Public Attitudes and Perceptions About Health-Related Research

Mary Woolley, MA
Stacie M. Propst, PhD

Public policy affecting the conduct of health-related research and health care in the United States is continuously shaped by elected and appointed decision makers, ie, officials who represent the public. These officials pay close attention to issues that concern the health of the public. Members of an enterprise that seeks to serve the public's interest, in this case, medical researchers and funders of health-related research, should be well informed as to the public's perceptions and attitudes concerning research and should understand the public context in which research is conducted. As elected officials well know, merely speculating about public attitudes is risky. In Mark Twain's words, "Supposing is good, but finding out is better."

In the early 1990s, Research!America began commissioning public opinion surveys to determine what Americans know and think about the nation's research enterprise. These surveys are designed to monitor public opinion and to better align messages and programs with the overarching goal of making medical and health research a higher national priority. In this article, we present information on public attitudes and perceptions about health-related research and health care by summarizing data from previously reported national and state opinion surveys.

METHODS

The data presented in this article are drawn from 70 state surveys and 18 national surveys commissioned by Research!America and conducted by Charlton Research Company and Harris Interactive from 1996 through 2005. Most had sample sizes of 800 or 1000 adults (range, 800-5377) surveyed by telephone interview, using random-digit-dial methods among a state or national sample. A sample generated using this method is representative and statistically projectable to the total population of adults having a telephone. To a 95% degree of confidence, a sample size of 800 yields a theoretical margin of error of ±3.5%, and a sample size of 1000 yields a theoretical margin of error of ±3.1%. In addition to these data, we include information from public opinion surveys commissioned by other groups using methods similar to our own, unless otherwise noted.

Data presented in this article were selected to summarize the public's general knowledge about and attitudes toward health-related research and health care by summarizing data from previously reported national and state opinion surveys.

RESULTS

Health and Research as National Priorities. Health care is often cited as a leading national priority. In December 2003, Americans rated increased funding for medical and health research as a very important national priority, along with education, Social Security, Medicare, and homeland security (TABLE). Similarly, in a 2005 survey commissioned by GlaxoSmithKline, on September 20, 2005 www.jama.com Downloaded from www.jama.com at GlaxoSmithKline, on September 20, 2005
CBS/New York Times Poll, Americans ranked health care (28%), education (22%), and jobs (20%) as the most important domestic issues. Maintaining world (global) leadership in health-related research is important to Americans. According to 2005 national data, 78% say it is very important, 17% say it is somewhat important, and 4% say it is not important for the United States to be a global leader in medical and health research. This high level of support has been apparent for more than a decade. When asked which other countries are leaders in medical and health research, 21% of respondents did not have a response or replied that they did not know. Cited countries included Great Britain (21%), Germany (10%), Japan (8%), Canada (8%), and China (5%).

In addition to global leadership, 47% of Americans say it is very important for their state to be a leader in scientific research, 37% say it is somewhat important, 14% say it is not important, and 2% say they don’t know. This finding is robust in state polling as well as nationally, i.e., residents of states with a high intensity of research are not significantly more likely to value state leadership than residents of states with less research intensity.

Investment in Research. A very high proportion of Americans (94%) say that medical and health research is important to the US economy, and 79% agree that basic science research should be supported by the federal government, “even if it brings no immediate benefits.” In state and national polls commissioned by Research!America since 1998, support for federal funding of basic research has consistently been about 80%. The National Science Foundation initially posed this question in a 1985 survey and has also consistently found the same level of support.

Moreover, an overwhelming majority (99%) of Americans say that it is important for the United States to educate and train individuals qualified to conduct medical and health research, and 90% say it is very important to do so. However, only 23% of Americans say the United States is performing very well in science and math education; 35% say that the United States is performing somewhat well.

More than half (55%) of Americans want more spent on research, and, most importantly, they are willing to pay for it. The majority (67%) of Americans are willing to pay $1 more per week in taxes for additional medical research, which represents an upward trend from 2004, when 46% said they were willing to pay more for health research (Figure 1). Support levels for spending more tax dollars for research has fluctuated significantly over the years (1996-2005) that Research!America has fielded this question.

However, Americans are concerned about barriers to research, and 61% believe that “too many regulatory barriers” is a reason medical research is not making more progress, 49% feel that not enough money is being spent on research, 45% say the tax burden on research and development is too high, and 40% feel there are not enough researchers. Many Americans (74%) agree that Congress should support tax and regulatory policies that encourage private industries to conduct more medical research.

Only 19% of Americans said that institutions conducting medical research in the United States, such as government, universities, and the pharmaceutical industry, work together to develop new treatments and cures; 73% said that these various types of research institutions are in competition; and the majority (95%) said that those research institutions should be working together.

