Final Report

Community Genetics Forum

Hosted by University of Washington

Sponsored by the National Human Genome Research Institute

May 21, 2005

Seattle, WA

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 on-going 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.

Introduction

On May 21, 2005 a community event entitled "DNA, Health, and Social Justice: A Community Forum on Genetics" (Forum) was convened at the University of Washington in Seattle. The event was sponsored by the National Human Genome Research Institute (NHGRI) and hosted by the University of Washington (UW). It was a public event with over two hundred fifty people attending. A wide range of topics was discussed, including health care applications of genetic information, careers in genomics, and the use of DNA-based tests in criminal law and ancestry testing. This report describes the process of planning, implementing, and evaluating the Forum. Throughout the report we highlight factors that supported or hindered planning and implementation of the Forum. Our intent is to provide guidance to future efforts to convene similar events to introduce the public to genomic science and its societal implications.

Planning the Community Genetics Forum

Environment

The University of Washington environment offered a wide range of resources to support the Community Genetics Forum. UW has multiple centers of genomics activity, including a Department of Genome Sciences, a Division of Medical Genetics within the Department of Medicine, a multidisciplinary Institute for Public Health Genetics, three NGHRI-funded Centers of Excellence, an NIEHS-funded Center for Ecogenetics and Environmental Health, a full range of clinical genetic services, and graduate programs in genome sciences and public health genetics. The faculty and students who planned and implemented the Forum were largely drawn from these centers, and their enthusiasm and expertise were essential contributors to the Forum. An existing educational outreach program based in the UW Department of Genome Sciences conducted a high school teacher training program in parallel to the Forum; participating teachers and their students were key participants in Forum activities. In addition, the Northwest Association for Biomedical Research (NWABR), a Seattle-based non-profit organization, included genomics as a topic area in its annual BioTech Expo, a science fair held each year in February that includes student projects ranging from experimental studies to literature to artistic performance; students whose projects focused on genomics were invited to perform or exhibit their work at the Forum.

Goals

Two initial goals for the Forum were identified through preliminary discussions among a Forum planning committee comprised of UW faculty and staff, NWABR, and representatives of the NHGRI (Table 1). The first goal was to share with the public the promises and challenges of genomics. As part of this goal, the planners sought to ensure broad diversity among the participants at the Forum. The second goal was to highlight career opportunities related to genomics research and the delivery of genetic health care services.

Main event and satellite activities

The main objective of this project was to hold a one-day public forum on genetics involving the community at-large, University of Washington faculty and students, high school students and teachers involved in the University of Washington Genome Sciences Outreach program, and NHGRI staff. To take advantage of the visit of NHGRI leadership to the Seattle area, several other events were organized around this public event including the following:

1. A *Student Genomics Forum* for University of Washington undergraduate and graduate students, with Dr. Collins as keynote speaker, followed by an NHGRI staff panel and student roundtable discussions with NHGRI staff and UW faculty.
2. An *NHGRI Grants/Fellowship Training* was conducted at the University of Washington for graduate students, post-doctoral fellows, and early-career faculty.
3. A *Genomics Luncheon* for regional health care stakeholders featuring Dr. Alan Guttmacher as luncheon speaker followed by question and answer session. (Appendix B: Genomics Luncheon Evaluation)
4. A *media event* was organized by UW Medicine News and Community Relations featuring Dr. Collins and NHGRI staff.
5. A *meeting of teachers* involved in the University of Washington Genome Sciences Outreach program, at which teachers had an opportunity to interact with Dr. Collins.

In addition, Dr. Collins was a featured speaker at the NWABR annual dinner, at which Seattle-based leaders in the Human Genome Project were honored. More than 400 participants were in attendance.

Planning Process

Timeline

The Project Timeline (Table 2) describes the tasks undertaken in planning, developing, implementing, and evaluating the Forum. Most activities can be grouped into five main domains: community engagement, institutional coordination and collaboration, program development, outreach, and evaluation. In general, activities involving community engagement began the planning process and provided valuable guidance for program planning, participant outreach, and program evaluation. Institutional coordination and collaboration required timely communication and clarity of expectations and roles. Activities in all five domains were iterative; for simplicity we present each as a linear process in this report, but progress in each domain was influenced by activity in the other domains.

Initial Planning

Planning Committee Dr. Wylie Burke convened a planning committee to engage various University of Washington departments, centers, and institutions involved in genomics and genetics research (Table 1). The primary role of this committee was to define the parameters of the NHGRI-sponsored event, define the scope and scale of a regional community event, identify ways to involve students and community members, and to

give thought to potential topics in genomics that might be of interest to the public. The faculty advisors were helpful in refining the key messages outlined by NHGRI and were critical to defining the initial goals of the Forum and for implementing the planning process. UW departments, centers and programs participating in the planning process included:

School of Medicine
- Department of Medical History and Ethics (W Burke, Chair)
  - Center for Genomics and Healthcare Equality (W Burke, PI)
- Department of Genome Sciences (R Waterston, Chair)
  - University of Washington Genome Center (M Olson, PI)

School of Public Health ad Community Medicine
- Institute for Public Health Genetics (M Austin, Director)
- Center for Genomics and Public Health (K Edwards, Director)
- Center for Ecogenetics and Environmental Health (D Eaton, Director)
  - Ethical, Legal, and Social Implications Core (M Austin, W Burke, Co-Directors)
  - Community Outreach and Education Core (T Brubacher, Director)

School of Law (Patricia Kuszler, Vice Dean for Research and Faculty Development)

College of Engineering
- Microscale Life Sciences Center (D Meldrum, PI)

Core Role of Faculty from the Institute for Public Health Genetics Faculty of the Institute for Public Health Genetics (PHG), a multidisciplinary program of the University of Washington (http://depts.washington.edu/phgen/) were solicited for their advice on planning the community event and identifying community contacts and leaders who might be interested in participating in the planning process. Several faculty members had previous experience working with community advocates as guest speakers in their classes or from previous research collaborations and had several recommendations. Faculty connections were helpful to event coordinators in establishing lines of communication with several community organizations including support networks within various disease-affected communities, religious leaders, and leadership in the legal non-profit sector. In addition, faculty also helped introduce coordinators to additional faculty in the humanities and social sciences in fields such as communications, philosophy, anthropology, etc. who eventually served as session leaders and attended the Forum.

Community Contacts The process of involving community contacts was based on existing relationships with community organizations and community leaders. The NHGRI-funded Center of Excellence in ELSI Research, the Center for Genomics and Healthcare Equality (CGHE), had previously engaged in a round of conversations with programs serving Native Americans in the Pacific Northwest region. Although some of these conversations had been initial contacts, they provided an avenue for additional discussion. In addition, the National Institute for Environmental Health (NIEHS)-funded Center for Ecogenetics and Environmental Health (CEEH) had relationships with community organizations and agencies that were a direct result of a Town Meeting hosted in 2000. These collaborators, whose interest lay mostly in environmental health

and justice, were approached regarding their interest in genetics and genomics. The coordinators also approached organizations with health, environmental and social justice missions such as The Church Council of Greater Seattle, the Health Justice Network, and the Asian Pacific Islander Coalition Against Tobacco. These organizations were interested in how the genetic research would unfold and ultimately impact the lives of the general public and especially communities of color and low-income community members. The coordinators had phone conversations, followed by in-person meetings with each community advisor. The community advisors met together once to review Forum planning and to discuss the breakout session topics. All other communication took place by phone, e-mail, or individual meetings.

The initial round of contacts with a handful of community representatives produced modest interest in the project. Over the course of two months, the project coordinators attempted to contact several additional community organizations by phone and email and eventually met in person with approximately 15-20 individuals. During these sessions we introduced ourselves, explained the background of the project, and solicited input as to the purpose of convening a community event and what topics or issues might be of interest to the contacts' community constituents.

Community Engagement

After initial discussions with professional and personal contacts, the coordinators asked several of these individuals to serve as community advisors. All but two initial contacts were willing able to serve in this advisory role; in addition, two UW faculty from perspectives outside University of Washington genomics activities agreed to serve in this advisory role (Table 3: Community Advisors). Serving in this role entailed providing input on the agenda and session topics and sharing notices about and invitations to the Forum with their constituents. Advisors helped to shape the Forum agenda to ensure that the elements comprising the day would be appropriate and relevant for community participants. For example, they saw value in having comments from a community perspective following Dr. Collins' keynote speech. The community advisors provided input on shaping the content and tone of the breakout sessions. After the session topics were agreed upon, the advisors gave much needed guidance on naming the breakout sessions. Community advisors were also critical for expanding the Forum's reach to include diverse community-based organizations and in extending personal invitations to their constituents.

Partnership and Collaboration with NHGRI

After our first round of contacts and preliminary discussions about both the planning process and evaluation, staff met with the NHGRI Chief of Education and Community Involvement Branch Vence Bonham to provide an update on planning progress and how the Forum was taking shape. An event summary sheet was developed from initial conversations with key informants and was shared at this meeting. Four elements were included (Appendix A: Event Summary Sheet: Why are we talking about communities and genomics?, What is this event?, How can you be involved?, Event Contacts). The summary emphasized the importance to communities of the implications of genomics in our lives, presented the event as an opportunity to learn and dialogue about the implications of genomics, and invited community members to help shape the content of

the Forum. Staff and Mr. Bonham agreed upon the direction and shape of the event and developed a list of tasks and timeline needed for information and materials to be exchanged between the NHGRI and UW staff.

Monitoring Planning and Outreach Process

Another important aspect of planning the Forum was to develop several working tools for program planning and outreach. One tool for outreach was a database of potential invitees. This list was comprised of community organizations and some individual community members. Several sources of information were used to compile the database including discussions with key informants, professional contacts brought to the project through CEEH and CEER, community advisors, and lists from directories of community organizations working in different social justice arenas. The final list included over one hundred community based organizations including contact information for individuals within organizations who were either known by the coordinators or identified based on their organizational role of role in community leadership.

A comprehensive Planning Document was created to keep track of progress on various elements of the Forum. This included elements such as: Title, Date, Background/Context, Goals/Objectives, Outreach Progress, Logistics (Room rentals, Directions/Transportation, Audiovisual, Room set up, Food, Floor plan/layout), Volunteers, Evaluation, Budget, Invited speakers, Tentative Agenda, Developing Session Topics, List of Advisors, etc. Elements of this document eventually became the starting point for separate documents used during in the event. For instance the Developing Session Topics became the list of topics we discussed with community advisors which in turn was the starting point for developing session summaries that were included in the event packet. The document also became the point of references for staff as they coordinated the different elements for the Forum and ensured that elements were addressed in a timely manner.

