Biobank participants' preferences for research updates: Tailoring communication services

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Abstract

Data and sample donation from diverse populations is critical for research findings to have a broad impact. The goal of this study is to better understand study participant attitudes and preferences for updates on biobank-related research activities. We also hope to understand if there are differences in these topics between demographic groups. In this analysis of 51 survey respondents, we found that younger adults prefer e-Newsletters significantly more than older adults (92% vs 62%), and adults of lower education status prefer text updates significantly more than adults of higher education status (20% vs 3%). However, we found no significant differences in preferences for frequency or type of update, nor in trust in Johns Hopkins Medicine staff with respect to age, education, and gender. These analyses can inform the design of communication services that can be tailored to the preferences of biobank participants, allowing for more robust and diverse research participation.

Introduction

Population-based biobanks are repositories of donated biological specimens and genetic, medical, and other personal data(1). Data is often donor specific, and is used frequently in longitudinal studies that measure factors influencing the progression, recurrence, and treatment of disease. Biobanks thus have important implications in basic, clinical, genomic, and translational research, and play a key role in personalized medicine, or the tailoring of medical treatment to the individual characteristics, needs and preferences of each patient(2).

The success of these biobanks is dependent on the publics' willingness to participate. In order to ensure broad applicability of findings, it is critical for these biobanks to achieve high participation from communities that are representative of all sub-populations. In fact, a lack of this representation can impede the evaluation of tools developed for clinical diagnosis and limit the ability to gauge the efficacy of treatments(3). This makes it critical to understand the factors that influence willingness to participate, and to see if there are differences between demographic groups. One predictor of willingness to join a biobank is trust in medical researcher(4,5). Recent studies have also found that people are more willing to participate in biobanks if there are more chances to learn and be updated regularly about the biobank(4,6). Importantly, a 2015 study on a DNA biobank for protocol-driven heritable neoplasia syndromes found that older, less educated, and lower-income respondents were more likely to prefer offline approaches such as mailed newsletters over digital approaches(7). However, there is still a dearth of information on diverse study participants' opinions about the use of their information in research, and on their preferences to be updated about research.

The evidence that there may be differences in preferences for updates among various populations motivates a need for tools to tailor what, how and when updates about a biobank are communicated to sample donors. Such tools could enable donors to specify (1) at what frequency they want to be notified of updates, (2) what mechanisms they prefer to receive updates (e.g., e-newsletter), and (3) what types of content they want to receive (e.g., educational material). Furthermore, allowing communication platforms to be customized to meet the needs of various demographic groups may empower biobank participants to feel more connected to the studies that they are involved in, ultimately increasing trust and willingness to donate to a biobank in the future.

In this paper, we present findings from a survey of Johns Hopkins Hospital (JHH) patients that have previously participated in a genetic research study. The particular focus of this analysis is on preferences for receiving updates, and differences in preferences between demographic groups. This work is part of our user-centered design process, providing valuable information for the development of new services targeted to study participants in the YourGift Gives initiative at Johns Hopkins University. The purpose of this initiative is to enable tailored communication with biobank donors and study participants. The ultimate goal is to encourage individuals from a wide variety of backgrounds to participate in research through enabling such communication as a form of reciprocity for their donation.

The specific contributions of this paper are, for a sample of JHH patients:
- Characterize the variability in communication preferences among study participants.
- Characterize the variability in frequencies that donors would want to be notified about research studies of interest.
- Determine whether there is a correlation between different demographic groups and communication preferences.

- Provide design considerations for tailoring communications with study participants.

