

ATTACHMENT 5
**Formative Research to Guide Development of the
Cancer Biomedical Informatics Grid (caBIG)**

**OMB #0925-0046-02
Exp. Date: 10/31/2006**

**National Cancer Institute
Cancer Biomedical Informatics Grid (caBIG)
Needs Assessment Web Survey**

[INITIAL SCREEN]

The National Cancer Institute (NCI) is conducting a survey to gather information about cancer researchers' bioinformatics needs and to determine how best to focus the development of the Cancer Biomedical Informatics Grid (caBIG). Your answers to these questions will help to guide the future development of caBIG to ensure that it best meets your needs.

Your participation in this survey is completely voluntary. Please be assured that your responses will be kept confidential and will not be disclosed to anyone except the researchers conducting the survey, except as otherwise required by law. Data will be provided to the NCI in aggregate form only, with any potentially identifying information removed. You may skip any questions that you prefer not to answer. This survey should take approximately 20 minutes to complete.

Content-related questions about this survey should be directed to Caitlin O'Brien at o'brien_caitlin@bah.com. Technical questions should be directed to poet@novaresearch.com.

Begin Survey

Section A—General Questions about caBIG. The first few questions are related to how caBIG may meet your bioinformatics needs and those of the broader cancer research community. If you are unfamiliar with caBIG or feel that you need a brief overview before you begin this survey, click here – [About caBIG](#) (PDF, [Click to download](#) Adobe Acrobat reader) – for a short description. Otherwise, please continue.

1. How familiar are you with caBIG?
 - a. Very familiar (i.e., you are already working with caBIG, or have extensive knowledge of it).
 - b. Somewhat familiar (i.e., you’ve read or heard details about caBIG prior to today).
 - c. Only slightly familiar (i.e., you know only what was provided in the brief overview to this survey).
 - d. Not at all familiar (i.e., have no knowledge of caBIG and didn't have time to read the brief overview).
[If d, answer only Q2, Q8-10, Sections D and E, and then end survey]

2. Which of the following best describes your (and your institution’s) most pressing overarching bioinformatics needs? (Check all that apply)
 - a. Data integration
 - b. Data management
 - c. Data sharing with others in the cancer research community
 - d. Sharing of techniques/tools
 - e. Standardization of data reporting
 - f. Vocabularies and common data elements
 - g. Other (Please specify)
 - h. Don’t know

3. Below is a list of your responses to the previous question about your informatics needs. For each, please specify if you think caBIG will address your needs or not. There are no “right or wrong” answers to this question. You should answer based on your knowledge of caBIG. *[Note to Reviewer: Only answer selections from Q2 will appear below in web version of survey.]*

	Yes, caBIG <u>will</u> address this need.	No, caBIG <u>will not</u> address this need	Don’t know
a. Data sharing with others in the cancer research community			
b. Sharing of techniques/tools			
c. Standardization of data reporting			
d. Vocabularies and common data elements			
e. Data integration			
f. Data management			
g. Other (Please specify)			

4. Which one of the following statements best describes the impact that you feel caBIG will have on **your work** by the end of the three-year pilot test?
 - a. I feel that caBIG will *greatly enhance* my work.
 - b. I feel that caBIG will *somewhat enhance* my work.
 - c. I do not feel that caBIG will affect my work *at all*.
 - d. I feel that caBIG will *somewhat detract* from my work.
 - e. I feel that caBIG will *greatly detract* from my work.
 - f. Don’t know

5. Which of the following statements best describes the impact that you feel caBIG will have on the work of the cancer research community as a whole when the project is completed?
- I feel that caBIG will *greatly enhance* the research.
 - I feel that caBIG will *somewhat enhance* the research.
 - I do not feel that caBIG will affect the research *at all*.
 - I feel that caBIG will *somewhat detract* from the research.
 - I feel that caBIG will *greatly detract* from the research.
 - Don't know
6. Thinking about the **cancer research community as a whole**, what specific collaborative efforts do you think could be made more efficient with appropriate support from caBIG?
Please type your response in the space below:
-
-

Don't Know

7. How can caBIG be modified to maximize its benefit to the cancer research community?
Please type your response in the space below:
-
-

Don't Know

Section B—Data Sharing. One goal of caBIG is to enable data sharing among members of the cancer research community. The next few questions are related to data sharing and the concept of intellectual property.

