Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG) Meeting Notes Twelth Annual Meeting, Hybrid (Virtual and In-Person) February 15, 2023 <u>https://www.genome.gov/ISCC-PEG</u>



N=121 registrations; 93 virtual; 28 in person

For videos and slides of presentations, please see the ISCC-PEG 12th Annual Meeting <u>Homepage</u>, including a <u>YouTube Playlist</u>. Abbreviated highlights of the meeting are included in the notes below.

Welcome and Introductions, ISCC-PEG Co-Chairs: ISCC-PEG: <u>Annual Meeting 2023 Roadmap</u> *Rich Haspel, M.D., Ph.D., Beth Israel Deaconess Medical Ctr and Harvard Medical School Donna Messersmith, Ph.D., Education and Community Involvement Branch, NHGRI*

- ISCC-PEG has over 286 members representing 58 organizations, 11 government/institutes, 7 companies, and 138 individual members.

- 31 new members have joined since the February 2022 meeting.

- The ISCC-PEG Scholars Program has entered its third year. The program pairs a Scholar with

an ISCC-PEG mentor who provides guidance on a Scholar-led project. Scholars were eligible to receive travel funds to attend this year's in-person Annual Meeting. There are two new Scholars

this year, for a total of five Scholars; the 2020-2022 Class of four Scholars graduated last October (<u>final presentations</u>).

2022-2024 Class of Scholars

Ava Willoughby, The Ohio State University Genetic Counseling Graduate Program; Mentor: Barbara O'Brien, M.D., Beth Israel Deaconess Medical Center

Molly Felix, Master of Science in Genetic Counseling, Virginia Commonwealth University; Mentors: Vinaya Murthy, MPH, M.S., LCGC, Indiana University School of Medicine and Ebony Madden, M.S., Ph.D.: Training, Diversity and Health Equity Office, NHGRI

Welcome, Eric Green, M.D., Ph.D., NHGRI Director: NHGRI Highlights

- Dr. Eric Green provided an overview of NHGRI's strategic vision, including priorities around workforce diversity, understanding genome function, and implementing genomic medicine. He highlighted advances in rare disease diagnosis, cancer genomics, newborn sequencing, and pharmacogenomics as examples of progress.

Keynote Presentation. *Delivering on Our Promise: DNA Results for All of Us Participants and What It Means for Healthcare Providers*, Josh Denny, M.D., M.S., CEO of *All of Us*

- Dr. Josh Denny presented on the All of Us research program, which has enrolled over 600,000 diverse participants so far. He discussed their goals around engaging participants, providing different tiers of data access, and making the platform easy to use for a wide range of researchers.

2021-2023 Class of Scholars Presentations

Abimbola Oladayo, University of Iowa: <u>Reviewing Genetics and Genomics Resources for OB-GYN</u> <u>Professionals</u>

Katharine Press Callahan, University of Pennsylvania: <u>Hospital-Level Variation in Genetic Testing</u> in Children's Hospitals Neonatal Intensive Care Units from 2016 to 2021

Sarah Roth, JHU/NIH Genetic Counseling Training Program, <u>'Multiple weights off my chest':</u> <u>Exploring Gender Diverse Experiences of Hereditary Cancer Care</u>

NHGRI Extramural Grant Opportunities

Dave Kaufman, Ph.D.: An Intro to [ELSI] Research Funding

Simona Volpi, Ph.D.: Funding Opportunity Announcements (FOAs)

- There was a discussion on grant opportunities from NHGRI, with tips for connecting with program officers and finding relevant funding announcements.

- NHGRI Extramural Program officers presented on grant opportunities, particularly R25 grants for educational programs.

Project Group Summaries and "Asks" of ISCC Membership

- The nursing genomics group is working on Frequently Asked Questions documents for different nursing audiences. They aim to have these completed by March.

- The DTC genetic testing group is seeking feedback on their existing FAQ document by March 15. They are also finalizing recommendations for primary care providers on responding to DTC results.

- Project groups provided 5-minute updates on their discussions and activities. Themes included disseminating resources, proposals for conferences, and collaborations.

