



The Feasibility of Using Electronic Health Records (EHRs) and Other Electronic Health Data for Research on Small Populations

Kelly J. Devers, Ph.D.

January 18, 2018

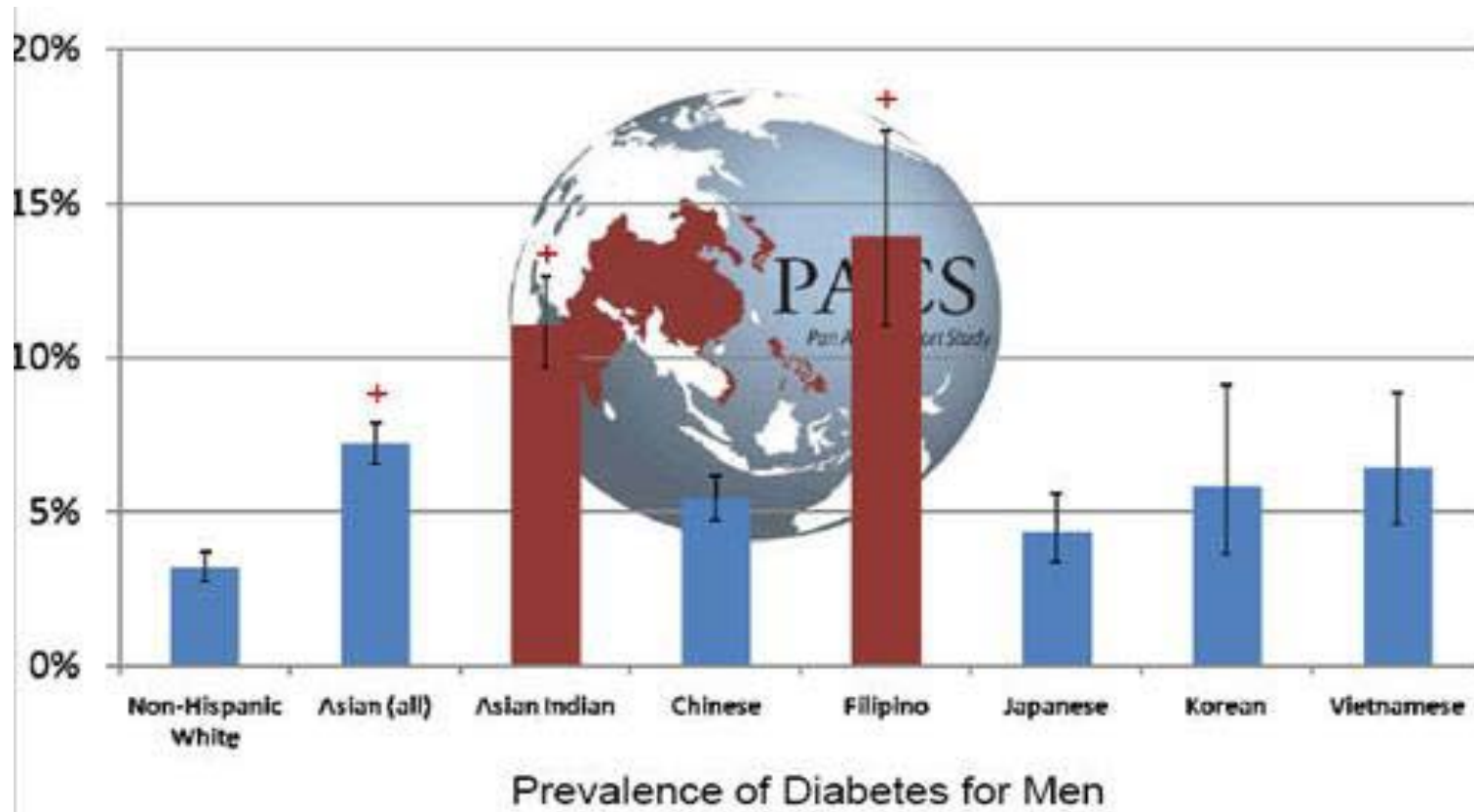
Outline

- The Importance of Studying Small Populations
- Some Challenges in Studying Small Populations
- Growing Availability of Electronic Health Records (EHRs) and other Electronic Health Data
- Potential Uses of EHRs and Other Electronic Health Data
- Future Research
 - Conditions for Greater Use of EHRs and Electronic Health Data
 - Potential Next Steps

Asian-American Sub-Populations

- For Asian Americans populations and sub-populations, researchers struggle to obtain adequate sample sizes upon which to conduct analysis
- A lack of consistent race/ethnicity categories makes this data collection even more difficult
- When sub-population analysis has been possible, the results reveal major differences in health

Pan-Asian Cohort Study: Preliminary Findings



Source: Pan Asian Cohort Study. "Preliminary Findings for Diabetes Prevalence." Palo Alto Medical Foundation. Accessed March 1, 2013. <http://www.pamf.org/pacs/men.jpg>.

