HHS Public Access

Author manuscript

AJOB Empir Bioeth. Author manuscript; available in PMC 2021 July 12.

Published in final edited form as:

AJOB Empir Bioeth. 2021 ; 12(3): 164–178. doi:10.1080/23294515.2021.1925775.

Deliberations with American Indian and Alaska Native People about the Ethics of Genomics: An Adapted Model of Deliberation Used with Three Tribal Communities in the United States

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Abstract

Background: This paper describes the design, implementation, and process outcomes from three public deliberations held in three tribal communities. Although increasingly used around the globe to address collective challenges, our study is among the first to adapt public deliberation for use with exclusively Indigenous populations. In question was how to design deliberations for tribal communities and whether this adapted model would achieve key deliberative goals and be well received.

Methods: We adapted democratic deliberation, an approach to stakeholder engagement, for use with three tribal communities to respect tribal values and customs. Public deliberation convenes people from diverse backgrounds in reasoned reflection and dialogue in search of collective solutions. The deliberation planning process and design were informed by frameworks of enclave deliberation and community-based participatory research, which share key egalitarian values. The deliberations were collaboratively designed with tribal leadership and extensive partner input and involvement in the deliberations. Each deliberation posed different, locally relevant questions about genomic research, but used the same deliberation structure and measures to gauge the quality and experience of deliberation.

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Disclosure statement

The authors report no conflict of interest.

Results: A total of 52 individuals participated in the deliberations across all three sites. Deliberants were balanced in gender, spanned decades in age, and were diverse in educational attainment and exposure to health research. Overall, the deliberations were positively evaluated. Participant perceptions and external observer datasets depict three deliberations that offered intensive conversation experiences in which participants learned from one another, reported feeling respected and connected to one another, and endorsed this intensive form of engagement.

Conclusion: The adapted deliberations achieved key deliberative goals and were generally well received. Limitations of the study are described.

Keywords

Genomics; deliberation; American Indian; Alaska Native; community engagement; ELSI

Introduction

Genomic research with American Indian and Alaska Native (AI/AN) peoples is an ethically and politically complicated proposition. A long history of mistreatment by the United States (US) government and federally funded researchers has sown ample mistrust among AI/AN communities and the risks of participation remain serious (Bowekaty and Davis 2003, Christopher et al. 2011, Dillard et al. 2018, Harding et al. 2012, Hodge 2012, Kelley et al. 2013, Morton et al. 2013, Harry and Dukepoo 1998, Di Chiro 2007, Strickland 2006, Greely 1999). The small size of some AI/AN tribes, and in some cases their unique genetic profile, increases the prospects that such research may identify and stigmatize communities (Goins et al. 2011). Additionally, the path from research to tribal health benefit is often long and unclear, and research may seem superfluous, given that limited access to basic medical services among some AI/AN communities and chronic underfunding of the Indian Health Service contribute fundamentally to AI/AN health disparities (Warne and Frizzell 2014, Rhoades and Rhoades 2014). Finally, tribal sovereignty, rights, and values have implications for study review and approval, recruitment and consent, return of results, and data stewardship that fail to align with current US federal policy and American individualism (Hull and Wilson 2017).

Yet, the promise of genomic research to improve individual and community health and healthcare have led to calls for cautious movement forward (Claw et al. 2018, Pacheco et al. 2013). Although the capacity for genomic research and medicine to reduce health disparities among minority and underserved populations is often overstated, these approaches may lead to more personalized predictions of disease risk, optimized clinical therapies, and improved health in some populations, including AI/AN people (Burke, Trinidad, and Schenck 2019, West, Blacksher, and Burke 2017, Bayer and Galea 2015). But, because less than 4 percent of research participants come from people of North American Indigenous, African, and Latin American ancestry, clinical tests and treatments may not be as effective in these patient populations as they are in patients of European ancestry, who comprise the overwhelming majority (more than 80 percent) of genomic research participants (Mills and Rahal 2019, Popejoy and Fullerton 2016).

In this context of peril and promise, tribal communities need opportunities for sustained and substantive deliberation about whether and, if so, how they can participate in genomic research in ways that comport with tribal values and protect tribal peoples. That aim is foundational to the Center for the Ethics of Indigenous Genomic Research (CEIGR), a National Institutes of Health Center of Excellence in Ethical, Legal, and Social Implications (ELSI) Research and its three tribal partners: Chickasaw Nation Department of Health's Division of Research and Public Health (CNDRPH), in Ada, Oklahoma; Southcentral Foundation (SCF), an AN tribal health organization based in Anchorage, Alaska; and Missouri Breaks Industries Research, Incorporated (MBIRI), an AI-owned private research organization based in Eagle Butte, South Dakota. In its first phase, CEIGR created the conditions in which members of each of these tribal communities could come together to learn about, discuss and debate, and weigh in on pressing ethical questions raised by genomic research and identify the values that may be in conflict by forgoing or pursuing participation in it. This paper describes the design of three deliberative forums and reports on key evaluation outcomes. The substantive results of each deliberation are reported elsewhere (Hiratsuka et al. 2020, Reedy et al. 2020) or in preparation.

