Patient Engagement Session – 10-01-15
Kim Kimminau

Taking the lead of 1.0 to 2.0 – right hand is Cheryl Jernigan – we work together on what we should be doing. Some stuff made since some stuff didn't.

Start talking about the role of patients and what the GPC needs to do. Bring out your experience. If you are starting at 0, you are not alone. Love that you are here. Come with open hearts and open minds. It takes a big step to come. We are just getting started. Speed dating – having coffee, just chatting. We become our own tribe. Other tribes don't get us, they want to be friends with us but they don't know how to get to know us. Pacific island cultures, you have to yell out who you are, by how you're related. Announce who you are, chant your lineage. The point is, you come to the shore of another tribe by who you are and what you bring. We are going to learn how to approach the other islands of the GPC. If you want us to participate, this is what we bring. We have a lot to bring and we are in a powerful position. The funder says, patients rule. Colleagues say that but they don't know how to live it. PCORi is saying we need to change the conversation, what we are doing and transform the way this is done. We are at the table. We are strong and powerful. We are a big vote. Positive opportunity for other patients on how this research is done. Just being at the table transforms things. Fierce because you have so much to offer and share.

First name basis – introductions – Name, Institution, what persuaded you to say yes to come here.

Cheryl – we have access to a lot of data. Its mind boggling. Its hard work but it needs to happen so we can have better clinical trials.

Andrea – UW Madison – program manager in Clinical trials office. CTSA through ICTR – Patient engagement officer for GPC and UW Madison. Interested in this research and what my role is.

PEO – Patient Engagement Officer – local academic connector to what is going on for the overall GPC. Helping connect at the local level. PEO is the main connector to help things happen at the local level and connect to central HUB.

Kelsey – CMH – PEO – worked with families to recruit them and their children for studies. The parent of a child being asked for research.

Teresa – SMS Dallas – population based studies – research subject advocate.

Sue Rodgers – Patient Rep University of MO. Retired – 40 years' experience of a nurse. Charting system. Director of nursing at women's and children hospital. Strongly advocate for patients – parents, husband, and sister.

Adel – Patient Rep – San Antonio Community health worker – voice her concerns for patients in his community.

Paula Winkler – PEO – Community engagement person – community engagement for 30 years. UT Health Science – San Antonio – 12 counties – Get to a point where we have a T-shirt.

Jane Corston – with KU as a patient. Love Cheryl and she drug me in. Breast cancer survivor. Patient.

David Ruper – UT San Antonio – Nurse – came to institution with Dr. Hale. Nurse for 4 years. Patient is first. There are a lot of people around the patient that don't pay attention to that. Data side. Pretty good at taking an acronym and helping people understand it. I fix cars, people and computers. Glad I'm here. Research has gotten really dry and just numbers. This seems like a good way to seed the ground so that things grow.

Deb Myer – University of Neb Med Center – research center advocate – working with communities and building trust – Dr. McClay – data geek – she likes people and has a passion

Charlotte Jay – University of MO – PEO – just found out last week. In the process of finishing up one position and starting a new one. New duties. Just learned about GPC last week. Nurse for 40 years. Always been a patient advocate – PhD that did a lot of metabolic issues. What does it mean for the patient that is sick? In the last week, the emails and phone calls, energy is very contagious.

David Guinn – Boston – Multiple Sclerosis – our CEO for PPRN – MS Patient Powered Network – we have a patient tissue repository. Recently introduced to PCORnet. Here to represent Boston. We are cross fertilizing.

Debra Hendricks – University of Minnesota – PEO for PCORnet – CTSI community engagement. 40 year nursing club. Most of career in public health nursing.

Angela Boston – UT San Antonio – software engineer. Soak up ideas, improve interactions.

Nancy – University of Iowa – patient and family advisory council – UI center on aging.

Liz Swanson – PEO= University of Iowa – leader at CTSA

Susan Scolman – Marshfield clinic – Deb friends – nursing administration. She introduced the GPC – 10 year Breast cancer survivor this month. Care giver for husband who had Parkinson's – retired to take care of him. Going to his doctor visits – he didn't understand what was going on and I was always asking questions. All this information would be so good to have to help doctor visits.

