

# Engaging a state: Facebook comments on a large population biobank

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**Abstract** Scholarship on newborn screening, dried bloodspot retention, and large population biobanking call consistently for improved public engagement. Communication with participants likely occurs only in the context of collection, consent, or notification, if at all. We ran an 11-week advertising campaign to inform Michigan Facebook users unlikely to know that their or their children's dried bloodspots (DBSs) were stored in a state biobank. We investigated the pattern and content of comments posted during the campaign, focusing on users' questions, attitudes and concerns, and the role the moderator played in addressing them. We used Facebook data to quantitatively assess engagement and employed conventional content analysis to investigate themes, attitudes, and social dynamics among user and moderator comments. Five ad sets elicited comments during campaign weeks 4–8, reaching ~800,000 Facebook users (\$6000). Gravitating

around broad, underlying ethical, legal, and social issues, 180 posts from 129 unique users related to newborn screening or biobanking. Thirty six conveyed negative attitudes and 33 conveyed positive attitudes; 53 posed questions. The most prevalent themes identified were consent, privacy, bloodspot use, identifiability, inclusion criteria, research benefits, (mis)trust, genetics, DBS destruction, awareness, and the role of government. The moderator's 81 posts were responsive—answering questions, correcting or clarifying information, or providing information about opting out. Facebook ad campaigns can improve engagement by pushing out relevant content and creating dynamic, responsive, visible forums for discussion. Reduced control over messaging may be worth the trade-off for creating accessible, transparent, people-centered engagement on public health issues that are sensitive and complex.

**Keywords** Newborn screening · Bloodspots · Biobanking · Community engagement · Attitudes · Health communication · Parent education · Facebook advertising · Social media

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## Background

Over the past decade, large-scale biobanks that store human biospecimens and data have proliferated in public and private sectors as resources for health research, including genomic studies that rely on large population repositories to achieve sufficient power (Simon et al. 2011; McGuire et al. 2011; Thiel et al. 2015; Lewis et al. 2011; Botkin et al. 2013). At the same time, ethical and regulatory aspects of large population biobanks (whose policies and practices vary widely) have provoked discussion, litigation, policy shifts, and public controversy around thorny issues of consent, commercialization, and confidentiality (Botkin et al. 2013; Knoppers et al. 2006;

Capron et al. 2009; Rothwell et al. 2010; Kaufman et al. 2009; Javitt 2013; Bayefsky et al. 2015; Critchley et al. 2015; Caulfield et al. 2014). Responding in part to evidence that the public would prefer to be asked to participate in biobanks, the US Department of Health and Human Services has been advancing proposals to revise the Common Rule since 2011—including one not adopted in its final rule that would have required broad, opt-in consent for future secondary research using deidentified biospecimens (Federal Policy for the Protection of Human Subjects 2017). Outside of the regulatory space, public engagement is an important tool for assessing and addressing ethical questions raised by large population biobanks that are said to depend on participant trust, founded on active and recurrent transparency (Hansson 2005; Petersen 2007; Hawkins and O’Doherty 2010; Wallace et al. 2012; Platt et al. 2013; Hayeems et al. 2016).

This study examines an 11-week Facebook advertising campaign that aimed to stimulate discussion while raising statewide awareness of Michigan’s biobank, a state repository of dried bloodspots (DBSs) left over from newborn screening. Specifically, we investigated the patterns of engagement, user comments, and the role of the moderator in Facebook discussions to elucidate (a) the role social networks and advertising could play to inform and involve the public in biobanking and genetic research initiatives, (b) public attitudes about biobanking and secondary research on DBS, and (c) the role that a dynamic communication platform with active moderation can play in meeting public health communications goals in biobanking and beyond.

About a third of all US states retain DBS for long-term uses (Lewis et al. 2011; Olney et al. 2006; Petrini et al. 2012), and studies show that the public strongly supports improved public education and notification of participants and parents about these practices (Botkin et al. 2012; Botkin et al. 2014; Davey et al. 2005; Tarini et al. 2010a). The Michigan BioTrust for Health is a program of the Michigan Department of Health and Human Services (formerly the Michigan Department of Community Health) that markets deidentified bloodspots that can be linked to public health data to health researchers. The BioTrust comprises two collections of DBS; one set, collected since May 2010, includes DBS only from participants whose parents gave written consent (at the time of collection of the newborn’s bloodspots) to have them stored for research purposes. The other set, the biobank’s “legacy” collection, includes DBS from virtually all children (~4.5 million) born in Michigan between July 1984 and April 2010. Parents and adult participants can opt out of the BioTrust—a provision that, notably, is meaningful only for those who are aware of their participation. Despite some engagement efforts (Thiel et al. 2015; Langbo 2010; Langbo et al. 2013; Thiel et al. 2014; Platt et al. 2014) and an IRB directive that the BioTrust be widely publicized (Langbo et al. 2013; Platt et al. 2014; Mongoven and McGee 2012), most people in

Michigan do not know about the state’s biobank or that a generation of people born in Michigan are a part of it (Thiel et al. 2015; Platt et al. 2014; Michigan State University 2011; Michigan State University 2013).

A consistent finding from the global literature on newborn screening, biobanking, and genetic research is the need to strengthen public engagement and education efforts to improve public awareness and understanding, assess opinion and expectations, foster inclusive discussion, and to inform and ensure ethical practices and policies in these contexts (Simon et al. 2011; Botkin et al. 2013; Rothwell et al. 2010; Botkin et al. 2014; Davey et al. 2005; Etchegary et al. 2013; Goldenberg 2009; Bombard et al. 2012; Cañada et al. 2015; van Teeffelen et al. 2016; Davis et al. 2006). The literature has called for improved, parent-centered educational materials (Botkin et al. 2013); improved timing of education to allow parents to process information in the prenatal period, rather than within 72 h of childbirth (Botkin et al. 2013; Rothwell et al. 2010; Davey et al. 2005; Davis et al. 2006); public engagement to help guide policy and diverse community engagement methods to account for diverse contexts and communities (Etchegary et al. 2013); informing of participants to legitimize opt-out policies (Goldenberg 2009); and further qualitative research to better understand parent and public attitudes about DBS storage and genetic research (Bombard et al. 2012; van Teeffelen et al. 2016; Rothwell et al. 2012).

