

Practice Based Research Networks and National Health Databases

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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



AHRQ PBRN Map



<https://pbrn.ahrq.gov/pbrn-registry/pbrn-registry-map>



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



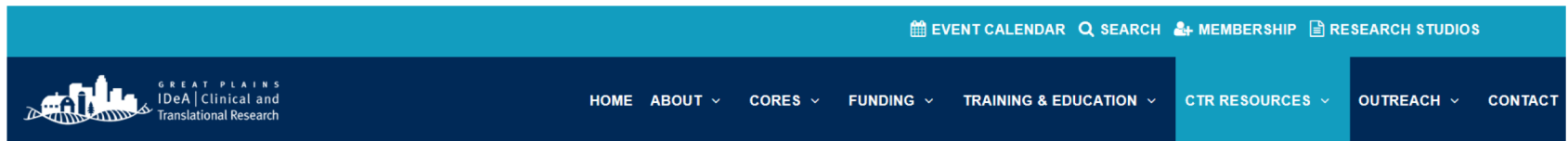
Chronic Kidney Disease (CKD) Local Learning Collaboratives

- 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 PBRN



Home > CTR-Resources > Great Plains Primary Care Practice Based Research Network

Software Licenses

SPARC

Research Studios

Clinical Research Toolbox

Evidence-Based Intervention Repository

Great Plains Primary Care PBRN

About The Great Plains Primary Care PBRN

Join The Network

Great Plains Primary Care PBRN Sites

PBRN Directory

Conduct A Study

PBRN Research

Education And Seminars

News And Events

Great Plains Primary Care Practice Based Research Network



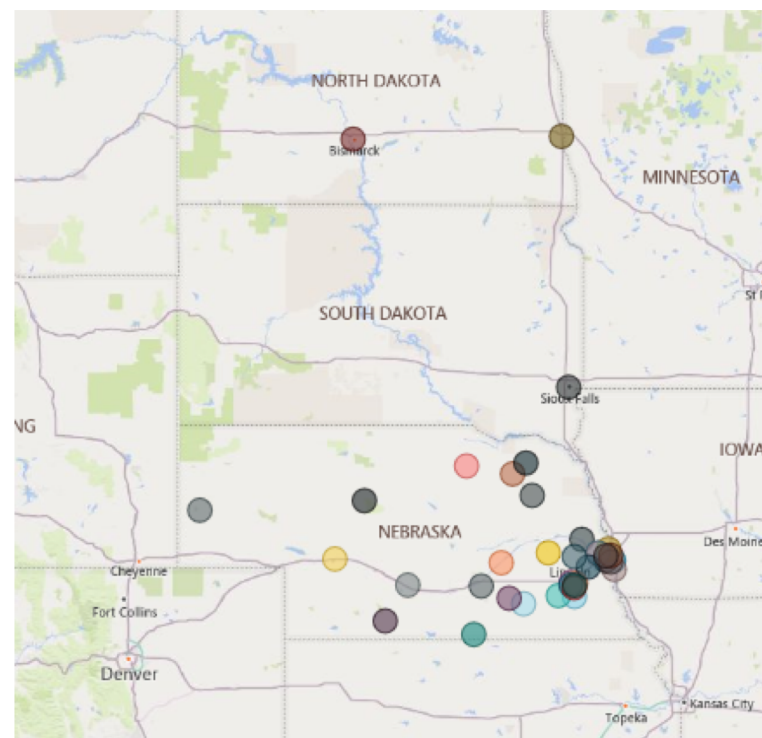
The Great Plains Primary Care Practice Based Research Network (PBRN) was established to improve access to healthcare resources and promote primary care research across the Great Plains. This PBRN encompasses a supportive and collaborative network of clinics, clinicians, and investigators who experience 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/>



