BIOPRESERVATION AND BIOBANKING
Volume 19, Number 3, 2021
Mary Ann Liebert, Inc.
DOI: 10.1089/bio.2020.0072

How Semantics Connotations May Influence Concerns About Donation of Biospecimens

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Introduction: Human biological specimen (biospecimen) donation is routinely requested for clinical care and research purposes. Successfully engaging patients and research participants in biospecimen donation depends on what they understand these initiatives entail, including their perceptions of risk. Human biospecimens are stored in facilities routinely referenced as biobanks or biorepositories, both of which labels are known to embody a variety of connotations. The words chosen to describe biospecimen facilities may influence decisions about donation.
Objective: To explore differences in likelihood of donation as a function of the words chosen to represent human biospecimen storage facilities and the commensurate concerns each label evokes.
Materials and Methods: Two-group experimental design. Participants completed a survey about a fictitious undertaking requesting that they consider biospecimen donation. The term used to describe the facility housing the biospecimens differed; one half of the surveys referenced a biobank, and one half referenced a biorepository.
Results: Two thousand five hundred ninety-six surveys were distributed; 586 completed surveys were received (response rate: 22.6%). Sixty-three percent of respondents, regardless of whether the label referenced a biobank or biorespository, reported being extremely likely to donate. There were no significant differences between the 2 groups on the 11 concerns sampled. Factor analyses revealed that concerns could be classified in two groups: use-related concerns and person-related concerns. The label biobank evoked significantly lower perception of importance of the person-related concerns sampled (e.g., personal or other benefit, discomfort or inconvenience).
Conclusions: Our results suggest that researchers may consider using the word biobank to describe the facility housing the biospecimen, as this term appears less subject to concern biases. These outcomes confirm that misunderstandings or misattributions of words used to refer to biospecimen facilities could deter participation in clinical care or research. Participation may be enhanced through ensuring clear understanding of what biospecimen donation entails and by directly addressing common semantic misunderstandings and associations.

Keywords: biobank, biorepository, biospecimens, recruitment, semantics

Introduction

Rapid advancements in patient care and biomedical research have led to increased use of human biological specimens ("biospecimens").[1] The clinical care efficiencies realized with human biospecimen donation, storage, and use include the capacity to link human biological material to personal (e.g., physical activity, nutrition, lifestyle) and health information (e.g., that arising in the diagnosis, treatment, and care of illness or injury), timeliness, and cost effectiveness. Similarly, availability of human biospecimens for research has advanced understanding of disease risk, treatment, and outcomes.[2,3]

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Although the general population is becoming increasingly familiar with the concepts and terms used to describe human biospecimen donation, scope, intent, storage, and use, misperceptions persist.[4–12] One source of confusion pertains to the words used to refer to facilities or structures where biospecimens are stored, by individual researchers, institutions, governments, or commercial entities.[12,13] The words biobanks and biorepositories have historically been used to describe biospecimen storage, although these labels are not without criticism.[12] Accordingly, alternative terms, including bioresources, biovaults, biodistributors, biolibraries, and biotrusts, have been introduced into the vernacular.[12–14] At present, the labels biobank and biorepository are used interchangeably in the literature. However, ambiguity about the meanings underlying these two labels among the general population as well as expert stakeholders, including pathologists, biobank managers, researchers, lawyers, and ethicists, remains.[15,16]

The ambiguity between the terms biobank and biorepository may be explained, in part, by the semantic differences between the denotative and connotative perspectives of the two labels. The strict, literal definitions of the words biobank and biorepository are the denotative perspectives, those that would commonly be found in a dictionary. A biorepository is generally defined as ‘‘the infrastructure within which biospecimens are identified, collected, processed, stored, and distributed.’’[17] Similarly, a biobank is generally defined as ‘‘an entity that receives, stores, processes, and/or distributes specimens, as needed. It encompasses the physical location as well as the full range of activities associated with its operation.’’[18] The connotative perspectives, by contrast, encompass the nonexplicit meanings that people attach to words, including assumptions, emotional influences, and positive and negative associations.[19] Variation in the connotations associated with the words biobank and biorepository exist from person to person, since connotation is shaped by an individual’s beliefs and past experiences.

