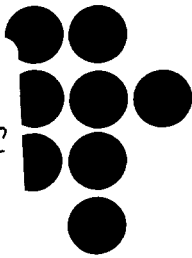




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COMMUNICATIONS FORUM

Dewey

**"Networked Health Care Delivery:
Opportunities and Challenges for the '90s**

**October 21, 1993
4:00 to 6:00 p.m.
Bartos Theatre
20 Ames Street
Massachusetts Institute of Technology
Cambridge, Massachusetts**

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MASSACHUSETTS INSTITUTE OF TECHNOLOGY

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Speakers:

**Neil Izenberg, Director
Nemours Center for Biomedical Communication**

**Linda Harris, Senior Advisor
Communication Technology Policy
U.S. Department of Health and Human Services**

**Joseph Henderson, Director
Interactive Media Laboratory
Dartmouth Medical School**

**Lee McKnight, Moderator
Digital High Resolution Systems Program
Massachusetts Institute of Technology**

**Kelly M. Greenhill, Rapporteur
Graduate Student, Dept. of Political Science
Massachusetts Institute of Technology**

Moderator LEE McKNIGHT (LM): Welcome to today's Communication Forum. All three of our speakers will be using video and/or slides as part of their presentations. This is not a fully networked health care demonstration, but it will hopefully give you some inkling of experiments and prototypes that are under development at the various institutions, which are active players both on the national policy level to those who are responsible for finding answers to patients real medical needs.

Our first speaker is Neil Izenberg. He is an M.D., F.A.A.P., a Board certified pediatrician, and a Fellow of the American Academy of Pediatrics and Adolescent Medicine Specialists. He is the director of Adolescent Medicine Consulting Clinic at Alfred I. DuPont Institute, Children's Hospital, Wilmington. Dr. Izenberg's academic appointment is as Professor of Pediatrics at Jefferson Medical School. His B.A. was from Columbia College in Anthropology, and his M.D. was from Robert Wood Johnson Medical School. He has held residencies in pediatrics at Long Island Jewish Hospital and at Children's Hospital of Philadelphia. He has had fellowships in pediatric endocrinology and diabetes, and in adolescent medicine.

Dr. Izenberg has recently joined the Nemours Foundation to create and serve as director of the Nemours Center for Biomedical Communication. The center has as its mission the creation and distribution of innovative media to help families and professionals learn about their own medical issues. He is working actively in the area of telemedicine, and is an accomplished video producer. We are very pleased to have Neil here with us today.

NEIL IZENBERG (NI): At Nemours we are a creator of applications, and at present we are concentrating on setting up telemedicine systems. Telemedicine is a natural outgrowth of the Nemours Foundation, which is an entity that operates children's hospitals and distributed rural health care clinics in Delaware and Florida. Nemours was originally started by A.I. DuPont, who changed the gunpowder company into DuPont Chemical Corporation. Part of his will reflects what we do at Nemours, that is, we are dedicated to the care of impoverished, underserved children.

Those of you who listened to Clinton's health care speech may have noticed his oblique reference to telemedicine, which had to do with the movement of information of remote locations. There are really two locuses of underserved health care needs, one is the urban poor and the other is rural. Our hospitals have distributive facilities in both, but our focus is rural because of Florida. We are talking about tiny communities in the Panhandle, where the greater metropolitan area may include only 6,000 people. Central Florida and the Panhandle are very poor; illiteracy rates, for example, can be as high as 40 percent. The Foundation designed a series of children's clinics that act like nice suburban private clinics, but are located far from other resources, and are certainly isolated from sub-specialties and other pediatricians.

The dilemma of how to care for underserved segments of the population is a problem that is getting worse. Many of the few hospitals that exist in rural locations are closing down. So, often if a child living in such an area needs to be hospitalized, often his/her family may have to drive many hours and/or they must pay other members of their family to drive them and for time away from their jobs.

