Wrestling with Public Input on an Ethical Analysis of Scientific Research

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It is increasingly well accepted that engaging members of the public is critical to ensuring that research addresses the needs, and is consistent with the values, of the people it is meant to serve. Members of the public have lived experiences, values, and interests that can and should inform the research that will purportedly benefit or might harm them. There are several approaches to engaging the public and communities in research, and these approaches vary in terms of how long the engagement runs and in the extent to which these groups are engaged as participants who are studied or as partners in research. Engagement on either or both of these axes can be low (as with focus groups or surveys that involve talking to a subset of people about a specific project), moderate (as in partnership with a community organization that will assist with implementation), high (as when a community advisory board [CAB] offers feedback on various study processes or a multiday deliberative-engagement event), or maximal (as in community-based participatory research in which the community and researcher act in partnership to jointly explore a problem).

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Although bioethicists frequently call for empirical researchers to engage the public in their research, they do not typically engage the public in their own *normative* scholarship. To be clear, empirical bioethics research frequently elicits the views of the public about various bioethics topics—most typically, through surveys, interviews, and focus groups—and normative bioethics research often uses the results of public engagements as important inputs into normative or prescriptive scholarship.[1] But is it equally important for those engaged in normative and other humanistic scholarship to engage members of the public in a more ongoing way and on equal footing as they do their conceptual and ethical analysis?

In this article, we describe our fledgling effort to integrate community perspectives into the work of our normative research project Wrestling with Social and Behavioral Genomics.[2] Specifically, we describe our creation of an eleven-member *community sounding board* (CSB) comprised of members of the public from across the United States. If ever there was an area of normative scholarship that warranted input from members of the public, it would seem to be scholarship concerning the ethics of social and behavioral genomics (SBG) research. After all, it is often members of the public—in particular, those with relatively less income or education,

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those with disabilities, sexual and gender minorities, racialized-minoritized communities, and those who have been impacted by the criminal justice system—who have experienced harms in the wake of scientific interest in genetic differences and human behavior.

We begin by describing our motivations for creating the CSB and its members' motivations for joining. We then describe the recruitment process, the final composition of the CSB, and the five virtual sessions and ad hoc consultations in which CSB members took part. We conclude by reflecting on the lessons learned from this engagement, including its potential benefits and limitations. We intend this article to help other normative scholars reflect on what might, and might not, be gained by including members of the public in ethics and other humanistic discussions about controversial scientific research.

Background and Motivation

Originally, Wrestling with Social and Behavioral Genomics did not include plans to work with members of the public. The two of us serving as co-principal investigators (co-PIs), Erik Parens and Michelle Meyer, intended to follow the familiar bioethical approach of bringing different academic perspectives to bear upon an emerging line of scientific research. In selecting members, they focused on forming an academic working group (AWG) comprised of scholars with significantly different perspectives on SBG research and diverse disciplinary backgrounds and life experiences. Specifically, they included economists, psychologists, sociologists, and geneticists engaged in SBG research who were enthusiastic about the science and its potential, along with scholars in history, science, technology, and society studies, law, and bioethics who were concerned about the risks. The AWG was also diverse in terms of racial or ethnic background, gender, and sexual orientation.

Although the AWG achieved some forms of diversity, a reviewer of the grant proposal wondered how the AWG would hear from those "with the most to lose" from SBG research. Parens and Meyer, moreover, recognized that there remained homogeneity among AWG members with respect to educational attainment and thus class privilege. With the funders' encouragement, part of the project budget was therefore redirected to engaging members of the public who represented communities that had historically been harmed by genetics research or had life perspectives or experiences missing from the AWG.

Initially, the co-PIs intended that engagement to take the more traditional forms of survey, semistructured-interview, or focus-group research. They planned to engage the AWG, once formed, in a discussion of what we hoped to learn from members of the public, or particular communities, and the best research methods for eliciting those data. Once members of the AWG convened, however, some suggested that something approximating a CAB would be more appropriate, and plans for empirical research were abandoned.

To design the CSB, to recruit its members, and to directly engage with the CSB members, Parens and Meyer formed a subcommittee comprised of AWG members (all the authors of this essay, that is). Chaired by Daphne Oluwaseun Martschenko, the subcommittee met regularly over the course of two years to plan engagement with the CSB. The subcommittee included both enthusiasts about and critics of SBG research—and people who bridled at being called either.

The subcommittee had no single template or precedent as it created the CSB. We were aware of the CAB model that medical researchers use increasingly often.[3] In the CAB model, community members are sometimes actively involved in the creation and execution of medical research aimed at achieving an agreed-upon goal. For instance, they might help decide which research questions should be addressed or how data should be collected. In other cases, CABs serve as liaisons between the community and the research team and provide advice about or even binding oversight of empirical research (such as making determinations about appropriate uses of biospecimens or data) but do not act as investigators themselves.

However, because our project on social and behavioral genomics was normative, not empirical, neither version of the CAB model was straightforwardly applicable. The risks and potential benefits of SBG research were at issue, but the AWG itself was not conducting SBG research (nor any other empirical research) that CSB members might join as investigators. Nor was there any obvious role for research oversight by the CSB; the AWG's recommendations themselves about whether or how SBG research should

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Box 1. AWG's Commitments to the CSB

- Set clear ground rules and expectations for how the CSB and the AWG will collaborate (that is, for the scope of work and the working relationship).
- Explain why the CSB brings value to this discussion; more specifically, during recruitment, explain why individuals were invited to join the group (for example, their expertise, experience, or community connection).
- Clarify that dialogue, not consensus, is the goal.
- Explain, in an accessible manner, what social and behavioral genomics is and why people conduct social and behavioral genomics research.
- Demonstrate that the AWG is taking the CSB's advice seriously and sometimes, as a result, altering the research—and if not, why.
- Consciously and consistently ask CSB members about what would be most useful/beneficial to them.
- Be mindful of where CSB members are in their lives and be careful not to ask too much of them.

be conducted, like most products of ethical reflection by scholars, would not be binding on anyone. Nor could we adequately compensate our CSB members for the amount of time that participating in something approximating a true CAB would require. We then chose to call this group a "community sound board" rather than a "community advisory board" because we were aware that we were not engaging members as partners, either in empirical research or in the AWG's normative scholarship. Instead, we hoped that members would serve the roles of providing feedback on the AWG's ideas as they emerged and helping us to see what we were missing. We wanted the group's name to reflect these goals. As we discuss below, even these aspirations were only partially achieved.

