## Journal of Public Deliberation

Volume 12 | Issue 1 Article 1

6-4-2016

# Negotiating Deliberative Ideals in Theory and Practice: A Case Study in "Hybrid Design"

Ann Mongoven

Michigan State University, mongove2@msu.edu

Danielle Lake Grand Valley State University, lakeda@gvsu.edu

Jodyn Platt
University of Michigan Medical School, jeplatt@UMICH.edu

Sharon Kardia
University of Michigan School of Public Health, kardia@umich.edu

Follow this and additional works at: https://www.publicdeliberation.net/jpd

Part of the Arts and Humanities Commons, Life Sciences Commons, Public Health Commons, and the Social and Behavioral Sciences Commons

#### Recommended Citation

Mongoven, Ann; Lake, Danielle; Platt, Jodyn; and Kardia, Sharon (2016) "Negotiating Deliberative Ideals in Theory and Practice: A Case Study in "Hybrid Design"," *Journal of Public Deliberation*: Vol. 12: Iss. 1, Article 1.

Available at: https://www.publicdeliberation.net/jpd/vol12/iss1/art1

This Article is brought to you for free and open access by Public Deliberation. It has been accepted for inclusion in Journal of Public Deliberation by an authorized editor of Public Deliberation.

## Negotiating Deliberative Ideals in Theory and Practice: A Case Study in "Hybrid Design"

#### **Abstract**

Much literature on deliberation is derived from ideal theory. However, deliberations are inevitably nonideal in two ways: (1) many deliberative ideals are in tension with each other; and 2) intended balancing of ideals cannot be attained perfectly amidst the messiness of real-world recruitment and conversation. This essay explores both kinds of non-ideality in respect to a case study: the 2011 community deliberative processes on a state public health "biobank," the Michigan BioTrust for Health. We follow two recommendations from major contemporary theorists of deliberation: to be transparent about how competing deliberative goals are negotiated in deliberative design; and to publicize case studies that report associated struggles and results. We present our "hybrid design" that sought to negotiate tensions within three families of deliberative goals: goals of representation and inclusion; goals of discourse-framing; and goals of political impact. We offer deliberative facilitators tentative suggestions based on this case study, concluding deliberations need not be "ideal" to be transformative.

## **Author Biography**

Ann Mongoven (Michigan State University) directed the BioTrust regional deliberative processes and was a co-investigator of the supporting NICHD grant. She wrote sections of the paper on the case study, and edited sections on deliberative theory and literature.

Danielle Lake (Grand Valley State University) co-facilitated one of the regional deliberative groups and contributed to post-deliberation evaluation. She wrote sections of the paper on deliberative theory and literature, and edited sections on the case study.

Jodyn Platt (University of Michigan Medical School) structurally integrated diverse modes of public engagement for the umbrella research grant. She provided project management throughout the deliberations, and editorial consultancy on the writing of the paper.

Sharon Kardia (University of Michigan School of Public Health) is the principal investigator of the NICHD grant, "Linking Community Engagement Research to Public Health Biobank Practice" (5-R01-HD-067264-02).

## Keywords

deliberation, biobanking, research ethics, informed consent, democracy and science, Michigan BioTrust

## Acknowledgements

The reflectiveness, dedication, and democratic spirit of the community deliberators deserve thanks beyond words. We gratefully acknowledge funding from the National Institutes of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD 5-R01-HD067264-02). The collaboration of the Michigan Department of Health and Human Services and the Community Values Advisory Board of the Michigan BioTrust were integral to the deliberative

process; particular thanks are due to Carrie Langbo, Janice Bach, Kevin Cavanagh, Harry McGee, Tressa Orthmeyer, and Rosalyn Beene Harris. Nigel Paneth and Aaron Goldenberg provided muchappreciated briefings to deliberators. Mentors Len Fleck, Toby Citrin, Vence Bonham, Scott Kim, and Linda Hunt provided wise counsel to process planning. University of Michigan grant colleagues Daniel Thiel, Tevah Platt, and Susan King supported the deliberative process in countless ways. Michigan State University Extension staff recruited participants and facilitated deliberations; special thanks to Stephen Lovejoy, Clare Layman, Richard Wooten, Brian Wibby, Julie Pioch, James Ribbron, and Kendra Wills. Co-facilitators and research assistants invaluably contributed to the deliberative process and its aftermath: Jeffrey Proulx, Audrey Wilson, Rekar Taymour, Phillip Proulx, Sara Marzec, Ayesha Bhavsar, Angela Nurse, Andrea Sexton, Ariel Brovont-Cribbens, Sonya Maria Johnson. Meta Kreiner masterminded the qualitative analysis database; Michigan Public Health Institute colleagues Clare Tanner, Jason Forney and Laurel Burchfield ably assisted its development. Colleagues at Michigan State University's College of Human Medicine, College of Arts and Letters, Center for Ethics and Humanities in the Life Sciences, Department of Religious Studies, Office of Outreach and Engagement, and Office of the Vice-President for Research provided myriad forms of support. Special thanks are due to Tom Tomlinson, Libby Bogdan-Lovis, Jan Holmes, Peggy Anderson, Jeffrey Dwyer, Karan Hassankhani, Arthur Versluis, Barbara Miller, Viki Gietzel, Hiram Fitzgerald, and Stephen Hsu. The essay benefitted from astute editorial review by colleague Darren Walhof at Grand Valley State University. We also thank two anonymous peer reviewers for incisive editorial comments.

"The normative legitimacy of a democratic decision depends on the degree to which those affected by it have been included in the decision-making processes and have had the opportunity to influence the outcomes" (Young, 2000, 6).

Much literature on deliberation is derived from ideal theory. However, deliberations are inevitably non-ideal in two ways: (1) many deliberative ideals are in tension with each other; and 2) intended balancing of ideals cannot be attained perfectly amidst the messiness of real-world recruitment and conversation. Moreover, deliberative participants rightly can (and should be able to) challenge or amend process design.

In this article, we explore both kinds of non-ideality in respect to a case study: the 2011 community deliberative processes on a state public health "biobank," the Michigan BioTrust for Health. The BioTrust must earn public trust by incorporating community values into democratically-informed research oversight.

We follow two recommendations from major contemporary theorists of deliberation: to be transparent about how competing deliberative goals are negotiated in deliberative design; and to publicize case studies that report associated struggles and results. We outlay how our "hybrid design" sought to negotiate tensions within three families of deliberative goals: goals of representation and inclusion; goals of discourse-framing; and goals of political impact. We offer tentative suggestions to deliberative facilitators based on this case study, concluding that non-ideal deliberations—in both senses of the term—can provide transformative resources for the wider citizenry.

### Promises and Challenges of Democratic Deliberation: The Need for Design Trade-offs and Case Studies

Democratic deliberation has the potential to address complex social problems fairly by involving those affected in public conversation and decision-making processes. Its potential may be particularly opportune for the kinds of social challenges sometimes tagged as "wicked": problems that are difficult to define; that experts alone cannot solve; that inherently require controversial value judgments and tradeoffs; that differentially affect different stakeholders; and that offer no perfect final resolution (Barrett, Wyman, & Coelho, 2012; Batie, 2008; Fischer, 2000; Ramley, 2014; Rittel & Webber, 1973).

However, even advocates of deliberation warn that it also presents endemic perils. Deliberations are not immune from the power dynamics that riddle society as a whole. If procedural and ethical challenges of deliberation are not well addressed,

1

deliberations can suppress important differences, generating only the veneer of democratic legitimacy (Hamlett & Cobb, 2006; Sunstein, 2006).

While deliberative bodies operate under inherently non-ideal circumstances, much of the literature on deliberation invokes ideal theory (Black, 2012; Black, Burkhalter, Gastil, & Stromer-Galley, 2010). This is problematic because inherent tradeoffs must be made even among deliberative ideals. Theorists disagree on the appropriate goals and associated means of deliberation. Disagreement clusters on who should be at the table; with what role to charge them; what kinds of prompts or tools to give them; what kinds of reason-giving are acceptable; what products to seek; and how to connect deliberation to policy-making.

Deliberative robustness can be repressed not only when deliberative ideals are overtly corrupted, but also when an inappropriate deliberative ideal is prioritized, or when a mistaken tradeoff between deliberative ideals is made, or when a desired balance between deliberative ideals is unattained. Even when deliberative designers are clear about their desired balancings, deliberation-in-practice is messy. Deliberations have an intentionally wild side. Deliberators rightly may have their own ideas about how tradeoffs among ideals should be negotiated and can exert influence accordingly.

