

Thoughts on Engaging Public Interest, Participation & Support

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President

Research!America

October 19, 2005

Secretary's Advisory Committee on Genetics

Health and Society

Bethesda, MD

Ten Considerations

- 1. Earning and maintaining public trust**
- 2. Assuring broad support of scientific community**
- 3. Big picture context issues**
- 4. Identify an urgent, compelling goal**
- 5. Involvement of public at each step**
- 6. Public engagement vs. public relations**
- 7. Words matter**
- 8. Messengers matter**
- 9. Media matters**
- 10. Funding**

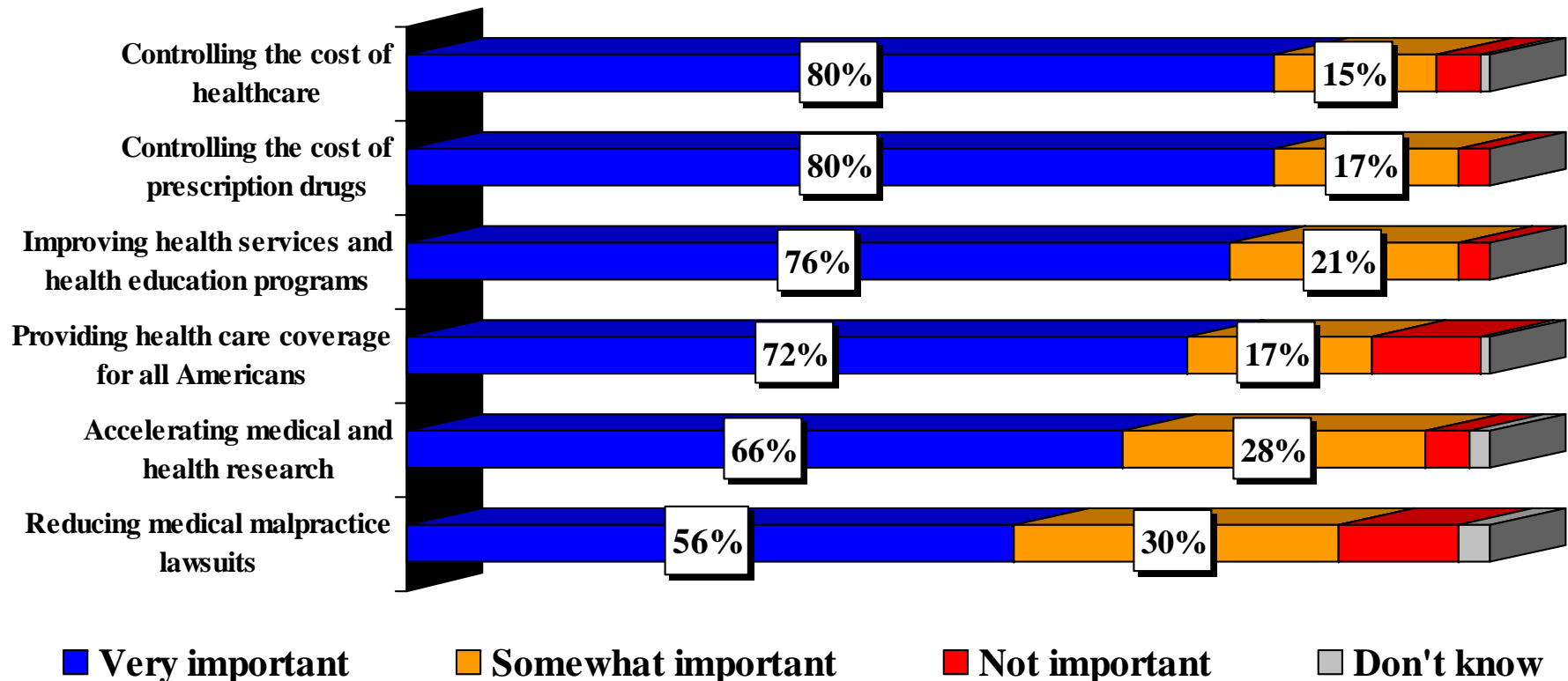
Ten Considerations

3. Big picture context issues

- Little open space on the public agenda
- General distrust of government
- Science education/literacy
- Health care cost, access and quality

