

Patient Engagement – Mock GPC Project Orchestration  
Kim Kimminau leading patient engagement for GPC.

Blending the cultures of Informatics and Patient Engagement.

Bhargav Adagarla – Informatics KUMC

Janel – San Diego

Nancy Davin

Ann with PPRN – Patient Powered Resource Network – Parent Project Muscular Dystrophy.

Pam – UT San Antonio – ALS cohort research study coordinators – responsible for getting surveys out.

Milwaukee Dude

Sue Rogers – University of MO

Sue – Deb Moltor PEO

Kieran Pemberton – PE

Dominique – GPC assistance – sustainable

Andrea – UW Madison

Jim – University of Neb – I’m a recovering Emergency Physician and PI for PCORnet

Teresa Eversol – UT Dallas

Charlotte Jay – University of MO PEO

Liz Swanson – PEO University of Iowa

Debra Hendricks – PEO

David Ruford – UT Health Science Center San Antonio – nurse but works with data Dr. Hale

Andrea – PEO at PCORnet – focus on PPRN in phase 2 what does it mean to be a network and how can others collaborate.

Kelsey – CMH PEO – coordinate weight management cohort.

Deb Meyer – Research advocate office at University of Neb.

This morning our goal is to try to further clarify this new found roll for PE officers – label now not a clear roll. Not sure what this roll is yet. Struggled with this in the first round of funding. Lots of work to get

done without a clear vision. No job description – still trying to explore what the roles are and bring value to the organization. Haven't clarified all rolls. Goal is to walk through a mock process to put more structure around the roll. Roll playing of info-metician and investigator. You've been asked to come to the table as a patient and coordinator. Do a pretend session. First development meeting. Bringing all organizers together. Infomatician, researcher, play out how we might interpret each perspective. Try to shed light on each roll. Explore what our concerns and questions are. Get to pivotal questions. Every time someone knocks on the data door, they also knock on the patient engagement door. Come up with fundamental principles to bring to the GPC. PPRN's can say, this is what we have learned already, here is an important piece. Leave today with a common direction for key steps that need to be in place regardless of the institution. This is a great opportunity to imbed this patient experience in the process. Say to the PI's and Data guys, here is how this should go. PEO go between the patient and data person. We need to discuss how the PEO fits in. Translate where the science fits in with the patient. WE don't want to through you into the deep end of the pool but we don't want to hold your hand as well.

PE from project inception to key questions to start with, make this a continuous process. Continuous loop. Have we thought about the administrative structure – health centers are strange organizations, who pays your salary, is there a formal office? WE need to go back to institutions to sell this position. How do you gauge success? We don't know how to do this. There are lots of ideas. DJo and Cheryl at Children's Mercy Hospital –

How do we get research engaged with patients? Needing a bridge between the clinical side and the research side. We have access to patients and research on the same campus. A lot of patient engagement officers and they do their community work. It's a different kind of engagement with their community. How do you deal with patients coming off and on with a trial? Most important thing within the first phase was calling this out on the table to begin with. Very passionate feelings because of the relationships with the community that have been forged and the lake of trust in the research community. Tug of war between patient engagement and community engagement. Doing a workshop next month on defining community engagement and patient engagement.

You represent patient voice, we need your input and want to hear ideas. At the same time there is research. How do you maintain the trust with the patient? How do you maintain that trust?

This is going to be a broad role that will involve a lot of work. Is it a full FTE? No, storm a little bit this get back to reality. Want us to talk about the rolls, try it out, how can I do this at my institution. Get to the reality check. Told it would be 5% of my position. If we look at those positions, we stay in a box.

Capture cares and concerns, put a job description around it, what do the roles look like. ½ hour to work in your group.

Patient advocates in one group.

PEO – in one group

Data geek – one roll.

Drive the research questions – PPRN join Jim. WE want to build into the group and include ree

Patient Engagement Officers Group –

Job Description? – VolunTold – Do we have groups of patients already?

Met with patients and asked them for input on how we bridge that gap. Group of 120 volunteers divided into 14 different areas of engagement. One that deals with medical records – one that deals with myChart. Work with patients and families on how myChart works. Want to use myChart to reach out to patients, but roadblock – we don't want them to perceive that we are using their information for research.

Do all of our institutions have this person in some shape or form – loosely... 5-10% effort, if someone is already doing this, support that person and get them into the GPC. That person typically doesn't work on the research end. Can we add that to someone that is already in patient engagement? Don't want to reinvent the wheel. Patient engagement is difficult. Relationships that are personal and take time to establish.

