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Biobanking for Genomic and Personalized Health Research: Participant Perceptions and Preferences

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Introduction: Biospecimens and associated data are invaluable tools in Genomics and Personalized Health (GAPH) research and can aid in the discovery of disease etiology and the development of therapeutics.
Objective: To examine the experiences of patients invited to a particular GAPH study, Spectrometry in TIA Rapid Assessment (SpecTRA), and to explore broader biospecimen and data sharing preferences among a larger group of patients who had opted into a Permission to Contact for research program.
Methods: An electronic survey was e-mailed to 515 participants. The survey was completed by 38% of participants, an unspecified number of whom were also SpecTRA participants.
Results: Of those respondents who recalled participating in SpecTRA, 96% strongly agreed, agreed, or were neutral when asked if they received enough information to make an informed decision. Seventy-two percent agreed and 20% were neutral when asked if their study questions were addressed. Ninety-six percent of all respondents felt that SpecTRA's aim to develop a proteomic test for stroke was a worthwhile investment for health care, 98% said they were willing to provide a sample and/or information to facilitate the project's goals, and 96% to health research in general. Fifty-three percent of all participants suggested they would be comfortable sharing health information collected during SpecTRA with for-profit organizations, 87% with nonprofit organizations, and 38% said it matters to them where in the world their sample/information would be sent.
Conclusions: Our results suggest that while there is room for improvement in providing adequate information to enable participants' understanding of the purpose of GAPH studies such as SpecTRA, patients are supportive of GAPH in general. Results also suggest that willingness to participate would likely be impacted by factors such as the study's commercial and national affiliations. This study indicates that further work is required to guide improvements on how the GAPH research community describes studies to potential participants, and to enable participation options that incorporate variable participant preferences.

Keywords: personalized medicine, biobanking, ethics, REDCap

Introduction

Genomics and Personalized Health (GAPH) research represents one of the fastest growing sectors of health research. For well over a decade, personalized health, or more recently, precision medicine,[1] has been widely viewed as the solution to improving the efficacy of medical therapies through individualized, targeted treatments.[2,3] Cancer and rare orphan diseases are exemplary of the clinical progress anticipated with genomics and precision medicine.[4] Meanwhile, the range of health targets for genomics and ''omics,'' broadly defined, is expanding to include chronic degenerative disorders (e.g., chronic obstructive pulmonary disorder and irritable bowel syndrome) or neurological diseases, such as epilepsy and acute stroke. The expansion in disease scope is occurring alongside technological advances, rapid and inexpensive gene sequencing, and a proliferation of validation sets (sequencing libraries).[5] Personalized therapies require targeted funding, and recent increases in federal funding for genomic and precision medicine projects have indeed solidified a national (and global) commitment to these rapidly evolving fields. These funds are often tied to

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grant-matching requirements that forge stronger industry partnerships and add external pressures on researchers to bring their GAPH products to the market quickly.

The surge in the number of new and ongoing GAPH-related projects is accompanied by subsequent demands for biological samples (biospecimens). Commercial, generic biospecimens serve the purpose of validation and quality assurance in most laboratories but are limited in their ability to validate omics-derived tests. In those cases, biospecimens are needed for immediate, real-time analyses, future validation work, and research in general.[6] Preservation of biospecimens for long-term analyses is particularly important in pediatric medical genetics, for example, where samples must be compared longitudinally, and therefore, long-term storage options are required. As GAPH research advances, more disease-specific consortiums with networked global platforms for biospecimen and data sharing are emerging.[7–9]

Patients increasingly have the option to ''bank'' samples for additional research, and secondary use clauses have become commonplace on most biobanking consent forms. Biobanking—the activity of collecting, processing, storing, annotating, and distributing biospecimens and associated data in an organized and searchable manner[10,11]—could play a significant role in realizing the clinical benefits of sharing research data within the GAPH network and beyond.

GAPH research does pose new challenges in the biobanking space. These challenges include balancing the need for full and transparent description of the research to potential participants, while acknowledging the rapidly evolving application of collected biospecimens and data as new techniques and capabilities emerge.[12,13] In the absence of broadly accepted informed consent frameworks for GAPH, investigators often veer toward using the traditional informed consent form standards, which may be a poor fit to effectively communicate the key elements to potential participants. Addressing this issue, among others, is critical to the continuity of GAPH research in Canada, particularly as there is a growing need to link specialized biospecimens with electronic health records and data warehouses across different host institutions and countries.[14]

Exploring public perceptions is one approach to developing ethics guidelines on complex health research topics such as biobanking. This approach can inform research ethics boards and institutional approval bodies and, importantly, aims to lessen the power differential between participants and researchers. Public engagement is perhaps most adopted in health services and policy, where patient-oriented research constitutes a major funding priority.[15,16] Although basic science has been slower to adopt public/patient/participant engagement approaches, these are increasingly used to gauge public perceptions on biobanking.[17–19] Some of the empirical findings to emerge from this work demonstrate that research participants and patients consistently express a desire to provide biospecimens and data.