Controlling Cost of Health Care Important to Americans

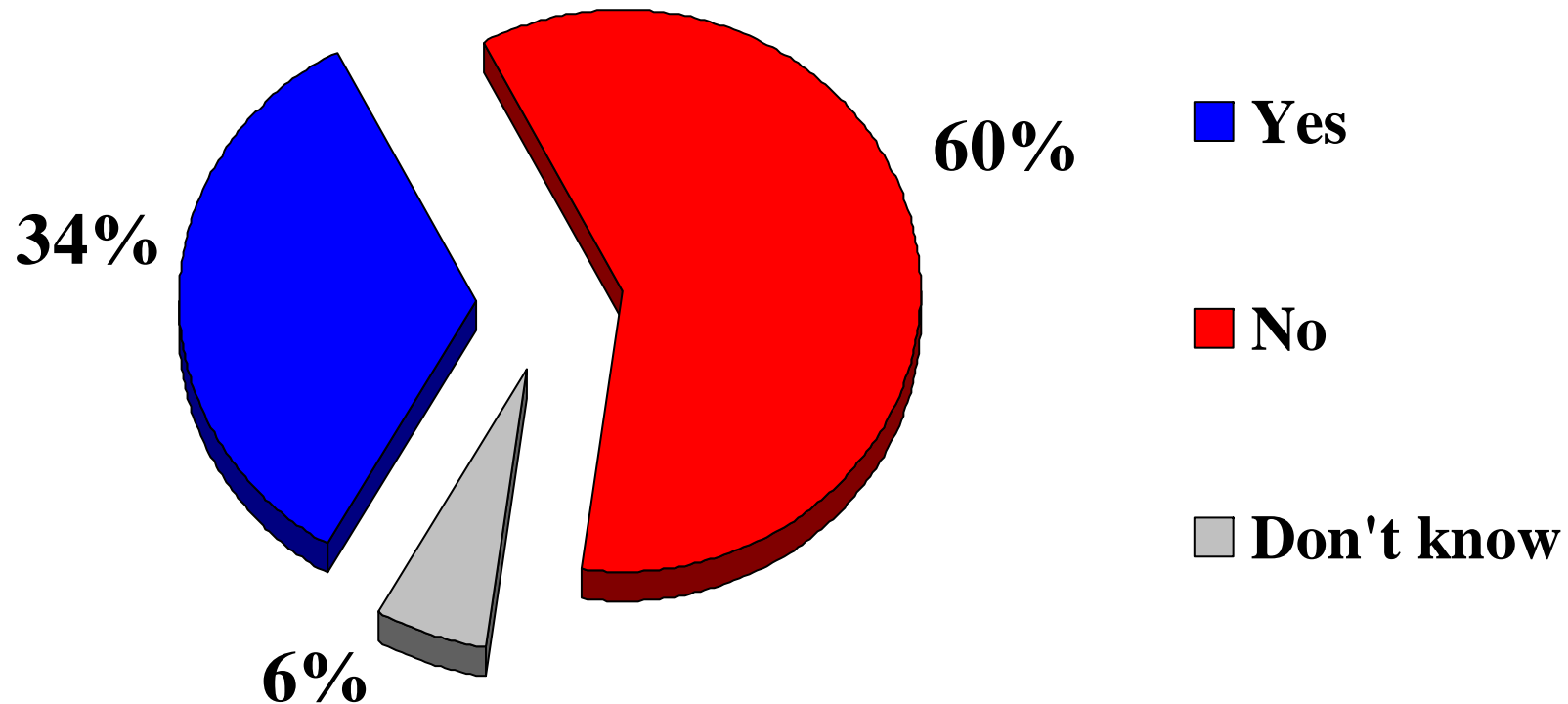
How important would you say each of the following health issues are in terms of national priorities?



Source: National Survey, 2005
Charlton Research Company for Research!America

Americans Say U.S. Health Care Not the Best

Do you believe that the United States has the best health care system in the world?



Source: National Survey, 2005
Charlton Research Company for Research!America

Ten Considerations

4. Identify an urgent, compelling goal

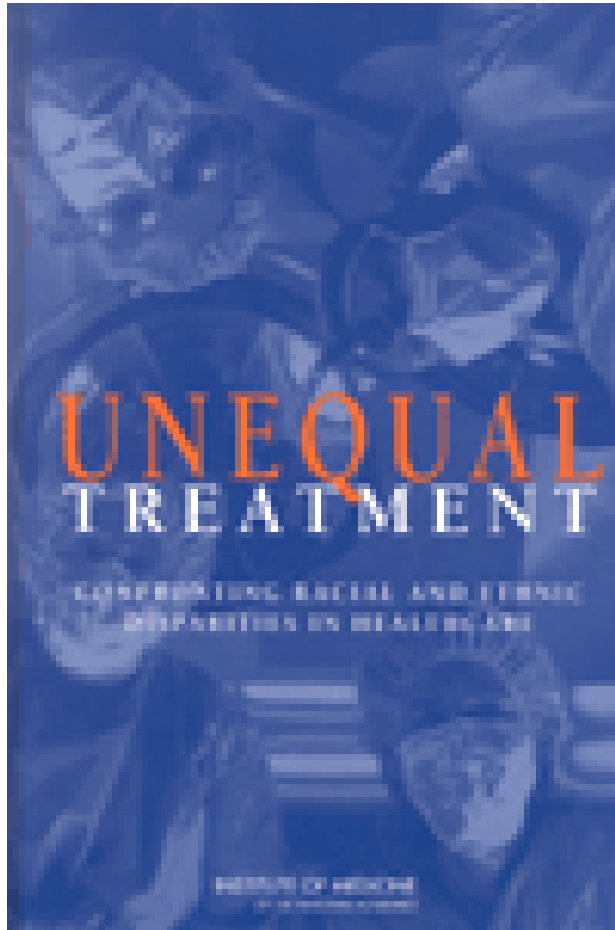
- Eliminate health disparities
- Eliminate childhood obesity
- Assure U.S. global competitiveness
- Save lives/save money



“[The goal] has to feel like history. Incrementalism leaves the audience in a snooze.”

Bono as quoted in *The New York Times Magazine* in reference to his call for 100% debt cancellation of the \$6 billion that the poorest African countries owe the U.S.

