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# Women and Healthcare: A National Profile
# July 7, 2005

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**DIANE ROWLAND:** Good morning and welcome to the Barbara Jordan Conference Center for this briefing on women and health care, a national profile with key findings from the Kaiser Women's Health Survey. I'm Diane Rowland, the Executive Vice President of the Kaiser Family Foundation and it's just a delight to see all of you here this morning and I hope you'll find this a very rewarding morning in terms of learning more about some of the choices and challenges that women make in their roles as both the caregiver and a family member, as well a consumer themselves of healthcare. We really enjoy doing this kind of a survey. Because we like to do in our work, a focus on people and what happens to people in the health care system. You come to a lot of briefings, many of you here where we talk about the Medicaid Program, the Medicare Program and the ways it interacts with its beneficiaries. Today we're here to talk about women as a group and the challenges they face in trying to access the health care system and trying to provide health care for themselves and their families. This is an issue that cuts across all of the policy work of the foundation, so I'm particularly pleased that we both have the survey to present to you this morning, as well as a wonderful panel to talk about not only the implications of the survey, but some of the issues facing women and their healthcare.

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This morning we're going to begin by asking our Vice President, Alina Salganicoff, to present the key findings from the survey and then we're going to follow up with what I know will be a lively and interactive discussion from our panel that Jackie Judd our Vice President in charge of helping us to formulate some of the better discussions we have will lead this and moderate a panel of Carolyn Clancy who is the director of the agency for Health Care Research and Quality, Paula Johnson who directs the Connors Center for Women's Health and Biology and is Chief of the Division of Women's Health at the Brigham and Women's Hospital in Boston, and Susan Starr Sered who is a Senior Research Associate at Suffolk University but also the author of a new book out called "Uninsured in America, Life and Death in the Land of Opportunity." I think each of them will bring some unique perspectives to this discussion and I know Alina's statistics and findings will be useful to all of you as you try and assess where women's health is going and what the challenges are. So without further adieu I'm going to turn the program over to Alina and ask her to both walk us through her findings and set the context for our discussion. Thank you again.

**ALINA SALGANICOFF, PH.D.:** Thank you Diane. I'll get us started here. Welcome I'm pleased to see such a loud crowd here today, we got a real enthusiastic response when we sent out the invitation for the survey. You're always a little bit

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nervous, are people going to come? And really this is an issue because of all of you are still keeping all of our feet to the fire on this issue, still generates a lot of interest. What I'm going to do today is just present some of the highlights from the report, really focusing on women's coverage, their access to care, their interactions with providers, and discuss a little bit about their family health roles and responsibilities. What I'm about to present today represents the work of many individuals, in particular I'd like to thank one of my co-authors, Usha Ranji [misspelled?] who's here today from Kaiser Family Foundation and Dr. Roberta Winn [misspelled?] who is at the UCLA Center for Health Policy Research. I'd also like to acknowledge PSRA International, Mary McIntosh [misspelled?], Kim Hewitt [misspelled?], and their other amazing staff have really been partners both with this survey and the previous survey that we did.

When we were pulling together the report we wanted to have a snazzy title, as you can see we ended up with "Women in Healthcare: A National Profile," so I really cast a very wide net and I got a lot of interesting suggestions but none that I could really use and keep my job or present to you here today. But a couple of weeks ago I was at the Medicaid commission meeting and we were having a discussion about Medicaid co-pay. People kept tossing around this term and people kept saying you know, "Beneficiaries need to have skin in the game." I

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thought, "What a great title." Too late, we went to press. Because really, I think that that really captures the situation for women. Women have lot of skin in the game in the health care system so if you could just cross out the title and put skin in the game in your report we'll have our snazzy new title.

I'm going to start now by sharing some of the findings with you right now. What I'm going to present today comes from the Kaiser Women's Health Survey, this is the second national survey of women that the foundation has conducted. The goal of the both of these surveys really is to better understand the key issues that are facing women, particularly sub populations of women that are much more at risk for experiencing problems and accessing health care services. We focus on women because so much of the research that we have really looks at populations in aggregate. That is not to say that the needs of men are not as important, or in many cases men are equally underserved as women but really it's important for us to understand what the different needs are of women and also the special populations of women and that's the goal today. This is a nationally representative survey, we surveyed women 18 and older so we included seniors which is a difference from the last survey that we did. They were about 25 minute interviews and they were conducted about a year ago today, actually, throughout the summer and early fall. We over sampled African

American woman, Latina, low-income really to allow us to have an analysis looking at different racial and ethnic groups, different poverty levels, and insurance coverage. There are groups of women that we were not able to look at, we really did not have adequate sample to look at Asian women, Native American survey, that's a limitation of the survey and I definitely think that this is an area where we need a lot more information and research. I always start out saying we need to do that and then unfortunately when we start doing the cost estimate it becomes prohibitively expensive but I definitely think that's an area that merits further research. Again, this survey was designed and analyzed by the researchers at Kaiser along with Princeton Survey Research and researchers at UCLA.

I'm not going to spend a lot of time really going over the demographics but I think what's important to glean from this survey is that we're talking about a very diverse population, both in terms of age, race, ethnicity, income, educational level and generally resources that they have available. We see here that half the women are of reproductive age, that's the group that often gets the most attention when we focus on women's health but in fact an additional third are in their midlife and 17% of women are seniors, so the other half are women that often don't get the attention that they really merit, particularly from those of us who are doing work on women's health. One quarter are women of color and half are

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women who have modest incomes, that's below 300% of poverty, one quarter are low income, that's below 200% of poverty, that's about $30,000.00 a year for a family of three. About half of women have either a high school education or lower, that's something that I think that we don't think about very often but that also is very important in terms not only the resources that they have in terms of coverage but also in terms of navigating an increasingly complex health care system.

I'm going to turn briefly now to women's health status. As I mentioned earlier, we did a smaller and shorter companion survey of men, while there's no statistically significant rate of the self reported health status, particularly fair to poor health, between men and women, women are more likely to have a chronic condition that needs ongoing treatment and this can range anything from diabetes and asthma, to allergies or medication to manage menopause. Women are also more likely to have arthritis, asthma, and obesity. They also are less likely than men but in significant numbers experience heart disease and more and more there's more and more awareness of the importance of heart disease for women. We also see that as women age their health needs rise, I think it's noteworthy here that while the scope is lower for younger women about 1 in 10 women of reproductive age report either fair or poor health or have a disability or condition that really limits their activities. Nearly one quarter have a chronic health condition

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that requires ongoing treatment, that rises to nearly half of women in their midlife years and nearly one in six for women over 65.

Another issue that is really under recognized as a women's health concern is mental health. We found that one in four women reported in the past five years that their doctor had told them that they had depression or anxiety, compared to 11% of men. Women who are younger or low income are more likely to report the diagnosis of depression or anxiety. It is notable that there are lower rates of depression or anxiety among African American women, whether this is really a true indication of incidence or reflects unmet need or poor detection is something we really can't tell from this survey.