Efforts to ascertain the public's attitudes and perspectives on particular ethical aspects of biobanking have thus far included issues such as unspecified future use, tissue ownership, compensation for commercialization of findings, return of results, and material versus incidental findings.[20–22] Given the scientific complexity and international collaboration typified by most GAPH studies, it remains unclear how well participants understand the nature and scope of their participation, as well as their preferences around sample and data sharing. Here we present the results of a survey that gauged understanding of the biobanking component and data sharing preferences among stroke patients participating in a GAPH study and disease-specific biobank.

Materials and Methods

Permission to Contact program

Island Health is the regional health authority for Vancouver Island and the surrounding islands in British Columbia, Canada. It services ~765,000 citizens in the region. The Island Health Permission to Contact (PTC) program is an opt-in registry of individuals who are interested in being contacted regarding study participation opportunities.[23] Patients with an Island Health encounter (i.e., an interaction with the health care system, such as an outpatient clinic or emergency department) may be asked during their registration process if they wish to participate in the PTC program. Participation involves permissions to (1) collect a minimal set of their personal data; (2) access their Island Health record for the purpose of prescreening for future study eligibility; and (3) contact them with information updates for targeted research opportunities. Access to and use of data from the PTC program is granted through a formal application process for all researchers and Island Health personnel conducting quality improvement studies and/or research activities. This application process includes consultation with the study's governing research ethics board.

Biobank: Spectrometry in TIA Rapid Assessment

Select participants of the Island Health PTC program were invited to complete an anonymous electronic survey that aimed to assess their experiences and preferences regarding the scope and delivery of information during the informed consent process of an Island Health-hosted GAPH biobanking project, Spectrometry in TIA Rapid Assessment (SpecTRA; see the subsequent ''Study Population'' section for details on participant eligibility). SpecTRA is a large-scale personalized medicine research project[24–26] with Island Health as its host institution and funded by Genome Canada, Genome British Columbia, and Genome Alberta. SpecTRA aimed to develop a diagnostic blood test based on protein biomarkers to better triage transient ischemic attack or mild stroke in emergency room departments.[27,28] The SpecTRA biobank is registered with the University of British Columbia Office of Biobank Education and Research Registration (BRC-00132). The biobank contains plasma in 0.5 mL aliquots from 1223 patients who presented to the emergency department with mild stroke-related symptoms and consented to having their blood drawn for the stroke study. Biospecimen collection took place over a 2.5-year period from four enrolling hospitals, and unused samples are stored in a locked, −80°C freezer.

Study population

As part of standard of care, SpecTRA study patients are referred to an ambulatory outpatient stroke clinic for neurological workup within the immediate days following their emergency department visit. When patients register at the ambulatory outpatient stroke clinic for consultation (regardless of their SpecTRA study status), the medical office

assistant invites the patient to opt-in to participate in the PTC program. In the present study, all PTC participants who were treated at Island Health as an outpatient stroke or possible stroke patient and who provided an e-mail address to the PTC program were eligible. These PTC participants may or may not have been a SpecTRA study participant, however, the survey instrument was designed to guide respondents to self-screen so that SpecTRA-specific questions were posed only to those respondents who recalled participating in SpecTRA (see the Survey Instrument section below). Any patient listed as deceased or for whom the e-mail address was unknown was removed from this initial screening, and recruitment messages were then sent to the remaining 515 patients.

Survey instrument

The survey instrument was created using Research Electronic Data Capture (REDCap).[29] REDCap is a secure, web-based application designed to support data capture for research studies providing the following: (1) an intuitive interface for validated data entry; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for importing data from external sources. It is a user-friendly and flexible informatics platform increasingly used within the translational research community.[30]

Using REDCap's branching logic design feature, it was possible to tailor the survey questions to each individual respondent based on the previous responses. The survey probed three related topics: (1) participant attitudes and interests regarding GAPH research (all respondents); (2) participant experiences and preferences while enrolled in SpecTRA, (respondents who were recruited but may not have participated in the SpecTRA study); and (3) participant acceptability of specific biobank activities (all respondents). The questions were formatted as either Likert scale or multiple choice, with free text comments enabled where suitable. The complete set of survey questions and branching design is provided in Supplementary Data. The survey was piloted with three lay reviewers who assessed it for readability, comprehension, appropriateness, accuracy of the branching logic, and anticipated completion time.

