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Exploring Mechanisms for Public Engagement



- Public engagement overview
- The Genetic Town Hall: Making Every Voice Count
- Considerations for a large population study on genetics, environment, and health



Levels of Engagement



- Inform
 - One way flow of information
 - Methodologies
 - Print or web materials
 - Media outlets



Levels of Engagement

- Consult
 - Obtain feedback from public
 - Methodologies
 - Surveys
 - Focus groups
 - Workshops
 - Scenario development
 - Deliberative democracy
 - Consensus conferences



Levels of Engagement



- Collaborate
 - Public involved in issue identification,
 framing, prioritization and agenda setting
- Empower
 - -Citizen juries or balloting

Inform Consult Collaborate Empower



Selection of Methods



- Goal of engagement
- Stage of issue development
- Where public is in evolution of coming to judgment
- Who is being engaged





Reproductive Genetic Technologies

- Surveys >6000 general public
- Focus groups 21 in 5 cities with 181 general public
- Interviews >270 with various stakeholders



Deliberative Democracy

- Broad Participation is broad and representative
- Informed The information provided is balanced and accurate
- Deliberative An environment where participants can deliberate with experts and fellow citizens
- Policymaker involvement through participation or follow up



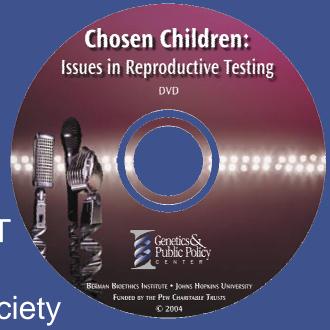
Chosen Children: Issues in Reproductive Genetic Technologies

