APPENDIX 1:
Educational Module Survey

Community Genomics Forums- Educational Topics Survey

The following questions represent possible educational topics that we hope will engage users in online interactive educational modules. Please rate each question based on your personal interest, regardless of your existing knowledge or understanding of genetics. Your responses will help us prioritize the creation of the modules.

1. Genetics and Me

How interested are you in learning about…	Not interested	Somewhat interested	Very Interested
Whether your behavior is due to your genes?			
How your genes make you who you are?			
How much of you is determined by "nature" vs. "nurture"?			
Whether the place you live affects your genome?			
Whether your destiny is determined by your genes?			

Are there any other issues regarding the topic 'genetics and me' that you are interested in learning about?

2. Genetics and Family History

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
Whether you can or should, halt the heritage of unwanted genes?			
Whether you have healthy genes?			
Whether your genes cause you to be healthier than your mom/dad/sister/brother/friend?			
What your ancestors' DNA can tell you about your future?			
Whether there are "gay" genes?			

Are there any other issues regarding the topic 'genetics and family history' that you are interested in learning about?

3. Genetics and Disease

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
Whether we should tailor drugs based on people's DNA or racial/ethnic background?			
Whether you can get personal medicine for your personal ailments?			
The genes for cancer?			
The genes that could make you sick?			
The genes that could be fatal?			

Are there any other issues regarding the topic 'genetics and disease' that you are interested in learning about?

4. Genetics and Privacy

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
Whether there is a federal DNA database?			
Who knows your genetic makeup right now?			
What can someone know about you if they can read your DNA?			
How you can protect yourself/your genome?			
Whether your genes can be patented or if they have already been patented?			

Are there any other issues regarding the topic 'genetics and privacy' that you are interested in learning about?

5. Genetics and Race

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
Whether race is genetic?			
Whether different races/ethnicities are genetically different?			
How your genes make you the color you are?			
Whether doctors should practice race-based medicine?			
Should we base new medicines on race/ethnicity?			

Are there any other issues regarding the topic 'genetics and race' that you are interested in learning about?

6. Genetics and Health Disparities

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
Whether there will be a genetic underclass?			
How the new technologies may lead to health disparities?			
How genetics could be used to reduce health disparities?			
Whether genes can cause health disparities?			
Who should be responsible for reducing genetic health disparities, the government, professionals?			

Are there any other issues regarding the topic 'genetics and health disparities' that you are interested in learning about?

7. Genetics and Technology

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
Whether we can make designer babies and if so, who gets to design their babies?			
What makes embryonic stem cells so unique/controversial?			
Whether we are playing God?			
Whether we are entering a new Era of Eugenics?			
How can food be genetically modified?			

Are there any other issues regarding the topic 'genetics and technology' that you are interested in learning about?

8. Genetics and Education

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
Whether minorities are well represented in the genetics field, and if not how can we increase these numbers?			
How can we engage younger generations from all backgrounds in genetics issues?			
How your community can play a role in the genetic education of the younger generations?			
Whether the media (newspapers, TV, radio, Internet) is a reliable source for information about genetics?			
How to judge the accuracy of information about genetics presented in the media?			

Are there any other issues regarding the topic 'genetics and education' that you are interested in learning about?

9. Genetics and Ethical Issues

How interested are you in learning about…	Not interested	Somewhat interested	Very interested
What benefits can you expect if you participate in genetic research?			
What harms could result if you participate in genetic research?			
How can you be assured that genetic research on different groups of people will benefit, and not stigmatize them?			
Whether your community should play a role in the conduct of genetics research?			
Whether religion should play a role in the conduct of genetics research?			
Who should own your genetic sample if you donate it to research. You, the government, or the research institution?			

Are there any other issues regarding the topic 'genetics and ethical issues in research' that you are interested in learning about?

10. Are there any other issues or topics relating to genetics that you would like to see in these modules?

11. Please let us know which organization you are from or from whom you heard about this survey, and what state you live in.

12. Please use this space or the back of this sheet to provide any additional comments.

APPENDIX 2:
Educational Module Survey Results

Community Genomics Forum Educational Topics Survey

Summary of the Results

Leaders of the community groups that are participating in planning and hosting the Community Genomics Forum were asked to fill out this survey and pass it on to members of their groups, in order to help us prioritize issues for the creation of educational modules. The survey grouped issues into nine major categories. 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. The categories are listed in order of their interest to the participants based upon their average ranking of 1-3. The issues within each category are contained in the tables below, and listed in order of those that garnered the most interest. The survey data comes from 42 participants, unless otherwise noted.

Participants by State:

Iowa: 8
Michigan: 14
Minnesota: 8
Missouri: 6
Unspecified: 6

1- **Genetics and Me** – 48% of participants are *very* interested in this category

Genetics and Me	Not Interested	Somewhat Interested	Very Interested
How much of your behavior due to your genes?	4.8%	45.2%	**50%**
How your genes make you who you are?	2.4%	**52.4%**	45.2%
How much of you is determined by "nature" vs. "nurture"? *	9.8%	39%	**51.2%**
Whether the place you live affects your genome?	2.4%	47.6%	**50%**
Whether your destiny is determined by your genes?	14.3%	40.5%	**45.2%**

* N= 41

Write-in questions:

- What's a genome?
- Why is there such an interest in Gonomics (sic) at this time or has the interest been there and we are just hearing about it in the past few years?
- Can you possibly change the outcome if your destiny is determined by your genes?
- Why we should or should not be concerned about genetics?

2- **Genetics and Family History** – 49% of participants are *very* interested in this category

Genetics and Family History	Not Interested	Somewhat Interested	Very Interested
Whether you can or should, halt the * heritage of unwanted genes?	17.5%	**45%**	37.5%
Whether you have healthy genes? **	0%	24.4%	**75.6%**
Whether your genes cause you to be healthier than your mom/dad/sister/brother/friend? **	2.4%	36.6%	**61%**
What your ancestors' DNA can tell you about your future? **	4.9%	41.5%	**53.7%**
Whether there are "gay" genes? *	**45.2%**	37.5%	20%

*N= 40

**N= 41

Write-in questions:

- What will the answers to these questions be used for?
- How genes distribute differently among siblings?
- How much of my genes will be passed on, and how that will affect my children in the "genetics and me" issues?

3- **Genetics and Disease** – 60% of participants are *very* interested in this category

Genetics and Disease	Not Interested	Somewhat Interested	Very Interested

Whether we should tailor drugs based on people's DNA or racial/ethnic background?	4.8%	40.5%	**54.8%**
Whether you can get personal medicine for your personal ailments? *	11.9%	37.5%	**54.3%**
The genes for cancer?	9.8%	19.5%	**70.7%**
The genes that could make you sick?	0%	35.7%	**64.3%**
The genes that could be fatal?	0%	38.1%	**61.9%**

*N= 41

Write-in questions:

- I don't really care to learn about the genes, I.m more concerned with how this knowledge will be inclusive or exclusive of providing opportunities
- I need to learn as much as possible about 'genetics and disease'

4- **Genetics and Privacy** – 65% of participants are *very* interested in this category

Genetics and Privacy	Not Interested	Somewhat Interested	Very Interested
Whether there is a federal DNA database?	9.5%	31%	**59.5%**
Who knows your genetic makeup right now?	4.8%	28.6%	**66.7%**
What can someone know about you if they can read your DNA?	2.4%	21.4%	**76.2%**
How can you protect yourself/your genome?*	0%	31.7%	**68.3%**
Whether your genes can be patented or if they have already been patented?*	7.3%	39%	**53.7%**

*N= 41

Write-in questions:

- What does question # 4 mean? How knowledge my "genome" can be used so that I even need to be concerned about protecting myself is the question I'm interested in having answered.

- If there is a federal DNA database, who has access to the information?
- How does HIPAA play a role in this topic of genetics?

5- **Genetics and Race** – 38% of participants are *very* interested in this category

Genetics and Race	Not Interested	Somewhat Interested	Very Interested
Whether race is genetic? *	14.6%	**53.7%**	31.7%
Whether different races/ethnicities are genetically different? **	7.5%	**50%**	42.5%
How your genes make you the color you are? *	12.2%	**56.1%**	31.7%
Whether doctors should practice race-based medicine? **	15%	**42.5%**	**42.5%**
Should we base new medicine on race/ethnicity? **	12.5%	**45%**	42.5%

*N= 41

**N= 40

Write-in questions:

- What do you mean by "race-based" medicine? If prevention and treatment are based on risk and symptoms, what's race and ethnicity got to do with it?

6- **Genetics and Health Disparities** – 66% of participants are *very* interested in this category

Genetics and Health Disparities	Not Interested	Somewhat Interested	Very Interested
Whether there will be a genetic underclass? *	22.5%	30%	**47.5%**
How the new technologies may lead to health disparities? *	0%	27.5%	**72.5%**

How genetics could be used to reduce health disparities? *	0%	25%	**75%**
Whether genes can cause health disparities? *	2.5%	25%	**72.5%**
Who should be responsible for reducing genetic health disparities, the government, professionals? **	7.9%	28.9%	**63.2%**

*N= 40

**N= 38

Write-in questions:

- Do we currently have "genetic" health disparities? Are you mixing political verbage on racial disparities with presumed genetic links?

7- **Genetics and Technology** – 38% of participants are *very* interested in this category

Genetics and Technology	Not Interested	Somewhat Interested	Very Interested
Whether we can make designer babies, and if so, who gets to design their babies? *	**43.6%**	30.8%	25.6%
What makes embryonic stem cells so unique/controversial? *	10.3%	43.6%	**46.2%**
Are we playing God? *	15.4%	41%	**43.6%**
Whether we entering a new Era of Eugenics? *	15.4%	**46.2%**	38.5%
How can food be genetically modified? **	10.5%	**52.6%**	36.8%

*N= 39

**N= 38

Write-in questions:

- Does a designer baby receive greater mental, physical, and therefore greater societal opportunities? What's Eugenics? Since Mendel, food has been genetically modified? What's # 5 really asking?

8- **Genetics and Education** – 55% of participants are *very* interested in this category

Genetics and Education	Not Interested	Somewhat Interested	Very Interested
Whether minorities are well represented in the genetics field, and if not how can we increase these numbers? *	7.7%	35.9%	**56.4%**
How can we engage younger generations from all backgrounds in genetics issues? **	7.9%	44.7%	**47.4%**
How can your community play a role in the genetic education of the younger generations? *	5.1%	41%	**53.8%**
Whether the media (newspapers, TV, radio, Internet) is a reliable source for information about genetics? *	5.1%	43.6%	**51.3%**
How to judge the accuracy of information about genetics presented in the media? *	7.7%	25.6%	**66.7%**

*N= 39

**N= 38

Write-in questions: no responses

9- **Genetics and Ethical Issues in Research** – 57% of participants are *very* interested in this category

Genetics and Ethical Issues in Research	Not Interested	Somewhat Interested	Very Interested
What benefits can you expect if you participate in genetic research? *	5.3%	34.2%	**60.5%**
What harms could result if you participate in genetic research? *	5.3%	28.9%	**65.8%**
How can you be assured that genetic research on different groups of people will benefit, and not stigmatize them? *	2.6%	36.8%	**60.5%**
Whether your community should play a role in the conduct of genetics research? **	5.4%	**54.1%**	40.5%

Whether religion should play a role in the conduct of genetics research? *	18.4%	31.6%	**50%**
Who should own your genetic sample if you donate it to research. You, the government, or the research institution? *	5.3%	28.9%	**65.8%**

*N= 38

**N= 37

Write-in questions:

- IS the topic Genetics or Genomics?

10- Additional write-in questions

- How are mental/physical disabilities related to genetics? How far back in a person's genetic history can you trace different physical characteristics? Are mental disorders/ADD/ADHD genetic?

- I do not know enough about the subject to answer your question. I have an interest in learning as much as possible. I am currently doing research on the subject.

- If you engage your faith based partners you would have a good handle on why there maynot be interest in this area. Many faith partners teaches what the Bible states about "genomics" or what they call generation curses. The Bible state that a generation curse can be upon a family for up to three generations. If you belive this with all your heart then you would know why some faith based people feel strongly about this subject. Just this Sunday I heard a pastor from a church in Columbia South America with a congregation of 500,000 speak on generational curses. Everything that you call in the genes is true, but the Bible calls it generational curses. Just sharing since we are in the Bible belt and have many faith partners. Thanks!

Ranking of Individual Issues (1-3)

3- very interested 2-somewhat interested 1-not interested

Overall Ranking	Average Ranking	Issue How interested are you in learning about…
1	2.76	Whether you have healthy genes?
2	2.75	How genetics could be used to reduce health disparities?
3	2.74	What can someone know about you if they can read your DNA?
4	2.73	How the new technologies may lead to health disparities?
5	2.70	Whether genes can cause health disparities?
6	2.68	How you can protect yourself/your genome?
7	2.64	The genes that could make you sick?
8	2.62	The genes that could be fatal?
8	2.62	Who knows your genetic makeup right now?
9	2.61	The genes for cancer?
9	2.61	What harms could result if you participate in genetic research?
9	2.61	Who should own your genetic sample if you donate it to research. You, the government, or the research institution?
10	2.59	Whether your genes cause you to be healthier than your mom/dad/sister/brother/friend?
10	2.59	How to judge the accuracy of information about genetics presented in the media?
11	2.58	How can you be assured that genetic research on different groups of people will benefit, and not stigmatize them?
12	2.55	What benefits can you expect if you participate in genetic research?
12	2.55	Who should be responsible for reducing genetic health disparities, the government, professionals?
13	2.50	Whether we should tailor drugs based on people's DNA or racial/ethnic background?
13	2.50	Whether there is a federal DNA database?
14	2.49	Whether minorities are well represented in the genetics field, and if not how can we increase these numbers?
14	2.49	What your ancestors' DNA can tell you about your future?
14	2.49	How your community can play a role in the genetic education of the younger generations?
15	2.48	Whether the place you live affects your genome?
16	2.46	Whether the media (newspapers, TV, radio, Internet) is a reliable source for information about genetics?
16	2.46	Whether your genes can be patented or if they have already been patented?
17	2.45	Whether your behavior is due to your genes?
18	2.43	How your genes make you who you are?
19	2.41	How much of you is determined by "nature" vs. "nurture"?
20	2.40	Whether you can get personal medicine for your personal ailments?

21	2.39	How your community can play a role in the genetic education of the younger generations?
22	2.36	What makes embryonic stem cells so unique/controversial?
23	2.35	Whether different races/ethnicities are genetically different?
23	2.35	Whether your community should play a role in the conduct of genetics research?
24	2.32	Whether religion should play a role in the conduct of genetics research?
25	2.31	Whether your destiny is determined by your genes?
26	2.30	Should we base new medicines on race/ethnicity?
27	2.28	Whether doctors should practice race-based medicine?
27	2.28	Whether we are playing God?
28	2.26	How can food be genetically modified?
29	2.25	Whether there will be a genetic underclass?
30	2.23	Whether we are entering a new Era of Eugenics?
31	2.20	Whether you can or should, halt the heritage of unwanted genes?
31	2.20	How your genes make you the color you are?
32	2.17	Whether race is genetic?
33	1.82	Whether we can make designer babies and if so, who gets to design their babies?
34	1.78	Whether there are "gay" genes?

Color-coding for categories:

- Genetics and Health Disparities
- Genetics and Disease
- Genetics and Privacy
- Genetics and Education
- Genetics and Ethical Issues in Research
- Genetics and Me
- Genetics and Family History
- Genetics and Race
- Genetics and Technology

APPENDIX 3:
Topics Survey

MIDWEST GENOMICS FORUM
CENTER FOR PUBLIC HEALTH AND COMMUNITY GENOMICS
UNIVERSITY OF MICHIGAN SCHOOL OF PUBLIC HEALTH

Topics Survey for NCC Member Organizations

This survey will be used to derive a semi-final list of topics for the forums to be held in your state, and can also facilitate topical discussion at meetings or other activities at your site. The two question areas address: A. general topics for selection; and B. sub-topics for selection. Please read the brief instructions for each section then fill-out according to your preferences. We recognize that each of the NCC sites has several key participants who have been participating in our Centra calls. We request that each site submit no more than 1 filled-out form. Several individuals can participate in filling-out portions of a single form. Forms can be filled-out and returned electronically or by mail. Please return by Friday June 29 to:

Dr. Stephen Modell
University of Michigan
2675 CBPH, SPH-I Tower
109 S. Observatory
Ann Arbor, MI 48109-2029

mod@umich.edu
Tel.: (734) 615-3141
Fax: (734) 936-0927

If you have any questions about the survey, contact Sally Meyer (734-615-3412; salmeyer@umich.edu) or Julie Woodroof (734-615-9449; julw@umich.edu).

A. Respondent Information

Name(s) of person(s) filling out the form: _____

Please indicate your NCC site location (city, state):

_____

B. General Topic Selection
For each general topic, please indicate priority (1=high preference; 2=some preference; 3=low preference) you feel it merits for use in the genetics forums*:

____ Arts and Crafts (DNA dance and drama, spooling DNA from cells)

____ Comprehensive Overview (genetic developments plus socio-ethical)

____ Current Research and Applications

____ Education and Training

____ Ethical-legal-social and Diversity issues

____ Health Services

____ Public Health

____ Religion and Spirituality

____ (Other): _____

____ (Other): _____

____ (Other): _____

____ (Other): _____

* Sub-topics will be fit under these more comprehensive general topics.

C. Sub-topic Selection

For each sub-topic, please indicate priority (1=high preference; 2=some preference; 3=low preference) you feel it merits for inclusion in the genetics forums. Please first indicate priority you assign it for the Presentations (plenary sessions), then indicate priority you assign it for the Break-out sessions:

- *Arts and Crafts*

DNA dance and drama Presentations ____ Break-outs ____

DNA extraction (spooling DNA from cells) exercise
Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs____

- *Comprehensive Overview*

Comprehensive overview (genetic developments plus socio-ethical)
Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

- *Current Research and Applications*

Behavioral genetics (relation of genes to personality, behavior, behavioral conditions)
Presentations ____ Break-outs ____

Genetics research focused on racial/ethnic communities
Presentations ____ Break-outs ____

Large scale population genetic studies (human genetic variation research, U.S. national study of genes and environment) Presentations ____ Break-outs ____

Specific genetic conditions, e.g., prostate cancer, sickle cell disease
Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

[**C. continued.** Please indicate priority (1=high preference; 2=some preference; 3=low preference) you feel it merits for inclusion in the Presentations and Break-out sessions]:

- *Education and Training*

Careers in genetics Presentations ____ Break-outs ____

Cultural competency of practitioners Presentations ____ Break-outs ____

Diversity in genetics education (educ. for and about diverse racial-ethnic groups) Presentations ____ Break-outs ____

Genetics 101 (fundamentals of genetics) Presentations ____ Break-outs ____

Genetic educational tools and curricula Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

- *Ethical-legal-social and Diversity issues*

Access and disparities issues Presentations ____ Break-outs ____

Ancestry testing, group identity Presentations ____ Break-outs ____

DNA identification (profiling) for criminal justice purposes Presentations ____ Break-outs ____

Environmental justice Presentations ____ Break-outs ____

Institutional review boards: role of community Presentations ____ Break-outs ____

Privacy and discrimination Presentations ____ Break-outs ____

Race-based medicine Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

[**C. continued.** Please indicate priority (1=high preference; 2=some preference; 3=low preference) you feel it merits for inclusion in the Presentations and Break-out sessions]:

- *Health Services*

Direct-to-consumer marketing of genetic testing
Presentations ____ Break-outs ____

Genetics in nursing Presentations ____ Break-outs ____

Genetics in primary health care Presentations ____ Break-outs ____

Nutrigenomics (genetic testing + nutrition counseling)
Presentations ____ Break-outs ____

Personalized (individually tailored) medicine Presentations ____ Break-outs ____

Pharmacogenomics (genetic testing + drug administration)
Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

- *Public Health*

Genetics and chronic disease (cancer, diabetes, heart ds., etc.)
Presentations ____ Break-outs ____

Gene-environment interactions Presentations ____ Break-outs ____

Genetic screening Presentations ____ Break-outs ____

Nutrition and gene expression Presentations ____ Break-outs ____

Use of family history Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

[**C. continued.** Please indicate priority (1=high preference; 2=some preference; 3=low preference) you feel it merits for inclusion in the Presentations and Break-out sessions]:

- *Religion and Spirituality*

Genetics and religion/spirituality topics Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

(Other):_____ Presentations ____ Break-outs ____

APPENDIX 4:
Topical Prioritizations

Midwest Genomics Forums
Topical Prioritizations*
(7/18/07)

Topic	Ave. Priority	Overall Rank	Illinois Priority	Iowa Priority (Shelley)	Michigan Priority (De Loney)	Minnesota Priority (Rosemarie)	Missouri Priority (Freda)
Arts and Crafts	2.8	6		2	3	3	3
Comprehensive Overview	1.8	3		2	3 (Ella 1)	1	1
Current Research and Applications	1.3	2		1	1	1	2
Education and Training	2	4		2	1	2	3
ELSI and Diversity Issues	1	1		1	1	1	1
Health Services	2	4		2	2	2	2
Public Health	2.3	5		2	3 (Ella 1)	2	2
Relig. and Spirituality	2	4		N/A (3)	3 (Ella 1)	1	1
Other	3	7		N/A (3)	N/A (3)	N/A (3)	N/A (3)

* 1=high preference; 2=some preference; 3=low preference

APPENDIX 5:
Sub-Topic Prioritizations

Midwest Genomics Forums
Sub-Topic Prioritizations*
(7/18/07)

Presentations [Break-outs]

Sub-Topic	Ave. Priority	Overall Rank	Illinois Priority	Iowa Priority (Shelley)	Michigan Priority (De Loney)	Minnesota Priority (Rosemarie)	Missouri Priority
Arts and Crafts							
DNA dance & drama				2 [2]	-- [2]	3 [3]	3 [3]
DNA extraction				2 [2]		2 [2]	2 [3]
Other							
Comprehensive Overview							
Comp. overview				2 [2]	1 [--]	1 [2]	1 [1]
Other							
Current Research and Applications							
Behavioral genetics				1 [1]	-- [2] Ella 1 [2]	-- [1]	2 [1]
Gen. research & racial/ethnic communities				2 [2]	1 [--]	-- [1]	1 [1]
Large scale popn. studies				1 [1]	-- [2] Ella 2 [1]	1 [2]	2 [1]
Specific genetic conditions				1 [1]	1 [--]	1 [--]	2 [1]
Other				--		1 [2]	
Education and Training							
Careers in genetics				3 [3]	1 [--] Ella 3 [2]	-- [1]	3 [3]
Cultural competency				3 [3]	Ella 3 [3]	1 [2]	2 [2]
Diversity in genetics education				3 [3]	1 [--] Ella 3 [3]	1 [2]	1 [1]
Genetics 101				2 [2]	-- [1] Ella 3 [1]	1 [--]	1 [1]
Tools & curricula				2 [2]	-- [2] Ella 3 [2]	-- [--]	3 [3]
Other							

ELSI and Diversity Issues							
Access & disparities				2 [2]	1 [--]	1 [--]	1 [1]
Ancestry				1 [1]	1 [--] Ella 3 [3]	-- [1]	1 [1]
ELSI and Diversity Issues continued							
Forensic testing				2 [2]	1 [--] Ella 3 [3]	--	1 [1]
Environmental justice				2 [2]	1 [--] Ella 3 [2]	1 [2]	2 [3]
IRBs				3 [3]	-- [1] Ella 3 [1]	1 [2]	3 [3]
Privacy & Discrim.				2 [2]	1 [--] Ella 3 [3]	1 [2]	2 [2]
Race-based medicine				2 [2]	1 [--] Ella 3 [3]	1 [--]	1 [1]
Other							
Health Services							
Direct-to-consumer marketing				2 [2]	-- [1] Ella 3 [3]	3 [2]	3 [3]
Genetics in nursing				2 [2]	Ella 3 [3]	2 [1]	3 [3]
Genet. in primary health care				2 [2]	2 [--] Ella 3 [3]	2 [2]	3 [3]
Nutrigenomics				2 [2]	-- [2] Ella 3 [3]	2 [2]	3 [3]
Personalized medicine				1 [1]	2 [--]	--	2 [1]
Pharmacogenomics				1 [1]	-- [2]	--	2 [2]
Public Health							
Chronic disease				1 [1]	1 [--] Ella 3 [1]	-- [1]	2 [2]
Gene-env. interx.				1 [1]	-- [1] Ella 3 [1]	1 [2]	3 [3]
Genetic screening				1 [1]	-- [1] Ella 3 [3]	1 [2]	2 [2]
Nutrition & gene expression				1 [1]	-- [1] Ella 3 [3]	2 [2]	2 [2]
Family history				2 [2]	-- [1] Ella 1 [1]	1 [2]	1 [1]
Other							

Religion and Spirituality							
Genet/relig/spirituality				2 [2]	-- [2] Ella 1 [1]	1 [2]	1 [1]
Other							
Other							

* 1=high preference; 2=some preference; 3=low preference;
X [Y] = Presentations Priority [Break-outs Priority]

APPENDIX 6:
Speaker Biographies

Paul Allwood, PhD., MPH, RS, *Assistant Director UHS/Assistant Professor*

Paul Allwood is the head of the Public and Occupational Health division in the University of Minnesota's (U of M) Department of Environmental Health and Safety, and Adjunct Assistant Professor of Environmental Health Science, in the U of M School of Public Health. He directs activities that protects faculty, staff, and students from public and occupational health hazards, and teaches his students about the variety of hazards to which we are potentially exposed in the physical environment. Paul has extensive academic and professional training in Public Health particularly in Environmental Health, and Infectious Disease Epidemiology.

