

GenoCommunity Think Tank

The GenoCommunity Think Tank: First National Meeting

DRAFT – 9/3/2010

Hyatt Regency St. Louis at The Arch
Regency D
315 Chestnut Street
St. Louis, Missouri
September 20-21, 2010

Convening Organizations

The National Community Committee of the Prevention Research Centers
Center for Public Health and Community Genomics, University of Michigan School of Public Health

Grantee and Meeting Administrator

Center for Public Health and Community Genomics, University of Michigan School of Public Health

Meeting Hosts

Prevention Research Center in St. Louis
The Genome Center, Washington University in St. Louis

GenoCommunity Think Tank Planning Committee

Jose Antonio Tovar-Aguilar, University of South Florida
Katie Barnes, University of North Carolina
Toby Citrin, University of Michigan
Suzanne Cupal, Genesee County Health Department
E. Hill De Loney, Flint Odyssey House
Diane Drago (ad hoc member), Diversified Management Services
Sandy Good (ad hoc member), University of Kentucky
Ella Greene-Moton, University of Michigan
Sarah Harding (ad hoc member), National Human Genome Research Institute
Sally Meyer, University of Michigan
Freda Motton, St. Louis University
James O'Leary (ad hoc member), Genomics Forum, American Public Health Association
Gaia Remerowski, Washington University in St. Louis
Rosemarie Rodriguez-Hager, Minnesota Department of Health
Cherilynn Shadding, Washington University in St. Louis
Jeanette St. Pierre (ad hoc member), Office of Public Health Genomics, CDC
Sharrice White-Cooper (ad hoc member), Prevention Research Center Program, CDC
Imogene Wiggs, Missouri Department of Health

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Meeting Outcomes

- Share best practices and promising practices for achieving community engagement to learn about genomics and its relevance to community health and the reduction of health disparities
- Share information about available funding to support community engagement about genomics and how community-based organizations might get technical support to realize these funding opportunities
- Consider strategies for incorporating genomics in the community-based participatory research agendas of prevention research centers
- Consider strategies for incorporating genomic applications (e.g. family health history) in the practice of local health departments and discuss strategies on how to get information about genomic applications out into the community in partnership with community-based organizations
- Share information on current and potential policy issues involving community interests in genomic research and its applications (e.g. direct-to-consumer testing; personalized medicine; mandatory registration of genetic tests) and consider how to engage community members in policy development
- Establish a Genomics Special Interest Group within the NCC to represent the community interest in genomic research and its applications.

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Draft Agenda

Monday, September 20, 2010

8:00 a.m. – 8:00 p.m.

8:00-9:00

Registration and Breakfast

9:00-9:30

Welcome

- National Community Committee; Antonio Tovar
- Center for Public Health and Community Genomics; Toby Citrin
- St. Louis Host Organizations
 - PRC in St. Louis; Katie Duggan
 - Genome Center, Washington University St. Louis; Elaine Mardis
- The Prevention Research Centers (PRC) Program of the CDC; Sharrice White-Cooper

Review of Agenda and desired outcomes

- Ella Greene-Moton , Center for Public Health and Community Genomics

Logistical Update

- Diane Drago, Diversified Management Services

9:30-10:30

Intervention Before the Intervention

Why are we here? (P.A.C. Isichei Model)

Facilitator: Mrs. E. Hill De Loney, Flint Odyssey House

3-person panel

Suzanne Cupal, Genesee County Health Department
Dana Thomas, University of Michigan
Kent Key, Community Based Organization Partners

Applying the Model to Genomics (Community, Communication, Trust, Equity (CTE):

Don Vereen, Director, Community-Based Public Health,
University of Michigan School of Public Health (10 minutes)

Discussion with audience (15 minutes)

10:30-11:00

Break

11:00- 12:00

Panel on Community Engagement in Genomics. Questions:

- Why should communities engage in genomics learning, research, practice, and policy development?
- What are the ways in which engagement has been successfully achieved?
- Where might communities find funding to support these engagement activities and technical support on how to secure funding?

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Facilitator: Cherilynn Shadding, The Genome Center, Washington University in St. Louis

Lead Presenter:

Vence Bonham, National Human Genome Research Institute

Panelists:

- Penny Kyler, Health Resources and Services Administration
- Sylvia Rickard, Hispanic Health Care Task Force
- Heather Aiono, Genetic Science Learning Center

Discussion with Audience

12:15-1:30

Lunch

1:30-2:45

Panel on Community Engagement in Genomics Research and Practice. Topics:

- How to engage communities in carrying out community-based participatory research incorporating genomics with other PRC partners
- How to partner with local or state health departments in using genomic tools in public health practice, and how to promote the utilization of these tools by health departments
- How to engage others in the community to join in these activities
- Potential funding to support these activities

Facilitator: Katie Duggan, PRC in St. Louis

Lead Presenter:

Sarah Gehlert, Institute for Public Health, Washington University, St. Louis

Panelists:

- Kristin Oehlke, Minnesota State Genomics Coordinator
- Yvonne Lewis, Faith Access to Community Economic Development
- Kimberly Kaphingst, Washington University St. Louis
- TBA, Scripps Whittier Center, San Diego

Discussion with audience

2:45-3:00

Break

3:00-4:45

Break-out Groups by NCC Region

How to incorporate these ideas into the agendas of the attendees

4:45-6:00

Break – On Your Own

6:00-8:00

Reception: Dinner Buffet and Networking

Slide show: Participating community organizations, their partners and their engagement work

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Draft Agenda

Tuesday, September 21, 2010

8:30 a.m. – 1:15 p.m.

8:30-9:00

Breakfast

9:00-9:20

Welcome and Opening of Second Day

- Muin Khoury Director, Office of Public Health Genomics, CDC

Logistical Update

- Diane Drago, Diversified Management Services

9:20-10:45

Panel on policy and ethics. Topics:

- Policy Issues Relevant to Communities
- Policy development opportunities
- Policy advocacy opportunities
- Community-Focused Advocacy Organizations
- Ethical issues affecting policy development and needing input reflecting community values

Facilitator: Ella Greene-Moton

Lead Presenter:

Vanessa Northington Gamble, George Washington University (20 minutes)

Panelists:

- Sharon Kardia, Director, Genetics Program, University of Michigan School of Public Health – Biobanks and biotrusts
- James O’Leary, Genetic Alliance – what’s on the federal and state policy agendas; how to carry out advocacy with these groups
- Phyllis Frosst, National Human Genome Research Institute – the NHGRI policy perspective

Discussion with audience

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10:45-11:45

Final Discussion

Facilitated by NCC leadership

This will be a discussion of next steps to incorporate ideas emerging from this meeting into the agendas of prevention research centers and their community organization, academic and health department partners. Questions discussed might include:

- Whether and how to form a dialogue group within the NCC to further genomic interests and activities
- How the GenoCommunity Think Tank website might be most useful in furthering the objectives of such a group and promoting the kinds of community engagement discussed at this meeting
- By whom and how should the group move forward to implement these suggestions after the meeting

11:45-12:00

Break

12:00-12:15

Evaluations

12:15-1:15

Served Lunch (with a to-go option available)

Wrap-up, and Summary – Toby Citrin

Meeting Adjournment

1:15-3:00

Meeting Debrief and Next Steps

(Planning Committee and NCC Leadership)