Research Facilitation and Data Collection in Practice-based Research Networks

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First Seminar: Introduction to Practice-based Research

• Paul Nutting, MD, MSPH
  – What is practice-based research?
  – What is the history of PBRNs?
  – What are some examples of practice-based research studies?
Practice-based Research Networks (PBRNs)

- Groups of community practices devoted to patient care, affiliated for research
- Often partner with academic or professional organizations
- Comprised of clinicians on the frontlines of patient care
- Produce findings that are generalizable, transportable & readily translated into practice

http://ahrq.gov/research/pbrnfact.htm
Illness in the Community

- **ADULT POPULATION AT RISK**: 1000
- **ADULTS REPORTING ONE OR MORE ILLNESSES OR INJURIES PER MONTH**: 750
- **ADULTS CONSULT A COMMUNITY-BASED PHYSICIAN ONE OR MORE TIMES PER MONTH**: 250
- **ADULT PATIENTS ADMITTED TO A HOSPITAL PER MONTH**: 9
- **ADULT PATIENTS REFERRED TO ANOTHER PHYSICIAN PER MONTH**: 5
- **ADULT PATIENT REFERRED TO A UNIVERSITY MEDICAL CENTER PER MONTH**: 1

Agenda

• What are the characteristics of PBRNs?
• How do PBRNs start?
• What are the components and costs of developing a PBRN?
• How is research facilitated in PBRNs?
• Local PBRNs?
• What methods are used to collect data in PBRNs?
Features of PBRNs
Geography

• National / bi-national
  – AAFP National Network, PROS

• State
  – WReN, MAFPRN

• Regional
  – RAP, COOP, NEON

• Single community
  – SNPSA
  – SURFNet

• Consortiums of Networks
  – Federation of PBRNs (58 networks, 6500 physicians, 16 million patients)
  – International Primary Care Research Network (IPCRN)
  – ePCRN (electronic Primary Care Research Network)

• Outside North America
  – UK: Wessex Primary Care Research Network
  – Netherlands: Nijmegen University Academic Network Family Medicine (CMR/NMP)
  – Taiwan: Chunan Practice-Based Research Network (CnPBRN)
Size / Participants

• A few practices - hundreds of practices
• Single specialty – multispecialty, NPs, PAs
• Family Medicine, Pediatrics, General Internal Medicine, Nursing, Oncology, Psychology
Affiliations

• National Academy
  – PROS, AAFP National Research Network

• State Academy
  – WReN, MAFPRN

• Academic Institution
  – RAP, NEON

• Electronic Health Records System
  – PPRNet

• Health System
  – CCF
Initiating Vision or Event

- Individual/group with a ‘bee in the bonnet’
- Knowledge gap
- Belief in wisdom gained from practice
- EHR system
- Teaching mission
- Single question or idea
Leadership

• Have a director and coordinator
• Open, collaborative style that directly engages clinicians
• An administrative structure that enables centralized coordination of research studies
Governance

• Board of Directors of participants
• Consensus (town meeting)
• Health systems
• Academic partners
• Community leaders
• State academies
Project Leadership

- Network leader(s) PI
- Clinician member(s) PI
- Outside PI
Idea Generation

- Clinician’s practice
- Family Medicine department
- Academicians
- Content experts
- Funding agencies
- Group process
Balancing Act

Academic-initiated  Clinician-initiated

Network Studies
Project Design/Refinement

- Small, transdisciplinary group
- Clinicians’ perspectives
- Methodological expertise
- Content expertise
- Pilot testing
Project Funding

- Opportunistic
- Foundation grants
- Department grants
- Research grants
- Academic department underwriting
- Academy underwriting
Scholarly Output

- Clinician - academician partnership
- Writing / editing teams
- Participant reviewers
- Planned - evolutionary
- Making time
Benefits for Clinicians

• Ask and answer questions of importance to clinicians and their patients
• Intellectual stimulation
• Make important contributions to the specialty
• Participate in the development of research publications
Study Feedback Report
Practice: XYZ
Most recent GlycoHgb test

GlycoHgb value  Number of months since most recent test

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<th>All other sites</th>
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Infrastructure Elements:
Determined by Mission and Resources