He holds Masters and Doctoral degrees in Environmental Health Sciences from the University of Minnesota, and is a member of Minnesota Environmental Health Association, National Environmental Health Association, Association of Food and Drug Officials, and the National Conference for Food Protection.

Vence L. Bonham, J.D., *Senior Advisor to the Director on Societal Implications of Genomics and Chief of the Education and Community Involvement Branch*

Mr. Bonham is a health care policy researcher whose work examines the intersection of public policy and genetics and the numerous questions that this prompts. Among the questions of interest to Mr. Bonham are the impacts of genetic discovery on the use of the constructs of race and ethnicity, health disparities, genetic discrimination, and medical decision making and subsequent considerations for public policy development. His research is conducted within the Public Health Genomics Section led by Dr. Colleen McBride. Mr. Bonham's primary research goal is to improve our understanding and use of genomics in communities, particularly in communities of color, and determine how genetic research will affect people in such communities

As chief of the Education and Community Involvement Branch, he is responsible for leading public education initiatives and structuring how the NHGRI reaches out and engages various types of communities, such as those who are underserved in biomedical research participation. For example, ECIB staff members coordinate the annual DNA Day Ambassador Program, during which NHGRI scientists travel to high schools throughout the country to expand students' knowledge of genomic science. They also coordinate courses that bring diverse communities to the NIH campus to learn about current issues in genomics and to gain information about the genetics of rare diseases. One such program is the annual Current Topics in Genomics Research Short Course, in which college faculty and students from historically minority-serving institutions have the opportunity to learn about the latest advances in genomic research directly from NHGRI faculty.

Trudy Burns, Professor, MPH, PhD, *Department of Epidemiology, University of Iowa*

Dr. Burns received her MPH and PhD in biostatistics from the University of Michigan. She currently teaches the course Genetics and Epidemiology in the Department of Epidemiology at the University of Iowa. She also holds academic appointments in the Carver College of Medicine, Department of Pediatrics, and in the College of Nursing. Since her arrival at the University of Iowa in 1982, her major research focus has been The Muscatine Study which began in 1970. Between 1970 and 1981, the school children in Muscatine, Iowa underwent biennial examinations that measured anthropometric and cardiovascular risk factor levels. A total of 11,377 children underwent 26,919 examinations. A representative cohort of these subjects (the Muscatine Study Longitudinal Adult Cohort, n=866) who have been followed since childhood is currently being examined for manifestations of early atherosclerosis as measured by coronary artery calcium, carotid artery intimal-medial thickness, and brachial artery flow mediated dilation. These investigations are examining associations between lifetime risk factor measures, genotypes at candidate genetic loci and the early indicators of atherosclerosis in the Cohort, whose members are now 45 to 55 years of age, as well as carotid and abdominal aorta intimal-medial thickness in their offspring. The research projects are also developing image analysis tools to evaluate the ultrasound images from the carotid and brachial artery examinations, and methodology for analyzing the resulting data. In addition, ability of systolic blood pressure and body mass index measurements from childhood, and of functional variants in candidate genes, to predict hypertension in middle-age is being investigated in this Cohort, along with the tracking of other risk factors. Dr. Burns also collaborates on a

number of research projects focused on the identification of genetic and environmental factors that contribute to phenotypic manifestations including bone development in children and adolescents, birth defects, and Von Willebrand disease. She recently helped to edit the book *Pediatric Prevention of Atherosclerotic Cardiovascular Disease*, Oxford University Press, 2006.

Robert Burrell Sr., *Pastor, Holy Ghost Church Ministries*
Pastor Robert Burrell Sr. has been Pastor at Holy Ghost Church Ministries for 12 years. He has a Master of Theology Degree from Destiny College International, Spring Hill, Florida. He has been married to Donna Burrell for 41 years. They have 3 adult children and 4 grandchildren. Pastor Burrell's vision is to see the Church restored to it's original glory and become the biblical New Testament Church, through his passion to teaching the Word of Faith. The church theme this year is "Living the Word".

LaJuan Chambers, M.D., *Regional Medical Director, Hemoglobinopathy Resource Center, University of Missouri – Columbia, Columbia, MO*

Dr. Chambers' primary interest is the comprehensive care of children with sickle cell disease and other hemoglobinopathies. She currently is an assistant professor at the University of Missouri – Columbia where she serves at the regional medical director of the State of Missouri's hemoglobinopathy resource center.
Dr. Chambers received her Bachelor of Science degree in biology at Prairie View A&M University in Prairie View, TX; her Doctor of Medicine degree at the University of Texas Medical Branch in Galveston, TX. She completed a pediatric residency at the University of Texas Medical Branch before completing a pediatric hematology/oncology fellowship at the University of Texas Southwestern Medical School in Dallas, TX.

Francis S. Collins, M.D. Ph.D., *Director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH)*

Dr. Collins is the director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH). He led the successful effort to complete Human Genome Project (HGP), a complex multidisciplinary scientific enterprise directed at mapping and sequencing all of the human DNA, and determining aspects of its function. A working draft of the human genome sequence was announced in June of 2000, an initial analysis was published in February of 2001, and a high-quality, reference sequence was completed in April 2003. From the outset, the project ran ahead of schedule and under budget, and all the data is now available to the scientific community without restrictions on access or use.

Dr. Collins received a B.S. from the University of Virginia, a Ph.D. in Physical Chemistry from Yale University, and an M.D. from the University of North Carolina. Following a fellowship in Human Genetics at Yale, he joined the faculty at the University of Michigan, where he remained until moving to NIH in 1993. His research has led to the identification of genes responsible for cystic fibrosis, neurofibromatosis, Huntington's disease and Hutchison-Gilford progeria syndrome. He is a member of the Institute of Medicine and the National Academy of Sciences.

Georgia M. Dunston, Ph.D., *Professor and Founding Director, National Human Genome Center and Director, Molecular Genetics, NHGC, Howard University*

Dr. Georgia Dunston is a professor in the College of Medicine at Howard University. Dunston, who has been with the University since 1972, is also the former Chair of the Department of Microbiology. Her research interests are the biomedical significance of genetic variation in African-Americans and dedication to increasing minority participation in human genetic research. These interests led to the establishment of the Human Immunogenetics Laboratory at Howard in 1985, where she served as founder and director of this core component of the National Institutes of Health funded Research Centers in Minority Institutions Interdisciplinary Program.

Dunston has been instrumental in increasing knowledge on human leukocyte antigen (HLA) polymorphisms in African-Americans. Her research examines the impact of population differences in HLA variation on

donor/recipient matching in clinical transportation and gene-based differences in immunoregulation and disease susceptibility. Dunston's research on the biomedical significance of human genome polymorphisms has been the vanguard of current efforts at Howard University to build national and international research collaborations focusing on genome-wide studies of diseases common in both African-Americans and people in the African Diaspora. This research has provided the scientific foundation for formation of the National Human Genome Center at Howard University with Dunston as the founding director.

In addition to her research and role as an educator, Dunston is a frequent speaker at universities and conferences throughout the U.S. and abroad; has several publications on HLA variation and disease associations in African-Americans; and has served on several national scientific councils and committees. Dunston earned a bachelor's degree in biology from Norfolk State University, a master's degree in biology from Tuskegee University, and a PhD in human genetics from the University of Michigan. She also conducted postdoctoral work in tumor immunology at NIH in the National Cancer Institute.

Debra Duquette, MS, CGC, *Public Health Genomics Coordinator, MI Department of Community Health*

Ms. Duquette has served as the MDCH genomics coordinator since 2004, and she is the project manager for a million dollar, 5 year cooperative agreement with the Centers for Disease Control (CDC) to increase genomics in public health programs. One of the objectives of the CDC cooperative agreement is "to educate the health workforce, policymakers, and the general public about the role of family history and genetic risk factors in chronic disease etiology, prevention and management", which is one of her primary interests. The MDCH public health genomics program is considered a national leader and model for other state programs. In her role as genomics coordinator, Ms. Duquette serves on several state chronic disease advisory committees, including the Michigan Asthma Advisory Committee, Diabetes Partners in Action, Cardiovascular Task Force, and Michigan Cancer Consortium. She also facilitates the Michigan Cancer Genetics Association and is a member of the Michigan Association of Genetic Counselors. She provides lectures on a routine basis for the public, graduate students, medical students, and health professionals.

Ms. Duquette received a MS in genetic counseling from Northwestern University in Chicago, Illinois, and a BS in biology and secondary education from Michigan State University. She is a board-certified genetic counselor with over 12 years of clinical genetics experiences, providing services to over 10,000 Michigan families. Her previous places of employment have included Hutzel Hospital in Detroit/SE Michigan from 1993-1998, Sparrow Hospital in Lansing/Mid-Michigan from 1992-1993, and Spectrum Health in Grand Rapids/West Michigan from 1998-2004, where she has been honored to serve and learn from diverse communities within Michigan.

Carla Easter, Ph.D., *Education Specialist, Education and Community Involvement Branch*

Dr. Easter is the Education Specialist with the Education and Community Involvement Branch of the National Human Genome Research Institute. From 2003-2006, she was Director of Outreach for Washington University School of Medicine's Genome Sequencing Center (St. Louis, MO). As Director, she was responsible for the initiation of partnerships with formal and informal educational institutions, the development of genetics/genomics educational materials, and the dissemination of these educational materials locally and nationally. Before assuming her role as Outreach Director, Dr. Easter was a Research Associate in the Department of Education at Washington University (2001-2003) exploring the notions of science among secondary students, educators, and administrators. She served as Project Associate for the Quality Education for Minorities Network and the Pre-College Coordinator for the NASA Summer High School Apprenticeship Research Plus (SHARP) Program in Washington D.C; and she conducted post-doctoral research on the virulence factors associated with *Streptococcus pyogenes* in the Department of Molecular Microbiology at Washington University School of Medicine (1997-2000). Dr. Easter earned her B.S. degree in Microbiology from the University of California, Los Angeles (1990) and her Ph.D. in Biology with an emphasis on Molecular Genetics from the University of California, San Diego (1997).

Dr. Elliott, *MI Forum, local spirituality leader – waiting for bio*

Milton A. English, Ph.D., *Senior Research Fellow, Genetics and Molecular Biology Branch, Division of Intramural Research*

Dr. English is a Senior Research Fellow at the Intramural Research Program in the Genetics and Molecular Biology Branch. He joined the NHGRI in November 2001 after completing his graduate work in Dr. Jonathan Licht's Lab at Mount Sinai Medical Center in New York. There, he worked on characterizing two tumor-derived mutations of the WT1 gene mutated in Wilms' Tumor, a pediatric tumor of the kidneys. His worked showed that the trans-activation and NOT the repression function of WT1 is correlated with the disease progression.

Currently, Dr. English work involved the use of zebrafish as a model system to study hematopoiesis and leukemogenesis. A large-scale mutagenesis screen has identified several lines of fish with a bloodless phenotype. His current work is focused on identifying the disease genes in these fish to further investigate their involvement in blood development and leukemogenesis.

Dr. English is a recipient of the (2003) UNCF/Merck post-doctoral fellowship award and a recipient of Acres of Diamonds Awards in the 2004 Minority Trainee Research Forum.

W. Gregory Feero, M.D., Ph.D., *Senior Advisor to the Director for Genomic Medicine, NHGRI*

In this position, Dr. Feero plays a key role in guiding the institute as it works to convert the discoveries of genomic research into advances in clinical medicine.

Dr. Feero holds a Ph.D. in human genetics from the Graduate School of Public Health at the University of Pittsburgh, as well as a medical degree from the same university. For the past five years he was a member of the clinical faculty at the Maine-Dartmouth Family Practice Residency Program in Fairfield, Maine, where he provided the full spectrum of family practice care to patients in a rural setting. That practical experience has given Dr. Feero a broad view of the challenges health care providers face as they integrate the results of genome research into their practices.

Among Dr. Feero's interests is making the Surgeon General's family history tool even more useful to health care providers by developing tools to analyze family history information, and give guidance to providers when creating a prevention or treatment plan to keep the patient healthy.

Dr. Feero is also working to connect the information gathered by the Surgeon General's family history tool to electronic medical records that are now widely used in medical practices, health maintenance organizations and hospitals. To transform family history from a passive repository of information to an active health care tool for all Americans will require its integration into the information systems now used by doctors to care for their patients.

To ensure that he stays closely connected to the needs of primary care patients and the challenges facing physicians in today's health care system, Dr. Feero continues to practice medicine, and educate family medicine physicians in training, one day a week as a family physician at the Harpers Ferry Family Medicine Center of West Virginia University's Robert C. Byrd Health Science Center in Harpers Ferry, W.V.

Phyllis Frosst, Ph.D., *Science Policy Analyst and the Acting Branch Chief of the Policy and Program Analysis Branch of the National Human Genome Research Institute*

Dr. Frosst's work focuses on issues such as genetic discrimination, the direct-to-consumer marketing of genetic tests, non-medical applications of genetics and genomics, and pharmacogenomics. Dr. Frosst serves on many science and policy committees throughout the NIH and the Department of Health and Human Services. She also functions as a "scientific translator," providing information about the Institute's many scientific endeavors for a variety of audiences, as well as responding to congressional inquiries and reporting requests. Dr. Frosst obtained B.Sc. and M.Sc. degrees with honors from McGill University in Montreal, Canada and received a Ph.D. in Cell

and Molecular Structure and Chemistry from the Scripps Research Institute in La Jolla California. She conducted research for as a postdoctoral fellow working on Adenoviral gene therapy for diseases of the retina. During this time she served as the president of the Scripps Research Institute Society of Fellows.

Ernest J. Garrison, *Pastor, Vernon Chapel A.M.E. Church, Flint, MI*

As a native Detroit, Ernest J. Garrison graduated from Wilbur Wright Cooperative High School in 1966. He furthered his education by attending Highland Park College and receiving an Associates of Arts Degree in Business Administration in 1971. He later attended Shaw College at Detroit and obtained his Bachelors of Science Degree in Business Administration with a Major in Accounting and Minor in Economics. After feeling a call on his life toward the Ministry, Ernest enrolled in Whittaker School of Theology (Anglican School of Theology) to obtain his Deaconate Certification and further his matriculation at SS. Cyril & Methodius Roman Catholic Seminary where he earned his Master at Arts in Religious Education.

Secularly, Ernest J. Garrison retired from DTE Energy (Detroit Edison) as a Claim Representative in 2001 after 35 years of service. He established Accounting Practice in 1976 until entering seminary in 1985. He is currently pastor of Vernon Chapel A.M.E. Church in the city of Flint.

Ernest Garrison also serves the connectional African Methodist Episcopal Church as Coordinator of the Church School Teacher & Christian Education Directors Training Program which consist of 20 Episcopal District in the United States, England, the Caribbean as well as Africa. He also serves as Director of Christian Education for the North District-Michigan Conference of the African Methodist Episcopal Church.

Alan Guttmacher, M.D., *Deputy Director of the National Human Genome Research Institute*

Dr. Guttmacher helps to oversee the Institute's efforts in advancing genome research, integrating the benefits of genome research into health care, and exploring the ethical, legal, and social implications of human genomics. Dr. Guttmacher also serves as the Director of the Office of Policy, Communications, and Education at the NHGRI. In that role, he directs the institute's health affairs, public policy, communications, community outreach, and public education functions.

Dr. Guttmacher came to the NIH in 1999 from the University of Vermont, where he directed the Vermont Regional Genetics Center and Pregnancy Risk Information Service, the Vermont Cancer Center's Familial Cancer Program, the Vermont Newborn Screening Program, Vermont's only pediatric intensive care unit, and an NIH-supported initiative that was the nation's first statewide effort to involve the general public in discussion of the Human Genome Project's ethical, legal, and social implications. He also had a busy practice in clinical genetics, conducted research, and taught. A graduate of Harvard College and Harvard Medical School, Dr. Guttmacher completed a residency in Pediatrics and a fellowship in Medical Genetics at Children's Hospital of Boston and Harvard.

Sarah Harding, M.P.H., *Community Outreach Analyst*

Ms. Harding joined the NHGRI in 2004 after receiving her Master's in Public Health in Public Health Genetics from the University of Washington. Her research involved studying population genetic databases, or gene banks, with a specific interest in the ethical, legal, and social implications of these databases while they were under development. In addition, during her training in Seattle, she worked on The Living Room Forums, a project that engaged people in discussions about genetics and how genetic information might affect their lives.

She currently works as the Community Outreach Analyst in the Education and Community Involvement Branch at the National Human Genome Research Institute. Her work involves engaging the public in activities and programs designed to educate them about genetics. This includes engaging students and teachers in discussions about opportunities in genetics and in thinking about the impact of genetics on society. Generally, the goal of the

Education and Community Involvement Branch is to develop education and community involvement programs to engage a broad range of the public in understanding genomics and accompanying ethical, legal, and social issues. Education programs include those to inform the public of the latest advances in genomics, as well as to support the dissemination of information to teachers, students, and consumers.

Cynthia Hickman, MPH, *District Epidemiologist – Metro, Minnesota Department of Health*

Cynthia Hickman has worked for the people of Minnesota as a public health epidemiologist at the Minnesota Department of Health (MDH) for over 14 years. She received her Bachelor of Science degree from the University of Minnesota and her Master of Public Health degree from The George Washington University.

During her time at MDH, she has worked in both acute and chronic disease epidemiology. While in the Infectious Disease Epidemiology, Prevention and Control (IDEPC) Division, Cynthia worked in the Tuberculosis and HIV surveillance units. She has also worked in the Health Promotion and Chronic Disease Division's Center for Occupational Health and Safety. Since 2003, Cynthia has worked as the Metro District Epidemiologist for the Epidemiology Field Services (EFS) unit.

Jean Jenkins, Ph.D., R.N., F.A.A.N., *Senior Clinical Advisor to the Director*

Dr. Jenkins received her B.S.N from the University of Maryland MSN at the Catholic University of America, and a Ph.D. in 1999, completing Innovation of Diffusion Research on Genetics Education for Nurses. Dr. Jenkins has assumed key leadership positions at NIH including nurse educator, developing a cancer nurse training program; research nurse, monitoring clinical studies; Chief of the Oncology Nursing Service; and Acting Deputy of the National Human Genome Research Institute Medical Genetics Branch. It was during a clinical internship as part of doctoral studies at George Mason University, Virginia, that she recognized the importance of advances in genetics research for all health care providers. She has been motivated and committed to the preparation of others to become aware, plan for, and integrate genetic concepts into their practice.

Sharon Kardia, Ph.D., *Associate Professor of Epidemiology, Director of the Public Health Genetics Program, Director of the Life Sciences & Society Program, and Co-Director of the Michigan Center for Genomics and Public Health, University of Michigan School of Public Health*

Dr. Kardia received her doctoral degree in human genetics from the University of Michigan, was a post-doctoral fellow in the Department of Microbiology and Immunology and continued post-doctoral work in the Department of Human Genetics. She joined the faculty of the University of Michigan School of Public Health in 1998.

Dr. Kardia's main research is on the genomic epidemiology of cardiovascular disease carried out at the Kardia Lab; she is particularly interested in gene-environment, gene-gene interactions, and in modeling complex relationships between genetic variation, environmental variation, and risk of common chronic diseases. Dr. Kardia is also working to move genetics into chronic disease prevention programs in state departments of health.

Kent Key, *MI Forum, local spirituality leader – waiting for bio*

Muin J. Khoury, MD, Ph.D., Director, National Office of Public Health Genomics

As founding director of CDC's National Office of Public Health Genomics, Muin J. Khoury, MD, PhD, is responsible for oversight of the ongoing assessments of the impact of advances in human genetics and the Human Genome Project on public health and disease prevention.

Doctor Khoury began his career at CDC in 1980, as an EIS officer in the Birth Defects Branch before taking the position of medical epidemiologist in 1987. In 1990, he became deputy chief of the same branch.

He received his BS degree in biology/chemistry from the American University of Beirut, Lebanon, and his medical degree and pediatrics training from the same institution. He received a PhD in human genetics/genetic epidemiology and training in medical genetics from The Johns Hopkins University. Dr. Khoury is board-certified in medical genetics.

He has been the recipient of many special awards, to include the Public Health Service Special Recognition award and Arthur Fleming award. In 1998, Dr. Khoury was credentialed by the Senior Biomedical Research Service for outstanding contributions to public health. In 2000, he received the CDC Research Honor Award for outstanding national leadership in genetics and public health. In 2005, he received the National Cancer Institute Visiting Scholar award for leadership and vision in genetic epidemiology and public health.

Doctor Khoury has published extensively in the fields of genetic epidemiology and public health genetics. He has over 300 scientific publications including articles, books, and book chapters. He is a member of many professional societies and serves on the editorial boards of several journals. Dr. Khoury is a frequent keynote speaker at many academic institutions, professional organization meetings, as well as state, regional, national, and international conferences. He also serves on several scientific, public health, and health policy national and international committees.

He is an adjunct professor of epidemiology at Emory's School of Public Health and an associate in the Department of Epidemiology at The Johns Hopkins University Bloomberg School of Public Health.

Susan King, D. Min., *Associate Director of Life Sciences and Society, University of Michigan*

Dr. King, as Associate Director of our Life Sciences and Society Program, has taken on the lead role of community outreach with faith groups and community advocacy groups to provide education and dialogue around the life sciences and their societal meaning. Within our county, she is the Chair of the Board and Coordinator of the Interfaith Roundtable of Washtenaw County and is also a member of the National Conference for Community and Justice. She is an ordained Interfaith Minister from the New Seminary in New York City. Her doctorate in ministry included a focus on science and religion, as well as the psychology and counseling of religious groups. She is an extraordinarily good community facilitator able to move smoothly among diverse groups of people building trust and openness within community groups. She will be directly responsible for creating and tending connections with community leadership, talking through the GEMINI objectives, organizing community meetings, facilitating the creation of community projects with the help of trained facilitators and research assistants.

David Larsen, *Interim Director of American Indian Studies at University of Minnesota, Mankato*

David Larsen was born and raised at Caŋ Sá Yapi in Morton, Minnesota. A Viet Nam era Navy veteran, David completed his Bachelor of Arts degree at Southwest State University in Marshall, Minnesota. Awarded a Newberry fellowship, he studied Dakota history at the Newberry Library in Chicago, Illinois.

Mr. Larsen served three terms as Chairman of the Lower Sioux Reservation Tribal Council. He spent 20 years as an educator for both the Morton and Redwood Falls schools. David taught American Indian history and cultural studies at the University of Minnesota, Minneapolis and also at Mankato State University. Mr. Larsen was appointed Chairperson of the first American Indian Advisory Council to the Minnesota Historical Society. For over 15 years, he served as a resource person to the People's Institute for Survival and Beyond, which conducts national workshops on undoing racism. He has provided individual and spiritual counseling for incarcerated American Indians for twenty years, currently volunteering at MN Correctional Facility, Shakopee. Mr. Larsen is an independent educational consultant providing American Indian culture and history lectures for groups aged kindergarten through senior citizens. He has just accepted the position of Interim Director of American Indian Studies at University of Minnesota, Mankato.

Dale Lea MPH, RN, CGC, FAAN, *Health Educator*

Ms. Lea is a Board Certified genetic counselor with more than 20 years experience in clinical and educational genetics. She is currently the Health Educator with the Education and Community Involvement Branch, National Human Genome Research Institute. As Health Educator, Ms. Lea develops consumer genetics health education and community involvement programs and resources; translates genetic and genomic research results into terms understandable by lay audiences; collects and assimilates data for Institute reports; and provides administrative support for public education and community involvement programs.

Ms. Lea received her BSN from Westbrook College, Portland, Maine, and her Masters in Public Health with a focus in health education and health promotion from Loma Linda University, Loma Linda California. She is a member and past President, past Chair of the Education, Bylaws, Social Policy and Annual Education Committees of the International Society of Nurses in Genetics (ISONG). She is the Co- Chair of the Ethics and Public Policy Committee. She is also a member of the National Society of Genetic Counselors, and the Oncology Nursing Society. She received the New England Regional Genetics, Leadership Award for Genetic Counseling in 1997, and the ISONG Founders Award in 1999 in recognition of outstanding nursing and patient education in genetics. In 2001, Ms. Lea was inducted as a new Fellow in the American Academy of Nursing, and serves on their Expert Panel on Genetics.

E. Yvonne Lewis, BBA, BS, *Executive Director, Faith Access to Community Economic Development (FACED)*

E. Yvonne Lewis has a rich history of working in community and faith-based organizations. Since 1990, she has assisted in establishing and coordinating programs and services to engage the faith community in community outreach and education activities. Yvonne serves on coalitions, partnerships and committees at the local, state and national level. Her involvement includes representation as a board member of the Greater Flint Health Coalition, the Michigan Cancer Consortium as well as the chair of the National Community Committee (NCC) of Centers for Disease Control and Prevention, Prevention Research Centers (PRC). Yvonne also served on the planning committee for 19th National Conference on Chronic Disease Control and Prevention.

Grisel Lopez, M.D., *Staff Clinician, NIH Parkinson Disease Clinic*

Grisel Lopez is a Staff Clinician at the National Institute of Neurological Disorders and Stroke (NINDS) and is in charge of the NIH Parkinson Disease Clinic. Before joining NINDS, she was a Staff Clinician at the National Human Genome Research Institutes from 2003-2006 working on disease mechanisms and genetic analysis of familial Parkinson Disease and other Movement Disorders. She is a neurologist and is currently Principal Investigator in several clinical protocols relating to the genetics of Parkinson Disease and co-investigator in other clinical protocols relating to the understanding of monogenetic diseases and their association to complex trait disorders. She obtained her medical degree, residency training and post-doctoral training at the University of Kansas Medical Center. Prior to her work at the NIH, she was Assistant Professor at the University of Kansas Medical Center. She has been consistently involved in community education and served as a Faculty Advisor for the Latino Medical Student Association.

