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PBRN Research Good Practices (PRGPs) Report

Presented By:

Anne Victoria Neale, PhD, MPH; Kimberly Campbell-Voytal, PhD, MSN; Rowena Dolor, MD, MS;
Barcey Levy, PhD, MD; LeAnn Michaels; Zsolt Nagykaldi, PhD

Moderated By:

Rebecca Roper, MS, MPH, Director, Practice-Based Research Network Initiative,
Agency for Healthcare Research and Quality

Sponsored by the AHRQ PBRN Resource Center

September 30, 2014



Agenda

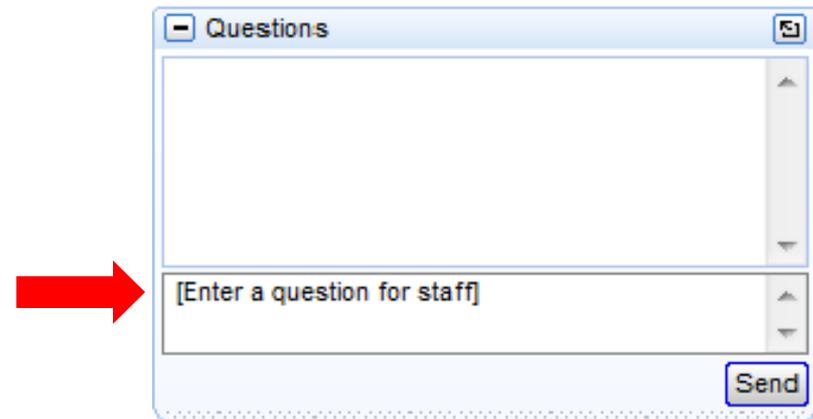
- Welcome and introductions
- Presentations
- Q&A session with all presenters
- Instructions for obtaining CME credits

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Today's Presenters

Overview of the Formative Research Process that Produced the PBRN Research Good Practices (PRGPs)



Anne Victoria Neale, PhD, MPH
Professor, Wayne State University;

Research Director, MetroNet;

Director, Primary Care MultiEthnic Network (PRIME Net) Center
for Practice-based Research and Learning



Today's Presenters

Engaging the Wisdom of 7 Experienced PBRNs with Team-Building Strategies



Kimberly D. Campbell-Voytal, PhD, MSN
Assistant Professor,
Wayne State University;
Member of MetroNet



Today's Presenters

Chapter 1: Building PBRN Infrastructure



Zsolt J. Nagykaldi, PhD

Associate Professor and Director of Research,
Department of Family and Preventive Medicine,
University of Oklahoma Health Sciences Center;

Research Director, Oklahoma Physicians Resource/Research Network
(OKPRN)



Today's Presenters

Chapter 2: Study Development and Implementation



LeAnn Michaels

Manager, Oregon Rural Practice-based Research
Network (ORPRN)



Today's Presenters

Chapter 3: Data Management



Barcey Levy, MD, PhD

Iowa Academy of Family Physicians Endowed Chair in Rural Medicine;

Professor of Family Medicine, University of Iowa, Carver College of Medicine;

Professor of Epidemiology, University of Iowa, College of Public Health;

Director, Iowa Research Network (IRENE)



Today's Presenters

Chapter 4: Dissemination Policies



Rowena Dolor, MD, MHS
Associate Professor of Medicine,
Duke University Medical Center;

Director, Primary Care Research Consortium (PCRC)



Polling Question:
Are you considering starting a PBRN, or in the first year of having a PBRN?



Polling Question:
Do you consider yourself (Check one):

Overview of the
“PBRN Research Good Practices (PRGP)”

National webinar brought to you by the
AHRQ PBRN Resource Center

September 30, 2014

Today's Forum Panel

- Victoria Neale (MetroNet)
- Kimberly Campbell-Voytal (MetroNet)
- Zsolt Nagykaldi (OKPRN)
- LeAnn Michaels (ORPRN)
- Barcey T. Levy (IRENE)
- Rowena Dolor (Duke PCRC)

Webinar Objectives

- 1) To review the background of how the *PBRN Research Good Practices (PRGPs)* were developed through a multi-stage process that involved the national PBRN community.
- 2) To introduce the *PBRN Research Good Practices (PRGP)*, a resource developed specifically for the context of PBR.