Naming the Event

The title of the Forum was the product of negotiation between stakeholders (Table 4: Title Progression). There were many iterations of the title of the event and the title evolved as the event evolved. Originally, the event was conceptualized as a symposium for community members to participate in, following a presentation by Dr. Collins. As the program developed into a day for community dialogue, it became important to reflect the open tone of the event in the title, hence the concept of a Forum emerged. Discussions with community advisors also pointed out that the term “genomics” was too far removed from the experiences of community members to hold meaning. Therefore, the terms “genetics” and later “DNA”- both perceived to be more readily identifiable and meaningful to members of the general public - were used in the title instead of “genomics.” Finally, as the theme of social justice developed through conversations with community advisors and played a larger role in the content of the Forum, it became appropriate to recognize “social justice” in the title of the Forum. In comparison, the student forum event, an opportunity for students to interact with Dr. Collins, was originally named Student Genomics Forum and kept that name throughout the planning process.

Development of Session Topics & Format

The development of session topics began with discussions with the planning committee, involved shaping from staff, and input from community advisors. The flowchart in Table 5 describes the changes and permutations through which the session topics underwent. . Based on the key messages and goals of the Forum, the planning committee suggested a set of current topics in genetics (column1). The set of topics then were presented to community advisors in individual meetings. The input from these meetings generated the second column of topics. Finally, the list of topics was discussed with community advisors during a group meeting, leading to the final topics and session titles identified in column 3.

The community advisors suggested breakout sessions on topics such as "Implications of Genetics for Environmental Justice" and "Racial Profiling and DNA Evidence" which were not originally identified by the planning committee. However, several session topics were identified by both planning committee and community advisors, including "Ancestry Testing", "Genetics in Healthcare" and "Behavior and Genetics."

Discussions with community advisors about how to implement the theme of community dialogue led to the format of the breakout sessions. Advisors and staff struggled with the reality that some community members may have little scientific knowledge about a genetics-related topic but would, at the same time, want to discuss the issues and pose questions related to the topic. This meant that each session required both a limited information sharing component and a facilitated discussion component. As a result it was decided that each session would have a facilitator and one or two session speakers. Session speakers would be limited to 10-15 minutes total for information sharing, with the information to include what seemed most relevant for informing the proceeding discussion. The discussion would be framed around either one or more case studies or a few key questions for consideration. Community advisors also emphasized the value of having community members in the role of facilitator or speaker.

The final schedule for the Forum is shown in Appendix B (also available online at http://www.genome.gov/14514655)

Session Leaders and Preparation

Conversations with community advisors affirmed the desire for a response panel following Dr. Collins's keynote address, with the panel focusing on community perspectives. Several possible candidates were proposed by staff and faculty including nationally recognized advocates and researchers addressing community issues and genetics. From this process, three individuals were identified who would reflect varied perspectives on genetics from different communities: Sharon Terry from the Genetic Alliance, Ralph Forquera from the Seattle Indian Health Board, and Makani Themba-Nixon from the Praxis Project. These three individuals represented local and national stakeholder communities and organizations that serve diverse functions for different communities, including community organizing, advocacy, health services, and community representation.

Breakout session leaders were sought who could provide information on genomic topics, including ELSI, and facilitate a community dialogue. Academic resources from the University of Washington were critical for providing genetics-related information in

the areas of ethics, law, health policy, medical anthropology, public health, genetic services, psychology, genetic epidemiology and genomics. NHGRI staff served as both providers of information and facilitators (e.g. Ancestry Testing, Behavior and Genetics, etc). Two scientific experts were drawn from outside the UW/NHGRI pool, including one from the public sector and one from the private sector. Four community advisors were involved in leading breakout sessions. In addition, several renowned UW genomic scientists and medical geneticists who had contributed to the planning of the Forum provided scientific expertise. These numerous human resources both academic and community-based provided a wealth of expertise to guide information exchange and community dialogue.

Prospective session speakers and facilitators were approached for their involvement in specific sessions 1-2 months before the Forum, although most had already committed to be available on the day of the Forum. Invitations were made individually in person, via phone call, or email. Staff described the format of the breakout session in the context of the overall Forum event and emphasized that the breakout sessions were opportunities for community dialogue. Some prospective session leaders, from both the community and UW were unable or unwilling to participate, most often due to scheduling conflicts or a lack of comfort with the proposed topic; most of those approached agreed to participate. Some of those approached asked for additional clarification of the session goals, and what was expected of them as session leaders.

Confirmed session leaders, both facilitators and speakers, were sent an email requesting session objectives, review and editing of the session summary, and a one-page summary handout for participants (in the case of speakers). Session leaders varied in their compliance to these requests, as expected. Staff assisted in introducing co-session leaders and, in some cases, facilitated the development of session objectives and how to organize the session. Session leaders were also sent logistical information including event location, event time, driving and parking directions, etc. Finally, session leaders were also instructed to make an announcement that a note-taker would be handwriting notes during the session and to ask participants to complete the session evaluation form.

Outreach

Participant Recruitment

The NHGRI developed a poster and staff coordinators developed the agenda, a registration form, and invitation letter for outreach (Appendices B, C, and D). With these materials, several strategies were employed to reach out to regional communities and to encourage participation in the Forum. In addition, approximately one-third of Forum attendees were comprised of high school teachers and students participating in UW Genome Education and Outreach program sponsored by the Department of Genome Sciences

1. *Mailings.* A packet consisting of the invitation letter, a draft agenda, the registration form and the poster was sent to all the community advisors and to community-based organizations (described above in Developing a plan for program planning and outreach), especially those who focused on health, environmental, or social justice. Invitations were directed at specific contacts in each organization and included a request for forwarding the invitation to the appropriate individuals within the organization.
2. *Direct contact at venues.* In addition to the mailings, materials were distributed at regional meetings and conferences. For example staff attended and distributed materials at the Regional Environmental Justice Conference and Asian Pacific Islander Coalition Against Tobacco monthly meeting, both held less than one month prior to the Forum.
3. *E-mails and listservs.* All the community advisors were sent a summary of the events, e-registration forms and a link to the website. They were encouraged to share the information to their constituents. Additional notices were distributed on regional listservs.
4. *Website*. The web pages contained a summary of each event (Student Forum and Community Forum) as well agendas, breakout session description, directions to the event and registration forms. In addition, a number of partner institutions and programs listed the Forum and linked to the Forum website.

Invitation to Elected Officials

Through the UW legislative liaison office, invitations were extended to Washington's U.S. Congressional delegation, selected state senators and representatives based on their previous interest in genetics related policy issues, and a number of local elected officials.

Role of Media

Earned Media

The coordinators in conjunction with the UW Health Sciences Media Services developed a press release for distribution to local press. (Appendix E: Press Release) Copies were mailed and e-mailed to all the local media services (print, radio, TV, and internet). The impact of earned media on attendance was not explicitly evaluated. However, attendance at the Forum may have been enhanced by stories on KPLU radio and in the Seattle Post-Intelligencer (local newspaper) the day before the Forum (May 20); these included

interviews with Dr. Wylie Burke and invited speakers. In addition, several smaller papers and media sources also ran notices of the Forum in their calendar listings. In addition to RSVPs received for the Forum (about 180), a number of "walk-in" attendees were present (for total attendance of about 250), possibly due in part to earned media coverage.

Press Event

The UW Health Sciences Media Services staff mobilized existing relationships with targeted journalists and convened a special meeting with several media representatives with Dr. Collins' and staff prior to the Student Genomics Forum.

Post-event Media Coverage

A few follow up articles regarding the Forum were published following the event (Appendix F: Articles). These articles primarily summarized the events of the day and the topics discussed. In addition, Dr. Collins wrote an Op-Ed piece that was published in the *Seattle Times* a few weeks after the Forum.

Evaluation Process

Planning the Evaluation

The evaluation of the project was conceptualized with the assistance of an evaluation consultant (Helene Starks, PhD, Assistant Professor, Department of Medical History and Ethics, University of Washington). After initial planning and conversations with community contacts had begun, staff began meetings with the consultant to develop a strategy for evaluating both the planning process and the outcome of the Forum. Given the pilot project nature of the event, the key function of evaluation was to inform possible replication by other similarly situated institutions in regionally defined communities throughout the United States. An evaluation team was formed, including the evaluation consultant (Starks), two staff coordinators, the Project director (Burke), and the CEEH Education Outreach Director (Burbacher). In the first step, the team defined the preliminary vision of the Forum, the basic goals of the event, the stakeholders and stakeholder interests, and the proposed planning process leading up to the event. This last step allowed for identifying points where evaluative information could be gathered without creating additional burden on staff. Given that this project had several stakeholders with varying interests, it became clear that the theme of convergence and alignment was an important element of the evaluation. Specifically, if and how did the project's intended agenda or message (e.g. genetics holds both promises and challenges for health and society) compare to that which would be eventually received by participants, and how in this exchange would the agenda be discussed, interpreted, and altered.

From this discussion, three key questions were developed for participant evaluation: (1) What did you expect? (2) How did that change? (3) How did it work out? The evaluation would be divided into two main sections: the planning process and the event evaluation, with the latter including an assessment of post-Forum impact. For the process evaluation, each coordinator kept a log of activities and reflections regarding the planning process and retained documentation of communications and planning documents from each stage of development, allowing for review of the steps and stages leading up to the Forum. For event evaluation, each session needed a goals statement. It was recognized that identifying goals for the sessions would involve an on-going process of drafting and revising session summaries as community advisors, staff, and session leaders shaped the sessions. Similarly, identifying participant expectations for each session would be an important element of the evaluation.

As staff completed conversations with key informants and as sessions were beginning to take shape, the evaluation team began to develop a specific evaluation methodology. One time surveys would be employed to collect relevant data such as demographics, response rate, to measure satisfaction, and to collect follow-up recommendations from participants. An assessment of satisfaction would be based on question regarding expectations, highlights, and suggested improvements. A survey would be distributed to all participants for evaluation of the overall event, and individual surveys would be designed for each breakout session. The survey methods were expected to capture a minimal snapshot of participant satisfaction.

Event Evaluation Tools and Note-Takers

The evaluation surveys designed for each breakout session are included in the appendix of this report (Appendix G: Sample Evaluation Survey). Each survey contained: the session title, session description, and session objectives. The breakout session objectives described both knowledge (content gained) and process (how the session flowed) goals of the breakout session. Session attendees were asked to complete the survey and return it to any "evaluation box" distributed throughout the conference site. The survey also explained that their input would be valuable in writing the final report that would be available to all participants, planning future directions and coordinate follow-up discussions, and informing how other institutions plan and implement similar community forums on genetics. Four elements comprised the body of each survey. The first element asked attendees to indicate the degree of agreement with the statement "This session met my expectations." The second element asked "How would you rate this session in terms of your overall satisfaction?" The third element asked "What was one highlight of the session for you?" The fourth element asked "What could we have done better or what else would you have wanted from this session?" These four elements were the same for all surveys including the overall Forum survey. Forms were color-coded to simplify compiling the returned surveys and entering data.

