Building Trustworthiness in PCORnet: Meeting Summary Report
March 28-29, 2016
Meeting Recording

DAY ONE: March 28, 2016

Welcoming Remarks
• What is the Patient-Centered Outcomes Research Institute (PCORI)?
  o The purpose is to advance quality and relevance of evidence
  o Mission is to help people make informed decisions
• What is the National Patient-Centered Clinical Research Network (PCORnet)?
  o Purpose is to conduct comparative effectiveness research faster and more efficiently
  o 13 CDRNs (Clinical Data Research Networks)
    ▪ System based that include academic medical delivery systems
  o 20 PPRNs (Patient Powered Research Networks)
    ▪ Often disease specific and community based
• Our Goal
  o Define and practice meaningful engagement across networks
• Meeting charge to workshop speakers and participants
  o Ask “How are we or are we not trustworthy?”

Session I: Current Landscape

Keynote: What constitutes trustworthiness? – Ruha Benjamin
• There is so much more attention to medical trust than “trustworthiness”
• Cannot effectively work with people who we do not love and respect
• Why is distrust considered an anomaly to overcome, rather than an incisive disposition to research?
• Cultural essentialism
  o Framing of group differences is part of the problem
• Research vs. Healthcare
  o Tension between research and healthcare
    ▪ “Why am I in such demand as a research subject when no one wants me as a patient?”
  o Tend to patients’ care on all points on the continuum of care
• Cultural humility
  o Essential to develop trustworthiness
  o Check power imbalances that exist in physician/patient dynamics
  o Process of self-reflection and self-critique
  o Let go of the false sense of security that stereotyping brings & admit when we don’t know

Discussion
• Need to counter false sense of accomplishment in reaching diverse populations
  o Cultural humility is ongoing
How do you institutionalize and ensure quality across a group responsible for millions of health records and make it consistent across health groups?
  o Build in patient concerns prior to the research process
  o “Patients need to be AT the table, not ON the table”

How do we get communities “research ready”?
  o Root science in children’s experiences
  o Develop mechanism where communities can find researchers

How can we learn from our failures?
Lessons learned and key questions
  • Issues around trust and mistrust are not going to go away
  • Can we be relied upon to be honest as a research enterprise?
    o We need to make a more trustworthy path forward
  • Can we be trusted to return research findings and translate them into practice?
  • Be specific when asking if research will benefit health outcomes
  • Ask for consent, rather than simply take it
    o If you want to do something, ASK. If you want to take something from us, at least ask us!
  • How do we scale trust?
  • Is trust scalable?
  • Need to overcome communication barriers, so that everyone who is at the table understands the conversation
  • How do we begin to share the power that is required to get action?
    o Need to show the benefits for patients and communities and share something
  • Is there an assumption that those who do the research are the ones who hold the power?
  • Every breach of trust has a ripple effect
  • What do patients want to learn and what is beneficial to learn?
    o Need to set out the steps for getting patients engaged
  • Need for trust and transparency; patients do not have a lot of patience!
    o Important to keep them informed and updated on the research process, even before results are published

Session II: Essential Elements of Trustworthiness

Attributes of trustworthiness
  • Can government play a constructive role in advancing trustworthiness?
  • How can government be a better partner and advance the values that we share?
  • Critical to delivery system reform that patients can be active participants in decision making
  • Robust efforts to ensure participants that their data will be safe and that they will have access to it

Respect
  • Imbalance of power in today’s “state of play”
  • Revised version of Maslow’s hierarchy to consider how to meet the needs of humanity and not the systems
  • Start working together to get to a healthcare system designed to serve humanity
    o Compliance and adherence are paternalistic
    o Participation is partnership
    o Partnership leads to trust and respect
• Cannot have partnership without collaboration
• Participation drives better outcomes
• Let patient leaders lead this effort
• The system is not broken – it was built this way. It is our responsibility to build respect and trust

Privacy
• Disparities in healthcare
• In talking about privacy, need to consider varying populations
• Consider providing a literal translation in addition to health literacy for a very complex topic
• Full disclosure – give patients context
  o Patients decide to share their data, so ensure patients understand their rights

Transparency
• Is transparency enough to ensure meaningful engagement?
  o Trust is on the decline
  o As trust recedes, transparency takes its place
  o Trust is about vulnerability
  o No control over whether someone will trust us, but control over whether we are trustworthy
• Trustworthiness dependent on three key attributes
  o Our ability to get things done
  o Our Integrity
  o Our benevolent intentions – honoring the trust of those who trust us

Discussion with speakers and participants
• When process trumps humanity- we lose
• No such thing as scalable trust. Either you have trust or they do not trust you!
• Does trust mean different things to different communities?
• How do we bridge the gap?
• If the audience does not understand your story, they aren’t going to hear you
  o Hire science translators and put language through Up-Goer Five
• Trust is difficult to get back
• How do you avoid misuse of information that gets out into public domain?
• How much do relationships matter in building trust?