Community Sounding Board Recruitment, Composition, and Compensation

We identified three aims to guide recruitment of CSB members:

- to build and foster dialogue between academic scholars and community members who represent perspectives not represented on the AWG and whose lives might be impacted by research into the phenotypes that SBG researchers currently study;
- to get public insights regarding the AWG's primary aims, namely, whether conducting some types of SBG research is not ethically permissible and, to the extent that SBG research is conducted, how it should be conducted and communicated; and
- to gather community insights on materials drafted by the AWG.

Going into the CSB recruitment process, the subcommittee reflected on commitments it wanted the AWG to make to CSB members (see box 1). These commitments were referred to regularly over the course of the CSB engagement.

As the subcommittee went about recruiting members for the CSB, we looked for people who represented perspectives not present in the AWG and/or whose lives might be impacted by research into the phenotypes that SBG researchers currently study. More specifically, we looked for people who brought a life experience that was missing from the AWG (for example, careers outside of science, a wide range of educational experiences, and life in rural or remote areas), exhibited a phenotype that can be relevant to contemporary SBG research (such as lower socioeconomic status and education), worked in a profession that is currently or soon to be affected by SBG research (such as education), or came from a community that historically has been harmed by genetic research (in particular, African Americans, American Indians, or Alaska Natives). We prioritized recruitment of members who met multiple criteria—that is, who brought a life experience that AWG members lacked and who embodied phenotypes that are both of interest to contemporary SBG research and have historically been the targets of genetics abuse. We also sought CSB members who had only limited or no prior familiarity with the methodologies of social and behavioral genomics. Finally, to the extent we were able to discern applicants' attitudes, we sought members who had a variety of initial perspectives about SBG research.

Individuals were invited to apply to the CSB via email, through postings in social-media groups, or via partnerships with community organizers, community groups, or nonprofits with which AWG members had preestablished ties (for recruitment materials, see appendix A, which is available online, along with the other appendices; see the "Supporting Information" section at the end of this essay). Given the disciplinary and geographic diversity of the AWG, we were able to reach a number of community groups and nonprofits around the United States. Many

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were willing to assist with our recruitment efforts because of their prior and positive interactions with AWG members. As applications came in, we were able to attempt to meet our recruitment goals for a diverse CSB by selectively inviting applications from respondents to a survey that one of us (Meyer) had previously conducted on attitudes toward SBG research.[4] These survey data allowed us to purposively recruit by phenotype and by attitudes toward SBG research. These techniques yielded applications from forty individuals (see appendix B for the application). The CSB subcommittee met to review applications and created a short list of potential CSB members who met the phenotype and viewpoint criteria. Seventeen individuals were invited to participate in a brief ten- to fifteen-minute phone interview. This interview was meant to introduce potential members to the chair of the CSB subcommittee; it also provided further information on expectations for the CSB (for example, time commitment, compensation, possible discussion topics) and answered potential members' questions. Of the seventeen people invited to interview, fourteen did so, all of whom were then invited to join the CSB. Thirteen individuals accepted that invitation and attended the first meeting. Box 2 details CSB members' motivations for joining the CSB in their own words. Over the course of eighteen months, the CSB settled to a consistent group of eleven members who spanned Western, Mountain, and

Box 2. Motivations for Participation—Reflections from Sounding Board Members[1]

CSB Member 1: I joined the sounding board because I don't really see many opportunities like it where community/public feedback on a scientific frontier of sorts is asked for. I thought that as a black person involved in my community, I might be able to lend a voice that until recently hasn't really been prominent in science.

CSB Member 2: I decided to join the sounding board for a couple of reasons. First of all, the topic. Although I had heard of it before it was only in passing, and I was curious to learn more about it. And let's be honest here, there are not too many gigs out there where you get paid to learn!

CSB Member 3: I wanted to be a part of the sounding board for many reasons. First, I was intrigued by the topic of social and behaviors genomics. Second, I wanted to learn more about the research and add my voice to the conversation. Finally, it was a good decision to be a participant of the sounding board. I have a greater understanding of the topic and the risks involved in using this science. My voice as a middle-aged African American woman matters and I felt my feedback was affirmed through the process.

CSB Member 4: I chose to join because it was a good opportunity for me as a community representative to speak up and advocate for my community (African refugees/immigrants), in terms of their health issues and how they can be improved if providers and communities work together.

CSB Member 5: I joined the sounding board because research is always interesting and important. Findings can often be beneficial to those affected by what the study is about. I did not know anything about genomics and thought that this would not only be a perfect opportunity to help with the research, but to also learn about genomics. I also wanted to bring the voice and thoughts of a Pacific Islander to the table.

CSB Member 6: I joined the sounding board to further my understanding of social behavioral genomics. Professionally, this information interests me and personally, my family has been tested for a possible connection between their symptoms and traits.

CSB Member 7: I thought participating on the sounding board would be an interesting learning experience. I found it to be just that. I feel I learned quite a bit not only on the subject of the study, but I was able to step back a bit from my preconceived notions and saw the issues from many different perspectives. I appreciate the opportunity to participate.

CSB Member 8: I said yes because I have never been offered something like this and it made me feel important and that my opinion actually matters.

CSB Member 9: I thought genomics sounded interesting. I also saw that they were looking for people to contribute their personal thoughts and opinions. I thought I could contribute different perspectives—my perspective of being a young black woman, first generation American, and my legal background.

CSB Member 10: I joined the sounding board in hopes of finding out more about myself and how genetics play a role in our everyday lives. What I learned turned into so much more. It was an enriching and fulfilling experience and I am so glad I was able to be a part of it.

CSB Member 11: To take part in something that would advance Natives and then definitely the benefit of humanity—especially marginalized communities as well having a voice in decision- or research making.

[1] Where necessary to improve readability, grammatical and spelling errors have been corrected.

