

Research Facilitation and Data Collection in Practice-based Research Networks

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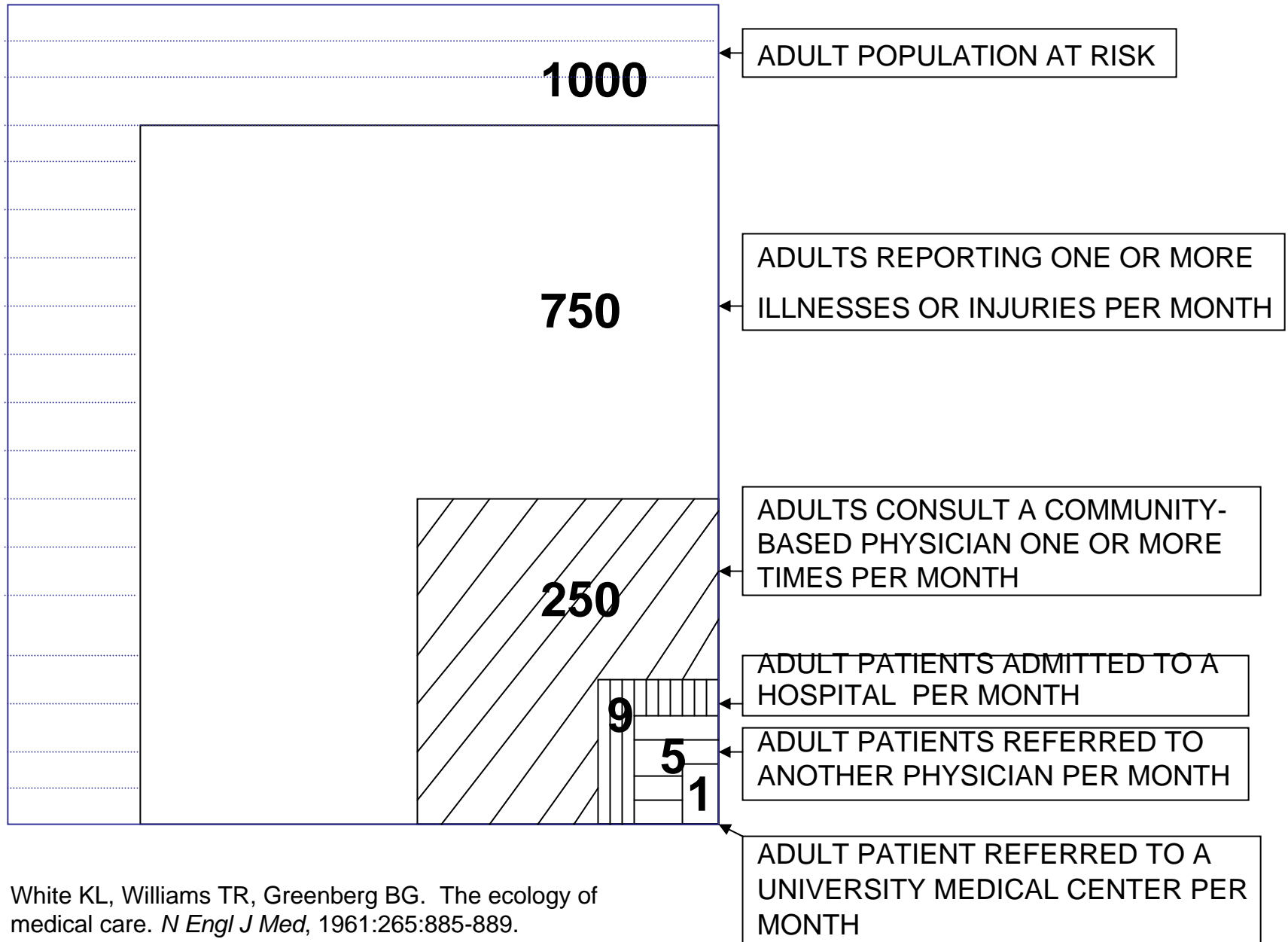
First Seminar: Introduction to Practice-based Research

- 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

Illness in the Community



White KL, Williams TR, Greenberg BG. The ecology of medical care. *N Engl J Med*, 1961;265:885-889.

