



Public Perception of Clinical Research

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Dec. 7, 2010

National Heart, Lung, and Blood Institute
Bethesda, MD

What Should We Believe?

February 20, 2007

The New York Times Risks and Remedies: Supplements May Help Prevent Stress Fractures

November 30, 2010

Bloomberg **Vitamin D, Calcium Supplements Are Unnecessary, Study Finds**

February 14, 2008

MailOnline **A second glass of red wine 'is bad for your heart'**

June 4, 2008

 **TODAY** Health

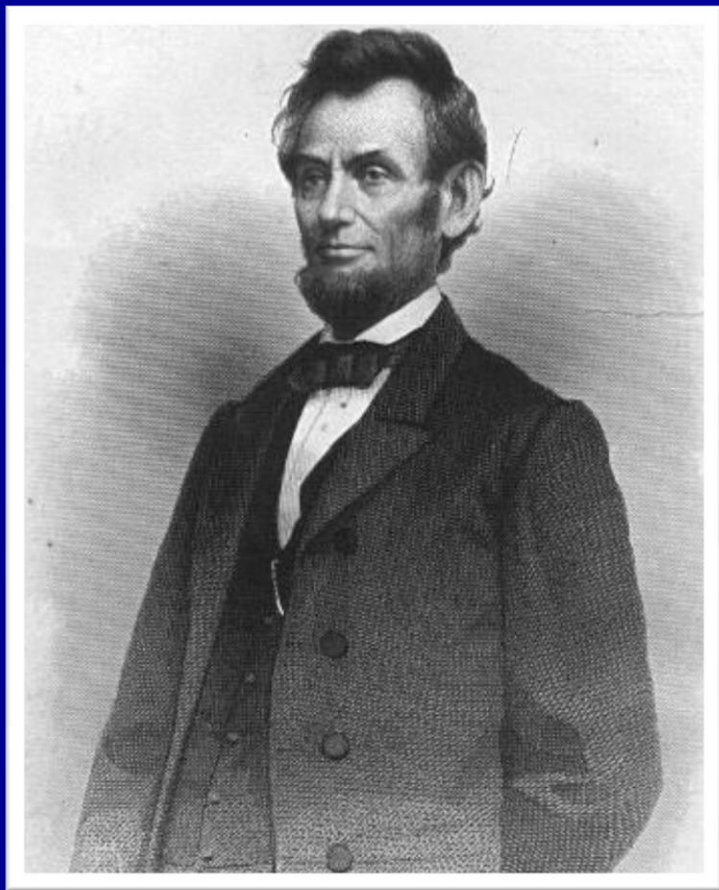
Is wine good for you?

In moderation, a glass or two can help your heart, prevent cancer and more

**RESEARCH
AMERICA**
AN ALLIANCE FOR DISCOVERIES IN HEALTH

Science in Real Time

- People are understandably confused by the three steps forward/two steps back *dynamic process* of science.
- By standing back or failing to engage, researchers aren't helping resolve public confusion.
- Public support for science, and public willingness to engage in research, are at risk.



“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

President Abraham Lincoln

Public Perceptions of Science and Scientists

Science's impact on society is:

Mostly positive 84%

Mostly negative 6%

Other/don't know 10%

Professions contributing "a lot to society's well-being":


