

Genomics, Community and Equity: A Continuing Dialogue Final Report

A. Executive Summary

The project, “Genomics, Community and Equity: A Continuing Dialogue” had the goal of implementing a community-based participatory research model of achieving community engagement in genomics. In furtherance of this goal, the Center for Public Health and Community Genomics (CPHCG) connected with 5 partners of the National Community Committee (NCC) of the CDC’s Prevention Research Centers (PRCs): Flint Odyssey House (Michigan), Pemiscot County Community Coalition (Missouri), Office of Minority and Multicultural Health (Minnesota), Latino Organization of the Southwest (Illinois), and Community Health Action Partnership (Iowa). Other partners included State Genetics Coordinators, Public Libraries, the National Network of Libraries of Medicine, the Principal Investigators of the two previous Community Genetics Forums, and the University of Michigan Life Sciences & Society Program.

CPHCG utilized a number of mechanisms to communicate with and seek input and feedback from its partners including: 1) a steering committee; 2) an advisory committee; 3) NCC partner monthly calls; 4) site visits. In most cases these meetings utilized Centra technology, a web-conferencing software.

CPHCG created several tools to facilitate forum planning and implementation in partnership with the 5 NCC partners and other Steering Committee members, including the following: 1) a timeline; 2) an educational module survey; 3) a resource binder; 4) an event planning guide; 5) a series of task lists; 6) a forum topics survey; 7) a customized tool kit of promotional and descriptive materials; 8) a facilitators’ and note takers’ guide; and 9) a technology table.

Four of the 5 NCC partners established planning committees to develop their forums. They used a variety of mechanisms to encourage participation including the following: 1) made email/in-person contacts with other community partners (all); 2) developed their own marketing materials (Illinois and Minnesota); 3) offered incentives such as refreshments (all), t-shirts (Illinois), transportation (Iowa), donations to community-based organizations (Iowa), mileage reimbursement (Iowa, Minnesota, and Missouri), bus fare (Iowa), stipends (Iowa, Michigan, Missouri); 4) hired additional staff (Iowa); 5) hotel room for individuals attending from other regions of the state (Minnesota and Missouri); 6) participants who completed evaluation forms were entered into a drawing for a door prize at the end of the forum (Minnesota); and 7) videoconferenced the forum to satellite sites (Missouri).

With the assistance of LSS, CPHCG established a web site (www.GenoCommunity.org) used to market the forums, register participants, share educational resources, and promote future engagement through discussions, blogs and connections with advocacy organizations. Throughout the developmental stages of the website, the 5 NCC partners and the rest of the Steering Committee offered input on design, functionality, and key components of the site.

Speakers for the forums came from a wide variety of backgrounds and were from both the national (e.g. National Office of Public Health Genomics at CDC, Howard University, National Human Genome Research Institute at NIH, University of Wisconsin-Madison) and local levels (e.g. academic institutions, community-based organizations, faith-based organizations, and health departments). Speakers and topics were

matched with each of the 5 forums based upon the prioritization of topics of greatest interest to each of the communities.

A major component of the forum project was the utilization of videoconferencing technology enabling portions of a forum presented “live” in one state to be shared via videoconferencing with one or more other states. Although several of the sessions that were intended to be videoconferenced to other sites were successfully transmitted, several were not. Following the forum we had a debriefing to determine both the benefits and risks of using this technology. The principle benefit of videoconferencing was the ability to share key speaker presentations (e.g. Francis Collins’ talk) among multiple Forums. Causes of videoconferencing problems were found to be: 1) varying or inadequate videoconferencing equipment; 2) lack of bridging equipment; 3) a full 5-state rehearsal in advance of the forums was not held; 4) inadequate time, support people, and funding to identify and address the videoconferencing problems leading up to the day of the forums.

A total of 495 people attended the forums in Illinois, Iowa, Michigan, Minnesota, and Missouri on October 12, 2007. An additional 24 individuals also viewed the forums from the University of Michigan site in Ann Arbor, for a total of 519 individuals that were engaged during the forums. Three hundred and eight individuals filled-out at least one evaluation form (demographic portion of Forum Participant Questionnaire; thematic and sessions portion of Participant Questionnaire; Break-out Questionnaire). Although these data are still being analyzed, preliminary results can be found in the attached report.

A series of debriefing meetings was held shortly after the forums with the U of M team members who attended each of the forums, with the technology consultant, with the Steering Committee, and with the NHGRI. Discussions centered around how many people attended each forum, the most valuable and weakest aspects of what occurred, the lessons learned, and how best to build on the engagement that was achieved in the forums.

Steering and NCC Committee members at the conclusion of the project year were e-mailed a committee process questionnaire developed with their input. NCC, public health department, and University of Michigan project team members taking part in these committee meetings were invited to fill out and return their forms. Although these data are still being analyzed, preliminary results are presented in the attached report.

After the project end date, the community dialogue on genomics that was started at the forums will be perpetuated through the GenoCommunity.org website. The “GenoCommunity.org” website will also be integrated into other CPHCG projects. The Science Education Partnership Award Program, through the CPHCG, sponsors genetics education in local schools and community events. The website may be integrated into the curriculum and community events for this program.

In addition, Genomics, Community, and Equity: A Continuing Dialogue might be continued through the recently proposed NIH Partners in Research Grant RFA-OD-07-001. This proposal calls for the Planning Committees convened in Michigan and Minnesota for the forums to be reshaped into Community Genomics Research Councils. The Councils will work together with CPHCG to carry out a variety of activities

expanding community engagement in genetics research, including the organization and implementation of discussions, dialogues, and components of organizational meetings, and the provision of mini-grants and other incentives to defray the costs of these activities. The National Community Committee Network, of which the Michigan and Minnesota forum hosts are a part, will be kept informed of project activities, and will be invited to participate in planning a national scale-up of the Council structure during the final 6 months of the project. Additionally, members of the Advisory Committee for the forum project will serve on the Steering Committee for the NIH Partners in Research Grant proposal.

B. Introduction to the Community-Based Model

In order to understand and address concerns, misgivings, and misunderstandings held by the public – and especially disenfranchised communities – toward genetics research, strategies of community interaction and engagement have been employed with differing levels of success. In October, 2005, Toby Citrin, the Director of the Center for Public Health and Community Genomics, and Ms. Yvonne Lewis, Director of Faith Action for Community and Economic Development, presented testimony before the Secretary's Advisory Committee on Genetics, Health and Society at its meeting on the proposed large-scale population study being contemplated by the National Human Genomics Research Institute. In their testimony, Ms. Lewis and Mr. Citrin called for a "partnership approach" to genetics research rather than continuing the traditional approach of "community consultation" or "community advisory boards." They pointed out that in order to build trust in the community, researchers needed to engage community members in all phases of research, ensuring that the research is understood

and accepted as a tool aimed at addressing community health issues, that community members play significant roles in the conduct of research, share in dissemination of research findings and in the benefits resulting from the research. They urged that only through this kind of partnership can communities feel a stake in ownership of the research, and only through this sense of co-ownership will the community gain trust in the research enterprise, fully participate in research projects, and support future investments of public funding in research.

The foundation of this partnership approach is the relationship between an academic institution or a professional public health practice-based organization and community-based partners. The community-based partners are locally based organizations that have established relationships in their communities. The community-based partners work together with the academic institution/professional public health practice-based organization to understand community needs and concerns and then to design and deliver programming that responds to these findings and that expands community engagement in genetics and genomics discussion and research. The community-based partners are the key in understanding community health concerns and community perceptions or experiences with health services and biomedical research. The academic institution/professional public health practice-based organization provides educational resources and other assistance in planning community engagement activities. This is the model that we sought to utilize in *Genomics, Community and Equity: A Continuing Dialogue*.

C. The Community-Based Participatory Research Model in Practice: Partnerships and Partner Roles

To implement the community-based participatory research model for the forums, partnerships were forged among national and regional organizations and local community-based partner organizations. The National Community Committee (NCC), of the CDC's Prevention Research Centers (PRCs), connected the Center for Public Health and Community Genomics (CPHCG) at the University of Michigan's School of Public Health with 5 of its network partners: Flint Odyssey House (Michigan), Pemiscot County Community Coalition (Missouri), Office of Minority and Multicultural Health (Minnesota), Latino Organization of the Southwest (Illinois), and Community Health Action Partnership (Iowa).

These 5 community-based organizations utilized strategies to encourage participation in planning, hosting, and marketing the forums. Each forum was unique in that it reflected the interests of each of their respective communities. The CPHCG assisted these 5 community organizations in matching forum programming and speakers with each community's interests and background with genomics issues. The CPHCG also provided forum presenters, resources, and materials – including the development of the genocommunity.org website with educational resources and forum information and registration. The CPHCG also provided technology resources for communication among all partners during forum planning and for communication among locations during the forums. The NCC promoted the forums throughout its network. Other partners included the State Genetics Coordinators in the Midwestern states, who assisted in planning and implementing the forums, as well as the National Network of Libraries of Medicine and the Public Library Association, which publicized the forums in

a web-based format and with more traditional marketing approaches for communities with limited computer access.

D. Description of Partner Organizations and Resources

Center for Public Health and Community Genomics (CPHCG)

The CPHCG at the University of Michigan's School of Public Health (UMSPH) is funded by the Centers for Disease Control and Prevention and the National Institutes of Health and aims to promote the integration of genomic discoveries into public health practice in furtherance of the public health goals of improving health and reducing and eliminating health disparities. The Center emphasizes the ethical, legal, and social issues associated with the application of genomics and public health and the importance of engaging the community at large in the development and implementation of public health genetics programs. Toby Citrin, Director of CPHCG, is also the Co-Director of the University of Michigan's Life Sciences and Society Program (LSS). The LSS Program also contributed knowledge, personnel, and resources to Genomics, Community, and Equity: A Continuing Dialogue. The UMSPH recently completed construction of its Crossroads Building which provided technology for conference calls, Centra communications, and video-conferencing.

