

INTER-SOCIETY COORDINATING COMMITTEE FOR PRACTITIONER EDUCATION IN GENOMICS (ISCC-PEG)

DESCRIPTION AND POLICIES

National Human Genome Research Institute (2024)

Description

ISCC-PEG is an interdisciplinary, volunteer-based community of healthcare provider educators, government representatives, professional society and industry representatives, and trainees. The group is convened by NHGRI through the Education and Community Involvement Branch (ECIB), and ECIB does not provide grants or funding. Members are free to compete for NHGRI grants through the extramural program. In some circumstances, NHGRI may provide in-kind support for the initiatives proposed by ISCC-PEG leadership and members.

Mission

To improve genomic literacy of healthcare professionals and enhance the effective practice of clinical genomic medicine by facilitating interactions among key stakeholders in genomics education. Through ISCC-PEG, members can collaborate to identify educational needs and potential solutions, share best practices in educational approaches, and develop and disseminate educational resources.

Goals

1. Convene experts in the field and facilitate dissemination of best practices and resources in genomics education to promote the translation of genomics into evidence-based clinical care.
2. Assist key stakeholders, including societies, professional organizations, NIH institutes, industry representatives, students/trainees, and individuals with expertise in medical education, in identifying gaps and barriers in genomics education for healthcare professionals and develop potential solutions.
3. Develop resources to promote healthcare professional education and the effective practice of clinical genomic medicine.

ISCC-PEG Composition

1. Membership:
 - a. ISCC-PEG Membership Application: [here](#).
 - b. Organizational Representatives: Groups with an interest in healthcare professional education in genomics, such as professional societies or accrediting bodies, will have one “lead” representative with additional representatives as desired. Terms are determined by the member organization; however, a three-year minimum term is preferred. This amount of time allows representatives to get a feel for and help contribute to project groups.

- c. Federal Agency Members: Individuals representing other NIH Institutes and/or federal agencies such as CDC, FDA, or HRSA. Terms are determined by the member; however, a three-year minimum term is preferred. This amount of time allows representatives to get a feel for and help contribute to project teams.
 - d. Industry Members: Individuals representing biotechnology, pharmaceutical, or genomics services companies. Companies may have one “lead” representative or their designee if unable to attend, with additional “listening” representatives as desired. Terms are determined by the member; however, a three-year minimum term is preferred. This amount of time allows representatives to get a feel for and help contribute to project teams. Industry members are permitted to join Project Groups, but they will be asked to recuse themselves from any discussions regarding CME development and/or potential conflicts of interest (Appendix 1).
 - e. Individual Members: Individuals with a demonstrated interest in genomic medicine and education may join for a three-year term which may be renewed. Members from universities or academic medical centers are typically considered Individual members (*not* typically organizational representatives). Student/trainee members are welcomed.
 - f. All members must abide by the Policy for Ensuring Independence in ISCC-PEG Activities (Appendix 1).
 - g. All requests for membership will be reviewed and approved by ISCC-PEG co-chairs with a goal of overall inclusion.
 - h. Although ISCC-PEG is focused on U.S. issues, international members are welcomed.
2. Organizational Structure:
- a. Chairs: ISCC-PEG will be chaired by designated NHGRI co-chair and non-NHGRI co-chair. Potential non-NHGRI co-chairs are identified by soliciting membership for volunteers. Non-NHGRI co-chairs are selected by NHGRI for a three-year term, with a fourth year to overlap with an incoming non-NHGRI co-chair. Additional terms may be considered on an ad hoc basis.
 - b. Project groups: These groups play a key role in addressing specific needs in genomics education and developing related resources. Each project group has a chair or co-chairs. Additional information related to the project groups is provided below (Appendix 2). Any resources developed by project groups should adhere to the Policy on Review of Materials and Dissemination (Appendix 3).
 - c. ISCC-PEG Scholars: The ISCC-PEG Scholars Program provides exposure to the broader genomics education community and experts in the field, with the opportunity to work on a genetics/genomics-related education project under the mentorship of an ISCC-PEG member. Each scholar presents their projects at the annual ISCC-PEG meeting as well as during a final presentation at the end of the two-year term. Opportunities for networking, publishing, and funded travel are features of this professional development program. Additional information: [here](#).

