NCI Best Practices for Biospecimen Resources - Online Survey Instrument

National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov

Introduction

OMB No.: 0925-0642 Expiration Date: 9/30/2014

Dear colleagues,

The lack of standardized, high-quality biospecimens has been widely recognized as one of the most significant roadblocks to the progress of cancer research. To address this issue, the US National Cancer Institute (NCI) Biorepository Coordinating Committee and the NCI Biorepository and Biospecimen Research Branch (formerly OBBR) published a set of best practices as a resource for the biobanking community in 2007 and an updated version was published in 2011.

You have been identified as a key stakeholder who can provide important insights that will inform how we develop and promote the future editions of these best practices and we would appreciate your participation in this survey. The survey will take about 10 minutes to complete. All responses must be received by August 31, 2013. After that date, the survey will be closed.

Your input really matters to us. You can help if you deal with biospecimens in any capacity; whether you administer informed consent for banking biospecimens, you collect and handle biospecimens, or you prepare IRB proposals and MTAs involving biospecimens.

Thank you in advance for your time and thoughtfulness.

Start Survey

Sincerely,

Jim Vaught, PhD Chief, Biorepositories and Biospecimen Research Branch Cancer Diagnosis Program National Cancer Institute Bethesda, Maryland

If you experience any technical difficulties, please contact the survey administrator at User-Centered Design at survey@user-centereddesign.com

Privacy Statement and Consent

Your participation in this survey is completely voluntary. Your responses to the questions will be kept secure to the extent provided by law and your responses will never be linked or associated with you.

You are free to stop participating at any point during the survey and have your responses deleted by clicking the "Opt out of survey" box at the bottom of each survey page.

This brief survey should only require approximately ten (10) minutes of your time.

Please click the "Next" button if you consent to taking this survey.

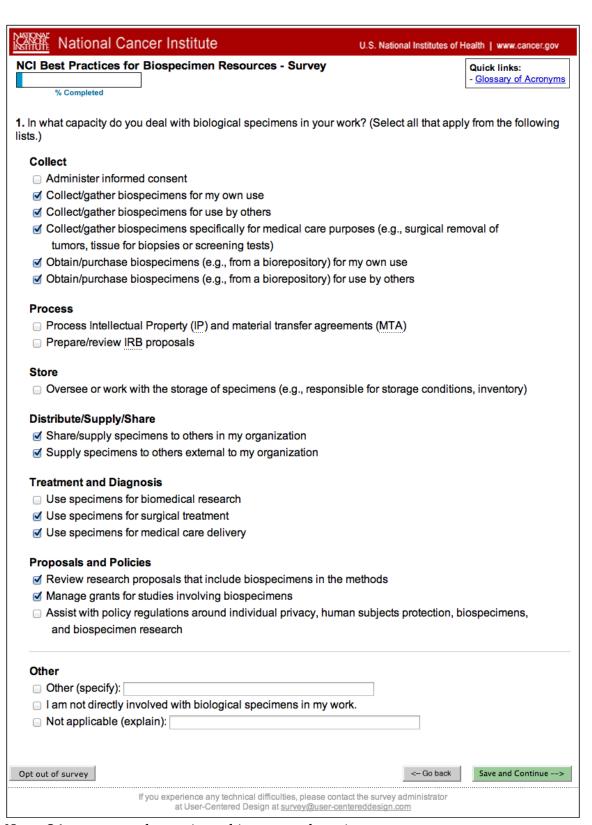
Opt out of survey

Next -->

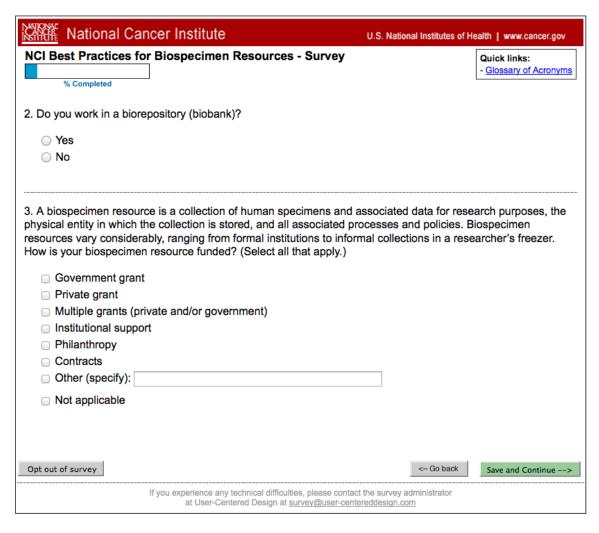
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Public reporting burden for this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0642). Do not return the completed form to this address.