The deliberation design and evaluative outcomes may interest ELSI and deliberation scholars alike for two reasons. First, the use of public deliberation to convene exclusively Indigenous people is novel. Public deliberation, sometimes referred to as democratic deliberation, is an approach to stakeholder engagement that convenes diverse members of the public to provide well-informed, carefully considered input on value-laden issues of collective concern (Abelson et al. 2013, Blacksher et al. 2012, Burkhalter, Gastil, and Kelshaw 2002, Curato 2012, Gastil and Levine 2005, Kim et al. 2009). Researchers have used other approaches (e.g., interviews, surveys) to gather input from AI/AN and Indigenous peoples on issues of genomic research (Bennett and Smith 2007, Garrison 2013, Hudson et al. 2019, Sahota 2014) and deliberative methods have been used to gather input about genomic research in several nations, including in Canada where Indigenous people were included among the participants (Avard et al. 2009, Dry et al. 2017, Lemke, Halverson, and Ross 2012, O'Doherty and Burgess 2009). Researchers have also used deliberative methods to gather input from other marginalized communities (i.e., African American) on ethical issues in genetics policy (Bonham et al. 2009). Finally, deliberative polling has been used to gather input from Indigenous and non-Indigenous people on matters of reconciliation in Australia (Fishkin 2011). We know of only one other US effort to date that has used democratic deliberative engagement to convene exclusively AI/AN people to consider ELSI issues in genomic research (under review).

Second, proponents and opponents of democratic deliberation have raised concerns about its use with diverse communities and those subject to structural inequities. Critics worry that, in conditions of significant background injustice, deliberation's emphasis on reason-giving, argumentation, and consensus may discount cultural differences and silence the voices of minority and socioeconomically marginalized populations (Fung 2005, Chambers 2003, Sanders 1997, Young 2001, Min 2014). Given concerns about diversity and inequity and the lack of a precedent for designing deliberations exclusively with and for tribal communities, we drew on frameworks of "enclave deliberation" and of community-based participatory research (CBPR) to guide our work.

Enclave deliberation and CBPR

Enclave deliberation and CBPR share egalitarian values that served as guideposts for our work. Enclave deliberation convenes people who share a collective history or social experience of disempowerment and resistance, as is the case for Indigenous peoples, in order to create space for them to talk together, separately from others (Karpowitz and Raphael 2014, Raisio and Carson 2014, Abdullah, Karpowitz, and Raphael 2016). The potential benefits of enclave deliberation are several. It can facilitate candor and conversation among those who share structural and cultural experiences and reference points. It can help to cultivate relationships and rapport among participants and identify areas of agreement and disagreement in a context of underlying solidarity. Finally, enclave deliberation can acquaint people with deliberative practices that may differ from their own (e.g., disagreeing in public, disagreeing with an Elder) and build capacity for and potential interest in participation in future deliberative democratic forums (Karpowitz and Raphael 2014, Abdullah, Karpowitz, and Raphael 2016, Raisio and Carson 2014).

Similarly, CBPR is an approach to collaborating with communities subject to social, material, and environmental conditions that compromise their health that aims to engage and incorporate their priorities and views throughout the research process (Horowitz, Robinson, and Seifer 2009, Jones and Wells 2007). CBPR recognizes communities as cultural and social entities with resources, knowledge, and capacities that are integral to research processes and outcomes (Israel et al. 1998). Both CBPR and enclave deliberation seek to empower participants and redress structural inequities by addressing power imbalances and ensuring that voices often sidelined or silenced are heard.

Close, ongoing collaboration with tribal leadership and commitments to shared power and resources, mutual learning, and co-capacity building animated our work at every step of deliberation planning, design, and implementation. Everyone had a lot to learn from each other, beginning with what deliberation is and how it might be appropriately used in and adapted for these unique tribal contexts. Although all the site teams were interested in and committed to using public deliberation, they were not familiar with it as a style of community engagement. In response, a training in deliberative democracy for key investigators and site leadership took place in August 2017. Monthly calls followed the training, which eventually overturned CEIGR's original assumption that all sites would take up the same deliberative question(s). Addressing issues related to return of results, for example, did not make sense for partners not working within health care delivery systems. Each site would instead take up a distinct deliberative question(s) that reflected site-specific concerns about and relationship to genomic research (see Table 1).

A second in-person planning meeting sought to translate democratic deliberative theory into practice and helped to (1) clarify what deliberation might look in these tribal settings (e.g., framing of questions, approaches to educational materials, use of experts and case scenarios, facilitation style) and (2) forge agreement on a subset of pre- and post-deliberation survey questions. Importantly, this meeting identified three cultural adaptations that would be needed, the first of which concerned facilitation. Deliberations often involve a facilitator to ensure respectful discussion and equal speaking opportunities (Black and Wiederhold 2014). Recognizing that the engagement approach, specific deliberative activities (e.g., ranking

exercises), and facilitation style would be largely unfamiliar to participants, we opted to use a co-facilitation model. One facilitator would be from and familiar to the community ("community-placed" facilitator) while the second facilitator would be experienced in deliberation design and facilitation and consistent across all three deliberations ("deliberation facilitator"). Greater detail about this approach and its utility are described, respectively, in the Deliberation Design and Methods and Discussion sections.

A second cultural adaptation was reserving space at the beginning and end of the deliberative events for customary and culturally appropriate oratory expressions at Indigenous gatherings. All agreed that each deliberation should open and close with prayer and blessing led by an Elder from each community. This long-held tradition in these particular tribal communities would, everyone agreed, help normalize a new experience for the deliberants as well as orient them to the importance, potential sensitivities, and responsibilities involved in the deliberations.