Colleen McBride, Ph.D., *Chief, Social and Behavioral Research Branch*

Dr. McBride's research focuses on developing innovative public health interventions to promote risk-reducing behaviors. Building on her behavioral epidemiology and genetics experience, she is investigating how genetic information can best be used to motivate people to behave in more healthful ways. Genetic testing is likely to become a leading medical tool for educating patients about their health risks and inspiring them to take preventive steps, although there are many obstacles to overcome before that can occur. Having the testing technology does not necessarily translate into better health behaviors.

As chief of the Social and Behavioral Research Branch (SBRB), which was established in 2003, Dr. McBride currently is articulating research priorities for the branch to help guide the use of genetics/genomics to improve the health and well-being of the population. Initially, the SBRB is focusing on smaller studies that address the basic science of risk communication, best practices for genetic counseling and education, clinical integration of

genetics, techniques for involving communities in dissemination of genetic discoveries, and related bioethical and social policy issues.

Kristin Peterson Oehlke, MS, CGC, *State Genomics Coordinator, Minnesota Department of Health*

Kristin Peterson Oehlke is a genetic counselor and has been with the Minnesota Department of Health (MDH) since 1995. Her background experiences include work both in clinical cytogenetic and DNA testing laboratories and genetic counseling for families with genetic conditions and concerns across the lifespan. She has been certified by The American Board of Genetic Counseling. Since coming to MDH, she has worked as the MCH Geneticist and in her current position as the Genomics Coordinator for the agency. In 2001, she embarked upon a two year program at CDC as an ATPM Career Development Awardee in the Office of Genomics and Disease Prevention, now the National Office of Public Health Genomics. Since returning to MDH in 2003, she has coordinated the Chronic Disease Genomics Project, a 5-year CDC funded project aimed at building capacity and planning for integrating genomics more broadly into public health activities within the Minnesota Department of Health and other public health activities within the state. She is particularly interested in the process by which genetic and genomic research knowledge is translated into practice, using genomic tools for primary disease prevention and health promotion and building genomics capacity in public health and health care provider communities.

Kimberly Noble Piper, RNC, BS, CPH, *Genetics Coordinator*

Kimberly Noble Piper is the State Genetics Coordinator at the Iowa Department of Public Health. Ms. Noble Piper is a registered nurse with a certification in inpatient obstetrics. She received her bachelor's of science in health administration from the University of St. Francis (formerly the College of St. Francis). She is certified in public health through the University of Iowa College of Public Health. Ms. Noble Piper has been the state genetics coordinator for three years, providing oversight for Iowa's genetics programs. Ms. Noble Piper will be speaking about the role of genetics in the provision of core and essential public health services.

Pilar Ossorio, Ph.D., J.D., *Associate Professor of Law and Medical Ethics*

Dr. Ossorio is Associate Professor of Law and Bioethics at the University of Wisconsin at Madison, and Program Faculty in the Graduate Program in Population Health at the UW. Prior to taking her position at UW, she was Director of the Genetics Section at the Institute for Ethics at the American Medical Association, and taught as an adjunct faculty member at the University of Chicago Law School.

Dr. Ossorio received her Ph.D. in Microbiology and Immunology in 1990 from Stanford University. She went on to complete a post-doctoral fellowship in cell biology at Yale University School of Medicine. Throughout the early 1990's Dr. Ossorio also worked as a consultant for the federal program on the Ethical, Legal, and Social Implications (ELSI) of the Human Genome Project, and in 1994 she took a full time position with the Department of Energy's ELSI program. In 1993 she served on the Ethics Working Group for President Clinton's Health Care Reform Task Force.

Dr. Ossorio received her JD from the University of California at Berkeley School of Law (Boalt Hall) in 1997. While at Boalt she was elected to the legal honor society Order of the Coif and received several awards for outstanding legal scholarship.

Dr. Ossorio is a fellow of the American Association for the Advancement of Science's (AAAS), a member of the editorial board of the American Journal of Bioethics, chair of an NHGRI advisory group on ethical issues in large scale sequencing, and a member of UW's institutional review board for health sciences research. She is a past member of AAAS's Committee on Scientific Freedom and Responsibility, a past member of the National Cancer Policy Board (Institute of Medicine), and has been a member or chair of several working groups on genetics and ethics.

Sharmini V. Rogers, MBBS, MPH., *Bureau Chief, Genetics and Healthy Childhood*

Dr. Rogers is the Chief of the Bureau of Genetics and Healthy Childhood in the Missouri Department of Health and Senior Services. She has overall responsibility of the Missouri Newborn Screening programs, Genetic Programs such as Cystic Fibrosis, Hemophilia, Sickle Cell and Formula Program for individuals identified with a metabolic disorder. She represents the Department as the State Genetics Coordinator and is involved as a steering committee member for the Heartland Regional Genetics and Newborns Screening Collaborative.

In addition, to the genetic programs, Dr. Rogers also has responsibility for programs that promote healthy pregnancies, healthy babies, children, and adolescents. Having a broad scope of programs under her supervision enables her to promote knowledge of genetics and health throughout the life cycle.

Elizabeth Thomson R.N., M.S., D.N.Sc., C.G.C., F.A.A.N.

In 1993, Dr. Thomson accepted a position at the National Institutes of Health where she currently serves as Program Director, Ethical, Legal, and Social Implications Research of the National Human Genome Research Institute. In 1998, she served as a consultant to the U.S. Centers for Disease Control and Prevention assisting them in establishing their Office of Genetics and Public Health. In 1999, she served as a consultant to the National Cancer Institute in the formation of their nationwide Cancer Genetics Network.

Dr. Thomson has been actively involved in a number of both genetics and nursing organizations, including the American Academy of Nursing, the American Society of Human Genetics, and the American College of Medical Genetics. In 1984, she co-founded the Genetics Nurse Network, which in 1989 became the International Society of Nurses in Genetics. In addition to publishing a number of papers regarding genetics; the Human Genome Project; genetic counseling; nursing roles in genetics; ethical, legal, and social issues related to genetics research; and the clinical integration of genetic technologies; she has given numerous presentations about these topics at local, regional and national conferences. Dr. Thomson co-edited a book, "Women and Prenatal Testing: Facing the Challenges of Genetic Technology," which was published by Ohio State Press (1994) and co-authored several papers published in JAMA (1995, 1997, 1997, 1998) regarding informed consent for genetics research using stored tissues, follow up recommendations for those found to have inherited breast, ovarian, and colon cancer risks, and genetic testing for hereditary hemochromatosis. She also co-edited a book (Oxford University Press, 2000), titled Genetics and Public Health.

Kao Kalia Yang, *Writer for the Hmong Community*

Kao Kalia is a graduate of Carleton College with a Bachelor Degree in American Studies, Cross-cultural Studies, and Women*s and Gender Studies. She earned her Masters of Fine Arts Degree from Columbia University in the City of New York. She specializes in creative nonfiction writing. Kao Kalia believes that the craft of writing is both an art and a practical necessity. In addition to writing, Kao Kalia spends her time teaching others how to relate to the written word. She started teaching English to adults in the Mount Airy Housing Project at the age of twelve in the Pals Program. In college, she privately tutored students year-round in the ACT and Hmong Youth Pride programs. In graduate school, Kao Kalia led creative nonfiction courses in the Our Word Writing Workshops to a variety of professionals, from college professors to community activists.

Kao Kalia has been recognized for her effective leadership and creative capabilities. Among them: the Page Scholarship by the Page Education Foundation for demonstrated leadership, academic achievement and commitment to community; the Gilman International Award for international spirit and the pursuit of studies in democracy; the Freeman in Asia Scholarship toward the study of inter/intra national models of development; Columbia University*s School of the Arts Dean*s Fellowship for the merit and reaches of her work; the Paul and Daisy Soros Fellowship for New Americans for exceptional leadership, originality and the potential to change the landscape of American society; and finally, Kao Kalia was selected as one of few U.S. student delegates to attend the 26th International Achievement Summit where she met such world leaders as President Clinton, President Karzai, President Chirac, first female astronaut Sally Ride and premiere film director

George Lucas. She is the winner of Lantern Books 2005 Essay Contest. This year, Kao Kalia*s work is published in Water~Stone Review, Two Lines, Satya Magazine and by Solbooks Publishing.

APPENDIX 7:
Final Agenda Table

GENOMICS, COMMUNITY AND EQUITY: A CONTINUING DIALOGUE DRAFT FORUM AGENDAS – 10/02/07

NOTE: (V) = Videoconferenced All times are Central times except for Michigan

TIME (CDT)	ILLINOIS	IOWA	MINNESOTA	MISSOURI	MI EDT	MICHIGAN
8:30			Welcome-Davis and Woolerton		9:30	Welcome
8:45			The Human Genome – Kardia (V)		9:45	The Human Genome – Kardia
9:15	Welcome & Intro's					
9:30		Welcome	Break-outs: (1) Genomics & Environmental Justice – Allwood (2) Family History and the Environment-Hickman & Oehlke	Welcome	10:30	Addressing Racial and Ethnic Health Disparities in the Genomic Era: Why We All Must Be Engaged Bonham
9:45	The Human Genome – Kardia (V)	The Human Genome – Kardia(V)		The Human Genome -Kardia (V)		
10:30	Break	Break	Break	Break	11:30	Break
10:45	Public Health Genomics: Closing the Gap Between Genome Discoveries and Population Health Khoury	Research; Ethical, Legal, and Social Issues; Community Engagement Guttmacher	Break-outs: (3) Spirituality/Cultural – Collins, Larsen & Yang (4) Education in Genetics and Career Opportunities -English	Discussion & Dialogue on Genomics, Spirituality, & Religion Dunston	11:45	Breakouts: 1)Discussion & Dialogue on Genomics, Spirituality & Religion-Dunston (V) (2) Discussion & Dialogue on Diversity, Disparities & Forensics-Bonham (3) Education in the Genomic Era: Emerging Careers and the Need for Diversity -Easter
11:45	Break	Break	Break	Break	12:45	Break
12:00	Lunch/Website Demo	Lunch/Website Demo	Lunch/Website Demo	Lunch/Website Demo	1:00	Lunch/Website Demo
12:30	Keynote talk on Genomics, Medicine, and Society- Collins; Q&A (V)	Keynote talk on Genomics, Medicine, and Society- Collins; Q&A (V)	Keynote talk on Genomics, Medicine, and Society- Collins; Q&A (V)	Keynote talk on Genomics, Medicine, and Society- Collins; Q&A (V)	1:30	Keynote talk on Genomics, Medicine, and Society- Collins; Q&A (V)
2:00	Break	Break	Break	Break	3:00	Break
2:15	Break-Outs: (1) Race-Based Medicine-Ossorio (Eng.) (2) Research and Special Populations-Lopez (Sp.) (3) Family History, Genes, and Chronic Disease-Feero (Sp.)	Break-Outs: (1) Genes, Environment & Chronic Disease-Burns & Guttmacher (2) Personalized Medicine: What does it mean for me? -Frosst	Genetics and Behavior – McBride	Panel on "Next Steps" for individuals; community organizations; health departments & other agencies- King, Lea, Jenkins, Rogers, Chambers, Dunston	3:15	Break-outs: (4) Race-Based Medicine-Ossorio (V) (5) Family History & Chronic Disease-Duquette (6) Discussion & Dialogue on Genomics, Spirituality & Religion- Lewis, Burrell, Elliot, Garrison, Key, Lidums, Kardia
3:15	Break	Break	Collins – Guitar/Singing Evaluation/Door Prizes		4:15	Collins – Guitar/Singing (V)
3:30	Break-Outs: (4) Race-Based Medicine-Ossorio (Sp.) (5) Research and Special Populations-Lopez (Eng.) (6) Family History, Genes, and Chronic Disease-Feero (Eng.)	Break-Outs: (3) Ethical, Legal, and Social Issues in Genomics Research and Health Care -Thomson (4) Genomics and Public Health-Piper	Adjourn	Adjourn	4:30	Adjourn
4:30	Adjourn	Adjourn				

APPENDIX 8:
Tool Kit for Missouri

Tool Kit Outline

Promotional Materials:

I. Brochure

The purpose of the brochure is to have something to give out to people that they can take home about the forums. It provides the forum website address; information on when and where the forums will be held; information about what the forums are; why community members should get involved; and why genomics is important for communities of color.

II. Fliers (4 versions)

The fliers are intended to be used by the host organizations and public health departments and distributed to any organizations/businesses that are affiliated with the target populations for the forums. They are intended to be posted but could also be passed out along with or instead of the brochure.

III. State/Community-Based Organization Specific Poster (2 versions)

These posters are intended to be printed large and be posted at the community host organization and any other organization/business that they feel is a key place to promote the forum. The poster is intended to be used by a limited number of organizations while the fliers can be used widely. The posters are more engaging than the fliers but will cost more to print.

IV. Generic Poster (1 version but design can be mixed and matched with other posters)

This is a generic poster about the project and website and does not include information about any specific location. It is intended for the library networks to distribute. It can also be used by the NCCs and public health departments that do not have a forum in their state. It is also meant to be printed large.

V. Save the Date Postcard

This can either be mailed out or e-mailed depending on the community-based organizations preference. It is intended to be sent this summer as an early reminder to potential participants to put the date on their calendar. It is meant to be sent out before any of the other materials that provide more information.

VI. Registration Postcard

This can be mailed out or handed out to individuals who wish to register for the forums but do not complete the online registration form.

VII. Website Handout

To be distributed before, during, or after the forums. This handout directs individuals to the www.GenoCommunity website and highlights some of the main features of the website.

VIII. Letterhead Template

This template, with the Community Genetics Forum tree logo, could be used by the organization in sending out letters to constituents or for other official documents.

Descriptive Materials:

I. PowerPoint Presentation

This PowerPoint provides a description of the overall forum project. It can be used by the community-based organizations to present to their partner organizations.

II. Project Description

This is a description of the forum project that can be given to partner organizations of the community-based organizations along with or instead of the PowerPoint presentation. It can also be given to additional organizations who will be promoting the forum.

III. National Community Committee (NCC) Description

This is a description of the NCC that the community-based organizations can share with partner organizations or organizations promoting the forum.

IV. Center for Public Health and Community Genomics (CPHCG) Description

This is a description of CPHCG that can be given to partner organizations along with the NCC and project descriptions.

Media Kit:

I. Press Release

This press release can be shared with local media within each state where a forum will be held.

II. E-mails

These 4 e-mails are intended to be sent out to potential participants at the various times listed. One or more of the e-mails can be used. All e-mails are stand alone so it is up to each organization how many and which ones they want to send.

III. State/Community-Based Organization Specific Newsletter Blurb

This is intended to be given to the community-based organizations and their partners to be included in newsletters. They will be specific to each state's forum.

IV. Generic Newsletter Blurb

This blurb can be given to organizations including the library network that are national or are in states where no forum will be located.

Educational Resources:

I. Key Articles

This is a list of key articles that can be provided to forum participants. All of these articles are located in the reference binder provided to the forum host organizations. The articles can be provided before or during the forum. The list can also be provided in print or e-mail form instead of or along with the actual articles.

II. Key Web Resources

This list of web resources can be given to forum participants prior to or at the forum. It is similar to the links that will be included on the project website.

III. Glossary of Terms

This is the same glossary of terms that was provided in the reference binder. It can be given to forum participants before or at the forums in order to get familiar with genomics terms.

How is genomics relevant to our health and our communities?

The way genomics gets researched, applied and understood, will either benefit or harm individuals facing health issues and groups currently experiencing health disparities, discrimination or stigmatization. It is important for people from diverse backgrounds to understand and influence how genomics gets studied and used.

Potential Benefits:

- Family health histories can identify risk and help prevent diabetes, stroke, and heart disease, conditions responsible for health disparities.
- Genetic population studies are showing how all of us are inter-related and may lead to increased appreciation for human diversity.

Potential Harms:

- Marketing of genetic test kits directly to the consumer may result in people getting inaccurate information about the meaning of their own genetic profile.
- Race-specific medicines like BiDil can reduce risk of heart disease in some African Americans, but will use of race in medical marketing label groups as having inferior traits?

For more information, please visit:
www.GenoCommunity.org

A Community Genetics Forum

National Community Committee
Prevention Diseases through Partnerships
In Partnership with the CDC's Prevention Research Centers Program

Pemiscot County Community Coalition
Presents:
Genomics, Community, and Equity: A Continuing Dialogue

PO Box 91
Caruthersville, MO 63830

Phone: 573-333-9865

Email: mottonfl@sbcglobal.net

Pemiscot County Community Coalition
Presents:

Genomics, Community, and Equity: A Continuing Dialogue

www.GenoCommunity.org

What is genomics?

Genomics is the study of all of the genes in your body and how they interact with your environment to contribute to your health, appearance and behavior.

What is *Genomics, Community, and Equity: A Continuing Dialogue?*

The forum is a chance to hear from leaders in the genomics field, get your questions answered and discuss your views on issues related to genomics. Topics will include basic information about genomics, current research in genomics and how genomics affects society.

There is also a website where you can continue the discussion and learn more. On the website you can watch animated stories about genomics and share your opinions and stories with others.

www.GenoCommunity.org

Genomics, Community, and Equity: A Continuing Dialogue

University of Missouri Delta Center
147 W. State Highway T
Portageville, MO

October 12, 2007
9:30 AM-3:30 PM

A Community Genetics forum funded by:
National Human Genome Research Institute/NIH

Why should I get involved?

- No matter what level of knowledge you have in genomics you will be able to learn something at the forum.
- Your voice is important, so come take part in a discussion about genomics.
- If you have questions about genomics or how it is being researched or used, this is the place to get them answered.

GENOMICS, COMMUNITY AND EQUITY: A CONTINUING DIALOGUE

- Come hear from public health genomics experts
- Learn about genomics and topics such as health disparities, spirituality, education, family history, chronic disease, and race based medicine
- Voice your views and get your questions answered

WHERE: UNIVERSITY OF MISSOURI DELTA CENTER
147 W. STATE HIGHWAY T
PORTAGEVILLE, MO
DATE: 10/12/07 TIME: 9:30AM-3:30PM
LUNCH IS PROVIDED

A Community Genetics Forum

National Community Committee
Preventing Diseases through Partnerships
In Partnership with the CDC's Prevention Research Centers Program

For more information, updates and to register for the forum, please visit:

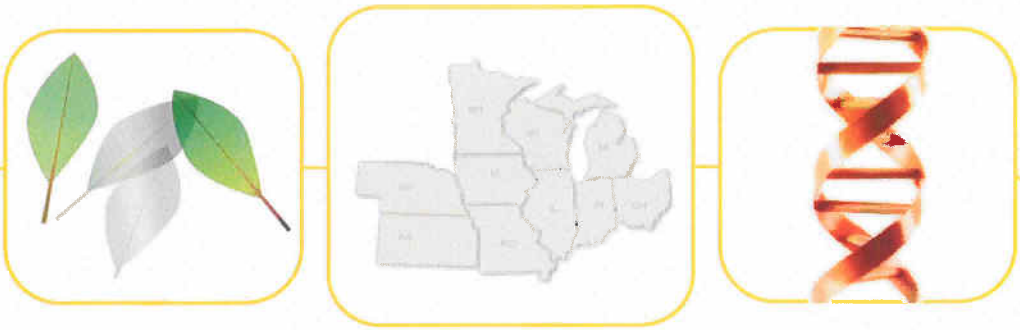
www.GenoCommunity.org

Hosted By: Pemiscot County Community Coalition.

Phone: 573-333-9865
E-Mail: mottonfl@sbcglobal.net

Funded by:
National Human Genome Research Institute/NIH

GENOMICS, COMMUNITY AND EQUITY: A CONTINUING DIALOGUE



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What: Genomics Forum When: 10/12/07 9:30-3:30
Where: 147 W. State Highway T, Portageville
www.GenoCommunity.org
Pemiscot County Community Coalition, Inc.
Phone: 573-333-9865 E-mail: mottonfl@sbcglobal.net

What: Genomics Forum When: 10/12/07 9:30-3:30
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- Learn about genomics and topics such as health disparities, spirituality, education, family history, chronic disease, and race based medicine
- Voice your views and get your questions answered

Come join us at our community forum

When: October 12, 2007 9:30am-3:30pm (Lunch will be provided)
Where: University of Missouri Delta Center
147 W. State Highway T
Portageville MO
Hosted By: Pemiscot County Community Coalition
Phone: 573-333-9865
E-mail: mottonfl@sbcglobal.net

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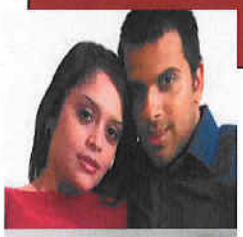



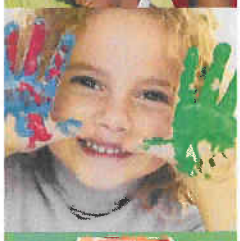
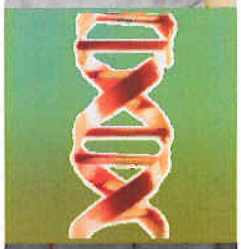
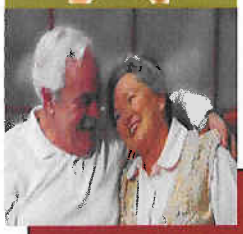

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- Voice your views and get your questions answered

Come join us at our community forum

When: October 12, 2007 9:30am-3:30 pm
Where: MO National Guard Ike Skelton Training Center
6900 N. Boundary Road
Jefferson City, MO 65101

Hosted By: Pemiscot County Community Coalition
Phone: 573-333-9865 E-mail: mottonfl@sbcglobal.net

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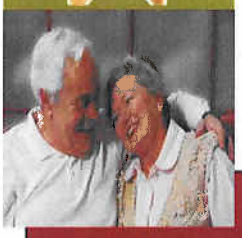

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When: October 12, 2007 9:30am-3:30 pm

Where: 315 S. Franklin
Kirksville, MO 63501

Hosted By: Pemiscot County Community Coalition
Phone: 573-333-9865 E-mail: mottonfl@sbcglobal.net

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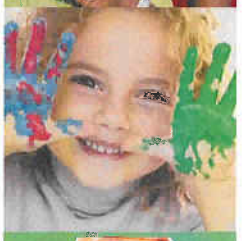

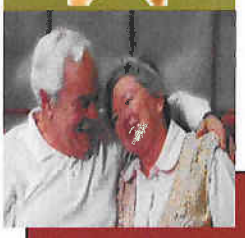

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Come join us at our community forum

When: October 12, 2007 9:30am-3:30 pm (Lunch is provided)

Where: University of Missouri Delta Center
147 W. State Highway T
Portageville, MO

Transportation will be provided at no cost by the Southeast Missouri Transportation Service, Inc. Pick up is at Twin Towers in Poplar Bluff at 8:30 am.

Hosted By: Pemiscot County Community Coalition
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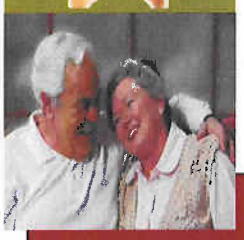

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When: October 12, 2007 9:30am-3:30 pm

Where: Missouri National Guard Armory
1201 W. Rolla Road
Salem, MO 65560

Hosted By: Pemiscot County Community Coalition
Phone: 573-333-9865 E-mail: mottonfl@sbcglobal.net

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Come join us to hear presentations from genomics experts and participate in discussion sessions. Learn more about why genomics is important to **you** and **your community**.

October 12, 2007
9:30 AM-3:30 PM
University of Missouri Delta Center
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For more information and to register for the forum, please visit:
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Hosted By:
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PO Box 91
Caruthersville, MO 63830
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Genomics, Community and Equity: A Continuing Dialogue

Genomics is the study of how your DNA and your environment interact to affect your health, appearance and behavior.

Please visit **www.GenoCommunity.org** to:

- Learn more about genomics and how it effects **you** and **your community.**
- Participate in online discussions about genomics.
- Find resources to help you host events about genomics.

A Community Genetics Forum

National Community Committee

Preventing Diseases through Partnerships

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National Human Genome
Research Institute/NIH

Genomics, Community, and Equity: A Continuing Dialogue

Save the date!

When: October 12, 2007
9:30 AM-3:30 PM

Where: University of Missouri Delta Center
147 W. State Highway T
Portageville, MO

What: A community forum on genomics

Why: Learn about why genomics is important to you and your community! Get your questions answered and voice your opinions!

For more information, and to register for the forum, please visit:
www.GenoCommunity.org

Hosted by:

Pemiscot County
Community Coalition

PO Box 91
Caruthersville, MO 63830

Phone: 573-333-9865

E-mail: mottonfl@sbcglobal.net

Pemiscot County Community Coalition

PO Box 91
Caruthersville, MO 63830

PLEASE
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Come Join Us!

