AcademyHealth

Federal Support for HSR: What Does the Future Hold?

Dr. Lisa A. Simpson, MB, BCh, MPH, FAAP
President & CEO

@DrSimpsonHSR

Outline

1. AcademyHealth Refresher
2. Trends Affecting HSR
3. Funding for HSR
4. Looking ahead
5. Discussion

AcademyHealth

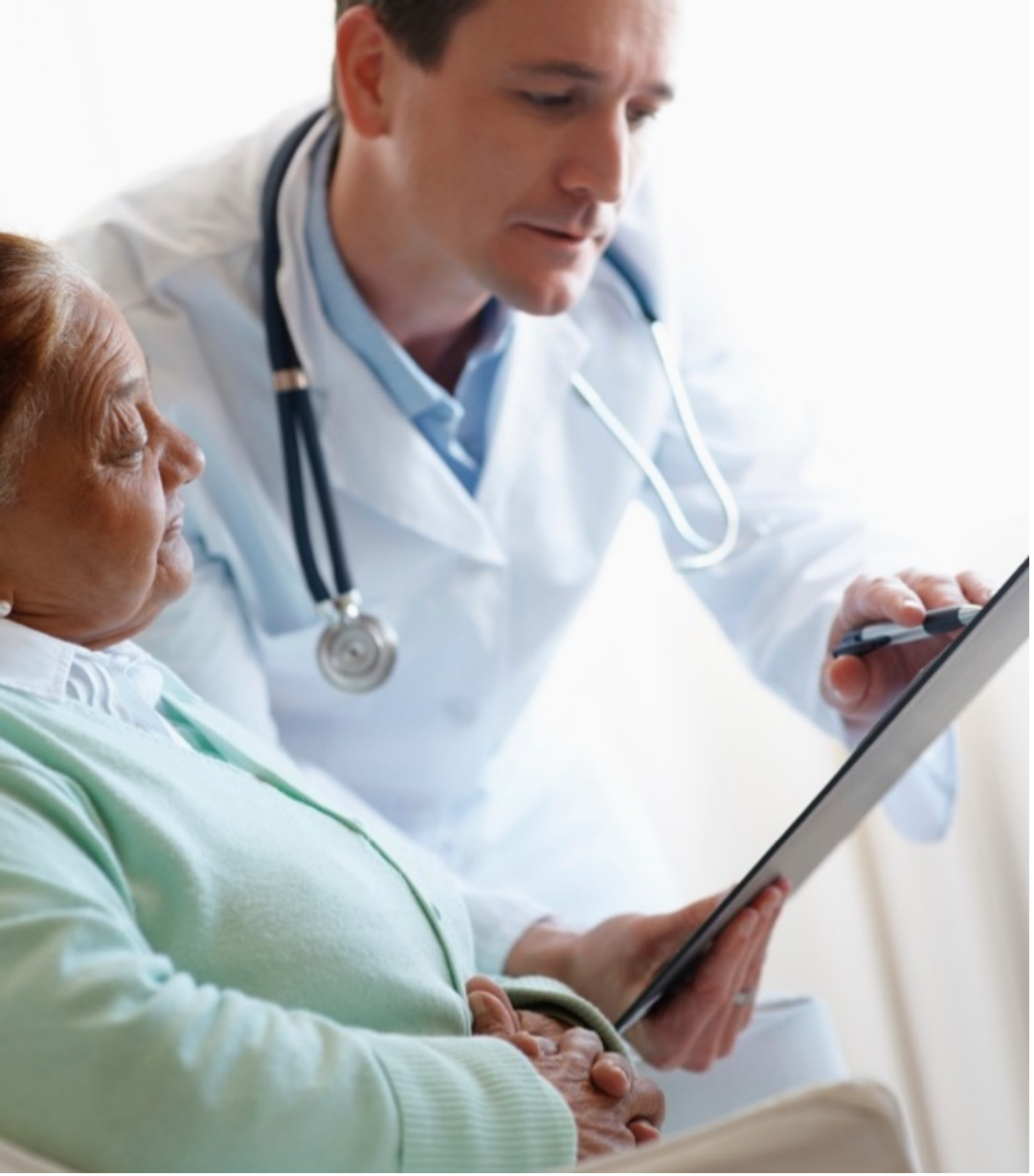
Mission, Programs & Services

VISION

AcademyHealth envisions a future where individuals and communities are made healthier by the use of evidence in decision-making.

MISSION

Together with its members, AcademyHealth works to improve health and the performance of the health system by supporting the production and use of evidence to inform policy and practice.



PRINCIPLES

Evidence is important
We believe policies affecting health and the performance of the health system should be informed by the best and
health servic

Evidence is a
We maintain
performance
common goo
infrastructure

We advocate for and support the development of the workforce, data and information infrastructure, and funding necessary to produce relevant, high quality, timely evidence.

Diversity of c
We believe that diverse perspectives lead to richer and more nuanced understanding of issues related to health and the performance of the health system. We support a big tent approach and encourage participation from all. Our activities are nonpartisan and seek to encourage and support diversity in the field.

AcademyHealth is 'of the field and for the field'
We strive to develop high quality programs and services that address the needs and concerns of our field and members, as well as anticipate, respond to, and raise awareness of a changing environment for health and the performance of the health system. The richness of these activities is enhanced through the efforts of our member volunteers. We will recruit and retain highly trained and motivated staff who represent, reflect and promote the field.