I'm going to spend some time on coverage and access to care. Women and men do differ in terms of their coverage. This figure focuses on non-elderly women, that is women under 65, because women over 65 nearly all universally in this country have Medicare coverage. While two-thirds of men and women have employer sponsored coverage, women are more likely to be covered as dependents, which means that they are more vulnerable to losing their coverage should they become widowed or divorced or should premium cost for family coverage become so expensive that families will opt to drop coverage because they can't afford it. Medicaid is also a very important program for women, particularly for low income women. Women

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are more likely to qualify then men because they're more likely to meet Medicaid's restrictive income and categorical requirements. In order to be eligible for Medicaid you need to fit into one of their neat little boxes; you either need to be a pregnant woman, or a mother of a dependent child, or to be disabled, or to be over 65 and meet the income criteria. Nearly one in six women are uninsured which is a rate that's similar to that of men. You can see here the difference here that having coverage makes in terms of allowing people to afford care. While overall one in four women delayed care they thought they needed because of cost, two-thirds of uninsured women reported this problem. It should be noted while it makes a difference, having coverage doesn't address all of the issues in terms of access and I'm going to talk about those in a little bit. We found that 17% of women with private insurance and 13% of women with Medicare also delayed or went without care because they couldn't afford it as did one one-third of women with Medicaid. While Medicaid only permits nominal cost sharing, even small costs may be prohibitively expensive for women and really serve as a barrier to their care. Also noteworthy is this a theme that appears throughout this report, is the difficulties that women in poor health are experiencing in gaining access to health care services. This is a consistent finding that once you get sick it becomes much more

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difficult for you to get the health care services that you feel you need or even find specialty care.

And because we conducted this survey in 2001 we were also able to look at some trends, but only among women 18 – 64. While much remained unchanged in the three years, we were hoping for some big changes that would garner a lot of interesting, but the findings were remarkably stable. We did find some differences, and here's a statistically significant in the share of women who report that they delayed or went without care because of cost. That rose overall from 24% of women in 2001 to 27%. The rise in the uninsured I think is particularly striking, that's an eight point increase but we also saw a four point increase in the women with private insurance who are reporting that they delayed or went without care they thought they needed because of cost.

But as I said earlier insurance is not the only reason that women delay or postpone care. For many it's often difficult to find time for their own health needs between balancing their work and their family responsibilities. In fact, lack of time affected about 20% of women in all of the categories that we looked it, it was one of these kind of universal coverage regardless of race, ethnicity, regardless of income, insurance status, almost all groups of women said that they couldn't find time, the one exception was women over 65. For low income women however taking the time from work, getting

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child care, gaining transportation, are all significant obstacles in getting care and really issues that they need assistance with.

Another area that we looked at was prescription drug use. Over half of women say that they use a prescription drug on a regular basis, higher than the rate of men 42%. Now this can be affected by many things, including health needs, access to care, insurance status, cultural beliefs, experiences with health care, and actually experiences with other medication. As you can see here, senior women are the most likely to be using a prescription drug on a regular basis although over one third of women in their reproductive years are also taking a prescription on a regular basis. Latinas are the least likely of all the race ethnicity's to be examined but they are also the most likely to be uninsured and are slightly younger as a population.

The insurance story is a little more complicated. The Medicare population, not surprisingly, is the most likely to be taken a prescription drug on a regular basis. Medicaid has rates that are similar to private insurance despite the fact that the Medicaid population is significantly sicker and significantly poorer so you would expect that their drug use would be even higher than privately insured women. Uninsured women, because they really have a lot of problems with affordability and even gaining access to care to even get a

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prescription from a physician is the lowest and one-third of uninsured women have said that they use prescription drugs.

You can also see here the important impact of having coverage on gaining prescription drugs. Across the board you see that uninsured women are significantly more likely to report that they either didn't fill a prescription because of cost, or they skipped or took smaller doses of prescription drugs, or that they spent less on basic family needs to pay for their prescription medication.

I'd like to shift gears a little bit now and talk a little bit about women's health experiences with the health care system. It's really increasingly becoming accepted that there's much that we can do to prevent illness and to promote health and well being. Counseling and education are increasingly becoming accepted as an important part of medical care. Unfortunately we found that few of these educational conversations actually occur in the health care setting. We asked women when was the last time that a doctor or nurse discussed the following topics with you and we went through these range of topics, the response was in the past year, between one and three years, or has it been more than three years, or never. This is really kind of the most positive light that we could shine on this particular issue. We found that while many topics are being addressed the most common was diet, exercise, and nutrition although 55% of women had said

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that they had this discussion in the past the three years. This was followed by discussions about the importance of calcium. Only one third of women however had discussed smoking or mental health issues and alcohol and drug abuse was only said it was discussed by 20% of women and their physician.

The rates are even lower for reproductive health issues. Where one in three women of reproductive age said that they had discussed their sexual history, STDs, or HIV with their doctor, only 14% of women had said that they had ever discussed emergency contraception with their health care provider and only 12% had ever discussed the issue of domestic or dating violence. These are very sensitive issues and women as well as doctors I think may be reluctant to raise these issues. In addition we're find more and more we're trying to compress more and more into a health care visit that's typically initiated to address an acute health care need. There might be a time or an opportunity in the medical visit to discuss these important women's health issues. And in addition, finally, we don't really pay doctors to provide this type of counseling so really these discussions often fall to the bottom of the list. Why this is worrisome is because still health care providers are overwhelmingly sought as the first line of information when women need to more about a health care issue. We found here that when we ask women where's the first source that they turn to when they need information, 53% said

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their health care provider. As you can see the Internet which we think is where everybody gets their information these days is only the first line of information for 15% of women, similar to friends and family.

Preventive services are also very important to women yet in many cases we still fall short. Most women have had a blood pressure check and about three-quarters have had either a breast exam, a pap smear, or a mammogram for women that are 40 and older. Two-thirds of women said that they have had a blood cholesterol screening in the past two years, but not quite in four in ten have had colon cancer screenings or an osteoporosis check in the past two years. Clearly these are areas that could be strengthened by both more provider input and greater public education and awareness about the importance of these screening services.

When we looked at trends over time we found something rather unexpected and a honestly a little difficult to explain and I think we're going to have to talk about it a little bit today in our discussion. Among women 64 and younger we saw both a fall off in both the mammography and pap smear rates. In recent years there's been quite a large amount of media attention on mammography that's really put into question I think in some peoples minds the value and the frequency and the appropriateness of mammography particularly among women 40 to 49. With pap smears, recommendations have changed in recent

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years and they are now based on personal risk and history rather than just a uniform, periodicity, recommendation. The drop off in pap smears could signal that care is now more appropriately targeted or it could be indicative of greater confusion among women and health care providers. Either way it's an area that we think is worthy of further monitoring and investigation.

We also asked women if they had concerns about the quality of their care. This is an area that's generated a lot of media attention in recent years with much more focus right now on the high problems with medical errors in the clinical setting. We found that 21% of women said that they have concerns about the quality care that they experienced in the past year, this was unchanged from 2001. Younger women, women of color, and women in fair or poor health were more likely to explain concerns about the quality of their care.

Despite the fact that quality is a concern for women changing doctors is often difficult. Overall 13% of women had said that they had tried to see a new doctor in the past year, but that the doctor wasn't accepting new patients. This was particularly a problem for women on Medicaid and women who were uninsured. Medicaid has had long standing problems with provider participation in the program in part because of low reimbursement rates compared to Medicare or private insurance. It's interesting to note here that the women on Medicare were

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the least likely to have difficulties finding new doctors. This could be because of Medicare's nearly universal participation among seniors and the doctors who see them.

Finally I'm going to turn to another critically important issue which is women and family health care. As we have long suspected, and as many of you will not be surprised women are the leaders in their family health care decision making. They're not only primarily responsible for choosing the child's doctor, but also taking the child to the doctor and making sure that the recommended care is followed through. Men tend to be involved to a greater degree in decision making about insurance for the family. We incidentally asked this of men and men concurred although they said that their participation was higher. We had higher saying that it was a joint responsibility, I'll just leave it at that [laughter].

Then another area that really I think is one that is very important to women that I think is also under recognized is women's role as caregivers. We found that overall 12% of women said that they were caring for a sick or disabled relative; this is up statistically significantly from 10% in 2001 now 12%. This compares to 8% of men so women do take on a larger role there. A sizable share of these women also have chronic health problems of their own, one-quarter report their own health is fair or poor. Many also, 40%, have kids under 18 also in the home and 20% are uninsured. As you can see here

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these women provide a very wide range of services for their family members, everything ranging from assistance with housework or transportation, finances, medical decision making, assistance with actual provision of medical care such as shots or taking medication, and basic physical care such as bathing and dressing.

