NINR History Project Telephone Interview #2 with Dr. Linda Aiken Conducted on August 17, 2009, by Philip Cantelon

PC:	I'm speaking with Linda Aiken on August 17 th , 2009. I have permission to record the
	call and use the information?
LA:	Yes.
PC:	Thank you very much. Nice to talk to you again after such a long time.
LA:	Yes. Same here.
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PC:	The first question I have is, are you currently doing any NINR-funded research projects?
LA:	Yes.
PC:	Could you explain what those are briefly for me?
LA:	The biggest one is a four-state study of the outcomes of hospital nursing care where
	we're looking at the impact of nurse staffing, education, and the quality of the care
	environment on patient mortality and other adverse patient outcomes.
PC:	Is this a multiyear study?
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LA: Yes. It's a five-year study.

PC: Looking back over twenty-five years of funding from NINR and NCNR, have these kinds of projects changed in your experience, that is the types and the directions that they're going?

LA: You mean our research specifically?

PC: Yes.

LA: Yes, and we have been continuously funded ever since the NINR was established. Our first grants were studies of smaller number of hospitals. The first NINR grant we did in the U.S. was a study of the outcomes of AIDS care in twenty hospitals, selected nationally from cities that had a very high incidence of AIDS. So we started out selecting hospitals and then going into each of those hospitals and examining the impact of some of these same factors that we're looking at now on patient outcomes. But we discovered that the kind of research that we wanted to do in developing more the causal chain between nursing interventions and patient outcomes really required us to scale up our research quite substantially. So then we developed a model that allowed us through survey techniques to study hundreds of hospitals at the same time, and that's what we've been doing more recently. And also the NINR funded us to extend our work

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internationally, so we have an international arm of our research as well. So now literally we're looking at the outcomes, counting the international side, of over a thousand hospitals and millions of patients and surveying hundreds of thousands of nurses. So we scaled up significantly to try to have a larger policy impact.

PC: And this is a recent development, the international growth?

LA: No, we were funded to start our international work as a supplement to a grant that we had, and I believe it was funded in 1999. And we've continued that work ever since then, most recently getting very large-scale funding to continue it from the European Union where we now have a fifteen-country study in the field.

PC: So building on the NINR funding?

LA: Right. All building on the NINR funding, international funding.

PC: When you say you first got funding, you really mean NCNR I guess initially, the National Center for Nursing Research?

LA: What year was that established?

PC: Nineteen eighty-six.

LA: See, I didn't really come to Penn until '88—

PC: NINR is in '93.

LA: Well I guess we overlapped because I believe our first nursing awards were when I came to Penn in 1990.

PC: Okay. Have you seen any other changes? You've been involved with a lot of nursing groups nationally and such. Any changes caused by or I suppose leadership from the NINR or from the kinds of things the leadership provided by NINR over the years in terms of shaping the national nursing research agenda? Have you seen any trends there?

LA: Let me give you—starting at the most macro level. I think one of the most important changes in any aspect of nursing in the last several decades has been the establishment of a national center and then the NINR on the impact of the influence of nursing nationally. So it's not necessarily something that the NINR staff or policies did, but I was on the Institute of Medicine's study that recommended the establishment of the NINR. In that recommendation we were hoping that having a very rigorous scientific peer-reviewed component of the NIH would propel nursing research into the mainstream of scientific and policy inquiry, and therefore give nurses opportunities to be involved in leadership roles in a variety of areas, and that has really happened. In the academic world where a

lot of the legitimacy for any of the professions come from, nursing is now taking its place, in the Institute of Medicine, individual members of the Institute of Medicine, we now see nurses on most kinds of commissions, and many of those folks are nurses that have established their national credentials, so to speak, through their scientific advances that were made possible by the NINR. So I think the NINR has had a very big role in really increasing nursing leadership's visibility on every aspect of nursing.

Certainly looking at a more micro level, I think the NINR has, through its agenda-setting, encouraged research in certain areas. I think by focusing on end-of-life care and management of chronic illness, they have sort of brought more researchers into the field. In my area, policy research has not been one of the sort of headline priority areas, but certainly the NINR has funded us and has made possible the influence of our research program. So in that regard I think the decisions have been very influential in nursing in the policy realm which is more where I work.