AcademyHealth works with its members and partners

1. To build a vibrant and diverse community of research producers & users
2. To advance the science of health services and policy research production & use
3. To move knowledge into action through synthesis, translation, dissemination & technical assistance

@DrSimpsonHSR

Advocacy: 2014-17 Policy Priorities

- Building a Robust Environment to Produce Health Services Research
  - Federal funding for research and the infrastructure—data, methods, and people—needed to produce it; including policies that uplift and model diversity, inclusion, and minority engagement in health services and policy research.
  - Policies that encourage—and do not unnecessarily restrict—the production of health services research.
  - Policies that enhance the quality, availability, timeliness, and affordability of data and tools used to produce research.

- Enhancing the Dissemination and Use of Health Services Research
  - Federal funding for research translation and dissemination.
  - Policies that enhance—and do not unnecessarily restrict—the dissemination of research results.
  - Policies that encourage—and do not unnecessarily restrict—the use of health services research in decision-making.

Outline

1. AcademyHealth Refresher
2. **Trends Affecting HSR**
3. Funding for HSR
4. Looking ahead
5. Discussion

Today's Environment

- Volatile
- Uncertain
- Complex
- Ambiguous

AcademyHealth

Trends Affecting HSR

- "Mega Trends"
  - Presidential and congressional priorities
  - Anti-science, anti-facts rhethoric
  - Future of the ACA: Pick your R
    - Repeal, replace, repair, reform, relive….
- HSR specific trends
  - Demand for:
    - timely, relevant research + maximizing rigor
    - consumer, patient, stakeholder engagement
  - Emphasis on innovation, value & population health
  - Expanding volume, variety, and velocity of data
  - New methods, changing workforce

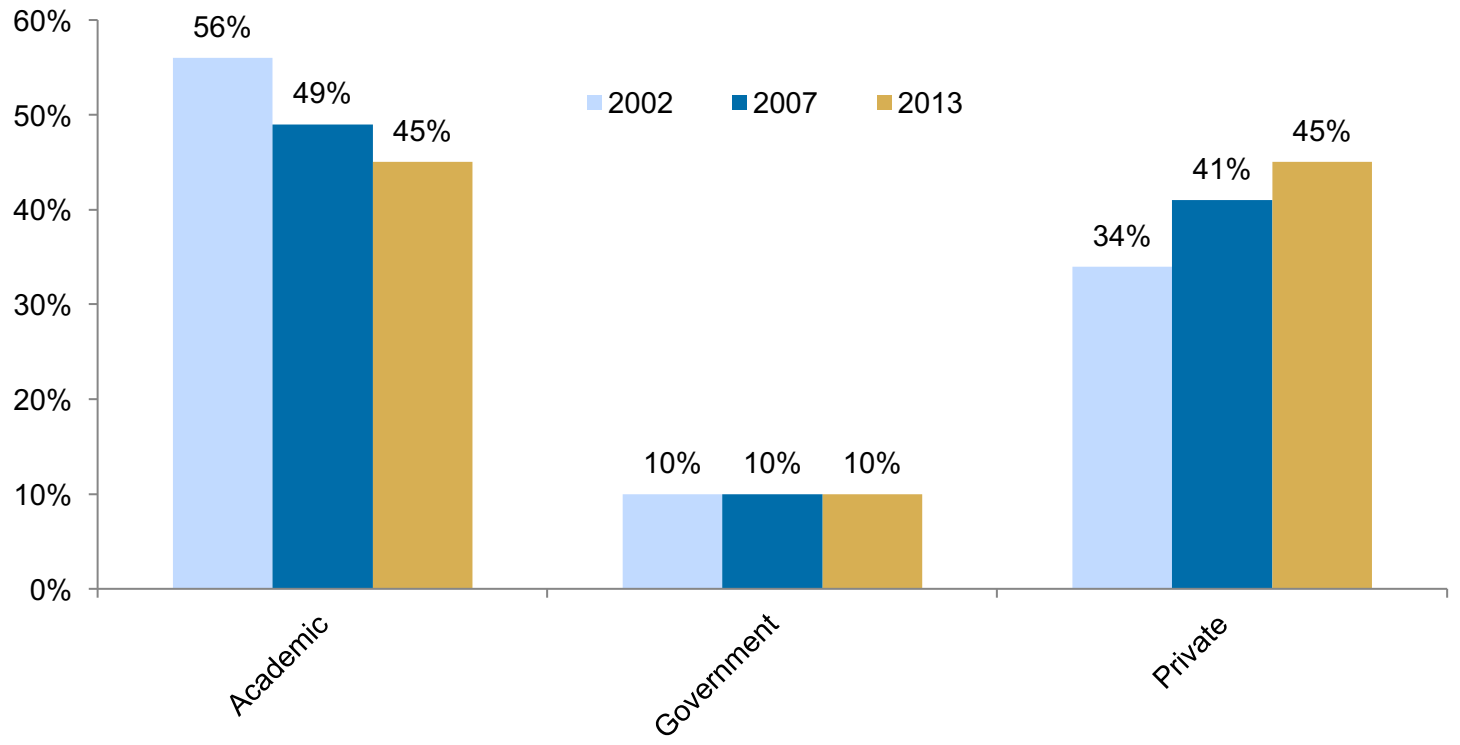
AcademyHealth's Workforce Initiative Taskforce

- Total of 6 studies.
  - 5 studies of the HSR workforce in the United States.
  - 1 study of the HSR international workforce.
- Convened in October 2016 in Washington, D.C to present preliminary findings.
  - AcademyHealth synthesized the recommendations into 10 distinct action items.

