

Summary of American Society of Bioethics and Humanities Strategic Planning Session Friday, October 25, 2019

On Friday, October 25, 2019, the National Human Genome Research Institute (NHGRI) held a strategic planning session at the American Society of Bioethics and Humanities (ASBH) Annual Meeting in Pittsburgh, Pennsylvania. The session was held during the Ethical, Legal, and Social Implications (ELSI) Affinity Group session and was open to all conference attendees. Around 70 people participated in the session.

NHGRI program officer David Kaufman gave an overview of past strategic planning events, including a session at the 2018 ASBH Annual Meeting and two summer webinars to put this session into context. Previous engagement with the ELSI, education and engagement communities had focused on drafting “grand challenges” in these areas that could become part of the Strategic Plan. With advanced drafts of these challenges complete, this session was used to examine the six challenges as a whole. One area of discussion was a possible framework proposed by NHGRI to assign the grand challenges into one of four categories: values, foundations, breaking barriers and bold research ideas. Prior to the meeting, NHGRI staff categorized each of the grand challenges using this framework. Participants did not voice strong opinions about NHGRI’s choice of framework categories for the ELSI, education and engagement challenges.

Participants commented on the inclusion of education in the challenges. There was a positive response to the emphasis on genomics education, but a distinction between funding educational components and funding research on education is needed.

Participants noted that many challenges focus on genomics as information while non-informational components, such as gene therapy, are perceived to have been left out. NHGRI Council member Jeff Botkin (University of Utah) remarked that there was discussion at September Council to consider including issues raised by interventional technology.

In the same way that more institutes at NIH are integrating genomics into their research profile, some other institutes are also beginning to increase their funding of ELSI research. A suggestion was made to establish a free-standing ELSI Institute or Office at NIH.

Concerns were raised that the importance and need for continued normative work was not given adequate emphasis. The point was made that all the challenges include normative aspects. However, the current framework does not allow for a detailed and nuanced description of the many types of ELSI research methods that would be used to address a given challenge.

Participants indicated that the term “community” needs to be clarified. The term is vague in the current context. Participants pointed out that “community” could include police, judges, and media – all important elements to the social component of ELSI research. Relatedly, many participants agreed that the current distinction between medical and non-medical uses of genomic information is not helpful, as the line between these two types of uses is increasingly blurring.

NHGRI staff acknowledged that due to the relatively short length of the Strategic Plan publication, it is unlikely that all suggestions will be included in the primary publication. Still,

feedback is extremely helpful for ELSI Program staff as they consider areas where ELSI research will be needed in the future.

To end the session, NHGRI staff explained the next steps of the Strategic Planning process. A draft of the Strategic Plan document will be released in April during a finale meeting. The final NHGRI Strategic Plan is expected to be published in October 2020.