Research Program Rationale

- PBRN-specific model of research governance needed to:
 - Promote reliable research processes
 - Tailored to PBRN research needs
 - Maintain quality processes across staff, sites and studies
 - Promote PBRN research professionalism and capacity as quality research organizations

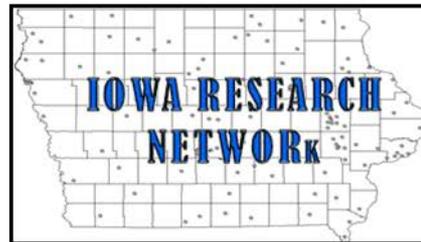
Initial AHRQ-funded study

- *Research Culture of PBRNs* (Neale R01)
- Participatory process with PBRNs, developed psychometrically-sound self-assessment tool for PBRNs to identify strengths/weaknesses in research practice
- “PBRN Research Best Practices Checklist”: 31 ‘essential’ research best practices specific to the PBRN setting

AHRQ-funded Demonstration Project

- Goal:
 - Develop and standardize operating procedures for PBRN research using QI methodology
- Participants:
 - Directors and key research leaders from 6 established PBRNs assembled into two “Expert Panels”
 - Consultants- group process facilitation
 - Leadership team- study management & evaluation





Study Phases

- Phase 1: Development
 - Moved from Best Practice SOP development to a more comprehensive set of “Research Good Practices”
- Phase 2: Peer Review
 - PBRN peers vetted practice guidelines over 15 months
- Phase 3: Dissemination
 - Paper & electronic formats, web-based

Process Facilitation

- Technical Advisors from the University of Calgary
 - Pamela Sterling, BSc, PMP, MA
 - Maeve O'Beirne, PhD, MD
- “Workshop” and “Group Consensus”
Communication strategies
- Technology of Participation® , Institute of Cultural Affairs



Methods



- **Team Consensus Process**

- Biannual onsite meetings: Chapter structure developed (subsections)
- Monthly webinar meetings: Chapter content and processes added



- Individual teams developing consensus on content
- Combined teams for training, feedback on study process, leadership capacity building
- Team-building at national meetings: kept the study on track; commitment to outcomes

PBRN Research Good Practices

Chapter 1: Building PBRN Infrastructure

Chapter 2: Study Development and
Implementation

Chapter 3: Data Management

Chapter 4: Dissemination Policies

Chapter 1:

Building PBRN Infrastructure

- Zsolt Nagykaldi, PhD (OKPRN)
- Cheryl Aspy, PhD (OKPRN)

Chapter 1 Background

- PBRNs have a unique mission: “to conduct research that matters in practice/community”
- This mission requires a unique infrastructure (multi-directional learning community)
- Three types of PBRNs: academic, mixed academic-community [e.g., 501(c)3], and fully community-based (e.g., CBPR-oriented)
- Infrastructure support is critical to all PBRNs

Chapter 1: Five Topic Areas

- 1.1 Developing & Maintaining Relationships
- 1.2 Strategic Planning
- 1.3 Building PBRN Infrastructure
- 1.4 PBRN Staffing
- 1.5 PBRN Funding

1.1 Relationship Building

- Purpose: Recruit and retain PBRN members, sustain and grow the organization in a participatory manner.
- Strategies:
 - Widely respected champion clinician/leader
 - Personal invitation and systematic recruitment process (multi-pronged outreach, member tracking)
 - Participatory, mission-oriented activities (ownership)
 - Direct value to members (resources, support, learning community, connectedness/linkages)
 - Effective, bi-directional communication/collaboration

1.2 Strategic Planning

- Purpose: Define a clear mission and vision for the organization that form the basis of its activities.
- Strategies:
 - Organize periodic and professionally facilitated strategic planning sessions
 - Find critical areas where value can be generated or provided for PBRN members
 - Translate SWOT/needs assessment into goals and select effective strategies to achieve these goals
 - Track progress and adjust approaches/resources

