Practice-Based Research Network
Research & Development

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Overview

Context:

- Practice-Based Research Networks (PBRNs)
  - Rationale / approach
  - Brief history
- The process of developing new knowledge
- Examples of PBRN research
- PBRN Organization & Development
  - Features
  - Principles
- Opportunities (what are you going to do?)
Fig. Results of a reanalysis of the monthly prevalence of illness in the community and the roles of various sources of health care. (Green LA et al., *N Engl J Med* 2001, 344:2021-2024)
PBRN Definition

• A group of practices devoted principally to the primary care of patients,

• Affiliated in their mission to
  – Investigate questions related to community-based practice
  – To improve the quality of primary care

• With an ongoing commitment to network activities

• A structure that transcends a single research project

• Often linking practicing clinicians with investigators

• Working to enhance the skills of network members

www.ahrq.gov/research/findings/factsheets/primary/pbrn/index.html
PBRN Approach

• Engage clinicians on the frontlines of patient care
  – Develop or frame research questions
  – Gather data
  – Interpret findings
  – Implement findings

• Top down and bottom up leadership

• Translation of research into practice and practice into research, on the problems that most people have most of the time.

• Produce findings that are generalizable, transportable & readily translated into practice


Growth In U.S. PBRNs

• 1994: 28 active PBRNs in North America
• 2008: 111 active PBRNs
• 2015: 176

AHRQ. Practice-Based Research Networks - Research in Everyday Practice. https://pbrn.ahrq.gov/

Early PBRNs

- Sentinel Networks in the UK and Netherlands
- Ambulatory Sentinel Practice Network (ASPN)
- Dartmouth Cooperative Information Project (COOP)
- Pediatric Research in Office Settings (PROS)
- Wisconsin Research Network (WReN)
Universe of Primary Care PBRNs

• 176 active in US
  – Diversity in size, location and focus
  – Estimated access to >10% of patients

• Federations of PBRNs*

• AHRQ-funded PBRN Resource Center**

• Funding by AHRQ, RWJF, NIH, PCORI, CTSA, CCSGs

https://pbrn.ahrq.gov/pbrn-registry
* https://pbrn.ahrq.gov/pbrn-registry/international-federation-primary-care-research-networks
** https://pbrn.ahrq.gov/
PBRNs Unite

• Research and quality improvement*

• Researcher and participant**

• Practice & community**


The Evolving Field of PBRNs

• More system – driven / supported
• More disciplines involved
• Emerging new models that
  – Recognize lack of ‘slack’ in current practice and organizations
  – Use existing (big) data
  – Build on organizations & relationships that meet other goals
  – Link with public health, patient groups…

Generating Transportable New Knowledge

The Dance of Design

What is the unique opportunity to generate transportable new knowledge?

The question

What is known ← What is feasible

Does the project develop network capacity?
Is it a deposit or a withdrawal from the relationship accounts?
7 Questions to Get Started

1. What is your research question?

2. What already is known, and how can this help you to refine your question?

3. Who would be the participants for the study (for example, patients in your practice)?

4. What would the study measure?

5. How would you collect data?

6. How can feasibility considerations (money, effort, time, skills, potential collaborators, etc.) help you to refine your question and research plan?

7. Why is the study worth doing?
Findings from PBRNs that change practice
Women with a spontaneous abortion rarely need a D&C.

- Ambulatory Sentinel Practice Network (ASPN)

Antibiotics are not needed for all children with otitis media

• ASPN & International Collaborative Network


Tailored QI strategies lead to sustained increases in preventive service delivery

• RAP


Diabetic patients blame themselves for poor control and change from ‘turning points’ in family & friends.

- SNPSA


Findings from PBRNs relevant to policy
Forced discontinuity diminishes quality of primary care

• RAP

Care of the “secondary patient” is frequent and well accepted in family practice.

- RAP & ASPN


Having both an FQHC medical home and continuous health insurance is critical to optimal chronic disease management

• OCHIN PBRN

Facilitation can yield dramatic improvements in quality and help launch an ACO.

