

# When Politics and Science Collide

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Where I work, as executive director of the Center for the Advancement of Health, we examine the many behavioral, social and environmental factors that go into health and illness. Our particular interest, however, is how to apply the scientific evidence about these factors in shaping policies and practices that will help people to live for as well and as long as they can. This is, as you know, neither an easy nor quick task, for many reasons. And this is what I will talk about today.

We know a lot about how to prevent disease generally and have some pretty good ideas about how to detect and prevent cancer particularly. But we seem to struggle to make use of that knowledge. We don't seem to be able to efficiently transform it into practices and policies that will make a difference to people's lives. Moreover, the transformation that does take place seems to be done unevenly. Some people benefit from the best science can offer but others do not.

Those of you here today, and particularly, Dr. Freeman, have been leaders in pointing out how and when this takes place and the tremendous preventable damage that is caused. What NCI has done in framing, studying and applying research into cancer disparities is a model for the rest of the federal government to emulate. We have known about racial and ethnic disparities in health for 40 years, but through both Democratic and Republican administrations, doing something about them has been a slow arduous battle. In fact, it was a Republican, HHS Secretary, Margaret Heckler, who first brought wide public attention to the issue of disparities, which led to creation of the Office of Minority Health within HHS. It was the first of many steps promulgated by both Republicans and Democrats to push this critical issue from the margins of the health care discussion in this country to the forefront.

Usually, when we embark on a discussion on the translation of research into practice and policy at a meeting like this, we immediately start talking about "system" inadequacies -- how physicians aren't trained to deliver certain kinds of services, how insurance doesn't cover certain kinds of procedures, how people don't participate in screenings and need post cards to remind them to do so, how we don't have the right behavioral research to know exactly how to get black teens to stop smoking, or Hispanic girls to get PAP tests.

I would like to talk about a different kind of barrier to the transformation of science into services, programs, and information that can help ALL people living in this country to live for as well and as long as they can. That barrier is the Jersey wall where politics and science collide, and it is located at the intersection of 16th Street and Pennsylvania Avenue.

We often turn our heads away from the carnage of collisions, and at too many meetings like this, politics seems unfit for discussion — impolite — beneath us. But we continue to ignore the ugly result at our peril -- because the journey of evidence from the laboratory to our living rooms is bumpy enough without having ideology intrude into biology.

First, it affects how research priorities are set. Are we going to look into the value of stem cell research, and, if so, which stem cells are off limits? Are we going to try to do something about arsenic and lead in the environment or are we going to appoint people to scientific advisory panels who profit from doing nothing about it? Do we want to keep teenage girls from having sex, and do we do it by moralizing or by approving effective contraception? Do we want to actually study reproductive health or do we want to stack advisory panels with people who believe the answer to PMS is prayer.?

Second, politics affect how scientific findings are reported to the public. Or are reported at all. It was only public pressure that caused Secretary Thompson to disown a draft report on racial disparities in health that didn't bother to mention the word “disparities.” Last year, HHS drafted a report about the importance of behavior in maintaining good health but never mentioned the word “sex,” one of the more dangerous disease vectors we know about. And it was public embarrassment that caused HHS to back down from its contention that abortion and breast cancer were somehow linked.

Third, the collision between politics and science influence how evidence is used to shape health care policies and medical practices in the United States and around the world — whether it is used at all or applied in order to reduce disparities in health. According to this administration, sugar is not as big a factor in obesity as the rest of the world thinks, and so, at the insistence of the United States, World Health Organization recommendations on dietary sugar intake were watered down. Really at the insistence of the U.S. sugar industry. The United States knows more about fighting AIDS — scientifically speaking, that is — than anyone else in the world, but ideological disputes with the rest of the planet caused Secretary Thompson to be heckled. As a result, most of the delegation of American government experts to the World AIDS Conference was told to stay home. And we hold U.S. dollars hostage to countries that don't promote abstinence as the first line of AIDS prevention, as opposed to the promoting the use of condoms, for which there is stronger evidence of success.

I want to emphasize here that by no means is this a one-party, or one administration phenomenon. The party that wins the most votes — I'm sorry, the party that wins the election -- wins the right to reflect, or impose, its values through policy-making.

Let's face it. We are sitting here a few blocks from Congress in one direction and from the White House in the other. The bulk of this nation's science funding emanates from the federal Treasury and much of the actual research goes on in Bethesda. So to avoid talking about politics would be to ignore the elephant in the room — or the donkey.

In 1992, the winning presidential candidate had a very simple platform — “It’s the economy, stupid.” Twelve years later, I would argue that in the politics of health, at least, “It’s the EVIDENCE, stupid,” which contradicts the prevailing premise of the White House.