September 18, 2005

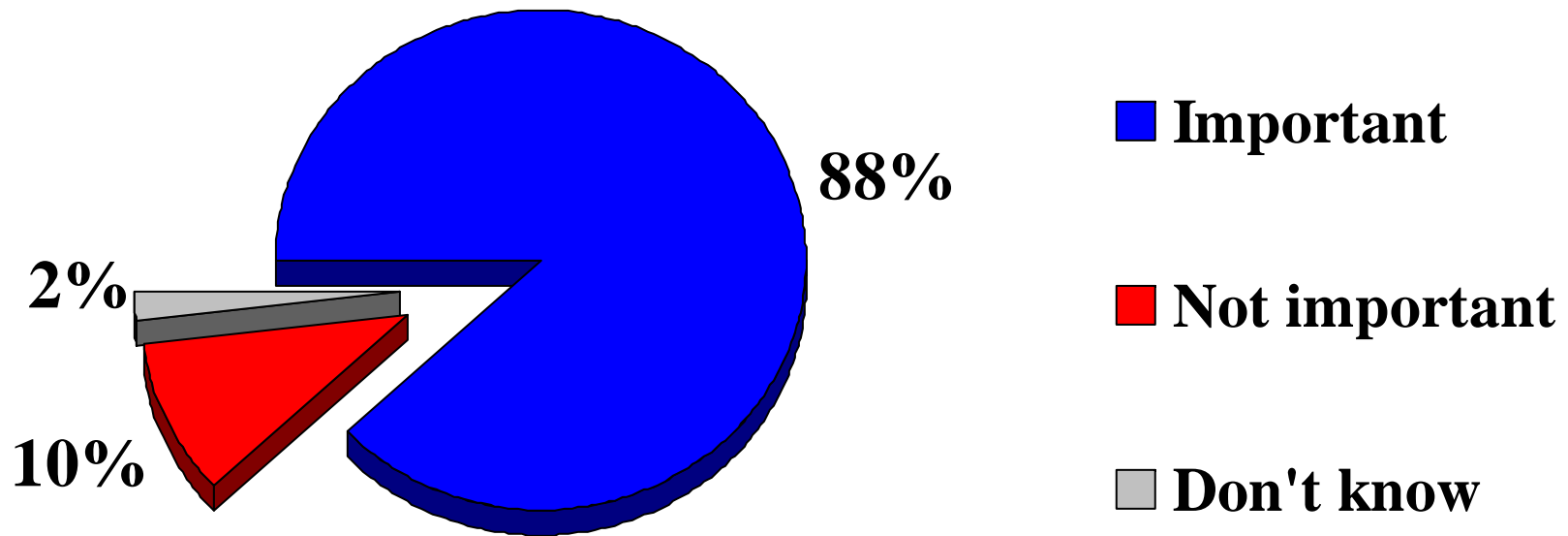


“Minorities are more likely to receive lower-quality health care, regardless of income and insurance coverage.”

Source: “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.” Report from the National Academies’ Institute of Medicine, March 2002

Important to Eliminate Health Disparities

Studies show that certain health problems such as diabetes, heart disease and infant mortality happen more often among citizens with lower incomes and minorities. How important do you feel it is to conduct medical or health research to understand and eliminate these differences?



Source: "Taking Our Pulse: The PARADE/Research!America Health Poll" conducted by Charlton Research Company, 2004

ROLL CALL



RESEARCH SHOWS THE BEST WAY TO FIGHT CHILDHOOD OBESITY IS TO PREVENT IT.

Prevention is sometimes so obvious, we often take it for granted. But it's prevention and public health research that are helping combat America's childhood obesity epidemic. By uncovering the genetic, social, economic, environmental and psychological causes of this disease, public health research is determining ways to keep our kids healthy. Fighting obesity through prevention and public health research contributes to health cost savings. Less than one cent of every healthcare dollar is spent finding these answers. Even so, agencies like the Centers for Disease Control and Prevention, which are leading the prevention effort, protect the health of our nation. To see what prevention means to you, visit researchamerica.org.

PREVENTION

Protecting what's important to you.