Lesbian, Gay, Bisexual, and Transgender Populations

- Many of the health issues—and research challenges—facing this population are related to stigma
 - Historically, researchers have hesitated to collect data on LGBT status thus preventing this population from identifying themselves
- Because of this, no standard definition exists with which to identify this specific population through surveys
 - Questions regarding behavior, attraction, and identity all result in different responses and each has important implications for health
- When research is available it shows differences in needs and disparities in care and outcomes

Adolescents with Autism Spectrum Disorders

- Much of the research here has specifically concentrated on the diagnosis of these disorders
- But very little is known about the health and health care of individuals with ASDs when they transition to adulthood—a precarious time for their future well-being
- Because this disability is inconsistently measured among children and adults, and because most surveys are cross-sectional, existing survey data has struggled to follow this population over time

Rural Populations

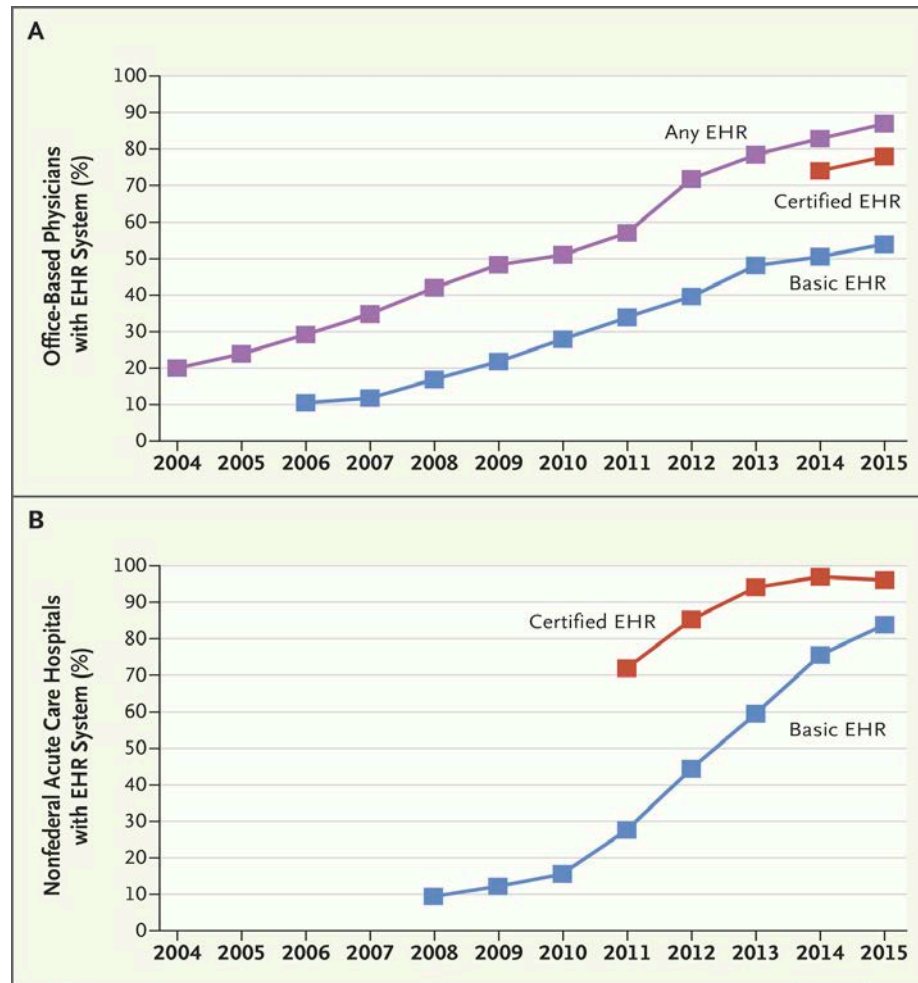
- For rural populations, geographic isolation and low population density have limited both their economic opportunities and their access to health services
- These populations face significant challenges: from the specific health care needs of aging populations to unique environmental health issues not present in other parts of the country
- In addition, many rural areas do not have consistent or well-defined boundaries, further complicating their study
 - E.g., Definitions may not align with county boundaries, the smallest geographic unit used in most surveys

Limitations of National Surveys for Small Populations

Population	General Problem: Small n relative to frame	General Problem: Lack of approaches to increase sample	Frame Problem: [*] Telephone number frame	Frame Problem: [*] Area frame samples	Data Collection Problem: Unit nonresponse	Data Collection Problem: Item nonresponse	Data Collection Problem: Instrumentation
Asian Americans	X	X		X	X		X
LGBT	X	X				X	X
Adolescents on the autism spectrum	X	X			X	X	X
Rural populations	X	X	X	X	X		X

