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ORIGINAL ARTICLE

‘Cool! and creepy’: engaging with college student stakeholders in Michigan’s biobank

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Abstract Large population biobanks, important resources for genomic research, also present ethical challenges. The Michigan BioTrust for Health makes dried bloodspots (DBS) leftover from newborn screening, including ~4.5 million collected before 2010 without written consent, available for health research. Absent prospectively gathered consent and/or current engagement with 18- to 29-year olds, little is known about opinions and beliefs from this age group about use of the bloodspots for research. We engaged 2,101 students—BioTrust participants and their peers—at information booths at 20 college campuses across the state to educate youth about the BioTrust and gather information about consent preferences and about hopes and concerns about this public health program. We surveyed student stakeholder DBS research consent preferences and fielded a “postengagement” survey to gauge the attitudes of participants and to evaluate the campus engagement. The most prevalent themes in open-ended comments were support for biobank research and concern that Michiganders are not aware of their participation. While 78 % of students said they would, if asked, opt in to the BioTrust, half of these preferred to be contacted *each time* a researcher sought to use their DBS. Students reported great interest in the topic and strong likelihood to share what they had learned. BioTrust participants are interested in learning about their role in an initiative whose goals they widely support. Public engagement is particularly important to biobank participants who, absent traditional consent practices, are unaware of their participation. Health-fair style engagements were effective for targeting college-aged stakeholders, communicating complex messages, and likely increasing knowledge. Retrospective biobanks and biobanks that collect proxy consent need policies to respect those who would opt out and will need resources to educate participants and conduct community outreach that is a safeguard to public trust.

Keywords Biobank · Public health · Informed consent · Newborn screening · Public attitudes · Community engagement · Public health education

Background

A generation of Michiganders (virtually everyone born in the state between July 1984 and April 2010) has residual newborn screening dried bloodspots (DBS) stored in a biobank in Detroit. Formally marketing these DBS for health research, the Michigan Department of Community Health (MDCH) manages one of the largest biobanking initiatives in the USA: The Michigan BioTrust for Health. This and other large population biobanks are valuable resources whose size, unbiased sampling, and linkability to public health data make them extremely valuable for public health assessment and for genomic and genetic research that require large sample sizes to achieve sufficient power (Couzin-Frankel 2009; McGuire and Beskow 2010). However, biobanks like these have also raised important ethical questions around consent, public awareness, and privacy (Botkin et al. 2013; Clayton 2005; McGuire and

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Beskow 2010; Rothstein 2010; Rothwell et al. 2010, 2011; Shickle 2006; Solbakk et al. 2009).

While informed consent is an ethical cornerstone of human subjects research, many biobanks, and especially those that comprise retrospective or secondary-use specimens, fall short of ensuring that subjects are aware of their participation, have weighed the related risks and benefits, and have made a voluntary decision to participate (Solbakk et al. 2009). Informed consent is failing to adapt to the current research environment in which being informed about one's participation in research is at once exigent and absent. Partnership models between researcher and researched are frequently advocated to counterbalance the ethical dilemmas raised by the open-ended and uncertain nature of future research studies using information in a biobank (Fullerton et al. 2010; Kaye et al. 2012). However, alternative governance structures that address the novel ethical landscape of biobanks have yet to shift the current paradigms that are either dominated by paternalism as they are in public health or by autonomy as they are in medical ethics (Kon 2010).

Recent technology has made residual DBS both more valuable *and* more identifiable, and public opinion surveys have demonstrated that most people prefer to give consent to participate in research using de-identified biospecimens (Botkin et al. 2012; Tarini et al. 2009). Opt-out consent models can only be meaningful for individuals who are informed of their participation (Petrini 2010). Without public awareness, population biobanks struggle to achieve accountability and partnership with participants that are necessary safeguards of trust (Campbell 2007; Meslin 2010). Lawsuits in Texas and Minnesota that led to the destruction of DBS stored in public health biobanks in those states underscore the need for awareness and buy-in among parents and participants (Carmichael 2011).

About a third of US states retain DBS leftover from newborn screening programs for long-term storage and potential secondary research, and policies governing the collection and storage of biospecimens for large population biobanks vary widely (Lewis et al. 2011; Therrell et al. 2011). Michigan is unique in that its BioTrust actively markets double de-identified DBS and related data to health researchers. The DBS in the BioTrust fall into two categories: Its "retrospective" collection includes about 4.5 million Guthrie cards stored from virtually all babies born in Michigan between July 1984 and April 2010—before consent mechanisms were put in place—while "prospective" DBS have only been added to the research pool with signed, blanket, parental consent since fall 2010. Under the BioTrust's current consent model, parents and adult research subjects can contact MDCH to request the destruction of DBS or their removal from the research pool.

In Michigan, low public awareness of the BioTrust is a lingering issue. In granting the waiver of consent that allows the BioTrust's retrospective collection of DBS to be used for research, the IRB included a provision that the BioTrust be widely publicized (Langbo et al. 2013; Mongoven and McGee 2012). Engagement on the BioTrust's retrospective collection is especially important because it provides an opportunity to educate and survey biobank participants and parents who were never educated about storage and research participation at the time of DBS collection. MDCH executed an awareness campaign that, by the end of 2011, reached 3,500 individuals (Langbo et al. 2013). Surveys of Michigan adults conducted through MSU's Institute for Public Policy and Social Research (IPPSR) in 2011, 2012, and 2013 indicate low public awareness statewide (Institute for Public Policy and Social Research). Community engagement by MDCH has been largely focused on educating parents in the neonatal setting.

Traditional methods of public health education such as health fairs, mass media campaigns, or information distributed in clinical settings can be used to raise awareness of biobanking among broad populations or the public at large. While recontacting millions of individuals is a practical challenge, outreach can strategically target adults who are likely biobank participants, or, where applicable, the parents of child participants (Platt et al. 2013). In this study, we used traditional components of health fair outreach (Dillon and Sternas 1997) to communicate a public health message. A point of distinction is that health fair outreach traditionally focuses either on screening or on health promotion (e.g., nutrition, substance abuse, and oral health), whereas we were raising awareness about a public health initiative. The goal of our engagements was not to build public trust, per se, but to reveal to biobank participants and their peers their sustained connection to the public health system, providing an "access point" that could be a foundation for establishing an active trust relationship and personal decision making about biobank participation (Giddens 1990; Platt et al. 2013).