Finally this I thought was pretty incredible, but these women spend many hours a week doing this. Overall 29% of women who are caregivers spend the equivalent of a full time job, 40 hours a week, providing this care. This is the case for 44% of low income women who don't have the resources to pay for someone else to assist them in providing this care. Nearly half of women said that they were very concerned about the impact of caregiving responsibility on their own health and on their family. Given that one-quarter of them report their own health as fair or poor, I think that that's not a surprising finding.

There's a large range of statistics I've reviewed, I really feel like we've just begun to scratch the surface here but I do think there's some really important findings that I hope we'll discuss in more detail with the next session. First of all we really need to be cognizant of the fact that women's health status and needs and use of the health care system really do evolve over the lives. Women's needs are not static and it's important for those of us who work in the health care

field and on health policy issues to recognize that. Second of all, health coverage private or public really matters for women. We see over and over women who lack insurance have the poorest access to care. There's a large body of research that really demonstrates that having no insurance translates into poor health outcomes. Addressing gaps in coverage for the nearly one in five uninsured should be a women's health priority. Also we see that health care costs increasingly pose a barrier to health care for many women. This problem is not only for women who are uninsured but also women with coverage both private, Medicare and Medicaid. In fact there are actually very solutions on the table to curb costs and we are concerned that this is something that's likely to increase in the future.

The other important issue is really the limited reach of preventative care and counseling services. This is the area that really could benefit by greater outreach and public education as well as more awareness in the clinical setting. Women need to realize that they are partners in their health but we also need to find options to expand the unique educational opportunity that the clinical setting provides for women.

Also women play really a central role in their family's health. Women are not only responsibility for managing their own health needs, but are coordinating and overseeing the

health care of their family members and ailing relatives. This is often done on top of work responsibilities and other family responsibilities. We need to be sure that we have policies in place that support women's roles as parents and as caregivers.

And finally we need to recognize and address the fact that women who are poor, who are sick, who are minorities, or uninsured face many barriers and often have the poorest experiences with the health care system. While most of enjoy good health and feel like we get care when we need it, the loss of coverage, the loss of a job, a life threatening illness or an injury or the need to care for a disabled family member cannot only change our lives, but also can have a dramatic impact on our experiences with the health care system.

**JACKIE JUDD:** Good morning everybody and thanks Alina. Carolyn Clancy I wanted to start with you. I saw you shaking your head, nodding when Alina was talking about the difficulties of access to care particularly women identifying a lack of time as one reason. In your view, what are the most important reasons that the numbers since 2001 in terms of accessing care have gone up.

**CAROLYN CLANCY, M.D.:** I think that what we're seeing is a very broad phenomenon as medical spending overall has gone up and that is that more and more costs are being shifted to individuals. That probably is the only specific strategy to contain costs that's being used right now. The challenge with

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that is that it actually works. It's a little bit hard to be very selective about it. The Rand health insurance experiment, the sort of landmark study from a little over 20 years ago found that indeed if people have to pay out of pocket before they make visits or use services they go less often. The challenge is of course that they go less often for trivial things that will resolve on their own as well really important things like chest pain and so forth so that's really the trick here. I think there's growing concern about that in terms of using the right services but while Alina is a right that women have more skin in the game, I think that this is something that everyone is experiencing right now.

**JACKIE JUDD:** But did it surprise you that a number of women with private insurance, I think it was 17%, said that they had trouble accessing services because of costs?

**CAROLYN CLANCY, M.D.:** No, because if you look at trends over the past decade, more and more major employers are actually their employees to pay out of pocket that the proportion that employees have to pay both in terms of the premium coverage as well as their co-pays has increased pretty steadily over that time period. If you talk to large employers I think they believe that they've kind maxed out on that strategy. Then the question is what's next.

**JACKIE JUDD:** What's next? Paula Johnson, Alina's study I think raises this basic question and that is how do

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women define health care? What do they view as health care? Is it preventive services? I'm sick, I need to see a doctor, screenings, et cetera? Then Sue I'd like you to follow up, Diane mentioned the book you just wrote if you could share some stories with us that would amplify answers to this question, what do they view as health care? Paula?

**PAULA A. JOHNSON, M.D., M.P.H.:** I think you'd probably get a variety of responses in terms of what women view as health care. I think most of us would view health care as direct services that encompass services when you are ill or services for a chronic condition which as we saw women are very high up on the list in terms of having significant numbers of chronic conditions and some of those are increasing. But we also know that the preventative services are incredibly important and although I think there would be consensus that this is a very important of healthcare, it's also the part that is on the whole left by the wayside in terms of really good strategies to address them. I think the survey really was wonderful in highlighting how women are not really being worked with their health care providers around these preventative services. I do think the issue that Carolyn just brought up also about the cost sharing, and the cost shifting is very important when it comes to the preventative services. When you have high deductible premiums there is going to be choice that lower income people are going to make given women are, on the

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whole, lower income than men this is a very important women's health issue.

**SUSAN STARR SERED, PH.D:** Something that I heard from women around the country is that a major concern in terms of defining good health care is to have an ongoing relationship with the provider who knows them and who knows their family. Because so many women are caring for children, they're caring for disabled relatives, they're caring for elderly parents, to just have someone who sees you as an individual outside of the family context isn't all that helpful. What I did see is that low income women and specifically women who don't have health insurance really have trouble finding a provider who will even be an ongoing provider for them, often women are going to clinics whether they're county clinics or federally funded clinics where they see a different provider every time they come. There's no possibility of really managing the complexities of a whole person's health issues much less the health issues of a family.

One of the most striking stories that I recall from my research concerns a woman in Mississippi. She had been married to a man in the military somewhere in the western part of the United States and he beat up. One time he beat her up really so severely that she decided she had to leave the marriage. She picked up her kids and she moved to Mississippi where she knew some people, she had some distant relatives. She had been

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living in Mississippi for about seven or eight years at the point that I met her. Three years after she left her husband she was cut off from her health insurance that she had because he worked for the military, so she had been uninsured for about four years at the point that I met her. She had chronic headaches, really, really severe disabling headaches as a result of her husband having beaten her up. In the years that she had been in Mississippi she had never found a doctor who even asked her any questions about her background that would help explain why she has the headaches. As a matter of fact she was generally going to the emergency room for treatment. If she was lucky she would get a shot. She'd also get a big bill for that shot. But nobody ever helped her put together these pieces of wow a history of serious domestic violence, a major head injury, the responsibility for raising three children, being all alone in a new state, chronic pain, severe migraines. She kept getting medication, medication, medication, without any sort of larger sense as her as a person in a family context. This is what I heard all around the country from women. They want to have a an ongoing relationship with a provider who knows them as human beings and understands their family situation.

**PAULA A. JOHNSON, M.D., M.P.H.**: I think just building on that point, we did a study last year looking at the affordability of healthy eating for low income women in two

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minority neighborhoods. I bring this up because it was important to see that about 50% or a little bit more of women did report that their physicians had talked to them about nutrition, exercise, et cetera. I would argue to say if we really dug even more deeply as to say what was that counseling, I think you would find frequently the counseling is, "Eat healthy and exercise." I think that that really brings up a major point because what we found is that to truly follow the guidelines around healthy eating is not a small proposition in terms of money and time. We put together menus for low income women that were culturally appropriate and found that if you were either on a full food stamp food benefit or even according to in our state, Massachusetts, our economic sufficiency standard, healthy eating was not affordable. That's the kind of culturally competent contextual information that needs to be shared and needs to be worked with in terms of women if we are going to lead healthy lives.