Members of military 84%

Teachers 77%

Scientists 70%

Medical doctors 69%

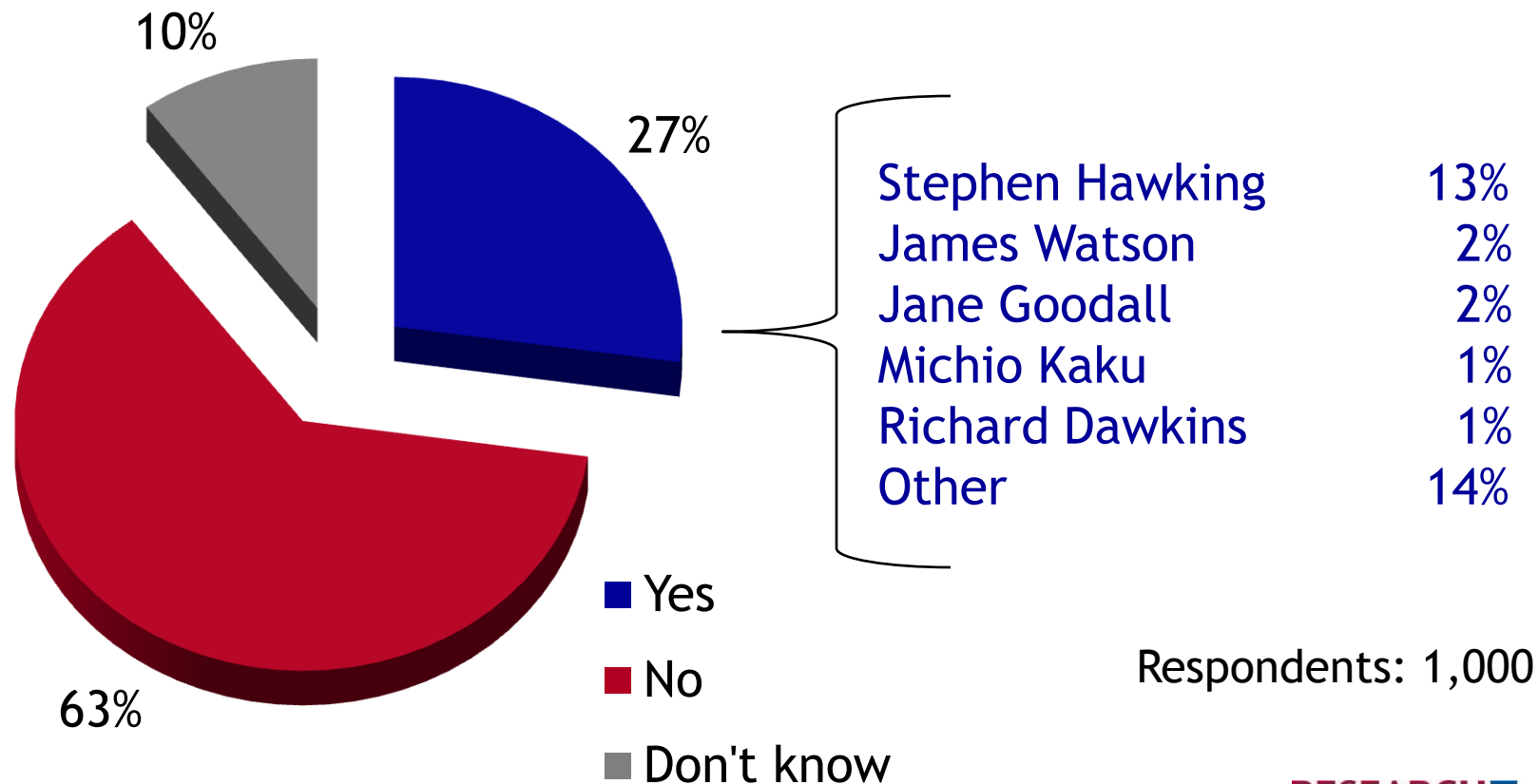
Respondents: 2,001



And Yet, Despite High Levels
of Public Confidence,
Scientists are Invisible in Our
Society...