This in-person planning meeting also identified cultural differences among the sites, which led to a third adaptation and a new approach to planning. First, all case scenarios would need to be developed in close collaboration with local site teams to ensure appropriate language, cultural nuance, and locality, about which we say more in the Deliberation Design and Methods and Discussion sections. Second, moving forward, each site would work independently with the core deliberation team to design its event.

Importantly, these community-driven processes were enabled by a consortium grounded in CBPR values. From its inception, CEIGR worked intentionally to create a trusting environment and positive working relationships. To those ends, the consortium provided resources (e.g., people, time, money) to overcome initial wariness of a new research method, enabling investigators (academic and community-based) considerable planning time to learn about deliberation and how to adapt it for use in these tribal communities. The strategic use of in-person meetings when introducing or incorporating new members of the team and forging agreement on key considerations helped investigators learn about and trust one another. Solid working relationships formed well before the deliberative events took place. Flexibility at the leadership level and deference to tribal site leadership to formulate distinctive deliberative questions suited to their respective communities was imperative.

CEIGR's 4-year funding timeline was also an essential ingredient in helping to create trustworthy relationships and processes. Research timeframes are an oft-cited challenge to building trustworthy partnerships (Minkler et al. 2003). The good working relationships and adequate timeline also enabled the sites to learn from one another. Planned sequentially, each successive event benefited from the lessons learned from the planning and execution of the previous deliberation(s). All team members involved in their planning were encouraged to share candidly about what worked well and what did not. The timeline enabled us to learn from one another and grow as investigators *together*.

None of the deliberation planning and design work began, however, until tribal leadership and Elders at each site approved the use of this unfamiliar form of engagement. In keeping with standards of conducting research with sovereign tribal nations, community-placed lead

investigators sought approval for this project, using site-specific review channels. Once community-level reviews were completed, the research protocol for each deliberation was reviewed and approved by boards at all sites: Alaska Area Institutional Review Board, the Chickasaw Nation Department of Health Institutional Review Board, and the Great Plains Institutional Review Board. The University of Oklahoma Institutional Review Board deferred all decisions to the appropriate tribal institutional review boards.

Deliberation design and methods

Recruitment

Best practices in deliberation suggest that gatherings should endeavor to ensure a balanced pool of deliberants that represents the diversity of the community to which they belong in hopes that a pluralism of perspectives will obtain (Gastil, Knobloch, and Kelly 2013, Knobloch et al. 2013). Given the modest size of face-to-face deliberations, achieving a sample representative of a larger population, in the same way a large survey can, is an oft-noted challenge (Collingwood and Reedy 2012, Siu and Stanisevski 2012). Only AI/AN people were recruited and those who participated were not necessarily politically and statistically representative of their tribal communities, due to the relatively small size of the events (15–21 per site). However, sites sought gender balance, and diversity in age, education levels, place of residence, and experience with the health system and research, believing these differences would support a pluralism of perspectives.

Recruitment at each site also faced challenges related to geography, e.g., populations dispersed over large geographical areas, and the potential difficulty of recruiting people who could take part in a day and a half event. Each site used recruitment techniques that had proven effective at their sites in the past and would likely generate a diverse deliberant pool.

Both CNDRPH and SCF employed a convenience sampling frame to recruit AI/AN adults. CNDRPH posted flyers at its healthcare facilities and disseminated an email posting via a secure distribution list to recruit AI individuals enrolled in any federally recognized tribe eligible to receive healthcare services within the Chickasaw Nation (CN) health facilities located across the tribe’s 13-county jurisdiction. CNDRPH also targeted community centers in four CN communities in order to oversample for representation of CN citizens living in diverse communities across tribal boundaries. SCF recruited in person in the lobby of its Primary Care Center. SCF limited its recruitment to adults who received services there in the last two years and were able to participate in a day-and-a-half deliberation.

MBIRI employed a two-tiered approach that, given its thirty-plus-years history of recruitment for research studies in the Cheyenne River Sioux Tribe (CRST), sought to minimize repeated sampling of past participants. Similar to CNDRPH and SCF, MBIRI conveniently sampled from tribal health events at each of the six CRST districts, followed by an additional step purposively to select the final deliberants based on screening questionnaire responses to promote maximum variation of backgrounds and perspectives. Eligibility was restricted to enrolled CRST members, and potential deliberants were stratified according to self-defined descriptors such as district, age, knowledge and interest in genetics.

Deliberation structure

The deliberations were conducted between September 2018 and September 2019: CNDRPH on September 14–15, 2018; SCF on January 14–15, 2019; and MBIRI on September 13–14, 2019. Given the lack of a blueprint for how to design deliberations adapted to tribal contexts and not knowing in advance whether and to what degree each deliberation might need to vary in response to local interests, customs, and values, a full review of the design elements could only be done post hoc. As it turned out, the only major difference among the forums were the questions addressed and the sites' respective use of their questions for polling; all other design elements were the same (Table 1).

Site-specific content

The core deliberation team worked with key personnel at each site to identify and formulate questions about genomic research that would benefit from community input. All three sites used a small set of questions to frame and structure the deliberations (Table 1). CNDRPH and MBIRI polled deliberants only on those questions during the events. SCF developed 18 questions about return of genetic results and polled deliberants on those questions twice during and once after deliberation using a paper survey (Hiratsuka et al. 2020).

