



**University Cancer Research Fund Listening Session
Transcription of Public Comments
Greenville, NC
January 24, 2008**

Major Themes

- How to reach low-income, rural residents and extend our reach far and wide across North Carolina and into underserved areas. Particularly interested in reaching individuals with information and support in meaningful, innovative, personal ways that seem relevant and likely to have an impact.
- Conduct research on how to identify and address factors beyond patients' control that affect cancer prevalence, prevention and treatment.
- Address fear and suspicion about cancer screening and treatment.
- Study long-term effects of:
 - New pharmacotherapies
 - Ongoing diagnostic imaging
 - Development of other cancers as a consequence of treatment
- Increase connections and collaborations with UNC and:
 - Primary care physicians
 - Local oncologists
 - Local cancer centers
 - Other comprehensive cancer centers at Duke University and Wake Forest University
 - Statewide partnerships like those associated with North Carolina's comprehensive cancer program
- Maintain and increase strength of professional relationships between local doctors and oncologists at cancer centers like Lineberger.
- Learn from the experience of others in building sustainable systems for cancer prevention, control and treatment, e.g., programs like the one in Nebraska.

- Make funding for pilot projects available at East Carolina University.
- Explore what can be learned about service delivery by non-oncology clinicians, including ways to increase their confidence in managing complex therapies.
- Conduct and engage others in more translational research, including the use of technology and its role in treatment delivery.
- Consider research on work force topics, including low numbers of physicians, including specialty providers.
- Build the field of research on issues related to surviving cancer.
- The public can't just take us "at our word" that UCRF money will be spent wisely; we need to demonstrate accountability and results.

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Detailed Transcription

Rep. Marian McLawhorn (*N.C. General Assembly*) – We were all delighted to vote for this at the General Assembly. How do you plan to get out there in to some of these very difficult areas to reach people who for some reason or another do not have care now? We have a wonderful facility here in Greenville, our hospital system reaches out into the eastern part of the state. I'm specifically speaking to the eastern part of the state now since that's where you are and you have this new collaboration. I know there are efforts that are being made now to reach folks who need service – we're pushing a new dental project – what are your ideas for going even farther into the remote areas of the eastern part of the state? I know you'll get to the west also, but how do you physically plan to get out there and do that? You mentioned about the health centers and needing that collaboration, but how do you get out there and before you can get people to change their habits, how do you reach them and identify them?

Dr. Shelley Earp – I would say that we have had research projects that have been effective. We had a breast cancer screening project that was done from the 90s to end of the 2000 that developed what we call the Lighthouse Advisor ... (*inaudible*). It was done on African-American women and those were chosen by their peers to be community leaders and we trained 160 of those women in five counties and showed that they were effective. So we have some research, the idea of the UCRF is to extend those researches into other rural areas. What I'll take away from your comment is that that should be one of the main things that we do...is to figure out how to get to the rural areas.

Rep. Marian McLawhorn – I really do think it's important that you reach the far and the wide in this part of the state because it has an impact on all kinds of healthcare. Thank you.

Dr. Stephen Willis (*Eastern AHEC*) – I hadn't intended to comment because I've cared for a lot of patients from the east over the years and going out as the executive director of Eastern AHEC out and about a lot, and I see so many factors that seem to me both as a physician and at my job now that seem to me to be completely beyond a control in any life, in any sort of factor at all of the people we serve essentially. We can talk about healthy eating, we can educate the public and we can educate health care buyers on which foods have been associated with higher incidents of cancer. It is difficult to get to a grocery store that sells a wide range of food that will give someone a choice, if they don't have a car, their only means of transportation is their feet, maybe. They might not be able to walk, and there are so many factors that are beyond a patient's control. I think that gaining insight into those types of factors, to the relative contribution of all of that, would be extraordinarily important as we target public health initiatives and others for the future. I think that for many health care providers and for many who should know better, and for much of the populous that I talk to, just friends and colleagues, people tend to blame the patients with non-compliance with prevention. I'm not so sure it's within the control of many of the folks that we serve.

