American Medical Informatics Association Nursing Informatics History project

Purpose

The overall purpose of the Nursing Informatics History Project is to document and preserve the history of nursing informatics.

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Carol Romano

Interviewer: What is your name?

Carol Romano: Carol Romano, R-o-m-a-n-o. I'm the Deputy CIO for Clinical Research Informatics at the Clinical Center of the National Institutes of Health.

Interviewer: How did the transition to informatics happen?

Carol Romano: Okay. I was a clinical nurse at the National Institutes of Health, working on a open heart, post-op open heart surgery unit. And the hospital had signed a contract implementing an electronic medical record. And that was in 1975. And part of the implementation process was to involve a cadre of individuals who would help to implement, design the system to meet the clinicians' needs, to implement the system and train clinical users. And I was selected as one of the nurses. There was going to be a team of 12 nurses that was going to direct this process. And I was representing the cardiac surgical area, and was commissioned as one of the key members because I was a clinical senior person, not because of any computer background.

And then the story began, a long career from there. I think I've been doing this about 33 years now. But it started, I think, because of the opportunity that was available, and also because of the vision of the nurse leader at the time, who said that if we're going to implement electronic information systems, nursing needs to be involved, and there needs to a nursing component to that system, which was very unique and unusual for that period of time. And I think in 1975, we were probably like the fourth or fifth hospital in the country to even think about or talk about, let alone implement full-scale an electronic medical records system.

Interviewer: Any point where you had an 'a-ha' moment?

Carol Romano: I think, initially, when I was asked to be part of the process or the program, my first thought was that there's going to be electronic systems, everyone's going to be using them in the future. I'd like to be on the front end of helping to direct that, rather than the back end, having to live with other decisions that are made. And I think when we talked about electronic medical records at the time, and, again, this was '75, the idea was that it was supposed to help support the mission of the organization, which was clinical research. And the idea was that nurses were involved in at least helping to implement those studies and collecting the data about the patients. And so the manual processes, certainly in federal government, from just overwhelming in terms of paperwork. And I used to work a lot of night shifts, so the night shifts got burdened with a lot of the record-checking and recordkeeping.

So from the very beginning, just the idea of making this an automatic process that was going to be more efficient and easier for the nurses, I think was in the back of my mind, and really why I was partly… pretty excited about being part of this electronic initiative that we didn't really have a name for. Of course, the term 'informatics' was not really used then. And it was sort of an innovative kind of opportunity. I didn't know a lot about it, and I think that was sort of what was… maybe not unusual at the time, because we were just sort of pioneers and going where no man had gone before, which gave us the opportunity to create the future, as opposed to trying to learn it. But I remember nurses asking me, 'Oh, do I have to go to computer class? Do I have to learn programming? What do I have to learn about the technology in order to use the computer?' And early on, we were really clear, and I think I have to give credit to Bernice Ferguson, who was the chief nurse leader at the time, and her philosophy and direction to the organization was that we're going to let the technology people worry about the technology, and we're going to worry about what it is about nursing care that the system can do for us, and what is the information piece for our nursing care process that we want to capitalize on.

And so that, I think… I don't know if it was an 'a-ha' after the fact. I think that was sort of setting a stage for the direction and what we really wanted to hold as the vision for what we want to accomplish.

Interviewer: Was there a point that you started thinking of yourself as an informatics nurse?

Carol Romano: I think that, in terms of how one identifies themselves as an informatics nurse is interesting, because at the time when we were implementing computers, people would say, 'Oh, well, if you don't like nursing, you could always go into computers.' And I would say, 'No, that's not what it's about. It's about how to make this technology work for nursing.' And I used to talk about this diagram that had a Nursing in Technology, and I always have the arrow going 'Nursing should drive the technology. It shouldn't be the technology telling us what nursing should do.' And so I never saw myself as a computer nurse or an informatics nurse. I saw myself as a nurse, trying to capitalize on the tools of our time, to be able to create better information structures to serve patients care. And I think as the field evolved, and… in terms of what is this body of knowledge for informatics, I believe I played a role in helping to define that by looking at my own experiences and articulating what is it that I needed to have that I didn't have. What were the skill sets? What was the focus or the emphasis of this field that needs to maintain the identity of nursing and the information components of nursing to be able to create individuals who could then better serve the field by working through the specialty of informatics?