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

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graph TD; A[Academic-initiated] --- C[Network Studies]; B[Clinician-initiated] --- C;
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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

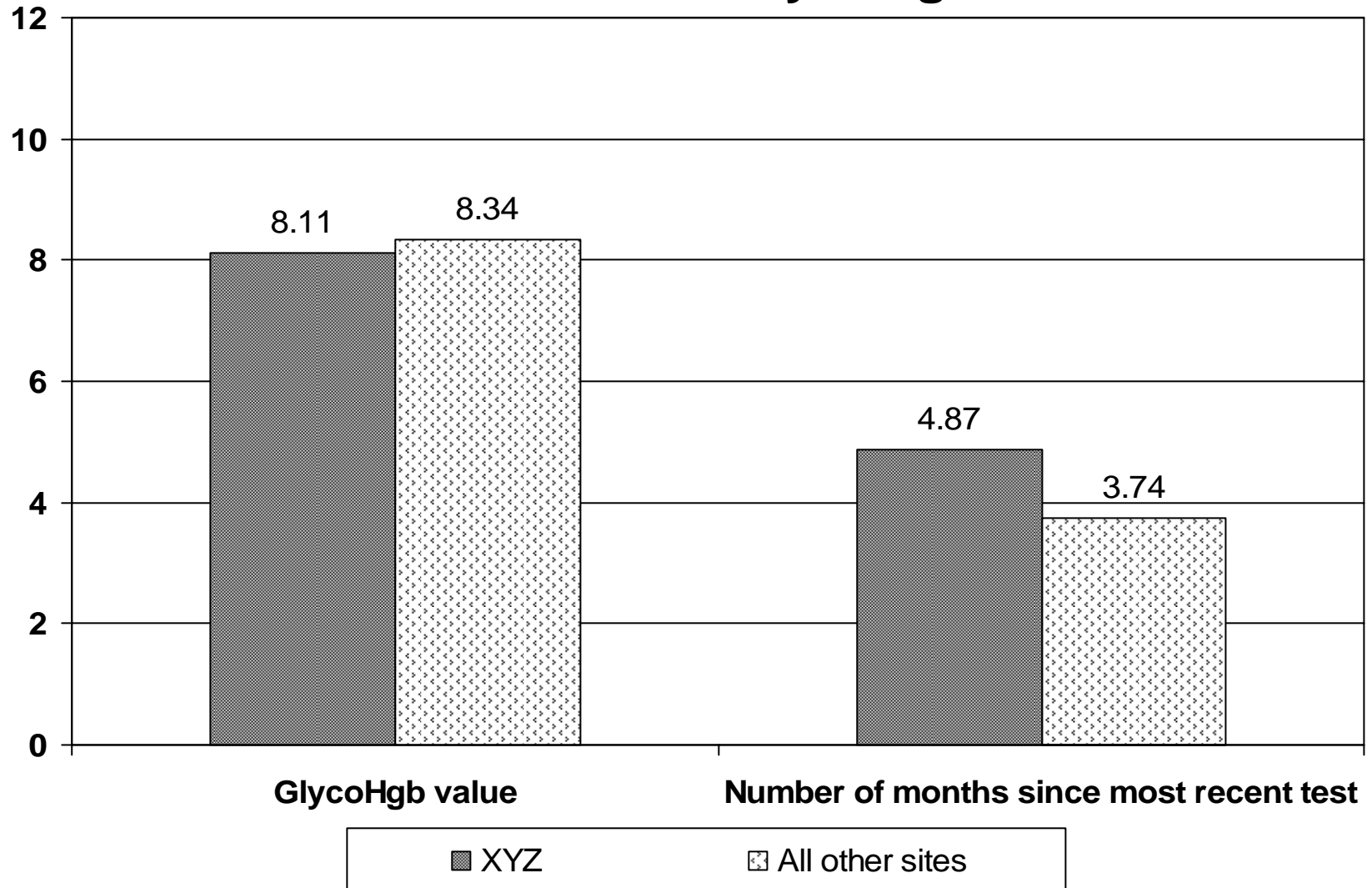
Benefits for Clinicians

- 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

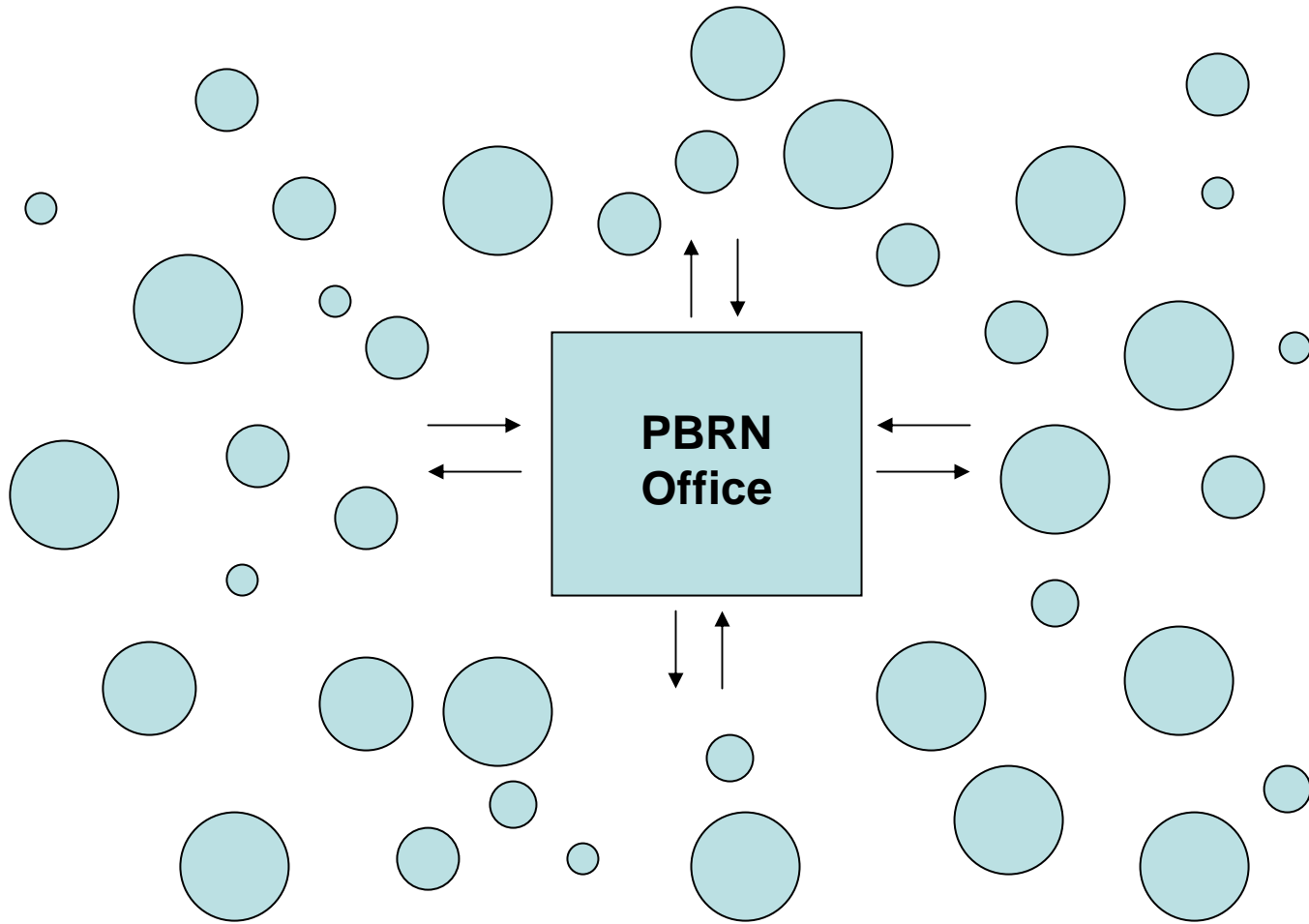
