Perceptions of Patients with Inflammatory Bowel Diseases on Biobanking

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Background: Little is known about beliefs, understanding, and perceptions of biobanking among patients with inflammatory bowel diseases. We aimed to further understand perceptions of biobanking in the inflammatory bowel disease community.

Methods: Subjects were recruited to participate in a 1:1 telephone interview on their perceptions of the risks and benefits of contributing specimens for research. These interviews informed a survey instrument evaluating perceptions of biobanking within Crohn's and Colitis Foundation of America Partners cohort. We used descriptive statistics to summarize participant responses, and bivariate statistics to compare willingness to participate in biobanking by disease and demographic factors.

Results: A total of 26 interviews were conducted. Various themes emerged from the interviews and aided in the development of the survey instrument. Concerns focused on storage, loss of confidentiality, outside uses, and life insurance discrimination. A total of 1007 individuals completed the survey. Overall, 397 (39.4%) reported that they would definitely donate samples, 568 (56.4%) would probably donate, 36 (3.6%) probably not, and 6 (0.6%) would definitely not donate. No significant differences in willingness to donate samples were seen for Crohn's disease versus ulcerative colitis ($P = 0.25$) or for remission versus active disease ($P = 0.14$). For sample-type preference, 956 (89.6%) would donate blood, 997 (93.5%) saliva, and 822 (77.1%) stool.

Conclusions: Majorities of patients with inflammatory bowel disease demonstrated willingness to donate specimens for biobanking, albeit with concerns. Addressing these concerns will enhance participation and engagement and create greater alignment between the desires of research participants and the governance structure and operating policies of biobanks.

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Biobanks are systematic collections of samples that include human body substances (e.g., organs, tissue, and blood) and DNA as a carrier of genetic information. Data that include information on the donor (demographic data, disease type) are also stored, either with the samples or separately.[1,2] Biobanks are created with the belief that the use of human biospecimens in research will lead to scientific discoveries that will ultimately benefit society. Public surveys and focus groups demonstrate strong support for medical research,[3] yet little is known about the beliefs, understanding, and perceptions of biobanking among patients with certain chronic disease states, including inflammatory bowel diseases (IBD).

IBD, including both Crohn's disease and ulcerative colitis, are chronic inflammatory disorders of the gastrointestinal tract of unknown etiology. These disorders are relatively rare, although increasing over time.[4] Both Crohn's disease and ulcerative colitis are thought to arise through a combination of factors, including genetic susceptibility, environmental exposures, alterations in the innate and adaptive immune system, and changes in the gut microbiota.[5,6] Researching the genetic and microbial factors involved in IBD pathogenesis (etiology and natural history) requires samples donated by affected patients. Such research is currently a high priority in IBD, creating the need for a national biobank containing samples of serum, saliva, and stool for genetic and microbial analyses.[7] The research community therefore needs to understand patient perceptions on biobanking. This understanding can be used to establish features of a biobank that are reflective of the desires and needs of patients with IBD. This in turn may improve recruitment efforts, facilitate greater participant understanding during the consent process, enhance IBD patients'

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engagement and experience participating in the biobank, and ultimately create greater alignment between patient preferences and biobank governance and operating policies.

We therefore sought to learn more about perceptions of biobanking in the IBD community through (1) a series of one-on-one interviews designed to understand attitudes related to biobanking among members of the Crohn's and Colitis Foundation of America (CCFA) Partners cohort, an Internet-based cohort focusing on patient-reported outcomes in IBD[8] and (2) a cross-sectional survey of participants in CCFA Partners to determine patient preferences and concerns about participation in a hypothetical IBD biobank. We further aimed to determine whether these preferences differed by demographic and disease-based characteristics.