Invitations to complete the survey were distributed via e-mail and included a link to the REDCap survey instrument. The survey was delivered in two phases: an initial pilot phase of 70 people; and 2 weeks later, a broader distribution to an additional 445 people (see Fig. 1 for the respondent participant flow diagram). This staggered distribution approach provided an opportunity to revise the invitation and survey after the pilot phase if issues were identified. Pilot reviewers did not identify any need for revisions to the invitation or survey. The survey remained open for 3 weeks. Responses are described using Likert-scale graphs.

Results

Of the 515 surveys sent out on the stroke clinic PTC list, 196 responses were received for a survey response rate of 38% (Fig. 1). The 196 respondents are all in the PTC program, 117 of whom recall an emergency department (ED) visit and of those, 36% recall being approached to participate in the SpecTRA study. Our survey did not ask sociodemographic questions. However, we know from the SpecTRA study that ~47% of participants are female, with an average age of 69 years, and ~90% self-identify their race (ethnicity) to be white.[31]

Biobank participant experience and perceptions

Survey respondents who indicated that they were SpecTRA study patients answered five questions. The first question asked them to select the best answer describing the study purpose and approximately half (51%) of the respondents answered correctly, in that they knew the study purpose was to develop a blood test to detect stroke, while 28% answered "I don't know." The second question asked about their experience with the study; almost all respondents (96%) who recalled enrolling in SpecTRA strongly agreed, agreed, or were neutral when asked if the SpecTRA experience was positive. The third question asked about the amount of study information that they received: 96% responded strongly agree, agree, or neutral to the question, "I received enough information to make an informed decision." The fourth question asked if "my questions about participating were thoroughly addressed" respondents largely agreed (72%) or were neutral (20%). Finally, in response to the question "I found it helpful to have a nurse call me after a few months' time to see if I was doing okay," surprisingly, ~30% said "no."

Interest in GAPH research and factors affecting participation

The majority of respondents (96%) felt that developing a blood test to detect stroke is a worthwhile investment for health care. It is perhaps unsurprising that nearly 98% said they would be willing to provide a blood sample to help develop a blood test for stroke, specifically. Ninety-six percent of respondents also said they would be willing to donate a sample and related health information to health research in general, and 93% said they would be willing to participate in an ongoing study to monitor changes in their health (Fig. 2). When asked whether or not it matters if the study purpose is to improve health care or simply generate new knowledge, 61% agreed the former was preferable.

Data sharing preferences

Respondents were less supportive of data sharing in general, particularly if a commercial entity was the recipient of the health information. As shown in Figure 3, only 53% of respondents said they would be comfortable sharing health information such as previous health conditions collected during their participation in SpecTRA with other studies sponsored by for-profit companies. When asked the same question regarding nonprofit organizations (universities, health care organizations), 87% said they would be comfortable sharing their health information. In addition, ~38% of respondents said that if they participated in an international research project, it would matter to them where in the world their sample and information were sent. We did not ask in the survey specifically what areas of the world generated concern or no concern.

The final sections of the survey pertained to specific components of data sharing. When asked about the types of information they would be willing to share with researchers,