Gordon Cole (*Colon Cancer Alliance*) – I'm here with a three-pronged approach, so to speak. I'm involved with fundraising with research projects here in North Carolina and have had the pleasure of working with Dr. Earp on funding some of the projects at Lineberger and we're getting ready to fund one at East Carolina as well this year. I'm also here as a representative of the Colon Cancer Alliance and have been working with 4CNC, which is working on outreach and screening programs for people in underserved areas. That said, what you mentioned, Marian, is how to find these people and what to do with it, that's the human side of the research. And it all ties into research because we get the people identified, then you also have your patient database for additional research for trials, you make people aware of trials so it is important to identify people and to get people to understand and to know what they're supposed to do. I know that from the colon cancer perspective, which is what we're focusing on with the High Point group, there are so many people that don't understand it, that have a lot of misconceptions, a lot of fears, unfounded fears from the screening process. So it is a huge thing and I hope there is some way to incorporate that into the fund.

From a scientific perspective, I am a stage 4 colorectal cancer survivor. I am almost four-and-a-half years out now and I've had every approved chemotherapy, but one that available to people like myself and I've had every type of radiation, ecological treatment and anything else you can think of and I'm still here because of people like Rich Goldberg and Shelly Earp. But because of the new medications available, not just in colorectal cancer, but in a lot of others also, these things are new; they have not been out long enough to determine what types of effects might present themselves. So the last point there, "Will people live longer, what's the impact?" from a scientific perspective I'd like to see specific research into the effects of ongoing diagnostic imaging. I've had a pot load of CT scans and oncologists have started to get a little concerned about that. What is the effect on the body long-term of new targeted therapies which aren't even poison? I'm on one myself now every other week and maybe indefinitely and I don't mind. But I'd sure like to know what potential or what potential harm it might do, so the long-term effects of toxicity in breast cancer patients some kinds of treatment can lead to other cancers. It can happen a lot just like with radiation, so I'm hoping to see a lot come out of that. From the Colon Cancer Alliance perspective, from survivor advocacy, that falls into that camp also, thank you.

Rep. Edith Warren (*North Carolina General Assembly*) – I just want to thank you. I'm very pleased, this is a partnership that we look forward to and the needs are so great, especially in eastern North Carolina. We have heard those statistics over and over again and there are some positive things

along the way because we have some people out there that are survivors that have been out there for a good long while. We want to have many more of them and I am proud to have been part of the vote to make some good research in North Carolina happen and I just want to thank you again and I want to say that we look forward to some of the good things that are going to happen along the way.

Female Commenter – I'm retired from the faculty of East Carolina, but I would hope that funds would be available to investigators in the Brody School of Medicine; the funding here is very limited. Our faculty has had meager resources and just a small portion of your grant funneled in this direction would be a tremendous help.

Dr. Rich Goldberg – I would like to make a comment about that. As I mentioned, Adam and Allison have invited me up here and we are already investing in clinical cancer research at the Brody School of Medicine by augmenting personnel in the clinical research office by including the faculty at ECU there as members of our cancer research and given them access to a number of our laboratories and by including the clinical faculty as investigators on a number of clinical research studies. I would say we are further ahead here than we are anywhere else in the state.

Dr. Etta Pisano – While we are talking about this maybe we should say that NIH funding has essentially gone down in the last eight years. It's flat, its research funding from the federal government. It's flat so compared to inflation it's dropped. We actually had fewer dollars here to spend than we did in 2001.

Gordon Cole – I would like to see the research money also and maybe by extension through collaboration that you already may have going with other companies, the cancer centers in North Carolina, or whatever, but particularly keep it in N.C., it would be nice to see continued or increased collaboration with other cancer centers.