METHODS

The source of participants was the CCFA Partners Internet-cohort. The details of this cohort are described elsewhere.[8] Briefly, this cohort was launched in 2011 with participants recruited through the CCFA e-mail lists, membership files, Website, social media outreach, promotion at educational and fundraising efforts, and through physicians' offices. To date, more than 13,000 individuals have enrolled in CCFA Partners. Participants are followed every 6 months with detailed surveys on disease factors and patient-reported outcomes. Data from this cohort have been used to investigate the role of various factors in IBD exacerbation.[9,10]

Participants in CCFA Partners were invited to participate in a one-on-one telephone interview with one of 3 trained qualitative researchers. Recruitment was continued until the data from the interviews became consistent without the introduction of new themes or concerns. The interview included questions on their perceptions of the risks and benefits of contributing specimens for research and various ethical and legal considerations of biobanking. Using standard interviewing techniques, including open-ended questions, responses were recorded and transcribed. Interviews averaged 35 minutes. The results of these interviews, along with co-authors' previous experiences conducting studies on perceptions of biobanking,[11] informed the development of a cross-sectional instrument to evaluate the cohort's attitudes about joining a hypothetical CCFA Partners' biobank. The survey was offered to CCFA Partners participants from August 2013 to October 2013 until a goal of 1000 responses were obtained.

Statistical Analysis

Interviews

All interviews were transcribed verbatim. After classical qualitative methods,[11] at least 2 members of our research team closely read each transcript and identified themes and patterns in responses across transcripts.

Survey

We summarized participant responses using descriptive statistics and compared willingness to participate in biobanking by disease type, gender, age, and severity of disease, and other factors using appropriate bivariate statistics.

For all analyses, a P value of 0.05 was considered statistically significant. Stata version 12.0 (College Station, TX) was used for all analyses. The Institutional Review Board at the University of North Carolina at Chapel Hill approved the study protocol.

RESULTS

Interviews

A total of 26 interviews were conducted with CCFA Partners cohort members. Various themes emerged from the interviews, including concerns about the personal burden of donating samples; unauthorized access and/or loss of confidentiality; use of samples for purposes outside of IBD research; and life insurance discrimination. Perceived personal and societal benefits of participating in the biobank included advancing IBD research, leading to a cure; altruistic feelings of helping others or family members with IBD; and hope that they might personally benefit. These themes aided in the development of a survey instrument to assess perceptions of biobanking. Examples of comments of participants with IBD on their concerns about biobank participation are seen in Figure 1. Example comments of participants with IBD on the potential benefits of biobanking are shown in Figure 2.

Survey

The survey was designed in sections relevant to different aspects of biobanking. These sections included willingness to participate, preferences for sample use, sample types, the process of giving samples, structure and role of an oversight committee in biobank research, withdrawing from the biobank, biobank closure, biobank funding, the role of minors and family members,

"For me it would be how much time out of work I would have to take to go wherever to get samples done."

"I mean the only real concern I think ... is a loss of confidentiality... the data being misappropriated."

"...names and data being used for some purpose other than... what was intended."

"Will it be secure? Only the scientists that are developing research are using it. That it's going to be safe from others."

FIGURE 1. Concerns of participants on biobank participation.

"Knowing that I helped to help someone else find a cure or come up with a new medication that possibly I would need or others in the future are going to need."

"It might feel like you're a little bit more in control of your disease and that – you know that you're doing something that could help hopefully find a cure some day or at least gain more knowledge about it."

"...if I could do something that would stop somebody else from having this or having to go through the same things, that would be something of value to overall society."

"I have a niece and a nephew ...that are at a higher risk because of being related to me. So I'd like to see them safe."

FIGURE 2. Participants' perceived benefits of biobank participation.

and attitudes surrounding biobanking including motivation for participation, future use of specimens, and expectations surrounding return of information.

A total of 1762 CCFA Partners cohort members were asked to participate in a survey of perceptions of biobanking, 1073 (60.9%) initiated the survey and 1007 (57.2%) completed the survey. The baseline characteristics of the sample who participated in the survey were similar to those who did not, except for educational background (see Table, Supplemental Digital Content 1, http://links.lww.com/IBD/A643). Those participating in the survey had a slightly greater percentage of college and graduate degrees (75.1% versus 65.5%, $P = 0.01$).

Participants were asked whether they would agree to contribute samples to the biobank if they were asked. Overall, 397 (39.4%) reported they would definitely donate samples, 568 (56.4%) would probably donate, 36 (3.6%) probably not, and 6 (0.6%) would definitely not donate. Individuals were categorized according to these responses into donors (n = 965) versus nondonors (n = 42). Table 1 shows the characteristics of the population by donor status.