Recent calls in the literature invite increased exploration of two linked axes of discussion. Some thinkers call for more explicit consideration of tensions between multiple theoretical ideals of deliberation (Holt-Shannon & Mallory, 2014; Ravazzi & Pomatto, 2014;). Others invite more case studies providing frank perspectives on the practical challenges of designing, implementing, and evaluating deliberative processes (Abelson et. al., 2003; Black, Burkhalter, Gastil, & Stromer-Galley 2010; Fung, 2006; Leighningner, 2012). In this article, we answer both calls by examining the challenges faced in designing, facilitating, and evaluating regional community deliberations on the Michigan BioTrust conducted in 2011. By documenting our efforts to negotiate the tensions articulated in the literature, we highlight our "hybrid design," discuss the results, and articulate lessons learned. We use the label "hybrid design" to flag how we intentionally sought to mediate competing ideals, enabling multiple deliberative goals to play formative roles in the design despite tensions between them. In our view, competing deliberative ideals each have genuinely ethical rationales, though they cannot be simultaneously maximized.

We next explain why the BioTrust is particularly conducive to deliberation, and then analyze our attempt to negotiate three families of unavoidable tradeoffs among deliberative ideals.

#### The Michigan BioTrust for Health: Ripe for Deliberation

The Michigan BioTrust for Health is a research biobank of residual blood samples leftover from the state's newborn screening program. (Newborn screening is a successful mandatory public health program that tests newborns for more than fifty serious diseases, enabling early treatment.) The samples are called "bloodspots" because they appear on a file card as a series of spots, created by a prick of the newborn's heel. Michigan is one of many states that now make leftover neonatal bloodspots available for health research, with names removed. Michigan's biobank comprises 4.5 million bloodspots collected over 30 years, before consent mechanisms were put in place, in addition to bloodspots stored for research with parental consent since 2010 (Erb, 2010).

Neonatal biobanks present a microcosm of both opportunities and ethical challenges in an emerging technological age. Biobanks like Michigan's BioTrust can enable population-wide health research, including genetic research. They can also facilitate research that links de-identified, coded biological samples to health data for the same individual contained in public health registries or electronic medical records. While these capabilities offer scientific promise, they also raise challenges of informed consent, privacy protection, proxy decision-making for children, determination of appropriate research goals for a public resource, assessment of risks and benefits, and research oversight.

Michigan's 2009 inauguration of the BioTrust occurred amidst a backdrop of controversy over bloodspot research in other states. Successful citizen suits in both Minnesota and Texas resulted in restrictions on research use or court-ordered destruction of bloodspots saved without donor knowledge (Botkin et. al. 2013; Carmicheal, 2011). The Michigan health department's desire to avoid such controversy influenced several aspects of the BioTrust's formation. <sup>1</sup>

In 2010, the National Institute of Child Health and Development (NIH-NICHD) awarded researchers at the University of Michigan and Michigan State University a five-year grant to conduct diverse community engagements on the BioTrust

\_

<sup>&</sup>lt;sup>1</sup> The state explicitly recognized the BioTrust as a special community resource, incorporating the biobank facility—the Michigan Neonatal Biobank—as a 5013c nonprofit organization. It established a Scientific Review Committee and a Community Values Advisory Board. It also required that the state's institutional review board (IRB) review BioTrust research for the protection of human subjects (Chrysler et. al., 201; Duquette et. al., 2010; Mongoven & McGee, 2012). The State also conducted initial public engagements, including basic questions about the BioTrust on the its broader behavioral risk survey, and convening focus groups (Langbo et. al., 2013).

(NICHD R01HD067264-01). Both universities shared results and considered how different engagements could inform each other. The University of Michigan researchers focused on strategic brief engagements with large numbers of people that linked them to wider resources. These included innovative surveying, a college campus campaign, and a social media campaign that reached 1.8 million people (Platt J.E. et. al., 2013; Platt T. et. al., 2014; Thiel, D.B., 2015). The Michigan State University researchers focused on conducting an in-depth regional citizen's deliberative process with a smaller group of recruits, the topic of this case study.

Deliberative approaches to bioethical issues, generally, and to biobanking, specifically, are burgeoning (Abelson, et. al., 2013; Avard et. al., 2009; O'Doherty & Burgess, 2009). The BioTrust was particularly ripe for deliberation for several reasons. The formation of the BioTrust presumed community consensuses on the good of publicly supported research and its appropriate range, presumptions that deserved discursive and empirical investigation. Preliminary community engagements conducted by the state and academic researchers had revealed virtually no prior public knowledge, and had highlighted intrinsic tensions between ethical goods at stake—for example, between robustness of informed consent and administrative feasibility. Most significantly, they had indicated that once briefed, many in the community considered BioTrust policy to entail basic matters of public trust rather than narrowly technical issues. A 2008 Lansing Citizen Deliberative Jury on the BioTrust inaugurated academic-state collaboration on deliberation, and provided results that informed the wider 2011 regional deliberations (Fleck, Mongoven, & Marzec, 2008). The state health department and the Community Values Advisory Board of the BioTrust agreed in advance both to provide briefings to the regional deliberations, and to receive concluding testimony from the deliberators.

In addition, deliberative methods are conducive to the BioTrust because it both embodies and transcends characterizations of "wicked problems." There are numerous stakeholders with different interests and diverse risk/benefit analyses. Goods such as privacy protection, participant choice, community oversight, and economic or administrative feasibility cannot be simultaneously maximized. Issues raised are scientifically, economically, politically, and ethically complex. But the BioTrust poses *opportunities*, not just problems. Most Michigan residents remain unaware of the BioTrust.<sup>2</sup> Citizen deliberation could play a formative role

<sup>&</sup>lt;sup>2</sup> Ninety percent of deliberators did not know that bloodspots could be both saved and used for research. Only one in 74 deliberators had heard the term "BioTrust." Half the deliberators were not aware of newborn screening, the source of neonatal bloodspots. In addition, state-wide surveys confirm that this low level of awareness accurately represents the broader Michigan population.

in reception of a new issue. Thus, the BioTrust offers pioneering opportunities for democratic oversight and scientific research, as well as leadership opportunities for Michigan within an emerging national landscape of public health biobanking. In the deliberations, deliberators with a wide range of views expressed a shared sense that they were participating in a moment of opportunity.

#### **Description of the Deliberations' Structure and Charge**

In the deliberations, 74 paid community deliberators completed 16-20 hour group deliberations in five regional in-person groups and two experimental Facebook groups also organized regionally. In-person sites were in Detroit, Benton Harbor, Grand Rapids, Michigan's "thumb" region, and Marquette in the Upper Peninsula. Facebook groups were in Detroit and the Upper Peninsula (excluding Marquette). In-person groups simultaneously deliberated over one weekend, with sessions Friday evening, Saturday morning and afternoon, and Sunday afternoon. Facebook groups deliberated over a three-week period. Michigan State University's Extension Service was a partner in the deliberations, with select Extension county educators recruiting for, and acting as facilitators of, the deliberations in their regions. ("Extension" refers to academic-community partnering organizations unique to land grant universities such as Michigan State.) Recruiting was conducted through more than 80 diverse community organizations and venues with no perceived special connection to the BioTrust.

Preparations for the deliberations were extensive. After reading briefing materials, Extension facilitators and academic co-facilitators attended a full-day training on the BioTrust and on the goals of the deliberation. A state official participated in

5

<sup>&</sup>lt;sup>3</sup> For purposes of this essay, results from both the in-person and online deliberations are grouped together. We focus on the design of the in-person groups rather than detailing how that was modified for online groups. Consonant with emerging literature about on-line deliberation, our experience challenged presumptions that in-person deliberation is the ideal to which on-line deliberation can only approximate. Rather, there seemed to be differences in the relative strengths and weaknesses of both forms. While they faced some challenges the in-person groups did not, our experimental social media groups allowed us to recruit younger parents and rural participants who otherwise could not have participated. They also demonstrated some unique capabilities to resist cascading consensus that related to the asynchronous nature of online deliberation.

<sup>&</sup>lt;sup>4</sup> Organizations from which nominations were solicited included region-focused, religious, and hobby-focused ones. Community venues through which nominations were sought included a public library. Health professionals were not targeted but were not excluded as deliberators. Organizations serving families of people with disabilities were included in solicitation of nominations. Organizations representing people with particular diseases were not. MSU Extension recruiters personally solicited leaders of community organizations to nominate members who were not leaders. They also advertised through list-serves of broad-based community organizations.

the training as an expert on BioTrust science, history, and policy. Process goals and design were addressed. Potential "difficult dialogues" were envisioned. Technological training was given for an "i-clicker" audience response system and audiotaping technology.

Major commitments were made to support deliberators with diverse educational levels and learning styles. Briefing materials included written materials, visual pictures, videos, PowerPoint slides, and aural briefings from different kinds of "expert" informers, both from within and outside the BioTrust, focusing alternatively on science, ethics, or administration. Presentations were followed by question and answer periods and group discussion time. Data was collected by a choice of online or paper surveys, i-clickers, workbooks, and group posters.

Deliberators were charged with identifying stakeholders, articulating hopes and concerns, determining ethical tradeoffs and their potential negotiations, sketching ranges of policy alternatives, and recording areas of consensus and disagreement. The invitation to articulate ethical and policy considerations was alternately left open-ended, or framed to insure addressing several specific topics, including: informed consent, privacy protection, criteria for appropriate research, risks and benefits of research, ethical oversight of research, and practical administration of research.

