
**Consumer Choice in Health Care:
How Could Reform Affect Our Choices? How Could
We Make Better Choices?
Alliance for Health Reform/Robert Wood Johnson
Foundation
June 25, 2009**

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ED HOWARD: Hi. I'm Ed Howard with the Alliance for Health Reform. Thank you all for coming. On behalf of Senator Rockefeller and Senator Collins, who are part of our leadership and our Board of Directors, I want to welcome you to this discussion about *Consumer Choice in Health Care*. Our partner in this program is the Robert Wood Johnson Foundation, America's largest philanthropy working to improve health and health care. Adam Coyne, who is the Director of Public Affairs at the Foundation, is with us today. So, if you have any questions that you want to direct to the Foundation, they do an awful lot of stuff about health reform as the little postcard about healthreform.org and I indicated in your packets. I am sure he'd be happy to respond to it.

We all know the choice is a rhetorical favorite in this health reform debate and Ted

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Kennedy's drafted bill bears the title *Affordable Health Choices*. The Tom Coburn and Paul Ryan Republican bill is the *Patients' Choice Act*, as in Obama and the Democrats want to offer people choices of plans in an exchange, including the choice of a public plan which Republicans say would ultimately erode consumers' choice by driving private plans out of business. Now, obviously, consumer or patient choice in health care can mean a lot of different things. Choice of health plan provider, choice of medication, choice of treatment, method, and we need to be careful to distinguish as we have this conversation among the different applications of the choice metaphor, and you heard most of them mentioned and discussed last night at the President's town meeting on ABC at which some of our panelists were present to take part. Today, we're going to confront the issue of how much

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choice health care consumers have now, what would the optimal level of choice, and how some of the reform proposals that are on the table would affect choice and whether that's good or bad.

Now, our panelists are a very distinguished group. They could dazzle you with their initial presentation but they've agreed to a format that maximizes their time to respond to your questions, a couple of kickoff questions that I'll offer, then most of our time will be reserved for you. Meantime, any problems or questions you have, I know most of you know Bill Erwin, our Director of Communications at the Alliance and he would be delighted to help you identify a source, identify some materials, identify background that could be helpful and he has lots of answers for you. So, without delaying further, let me just punch right into it. I'll give you the briefest

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of introductions. You might not have heard the mic check.

Immediately to my right, Joe Antos is a scholar in Health Care and Retirement Studies at the American Enterprise Institute. He's a former senior official at CBO and OMB and Health and Human Services. He was one of the two deans that we used at the Alliance for a series of briefings of senior congressional staff sponsored by the Alliance and Robert Wood Johnson, as a matter of fact, for the past nine months.

Next to him is Tony Coelho, the Chairman of the Partnership to Improve Patient Care. He's also on the board of the Epilepsy Foundation, former six-term U.S. representative from California, former House Majority Whip, and a sponsor of the Americans with Disabilities Act while it was in Congress.

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To my immediate left is Uwe Reinhardt, the James Madison Professor of Political Economy and Economics at Princeton. He's a member of the Institute of Medicine, served nine years on what is now MedPAC, recently presided over the Governor's Health Reform Commission in New Jersey.

That leaves at the far end Daniel Callahan, who's a co-founder of Hastings Center, which I know most of you have been familiar with. It's a leading voice on the examination of ethical issues in health care and biology and the environment. He's now Senior Researcher and President Emeritus at that center. And his new blog on health care cost, if you haven't seen it, is definitely worth checking out. So, with that as a very brief introduction that you can supplement by looking in your materials, let me just put one on the table for our panel to respond to. [Clears throat] Excuse me. Most people

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believe that choice in health care is a good thing as we notice by the appropriation of politicians of all different stripes of the word in their legislation. But the question is, is that right? Is choice in health care a good thing? True or false, and we'll give you a choice of deciding which choice that you will choose to address in answering that question. And since Joe seems to have written an essay beforehand-

JOE ANTOS: You sent it to me, Ed.

ED HOWARD: Oh! [Laughter] But if you'd like to respond, start off the discussion Joe. Is health care choice a good thing or a bad thing?

JOE ANTOS: Health care choice is a good thing. I'm glad to be here. Thanks. It is a good thing, a lot of people, most people in fact- Excuse me. [Cough] A lot of people don't have choice of health insurance; people with employer-sponsored health care generally get the choice

that somebody else made for them. And, as most of you know, for younger people, lower income people, those choices aren't necessarily the right choices for them. You know, the question Ed winded up very well is its insurance, its providers, its treatment, and in every one of those cases, having some choice makes some sense but has to be informed choice. Ultimately, if it's random then you get very poor results. People have to have some understanding, considerable understanding of what the choice is about, and may generally need help especially with regard to their choice of treatment but also with regard to the choice of a doctor and the choice of insurance. So, yes, choice is good but it has to be informed.

ED HOWARD: Anybody want to amplify or disagree with that? Tony?

TONY COELHO: I agree, totally. I think choice is very important for patients but I do

think better informed is what's important. And I think that, you know, with the technology today that option is available and I think we need to do a better job of making sure that patients are better informed, and that is very possible, so that they can make the right choice. And I think with the right information they can easily make the right choice.

ED HOWARD: Uwe?

