Patient-Centered Research Priorities in Pediatric Health in Colorado

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Disclosures

The authors have no financial relationships to disclose or Conflicts of Interest (COIs) to resolve
Objectives

1. Describe the process of applying for a PCORI Engagement Award
2. Identify strategies for successfully engaging patients in setting a research agenda in a PBRN context
Outline

• The ‘story’ of why we applied for PCOR-funding for COCONet
• The process of applying
• Summary of our PCOR project
• Progress so far
• Next steps and future directions
Background

2013: New leadership of Colorado Children’s Outcomes Network (COCONet), Colorado’s Pediatric Practice-based Research Network
Background – What is a PBRN?

Groups of primary care clinicians and practices working together to
– answer clinically-relevant research questions
– translate research findings into practice
Background

Colorado Children’s Outcomes Network

- Approximately 15 years of practice-based research partnerships
- Formalized in 2011
- 58 member practices (20 currently engaged in active studies)
- Steering Committee: 7 clinician representatives
- Research Advisory Board: 6 academicians
What does a PBRN Director do?

- Organize
- Support current studies
- Help decide what studies are appropriate for network
- Grow the network
- Solicit study ideas from clinicians
PROBLEM

• Traditionally in PBRNs study ideas come from the clinicians in the PBRN

• Clinicians are increasingly busy
  – EHR transitions, Meaningful Use, PCMH, etc

• We were having trouble getting research ideas from our clinicians
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WHAT’S MISSING?
What’s Missing? The Patients!

- Most PBRNs engage clinicians in developing research questions

- Few PBRNs engage patients or stakeholders in developing research questions

- Some PBRNs have patient advisory boards – we were aware of none that focused specifically on child health
Project Idea

- Generate research questions from the parents within our PBRN
- Funding source?
Eugene Washington Engagement Awards

Knowledge, Training and Development, and Dissemination Awards

– Up to $250,000; up to 2 years Project Term
– Competitive LOI
– Application due 40 days after invitation
Our Letter of Intent

• General goal: work with parents to generate research questions for PBRN
• More specific: develop a replicable model for engaging patients/parents and clinicians in the collaborative development of research questions and patient-centered research in the pediatric PBRN setting
• 90 key informant interviews (60 parent, 30 clinician)
• Process would inform 4-6 working groups to develop the questions
PCORI Feedback

- Invitation to apply (!)
- Modify the budget
- 90 interviews – too many?
- 4-6 working groups – too ambitious?
- Parent and clinician interviews – awesome, but what about other stakeholders?
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<th>Stakeholder Communities</th>
<th>PCORI Populations of Interest</th>
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Key parts of application...

- (Well-paid) Parent Advisors who would become part of study team
- (Well-paid) Community Partners
  - Family Voices Colorado
  - Family Leadership Training Institute
  - Colorado Children’s Campaign
- Large incentives for interviews that are equal between parents and stakeholders, including clinicians
- Food and childcare for meetings
Specific Aims

1. Identify patient-centered research priorities for child health research in Colorado

- 15-20 interviews with stakeholders such as clinicians, payers, policy makers.
- 35-40 interviews with parents, 5-10 interviews with adolescents
- Analyze interview data, rank research priorities with parents and other stakeholders.
Specific Aims

2. Develop a sustainable statewide network of parents with a focus on parent- and patient-identified child health issues which will inform the pediatric PBRN research agenda and ensure that any research conducted is patient-centered

- Identify 2 parent leaders for the Project Team
- Include parents and other stakeholders on our Network Advisory Board
- Designate 2 to 3 Working Groups
- Identify parents and clinicians to serve on Working Groups
- Provide Community Engagement Research Training to parents and clinicians
Specific Aims

3. Collaboratively develop with
   – parents,
   – adolescents,
   – child-health researchers,
   – clinicians at PBRN member practices

**specific** research questions related to the identified research priorities from Aim 1. These questions will form the foundation of future research studies and grant proposals.
Specific Aims

