that your responses will be kept private and will not be disclosed to anyone outside NCI or its contractor, User-Centered Design, Inc. All data will be reported in aggregate only -- no names will be included in any reports. You may skip any questions that you prefer not to answer or withdraw at any point during the survey. If you choose to withdraw and want to delete your data, simply click the "Opt out of survey" link at the bottom of each page.

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Information about You and Your Work

In order to better understand your responses, we would like to know a little more about you and your field of work.

% Completed

1. Which of the following best describes your primary role on a day-to-day basis (as it relates to the biomedical field)?
(Please select one.)

- Clinical researcher
- Surgeon
- Oncologist/other physician
- Nursing personnel/clinical research coordinator
- Other clinical or healthcare staff
- Pathologist
- Laboratory scientist/researcher
- Laboratory personnel/technician
- Non-laboratory scientist/researcher
- Bioinformatics specialist
- Information technology specialist
- Executive/administrator (e.g., leader in an organization)
- Policy analyst
- Health educator
- Patient/patient advocate
- Biorepository manager
- Other (specify):

2. How many years have you been involved in the biomedical field?

- Less than 1
- 1-5
- 6-10
- 11-15
- 16-20
- More than 20

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Information about You and Your Work (cont'd)

% Completed

3. In what type of organization are you currently working or involved? (Please select the one that most closely applies.)

- Academic/research institution
- NCI-designated cancer center
- Other cancer center
- Hospital, clinic, or other healthcare setting
- National Cancer Institute (NCI)
- NIH institute (other than the NCI)
- Federal government agency (other than the NIH)
- State/local government agency (other than academic institutions)
- Nonprofit organization (e.g., foundation)
- Advocacy organization
- Pharmaceutical/biotechnology company
- Other biomedical company
- Other (specify):

4. Do you work in a biorepository (biobank)?

- No
- Yes

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Experience with Biological Specimens

% Completed

5. In what capacity do you deal with biological specimens in your work? (Select all that apply from the following lists.)

Collect

- Administer informed consent
- Collect/gather biospecimens for my own use
- Collect/gather biospecimens for use by others
- Collect/gather biospecimens specifically for medical care purposes (e.g., surgical removal of tumors, tissue for biopsies or screening tests)
- Obtain/purchase biospecimens (e.g., from a biorepository) for my own use
- Obtain/purchase biospecimens (e.g., from a biorepository) for use by others

Process

- Process Intellectual Property (IP) and material transfer agreements (MTA)
- Prepare/review IRB proposals

Store

- Oversee or work with the storage of specimens (e.g., responsible for storage conditions, inventory)

Distribute/Supply/Share

- Share/supply specimens to others in my organization
- Supply specimens to others external to my organization

Treatment and Diagnosis

- Use specimens for biomedical research
- Surgical treatment
- Medical care delivery

Proposals and Policies

- Review research proposals that include biospecimens in the methods
- Manage grants for studies involving biospecimens
- Assist with policy regulations around individual privacy, biospecimens, and biospecimen research

Other (specify):

I do not directly deal with biological specimens in my work.

Access to Biospecimens

% Completed

Before we ask your opinions about a national biospecimen database, we would like your input on accessing biospecimens today.

6. What percentage of the biospecimens you work with/obtain come from each of these sources?
 (Please enter integers only.)

- % - My patients/study participants/volunteers
- % - Other patients/volunteers in my organization (e.g., tissue procurement services, other IRB-approved projects)
- % - Other medical care facilities (e.g., community hospitals)
- % - Other research institutions (e.g., Specialized Programs of Research Excellence [SPORES], other academic hospitals)
- % - Nonprofit biobank
- % - Commercial biobank in the U.S.
- % - Commercial biobank outside the U.S.
- % - NCI's Cooperative Human Tissue Network (CHTN)
- % - Other:
- Does not apply to me

6a. Some researchers have collaborative agreements with other researchers about sharing specimens. What proportion of biospecimens you work with come from individuals or organizations who are your research collaborators (excluding biospecimens you collect yourself or receive from your patients or other biorepository)?