Wrap up/future directions

- The group proposed having additional "best practices" meetings in off-months to cover topics like cultural sensitivity training.

- There was discussion around improving accessibility of resources and avoiding ableism in educational materials.

- Plans were made for the next in-person meeting, and discussions about the final scholar presentations in Fall 2023.

- Participants were encouraged to reach out to expand membership and disseminate resources to relevant organizations.

The main action items were providing feedback on existing resources, disseminating new resources once finalized, recruiting new members, and determining topics/structure for supplementary education meetings.

Chat Excerpts from Annual ISCC-PEG Meeting 2/15/23

02:28:49 Tracey Weiler: We will be working to update the FAQ at this meeting. https://www.genome.gov/For-Health-Professionals/Provider-Genomics-Education-Resources/Healthcare-Provider-Direct-to-Consumer-Genetic-Testing-FAQ If you have any suggestions, please do let us know! tweiler@fiu.edu 02:31:17 Tracey Weiler: @Barbara O'Brien - I would love to know how your curriculum for the OB-GYN residency compare to the APHMG UME core competencies.

02:37:53 Barbara O'Brien: We queried via the delphi method this group to see what the group thought would be the most important for specifically OB/GYN residents (as opposed to genetics residents)

02:39:58 Anne Ersig: If anyone really wants the ISCC-PEG policy document, it's here: https://www.genome.gov/sites/default/files/media/files/2020-05/2020 ISCC-

PEG_Description_and_Policies_Final.pdf

02:47:38 Tracey Weiler: Replying to "@Tracey Weiler would..."

People from the APHMG and the ACMG Education committee are discussing the use of the med student core competencies developed by the APHMG for other groups beyond med students.

https://www.gimjournal.org/article/S1098-3600(22)00858-9/fulltext

02:52:20 L Brody: RE: Slides - We can make them available after the meeting. Look for an email as to how and where to download.

02:54:16 L Brody: If you have questions during or after the talks feel free to use the raise hand function or post your questions in the chat.

03:01:50 Tracey Weiler: As genomics is becoming more profoundly relevant to society, how do we ensure that genomics becomes more integral to the undergraduate medical education curriculum? Genomics cannot be a peripheral anymore!

03:06:03 Katherine Hyland: @Tracey - INDEED!! We need to convince non-geneticist clinical educators of the importance of genetics/genomics across fields, so we can get buy-in and reinforce g/g in clinical training.

03:07:00 Barbara O'Brien: Replying to "@Tracey Weiler would..."

Thank you. This curriculum will be for OB residents as you know there are no guidelines. I would love to get involved in the ACMG education committee. I am an MFM/geneticist.

03:08:58 Katherine Hyland: Replying to "@Tracey Weiler would..."

Hi Barbara - it would be great to have you involved in APHMG too https://www.aphmg.org/ - we focus on genetics/genomics UME and GME.

03:09:16 Tracey Weiler: Replying to "@Tracey Weiler would..."

Barbara - reach out to Jane Radford @ ACMG. She is also a member of ISCC-PEG.

03:11:05 Barbara O'Brien: Replying to "@Tracey Weiler would..."

Wonderful.Thank you. I definitely will.And Katherine Hyland I will also get involved with APHMG!03:12:13Katherine Hyland:Replying to "@Tracey Weiler would..."

Terrific! we'll be very happy to have you join us at APHMG!!

03:14:01 Tracey Weiler: With respect to training, what are your thoughts about training for "genetics and genomics literacy" for non-geneticist healthcare professionals? How does this fit within the NHGRI strategic plan?

03:14:21 Anne Ersig: I love the talking glossary for my students - so glad to see it's been updated.

03:16:31 Karen Niemchick: Tracey-I am very involved in public health genomics education. I agree with your question on non-geneticist professionals.

03:16:42 Tracey Weiler: Reacted to "Tracey-I am very inv..." with 😃

03:21:14 Maya Sabatello:Can you pls post the link to the new edu material/genomic terms?