Session III: Special Issues for Special Populations

Contextualizing trust: Act locally
Underserved Communities
• Trust is a barrier
• With vulnerable populations, language that is used is incredibly important – can shut a person down or open them up
  o When we can speak in a way that invites someone to a conversation, we can make small inroads into establishing trust and trustworthiness
• How can you have a discussion with someone when you begin by saying they have “low literacy”?
• Everyone matters, whether they know they have data or not.
• How do the powerful empower those who do not know or are not aware of their power?
Sexual and gender minorities

- Lack of understanding patients
- First step is planning
  - Plan to ask about sexual orientation and gender identity
  - Current piece of invisibility in this community that does not engender trustworthiness
- Get feedback and guidance from sexual and gender minority stakeholders
  - Language can vary
- How do we report our research as important?
  - Need to have a theoretical model
- Be clear about your agenda and your team members
  - Link to your website
  - Say who your researchers are and share their background

Children

- Patient engagement is the product of compassionate medicine
- Patient engagement is the product of a culture, transparency, and sharing culture
- Pediatric engagement is a myth; it’s an afterthought
- Operate on a collective agenda
  - Advance meaningful research by involving children in research

Decisionally compromised and caregivers

- Avoid soft titles
  - Trust requires truth in labeling
- Who would you trust to be your caregiver?
  - Think about the duality and trust required
- Caregivers have been put into a position where they are asked to take rights away from the patient
  - Caregivers are unjustly asked to be an “informant” or “study partner”
- Lifetime engagement
  - Caregiver is the principle and the patient
- Trust is the end of paternalism in medicine
- Families are lost in this process
- Caregivers count—impacts for health on all

Mental health and other stigmatizing issues

- Vast majority of public will give consent if asked
- HIPAA is the enabler in the disbursement of your data
- Does trust scale? – Absolutely not!
  - Trust is between two people

Recommendations

- Separate “informed” from “consent”
- We don’t need IRBs to make decisions about health records
- Stop letting providers hide behind the IRBs as an excuse for their behavior
- Communicate value and respect for those who are seeking information
- Eradicate the word “subject” from all research
- Treat participant as a partner, rather than a patient
- Follow-up with patients
Session IV: Policy Approaches and Legal Framework

Accelerators and roadblocks in national policies and guidance

- In talking about regulations, how do we see ourselves as actors in this policy framework?

OHRP Policies

- Consistency issue
- Make sure we are appropriately getting consent

IRB issues

- Conducted studies to find out what participants think about certain types of studies
  - Built informed consent with assumptions
- How do we engage public in this bigger conversation?

Information blocking

- What does it look like when participant is co-creating research?
  - Can they collect their own data?
- As we move forward in this space, take guidance from fair practice guidance principles
- Need to decide whether we need new kinds of entities

PMI White House privacy guidance

- Privacy and trust are the most important words
- Launched this group before activities because the president believes privacy and security should be part of the building rather than just an add-on
- Development process
  - Made assumptions about what PMI would look like
  - Wanted principles to be broader than just the cohort

Community-Campus Partnerships for Health rewrite of Common Rule and Belmont Report

- Name is intentional in terms of bridging partnerships between community and campus
- Recommendations from the common rule and the Belmont report
  - Replace the term “subjects” with “participants”
  - Community needed to be included
- Culpability of US government
  - Community should be included in research
  - Recognize that communities are impacted by research
- Core competencies
  - Humility
  - Relational integrity
  - Accountability
- Look at community-campus partnerships website to find out more about their principles of partnerships

Discussion with speakers and participants

- What is at your core and what drives your decision-making?
- Hope that government can play a role in laying down the conditions for change
- How can we accelerate a return of results and invite collaborators to participate?
- What is the next frontier for moving forward with recommendations?
- Consent process needs to adapt
- How do we make this process rewarding?
  - As part of collaboration, engage in attempt to make this a joyful and rewarding experience for the various different participants
- How do people hold me accountable for my actions or lack of actions?
- Understand our own culpability
• How do we check our privilege and assumptions?