The evaluation team decided that it would also be important to capture the discussions in the breakout sessions in a non-intrusive manner. Note-takers were recruited through faculty and departmental contacts. Several of the students involved in the Student Genomics Forum served as note-takers as well as many students from the Public Health Genetics program and other students professionally interested in genomics. Note-takers were encouraged but not required to attend a note-taking training. Note-takers received instructions for note-taking and note-taking tips (Appendix H: Note-taker Instructions). Overall, the note-takers were asked be observers, to focus on writing, and to not participate in the discussions. Rather than typing notes and potentially distracting the participants or taping the session and raising issues of confidentiality and comfort, the faculty evaluator recommended that session note-takers handwrite notes on the session discussion, as close to verbatim as possible. Note-takers were asked to type up their transcription notes after the session and to write field notes describing the group and conversation, paying close attention to physical and emotional environment, and group dynamic. In addition, field notes could include the note-taker's own impressions of the session and the process of taking notes.

Summary of the Event

The Forum consisted of a one day event (Appendix B). The morning session opened with a student performance, followed by a keynote address by Dr. Francis Collins, a response panel of community leaders, and a question and answer period. After this plenary session, participants attended one of eight breakout sessions followed by lunch. During lunch participants had the opportunity to review a display of high school student Biotech Expo posters focused on genomics issues and/or to watch additional student performances. A group of communities of color held a small meeting to reflect on the morning's activities. Following lunch, participants attended another round of breakout sessions and reconvened as a whole to comment and hear from Dr. Collins at the end of the day. The following analysis is based on evaluation surveys for the event as a whole and for each breakout session and on field notes generated by note takers each in breakout session.

First Plenary Session

Keynote Address: Francis Collins, NHGRI

Dr. Francis Collins, Director of the National Humane Genomic Research Institute, gave the keynote plenary session at the Community Genetics Forum. Overall, Dr. Collin's presentation provided an overview of the Human Genome Project, the pathways through which genetics may impact health and health care, and the ethical, legal and social implications raised by each potential application. He ended his formal comments by raising a series of fundamental questions that require attention in order for genetics to contribute safely to human health, and proposed a vision of genetic applications in future decades.

Dr. Collins began by emphasizing the importance of listening to audience concerns in order to influence the direction of genomics, especially in both medical and non-medical applications. He explained that full societal involvement will be necessary to "reduce ways in which [genetics] is used to injure people." He acknowledged the diversity of the audience and encouraged everyone to be "completely freed up" to ask tough questions and provide comment.

In order to describe the role of genetics in health and disease, Dr. Collins contrasted the media's sensational portrayal of genetics to actual applications in understanding disease etiology, to frame the claim that genetics is a "major breakthrough in the future of medicine." Although he acknowledged claims against over-exaggerating the importance of genetics, he argued that all diseases had some genetic components and that all people carried some genetic susceptibilities. He provided three diseases as examples of how genetics impact health and disease: sickle cell disease, adult onset diabetes, and AIDS. He also explained that most susceptibilities would likely be relevant only in the context of environmental exposures and encouraged us to not under estimate the environment; he positioned genetics as a perspective through which to learn more about the environmental contributors to disease.

Dr. Collins explained the molecular role of genetics using the analogy of a factory. DNA serves as the instructions for factories in our cells to produce proteins that make and comprise life. The Human Genome Project was a "bold audacious project" to decode this instruction book and make it available for all as a public resource. Although many in the scientific community had doubts, the project was completed two years ahead of schedule and under budget. A private venture to sequence the genome had also successfully sequenced the human genome and was now releasing its sequence into the public domain reinforcing the notion that "openness is a good thing."

Dr. Collins described four different pathways through which genomics will influence the practice of medicine. Identifying the genes involved in disease with a genetic component will impact medicine's diagnostics abilities and provide a better understanding of the biological defect leading to disease. Better diagnostics create the possibility for better preventive medicine and better use of pharmaceuticals (pharmacogenetics). Identifying disease genes may yield new therapeutic approaches to disease such as gene therapy. Understanding biologic defects will also aid the development of new drug therapies.

Diagnostic genetic tests raise the questions of who wants to know the information derived from the test and whether any actions are available based on a genetic diagnosis. Similarly, pharmacogenomics tests requires that doctors know how to adjust drug selection or dose to improve treatment. Both approaches raise the issue of medical education. On gene therapy, Dr. Collins noted that the scientific challenges are formidable with little progress to date. Conversely, Dr. Collins used the Gleevac, a drug was designed to target the key protein that results from the misjoining of two chromosomes and causes leukemia, to highlight the possibilities of genomic-based drug therapies.

After reviewing the promises of genomics, Dr. Collins focused on the ethical, legal, and social implications (ELSI) of genomics. The NHGRI ELSI research program was an unprecedented commitment of scientific research resources to examining the complex issues that arise from the Human Genome Project. It involves a wide range of scholarly disciplines, including social sciences, humanities, ethics, and law. Dr. Collins presented six critical ELSI issues that must be addressed if genetics will have its intended and best impact on medicine.

(1) The possibility of discrimination based on genetic information potentially prevents the use of genetics. Proposed legislation, Senate Bill S306 has been passed in the Senate and its corresponding House Bill HR1227 is making its way through the U.S. House of Representatives in an effort to maintain the privacy of genetic information. (2) Genetic education will be increasingly important for the public, as consumers of genetic technologies. An educated public must be prepared to handle the increasing number of commercial genetic products so as to make good consumer choices. (3) The question of who will have access to genetic services raises two issues. First, the fact that U.S. is the only developed country without universal health care is a barrier for equal access to genetics. Second, we in the U.S. must grapple with the question of access to genetic services for the rest of the world. (4) How will research into human genetic variation impact health disparities? Will we focus on the differences or the similarities? Ancestry testing and forensic uses of genetic technology are two non-medical applications that have significant social consequences. (5) What should be the limit for genetic

technologies? Arguments that genetic technologies will give rise to designer babies serve as an example of society attempting to address this issue. (6) Philosophically, where it the common ground for spiritual and scientific world views? Genetics does not define our humanity but rather contributes to a much larger whole.

Dr. Collins ended with a vision of the future. In 2010, he predicted that individualized medicine will be increased, that the predictive power of genetic information will be greater, that pharmacogenomic tests will be part of the standard of care, that legislative solutions will protect privacy, and that access to health care and health disparities will be resolved. In 2020, he predicted that there would be many more Gleevac-type drugs, for many diseases, gene therapy will be available for a limited number of conditions, medical records will contain a person's entire genomic sequence using low cost sequencing technologies, and we will have established boundaries for non-medical uses of genetics.

Finally, Dr. Collins again welcomed everyone to the Community Genetics Forum and encouraged everyone to learn and discuss.

Community Response Panel: Sharon Terry, Genetic Alliance; Ralph Forquera, Seattle Indian Health Board; Makani Themba-Nixon, The Praxis Project

Sharon Terry from the Genetic Alliance began the session by recounting her family's experience with pseudoxanthoma elasticum (PXE), and the development of PXE International, an organization for families affected by PXE. PXE has now developed a "biobank" of biological samples and clinical data from people with PXE, with the goal of supporting research to find a cure for this disease. In this effort, the Terrys have worked with scientists to patent the gene involved in PXE and are now working on a diagnostic DNA-based test for PXE. This work led to Terry's role as CEO of Genetic Alliance, and the original biobank has expanded to the development of the Genetic Alliance Biobank, which includes samples from families affected by a range of genetic diseases. After recounting this story, she emphasized that the specific disease is not important but rather the common experiences of communities of people who experience genetic diseases. Building on this theme, she pointed out that communities have a lot to contribute to genetics because they have the "end goal in mind." Together with science, community perspectives are very powerful. Sharon Terry recounted lessons learned in her experience working between the two cultures of researchers and research participants. She summarized "I think the bottom line for me is how can we participate, helping policy makers, helping the scientists understand what we need as community members and make sure that our voice is as strong as any other player at the table so that we can see the advances, not …hype but hope."

Makani Themba-Nixon of The Praxis Project began by referring back to Dr. Collin's articulation of the promises and worries of genetics. She recounted her own experience as a sickle cell trait carrier and the counseling she received for selective termination of a fetus before her husband had been genotyped for carrier status. Her experience showed the importance of social context in how genetics is used. Themba-Nixon raised three questions for the audience to consider. First, how does knowledge get produced? She raised concern with public/private partnerships in technology and the role of the market in deciding what knowledge is produced and for what purpose. Second, what can genomics learn from community based participatory research (CBPR)? The 50

year history of CBPR may contribute to how genetics should and will be used in society. Third, how is discourse on genetics obscuring important sociopolitical perspectives? This concern was raised in the context of a breast cancer study focusing on genetics while missing the environmental factors in a particular community. Ultimately, the challenge is how to get the best technology but also to examine how it is contextualized. How will genetics interact with people and how will that change how we see each other?

Ralph Forquera of the Seattle Indian Health Board began by introducing the issue of ancestral conflict raised by genetics for some Native American communities. While almost all Native American communities have an understanding of how they came to be in this land, genetics presents a conflicting story of ancestral peoples migrating from Asia to the now American continents. This raises a conflict of origin for some Native American peoples. Forquera told of his early encounter with Jonas Salk, the inventor of the polio vaccine, really sparked his interest. In that encounter he learned that scientists really care about people, but that we often forget this. His main concern is that science expands faster than our ability to adapt to it. Despite the potential contributions of genetics to health care, Native peoples may not benefit because they have limited access to health care and often lack basic services. Until the problem of access to health care is solved, inequality to genetic services will continue. With regards to genetic research he stated "I don't think we can stop genetic research, neither do we want to, but it must be done …protecting communities." Educating people about the implications of genetics will help to prevent potential harms but will require improving the scientific literacy of the public. While the scientific method challenges and questions, we don't see society doing this type of questioning. Ultimately, there is a need for cultural understanding in both directions.

Question and Answer Session

1. For Dr. Collins posed by a medical librarian: Medical genetics is not a primary care issue. Why not?

FC: This is a point of debate. In the future, genetics has to be more a part of primary care, people will need a referral network for complicated situations. This raises a larger issue of needing to educate all of the health care sector. www.nchpeg.org is a good resource.