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Hosted by: Pemiscot County Community Coalition
Phone: 573-333-9865
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Please fill out the below information and return this self-addressed postcard to register:

Name:

Address:

E-mail:

How did you hear about the forum:

Pemiscot County Community Coalition
PO Box 91
Caruthersville, MO 63830

PLEASE
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Genomics, Community, and Equity: A Continuing Dialogue

www.GenoCommunity.org

Visit the project website for information on how you can participate in the ongoing dialogue about genomics and related issues. At the website you can:

- Find out more about the Community Genomics Forums being held in five Midwest States on October 12, 2007 and see archived presentations
- Access educational materials to learn more about genomics
- Participate in an ongoing web dialogue through blogs, an online forum, web conferencing, webcasting, and/or webinars
- Find materials to help your organization host events to engage your community in discussions on genomics

Funded by:
National Human Genome
Research Institute/NIH

A Community Genetics Forum


A Community Genetics Forum

Genomics, Community and Equity: A Continuing Dialogue

A Community Genetics Forum

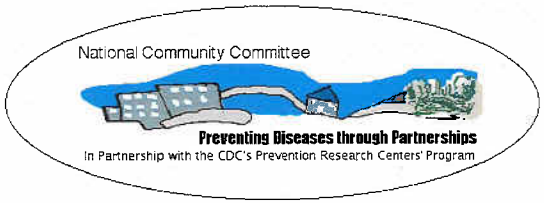
Funded by:
National Human Genome Research Institute/NIH

Objectives

- Hold 5 Forums in Midwest States with at least 400 participants total
- Design a model of community education for genomics using print and web materials
- Enable community dialogue about social implications of genomics
  - Family history
  - Research that benefits and/or harms the community
  - Reducing health disparities

Partners

- Center for Public Health and Community Genomics
- University of Michigan Life Sciences and Society Program
- National Community Committee (NCC)
  - 33 CDC funded prevention research centers



- Community-Based Organizations (CBOs)
  - Illinois: Latino Organization of the Southwest
  - Iowa: Community Health Action Partnership
  - Michigan: Flint Odyssey House
  - Minnesota: Office of Minority and Multicultural Health, Minnesota Department of health
  - Missouri: Pemiscot County Community Coalition
- National Networks of Libraries of Medicine
- State Departments of Health

Agenda

1. Welcome
2. Overview w/ Q&A – Kardia
3. Genetics, Spirituality, Religion- Dunston
4. Web demo
5. Keynote Address- Collins
6. Next Steps Panel- Lea & Kolberg, others

Website

- ~20 animated modules on five main topic areas with diverse cast of characters
  1. Basic Genetics
  2. Genetics and Race
  3. Genetics and Family History
  4. Genetics and Disease
  5. Genetics and Health Disparities

- Online Resources
  - eg. Surgeon General family history project, HapMap website, NHGRI websites

- Community GenoBlogs for continuing discussion

Evaluation

- 3 Surveys at the Forum
    1. Demographic
    2. Presentations/Break-out Sessions
    3. Topical
- Student Observer/Note Takers During Presentations and Break-outs
- Website
    - Number of Users
    - Demographic Information
    - Content Analysis of Postings
- Community Activity Assessment
    - Number of Participants at Community Events
    - Successes in Community Organizing and Recruiting Strategies


Questions?

Genomics, Community and Equity: A Continuing Dialogue

Since completing the Human Genome Project, governmental agencies, academic and community partners have focused on how to engage communities in a dialogue about issues in genetics and genomics. In 2004, the National Human Genome Research Institute (NHGRI) began funding community engagement projects in different regions of the country. This project will be the third in this series, focusing on the 10 state Midwest Region (Illinois, Indiana, Iowa, Kansas, Nebraska, Ohio, Michigan, Minnesota, Missouri, and Wisconsin).

Genomics, Community and Equity: A Continuing Dialogue will include a set of 5 community dialogue forums and an interactive web-based continuing dialogue that focuses on education and further community involvement. Materials will also be created to aid community organizations and libraries in organizing events to engage the public in this ongoing dialogue. This project is a partnership between the Center for Public Health and Community Genomics (CPHCG) at the University of Michigan School of Public Health and the National Community Committee (NCC) of the CDC-funded Prevention Research Centers. Local educational resources will be provided by the state health departments in the five forum states, and both educational and dissemination support will be provided by the National Network of Libraries of Medicine (with special emphasis on health professionals) and their respective state associations of public libraries (with special emphasis on lay members of their communities).

Community Dialogue Forums

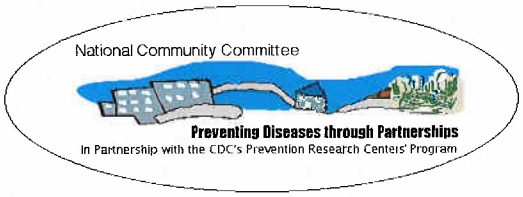
The forums will be held in 5 of the 10 states in the region (Illinois, Iowa, Michigan, Minnesota and Missouri) simultaneously and will combine general topics as well as topics specific to the host states and their surrounding areas. Video conferencing will be used to connect the forums while they are occurring. The NCC of that state will host that state's community forum and will be responsible for recognizing issues specific to the areas that they serve. The goal of each forum is to engage at least 80 people (a total of 400 people, including all five forums) and encourage participants to go online and continue the dialogue.

Interactive Web-based Continuing Dialogue

The Center for Public Health and Community Genomics is collaborating with the Life Sciences & Society Program at the University of Michigan in the creation of a website and online educational materials that will utilize blogs, web conferencing, webcasting, and/or webinars to engage groups in the focus area to participate in forums or forum-related activities

Continuing Community Engagement

The ongoing community dialogue about genomics issues will also continue in the form of events and meetings held by community organizations, libraries, and other groups. A set of resources will be produced to assist groups that wish to engage community members in the ongoing discussion about genomics and related issues.



The National Community Committee (NCC) is a network of community representatives engaged in equitable partnerships with researchers to define local health priorities, drive prevention research agendas, and develop solutions to improve the overall health and quality of life of all communities. Each NCC member is affiliated with a CDC-funded Prevention Research Center (PRC) in that state or region. The NCC members are responsible for:

- developing and facilitating education, training, resource sharing and technical assistance opportunities that encourage and enhance participation in research activities
- creating a supportive and culturally competent environment in which representatives can share successes, concerns, and other lessons learned
- advocating for policy change
- making recommendations to advance the work of individual community representatives, local centers, and the National PRC Program

MICHIGAN: Flint Odyssey House, Inc. Health Awareness Center
The Flint Odyssey House, Inc. Health Awareness Center provides intervention, 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 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 attention on the health disparities among their target population.

ILLINOIS: Latino Organization of the Southwest
The mission is to work with Latinos in Southwest Chicago to create awareness of 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, their mission 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.

CENTER FOR
Public Health and
Community Genomics

CONNECTING RESEARCH, EDUCATION, PRACTICE, AND COMMUNITY

The Center for Public Health and Community Genomics (CPHCG) aims to further integrate genomic discoveries into public health practice by providing technical assistance and training to the public health system in Michigan and beyond. CPHCG interventions and programs broadly emphasize a community-based approach, developing partnerships with community members and other key stakeholders, while focusing on ethical, legal, and social issues associated with the genomic applications to public health.

The Center for Public Health and Community Genomics' three broad goals are:

- To increase the genomics and public health knowledge base.
- To provide technical assistance to state, regional and local public health entities in the integration of genomics into public health practice.
- To train members of the current and future workforce in genomics.

Training materials that have been developed include:

- Six Weeks to Genomic Awareness
- Issues in Public Health Genetics
- Genomics for Public Health Practitioners

Formed in 2001, CPHCG is supported by grants from the Centers for Disease Control and Prevention (CDC) and other federal agencies.

For More Information, Please Contact:

Sally Meyer, MPH, Assistant Director
Center for Public Health and Community Genomics
Email: salmeyer@umich.edu

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F 734-998-6798

Press Release

Genomics, Community, & Equity: A Continuing Dialogue

<Insert City, State> -- <Insert Date>

On Friday, October 12, 2007, Pemiscot County Community Coalition, Inc. will host a community forum entitled "Genomics, Community, and Equity: A Continuing Dialogue." Members of the community are invited to attend the forum, which will be an opportunity for community members to participate in a dialogue about issues in genomics. The forum will be held at at the University of Missouri Delta Center at 147 W. State Highway T in Portageville from 9:30am-3:30pm as is free of charge. Lunch will be provided. National experts on issues related to public health genomics will be featured speakers. The presentations include:

- An overview of genomics by Sharon Kardia, Ph.D, University of Michigan
- A keynote address by Francis Collins, M.D., Ph.D., National Human Genome Research Institute
- A presentation on Genetics, Spirituality and Religion by Georgia Dunston, Ph.D., Howard University

Following the presentations will be a panel discussion about what next steps should be taken for the state of Missouri in the field of genomics.

This forum is one of five happening simultaneously in states of the Midwest region including Illinois, Iowa, Michigan, Minnesota, and Missouri. Video conferencing will be used to connect the forums while they are occurring. Following the forums, an interactive website will allow forum participants and those who could not attend the forums to participate in a continuing dialogue on genomics issues through blogs, web-conferencing, webcastings and/or webinars. The website will also provide additional educational materials for individuals and communities, provided by experts at the University of Michigan. For more information and to register for the forum, please visit www.GenoCommunity.org.

This community forum is funded by the National Human Genome Research Institute. Forum partners include the University of Michigan Center for Public Health and Community Genomics and the National Community Committee of the CDC-funded Prevention Research Centers.

For more information contact Freda Motton at mottonfl@sbcglobal.net or 573-333-9865.

First Email—save the date/create buzz (a few months before):

On Friday, October 12, 2007, the Pemiscot County Community Coalition, Inc. will host a forum on "Genomics, Community, and Equity: A Continuing Dialogue," funded by the National Human Genome Research Institute. This community forum will be held at the University of Missouri Delta Center at 147 W. State Highway T in Portageville from 9:30am-3:30pm. This forum will be an opportunity for community members to participate in a dialogue about issues in genomics and is free of charge. National experts on issues related to public health genomics will be featured speakers and you will have a chance to get your questions answered and voice your views on genomics issues in small group breakout sessions. Please save the date so you can join us in this exciting discussion! For more information contact Freda Motton at mottonfl@sbcglobal.net or 573-333-9865. Watch for another email with further details as the forum date approaches!

Second Email—in depth (a few weeks before):

The Pemiscot County Community Coalition, Inc. invites you to attend a Community Genomics Forum, funded by the National Human Genome Research Institute (NHGRI). The forum, entitled "Genomics, Community, & Equity: A Continuing Dialogue," will be held on Friday, October 12, 2007 at the University of Missouri Delta Center at 147 W. State Highway T in Portageville from 9:30am-3:30pm. This forum is free of charge and will be an opportunity for community members, researchers, and academics to participate in a dialogue about issues in genomics. National experts on issues related to public health genomics will be featured speakers. The presentations include:

- An overview of genomics by Sharon Kardia, Ph.D, University of Michigan
- A keynote address by Francis Collins, M.D., Ph.D., NHGRI
- A presentation on Genetics, Spirituality and Religion by Georgia Dunston, Ph.D., Howard University

Following the presentations will be a panel discussion about what next steps should be taken for the state of Missouri in the field of genomics.

Please visit the forum website at www.GenoCommunity.org to register for the forums and for more information. If you have further questions, please contact Freda Motton at mottonfl@sbcglobal.net or 573-333-9865.

Forum partners include the University of Michigan Center for Public Health and Community Genomics and the National Community Committee of the CDC-funded Prevention Research Centers.

We hope to see you on October 12, 2007 for an exciting dialogue about genomics!

Third email—reminder (week of the forums):

This is a reminder that on Friday, October 12, 2007, the Pemiscot County Community Coalition, Inc. invites you to attend a forum on "Genomics, Community and Equity: A Continuing Dialogue," funded by the National Human Genome Research Institute. At this community forum, you will have a chance to hear about public health genomics from national experts!

The forum is a chance for you to get your questions about genomics issues answered and learn about important genomics issues that may impact your health and your community. In breakout sessions after the presentations, you will also be able to voice your views on how genomics research is conducted and how genomic technologies get used.

Register for this community forum by visiting the website at www.GenoCommunity.org. The forum is free of charge to attend. If you can't attend the forum, you can still participate! This interactive website will allow you to participate in a continuing dialogue on genomics issues through blogs, web-conferencing, webcastings and/or webinars. The website will also provide additional educational materials for individuals and communities, provided by experts at the University of Michigan.

For more information contact Freda Motton at mottonfl@sbcglobal.net or 573-333-9865.

We hope to see you on October 12, 2007 for an exciting dialogue about genomics related issues!

Email following the forums:

Thank you to those of you who were able to attend the recent forum on "Genomics, Community and Equity: A Continuing Dialogue," hosted by Pemiscot County Community Coalition, Inc. and funded by the National Human Genome Research Institute. The forum was a success in initiating a dialogue between community members about issues related to genomics!

If you weren't able to attend the forum, we hope that you will be able to participate in an ongoing dialogue through the interactive forum website. Visit the forum website at www.GenoCommunity.org to participate in a continuing dialogue on genomics issues through blogs, web-conferencing, webcastings and/or webinars. The website also provides additional educational materials for individuals and communities, provided by experts at the University of Michigan.

Once again, thank you for your participation in this ongoing discussion about key genomics issues and how they impact your health and your communities! Please contact Freda Motton at mottonfl@sbcglobal.net or 573-333-9865 with any questions you may have or for further information.

State Specific Newsletter Blurb:

Genomics, Community, and Equity: A Continuing Dialogue

On Friday October 12, 2007, Pemiscot County Community Coalition will host "Genomics, Community, and Equity: A Continuing Dialogue," funded by the National Human Genome Research Institute. Members of the community are invited to attend this forum, which will be an opportunity to participate in a dialogue about issues in genomics. The forum will be held at the University of Missouri Delta Center at 147 W. State Highway T in Portageville from 9:30am-3:30pm and is free of charge. Lunch will be provided. National experts on issues related to public health genomics will be featured speakers and forum participants will have a chance to take part in break out discussions on related topics. Please visit the forum website at www.GenoCommunity.org for more information and to register for the forum.

General Forum Information Newsletter Blurb:

Genomics, Community, and Equity: A Continuing Dialogue

On Friday, October 12, 2007, community forums on genomics will be held simultaneously in five Midwest States including Illinois, Iowa, Michigan, Minnesota, and Missouri. These forums, entitled "Genomics, Community, and Equity: A Continuing Dialogue," are funded by the National Human Genome Research Institute. The forums are an opportunity for community members, researchers, and academics to participate in a dialogue about issues in genomics and are free of charge. Following the forums, an interactive website will allow forum participants and those who could not attend the forums to participate in a continuing dialogue on genomics issues through blogs, web-conferencing, webcastings and/or webinars. The website will also provide additional educational materials for individuals and communities, provided by experts at the University of Michigan. The ongoing community dialogue about genomics issues will also continue in the form of events and meetings held by community organizations, libraries, and other groups. A set of resources will be produced to assist groups that wish to engage community members in the ongoing discussion about genomics and related issues. Please visit the forum website at www.GenoCommunity.org for more information and to register for the forum.

Key Articles

1. Citrin, T. and Modell, S.M. (2003). Genomics and Public Health: Ethical, Legal, and Social Issues. *Genomics and Population Health: United States 2003, Ch. 8.*

2. Guttmacher, A.E. and Collins, F.S. (2002). Genomic Medicine—A primer. *The New England Journal of Medicine, 347, 1512-1520.*

3. Collins, F.S., Green, E.D., Guttmacher, A.E. and Guyer, M.S. (2003). A Vision for the Future of Genomics Research. *Nature, 422(6934), 835-847.*

4. Guttmacher, A.E., Collins, F.S. and Carmona, R.H. (2004). The Family History - More Important Than Ever. *The New England Journal of Medicine, 351(22), 2333-2336.*

Web Resources for Genomics

1. Genomics, Community and Equity: A Continuing Dialogue
www.GenoCommunity.org
-On this website you can access educational materials and animated stories about genomics. Links are provided for more information. You can also discuss genomics with other through GenoBlogs.

2. National Human Genome Research Institute (NHGRI)
www.genome.gov
-This is the main website for the branch of the National Institutes of Health (NIH) that deals with genomics research. It is a good resource to learn basics about genomics.

3. National Office of Public Health Genomics
www.cdc.gov/genomics
-This is the main website for the branch of the Centers for Disease Control and Prevention that deals with genomics. It is a good place to learn about how genomics is can be used to improve health.

4. Genetic Alliance
www.geneticalliance.org
-Genetic Alliance is a non-profit organization that provides support to genetics advocacy groups. This site provides basic information about genomics and has a Disease InfoSearch with information on different genetic conditions.

5. GeneTests
www.genetests.org
-GeneTests provides information about current genetic tests. It is a great resource for learning about what genes have been discovered that contribute to disease.

6. Department of Energy Genome Resources
http://genomics.energy.gov/
-This website includes materials related to the Human Genome Project.

7. Human Genome Project (NHGRI)
http://www.genome.gov/10001772
-The Human Genome Project was completed in 2003 and this website details the research areas covered by the project.

8. U.S. Surgeon General's Family History Initiative
http://www.hhs.gov/familyhistory
-The Surgeon general started a campaign to encourage families to record their health histories. This website includes a tool, in both English and Spanish, that can be used to help record family histories.

9. National Human Genome Center at Howard University
http://www.genomecenter.howard.edu/intro.htm
-This Center focuses on exploring multicultural perspectives about genomics and how they impact health.

10. Johns Hopkins Genetics and Public Policy Center
www.dnapolicy.org
- The Center works to help policy leaders, decision makers, and the public better understand the rapidly evolving field of human genetics and its application to healthcare.

Glossary of Terms:

Codon: A single unit of the genetic code that is made up of three (triplet) nucleotide bases in a DNA or RNA molecule specifying a single amino acid.

DNA (deoxyribonucleic acid): The molecule that encodes genetic information. DNA is a double-stranded molecule made of two twisting, paired strands held together by weak bonds between base pairs of nucleotides.

ELSI: The Ethical, Legal, and Social Implications involved in genomics.

Gene: The fundamental physical and functional unit of heredity. A gene is an ordered sequence of nucleotides located in a particular position within the genome that encodes a specific functional product (i.e., a protein or RNA molecule).

Genetic Code: The sequence of nucleotides, coded in triplets (codons) along the mRNA, that determines the sequence of amino acids in protein synthesis. A gene's DNA sequence can be used to predict the mRNA sequence, and the genetic code can in turn be used to predict the amino acid sequence.

Genome: All the genetic material of a particular organism; its size is generally given as its total number of base pairs or as its total number of genes.

Genomic Era: The new era in genetic research featuring rapid acquisition and integration of increasingly advanced genetic information resulting from the progress and completion of the Human Genome Project.

Human Genome Project: Research and technology development effort aimed at mapping and sequencing the entire genome of human beings.

mRNA: A molecule that can move from the nucleus to the cytoplasm of cells that serves as the crucial connecting message between information contained in the gene and protein synthesis. The structure of RNA is similar to that of DNA. The mRNA molecule serves as a template for the specific amino acid sequence of a protein.

Nucleotide bases: The basic subunits of DNA or RNA. Thousands of nucleotides are linked to form a DNA or RNA molecule. The four nucleotides in DNA contain the bases adenine (A), guanine (G), cytosine (C), and thymine (T). In nature, base pairs form only between A and T and between G and C; thus the base sequence of each single strand can be deduced from that of its partner.

Protein: A large molecule composed of one or more chains of amino acids in a specific order; the order is determined by the base sequence of nucleotides in the gene that codes for the protein. Proteins are required for the structure, function and regulation of the body's cells, tissues and organs, and each protein has unique functions. Examples are hormones, enzymes, and antibodies.

Ribosome: A cytoplasmic organelle that serves as the molecular machine on which polypeptide synthesis from mRNA occurs.

Sequencing: Determination of the order of nucleotides (base sequences) in a DNA or RNA molecule.

Transcription: The synthesis of an mRNA copy from a sequence of DNA (a gene), the first step in gene expression.

Translation: The process in which the genetic code carried by mRNA directs the synthesis of proteins from amino acids.

tRNA: A class of RNA that recognizes the triplet nucleotide coding sequences of mRNA and carries the appropriate amino acid to the ribosomes, where proteins are assembled according to the genetic code carried by mRNA.

Prepared by:
The National Human Genome Research Institute
National Institutes of Health
U.S. Department of Health and Human Services

April 2003

For More Information:

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National Institutes of Health
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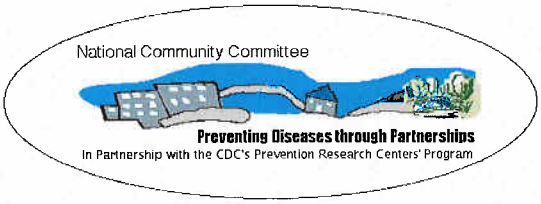
31 Center Drive, Room 4B09 MSC2152
Bethesda, MD 20892-2152

Phone:
(301) 402-0911

Website:
www.genome.gov

Related Websites:
U.S. Department of Energy Genome Programs: www.ornl.gov/hgmis
Medicine and the New Genetics: www.ornl.gov/hgmis/medicine/medicine.html
Ethical, Legal, and Social Implications: www.nhgri.nih.gov/About_NHGRI/Der/Elsi/
FAQs about genetics: www.genome.gov/page.cfm?pageID=10001191

APPENDIX 9:
Folder Materials for Missouri



Genomics, Community, and Equity: A Continuing Dialogue

Hosted by the Pemiscot County Community Coalition

Missouri Forum
Friday, October 12, 2007
9:30 AM-3:30 PM (CDT)

9:30 AM	Welcome
9:45 AM	The Human Genome followed by Q&A Session (V) *Sharon Kardia, Ph.D.*
10:30 AM	Break
10:45 AM	Discussion and Dialogue on Genomics, Spirituality, and Religion *Georgia Dunston, Ph.D.*
11:45 AM	Break
12:00 PM	Working Lunch with a Web Demonstration of www.GenoCommunity.org
12:30 PM	Keynote talk on Genomics, Medicine, and Society followed by Q&A Session (V) *Francis S. Collins, M.D., Ph.D.*
2:00 PM	Break
2:15 PM	Next Steps Panel *Susan King, D. Min., Dale Lea, M.P.H., R.N., C.G.C., F.A.A.N.; Jean Jenkins, Ph.D., R.N., F.A.A.N.; Sharmini V. Rogers, M.B.B.S., M.P.H.; LaJuan Chambers, M.D.; Georgia Dunston, Ph.D.*
3:30 PM	Adjourn

(V) Indicates interactive video-conferenced sessions. All other presentations are live.

Funded by: National Human Genome Research Institute/NIH

A Community Genetics Forum

National Community Committee
Preventing Diseases through Partnerships
In Partnership with the CDC's Prevention Research Centers' Program

Genomics, Community, and Equity: A Continuing Dialogue

Hosted by the Pemiscot County Community Coalition

Missouri Forum Speaker Biographies

LaJuan Chambers, M.D., *Regional Medical Director, Hemoglobinopathy Resource Center, University of Missouri – Columbia, Columbia, MO*

Dr. Chambers' primary interest is the comprehensive care of children with sickle cell disease and other hemoglobinopathies. She currently is an assistant professor at the University of Missouri – Columbia where she serves at the regional medical director of the State of Missouri's hemoglobinopathy resource center.

Dr. Chambers received her Bachelor of Science degree in biology at Prairie View A&M University in Prairie View, TX; her Doctor of Medicine degree at the University of Texas Medical Branch in Galveston, TX. She completed a pediatric residency at the University of Texas Medical Branch before completing a pediatric hematology/oncology fellowship at the University of Texas Southwestern Medical School in Dallas, TX.

Francis S. Collins, M.D. Ph.D., *Director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH)*

Dr. Collins is the director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH). He led the successful effort to complete Human Genome Project (HGP), a complex multidisciplinary scientific enterprise directed at mapping and sequencing all of the human DNA, and determining aspects of its function. A working draft of the human genome sequence was announced in June of 2000, an initial analysis was published in February of 2001, and a high-quality, reference sequence was completed in April 2003. From the outset, the project ran ahead of schedule and under budget, and all the data is now available to the scientific community without restrictions on access or use.

Dr. Collins received a B.S. from the University of Virginia, a Ph.D. in Physical Chemistry from Yale University, and an M.D. from the University of North Carolina. Following a fellowship in Human Genetics at Yale, he joined the faculty at the University of Michigan, where he remained until moving to NIH in 1993. His research has led to the identification of genes responsible for cystic fibrosis, neurofibromatosis, Huntington's disease and Hutchison-Gilford progeria syndrome. He is a member of the Institute of Medicine and the National Academy of Sciences.

Georgia M. Dunston, Ph.D., *Chair, Department of Microbiology / Founding Director, National Human Genome Center and Director, Molecular Genetics, NHGC, Howard University*

Dr. Georgia Dunston is a professor in the College of Medicine at Howard University. Dunston, who has been with the University since 1972, is also the former Chair of the Department of Microbiology. Her research interests are the biomedical significance of genetic variation in African-Americans and dedication to increasing minority participation in human genetic

research. These interests led to the establishment of the Human Immunogenetics Laboratory at Howard in 1985, where she has served as founder and director of this core component of the National Institutes of Health (NIH) funded Research Centers in Minority Institutions Interdisciplinary Program.

Dunston has been instrumental in increasing knowledge on human leukocyte antigen (HLA) polymorphisms in African-Americans. Her research examines the impact of population differences in HLA variation on donor/recipient matching in clinical transportation and gene-based differences in the immune response to organ transplants. Dunston's research on the biomedical significance of human genome polymorphisms has been the vanguard of current efforts at Howard University to build national and international research collaborations focusing on genome-wide studies of diseases common in both African-Americans and people in the African Diaspora. This research has provided the scientific foundation for formation of the National Human Genome Center (NHGC) at Howard University with Dunston as the founding director.