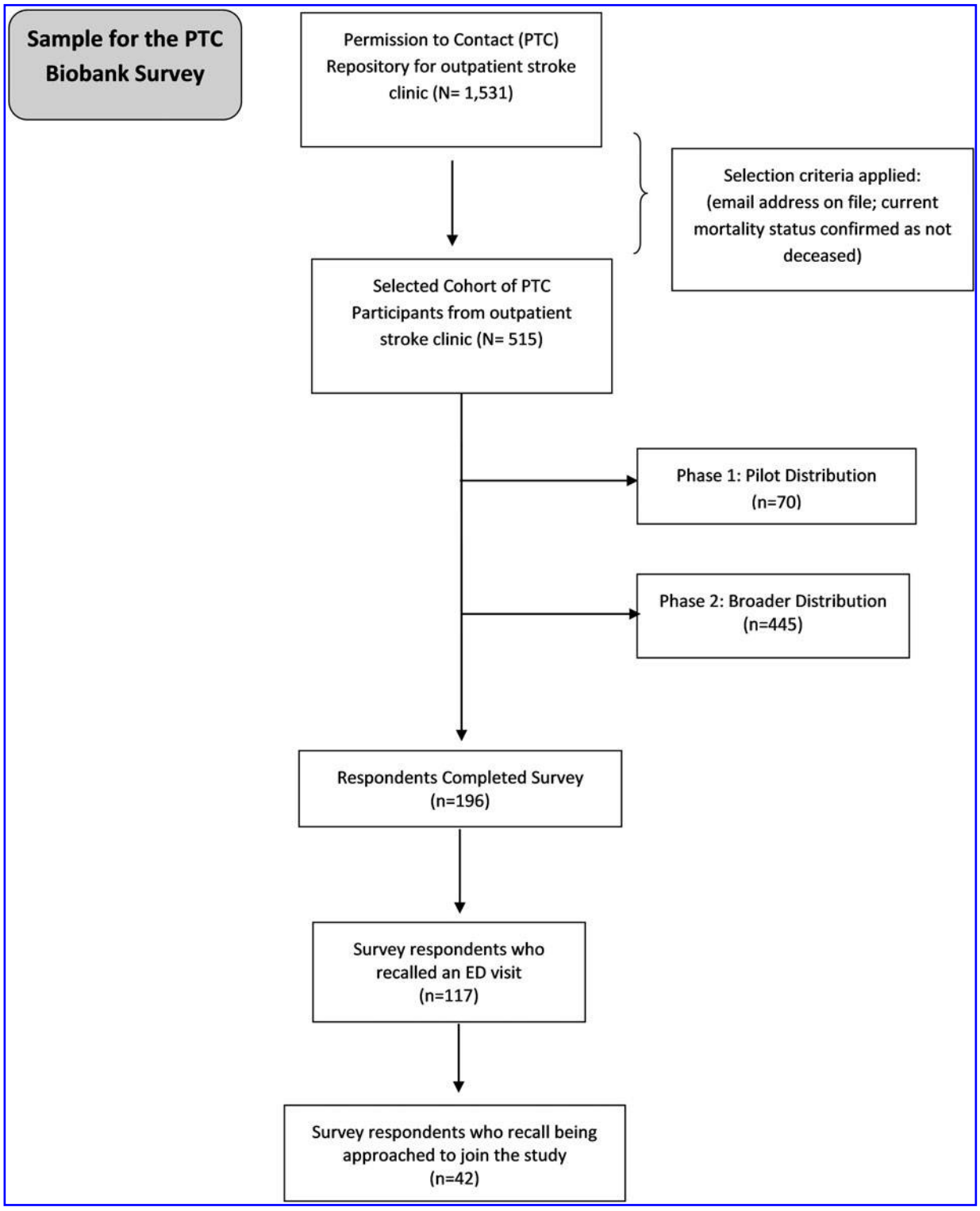

FIG. 1. Survey respondent participant flow diagram. ED, emergency department; PTC, Permission to Contact.

survey respondents largely supported sharing their data, including information on previous health conditions (99%), updates on their health status (96%), and information resulting from previous health research studies (93%). Yet only 79% said they would be willing to share their personal information, such as name, date of birth, and sex (Fig. 4). If the research team discovered information relevant to the patient's health care, respondents reported they would want this information disclosed to them (99%), disclosed to their doctor (98%), and incorporated into their health record (92%) (Fig. 5).

Discussion

In recent years, several biobanking best practices and policy recommendations have been developed to address the