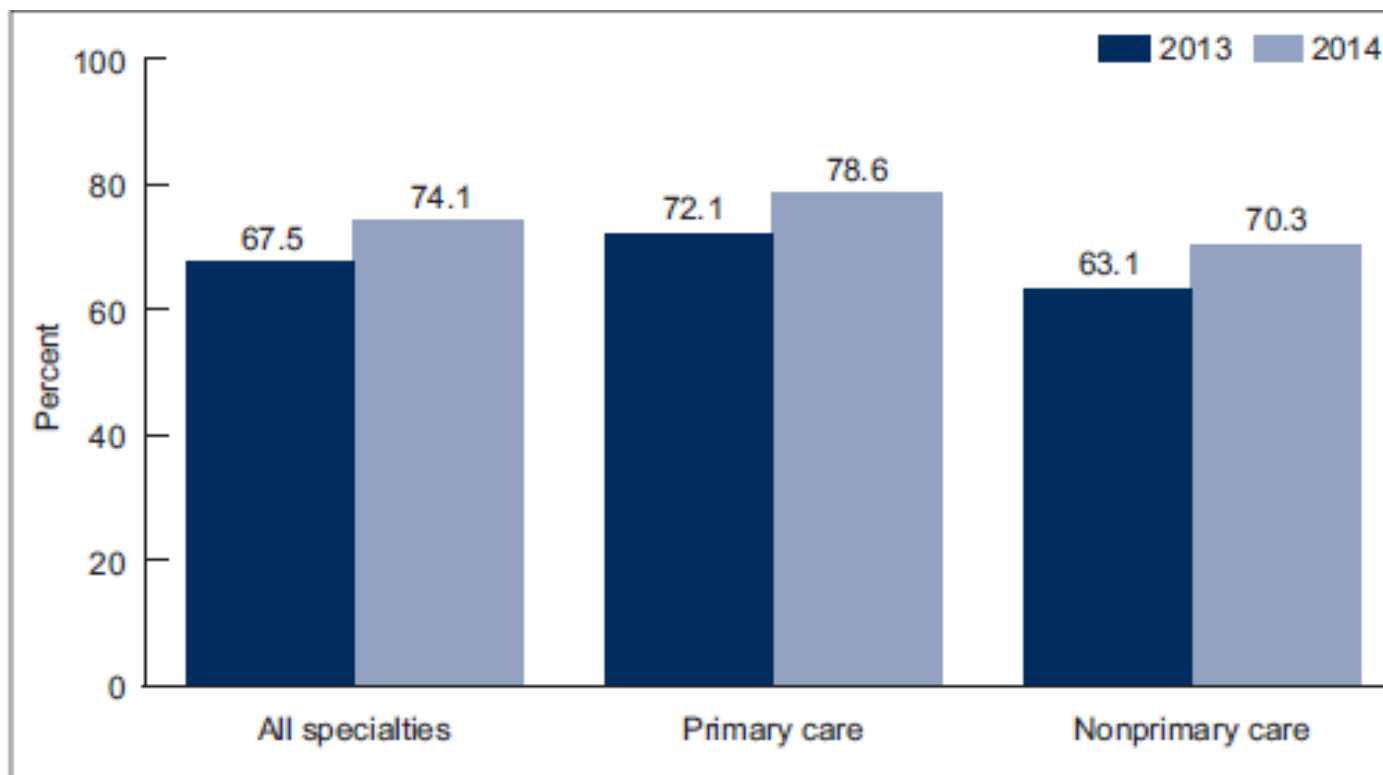
* These frame problems refer to specific challenges to constructing sampling frames based on telephone numbers or geographic areas. See the “Limitations in Survey Data” section for more information on general problems obtaining an adequate frame for small sample size groups relative to the rest of the population.

Percent of Office-based Physicians (Panel A) and Acute Care Hospitals (Panel B) with EHR Systems



Source: Washington, V. et al., "The HITECH Era and the Path Forward," N Engl J Med 2017; 377:904-906, September 7, 2017

Office-based Physicians with a Certified Electronic Health Record System, by Physician Specialty: United States, 2013-2014

