

Exploring Mechanisms for Public Engagement
Mary Woolley, M.A.

DR. WILLARD: The final speaker for this session, before we open it up to a panel discussion, is Mary Woolley. Mary is the president of Research!America and has served in that capacity since 1990. Research!America has been probably the strongest advocate of the biomedical research community nationally, and Mary personally has been tireless in her support not only for biomedical research but in engaging the public and in finding out what the public is thinking and bringing knowledge back to policymakers of exactly how much support the public has in general for biomedical research.

Under her leadership, Research!America's membership has more than quadrupled. It has earned the attention and respect of not only researchers but the media and community leaders in general with public opinion surveys and advocacy resource materials.

So, Mary, thank you very much for being with us today.

MS. WOOLLEY: Thank you, Dr. Willard, and thank you to everyone on the committee for this wonderful opportunity this morning and the first part of this afternoon to learn from many of you. I have indeed learned, and I'm going to be modifying some of the things I say as I go along to put that right into practice.

So I'm going to talk to you about some but actually not all of these 10 considerations that my colleagues at Research!America and I laid out as things that occurred to us as we took a look at the plan for this study, which I've also learned now we might want to think of as a resource rather than a study.

So starting out, one that doesn't need any more explication from me because you've heard it quite eloquently from several people today is the importance of earning and maintaining the public's trust, and trust certainly does come from co-ownership in our experience, and I would say from everyone's experience in life. As I say, you've heard this eloquently from many others.

Secondly, assuring the broad support of the scientific community is important for many reasons, starting with it takes a broad scientific effort to assure that better health can be obtained for all the members of the public. It's not about one project or two, or even a thousand; it's about many, many aspects of science proceeding along in partnership, and all of them, by the way, well funded, which I'll get to at the end.

Now, I do want to spend just a moment on some big-picture context issues that, of course, have to be considered not just now at the beginning in the planning kinds of processes that you're going through, but on an ongoing basis. This has also been touched on by several of the speakers. At the moment, were this group or we in partnership with others trying to get this study, this resource, on the public agenda, we'd be competing with a lot of other things that are on the public agenda right now, and that is likely to be the case for some time into the future.

It's also true, and this has been mentioned, that there is a general distrust of the government now apparent among our population, and finding a way to position this new program in a fashion that will underscore the fact that researchers work for the public and not the other way around would go a long way toward addressing this distrust problem, at least in the part of it that we have some ability to influence. At this juncture I'll say that one of the things that we say over and over again to the research community is that we need to get better at saying and conveying to the public and

its decisionmakers "I work for you," and then wait and see what the questions are that come back from whomever you're addressing, and then answer those questions rather than the ones that you think or are afraid or are guessing that the public has in mind. So "I work for you" will go a long way toward minimizing or offsetting distrust of government.

We also have a big-picture context issue right now and we have for some time in that science education and science literacy are not highly valued, or appear not to be highly valued, by many people in our society, and this needs to be addressed as well, and we all have to keep it in mind.

Then there's the issue of the overall health care costs, and most people when asked how they feel about medical or health research of any kind immediately bring health care concerns to mind. So these things are connected. One of the ways that we've seen this, and others have as well, is in a national survey conducted earlier this year where you can see where medical and health research ranks in comparison with other issues very much on the minds of the public in terms of health issues as national priorities. This does not mean that research is low, by the way. I would not say that 66 percent is a low number. But all of this happens in the big overall context of things people have in mind, in the big overall context of health care delivery and the cost, importantly, the cost of health care.

It's also a fact right now, another piece of not so good news but it's part of the context, 60 percent now believe that the United States does not have the best health care system in the world. This is an indicator not of whether they're right or wrong about that, by the way, but of a perception that things aren't so good right now. I would say that the public is catching up to, or maybe it's even preceding expert opinion in this expression of their attitude. This is a big problem and a contextual issue, as I said.