Community engagement about large population biobanking in Michigan and beyond is, in sum, a potentially critical step in ensuring that stakeholders are aware of their participation and their consent options; it can be an opportunity for identifying and addressing public questions and concerns, for establishing open communication around which trust may be earned, and for developing practices that meet participant expectations and ensure the ethical conduct of biobank research. On the other hand, conducting effective engagement can be challenging. Audiences may be large, transient, or hard to reach; the issue can be sensitive and takes time to explicate; and funding for outreach is often limited.

We chose to use Facebook as a tool for engaging Michiganders on this subject because it could reach a large population of the state biobank’s participants and parents at a relatively low cost, link Facebook users to relevant information, and create a forum for multi-way discussion. Facebook is the most popular social networking site in the USA and the world, with more than a billion users (Platt et al. 2016; Caputo et al. 2014). In a survey of our target audience (Michiganders 18–64), we found that 73.2% were Facebook users; 61.8% used the site at least once a week and 27.4% used it multiple times a day. Household income level, race/ethnicity, and geographic location have been shown to not significantly impact participation in social networking sites, although samples may over-represent females and young adults (Platt et al. 2016; Reaves and Bianchi 2013).

In 2015, the University of Michigan’s Life Sciences and Society Program conducted an 11-week advertising campaign to raise statewide awareness of the state’s newborn screening and biobanking programs (Platt et al. 2016). Our goal was to both reach Michiganders broadly and engage people in meaningful conversation and multi-way interactions. In this paper, we focus particularly on 191 substantive comments from Facebook users and 77 from the moderator on the topics of biobanking and newborn screening. This paper examines the content of these comments, addressing three research questions: (1) What patterns of engagement and social dynamics characterized Facebook comments during this campaign? (2) What questions, attitudes, and concerns about biobanking and newborn screening did Facebook users convey in this forum? (3) And what role did the moderator play in this forum? These questions respond to widespread calls from two bodies of literature—one on public health uses of social networking sites and the other on public engagement on genetic research—to better *involve the public* in public health.

## Methods

### Facebook ad campaign

With a Facebook advertising budget of \$15,000, we conducted an 11-week advertising campaign on Facebook, targeting Michigan Facebook users aged 18–64, a group that would include both parents and adult participants in Michigan’s biobank. Ads ran separately to three age cohorts to allow comparison of results among ages 18–30, 31–45, and 45–64. In some cases, slight variations in language and content allowed us to tailor ads addressing biobank participants vs. parents. The campaign included eight sets of ads, allowing us to diversify content; to experiment with ad setup variables such as duration, bid type, and budget; and to use four distinct ad types aligned with engagement objectives: (1) page likes, (2) web clicks, (3) video views, and (4) engagement with posts on our Facebook page, [facebook.com/mybloodspot](https://www.facebook.com/mybloodspot), including photo albums. In two ads, we used the tagline, “Where were you spotted?” and invited Facebook users to write comments about where in Michigan they (or their kids) were born. In Platt et al. 2016, we describe our campaign strategy and the methods for creating and running the ads, including photo sessions to generate content (Platt et al. 2016).

Table 1 shows the inputs and results of all ads that ran in the 11-week campaign. The vast majority of comments occurred during a 5-week period (shaded in Table 1) and responded directly to five ads (a–e) shown in Fig. 1. The biobank video and photo albums can be viewed in full on our Facebook page.

### Facebook wall

A Facebook wall is the area on a page where both administrators and “friends” or “fans” can post comments and content that is visible to the public. To maintain activity on the page, the moderator posted content to the Facebook wall 15 times, about once per 4 days of the campaign. Of these, six posts were “sponsored,” (i.e., they doubled as advertisements (b, c, and d) as their distribution was boosted by advertising dollars).

### Moderation

The moderator (i.e., the first author) was a member of the research team (the University of Michigan Life Sciences and Society program) that ran the advertising campaign. She created and managed the ads, posted wall content, and responded to user comments throughout the campaign. The moderator had previous experience developing educational materials and engaging with the public on Michigan’s newborn screening and biobanking programs (Langbo et al. 2013; Platt et al. 2014; Mongoven and McGee 2012). This expertise was helpful for addressing the complexity and sensitivity of the subject matter and anticipating questions and concerns. Once the content and communications plan were established, running the campaign took approximately 5–10 h per week (1–2 h per day). In addition to running ads, the moderator posted to the wall and responded to user comments throughout the campaign. The moderator’s goals included providing information relevant to users’ questions and concerns, maintaining a neutral tone and a forum that validated divergent opinions, and raising awareness of newborn screening and biobanking in Michigan.

### Data collection and analysis

We used aggregated, quantitative data from Facebook’s Ad Manager to examine the overall engagement and performance results of campaign advertisements.

To qualitatively analyze comments posted to the ads and wall, we followed a conventional content analysis approach (Hsieh and Shannon 2005). After reading through the entire set of comments several times, we iteratively developed a codebook comprising the following five code groups: “comment set” codes to group comments by Facebook location (i.e., wall posts, ad comments), “speaker” codes to identify moderator and Facebook user comments, “themes” to capture content topics, “emotional valence” codes to capture feelings and attitudes conveyed in comments, and “comment attributes” to capture notable and social characteristics of comments. The codebook is included as Supplementary Appendix A.

All comments were compiled and coded using Atlas.TI 1.0.46.