03:21:40 Rosann Wise: https://www.genome.gov/genetics-glossary

03:22:09 Tracey Weiler: Collaborative efforts between NHGRI, APHMG, ACMG, AAMC, ASHG are critical!

03:22:22 Holly Snyder: Stuart Flynn, the Dean of the Burnett School of Medicine at TCU is doing amazing things with the new program there to integrate genomics from the first year!

03:22:25 Rosann Wise: https://www.genome.gov/about-genomics/educational-resources/fact-sheets/human-genomic-variation

03:22:39 Anne Ersig: Don't forget all the non-physician groups, too! NSGC, ISONG, etc.

03:22:44 Tracey Weiler: Reacted to "Stuart Flynn, the De..." with 👍

03:22:54 Elizabeth Kudron: Would love to hear how to get involved with APHMG

03:22:54 Tracey Weiler: Reacted to "Don't forget all the..." with 👍

03:23:43 Katherine Hyland: UME Genetics Core Competencies from APHMG are available here: https://www.aphmg.org/Papers-&-Collaborations

03:24:27 Shoumita Dasgupta: @Elizabeth and all, please visit aphmg.org and sign up for the contact list. Also feel free to reach out to Kathy Hyland (President), myself (Past President), Kate Garber and Tracey Weiler (ISCC members and APHMG members).

03:25:44 Katherine Hyland: @Elizabeth, Barbara and others - our APHMG annual meeting is May 2-5 at Kiawah Island, SC https://www.aphmg.org/2023-Annual-Meeting

03:42:48 alissa terry: I'd love to brainstorm how our work as the HRSA funded regional genetics network that covers Puerto Rico and US Virgin island could possibly support All of Us efforts in those territories. Our team travels there at least annually to do community and professional genetics outreach.

03:44:12Tracey Weiler: It is really interesting that All of Us can be linked to healthcareprofessionals.How do we increase capacity for these professionals to be able to use this information?03:44:46Rachel Mills, MS, CGC (she/her):Replying to "It is really interes..."

I have a similar question, Tracey. Specifically regarding clinical confirmation of AOU research results that participants receive.

03:49:02 Elizabeth Kudron: Are these clinical results or do they need to be validated to be used in clinical decision making?

03:54:58Larry Brody - NHGRI:All of Us data browser: https://databrowser.researchallofus.org03:56:55Tracey Weiler:I think that this Researcher Workbench would be really great forstudent research projects.Can individual students authenticate? or does this need to be faculty?

04:00:17 Katherine Hyland: We're going to have a plenary on leveraging large scale genomic projects for student/trainee education and research projects. We'll have someone specifically speaking about using the All of Us database for research/training projects https://www.aphmg.org/2023-Annual-Meeting

04:00:51 Katherine Hyland: ^^ At the APMG annual meeting May 2-5 in Kiawah Island, SC https://www.aphmg.org/2023-Annual-Meeting

04:01:17 Larry Brody - NHGRI: RE: All of US researcher workbench:

04:01:20 Larry Brody - NHGRI: How can I access All of Us genomic data?

All of Us genomic data are only available through the Controlled Tier of the Researcher Workbench. Currently, only registered researchers whose institutions have Data Use and Registration Agreements in place with All of Us that include the Controlled Tier can access genomic data. Visit the Institutional Agreements page to check your institution's access.

If your institution has access, you can follow the steps on our Access page to become an All of Us researcher. If your institution does not have a Data Use and Registration Agreement (DURA) in place with All of Us, or if your institution's current DURA does not yet allow for Controlled Tier access, you can initiate the process here.

04:01:31	Larry Brody - NH	GRI: https://www.researchallofus.org/data-tools/workbench/
04:01:55	Heewon Lee:	Reacted to "^^ At the APMG annua" with 🌑

04:04:00 Vinaya Murthy: @Larry Brody - how do you know if your institution has an agreement in place?

04:04:24 Tracey Weiler: https://www.researchallofus.org/institutional-agreements/

04:05:46 Anne Ersig: You can create a notebook, though, right? Even though the person testing it adapted an existing one?