Another major problem is recruitment and retention of physicians in rural areas. Most doctors are trained in high-tech environments, where they are used to interacting with colleagues; they are accustomed to a certain cultural atmosphere. To leave such an environment and voluntarily isolated oneself, forced, at the same time, to do everything alone, is both frightening and to some extent, stultifying. Hence, there is the additional important issue of distance learning and consulting with colleagues, which need to be addressed if rural health care is to survive.

Telemedicine can be defined in a number of ways, but one possible definition is "the transmission of high quality video images between physicians and nurses in underserved areas, and other physicians, usually at a central base." There are many

possible configurations of such a system. A telemedicine system in a remote district would have, for example, perhaps a camera to see the general office set-up, a small additional camera on a stand for documents, and maybe a system for downloading data. I think this type of arrangement is a particularly cumbersome system. It is one that is used by the Medical College of Georgia; it has quite a few monitors, some of which reflect high-resolution X-ray monitors. X-rays are somewhat of a problem because radiologists believe very high resolution picture is needed for correct interpretation. For digital, for example, you might need a 2K by 2K display.

Most telemedicine systems are adaptations of business teleconferencing systems, such as Picture Tel and CLI. When you look at television, the signal will be six megahertz, which would be equivalent to 20 to 25 megabits, which is a great deal of information. You cannot, for example, get 20 megabits through your telephone. Even if you think you have a really fast modem, you actually do not get more than nine kilobits. As you see, there are many orders of magnitude difference. Therefore, the issue of getting enough information across is quite a problem.

Original telemedicine programs, such as the Harvard system that used microwaves, or the Mayo clinic system which uses its own satellite system, are impractical on the clinic level. However, through adaptation of current equipment, we can create useful telemedicine systems. We can, for example, employ video otoscopes, small cameras adapted with a fiber optic light source, which feeds the information back to a Codec decoder. This real time video is compressed into a digital stream with the use of this system, which compresses, decodes, (while discarding some information), and creates a picture on the other side. Depending on the bandwidth of your data pipeline, you will get different quality pictures. For instance, PictureTel systems provide approximately fourteen frames per second via an NTSC signal, which may not be adequate for medical diagnostic use.

There are, in addition, many other applications for imagery in education. For example, if you have ever had an arthroscopy, a laparoscopy--you know there are many places doctors can stick little cameras into you. Moreover, currently there are many cases where surgery is being done, and the surgeons are looking at a television screen. Imagery is also important for teaching and medical record keeping.

The benefits of telemedicine are multifold. First, pretending for the moment that bandwidth is not an issue--since soon it will not be--obviously telemedicine will be an important tool for increasing access in both core urban and rural areas. There are some studies that indicate that it will also be cost-saving. For example, ten years ago a Codec (the compressor/decompressor) was the size of two flatbeds, required five people two days to assemble, and cost \$250,000. Now, Codec costs about \$25,000 and is the size of a VCR. Soon, it will simply be a card that goes into a computer and will only cost \$2,500. The technology is dramatically changing, which will have many implications for the delivery of health care.

Second, there are lots of costs built in to the current system, including travel time, "windshield time," the delayed care costs, and the fact that specialists cannot help diagnose, which can be mitigated through the use of telemedicine. Arthur D. Little did a communications study, and estimated that the costs of telecommunications for all medicine would be \$40-60 billion per year. The telemedicine aspect alone would mean a savings of \$200 million per year.

Third, Nemours believes that the quality of care should increase, and hopes that telemedicine will allow us to pay more attention to the practice methods of physicians in rural areas. These rural physicians are placed in rural areas that would give people on the eastern corridor goose bumps because these places are so isolated. So these are physicians who are, by their very nature, pioneer, independent people. Therefore we want to know what these people are doing, and make sure they feel they can call upon their colleagues; this could have a very important social networking effect. One of the problems physicians have is that when they leave their residency and being their practice, they can "rust" pretty

quickly. It is, therefore, important to have continuing education. With telemedicine, we can recreate "morning report", regular meetings which physicians have in large hospitals, where they consult each other and discuss various cases.