Susan Lamar (*Cancer Patient*) – I am a cancer patient right now and have been treated at the Lineberger Center and I'm so appreciative of the care that I've gotten. One thing that I've had that I wish for everyone is a very good relationship between my local oncologist and the doctors in Chapel Hill and I realize that that's not always the case. The doctors that are out here serving the people in the counties that don't have stoplights might not have a relationship or feel like they can pick up the telephone and call to make a referral or ask questions. So my question is, how can you do outreach to doctors that are too busy to come to meetings? I understand that, but how do you connect the people that are primary care physicians that need to know about what's happening, that need to know what would be available to their patients?

Dr. Stephen Willis – It's called the North Carolina AHEC system; I think it's the premier AHEC system in the country to be honest with you. Our primary core service is to educate healthcare providers in continuing education. It will be very important of course, that as new knowledge is generated by this partnership that we are effective in disseminating it into the region for the primary care physicians. In particular, with the counties without stoplights have physicians and some don't in our 23-county area. Whether they want to be or not, they're usually the primary care physician folks that come to see them, and that clearly to me would be an important to get the information out too as well...lots of obstacles to overcome, not just obstacles of knowledge and skill, but obstacles of what's realistic in a small community with few physicians.

Dr. Pisano – Actually the problem with us today, for someone from Chapel Hill who’s actually been studying the issue of dissemination of information and technology Cathy Melvin, do you want to stand up and say a word or two about this?

Cathy Melvin – Hi, I’m Cathy Melvin, I’m director of the core dissemination facility at Lineberger, and our whole purpose for being is to speed up the process for getting research into practice across the state. We’re launching a new program called SPEED. It’s a statewide push for excellence and engagement in delivery. It addresses your question directly which is, how can we undertake research to help us understand how to better reach physicians and people in communities and community-based organizations and others with the information they need to be effective collaborators with us as we conduct research, to actively deliver new treatments as they come on by and to have an opportunity to help people. Also, to evaluate those outcomes, so we’ll be putting people out into the state who are research associates who will work with us back at Lineberger who can make researchers at Lineberger aware of community issues of interest by having other forums like this across the state and listening to people.

We’ll also help identify organizations that work with community partners like we’re doing in High Point to develop systems of care for working with patients who have cancer or survivors of cancer. Those people will also help with the research process, helping enroll patients and help us do things that all of us do not like to do like the Institutional Review Board do the subject activities and HIPPA requirements, all those things that we can do more efficiently on the ground away from Chapel Hill, but coordinated through our efforts in Chapel Hill, so we hope to build a dense network of activity across the state that will make those things that you mentioned happen faster.

Gordon Cole – Not to antagonize the panel or anything, but the article that came out several months ago in the Triangle Business Journal had a headline, “UNC: Accountability is Key to N.C.’s Billion Dollar Cancer Pledge” and the doctor goes on and is quoted there in going on in saying basically, “You’ve got to perform.” So I hope the public can take you at your word that with all this money, that it’s not wasted, that it’s really focused and carefully used in whatever research because I know you’ll pick the right research, I know you’ll do that correctly so it’s going to be done, so I would like say that everyone particularly in these economic times would like to make sure that that money is well spent and not wasted.

Dr. Pisano – Hear, hear. We are taxpayers, too, of course, but we are great stewards of that. We hope that as we look back on this in five or 10 years, you all will be proud of what the legislature has accomplished by making this large fund because we have to prove ourselves every single year, we’re looking at like “Rome wasn’t built in a day”, but that’s one of the reasons why we are here today, because we want to do the things that the people of the state want us to do. Clearly, we talk to the experts, we know what MD Anderson does, we know what Dana Farber does, we’ve talked to people from all over the country, in fact all over the world, in fact there are people from other countries that have contacted us and said, Wow, what a wonderful thing you’ve got.” A billion-dollar endowment is amazing. But it really is important that you show results and we’re very conscious of that and we’re very attentive to that, we have outcome measures. In fact, we are hiring someone who will help us measure our results so this is really something we’re conscious of and we’re dedicated to doing. Really, if you can’t think of what you want to say today, we welcome your comments, send us emails, we’re all available publicly on the Web so you can find us, we really want to know what you think and we want to make you proud.