National Community Committee (NCC)

The NCC is a network of community representatives engaged in equitable partnerships with researchers through the CDC-funded Prevention Research Centers to define local health priorities, drive prevention research agendas, and develop solutions to improve the overall health and quality of life of all communities. Past President, Ella Greene-Moton, served as the Community Coordinator for the forums.

State Genetics Coordinators

State Genetics Coordinators from State Health Departments in the 10 state DHHS Regions V and VII were contacted about participating. The State Genetics Coordinators served on the Steering Committee or Advisory Committee and offered educational resources and expert recommendations in forum planning.

National Network of Libraries of Medicine (NN/LM)

The NN/LM has biomedical and public health resources available for professionals and health consumers. Their network includes libraries and information centers across the country.

Public Library Association (PLA)

The PLA, located in Chicago, has diverse programming interests including communication, advocacy, and programming for public libraries among their network membership.

E. Community-Based Partners:

MICHIGAN: Flint Odyssey House, Inc. Health Awareness Center

The Flint Odyssey House, Inc. Health Awareness Center provides intervention as well as primary and secondary substance abuse prevention and treatment services to the community of Flint, MI. Through programs aimed toward positive youth development, they provide long term and residential outpatient treatment programs for chemically dependent women and their children.

MINNESOTA: Office of Minority and Multicultural Health

The mission of the Office of Minority and Multicultural Health is to strengthen the health and wellness of the target populations in the state of Minnesota by engaging

diverse populations in health systems, mutual learning, and actions essential for achieving health parity and optimal wellness. Working with a racially/ethnically, culturally and tribally diverse population, they focus on health disparities.

ILLINOIS: Latino Organization of the Southwest

The mission of the Latino Organization of the Southwest is to work with Latinos in Southwest Chicago to create awareness of the social, political, economic, and cultural reality of their target population in order to develop critical thinking and knowledge for further growth as individuals. They strive to achieve this mission through educational, cultural and social programs in the area.

IOWA: Community Health Action Partnership

Based in Keokuk County, in rural Iowa, the mission of the Community Health Action Partnership is to incorporate community-based participatory research, evidence-based strategies to address community health issues, and the evaluation of health promotion activities. In order to achieve this mission, they have created four working groups, on adolescent alcohol prevention, nutrition, walking and biking trails and healthy environments.

MISSOURI: Pemiscot County Community Coalition

The Pemiscot County Community Coalition aims to address the high rates of chronic disease in their target population of rural African Americans in Pemiscot County, Missouri. They also work to address the effects that social determinants have on the health of their target population.

F. Planning Process

1. Project Goals

Several goals for the Genomics, Community and Equity: A Continuing Dialogue were delineated at the onset of the project. The project aimed to build on earlier community genetics engagement activities, including two prior NHGRI-funded Community Genetics Forums. The project also sought to develop and implement a model of community education and engagement through community forums in five of the ten Midwestern states comprising DHHS regions V and VII (Illinois, Iowa, Michigan, Minnesota, and Missouri). The goal of this model of community education and engagement was to utilize web-based educational and communication resources, which could eventually be extended throughout the U.S. and beyond the program period. The project sought to stimulate and facilitate ongoing community dialogue around socio-ethical issues connected with genetics research and practice, with special focus on the importance of and issues connected with taking family health histories, genetics research aiming to benefit communities and populations, and the relationship of genetics to health equity and the reduction of health disparities. In Genomics, Community and Equity: A Continuing Dialogue, an additional goal was to engage a broad cross-section of the population, including significant representation of minorities and special populations. To obtain these goals related to community engagement and education, the project also aimed to engage networks of community-based organizations, health departments, educational institutions and libraries. The evaluation of the program's performance was also an important consideration. Finally, a goal was to develop and make available a set of print-based and electronically-based materials

including educational resources, planning guides, evaluation, reports and findings that incorporate the program's experience and enable other organizations to replicate the program's methods.

2. Steering Committee

A Steering Committee was convened to guide the project throughout the planning and implementation phases. The Steering Committee included representatives from each of the NCC members in the five designated forum states. Individuals from the State Departments of Health in each of the ten states in the Midwest focus region were invited to participate, although several declined to participate in the calls. The Steering Committee also included team members from the University of Michigan School of Public Health Center for Public Health and Community Genomics and the Life Sciences and Society Program. The Steering Committee held monthly meetings throughout the duration of the project. These meetings utilized Centra technology, a web-conferencing software that allows highly interactive group learning and communication bringing together voice, video, data, and graphics in a structured online environment. Conventional telephone conference calls were used for the audio portion of these Steering Committee meetings, while the Centra technology was used to show documents and items on the web to all conference call participants.

3. Advisory Committee

An Advisory Committee was also convened to provide guidance throughout the project. The Advisory Committee initially included the Principal Investigator, Project Administrator, Information and Evaluation Coordinator, and GEMINI contact from the University of Michigan Team, representatives from Public Libraries and the National

Network of Libraries of Medicine, a Program Consultant from the National Human Genome Research Institute, and the Directors of the previous NHGRI-funded Community Genetics Forums. The Advisory Committee met as a full group on an ad-hoc basis, but eventually transitioned to smaller group meetings as needed. Centra technology was again used to augment conference calls.

4. NCC Organization Conference Calls

Representatives from the NCC organizations in each of the five forum states also participated monthly in meetings pertinent to the planning and implementation of the forums in each of the states. These meetings addressed planning issues relevant to all states, as well as issues unique to each individual forum location. Additionally, members of the University of Michigan team met with representatives from each state NCC for separate planning meetings prior to the forums. The purpose of these meetings was to create and finalize agendas and speakers for each forum site, talk about the logistics of the day and any special considerations for each forum location, and to discuss special interests or goals for each of the five forums.

5. Site Visits

Prior to the forums, Toby Citrin, the Principle Investigator and (for all but one visit) Ella Greene-Moton, the Community Coordinator, traveled to each of the five forum states and met with the NCC representatives and the planning committees in each of the states. On these site visits, Mr. Citrin and Ms. Greene-Moton provided state NCC members with informational folders with background information about the project and, in most cases, the results of the educational module and/or topics surveys (see below). Mr. Citrin and Ms. Greene-Moton also presented a PowerPoint with background

information on the project, and talked with NCC members about their individual planning processes.

6. Project Timeline

A timeline was created at the onset of the project as a guideline for initiation and completion of project tasks. Eventually, as the forums drew near, this timeline was merged with the event planning timeline.

G. Educational Module Survey

In order to prioritize issues for the creation of educational modules being developed for the forum website, leaders of the community groups that were participating in and hosting the forums were asked to fill out a survey (collected via Survey Monkey) and pass it on to members of their groups (see Appendix 1). The survey grouped issues into nine major categories, including genetics and privacy, genetics and health disparities, genetics and disease, genetics and ethical issues in research, genetics and family history, genetics and me, genetics and education, genetics and race, and genetics and technology. Participants rated each issue from 1 to 3, 1-not interested, 2-somewhat interested, 3-very interested and were asked to write-in any additional issues of interest. A total of 67 individuals completed the questionnaire and the top ranked individual issues were in the categories of: genetics and health disparities, genetics and disease, genetics and privacy, and genetics and family history (see Appendix 2).

H. Resource Binder

A resource binder on public health and community genomics was created to aid NCC members as they set the agenda and plan for the forum in each of their states.

The binders were comprised of articles, fact sheets, example discussion questions, web resources, and other materials to introduce or elaborate on topics previously discussed on conference calls as possible forum topics. The categories of information included in the binder were: general information about genomics, genomics education, genomics research, family history, racial-ethnic group concerns and disparities issues, and spirituality. This binder was meant as a resource for NCC members to consult if they wanted to know more about a certain topic as they were setting their agendas. At the beginning was a summary of topics that were highly rated as very interesting in the Educational Module Survey (described above) that was sent out to each of the five focus states. Each of these topics, that were found to be of high interest, was cross referenced with a section or certain material of the binder. Before distribution to the NCC representatives, the materials were shared with the entire Steering Committee for feedback.

I. Event Planning Process

The event planning process of Genomics, Community and Equity: A Continuing Dialogue started with monthly Steering Committee and NCC Representative calls. These calls allowed the group at the University of Michigan to get a better sense of the planning status of each site and evaluate further action needed to assist in their planning process.

At the beginning of the process, the University of Michigan sent out a list of things to consider when planning the individual forums. This document was developed with the assistance of Diane Drago, a professional event planner from Michigan who served as a consultant on the project. The document discussed things to consider

when choosing a venue, catering, etc. Each site was instructed to reserve a site that had IP or ISDN-based video conferencing capabilities.

This document was followed by a series of one-on-one calls with the community hosts and Corey Turner to assess their planning process. These calls took place on an as-needed basis and gave the community hosts the opportunity to voice concerns about the planning of their forums. The calls also allowed the University of Michigan to assess any problem areas and address them in advance of the forums. Each of the different sites had different needs. Some of the sites were larger entities that were familiar with hosting large events and some sites were small community-oriented organizations that were less familiar with hosting events. The University of Michigan team worked closely with these small sites to identify possible locations, work through technology issues, identify catering arrangements, and accommodations for out of town guests.

A series of task lists were developed by the University of Michigan to track the progress of the sites. Task lists were developed for each of the entities involved in the planning process, as well as each of the steps of the planning process. These lists were shared with the NCC representatives and discussed on the monthly calls.

Corey Turner also met with Diane Drago throughout the process. Ms. Drago has experience in planning large scale events and was able to provide insight and assistance that aided the planning of the forums.

J. State-Specific Planning Committees and Engagement Strategies

The Midwest Region of the National Community Committee of the CDC's Prevention Research Centers is one of six regions working within the National Community Committee Network. The regional aspect was designed to provide a

"community driven" approach to engaging communities in all aspects of health and wellness as well as research.

