

Practice-Based Research Network Research & Development

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Overview

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- 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?)

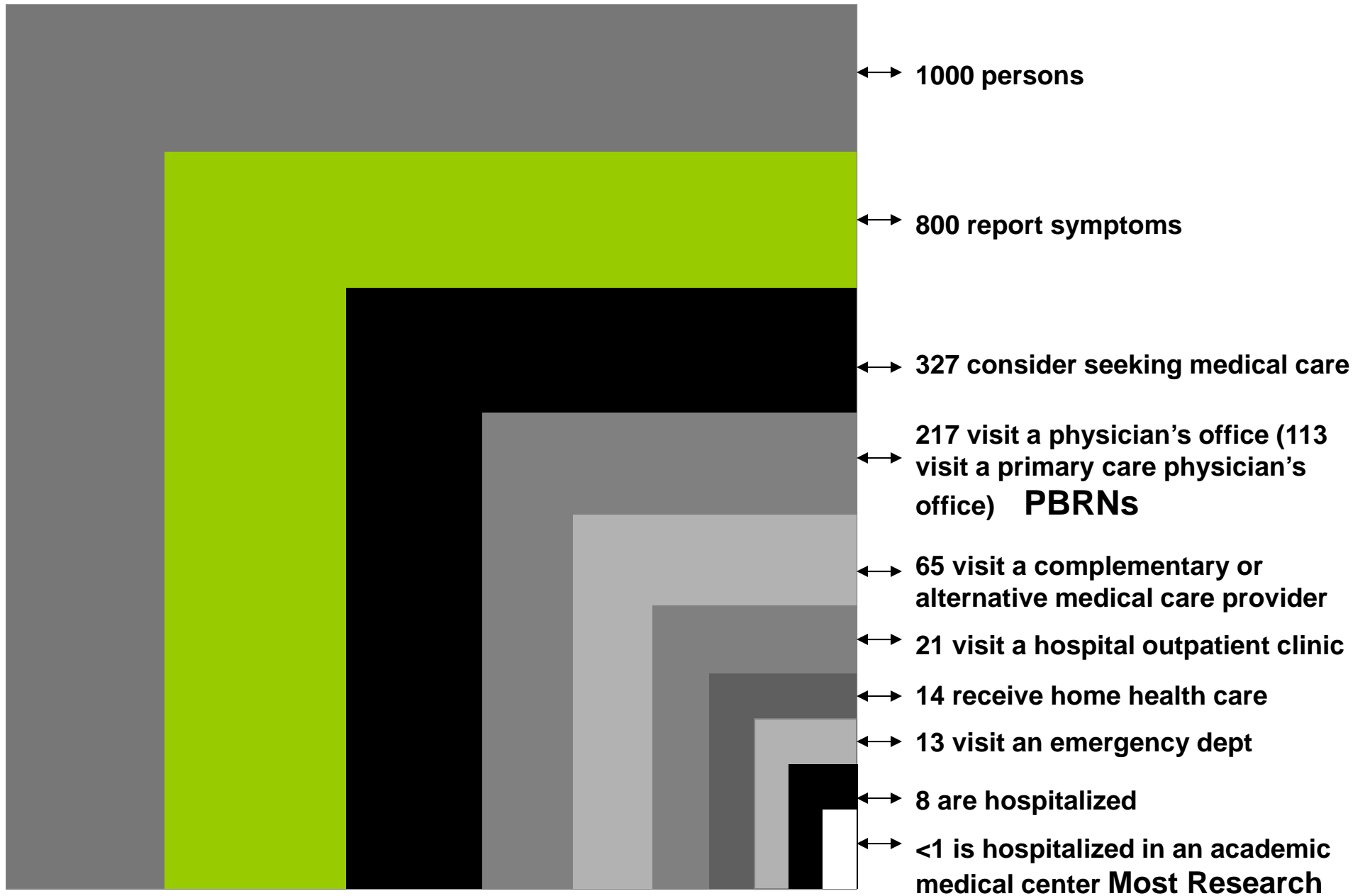


Fig. Results of a reanalysis of the monthly prevalence of illness in the community and the roles of various sources of health care. (Green LA et al., *N Engl J Med* 2001, 344:2021-2024)²

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

Nutting P, Beasley J, Werner J. Practice-based research networks answer primary care questions. *JAMA*. 1999;281:686-688.