Research America
A COMMITMENT TO PUBLIC HEALTH



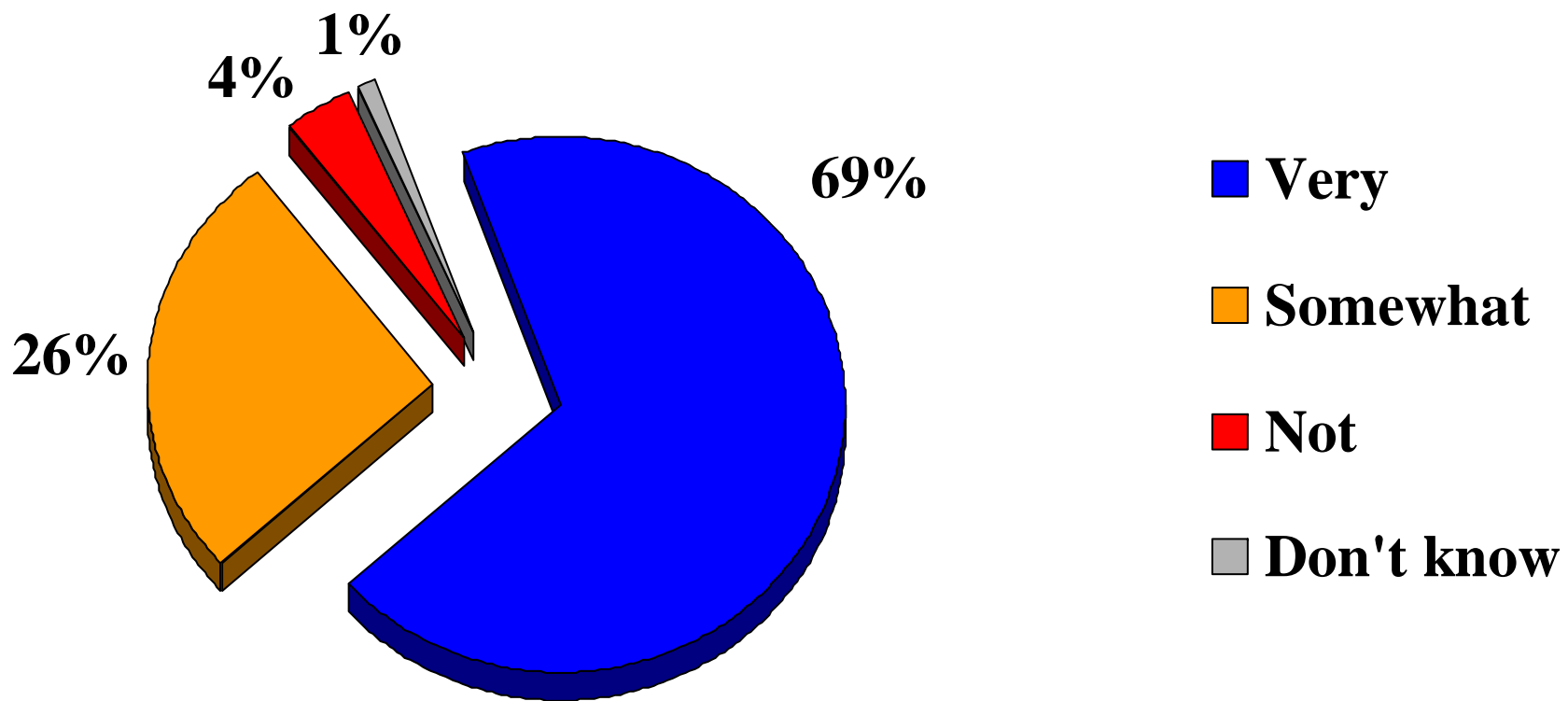
ASPHI
ASSOCIATION
OF STATE
PUBLIC HEALTH OFFICIALS



NATIONAL
ASSOCIATION OF
COUNTY & CITY
HEALTH OFFICIALS

U.S. Should Be Global Leader in Medical and Health Research

How important do you think it is that the U.S. maintains its role as a global leader in medical and health research?



Source: National Survey, 2005
Charlton Research Company for Research!America

SAVING LIVES

SAVING MONEY

HOW RESEARCH SAVES LIVES:

- ⌘ Since 1970, death rates from cardiovascular diseases have fallen by almost 50 percent and death rates from stroke have fallen by 60 percent, yet they are still the number one cause of death.*
- ⌘ The National Institutes of Health-sponsored Framingham Heart Study identified smoking, high cholesterol and high blood pressure as risk factors for heart disease and stroke. Awareness of these risk factors by physicians and the public resulted in a major decrease in heart disease and stroke since 1970.**
- ⌘ Cholesterol reducing drugs such as statins are being used by millions of Americans to prevent heart disease and strokes, to decrease recurrence of heart attacks and to reduce the need for bypass surgery. Statins also improve survival of heart transplant patients.**

*SOURCE: THE CENTERS FOR DISEASE CONTROL AND PREVENTION (WWW.CDC.GOV)