An ongoing challenge for public engagement of retrospective biobank participants has been scaling up engagement efforts to reach large numbers without sacrificing meaningful, two-way communication about a complex and controversial topic (Platt et al. 2013). On a modest scale, in-person engagements on the BioTrust have included focus groups and presentations by the Michigan Department of Community Health, deliberative juries conducted by Michigan State University and statewide community meetings led by the University of Michigan (Fleck et al. 2008; Langbo et al. 2013; Thiel et al. 2013) The campus tour in the spring and fall of 2012 (N=2,101) that is discussed in this study represented an arm of outreach by the University of Michigan's Life Sciences and Society Program intended to scale up in-person community engagement and to target Michiganders aged 18 to 28, including biobank participants and their peers. The campus events ran in conjunction with a Facebook advertising campaign (Platt et al. 2013) and built on pilot engagements held at the University of Michigan (Thiel et al. 2013).

These campus engagements represented one of the first efforts in Michigan to raise awareness and survey opinion among the state's college-aged population of actual BioTrust participants. As participants, peers, and future or present parents of Michigan's next generation of BioTrust participants, engagees were biobank "stakeholders" with a special interest in the BioTrust initiative. Given the absence of prospectively gathered consent and/or targeted current engagement with 18- to 29-year olds, our goal was to educate college-aged stakeholders about the BioTrust and gather information about consent preferences and about hopes and concerns about this public health program. In this paper, we describe and evaluate our engagement and present our findings regarding students' attitudes about biobanking.

Methods

In the spring and fall of 2012, the Life Sciences and Society (LSS) program undertook a tour of 20 campuses throughout the state of Michigan to inform and engage retrospective participants in Michigan's biobank and their peers about the Michigan BioTrust for Health. Three to four staff members with expertise in the subject matter (including the first four authors) attended and ran each event.

Preparation for events included scheduling the campus visits with the colleges. Subject to availability, we selected sites at colleges and community colleges throughout the state to achieve broad demographic diversity and geographic coverage across the state. As shown in Fig. 1, campuses, including seven community colleges, were located in southeast Michigan (8), central Michigan (6), western Michigan (2), northern Michigan (1), and the Upper Peninsula (3). Several campus visits were slotted into campus events such as school orientations or health fairs. We sought to stage events in heavily trafficked areas on campus.

By convening at college campuses, we were able to speak directly with individuals in this target group: i.e., Michigan natives between the ages of 18 and 29. To calculate the percentage of Michigan students who were born in Michigan, we extracted a 1 % sample from the 2010 Census (Ruggles et al. 2010) and tabulated the population-weighted fraction of native Michiganders who were attending college in Michigan in 2010. This exercise showed that 76.8 % of Michigan students were born in Michigan. The enrollments of colleges we attended ranged from 1,621 to 20,880 and averaged 8,836 (IPEDS Data Center).

Campus engagements included traditional health fair components, including information presented in printed materials, interactive computer displays and surveys, expert presenters, giveaway incentives, and pamphlets (Dillon and Sternas 1997). To attract participants to our information booths, we created banners, backdrops, and podiums for tablet computers allowing visitors to interact with our website (mybloodspot.org). We used hotspots at events to ensure consistent web access. Promotional and informational materials for the events included T-shirts, chocolates, coasters, 1 Gb USB keys, trifold, and, in the fall, postcards promoting our survey. Our materials "branded" our work under the title "mybloodspot.org" to leave participants with a memorable URL for access to relevant information.

Campus visits ran for 3 to 5 h and discussions with participants typically lasted between 3 and 7 min. Most participants were engaged individually (one-on-one), but in some cases LSS staff presented material to assembled groups. We tallied the number of participants engaged by counting our T-shirt giveaways.

At each event, we stationed banners around information tables to draw attention to our presentation and to communicate the message that many Michigan natives have bloodspots stored for health research.

The script of our interactions varied, but a *typical* interaction began as follows:

> Staffer: Were you born in Michigan?
> Visitor: Yes.
> Staffer: Are you under 28?
> Visitor: Yes.
> Staffer: Did you know that your blood samples were stored for health research? (or, Have you heard about Michigan's Biobank?)
> Visitor: No.

If participants were born outside of Michigan, we continued with the presentation but also used a tablet to look up the DBS retention and research use policies in the participant's native state, if possible, via the Website babysfirsttest.org, an educational resource on newborn screening.

The information delivered to participants aimed to *always* include the following four key topic areas: (1) newborn screening, (2) biobanking, DBS storage and research use, (3) de-identification and informed consent, and (4) consent options. Sample content that was consistently delivered around these key topic areas is included in Table 1.

The information provided *sometimes* included examples of diseases tested by newborn screening, examples of studies conducted using DBS in the BioTrust,