In addition to her research and role as an educator, Dunston is a frequent speaker at universities and conferences throughout the U.S. and abroad; has several publications on HLA variation and disease associations in African-Americans; and has served on several national scientific councils and committees. Dunston earned a bachelor's degree in biology from Norfolk State University, a master's degree in biology from Tuskegee University, and a PhD in human genetics from the University of Michigan. She also conducted postdoctoral work in tumor immunology at NIH in the National Cancer Institute.

Jean Jenkins, Ph.D., R.N., F.A.A.N., *Senior Clinical Advisor to the Director*

Dr. Jenkins received her B.S.N from the University of Maryland MSN at the Catholic University of America, and a Ph.D. in 1999, completing Innovation of Diffusion Research on Genetics Education for Nurses. Dr. Jenkins has assumed key leadership positions at NIH including nurse educator, developing a cancer nurse training program; research nurse, monitoring clinical studies; Chief of the Oncology Nursing Service; and Acting Deputy of the National Human Genome Research Institute Medical Genetics Branch. It was during a clinical internship as part of doctoral studies at George Mason University, Virginia, that she recognized the importance of advances in genetics research for all health care providers. She has been motivated and committed to the preparation of others to become aware, plan for, and integrate genetic concepts into their practice.

Sharon Kardia, Ph.D., *Associate Professor of Epidemiology, Director of the Public Health Genetics Program, Director of the Life Sciences & Society Program, and Co-Director of the Center for Public Health and Community Genomics, University of Michigan School of Public Health*

Dr. Kardia received her doctoral degree in human genetics from the University of Michigan, was a post-doctoral fellow in the Department of Microbiology and Immunology and continued post-doctoral work in the Department of Human Genetics. She joined the faculty of the University of Michigan School of Public Health in 1998.

Dr. Kardia's main research is on the genomic epidemiology of cardiovascular disease carried out at the Kardia Lab; she is particularly interested in gene-environment, gene-gene interactions, and in modeling complex relationships between genetic variation, environmental variation, and risk of common chronic diseases. Dr. Kardia is also working to move genetics into chronic disease

prevention programs in state departments of health.

Susan King, D. Min., *Associate Director of Life Sciences and Society, University of Michigan*

Dr. King, as Associate Director of our Life Sciences and Society Program, has taken on the lead role of community outreach with faith groups and community advocacy groups to provide education and dialogue around the life sciences and their societal meaning. Within our county, she is the Chair of the Board and Coordinator of the Interfaith Roundtable of Washtenaw County and is also a member of the National Conference for Community and Justice. She is an ordained Interfaith Minister from the New Seminary in New York City. Her doctorate in ministry included a focus on science and religion, as well as the psychology and counseling of religious groups. She is an extraordinarily good community facilitator able to move smoothly among diverse groups of people building trust and openness within community groups. She will be directly responsible for creating and tending connections with community leadership, talking through the GEMINI objectives, organizing community meetings, facilitating the creation of community projects with the help of trained facilitators and research assistants.

Dale Lea MPH, RN, CGC, FAAN, *Health Educator*

Ms. Lea is a Board Certified genetic counselor with more than 20 years experience in clinical and educational genetics. She is currently the Health Educator with the Education and Community Involvement Branch, National Human Genome Research Institute. As Health Educator, Ms. Lea develops consumer genetics health education and community involvement programs and resources; translates genetic and genomic research results into terms understandable by lay audiences; collects and assimilates data for Institute reports; and provides administrative support for public education and community involvement programs.

Ms. Lea received her BSN from Westbrook College, Portland, Maine, and her Masters in Public Health with a focus in health education and health promotion from Loma Linda University, Loma Linda California. She is a member and past President, past Chair of the Education, Bylaws, Social Policy and Annual Education Committees of the International Society of Nurses in Genetics (ISONG). She is the Co- Chair of the Ethics and Public Policy Committee. She is also a member of the National Society of Genetic Counselors, and the Oncology Nursing Society. She received the New England Regional Genetics, Leadership Award for Genetic Counseling in 1997, and the ISONG Founders Award in 1999 in recognition of outstanding nursing and patient education in genetics. In 2001, Ms. Lea was inducted as a new Fellow in the American Academy of Nursing, and serves on their Expert Panel on Genetics.

Sharmini V. Rogers, MBBS, MPH., *Bureau Chief, Genetics and Healthy Childhood*

Dr. Rogers is the Chief of the Bureau of Genetics and Healthy Childhood in the Missouri Department of Health and Senior Services. She has overall responsibility of the Missouri Newborn Screening programs, Genetic Programs such as Cystic Fibrosis, Hemophilia, Sickle Cell and Formula Program for individuals identified with a metabolic disorder. She represents the Department as the State Genetics Coordinator and is involved as a steering committee member for the Heartland Regional Genetics and Newborns Screening Collaborative.

In addition, to the genetic programs, Dr. Rogers also has responsibility for programs that promote healthy pregnancies, healthy babies, children, and adolescents. Having a broad scope of

programs under her supervision enables her to promote knowledge of genetics and health throughout the life cycle.

Genomics, Community, and Equity: A Continuing Dialogue

www.GenoCommunity.org

Visit the project website for information on how you can participate in the ongoing dialogue about genomics and related issues. At the website you can:

- Find out more about the Community Genomics Forums being held in five Midwest States on October 12, 2007 and see archived presentations
- Access educational materials to learn more about genomics
- Participate in an ongoing web dialogue through blogs, an online forum, web conferencing, webcasting, and/or webinars
- Find materials to help your organization host events to engage your community in discussions on genomics

Funded by:
National Human Genome
Research Institute/NIH

A Community Genetics Forum

A Community Genetics Forum

National Community Committee
Preventing Diseases through Partnerships
In Partnership with the CDC's Prevention Research Centers' Program

Genomics, Community, and Equity: A Continuing Dialogue

Community Event Tool Kit

Genomics, Community, and Equity: A Continuing Dialogue is a project centered on the community genetics forums to be held in five Midwest states in the Fall of 2007. The forums will feature presentations by national experts on genomics and allow community members to voice their views during dialogue sessions.

Following the forums, the project website www.GenoCommunity.org, has several components that will allow the dialogue to continue. A tool kit has been created for organizations and libraries who wish to hold events to help engage their own communities in further dialogue.

There are several parts of the tool kit that organizations planning events related to genomics issues may find helpful, including:

- Marketing materials that can be customized for each event. These are available in Microsoft Publisher format, and can be easily changed to accommodate an organization's needs.
- Educational materials that may be helpful in planning the event or may be given out during the event
- Information about the project and website

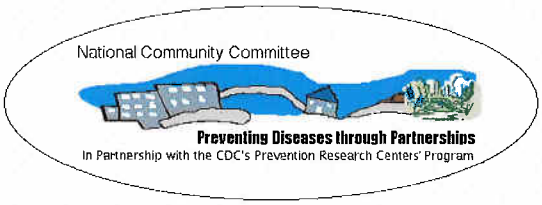
Another important component to this toolkit is information on how to plan an event, including:

- Tips for planning an event and choosing an event location
- Information on how to write a press release for an event
- Important tips for contacting resource people in your region and a list of NHGRI speakers who are available for videoconference presentations
- Examples of the types of events that you may wish to hold
- A questionnaire to give to participants to evaluate the event

There are also additional documents you may want to consider based on the type of event you wish to hold:

- Tips for facilitators to help make discussions run smoothly
- Instructions for using Centra technology, a web conferencing tool

Please visit the project website at www.GenoCommunity.org for more information about the entire project and to download materials to use in planning your own event. We hope that your organization will consider holding an event to help continue the important dialogue on genomics and why it is relevant to you and your community.



Genomics, Community and Equity: A Continuing Dialogue

Since completing the Human Genome Project, governmental agencies, academic and community partners have focused on how to engage communities in a dialogue about issues in genetics and genomics. In 2004, the National Human Genome Research Institute (NHGRI) began funding community engagement projects in different regions of the country. This project will be the third in this series, focusing on the 10 state Midwest Region (Illinois, Indiana, Iowa, Kansas, Nebraska, Ohio, Michigan, Minnesota, Missouri, and Wisconsin).

Genomics, Community and Equity: A Continuing Dialogue will include a set of 5 community dialogue forums and an interactive web-based continuing dialogue that focuses on education and further community involvement. Materials will also be created to aid community organizations and libraries in organizing events to engage the public in this ongoing dialogue. This project is a partnership between the Center for Public Health and Community Genomics (CPHCG) at the University of Michigan School of Public Health and the National Community Committee (NCC) of the CDC-funded Prevention Research Centers. Local educational resources will be provided by the state health departments in the five forum states, and both educational and dissemination support will be provided by the National Network of Libraries of Medicine (with special emphasis on health professionals) and their respective state associations of public libraries (with special emphasis on lay members of their communities).

Community Dialogue Forums

The forums will be held in 5 of the 10 states in the region (Illinois, Iowa, Michigan, Minnesota and Missouri) simultaneously and will combine general topics as well as topics specific to the host states and their surrounding areas. Video conferencing will be used to connect the forums while they are occurring. The NCC of that state will host that state's community forum and will be responsible for recognizing issues specific to the areas that they serve. The goal of each forum is to engage at least 80 people (a total of 400 people, including all five forums) and encourage participants to go online and continue the dialogue.

Interactive Web-based Continuing Dialogue

The Center for Public Health and Community Genomics is collaborating with the Life Sciences & Society Program at the University of Michigan in the creation of a website and online educational materials that will utilize blogs, web conferencing, webcasting, and/or webinars to engage groups in the focus area to participate in forums or forum-related activities

Continuing Community Engagement

The ongoing community dialogue about genomics issues will also continue in the form of events and meetings held by community organizations, libraries, and other groups. A set of resources will be produced to assist groups that wish to engage community members in the ongoing discussion about genomics and related issues.

Genomics, Community, and Equity: A Continuing Dialogue
A Community Genetics Forum

[Participants: Please fill-out at the beginning of the day.]

Location [City, State] (Please mark): _____

Demographic Survey

We ask that you complete the questions below, which are required by the sponsor and will help us in reporting genetics forum findings.

1. What were your primary motivations for coming to this forum? (Check all that apply):

   - ☐ Relationship of my occupation to the health care system
   - ☐ Known or suspected genetic condition in my family
   - ☐ Desire to learn about subject
   - ☐ Sponsorship by host organization
   - ☐ Other. Please specify:_____

2. How old were you on your last birthday?
   _____years old

3. Are you male or female?
   - ☐ Male
   - ☐ Female

4. How do you describe yourself? (Check all that apply):
   - ☐ American Indian or Alaska Native
   - ☐ Arab or Middle Eastern
   - ☐ Asian
   - ☐ Black or African American
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ White
   - ☐ Hispanic/Latino
   - ☐ Other (please specify):_____

5. What is the highest year of school that you have completed? _____

6. Which is/are your occupation(s)? Please specify:_____

7. Which of the following categories includes your annual household income level?

   - ☐ Less than $15,000
   - ☐ $15,000 - $45,000
   - ☐ $45,000 and over

Genomics, Community, and Equity: A Continuing Dialogue
A Community Genetics Forum

[Please fill-out by end of the day's event.]

Forum Participant Questionnaire – Overall Event

Here are some statements about today's event. Please circle the answer that comes closest to expressing the way you feel. There are no right or wrong answers, and your name will not be associated with your answers in any way.

Whole-Group Sessions:

1. The whole-group presentations added to my overall understanding of genomic issues.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

2. Speakers explained technical content in an understandable way.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

3. Participants felt comfortable asking questions.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

4. As a result of the whole-group sessions, I have a better appreciation of the complexity of genomic issues.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

5. Please rate each individual whole-group presentation, from 1= Strongly Disagree to 5 = Strongly agree, for the following two statements –

- Overall, this was an engaging presentation (Engaging)
- The topic presented was of value to me (Of Value)

[Speaker 1]; [Topic 1]	Engaging:	1	2	3	4	5
[Speaker 1]; [Topic 1]	Of Value:	1	2	3	4	5
[Speaker 2]; [Topic 2]	Engaging:	1	2	3	4	5
[Speaker 2]; [Topic 2]	Of Value:	1	2	3	4	5
[Speaker 3]; [Topic 3]	Engaging:	1	2	3	4	5
[Speaker 3]; [Topic 3]	Of Value:	1	2	3	4	5
[Speaker 4]; [Topic 4]	Engaging:	1	2	3	4	5
[Speaker 4]; [Topic 4]	Of Value:	1	2	3	4	5

Break-out Sessions:

6. The break-out presentations added to my overall understanding of genomic issues.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

7. Break-out leaders explained technical content in an understandable way.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

8. As a result of the break-out sessions, I have a better appreciation of the complexity of genomic issues.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

9. As a result of the break-out sessions, I have a better understanding of the views of others on genomic developments.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

Panel Discussion [Missouri Only]:

10. The combination of discussants was more effective than if each had presented alone.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

11. The panel discussion communicated important points held by community members.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

Overall Event:

12. The rooms and building where the event was held were comfortable.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

13. The event touched on major issues I wanted to see addressed.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

14. Attending today's forum interested me in learning more about genomics.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

15. Have you previously used the project web site demonstrated at the conference?

Yes No

16. [For those who have not previously used the project web site]:
I intend to use the project web site demonstrated at the conference.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

17. As a result of today's forum, I am more likely to consider for myself or suggest to others a career in a genetics-related field.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

18. I would feel comfortable engaging in genetic testing to tailor medical treatment to my personal health needs.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

19. I would feel comfortable becoming a participant in a genomics related research study.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

20. I would feel comfortable encouraging my family members to collect a health family history recording our past and current health conditions.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

21. Those I know - family and friends - would be willing to participate in a national study looking at the roles of genetics and the environment in disease.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

22. How much did you know about genomics before attending today's forum?

1	2	3	4	5
I knew nothing	Very little	Some knowledge	A moderate amount	Very knowledgeable

23. Did the amount you know about genomics change as a result of attending today's forum?

1	2	3	4	5
Not at all	A little	Somewhat	Moderately	A great deal

24. What can be done to increase your community's understanding of genomics? (please use space below)

25. General comments (please use space below)

Thank you for your participation!

Genomics, Community, and Equity: A Continuing Dialogue
A Community Genetics Forum

[Please fill-out at end of the break-out session.]

Break-out Leader's Name: _____ Time: _____

Name of Break-out Session: _____

Break-out Session Questionnaire

Please circle the answer that comes closest to expressing the way you feel about the session.

1. Overall, this was an engaging break-out session.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

2. The topic discussed was of value to me.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

3. The majority of participants felt comfortable making comments and asking questions.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

4. What was one highlight of the session for you?

What could we have done better or what else would you have wanted for this session?

Thank you for your participation!

APPENDIX 10:
Facilitators' and Notetakers' Guide

Genomics, Community, and Equity: A Continuing Dialogue
A Community Genetics Forum
Illinois – Iowa – Minnesota – Missouri - Michigan
October 12, 2007

Conference Introducer / Speaker / Facilitator / Note taker Guide

Kudos –
Thank you to the many individuals – conference introducers, speakers, facilitators, note takers – who have given their time and energy to make the Midwest region Genomics Forums a unique and productive effort. The idea behind the Forums is to spark a multidirectional flow of ideas, views, and suggestions on new genomic technologies and approaches. We hope to capture enough of the content of what is presented and discussed to report accurately what the participants have learned and expressed, and describe the overall directions, positions, and suggestions voiced. The Forums have been organized to also lend a sense of how events at the individual sites have gone, information important to future event organizers.

Conference Introducers at the various sites: Please see page 3 on Evaluation timing

Speakers: Please see Sections I-III

Facilitators and Speakers who anticipate facilitating Break-out Sessions:
Please see Sections I-II, IV-V

Note takers: Please see Section VI. Other relevant Sections: II (pages 4, 5)

Contents	**Pages**

Forum Agenda, Topic Summaries, Speaker Biographical Sketches will be circulated prior to the Forums

I. Nature and Timing of Sessions

- *Personnel:*

A. Conference Introducers (one per site): open the Forum, introduce the day's events, explain filling-out and handing-in of the evaluation forms (page 3)

B. Speakers: deliver Plenary and Break-out session talks, share contact information with note takers (Break-outs)
C. Facilitators: make sure video-link is focused on speaker, introduce speakers, direct discussions following talks (unless the speaker prefers to do this), ask participants to fill-out the Break-out session evaluation form, share contact with note takers (Panel sessions)
D. Note takers: check room arrangement and audio-visual equipment, take notes during Break-out sessions, cross-check summary points with speakers or facilitators, convey transcripts and summary points to the Evaluation director

- *Types of Sessions:*

The Genomics Forums involve 4 types of sessions:
A. Plenary or Whole-group, involving everyone attending the Forum
B. Break-out with presentation and discussion, where time is allocated between the speaker's presentation, and discussion with and between the audience members
C. Break-out with discussion only, where the time is fully occupied by group discussion
D. Panel presentation

- *Conduct of Sessions:*

The Forums differ from standard communication in several respects:
- multiple sites will be linked via video-conferencing, allowing 2-way communication between sites
- the Break-out sessions will involve both speaker-participant and participant-participant interactions
- opportunities for speaker-participant communication in the Plenary and Break-out sessions will be 2-way interactive
- the Plenary sessions will be digitally recorded for archiving on the publicly accessible GenoCommunity web site

A. The Plenary sessions conducted by Francis Collins in Minnesota, and Sharon Kardia in Michigan will occur in one state and be broadcast simultaneously to the other four states. The majority of Plenary sessions will be conducted in one state only.

B. Break-out sessions with presentation and discussion (between audience members, and between speaker and audience) will occur in every state. Two Break-out sessions are being transmitted from one site to another: Race-Based Medicine at 2:15 CDT/3:15 EDT with Ossorio (transmitted from Illinois to Michigan) and Genetics, Spirituality & Religion with Dunston at 10:45 CDT/11:45 EDT (transmitted from Missouri (Plenary) to Michigan (Break-out)). Discussion will be shared between the two sites.

C. Break-out session with discussion only: the 11:45 Discussion & Dialogue on Diversity, Disparities & Forensics session with Bonham, taking place in Michigan. This Break-out immediately follows his 10:30 Plenary session on Disparities.

D. Minnesota will host a panel presentation at 10:45 CDT – Spirituality & Culture. Missouri and Michigan will host panel presentations at 2:15 CDT/3:15 EDT – Missouri on "Next Steps" (as a Plenary session), and Michigan on Genetics, Spirituality & Religion (as a Break-out session). The Michigan panel may address points made in the Dunston session at 11:45 EDT.

- *Session Timing:*

Facilitators, or someone designated by them, must keep time for the sessions. Note takers have been assigned this role for the break-out sessions in which they are present. Speakers should be signaled when 5 minutes are left (for panelists: when 1 minute is left).

*** Timetables must be strictly adhered to, due to the interconnected schedules of sessions taking place within and across sites, and transportation plans based on prompt adjournments.**

A. Plenary sessions: Length of sessions vary. The majority of time is allotted to the presentation itself. One hour sessions should leave at least 20 minutes for Q&A with the audience. The 1&1/2 hour keynote session with Francis Collins will leave 45 minutes for Q&A.

B. Break-out sessions with presentation and discussion: These sessions are one hour long. The initial presentation should be limited to 20 minutes; the rest of the time should be devoted to discussion. Three minutes should be left at the end for participants to fill-out Break-out session evaluations.

C. Break-out session with discussion only: This session with Vence Bonham is one hour long. The entire period should be allotted for discussion. Three minutes should be left at the end for participants to fill-out Break-out session evaluations.

D. The Panel sessions are one hour long. Individual panelists and cross-panel discussion should not exceed 30 minutes. The remaining time should be devoted to interaction with the audience. Three minutes should be left at the end of the Michigan and Minnesota Panel sessions for participants to fill-out the panel Break-out session evaluation. The Missouri Panel session will be evaluated at the end of the day.

- *Evaluation Timing:* **[Conference introducers: Please mention these details when opening your Forum.]**

A. Break-out session evaluation forms: to be filled-out at the end of each Break-out session.
B. Forum participant questionnaire: to be filled-out by the end of the day.

All forms are to remain clipped together and returned by participants to the front desk at the end of the day before they leave the building.

II. Roles of Speakers and Facilitators

The speakers, drawn from NIH, CDC, and elsewhere, have the role of presenting the material of a given session for the participants' consideration and discussion. The NCC organizers at each site should arrange for a person who can facilitate what occurs throughout the entire session. Facilitators have the following roles:

A. Plenary Sessions – Plenary session facilitators will:
- (very beginning) check with the other sites that he/she can be seen and heard while standing in the speaker's position ("Can the other states see and hear me?")
- introduce the plenary speaker
- direct questions and comments from the immediate audience to the speaker
- direct on-screen questions and comments from transmitted sites to "live" sites when called upon by the "live" site facilitator
* equal time should be provided for questions and comments from other sites joined by videoconference

*** Note to MI Facilitator of the Kardia plenary: for the 9:15 CDT / 10:15 EDT Q&A portion of the educational Plenary Session with Sharon Kardia, the facilitator in Michigan is asked to alternate questions between the two sites.**

*** Note to MN Facilitator of the Collins keynote: for the 12:30 CDT / 1:30 EDT shared talk with Francis Collins, the facilitator in Minnesota is asked to distribute the 45 min. Q&A portion with 9 mins. to each state in order of the Forum agenda (IL, IA, MN, MO, MI).**

B. Break-out Sessions with presentation and discussion – Facilitator will:
- introduce the speaker
- moderate the discussion after the talk is finished or turn it over to the speaker at their request
- have attendees fill-out their break-out evaluations (3 minutes) at end of session
- in the case of a transmitted Break-out session, the facilitator at the originating site has the responsibility of asking for questions from the audience at the recipient site. The facilitator at the recipient site selects the person asking the question.

C. Break-out Session with discussion only – Facilitator will:
- introduce the speaker
- allow time at the beginning for the speaker (Vence Bonham) to orient the discussion
- moderate the discussion or turn it over to the speaker at his request
- have attendees fill-out their break-out evaluations (3 minutes) at end of session

Note taker (B. and C.) will:
- take notes during the session (See VI. Note taker Protocol)
- exchange phone #'s and e-mail addresses with the speaker for comparison of summary points at a later time
- convey notes transcript and summary points to Evaluation director

- 2:15 CDT/3:15 EDT Race-Based Medicine with Ossorio: a note taker is required at the Illinois but not the Michigan site. Note taker is to record discussion from both sites.
- 10:45 CDT/11:45 EDT Genetics, Spirituality & Religion with Dunston: this session will be recorded – no note taker is required

***[Conference organizers are to determine whether one or two people fill the facilitator / note taker roles]**

D1. Plenary Panel Presentation – Missouri (2:15; Recorded) – Facilitator will:
- (very beginning) check with the other sites that he/she can be seen and heard while standing centrally in the panelists' location ("Can the other states see and hear me?")
- introduce the speakers
- assure session sequence (4 speakers followed by a response from Dunston, ~7 minutes each)
- direct audience questions and comments to the panel

D2. Break-out Panel Presentations – Minnesota and Michigan (10:45 and 3:15, respectively; Not Recorded) – Facilitator will:
- introduce the speakers
- assure session sequence and moderate any cross-panel discussion (< 15 minutes)
- direct audience questions and comments to the panel
- have attendees fill-out their break-out evaluations (3 minutes) at end of session

A separate Note taker (Michigan only (Missouri recorded)) will:
- take notes during the discussion
- back-up facilitator on speaker timing (~7 minutes per panelist)
- exchange phone #'s and e-mail addresses with the facilitator to compare summary points of the discussion at a later time

III. Presentations – General Description

- Presentation content has been discussed between NCC members and speakers. Forum agenda, topical summaries, and speaker biographical sketches will be circulated prior to the Forums.
- Presentation timing appears in Section I. above.
- Plenary and Break-out session speakers will be introduced by a session facilitator, who will help direct questions and comments unless the speaker asks to take over this duty.
- Plenary session Q&A periods are devoted to exchange between the speaker and audience, whereas break-out session discussion periods involve both speaker-participant exchange and participant-participant exchange.
- All Break-out session speakers, except panelists, are asked to correspond with note takers on session summary points (see Section VI. Note taker Protocol, below). Speakers will be contacted by the note takers.

IV. Tips on Conducting a Break-out Session [For Facilitators and Speaker-facilitators]

- Not everybody takes the opportunity to speak during a group session, though many wish they had added their input. A goal is to get everyone who wishes to speak to contribute. Ways to include more of the audience:

  - Ask if anyone else has a comment who has not yet spoken. (Not good to single out individuals, though.)
  - State, "Let's hear from someone who has not yet spoken," then consciously look around the room for people who look like they are ready to speak.
  - Wait an adequate time (>10 seconds) for people who are reluctant to raise their hand or volunteer their comment.
  - Ask, "Do people agree or disagree with that last comment?".

- In dialogues that involve a technical dimension, sometimes just those members familiar with the field speak their mind. People pressed by other concerns, the demands of daily life, may hold their opinion. The upshot is just a few people steering the discussion – "small group dominance". Small group dominance can seriously compromise people's satisfaction with the session. This occurrence can be avoided by:

  - Focusing the gaze more on people who have not talked yet, or on sections of the room that have remained relatively quiet.
  - Asking: "Is there anyone who has not yet talked who would like to do so?".

- Other conduct-related factors that can help with the quality of the discussion:
  - Speakers and facilitators giving focus and direction to the discussion based on the nature of the talk (as opposed to letting the discussion drift in unrelated directions)
  - Insuring that participants genuinely feel listened to – grant them adequate time to voice their comment
  - Speakers listening with full attention to points being made (plenty of opportunities exist for distraction in a break-out group)

- Some presentations will cover issues-oriented aspects or implications of genetic developments. We would like to hear people's thoughts and opinions on the issues. You can ask the audience if they have any recommendations or suggested policies in line with what is being discussed.

