

AACP: Embracing the PBRN Model to Improve the Medication Use Process  
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### **How a Network is Born**

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**Earlene Lipowski:** Last night after the formal presentations, and one of the big topics of conversation is how do you get people to join the network? What makes people want to do this? And I guess a lot of our conversation revolve around a sales job of having someone with a lot of enthusiasm go in there and just really fire up practitioners to join the network. And Dr. Mold is sort of—I'm ready to join his network. And he takes it entirely different. It's not a high-pressured sales pitch. But I think he's given us a lot of things to think about in terms of do the right thing and then we'll come together and we'll meet around our common goal and our common interest.

We're still flying at a pretty high level. And there's still a lot of questions. We have some idea that we can tackle this problem if we put our energies and our focus in the right place and we gather the right people together, but I still want to know more about the nuts and bolts, the day-to-day. How do you start from the beginning and what are the kinds of decisions and steps that you take to really build a series of studies in a successful network? And that's why we've asked Grace Kuo to join us. Grace is program director for the practice-based research network that's based at Baylor College of Medicine. It's unique because she's a PharmD trained individual who was tapped for this position. So she's affiliated with—she's an assistant professor of family and community practice—community medicine. She has seven healthcare organizations, seven members in the greater Houston area. Fairly small regional area. That total accounts for 30 clinics. There are 300 primary care clinicians. And close to a million, 980,000, patient encounters annually. So Grace is going to talk with us about her experiences in actually getting some studies up and running. So, Grace, welcome.

**Grace Kuo:** Thank you, Earlene, Ken, Lucinda, and conference planning committee. It's a pleasure to be here. Thank you for inviting me here to tell our story at SPUR-Net. And I will also want to tell you, this is such a great pleasure for me to meet with so many of you who have many years of experience doing practice-based research. And this title was assigned to me "How a Network is born and grows to Maturity". If you ask me, I don't think I'm qualified to give this particular talk. What I can tell you is how we are—about our growing process and I hope that a little bit of the information about the administrative cores that I primarily work in, will be helpful to you.

SPUR-Net stands for—this is an acronym—Southern Primary Care Urban Research Network. We were trying to be very inclusive and so we actually had a bet in our organization when we first started, and one of the staff in our department came up with this acronym. And we loved it very much until my IT manager told me when we were trying to come up with a name for our Web site, to say never do [www.spur](http://www.spur) something because it actually will lead to some other sites

that I never really want to visit. And so I just kind of believed him. And I said, “Oh, okay.” And then we were wrestled with this trademark sort of concern. And so we had to have our legal person at Baylor College of Medicine try to find out about copyright issues because of the Spurs team in San Antonio. And when we trademarked something we needed to know from the legal end that we were well protected. And so I learned a lot through that process.

Well, SPUR-Net was born as a strategic effort from our department. Our department chair had a great vision. And of course what was very helpful at the time, about 1999, about 2000, was that both HRSA and AHRQ, as Dr. Mold had just mentioned, were both very interested in funding primary care research and infrastructure. And nowadays that I think it’s becoming harder and more challenging to get money funding just for the infrastructure without a research project. But we started out that way. And that was actually before I was recruited. I started in 2001 and started to serve as a project director and later became a program director. And so we had a number of faculty members, over about 100, working in the community setting, community clinics, and also we had preceptors who precepted our medical students. And so those were the folks that we went to recruit as the first round. And then we gradually expanded our network.

So with the two funding support sources from HRSA and AHRQ we were born. And we were very, very fortunate. And we had, I think the two combined together about \$600,000 as a startup fund. And so we had a dream team. We assembled researchers. We had clinicians. We had the infrastructure, the administrative core within the department. We also tried to engage the community in a way to sort of share this vision with them. And of course one of the first things we had to do, a physician colleague of mine and I, we drove all over town around Houston. Now I was pretty new to Houston at the time and so it was a great sightseeing tour for me every week. We would go out and visit a clinic, and we would get about three, if I have to categorize, three types of responses from our physicians. They would say, “Oh, we love the idea. We know what it’s like,” because Houston has two medical schools and there are a lot of clinical trials going around. And many researchers from other disciplines would go to primary care clinics to gain access to patients. And so they said, “Well, we know what research is about, but you know, we’ve been used so often. We are so used to having researchers come, researchers go. They come for a few months. They do this intervention. Then they pack up, they leave. And so what do we gain from that?” And then we have a second type of people that would say, “Well, I’m interested, but I just can’t afford to be involved.” And, in fact, this theme came across every single place that we went to visit because they would say, “Well, we’re very busy. We only have 10, 15 minutes per patient.” And I think for pharmacists too we only have a couple of minutes to in the community setting, in the hospital setting, in the nursing home setting, to review the medications, to provide counseling, how can you add even one minute per patient’s time or per prescription to fill out this survey?