**Table 1** Facebook ad campaign inputs and results

Schedule	Ad set name	Ad ID <sup>b</sup> /Variants	Budget <sup>c</sup>	Reach (frequency) <sup>d</sup>	Ad objective (results) <sup>e</sup>	User comments on Facebook ads
Weeks 1–11	Page like ads	Variable images	\$4,125 (~\$375/week)	142,571 (2.2)	Page likes (9,009)	0
Week 3	Newborn screening video		\$1,500	134,521 (1.66)	Video views (85,283)	0
Week 4	Web click ads (CPC bid) <sup>a</sup>	Ad a (variable images)	\$2,250	342,516 (1.18)	Website clicks (9,563)	99
Week 5	Map ad	Ad b	\$375	121,966 (1.07)	Page post engagements (12,108)	374
Week 5	Birthplace photo albums	“Where were you spotted?” Photo album (Ad c)	\$125	30,798 (1.10)	Page post engagements (1,266)	152
		“Where were your kids spotted?” Photo album (Ad c)	\$250	57,249 (1.07)	Page post engagements (4,992)	29
Week 6	Poster photo albums	“Today I learned” (Ad d) I hope” and “I’ll share” album variants (not shown)	\$750	174,744 (1.18)	Page post engagements (16,413)	37
Weeks 7–8	Biobank video	Biobank video (Ad e)	\$2,250 (~1,125/week)	305,910 (1.54)	Video views (146,212)	11
Weeks 9–11	Web click ad (CPM bid) <sup>a</sup>	Ad a	\$3,375 (~\$1,125/week)	1.2 m (4.52)	Web clicks (6,953)	1
Totals			\$15,000	1.8 m		703 <sup>f</sup>

<sup>a</sup> All ad sets were set to incur costs based on clicks (CPC) except for the one noted, which incurred cost per 1000 views (CPM)

<sup>b</sup> Ads a–e are shown in Fig. 1; these ran during a peak discussion period of weeks 4–8. During this time period, ads reached 788,362 Facebook users with a frequency of 1.66, for a total cost of \$6000

<sup>c</sup> Figures are rounded to the nearest dollar

<sup>d</sup> “Reach” is the number of viewers who saw ads, and “frequency” is the average number of times a viewer saw an ad

<sup>e</sup> “Ad objectives” determine the function and format of an ad, and “results” measure the number of times an ad met the objectives, i.e., page likes, video views (3 s or more), web clicks, and page post engagements, which include shares, comments, and photo views

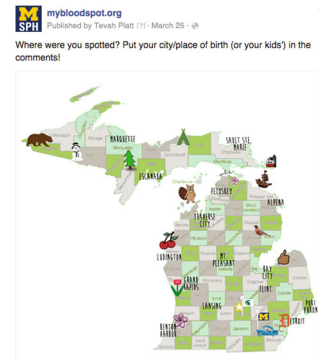
<sup>f</sup> This total excludes user posts on the Facebook wall (21) and moderator comments (81)

**Fig. 1** Facebook advertisements (a–e) that elicited comments in a campaign to raise awareness of biobanking and newborn screening in Michigan

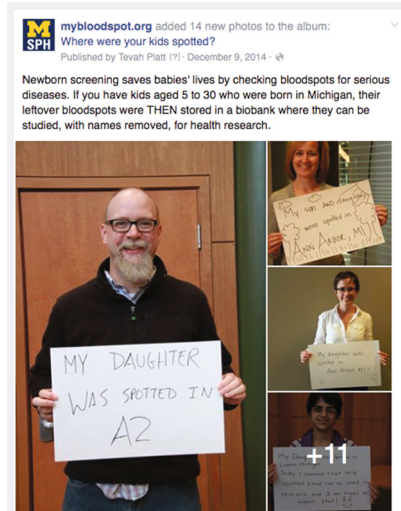
(a) Web click ad



(b) Map ad



(c) "Where were you spotted?" / "Where were your kids spotted?" photo albums



(d) "Today I learned..." photo album



(e) Biobanking video ad



Coding was completed by two investigators (TP and JP), who coded approximately one third of the comments together to establish consensus about the interpretation of ambiguous or vague comments. The remaining two thirds were coded

separately. The coding was then validated by a third investigator (DT) who reviewed all codes for outliers or inconsistencies in the application of codes. Disagreements about specific cases were resolved through consensus. In addition, we

used Atlas.TI's keyword function to identify and report notable keywords and the frequency with which they appear in the collection of comments. Supplementary Appendix A contains theme definitions.

To investigate patterns of engagement and social dynamics that characterized Facebook posts, we looked at the breakdown of comments by speaker, age group, post location, and frequency. We examined questions, attitudes, and concerns about biobanking and newborn screening by coding 180 substantive comments (i.e., posts about biobanking and newborn screening) by theme and emotive valence. In a separate round of coding, we assessed social dynamics within comment threads (chains of two or more comments), including the number of comments from the moderator and user/s, the primary topic of discussion, prompts for moderator involvement, tone of discussion, and the role the moderator played in resolving questions and concerns.

This research was conducted with prior approval from the University of Michigan IRB. The work reported herein was deemed exempt from IRB oversight as it is publicly available data. We follow the procedures taken by Syred and colleagues (2014) and others in using non-verbatim quotes to obscure the identity of users.

## Results

### Patterns of engagement

The \$15,000 campaign reached 1.88 million Michigan Facebook users. Engagement results included 9009 page likes, 15,968 website clicks, 12,909 complete video views, and 724 Facebook user comments (703 responding to ads and 21 posted to the wall). Discussion peaked in weeks 4–8 with ad sets that optimized user engagement with posts, photo albums, and our website. Activity on our Facebook page decreased dramatically once advertising stopped, indicating that ads were critical to stimulating and maintaining user engagement.

Figure 2 shows the breakdown of 805 total comments posted by users (724) and the moderator (81) over the course of the campaign. The total number of Facebook user comments was 724, from 666 unique users (Fig. 2b). The majority of these (507) responded to ads that *prompted* users to share their birthplace. The total number of “substantive comments,” defined here as comments related to newborn screening or biobanking, was 180, from 129 unique Facebook users (Fig. 2e). The moderator posted 81 comments.

The vast majority of Facebook user comments—all but 21 posted to the wall—responded directly to *ads* (Fig. 2c). The map ad (b) that prompted users to post their birthplace elicited the most comments (374), but the web click ad and photo

albums elicited the most substantive comments during the campaign (Fig. 2d).

Length of discussion and frequency of posts can be indicators of learning and active engagement. Most users commented just once (92%). While 43 (7%) commented twice, only 7 users (1%) posted more than two times, with 6 as the highest number of posts from a single user. Among 58 *comment threads* (posts with responses), all but two were related to biobanking or newborn screening. These threads ranged from 2 to 19 comments in length and involved 1 to 8 Facebook users. About 38% (22) were more than three comments long, and 82% (35) involved an interaction between the moderator and one Facebook user.