4. Produce a
   – workbook and
   – process model
for engaging parents in all phases of practice-based and patient-centered outcomes research, including issue and question development, network-building and dissemination of results.
Year One
Year Two

Meeting 1 Objective: Stakeholder Feedback Set Priorities
Group 1: Meeting 1
Group 2: Meeting 1
Group 3: Meeting 1

Meeting 2 Objective: Bring in Researchers Home research questions
Group 1: Meeting 2
Group 2: Meeting 2
Group 3: Meeting 2

Meeting 3 Objective: Finalize Research Questions Action Plan for Future Grant Proposals
Group 1: Meeting 3
Group 2: Meeting 3
Group 3: Meeting 3

OUTCOME: Meeting minutes
OUTCOME: Meeting minutes
OUTCOME: Action Plan for Project Proposals

Parent and Stakeholder Leaders Identified for Long Term Engagement
Sustainable Network Advisory Board
Progress So Far

• First step: Hired 3 parent advisors
• Semi-structured interviews and focus groups with 53 stakeholders from June 2015 – February 2016
• Purposive sampling for parent leaders and key informants
Progress So Far

- **29 parent interviews**
  - 9 Spanish-speaking parents
  - 12 (41%) parents of children with special health care needs

- **12 adolescents patients**
  - 2 interviews
  - 10 participated in 1 focus group.

- Interviewees represented geographic, socioeconomic, and racial/ethnic diversity.

- **12 stakeholder interviews***:
  - 3 Clinicians
  - 2 Public health
  - 2 Payers
  - 2 Policymakers
  - 2 Content experts
  - 4 Advocates

8 stakeholders were also parents of children <18 y.o.

*Stakeholder groups are not mutually exclusive.
Design/Methods

• Interview questions covered child health issues including
  – Personal healthcare experience;
  – Health issues that affect the interviewee and their community, and the healthcare system;
  – Researchable questions related to experience and issues

• Interviews were recorded, transcribed, translated, and placed into ATLAS.ti for analysis

• Stopped interviewing when thematic saturation was reached
Design/Methods

• Interviews were reviewed immediately for the emergence of key topics and themes
• Parent advisors participated with researchers in coding and analysis of transcripts
• Formal analysis followed an editing approach focused on identification of priority
  – Health topics
  – Health care processes
  – Research questions
  – Ideas for solutions/interventions
Results

Priority Health Issues

• Obesity
• Food and nutrition
• Immunizations
• Mental health
• Sexual health
• Drug use and substance abuse
Immunizations

“[Immunizations are] a huge, huge topic. And again being a Colorado native I'm kind of ashamed frankly or embarrassed by the recent trends in the vaccination rates for kindergartners in my home state. Because we're moving in the wrong direction. If the outbreak of measles at Disneyland, if it wasn't a wakeup call I don't know what is.” – Parent and child health advocate
Pediatric Mental Health Care

“I think our societal understanding of mental health is not very good. Mental health, it still has a huge stigma around it for people that struggle with mental health issues as a whole, leaving them feeling more isolated, I think, than other issues in particular.

I think, how do we identify those things in kids and how do we make it a normal or healthy enough thing to be talking about that they’re willing to say when they’re struggling with whatever, without feeling like they’re going to be stigmatized.” - Parent
Results

Health Care System Priorities

• Care coordination
• Patient-provider relationships
• Provider-to-provider communication
• Accessibility and availability of care
• Early childhood education
• Parent education on childhood health
Access and Availability

“I don't know that we have any pediatric providers in the county. There's not a medical clinic. There's not a pediatric provider within the county. So that just makes our public health department that much more important, as far as being a resource for information. But I don't know if they do referrals or help guide people to appropriate providers. [...]”

– Parent and early childhood education advocate
Emerging Research Questions:
• How can private practices improve the coordination of care and communication between providers?

• Why are parents hesitant about vaccination and how do we increase immunization rates in Colorado?
Doctor-Patient Relationships

“It wasn't a big secret that we would have somebody as our main pediatrician, but that probably we wouldn't actually be seeing that person every time we went in.

