Assessing the stability of biobank donor preferences regarding sample use: evidence supporting the value of dynamic consent

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Abstract
Dynamic consent has been proposed as a strategy for addressing the limitations of traditional, broad consent for biobank participation. Although the argument for dynamic consent has been made on theoretical grounds, empirical studies evaluating the potential utility of dynamic consent are needed to enhance deliberations about the merits of dynamic consent. Few studies have assessed such considerations as whether donor preferences may change over time or if participants would use a dynamic consent mechanism to modify preferences when they change. We administered a 66-item survey to participants in a large DNA biobank. The survey sought to gauge the stability of donor preferences specified at the time of biobank enrollment, specifically the stability of donors’ preference regarding posthumous availability of biospecimens to next-of-kin. We received 1164 completed surveys for a response rate of 72%. Forty percent of respondents indicated a preference regarding sample availability on the survey (T2) that was inconsistent with the preference they had expressed when they enrolled in the biobank (T1). Most (94%) individuals with inconsistent preferences regarding sample availability had initially restricted sample availability at T1 but were comfortable with broader availability when asked at the time of the survey (T2). Our findings demonstrate that preferences regarding sample use expressed at the time of enrollment in a DNA biobank may not be reliable indicators of donor preferences over time. These findings lend empirical support to the case for a dynamic consent model in which biobank participants are approached over time to clarify their views regarding sample use.

Introduction
Dynamic consent has been proposed as a mechanism for respecting the interests and preferences of biobank donors [1, 2]. Dynamic consent uses web-based interfaces to allow biobank donors to clarify their individual preferences regarding sample distribution and use. Dynamic consent could also provide a portal through which biobank donors are able to track which studies are utilizing their biospecimens and health data, and serve as a mechanism for researchers to communicate results of specific studies back to donors [3].

Consideration of dynamic consent is timely as several new DNA biobanks, including the All of Us Research Program [4], are recruiting very large numbers of sample donors and are considering how best to manage these important collections over time. Although dynamic consent has been proposed as a strategy for addressing the limitations of traditional, broad consent for biobank participation [5–9], it is unclear whether biobank participants would have reasons to use a dynamic consent mechanism to adjust their sample use preferences. Little data exists to suggest whether biobank donors’ sample use preferences evolve or remain stable after participants enroll in a DNA biobank. Although the argument for dynamic consent has been made on theoretical grounds, empirical studies evaluating the potential utility of dynamic consent are much needed to enhance deliberations about the merits of dynamic consent, especially given the costs of such a mechanism and the practical challenges of migrating existing large collections to a
dynamic consent platform. Before efforts are launched in support of implementing dynamic consent, data are needed to assess whether biobank donor preferences regarding sample use may change over time, which may be a predictor of whether biobank participants would use a dynamic consent mechanism to update their preferences when they change.

To begin to address the first of these empirical questions, we took advantage of an opportunity to examine the stability of a particular donor preference expressed at the time donors were enrolled in a large DNA biobank. Our objective was to examine the stability of this preference over time, contributing empirical data on the potential utility of a dynamic consent model for biobank participation.

Materials and methods

Participants

The sample was drawn from the Mayo Clinic biobank (n = 50,702 at the time of the survey). Informed consent for biobank participation had been obtained in-person for a small percentage of early participants (n = 1302, 2.6%), with the majority of participants enrolling via a mailed consent form accompanied by an informational brochure[10]. The consent form signed by biobank participants at the time of enrollment provided an option for participants to restrict posthumous availability of their biospecimens to the donor’s legal next-of-kin (see Fig. 1). This preference was solicited from participants during the biobank enrollment process based on a recommendation by the community advisory board serving the Mayo Clinic biobank. No education or ancillary information regarding this opt-out opportunity was provided in the context of biobank enrollment (i.e., in the consent form or in the informational brochure provided in the mailed enrollment opportunity). A small subset of biobank enrollees (n = 1314, 2% at the time of the study) selected the option to restrict posthumous availability of their biospecimen to their legal next-of-kin. After screening this group to verify vital status, study eligibility, and mailing address, we identified a subset of 840 biobank donors whom we defined as “T1 restrictors.” In addition to these individuals, 840 biobank enrollees who selected the option to permit posthumous availability of their sample by legal next-of-kin (“T1 permitters”) were matched on age and sex to those from the biobank population who restricted posthumous biospecimen availability.