Most Americans Can't Name a Living Scientist

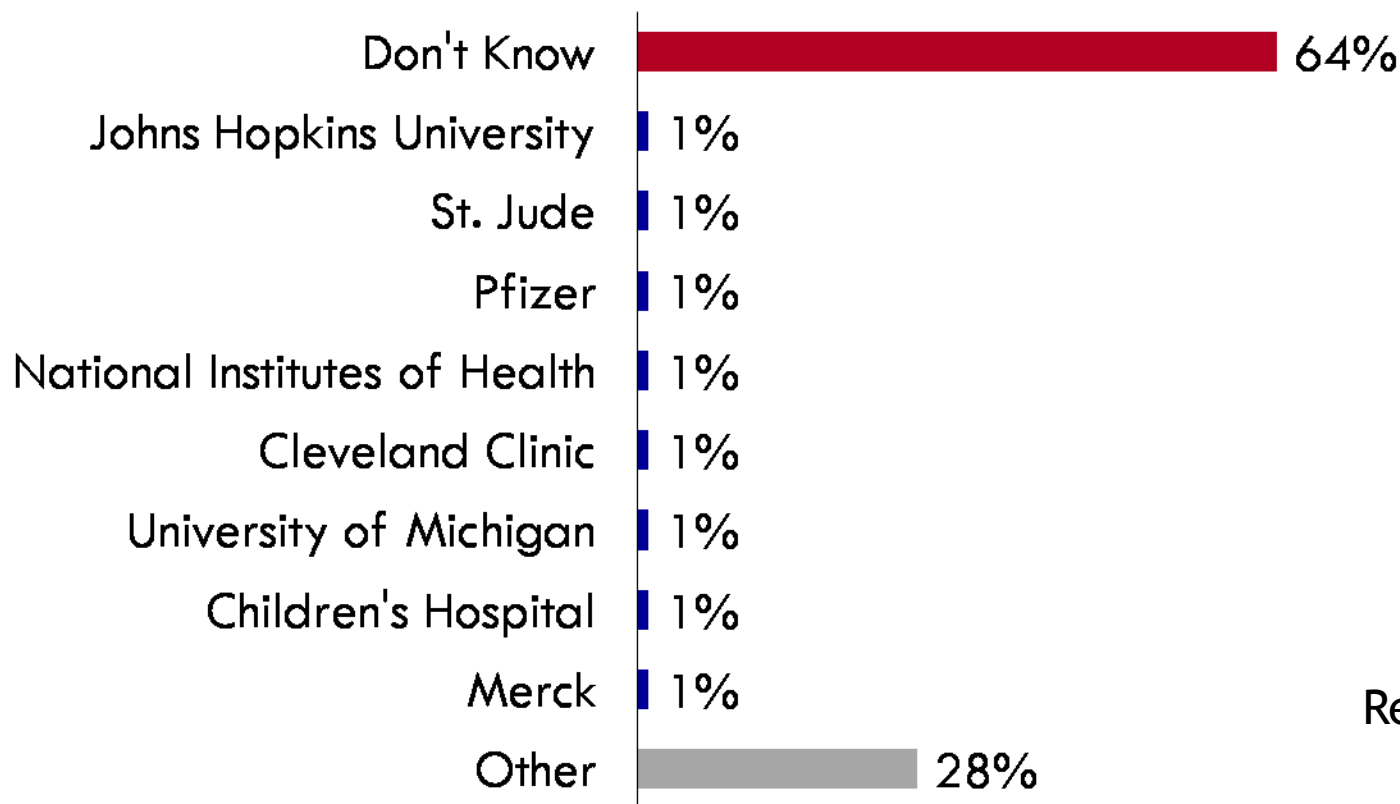
Can you name any living scientists? (% total volunteered responses)



Do Americans Know Where Research is Conducted?

Americans Don't Know Where Research is Conducted

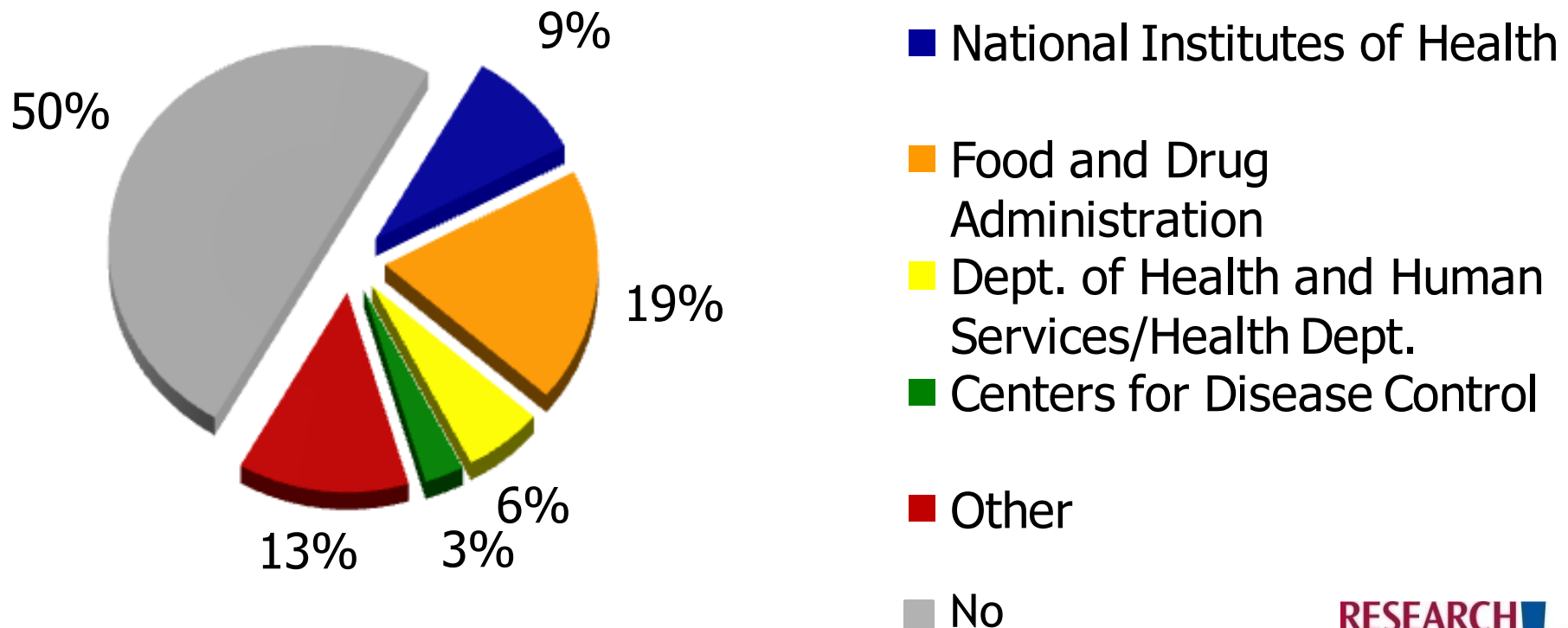
Do you know of any institutions, companies or organizations where medical or health research is conducted?