**PAULA A. JOHNSON, M.D., M.P.H.:** I think that actually is the critical issue because it relates to all of these issues like domestic violence, drug use, alcohol use, you raise these issues, these are really important issues but we need to also enable health care providers to have some resources in order to deal with these issues. They're very complicated issues and they deal with economic issues, relationships.

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**JACKIE JUDD:** Alina you and I spent a lot of time discussing in the results of this survey, what in the world are women talking to about their doctors? If they're not talking about significant issues like smoking, nutrition, exercise, calcium intake et cetera, what are they talking about? And Carolyn Clancy I guess I would ask you, do doctors need to be trained differently to initiate these kinds of conversations? Is more of the burden on the patient? What needs to be done?

**CAROLYN CLANCY, M.D.:** Historically physicians have not gotten a lot of training. Paula's observation that the counseling was probably along the lines of "Eat healthy," is, I think, on track. I think the good news is that today's students are getting more training in that and not only that they're being evaluated on how well they do and how well they communicate with their patients which I think is terrific. I, myself, was actually quite shocked that diet and exercise was the highest because if you ask doctors what they do it's not at the top of the list at all. Now some of that makes me wonder to what extent are women bringing this up and then recalling that they were counseled about it or that they had a conversation about it. I actually think it's very important that women have a list of issues that they go in with and the one piece of advice that I would give anyone going into health care is you need to prepare in the same way that if you were going to the car mechanic. You wouldn't kind of wander in

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there and say, oh whatever, and take everything at face value. If they said well your bill is going to be $3,000.00 for what you thought was a tiny problem you wouldn't say, "Okay fine." Especially if you didn't have $3,000.00. But I don't think a lot of people put that sort of thought in before they go in and Alina noted they have very limited time with the doctor both docs and patients are pretty frustrated by this at the moment and then these issues don't take place.

**JACKIE JUDD:** Susan you wanted to jump in on this?

**SUSAN STARR SERED, PH.D:** Yeah I wanted to jump in on both of these points. In the interviews that I did with women around the country I did ask them what they spoke to their doctors about and what happened at the appointments. Overwhelmingly the answer was payment. That the doctor would say, "You need to see a specialist." And the woman would say, "Do you know how much that's going to cost?" And the doctor would say, "Well it would be about $200.00." And the woman will say, "I don't really have that." This was actually eating up a large portion of the time that the doctor's had with the women. With uninsured women doctors would often very kindly spend time helping them figure out where they could access free care. So money was actually replacing things like lifestyle choices in the conversations with the doctors. I also heard from many women exactly what you said. The doctor says, "Eat healthy." Some women said to me, "Well I don't really know

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what it means to eat healthy," but far more of them said, "I know what it means to eat healthy," and these are the two most common follow ups to that, "I don't have time to prepare healthy food." You know when we look at the statistics that Alina presented of the family caregiving responsibilities that women have and you couple that with the fact that the vast majority of women in this country do work outside the home as well, unless you have a lot of help in the household to prepare your wonderful tiny cut up tofu and stir fry vegetables it's something that you can't do so easily. You can't get your kids to eat them. The second response or follow up to, "The doctor told me to eat healthy but I can't do it," was even more interesting. It was, "The doctor told me to eat healthy, to eat a lot of fruits and vegetables but my teeth hurt and I can't find a dentist who will see me. I live with toothaches all the time so I can't eat the things that are healthy."

**CAROLYN CLANCY, M.D.**: I think that the survey really pointed out quite beautifully that there is a very high percent of women who are living with chronic conditions. And the percent of women who are in fair and poor health and the concentration of those women in those poor socio-economic categories. I think what women are discussing with their doctors are their chronic conditions. In a 15 minute visit, I'm a cardiologist, in a 15 minute visit I'm usually managing their heart failure, managing their angina, and figuring out

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the rest kind of as we go along. I think that there's got to be a very significant attention to the quite significant illnesses that women are brining to the offices.

**JACKIE JUDD:** One of the diseases that increased in a statistically significant way was diabetes, from 5 % to 8%, Carolyn Clancy is that because women are truly less healthy? Are they being diagnosed more often? What's the reason?

**CAROLYN CLANCY, M.D.:** My best guess is that there's at least two things going on; one is the increasing prevalence of obesity, perhaps meaning that the actual prevalence is increased. The second is, I think, a number of campaigns trying to identify the disease earlier with the hope and expectation that early intervention will postpone or even defer complications associated with diabetes. I don't know of any data that actually teases those two out, but that would be I think the main sources for why we're seeing that.

**JACKIE JUDD:** I wanted to talk ab out screening tests which again Alina highlighted in her presentation, particularly mammograms. I'm curious to find out, Paula if you want to take this question, are fewer women in their mid-years getting mammograms because of the confusion over the guidelines about when it's needed? Is it more cost? What are the issues behind that?

**PAULA A. JOHNSON, M.D., M.P.H.:** I think we don't know and I think that this another really very important thing that

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the survey has pointed out in terms of a small but significant decrease in the number of women actually having mammograms. This is an issue that we would have thought we would have been beyond. I think that there has been confusion around recommendations for women between the ages between 40 and 49. There are I think some other very important points though, if we think about women who are either uninsured or under insured and I think another important statistic is that 10% of women who had insurance at the time of survey actually were uninsured at some point during the year. If you add that to the 17% who were uninsured, you get 27% who were uninsured at some point during the year. If we think about mammography being very linked to ongoing preventative care, I think that's something we need to look at in terms of are we creating the right safety nets for women as they come in and out of insurance. I think there's another very big issue around mammography, which is the field, I believe in crisis. There are fewer, and fewer radiologists who want to do mammography. There are a host of reasons for that. There are breast centers in terms of mammography centers that are opening and closing in different parts of the country, we haven't looked at that. Access in some places in terms of wait lists are quite significants and if we couple that with all the issues that women are having in terms of waiting to be seen or transportation or child care, put that all together, and it may be decreasing and we may be

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seeing a trend. So I do think this really requires further follow up and really the need to look at the whole area of mammography, it's going to be very important.

**JACKIE JUDD:** Carolyn do you want to jump in here and talk about some of these issues that Paula just identified because particularly not enough radiologists? And then Susan I would ask you about when you interviewed women across the country who were insured was mammography even on their radar? Carolyn?

**CAROLYN CLANCY, M.D.:** Yeah, I just want to reinforce the point that Paula just made. I have heard repeatedly from radiologists that this part of the field is in crisis. Some of this relates to reimbursement, some of it relates to perceived increased burden of regulation and a variety of factors but there are growing concerns about access and that might be an issue that we could follow up on with the Kaiser Family Foundation. Pap smears, I think may be more complicated, both statistics obviously bear careful monitoring, to see is this part of a trend, is this a blip or whatever? To some extent I think many women, particularly women in the baby boomer years are sort of conditioned early on that you needed to go every six months or a year for a pap smear. As a physician I have to say it's been a slow message to get across that actually at many points in your life you don't need to get them that often. So whether we're actually seeing people finally grasping that

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they don't need to have them all the time or every single year and that's what we're seeing in the decreased statistic, I'm not sure, but both bear careful attention.

**SUSAN STARR SERED, PH.D:** Yeah, adding to what Paula said about 27% of women actually being uninsured for at least part of the year, what I heard from women around the country is that they would have gone once for a mammogram at a particular clinic, often at a city public health office that was having some kind of a mammogram week. Then the next year they'd go back and it didn't exist anymore. Not only are women cycling on and off insurance and Medicaid but a lot of the free programs open and close, open and close, and shift their hours and shift their eligibility thresholds so there really was nowhere for women to go to get that kind of yearly testing done.