Thomas P, Griffiths F, Kai J, O'Dwyer A. Networks for research in primary health care. *BMJ*. 2001;322:588-590.

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/>

Hickner J, Green LA. Practice-based Research Networks (PBRNs) in the United States: Growing and Still Going After All These Years. J Am Board Fam Med. 2015Sep-Oct;28(5):541-5.

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**

* Mold JW, Peterson KA. Primary care practice-based research networks: working at the interface between research and quality improvement. *Ann Fam Med*. 3 Suppl 1: S12-S20. 5/2005. www.annfammed.org/cgi/content/full/3/suppl_1/s12

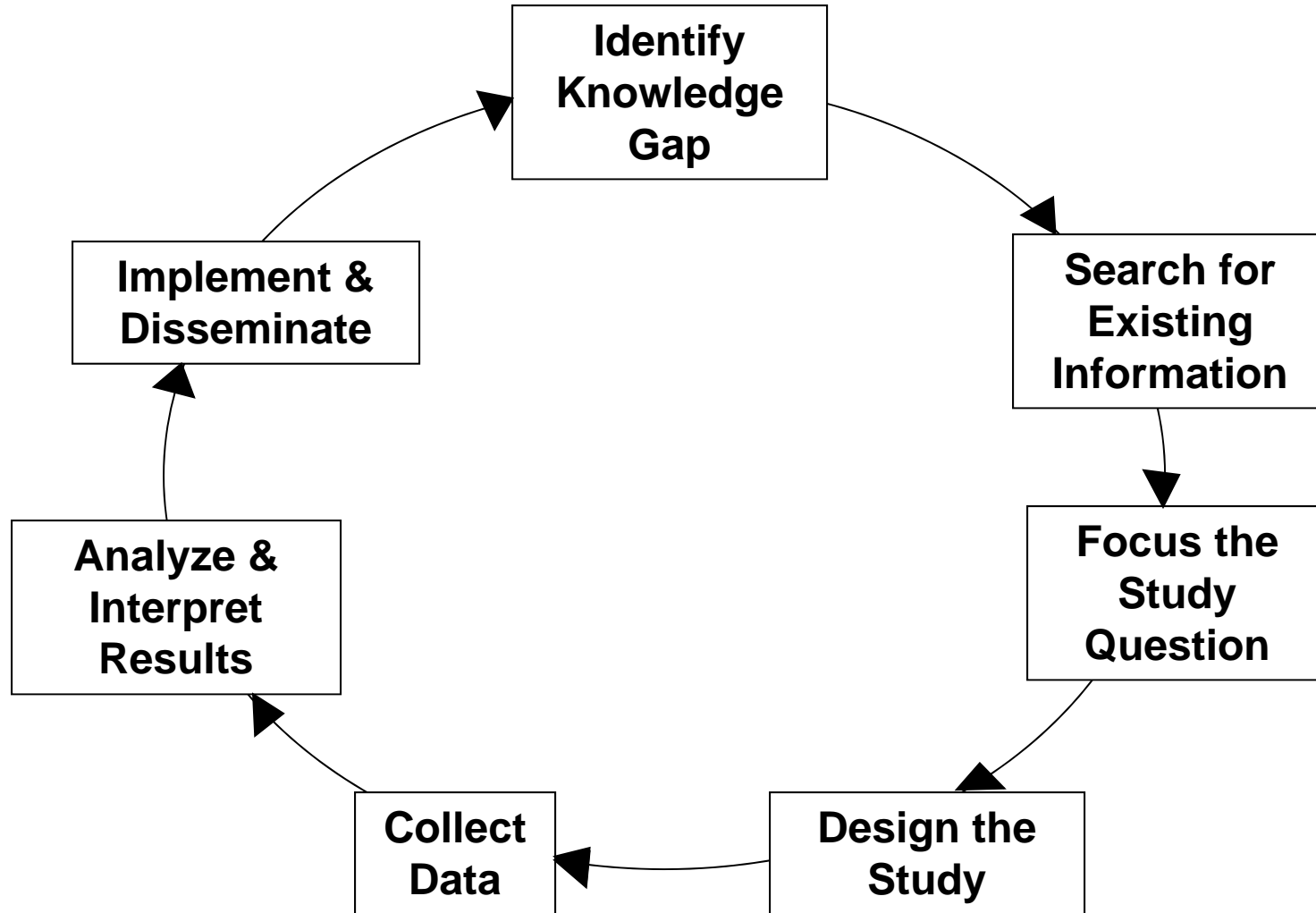
** Westfall JM, VanVorts RF, Main DS, Herbert C. Community-based participatory research in practice-based research networks. *Ann Fam Med* 2006;4(1):8-14. www.annfammed.org/cgi/content/full/4/1/8