**SOURCE: NATIONAL INSTITUTES OF HEALTH (WWW.NIH.GOV/)

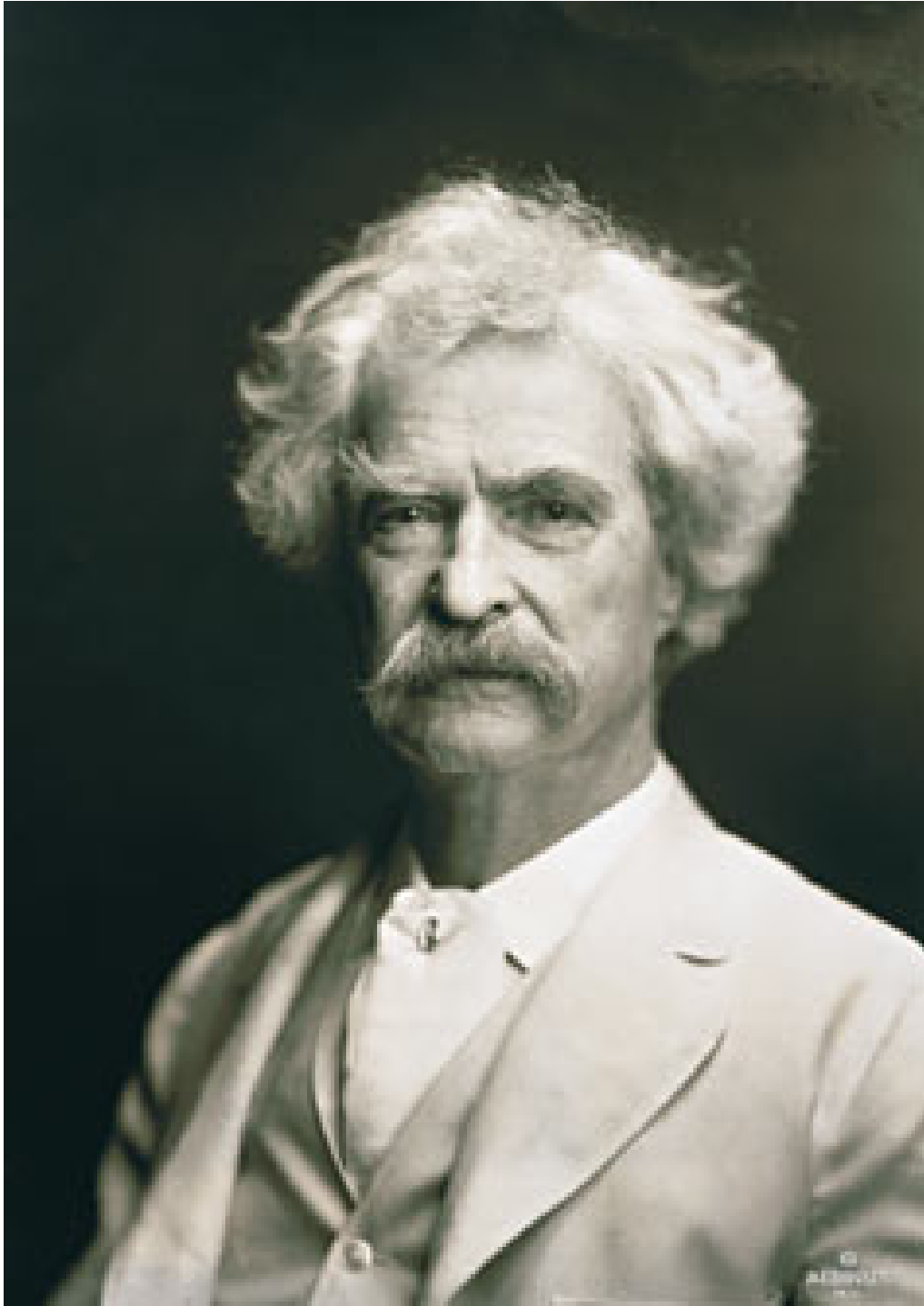
How Research Saves Money:

- **Treatments that delay the onset and progression of Alzheimer's disease by five years could save \$50 billion a year in health care costs.**
- **Researchers have developed treatments that delay or prevent diabetic retinopathy, saving the U.S. \$1.6 billion a year.**
- **Preventing HIV transmission from an HIV-infected pregnant woman to her baby would save an estimated \$650,616 in medical costs and lost productivity over the child's lifetime.**

Ten Considerations

5. Involvement of the public at each step

- Planning, participation, oversight and reporting
- Track public attitudes
- Respond to public concerns



“Supposing is
good, but
finding out is
better.”