Interviewer: What do you see as what you have contributed to the field?

Carol Romano: Okay, I think… I've been in the field for a long time, and when I reflect back on what my contributions were, I think about working in the field early on when there wasn't an opportunity learn from other people, or to go to the literature or to find out what's actually being done. So one of, I think, my contributions is to help to create the

definition of the field, and to help define the role of the informatics nurse, and how they can serve patients through addressing information needs.

The… in the process of implementing a… an electronic system, one of the things that became, I think, important and useful to other organizations was the articulation of a model for the information that represents the practice of nursing. And so I had published in, I think, the late 70's or early 80's, a clinical model, a framework for the interdependent and the dependent role that nurses play in terms of their information handling. So it was about the information about assessments, the information that relates to care planning, to patient observations, and evaluations that focused the independent aspect of nursing care that one needs to design the computer system to support.

In addition, we also had to articulate the interdependent aspects of nursing care that relate to executing the medical plan. And so order entry and designing what kind of orders not that physicians write, but that nurses need to understand, and so that the framework of framing those orders in a way that the nurse who executes them understands what the information is and what they're required to do. And then, also, the evaluations and observations that nurses make about the patient's response to the medical plan of care is the information component that needs to get represented in clinical systems.

So I think one of my first contributions was to articulate this model for clinical information from the nursing perspective that needs to get incorporated in designing information systems.

As I worked in the field, I noticed that…

Interviewer: Were you working with those agencies then?

Carol Romano: No, I've always worked with the National Institutes of Health at the Clinical Center. And because of my informatics expertise, I was tapped as a consultant to work with other

federal agencies to either review research grants, to help advise on research priorities in the field of informatics, to look at how information technology can be used appropriately or inappropriately in some of the grant proposals, and to advise in that capacity.

In addition to working as a nurse in informatics, it became pretty clear early on that nurses need some education to do this. And as I worked with nurse leaders or administrators and talked about informatics, it was obvious that they didn't have a background on what it is that informatics was, and what it is about computers that nurses needed to get involved in. And I also had nurses who were interested in the field and said, 'Where do I go to learn about this?' So one of my contributions, I believe, and it was more self-centered because I wanted to work with people who I could speak with, and who I could help to move to realize the benefits of the technology, was to work with the University of Maryland, and develop the world's first curriculum in nursing informatics at the graduate level, so that we could prepare nurses to serve as leaders in informatics, and to help to drive the development, the implementation, and the evaluation of information systems that would support patient care.

And I believe that the… we had… the university had submitted a grant under the leadership of the dean at the time, Dr. Barbara Heller, who had the vision to, to see—she had done a sabbatical or an… a sabbatical at the clinical center, and worked with me in terms of seeing how nurses were using the technology. And she was my graduate advisor at the time, and we had talked about the idea of preparing a formal educational program for nurses, so that I could work with this group that she would graduate, and I could hire them, and have a cadre of people that could function in the field.

And so in 1985, I believe I taught the first course in that program, and we actually developed the graduate curriculum. We had an advisory board of nurses who were working in the field, who looked at the progression and how the graduate students were doing. And it's been a very successful program. The… some of the curriculum has been used, or at least modeled by other educational institutions to prepare, and… and now,

looking at the basic competency that all nurses have to have in informatics, let alone those who are prepared as leaders in the field.

Interviewer:

Carol Romano: I would say that I've worked with other organizations, both educational and federal government more in a consultive capacity. For example, HRSA and…

Interviewer:

Carol Romano: Right, whenever there were informatics grants, they asked me to sit on the panel, the review panels to review their studies, to interject the informatics perspective. Or when schools had submitted grants to develop educational programs, they asked to sit on those grant review boards. So I think on my CV it actually talks about research grant reviews. I'm a reviewer for those organizations.

Interviewer: What was your role in reviewing the grants?

Carol Romano: In, in consulting with other organizations and in sitting on review boards for grants it was important to have an informatics perspective on some of these grants. For example, if a grant would come through about implementing an initiative in using computer technology I was able to advise about the appropriateness of the technology or about the feasibility of implementing that technology and whether the study was realistic in terms of the resources or in terms of the expectations that the principal investigators had about being able to accomplish the goals of the study.