** Macaulay AC, Nutting PA. Moving the frontiers forward: incorporating community-based participatory research into practice based research networks. *Ann Fam Med* 2006;4(1):4-7.

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...

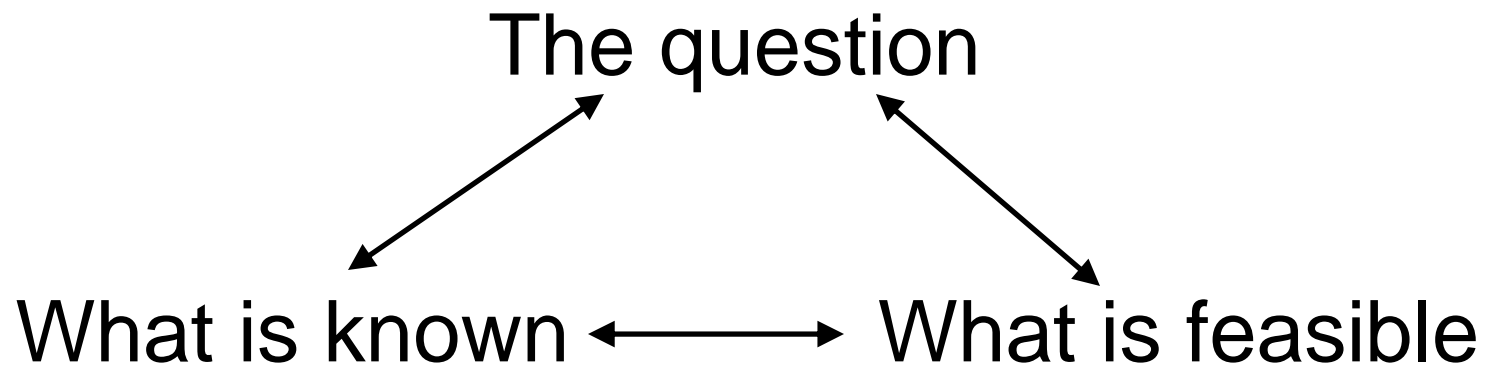
Generating Transportable New Knowledge



Adapted from: Nutting, PA, Stange, KC. Practice-based research: The opportunity to create a learning discipline. In: *The Textbook of Family Practice, 6th Edition*. Rakel RE (ed.), W. B. Saunders Company, 2001. 11

The Dance of Design

What is the unique opportunity to generate transportable new knowledge?



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)
- Green LA, Becker LA, Freeman WL, Elliott E, Iverson DC, Reed FM. Spontaneous abortion in primary care: a report from ASPN, part 1. J Am Board Fam Pract. 1988; 1:15-23.

Antibiotics are not needed for all children with otitis media

- ASPN & International Collaborative Network
- Froom J, Culpepper L, Jacobs M, DeMelker R, Green L, vanBuchem L, Grob P, Heeren T. Antimicrobials for acute otitis media? A review from the International Primary Care Network. *BMJ*. 1997;315:98-102.
- Green LA, Fryer GE Jr, Froom P, Culpepper L, Froom J. Opportunities, challenges, and lessons of international research in practice-based research networks: the case of an international study of acute otitis media. *Ann Fam Med*. 2004 2(5):429-33.