Phase 1 we had patients last year to participate – Breast cancer and ALS person. We reached out to people that were interested. We contacted them through the clinic. Asked the clinic if they had patients that were interested in this. There was no communication back to them about what the patients were being asked to do. A big responsibility was to keep them in the loop. Researchers don't have any plan to follow up with the patients. A big role is to keep the PEO and the patient informed of the results. PI's need to be educated on communication. PI's have the great idea but don't want to keep the community informed. How do you bridge clinical research with patient engagement? Start with people that are already involved with research and then the next time around they would be more willing. Next time you do your study you need to do this. Part of the research advocates job duties. Have to start with logistics and current research studies –

University of MO – covers a large area – people from long distances come to see specialty doctors. Recruiting people from the cardiology clinic and they are driving a long time. Sometimes spending the night – we want them to come back for research study – coordinate doctor visit with research and fasting and blood draw. Research silo, clinical care silo, and then we have the patient silo. WE need to make walk ways between silos.

Community Navigator – this role is a great addition for the navigator. Good position to leverage. RSA – in touch with the patient. How are we going to get in touch with the community unless we tap into the community? Navigators and community health advocates. Public health student that can help you do the mapping. Meet with them constantly.

Keep them engaged, keep meeting with the groups. Bring in speakers. PEO's roles for just PCORi?

Very much in the CTSA group as opposed.

What are we doing for recruiting both for research studies and patients?

Come up with a job description for Patient advocate – That will take an FTE. Come up with how this is done.

Constantly doing new orientation but work with champions that are in the community. CMH works with El Centro – she looks at the materials to hand out to the community to decide if this is good.

#### Job Description

- Patient champion – which the community likes. Different facets of the community.
- Identify community health issues
- Bridging the research with the community
- Liaison between community and research
- Engage and communicate and educate
- Closing the loop in the process
- Maximize existing network/relationships

All the different groups came back together to present roles.

Jim – Research question they want to study.

WE have Duchene – look at incidents with anxiety disorder and OCD.

It's basically junk until you turn it into information.

Envision PE coming into play.

Do you have an IRB protocol? Once we have that we can give you the data. Can you give him an overall number to know if we have what we need to do the study? Give a practical research number before you go forward. One can run that themselves to see this. He can give you some of the parameters of the information that I will provide.

Qualify – researchers are very specific. Ask an actual research questions. Collect these patients into their network, take the IRB out of it, ask the patients directly. The patients volunteer to give you that information. Once we contact the patient, you can ask the patient to provide that information. How do you get the patient information? How did you identify the patient?

Step 1 and 2 were skipped – How does this affect the community? The PEO's should be going to the investigators to say, this is important to the community.

Typically in the academic/medical community the investigator starts the research. Figures out the finesse of the research and then they fill out the details. Researchers are the center of the universe, then they go out and look for who /what is available. Traditional model – sun and all of us plants. What has happened in GPC 1.0, the investigator in the middle and the planets around it?

WE need to come up with ways to adjust and change the dynamic.

AS an investigator, I investigate where the light is brightest. I can't come up with a research protocol that is easiest for me to do and get funded. Struggling to get people involved. Breast cancer has a population. Questions come from where they can have the best results.

PEO – Where is space for PEO to change this dynamic. How do we get more attention and focus to get this world engaged? We struggle with the overlap. The biggest points of identifying community champions. It's either research idea or community idea. How do these circles overlap? Kept coming back to community champions – someone came to you and said, I'm looking for this set of people. Someone who can identify groups that are needed. Bring the researcher to the community members and this is the concerns that we have. WE need to educate the community.

PCORi is asking for patients that have lived with this disease. WE need to go to them. If you haven't lived it then you can't think about what is going on with it. If a researcher is research this particular disease they need to work with patients/families that have lived with this disease.

The point is, there is no step that isn't important. We start with the investigator, but how do you get all of them to work together. The researcher needs to go to the PEO first. PEO is connected with all the groups. Patients should drive the research?

We want a norm to accept the fact and engage the community. Can we make a standard practice, adopt a way, researcher's come through GPC to work with the PEO at their institution first and then bring that forward to GPC wide group. We can activate as GPC if they work together. Maybe

11:00 –

PPRN's and CDRN's – what does it mean to be a network and collaborate.

PPRNs: Experts in Patient Engagement. Rich relationships with community members and leaders. Valuable outreach in communities and recruitment. Help define patient outcomes. Resources for engagement with a common infrastructure. Effective messaging, access to effective partners, training materials and tools, PPRN to conduct qualitative research.

CDRNs – help with analyses and recruitment

Trusted providers, methods specialties statistical analysis and compare demographics. Computable phenotype – CDRN want to access populations for PPRNs. Computable phenotype – Algorithm or logical thinking used to find that population. What other features would lend itself to this research. Narrow it down by all males, this age. Not just something we talk about, it gets down to the point to write a computer program to pull the data. If it's not in the database it can't be searched. It could be that it's in other kinds of records. Med Records and Billing systems. Need other characteristics to define the population and narrow the search.

The goal for phase 2 that many of the diseases are sharing their code and makes it identifiable. The CDRN network can identify populations. Value to PPRN and CDRN to compare and validate.