Although the word biorepository predates the word biobank, currently, as a term, biobank is more widely used, and therefore, more familiar than the word biorepository.[12] Expert panels and op-eds that have explored these terms have suggested that both evoke both positive and negative connotations within the scientific community. Biobank is viewed by a number of scientists and professionals involved in sample collections as a word that is short, neat, simple, convenient, meaningful, and widely recognized.[12–16] However, biomedical researchers also argue that the word biobank does not aptly describe its purpose and can connote possession, hoarding, and limited access.[12–15] The word biorepository is more popular in the United States and, free from the negative connotations of biobank, viewed by scientists as positively associated with the evolution of biospecimen availability, distribution, and utilization. Among the general population, it is suggested that the word biobank can be intimidating, confusing, and misleading, as it implies that a research participant can make a withdrawal of their own sample from the bank.[13] At the same time, the word biorepository is less familiar to lay people and can be viewed as equally intimidating.

Successfully engaging patients and research participants in biospecimen donation depends on what they understand these initiatives entail, including informed consent considerations and perceptions of personal risk. The terms biobank and biorepository may yield discrepancies in connotations of specimen ownership, privacy, access, and control considerations, all of which may be relevant to the public’s willingness to support such endeavours.[20–22] Maximizing research participation of diverse members of target populations is essential to the success of research goals and meeting the ethics principle of justice.[9,23–25]

To our knowledge, the semantic influences of labeling the biospecimen storage facility as either a ‘‘bank’’ or a ‘‘repository’’ are primarily anecdotal in nature and have not yet been quantified. The present study addresses this gap. The objective of this study was to examine whether the terms used in soliciting human biospecimen donation for future clinical or research use influenced participation rates. We asked whether individuals displayed a greater willingness to participate in biospecimen donation when the facility was called a biorepository compared with when the facility was called a biobank. Further, we asked participants to identify, from a list of potential issues related to biospecimen donation, their levels of concern about the same.

Materials and Methods

A two-group experimental design was used. Participants were asked to indicate the likelihood that they would donate biospecimens to a hypothetical storage facility. They were reassured that they were not being asked to donate biological samples at this time. The groups differed by labels used to represent the biospecimen facility; group 1 was assigned to consider donation to a ‘‘biobank’’ and group 2 was assigned to consider donation to a ‘‘biorepository.’’

Survey development

The study material was developed in Qualtrics (Provo, UT). It consisted of an information sheet describing a hypothetical biospecimen storage facility and a 25-item survey (see Supplementary Material). The material for the two groups was identical, with the exception of the term used to describe the facility that housed the biospecimens. As described earlier, for group 1, the term ‘‘biobank’’ was used; for group 2, the term ‘‘biorepository’’ was used.

The information sheet provided a brief description of a hypothetical undertaking, including the purpose, required procedures (one-time donation of blood and urine specimens with linkage to health information), general risks and benefits, voluntary nature of participation, and confidentiality provisions.

In the survey, ten-point Likert scale questions assessed the likelihood that participants would donate biospecimens for either clinical and/or research purposes. In addition, 10-point Likert scale questions were used to capture the extent to which participants were concerned with a number of issues related to such donations (e.g., confidentiality, information misuse, research purpose). Participants were invited to describe any other concerns that might impact their willingness to donate to a biobank or biorepository (depending on the group they were in) in open-ended questions. They were also asked to describe what the terms ‘‘biobank’’ or ‘‘biorepository’’ meant to them, depending on the group they were in. General socio-demographics, English language proficiency, and previous experience with research were also captured. No identifying information was requested. Face and content validity of the survey tool were assessed before distribution by bioethicists and researchers familiar with human biospecimen donation, storage, and use. The survey was reviewed for clarity and comprehensibility by six lay people independent of the research team before finalization.

Recruitment

The sampling frame consisted of previous or current patients of a multiple sclerosis clinic in Calgary, Alberta, Canada (metropolitan population; 1.5 million). Eligible patients were those for whom consent to contact for research purposes had previously been obtained. Those who had provided such consent were emailed an invitation to the study, including the survey link ($N = 2596$). The survey link alternated between the biobank and biorepository versions. A single reminder email and invitation was resent 1 week later. The link was open for 4 weeks after the second invitation. Consent was implied by survey completion. The study received approval from the Conjoint Health Research Ethics Board at the University of Calgary (REB17-1917).

Quantitative analysis

Quantitative survey data were exported to SPSS[26] and summarized by using descriptive statistics (means, proportions, and frequencies). Mann–Whitney *U* tests were used to examine the differences between the biorepository and biobank groups in terms of the willingness to donate biospecimens and individual concerns regarding donating biospecimens.