Deb – Marshfield Clinic – not a nurse – been in research 18 years after 10 years at hospital. Worked on large number of research studies. Working with patient side of it. Questionnaire to administer – what are they thinking? It's important to get patients involved up front. Reward from getting info out to patients. Research takes a long time.

Evidence based research – how long does it take to get to Primary Care Clinic – 17 years. Figure it out then get it out to the patient. Information is there but not in action. The delay in moving this information is complicated by a bunch of stuff. It's so unreasonable. Get smarter faster, get cures out better. Make the system spin better. The reason PCORnet is putting money into this, it's hopeful notion,

data that is sitting there, carefully collected – notion that if we can harness that information and spin it down to answer who does better on this dose rather than that dose, we should be able to answer the question. We have millions and millions of records. Generous of us to share, move to a level of trust, so that we contribute our little piece, we have the answer. When you watch the informaticions clicking dragging doing – lots of data fields – he can get the data – add all the data points – see how many people are involved. He builds it and we have this number of patients with the same surgery, medications and conditions. Now we have the pool to answer the question. HIV, aspirin, ALS – all of the data is nicely aligned so that when he puts the code together, all of the patient's data is in that query. It's the data pent up in those records is helping. That is monumental. They aren't asking the research questions, they are making sure the data is strong and aligned. Then it's up to us as PEO's working with researchers to ask the right questions. We can start to engage on how the questions get shaped. Do we really care about this issue? We can move the priorities, not as important as this question….

We get a voice in that. Infuse and push the kinds of questions. If we are listening to each other, community partners and patients we are bringing everyone together. Be at the table to talk about it.

Cheryl – no you can ask the questions using retrospective data – now it's more efficient and a lot less burdensome for patients and clinicians.

First conversation – T1 vs T4 – Survey's as being a source of data. What kind of research are we talking about? What kinds are there and particularly in the data driven, architecture coming out of electronic health records. How would this information help us advance research? People in clinical trial institution – share what you think is an important piece of research.

Anwar – Clinical Trial Network – What is a clinical trial? New definition – NIH – Usually is a prospective – going forward in time – EPIC system – retrospective looking back in time. Clinical trials are prospective – I can go to the i2b2 and pull the information from the past. This is what happened with those patients. End points – what is the outcome I'm looking for – Define what I'm looking for. ICD – codes used for billing. Every diagnosis is numbered – sort of like a library – program to go out and get everyone that has the same codes. Diagnostic codes and treatment codes – can use these codes to answer research questions. Very specific, very quickly. None of this is a clinical trial. Clinical trial is prospective – which something that starts today and follow it for a period of time. Another key feature is the treatment and intervention. Comparing a drug to a new drug, compare the outcomes. Rare condition – not many treatments – clinical trials are the gold standard – identify what you need the data you gather from the beginning is the gold standard. Perspective, has interventional arms – key components – bio stats up front, need to ask the good questions, need a good sample size, need good control confounders – other conditions that affect the outcome. Eliminate other conditions. Want a pure case. Have to account for things. This is not fair from the patient's point of view – rural communities have small numbers. How do you alleviate this? Randomization. Part of a good clinical trial is the consent of the patient. All things should be explained. Kept like this so you get good data. Doing a trial to try a new drug – it's very important to have the blinding – and randomization. If the investigator does well – then you can have a cross over design. Data people start getting glossy eyed when you start talking about the numbers. We are doing this to make it better for those who come after me.

IRB folks – their job is to make sure we maintain the highest level of justice in research. Consent is a process. Ongoing discussion that investigators should have. Exchange and process – if there were this drug and it's great. The IRB are required to say we are stopping this trial right now because we have enough compelling evidence that it's curative. We've got the data, call a stop to the trial, not enroll another patient and close the trial early. There is also the counter, we can't get enough people engaged in the process to get enough data in the study. The rules are for protection of the study participants.