A second thing that I heard and I don't know whether this is something that is common enough to affect statistics, but it is a story that I heard from several people. They were able to get diagnostic work done, so women were able to get a mammogram, able to get a pap smear, in the case of one man I interviewed he was able to get tested for colon cancer. But when they were diagnosed with the cancer they couldn't get treatment anywhere. I don't know whether that has a snowball effect in which other people in the community say, "Why should I even bother going to be tested because all that I'll do is

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find that I have cancer and I won't be able to get me treatment." Let me put that out there for what it is.

**PAULA A. JOHNSON, M.D., M.P.H.:** Medicaid has the breast and cervical treatment program. We did some focus groups in California and one of the issues when we asked the women who were involved in the program, they said before they knew about the program they didn't want to get screened for that very same reason. They felt like, well they found out they had cancer, kind of like a death sentence, you know without knowing that they had opportunities now with this program. On one level it's very good, on another level breast and cervical cancers are not the only cancers that affect women and the population. But that was really, in the past one of the barriers to screening services that we found.

**CAROLYN CLANCY, M.D.:** I do think having the Medicaid program that really does allow women to be screened and treated, Massachusetts as liberal as it is was one of the last states to actually include treatment, last year actually in their policy. I do just want to highlight again this issue around mammography and the crisis in this area is an unknown issue. I think that if you talk to most women around the country and even women who are very much in the know there is a lack of understanding around this. Not only is there a need for research and understanding what can be done in the field,

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but there needs to be some way in which this word gets out because this could be a major advocacy issue as well.

**JACKIE JUDD:** Are you saying there's a lack of understanding about the importance of mammography?

**CAROLYN CLANCY, M.D.:** No a lack of understanding that the field is in crisis.

**JACKIE JUDD:** Okay.

**CAROLYN CLANCY, M.D.:** And that there is a shortage of mammographers, if you survey radiology residents who are leaving their training, decreasing numbers are willing to actually read significant numbers of mammograms.

**JACKIE JUDD:** We have a large audience I want to get to questions as soon as possible, if you want to raise your hand. When you get handed the mike your name and your affiliation and we'll probably just alternate sides of the audience. Up here? While the mike is being moved over just one quick question to Susan Sered, I know you found intriguing in this report the statistics on mental health. Why?

**SUSAN STARR SERED, PH.D:** They are so high. I was shocked when I saw the incredibly high number of women who reported depression or anxiety but was even more upsetting when I saw that is that was the number of women who had been diagnosed by a physician with depression or anxiety. I'm guessing that's probably a small percentage of the total number of women who experience depression or anxiety. I can tell you

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of the women that interviewed around the country, and I conducted 120 interviews almost all of the uninsured women that I interviewed spoke about depression or anxiety, often in the wake of other kinds of health problems. I think this really has to be seen as an epidemic in our society right now.

**PAULA A. JOHNSON, M.D., M.P.H.:** It is an epidemic and actually the projections for the year 2020 is that depression is going to be the number two cause of death and disability in the world. It is a major problem and it's one that is very much linked to other illnesses. It's an illness in and of itself but it's linked to many other illnesses. There are fields now where we are beginning to recognize the importance of diagnosing and treating depression, for example in cardiology where women who are depressed will increase their incidence of having a second heart attack once they've had the first. I think we also have a lot of work to do in helping clinicians understand, how do we diagnose it appropriately? What is appropriate treatment? What is appropriate support? How do we follow patients? Once again another major area for focus.

**CAROLYN CLANCY, M.D.:** I just wanted to build on that you were talking about screening tests, I think it's important to understand that asking the right questions, providers asking patients the right questions is a very important screening tests. One of the statistics that really disappointed me was

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the proportion of women that reported that a provider had ever mentioned mental health or issues related to depression. We sponsor the work of the U.S. Preventive Services Task Force who two years ago made a very clear recommendation after extensive thought and deliberation that actually all adults should be screened for depression with a few short simple questions and then either treated or referred as appropriate. It's very important to understand that many patients actually are detected and treated by primary care physicians for a whole variety of reasons.

**JACKIE JUDD:** Would a few short simple questions really get a diagnosis?

**CAROLYN CLANCY, M.D.:** What it does is identifies the people who are at highest risk and those are the people with whom you would do more follow up. For years the task force was a little bit worried that a) those questions the yield wasn't sufficiently good enough or specific enough to be helpful and that it wasn't clear that follow up treatment would actually make a difference. Those issues have been resolved and as Paula notes both in cardiac disease and particularly in pregnancy depression matters a lot and it's very, very common.

**JACKIE JUDD:** Not if you ask Tom Cruise.

**FEMALE SPEAKER:** Brooke Shield did give him a very good retort.

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**JACKIE JUDD:** She did, didn't she. Yes, the lady in front, please stand.

**SARAH SODELMEYER:** Hi my name is Sarah Sodelmeyer [misspelled?] and I'm a Truman Scholar at the Veteran's Health Administration so it's nice to be talking about women's health today, I spend a lot of time dealing with men's health over there. I noticed that in your study and due to legal reasons or for whatever reason you surveyed women 18 and up. A lot of issues that we talked about today are issues that I think would be relevant to women below 18, at least from an educational perspective. I was wondering if you knew of any programs or what Kaiser's doing or research that you've come across that shows effective ways maybe to make this a key issue for women who are under 18.

**ALINA SALGANICOFF, PH.D.:** Surveying women who are under 18 is a complicated endeavor because particularly if you get into some of the more personal issues it requires parental consent. We can't responsibly do this without getting parental consent. Once you get parental consent than it's a concern whether you're getting, if my mom is standing right there next to you while you're on the phone, how accurate are the response that you're going to get. I mean I concur with you, I think it's really important that we start with young women in terms of educating them about what they can do to keep themselves healthy, how they navigate the health care system, particularly

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if you've been in a situation where your family has been uninsured. A lot of what we know about going into the health care system is behavior that's modeled that we see when our parents, we see when our mom calls and makes an appointment to the doctor and that's what you need to do. I think there's a lot of important things we can do to work with women.

**CAROLYN CLANCY, M.D.:** If you look at the most common reason that adolescent women seek medical care it's for prenatal care which has a lot of disturbing implications obviously. I don't think most adolescents have the same mindset for going in for health maintenance that us older folks do, that's kind of an acquired life skill I guess. Having said that we have supported some work with the Kaiser Health Plan, not to be confused with the foundation, where physicians who have been focused on this have been, I think very innovative in trying figure out for example, how do you identify chlamydia and how do you make sure that they get appropriate testing and treatment? And the way you do that is that you weave it in to the visits that they come in for for other reasons which tends to be much more episodic care. But it is an area we need to learn much more about.

**JACKIE JUDD:** Susan did you talk to any young teenage women?

**SUSAN STARR SERED, PH.D:** No, it's for the same reason, it's all very complicated.

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**JACKIE JUDD:** Gentlemen, we are going to recognize men today. Right back there.

**CHUCK GUERRO:** Thank you. My name's Chuck Guerro [misspelled?] I'm with Eli Lily and Company. In the section that you looked at the women in the role that you looked at women and their role as health care providers for their families, I noticed that you didn't separate out the [inaudible] women from white women. In those role [inaudible]?

**ALINA SALGANICOFF, PH.D.:** Unfortunately we were not able to present most of the information just in a presentation here. If I remember correctly I do think that women of color, Latinas and African American women, were more likely to be caregivers and provide more hours. Whether that's connected to cultural issues or whether that's also linked to economics is something that's hard to tease out.

**LOIS HUTLEY:** Hi I'm Lois Hutley [misspelled?] Director of the Merger Watch Program [misspelled?]. I'm interested in your findings about provider health counseling or lack thereof about specific health issues. I know just comparing with my own recent experience in visiting my primary care doctor who had a whole checklist from my managed care plan of what she should talk to me about and specifically ask me about all these different things. It led me to think about, at least for insured women, including those on Medicaid. What's the

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potential role of third party payers, managed care plans, insurers in trying to insure that these conversations happen.