Session V: Breakouts

Being Trustworthy
The Public Good
• Watched video that illustrated lack of concern for the patient
  o Need to acknowledge the patient’s experience
• Do research on patient’s history before trying to recruit them for a clinical trial
• Often researchers are driven by outcomes and promotions
• Consensus illustrated through key words: empathy, listening, ethical principles, redesign medical education, access to healthcare, address institutionalized racism, unconscious bias, disconnect

Affinity Communities
• Requirements and mandates for PCORnet and PCORI
  o Ensure patients and stakeholders are listened to and incorporated
  o Aid patients in finding academic institutions
• Characteristics to ensure trust
  o Capability, caring and loving, dependable track record
• Barriers to trustworthiness
  o Lack of resources and time
  o Intellectual property
• Recommendations and opportunities
  o Challenge barriers by educating children early on (i.e. incorporating messages about the importance of research and patient-centered research in schools)
  o Improve communications between researchers and communities
  o PCORI ambassadors
    ▪ Start conversations about researchers
    ▪ Hold talks at churches, community centers
• How do you get individuals involved?
  o Make things more transparent
  o Build trust by any means necessary

Clinicians and Researchers
• Barriers
  o Dichotomy between researchers and research
  o Therapeutic misconception on parent end
  o Often clinician is not the person you want to engage in a healthcare system
• Build a science around patient engagement

Health Systems
• What is the sustainability?
• Clear communication is an essential element
• Barriers to trust
  o Fear factor - what is going to put organization at risk?
• How can we build on successes?
• Value proposition - research brings prestige to organization
  o Leverage this value
  o Research is important for organization and patients
DAY TWO: March 29, 2016

Session VI: Building Trust

Case study for building trust: CPPRN

- Partnership approach with patient, family, community co-leadership leading all aspects
- Focus on under-resourced communities of color
- Use infrastructure in the community
- Long journey to figure out effective community engagement, build trust over time, and work with community on ownership, accountability, and action
- Academia needs community
- Importance of co-production: not a new idea!
- Community coming together and pushing the research agenda
  - Act as a facilitator to getting the community voice to the researchers
- Find a way to engage community in a commonality
- Consider political organizing as a model for national scaling
- Training community members to be research ready
- Campus-community memberships should be advocating on behalf of community members to not accept what we currently know as the informed consent process
- Important to know what you don’t know
- PCORnet has to look at the shape of its river
  - Need community at the table for the governance structure of PCORnet
  - Put up pictures of people involved in the PCORnet governance structure
  - Be clear about who is involved. Where is community?

Session VII: Trust in Other Contexts

Mobile technology and education

- When we look at the data, our communities have cellphones and texting is ubiquitous
- Reliant on community partners to reach women
- Successes
  - Reaching moms at higher rates
  - Not able to accomplish successes without partnerships
  - Community partners have trust and know how

Community places to play

- Most community work focuses on building trust and long lasting relationships
- Difficult to understand political backdrop and form long lasting communities with short interactions with communities
- Able to have accomplishments by doing the following:
  - Ask parents to be part of the planning process
  - Ensuring every single person has a place at the table
  - Community members are involved and engaged from a philosophy of partnership

Police and the community

- Community not always trusting of the police
- Introduce yourself to the community in order to build trust
- Set out to work on the basis of problems
- People will look to you for resources and information if you build trust with them
- Living in the community is a benefit to building trust
Cultural competency-bridge to trust

- Critical to consider the culture that we all bring to the table
- When we understand each other better, we build a bridge to trust
- Our words, action, clothing represent the cultural aspect of who we are
- Culturally tailor healthcare
- Utilize funding to use culture as a vehicle of prevention
- Outcomes
  - Decrease in health disparities
  - Increase in productivity
  - Creation of opportunity
  - Replacement of fear with TRUST

Discussion with speakers and participants

- Research is showing communication is best through non-traditional channels
- Critical to listen and not drive your own agenda and outcome
  - Community able to own part of the process
- Major issue is that researchers don’t listen to the people themselves
  - Someone else is speaking for them
  - Allow people to share their thoughts and strategies
- Don’t assume that you have the answer, but talk to the people who have the issues
- Important to think about how the groups that we identify with shape the way we see things
- Key themes:
  - Ownership
  - Our work never ends
  - Transparency
  - Don’t let someone be a stranger
  - Follow-up
  - Lead by example
  - Don’t abandon a community after a project concludes

Session VIII: Trustworthiness within PCORnet

- Leading questions
  - What do you hope to learn from this community?
  - What do I have to give?