- None (0%)
- Few (1-25%)
- Some (26-50%)
- Many (51-75%)
- Most (76-99%)
- All (100%)
- Don't know
- Does not apply to me

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Access to Biospecimens (cont'd)

% Completed

7. What types of biospecimen samples do you most want or need for the research you conduct? (Select all that apply from the following lists.)

Patient demographics:

- Fetal
- Neonatal
- Pediatric
- Adolescent
- Young adult
- Aged
- Gender
- Race/ethnicity
- Other (specify):
- Does not apply to me

Biospecimen characteristics:

- Normal blood
- Normal serum/plasma
- Blood (disease states)
- Serum/plasma (disease states)
- Cell lines from human tissue
- Normal healthy tissue
- Cancer
- Pre-malignant (dysplastic, adenomatous, intraepithelial, neoplasia, etc)
- Inflammatory/autoimmune states
- Infectious
- Degenerative
- Brain/central nervous system
- Urine
- Saliva
- Duct secretions
- Other (specify):
- Does not apply to me

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Access to Biospecimens (cont'd)

% Completed

8. What information do you typically know about the biospecimens available to you in your work? (Select all that apply.)

- Biospecimen type (e.g. cell, fluid, tissue)
- Anatomical location (e.g., where sampled from on the body)
- Collection procedures
- Storage procedures
- Transfer procedures
- Patient demographics
- Patient complaint/history of current illness
- Patient past medical history
- Patient family history
- Patient's health behavior and lifestyle characteristics
- Clinical diagnosis
- Pathological diagnosis
- Patient treatment information
- Patient treatment outcomes
- Patient consent/authorization status (e.g., HIPAA, informed consent)
- Quality control data on the biospecimen itself (e.g., standard operating procedures used by the facility)
- Quality assessment of the biospecimen (e.g., fits diagnosis, tissue is viable)
- History of how each biospecimen has been collected, stored, and managed
- Other:
- Does not apply

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Access to Biospecimens (cont'd)

% Completed

9. Thinking about the information you typically know about the biospecimens you work with, which statement best describes your situation?

- I usually have enough information about the biospecimens and do not need more.
- I usually have enough information about the biospecimens, but I would like to have more.
- I usually do not have enough information about the biospecimens.
- I am not sure whether or not I have the information I need or should have.
- Does not apply to me

10. How easy or difficult is it for you to obtain the number of biospecimens you need for your work?

- Very easy
- Easy
- Somewhat easy
- Somewhat difficult
- Difficult
- Very difficult
- Does not apply to me

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Perceptions of the Quality of Biospecimens



11. If all barriers were removed, what information or characteristics about biospecimens would you consider ideal to know in order for you to consider them "high quality"?

- Biospecimen type (e.g. cell, fluid, tissue)
- Anatomical location (e.g., where sampled from on the body)
- Collection procedures
- Storage procedures
- Transfer procedures
- Patient demographics
- Patient complaint/history of current illness
- Patient past medical history
- Patient family history
- Patient's health behavior and lifestyle characteristics
- Clinical diagnosis
- Pathological diagnosis
- Patient treatment information
- Patient treatment outcomes
- Patient consent/authorization status (e.g., HIPAA, informed consent)
- Quality control data on the biospecimen itself (e.g., standard operating procedures used by the facility)
- Quality assessment of the biospecimen (e.g., fits diagnosis, tissue is viable)
- History of how each biospecimen has been collected, stored, and managed
- Other:
- Does not apply

Elaborate on how you would define a "high quality" biospecimen by completing the following sentence:

A biospecimen is "high quality" for my work when it ...

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Perceptions of the Quality of Biospecimens (cont'd)



Note: For the remaining questions about "high quality" biospecimens, please think of the information about biospecimens (see question 11) that you defined as ideal for the work you do and for producing quality outcomes.

12. What percentage of the time in your work with biospecimens is the use of "high quality" biospecimens necessary?

- Never (0%)
- Rarely (1-25%)
- Sometimes (26-50%)
- Often (51-75%)
- Usually (76-99%)
- All (100%)
- Don't know
- Not applicable

In what situations with your work is it necessary or desirable to use these "high quality" biospecimens?