2. What is the place of patents in genomics? My concern is that the material of an individual will belong to some company.

ST: This is really complicated, and has legal, ethical, and practical baggage. In their patenting of the PXE gene, their interest was in stewardship of the gene recognizing the potential for misuse. Another question of a patent is how to license it? Who owns material that led to the patent? Some answers are legal and cultural, some social.

MT: The key question, whether market rules should apply, needs to be debated and examined. We need you all to participate, need to de-link knowledge from profit.

3. How will HGP inform our evolutionary past?

FC: 0.1% of our DNA supports conclusions that all present human beings descended from common ancestors from East Africa, from a pool of about 10,000 people. This is the out of Africa story. As a result all genetic variation is found in all groups of people but at different frequencies. There have been only about 5000 generations between our common ancestors and all of us now. Comparative genomics, they study of genetics between species tell us that there is a single origin of life. These findings are easy for some people and hard for others; sometime compatible sometime incompatible with one's beliefs in evolution and religious faith.

RF: Aboriginal groups have origin stories that are not linked to science but important to their identity. Will biology create a cultural crisis of identity? We are learning more about biology but these findings don't fit into common origin stories. This is critically important for Native peoples.

4. Comment. One audience member articulated a need to expand concept of identity;. What can we do to help everyone understand what is going on?

5. Therapeutic uses, where do we draw the line between therapy and enhancement?

FC: This is a central issue. It's okay to cure diseases but what about enhancement? Enhancement generates anxieties immediately but vaccinations are biological enhancements, piano lessons too. Most scenarios for enhancement (designer babies) are unlikely because they assume that genetics is deterministic and this is really unlikely. Pre-implantation genetic diagnosis is closest thing to enhancement and is being used for screening for severe diseases. Part of our problem is that it is hard to know the boundary, when is it a trait or a medical condition? We have time to address this question.

ST: We worry about this. Some members of the disability community argue that health and disease are not clear distinctions. Blindness is a complication of PXE; ST's kids see vision/not vision as both normal.

MT: Looking at the Icelandic database through a race lens. There are implications for self identify for kids, but discourse can also be about what you should look like. How are we recreating ourselves in our heads?

6. Comment. Regulation in the U.S. will cause a brain drain of researchers and ultimately prevent research in the public's interest. Education is very important, strict regulations over scientific research will hurt the United States.

7. WB: We have heard that genetics may obscure environmental causes of disease, and that for many, the basic health concerns involve health care access. What are the most important things that should be happening in research and among communities to address these issues?

RF: Find common language between researchers and the general population. Depoliticize some of this stuff, science can be beneficial for national policy but can be ignored for political/religious reasons.

MT: CBPR offers instances to learn from. Political/market context needs to be addressed as world community need to stay involved, need to remember to stay engaged. We have to give people sense of what's at stake, need better discourse.

FC: We need research to look at both genes/environments. Need big cohort study, big community study like the Framingham study of about 500,000 people. We would learn a lot and create a large community of informed people. But before doing this we need to determine if this is something we want to do? It would also cost a lot and so would have to be a priority.

ST: Promote research enterprise shift, all of us as participants. Incentivize researchers to work with end of better health outcomes in mind. Assume responsibility for this dialogue, communities must own it. Think critically about the evidence, don't wait for others to convene the dialogue.

Small group sessions

Careers in Genetics

Session Leader:
David L Eaton, PhD, Professor, Environmental and Occupational Health Sciences, Associate Dean for Research, UW School of Public Health & Community Medicine

Panelists:

- Allison Kang, MPH, PhD Candidate, Curriculum and Instruction, College of Education, Research Technologist, Genome Center
- Belen Hurle, PhD, Senior Research Fellow and Science Educator Fellow, National Human Genome Research Institute
- Debra Lochner Doyle, MS, CGC, State Genetics Coordinator Manager, Washington State Department of Health
- Kelly Hills, UW undergraduate, Comparative History of Ideas major, Medical History and Ethics minor
- Lisa Peterson, Director, UW GenOM Project
- Phyllis Frosst, PhD Science Policy Analyst, National Human Genome Research Institute
- Sara Michelson, MS, CGC, Certified Genetic Counselor, Medical Genetics Clinic
- Yuri Rabena, UW undergraduate, double-major in Microbiology and Nursing, Study Assistant.

Session Summary (provided by Session Leader): This session is designed for high-school-aged participants and will provide an overview of opportunities for careers and research

in genetics, translational/clinical research, and research into the ethical, legal, and social implications of genetics. Students will have the opportunity to hear directly from NHGRI staff, UW students and staff, and other professionals.

Objectives

1. Students will learn how genetics involves both scientists and non-scientists.
2. Students will have the opportunity to hear about the varied career paths of the panelists.

Content Summary: Genetics as a discipline is marked by continuous expansion and innovation. The wide-spread career opportunities that accompany such a versatile field may not be fully realized by the lay public. Nine panel members currently engaged in genetic-related careers offered to discuss their professional experiences with the community, answering questions and providing general insight into the exciting possibilities that define genetics as a work specialty. The panel represented professors and researchers, undergraduate students, graduate students, genetic counselors, community educators, lab scientists, government consultants, and health officials. Many questions posed by community members related to the cost and time investments associated with genetic careers (i.e. many years of expensive schooling). There was also an interest in the accuracy of the genetic information portrayed by science fiction novels and cinema as well as artistic expressions of genetics. Overall, both the panelists and the community participants seemed to welcome the opportunity to cross discipline boundaries that normally influence daily interactions and to discuss fresh options and perspectives.

Behavior and Genetics

Session Leaders:

- Clarence Spigner, PhD, Associate Professor, UW Health Services
- Deborah Bowen, PhD, Professor, UW Health Services, and Public Health Sciences Division, Fred Hutchinson Cancer Research Center
- Colleen McBride, PhD, Chief, Social and Behavioral Research Branch, NHGRI

Session Summary (provided by Session Leader): This session will focus on the suggestion that genetics may contribute to some behaviors. They will offer a chance to discuss the state of the science and the implications and assumptions of these theories.

Objective:

Participants will have an opportunity to explore the implications of behavioral genetics for diverse communities.

Content Summary: The suggestion that genetics contributes to some behaviors is ingrained in longstanding assumptions regarding the relationship between physical appearance (often race) and more subtle attributes such as potential intelligence, athletic ability, likeliness to be aggressive, or susceptibility to certain diseases. Unfortunately, connections between genetics and behavior are often extended to maintain notions of

biological determinism and "scientific" theories which are employed to justify the low income status of many individuals and racial discrimination (eugenics). Genes and behavior may be related, yet the connection between environment and behavior is arguably more powerful. To be accurate, the location of causal arrows contributing to human behavior should include simultaneous inputs from both genetics *and* the environment. Why then, do so many people study the singular relationship between genetics and behavior? Are the justifications for conducting such research ethical, unethical, or both? After discussing the complexities of this three-pronged dynamic, panel members and community participants jointly recognized the dangers of oversimplifying the research and the interpretation of this topic. The group uniformly confirmed the importance of societal education that is focused on the linkages between genetics, environment, and behavior.

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

Session Leaders:

- Nancy Press, PhD, Oregon Health Sciences University
- Sharon Terry, President and CEO Genetic Alliance
- Ralph Forquera, MPH, Executive Director SIHB

Session Summary (provided by Session Leader): This session will explore the issues that arise from the use of DNA samples in research including who has control of DNA samples; recruitment and informed consent; ensuring privacy for participants, families, and communities; and the role of community-institutional review boards.

Objective:

Participants will discuss some of the successes and challenges of community research.

Content Summary: This session, surrounding the control and ownership of DNA samples, elucidated broader issues of scientific and medical empowerment, competency, and protection of the general public, particularly minority groups. The outcomes of new genetic research have widespread impact; however, genetic research and resources are not ubiquitously distributed. In the context of our current reality, equitable public benefit cannot be assumed and must be energetically pursued through informed and deliberate activism. People like Sharon Terry and activist groups such as Genetic Alliance have achieved success through ownership—assuming a personal responsibility to obtain information about genetic issues that influence and interest them, literally inserting themselves into the field of genetics and asserting their right to interact as integral facilitators of genetic research. Opposite on the spectrum, The Seattle Indian Health Board (SIHB), is a group that has struggled with fatalistic attitudes and avoidance of new scientific developments. These cultural tendencies undoubtedly stem from a history of consistent subjugation by the federal government and involvement in what have ultimately been exploitative federally funded scientific research projects. American Indians have never been allowed to achieve authority over their own affairs. SIHB, minority groups, and the public in general, can look to Genetic Alliance for instruction on

how best to extract benefits from the advancement of genetics. Through active research and investment in partnerships to establish stronger support for mutual interests, minority groups can make profitable demands and achieve the services that they deserve. Interdisciplinary cooperation between advocacy groups, researchers, technology corporations, and governmental organizations is universally beneficial and should be collectively pursued; as Sharon Terry insightfully declared, "There is no us vs. them, it is all US!"

Cultural competency and family history

Session Leaders:

- Janelle Taylor, PhD, Assistant Professor, UW Anthropology
- Karen L Edwards, PhD, Assistant Professor, UW Epidemiology/Institute for Public Health Genetics

Session Summary (provided by Session Leader): This session will look at the cultural meanings of family history and implications of using family history in healthcare. It will be an opportunity to discuss cultural competency at the provider and institutional level, and how to ensure that genetics policies are culturally competent.

Objective:

Participants will discuss how family is defined across cultures and how that may contribute to individuals understanding health risks.

Content Summary: The session started with a discussion of the use of family history in risk assessment, and the importance of developing culturally appropriate ways to gather family history information. The discussion evolved into a discussion of gene-environment interactions after concerned residents of agricultural regions in Eastern Washington questioned the connection between crop dusters and the prevalence of cancer in their communities. Throughout the session, the presenters and the audience were in slight discordance in terms of discussion objectives; however, the various positions and interests generated stimulating conversation and broad exposure to a diversity of subjects. The presenters stressed the application of the Surgeon General's "My Family Health Portrait" tool as a means to alleviate fatalistic interpretations of genetic information and to emphasize informed disease prevention. The audience capitalized on the idea of prevention and expressed the need for easy access to more information so that protective strategies could be learned and realized by members of their communities. Commentary from the audience emphasized the perception that genetic information and technology was disproportionately maintained in urban environments and academic institutions. The session concluded in collective agreement that a greater investment in online resources and community genomics forums might alleviate the confusion, controversy, and fear that often preoccupies the public perception of genomic developments.