1.3 Building the Infrastructure

- Purpose: Develop an organizational structure that can turn ideas into successful PBRN projects.
- Strategies:
 - Create venues for soliciting project ideas from members (e.g., listserv, convocations, social media)
 - Build a structure for vetting ideas based on priorities
 - Establish professional partnerships (web of expertise)
 - Develop an effective member database for membership tracking and ongoing organizational improvement

1.3 Building the Infrastructure (2)

- Design information management infrastructure (study management, communications, process improvement)
- Implement innovative processes for ongoing feedback to members (research, QI, resources)
- Employ best practices for effective dissemination of innovations
- Explore alternative, locally or nationally available infrastructural resources (e.g., CTSI, foundations, AHRQ)

1.4 Staffing the PBRN

- Purpose: Provide the necessary expertise that can support the mission of the organization.
- Strategies:
 - Based on the mission/vision, create a strategic organizational structure (relationships)
 - Hire and retain qualified, passionate and respected leadership (director, coordinator, facilitators/RAs)
 - Design a professional development and training approach for key personnel (see other chapters also)
- Periodically evaluate needs and (re)train/hire

1.5 Funding the PBRN

- Purpose: ensure the long-term sustainability of the organization (infrastructure, human resources, capacity).
- Strategies:
 - Use creative means to acquire infrastructural support (leverage projects to carve out “admin” funding)
 - Diversify network portfolio and sources of support (grants, contracts, donations, co/matching-funding)
 - Strongly and strategically “market” the PBRN internally (campus), in the state and nationally emphasizing value and benefit to others

Chapter 1: Other Contributors

- Anthony Brown (SPUR Net)
- LJ Fagnan (ORPRN)
- Chet Fox (UNYNET)
- Angela Wisniewski (UNYNET)
- David Hahn (WREN)
- the NAPCRG CASFM PBRN workgroup
- And the team...



Polling Question:

What infrastructure-building strategies do you already have in place in your PBRN? (Check all that apply)

Chapter 2: Study Development and Implementation

- LeAnn Michaels, BS, CCRC (ORPRN)
- Jeanette M. Daly, RN, PhD (IRENE)
- Beth Patterson, RN, BSN, CCRC (Duke PCRC)

Chapter 2 Background

- Investigators who conduct practice-based research often include geographically dispersed practices.
- This dispersion requires extra work by the investigators to educate the practice staff so that they can complete the research tasks in a consistent manner.
- Conversely, the practice staff will need to educate the investigators on what is feasible in a busy practice.
- The purpose of this chapter is to outline processes to promote research quality management and quality performance.

Chapter 2: Ten Topic Areas

- 2.1 Pre-Project Development
- 2.2 Research Project Staff Roles & Responsibilities
- 2.3 Staff Education
- 2.4 Community Partner Involvement
- 2.5 Study Personnel Evaluation and Feedback
- 2.6 Procedure Manual
- 2.7 Communication Plan
- 2.8 Quality Management Plan
- 2.9 Guidelines for Audit
- 2.10 Study Close-out

Chapter 2: Overview

Pre-Project

- PBRN works with PI to develop and approve project within particular PBRN setting

Project Implementation

- Determine staffing with roles and responsibilities
- Educate staff and develop Manual of Procedures
- Involve community partners
- Establish meeting structure to ensure study progress and provide venue to discuss questions and concerns

Chapter 2: Unique Aspects

- Table of PBRN staffing terms and definitions
- Data collection tips
 - Practical strategies to consider when creating a robust data collection training plan
- Maximizing partnerships with community partners
 - Involve partners “at the top of their license”
 - Provide appropriate training and support
 - Minimize impact

Unique Aspects (cont.)

- Manual of Procedures elements
 - Backbone of protocol implementation
- Example of Memorandum of Understanding
 - Agreement co-signed by investigator and study site outlining expectations and reimbursement information
- IRB considerations (e.g. FWA, IAA, etc.)
- Example of Regulatory Binder Index for both Clinical Trial and Retrospective Chart Review

Chapter 2: Other Contributors

- Valory Pavlik, PhD, Baylor College of Medicine
- Michael Potter, MD, University of California, San Francisco
- John Ely, MD, MPH, University of Iowa
- And the team...