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Eastern time zones.[5] CSB members brought racial, ethnic, income, and occupational diversity (see table 1 for CSB demographics). The group included undergraduate and graduate students, caregivers, and individuals with work experiences in education, retail, mental health, community health, the restaurant industry, and the police force. CSB members also held various religious beliefs, including Muslim, Mormon, Catholic, Baptist, and other Protestant beliefs. We were only modestly successful in including members of diverse educational attainment. We were even less successful in recruiting politically conservative applicants (a perspective also lacking in the AWG) and members of the LGBTQ community. (Multiple members of the AWG identify as members of this community but are privileged in ways that likely shape their experience as sexual or gender minorities). Additionally, although one CSB member identified as a person with a disability, the subcommittee did not specifically recruit individuals with disabilities. Furthermore, consistent with sample demographics of surveys and many other kinds of research, the CSB skewed heavily toward members who identify as women, and we also lacked older members (people sixty-five and older).[6]

The project's original budget line for community consultation was adequate to incentivize research participants to participate in one-time surveys, interviews, and focus groups, but not adequate to engage a CSB for many hours over many months. We were able to increase that budget significantly when, at the start of the Covid-19 pandemic, we were no longer able to host AWG members at in-person annual project meetings. As a result, we were able to pay CSB members a flat rate of $1,550 for their eighteen months of participation, which came to an hourly wage of approximately $50 for a maximum of thirty-one hours of engagement. Put another way, CSB members were, on average, expected to contribute less than two hours a month over the course of eighteen months. Given the nature of this project, however, participants were asked to contribute more in some months than others.

Box 3. The CSB Process: *A CSB Member's Perspective*

I, of course, got to learn about a relatively new field and how scientists are not only approaching it now, but also the potential ramifications further down the line. But I also got a great deal out of just listening to my fellow sounding board members. Their thoughts and their life experiences (whether I agreed with them or not) helped me to better understand the complexities of this diverse landscape we call our home. I'd like to think that this experience has made *all* of us a bit more well-rounded. The best part of being on this sounding board was its diversity. We were a group of people from all across the country, with different lines of work, different upbringings, and, of course, different ethnic groups.

The only problem that I felt existed was time constraints. And I have no suggestions on how to make it better. I'm sure there were times when subject matter was left out due to time constraints. But you just can't cut someone off when they have something to say, because what people are saying is what the sounding board is all about.

—CSB Member 2

Logistics and Content

CSB members participated in an introductory session and four core sessions (five in total). These ninety-minute sessions, which were held on Zoom and recorded, were scheduled in afternoon or evening hours that accommodated three time zones and CSB members' work and personal schedules. In addition to these videoconference meetings, CSB members provided ad hoc consultations. The two primary consultations included commenting on materials drafted by the subcommittee that endeavored to summarize discussions from the first three CSB sessions and taking an informal survey that mirrored one administered to the AWG on the risks and potential benefits of SBG research.

CSB members and members of the subcommittee engaged in a colearning process that aspired to break down the dichotomy between "experts" and "the public" that can occur in other engagement processes.[7] CSB members were valued for their lived experiences, and members of the subcommittee (as a subset of the AWG) were, we felt, equally valued for their academic perspectives. To facilitate successful colearning, CSB members received a primer on social and behavioral genomics (describing, for example, what SBG researchers study, why they study it, and what they have found). To assist with these informational discussions, members of the AWG subcommittee delivered brief presentations and provided CSB members with accessible materials to review and ask questions about (including media articles and an interactive website[8] on polygenic indexes (PGIs, also called "polygenic risk scores" and "polygenic scores").[9] Presentations included example cases (such as SBG research on educational attainment) that were designed to engage CSB members by speaking to their lived experiences.

The exact nature of each session was dependent upon this colearning process. Planning the four core sessions required that CSB members communicate any gaps in their existing knowledge that they wanted filled. It also depended on whether CSB members raised questions that they wanted to discuss. Session planning also required the

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Table 1.
Community Sounding Board Demographics

Demographic item		*% of N*[1]
Age in years	18 to 25	18
	26 to 35	9
	36 to 45	18
	46 to 55	18
	56 to 65	36
	65 +	0
Gender identity	Woman	73
	Man	27
Race or ethnicity[2]	Black or African American	36
	American Indian or Alaska Native	9
	Hispanic, Latino, or Spanish	18
	Native Hawaiian or other Pacific Islander	9
	White	18
	Asian	9
Highest education	Advanced degree	46
	College for four years or more	18
	One to three years after high school	27
	Grade twelve or GED	9
Household income	$200,000 or more	9
	$150,000-$199,999	9
	$100,000-$149,999	25
	$75,000-$99,999	0
	$50,000-$74,999	18
	$35,000-$49,999	9
	$25,000-$34,999	9
	$10,000-$24,999	9
	Less than $10,000	9
	Prefer not to answer	9
Political orientation (on social issues)	Very liberal	27
	Liberal	55
	Moderate	9
	Conservative	9
	Very conservative	0
Political orientation (on economic issues)	Very liberal	18
	Liberal	46
	Moderate	27
	Conservative	9
	Very conservative	0
Religiosity	Not at all religious	0
	Not very religious	18
	Somewhat religious	46
	Pretty religious	36
	Very religious	0
Residence	Suburban	36
	Urban	36
	Rural	27
Sexual orientation	Straight	91
	Gay	0
	Lesbian	0
	Bisexual	9

[1] This table represents the final eleven-member CSB; it does not include data about the two individuals who attended only the first session. Percentages do not always sum to 100 due to rounding.
[2] Participants were allowed to select more than one racial or ethnic group when self-identifying.

subcommittee to reflect on the questions that they had for CSB members and to ensure, via CSB feedback, that summaries of each session were accurate. Through bidirectional conversation and education, members of the CSB and the subcommittee were able to codesign and agree upon the structure of each session.

Before each session, CSB members were given clear instruction on how best to prepare. After each session, CSB members received a video recording of the session as well as a written summary of it; they were invited to provide additional comments or make clarifications to the summary. Box 3 provides a reflection from one CSB member about the CSB engagement process.

SESSION ONE: Establishing group expectations and norms. To begin, CSB members participated in a ninety-minute introductory meeting that was designed to establish the culture and ethos of the group, explain why the CSB was created, introduce the AWG and subcommittee, and briefly outline potential topics for discussion in future sessions that were subject to CSB feedback. A key goal of this first session was to have the CSB define their own commitments to the AWG and to collectively clarify, modify, and discuss expectations and basic ground rules. Box 4 describes the CSB commitments to the AWG.

Box 5 outlines the group norms for the CSB. These norms were codeveloped by the CSB and the CSB subcommittee during session one. This list was dynamic—meaning that it was modifiable by CSB members at any point in the process.