Respondents: 800

Few Americans Recognize the National Institutes of Health

What is the name of the government agency that funds most of the medical research paid for by taxpayers in this country? (first volunteered responses)



Source: Research Enterprise Poll, February 2010
Charlton Research Company for Research!America

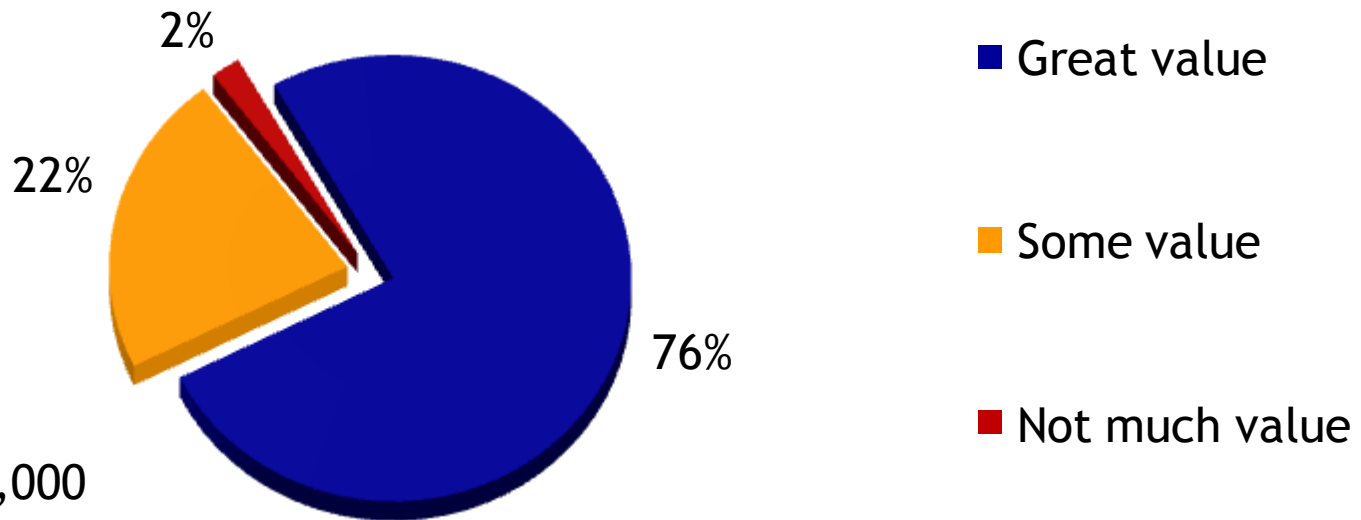
Respondents: 1,000

Research!America Poll Data

- Commissioning public opinion polls on research issues for nearly 20 years:
 - National Polls
 - State-Based Polls
 - Issue-Specific Polls
- Telephone (random-digit dialing) polls are conducted with a sample size of 800-1000 adults (age 18+) and a maximum theoretical sampling error of +/- 3.5%. Data are demographically representative of adult U.S. residents (state or national).
- Online polls are conducted with a sample size of 1000-2000 adults and sampling error of +/-3.1%. The data are weighted in two stages to ensure accurate representation of the U.S. adult population.