~ *Mark Twain*

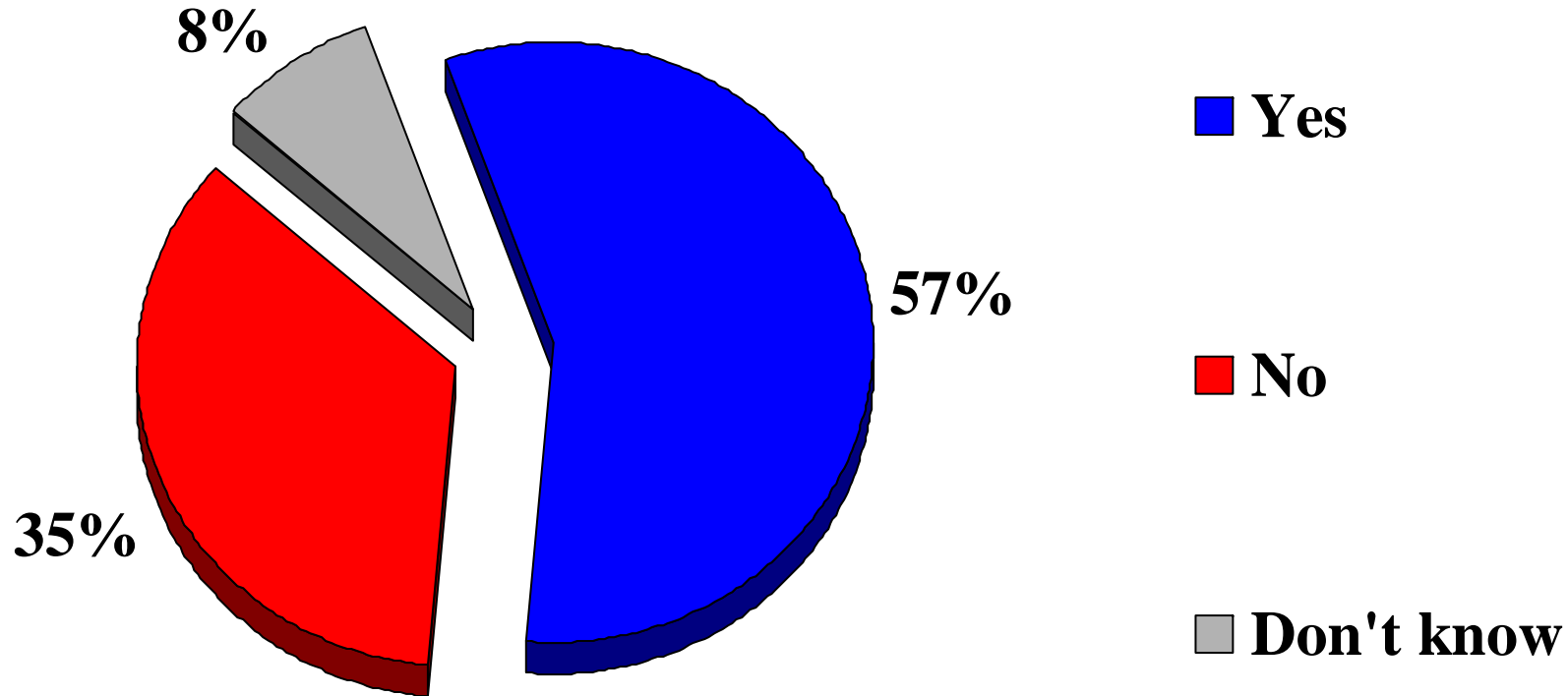
Concerns About Genetic Testing

What concerns, if any, do you have about genetic testing? (*first mentions*)

No concerns	39%
Safety/possible misuse of information	15%
Privacy invasion/Database of everyone	11%
Don't understand it	8%
Don't want it used for cloning	6%
Cost	4%
Might not be accurate	4%
Other (Less than 4% of responses)	8%
Don't know	5%

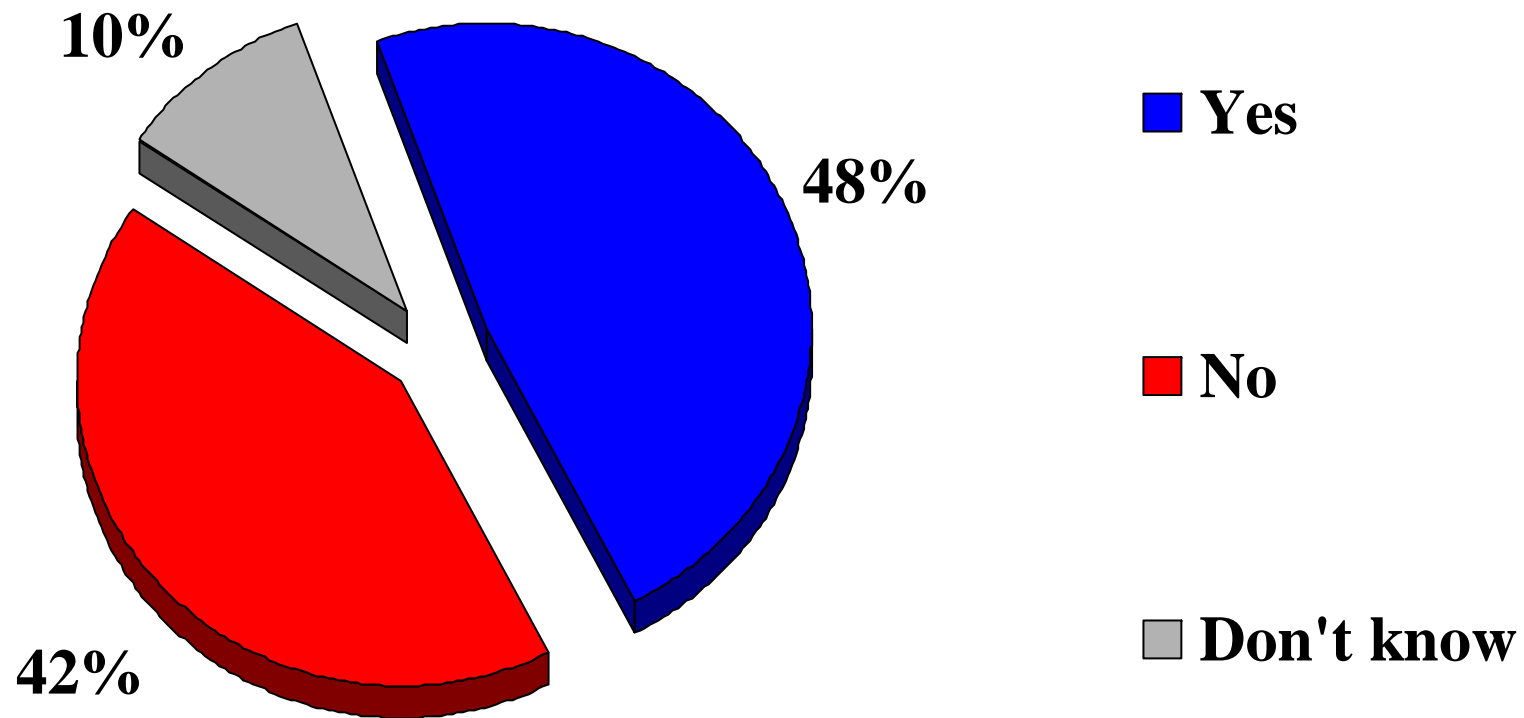
Americans Willing to be Genetically Tested

Researchers recently completed mapping the human genome and can now analyze an individual's complete genetic makeup. Would you be willing to be genetically tested to help doctors diagnose and prevent disease?