TABLE 1. Characteristics of the CCFA Partners Population by Willingness to Donate Biological Samples (Donor Defined as Definitely or Probably Yes and Nondonor Defined as Probably or Definitely No)

	Donor (n = 965) or Median (IQR)		Nondonor (n = 42) or Median (IQR)		
Characteristic	n	%	n	%	P[a]
Disease type					
Crohn's disease	612	96.4	23	3.6	0.25
Ulcerative colitis	352	94.9	19	5.1	
Age at diagnosis	961	26 (20–38)	42	29.5 (23–39)	0.11
Gender (% female) Education	705	73.1	31	73.8	0.92
College[b]	703	95.8	31	4.2	0.77
Less than college	229	96.2	9	3.8	
Ostomy (% yes)	76	8.0	2	4.8	0.45
Disease activity[c]					
Remission	471	94.8	26	5.2	0.14
Active disease	368	96.8	12	3.2	
Medications					
Biologics (anti-TNF)	353	36.6	16	38.1	0.84
Immunomodulators	279	28.9	11	26.2	0.70
Corticosteroids	133	13.8	7	16.7	0.60
5-ASA	416	43.1	13	31.0	0.12
Body mass index, kg/m^2	956	24.2 (21.4–28.2)		23.3 (20.8–28.4)	0.34

[a]By Wilcoxon rank sum or chi-square test as appropriate.
[b]College graduate or professional degree.
[c]Defined by short Crohn's disease activity index <150 for Crohn's and simple clinical colitis activity index ≤2 for ulcerative colitis.

TABLE 2. Comfort Levels of Participants for Allowing Use of Their Samples in Various Types of Research or Investigators

Research Type or Investigator	Very Comfortable, %	Somewhat Comfortable, %	Somewhat Uncomfortable, %	Very Uncomfortable, %
Genetic studies of IBD	84.6	11.6	2.0	1.8
Any genetic study	67.3	17.5	8.8	6.5
Studies of immune system	87.1	10.4	1.2	1.3
Studies of microbiota	87.5	10.0	1.5	1.0
Pharmaceutical company researcher	49.3	25.8	15.3	9.4
University researcher in the United States	84.6	12.7	1.4	1.3
University researcher in other countries	55.5	20.7	12.5	11.3

Preferences for Samples

Regarding comfort levels for biospecimen use in certain types of research or by certain groups of investigators, participants overwhelmingly supported immune system, microbiota, or genetic research specific to IBD (Table 2). Participants were asked their preferences for donation of biological samples by type. In total, 956 (89.6%) would donate blood, 997 (93.5%) saliva, and 822 (77.1%) stool. The majority of patients preferred collection of serum at the time of a clinical visit with a health care provider (47.1%), 34.2% had no preference, and 18.7% preferred a mobile phlebotomy service. Those willing to donate stool were offered varying hypothetical frequencies of stool collection. A total of 96.7% would donate 1 time in remission when feeling well, with 91.0% willing to donate 1 time during a disease flare. Markedly fewer (39.9%) were willing to donate daily over a 2-week time period, regardless of disease activity. A total of 58.4% would be willing to donate once a week for 8 weeks and 73.9% would be willing to donate once a month for 12 months.

Structure and Role of an Oversight Committee

Participants were asked whether various community members should be a part of an oversight committee for an IBD biobank.

TABLE 3. Preference for Members of an Oversight Committee for and IBD Biobank

Potential Member	Reporting that They Should Be Included in Panel, %
Foundation staff (CCFA)	83.2
IBD researchers	94.9
IBD physicians	94.8
IBD patients	80.7
People who donated samples	65.9
Lawyers	47.1
Ethicists	60.5
Members of the clergy	15.8

These results are shown in Table 3. Overwhelmingly, respondents believed that IBD physicians and researchers should be included on this panel, whereas lawyers and clergy members were not felt to be as integral a component to an oversight committee.

Withdrawing from a Biobank

The participants were nearly evenly split on how they would like their samples managed if they decided to withdraw from an IBD biobank. Participants were offered withdrawal options of (1) continued use of previously donated samples for research after withdrawal but no requests for additional samples, (2) continued use of samples for research with destruction of linked personal data, or (3) destruction of samples without any further research use as options. A total of 34.0% would allow the samples they had previously donated to be used for further research but would not want to be asked again for samples, 28% would allow prior samples to be used but would want any link to their name destroyed, and just more than one-third of patients (36.9%) would want their samples destroyed upon their request. In a similar fashion, regarding genetic or phenotypic information linked to the samples, 38.9% would allow data to be retained and used for future studies, 44.0% would want a link to their name removed, and only 17.6% would want this information destroyed and no longer used. An overwhelming percent (82.2%) believed that it would be important for the biobank to advise patients before they agreed to participate on what would be done with their samples and data should they choose to withdraw in the future.

