WP1 PBRN to CBRN: Moving from Practice-Based Research Network to Community-Based Research Network in Michigan

Leslie Paulson, MSW; Michael Klinkman, MD, MS; Elisabeth Cross, MPH, CHES, CPH; Amy Schultz, MD, MPH Richard Thoune, MS

<u>SESSION SUMMARY;</u>
Practice-based research networks (PBRNs) have proven their value in carrying out translational research ranging from clinical trials to comparative effectiveness to community-based epidemiology. However, the past few years have seen rapid change in organization of primary care services, with practices increasingly owned by larger entities, systems struggling to integrate care, and a growing role for community stakeholders.   In this environment, questions of immediate importance to primary care have expanded to include health care redesign and transformation from HealthCare 1.0 (episodic) to HealthCare 2.0 (accountable care) – to HealthCare 3.0 (community integrated care). This changing landscape has impacted primary care PBRNs in profound ways.   Two years ago, in a participatory PBRN Conference workshop, PBRN Directors described collective experience of 4 established PBRNs (GRIN [Michigan], ORPRN [Oregon], SNOCAP [Colorado], and the Shared PBRN Shared Resource at CWRU [Ohio]) in dealing with these forces, focusing on strategic plan development, change management, and exploring new partnerships. This forum will describe the 'next steps' taken by GRIN to better serve the needs of patients and practices through creation of a 'Community-Based Research Network' in Jackson, Michigan.   PBRN to CBRN will describe transformation from 'classic' PBRN to a long-term partnership between community stakeholders, health care delivery systems, and investigators to address the broader community context in which health care occurs. Presenters will review steps taken by GRIN, the Michigan Institute for Clinical and Health Research (MICHR, GRIN's 'parent' CTSI), and the Jackson community to build this partnership to become a Community of Solution, and progress to date in forging a common agenda for behavioral health integration and community-wide interventions to guide our transition to HealthCare 3.0.   A series of short, interactive presentations will focus on several key steps: • GRIN history and context, and the growing limitations of its structure • MICHR (CTSI) history and context, and the disconnect between community engagement and clinical practice   • The Jackson community context: community demographics and grassroots health improvement efforts • The Invitation: how the partnership was launched • The Partners: the full roster of community and academic partners, and how they connect • Co-evolution of GRIN, CTSI, and community (partnership time line): creation of the Jackson Health Network to support community-wide health improvement, clinical practice transformation, and research and development. • Accomplishments (and disappointments) to date • Problems encountered along the way and lessons learned At the end of the session, participants will be able to understand the costs and benefits of this transformation, and can 'take home' one potential approach for aligning CTSI, PBRN, and community stakeholders to carry out this task.

<u>MEASURABLE OBJECTIVES:</u>
1. Analyze the costs and benefits of leveraging established PBRNs to form a 'CBRN' 2. Describe the differences in approach and operation for a traditional research network versus an integrated community-based network 3. Describe the essential steps in developing an academic-community partnership around a shared agenda for community-integrated care 4. 'Take home' one potential approach for aligning CTSI, PBRN, and community stakeholders

<u>AGENDA OUTLINE:</u>
Part 1 (45-60 min, depending on level of interaction) A series of short, interactive presentations by GRIN staff and community stakeholders: • GRIN history and context, and the growing limitations of its structure • MICHR (CTSI) history and context, and the disconnect between community engagement and clinical practice   • The Jackson community context: community demographics and grassroots health improvement efforts • The Invitation: how the partnership was launched • The Partners: the full roster of community and academic partners, and how they connect • Co-evolution of GRIN, CTSI, and community (partnership time line): creation of the Jackson Health Network to support community-wide health improvement, clinical practice transformation, and research and development. • Accomplishments (and disappointments) to date • Problems encountered along the way and lessons learned Part 2 (30-45 minutes) Questions and answers - with panel of all presenters, to respond to questions not addressed in part 1, or to provide more in-depth responses to issues addressed in part 1

<u>RELEVANCE STATEMENT:</u>
PBRN to CBRN will discuss and provide insight on forging a common agenda from clinical, research, and community perspectives, and vision for transforming a practice-based research network into a community-based research network.