The Current Stock

- Combined data from:
  - AcademyHealth membership rosters
  - Conference attendance
  - Journal publications
  - HSRProj data
  - ResearchGate
  - LinkedIn
- A 25% increase in researchers.
  - From 12,000 to 15,000

A Field in Transition



Source: AcademyHealth Salary Surveys, 2002, 2007 & 2013

Diversity in the Workforce

- Surveying and interviewing AcademyHealth organizational members on policies and practices pertaining to diversity and inclusion.
- Almost all organizations who completed the survey have a public facing diversity statement.
  - Nearly all of those have a designated officer or administrator responsible for diversity initiatives.
- Much less focus was put by organizations on the retention of underrepresented minorities in the HSR workforce.
  - Creating a diverse and inclusive environment was recognized as being more complex by responding organizations.

Outline

1 | AcademyHealth Refresher

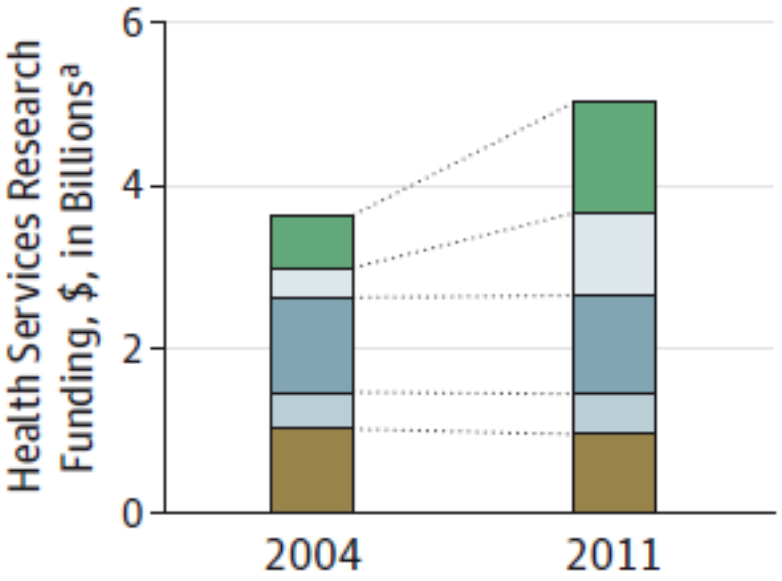
2 | Trends Affecting HSR

3 | **Funding for HSR**

4 | Looking ahead

5 | Discussion

U.S Funding for Health Services Research by Source



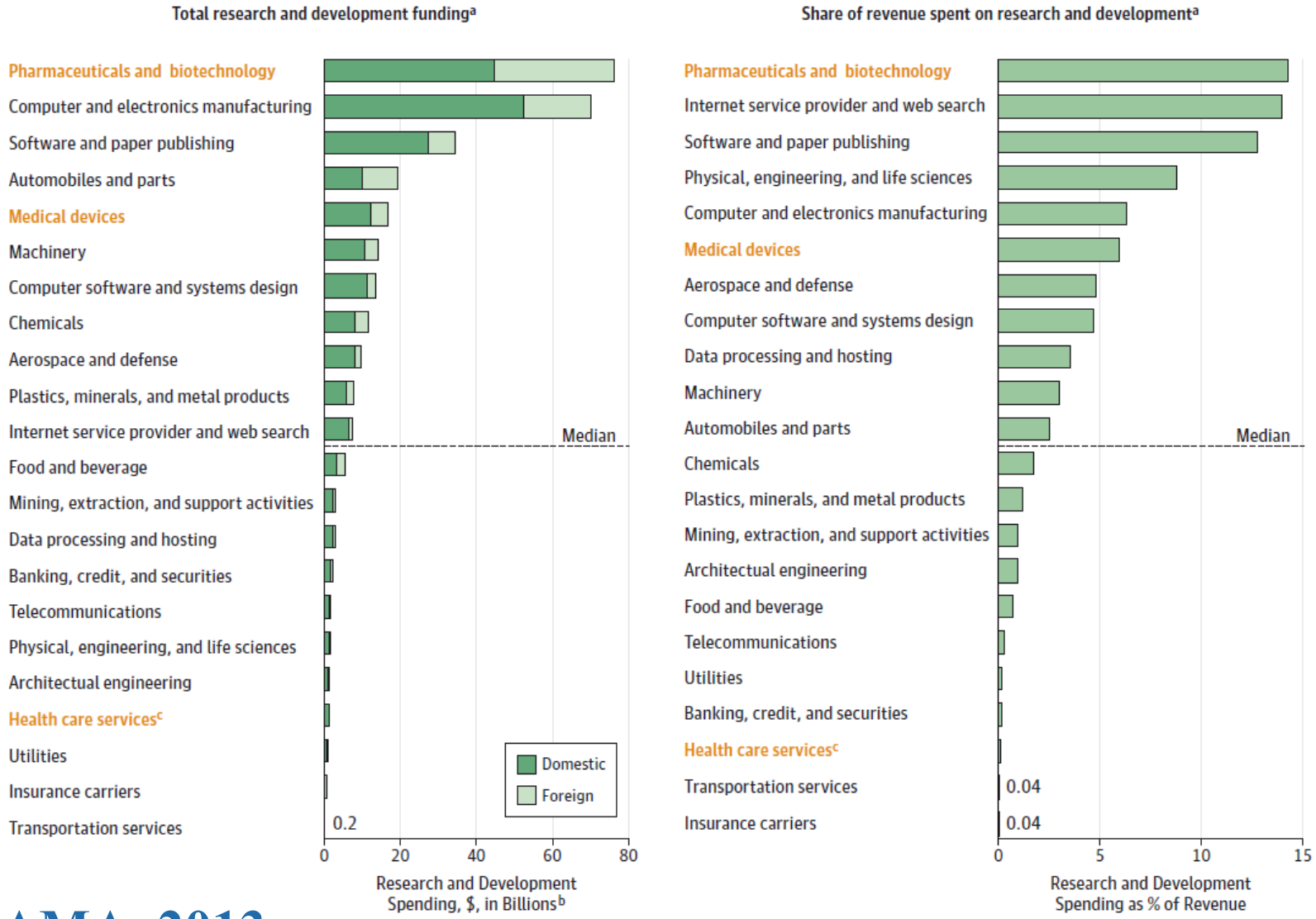
Funding source	Health Services Research Funding, $, in Millions (%)[a] 2004	2011	Compound Annual Growth Rate, %[b] 2004-2011
Health services industry[c]	653 (18)	1352 (27)	11.0
AHRQ	365 (10)	1018 (20)	15.8
NIH	1158 (32)	1189 (24)	0.4
Other federal[d]	442 (12)	494 (10)	1.6
Foundations[e]	1034 (28)	967 (19)	-1.0
Overall	3652	5019	4.6