Survey

We designed a 66-item questionnaire containing both investigator-developed items and items from previously validated psychosocial instruments. At the beginning of the survey, we included a question which asked participants to indicate their current preference regarding the posthumous availability of their biospecimen to their next-of-kin. Since this preference was initially solicited from participants in the biobank consent form, we included the explanatory text from the consent form and reminded participants that they had previously indicated their preference when they enrolled in the biobank. No educational information was provided regarding this preference (i.e., nothing beyond information provided in Fig. 1), and care was taken to present the preference in the same manner as it was presented during biobank enrollment. The question was cast as a hypothetical choice (i.e., “If you were presented this option today...”) so as not to indicate to participants that they were effectively modifying their biobank registration. To avoid influencing their current response, we did not remind participants of the specific preference they had provided previously. The survey then asked respondents to rate the strength of their current preference immediately after indicating whether they would choose to restrict or permit posthumous availability of their sample to their next-of-kin. Participants rated the strength of their current preference on a 3 point scale ("very strongly, somewhat strongly, not at all strongly").
Additional study-specific items included a list of nine statements addressing decision-making factors (e.g., “I believe my family might worry about genetic results they could learn if they had access to my sample”), followed by an “agree–unsure–disagree” response set. Participants were asked to indicate the level of importance (i.e., “not at all important, somewhat important, very important”) of each of these factors and finally to identify one factor as a prevailing decision-making priority. A write-in option was provided to enable participants to record factors that were absent from our list but that influenced their decision to restrict or permit family access. Not all survey data are presented in this paper.

Surveys included the Self Concealment Scale (SCS) [11] and three subscales from the Family Environment Scale (FES) [12]. The SCS measures an individual’s tendency to hide information from others. From the FES, we included three subscales—cohesion, expressiveness, and conflict—to examine relationships between these aspects of family functioning and preferences for posthumous sample availability. We hypothesized that an individual’s tendency toward self-concealment (SCS), or family environments low on cohesion and expressiveness and high on conflict (FES), would be associated with a tendency to restrict posthumous availability of their sample to family members.

Data collection

The study was deemed exempt by the Mayo Clinic Institutional Review Board (#15-000752). Biobank participants were mailed a copy of the survey along with an explanatory cover letter and a postage-paid return envelope, with one repeat mailing to nonresponders. Returned surveys were processed by research support staff who followed established procedures and methods to enhance data quality, including response tracking and double data entry.

Data analysis

Participant responses to the survey question about posthumous availability of their biospecimen were compared with their response to the same question elicited at the time of their initial enrollment in the biobank. This exercise identified four subgroups for analysis: (A) participants who permitted availability both at biobank enrollment (T1) and on the survey (T2), (B) participants who restricted availability at both T1 and T2, (C) participants who permitted availability at T1, but at T2 changed their preference to restrict availability, and (D) participants who restricted sample availability at T1, but at T2 changed their preference to permit availability. Groups A and B were considered “consistent” in their preference (i.e., “consistent permitters” and “consistent restrictors”), while groups C and D were considered “inconsistent” in their preference (i.e., “inconsistent permitters” and “inconsistent restrictors” with respect to their initial preference indicated at biobank consent). Figure 2 illustrates this fourfold division of participants based on participants’ preferences elicited at T1 and T2.

Descriptive statistics were calculated for demographic variables, for factors influencing participants’ preference for biospecimen availability, for the SCS and FES scales, and for the access preference variable. Chi-square and t tests were run to compare the distribution of responses across key demographic variables for participants with static and fluid preferences and by access preference. Statistical software packages SAS 9.4 (SAS institute Inc. Cary NC) and R 3.1 (R Foundation for Statistical Computing, Vienna, Austria) were used for data analysis.

Results

A total of 1207 individuals returned a survey for a response rate of 71.9%. Forty-three of these responses were refusals to participate, resulting in 1164 records for analysis (69.3% of the original sample). Responses received were evenly distributed between participants who restricted posthumous availability of their sample at the time of biobank consent (T1) (n = 584, 50.2%) and those who permitted availability at T1 (n = 580, 49.8%).