If you experience any technical difficulties, please contact the survey administrator at User-Centered Design at survey@user-centereddesign.com

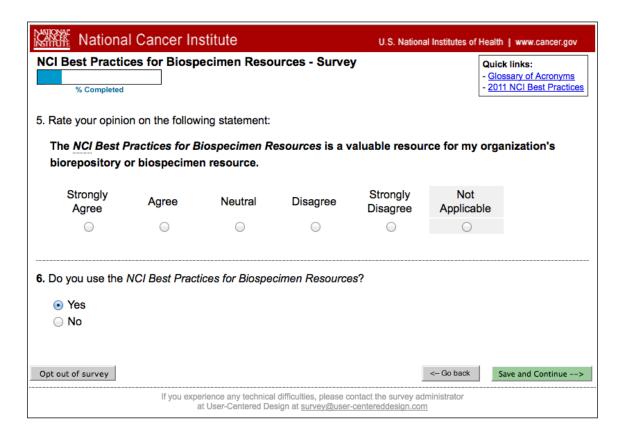


Note: Q1 responses determines skip pattern later in survey.

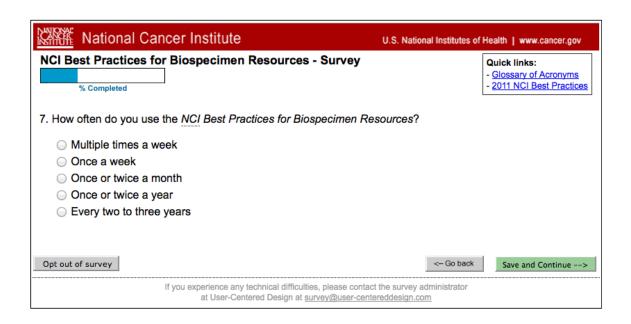


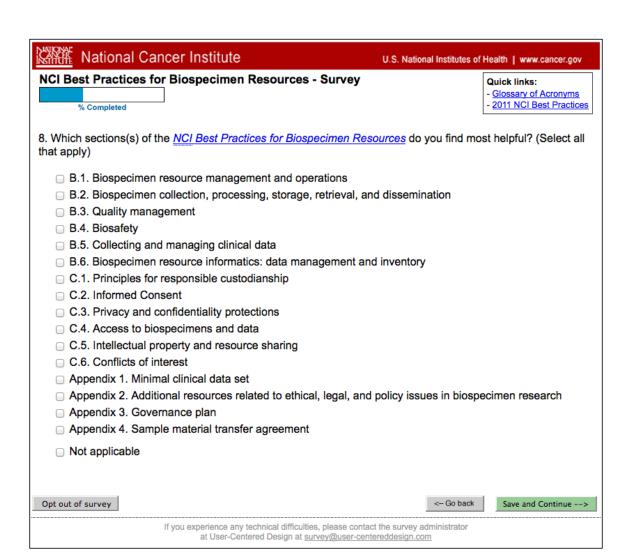


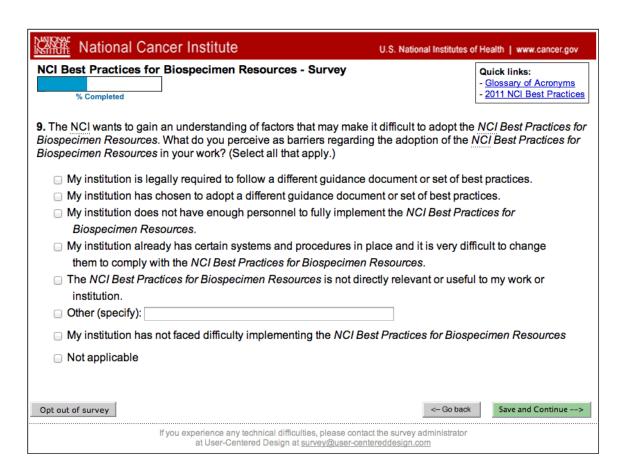
Note: If user selects "yes" to Q4, they proceed to Q5 below. If "no" is selected, they follow this alternative.