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Perceptions of the Quality of Biospecimens (cont'd)



13. Below is a list of possible challenges to accessing "high quality" biospecimens. For each one, please indicate how much of a problem it is overall for you in your work.

	Not a problem					Very big problem
Lack of evidence-based best practices for collection of biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of evidence-based best practices for processing biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of evidence-based best practices for storing biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of adherence to existing best practices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time needed to find and obtain biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Restrictive nature of HIPAA and human subjects guidelines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of standardized IRB review	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of funding or reimbursement to collect or process biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High cost of biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of willingness of researchers to share biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of standardized patient recruitment and consent procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of patient willingness to provide or donate biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What other problems or barriers, if any, would you say impede access to biospecimens?

Perceptions of the Quality of Biospecimens (cont'd)



14. In general, how easy/difficult do you think it is to access "high quality" biospecimens when they are needed?

- Very easy
- Easy
- Somewhat easy
- Somewhat difficult
- Difficult
- Very difficult
- Don't know

15. How often, if ever, have you questioned findings/outcomes from your work because you had concerns about the quality of the biospecimens you had available to use?

- Never (0%)
- Rarely (1-25%)
- Sometimes (26-50%)
- Often (51-75%)
- Usually (76-99%)
- Always (100%)
- Don't know
- Does not apply to me

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Perceptions of the Quality of Biospecimens (cont'd)



16. How often, if ever, have you limited the scope of your work/objectives because of difficulty obtaining biospecimens that met your needs?

- Never (0%)
- Rarely (1-25%)
- Sometimes (26-50%)
- Often (51-75%)
- Usually (76-99%)
- Always (100%)
- Don't know
- Does not apply to me

17. Typically speaking, what percentage of the time are you unable to use specimens you collect or acquire from a biorepository because of poor quality or other problems with the biospecimen itself?

- Never (0%)
- Rarely (1-25%)
- Sometimes (26-50%)
- Often (51-75%)
- Usually (76-99%)
- Always (100%)
- Don't know
- Does not apply to me

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Perceptions of the Quality of Biospecimens (cont'd)



18. To what degree do the following existing sources meet your needs for "high quality" biospecimens?

	Never	Rarely	Sometimes	Often	Usually	Always	Don't know	Not applicable
My patients/study participants/volunteers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other patients/volunteers in my organization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other medical care facilities (e.g., community hospitals)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other research institutions (e.g., SPORES, other academic hospitals)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nonprofit biorepositories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Commercial biorepositories in the U.S.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Commercial biorepositories outside the U.S.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NCI's Cooperative Human Tissue Network (CHTN)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Imagine all challenges were removed and you had unlimited access to "high quality" biospecimens. How might this change the work you conduct? That is, what possibilities might it create for furthering biomedical research and product development?

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Perceptions of a Standardized Repository for Biospecimens



Please read the description below before answering the remaining questions:

National Cancer Biobank

The NCI is developing a long-range plan to:

- Address the challenges raised by current biorepository practices and procedures
- Investigate the current state of demand and supply of biospecimens around the country
- Identify areas where increased resources would be helpful in increasing biospecimen supply

One possible way to increase resources to address unmet biospecimen needs would be to develop a national cancer human specimen biobank. The NCI envisions that a national cancer biorepository would:

- be a nonprofit, public service entity
- collect and store biospecimens of high quality
- use an open and transparent access and distribution policy
- select tumor types and volumes that correspond to specific needs that exist in the research community, including normal tissue
- be a resource that would complement, not replace, existing tissue collections
- be a resource that could provide infrastructure to groups without the required expertise to build their own biorepository
- include a comprehensive public database that captures clinical data, specimen handling data, and molecular profile data on all collected specimens

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Perceptions of a Standardized Repository for Biospecimens (cont'd)



20. After reading this description, what is your initial reaction to the idea of creating a standardized, national repository for "high quality" biospecimens?

- Mostly positive
- Positive
- Somewhat positive
- Somewhat negative
- Negative
- Mostly negative

Please elaborate. Tell us why you think this way. What potential benefits or drawbacks do you foresee?

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Perceptions of a Standardized Repository for Biospecimens (cont'd)



21. If a biorepository like the one described in this survey was created, how likely do you think you would be to obtain biospecimens from it for your work?

