

The Genetic Town Hall: Making Every Voice Count

Genetics and Public Policy Center
Johns Hopkins University

Genetics and Public Policy Center

To create the environment and tools needed by decision makers in both the private and public sector to carefully consider and respond to the challenges and opportunities arising from advances in human genetics.

Reproductive Genetics Initiative Goals

- Assess public knowledge and attitudes
- Educate and engage stakeholders & opinion leaders
- Create comprehensive information resources for policy makers, press, and the public
- Develop policy options to guide the development and use of reproductive genetic technologies

- We have a problem with trust.
- Be careful about making “non-scientific” claims about what the public does and does not know.
- Public engagement, once thought to be “just a good idea”, is now essential.

A Matter of Trust

MEG: “[Genetics] is moving so fast and it's also owned by companies that have to make a profit, they've got to put this out there before we can fully evaluate it. They do, they have to make money. I don't think it's possible for us to stop scientists. They'll do whatever they want wherever they want to do it.”



A Matter of Trust

HAYDEE: Yes, but you know what? You are a reasonable person. We are responsible people here, but some of those scientists, because of the science and because of their warped minds, they will do something stupid like that, and you know they can, and they will.



Public Views About Science/Scientists

N=4,834

Survey says

- | | |
|---|-----|
| A. Scientific research is essential for improving the quality of human lives | 88% |
| B. Scientists these days don't pay enough attention to the moral values of society. | 50% |
| C. I trust scientists to put society's interests above their personal goals. | 20% |

Scientists' Thoughts on the Public

"I don't think that the general uninformed public should have a say, because I think there's a danger. There tends to be a huge amount of information you need in order to understand. It sounds really paternalistic, but I think this process should not be influenced too much by just the plain general uninformed public..."

Be careful about making “non-scientific” claims about what the public does and does not know

Ignorance as the Basis of Opposition

“When people are asked to draw an embryo they usually draw a fetus.”

Irv Weissman
Stanford University

What Do They Know?



72.1% correctly identified image of one-week
24.8% misidentified a 4 week fetus
1.2% misidentified a 16 week fetus.

No significant demographic correlates
No correlation with support for ESC research

Public Understanding of Science

- Information Deficit Model
 - Assumes direct correlation between increased knowledge and support
 - Assumes one way flow of knowledge from experts to the public
 - Driven communication of S&T since WWII
 - Public support for S&T has not changed as a result

Public Understanding of Science

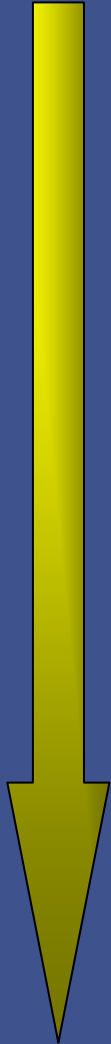
- Contextualized Model
 - Assumes public has other knowledge and experiences
 - Assumes experts and policymakers can learn from the public

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
- *Decision maker involvement* – through participation or follow up

Levels of Engagement

- Inform
- Consult
- Collaborate
- Empower



Content: Reproductive Genetic Testing: Carrier testing, PND, PGD

- Should there be limits on the use of these tests. If so, what are those limits and who should set them?
- Are they safe and accurate?
- What is the impact of parents' ability to choose the characteristics of their children on individuals, families, and society?

Preimplantation Genetic Diagnosis



In vitro fertilization



Embryos



DNA



Genetic Testing



Embryos selected for transfer
(absence of gene mutation or presence of
desirable genetic characteristic)



