

## Overview of Concept Mapping and Review of the Map Transcript

### Slide 1

MS. KANE: Thank you. Is this one on Yes, indeed. Great when it works. Good afternoon, everyone. DR. KERNER: Try again. MS. KANE: Good afternoon, everyone. I want to thank you all for taking part in the work that we've done so far and I'm really anxious to share it with you, but first I wanted to thank my friend and partner in crime here, Jon Kerner, for the opportunity to work with and to get know a little bit, and I mean a very little bit, about the area in which you are so committed. And I just want to add my personal thanks for your commitment and the commitment to your colleagues to this issue. I'd also like -- and I also wanted to mention a couple of other people I wanted to thank. One is Cynthia Vinson, who is slaving in the back there, and Dr. Freeman, for hosting us during this meeting. And I also wanted to introduce quickly to you my pal, Dan McLinden, who is hovering in the back. Dan and I work together on a lot of engagements like this, and the scope of the things that we have been working with in this arena have really educated us and really humbled us through the efforts that go into the work that you all are doing. I just wanted to quickly mention to you that I've just been overwhelmed by your commitment to this effort and during the data presentations this morning -- the things you were absorbing everything that was being told to you. And I have to tell you frankly, it was incredibly interesting, but a little overwhelming for a layperson like me. But during those data presentations, you were really articulating very specific issues, concerns and points of view that you bring from your own position. Whether you're an oncologist, a researcher, an economic researcher, a public health practitioner, an advocate -- you each come to a meeting like this, and you know what needs to be done. As I think Dr. Partridge said earlier, we know what the issues are, we know what needs to be done. But when we think about it in that way, we're thinking about it from our perspective, where we see the picture, where we see the slice of the picture. And so the things that we're going to be able to share with you, I think, today, a little bit are, the bigger picture which has been contributed to by most of you in this room, in one way or another. So this is a little different take on what we mean when we say what's the issue for -- what is the issue around cervical cancer control and the disparities of that particular illness or disease in particular areas So with that in mind, I was really interested to hear you say things like, you know, what about the economic burden, and that also means a cost-benefit kind of approach. The issues of survivorship. The roles of providers. The relationship between one's education or the educational level in a community to the disease, and so on. And all of these things you're going to see have cropped up in this presentation that we're going to show you, and this is going to be something that we're going to use as a framework for the next couple of days. So it's a good thing that many of you did take part, and we really appreciate that. Now, as I mention, you've been talking about data all morning, and then of course, over lunch. Because we can't eat lunch without dessert, and I guess data was the dessert. And, what we're going to do, though, now, is to turn the tables a little bit and we're going to start talking about the data that you gave us. And so you're still going to be seeing charts and graphs and all sorts of stuff like that, but I think it's going to be in a form that's going to be of interest to you, and you're the ones that authored it. And that's something that I just wanted to share with you before we get started. What I'm going to do now is just to show you a little bit about the method that enables us to do this kind of thing. And we do this long distance, as you know. So, although we know how you think, we've never met you before, so this is a real pleasure for us as well. And then what we're going to do is to show you the results of this process and how you've all been engaged in it, and then we're going to actually ask you to do a little deeper thinking about that. And so we're going to, over the course of the next short

period of time, get into -- actually beginning discussions at your tables about what this stuff means, about what we ought to be thinking about, what some obstacles to doing the things that you said need addressing are going to be, and how we can then, move this forward into a sort of an action frame of mind, instead of: Yes, we know, but what needs to be done, but we're stymied by the breadth of it. So here we're going to, sort of, uncouple all of that stymied stuff, and really get at a much more organized view of what you really think.

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So how do we do this There's a generic thing that's called concept mapping. The concept mapping that we do is pretty straightforward. By the way, you have these little cheat sheets on your table. And if you like, you can play along at home. And take notes if you like. Concept mapping is a generic term, but when we do it in the concept system, it has a very particular approach, and we do these certain steps in a certain order to get the result in a very short period of time, that's actually usable for the folks involved. The key concepts for the concept system are that we use the information from you individually what you know and what you believe and what you think to create a vision, a taxonomy of a group's thinking, rather than carving it out into: the people in this side of the room think this, and the people in this side of the room think that. It helps us to represent the ideas of the group in a picture or in a series of pictures so that we have this graphical or visual representation of what we're going to be showing you. Which really helps us to save that information -- to store that information in ways that are more meaningful to us and also a lot more translatable for the folks back where it is you are going to go when you leave here to help move this out of this room back into an action framework wherever you go when you leave here. The encouragement of teamwork is no small thing, as you probably know by now because you're all grownups. And this is a methodology that enables people to concentrate on the topic and to concentrate on the framework which is represented rather than continuing to represent their own viewpoints, and sometimes, at the cost to other people's viewpoints. So it is a real community-building effort as well on an issue, which is, in this case, of concern to all of us. And then, a key ingredient is that it doesn't stop there. It's great to get understanding of our mutual concerns and issues. It's great to get agreement that some things are more critical than others. It's great to understand all those things, but unless we move into action, then it's simply an exercise congratulating ourselves on what we know. And we really need to be beyond that.