- It is perfectly natural for discussion in the break-out sessions to center on communication between the speaker and participants. Participant satisfaction with break-outs is often also linked with the quality of interaction between participants. Try to promote not just speaker-participant, but participant-participant discussion as well.

- All those at the session are to be **respected as equals**. Although the speaker may have a premium on knowledge regarding their particular subject, participants come to these conferences with a range of experiences and insights that neatly complement points made during the formal presentations. Speakers and participants each represent a unique body of experience equally deserving of expression.

- The presentations and discussions are to be undertaken with the goal of **mutual understanding** in mind. The Forums are especially designed to provide fundamental information eliciting people's sincere opinions. The presentations need to be framed in a manner that is understandable to the lay audience. Participants also seek to be clearly understood by one another. Giving people adequate time to speak; asking people for the reasons, values, or background behind what they are saying; asking for clarification serve here.

V. Discussion Points

The facilitator or speaker can hold the following 12 dialogue questions (adapted from Leonard M. Fleck, Communities of Color and Genetics Policy Project) in mind when engaging participants. These points are not meant to be used as a checklist in an obligatory sense; rather, as background for facilitators wishing to extend the discussion:

1. Do participants express **uncertainty and thoughtful deliberation over the new issues** posed by the technologies / approaches being presented and discussed?

2. Are discussion participants more consistently than not **giving reasons or clarifying background** for their point of view?

3. Are participants recognizing / identifying the **underlying values** that have a bearing on the particular problem they are discussing?

4. Is the discussion capturing **grassroots feelings and values** to at least an equal extant as the technical aspects of the problem being discussed?

5. Do discussion participants feel comfortable because they are genuinely being **addressed by the speaker and conversing with one another as equals**?

6. Is there evidence in the discussions that **mutual understanding and appreciation** of one another's views is being achieved?

7. Are the participants expressing viewpoints that will **benefit their community**, and are those viewpoints being recorded accurately?

8. Have discussion participants been able to cite what they regard as **public or community interests** that ought to be used as reference points for considering public policies related to genetics and emerging genetic technologies?

9. Have participants been able to express **concerns with which they as an individual and member of a community identify** when approaching the problem being discussed?

10. Is there evidence from the presentations and discussions that an **educational process** has taken place, involving individuals in learning from one another to make better judgments in the genomics policy arena?

11. Is there evidence from the discussions that people have a **clearer understanding and stronger appreciation** of the **complexity of the issues** they have been discussing?

12. Do discussion participants see and express themselves as having **greater toleration** for genomics-related choices that others might make, and that they might not otherwise make for themselves?

VI. Note Taker Protocol [Break-out Speakers and Facilitators – Please also read]
Important to the success of the Genomics Forums is the capture of participants' expressed views, values, and suggestions, and the accurate reporting of what they communicate in discussions. Note takers are an essential part of the Break-out sessions. Unless otherwise specified by the conference organizer for the site, they are generally not required at the Plenary sessions, which will be recorded. It is requested that note takers use pen rather than lap top unless absolutely necessary. Typing on lap tops, unless fairly silent, can be distracting to break-out participants.

Note taker protocol is as follows –

A. Before the Session:
- Please introduce yourself to the session speaker and facilitator. Let him/her know you are the person who has been asked by the Forum planners to take notes.

- Check to make sure the speaker's audio-visual needs are taken care of. If not, quickly go to the central desk for assistance.

- Begin the session by drawing on a sheet the seating arrangement, and labeling where the participants are sitting [males (M1, M2, …); females (F1, F2, …)] on the picture. Under or on another sheet, please record:
  - the number of audience participants in the session
  - the general racial-ethnic composition of the group

B. During the Presentation:
- Keep time – 20 minutes of presentation (30 minutes for panel sessions), followed by audience questions and comments. Signal speakers when 5 minutes are left (for panelists: when 1 minute is left).

- Take down pointers that will allow you to briefly describe (about one paragraph) the material covered by the speaker.

- (Panel break-outs: Record pointers allowing you to write a brief paragraph on what each panelist covers.)

C. Relating to the Discussion:

- Complete your drawing of the seating arrangement and participants if this has not yet been done.

- Capture as best you can the drift of what a participant is saying using whatever form of shorthand or abbreviation is most comfortable for you as people speak.

- Example passage –
  M3: "Do not think prenatal testing to be used here. Disease only later in life. Need policies. Diff. from newborn scr. (severe cond.)."

  F2: "Fam hx interests me as a possib. Can detect cond. in family way ahead. Take early steps."

- Signal the facilitator when the hour is almost finished. Leave ~3 minutes at the end for participants to fill-out the break-out session form. All forms get collected at the end of the day.

*** The 1-hour timetable must be strictly enforced, due to the interconnected schedules of sessions taking place within and across sites, and transportation plans based on prompt adjournments.**

- **When the session ends, exchange your phone # and e-mail address with the speaker (if just 1 speaker) or facilitator (if panel).** This information is needed to compare summary points later on.

D. After the Session:

Write-down the following summary points (can be adopted to the specifics of the session) –

- Jot down the 3-5 issues that were the focus of the conversation that evening.

- Write down the 3-5 "conclusions" that might be distilled from the discussion. These conclusions might be moral judgments or policy suggestions from within the group on particular technologies, proposed programs, or approaches towards genomics.

- Also indicate how widely and strongly endorsed they seemed to be. The conclusions may take either a positive or negative stance, and are a result of your interpretation of what was discussed.

- Write a paragraph on your impressions of the quality of the dialogue:

  - the degree to which people seemed to understand what the speaker discussed;
  - people's satisfaction speaking with one another (speaker-participant and participant-participant interactions);
  - the extent to which people listened to one another
  - whether small group dominance (a small number of people taking over the conversation seemed to be taking place
  - whether people seemed to be seeking common ground or conflicting
  - whether the mood shifted during the course of conversation, and if so, why?

E. Later on (at home):

- Type-out your notes in non-shorthand form.

- Communicate your summary points to the speaker or facilitator (panel sessions) and get their feedback on any changes / additions they would make. Transmit by October 31 your typed transcript and agreed-upon summary points to Stephen Modell, Forums evaluation (e-mail preferred):

Dr. Stephen Modell
University of Michigan
2675 SPH-I Tower / Crossroads
109 S. Observatory
Ann Arbor, MI 48109-2029

Tel: (734) 615-3141
Fax: (734) 936-0927
*mod@umich.edu (preferred)

APPENDIX 11:
Break-Out Session Packets

I. Break-Out Session packets

1. **Race-Based Medicine (IL and MI)**
   - Exploring Genetics Issues Relevant to Minority Communities www.ornl.gov/hgmis/elsi/minorities.html
   - Qureshi, N. and Kai, J. (2005). Genomic Medicine for Underserved Minority Populations in Family Medicine. *American Family Physician, 72(3), 386-387.*
   - Race-Based Medicine Arrives-Forbes magazine 5-10-05 http://www.forbes.com/2005/05/10/cx_mh_0509racemedicine.html
   - Genetic Find Stirs Debate on Race-Based Medicine- New York Times 11-11-05 http://www.nytimes.com/2005/11/11/health/11heart.html?_r=1&adxnnl=1&adxnnlx=1190909992-RIu8eUR4cQdgmhLmti3xyg&oref=slogin

2. **Research and Special Populations (IL)**
   - Exploring Genetics Issues Relevant to Minority Communities www.ornl.gov/hgmis/elsi/minorities.html
   - DNA of Blacks to be Gathered to Fight Illness- New York Times 5-27-03 http://query.nytimes.com/gst/fullpage.html?res=9C03E5DE1031F934A15756C0A9659C8B63
   - DNA Gatherers Hit Snag: Tribes Don't Trust Them- New York Times 12-10-06 http://www.nytimes.com/2006/12/10/us/10dna.html?_r=1
   - Genetic Research Thrives Amid Amish Population-Seattle Times 8-5-05 http://seattletimes.nwsource.com/html/businesstechnology/2002349195_btamishgene27.html

3. **Genes, Environment, and Chronic Disease (IL and IA w/ different speakers)**
   - Chronic Disease Fact Sheets (from NHGRI)
   - Gene-Environment Interaction Fact Sheet http://www.cdc.gov/genomics/training/perspectives/factshts/geneenviro.htm
   - Address to Secretary's Advisory Council on Genetics, Health and Society http://www.epidkardia.sph.umich.edu/news.php?displayMessage=1&MessageID=44
     - Genes, Environment, and Cardiovascular Disease http://www.epidkardia.sph.umich.edu/files/papers/2003/Sing_ATVB_2003.pdf
     -

4. **Personalized Medicine, Pharmacogenomics, DTC (IA)**
   - Race-Based Medicine Arrives-Forbes magazine 5-10-05 http://www.forbes.com/2005/05/10/cx_mh_0509racemedicine.html
   - Genetic Find Stirs Debate on Race-Based Medicine- New York Times 11-11-05 http://www.nytimes.com/2005/11/11/health/11heart.html?_r=1&adxnnl=1&adxnnlx=1190909992-RIu8eUR4cQdgmhLmti3xyg&oref=slogin

- At-Home Genetic Tests: A Healthy Dose of Skepticism May Be the Best Prescription-Federal Trade Commission
  http://www.ftc.gov/bcp/edu/pubs/consumer/health/hea02.shtm
- Over the Counter Genetic Tests and Nutrition: What We Know Today
  http://www.health.state.mn.us/divs/hpcd/genomics/resources/fs/nutrigenomics.html
- **Home DNA tests create medical, ethical quandaries**
  http://geneticsandsociety.org/article.php?id=3622

5. **ELSI and Large Scale Population Studies (IA)**
   - The Role of ELSI Research & Policy Activities in the NHGRI Plan
     http://www.genome.gov/10005516
   - ELSI Planning and Evaluation History
     http://www.genome.gov/10001754
   - Human Genome Project
     http://www.genome.gov/10001772
   - The Human Genome Project Completion: Frequently Asked Questions
     www.genome.gov/11006943
   - Genome-Wide Association Studies
     www.genome.gov/20019523
   - Gene Advances Bring Ethical Quandaries-Boston Globe 5-11-07
     http://www.boston.com/news/nation/articles/2007/05/11/gene_advances_bring_ethical_quandaries/

6. ***Genomics and Public Health (IA)**
   - Chronic Disease Fact Sheets (from NHGRI)

7. ***Genomics and Environmental Justice (MN)**
   - Can Gene Altered Rice Rescue the Farm Belt?-New York Times 8-16-05
     http://www.nytimes.com/2005/08/16/business/16biorice.html?_r=1&oref=slogin
     - **Open Source Practices for Biotechnology**
       http://www.nytimes.com/2005/02/10/technology/10gene.html?_r=1&oref=slogin

8. **Education; Career Opportunities (MN and MI)**
   - The Future of Genetics: Career Opportunities for Young Scientists
   - http://sciencecareers.sciencemag.org/career_development/previous_issues/articles/2006_09_29/the_future_of_genetics_career_opportunities_for_young_scientists/(parent)/68
   - Special Feature: Human Genetics and Health Careers
   - http://sciencecareers.sciencemag.org/career_development/previous_issues/articles/2006_09_29/special_feature_human_genetics_and_health_careers/(parent)/68
   - Follow that Gene: The Story of Three Young Scientists

- http://sciencecareers.sciencemag.org/career_development/previous_issues/articles/2006_09_29/follow_that_gene_the_story_of_three_young_scientists/(parent)/68
- Careers and Grad Programs for B.S. and M.S. Scientists: Testing the Waters
- http://sciencecareers.sciencemag.org/career_development/previous_issues/articles/2007_09_28/science_opms_r0700040
- Your Genetic Future
- http://sciencecareers.sciencemag.org/career_development/previous_issues/articles/2006_09_29/your_genetic_future/(parent)/68
- Career Opportunities and Recruitment: Developing Themes
- http://www.nature.com/naturejobs/2004/040715/full/nj6997-382a.html
- Careers in Genetics and the Biosciences
- http://www.ornl.gov/sci/techresources/Human_Genome/education/careers-6new.pdf
- NIH Funds Seven Science Education Programs http://www.nih.gov/news/pr/jul2006/ncrr-24.htm

9. *Spirituality/Religion/Culture (MN and MI)

- Kluger, J. (2004). Is God in Our Genes? *Time, 164(17), 62-68, 70-72.*
- Is 'Do Unto Others' Written Into Our Genes?- New York Times 9-18-07 http://www.nytimes.com/2007/09/18/science/18mora.html
  - **Stem Cell Oracles: Is there a Jewish Position on Stem Cell Research? http://geneticsandsociety.org/article.php?id=3031**

10. Family History and the Environment (MN)

- Family History is Important for Your Health http://www.cdc.gov/genomics/public/famhix/fs.htm
- Family History is Important for Your Health- Spanish http://www.cdc.gov/genomics/public/famhix/fs.htm
- Family Health History Toolkit Questions and Answers http://health.utah.gov/genomics/familyhistory/toolkit.html
- 10 Questions to Ask Your Family http://health.utah.gov/genomics/familyhistory/toolkit.html
- Family History Fact Sheets (from NHGRI)

11. Diversity, Disparities, Forensics (MI)

- Exploring Genetics Issues Relevant to Minority Communities www.ornl.gov/hgmis/elsi/minorities.html
- Qureshi, N. and Kai, J. (2005). Genomic Medicine for Underserved Minority Populations in Family Medicine. *American Family Physician, 72(3), 386-387.*
- Genetic Find Stirs Debate on Race-Based Medicine- New York Times 11-11-05 http://www.nytimes.com/2005/11/11/health/11heart.html?_r=1&adxnnl=1&adxnnlx=1190909992-RIu8eUR4cQdgmhLmti3xyg&oref=slogin

- Race-Based Medicine Arrives-Forbes magazine 5-10-05
  http://www.forbes.com/2005/05/10/cx_mh_0509racemedicine.html
- Genes and Behavior: A Complex Relationship
  http://www.ornl.gov/sci/techresources/Human_Genome/publicat/judicature/article4.html

12. Family History and Chronic Disease (MI)

- Family History is Important for Your Health
  http://www.cdc.gov/genomics/public/famhix/fs.htm
- Family History is Important for Your Health- Spanish
  http://www.cdc.gov/genomics/public/famhix/fs.htm
- Family Health History Toolkit Questions and Answers
  http://health.utah.gov/genomics/familyhistory/toolkit.html
- 10 Questions to Ask Your Family
  http://health.utah.gov/genomics/familyhistory/toolkit.html
- Chronic Disease Fact Sheets (from NHGRI)
- Family History Fact Sheets (from NHGRI)

13. Next Steps Panel

- Missouri Expands Newborn Screening-KSDK 8-20-04
  http://www.ksdk.com/news/health/healthbeat_article.aspx?storyid=65612
- Family History
  http://www.dhss.mo.gov/FamilyHistory/
- NIH Funds Seven Science Education Programs
  http://www.nih.gov/news/pr/jul2006/ncrr-24.htm
- Family Health History Toolkit Questions and Answers
  http://health.utah.gov/genomics/familyhistory/toolkit.html
- 10 Questions to Ask Your Family
  http://health.utah.gov/genomics/familyhistory/toolkit.html
- Family History Fact Sheets (from NHGRI)
- Family History is Important for Your Health
  http://www.cdc.gov/genomics/public/famhix/fs.htm

II. Plenary session packets

1. *Overview- Kardia

- Genomics and Population Health: United States 2003-Genomics Lingo
  http://www.cdc.gov/genomics/activities/ogdp/2003/2003_lingo.htm
- CDC FAQs on Genomics
  http://www.cdc.gov/genomics/faq.htm
- A Brief Guide to Genomics (NHGRI)
  http://www.genome.gov/18016863
- NHGRI Glossary (from Tool Kit)

2. * Public Health Genomics: Closing the Gap Between Genome Discoveries and Population Health -Khoury

- Exploring Genetics Issues Relevant to Minority Communities

www.ornl.gov/hgmis/elsi/minorities.html
- Qureshi, N. and Kai, J. (2005). Genomic Medicine for Underserved Minority Populations in Family Medicine. *American Family Physician, 72(3), 386-387.*
- Race-Based Medicine Arrives-Forbes magazine 5-10-05 http://www.forbes.com/2005/05/10/cx_mh_0509racemedicine.html
- Genetic Find Stirs Debate on Race-Based Medicine- New York Times 11-11-05 http://www.nytimes.com/2005/11/11/health/11heart.html?_r=1&adxnnl=1&adxnnlx=1190909992-RIu8eUR4cQdgmhLmti3xyg&oref=slogin

3. **Keynote-Collins**
   - Human Genome Project http://www.genome.gov/10001772
   - The Human Genome Project Completion: Frequently Asked Questions www.genome.gov/11006943
   - Genome-Wide Association Studies www.genome.gov/20019523
   - Implications of the Genome Project for Medical Science http://www.genome.gov/25019925

4. ***Research; Community Engagement-Guttmacher**
   - Benefits of Community Engagement http://www.genomecenter.howard.edu/units/genethics/benefits.htm
   - Public Education Critical to Population-Wide Genomics Research http://jnci.oxfordjournals.org/cgi/reprint/jnci%3b96/16/1196.pdf

5. **Genetics and Behavior-McBride**

6. **Genomics, Spirituality, and Religion-Dunston**
   - Kluger, J. (2004). Is God in Our Genes? *Time, 164(17), 62-68, 70-72.*
   - Is 'Do Unto Others' Written Into Our Genes?- New York Times 9-18-07 http://www.nytimes.com/2007/09/18/science/18mora.html
   - **Stem Cell Oracles: Is there a Jewish Position on Stem Cell Research? http://geneticsandsociety.org/article.php?id=3031**

7. **Diversity, Disparities-Bonham**
   - Exploring Genetics Issues Relevant to Minority Communities www.ornl.gov/hgmis/elsi/minorities.html
   - Qureshi, N. and Kai, J. (2005). Genomic Medicine for Underserved Minority Populations in Family Medicine. *American Family Physician, 72(3), 386-387.*
   - Race-Based Medicine Arrives-Forbes magazine 5-10-05 http://www.forbes.com/2005/05/10/cx_mh_0509racemedicine.html
   - Genetic Find Stirs Debate on Race-Based Medicine- New York Times 11-11-05 http://www.nytimes.com/2005/11/11/health/11heart.html?_r=1&adxnnl=1&adxnnlx=1190909992-RIu8eUR4cQdgmhLmti3xyg&oref=slogin

APPENDIX 12:
Video Conferencing and Video Recording Table

Genomics, Community, and Equity: A Continuing Dialogue
Video Conferencing and Video Recordings - 9/28/2007

CST	8:30-8:45	8:45-9:30	9:30-9:45	9:45-10:30	10:30-10:45	10:45-11:45	11:45-12:30	12:30-2:00	2:00-2:15	2:15-3:15	3:15-3:30	3:30-4:30
EST	9:30-9:45	9:45-10:30	10:30-10:45	10:45-11:30	11:30-11:45	11:45-12:45	12:45-1:30	1:30-3:00	3:00-3:15	3:15-4:15	4:15-4:30	4:30-5:30
Illinois				CCCCC		DDDDD		GGGGG		HHHHH		
Iowa				CCCCC		EEEEE		GGGGG				
Minnesota		AAAAA						GGGGG		IIIII	KKKKK	
Missouri				CCCCC		FFFFF		GGGGG		JJJJJ		
Michigan		AAAAA	BBBBB	BBBBB		FFFFF		GGGGG		HHHHH	KKKKK	
U of M		AAAAA	BBBBB	BBBBB		DDDDD		GGGGG		IIIII	KKKKK	

Legend:

AAAAA----- The Human Genome -Kardia (From Michigan)
BBBBB----- Addressing Racial and Ethnic Health Disparities in the Genomic Era: Why We All Must Be Engaged -Bonham (From Michigan)
CCCCC----- The Human Genome -Kardia (Pre-Recorded in Michigan)
DDDDD----- Public Health Genomics: Closing the Gap Between Genome Discoveries and Population Health -Khoury (From Illinois)
EEEEE----- Research; Ethical, Legal, and Social Issues; Community Engagement -Guttmacher (From Iowa)
FFFFF----- Discussion & Dialogue on Genomics, Spirituality and Religion-Dunston (From Missouri)
GGGGG----- Keynote talk on Genomics, Medicine, and Society -Collins (From Minnesota)
HHHHH----- Race-Based Medicine-Ossorio (From Illinois)
IIIII----- Genetics and Behavior-McBride (From Minnesota)
JJJJJ----- Panel on Next Steps for Individuals, Community Organizations, Health Departments, and Other Agencies-Lea, Jenkins, Rogers, Chambers, and Dunston (From Missouri)
KKKKK----- Guitar/Singing-Collins (From Minnesota)

APPENDIX 13:
Forum Participant Questionnaire Evaluation Results

Genomics, Community, and Equity: A Continuing Dialogue
A Community Genetics Forum

[Participants: Please fill-out at the end of the day.]

Forum Location (Please mark): _____

Forum Participant Questionnaire

Please take 5 minutes of your time to fill-out this evaluation which will help us to assure that community voices on genomics are shared and will help plan future community genetics forums. Evaluations are anonymous.

- Number of individuals turning in at least 1 form:

Illinois	5
Iowa	32
Michigan	134
Ann Arbor	(24; demographic only)
Flint	(110)
Minnesota	82
Missouri	55
Jefferson City	(7)
Portageville	(50)
Total	308

1. What were your primary motivations for coming to this forum? (Check all that apply):

☐ Relationship of my occupation to the health care system

Illinois	0%
Iowa	18.8% [6]
Michigan	37.6% [50]
Ann Arbor	(54.2%) [13]
Flint	(33.9%) [37]
Minnesota	46.3% [37]
Missouri	44.2% [23]
Jefferson City	(71.4%) [5]
Portageville	(40.4%) [19]

☐ Known or suspected genetic condition in my family

Illinois	20.0% [1]
Iowa	12.5% [4]
Michigan	20.3% [27]
Ann Arbor	(4.2%) [1]
Flint	(23.9%) [26]
Minnesota	17.5% [14]
Missouri	26.9% [14]
Jefferson City	(28.6%) [2]
Portageville	(27.7%) [13]

☐ Desire to learn about subject

Illinois	100% [5]
Iowa	59.4% [19]
Michigan	78.2% [104]
Ann Arbor	(66.7%) [16]
Flint	(80.7%) [88]
Minnesota	75.0% [60]
Missouri	73.1% [38]
Jefferson City	(42.9%) [3]
Portageville	(76.6%) [36]

☐ Sponsorship by host organization

Illinois	40.0% [2]
Iowa	43.8% [14]
Michigan	28.6% [38]
Ann Arbor	(8.3%) [2]
Flint	(33.0%) [36]
Minnesota	6.3% [5]
Missouri	26.9% [14]
Jefferson City	(28.6%) [2]
Portageville	(25.5%) [12]

☐ Other. Please specify:_____

Illinois	0%
Iowa	3.1% [1]
Michigan	7.5% [10]
Ann Arbor	(8.3%) [2]
Flint	(7.3%) [8]
Minnesota	13.8% [11]
Missouri	5.8% [3]
Jefferson City	(14.3%) [1]
Portageville	(4.3%) [2]

☐ Total (can mark multiple categories)	[302]
Relationship of my occupation to the health care system	38.4% [116]
Known or suspected genetic condition in my family	19.9% [60]
Desire to learn about subject	74.8% [226]
Sponsorship by host organization	24.2% [73]
Other motivation	8.3% [25]

2. How old were you on your last birthday?

☐ Under 30

Illinois	0%
Iowa	25.0% [8]
Michigan	17.8% [23]
Ann Arbor	(41.7%) [10]
Flint	(12.4%) [13]
Minnesota	35.1% [27]
Missouri	3.8% [2]

Jefferson City	(0%)
Portageville	(4.2%) [2]

☐ 31-50

Illinois	60.0% [3]
Iowa	9.4% [3]
Michigan	38.8% [50]
Ann Arbor	(41.7%) [10]
Flint	(38.1%) [40]
Minnesota	44.2% [34]
Missouri	20.8% [11]
Jefferson City	(42.9%) [3]
Portageville	(20.8%) [10]

☐ 51-60

Illinois	40% [2]
Iowa	15.6% [5]
Michigan	19.4% [25]
Ann Arbor	(12.5%) [3]
Flint	(21.0%) [22]
Minnesota	14.3% [11]
Missouri	32.1% [17]
Jefferson City	(42.9%) [3]
Portageville	(29.2%) [14]

☐ 61+

Illinois	0%
Iowa	50.0% [16]
Michigan	24.0% [31]
Ann Arbor	(4.2%) [1]
Flint	(28.6%) [30]
Minnesota	6.5% [5]
Missouri	43.4% [23]
Jefferson City	(14.3%) [1]
Portageville	(45.8%) [22]

☐ Total [296]

Under 30	20.3% [60]
31-50	34.1% [101]
51-60	20.3% [60]
61+	25.3% [75]

3. Are you male or female?

☐ Male

Illinois	20.0% [1]
Iowa	40.6% [13]
Michigan	32.1% [43]
Ann Arbor	(41.7%) [10]

Flint	(30.0%) [33]
Minnesota	22.5% [18]
Missouri	7.3% [4]
Jefferson City	(0%)
Portageville	(8.0%) [4]