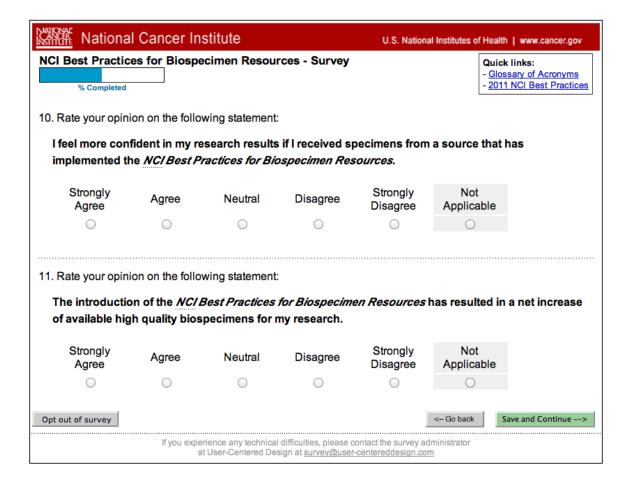


Note: if user selects "yes" to Q6, they proceed to Q7 below. If "no" is selected, they follow <u>this alternative</u>.

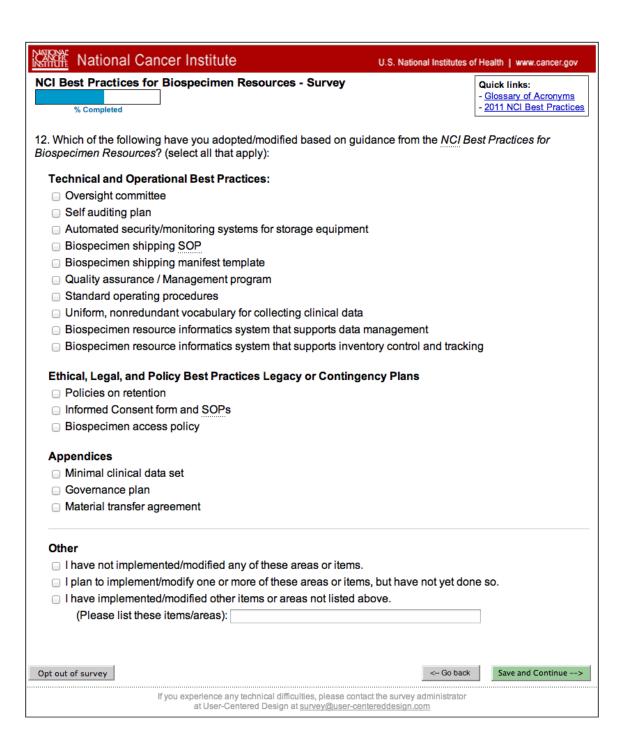








Note: Q10 and Q11 are asked only if user has selected any of the 11 options shown as checked in Q1 above. If none of those is selected, user proceeds from above to Q12 below. Questions renumber automatically as required by user's response pattern.



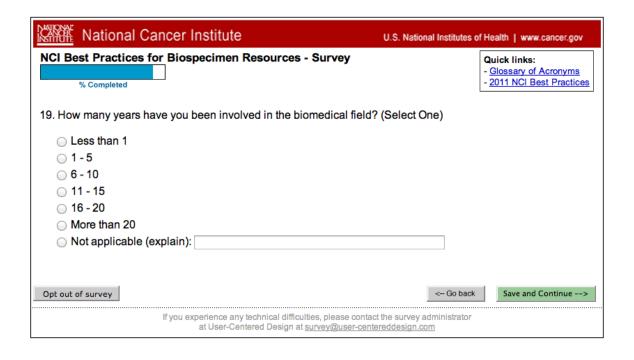
National Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey % Completed	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices
13. What information or additional topics would you like to see addr Practices for Biospecimen Resources?	ressed in future versions of the NCI Best
Opt out of survey	< Go back
If you experience any technical difficulties, please cont at User-Centered Design at <u>survey@user-ce</u>	