- **PC:** With the current healthcare debate, will the whole policy research area now become more important?
- LA: Yes. Definitely. And to their credit, the NINR has now kind of moved into identifying cost effectiveness research just within their domain. This is an area in the past that NINR has not emphasized, indeed the whole NIH has not emphasized, but I think the NINR realizes that it has really influential research that has been done at the clinical level and

it's now striving to convert that into comparative effectiveness and cost effectiveness research which I think holds the promise of having a much bigger policy impact, especially in the health reform debate, and I think that's a decision that has been a very good one on the part of policy in the NINR.

- PC: Who's establishing NINR policy? Is it still through extensive discussions? There used to be these meetings, core meetings with the nurses coming in, meeting in Bethesda, and then that changed a bit where they'd bring fewer people in or they'd do it at conventions. Is that still happening?
- LA: I wasn't really aware that this has kind of ebbed and flowed over a period of time, but this year there's been a whole series of meetings that have been organized and attended by the senior staff of the NINR, including the director, on new directions in science and policy. And out of one of these meetings, or several of them, and the input from people in the field, I think, the NINR was encouraged to move more into cost effectiveness and comparative effectiveness research. So this year I seem to be more active in assembling people from the scientific community to think about new directions than I remember them being in the past. I've never been on the council, but I presume the council does have a role in discussing and promoting the various programmatic priorities.

- **PC:** You mentioned the importance of the academy in all of this. I wonder if there have been changes as you've watched at Penn, for example in nursing research curriculum over the past twenty years let's say.
- LA: Yes. [Inaudible] and I think they're going to be bigger in the future. I think a trend is going to be—and we're certainly doing this at Penn and I know other universities are doing it, too—to try to attract students more quickly into research careers as undergraduates and then promote these expedited B.S. and Ph.D. programs so that we have more nurses that begin their research careers at a much earlier age, more comparable to that of the ages of people in other fields. So that's kind of a big area that I think is sweeping the leading universities. So we would expect to see sort of less conventional statistics and things that bore students and more involvement in NINR research. Like one of the things we're doing at Penn is we have a whole track now that we're developing that will try to attract freshman students into research and locate those young undergraduates in one of our six research centers. And Penn [inaudible] to establish research centers primarily on the basis of having substantial amounts of NINR funding. So we have research centers in almost every clinical field at this point, and so we're going to locate the students in those centers, and they're going to actually start working on and understanding NINR research. We think it's very exciting, and we think if we really showed it to them, they would also.

- PC: You've done a lot of work on the retention in nursing and the like and outcomes and nursing satisfaction. One of the things that I was reading about is that the generation of researchers, that is I would guess the people who came in in the eighties, is starting to age—I hate to use that word but I guess we're all getting there—and that now they're not being replaced fast enough. Is that indeed the case or not?
- LA: Well I think there are sort of two things going on there. I think we have a larger cadre of young investigators than we did in the eighties, but what gives us the perception that there are not enough of them is that we have so much greater need. We need so many more than we did in the eighties just because higher education has expanded, we have many more nursing schools, they all need faculty with a doctoral education, and all the universities would like to have funded researchers. So the whole scale of the requirements for nursing research has increased and including lots of nurses employed in the service sector. I was just recently in the Massachusetts General Hospital, and they have forty, four-o, Ph.D. nurses just at Mass General. So I think there's a perception that there are not enough nurses replacing the older cohort, and I think numerically that's not really true. It's just that the gap between how many we have and how many we need is greater because of the growth of demand for nurses with doctoral degrees. I think the nurses that we have coming up now are much better trained. They're going to be much more successful in getting research funding from a variety of institutes within the NIH and from a variety of non-federal resources. So I think they're better trained than we were, and they're going to be more successful in the long run.

PC: I always thought I'm glad I don't have to go back to school now. I'm not sure anybody would want me.

LA: I'd never get into any of these schools I got into. [Laughs]

PC: One of the other trends that we're hearing more and more about is more emphasis on prevention rather than treatment of disease, and there's been a new phrase that has been kicked around called healthcare navigators—nurses as healthcare navigators. Have you followed any of that?