- Definitely would
- Very likely
- Somewhat likely
- Somewhat unlikely
- Very unlikely
- Definitely would not
- Don't know
- Does not apply to me

22. How willing would you be to contribute biospecimens to a national resource like the one described in this survey?

- Completely willing
- Very willing
- Somewhat willing
- Somewhat unwilling
- Very unwilling
- Not at all willing
- Don't know
- Does not apply to me

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Perceptions of a Standardized Repository for Biospecimens (cont'd)



23. Which of the following aspects do you think are the **most important** for a national resource to provide? (Mark up to 5 aspects that are most important to you.)

- Provide highly-annotated biospecimens
- Provide enough samples for statistical analyses
- Provide a central resource for investigators to access available biospecimens
- Provide quality criteria met by each biospecimen to allow researchers to choose biospecimens that fit the needs of their research
- Be available for inclusion in proposals as a trusted entity that could potentially expedite grant support
- Provide a searchable database to quickly find out information about biospecimens and locate available biospecimens
- Provide an equitable process to gain access to biospecimens
- Use an application process that appropriately matches the requirements of the proposed research and the characteristics of the biospecimens
- Serve as a standard for other groups that are establishing biorepositories
- Serve as a leader for standardized human subjects and HIPAA protocols to other groups collecting biospecimens
- Enable addition of follow-up data over time to biospecimen annotations
- Establish standardized quality control and assurance mechanisms
- Provide standardized "reference samples" to serve as controls during validation of discovery research and technology development
- Enable comparison of findings across research studies
- Enable interdisciplinary and multidisciplinary research
- Other (specify):

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Perceptions of a Standardized Repository for Biospecimens (cont'd)

% Completed

24. Based on the description of the proposed repository, how concerned are you about each of the following issues?

	Not at all concerned					Very concerned
Potential for the biorepository to shift funds from other current biomedical projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expense of such a biorepository	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establishment of appropriate procedures for being provided access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality of the biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of biospecimens relevant to my work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Potential for underusage because researchers will continue to use their current sources for biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Potential lack of long-term funding or commitment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inadequate infrastructure to manage such a large enterprise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Challenges posed by the U.S. medical system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intellectual property rights of investigators providing biospecimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being acknowledged appropriately for providing biospecimens to the biorepository	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Process for getting access to biospecimens could be unwieldy or time-consuming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appropriate protections for the rights of human subjects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. What other concerns, if any, would you have about a standardized biorepository resource?

Recommendations for Alternative Measures to Improve Access to "High Quality" Biospecimens



26. Of the following actions that NCI could take as an alternative to developing a national-scale biorepository for "high quality" biospecimens, which of these alternatives would you consider worth pursuing? (Choose up to three.)

- Developing a virtual biorepository that links researchers to biospecimens at various host institutions
- Supporting the infrastructure and science of biobanking with grants
- Managing a consortium of cancer centers to share biorepository practices and samples
- Continuing or expanding research on best practices for collecting, processing, storing and distributing high quality biospecimens
- Creating a smaller scale biorepository focused on specific or rare diseases
- Creating a smaller scale biorepository focused on reducing health disparities (e.g., collecting/providing biospecimens from underserved populations)
- Creating a smaller scale biorepository focused on providing biospecimens to particular researchers (e.g., investigators just beginning their careers)
- Developing a public partnership or campaign to increase interest among the public in donating biospecimens
- Developing a public partnership or campaign to increase interest among specific health care providers in collecting biospecimens
- Developing an outreach effort designed to foster greater collaboration and sharing among investigators

Please share any other suggested approaches that come to mind for fulfilling the mission of the NCI Office of Biorepositories and Biospecimen Research to make high quality biospecimens available.

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Final Thoughts



% Completed

27. Are there any other details about normal and cancer biospecimens or biorepositories that have not yet been mentioned that you would like to comment on? Please elaborate below.

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Survey Complete



% Completed

Thank you for completing this survey!

The information you provided will be useful as NCI explores issues and shapes solutions related to the availability of human specimens (biospecimens) for cancer research.

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