UWE REINHARDT: I would differentiate the choices. There's the choice among insurance carrier, financial intermediary, choice among providers, and the choice among therapies. And these totally different choices take place at quite different levels of the mind. The choice of insurer, Americans make a big, big deal of it. Although I have often wondered how many Americans actually lie in bed awake at night at 3 a.m. and worry about the choice of insurer, and are willing

to give up choice of provider so that they have a choice of insurer which Americans do, while a Canadian or a German said, "I don't really care who insures me but I want choice, free choice of doctor and hospital." So, we seem to trade off in a way that a European would find hard to understand. Because with an insurer you pick your own regulator, basically, right? Whether it's public or private, they'll tell you what they'll pay for and what they won't. And then when it comes to degree of therapy, economists strut out the idea of asymmetric information the very reason doctors exist is precisely because as a patient you really don't know how to pick the right therapy. So, choosing the right therapy basically means having the right to parent your own physician. That's what it really means. Now, again, you can have too much choice. There is choice theory in psychology and economics. There

comes a point when there are so many choices that it paralyzes you and also the probability of regret increases when you have too many choices that you say 'I'm now confused, I'll pick this.' But the chance that you will regret your choice is much higher when you have more choice. So, this is a far more complicated area than I think the clichés on TV, et cetera, make you believe. This is deep stuff.

ED HOWARD: Dan? How about limits on choice. Are there permissible or desirable ways to end up with choices that are less than unfettered?

DANIEL CALLAHAN: Let me answer that by just going back one step. I think when we talk about choice; there are really two possible models of choice. One is a consumer business school model of choice based on selling products in our society. The other is what I would call the

medical model of choice. The business model is very well-developed and suffuses our culture. It assumes that people can make clear-cut choices all against proper information, range of choices; they can get it all right. The medical model is based on uncertainty about what's wrong with you, uncertainty about what the treatment will do for you— and it seems to me that that I see as two very competing different notions of uncertainty. Now, on the second model, if you use a medical model, that it seems to me, and particularly talking about the economics of health care, you have to talk about the limiting of choices if one agrees that we now have a cost control problem, that cost control means you have to say no to people, and that means I can't have all the choices I want. I learned that, and I think about age 7, that why do people want to be rich? They want to be rich because they have all sorts of

choices. They can choose limos; they don't have to go airports- they have their own planes, and so for and so on. And we've lived in a culture which wants everybody to be rich and to have maximum choice and now we're finding that as a bad road to go down.

ED HOWARD: Well, how about the- you gentlemen are in a position to have followed this debate more closely than most of us, are there choice implications in the various plans that are on the table, notably the two that I mentioned and the ones that are being talked about by the President and the people in the Senate Finance Committee in the House Tri-Committee proposal? Are there choice implications in, for example, the exchange with or without a public plan question?

JOE ANTOS: May I?

ED HOWARD: Please!

JOE ANTOS: I'll address it but let me just say, respond a little bit to Dan's point. You know, it's not just choice that Dan's talking about. It's also who pays. And so the question is not should we sever choices, but how do we give people the opportunity to make reasonable research decisions and health decisions in spite of the fact that our entire health system acts as if there are no resource constraints, there really are. I mean I think that's one of our big challenges. Now, as far as some of the new proposals that are very slowly working their way through congress, I think there are several issues that, you know, seem like opportunities and they might well be. In particular, Ed, you mentioned the idea of an exchange. For a lot of people, including people who have employer-sponsored coverage, their choice is take it or leave it. If they were eligible to participate in an exchange

where sort of one stop shopping for all the insurers that are available in your area, then again with proper information and guidance they could be better off. Then often the sense that the choice they make might be more compatible with their health condition, their preferences, and their willingness to pay with or without whatever subsidy Congress decides to give them. So, I think that's a real opportunity. The Federal Employees Health Benefits program is a great example but keep in mind that is an employer-sponsored plan against choice. That's not some national exchange that already exists. We have to work on it.

(The transcript has been edited at this point to omit a series of statements from an audience member who made inflammatory and inaccurate personal charges against a speaker.)

ED HOWARD: Jill?

JILL: Jill Wechsler, Pharmaceutical Executive Magazine. Do you feel that it's primarily resources and costs that's the main limiting factor on choices if there were unlimited resources that that would eliminate the need to narrow choices or to define choices more closely in health care?

ED HOWARD: Uwe, do you want to start?

UWE REINHARDT: I mean what really limits most people's choice is that the typical patient is like somebody who's blindfolded and pushed into Macy's and say, 'Choose.' I would call that limited choice, and that's what most of us now have. And what the health reform bill as I understand it is trying to do is to create the information to allow you to take the blindfolds off and say 'What is this thing I'm actually paying for?' Cost-effectiveness analysis or comparative effectiveness analysis is all about

that. I happen to know it because I actually teach this stuff. So, I really know it unlike many people who talk about it but have no clue what this is really all about. It is simply to inform people on choices. Now, the issue of rationing should be well-defined. One thing you can do is I can say I will not pay for something but you're free to buy it. Most countries do that. We do it in the U.S., of course, as well. That isn't really rationing in the sense that you're withholding something from someone who therefore is led to die. The problem is cost-effectiveness analysis is, in fact, designed to help us not make choices when that is actually harmful. If we actually find out a drug or a device or a therapy really works, that is exactly why you wouldn't withhold it. If for instance, NICE, the English cost-effectiveness analysis institute, National Institute for Clinical

Excellence, it is not known but very often their findings actually diffuses technology faster and tells physicians you should be using this drug.

MALE SPEAKER: So, how do you know that that [inaudible].

ED HOWARD: Yeah. Joe, do you want to respond?

JOE ANTOS: Yeah. I think Uwe makes a good point. I think there's a real issue though as to the substantial limitations that the kind of research that we're talking about, comparative-effectiveness research has in giving clear-cut guidance to insurers, doctors, or anybody else about what precise treatment you should give to the specific patient that is in front of that doctor. I think that's a real challenge. There's a great deal of genetic and behavioral variability from patient to patient. And a good doctors, and I hope everybody has at least one good doctor,

actually knows something about you and knows that, you know, if he says you need to lose a few pounds, you're not going to do that so let's think of some other approach. In terms of actual medical therapies, there is a legitimate question here and let's keep in mind that insurance companies ultimately do have to make coverage decisions. They have to decide what they're going to pay for and you want them to do that. You don't want them to pay for anything that anybody ever thought of not just because of ineffectiveness but also because you don't want to spend \$50,000 a year on your health insurance. So, there's a real tradeoff here and your point that resources matter, they do.

