Practice Based Research Networks and National Health Databases

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College of Public Health
Learning Objectives

1. Describe the purpose of practice-based research networks (PBRNs)
2. Discuss potential ideas for research using PBRNs
3. List administrative databases
4. Describe strengths and limitations of administrative data bases
5. List federal agencies conducting health surveys
6. Discuss potential uses of national health surveys
Practice-Based Research Networks (PBRNs)
What are PBRNs?
What are (Primary Care) Practice-Based Research Networks?

PBRNs are groups of primary care clinicians and practices working together to answer community-based health care questions and translate research findings into practice.

PBRNs engage clinicians in quality improvement activities and an evidence-based culture in primary care practice to improve the health of all Americans.

From AHRQ https://pbrn.ahrq.gov/
AHRQ PBRNs

- Agency for Healthcare Research and Quality (AHRQ)
- “Established” primary care PBRNs must have:
  - 5 practices
  - Mission statement
  - PBRN Director
  - 5 practices and 15 clinicians
- “Developing” primary care PBRNs do not meet established PBRN criteria
AHRQ PBRNs (cont’d)

• Coverage
  • National
  • Regional
  • State
  • Local

• Types
  • Mixed
  • Family medicine
  • Pediatric
  • Internal medicine
  • Pharmacy
  • Dental
  • Other
PBRN Capacity-Building Activities

- Participate in developing research agenda/ grant submissions
- Co-author research presentations / publications
- Training human subjects protection / research ethics
- Practice facilitators / coaches
- Technical assistance for practice transformation efforts (e.g., meaningful use)
- Financial compensation for research participation
- Participate in learning collaborative
- Performance evaluation / feedback
- Conferences or journal clubs
What are potential research ideas using PBRNs?
Discussions

• Think about your own research topics / ideas
• What kind of research questions can be tested using PBRNs?
• What types of PBRNs are most suitable for your potential research study?
• What are most suitable approaches / methods? (trials, descriptive studies, secondary data analysis, data mining, etc)
OCHIN Electronic Portal Use Study

• Oregon Community Health Information Network (OCHIN)
• Started in Oregon, joined by 12 other states
• Geographically and demographically diverse patient population

• Total 26,204 adult patients (2012-2013)
• Studied the patterns of MyChart use by vulnerable patients

Wallace LS, et al. 2016. JABFM
Chronic Kidney Disease (CKD) Local Learning Collaboratives

- Local learning collaboratives (LLCs)
- Data-driven group / network of change teams from organizations with commonality of care that work collectively to **enhance performance through process improvement**
- Four regional PBRNS in Oklahoma, California, Wisconsin, Minnesota, and a research corporation (Westad)

- Studied diffusion of treatment guidelines for CKD through LLCs

Lipman P.D. & Aspy C.B., JABFM 2016
Great Plains Primary Care Practice Based Research Network

The Great Plains Primary Care Practice Based Research Network (PBRN) was established to improve access to healthcare resources and promote primary care research across the Great Plains. This PBRN encompasses a supportive and collaborative network of clinics, clinicians, and investigators who experience similar healthcare challenges and shared research goals. Through resources provided by the PBRN, members conduct research to gain clinical knowledge to better serve their patients and community, resulting in improved health and quality of life across the region.

https://gpctr.unmc.edu/ctr-resources/pbrn/
<table>
<thead>
<tr>
<th>Clinic Name</th>
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<tr>
<td>Omaha Family Medicine PC</td>
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Nebraska PBRN Contact

Phone: 402-552-2260

Email: gpctr@unmc.edu

Website: gpctr.unmc.edu
National Databases for Health Research
What are databases?

Database = Any collection of data, or information, that is specially organized for rapid research and retrieval by a computer

Encyclopedia Britannica
https://www.britannica.com/technology/database
Two types of databases for today’s talk

1. Healthcare administrative databases
   - US Government
   - Private (e.g., GE Health, IBM Watson Marketscan)

2. Health survey databases
   - Healthcare quality assessment
   - Disease prevalence
   - Health behavior
   - Lab / genetic data
Administrative data

- Information collected primarily for administrative (not research purposes)
- Collected by public and private organizations
- For registration, transaction, and record keeping, during the delivery of a service
Patient seeks care

Routine clinical care

Provider notes care

Coding by staff

Insurance company

Record Generation Process

- Patient has symptoms, acute illness etc.
- Encounter with health professional
- Examination, history, diagnostics
- Diagnosis
- Interventions including drug prescribing
- EMR
- Coding claims
- Filling of complete claims
- Filing and adjudication of final claims

Potential Sources of Bias

- Indigent patients without coverage and patients with insufficient insurance are less likely to seek professional care
- Incomplete documentation of clinical status; misdiagnosis; false ranking of "primary diagnosis"
- Miscoding of drug, strength, dose; non-recording of free samples and over-the-counter drugs
- Incomplete record keeping
- Miscoding of primary and secondary diagnoses; miscoding of procedures; failure to file claims
- Transaction error; late-time until adjudication and final filing; loss to follow-up if patient has left the system
- Incomplete / false record linkage