WP2 Boot Camp Translation: a tool to engage communities for patient-centered outcomes

Jack Westfall, MD, MPH; Linda Zittleman, MSPH; Don Nease, MD; Maret Felzien, MA Ned Norman High Plains Research Network Community Advisory Council Paige Backlund Jarquin, MPH Montelle Tamez High Plains Research Network Community Advisory Council

SESSION SUMMARY;
Community engagement is essential to translating the best medical evidence into community and clinical practice to improve the health of a population. A crucial, yet frequently incomplete step is the translation of scientific evidence-based guidelines and recommendations into constructs and language meaningful to patients and community members. Built on the principles of community-based participatory research, Boot Camp Translation (BCT) is a process by which medical information and clinical guidelines are translated into concepts, messages, and materials that are understandable, meaningful, and engaging to community members. Developed in a practice-based research environment, BCT utilizes the skills and expertise of academic researchers, medical professionals, and community members to make the vast array of medical information accessible to every-day folks from all walks of life. Through this process, partnerships determine the health messages, tools, and ways to disseminate the messages and tools in ways that combine scientific integrity with local cultural relevance. BCT has translated evidence-based medical guidelines and recommendations into reliable clinical opportunities for communities to improve rates of colon cancer testing, asthma diagnosis and management, high blood pressure care, implementation of self-management tools, cancer survivorship care, and patient centered medical home implementation. BCT helps develop and strengthen the necessary relationship between community members, patients, practice staff and providers, and academic partners essential for truly effective patient-centered outcomes research. This workshop will introduce participants to the BCT process, concepts, steps, team skills, timelines, and budget considerations. Examples from completed BCT projects will be shared to illustrate how the process has been used by practice-based research networks in practice and community settings. Participants will explore ways the BCT process can be applied to their projects and work environment. Stakeholders and community members who have participated in the BCT process will help lead the session. Information about BCT training and the BCT Guidebook will be available.

MEASURABLE OBJECTIVES:
Participants attending this workshop will be able to: 1. Describe the aims and components of the Boot Camp Translation (BCT) process. 2. Identify examples of how BCT has enhanced and altered practice-based research projects. 3. Identify potential application of the BCT process in current and future research projects, including personnel and financial needs.

AGENDA OUTLINE:
This will be an interactive session with time for questions and discussion built into each section.   Welcome and Introductions (5 minutes) Boot Camp Translation: what it is, what it's not (15 minutes) Brainstorming Your Boot Camp Translation (15 minutes; including when to use BCT and when not to) What goes into a Boot Camp Translation? (10 minutes) • Team • Timelines • Budgets Your Boot Camp Translation Redux: Further fleshing out your BCT ideas (20 minute)   Additional BCT resources (5 minutes) Wrap up (5 minutes)

RELEVANCE STATEMENT:
There is a growing demand for tools that effectively engage community members in research that matters to patients and improves health. Boot Camp Translation (BCT) is one tool that can help develop and strengthen the necessary relationship between community members, patients, practice staff and providers, and academic partners essential for truly effective patient-centered outcomes research. BCT does this by using the skills and expertise of all project partners to help make a variety of medical information more accessible to every-day folks from all walks of life.

WP3 Moving Beyond the Job Description: Exploring How Practice Facilitators Support Primary Care

Ann Romer, MS; Beth Sommers, MPH, CPHQ; ; LeAnn Michaels; Molly Hamlin; Mark Remiker, MA

SESSION SUMMARY;
The Practice facilitator (PF) can play an essential role in how PBRNs support quality improvement and practice transformation work in primary care. The role of a facilitator is typically highly variable, and must bridge the world of academia and the realities of daily practice operations. Practice facilitation is predicated upon the importance of relationship building. Developing relationships with practices is critical to determining what components of facilitation are needed to be effective in supporting practices in their improvement efforts. Long-term relationship building allows PFs to influence practice re-design and can support the sustainability of practice change, but relationships of any duration require the PF to be knowledgeable about a variety of issues common or specific to how a practice functions as a whole. Practices are often unaware of or unable to articulate their specific barriers or needs, thus the skill of a facilitator is called on to build both QI capacity as well as more basic organizational awareness. In addition, because practice facilitators support multiple practices simultaneously, they are well-positioned to disseminate good or "best" practices, as well as provide objective and sincere feedback on practice needs and concerns.   The three projects that will be discussed in the presentation are representative of some of the objective criteria common to PBRN projects that utilize practice facilitation. Criteria that will be described include the ratio of PF to number of practices; baseline practice readiness; duration/frequency of outreach; and PF objective's specific to each project. Project scope may define a set amount or type of facilitator contact with practices– phone, email, in-person visits, but it is often up to the facilitator to ascertain how best to engage and support the practices in meeting project objectives. Presenters will describe how a PF balances the requirements of a project with the relative capacity of a given practice. Session presenters will describe their work as practice facilitators and identify lessons learned in three projects, then engage audience members to discuss their experiences and share their input on the topics discussed in the session.