ED HOWARD: Tony, your partnership has been sounding a cautionary note about some of the comparative effectiveness or cost effectiveness ideas that we've been hearing about.

TONY COELHO: Yeah. Yeah. We're very supportive of comparative back in this research. I think research is critically important as we move forward in health care. I think it's what you do with it and who makes decisions. We want to make sure that the patient and not the consumer. There's a big difference between the patient and the consumer. If you look at some of the bills, they want to make sure that consumers are involved in advisory consoles and so forth. We take offense in that. We want to make sure that patients are involved. And if you take the Baucus-Conrad Bill, basically it sets up a system whereby you have the patients and providers and the government, insurers, and so forth involved in decision-making process. We want to have patients and providers at the table actually making decisions. Those are the choices that we think are important. As a patient, I resent the fact

that, you know, bureaucrats and professors and others think they know what's best for me. Myself and my doctor I think know what's best for me, and if we're properly educated, contrary to what some people say and think— and I've read some things that people say and think— we're not going to pick the most expensive and so forth; we're going to pick what is most effective for my particular problem. It was interesting to listen to the President last night when questioned what are you going to do if your wife or your children, or your mother-in-law, whatever, is in a critical situation. He had trouble answering that question and I'm a committed Democrat as everybody knows, but I think that's the issue. And I think that patients need to be at the table making decisions. And for far too long, we have basically put patients aside and we have said 'We'll take care of you' instead of letting patients be at the

table helping take care of themselves. I think that's the issue here and Baucus-Conrad and the Schrader bill on the House side address that issue appropriately and that's why I'm so involved in this issue, and that's why our partnership is involved.

ED HOWARD: Thank you. Dan?

DANIEL CALLAHAN: I'd like to say cost-effectiveness, the debate, I was struck by the fact that the Senate Finance Committee in some earlier papers said that the results should never be used to either deal with coverage decisions or even recommendations. It seems to me if they do not deal with coverage decisions and recommendations or both, it's going to be a toothless tiger. That will make it much too soft. I want a doctor who has been forced, I mean literally forced, to look at the evidence and take it seriously because otherwise I don't know any

better as a lay person. And I don't trust the doctor just because he's a doctor that he will have all the knowledge he needs, and here is where I think the role of government is important. Set some standards and force particularly the doctor to pay attention to you.

TONY COELHO: Why would you trust a doctor over a patient or over a provider? I mean over somebody else. I don't know why the government has got- [Interposing]

DANIEL CALLAHAN: No, what I want-

TONY COELHO: I've been in government for amount of years. I don't think we know everything.

DANIEL CALLAHAN: I want an educated doctor. That is to say, one educated by the available data that that doctor has been, more or less, coerced to pay attention to, whether he wants it or not. I wouldn't trust such a doctor

if he said, well, I've made— what we know there's a lot of data recommendations that are out there but doctors don't pay any attention to it all because nobody makes them pay attention to it. So, I'm really asking for—

TONY COELHO: So, a body that would have a doctor, a patient, the government, and insurers and so forth where you have an honest to goodness debate and discussion seems to be the answer to your concern, as opposed to government making decision on its own.

DANIEL CALLAHAN: No, no. Well, the government would say that everyone with high blood pressure should be treated medically. I think a lot of doctors ignore that. We know that the treatment is very poor, though the evidence has been right there for a long time. I would make that a requirement of good medicine that there are certain standards doctors must meet including

knowledge of what is best for the patient based on science. Medicine is part science.

UWE REINHARDT: No one wants to actually interfere in that decision, but at some point I think a taxpayer should have the right or their representative to say for some of these decisions, we will financially underwrite. But others, we really can't ask every taxpayer just to underwrite whatever some doctor and some patient— Now, I know it sounds harsh but this is the reality. And it's true with Aetna and WellPoint, too. At some point they have to say 'We cannot underwrite every single decision that gets made.'

TONY COELHO: Don't you think that we as patients are taxpayers? I think what I resent to some extent about this line of thinking is that there are people who really don't think that we as patients are taxpayers and are concerned about where the next dollars are coming from and so

forth. We are as concerned as anybody else and if we are given the right to participate and are informed. I think one of the huge problems today is that there's lack of information for the patient and for the provider, and that this information is at a level that patients and providers really don't understand. And with modern technology today, it should be made more accessible and more usable. And with \$1.1 billion instead of reinforcing the old system, they ought to be using that \$1.1 billion to make more information more usable. That's what is happening throughout the country today on everything. Technology is demanding it. For example in a lot of the trials that take place, it's representative of five of us here, white men over 50, as opposed to if you take in my state of California, white men over 50 are an extreme minority. And that, you know, the trials need to be representative of

what the American population is. And that is not what is taking place. And I think that as patients we want to be better informed and we'll make better decisions. And I think that a lot of studies have shown that that is the case.

ED HOWARD: By the way, we have a diverse panel here. You may not have noticed but we have both blue suits and grey suits. [Interposing] [Laughter] Let me just wrestle with this one more round, if I can. Recently there's been a controversy about whether Medicare should cover virtual colonoscopies. Personally, I don't like talking about colonoscopies of any kind, but clearly there is disagreement about the efficacy of that intervention, that test. And Tony had talked about the extent of which there was good evidence that was being ignored or not being shared in a useful way with providers and patients. To what extent is there good evidence

on most of the things on which expensive decisions
sometimes have to be made?

