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

# National Human Genome Research Institute (2018)

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

#### Goals:

- 1. Gather and facilitate dissemination of best practices and resources in genomics education and promote their translation into evidence based clinical care.
- 2. Assist key stakeholders, including societies, professional organizations NIH institutes, industry and individuals with expertise in medical education, in identifying gaps and barriers in genomics education for healthcare providers and potential solutions.
- 3. Develop resources to promote healthcare provider education and effective practice of clinical genomic medicine.

### **ISCC Composition**

#### 1. Membership

- a. Groups with an interest in health care provider education in genomics, including professional societies, NIH Institutes and industry, will have one "lead" representative with others as desired. Terms are determined by the member organization.
- b. Individuals with a demonstrated interest in genomic medicine and education for a three-year term which may be renewed.
- c. Members must abide by the Policy for Ensuring Independence in ISCC Activities (appendix 1).
- d. All requests for membership will be reviewed and approved by ISCC co-chairs with a goal of overall inclusion.

## 2. Organizational Structure:

- a. ISCC will be co-chaired by a non-NIH representative and an NHGRI representative.
   Potential non-NIH co-chairs are identified by soliciting membership for volunteers. Co-chairs are selected by NHGRI for renewable three-year terms.
- 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 in appendix 2.

### **Funding and Staff Support**

- 1. Groups with an interest in health care provider education in genomics, including professional societies, NIH Institutes and industry, support the ISCC-related activities of their representatives and their travel to ISCC meetings.
- 2. Although funding opportunities will be explored, individual members should also plan on paying for their own travel.
- 3. Members are encouraged to obtain outside independent funding for ISCC-related projects (i.e., agreements regarding the funding would be between the funder and the ISCC member's institution/organization), but any ideas in this regard should first be discussed with the ISCC cochairs and NHGRI leadership consulted. If consistent with the Policy for Ensuring Independence in ISCC Activities (appendix 1), this funding may come from ISCC members, companies, foundations, NIH and other related sources.
- 4. At the present time, NHGRI will provide administrative support for ISCC (arranging conference calls, maintaining a roster, website management, minutes and other administrative tasks).
  NHGRI will also support one in-person meeting per year. As the committee's activities grow, sustainable support is being sought from other sources.

## **Member/Representative Expectations**

- 1. Participating in the annual ISCC in-person meeting.
- 2. Participating in bi-monthly "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 on project groups).
- 4. Contributing to the bi-annual update of the ISCC Compendium of member organization activities and resources.
- 5. Actively participating in discussions related to the goals of ISCC.
- 6. Adhering to Policy for Ensuring Independence in ISCC activities (appendix 1).

### <u>Appendix 1: Policy for Ensuring Independence in ISCC Activities\*</u>

ISCC 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-developed resource must promote improvements or quality in healthcare and not a specific interest. The following guidelines also apply:

- 1. ISCC co-chairs should not have a relevant financial conflict of interest.\*\*
- 2. ISCC 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 in-person meetings. A "virtual" roll call through an automated computer poll will be taken at the beginning of a call or meeting so participants are aware of the groups represented.
- 4. Any concern regarding independence in ISCC 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 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 a resource that may be used for continuing medical education (CME):
    - 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.

#### Appendix 2: Project Groups

Project groups are proposed by and made up of ISCC members. These groups play a key role in addressing specific needs in genomics education and developing related resources. Examples of resources developed include genomics competencies for healthcare providers and "plug and play" universal genomics education exercises adapted by several organizations and used at their annual meetings. As often as possible, an NHGRI staff member will serve as a Project Group Coordinator to help organize, track progress and provide input to the different project groups.

- 1. Proposing a project group
  - a. Any ISCC member may propose a project group.
  - b. A member interested in starting a project group should first contact the ISCC Co-chairs. Proposals will then be presented during an ISCC conference call or face-to-face meeting for member feedback and interest in joining the project group.
- 2. Chair or Co-chairs
  - a. Two co-chairs, as opposed to a single chair, 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

<sup>\*</sup>Adapted from Accreditation Council for Continuing Medical Education (ACCME) materials.

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

- i. Develop a description of the Project Group for the ISCC website.
- ii. Guide the process of clarifying the mission of the Project Group and relation to mission of ISCC.
- 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 between project group members.
- vi. Reporting on project group progress on the bi-monthly plenary calls and at the in-person meetings (though reports can be made remotely).
- vii. A minimum of bi-monthly check-ins with the Project Group Coordinator
- viii. A minimum of quarterly check-ins with ISCC Co-chairs.

### 3. Project Group Membership

- a. Any ISCC member may be a member of a project group.
- b. If, however, the group is planning on developing a resource that may be used for continuing medical education (CME):
  - 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 CME standards.

### 4. Logistics

- a. Project groups decide themselves how often to meet although regular monthly or bimonthly co-chair-run conference calls are recommended.
- b. NHGRI can support conference call scheduling/WebEx, discussions at ISCC in-person meetings and writing and distribution of minutes to members.
- c. Members are encouraged to obtain outside independent funding for ISCC-related projects (i.e., agreements regarding the funding would be between the funder and the ISCC member's institution/organization) but any ideas in this regard should first be discussed with the ISCC co-chairs and NHGRI leadership consulted. If consistent with the Policy for Ensuring Independence in ISCC Activities (appendix 1), this funding may come from ISCC member societies, companies, NIH and related sources.