Each Midwest Region NCC member brings a different set of community norms, cultures, and mechanisms for working efficiently and effectively within its own state as well as across the five state collaborative.

1. *Illinois*

The Illinois NCC, the Latino Organization of the Southwest (LOS), did not utilize a planning committee. LOS targeted the southwest side of Chicago – the immigrant Latino population, and impoverished communities / the working class poor, particularly African American communities. The process started with direct contacts at the higher level – LOS sent e-mails to staff, who then contacted volunteers within organizations to spread the word. LOS sent invitations throughout their local university and went into a senior citizen home to recruit participants. In addition, LOS did door-to-door recruiting within client neighborhoods of their organization. LOS also made their own flier, "The Study of Your Genes," which cited areas of interest such as one's family lineage, diabetes in the family (increased frequency in the communities they targeted), and familial cancer. Students were motivated by the presence of a Health Day in Chicago in the following month, which resonated with forum themes. Finally, a "Save this date" postcard was sent to all contacts in the database. Many Latino attendees had to leave half way through due to an immigrant rights event that also directly involved them. They had also hoped to recruit the Muslim community. Muslim community members were unable to attend due to a religious holiday, but expressed interest in attending future

dialogues. All marketing materials were prepared in both English and Spanish. A total of 40 people attended the forum in Illinois.

LOS provided the following incentives for participation:

- refreshments
- t-shirts with the forum logo and the words: 'My Roots...My Family...My Future' were offered to the first 10 people to sign-up and show-up.

2. Iowa

The membership of the Iowa Planning Committee consisted of staff members of the Community Health Action Partnership, Kim Piper, the State of Iowa Genomics Coordinator, and Dr. Trudy Burns, Epidemiology Professor at the University of Iowa. A consultant was hired to assist in carrying out the project. The following groups were contacted by phone and e-mail to attend the forum: Autism Society of Iowa, Juvenile Diabetes support groups, Iowa Lung Association, Iowa Asthma Coalition, Cystic Fibrosis, Alzheimer's Association, American Cancer Society, Leukemia & Lymphoma Society, Proteus Migrant Health Project, various hospitals in Des Moines, faith-based organizations, March of Dimes, Iowa PKU Foundation, Iowa public health nurses, and the Iowa Stillbirth Surveillance Project. Three colleges participated in this event. All in all, the forum went well with 60 participants.

A number of strategies were employed to engage diverse communities as follows:

- Senior citizens were provided with transportation and a donation to their meal site to attend the forum.

- Students were encouraged to attend by their professors as it would be applicable to their field of study.

The following incentives were offered to forum participants:

- Monetary donations were given to organizations that participated
- Mileage reimbursement
- Stipends for note takers, facilitators, tech support, and organizers
- Food
- Bus fare

3. Michigan

The planning process was a collective process involving the seven member organizations of the Community Based Organization Partners (CBOP). CBOP designated Flint Odyssey House, Inc. Health Awareness Center (FOHIHAC) as the lead organization for this project. CBOP meets monthly as a whole and holds weekly committee meetings. These weekly meetings were utilized to plan the forum. The Flint Public Library was also recruited to participate in the project (to join the other state public libraries that had been previously recruited). Each of the seven CBOP organizations was asked to recruit participants (adults and students) by September 2007 using multi approaches that worked for them. The most effective marketing strategy was word-of-mouth. It was so successful that plans to market the event through a local newspaper were cancelled for fear of having to turn away more people. Nearly a hundred people received letters that they could not be accommodated at this forum but would be placed at the top of the list for future ones. There were still 45 more people than the goal of 100 participants.

Incentives for forum participants included the following:

- Monetary donations were given to grassroots community members
- Professionals came without receiving incentives
- A healthy continental breakfast, lunch, and afternoon snack were served to all participants
- Bus transportation was provided for community members
- Name tags were provided for each participant

A committee member was designated as a chairperson for recruiting greeters, speakers, and note-takers. Note-takers were recruited from local organizations, the university, local colleges, and community members with note-taking experience. The chairperson assigned note takers to various sessions.

The uniqueness of the collective of the Community Based Organizations Partners (CBOP) to carry out such a project highlighted the power of a collaborative. CBOP was able to recruit people who had never heard about genomics. Participants remained the full day and wanted suggestions of where to learn more.

4. Minnesota

The Minnesota Planning Committee included people that represented all of the major population groups in Minnesota, which include African American, Asian American, American Indian, Tribal populations, Latino, and Anglo populations. There was also representation from across the state from both rural and urban populations. Individuals represented local public health, state health departments, community-based organizations, tribes, county agencies, educational institutions, faith-based institutions, and private individuals. The process of forming a Planning Committee began on April

24, 2007 with a community meeting that included a presentation from Toby Citrin, the Principal Investigator of Genomics, Community and Equity: A Continuing Dialogue. After the meeting, priorities were identified from the large group of more than 30 representatives and all were invited to join the planning committee. The priorities were used to set the agenda for Minnesota's forum. The Planning Committee met monthly after the first meeting, and also made decisions through email.

In order to engage diverse communities, the Minnesota NCC ensured that the priorities of the Planning Committee would be respected in Minnesota's agenda, topics, speakers, and materials. The Planning Committee also had leaders from each of the communities (ethnic/racial and geography) involved from the beginning and they helped to build the momentum to the forum. The Planning Committee sought to have speakers from the local community and also speakers that represented/reflected the populations it was seeking to engage. The Minnesota NCC also made sure to include the agenda items that were important to them, so that they felt they walked away with something. In all, 176 people attended the forum in Minnesota. The Minnesota NCC has a group of individuals who are ready to continue on with the work, and were able to meet Vence Bonham, JD, from the NHGRI, on February 4, 2008.

Incentives for forum participants included the following:

- travel and a hotel room for individuals attending from other regions of the state
- food and other refreshments
- all participants who completed evaluation forms were entered into a drawing for door prizes at the end of the forum

In addition to the forum, the Minnesota NCC worked on a youth project that started in October 2007. They targeted four schools, Minneapolis Public Schools-Community Education, Roosevelt High School, Macalester College, and the University of Minnesota. They utilized their connections in order to work with a total of 29 middle and high school students and 13 college students. Each school participated in a program to increase their awareness and experience in Science and Genomics with a goal of creating a product that would teach younger students about Genomics and Science. The Minnesota NCC concluded the youth project with a presentation on February 4 at the Science Museum at which Vence Bonham from the NHGRI was present. The youth presented two products:

1. Board Game- Circles of Life-which provides a person with their genetic make-up, and teaches them how everything impacts their lives (e.g. environment, decisions, behavior).
2. Commercials – 3 commercials that illustrate why science is important. Each commercial is 30 seconds long and will be played in local stations and public schools.

Each of the student groups were able to attend different field trips:

1. Dental School – where they utilized a simulation lab with dental students
2. Medical School – where they utilized the laser surgical instruments, learned how to suture, and felt real hearts and lungs
3. Veterinarian School – viewed dental operations on animals and learned about becoming a veterinarian

4. Lunch in a Dorm – manager gave a presentation on how food science relates to future career fields
5. Admission Counseling – had a presentation on how to apply and what resources are available to them
6. Introduction to Genomics – met with Professors at Macalester College

The Minnesota NCC is currently exploring how they can continue this project.

Without the partners, this project could not have been done. Without having the contacts, the Minnesota NCC would not have been able to reach out to the institutions.

The partners for the youth project included the following:

1. Hennepin County
2. Minneapolis Public Schools
3. Macalester College
4. University of Minnesota
5. Minneapolis Public School Community Education
6. Science Museum

5. *Missouri*

The Missouri Planning Committee included representatives from the Missouri Health Department, the PRC Community Advisory Board from the Bootheel and Ozark regions of the state, board members of the hosting agency such as Lincoln University Extension, Local Housing Authority, school officials, local health department, University of Missouri Extension and representatives from other local programs. Engaging community members from two different regions of the state (Bootheel and Ozark) provided forum participants who were diverse in ethnicity, age, occupation, and income.

The Missouri forum was videoconferenced to two satellite sites in other regions of the state. The Missouri Planning Committee met initially in person and then held conference calls on a bi-monthly basis. A total of 74 people attended the forum in Missouri.

Incentives for the forum participants included the following:

- Stipends to help offset travel expenses
- Hotel rooms for participants who traveled a great distance from rural areas in order to participate
- Food and other refreshments

K. Topics Survey for NCC Member Organizations

A 4-page list of potential genetics forum topics was generated from a review of three sources: (1) descriptions of intra- and extramural programs (including the Education and Community Involvement Branch and the Ethical, Legal and Social Implications Research Program) on the official NHGRI web site to identify key areas of research; (2) the University of Washington genetics forum web site; and (3) the University of North Carolina genetics forum web site. Further input on topics was received from the Educational Module Survey results and from topics discussion at the Steering Committee conference call meetings. This information was used to develop a 6-page Topics Survey for NCC Member Organizations (see Appendix 3) containing the following categories: Arts and Crafts (e.g., DNA Dance, DNA Extraction Experiment); Comprehensive Overview; Current Research and Applications; Education and Training; Ethical-Legal-Social and Diversity Issues; Health Services; Public Health; and Religion and Spirituality. Each of the overall topics contained from one to seven sub-topics (e.g.,

Education and Training containing Careers in Genetics, Genetics 101, Genetic Educational Tools and Curricula, etc.). Steering Committee members were asked for their suggestions on survey content. Comments received touched on specific topic areas and their proper wording.