MEASURABLE OBJECTIVES:
1.) To understand the similarities and differences between practice facilitation scope relative to QI project type. 2.) Understand the generalizability of practice facilitation competencies in different project settings. 3.) To share audience experiences with different practice facilitation approaches/competencies.

AGENDA OUTLINE:
0 – 5 mins: Welcome and Presenter Introductions (Moderator: Ann Romer); 5 – 20 mins: Project Example 1: TOPMED (Beth Sommers); 20 – 35 mins: Project Example 2: CPCi (Ann Romer); 35 – 50 mins: Project Example 3: BHH (Beth Sommers); 50 – 75 mins: Interactive Discussion

WP4 Creating the value proposition for practice and clinician recruitment in PBRN studies of practice change/transformation

LJ Fagnan; Steve Ornstein, MD; Michelle Greiver, MD, MSc; Mickey Eder, PhD; LJ Fagnan, MD fagnanl@ohsu.edu

<u>SESSION SUMMARY;</u>
PBRNs are challenged with recruiting and engaging practices in PBRN studies.   Competing spheres of authority and priorities at the practice, health system, regional and national levels create barriers to participation at a time when collaboration and shared learning is needed. PBRN researchers will share their experience and approaches to recruiting, engaging and retaining primary care practices and clinicians in practice change and quality improvement studies.   Workshop participants will participate in small group discussions to explore PBRN recruitment strategies and methodologies.   Developing incentives and creating value propositions that align with the practices goals and operational imperatives are part of each PBRNs recruitment strategies. It is not easy to develop and implement project incentive packages as these packages must appeal to and balance the mix of internal and external factors driving practice change. Lee and Cosgrove have adapted Max Weber's typology of social action to engage physicians in redesigning health care—Harvard Business Review, June 2014.   The four motives categorized as traditional, self-interest, affective, and shared purpose will be used to develop a motivational tools template for PBRNs. The template will form the foundation for creating a value proposition statement or statements to take on the practice recruitment road.

<u>MEASURABLE OBJECTIVES:</u>
1. Identify type of practice change/transformation projects conducted by PBRNs in Canada and the U.S. 2. Develop a list of challenges confronting PBRNs in practice recruitment. 3. Apply the four motivations for social action to create a motivational tool template for PBRNs to use in developing value propositions. 4. Create examples of value propositions to use in recruiting practices.

<u>AGENDA OUTLINE:</u>
1. Introduction of participants—getting acquainted. 5 minutes 2. Workshop overview of—5 minutes 3. Brief presentations of the practice recruitment challenges and strategies to recruitment—20 minutes 4. Development of the PBRN motivational tool template based on the Weber typology. Working in groups of 6 to 8 participants. Include report out—20 minutes 5. Create examples of value propositions to recruit practices for quality improvement and practice transformation studies—20 minutes

<u>RELEVANCE STATEMENT:</u>
Recruiting primary care practices to participate in practice change and improvement studies requires an alignment of incentives. The Weber typology for social action—creating shared purpose, appealing to self-interest, earning respect and embracing tradition is a useful tool to create value propositions for PBRNs to use in practice recruitment.

WP5 Qualitative comparative analysis: What it is, when to use it, and how it works for PBRN research

Jodi Summers Holtrop, PhD; Douglas Fernald, MA; Donald Nease, MD

SESSION SUMMARY;
Important questions applicable to PBRN research examine characteristics of practices, patients, the community and how these characteristics interact with a particular intervention to affect an outcome of interest. To determine the necessary (or always needed) and sufficient (needed in some situations) combination of elements important to effectively implement an intervention, analytic methods are needed to identify these important elements. Unfortunately, common statistical methods do not apply well to this type of work. Qualitative Comparative Analysis, or QCA, builds on both qualitative and quantitative data commonly collected in PBRNs, while offering advantages over standard statistical methods. In this session, we will present the qualitative-quantitative method of QCA. QCA is an analytical method based on set theory, developed in the social sciences, to address two needs: 1) comparative analysis of "small-N" case studies, with samples in the 5-50 range, and 2) to study causal complexity. Causal complexity includes equifinality, i.e., multiple paths to the same outcome, and configurational causation, i.e., any given factor may have an impact on the outcome only when other factors are present or specifically absent. Use of the QCA method allows researchers to examine data collected both quantitatively and qualitatively to examine patterns (or combinations) in the data associated with a desired outcome. Further, it allows the researcher to determine both what might be necessary (must be present to produce a positive outcome) and sufficient (condition or set of conditions that can produce a positive outcome). Completing a QCA requires consideration of the cases under examination, the outcomes of interest, and the inputs (or "conditions") that are most impactful on the outcome of interest. The analysis of QCA data requires completion of the following steps: calibration of the data set, necessity analysis, and sufficiency analysis.   During the session, we first will describe what QCA is, how it can be applied to PBRN research, and sources for more information on learning about it. Next, we will provide two examples of how QCA works utilizing two separate research projects funded by AHRQ: 1) A Comparison of Provider versus Health Plan Care Management in Michigan and 2) INSTTEPP (Implementing Network's Self-management Tools Through Engaging Patients and Practices). Most of the session will be working through a simple example with QCA in small groups. Finally, a brief discussion of the utility and lessons learned will be shared across the group.