Genetic Town Halls: Making Every Voice Count

15 On-line Town Halls
July-Aug, 2004

6 In-person Town Halls

Sacramento, CA June 29

Seattle, WA July 1

Kalamzoo, MI July 19

Fort Worth, TX July 31

New York, NY Aug 2

Nashville, TN Aug 4



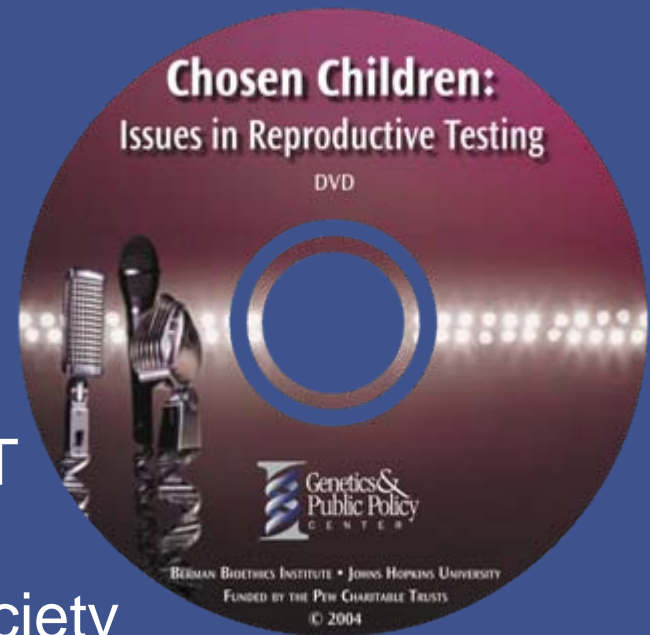
Chosen Children: Issues in Reproductive Genetic Technologies

The Science of RGT

The Ethics of RGT

The Safety and Accuracy of RGT

Implications for Families and Society



Methods: Online Discussion Groups

- Took 80 item pre-discussion survey
- Mailed headsets, instructions, videos
- Groups met online for 1 hour for 3 consecutive weeks
- Genetic counselor moderators
- One topic each week
 - Ethics of reproductive genetic testing
 - Safety and accuracy
 - Implications for families and society
- Voice chat, but could also text message

Sametime Meeting Room - Demo Meeting - Microsoft Internet Explorer

Meeting Edit View Tools Permissions Help

The text you type appears to all meeting participants here.

Request / Release Microphone button

Raised hand icon, used for informal poll

Icons indicate who has the microphone. Solid icon shows person currently speaking, outline icon shows person who has requested the microphone and is waiting for their turn.

List of meeting participants

Chat: Used for typed text communication
Web Pages: List of web pages that the moderator has sent participants
Poll: Poll questions asking during the session

Release Microphone

Mute

Mute

ssubias

Name
Participant 1
Participant 2

I Am Active

You have all permissions.

Chat Web Pages Poll

Participant2 joined the meeting.

1 2 Participants 00:31:40

The screenshot shows a web browser window titled "Sametime Meeting Room - Demo Meeting - Microsoft Internet Explorer". The interface includes a menu bar (Meeting, Edit, View, Tools, Permissions, Help), a large text area for chat, and a right-hand sidebar. The sidebar contains a "Release Microphone" button, two "Mute" buttons with progress bars, a participant list for "ssubias" showing "Participant 1" and "Participant 2", and a status bar at the bottom indicating "I Am Active" and "You have all permissions." At the very bottom, a status bar shows "1 2 Participants" and a timer at "00:31:40". A chat log at the bottom left shows "Participant2 joined the meeting." Callout boxes with red arrows point to specific UI elements: "Request / Release Microphone button" points to the "Release Microphone" button; "Raised hand icon, used for informal poll" points to a hand icon in the participant list; "Icons indicate who has the microphone..." points to the microphone icons in the participant list; "List of meeting participants" points to the participant list header; "Chat: Used for typed text communication" points to the chat text area; "Web Pages: List of web pages that the moderator has sent participants" points to the "Web Pages" tab; and "Poll: Poll questions asking during the session" points to the "Poll" tab.