Shared structural elements

The design of the deliberations aimed to achieve key deliberative goals (e.g., equal opportunities for speaking, informed and careful consideration of issues) while remaining open to reimagining those commitments to ensure the events suited each tribal setting.

Duration. Deliberative methods vary considerably in length from 2.5 hours to multiple hours or days over several weeks (Carman et al. 2015). These 1.5 day (10 hours total) deliberations sought to promote learning, discussion and exchange, and careful consideration of the issues, key features of quality deliberation (Blacksher et al. 2012, Burkhalter, Gastil, and Kelshaw 2002), as well as be practicable in these communities and manageable for budgets. Convening the deliberation over two days enabled overnight reflection, rapport building, and the use of varied discussion and value elicitation techniques (e.g., small group discussions grounded in case scenarios and polling exercises in which participants could stand up, move around, and interact while casting ballots or ranking priorities), which supported varied learning and discursive styles. These techniques and the 1.5 day duration sought to enhance inclusiveness and deepen deliberants' understanding of their own and others' perspectives.

Size. The number of participants in a face-to-face deliberation can vary, with anywhere between 12 and 25 participants being common (Carman et al. 2014). These deliberations ranged from 15 to 21 participants, a number small enough to enable opportunities for all to speak, yet large enough that variation in perspectives is likely to obtain.

Co-Facilitation Structure. The co-facilitation model—a "community-placed" and a "deliberation" facilitator—created continuity between the community and local customs while also building a bridge to this new form of engagement and set of researchers. The community-placed facilitator at all three sites delivered the opening (welcome, purpose of and ground rules for deliberation) and closing remarks, integrating local customs, language,

and communication styles with norms of deliberative practice. For example, deliberants were reminded to be mindful that all should have the opportunity to speak and to listen when others are talking. The deliberative facilitator introduced the deliberative questions and initial probing and led deliberants in voting or ranking activities. Other activities were split between them.

Information Base and Role of Experts. Deliberations aim to be grounded in an information base that is sufficient to support knowledge gain but does not overwhelm deliberants and is factual and neutral, informing reasoning without unduly influencing the outcomes of deliberants' reasoning (Goold et al. 2005, Gastil 2008, MacLean and Burgess 2010). It is common to send printed briefing packets about topics to be discussed and the purpose of deliberation in advance; experts may also present on the subject matter during the event. All three sites agreed that the best strategy for delivering content to their respective communities was to have experts present educational content in person during the event. Individuals with active affiliations and relationships in each community were chosen with the goal of engendering a trustful atmosphere. In-person interactions lay the foundation for transparent research practices and are an expectation in many AI/AN contexts (Beans et al. 2018, Claw et al. 2018, Christopher et al. 2008, Weaver 1997, Tuhiwai Smith 2020). The format of the experts' presentations differed across sites, based on each site's assessment of appropriate methods for presenting information to their respective communities (e.g., presentations with PowerPoint slides at two sites, an oral presentation without slides at one site).

Once experts and formats were chosen, the core deliberation team devoted considerable time discussing the expert role and working with experts to develop the content of each presentation to ensure it provided an adequate information base for the deliberative questions and was neutral in its framing (Friedman 2007). Although questions varied across sites, some informational elements were common to all three (i.e., what genomic research entails). To ensure neutral framing, presentations of what genomic research is included not only a plain language discussion of the science involved, but a balanced representation of widely recognized potential benefits and risks of genomic research. The team reviewed presentation language with an eye to not overstating either the promises or perils of genomic research for AI/AN communities. Additionally, in prepping the experts for their role, the core deliberation team emphasized that they were there to supply information, not to weigh in on the deliberations. Experts were also prepared for the possibility that deliberants might ask them to do so and were offered approaches for how to respond to such requests in such instances.

Case Scenarios. Case scenarios were used across all sites to ground small group discussions. While varied to reflect each site's specific content, the scenarios depicted potential concerns and benefits of genomic research specific to AI/AN communities.

A member of the deliberation team, who is himself AI and a doctoral student in Anthropology, worked closely with the local site teams to draft the scenarios and ensure cultural nuance and locality in their content. Iterative discussions and drafts sought to develop language relevant to the topic that was also respectful and, when possible, familiar to local participants. For example, the scenarios referenced familiar institutions and social

activities relevant to each site. One scenario presented at two sites, for example, had a situation in which an individual had attended a doctor's visit. Because the healthcare delivery systems differed at each site and the participants would be familiar with those differences, site-specific terminology was used to describe these systems. The social event of the powwow was referenced in a scenario at one site but not the other two, because this type of social event is common to some but not all AI/AN communities. Additionally, we chose scientific verbiage carefully and used plain language explanations to avoid confusion or misunderstanding, resulting in scenarios with a reading and comprehension level that was accessible to all participants in attendance.

Finally, the case scenarios foregrounded real-world issues meaningful to the AI/AN participants. Issues addressed ranged from concerns around genomics and individual health, genomics and community privacy, the impact of genomics on Native American identity to the potential of big data to address community concerns. For example, one scenario challenged the participants to discuss the potential of genomics to assist in the recovery of murdered and missing Indigenous women. Because perspectives on the potential usefulness of genomic research and data vary widely in AI/AN communities, the scenarios were tailored to encourage wide ranging and rich discussions.

