Assessing the Need for a Standardized Cancer HUman Biobank (caHUB): Findings From a National Survey With Cancer Researchers

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Background  
Before developing a national standardized cancer HUman Biobank (caHUB), the National Cancer Institute sought feedback from the cancer research community.

Methods  
NCI conducted an online survey (N = 727) about current biospecimen needs and reactions to creating a national resource cancer researchers and others.

Results  
Most (56%) participants obtained biospecimens within their own institutions, and 63% wanted more information about their biospecimens. Large proportions reported difficulty obtaining biospecimens of adequate numbers (39%) and quality (47%). Low-quality biospecimens resulted in 60% questioning their findings and 81% limiting the scope of their work. Nine in every 10 (91.3%) respondents reacted positively to the idea of a national biospecimen resource, with 62% reporting that they would obtain biospecimens from it and 53% reporting that they would be willing to contribute biospecimens to it.

Conclusions  
Initial reactions to caHUB were positive and seen as a feasible option to addressing respondents’ research challenges. National Cancer Institute will need to address several concerns to assure its adoption, including standardization and sustainability.

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The National Cancer Institute (NCI) recognizes that high-quality biospecimens with appropriate clinical annotation are critical to advancing basic and translational cancer research, particularly with the development of genomic research, in which researchers are searching for the specific genes and proteins responsible for cancers’ start and spread (1). The current system for collecting and maintaining biospecimens, however, has been described as decentralized and ad hoc, resulting in poor quality biospecimens, inefficient processes, and limited utility (1). Several other countries have begun efforts to develop infrastructure for national biobanking systems (1), and NCI has also been exploring the need for and feasibility of such a resource (called the cancer HUman Biobank (caHUB)) in the United States to make high-quality tissues and data available to the cancer research community.

Before moving forward with plans for a national caHUB, the NCI Office of Biorepositories and Biospecimen Research (OBBR) collaborated with the NCI Office of Communications and Education to conduct a survey with NCI’s grantee cancer research community. This community included stakeholders representing a variety of roles related to biospecimen research, including laboratory scientists, clinical researchers, biorepository managers, and others. These are people who might want to acquire biospecimens or contribute biospecimens from such a resource. Input from this specified group was deemed critical to assess the extent to which caHUB would be used, determine a market for such a resource, identify important considerations for the resource’s development, and identify potential barriers that might need to be addressed to ensure success.

Seeking input from these cancer research constituencies was critical for several reasons. The potential rewards of a well-executed resource like caHUB are significant, but the potential risks of creating such a resource without fully understanding design considerations and the contours of the market for it are even more substantial. Without input from the intended users, there is a potential risk of myopic “technological utopianism”—that is, flawed thinking that “amplifies the possibility of valued social change, and underplays the possibilities of significant problems as a byproduct of the technology” (2). Moreover, as Gilb (3) described, “Once a system is in development, correcting a problem costs 10 times as much as fixing the same problem in design. [Once released], it costs 100 times as much.” Furthermore, although caHUB has the potential to revolutionize aspects of cancer research, it will only be useful—and worth the investment of resources—if researchers need, want, use, and value it.

Including the input of various groups in the needs assessment process also creates a culture of collaboration rather than limiting the relationship to supplier and consumer (4). The active engagement of the intended user groups will be necessary to the long-term success of a national caHUB by building buy-in and commitment to the effort. Stakeholders must also be active partners in building the inventory of biospecimens and helping to decide how the biospecimens will be disseminated among the research community.
To understand the views of potential users and contributors, NCI conducted a survey with its grantee cancer research audience, while caHUB was still in its conceptual stages. The survey was designed to illuminate researchers’ current biospecimen needs, collect reactions to the idea of caHUB, and gauge perceived advantages and challenges of a resource like caHUB.

Methods
Sample and Instrument
Potential users and contributors to a national caHUB were defined as NCI-funded cancer researchers who conduct tissue-based research, patient and research advocates, and biobank managers. A list was compiled of 5314 potential participants composed of NCI grantees and NCI-affiliated collaborators. The NCI did not have the ability to parse this list of participants by those who had direct involvement with biospecimens. The invitation specifically requested that if the recipient did not have direct involvement with biospecimens, they pass the invitation to persons in their institution who did. Therefore, the list of 5314 represented a population broader than the intended target audience.

