Virtuous but Invisible Interplay of Science, Policy and Population Health

Mary Woolley, President, Research!America
On November 23, Research!America and leading public health organizations will take time to recognize public health professionals who work tirelessly every day to protect us from disease, injury, and other health threats.

Join us in thanking public health professionals in your communities.

Visit www.publichealththankyouday.org to learn more and join the conversation!
"Without research, there is no hope."

Former chair of the Subcommittee on Health and the Environment of the US Congress. Author of: Migrant Health Act, Clean Air Act, Health Manpower Training Act, National Cancer Act, Noise Control Act, Safe Drinking Water Act, Community Health Centers Act, Medical Device Amendments of 1976, the Health Maintenance Organization Act, Emergency Medical Service Act, National Arthritis Act, National Health Promotion and Disease Prevention Act...and more!

The Hon. Paul G. Rogers (1921-2008), aka “Mr. Health” Emeritus Chair, Research!America
“Every public health decision is made on a political decision.”

William Foege, MD, MPH
Senior Fellow, Bill & Melinda Gates Foundation; Former Director, CDC
Current Political/Policy Climate

- Questioning of all public expenditures
- Overriding importance of job creation, economic growth and competitiveness
- Election-year politics
- Health care issues remain on front burner, especially health care cost
- Scientists are not speaking out
- Everyone is looking for solutions
- We’re having a bit of a “moment” on Capitol Hill: budget deal, 21st C Cures
Congress is Paying Attention...and it’s complicated

- Efforts to repeal Obamacare
  - including efforts to eliminate or restrict the Prevention and Public Health Fund
- Gun Violence
- Global Warming
- Mental Health Access and Research
- Reproductive Rights
Congressional Initiatives on Medical Progress

- **House:**
  - Passed 21st Century Cures Act (HR 6) in July with bipartisan 344-77 vote
  - Five year Innovation Fund $8.75B for NIH and $550M for FDA
  - Culmination of year-long Energy & Commerce Committee with broad stakeholder input to advance “discovery, development & delivery”

- **Senate:**
  - HELP Committee is currently gathering stakeholder input and drafting legislation, to be released soon
  - Planning mark up of legislation late 2015/early 2016

- **End Goal:**
  - Both chambers reach a conference agreement that is signed into law asap
Letter to the Committee on Energy & Commerce voicing support for the NIH Innovation Fund in the 21st Century Cures Act

188 organizations signed-on; helping assure this remained in the bill as passed by the House
Advocacy at work

October 1, 2015

The Honorable Nancy Pelosi
Democratic Leader
U.S. House of Representatives
Washington, DC 20515

The Honorable John Boehner
Speaker
U.S. House of Representatives
Washington, DC 20515

Dear Speaker Boehner and Leader Pelosi,

On behalf of Research!America, the nation’s largest nonprofit alliance committed to making medical progress a higher national priority, I urge you to reject any attempt to reduce or eliminate the Prevention and Public Health Fund (PPHF). This fund, which would be eviscerated under the reconciliation legislation that passed the Committee on Energy and Commerce on Tuesday, September 29, should instead be embraced; it is being deployed to fight some of the most deadly and costly diseases confronting the American people.

Importantly, the PPHF is being invested in disease prevention. Analyses of economic outcomes have consistently concluded that prevention programs can save huge amounts of money in the short- and long-term. Looking at obesity alone, a 5 percent reduction in BMI nationwide would save the U.S. nearly $30 billion in just 5 years, and over $610 billion in 20 years. It is estimated that just $10 per person per year dedicated to evidence-based community-supported disease prevention programs would lead to a $2.8 billion net savings in healthcare costs within two years of the investment, and within five years, the savings would reach $16 billion. The PPHF provides resources for prevention programs throughout the country spanning a wide array of conditions, including heart disease and stroke, substance abuse, obesity, cancer, lead poisoning, suicide, and diabetes.

The fund also provides resources for vital infectious disease surveillance and response systems, which allow communities to better prepare and protect their citizens. And it is being used to reduce healthcare-associated infections, which take the lives of tens of thousands of Americans each year, and to reach disenfranchised populations with lifesaving cancer screening services. The benefits of the PPHF extend far beyond these examples, but they are indicative of its positive impact.

We firmly believe that, whether the goal is to advance the wellbeing of Americans or reduce the Nation’s healthcare bill, it makes sense to do more, not less, to prevent disease and build a stronger public health infrastructure. Please protect the Prevention and Public Health Fund. Thank you for your leadership and your stewardship over American priorities.