Diagnosed with Breast Cancer – oncologist wanted to do a clinical trial. Couldn't do it because the insurance company wouldn't pay the claim.

Role of insurance companies in promoting or dissuading participants.

Rural – different angle – smart phones – throws and artificial pool into the pile.

Understanding the numbers, the impact, reading level, comfort.

A big piece of our concern is getting people involved. Making assumptions of people - this affects the whole pool. Be out there with them and deal with them. Ultimately you have to do a multisite trial.

Confounders and the group that you need the information from.

Randomization – how is that fair – PCORi is running models to quantify the effect it would have on you if you participated in this particular group.

There is the advantage to pull people into the trail, but when you are desperate to get a new medication or therapy, wouldn't you sign anything? People are vulnerable when it comes to research and rare diseases. Part of this is the balance, we want people involved in clinical research but it's immoral to take advantage of them and feed into concerns and fears to engage in research. Having open conversations with patients – huge power position as a researcher – all of the rules of engagement – historically patients haven't had the voice on the trapeze. They have just been there to participate. Trying to change that whole dynamic to get the patient voice in there at the beginning. Take care of the most vulnerable who are least likely to voice concerns.

Fairness - it's a point of trust. Research has diminished this. We are also seeing every day – coffee is good, no coffee is bad – we aren't eating enough fat – the whole issue is trust where the patient resides every day. The thought – we have to think of it as a movement, not a deliverable – how can we as a community to move towards the bigger public health component. How can we start separating the data geeks from the researchers from Aunt Betty? CHW – community based organizations play a huge roll. When you go to a community – educate them on what research is and what it means for them. You're coming to me because you need the patients or you're funding runs out. Research works both ways. But it's ultimately for the community.

Think about this, we are on different points of the wave – they are on a surf board, research, build career, but they have to have the patients that are willing to go along on that wave. Communities and

individual patients, there are a lot of surf boards catching different waves. Can't catch the GPC wave without patients. They need to understand

Charlotte – emergency room nurse – when started into research – didn't have a clue – we have to learn to speak that language and give that over to who we are advocating for. Each little aspect of the research has to have integrity.

Do a lot of study with health population – trust issue – engage the community and build the trust. Good consenting process. Have to have ways to explain why you are doing the research. Why you're not going to see the results for 10 or 20 years.

Shift gears – talk about observational trials. – Could be on a patient population volunteers. Dallas heart studies – population based research study based on where they live, age and ethnicity. Focus was heart disease. Brought everyone in, gathered data, health survey, and bunch of tests that didn't involve treatment. Collecting data – survey info, looking at these people as a person and no intervention, no drugs. Data analysis on many different things. Using blood pressure – strategize on who we were looking at. Divide them into as many different groups – community – clinical trial, phase 1/phase 2. Doing research but it's not a clinical trial. Come back to explanation. It's difficult for patients to say, I don't understand. Staff training you have to get this in. No where would I use observational study. Clinical trial term is different than in the academic world. Clinical trial is used as an umbrella about research.

We frequently think the clinical people are not the ones to get this. Kim works with doctors to teach them how to be a doctor – specialty is primary care doctor – what's research. New doctors and clinicians don't know clinical trials either – a physician to say to you, "you qualify for a clinical trial" – that is amazing that they do that. Not only is the community confused, there are a lot of doctors that don't get it either. The point is, even if they don't think its research, the IRB decides if its research or not.

I save lives and you're telling me I don't know research?

Quantitative vs Qualitative – Quantitative is numbers – Quality of research – Qualitative research is more descriptive – not numbers that clearly fit in a database – an example – dr. hale we have focus groups asking parents who makes the nutritional and physical decisions in the home. Only women showed up. Middle of the day. Let's go recruit parents in a focus group with school age kid's tell them to come to the library and answer 10 questions. Mom and dad answered questions. The kids make the decisions. Qualitative data – tends to be structured around a question. When we start talking about research as asking a good question. This is where we start with research. Make sure you're not wasting time. Ask good questions. No one has a corner on asking good questions. Anyone who experiences health and is in the community can ask a good questions. I wonder if other patients like me have this side effect. Why does this drug cause this reaction? There is no corner on the market.