Table 1 compares demographic variables of all participants in the Mayo Clinic Biobank who permitted availability of their biobank sample at T1 (N = 49,388) with those who restricted availability of their biobank sample at T1 (N = 1314). All differences reported are statistically significant. More permitters than restrictors were married, and fewer permitters were single or
biobank sample at T1 irrespective of their T2 preference. Respondents who permitted posthumous availability of their sample of individuals restricting access at time of consent. Those who permitted availability of their sample at T1 differed from those who restricted availability at T1 and from consistent restrictors in that more respondents who permitted access at T1 were members of the biobank for >1 year. In addition, more respondents who permitted access at T1 had never been invited to research requiring reconsent ($p < 0.0001$ for all comparisons). More consistent restrictors were single and separated/divorced/widowed than those who permitted sample availability at T1 ($p = 0.003$). Fewer consistent restrictors (56.8%) were survived by siblings than those who permitted sample availability at T1 (88.5%, $p = 0.04$). Fewer restrictors at T1 and consistent restrictors (77.5% and 56.8%, respectively) were survived by children than participants who permitted availability at T1 (88.5%, $p < 0.0001$ for both).

Figure 3 describes the stability of participants’ preferences for posthumous sample availability as reported at the time of consent (T1) and time of the survey (T2). Participants whose preference at the time of the survey agreed with their preference at time of consent are compared with participants whose preference changed between time points. Importantly, over 40% of the entire sample had inconsistent preferences between T1 and T2. Further, 94% of those with inconsistent preferences shifted from a T1 preference to restrict posthumous availability of their sample to a T2 preference to make the sample available to their legal next-of-kin. 76.7% of those who restricted availability at T1 chose to permit availability at T2, leaving only 136 (23.3%) “consistent restrictors” who indicated a restrictive preference at both T1 and T2. Since those who restricted availability at T1 already represented a small subset of the entire biobank (~2%), the residual percentage of “consistent restrictors” in the entire biobank is remarkably small.

Consistent permitters indicated a “very strongly” held preference more frequently (68.9%) than consistent restrictors (47.4%, $p < 0.0001$). Participants with inconsistent preferences indicated a “very strongly” held preference more frequently than consistent restrictors, but less frequently than consistent permitters. Over 70% of T1 restrictors who were members of the biobank for less than 1 year at the time of the survey indicated a preference change at T2.

Table 3 examines the preference stability of the groups shown in Fig. 3 across demographic variables. Inconsistent permitters who chose to restrict access at T2 were older (mean = 71.5 years, SD = 12.4) than consistent permitters (mean = 66.1 years, SD = 13.1, $p = 0.0343$). One hundred percent of inconsistent restrictors who permitted access at T2 were survived by at least one blood

Table 1 Comparison of demographic characteristics of all biobank participants\(^a\) by choice, at time of consent, to restrict or permit posthumous availability of biospecimens.