It is hard to promote disparities research related to cancer, much less any kind of disparities research, in the current political climate.

President Bush said more than two years ago, “When we make decisions, we want to make sure we do so on *sound* science...” But since then the administration’s record is one, not of “sound science” but of what sounds like science. This should come as little surprise since the president’s own science adviser was stripped of the position’s traditional title of “assistant to the president” and banished from the White House. The science adviser in the White House now has the same rank as the president’s chief baggage handler.

Instead of acknowledging that science is produced by a lengthy, back-and-forth, peer-reviewed, intensely scrutinized methodology, the ideological poohbahs of purity in Washington pay little heed to evidence -- as we saw in the search for WMD. They must think “evidence” is a French word. Well, actually, it turns out that it is — “Old French,” according to the dictionary.

Just one year ago this month, the House of Representatives came within two votes of cutting off funds for several NIH-funded investigations because they had to do with the subject of sex. Those efforts are being made again, and now grantees in this and other areas are being warned furtively to be careful about how they word future grant applications, lest some bluenose bully in Congress finds out about it.

Behind this drive is an organization calling itself “The Traditional Values Coalition” and a group of congressmen apparently afraid that some of their constituents may be having unauthorized sex.

The executive director of the tax-exempt “Traditional Values Coalition,” Andrea Lafferty, sneers at the NIH as “the National Endowment for the Arts with a chemistry set” and claims that “some NIH grantees were being funded to examine bizarre sexual practices with little or no bearing on public health.” She calls some of the studies downright “prurient.”

To her, maybe.

Among the studies that annoyed her were those on gay and lesbian Native Americans, on the sexual habits of older men and on prostitutes at truck stops. The purpose of these and similar studies was not to arouse the investigators but to figure out how to stop the transmission of STDs. Like all other benign-sounding studies — whether on cancer, sudden infant death syndrome or heart disease — these investigations were approved by expert and neutral panels of the leading scientists in the field.

Such panels also advise federal regulatory bodies like the EPA and FDA, although their expertise is being watered down by the removal of scientists who refuse to say who they voted for in the last election or who actually have different expert opinions than the administration would like to hear.

Oh, wouldn't it have been nice to have neutral panels of experts at other government agencies -- like maybe the CIA? Instead, we have a government that believes public health is now a matter of personal responsibility. It has:

- overturned ergonomics regulations in the workplace
- refused to raise taxes on cigarettes even though we KNOW it dramatically cuts teenage smoking rates
- ignored the rising urban asthma rates when considering revisions to the Clean Air Act
- And continued to insist, all evidence to the contrary, that condom distribution promotes promiscuity.

We hear so much about values, don't we? Well there are a lot of different values. Taxpayers ought to value that fact that studies on human behavior are vital to efforts to improve the health of individuals and the public. Just look at the news that obesity costs the Treasury 75 billion dollars a year in direct medical costs. And sexual behavior is one of the leading causes of death and disease. Relevant for federal research? A value for our nation's health? You bet!

Now, I am not saying that everything a scientist proposes or discovers is, on the face of it, correct. We have seen examples of misguided or misused science long before this administration was installed. By its very nature, science is uncertain (thank you, Dr. Heisenberg.) But we have never before seen such purposeful attempts to certify ideology over methodology, or as Sir Michael Marmot describes it, the making of "policy-based evidence."

Every year this nation spends about 100 billion dollars on health research, more than a quarter of that directly from taxpayers. What a scientific shame, what an economic crime, to flush the results of that investment into the sewer of partisan politics.

To be truly effective, research needs to be understood by the public, and it must answer questions that are critical to improving the health of the nation, regardless of the political winds blowing at any given time.

(Parenthetically, I must add that improving public understanding is a job that could make finding a cure for cancer look easy! A journalism professor from Iowa giving a lecture at NIH last week talked about her findings that the credibility of a source is the largest single predictor of how effective a health message is. In one experiment, she found, that undergraduates given messages about the danger of skin cancer, gave the views of a medical doctor the same weight as those views when attributed to Anna Kournikova or Andy Roddick. But the experiment reinforces a lesson that health messages are best received when the source is "someone like me." And I am proud to say that our Center's Men's Health Initiative had a great deal of success in bringing a health message to African American men through a television public service announcement starring Danny Glover.)

But back to the point, here. With so many anti-science incumbents in office, it is incumbent on us to make science a part of this and every future political campaign. In this election year, and in all years, we must ask candidates and office holders at all levels whether they believe policy should be made on the basis of what we know or on the basis of what we would like to believe.