DANIEL CALLAHAN: I think in this case
there have been some particular studies done and
showed that, by and large, there are some reasons
to worry that the virtual colonoscopy is not quite
as good. It has got some benefits and it has got
some losses as well. Then we get down to the
question, given the uncertainty of the data, to
what extent should a patient have a totally free
choice of going one way or the other or a
physician to prescribe one way or the other, and
it seems to me it would be appropriate, say, for
an insurer or for Medicare basically to say 'We
will support A but not necessarily B,' or they
might say 'The evidence is mixed enough that we
will leave the choice to the physician.' Now the
poor patient is not- unless they're spending time
reading this stuff- will not be a very good judge

of what to make of that particular evidence. So, one way or the other, we can be heavily dependent on physicians to educate us about the evidence and basically they'll have to do it in laymen's language and so forth. [Interposing] I hope they actually bother reading it, which is another problem.

JOE ANTOS: You bring up an uncomfortable subject. As it happens, I visited my— I don't like to think of it as my gastroenterologist but I saw him last week. And I asked him this question and he made a very good observation that's highly relevant to this in general, which is that a lot of people get their advice from the newspaper, at least those few of us who's still reading the newspaper. I guess its white men over 50. [Laughter] And so leaving aside the specific condition, the fact is that if you read the newspaper you know that seemingly there's

contradictory advice. If you read over the course of three or four months, you come away saying 'Oh, gee. Is that a good idea or not? Does that apply to me or not?' So, what it really says is, again, you need the intervention of, and I agree with Dan, you need the intervention of somebody who's paying attention, but I think if you set standards that treat doctors as cogs in the wheel rather than as professionals, you won't get what you want. As Uwe said, choice is fundamentally a psychological question. And let's not forget that even doctors may be human. 'The tests aren't finished yet but we're looking into that.' And physicians know if there has been parent's uncertainty about test results, about clinical trials, and about how even the strongest seeming results apply to their patients. So, I think some common sense, shockingly enough, needs to be applied here.

ED HOWARD: Yes?

FEMALE SPEAKER: [Inaudible]

ED HOWARD: You would want to wait until someone gets to you with a microphone so that the others can hear you.

AYANA NIZUMA: Ayana Nizuma. Can I address my question to the former congressman?

TONY COELHO: Mm-hmm.

AYANA NIZUMA: Around health care disparities and cultural competency as it relates to cost, you were talking about the five white men in front of the room and it's interesting when it comes to asking questions, and I just want to give a little lead on why I'm asking this. My dad last summer was ill and was scheduled for surgery—he'll be 88 next Friday— and was scheduled for colon cancer surgery, had told the doctor who was a 70-year-old white male that his daughter is maybe calling to ask some questions regarding the

surgery. In doing so, as I began to ask a long list of questions, at one point he finally said to me, 'It seems like you need a second opinion. We're going to cancel that surgery and let you go do that.'

Now, typically you say information is power. We're trying to get to the heart of why this was scheduled. He's an elder so of course anyone who has an 88-year-old father you're going to ask a question or two. As it turned out, canceling the surgery was probably the best thing that could have ever happened because we found a new doctor and he began to run a series of tests. He found out that not only that my father need triple bypass heart surgery to be able to withstand the colon surgery. Of course, my father was very annoyed with me by asking so many questions because you know we could have had this done with, but then I indicated to dad if I had

not asked the questions, they would have not canceled the surgery. And maybe because, back to the cultural competency health care disparity question, what do you know? Why are you asking questions? Congressman, would you mind addressing that question?

TONY COELHO: That's what I was referring to before. I think that to a great extent what we do with our society is we base things based on a lot of the trials. A lot of the trials don't include people of color; don't include women in proportionate numbers and so forth. And I think a lot of the results would be different if they did. And so, I think that a lot of this needs to be fair and more reflective of our society. And I think that's one of the issues that needs to be aggressively addressed and that's where we come down [inaudible].

ED HOWARD: I'm going to recognize you and I would ask you to keep your questions short and simple and to identify yourself.

[The transcript has been edited to omit a series of statements made from the floor at this point by an audience member who made an inflammatory and inaccurate charge against the Hastings Institute.]

FEMALE SPEAKER: In this packet that you guys you handed out, there is a statement. The statement is, 'Yet there's nothing of importance left to do other than to reduce benefits.' That would mean denying elderly patients both what they might want and need. And you draw the line at 80 years old. Just as a side note, I think Benjamin Franklin was well into his 80s when he drafted the Constitution, so a very wise man at the end of his life who's able to do a lot or we wouldn't be sitting here otherwise.

DANIEL CALLAHAN: I am now 79 years old. I talk about reducing benefits because the Congressional Budget Office is a reputable advocate and said, 'Given the Medicare crisis, we can either double taxes or cut benefits.' I think we'll probably have to do some of both, and it seems to me I don't have to use age as a flat-hard standard. I'm saying after age 80, which I'm nearing, then we should begin to think of the burden on younger people paying for the excessive care of people over 80, or we prepare to raise taxes. If we want to double everybody's taxes, no problem; I'd get rid of my standard.

FEMALE SPEAKER: It says in the speech that you gave that you don't know why people over 80 would choose to live with a poor quality of life rather than be dead.

DANIEL CALLAHAN: Well, people my age who basically said I would prefer to die rather than

live a terrible quality of life. That's why we have a hospice movement, which precisely deals with people who have a poor quality of life and want no further medical treatment.

FEMALE SPEAKER: How can you put a price tag on life, though? How can you put a price tag on life?

ED HOWARD: Actually, that's a very good question and it's something that our economist friends have been doing in all of the various comparative effectiveness in agencies that we were discussing at a forum a couple of weeks ago: quality adjusted life, years for a given amount of money. Uwe?