Models of trustworthy engagement in communities and health systems

DuchenneConnect PPRN

- Transparency and trust come with empowerment, but also vulnerability
- Successes
  - Networks sharing shared philosophies
  - Process is where we build trust, not the outcome
- Barrier
  - Even if outcome worked well, the process was not appropriate
    - Cannot assume we know the best process for our stakeholders
    - Need to continue working on the process

PRIDEnet PPRN

- Partner with community
• Partner with advocacy and service organizations
• Studies need to be low-burden for participants
• Be accessible through technology and paper
• Research needs to be thorough from beginning until end
• Believe that participants know best
  o Don’t allow research unless there is an engaged community
• Lessons learned
  o Be innovative and risk taking
  o Admit mistakes
  o Communicate and listen clearly
  o Embrace successes and failures

**SAPCON**
• Patients want immediate wins and solutions. Need to reconsider mission if it’s not meeting the needs of the stakeholder community
• Challenges
  o No common language and mission for the patient advocacy organizations and patient partners
  o Build transparency by acknowledging everyone’s talents and their time contributed
• Leverage existing resources
• Create agile teams
  o Given research timelines, how do you create these teams to accomplish successes?
• What are short-term missions and goals, and how do you translate them into doable activities?

**PEDSnet CDRN**
• Engagement is not only part of the healthcare system, but also improving the health of the system
• Develop tools that help patients interact together
• Goal is to build distributed capacity in which everyone in the system can work together to make contributions
• Co-production change package=tools for everyone in the system

**Mid-South CDRN**
• How are we going to know we are successful in building trust if we cannot measure it?
  o Looking at the literature, what do we know about instruments and what do we use?
  o Over 40 instruments that measure trust (2 of them related to research)
• Influencers of trust
  o People with more resources are more likely to relate trust to things like competency and education
  o For marginalized groups, they relate trust more to fairness and honesty

**REACHnet CDRN**
• In a large project, can’t house trust in one person or a single organization
  o Create a web of trust
• Partners are able to come together over a common goal - improve health outcomes
  o In order to support partners, have to engage with them

**Lessons learned in designing PCORnet demo projects**

**ADAPTABLE**
• How do we make sure we are creating space in meetings?
• Important to have a trusted mediator to give negative feedback and ask questions
• Be mindful about inclusive communication and scheduling
  o Create a world view for adaptors so they know their time is valued
• Close feedback loop
  o Follow-up with other networks

**Obesity**

• Lessons learned
  o Engage early in the process
  o Communication is imperative
  o Use innovative processes to listen to stakeholders
  o Develop processes to bring to the stakeholders
  o Bring concrete evidence to stakeholders so they have something to react to
  o Be proactive about identifying issues with partners
  o Respect others’ time
  o Slow down so that everyone is part of the process and understands the language
  o Respect for difference in background

**Discussion with speakers and participants**

• Hidden history and details cannot be uncovered until you have conversations
  o Make no assumptions about where the trust is or isn’t
  o Mistrust is bidirectional
• Can’t assume trust exists in partnerships; it’s something you have to build overtime
  o When you start to build accountability, that’s when you begin to build trust among patients and stakeholders
• Trust is an individual property, but can be influenced by properties of the systems that we design
• Identify where powers lie and use this to foster trust in communities
• What can we measure about the individuals who we failed to bring into our networks?
  o Capture the same information for those who are engaged
  o There are individuals who will participate even though they don’t trust the process
• Need to talk about big data and getting patients to lend their data to PPRNs and CDRNs. How do we build trust in order to do this?
  o Need to think about how we share resources and engagement plans among the networks
• Include nurses in the conversations
• Need to understand what has gone wrong historically to understand where there is a breach in trust

**Session IX: Recommendations for PCORnet**

**Breakouts considering topics that emerged and crafting draft recommendations for PCORnet Recommendations**

• High-level themes in recommendations:
  o Innovation (Commons)
  o Transparency in Dissemination: (share who leads, who participates, with bios and pictures, etc.)
  o Inclusion (all stakeholders)
• Create a discoverable directory
- Drop down menu for a directory that would include electronic information, endorsements, engagement awards
- If we had a scalable score, and people met 2 or 3, their score would differ
- Have numbers for the IRB hotline if patients have questions that haven’t been answered