It is, essentially, a matter of getting value for our research investments. Government-sponsored research over the past 50 years has produced a body of evidence on how diseases develop and spread -- and how they disappear when prevented and treated properly.

We know for certain, for example, that aspirin is an effective means of preventing second heart attacks. We know for certain that immunizing elderly people against flu and pneumonia saves lives. We know for certain that public education and blood screening can prevent the spread of HIV/AIDS. We also know that needle exchanges and condom distribution do so, as well. And we know that sexual dysfunction can be an early signal of diabetes and heart disease. But we didn't know those things without first having had federal support for behavior research projects whose titles might have scandalized Ms. Lafferty and her colleagues.

I would like to think that this is just one of those political flights of fancy for a couple of insecure politicians, but it looks more and more like an all-out assault by rectors of righteousness on a system of scientific research that has been responsible for the world's most magnificent discoveries about human health in the past half century. There is not a single scientist of any repute who would support these efforts to trash the bedrock principle of peer review of research in favor of political control from pressure groups. The tragedy is that there are so many elected leaders who would.

“Well OK,” you might say. This is really just politics as usual — maybe a little more intense.”

That may be. But what concerns me particularly about the current collisions between science and politics is that we are at the vortex of three accelerating trends that vastly increase the stakes of investigating the right questions and applying that knowledge to decrease health disparities and maintain the health of all who live in America.

One trend is the increasing complexity of health decision-making required by consumers.

A second trend is demographics.

And a third trend is health technology.

Together, they add up to a situation that will increase the devastation wrought by health disparities unless we act to anticipate them.

The first accelerating trend: While we have more options about preventing and treating diseases than ever before, most of us have to struggle to figure out the best choices for ourselves and our families. One out of three Americans will be without health insurance at some time

in the next two years. Many of us are underinsured. And those of us who are accustomed to receiving health insurance through our workplace are in for a big surprise over the next couple of years. A recent survey found that 73 percent of employers are planning to offer Health Savings Accounts to employees over the next two years.

Such accounts are usually accompanied by implementation of a high deductible catastrophic health insurance plan. This means that all of us -- with insurance and without -- will be making unfamiliar judgments about various services from various doctors and various hospitals — on our own.

Even when you do have insurance -- even when you are a health professional -- you will find that the health care delivery is fragmented and uncoordinated and that you are bombarded with advertising promising to make you potent, hairy or continent.

The result is we all wind up acting as our own diagnosticians and medical historians as we piece together care that works for ourselves, our kids and our parents. Those who struggle with health literacy, lack material resources, and are ill and disabled are particularly disadvantaged by this cleverly named effort, “consumer-driven health care” to make health decisions the responsibility of “the consumer” alone.

The success of medical discoveries in improving health depends increasingly on the most fragile link between scientific knowledge and outcomes — that individual, that “consumer.” While biomedical research is producing innovations that might improve health, our risk of preventable illness is growing due to a confusing welter of choices that we are unprepared to make.

The missed opportunities that result from depending on individual behavior to connect knowledge and practice will only be multiplied by two larger trends — demographics and technology.

The second trend — demographics — is as predictable as the return of the cicadas in 2021. These facts are familiar to you:

- In five years, the 78-million Baby Boomers will begin to retire, peaking in 2015. The 45 million born into the following generation won't be nearly enough to replace them, much less to fill the 22 million white collar jobs expected to be created by then.
- The racial and ethnic makeup of the country also will change significantly: Whites as a share of the total population will decline from the current 74 percent to about 65 percent by 2015, which means a broadening of language and cultural diversity in America.
- A recent report by the Institute of Medicine on health literacy found that poor understanding of health information is clustered in those groups that are expected to increase in size in the next 10 years — the poor, some minorities, the elderly and the chronically ill.

The third trend — technology — will change the map of biomedicine at precisely the same time individuals are less able to navigate it.

- Personalized medicine will tailor interventions to fit each individual's unique genetic make-up.
- The management of chronic conditions will be greatly enhanced with the use of in—home monitoring devices, 24/7 electronic contact with health care advisers to prompt medication compliance.
- Advances in cancer care will mean less invasive treatment and more refined diagnostic technologies. Better, longer-lasting artificial joints will mean more independence for older people, and premature babies will be kept alive through advances in prenatal steroids and high—frequency oscillatory ventilators.

That's the great news. The less great news is that each of these innovations will require people to weigh the benefits and costs and examine the short- and long-term consequences in order to make decisions reflecting their values, preferences and resources. And then they will have to participate in their increasingly complex regimens to prevent and treat disease. Given what we currently know about people's willingness and abilities to comply with complex medical regimens, this is not going to be a slam dunk.