The Science of RGT

The Ethics of RGT

The Safety and Accuracy of RGT

Implications for Families and Society

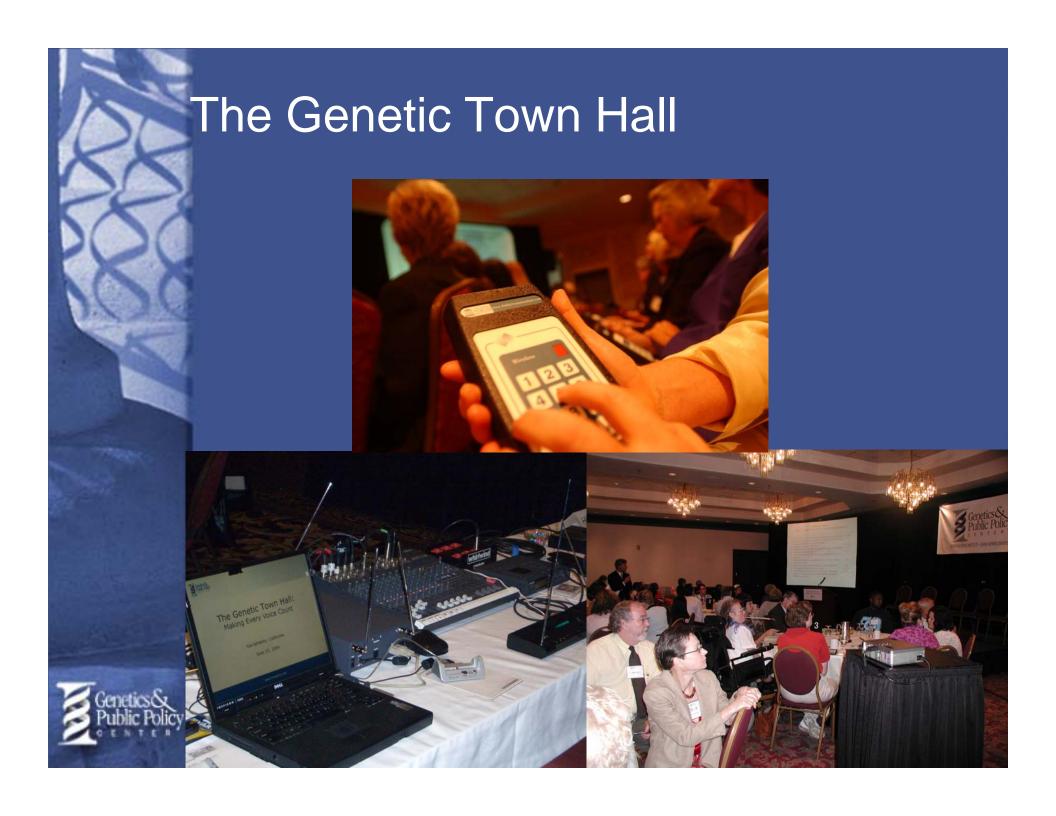




Methods: In-person Town Halls

- Partnered with Public Forum Institute (PFI)
- Recruitment through local coordinators
 - Community outreach
 - Community organizations and leader outreach
 - Media outreach
- Table facilitators local genetic resource or recruited from participants
- 36 item pre-test, 8 repeated at end
- 3 ½ hours, interactive program to provide variety of content and large and small group discussions

Genetic Town Halls

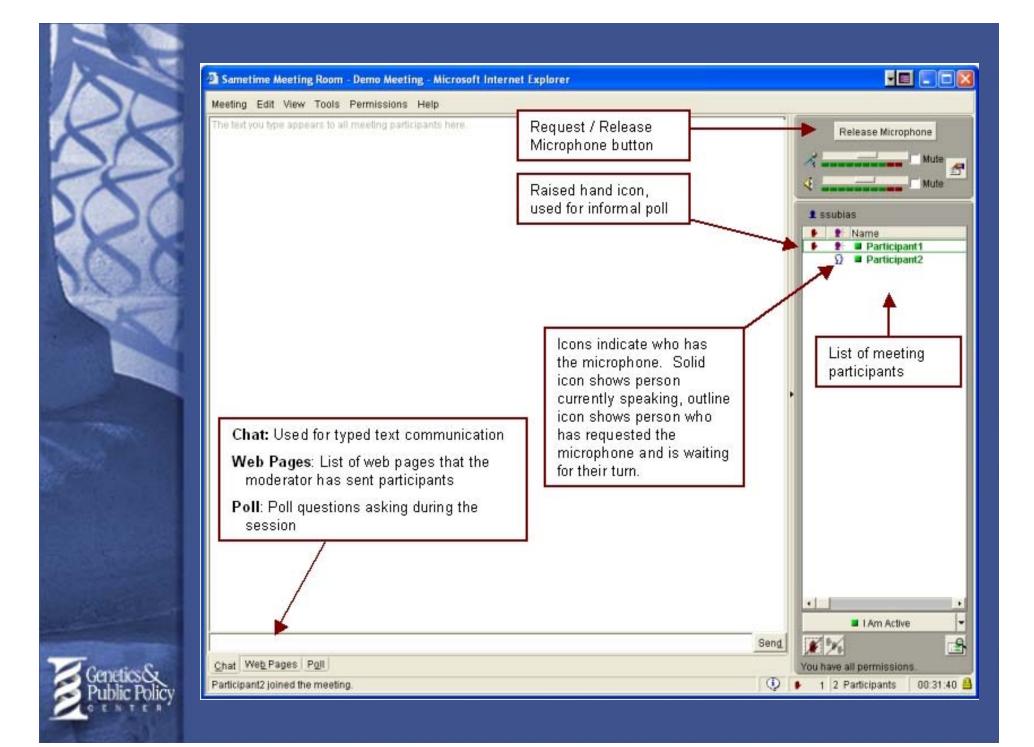






Methods: Online Discussion Groups

- Met on-line for 1 hour for 3 consecutive weeks
- Recruited through Knowledge Network's "web-enabled", representative panel
- Took 80 item pre-discussion survey
- Mailed headsets, instructions, videos
- Sessions moderated by genetic counselors
- Voice chat, but could also text message