Moses et al, JAMA, 2013

@DrSimpsonHSR

AcademyHealth

Research and Development Investment Ranking of Industrial Sectors Among US-Based Companies



Moses et al, JAMA, 2013

@DrSimpsonHSR

AcademyHealth

Federal Funding for HSR, 2010-2016

Agency	FY2010	Funding (in millions) FY2011		FY2012		FY2013		FY2014		FY2015		FY2016	
Agency for Healthcare Research and Quality	$397.1	$384	$389.6[i]	$409.9	$389.6	$433	$409.9	$464	$431.5	$465	$427.8	$428	$391
CDC: National Center for Health Statistics	$138.7	$168	$161	$159	$161	$168	$159	$153.9	$159	$155.4	$143	$160.4	$146.8
CDC: Prevention Research Centers	$33.7	$28	$26.8	$22.2	$26.8	$23.4	$22.2	$25.5	$22.4	$25.5	$23.5	$25.5	$23.3
CMS: Research, Demonstration & Evaluation Projects	$36	$35	$20.4	$19	$20.4	$20.1	$19	$20.1	$18.7	$20.1	$18.5	$20.1	$18.4
HRSA: Rural Health Policy Development	$10	$9.9	$9.6	$8.8	$9.6	$9.3	$8.8	$9.4	$8.7	$9.4	$8.6	$9.4	$8.6
National Institutes of Health	$1,131	$1,116	$1,119.8	$985.5	$1,119.8	$1,041	$985.5	$1,077	$1,001.6	$1,057	$972.4	$1,155	$1,055.7
Patient-Centered Outcomes Research Institute	--	--	$28.8	$209.1	$28.8	$220.9	$209.1	$278.2	$258.7	$445.8	$410.1	$498.6	$456.2
Veterans Health Administration	$84	$91.3	$86.6	$85.5	$86.6	$90.3	$85.5	$96	$89.3	$91	$83.7	$97.8	$89.4
Total	$1,813	$1,832	$1,843	$1,899	$1,843	$2,006	$1,899	$2,124	$1,990	$2,270	$2,088	$2,344	$2,189

[i] Figures in the right column for each year are adjusted for inflation.

Number of Projects (Not $$) Supported by Top HSR Funders, 2005 - 2015

	2005	2007	2009	2011	2013	2015	Percent change 2005-2015
National Institutes of Health (combined)	625	547	831	598	531	379	-39.4%
Robert Wood Johnson Foundation (RWJF)	341	294	189	139	130	66	-80.6%
Agency for Healthcare Research and Quality (AHRQ)	122	187	207	140	245	230	88.5%
Centers for Medicare and Medicaid Services (CMS)	95	31	22	11	15	7	-92.0%
Health Resources and Services Administration (HRSA), Office of Rural Health Policy	81	22	27	20	28	27	-66.7%
Department of Veterans Affairs (VA)	69	106	201	210	284	107	55.1%
Patient-Centered Outcomes Research Institute (PCORI)	0	0	0	0	134	112	--
Commonwealth Fund	50	100	42	112	39	63	26.0%
Canadian Institutes of Health Research (CIHR)	5	2	38	162	317		
Total	1388	1289	1557	1392	1723	991	