SESSION TWO: Introducing SBG, part 1: What do SBG researchers study and how?

The second session was an informational one on social and behavioral genomics. CSB members learned about how genes and the environment influence behaviors and outcomes. They were also introduced to genome-wide association studies (GWAS), PGIs, and case examples of research missteps in human genetics, such as the experiences of the Havasupai Tribe and the Nuu-Chah-Nulth Tribe. Given limited time and the fact that the most immediate potential benefits of SBG research—such as improving social science and health research—are complex to explain to nonresearchers, the CSB subcommittee chose

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Box 4. CSB Commitments to the AWG

- Serve as a resource for the AWG by providing real-life experiences as context experts.
- Ask probing questions.
- Create, in tandem with the AWG subcommittee, a safe space for voicing opinions and giving [and] receiving feedback.
- Demonstrate commitment to developing an understanding on issues that may be unfamiliar or new.
- Communicate regularly with the AWG subcommittee about what CSB members need to feel informed and to benefit from the engagement.
- Voice perceived concerns about and/or hopes for SBG research.
- Share what they understand or misunderstand about SBG research.

to focus on risks of SBG research rather than its potential benefits. (Box 6 describes key points the subcommittee intended to convey during session two.) Throughout this session, CSB members were invited to ask questions and share what was on their minds. Toward the end of the session, CSB members were asked to describe, based on what they had learned thus far, what made them excited and what made them nervous about SBG research. These thoughts shaped session three, which we now describe.

SESSION THREE: Introducing SBG, part 2: What excites or makes CSB members nervous about SBG?

Coming out of session two, participants had specific questions about what (if anything) genetics might be able to say about educational attainment. There were also more general concerns about the ethical implications of PGIs, including the implications of assigning a "score" to an individual and privacy considerations related to who would have access to PGIs and how they might be used. In response to these questions and concerns from CSB members, session three focused on the case example of SBG research on educational attainment and probed two broad topics: what worried CSB members about SBG on educational attainment and what their thoughts were on whether and how SBG research should proceed.

Box 5. CSB Group Norms

Create a space where we all

- celebrate our differences;
- are patient with and respectful of each other and our different views;
- feel comfortable and safe;
- treat others as we want to be treated;
- have fun;
- share our opinions honestly and openly;
- are active listeners;
- speak our truth—don't hold back;
- are not afraid to explain how we feel, to ask questions, to offer comments;
- have a sense of confidentiality;
- are curious (we are open to growing and developing new perspectives); and
- speak up early and often about what information or help we need.

Session three began with a brief informational discussion about GWAS and PGIs for educational attainment, including what the most recent findings and limitations of those findings were (for example, that PGIs are not good for predicting educational outcomes for individuals). CSB members also asked about potential applications of PGIs, and members of the subcommittee discussed existing proposals to use PGIs in education, in reproduction, in the criminal justice system, and society broadly, as well as the limitations or limited practical validity of such uses. Each of these potential applications of SBG raised important concerns among CSB members that were also discussed, such as whether insurance could discriminate against people by using their PGIs and how industry might try to profit from SBG data.

AD HOC CONSULTATIONS: Exploring the risks and potential benefits of SBG.

In between sessions three and four, CSB members took part in two ad hoc consultations. The first consultation was to provide feedback on a summary of the first three sessions (see table 2). This summary focused on the questions CSB members had asked and the risks and potential benefits of SBG research that members had thus far identified. This ad hoc exercise confirmed that CSB members were worried that SBG could risk reinforcing or exacerbating racism (by providing putative evidence of biological differences between racial groups) and social stratification through eugenics (such as through the creation of designer babies). Additionally, CSB members reiterated their concern about inequitable access to genomic technologies. CSB members

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The AWG survey incorporated concerns raised by CSB members that had not been extensively discussed by the AWG; specifically, it incorporated the deep concern some CSB members had expressed about for-profit, industry uses of SBG research.

were also worried about the use of genetic information to deny insurance, reduce funding for certain communities, and absolve society of responsibility for unjust social structures. Finally, they discussed their concerns about the privacy of their own genomic information and about the prospect that SBG researchers will use research participants' genomic data for purposes other than those to which the participants originally agreed. In addition to providing feedback on the summary (such as whether it accurately captured individual and collective views), members were asked to pose any questions they had about anything discussed thus far.

The second ad hoc consultation was to complete an informal survey adapted from one administered to AWG members about their views on the risks and potential benefits of SBG research (see appendix C for the survey items). The purpose of surveying the AWG was to guide the development of its final report by gaining a better sense of where the AWG members did and did not agree about the major issues the group had discussed over many months. The survey asked respondents to rate their level of agreement with a series of statements that might be made in the AWG's report. Because the CSB subcommittee was interested in the extent to which the views of CSB and AWG members converged or diverged, the subcommittee decided to administer a version of the AWG survey (adapted for readability) to the CSB.

Importantly, the AWG survey incorporated concerns raised by CSB members that had not been extensively discussed by the AWG; specifically, it incorporated the deep concern some CSB members had expressed about for-profit, industry uses of SBG research. Although AWG members were aware of for-profit uses of SBG research and had briefly discussed some of these uses at its first meeting, AWG discussions had until that point focused on the nature and ethics of SBG research itself (including, for instance, the practice of including and excluding GWAS participants based on genetic ancestry and the problematic labels used to describe these populations), rather than on its potential downstream uses. These two ad hoc consultations informed the design of sessions four and five.

SESSION FOUR: Answering CSB questions and discussing CSB survey results. Session four had three aims. The first was to answer some of the questions CSB members had raised in their feedback on the first three sessions. In the interest of time, the CSB subcommittee chose to focus on CSB questions related to the AWG's mission and aims and on what would happen if the CSB advocated for discontinuing SBG research. Both sets of questions reflect some understandable lingering confusion among some CSB members about the nature of their engagement in a normative project. Upon conclusion of session four, CSB members were given a document with written answers to the questions brought up for discussion (see box 7 for some of the questions and answers).