Methods: Online Discussion Groups

- Participants took 76 item post-interview survey following last session
- 403 controls took pre- and post-surveys

Methods: In-person Town Halls

- Recruitment through local coordinators
 - Community outreach
 - Community organizations and leader outreach
 - Media outreach
- Neutral location
- 3.5 hour “town hall” style meeting

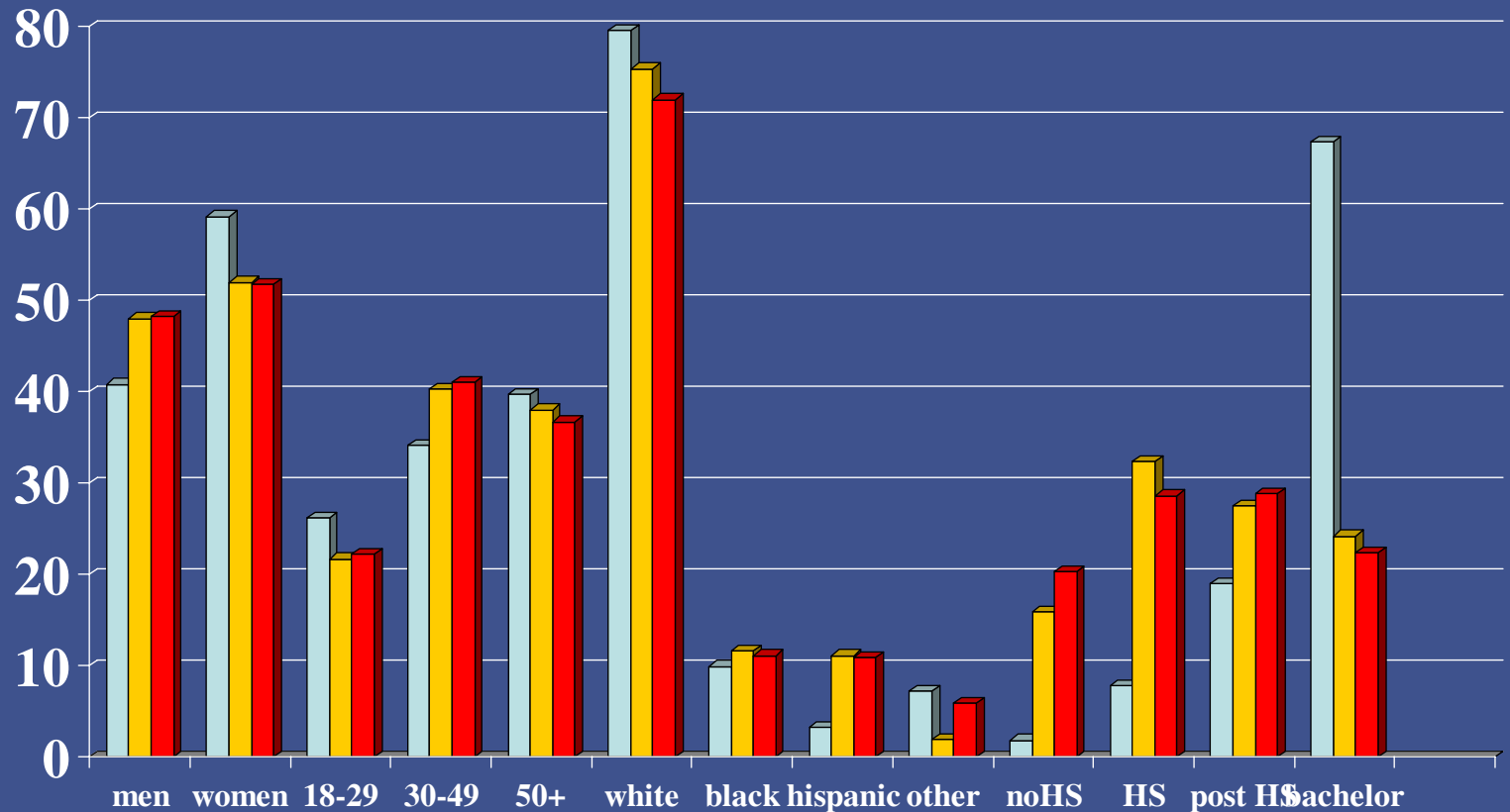
Genetic Town Halls



The Genetic Town Hall

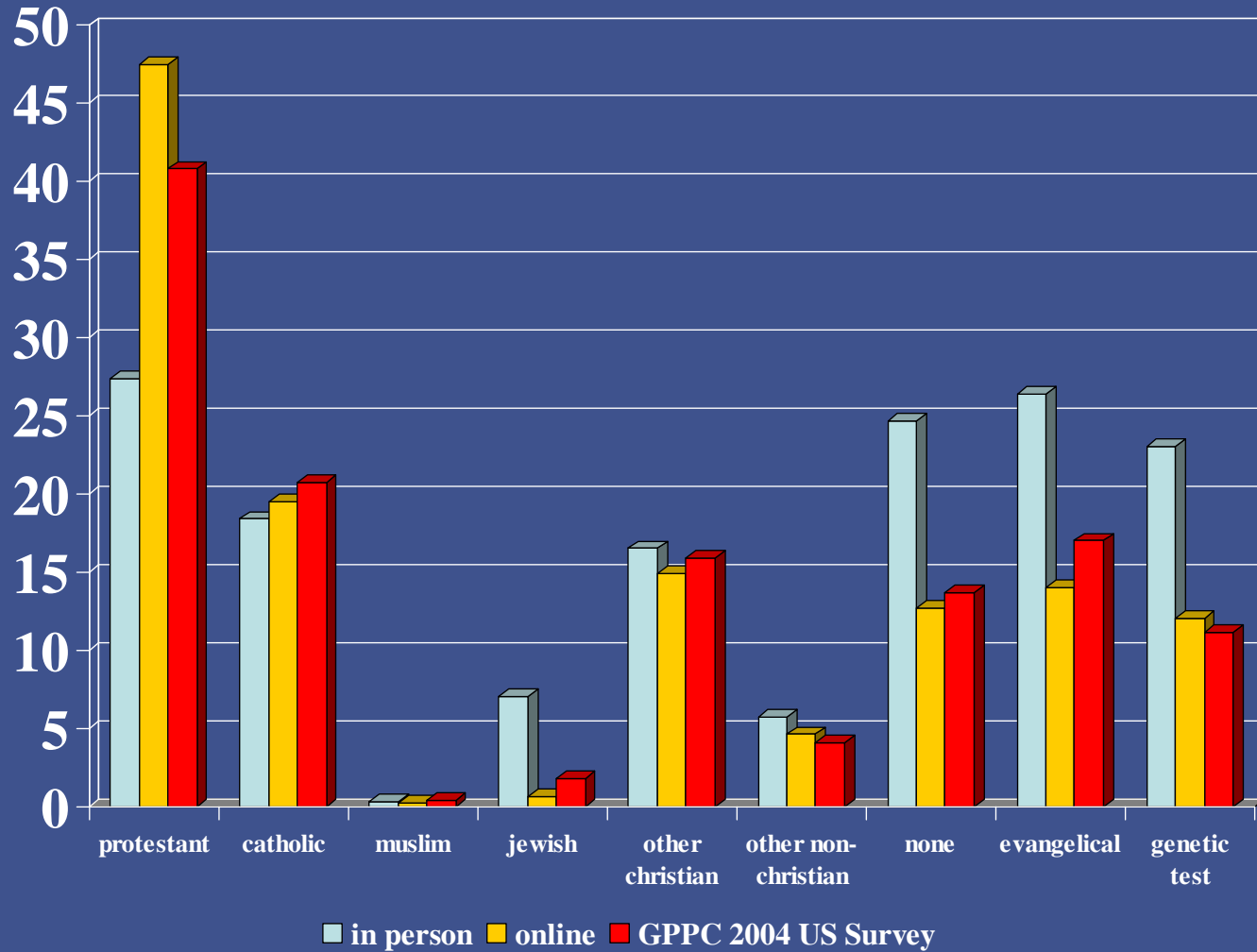