In the final deliberative session, groups developed points and recommendations for state testimony, including articulations of areas of consensus and disagreement as well as policy recommendations. Through a several-month process following deliberations, summaries of deliberative results were written and testimony ratified by deliberators. In the spring of 2012, four deliberators presented the testimony to the state health department and BioTrust Community Values Advisory Board (CVAB) (Testimony of the BioTrust Deliberations, 2012). In the spring of 2013, the state and CVAB provided a formal written response to the deliberators (Jackson, & Langbo, 2013).

The final deliberative session of all in-person groups and the full Facebook conversations were transcribed, coded for themes, and developed into a qualitative analysis database in NVivo computer software. Facilitators used the qualitative database to explore how recommendations developed, to map the interrelationship of themes, and to assess deliberative inclusiveness and robustness. In addition, mixed-methods approaches were used to enable deidentified linking between sets of quantitative data, and between qualitative and quantitative data. While details of the qualitative and mixed-methods analyses are

beyond the scope of this essay, they both confirmed and enhanced our perception of the general observations discussed here.

The conceptual mapping of ethical and policy issues developed by deliberators was used to develop an interactive online learning tool about the BioTrust. Available in English, Spanish, and Arabic (Michigan's most prevalent languages), the tool both informs and empowers the community. It informs them about their bloodspots in the biobank and helps them think through what choice is best for them (BioTrust Your Choice, 2015). Deliberators provided feedback at several points of tool development; the state reviewed it for factual accuracy, and the tool was piloted in multi-lingual focus groups.

#### **Three Families of Deliberative Tensions**

As designers of the BioTrust deliberative process, we faced challenges negotiating tensions among ideals for three aspects of deliberation: representation and inclusion, discourse-framing, and the hope for political impact. In the next three sections we address each of these sequentially. For each family of tensions, we first summarize challenges from the theoretical literature, identifying tensions among deliberative ideals as well as practical constraints. We then describe our "hybrid design," articulating how it sought to balance deliberative ideals in tension, and report the results. We invoke deliberators' substantive views on bloodspot policy only to illuminate our focus on process design. We assess how the deliberative process supported robust deliberation by enabling identification of stakeholders, ranges of policy alternatives, areas of consensus and disagreement, and considered values-tradeoffs.

#### **Negotiating Tensions Related to Representation and Inclusion**

#### **Tensions Among Ideals**

Deliberative theorists increasingly articulate tensions related to representation and inclusion (Collingwood & Reedy, 2012; Leighninger, 2012). These tensions may be the most fundamental for deliberative designers to address. Who comes to the table and who participates profoundly shapes the deliberation. Size matters greatly. On the one hand, larger groups may better encompass the demographics of an area, while on the other hand smaller groups better enable conversation. To inform democratic processes, deliberative participants should in some way "look like" that community. However, seeking to recruit deliberative groups that are a microcosm of an overall community demographic may disadvantage racial,

ethnic, religious, or gender minorities, since research indicates members of minorities or disempowered social groups are more likely to participate if they perceive a quorum of members who are "like them" socio-demographically. Designs that do not isolate members of such groups better avoid what Iris Young calls "implicit exclusion" of those formally included (Young, 1990, 2000, 2001).

#### **Constraints in Practice**

While the literature focuses on well-recognized challenges of inclusion for women and minorities, we encountered demographic challenges that defied those categories but were anticipated by advisors with significant recruitment experience: successfully recruiting men and young adults. Even carefully recruited deliberative processes face selection bias in that the more civically inclined are attracted to such endeavors (Melville et al., 2005). Moreover, there are trade-offs between random versus non-random recruiting, and between "widenet" recruiting versus recruiting through more narrowly targeted community venues. There are also tradeoffs between recruiting participants recognized as community leaders—even in ways unrelated to the topic of deliberation—and those who are not.

#### **Our Hybrid Design**

We sought to balance ideals related to representation and inclusion by having different recruitment goals for the full deliberative pool and for each regional group. We aimed to make the pool large enough to insure broad ranges of views and to reflect overall demographic features of the state. By utilizing demographic categories and data from Michigan's annual State of the State Survey, we benchmarked parallel recruiting goals for percentage breakdowns for gender, race, ethnicity, and socio-economic status. In contrast, in the regional groups we sought to over-represent different targeted minority and lower socioeconomic groups to prevent individuals from various sub-groups from feeling isolated. We strove for a range of 16-20 participants per group, consonant with the 12-24 range recommended in literature on deliberative juries and with the positive experience of the 20-person pilot (Fleck & Mongoven, 2008; Smith & Wales, 2002). Deliberative groups must be large enough to encompass multiple views and discursive styles, while small enough to enable conversational intimacy.

#### Results

Our overall pool of 74 deliberators largely attained our goal of looking like a microcosm of Michigan, closely matching the overall Michigan population across

metrics assessing racial/ethnic, socio-economic, educational, and religious indicators (Testimony, 2012). However, simply stressing the match between deliberators' and state demographics at the "macro" level obscures some failures in our recruitment efforts within subgroups. While we attained the targeted number (18-20) in some groups, we fell short in others, with a range of 7 to 20 participants per group and an average of 12. We best met both our size and representational recruitment goals for deliberative groups in regions where we developed thicker partnerships with a smaller number of community organizations. In retrospect we conclude that the concern prompting our initial impetus to wide-net recruiting, namely the desire to avoid undue distortion if targeted organizations had unanticipated group vestments related to the BioTrust, was unfounded. Given the newness of the issue and our choice of community organizations with unrelated foci, narrower recruiting strategies offered more advantages.

We found that succeeding in the intended second personal contact of recruited participants in the days directly preceding the deliberation was a key factor in attendance. Based on our experience, we recommend recruiters confirm 25% more participants than the target aim in advance of the deliberation, and then aggressively pursue 100% second-contact.

We sought to mitigate the inevitable selection bias that deliberation attracts the more civically inclined by focusing recruitment on members rather than leaders of target community groups. (Since the 2008 pilot deliberative jury had targeted community leaders, our approach was also an effort to balance recruitment goals of different deliberations.) By using officer positions as a proxy for leadership we found that actually three-quarters of deliberators were members and one-quarter leaders. This un-intended mix served well. The deliberators with organizational leadership experience contributed relevant facilitative skills without having any greater substantive familiarity with the issue at hand.

For each regional group, we prioritized inclusion of specified underrepresented or minority populations, in ways that were consonant with the local community, but were not a straightforward "microcosm." For example, in Detroit we prioritized recruitment of non-affluent African-Americans, the majority demographic of that city. This meant that by design we included a smaller percentage of participants from other races or ethnicities than are represented in Detroit as a whole. Some deliberators criticized both what were successes and failures according to our own goals. A deliberator in Detroit complained about being the only white male at the table. In context, he felt an isolated minority. In contrast, several deliberators in Grand Rapids, where "no-shows" were disproportionately minority or lower

income recruits, commented that their group seemed "too white" and too education top-heavy.

Our partial successes and failures in recruitment reminded us that diversity is multiply-layered and complex. For example, in one regional group (Benton Harbor) where our biggest recruiting goal was a target racial balance, we failed to attain that. However, further analysis revealed the group included remarkable balances of other demographic divisions endemic to that region, reflecting a virtual even split between union and non-union affiliated workers, and between Democrats and Republicans.

One of the biggest lessons we learned is that there are major gaps between practical challenges of inclusive recruiting and the theoretical literature, which focuses on ensuring participation for minorities and women. While our experience confirmed the validity of such oft-voiced challenges--for example, there was male conversational dominance in one of our groups with relatively equal numbers of men and women—it also suggested recruiting challenges unaddressed by deliberative theorists. Our Extension county educators and others with practical experience convening civic dialogues had warned us that men are harder to recruit than women, and that young people and parents of minors are also much harder to recruit than the middle-aged and elderly. Correspondingly we made disproportionate efforts to recruit both men and young adults. Since adults under thirty and those raising children have their own or family bloodspots in the biobank, they are key stakeholder groups.

Yet despite our efforts, the forewarned demographic groups proved hardest to recruit. Two-thirds of the overall pool were women, with some groups more or less gender-disproportionate. Only three in-person deliberators were young enough to be in the biobank themselves (born since 1984), though others felt personally connected through children or grandchildren.

Young adults, with pressures of early employment histories and young families, may be harder to recruit because of time-press. It is possible that gendering occurred in part due to conventional framings of gender issues. Perhaps some people interpreted the BioTrust as a children's, and thus "maternal," issue. But the fact that men and women up to age thirty-two have blood samples in the BioTrust challenges that potential explanation. The ability of experienced local conveners to predict that we would have greater difficulty recruiting men raises an important question for further scholarly exploration. Could public deliberation itself subtly be culturally gendered "feminine?" This is an explanation we find both possible and troubling.