The second aim of session four was to present the results of the informal survey that the CSB members had taken and to discuss survey items for which there was no consensus among members. Discussion about the survey focused on unpacking perspectives on four specific survey items:

Box 6. Session Two: *Key Points*

- Genes play a role in essentially every aspect of who we are, including which diseases we're likely to get, what we like and don't like, and how we behave.
- Environmental factors also play a role in essentially every aspect of who we are, including which diseases we're likely to get, what we like and don't like, and how we behave.
- Many things influence human behavior and life outcomes besides genes, such as our families, friends, and communities; the physical environment where we live and work; income; education; and more.
- Any particular outcome may be influenced by many genes, many "environmental" factors, and the interactions between and among them. Figuring out which genes and which environmental factors have an influence, and how much, is really hard!
- Even though we are born with certain genes and those genes can play important roles in predisposing us to certain health and other outcomes, genes aren't destiny.
- Unfortunately, there is a long history of people misinterpreting or misapplying genetic research. This makes the future uncertain—helping to shape that future is why we have you here.

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Table 2.
Potential Risks and Benefits of SBG Research Identified by the CSB

Potential risks		
Example questions raised in CSB discussions	**Why the question is important**	**Example quotations from CSB members during sessions one to three**
Could genetics be used to regulate or extinguish a person or group?	The risk of using genetic information to prevent people from having children or to restrict their ability to make decisions	"There are regimes out there, or countries or states, who probably would want to have data and information about their population and might use that to, I don't know, sterilize or to regulate and stuff like that." "Restrict people who are more prone to aggression."
Can polygenic scores be used to discriminate against people? Who will use them to discriminate and how?	The risk of using genetic information to discriminate in insurance, financial lending, education, or the law	"I and many people from the African immigrant community, we, just like other people of color in this country, we sometimes get worried about how research data is used by law enforcement to stereotype the whole population."
Who will have access to polygenic scores?	The risk of losing privacy to something deeply personal (genetics) through, for example, data breaches	"[There is] nothing as basic as your genetic makeup that can identify you."
What are the consequences of genomic studies that have a lack of diversity in terms of who conducts them and who is included in them?	The risk of restricting the potential benefits of genomics research to a small group The risk of restricting who gets to do the research	"Coming from a native population in a lot of researchers' research, there are basically middle-aged White men, because they have access to all of the resources in the world, [they] are the first ones to be researched, and assumptions are made . . . and it leaves out smaller groups like mine." "That's where we see discrimination because maybe there was no good representation from the beginning."
What happens if we start to rely too much on genetics to make decisions?	The risk of focusing too much on genetics when we make decisions or think about ourselves or others	"My first concern was the ethical implications of studying people's genes and attaching scores for things."

- Social and behavioral genomics research poses risks to society.
- There are lots of social and behavioral traits and outcomes. It is more ethically concerning to study and develop "scores" for some of these than for others.
- Social and behavioral genomics research can lead to better policies and practices.
- Today, polygenic scores do not benefit everyone from different backgrounds equally. Researchers are trying to change this, but in the meantime, we should still make polygenic scores available to those who might benefit.

CSB members were invited to discuss their views on why they agreed, disagreed, or were uncertain about each of the four statements. This discussion was undertaken for several reasons. One reason was to identify whether a lack of consensus on a statement was because the wording of the survey item had caused confusion (which turned out to be true of survey item 3) or because participants held clear views and simply disagreed with each other (which was true

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Table 2.
Potential Risks and Benefits of SBG Research Identified by the CSB continued

Potential benefits		
Example questions raised in CSB discussions	**Why the question is important**	**Example quotations from CSB members during sessions one to three**
Could genomics research help answer new questions about humankind?	The benefit of discovering new knowledge and finding answers	"Science is about constantly learning things; it's about learning facts . . . . We'll have answers as we do more research."
Could genomics research help the world better personalize interventions or treatments to the unique situation of an individual?	The benefit of abandoning a one-size-fits-all approach and personalizing to the individual	"If schools had this research, and if they have certain schools that are . . . [if] some schools focus on experiential and some schools are traditional, I mean the outcome for students could be wonderful, just great."
Could genomics research, including research on social and behavioral traits, help us understand the causes of differences or similarities between people?	The benefit of understanding the causes of differences between people, including differences in health outcomes	"I want to know if there's things that you know have happened because of genetics . . . . My father, he dropped out of school in like ninth grade, and I dropped out of college, and then my oldest daughter dropped out of high school, and so, you know, is that part of our part of our genes—is that in our genetics?"

for item 4). Another reason was to try to qualitatively understand CSB members' responses to these survey items (as was the case with items 1 and 2). The subcommittee was particularly interested in better understanding why at least two-thirds of CSB members agreed with survey item 2; the subcommittee wanted to know which social and behavioral traits and outcomes the CSB members thought were more ethically concerning to study than others. The subcommittee was also interested in exploring potential reasons for a lack of consensus among CSB members about the statement "Social and behavioral genomics research poses risks to society." This was especially intriguing because there was complete consensus (all CSB members selected "agree" or "strongly agree") or almost complete consensus (two-thirds of CSB members selected "agree" or "strongly agree") on other statements about the potential risks of SBG (such as the potential risks of industry use and of using genetics to explain racial differences). Reasons for lack of consensus on survey item 1 remain unclear because, as the next section explains, CSB members identified and acknowledged the risks of SBG to society during every session and in their responses at both ad hoc consultations.

The third aim of session four was to collectively discuss plans for the final session (session five). The CSB decided on a town hall format that additional members of the AWG were encouraged to join. An underlying motivation for this approach to session five was a desire on the part of both CSB and AWG members to ask questions of each other in an informal, semistructured format.

SESSION FIVE: Town hall. As a town hall, session five focused on facilitating dialogue between the CSB and the AWG. Prior to the session, AWG and CSB members were invited to share potential questions for discussion, although it was made clear that these questions would serve only as a guide. Ahead of the final session, CSB members posed the following questions to the AWG:

- "What are common misconceptions about behavioral genomics?"
- "Why is a [CSB] important for this field?"
- "What are some of the things you've learned from observing our [CSB]?"
- "Have we [the CSB] made a difference [by being part of this engagement]?"
- "Are we going to see more studies involving genomics?"
- "Do genes play a role in sexual orientation?"
- "Do genes play a role in poor financial decisions?"
- "What are the next steps for the AWG, and how has the [CSB] shaped those next steps?"