To summarize respondents' concerns, we conducted an exploratory factor analysis on the eleven concern items. Factor analysis examines the covariation among a set of variables and summarizes the relationships among the variables by producing factors.[27] In our data, two factors accounted for most of the variation among the eleven concern items. A score was calculated for every individual on each of the factors. We conducted a multivariate regression analysis to examine the effect of terminology on the willingness to donate and on the individual factor scores, net of demographic characteristics of respondents. Finally, we ran multiple regression models predicting the effect of terminology on willingness to donate controlling for both factor scores and demographic variables.

Comments were analyzed by using qualitative description.[28]

Results

Sample characteristics

We received 586 completed surveys, with 292 respondents in the biobank group and 294 respondents in the biorepository group. Sociodemographic characteristics of the participants are given in Table 1. Approximately 80% of the sample (462) was female. The average age was 53 years old, with a standard deviation of 11.73 years. The majority (98%, $N = 572$) of respondents spoke English as a first language. Most respondents had at least some postsecondary education (63%, $N = 368$). Sixty-four percent ($N = 377$) had previously participated in research. Only 13% (76) lived in a rural area. Note that there were no significant differences in any of the demographic characteristics between the biobank and the biorepository group.

Table 1. Characteristics of Survey Respondents ($N = 586$)

Variable	*Proportion* (N)
Sex	
Male	21.2 (124)
Female	78.8 (462)
Age (years old)	
18–24	0.3 (2)
25–34	5.8 (34)
35–44	21.6 (126)
45–54	24.0 (140)
55–64	33.6 (196)
Older than 64	14.7 (86)
No response	0.3 (2)
Mean (SD)	52.82 (11.73)
English as first language	
Yes	97.6 (572)
No	2.0 (12)
No response	0.4 (2)
Highest education level	
Less than high school	1.4 (8)
High school graduate	9.7 (57)
Some postsecondary	25.6 (150)
Diploma or degree completed	49.1 (288)
Postgraduate training	13.7 (80)
No response	0.5 (3)
Area of residence	
Calgary or other urban area	86.9 (509)
Other/rural	13.0 (76)
No response	0.2 (1)
Previous research participant experience	
Yes	64.3 (377)
No	33.4 (196)
No response	2.2 (13)

SD, standard deviation.

Quantitative data

Willingness to participate in biobanks vs. biorepositories. We asked respondents about the likelihood that they would donate biospecimens to a hypothetical biobank or biorepository for clinical and research purposes. Respondents reported being extremely likely to donate. On a scale of 1 to 10 with 1 being not at all likely and 10 being extremely likely, respondents averaged 9.0 (standard deviation [SD] 1.70). A full 63% of respondents answered 10 on this scale. There were no significant differences between the biobank and the biorepository groups.

Concerns associated with donation. Participants were asked to rate the extent to which they were concerned with 11 aspects associated with biological specimen donation on a 10-point Likert scale. The results are summarized by group in Table 2. The highest levels of concern were expressed for the possibility of samples being used by insurance companies to make insurance decisions (mean 7.14, SD 3.40) and the possibility of samples being used by drug companies for profit (mean 6.23, SD 3.45). The lowest levels of concern were expressed for the possibility of experiencing discomfort from having blood drawn (mean 1.74,

Table 2. Extent of Concerns Associated with Biological Specimen Donation by Group

No.	*Concern 1 = not at all concerned 10 = extremely concerned*	*Biobank (N = 292)*	*Biorepository (N = 294)*
1	Confidentiality of biological/genetic information	5.3 (0.20)	5.0 (0.20)
2	Confidentiality of medical information	5.8 (0.20)	5.3 (.20)
3	Samples used by drug companies for profit	6.2 (0.20)	6.3 (0.20)
4	Samples used by insurance companies to make insurance decisions	7.0 (0.20)	7.3 (0.20)
5	Samples used to make employment decisions	6.0 (0.22)	6.2 (0.22)
6	Samples used by researchers who are not part of a university	4.3 (0.18)	4.6 (0.18)
7	No personal benefit from the sample donation	2.5 (0.14)	2.7 (0.15)
8	Other patients do not benefit from the sample donation	3.7 (0.17)	3.9 (0.18)
9	Samples being used for research I might not be comfortable with	4.2 (0.18)	4.6 (0.18)
10	Experiencing discomfort from having blood drawn	1.6 (0.10)	1.9 (0.12)
11	Time commitment required	2.9 (0.15)	3.3 (0.16)

Mean (SE) shown. There were no significant differences between the groups, and Mann–Whitney *U* tests were performed.
SE, standard error.