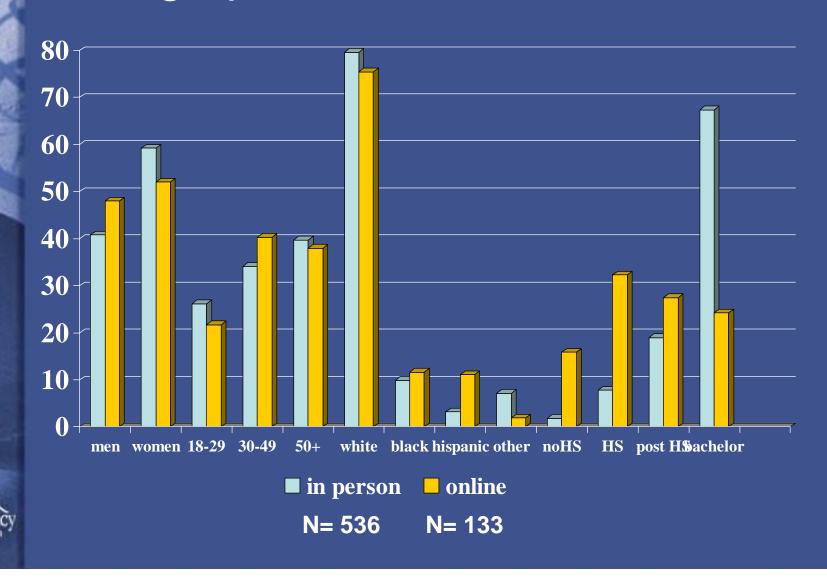




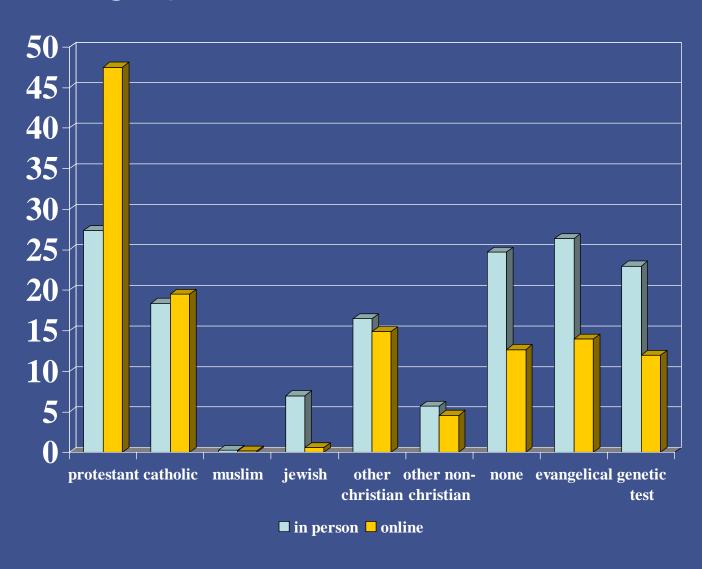
Methods: Online Discussion Groups

- Took 76 item post-discussion survey following last session to document changes in knowledge and opinions
- Only those who participated in 2 of the 3 sessions were counted in results
- 403 controls took pre & post-surveys