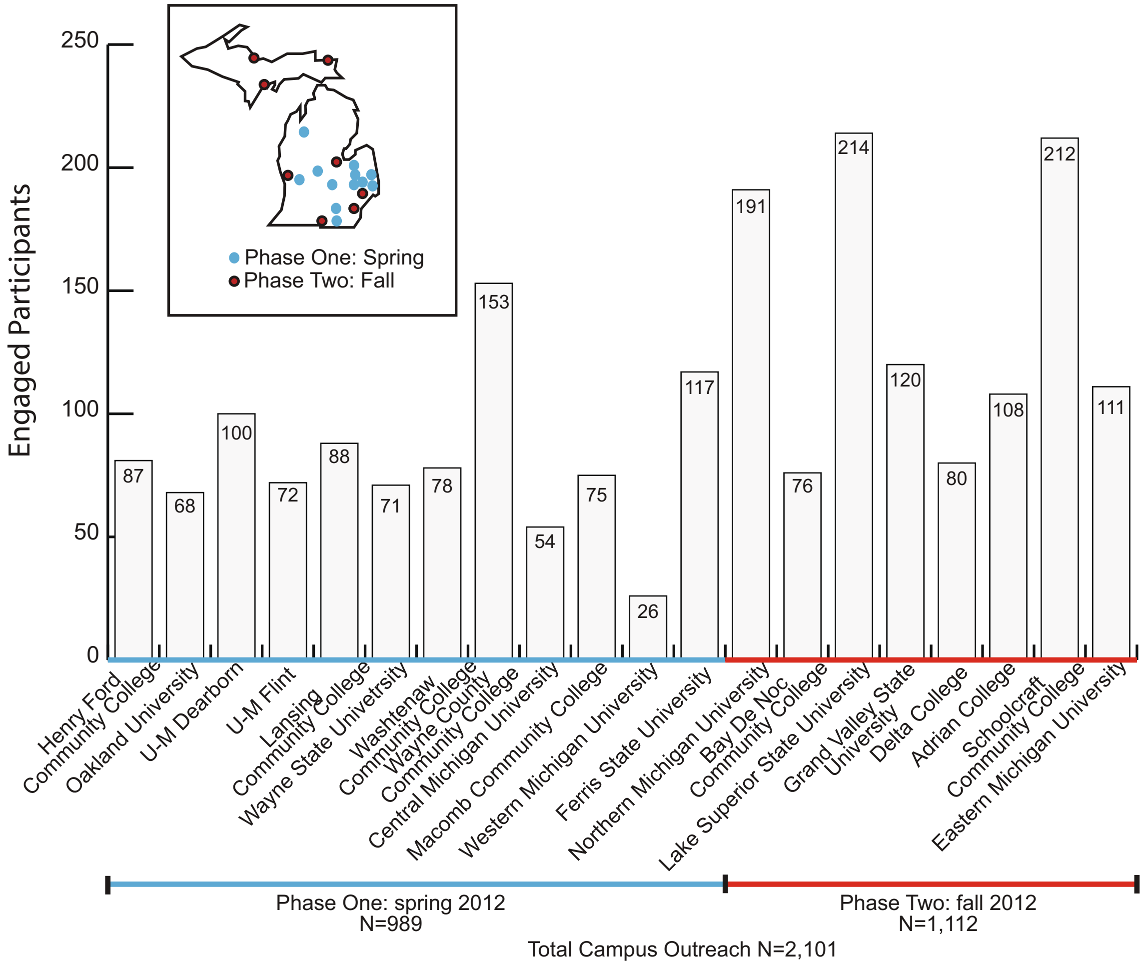

Fig. 1 Event locations and numbers engaged: Campus engagements raising awareness about Michigan's biobank among college-aged participants (listed chronologically) reached 2,101 students. Outreach was conducted in the spring and fall of 2012, and 20 colleges were selected to achieve broad geographic and demographic coverage of the state

examples of linkable health databases, and information about the risks and benefits of biobank participation. The variance in length and "depth" of these interactions was the result of our conversational approach; staff members took cues from visitors' apparent level of interest, the questions they asked, and their availability to discuss the subject.

Particular care was taken to distinguish between biobanking and newborn screening and to present information neutrally. Staffers were open to acknowledging and discussing ethical gray areas around biobanking but careful to present information even-handedly with the aim of querying participants' opinions.

Conversations between staffers and participants were the primary channel for our educational content, but participants also received trifold pamphlets that summarized key points (Supplementary Fig. 1). Participants were also encouraged to review online materials, including an FAQ and educational videos on our Website, mybloodspot.org, during or after our campus events.

At the end of each discussion, we distributed giveaways, including T-shirts promoting our Website and asked students to participate in one or more surveys.

Phase one

During the first (spring 2012) phase of our campus engagements, we spoke with 989 students at 12 campuses (see Fig. 1). Immediately following conversations held during these campus visits, we asked students to participate in our survey of consent preferences. This survey was hosted on our Website but conducted in person and on site using tablet computers. The survey question read: "Researchers looking for cures can use your bloodspots without asking for your permission. If you were asked, what would you say?" Respondents selected from four options:

- Opt in: "If I had a vote, I'd 'opt in' today to be a part of the BioTrust."

Table 1 Script for presentations by theme

Theme	Sample content
Newborn screening	*When you were a day or two old, a heel-prick test was done to check you for serious but treatable health conditions. This is a very successful public health program that saves babies lives and is conducted on every baby born in the United States. Five dime-sized splotches of blood that were taken from your heel were placed on an absorbent paper card. Typically, that is more blood than is needed for conducting newborn screening tests. The policies for storing the leftover bloodspots vary from state to state. In some states, bloodspots left over from newborn screening are thrown away. In Michigan, bloodspots from babies born as far back as 1984 were stored*
Biobanking, DBS storage, and research use	*We are here to educate people about a program called the Michigan BioTrust for Health. Your bloodspots are located at Wayne State University in Detroit, where they are part of a biobank of about 4.5 million bloodspots that have been collected from an entire generation of Michigan natives. They can be used by researchers to study important health questions*
De-identification and informed consent	*When your bloodspots were taken, there was no system in place to ask for your parents' permission. It was only a few years ago that Michigan's health department began to actively market its collection of bloodspots to health researchers. They realized that a collection of this size could be extremely valuable for health research. Because it would be very difficult to reach all 4.5 million individuals with bloodspots in the biobank, along with their parents, the BioTrust has a waiver that allows them to provide bloodspots to researchers, with names removed, without traditional, written informed consent. Even though names are removed, they aren't exactly anonymous. Researchers could ask to study bloodspots from a particular county or birth year or even a population like children with cancer. But a coding system would be used so that they wouldn't see your name*
Consent options	*You can opt out of the BioTrust by contacting MDCH, or you can remain in the BioTrust by default. Now (and since fall 2010) MDCH asks for parents' permission before adding new bloodspots to the biobank. We are researchers from the University of Michigan. We are not here to say whether or not you should be a part of Michigan's Biobank. We can talk to you about the risks and the benefits of participation and we would like to hear what you think. We do think that people in Michigan should know about this program. We have a grant to study effective ways of engaging the community on this issue*

- Opt out: "If I had a vote, I'd 'opt out' today from being a part of the BioTrust."
- Contact me: "If I had the option, I'd want to be contacted each time a health researcher asks to use my bloodspot."
- I don't care: "By selecting "I don't care," I am letting you know that this is not an issue for me."

Results were tallied and displayed graphically in real time at www.mybloodspot.org/voices.

Phase two

During the second (fall 2012) phase of the campus visits, we spoke with 1,112 students at eight campuses. We asked students to participate in the consent survey as described in "phase one" and also asked students to follow up by participating in an online, postengagement survey. The purpose of the postengagement survey was to evaluate our engagement, to gauge students' uptake of the complex information that we presented and to collect open-ended comments gathering a range of student perspectives, including hopes and concerns about the BioTrust that might underlay their consent preferences. A complete list of questions posed in the postengagement survey is included in Supplementary Table 1. Our goal was to collect 100 responses. We distributed postcards to promote the survey and offered participants entry into a raffle with three drawings for $100 gift cards as an incentive.