Fourth, the issue of getting specialists into these areas may be solved through telemedicine. This will obviously not replace the need to see subspecialists completely, but might be good for follow-up appointments and emergency consultations. As telemedicine gets more networked, then the nurse clinician, who may be called in the middle of the night, can have a consultation with a board certified specialist. In addition, another one of the future directions that will radically change health care is by bringing it directly into the home, so that monitoring can again be done in the home through two-way video communication.

(Dr. Izenberg shows his NBC news video on telemedicine. The video talks about how telemedicine can be used to connect rural areas to large urban hospitals, and how it increases efficiency and lowers costs. The video focuses on one young girl, who at a very young age, suffered a brain hemorrhage and now needs fairly regular medical consultations. Because she lives in a remote rural area, telemedicine technologies are particularly important for her situation.)

There are many further issues that could be discussed, but I will leave that for the question and answer period.

LM: Our next speaker is Linda Harris, a senior policy analyst with the Advanced Projects Agency (ARPA) and the U.S. Public Health Service. Linda has served as a senior research fellow in the Department of Health and Human Services, the Office of Disease Prevention and Health Promotion, since 1986. *(the tape is marred by feedback and low volume in this area. Please feel free to add any information about your position.)* She is currently on detail to ARPA in the Department of Defense (DoD), where she will coordinate an ARPA/U.S. Public Health Service health education and research effort. *(The sound died again here. Please feel free to add anything.)* She is very distinguished, and we are very happy to have her here with us.

LINDA HARRIS (LH): I thought I would talk today about the conceptual apparatus that we are trying to build between DoD and the Department of Health and Human Services. I must tell you, however, that I am speaking only for myself. I have not been at DoD long enough to know whether I am making sense from their perspective. This is my first effort to explain what should be of mutual interest not only to those building military technology, but also for those interested in technologies related to computer and telecommunication sciences, as well as those trying to develop health care technologies.

The organizing principle we are working with is the notion of collaboration, and the reason we think it will be a powerful one is that it is at such cross purposes with the way society operates. In a book that I have recently read, *Shared Minds* by Michael Schrage, the author argues that the notion that an individual can know something in and of him or herself is really not the way we actually discover ideas. Throughout history we have been far more able to create and be innovative by working together. For instance, Nobel prize winners are far more likely to collaborate than other scientists, so we know the really successful ones have been so through collaboration. Of course, he (Schrage) is arguing that "the team" should actually be viewed as the hero. What we are going to be about (all of us) for awhile is learning tools for collaboration. Since this, in fact, has not been a value in our society, it makes sense that we do not have tools, either conceptual or physical, for doing things as a team.

All of us who are trying either to build the information infrastructure, reform health care, or recreate government--whatever we are about--we will probably come up against those people who are trying to do these same things in collaboration with each other. As

you know, we are all isolated in different parts of the world, and it is very difficult for us to know how to bring the value of collaboration as a concept to the fore. We think that if we can pull together not only the principles, but also the protocols and the tools for collaborations, that we may become better collaborators in the process.

The faith I have in Michael Polanyi suggests that when we build tools they become such a part of us that we are shaped by the tools we make. If this is really true, if we really can create an environment where we are building tools, than maybe we can shift from an individualistically based society, where the individual gets the reward, to one where collaboration, cooperation, and teamwork are more valued. That is, in the process of building the tools that should help us do that, they may, in fact, also help us become a collaborative society.

I will talk a bit about how this fits with the Administration's interest on the policy level, in health care reform, in the information infrastructure, and in reinventing government. I would like to share with you a little project I have been working with for the last couple of years in the HHS, which will come with me to DoD. This will be our first cooperative effort to try to learn about collaboration. It turns out that this project is the counterpart to the one Neil is working on, which is to say, this project works with the underserved in urban areas. The project called "The Community Services Network," is an effort to build a system that will support the coordination of care at the community level, so that providers all over a community can act as if they are in one building, which in turn provides for the patient a one-stop shopping environment.