UWE REINHARDT: First of all, how can you put a value on life? It's done all the time. It's done when you decide, for example, not to have brand new subway cars all the time. It's done when you decide whether or not to light a

street. Recently, a congressman asked me, of how I come to this and I said, well, I actually have never made such a decision but you have because my son was a Marine and those guys were under-equipped, and don't tell me you congressmen didn't put a price on his life and I'm rather offended how low it was because unarmored HUMVs, no flak jacket, and so on. So, we do it all the time. And health care is the only place where in fact we don't.

FEMALE SPEAKER: So, why don't we stop doing it? Why don't we stop doing it instead of-

UWE REINHARDT: Talk to the Congress about our military. That's where you should start. That's where you should start with the military.

FEMALE SPEAKER: No, we should-
[Interposing]

UWE REINHARDT: The men and women who died who shouldn't have.

ED HOWARD: Yes, Marilyn.

MARILYN: Can we turn the conversation just a little bit to [inaudible]? We're talking about choices and at the same time there were also talking cost containment as very big issue as we approach health reform. And I really like to get the thoughts of some of you gentleman about specifically in health reform, where is the line, where do we find the balance between providing patients with choice, which we all lived through the backlash of detour the HMOs because people were not happy that they did not have choice. And Uwe you talked about, you know, people not staying at night thinking about their choice of insurance companies, but at the same time when you have, some people do acquaint choice of insurance with which doctors they will get to see, with which services they may get. So, really, where do we find this balance between providing patients with

a kind of choice that we've seen over the years that they demand and yet at the same time controlling costs?

TONY COELHO: I'll give it a shot. First of all, people don't usually worry about which insurer; they worry about what their benefits are going to be. That's the right decision. And they do need information and help with that. But I think you're really sort of posing an almost a false question. It isn't just choice, whatever you really mean by that, because I'm not sure there are a lot of choices that congress is thinking about it, all sorts of different levels, and some of them have serious cost considerations and some of them don't. It's just not at all clear. But I think you have to look more broadly than that. I think choice isn't the pivotal point around which reform legislation is actually rotating.

MARILYN: But at the same time, it is rotating quite a bit around [inaudible] rotating around, and cost is such a major consideration, do we risk losing some choices?

TONY COELHO: Well, we would be better off if we lost some choices that ought to be outside the choice set. Now, remember what I said about comparative effectiveness research, I'm fairly skeptical about the possibilities that we will get clear yes or no answers out of that research. But if we did, that would be very positive. If we could find a way to encourage primary care doctors to actually provide primary care rather than shipping you off after the 10-minute office visit to a specialist to get an expensive test that wasn't necessary if the primary care physician used his five senses and his stethoscope. And, you know, there are some choices that are being made for us that we all would be better off if we

didn't have. So, the word choice is a neutral term. It doesn't say good or bad. There are some things that are good, and some things that aren't.

UWE REINHARDT: Marilyn, there are really two issues. One is that in America you choose your providers with your insurers. That's unique here. In Canada, you have completely free choice of doctor and hospital, and no choice of insurer. And in Switzerland, you have complete choice of insurer and complete choice of doctor. And in Germany you have 200 insurers you can pick from and free choice. So, we're almost unique in telling people that when you buy a health insurance you limit your choice of doctor. Why we did this, I don't know. I just recently got here, so to speak. [Laughter]

I think on the second question, let me give you some numbers, choice is obviously a luxury that has a price. And one could fairly ask

Americans, the middle class particularly, how much are you willing to pay for this, because after all that goes with choice how much you're willing to pay. If you look at the Milliman Medical Index, they add together what the cost, totally, for an American family of four for health care, that's employer-paid premium, the employee's contribution, and the cost sharing are added. And the reason that's reasonable because the employer-provided insurance really comes out of the paycheck of the employee. We all believe that. It's now \$16,700, and it will be 18,000 next year. That was 8,114 in 2001. So, in 10 years, health spending per family of four has doubled. So, put yourself 10 years down the pipe, it'll be \$36,000 per average American family of four to get health care. That has to come out of their gross wage base, which is the wages before deduction of employer, or employer-provided anything. It's

what the price of labor is to business. If somebody has a wage base now of 60,000— at recent growth rates of wages 3-percent per year, Joe, you would say that's optimistic.

JOE ANTOS: Very.

UWE REINHARDT: That would be 80,000. So, 10 years from now, an \$80,000 wage base has to set aside 36,000 just for health care, and everything else— college, taxes, social security— has to come out of the rest. So, one would really look the American middle class in the eye and say, my friends, is that what you like? Because you can have this; you can have this wild, free [inaudible] choice. In fact, you don't really have it. Once you choose an insurance company, you don't have free choice of doctor. But whenever you guys really love this system, you can have it. The price tag is 36,000 out of your 80,000 if you want to buy it. And I think if

anyone every really told the American people that's the deal the health system offers them, they may not buy it. And that would, of course, be the rationale for what we call health reform, right? That you say, we don't want to buy this deal anymore, which is what I believe the president is really talking about.

TONY COELHO: I think one of the things that we forget is that our system is a political system. We can sit here talk about all these things all we want but it's ultimately a political system. And we had the Patients' Bill Of Rights, if you remember all that discussion. Basically, it was patients and providers versus the insurers and government. And we know where that fight ended up: patients and providers. Congress is not willing to go against patients and providers. You also recall when congress decided that they were going to take on patients and within months they

had to retreat and redo the legislation, withdraw it and redo it because the country blew up on them and they got booed and hissed and people following on cars as they drove into places and so forth.