| Characteristic\(^b\) | Permitters\(^d\) | Restrictors\(^c\) | $p$ |
|----------------------|-----------------|----------------|-----|
| Age                  |                 |                |     |
| Mean (SD)            | 62.4 (15.6)     | 66.3 (14.3)    | <0.0001 |
| Median, range        | 64.4, 18.2-103.5| 67.8, 19.8-98.3|     |
| Time since biobank   |                 |                | <0.0001 |
| enrollment           |                 |                |     |
| ≤1 year              | 9402 (19.0%)    | 313 (23.8%)    |     |
| >1 year              | 39,986 (81.0%)  | 1001 (76.2%)   |     |
| Last invited to      |                 |                | 0.0176 |
| participate in       |                 |                |     |
| research             |                 |                |     |
| Never invited        | 39935 (80.9%)   | 1078 (82.0%)   |     |
| ≤1 year              | 2173 (4.4%)     | 74 (5.6%)      |     |
| 1–3 years            | 3037 (6.1%)     | 63 (4.8%)      |     |
| >3 years             | 4243 (8.6%)     | 99 (7.5%)      |     |
| Gender               |                 |                | <0.0001 |
| Male                 | 20276 (41.1%)   | 422 (32.1%)    |     |
| Female               | 29112 (58.9%)   | 892 (67.9%)    |     |
| Race                 |                 |                | 0.0220 |
| White                | 44900 (92.4%)   | 1178 (90.7%)   |     |
| Non-White            | 3695 (7.6%)     | 121 (9.3%)     |     |
| Education            |                 |                | <0.0001 |
| Less than high       | 829 (1.7%)      | 29 (2.3%)      |     |
| school diploma       |                 |                |     |
| High school          | 6963 (14.6%)    | 258 (20.4%)    |     |
| diploma or GED       |                 |                |     |
| Some college         | 15454 (32.3%)   | 446 (35.2%)    |     |
| College graduate     | 12281 (25.7%)   | 272 (21.5%)    |     |
| Graduate education   | 12295 (25.7%)   | 262 (20.7%)    |     |
| Marital status at    |                 |                | <0.0001 |
| time of consent      |                 |                |     |
| Single               | 3448 (7.3%)     | 131 (10.3%)    |     |
| Married              | 37848 (79.8%)   | 904 (71.3%)    |     |
| Separate/divorced/   | 6161 (13.0%)    | 232 (18.3%)    |     |
| widowed              |                 |                |     |

\(<p\)All participants at the time the survey was fielded (July, 23, 2015).  
\(^{b}\)Unless otherwise noted, the format for all values is $N$ (%).  
\(^{c}\)This represents the study sample frame from which we derived our sample of individuals restricting access at time of consent.  
\(^{d}\)This represents the study sample frame from which we derived our matched controls.  

separated/divorced/widowed ($p < 0.0001$). More women than men restricted access, and permitters were slightly more educated ($p < 0.0001$ for both).

Table 2 compares demographic characteristics of survey respondents who permitted posthumous availability of their biobank sample at T1 irrespective of their T2 preference
relative, compared with 97.1% of consistent restrictors ($p = 0.0028$). 83.7% of inconsistent restrictors who permitted access at T2 compared with just 56.8% of consistent restrictors were survived by at least one child ($p < 0.0001$). These demographic differences may highlight the role that family composition plays in decisions about posthumous sample availability.

### Discussion

Results from our study suggest that biobank participants’ preferences regarding sample access may change over time, providing some initial empirical support for the claim that biobank participants may have reason to utilize a dynamic consent mechanism to manage their participation. Kaye
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biospecimen to be available to blood relatives. While it is impossible from our data to ascertain the motivations behind these preference changes, these, and other explanations seem plausible.

Our data also suggest that preferences collected during the initial consent process do not dependably predict long-term opinions of biobank participants. Studies have found that a high percentage of those approached about biobank membership have never heard of a biobank [31, 32]. This suggests that many individuals who enroll in biobanks may be expressing preferences at the same moment in time in which they are learning what a biobank is and what their participation entails. Soliciting broad consent in this context presumes that donors are capable of quickly integrating information they receive at the time of consent into their own personalized risk-benefit calculus and making an informed decision that will be consistent with their preferences over time. Whether or not this is an appropriate presumption, there is reason to believe that preference adjustments made in the months or years after enrollment