**JACKIE JUDD:** Carolyn?

**CAROLYN CLANCY, M.D.:** Sure and let me share with you some good news. First there have been studies in the past that have found that women enrolled in managed care plans or arrangements were more likely to get preventive care precisely because those plans had some kind of strategy for reminding people to do it and some of them actually report on how they're doing in terms of quality of care. Very recently we convened a working alliance with America's health insurance plans, the American Academy of Family Physicians, and American College of Physicians to talk about how to assist the quality of ambulatory care. Preventive health care is a big part of this and early in 2006 across all payers there is going to be a voluntary effort to report on this stuff publicly which I think will get at some of the issues that you've just identified. Some docs are going to need more help than others. Many docs I think it's fair to say think they're doing a much, much better job at these issues than they are. In fact when confronted, that may be the wrong word, when they have an opportunity to see how they're doing they're actually incredibly disappointed and interested in figuring out how to do a better job.

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**JACKIE JUDD**: Are they age gaps? Are older physicians less accustomed to having these conversations than younger ones?

**CAROLYN CLANCY, M.D.**: I think it's fair to say that younger ones have probably been exposed more to the important clinical prevention, the evidence based for why it's important and so forth is part of their training, particularly clinical training. Having said that, one factor which doesn't seem to be associated with age is how physicians organize their practices. For example what happens to me a lot when I'm seeing patients is I say to a woman, "It's time for your mammogram," and she agrees and then we move on back to the chronic care issues that Paula mentioned. Then of course she leaves and I forget to give her the paper. If I'm really fast I remember that in two seconds, I go zooming out the door, and I give her the appropriate paper. If I miss her, then I've just set up a whole array of non-financial barriers at a minimum for her to get the appropriate paper to go the mammogram, et cetera, et cetera, to say nothing of the time and out of pocket cost an so forth. Doctors who are really good this actually know how to organize it so that you can't leave without that piece of paper and there are a number of kind of defaults in place so that the right things are easy to do. That's what I mean by organizing the practice.

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**PAULA A. JOHNSON, M.D., M.P.H.:** I think that the whole area of third party payers and pay for performance will have a positive effect and already has in many areas. The issue around how do it, and kind of looking at some of these best practices. How do we take the movement towards electronic medical records to really help build in reminders? Then how do we actually get the counseling done? Is that through allied health professionals et cetera? How do we actually pay for that? I think those are very big issues around the how?

**JACKIE JUDD:** This keeps going back to the subject of counseling. Is there anybody else who has a follow up question about that before we move on?

**CELIA MAXWELL:** Celia Maxwell [misspelled?] a physician at Howard University, hi Paula. The question is counseling is really important and I think most of us recognize it but as you know Paula most of our patients that we see come in with acute problems. They don't come in with hyperglycemia, they're in diabetic ketoacidosis. They don't come in with low cholesterol, we seem them at 500. So did any part of the report look at the differences particularly of a woman of color to see what were the factors or variables that promoted less attention to prevention? I think I know some of them. And just gravitated to dealing with more serious problems because we hardly ever get to deal with the preventive aspects, we get

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to deal with just what I'm describing the diabetic ketoacidosis so I would like some comments on that.

**ALINA SALGANICOFF, PH.D.:** We were really able to only look at a point in time. What you're saying is a really important thing to look at is kind of what the evolution of a disease and at what point do women actually make a medical intervention? When do they first try? I think if you look at Susan's book you can see that a lot of women try really hard. They know that they need care, they know that they need to get in, but they either can't afford it or because of other issues. We look at kind of the barriers but we weren't able to look at the whole process of care unfortunately.

**CAROLYN CLANCY, M.D.:** There are a lot of studies that show that people who have one or more chronic illnesses are significantly less likely to get recommended preventive care. Now clearly if someone has a terminal illness with a very short life span left you may spare them the colonoscopy that would probably be the smarter thing to do. On the other hand this is not about people with terminal illnesses, this is about people with diabetes, high blood pressure, arthritis issues and on the face of it doesn't make sense. If you have all these conditions having breast cancer doesn't seem like a great idea. I think a lot of that comes back to how to do you organize the practice, how do you manage your time, and frankly for some patients how do you figure out how to allocate more time.

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**JACKIE JUDD:** The lady at the end of the row there. The mike is towards you now, if not just shout.

**CATHERINE HESS:** Hi Catherine Hess [misspelled?] with the National Academy of State Health Policy. Given the prominence of mental health issues in the survey and then actually also the comments about not being able to eat healthy due to dental pain, I was wondering in the survey or from the other experts if you have comments about to mental health clinicians and to dentists.

**JACKIE JUDD:** Susan do you want to take that? I know in your book you kept coming back to that issue of dental care.

**SUSAN STARR SERED, PH.D:** For low income women getting to access to dental care is very, very difficult. Certainly if you're uninsured you probably can't find any dental care. Even communities that have some kind of a free clinic or some kind of a safety net available for medical problems for the uninsured are very unlikely to have dental care available. Then moderate and low income women even if they have insurance very well may have insurance that doesn't cover dental care. I think this is a enormous issue. Now in terms of mental health care I found a surprising number of women who were taking antidepressants. Ironically they were trading off antidepressants with other medication they needed. So they might have received three different prescriptions, maybe one for high blood pressure, one for arthritis, one for depression

and they couldn't afford to fill all the prescriptions so one month they'd take the antidepressant, one month they'd take the high blood pressure medication. Clearly this is worse for their health than not taking any of the medicine at all. This is an enormous, enormous issue and I think it's interesting to think about mental health services and dental care together because I think there's a kind of cycle that goes. If you live in chronic pain you're mental health suffers from that and if you have mental health issues you tend to be less resourceful at trying access whatever little crumbs of care at low cost or for free in your community.

**JACKIE JUDD:** Paula, then Alina.

**PAULA A. JOHNSON, M.D., M.P.H.:** In the survey only 10% of women saw a mental health professional. If we think about the numbers who were diagnosed with either depression or anxiety and those who we think are either or under diagnosed that doesn't speak to very good access. I think talking on a personal basis, you know, mental health now, we have improved in terms of including it as a carve out in through many third party payers but it tends to be incredibly poorly reimbursed. If you try to find mental health professionals who will actually take, insurance not just Medicaid but any insurance, it is abysmally low. If you think about programs in which there is a focus on the Medicaid, not uninsured but the Medicaid population, the access is near impossible. Once again

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this is an issue where not only do we probably have under diagnosis but access to the professionals and what is the correct role of the professional once again needs further explanation.

**ALINA SALGANICOFF, PH.D.:** I would agree. I was going to say this point about the 10% of women. I do even think that private insurance does a terrible job and you end up paying if you want psychotherapy even for a short period of time you end up paying enormous amounts of money out of pocket. I think that's why we see so much of the prescriptions for the Prozac because that's actually an inexpensive to at least think like your addressing this issue.

**PAULA A. JOHNSON, M.D., M.P.H.:** There is an interesting demonstration project going on in *New York City*, I probably read it in the New York Time a few months ago where several of the city run institutions are going to be using one of these very short instruments, I think it's the nine question one to actually screen their patients and provide tools for the primary care physicians to actually work effectively to actually care for them. That's a very big project and I think the good news is that at least the word is getting out there that there that this is a very important illness and one that really needs attention.