HSRProj Analysis, AcademyHealth, 2017

@DrSimpsonHSR

AcademyHealth

Changes in the Number of HSR Projects by NIH Institute, 2005-2015

	2005	2007	2009	2011	2013	2015	Percent change 2005-2015
National Institute of Mental Health (NIMH)	192	117	121	65	53	39	-79.6%
National Cancer Institute (NCI)	91	87	155	104	53	37	-59.3%
National Institute on Drug Abuse (NIDA)	58	66	76	50	46	41	-29.3%
National Institute of Child Health and Human Development (NICHD)	51	55	73	58	65	37	-27.5%
National Institute of Nursing Research (NINR)	41	20	33	38	37	10	-75.6%
National Institute on Aging (NIA)	38	45	54	45	62	53	39.5%
National Institute on Minority Health and Health Disparities (NIMHD)	38	23	121	65	37	18	-52.6%
National Heart, Lung, and Blood Institute (NHLBI)	32	38	69	41	32	24	-25.0%
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)	21	20	34	47	22	37	76.2%
National Institute on Alcohol Abuse and Alcoholism (NIAAA)	21	21	23	19	13	10	-52.4%
National Institute of Dental and Craniofacial Research (NIDCR)	7	11	13	22	12	10	42.9%

Federal Funding for AHRQ

- The Agency for Healthcare Research and Quality (AHRQ) has been forced to operate under an increasingly tight budget:

Fiscal Year	President's Budget	House	Senate	Final	+ PCOR Trust Fund
**Numbers listed below represent AHRQ's budget authority. From year to year the agency may also receive funding via other mechanisms.*					
FY 2012	$366 million	$324 million	$372 million	$372 million	$24 million
FY 2013	$334 million	$0	$364 million	$369 million	$57.5 million
FY 2014	$334 million			$364 million	$65 million
FY 2015	$334 million	$373.3 million	$373.3 million	$364 million	$79 million
FY 2016	$276 million	$0	$236 million	$334 million	$94 million
FY 2017	$280 million	$280.24 million	$324 million	$324 million	$92 million **Projected*
FY 2018	$0 | Proposed move to NIH Institute	NA	NA	$272 million	NA

Outline

1 | AcademyHealth Refresher

2 | Trends Affecting HSR

3 | Funding for HSR

4 | **Looking ahead**

5 | Discussion

AcademyHealth

What's Next for Congress?

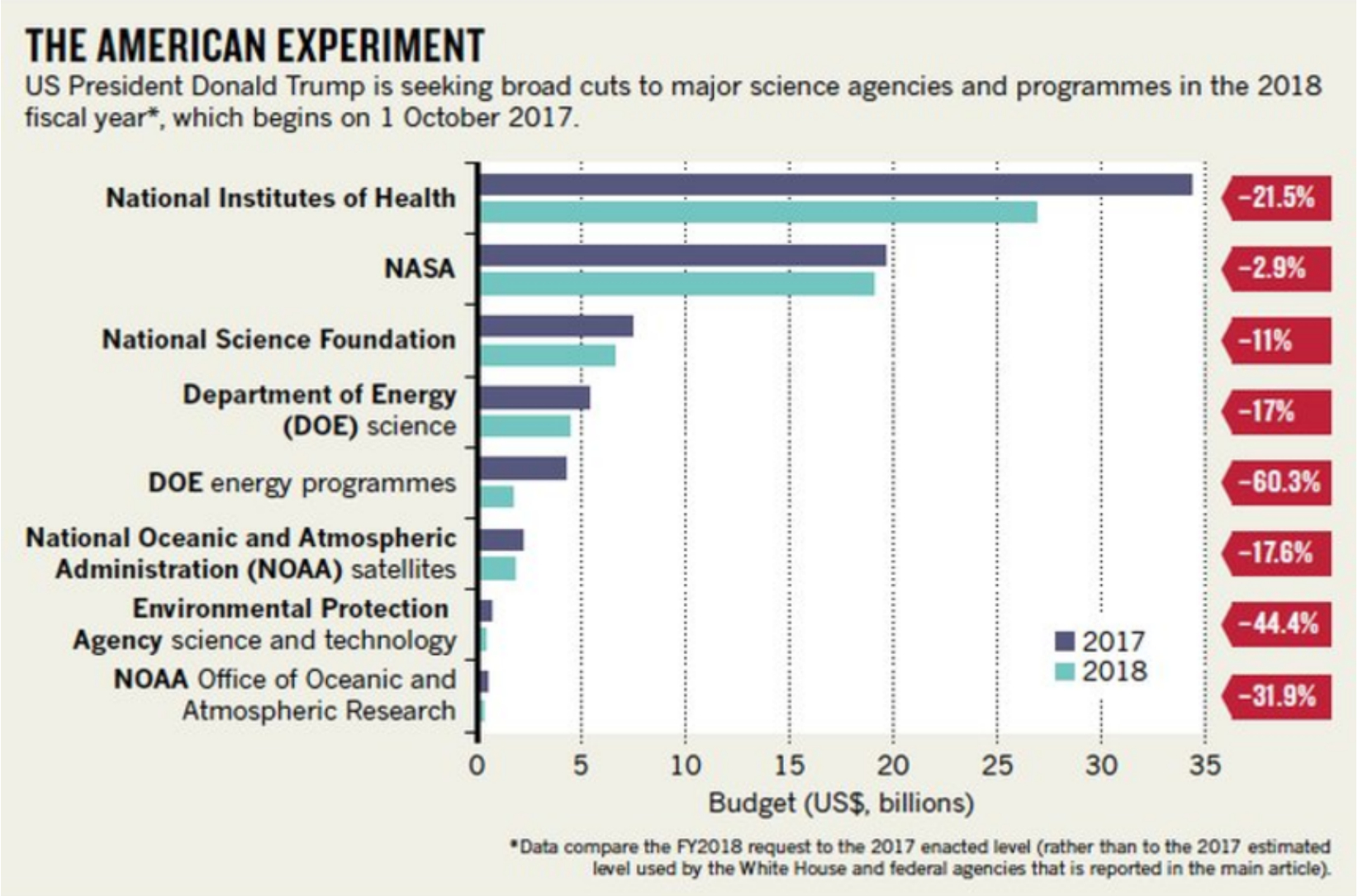
- 2017 Government Shutdown: Averted
- Now Onto Fiscal Year 2018 Negotiations
- Continue to Monitor American Health Care Act (AHCA) Developments
- DEBT CEILING NEGOTIATIONS