(Ms. Harris shows a video about "The Community Services Network," which shows a variety of the services offered by the network and how they work. The emphasis of the video is coordinating cooperation and use of available technologies, to help urban clientele. The video also discusses "Point of View Television," a project in which teens learn to use video recording equipment, and go into the community to record different health concerns. The video shows a group of young men who are soon to become teen fathers, discussing their predicaments, The video also shows a clip from a video presentation about a residential shelter for battered women. The premise behind this is a that women can view this video before deciding if they are interested in becoming a part of the residential program at the shelter.)

The most important feature of this project is that the collaboration and the creativity is really a function of the coalition of providers, who are creating their own system. They define what is important to the project, and they go out and find other members of the community to work with them to produce the kind of information they think is valuable. We hope that through further collaboration between the DOD and HHS, we can encourage communities all over the country to use these technologies to reconnect people to each other--to form a seamless system of care.

There have been three relevant policy documents coming out of this Administration, which converge in one set of exciting forward looking opportunities for us. The first one deals with the national information infrastructure, in which the Administration calls for a set of "collaboratories", a set of laboratories where there are no laws, where researchers can collaborate as if they are in the same room. One might then ask, what do they collaborate about?

Second, the foremost health care concern revolves around trying to reform the way care is paid, but that number one priority is allowing the rest of us to reform the way health care is delivered, and create a seamless system of care (including specialists) available to everyone. Moreover, we want to create a system in which when a person is cared for by a provider, that person should feel confident that anyone else who cares for them is fully aware of what is going on, that they are acting as a team. Today that is simply not the case. Rarely do providers have the opportunity to talk with each other. So we want to rebuild a safety net that is really fully connected; this what this collaboration has got to be about.

Third, and finally, we are trying to reinvent government, and since we are part of the problem, we really want to learn to collaborate, not only across space, but also across bureaucratic walls, which (as I myself have experienced in moving from HHS to DoD) is not a trivial barrier. I want to leave you with just a few conceptual questions. We will be looking at the collaboratory, trying to develop one between these two agencies in the development of a high speed network over which we will be able to collaborate. I want to leave you with the notion that we are looking not just at the technological tools, but at the principles of collaboration. That is one of the reasons I am here, to understand the human factor in this rather new effort to collaborate. I, too, have a few fundamental questions I would like answered. Perhaps here at MIT, where many of you have been working on this sort of thing, someone can tell me how one collaborates successfully, and whether or not it makes a difference.

LM: Our final speaker today is Dr. Joseph Henderson of the Interactive Media Laboratory at Dartmouth Medical School. His main research interest is in the use of computer communications and media technology for the education of health care providers and recipients. He is also interested in using virtual environments to provide access to large multimedia data sets. Lately, he has become involved in network multimedia, having acquired an IBM PowerServer 970, with 512 megabytes of RAM and 53 gigabits of hard disk storage. Recently, touch tone dialing reached his home. To tell us what this all means with relation to health care reform and information superhighways, here is Dr. Henderson.

JOSEPH HENDERSON (JH): There are so many different aspects of this domain that we could discuss. Essentially, however, we are talking about the intersection of three things: telecommunications, computers, and media. Today, I would like to emphasize the media because, in that arena, we have a great deal of experience. From the beginning (since the days of the caveman), we have told stories to educate people. I think Linda showed a good example of how media can be used to help people make decisions about the kind of care they want. The same is true of care providers; the closer we can tie what we teach in an abstract setting like this to the real world of practice, the more help people will get in making decisions.

That is really what we are about in the Interactive Media Lab at Dartmouth—the telling of stories to convey information. To do that, I will show you a work in progress, which we are completing with Columbia School of Nursing, on HIV. The project is an interactive program for health professions, which desires to teach from the molecular level up to the psycho-social level. Though the program is interactive, it uses a fairly traditional model of teaching (lecture format), but with that format we have real people talking about their lives. In addition, we employ different media, such as 3-D computer graphics, to make some medical points.