Before development of the instrument, 22 in-depth interviews were conducted with National Institutes of Health stakeholders and select members of the target audiences, including NCI-funded researchers, biobank managers, and patient and research advocates. These interviews focused on the availability and perceived quality of biospecimens currently available; barriers to access and quality; and potential solutions for improving availability, access, and quality. Interviewees were also asked specifically to react to the idea of a national centralized biorepository resource managed by the NCI.

Following the interviews, a survey instrument was drafted with a combination of closed- and open-ended questions. These were reviewed by NCI OBBR and pilot tested with four individuals who had participated in the in-depth interviews for clarity and comprehension. The final survey instrument was then converted to a computer-based survey. Several rounds of additional pilot testing were conducted to ensure that formatting was clear and that data entry errors would be minimized. As a result, a survey instrument with 27 items was created containing the following sections: information about you and your work, access to biospecimens, and perceptions of a standardized biorepository for biospecimens. See Appendix 1 for the survey items included in the analysis.

Data Collection
An e-mail was distributed to all potential survey respondents on October 14, 2008, to announce an imminent invitation to complete a survey from the NCI OBBR. On October 16, 2008, survey invitations were distributed by e-mail with a link to the survey. Survey reminders were distributed via e-mail on October 22 and 27, 2008. The survey was closed to respondents on October 28, 2008.

A unique identification number was sent to each potential respondent in the survey invitation to ensure that the respondent did not distribute the link to multiple members of their organization and thus skew the results. Although the identification number was set up for a single respondent’s access to the survey and could only be used once, the people initially contacted were asked if they had direct involvement with biospecimens and were encouraged to forward the survey invitation with the unique identification number if a different person in their institution met the requirement and could more appropriately respond to the survey. Identification numbers were generated randomly and were not associated with an individual’s responses or stored with any survey responses.

Statistical Analysis
Of the 5314 individuals invited to respond to the survey, 727 of them submitted surveys, which represented a 14% response rate from the complete list of invitees; however, the response rate is likely higher because the list represented a broader population than the desired sample population.

Handling of incomplete surveys. Respondents could opt out of the survey at any point, so the number of missing answers increased slightly as the survey progressed. Surveys were excluded from analyses if the first five questions describing the respondents were not complete: 1) primary role in biomedical field (eg, clinical researcher, oncologist, and biorepository manager), 2) years in the biomedical field, 3) organization (eg, academic institution, cancer center, and pharmaceutical company), 4) whether they worked in a biorepository, and 5) the capacity in which they worked with biospecimens. Of the 727 submitted surveys, 682 answered questions beyond these five demographic questions and were included in the analysis.

Recoding of “Other” responses. Most of the survey questions offered the respondents the opportunity to check an “other” category and specify the meaning. Each response in the “other” categories was reviewed by the research team and, when possible, was coded back into an existing category from the original response list. New categories were created when appropriate.

Collapsed variables. For some variables, it was decided to collapse responses into fewer categories (ie, sample size was too small in some categories and certain categories were logically fit together) to aid in summarizing responses. Variables for which categories were collapsed include primary role, organization type, and years in biomedical field.

Percentages and crosstabs were calculated for the overall sample and by primary role. For Likert items related to challenges of accessing biospecimens, means and standard deviations were calculated, and one-way analyses of variance were calculated to determine whether perceptions of different audiences varied significantly.

Findings
Sample Characteristics
Responses to participants’ primary role and years of experience showed that the largest percentage of respondents was laboratory researchers (46.9%) and had at least 16 years of experience in the biomedical field (64.2%) (Table 1). Respondents who indicated their primary role was “other” than the roles listed included consultants, an engineering professor, and other general roles that could not be categorized (eg, principal investigator, senior scientist, and university faculty).
When reporting the primary type of organization for which they worked and whether they worked in a biorepository, the largest proportion of respondents reported working in an academic or research institution (48.2%), followed by those working in NCI-designated cancer centers (16.9%) and the pharmaceutical or biotechnology industries (9.4%). One-fourth of all respondents reported working in a biorepository (23.2%). The respondents reported a broad range of experience in biospecimen-related tasks; a majority had experience in biospecimen collection (79.5%), use of biospecimens in medical treatment and diagnosis (73.3%), and in infrastructure and support roles (71.0%). Around half of the respondents indicated experiences in processing biospecimens (54.7%), biospecimen storage (47.4%), and managing distributing biospecimens to others (44.9%).