SD 1.79) and the possibility of no personal benefit from the sample donation (mean 2.59, SD 2.45). Although there were no significant differences between the two groups on any of the individual concerns, respondents in the biobank group reported lower levels of concerns than those in the biorepository group on all except the confidentiality concerns.

To better understand the concerns expressed by respondents, we performed a factor analysis on the 11 concern items (Table 3). Varimax rotation was used, and coefficients below 0.6 were suppressed. Two factors resulted from the factor analysis, which together accounted for 63% of the variation in responses.

The first factor, Factor I (42% variance explained; Cronbach's $\alpha = 0.91$), loaded the following seven items together: (1) confidentiality of biological/genetic information, (2) confidentiality of medical information, (3) samples used by drug companies for profit, (4) samples used by insurance companies to make insurance decisions, (5) samples used to make employment decisions, (6) samples being used for research that the participant might not be comfortable with, and (7) samples used by researchers who are not part of a university. We labeled this factor ''use-related concerns.'' The second factor, Factor II (21% variance explained, Cronbach's $\alpha = 0.71$) included: (1) no personal benefit from the sample donation, (2) other patients do not benefit from the sample donation, (3) experiencing discomfort from having blood drawn, and (4) time commitment required. We labeled this factor ''person-related concerns.''

Although the average scores on use-related concerns factor did not differ between the biorepository and the biobank group, on average members of the biobank group scored significantly lower on the person-related concerns factor than members of the biorepository group. We conducted a regression analysis by using the factor scores as the dependent variables to assess whether demographic variables affected the factor scores. Results are depicted in Table 4. The only variable affecting use-related concerns scores was education. Those with higher levels of education scored higher on use-related concerns, net of other demographic variables, and regardless of which group they were in. Person-related concerns scores were affected by education in the opposite direction, with those with higher levels of education scoring lower on this factor. Those who participated in research previously also scored lower on this factor, net of other variables. Those in the biobank group still scored lower than the biorepository group on person-related concerns, even while controlling for the demographic variables.

Finally, we conducted a regression analysis of the likelihood to donate, first with the demographic variables and

Table 3. Factor Analysis of Concerns

	Factor loading	
Item	*I*	*II*
Confidentiality of biological/genetic information	0.806	
Confidentiality of medical information	0.805	
Samples used by drug companies for profit	0.789	
Samples used by insurance companies to make insurance decisions	0.829	
Samples used to make employment decisions	0.808	
Samples being used for research I might not be comfortable with	0.685	
Samples used by researchers who are not part of a university	0.773	
No personal benefit from the sample donation		0.722
Other patients do not benefit from the sample donation		0.614
Experiencing discomfort from having blood drawn		0.740
Time commitment required		0.727
Percent variance explained	42.00%	21.00%
Cronbach's alpha coefficient	0.91	0.71

Factor loadings less than 0.60 were suppressed.

Table 4. Regression Analysis for Concern Factors

Independent variables	*Factor 1 score*	*Factor II score*
Age	0.003 (0.004)	–0.005 (0.004)
Female	–0.081 (0.103)	0.139 (0.101)
Education level	0.099* (0.048)	–0.144** (0.048)
English as first language	–0.017 (0.293)	–0.310 (0.289)
Urban	–0.109 (0.124)	–0.091 (0.122)
Participated in research earlier	–0.038 (0.090)	–0.297** (0.089)
Biorepository group	–0.024 (0.084)	0.203** (0.083)
R^2	0.01	0.06

$N = 586$. Reported as b (SE) where b = unstandardized regression coefficient.

$*p < 0.05$, $**p < 0.01$ (two-tailed tests).

then adding in the Factor scores. Results are shown in Table 5. The only demographic variables that affected the likelihood of donating were age (positive) and having participated in research earlier (also positive). These effects remained when we controlled for both the person-related and use-related concern scores, both of which were negatively related to the likelihood of donating. There was no effect of the group on likelihood of donating, even after controlling for concern scores.