8. With regard to sharing your data, is intellectual property a concern for you?
- Yes
 - No **SKIP to Q11**
 - Don't Know **SKIP to Q11**
9. Which of the following are concerns for you in regard to intellectual property and caBIG (Check all that apply)?
- Risk of data being interpreted out of context
 - Patient privacy
 - Need to restrict access to data prior to publication
 - Assignment of credit to primary investigator for the development of data in subsequent, follow-up research
 - Other (Please specify)
 - Don't Know
10. What is the best way to address your concern (Check all that apply)?
- Identify patients willing to share their data for research purposes
 - Patient anonymity via encryption
 - Restricted access until principal investigator sign-off and/or publication
 - Secure electronic information exchange using electronic signatures, smart cards, biometrics and similar technology
 - Other (Please specify)
 - Don't Know

11. Which of the following best describes how you prefer to provide your data for use on caBIG (Check all that apply)?
- Share all data (i.e. raw data, tools/techniques) post-publication only
 - Share all data (i.e. raw data, tools/techniques) pre-publication
 - Share all data (i.e. raw data, tools/techniques) pre- and post-publication
 - Share only information on tools/techniques
 - Share only “incidental” data that is not relevant to study outcomes
 - Share unpublished results at some future time
 - Other (Please specify)
 - Don’t Know
12. Which of the following statements do you most agree with related to the data that is shared on caBIG?
- Both current and past data should be shared
 - Only current data should be shared
 - Only past data should be shared
 - Don’t know

Section C1—caBIG Workspaces. The next few questions will ask you about the caBIG **Workspaces**. Below is a brief description of caBIG **Workspaces** that may help you answer the questions in this section.

caBIG Workspaces are defined as focal areas for caBIG developmental activities. Three domain Workspaces are currently being developed as a result of previous input from the Cancer Center community. The domain Workspaces are:

- Clinical Trial Management Systems Workspace
- Integrative Cancer Research Workspace (i.e. bench to bench, bench to bedside, etc.)
- Tissue Banks and Pathology Tools Workspace

Additionally, two cross cutting Workspaces are focused on producing documentation and tools to support greater consistency and congruence between the domain areas. The cross cutting Workspaces are:

- [Vocabulary and Common Data Elements](#)
- [Architecture](#)

If you feel like you need more information on Workspaces before you complete the next few survey questions, [click here](#) (PDF, [Click to download](#) Adobe Acrobat reader). Otherwise continue on to the next survey question.

13. How well do these Workspaces cover your areas of need?
- These Workspaces adequately cover my areas of needs.
 - I would like to see other domain Workspaces developed. (Please briefly specify in the space below the domain Workspaces you would like to see developed for caBIG.)
-
-
- c. Don’t Know

14. Which of the following **domain** Workspaces is relevant to the work you do (Check all that apply)?
- Clinical Trials Management
 - Integrative Cancer Research
 - Tissue Banks and Pathology Tools
 - Don’t Know **SKIP to Q24**

[Note to Reviewer: Respondents will only answer questions in the next sections if they identify the Workspace as “relevant” in Q14; we found in focus group testing that participants were unable to provide useful information for Workspaces they perceived as not directly related to their work.]

Section C2—Clinical Trials Management Systems Workspace. The next few questions will ask specifically about the **Clinical Trials Management Systems Workspace**.

15. How would you rate each of the following features related to the **Clinical Trials Management Systems Workspace** in terms of how important it is to your work or that of the broader cancer research community?

	Very important	Somewhat important	Unimportant	Don't Know
a. Adverse Events Reporting				
b. CDU/Theradex/CTEP Reporting				
c. Financial/Billing				
d. Interfaces to Lab Systems				
e. Internal Review Board Management				
f. Patient Management				
g. Patient Recruitment				
h. Quality-of-Life Tools				
i. Study Monitoring				
j. Study Protocol Design				

15a. Would you be interested in accessing shared clinical research data information through the caBIG structure?