So from that perspective, I think I've helped influence the field by advising and directing some of the studies and offering critiques and maybe suggestions for improvements to hopefully, to help to get those studies funded by helping to make sure that they… the

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focus is realistic and appropriate. And focus on the… maximizing the benefits for the information requirements for patient care.

Interviewer: Talk about your current assignment.

Carol Romano: Okay. Currently, I work as the Deputy CIO, that's the Chief Information Officer at the Clinical Center of the National Institutes of Health. And the Clinical Center is a hospital, research hospital. It's the intramural program of NIH. And we have had information technology there since 1975. My role has evolved in that organization over time. Currently, I play an administrative role, where our department is responsible for all of the clinical systems that support clinical care, that's required by the research studies that we do. So we have recently implemented the next generation of a research information system that helps to collect clinical data, and that eventually the clinical data populates a warehouse, where eventually we'll be able to extract the data in a data mining process to be able to do studies across protocols, across patient pop… patient populations, and opens just a whole new area of research in terms of collecting data once and using it for multiple studies.

We're also in the process of implementing clinical systems in other areas, such as pharmacy scheduling the OR nutrition systems. And I think as one looks at all of the different types of clinical systems that are used in a healthcare environment, it becomes important to understand how the interfaces of these systems need to work. For example, a nutrition system is important, but it needs to connect with the diet order, and then how the nurse communicates electronically to let the dietary system know when the patient is MCO, or when diet trays have to be served, and whether diet drug allergies are integrated into the clinical systems, and the information not only ordering but observations that are made about patients.

And so having a nurse involved in that process helps really to articulate the information flow throughout the healthcare delivery system. And nurses have always been in a critical

position to handle information and to integrate it across the discipline. And as we become more overt about what that information is, as you develop technologies to support that, it becomes even more important to have a nurse speak to the need to for these systems to function together as opposed to these silos. I've always believed that the fragmentation of information in care is, is, is really what contributes to the fragmentation in care. So if we unfragment our information and our information systems, hopefully, we have better continuity of care, and better service to patients.

Interviewer: You work in a coordinating capacity?

Carol Romano: Well, in the hospital, we have a department called Clinical Research Informatics. And that department then connects with all of the different clinical users, so it's research investigators, but it's also the pharmacists, and the nurses, and the dieticians who have to execute care the way they would do in an in-patient or out-patient care facility. And so as they present their information requirements, our department works to help them articulate those information requirements, helps them to… helps us to match either vendor systems or potential capabilities for design of systems to meet those requirements, but more importantly, to see how those requirements affect the other areas and other players of a healthcare delivery system, so that no one is going off on a tangent by themselves. And we work, certainly, with users and customers because the system should serve the people who use it. It's not that it belongs to an information department.

But helping to reconcile differences of opinions and conflicting information requirements becomes important, especially when healthcare becomes complex, and information technology becomes complex. You need someone to balance and evaluate critically, and to look at when the systems are working well and when they're not, and what are the information flow requirements that need to happen. And maybe times in implementing information technology and in the field of informatics, it's not about the technology. It's about the workflow and it's about the way people do work. And it's difficult, it's very difficult to implement changes and innovation in the way we give care, and in the way we

Dr. Carol Romano   Nursing Informatics Pioneer Interview   Page **9** of **18**

communicate across disciplines. And I think the interdisciplinary information needs and requirements are in the future where we need to focus. Not in looking at one at a time, but in an aggregate, all sitting down at the table together, and saying, 'What are patient information needs, and how does that need to flow to and from each of the different players, and then how to we get systems to be developed to meet that need?'

So sometimes the difficult with technology is not about fitting the technology to our old practices. It's about, I think, transforming the technology and transforming the practice as an iterative process. And I think over the years it's become clearer and clearer to me that it's not that the computer is bad, and it's not that the people who can't use it, or don't want to use it, or have trouble accepting it are bad. I think it's just a transition process that we have to recognize that there are things that we need to do in this interaction, and it's an ongoing process.

I used… people used to think, 'Well, you implement a system and you're done. You know, what are you going to do next?' And I've always said implementation is never a time-defined activity. If your systems are supposed to stay alive and continue to meet the changing needs of care and of practice, then you have this ongoing process, where new initiatives come forward and you reevaluate the technology capacity, and you change the technology, or you relook at the delivery processes and say, 'How can we make them better? How can we streamline them? How can we make them safer, in order to deliver better quality care?'