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And so the steps in concept mapping are very, very straightforward. I mean, we were talking today at lunch -- and it's true, that it consists, very simply, of all of things that you are used to doing. You come up with a specific idea, just like in typical brainstorming, and then you respond to that idea. In the case of this process, the focus idea, and this was really Jon's authorship, he gets credit or blame. And in this case, this was something that you were asked to respond to. I'm sure many of you took part Yes Go like this. Just humor me. Thank you. There were about 75 no, no, there were more -- I think it was a little over a hundred people who brain- stormed in the process, which was really a terrific return, so I want to thank you for your input. In this case, we asked you to be very Specific, if you remember. And we gave you this sentence to complete. And we said, go to this Web site, complete this sentence as often as you want, and be as specific as you possibly can. So we said, "An action that we could take in our state or region to reduce cervical cancer mortality and eliminate disparities from our high-mortality counties is --." Now that's a mouthful, but it really was you were all very, very good at responding to it.

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So then, after we create that idea, we then, identify the participants, which was easy because Jon had already identified those people who were going to be critical to the success of this conference.

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And then we get to the point of generating the ideas. And this is something you did extremely well. We had over 400 specific concepts or specific views of the things that answered that focus question. And this was given to us through the Web site, which many of you visited and then also for those who didn't have access, we had other ways to deal with that, and many of you faxed back ideas to us as well. And some of the things that were generated are up here on the screen just to give you a little bit of a flavor of what you were looking at. Identify rarely or never screened women and direct culturally specific efforts to reach them. Identify promising ways to increase screening for cervical cancer among hard to reach populations. Promote Pap screening at work sites, and so on. Research cancer registries for patterns of entry by age, ethnicity, etc. So that's a pretty good sample of what you came up with, but as I mentioned, you actually did a really bang-up job and came up with over 400.

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We, as a team, worked with Jon and his team, including the other folks who are presenters here today, at the National Cancer Institute to edit and to get rid of the redundancies and edit for form and consistency and clarity and so on. And we actually got those ideas down to 109, which is still a lot of meat on this structure. We then asked you to do a couple of things that were if you like data, they were probably fun. One was a simple affinity sort that each of you was asked to do. And we had a couple of ways for you to do that.

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And then the second was the ratings, which we also asked you to do. And they were specific to two different things. We asked you to rate importance. How important was that specific item to the focus statement And then we asked you to rate on the issue of feasibility. In your opinion, how feasible will it be to actuate that specific statement And the next step was then what we do internally, and that was to provide -- to do the data input and do the analysis and provide the results. And so that's were we are today.

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Actually, here's where we are today. So we're actually going to do some of this today with you just to show you what we've come up since then.

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This is what we're going to be doing a little bit of today and tomorrow. I think that the goal of the conference, or one of the goals of the conference, is to take a look at this taxonomy, this conceptual framework that we will be sharing, and really begin to think about specific actions which need to be taken: who should be taking them. And then tomorrow, there will be a session that we're going to be talking about specifically to provide guidance for the federal level organizations to have some impact on this issue. Everybody with me It's after lunch, you shouldn't have had those cookies, I'm telling you.

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So here's how we build a concept map.

#### **Slide 11**

Here's how we build yours. This is a concept map. This is not a connect the dots

picture I don't think. And in this case, this is your concept map. So each point on the map represents one of the brain-stormed ideas that you came up with. How the points end up on the map is the result of a couple of statistical analyses that are run on the database that consist of multi-dimensional scaling and hierarchical cluster analysis together. And so that the key concept here is: The closer two points are on the map, the two points that represent statements, the closer in meaning, the more similar in meaning, the group at large, based upon your individual sorts, thinks those two ideas are. And we have a whole bunch of information on that if anybody is really, really interested in that. And I'd be happy to share it with you afterwards. And Dan has a standing offer, and that is that, for the price of a good glass of bourbon, he'll wax poetic on this topic for hours.