• Common Collaborative Environment which would include collective terms
• Link to charters and governance of various organizations and committees in addition to biographies of those serving on committees
• Recognize diversities and histories faced by different patients/patient groups
• Increase education and awareness about PCORnet
• PCORnet wiki (with best practices and lessons learned)
• Common collectives for terminology
• Publicize charters and information on Committees and Committee members
• Recognizing history
• Ensure adequate patient and other stakeholder representation on all Committees
• Gathering all resources shared to develop a resource that encapsulates the part that PCORnet plays; PCORnet action plan and best practices to date
• Public facing website with impactful defining for the general public
• Improving how we describe our governance structure
• Have adequate representation on stakeholder committees
• Acknowledge powers and dynamics within PCORnet
• Aggregate resources to shorten the time for co-creation of things
• Create stronger public-facing website
• Develop standard language to be used across different groups

Responses from PCORnet Leadership
• Working on revamping website
• Internally focused on providing information to the wider community
• Creating a creative Commons to share best practices and resources with the community
  o Genetic Alliance Coordinating Center is launching the Commons in July
• Goal of PCORnet is to be an open network where more communities/networks can use the various learnings of PCORnet
• Everyone can make a contribution
  o Unique opportunity to create something that doesn’t exist
  o Collectively need to do more of what works and less of what isn’t
• Inviting everyone to shift from focusing individually to focusing across the different networks/organizations
• 3 broad categories of barriers
  o Transparency and dissemination
    ▪ Transparency of bios and governance
    ▪ Communication plan
  o Inclusion
    ▪ Broad representation on governance
    ▪ Be more intentional about getting this information out to the public
    ▪ Public facing website – link to other individual websites so that people can see throughout
  o Innovation
• Infrastructure building focused internally rather than externalizing it
• Interface for transparency
  o Opening front-door to PCORnet to entertain how we partner with PCORnet
  o Looking at matchmaking interests and seeing how we connect people who have a common question
• How do we get results back to participants?
  o Soft launch of the front-door

**Session X: Conclusion**
• As long as there is absolute harmony, we haven’t gotten through to the issues/problems
• Plans to continue conversation: stay tuned for more information on how you can be involved moving forward!

**Summary of Comments from Building Trustworthiness in PCORnet Meeting Post-It Note Boards**

**General**
• I am a person of culture – know me
• Thank you for the opportunity, for wanting to hear and understand
• Create a climate and infrastructure for patients/participants/partners to expect and demand trustworthiness
• Thank you for organizing an open, welcoming forum for patients to participate, contribute and learn
• Trust is built through consistency
  o Know yourself and avoid high risk times for communication

**Respect**
• Stop using the term “subject”
  o People participate in research and are not lab rats
• Disseminate research results back to study participants
  o Put in the effort that it takes to convene them for a presentation and Q and A session
• Do patients want to hear about research that fails?
• Researchers need to use their roles at academic institutions to advocate for the institutional changes that community partners want to see and help open the party for communities to bring their own voices to the institutions
• “Trust issues” are the rule
• I have power so you CANNOT take it away
  o EMPOWERMENT implies you give me power and can take it away
• Respect the value of data – don’t exploit patients, instead give back for the value they provide
• More nurses at the table
• I look around the room and the participants are primarily white women
  o A few men, mostly physicians
  o Some minorities, mostly black women
  o PCORnet/PCORI needs to continue to work in diversity – race, ethnicity, and age

**Privacy**
Privacy
- Scenario: large medical setting w/ research data repository for EHR mining
  - Q: how do you adequately and appropriately obtain consent for data to go into repository?
- If your data is not connected to your IDENTITY – IS THAT ENOUGH?
  - HIPPA identifiers
- It is important to educate IRB on patient engagement and new methods for recruitment and data collection
- We need to re-think the culture of IRBs.
  - Research is not the enemy!

Transparency
- How is what PCORnet does different than the care.data project in the UK?
- How to involve patient communities in the need for basic research
- Asking patients for access to their data/medical records is a good idea but may increase disparities for those populations you cannot reach through technology or traditional methods
- FREE THE RESEARCH
  - Require publications to be available free to the public
  - Patients want to read the literature
- Greater transparency around funding opportunities
  - Tell us what’s coming
  - Tell us what to expect
  - Future opportunities
- Do not BREAK rules
- Transparency – keep it clear so all can see
- Create general email address for committees that go to all members for comments and communication ex. engagementcommittee@pcornet

