

A Report on the Work and Findings of the SACGHS Education Task Force

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Task Force Charge

- Collect information on health professional organizations' activities in genetics education and training
- Organize and facilitate a roundtable on genetics education and training
- Draft a resolution to the Secretary on genetics education and training

Information Gathering

- Solicited Information from 26 organizations on activities in and attitudes toward genetics education and training
- Goal was to identify key concerns, activities and issues to inform development of the Resolution

Information Gathering: Organizations

- *Genetic Specific Organizations (9 total):*
e.g.: APHMG, ASHG, and NCHPEG
- *Health Professional Education Organizations (8 total):* e.g.: AACN, AACP, and AAMC
- *Health Professional Organizations (9 total):* e.g.: AAP, ACP, and AMA

Information Gathering: Respondents

- Responses received from 15 out of 26 organizations (58%)
 - 4/9 Genetic Specific Organizations
 - 6/8 Health Professional Education Organizations
 - 5/9 Health Professional Organizations

Information Gathering: Respondents

- ASHG
- ISONG
- NCHPEG
- NSGC
- AACN
- AACP
- AAMC
- ADEA
- ASAPH
- NONPF
- AAP
- ACP
- AMA
- ANA
- NMA

Information Gathering: Types of Practitioners

- Physicians
- Pediatricians
- Internists
- Dentists
- Pharmacists
- Genetic Counselors
- Nurses
- Nurse Practitioners
- Allied Health Professionals
- Geneticists

GENETIC SPECIFIC ORGANIZATIONS' RESPONSES

Questions

- Do you have any ongoing activities and initiatives that promote and enhance the diversity of the genetics workforce?
- Do you have any ongoing activities or initiatives that generally enhance genetics/genomics curricula for health professionals?
- Do you have any ongoing activities or initiatives that promote the incorporation of genetics and genomics content into the licensure and certification process for other health professionals?

Current Activities to Promote and Enhance Diversity

- Focus on the very early stages of the workforce pipeline
 - Enhance genetics education in K-12 setting and conduct outreach activities
- Develop effective recruitment strategies to enhance diversity in genetic counseling
 - Update career materials to target and include minority populations

Current Activities to Promote and Enhance Diversity

- Targeted outreach to minority health professionals with information about genetically based care
- Outreach to traditionally minority colleges and to high schools, colleges, and universities that serve minority populations
- Incorporate enhanced diversity within the structure of the organization
 - NSGC's Diversity Subcommittee (standing Subcommittee within the Membership Committee)

Current Activities to Enhance Curricula

- Educational outreach, including:
 - Searchable speaker's bureau, short courses, regional conferences open to all health professionals, Annual Education Meeting
- Collaboration among professional organizations
- Development and dissemination of position papers and practice guidelines

Current Activities to Enhance Curricula

- Development of core competencies in genetics
- Development of online materials:
 - Newsletters, web-based instructional programs (or interactive CD-ROMs), search engines/information clearinghouses
- Courses to train faculty to teach genetics content

Current Activities in Licensure and Certification

- Credentialing programs in genetics
 - Genetics nurses and advanced practice genetics nurses
- Core competencies have informed programs that lead to licensure and certification
- Bi-annual genetics review course to prepare for boards, certification or licensure requirements

Recommendations for SACGHS Resolution

- “Be strong in your appeal to the HHS Secretary to actively support a wide variety of endeavors based in or funded by any of the HHS-based agencies, as well as seeking partnerships with other relevant Federal agencies.”
 - American Society of Human Genetics

HEALTH PROFESSIONAL
EDUCATION ORGANIZATIONS'
RESPONSES

Questions

- Please characterize the need, from the perspective of your organization, for the integration of genetics/genomics into the curriculum and training of health professionals.
- Are there barriers to the integration of genetics/genomics into the curriculum and training of health professionals? If so, what are they?
- Do you have any ongoing activities and initiatives in genetics/genomics curricular development? Do any of these activities incorporate cultural competency into curricula?

Perceived Need

- Need to acknowledge that genetic science is for both generalists and specialists
- Need improved access to new knowledge
- Need to be able to evaluate product claims
 - SNPs in interleukin-1 gene for periodontitis

Perceived Need

- Need to redefine and recast genetics as an inherent and overarching part of health
 - Need to provide a broad view of genetics and change attitudes about genetics
- Need to improve communication between all health professionals and the public about how genetics affects health

Perceived Need

- Need to determine level of knowledge needed
 - Who needs to know what?
- Need adequate education to answer patients' questions and direct them to information
- Need to provide tools for life-long learning
 - Develop new skills and acquire new knowledge

Barriers

- Difficult to find current case examples and role models
 - Problems applying genetics content to actual health care situations
- Lack of trained faculty broadly competent in genetics/genomics
- Integration of genetics into health care is undetermined and likely will occur gradually and at different rates in different areas of medicine

Barriers

- Difficulty in motivating students to learn something based on the promise of its future importance
- Over-crowded curricula and integration of basic science with clinical practice
- Genetics is still considered an esoteric field
 - Use of obscure illustrations in the learning setting

Current Activities

- Membership in NCHPEG
- Integrating NCHPEG's core competencies into entry-level competencies
- Survey on faculty competency in and understanding of genetics/genomics