If you put all this together, what you get is a picture that looks like this: Decentralized medical authority with you at the center of decision-making in a country that will soon include a very large group of old people, the majority of whom are white and who have chronic or disabling conditions. They — or we -- will be cared for by a younger population that is largely nonwhite or foreign born, with less income and whose taxes will pay for the older generation's care.

Each of these trends will present those of us in this room with challenges that it will be tough to confront. But what look like challenges to us look like the wholesale abandonment of many in this country. The privatization of public health, the abandonment by government health services of vulnerable individuals, and the economic, environmental, and family policies that have been put in place during the last few years will lead to greater health disparities, not less, as these trends accelerate.

What is to be done?

One obvious answer is to start valuing and supporting research at every level of the scientific enterprise, from molecular biology to effective public health, economic and social policies at community, state and national levels.

Imagine what would have happened if we had devoted efforts exclusively to working out all the basic mechanisms of how polio caused paralysis, but we had no vaccine, no way to effectively deliver it or no rehabilitation services? What if there were no treatment centers for those who got the disease and needed to be sustained? No rehabilitation services to help people return to optimal functioning in their communities?

The effort in which you are participating here is a great example of what must happen on a broad basis in order to truly benefit from advances in scientific knowledge.

Let's look at obesity -- a good example for what can happen when politicians get behind an issue the right way.

We are not going to beat obesity with a pill, and the current HHS administration has mounted a public relations campaign in favor of fitness and proper diet. The Republican leader of the Senate has, with bipartisan support, introduced legislation to establish pilot programs on weight reduction.

And last week, the Medicare program announced that it was no longer ruling obesity out as a disease eligible for coverage. The government said it will now look at actual evidence to determine which obesity treatments may be effective and then decide whether to cover them ... as individuals make formal requests. The head of CMS, Dr. Mark McClellan, said he views Medicare as a public health program and that henceforth cost-savings will come from adopting regulations based on outcomes — on evidence.

Thus we are seeing the development of national policies, in combination with local and state policies regarding physical education, school cafeteria menus, and safe, walkable neighborhoods that build on public-private collaborations and efforts of foundations and thousands of volunteers nationwide in hopes of influencing the factors that support the obesity epidemic. I am greatly encouraged by these initial efforts

On the research side, there is also hope in the performance of the NIH leadership under Dr. Zerhouni and Dr. Kington, in the steady presence of Dr. Gerberding at CDC and in the evidence-based products of AHRQ under Dr. Clancy.

But here is the crux of the matter.

Those of you in this room and your colleagues across the country have made a heroic effort over the years to understand and ameliorate the burden of disease for those whose circumstances confer greater risk for cancer, who have no access to treatment, and whose treatment is shaped by racism. Your work has taken place during Republican and Democratic administrations and you have been joined and supported by members of both parties. After all, cancer has no political preference.

But as I have described, we are at a point in the history where the urgency to close the gap between what we know to prevent and treat cancer and how we make use of this knowledge has never been greater. Government-sponsored research in the past 50 years has produced a body of evidence on how to do this and you are deepening this knowledge with the work you do now. Support for those discoveries came directly from taxpayers, and we ought to be demanding full use of the knowledge we have paid for.

Even those suspicious of big government generally accept cancer prevention and detection as a proper federal responsibility, but placing ideology over evidence — by putting a political spin on politically inconvenient findings about health disparities and ignoring sex, for example, devalues and discredits the scientific enterprise. And wastes our money.

The examples I have used today illustrate only the most recent and vivid cases of scientific evidence being treated as just one of a number of factors that are weighed in the development of public policy. The parochial interests of constituents — those who contribute to campaigns and those who vote — always compete with the public good to control the policy agenda. And don't kid yourself that this is any less or more true for either political party: these trade-offs are always operating.

So what does this mean about those of you who are working to reduce health disparities related to cancer?

I want to once again recognize the tremendous stake the nation has in you — those of you here — doing your job well. You possess — and pass along some of the most important keys to the health of the people you work with every day. And at the same time, through your actions and interactions with them, you are making more accurate the roadmap that will, if followed, reduce the terrible burden of cancer for the most vulnerable in our nation in the future.

So in this election year, and in all years, ask candidates and office holders at all levels whether they believe policy should be made on the basis of what we know or on the basis of what we would like to believe. There is plenty of “junk science” on both sides of the political aisle. It is our duty as scientists, and clinicians, as individuals committed to reducing the burden of cancer, and as citizens -- to help separate the wheat from the chaff. And stop electing the chaff.