LA: I don't know if I'm familiar with that particular term navigator, but I assume this is all in this kind of genre of healthcare coaches and all of this kind of thing, and I think there's a great interest in the service side in having such practitioners. We have a lot of evidence, particularly from all the research on nurse practitioners, that the patients of nurse practitioners do much better than those only having a physician provider in terms of their ability to take care of themselves, to implement their prescribed regimens, to stay out of the hospital, etc., so I think nurses have a substantial record in this field. It seems to me it's in the interest of some stakeholders to try to suggest that this is new, and I think that's where you're seeing this idea of the nurse navigators or coaches or whatever. It's not really new, and nurses are the only providers that have a record in this field, and so

there's a big battle with regard to health reform and payment about who's going to do these new tasks if these roles are defined in payment terms.

PC: So it's more a new term than a new development.

LA: Yes. Definitely.

PC: You mentioned what you thought was, in the macro view, the important impact of NINR over the years. Since you were on that IOM report, what do you think has been a failure or lack—what hasn't it been able to accomplish that you hoped it might?

LA: I think the funding has never really been as great as we imagined that it could be, and so the overall funding is a constraining factor in terms of the ability of the NINR to really make significant progress. For example, some of the agenda areas that it has selected like end-of-life care and chronic care coordination, all the sort of caring roles that are different from cure, there are no other institutes that really devote their attention to that.

Now when we made that recommendation from the IOM, we were anticipating that the NINR would be the institute that would establish the science base of caring, and it would fund any investigator of any discipline that had a good idea. But I think that the NINR's been limited in their capacity to really fund up to scale that kind of research just because they don't have the resources. I think secondly, the IOM committee believed that the NINR would play a bigger role in policy than it has played to date, that we thought that,

you know, like the clinical care research that they've been doing that they would also be the basis for science in health services, research, and policy, and that has been interpreted to be a more difficult area for the NINR to be in. And I think as a result, progress in terms of nursing research on policy-relevant issues has not grown as rapidly as it could grow if the NINR put it as a bigger priority. But again, I think that is in part related to the overall mission of the NIH, but to the NINR's funding.

PC: What directions do you see for the future? If we looked over, here are the changes that nursing's been brought over the past quarter century, where do you think things might change, easy answer, the next ten or fifteen years?

LA: Nursing? Not nursing research?

PC: I'm sorry. Nursing research.

LA: I think one of the big changes is that we have so many more really highly knowledgeable and skilled investigators, and they're going to be scaling up their research and doing sort of multisite trials, and we're going to have more nurses as head of projects that also include other investigators. I think we're going to have more nurse-led research on clinical problems and other issues seen through this sort of special lens of nursing. But how much that develops again depends upon what happens on the funding front for the NIH, because all of these larger scale initiatives that are really needed in nursing require

pretty large funding. So either the NINR must have a larger budget or nurses have to become more influential in the other institutes in order to get these larger multisite trials funded. A lot of nursing research, especially funded by the NINR, is still pretty small, and my observation is that the cumulative knowledge base is not growing as fast as it should because the clinical trials are—like one site clinical trials of a hundred people or two hundred people, and that's just not large enough anymore to change practice or policy. So I think for nursing to really come into its own, it's got to scale up, and either the NINR will help facilitate that or nurses have to be more creative in raising the money elsewhere. But I think they will do it. It's a natural kind of growth of science at this point.

- **PC:** I take it what you mean here is you're also talking about interdisciplinary things as well.
- LA: Yes. Pretty much all of nursing research is now interdisciplinary, I should have said. I think that's one outcome, one accomplishment that has been fostered by the NINR is that nursing research has scaled up and become more mainstream. One of the definitions of that means that it is interdisciplinary and it's being published in interdisciplinary journals, and it's adding to the cumulative interdisciplinary knowledge base on a number of issues. I think really the NINR made that possible.
- **PC:** From someone who is attracting extramural funding, what was your reaction to the NINR's intramural research program?

LA: I don't really know much about it. To me, it doesn't have much visibility. That's not necessarily a positive or a negative. Since the other institutes do have intramural programs and I think maybe part of the prestige of an institute within the NIH has to do with what they do in the intramural program, I think it's probably important. But I don't myself see much of an impact, which is not to say there isn't one. It's more clinical and my work is not that clinical, so it may be just that I don't see it.