Data analysis

We present our data in two sections, focusing first on participants' attitudes about the BioTrust and second on the impact of our engagement.

Attitudes about the BioTrust

We describe the results of our consent preferences survey and compare them against the findings of both hypothetical surveys conducted among Michigan's general population and actual consent participation rates among recent parents who since 2010 have had the opportunity to give or withhold consent to have their children's DBS added to the BioTrust.

Content analysis (Green and Thorogood 2009; Kimber et al. 2013) was used to analyze qualitative responses from the postengagement survey. Responses were read several times, line-by-line, by the first author (TP), in order to identify, define, and refine thematic and discursive codes compiled in a codebook (Table 2). To confirm reliability, the second author (JP) independently coded 25 % of the data; disagreements were resolved by consensus. Codebook definitions were

Table 2 Code book for postengagement survey (qualitative responses)

Thematic codes	A	Awareness (frequency: 39)	Comment refers to personal, parental, or public awareness about the BioTrust. Include comments that are descriptive (e.g., people are not aware) or prescriptive (e.g., people should be informed)
	+	Support for Research ("Cool!") (Frequency: 29)	Commenter makes a positive comment regarding the health research value of the BioTrust
	U	Concern about Use of DBS (Frequency: 7)	Comment refers to concern that DBS could be misused
	Cd Cp	Consent (Frequency: 25)	Comment refers to personal, parental, or public granting of consent or permission to use DBS. *Comments on this theme are subcategorized as either descriptive or prescriptive*
	CR	"Creepy!" (Frequency: 14)	Comment expresses or connotes respondent's discomfort regarding Biobank participation or policies (past, present, or potential)
	S	Surprise (Frequency: 15)	Comment refers to or connotes a reaction of surprise upon learning of participation in the BioTrust (also tagged as A)
Discursive codes	1	First person	Comment refers to "my" or "our" DBS
	P	Parent	Commenter self-identifies as a parent of a child in the BioTrust
	?	Question	Comment poses a question
	–	Insufficient detail	Comment is not sufficiently detailed to address the question posed
	0	No hopes or concerns	Comment specifies that respondent has neither hopes nor concerns about the BioTrust to share when prompted
	Q	Quotation	Coder deems quotation noteworthy and/or representative of an identified trend
	M	Mistake	Coder notes the respondent may have had a misconception about the BioTrust

consulted and refined and all responses were re-evaluated according to the refined codes. The six codes applied to respondent comments were: awareness; support for research (in vivo code: "Cool!"); consent; concern about DBS uses; discomfort (in vivo code: "Creepy!"); and surprise.

Evaluation of Campus Engagements

We use quantitative data from the postengagement survey to assess the effectiveness of the campus events, reporting baseline awareness of the BioTrust; responses to four true/false knowledge questions about the information we presented, and responses to four assessment questions: "After meeting us on campus, how informed do you feel about Michigan's Biobank?" "Was the information presented at the mybloodspot.org campus event interesting to you?" "How likely are you to tell others about what you learned at the campus event?" and "Do you think our campus event was an effective way of informing people about Michigan's Biobank?"

We present qualitative responses to this survey, including suggestions to improve campus visits and answers to the prompt, "What key point/s did you take away from our campus visits?" to gauge respondents' uptake of the information presented.

Results

The number of participants engaged during the first phase (spring 2012) of our campus tours totaled 989; on average, we spoke with 82 participants at each event.

The number of participants engaged during the second phase (fall 2012) of our campus tours totaled 1,112; on average, we spoke with 139 individuals at each event.

Fielded through both phases of engagement, 856 participants completed our consent preference survey. In the fall, 94 participants completed our postengagement survey.

Attitudes about the BioTrust

Consent preferences

Among 856 respondents to our consent survey, 347 (41 %) said they would opt in if they were asked to participate in the BioTrust. Another 338 (39 %) said they would want to be asked each time a researcher sought to use their DBS. The number of students opting out was 101 (12 %), and 90 (11 %) said they did not care about the issue (Fig. 2).

"Cool! and Creepy"

In the postengagement survey (N=94), students responded to the open-ended questions, "What key point/s did you take

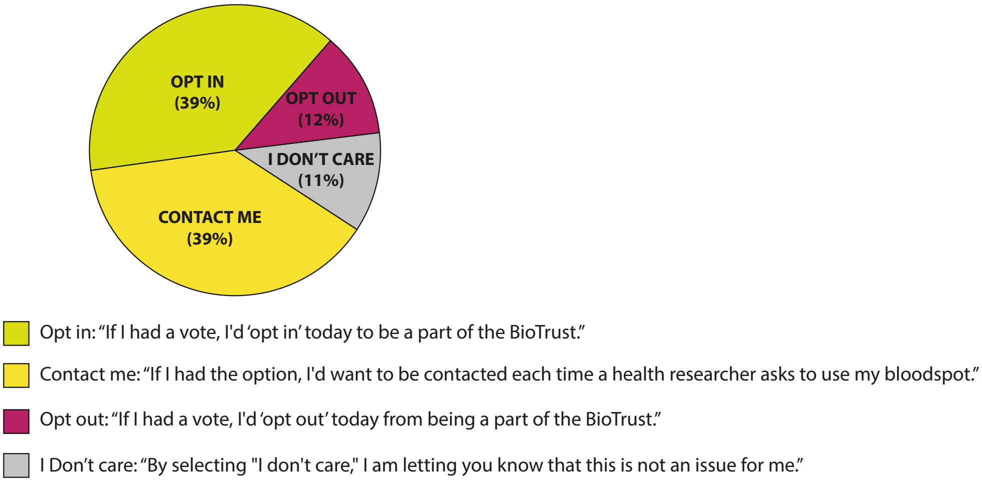

Fig. 2 Consent survey: College-aged, BioTrust stakeholders were asked whether, if asked, they would consent to participate in Michigan's biobank. Most (78 %) of the 856 college students responding said they would opt in, but half of these said they would want to be asked to grant permission each time a researcher sought to use their DBS. Twelve percent said they would opt out and 11 % said they did not care about this issue

away from our campus visit?" and "Please list any hopes and concerns that you may have about Michigan's Biobank." The six thematic codes applied to respondent comments were: Consent; awareness; support for research ("Cool!"); concern about DBS uses, discomfort ("Creepy!") and surprise.