Demographics



■ in person ■ online ■ US Census, 2000 >18
 N= 536 N= 133

Demographics

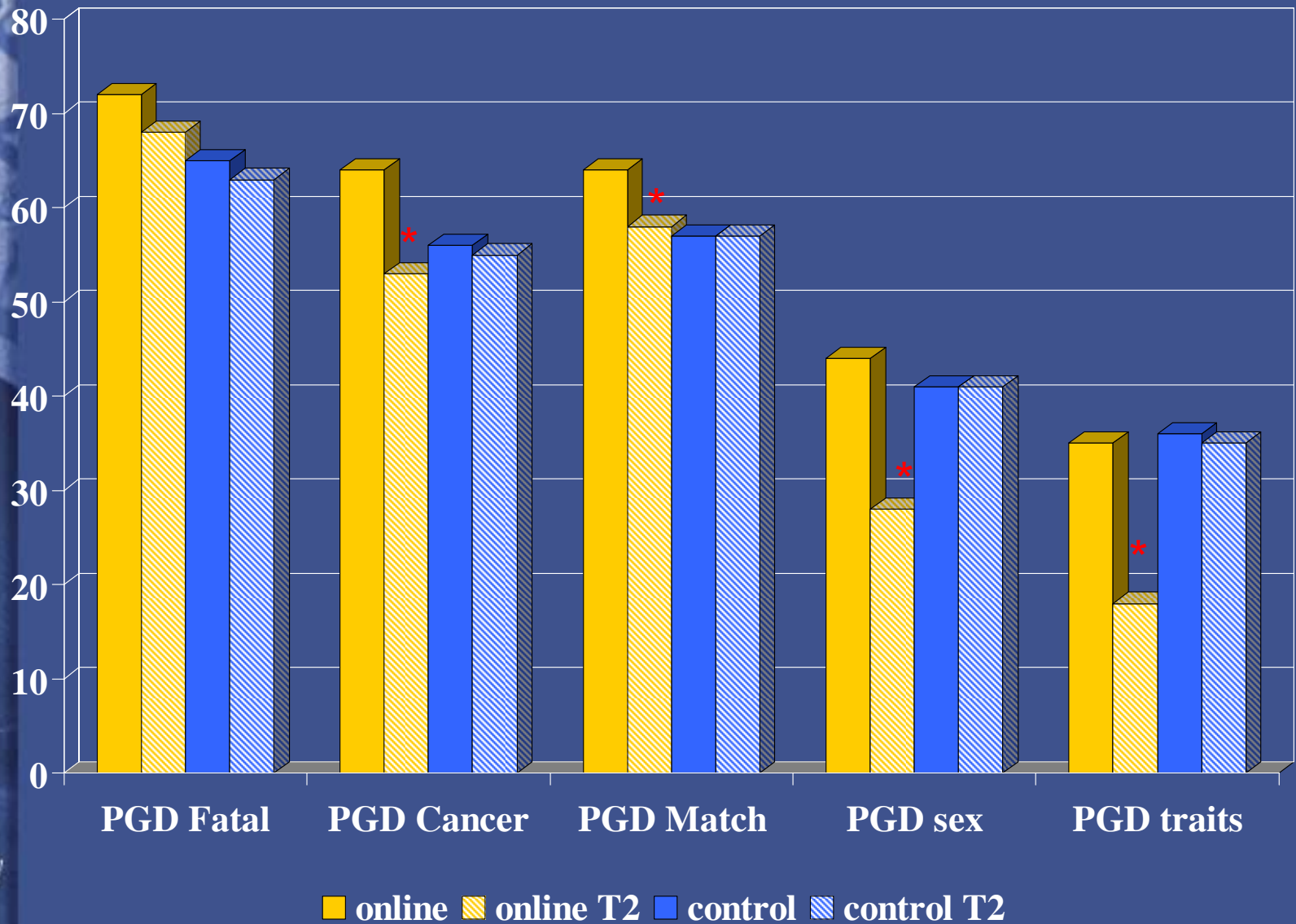


Approval of uses of PGD

Do you approve, strongly approve, disapprove or strongly disapprove of using PGD to test for...