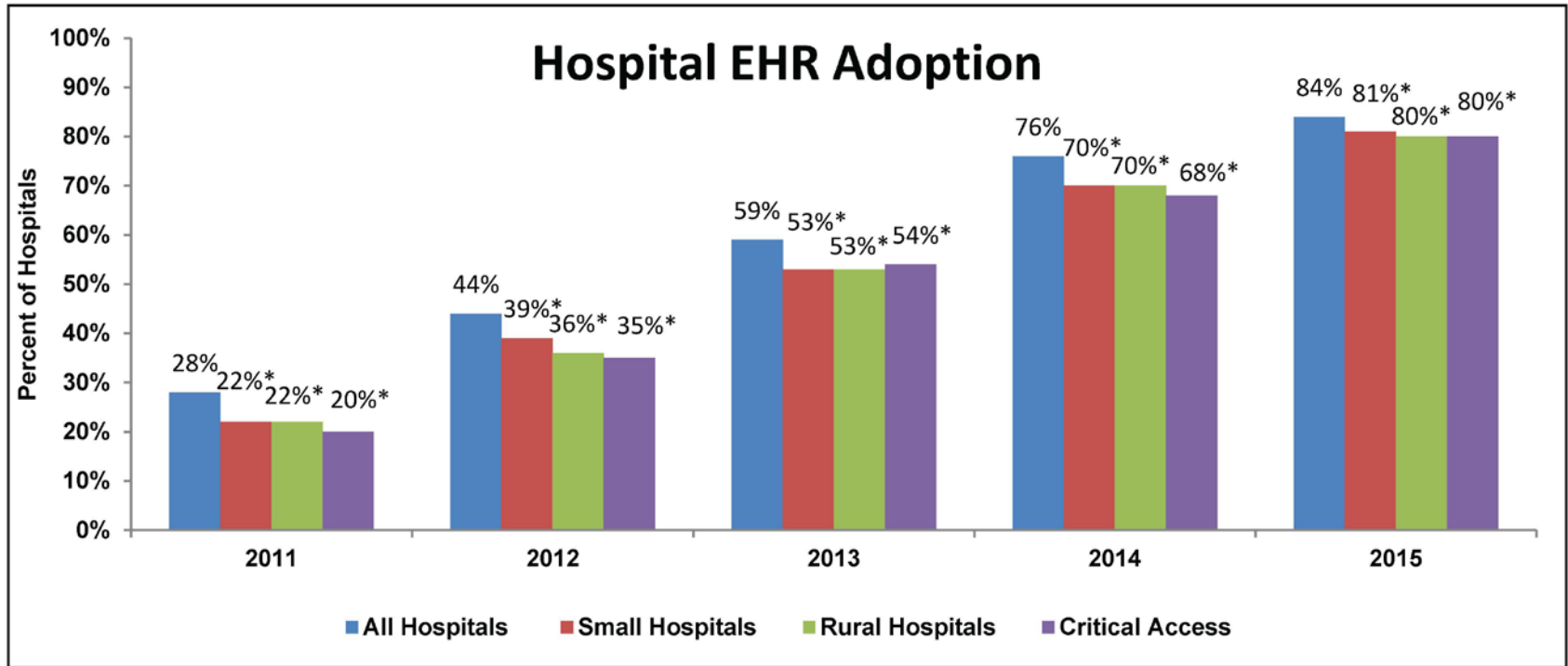


NOTES: Primary care includes family or general practitioners, internists, pediatricians, and obstetricians or gynecologists. Having a certified electronic health record system was defined by physicians answering "yes" to "Does your current system meet meaningful use criteria as defined by the Department of Health and Human Services?" Estimates are based on nonfederal, office-based physicians and exclude radiologists, anesthesiologists, and pathologists. All percentage differences by year and specialty are statistically significant ($p < 0.05$).

SOURCE: CDC/NCHS, National Electronic Health Records Survey, 2013–2014.

At least 8 out of 10 small, rural, and critical access hospitals adopted a Basic EHR