Funding and Staff Support

1. Organizational and industry representatives participate in ISCC-PEG-related activities on behalf of their organization, and travel to ISCC-PEG meetings should be covered by the representative's organization when possible.
2. Although funding opportunities will be explored, individual members should also plan to pay for their own travel.
3. Members are encouraged to obtain outside independent funding for ISCC-PEG-related projects (Appendix 1).
4. At the present time, NHGRI will provide administrative support for ISCC-PEG, for example, by arranging Plenary conference calls, maintaining a roster, website management, minutes and other administrative tasks for ISCC-PEG general business. NHGRI will also support one Annual Meeting per year.
5. Project Group co-chairs maintain rosters of individual Project Group members and organize calls at regular intervals using their preferred institutional mechanisms (Zoom, Google, other) to facilitate collaboration.

Member Expectations

1. Participating in the ISCC-PEG Annual Meeting.
2. Participating in bimonthly "Plenary" telephone conference calls.
3. Joining a project group(s) and participating in project group conference calls as necessary (see Appendix 2 for additional information).
4. Contributing to the bi-annual update of the ISCC-PEG Compendium of member organization activities and resources.
5. Actively participating in discussions related to the goals of ISCC-PEG.
6. Adhering to Policy for Ensuring Independence in ISCC-PEG activities (Appendix 1).
7. Adhering to Policy on Review of Materials and Dissemination (Appendix 3).

Dissemination of Member Events

1. To limit the number of emails, only NIH or ISCC-PEG projects and events deemed appropriate will be included in communications with ISCC-PEG members directly.
2. If ISCC-PEG members and their organizations would like to share information about genomics-related events and resources they can be posted on the moderated NIH listserv, HCPGENOMICSED.

Appendix 1: Policy for Ensuring Independence in ISCC-PEG Activities*

ISCC-PEG welcomes diverse input. Membership includes professional societies, NIH Institutes, individuals, industry and others with an interest in genomics education. It is, however, critical that any educational resources are accurate, reliable, free of bias, and based on scientific evidence or otherwise accepted in the practice of medicine. The content or format of any ISCC-PEG-developed resource must promote improvements or quality in healthcare and not a specific interest.

To maintain impartiality, ISCC-PEG will not distribute free or paid educational materials affiliated with any commercial product through the listserv, ISCC-PEG website, or other formal communications channels.

Conflict of Interest

The following guidelines also apply:

1. ISCC-PEG Co-chairs should not have a relevant financial conflict of interest**.
2. ISCC-PEG Co-chairs should be notified of any potential members' financial conflicts of interest. A roster listing member affiliations and potential financial conflicts of interest will be circulated to members annually and members will be expected to update status.
3. All members may participate in "Plenary" calls and Annual Meetings. A list of participants in Plenary calls can be viewed through the zoom functions so that attendees are aware of the groups represented.
4. Any concern regarding independence in ISCC-PEG activities or financial COI should be brought to the attention of the co-chairs and/or NHGRI staff. The co-chairs and NHGRI staff will work with the involved parties to resolve the concern.
5. Any ISCC-PEG member may be a member of a project group. However,
 - a. Project groups should not be chaired by individuals with a relevant financial conflict of interest related to the resource being developed.
 - b. If the group is planning on developing an education product that has a perceived conflict of interest such as that defined by ACCME for continuing medical education:
 - i. Based on ACCME standards, industry members with a financial conflict of interest should be excluded from the project group.
 - ii. Early involvement of a society or organization that is ACCME accredited is strongly recommended to ensure adherence to ACCME Accreditation Criteria, Standards for Commercial Support and Policies.

*Adapted from Accreditation Council for Continuing Medical Education (ACCME) materials.

**Financial Conflict of Interest: A Financial Conflict of Interest exists when an ISCC-PEG member's financial interests could create or appear to create an incentive to directly affect the conduct of ISCC-PEG activities and/or development of ISCC-PEG resources.

Solicitation of Outside Independent Funding for ISCC-PEG Activities

There may be circumstances in which members of ISCC-PEG would consider outside funding agreements, and the terms of these agreements must be negotiated between parties. Solicitation and/or management of outside independent funding must occur outside of the boundaries of ISCC-PEG and NHGRI staff support. Federal employees are unable to participate in any conversations with industry partners about funding for projects or initiatives.

Appendix 2: Project Groups

Project groups are proposed by and made up of ISCC-PEG members. These groups play a key role in addressing specific needs in genomics education and developing, disseminating, and evaluating related resources. Examples of resources developed include genomic competencies for healthcare professionals and “plug and play” universal genomics education exercises adapted by several organizations and used at their Annual Meetings.