Interviewer: Who were some of the people that you've collaborated with?

Carol Romano: One of the disadvantages to being a pioneer or one of the first people in the field is that there aren't a lot of footsteps to follow. And so, therefore, I think in my own career what I'd have to do is identify nursing leaders who had vision about the potential for the field, and the opportunities that technology and informatics could hold for developing nursing. Of particular note is Bernice Ferguson, who was a chief nurse at the time, who I think

was the leader of one of the first implementations of a clinical system for nursing. When… usually, when technology is implemented, it's usually the lab, or medical orders, or something that's non… not too, too much of an impact on nurses.   What was different at NIH is Bernice insisted that nursing play a critical role in leading the implementation, and that nursing components be live day one when the systems were installed. And so I think her, her vision, not only I think role model, leadership for me in my own career, but I think certainly set forth the expectation that innovations are good, that nursing leadership is appropriate and important, and that it needs to be asserted. If not given the opportunity, then one needs to take the opportunity.

I also think that from an educational perspective, Dr. Barbara Heller, who was the Dean at the University of Maryland at the time we had created the first curriculum in informatics. And I think it takes vision for a dean to say there's a new program, and education needs to be responsive to the changes that are occurring in the practice. And so there have been many educational leaders. I think Dr. Heller was one that I think I worked directly with, and would not have been able, certainly, to implement the curriculum as a co-architect without her commitment to do that.

I, I also think that there were many nurses who were involved in informatics about the same time that I was. And so at some of the early conferences or meetings, there was sort of a networking that was supportive by being able to interact in an ongoing, or even if we'd meet, I think, maybe once or twice a year, there was this bond, and this shared area of concern. And Rita Zielstorff, Virginia Saba, Judy Ozbolt, just to name a few, were people that had been interested in working in the field, and I think we were introduced to each other through the literature, because in 1981, NIH sponsored the first National Conference on Computer Technology in Nursing. And we were interested in sharing the NIH experience, which was the reason we had decided to plan the conference, and we had done it as an effort with the military, because at the time, the tri-services were putting together the electronic record for the military systems, and with HRSA, Human… the agency for healthcare…

Interviewer:

Carol Romano: And we were also worked… we also worked with HRSA. So the three organizations co-sponsored a conference to share our experiences from the perspective of what kinds of grants were being funded at the time, what was the military doing, and what was the federal government doing at NIH. When we planned the conference, we went to the literature, and we looked at who was publishing in the field, and there were very few people, but the people whose name… people whose names appeared more than one we invited as speakers on the program, and so half the program was external speakers, and half the program was our reporting the federal work. And we thought we would get maybe a hundred people, and this was 1981. And… so sent a brochure out, and I think to all the schools of nursing, and to public health agencies, and we were shocked to get a thousand people come to the conference. We just… we could not believe it. So we filled two auditoriums and we had teleconferencing at the time, and it was, I think, one of the first interactions where those groups of people came together saying, 'I didn't know anyone else was doing this.' And that was a common theme.

And I think it was interesting because in 1981, the micro computers were becoming available in homes. So people were owning them, and they knew a little bit about computers, and…

[change tape]

Carol Romano: So in 1981, we decided to share the NIH experience by holding a conference, and we didn't know exactly how many people would be interested, but we sent invitations and brochures to schools of nursing and public health agencies, and we had an auditorium planned. And we were shocked, because we got over a thousand applications to attend the conference, and we actually had people on waiting lists. What I think happened in 1981 is the micro computer became available and people were using them in their homes. So

there were more people who knew that there was a computer, and making asking, 'Well, what can I do with this in my… in healthcare?'

There was also a group of nurses out there who were, as we were doing at NIH, either beginning to talk about, or using computers in their practice in some… in some way. And they were asking, 'Where do I go to get information?' And when they saw the brochure, there was this, 'I didn't know anyone else was doing this.' And so they wanted to come to this conference to dialogue and see what was going on.

It was a one-day conference. It was very well received. We had published the proceedings, and we did a government publication on that at the time. And we just had… I don't know how many thousands of copies we printed, but we had sent copies to libraries, because even when it was out of print, we still had people asking for the proceedings of the conference. So the idea of the information being available and the idea of people coming together to discuss common needs, was really very surprising, but very interesting because it directed the next… at least the next decade at NIH of, of how we address the information sharing.