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AWG members, in turn, proposed the following questions (some of which the group then paraphrased) to be directed to the CSB:

- When should SBG research be limited or stopped?
- AWG members feel less strongly than the CSB that researchers have a responsibility to limit risks. How do CSB members feel about the reasons that AWG members feel less strongly about this?
- How should researchers determine whether a research project is too risky to do?
- Do you see a difference between research that is controversial and research that is too risky to fund, do, publish, or report on?
- Should researchers who conduct research that is used by others to justify discrimination and bias directly confront these uses by bad actors, or should they ignore them and avoid bringing further attention to them?
- What are you looking for from researchers to ensure research is transparent and that researchers are accountable to the public?

Given time constraints, the AWG subcommittee took the proposed questions from CSB and AWG members and proposed the following suggested outline for the town hall:

- To the AWG: "What are common misconceptions about SBG research?"
- To the CSB: "Can you envision SBG research that is so risky that scientists should be prohibited from doing it?"
- To the CSB: "What are CSB members looking for from researchers to ensure research is transparent and that researchers are accountable to the public?"
- To the AWG: "What has the AWG learned from the CSB? That is, has it made a difference to the AWG's next steps or to the field's? Why are CSBs important as SBG research continues to develop?"

In relation to the first in this third set of questions, AWG members responded that common misconceptions include genetic-determinist notions, such as that "your genes are your fate" or that "there is no way to change anything" when it comes to the relationship between a person's genes and social and behavioral characteristics, and the idea that something is the product of either nature or nurture, when, in reality, it's a complicated combination of both. Answers to the second and fourth questions in this set are discussed in the next section.

Lessons Learned

CSB perspectives on the risks and potential benefits of SBG. In general, in this fledgling effort to engage public views for normative analysis of controversial scientific research, CSB members did not significantly affect the academics' normative perspectives or conclusions. During the CSB's eighteen-month tenure, it articulated risks and

Box 7. Samples of AWG Answers to CSB Questions

1. Is this study part of a larger study? If so, what are the other "areas" that are being looked at? What are the other members of the team looking at in regards to this study? Looking forward to subsequent studies, what do you see as potential follow-up projects?

This project on the ethics of SBG research is not part of any larger project. Since December of 2019, the AWG has met once in person and fourteen times by Zoom. The questions in the survey you took should give you a good sense of the kinds of things we have been discussing. We expect one of our AWG's next steps to be a conference with members of the media about how to responsibly communicate about SBG research.

2. Will the AWG be using their SBG research for the benefit of humanity and not for profit? How?

Please know that your questions about industry profit made it into our AWG's survey! The core team has a small part of their salaries funded by the grant. All other AWG members, like CSB members, receive modest honoraria. We will publish papers in peer-reviewed academic journals and are not paid for doing do. We hope our papers and presentations will provide helpful guidance to SBG researchers, funders, journal editors, and the media.

3. If this CSB were to advocate for discontinuing the research, what impact would that have?

This project's funders have funded SBG research in the past and are very interested in your views about it. We plan to write a paper that describes not only the AWG's views but also your views, and that may be influential among other funders considering funding SBG research, editors considering publishing it, and researchers considering conducting it. That said, it is very likely that at least some SBG research will continue, no matter what the AWG or the CSB says.

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While the risks identified by CSB members were not different from those identified by the AWG, it is possible that the CSB and AWG members prioritize the risks (and potential benefits) differently.

potential benefits of SBG that were largely already familiar to the AWG (see table 2). According to the informal survey results, there was considerable overlap and agreement between CSB and AWG members' views about the risks and potential benefits and the ethical responsibilities associated with conducting SBG research (see appendix D). We note, however, that academic scholars' and the public's views on these topics might usefully diverge more in other research contexts, and indeed might have diverged more in the context of SBG research had we had more time and funding to engage the CSB or had we engaged them differently. We note also that this null finding, the lack of any substantial disagreement among AWG and CSB members, is itself useful.

While the risks identified by CSB members were not different from those identified by the AWG, it is possible that CSB and AWG members prioritize the risks (and, separately, the potential benefits) differently. For instance, CSB members spent more time talking about potentially harmful for-profit, industry applications of SBG data than did AWG members. However, this divergence could be explained by the fact, noted above, that the AWG was convened to focus on the nature and ethics of SBG research itself. The AWG was not originally intended to examine SBG's downstream applications. Although it became clear that part of the ethical analysis of SBG research is how such research might be used downstream, the AWG took longer than anticipated to discuss several topics, including whether and how the use of ancestry categories in GWAS could produce downstream harms that reify race as a biological category; this left less time for subsequent discussions about the potential downstream harms and benefits associated with industry applications of SBG research.

In addition, there was greater consensus among CSB members than among AWG members that the social risks of some scientific research questions call for researchers, funders, and the media to carefully consider whether to conduct, fund, or report on such research. One reason for this difference in survey responses could be that AWG members, who were all academics, were more likely to consider and care about academic freedom (or more skeptical of the feasibility of fairly restricting academic and press freedom) than were CSB members; therefore, AWG members may have been more resistant to the idea that some kinds of research might be too socially risky for funders to fund or journalists to report on.

Although CSB members' survey responses captured their view that there are important social risks of SBG research that researchers, funders, and the media need to consider, they did not at any point in the survey or during any discussions name any specific phenotypes that were too socially risky for researchers to study, even when, in sessions four and five, they were directly asked to do so. At the same time, CSB members felt that certain areas of SBG research posed significant risks because of how they could be interpreted or used. Specifically, they classified two areas of SBG research as very risky: SBG research that made comparisons between different racial and ethnic groups and SBG research into criminal behaviors.

On the survey, CSB members were in consensus agreement that "a significant risk of social and behavioral genomics research is that it could be used to say that biology can explain why different racial groups have different outcomes." In discussions throughout the engagement, CSB members expressed concern that SBG research, especially SBG research on criminal behaviors, could be used to perpetuate racial stereotypes. For instance, in session three, one CSB member explained that SBG research, like other kinds of research, could be used by law enforcement to "stereotype the whole population [of people of color]." In the same session, a different CSB member worried that SBG research could be used to "restrict people who are more prone to aggression." And in the final CSB session, another member explained, "Criminal activity might be an area of social and behavioral genomics that could be very risky. . . . There are certain topics that I think should be handled more carefully than others . . . something like, 'What genes are different in this race that makes them more criminal than in this race?'"