NHGRI does not assume responsibility for hosting and/or disseminating all materials created by Project Groups. Early in the creation of a project group, an NHGRI staff member may serve as a Project Group Coordinator to help organize, track progress and provide input to the different project groups. Project groups are encouraged to take on organizational and administrative responsibilities as soon as possible, following this initial “start-up” phase.

1. Proposing a Project Group
 - a. Any ISCC-PEG member may propose a Project Group.
 - b. A member interested in starting and chairing a Project Group should first contact the ISCC-PEG co-chairs.
 - c. Proposals will then be presented during an ISCC-PEG Plenary call or in-person meeting for member feedback and interest in joining the Project Group.
 - d. Consultation with ISCC-PEG co-chairs and NHGRI leadership about the feasibility of projects that require resources beyond the scope of the Project Group members’ time and effort, for example web materials or publications.
 - e. ***See Appendix 3 for the Policy on the Development, Review, and Dissemination of Educational Materials and Publications.***
2. Project Group Chair(s)
 - a. Two co-chairs are strongly encouraged to allow for sharing of effort and diversity of opinion. Co-chairs may be the individual(s) who proposed the group or other volunteers. The chair or co-chairs must not have a relevant financial conflict of interest related to the proposed resource or initiative (see Appendix 1).
 - b. Responsibilities
 - i. Develop a description of the project group for the ISCC-PEG website.
 - ii. Guide the process of clarifying the mission of the Project Group and relation to mission of ISCC-PEG.
 - iii. Identify measurable goals and other metrics to evaluate progress and decide when/if the group has concluded its purpose.
 - iv. Determine and help arrange, with NHGRI assistance as available, conference calls. Regular monthly or bi-monthly co-chair-run conference calls are recommended.

- v. Facilitate creating connections within Project Group members and between relevant other Project Groups.
 - vi. Reporting on Project Group progress on the bi-monthly plenary calls and at the Annual Meetings (reports can also be made remotely).
 - vii. A minimum of quarterly check-ins with ISCC-PEG co-chairs.
 - viii. Identify candidate Co-chairs for succession planning of the group, should the group need to continue past the Co-chair's term or availability for the project.
3. Project Group Membership
- a. Any ISCC-PEG member may be a member of a project group.
 - b. Principles of diversity, equity, and inclusion are to be incorporated into decisions regarding membership, leadership, and genomic education resource development and dissemination.
 - c. If the group plans to develop a resource that may be used for continuing medical/healthcare education (CME), see Conflict of Interest (Appendix 1).
 - d. ***See Appendix 3 for the Policy on the Development, Review, and Dissemination of Educational Materials and Publications.***
4. Funding
- a. Members are encouraged to obtain outside independent funding for ISCC-PEG-related projects (i.e., agreements regarding the funding would be between the funder and the ISCC-PEG member's home institution/organization). Any ideas in this regard should first be discussed with the ISCC-PEG co-chairs and NHGRI leadership consulted. If consistent with the Policy for Ensuring Independence in ISCC-PEG Activities (Appendix 1), this funding may come from ISCC-PEG member societies, companies, NIH and related sources.
 - b. ISCC-PEG Members will only receive publicly available information about NIH funding announcements and other extramural activities. If groups of ISCC-PEG members are interested in applying for NIH funding through the extramural research program (ERP), they may do so under the following conditions:
 - i. No NHGRI staff may serve as PIs, Co-PIs, or key personnel in the proposal.
 - ii. No NHGRI staff may provide letters of support for funding proposals, or otherwise act in any way to influence independent scientific review.
 - iii. ISCC-PEG Members may reference their participation/membership in ISCC-PEG in their application materials, but no existing or proposed activities may be communicated as NHGRI-endorsed.
5. Project Group Surveys: Project group surveys are under the oversight of the Project Group Chairs with ISCC-PEG input as needed.
6. Conflicts of Interest: Issues of Conflict of Interest are to be managed by the Project Group Chairs.
7. Sunsetting a Project Group: When the project group deems it has completed its core task/mission, it is acceptable (and encouraged) for the group to wind down activities and meetings. Project groups are not expected to be maintained in perpetuity, and members are encouraged to join other project groups to contribute new expertise.

Appendix 3: Development, Review, and Dissemination of Educational Materials and Publications

All materials developed through or with the assistance of ISCC-PEG should acknowledge the contribution of ISCC-PEG. These materials may include educational resources and publications (e.g., manuscripts or abstracts).