So onto another consideration, the importance of identifying an urgent, compelling goal. The reason people get excited about something, want to participate in it, want to help plan it, want to be part of it in any way, shape or form, including paying for it and benefiting from it eventually, is that they want to be associated with something that's exciting, that they can understand immediately, even to the bumper sticker level, and get behind. Some candidate goals that certainly need addressing in this country, whether through this project or in other ways, are the importance of eliminating health disparities; childhood obesity; a very different kind of goal, but assuring the maintenance of U.S. global competitiveness, a very big issue; and then finally and always, saving lives and saving money.

I thought that Bono expressed the importance of having a big, exciting goal very well indeed. He was talking about his own work, which has been substantial, in calling for 100 percent, not 10 percent, not 30 percent or even 80 percent, 100 percent debt cancellation of the \$6 billion that the poorest African countries owe the U.S. What he said was the goal has to feel like history. Incrementalism leaves the audience in a snooze. That, by the way, is why doubling the NIH budget over five years was so much more a successful strategy than let's increase it by 2 percent more than inflation for the next X number of years. People want to feel like they're part of history in order to get behind something.

I've already mentioned and it's been well covered that there are a lot of reasons to address unequal treatment or health care disparities, and the public, by the way, strongly supports that. Let's put research to work to eliminate health disparities.

I've mentioned the importance of fighting childhood obesity, important on some many levels. It's easy to say that research shows the best way to fight childhood obesity is to prevent it, but the

dollars and the commitment we've made to preventing it are actually quite trivial. But getting people to understand that paying for prevention, and there's a lot of different ways to go at prevention, is a tricky communication. But if more people are involved in figuring out how to communicate it and are agreed upon the goal, we can get there.

I mentioned global leadership. The public very strongly supports having the U.S. maintain its role as a global leader in medical and health research. That leadership is by no means assured anymore. There are lots of indications that it's at risk, but it's something that's just as important to the public as it is to decision makers.

Saving lives and saving money. Very important, simple messages about saving lives and saving money is another way to demonstrate to the public and to decisionmakers about the value of the program you're talking about, or any other research project for that matter.

I think this point has been very well covered, particularly by my colleagues on this particular panel, the importance of the involvement of the public at every step along the way, of constantly keeping one's finger on the pulse of public attitudes and responding to real questions that the public asks. I think Mark Twain said this better than anybody, perhaps: "Supposing is good, but finding out is better." That really is what research is about, but it's very much what interacting with the public is about as a researcher. You can do a lot of imagining or supposing about what the public thinks or will do or how they will be involved, but there's no substitute for finding out.

You're going to hear a presentation tomorrow, I believe, with some up-to-date data on concerns the public has about relevant issues. I'm going to show you just a few things from our own work.

First of all, an open-ended question, which is always useful information to get, what's on people's minds when they hear certain terms or when they hear about certain kinds of activities. It's very important to pay attention to open-ended data and information. What I'm going to show you is just touching the very tops of public perception. It's not in-depth in ways that Joan was talking about, for example, earlier, but it's worth considering nonetheless.

People say they are willing to be genetically tested, for example, but a substantial portion says no, again not in a lot of depth about this. People say they will contribute a sample of their DNA to a national databank to be used only -- emphasis on "only" -- for health-related research. People are a little more closer to split on this one. It's that how it's used issue that's been touched on by others.

Then we've also, as have others, asked some questions about personalized medicine, which has the very great attribute of having a great name. It sounds good, and I think that's what people are responding to in a positive way. They probably have very little real-life experience with what it means, and in fact a lot of us don't really know yet what it means, but we'll get there.

Now, public engagement has been stressed about what it really means. One of the things it doesn't mean, and that's the point of this slide, is public relations. By the time you're doing public relations, you're in a different area of expertise. It's important, it's necessary, but it's not the same as public engagement. Public relations comes down the road apiece, and I think always still should be driven by researchers saying and conveying "I work for you." That's the very best kind of public relations any of us can engage in.