(Dr. Henderson shows a clip from his HIV video program. Much of the clip is devoted to people talking about their personal experiences as patients with HIV, and how it affects their lives. Some of the video is also devoted to explanatory graphics, displaying, among other things, the binding of tissue cells and HIV virus.)

Use of media as you have just seen, whether it is real people talking about their real lives, or carefully crafted audio-visual representations of a fairly complex topic, both can result in very memorable learning. So when we talk about a new information age, I think we must obviously talk about content, and the power that these video technologies give us, making things memorable and allowing people to tie the facts we give them to real stories.

Let me now show you a promotional videotape that describes a series that we developed for The Foundation for Medical Decision-Making. The tape is a clip from a series based on shared decision programs. In this case, the collaboration is between the provider of care and the recipient of care. The model is that when one is faced with a

significant medical decision, in which the values of the patient are important, that this is a decision to be shared. It is the informed patient that makes the decision, but it is the care provider that helps the patient be informed in making that decision. To promote that model, the Foundation has commissioned a series of interactive media programs that convey information, but also give a patient a chance to hear from patients who have gone before, chosen differently, and perhaps experienced good and bad outcomes. I will now show a videotape that describes two programs we did on breast cancer.

(Dr. Henderson shows clips from the interactive videos about breast cancer, and the choices available to women who have this cancer. The video focuses on the experiences of other women who have had breast cancer, and the disparate choices they made.)

I think that gives you a sense of the series. I want to emphasize that the information presented to the patient is tailored to each individual, to the extent that we are aware that different characteristics can influence what the person might decide. For example, with respect to the therapy decision, it is age that dictates what kind of medication one gets, the number of lymph nodes and the size of the tumor both bear on the prognosis, and the likely effects on this therapy. So there are really quite different messages that patients get, depending on the prognosis.

The last thing I would like to show is all simulated, but it is a great story. Also, I think it will pull together many of the themes we have heard today from all of our speakers. So, I will go ahead and play this; take it for what it is worth.

(Dr. Henderson shows a video about a rural farmer who has a condition called Hutchinson's Freckle, a superficial cancer that nonetheless needs to be monitored over long periods of time. The "freckle" seemed to be changing size and shape, and therefore needed to be evaluated. Normally that would mean a long 50 mile car ride to the nearest tertiary care facility. The video shows a technology that should be available within a year or so. It represents a revolutionary health care delivery system that for the first time focuses on the family practitioner acting as the guide into the medical system. It also brings that medical system to the patient instead of forcing that patient to go to a tertiary care center for every visit. This technology gives both parties access to sophisticated information, and permits interactions with a specialist in the patient's own hometown, saving time and money, while delivering better care.

The video also shows how, after the farmer's condition is evaluated by both his family practitioner and specialists at the hospital 50 miles away, the family doctor receives instructions about how to treat the cancerous growth. The video shows how telemedicine can provide benefits for both the patient and the family practitioner, who has learned how to perform a new procedure without leaving her office.)

I think I will turn the floor over for discussion.

QUESTION 1: We spoke only briefly about the national health care reform, but a cost savings of \$200 million was mentioned. However, in an health system where overall estimated costs are around \$800 billion, I wonder if we are talking about a major change in the health care system, or just some savings and alterations in quality on the margins?

LH: I was actually involved in the study that came up with these numbers, and I believe the savings are actually underestimated because of the limitations inherent in the data used. For instance, the data, which is based on the medical model, does not include prevention, education, and most home care. So I think that this study was terribly conservative. The value of such a study is that it throws out some number, but this number should really be treated as a very conservative estimate.

QUESTION 2: I was thinking that perhaps Joe could provide us with a better estimate of the benefits to be derived from the use of shared medical systems. I think, from my knowledge of the medical system, this would save a tremendous amount of money in that it would greatly reduce unnecessary medical procedures by far more than \$200 million. Care to comment?