Once finalized, the Topics Survey for NCC Member Organizations was circulated to Steering Committee members via e-mail. Members were asked to mark the priority they assigned to a particular topic and sub-topic for the forum plenary (collective) sessions and break-out sessions (1 = high preference; 2 = some preference; 3 = low preference). There were also several blank spaces for participants to write in other topics of interest. Four states returned 5 forms; 1 state (Illinois) was unable to return its form in time for assessment. In some cases, the leadership of the NCC completed the survey whereas in other cases, the NCC leadership consulted with a network of community partners to complete the survey. The project evaluation specialist, Stephen Modell, divided the results into two tables – one depicting topical prioritizations per state (see Appendix 4); the other sub-topic prioritizations (see Appendix 5). The two tables were utilized in 1-on-1 meetings with the states to decide on the topics and speakers for each of the 5 states. Illinois' decision making depended purely on discussion with its NCC leaders. Discussion with the states yielded topic and speaker agendas that were synchronized between state forums that would be held in Eastern and Central time zones.

L. Forum Speakers

Speakers for the forums came from a wide variety of backgrounds and were comprised of individuals from positions at both the national and local levels. Speakers

were chosen by discussions between host organization leadership, Center for Public Health and Community Genomics leadership, and representatives from the National Human Genome Research Institute. Selections were based upon the prioritized topics of interest at each site, the characteristics of the anticipated audience, and the availability of speakers. Guest speakers included individuals from the National Office of Public Health Genomics at CDC, Howard University, the National Human Genome Research Institute/NIH, and University of Wisconsin-Madison, who traveled from their home locations to the Midwest forum sites. Additionally, each forum site recruited local genomics experts to speak. These individuals came from academic institutions, community-based organizations, faith-based organizations, and health departments within the home state of each of the forums (see Appendix 6 for speaker biographies). In certain cases, speakers from both the national and local level gave combined presentations during breakout sessions. In Missouri, for example, a panel on the Next Steps for Genomics in Missouri was comprised of both local leaders and NHGRI representatives.

M. Forum Agendas

While the agendas for each of the five forums differed significantly based on the needs and interests of each site, each of the states followed similar presentation formats, and even shared some of the same sessions via videoconferencing. This videoconferencing was a unique aspect of the forums, and allowed for interaction between all five locations at certain times in the day. All of the states had a combination of plenary sessions and breakout sessions. Plenary sessions were one hour in duration, and followed a traditional lecture format followed by a period for question and

answer. Breakout session format varied depending on the presenters, but generally were designed to encourage more audience participation and discussion with the presenter. Missouri was the one state where a panel discussion was held instead of breakout sessions, due to travel considerations for their participants. In addition to the plenary sessions by Dr. Kardia and Dr. Collins, each state had at least one additional plenary session on a variety of topics. Each state also had several breakout sessions for participants to choose from, on topics identified as of interest by a survey given to each of the states, as described above. A table of the final agendas for each of the five forums is attached (see Appendix 7).

N. State-Specific Forum Preparation Conference Calls

Once the agendas for each forum were set, preparatory meetings were held separately for each state. These meetings included the NCC representatives, University of Michigan team members, representatives from the NHGRI, individuals from the state health department in each forum state, and speakers that would be speaking at that particular location. These preparatory meetings were meant to ensure that everyone was up to date on the agenda for the day of the forums and to open up discussion for how each speaker could tailor his or her presentation to meet the needs and interests of the host community. In a separate videoconference, all of the speakers from the NHGRI met with project team members from the University of Michigan, including the technical consultant, for a debriefing on the goals and objectives of the forums and the role that each speaker would be playing in each forum.

O. Forum Toolkit

A toolkit was created with materials to aid states through the advertising and forum implementation process. The toolkit was created and given to the host organizations in advance on a CD (see Appendix 8 for Missouri's tool kit). The toolkit consisted of promotional materials, descriptive materials, a media kit, and educational resources. The promotional materials included a brochure, several options for fliers and posters, and a save-the-date postcard. The descriptive materials included a Power Point presentation about the project and one-pagers about the overall project, the NCC, and the CPHCG. The media kit consisted of a press release, a series of four marketing emails to be sent out before and after the forums, a newsletter blurb specific to each forum, and a general blurb about the project. The educational resources included a list of key articles related to genomics, a list of key web resources related to genomics, and a glossary of terms.

All materials, with the exception of the glossary of terms, were created by UM team members and given to states in a print-ready format. Minnesota received a copy of these materials, but ended up creating and using materials of their own design. Materials were customized to each state, to include state specific forum details, contact information, pictures picked by state NCC members, and the host logo on certain materials. The materials also all included the project specific logo, which consisted of a green and orange tree, with a helix for a trunk and the words "A Community Genetics Forum" on one of the extended branches, as well as the logo for the National Community Committee. A funding statement was also included on all of the materials. Both the Steering Committee and individuals from the NHGRI had input during the

formation of these materials. It was left up to the states to choose which of the materials to utilize, and how. Several states used the advertising materials prior to the forums to recruit individuals to participate.

Another set of materials was also created for states to use on the day of the forums. The first sets of materials were for inclusion in folders that were handed out to participants at the forums. States chose what to include at their forums. They were provided with electronic versions of an agenda, a list of speaker biographies, break out session descriptions, a handout about the www.GenoCommunity.org website, a one-pager about the event tool kit on the website, and a one pager about the project in general (see Appendix 9 for Missouri's materials). Again, when appropriate, materials were customized for each state by U of M project staff as described above. Each forum state was then responsible for printing out the materials that they wanted to use and purchasing the participant folders. Folder labels, with the name of the event, the project logo, the NCC logo, and host organization logo were created and multiples were printed off by U of M staff and mailed to each of the state NCC representatives. Additionally, coded hard copies of evaluation forms were mailed to each of the states. For each forum participant, there was a demographic form, break out session forms specific to each state, and an overall evaluation form. Finally, hard copy multiples of informational materials were mailed to the states by NHGRI, including a Family History Tool, FAQ on Family History, FAQ on genetics and genomics, Genetic Testing brochure, NHGRI brochure, and DNA day materials.

Additional materials were provided to the states to be used in other capacities on the day of the forums. A series of 8 customized signs to be used around the forum

venue were provided, as were certificates of participation for forum participants, sign-in sheets, a template for name tags, and a blank copy of the registration form. All of these materials were sent to states electronically, for them to print out and use at their discretion. Again, all materials for the day of the forums were created with input from the Steering Committee and based on feedback from NCC representatives in each state. Additionally, Michigan, Iowa, and Missouri were mailed hard copy multiples from NHGRI of disease specific fact sheets created by the University of Cincinnati, as the fact sheets only dealt with subjects addressed at these three forums. A Facilitators' and Note Takers' Guide (see Appendix 10) was also sent electronically to aid facilitators of the breakout sessions (please see the following section for more information). Finally, a master contact list was also sent electronically to all project team members and NCC representatives. This contact list included contact information for all community organization contacts, technical staff, organization staff, and all other pertinent personnel in order to aid communication on the day of the forums.

As a back up, a pre-recorded copy of Dr. Francis Collins' talk was sent on a CD to each of the forum locations from the NHGRI. Additionally, U of M staff traveling to each forum location brought a CD with a pre-recorded copy of Dr. Sharon Kardia's talk. Finally, a list of possible materials that could supplement state specific breakout sessions (see Appendix 11) was sent via email to each of the NCC representatives in advance. Each state made the determination about which, if any, of these materials to print and distribute on the day of the forums. These materials were chosen with the input of the Steering Committee, breakout session speakers, and the NHGRI.

P. Facilitators' and Note Takers' Guide

The Facilitators' and Note Takers' Guide benefited from several prior documents – the Dialogues Facilitator Guide put together by ethicist Leonard Fleck for the NIH-sponsored Communities of Color and Genetics Policy (CCGP) project; a note taker's guide from the same project; and the University of North Carolina's Genetic Forum Facilitators' Guide. Since roles and duties intersected, it was decided to make a guide suiting the combined needs of session facilitators, note takers, plenary and break-out session speakers, and speaker introducers. The 10-page guide was written by the project evaluation specialist with input from committee members and the project P.I. The process took about two weeks, yielding 6 sections after a number of potential sections were added and others dropped: (1) nature and timing of sessions; (2) roles of speakers and facilitators; (3) presentations; (4) tips on conducting a break-out discussion; (5) discussion points; and (6) note taker protocol. The decision was made to circulate the forum agenda, descriptive topic summaries, and speaker biographical sketches independently of the 10-page document. The draft document was circulated for comment 10 days before the forums. The final version was then circulated by e-mail to relevant conference personnel, organizers, and speakers.

Q. Evaluation Process

Two forms were distributed to forum attendees: (1) a Forum Participant Questionnaire and (2) a Break-out Questionnaire. The University of Michigan IRB determined that the project was educationally- rather than research-oriented, obviating the need for consent forms. Demographic questions appeared on the first page of the overall participant questionnaire. The participant session-related and demographic

question items benefited from previous question items used in the CCGP project. The break-out session form was modeled after the break-out form used in the North Carolina genetics forum. Analogous demographic questions were also loaded onto the forum's web site, www.genocommunity.org. Each of the forms went through approximately 4 iterations before being finalized, with successive input from the Project Administrator Sally Meyer, project P.I. Toby Citrin, and Steering and NCC Committee members. Involvement of the latter involved sending e-mail drafts to committee members and receiving their input by e-mail and during Centra conference calls (the forms were visually displayed on committee members' computers).

Major areas of decision involved whether and how to combine the demographic question items with session-related items; whether any of the session-related items should be pre- and post-tested; how the break-out sessions should be assessed; and whether a qualitative survey of a sample of forum participants should be undertaken. Separate pre- and post-testing was ultimately deemed unnecessary given the inclusion of an adequate set of learning and interest-related items to be filled-out after the forum. Resource limitations and consent requirements precluded the participant qualitative assessment. Question items related to the socio-economic profile of participants; cognitive and genetic intervention-related items; and the precise wording of question items in general benefited immensely from the input of the three project partners (University of Michigan; National Community Committee; and Departments of Public Health) and helpful faculty members at the University of Michigan School of Public Health.