| Characteristic | Consistent permiters | Inconsistent permiters | Consistent restrictors | Inconsistent restrictors |
|---------------|----------------------|-----------------------|------------------------|-------------------------|
| Permit→Permit | (N = 553)            | (N = 27)              | Restrict→Restrict      | (N = 136)              |
| Age           | 0.0343               | 0.1241                | 0.4665                 | 0.1022                  |
| Mean (SD)     | 66.1 (13.1)          | 71.5 (12.4)           | 64.9 (15.2)            | 67.0 (12.9)             |
| Median, range | 67.8 (20–97)         | 73.8 (38–95)          | 66.4 (23–95)           | 68.3 (20–97)            |
| Time since biobank enrollment |                  |                       |                        |                        |
| ≤1 year       | 149 (26.9)           | 9 (33.3)              | 61 (44.9)              | 166 (37.1)             |
| >1 year       | 404 (73.1)           | 18 (66.7)             | 75 (55.1)              | 282 (62.9)             |
| Last invited to a research study |                |                       |                        |                        |
| Never invited | 524 (94.8)           | 26 (96.3)             | 113 (83.1)             | 379 (84.6)             |
| ≤1 year       | 1 (0.2)              | 1 (3.7)               | 17 (12.5)              | 37 (8.3)               |
| 1–3 years     | 11 (2.0)             | 0 (0)                 | 1 (0.7)                | 11 (2.5)               |
| >3 years      | 17 (3.1)             | 0 (0)                 | 5 (3.7)                | 21 (4.7)               |
| Gender        |                      |                       |                        |                        |
| Male          | 172 (31.1)           | 10 (37.0)             | 46 (33.8)              | 150 (33.5)             |
| Female        | 381 (68.9)           | 17 (63.0)             | 90 (66.2)              | 298 (66.5)             |
| Race          |                      |                       |                        |                        |
| White         | 510 (92.6)           | 24 (88.9)             | 123 (90.4)             | 412 (92.2)             |
| Non-White     | 41 (7.4)             | 3 (11.1)              | 13 (9.6)               | 35 (7.8)               |
| Education     |                      |                       |                        |                        |
| Less than high school diploma |             |                       |                        |                        |
| High school diploma or GED | 88 (16.1) | 3 (11.1) | 29 (21.3) | 84 (19.4) |
| Some college  | 174 (31.9)           | 10 (37.0)             | 43 (31.6)              | 145 (33.4)             |
| College graduate | 126 (23.1) | 3 (11.1) | 29 (21.3) | 97 (22.4) |
| Graduate education | 151 (27.7) | 10 (37.0) | 30 (22.1) | 104 (24.0) |
| Marital status at time of consent |                  |                       |                        |                        |
| Married       | 440 (80.1)           | 17 (65.4)             | 91 (67.4)              | 339 (76.7)             |
| Single        | 79 (14.4)            | 7 (26.9)              | 17 (12.6)              | 72 (16.3)              |
| Separate/divorced/widowed | 79 (14.4) | 2 (7.7) | 27 (20.0) | 31 (7.0) |
| Survived by   |                      |                       |                        |                        |
| Anyone        | 551 (99.6)           | 22 (81.5)             | <0.0001                | 132 (97.1)             |
| Grandparents  | 25 (4.6)             | 0 (0.0)               | 0.6161                 | 10 (7.6)               |
| Parents       | 185 (33.8)           | 4 (18.2)              | 0.1668                 | 46 (34.8)              |
| Siblings      | 486 (88.2)           | 21 (95.5)             | 0.4964                 | 108 (81.8)             |
| Children      | 490 (88.9)           | 19 (86.4)             | 0.7264                 | 75 (56.8)              |

*Unless otherwise noted, the format for all values is N (%).
are either the product of greater reflection on the implications of permitting sample availability or are a response to changing life circumstances.

The practice of not regularly revisiting and collecting the current preferences of biobank donors may result in missed opportunities for responsible sample stewardship. Biobank donors are part of complex social and familial networks. Changes in donor preferences regarding sample uses may reflect changes in life circumstances, changes in familial relationships, or changes resulting from significant life experiences such as illness or the death of a family member. Failing to acknowledge and seek to accommodate these changing life experiences and their impact on personal preferences might be seen as a type of disrespectful treatment. In addition, failing to revisit donor preferences over time may be a missed opportunity to strengthen the trust of biobank donors by acknowledging their gift and reaffirming a commitment to using it in a manner that is consistent with their preferences. Donors need not express a preference change in order to appreciate good-faith efforts to accommodate evolving donor preferences.

The consent form used in the biobank we examined provided a single option regarding posthumous availability of donated biospecimens and did not solicit other specific preferences from sample donors. Other potentially fluid preferences might include preferences regarding the reporting of individual research results, the communication of aggregated study findings, or the notification of sample sharing with specific researchers. Future research could seek to clarify whether these and other specific preferences are more or less fluid as a result of changing family structures or evolving life circumstances. The specific preference we examined in this survey study is highly unique in that it requires individuals to reflect on whether the availability of a donated biospecimen would have potential benefits for family members or pose risks to one’s family or one’s personal reputation after death. Donors must weigh these abstract risks and benefits and choose which option they prefer. This decision may be cognitively burdensome because it requires donors to conceptualize the scope of their sharing and the potential implications of posthumous specimen availability. Other preferences, such as return-of-results preferences, may not be as burdensome to evaluate or have as complex implications for others, and thus may not be as likely to change over time. It is unclear which donor preferences regarding sample use are most likely to change over time.