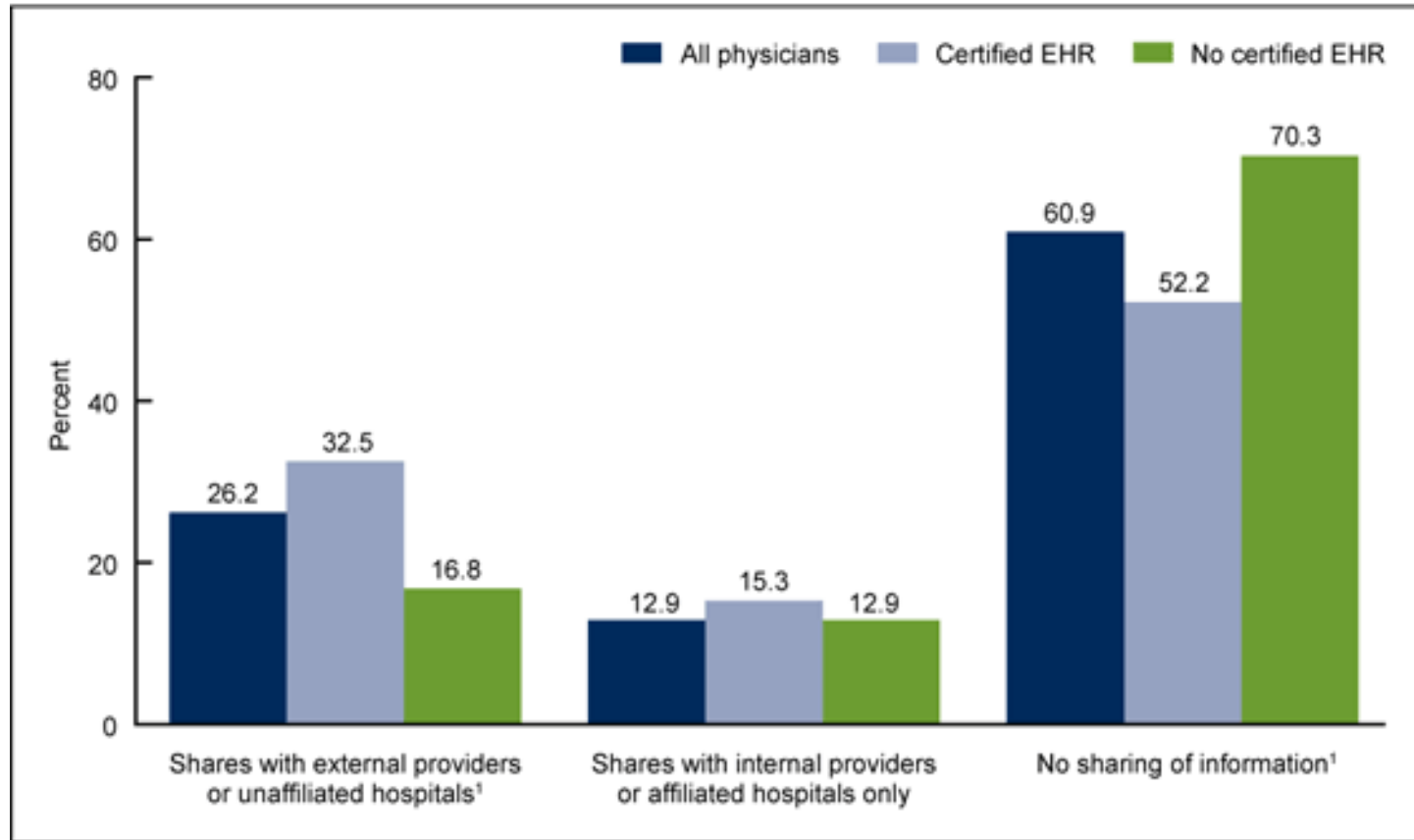
Percent of non-federal acute care hospitals with adoption of at least a Basic EHR system by hospital type



Source: ONC/American Hospital Association (AHA), AHA Annual Survey Information Technology Supplement.

Source: Henry, J. et al. "Adoption of Electronic Health Record Systems among U.S. Non-Federal Acute Care Hospitals: 2008-2015," ONC Data Brief, No. 35, May 2016

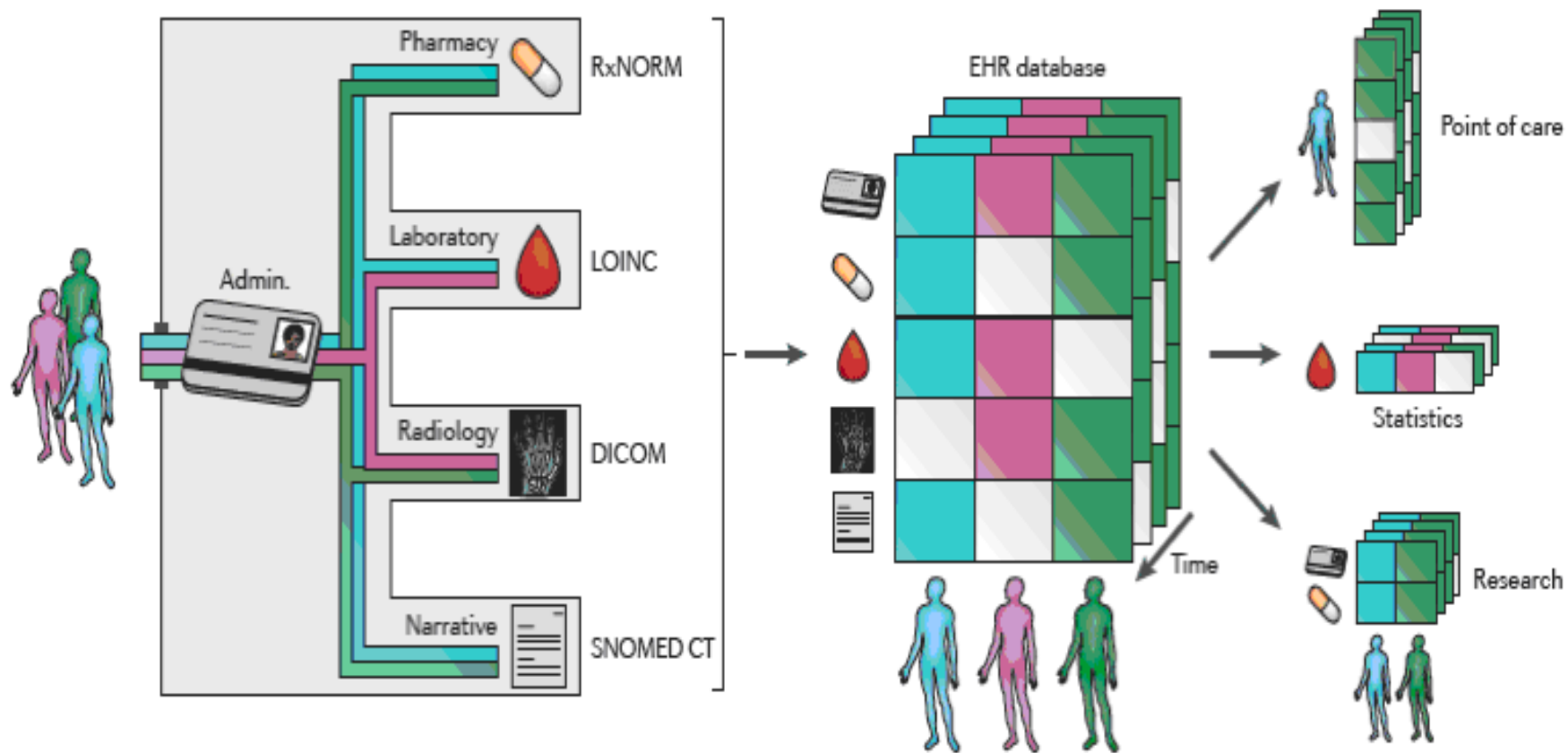
Office-based physicians with EHR systems who shared patient health information electronically with other providers: United States, 2014