Our experience also verified that compensation and practicality matter greatly in recruiting. Elimination of child-care conflicts may be one reason we were more successful recruiting parents of young children for the Facebook groups. The \$200 stipend for about 20 hours of effort was less than we thought merited (especially for the in-person deliberators working over an intense weekend from Friday evening through Sunday afternoon), but high by conventions of Institutional Review Boards--whose historical worry has been undue inducement to participate in research that might be risky. For deliberators in some situations, the stipend may not have been enough to enable participation given real costs or inconvenience to participate. Conversely, several financially well-off deliberators said it was not enough to make it "worth it to them" though the opportunity for civic contribution was.

Issue-specific reasons may also challenge recruiting. For example, communities that include large numbers of undocumented Michiganders have a special stakeholder interest, insuring the strength of the firewall between the biobank and law or immigration enforcement. But the informed consent process for the deliberations itself unsettled some low-income Hispanic Michiganders, who seemed to fear even talking at the deliberations could endanger someone they knew. Declining was viewed as the safest response.

On the other hand, we found that recruitment challenges can be mitigated by a process mechanism that allows for "cross-fertilization" between the groups at the midpoint of deliberation enhanced lour recruitment strategy. Originally designed for the convenience of guest briefers—so they could present once to multiple groups deliberating over the same weekend—the structure connected all in-person groups virtually for the "expert" briefings and question and answer sessions. A commercial web-meeting program was used that allowed visual and oral connection between the speaker and the deliberating groups, along with an oral connection among the groups. Sitting together in each location, deliberative groups were provided with time to ask questions sequentially and receive feedback as a collective. This led each deliberative group to realize other groups were focusing on different kinds of questions altogether (for example, embodying respective foci on privacy, consent, criteria for BioTrust research, or fairness in distributing benefits and burdens of research). In subsequent sessions, deliberators explicitly discussed the difference in questions across groups, with some groups broadening their own agenda in response. This cross-fertilization between groups fostered an exchange between our competing large-pool versus small-group recruiting goals, as well as between specific deliberative groups.

We conclude that our differential goals for individual groups versus the overall deliberative pool balanced recruitment tradeoffs productively. Different regional foci emerged and were integrated into final recommendations and testimony. While facilitators of a process with just one deliberating group may face less logistical challenges than we did, they may face greater challenges to balance competing recruitment ideals. We felt the literature on deliberation failed to assist us in some of our most practical recruiting challenges—recruiting men, young adults, and parents of minor children. The question of why, at the population level, men may be less likely than women to accept recruitment into facilitated civic dialogues does not fit neatly into conventional gender politics—but it seems a profoundly important issue to explore.

#### **Negotiating Issues Related to Framing the Discourse**

#### **Tensions Among Ideals**

Even what deliberators are asked to represent at the table is fraught with tension. Are they to represent solely their own views, or should they in some way try to represent a larger group of the community with which they identify? Should they speak personally or "qua citizen," or are those roles related? Is it desirable that they move back and forth between different imaginative roles and ways of speaking? What kinds of reason-giving are appropriate--generalized statements, personal and communal narratives, both? Scholars of deliberation have been wrestling with these questions for years (Audi, 2000; Gastil, Knoblich, & Kelly, 2012; Gutmann & Thompson, 2004; Habermas, 1994; Rawls, 1977; Ryfe, 2006; Sunstein, 2006; Young, 2000).

Facilitators confront tensions in goals related to how deliberative talk should be framed. Challenging overly-narrow expert frameworks with broad community perspectives is an overarching purpose of deliberation, but deliberators may need some expert input. On the one hand, providing a common set of definitions, base facts, and initial identification of tradeoffs can enable informed deliberation and counter unreflective biases (Black, 2012). On the other hand, giving deliberators free reign to construct together the parameters of an issue is one value of deliberation (Fung, 2006; Irwin, 2006). They may identify stakeholders, hopes, concerns, relevant facts, or policy tradeoffs differently than previously developed accounts.

#### **Constraints in Practice**

Finding an appropriate mean balance between structured briefing and open-ended deliberation is further complicated by the need to address different learning styles and educational levels among deliberators. Using multiple modalities of learning materials and diverse ways of demonstrating views can increase inclusivity, but such multiplicity faces constraints of time, dangers of redundancy, and challenges of ordering. This family of tensions begs questions about how to construct deliberative tools that help deliberators comprehensively construct their own conceptual landscape of the issue. Successful negotiation of these challenges increases the likelihood that deliberation will meet one of its fundamental goals, moving discussion beyond simple aggregation of individual interests (Gastil, Knobloch, & Kelly, 2012).

Since deliberation presents opportunities and challenges beyond those found in other kinds of civic dialogues (such as polls, focus groups, or consensus processes), process designers are challenged with how to train both facilitators and participants (Fischer, 1993; Fung, 2006).

#### **Our Hybrid Design**

We chose to privilege robust conversation as the most important product of the deliberations, striving for facilitated but not top-down deliberation, and for research-supported but not research-driven deliberation. To achieve that vision we sought balances among: forms of educational materials with overlapping content; kinds of reason-giving; ways to encourage trade-off negotiation; discursive spaces for individuals and groups; degrees of uniformity and flexibility between groups.

Balancing materials to support deliberation. We constructed an educational "big tent" by using materials geared to different kinds of learning and communication styles, despite redundancies entailed for multi-style learners. Educational materials included written and aural sources, videos, slides, photographs, and cartoons. Briefers included relevant experts inside and outside of Michigan state government and the BioTrust. We balanced conflicting aims of consistency and flexibility by requiring some key materials to be addressed by all groups, while giving groups flexibility regarding relative time-allocation and use of optional materials.

One decision we pondered with ambivalence, including receiving conflicting advice from mentors with extensive experience, was whether to request any advance preparation from deliberators. "Pre-work" can be intimidating to deliberators with less education or literacy. On the other hand, the newness of the topic and the technical issues underlying it meant that much time might be needed

to establish basic facts if everyone came to the deliberations "cold." In the end we decided to request participants review materials in advance because of a commitment to the state to probe effectiveness and clarity of its educational brochure. <sup>5</sup> However, we told deliberators that they could "pass" on these materials if they found them difficult, noting we would assist in the understanding of these background facts at deliberation.

**Results.** Generally the mixed materials worked well, and were well-reviewed, averaging 90% approval ratings in evaluations.

Our biggest retrospective regret was the use of pre-materials. While most deliberators completed them, two accepted the option to decline because they found them difficult. Nonetheless, we think they inhibited participation and conversation. Having deliberators work alone in advance attenuated the creative emotional electricity of their discovering together that they had different first reactions. Moreover, we concluded pre-materials likely discouraged the participation of low-educational-level recruits, especially in one region characterized by a mix of highly affluent residents with much less privileged populations.<sup>6</sup>

The pre-materials also unintentionally privileged the state as a first "speaker" by using the state educational brochure as a basic introduction. While the majority of deliberators initially gave positive marks to the state brochure for clarity, over the course of the process they came to question what it did not address. Compared to the state, deliberators identified more stakeholders and sub-issues important to citizen education. In retrospect, we believe the discursive generation of an expanded "issue-web"— one of the biggest accomplishments of the deliberations – took more time than otherwise might have with a different starting point.

Despite the drawbacks of using pre-materials, they offered some benefits. Deliberators with a solid grasp of the pre-materials became resources for others, enabling deliberators to play facilitative roles "from the get-go."

<sup>&</sup>lt;sup>5</sup> The pre-materials, which could be accessed online or on paper copies mailed to participants, explored any prior knowledge, then used the state brochure to introduce the BioTrust. Associated questions asked about brochure comprehension, and also probed initial attitudes, hopes, or concerns. Ranges of response provided some initial fodder for discussion.

<sup>&</sup>lt;sup>6</sup> We believe this may be true despite it not being cited as a reason in telephone follow-up with confirmed deliberators who were "no-shows," and despite the fact that only 4% of in-person deliberators evaluated the pre-materials unfavorably. Indeed the very delicacy of trying to explore their effect on a diverse group is one reason we concluded the use of pre-materials was a mistake.

**Balancing goals of reason-giving.** To balance deliberative goals related to reason-sharing, we emphasized that deliberation requires a willingness to give reasons, while also articulating a broad understanding of what counts as reasons—including narrative experience and community history. Deliberators were reassured that they were not being asked to speak *for* communities, but that they should feel free to speak *from* communities.

We asked deliberators to take alternative imaginative stances at different times, thinking about the BioTrust as parents, citizens, scientists, and government officials. We also invited them to analogical play, asking what other issues the BioTrust seemed like and why.

**Results.** The alternation of imaginative perspectives likely led to more fruitful results than singular pursuits of either personal narratives or "public" reasongiving. For example, we learned that several deliberators uncomfortable having family bloodpots in the biobank were supportive of the state having a biobank.