☐ Female

Illinois	80.0% [4]
Iowa	59.4% [19]
Michigan	67.9% [91]
Ann Arbor	(58.3%) [14]
Flint	(70.0%) [77]
Minnesota	77.5% [62]
Missouri	92.7% [51]
Jefferson City	(100%) [7]
Portageville	(92.0%) [46]

☐ Total	[306]
Male	25.8% [79]
Female	74.2% [227]

4. How do you describe yourself? (Check all that apply):

☐ American Indian or Alaska Native

Illinois	0%
Iowa	0%
Michigan	5.3% [7]
Ann Arbor	(0%)
Flint	(6.4%) [7]
Minnesota	6.4% [5]
Missouri	1.9% [1]
Jefferson City	(0%)
Portageville	(2.0%) [1]

☐ Arab or Middle Eastern

Illinois	0%
Iowa	0%
Michigan	0%
Minnesota	0%
Missouri	0%

☐ Asian

Illinois	0%
Iowa	3.1% [1]
Michigan	3.0% [4]
Ann Arbor	(16.7%) [4]
Flint	(0%)
Minnesota	23.1% [18]
Missouri	0%

☐ Black or African American

Illinois	0%
Iowa	0%
Michigan	78.2% [104]
Ann Arbor	12.5% [3]
Flint	92.7% [101]
Minnesota	20.5% [16]
Missouri	33.3% [18]
Jefferson City	(0%)
Portageville	(36.0%) [18]

☐ Native Hawaiian or Other Pacific Islander

Illinois	0%
Iowa	0%
Michigan	0%
Minnesota	1.3% [1]
Missouri	1.9% [1]
Jefferson City	(16.7%) [1]
Portageville	(0%)

☐ White

Illinois	20.0% [1]
Iowa	90.6% [29]
Michigan	17.3% [23]
Ann Arbor	70.8% [17]
Flint	5.5% [6]
Minnesota	28.2% [22]
Missouri	64.8% [35]
Jefferson City	83.3% [5]
Portageville	62.0% [31]

☐ Hispanic/Latino

Illinois	80.0% [4]
Iowa	0%
Michigan	0.8% [1]
Ann Arbor	(0%)
Flint	(0.9%) [1]
Minnesota	29.5% [23]
Missouri	0%
Jefferson City	(16.7%) [1]
Portageville	(0%)

☐ Other (please specify):_____

Illinois	0%
Iowa	3.1% [1]
Michigan	6.0% [8]
Ann Arbor	(4.2%) [1]
Flint	(1.8%) [2]
Minnesota	11.5% [9]

Missouri	3.7% [2]
Jefferson City	(0%)
Portageville	

☐ Total (can mark multiple categories)	[302]
American Indian or Alaska Native	4.3% [13]
Arab or Middle Eastern	0%
Asian	7.6% [23]
Black or African American	45.7% [138]
Native Hawaiian or Other Pacific Islander	0.7% [2]
White	36.4% [110]
Hispanic/Latino	9.3% [28]
Other	2.6% [8]

5. What is the highest year of school that you have completed? _____

☐ Less than H.S.	
Illinois	20.0% [1]
Iowa	6.3% [2]
Michigan	9.2% [12]
Ann Arbor	(0%)
Flint	(11.3%) [12]
Minnesota	12.8% [10]
Missouri	11.3% [6]
Jefferson City	(0%)
Portageville	(12.5%) [6]

☐ 12 years	
Illinois	0%
Iowa	56.3% [18]
Michigan	35.4% [46]
Ann Arbor	(0%)
Flint	(43.4%) [46]
Minnesota	9.0% [7]
Missouri	30.2% [16]
Jefferson City	(14.3%) [1]
Portageville	(31.3%) [15]

☐ Some college	
Illinois	20.0% [1]
Iowa	15.6% [5]
Michigan	21.5% [28]
Ann Arbor	(0%)
Flint	(26.4%) [28]
Minnesota	20.5% [10]
Missouri	18.9% [6]
Jefferson City	(0%)
Portageville	(20.8%) [10]

☐ College graduate

Illinois	20.0% [1]
Iowa	6.3% [2]
Michigan	15.4% [20]
Ann Arbor	(29.2%) [7]
Flint	(12.3%) [13]
Minnesota	28.2% [22]
Missouri	22.6% [12]
Jefferson City	(57.1%) [4]
Portageville	(20.8%) [10]

☐ Some grad school

Illinois	20.0% [1]
Iowa	6.3% [2]
Michigan	9.2% [12]
Ann Arbor	(70.8%) [17]
Flint	(6.6%) [7]
Minnesota	12.8% [10]
Missouri	11.3% [6]
Jefferson City	(28.6%) [2]
Portageville	(14.6%) [7]

☐ Total	[298]
Less than H.S.	10.4% [31]
12 years	29.2% [87]
Some college	20.1% [60]
College graduate	19.1% [57]
Some grad school	21.1% [63]

6. Which is/are your occupation(s)? Please specify:_____

☐ Commercial

Illinois	0%
Iowa	18.8% [6]
Michigan	12.9% [16]
Ann Arbor	(0%)
Flint	(16.0%) [16]
Minnesota	9.1% [7]
Missouri	14.9% [7]
Jefferson City	(0%)
Portageville	(16.7%) [7]

☐ Health professional

Illinois	40.0% [2]
Iowa	6.3% [2]
Michigan	17.7% [22]
Ann Arbor	(33.3%) [8]
Flint	(14.0%) [14]
Minnesota	24.7% [19]
Missouri	34.0% [16]

Jefferson City	(71.4%) [5]
Portageville	(26.2%) [11]

☐ Other professional

Illinois	20.0% [1]
Iowa	3.1% [1]
Michigan	2.4% [3]
Ann Arbor	(4.2%) [1]
Flint	(2.0%) [2]
Minnesota	7.8% [6]
Missouri	2.1% [1]
Jefferson City	(0%)
Portageville	(2.4%) [1]

☐ Householder

Illinois	40.0% [2]
Iowa	21.9% [7]
Michigan	4.0% [5]
Ann Arbor	(0%)
Flint	(5.0%) [5]
Minnesota	1.3% [1]
Missouri	12.8% [6]
Jefferson City	(0%)
Portageville	(14.3%) [6]

☐ Media

Illinois	0%
Iowa	3.1% [1]
Michigan	0%
Minnesota	0%
Missouri	0%

☐ Social services

Illinois	0%
Iowa	3.1% [1]
Michigan	7.3% [9]
Ann Arbor	(0%)
Flint	(9.0%) [9]
Minnesota	11.7% [9]
Missouri	8.5% [4]
Jefferson City	(0%)
Portageville	(9.5%) [4]

☐ Student

Illinois	0%
Iowa	15.6% [5]
Michigan	15.3% [19]
Ann Arbor	(50.0%) [12]
Flint	(7.0%) [7]
Minnesota	18.2% [14]

Missouri	0%

☐ Educator

Illinois	20.0% [1]
Iowa	6.3% [2]
Michigan	9.2% [12]
Ann Arbor	(12.5%) [3]
Flint	(6.0%) [6]
Minnesota	12.8% [10]
Missouri	11.3% [6]
Jefferson City	(28.6%) [2]
Portageville	(4.8%) [2]

☐ Unemployed or retired

Illinois	0%
Iowa	18.8% [6]
Michigan	27.4% [34]
Ann Arbor	(0%)
Flint	(34.0%) [34]
Minnesota	1.3% [1]
Missouri	14.9% [7]
Jefferson City	(0%)
Portageville	(16.7%) [7]

☐ Other

Illinois	0%
Iowa	3.1% [1]
Michigan	5.6% [7]
Ann Arbor	(0%)
Flint	(7.0%) [7]
Minnesota	0%
Missouri	8.5% [4]
Jefferson City	(0%)
Portageville	(9.5%) [4]

☐ Total	[285]
Commercial	12.6% [36]
Health professional	21.4% [61]
Other professional	4.2% [12]
Householder	7.4% [21]
Media	0.4% [1]
Social services	8.1% [23]
Student	13.3% [38]
Educator	11.6% [33]
Unemployed or Retired	16.8% [48]
Other	4.2% [12]

7. Which of the following categories includes your annual household income level?

☐ Less than $15,000

Illinois	0%
Iowa	9.1% [2]
Michigan	41.1% [53]
Ann Arbor	26.1% [6]
Flint	44.3% [47]
Minnesota	8.2% [6]
Missouri	26.9% [14]
Jefferson City	(0%)
Portageville	(29.8%) [14]

☐ $15,000 - $45,000

Illinois	0%
Iowa	45.5% [10]
Michigan	38.0% [49]
Ann Arbor	21.7% [5]
Flint	41.5% [44]
Minnesota	37.0% [27]
Missouri	40.4% [21]
Jefferson City	(42.9%) [3]
Portageville	(42.6%) [20]

☐ $45,000 and over

Illinois	100% [4]
Iowa	45.5% [10]
Michigan	20.2% [26]
Ann Arbor	47.8% [11]
Flint	14.2% [15]
Minnesota	54.8% [40]
Missouri	32.7% [17]
Jefferson City	(57.1%) [4]
Portageville	(27.7%) [13]

☐ Total

Less than $15,000	26.8%% [75]
$15,000 - $45,000	38.2% [107]
$45,000 and over	34.6% [97]

Whole-Group Sessions:

8. The whole-group presentations added to my overall understanding of genomic issues.

1	2	3	4	5
Strongly Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Strongly Agree

☐ Strongly Agree

Illinois	0%
Iowa	46.2% [12]
Michigan (Flint)	64.5% [69]
Minnesota	52.6% [41]

Missouri	40.7% [22]
Jefferson City	(57.1%) [4]
Portageville	(38.8%) [19]

☐ Somewhat Agree

Illinois	50.0% [2] (25.0% [1] Neither agree nor disagree; 25.0% [1] Strongly disagree)
Iowa	23.1% [6]
Michigan (Flint)	20.6% [22]
Minnesota	41.0% [32]
Missouri	46.3% [25]
Jefferson City	(14.3%) [1]
Portageville	(49.0%) [24]

☐ Total	[269 respondents]
Strongly disagree	4.5% [12]
Somewhat disagree	4.8% [13]
Neither agree nor disagree	4.8% [13]
Somewhat agree	32.3% [87]
Strongly agree	53.5% [144]

9. Speakers explained technical content in an understandable way.

1 Strongly Disagree	2 Somewhat Disagree	3 Neither Agree Nor Disagree	4 Somewhat Agree	5 Strongly Agree

☐ Strongly Agree

Illinois	0%
Iowa	46.2% [12]
Michigan (Flint)	63.6% [68]
Minnesota	50.0% [39]
Missouri	50.0% [27]
Jefferson City	(42.9%) [3]
Portageville	(49.0%) [24]

☐ Somewhat Agree

Illinois	25.0% [1] (25.0% [1] Somewhat disagree; 50.0% [2] Strongly disagree)
Iowa	34.6% [9]
Michigan (Flint)	27.1% [29]
Minnesota	41.0% [32]
Missouri	35.2% [19]
Jefferson City	(57.1%) [4]
Portageville	(34.7%) [17]

☐ Total	[269 respondents]
Strongly disagree	3.3% [9]
Somewhat disagree	6.3% [17]
Neither agree nor disagree	2.6% [7]

Somewhat agree	33.5% [90]
Strongly agree	54.3% [146]

10. Participants felt comfortable asking questions.

1 Strongly Disagree	2 Somewhat Disagree	3 Neither Agree Nor Disagree	4 Somewhat Agree	5 Strongly Agree

☐ Strongly agree

Illinois	0%
Iowa	26.9% [7]
Michigan (Flint)	55.2 % [58]
Minnesota	59.7% [46]
Missouri	47.1% [24]
Jefferson City	(71.4%) [5]
Portageville	(43.5%) [20]

☐ Somewhat agree

Illinois	50.0% [2] (25.0% [1] Neither agree nor disagree; 25.0% [1] Strongly disagree)
Iowa	50.0% [13]
Michigan (Flint)	33.3% [35]
Minnesota	35.1% [27]
Missouri	47.1% [24]
Jefferson City	(57.1%) [4]
Portageville	(34.7%) [17]

☐ Total	[263 respondents]
Strongly disagree	4.2% [11]
Somewhat disagree	1.5% [4]
Neither agree nor disagree	4.6% [12]
Somewhat agree	38.4% [101]
Strongly agree	51.3% [135]

11. As a result of the whole-group sessions, I have a better appreciation of the complexity of genomic issues.

1 Strongly Disagree	2 Somewhat Disagree	3 Neither Agree Nor Disagree	4 Somewhat Agree	5 Strongly Agree

☐ Strongly Agree

Illinois	0%
Iowa	35.7% [10]
Michigan (Flint)	66.0% [70]
Minnesota	61.5% [48]
Missouri	46.3% [25]
Jefferson City	(57.1%) [4]

Portageville (44.9%) [22]

☐ Somewhat Agree

Illinois	50.0% [2] (25.0% [1] Neither agree nor disagree; 25.0% [1] Strongly disagree)
Iowa	32.1% [9]
Michigan (Flint)	21.7% [23]
Minnesota	32.1% [25]
Missouri	42.6% [23]
Jefferson City	(42.9%) [3]
Portageville	(42.9%) [21]

☐ Total [270 respondents]

Strongly disagree	4.1% [11]
Somewhat disagree	3.7% [10]
Neither agree nor disagree	5.2% [14]
Somewhat agree	30.4% [82]
Strongly agree	56.7% [153]

12. Please rate each individual whole-group presentation from 1= Strongly Disagree to 5 = Strongly Agree for the following two statements –

- Overall, this was an engaging presentation (Engaging)
- The topic presented was of value to me (Of Value)

Kardia; Human Genome Engaging: 1 2 3 4 5

☐ Strongly Agree

Illinois	0%
Iowa	22.2% [6]
Michigan (Flint)	68.3% [71]
Minnesota	39.4% [13]
Missouri	36.6% [15]
Jefferson City	(50.0%) [1]
Portageville	(37.5%) [15]

☐ Somewhat Agree

Illinois	50.0% [1] (50.0% [1] Neither agree nor disagree)
Iowa	37.0% [10]
Michigan (Flint)	13.5% [14]
Minnesota	24.2% [8]
Missouri	24.4% [10]
Jefferson City	(0%)
Portageville	(25.0%) [10]

☐ Total [207 respondents]

Strongly disagree	7.7% [16]
Somewhat disagree	4.8% [10]
Neither agree nor disagree	15.9% [33]
Somewhat agree	20.8% [43]

Strongly agree 50.7% [105]

Kardia; Human Genome Of Value: 1 2 3 4 5

☐ Strongly Agree
Illinois 0%
Iowa 20.8% [5]
Michigan (Flint) 72.4% [63]
Minnesota 38.7% [12]
Missouri 41.2% [14]
Jefferson City (0%)
Portageville (42.4%) [14]

☐ Somewhat Agree
Illinois 100% [1]
Iowa 45.8% [11]
Michigan (Flint) 11.5% [10]
Minnesota 29.0% [9]
Missouri 26.5% [9]
Jefferson City (50.0%) [1]
Portageville (27.3%) [9]

☐ Total [177 respondents]
Strongly disagree 9.0% [16]
Somewhat disagree 3.4% [6]
Neither agree nor disagree 11.9% [21]
Somewhat agree 22.6% [40]
Strongly agree 53.1% [94]

Collins; Genomics, Medicine, and Society Engaging: 1 2 3 4 5

☐ Strongly Agree
Illinois 0%
Iowa 59.3% [16]
Michigan (Flint) 63.5% [61]
Minnesota 76.7% [56]
Missouri 56.9% [29]
Jefferson City (57.1%) [4]
Portageville (56.5%) [26]

☐ Somewhat Agree
Illinois 50.0% [1] (50.0% [1] Strongly disagree)
Iowa 25.9% [7]
Michigan (Flint) 15.6% [15]
Minnesota 20.5% [15]
Missouri 29.4% [15]
Jefferson City (42.9%) [3]
Portageville (28.3%) [13]

☐ Total [249 respondents]
Strongly disagree 2.8% [7]
Somewhat disagree 4.4% [11]
Neither agree nor disagree 6.4% [16]
Somewhat agree 21.3% [53]
Strongly agree 65.1% [162]

Collins; Genomics, Medicine, and Society Of Value: 1 2 3 4 5

☐ Strongly Agree
Illinois 0%
Iowa 58.3% [14]
Michigan (Flint) 62.2% [46]
Minnesota 87.1% [61]
Missouri 59.5% [25]
Jefferson City (71.4%) [5]
Portageville (59.5%) [22]

☐ Somewhat Agree
Illinois 0% (100% [1] Neither agree nor disagree)
Iowa 29.2% [7]
Michigan (Flint) 18.9% [14]
Minnesota 12.9% [9]
Missouri 31.0% [13]
Jefferson City (28.6%) [2]
Portageville (29.7%) [11]

☐ Total [211 respondents]
Strongly disagree 3.3% [7]
Somewhat disagree 2.8% [6]
Neither agree nor disagree 4.3% [9]
Somewhat agree 20.4% [43]
Strongly agree 69.2% [146]

[Speaker 3]; [Topic 3] Engaging: 1 2 3 4 5

☐ Strongly Agree
Illinois 0% (Khoury - Public Health Genomics)
Iowa 48.1% [13] (Guttmacher - Research; ELSI: Community)
Michigan (Flint) 68.3% [71] (Bonham - Racial and Ethnic Disparities)
Minnesota 59.6% [31] (McBride - Genetics and Behavior)
Missouri 61.5% [32] (Dunston - Genomics; Spirituality; Religion)
Jefferson City (57.1%) [4]
Portageville (61.7%) [29]

☐ Somewhat Agree
Illinois 100% [2]
Iowa 33.3% [9]
Michigan (Flint) 16.3% [17]

Minnesota	23.1% [12]
Missouri	23.1% [12]
Jefferson City	(42.9%) [3]
Portageville	(21.3%) [10]

☐ Total [237 respondents]

Strongly disagree	3.4% [8]
Somewhat disagree	2.1% [5]
Neither agree nor disagree	10.5% [25]
Somewhat agree	21.9% [52]
Strongly agree	62.0% [147]

[Speaker 3]; [Topic 3] Of Value: 1 2 3 4 5

☐ Strongly Agree

Illinois	0%	(Khoury - Public Health Genomics)
Iowa	54.2% [13]	(Guttmachher - Research; ELSI: Community)
Michigan (Flint)	69.1% [56]	(Bonham - Racial and Ethnic Disparities)
Minnesota	66.0% [33]	(McBride - Genetics and Behavior)
Missouri	47.7% [21]	(Dunston - Genomics; Spirituality; Religion)
Jefferson City	(28.6%) [2]	
Portageville	(51.3%) [20]	

☐ Somewhat Agree

Illinois	100% [1]
Iowa	29.2% [7]
Michigan (Flint)	13.6% [11]
Minnesota	28.0% [14]
Missouri	34.1% [15]
Jefferson City	(71.4%) [5]
Portageville	(28.2%) [11]

☐ Total [200 respondents]

Strongly disagree	4.0% [8]
Somewhat disagree	2.5% [5]
Neither agree nor disagree	8.0% [16]
Somewhat agree	24.0% [48]
Strongly agree	61.5% [123]

"Next Steps" Panel Discussion [Missouri Only]:

13. The combination of discussants was more effective than if each had presented alone.

1	2	3	4	5
Strongly Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Strongly Agree

☐ Strongly Agree

Missouri	41.9% [18]
Jefferson City	(20.0%) [1]

Portageville (44.7%) [17]

☐ Somewhat Agree
Missouri 39.5% [17]
Jefferson City (40.0%) [2]
Portageville (39.5%) [15]

☐ Total [43 respondents]
Strongly disagree 0%
Somewhat disagree 2.3% [1]
Neither agree nor disagree 16.3% [7]
Somewhat agree 39.5% [17]
Strongly agree 41.9% [18]

14. The panel discussion communicated information important to community members.

1	2	3	4	5
Strongly Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Strongly Agree

☐ Strongly Agree
Missouri 60.5% [26]
Jefferson City (40.0%) [2]
Portageville (63.2%) [24]

☐ Somewhat Agree
Missouri 32.6% [14]
Jefferson City (60.0%) [3]
Portageville (28.9%) [11]

☐ Total [43 respondents]
Strongly disagree 0%
Somewhat disagree 0%
Neither agree nor disagree 7.0% [3]
Somewhat agree 32.6% [14]
Strongly agree 60.5% [26]

Overall Event:

15. The rooms and building where the event was held were comfortable.

1	2	3	4	5
Strongly Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Strongly Agree

☐ Strongly Agree
Illinois 100% [3]
Iowa 19.0% [4]
Michigan (Flint) 63.6% [63]
Minnesota 48.6% [35]

Missouri	75.0% [39]
Jefferson City	(66.7%) [4]
Portageville	(74.5%) [35]

☐ Somewhat Agree

Illinois	0%
Iowa	66.7% [14]
Michigan (Flint)	31.3% [31]
Minnesota	43.1% [31]
Missouri	19.2% [10]
Jefferson City	(33.3%) [2]
Portageville	(19.1%) [9]

☐ Total	[247 respondents]
Strongly disagree	1.6% [4]
Somewhat disagree	2.4% [6]
Neither agree nor disagree	2.8% [7]
Somewhat agree	34.8% [86]
Strongly agree	58.3% [144]

16. The event touched on major issues I wanted to see addressed.

1	2	3	4	5
Strongly	Somewhat	Neither Agree	Somewhat	Strongly
Disagree	Disagree	Nor Disagree	Agree	Agree

☐ Strongly Agree

Illinois	0%
Iowa	13.6% [3]
Michigan (Flint)	50.0% [48]
Minnesota	50.0% [39]
Missouri	52.9% [37]
Jefferson City	(33.3%) [2]
Portageville	(46.8%) [22]

☐ Somewhat Agree

Illinois	33.3% [1] (33.3% [1] Somewhat disagree; 33.3% [1] Strongly disagree)
Iowa	54.5% [12]
Michigan (Flint)	38.5% [37]
Minnesota	41.4% [29]
Missouri	42.3% [22]
Jefferson City	(50.0%) [3]
Portageville	(40.4%) [19]

☐ Total	[243 respondents]
Strongly disagree	2.5% [6]
Somewhat disagree	3.7% [9]
Neither agree nor disagree	6.6% [16]
Somewhat agree	41.6% [101]

Strongly agree	45.7% [111]

17. Attending today's forum interested me in learning more about genomics.

1 Strongly Disagree	2 Somewhat Disagree	3 Neither Agree Nor Disagree	4 Somewhat Agree	5 Strongly Agree

☐ Strongly Agree

Illinois	0%
Iowa	36.4% [8]
Michigan (Flint)	64.3% [63]
Minnesota	66.7% [48]
Missouri	61.5% [32]
Jefferson City	(83.3%) [5]
Portageville	(59.6%) [28]

☐ Somewhat Agree

Illinois	50.0% [1] (50.0% [1] Neither agree nor disagree)
Iowa	27.3% [6]
Michigan (Flint)	27.6% [27]
Minnesota	29.2% [21]
Missouri	30.8% [16]
Jefferson City	(0%)
Portageville	(34.0%) [16]

☐ Total [246 respondents]

Strongly disagree	1.6% [4]
Somewhat disagree	2.8% [7]
Neither agree nor disagree	5.3% [13]
Somewhat agree	28.9% [71]
Strongly agree	61.4% [151]

18. I intend to use the project web site demonstrated at the conference.

1 Strongly Disagree	2 Somewhat Disagree	3 Neither Agree Nor Disagree	4 Somewhat Agree	5 Strongly Agree

☐ Strongly Agree

Illinois	33.3% [1]
Iowa	25.0% [5]
Michigan (Flint)	42.3% [41]
Minnesota	46.5% [33]
Missouri	51.0% [26]
Jefferson City	(33.3%) [2]
Portageville	(52.2%) [24]

☐ Somewhat Agree

Illinois	33.3% [1] (33.3% [1] Strongly disagree)
Iowa	30.0% [6]
Michigan (Flint)	35.1% [34]
Minnesota	25.4% [18]
Missouri	33.3% [17]
Jefferson City	(33.3%) [2]
Portageville	(32.6%) [15]

☐ Total	[242 respondents]
Strongly disagree	3.3% [8]
Somewhat disagree	5.0% [12]
Neither agree nor disagree	16.5% [40]
Somewhat agree	31.4% [76]
Strongly agree	43.8% [106]

19. As a result of today's forum,

a. I am more likely to consider for myself or suggest to others a career in a genetics-related field.

1	2	3	4	5
Strongly	Somewhat	Neither Agree	Somewhat	Strongly
Disagree	Disagree	Nor Disagree	Agree	Agree

☐ Strongly Agree

Illinois	0%
Iowa	25.0% [5]
Michigan (Flint)	33.7% [33]
Minnesota	31.4% [22]
Missouri	32.7% [17]
Jefferson City	(0%)
Portageville	(36.2%) [17]

☐ Somewhat Agree

Illinois	66.7% [2] (33.3% [1] Neither agree nor disagree)
Iowa	50.0% [10]
Michigan (Flint)	48.0% [47]
Minnesota	40.0% [28]
Missouri	26.9% [14]
Jefferson City	(66.7%) [4]
Portageville	(23.4%) [11]

☐ Total	[243 respondents]
Strongly disagree	2.1% [5]
Somewhat disagree	2.9% [7]
Neither agree nor disagree	21.8% [53]
Somewhat agree	41.6% [101]
Strongly agree	31.7% [77]

b. I would feel more comfortable engaging in genetic testing to tailor medical treatment to my personal health needs.