The greatest challenge against implementing preference-sensitive mechanisms like dynamic consent for ongoing biospecimen management is the cost of implementation and maintenance. Biobanks containing thousands or tens of thousands of samples might struggle to transition from their current sample management procedures to some sort of dynamic consent approach. In some cases, additional IRB requirements may apply, including expectations that patients be recontacted and informed about these changes. While difficult to quantify, the level of trust instilled by such a system—both among those who modify their preferences and among those who are simply grateful that such an option exists—is a strong argument for considering the adoption of a dynamic consent model.

As one of the first studies of the stability of biobank donor preferences over time, our study has multiple limitations. First, participants in the biobank we examined were predominantly white, over 50 years of age, and well educated, as illustrated by demographic data in Table 2. As a result, it would be inappropriate to generalize our findings (e.g., the frequency of preference change) to more diverse populations or other research settings.

Second, as noted above, the question about posthumous sample availability is unusual, and it is possible that those who restricted access at T1 may have misunderstood the question when initially asked. This particular preference was the only preference solicited during the biobank enrollment process (see Fig. 1), and preferences around other, less abstract options may have been more or less stable between time points. In scenarios like this, where the approach to ascertaining a specific preference may have been deficient for some participants, dynamic consent could provide opportunity for corrections. The consent form provided no explanation of the potential value of restricting or permitting access to next-of-kin, and some individuals may have defaulted to a preference of greater control simply because they were not aware of any reason to do otherwise.

Third, our study did not approximate a simulation of a dynamic consent mechanism, which would facilitate preference modification but would not actively prompt participants to reevaluate their preferences as we did in our survey study. Further, had we reminded participants of their previous preference (as would be the case in a dynamic consent model), we might not have seen as much preference change as we observed in our study because some participants may have deferred to their previously expressed preference. Therefore, while our data suggest that biobank donor preferences may be fluid when elicited at two time points, they do not suggest whether preference modification mechanisms would be utilized by participants. Our data also do not speak to the comparative impact on preference stability of “opt-in” preference elicitation compared to “opt-out” preference elicitation.

Our study was also limited by a lack of a several important repeated measures that might clarify contributors to preference instability. Specifically, we lacked data at T1 (biobank enrollment) regarding the “survived-by” status of biobank participants. We collected this data at T2 (survey) but could not examine changes in family survivorship...
dynamics between time points. Similarly, we collected marital status at T1, but did not collect marital status at T2. This represents a missed opportunity to examine the impact of changes in family structure on biobank participant preferences. Our dataset also lacked information on changing health status between T1 and T2, as well as information on self-reported positive and negative research experiences. We did not anticipate the potential value of these measures during survey development because they were either (1) not feasible to collect, or (2) attained meaning only after we observed considerable instability of donor preferences in our sample.

Despite these limitations, it is clear that our data challenge assumptions about the stability of biobank donor preferences over time. Future research should examine potential explanations of this instability in more diverse biobank populations and with respect to a broader array of preferences regarding sample use and distribution. Future research should also examine more robustly whether or not modern family dynamics lie behind much of the sample use concerns and preferences of prospective and current biobank donors. Such findings would greatly enhance not only the debate about the merits of dynamic consent but also more high level considerations in biobank stewardship.

Conclusion

Is dynamic consent a solution to the potential shortcomings of traditional, broad consent for biobank research? While that is still a normative question, the answer must not neglect empirical realities, such as the extent to which the initial preferences indicated by sample donors actually change in substantive ways over time. More fully characterizing the stability of biobank donor preferences is a necessary first step in making an empirical case for the utility of dynamic consent for honoring participants’ current sample use preferences. To the extent that biobanks curate not only biospecimens and health histories, but also public trust, sensitivity to evolving donor preferences is essential to the long-term success of these critical research resources.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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