The questions you ask as patients, moms, dads, daughters, brothers, spouses, listeners, those questions are ones that the researcher never thought to ask. The qualitative data can round out the story and change the kind of story we are asking. The beautiful melding of two separate things. Quantitative and our stories, our experiences – talking to patients. Take the qualitative experience and blend with the

quantitative. Build trust. When I ask again, they will do it again. Build relationships. This also connects people together. Focus groups – for this service, how many would be willing to give to science?

It's not always just you and your stuff, its concerns for your family. Can the insurance company use this against me? Is a lot of the no or confusion is that the communication about the study was poor? Signing the consent of treatment form, brings up other questions. Not training the front desk people well enough. Who is going to do research? Research – who has access to this bank? It's an easy picture to paint in your mind.

The government is now proposing new rules within the consent form about tissue banking and what is going to be done with "leftover" donations.

In relation to consent, there is a lot of boilerplate statements used, like a form. Then you have things like yahoo and other companies that are demystifying, their end use license agreement. It seems to me that that's exactly what we should be advocating at the GPC.

Where are the opportunities to bring these issues to the GPC work?

Consent forms – focus group and talk; clinical trial; is that consent process like the old fashion – pharmacist consent form. Bio bank 10, page consent form. Institution template, involves DNA, written to meet all the legal requirements. Lots of detail and regulatory issues, the IRB – patients serve on these. We have one here. The IRB process and the simplification – we have to make it clearer – we run into legal issues, federal regulatory issues and others that make it difficult. Where we can make improvements in the process – wouldn't you want to be involved? Patient centered, family respectful – this space is grey – we can shine a light on it from patient engagement perspective. Opportunities where we can push to work collective with patients. Not simplistic or talking down to patients, but make the researchers more willing to contact the patient after the research is completed. My motivation may be "what did you learn" I want to know.

They need to be in English and Spanish. Cultural and linguistically tailored. Do it together. Program manager to do the consent together – bring the resources together to help the patient make a decision. Explain and encourage the patient to participate.

We need to go back to principles of PCOR. Going back to their principals, patient representative component at each pillar. Across all the rows and all of the columns. How representative is that IRB. Are there patient groups, like MS-ALS-Alzheimer – are they part of this process. Partners through the beginning and the end. It goes across the spectrum. There is a term – Research Continuum – T1 thru T5. Research is academic driven, break down the ivory towers – becomes bilateral.

Ideas Opportunities to bring patient concerns to the table – community concerns

Results – would like to see a list of publications of what the study found. We expect that as you come in to request data you will push that information out beyond the community. The patients that participated are provided the results, no matter what they are. Details of number of people, how old

they were. Newsletter – as part of GPC you are expected to publish statistics and outcomes. If you want to know, here is where you can find the information.

Develop training that explains the research process – YouTube video – Patient research registry. Check a form that you are interested and put in a database. Shot a video on what research is and how to sign up. Something to read when I take home. Comes down to the beginning – patients signing up.

Training for Scholars and investigators – how to communicate with their community the results. Train researcher on how to interact with patients.

Bio banks – provide patients the opportunity to get feedback on their own personal data. Similar to enrollment. What have you done with my DNA? Collating data to return to people. Make provisions.

Education – Health literacy – templates on what that is. Teach back. Are we making sure we are giving an informed consent? Are we using the laymen's terms that people understand? Research literacy. Resources that we can all have access to nationwide. Common understanding.

Culture of governance – End of phase 2 mode for research and governance.

GPC should be the Angie's List for Research – when you come to us we've got a basic trust level. Snap a picture in a general since. Some level of trust across any patient involved we respect these values. We have to go back to our own GPC team to make that happen.

Quality indicators – patients can evaluate what just happened to them.