1 Strongly Disagree	2 Somewhat Disagree	3 Neither Agree Nor Disagree	4 Somewhat Agree	5 Strongly Agree

☐ Strongly Agree

Illinois	0%
Iowa	10.0% [2]
Michigan (Flint)	43.4% [43]
Minnesota	31.9% [23]
Missouri	34.0% [17]
Jefferson City	(33.3%) [2]
Portageville	(35.6%) [16]

☐ Somewhat Agree

Illinois	66.7% [2] (33.3% [1] Neither agree nor disagree)
Iowa	45.0% [9]
Michigan (Flint)	36.4% [36]
Minnesota	47.2% [34]
Missouri	38.0% [19]
Jefferson City	(57.0%) [3]
Portageville	(35.6%) [16]

☐ Total [244 respondents]

Strongly disagree	3.7% [9]
Somewhat disagree	7.0% [17]
Neither agree nor disagree	13.5% [33]
Somewhat agree	41.0% [100]
Strongly agree	34.8% [85]

c. I would feel more comfortable becoming a participant in a genomics-related research study.

1 Strongly Disagree	2 Somewhat Disagree	3 Neither Agree Nor Disagree	4 Somewhat Agree	5 Strongly Agree

☐ Strongly Agree

Illinois	0%
Iowa	25.0% [5]
Michigan (Flint)	30.3% [30]
Minnesota	29.7% [22]
Missouri	25.5% [13]
Jefferson City	(33.3%) [2]
Portageville	(26.1%) [12]

☐ Somewhat Agree

Illinois	33.3% [1] (33.3% [1] Neither agree nor disagree; 33.3% [1]

Somewhat disagree)

Iowa	20.0% [4]
Michigan (Flint)	39.4% [39]
Minnesota	37.8% [28]
Missouri	41.2% [21]
Jefferson City	(50.0%) [3]
Portageville	(39.1%) [18]

☐ Total	[247 respondents]
Strongly disagree	6.1% [15]
Somewhat disagree	8.1% [20]
Neither agree nor disagree	19.8% [49]
Somewhat agree	37.7% [93]
Strongly agree	28.3% [70]

d. I would feel more comfortable encouraging my family members to collect a family health history recording our past and current health conditions.

1	2	3	4	5
Strongly Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Strongly Agree

☐ Strongly Agree

Illinois	33.3% [1]
Iowa	45.5% [10]
Michigan (Flint)	71.2% [74]
Minnesota	67.1% [49]
Missouri	58.8% [30]
Jefferson City	(66.7%) [4]
Portageville	(58.7%) [27]

☐ Somewhat Agree

Illinois	66.7% [2]
Iowa	31.8% [7]
Michigan (Flint)	17.3% [18]
Minnesota	26.0% [19]
Missouri	27.5% [14]
Jefferson City	(33.3%) [2]
Portageville	(26.1%) [12]

☐ Total	[253 respondents]
Strongly disagree	1.6% [4]
Somewhat disagree	2.8% [7]
Neither agree nor disagree	7.1% [18]
Somewhat agree	23.7% [60]
Strongly agree	64.8% [164]

e. I would be more likely to encourage those I know - family and friends - to participate in a national study looking at the roles of genetics and the environment in disease.

1	2	3	4	5
Strongly Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Strongly Agree

☐ Strongly Agree

Illinois	0%
Iowa	31.8% [7]
Michigan (Flint)	51.5% [53]
Minnesota	43.8% [32]
Missouri	35.3% [18]
Jefferson City	(16.7%) [1]
Portageville	(37.0%) [17]

☐ Somewhat Agree

Illinois	33.3% [1] (33.3% [1] Neither agree nor disagree; 33.3% [1] Somewhat disagree)
Iowa	59.1% [13]
Michigan (Flint)	31.1% [32]
Minnesota	28.8% [21]
Missouri	41.2% [21]
Jefferson City	(83.3%) [5]
Portageville	(37.0%) [17]

☐ Total	[252 respondents]
Strongly disagree	2.8% [7]
Somewhat disagree	5.2% [13]
Neither agree nor disagree	13.5% [34]
Somewhat agree	34.9% [88]
Strongly agree	43.7% [110]

20. How much did you know about genomics before attending today's forum?

1	2	3	4	5
I Knew Nothing	Very Little	Some Knowledge	A Moderate Amount	Very Knowledgeable

☐ Very Knowledgeable

Illinois	0%
Iowa	21.7% [5]
Michigan (Flint)	12.6% [13]
Minnesota	9.3% [7]
Missouri	8.0% [4]
Jefferson City	(16.7%) [1]
Portageville	(6.7%) [3]

☐ A Moderate Amount

Illinois	0%
Iowa	34.8% [8]

Michigan (Flint)	17.5% [18]
Minnesota	33.3% [25]
Missouri	24.0% [12]
Jefferson City	(33.3%) [2]
Portageville	(22.2%) [10]

☐ Some Knowledge

Illinois	33.3% [1]
Iowa	13.0% [3]
Michigan (Flint)	28.2% [29]
Minnesota	25.3% [19]
Missouri	20.0% [10]
Jefferson City	(50.0%) [3]
Portageville	(17.8%) [8]

☐ Very Little

Illinois	33.3% [1]
Iowa	21.7% [5]
Michigan (Flint)	29.1% [30]
Minnesota	25.3% [19]
Missouri	36.0% [18]
Jefferson City	(0%)
Portageville	(40.0%) [18]

☐ I Knew Nothing

Illinois	33.3% [1]
Iowa	8.7% [2]
Michigan (Flint)	12.6% [13]
Minnesota	6.7% [5]
Missouri	12.0% [6]
Jefferson City	(0%)
Portageville	(13.3%) [6]

☐ Total	[254 respondents]
Very Knowledgeable	11.4% [29]
A Moderate Amount	24.8% [63]
Some Knowledge	24.4% [62]
Very Little	28.7% [73]
I Knew Nothing	10.6% [27]

21. Did the amount you know about genomics change as a result of attending today's forum?

1	2	3	4	5
Not At All	A Little	Somewhat	Moderately	A Great Deal

☐ A Great Deal

Illinois	0%
Iowa	16.7% [4]

Michigan (Flint)	63.5% [66]
Minnesota	48.0% [36]
Missouri	39.2% [20]
Jefferson City	(50.0%) [3]
Portageville	(39.1%) [18]

☐ Moderately

Illinois	0% (66.7% [2] Somewhat; 33.3% [1] A Little)
Iowa	25.0% [6] (33.3% [8] Somewhat)
Michigan (Flint)	19.2% [20]
Minnesota	30.7% [23]
Missouri	25.5% [13]
Jefferson City	(16.7%) [1]
Portageville	(26.1%) [12]

☐ Total	[257 respondents]
Not At All	1.9% [5]
A Little	9.3% [24]
Somewhat	15.6% [40]
Moderately	24.1% [62]
A Great Deal	49.0% [126]

22. What can be done to increase your community's understanding of genomics? (please use space below)

Continued communications and information distribution	17.9% [55/308 participants]
Education and awareness-raising	27.9% [86/308]
(Includes "continue community forums" and "expand discussion to other locations")	
Greater use of media and event marketing	5.2% [16/308]
Greater use of the Internet	1.0% [3/308]
Insure language and content culturally appropriate	4.9% [15/308]
Modify content or format of presentations	1.6% [5/308]
Training and utilization of health professionals	0.6% [2/308]
Other suggestions	6.8% [21/308]

23. General Comments (please use space below)

Comments on services provided	1.9% [6/308 participants]
Favorable comments on speakers and material discussed	6.5% [20/308]
Suggestions where speakers and material could improve	1.3% [4/308]
Comments on technical arrangements	3.6% [11/308]
(Illinois 0; Iowa 3; Michigan 2; Minnesota 5; Missouri 1)	
Comments on translation and language interpretation	1.6% [5/308]
Comments on educational value of the sessions	15.3% [47/308]
Comments on personal and societal implications	4.2% [13/308]
Comments on presentation format and timing	2.9% [9/308]
Comments on representativeness of those attending	1.0% [3/308]
Suggestions for further activity	3.2% [10/308]
Other comments	8.4% [26/308]

APPENDIX 14:
Break-Out Session Questionnaire Evaluation Results

Genomics, Community, and Equity: A Continuing Dialogue
A Community Genetics Forum

[Please fill-out at end of the break-out session.]

Break-out Leader's Name: _____ Time: _____

Name of Break-out Session: _____

Break-out Session Questionnaire

Please circle the answer that comes closest to expressing the way you feel about the session.

1. Overall, this was an engaging break-out session.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

Illinois		(No filled-out break-out forms)
Iowa	63.6% [7/11 filled-out forms]	(Burns Guttmacher – Genes Environment)
Iowa	46.7% [7/15]	(Frosst – Personalized Medicine)
Iowa	20.0% [2/10]	(Piper – Public Health)
Iowa	30.8% [4/13]	(Thomson – ELSI Issues)
Michigan (Flint)	69.4% [25/36]	(Bonham – Diversity Disparities Forensics)
Michigan (Flint)	46.9% [23/49]	(Dunston (Video) – Genomics Spirituality Religion)
Michigan (Flint)	85.0% [17/20]	(Duquette – Family History)
Michigan (Flint)	59.1% [13/22]	(Easter – Education Genomic Era)
Michigan (Flint)	69.2% [18/26]	(Lewis et al. – Genomics Spirituality Religion)
Michigan (Flint)	38.3% [18/47]	(Ossorio (Video) – Race-Based Medicine)
Minnesota	48.0% [12/25]	(Allwood – Genomics Environmental Justice)
Minnesota	60.9% [39/64]	(Collins Larsen Yang – Spirituality Cultural)
Minnesota	18.5% [5/27]	(English – Education Genetics Career)
Minnesota	71.2% [42/59]	(Hickman Oehlke – Family History)
Missouri		(No break-out sessions)

☐ Somewhat Agree

Illinois		(No filled-out break-out forms)
Iowa	9.1% [1/11]	(Burns Guttmacher – Genes Environment)
Iowa	46.7% [7/15]	(Frosst – Personalized Medicine)
Iowa	50.0% [5/10]	(Piper – Public Health)
Iowa	61.5% [8/13]	(Thomson – ELSI Issues)
Michigan (Flint)	19.4% [7/36]	(Bonham – Diversity Disparities Forensics)
Michigan (Flint)	40.8% [20/49]	(Dunston (Video) – Genomics Spirituality Religion)
Michigan (Flint)	10.0% [2/20]	(Duquette – Family History)
Michigan (Flint)	27.3% [6/22]	(Easter – Education Genomic Era)
Michigan (Flint)	30.8% [8/26]	(Lewis et al. – Genomics Spirituality Religion)
Michigan (Flint)	36.2% [17/47]	(Ossorio (Video) – Race-Based Medicine)
Minnesota	40.0% [10/25]	(Allwood – Genomics Environmental Justice)

Minnesota	28.1% [18/64]	(Collins Larsen Yang – Spirituality Cultural)
Minnesota	66.7% [18/27]	(English – Education Genetics Career)
Minnesota	16.9% [10/59]	(Hickman Oehlke – Family History)
Missouri		(No break-out sessions)

☐ Total [424 respondents]

Strongly disagree	3.4% [18]
Somewhat disagree	1.3% [7]
Neither agree nor disagree	5.6% [30]
Somewhat agree	25.8% [137]
Strongly agree	43.7% [232]

2. The topic discussed was of value to me.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

Illinois		(No filled-out break-out forms)
Iowa	63.6% [7/11]	(Burns Guttmacher – Genes Environment)
Iowa	46.7% [7/15]	(Frosst – Personalized Medicine)
Iowa	20.0% [2/10]	(Piper – Public Health)
Iowa	50.0% [6/12]	(Thomson – ELSI Issues)
Michigan (Flint)	63.9% [23/36]	(Bonham – Diversity Disparities Forensics)
Michigan (Flint)	46.0% [23/50]	(Dunston (Video) – Genomics Spirituality Religion)
Michigan (Flint)	90.0% [18/20]	(Duquette – Family History)
Michigan (Flint)	45.5% [10/22]	(Easter – Education Genomic Era)
Michigan (Flint)	80.8% [21/26]	(Lewis et al. – Genomics Spirituality Religion)
Michigan (Flint)	41.3% [19/46]	(Ossorio (Video) – Race-Based Medicine)
Minnesota	75.0% [18/24]	(Allwood – Genomics Environmental Justice)
Minnesota	70.3% [45/64]	(Collins Larsen Yang – Spirituality Cultural)
Minnesota	25.9% [7/27]	(English – Education Genetics Career)
Minnesota	64.4% [38/59]	(Hickman Oehlke – Family History)
Missouri		(No break-out sessions)

☐ Somewhat Agree

Illinois		(No filled-out break-out forms)
Iowa	9.1% [1/11]	(Burns Guttmacher – Genes Environment)
	(27.3% [3] Neither agree nor disagree)	
Iowa	33.3% [5/15]	(Frosst – Personalized Medicine)
Iowa	40.0% [4/10]	(Piper – Public Health)
	(40.0% [4] Neither agree nor disagree)	
Iowa	41.7% [5/12]	(Thomson – ELSI Issues)
Michigan (Flint)	22.2% [8/36]	(Bonham – Diversity Disparities Forensics)
Michigan (Flint)	36.0% [18/50]	(Dunston (Video) – Genomics Spirituality Religion)
Michigan (Flint)	5.0% [1/20]	(Duquette – Family History)
Michigan (Flint)	36.4% [8/22]	(Easter – Education Genomic Era)
Michigan (Flint)	19.2% [5/26]	(Lewis et al. – Genomics Spirituality Religion)

Michigan (Flint)	43.5% [20/46]	(Ossorio (Video) – Race-Based Medicine)
Minnesota	16.7% [4/24]	(Allwood – Genomics Environmental Justice)
Minnesota	20.3% [13/64]	(Collins Larsen Yang – Spirituality Cultural)
Minnesota	55.6% [15/27]	(English – Education Genetics Career)
Minnesota	20.3% [12/59]	(Hickman Oehlke – Family History)
Missouri		(No break-out sessions)

☐ Total [422 respondents]

Strongly disagree	3.4% [18]
Somewhat disagree	1.7% [9]
Neither agree nor disagree	6.0% [32]
Somewhat agree	22.4% [119]
Strongly agree	46.0% [244]

3. The majority of participants felt comfortable making comments and asking questions.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

Illinois		(No filled-out break-out forms)
Iowa	81.8% [9/11]	(Burns Guttmacher – Genes Environment)
Iowa	40.0% [6/15]	(Frosst – Personalized Medicine)
Iowa	40.0% [4/10]	(Piper – Public Health)
Iowa	36.4% [4/11]	(Thomson – ELSI Issues)
Michigan (Flint)	71.4% [25/35]	(Bonham – Diversity Disparities Forensics)
Michigan (Flint)	44.7% [21/47]	(Dunston (Video) – Genomics Spirituality Religion)
Michigan (Flint)	89.5% [17/19]	(Duquette – Family History)
Michigan (Flint)	45.5% [10/22]	(Easter – Education Genomic Era)
Michigan (Flint)	76.9% [20/26]	(Lewis et al. – Genomics Spirituality Religion)
Michigan (Flint)	39.5% [19/43]	(Ossorio (Video) – Race-Based Medicine)
Minnesota	47.8% [11/23]	(Allwood – Genomics Environmental Justice)
Minnesota	55.6% [35/63]	(Collins Larsen Yang – Spirituality Cultural)
Minnesota	37.0% [10/27]	(English – Education Genetics Career)
Minnesota	67.8% [40/59]	(Hickman Oehlke – Family History)
Missouri		(No break-out sessions)

☐ Somewhat Agree

Illinois		(No filled-out break-out forms)
Iowa	0%	(Burns Guttmacher – Genes Environment)
Iowa	40.0% [6/15]	(Frosst – Personalized Medicine)
Iowa	40.0% [4/10]	(Piper – Public Health)
Iowa	18.2% [2/11]	(Thomson – ELSI Issues)
Michigan (Flint)	14.3% [5/35]	(Bonham – Diversity Disparities Forensics)
Michigan (Flint)	38.3% [18/47]	(Dunston (Video) – Genomics Spirituality Religion)
Michigan (Flint)	0%	(Duquette – Family History)
Michigan (Flint)	40.9% [9/22]	(Easter – Education Genomic Era)
Michigan (Flint)	23.1% [6/26]	(Lewis et al. – Genomics Spirituality Religion)

Michigan (Flint)	39.5% [17/43]	(Ossorio (Video) – Race-Based Medicine)
Minnesota	39.1% [9/23]	(Allwood – Genomics Environmental Justice)
Minnesota	27.0% [17/63]	(Collins Larsen Yang – Spirituality Cultural)
Minnesota	33.3% [9/27]	(English – Education Genetics Career)
Minnesota	60.3% [12/59]	(Hickman Oehlke – Family History)
Missouri		(No break-out sessions)

☐ Total	[411 respondents]
Strongly disagree	2.8% [15]
Somewhat disagree	2.6% [14]
Neither agree nor disagree	7.3% [39]
Somewhat agree	21.5% [114]
Strongly agree	43.1% [229]

4. What was one highlight of the session for you?

[In Process]

5. What could we have done better or what else would you have wanted for this session?

[In Process]

APPENDIX 15:
Steering/NCC Committee Member Questionnaire Evaluation Results

Genomics, Community, and Equity: A Continuing Dialogue
A Community Genetics Forum

Date: _____

Your Affiliation: _____ NCC
_____ Public Health Department
_____ University of Michigan Project Team

Steering / NCC Committee Member Questionnaire

Here are some statements about Steering and NCC Committee process. Questions are to be answered by all NCC, public health, and University of Michigan Project Team (investigators and staff) participants in the bimonthly meetings. Please circle the answer that comes closest to expressing the way you feel. Forms will remain anonymous.[1]

1. Project leadership has promoted shared decision-making between University of Michigan leadership and Steering / NCC Committee members.

1	2	3	4	5	
	Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

NCC	83.3% [5]
Public Health Department	50.0% [1]
University of Michigan Project Team	100% [4]

☐ Somewhat Agree

NCC	0%
Public Health Department	50.0% [1]
University of Michigan Project Team	0%

☐ Neither Agree Nor Disagree

NCC	16.7% [1]
Public Health Department	0%
University of Michigan Project Team	0%

☐ Total [12 respondents]

Strongly disagree	0%
Somewhat disagree	0%
Neither agree nor disagree	8.3% [1]
Somewhat agree	8.3% [1]
Strongly agree	83.3% [10]

2. Members of the University of Michigan Project Team listen to the points of view of the

NCC and public health department members, even if they disagree.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

NCC	100% [6]
Public Health Department	0%
University of Michigan Project Team	100% [4]

☐ Somewhat Agree

NCC	0%
Public Health Department	50.0% [1]
University of Michigan Project Team	0%

☐ Neither Agree Nor Disagree

NCC	0%
Public Health Department	50.0% [1]
University of Michigan Project Team	0%

☐ Total [12 respondents]

Strongly disagree	0%
Somewhat disagree	0%
Neither agree nor disagree	8.3% [1]
Somewhat agree	8.3% [1]
Strongly agree	83.3% [10]

3. NCC members of the Steering / NCC Committee listen to each others' points of view, even if they disagree.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

NCC	66.7% [4]
Public Health Department	50.0% [1]
University of Michigan Project Team	100% [4]

☐ Somewhat Agree

NCC	16.7% [1]
Public Health Department	50.0% [1]
University of Michigan Project Team	0%

☐ Neither Agree Nor Disagree

NCC	16.7% [1]
Public Health Department	0%
University of Michigan Project Team	0%

☐ Total [12 respondents]
Strongly disagree 0%
Somewhat disagree 0%
Neither agree nor disagree 8.3% [1]
Somewhat agree 16.7% [2]
Strongly agree 75.0% [9]

4. I feel comfortable expressing my opinion in the Steering / NCC Committee meetings.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree
NCC 66.7% [4]
Public Health Department 50.0% [1]
University of Michigan Project Team 50.0% [1]

☐ Somewhat Agree
NCC 33.3% [2]
Public Health Department 50.0% [1]
University of Michigan Project Team 50.0% [2]

☐ Neither Agree Nor Disagree
NCC 0%
Public Health Department 0%
University of Michigan Project Team 0%

☐ Total [12 respondents]
Strongly disagree 0%
Somewhat disagree 0%
Neither agree nor disagree 0%
Somewhat agree 41.7% [5]
Strongly agree 58.3% [7]

5. My input in the Steering / NCC Committee meetings is incorporated into the overall project.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree
NCC 66.7% [4]
Public Health Department 0%
University of Michigan Project Team 50.0% [2]

☐ Somewhat Agree
NCC 33.3% [2]
Public Health Department 100% [2]

University of Michigan Project Team 25.0% [1]

☐ Neither Agree Nor Disagree
NCC 0%
Public Health Department 0%
University of Michigan Project Team 25.0% [1]

☐ Total [12 respondents]
Strongly disagree 0%
Somewhat disagree 0%
Neither agree nor disagree 8.3% [1]
Somewhat agree 41.7% [5]
Strongly agree 50.0% [6]

6. I feel comfortable communicating (in Centra meetings, via e-mail, and by phone) with other Steering / NCC Committee members.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree
NCC 66.7% [4]
Public Health Department 50.0% [1]
University of Michigan Project Team 75.0% [3]

☐ Somewhat Agree
NCC 33.3% [2]
Public Health Department 50.0% [1]
University of Michigan Project Team 25.0% [1]

☐ Neither Agree Nor Disagree
NCC 0%
Public Health Department 0%
University of Michigan Project Team 0%

☐ Total [12 respondents]
Strongly disagree 0%
Somewhat disagree 0%
Neither agree nor disagree 0%
Somewhat agree 33.3% [4]
Strongly agree 66.7% [8]

7. The Centra networking system provides effective communications for the Steering / NCC Committee meetings.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

NCC	83.3% [5]
Public Health Department	0%
University of Michigan Project Team	25.0% [1]

☐ Somewhat Agree

NCC	16.7% [1]
Public Health Department	100% [2]
University of Michigan Project Team	75.0% [3]

☐ Neither Agree Nor Disagree

NCC	0%
Public Health Department	0%
University of Michigan Project Team	0%

☐ Total	[12 respondents]
Strongly disagree	0%
Somewhat disagree	0%
Neither agree nor disagree	0%
Somewhat agree	50.0% [6]
Strongly agree	50.0% [6]

8. The Steering / NCC Committee has influenced decisions that affect the Midwest Community Genomics Forums Project as a whole.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

NCC	83.3% [5]
Public Health Department	50.0% [1]
University of Michigan Project Team	100% [4]

☐ Somewhat Agree

NCC	16.7% [1]
Public Health Department	50.0% [1]
University of Michigan Project Team	0% [0]

☐ Neither Agree Nor Disagree

NCC	0%
Public Health Department	0%
University of Michigan Project Team	0%

☐ Total	[12 respondents]
Strongly disagree	0%
Somewhat disagree	0%
Neither agree nor disagree	0%

Somewhat agree	16.7% [2]
Strongly agree	83.3% [10]

8.b Please give an example illustrating why you agree or disagree with the above statement:

9. The project is achieving the goals set for it by the Steering / NCC Committee.

1	2	3	4	5
Strongly Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

☐ Strongly Agree

NCC	50.0% [3]
Public Health Department	0%
University of Michigan Project Team	25.0% [1]

☐ Somewhat Agree

NCC	33.3% [2]
Public Health Department	50.0% [1]
University of Michigan Project Team	75.0% [3]

☐ Neither Agree Nor Disagree

NCC	0% (16.7% [1] Somewhat Disagree)
Public Health Department	50.0% [1]
University of Michigan Project Team	0%

☐ Total	[12 respondents]
Strongly disagree	0%
Somewhat disagree	8.3% [1]
Neither agree nor disagree	8.3% [1]
Somewhat agree	50.0% [6]
Strongly agree	33.3% [4]

10. How important are the goals of this Project to you?

1	2	3	4	5
Not at all important	Somewhat unimportant	Neither important nor unimportant	Somewhat important	Very important

☐ Very Important

NCC	83.3% [5]

Public Health Department	0%
University of Michigan Project Team	100% [14]

☐ Somewhat Important

NCC	0%
Public Health Department	100% [2]
University of Michigan Project Team	0%

☐ Neither Important Nor Unimportant

NCC	16.7% [1]
Public Health Department	0%
University of Michigan Project Team	0%

☐ Total	[12 respondents]
Not at all important	0%
Somewhat unimportant	0%
Neither important nor unimportant	8.3% [1]
Somewhat important	16.7% [2]
Very important	75.0% [9]

11. In your opinion, how much trust exists between NCC members of the Steering / NCC Committee and the University of Michigan Project Team?

1	2	3	4
Almost None	A small amount	A moderate amount	A great deal

☐ A Great Deal

NCC	83.3% [5]
Public Health Department	50.0% [1]
University of Michigan Project Team	100% [4]

☐ A Moderate Amount

NCC	16.7% [1]
Public Health Department	50.0% [1]
University of Michigan Project Team	0%

☐ A Small Amount

NCC	0%
Public Health Department	0%
University of Michigan Project Team	0%

☐ Total	[12 respondents]
Almost none	0%
A small amount	0%
A moderate amount	16.7% [2]
A great deal	83.3% [10]

12. Please add any other comments or feedback in the space below.

[1] Adapted from items developed by Cleo Caldwell as part of the Communities of Color and Genetics Policy Project, University of Michigan School of Public Health, funded by the National Human Genome Research Institute, and Barbara Israel et al. Methods in Community-Based Participatory Research for Health. Jossey-Bass (2005).