Dr. Goldberg – I would also say that we realize that a dollar spent with us is a dollar that is not being spent on education or on better roads or on other things, therefore we feel a responsibility that has been quite a weight to be sure that we are effective stewards of this money.

Dr. Earp – Are there other comments from ECU faculty in the room about your hopes for the relationship that we are clearly committed to, how you think that fund should work to improve the situation for faculty, doctors and nurses that do take care of patients in this area?

John Lehman (*professor of pathology at ECU*) – I guess I was able to follow over the last 25 years what has happened in the state of Nebraska. Nebraska population voted for a two-cent tax for cigarettes. Nebraska has a very high incidence of lung cancer, as well as cancer, because they do a lot of agriculture and farming there. Those two cents provides you with a lot of seed money to get collaborations going with a number of faculty at the two medical institutions in the state, Creighton and the University of Nebraska. Since I sat on the review for many years, still on it actually, I was able to see how that two cents which they multiply to about six cents and so they gave about 4 million dollars a year for the past 20 years to each of those cancer centers and has moved Nebraska in point of view from competitiveness, they've seen a reduction in lung cancer. In fact, they're worried that a lot of that two-cent tax will start to go away, so prevention worked very well. Whether they made major inroads to understanding the mechanism, those collaborations with the physicians as well as the distant communities somewhat similar to what we're talking about here in eastern North Carolina and western North Carolina I think worked very well. So this kind of innovation and collaboration works very well between Creighton and University of Nebraska, East Carolina University and University of North Carolina and we shouldn't leave out Wake Forest and Duke either because they're also major players from a basic point of view, but also from clinical point of view.

And the key is collaboration because in the long run it helps science in general...but also patients in the long run. Having only been here a short period of time, I understand we have a very major problem when I listen to my clinicians about the patients in eastern North Carolina because they really don't have the opportunity to really come to major centers such as Lineberger or even here in Greenville. We have to basically go out there and I think there are a lot of interesting data from the prevention and epidemiological point of view as was pointed out by our AHEC, the doctors in this area can really give a lot of input into some really peculiar things that at the base level can really help the patients a lot, so I think this could really be a positive interaction. The model of Nebraska is a very interesting one; you need to look at that from the perspective of what we've done over the past 25 years because I'm very impressed what the state has done at Nebraska for the cancer program.

Dr. Pisano – I think that what will be very evident at the time is that this is research that is just the beginning of many collaborative projects. I think this is just a first step in the right direction, we've been collaborating some the previous years, but I think it is inevitable that as we get to know each other, we'll find things to collaborate on. I think that's already happening in some other areas....and that's just a really positive thing for people in other areas of the state.

Lloyd Mickens (*N.C. Comprehensive Cancer Center*) – My name is Lloyd Mickens. I'm with the North Carolina cancer program and in part in answer to your question about the collaboration, within the last two to three years we've established collaboration with several different collaborations statewide. That's one of the tenets of our program, also, answering your question, we are doing a lot of research trying to find the community-based organizations, finding individuals that organize access

to care that or that are having difficulty having access to care. We're trying to link things all the way from the research center down to the family physician. We do a lot of collaborations, we go into a lot of communities and we try to set things up to benefit more patients. We do have a cancer plan, it's at NCcancer.com, I advise everybody to take a look at the plan and critique it...

(Tape inaudible)

Dr. Earp – ...listening session and it will be over with the meeting that Walther Sheppard was chair, is bringing a lot of the cancer people together and we'll be listening to a lot of experts there. Lastly in back, what Cathy's holding up, Cathy do you want to describe that for us?

Cathy Melvin – Which of you has one of these? It's a report card for North Carolina on how we're doing with regard to cancer. I just wanted to tell you that our purpose talking about cancer, this will give you more information telling us about how we're doing....This is the first ever edition of this.

Dr. Goldberg – It won't be the last edition; we'll be doing that yearly.