Biospecimen Sources and Needs

The survey sought to capture information about the present situation in terms of how respondents currently obtain and use biospecimens. Participants were asked to indicate what percentage of the biospecimens they work with come from each of nine sources (Table 2). Respondents reported that they obtained more than half (56.4%) of the biospecimens they work with from their own sources, meaning from their own patients or volunteers or from those patients or volunteers who are involved with the researchers’ own organization in some way. A majority of respondents reported that they wanted more information about biospecimens than they currently have. Specifically, when they were asked to think about what information they typically know about the biospecimens with which they work, one-fifth (20.3%) reported that they do not have enough information and 42.5% have enough but would like to have more. Just over one-third (34.6%) indicated that they had enough information and did not want more. Very few respondents (2.5%) reported that they were not sure whether they had enough information.

Respondents were asked to check off items they typically know about biospecimens being used in research today from one list and then asked to revisit that list to indicate which items would be ideal to know (Table 3). Biospecimen type, anatomical location, and pathological diagnosis topped both the list of what is typically known and what would be ideal to know. Yet, there was a degree of disconnect between what is known and would be ideal to know. The three types of information with the greatest gap (ie, percent difference) between what is typically known and what would be ideal to know were 1) patient treatment outcomes (32%), 2) quality assessment of the biospecimen (29%), and 3) patient treatment information (29%).

Respondents were asked how easy or difficult it was to obtain the number of biospecimens they need for their work (Table 4). More than one-third (38.7%) indicated that it was difficult or very
difficult to do so, and another 30.6% thought that it was at least somewhat difficult. When asked how easy or difficult it is for them to obtain high-quality biospecimens when they were needed, almost half (47.5%) indicated that obtaining high quality when needed was difficult or very difficult and 32.1% thought that it was at least somewhat difficult.

Sixty-one percent of respondents reported that high-quality biospecimens were usually or always needed in their research (Table 5). More than half (60.1%) reported questioning their findings at least sometimes because of concerns about the quality of the biospecimens available to them. Eight in 10 respondents (81.3%) have limited the scope of their research at some time. When asked what percentage of the time they cannot use biospecimens they have obtained from a biorepository because of poor quality or other problems with the biospecimen itself, about half (49.0%) of the respondents said that this situation arises at least “sometimes.” Lack of quality biospecimens resulted in 60% questioning their findings and 81% having limited the scope of their research at some time.

The second portion of the survey explored reactions to the NCI-proposed caHUB. Initial reactions to the idea of a national caHUB were positive (Table 6). Overall, three-quarters (75.3%) felt positive or very positive and 32.1% felt at least somewhat positive. Less than one-tenth (8.7%) registered a negative reaction. Reactions differed significantly by primary role (F = 5.45, P = .000). Post hoc comparisons showed that biorepository managers had a significantly less positive initial reaction compared with clinicians, laboratory scientists, executives/administrators, and advocates/educators. In addition, advocates/educators had a significantly more positive reaction than pathologists.

More respondents indicated that they would likely obtain biospecimens from caHUB than indicated that they would not. Specifically, 61.9% reported that they definitely would do so or were very likely to do so. An additional quarter (24.7%) reported that they were somewhat likely to do so. Altogether, 86.6%, or nearly nine out of every 10 respondents, reported that they were— to some degree—likely to obtain biospecimens from caHUB. The likelihood of obtaining biospecimens from caHUB also differed significantly by primary role (F = 4.87, P = .000). Laboratory scientists were significantly more likely than advocates/educators to indicate that they would obtain biospecimens from a national caHUB; no other post hoc comparisons were significant.