Polling Question:

How does your PBRN typically train staff and participating partners to conduct studies? (Check all that apply)

Chapter 3: Data Management

- Barcey T. Levy, PhD, MD (IRENE)
- Hannah Louks, MS (formerly WREN)

Chapter 3: Background

- Data management is critical for scientific reliability and validity.
- PBRN research involves a wide range of data sources and types.
- A systematic approach to collecting, transferring, entering, cleaning, confirming, and storing data will minimize potential risk to participants and improve results.

Chapter 3: Seven Topic Areas

- 3.1 Database Development
- 3.2 Data Storage and Security
- 3.3 Data Collection
- 3.4 Data Entry
- 3.5 Data De-identification
- 3.6 Data Cleaning
- 3.7 Data Transfer

3.1 Database Development

- Purpose: Build databases appropriate to the standards and goals of each research study, compatible with the office systems of multiple clinical sites.
 - Data sources and method(s) of data collection are driven by the research question(s)
- Strategies:
 - Determine data sources and format;
 - Develop a data dictionary and codebook;
 - Develop the study database





3.2 Data Storage & Security

- Purpose: Ensure participant confidentiality for the entire study period and beyond.
- Strategies: only those with “need to know” have full data access, password protection, encryption, Data Use Agreements.
- Always log any changes to data files with the change, reason for change, staff making change, and date.



3.3 Data Collection



- Purpose: Use or create instruments to collect data appropriate to the standards and goals of each research study, compatible with the office systems of multiple clinical sites.
- Strategies: Identify data collection components, Establish data and task tracking, and Methods for data collection.
- Pilot test all methods before starting “real” data collection



3.4 Data Entry

- Purpose: Promote timely data entry and ensure data accuracy.
- Strategies: Flow of data: acquisition, data entry in de-centralized locations, and appropriate documentation of data entered.
- Data entry in a de-centralized location is common to PBRN studies and requires:
 - Staff training, communication, quality control



3.6 Data Cleaning



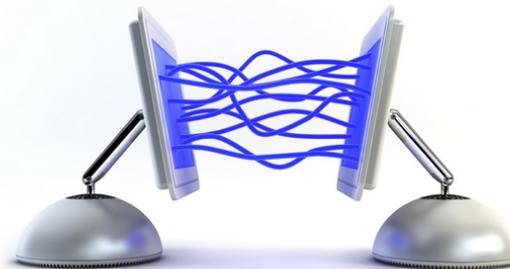
- Purpose: Ensure data validity through procedures used to identify illogical values, missing values, etc.
- Strategies: Missing data, data verification, documentation





3.7 Data Transfer

- Purpose: To describe and outline data transfer procedures, including how paper data is entered into an electronic format, transmitted between parties, or archived.
- Strategies: IRB approval, data security procedures



Chapter 3: Other Contributors

- Karen Hagglund, MS
- Rhonda Dailey, MD
- Yinghui Xu, MS
- And the team...



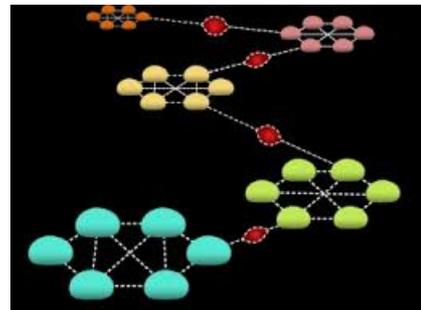


Polling Question:

What elements does your PBRN typically use to ensure data consistency and integrity? (Check all that apply)

Chapter 4: Dissemination Policies

- Rowena J. Dolor, MD, MHS (Duke PCRC)
- Kimberly Campbell-Voytal, PhD, MSN (MetroNet)



Chapter 4 Background



- Dissemination of findings is important to:
 - Influence policy
 - Build and sustain relationships
 - Inform practice settings about emerging trends
 - Acknowledge stakeholder collaboration
 - Improve science
- Dissemination product will vary based on audience you want to reach

Chapter 4: Five Topic Areas

- 4.1 Priorities and Alignment
- 4.2 Dissemination Team
- 4.3 Dissemination Plan/Process
- 4.4 Publication Standards/Authorship Guidelines
- 4.5 Process Management