A student responding to the question, "What key point/s did you take away from our campus visit?" wrote the comment quoted in the title of this paper: "My blood is in the Biobank. That is cool! And creepy at the same time!" The response represents the most salient themes we found in this analysis: *BioTrust participants were highly supportive of the program and its research goals but surprised and in many cases unsettled about their unknowing participation*.

Many students were hopeful that DBS research would answer important health questions and benefit future patients; students wrote, for example:

- "I hope they are able to use the blood to further research so that by the time I have kids we will have more ways to keep them safe and healthy."
- "I hope that my leftover bloodspot may be used in the future to help someone as a result of current research."
- "I hope they continue to grow a supply of blood spots for research, it is an amazing idea!"

At the same time, they were concerned about lacking personal, parental, and public awareness of the BioTrust. "I have concerns about the fact that they have all these bloodspots without the parents of the children, or the children themselves, knowing that they have them," wrote one student. Another wrote: "My blood can be sold without my consent, which is not all right!" In discussions with staff, some students reflecting on the ethics of permission and recognition referred to the Henrietta Lacks case. One student wrote in her survey comments: "I hope someday they can let people know what kind of tests their blood spots are being used for. Like, if someone's blood was used to find the cure for cancer or something. They should let the people whose blood it is know."

Students frequently conveyed surprise during campus engagements upon learning of their biobank participation, a theme that was also reflected in written comments. They wrote, for example:

- "I didn't know that we got our blood taken from us when we were born!"
- "Let me know before you take my blood!"
- "A small portion of my blood is out there and I wasn't even aware of it. I have the choice to keep it out there or have it destroyed."
- "They have bloodspots from so many different people without their knowledge. I know I was never informed about what happened with the heel-stick blood after they ran the test."
- "One of my first life experiences was having my heel pricked for blood, and this little part of me has been stored away for two decades. Totally trippy stuff."
- "Our blood could be being used in crazy studies right now and we didn't even know! I think that's cool."
- "I had no clue that they were allowed to take our blood and sell it at their will."

In discussions and written comments, students raised a range of concerns about Michigan's biobank, including assertions that DBS should only be used with permission from parents or participants, anxiety that DBS could be misused, and apprehensions about privacy. Individual respondents conveyed uncertainties about the transparency, morality and legality of the initiative.

Evaluation of campus engagements

Participation, completion rates, and targeting

During the campus engagements, we spoke with 2,101 students, 41 % of whom completed the consent survey fielded at the end of "Discussions." The postengagement survey had an 8 % completion rate among the 1,112 students engaged during the second phase of our outreach. We estimate from Census data that more than 75 % of students engaged were Michigan natives in our target age group, and about half of postsurvey respondents self-identified in their comments as a biobank participant (e.g., "I am part of a Biobank").

Student evaluations

According to survey respondents, the campus engagements were an effective way of communicating with students about the Michigan BioTrust. Survey responses showed that 94 % of students felt "somewhat" or "very" informed about Michigan's Biobank after meeting us on campus, and 98 % affirmed that the campus event was "an effective way of informing people" about the Biobank.

The vast majority of postengagement survey participants—91 %—said they were interested in the information presented at the campus events. Respondents also reported that they would likely tell others about what they learned at the campus event: 45 % were "somewhat" or "very" likely to share information and an additional 41 % responded: "I have already told others about what I learned" (Fig. 3).

Students were prompted to list suggestions about how we could improve campus visits, or other ways we could engage the state of Michigan on this issue. Most responses included either general (e.g., "This presentation was fantastic!") or specific positive feedback. In particular, students commended the "giant display," the use of tablets, the give-aways, and the centrality of event locations. The most common theme among the suggestions was to do more to promote awareness by advertising, going to high schools, sending campus-wide e-mails, and presenting more frequently. Other suggestions included using the T-shirts as an award for completing a tutorial; taking a stronger stance (as presenters) on biobanking ethics, and creating a video with subtitles.

Uptake of key points

The percentage of participants who indicated in our postcampus visit survey that they had heard of Michigan's Biobank or BioTrust prior to our campus events was 19 %. This finding, which was recorded to assess baseline awareness, is accorded special attention in the discussion because this figure was much higher than expected.

Responses to knowledge questions showed students had a fairly high comprehension level (77 to 94 %) of our key points (Fig. 4). The true/false prompt, "Adults with bloodspots in the Biobank can contact the health department to remove their spots," had the lowest percentage (77 %) of correct responses.

Among the 76 respondents who said in the postengagement survey that they had not heard of Michigan's biobank prior to our event, 62 (82 %) correctly identified as true the statement, "Michigan's Biobank is a collection of dried bloodspots that are left over from Newborn Screening."

In general, answers to open-ended survey questions were accurate reflections of the content that was communicated; specifically, 81 responses (87 %) to the postengagement survey question, "What key point/s did you take away from campus visits?" were sufficiently detailed and accurate to include information from one or more of the key topic areas covered by the engagement.

A small number of responses from each open-ended question on the postengagement survey were tagged for conveying a possible misunderstanding about information presented. These were typically minor errors (e.g., mistakes in terminology or precision of dates) but four demonstrated fundamental confusion about our message (e.g., "They asked us if we wanted to be put on the donors list").

Discussion

Consent preferences

The majority of students who responded to our consent survey said that, if they were asked, they would assent to have their DBS in the BioTrust's research pool. But nearly half of these stipulated that they would want to be asked for permission each time a researcher sought to use their DBS. Twelve percent of respondents said they would opt out of the BioTrust. These data suggest that many BioTrust participants may prefer a more active role in research participation than the biobank's current processes allow.