Besides obtaining biospecimens from caHUB, respondents indicated that they were also willing to contribute biospecimens to it. More than half (53.3%) reported that they would be completely (20.9%) or very (32.4%) willing to do so. An additional 31.1% reported that they would be somewhat willing to contribute. In sum, more than eight out of 10 (84.4%) expressed some willingness

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**Table 3.** Type of information about their biospecimens that researchers typically know and consider ideal to know

<table>
<thead>
<tr>
<th>Type of information</th>
<th>Typically known, N (%)</th>
<th>Ideal to know, N (%)</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient treatment outcomes</td>
<td>230 (33.7)</td>
<td>446 (65.4)</td>
<td>+31.7</td>
</tr>
<tr>
<td>Quality assessment of the biospecimen</td>
<td>234 (34.3)</td>
<td>431 (63.2)</td>
<td>+28.9</td>
</tr>
<tr>
<td>Patient treatment information</td>
<td>272 (39.9)</td>
<td>468 (68.6)</td>
<td>+28.7</td>
</tr>
<tr>
<td>Quality control data on biospecimen</td>
<td>271 (39.7)</td>
<td>452 (66.3)</td>
<td>+26.6</td>
</tr>
<tr>
<td>Patient family history</td>
<td>170 (24.9)</td>
<td>332 (48.7)</td>
<td>+23.8</td>
</tr>
<tr>
<td>History of collection, storage, and management</td>
<td>251 (36.8)</td>
<td>411 (60.3)</td>
<td>+23.5</td>
</tr>
<tr>
<td>Patient’s health behavior and lifestyle characteristics</td>
<td>145 (21.3)</td>
<td>304 (44.6)</td>
<td>+23.3</td>
</tr>
<tr>
<td>Patient medical history</td>
<td>232 (34.0)</td>
<td>387 (56.7)</td>
<td>+22.7</td>
</tr>
<tr>
<td>Transfer procedures</td>
<td>291 (42.7)</td>
<td>403 (59.1)</td>
<td>+16.4</td>
</tr>
<tr>
<td>Patient complaint/history of current illness</td>
<td>234 (34.3)</td>
<td>324 (47.5)</td>
<td>+13.2</td>
</tr>
<tr>
<td>Collection procedures</td>
<td>428 (62.8)</td>
<td>512 (75.1)</td>
<td>+12.3</td>
</tr>
<tr>
<td>Clinical diagnosis</td>
<td>429 (62.9)</td>
<td>492 (72.1)</td>
<td>+9.2</td>
</tr>
<tr>
<td>Storage procedures</td>
<td>450 (66.0)</td>
<td>509 (74.6)</td>
<td>+8.6</td>
</tr>
<tr>
<td>Pathological diagnosis</td>
<td>487 (71.4)</td>
<td>523 (76.7)</td>
<td>+5.3</td>
</tr>
<tr>
<td>Patient demographics</td>
<td>398 (58.5)</td>
<td>434 (63.6)</td>
<td>+5.1</td>
</tr>
<tr>
<td>Patient consent/authorization status</td>
<td>342 (50.1)</td>
<td>360 (52.8)</td>
<td>+2.7</td>
</tr>
<tr>
<td>Other</td>
<td>8 (1.2)</td>
<td>24 (3.5)</td>
<td>+2.3</td>
</tr>
<tr>
<td>Anatomical location</td>
<td>525 (77.0)</td>
<td>510 (74.8)</td>
<td>−2.2</td>
</tr>
<tr>
<td>Biospecimen type</td>
<td>570 (83.6)</td>
<td>540 (79.2)</td>
<td>−4.4</td>
</tr>
<tr>
<td>Does not apply to me</td>
<td>76 (11.0)</td>
<td>75 (11.0)</td>
<td>0.0</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0.0)</td>
<td>7 (1.0)</td>
<td>7.0</td>
</tr>
<tr>
<td>Total</td>
<td>682 (100)</td>
<td>682 (100)</td>
<td>0.0</td>
</tr>
</tbody>
</table>

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**Table 4.** Ease of accessing the quantity and quality of biospecimens needed

<table>
<thead>
<tr>
<th>How easy or difficult is it to . . .</th>
<th>Obtain the number of biospecimens needed</th>
<th>Obtain “high quality” biospecimens when needed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>Valid %</td>
</tr>
<tr>
<td>Very easy</td>
<td>16 (2.3)</td>
<td>2.8</td>
</tr>
<tr>
<td>Easy</td>
<td>45 (6.6)</td>
<td>7.9</td>
</tr>
<tr>
<td>Somewhat easy</td>
<td>114 (16.7)</td>
<td>20.0</td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>174 (25.5)</td>
<td>30.6</td>
</tr>
<tr>
<td>Difficult</td>
<td>121 (17.7)</td>
<td>21.3</td>
</tr>
<tr>
<td>Very difficult</td>
<td>99 (14.5)</td>
<td>17.4</td>
</tr>
</tbody>
</table>
to contribute. Significant differences by primary role were found in willingness to contribute biospecimens (F = 3.22, P = .002): Both laboratory scientists and advocates/educators were significantly more likely than nonlaboratory researchers to be willing to do so.