- a. Yes
- b. No
- c. Don't Know

15b. With appropriate confidentiality measures in place, would you be willing to share your own clinical research data through the caBIG structure?

- a. Yes
- b. No
- c. Don't Know

16. What other areas (if any) do you feel should be addressed in the Clinical Trials Workspace in order for it to benefit your research or that of the broader cancer research community?

Please type your response in the space below:

Don't Know

17. What concerns do you have (if any) about potential barriers in regard to the Clinical Trials Workspace?

Please type your response in the space below:

Don't Know

Section C3— Integrative Cancer Research Workspace. The next few questions will ask specifically about the **Integrative Cancer Research Workspace**.

18. How would you rate each of the following features related to the **Integrative Cancer Research Workspace** in terms of how important it is to your work or that of the broader cancer research community?

	Very important	Somewhat important	Unimportant	Don't Know
a. CGH				
b. Correlations among Different Types of Data				
c. Data Collection, Storage, Retrieval				
d. DNA/RNA Sequencing				
e. Gene Expression/Microarrays				
f. Immunohistochemistry				
g. Modeling and Pathway Analysis				
h. Proteomics, Protein Expression				
i. SNPs				
j. Statistics (Experiment Analysis and/or Population Incidence)				
k. Study Protocol Design, Standardization, Submission				
l. Tissue Arrays				

18a. How important is it to you to gain shared access to the following types of data?

	Very important	Somewhat important	Unimportant	Don't Know
a. CGH Data				
b. DNA/RNA Sequencing Data				
c. Gene Expression/Microarrays Data				
d. Immunohistochemistry Data				
e. Modeling and Pathway Analysis Data				
f. Proteomics, Protein Expression Data				
g. SNPs Data				
h. Tissue Arrays Data				

18c. Would you be willing to share your own data through the caBIG structure?

- a. Yes
- b. No
- c. Don't Know

19. What other areas (if any) do you feel should be addressed in the Integrative Cancer Research Workspace in order for it to benefit your research or that of the broader cancer research community?

Please type your response in the space below:

Don't Know

20. What concerns do you have (if any) about potential barriers in regard to the Integrative Cancer Research Workspace?

Please type your response in the space below:

Don't Know

Section C4—Tissue Banks and Pathology Tools Workspace. The next few questions will ask specifically about the **Tissue Banks and Pathology Tools Workspace**.

21. How would you rate each of the following features related to the **Tissue Banks and Pathology Tools Workspace** in terms of how important it is to your work or that of the broader cancer research community?

	Very important	Somewhat important	Unimportant	Don't Know
a. Anatomy, Organ Physiology				
b. Data Management: Labeling, Tracking				
c. Environmental Testing				
d. Histology/Histotechnology				
e. Imaging/Visualization				
f. Immunology, Serology				
g. Microbiological Testing				
h. Pathology, Morphometrics				
i. PCR Testing				
j. Storage, Preservation				

21a. Would you be interested in gaining shared access to tissue bank information through the caBIG structure?

- a. Yes
- b. No
- c. Don't Know

21b. Would you be willing to share tissue bank information through the caBIG structure?

- a. Yes
- b. No
- c. Don't Know

22. What other areas (if any) do you feel should be addressed in the Tissue Banks and Pathology Tools Workspace in order for it to benefit your research or that of the cancer research community, in general?

Please type your response in the space below:

Don't Know

23. What concerns do you have (if any) about potential barriers in regard to the Tissue Banks and Pathology Tools Workspace?

Please type your response in the space below:

Don't Know

Section C5—Cross Cutting Workspaces. The next few questions will ask specifically about the two **Cross Cutting Workspaces** (i.e. [Vocabulary and Common Data Elements](#) and [Architecture](#)).

24a. Have you used common data elements in your work in the past?

- a. Yes
- b. No
- c. Don't Know

24b. How important are data standards to your work?