For the 10 years between '81 and '91, we had held six national conferences, and we published the proceedings from the first two, and then we worked with the, the new journal at the time, *Computers and Nursing*, and we had a agreed… I sat on the editorial board of that, and we had negotiated to publish the… all the papers from the conference in the journals, in the *Computers and Nursing Journal* as a special issue every time we had a conference.

We started every year to have the conference, and then it went to every two years, and then every three years, and it just became just… this was sort of other duties as assigned in terms of my work. But it… we had stopped the conferences because the symposium for medical… or Computer Applications in Medical Care also began their sessions in '81 with nursing and Virginia Saba. And, actually, Virginia was on our planning committee

at NIH, and so some of the papers that were presented there we had advised in terms of setting up some of the first nursing sessions at AMIA. And… So then the SCAMC, the precursor to AMIA became the networking forum for people to meet, and so then we stopped having the NIH conferences.

Interviewer: How did that first conference help shape the next decade?

Carol Romano: Well, I think… when I say it helped shape the next decade, I think it, it, it presented the need that nurses are in this field and they're interested, that they need to come together and share information at conferences. There needs to be papers for people who can't come to the conferences to read about. And there needs to be a forum where they can come and talk with each other to share the concerns, the questions, because the information wasn't in the literature yet.

And so when I think… when I say it shaped, I think the, the need for what nurses had to do, I think, became very visible when we had that conference. And I guess one goes with… you know, what does the customer express as… you know, there's a void here, and that's what we tried to meet. And I think that NIH just sort of kicked-off. It wasn't the only conference. There were other conferences that were beginning at the time, but I think that this was a large-scale one. And because it was federal, people wanted to know how federal dollars were being spent, and what leadership NIH was showing in this area.

So I think a lot of the things that we've continued, and I think the things that really direct and define a specialty started there—the idea of special interest groups, the idea of a body of knowledge, the idea of a focused area of practice. Although we didn't talk about scope of practice, we did talk to each other about, 'Well, what do you do? And what do you call it?' I remember going to a meeting one time where a group of nurses sat around the table, and everyone introduced themselves and their title. And I wrote them down. There were like 50 different titles. I mean, the nurses were basically doing more or less the same thing. Some were doing more than others, but there was a continuum, but there was

still a set of activities. And I think we were struggling for what you call this, because we didn't have the language of an informatics nurse. And so it was Computer Nurse Analyst, and Computer Training Analyst, or Nurse… Computer Nurse, and a… just a variety of terms, and I think we were struggling for that.

So I think the field evolved, and… there's good and bad to being part of that. You don't have the footsteps when you've created so you go through the struggles. But it also, I think, helps to direct what don't we have, and why don't we have it. Like, 'We don't have an education program.' 'Well, why don't we have one, and what do we need to put it together?'

From my own personal experience, I had… I was in graduate school, and then I went on to my doctorate. And there wasn't a curriculum, there wasn't an education program that I could go do, which is partly why I got interested in developing a curriculum because if you looked at… I looked at 'What were my information needs?

Interviewer: You were talking about the curriculum.

Carol Romano: When I looked at my own educational needs, I went to see where could I get information about informatics and, and what's been written in the field. And there wasn't very much there at all. And that became an incentive for me both to create the curriculum and work with the education programs, and also I felt the responsibility to begin to publish a lot. People were calling NIH and asking for information, and I was writing these long letters explaining things to people. And after awhile it was like this is very time-consuming. I need to put this in the literature and then just refer people. And so I… there wasn't any incentive to publish sort of in a… similar to an academic environment, but it became the only way that I can communicate and respond to all the people that were asking their government, 'How did you do this?' And what is going on at NIH? And how can it help to inform what we're doing?'