While CSB members devoted more time on the potential harms of SBG research than on potential benefits, they also identified potential benefits that they thought might come from SBG research. Benefits included enhanced health and knowledge, greater personalization in policy and health interventions, and reduced human suffering (see table 2). For example, members spoke about how PGIs could be used to provide additional support or resources for those identified as being at risk of struggling in educa-

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tional settings and subsequently could promote resilience in those people.

CSB perspectives on the responsible conduct of SBG research. Our subcommittee came into the CSB process interested in understanding whether members of the public thought there were any types of SBG research or specific phenotypes that should not be studied. However, as the last section detailed, CSB members did not identify any specific phenotypes or areas of SBG research that should be prohibited from study. Instead of focusing on what should or should not be studied, CSB members emphasized that it would be better to focus on several points that could aid in the respectful and responsible conduct of SBG research. In doing so, they provided answers to the third question of the proposed town hall outline.

First, the CSB felt that why a researcher chose to study a particular phenotype was more relevant for determining whether their work was responsible than what the particular phenotype they studied was. For instance, in session five's town hall meeting, one CSB member said, "I don't think anything is off limits as long as they are respectful of all humans and also animals." And another later explained, "It's how you frame it, what you're doing, why you're researching this, what it's going to be used for." The CSB felt that researchers should provide reasonable and transparent justifications for their scholarship.

Second, CSB members expressed the importance of researchers recognizing, acknowledging, and reflecting on the ugly history that underlies genetic research. In session five, CSB members expressed that they found it reassuring to have come into dialogue with SBG researchers who recognize their field's ugly history and accept their social responsibility to explain their motivations for doing their research. This combination of transparency and reflexivity on the part of researchers was identified as critical for relationship and trust building between researchers and local communities.

Third, CSB members felt it was very important that researchers sustain bidirectional communication instead of being "helicopter people coming in and taking advantage of our community and then go[ing] out and com[ing] to some kind of conclusion without us [the community] saying, 'Yeah, that makes sense,' or, 'No, you are off on the left here.'" They voiced their frustration at seeing their local communities getting involved in empirical, medical research but failing to receive the benefits of their contributions. And while they were deeply interested in seeing their perspectives translated into action, they had little insight into whether and how this had happened in the past or would happen in the future. CSB members were interested in AWG perspectives on public engagement because they viewed public engagement as a way not only to increase the accessibility of research findings but also to gain insight into how their contributions might be translated into action. The CSB thus wanted to know if the AWG felt similarly to them about the importance of public engagement. In response, AWG members talked in the final session about how poorly trained researchers are in public engagement. It appears, then, that at least some researchers and some members of the public would like there to be more training in and more opportunities for bidirectional engagement.

Additionally, CSB members talked about factors that drive the risks and potential benefits of SBG, which provided further considerations for the responsible conduct of SBG research. For example, CSB members spoke about how corporations are driven by profits and individuals by self-gain. There was concern among CSB members that the profit-driven interests of companies might lead them to sell SBG data for any purpose, regardless of the harms it might bring to members of the public. Similarly, CSB members were concerned that research teams might focus on the benefits of research as it pertains to their self-interests and neglect to consider how to benefit the people affected by the research. Given these potential outcomes, the CSB felt that proper regulations and oversight were needed to prevent and counteract bad actors who might use SBG research to inflict harms on others. Per the survey, CSB members were in complete agreement on two key points:

- "Social and behavioral genomics researchers have a responsibility to try and limit the potential risks of their work. Relatedly, because social and behavioral genom-

Box 8. Future Engagements: *A CSB Member's Perspective*

Considering the rare opportunity that members of the public were given to be able to share their opinions on an emerging topic of genomics research, I feel that it is a valuable endeavor to consider the opinions of the general public in these types of research. With the eugenics movement, people thought certain groups had certain genes and had certain intellectual limits—and considering that history, dialogue between the public and researchers is really valuable.

I strongly believe that these discussions between the public and researchers about the future of genomics research, as well as the opinions of certain minority groups toward the medical and scientific community at large, should be continued. It's one thing if researchers are developing a therapeutic drug for a certain group. It's another thing when your research has broad effects that anyone in the global population can be harmed or helped by. In an effort to continue examining the ethical considerations of SBG, taking into account the opinions of nonscientists is essential.

—CSB Member 1

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It will be important to gain clarity about whether it is reasonable to expect that public engagement in normative scholarship will yield instrumental value.

ics research has risks, social and behavioral genomics researchers have an ethical duty to be more confident about their findings than researchers in other fields do before making their findings public."

- "Before polygenic scores are used in the real world, we need to carefully think about the risks and benefits. We need to ensure that the positives (benefits) outweigh the negatives (risks)."

How to improve future engagements. There are numerous shortcomings to this CSB engagement from which other scholars interested in taking a similar approach in the future can learn. Here, we respond to the fourth question of the proposed town hall outline as we reflect on procedural lessons learned. First, despite focused recruitment efforts, the subcommittee failed to secure adequate representation of individuals who identified as transgender, nonbinary, or politically conservative. These demographic perspectives were either altogether absent from or deeply underrepresented in both the CSB and AWG. Furthermore, we failed to explicitly consider the lived experiences and perspectives that individuals with disabilities could bring to these conversations. This is a major and regrettable shortcoming. Renewed focus should be given to understanding these perspectives in future engagements, which requires understanding how best to recruit such individuals to CSBs and CABs.

Second, our AWG could have done a better job of establishing connections between the CSB and the AWG. While the subcommittee was present for all the CSB meetings and engaged in frequent correspondence with CSB members, the larger AWG remained relatively uninvolved in the CSB engagement. There are several potential reasons for this failing. First, given the divergent academic perspectives within the AWG and the substantial time spent by that group on fairly inaccessible issues related to population stratification and genetic ancestry, the process of arriving at a draft of the AWG's report took much longer than anticipated. Thus, the CSB was asked to provide their comments and perspectives on many of the same key issues that the AWG was continuing to discuss but did not have an opportunity to comment on the final materials drafted by the AWG, even though this had been an initial aim of the CSB.

Third, because of delays in the AWG, there were large gaps between CSB sessions. These two issues reinforced one another: we could have waited to hold the final CSB sessions until the AWG report was drafted and could be reacted to, but doing so would have widened the already-considerable gaps between CSB sessions. In final feedback, several CSB members reflected that more meetings, scheduled more closely together, would have improved the experience and helped them build on prior sessions. At least one CSB member felt that, alongside more frequent CSB discussions, more joint discussion between AWG and CSB members might have enabled both groups to learn even more from each other. This feedback from the CSB signals that, even though CSB members were volunteers with limited time, their desire for deeper forms of engagement was strong.