PBRN SITES

Clinic Name	City, State & Zip
Omaha Family Medicine PC	Omaha, NE 68130
Boys Town Pediatrics Lakeside Clinic	Omaha, NE 68130
Beacom Health	Fremont, NE 68025
South Omaha Medical Associates Inc	Omaha, NE 68107
Family Medicine Specialists Clinic	Lexington, NE 68850
Wausa Medical Clinic	Wausa, NE 68786
Sandhills Family Medicine	Mullen, NE 69152
CAPWN Health Center	Gering, NE 69341
Remedy Health PC	Bellevue, NE 68123
Nebraska Medicine Fontenelle Clinic	Omaha, NE 68104
Tri Valley Health System Cambridge Clinic	Cambridge, NE 69022
Cedar Plains Family Medicine	Hickman, NE 68372
Elkhorn Valley Family Medicine	O'Neil, NE 68763
Central City Medical Clinic	Central City, NE 68826
Priority Family Medicine	Plainview, NE 68769
Ross Internal Medicine PC	Lincoln, NE 68506
Complete Childrens Health	Lincoln NE 68505
Holistic and Family Healthcare	Papillion, NE 68046
Inpatient Physician Associates	Lincoln, NE 68502
Hart Family Health PC	Lincoln NE, 68510
Chitrita Roy MD PC	Bellevue, NE 68005
Real Life Health	Ashland, NE 68003