SOURCE: CDC/NCHS, National Electronic Health Records Survey, 2014

Jamoom, EW, Yang, N, and E. Hing, "Adoption of certified electronic health record system and electronic information sharing in physician offices: United States, 2013 and 2014. NCHS data brief, no 236, Hyattsville, MD: National Center for Health Statistics, 2016

EHRs and Other Electronic Health Data are Potentially Rich and Powerful Resources to Identify and Study Small Populations



Source: Jensen PB, Jensen LJ, and Brunak S. Mining electronic health records: towards better research applications and clinical care. *Nature Reviews*, June 2012 (13): 395-403.

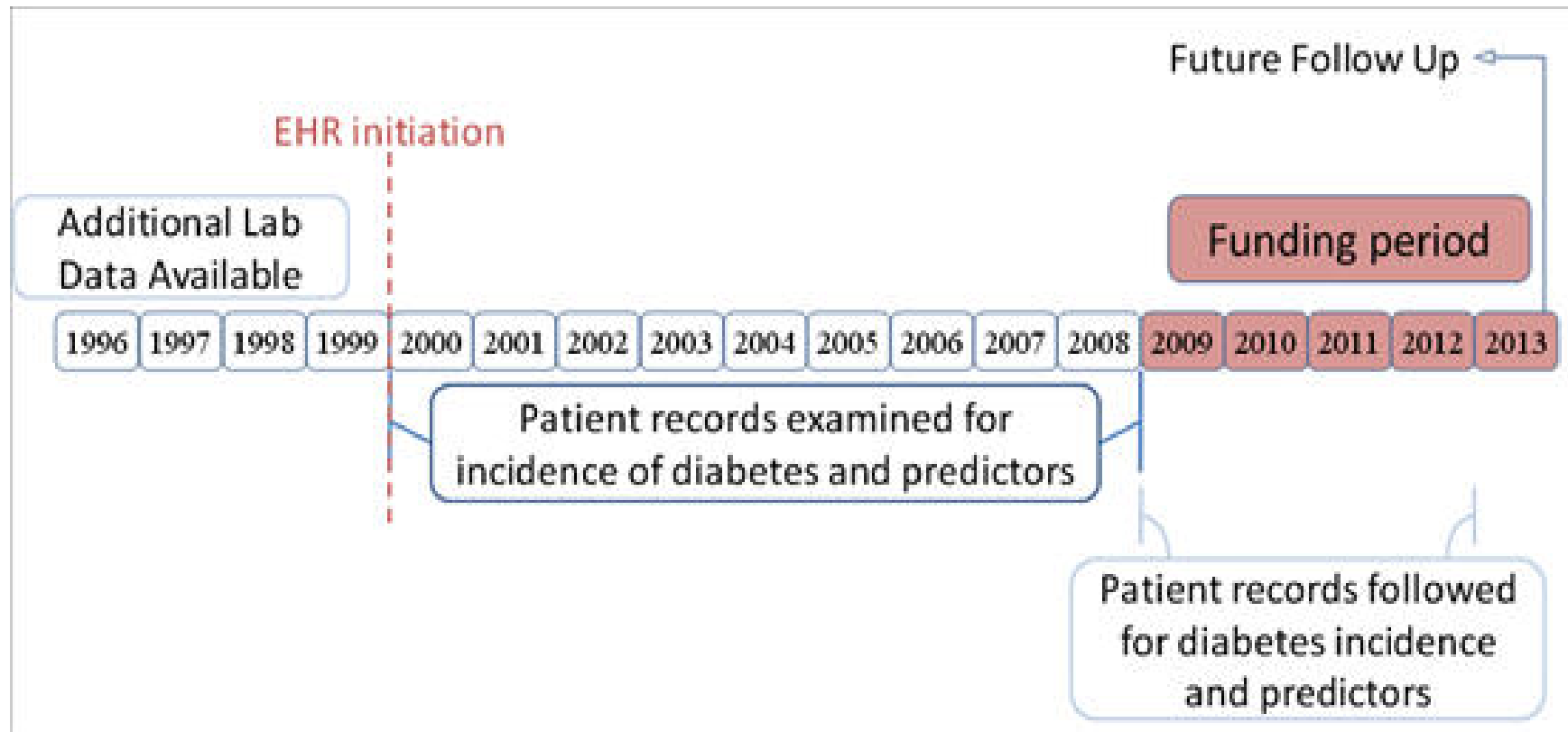
Characteristics of EHRs and Other Electronic Health Data That Make Them Useful for Research