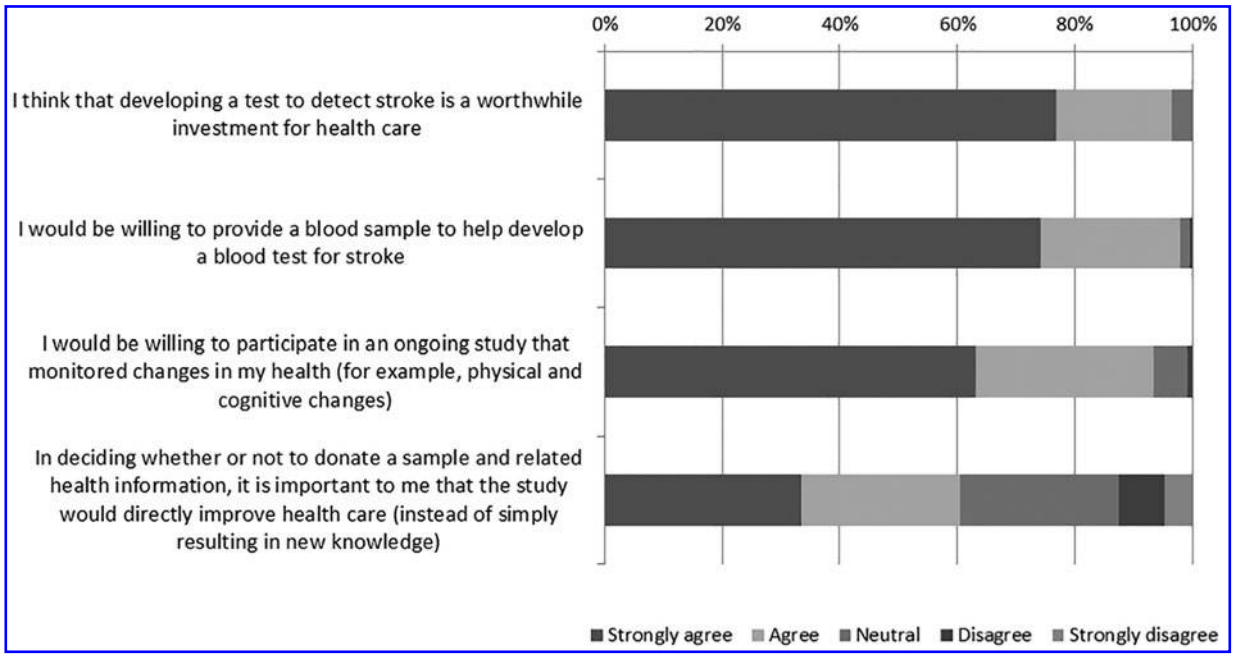

FIG. 2. Participant perceptions. Likert-scale outcomes with reversed variables.

ethical, legal, and social issues of emerging biobanking technologies and data capabilities.[32,33] For some time, one recurring issue has been how to achieve full and informed consent when enrolling participants into GAPH studies that include a biobanking component.[12,13] Achieving this comprehensive level of patient understanding can be particularly challenging for GAPH researchers to impart on participants due to the multidisciplinarity of the science and diversity of collaborators. However, there now exists a large international set of recommendations, guidelines, and policies that support the ethical viability and validity of a ''broad consent'' approach in biobanking,[34,35] in addition to evidence of high patient acceptability of such approaches.[36] Indeed, within Canada, broad consent is an approved norm, as supported by the Tri-Council Policy Statement, Chapter 12, which states that biological materials, ''…may be collected for research or medical or diagnostic purposes with some expectation that they may, or will, also be used in future research, although the precise research project(s) may not be known at the time.''[37] The use of broad consent is also seen