Evaluation. We took a global (versus cross-site comparative) approach to evaluation to determine whether an adapted approach to deliberation that incorporated culturally appropriate norms and customs of engagement would also meet standard deliberative criteria. It did, as we show and elaborate on, respectively, in the Results and Discussion sections. This global approach was appropriate given that little to nothing is yet known about how best to adapt and use deliberative approaches to convene exclusively tribal community members and our fundamental question was whether the forums would meet established criteria for deliberation. Future manuscripts may explore site differences in a comparative approach, grappling at that time with issues of the measurement of deliberative quality across cultures more explicitly.

We used two approaches to assessing deliberative quality (Appendix). Pre- and post-deliberation surveys with an identical core set of questions were completed by deliberants at each site. A pre-deliberation survey captured demographic information to assess deliberant diversity; the post-deliberation survey posed 15 questions to gauge deliberants' perceptions of the quality of the deliberations. The post-deliberation measures are widely used criteria of deliberative quality, such as whether deliberants felt the information presented was clear, they had an equal opportunity to speak, their opinions were respected even when others disagreed, deliberation impacted their views, and whether they valued participating (Bonham et al. 2009, Goold et al. 2012).

A second form of evaluation assessed social and analytic components of deliberation based on prior theoretical and empirical analysis (Gastil 2008, Knobloch et al. 2013), and was conducted by an observer experienced at evaluating deliberations using well-established deliberative criteria reflected in a rubric; see Table 2 (Gastil et al. 2016, Reedy and Anderson 2019). This analysis involved the observer monitoring each deliberative event in its entirety and taking detailed field notes about the proceedings from the perspective of deliberative

quality, as well as using a real-time observation scheme for noting the prominence of several important components of robust deliberation (described in more detail below). In addition, the observer discussed his observations with other members of the research team present to develop a shared sense of the performance of the process (Knobloch et al. 2013). The observer, based on field notes from and observations of the process, rated the deliberative process on several social process markers of good deliberation, such as equal opportunities for participants to speak, apparent respect between participants, mutual comprehension of others' comments, and consideration of others' ideas and arguments; and on several analytic process markers of good deliberation, including the building of a strong base of information about the topic, analysis of the underlying values related to the topic, consideration of pros and cons of various policy choices, and evaluation of potential solutions. In addition, several markers of a good approach by the deliberation organizers were also analyzed by the observer, such as unbiased framing of issues, representation of diversity within the community (either through the diversity of participants or views shared and represented in their comments), clearly defined tasks for the deliberants, and opportunities for the deliberants to give feedback about the process and the topic. Each of these indicators for a robust deliberation were scored on their prominence or reoccurrence in each major segment of the event (i.e., Friday evening, Saturday morning, and Saturday afternoon), with scores ranging from zero (meaning they never occurred or were not found in that segment) to five (meaning they were often/always occurring); see Table 2. Those markers that did not apply in a particular segment (e.g., potential solutions were not introduced until day two) were noted with N/A.

We also reviewed key segments of the transcripts for evidence of participants' views of the deliberative process. The second day of the deliberations all began with a "morning debrief" and closed with "concluding thoughts," during which participants were invited to share any observations about the deliberations and about the process itself, including what could have been done differently or better. We did not conduct a formal qualitative analysis of these relatively brief stretches of discussion. Instead, three members of the research team reviewed these portions of the transcript separately to identify comments that captured indicators of good deliberation, after which we discussed and decided as a team which quotes best illustrated key indicators of good deliberation.

Results

Demographics

A total of 52 individuals participated in the deliberations across all three sites. CNDRPH had 16; SCF, 21; and MBIRI, 15. Deliberants at all sites reported being of AI/AN heritage alone or in combination with another race and 94% reported not being of Spanish, Hispanic or Latino ethnicity. Participant age ranged from 22–74. At all sites, the majority (65%) of participants self-identified as female. Participants ranged in their self-reported highest completed education level from some high school to post-baccalaureate degree completion, with 75% of participants across all sites reporting completing some college or a 2-year degree. At all sites, almost a third of all participants reported speaking a language other than English at home.

Post-Deliberation survey: deliberant perceptions of deliberative quality

At the conclusion of each deliberation, participants completed a 15-item survey on perceptions and impact of the deliberation event. Deliberants across all three sites reported feeling interested during group discussion; that even when people disagreed, they respected each other's opinion; that information was presented in a manner that was clear and easy to understand; that facilitators made sure all opinions were considered; and that the event was well organized. Overall, deliberants at all sites reported feeling like their opinion was respected by other deliberants with only one participant at one site strongly disagreeing. Nearly all of the deliberation participants across the sites reported that they spoke as much as they wanted during the deliberation (97%), felt that the purpose was clear (94%); and thought there was enough time to fully discuss all the relevant issues (96%). In agreement with the qualitative data and the polling questions, the majority (73%) agreed that the discussion led them to change some of their opinions and nearly all (97%) thought the group discussion affected their opinions. The impact of educational presentations on deliberant opinions varied across sites, from "not at all" to "a lot." Finally, the majority of participants across all sites felt strongly that deliberative forums should be used to gather community members' views.

Social and analytic elements: observer evaluation of deliberative quality

All three events performed very well on the criteria for deliberation rated by the observer, indicating that all three represented robust, well-executed deliberative forums (Table 2). The events had segments in which certain criteria were not applicable due to the design of those portions of the events; however, those criteria were addressed at some point during the 1.5 day event (e.g., waiting until Day 2 to discuss potential solutions and policy outcomes). All three events performed very well on the social components of deliberation, such as expressing mutual respect, authentically participating, sharing personal knowledge and experience, and considering other ideas.