A Steering / NCC Committee process evaluation form was developed using community-based process items described in Israel et al. *Methods in Community-Based Participatory Research for Health* (2005). Content of the form was developed by the project evaluation specialist in concert with all 3 project partners. This form was constructed at the same time as the participant forms, and circulated to committee members at the close of the project. The project P.I., Project Administrator, and Evaluation Specialist held follow-up debriefings with NCC site leaders once the forums had taken place.

R. Community Engagement Website

With the assistance of LSS, CPHCG established a web site (www.GenoCommunity.org) used to market the forums, register participants, share educational resources, and promote future engagement through discussions, blogs and connections with advocacy organizations. Throughout the developmental stages of the website, the Steering Committee offered input on design, functionality, and key components of the site. Input was then incorporated into the overall construction by the U of M team members of the CPHCG and LSS who were actively involved in website creation. Overall site page layout and graphic combinations were created by Michigan Marketing and Design.

GenoCommunity.org, which was officially launched on the day of the forums, is rooted in the fundamental goal of facilitating people working together on genomics education, discussion and advocacy in a spectrum of community settings. In order to extend conversation beyond non-English speaking communities, the site offers a Spanish option.

From the GenoCommunity main page, one can access linked pages dedicated to community events, community forums, knowledge modules, online discussions, blogs, educational resources, and advocacy. Coinciding with the mission of the website, the Community Events page aims to encourage and help facilitate community organizations, libraries, and museums in hosting events related to genomics by providing a number of resources. Available on the site is a tool kit which includes marketing materials, educational materials, and information on planning an event.

The Community Forums page was principally created to aid in the promotion and registration for the forums held in October 2007. From this page, one can access forum site-specific information based on state preference.

In order to further web-based education and awareness on genetics-related issues, knowledge modules were created on topics such as genetics and criminal justice, genetics and family history, genetics and me, genetics and privacy, and genetics and race.

An Online Discussion page was created to continue the dialogue from the forums and serve as a venue for web-community communication.

Through the Blog page, participants have the opportunity to start their own blog, which can be used to further community dialogue and interaction.

The Educational Resources page offers links to a myriad of genetics-related organizations, national genetics centers, and genetics-based projects. The page also offers key articles about genomics.

The Advocacy section of GenoCommunity.org is intended to encourage and assist community members in learning about genetics policies being considered,

identifying and communicating with advocacy organizations that influence genetics policies, and having community member voices heard by those who are in decision-making positions that affect genetics policies.

The use of the website will be analyzed using Google Analytics to evaluate the number of hits per day, the geographic location of users, search engines used, key words leading to the site, the bounce rate, referring pages, time spent on the site, and how people navigate the site.

S. U of M Team Members Presence at State Forums

On the day of the forums, the U of M team sent a pair of individuals to each forum location to aid the host organizations during the forums. Two individuals also stayed in Ann Arbor to run things at the forum viewing at the U of M School of Public Health and to act as the contact people for team members in each of the five forum locations. Additionally, the technology coordinator was stationed in Ann Arbor to coordinate videoconferencing efforts. Throughout the day, U of M team members at the five forum sites directed questions regarding technology or other problems to the team members in Ann Arbor. A contact chart, including cell phone numbers for all community organization contacts, technical staff, organization staff, and all other pertinent personnel was provided to each U of M team member in order to facilitate communication on the day of the forums.

Each U of M team member traveling to forum sites was also provided with a checklist and additional materials to bring with them to the sites. The checklist included a laptop computer and flash drive for the website demonstration and other presentations as needed, a CD of the pre-recorded talks by Dr. Francis Collins and Dr. Sharon Kardia,

a copy of primers and brochures to promote the related WE-ACT conference, the most recent contact list and agenda table, a script for the website demonstrations (which the U of M team members conducted during the forums), and a digital camera for taking pictures during the forums. Also included were instructions for the U of M team members to check-in with the forum host at least an hour before the forums began and to offer assistance as needed. U of M team members were also charged with making sure that facilitators, note takers, and the person giving the welcome were in place and understood their duties. The U of M team members also made sure that the forum locations was properly set-up, including the registration table, breakout session rooms, videoconferencing equipment, and other technological and physical arrangements.

T. Technology

This portion of the report is divided into four sections: 1. The Technology Plan, 2. What Worked, 3. What Didn't Work and Why, and 4. Lessons Learned for the Future.

1. The Technology Plan

A major component of the forum project was the utilization of videoconferencing technology enabling portions of a forum presented “live” in one state to be shared via videoconferencing with one or more other states. This enabled us to “share” sessions, especially the one presented by Dr. Collins, across a very wide geographic and demographic span of audiences. The decision to utilize this technology was also prompted by the recent installation of state of the art communications technology at the University of Michigan’s School of Public Health’s new “Community Crossroads” building.

Appendix 12 indicates, with the capital letter (V) those sessions which were to be videoconferenced to the state indicated. Two sessions, the Introductory session presented live by Dr. Kardia in Michigan and the keynote address presented live by Dr. Collins in Minnesota, were to be shared with all 4 other states. The session presented live by Dr. Dunston in Missouri was to be shared as a break-out with Michigan, and the break-out session presented live by Dr. Ossorio in Illinois was to be shared as a break-out in Michigan. Dr. Collins' wind-up session with guitar presented live in Missouri was to be shared with Michigan. All videoconferenced presentations were to have their subsequent question and answer sessions interactive, enabling the states receiving the session via videoconference to be viewed by the other states as questions were asked by members of the audience in those states. All of the sessions identified above, plus the session presented by Dr. Khoury in Illinois, Dr. Guttmacher in Iowa, Dr. McBride in Minnesota, and the panel presentation presented in Missouri, were to be captured at the University of Michigan utilizing the same videoconferencing technology. All of the sessions identified above were to be viewed at the School of Public Health, where a varying group of students and faculty were able to see and hear those portions of the forums in all states using the technology. Finally, all of these sessions were to be captured and video-recorded at the School of Public Health for posting on the forum's web site, enabling viewers of the web site to see and hear the sessions on streaming video.

In order to assure that the two addresses shared across all sites (those presented by Dr. Collins and Dr. Kardia) were not prevented by problems with the

technology, those presentations were video-recorded on CD-ROMs in advance of the forums, with CDs distributed to each site for use in case of technological problems.

Each of the host organizations in the 5 forum states was given advance information on the technology that would be needed at the sites chosen for their forums, and were asked to provide the School of Public Health team with contact information for the person(s) responsible for the operation of the technology at their site. Dr. David Mendez, who has been one of the principal leaders in advancing the use of instructional technology at the School of Public Health, assumed the lead role in coordinating the technology across all 5 sites. Before the forums, a table was created to aid technology personnel at each of the forum locations. The table included information on the times and locations that necessary connections had to be made in order to facilitate sharing of select plenary and breakout sessions across the states. Tests were made of the videoconferencing connection in each state in advance of the day of the forum.

2. What Worked

The keynote presentation by Dr. Collins was viewed by all states, although the technology in the room where Dr. Collins presented “live” left him uncertain whether he was being seen and heard, for a time. Each of the states had an opportunity for one or two people to go “on screen” and ask questions to Dr. Collins. Certainly the absence of videoconferencing would have made the decision of where Dr. Collins was to speak a much more difficult one, with the potential of hard feelings with some of our community partners, and would have prevented him from sharing his presentation with a large audience spanning a very broad geographic and demographic spectrum.

Dr. Kardia's presentation was also shared successfully with 2 of the other states, but had difficulty in Minnesota and Illinois for reasons described below. Dr. Dunston's presentation was successfully shared with Michigan, enabling Michigan to combine that presentation with a later break-out session on the spirituality and genomics theme highlighted by Dr. Dunston's talk.

Dr. Collins' wind-up folk singing session with guitar was successfully shared with Michigan.

Students and faculty at the School of Public Health were able to see and hear the sessions presented by Dr. Kardia, Dr. Collins, Mr. Bonham, and Dr. Dunston, as well as the guitar session with Dr. Collins at the close of the forums.

Most of the videoconferenced sessions were successfully captured for later viewing as streaming video on the forum's web site.

3. What Did Not Work and Why

Dr. Kardia's session was not received in Minnesota, and was received with poor transmission in Illinois. Dr. Collins "stepped into the breach" in Minnesota, having viewed Dr. Kardia's presentation in advance, and made an Introduction to Genomics presentation in lieu of what would have been videoconferenced.

Dr. Ossorio's session was not received in Michigan, resulting in the need to consolidate two break-outs into one session in that state.

The equipment in Illinois was not suited to the videoconferencing needs, resulting in the failure of capturing Dr. Khoury's talk, and poor transmission of Dr. Kardia's talk.

While most of the videoconferenced sessions did, in fact, take place as planned, the quality of the video was not consistent across the sites, and in most cases either

PowerPoints or the view of the speaker was sacrificed in order to maximize the quality of the other component.

The presentation by Dr. McBride in Minnesota wasn't entirely captured by the videoconferencing equipment, and thus will not be completely available for video streaming on our web site.

The recording quality of the presentation by Dr. Dunston was rather poor, so that video streaming in our web site will not be of good quality.

Dr. Guttmacher's presentation in Iowa was not recorded, and thus will not be available on the web site.

In addition to the above described problems, sessions that did work well were delayed as one or more of the sites needed time to make the necessary connections or adjust the equipment.

Following the forum we had several debriefings to determine the causes of videoconferencing problems. The major causes of these problems were found to be:

1. Forum sites had varying quality of videoconferencing equipment. While basic requirements for this equipment had been shared with all sites, the lead person for the community-based organization host was not a technical expert, and left the determination of equipment to the technical person identified for that aspect of the forum. In some cases that technical person shifted to another person for the forum itself.

2. Some selected sites did not have all of the equipment necessary on site to make the various "bridging" arrangements, and were, in fact, satellites to bridging facilities that handled multiple videoconferenced sessions simultaneously. As a result,

communications made between Dr. Mendez and the “technology lead” in a forum site, omitted the technical personnel managing the bridging between the site and the University of Michigan’s main bridge.