Materials & Methods

Recruitment

We recruited study participants using a method that aimed to identify a population similar to that of the electronic medical records and genomics (eMERGE) study population. eMERGE is a national network funded by the NIH National Human Genome Research Institute that combines biobanks with electronic health records (EHR) for large scale genetic research(8,9). Our approach involved first identifying Johns Hopkins Medicine (JHM) patients who were on a research study protocol and who had an activated MyChart account (the patient portal for the Epic® EHR system across JHM). The JHM Center for Clinical Data Analysis queried the Epic Clarity reporting database to extract an email list for all patients aged 18 or older who were seen as inpatients or outpatients at Johns Hopkins Hospital, who were a participant on one of 35 studies registered with the database of Genotypes and Phenotypes (dbGaP)(10), and who had logged into their MyChart account within the last 12 months. Patients were excluded if they were known to be deceased, had previously opted out of being contacted for recruitment via MyChart, or had an invalid or null email address. JHM data collection occurred from February 20th, 2017 to March 20th, 2017.

Web-based survey instrument

A web-based survey instrument was developed using Qualtrics (Qualtrics, LLC, Provo, UT, USA). The survey consisted of 39 questions covering: trust and opinions about using clinical information in research (6 questions), desire for updates (4 questions), preferences for different types of updates (7 questions), preference for different frequencies of updates (8 questions), preferences for different mechanisms to receive updates (5 questions), costs of providing updates and engagement activities (1 question, not assessed in this work), and demographic information (8 questions).

Data analyses

We report frequencies of comfort with JHM staff and preferences for updates. To assess differences in preferences by demographic groups, chi-square analysis was performed. All statistical analyses were performed using Stata 13.1 (StataCorp LP, College Station, TX, USA).

The Johns Hopkins University Institutional Review Board (IRB) supplied ethical approval for the study (IRB00107475).

Results

Study population

We identified 35,965 Johns Hopkins Medicine (JHM) patients who were on a research study protocol and that also had an activated MyChart account (as of January 1, 2017). Among those patients, our Web-based survey was sent to 210 current and previous participants in a selected research study that also authorized future contact. Fifty-one individuals completed the web-based survey, resulting in a response rate of 24.3%. Demographic characteristics of respondents are presented in Table 1. Most were male (76%), spoke English as their first language (96%), and were white (90%). All identified as non-Hispanic. Most were aged 60 or older (76%), and most had at a college education or higher (61%). Though all people surveyed had donated tissue to the biobank, only 47% of respondents indicated that they had donated tissue of any kind before for use in research.

Table 1. Demographics of the study population.