The request to imagine different stakeholder perspectives counteracted tendencies toward dismissal of personal narratives. Many deliberators recounted personal stories underlying their reactions to the BioTrust. Fellow deliberators only rarely questioned the standing of those narratives. However, often the speakers themselves closed by questioning the validity of their perspective, saying something like "but that is just my personal experience." There was also a significant difference across regional groups in the extent to which personal or communal narratives were offered. Some deliberators seemed to presume a narrow internalized sense of what should count as a "public reason" (Rawls, 1997). Yet invited alternation of imaginative perspectives also opened discussions of lived experience. For example, asking all deliberators to answer the next question by imagining themselves as parents, or as administrators, enabled actual parents or administrators to talk about their relevant experience. Imaginative role alteration paradoxically required that all participants imagine *and* enabled them to discuss their actual life experience.

The use of analogies also helpfully highlighted diverse background interpretive frameworks. Asked to identify what other issues the BioTrust seemed like, respondents provided answers as varied as: the development of the Salk polio vaccine, organ donation, and stealing or identity theft. These answers brought to the fore different hopes and concerns as well as different life experiences.

Significantly, both imagining different stakeholder perspectives and considering differences among the group pool of analogies fostered articulation of ethical or policy tradeoffs.

**Facilitating trade-off negotiation.** There are intrinsic tradeoffs among potential goods of BioTrust policy such as informed consent, protection of privacy, fair distribution of research benefit and burden, cost-effectiveness, and administrative feasibility. None of these values can be maximized without limiting the extent to which others can be pursued. In the design stage we wrestled with how to facilitate deliberators' identification and negotiation of tradeoffs.

We considered requiring deliberators to fill in visual shells of decision matrices by elaborating relevant values, alternatively weighting them, and assessing how differential weightings supported different policy alternatives. In the end we chose not to do that because decision matrices treat values to be negotiated as independent variables, while participants in previous engagements on the BioTrust had found relevant values interdependent. For example, the degree of stringency necessary for informed consent may depend on the level of trust in research oversight. Instead, we organized workbooks to try to elicit tradeoffs more organically, by giving spaces to list stakeholders and values, and to note individual and group perceptions of ranking.

**Results**. While deliberators did successfully negotiate several value tradeoffs, they often proved better at identifying than at negotiating trade-offs. Identification of conflicts among multiple goods often led to an abrupt change of conversational focus, despite facilitative prompts urging negotiation. At other times it led to the conclusion that more education was needed, though education does not of itself resolve the tradeoffs. In hindsight, we wished we had used decision matrices or other visual tools to press trade-off negotiation. A more systematized mapping process for trade-off negotiation could have encouraged quiet deliberators, who in several cases seem to have been weighting shared values differently rather than embracing different values. In addition, such systematization may have restrained the power of existent policies to shape deliberation.

<sup>&</sup>lt;sup>7</sup> For example, they accepted, with conditions, the permissibility of "opt-out" consent for legacy bloodspots even though they highlighted that such "consent" cannot meet some of the basic elements of informed consent—weighting administrative feasibility more heavily than stringent informed consent. Most deliberators prioritized privacy protection and administrative feasibility over enabling the return of individual research results, though a few deliberators strongly disagreed.

Ensuring full group understanding of how alternate weightings of widely-shared values generate different ethical tradeoffs is an important precursor to further deliberation. In an age of "cross-fire" media formulation of political issues, citizens may have seen few examples of systematic, transparent public evaluation of values tradeoffs and their policy implications. We suggest this is one area in which more, not less, directive facilitation can enable robust deliberation, and we encourage the development of associated deliberative tools.<sup>8</sup>

Balancing individual and group voices. We sought to resist and to monitor dangers of prematurely "cascading consensus"—a process whereby deliberators' influence over one another silences privately held knowledge valuable to the deliberative process (Sunstein, 2006)—by including means for deliberators to express individual views anonymously. They could do so publicly through the "i-clicker" audience response system, or privately through workbooks collected at the close of deliberation. Throughout the deliberation, we polled five key questions by "i-clicker," using a Likert scale. I-clickers allow instantaneous visualization of group polling results without identifying the respective views of individual respondents. Periodically repeated "i-clicker" questions probed general emotional reaction to the BioTrust, risk/benefit analysis, whether permission for bloodspot research was deemed necessary, personal willingness for use of family bloodspots in research, and trust that the BioTrust would be conducted according to community values.

By contrast, the workbooks afforded opportunities for completely private dissent, by providing spaces for the deliberators at various points to compare and contrast their foci or priorities with perceived group foci or priorities. However, the workbooks were not systematic data. Unlike the i-clicker questions required across all groups, they were offered as an optional tool and some groups used them more or less.

**Results.** The anonymity afforded by i-clickers had several positive results. Their use visibly sanctioned changes of views as a result of deliberation, and enabled the group to see when the process changed or reaffirmed group ranges. Most significantly, i-clicker results demonstrated about 10%-15% of deliberators remained consistently distrustful of the BioTrust throughout the deliberations, though that view was not proportionately voiced in aural deliberation.

17

<sup>&</sup>lt;sup>8</sup> For a discussion of the use of decision matrices in policy deliberations, see Kiker et. al., 2005. For a discussion of a game-board-like tool used for trade-off negotiations in deliberative discussions of health care allocation, see Goold et. al., 2005.

However there may also have been unintended negative effects of i-clicker use. In two groups there was evidence of a "norming" effect after the first use, with initial outliers on several questions quickly moving toward more prevalently chosen options in the next polling. While it is impossible to discern whether this was the result of genuine deliberation or an undue norming effect, we could have avoided the latter possibility by not making initial answer ranges to key questions public. It was more important for the facilitators and researchers to have a baseline than for deliberators. Such a baseline can, for instance, validate the presence of initial statistical outliers or foster retrospective comparisons to results deliberators did not initially see.

While audience response systems like i-clickers offer much to deliberative processes, we were reminded that low-tech can be high-value. Among the most effective tools were giant "post it" self-sticking poster boards and a set of colored markers. All in-person groups used these materials; each in different ways. Group discernment about how to use the posters was a bonding experience that became constitutive of the process, and the posters themselves became important data. Posters flagged disagreement and questions, in addition to consensuses, through means such as color codes, rotations of deliberators among posters, or peer-review systems.

Balancing uniformity and flexibility for groups and deliberative facilitators. We attempted to balance consistency across the deliberative process with flexibility for groups and group facilitators. For instance, we required a common training for facilitators, and the use of common briefing materials, surveys, and i-clicker questions, while providing optional participant workbook exercises and slide-sets that addressed sub-issues in more depth.

Results. Facilitators' views and approaches clearly influence deliberation (Fischer, 2000). The MSU Extension facilitators received consistently affirmative reviews for fairness, and we believe that community recognition of Extension as a trusted institution without vestment in the BioTrust helped to establish an open atmosphere. Despite common training of the Extension facilitators, there were significant differences amongst their approaches. Facilitative freedom in part was meant to foster deliberative flexibility. For example, facilitators effectively allocated different amounts of time to small and large group exercises. Other variability, however, was not intended; for example, wide variability in the amount of time that facilitators, as opposed to deliberators, talked. Most facilitators encouraged deliberator input into the formation of ground rules as intended, but time spent varied and one treated it as "pro forma," simply listing rules the facilitator deemed "common sense." Two facilitators used the optional

materials more comprehensively than envisioned-- curtailing conversation to "get through" materials intended as supports to conversation.<sup>9</sup>

Community deliberators are the key participants in a deliberation. Acknowledging this, recent literature underscores the desirability of training them for their roles (Ferkany & Whyte, 2011; Fung, 2006). We wish we had included more participant training, with deliberators and facilitators together, on the goals and methods of deliberation and on desired products of deliberation--separately from any topical discussion on the BioTrust.

Given that the purposes of these deliberations were different from forums our community facilitators were highly experienced at moderating (such as consensus processes), participant training could have enabled the collective creation of strategies to embrace differences; to discern consensuses or areas of disagreement; and to identify and negotiate tradeoffs--underscoring robust conversation as itself the prime product of deliberation.

Despite the lack of formal participant training, community deliberators embodied virtues that enabled the deliberations to be productive even when constraints were encountered. They deeply appreciated the invitation to make their reflections a community resource. When confusion arose about process or goals, they requested clarifications or suggested ways to move forward. They were grittily committed to an extended process of deliberation, and to making their deliberation a policy-related and educational resource. Many voluntarily remained in touch with facilitators and provided additional feedback to the state on issues related to the BioTrust, for years. Their flexibility and commitment amidst an evolving process were a greater resource than any design strength, and overcame design flaws. Clearly deliberation offers diverse community wisdom on how to proceed with complex conversations, not only diverse community wisdom on substantive issues at hand.