PC: What about the changes in science, for example genetics, on nursing?

LA: Are we talking about the impact of the NINR?

PC: Yes. For example, they sponsor this Summer Genetics Institute for nurse scientists to get people involved in that.

LA: I think those things are good, but I think it may be a little too early to tell whether they're impacting the development of nursing research in the field. Again, this kind of gets back to that funding issue. I'm not sure the NINR really has enough resources to fund serious research in genomics.

PC: I think what they do is they fund the students to come in for the summer, whether they are attached to NIGMS or whatever it is, I just don't know.

- LA: It's a part of that, but no, there's not going to be any progress unless there is research money for all those students later in their careers to help them establish their research programs. I don't know about that. I think it's a good beginning, but my impression is that that's what it is is the beginning.
- PC: We mentioned about getting people through on their research degrees more quickly now. Have we really lowered the age of nurse researchers? I remember Ada Sue Hinshaw told me that one of the problems was that, by the time they got finished, they were in their late forties or mid-forties before they finished all their programs because people kept delaying it, and she was trying to push that age down.
- LA: I never really looked at that to say that we've impacted the trend line yet, but if we haven't impacted it yet, I think it's going to be an impact in the future because certainly the University of Pennsylvania, we look for younger students, we are encouraging the BSN-to-Ph.D. option and many other schools are as well. I think that will happen. I'm not sure it has happened yet.
- **PC:** You've spent your life in policy. What advice would you give or what remains to be done if you were going to be the next head of NINR?

- LA: Well, one of the great things I think that's happened over the past twenty years is that all of a sudden, research matters to policymakers, and instead of just arguing on a case of one anecdotally, the Congress and state legislatures and the executive branch, everybody is paying attention to research, and in some ways fighting over which research is best, etc. But I think the basic great thing that's happened is now all the policymakers think that research is relevant, which they didn't used to think. So that being the case, I guess if I were the director of NINR, I would look for strategically to support programs of research that were going to generate research findings that would be pertinent to the policy debates of the time to try to be able to have impact on them.
- **PC:** What would the opposite side, that is the people who want to do more basic science, that would not be applied as quickly I suppose.
- LA: Well, I think we need every kind of science because from that basic science then we get the ideas for how to apply it. So in my comments I didn't mean that we should exclude any kind of basic research. But I think I would put relatively more emphasis on the significance of research, and I think the whole NIH is doing that. So to ask the question about whether a minor change in an intervention in another clinical trial of a hundred or two hundred people is really going to make that much difference, and go for something of a larger scale to the extent possible. But we certainly need a lot more nursing research in the basic sciences, and we don't really have enough now of it, you know, nurses working in the lab sciences for example. So that's really an area that needs more investigation

because nurses that really have a good education and access to resources can then infiltrate these high-level scientific teams that are studying things that Congress wants to know about like cancer prevention and care, and a lot of that comes from the basic science.

PC: If you were to capture the changes in the past twenty years in an anecdote for me, what might that be?

LA: That's kind of a tough question.

PC: The people with the best answers get the toughest questions.

LA: Well, I guess I could give a lot of examples of the increased influence of nurses in all kinds of different roles in healthcare which I think has been supported by advances in research. Now we have for the first time ever a nurse administrator of the Health Resources and Services Administration, Mary Wakefield, the highest ranking nurse that we've ever had I believe in the executive branch. We have a number of nurse members of Congress that are very active. We have nurses that are heading up big service organizations and have a lot of influence along with other disciplines, CEOs and physicians in the service sector, and we have the service sector paying attention to nursing research in the development of their new products, like AETNA and Kaiser paying attention to the work of Mary Naylor at Penn on transitional care. That was very

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long for an anecdote, but I think I could say that nurses have much more influence now.

Maybe the anecdote is that all these so-called new ideas in health reform, many of them

are really old ideas that nurses have been doing for a long time so that the mainstream is

catching up with where nursing has been for a long time.

PC: Terrific. Thank you. It's always great to speak with you. Thanks very much.

LA: Okay. Good luck on your project. Bye.

PC: Bye.

End of interview