**SUSAN STARR SERED, PH.D:** As balanced of a discussion as we've had about need for mental health services to just

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remind us that if such enormous numbers of women are being diagnosed with mental health problems we really have to ask what's going on at a social level. It's hard for me to believe that there's really something genetically, physiologically wrong with a third or a half of women in American society. I think that it's really important for us to be careful about over medicalizing what might just be normal, healthy, natural responses to living in a society in which it's hard to make enough money to support your family the way that you want to, in which relationships crumble faster than they can be rebuilt, in which kids move away from their parents and so elderly people are often left without family members around to support them. There's just so many social pressures, I just want that to be on the table as part of the picture and warn us from embracing too much of an over medicalized explanation for our mental health issues.

**JACKIE JUDD:** A question all the way in the back there, whoever you pick Sarah.

**ANN SUMMERS:** Hi Ann Summers [misspelled?] with the American Association of People with Disabilities and former Anthem Blue Cross Blue Shield employee. Something that wasn't mentioned at all today but something that interests me quite a bit and I was hoping you could touch on it, is the fact that so many women today have multiple doctors in multiple specialty areas. And something that I've personally experienced as a

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person with a disability and have heard lots of stories about is women are getting medicated by different doctors for different reasons and the doctors are not communicating with one another. There's a lot of over medication as a result of that. There's drug interactions going on that women are not aware of and that sort of things. I'm wondering if a large part of the statistics that you've shown today in your study are a result of women that are over medicated and misdiagnosed and having incompatible diagnoses because their doctors are not communicating across the board.

**JACKIE JUDD:** I think Susan did touch on that earlier when you talked about the fragmented care that so many women receive. Alina?

**ALINA SALGANICOFF, PH.D.:** We found that half of women said that they basically see two doctors for their care which is a rate that's higher than for men. We really can't tell from this survey who's being over medicated, under diagnosed, that's too hard from a survey where you actually interview individuals about their health care and health experiences. We can all look at our own health experiences just to see that often there's not a communication between the doctors, particularly when you need specialty care and also ourselves in terms of communicating what the issues are between the doctors. It's very difficult because we tend to, in women's health, I mean in the whole field we tend to put reproductive health in

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one pocket, and all our other health care issues here, and the mental health care over here, without really thinking about we really need some kind of an integrated system because they're all connected.

**CAROLYN CLANCY, M.D.**: Yeah just to make the point that a couple of years ago that there was a really terrific survey of people in fair or poor health in five countries. What struck me about it was all the issues that you just raised people reporting that they had redundant tests or that not all of their providers had all the relevant information. In a survey that we did with the Kaiser Family Foundation one-third of Americans said that they actually had created their own medical record so that all of their providers would have all their information. My husband said, "I don't believe that. They must just have a folder with a lot of paper in it." And I said, "Honey, that is a medical record." [Laughter] but the point is I think that this is an area where electronic health records and the strong focus now on the appropriate use of health information technology can make a difference. Having said that I also think it gets right back to the issues of communication because oftentimes I think what happens, particularly people with an established chronic illnesses, disabilities, and so forth, is that there's not necessarily a shared understanding between the individual and all the doctors. For example a specialist physician may assume that

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the woman has a primary care clinician who is effectively serving as the kind of quarterback if you will, I don't feminine term for that, maybe it would just be caregiver that seems like the sort function, and in reality that woman does not or effectively she has to be her own quarterback negotiating between multiple clinicians. That I think remains a huge challenge and one that we're going to need to address.

**JACKIE JUDD:** Susan do you want to jump in on that?

**SUSAN STARR SERED, PH.D:** Very quickly most of the interviews I conducted, I conducted in people's houses and one of the questions I asked was to show me all the medicine they had in the house. Generally people went to five different rooms, pulled out stuff from all different drawers, cabinets, all over the place, they'd have five different tubes or bottles of the same thing, they didn't even know what half the things were, different doctors have prescribed two different medicines that actually were identical, one was a generic and one was a name brand and they were taking both of them, they were taking neither of them. When I sat down and mulled over this, and the issue of patients taking responsibility for keeping their own medical records I realized the irony, the paradox, and I don't know what to do with. As someone who cut my teeth on the women's health movement, the mantra that I learned was let's get rid of all this paternalism in medicine but I feel that so many of the women that I interviewed in doing this research,

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they need some paternalism. There's just nobody helping them keep track of their problems and of their treatments and this is an enormous, enormous problem and overseeing, taking charge of that kind of coordination and advocacy for oneself is just beyond what these people can do in their lives. Absolutely. If you're at all geographically mobile you lose your records when you move from place to place. If you're someone who works in kind of jobs where there's a lot of turnover, seasonal work, even if you're insured you're going to be switching providers and switching plans. It's very hard to keep track of this kind of stuff.

**ALINA SALGANICOFF, PH.D.**: I just want to say that I think that it's not an issue that just effect low income women or uninsured women. I mean all you need to do is be confronted with a major illness, your own or your family member's and you pretty soon, pretty quickly you've got one of those files going when you consult multiple doctors to try to figure out what the next steps are. This is an issue, we're here discussing women's health but it's really a systemic issue that really plagues our system here. When you talk about the fact that half of women have a high school education or less, we are really poorly equipped to deal with these issues and many of these are very specialized. Now with the super specialization of medicine and so we're given in many cases lots of choices and not very well equipped to make sound decisions.

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**LEAH CARLSON:** Hi I'm Leah Carlson [misspelled?] [inaudible]. I'm wondering as I was hearing about the different barriers to women getting care what employers can do maybe to break down some of those barriers or insure that people are getting the prevention that they need and seeing the doctors when they need to?

**JACKIE JUDD:** Good question. Carolyn?

**CAROLYN CLANCY, M.D.:** Let me say that one of the pieces of good news I've seen in the past few years is that many of employers recognize that they do have a strong role. This past year the National Business Group on Health actually developed a sort of program which is available electronically and in a nice big notebook based on the recommendations from the US Preventive Services Task Force. The task force recommendations are aimed at clinicians. These are aimed at those folks who write benefits to talk to them about coverage and not only that to convey the incredibly important message that coverage doesn't mean you get it, it's necessary but not sufficient. It actually gives them very specific strategies for information that can be provided in work places and so forth. I agree with Susan's comments about it's hard to keep track of all this information, at the same time a lot of the really positive changes that have taken place in health care have come about because of patients insisting that no we don't have to do it this way. I'd have to say a lot of these

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movements and initiatives were led by women. On the one hand I certainly don't want to let people down who may need some help and assistance getting on that track. On the other hand when I look at statistics about use of antibiotics for colds, it's down quite a bit which is great news. I do not believe personally that it came about from nudging providers because we funded a lot of studies to do that and if you nudge providers a whole lot they'll change a little bit. But they say patients demand it. I actually the drop is because patients have stopped demanding. I think informed women who can begin to play an active part and consider themselves as partners in their care is really where we need to be headed.

**JACKIE JUDD:** Paula?

**PAULA A. JOHNSON, M.D., M.P.H.:** The other place where, I think, we can really do some work in the survey one of the barriers especially to lower income women is the fact that they couldn't get time off from work to visit their health care provider. I think that how we develop work places that integrate work and life is going to be very important. It's important for everybody but it's particularly important for women given that women are balancing so many roles.

**JACKIE JUDD:** The gentleman up here.

**BOB ROAR:** I'm Bob Roar [misspelled?] with BMJ. Is there any transnational comparing the US system with other system where there are single payers or universal coverage?

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Mainly I'm trying to get to a sense of how m any of these problems are endemic to any system and how much of these problems are because of our very fragmented coverage and non-coverage systems.

**CAROLYN CLANCY, M.D.:** The most recent source I can think of is this survey from a couple of years ago which surveyed people in fair or poor health from the US, the UK, Australia, New Zealand and Canada. What also surprised me about that survey wasn't that the US was struggling as reported by these patients, but that actually the other four nations where there is universal coverage and sort of centralized financing, more or less a single payer model, had exactly the same issues. Some of ours were a bit more unique payment is a barrier for specialty care, it was more marked for US citizens and I can get you the reference afterwards. But all of these other issues above not all providers have the right information and I'm getting what feels like redundant tests and I don't think that I needed again I think that the result just wasn't transferred from one person to another were family common. Similarly in terms of preventive care there's been a number of surveys comparing the US and Canada and Canada doesn't do all that much better which I find surprising. I think that has something to do with the profession's historic definition of what are the boundaries of medical care and what's public health and so forth. I think we're starting to think more

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creatively about that but I don't think that's purely financing.