Researchers Must Remain Vigilant in Environment Pushing Back on Science

Threats to Science Encroaching from All Angles

- Proposed Cuts to Federal Science Funding
  - President's budget contained troubling cuts to scientific enterprise as a whole: $7 billion from NIH; 17 percent for CDC; 31 percent for FDA (though administration proposed making up loss by increasing industry fees)
- Current "Anti-Science" Mentality
  - People respond to evidence that reaffirms already-held beliefs
  - Government officials pushing back on "fake news"
- Potential for Data Corruption and Suppression

Trump Redoubles Plan to Slash Science Spending

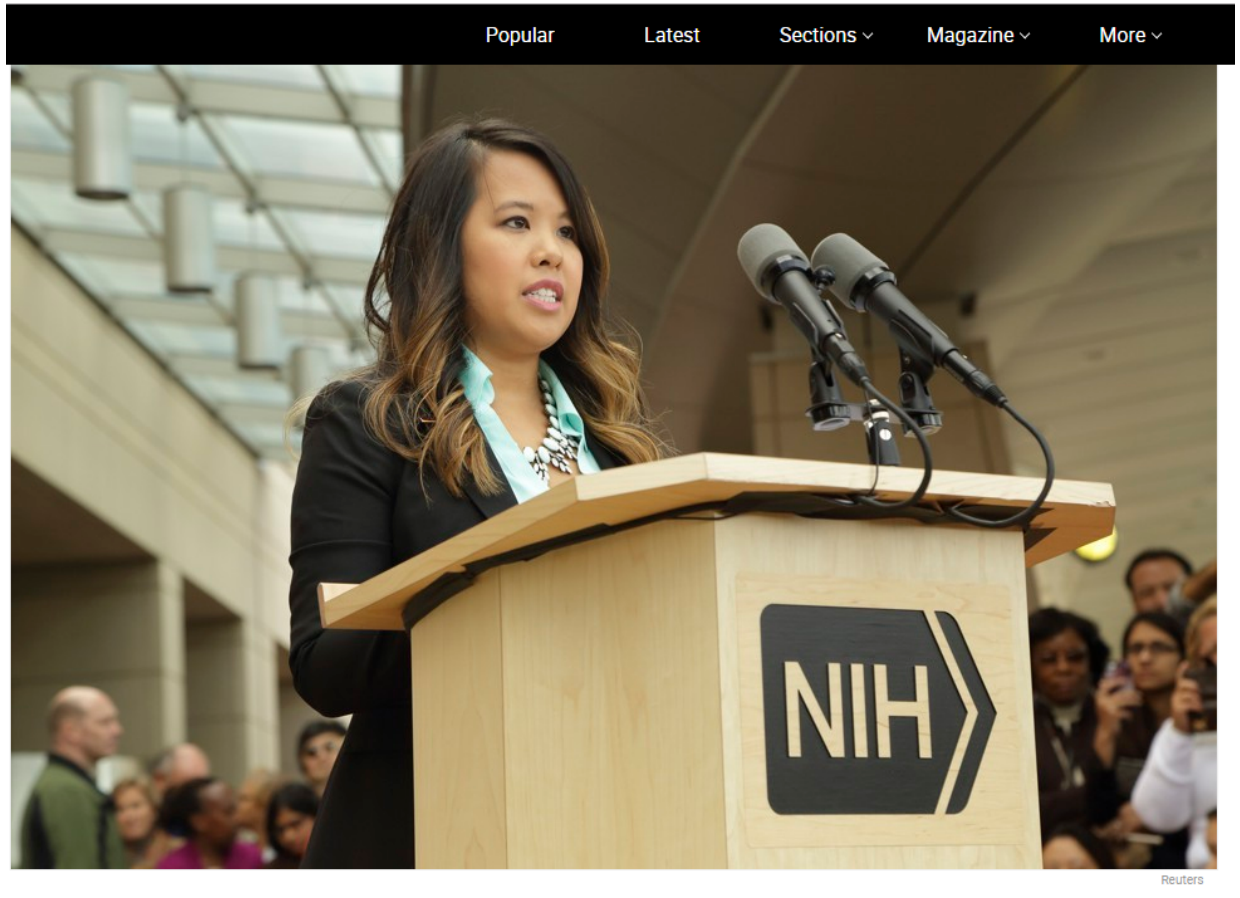


Nature, May 23, 2017

@DrSimpsonHSR

AcademyHealth

The Impact of the President's Budget



"And although the President's budget may just be a suggestion to Congress, it's a moral document.

It tells the world about America's priorities, and in this case, it says that science isn't one of them."