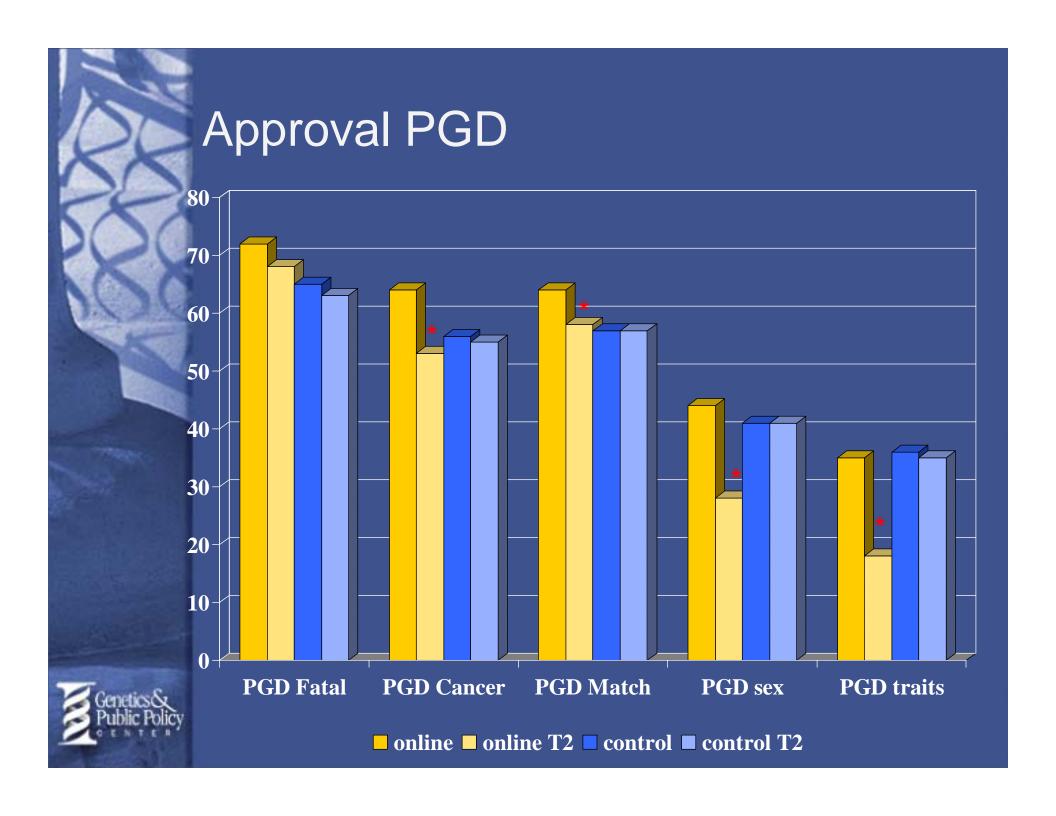
Demographics: Genetic Town Halls



Demographics: Genetic Town Halls









Participant Concerns

- Genetic discrimination
- Equal access



Comparison

- Both methods allow for nuanced deliberative discussions and help participants refine opinions
- Online
 - More representative
 - Better to document changes in attitudes
 - Ability to track attitudes over time
- In-person town halls
 - More stakeholders
 - Wider effect
 - Media involvement
 - Community leaders





- Multiple methods will probably be needed
 - Different goals for phases of project
 - Different segments of population to reach
- Methods we use are expandable
 - Link several cities regionally or nationally
 - Televising town halls
 - Increase media involvement
- Allow for quantitative tracking over time
- Resources on the web to support communities and participants





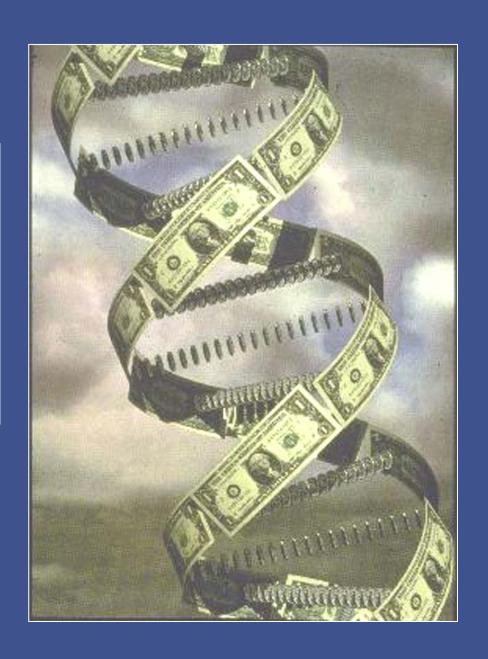
Public Engagement about a Large Population Study



- Receptivity
 - Public concerns about
 - Genetic discrimination
 - Equal access
- Challenges
 - Broad representation and participation
 - Credibility



The Pew Charitable Trusts





www.DNApolicy.org