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So, someone will take him up on it one of these days. So then what happens after that As I mentioned before, conceptually similar . MS. KANE: (continued from Tape 3. Side B.) . statements, such as develop bilingual and multi-lingual education materials; an extensive network of translation services; train lay people -- lay leaders in minority communities to provide health education information. So those are ideas that ended up somewhat close to each other on the map. Quite far away from those ideas is another group of ideas: research cancer registries for patterns of entry; determine why women in low-income, rural communities are not obtaining; screening; rigorously evaluate existing cervical programs; and obtain local data on who is not getting screened. So those, in terms of there core concepts, are pretty different from the ones up above, would we say Does that make sense They're similar to each other, and they're all clustered in a clump in that part of the map, but they're very different from the other things that are on other parts of the map.

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So there's how your map, divided up into clusters or conceptual themes. The concept map -- this particular analysis is based on the hierarchical cluster analysis that I mentioned before. And given the information that you provide, through the analysis, the program parses things up and comes up with an analysis like this. The good news about the cluster analysis is that we have flexibility and can really create any number of clusters that are going to serve our purposes. Which is really great, because if we want to finer-grain approach, we can do that. If we want a really high level approach, we can do that. In the case of this particular example, we felt, with the help of Jon and the whole team at NCI, that the content really pulls together very nicely in these clusters and holds up well when we keep in mind that what we want to do is take action on this. This is not something that we just want to sort of write a report about. We actually want to make progress on it.

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So when we talk about those ideas in groups, we came up with some suggested sort of headlines or titles for the chapters, as it were, on the map. And these are some of the things that emerged out of what you gave us. So the main topics fell out in this way. Now don't be too concerned about this, because that you will see this over and over again. I'm just sort of giving you an overview at the moment, and pretty soon you're actually going to get down and get back into the clusters and the contents themselves. But in this case, as you can see, we have stuff up on the right, top right: targeted public education and culturally appropriate education. And then, moving from there, we have expanding of screening and reaching high risk and underserved. The lower right quadrant, interestingly has improved health care training and workforce, which also sort of begins to point toward the middle, where we have reach high risk and underserved. And then along the bottom we have things having to do with research, surveillance, and testing. So there's a layer there, and Jon's going to talk more about

the conceptual, the bigger picture, along these lines as well. And on the left side, we have the policy and funding construct, which comes up over and over again in our conversations, of course. So this is a kind of a nice pattern of a plan, but these things also hold in and of themselves, as you will see when we get inside them.

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Here is the one that I was just mentioning. Policy to increase funding and reimbursement is the title that the planning group gave this group of ideas. Did we distribute the statement list by cluster MALE VOICE: No. (slide) MS. KANE: No Okay. Okay. So let's just -- can you read this okay Okay. The blues --the blues at the bottom. DR. KERNER: That's excellent. Tell Dan to (inaudible). MS. KANE: So what I'd like to do is just to give you a little tour of the map and the stuff that's inside each of the clusters. And just so that you can get a little bit familiar with it, and then we're going to ask you to just chat with the folks at your table in an organized way. This is an important time of the day for you to be doing something other than listening to me, I can tell. So when we look at the Policy to Increase Funding and Reimbursement section, here are the things that we find: have national breast and cervical cancer early detection program re-visit its policy regarding screening intervals; develop a sense of urgency to policy makers about this disease; reimburse cervical cancer; lobby for increased funding; develop a process to identify and acquire funding; provide Medicaid coverage; fully fund the CDC Breast and Cervical Program; advocate in a legislative arena; address insurance coverage; and assess the impact of immigration laws on access. You know, it's interesting, when I think about what I've heard so far today, it's amazing how many of these things came up in our conversation already. So when people spoke at the microphone, or when our presenters were speaking, virtually every single one of these statements came up in someone's question or someone's comment or someone's plea. So that's over on the West Coast -- that's the left side of the map, and then we're sort of going to "go around the horn," so that we can see how these things relate to each other.

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Yeah. DR. KERNER: I want to make a quick announcement. The clusters that are being handed out to your table: There should be two clusters per table. Is that correct So you're not going to have all of the cluster statements by cluster that Mary's about to go through, because in a minute we're going to ask you to do something with these clusters. So just in case your worried that you've only got two, that's what you're supposed to have. Go ahead. MS. KANE: Okay. Thanks. You should each have two. Each person should have a copy of two different cluster contents, and that's for the exercise. That's actually for the activity. We have a party gift for you at the end of the day, which is the whole folder of all of the contents that you will ever wish to see on this particular process. FEMALE VOICE: (inaudible) over there MS. KANE: Yes. So let's look up here, if you can. Can we turn those lights off DR. KERNER: Nobody's sleeping - allowed to sleep in the front. (slide) MS. KANE: Nobody's sleeping. So let's look up here, for now, so that we're all on the same page. The virtual page, but there you are. So the cluster that is next -- now remember, we had the policy and funding one, and now we have collaborations and partnerships, and that included things like this. If you're thinking about action planning, all of these ideas ought to form the core of what you're thinking about, but in the action planning, these are kind of like the starter kit on what you would start working on. So, under collaborations and partnerships, we're talking about encouraging partnerships to focus more attention on cervical cancer; develop community advisory boards of local leaders and health professionals; collaborate with Mexico regarding screening and follow-up; encourage cancer centers, academic institutions, and community-based organizations to work towards the common goal, which is something that we heard a couple of times this morning; and provide support groups for women with cervical cancer. And so again, as