JH: The goal of these shared decision systems is obviously to take a consumers' union approach, which is that we want to act on behalf of the patient, not specifically to bring down costs. There may be a reduction in costs, but that is not the goal of the program. That said, preliminary reports show that the use of shared decision programs, in certain cases, have reduced the number of people willing to undergo some surgeries. Some men who had originally decided to have prostate surgery did change their minds after watching the prostate-related videos. There are some other things that Jack Winberg could tell you about, but I do not know much about specific savings. So, though I do not have any specific figures, there is some indication that when the alternatives are between high cost care and relatively low cost care, there may be a cost savings associated with using these techniques. However, I can't tell you how that is going to generalize.

LH: This idea is especially interesting with respect to end of life decisions. I think most people who care about shared decision making as a paradigm assume that lots of people prefer a de-institutionalized choice, rather than an institutionalized choice. We do not really know that they do, but this is more than likely the case at the end of life that people will prefer to stay at home rather than going into intensive care in a hospital. I think Joe is right. None of this stuff was done with the purpose of saving money, but when people get to make choices they will often prefer non-institutionalized care. If when you can make expertise portable, then it is not really necessary to have institutionalized care so often, which is where most of the expenses really are.

QUESTION 3: Two questions. First, do you have a reference for further information on "Community Services Workstation?" Second, it seems like much of the savings in telemedicine have little to do with medical care. It has to do with trip reduction, less time lost on the job, etc. I wonder if anyone is looking the economic modeling of those savings.

LH: I can provide anyone who is interested with the reference afterwards.

NI: In response to the second question, those savings were factored into the Arthur D. Little study. The study focused on both direct and indirect savings, and if you are interested, I think they will provide you, free of charge, with an executive summary of their study. There is a great deal of assumed savings in the model for when one is making early diagnosis, and for avoiding the costs of erroneous treatment. These factors are also part of their economic model, and have been included in their calculations.

LH: I am a bit troubled by the fact that these things are being presented within a model of how health care is delivered today. That will simply not be the case for very much longer. We need to think about the distributed model of health care because it is simply what is happening, whether reform comes from inside the Beltway or not. Somebody who can really understand the distributed model of health care will really make a contribution.

With regard to the video with Koop, the most interesting part was where a specialist transferred knowledge to a family practitioner with the patient right in the room. That is totally different from having to go to specialists for every organ in the body. And, unfortunately, the cost analysis in the aforementioned study, is really based on that model rather than primary care based, distributed based, home based care system.

NI: When we establish a new paradigm we do not always know the consequences of the paradigm. You can, for example, right now purchase an otoscope, and look in your baby's ear at home. Well, can you imagine, if in five years perhaps everyone will dial 1-800-EAR PAIN through their computer, and use their own otoscope. Then they could plug the data into their computer, somewhere there will be a technician looking at the 1-800 patient's tympanic membrane (ear drum), delivering their expert opinion. There are lots of logical reasons why that might not happen, but I can also give you a number of reasons why it will. Would that be a good thing? For some things, it would be and for others it would not be. It is not clear where all this information is going to take us. We are clearly on the information highway, so we have to look both ways, as the pediatrician would say.

QUESTION 4: This is a question for Ms. Harris. I would like you to speak about your experience with some of the obstacles to collaboration.

LH: Yeah, turf! In the project I described on the local level, I was privileged to be a part of a coalition, in fact saw it formed from the very beginning. I witnessed the blood on the floor of the battles that had to take place before these providers could be sincere and authentic in their commitments to share territory. One example is in the area of privacy and confidentiality, which can be a show stopper if unresolved. Not only do we have to protect people from having their information disseminated to department stores, credit unions, etc., but we also have to protect against personal information being used to protect turf. For instance, someone might say, "I cannot disclose that information about my patients; they are my patients. It is my responsibility to maintain confidentiality." That kind of thing is real to them, it is their responsibility. We each have a kingdom, and to pull any real estate out from under that kingdom is very, very threatening. We have to offer rewards and incentives for the synergy that comes about from giving up some of that turf.