Quality Healthcare Clinic	Sutton, NE 68979
LifeArts Integrated Health Center PC	Plattsmouth, NE 68048
Doniphan Family Clinic	Doniphan, NE 68832
Butler County Clinic	David City, NE 68632
Main Street Medical Clinic	Red Cloud, NE 68970
Family First Health Center	Sutherland, NE 69165
Milk Works	Lincoln, NE 68516
Norfolk Medical Group	Norfolk, NE 68701
Saunders Medical Center	Wahoo, NE 68006
McGill Family Practice PC	Papillion, NE 68046
Yvonne Stephenson MD	Omaha, NE 68127
Childrens Center for the Child and Community	Lincoln, NE 68508
Fillmore County Medical Center	Geneva, NE 68361
Crete Area Medical Center	Crete, NE 68333
Sanford Medical Center - Sioux Falls	Sioux Falls, SD 57117
Sanford Medical Center - Bismarck	Bismarck, ND 58501
Sanford Medical Center - Fargo	Fargo, ND 58104



Nebraska PBRN Contact

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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

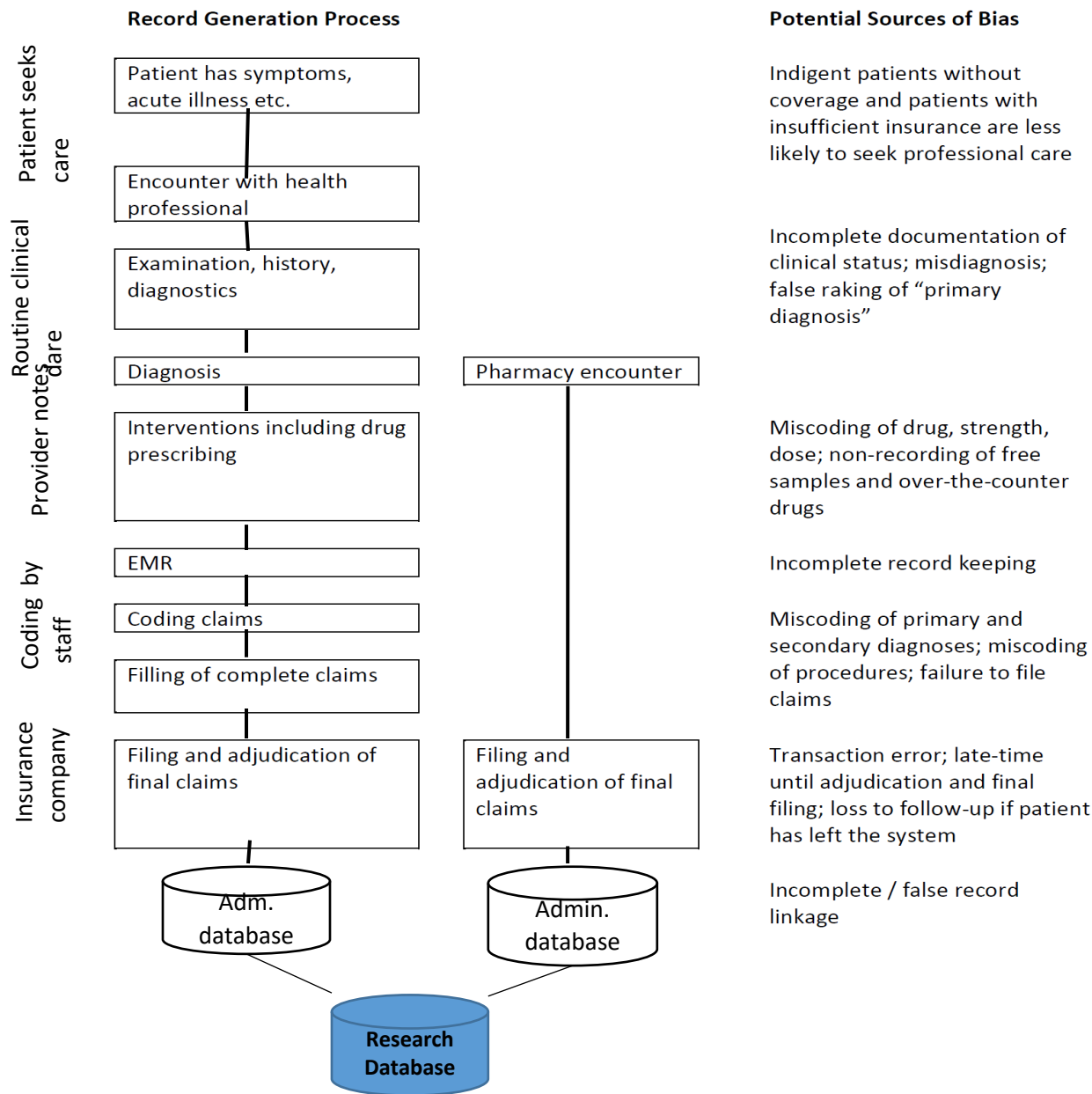
- Healthcare quality assessment
- Disease prevalence
- Health behavior
- Lab / genetic data