Biobank Closure

Participants overwhelmingly (82.2%) reported that before participation in the IBD biobank, it would be important to know the plan for biological samples and genetic data in the event of a closure. Participants were most comfortable with giving these samples and data to other IBD researchers or destroying the samples and data (Table 4).

Biobank Funding

Approximately half of participants felt that funding source did not affect their willingness to participate in the biobank.

TABLE 4. Attitudes Surrounding Biobank Closure Regarding Remaining Biological Samples and Genetic Data

Biological Samples	Very Comfortable, %	Somewhat Comfortable, %	Somewhat Uncomfortable, %	Very Uncomfortable, %
Given to other researchers conducting only IBD research	68.9	20.4	4.8	5.9
Sold to other researchers conducting only IBD research	17.6	13.1	25.9	43.4
Given to other researchers for other types of research	32.4	21.7	18.2	27.7
Sold to other researchers for other types of research	11.0	7.9	22.8	58.4
Destroyed	73.8	15.9	6.3	4.0
Genetic data	**Very comfortable, %**	**Somewhat comfortable, %**	**Somewhat uncomfortable, %**	**Very uncomfortable, %**
Given to other researchers conducting only IBD research	63.5	23.4	5.4	7.7
Sold to other researchers conducting only IBD research	16.9	12.6	22.2	48.4
Given to other researchers for other types of research	32.4	21.7	18.2	27.7
Sold to other researchers for other types of research	11.0	7.9	22.8	58.4
Destroyed	74.6	13.8	6.6	5.1

Among those who were influenced by funding source, federal government or foundation funding made them more likely to participate, whereas pharmaceutical company funding provided a negative influence (Table 5).

Role of Minors and Family Members

A total of 56.6% of participants reported that they would be willing to give the names and contact information of their immediate family members so that they could also donate to the biobank. A total of 225 (22.4%) had children younger than 18 years at the time of the survey. These individuals were asked whether they would be willing to provide consent for sample donation from their minor children. Of these, 44.2% would consent for their child's serum donation, 68.2% for their saliva donation, and 43.8% for their stool donation.

Attitudes Surrounding Biobanking

Nearly, all patients (98.7%) believed that contributing to the biobank would make them feel as if they were helping others with IBD. A similar percentage (95.1%) believed that participation in a research study through sample donation could potentially benefit their own health as well. Only a minority were afraid that their privacy would not be protected if they agreed to participate in the biobank (35.4%). More than half of participants feared that health or life insurance companies would use the research findings to discriminate against them regarding coverage (53.1%). Participants were asked about the role of incentives for participation and return of information from the biobank. Only 42.2% of participants reported that monetary compensation would increase the likelihood of their participation in the biobank. In comparison, a majority of participants (70.0%) reported that return of information in the form of newsletters reporting general results from studies would increase the likelihood of their participation. An even greater percent (83.7%) felt that return of research results specific to them as individuals (such as genetic risk factors for more aggressive disease) would increase their participation rate. In all, 98.3% of participants believed that this hypothetical biobank should be created.

TABLE 5. Participants' Likelihood of Participation in a Biobank due to Funding Source

Funding Type	More Likely, %	Less Likely, %	Not Affect Decision, %
Federal government (NIH[a])	49.5	4.6	45.9
Pharmaceutical companies	16.5	32.0	51.5
Private foundations	46.6	4.2	49.2

[a]National Institutes of Health.

Consent for Biobanking

Participants were comfortable offering broad (general) consent for their samples to be used in all future research studies approved by the biobank's oversight committee (89.6%). However, the majority of participants would want to be informed when their samples or data were going to be used in a research study (68.8%), whereas 22.9% said it would not matter and 8.3% did not want to be informed. A total of 58.0% of participants would want the opportunity to say "no" to the use of their samples in specific studies. The majority were very comfortable (54.8%) or somewhat comfortable (32.0%) allowing the biobank to keep their samples and data indefinitely.