Genetics 101

Session Leader:
Amanda Schivell, PhD, Genome Sciences, UW

Session Summary (provided by Session Leader): This session will provide participants with a background of key concepts in genetics, review applications of genetics in society, and introduce the concept of ethical, legal, and social implications (ELSI). This session will be presented in lecture format with time for question and answer.

Objectives:

1. Participants will learn about and discuss how genes affect our daily lives using a few examples.
2. Participants will discuss two cases relating to advances in genetic technologies.

Content Summary: The session provided participants with a background of key concepts in genetics including chromosomal configuration, DNA structure and its relationship to protein formation, and the significance of DNA mutations. The speaker encouraged the community participants to interact and engage in a dialogue about the material, much of which was new to most participants. The speaker drew effective connections between microscopic, genetic processes and their large scale manifestations contributing to human health. The community participants seemed excited by the medical prospects arising from these connections and asked many questions.

Genetic Discrimination

Session Leaders:

- Tim Leshan, M.P.A., Chief, NHGRI
- Rick Carlson, JD, Director UW Health Policy Analysis Program

Session Summary (provided by Session Leader): This session will focus on the issue of genetic discrimination, including current efforts to prevent such discrimination.

Objective:

Participants will be updated on policy efforts to address genetic discrimination.

Content Summary: Genetic discrimination is the misuse of genetic information by insurance companies and by employers. The issue of genetic discrimination is paramount to the direction of future genetic research and product development; specifically, public faith in their protection from genetic discrimination will support public involvement in clinical trials and public contributions to research and general knowledge. Furthermore, the use and potential misuse of genetic information will influence individual healthcare benefits and potential healthcare losses. Genetic health status may be used to dictate (perhaps limit) employment and insurance plans or conversely, may create more personalized options, specifically catered to the individual. Access to genetic information thus produces both positive and negative effects. Legislation protecting the

public from genetic discrimination has historically been managed by the states and has resulted in "scattered protection" at the national level. In an effort to resolve the inconsistencies, on March 10, Representative Judy Biggert (R-IL) introduced H.R. 1227, the Genetic Information Nondiscrimination Act of 2005. H.R. 1227 would prohibit discrimination in health insurance and employment on the basis of predictive genetic information. Given the opportunity to discuss genetic discrimination and the development and implications of H.R. 1227, panel members and community participants highlighted a variety of pertinent issues. The group discussed the preventative nature of the federal legislation and the impact that it might have on public perception and public willingness to utilize genetic services. Community participants recognized the strain that is generated by complex individual circumstances in light of a federal law, which by nature is "one size fits all." The community additionally expressed a repeated interest in the relationship between the genetic discrimination debate and universal health care, anticipating that federal action regarding genetic discrimination might promote further consideration of a universal, single payer system.

Racial Profiling and DNA Evidence

Session Leaders:

- Paul Steven Miller, JD, Professor, UW School of Law
- Gary Shutler, PhD, DNA Technical Leader, Washington State Patrol
- Makani Themba-Nixon, JD, Director, The Praxis Project

Session Summary (provided by Session Leader): In general this session will be about the uses of DNA in the legal system. In particular, the session will focus on the influence of genetics on racial profiling in the criminal justice system, and the role of DNA evidence in the legal system and its implications for racial minorities.

Objectives:

1. Participants will be introduced to some DNA testing techniques.
2. Participants will discuss the implications of DNA evidence for racial minorities.

Content Summary: Not available

Innocence Project

Session Leaders:

- Jacqueline McMurtrie, PhD, Assistant Professor, Director, Innocence Project NW Clinic, UW School of Law
- Patricia Kuszler, PhD, Associate Dean for Research and Faculty Development, UW School of Law

Session Summary (provided by Session Leader): Since the early 1990s, when DNA testing first came available, over 150 people have been released from prison after DNA tests unequivocally proved their innocence. This session will examine the causes of wrongful convictions including: mistaken eyewitness identification, unreliable informant

testimony, false confessions, faulty scientific testimony, poor crime scene work, inadequately funded public defender organizations and misconduct by prosecutors and the police. The session will explore national efforts to improve the administration of justice and guard against conviction of the innocent. It will discuss the role of the University of Washington School of Law's Innocence Project NW Clinic in this effort.
Objectives:

1. Provide an opportunity to discuss the intersection between post-conviction DNA testing and the legal system and its impact upon the criminal justice system.
2. Participants will be introduced to the causes of wrongful convictions and to what reforms should be enacted to guard against conviction of the innocent.

Content Summary: The Innocence Project Northwest (IPNW) Clinic has grown out of a volunteer effort aimed at freeing inmates who have been wrongfully convicted of crimes. UW Law students screen inmate requests for legal assistance to identify cases where there may be a viable claim of innocence and where evidence such as post-conviction DNA testing supports the claim. The panelist and director of the UW project utilized an exciting and interactive approach to introduce the subject. She encouraged audience members to engage in the identification of John Doe after viewing a crime caught on video. The session illuminated many patterns in law enforcement and the court system which have historically led to unreliable criminal identifications, including: slanted eyewitness procedures, false confessions, police and prosecutorial misconduct, scientific fraud, or gross exaggeration by forensic scientists. Despite the potential for human error (e.g. mishandling or contamination of samples by forensic scientists), DNA analysis has allowed old cases to be re-opened and many convicted individuals have been found innocent and released. After presented with a few examples of current eyewitness criminal identification procedures, many community participants became animated and expressed their disappointment in the state of law enforcement today. The group was unanimous in its support of forensic uses of DNA and expressed an interest in learning more about the subject.

Testing for Ancestry: race and genetics

Session Leaders:

- Vivian Ota Wang, PhD, Program Director NHGRI
- June Beleford, Health Educator
- Tia Aulinskas, PhD, Chief Scientific Officer, Genelex Corporation

Session Summary (provided by Session Leader): This session will provide an opportunity to discuss the use of genetics to identify racial ancestry and the concepts associated with racial descriptors. This session will use visual materials and excerpts from the video series Race, The Power of an Illusion to generate a participative discussion.

Objectives:

1. Participants will have the opportunity to consider the implications for multi-racial /multi-ethnic people.

2. Participants will be encouraged to share their experiences and participate in a lively discussion about the possible health and human associations

Content Summary: The recent advent and advertisement of genetic ancestral testing illuminates a tension between personal conceptions of self and societal assumptions and categorization practices, particularly with regard to race. Most people believe that race consists of certain physical attributes which correlate to heredity—characteristics such as eye color, eye shape, skin tone, hair type, and aspects of bodily stature. Assigning a 'race' to a person, however, is far more complicated than a physical assessment. Most gene expression is influenced by the environment. Radically different phenotypic expressions of a single gene occur through only minor alterations in the environment; thus, a person of certain ancestry may not "appear" to be so (according to our societal standards for race) and may or may not associate themselves with the "race" or "races" identified through a probabilistic interpretation of their genes. Using current technology it is possible to draw general conclusions about the likely regional origins that have contributed to a person's unique genetic composition. What do such results tell us about race or ethnicity? To what extant is novel genetic information regarding individual identity damaging to the individual's preconceived notions of self? It is important to remember that genetic variation exists on a continuum and does not fit squarely within discrete, social definitions of race. Walking from the Tropics to the Netherlands, we would see a continuous change in skin tone. At no point along the way would we be able to say "Oh, this is the place in which we go from the dark race to the light race." In conclusion, science is unable to generate comprehensive and authoritative claims regarding the race of an individual and ultimately points to our common origins as a species, indicating truthfully that we hold far more genetic commonalities than differences.

Using Genetics in Healthcare (Morning)

Session Leaders:

- Debra Lochner Doyle, MS, CGC, State Coordinator for Genetic Services, Washington State Department of Health
- Jean Jenkins, RN, PhD, Senior Clinical Advisor to the Director, NHGRI

Session Summary (provided by Session Leader): This session will focus on the application of genetics in healthcare for procedures such as risk identification, diagnosis of genetic disease, tissue matching, prescribing drugs and reproductive medicine. It will highlight who has access to these procedures and how everyone can learn to navigate the system for genetic services

Objectives:

1. Participants will be introduced to applications of genetics in health care.
2. Participants will use case studies to discuss the issues.

Content Summary: Advances in human genetics are transforming medicine. New insights into health and disease, new diagnostic and prognostic tests, and new therapeutic

possibilities have spawned from significant investments by the public and by private businesses. These developments are not limited to uncommon disorders traditionally labeled as "genetic diseases," but have the potential to affect all individuals. Genetic research has revealed outstanding information regarding individual disease susceptibility; enabling well-received preventive strategies such as changes in diet and exercise habits, but also the unwelcome possibility of genetic discrimination and barriers to healthcare access. In the current American healthcare system, information about an individual's risk of disease often plays a crucial role in determining access to healthcare coverage. Consequently, people may be discouraged from obtaining genetic information that might be useful in disease prevention, early treatment, or care planning and management because the same information has the potential to jeopardize their access to healthcare coverage. Genetic risk information can be especially powerful because an individual's genetic health risks may furthermore embody information about risks shared by children, parents, brothers, sisters and other relatives. Panel members and community participants attending this session explored this new environment and expressed a particular interest in the relevance of new genetic information for individuals, given the responsibility to family. Are individuals obligated to reveal personal genetic information to their family members? Can a biological parent ethically withhold genetic information from a child raised by adopted parents? Implications for reproductive choices, potential discrimination, and stigmatization were also of interest to the group. Ultimately the group acknowledged the complexity of the decision to undergo genetic testing and affirmed the importance of autonomous an informed decision making with regard to genetic tests.

Using Genetics in Healthcare (Afternoon)

Session Leaders:

- Wylie Burke, MD, PhD, Professor and Chair, Medical History & Ethics, UW School of Medicine
- Elizabeth Thomson, MS, RN, Clinical Genetics and Research Ethics, Office of the Director, NHGRI

Session Summary (provided by Session Leader): This session will focus on the application of genetics in healthcare for procedures such as risk identification, diagnosis of genetic disease, tissue matching, prescribing drugs and reproductive medicine. It will highlight who has access to these procedures and how everyone can learn to navigate the system for genetic services

Objectives:

1. Participants will be introduced to applications of genetics in health care.
2. Participants will use case studies to discuss the issues.

Content Summary: Not available

Environmental Justice

Session Leaders:

- Ticiang Diangson, MA, Supervisor, Neighborhood Resource Group Community Services Division, Seattle Public Utilities
- Kelly Fryer-Edwards, PhD, Assistant Professor, Medical History and Ethics, UW School of Medicine

Session Summary (provided by Session Leader): This session considers the role of genetic information, testing, and knowledge in the environmental justice movement. It will provide an opportunity to strategically consider where and when genetics is helpful or harmful to an environmental justice agenda.

