



PARTNERSHIP FOR PUBLIC ENGAGEMENT

E. Yvonne Lewis and Toby Citrin

Secretary's Advisory Committee on
Genetics, Health and Society

October 19, 2005

PRESENTATION OUTLINE

- Three engagement projects
- What we learned from them
- How we can apply what we learned to the proposed Large Population Studies



THREE ENGAGEMENT PROJECTS



THREE ENGAGEMENT PROJECTS

GENE Project

Genetics Education Needs Evaluation

Michigan Demonstration



THREE ENGAGEMENT PROJECTS



WHAT WE LEARNED

- Communities will support genetics research IF conducted as a partnership
- Communities must be meaningfully involved at all stages of the study



WHAT WE LEARNED

- Distrust comes from history of “them” studying “us” with benefits to “them”
- We must directly face the issues of race and racism in the U.S.
- Trust comes from co-ownership of the project by all of us



WHAT WE LEARNED

- Education should not precede engagement
- Engagement leads to a desire for education



WHAT WE LEARNED

- The community's expectations for the study must be clearly understood. Not fulfilling these expectations leads to distrust and opposition.



WHAT WE LEARNED

- Community-based organizations (CBOs) are valuable “intermediaries” representing grass-roots communities and participating in study partnerships
- CBOs can be local and CBO networks can be national and state-wide



WHAT WE LEARNED

- Academic-community dialogue, following the model of community-based participatory research (CBPR), results in bi-directional learning strengthening studies, building trust and insuring engagement



WHAT WE LEARNED

- Genetic research needs to reflect a **PARTNERSHIP** between researchers, those being researched, and those having a stake in the research.
- “Consultation” or “advice” is not sufficient to build trust and assure engagement.



WHAT WE LEARNED

- The process of partnership-building must be evaluated continuously, along with evaluation of the research itself, to assure progress, identify stumbling blocks, and develop strategies to overcome them.



APPLYING WHAT WE LEARNED

- The proposed large-scale studies pose a major risk of generating distrust among vulnerable communities.
- Avoidance of distrust and attainment of participation and support depends upon organizing the project as a partnership between those studying, those studied and those with a stake in the study.



APPLYING WHAT WE LEARNED

- Decision-making in planning the studies must engage a representative group of stakeholders NOW and on a continuing basis and at all levels (federal, state and local).



APPLYING WHAT WE LEARNED

- The study process must explicitly include a plan and method to address issues of race and racism
- Individuals representative of racial and ethnic groups with a stake in the study must be meaningfully involved in developing these plans and methods



APPLYING WHAT WE LEARNED

- National networks of local organizations can foster community engagement at all levels
- Public health agencies and academic institutions can partner with community-based organizations to foster engagement



APPLYING WHAT WE LEARNED

- Community-based stakeholder groups should be involved in development of materials fostering engagement and education



APPLYING WHAT WE LEARNED

- Community-based dialogue should be fostered to generate engagement, education, a forum for voicing concerns and recommendations, and a vehicle for reaching consensus



APPLYING WHAT WE LEARNED

- Networks of community-based organizations partnering with scientists, academics and health professionals can foster community-based dialogue



APPLYING WHAT WE LEARNED

- Media can be used to stimulate public dialogue and to replicate dialogue on radio, television and in print.
- Media focused to reach groups with the potential of lacking trust and fearing harm must be selected.



APPLYING WHAT WE LEARNED

- Institutional Review Boards should consider group risks as well as individual risks in their review of the studies
- Informed consent materials must reflect individual and group risks and benefits
- Stakeholder groups with risks of harm must participate on IRBs and in the development of informed consent materials



APPLYING WHAT WE LEARNED

- The study design must include assurances that the fruits of the study will further the health of the public, will be accessible on an equitable basis, and will result in the reduction and not the widening of health disparities



APPLYING WHAT WE LEARNED

- These assurances may be satisfied by a continuing process of meaningful public participation, and a commitment to maintain public ownership of the resulting data and the technology it spawns.



APPLYING WHAT WE LEARNED

- Continuous evaluation, with the participation of community-based stakeholders, should monitor public engagement and trust along with the research itself.



APPLYING WHAT WE LEARNED

- Study participants should be treated as study partners rather than “subjects”
- Continuing communications; newsletters; reports of findings; websites; can help develop a sense of co-ownership.



CONCLUSION

- Successful implementation of the contemplated large population studies depends upon whether the studies are perceived as a project being carried out **BY** the public or **ON** the public.
- **PARTNERSHIP** is the key to success.