Health Care. In the CBS/New York Times Poll, Americans considered health care one of the most important domestic issues. In a 2005 survey, health care costs were the leading concern in terms of national priorities, although accelerating medical and health research rated as very important to 66% of those surveyed and somewhat important to another 28%. Importantly, 58% indicate that as the United States looks for ways to manage health care costs, the national commitment to health-related research should be higher.

Americans are losing confidence in their health care system. In 2005, 60% of Americans said that they did not believe the United States has the best health care system in the world. Similar evidence of declining confidence in the health care system was found in a joint survey project of the Kaiser Family Foundation, the Agency for Health and Research Quality, and the Harvard School of Public Health. Those results indicate that the public was more likely to say that they are dissatisfied with the quality of health care in this country in 2004 than in 2000. In fact, they were more than twice as likely to say that health care has gotten worse in the past 5 years rather than better. More than half (55%) of the public say that they are currently dissatisfied with the quality of health care in this country, compared with 44% who reported the same in 2000.

In December 2003, 66% of Americans responded that it is very valuable

©2005 American Medical Association. All rights reserved.
important it is that the United States support research that focuses on how well the health care system functions and how it could function better, 70% said it is very important and another 25% said somewhat important.

Americans view research as an important basis for good health care. Almost all (95%) say that health care services should be based on the best and most recent research available, and 96% say it is important to invest more in research to ensure that there is a solid scientific base for health care.

Clinical Research. The majority (68%) of Americans perceive clinical research as having great value. In 2004, 55% said they would be likely to participate in a clinical research study, a decrease from 2001, when 63% said they would be willing to participate. The level of awareness of clinical trials is a major issue in participation in research. In a 2000 poll commissioned by the American Society of Clinical Oncologists and conducted by Harris Interactive, 84% of nearly 6000 patients with cancer said they were either unaware or not sure that participation in a clinical trial was an option.

Despite their lack of awareness, Americans remain generally amenable to participating in clinical research and to sharing personal health information. Sixty percent of Americans say that they are willing to release their health information if it would help physicians and hospitals improve their services.

In addition, in 2004, 46% of Americans said that they would be much more likely to believe a hospital was good if they knew research and training of medical students and other health professionals was taking place there. Whereas 36% said they would be somewhat more likely to believe so, 9% said they would be less likely, and 9% did not express an opinion. In a 2004 polling project initiated by the Association of American Medical Colleges, members of the public were asked to rate their favorability toward certain types of hospitals. Children’s hospitals rated the highest in favorability at 78%. Teaching hospitals and medical schools also earned high favorability ratings of 63% and 60%, respectively.

When asked about potential changes to Medicare, 65% of Americans said it was very important that any changes should ensure the ability of teaching hospitals to train physicians and other health professionals, and 60% said it was very important for teaching hospitals to provide health care to underserved communities.

Disparities. Certain health problems occur more often and have increased adverse outcomes among people with lower incomes and among minorities. Most Americans (95%) feel it is important to conduct health-related research to understand and eliminate these disparities (aggregate data from state polls conducted by Harris Interactive, 2004-2005). This high level of support for correcting differences in the quality of health care has remained stable from 2000-2005 (national and state polls conducted by Charlton Research Co and Harris Interactive). In a 2004 poll, the most important factors determining whether a patient receives high-quality health care were access to health insurance (65%), employment status (46%), income (44%), age (37%), urban location (33%), race/ethnicity (29%), and sex (24%).

Public Health and Prevention. Public awareness of the value of the public health system in improving health and longevity in the United States is strong. A majority (55%) of Americans have said that preventable diseases and injuries are a major health problem in the United States today and 37% that they are a minor problem, while only 4% said they are not a problem and 4% that they did not know. When asked to choose whether research to prevent disease or research to cure disease is more valuable, almost half (48%) said prevention research is more valuable. 36% said research to find cures, and 14% said that both are equally important.

However, many Americans (66%) say the United States is spending too little on public health research, and 64% say
at least twice as much should be spent (Figure 2) (aggregate data from state polls conducted by Harris Interactive, 2004-2005). Approximately the same percentage (68%) said it is important for the US government to invest in research that helps the Centers for Disease Control and Prevention fulfill its mission to protect the health and safety of Americans at home and abroad.6

Issues Affecting Research. In a 2005 survey about concerns regarding medical and health research, 20% of respondents said they had no concerns, 13% said they didn’t know, 9% had concerns about research being profit-driven, 9% said finding cures for diseases was a concern, 8% were concerned about wasting money, 6% said research is needed, 5% were concerned that there is not enough funding for research, and another 4% said research takes too long.6

Only 4% mentioned stem cells and cloning, and 1% said they were concerned about animal testing and abuse. In addition, 76% of Americans currently believe that the use of animals in medical research is necessary for progress in medicine,6 and this response trend has been consistently positive since 1996 (Research!America statewide and national polls, 1996-2005).