Objectives:

1. Participants will be introduced to environmental justice principles and some ethical frameworks that may be used to help address the issues.
2. Participants will discuss specific cases of environmental exposures where genetics may have a role.

Content Summary: Not available

Second Plenary Session

The group reconvened after the second break-out session. Dr. Collins provided summary comments based on his observations of several break-out sessions. He was impressed with the quality of the discussion in different group sessions and emphasized the importance of community participation in discussions of the many tough issues arising from genomic research and its use for medical and other purposes. He thanked the participants and expressed the hope that they would bring the conversation about genomics back to their friends, families and communities, to allow an even greater participation in discussion of these important topics. Dr. Wylie Burke, Chair of the UW Department of Medical History and Ethics joined Dr. Collins in thanking the participants for their contributions to the success of the Forum, and invited all who wished to participate in further discussions to contact Forum organizers or the UW Center for Genomics and healthcare Equality.

A question and answer session followed.

Dr. Collins closed the session with a song to guitar accompaniment. The audience joined in with great enthusiasm, and gave Dr. Collins a standing ovation.

Results of the Evaluation

Evaluation of the Forum as a Whole

Participants / Overall Satisfaction

Participants were asked to complete a survey regarding the Forum as a whole. Ninety-two completed surveys were returned. Approximately one-third of respondents were between the ages of 10-20 and primarily represented high school students. Another third were between the ages of 21-40 and the remaining third were age 41 and over. Twice as many females responded than males. About half of all respondents were affiliated with high school presumably as teachers or students. Twenty percent of respondents were affiliated with community or religious institutions and the remainder were affiliated with a university or other educational institution. There was a diversity of responses to the question "What was a highlight for you?" On average, participants "agreed" with the statement that "this community forum met my expectations" and rated the Forum as "very good" in terms of overall satisfaction.

Highlights

Several elements of the Forum were listed repeatedly as highlights by participants: the availability and approachability of Dr. Collins and NHGRI staff. For example, one participant commented that "the breakout sessions were nice and informal conversations with NHGRI staff at the breaks was a highlight." Several listed Dr. Collin's musical performance as a highlight of the event.

Students seemed to enjoy the sessions designed with their needs in mind, especially the Genetics101 and Careers in genetics sessions. In addition to these targeted sessions high school students noted the Behavior and genetics session.

Community members and members of the academic community 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 for some, "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 openness and dialogue theme of the forum. One highlight from an academic perspective was the "Community perspectives--absolutely inspiring panelists; empowering for audience to hear their stories."

Suggested Improvements

On the whole participants wanted more of what was offered. Repeatedly participants asked for more sessions, time, science, and ELSI discussions. Students and teachers asked for more interaction and dialogue within some sessions. A 2.5 hr plenary was too much for high school students. While some participants requested more time for discussion, others suggested using hands-on learning approaches. Some people wanted more handouts and more formal "powerpoint" lectures. Overall, different groups of participants wanted more tailored programming, sometimes meaning more or less academic, sometime more or less practical.

Some participants pointed out lack of coordination between session leaders as a problem. This point is discussed further in the evaluation of each session.

One participant astutely pointed out that some groups were not in attendance and thus represented missing perspectives from the community dialogue: "Missing reps from disabled community and gender issues. What about research we all (some) don't "want to get done."

Breakout Sessions

Comparison of Breakout Sessions

Quantitative evaluation survey data found that Racial Profiling and Ancestry Testing sessions were the least satisfying and least met the expectations of session participants. By contrast, the session by Project Innocence was the most satisfactory and best met participant expectations based on only three respondents, followed by Genetics in Health Care and Behavior and Genetics (Figures 1 & 2).

Summaries by session

Each session was summarized by assigned note-takers. Almost all the note takers expressed the challenge of capturing what was discussed in these sessions. Most took transcription-style notes and then reconstructed the session's discussion into "session notes." The "field notes" are comprised of note takers comments and observations and tended to agree with session notes. The session summaries, including both session notes and field notes, agreed with evaluation survey results, although sometimes the session notes were difficult to follow.

Careers in Genetics

Observations and Reflections: Approximately 30 participants attended this session. The audience was mostly female. Participants in this session were primarily seeking a combination of information, advice and opinions about careers in genetics. Of interest is the number of questions from participants about the connections between genetics and other fields. Questions included what is needed for specific careers and what motivated speakers to pursue their occupations.

Behavior and Genetics

Observations and Reflections: The room was approximately half full. The audience was mostly female and composed largely of high school teachers and students. The mood was inquisitive, attentive and responsive. Both audience members and panelists made

efforts to remain as open as possible. Initially this flexibility may have generated some uncertainty and uneasiness concerning the lack of clear direction for discussion; however, the purpose of the session became more defined as the discussion progressed and participation expanded. The discussion lead to an understanding of the complex nature of behavioral genetics research and led to "more questions than answers" (field notes). The discussion ultimately focused on how to educate society about this topic. Participants struggled with whether to, and if so, how to discuss the complexities of this topic in the class room. Teachers also identified the challenge of teaching complex topics when evaluation mechanisms such as the WASL [Washington State standardized testing] discourage discussions. Some participants expected more information about current behavioral genetics research but even those tended to find the larger discussions rewarding. "I thought I'd get some "facts"--research results being done in the field. Although it wasn't what I expected, I found the session very interesting" (session survey).

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

Observations and Reflections: The morning session had about 25 attendees while the afternoon session had about 10. The sharing of stories featured prominently in this session and was most memorable for participants. People had different expectations, some wanted more information about how to develop collaborations. While some participants expressed a desire for consensus or perhaps a recommendation on whether communities should take control of DNA samples, session leaders focused on contextualizing their experiences and raising issues that others could consider in making up their own decisions. The session also raised an important question about what constitutes a community and was highlighted by comparisons between PXE and Native American communities. One participant felt he or she did not have the background information regarding the history of discrimination in research to understand the issues raised in genetic research.

Cultural Competency and Family History

Observations and Reflections: This morning session had about 10 attendees. Speakers focused on the potential uses of family history and the complications of talking about cultural differences with regards to family history within a medical culture. Lots of personal questions were posed by participants. Considerable attention was paid to the role of schools as possible key locations in which to have more dialogue about these issues. The speakers focused on the need for new models of engaging and approaching these issues between communities and academics, citing the Forum as one example. This theme is similar to the theme of community campus partnerships discussed explicitly at the Control of DNA Samples sessions. Participants in this session as with many other sessions wanted more information and answers to the many questions. Some wanted more information *about* different cultures.

Genetics 101

Observations and Reflections: This session was attended by approximately 26 people of whom 16 were high school students. The community participants were excited and genuinely interested in obtaining a greater understanding of genetic material, particularly regarding the influence of genetics on health, medicine, ethics, and associated

governmental policies. Adults and students asked similar questions and these questions often occurred after the speaker had moved on to another topic suggesting that participants needed time to process the information and to formulate their questions.

Genetic Discrimination

Observations and Reflections: This session was attended by 20-25 people. Initially, the mood of the group appeared quiet and neutral. Community participants were patient as the panel members delineated both sides of the current debate surrounding genetic discrimination and appropriate protection measures. As dual-sided interaction increased between panel members and community participants, the energy and excitement in the room began to escalate and the group achieved broader participation. The range of discussion about discrimination and its implications was comprehensive, including definitions of genetic discrimination and consideration of how genetic discrimination may promote universal health care. This session was particularly interesting because it was an NHGRI-initiated and NHGRI-led session. The transcript notes show a strong balance between presented information and discussion. ". . . audience members had more of a back-and-forth dialogue with a panelist than a straight question and answer." The use of case examples for discussion was especially thought/discussion provoking. One suggestion was to include "a broader discussion of genetic discrimination and social implication of said discrimination, effects on identity, etc. (How would/could the potential of discrimination affect interpersonal, familial, and social relations.)" (evaluation survey).

Racial Profiling and DNA Evidence

Observations and Reflections: This session was well attended, approximately ¾ of the lecture hall was full. Several participants commented on the quality of the presentations and the question and answer session. Participants took away both a greater understanding of the technology of DNA-based forensics and correspondingly a greater appreciation for its limitations. As one individual wrote "The highlight of the session for me was finding out how or when they use racial and DNA evidence and how it ties into the community. Finding out that racial profiling has its flaws, and knowing that it's not perfect yet, because it takes time to process these things" (eval survey). In addition, "The balance of scientific and social science information and discourse seemed very fruitful" (eval survey). Despite these positive statements, participants had a heterogeneous list of improvements ranging from more information on the science and the ethical, legal, social implications to more visual aids to assist in technical explanations. These recommendations may suggest the need for greater attention to this topic and for leadership from the ELSI and genetics staff of the NGHRI.

Innocence Project

Observations and Reflections: This session had relatively few attendees (10) and was located in a large room with capacity for 100. The mood of the group was introspective and sincere. The audience seemed concerned with the current state of forensics and the legal system, but was hopeful that the use of DNA might provide more justice to a system fraught with too many false convictions. The topic of racial discrimination in the criminal justice system was an important but difficult topic for the participants of this

session, “the subject matter was intense and racially charged” (field notes). One theme was the “confusion about the dichotomy of not wanting to convict innocents, but WANTING to convict” (field notes) and how this dichotomy fuels the desire to accept methods for DNA-based profiling despite limited accuracy because law enforcement wants to close cases.

Testing for Ancestry: race and genetics

Observations and Reflections: The morning session was attended by approximately 25 people while the afternoon session was almost full. People had very different reasons for attending this session. Some wanted to discuss the science and some the implications while some wanted to learn more about the tests as a potential consumer. Although the morning session focused a great deal on technology for ancestry testing, participant evaluation comments suggest that the terminology and science was a challenge for many participants. “The confusion that many attendees left with wasn’t the “good” kind-more like frustration” (field notes). The afternoon session was less technical and focused more on implications of ancestry testing but yet people still wanted better explanations and more scientific information. Most of the suggestions for improvements were directed at the speakers. The presence of scientific advisors from the University of Washington provided an important lens for interpreting the scientific information for participants; some viewed the presentation from the representative of a company offering ancestry testing as scientifically inadequate.

Using Genetics in Healthcare (Morning)

Observations and Reflections: The morning session was well attended. Participants appreciated the use of cases studies and commented on the range of both perspectives and topics in this session. Suggested improvements were limited and primarily consisted of requests for more time and more information. Moderators did an excellent job of organizing people’s thoughts into issues for additional discussion. Overall participants’ awareness of the complexity of using genetics in health care increased.