PPRN incentives – CDRN incentives – Pull from PowerPoint.

Summarize – this session is talking about PPRN and CDRN relationship and how do we build this. PCORnet is building that infrastructure. Hopefully it will be brought to you. Engagement infrastructure. GPC has that down more than other networks. Based on network science and sustain that beyond this contract period.

Recipe that gives you the instructions on what to pull off the shelf to make the cake. Also tells you what you need on the shelf to make the cake. How do you identify a cake is a cake. How would you define a cake? Recipe book and each page is a type of cake.

Deb works with investigators and it people. We give them the story – want to do diabetes – she goes to the data person what type of diabetics do you want. Do you want rich data? Where does infrastructure across PCORnet come from? Right now there isn't a structure to test these, but they are being submitted through PCORnet.

How do you shop around – BKB.org flow chart – list for how to put together a query?

Babel site to upload phenotypes. – Phenotype knowledge base.

Jason – Vasculitis

Goals of V-PPRN – represents the joint efforts of the VCRC. Group of vasculitis doctors. Expand research and take down barriers in research. Who can join, anyone with diagnosis of vasculitis? Parents, caregiver – What is vasculitis – generic term – whole list of diseases. Rare diseases and geographically spread out. Research we've done is more from physician than patient. Collect at the clinic level, then sent to data base. Also need a paradigm shift.

TAPIR Trial – one form of vasculitis – 2 arms of the trial. Traditional and then Patient Centric.

Summary of Operations and Processes – patient learns of research recruitment – contacts and enrolls – signed medical release – physician agrees to dosage – patient goes back to website to.

GPC is helping them bring all the information together.

How do you get a project funded when you don't know how many patients you have? We have a general idea based off.

AS an advocate can I reassure that patients will only be contacted by my physician? They may be contacted, but primarily through their physician.

Next speaker – David Glidden from accelerated care iConquerMS PPRN.

Involved in a lot of activities to accelerate research towards a cure for MS. Planning a large clinical study, funded by pharmaceutical companies. Resource of patients; patient driven MS research. MS in the US today. Studies and therapeutics. Focus on immune response. Part of PCORnet. WE collaborate with all MS organizations.

Outcomes that matter most to people with MS. – Clinical trial outcomes often focus on walking, patients are more interested in other outcomes. Dashboard the patient sees. Upload health records and clinical data. Examples of what is occurring in the network. GPC-iCMS Mutual support – patient engagement is key to us. Patient awareness and access to research and development results. Mutual support for sustainability. Still recruiting folks for the iConquer MS. Just blood sample repository. Immune cells in the blood, serum, plasma and DNA. Our repository contains samples of people with other disorders. Patients that donate samples, what controls do they have – how do they maintain their voice. Do they sign that away when they consent to donating? They get to decide how their sample can be used. The patient provides approval. Healthy controls from family members without the disease. Some of the other groups are involved in the governance. Is there a starting point that you want the GPC to assist you with?

Ann Lucas from Duchene Connect Registry – Patient Registry. DMD for short – Both caused by changes in the same gene. No cure – Put on steroids and stay on them most of their life. DBMD. Parent Project Muscular Dystrophy – Patient could register their data and compare to others in the community. Help with research. PPRN with separate advisory board that help guide us. Goal is to educate and connect the community to one another. Patients can create an account. Can pay for testing and compare data to other people. Survey modules – upload test results – link family members to their account. This is a genetic condition. Can invite others to the registry. Link healthcare providers. Annual meeting of care givers, patients, and doctors. Advocacy conference to train families to advocate with congress. FB but its closed to only families with DMD. Free genetic testing. Goal – improve data we were collecting. Long process. Increase number and diversity of registrants, Integrate data into registry. We've done a lot of online focus groups because most are wheelchair bound and it's easier for them to access. It's hard for families to figure out which research trial works for them. That's probably the only drug trial they will be able to participate in.

ABOUT Network – Colleen Maguire – American BRCA outcomes and utilization

Hereditary breast and ovarian cancer – a large portion of people are not aware they have HBOC. With PCORnet, big data. Doctors' offices and insurance companies compile a lot of data about patients. Use this data that is already being collected. Participatory research – get a larger number of people involved in clinical research. HBOC connect to PCORnet. Provide CDRN's with patients. BE representative and diverse. Any one that has personal or family history of Breast or Ovarian Cancer. Accomplished tasks in phase 1 and beginning phase 2 – developed tools to collect patient experiences. GAP process. Communication and genetic testing. Consumers help guide the research process. WE need to know what consumers know. Using lots of tools to find out what consumers do know and identify and prioritize processes.

What is ABOUT doing phase 2 – surveys of all that might be at risk? Combining phenotype information. Keep patients involved in governance, use data to answer research questions. Continue collaboration with GPC – ideal for sharing information and data.