Clinical Research is a Great Value

One kind of research, often referred to as clinical trials, is clinical research. In this, patients choose to participate to test the safety and effectiveness of certain treatments, drugs or devices. How important is this kind of research? Would you say it is of...

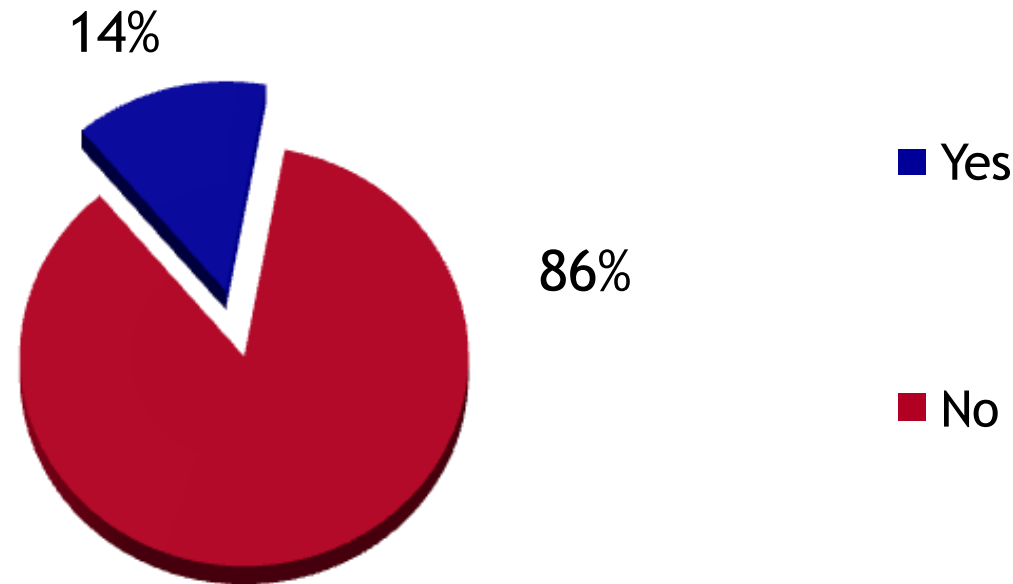


Respondents: 1,000

Source: Research Enterprise Poll, February 2010
Charlton Research Company for Research!America

Most Americans Have Not Participated in Clinical Research

Have you or anyone in your family ever participated in clinical research?

