

# Community Genetics Forum 2005

University of Washington

## Executive Summary

On May 21, 2005, the University of Washington hosted a community event in Seattle, entitled “DNA, Health, and Social Justice: A Community Forum on Genetics” (Forum). The event was sponsored by the National Human Genome Research Institute (NHGRI). Two hundred and fifty members of the public attended the event, a third aged 10 to 20 (predominantly high school students), a third aged 21 to 40, and a third over age 40. Community outreach to leaders of diverse organizations in the Seattle area was used to notify members of the public about the Forum. Community leaders also helped to shape the content and presentation of the Forum.

## Content of the Forum

The Forum began with a plenary session that included students presenting original art based on genomics themes; a keynote speech by Dr. Francis Collins, Director of the National Human Genome Research Institute; and a panel of respondents drawn from the community, including Sharon Terry, Chief Executive Office of the Genetic Alliance, Makani Themba-Nixon, of the Praxis Project, and Ralph Forquera MPH, Executive Director of the Seattle Indian Health Board.

Following the plenary session, participants had the opportunity to participate in several break-out sessions consisting of brief presentations of topic information followed by interactive discussion. Most break-out sessions were limited to 25 participants, to ensure adequate opportunity for discussion. Each participant had the opportunity to participate in two break-out sessions, one before lunch and one after lunch. Several sessions were repeated in both the before-lunch and after-lunch time slot. Session leaders were drawn from UW, NHGRI, and the community. Session topics included:

Behavior and genetics

Careers in Genetics

Control of DNA samples: genetics research and community-campus collaborations

Cultural competency and family history

Genetic discrimination

Genetics 101

Implications of genetics for environmental justice

Innocence Project

Racial profiling and DNA evidence

Testing for ancestry: race and genetics

Using genetics in healthcare

The Forum also included poster presentations by students of genomics projects created for a local science fair, and additional student performances at lunchtime. After the second breakout session, the group convened for a concluding plenary session. This session featured summary remarks by Dr. Collins and Dr. Wylie Burke, Chair of the UW Department of Medical History and Ethics, and a question and answer session for all participants. Dr. Collins closed the event with a round of song to guitar accompaniment, and received a standing ovation.

## **Evaluation of the Forum**

The availability and approachability of Dr. Collins and NHGRI staff were listed repeatedly as highlights by participants in the Forum. Several listed Dr. Collin's musical performance as a highlight of the event. Participants appreciated the framing of the opening plenary, the overall theme of open dialogue, and the interactive nature of the Forum. "The opening remarks gave a clear and concise introduction to many of the related issues addressed by this forum. The caliber of those presenting was appreciated." "The way the conversation/issues were framed--using a variety of frameworks--scientific, ethical, political, personal, racial, etc.--all critical components." Several commented on the morning session as being a highlight because of the audience interaction with the speakers and the quality of the speakers in general.

The diversity of the perspectives represented by attendees was also cited as a highlight, "I enjoyed the variety of people, age, race, [and] religion. This provided numerous opinions." "Getting to listen to different opinions and see how genetics impacts people from all different walks of life." Participants also acknowledged that this diversity contributed to the quality of the interactions and was appropriate given the themes of openness and dialogue. One academic participant emphasized "Community perspectives--absolutely inspiring panelists; empowering for audience to hear their stories." Most participants affirmed that their expectations were met, and most rated the Forum "very good."

## **Lessons Learned**

Community outreach is an essential component of an interactive forum. We found that many community leaders were uncertain about the relevance of genetics to their community, and could identify genetics topics of concern to their communities only after a period of discussion. Community leaders were instrumental in formulating the Forum with an emphasis on interactive discussion and to include topics addressing non-genetic uses of genetic information, such as forensics and ancestry testing.

The detailed evaluation process also provided much useful feedback to forum organizers. Evaluations were generally positive, but some small group sessions were more successful than others. Evaluations emphasized the need for coordination among session leaders, careful description of session content and objectives, and adequate opportunity for participants to ask questions. In some cases, participants expected clearer and simpler answers than genetic science can provide – notably in sessions on behavioral genetics and

DNA-based ancestry testing – suggesting that these are important topic areas for ongoing discussion.

## **Conclusions**

The Community Genetics Forum demonstrated that members of the community are looking for answers to tough questions about controversial topics such as race and genetics, are beginning to recognize the complexity of the implications of genetics, and are looking for more education and opportunities for dialogue. The focus on ethical, legal, social implications of genomics produced considerable dialogue between Forum participants.

Many participants commented that the Forum was a good example of how to create dialogue. Several comments were made that dialogue should continue, especially in smaller groups throughout different communities. The UW experience suggests that a Community Genetics Forum can provide a positive environment for community dialogue. Reflecting on the Forum held at the University of Washington on May 21, 2005, we have several recommendations for future planners of similar community events.