- Rainbow Research Network
PBRN methodology findings
PBRN weekly return cards are accurate.

- ASPN
Patient Engagement Panel

• OCHIN PBRN

A study of the card study method can streamline IRB approval by submitting new studies as addenda

- RAP, SNPSA

A NAMCS Replication Study is a Cool Way to Show the Representativeness of the PBRN and Answer Other Questions at the Same Time

• Several PBRNs

• [www.cdc.gov/nchs/ahcd/ahcd_survey_instruments.htm](http://www.cdc.gov/nchs/ahcd/ahcd_survey_instruments.htm)
<table>
<thead>
<tr>
<th>1. PATIENT INFORMATION</th>
<th>5. PROVIDER'S DIAGNOSES FOR THIS VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of visit:</td>
<td>Diagnoses written in ita, does the patient new name:</td>
</tr>
<tr>
<td>a. Gender:</td>
<td>Mark (x) all that apply:</td>
</tr>
<tr>
<td>b. Race/Ethnicity:</td>
<td>1. Primary diagnosis:</td>
</tr>
<tr>
<td>c. Date of birth:</td>
<td>a. Asthma:</td>
</tr>
<tr>
<td>d. Tobacco use:</td>
<td>b. Hypertension:</td>
</tr>
<tr>
<td>e. ZIP Code:</td>
<td>c. Hyperlipidemia:</td>
</tr>
<tr>
<td>2. INJURY/Poisoning</td>
<td>d. Hypothyroidism:</td>
</tr>
<tr>
<td>ADVERSE EFFECT</td>
<td>e. Diabetes:</td>
</tr>
<tr>
<td>3. CONTINUITY OF CARE</td>
<td>f. Depression:</td>
</tr>
<tr>
<td>a. Patient's complaint(s), symptom(s), or other reason(s) for this visit:</td>
<td>g. Obesit:</td>
</tr>
<tr>
<td>b. Was patient seen in the last 12 months?</td>
<td>h. Osteoarthritis:</td>
</tr>
<tr>
<td>4. REASON FOR VISIT</td>
<td>i. Osteoporosis:</td>
</tr>
<tr>
<td>5. VITAL SIGNS</td>
<td>Other:</td>
</tr>
<tr>
<td>a. Weight:</td>
<td>b. Height:</td>
</tr>
<tr>
<td>b. Age:</td>
<td>c. Temperature:</td>
</tr>
<tr>
<td>6. DIAGNOSTIC/SCREENING SERVICES</td>
<td>Blood pressure:</td>
</tr>
<tr>
<td>a. Mark (x) ordered or provided at this visit:</td>
<td>1. Electrocardiogram:</td>
</tr>
<tr>
<td>b. Imaging:</td>
<td>2. Echocardiogram:</td>
</tr>
<tr>
<td>c. Blood tests:</td>
<td>3. Chest x-ray:</td>
</tr>
<tr>
<td>d. Other tests:</td>
<td>4. Lung function test:</td>
</tr>
<tr>
<td>7. HEALTH EDUCATION</td>
<td>5. Other:</td>
</tr>
<tr>
<td>a. Mark (x) ordered or provided at this visit:</td>
<td>6. Other:</td>
</tr>
<tr>
<td>8. NON-MEDICATION TREATMENT</td>
<td>7. Other:</td>
</tr>
<tr>
<td>a. Nutrition education:</td>
<td>8. Other:</td>
</tr>
<tr>
<td>b. Diabetes education:</td>
<td>9. Other:</td>
</tr>
<tr>
<td>c. Tobacco use cessation counseling:</td>
<td>10. Other:</td>
</tr>
<tr>
<td>9. MEDICATIONS &amp; IMMUNIZATIONS</td>
<td>11. PROVIDERS</td>
</tr>
<tr>
<td>a. Medications ordered:</td>
<td>1. Physician:</td>
</tr>
<tr>
<td>b. Immunizations, allergy shots, eye exam, mammogram, laboratory tests, and other procedures that were ordered, supplied, administered, or continued during this visit:</td>
<td>2. Other:</td>
</tr>
<tr>
<td>c. Vaccinations:</td>
<td>3. Other:</td>
</tr>
<tr>
<td>10. TIME SPENT WITH PROVIDER</td>
<td>13. Continue on reverse side:</td>
</tr>
</tbody>
</table>
Features of PBRNs
Geography & Size