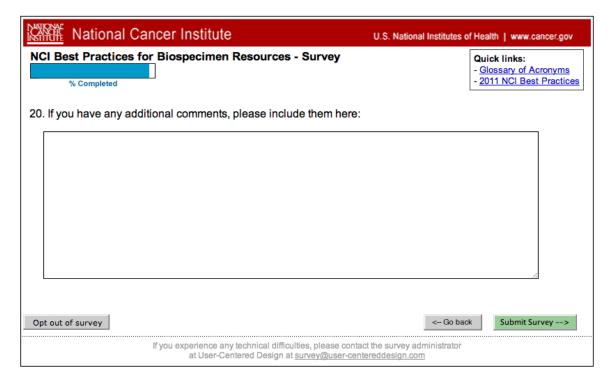
Nation	al Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practi	ces for Biospecimen Resources - Survey	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices
collection, process for carrying out continued the guidance. This evidence-based is would like your in evidence-based is below and rank the	eveloping a new project to provide evidence-based passing, and storage. These "Evidence-based Biospectrain procedures and will be annotated with summars guidance is intended to support the research combination of the procedures (SOPs) based on in a put regarding the biospecimen collection, processing guidance is most needed. Please review the list of Enem from 1-4 in order from lowest to highest priority our lowest priority as 1).	cimen Best Practices" will provide guidance aries of the scientific literature that pertains to amunity in the development and execution of advidual or institutional needs. The NCI ng, and storage procedures for which Evidence-based Biospecimen Best Practices
Plasma/se	ogen freezing procedural best practices frum processing procedural best practices ixation paraffin embedding best practices	
	frozen storage of tissue specimens best practices	
	idence-based Biospecimen Best Practices would you the NCI and published as a public product for the re-	-
Opt out of survey		< Go back Save and Continue>
	If you experience any technical difficulties, please contac at User-Centered Design at survey@user-cente	

National Cancer Institute	.S. National Institutes of Health www.cancer.gov	
NCI Best Practices for Biospecimen Resources - Survey % Completed	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices	
15. What other guidance documents/resources do you use in regards to biobanking besides the NCI Best Practices for Biospecimen Resources?		
 ISBER Best Practices for Repositories: Collection, Storage, Retrieval, and Distribution of Biological Materials for Research (any edition) 		
 □ College of American Pathologists (CAP) guidelines □ American Association of Tissue Banks Standards for Tissue Banking (any edition) 		
☐ World Health Organization, International Agency for Research on Cancer, Common Minimum		
Technical Standards and Protocols for Biological Resource Centres Organization for Economic Co-operation and Development (OECD) Best Practice Guidelines for		
Biological Resources Centres Australasian Biospecimen Network Biorepository Protocols		
Other (specify):		
☐ I do not use other guidance documents or resources in regards to	biobanking	
Opt out of survey	< Go back Save and Continue>	
If you experience any technical difficulties, please contact the survey administrator at User-Centered Design at <u>survey@user-centereddesign.com</u>		

National Cancer Institute	U.S. National Institutes of Health	www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey % Completed		links: sary of Acronyms NCI Best Practices
16. In what country are you currently working? (Select one)		
Select ‡		
17. In what type of organization are you currently working or involved applies.)	? (Please select the option	that most closely
Academic/research institution		
 NCI-designated cancer center 		
Other cancer center		
 Hospital, clinic, or other healthcare setting 		
National Cancer Institute (NCI)		
 US National Institutes of Health institute (other than the NCI) 		
 US Federal government agency (other than the NIH) 		
US State/local government agency (other than academic instit	utions)	
○ Government (non-US)		
○ State (non-US)		
 Nonprofit organization (e.g., foundation) 		
Advocacy organization		
 Pharmaceutical/biotechnology company 		
Other biomedical company		
Other (specify):		
Opt out of survey	< Go back	ve and Continue>
If you experience any technical difficulties, please contac at User-Centered Design at <u>survey@user-cent</u>		

