Engaging Diverse Stakeholders to Inform Biobank Governance

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Introduction

STAKEHOLDER ENGAGEMENT is an important component of biobank governance, but which stakeholders are engaged and how they are engaged varies within the biobank research community.^{1–4} Some biobanks have focused on engaging lay stakeholders (e.g., patients or community members) while others have engaged experts, including ethicists, biobank leaders, institutional review board (IRB) officials, and research administrators. As biobanks assume a central role in initiatives such as precision medicine of unknown future implications, it is helpful for biobank governance to be informed by diverse perspectives, including diverse members of the public and experts of varied roles and institutional affiliations.⁵

Recent literature on biobank governance includes few empirical studies of attempts to bring diverse experts together with laypersons for deliberative engagement. This short report describes a lay-expert workshop at the University of California (UC) that explored diverse stakeholders' ability to engage each other in self-directed and open-ended discussion of issues related to biobank operations and governance. We expected that stakeholders' ability to engage each other in the workshop presages their capacity to participate constructively on a biobank advisory board. Conversely, if the workshop failed to initiate meaningful engagement among stakeholders, it might be reasonable to consider what additional steps might be advisable before attempting to begin development of a multistakeholder advisory board.

Materials and Methods

This workshop was a component of EngageUC, an NIH-funded project that sought to harmonize biobanking policies and practices across five UC campuses.⁶ EngageUC convened both lay and expert stakeholder groups to discuss biobanking within the UC system. Lay stakeholders were California residents of diverse age, income, race/ethnicity, and sex, selected using the California Health Interview Survey.⁶ They were not necessarily patients or disease advocates, but a separate component of EngageUC brought all lay stakeholders together for a multiday deliberative community engagement

that included education and discussion of biobank research, operations, and governance issues.⁶ The expert group was drawn from all of the five UC campuses with medical centers as well as the UC Office of the President (UCOP) and included ethics researchers, biorepository leaders, UC IRB officials, and university research administrators.⁶ The experts had previously been brought together to discuss biobanking by multiple UC initiatives, including EngageUC. For the workshop, both lay and expert EngageUC participants were selected to ensure a diversity of roles and institutional affiliations among the experts; and of ethnicity, occupation, and geographic location among the laypersons (see Table 1; also see Garrett et al.⁶).

The 1-day workshop was convened at UCOP headquarters in Oakland, California in November 2014. It was the first event that brought members of both the expert and lay stakeholder groups for engagement.

The EngageUC team consulted with a professional facilitator to plan the workshop. After considering the workshop goals and its diverse participants, the facilitator recommended open space technology (OST), an unstructured approach for facilitating discussion and engagement within groups whose members are highly diverse and marked by differences in social power.⁷ A key goal of OST is to ensure that expert stakeholders do not play an outsized role in setting discussion topics or event structure. Thus, it differs notably from approaches to stakeholder inclusion that engage members of the public, but only after experts have set the discussion topics and structure of the event.⁸ In OST, all stakeholders share the responsibility and power to develop an agenda that responds to the workshop theme, to raise and discuss topics they feel are important, and to foster meaningful conversations across topics and between stakeholders of diverse roles.

At the start of the workshop, the OST facilitator described the workshop format, and invited participants to propose discussion topics related to the theme: "What are your hopes, concerns, and questions for achieving the vision of ethical, responsible, efficient, coordinated, and sustainable biobanking across the UC system?" Participants volunteered twenty discussion topics, organized a schedule for discussing them, and joined any discussion sessions that were of interest. Stakeholders took notes during each session, and all notes

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TABLE 1. STAKEHOLDERS' AFFILIATIONS, DISCUSSION TOPICS, AND PARTICIPANTS IN DISCUSSION GROUPS