Even the Threat of Budget Cuts Can Hurt American Science

A climate of uncertainty leaves the National Institutes of Health unable

The Atlantic, May 31, 2017

Troubling Trend in World of Data Collection and Generation

- Data sets increasingly targeted due to type of information collected:
  - **Confidentiality of Substance Use Disorder Patient Records (42 CFR Part 2)**
    - Data scrubbing of patients with substance use disorders from Medicare and Medicaid claims files
    - Final rule went into effect on March 21, 2017
  - **Local Zoning and Decisions Protection Act**
    - Included provision we were concerned, if enacted, may preclude federal agencies from being able to collect geospatially specific demographic data by geographic area
  - **Elimination of LGBT Questions in Two HHS Surveys**
    - The National Survey of Older Americans Act Participants
    - The Annual Program Performance Report for Centers for Independent Living

AHRQ ⟶ New Institute at NIH?

- President's budget for FY18 called for AHRQ to be transformed into new National Institute for Research on Safety and Quality (NIRSQ):
  - Intended to "improve efficiency, minimize potential overlap, and increase coordination of health services research"
  - Funded at **$272 million** in discretionary funding, a decrease of 18 percent compared with annualized CR level for AHRQ (comparable to NIH)
  - Budget language calls for a "review of health services research across NIH and develop a strategy to ensure that the highest priority health services research is conducted and made available across the Federal Government."

But Not So Fast…

- Cannot create a new Institute or Center without legislation
  - Unless eliminate an existing one
- AHRQ's authorization expired in 2005!
- NIH is not due to be reauthorized until 2019 via the renewal of the 21st Century Cures Act
- Just being at NIH is ***no guarantee of future safety***
  - Many safeguards needed
  - Continued vigilance

AcademyHealth

Do you think AHRQ should continue?

Yes, with the same mission and priorities

Yes, but with a different mission and priorities

No, it should become a different agency/institute

Start the presentation to activate live content

If you see this message in presentation mode, install the add-in or get help at PollEv.com/app

Do you support AHRQ becoming an NIH Institute

yes **A**

no **B**

Start the presentation to activate live content

If you see this message in presentation mode, install the add-in or get help at PollEv.com/app

Where We Go From Here

- Stakeholders: Speak Up and Speak Out!
  - “If you’re not at the table, you’re on the menu”
- When Called Upon - Advocacy Works
  - Tweets, calls, meetings, and letters have an impact
  - Without it, there will be very real consequences for the health research community
- #SaveAHRQ & #SaveHSR Campaign

**Note: Many employers have policies related to advocacy. If you are engaging in advocacy, it’s a good idea to ensure you understand your employer’s guidelines related to personal speech and its distinction from advocacy.*

AcademyHealth

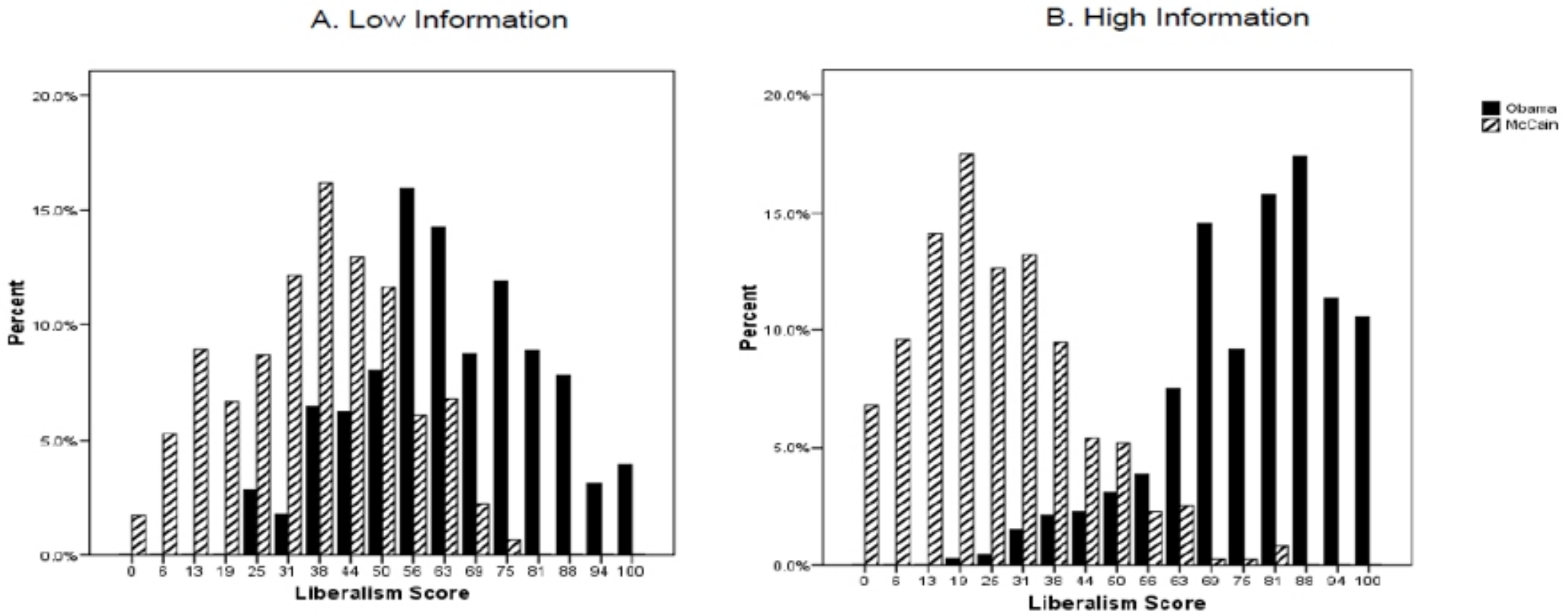
Words Matter

- Affordable Care Act
- Entitlement reform
- Public health
- Smoking Ban
- Global warming
- Gun control
- Risk assessment
- Obamacare
- Medicare cuts
- Nanny state
- Smoke-free
- Climate change
- Gun safety
- Scare tactics