The events also performed very well on the analytic components. All three events had positive contributions to a good information base from the expert presenters, and information shared in the groups was generally very accurate and well-supported. As noted above, there were also times at which a wide range of potential solutions was not addressed in the deliberation, or may have received comparatively less attention, but those were choices of design, and these areas were addressed in later segments of the event.

One criterion in which all three events performed somewhat less well was in evaluating evidence, which was present but observed somewhat less often than other markers of a strong analytic process. However, when information was discussed, the evidence used was very accurate in all the forums, based on the assessments of the deliberative observer which were then checked against the observations of other research team members present. One factor that may have contributed to the evaluation of evidence being less present in these deliberations is that the information presented—e.g., what genomic research is, tribal research review processes at each site, what a biobank is—did not play a pivotal role in the normative questions posed at each site. Although questions about, for example, whether the potential risks of genomic research outweigh its potential benefits do turn on an

understanding of what genomic research entails and what the consequent risks and benefits are or might be, deliberants demonstrated knowledge of those realities and potentialities and focused on what they – as a community – should or should not do about them. These deliberations were arguably less like those focused on whether, for example, a particular chemical should be banned from agricultural use because it poses a health hazard, making the scientific evidence of its relative safety imperative to the normative question at hand (Knobloch et al. 2013). Overall, the forums encouraged deliberants to discuss and understand the issues with respect to their ethical implications for AI/AN peoples.

Participant experience

The following quotes illustrate the value deliberants placed on the opportunity to learn about an important issue directly relevant to them and to engage in substantive dialog with others in their tribal community. These quotes supply some supplemental evidence that key goals of deliberation and enclave deliberation were achieved. First, the following statements suggest that deliberants gained deeper insight into their own and others' views.

> "I would say I feel more informed about the opinion I did have before. It made me consider things I hadn't thought about before, but it didn't change my mind about it."
>
> (CNDRPH deliberant)

> "I think just learning a lot of different perspectives is what I've taken away. Cause there are things that [man's name] has shared from the multiple groups that I never would have thought about in a million years."
>
> (SCF deliberant)

> "…hearing everybody's thoughts, it kind of sways you a little bit. But I think in the end it eventually reaffirmed what I initially felt about it. Even though you hear other people's opinions on things."
>
> (CNDRPH deliberant)

> "I like coming to research groups and I would like to be part of more. It's very eye opening. I knew just a little bit about genomics but seeing everybody on a different level of where they [are] versus where I was … you know, not everybody is going to be on my same page and that's great because then it gives you more insight and more information. It's great."
>
> (SCF deliberant)

Second, the following quote is representative of comments we heard during and often after the deliberations suggesting that participants especially appreciated the collective experience of talking together with members of their tribe.

> "But even just sitting in or taking part in this discussion, I'm kind of glad I know more about what other people think just because, I don't know, it just feels good to know …. I feel like part of the group."
>
> (SCF deliberant)

Finally, deliberants strongly endorsed this approach to gathering input in their communities and expressed an interest in participating in future deliberations.

> "I feel privileged to be able to come here to be able to participate in this. I got to meet really cool people…but I got more of an understanding about this, so I just feel really lucky to be able to be here. I just appreciate it. Thank you. And I want to participate in more if there is some."
>
> (SCF deliberant)

> "I couldn't quit thinking. Couldn't go to sleep and then got up at 3:00 thinking…"
>
> (CNDRPH deliberant) (this prompted others in the room to recount the conversations they had with one another during their car rides home and back again the second day)

Deliberation report

A two-page deliberation report was prepared and draft versions were sent to deliberants for input. Final reports were sent to the deliberants and to tribal leadership within 6 weeks of the events as a formal record of the event and its outcomes. These local deliberative reports have enabled tribal leadership to reflect on their members' views and values about complex ethical issues in genomic research that are not well described in any population, let alone small tribal populations that participated in the three deliberations.

Discussion

This research project is, to our knowledge, the first to design and implement deliberative public engagement exclusively for and with tribal citizens on ethical issues in genomic research. Our results suggest not only that deliberative approaches can be culturally adapted for use in tribal communities with good outcomes, but also that the processes used to plan these events and the deliberation design implemented in all three sites have broad applicability and transferability to research seeking input from AI/AN peoples on complex, value-laden questions. We attribute the relative success of these forums to several factors, the first of which we have already described in some detail—the community-centered values that guided CEIGR leadership in the daily operations of the consortium.

Cultural adaptations also played pivotal roles. The co-facilitator model and development of culturally nuanced case scenarios proved especially important. The community-placed facilitator set the tone early in the deliberation, welcoming people, explaining the purpose of the research project, and ground rules for deliberation, the latter of which was infused with local nuance. The community-placed facilitators' familiarity with the context and people helped break the ice, with appropriate moments of humor, in preparation for undertaking what to many may have seemed daunting—a day and a half "deliberation." The ground rules for deliberation incorporated both deliberative and community norms, often drawing on familiar language, family relations, and colloquialisms. For example, community facilitators introduced themselves by situating their stories in relation to specific familial, geographic, and tribal histories, thereby establishing familiar ways of relating to one another based on

specific community customs. All three community facilitators also used humor effectively to mitigate tension and lighten the mood (Kongerslev 2020, Garrett et al. 2005, Johansen 2003). One community-placed facilitator, for example, noted the importance of starting on time after breaks and asked deliberants to not "run on Indian time," which brought a burst of collective laughter. Community-placed facilitators also encouraged the practice of taking home leftover food. This customary practice is a subtle but poignant indicator of familiarity that establishes a sense of communal hospitality.