Tailored QI strategies lead to sustained increases in preventive service delivery

- RAP
- Goodwin MA, Zyzanski SJ, Zronek S, et al. A clinical trial of tailored office systems for preventive service delivery: the Study To Enhance Prevention by Understanding Practice (STEP-UP). *Am J Prev Med.* 2001; 21:20-28.
- Stange KC, Goodwin MA, Zyzanski SJ, Dietrich AJ. Sustainability of a practice-individualized preventive service delivery intervention. *Am J Prev Med,* 2003; 25:296-300.
- Ruhe MC, Weyer SM, Zronek S, Wilkinson A, Wilkinson PS, Stange KC. Facilitating Practice Change: Lessons from the STEP-UP clinical trial. *Prev Med,* 2005; 40:729-734.

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

- SNPSA
- Reichsman A, Werner J, Cella P, Bobiak S, Stange KC, SNPSA Diabetes Study Working Group. Opportunities for improved diabetes care among patients of safety net practices: a Safety Net Providers' Strategic Alliance (SNPSA) study. *J. Natl. Med. Assoc.* 2009;101(1):4-11.
- Madden MH, Tomsik P, Terchek J, et al. Keys to successful diabetes self-management for uninsured patients: social support, observational learning, and turning points: a safety net providers' strategic alliance study. *J. Natl. Med. Assoc.* 2011;103(3):257-264.

**Findings from
PBRNs relevant
to policy**

Forced discontinuity diminishes quality of primary care

- RAP
- Flocke SA, Stange KC, Zyzanski SJ. The impact of insurance type and forced discontinuity on the delivery of primary care. *J Fam Pract.* 1997;45:129-135.

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

- RAP & ASPN
- Flocke SA, Goodwin MA, Stange KC. The effect of a secondary patient on the family practice visit. *J Fam Pract.* 1998;46:429-434.
- Orzano AJ, Gregory PM, Nutting PA, Werner JJ, Flocke SA, Stange KC. Care of the secondary patient in family practice. A report from ASPN. *J Fam Pract.* 2001; 50:113-118.

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

- OCHIN PBRN
- Gold R, DeVoe J, Shah A, Chauvie S. Insurance continuity and receipt of diabetes preventive care in a network of federally qualified health centers. *Med Care.* 2009 Apr;47(4):431-9.

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

- Rainbow Research Network
- Meropol SB, Schiltz NK, Sattar A, et al. Practice-tailored facilitation to improve pediatric preventive care delivery: A randomized trial. *Pediatrics*. 2014.

PBRN
methodology
findings

PBRN weekly return cards are accurate.

- ASPN
- Green LA. The weekly return as a practical instrument for data collection in office-based research: a report from ASPN. *Fam Med.* 1988;20:185-188.
- Green LA, Reed FM, Miller RS, Iverson DC. Verification of data reported by practices for a study of spontaneous abortion. *Fam Med.* 1988;20:189-191.
- Westfall JM, Zittleman L, Staton EW, Parnes B, Smith PC, Niebauer LJ, Fernald DH, Quintela J, Van Vorst RF, Dickinson LM, Pace WD. *Ann Fam Med.* 2011;9(1):63-8

Patient Engagement Panel

- OCHIN PBRN
- Arkind J, Likumahuwa-Ackman S, Warren N, Dickerson K, Robbins L, Norman K, DeVoe JE. Lessons Learned from Developing a Patient Engagement Panel: An OCHIN Report. J Am Board Fam Med. 2015 Sep-Oct;28(5):632-8.

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

- RAP, SNPSA
- Hamilton MD, Cola PA, Terchek JJ, Werner JJ, Stange KC. A novel protocol for streamlined IRB review of Practice-based Research Network (PBRN) card studies. *J. Am. Board Fam. Med.* 2011;24(5):605-609.

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

FORM NAMCS-30 (11-15-2010) U.S. DEPARTMENT OF COMMERCE Economics and Statistics Administration U.S. CENSUS BUREAU ACTION: AS DATA COLLECTION AGENT FOR THE U.S. Department of Health and Human Services Centers for Disease Control and Prevention National Center for Health Statistics	PATIENT RECORD NO.: _____
	PATIENT'S NAME: _____
NATIONAL AMBULATORY MEDICAL CARE SURVEY 2011 PATIENT RECORD	
Assurance of confidentiality - All information which would permit identification of an individual, a practice, or an establishment will be held confidential; will be used for statistical purposes only by NCHS staff, contractors, and agents only when required and with necessary controls; and will not be disclosed or released to other persons without the consent of the individual or the establishment in accordance with section 306(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).	