Insurance – lot of people don't know how to manage their insurance. They go to the doctor and says I have a co-pay. Role of insurance in healthcare and research. What research study can I be in? Include the patient groups in publications and tell their stories. If they want to be identified. Offering patients the opportunity to have academic experience.

How do we capture more people so that we have a larger cross section? Learning from each other. Community and recruit from all these groups involved. PEO – bring it to the Hub so that we can share. Start to learn from each other.

When you apply for NIH funding – we are going to give you less than what you budgeted for? What resources are available to drive these things? Limited by funding. The larger issue is patient engagement shouldn't be where you shave off money. WE have to look at the tiered system that we work in. Institutional guidelines and how we can impact higher level decisions and what trickles down to patient involvement. System assessment. Work in concentric circles of systems.

Patient Engagement 1:00 to 3:00 10-1-15

Woman told the story of 6 year old Kyle's journey through cancer, Leukemia. Battled fungus. Engaged in his care all along. Now 22 years old and in the school of nursing.

TJ Miller – Parent from CMH – kid's journey – defining moments of our lives are never planned. Her daughter had cancer – whatever she had to do to get her cured and out of the bed. Respected for the amount of involvement in her own care. It's to the point where they bring in a patient/parent to get that perspective.

Creating the environment and culture of patient involvement. 100 parent volunteers that sit on different committees. Including, engaging, empowering patients and families in their care. EVP/COO has been at every meeting.

Listen for systems – ways they have been able to help and transform health systems.

What is the recruitment method – If we are looking to start something we go to clinicians and ask them. They can think of families that they would like to place in front of someone else. We will contact the parent and say, you've been recommended. Some people are flattered. These families are seeing what isn't working and when they know you want their feedback, they are happy to help. In clinics and inpatient care. Family advisory board. Publicize it on our website, people can self-apply.

Children's Advisory Council and Adult – we have some staff that attend both. We create teams. We do have some where parents are on family board and teens are on children's board. Once a year we have an annual meeting and invite other advisory boards.

Is there compensation for their time – These two are paid, but at CMH our volunteers are not paid. We track their hours and give them a gift at the end of the year. We circle back and follow up on things that have been done. We have some that host residents in their home. Someone who graduated from med school and are going to each department to learn hands on. We give them a $300 stipend. CMH has free parking and we feed them.

Had resources and education and great network – what about families that don't have resources. Do you have help for them? Their life circumstances make it difficult for them to attend – one thing is that we do family experience tracers. Introduce ourselves as parents. We want to know their perspective. Did the family experience it?

Tracer – we have a set of conversation points. Interview as such. Guided conversation. We monitor after joint commission comes in to check the hospital. How do we insure that the family actual experiences it the way the hospital expects that they did. We ask about nurse communication and we end with what can CMH do to improve your experience. RL6 solutions database. Patient satisfaction surveys.

At CMH we have patient advocacy. If the patient has a problem they can tell us trends. Do you integrate research? Some – we work with them when they are writing proposals. Staff has learned to trust that this is how we do the prep work. We will have a meeting to do background information share.

How do you turn people down? On the application – its simple – name address date and child's name and then their experience. Any ideas implemented or suggestions and then staff recommendation. If the staff tells us no, our board is full, we have other opportunities. People that can look at the system level and make changes for the hospital not just for them personally. Lots of other avenues. Staff recommendation, then our current chair calls and interviews them. We are not a resume builder.

Enrich it by any other sites that have this experience. Share do you have community members and patients that have similar experiences?

Nancy – University of Iowa – adult patient and advisory council – we have been tossing around the idea of research – CTSA at Iowa and approached the council about research – potentially trying to find test subjects.

Attorney – pier reviewer for different research projects – as a consumer look at – lawyer doing grant writing – it's an effective measure

Good way to frame – U of Iowa – early phase of just thinking about this. Just walked into the store – potential collaboration patient and institute.

Clearly a role for reviewing proposals – how do we bring patients and consumers into reviewing? How can we view whether the application is consumer informed?