**Evaluating overall inclusivity.** We spent significant time retrospectively analyzing the deliberation to identify factors that affected robustness and inclusivity, through audiotapes, the qualitative database, and participant-observer

\_

<sup>&</sup>lt;sup>9</sup> In post-deliberation review, facilitators emphasized the stress they felt at not being experts on biobanking issues themselves, and how that inhibited some of their own decision-making about facilitation. Yet the ability of the facilitators to empathize with initial reactions and questions of the deliberators, as fellow community members and recently briefed newcomers to the issues, was validating to deliberators. While we think the combination of academic and community-embedded facilitators served the deliberation well, we would reverse roles in future deliberations, with an academic facilitator and a community-representative serving as co-facilitator.

notes. As many scholars of deliberation have noted, however, the nuances of deliberation resist many evaluative measures (Black, Burkhalter, Gastil, & Stromer-Galley, 2010; Stromer-Galley, 2007). For example, evaluators attempted to use interruptions as one negative marker. But the qualitative database revealed that interruption can be negative or positive. Sometimes interruption shut a deliberator down. Other times interruptions marked an attuned cheerleading of the speaker.

We concluded that creating a comprehensive database for evaluation was more important than trying to track discrete proxy factors. But taping, whether audio (as we did) or audiovisual, ethically requires unanimous consent of deliberators, and may introduce distraction as well as offering a verbatim record. Not all community deliberations have the resources to construct a qualitative database like the one that enhanced our analysis. For the in-person deliberations, we were impressed by how much we learned from anthropologically-oriented notes taken by our co-facilitators that included observations of body language, tone, and use of geographic space together with detailed paraphrases of conversations. We thus recommend appointing a staff person for the demanding role of note-taker.

As with recruitment, the deliberations imperfectly embodied our intended negotiations for framing the discourse. However, the balances attained in practice were sufficient to enable deliberation that continuously expanded considered stakeholder interests and the perceived complexity of related sub-issues.

#### **Negotiating Tensions Related to the Hope for Political Impact**

#### **Tensions Among Ideals**

Recent findings suggest citizen deliberations often do impact policy (Barrett, Wyman, & Coelho, 2012), though the relationship between policy impact and deliberative design is not yet clear (Weiksner, Gastil, Nabatchi, & Leighninger, 2012). Scholars debate how directly connected to policy-making processes deliberations should be, since connection and disconnection offer different opportunities and limits.

One potential value of community deliberation is its independence from policy-making circles, since they often have their own biases and blind spots. Deliberators insulated from governing political bodies can radically transform the portrayal of an issue, expanding the range of perceived policy alternatives. Working outside of official circles can avoid manipulation or window-dressing (Arnstein, 1969; Young, 2001). Arnstein (1969) advocates political insulation for

deliberation to accomplish the redistribution of power which is its core value. On her participatory scale, deliberations move from entirely manipulative processes to full citizen control through a "ladder of citizen power" (p. 217).

However, too much insulation can make it difficult for deliberation to impact policy-making concretely. Deliberators rightly may feel frustrated if their robust conversations or transformative formulations remain isolated thought experiments. Yet even when deliberation is consultative to policy bodies, there is no guarantee that those bodies will actively and nonselectively listen to deliberative results, or incorporate them into policy-formation. Archon Fung argues the best balance comes from "de-centered" deliberative processes that are still linked to "top-down legitimation of [participants'] involvement" within political structures (Fung, 2006, p. 210).

#### **Constraints in Practice**

These tensions complicate evaluation of deliberation. Judging the success of a deliberative process by weighing only participant satisfaction, community building, and increased knowledge of the issue may fail to address concerns about placation; while measuring only concrete policy impact may undervalue positive democratic cultivation for individuals and communities that may have long-term impact on the given issue and others.

#### Our Hybrid Design

Our deliberative process tried to actualize Fung's model of a process de-centered from—but connected to—policy organs. State support for the deliberations offered newly developed materials and briefings to the participants, as well as a designated channel for them to present their testimony and recommendations back to the Community Values Advisory Board and the state health department. At the same time, even within state briefings, alternate perspectives were provided. For example, the state Institutional Review Board (IRB) director spoke about his board's charge to protect participant interests in BioTrust research through proposal review, even if that meant rejecting or delaying scientifically exciting proposals. He also included a brief history about research ethics regulation in the U.S. and its scandal-driven history.

Moreover, the state was not the only briefer, nor state materials the only materials. For example, an academic bioethicist posed a range of ethical issues raised by neonatal biobanking. Articles, pictures, and slogans from the citizen backlash against bloodspot biobanking in other states were presented and explained. In

addition, state policy was contextualized by facilitators highlighting a range of potential policy responses. Deliberators were repeatedly told that they could offer views that differed from current state policy—including outright rejection of state involvement in neonatal biobanking.

#### **Results**

Deliberators expressed great appreciation for their access to the department of health liaison on the BioTrust, the IRB director, the state laboratory director, a researcher who uses bloodspots, and the chair of the Community Values Advisory Board. Yet they also showed a willingness to press them. In an electric moment when groups were conjoined virtually, deliberators challenged a state official's claim that the BioTrust Community Values Advisory Board meetings were open to the public. The deliberators pointed out that the schedule of meeting dates on the BioTrust website included no explicit invitation to the public, nor did it list meeting locations, times, or instructions for the option to attend via conference-phone. They obtained a commitment for such information to be included.

Deliberators' own desires to be politically relevant played a significant role in conversation, sometimes helpfully and sometimes repressively-- a feature of deliberation on which the scholarly literature offers little advice. One disadvantage our deliberators faced is that initial policies on the BioTrust had been set shortly prior to the deliberation. While facilitators reminded deliberators they were not bound by that, deliberators worried about whether advocacy far afield from current policy would "be listened to" in the political arena. <sup>10</sup>

In the end, the deliberations sought "a redistribution of power" on Arnstein's terms within a context of top-down legitimation by balancing the state's role and by involving deliberators in post-deliberation political processes. Representatives from each deliberative group assisted in the development of testimony, as a check against projection by deliberative facilitators. <sup>11</sup> Four group representatives presented the testimony to the BioTrust Community Values Advisory Board (Testimony 2012).

<sup>&</sup>lt;sup>10</sup> For example, a deliberator mulling whether an opt-out option was adequately fair to people whose bloodspots were banked without consent resolved her own ambivalence by deciding that the state was more likely to listen to a critique of its education and implementation for opt-out policies than to an insistence on explicit informed consent for bloodspots collected in the past.

<sup>11</sup>We adapted this process from the example of mentors Leonard Fleck, Toby Citrin, and Vence Bonham, who fruitfully employed it in extensive deliberations among communities of color on bioethical issues raised by genomics (Bonham et. al., 2009).

#### The testimony:

- voiced general support for using bloodspots as a community resource for research, while identifying an expanded list of stakeholders and ethical factors;
- advocated development of a multi-pronged educational campaign that includes examples of BioTrust research as well as information on privacy and consent options--stressing that the fairness of optout policies depends on such education;<sup>12</sup>
- requested public reporting of BioTrust studies;
- suggested a more streamlined system for opting in or out; and
- urged the expansion of seats on the board for representatives of the general community.

From the outset, a commitment was made to develop educational materials on the BioTrust from the deliberations. The resultant presentation is an interactive online tool available in the state's three main languages (BioTrust Your Choice, 2015; mybloodspot.org). Conceptually, the aim is to include community voices, not only experts, in education to enable informed consent. Deliberators provided feedback to the tool-in-development at several points; the state reviewed the presentation for factual accuracy; and multi-lingual pilots were conducted. This presentation is web-linked to the state website and other relevant venues that serve parents, young adults, and teens.

Consistent with the deliberation, the presentation addresses a wider array of stakeholders, questions, and sub-issues about the BioTrust than the state materials. For example, it includes identification of group as well as individual risks and benefits, examples of BioTrust research, and information about oversight. The presentation includes a Camtasia recording with slides and narration as well as a survey that anonymously collects basic information about the users' knowledge and attitudes. Thus, this learning tool is a mechanism for further community voice, and results will be provided periodically to the BioTrust Community Values Advisory Board.

The state health department and the Community Values Advisory Board formally responded to the deliberators (Langbo, 2013). The most significant response was to accept the deliberators' recommendation to add "general community" seats to the board, and to insure representation from people young enough to have

23

<sup>&</sup>lt;sup>12</sup> Consistent with national findings (Tarini, 2010), the deliberators affirmed that most felt permission from donors is ethically required though an opt-out policy for bloodspots collected in the past would be acceptably fair with adequate public notice.

bloodspots in the biobank.<sup>13</sup> This expansion of three seats to the currently 18-seat board poses the potential to significantly transform board conversation and voting outcomes.

The board also accepted deliberators' recommendations aimed at making BioTrust research studies accessible to the lay public. As requested the state now provides an online chart of all blood spot studies that includes a lay description of the study and of results to date. It also periodically publishes a "research report" newsletter highlighting select research. The state edited its consent forms and streamlined some aspects of its website to improve clarity in accord with suggestions from the deliberators. It commended the deliberators for their concern for, and ideas on, increased public education on the BioTrust.