Please leave (X) marks inside of boxes → Correct Incorrect Office Location

1. PATIENT INFORMATION		2. INJURY/POISONING/ADVERSE EFFECT	
a. Date of visit Month Day Year _____ 1 _____	d. Sex <input type="checkbox"/> Female <input checked="" type="checkbox"/> Male	g. Expected source(s) of payment for this visit - Mark (X) all that apply. <input type="checkbox"/> Private insurance <input type="checkbox"/> Medicare <input type="checkbox"/> Medicaid or CHIP <input type="checkbox"/> Worker's compensation <input type="checkbox"/> Self-pay <input type="checkbox"/> No charge/Charity <input type="checkbox"/> Other <input type="checkbox"/> Unknown	Is this visit related to any of the following? <input type="checkbox"/> Unintentional injury/poisoning <input type="checkbox"/> Intentional injury/poisoning <input type="checkbox"/> Injury/poisoning - unknown intent <input type="checkbox"/> Adverse effect of medical/surgical care or adverse effect of medicinal drug <input type="checkbox"/> None of the above
b. ZIP Code _____	e. Ethnicity <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Not Hispanic or Latino	h. Tobacco use <input type="checkbox"/> Not current <input type="checkbox"/> Unknown <input checked="" type="checkbox"/> Current	
c. Date of birth Month Day Year _____	f. Race - Mark (X) one or more. <input type="checkbox"/> White <input type="checkbox"/> Black or African American <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> American Indian or Alaska Native		
3. REASON FOR VISIT		4. CONTINUITY OF CARE	
Patient's complaint(s), symptom(s), or other reason(s) for this visit - Use patient's own words. (1) Most important: _____ (2) Other: _____ (3) Other: _____		a. Are you the patient's primary care physician/provider? <input type="checkbox"/> Yes - SKIP to item 4b. <input type="checkbox"/> No <input type="checkbox"/> Unknown Was patient referred for this visit? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	b. Has the patient been seen in your practice before? <input type="checkbox"/> Yes, established patient - How many past visits in the last 12 months? Exclude this visit. _____ Visits <input type="checkbox"/> Unknown <input type="checkbox"/> No, new patient
		c. Major reason for this visit <input type="checkbox"/> New problem (<3 mos. onset) <input type="checkbox"/> Chronic problem, routine <input type="checkbox"/> Chronic problem, flare-up <input type="checkbox"/> Pre/Post surgery <input type="checkbox"/> Preventive care (e.g., routine prenatal, well-baby, screening, insurance, general exams)	
5. PROVIDER'S DIAGNOSIS FOR THIS VISIT			
a. As specifically as possible, list diagnoses related to this visit including chronic conditions. (1) Primary diagnosis: _____ (2) Other: _____ (3) Other: _____		b. Regardless of the diagnoses written in 5a, does the patient now have - Mark (X) all that apply. <input type="checkbox"/> Arthritis <input type="checkbox"/> Chronic renal failure <input type="checkbox"/> Hypertipidemia <input type="checkbox"/> Asthma <input type="checkbox"/> Congestive heart failure <input type="checkbox"/> Hypertension <input type="checkbox"/> Cancer <input type="checkbox"/> COPD <input type="checkbox"/> Ischemic heart disease <input type="checkbox"/> Cerebrovascular disease/history of stroke or transient ischemic attack (TIA) <input type="checkbox"/> Depression <input type="checkbox"/> Obesity <input type="checkbox"/> Diabetes <input type="checkbox"/> Osteoporosis <input type="checkbox"/> None of the above	
6. VITAL SIGNS		7. DIAGNOSTIC/SCREENING SERVICES	
(1) Height: _____ ft _____ in OR _____ cm (2) Weight: _____ lb _____ oz OR _____ kg _____ gm (3) Temperature: _____ °C / _____ °F (4) Blood pressure: Systolic _____ Diastolic _____	Mark (X) all ordered or provided at this visit. Examinations: <input type="checkbox"/> NONE <input type="checkbox"/> Breast <input type="checkbox"/> Foot <input type="checkbox"/> Pelvic <input type="checkbox"/> Rectal <input type="checkbox"/> Retinal <input type="checkbox"/> Skin <input type="checkbox"/> Depression screening Imaging: <input type="checkbox"/> X-ray <input type="checkbox"/> Bone mineral density <input type="checkbox"/> CT scan <input type="checkbox"/> Echocardiogram <input type="checkbox"/> Other ultrasound		