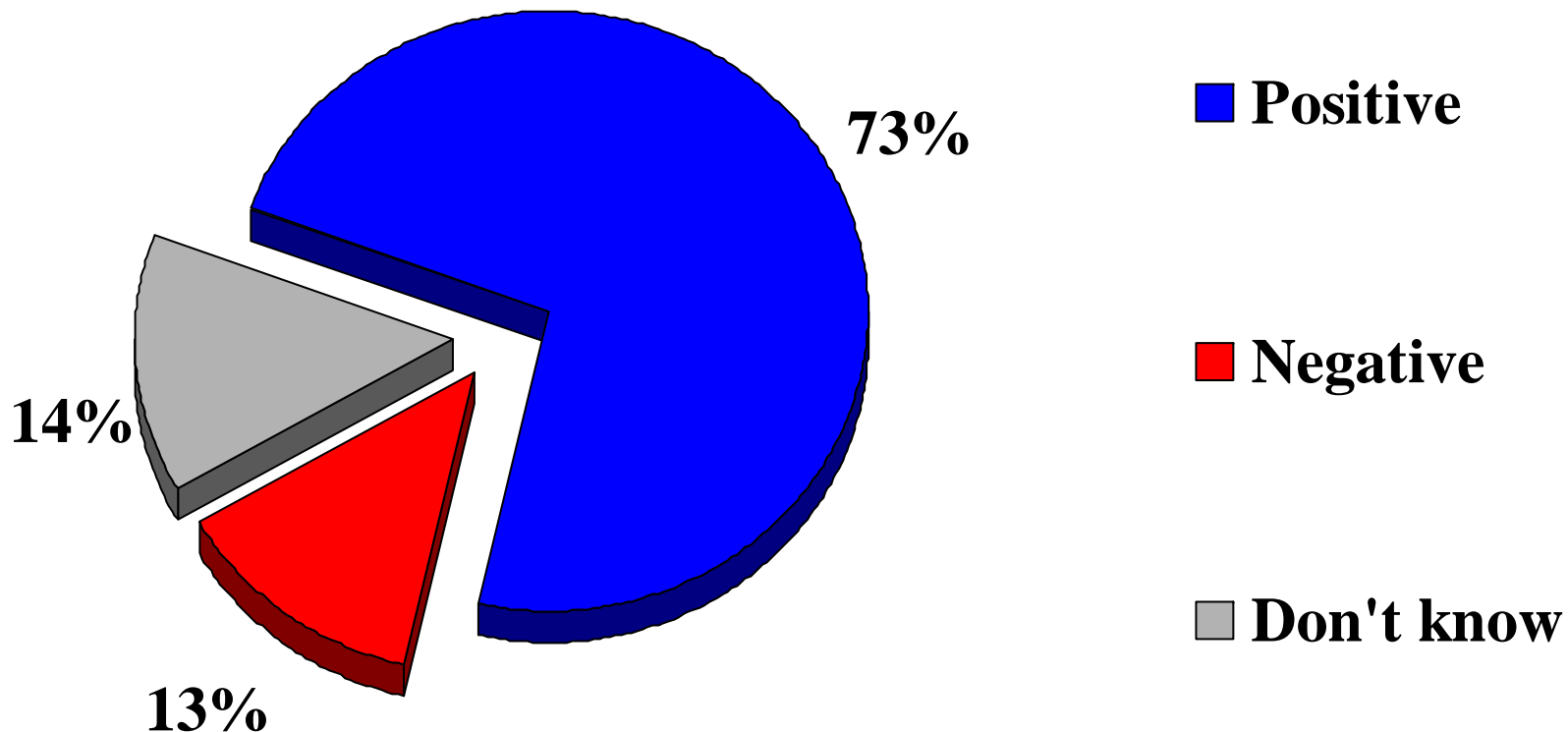
Many Americans Willing to Contribute DNA for Research

Would you be willing to contribute a sample of your DNA to a national databank to be used *only* for health related research?



Personalized Medicine Will Have Positive Impact

Personalized medicine refers to testing and treatment customized to an individual's genetic makeup. Do you think that personalized medicine will have a positive or negative impact on future health care?



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Words Matter

- “Environment” means many things
- “Research projects” vs “research grants”
- “Volunteers” instead of “subjects”
- “Teaching and research hospitals” better than “academic medical center”
- “Fellow citizens” not “laypeople”
- The fewer words, the better...

THREE SENTENCES OR LESS:

MAY 4, 2005

COMMUNICATING PUBLIC HEALTH RESEARCH IN AN ERA OF HEADLINE NEWS

REGISTER FOR A SPECIAL ONE-DAY FORUM DEVOTED TO
COMMUNICATING PREVENTION AND PUBLIC HEALTH RESEARCH

MAY 4, 2005

JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH
615 North Wolfe Street / Baltimore, MD 21205

ADVOCACY TRAINING WORKSHOP 8:30 a.m. to 12:30 p.m.

Learn skills to effectively communicate the value of public health research to the media, elected officials, decision makers and the public. LIMITED TO 40 PARTICIPANTS

PANEL DISCUSSION 1:30 to 3:30 p.m.