04:13:13 Cyrine Haidar: Great presentation Josh! You mentioned that genetic counselors speak to patients about their pharmacogenomic test results. Do you have pharmacists as part of this team? If yes, what is the role of the pharmacist?

04:14:51 Tracey Weiler: So exciting to see the shift away from white participants. What is All of Us doing to reassure participants that their data is being handled correctly? I imagine that this needs to be a frequent and nuanced conversation with the research participants.

04:17:34 Jerryl Somani: Everyone, If you have a question that you wanted to ask during the Q/A after presentations, please raise you hand and we'll recognize you to unmute yourself to ask your questions.

04:19:31 Jeneva Gularte-Rinaldo: Reacted to "Everyone, If you hav..." with 👍

04:21:25 Jerryl Somani: Please note. Due to time constraints you might not be able to ask questions so it's also best to enter you questions in Chat and it can be followed up on later

04:21:56 Rene Begay: Reacted to "Everyone, If you hav..." with 🐴

04:22:26 Jeneva Gularte-Rinaldo: Agreed. Chat is better for time management with Q & A and can be communicated by the facilitator. Thanks, Jerryl!

04:22:46 Rene Begay: @Tracey. Valid question. Same question I had

04:23:03 Jerryl Somani: Trying to give some equity to remote users :-)

04:24:15 Jeneva Gularte-Rinaldo: Reacted to "Trying to give some ..." with 🐴

04:25:18 Sarah Roth: Reacted to "Trying to give some ..." with 👍

04:25:53 Jeneva Gularte-Rinaldo: Thank you for this All of Us presentation @ today's 12th Annual ISCC-PEG Hybrid Meeting. I was a co-PI for one of the NAHN pilot program in California and co-authored a publication "Increasing Awareness of the All of Us Research Program in Latino Communities" in Hispanic Health Care International.

04:38:03 Tracey Weiler: Reacted to "@Tracey. Valid quest..." with 🐴

04:39:31 Jeneva Gularte-Rinaldo: You're muted

04:53:55 Erin DeBruin: The NIH materials are now accessible to anyone for a year, for a minimal charge (15 pounds)

04:56:50 Erin DeBruin: The NHS course materials are now available for anyone outside of the system for a nominal fee (15 pounds)

04:59:03 Cyrine Haidar: Erin, could you please send us the link to the course material?

05:00:33 Katherine Hyland: Maintaining a central repository, like genome.gov, as a go-to education resource place, and keeping resources updated is key!

05:00:49 Tracey Weiler: Reacted to "Maintaining a centra..." with 👍

05:01:04 Rachel Mills, MS, CGC (she/her): findageneticcounselor.com!

05:01:41 Tracey Weiler: ..https://clinics.acmg.net/

05:02:10 Tracey Weiler: https://www.acmg.net/ACMG/Directories.aspx

05:02:24 Emily Edelman: Thanks, Rachel and Tracy! Yes, NSGC and ACMG have good tools for finding genetics professionals.

05:02:40 Adriana Malheiro: GTR has a list of organizations that have directories of genetics professionals, including NSGC and ACMG

https://www.ncbi.nlm.nih.gov/gtr/docs/resources/#locate_geneticist

05:15:01 Tracey Weiler: What is the distribution of genetic expertise in NICU?

05:16:47 Karen Niemchick: As this was an exploratory study (very nice!) what would you see as a next step?

02:17:33 Tracey Weiler: Can you correlate the genetic testing rates with the presence of genetic residencies/genetics clinics at the sites?

02:19:33 Sabrina Malone Jenkins: and educating neonatologists :)

02:20:10 Karen Niemchick: Thank you 🙂

02:22:09 Tracey Weiler: Which suggests that we need to broaden the genetics

expertise/genetics training programs around the country!

02:42:25 Anne Ersig: Link to Call article (if interested):

https://link.springer.com/article/10.1007/s11920-021-01245-9

02:50:51 Sarah Roth: Thanks, Anne!