MEASURABLE OBJECTIVES:
By the end of the session, participants will be able to: 1. Describe what QCA is and its relevance to PBRN research. 2. Describe examples of how QCA can be used in PBRN research. 3. Advantages and disadvantages of QCA compared to other analyses. 4. Work through a basic QCA analysis and know where to go for further resources and training.

AGENDA OUTLINE:
In this workshop, we will 1. present an overview of QCA – what it is, advantages and drawbacks to its use and basic background of how it works – lecture 10 minutes 2. provide examples of the use of QCA – lecture 15 minutes 3. work through examples of how to use it – small group and discussion 45 minutes 4. resources for further learning about QCA – discussion 5 minutes

RELEVANCE STATEMENT:
PBRN research often includes the practice as the unit of measurement and therefore is constrained by a limited sample size. Also, PBRN research involves complex interventions in which multiple conditions should be considered. QCA provides a way to handle both qualitative and quantitative information for a small to medium set of cases and examine the patterns that lead to success. Therefore, this method has high relevance to the PBRN community. Doing QCA well requires understanding and practice to maximize its benefit.

WP6 Jump Start Your Stakeholder Engagement with a Community Engagement Studio

Tiffany Israel MSSW; Yvonne Joosten MPH; Helena Farrow MSP

SESSION SUMMARY;
The Community Engagement Studio (CES) is a guidance session to facilitate project-specific input from diverse stakeholders. This structured yet simple process is effective for engaging patients, caregivers, health care providers and other non-researcher stakeholders. A unique panel of stakeholders is created for each CES, tailored to the focus of the research. These stakeholders are selected because of their firsthand knowledge or lived experience of condition, experience or community that is the focus research. The stakeholders are consultants, not research subjects and receive equitable compensation for their time.   Investigators may request a CES at any stage of their project, but are encouraged to do so in the early stages of idea generation or proposal development. The CES team works with the researcher to clarify their goals, determine the characteristics of the stakeholder panel and formulate the specific questions that will be posed to the stakeholders. The face-to-face CES meeting is facilitated by an experienced, neutral moderator trained to ensure that the stakeholders are comfortable sharing their experiences and opinions and that the researcher's questions are addressed. Each CES begins with a brief presentation from the researcher. Two to three key questions are presented to the stakeholder panel, and the moderator facilitates the ensuing discussion. Researcher and stakeholder evaluation of the CES process indicates that participating in a CES increases the researcher's understanding of the stakeholder's perspective and creates an awareness of stakeholder priorities and needs. Stakeholders indicate that their experience increases their understanding of the research endeavor. From the researcher perspective, the benefits of a CES include: access to diverse stakeholders without the complexity of scheduling multiple meetings; immediate feedback at different stages of project development and implementation; potential to build on-going relationships with stakeholders who are interested in serving in a research advisory role or as a member of a research team. For researchers who are not experienced in stakeholder engagement, it can open the door to a more patient-centered approach to their work. The CES model has been used to enhance the planning, design, implementation, translation and dissemination of research and is well suited to strengthen patient-centered outcomes research. Attendees will have the opportunity to experience the CES process and will gain new understanding of how stakeholders can contribute meaningfully to research. The CES team will also share ideas on how to recruit stakeholders and grow their capacity to contribute to research.

MEASURABLE OBJECTIVES:
1. Gain access to tools needed to implement the Community Engagement Studio model to improve patient/stakeholder engagement in your PBRN. 2. Increase understanding of the areas in which stakeholders can contribute to the development, implementation and dissemination of research. 3. Gain new knowledge about how to recruit stakeholders and grow their capacity to contribute meaningfully to research.