I mentioned, these are the things which, when you folks group them in the affinity sorts that you did individually, and we aggregated those -- these are the things that hung together as a group.

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Now here is a nice rich one. Targeted public education and communication was a big concern for many of the people who participated. It's pretty clear that that's going to continue to be one, and some of the information you'll see later from this analysis I think will, be very interesting to you. But in this case we have things like: provide effective intervention models and materials from studies to help departments for distribution; address the risk factors through campaigns and public health education -- and again, this was something else they were talking about this morning. This is not simply a slice of a woman's health; this is something that has to do with social, cultural, and other health issues. And so these things come up on the map as well. Direct an educational campaign to men; use community gatherings as opportunities to teach women about regular Paps; reinforce screening messages via mass media; get more involvement of the faith community in screening; implement a public health campaign to reduce the stigma of cervical cancer. Again, these are just a few of the things that are up here, but they give you a flavor of what's included, and I would hazard a guess that if each of us were asked to provide -you know -- what should we do in public education, we'd each come up with something different. But in this way we can see everybody's ideas in an organized way, and so, that way we can make a judgment about the things that are going to be more important as a group, and the things that are going to be more feasible as a group, rather than by on a sort of a case by case basis - - whoever talks longest or loudest.

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Next to that one we had this. So there's a really nice set of ideas up at the top there between public education and culturally appropriate education and communication. This was a very big concern; it came up over and over again in the list of statements that people generated. And some of the ideas that were generated were these: develop bi-lingual and multi-lingual educational materials; develop an extensive network of translation services; culturally appropriate education for women 40 and over on signs and symptoms; train lay leaders in minority communities to provide health education; develop interventions that are culturally sensitive; and so on. And so these were very specific, and again, we asked you to be really, really specific, because when we gather these ideas into a group, then we can build up from there to the larger concept. But we've got to have the fuel to work with: where people live and where they work and what they know. And so that's why it was important for you to be able to contribute at that level.

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On the right hand side there, we also had a big cluster on the improvement of health care providers and the health care workforce so that they are better prepared to do the kinds of things that are needed to do to reduce disparities. And they included things like: encourage physicians to review screening history and to advise about screening at each visit by a woman. And again, these are some of the things that we did talk about already this morning: ensure culturally competent care, in primary, secondary and tertiary prevention; ensure cultural competence among health care providers; develop clear guidelines for providers on the evaluation and management of abnormal screening tests; have women providers do the exams -- in some cultures that's the better way; improve follow-up and reminder systems to enable M.D.s to recommend Paps; train more OB/GYNs and FPs who are members of minority communities. So again, this really focuses on the issue ensuring that those who are providing health care, especially from the screening and early detection point, are

able to be culturally aware and to be appropriately representative, sometimes, of that culture, but at the same time, to be able to provide the service in a concrete way and a supportive way.

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The next thing that we were looking at is research on screening, diagnosis, and treatment access, and this consisted of these things: assess target groups' attitudes, beliefs, and values about screening and treatment -- that's a good one; a request by the American College of Surgeons liaison to physicians for a patient care evaluation study on cervical cancer -- that's very specific; monitor Medicaid managed care providers on cervical cancer screening and treatment; assess the introduction of other types of screening tests, thin prep and at home, into high risk populations. So again, as I mentioned, this was very specific, but that builds up into our ability to talk about, on the scale of actually taking some action, what we need to do in order to improve the research on screening, diagnosis, and treatment and to use it better.

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And here's a little cluster at the bottom that is surveillance and monitoring: improve systems to link data from low SES and other populations; track access for tracking and follow-up. I'm reading these only because I'm afraid you can't. Am I right, still DR. KERNER: Yes, we can't MS. KANE: Yes. Okay. Identify disparities and access to care for low high and low mortality counties; use Medicare records to identify prevalence of screening practices; rigorously evaluate existing cervical cancer control programs to determine if they are reaching target populations; identify the variation in quality of laboratories reading the smears; and there are a few others in there as well. But the flavor is one of providing a surveillance and monitoring function to control better the process of screening itself.