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





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

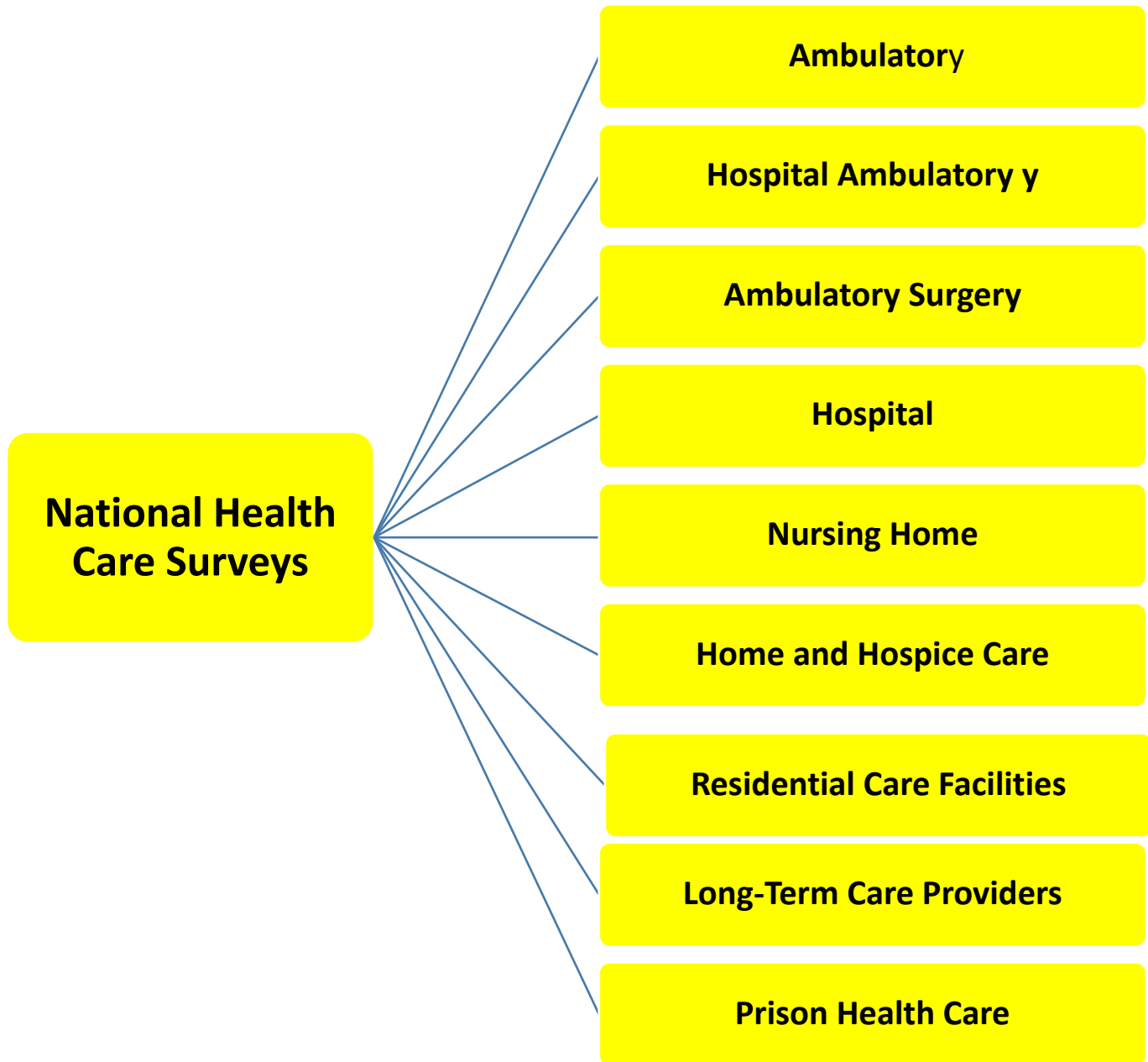
National Health Care Surveys (NHCS)