Qualitative data

Meaning of terms. Most participants provided a response to the question about meaning of the target term (241 biobank, 232 biorepository). Responses varied in detail and revealed nuances of understanding. There was little thematic difference in the comments by group, so these findings were combined.

A few respondents in each group provided responses indicating that they did not know, were "not sure" or had "no idea" about the meaning of the terms. Recognizing the limits to quantifying qualitative data, this uncertainty occurred more for those asked about the term "biorepository" ($N = 13$) compared with those asked about the term "biobank" ($N = 5$). A couple of participants in each group wrote that they had not heard the respective term before the survey.

Table 5. Regression Analysis for Likelihood of Donating

	Model I	*Model II*
Independent variables	*Likelihood of donating*	*Likelihood of donating*
Age	0.016** (0.006)	0.014* (0.006)
Female	0.021 (0.175)	0.073 (0.161)
Education level	–0.023 (0.082)	–0.071 (0.076)
English as first language	–0.642 (0.497)	–0.829 (0.457)
Urban	0.043 (0.211)	–0.050 (0.194)
Participated in research earlier	0.532** (0.153)	0.345* (0.095)
Biorepository group	0.114 (0.143)	0.224 (0.132)
Factor 1 score		–0.363** (0.066)
Factor 2 score		–0.584** (0.067)
R^2	0.04	0.20

$N = 586$. Reported as b (SE) where b = unstandardized regression coefficient.

$*p < 0.05$, $**p < 0.01$ (two-tailed tests).

Most consistently, participants responded that the terms "biobank" and "biorepository" referred to places where biological material is stored. Many participants described that materials would be used in the future by investigators for research, and others specified use aimed at finding a cure for multiple sclerosis. Infrequently, clinical and educational uses were referenced. In contrast, others presented a more static perception that such places held tests results and information about them ("Physical and/or data storage of molecular and biological information about me").

Some participants reflected awareness that access was not free-for-all and that those wishing to use biosamples would have the appropriate authority or permission to do so ("A place that stores biological items such as blood in a secure way that limits who can enter or use the items"). Consistent with this understanding, participants described the facilities as "safe," "secure," "controlled" and their information as being confidential. One individual specified that sample use had to be congruent with the permission they gave ("A facility where my biology samples will be held securely and used only for purposes for which I have given my permission").

The organization of these facilities was mentioned by several and illustrated by comments about cataloguing, analogies to libraries, or being able to search facility contents ("Repository for bio material that can be referenced by medical condition, donors age and physical circumstance meaning any allergy, disease ailments or conditions," "Bank that stores biological materials as a database").

Some participants used possessive pronouns when describing the specimens (e.g., "a collection of my samples," "storage of my genetic materials or information pertaining to my personal genetics"), contrasting with those who were more abstract or impersonal (e.g., "a collection of biological samples from a group of individuals," "A storage of biological tissue samples for the purpose of medical research where donors remain anonymous"). Again acknowledging limits to tallying qualitative data, it is possibly noteworthy that the possessive pronoun was used more by those in the biobank group (19 people vs. 11 people).

Within the biobank group, a comment salient to our research question was made:

> I understand your use of the word biobank for a research sample collection. To the general public, the word may pick up an unintended implication, by analogy to sperm/ovum bank or the financial banking system. The implication is that samples deposited may be withdrawn for the use/benefit of the depositor. Biosample repository or biosample archive might be more accurate in describing the purpose of the collection. Even more accurately "biosample research archive."

Directly relevant to our research question, within the biorepository group, one person stated, "Well, a repository is a synonym for a bank, so I guess an biorepository is a bank for specific bio data." Several people from each group used the alternate word in their description of the meaning (i.e., in the biorepository group the word "bank" was used to define meaning whereas in the biobank group "repository" was used to define meaning.)

Concerns. Participants were asked to describe concerns not already identified that would influence their willingness to contribute biospecimens. One hundred eighteen participants commented ($n = 55$ biobank, $n = 63$ biorepository). Many reiterated concerns already captured in the survey (e.g., security and confidentiality of information, misuse by employers or insurance companies [for profit] by pharmaceutical companies, and inconveniences [e.g., time, travel] of donation). Curiously, eight people in the biorepository group used the work ''hack'' to express concern with inappropriate access, whereas none used this term in the biobank group. Some expressed discomfort should research be incongruent with personal values; concerns with cloning and animal testing were raised by a few.