• International International Collaborative Network, IFPBRN
• National / bi-national (ASPN), NatNet, PROS, PPRNet
• State WReN, MAFPRN
• Regional COOP, UPRNet, RAP
• Single health care system PPRG, Rainbow Network
• Common EMR Practice Partners Network
• Consortium of Networks FPBRN
Affiliations

• National Academy
  – PROS, AAFP Research Network

• State Academy
  – WReN, MAFPRN

• Academic Institution or Entity
  – RAP, NEON, COOP

• Hospital / Health System
  – PPRN

• EMR Vendor or Service Organization
  – PPN, OCHIN PBRN
Initiating Vision or Event

- Mission
- Individual/group with a bee in the bonnet
- Belief in wisdom gained from practice
- EMR system
- Single question or idea
- Funding opportunity
- QI or sharing best practices

Leadership

• Network
  – Top down
  – Bottom up
  – Coalition / whole system leadership

• Specific projects
  – Network leader(s)
  – Clinician member(s)
  – Outside principal investigator


Idea Generation

- Clinician’s practice
- Content experts
- Funders
- Group process
Project Design/Refinement

- Small, transdisciplinary group
- Practitioner perspective
- Methods expertise
- Content expertise
- Access to literature
- Pilot testing
Funding

• Opportunistic, ad hoc
• Grants
  – NIH, AHRQ, HHS, PCORI
  – Foundations
• Academic department underwriting
• CTSAs, other center grants
• Professional organization underwriting
• Endowment
Skill Development

- Nike school
  - Working through specific projects
  - Watching
  - Contributing to different steps in different projects

- Workshops

- Fellowships

- Distance learning
Levels of Involvement

• Leadership
  – Network administration
  – Steering committee
  – Specific project
  – Subnetwork
  – Practice

• Contribute data

• Participate in different stages from idea to implementation

• Varies over time and project
Data Collection

• Data collection by
  – Practice
  – Research team
  – EMR support
  – Health care system

• Data collection method
  – “Weekly return” card
  – Computerized data
  – Medical record
  – Survey / interview
  – Direct observation
Data Analysis

- Network staff
- Investigator
What Are The Characteristics Of Successful Networks?

• Clear clinician involvement network governance & operation
• Clear rewards for clinicians participating
• A “network of researchers” who have learned how to work within a network
• Visionary, steadfast or servant leadership
• A huge dose of commitment and voluntarism by all players
• A diversified revenue stream: consistent infrastructure support and a varied stream of project revenue
• A benevolent academic program(s) that does not try to “own” or “use” the network
Scholarly Output

- Academician or clinician
- Clinician - academician partnership
- Collaborators
- Writing / editing teams
- Participant reviewers
- Making time
- Write the abstract first
A Few Take-Home Ideas/Principles

• Consider what’s in it for (diverse) participants
• Everyone / everything doing what it does best
• Both top-down and bottom-up
• Both research and development
• Natural experiments of the policy environment
• Mix of in-person and asynchronous contact
• Blurring QI and research
• Diversification of funding
• Lean, expandable infrastructure
• Part 4 Maintenance of certification
• Reflection / action cycles (make time for reflection)
What are you going to do?

• Learn by collaborating on a PBRN project?
• Provide ‘sweat equity’ on a else’s project?
• Work on an ongoing PBRN study?
• Propose a new study to a PBRN?
• Start out with a card study?
• Characterize a new PBRN with NAMCS data?
• Work to draw out clinician questions?
• Start a patient advisory committee?
• Link practice, system and public health data?
• Launch a new (kind of) PBRN?
• ???
Presentations available at:

http://blog.case.edu/jjw17/