3. In the case of Illinois, the person initially identified to handle the technology was not given adequate information by the host organization and was not in Chicago on the day of the forum, resulting in the need to identify a technology team and equipment at the last minute on the day of the forum. The equipment hastily found and placed in the auditorium was not of the quality necessary for adequate videoconferencing.

4. In spite of our repeated attempts to hold a comprehensive 5-state rehearsal of the videoconferencing equipment, we were only able to hold a 4-state rehearsal in addition to the one-on-one tests of communications from a single site to the School of Public Health.

5. The shifting identification of persons responsible for the technology and the variation of the quality of the equipment, resulted in some sessions that were to have been recorded but not videoconferenced, not being recorded, or being recorded in poor quality.

6. Some of the “bridging” equipment scheduled for installation at the School of Public Health wasn’t available for the forum, resulting in the need for the School to utilize another “bridging” facility at the University. While this facility operated satisfactorily, it posed another communications challenge, when combined with the various satellites and bridging combinations at some of the forum sites.

7. Dr. Mendez, who clearly had both the vision and expertise to coordinate this complicated set of videoconferencing requirements, did not have sufficient time or

support people available during the planning period in order to identify and address the problems described above. While he had initially anticipated having 5 key technology people to deal with, the combination of satellites, bridging centers and community hosts resulted in his having 18 different people (some identified later than others) to deal with in coordinating the technology.

8. Even had some of the problems described above been identified sufficiently in advance of the forums, they would have pointed to the need for a substantial increase in funding in order to be adequately addressed (e.g. hiring technical experts; renting higher quality equipment).

4. Lessons Learned for the Future

After considering the successful and unsuccessful aspects of our technological experience, we have concluded that videoconferencing is a technology that can play a significant role in connecting genomics experts with communities, expanding the reach of education and the size and diversity of the communities engaged with experts. But we have concluded that success in utilizing technology for these purposes necessitates that the following items be addressed:

1. A single person needs to be clearly identified as the technology lead at each site, and needs to have both technological expertise and authority to direct all of the technological operations at a particular site.

2. A detailed description of the necessary technology needs to be made available to each forum host far in advance of the forums, and assurance provided that the chosen site, coupled with the technology lead and those supporting him/her, will satisfy all of these requirements.

3. A carefully constructed budget needs to be developed in advance, covering all needs of personnel, equipment, site rental, etc., to assure a high quality result.

4. A master document with all of the details needed for coordinating the technological aspects of the forums needs to be prepared and distributed to the technology leads and any other technology support people in advance of the forums.

5. The coordinating site needs to have a person with the technological expertise, the managerial expertise, and the available time and support personnel to direct all aspects of the technology during the planning period and during the implementation of the forums.

6. A comprehensive rehearsal needs to be held several days in advance of the scheduled event, in which all of the various videoconferencing combinations need to be checked out, including a presenter and Powerpoint presentation at each site.

7. To the extent that some of the above needs (e.g. budget) cannot be assured far in advance of the event, the event needs to be scaled down to the point that high quality can still be assured. For example, concentrating on just one shared presentation by Dr. Collins, or reducing the number of sites to 3, would have simplified our forum event's technological complexity.

One final note: The state of videoconferencing technology is advancing rapidly, as is the availability of high-quality equipment to support this technology. Carrying out an event with multiple sites connected by videoconferencing technology will become simpler and less costly in future years, and an increasing number of sites will have high quality technology of the type necessary. We still believe that a combination of live presentations and videoconferenced sessions provides a powerful method of

connecting genomics experts with diverse communities across a wide geographic span. Careful attention to the lessons we have learned with our forums should enable future events to utilize this technology in ways that maximize benefits and minimize problems.

U. Outcomes

1. Number of Participants

A total of 495 people attended the forums in Illinois, Iowa, Michigan, Minnesota, and Missouri on October 12, 2007. An additional 24 individuals also viewed the forums from the University of Michigan site in Ann Arbor, for a total of 519 individuals that were engaged during the forums.

There was a high of 40 individuals attending the Illinois forum, although this number decreased to 13-14 for certain sessions, as individuals came and went at separate times. In Iowa, 60 individuals attended the forum. Towards the end of the day, however, a large number of these individuals had to leave to catch a bus, and so the last breakout sessions by Dr. Elizabeth Thomson and Ms. Kimberly Noble Piper were combined into one session, to better accommodate the approximately 15 individuals left. The Michigan forum site ended up having 145 individuals attend, which exceeded their goal. In Minnesota, approximately 176 people attended the forum throughout the day. Finally, Missouri had 69 individuals attend at the Portageville site. A handful of other individuals (5) were also able to watch the forum from viewing sites in Jefferson, Kirksville, and Salem, Missouri. Although individuals were able to view all presentations made at the Portageville site from these locations, the technology in these locations did not allow them to interact with the speakers and audience members in other forum locations.

2. Debriefing Meetings

a. University of Michigan Team

A series of debriefing meetings was held shortly after the forums, in order to capture the observations of the day while they were still fresh in the minds of all involved. The first debriefing meeting held included all U of M team members who attended the five forums in Illinois, Iowa, Michigan, Minnesota, and Missouri, as well as the two team members who facilitated the viewing in Ann Arbor at the University of Michigan School of Public Health. As a means of guiding discussion, questions were sent out ahead of time for team members to consider, including how many people attended each forum, the most valuable and weakest aspects of what occurred, the lessons learned, and how best to build on the engagement that was achieved in the forums.

One theme that emerged at this meeting was the difficulty in getting people to talk about genetics. It was noted that Minnesota and Missouri—two states that did not offer monetary incentives to participants—were able to engage their community members by focusing on why people should be interested in this topic throughout the planning process. This is in contrast to the low turnout numbers in Illinois, where recruitment techniques were not as successful as anticipated.

A discussion also ensued about the lessons learned and the high and low points of each of the forums, as identified by University of Michigan team members. At the Illinois forum, the largest lesson learned was that there needs to be a check-in process with the community members planning the forums. One way of doing this would be to

have certain milestones that must be reached within certain time frames before all funds are distributed.

The highlight of the Iowa forum, as described by U of M team members, was the breakout session presenters and their ability to connect to audience members. One downside of the day was that a bus full of senior citizens had to leave before the last breakout session. The last breakout session thus became a combined effort between two presenters and turned into more of a lecture format due to time constraints. Also, since the audience had not been identified when the interest surveys were completed, the audience did not have much input into the content of the forum.

In Michigan, the people were attentive and engaged. The spirituality and genetics sessions were thought to be an especially strong part of the day, during which the community was receptive and open to expressing their concerns. The continuing relationship between the community and the ministers and pastors that took part in this session was a good lesson. The sessions that were not directed at a community audience were least successful. One lesson is that more dialogue may help to “myth bust” some of the issues that were not addressed in these talks.

The Minnesota forum was highlighted by the diverse group of individuals who attended, and by Dr. Francis Collins’ interaction with the community. Another strength of the Minnesota forum was the host organization having extensive experience in putting together a large event. As with several of the other forums, technology glitches proved to be a weakness with unsuccessful connections. When the technology did work during Dr. Francis Collins’ talk, however, it showed the potential of technology for future events.

In Missouri, Dr. Georgia Dunston in particular was cited as providing a good example of successfully engaging and exciting the participants. The panel discussion was also a highlight—as they spent time listening to the concerns of the community. An important lesson learned was that by knowing the audience ahead of time, talks could be tailored to meet the needs of a particular group. The community did not appear to be successfully engaged by the technology, however, and the technology glitches exacerbated this problem. Not having any live presentations until the afternoon proved to be a slow start to the day.

In the Ann Arbor site, the technology was once again the focus of the discussion. While it was unique to be able to see events happening simultaneously around the Midwest, problems with properly establishing connections proved to be disappointing to participants who wished to see certain speakers that were not available via video.

b. Steering Committee

A debriefing meeting was also held with the entire Steering Committee, including the NCC hosts in each of the forum states. A separate debriefing was held with the Minnesota NCC host, who could not attend the Steering Committee Call. Each of the NCC hosts verbalized what they considered the most significant achievements of each of the forums. In Missouri, it was the people that were engaged in the forums, and the fact that most were grassroots level participants. In Illinois, reaching out to the Spanish community, as well as bringing together individuals from all over the Chicago area working on health was seen as an achievement by the NCC host. The Iowa and Michigan hosts both appreciated how the speakers interacted with the community and the support of U of M team members on the day of the forums. In Minnesota, having all

of the knowledge and expertise readily available and previously existing community partnerships contributed to the success of the day.

Problems with technology were cited as the weakest aspect of the day by the NCC hosts in Missouri, Iowa, Michigan, and Minnesota. Although it was recognized by the Steering Committee as a new element not utilized in the way community work is usually done, it was concluded that there were advantages to be gained for events such as these if the technology could be more reliable. The Illinois NCC representative also mentioned how much work needs to be done in the Latino community around genetics to motivate individuals to come to such an event. The Missouri representative also expressed a desire for more one-on-one engagement with the panel discussion, and the Michigan representative also stressed a desire to have the forum materials earlier to avoid the last minute rush of putting together folders for participants.

In terms of the lessons learned for the future, the NCC representatives mentioned many opportunities for further community engagement in genomics. Illinois, Michigan, and Missouri expressed a desire for similar events or targeting different groups within their communities in the future. Michigan mentioned it would be beneficial to hold more such sessions, but with smaller groups. Both Iowa and Minnesota noted that it is important to find the right combination of speakers that are able to engage the community on meaningful topics, and that some of the local speakers live at the forum sites were particularly good at doing this. Minnesota also stressed the importance of having the community represented on the planning committee and working on the project right from the beginning to put something together that represents what the community could benefit from and what they are interested in.