In this campaign, younger Facebook users (18–30) posted more comments than their older counterparts (31–64). As tallied by Facebook's ad manager, the younger age group accounted for 60% of all campaign comments, with 26% of comments responding to ads that targeted users 31–44 and 14% responding to ads targeting ages 45–64.

### Content analysis: questions, attitudes, and concerns about Michigan's biobanking and newborn screening programs

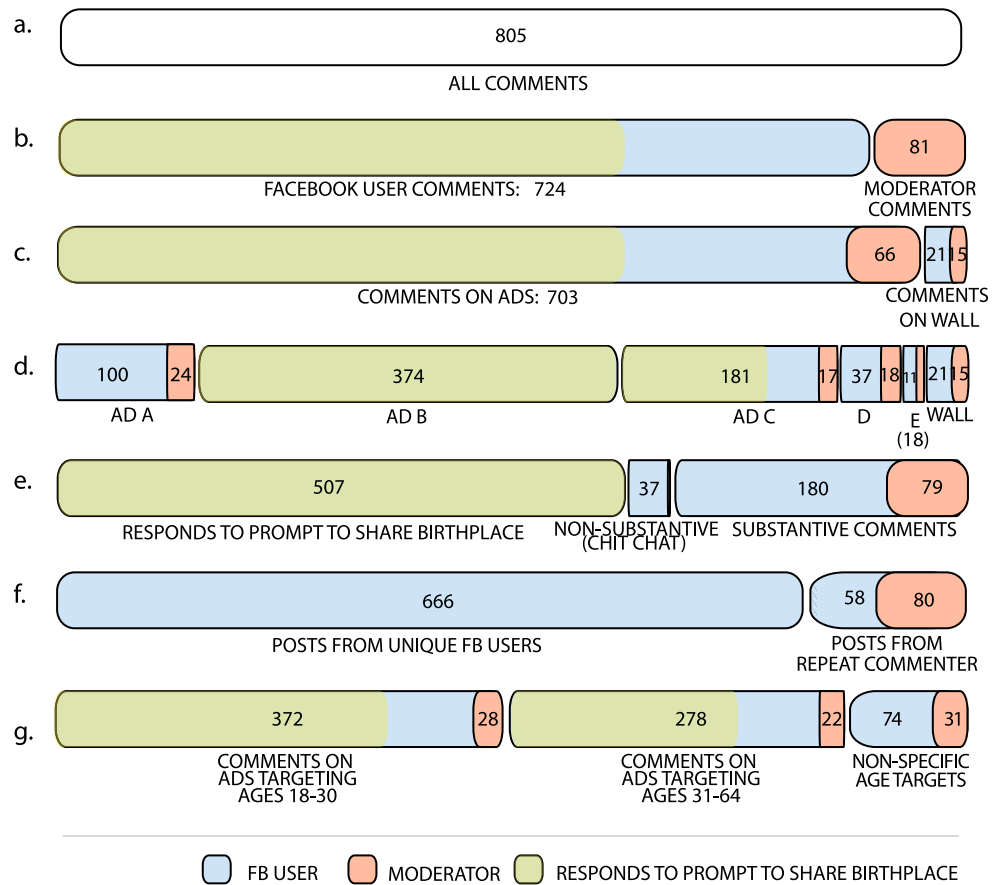
We qualitatively analyzed the 180 comments that related to biobanking and newborn screening. Key issues and themes in these posts included consent (48), privacy (39), bloodspot use (23), identifiability (23), and benefits of health research (18). Table 2 presents a list of themes discussed, with sample quotations.

Only 14 comments dealt with newborn screening as a discrete program; 5 of these were positive and 1 negative in tone.

Among all substantive comments, coders perceived a positive tone in 33 posts and a negative tone in 36. Emotive comments also conveyed surprise (9), apathy (5), and mixed feelings (16). Positive comments often conveyed support for health research (14) and altruism (11). The top themes among negative comments were privacy (28), consent (16), and government (9); 11 users conveyed that they did not want to participate in the biobank.

Users posted 53 questions. Most frequently, users asked questions about inclusion criteria or how to confirm whether they or a family member were in the biobank (e.g., “How do I find out about my girls?”). The next most frequent questions related to identifiability of DBS (e.g., If names are removed, how can people withdraw?) and consent (e.g., Was this done without permission?). Several users posed a general question, e.g., What is this about? Users also asked about options for opting out or opting in; how bloodspots had been used; return of research results; whether bloodspot retention was legal; newborn screening; whether DBS could be subpoenaed; how DBS were collected; whether DBS could be used for stem cell research, cloning, or malicious purposes; and

**Fig. 2** Patterns of comments posted in response to a Facebook campaign to raise awareness of biobanking and newborn screening in Michigan



whether DBS contained DNA. Questions about cloning appeared to be facetious.

In 21 comments, Facebook users opposed or criticized other users’ perspectives. Contention among users often stemmed from users’ varying levels of comfort or trust, with comments directed against others’ paranoia, on the one side, and on the other, naivety, as in this thread, for example:

User 1: What’s wrong with you people? Why would you let the government have your kids’ DNA?

User 2: You mean people. And I’m proud that I donated my kids’ blood for research.

User 1: Sorry for the spelling mistake. But still, enough with the government controls.

User 3: LOL, User 1, you’re so paranoid. What are you worried about, helping kids or eliminating diseases?

User 4: User 1, it must suck to be so paranoid. You probably think immunizations are a government conspiracy.

User 5: Oooh, it’s a conspiracy!

Moderator: Biobanks like the one in Michigan are tremendously important resources for health research. But people have different levels of comfort with participation—that is why there are options to stay in, opt out of research, or have bloodspots removed.

User 6: I didn’t think it was DNA?

User 7: Your hairdresser has DNA on the hairbrush. LOL

User 8: I’m with User 2, if it helps sick kids, I’m all for it.