Female Commenter – I think it's probably obvious that one area of research that I would like to see you emphasize is translational research, where you move the discoveries from the research laboratories into the patient-care setting and the only way we're going to get new treatments is to emphasize that. Lots of times there are a lot of good things coming out of the basic science labs but they don't really get moved on very well.

Dr. Earp – Very important point. As an aside, the marriage of technology that's going on in physics and chemistry is allowing us to do translation a lot faster. If we can actually access patients in this area of imaging, the idea of functional imaging is really coming to the fore. So, it's a wonderful point and one that we are all very much engaged in as a nation, we're doing better but the UCRF will be a major part of it.

Dr. Stephen Willis – It also bears mentioning that one important question to answer, and it may have been answered, part if translational research, particularly for the east and also for the west, because most people quite simply don't have access to oncologists, look at the N.C. Medical Board Web site, oncologists who are in the state are all clustered around large to medium sized towns. What can be done from the delivery standpoint beyond prevention, safely and effectively by the non-oncologist physician and the interdisciplinary practice that surrounds that person, because I'm a family doc and I think quite frankly many primary care physicians don't leave training feeling comfortable and confident that they know enough or have the skills necessary to manage a complicated chemotherapy regiments say back at home, so to speak. And I have an idea that we could get a much better idea that has some impact and training that certainly the whole issue of technology and the remote ability to transmit data, both radiographic and laboratory data remotely essentially instantly would impact on that. I think that would also be an important part of translational research because I think that would be in the foreseeable future, we know that there's a shortage of doctors period in North Carolina. I think that for the foreseeable future the oncologist available will be clustered in medium-sized to large cities where there's a critical mass of patients who don't have to go, quite frankly, that far to see them.

Dr. Goldberg – I would actually respond to that by saying Spencer Rod, who ran the cancer center here was way ahead of his time trying to establish the network of cancer doctors in the eastern part

of the state and those clinics still exist. One of the things that we're hoping to do is to connect with those individuals using Web-based and teleconferencing capabilities that will be in the cancer hospital, so that those practitioners won't feel like lone-rangers out on the frontier but will be connected to the university and their colleagues for helping them to make decisions.

Dr. Earp – One of the parts that I didn't emphasize in the middle of that diagram is what's called clinical excellence and outreach and as Richard described it, Tom Shea, who is head of our Bone Marrow Transplant Program and has worked very widely with the people at East Carolina, would be the associate director of clinical outreach and he's got a number of ideas exactly along that direction. It will be an interesting conundrum about how can you get the oncologists out and how do you use the family practitioner? One of their roles, survivorship, is certainly an area that we need to move into. The other workforce issue that I have been quite excited about is that the school of nursing is going to start an oncology nurse practitioner certificate program which will start next July 1st. A wonderful nursing Ph.D., Deborah Mayer, who has been a president of the oncology nursing association and now has come onto our faculty. I think that's another aspect of the workforce that may have a profound affect; she would be doing as time goes on, a distant learning oncology nurse practitioner certification which will help us serve the state.

Dr. Pisano – I think this is an opportunity to tell you about another (*inaudible*) that is under way that is in the study phase. Referring to your point about the shortage of physicians in the state, there is a study that's been going on for the last year about physician workforce shortage in the state of North Carolina. There was a report in 2006 by the Institute of Medicine in North Carolina about healthcare workforce shortages not only in medical but nursing and allied health as well. It's clear that we won't have enough personnel with the growing and aging population so we've been studying that issue for about a year in conjunction with partners around the state including ECU. We are poised to report to the Board of Governors of the UNC system about that in the next month so we are considering some remedies to that but there's along way between here and there, but I'll tell you that that's on our radar screen too and we have been collaborating with people at ECU as well as in Charlotte and Asheville. But it can't be solved by UCRF; it has to be solved by a more broad based effort by physicians in the state as well as other personnel.

Dr. Goldberg – I think we owe the legislators here a vote of thanks for taking courage in supporting this somewhat controversial action in the legislature. I believe that it's a sign that North Carolina is a forward-thinking state and is leading the charge and I would like to give you guys a round of applause.