Most recent GlycoHgb test



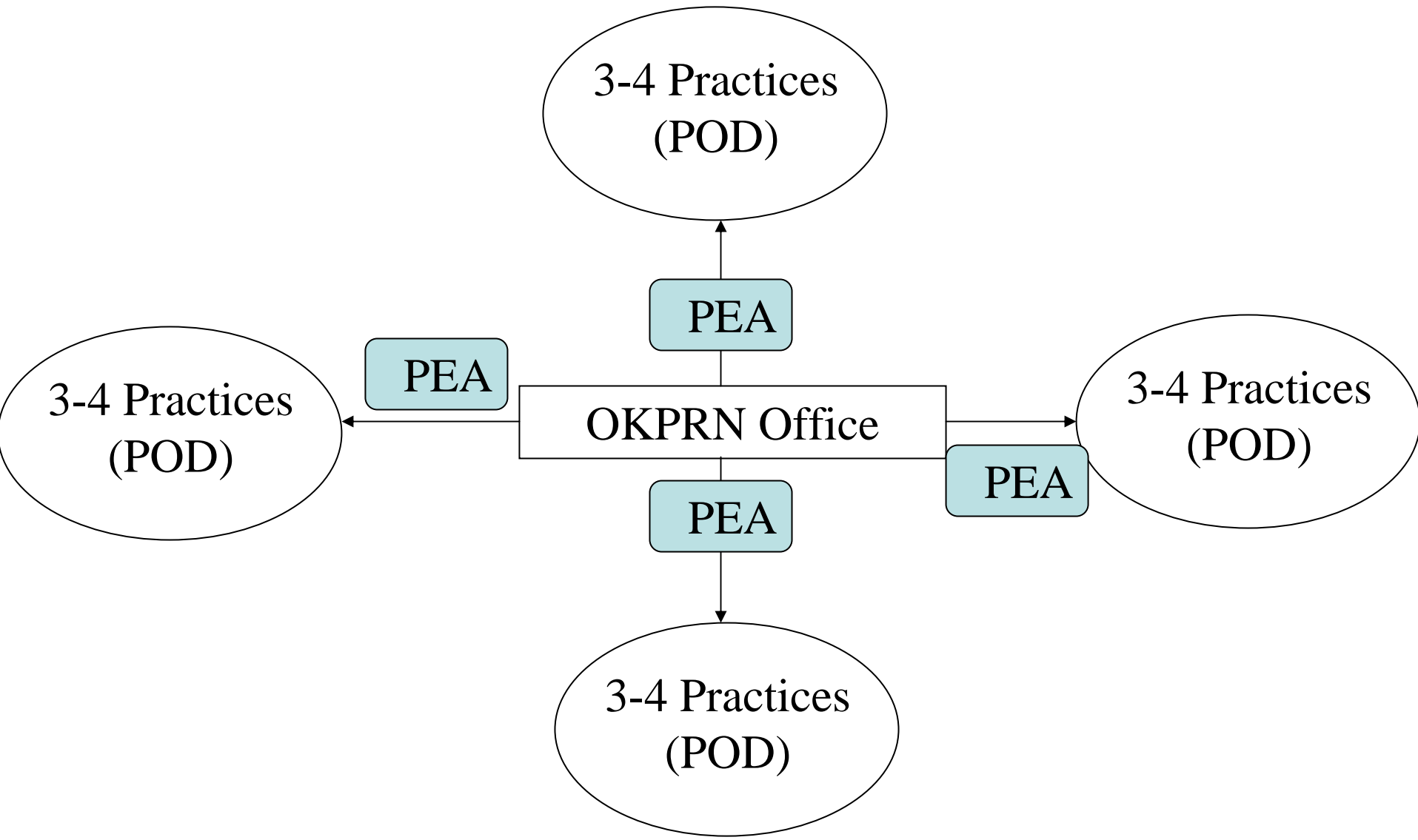
Infrastructure Elements: Determined by Mission and Resources

- 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



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.”