Following the question about overall reaction to the centralized caHUB, respondents were asked to answer an open-ended question about potential benefits and drawbacks to the idea. A review of responses showed that respondents who were favorable to the idea envisioned several benefits, such as having a centralized resource, basing biospecimen management upon standardized practices, and addressing drawbacks of the current situation (eg, assuring adequate quantity and quality of biospecimens and providing highly annotated biospecimens). Several also indicated that the idea was important and worthwhile.

“I imagine a national repository would be extremely helpful to researchers in terms of the quality of specimens, access and standardization of methodology for collection, storing, etc., resulting in higher quality, more dependable results.”—Patient Advocate

“It would be a great resource for many researchers. Individual institutions usually cannot collect enough specimens fast enough to provide those in need.”—Director of Cancer Center Tissue Bank

At the same time, potential drawbacks and concerns were acknowledged by both those who had positive reactions to the idea and those who reacted negatively. Concerns centered on how to best standardize processes, how accessibility would be determined, and those who reacted negatively. Concerns centered on how to best standardize processes, how accessibility would be determined, and the potentially large financial cost and bureaucracy that could accompany a national-level undertaking.

“The benefits are obvious. The major drawback could be [that] the demand might outstrip the supply unless a great deal of money was invested.”—Executive/Administrator

“‘Ideally a national repository would facilitate biomedical research, product development and health care in general. However, the biggest drawback is that it is currently cost prohibitive. Additionally, there is a lack of standardization of best practices; lack of specialized trained personnel at all levels and no realistic comprehensive cost support provided in current funding sources.’”—Biorepository Manager

**Discussion**

The quality of biomedical research is rooted in the quality of the biospecimens scientists use (5), and progress in the fight against cancer appears to be threatened by inadequate access to quality biospecimens (6,7). As a result, the NCI OBBR initiated an effort to gather input from several key stakeholder groups with a vested interest in cancer research and experience in using biospecimens in their work. Researchers working with NCI’s Office of Communications and Education began the market research process by conducting in-depth interviews and a needs assessment survey with stakeholders in the scientific, governmental, industry, and advocacy communities to elicit the attitudes and advice of those core constituents.

The survey gathered a great deal of input from the research and academic communities, especially from respondents who work in laboratories. A majority of the respondents also reported having many years of experience in the biomedical field, including specific work experience at biorepositories and experience with collecting, storing, processing, and distributing biospecimens. Those from academic and research institutions and NCI-designated cancer centers were the constituencies most often represented in the survey. However, two important constituencies, advocacy groups and industry representatives, were not well represented. This disparity was likely due to the smaller number of invitees from these organizations rather than lack of interest among them.
From these data, a picture emerged showing the cancer research enterprise to be largely a loose collection of investigators or groups of investigators working independently. Most of the respondents who used biospecimens reported that they were likely to get the biospecimens from their own patients and volunteers or from other patients and volunteers in their institution. This situation suggests that access to biospecimens is isolated primarily to an investigator’s own institution creating silos that are difficult or impossible to access by those outside the institution. As such, their research questions are likely to be limited by the scope of the biospecimen samples available from their institutions, in effect preventing researchers from answering larger questions or from generalizing findings across patient populations.

Most respondents reported that obtaining the quality and quantity of biospecimens needed was difficult, and they wanted more information than they currently have on the biospecimens they use in their work. The findings also demonstrated the serious consequences of inadequate biospecimens on research. Poor or unknown quality of biospecimens leads investigators to question their findings and to limit the scope of their research questions.

Study findings elucidate the gap between what was usually known about biospecimens and what respondents considered ideal. Compared with information that was typically known about biospecimens, more information about patients (e.g., family medical history, lifestyle, treatment, and treatment outcomes) and how biospecimens have been handled (e.g., quality control, quality assurance, and history of processing and storage) was considered ideal. Expanding the amount of clinical information on patients and process information used for biospecimen handling may be best achieved by developing standard operating procedures in both areas that define best practices and provide a means to track adherence to these guidelines. Not only could these standard operating procedures be integrated into the caHUB, they could also be integrated into other biorepositories.