AGENDA OUTLINE:
1. Context setting for demo Community Engagement Studio 2. Demo Community Engagement Studio 3. Presentation on CES implementation process 4. Discussion

RELEVANCE STATEMENT:
Stakeholder engagement is fraught with challenges to clinical researchers and can be intimidating for the stakeholder who is new to the concept. The Community Engagement Studio provides a structured yet simple approach that elicits meaningful stakeholder input and creates a pathway for ongoing stakeholder involvement in research.

WP7 Moving Practice Based Research Networks Beyond the Physician's Office: Affiliate PBRN Contributions and Opportunities for Collaboration

Rosa Hand, MS, RDN, LD; Margie Snyder, PharmD, MPH; Diane Mastnardo, BS, LMT; Eric Sauers, PhD, ATC, FNATA;

SESSION SUMMARY;

PBRNs originated with primary care physicians but the methodology and goals are relevant to many other health professions. Just as health care is becoming more collaborative, PBRN research must also become multi-disciplinary. This panel will focus on four PBRNs that represent dietetics, massage, pharmacy, and athletic training. Each network's director will share their contributions to the PBRN field and their vision of opportunities for collaboration with other affiliate and traditional PBRNs. Besides representing different professions, the four selected PBRNs also represent different geographic ranges, stages of development, and experience with collaborations, which will provide additional insight into opportunities for PBRNs to move beyond the physician's office. There will be significant time for question and discussion from the audience with a focus on network collaboration. A short summary of the four participating networks is below: --The Dietetics Practice Based Research Network (DPBRN) has existed for 12 years and is based out of the professional organization of registered dietitian nutritionists (RDNs). The DPBRN has a history of successful single-network projects including a large card study on the job duties of RDNs and a collaboration with the Pediatric Research In Office Settings (PROS) network.   --The Massage of Northern Ohio Practice Based Research Network (MNOPBRN) is a regional network made up of individually practicing licensed massage therapists that was formed in May of 2014. Their mission is to improve access to Massage Therapy, to conduct research on massage efficacy, and to educate the public, healthcare providers, and policy makers about massage. MNOPBRN is currently proposing a card study that will investigate healthcare provider recommendation of massage therapy for their patients.   --The Medication Safety Research Network of Indiana (Rx-SafeNet) is a statewide practice-based research network of approximately 170 community pharmacies throughout Indiana. Their mission is "to improve medication safety and advance community pharmacy practice in Indiana through the conduct and dissemination of collaborative, patient-centered, practice-based research." ---The mission of the Athletic Training PBRN is to improve the quality of care and patient outcomes in patients under the care of certified athletic trainers. The PBRN is administered through A.T. Still University and consists of partnerships with Professional (a.k.a., entry-level) and Post-Professional Athletic Training Education Programs as well as hospital groups and clinics, establishing a geographically diverse group of over 70 clinical sites across the United States.

MEASURABLE OBJECTIVES:

Attendees will be able to describe the membership characteristics of four affiliate PBRNs Attendees will be able to explain one completed project of each of the four affiliate PBRNs Attendees will be able to discuss opportunities for affiliate PBRNs to work with eachother or traditional PBRNs.

AGENDA OUTLINE:

5 minute introduction 10-15 minutes per network to discuss membership, completed projects, and opportunities 15 minutes for questions/discussion with audience

RELEVANCE STATEMENT:

Many health professionals contribute to the care of a patient; therefore research must also become collaborative within professions. This session will discuss research being conducted by non-physician health professionals and provide an opportunity for discussion about how those networks can work together.

WP8 ADAPT-NC: A Multi-Institutional Approach to a Shared Decision Making Dissemination Study from Practice Facilitators' Perspective

Jennifer Rees RN, CPF; Jennifer R Rees, RN, CPF; Kelly W Reeves, BSN, RN; Lori Hendrickson, RN, BSN, CCRP; Beth Patterson, RN, BSN; Delane Gewirtzman, MSN, RN; Lindsay E. Kuhn, MHS, PA-C; Paul Bray, MA, LMFT; Kathleen Mottus , PhD; Madeline Mitchell, MURP; Thamara A. Hege, MSPH

SESSION SUMMARY;