Recent polls show that Americans strongly oppose (77%) the use of cloning technology to create a child (also referred to as reproductive cloning), whereas they consistently support (66%) the use of cloning technology to help in the search for possible cures and treatments for diseases and disabilities (also called therapeutic cloning).6 In a number of states, including Alabama, Indiana, Missouri, and Oklahoma, support for therapeutic cloning exceeds 60% among those surveyed (data available from authors on request).

In 2005, a PARADE/Research!America Health Poll7 that focused on stem cell research found that 45% of Americans said they are following the stem cell issue somewhat closely, 17% very closely, 25% not too closely, 12% not at all, and 1% that they did not know. Thirty-four percent said that they strongly favor the research, while 24% said they somewhat favor it—for a majority of 58% who favor embryonic stem cell research. A substantial portion (13%) did not express an opinion, 11% were somewhat opposed, and 18% were strongly opposed. Of the 29% who were opposed, 57% said that their opposition was based on religious objections. These data correlate well with those from polls conducted by other organizations, such as the CBS News Poll,15 the CNN/USA Today/Gallup Poll,16 and the ABC/Washington Post Poll.17

In light of changing federal policies and regulations concerning the implementation of evidence-based prevention practices and the pursuit of certain types of research, we asked Americans if they believe that an abstinence-only approach to teen sex education will successfully prevent sexually transmitted diseases and unwanted pregnancies. A majority (56%) said no, while 39% said yes and 5% did not know.14 In a 2004 PARADE/Research!America Health Poll, we asked Americans how important they believe it is to study issues that may affect their sexual and reproductive health. A substantial majority (79%) said that it was important, while 18% said it was not important and 3% did not express an opinion.6

A majority of Americans (67%) have reported that they would like to see more about scientific and medical research in the media (ie, newspapers, magazines, and television).6 Additional media exposure for research may help address the fact that Americans are generally unaware of the scientists and the research institutions in their communities. Only 18% say that they personally know a scientist; of this small percentage, 36% identify the life sciences as the field in which the scientist(s) they know works. When asked who comes to mind when they hear the word “scientist,” 30% said Albert Einstein and 17% mentioned researchers and doctors generally.

Americans are largely unaware of where research is taking place. In a recent national poll, 62% were unable to name any institution, company, or organization where medical and health research is conducted. In surveys of whether Americans can name relevant federal agencies based on a description of the agency’s mission, the Food and Drug Administration is highly recognizable to the public—68% of Americans are able to name it. The Centers for Disease Control and Prevention fares less well, with 32% recognizing it, and 53% responding that they do not know. A greater majority of Americans (73%) cannot name the National Institutes of Health as the government agency that funds most of the medical research paid for by US taxpayers. Similarly, 82% could not name the National Science Foundation based on a description of its mission (Research!America 2005 National Survey unpublished data).

COMMENT

Despite controversies that periodically emerge to threaten the research enterprise, there is no hard evidence that the public has abandoned its high regard for health-related research. Many of the challenges facing the research community are not new but are certainly more visible to the public. This heightened visibility—such as adverse events experienced by volunteer participants in clinical trials and highly

Figure 2. Percentage of Americans Wanting More Money Spent on Public Health Research, Categorized by Cents Out of Each Health Care Dollar

Surveys of 8 states (N = 6400). Six percent of respondents replied that they did not know. Aggregate data from state polls conducted by Harris Interactive, 2004-2005.

©2005 American Medical Association. All rights reserved.
PUBLIC ATTITUDES AND PERCEPTIONS ABOUT HEALTH-RELATED RESEARCH

...every opportunity to engage the public in an effort to answer their questions and put a human face on research. Ongoing public opinion survey research plays an important role in informing the research community about trends in public knowledge of and attitudes toward the many elements of the research endeavor.

National and state-based public opinion polls conducted in the past decade might be said to reveal a remarkable tolerance for the imperfections of the medical, health, and scientific research enterprise. The widespread public support for research and researchers is now, as it has long been, entirely consistent with public aspirations for better health and well-being, and for longer and more productive lives. Research epitomizes the spirit of limitless possibilities and the widespread belief in better days to come that has long characterized the American dream. Speaking to the Democratic Convention in July 2004, US Senate candidate and Illinois State Senator Barack Obama spoke of “the audacity of hope.” He was not referring to medical research, but medical research nonetheless exemplifies the spirit of his remarks about what makes the United States enduringly strong.

Financial Disclosures: None reported.

Disclaimer: Research!America is a 501(c)(3), membership-supported public education and advocacy alliance founded in 1989 and has 500 member institutions, organizations, and businesses.

Acknowledgment: We thank our colleagues at Research!America, Heather Jameson, BA, and Emily Connolly, MA, for editorial assistance and for producing supporting materials. We are also grateful to Charleston Research Company, particularly Sarah Long, for reviewing the data description and methodology.

REFERENCES