Other real barriers include funding streams. That is to say, every organ in the body has an institute that specializes in giving away money to cure or prevent an ailment, or finding the needed treatment for that ailment. Each community has hundreds of funding streams, each with its own disparate administrative requirements. In addition, each of these institutions have different patient requirements. So eligibility requirements, funding streams, privacy, and just simple orientation towards individual productivity and success are real boundaries. The human infrastructure building process is the most difficult process. That is why I will not work with a project where such an infrastructure is not already in place.

QUESTION 5: In the era of outcomes research, is anybody using the multimedia as a way to standardize outcomes, or standardize initial diagnoses?

JH: The shared decision programs are a direct result of outcomes research and initiatives. Jack Winberg was one of the founders of the idea of outcomes research. Now the issue has become, how does one disseminate the results of outcomes research? Traditionally it has been through medical research, which tends to be a rather slow process, and only goes to the physician. Shared decision making short-circuits this process, and takes the results directly to the patient, who should at least be participating in the decision-making.

The other aspect of outcomes research is that while providing information, they programs simultaneously gather further research data for outcomes research. In other words, in the process of registering a patient to see the program, we gather baseline data that is used to track these patients over time. That obviously is part of an outcomes research project.

QUESTION 5, II: What about patient pictures, like those of the freckle? How does one standardize those kinds of inputs into records, so that someone who is going to look at outcomes can get a handle on where someone started and where they ended? Are there

plans, or fundamental data structures, in place that are understood in the medical community?

JH: I am not really in the policy area. I am an applications maker, but I know there are some agencies, such as AACPR, which have funded patient outcomes research teams, so-called PORTS, which specialize in high-impact diseases. These diseases are deemed high-impact in terms of their effects on the costs of medical care and in terms of the number of people affected. Jack Winberg has, at Dartmouth, the PORT for prostate. Others have them for cardio-vascular disease, bypass surgery, low back pain, etc., and they are standardizing the methods of analysis and dissemination. As far as the rest of the world goes, though, I am not sure.

LH: I think that this is an excellent question, and it points to an area of whose outcomes we are unsure. There are two ways of doing outcomes research right now. Jack Winberg is brilliant, but he is definitely on the "bleeding edge" of that area. There are many guidelines that are being determined right now, not with patients' inputs into outcomes research, but by a group of experts sitting somewhere else, being paid to determine guidelines in the abstract. In other words, they are examining the boundaries that can be recommended based upon the data. Hence, there are two potential scenarios. One is that a patient comes in, and has a fixed number of options set before him or her. These are options that the expert panel has determined are scientifically valid, and will therefore be reimbursed. The second scenario is that a patient comes in and says, yes, I see these are options validated by an expert, but I want an option outside of this boundary. Then the question becomes "who pays?", and "how do those boundaries increase?" as patients begin to assimilate new choices, choices that are more likely to be alternative medicine, which lie outside of the medical model that has been the basis of this research all along?

JH: Actually, that is not quite true. With the prostate PORT, we present many options, some of which have good research behind them and some of which do not, a fact we make known to patients.

LH: That is why I said that Jack was on the "bleeding edge." It has not yet become mainstream because the guidelines will determine what gets reimbursed. We do not know yet whether what Jack is doing, that is shared decision making, will become a part of what gets reimbursed. The key issue for the patient is whether their choices about lifestyle and habits get integrated into the formula for outcomes research. I am not sure who is in the position to make those kinds of decisions, but they will be really crucial.

QUESTION 6: In terms of the application of telemedicine technology, can you tell me where the U.S. sits relative to developments in other countries? Are we leading the way, or are there things we should be learning from other countries?