Asthma is a common disease that affects people of all ages and has significant morbidity and mortality. Poor outcomes and health disparities related to asthma result, in part, from the difficulty of disseminating new evidence and care delivery methods such as shared decision making (SDM) into clinical practice. The ADAPT-NC asthma shared decision making intervention was developed in prior studies and showed marked improvement in patient outcomes (improved medication adherence and decreased asthma exacerbations) with increased patient involvement in the creation of their care plan. The current 3-year study explores the effectiveness of disseminating a SDM toolkit using practice facilitation approach across 30 primary care practices across North Carolina. The practices were randomized to one of three dissemination method arms: (1) control, no active dissemination; (2) traditional dissemination, one didactic session a year and distribution of educational material; and (3) facilitator-led participant owned (FLOW) dissemination that includes a series of up to 12 on-site visits to help guide change towards enhanced use of shared decision making. The dissemination approaches will be evaluated by: 1) asthma outcome measures, including asthma exacerbations; 2) level of patient involvement in the decision making process through survey collection; and 3) qualitative assessments from patients and providers through focus group participation. The primary research question is: Which strategy most effectively increases practice adoption of shared decision making in asthma management? The study will provide crucial data to support best practices in dissemination of an evidence-based toolkit and implementation of shared decision making in primary care. During the panel discussion, Practice Facilitators (PFs) representing the 4 participating PBRNs will describe: (1) successes; (2) challenges/barriers overcome; and (3) lessons learned. They will discuss common themes including, but not limited to, practice and patient recruitment, practice readiness to participate, staffing dynamics, organizational barriers, individual tailoring of the toolkit, effective identification and engagement of a "practice champion," provider concerns about the impact of the intervention on productivity, provider and staff "buy in" relating to potential improvement in patient outcomes, and efficient implementation of SDM visits. They will discuss how supporting each other, effective communication, and sharing of best practices were instrumental in the successes experienced thus far.

MEASURABLE OBJECTIVES:

By the end of this sessions, participants will be able to: 1. Describe mutual challenges that occurred across the 4 PBRN's 2. Recall strategies used by each PBRN to overcome their challenges 3. Apply lessons learned from this project to their own future projects or projects already underway

AGENDA OUTLINE:

5 minute introduction to study 5 minutes introduction of panel members and moderator 45 minutes panel to answer 3 questions 15 minutes questions and answer from the audience 5 minutes moderator summary and wrap up

RELEVANCE STATEMENT:

A patient centered multi-institutional asthma shared decision making intervention can be successfully completed with good communication, mutual understanding, and respect of individual site's challenges and with cross institutional encouragement and support.

WP9 Engaging Parents in Research: Creation of a Parent Research Advisory Board in a Pediatric PBRN

James Massey, RN, MBA; Louis Bell, MD; Alexander Fiks, MD, MSCE

SESSION SUMMARY;
Engaging families, caregivers, clinicians, other stakeholders and researchers throughout the research process is critical to successfully performing clinical effectiveness and patient-centered outcomes research in practice settings.   In an effort to be responsive to parents and families in research protocol development and implementation, the Pediatric Research Consortium at The Children's Hospital of Philadelphia created a PBRN-supported Research Parent Advisory Board, tightly integrated with the process for study review and approval. Through this process, parents, trained by the hospital's family advisors and the PBRN, provide feedback about all proposed research studies and inform discussions of the network's Steering Committee. With this successful program, parents now review and contribute to the approval of all research studies.   This presentation details the creation and use of a Research Parent Advisory Board as an integral part of a thriving PBRN. We will review how prospective parents were identified with the help of the network; how Parent Advisory Board members were selected and trained; reimbursement; the infrastructure used to asynchronously communicate study information and gather feedback; and the process used for parents and researchers to discuss study issues and resolve concerns. Overall statistics and multiple specific case examples will be provided to demonstrate the effectiveness of the process.   Thus far, parents have informed the development of 18 studies, all of the proposals submitted to the PBRN since the creation of the Parent Advisory Board. 15 have been approved without modification and 3 generated discussion to resolve concerns. Although just completing its first year, we expect the board to play a growing role in supporting applications involving the PBRN to the Patient-Centered Outcomes Research Institute (PCORI) and other groups prioritizing the engagement of families as well as other stakeholders.

MEASURABLE OBJECTIVES:
1. Participants will be able to utilize their PBRN clinicians to identify appropriate parent volunteer referrals for a Research Parent Advisory Board. 2. Participants will understand the needed infrastructure to support a Research Parent Advisory Board. 3. Participants will be able to leverage the strengths of the Research Parent Advisory Board to identify appropriate research studies for their PBRN and help them succeed.

AGENDA OUTLINE:
• Describe the overall scope and structure of a Research Parent Advisory Board. • Strategies for engaging PBRN clinicians and practices to solicit referral of prospective parent volunteers. • Process of communicating with parent nominees and the selection and training of parents to be effective partners. • Strategies for soliciting feedback from parents about specific research studies. • Approaches for communicating parent concerns about studies to researchers and negotiating different perspectives. • Presentation of case examples of PBRN studies reviewed by our Research Parent Advisory Board and their outcomes.