		Other tests: <input type="checkbox"/> Biopsy - Specify _____ <input type="checkbox"/> Ocriamydia test <input type="checkbox"/> EKG/ECG <input type="checkbox"/> HIV test <input type="checkbox"/> HPV DNA test <input type="checkbox"/> Pap test <input type="checkbox"/> Pregnancy/HCG test <input type="checkbox"/> Urinalysis (UA) <input type="checkbox"/> Other exam/test/service - Specify _____	
8. HEALTH EDUCATION		9. NON-MEDICATION TREATMENT	
Mark (X) all ordered or provided at this visit. <input type="checkbox"/> NONE <input type="checkbox"/> Injury prevention <input type="checkbox"/> Stress management <input type="checkbox"/> Asthma education <input type="checkbox"/> Diet/Nutrition <input type="checkbox"/> Tobacco use/Exposure <input type="checkbox"/> Exercise <input type="checkbox"/> Family planning/Contraception <input type="checkbox"/> Weight reduction <input type="checkbox"/> Other		Mark (X) all ordered or provided at this visit. <input type="checkbox"/> NONE <input type="checkbox"/> Psychotherapy <input type="checkbox"/> Other non-surgical procedures - Specify _____ <input type="checkbox"/> Complementary alternative medicine (CAM) <input type="checkbox"/> Other mental health counseling <input type="checkbox"/> Durable medical equipment <input type="checkbox"/> Excision of tissue <input type="checkbox"/> Home health care <input type="checkbox"/> Wound care <input type="checkbox"/> Physical therapy <input type="checkbox"/> Cast <input type="checkbox"/> Radiation therapy <input type="checkbox"/> Splint or wrap	
10. MEDICATIONS & IMMUNIZATIONS		11. PROVIDERS	
<input type="checkbox"/> NONE Include Rx and OTC drugs, immunizations, allergy shots, oxygen, anesthetics, chemotherapy, and dietary supplements that were ordered, supplied, administered or continued during this visit.		Mark (X) all providers seen at this visit. <input type="checkbox"/> Physician <input type="checkbox"/> Physician assistant <input type="checkbox"/> Nurse practitioner/Midwife <input type="checkbox"/> RN/LPN <input type="checkbox"/> Mental health provider <input type="checkbox"/> Other	
(1) _____ New <input type="checkbox"/> Continued <input type="checkbox"/> (2) _____ New <input type="checkbox"/> Continued <input type="checkbox"/> (3) _____ New <input type="checkbox"/> Continued <input type="checkbox"/> (4) _____ New <input type="checkbox"/> Continued <input type="checkbox"/> (5) _____ New <input type="checkbox"/> Continued <input type="checkbox"/> (6) _____ New <input type="checkbox"/> Continued <input type="checkbox"/> (7) _____ New <input type="checkbox"/> Continued <input type="checkbox"/> (8) _____ New <input type="checkbox"/> Continued <input type="checkbox"/>		12. VISIT DISPOSITION Mark (X) all that apply. <input type="checkbox"/> Refer to other physician <input type="checkbox"/> Return at specified time <input type="checkbox"/> Refer to ER/Admit to hospital <input type="checkbox"/> Other Continue on reverse side →	
		13. TIME SPENT WITH PROVIDER Minutes: _____ <small>(Enter zero if no provider seen)</small>	

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

Thomas P, Griffiths F, Kai J, O'Dwyer A. Networks for research in primary health care. *BMJ*. 2001;322(7286):588-590.

Thomas P, Graffy J, Wallace P, Kirby M. How primary care networks can help integrate academic and service initiatives in primary care. *Ann. Fam. Med*. 2006;4(3):235-239.

Thomas P. *Integrating Primary Health Care: Leading, Managing, Facilitating*. Oxford, UK: Radcliffe Publishing; 2006.

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
- CTSAAs, 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/>