**Role of the moderator**

The moderator posted 81 comments during the study period, 66 in the comment section of ads and 15 on the Facebook wall. Wall posts always included visual content and sometimes included a prompt for users to comment. They were all by definition initiated by the moderator but in some cases responded directly to questions arising in Facebook user comments. For example, wall posts provided details about research studies that had used Michigan’s DBS, inclusion criteria, and deidentification. For example,

[Wall post]: Some people are asking, “If names are ‘removed,’ then how can people go in and find their bloodspots if they wanted to opt out?” Here’s the answer! A coding system using numbers and bar codes allows bloodspots to go to researchers stripped of names or other information that would identify you. They are ‘deidentified,’ which is not quite the same thing as

**Table 2** Facebook user comments on biobanking and newborn screening: themes and sample quotations (paraphrased)

Theme (frequency)	Sample quotations
<b>Content themes</b>	
Consent (48)	<ul style="list-style-type: none"> <li>• I never signed a consent form, and neither did my parents. What a violation of rights!</li> </ul>
Privacy (39)	<ul style="list-style-type: none"> <li>• Isn't this against the 4th amendment?</li> <li>• I don't want the government to have my genetic information; they may not share your name, but they've got it.</li> </ul>
DBS use (23)	<ul style="list-style-type: none"> <li>• Is it possible to find out which studies my bloodspot has been used for?</li> <li>• I wonder if they could be ever be used unethically.</li> <li>• Can they be used for stem cell research?</li> </ul>
Identifiability (23)	<ul style="list-style-type: none"> <li>• If "names are removed," how can they be destroyed? There must be personal info attached.</li> </ul>
Inclusion (21)	<ul style="list-style-type: none"> <li>• I don't remember whether I signed a form 20 years ago or not. Is it possible to find out if my kid is in this?</li> <li>• What if I was born at home?</li> </ul>
Benefits (18)	<ul style="list-style-type: none"> <li>• Why would you waste a resource that could otherwise help people and find a cure a serious disease?</li> </ul>
Trust or mistrust (18)	<ul style="list-style-type: none"> <li>• I don't believe they'd only use this for health research.</li> <li>• You're naïve if you think the government isn't storing all our information.</li> <li>• You're paranoid. This isn't a conspiracy, it's a program to help people.</li> </ul>
Destroy (18)	<ul style="list-style-type: none"> <li>• How can I get my bloodspots removed or destroyed?</li> </ul>
Genetics (17)	<ul style="list-style-type: none"> <li>• Do the bloodspots contain DNA?</li> <li>• Hahaha! Now the government has our genes. Yay!</li> </ul>
Government (16)	<ul style="list-style-type: none"> <li>• This is an abuse of government power.</li> </ul>
Awareness (14)	<ul style="list-style-type: none"> <li>• It's scary that this was done without me knowing.</li> <li>• I'm ok with this but only if people know about it. Transparency would help.</li> </ul>
NBS (14)	<ul style="list-style-type: none"> <li>• I remember the heel-prick test, but I don't remember them asking about storing the blood for research.</li> <li>• What illnesses can the newborn screening tests detect?</li> </ul>
Altruism (14)	<ul style="list-style-type: none"> <li>• People should support beneficial research. It's selfish to do otherwise.</li> </ul>
Law (7)	<ul style="list-style-type: none"> <li>• Can these samples be used for law enforcement with a subpoena?</li> <li>• I feel like this is a violation of my constitutional rights.</li> </ul>
<b>Attitudes/emotive valences</b>	
Negative valence (36)	<ul style="list-style-type: none"> <li>• It's BS that they took my children's blood without permission.</li> <li>• Destroy mine—I'll pass on having my DNA stored.</li> </ul>
Positive valence (33)	<ul style="list-style-type: none"> <li>• It's awesome to think my bloodspot is out there helping people.</li> <li>• All newborns should donate blood for research for the good of all. People who don't agree would change their minds if they had a baby who was seriously ill.</li> </ul>
Surprised (9)	<ul style="list-style-type: none"> <li>• You took my blood and stored it for 25 years?! I had no idea. WTF!</li> </ul>
NBD (5)	<ul style="list-style-type: none"> <li>• Who cares?</li> </ul>
Conflicted (4)	<ul style="list-style-type: none"> <li>• I have mixed feelings about this. It seems like a good idea, but also creepy.</li> </ul>
<b>Comment attributes</b>	
Answers a question: 12	Tags another Facebook user: 30
Asks a question: 53	Conveys humor: 26
Relates a personal experience: 41	Judges other views: 21
Includes a link: 35	Conveys a mistake: 14
	Question/mistake not addressed: 4
<i>Keywords</i> DNA (16), LOL/LMAO (13), <specific health conditions> (8), clone (5), creepy (5), cord blood (4), WTF (3), catalog (2), Henrietta Lacks (1)	



‘anonymous.’ Many biobanks use deidentified samples for a few reasons: (1) so that people can withdraw the samples if they want to, (2) so that people can use the samples for personal uses, or (3) so that researchers can link samples to useful but not identifying information. For example, researchers could request bloodspots from kids with childhood cancer, or they could request bloodspots from a certain county in order to study something such as pollution levels in that county.

The moderator’s posts in turn elicited 15 comments from Facebook users.

In all but one instance, moderator comments on ads were reactive. The moderator addressed questions 51 times or in 63% of her comments. The moderator participated in 50 of 58 (86%) comment threads (chains of 2+ comments), contributing about a third of all 199 comments made within threads. In most cases (60%), direct questions prompted the moderator to participate in conversations; in nearly all other instances, the moderator participated to address concerns or provide opt-out information to users expressing negative attitudes about the biobank (19) or to correct or clarify information contained in the thread (5). The moderator participated in threads that contained negative or conflicted attitudes about Michigan’s biobank 8 times more often than she participated in threads that contained only positive attitudes (24 vs. 3).

In 32 posts, the moderator included a link to provide users with further information on topics such as newborn screening, the biobank’s consent process, and bloodspot research uses. Content contributed by the moderator frequently included information to clarify the distinct consent processes for the two DBS collections (13) and to describe safeguards in place to protect privacy (13). Consent (37), DBS use (15), and inclusion (10) were the most frequent themes addressed in moderator comments.