RELEVANCE STATEMENT:
A Research Parent Advisory Board, when carefully implemented and supported, can be critically important to promote engaging, meaningful PBRN supported research.

WP10 Gathering Sexual Orientation and Gender Identity Demographics in the Clinical Setting

Harry Reyes Nieva; Harry Reyes Nieva; Jeffrey Linder, MD, MPH, FACP

SESSION SUMMARY;
The U.S. Department of Health and Human Services, Institute of Medicine, and Joint Commission support gathering health data on LGBT populations to improve patient care, facilitate research, and reduce LGBT health disparities. In a recent national study, the Fenway Institute and Center for American Progress demonstrated that gathering information on sexual orientation and gender identity (SO/GI) is acceptable to patients and feasible. Despite the potential to improve care and advance much needed health-related research, few institutions currently include sexual orientation and gender identity among the core set of demographics routinely collected in the clinical setting. During development and rollout of a new electronic health record (EHR), members of PBRN LGBT employee resource groups created a successful task force to advocate for gathering SO/GI demographics across the institutions of their large, academically-affiliated health system and formed a working group to develop and implement a data collection framework for their network. This session will 1) summarize national policy and key recommendations regarding the collection of SO/GI information in the clinical setting; 2) provide a case study of the advocacy and implementation efforts of PBRN LGBT employee resource groups involved in championing the inclusion of SO/GI demographics in their EHR; and 3) develop strategies for PBRN members interested in forming similar initiatives at their institutions.

MEASURABLE OBJECTIVES:
By the end of this workshop, participants will be able to: 1. Describe how national policy and key stakeholders demonstrate support for collection of sexual orientation and gender identity demographics by healthcare providers to improve patient care, facilitate necessary research, and reduce disparities. 2. List strategies to advocate for the inclusion of sexual orientation and gender identity among the core set of demographics routinely collected in the clinical setting. 3. Discuss implementation concerns, issues, and solutions regarding the collection of sexual orientation and gender identity demographics in the electronic health record.

AGENDA OUTLINE:
1. Introduction to gathering sexual orientation and gender identity demographics in the electronic health record (20 minutes) — Didactic presentation using PowerPoint 1-1. Background on the LGBT data collection gap, national support for gathering SO/GI information in the clinical setting, and the role of electronic health records in standardizing data collection and facilitating improvements in care and research (10 minutes) 1-2. Case study of an employee-driven initiative to advocate for gathering SO/GI demographics in a large, academically-affiliated health system; implementation concerns, issues, and solutions from a SO/GI data collection working group (10 minutes) 2. Small group break-outs (30 minutes) 2-1. Strategies for building a coalition to advocate for the collection of SO/GI demographics (15 minutes) 2-2. Forming a working group to plan implementation of a SO/GI data collection framework (15 minutes) 3. Report back and large group discussion (20 minutes) 4. Wrap-Up & evaluations (5 minutes)

RELEVANCE STATEMENT:
Gathering information about patients' sexual orientation and gender identity improve understanding about how sexual orientation or gender identity can affect health, helps healthcare providers deliver higher quality care, and has the potential to reduce disparities in health for LGBT people.

WP11 PBRN Research Best Practices: Stakeholder Engagement

Maeve O'Beirne, MD, PhD; Kimberly Campbell-Voytal, PhD, RN; Rowena Dolor, MD, MHS; Katrina Donahue, MD, MPH; Margaret Love, PhD; Sveta Mohanan, MD; Victoria Neale, PhD, MPH; Hazel Tapp, PhD

<u>**SESSION SUMMARY;**</u>
This interactive session will identify essential strategies for engaging stakeholders in the work of a PBRN. Stakeholders may include: funders, researchers, primary care clinics, patients, the public, learners, and others as decided by the workshop participants. During the course of the session, both the workshop leaders and the attendees will share strategies and examples from their experience of being part of a PBRN.   Attendees will learn effective strategies they can use to engage stakeholders within their own PBRNs. Participants will determine strategies for the engagement of stakeholders in PBRN work and determine best practices for the use of these strategies by a PBRN.   The session will start with a brief overview, where workshop leaders present a short literature review of others' work in this area to set the context and stimulate subsequent discussion. Small group work will follow, where pre-identified questions focus their "table top" discussions (eg. strategies for different stakeholders, for the PBRN as a whole, and for specific projects). Good practices will also emerge from discussion of positive outcomes to engagement, supports and barriers to engagement, and methods to overcome barriers. When the small groups report back to the larger group, participants will not only exchange strategies, but also collectively identify areas in which they continue to seek solutions.   This session was developed by the Practice-Based Research (PBR) Working Group of the NAPCRG Committee on Advancing the Science of Family Medicine (CASFM). The PBR Working Group has prepared the electronic document, "PBRN Research Good Practices" (Neale et al.). Participants' input will lay the foundation for the new chapter about Stakeholder Engagement (O'Beirne et al.). The workshop leaders represent a diverse set of U.S. and Canadian PBRNs. They contribute their experience in developing PBRN infrastructure and conducting PBRN research, as well as their skills in facilitating collaborative group processes and problem solving.   Participants at all levels of experience are welcome and would make a valuable contribution to the workshop.