AcademyHealth

Challenge: Evidence Can Polarize

Figure 6.1. Ideology Scores of Obama and McCain Supporters by Political Information



Source: Abromowitz, A. The Disappearing Center. Yale University Press

AcademyHealth

Framing research to inform politicized policy

(Insights from political science & climate change)

- **As politics dominates, evidence can be challenged by "ordinary knowledge,"** *a combination of common sense ideas & biases held by average people.*
- **People look for cues that confirm what they already "know."**
- **Framing gives greater weight to some considerations over others.** *Communicates personal relevance and shared interests or values.*
- **Trusted expert organizations can be honest brokers of information.**

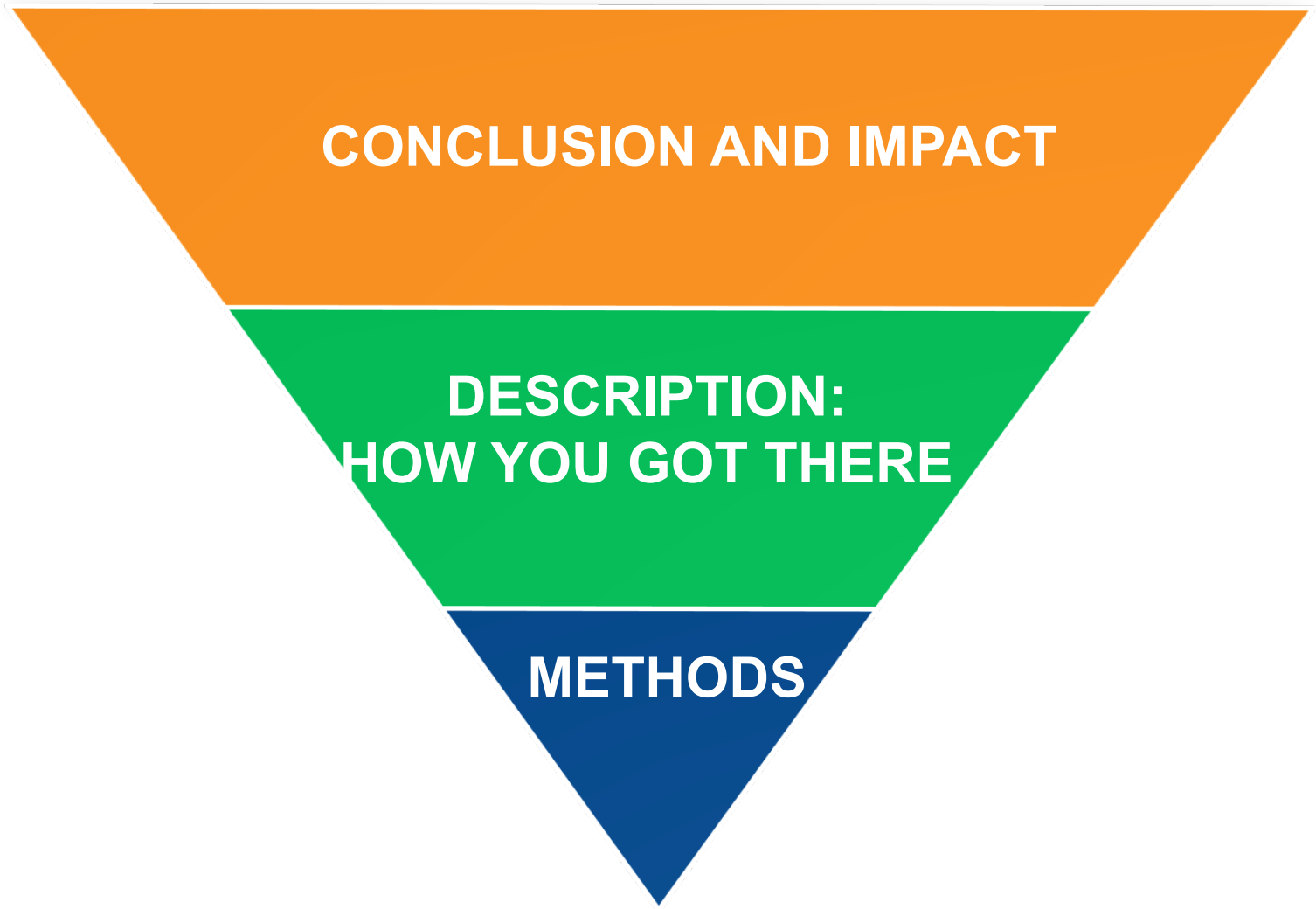
AcademyHealth

Communication Depends on Situation, Context, Audience

- What do you want to accomplish?
- What do *they* think now?
- Does your evidence confirm/conflict with “street knowledge”?
- Why would *they (and their readers/listeners)* care?

AcademyHealth

Delivery: Invert the Abstract



AcademyHealth

Communications Universal Truths

- Be relevant
- Be honest, authentic
- Be quotable, interesting
- Be reliable
- Be timely

AcademyHealth

AcademyHealth