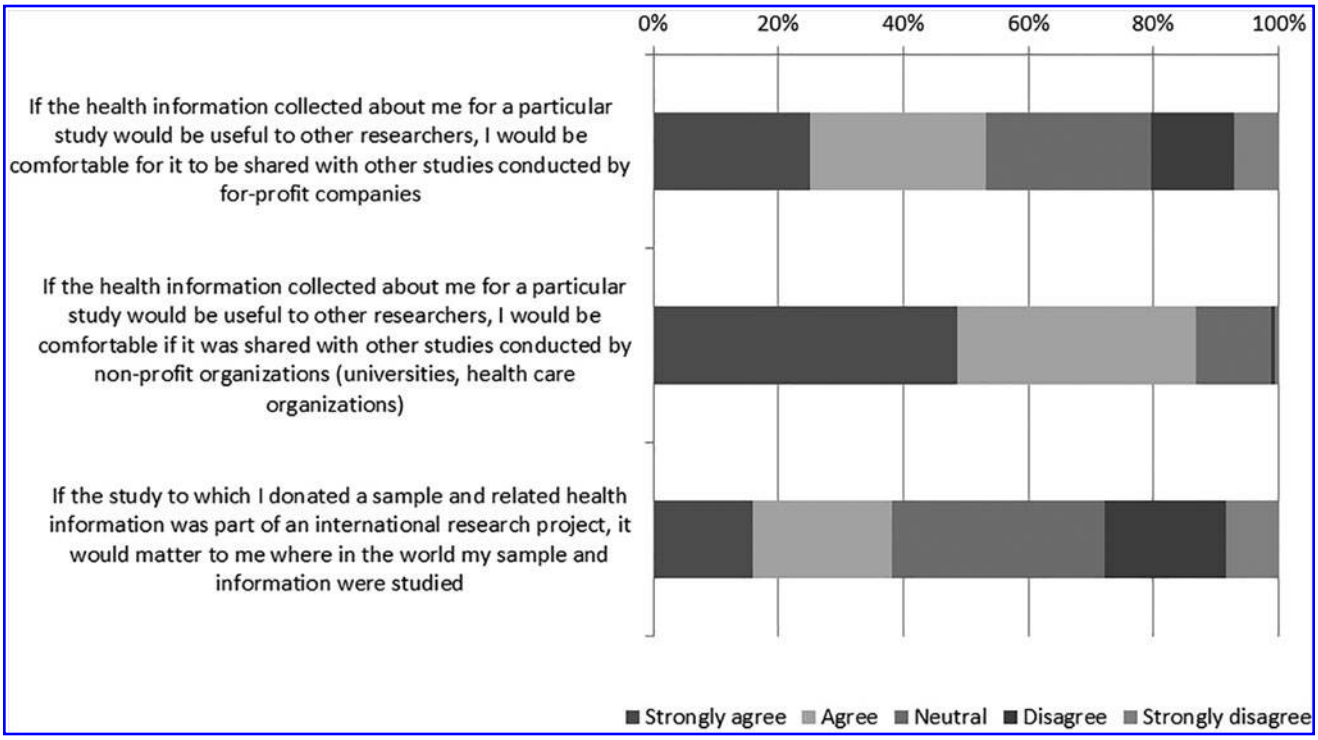

FIG. 3. Data sharing preferences—researcher affiliations. Likert-scale outcomes with reversed variables.

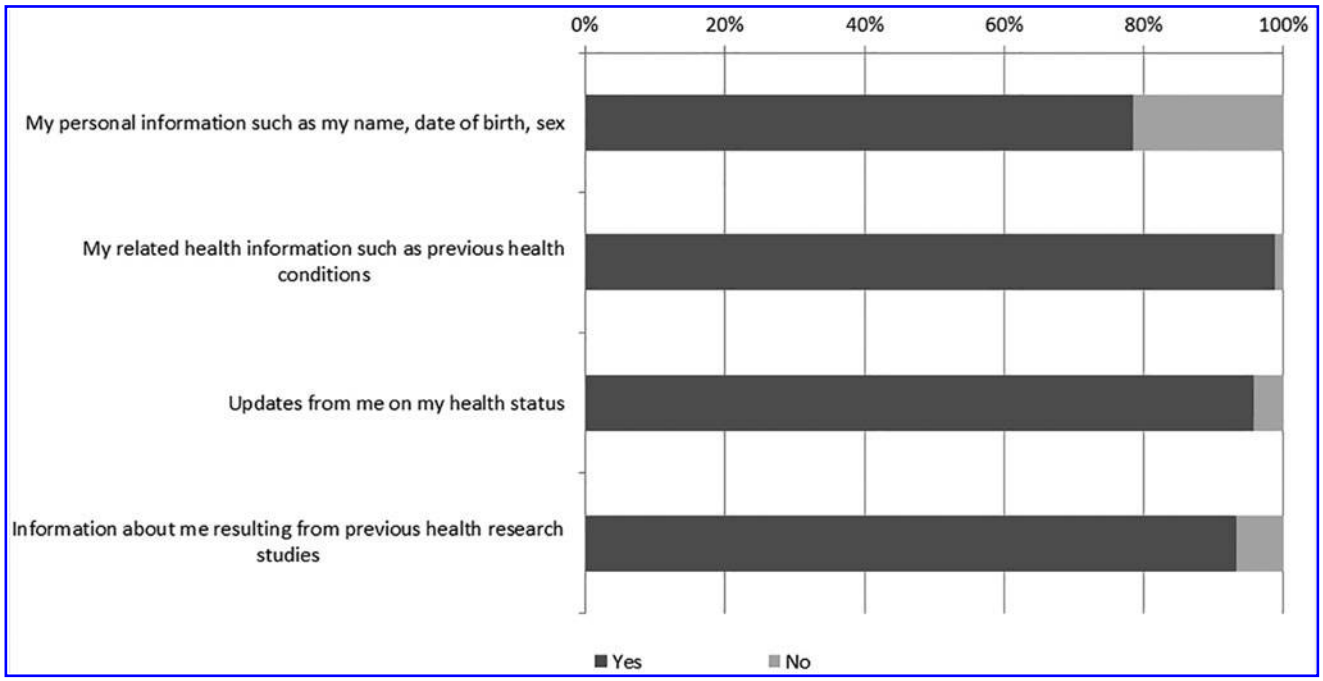

FIG. 4. Data sharing preferences—types of participant information. Likert-scale outcomes with reversed variables. *I would be comfortable with the following types of information being shared securely with other studies…*

in practice through several large, national initiatives—the Canadian Partnership for Tomorrow Project,[38] the Canadian Longitudinal Study on Aging,[39] and the Canadian Health Measurements Survey.[40]

Our results indicate that while understanding the purpose of the GAPH study to which participants donated biospecimens was relatively low (roughly 50% of participants surveyed), an overwhelming majority of participants were supportive of the particular study (developing a blood test to detect stroke) and indicated they would choose to participate. These results mirror the recent findings by Merdad et al.,[41] however, it is important to recognize that the survey participants in the present study had recent lived experience in the therapeutic area addressed by the SpecTRA study