So, they had to withdraw the bill. It's the same issue today. And I submit to you that, to a great extent, if everybody wants to focus on cost, like Orzac and so forth, that cost is the only thing, I think they're going to find out that the American people are not going to go along with that. If you take this to an extreme, we would have never developed the iron lung. If you take it to extreme, we would have never found a cure for HIV-AIDS. We in America have basically not only found cures for a lot of the diseases for our people, but we've led the world in regards to what we've done. That is our American system. We believe in that. We strongly believe in that and I think that what we need to be doing is to find

ways to educate the patients and educate the providers to be better informed to make better decisions. I think people forget that one-fifth of our population has a disability. Those are patients. And they have loved ones who are related to those patients, and so that's a strong political constituency that are impacted by these decisions. And so I think that in all this debate it's fine for people to sit in their ivory towers and make these judgments, but it comes down to raw politics. And I think that's what's going to prevail in this whole process.

ED HOWARD: Yeah.

DANIEL CALLAHAN: Uwe has laid out the financial facts, how do we persuade the raw politics, mainly the people, to understand that, hey, we can't go on this way and the only choice is we can either raise taxes or cut benefits, we cannot do both.

TONY COELHO: Well, I don't think that's
the— [Interposing] I think your premise is wrong.
I don't think that's the choice.

DANIEL CALLAHAN: What is the choice then?

TONY COELHO: I think there are other
choices.

DANIEL CALLAHAN: Like what?

TONY COELHO: Pardon?

DANIEL CALLAHAN: Like what?

TONY COELHO: I think the better choices
are is to better educate. First off, I think
everybody admits that the information flow is not
good. There is no way that providers and patients
get the information today that they need.
Somebody in the ivory tower knows and that people
write books and do all kinds of things based on
this information, but it doesn't get to patients
and to providers. There seems to be a way with
technology today that is very doable so that

patients when they're told about X they can go and find out what that means.

Now, people immediately think that somebody who has got a problem that they are either too old or too disabled or whatever it is the impression you get is that they are not interested in finding that out. That is just so erroneous. They want to find out. And so if you give them a way to find out, if you give them a way that they can help make that decision either to their loved ones or themselves, they'll find out. And also in going to hospitals and cutting back expenses, there are ways of doing that all across the board. And so I think that what we need to do is instead of concentrating like Orzac does that it's cost at all cost, we've just got to cut cost and irregardless of what anybody else says, that is I think a false choice and I don't think congress will go there.

DANIEL CALLAHAN: You're confident, in short, that if we did all of that we would not see a doubling of cost. Do you really have the figures to back that up? Do you really think— all of those things are great things. They'd make some difference but we're talking about a radical problem with cost in this country, not one to be just tinkered with and simply a little more choice, a little better technology assessment will get all of this. I see no reason to be confident that we will get in the dramatic imperative way that we need it. Yours is a smiley face solution. Nobody is going to be hurt. Nobody has to give up anything. Everybody is going to be better educated. I think this is a fool's errand.

TONY COELHO: Well, I think the fool's errand is this: Is that when you talk about cost that you are permitting or you are advocating that bureaucrats will decide, for instance for somebody

like me who has epilepsy, that the bureaucrats will decide what treatment I get is what you're saying. And so basically it has nothing to do with my quality of life. And so if I'm drugged up so I can't function and I can't provide and pay taxes and so forth, if my family is impacted as a result of that, what is the cost involved? There are costs across the board as a result of this and I think that's what needs to really be discussed. That's why I'm for the Baucus bill, basically, because there are several people at the table making decisions and not just some bureaucrats making decisions, that there are several at the table and decisions to be made. If some costs need to be contained, then they can be contained. But I want people, patients at the table, and I want providers at the table, and I'm saying that the Baucus bill has government at the table and so

forth. But I want patients and providers at the table, too.

DANIEL CALLAHAN: I absolutely agree with you but I think the question is will that do the job, and I doubt that that's all.

ED HOWARD: Let me just— well, go ahead, Joe.

JOE ANTOS: I just wanted to sort of amplify this discussion a little bit and raise the question about whether, for example, the Medicare program we're doing, what kind of a job on this question, and I'll give you an example; example that congress is well aware of and certainly an example that patients with severe kidney disease are well aware of. People who have end stage renal disease are dialyzed. Dialysis is a difficult process. You have to do it on a very regular basis. Every patient who is on dialysis wants a new kidney. There are issues related to

supply, which I won't get into, but here is the defect in Medicare's policy. Medicare, by the way, pays for all of this. Nobody else does. For kidney transplants, it's the private insurance who does— well, very little; very little. Once you qualify, then Medicare takes over.

JOE ANTOS: So, with Medicare they have a really penny-wise pound-foolish policy. As you know, once you get an organ transplant you need anti-rejection drugs that are very expensive. Medicare will pay for anti-rejection drugs for either two or three years— I don't remember precisely— three years. After that, if you are low income and you don't have other means of support, your kidney is going to die and you're going to go back on dialysis. And you're actually going to cost the taxpayers a lot more money. Now, the point of this is, first of all, you raised a very important issue that the congress

has to deal with. But the other point is that we do have to ask whether we can count on people in Washington to make the right decisions among all the decisions that they'll end up making. I'm concerned about that.

Clearly, it is a political process and clearly here's a group of patients whose voice isn't heard. And by the way the taxpayers are unaware of this so their voice is unheard either. I think this is a very, very serious problem. There's no simple solution here and Marilyn's point about where the line is drawn, that's just it. The line is about 50 yards wide and it's all kind of grey.

ED HOWARD: Yes, go ahead.