Join a lively panel of eminent professionals representing research, politics and the media to hear how news coverage both informs individuals and shapes public policy agendas. Moderated by Alfred Sommer, MD, MHS '73, Dean of the Johns Hopkins Bloomberg School of Public Health.

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“I don't see how we can turn our backs on [embryonic stem cell research]. We have lost so much time. I just can't bear to lose any more.”

~ *Nancy Reagan*, former first lady

“Nancy Reagan makes a rare speech urging more research, which is limited by U.S. policy,” by Stephanie Chavez. LA Times, May 9, 2004.

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The Influence of the Media



- **Policymakers respond to media**
- **Constituents learn from the media**
- **Media attention can create public pressure**

PARADE/Research!America Poll
on "Stem Cell Research: What
Americans Think" July 10, 2005

PARADE

Now...what the American people think about

Stem Cell Research

A New PARADE/Research!America Health Poll

answers

*The hype could be getting
in the way of science.*

**Nancy Reagan Calls
For Stem Cell Research**
Former First Lady Makes Plea in Speech

in the stem cell debate

Catholics Split on Embryo Issue

'Adoption' Embraced by Evangelicals in Stem Cell Debate

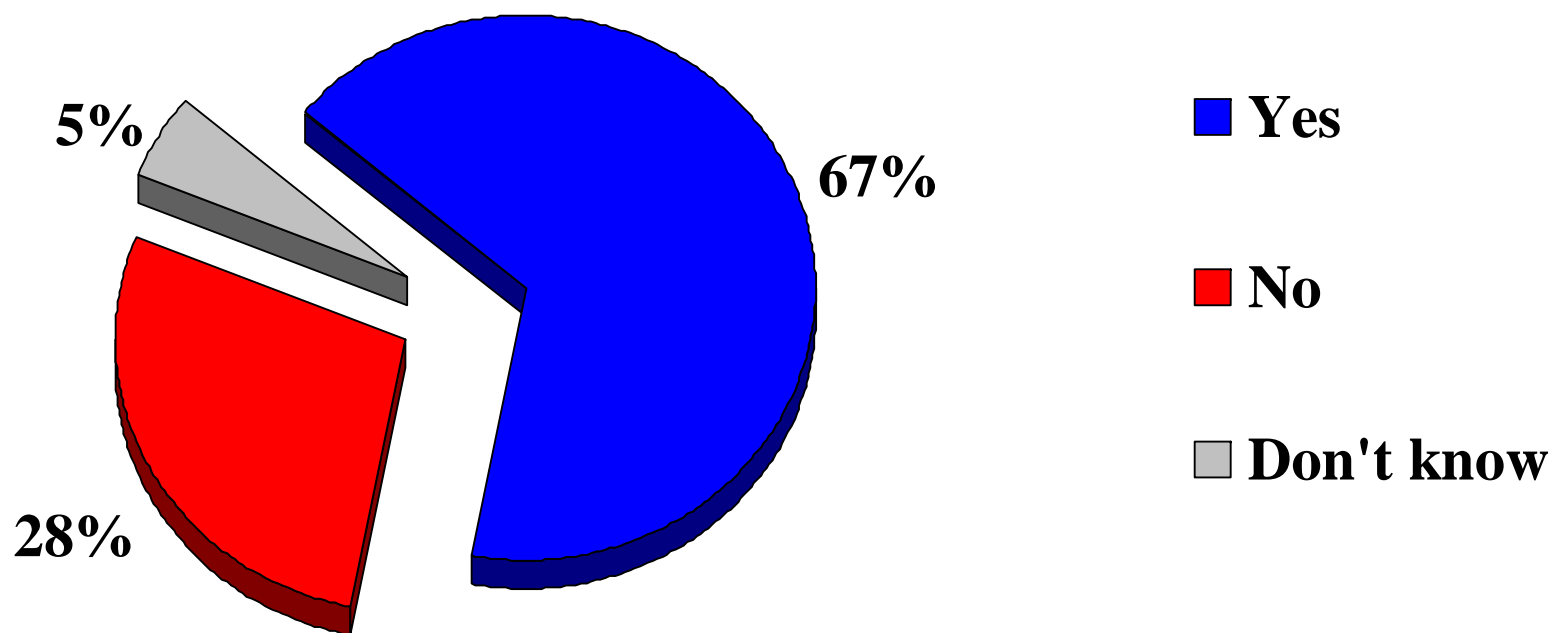
Stem-cell research limit asked
Right to life wants legislators to restrict use of state money

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Americans Willing to Pay More Taxes for Medical Research

Would you be willing to pay \$1 per week more in taxes if you were certain that all the money would be spent for additional medical research, or not?



Source: National Survey, 2005
Charlton Research Company for Research!America

“Dollars & Sense”



- Web shoppers spent \$114 billion in 2003.
- That amount would fund the National Institutes of Health for 4 years!

Sources: *The State of Retailing Online 7.0*, Forrester Research, May 2004; NIH

“Dollars & Sense”



- The golf industry has revenue of \$2 billion a year for clubs and golf balls alone.

- That amount would fund the National Human Genome Research Institute for over 4 years!

Sources: NY Times 2003, NIH

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Acknowledgements

To my colleagues for their assistance and consultation on this presentation, thank you!

Christine Brown, Ph.D.

Karen Goraleski

Heather Jameson



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