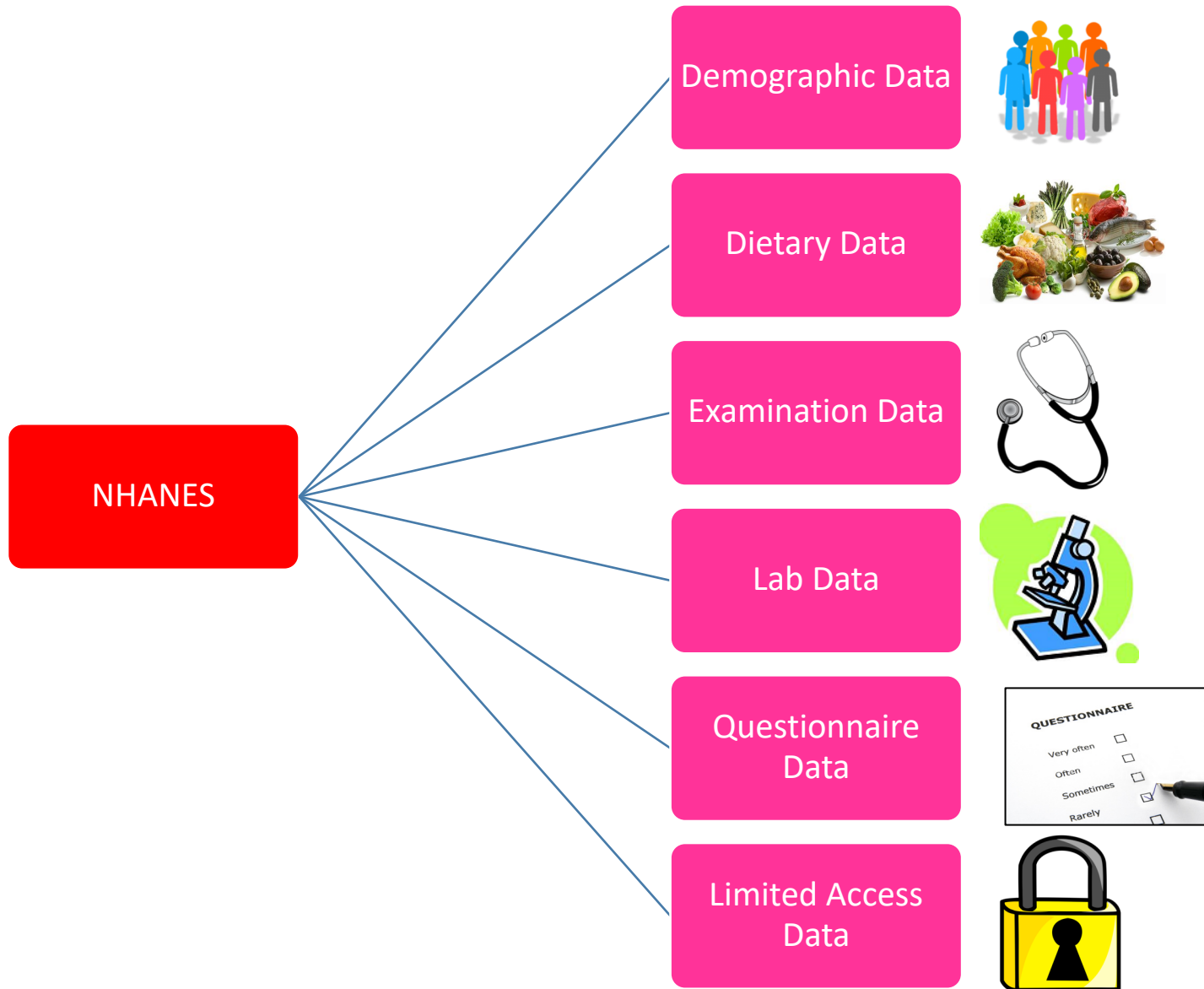
National Health and Nutrition Survey (NHANES)