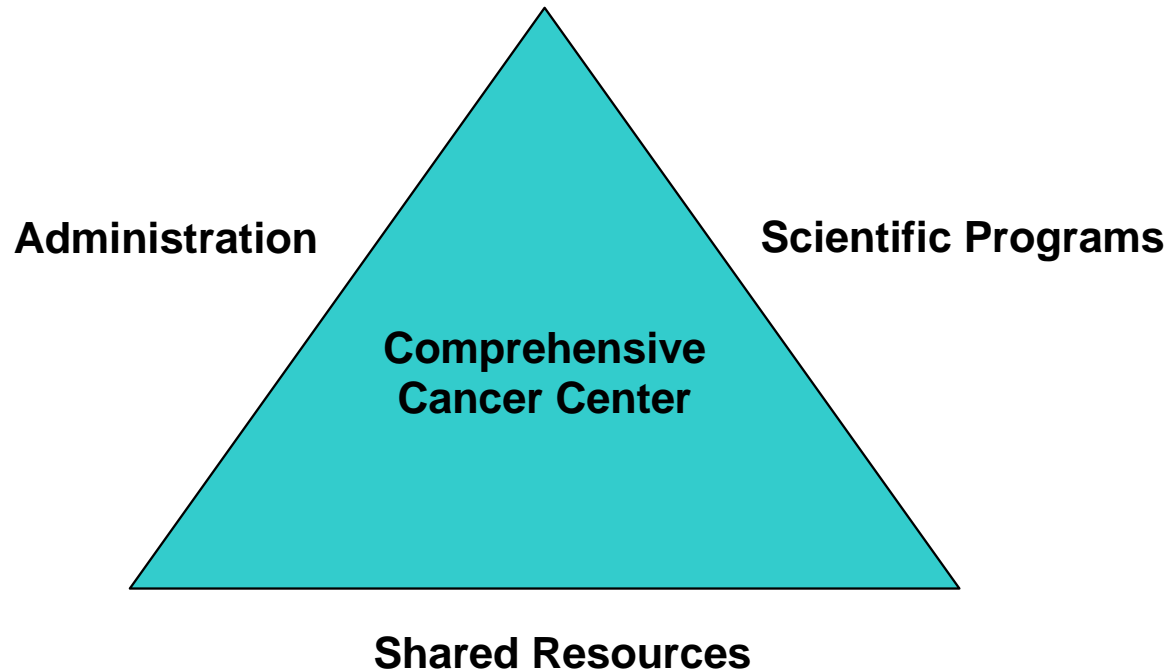
- Minimal staff resources

“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.

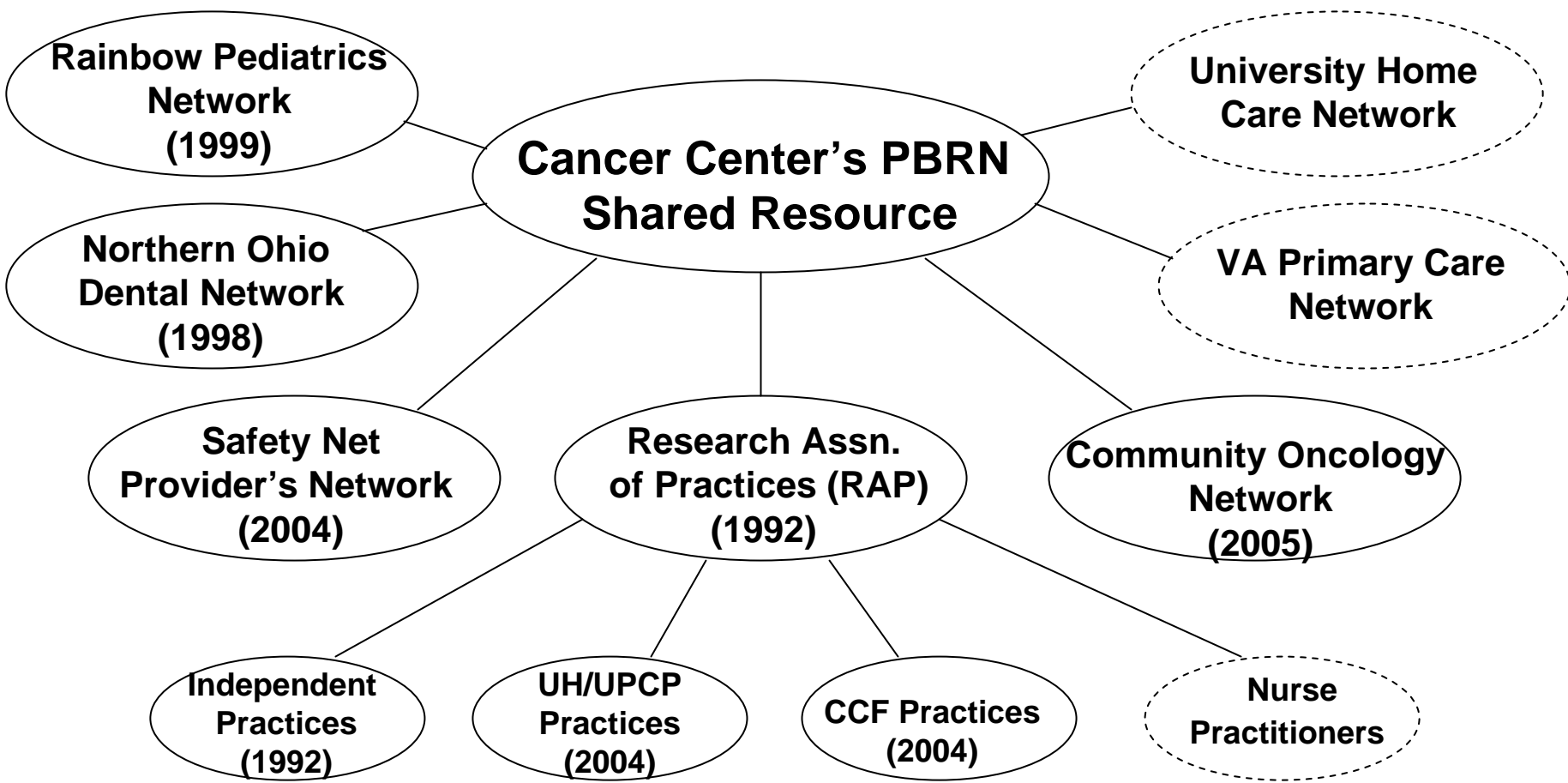
Structure of Comprehensive Cancer Centers