The respondents had an overwhelmingly positive reaction to the idea of a national caHUB. Three out of every four respondents reported that they felt positive or very positive about the proposed resource. Most also reported that they would be likely to obtain biospecimens from the national resource, especially laboratory scientists and NCI-funded researchers from academic institutions. When asked about their willingness to contribute biospecimens to the national caHUB, the majority reported that they were at least somewhat willing. The advantages appeared very evident to the majority of respondents because the current state of biospecimen access and management was seen as dysfunctional and fragmented. Specifically, respondents thought that the value of caHUB was its potential to provide high-quality biospecimens that were collected and maintained using standardized protocols and that had detailed annotations.

Advocates/educators had the most positive reactions to the idea of the national caHUB and were most willing to contribute but least likely to use it to obtain biospecimens. These findings were consistent with the role of advocacy groups as sponsoring research and providing resources to their constituencies than as conducting the research themselves.

Although reactions were very favorable, some groups were somewhat less positive about the idea of the national caHUB, such as those working in the roles of biorepository managers and pathologists. These constituents may perceive that they have managed well under the current circumstances or that they do not want to become part of a larger entity where they have less control.

Clinical researchers were also less willing to contribute biospecimens to a national caHUB. Given that the demand for high-quality biospecimens will very likely always exceed the supply, the cautiousness expressed by some to relinquish valuable and limited biospecimens was understandable. However, once clear rules of access to and cost structure of caHUB have been established, the willingness of these stakeholders to contribute their biospecimens may increase. In addition to paying for the biospecimens contributed to caHUB, other rewards for contribution may also be of value to these stakeholders, such as standardized processing of the biospecimens and the resulting data. Further research is recommended to test the access and cost proposition with stakeholders who have biospecimens to contribute to caHUB and what their requirements for contribution will be.

Answers to the open-ended questions suggested that individuals were excited by the prospect of a national caHUB but wanted to see how it actually would take shape before committing to it fully. They had deep concerns related to several issues, chief among them was the ability of caHUB to gain long-term support, limit bureaucracy, and establish the appropriate infrastructure. Getting continued input and buy-in from these constituencies was seen as crucial for creating a trusted resource and a transparent process for gaining access to the biospecimen inventory. Stakeholders, who have the ability to contribute biospecimens to caHUB, should have a voice in the development of its rules of engagement and infrastructure design, either through an advisory board or a working group because their willingness to participate in caHUB will be contingent upon perceived benefits to them.

Limitations
This study had several limitations, including response rate and self-report data. The list of potential participants was not targeted due to lack of information allowing identification of appropriate respondents. However, the vast network already available to the NCI could be leveraged and queried. In addition, although the response rate was not large, the individuals who responded to the survey reported high rates of biospecimen-related knowledge and experience, adding greater confidence that we were able to get a good sense of whether a national caHUB was a welcome idea and one that had the potential to make a difference among the sample population. As with any survey research study, another limitation was the use of self-report data. If the NCI proceeds with plans to develop a national caHUB, the actions of the cancer research community will need to be monitored to assess acceptance and use of such a resource.

Recommendations for Future Research
This market research determined that a need exists for a national caHUB, and researchers are poised to participate in and take advantage of one, especially if concerns about support, bureaucracy, and infrastructure can be addressed. To further explore the needs of underrepresented constituencies, more input should be collected from advocacy and pharmaceutical and other biotechnology industries. Continued research would also enable the expansion of questions...
about biospecimen types, patient populations, and analytical information (e.g., genetic analysis) not included in the original survey.

Continued research into the nature and scope of a national caHUB is also recommended. For example, future research should provide an ongoing inquiry into the feasibility and acceptability of the steps that might be taken to develop and implement a national caHUB. Quantifying the perceived advantages and challenges would help to identify those that are most important and can be incorporated into the caHUB rules of engagement and infrastructure. Given the range of interested parties and demands of implementation, further research and consultation with target audiences could facilitate successful development and deployment of a national biospecimen resource. In the long term, evaluation research will be necessary to assess whether caHUB is being used as intended and if it improves the ability of researchers to expand the scope and trust the results of their work.