FEMALE SPEAKER: [Inaudible] I was a kidney donor four years ago so I am very concerned about my friend being able to keep that kidney in a healthy state. And there is now some discussion

around that the donor being taken cared of because they forget about us. After three years, you're on your own. But the other question I'm going to ask about was the electronic health record and the cost consideration for that. Would you gentlemen mind addressing that? You mentioned technology—
[Interposing]

UWE REINHARDT: Well, there are two kinds in health IT. The electronic medical record typically refers to a record written in clinical language that physicians can share across institutions ideally with authorization and privacy protection nationwide. SWA [misspelled?], for example, has it. The other one is the electronic personal health record which is an interface between patients and their delivery system at the very least to a medical home, but ideally, say, in the Kaiser Permanente Plan to everyone. You can, at midnight, look up your

record; see what benefits you know, test results, if you want to know what that means you can click, get layman's language. If you want to read New England Journal, they'll take you there. If you want to make an appointment with a doctor you can make it, and so on. Those things are not yet widespread in the rest of the insurance in this regard but they're coming. I know Humana have been working on it, and I think all of them are working on it. I see absolutely nothing wrong with it. In fact, I think it's a marvelous tool. But that's an interface between the system and the patient written in patient's language, and the other one would make— if anywhere in America where you collapse or had an accident, that doctor should be able, ideally, to get access to your file if someone authorizes it. And that's a good thing.

FEMALE SPEAKER: Well, the cost consideration is what I'm really concerned about.

UWE REINHARDT: Oh. I don't think it will save a bundle of money as some, as I think the President expects. It will initially cost more to put this in place, but I think it'll enhance the quality of the treatment because it's much better informed.

TONY COELHO: Yeah. I think Peter Orszag is actually on record repeatedly saying it's not going to generate a lot of savings all by itself. But he is interested in the comparative effectiveness approach, applying the data that you get from these electronic records in a way that leads you to more efficient systems that might save money in the long run.

UWE REINHARDT: I mean on cost effectiveness, I would agree with Tony that it, by itself, should never be binding. It should be

information that's there for a user to use, and the users could be patients, could be physicians, could be insurance carriers to decide what to pay for or not. But it should never be binding that a bunch of eggheads made this conclusion and therefore it's binding on payers. I don't think anyone is talking about that though.

JOE ANTOS: Well, you mentioned insurers, and that's the obvious application. Once you have information, you know, coverage decisions are made everyday. They're made by physicians who are employees, typically the consultants of insurance companies, and they use the best information they can get but it isn't everything, which is one of the reasons why, in fact, these coverage rules aren't all that binding. There's an appeals process because they know that there's an inherent fuzziness in this whole thing.

UWE REINHARDT: Yeah, but the alternative of having no information is better than having some—

JOE ANTOS: No, no, absolutely. We need to improve that information because we can get better decisions, absolutely.

ED HOWARD: Yes, Jill.

JILL: Just to follow-up on that little debate I believe on the hill right now is whether the legislation should specifically prohibit Medicare from using that information and making its coverage decisions, which should have twisted around the other way. Is that a useful approach?

DANIEL CALLAHAN: Well, it should be one of the greater rationale is whether the cost is 'the' problem or not, leave that aside. We all agree it's a very serious problem. It is utterly strange in your rationale that the Medicare program has never been allowed to take cost into

account. How can one justify a policy of that kind at a time of a cost crisis?

UWE REINHARDT: Take, for example, recently a study two days ago came out that said actually knee replacements, over the long run, is cheaper than an alternative conservative treatment, whatever else medical treatment. So, what the congress then said, oh, this information we should never use. Right? [Laughter] I mean this seems almost silly on its face. I'm not saying congress doesn't do silly things, but that seems— well, the flexible spending here comes close. But I think for congress not to be able ever to take something, I mean, what if cost effectiveness analysis finds out that one drug really isn't terribly effective and the other one really is? You mean, that shouldn't be taken into account? That somehow patients should know this

isn't a more effective drug? I just find it very strange, but I could see who motivates it. That may have been a form of prejudice affection, frankly.

TONY COELHO: Well, the reason that that was put in was because that group of folks are the most vulnerable. And if not careful, that group of folks would be the ones that would get all the cuts and so on. And so being a political body, basically the political body said I'm going to protect this group of folks. And so you can understand why it was done. Now, as to how they addressed it might be a different issue.

ED HOWARD: By the way, a couple of weeks ago we did a small meeting that was not advertised and so most of you probably didn't attend in which we brought together the people who run comparative effectiveness institutes like the NICE Institute in Great Britain from four countries including

also Germany, France, and Australia. In every instance even where they started with a mandate that said we will not consider costs, they ended up considering costs. So, if you'd like to go on our website, you can look at the presentations and the materials that we've put together for that. Any further questions?

TONY COELHO: I would say that comment you just made is the big concern that we have.

UWE REINHARDT: But ultimately people, of course, will. I believe, in fact, when they struck cost out of the bill, the stimulus bill, and made it just comparative effectiveness analysis, I don't think that was a big deal because an institute like that wouldn't even know what cost is since Aetna gets a different price from WellPoint, gets a different from Avera, and what is cost? So, what I think, once comparative effectiveness data exists, any good policy one can

take that as an input, add their costs to it like an insurance company, and then decide whether to buy it or not. My own view is at the moment for the next 10 years, at least, we actually don't really ever have yet to come to the question what is the maximum price we Americans would pay for a quality-adjusted life. I don't think we're near there because there's so much waste of totally obvious ways available. I mean, for one, if we learn how to administer insurance claims the way every other country knows how to do it, Taiwan or Germany or Canada, we would save enough money to pay for all the uninsured. I mean, the money is just lying on the street to pick. The problem is, there's a huge constituency for waste in America and in American health system. Why there isn't a common claims form? Why there is still paper in insurance? And I guess, is there in Medicare, Joe? I think it's electronic, right?

JOE ANTOS: There's plenty of paper everywhere.

UWE REINHARDT: Yeah. [Laughter]

JOE ANTOS: Including in Medicare.