4.1 Priorities and Alignment

- Dissemination products should align with and help advance the PBRN mission
- Engage relevant stakeholders – clinicians, practice staff, community members, participants



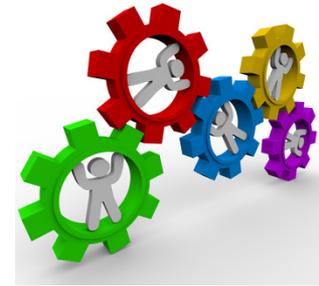
4.2 Dissemination Team

- Composition: study team members, those who need to know findings (clinicians, patients, community members), and dissemination experts.
- Purpose: Create dissemination conceptual model and plan
- Can convene smaller sub-teams for specific dissemination products



4.3 Dissemination Plan/Process

- Determine number and type of dissemination products
- Develop timeline for each product
- Specify audience for each product
- Map a range of topics for dissemination
- Consider feasibility and approach to monitoring dissemination outcomes



4.4 Publication standards

- Lots of communication standards and guidelines available as info links (AHRQ, CDC, HHS, ICMJE)
- Authorship guidelines, especially engaging community practices & partners as authors
- Acknowledgement of individuals, organizations, coalitions who contributed



4.5 Process Management

- PI and project manager should manage and monitor the timeline and deliverables
- Keep a master listing of all completed, published dissemination products on PBRN website and newsletters
- Send congratulatory message to authors and contributors with info on how to reference the product on their CV or resume

Chapter 4 Other Contributors

- Katrina Donahue
- Doug Fernald
- William Hogg
- Paul Meissner
- Jim Mold
- Maeve O'Beirne
- the NAPCRG CASFM PBRN workgroup
- And the team...





Polling Question:
When does your PBRN typically begin to plan for dissemination?

PGRP Dissemination

- Posted on NAPCRG website:

<http://www.napcrg.org/Portals/51/Documents/PBRN%20Conf%20Handouts/PRGP%202014-09-29.pdf>

Discussion: Benefits and Utility

- How affected research practice?
- Use in collaborations?

Discussion: Next Steps

- How to encourage adoption?
- Consider *crowdsourcing* as a mechanism to keep the document alive??



Polling Question:
How will you use the PRGPs? (check one)



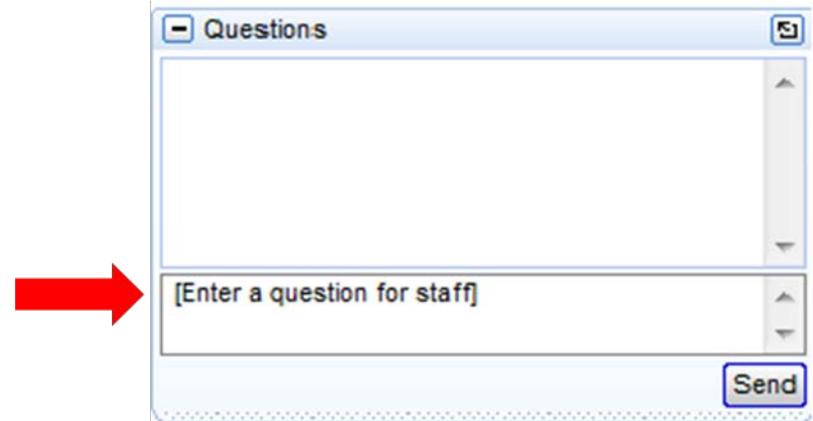
Polling Question:

On which chapters do you want additional discussion or resources? (check all that apply)



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Upcoming Events

Invitation to Oct 1st Brainstorming Call for PBRN Pragmatic Research and Translation Learning Group

October 1st, 1pm – 2pm ET

Paul Meissner, Rowena Dolor, and Jonathan Tobin invite you to join the “renewed” learning group for PBRNs engaged in pragmatic trials and practical strategies for translation into practice.

If you are interested in participating in this learning group, e-mail PBRN@abtassoc.com with the subject line ***PBRN PRT LG Call***.

Visit <http://pbrn.ahrq.gov/events> for details on other upcoming PBRN-relevant webinars and events

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