Current Activities

- Sponsoring relevant legislation
 - Allows for development of curricula on topics, like genomics, that are critical to prepared practitioners
- Cultural competency is addressed broadly in the context of outreach to underserved populations
 - Not genetics specific

Recommendations for SACGHS Resolution

- Schools and professional organizations must provide leadership in preparing the next generation of health professionals in genetics
- CE is needed to “train the trainer”
- More funding is needed to support training and education in genetic technologies and to facilitate the incorporation of new knowledge and skills

HEALTH PROFESSIONAL ORGANIZATIONS' RESPONSES

Questions

- Characterize the need for the integration of genetics/genomics into curriculum and training of health professionals.
- What initiatives or activities are currently ongoing within your organization in this area?
 - Do they involve partnerships? Are they interdisciplinary? Have they resulted in educational products? What were their outcomes? Have you evaluated their impact?
- What steps is your organization taking to increase the diversity of health professionals who are competent in genetics?

Questions

- What are your organizations' particular concerns or issues with respect to genetics education and training?
- Please provide recommendations on the need for genetics education and training of health professionals and the appropriate role for different entities in meeting this need.

Perceived Need

- All health professionals need a strong knowledge base in genetics and genetic testing
- Need to understand how genetics interfaces with practice

Perceived Need

- Need to keep health professionals up to date with advances in genetics
- Need to integrate genetic information into all levels of the curriculum and commit to life-long learning

Current Activities

- Types of activities include:
 - CME educational sessions
 - Policy statements/White papers
 - Technical/Clinical reports
 - Web-based educational tools
 - Newsmagazine articles
 - Membership in NCHPEG
 - Symposia and education workshops at annual conferences
 - Journal articles

Current Activities: Interdisciplinary Nature and Partnerships

- Organization partnerships involve a variety of partners, including:
 - Federal agencies
 - Genetic specialty societies
 - Medical specialty societies
 - Non-profit organizations
 - Private companies
- The majority of organizations report that their activities are interdisciplinary

Current Activities: Outcomes and Evaluation

- Continued/High interest in genetics
 - Genetics sessions at national conferences are well-attended and highly-regarded
- High use and dissemination of genetics resources:
 - Hits to genetic websites
 - CME certificates for genetic CME programs
 - Distribution of paper based genetic education materials

Current Activities: Diversity of Health Professionals

- Efforts focus on:
 - Community outreach
 - Career Development
 - Education
 - Research
 - Advocacy
 - Organization position statements

Concerns

- The science underlying issues of “race” in medicine needs to be examined and integrated into genetics education and training
- For many physicians, genetics does not have immediate, daily, clinical applicability
- Genetics education must be represented throughout the entire continuum of medical education

Concerns

- Educational programs must have a focus on pediatrics and genetics
- Physicians prefer interactive learning with case studies
 - Case studies must emphasize current clinical applicability of genetics
- Effect of nursing shortage on patient education and informed consent
 - Key issue with respect to genetics

Recommendations

- Ongoing CE should be the responsibility of licensing agencies and professional organizations
- Development of profession specific materials should be left to the health professions
- Support genetics education programs would be an appropriate role for the government

Recommendations

- Funding is needed for new programs that feature educational practices known to change physician behavior
- Efforts in genetics education must extend to related areas of molecular medicine
- Benchmarks should be instituted to inform and assess the bidirectional impact of translational research (i.e., from the bench to the bedside and the reverse).

Recommendations

- Education and training should address:
 - population-based genetic variation and its utility in the emerging era of individualized medicine
 - the impact of genetic polymorphisms on the determination of “what is normal” in the era of molecular medicine
 - the scientific relevance and significance of minority participation in clinical trials to the quality of health care in emerging era of genomic medicine
 - the diagnostic importance of obtaining a good and complete family history on all patients

Education Roundtable

Purpose and Goals

- Discuss in detail organizations' efforts in and attitudes about genetics education and training
- Identify key concerns and barriers with respect to this issue from an organization perspective
- Inform the development of the Resolution for the Secretary

Education Roundtable

Participating Organizations

- American Association of Colleges of Nursing
- American Society of Human Genetics
- Association of American Medical Colleges
- Association of Schools of Public Health
- International Society of Nurses in Genetics
- National Coalition for Health Professional Education in Genetics
- National Medical Association
- National Society for Genetic Counselors

Education Resolution Purpose

- To arrive at a consensus of the Committee on the issue of genetics education and training
- To convey this consensus to the Secretary
- To make recommendations to the Secretary on possible steps to address this important issue

Education Resolution Conclusions

- Genomics can improve health
- Adequate education and training in genetics and genomics is essential to integrating genetics into the health care system
- Access is contingent upon effective integration

Education Resolution

Conclusions

- Education and professional organizations identified the following needs:
 - Inventoried, widely relevant clinical applications;
 - Educational models that use such applications;
 - Broadened focus from genetics to genomics;
 - Appropriately trained faculty; and
 - Training programs that address genomics and public policy.

Education Resolution Recommendations

- Do not employ a genetic exceptionalist approach in genetics education and training programs and policies
- Support programs that enhance diversity among and cultural competency of health professionals
- Engage other stakeholders in the process of cataloguing genomics applications to clinical medicine and public health

Education Resolution Recommendations

- Support programs that “train the trainers” in genomics/genetics education
- Promote communication between faculty to enhance use of genomics educational models
- Encourage incorporation of genetics/genomics into the certification and licensure process