Policy
- Mandate open journal access for IRB approved human subject research
- Separate the consent from the information
- We need to have a chain of custody for our data and know how our data flows
- Publish RULE and APPEALS process for transparent info on what = “reasonable fee”
  - Complaint to a patient is asking to be a problem/troublemaker and complainer to HHS
  - opening a case study/generating a lead
- Stop the sale of community and lab datasets that do not achieve next-level consent
  - Consider 23andMe, PatientsLikeMe, Iodine and others beyond formal consent
- In addition to a sustainability and dissemination plan, require an access to care plan
  - For technologies and resources developed through research funding

Recommendations
- PCORnet blanket statement about data used, specific definitions, info on workgroups, tasks – frequency
  - How is data held and secured
• Prepare formal announcement outlining network-wide goals in the IRB sphere to share with IRBs from all partner health systems
  o Increase IRB’s collective trust in PCORnet capacity
• We need to design a governance that is built around citizens rather than oriented around researchers
• Network governance and research ideas should come from the community
  o Grassroots up
• Requesting that patient advocates be able to present to the IRB’s that are evaluating proposal
  o Someone supported with “Great idea!”
• Registry
  o Seal of approval awards
  o Profile
• Can PCORI share tools and mandates for disseminating research results to participants with PCORnet networks? The CDRNs need to be hand-held and mandated until this becomes the norm
• Assemble and fund the broadcasting of PCORnet data consent standards
  o Publish broadly, open sourced and allow for community feedback, evolutions, etc....
     (ala GitHub, pinterest, etc...)
  o Though we may not end up with pinterest fail analogy
• Is community at the table on PCORnet
• Draw from best practices/lessons learned in other research and community engagement efforts such as CBPR literature, CES4Health, programs with a health partnership
• Many investigators want to do patient-centered research but have no idea how to do it!
  o Train and support researchers so that they can do PCOR
• We need to disambiguate data de-identification used in a legal way from what is happening in care delivery being portrayed as illegal
• Build cultural humility
• Common collaborative environment
  o Intra PCORnet wiki where we can add and edit
  o Where is NIH 8th grade research
  o Best practices
  o Link to engagement and recruitment tools
• More transparency in PCORnet is important
• Document to show and to enter as individual clinicians/researchers to share data/ideas
  o Discoverable directory of PPRN CDRN collection points
• Develop a standardized checklist/guidance doc that CDRNS and PPRNS can share with researchers to guide dissemination throughout the research process
  o “PCORnet requires that you…”
• Need to hear the play by play
• PCORI and PCORnet is encouraged to work on educating in conjunction with researchers and voluntary health agencies around trial process, consent and trustworthiness

• Identify best practices  
  o Ask PPRNs and CDRNs to write up a summary of formal trainings that they use for researchers, clinicians, and patients --> synthesize --> share resources --> create standardized materials

• Both PCORI and PCORnet websites are nothing but a circle of jargon and buzzwords  
  o No transparency or real content

• Provide $ in project budgets for engagement, dissemination

• Don’t forget about accountability in trustworthiness practices  
  o Relationships and accountability matter  
  o See Yarborough et al, AcadMed

• Place for citizens to go offer services  
  o More resources for clinicians to engage in research

• Advocacy groups do not have resources to negotiate indirects. Our overhead is more than 10%. In the meantime, academic institutions have huge indirect rates

• Networks tracking and sharing engagement data, instead of relying on anecdotes and “best practice” alone  
  o Use systematic, participant level track to monitor  
  o E.g., how many of those patients approached actually enroll? How do they rate the appropriateness of questions asked, methods used, and researcher actions?

• Having more trainings for community

• Funding mechanisms for diversity of projects and collaborations – PPRN – CDRN collaborations  
  o Smaller PCORnet studies  
  o Larger and long term studies

• Listing of committee membership  
  o Brief bios  
  o Contact info?

• Good housekeeping seal of approval  
  o Ability and competence  
  o Deliverables  
  o Integrity or ethics  
  o Listening  
  o Benevolence  
  o Rated outcomes  
  o Communication plans for dissemination of research  
  o Who is on committees of expertise

• PCORnet wiki  
  o Info edited reviewed by people off committee on workgroups  
  o A launch or share  
  o Communication message board

• Portal or place for things available  
  o Best practice site story format  
  o Principles and guidance  
    ▪ People have to live to do this work  
    ▪ Screened and approved as trustworthy

• Recognize diversity
- Increases awareness of PCORnet
- 2-way communication
- Acknowledging power of dynamics
- Gather resources shared
  - Bank of best practices
  - PCORnet DC to have resources to shorten time for co-creation
  - Internal and external communication