It was just very—almost impossible, even though they loved the idea. And so because of that, from the get-go, we made a commitment, a pretty strong commitment, maybe a commitment sometimes it was very hard for us to live up to, and that was to always trying to provide a research person on-site to help with the effort, whether it be providing or filling out the survey, shadowing the clinicians, and then fill out the bubbles, or in trying to sort of translate some sort of intervention in the clinic. And then we got the third type of responses, and that is they never even return any phone call or emails and then we knew perhaps they were not interested.

So in 2000, and SPUR-Net is right, you know, where Houston is located, so we're very fortunate to have received the first round of funding from AHRQ for PBRNs. Then we got the second round of PBRN funding for a different type of project. During the first round we were all required to do a survey. It's called a PRINS survey, that was based on the NAMCS survey. And the article was just recently published in the *Annals of Family Medicine*. It was a description of all these—the first 19 PBRNs, the physician demographics, and also patient demographics.

Now I've included for you here on this slide the requirements of a PBRN according to AHRQ. And that is a network must be—must have at least 15 practices and/or 15 clinicians in the network that's devoted to primary care practice. That's AHRQ's definition. Of course, AHRQ's primary focus is in primary care. Location is within the U.S. and has a structure that transcends over and beyond just one particular study. You don't form a PBRN for one project and then dissolve that PBRN, then you restart again depending on what it is. What they're looking for is to have a consistent infrastructure that will provide a structure that will transcend beyond one single study and that it's very important to have a mission for research endeavor. You need to have a director. You need to have at least one support personnel. And also you need to have a mechanism where you can get community feedback, whether it be community physicians, community clinicians, community patients. You need to have a feedback for doing that.

I've added one slide that's not in your handout, and that is from the NIH that clinical research network has certain requirements also set up by the NIH, and that is you also need to have a research mission. You need to have scientific leadership. And, of course, I think this is where PBRN is so helpful as a clinician to see that the clinicians can help develop research ideas, not just those from the “scientific” core. But the two really have to work together in order to continue to generate ideas that's scientifically sound and translatable. Multi-study capability beyond one particular study is also important. And, in fact, they say you need to, as a network, have already published two studies in order to be registered as a CRN or a clinical research network. And that you need to include at least three independent entities in your organization, like the 15 practices or practitioners.

So for us at SPUR-Net when we first started out, our mission was to improve the quality of healthcare in primary care settings. We did not bound ourselves necessarily within the Houston area, even though when we first started all of our projects were about the patients or clinics or about the clinical sort of processes of care in Houston. Later on we added the safety component as well because we had several safety—patient safety initiatives. So we wanted to make sure that both quality and safety were included. And we wanted to identify and solve problems that are very common in our practices and also to have a mechanism so that we can have short-cycled research. And one of the reasons is because when we started, all the grants that we had were very short-lived. So in one year's time we had to do this PRN study and we had to figure out a way to do it. And maybe in the middle of the year we would get another grant or maybe towards the—before the end of that year we have to be thinking about writing for another grant. And so we had to in the process of growing up how to figure out a mechanism to do that.

And also the research projects, we wanted to have a way to maximize the way we collect data. So because of that, from the beginning we worked with the IT professionals in different

organizations with our members to figure out a way that we can do that, to also avoid disruption of patient services, I've already mentioned about it. So we had to be pretty innovative. And the methods may change from project to project, depending on the level and extent of data collection.

And this is just my humble drawing to illustrate how our organization, the administrative core, will work with all these different committees. Some of the elements are common for a lot of the practice-based research networks. It's certainly not the only way. But this is one case example at SPUR-Net. So I serve in the administrative infrastructure core. When I first started out I was actually in the scientific advisory core. And this particular group in the administration core will work with all these different committees to bring ideas together, perhaps we will have a research idea from a researcher. Then we have the idea screened by the administrators and also by the scientific advisory. We try then to work with the clinician committee. If a project is very good, even with funding already available, if our clinicians do not have the buy-in, if I cannot find a physician champion, then we will not be able to continue with that particular project. And then some of the times we also have to work with the patients. And I'll give you an example a little later of how patients can be very helpful to our research and I've already mentioned about the information systems, the IT folks, are also very important.