The community-placed facilitators also successfully navigated their dual roles as research team members and community members. For example, as discussion on the end of day 1 began to conclude at one site, the community-placed facilitator acknowledged the powerful contributions of those present and remarked, "This (process) makes me proud to be from here."

The value-added of site-specific case scenarios—reflecting distinct relationships to genomic research, exposures to research harms, among other salient social and cultural variations—was borne out in the deliberations. Observers of the small group discussions noted rich discussions in which participants from any background were able to speak about a range of topics and to express deeply held values. The scenarios were particularly effective in motivating participation from those who spoke up less in large group discussions. At no point during any of the small group discussions was there a shortage of conversation among deliberants; instead, responses to the scenarios prompted lively and sometimes deeply personal commentary that often spilled over into the plenary discussions.

Finally, we believe the relative success of the forums is attributable to what deliberation is in the base case and the inclusion of only AI/AN people ("enclave deliberations"). To the first point, sound public deliberation creates conditions in which all participants can learn and talk together with mutual respect (Abelson et al. 2013, Carman et al. 2015, Carpini, Cook, and Jacobs 2004, Gastil, Bacci, and Dollinger 2010, Goold et al. 2005, Wang et al. 2015). Deliberants are situated as experts in their own right; their views and values are being solicited on a topic of direct relevance to their well-being and that of their communities. These goals and values stand in stark contrast to a history of mistreatment of AI/AN people by the US federal government, as well as a history of exploitation by some in the research enterprise, and that contrast may help explain deliberants' positive appraisals of these events.

The opportunity to deliberate candidly with only AI/AN community members seemed to be reflected in comments where deliberants talked freely about their comfort or discomfort with non-AI/AN researchers and companies, as reflected in the following exchange about biobanks. For example:

> Participant 1 asks Participant 2: "Say we [the tribe] hired somebody…would you be more comfortable going with a non-Indian firm or entity or another tribe? Or would it even be a factor?"
>
> Participant 2: "I never thought about that. I like that option."
>
> Participant 3: Can I add to that? (Participant 3 went on expressed the view that "Natives working native is more comforting."

(MBIRI deliberants)

There is some evidence that members of minority and marginalized groups may find deliberation a particularly valuable experience (Wang et al. 2015). Although the grounds for these findings are not established, it stands to reason that social groups that have been or are mistreated, ignored, or otherwise marginalized from a society's mainstream deliberative processes, which is the case for AI/AN peoples, might find it especially meaningful to participate in a carefully designed event that solicits input for purposes of informing tribal leadership and, ultimately, leadership at the National Institutes of Health. These deliberative events may, then, have represented a rare opportunity to weigh in on a topic of special concern to AI/AN communities: the ethical conduct of genomic research with AI/AN peoples. In this and other ways already described, public deliberation's central goal to create the conditions in which all participants are heard and respected, even in the context of disagreement, may be especially appreciated by people who too frequently have been ignored or disrespected by majority powers. Such deliberations may also bring more accountability, legitimacy, and transparency to decision-making and governance structures in an era of genomic research and medicine (Button and Ryfe 2005, O'Doherty, Hawkins, and Burgess 2012).

Beyond the evaluative results from the post-deliberation surveys, the expert observer datasets, and direct comments, deliberants seemed to signal their appreciation of the events in other ways. At one site, a deliberant brought traditional food to the event on the second day, despite provision of ample food and snacks served at the event. During lunches, designated as 'no work' times, many deliberants joined investigators who were often eating lunch at a separate table or invited investigators to take short walks with them on breaks. A couple of deliberants at one event invited the research team to attend community events at later dates, and others introduced investigators to their family and friends who came to transport deliberants. At all events, spontaneous hugging occurred at the end of the deliberation event between the deliberants and the deliberation team, all of whom were new to the community. These activities no doubt reflected the hospitality and good will of the deliberants, but they may also speak to their appreciation of the deliberation events.

There may, however, be another explanation for deliberants' generally favorable views of this deliberative approach. While distinct in practice and social organization, some Indigenous nations have historically governed themselves in communal ways that valued kinship, reciprocity, and consensus decision-making (Lee 2013, Korovkin 2001). Thus, a deliberative approach wherein community members are the experts and decision-makers may be culturally consistent. The culturally adapted design allowed for social dynamics and oratory customs in the discussion and created a space for everyone to participate in ways that were perceived as egalitarian and respectful. For example, at one site deliberants appeared to engage in a practice of deferring extra time and respect for Elders to speak on matters of cultural knowledge and traditions, while the Elders were careful to then acknowledge the specific expertise and experiences of other deliberants.

Limitations of this approach need also to be noted. As with other research methods, deliberants were individuals who could willingly participate in the research, and, in the case

of these deliberations, offer a minimum of a day and a half of their time, and more for those who had considerable travel time. The nature of self-selected volunteers lends itself to a type of response bias in that individuals who are more willing to engage in research may also have more positive perspectives than non-participants. Also, the expert presenters were intentionally chosen because of their familiarity to the deliberants' community in hopes of cultivating a trustful atmosphere. While this approach seemed successful in generating trust, in retrospect, we do not know whether this design choice had unintended and unmeasurable effects (i.e., deliberants overly trusted a familiar source or were reluctant to ask uncomfortable questions) and whether similar effects would be seen if this technique were applied in a different community or context.