• Network Director
• Board of Directors/Steering Committee
• Network Coordinator
• Research Assistants
• Support staff
• Access to design & data analysis expertise
• Membership database
• News-sharing (newsletter, web site, listserv)
• Meetings
Typical PBRN Model

[Diagram of PBRN Model with interconnected circles and a central square labeled "PBRN Office"]
Oklahoma Practice Research Network (OKPRN): ‘PEAS in a Pod’
Challenges in Starting a PBRN

- Funding
- Communication
- Project management
- Clinician autonomy – independent or health system
- IRB and HIPAA compliance
- Longitudinal research
- Methodological issues
  - Patient-level randomization
Need for Infrastructure Support

• Lack of support for core activities
  “Many if not most PBRNs struggle to build or sustain an infrastructure capable of recruiting and retaining participating practices, supporting network activities, and generating fundable projects.”

• Limited bridge funding
  “…few networks receive significant, ongoing funding from any academic institution or other organization, support which can be especially important in those periods between major funded research efforts.”

• Minimal staff resources
  “All PBRNs appear to rely heavily on volunteerism for central staff support and the cooperation of participating practices and investigators.”

A Shared Resource for Practice-based Research Networks

To support community- and population based research in cancer prevention and control through the development of practice-based research networks.
Structure of Comprehensive Cancer Centers

- Administration
- Scientific Programs
- Shared Resources
Key Personnel in PBRN Shared Resource

- Jim Werner, PhD
  - Practice-based research network development, methods
- Kurt Stange, MD, PhD
  - Mixed method research design, community partners
- Sharon Weyer, MSN, RN, NP-C
  Practice-based research project development and implementation
Local PBRNs

- Northern Ohio Dental Network (1998)
- Independent Practices (1992)
- University Home Care Network
- VA Primary Care Network
- Community Oncology Network (2005)
- Nurse Practitioners
- Cancer Center’s PBRN Shared Resource
Services

• **Initiate and develop PBRNs in response to needs to access patients, practices, & communities**
  – Recruit clinicians and practices
  – Develop clinician-investigator-community steering committees
  – Guide implementation of studies in PBRNs
  – Connect researchers and clinicians – translate research into practice
  – Channel clinical insights of clinicians – translate practice into research

• **Develop PBRN infrastructure to support research**
  – Communications: newsletters, web sites
  – Design data collection and management systems
  – Informatics: electronic data systems

• **Develop PBRN Methods**
  – Efficient methods for conducting research in busy practices
    » Grant writing
  – IRB and HIPAA issues for PBRNs
PBRN-Cancer Control Training
Post-doctoral Research Fellowship

• NCI-funded; PBRN & Cancer Control

• Develops clinical researchers
  – Clinicians are eligible: MD/DO, DDS, NP with doctorate
  – Training in PBRN research methods, building PBRNs, cancer prevention & control methods
  – MPH available; 20% clinical time

• Advisory Board and Faculty Mentors from Case, CCF & MetroHealth
Case Study: Safety Net Provider’s Strategic Alliance (SNPSA)

• 12 safety net practices in 3 CHCs & 2 free clinics
• Formed SNPSA to better understand & meet patients’ needs; advocate for patients
• Approach: Developed subcommittees for research and advocacy
• Researchers collaborated with Case researchers to develop cross-sectional study of type II diabetes
Process

• Research sub-committee monthly meetings began in September, 2004
• Pre-identified diabetes as topic of interest
• Highly collaborative process between clinicians, researchers, and administrators
SNPSA Diabetes Study Timeline

- October, 2004 - January, 2005: refined research questions, developed instrument
- February - June: IRB submissions
- July-August: data collection
- September: feedback to practices
- October-December: analysis
- January, 2006 - March: developed publication
- March: identify and refine new research questions
Diabetes Study

• Cross-sectional card study developed
  – Patient demographics, methods of payment, HbA1c, BMI, aspirin adherence, self-mgmt goals, barriers, enabling factors

• 19 clinicians collected data about visits by 10 consecutive patients with type II diabetes

• Approximately 3 to 5 minutes for data collection per individual; 30-50 minutes/clinician total

• Key findings: clinicians identified systemic barriers far more often than patients; aspirin adherence much better if aspirin given at practice
Resources: All donated

• Time
  – Clinicians (250 hours)
  – Administrators (45 hours)
  – Case faculty (170 hours)
  – Data analyst (30 hours)
  
