00:32:28 Angelica Johnson: Welcome to ELSIconversations! We are glad you will spend the hour with us. We ask that all attendees please abide by the code of conduct, which can be found here: https://elsihub.org/news/code-conduct

00:33:11 Angelica Johnson: Join the ELSI scholar directory: https://elsihub.org/form/submit-scholar

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00:33:40 Angelica Johnson: This Q&A/networking event will last approximately one hour

Use the "Raise Hand" zoom feature to speak or enter your questions/comments in chat. Remember to lower your hand after you’ve been called on

If you require assistance send a direct message to Dounya Alami-Nassif in this meeting or email info@elsihub.org

We will be spotlighting the moderator and speakers. Please click the “View” button in the upper right hand corner to switch between gallery and speaker view.

00:40:03 Lawrence Brody: Recent related reprint: A systematic review of guidelines for the use of race, ethnicity, and ancestry reveals widespread consensus but also points of ongoing disagreement. https://arxiv.org/abs/2204.10672

00:41:38 Mildred Cho: Thanks, Larry! That is indeed recent.

00:42:30 Angelica Johnson: Moderator: Mildred Cho, PhD

Biography: https://elsihub.org/directory/mildred-k-cho

Panelist: Alice Popejoy, PhD

Biography: https://elsihub.org/directory/alice-b-popejoy

Panelist: Gillian Hooker, PhD, ScM, CGC

Biography: https://www.concertgenetics.com/team/gillian-hooker-phd-cgc/

Panelist: Hannah Wand, MS, CGC

Biography: https://www.clinicalgenome.org/about/people/staff/wand-1955

00:52:23 Lee Ifhar: Can you put the link for the website for the pull in the chat box?

00:52:24 Bob Cook-Deegan: Alice, can you put the number in the chat with a link, to make it easy?

00:52:41 Gillian Hooker: Pollev.com/popejoy is the website

00:53:11 Lawrence Brody: Inertia in this area is a major force resisting movement. OMB categories have changed over time. Can we learn anything from the past about how the health system adapted to changes inn OMB categories?

00:53:12 Sandra Soo-Jin Lee: 1 747 444-3548

01:00:03 Sandra Soo-Jin Lee: Pre-recorded videos for this session can be found at https://elsihub.org/news/elsiconversations-0

01:06:44 Alice Popejoy: https://onlinelibrary.wiley.com/doi/epdf/10.1002/ajmg.a.31575

01:08:02 Lawrence Brody: For BRCA1 and BRCA2 we have very good data that tells us that high allele frequency (within an order of magnitude of the Ashkenazi alleles) founder mutations are not found (so far).

01:15:00 Mildred Cho: 100% Lynette

01:15:06 Bob Cook-Deegan: Gillian, you’ve alluded to cost of multi-gene panels dropping. Is that actually happening? Cost yes, but price?

01:17:12 Gillian Hooker: @ Bob - In my opinion, not enough - we don't have a very transparent payment system that would enable that

01:18:12 Norbert Tavares: +1 to Lynette, thanks for bringing up that point.

01:18:16 Carolina Mayes: Lawrence just to respond to your history question, there have been several pushes to update OMB categories (particularly to add a MENA option) but to my knowledge they were last revised in 1997

01:20:31 Maren Scheuner: can you repeat the question?

01:20:38 Stephanie Gogarten: +1 to being clear about why the question is being asked. Personally I answer the question very differently depending on whether my data is being collected for genetic risk or for tracking disparities.

01:21:04 Alice Popejoy: @Maren How have you handled discussions with patients about these questions/categories?

01:21:06 Maren Scheuner: I let patients know that it might help in the interpretation of the findings.

01:21:43 Lawrence Brody: @Carolina - thank you. 1997 is recent to me. The speakers also mentioned that that healthcare systems are not required to change when OMB does.

01:22:28 Alice Popejoy: 100% Lynette

01:23:56 Bob Cook-Deegan: I asked about price because to become practical as a screen, costs would have to drop another order of magnitude. Core costs might drop; wonder if prices will.

01:27:09 Alice Popejoy: Thank you!

01:28:55 Lawrence Brody: @Bob. - Screening for anything and everything? Most multigene panels have some condition/risk focus.

01:29:51 Alice Popejoy: @Larry - There were changes to the latest Census (2020) that included piloting questions on ‘Hispanic ethnicity’ as either: 1) separate ethnicity question, apart from race; 2) combined into the race question so that people can select ‘Hispanic or Latino’ as a race category. The data show that integrating this category into the race/ethnicity question results in fewer ‘other’ designations because many folks don’t want to select a different race.

01:29:51 Angelica Johnson: We invite you to register for our next ADWG ELSIconversations session - Utility of Population Descriptors in Clinical Genetics

https://us06web.zoom.us/meeting/register/tZAofuyrrzkrE9y0ATWKfn1S3cq5Vu8XiqeF

We would appreciate your feedback. Please fill out our survey to discuss your experience and to make suggestions for topics and speakers:

https://cumc.co1.qualtrics.com/jfe/form/SV\_5yzJNJtFqFgvAQm

01:30:31 Carolina Mayes: Thank you speakers!

01:30:35 Lawrence Brody: Great discussion. Thank you Gilliann, Hannah and Alice.

01:30:43 Stephanie Rouse: Thank you very much!

01:30:48 Marie Legendre: Thank you!