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



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

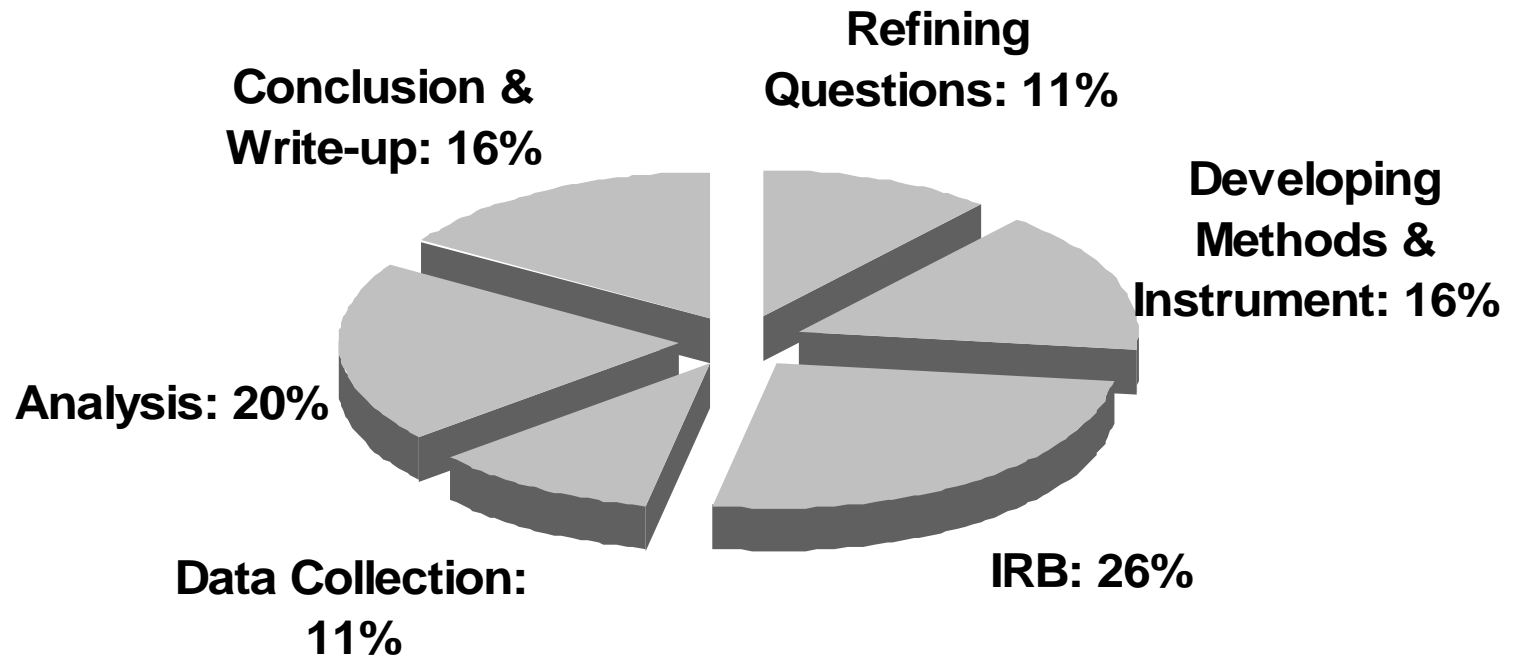
- Research sub-committee monthly meetings began in September, 2004
- Pre-identified diabetes as topic of interest
- Highly collaborative process between clinicians, researchers, and administrators