NI: There is actually an international telemedicine movement. In fact, the first telemedicine conference was in Norway last May. It is certainly not limited to the U.S. A good deal of it has to do with basic communications infrastructure, which is dramatically different even within the U.S. For instance, states such as Iowa are putting down a whole network of fiber optic cable, while other states barely have telephone lines into certain sections. This is true for other countries as well.

QUESTION 7: My question follows on what was mentioned about the future sociology of all of this. You brought up using telemedicine to reach those areas that have inadequate specializations. What if, for example, I sit here in Boston where they are supposed to have some of the best hospitals in the world, with some weird condition that experts out in L.A., or perhaps in Germany, are even more expert than the doctors in Boston. I could see how

we might create a demand for the very best care in the world. At present, people do take advantage of medical center specializations, but there are restrictions due to costs and time. Now it seems telemedicine can offer these kinds of things at much lower costs, so that essentially any specialist in the world will be available to anybody.

NI: Well, you posed the problem well; I do not know the answer. Certainly people are going to have access to experts all over the world. But a given set of experts is going to have a limited amount of time. So telemedicine will diffuse knowledge; that is the very positive aspect. On the other hand, if everyone says, I must have the "best" in the world, there are going to be big problems.

QUESTION 8: Even before Clinton introduced his health plan on television, Senators Bond and Riegel had introduced bi-partisan legislation for a national health data information highway. I wondered if any of you had read that legislation, and what you thought of it.

LH: Have you read it?

RESPONSE: After I called Senator Bond's office, they sent me "Cliff Notes" of a sort, written for people who knew little or nothing about this. I have not read the whole thing, but the notes I looked at were not terribly helpful.

LH: I have not read the legislation either, but my guess is that unless it is connected to the national information infrastructure or health care reform, it will not fly, whatever it is.

RESPONSE: Well, I was told it dealt with the Smart Card. But, based upon what I was sent, it does not seem to deal with privacy concerns at all, which are, of course, a very important issue with respect to Smart Cards.

LH: Really? Well, then it is dead. It is just not economically feasible to build a whole structure around health care. It just will not happen.

NI: I would like to address the issue about using Smart Cards as portable data banks of individuals' medical histories that people carry around with them. The controversy surrounding lost and duplicated medical records is incredible--it is an unbelievable problem. Surveys show that 30 percent of medical records are not available at any given time. Likewise, many records are duplicated by labs, who either do not trust other labs' results or cannot find the needed records. The cost implications of such behaviors are staggering. I do not know if the Smart Card is designed to deal with this, but clearly the issue of duplicated medical forms, the loss and duplication of tests, must be solved.

QUESTION 9: I have a curiosity question about these data bases you are building. How often do you update them, and how do you get that information into them? And for Ms. Harris, will money be made available for small communities to develop these systems?

LH: Well, at the heart of our project is a collaborative software, or shareware system, which allows updating to occur at the point of service delivery. Everything is updated automatically, and in fact, that information is distributed to everybody else on the team instantaneously. There are many other data bases that need to be updated all the time; that is just a given.

Our hope is to do two things for communities: to provide them with technical assistance to move them from wherever they are to wherever they want to be, and to provide some incentives to allow communities to compete for pots of money to help them move forward. It is really our hope that between ARPA and HHS (perhaps with the help of foundations) that we can really encourage communities to work together to build



communities networks. We have to be broad in our thinking, and consider the economic implications of whatever proposals we make.

JH: One of the goals for putting in an information infrastructure should be to have very tight linkage between the practice of medicine, the outcomes of that practice, and education. In order to achieve that, we need better methods than we have today, to gather information that is accurate and appropriate, which sufficiently describes the situation. I think there are things yet to be invented to deal with that situation. It is not a technology question, it is a conceptual question.

We must come up with analyses that measure more than central tendencies, or give contingency tables in order to make decisions. The danger arises when we have this tight coupling. If information is to be input into the system right away, we better make sure it is really good information, otherwise, we are going to have a great many problems with the widespread promulgation of misinformation.

LM: I would like to thank all of our panelists for their participation in this session, and thank you all for coming.