A few comments reflected a fear of exploitation (''We would be very concerned if the University sells this info we give, or the research results to drug companies in an effort to validate the research results. If they work together with the pharmaceutical, that would be acceptable, but we do not like to be cheap ginnie *(sic)* pigs''). Some raised concerns with the duration of time that samples would be retained (''I would be concerned about how long these samples would be stored. Indefinitely? Tossed without being used? Is it futile? Also, I don't want my samples stored forever, how much resources would that entail?'').

Desires to be informed of research undertaken and the conclusions of research were expressed by several (''I would like feedback on any progress or breakthroughs the research uncovers,'' ''How will we know if my sample helped at all?''). Some wondered about return of results should an unexpected finding be identified in their sample (''If disease markers for a disease I'm not aware of are found in my samples at some point in time, during analysis and research, would I be contacted and informed of this, so that I can take the necessary measures?'')

Discussion

This study explored whether the terms ''biorepository'' or ''biobank'' evoked different semantic connotations in individuals approached to donate biospecimens for clinical care or research purposes. Overall, receptivity to donate biospecimens for both clinical and research purposes was extremely high, regardless of the label used to describe the biospecimen storage facility. Indeed, qualitative analyses identified that participants reported that both labels most consistently referred to ''places where biological material is stored.'' With respect to apprehensions connected to biospecimen donation, both labels evoked equally high levels of concern about the possibilities of samples being used by insurance companies to make insurance decisions and samples being used by drug companies for profit. Both labels evoked equally low levels of concern about experiencing discomfort from having blood drawn and no personal benefit from the sample donation.

A factor analysis comprised of all eleven areas of concern sampled in the survey revealed two distinct factors underlying respondents' apprehensions; use-related concerns (those that represent institutional, privacy, and commerce concerns such as compromised confidentiality or potential economic loss) and person-related concerns (those that represent personal and immediate concerns such as direct personal or other benefit, balanced with the temporary nature of discomfort or inconvenience). Compared with the ''biorepository'' label, the word ''biobank'' was associated with significantly lower person-related concerns (e.g., lack of benefit, discomfort, or inconvenience), suggesting that the word ''biorespository'' was less personally reassuring than the word ''biobank.'' Those who identified as having participated in research previously had lower person-related concerns, regardless of which word was used, implying that they may already possess an understanding of what donation entails. Regardless of the label used, those with higher levels of education had significantly higher use-related concerns (e.g., confidentiality and profit motives), and lower person-related concerns. Use-related concerns of privacy breaches and commercial gains parallel a body of research exploring the link between education level and institutional skepticism.[29]

Access to human biospecimens for clinical and research purposes is important for the continued advancement of both precision medicine and research initiatives, and efforts directed to enhancing participation rates are important. Our findings suggest that use of the term ''biobank'' may be less negatively value-laden and might possibly yield higher participation rates. We suggest that as a more familiar term, at this point in time, ''biobank'' may evoke more connotations related to governance, security, and accessibility than the word ''biorepository.''[16]

Overall, these outcomes confirm that misunderstandings or misattributions of the words used to refer to biospecimen storage facilities have potential to deter participation and highlight a need for those soliciting donations to carefully consider the delivery of key information upfront in a way that is easily, immediately, and accurately understood by participants. It would be beneficial for those soliciting donations to assess prospective participants' understanding of biospecimen donation. In particular, it is important to ask for participants' understanding of the mandate of the storage facility, including sharing, ownership, privacy, and profit considerations, to correct misconception or semantic misattributions, and to provide opportunities to have questions and concerns addressed.

Of note, participants in this study represented those already predisposed to volunteer for research and therefore, their perceptions may be biased. This is considered both a limitation and a strength. The fact that the label ''biobank'' evoked lower person-related concerns with a population at greater probability to have been previously exposed to both ''biobank'' and ''biorepository'' labels strengthens the suggestion that the word ''biobank'' may be less predisposed to negative semantic connotations.

Acknowledgments

The authors are grateful to Foothills Medical Centre Multiple Sclerosis Clinic, and Ms. Jamie Greenfield, for assisting them with data collection, and to the patients/family members who completed the survey.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

This study was supported by a team grant from the Canadian Institutes of Health Research under the Inflammation in Chronic Disease Signature Initiative.

Supplementary Material

Survey Biobank Version
Survey Biorepository Version

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