University of MO Columbia – art grant steering committee – just formed a patient advisory board to take the proposals – its nurses and educators trying to train researchers to bring patients in. patients and family members to bring proposals to. Forming a patient consumer group. FAB vs. recruitment – Patient Family Advisory Councils.

County level patient groups we meet – translate research out to counties – 7 counties. TAB – meeting monthly for 7 years. Size has been large and small. AHAB is another

Minnesota – patient representative – nurse – we don't have the connection between research and our advisory board – we don't have paid positions. Does that make any difference – what we say is that being employees of the hospital we are involved 40 hours a week. We've gained insight in how the hospital works. We are able to bridge the gaps. Because we sit on a lot of committees – Navigate the highway that is the hospital. Are you going to get a volunteer to be at a meeting at 6:30 am? They have signed the same confidentiality agreements as other employees.

Kim – wants to talk about getting more at the how. Consent process story – son as a cancer survivor. Effects on his heart around the chemotherapy. She went through the consent form very well. How are we creating an environment of empowered? Teach them to ask the right questions.

What other ideas does this stir up on how we can encourage establishing the right kinds of

How do we do this around the GPC – Advisory boards and committees are good but are we finding out how they actually work. You know your own institution try's this, community advisory board for a particular grant – one idea bounced around – why not have a multi stakeholder patient engagement voice. A patient voice from each site and have them convene? – We know how to run groups but would it be valuable to have this board – what would the patients be getting.

Wisconsin – community based workshops – community members and investigators they come up with a research plan. CTSI will take you through the steps of developing a research plan. One way of doing it in Texas may not be the best way in Wisconsin.

How do you keep patients engaged from the start and then at the end. What about keeping them engaged in the middle. How do we fertilize the work, cull the information and share it, how do we help keep patients and consumers involved from the beginning to the end. Still have team meetings. What problems are we dealing with – dual roles of engagement in the middle – building relationships with your advocates, they are learning about what this means from start to finish. They bring a conscience, keeps it going, they help keep the team on task and remember why we are doing this.

Clear charge – make sure people make a difference and it's not window dressing. Would like the opportunity and want to know what I can contribute. Each time I learn more. It fuels desire to be involved.

Being transparent and saying you want to do this better – Don't have to have a plan but just knowing that you want to work with us. Not just a token parent.

Cheryl – since she started 15 years ago – reviewed grants – it was a learning process. Even more for researchers because they don't understand patients. Jump in the water and start treading and gradually learn how to swim. Now serving on scientific advisory board for Susan G. Komen. Sometimes I can add to discussion and sometimes I don't. Not representing my own story. It's important for patients to understand the research. Teach researchers how to talk to patients. Patients paint pictures Researchers why it's important and be assistive and they can be better researchers.

Most research trials fail but that's why we do it. Every research leads us to what fails and what goes right. We have too many people suffering and dying to screw around with this. We need to work with each other. She is perfect example of a researcher that encourages patients. All of us can feel drowned in the process – buddy system – don't want any patient to feel alone. PEO role and help the willing patient who is going to put their feet in the water. Bigger picture – researchers are used to getting on the phone and emailing one another – they demand the answers – if I'm a patient it feels like shark infested waters. Need personal connection at the local level. WE can help each other dive together. Can we think of other ways to help the patient? Do we have these meetings more than once a year? Video conferencing – get us feeling like we can get in the water and have some support. Relationship with local PI's help.

When researchers don't see patients – they don't think about the impact of what they do. They get so caught up in the research – they like to get reconnected to the patients. Panel of patients that you have – could those people be contacting the researchers? Clinical trial people making phone calls and say how are you doing?

Not many research institutions – CTSA's – 62 across the country – no standard patient participant survey. There are pits and pieces – No standard of approach – you've been through this, your data has been provided how do you feel about this? What was it like, what could have been different? Kim just built one. There is no validated tool. Can we get a survey in place? We have to go through IRB. Get rejuvenated for world café.

Open up for sharing anything!