The moderator conveyed a neutral-to-positive attitude toward Michigan’s newborn screening and biobanking programs. Moderator comments affirmed their value for health and health research but also acknowledged ethical challenges and validated varying perspectives and levels of comfort. For example,

[Moderator]: Thank you for commenting! Our goal is to raise awareness about this program and to learn what people think about it. Biobanks are important tools for health research that often present ethical challenges around this issue of permission. In this case, a legal waiver allows for these 4.5 million bloodspots to be part of the biobank. We have found that most people in Michigan support this program, but they also really want to know that they are a part of it!

The moderator responded about half the time to users expressing negative attitudes about Michigan’s biobank (19 of

40). In all cases that a Facebook user communicated that they wanted their or their child’s DBS destroyed or removed from Michigan’s biobank, the moderator provided a link to the state’s opt-out form. The moderator provided information relevant to user concerns (e.g., information about protections in place to protect biobank participants’ privacy) but did not attempt to persuade users’ opinions.

Some Facebook users (14) conveyed mistakes or misunderstandings related to the campaign’s educational content. For example, both users and the moderator stepped in to clarify points of confusion surrounding the biobank’s inclusion criteria and its dual consent policies (i.e., bloodspots were included in the biobank before 2010 *without* written consent), the source of the Facebook campaign (i.e., University of Michigan researchers, not the health department or the BioTrust), and confusion between DBS and cord blood. In four instances, the moderator neglected to respond to questions or mistaken inferences.

Two thirds of all comment threads that involved the moderator *ended* with a moderator response (32). Nine more threads ended with a user posting “thanks” or a similar follow-up to a moderator response (nine), while ten others ended in discussion among users.

## Discussion

In this discussion, we address the study’s significance across the domains of public health communications (generally) and biobanking and newborn screening practice and policy (in particular).

### Patterns of engagement

This campaign aimed to promote conversation on a topic likely to be perceived as unfamiliar, complex, and sensitive. We found that both dissemination of information and discussion relied on advertising spending; in this case, funding was critical for pushing out information and engaging users, but not sufficient for establishing a self-sustaining online community. Because biobanks differ across composition, policy, and purpose, both the potential and value of a self-sustaining biobank donor “community” would depend on context. They could be venues for biobanks to solicit participation, seek input, or share information on research and findings. Feasibility would depend on sufficient interest from the donor community to maintain connection.

Brian Wynne (Wynne 2008) emphasizes the distinction between uninvited vs. invited public engagement on issues involving science and technology; invited engagements are connected to institutional policy-making and have a predetermined agenda and framing, while uninvited engagement occurs independently and may clash with institutional

concerns. Further, Wynne argues that invited engagements tend to occur “too far downstream in the life cycles of innovation, regulation, and impacts.” The present study is a case of downstream engagement by a third party, “inviting” the public to develop awareness of a biobank whose activation required funded outreach. This illuminates the paradoxical feature of soliciting public engagement that requires institutional funding and effort—as well as the oddness of addressing a donor community that is neither a community nor a group of donors in the traditional sense. As Soulier et al. (2016) note in their examination of attitudes toward genetics in medicine among various French publics, invited public engagements necessarily imply a power imbalance given that the “framework of engagement” itself is controlled by those soliciting input. It was not likely that an uninvited, spontaneous community would emerge in this context in the absence of a catalyzing event or controversy. The controversies that led to the destruction of DBS repositories in Texas and Minnesota may have been avoided with earlier, upstream public engagement on the issue of DBS retention and uses. As Wynne notes, community engagement around science and technology also suffers when it limits the frame of “possible futures” to those envisioned by the creators of a project. Early and ongoing involvement of biobank participants would allow biobanks to solicit “imagined futures” that are salient to donors and which could potentially guide biobank policies and practices to better meet their social and ethical expectations.

We encouraged user engagement by running multiple ad types, including multi-media content and visual content on all posts, optimizing ads for engagement, and prompting users to comment through the use of our campaign tagline, “Where were you spotted?” This prompt was particularly successful, eliciting 505 comments on ads b and c. The website click (a) and photo album ads (c and d) yielded the most substantive user comments, possibly due to succinct messaging and engaging, non-stock photo content. Overall, younger Facebook users in this study (ages 18–30) were consistently more likely to engage in substantive conversation than older counterparts (31–64), who were more likely to like our page (Platt et al. 2016). Motivating factors to comment on this campaign were doubtless specific to the context and likely included the novelty and relevance of the information, its potential sensitivity and controversial nature, and the complexity of the information that prompted questions. Recommendations about how to promote engagement using Facebook ads are included as Supplementary Appendix B.

A small but significant number of users posted comments more than once (50), tagged other users in their posts (30), or took part in multi-way conversations (56 comment threads). It was not known a priori whether Facebook users would post substantive comments during this campaign. The presence of active conversation was significant for a variety of reasons. Substantive comments and dynamic conversation are

indicators of online learning and represent a high level of engagement within the Facebook domain (Hrastinski 2008). Conversation took place publically in the immediate and transparent context of the campaign, as ads were delivered and shared with other users’ responses directly attached. And without user comments, it can be difficult or impossible to know how users are responding to ad content. In this case, Facebook users conveyed a similar breadth of questions and themes as have been found in more traditional forms of public and stakeholder engagement activities, as discussed below.

### Content analysis

In this study, we focused on 180 substantive comments, of which 156 related to biobanking and 24 dealt exclusively with newborn screening. The top two most common themes among substantive comments were consent and privacy, and 20% of substantive comments conveyed negative feelings about Michigan’s biobank. Concerns included identifiability of participants, potential for DBS misuse, perceived individual “rights” violations, and government “overstepping.” About 18% of comments conveyed positive attitudes, often citing the benefits of health research. In several conversation threads, the fundamental issue of trust seemed to lay at the fulcrum of opposition and support.

The proportion of Facebook users who conveyed negative attitudes was not surprising. In state surveys we fielded previously to gauge public opinion, we found that one in four Michiganders somewhat (16.5%) or strongly (8.5%) oppose “the state of Michigan making bloodspots available for health research,” (Michigan State University 2011) and 22.4% indicated that they would not feel “comfortable with [their] child’s bloodspots being available for health research” (Michigan State University 2013). When a written consent process was put into place to add new DBS to Michigan’s biobank, 59.2% of consent forms were signed by parents during 18 months of 2010–2012, while 15.5% declined (17% of forms returned blank and 8% were not returned) (Duquette et al. 2012). Using the same comparators, the proportion of Facebook users who conveyed positive attitudes was notably low. Our state surveys have consistently found that about three in four Michiganders somewhat or strongly favor the program (range 73.4–77.1%) (Michigan State University 2011; Michigan State University 2013).