Adm. database

Admin. database

Research Database

Adopted from Schneeweiss, S. & Avorn, J. J Clin Epidemiolol 2005
Example uses

1. Descriptive epidemiology research
2. Comparative effectiveness research
3. Public health surveillance
4. Policy analyses / evaluation
5. Economic evaluation
6. Clinical studies
7. Risk adjustment
US public administrative databases - examples

• Healthcare Cost and Utilization Project (HCUP)
  • Nationwide Inpatient Sample (NIS)
  • State Ambulatory Surgery Databases (SASD)
  • State Emergency Department Databases (SEDD)
  • Kids’ Inpatient Database (KID)
• Medicare
• SEER-Medicare linked databases
• Veterans Administrative databases
Strengths of health care utilization data

1. Relatively quick and less costly
2. Most contain large samples
3. Can study effectiveness, safety, and utilization using “real world” data
4. Continuous assessment (longitudinal)
5. Objective data
Limitations of health care utilization data

• Requires “encounter” with health care system
• Generalizability may be limited
• Socioeconomic data and health behavior (e.g., smoking, nutrition) often lacking
• Potential misclassification of exposure, outcomes and covariates
• Turnover rate in health care plans needs to be taken into consideration
• May not be track individuals longitudinally
• May be difficult / impossible to obtain or link other important information (e.g., physician notes, labs, mortality)
Survey databases
Health surveys by federal agencies – examples

1. Centers for Disease Prevention & Control (CDC)
2. Agency for Healthcare Research and Quality (AHRQ)
3. Substance Abuse and Mental health Services Administration (SAMHSA)
4. Medicare
5. National Cancer Institute (NCI)
CDC Data Collection System

- National Health Care Surveys (NHCS)
- National Health and Nutrition Survey (NHANES)
- National Health Interview Survey (NHIS)
- National Survey of Family Growth
- National Vital Statistics
National Health Care Surveys

- Ambulatory
- Hospital Ambulatory
- Ambulatory Surgery
- Hospital
- Nursing Home
- Home and Hospice Care
- Residential Care Facilities
- Long-Term Care Providers
- Prison Health Care
Example published studies

• Exposure estimates of nitrate and nitrate from consumption of cured meat products
• Adiposity and insulin resistance on the impaired lung function in asthmatic adults
• Blood cadmium concentration and kidney function
• Nonalcoholic fatty liver disease and smoking on mortality
• Caffeine intake and depressive symptoms
# NHIS 2019 Proposed Revisions (Adults)

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<th>2021</th>
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### NHIS 2019 Proposed Revisions (Children)

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<td>2019</td>
<td>Household Roster - Selection of Sample Child - Identification of Parent/Guardian Respondent - Informed Consent</td>
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<td>2020</td>
<td>Demographic Characteristics - Health Status - Asthma - Diabetes - Developmental and Learning Disabilities</td>
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<td>2021</td>
<td>Difficulties with Vision, Hearing, Mobility, Self-Care and Upper Body, Communication, and Cognition</td>
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<td>Anxiety - Depression - Behavior Social/Emotional Screening for Very Young Children</td>
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#### Rotating Core Data Collection Areas
- Mental Health Assessment
- Injuries
- Stressful Life Events
- Phys Activity and Sleep

#### Dental, Mental, Other Care Utilization
- Rotating Conditions

#### Rotating Conditions
- Mental Health Assessment
- Injuries
- Stressful Life Events
- Phys Activity and Sleep
Vital Statistics

- Birth Data
- Mortality Data
- Fetal Death Data
- Linked Birth and Infant Death Data
Secondary Data Analysis Study – “Condensed” Version of Steps to Follow
Research ideas
Potential data sources
Hypotheses based on available variables
Download public data or data request
How to access data

1. Most of the data sets described in this lecture are available as public data sets (open access)
2. Public data sets can be downloaded from CDC websites
3. Basic queries and analysis can be also done for some of data sets
4. For data sets with detailed information / restricted information, a research proposal needs to be submitted
In conclusion…

• There are a variety of administrative and survey data sets
• Population representation and large sample sizes are strengths
• Suitable for secondary data analysis studies
• Some grant mechanisms support / promote innovative uses of existing data sets
• Once you have research ideas, consult with biostaticians, epidemiologists, and/or informatics specialists about the study design and analytical approach
Resources from GP-IDEA CTR

1. Biostatistics, Epidemiology, & Research Design (BERD) KCA
   - Study design
   - Acquisition of data for secondary data analysis
   - Database development & management
   - Data analysis

2. Biomedical Informatics & Cybersecurity (BMI) KCA
   - I2b2 data use training and access
Questions?