A number of state and national surveys of consent preferences for DBS biobanking have previously found that the public generally supports such initiatives but only if donors are first consented (Botkin et al. 2012; Tarini et al. 2009; Thiel et al. 2013). Tarini's 2009 study surveyed a nationally representative sample of adults (n=1,508) and found that 76.2 % of respondents supported secondary research uses of DBS, *when donors are first consented*, but a mere 28.2 % supported such research in the absence of consent. In recent state-wide surveys, 75 % of Michiganders have indicated support for secondary research uses of DBS with 74 % indicating a preference for parental permission (Institute for Public Policy and Social Research). In 2008–2009, MDCH conducted focus

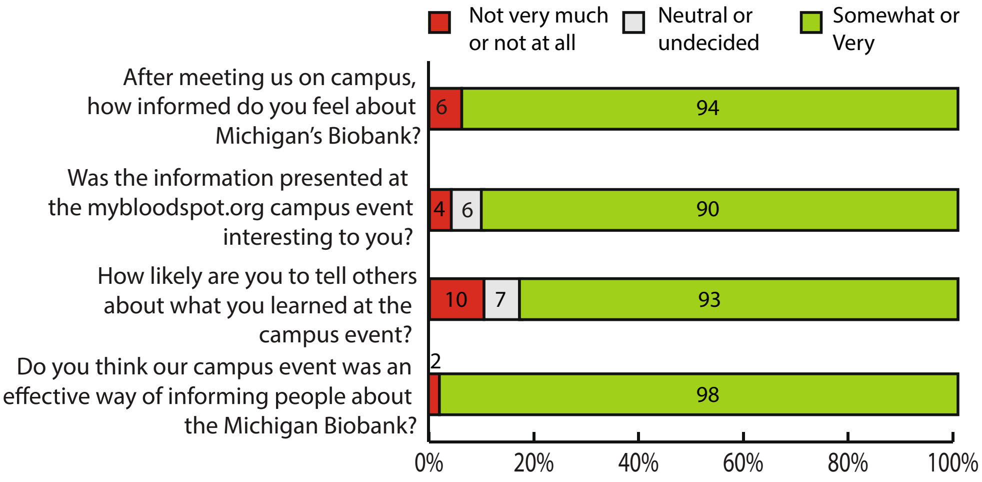

Fig. 3 Event assessment: among students responding to our postengagement survey ($N=94$), 90 to 98 % affirmed ("somewhat" or "very" much) that: they were interested in the information presented; they would likely share what they learned with others; they felt informed about Michigan's biobank after meeting us on campus, and they thought the campus events were an "effective way of informing people about the Michigan Biobank"

groups to solicit public input on the BioTrust ($n=87$). Overall, 78.6 % of respondents in the pre-survey and 88 % in the postsurvey said they would be willing to have their own DBS used for research (Duquette et al. 2012).

Little research thus far has focused on large numbers of actual biobank participants. Focus groups conducted by Duquette et al. included 36 individuals aged 18–39, but the report did not indicate how many, if any, in this age bracket were biobank participants, Michigan natives, or in the age range of biobank eligibility. Notably, willingness to have one's child or one's own personal DBS used for research increased overall among focus group participants between pre- and postsurveys (78.6 to 88 %), but actually went down among participants in the younger age group (86.1 to 83.3 %), with those "not willing" jumping from 2.8 to 8.3 % in that study. It is difficult to interpret that anomaly given the small sample size. The authors concluded that overall, "the demonstrated increase in level of support following provision of information and discussion among focus group members underscores the importance of community outreach and public education." This data and conclusion raise questions about what attitudes underlie consent preferences for biobank stakeholders (the 18 to 39 age group might include biobank participants and parents of participants), and about the need to inform and respect the attitudes of these participants—one might even argue, regardless of their willingness or the directionality of their changed willingness to opt in or out.

Thiel's study of attitudes fielded in community meetings throughout Michigan ($n=392$) included 91 individuals under age 25, 27 of whom were students at the University of Michigan in Ann Arbor. In this age bracket, 43 % affirmed that they would "give researchers permission to use their (or their child's) bloodspot," a figure comparable to the 41 % in our study who said they would opt in to the BioTrust. Notably, in this age group, 73 % of Thiel's respondents said they would prefer to be asked each time a researcher sought to use their DBS, significantly higher than the 39 % indicating an "ask each time" preference in this study. Thiel's analysis showed

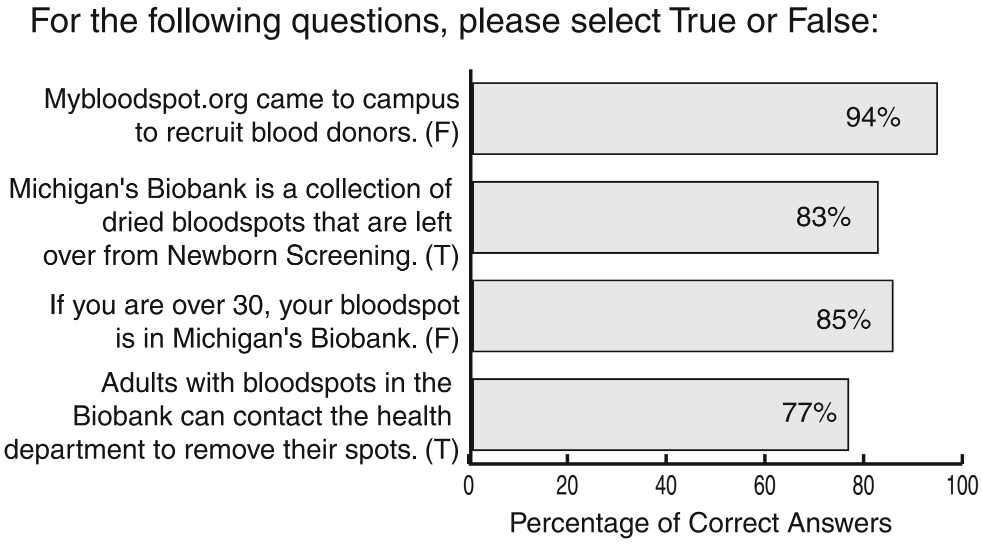

Fig. 4 Student uptake: Participants responding to our postengagement survey ($N=94$) generally answered knowledge questions about the information that we presented correctly (ranging from 77 to 94 % correct)

that age and education level were not statistically significant factors in survey responses, but suspicion was a theme that emerged among Ann Arbor discussion and workbook comments, including one that referred to the BioTrust as "1984–esque."

The student stakeholders we engaged were largely unknowing participants whose DBS had been stored and added to Michigan's biobank without written consent. Given the potential for a "surprise" effect to create alarm, one might have expected a stronger dissenting trend among this population. Students' appreciation for being actively informed about their participation may have countered this effect. Students said they appreciated the opportunity to learn about the biobank and their options.

Our survey was distinctive among the consent surveys that have been fielded in Michigan in two significant ways. First, we collected data on consent preferences from 856 young Michiganders, a much larger sample size than those from the studies cited. Second, the community engagement exercise associated with our data collection was conducted on a scale that would be practicable for reaching large numbers, in this case, 2,101. Town hall-style meetings and focus groups are methodologically useful for informing policy but not for educating large populations. The complex history and ethical terrain of Michigan's biobank make it a challenge to solicit opinions or even consent decisions from the public that are meaningfully informed.