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

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

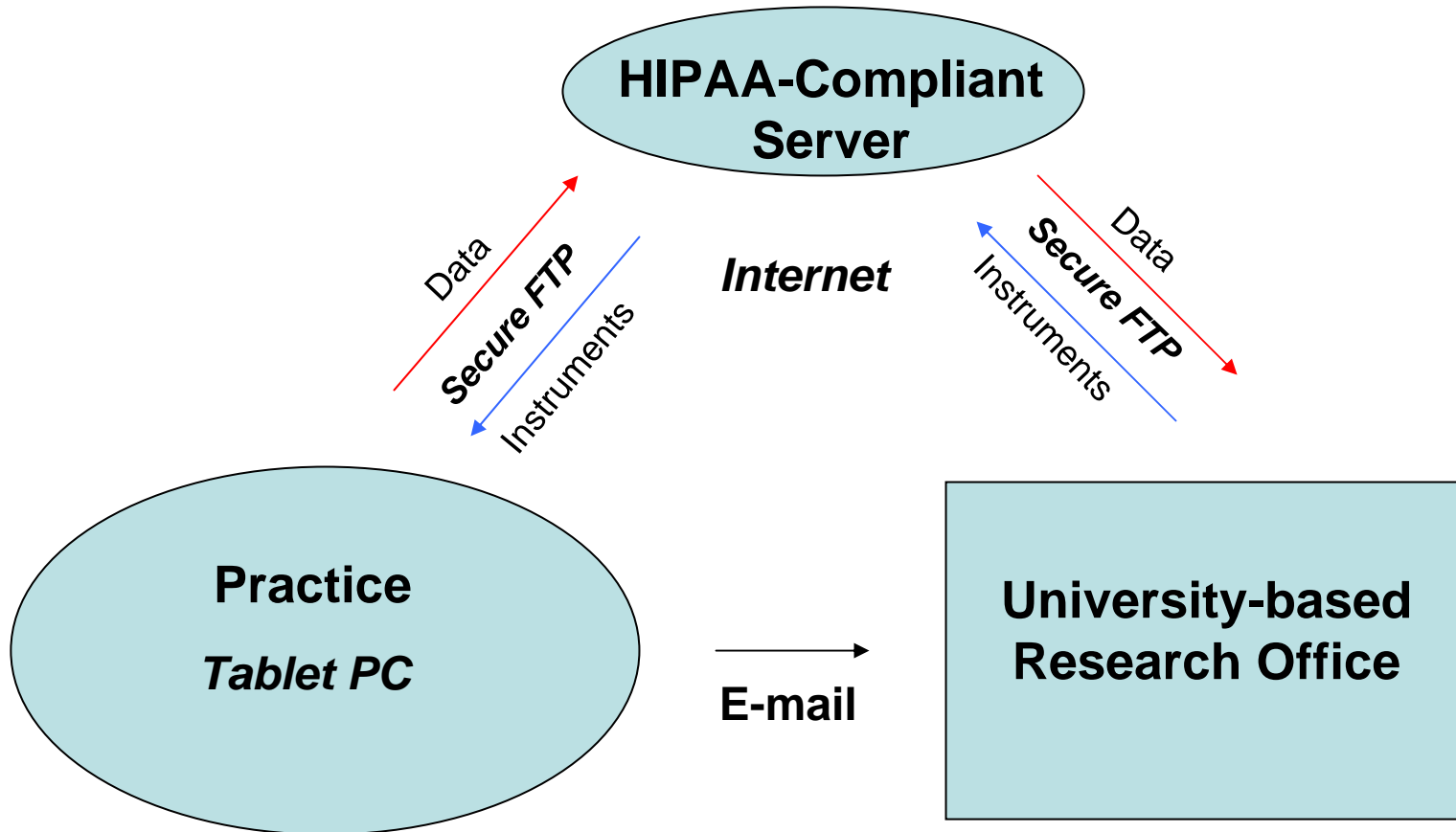
- **Capital investment in point of care systems**
 - **Software, hardware**
 - **IT staff**
 - **Trainers**
- **Integration with EHRs**
- **Clinician's time for training**
- **Long-distance troubleshooting**
- **Assessing technologies as they rapidly evolve**

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



Online Survey Services

[Zoomerang™](#)

[SuperSurvey](#)

[Greenfield Online](#)

[Infopoll](#)

[Perseus](#)

[PollCat](#)

[Inquisite](#)

[Cool Surveys](#)

[Survey System](#)

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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/>.

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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.