- a gene mutation associated with a fatal childhood disease
- a tendency to develop a disease later in life such as cancer
- a hypothetical gene associated with intelligence or strength
- for the sex of the baby
- to determine if the person will be a good tissue match for a sick sibling in need of a transplant

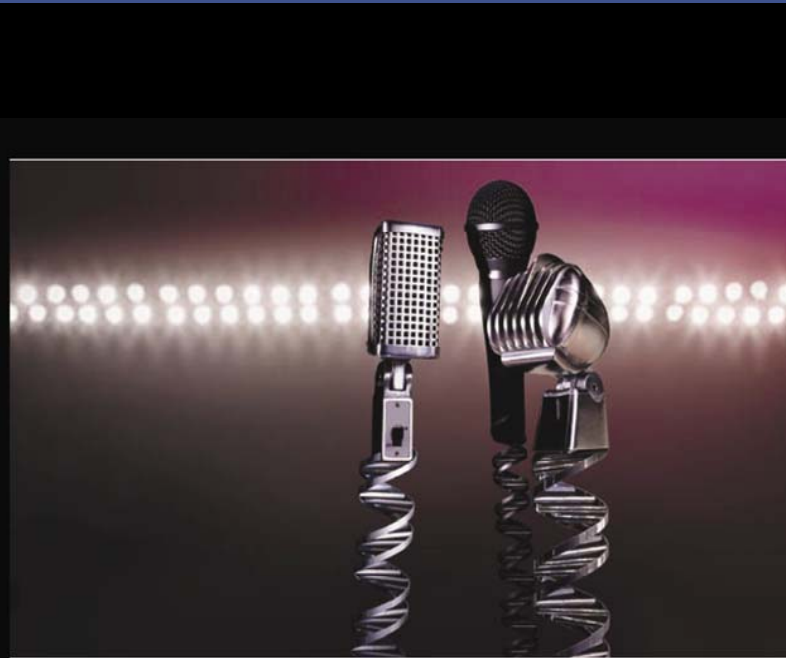
Approval



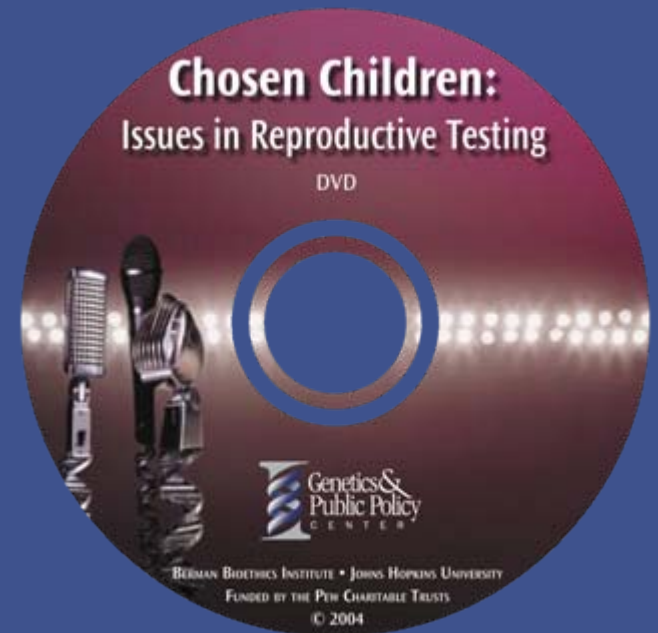
- Both methods allow for nuanced deliberative discussions
- Intervention appears to help individuals learn more about technologies and the issues
- Helps participants refine opinions
- Unknown how stable the changes are over time

- We have a problem with trust.
- Be careful about making “non-scientific” claims about what the public does and does not know
- Public engagement, once thought to be “just a good idea”, is now essential.
- Know, before you start, what you will DO with what YOU learn.
- Public engagement is expensive—is the juice worth the squeeze?