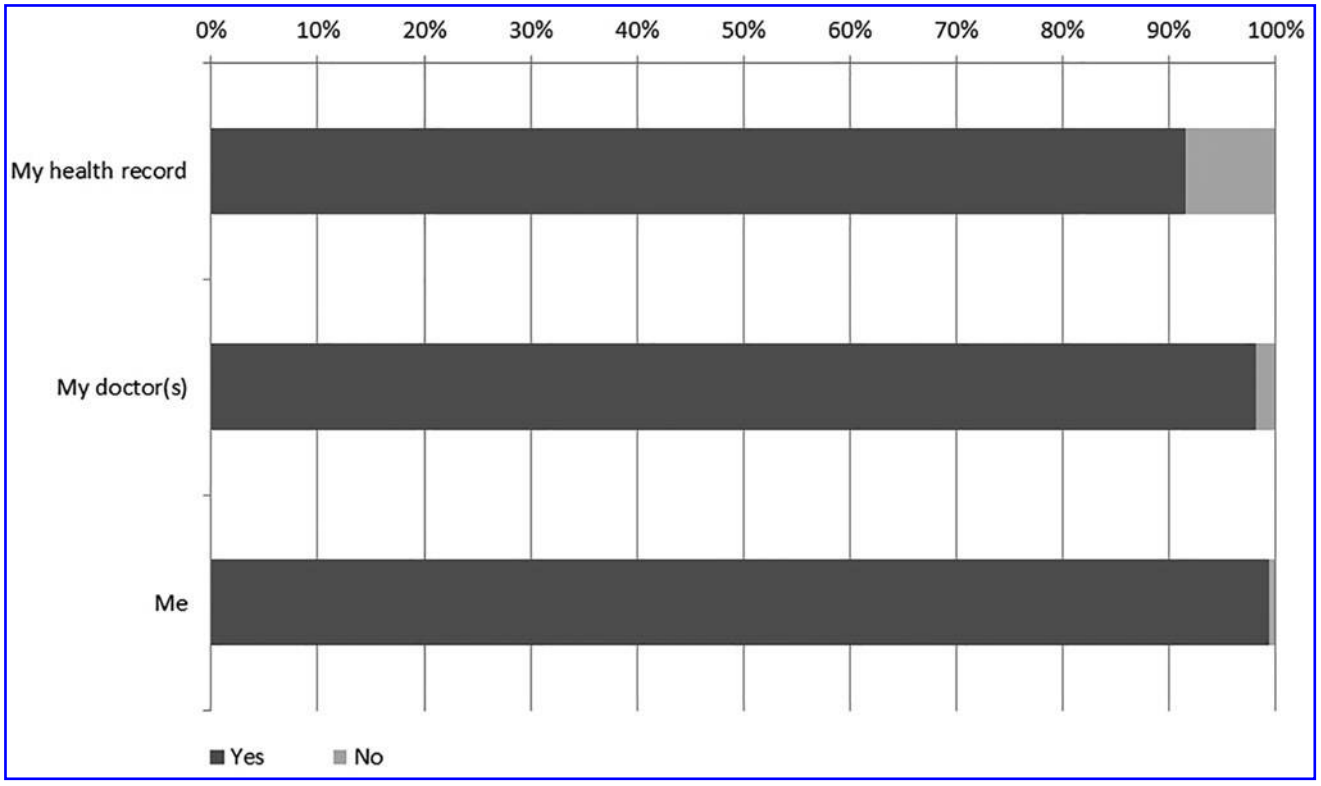

FIG. 5. Data sharing preferences—who receives research results. Likert-scale outcomes with reversed variables.

(i.e., stroke and transient ischemic attack) and it is expected that this would create a positive bias in their responses. Support for data sharing was also high if the research was perceived as being conducted for nonprofit/academic purposes. This finding aligns with a previous survey which found that the affiliation of the research organization, nonprofit or for-profit, appears to impact the willingness to participate.[42] It may be worthwhile for the biobanking community to work toward addressing public/patient misconceptions around the industry sector of biobanking and its shared goals in the academic sector to support discovery.