National Health Interview Survey (NHIS)

National Survey of Family Growth

National Vital Statistics





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

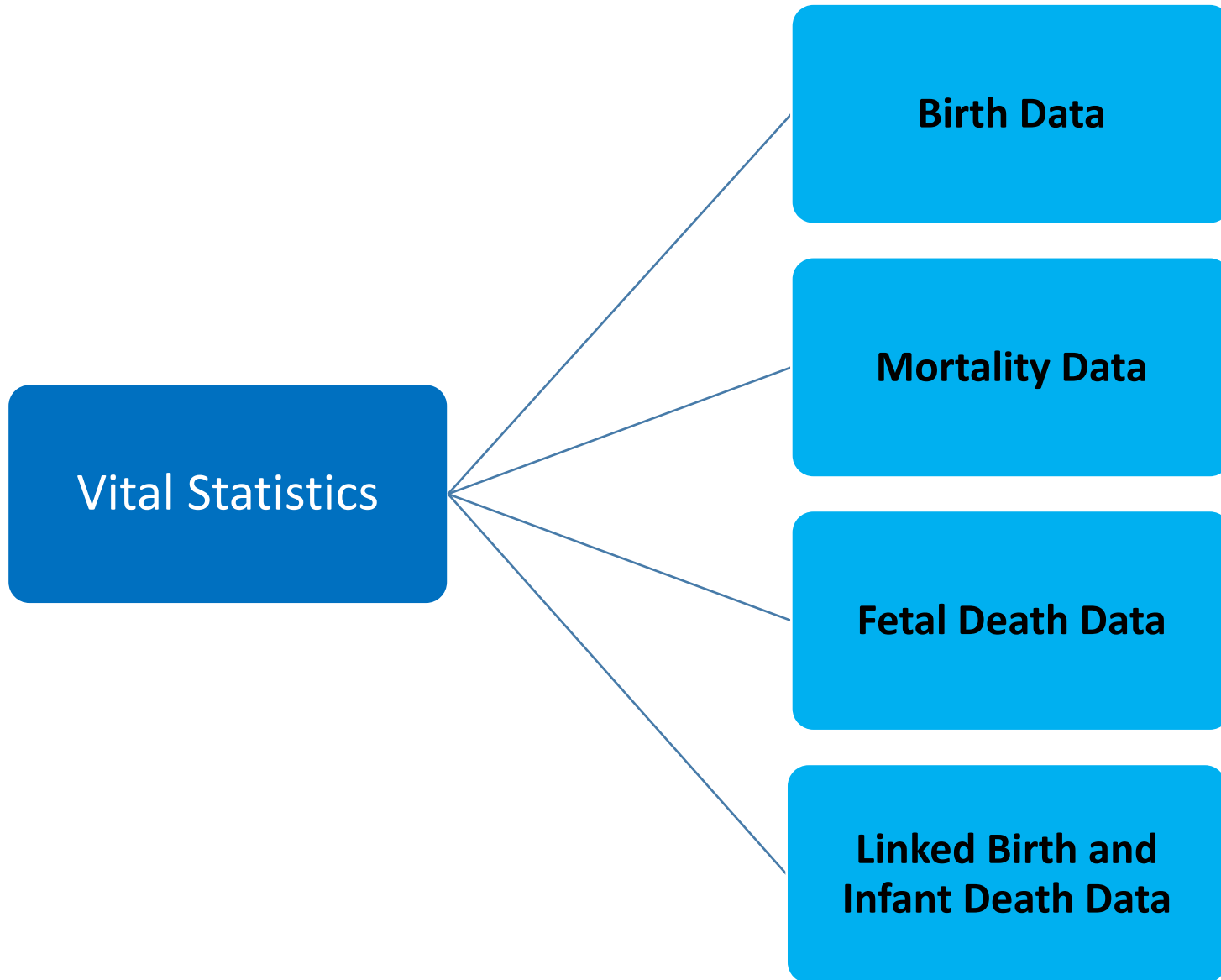


NHIS 2019 Proposed Revisions (Adults)

	2019	2020	2021	2022	2023	2024	2025	2026	2027
	Household Roster - Selection of Sample Adult - Informed Consent								
Annual core	Demographic Characteristics - Health Status - Hypertension - High Cholesterol Cardiovascular Conditions - Asthma - Cancer - Diabetes - Other Chronic Conditions Height and Weight Difficulties with Vision, Hearing, Mobility, Communication, Cognition, and Self-Care Social Functioning - Health Insurance Status and Continuity Financial Burden of Medical Care - Health Care Utilization and Access Prescription Medication - Immunizations - Anxiety - Depression Cigarettes and E-cigarettes - Sexual Orientation Marital Status - Veteran Status - Nativity - Schooling - Employment of Adult Family Members Family Income - Food-Related Program Participation - Housing Telephone Use - Linkage Information								
Rotating core	Dental, Mental, Other Care Utilization		Rotating Conditions	Dental, Mental, Other Care Utilization		Rotating Conditions	Dental, Mental, Other Care Utilization		Rotating Conditions
	Mental Health Assessment	Employment Detail - Injuries		Mental Health Assessment	Employment Detail - Injuries		Mental Health Assessment	Employment Detail - Injuries	
	Chronic Pain - Preventive Services	Health Behaviors	Chronic Pain - Preventive Services	Health Behaviors	Chronic Pain - Preventive Services	Health Behaviors	Chronic Pain - Preventive Services	Health Behaviors	Chronic Pain - Preventive Services