V. Results of the Evaluation

1. Demographic Profile

Three hundred and eight individuals filled-out at least one evaluation form (demographic portion of Forum Participant Questionnaire; thematic and sessions portion of Participant Questionnaire; Break-out Questionnaire). In the following evaluation sections 1 through 3, the evaluation results described are limited to the information collected from those participants who completed evaluation forms (308 of the total 519 participants). Minnesota contributed the largest number of participants (176), followed by Michigan (145). Ann Arbor was a non-interactive forum site. It coordinated the technical link-ups on the day of the forum, but attendees in Ann Arbor merely observed, neither communicating with the other sites nor filling-out Forum Participant Questionnaires. Many of the Illinois participants left early due to an immigration rights event that split their day. The early departure resulted in a shortage of returned forms (returns were mostly from professionals who attended).

Straightforward 'desire to learn about subject' proved the most frequent motivation for attending the forums. The second most frequently cited reason was the person's occupational involvement with health and the health care system. Jobs ranged from health promotion to public health and medical practice. The fact that a person's community organization helped sponsor the forums ranked as the third motivator. It appeared marked on the forms only one third as frequently as desire to learn. Persons attending seemed earnestly ready to learn.

Only 60 people (19.9%) of all participants indicated a genetic condition in the family prompted them to attend. It could be this was only an ancillary reason in drawing

participants. Participants from Flint, Michigan and the two Missouri cities more frequently marked family history as a motivator. As these sites drew more African American participants than the other locations, it is possible concern with sickle cell or a number of chronic diseases served as the reason for people marking this category of motivator. The number itself is reminiscent of the 20-50% of participants in the NHGRI-sponsored Communities of Color and Genetics Policy Project reporting the presence of genetic illness in a family member.

The majority of forum participants across the 5 states were female (74.2%). 25.8% were male. The Iowa audience was the most balanced gender-wise, with a female to male ratio of 6 to 4. The forum attendees displayed a wide racial-ethnic distribution. 45.7% (138) participants were African American; 36.4% (110) were Caucasian. The Flint, Michigan and Iowa sites were major contributors to these two categories, respectively. Minnesota hosted the largest number of Latino (23) and Asian (18) participants. Of those Illinois participants who returned forms, 80% (4 persons) were Latino. Flint and Ann Arbor, Michigan recruiting did not touch the Arab American population of Detroit, possibly due to the geographical focus of the University of Michigan and the community-based organization efforts in Michigan that were centered in Flint. Flint, however, contributed the largest number of Native American participants to the effort – 7 individuals. Representation of the various age categories, from ‘under 30’ to ‘61+ years’, was evenly distributed.

Project participants were widely distributed along measures of socio-economic status. Roughly 60-80 participants occupied each of the educational categories from 12 years of school to some grad school, with 30 participants having less than 12 years of

education. Household income categories were also evenly distributed: 75 participants earning less than \$15,000 per year; 107 earning \$15,000 to \$45,000, and 97 individuals earning \$45,000 and over. The history of community dialogue efforts in general, from the Oregon Medicare project to the more recent genetics policy projects, show an effort in balancing racial-ethnic and socio-economic categories often resulting in mixed success. In the current instance, the reach of the recruiting organization, the National Community Committees, is national in scope, which has led to the observed wide distribution in categories of forum participants. Involvement of the medical and public library systems has assisted in this effort.

Occupational responses of participants fit several categories. The largest number of participants came either from the 'Health Professional' category (21.4%), or were 'Unemployed or Retired' (16.8%). All the states contributed to the former category. The Chicago group turning in forms and the Jefferson City, Missouri group both had large proportions of professionals. Thirty-four of the 48 unemployed or retired forum attendees were from Flint, Michigan, making this site an important ingredient in assuring an equal voice in the project. Half of the Ann Arbor attendees were students. See Appendix 13 for Forum Participant Questionnaire evaluation results across the five forums.

2. Plenary and Panel Sessions

The two types of statements posed to forum attendees for the major talks heard by everybody were: (1) Overall, this was an engaging presentation; and (2) The topic presented was of value to me. At least 50% of forum attendees marked 'Strongly agree' for the two question items relating to each type of plenary session – "The Human

Genome” with Sharon Kardia, “Genomics, Medicine, and Society” with Francis Collins, and the general category of third speaker – when responses were averaged over the 5 states. At least 20% of attendees marked ‘Somewhat agree’ to these two statements. Illinois had only two respondents for these questions, one of whom marked ‘Neither agree nor disagree’ and ‘Strongly disagree’ for the engagement question on both major speakers. This person’s responses reflect the need to make genetic talks as understandable as possible to general audiences, and the need to construct community forums so organizational dilemmas (technical equipment, scheduling) do not affect reception of the talks. Participant comments to Illinois session organizers suggest these two points. The overall ratings do, however, indicate the plenary talks were well received. The sessions with Francis Collins received markedly high ratings. Participants felt engaged and that the topics presented had personal value.

Two states – Michigan and Minnesota – gave consistently higher ratings to speakers Kardia and Collins than the rest of the states. This finding suggests two possibilities. First, both locations are connected with research universities, the University of Michigan and Minnesota, which are heavily involved in genomic research and biomedical community-based outreach activities. Those persons attending the forums in these states may have already been exposed to genetic topical areas before attending the forums, bolstering the value of their experience at the forums.

A locations effect is also visible. Speakers talking at a particular location tended to have the highest ratings from participants at that location. Their talks were appreciated by audiences in the other states, made possible by communications

technology, but the greatest reception was in the states where speakers were physically present.

The third set of plenary session speakers, addressing a variety of topics chosen by the states, also followed the 60%/20% ratings pattern over all the states. Vence Bonham's talk, "Addressing Racial and Ethnic Health Disparities in the Genomic Era", and Colleen McBride's talk on "Genetics and Behavior" received especially high ratings. These talks were likewise hosted in Michigan and Minnesota. Beyond the locations effect, the speakers and topic area seemed to have a special resonance with their audiences. The mechanism of allowing states to choose their topic and speaker seems to have had a real payoff in these states.

Resonance with the audience is not to be discounted. Within Missouri, the talk with Sharon Kardia was more strongly received by attendees in Portageville (the Ozarks), having more low SES attendees, whereas the talk by Francis Collins was more strongly received by the higher SES Jefferson City audience.

The Missouri "Next Steps for Individuals, Community Organizations, Health Departments, and Other Agencies" panel session had ambiguous results. Reception of the message of the panel session was quite strong, with 60.5% of listeners strongly agreeing, and 32.6% somewhat agreeing the panel session communicated information important to community members. In contrast, 41.9% of listeners strongly agreed, and 39.5% somewhat agreed the combination of discussants was more effective than if each had presented alone. In this case, the "message" seemed more important than the "medium." See Appendix 13 for Forum Participant Questionnaire evaluation results across the five forums.

3. Break-out Sessions

The personal engagement and personal value questions were also applied to the separate break-out sessions. The two family history break-out sessions, with Duquette and Hickman / Oehlke, consistently garnered on these two question items the highest rating from attendees. In the Communities of Color and Genetics Policy Project, African American and Latino participants voiced the hope that genetic advancements could bring relief to family members with diabetes, sickle cell disease, and high blood pressure. Though family history by itself did not reveal itself to be the prime motivator for people who attended the forums, it was a subject that was on people's minds, and occupied a major spot in their enthusiasm with the topics presented.

Next in overall satisfaction came the break-out session on "Diversity, Disparities & Forensics" with Vence Bonham and the two spirituality-related sessions (Lewis et al. and Collins et al.). The value participants placed on these sessions reflects the level of guidance cultural and religious values, beliefs, and feelings provide in people's lives. The content of the sessions overlapped lived experiences. It should be noted, however, that a substratum of some 2-5 individuals per session did not agree the break-outs were engaging or of value. In such instances, it was often the technical load of what was presented that was the 'Achilles heel' for an otherwise strong session. The third most highly marked break-out session was "Genes, Environment & Chronic Disease" with Burns and Guttmacher. This session received slightly higher ratings than Professor Guttmacher's research plenary session. The difference would appear to be the subject material. People have an interest in chronic disease, which personally touches them.

The sessions by Thomson (“ELSI in Genomics Research and Health Care”) and English (“Education in Genetics and Career Opportunities”) received the highest ratings in the ‘Somewhat agree’ (engagement and value) category. People were interested in and valued these sessions, which dealt with the personal and societal implications of what was being discussed. In looking topic-wise at all the break-outs, the closer a subject area impacted the individual, in terms of the values they hold and the health they and family members experience, the more engrossed they were with the session.

Two personal dynamics lessons also stand out from the break-out session results. Those sessions in which participants felt most engaged and to which they assigned the highest personal value generally were also highly rated in terms of the presenter’s ability to make the individual feel comfortable lodging comments and asking questions. The presenter’s listening and responding ability mattered to the participants. Secondly, the video break-out session with Dunston (the Ossorio video session was replaced at the last moment) garnered in the 47% territory on numbers of participants agreeing the session was engaging and of value. Georgia Dunston is known to be an arousing speaker and her plenary session rated in the 60% territory. It would appear the lower rating for the break-out session occurred because it was received in video form. This session format creates distance between the presenter and session participants, and disallows question and answer. The videoconferencing technology can be technically successful, with ability to connect remote sites, yet seems innately less successful than direct interaction in fostering full appreciation for the material being discussed. The Kardia and Collins plenary sessions suggest nonetheless that talks organized in advance to reach out to separate audiences can overcome the distance

factor. See Appendix 14 for Break-out Session Questionnaire evaluation results across the five forums.

4. Overall Event

The forms asked a number of questions relating to the impact of the forums on attendees. One hundred-eleven participants (45.7%) strongly agreed that the event touched on major issues they wanted to see addressed; 101 participants (41.6%) somewhat agreed with this statement. The response was neither weak nor strong in terms of people's feelings that their personal topic areas were hit. The NCC leaders who selected the topics for their constituents had an effective handle on what they might be interested in, yet could not project the range of individual interests. It would appear that another mechanism, such as focus groups, would be needed to more closely forecast participants' interests.