In general, it takes significant time to assess whether deliberations affect policy. Discerning the role of deliberation in comparison to other factors that influence policy transformation is also challenging. Evaluating effects of deliberation is different from evaluating optimism or pessimism of deliberators that they will have an effect. In this case, the state itself articulated a direct relationship between deliberative testimony and initiatives such as increasing board seats, publicizing BioTrust research, and clarifying consent forms. Many deliberators have expressed appreciation for the state's direct response.

However, many have expressed discontent with the failure to pursue a mass state-sponsored public education campaign: their number-one consensus recommendation. Deliberators worry that without such a campaign, few Michiganders will understand scientific and community issues at stake in the BioTrust. Moreover, individual rights could be violated for those whose blood samples were collected before there was a consent process, since to quote what became a refrain in the deliberations "you can't opt out if you don't know you are in." Given the voluntary nature of post-deliberation communication, we cannot

<sup>&</sup>lt;sup>13</sup> The deliberators felt board representation was made up of too heavily of nominees from public health or medical organizations that might have professional biases, while members nominated by non-medical community groups were generally from organizations representing defined sub-populations. They thought both that people in the biobank should be considered a sub-population of special interest, and that the board would benefit from increased representation from the community-at-large. In response the board instituted a "wide-net" nominating process to invite nominees for two new general community seats, and created another seat that would be filled by a nominee from a designated organization whose membership charter focused on young adults in the age bracket likely to be in the biobank. (The nominating organization chosen for the first term of that seat, a graduate student organization of genetic counselors in training, accomplished that but did not embody the deliberators' goal of balancing the influence of health professionals on the board.)

systematically assess how the deliberators' long-term views on political impact compare to those expressed directly after deliberation—when 93% expressed optimism that their deliberations would impact policy favorably. However our sense is that initial optimism has waned considerably due to lack of public visibility of the BioTrust

#### **Conclusion: The Virtues of Non-Ideal Deliberation**

The BioTrust deliberations partially attained the goals of our hybrid design. Despite imperfectly embodying the intended balances of recruitment, inclusive participation, and political goals, they transformed the discursive and policy landscape in several ways. Compared to previous state portrayals, the deliberations broadened the list of recognized stakeholders and factors in need of consideration. They resulted in increased community representation on the relevant advisory board. They contributed to improved user-friendliness of the state's BioTrust website and consent forms. They enabled new educational materials that drew on the insights of the deliberative conversation as a vicarious resource for the wider public.

Amidst the theoretical and practical struggles of deliberative design, promoters of deliberation may find it reassuring that deliberations need not be ideal to be effective and significant. Of course, they should strive for fair deliberative outcomes by working to develop best practices that transparently embody negotiated tradeoffs in deliberative ideals. In closing we offer suggestions for further testing and discussion based on our experience in the BioTrust deliberations.

#### **Recommendations: Fodder for the Future**

1. Recruitment. Designers should explicitly prioritize or balance different representational goals, such as encapsulating a microcosm of the wider body or insuring conversational comfort for oft-marginalized groups. They should consider how the time and length of the deliberative process, as well as any predeliberation requirement, may impact recruitment. They should consider whether any issue-specific factors are relevant to recruitment venues. Deliberative scholars should design and publish studies that retrospectively interview participants, noshows, and drop-outs in order to assess factors that influence deliberative participation.

- 2. Participant Training. Despite the time-presses of deliberation, facilitators should prioritize participant training and the co-creation of ground rules at the outset, reserving time for participant training and an exploration of the goals of deliberation. An investment in collaborative framing can establish appropriate tone and infrastructure for the entire deliberation. This training time can be used for (a) ritual introduction, which can include playful "ice-breaking" activities; (b) establishing ground rules whose formation as well as content enables trust; (c) underscoring robust and inclusive conversation as the fundamental "product" of deliberation; (d) highlighting the expectation of tradeoff negotiation and enlisting participants to think about how to do that and; (e) addressing tensions between goals of discerning consensus and disagreement, while developing a group commitment to resist cascading consensus. A devoted time-block for participant training can both model and develop participant virtues. Deliberative scholars should design case-control studies that explore the difference between deliberations that do and do not include participant training, determining the most efficient relative time between participant training and engagement with the substantive issue.
- **3. Diverse Learning and Communication Styles**. Designers and facilitators should consider diverse learning and communication styles, resisting the historical bias of deliberation that privileges aural vehicles. Not only should educational materials include an array of aural and visual elements, but deliberators should be given visual as well as aural, and anonymous as well as public, ways of communicating views. Research goals traditionally encompassed by pre and post-surveying should be pursued by means that insure they measure the results of deliberation rather than becoming formative of deliberation.
- **4. Alternative Forms of Perspective-Taking**. Designers and facilitators should consider negotiating tensions between various forms of reasoning by asking deliberators to explicitly consider their own *and* others' interests, and to alternate perspectives imaginatively. The encouragement of a perspectival dialogue opens discursive space and enables local or personal insights to emerge. Facilitators should be aware that presumptions about what kinds of reasons are expected in civic forums can influence deliberations as much as stated ground rules.
- **5. Tradeoff Negotiation.** Designers and facilitators should not assume that tradeoff negotiations will emerge organically among well-briefed deliberators. Rather, they should consider strategies and tools that can help deliberators conceptualize and visualize tradeoffs, and then understand policy implications of different alternative weightings of competing values.

**6. Data for Evaluation.** Designers should create some comprehensive, multifactorial record for "Monday-night quarterbacking" of deliberative robustness, since all discrete measures are flawed. Different potential strategies such as videotaping, enlisting anthropologically-oriented detailed note-takers, or creating a qualitative-analysis database have relative advantages and disadvantages in terms of expense, comprehensiveness, and potential disruption to, or formative effect on, the deliberations.

Scholars of deliberation can use multi-factorial records to analyze retrospectively what discrete measures are the best proxies for overall deliberative robustness. Over time, the development of such measures may allow meaningful comparison of the quality of deliberations held on different substantive topics.

**7. Political Insulation and Political Engagement.** Designers and facilitators should weigh the value of state-sanctioned processes against concerns to protect independence. Decisions about the appropriate role for stakeholders with considerable political power must be made thoughtfully. Determining the order of materials or of briefings is as significant as decisions about content. We recommend that current policy-insiders not be given the first voice in process order.

Facilitators and deliberators should consider explicitly how deliberation could become a vicarious resource for the wider population. Strategies can include policy-oriented testimony, proposal of appropriate metrics, or creation of public educational materials. It may take significant time for deliberators to assess their experience, and for the public impact of a deliberation to be evaluated. Process designers should consider that in funding proposals or in budgeting. Deliberative scholars should interview both deliberative participants and policy-makers to assess perceived political impact of a deliberation over time.

#### References

- Abelson, J., Blacksher, E. A., Li, K. K., Boesveld, S.E., & Goold, S. D. (2013). Public deliberation in health policy and bioethics: mapping an emerging, interdisciplinary field. *Journal of Public Deliberation*, 9(1), Article 5.
- Abelson, J., Forest, P.G., Eyles, J., Smith, P., Martin, E. & Gauvin, F.P. (2003). Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science and Medicine*, 57, 239-251.
- Alpaslan, C. & Mitroff, I. (2011). Swans, swine, and swindlers: Coping with the growing threat of mega-crises and mega-messes. Stanford, CA:Stanford University Press.
- Arnstein, S. R. (1969). A ladder of citizen participation. *The Journal of American Institute of Planners*, 35 (4), 216-224.
- Avard, D., Bucci, L. M., Burgess, M. M., Kaye, J., Heeney, C., Farmer, Y., & Cambon-Thompson, A. (2009). Public health genomics (PHG) and public participation: Points to consider. *Journal of Public Deliberation* 5 (1), Article 7.
- Barrett, G., Wyman, M., & Coelho, V.S. (2012). Assessing the policy impacts of deliberative civic engagement. In T. Nabatchi, J. Gastil, G. M. Weiksner, & M. Leighninger (Eds.), *Democracy in motion* (pp. 181-204). New York, NY: Oxford University Press.
- Batie, S. S. (2008). Wicked problems and applied economics. *American Journal of Agricultural Economics*, 90(5), 1176-1191. doi:10.1111/j.1467-8276.2008.01202.x
- Beierle, T. C. (1999). Using social goals to evaluate public participation in environmental decisions. *Review of Policy Research*, 16(4), 75-103.
- BioTrust Your Choice (English Version). (2015). Your blood spots—your choice.