Participants	
IRB representatives (IRB)	4
University administrators (UA)	5
Biobankers (BB)	5
Ethics researchers (ER)	4
Laypersons (LAY)	10
Study team	4
Total	32
Discussion topic	Participants
Community involvement in biobanking	IRB: 1 UA: 1 BB: 1 ER: 0 LAY ^a : 2 Total: 5
Donor liability	IRB: 0 UA: 0 BB: 0 ER: 1 LAY ^a : 1 Total: 2
"Socialism" In research—challenges in sharing	IRB: 1 UA ^a : 2 BB: 0 ER: 2 LAY: 3 Total: 8
What does a biobank sample actually look like?	IRB: 1 UA: 0 BB: 1 ER: 0 LAY ^a : 1 Total: 3
Who is EngageUC using to replicate the biobanking model on/after? what are successes and challenges?	IRB: 1 UA: 0 BB: 0 ER: 2 LAY ^a : 1 Total: 4
How do we know we aren't hyping biobanks way too much?	IRB: 0 UA: 0 BB: 0 ER ^a : 2 LAY: 0 Total: 2
When and how to ask patients to contribute to biobanks?	IRB: 1 UA: 1 BB ^a : 2 ER: 0 LAY: 3 Total: 7
How are biobanks funded? where has funding come from so far?	IRB: 0 UA: 0 BB: 1 ER: 1 LAY ^a : 3 Total: 5
What can we do today to help people feel good about biobanks twenty years from now?	IRB: 0 UA: 0 BB: 0 ER ^a : 1 L: 0 Total: 1
Ownership of biospecimens	IRB: 0 UA ^a : 1 BB: 3 ER: 1 LAY: 1 Total: 6
Who or what is going to reassure the public that we are ethical, responsible, efficient, coordinated, and sustainable?	IRB: 0 UA: 0 BB: 1 ER: 2 LAY ^a : 3 Total: 6
How do we respect differences between "Communities"?	IRB ^a : 2 UA: 1 BB: 0 ER: 0 LAY: 1 Total: 4
Why is the public wary of scientific research participation	IRB: 1 UA ^a : 2 BB: 0 ER: 0 LAY: 2 Total: 5
How do we integrate electronic medical records in the biobanking workflow?	IRB: 0 UA: 0 BB ^a : 2 ER: 1 LAY: 3 Total: 5
Consistency and equality for the collection of samples and data	IRB ^a : 1 UA: 3 BB: 0 ER: 0 LAY: 4 Total: 8
Race, gender diversity in collecting samples for biobanking	IRB: 1 UA: 2 BB: 1 ER: 1 LAY ^a : 1 Total: 6
Still wondering how to inform, or educate, or let the community know about biobanks?	IRB: 0 UA: 0 BB: 0 ER: 1 LAY ^a : 3 Total: 4
Should we be concerned about privacy?	IRB ^a : 3 UA: 1 BB: 3 ER: 2 LAY: 2 Total: 11
Can we really deidentify biospecimens?	IRB: 0 UA: 0 BB ^a : 1 ER: 1 LAY: 1 Total: 3
Reflective thoughts on biobanking	IRB: 0 UA: 0 BB: 0 ER: 0 LAY ^a : 1 Total: 1
Total conveners by stakeholder group	IRB: 3 UA: 3 BB: 3 ER: 2 LAY: 9 Total: 20

^aDenotes convener.

IRB, Institutional Review Board.

were assembled into a final workshop Book of Proceedings. At the end of the day, participants shared their reflections in a closing circle and were invited to complete an anonymous evaluation of the event that included open- and closed-ended questions. All appropriate IRBs approved this study.

Results

Members of each stakeholder category proposed discussion topics and attended discussions of topics proposed by members of other groups. Table 1 shows the role of workshop participant (lay or type of expert), the topics proposed (verbatim) during the agenda-setting phase of the workshop, and the composition of participants who joined each discussion group. The EngageUC team circulated among the groups to observe the quality of discussion, and they noted respectful and substantive dialog between participants such as active listening without interruption and asking probing questions of each other.

Evaluation surveys ($N=18$) revealed that 83% of respondents strongly agreed, and 17% agreed with the statement "the event allowed for discussion among people with diverse perspectives." Seventy-eight percent strongly agreed, and 22% agreed with the statement, "diverse opinions were respected." At the closing circle, participants of diverse roles

expressed their appreciation for the opportunity to interact with other stakeholders and stated that they had learned a great deal from the event and, in some cases, that they were surprised by what they had learned.

Discussion

During this OST workshop, stakeholders of different roles and affiliations collectively and organically generated a meeting agenda related to hopes, concerns, and visions for biobanking at the University of California. The participants then undertook and documented substantive discussion of topics of shared interest related to this theme.

These workshop results suggest that these stakeholders are capable of acting collectively in activities similar to those a biobank advisory board might undertake. The future benefits and quandaries associated with biobanking cannot be fully anticipated,⁵ so dynamic, open-ended, multidirectional exchange among diverse stakeholders may be helpful for fostering trust, and collaboration among biobank advisory board members. Such collaboration may be a boon to stakeholder engagement and biobank governance and policy-making.

The results of this workshop also suggest that OST, or similar methods, may be well suited to certain types of biobank

governance. For example, empowering diverse stakeholders to collaboratively set the agenda for discussion, rather than relying on expert-driven agendas, may enable biobank governance boards to more rapidly and comprehensively identify emergent concerns and to address these concerns in an inclusive manner.

These results illustrate that biobanking stakeholders with diverse backgrounds, expertise, and power are capable of constructive self-directed engagement and discussion. The implications of the EngageUC experiences at this single event are necessarily limited, but the success of these efforts suggests that other biobanks might consider attempting similar types of engagement with diverse stakeholding groups.

Acknowledgments

The authors thank Giuseppe Cavaleri, Lisa Heft, and Jen R. Hult for their contributions to the planning and execution of the stakeholder workshop.

This work was supported by a grant from the University of California Office of the President's Research Opportunity Funds as well as with support from the National Center for Advancing Translational Sciences of the National Institutes of Health (UL1 TR-000004-07S2; Grady, PI). The content is solely the responsibility of the authors and does not necessarily represent the official views of the University of California or the National Institutes of Health.

Author Disclosure Statement

No conflicting financial interests exist.

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