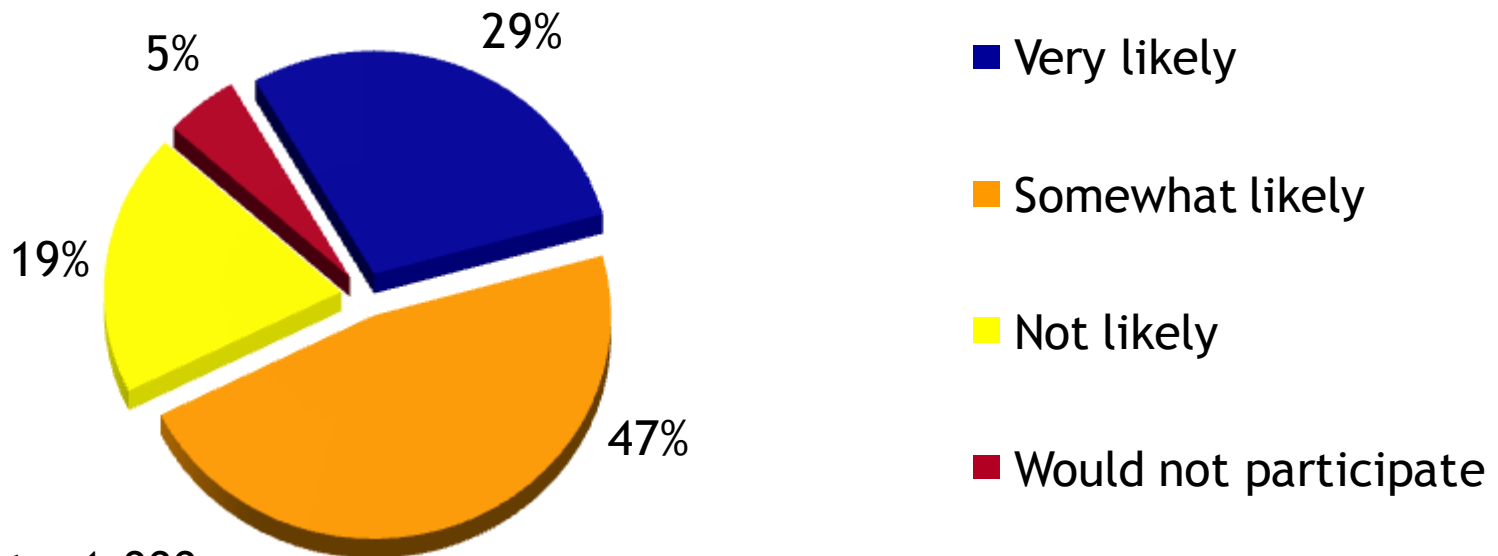


Respondents: 1,000

Source: Research Enterprise Poll, February 2010
Charlton Research Company for Research!America

Many Americans Likely to Volunteer for Clinical Research

Please consider your own possible participation as a volunteer in clinical research. How likely would you be to participate in a clinical research study?

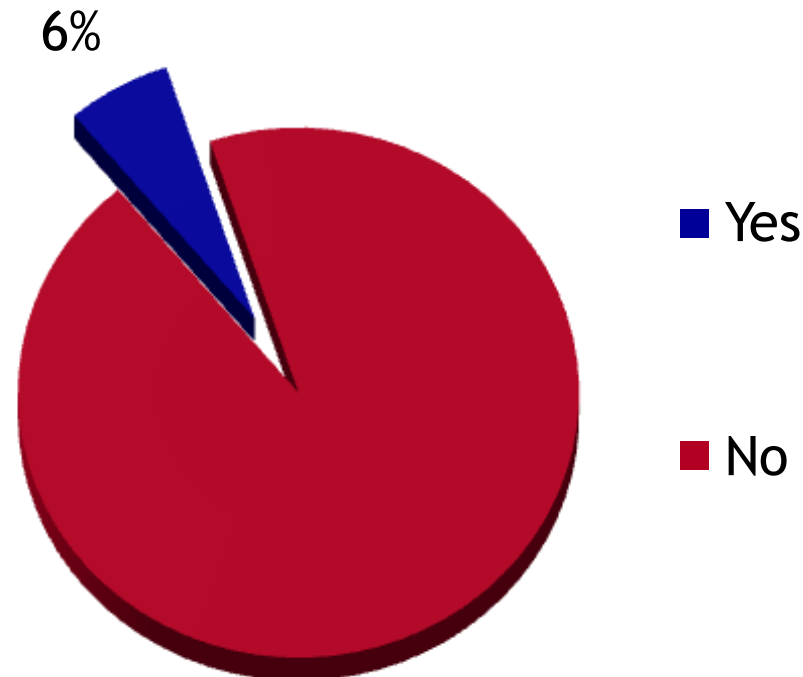


Respondents: 1,000

Source: Research Enterprise Poll, February 2010
Charlton Research Company for Research!America

Most Doctors Do Not Suggest Participating in Clinical Research

Has your doctor ever suggested that you participate in a clinical research study?