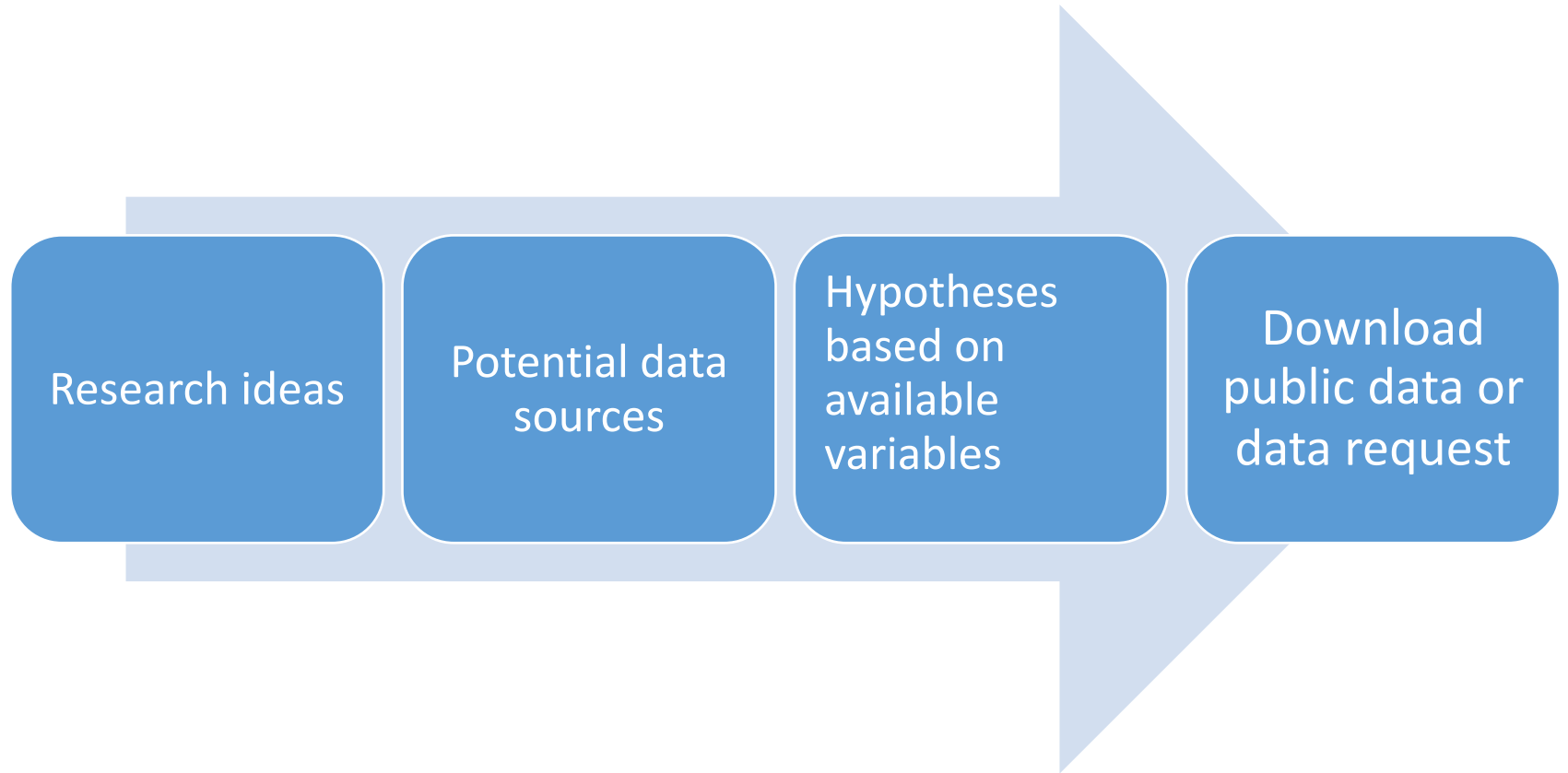
NHIS 2019 Proposed Revisions (Children)

	2019	2020	2021	2022	2023	2024	2025	2026	2027
	Household Roster - Selection of Sample Child - Identification of Parent/Guardian Respondent - Informed Consent								
Annual core	Demographic Characteristics - Health Status - Asthma - Diabetes - Developmental and Learning Disabilities Difficulties with Vision, Hearing, Mobility, Self-Care and Upper Body, Communication, and Cognition Anxiety - Depression - Behavior Social/Emotional Screening for Very Young Children Schooling - Health Insurance Status and Continuity - Financial Burden of Medical Care Health Care Utilization and Access - Prescription Medication - Immunizations Parent Demographics - Nativity Employment of Adult Family Members - Family Income and Sources of Income Food-Related Program Participation - Housing - Telephone Use - Linkage Information								
Rotating core	Dental, Mental, Other Care Utilization		Rotating Conditions	Dental, Mental, Other Care Utilization		Rotating Conditions	Dental, Mental, Other Care Utilization		Rotating Conditions
	Mental Health Assessment	Injuries		Mental Health Assessment	Injuries		Mental Health Assessment	Injuries	
	Stressful Life Events	Phys Activity and Sleep	Stressful Life Events	Phys Activity and Sleep	Stressful Life Events	Phys Activity and Sleep	Stressful Life Events	Phys Activity and Sleep	Stressful Life Events



Secondary Data Analysis Study – “Condensed” Version of Steps to Follow





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 biostatisticians, 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?