Using Genetics in Healthcare (Afternoon)

Observations and Reflections: Not available

Environmental Justice

Observations and Reflections: Not available

Lessons Learned

Lessons from the Evaluation

NHGRI approach was important for helping to set the tone

As with the overall event evaluation, the approachability of NGHRI leadership was important to the event's success. This element was also important and felt by participants during the breakout sessions. One participant stated "Dr. Collins' presentation and his presence in sessions and in the hallways [was a highlight]. It was so clear that he cared about what people asked" (eval survey, Genetic Discrimination). The presence and approachability of the NHGRI caused one person to state this highlight, "That there is an effort, desire to reach out to community needs for information, understanding, and working together."

Involvement of NHGRI staff was informative and revealed agendas and questions of NHGRI, perhaps allowing for more of a collective understanding of the issues. The Genetic Discrimination session was educational and provided an opportunity for participants to learn about federal legislation to protect privacy interests that develop with genetic information. Specifically, NGHRI staff explained how protecting personal genetic information was in the interests of the advancing utilization of genetic health care. It also revealed NGHRI positioning of genetics in the context of civil rights, "just like race or gender, you can't control your genes so shouldn't be subject to discrimination" (field notes). At the same time, one could interpret this statement as equating social factors such as race as being as static as genetics. Genetics knowledge was presented as an important element for assuring personal health care decision-making. "The hope with the Institute is for people to have a basic understanding of genetic tests so when they go to the doctor they understand what the test means and do not get a test that they do not need."

Participants came with a range of specific expectations

In both the session on Racial Profiling and Ancestry Testing, participants had questions about the science as well as the social implications of the technology and its uses. For some attendees of the racial profiling session, the implication of these technologies for communities was most interesting. "The highlight of the session for me was finding out how or when they use racial and DNA evidence and how it ties into the community. Finding out that racial profiling has its flaws, and knowing that it's not perfect yet, because it takes time to process these things" (evaluation survey). In addition, "The balance of scientific and social science information and discourse seemed very fruitful" (evaluation survey). People had very different reasons for attending the Ancestry Testing session. Some wanted to discuss the science, some the implications, while some wanted to learn more about the tests as a potential consumer.

People came with expectations that were sometimes difficult to fully capture from the dialogue and therefore potentially difficult to meet. Creating a dialogue can engender a range expectations and perceived needs. It is possible that an effort to convene affinity groups or some attempts to coordinate discussion between groups of similar stakeholders

(e.g. high school students, teachers, communities of color) may have been appropriate for at some point during the day.

We want and are drawn to simple answers

In several sessions, participants were looking for simple answers. The session on Control of DNA Samples serves as an example: participants expected clear recommendations on the topic. While some participants expressed a desire for consensus or perhaps a recommendation on whether communities should take control of DNA samples, session leaders focused on contextualizing their experiences and raising issues that others could consider in making up their own decisions. Participants in the session on Cultural Competence and Family History also wanted more information and answers to many questions about the utility of family history. What could family history really tell us? Some participants in this session just wanted information about different cultures.

Although most participants gained a deeper understanding of the complex nature of behavior and the importance of non-genetic factors that contribute to behavior, some attendees of the Behavior and Genetics session articulated the belief that genetics determined some behaviors and were perhaps hoping to find some examples in the session. One individual explained "A lot of people think the genome is complex, and it isn't. I used a book called Insights in Technology. They have isolated the sex gene in fruit flies and when you remove it, the fruit flies aren't interested in sex anymore. Are there examples like the fruit flies' sex gene?" (session field notes).

Complex issues require transparency, education, and community dialogue

The theme of complexity developed in several sessions. In the discussion of healthcare and genetics one participant commented "All this time, we have been framing our questions as binomial, which they're not. They are complex" (field notes). Recognition of the theme of complexity added value to the opportunity for dialogue embodied by the Forum. When asked by NHGRI staff "How from a community standpoint can we address these issues?" the participant returned to the function of forums "This kind of forum. Bring people together, to listen to each other, have an open mind, and discuss issues." As another participant put it, "I think it's beautiful the way this discussion has been complicated. Its complication is exactly what we should be doing. We should think about how we model this forum in our classrooms and at home" (field notes, Behavior and Genetics).

In several sessions consensus was reached that more education and giving people the opportunity to talk about the issues related to genetics is important. In the session on cultural competency and family history, one participant pointed out the dual function of the Forum to both inform and hear from communities on the subject of genetics. Furthermore, education is needed to have meaningful discussions. One individual attending the Control of DNA Samples session shared "I don't understand problems of small groups and the reason for their distrust of research. What problems have occurred in the past? I felt as though I didn't have the background to truly understand the issues the groups faced." Another participant in the Family History session wanted "[m]ore answers alongside the proposed questions" suggesting there is an expectation of science to produce answers.

Topics are inter-related

Some session topics came out in several sessions and may reflect the interconnectedness, complexity, and mutual dependence of discussions about different topics within genomics. One was family history. For instance, NGHRI staff promoted the family history in the Genetic Discrimination session. "The institute is working on a concept of family history. We are working with the surgeon general who has an initiative now where you can go to his website, and input your family history online, print it out, and bring it to your doctor's office to ask about risk." Although the focus is on personal risk assessment, the family history initiative also reveals another important goal "[w]e want people to not be afraid to use this information." Another was race and genetics. In addition to the explicit discussion in the Testing for Ancestry session and Racial Profiling and DNA Evidence session, race and genetics and related issues of health disparities and vulnerable populations was raised in several sessions including the Innocence Project, Behavior and Genetics, and Control of DNA Samples by both speakers and participants. This suggests that the topic is one that warrants greater attention in the context of holding additional Community Genetics Forums.

The careers in genetics session for high school student attendees reflected a growing interdisciplinary perspective on the field of genetics. A number of questions asked about the connections between genetics and other fields of study. One student asked the panelists "several of you have had multiple careers. To us, this seems scary, why should I go into genetics instead of a more stable career?" Another asked "If you're interested in art, how can you combine your interest in art and genetics?" Another asked "Do all of your departments communicate with each other? How often do you communicate with researchers from fields outside of genetics/biological health sciences?" (session field notes). This theme reflected in the questions suggests that these high students may understand genetics as having implications beyond the biological science.

Importance of personal experience

Personal stories were an important element of the dialogue in many sessions. People often wanted to know about issues that were "close to home." Participants attending the Behavior and Genetics, the Family history, and the Genetics in Healthcare sessions often shared a personal story that motivated them to attend the Forum and the specific breakout session. These stories and their experiences led individuals to ask questions regarding scientific accuracy and predictability of genetic information, the role of environmental factors as compared to genetic factors, the origins of a genetic disease, and more. Although personal stories were not explicitly raised in the evaluations either as a highlight or a hindrance, the value of diverse perspectives, and in the case of personal stories, lived experiences is that they contribute to the diverse perspectives that *were* explicitly valued at the Forum.

Practical Lessons

Two practical lessons were learned from planning and implementing breakout sessions. First, match the session size to the room size. In the Project Innocence session the note taker observed "the discussion was dominated by a few people who asked lots of questions and gave lots of feedback. Almost everyone else listened more than they

spoke. I think the size of the room has something to do with this. The few people were dispersed around the room. It did not feel intimate." "One of the important things is having the opportunity to discuss things in a safe place." In addition to room size, the size of the group also had variable effects. In some instance small group size was a benefit to discussion in others it focused discussion among the session leaders and only a few individuals. Second, ensure that session leaders are well prepared, specifically to work together to lead a session. For instance, the evaluations for the Testing for Ancestry session raised several suggestions for improving the presentation of information and handling of challenging questions. In addition, additional coordination between facilitators and speakers would have been of benefit given the enormity and complexity of the topic. In general, careful attention to venue, group size, session format and facilitation are important for small group sessions.

Importance of Context, Resources, and People

During our initial key informant interviews with contacts from community based organizations, several contacts wanted to know why we were contacting them and what relevance this project might have for their institutions and constituents. Several contacts expressed concern over their own lack of knowledge or expertise on the subject of genomics. This concern was not only presented as a statement of fact but also may have been proposed as resistance to our inquiries and a reason for not participating in the planning process. Once we explained that we were seeking expertise in working with communities and advocating for community issues, contacts became more receptive to our request for involvement. Contacts with whom we had a previously established relationship were immediately receptive to our inquiries while new contacts required a period of relationship-building involving repeated points of contact and conversations over time to generate a trusting relationship. Although this process may be indicative of any outreach activity, we had the impression that the topic of genomics required a more persistent and open tone for our relationship building process than might be the case for other topics of more apparent relevance to community organizations.

Contacts recognized that the topic of genomics was challenging because community members have little background either in knowledge or real world experience with genomics. Discussions about the initial Forum title "Community Genomics Forum" were informative. Few contacts could identify the meaning of the term "genomics" and implored us to refrain from using this term in a community context. Although comprehension of "genetics" was also questioned, contacts assumed that the term would be recognizable for most community members. In addition, one contact encouraged us to identify instances in which genetics played a role in people's lives as a framework from which to develop an agenda. This individual gave examples such as organ donor matching, Medicaid drug formularies, and cultural implications of bringing attention to family history to help connect community members to the topic of genomics.

In addition, contacts were concerned that an event involving academics, researchers, and a federal agency (the National Human Genome Research Institute) might not be designed appropriately for community members. This concern was often

presented in reference to previous experiences where community interaction with these entities was less than ideal. One minority tobacco control advocate made reference to the challenges faced by their organization in working with Washington State Department of Health (WA-DOH). The contact expressed frustration with the resistance of WA-DOH to allow a statewide coalition to develop their own priorities for conducting their work and its inability to conduct itself in a community friendly manner. On the other hand, contacts also were able to identify instances in which community-oriented events were well planned and executed. One example was the annual regional environmental justice conference held by the Community Coalition for Environmental Justice. Although this event was often held at the University of Washington, the community-directed nature of the event resulted in excellent community attendance and relevant session topics. These comments pointed to the need for the conference to be open to the views of community advisors, and promote interaction.

Repeatedly, contacts pointed out the desire to avoid "talking heads" and encouraged a combination of appropriate education and community dialogue. The initial plan to hear from Dr. Francis Collins, Director of NHGRI, was met with ambivalence. Although most contacts acknowledged the appropriateness of including a presentation by the director of the funding agency, Dr. Collins' name had little recognition value within the community. Community contacts approved the idea of having local and national community representatives as plenary speakers. When prospective speakers Ralph Forquera, Sharon Terry, and Makani Themba-Nixon were proposed, most contacts were in favor. These speakers were perceived to represent community perspectives in contrast to academic or government perspectives and perhaps allowed contacts to imagine a more community-oriented event. This in turn may have supported the vision of a Forum where community dialogue would be a priority goal.