- EHRs have the potential to reach more individuals than previous methods—in some cases potentially reaching the majority of the population
- Types of data include:
 - Claims and administrative data
 - Clinically rich, detailed information
 - Patient-reported data
- EHRs could also identify sub-populations in novel ways
 - E.g. Natural language processing
- Potential to link with other data sources (e.g., surveys)
- Potential longitudinality of some data sets

Examples of EHRs and Electronic Health Data to Study Illustrative Populations

- Asian Americans
 - The Pan Asian Cohort Study, on which the earlier diabetes results were based, is an EHR based study
 - Kaiser Permanent Northwest collects information about primary language spoken at home as well as need for translation services, and has standardized this variable across health plans so someone could easily look up language sub-groups, such as patients who speak Tagalog
 - At University of Vermont, refugee and immigrant patients have been identified through billing data where interpreters were used

Pan Asian Cohort Study Design and Methods: Virtual EHR Cohort of Asian and White Patients Age 35 and Older



Source: Palo Alto Medical Foundation, Sutter Health, Pan Asian Cohort Study
<http://www.pamf.org/pacs/design.html>

Examples of EHRs and Electronic Health Data to Study Illustrative Populations

- Lesbian, Gay, Bisexual, and Transgender Populations
 - Vanderbilt University Medical Center found that the time between when patients were first seen and when their LGBT status appeared in their medical records averaged 30 months
 - By applying natural language processing (NLP) to unstructured EHR data, researchers can identify and analyze information about sexual orientation, gender identity, and sexual behavior
 - Both Vanderbilt and UC-Davis health systems are collecting information about patient's sexual orientation through EHR patient portals as well
 - Stage 3 Meaningful Use certified EHRs are required to add gender identity, sexual orientation capabilities

Examples of EHRs and Electronic Health Data to Study Illustrative Populations

- Adolescents with Autism Spectrum Disorder
 - Kaiser Permanente in Northern California has developed a list of valid autism diagnoses based on ICD codes and who made the diagnosis
 - The EHR sub-network of the Pediatric Research in Office Settings network, known as ePROS, is led by the American Academy of Pediatrics
- Rural Populations
 - Kaiser Permanente Northwest identified rural Hispanic patients whose primary language is Spanish, in order to study the problem of drug-seeking behavior
 - Intermountain Health has studied rural residents with three or more chronic conditions
 - The Oregon Community Health Information Network (OCHIN), a network of nearly all federally qualified health centers (FQHCs) in the state of Oregon, is also studying drug-seeking behavior by identifying individuals who have attempted to obtain opiate-containing drug products from multiple FQHCs
 - OCHIN has also harnessed the system to study other rural and racial/ethnic sub-populations

Technical Conditions Required for Research Using EHRs and Other Electronic Health Data

- Data extraction and formatting
- Processing free-text data
- Missing data and data quality
- Restricted data
- Legacy systems and longitudinal data
- Expertise