Furthermore, the CSB process challenged the subcommittee to articulate background on SBG research in a readily digestible format. Addressing this challenge left less time for dialogue than we originally envisioned, and, given financial constraints, we could not adjust by scheduling more sessions. The ad hoc consultations were one attempt to facilitate dialogue without the burden of another scheduled meeting. Nonetheless, future engagements would benefit from additional time and funding. Greater time and funding should also be devoted to studying the value, for members of the public and for scholars engaged in normative research, of engagements of the sort we created. More generally, greater time and funding should be devoted to studying the various forms of public engagement that are currently on offer and which forms are most appropriate for normative research.

In addition, more needs to be done to understand what members of the public expect, and reasonably can expect, from their participation in normative research. As one CSB member detailed in a reflection written for this manuscript, their involvement in this project provided what they considered to be both a "rare" and "valuable" experience (see box 8). They emphasized how important they consider public engagement to be for research that has broad societal implications.

However, we recognize that there is much more to learn about the ways in which public engagement in normative scholarship can be important. It is one thing to hope that the public's involvement in answering normative research questions can be intrinsically valuable for those who participate; it is another to hope that such participation can

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produce the kind of instrumental value that is promised in the context of empirical research, which has a more direct line to policy. The intrinsic and instrumental benefits of public engagement are both important. Nevertheless, it will be important to gain clarity about whether it is reasonable to expect that public engagement in normative scholarship will yield instrumental value.

Finally, our AWG learned that it might be worthwhile for researchers to take the time to expressly reflect on the titles they give to their projects, especially when they seek to engage the public. CSB members were invited to review this manuscript and provide feedback via email, text, or phone call or by attending any of a number of virtual feedback sessions. In one such feedback session, a CSB member candidly shared their reactions to the title of our project. They had found the word "Wrestling" (in "Wrestling with Social and Behavioral Genomics") to be a "combative word." They went on to say, "In my field [outpatient behavioral therapy], we are very wordsmith oriented. How does a word land? How does it help people feel, one way or another? Maybe it's ['Wrestling' is] not the most accurate representation of the tension. 'Wrestling' implies the tension, but I never felt there was any combative nature to the tension. What you all [the AWG] were wrestling with was, how are we [researchers] intentionally connecting with representatives of invested people? The challenge is, how do we [researchers] appropriately engage our community and gather perspectives?"

This CSB member wondered whether the use of the term "Wrestling" in the project title might have discouraged some members of the public from applying to participate in the CSB, adding, "[W]ords matter too; titles matter too." In naming the project, the co-PIs intended to communicate the idea that the members of the AWG would be wrestling—not with each other or any other people—but with the historical, scientific, and social facts relevant to the ethics of SBG research. Hearing this CSB member's concern was one more reminder of how conversation with people beyond our academic bubble can help us see things we would otherwise miss.

Reflecting on the Value and Goals of Public Engagement

Bioethicists often invoke the need for CABs in medical and other empirical research, but they rarely, if ever, employ anything like CABs in their normative research—despite the fact that many of the same arguments supporting the use of CABs in empirical research seem to apply to normative research. We hope that this detailed description of our effort will be of use to other bioethicists as they contemplate creating something like a CSB to accompany one of their normative projects.

Although it is not possible to generalize from our effort, we can point to two aspects of the experience that stand out for us. First, at least some members of the public appear to have a significant desire to learn about cutting-edge research—both about the science and about the ethical questions it raises. Our CSB members reported that participation in the process was of intrinsic value for them: learning about the issues and talking with other members of the public and with professionals were inherently interesting. For the AWG, the process was beneficial because it provided insight into the possibility that nonresearcher, nonacademic stakeholders might differentially weigh the risks and potential benefits of social and behavioral genomic research. It could thus be valuable to broaden and diversify who is included in normative discussions about the harms and benefits of scientific research.

The members of our CSB, however, also hoped that their participation would have what could be called "instrumental value"—that is, they hoped it would make a difference in the world of policy. We remain open to the possibility that such engagements can have such instrumental value of the sort that the CSB members (and we ourselves) originally envisioned. But we want to acknowledge that we were struck by the extent to which the CSB's concerns (and hopes) were exceedingly similar to those of the AWG. This is not to say that the concerns of the public and of professionals are identical. Nor is it to say that the two groups weigh the risks and potential benefits in the same way (the opposite may be true). However, it is to say that much more research is needed to understand whether, in addition to being of great intrinsic value, such processes are of great instrumental value in the sense that we and the members of our CSB had originally hoped.

Supporting Information

The four appendices are available in the "Supporting Information" section for the online version of this article and via the *Hastings Center Report*'s "Supporting Information" page: https://www.thehastingscenter.org/supporting-information-hcr/.

Statement of Authorship

Michelle N. Meyer and Erik Parens contributed equally to this article.

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Notes

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8. "Polygenic Scores Explained," Polygenic Scores, accessed December 12, 2022, http://polygenicscores.org/explained/.

9. To be consistent with the AWG report and emerging practice, we use the term "polygenic index," which was introduced in J. Becker et al., "Resource Profile and User Guide of the Polygenic Index Repository," *Nature Human Behaviour* 5, no. 12 (2021): 1744-58. As explained there, the term was proposed by Martha Minow because the word "score" in the commonly used terms "polygenic risk score" and "polygenic score" connotes a value judgment, which is especially inappropriate outside of clinical phenotypes. This shift is similar to an earlier shift from "polygenic risk score" to "polygenic score" (omitting "risk," which also conveys a sense that may not be intended or appropriate). "Polygenic index" is gaining wider acceptance among other research teams. See K. P. Harden, "'Reports of My Death Were Greatly Exaggerated': Behavior Genetics in the Postgenomic Era," *Annual Review of Psychology* 72, no. 1 (2021): 37-60, and D. Bann et al., "Polygenic and Socioeconomic Risk for High Body Mass Index: 69 Years of Follow-Up across Life," *PLoS Genetics* 18, no. 7 (2022): e1010233. However, in discussions with the CSB, we used the more traditional term "polygenic score." As we discuss below, CSB members did react to the idea of "scoring" people according to social and behavioral phenotypes.

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