02:51:19 Sarah Roth: If anyone wants to get in touch, you can reach me at:

sarahroth@jhu.edu 😊

02:54:23 Rosann Wise: https://reporter.nih.gov/

02:55:05 Rosann Wise: https://reporter.nih.gov/matchmaker

02:55:42 Jeneva Gularte-Rinaldo: Reacted to "https://reporter.nih..." with 👍

03:00:46 Tracey Weiler: What does "training" mean in the context of grant funding?

03:01:48 *Simona Volpi: I'll show some examples in my presentation

03:05:52 *Simona Volpi: training contacts: Heather Colley, heather.colley@nih.gov and Lucia Hindorff hindorffl@mail.nih.gov

03:20:51 Tracey Weiler: It looks like most of these opportunities are focused on increasing the capacity for geneticists. What about programs for non-geneticists?

03:21:32 Tracey Weiler: ^^ genetics for non-geneticists?

03:22:23 Katherine Hyland: @Tracey - agree, we need funding to support training in genetics/genomics of non-geneticist clinicians

03:23:01 Tracey Weiler: Reacted to "@Tracey - agree, we ..." with 🐴

03:24:12 Tracey Weiler: We have so many clinicians that do not have the competencies they need

03:27:14 Katherine Hyland: ^^AND if NHGRI would have funding to demonstrate specific support for training non-geneticist HCPs, that would help get buy-in from leadership for getting dedicated time for clinicians in different specialties.

03:27:57 Tracey Weiler: Reacted to "^^AND if NHGRI would..." with 💙

03:29:31 Erin DeBruin: Reacted to "^^AND if NHGRI would..." with 🎔

03:29:38 Jeneva Gularte-Rinaldo: would you recommend virtual attendees to stay on Zoom or log off and return after lunch?

03:30:39 Katherine Hyland: What time are we now starting break-outs?

05:57:45 Tracey Weiler: We are missing out being on Zoom instead of in person!

05:58:00 Kelsey Bohnert (she/her): Reacted to "We are missing out b..." with 💙

05:58:10 Katherine Hyland: Reacted to "We are missing out b..." with 💙

05:58:39 Kelsey Bohnert (she/her): I was just thinking that!

05:59:19 Tracey Weiler: Reacted to "I was just thinking ..." with 🤣

05:59:28 Tracey Weiler: Replying to "I was just thinking ..."

Next year - In person!

06:04:59 Tracey Weiler: Amazing logistical feat.

06:06:22 Nguyen Park, DMSc, MS, PA-C, DFAAPA: Reacted to "Next year - In perso..." with 💙

02:17:07 Anne Ersig: If anyone is interested in learning more about this group, please email Trina & me: trinawalker@creighton.edu, anne.ersig@wisc.edu

02:18:44 Barbara O'Brien: I'd be interested

02:19:25 Barbara O'Brien: bmobrien@bidmc.harvard.edu

02:20:35 Tracey Weiler: https://www.genome.gov/For-Health-Professionals/Provider-Genomics-Education-Resources/Healthcare-Provider-Direct-to-Consumer-Genetic-Testing-FAQ

Comments and Requests to Houriya.Ayoubieh@ttuhsc.edu; tweiler@fiu.edu; Deadline: March 15, 2023

02:24:23 Tracey Weiler: In the compendium, there is a link to G2C2. Shouldn't that be GenomeEd now?

02:26:03 Nguyen Park, DMSc, MS, PA-C, DFAAPA: https://www.genomicscases.net/en

02:28:18 Tracey Weiler: With respect to the genomics cases, has there been a review of the language vis-à-vis the AMA/CDC/AAMC guidelines that have come out recently?

02:31:28 Lisa Howley (She/Her) AAMC: I am sorry to have missed the group photo AND to be there in person and had to hop off in mid day today

02:32:33 Tracey Weiler: Reacted to "I am sorry to have m..." with 👍

02:36:10 Tracey Weiler: Could we use one of our ISCC-PEG general meetings for a workshop/training?