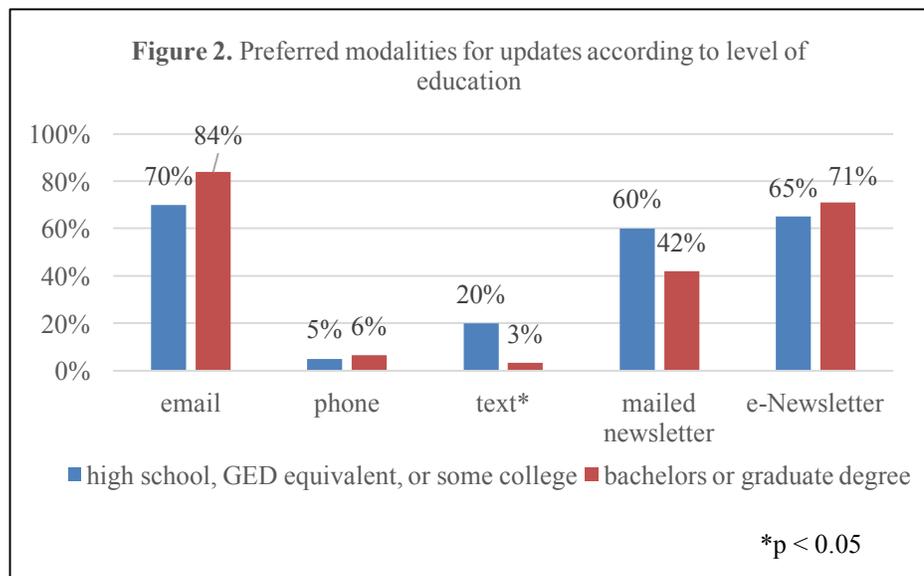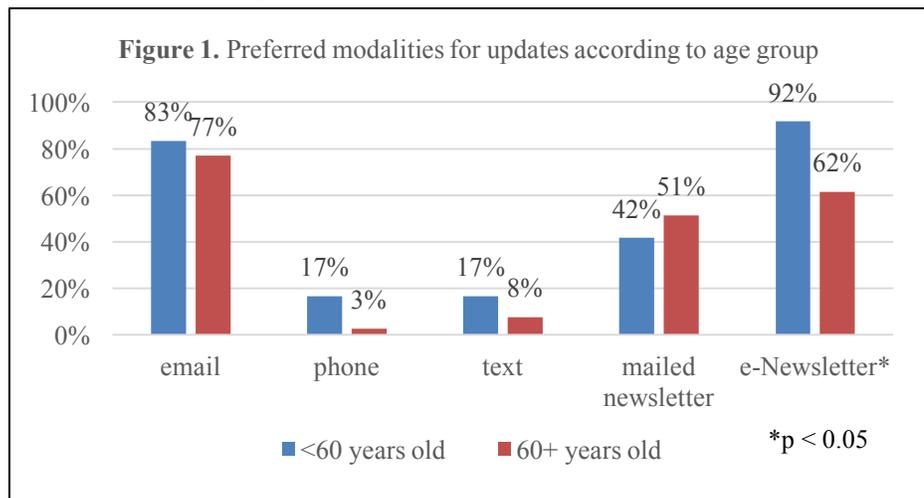|	Respondents (N=51)
Donated tissue	
Yes	24 (47%)
No/Unsure	27 (53%)
Gender	
Male	39 (76%)
Female	12 (24%)
English as 1st language	
Yes	49 (96%)
No	2 (4%)
Ethnicity	
Non-Hispanic	51 (100%)
Race	
White	46 (90%)
Non-white (Black & Asian)	5 (10%)
Age group	
>=60	39 (76%)
<60	12 (24%)
Highest education level	
College, graduate or professional degree	31 (61%)
Some college	14 (27%)
High school or GED	6 (12%)

80%-90% of respondents trusted their doctors, Johns Hopkins Medicine (JHM) researchers, and JHM research ethics committees to decide how to use their tissue samples, medical history data, test results (e.g., x-rays) and genetic test information. Of note, we found no significant differences in trust in doctors, JHM Researchers, and the JHM Ethics committee between different age groups, education statuses, or genders ($p < 0.05$).

When asked about preferences for updates, most respondents wanted research updates only on specific health topics of their choice (84%), about research that uses tissue samples and clinical information from JHM (59%), and about research that uses their tissue samples and clinical information (76%).

The types of updates preferred by the majority of respondents included brief descriptions of major findings from the research (82%), brief descriptions of the research (e.g., purpose and goals, 77%), educational material about the research (67%), and brief descriptions about any media coverage about the research (53%). Fewer respondents indicated a preference for the number of published articles (45%), announcements about online platforms to interact with others with similar interests (45%), or community events about the research (41%).

Among the proposed frequencies to receive updates, in ranked order, 78% of respondents preferred to be updated when findings are published, 76% when the research ends, 73% when findings are reviewed by other researchers, 73% when educational material about the research is available, 71% when there is a change in the status of the research, 61% where there is a media release about the research, and 43%

Figure 1. Preferred modalities for updates according to age group

*$p < 0.05$

when there is a community event about the research. We found no significant differences in preferences for frequency of updates between different age groups, education statuses, and genders.

When asked about preferred modalities for updates, there were some differences between demographic groups. Younger adults preferred e-newsletters significantly more than older adults (Figure 1). In addition, adults with lower education status (having completed high school, GED, or some college) preferred text updates significantly more than adults with a bachelors degree or higher (Figure 2). Between genders, there was no significant difference in modality preferences.