One notable observation pertains to the impact of deferred consent on the opt-in rates for biobanking materials among study participants. The SpecTRA study was a multisite biomarker study. At the main enrolling sites, where there were paid study personnel, nurses approached patients to be study participants and sought formal (signed) informed consent. They walked through the consent form with the patients and their family, and outlined the opt-in section for the participants who could say that ''yes'' they wanted their blood sample to be saved for future and related research on stroke or cardiac biomarkers outside of the present study. With the formal consent route, there was a high opt-in rate for banking samples ($\sim$88%). In the smaller study sites, without formal paid study staff, we trained emergency department clinical nurses on the study protocol and Good Clinical Practice certification. Those nurses screened patients for inclusion as part of their normal clinical workflow and would ask the medical laboratory assistants to draw an extra tube of blood during the standard-of-care blood draw. The medical laboratory assistants would ask the patients if they would like to provide an extra tube of blood (4 mL) for stroke research and that they would have an opportunity to discuss the study and give formal consent for their blood sample to be used during their emergency department or follow-up visit. The medical laboratory assistants would check a box on the laboratory requisition stating that verbal consent was obtained and collect a study sample. At a later date, sometimes days later, the same patient was invited to formally consent to the study using the approved informed consent form. Through the deferred consent route, 321 blood draws were taken in the ED by the laboratory assistants and, of those, only 148 (46%) actually enrolled into the SpecTRA study, constituting less than 12% of the overall target enrollment of 1200 patients for all sites. The screen failure rate was high (54%) at the deferred consent site, even though 76% of those 321 blood draws were appropriately taken (i.e., patient met inclusion criteria). Of the 148 enrolled, the permission to bank samples was low (36%) relative to the formal, shepherded consent process. This suggests that a deferred consent process where participants opt-in for banking their biospecimen samples may not be as viable as a formal, shepherded consent process. However, a thorough examination of the different response rates from the two different consent pathways should be conducted, including gender, age, and stroke severity, before suggesting one consent pathway is more productive than the other. Due to the unique and time-sensitive manner in which the plasma samples had to be collected and processed, it was not an option to use a default consent process in which discarded or remnant patient samples could be used.

The present study presented several limitations. First, we are unable to validate that people who answered survey questions on the SpecTRA study had in fact been invited to participate. Second, as mentioned above, the fact that participants had recent lived experience in the therapeutic area that the survey pertained to, we would expect this would create a positive bias in their responses regarding support for the study, including their willingness to provide and to bank biospecimens. The biospecimen procurement mechanism and its correlation to biobank participation is an oft-studied phenomenon that was not addressed in our survey, namely because the procurement mechanism for the SpecTRA study is embedded into the routine clinical workflows. As L'Heureux et al.[43] report, ''inconvenience'' is among the primary factors that deter potential biobank participants. One respondent to the present survey corroborated these findings when he or she noted, ''My only problem with providing blood samples is getting to the location. I am very busy and would not be willing to spend more than a few minutes' time traveling for the sampling.'' An additional limitation relates to the fact that the results reflect only the views and preferences of SpecTRA participants who opted in to bank their plasma samples for ''secondary analysis for stroke and/or cardiac research'' ($\sim$25%). Perceptions from the opt-out group are valuable in better understanding how they rate the importance of biobanking to biomarker research in stroke; yet in practice do not provide samples for additional study. Furthermore, this study may have introduced a positive bias considering that all invitees chose to participate in the PTC program, and thus had an expressed interest in participating in health research in general.[43] Finally, we are unable to validate the total percentage of the respondents who were approached about SpecTRA participation; the metric used in the survey was based on respondents' recall on whether or not they had been approached to join the study. However, none of the patients in the SpecTRA study had legally authorized representative (or proxy) consents in place, indicating that cognitive impairment was not an issue, and so should not factor into recall concerns. Furthermore, the inclusion criterion into the SpecTRA study was an NIH Stroke Scale Severity of four or less, which by definition is a mild stroke with favorable clinical outcomes and return to functional independence. Finally, not all of the patients who attend the stroke rapid assessment outpatient unit had a transient ischemic attack, or mild stroke. About 25% of the outpatients, on average, have what is referred to as a mimic condition, a clinical episode that mimics stroke but is attributable to other factors, such as migraine, seizure, Bell's palsy, among others. Regardless of our inability to identify through this survey responses who was in the SpecTRA study and who was not, all patients of the outpatient clinic who were in the PTC program have perceptions and preferences about biobanking, independent of study participation.

Our results support previous findings on public perceptions on research studies involving biobanking by showing that the majority of patients affected by a particular condition are keen to provide biospecimens and related data to research aimed at improving our understanding of that condition. This study also indicates that further work is needed to understand how the GAPH research community can design study background and consent information to adequately describe their studies to potential participants, and to align with participants' variable preferences around biospecimen and data sharing.

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Authors' Contributions

All authors contributed to the ideas presented here and to the development and preparation of the article. All authors read and approved the final article.

Author Disclosure Statement

There are no conflicts of interest to disclose.

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Supplementary Material

Supplementary Data

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