From our initial conversations we had learned that community relevance was an important consideration. The significance or lack of significance of genomics in the context of other priority community issues was a constant theme articulated both directly and indirectly. Communities were viewed as knowing and caring little about genomics while ensuring relevance was a top priority. The latter desire was fueled by the increasing awareness on the part of our contacts of the implications of genetics both within and outside of the health care setting. They came to express enthusiasm for the subject as discussions about the implications of genomics in forensics, drug selection, cultural difference in understanding family history, and racial profiling in medicine deepened. Although privacy was raised as a topic frequently addressed in public discussions about genetics, this topic did not create the same level of interest among our community contacts as the aforementioned topics.

While we as coordinators wanted topics to develop from the process of discussion among community advisors, the community advisors wanted us to take the lead in planning programs and sessions. This location of responsibility was driven by several possible factors: inability and lack of desire to take on the task of developing a session on their own, the perception that they did not have sufficient knowledge about the topic, and their trust in our (the coordinators) understanding of what would be important to communities. Ensuring that we "got it" was born out of the relationship building process. Ultimately, it was our job to solicit, listen, and synthesize the myriad conversations into a coherent program into which some community advisors would directly participate as

session leaders. Again, it was articulated repeatedly that the sessions had to be relevant to the lives of community members.

In summary, the process of working with community advisors to plan the Forum highlighted several issues for communities in engaging on the topic of genomics. The issue of significance and relevance of genomics was persistent. The perceived lack of community knowledge and comprehension of genetics was also a struggle in terms of planning. Foremost, genetics needed context, in people's daily lives, interactions with health care, in health services or advocacy work or justice work. The theme of justice may reflect a bias of the individuals and organizations we solicited for involvement in the Forum.

Negotiating Agendas

Developing and sharing vision(s) of both the overall event and the different elements of the event was a critical process for the success of the Forum. As one might glean from the description of the planning process, different stakeholders had different needs, not all needs were met and certainly not met completely, but the process of negotiation over time resulted in a product for which the community advisors, participating UW academic units and participating NHGRI staff all shared ownership. At the same time, two factors limited the degree of negotiation possible. First, the UW coordinators were not objective third parties but had practical and clear interests in the success of this event and contributed heavily to shaping the event in ways that they perceived would increase the success of the program. Given the timeline, the UW participants were largely drawn from existing UW programs in genomics, and little time and energy was spent recruiting individuals from the broader UW academic community or other regional institutions. Second, the outreach process of key informant interviews and solicitation of community advisors was limited to a first order circle of contacts, primarily of comprised of community based organizations. Given more time and resources, coordinators might have spent additional energy meeting with the constituents of these organizations, e.g. those served, and would likely have identified additional issues or approaches to engage community members in the Forum activities.

Challenges and Responses

Three challenges arose in the planning and implementation of the Forum: timeline; implications of the genomics topic; and interests of the sponsoring and hosting institutions.

Timeline: The timeline for planning the Forum was tight and impacted the extent of outreach. Although community advisors provided a great deal of input and guidance, the advisors were engaged primarily on a one-to-one basis. Ideally, a community advisory committee would have been formed earlier in the planning process and functioned as body through which decision-making and advice would be sought

throughout the planning process. The limited timeline also impacted the ability to provide support and guidance to breakout session leaders and may have affected the quality of the program. Staff made an early strategic decision to target existing contacts and to focus on contacts at community based organizations in order to address the limited timeline. Extensive effort was made to gather input from conversations and direct solicitation for input on specific issues or activities during the planning process.

Date and venue were determined prior to community engagement. The pilot project nature of the event meant that the idea of the Forum preceded community engagement. The result of this limitation is unknown. Although the William H. Gates Hall in the UW Law School, where the Forum was held, is a wonderful venue, it is possible that a venue within the community, rather than at UW, may have attracted other community members to attend the Forum. Also, competing community events such as the University District Street Fair may have impacted attendance, at least from the immediate UW neighborhood.

Our approach to this challenge was to work one-one-one with community advisors to seek the best approach to getting the message out, and (as outlined above) to create a program that was responsive to the needs and interest identified by the community advisors. As measured by attendance, we succeeded in eliciting interest within the community; with a longer timeline, it is possible that we could have attracted a even wider and more diverse audience.

Topic As we learned in our initial interactions with community representatives, "genomics" elicited mixed reactions. Questions were raised about the relevance of genomics to a community-based audience. In a sense, this challenge was inherent to the process of creating the Forum, and underscores the need for community outreach around genomics topics. In addition to adjusting the topics and structure of the Forum in response to feedback from community advisors, we emphasized our willingness to engage in on-going conversation with interested groups and provided email and telephone contact information. Little follow-up has occurred, however; and all follow-up has been at our initiative.

Interests of UW and NHGRI Although our goal was to reach out to diverse communities, and to engage community advisors in the planning of the Forum, the UW and NHGRI planners also entered the process with specific goals in mind: We wished to have a well-attended event, in which information about genomics topics was presented. We had the specific goals of presenting information about the implications genomics in health care and about careers in genomic research and related health care services. Thus, the overarching themes of the Forum were non-negotiable, although the actual structure of the Forum was open to community input. Our approach to this challenge was to be straightforward with community advisors, and in informational materials, about the theme and goals of the Forum.

Stakeholder Impressions

Community Advisors

Community advisors were overall satisfied with the fruits of their labor. As individual participants of the event, several left with greater enthusiasm for developing community

dialogue and projects for community education about genomics. One advisor/participant is interested in convening smaller discussions in the home setting. Another is interested in developing a project to bring the discussions of race and genetics from the Forum into the public schools. While satisfaction and enthusiasm is high, there is also the important recognition that many communities were not represented at the Forum. Limited efforts were not successful in reaching communities of people living with disabilities and people who identify as lesbian, gay, bisexual or transgender or transsexual. In addition, many medically underserved communities especially those who are economically or linguistically isolated were not reached. As one advisor who works with high school students said, "I sure wish we could have seen some teenage boys with baggy pants."

Follow up and impact

Effect of the Forum on the UW CEER (Center for Genomics and Healthcare Equality)

The experience of the Community Genetics Forum has validated the importance of working within the framework of community-based participatory research. The Forum showed that community dialogue is possible and that scientific and community agendas can be negotiated to produce common understanding and to identify common priorities. The Forum event has become a reservoir of experience from which to draw upon during discussions about how and what to work on among some CEER investigators and students at the UW.

Community Impact

Overall, the Forum has sparked modest community interest in genomics especially among individuals already working on other community health issues in communities of color.

Environmental health and environmental justice partners working with the Center for Ecogenetics and Environmental Health have expressed interested in continuing dialogue with their constituents. One partner actually plans to host a dinner at her house and invite local leaders - such as members of the Minority Executive Director's Coalition - for an informational session.

Community participation in the Forum may have raised awareness of the issues explored at the Forum and may contribute to public discourse. For instance, a session leader and community partner brought up the Forum at a local coalition - the Collaborative on Health and the Environment - and urged everyone to think more about genetics.

Additional attention to genomics issues in the ethnic media may be a direct result of the Forum. Staff has received interest from a local multicultural journal seeking to write a feature on genetics research and communities of color.

Impact on UW

Several UW partners are discussing ways to introduce more ELSI learning experiences on topics such as race and genetics into area high schools serving communities of color.

The Forum on Science, Ethics and Policy (FOSEP), a UW graduate student organization, is seeking ways to model its activities after the Forum, especially the

breakout session and the student discussions from the Student Genomics Forum. One Forum coordinator has met with FOSEP planning committee that is developing a Forum on Pharmaceuticals to share the methodology employed in planning and implementing the Community Genetics Forum. This might be an example of how approaches and methods of engaging communities can be promoted within the science community.

Conclusions

Overall, one can summarize the Forum with the following themes: community members are looking for answers to tough questions about controversial topics such as race and genetics, community members are beginning to recognize the complexity of the implications of genetics, and community members are looking for more education and opportunities for dialogue. These themes played out in various ways in each Forum session; on the whole we conclude that focusing on the 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. After the event, a great deal of enthusiasm for discussion was reported by some community advisors, especially those already involved in health advocacy or environmental justice. Given that the Forum helped to raise awareness of the implications of genetics among different communities, what responsibility do we now have especially to communities who are medically underserved? It is the hope that through this and additional Forums communities we will develop a greater understanding of the potential benefits and risks of genomic applications, research, healthcare, and non-medical settings. Ideally, this understanding will lead to active participation in policy-making, to ensure that genomic information is used responsibly.

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.

Recommendations for Future Community Genetics Forums

1. *Community engagement*
    - Determine up-front the scope to which community engagement will be conducted, taking into account timeline and resources.
    - Develop a clear statement of goals and process to discuss with community contacts.
    - Engage community-based organizations as important stakeholders at the earliest stage of outreach; involve community advisors from the beginning of the event planning process to the extent possible.

- Begin outreach with existing community contacts where relationships are already established.
- Plan for an iterative process of engagement with community contacts, advisors, and partners.

2. *Institutional coordination and collaboration*
   - Be inclusive of the various institutional stakeholders and develop a common vision for developing initial plans.
   - Expect to work closely with NHGRI staff in negotiating institutional and community agendas.
   - Develop and actively utilize lines of communication with stakeholders within the host institution involved in various aspects of the event.

3. *Program development*
   - Develop possible themes and topics for the Forum and expect that these will change over time through the community engagement process.
   - Allocate sufficient time for determining program topics, soliciting speakers and session leaders, and working with them to shape event sessions.
   - Through the process of community engagement, determine what aspects of genomics are most relevant for community members and potential participants.
   - Utilize the rich expertise within the host institution, communities, and the NHGRI to identify session speakers and leaders.
   - Provide guidance and support to session speakers and leaders especially with respect to potential participant expectations.

4. *Outreach*
   - Be strategic about who is invited to attend the event with an eye to balancing community involvement with academic interests and expertise.
   - Given space or financial limitations, develop a tiered approach to outreach ranging from personal invitations to earned media.
   - If possible, conduct outreach directly with the constituents of organizations within diverse communities in the form of announcements and presentations at existing meetings. These efforts are coupled ideally with the community engagement process.

5. *Evaluation*
   - Begin the evaluation planning process at the earliest phase of planning.
   - Develop a clear goal for evaluation, paying attention to the eventual audience(s).
   - Develop the evaluation approach and methods for data collection that minimize staff time and capitalize on existing sources of information.