The forums had the overall effect of making people interested in learning more about genomics. This finding shows in the data from the individual states as well as the states collectively. In total, 90.3% of participants either strongly or somewhat agreed (more the former) the sessions interested them in genomics further. While part of this effect may be due to self-selection given the professed desire of those who signed up for the event to learn, a large share of it is to be attributed to the forums themselves.

As to whether participants felt they actually learned from the sessions, the responses were in midrange. One hundred-twenty six individuals (49.0% of participants) felt they learned a great deal; 24.1% a moderate amount. Attendees from Michigan and Minnesota, states attaching the greatest importance to the plenary sessions, were also those individuals to most strongly feel they learned from the

sessions. Attendees were asked at the end of the Participant Questionnaire to record general comments on the event and sessions. The evaluation team broke these general comments into 11 categories, from services provided (such as meals) to presentation quality and further suggested activities. The category of comment that appeared most frequently related to the educational value of the sessions. Favorable comments on the speakers and material covered were next most frequent. Project investigators felt application of pre- and posttests would unduly complicate the one-day forums, though they might have revealed more detail on these findings.

Given the positive comments by participants on the educational value of the sessions, it is likely a qualitative shift in the format of the forums would be needed to increase their educational value (stretching the forums into a series or holding follow-up workshops). Participant responses to Question 22, "What can be done to increase your community's understanding of genomics?", would seem to support this conclusion. The most frequent participant response to this question fell into the area of more education and awareness raising. Multiple individuals suggested continuing the community forums, and expanding the discussion to other locations. The second most frequent to appear basket of suggestions for increasing community understanding of genomics related to the need to continue communications about events and sources of information, and to distribute information further.

One hundred-six participants (43.8%) of people strongly agreed they intended to further use the project web site demonstrated at the forums. This level of response was to be expected given people often depend on other forms of media (television, newspapers) for their information. Sheer inaccessibility of the Internet is also a factor.

Employment of library systems to make available the technology to tap genome web sites (an endeavor of the current project) is one way to reduce access barriers.

The Participant Questionnaire also asked individuals their degree of comfort in participating in various forms of genetic research having attended the forums. The most positive response was voiced for encouraging family members to collect health family histories. High percentages of people at the Michigan and Minnesota forums, in the 70% range, strongly agreed they would feel comfortable encouraging family members, and 2 of the 3 Illinois participants filling out the form somewhat agreed they would feel comfortable doing so. The break-out sessions seemed to have a positive influence on people's willingness to engage in research. The family history break-out sessions occurred in the above two states. In addition, a larger proportion of individuals in Iowa (59.1%) compared to the other states somewhat agreed they would be more likely to encourage family and friends to participate in a national study looking at genetics and the environment. Iowa is the state where the break-out on genes and the environment was held. Michigan residents also showed a vigorous interest in advocating this line of research, connecting genetic with environmental factors, once again highlighting a possible concern with chronic disease and its prevention.

Positive responses to engagement with genomics research in general and with personalized testing and management did not reach the level of the above two technologies. It could be people feel ambivalent about personalized genetic testing given that it has a range of potential consequences. Messages about family history and gene-environment impacts seemed to resonate more closely with their interests.

31.7% of participants (77 individuals) strongly agreed and 41.6% (101) somewhat agreed they would be more likely to consider or advocate a career in genetics having attended the forums. Either more information needs to be provided, or more intensive encounters with the career area need to be experienced for people to be persuaded this career is for them. Further analysis of responses, comparing attendees who did and did not attend the career-related break-out session, could be revealing. See Appendix 13 for Forum Participant Questionnaire evaluation results across the five forums.

5. Steering / NCC Committee Process

Steering and NCC Committee members at the conclusion of the project year were e-mailed a committee process questionnaire developed with their input. NCC, public health department, and University of Michigan project team members taking part in these committee meetings were invited to fill out and return their forms. With the exception of one public health student who took part in the meetings, the respondents were employees in these three categories.

100% of responding NCC Committee members and University of Michigan (U-M) team members (10 individuals total) strongly agreed that U-M project members listened to the points of view of the other committee partners. This finding suggests “good chemistry” existed between these two parties, at least in the context of the meetings. The one public health department respondent somewhat agreed they felt U-M members listened to their point of view, implying some room existed for their suggestions to be further listened to and incorporated. Likewise, two public health

respondents marked 'Somewhat agree' in regards to Question 5 dealing with incorporation of people's input into the overall project.

Interestingly, only 4 out of 6 NCC respondents strongly agreed with the statement 'NCC members of the Steering / NCC Committee listen to each other's points of view'. NCC members consistently gave each other a chance to talk during the meeting communications. They rarely contradicted one another, and often built on each other's ideas. The finding shows that a group can serve as its own most serious critic.

Two question items (4. and 6.) dealt with comfort in communicating. Four of 6 NCC participants strongly agreed they felt comfortable expressing opinions at the meetings, further indicating a style of encounter that promoted shared engagement. The broader item dealing with ease of communication both within and outside of Centra meetings yielded more mixed results, with 1 to 2 individuals in each group marking 'Somewhat agree' to Question 6. This finding may be interpreted as showing the time and distance barriers people spread across 5 states needed to overcome in connecting with one another, or alternatively, the value of the Centra meetings in overcoming barriers and bringing committee members together. It is uncertain to what extent perceived differences in members within separate groups posed an obstacle.

Committee members seemed more enthused with embracing computer technology than participants filling out forms on the day of the forums. Half of the committee members strongly agreed that Centra networking provided effective communications for their meetings; half somewhat agreed. NCC members were especially enthusiastic about the effectiveness of this means of communication.

Ten of 12 respondents strongly agreed that project leadership has promoted shared decision-making between the three different groups. One individual marked 'Somewhat agree,' and one marked 'Neither agree nor disagree'. This small amount of uncertainty indicates the need to explicitly discuss decision-making protocol from the project start. The need to hammer out an initial set of norms for working together, and to periodically review committee process, is also reflected by the two individuals who marked 'A moderate amount' in response to the statement 'In your opinion, how much trust exists between NCC members and the University of Michigan Project Team?' (Question 11.).

The questionnaire also contained a series of project goals-related items. 100% of University of Michigan project team members, and 83.3% of NCC respondents indicated the project goals were very important to them personally. This finding demonstrated personal investment in the project, a predictor of project success. In addition, 83.3% (10) respondents indicated strong agreement with the contention that the Steering / NCC Committee was influencing decisions affecting the project as a whole. Question 9., asking participants whether they agreed the project is achieving goals the committees set for it, stands in contrast to these two findings. Only a third of respondents strongly agreed that it was doing so. One individual marked 'Neither agree nor disagree,' and one marked 'Somewhat disagree.' It must be recalled that the Steering and NCC Committees set for themselves not just goals related to the day of the forums (i.e., participant numbers, diversity of sessions), but also a number of outreach goals. The ambition was to fan out to the communities and reach large numbers of people through the project web site. These processes are not yet

concluded as of the writing of this report. It remains to be seen whether all the various goals members set for themselves prove achievable or some remain as ideals. See Appendix 15 for Steering/NCC Committee Member Questionnaire evaluation results.

W. Next Steps

After the project end date, the community dialogue on genomics that was started at the forums will be perpetuated through the GenoCommunity.org website. The recently proposed NIH Partners in Research Grant RFA-OD-07-001 has website development as a main objective. Specifically, a portion of the grant is aiming to continue the enhancement and utilization of the GenoCommunity.org web site to provide tools for community involvement in research facilitating the activities promoted by the Councils in Michigan and Minnesota as well as similar activities throughout the United States. Web content includes resources for community events, knowledge modules furthering understanding of genomics, genetic research, and the potential of genetic research to address community health issues and reduce health disparities, online discussions enabling community members to engage in discussion with each other and with genetic scientists on ethical, legal and social issues relating to genetic research, blogs enabling individuals, community-based organizations and research institutions to disseminate opinions on genetic research and receive feedback, and links to policy and advocacy organizations facilitating the engagement of community residents and community-based organizations in the development, advocacy and adoption of policies furthering genetics research applied to the improvement of community health and the reduction of health disparities.

Within the NIH Partners in Research Grant, the Community Genomics Research Councils, with the support and advice of the Institutional Partner, will facilitate and promote a variety of activities to achieve community engagement in genomics research. Proposed activities include reviewing and improving www.GenoCommunity.org and its resources with community groups (e.g. the Science and Religion Breakfast Group) affiliated with LSS and encouraging community participation in the www.GenoCommunity.org web site, including utilization of web-based resources for meetings, access to educational modules and links, posting of opinions expressed at community meetings on the discussion pages of the web site, hosting of GenoBlogs, and utilization of the advocacy section of the web site to transmit community-based policy recommendations to advocacy and policy groups.

The NIH Partners in Research Grant will also build on the forums in other ways as well. The Planning Committees convened in Michigan and Minnesota for the forums will be reshaped into Community Genomics Research Councils. The Councils will work together with the Institutional Partner to carry out a variety of activities expanding community engagement in genetics research, including the organization and implementation of discussions, dialogues, and components of organizational meetings, and the provision of mini-grants and other incentives to defray the costs of these activities. The National Community Committee Network, of which the Michigan and Minnesota forum hosts are a part, will be kept informed of project activities, and will be invited to participate in planning a national scale-up of the Council structure during the final 6 months of the project. Additionally, members of the Advisory Committee for the

forum project will serve on the Steering Committee for the NIH Partners in Research Grant proposal.

The “GenoCommunity.org” website will also be integrated into other CPHCG projects. The Science Education Partnership Award Program through the CPHCG sponsors genetics education in local schools and community events. The website may be integrated into the curriculum and community events for this program.