- a. Very important
- b. Somewhat important
- c. Unimportant
- d. Don't Know

24c. Do you have specific needs with regard to standard vocabulary that should be considered as caBIG is developed?

Please type your response in the space below:

Don't Know

25a. Are you familiar with what the caBIG architecture is?

- a. Yes
- b. No
- c. Don't Know

25b. How important do you think it is that the NCI adopt a common information architecture?

- a. Very important
- b. Somewhat important
- c. Unimportant
- d. Don't Know

25c. Would you be willing to develop tools utilizing a common architecture?

- a. Yes
- b. No
- c. Don't Know

25d. Do you think the caBIG architecture will facilitate informatics application development?

- a. Yes
- b. No
- c. Don't Know

25e. Do you have specific needs with regard to architecture that should be considered as caBIG is developed?

Please type your response in the space below:

Don't Know

Section D—caBIG Training Preferences. The next few questions will ask you about your **preferences** for training on caBIG, including its tools, resources, and other components and **availability** of specific training technologies in your work environment.

26. **How much time would you be willing to devote to learn about using a caBIG resource?**

- a. None
- b. 1-2 hours
- c. 3-4 hours
- d. 5-8 hours
- e. 9-12 hours
- f. 12+ hours
- g. Don't Know

27. **In terms of caBIG training, how useful would you find each of the following methods?**

	Very useful	Somewhat useful	Not useful	Don't Know
a. caBIG Overview (1-2 hours)				
b. CD-ROM Training				
c. Face-to-face Training (More than 1 day)				
d. Face-to-face Training (1 day or less)				
e. Self-study Documents				
f. Training Video				
g. Web-based Training				
h. Webcast (Archived)				
i. Webcast (Interactive)				
j. Workshops at a Scientific Meeting				
k. Other (Please specify)				

28. **When you don't have the opportunity to attend face-to-face training, how helpful are these other training resources to you?**

	Very helpful	Somewhat helpful	Unhelpful	Don't Know
a. Written Documentation (e.g., user manuals, "how-to" guides)				
b. Technical Support using Telephone, Email, etc.				
c. Webcast				

29. **Which of these training platforms do you have available in your work environment?**

	Available	Unavailable	Don't Know
a. High Speed Internet Connection (56 Kbps and above)			
b. VPN access to SWAN			
c. CD-ROM drive			

d. Audio output from your computer			
e. Audio tape player			
f. Telephone			
g. Video tape player (any format)			
h. Video recorder			
i. Videoconferencing equipment			

30. Which of these platforms do you have access to in your office?

	Available	Unavailable	Don't Know
a. Windows 95/98/ME?			
b. Windows NT/2000/XP?			
c. Mac OS prior to OSX?			
d. Mac OSX?			
e. Linux?			
f. Other UNIX? (Please specify)			

31. Which platform do you use most often?

- a. Windows 95/98/ME?
- b. Windows NT/2000/XP?
- c. Mac OS prior to OSX?
- d. Mac OSX?
- e. Linux?
- f. Other UNIX? _____
- g. Don't Know

Section E—Demographic Information. This last item is for you to tell us about yourself, so that we can consider your information within the context of your role as part of the cancer research community.

32. Which best describes you (Check all that apply)?

- a. Cancer Center Administrator
- b. Clinical Trialist
- c. Clinician
- d. Database Manager
- e. Epidemiologist
- f. Extramural Scientist
- g. Geneticist
- h. Informatics Expert
- i. Intramural Scientist
- j. Molecular Biologist
- k. Other (Please specify)

33. In which state do you live?:
[50-state dropdown menu here].

Please click the “SUBMIT SURVEY” button to complete the survey, and thank you for answering these questions. Your feedback will help guide the future development of caBIG.

[Final screen:]
The survey is now complete.



Thank you for your time.

For more information about the Cancer Biomedical Informatics Grid (caBIG) visit <http://cabig.nci.nih.gov/caBIG/>. If you would like to receive information on the caBIG initiative via the caBIG mailing list, please go to http://list.nih.gov/archives/cabig_announce.html and sign up.