DISCUSSION

Biobanks have become much more prevalent in recent years; yet, there is no uniform guidance for those establishing biobanks on how to develop governance models that respond to the ethical and legal challenges that biobanks may face.[12,13] Rules for biobank governance and informed consent vary internationally. Biobank participation rates in other populations and disease types have also varied. For example, in a general clinic population, 69% reported they would participate in a biobank.[14] In a group of Chinese Americans with hepatitis B, only 46.3% reported willingness to participate.[15] Factors influencing participation are multifold, including ethnic, cultural, and disease-specific factors. In contrast, studies in patients with cancer have found much broader support for biobank participation, as long as informed consent and confidentiality could be assured.[16] In our study, we found similar sentiments in the IBD population to those of cancer populations, with general support for biobanking (>90% definite or probable participation) and chief concerns of loss of confidentiality and the potential for discrimination in health or life insurance due to research findings. It is clear that participants support biobanking for altruistic reasons, such as improved disease understanding or treatment of IBD. Additionally, participation in the hypothetical IBD biobank was influenced more by return of information to the participants than by monetary compensation. Return of information has been shown to be a motivating factor for biobank participation in other populations as well.[17] Addressing concerns and motivating factors of participants will be important in the design of a national IBD biobank and could also apply to epidemiological, clinical, and translational studies of other chronic conditions that require the collection and storage of biological samples and/or genetic data.

Biobanks must navigate the sometimes difficult tension between promoting use of their samples and data to facilitate research and assuring the respect and protection of participants.[13] Many biobanks prefer to seek from potential participants general consent for future unlimited uses of their samples, whereas others choose to contact enrolled participants to ask them to reconsent to use a previously obtained sample.[18] Those within our study overwhelming supported sample use in studies specific to IBD, the immune system or microbiota. There was less support for studies outside of IBD, and therefore a commitment at the time of informed consent to limit future uses of samples and genetic data to IBD research would be valuable. Alternately, the biobank could seek broad consent with assurances that people be notified of the use of their samples in research studies and be offered an opportunity to opt out. Ultimately, participants want choice or tiered consent with options to specify how their samples can be used in the future.

A new form of consent, dynamic consent, has recently been proposed as a modern-day approach to the consenting process. Central to this form of consent is a personalized digital communication interface that connects researchers and participants, allowing greater participant involvement in decision-making. This moves beyond the static paper-based current form of consent, which is organized around national boundaries and legal frameworks.[19] Such a form of consent would likely meet participants' expectations of retaining some control over the samples that they donate. Participants would like the ability to withdraw their consent and specify whether samples and data could be further used or whether these samples should be destroyed. At a minimum, participants would like options for withdrawal and a plan for sample use or destruction after a biobank closure outlined to them at the time of initial consent.

There are several strengths to this study. The interviews allowed focused themes specific to IBD to emerge and then inform survey instrument development. The sample size of the survey portion of our study was large, allowing for precise estimates of participants' perceptions on biobanking in the survey. Finally, the CCFA Partners cohort, although not a random sample of patients with IBD in the United States, is geographically diverse (it contains patients in all 50 U.S. states and 4 territories) and includes patients seen in multiple care settings (both private and academic). There are also limitations to this cross-sectional study. First, the participants were recruited from CCFA Partners, which is an Internet-based cohort of predominantly individuals living within the United States. U.S. perceptions may or may not align well with international perceptions, other cultures, or ethnicities. We also do not have data directly from children and adolescents on their perceptions, although we do ask parents about sample collection from their children. Although large and diverse, the CCFA Partners cohort may not be generalizable to the IBD population as a whole. Disease characteristics within the cohort are also not uniformly validated. However, in a validation sample, 97% of participants' IBD diagnoses were confirmed.[20] Although this methodological design provides a good sense about survey respondents' attitudes toward a hypothetical biobank supported by CCFA Partners, an individual's actual willingness to participate in a biobank may vary from his or her survey responses.[21]

In summary, as biobanking efforts in specific disease states, such as IBD, become more prevalent, incorporating patient's preferences into the process of informed consent and other policies, and governance decisions are integral to ensuring patient engagement, participation, and ultimately sustainability of biobanks. Return of information to participants will be an important factor influencing participation. As the field of IBD advances and the need for reliable biospecimen storage and genetic and phenotypic information increases, biobanking will need to become more centralized. As we design a 21st century IBD biobank, understanding the beliefs, understanding, and perceptions of patients with IBD regarding the ethical and legal aspects of biobanking will be of utmost importance.

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