So as of now, and we continue to grow, depending on what opportunities are out there and sometimes people are very interested once they hear about practice-based research, even for practitioners if they know about friends' friends, they will be interested in this particular concept. For us our recruitment strategy is top down, even though our research ideas could be bubbling up from the practitioners or from the researchers or both clinicians and the researchers, but the way we recruited members are all based on organizations and clinics. So for example we went to a managed care organization that has 16 different clinics in Houston. We shared the vision with them. They are very interested in wanting to collaborate. And so once we had the administrators buy-in then all—we had then the freedom or their endorsement to go and meet with their clinic directors, with their clinicians during their staff meetings, to share about this vision or different projects that we have available for our network.

So currently we have about 30 clinics, actually about 36, depending on which particular projects; they may or may not participate all at the same time. And we have about 200 some physicians, so and all together with some of the researchers we do have over 300 members in our network at this time. And the composition of our network members are half of them are family physicians, a quarter of them are pediatricians, and another 25% are general internists. And together we serve about a million patient visits per year. So that is a very rich sort of data set that we work with.

All the clinics are within probably about 40 minute drive (without heavy traffic) in the metropolitan Houston area. So that makes it a lot easier. And that's why we could make the commitment of sending out a research assistant to the different clinics for each particular project. Now this may be difficult in some other geographical locations when the clinics are far away. And so there are other models for this, but this is the case example from SPUR-Net in Houston.

So far we have had affiliations with the AHRQ because our main sources of funding to about a few years ago were all from AHRQ. And so we're registered with the AHRQ sponsored PBRN resource center as a PBRN. We are also a member of the Federation of Practice-Based Research

Networks from the American Academy of Family Physicians Organization. We're also registered as a NIH clinical research network because we qualify for the criteria. And we're a member of Prime Net. So we have a PBRN in Houston. We were asked by the PBRN in New Mexico to collaborate with them and with another PBRN in Colorado and another PBRN in Georgia, another PBRN in Northern California. So all of us, the few PBRNs are combining our forces to reach out to multi-ethnic patient-based research. And this is one of the NIH Roadmap efforts. So it's very exciting to have that kind of collaboration and network.

So as I've already mentioned, serving in the administrative support role, I help with the bylaws, the policies. We have to figure out what membership criteria to set for SPUR-Net. We also have certain policies as to how we review the concept papers, to have certain flow for project management and collaboration. When we first started, the first two or three years, we did research only within our department and our community partners. As many of you know, the reality of research in the academic setting is that you wax and wane, depending on the funding cycle. And so we've gone through our valley. And during that valley time one of the plus things about PBRNs is that we collaborate and network. We invited Dr. Hickner and Dr. Mold to come to SPUR-Net to give us consultation because we at that time did not know whether we could continue to exist and the college was going through a lot of changes also.

And so we learned then from our consultants, well, you know, look they're from outside of Houston, but they have such a great insights. They pointed out certain things and say, "Look, you have two medical schools here. You have tons of researchers, not just in primary care but in specialty. Perhaps there will be some common interests that you want to explore and look into." And so when we started doing that, we of course had requests from some of the researchers in Houston area who did not meet our mission statement. For example, they wanted to do research to compare how a specialist take care of patients versus primary care and or other topics that were not exactly of our interest. And we had to think hard about how that may go with our members' interests. And so once we tried to open that up, now we are pretty happy. And, in fact, I'm just overwhelmed with a lot of opportunities that opened up collaborating with other people in Baylor, also with UT, and also with MD Anderson, and now you've seen with other states, PBRNs, throughout other regions as well.

Now I also help facilitate the IRB process. Can you imagine, with one simple survey we have to go through five different boards. And it's really time consuming. And so sometimes, you know, depending on the level of the type of project, we have to write in the first three months as the project preparation time for IRB. And sometimes we even have to start that process when we submit the grant application. And then we have to—some of the other boards have this requirement, and that is they will not even review the protocol until Baylor's IRB had already approved it. And so that slows us down even further. And so now we've learned a mechanism in fact, we have to go and talk to the IRB folks, the chairs, because they were not familiar with practice-based research at Baylor, and then we had to go and talk to the individual organizations research committee boards and their chairman and just to say, well, how this process may be able to be changed. And, in fact, now the community county hospital district sort of mechanism has changed in that we could submit the application simultaneously and it has helped facilitate that process a whole lot for us.

And then we—I am involved in trying to put a screen for the different types of grant availabilities that project collaborations are trying to identify researchers that we can work with, the consultants that would be available that can be helpful. And it's truly an exciting sort of opportunity for us. And I know that many of you in your regions have a physician-based PBRN and I think it'll be very exciting to collaborate with them as well at this time.