In 2010, the BioTrust initiated a written consent process requiring parental consent for new DBS to be added to its research pool. Over an 18-month period from 2010 to 2012, 59 % of consent forms were signed (granting consent); 16 % were marked, "parent declined," (documenting dissent); 17 % were returned blank and 8 % were not returned (N=166,992). The number of requests for stored DBS to be destroyed or removed from the research pool totaled 71 in 2010 and 67 in 2011 (Langbo et al. 2013). A likely reason for the wide disparity between the percentage of opt-outs among the participants in the prospective vs. retrospective biobank collections is that the system in place is primarily focused on providing point-of-contact education and explicit consent collection from prospective participant parents, a group that is easier to reach than the 4.5 million participants in the retrospective collection. MDCH recently added information about its retrospective collection of DBS on a brochure provided to parents of newborns in Michigan about secondary DBS research use (Michigan Department of Community Health 2013). This information is also available on the MDCH Website. Disseminating this information more broadly remains a duty and a challenge for the state (Langbo et al. 2013; Mongoven and McGee 2012).

A problem in public health biobanking generally has been whether and how traditional informed consent practices designed to respect the autonomy of research subjects can or should apply (Gunderson 1990; Hofmann 2004). An ongoing question for the BioTrust will be that of respecting preferences of retrospective participants who would opt out of research participation, but only if they were aware of it. Michigan's biobank and others that use a broad consent form for unspecified research should look for ways to make prospective biobank participation more active, whether by providing multiple options on the consent form (e.g., research and contact preferences) or by maintaining communication with participants so that they remain informed about the meaning of their participation. Targeted, active communication with adults and parents of participants in the retrospective collection is valuable for informing the public about their consent options, as well as for maintaining trust. The vast majority of biobank participants want to be informed. We specifically gave students the option to select "I don't care" on our consent survey because grounds for paternalistic decision making may include presumed lack of public interest.

The history of public health biobanking has been determined in no small part by a paternalistic calculus weighing the collective benefits of biobank research against what are widely accepted to be minimal individual risks (Hofmann 2003, 2004, 2008). At the same time, when a public health screening program is given added purpose as a tool for health research, the significance of autonomy becomes critical as a foundational principle of informed consent. Moving toward shared decision-making models is gaining traction in the clinical world and could prove fruitful for researchers and participants in determining how decisions are made about the research uses of a participants' information. Effective shared decision-making balances rights and responsibilities as well as the strengths and shortcomings of both paternalism and autonomy. In order for a shared decision-making model to be successful, there needs to be effective communication and a trusting relationship (Kon 2010).

Attitudes about the BioTrust

The six most salient themes identified in students' written comments were consent, awareness, support for research (cool!), concern about DBS use, discomfort (creepy!), and surprise.

Students said it was important to them to *know* about their participation and their consent options. This theme was consistent with our findings from broader community meetings held around the state of Michigan (Thiel et al. 2013). Notably, in open-ended responses to our survey, respondents were far more likely to raise the problem of awareness than the problem of consent. Our survey data suggests that Michigan biobank participants and their peers are both extremely unaware and extremely interested to both learn about their biobank participation and discuss it with others. Hope for increased public awareness emerged as the most prevalent theme among respondents' open-ended comments.

Student comments were made in the context of low statewide awareness of the BioTrust. The percentage of postengagement survey respondents who reported to have heard of the Michigan BioTrust prior to our campus events was, at 19 %, much higher than expected. Four staff members who directly asked students at campus events whether they had heard of Michigan's biobank independently estimated that 1 to 3 % of participants said in person that they had heard of the program, typically from classes that discussed our upcoming engagements, or in relevant health courses, such as neonatal phlebotomy. Statewide surveys fielded annually from 2011 to 2013 also yielded higher-than-expected results, finding that the percentage of Michiganders affirming that they had "read or heard about the research program called the Michigan BioTrust for Health" ranged, in these years, from 7 to 11 %. To test the possibility that the results from these surveys may have been skewed by an agreement bias, we queried respondents' awareness of a nonexistent biobanking institution on the 2013 version of the statewide survey. Ten percent of respondents (n=978) indicated they had heard of a nonexistent entity (Michigan BioTech Development Consortium), while 7.2 % indicated that they had previously read or heard about the BioTrust. We infer from these data that an agreement bias may be inflating the numbers of people who are reporting previous familiarity with the BioTrust.

Biobank participants, including the students consulted in this study, have a wide range of attitudes about long-term participation in research, including many that would express surprise about participation and pivot on this "Cool! But creepy!" fulcrum that was represented in student comments. It is important to note that the students we spoke with may have been more accepting and less anxious about the initiative because the engagement itself actively informed them of their participation. Populations who are unaware of their biobank participation are understudied in the literature, and the themes of discomfort and surprise we found among stakeholders are distinct.

To respect the values of stakeholders regarding awareness and consent, large population biobanks should create and maintain channels of communication to establish ongoing opportunities for participant awareness and decision making. Retrospective biobanks and those that collect proxy consent will need funding and resources to conduct community outreach to raise public awareness about population biobanks, the privacy protections they have in place, and options for consent (McCarty et al. 2008; O'Doherty et al. 2011). Without widespread engagement, population biobanks lose opportunities for accountability and partnership with participants that are safeguards of public trust (Campbell 2007; Harmon et al. 2013).

Outreach effectiveness

Traditional components of health fair outreach were found to be effective in capturing students' attention and for conveying information on a complex topic. In the statewide survey, we conducted in 2013, we asked Michiganders if they were aware that newborn screening bloodspots were kept. Adjusting for agreement bias by asking about the fictitious biobank, we found that only 15 % of respondents born in Michigan after 30 June 1984 were aware that DBS were kept. Given that 82 % of respondents to the postengagement survey answered a comparable question correctly ("True/False: Michigan's Biobank is a collection of dried bloodspots that are left over from Newborn Screening," we conclude that the campus events likely increased knowledge.