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And here, I think, is the last cluster. And that's HPV prevention and testing. And the key concept is the issue of a vaccine against HPV, and investigate cost reimbursement of cervical cancer screening and diagnostic follow-up was also included because it's a testing issue. Investigate factors with acceptability of possible prophylactic HPV vaccine among at-risk populations. Create a state registry of cervical cytology and histology results. Test concept of self-administered HPV testing in select populations.

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So what you have - oops, I'm sorry; I have one more. Case management and follow-up, and this was really leaning toward the policy one as well and also toward making sure that we were covering the at-risk populations. Expand breast-cervix cancer programs to provide treatment for combined illness, and that's something that we discussed earlier. Provide case management support for all women with abnormal Pap. This is where we begin to get into the little about the sort of the larger picture of case management. You know, the sort of beginnings of a global health approach. Provide resources to providers and county health departments to ensure follow up of women with abnormal tests results. Ensure persons eligible for Medicaid receive screening. Establish follow up of abnormal Pap tests as a quality monitor for health plans. Implement policies that support in-reach interventions and clinics, emergency departments, and hospitals.

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So, my gosh, we were verbal. Expanding treatment and screening opportunities was right in the middle of the map. And that is having to do with how people get screening and treatment. Strengthen workplace health programs; promote Pap screening at worksites; offer incentives for high-mortality counties; offer women incentives to be

screened; provide out-reach clinics and to rural counties; develop clear materials and information on the costs of screening versus treatment; promote availability of Paps during evening and weekend hours. So this particular one was really about, again, taking the screening and treatment to the folks who need them most.

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Reaching the high risk and underserved was a small cluster right next to that, and it had to do with: identify rarely or never screened women, and direct culturally specific efforts to them; identify promising ways to increase screening; develop screening interventions of cervical cancer among minority populations at risk; provide more timely treatment services to women at risk; integrate cervical screening for older women into other screening; recommend and improve annual screening rates for women at high risk. With that whole map then, which you have on the top of your sheets, I believe, that's the whole picture of the ideas. And I hope that you have a sense -- and I do apologize for the technology. We didn't know that it wasn't readable, and that's a drag. But I think that you have a pretty good picture of the map itself now, and the relationship of the clusters to each another.

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For instance, the one that I was just looking at is really similar to the one -- or leaning towards the one -- about policy and funding. Because there are issues in here about policy, but they're a different cast. The map itself has a relationship from cluster to cluster, just like the points are related from point to point. The closer the points are to each other, the more similar in meaning they are, so that, then, those clusters that are near each other ought to have something to do with each other as well. So that's just a little piece of information for you. Now, are you thoroughly confused Yes Who's thoroughly confused FEMALE VOICE: We are. MS. KANE: No, your smarter than that. Yes FEMALE VOICE: What do you want us to do

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What I would like you to do is -- if we can turn the lights back on. At your table you have two clusters in your hot little hands, yes DR. KERNER: Table 6 has four. Nancy's and my group. MS. KANE: Table Six has four. Okay. The labels Describe what's in each cluster at a general level. Those are the labels that you just saw us review. So what we would like you to do is to review and discuss these things: What are the key ideas that, in your opinion, describe the core issues expressed in the cluster So talk about, from your point of view, in each of those clusters: What are the key things in there that you really don't want to lose That we want to have as kind of the standard bearers for that cluster. So look at that and come up with a couple in that cluster that are really the most meaningful, the most comprehensive, the most central to that idea. And then: How did these issues show up this morning in the literature and data review You might want to talk about that a little bit, linking this stuff on the map, which is what you folks have said, to all of the things that you heard this morning. How are these issues related to the obstacles for cervical cancer reduction that were described earlier And when I mean "the obstacles," I mean the things that people -- that were emerging from the participants' comments during the open mic sessions. And then your opinion among the ideas in each cluster. Which would you consider as a group -- you at your table -- which would you consider are most important and which ones are most feasible And we're going to take a look at that stuff later on. Okay And then I would like you to share your key points with the large group, and we're just going to do that with -- at the microphones later, or with the traveling mic. DR. KERNER: And let me just add. At each table, there should be at least one federal employee, and we're going to ask the federal employee to sort of keep a record of sort of the critical issues that come out. Yes, you're the lucky ones. But, after the break, when we're going to share back what came out of this exercise -- and you have until

2:45 to complete this -- pick one person or have one person to volunteer -- not the federal employee -- to be the spokesperson for your group, to sort of answer the comments up here, report back on the core issues and, sort of, how they relate to what you heard this morning and what's most important and feasible. So, please go to work. Thank you.