Sincerely,

Mary Woolley
President and CEO
Letters to the Editor

Make research and innovation a higher national priority

October 25, 2015 12:00 am

Congress should increase spending for federal science agencies

Scientific research is the most powerful tool we have against disease. Discoveries made in the lab today are vital to developing new treatments... Read more

Mary Woolley: Fund federal health research

The May 12 editorial "F苹果 core" wrongly accused the University of North Carolina for receiving tens of millions of dollars in research grants from the National Institutes of Health. The $108 million it received in 2013 was in fact a small part of its overall $944 million in... Read more

It's time to talk openly about mental illness: Your Say

USA TODAY 11:35 p.m. EDT October 14, 2015

Letter to the editor:

We applaud Patrick Kennedy's call for presidential candidates to have a detailed plan for how they would "dramatically improve diagnosis, treatment... Read more
Op-Eds

**Science Translational Medicine**

Research in academic medical centers: Two threats to sustainable support

**ROLL CALL**

**Beltway Insiders**

Saving Lives in the 21st Century and Beyond | Commentary

By Mary Woolley

New technology such as CRISPR-Cas9, a genuine scientific breakthrough, is raising hope for patients with cancer, cystic fibrosis, sickle-cell anemia and other major health threats. The gene editing tool, used in precision medicine, allows changes to be introduced into the DNA of any living cell — potentially enabling repair of disease-causing mutations. Medications designed to...
Campaign for Cures: 2016 Voter Education Initiative

- Elevate medical research in the national conversation during the election season
- Encourage voters to ask candidates their views on issues affecting the pace of medical progress
- Increase public awareness of how public and private sector research contributes to the health and economic security of our nation
Candidates Should Have a Basic Understanding of Science

How important do you think it is that candidates for President and Congress have a basic understanding of the science informing public policy issues?

- **Very Important**: 59%
- **Somewhat Important**: 28%
- **Not Very Important**: 3%
- **Not Important At All**: 2%
- **Not Sure**: 8%

Source: A Research!America and ScienceDebate.org poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
How important is it that elected officials at all levels listen to advice from scientists?

- Very Important: 38%
- Somewhat Important: 2%
- Not Too Important: 8%
- Not At All Important: 10%
- Not Sure: 42%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
“Wouldn’t it be wonderful if all candidates had science advisers or science advisory committees? They will, if individual scientists step up to the plate.”
“Vaccines are very important. Certain ones. The ones that would prevent death or crippling. There are a multitude of vaccines which probably don’t fit in that category, and there should be some discretion in those cases.”
-- Ben Carson, retired neurosurgeon

“I’m for vaccines, but I’m also for freedom. Even if the science doesn’t say bunching them up is a problem, I ought to be able to spread my vaccines out a little bit, at the very least.”
-- Rand Paul, Senator (R-KY), ophthalmologist

“Just the other day, 2 years old, 2½ years old, a child, a beautiful child went to have the vaccine, and came back, and a week later got a tremendous fever, got very, very sick, now is autistic.”
-- Donald Trump
How confident are you in our current system in the U.S. for evaluating the safety of vaccines and recommendations for when they should be given?

Source: Public Opinion Polls, 2008-2015
Confusing headlines and “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. Healthy skepticism is a scientific mindset!
- Public support for science, and public willingness to engage in research, are at stake.
Important for Scientists to Engage with Public on Research

How important is it for scientists to inform elected officials and the public about their research and its impact on society?

- 51% Very Important
- 33% Somewhat Important
- 10% Not Very Important
- 5% Not Important At All
- 2% Not Sure

Source: A Research!America and ScienceDebate.org poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
“...public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed.”

Abraham Lincoln
Research!America Polling

- Commissioning public opinion polls on research issues for more than 22 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.
Do you agree or disagree with the following statement? “Even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the federal government.”

Strong Majority Agree Basic Science Should be Supported

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
How important is it that the federal government funds research that identifies ways to help our health care system function more effectively and efficiently?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
Studies show that certain health problems such as diabetes, heart disease and infant mortality happen more often among minorities or citizens with lower incomes. How important do you feel it is to conduct medical or health research to understand and eliminate these differences?

![Pie chart showing the percentage of respondents who feel the research is very important, somewhat important, not too important, not at all important, or not sure.]

**Very Important: 34%**

**Somewhat Important: 35%**

**Not Too Important: 13%**

**Not At All Important: 5%**

**Not Sure: 13%**

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Do you agree or disagree that Americans will be better off if the U.S. government invests in research designed to improve health around the world?