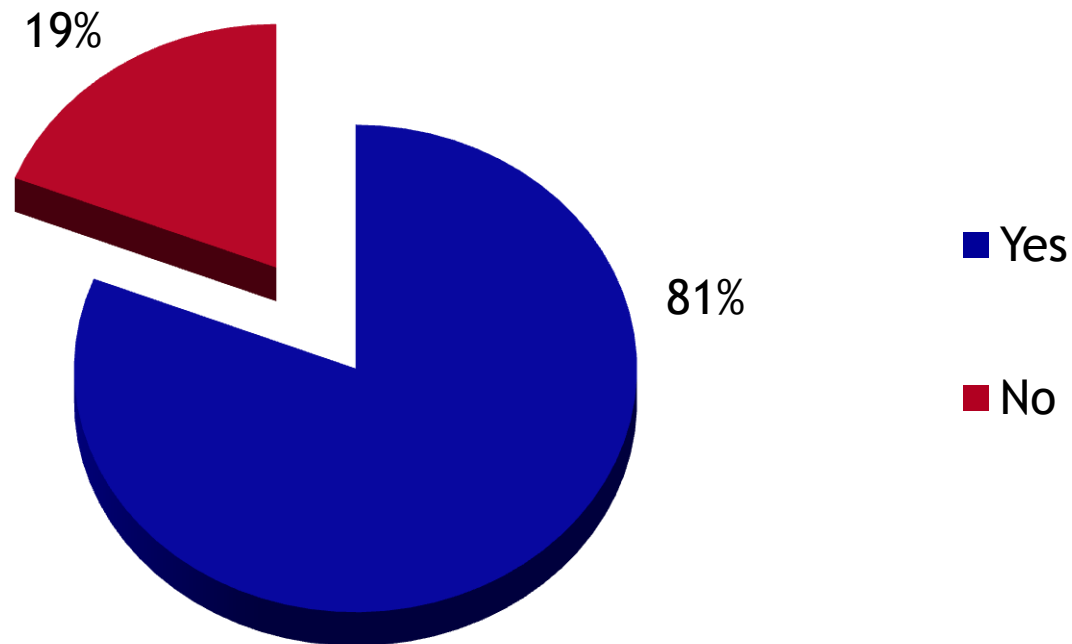


Respondents: 1,000

Source: Research Enterprise Poll, February 2010
Charlton Research Company for Research!America

Americans Willing to Share Personal Information for Health Research

Assuming that appropriate privacy protections were used, would you be willing to share your personal health information so researchers can better understand diseases and develop new ways to prevent, treat and cure them?



Respondents: 1,000

Source: National Poll, May 2010
Charlton Research Company for Research!America

Public Perceptions of Clinical Trials (Slide 1)

“Using the scale below, please indicate how strongly you agree or disagree with the statements below. People who participate in clinical research studies...”

Percent saying strongly or somewhat agree:

Are making a contribution to science	86%
Are part of an experiment to test medications/treatments not already available to the public	79%
Learn more about their condition and health in general	76%
Have a chance to get free medicine	65%
Do not have to pay for medical care	53%

Public Perceptions of Clinical Trials (Slide 2)

Percent saying “strongly agree” or “somewhat agree”:

Are taking a gamble with their health	49%
Get the best possible treatment	48%
Are like guinea pigs	46%
Have access to the best physicians	46%
Spend a lot of time at the doctor’s office	34%
Are part of an experiment to test medications/treatments already available to the public	33%

Respondents: 2,261

Clinical Trials: Risks

Which of the following do you consider to be the greatest risk of participating in a clinical research study?

Possible side effects	47%
Health risks	32%
Unproven therapy	9%
Receiving a placebo (sugar pill)	5%
Privacy concerns	2%
Other	1%
None; I do not believe there are any risks	4%

Respondents: 2,261

Clinical Trials: More Perceptions (Slide 1)

- **93%** said they believed that all possible measures would be taken to protect their safety; **94%** said they believed that all possible measures would be taken to protect their privacy.
- **56%** said that clinical trials sponsored by a pharmaceutical company would likely have a conflict of interest.

Respondents: 400

Clinical Trials: More Perceptions (Slide 2)

- **76%** said they expected their treating physician to inform them about current trials
- **91%** said they wanted to be informed about the results of the study; if they were not informed, **68%** would refuse to participate.

Respondents: 400

“Nothing about us without us.”

—Slogan credited to Disabled People South Africa in 1993

From the book “Nothing About Us Without Us: Disability Oppression and Empowerment” by James I. Charlton

Recommendations for NHLBI

- Do more to engage media and thus, the public. Build on existing partnerships and brands.
- Change the culture of science to embrace patient engagement in all aspects of clinical research. Work with COPR and others to make this an NIH-wide priority.
- Work with grantee organizations and others to encourage more clinicians to speak to patients about clinical research.