02:36:33 Lisa Howley (She/Her) AAMC: We are part of a new collaborative called ABC3 to better serve patients with IDD https://www.ie-care.org/abc3 and may be good connections here for this work as well

02:38:19 Maya Sabatello:Lisa, that's great! Let's connect ... my email is: ms4075@cumc.columbia.edu

02:39:28 Maya Sabatello:Also Shoumita's email: dasgupta@bu.edu

02:40:17 Tracey Weiler: Nguyen Park is a PA.

02:40:40 Kelsey Bohnert (she/her): If you have interest in the LGBTQ+ working group feel free to reach out to Lee and myself: williamsk38@upmc.edu and kelsey.bohnert@chp.edu

02:46:53 Shoumita Dasgupta: Thank you, Lisa - glad our paths cross again!

02:48:03 Tracey Weiler: Also - a shout out to Roseann Gammal leading a group of DTC-GT and PGx people on a paper for Annals in Internal Medicine describing a case of a patient with DTC and PGx results and what to do with them.

02:50:11 Tracey Weiler: @Donna - we had started a "best practices" for FAQ development. Can we extend that to other types of resources?

02:50:41 Rosann Wise: https://www.genome.gov/event-calendar/Healthcare-Professionals-Genomics-Education-Week

02:52:03 Rosann Wise: Please fill out the ISCC-PEG Annual Meeting Evaluation Survey: https://www.surveymonkey.com/r/isccpeg2023mtg

02:56:52 Amy Nisselle: Thanks, it's much nicer to see the person speaking in the room, rather than just a voice :)

02:56:57 Katherine Hyland: I think it would be super helpful to have a session on inclusive, sensitive language at a monthly meeting or additional virtual meeting, since that is something we should all be aware of when developing our resources, and use in our own teaching!

02:57:25Amy Nisselle:I agree, Katherine. Everyone would benefit from a session like that02:58:50Tracey Weiler:ACMG is hosting a "meet the patient" session at the medical studentlevel for Down Syndrome tomorrow night. Go to the Genetics Academy at ACMG to sign up.Registration is free.

02:59:00 Anne Ersig: Reacted to "I think it would be ..." with 🌑

02:59:20 Sarah Roth: Reacted to "I think it would be ..." with 🚫

02:59:35 Shoumita Dasgupta: Speaking of which, abstracts for APHMG due in two weeks! https://www.aphmg.org/2023-Annual-Meeting

02:59:35 Tracey Weiler:

https://www.acmgeducation.net/Public/Catalog/Details.aspx?id=ZQqG76v2DOD3RLFAKKuOrw %3d%3d&returnurl=%2fUsers%2fUserOnlineCourse.aspx%3fLearningActivityID%3dZQqG76v2DOD3RLFAKKuOrw%253d%253d

03:00:36 Tracey Weiler: Replying to "https://www.acmgeduc..."

Everyone is welcome, please share!

03:00:46 Anne Ersig: thank you for making this hybrid!!!! So nice to have such broad representation!

03:00:54 Tracey Weiler: Reacted to "thank you for making..." with 👍

03:00:56 Wesley Patterson: Reacted to "thank you for making..." with 👍

03:02:17 Claudia Mikail: Thanks for bringing everyone together live and online today. Good to see genomics education expanding into broader directions.

03:02:27 Katherine Hyland: Reacted to "thank you for making..." with 👍

03:03:06 Nguyen Park, DMSc, MS, PA-C, DFAAPA: It was so wonderful to see everyone and to see the momentum that ISCC-PEG has going!

03:03:08 Tracey Weiler: Thanks Donna and Rich and Rosann and Jerryl!

03:03:09 Katherine Hyland: Yes, thank you for making this a hybrid meeting so those who couldn't attend in person could still participate! Terrific meeting thanks all!

03:03:16 Amy Nisselle: Thanks, everyone - was great to 'see' you all!

03:03:19 Sarah Roth: Thanks everyone!

03:03:27 Sarah Roth: Reacted to "thank you for making..." with 👍

03:03:30 Wesley Patterson: Thanks everyone!!

03:03:44 Kathleen Blazer: Thank you for making this happen. Great experience as always!