Notably, 23 % of respondents responded incorrectly to the True/False prompt, "Adults with bloodspots in the Biobank can contact the health department to remove their spots." Staff members may have been less effective at communicating the option to destroy or remove DBS from the research pool, possibly because presenters de-emphasized the option in seeking to be nondirective. Survey respondents said they were likely to share the information they learned with others, or that they had already done so. This was an important indicator not only that students were interested but also that the engagements were successful. Campaign messages that spark dialogue among the target audience are likely to increase the reach and impact of public health campaigns (Noar and Seth 2006).

Outreach methods for community engagement on biobanking need to be multiple and varied in order to effectively engage large populations and tailor messages across gaps such as age, affinity, or education level. Engagement methods on the BioTrust have included deliberative juries (Fleck et al. 2008), community meetings (Thiel et al. 2013), state surveys (Institute for Public Policy and Social Research), a pilot test of an online consent tool to be described in a future paper, and a Facebook advertising campaign targeting Michiganders aged 18 to 28 (Platt et al. 2013), yielding varying results in terms of scope (i.e., numbers reached), depth (i.e., the level of detail in our communication), and the impact of engagements.

In conducting these various modes of engagement, we have encountered a kind of "Goldilocks" problem. Efforts that target a very large audience (as with an online social media campaign or a random digit-dial survey) sacrifice depth for large numbers. Conversely, deliberative juries and town hall style meetings create excellent forums for in-depth investigation and ample time for processing new information, but can only reach a small percentage of the total population impacted by the biobank. The campus engagements, and other similar efforts, offered a middle ground, being both broad in scale and effective at conveying information, sparking interpersonal exchange, igniting interest, and communicating effectively in the eyes of participants. Engagements with a small or moderate effect that reach thousands have a stronger impact than intense individual or small-group interactions (Noar and Seth 2006).

Broader significance

Community engagement has been widely deemed a crucial activity for biobanks that rely on public trust, but increasing public awareness statewide has been a challenge in Michigan. Insofar as it reached a large number of actual biobank participants, demonstrated increased knowledge among survey takers, and provided opportunities for dialogue among the target audience, this engagement could be a model for other biobanks, globally, or for newborn screening programs in other US states that retain DBS for long-term storage or secondary research use.

The implications of this study extend beyond Michigan to biobanks with comparable attributes: Those with de-identified biospecimens and linkable health data, those that collect consent by proxy; those that store biospecimens for secondary use, those that apply an "opt-out" policy for retrospective collections, those that collect blanket consent, and/or those that operate in the context of low public awareness. Lessons from this study may also apply to other contexts, as large population biobanks are like canaries in the coalmine predicting ethical issues that will continue to arise in this era of integrated health information technology. Understanding participant preferences regarding consent, transparency and involvement will continue to be key to guiding policies and ethical practice.

Limitations and future studies

We did not ask survey respondents about their demographic background and our sampling, while broad, was not intended to be representative of the demographics of Michigan. We focused upon adult Michigan BioTrust participants and their peers by visiting campuses that were geographically, demographically, economically and academically diverse and heavily populated by Michigan natives in our target age bracket. Seven of the campuses we attended were community colleges granting certificates, diplomas, and associate's degrees. College students almost by definition have a higher level of educational attainment than the general college-aged population, but almost 40 % of 18- to 24-year olds in Michigan are enrolled in college (NCHEMS). Based on percentages of students receiving (need-based) federal aid from each college we attended, we estimate that greater than 50 % of our sample pool came from families with household incomes below $50,000; the median income in Michigan in 2010 was $56,101 (McVicar 2014).

In other studies and population surveys evaluating awareness and support for the BioTrust and its activities, we have found little variation in support by demographic characteristic (Thiel et al. 2013; Platt et al. 2014). In addition, preliminary analysis of a statewide probability-based survey (*Institute for Public Policy and Social Research*) to be reported later (Platt et al, "Predictors of awareness and support for research uses of newborn screening bloodspots," in preparation) indicates that demographic factors in this age group ($n=219$) do show that college students and graduates more strongly favor research use on DBS ($p=0.036$), and thus our results may be more positive than individuals in this age group without college experience. This study found no significant differences by sex or race/ethnicity. More salient contributors in determining support for research include whether an individual is a stakeholder and personal beliefs with respect to values and perceived benefits about research.

While the number of students participating in our postengagement survey was modest, we fell just shy of our goal of collecting 100 qualitative responses to capture a wide range of perspectives on biobanking that have yet to be documented for this crucial age group; qualitative data presented by Thiel et al represent an exception, but these were generated from intensive community meetings that lasted several hours. The postengagement survey also gave us a better opportunity for evaluating our engagement than would have been possible during the engagement itself. Students who elected to participate in the postengagement survey were self-selecting, which may have made them more likely to self-report that they were interested in the content presented and possibly more optimistic or concerned about the BioTrust. As it is not possible in this type of engagement to assess these factors, we have conducted other population-based, representative studies and situate our results in that context (*Institute for Public Policy and Social Research*).

Survey response rates in general are in decline, particularly among college students (Sax et al. 2003). In our study, the response rate among students evaluating our engagements was particularly low, given that 91.5 % of those engagees were not willing or able to complete the postengagement survey. A study of nonresponse bias in Web and paper surveys among students noted that low response rates alone do not necessarily suggest bias; from our data it is not possible to know whether respondent characteristics are representative of nonrespondents. However, we must acknowledge that our study's survey takers' assessments of the event may have been skewed upward by agreement bias that arises when survey takers incline toward providing positive or socially acceptable responses.

Future research evaluating the outcomes and comparative effectiveness of the broad range of public engagement for public health biobanks would greatly benefit these increasingly prevalent organizations as well as emerging big health data initiatives. Further investigation of the effectiveness of outreach and communications will inform efforts to build trust, create environments that can support shared decision making, and assure the goals of informed consent.

Conclusions

Public engagement is particularly important to biobank participants who, absent traditional consent practices, are unaware of their participation. Many biobank participants are likely to prefer a more active, ongoing role in decision making than blanket or broad consent forms provide. Students we surveyed generally favored use of DBS for health research but called for greater statewide awareness. Health-fair style engagements were effective for targeting college-aged stakeholders, communicating complex messages, and likely increasing knowledge about Michigan's biobank. This engagement could be a model for other biobanks and newborn screening programs that retain DBS. In particular, retrospective biobanks and biobanks that collect proxy consent will continue to need funding and resources to conduct community outreach that is a safeguard to public trust.

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Compliance with Ethics This study was conducted with oversight by the University of Michigan IRB and in compliance with current laws in the USA. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was not obtained from survey participants because the responses were anonymous.

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