The Genetic Town Hall: Making every voice Count

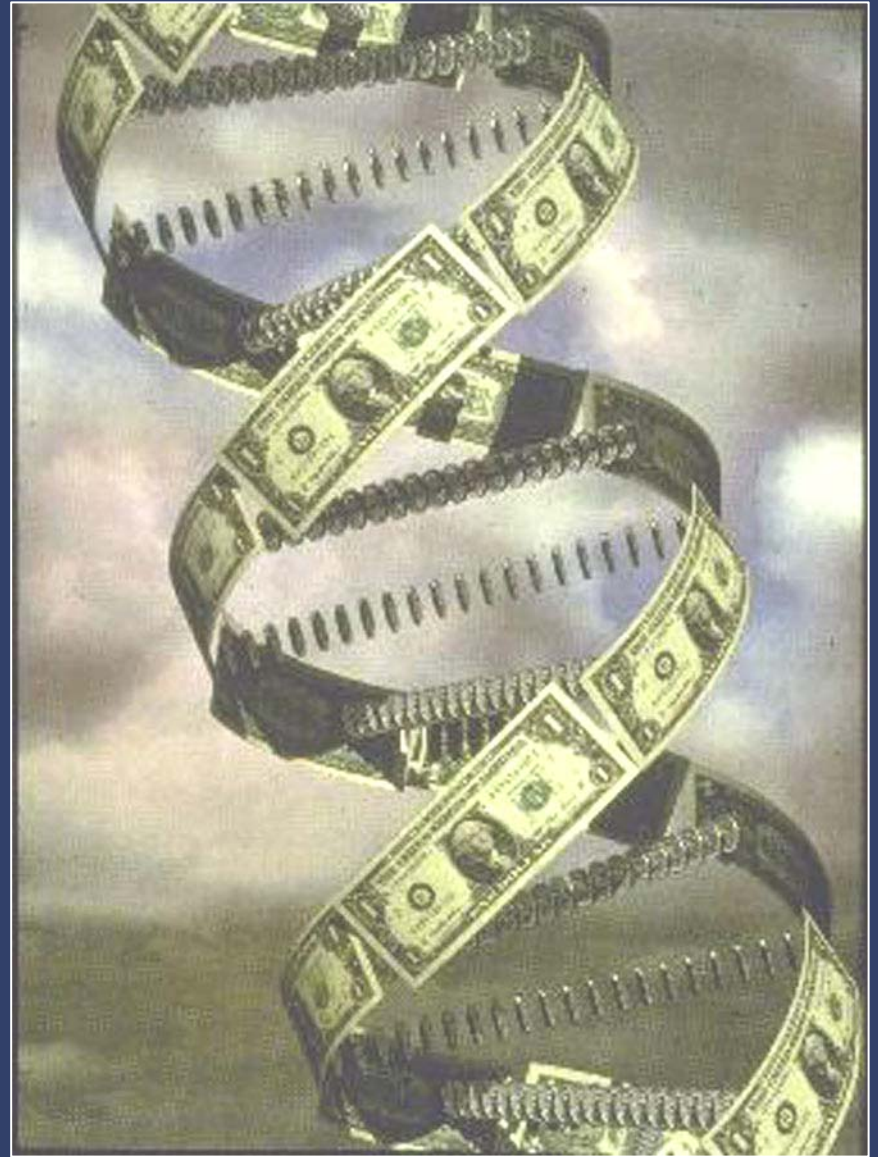


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www.dnapolicy.org

The Pew Charitable Trusts





www.DNAPolicy.org