<u>**MEASURABLE OBJECTIVES:**</u>
Attendees will learn effective strategies they can adopt for engaging stakeholders within their own PBRNs by: (1) Determining strategies for the engagement of stakeholders in PBRN work (2) Determining best practices for the use of these strategies by a PBRN (3) Laying the foundation for a "Good Practices: Stakeholders Engagement" chapter as part of the document "PBRN Research Good Practices" developed by Neale et al.

<u>**AGENDA OUTLINE:**</u>
Opening Panel (10 minutes): The session will start with a brief overview, where workshop leaders present others' work in this area to set the context. Abbreviated examples will stimulate the small group work to follow.   "Table Top" Small Group Discussions (50 minutes): Session participants will generate essential strategies for engaging stakeholders based on their experience working in PBRNs. Workshop leaders will facilitate each small group with pre-identified questions and discussion prompts.   Large Group Discussion (15 minutes): The small groups will report back to the larger group to exchange their successful strategies and further discuss best practices.

<u>**RELEVANCE STATEMENT:**</u>
Stakeholders, including funders, researchers, primary care clinics, patients, the public, and learners, are increasingly important partners in practice based research networks.   This workshop will identify strategies and best practices for stakeholder engagement.

WP12 Integrating Maintenance of Certification (MOC) Part IV Requirements in PBRN Research

Tana Brown; Michael Parchman, MD, MPH; Rebecca Roper, MS, MPH; ;

<u>SESSION SUMMARY;</u>
The AHRQ PBRN Resource Center will present an overview of a field guide developed to help primary care practice-based research networks (PBRNs) better understand how they can be a resource to and support their members in meeting Maintenance of Certification (MOC) requirements from the three primary care medical specialty boards, specifically MOC Part IV requirements, which relate to quality improvement (QI). This is not a "how to" manual, but provides guidance about MOC Part IV requirements of the three primary care medical specialty boards: the American Board of Family Medicine (ABFM), the American Board of Internal Medicine (ABIM), and the American Board of Pediatrics (ABP). This guide was created for PBRNs that wish to better align their mission with the needs of their members. The intended audience is primary care PBRN directors, assistant directors, coordinators and other PBRN staff such as practice facilitators. Topics covered will include an overview of the MOC process, examples of different levels of support that a PBRN might provide its members, how a research study might be used to meet MOC Part IV requirements, how PBRN resources and infrastructure are currently configured or might be reconfigured to support MOC Part IV activates, and a comparison of similarities and differences across the three primary care specialties boards of MOC Part IV requirements.

<u>MEASURABLE OBJECTIVES:</u>
1. Describe the purpose of MOC Part IV requirements. 2. Give examples of different levels of support that PBRNs might provide in assisting their members in meeting MOC Part IV requirements. 3. Explain how MOC Part IV activities can be integrated into a research study. 4. Compare and contrast MOC Part IV requirements across the three primary care specialty boards.

<u>AGENDA OUTLINE:</u>
1. Introduction to the Guide (Rebecca Roper) [5 min] 2. Overview of the Guide (Michael Parchman) [40 min]   a. Leveraging PBRN Capacity to Develop an MOC Part IV Infrastructure   b. How PBRNs can help their Members Meet MOC Part IV Requirements   c. Integrating MOC Part IV Credit within a PBRN Research Project   d. How to develop and apply for an MOC Part IV Activity   e. Practical Tips and Advice   f. The ABMS Multi-Specialty MOC Portfolio Program 3. Conclusion / Q&A (Michael Parchman, Rebecca Roper) [30 min]

<u>RELEVANCE STATEMENT:</u>
This session will provide an overview of how a PBRN can support primary care clinicians in improving the quality of care they deliver by fulfilling requirements from their medical specialty board.