- Your child's blood spots—your choice. Retrieved from http://go.cal.msu.edu/BioTrustYourChoice\_English
- Black, L. W. (2012). How people communicate during deliberative events. In T. Nabatchi, J. Gastil, G. M. Weiksner, & M. Leighninger (Eds.), *Democracy in motion* (pp. 59-81). New York, NY: Oxford University Press.
- Black, L., Burkhalter, S., Gastil, J., & Stromer-Galley, J. (2010). Methods for analyzing and measuring group deliberation. In E. Bucy & R. L. Holbert (Eds.), Sourcebook for political communication research: Methods, measures, and analytical Techniques (pp. 323-345). Mahwah, NJ: Routledge.
- Bonham, V. L., Citrin, T., Modell, S. M., Franklin, T. H., Bleicher, E. W. B., & Fleck, L. M. (2009). Community-based dialogue: engaging communities of color in the United States genetic policy conversation. *Journal of Health Politics, Policy and Law*, 34(3), 325-359.
- Brown, V. A. & Lambert, J. A. (2013). *Collective learning for transformational change: A guide to collaborative action*. New York, NY: Routledge.
- Chrysler, D., McGee, H., Bach, J., Goldman, E., & Jacobson, P. D. (2011). The Michigan BioTrust for Health: Using dried bloodspots to benefit the community while respecting the individual. *Journal of Law, Medicine, and Ethics*, 9(s1), 98-101.
- Collingwood, L. & Reedy, J. (2012). Listening and responding to criticisms of deliberative civic engagement. In T. Nabatchi, J. Gastil, G. M. Weiksner, and M. Leighninger (Eds.), *Democracy in motion* (pp. 233-259). New York, NY: Oxford University Press.
- Duquette, D., Rafferty, A.P., Fussman, C., Gehring, J., Myer, S., & Bach, J. (2012). Public support for the use of newborn screening dried blood spots in health research. *Public Health Genomics* 14(3), 143-52.

- Erb, R. (2010, April 8). In blood debate, new consent effort aims to open research doors. *Detroit Free Press*.
- Ferkany, M. & Whyte, K. P. (2011). The importance of participatory virtues in the future of environmental education. *Journal of Agricultural Environmental Ethics* 25(3), 419-434.
- Fleck, L., Mongoven, A., & Marzac, S. (2008). Informing the debate: stored bloospots—ethical and legal challenges. *Michigan State University Institute for Public Policy and Social Research*. Retrieved from http://ippsr.msu.edu/Publications/ARBloodSpots.pdf
- Fischer, F. (2000). *Citizens, experts, and the environment: The politics of local knowledge*. London: Duke University.
- Fischer, F. (1993). Citizen participation and the democratization of policy expertise: from theoretical inquiry to practical cases. *Policy Sciences*, 26(3), 165-187.
- Fung, A. (2006). *Empowered participation: Reinventing urban democracy*. Princeton, NJ: Princeton University Press.
- Gastil, J., Knoblock, K., & Kelly, M. (2012). Evaluating deliberative public events and projects. In T. Nabatchi, J. Gastil, G. M. Weiksner, and M. Leighninger (Eds.), *Democracy in motion* (pp. 205-230). New York, NY: Oxford University Press.
- Goold, S.J., Biddle, A.K., Klipp, G., Hall, C.N., & Danis, M. (2005). Choosing health plans all together: a deliberative exercise for allocating limited health care resources. *Journal of Health Politics, Policy and Law*, 30(4), 563-602.
- Gutmann, A. & Thompson, D. (2004). *Why deliberative democracy*. Princeton, NJ: Princeton University Press.
- Hamlett, P. W. & Cobb, M. D. (2006). Potential solutions to public deliberation

- problems: Structured deliberations and polarization cascades. *The Policy Studies Journal*, 34(4), 629-648.
- Hendricks, C. M. (2005). Consensus Conferences and Planning Cells. In J. Gastil & P. Levine (Eds.), *The deliberative democracy handbook: Strategies for effective civic engagement in the 21<sup>st</sup> Century* (pp. 80-110). San Francisco, CA: Jossey-Bass.
- Holt-Shannon, M. & Mallory, B. L. (2014). The compost of disagreement: creating safe space for engagement and action. *Journal of Public Deliberation*, 10(1), Article 22.
- Irwin, A. (2006). The politics of talk: coming to terms with the 'new' scientific governance. *Social Studies of Science* 36(2), 299-320.
- Jackson, T. & Langbo, C. (n.d.). Response to the deliberative process on the BioTrust. Retrieved from http://www.msu.edu/~mongove2/DeliberativeProcessStateResponseLette 3.2013.pdf
- Langbo, C., Bach, J., Klein, M., & Downes, F. (2013). From newborn screening to population health: implementation of the Michigan BioTrust for Health. *Public Health Reports* 128(5), 377-84.
- Leighninger, M. (2012). Mapping deliberative civic engagement: pictures from a (r)evolution. In T. Nabatchi, J. Gastil, G. M. Weiksner, and M. Leighninger (Eds.), *Democracy in motion* (pp. 19-39). New York, NY: Oxford University Press.
- Melville, C., Willingham, T. L., & Dedrick, J. R. (2005). National issues forums: A network of communities promoting public deliberation. In J. Gastil & P. Levine (Eds.), *The Deliberative Democracy Handbook: Strategies for Effective Civic Engagement in the 21<sup>st</sup> Century* (pp. 37-58). San Francisco, CA: Jossey-Bas.

- Mongoven, A. & McGee H (2102). IRB review and public health biobanking: A case study of the Michigan BioTrust for Health. *IRB: Ethics and Human Reseearch* 34(3), 11-16.
- *Mybloodspot.org* (2015).
- O'Doherty K. C. & Burgess, M. M. (2009). Engaging the public on biobanks: results of the B.C. biobank deliberation. *Public Health Genomics* 12, 203-215.
- Platt, T., Platt, J., Thiel, D. B., Fisher, N., & Kardia, S. L. R. (2014). 'Cool! And creepy': Engaging with college student stakeholders in Michigan's biobank. *Journal of Community Genetics* 5, 349-362.
- Platt, J. E., Platt, T., Thiel, D., Kardia S. L. (2013). 'Born in Michigan? You're in the biobank': Engaging biobank participants through Facebook advertisements. *Public Health Genomics*, 16(4), 145-158.
- Ramley, J. A. (2014). The changing role of higher education: learning to deal with wicked problems. *Journal of Higher Education Outreach and Engagement*, 18(3), 7-22.
- Ravazzi, S. & Pomatto, G. (2014). Flexibility, argumentation and confrontation: How deliberative minipublics can affect policies on controversial issues. *Journal of Public Deliberation*, 10(2), Article 10.
- Rawls, J. (1997). The idea of public reason revisited. *University of Chicago Law Review*, 64, 765-807.
- Rittel, H. W. & Webber, M. (1973). Dilemmas in a general theory of planning. *Policy Sciences* 4, 155-169.
- Ryfe, D. (2006). Narrative and deliberation in small group forums. *Journal of Applied Communication Research*, 34(1), 72-93.
- Salwasser, H. (2004). Confronting the implications of wicked problems: changes

- needed in Sierra Nevada national forest planning and problem solving. *USDA Forest Service Gen. Tech Rep.* Retrieved from http://www.fs.fed.us/psw/publications/documents/psw\_gtr193/psw\_gtr193\_1\_05\_Salwasser.pdf
- Siegfried, C. H. (1996). *Pragmatism and feminism: Reweaving the socialfFabric*. Chicago, IL: University of Chicago Press.
- Steenbergen, M., Bachtiger, A., Sporndli, M., & Steiner, J. (2003). Measuring political deliberation: A discourse quality index. *Comparative European Politics*, 1, 21-48.
- Stromer-Galley, J. (2007). Measuring deliberation's content: a coding scheme. *Journal of Public Deliberation*, 3(1), 1-35.
- Sunstein, C. R. (2006). Deliberating groups versus predicting markets. *Episteme:* A *Journal of Social Epistemology*, 3(3), 192-213.
- Tarini, B. A., Goldenberg, A., Singer, D., Clark, S. J. Butchart, A., & Davis, M.
  M. (2010). Not without my permission: parents' willingness to permit use of newborn screening samples for research. *Public Health Genomics* 13 (3), 125-130.
- Testimony of the Citizen's Deliberative Processes on the Michigan BioTrust (2012). Retrieved from http://www.msu.edu/~mongove2/Testimony\_BioTrust\_Deliberation\_2012. pdf
- Thiel, D. B., Platt, J., Platt, T., King, S.B., Fisher, N., Shelton, R., & Kardia, S. L. R. (2015). Testing an online dynamic consent portal large population biobank research. *Public Health Genomics* 8, 26-39.
- Weiksner, G. M., Gastil, J., Nabatchi, T., & Leighninger, M. (2012). Advancing the theory and practice of deliberative civic engagement. In T. Nabatchi, J. Gastil, G. M. Weiksner, and M. Leighninger (Eds.) *Democracy in motion* (pp. 261-273). New York, NY: Oxford University Press.

- Young, I. M. (2001). Activist challenges to deliberative democracy. *Political Theory*, 29(5), 670-690.
- Young, I. M. (2000). *Inclusion and Democracy*. New York, NY: Oxford University Press.
- Young, I. M. (1990). *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press.