  Total time: 495 hours

• Costs
  – Materials ($50)
  – Meals ($1500)
  – Meeting space
  
  Total cost: $1550
Strengths

- Strong clinician leader
- Strong communications coordinator
- Clinicians dedicated to completing study
- Committed academic faculty experienced in developing clinician-initiated projects
- Shared resource
Observations

• Collaborative team, spirit of cooperation, shared mission
• Larger organizational structure conferred stability and positive pressure
• Group did not focus on starting a PBRN
  – Focused on the project rather than on organizational or structural issues
Observations

• Allowing clinicians have a major role in shaping the study
• Data collection can be fast with highly motivated clinicians
• IRB process can be lengthy and unpredictable
Projects Stimulate PBRNs

- Often easier to develop a PBRN by focusing more on developing a project than an organization
- Projects stimulate the development of the PBRN
Early Victories are Key

- Design a ‘do-able’ first study
- Clinician-initiated
- Short-term
- Rapid feedback
- Rapid analysis
- Clinicians’ interpretations
- Publish promptly
- The experience inspires clinicians to do more
Data Collection Methods
Data Collection

• Data collected by
  – Clinician, staff
  – Research Assistants
  – Health system

• Data collection method
  – **Pencil & Paper**
    – “Weekly return” card
    – Surveys
    – Chart abstraction
  – **Electronic**
    – Dedicated electronic data collection systems
    – EHR-based
**Weekly Return Card Study**

**TOTAL PRACTICE ENCOUNTERS THIS WEEK:**

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<th>BIRTH DATE</th>
<th>SEX</th>
<th>RACE</th>
<th>HISPANIC</th>
<th>WHO FIRST SUSPECTED COGNITIVE IMPAIRMENT? (mark one)</th>
<th>SUSPICION THE RESULT OF A ROUTINE SCREEN?</th>
<th>BASIS FOR CONCERN (mark all that apply)</th>
<th>WHY WAS THE CONCERN EXPRESSED TODAY? (mark all that apply)</th>
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**OUR/MY PRACTICE'S SERVICES WERE AVAILABLE:**

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Electronic Data Collection

Current Status

• Some PBRNs have ventured into electronic data collection

• Paper-based methods still prevail -- simple and reliable

• Technologies are increasingly more reliable and cost-effective
Benefits of Electronic Data Collection

• Rapid distribution of data collection forms

• Automated patient identification, patient registries

• Eliminates paper shuffle on both ends: opening, sorting, completing, checking, copying, folding, labeling, mailing, etc.

• Rapid and secure transfer of collected data
Benefits (cont.)

- Eliminates need for manual data entry
- Can result in improved data quality
- Enables rapid feedback for clinicians
- Can reduce time from study launch to publication
- May be possible to implement iterative studies more rapidly (rapid-cycle studies, QI work)
Data Collection Tools

• PC-based Web-form data entry
  – Fast
  – Simple implementation
  – Inexpensive
  – Low portability
  – Well-suited for physician surveys, not POC applications

• Handheld/Tablet Computer data entry
  – Fast
  – More complex implementation
  – More expensive
  – High portability for collection at point of care
  – Broad range of POC applications
Challenges

• Capital investment in point of care systems
  – Software, hardware
  – IT staff
  – Trainers

• Integration with EHRs

• Clinician’s time for training

• Long-distance troubleshooting

• Assessing technologies as they rapidly evolve
Suggestions (cont.)

• Don’t underestimate time for training & troubleshooting

• Offer paper-based or web-based back-up

• Assess technology performance in terms of time, money and data quality
EPOCHS
Chart Audit & Abstraction

Practice
*Tablet PC*

University-based Research Office

HIPAA-Compliant Server

Data
Secure FTP

Internet

Data
Secure FTP

E-mail
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Audio and Powerpoint Presentations

Practice-based Research Networks Seminar Series Podcast

Audio podcasts and the accompanying PowerPoint slides of the Practice-based Research Networks Seminar Series are available online at http://blog.case.edu/jjw17/.

Listen and learn online.

To listen to the podcast in your Web browser, follow the link to the .mp3 file for that week's entry. The file will then play in QuickTime or your preferred audio player.

To view the accompanying slides just follow the link to the .pdf file to either view the slides on your computer or to print them out.