**JACKIE JUDD:** Susan, I know you've worked internationally do you want to take that question too?

**SUSAN STARR SERED, PH.D:** I can just speak anecdotally. I lived in Israel for twenty years and as an anthropologist I've done field work in Okinawa, Japan. My sense was that in both of those places care is less fragmented, people are more likely to have an ongoing provider but that's purely anecdotal.

**JACKIE JUDD:** All the way in the back row.

**EKANU EKEEZIE:** Hi Ekanu Ekeezie [misspelled?] the Advisory Board Company. We've been seeing in some of our research what appears to be a proliferation of women's health services within hospitals and health systems across the nation. In part because of the mission, but also in part because it appears to be a good business decision as some of your data has shown that women are the majority decision makers for a lot of health care decision. With that in mind I'm curious to know, how effective do you think these women's health centers are in addressing some of the access issues that we've talked about?

**JACKIE JUDD:** Paula that seems to be perfect for you.

**PAULA A. JOHNSON, M.D., M.P.H.:** There are, and Wanda Jones is here in the audience, some good data to suggest that more comprehensive women's health centers are actually better at providing a lot of the preventative services to women and

that goes beyond mammography and pap smear. There is a focus on approaching women in a more wholistic way that actually looks at them in the context of their complicated lives which is what we've seen in this survey. I think there's still a lot of work, though, to be done in terms of how we begin to think about women with complex problems being served in this type of environment. One of the things that we are doing is actually looking at developing a new model in which there truly is not just a multi-specialty but truly integration in which there is communication, in which there is a more wholistic approach and one that begins to weave in many of the psycho-social issues along with some of the very complex health issues. I think the biggest challenge here is to not only create the environment and to do it but to also measure the outcomes and to make sure we understand what we're doing. It is a major, I think, responsibility of women to insure that when there's a label of women's health that this really is women's health. This is not a pure marketing tool, that we are discussing what is best for women and how to provide what women need.

**JACKIE JUDD:** Do you know if there are more and more private physicians who are tailoring their practices to women's health only?

**PAULA A. JOHNSON, M.D., M.P.H.:** I don't know the answer to that. I think that we went through a period of time where many of these centers were being created. I'm not so

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sure that there's the movement as much as it was to do that. I think another issue here, a workforce issue that we've touched on little bit is that of primary care in general which is interesting that a significant percent of women who tried to get new appointments with internists could not or were turned away, people were booked. I think probably if we went around the room and had people raise their hand about their own experiences, I can tell you terms of my experience I spend, I get at least 5 to 10 phone calls every week asking me can I please arrange primary care for somebody. That person has contacts. I do think this whole issue of where is the field of primary going? How are we going to nurture and support our primary care physicians who we expect so much of and are so critically important to all of our health but particularly women? The numbers of physicians going into primary care is on the decline, so once again another important issue.

**JACKIE JUDD:** The lady in blue back here. We're running short of time so after this lady asks her question if there's anyone who wants to ask a question that was about an issue we haven't discussed yet let me know.

**FEMALE SPEAKER:** Hi I'm with the Office on Women's Health of HHS and I'm interested in health communication and maybe this is a question for the moderator. How can we better utilize how health communication to improve on health literacy to solve some of these problems?

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**JACKIE JUDD:** Carolyn I think that's a good one for you.

**CAROLYN CLANCY, M.D.:** Thanks for being that up because that's an issue that we've worked very closely with others in the Department of Health and Human Services on. There's a fairly shocking proportion of the US population whose literacy in terms of health and health care needs is fairly low. This includes folks who can't read, it includes who folks whose first language who may not be English, and it includes folks who don't understand a great deal about health and health care and may not ask questions about what is it that I need to do and so far. And I think that when we, I'm reminding myself, somewhat blithely say, "It's very important to inform and educate women" because I think they will be the leading edge of patients getting more involved in their care and participating as partners in their care, we have to remember that that's going to take a variety of formats. Having said that I think that we often mistake this for, we need to educate all these women and they need have to this much knowledge in order to do that. A real big part of this is self efficacy the belief that what you do makes a difference. That's actually much, much more important than knowledge. What I think we have to catch up with is how we capitalized on that and give people the skills to believe that we need to be asking questions, that

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they need to be active participants in their care, and that I would see as very much a future agenda item.

**JACKIE JUDD:** On this side, a question that hasn't been brought up?

**AUDREY SHEPHARD:** Audrey Shephard [misspelled?] I'm a woman's health consultant. I think everyone here would agree that this has been an incredibly well crafted survey and an outstanding presentation. We've heard just enormous reference to changes that are needed and so forth. I guess I'm wondering what, and this obviously very preliminary, but what's going to come of all this? What does Kaiser have planned? What do other institutions represented here, government and others, have in mind so that we could begin rolling up our sleeves and tackling some of these.

**ALINA SALGANICOFF, PH.D.:** Well I would turn to you and say, "What's going to come of this?" I mean we're going to do more research on this survey and Carolyn can speak to that. I think that what happens in terms of women's health. I had the privilege of seeing the participants list and we have an incredible diversity of groups represented here in this audience. It's very exciting because I would venture to guess a lot of you don't get together quite the often. One of the questions I think, and one of my goals, is always to get people who feel like to understand that women's health is not just kind of an issue that we put into a box. Right now we're

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having a important discussions on the Hill and in state capitols about Medicaid. We're having important discussions right now about the implementation of the Medicare drug benefit and also likely changes also in Medicare. We've got 45,000,000 uninsured people and there's lots of options out there. There's a lot of agreement on both sides of the aisle that there is a problem there, how do we kind of work towards finding a solution? We are trying to provide information to inform the debate that's going on there but I am really hopeful that all of you also feel empowered to weigh in to these important discussions right now.

**CAROLYN CLANCY, M.D.**: Let me just speak about the new Medicare drug benefit for a moment. We need as much as help as we can get from the people in this room and the groups that you work with for getting the word out, particularly to low income elderly women who stand to benefit the most and gain the most from this new benefit and I think who are the hardest to reach. These are not people who are necessarily online checking the web site and so forth. Some may not be that well connected at all so if you have any ideas I'd certainly love to hear them, Wanda Jones, others here would love to hear them as well. The bill is actually much more than a drug benefit and a couple of the very exciting developments is a consistent focus across several different large demonstrations on improving chronic illness care. This is a message that Mark McClellan

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[misspelled?] gets very, very much. I think the large context here is that women live longer in this country than men do and that's good but they suffer more from a burden of chronic illnesses and this is not an area where our health care system has excelled. In fact the one disappointing statistic or surprising statistic to me is the proportion of women who think that quality of care is a problem because it should be much, much higher. We have a huge gap to close for everyone regardless of insurance between best possible care and the care that's routinely provided. Having said that there's a lot of interest in the private sector and very, very focused demonstrations in the Medicare bill that I think are going to help us understand how to use payment, the "how" that Paula referred to earlier. How do we organize practices? What kinds of incentives are needed to actually address the chronic illness challenge?

**JACKIE JUDD:** I think those comments are terrific to end this event on. I want to thank the panelists who were all terrific, Alina as always wonderful. Thank you've been a great audience. I know some of you have some more questions, I'm going to ask if the panelists could just stay for a minutes if any of you want to come up and go through any ideas with them. Thank you.

[END RECORDING]

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