Now this is from an article published in *Annals of Family Medicine* in 2005. And it gives us some basic idea about administrative cost, what you need to have basically if you want to have a basic network versus a moderate to complex network, the type of cost for the department or for the entity. And I projected in the yellow just about our dollars today what that may look like. And sometimes, you know, with the funding status, that range may change and shift anywhere in between, and it could be even more if your department has the resources to do so. But at least a director's time, at least 20% time, when we first started out I actually had 50% time the first half a year to a year's time. So it was very helpful for us. And a coordinator could be very helpful in setting up meetings, in coordinating projects. They almost serve as the project manager's role. Of course, each network has a different role for their coordinators. Some of them make certain meetings, recruit members, and so the coordinator's role can vary.

Research assistants usually are based on the different projects, and we train our research assistants so that they will be multitasking. They can do mixed methods, qualitative interviews, or focus groups. They also then would go and collect some of the qualitative data—quantitative data. And so it depends on the mix of the research assistants that you have to work with the researchers.

And then we also have a departmental subdivision research secretary. We actually have two of those. So it's very helpful to bring in resources that we need. Computers, technical support, printing, maintain cost are written in there and I think that's very important. Was it yesterday or sometime today there was a question about how you train the network, the community practitioners. One of the ways to do this is to have a convocation, a meeting where people will get together every so often. You can share about the results that from studies that they have participated in. You can also use that opportunity to train them about the IRB process or to have a time to dream about what you would like to do.

And, in fact, when we went to visit practitioners at their sites, when we talked with them, that was when we found out about the challenges, the problems that they encounter in their practice. We knew about the research interest that they have without having to ask them hard questions about, well, "What is your research agenda and what is your research question?" Just by knowing better about their practice and to be there at the clinic gave us a lot of insight.

Now we have to focus a little bit more about our research areas. And so for our department, for our group, for our SPUR-Net, we have researchers and clinicians who are interested in these areas, cancer prevention, chronic disease management, patient safety, and of course with it patient and physician relationships, the shared decision making, that process of making sort of that improvement in quality and care and safety of care is very important.

And sometimes the clinicians may have—may bubble up a research idea that's excellent. And we've done lit search and we identify that area. Then we'll go and apply for funding. And sometimes unfortunately the funding may not come through. So in that particular case sometimes it'll be good for us to generate some seed money or seed funding if that's available to have a smaller pilot studies. So right now currently since 2000 we have received grants from AHRQ, from HRSA, from NIH, from CDC, from AFP about—a little over 2% are from industry, pharmaceutical industries. And all together we have \$8.5 million. And these are not the total costs either. These are the costs, let's say for example, if we were collaborating with another organization, let's say UT or MD Anderson, we will get the cost that I included here as the portion that was due to the department or to SPUR-Net also.

And we've completed several studies. I don't want to take the time to go over all of them. I do want to point out some of them just to let you know how these projects came about. So for example, the microalbumin screening study came about as a pilot study. And one of the clinicians' organization they had been giving the physicians some report cards. So every month or every quarter they'll get an idea of how well they're doing, are they ordering microalbuminuria tests or not.

And so then when we were talking we finally realized that, well, this other organization clinicians do not ever have a report card. And then this other organization had a performance indicator that did not include microalbuminuria but that included hemoglobin A1c. And so because of that we said, "Okay, well let's just do a feasibility pilot study. Let's see how our IT folks can work together and how our research assistants can work together." And so because of that idea we just went to the clinics, collected the data, and we found discrepancies between what the computerized database says and what the actual chart says. So we actually had to verify the information that we collected from the computer-based sort of programming data versus the real data when you do the chart review.

And then we also found out that the method of the first way of having a report card actually did not make a big difference. It was not significantly so. Nevertheless, we found out that discrepancies, or the discrepancies we found in the first part was partly due to not having the clinical endpoint, the variable translatable or dumped into the database. And so we had to fix that problem. And then also we found out since the organizations have different methods of doing the sort of feedback or no feedback, that perhaps quality improvement in a way, depending on how you look at it, may or may not matter. But the only way to really know is to go and do a study, but then also to learn a better way, the best way to organize this effort for our clinicians.