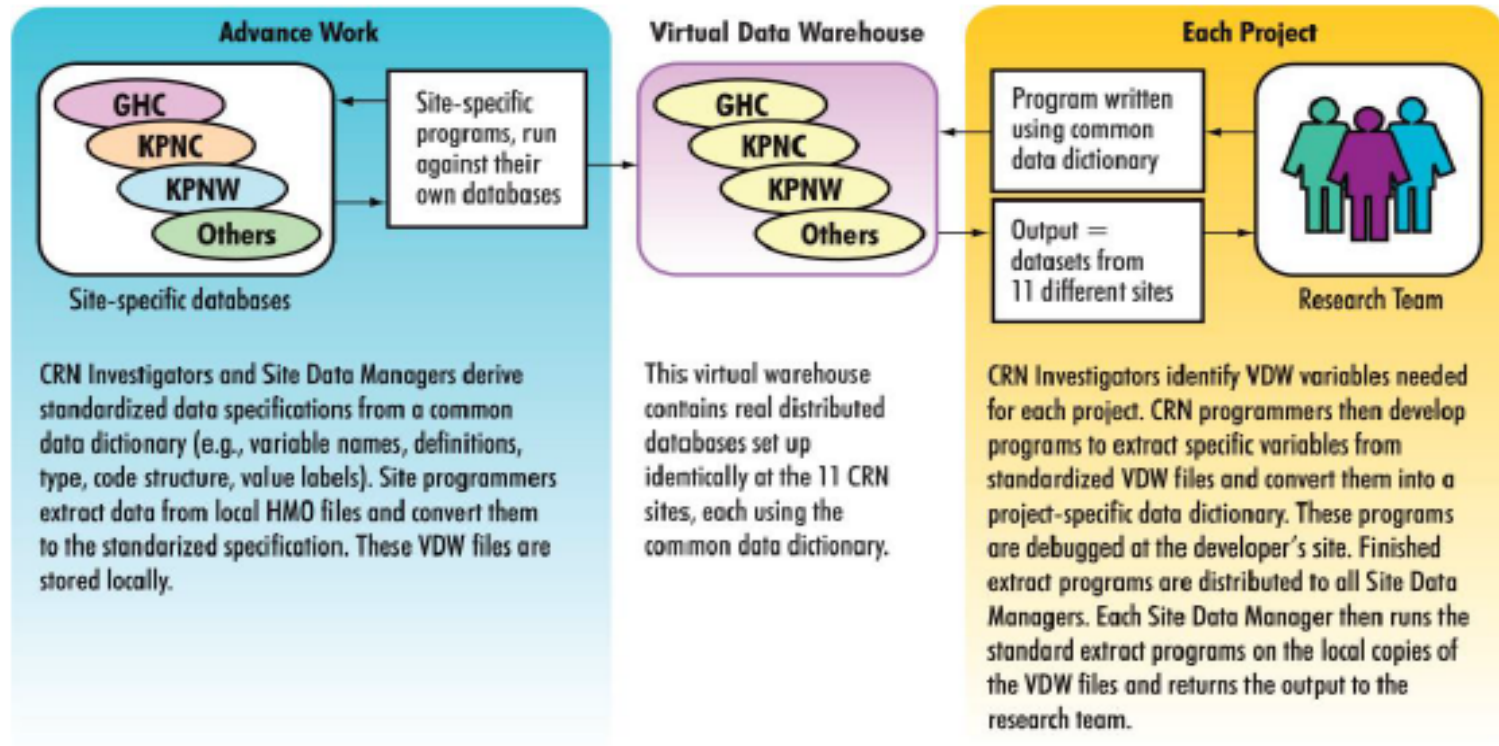
Privacy and Security Conditions Required for Research Using EHRs and Other Electronic Health Data

- Legal landscape
 - HIPPA and the Common Rule
- Opportunities for patients to make meaningful choices
- De-identified data
- Data governance
 - Ownership, control, and regulation

Organizational Conditions Required for Research Combining Multiple Data Sources

- Using EHR and other electronic health data from multiple organizations
- Interoperability of EHR systems
- Research networks
- Regional health information exchanges
- Linking EHR and other electronic health data with other data sources
 - Patient registries
 - Genetic data
 - Other Data Sources, including surveys and claims

Example: The Cancer Research Network (CRN) Virtual Data Warehouse



Source: Hornbrook et al. "Building a Virtual Cancer Research Organization."
Journal of the National Cancer Institute Monographs. 2005 (35), 12-25

Potential for Future Research on Small Populations

- Data validation
- New tools and/or methods
- Descriptive studies
- Outcomes research
- Stakeholder engagement and collaboration
- Legal framework and other policy issues

Summary and Conclusion

Though EHRs and other electronic data can fundamentally improve research on the health and health care needs of Americans—from large populations to key small demographics—many of the conditions required for success are already present or are close to being realized.

While some significant barriers remain, innovative solutions and promising approaches are being developed in the public and private sectors.

We have already identified possible suggestions and know the next steps we must take to move the field forward.

Thank You!



NORC
at the UNIVERSITY of CHICAGO

For Further Information Contact:
Kelly J. Devers, Ph.D., M.A.
Senior Fellow
Devers-Kelly@norc.org
301-634-9523

 insight for informed decisions™