Most questions posed by Facebook users dealt with consent, confidentiality, and inclusion criteria for Michigan’s biobank. Six users asked follow-up questions about deidentification (e.g., If names are removed, how can people withdraw?) Questions conveyed both curiosity and concerns about how DBS had been or could be used. Questions specifically identified gaps that we could immediately address in our communication (e.g., to explain why and how DBS were

deidentified) and broadly conveyed that users were interested to know more about their inclusion in the research process.

This campaign raised awareness of biobank participants among a large population that had not been traditionally consented and was largely unaware of their participation. Less than 10% of Michiganders reported knowing on the 2013 state survey that “after newborn screening, the state of Michigan keeps the leftover bloodspots” (Michigan State University 2013). These points bear on both the results of this study and their significance. Awareness of DBS research is ubiquitously low (Botkin et al. 2014; van Teeffelen et al. 2016; Davis et al. 2006; Newcomb et al. 2013), and criticism and controversy have arisen over real or perceived lack of transparency about routinized storage. National studies find that people want to know that they are biobank participants and prefer to have the option to choose to participate (Botkin et al. 2013; Rothwell et al. 2012; Tarini et al. 2010b; Garrison et al. 2015). Michigan offers an important case for assessing expectations and attitudes among actual yet *mostly unknowing* participants. States with biorepositories of residual bloodspots now or in the future might consider the questions, attitudes, and concerns raised here to develop policies, practices, and engagement materials that address participant expectations, preferences, and needs. For example, user responses suggested that biobank parents and participants as a group have a deep desire for information about the program, have questions about its consent policies, want to know what studies have been conducted using DBS, need details about deidentification, largely support the goal of health research, and may have significant anxieties about privacy and especially genetic information sharing (see Supplementary Appendix B).

The breadth of substantive themes covered in comments responding to a Facebook ad campaign on this topic is significant and somewhat surprising, given the brevity of the educational content it disseminated. A US study assessing public attitudes on the retention and use of DBS for research developed the following six categories to represent emergent, policy-related themes across 14 focus groups ( $n = 128$ ): research with residual samples, conditions for allowing research, length of storage and ownership of the sample for research, perceived risks and benefits of research, the importance of education, and ethical considerations with respect to residual samples (Rothwell et al. 2012). While not remotely as rich in detail, the Facebook comments touched on all these categories. This is not to argue that Facebook discussion can or should take the place of other methods to engage community stakeholders, but merely that it is possible for such discussions to capture a broad range of perspectives. A 2013 study of public attitudes and expectations about genetic research points specifically to the need for diverse community engagement methods to take into account “both the research goals and the unique characteristics of the local community to be engaged” (Etchegary et al. 2013). Public engagement via

social media could be one answer to this call. This campaign reached a large, specified population and was able to engage a fair number of users (127) in dialogue in a public forum.

Communication about biobanking via social networking sites could help realize gains for initiatives to promote consent, transparency, viability, public engagement, and patient partnership. It could expand and enhance the consent process for biobanks by educating participants and potential donors, notifying participants of ongoing research uses, and facilitating or curating the consent process. It could improve the legitimacy of the consent process by ensuring that participants are aware of their donation, consent options, and the meaning of their participation, including risks and benefits. It could raise the profile of biobanks and biobanking, building partnerships with individuals and groups. And importantly, social networking sites can facilitate ongoing communication linking patients, participants, and publics with the research enterprise. Increasing the visibility of biobanks could potentially enhance donor participation to biobanks, increase utilization of biobank resources, and serve as a tool for biorepositories that recruit participants. Informing the public could, of course, prompt participants to opt out of a large population biobank. While not in service of biobanking efficiency, it fulfills an ethical obligation; in a dark room, it is necessary for an “opt-out” initiative to provide a lighted exit sign.

### Transparency and trust

Onora O’Neill has laid out compelling grounds that we should question the expectation that transparency—which, perversely, can encourage tokenism, spin, and dishonesty—leads to trust (O’Neill 2002). While less skeptical of transparency per se, David Heald argues that it is to be valued not as an end in itself but as a means to such valued ends as effectiveness, accountability, legitimacy, and fairness (Raab 2008). It may be worthwhile to unpack the expectations and challenges raised by pushing the boundaries of both transparency and trust in biobanking, a domain prone to public suspicion. To appreciate this context, we might consider the gamble involved in the decision to actively inform large populations about unexpected uses of their biospecimens and health data. There are costs and burdens associated with communicating this point, there is the risk of losing participants, and there is the risk of inviting controversy and mistrust that can extend not only to the practice in question (e.g., biobanking) but also to related practices (e.g., newborn screening, data sharing) and to institutions (e.g., hospitals, health departments, government). The public cannot actively trust or mistrust a biobank if they are not aware of its existence. An institution at risk of inspiring mistrust may be motivated to scale down public engagement in order to maintain *the absence of public mistrust*. There is risk, on the other hand, in *not* informing

the public, as non-disclosure or under-disclosure present the potential for greater controversy and backlash upon exposure (Cunningham et al. 2015)—while delegitimizing the opt-out consent process that ostensibly ensures the relationship is not based on coercion or deception (O’Neill 2002). The goal of this information campaign was *not* to increase trust in Michigan’s biobank but to provide a forum for both information and inquiry that could occasion trust or mistrust alike.