I remember growing up and having a relationship with my pediatrician and sort of having that trust […] and I think for young people it's especially important to be able to gain that trust in somebody that's poking and prodding you or whatever.

I was kind of disappointed in that because not only did I want my kids to have a relationship with their pediatrician, but I also wanted to have a relationship with their pediatrician to talk candidly about things.” - Parent
Results

Emerging Research Questions:

• How can parents be better advocates for their child’s health in the health care setting?
  – (Or teens for their own health?)

• How can you improve the doctor-patient relationship in pediatric settings? Does this improve health outcomes?
Parents as Advocates

“And you know you have parents who are not well-educated, they don't have a good understanding of what their rights and responsibilities are […]. How are they supposed to be effective advocates for their kid?” - Parent

“Nobody teaches you how to really prepare for a doctor visit, or how to really formulate questions or, you know. For myself, I struggled with healthcare. There's no -- they're not creating the space for any kind of a dialogue. We haven't had that in the pediatrics setting, but I would imagine a lot of people do or could. So what's that space? I'd love to see young girls be totally empowered around medical stuff and their bodies. Wouldn't that be so cool?” - Parent
Synthesis of Topic Areas Emerging from Qualitative Work

• Access to and availability of care including mental health
• Coordination of Care with and among Specialists and PCP’s
• Immunization refusal and Colorado’s low rates
• Pediatric Mental Health – Coordination, Communication and/or Integration with PCP
• Models for improving the Doctor-Patient Relationship
• Training Parents (or Teens) as Advocates for Care with Goal of Improved Health Outcomes
Ranking Survey

- Surveyed interview population plus other identified stakeholders to help provide some quantitative data for the Network Advisory Board
- 77% response rate (75/98)

Count of Respondents Identifying with Roles in Child Health
(Total N=73)*

- Practice Management: 2
- Payers: 4
- Policymakers: 6
- Patients/Adolescents: 11
- Health Researchers: 18
- Other: 19
- Advocacy staff/volunteers: 22
- Providers (MD, DO, etc): 32
- Parents: 47
## Ranking Survey

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Network Advisory Board

• Half parents, other half clinicians, academicians, advocates
  – Some interviewees, others suggested by interviewees and parent advisors
• First task was determining 3 Working Groups based on data from interviews and survey
• Met April 2016 for a 2-hour meeting
Network Advisory Board Meeting

• We suggested -- based on survey and interviews -- that mental health be one of the Working Groups, without objection

• Otherwise no guidance on how to choose the other two topic areas

• All participants actively involved in discussion

• Consensus reached in less than 2 hours
Final Topic Areas

1. Pediatric Mental Health – Coordination, Communication and/or Integration with PCP
2. Immunization refusal and Colorado’s low rates
3. Training Parents (or Teens) as Advocates for Care (with potential to incorporate other topic areas, such as care coordination or transitions)
Working Groups

• Selection of Working Group Membership
• Community Engaged Research Training
• Working Group meetings:
  – 3-4 over 6-8 months
  – Partner with researcher between meeting 1 and 2
  – Using online collaboration to maintain momentum
• Minimum goal is to have a Specific Aims page for a future PCOR grant (PCORI, AHRQ, or other)
• Sustainable Network Advisory Board
Future Directions

• Priority topics not in the top 3 will not be forgotten – future research topics
Study Team

- ACCORDS - University of Colorado Denver
  - Sean T O'Leary, MD MPH
  - Sarah Brewer, MA
  - Jodi Holtrop, PhD

- COCONet Parent Advisors
  - Natalie Crump, MS
  - Sean Crump
  - Cody Belzley

- COCONet Leadership Team
  - Elaine Morrato, DrPH MPH
  - Jack Westfall, MD
  - Don Nease, MD
  - Maret Felzein

- Collaborating Organizations
  - Tom Rose, Family Voices
  - Colorado Children’s Campaign
Acknowledgements

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• Thank you to Family Voices Colorado and the Colorado Children’s Campaign It’s About Kids Committee for assistance in identifying and recruiting parent leaders across the state.