National Cancer Institute	U.S. National Institutes of Hea	alth www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey % Completed	- <u>G</u>	ick links: lossary of Acronyms 011 NCI Best Practices
18. Which of the following best describes your primary role on a datield)? (Select the option that most closely applies.)	y-to-day basis (as it relate	s to the biomedical
Clinical researcher		
Surgeon		
○ Oncologist		
Non-oncologist 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		
Environmental biology researcher / biobanker		
Human subjects or regulatory affairs specialist		
Other: (specify):		
Opt out of survey	< Go back	Save and Continue>
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National Cancer Institute	U.S. National Institutes of Health www.cancer.gov	
NCI Best Practices for Biospecimen Resources - Survey % Completed		
Thank you for completing this survey! Your responses to the questions will be kept secure to the extent provided by law and your responses will never be linked or associated with you. Your responses have been submitted.		
If you wish to receive further updates regarding the NCI Best Practices for Biospecimen Resources, please click here. Please note, this request is separate from the survey you just completed. Your contact information will not be shared with anyone and your name will be not tied in any way to your survey responses.		
If you do not wish to opt in to the mailing list, you may now close this window.		
If you experience any technical difficulties, please o at User-Centered Design at <u>survey@user-</u>		

Clicking on the link above will bring to user to this form:

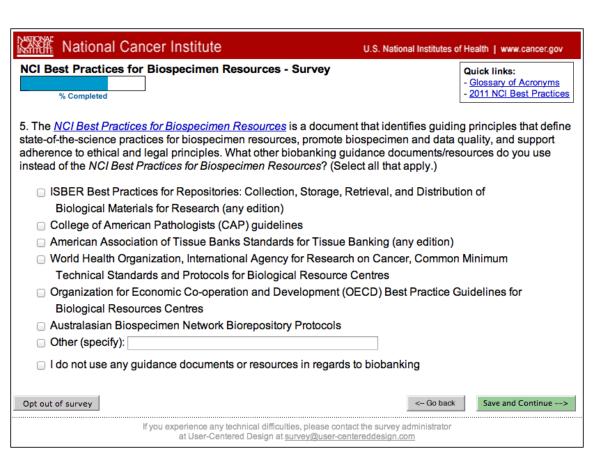
National Ca	ncer Institute	U.S. National Institutes of Health www.cancer.gov
If you wish to receive fur provide the contact infor	ther updates regarding the NCI Best Practice mation below.	s for Biospecimen Resources, please
Name:		
Business Phone:		
Business Email:		
Your Organization:		
		Submit
	If you experience any technical difficulties, please contact at User-Centered Design at survey@user-cente	

National Cancer Institute	U.S. National Institutes of Health www.cancer.gov		
Thank you for your time.			
You may now close this window.			
If you experience any technical difficulties at User-Centered Design at <u>sur</u>			

END of Survey.

Alt #1: User selects "NO" to Q4:

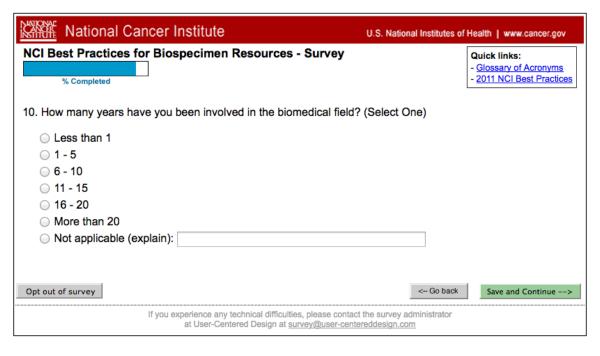


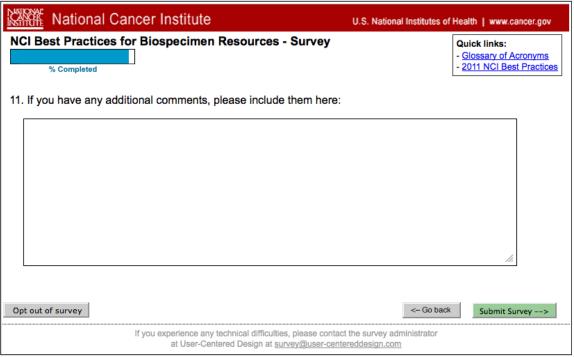


National Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey % Completed	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices
6. The NCI is developing a new project to provide evidence-based procollection, processing, and storage. These "Evidence-based Biospeci for carrying out certain procedures and will be annotated with summate to the guidance. This guidance is intended to support the research coof evidence-based Standard Operating Procedures (SOPs) based on would like your input regarding the biospecimen collection, processing evidence-based guidance is most needed. Please review the list of Enbelow and rank them from 1-4 in order from lowest to highest priority as 4 and rank your lowest priority as 1).	men Best Practices" will provide guidance ries of the scientific literature that pertains mmunity in the development and execution individual or institutional needs. The NCI g, and storage procedures for which vidence-based Biospecimen Best Practices
Liquid nitrogen freezing procedural best practices	
Plasma/serum processing procedural best practices	
Formalin-fixation paraffin embedding best practices	
Prolonged frozen storage of tissue specimens best practices	
What other Evidence-based Biospecimen Best Practices would you developed by the NCI and published as a public product for the res	
	fi.
Opt out of survey	< Go back Save and Continue>
If you experience any technical difficulties, please contact l at User-Centered Design at <u>survey@user-center</u>	

National Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices
7. In what country are you currently working? (Select one)	
Select \$	
8. In what type of organization are you currently working or involved? applies.)	? (Please select the option that most closely
Academic/research institution	
NCI-designated cancer center	
Other cancer center	
 Hospital, clinic, or other healthcare setting 	
National Cancer Institute (NCI)	
 US National Institutes of Health institute (other than the NCI) 	
US Federal government agency (other than the NIH)	
US State/local government agency (other than academic instit	tutions)
Government (non-US)	
○ State (non-US)	
 Nonprofit organization (e.g., foundation) 	
 Advocacy organization 	
 Pharmaceutical/biotechnology company 	
Other biomedical company	
Other (specify):	
Opt out of survey	< Go back Save and Continue>
If you experience any technical difficulties, please contact at User-Centered Design at survey@user-cente	

National Cancer Institute	U.S. National Institutes of He	ealth www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey	-	Quick links: Glossary of Acronyms
% Completed		2011 NCI Best Practices
9. Which of the following best describes your primary role on a da field)? (Select the option that most closely applies.)	y-to-day basis (as it relate	es to the biomedical
Clinical researcher		
○ Surgeon		
○ Oncologist		
Non-oncologist 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)		
O Policy analyst		
Health educator		
O Patient / patient advocate		
Biorepository manager		
Environmental biology researcher / biobanker		
Human subjects or regulatory affairs specialist		
Other: (specify):		
Opt out of survey	< Go back	Save and Continue>
If you experience any technical difficulties, please cont at User-Centered Design at survey@user-ce		





National Cancer Institute	U.S. National Institutes of Health www.cancer.gov	
NCI Best Practices for Biospecimen Resources - Survey % Completed		
Thank you for completing this survey! Your responses to the questions will be kept secure to the extent provided by law and your responses will never be linked or associated with you. Your responses have been submitted.		
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If you do not wish to opt in to the mailing list, you may now close this window.		
lf you experience any technical difficulties, please of at User-Centered Design at <u>survey@user-</u>		

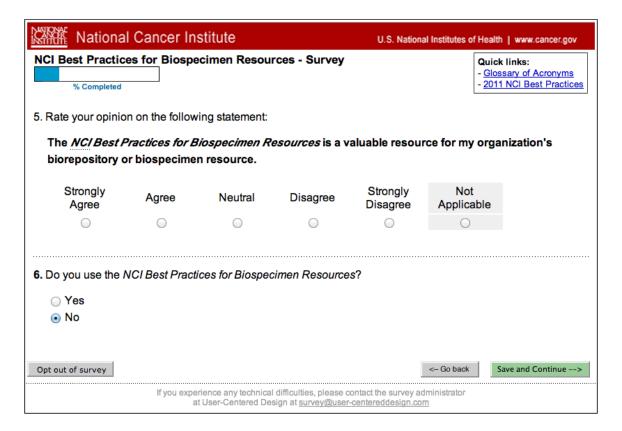
Clicking on the link above will bring to user to this form:

National Ca	ncer Institute	U.S. National Institutes of Health www.cancer.gov
If you wish to receive fur provide the contact infor	rther updates regarding the <i>NCI Best Practice</i> mation below.	s for Biospecimen Resources, please
Name:		
Business Phone:		
Business Email:		
Your Organization:		
		Submit
	If you experience any technical difficulties, please contact at User-Centered Design at survey@user-cente	

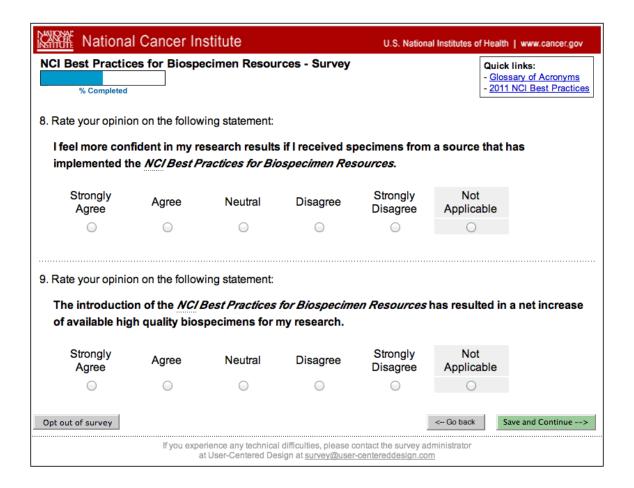
National Cancer Institute	U.S. National Institutes of Health www.cancer.gov	
Thank you for your time.		
You may now close this window.		
If you experience any technical difficulties at User-Centered Design at <u>sun</u>		

END of survey.

Alt #2: User selects "NO" to Q6:



National Cancer Institute	U.S. National Institutes of Health www.cancer.gov	
NCI Best Practices for Biospecimen Resources - Survey % Completed	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices	
7. The NCI wants to gain an understanding of factors that may make a Biospecimen Resources. What do you perceive as barriers regarding Biospecimen Resources in your work? (Select all that apply.)		
 My institution is legally required to follow a different guidance of 	ocument or set of best practices.	
My institution has chosen to adopt a different guidance document or set of best practices.		
 My institution does not have enough personnel to fully implement the NCI Best Practices for 		
Biospecimen Resources.		
them to comply with the NCI Best Practices for Biospecimen I		
☐ The NCI Best Practices for Biospecimen Resources is not dire	ctly relevant or useful to my work or	
institution.		
Other (specify):		
□ Not applicable		
Opt out of survey	< Go back Save and Continue>	
If you experience any technical difficulties, please contac at User-Centered Design at <u>survey@user-cente</u>		



Note: Q8 and Q9 are asked only if user has selected any of the 11 options shown as checked in Q1 above. If none of those is selected, user proceeds from Q7 above to Q10 below. Questions renumber automatically as required by user's response pattern.

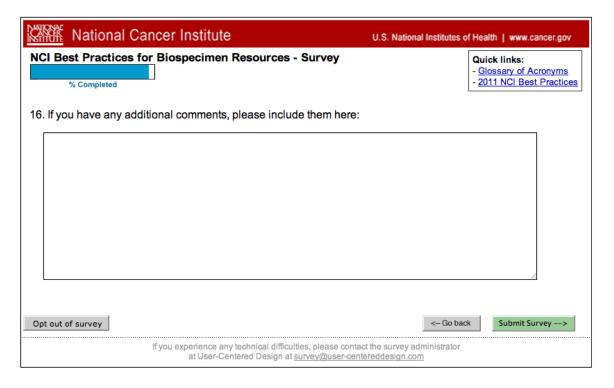
National Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey % Completed	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices
10. What guidance documents/resources do you use in regards to bio	obanking?
 ISBER Best Practices for Repositories: Collection, Storage, Re Biological Materials for Research (any edition) College of American Pathologists (CAP) guidelines American Association of Tissue Banks Standards for Tissue Ba World Health Organization, International Agency for Research Technical Standards and Protocols for Biological Resource C Organization for Economic Co-operation and Development (OB Biological Resources Centres Australasian Biospecimen Network Biorepository Protocols Other (specify): 	anking (any edition) on Cancer, Common Minimum Centres
☐ I do not use other guidance documents or resources in regards Opt out of survey	s to biobanking <- Go back Save and Continue>
If you experience any technical difficulties, please contact at User-Centered Design at survey@user-cente	ct the survey administrator

National Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey % Completed	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices
11. The NCI is developing a new project to provide evidence-based prollection, processing, and storage. These "Evidence-based Biospector carrying out certain procedures and will be annotated with summathe guidance. This guidance is intended to support the research comevidence-based Standard Operating Procedures (SOPs) based on in would like your input regarding the biospecimen collection, processing evidence-based guidance is most needed. Please review the list of Ebelow and rank them from 1-4 in order from lowest to highest priority as 4 and rank your lowest priority as 1).	cimen Best Practices" will provide guidance tries of the scientific literature that pertains to munity in the development and execution of adividual or institutional needs. The NCI ag, and storage procedures for which evidence-based Biospecimen Best Practices
Liquid nitrogen freezing procedural best practices Plasma/serum processing procedural best practices Formalin-fixation paraffin embedding best practices Prolonged frozen storage of tissue specimens best practices	
What other Evidence-based Biospecimen Best Practices would yo developed by the NCI and published as a public product for the re-	,
	4
Opt out of survey	< Go back Save and Continue>
If you experience any technical difficulties, please contac at User-Centered Design at <u>survey@user-cent</u> e	

National Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practices for Biospecimen Resources - Sur	
12. In what country are you currently working? (Select one) Select :	
13. In what type of organization are you currently working or applies.)	involved? (Please select the option that most closely
Academic/research institution	
 NCI-designated cancer center 	
Other cancer center	
 Hospital, clinic, or other healthcare setting 	
 National Cancer Institute (NCI) 	
OUS National Institutes of Health institute (other than the	e NCI)
 US Federal government agency (other than the NIH) 	
 US State/local government agency (other than acade 	mic institutions)
○ Government (non-US)	
○ State (non-US)	
 Nonprofit organization (e.g., foundation) 	
 Advocacy organization 	
 Pharmaceutical/biotechnology company 	
Other biomedical company	
Other (specify):	
Opt out of survey	< Go back
Fugure registrate and to place and the second secon	and contact the current administrator
lf you experience any technical difficulties, plo at User-Centered Design at <u>survey</u> (

National Cancer Institute	U.S. National Institutes of Health www.cancer.gov
NCI Best Practices for Biospecimen Resources - Survey % Completed	Quick links: - Glossary of Acronyms - 2011 NCI Best Practices
14. Which of the following best describes your primary role on a day field)? (Select the option that most closely applies.)	-to-day basis (as it relates to the biomedical
Clinical researcher Surgeon Oncologist Non-oncologist 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 Environmental biology researcher / biobanker Human subjects or regulatory affairs specialist Other: (specify):	< Go back
If you experience any technical difficulties, please contact	





National Cancer Institute	U.S. National Institutes of Health www.cancer.gov	
NCI Best Practices for Biospecimen Resources - Survey		
Thank you for completing this survey! Your responses to the questions will be kept secure to the extent provided by law and your responses will never be linked or associated with you. Your responses have been submitted.		
If you wish to receive further updates regarding the NCI Best Practices for Biospecimen Resources, please click here. Please note, this request is separate from the survey you just completed. Your contact information will not be shared with anyone and your name will be not tied in any way to your survey responses.		
If you do not wish to opt in to the mailing list, you may now close this window.		
If you experience any technical difficulties, please cont at User-Centered Design at <u>survey@user-ce</u> r		

Clicking on the link above will bring to user to this form:

National Ca	ncer Institute	U.S. National Institutes of Health www.cancer.gov
If you wish to receive fur provide the contact infor	rther updates regarding the <i>NCI Best Practice</i> mation below.	s for Biospecimen Resources, please
Name:		
Business Phone:		
Business Email:		
Your Organization:		
		Submit
	If you experience any technical difficulties, please contact at User-Centered Design at survey@user-cente	

National Cancer Institute	U.S. National Institutes of Health www.cancer.gov	
Thank you for your time.		
You may now close this window.		
If you experience any technical difficulties at User-Centered Design at <u>sun</u>		

END of survey.