The following policy has been implemented to ensure a balance between member independence and NHGRI oversight.

Development

Upon project proposal and feasibility checks, the development of materials is the responsibility of the Project Groups (as described above).

- If the proposed project is an educational resource that is desired to be published on NHGRI's website (genome.gov), consultation with the NHGRI Office of Communications team is **required** before embarking on the project. Co-chairs and members will be asked to submit an outline of the proposed webpage/document, including (if relevant):
 - Objectives:
 - Target Audience:
 - Approximate Length for each part, for example: 4-6 questions, 300-500 words or less.
 - Expert commentary videos to accompany key questions.
 - Language level:
 - Supplemental materials:
 - Sample questions:
 - Sample answer:
 - Learn more links:
 - Proposed timeline for completion:

Authors are expected to include their affiliation with ISCC-PEG in the **Acknowledgements** section of the publication or resource, using the template language below:

"All authors are members of the National Human Genome Research Institute's Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG) NAME Project Group. The content/opinions expressed in this resource/article/publication is/are solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, U.S. Department of Health and Human Services, the United States Government, or the authors' affiliated institutions."

Authors are also encouraged to include their ISCC-PEG affiliation in the authorship line if the journal permits. If the project is a scholarly publication, there is no expectation that NHGRI staff must be authors unless they contribute substantially to the publication. In this event, NHGRI may consider providing the fees associated with publishing a manuscript on behalf of an ISCC-PEG Project Group.

Because ISCC-PEG is not an accrediting body, authors should refrain from using phrases such as Guidelines, Recommendations, Position Statements, etc. Instead, authors may use phrases such as resource, guide, playbook, methods, practices, points to consider, the evolving use of..., and other similar phrases when appropriate.

Review

Prior to any dissemination or submission of materials, including abstract submissions, ISCC-PEG Co-chairs should be given an opportunity to review content. Materials must be approved by Co-chairs before release with any association to ISCC-PEG. This review will serve two purposes:

- 1) To provide input to help improve the materials. The Co-chairs may also recommend additional outside review or review by ISCC-PEG members with specific expertise.
- 2) To ensure materials are consistent with ISCC-PEG and NIH policies. These include conflicts of interest (see also the "ISCC-PEG Description"). Any issues that may arise should be addressed prior to dissemination or submission. If needed, the Co-chairs may engage other NIH staff to provide expertise. Consistent with NIH policy, once a final version is approved, the materials should have the above disclaimers.

The NHGRI Co-chair will facilitate consultation(s) with Office of Communications for products that have been pre-approved to be posted on NHGRI's website.

Dissemination

All materials developed by ISCC-PEG project groups should be **available at no charge**. Materials (or information on how to access the material at no cost) will be posted on the ISCC-PEG website and additional locations on genome.gov. Links may be posted to approved partners who provide optional fee-based continuing education credit for completion of an educational resource.

ISCC-PEG members who present in public ISCC-PEG meetings and/or webinars (including Healthcare Provider Education Week), do so with the understanding that all relevant materials, PowerPoint slides, and video recordings are to be made publicly available on NHGRI's website and YouTube Channel (GenomeTV) after the meetings. Materials posted after meetings are done for the sake of transparency and the benefit of those unable to attend.

Please ensure that PowerPoint slides 1) do not contain unpublished data or 2) reference unpublished materials or contain sensitive content.

Any exceptions to this policy must be accompanied by an MOU/written agreement prior to the development and dissemination of the event.

If educational materials are to be converted into commercial products, the product will no longer be considered an ISCC-PEG Project Group product. The developer(s) will be responsible for ensuring they have the intellectual property rights necessary from that point forward.

All ISCC-PEG members should be made aware of new materials and assist, when possible, in dissemination (e.g., on an organization website, email to membership).

When appropriate, NHGRI will assist in dissemination of the resources through newsletters, social media posts, and presentations, crediting the members of ISCC-PEG for the work.

Project groups should **also** consider developing a strategic communications or marketing plan for their resources, including:

- a description of the intended audience (and sadly, no, “all healthcare professionals” isn’t specific enough)
- a few concrete communication goals (e.g. do you want to reach 10k people on social media, or do you want to have 20 people use the resource in their teaching)
- platforms, tactics, or ways of reaching that intended audience
- concise messaging to accompany the resource

Program Evaluation

NHGRI encourages all Project Groups to include a program validation and evaluation plan. NHGRI staff can advise on the development of evaluation plans.