### Role of the moderator

As a field, public health has often been cited for falling short of harnessing the social characteristics of social networking sites (Platt et al. 2016; Caputo et al. 2014; Neiger et al. 2012; Neiger et al. 2013; Heldman et al. 2013; Hether 2014; Ramanadhan et al. 2013; Burke-Garcia and Scally 2014). A general call has emerged from the literature on the use of social media for public health communications, encouraging organizations to “shift from the traditional command-and-control approach to a more participatory approach” (Ramanadhan et al. 2013). Stimulating discussion and user-generated content is important to the success of a Facebook campaign because interactivity influences reach and relevance as new participants observe and join the conversation and may be more likely to care about, learn from, and act on information mediated by personal connections. Conversation is also an opportunity for listening, adapting messages to address specific populations, and responding to public questions and concerns (Heldman et al. 2013; Hether 2014; Burke-Garcia and Scally 2014). In the context of newborn screening, biobanking, and genetic research, the literature has called for greater efforts to identify and develop appropriate strategies to meet the public’s need for more information and input (Tarini et al. 2010a; Etchegary et al. 2013; Rothwell et al. 2012; Cunningham et al. 2015; Lemke et al. n.d.).

We see social networking sites as potentially powerful tools to achieve this goal, with some caveats. It was beyond the scope of this study to identify the impact of the medium of the campaign on its message. Nonetheless, the literature on technologies of information and communication includes substantial caution against “deterministic techno-optimism” (Fuchs 2009) that online engagement must lead to positive ends such as democratization, fairness, and accountability (O’Neill 2002; Fuchs 2009; Morozov 2011; Pilkington 2011). O’Neill notes that new information technologies are often used in ways that are anti-democratic and undermine users’ capacity to judge others’ claims and to place trust. Mistrust in Facebook itself—or the fact that social networking platforms are large collections of personal information that can be used for purposes unintended by the user—can rebound on propensities to trust or engage with Facebook content; we observed this as several user comments debated the prudence of responding to the campaign’s prompt to share

their place of birth. Suspicion may have been especially salient given the content of our campaign; public concern about social media surveillance may have impacted and overlapped with concern about surveillance or privacy in the biomedical sphere. While we found it advantageous that Facebook enabled two-way communication while also reaching a large population, it is worth noting that the medium itself cannot ensure that the communication was honest, accessible, or empowering.

Public health communicators may be underutilizing the potential for dynamic interactions on social media due to lack of funding, resources, or strategic planning, but concern over message control has also been identified as a constraint (Tonja 2014). Comments shared on social media networks can include content that is erroneous, critical, offensive, off-topic, incendiary, and counter to an organization’s goals. This study demonstrates that an active moderator (and other users) can immediately respond with answers, corrections, and clarifications. In so doing, they can demonstrate transparency on issues of public concern. These opportunities are especially important when a message is controversial, sensitive, or complex. Listening to the public is an ethical imperative for public health, and discussion and active inquiry may be more important and effective for establishing trust than merely providing information (O’Neill 2002).

The moderator played an important role in addressing questions, misunderstandings, and concerns that arose in this forum. We specifically looked at the moderator’s 81 comments to investigate how these issues were addressed and to identify factors that stimulated and maintained discussion. The approach to moderation described in a 2014 study of a chlamydia health education campaign (Syred et al. 2014) was similar to ours; in that, the moderator filled the role of maintaining quality of information in a tone that was primarily reactive and professional. Our moderator’s comments primarily answered questions, provided clarification, or delivered information relevant to a user’s direct concern. She also adapted wall content based on user questions and feedback. Notably, our goal was neither to promote nor oppose Michigan’s biobank but to raise awareness and connect participants with information that was relevant to them. In our study, the moderator did not address every question, error, and concern raised by Facebook users evaluating Michigan’s biobank but still played an active role as a clarifier, validator, and provider of information relevant and responsive to users’ concerns. In this context, it was necessary for a moderator with topic expertise to commit time to responding to users; resources are needed to address professional and time constraints on public health communications.

A notable feature of this engagement is that it was funded, conducted, and moderated not by the biobank itself but by third parties—in this case, the University of Michigan researchers funded by the National Institutes of Health, a grant

source with no relationship with state public health programs. Funding for participant or public engagement around biobanking exists on a continuum of alignment with different goals. Public health programs need funding to conduct education and outreach. They may turn to community-based organizations, partners, and beneficiaries to aid those efforts. Where there may be real or perceived conflicts of interest, a third-party funder and broker can be an important signal of neutrality. Throughout this campaign, we were aware that we were treading on sensitive terrain that could impact public trust in the state's health department and its programs. We took pains to make our identity and independence clear in our materials and used the university's logo in our profile image with the intended goal of signaling our credibility as a source of information. This is worth pointing out as the dynamics of our engagement may have been different had we been spokespersons for the biobank or framed discussions around its institutional interests.

## Conclusion

This study adds to a body of recent research aiming to ascertain public opinion on biobanking and demonstrates how Facebook can operate as a forum for transparent discussion of a complex and sensitive public health topic. Our 11-week Facebook ad campaign raising awareness of biobanking and newborn screening among Michigan Facebook users elicited 180 substantive comments. The vast majority of comments responded to content that was advertised, and comments ceased after the advertising stopped. Among substantive comments, the most prevalent themes identified (>10) were consent, privacy, bloodspot use/s, identifiability, inclusion criteria, research benefits, trust, genetics, destruction of biospecimens, awareness, and the role of government. About 20% of substantive comments conveyed negative feelings about Michigan's biobank, while 18% conveyed positive attitudes. The moderator contributed 81 comments, playing a responsive role to address questions, clarify uncertainties, and provide relevant information, including opt-out instructions to users who conveyed negative feelings about the biobank. Within an ad campaign that reached nearly 2 million Michigan Facebook users, comments among Facebook users and the moderator created an ongoing, open, multi-way forum that included and responded to the public in ways that cannot be achieved with the one-time consent model of participant interaction.

## Limitations

Facebook users ( $n = 127$ ) who opted to substantively comment on this advertising campaign that reached nearly 2 million were self-selecting and may not represent the opinion of Michigan's general public. Users with particularly strong

feelings of support or opposition may have been more motivated to comment than others. We presume that low-level engagement (e.g., likes) stimulated higher-level engagement (e.g., discussion) during this campaign, but this study did not examine this relationship. This community engagement effort was limited to the English language. As noted, the present study could only speculate about the role that the social media format itself may have played in framing and determining our interactions with the public. We also acknowledge that our analysis was primarily grounded in traditional ELSI analytical categories.

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