**Appendix 1: Survey Items Included in the Analysis**

<table>
<thead>
<tr>
<th>Survey item</th>
<th>Response options</th>
</tr>
</thead>
</table>
| Which of the following best describes the primary role you undertake on a day-to-day basis? (Please select one.) | □ Clinical researcher  
□ Surgeon  
□ Oncologist/Other MD clinician  
□ 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  
□ Program manager  
□ Policy analyst  
□ Health educator  
□ Patient/Patient advocate  
□ Biorepository manager  
□ Other: _________ |
| How many years have you been involved in the biomedical field? | □ <1  
□ 1–5  
□ 6–10  
□ 11–15  
□ 16–20  
□ More than 20 |
| In what type of organization are you currently working or involved? (Please select one.) | □ Academic/Research institution  
□ Hospital, clinic, or other care setting  
□ NCI  
□ NCI-designated cancer center  
□ NIH institute other than NCI  
□ Federal government agency (other than NIH)  
□ State/local government agency  
□ Non-profit organization (eg, foundations)  
□ Advocacy organization  
□ Pharmaceutical/Biotechnology company  
□ Other biomedical company  
□ Biospecimen “broker” or commercial biobank  
□ Other (specify): |
| Do you work in a biospecimen bank? | □ Yes  
□ No |
| In what capacity do you deal with biospecimens in your work? (Select all that apply.) | □ Collection  
□ Processing  
□ Storing  
□ Distribute/supply/share  
□ Support treatment and diagnosis  
□ Manage proposals and policies |
| What percentage of the biospecimens you work with or obtain come from each of these sources? | __ % - My patients/study participants/volunteers  
__ % - Other patients/volunteers in my organization  
__ % - Other medical care facilities (eg, community hospitals)  
__ % - Other research institutions (eg, SPORES)  
__ % - Nonprofit biobank  
__ % - Commercial biobank in the U.S.  
__ % - Commercial biobank outside the U.S.  
__ % - Cooperative Human Tissue Network (CHTN)  
__ % - Other:  
__ Question does not apply to me |

(Appendix continues)
### Survey Item

**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
- □ Collection procedures
- □ Storage procedures
- □ Transfer procedures
- □ Patient demographics
- □ Patient complaint/history of current illness
- □ Patient past medical history
- □ Patient family history
- □ Clinical diagnosis
- □ Pathological diagnosis
- □ Patient treatment information
- □ Patient treatment outcomes
- □ Patient consent/authorization status
- □ Quality control data on the biospecimen itself (e.g., use of standard operating procedures for collection, storage, and management)
- □ Does not apply
- □ Other: _________

**If all barriers were removed, what information or characteristics about biospecimens would you consider ideal to know in order for you to label them “high quality”?**

- □ Transfer procedures
- □ Patient demographics
- □ Patient complaint/history of current illness
- □ Patient past medical history
- □ Clinical diagnosis
- □ Pathological diagnosis
- □ Patient treatment information
- □ Patient treatment outcomes
- □ Patient consent/authorization status
- □ Quality control data on the biospecimen itself (e.g., use of standard operating procedures for collection, storage, and management)
- □ Does not apply
- □ Other: _________

**How easy or difficult is it for you to obtain the quantity of biospecimens you need for your work?**

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

**In general, how easy/difficult do you think it is to obtain “high quality” biospecimens when they are needed?**

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

**What percentage of the time in your work is biospecimens of “high quality” necessary?**

- □ Never (0%)
- □ Rarely (1–25%)
- □ Sometimes (26–50%)
- □ Often (51–75%)
- □ Usually (76–99%)
- □ Always (100%)

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

- □ Sometimes (26–50%)
- □ Often (51–75%)
- □ Usually (76–99%)
- □ Always (100%)
- □ Don’t know
- □ Not applicable

**How often, if ever, have you limited the scope of your work/objectives because of difficulty obtaining biospecimen samples that met your needs?**

- □ Often (51–75%)
- □ Usually (76–99%)
- □ Always (100%)
- □ Don’t know
- □ Not applicable

**What percentage of the biospecimens you typically acquire for your work/objectives are you unable to use because of poor quality or other problems with the sample itself?**

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

**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

**If a biospecimen resource 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

### References


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