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in September 2015.
Americans Willing to Share Personal Health Data for Research and Patient Care

For which of the following would you be willing to share your personal health information (Choose all that apply)?

- So health care providers can improve patient care 60%
- To advance medical research 55%
- So public health officials can better track disease and disability and the causes 46%
- None 10%
- Not Sure 13%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
Public Confidence: Steady but Support is Nuanced

Also: 50% of respondents strongly or somewhat agree that scientific research has created as many problems for society as it has solutions.
Workshop hosted by the National Academies of Science, Engineering and Medicine
May 5-6, 2015

- Asymmetry of information—negative information has stronger influence on public perception
- Scientists must trust that a public audience is capable of understanding the science
- Form alliances with other groups to convey trustworthy messages
- Illustrate value of research and be willing to share personal stories
- Remember that science is not partisan

Access the full report online at http://www.nap.edu/
“Scientists should not presume to claim to have better value judgments, to have a better sense of democratic values, than non-scientist citizens,” Holt explains, “but we can teach the principles, as well as the excitement and the beauty of the science, and we can help them understand the key points that go into making the political, social and value judgments.”

Rush Holt, PhD, board member, Research!America CEO of AAAS and former U.S. Representative (D-NJ)
Most Trusted Spokespersons for Science?

How trustworthy do you consider each of the following to be as spokespersons for science?

- Scientists
  - Very trustworthy: 33%
  - Somewhat trustworthy: 48%
  - Not very trustworthy: 9%
  - Not at all trustworthy: 9%

- Health care professionals
  - Very trustworthy: 24%
  - Somewhat trustworthy: 52%
  - Not very trustworthy: 12%
  - Not at all trustworthy: 9%

- Patient organizations
  - Very trustworthy: 19%
  - Somewhat trustworthy: 47%
  - Not very trustworthy: 16%
  - Not at all trustworthy: 15%

- Journalists
  - Very trustworthy: 8%
  - Somewhat trustworthy: 34%
  - Not very trustworthy: 32%
  - Not at all trustworthy: 16%

- Bloggers
  - Very trustworthy: 7%
  - Somewhat trustworthy: 21%
  - Not very trustworthy: 37%
  - Not at all trustworthy: 20%

- Business leaders
  - Very trustworthy: 7%
  - Somewhat trustworthy: 31%
  - Not very trustworthy: 34%
  - Not at all trustworthy: 16%

- Elected officials
  - Very trustworthy: 5%
  - Somewhat trustworthy: 16%
  - Not very trustworthy: 34%
  - Not at all trustworthy: 33%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2014
And Yet, Despite Relatively High Levels of Public Confidence, Scientists are Invisible in Our Society...
Can Americans Name a Living Scientist?
Most Americans Can’t Name a Living Scientist

Please name a living scientist.

- I can
- I cannot

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, with support from the American Society of Hematology, in November 2013.
Do Americans Know Where Research is Conducted?
Most Americans Don’t Know Where Research is Conducted

Please name any institution, company or organization where medical or health research is conducted.

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics, with support from the American Society of Hematology, in November 2013.
To the best of your knowledge, would you say that medical research in the U.S. is conducted in all 50 states?

- Yes: 26%
- No: 39%
- Not Sure: 36%

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2015.
What Can You Do?

- Talk about aspirations for better health, for more research, and talk about return on investment
- Use in-the-moment news to illustrate public aspirations for better health
- Emphasize how research drives economic activity in every state and creates good jobs
- Convey your personal commitment
- Encourage your colleagues to engage the public
- Support the 21st Century Cures initiative
Leaders Who Understand Policy and Politics: More Needed!

(Left to right) Research!America board member Georges Benjamin, M.D., executive director, American Public Health Association (APHA); Tom Frieden, M.D., M.P.H., director, Centers for Disease Control and Prevention (CDC); Lynn Goldman, M.D., M.S., M.P.H., dean, George Washington University Milken Institute School of Public Health; and Richard Kronick, Ph.D., director, Agency for Healthcare Research and Quality (AHRQ) at Research!America’s 2014 National Health Research Forum.

Research!America Vice Chair Hon. Michael Castle and Mary Woolley presented the Edwin C. Whitehead Award for Medical Research Advocacy to Reps. Fred Upton (R-MI) and Diana DeGette (D-CO).
“Everybody in the science and technology community who cares about the future of the world should be tithing 10 percent of his or her time to interacting with the public in the policy process.”

John P. Holdren, PhD
President Obama’s Science Adviser
Put a Face on Research: YOURS!
Remember the most important four words a researcher can say and convey:
“I work for you.”
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