Figure 2. Preferred modalities for updates according to level of education

*$p < 0.05$

Discussion

Our results show that most respondents trust JHM staff (their doctor, researchers, and the ethics committee) to decide how their donated specimens and information are used in research. Keeping in mind that all respondents had donated samples for use in genetic research in the past, this finding provides further support to the correlation between trust in institution and willingness to donate to a biobank as identified by others (3,5). However, different from previous studies that have found higher educational attainment and older age to be correlated to increased trust in provider (11,12), we found no significant difference between educational levels or age groups with respect to trust in their doctor, Johns Hopkins researchers, and Johns Hopkins ethics committees deciding how to use samples and data in research among our study sample.

In addition, our work illustrates that study participants may have variable preferences for when and how they would like to be updated about studies that use their samples and clinical information. Since the findings of others indicate that willingness to participate in biobanks is correlated to opportunities to be updated about the biobanks, (1) we believe that considering the preferences surveyed in this research will be key to maintaining successful and patient-centered population biobanks.

Design Considerations for tools to Enable Tailored Communications with Study Participants

Many respondents indicated a desire for multiple frequencies to be notified, with the two most popular frequencies being notifications when research ends and when findings are published. Among the frequencies we surveyed, these are the most feasible to implement given requirements imposed by funders of many studies to publish the status (e.g., active, completed) and study results (e.g., scientific publications) publically. Furthermore, we provide yet another motivating factor to enable data citation (i.e., access for data and sample donors). While there still remains an absence of links to data within journal publications, there is general agreement in the importance of data citation for the development of science(13).

In addition, the most popular preferences for types of updates were brief descriptions of the research design (e.g., purpose and goals) and major findings from the research. This finding indicates a need to prioritize mechanisms to share this information with study participants. Given that most research descriptions are not targeted to a lay audience, we believe that a priority design consideration should be to enable mechanisms for study team members skilled in research and health communication to create and disseminate lay descriptions of this information to their study participants.

Lastly, most study participants indicated a preference for digital modalities (email & e-newsletter) and fewer indicated a preference for phone and text. This finding re-enforces our current emphasis in local work to enable digital communication services for study participants. As an important note, however, work here (Figures 1 and 2) and that of others(7) indicate that options for both specific offline and digital approaches are needed, especially in a broader research setting.

Limitations and Implications for Future Research

Our analysis should be understood in the context of some limitations. First, our recruitment of previous participants in genetic research may limit the generalizability of findings and may not be representative of all individuals with MyChart accounts who could potentially volunteer for research at Johns Hopkins University. Additional work is also needed to assess if these preferences for biobank communication identified in this study match actual behavior with access to new communication services.

Findings and limitations of this study serve to inform our current work and the work of others. The aforementioned design considerations, for example, are part of our user-centered design process in the YourGift Gives initiative at Johns Hopkins University. With our goal to leverage technology to enable improved communication with study participants, the concept of personalized medicine is expanded to also include the tailoring of communication to the specific needs, characteristics, and preferences of individual patients that choose to participate in research. For example, one design approach could use the range of communication preferences we documented in this work to develop personas. Personas are short descriptions of the behavioral patterns, goals, and attitudes of different "user types." (14) In this context, personas have potential to aid in developing a tailored communication system, and in assessing preferences for communication features. By considering preferences for research study updates, a tailored communication strategy has potential to empower biobank and study participants to feel more valued and connected

to the studies for which they are a part. In addition, the increase in transparency and support for reciprocity has potential to improve trust in both the institution and in research, thus propagating a cycle of trust and re-participation.

Conclusion

Although a call to increase communications between biobank managers and sample donors has been recognized(7), it is not certain what the most effective methods to do so are. In this paper, we present an analysis of preferences for communication among a population of previous participants in genetic research, and differences in preferences among demographic groups. Previous findings indicate that providing results to study participants affirms the value of their contributions to research, results in greater awareness of the impact of clinical research, and supports public trust in the research enterprise(13). Findings from our analysis informs our local research initiatives that includes future efforts to enable sharing research findings with data and sample donors. Our hope is that such support would encourage individuals from a wide variety of backgrounds to participate in research through promoting a greater sense of transparency and reciprocity for their contributions.

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