And the primary care network survey, the PBRN survey, was the one that I told you about. It's a description about all the networks. And so in one year's time we have about two or three months in the beginning to sort of go to all the networks to get all the approvals, to have the IRBs all set, set up, and then in six months' time we had shuttled clinicians in 24 different clinics to gather patient encounters, 1,500 of them. And so it was very challenging. I had two research assistants who were very enthusiastic. We always learned a lot from them. And to collect that information once we had the information we'd write it in in our grant proposals in the years to come and trying to update that information periodically whenever we can.

The example of herbal use survey is also another pilot study when we first started. And we were, I was interested in that particular study because herbal use was a hot topic at the time. We didn't know whether this was a problem that we encounter in our clinics for our patient. So we went to the clinics who wanted to conduct the study. And I'd like to give this, one of my favorite stories, of learning from our patients.

We took the survey forms to our patient advisory group. And one of the groups, the feedback came back from downtown Houston area and said, "You know, we really love to help you with this survey, but when we hear the term herb we think about marijuana." And it dawned on me, "Oh, you know, herb has different meanings to everybody." And so then we had to revise our forms in order to collect the data we wanted to collect. So patients have great wonderful insights for us.

And also one of the sites we went to is a county hospital district clinics. We were, every patient that we talked to just said, "Oh, no, we're not using any herbs or any complementary alternatives." We said, "We have to change our language." One of the nurses there told my research assistant and said, "You know, so many of our patients are taking them." And my research assistant goes, "But nobody told me so." So the nurse asked my research assistant how she was asking patients the question. And so the nurse says, "Oh, no, you've got it all wrong. You have to ask them what do you take when you run out of your prescription medications for your hypertension or for your diabetes?" And so we learned from the community and they have great insights for us too.

Then the compliance with ATP-III lipid management guidelines was one that we received funding to do cluster randomization. We designed the EMR forms to put the ATP-III guidelines right in the electronic medical records system. And then we also had a reporting program and we randomized just four clinics into this particular feasibility study to compare the performance and the rate of screening in managing our patients with hyperlipidemia.

We had the Project CONNECT and the STOP Worry projects that did not come from SPUR-Net initially but it was a collaborative effort because researchers in the Baylor campus wanted to—they had received funding and wanted to have some collaborative opportunities with SPUR-Net. And we reviewed their project aim and we also agreed that the methodology was very feasible and fits our aim and our mission. So we conducted those projects.

I actually received a grant to conduct the study to compare the effects of EMR on medication safety in the primary care clinics. And one of the first things that we discovered when we went to recruit our members in the first round, about was that there were clinicians that knew they were being recruited from different organizations. So they automatically sort of told us and compared and said, "You know, I heard that this other clinic is starting to use EMR. And, you know, I'm not—I think that will be wonderful. I wish we had one." And then we will go the clinic that were using EMR and those clinicians would tell us, "You know, since we started EMR our lives have become so miserable. It's taking a long time to fill out the forms and to complete the charts. I have to stay overtime and I have to have work done at home." And so I was just intrigued about the feedback they told us. So of course we were very fortunate to have funding resources to compare that.

And then we have this—the first one is physician uncertainty reduction for hypertension control from NIH. And in that particular study we are combining efforts between the clinicians and patients. So it's a very heavy sort of patient centered driven research project. And first ever that we are doing intervention based instead of like a survey or just to know what's going on in our networks.

Then I also received another funding from NIH to assess the effect of health literacy on medication safety. And so in that particular study we're also again using the mixed methods, both the qualitative and the quantitative methods, to find out from our patients and then to also review charts, to talk with our clinicians about the type of medication errors, and the type of things that they would prefer that we do better for our patients.

We recently have also - not SPUR-Net, but SPUR-Net is a part of the CERT funded by AHRQ in the Houston area. So we're pretty excited about that. To find a good way to disseminate information from the FDA, especially black box warnings into the practices. And as a result, in this process of becoming sort of better at doing practice-based research, I became a clinical researcher. When I first started and was , I was really recruited to do more administrative tasks. And because I'm just so inspired by working with researchers who have such a great passion for practice-based research, I looked at my own career training up to that point of becoming a clinician, not knowing what to do with research, and I had done pharmacology research working with animal models, hypertensive models, and I got hypertensive too as a result. And I concluded that rat-based—I shouldn't say that—that laboratory-based research was not for me. But then I didn't know what I could do in terms of research in the clinical, you know, my practice-based realm. And Dr. Hickner, Dr. Mold, they're my KOA mentors, clinical scientists and mentors, and they guide me through the different opportunities to do projects and just to be inspired. And I know that next year perhaps, maybe before next year is up, I will be hearing stories from you about how your PBRN is born and continue and starts and continues to grow. Thank you.

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