Words matter. Words matter a lot. This has been discussed. Some of these points have, in fact, been directly addressed. One of the points I would change now, and will from now on in this

presentation, is instead of saying "volunteers" instead of "subjects" in projects, we should be talking about "partners." I certainly subscribe to that, just never thought about using it as a better descriptor than "subjects," which really should be a word that's banned from the research vocabulary altogether. There's a few other things here that we're familiar with and over time have really made a difference, even as simple as talking about research projects rather than grants. "Grants" really conveys a sort of entitlement mentality that too many people associate with the science community.

Finally, the fewer words, the better. We do a lot of programming around the country to help researchers get comfortable in talking about their work in three sentences or less, three short sentences by the way. We're not talking about Faulkner here.

(Laughter.)

MS. WOOLLEY: Messengers matter. Who is talking matters. The first point to make there is that the community, the authentic messenger makes a great deal of difference. That point has been very well described already. But celebrities matter, too, and this is important to keep in mind at the right time, at the right place. Celebrities, and in this case we're talking about Nancy Reagan talking about stem cell research, which made a huge difference to the passage of Proposition 71 in California about a year ago. She was not the only person who made a difference. You can also get into warring celebrities. The appropriate use of celebrity spokespeople is something to get help with rather than guess about. It's a job for experts' advice, but it does make a difference, and pretending otherwise is not useful.

Media matters. This has also been touched on by several speakers, and that follows on the celebrity piece, because the media pays attention to celebrities. The media pays attention to a lot of things, including controversy and conflict. It cannot be ignored. But again, some expert help makes a lot of difference. Sometimes topics just aren't ready for prime-time media. Stem cell research was one that a year ago wasn't ready. But as we all know, it's very much in the news now, and this was the cover of Parade Magazine back on July 10th. Research!America has been working with Parade for some time now, many years, and we're aware from talking to the editors and writers and others there of how important it is not to prematurely try to engage the public before they're ready. Parade Magazine is the most widely read weekly publication in this country, with 75 million readers. So when Parade Magazine is ready, the country is probably ready, and sure enough, that's what happened with the stem cell research discussion, not only because it was in Parade, of course, but from the middle of this summer onwards you've probably noticed that stem cell research has been in the media virtually every single day. That can and probably would help with a project of the magnitude that you all are considering, but it wouldn't happen right at the beginning. That's very unlikely, at least at this level of publication.

Finally I'm going to say a few words about funding. I consider funding the least significant of these considerations -- that's why it's number 10 -- because I believe that if the value has been established, and the need, and the confidence of key people in the public, the decisionmaker and the scientific community, the money will follow. It's been demonstrated over and over again that this is the case. It's not about robbing Peter to pay Paul, and it's very dangerous to get into that mindset, I believe, so that we end up talking about X number of one kind of grant compared to one big project. There is plenty of historical precedent for how money is added to the NIH budget or other agency budgets when the need is real and palpable and the public supports it.

We have a lot of public opinion poll data that gets at this point, including the sort of rubber meets the road question. When we ask people if they would pay more per week in taxes -- imagine

SACGHS Meeting Transcript
October 19-20, 2005

raising taxes to pay for medical research. But actually that is, as you can see here, very well supported by the public. By the way, we've been asking this question for 12 years. This is the highest level of support for tax dollar support that we have ever seen, but it's never been below 50 percent. So it is, I think, sometimes shocking to the research community to realize that the public would be very willing to pay for more research, because fundamentally, down deep, they subscribe to the fact that without research, there is no hope; without research, we won't have better health. They have a considerable amount of confidence in the research community to deliver on that hope, and they will pay for it.

Just to underscore the point that there's a lot of money out there, this is a wealthy country, I think it's useful to think about what we spend money on in discretionary ways versus what we pay for with our federal tax dollars. These are just a couple of examples that illustrate the nature of the amount of dollars that are actually there and I think can and will be ultimately tapped to help pay for a program of the caliber that I'm confident all of you will design and ultimately implement. When you do so, I'll be very proud to represent it to the American public and their decision makers. Thank you.

DR. WILLARD: Thank you very much, Mary, for those comments and for all that you and your organization does.