In addition to that, we also, besides holding conferences, I was also asked to do… people wanted to come and see. 'Let me… let me look at… what does it look like to have an electronic information system?' [siren]

Interviewer:

Carol Romano: When people became aware that NIH had a clinical system, I had lots of requests for tours, because nursing understood there were computers, and then there was the stuff they were doing. And how, how do you articulate that? What does it look like? And so it wasn't only clinicians. It was educators who said, 'You know, if we have to teach nurses about this, what does it look like?' And… so we would conduct tours, and we had internships, we had faculty from different schools come and spend some time with us so that they can understand how… the environment that they were preparing nurses to work in. And in the 80's, I would venture to say we would see… I would organize 3- to 400 site visits a year… visitors a year, just to be able to see the technology, the touch it, to do a demonstration, and then to go back and say, 'Okay, now, I have an idea. I can either learn it, or I understand what my hospital is doing, or I understand at least a model of how NIH created what they're doing.'

And we had a lot of people take the work that we did and then just mold it to their system, because technology… when people purchased software, they didn't actually buy content, and so this idea of starting from scratch to develop nurse… information that represents the practice of nursing is just… it's laborious. It was very time-consuming. And it's interesting, at NIH, when we implemented the computer system, we thought that in 5 to 10 years we would really be outdated and behind, you know, in terms of what needed to get done next. In fact, what we found out is that 10 years later, 1985 or so, there was still less than 5% of the hospitals in the country using this technology, and that even though our technology is aging I was still state-of-the-art and pretty avante gard in terms of the scope to which we defined the information content.

Interviewer: Lessons learned.

Carol Romano: Okay. From a leadership perspective, I think informatics has a lot of opportunity. When I reflect back on my own career, I'd have to say that leadership is about, you know, setting the vision, and then working toward accomplishing that, but being very clear on what the vision is. And in informatics, I think the vision is about the clinical needs of people and people care, and informatics is about meeting those needs through information. And I think that in the technology field it's very easy to get sidetracked by the latest, you know, lights and whistles… buzzes and whistles and lights and, and whatever, and to get engrossed in learning about the technology and what its capacity is, and that's very important. But it's important as a leader to maintain the focus on what informatics is really intended to do. And as we look at information systems for nursing and for health care, we need to be ever cognizant of the fact that patients and people are part of that process, and that moving the technology to patients is just a matter of time, because as we give care to patients and give them ownership for their care, we have to give them ownership of their information and the ability to manage it. And so the field as it's moving has to keep… maintain that focus.

So for leadership, I think it's, it's very difficult to get distracted by the politics, by the technology, by the struggles and the transitions that are important in moving change forward, and that leaders need to maintain the vision and they need to develop the skills to working with and developing partnerships and collaborations with many stakeholders, because no one can do… no one can transform healthcare alone. I think nurses play a leadership role, and I think it's important for leaders to recognize how important the role for nursing is, because we are the, the discipline that advocates for the patient, and that articulates those needs to other policymakers, administrators, and other disciplines who see the compartmentalization of the care that they give.

Interviewer: Do you get to influence policy at the NIH?

Carol Romano: I think in my role at NIH, I serve as the chief informatics nurse voice for clinical systems that are put forward. And as we develop at the… and this is at the… at the clinical program area. I think as we move forward to ask the question, 'How does the clinical data that we collect at the bedside fuel the research so that one collects data clinically that can be used for research, as opposed to… in the normal healthcare delivery process, research data collection as a separate information activity?' And as we're looking at creating those processes, I think the… I get the opportunity and the ability to, to frame how that information is structured so that it can move into a warehouse or a repository that could be tapped for future use. I get the opportunity speak to and for the need for standardization of languages and terminology for the ability… so that we have the ability to extract and analyst the information on other dimensions.

Interviewer: What have you enjoyed the most about your career?

Carol Romano: What I've enjoyed most about my career I think is having had the opportunity to create the future, to work on innovative things that are important. And for myself, my job is to improve the health of the nation. That's a very empowering kind of mission. And I think of when you think of the bigger picture, you tend to deal with, I think, the day-to-day activities or aggravations, recognizing that there's a bigger picture that I'm trying to accomplish. And I think having had the opportunity to work at NIH, where it's an environment of innovation and an environment of trying new things, evaluating them, moving on, has been a gift, has been a gift.

I think… I've also had the opportunity to grow and learn. And the knowledge in this field is just exploding. If anything, it's just very difficult to keep up. But I think the opportunity learn and grow has always been important to me, and I think has help… kept me invigorated, and I think eager to continue to contribute to the field and to the profession.

End of Interview

Dr. Carol Romano   Nursing Informatics Pioneer Interview   Page **18** of **18**