UWE REINHARDT: Including in Medicare. That's not true in other countries, you know. So, I think if we actually, first of all, spend this decade just harvesting the waste, we could defer this difficult decision to our kids and let them deal with it. [Laughter] Like Louie XIV said after meeting the flood [misspelled?] [inaudible], let them deal with it. We have so much free money out there that doesn't at all involve agony or depriving patients of everything that's really useful. Maybe we should go after that first.

DANIEL CALLAHAN: Uwe, I would only add that American culture really lives off of the idea of waste. We don't like to think what we're doing is wasteful at all. You've got to change people's

perception of what counts as waste. For many people like me who want to set some limits, somebody would not think it wasteful to do operations at 100,000 chance on the grounds that 100,000 is better than zero hundred thousand. And that's not always where we spend the money on, I would argue that it is. But that's the way— if you think life is priceless, then there is no such thing as waste spending money to make people healthier.

UWE REINHARDT: I know. That's exactly my point though. At some point, this country too will have to come to the question what is the maximum price we pay. A million? 10 million? And so on. But I'd say, fortunately for our generation, there's still so much waste where you don't have to raise this question. Like, you know, if you actually got the private insurance

industry finally to use a common claims form, no one would die over this, right?

MALE SPEAKER: Which Dr. Bowen tried to do in the 1980s unsuccessfully.

UWE REINHARDT: Yeah. The insurance industry refusing to do that is truly puzzling to me. What is even more puzzling is that we allowed them to get away with it.

ED HOWARD: Tony and then Joe.

TONY COELHO: [Interposing] -said that removing cost from the stimulus bill is not such a big thing. He was talking about something different. But I would just tell you that it was a big thing because basically it was a political reaction. I talked about that this is politics, is that once that memo or that report had that entered in the omnibus language in the House, the patient community went into an uproar. And as a

result of that, it had to be removed from the House language. So, there was a bit of a consequence and it was removed before it went through. So, I think that was a good signal to you that politics does play a big role in this whole thing.

ED HOWARD: Joe?

JOE ANTOS: I want to move back to this real fundamental question which I think has not been treated seriously about having controlled costs. And the aspect that really hasn't come up yet has to do with, again, it's psychological; it's what people expect. Now, if you have insurance— and everyone in this room probably does— you paid for it, right? And so you paid for it and so you're going to get services. That's in your mind; that's in everybody's mind. Your Medicare beneficiary, even if you really didn't pay for, you paid for it and you're going to get

services. In fact, the only people who don't have an entitlement mentality in this country are the uninsured. Everybody else paid for it and they're going to get services. Part of the problem is that they don't see anything like the full cost of routine expenses. Yeah, people are now up to maybe \$500,000 worth of deductible for the middle class, and higher income people that's practically nothing. That \$20 office visit, that's what it costs, right? Not the \$100 that it really costs. And so, you know, it's great to dream that, as Uwe I think correctly pointed out that health IT is a good idea but it'll probably improve quality, probably won't save cost anytime soon. We can have the dream that cutting administrative costs are going to somehow solve the problem, but the problem is us. The problem is the structure of insurance. The problem is we're all entitled. It says we act that way and our doctors act that way

because they know we're entitled. That's what's driving health care and that's why health IT isn't going to save any money because to save money you've got to change that behavior. Health IT doesn't touch that.

ED HOWARD: Well, go ahead.

UWE REINHARDT: There I agree with— or was it you who said it's in our culture. Yeah. I said it on NPR so I'll repeat it here. My mother needed a thrombosis on her leg in Germany and she told me, "Oh, I have to wait two weeks for that hospital in nearby town to have a bed." And I said, oh my goodness, she's got two weeks. I said I know people over there. Let me call the hospital's nurses station. I'll get you in. Ah, she gave me lecture. She says, "What a social thinking this is. Because if you get me and then somebody else was ahead of me and now has to stay back." She says, "That's not how we think over

here." And she really gave me hell. She said, "This is very asocial thinking that you do." And I was ashamed and I said, hey, sorry. This is how we do it here. You know, everyone for himself. And so there is a different cultural mentality that people do think of their country. They think of what premiums would be if everyone just got everything they wanted. But it is true, we don't. And Joe is right. He described this exactly right. Once you have that little gown on, you're entitled, right? MRI, CAT scan, you name it.

DANIEL CALLAHAN: A phrase I hear over and over again that I find most distressing is the cultural side of people saying, yes, we do have a cost problem, yes, we're going to have to set some limits but not if it's my wife, child, or spouse. [Laughter] Now, if everybody reduces all these problems down to the most self-interest in level, you can't have a coherent health policy at all.

ED HOWARD: You were quoting the President there, weren't you? [Laughter]

MALE SPEAKER: Pretty much. [Interposing]

ED HOWARD: Well, we've come to the end of our appointed time. It was a lot more exciting than I was hoping. [Laughter] And let me just end on what I think is a hopeful note anyway. 25 years ago, Jack Wennberg started putting together these patients' videos when people had prostate cancer. And what he found was that those decision support videos were actually viewed and people had a chance to see what chances of various treatments were that they often chose the less invasive, less expensive course of treatment. So, maybe if we can share the right information and generate some more information, we can at least postpone what may or may not be inevitable in the way of hard choices long enough for us to get through the system anyway if you're over 50.

Consumer Choice in Health Care: How Could Reform 71
Affect Our Choices? How Could We Make Better
Choices?
Alliance for Health Reform and Robert Wood Johnson
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6/25/09

And I want to thank each of you for sticking with us in some tough times, but for some very lively discussion. Thank you Robert Wood Johnson Foundation for its support and its interest in this. And we'll dial back into this debate as we come across the next few weeks and choose the alternatives in congress. Thanks very much. [Applause] Thank you to our panel explicitly.

[END RECORDING]