Conclusion

In summary, participant perceptions and statements, external observer datasets, and direct investigator observations and experiences depict three deliberations that offered intensive conversation experiences in which participants felt connected and respected and had expectations that their views on research conduct are valued and would be heard. The views, observations, and values shared by participants in the deliberations enabled richer, more in-depth insight into participant perspectives than what can be achieved by surveys, interviews, and focus groups. Early worries that the duration of the event and intensity and complexity of topic might burden participants proved not to be the case. Many participants commented that more such events should be held, and they made quick and sophisticated use of the ideas introduced (Hiratsuka et al. 2020, Reedy et al.. 2020).

Designing deliberations for specific tribal contexts requires a purposeful approach to engagement with AI/AN communities. Tailoring deliberations to local contexts centers community structures and leadership (e.g., recruitment techniques, leadership involvement in development of research questions, equity in research process), and the specific communities in which the deliberation will take place. The events confirmed the importance of the meaningful involvement of AI/AN tribes, their staff, and their community members in discussion of policy and practice that impact AI/AN communities. Deliberation as a method of engagement can provide an equitable approach to gathering needed community-level data for policy makers and decision-makers at various levels that otherwise might not be captured.

Acknowledgements

We would like to thank those who participated in the deliberations who made this work possible and for reasons of confidentiality remain anonymous. Deliberations are only as good as the people who choose to take time out of their busy lives to come together, listen, talk, and learn from one another. We are grateful for what we learned from each of them.

Funding

This research was supported by the National Human Genome Research Institute of the National Institutes of Health, grant numbers RMHG009042 (P.G.S.), R01HG009500 (V.Y.H.), and R25HG010132 (J.W.B.) and the National Institute of General Medical Services, Native American Research Centers for Health (NARCH) S06GM123545 (V.Y.H.) and IDeA-CTR grant in Oklahoma, U54GM104938 (P.G.S.). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Table 1.

Deliberation design.

Site-Specific Content
CNDRPH – Participation in Genomic Research
• Do the potential benefits outweigh the potential risks of tribal participation in genetic studies, e.g., All of Us?
• Do the potential benefits outweigh the potential risks of tribal participation in biobanks?
SCF – Return of Results
• What are the potential benefits and harms of genetic testing and return of results?
• What are the potential benefits and harms of direct-to-consumer testing?
MBIRI – Data Governance
• What types of data should be protected?
• What form of data governance do we trust?
• What does good tribal data governance look like to us?
Shared Structural Features
• Length of deliberation: 1.5 days with shared meals
• Number of deliberants: 15 to 21 deliberants
• Structure of facilitation: one community-placed facilitator, one deliberation facilitator
• Ground rules for discussion that incorporate culturally familiar practices and language; deliberations opened and closed with prayer led by a traditional leader
• No advance educational materials; experts present balanced plain language information during events
• Agenda: welcome, introductions, ground rules; expert presentation and Q&A; whole group discussion followed by small group discussions with case scenarios; flip charts to track deliberation themes and deliberant “check-ins” to ensure accuracy of themes; polling and voting exercises to assess deliberant views and priorities;
• Pre- and post-deliberation survey;
• All participants paid $25/hr stipend for participating in 1.5 day event
• Deliberation report for deliberants and tribal leadership, with deliberant review and input prior to finalizing
• Consistent deliberation team members to carry out range of activities

Table 2.

Deliberation event assessment*.

		"A"			"B"			"C"		
		Day 1 PM	**Day 2 AM**	**Day 2 PM**	**Day 1 PM**	**Day 2 AM**	**Day 2 PM**	**Day 1 PM**	**Day 2 AM**	**Day 2 PM**
Analytic	Information base: Participants	4	4	4	3	5	5	3	4	4
	Information base: Experts	4	N/A	N/A	3	4	5	5	4	4
	Info accuracy and support	4	3	4	4	4	4	4	4	4
	Prioritize values	3	5	4	4	5	5	4	4	5
	Range of solutions	N/A	N/A	4	4	4	5	N/A	5	5
	Evaluating evidence	N/A	3	3	3	3	4	N/A	4	4
	Weigh pros and cons	4	5	5	3	4	4	4	4	5
Social	Equal speaking opportunity	5	4	5	5	4	4	5	3	4
	Sharing personal experience	5	5	4	5	5	5	4	5	5
	Sharing personal knowledge	4	5	4	4	5	5	5	5	5
	Mutual comprehension	5	5	4	4	4	4	4	4	4
	Consider other ideas	5	5	5	4	4	4	4	4	4
	Authentic participation	4	4	5	5	5	5	5	5	4
	Mutual respect	5	4	5	5	5	5	5	5	5
Approach	Unbiased framing	4	5	5	3	4	4	5	5	5
	Representativeness	5	5	5	3	4	4	5	5	5
	Clearly defined tasks	3	4	4	5	5	5	4	4	4
	Opportunities for feedback	5	4	5	5	5	5	4	5	4
	Community/Group identity	N/A	5	5	5	5	5	5	5	5

*Tribal site names have been anonymized and are not listed in the order the events occurred.