Grand Rounds EHR Workshop Series - Advances at the Intersection of Digital Health, Electronic Health Records and Pragmatic Clinical Trials

Keys to Success in the Evolving EHR Environment

Guest Moderator: Keith Marsolo, PhD Duke University

Panel:

Teresa Zayas-Caban, PhD Office of the National Coordinator for Health Information Technology (ONC)

Christopher A. Longhurst, MD, MS UC San Diego School of Medicine

Health Care Systems Research Collaboratory

George (Holt) Oliver, MD, PhD

Rachel Richesson, PhD

Duke University School of Nursing

ICD Pieces Demonstration Project

National Health Information Technology (IT) Priorities for Research: A Policy and Development Agenda

Teresa Zayas Cabán, PhD, Chief Scientist Keys to Success in the Evolving EHRs Environment Advances at the Intersection of Digital Health, Electronic Health Records, and Pragmatic Clinical Trials June 26, 2020







At the Intersection Between Research and Care Delivery

- Develop and evaluate ONC's scientific efforts and activities
- Recommend scientific policy to the National Coordinator
- Promote and lead activities that spur innovation, support patient-centered outcomes research, and advance precision medicine



https://www.healthit.gov/topic/scientific-initiatives



Health IT is Foundational to Research



- Enormous array of data will require new thinking and pathways for storing, accessing, and analyzing the information.
- Success will require portable electronic health information that is actively exchanged among health care providers, researchers, and individuals



Advancing Health Data and the IT Infrastructure for Research into the 21st Century

- Increased availability of electronic health data for research
- Challenges to leveraging those data and the health IT infrastructure for research remain





The Vision

Health IT infrastructure that supports alignment between the clinical and research ecosystems so research can happen more quickly and effectively.

https://healthit.gov/research-agenda





Agenda Goals and Associated Priority Areas

Goal 1: Leverage High-Quality Electronic Health Data for Research

- Improve Data Quality at the Point of Capture
- Increase Data Harmonization to Enable Research Uses
- Improve Access to Interoperable Electronic Health Data

Goal 2: Advance a Health IT Infrastructure to Support Research

- Improve Services for Efficient Data Storage and Discovery
- Integrate Emerging Health and Health-Related Data Sources
- Aggregation
- Develop Tools and Functions to Support Research
- Leverage Health IT Systems to Increase Education and Participation
- 8
- Accelerate Integration of Knowledge at the Point of Care





the pursuit of more complex research questions,

the development of more rapid and reliable discoveries about health and healthcare to improve outcomes,

and the engagement of a broader, more representative population in research participation.





Advancing the Agenda to Address Research Agency Priorities

- ONC's Role
- Alignment between priorities and other agencies' data and infrastructure needs





Thank you!

Contact us!

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Health Care Systems Research Collaboratory

Evidence-based Medicine in the EMR Era

Christopher A. Longhurst, MD, MS

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UC San Diego Health

Journal of the American Medical Informatics Association, 0(0), 2020, 1–7 doi: 10.1093/jamia/ocaa037 Research and Applications



OXFORD

Research and Applications

Rapid response to COVID-19: health informatics support for outbreak management in an academic health system

J. Jeffery Reeves (1)¹, Hannah M. Hollandsworth¹, Francesca J. Torriani², Randy Taplitz², Shira Abeles², Ming Tai-Seale³, Marlene Millen⁴, Brian J. Clay⁴ and Christopher A. Longhurst (1)⁴

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New England Journal of Medicine, Nov 2011

Evidence-Based Medicine in the EMR Era

Jennifer Frankovich, M.D., Christopher A. Longhurst, M.D., and Scott M. Sutherland, M.D.

Many physicians take great pride in the practice of evidence-based medicine. Modern medical education emphasizes the value of the randomized, controlled trial, and we learn early on not to rely on

anecdotal evidence. But the application of such superior evidence, however admirable the ambition, can be constrained by trials' strict inclusion and exclusion criteria - or the complete absence of a relevant trial. For those of us practicing pediatric medicine, this reality is all too familiar. In such situations, we are used to relying on evidence at Levels III through V - expert opinion - or resorting to anecdotal evidence. What should we do, though, when there aren't even meager data available and we don't have a single anecdote on which to draw?

We recently found ourselves in such a situation as we admitted to our service a 13-year-old girl range proteinuria, antiphospholipid antibodies, and pancreatitis. Although anticoagulation is not standard practice for children with SLE even when they're critically ill, these additional factors put our patient at potential risk for thrombosis, and we considered anticoagulation. However, we were unable to find studies pertaining to anticoagulation in our patient's situation and were therefore reluctant to pursue that course, given the risk of bleeding. A survey of our pediatric rheumatology colleagues - a review of our collective Level V evidence, so to speak - was equally fruitless and failed to produce a consensus.

approach, using the data captured in our institution's electronic medical record (EMR) and an innovative research data warehouse. The platform, called the Stanford Translational Research Integrated Database Environment (STRIDE), acquires and stores all patient data contained in the EMR at our hospital and provides immediate advanced text searching capability.1 Through STRIDE, we could rapidly review data on an SLE cohort that included pediatric patients with SLE cared for by clinicians in our division between October 2004 and July 2009. This "electronic cohort" was originally created for use in studying complications associated with pediatric SLE and exists under a protocol approved by our institutional review board.

Of the 98 patients in our pediatric lupus cohort, 10 patients developed thrombosis, documented

Health

New England Journal of Medicine, Nov 2011

Evidence-Based Medicine in the EMR Era

Jennifer Frankovich, M.D., Christopher A. Longhurst, M.D., and Scott M. Sutherland, M.D.

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Results of Electronic Search of Patient Medical Records (for a Cohort of 98 Pediatric Patients with Lupus) Focused on Risk Factors for Thrombosis Relevant to Our 13-Year-Old Patient with Systemic Lupus Erythematosus.*

Outcome or Risk Factor	Keywords Used to Conduct Expedited Electronic Search	Prevalence of Thrombosis	Relative Risk (95% CI)	
		no./total no (%)		
Outcome — thrombosis	"Thrombus," "Thrombosis," "Blood clot"	10/98 (10)	Not applicable	
Thrombosis risk factor				
Heavy proteinuria (>2.5 g per deciliter)				
Present at any time	"Nephrosis," "Nephrotic," "Proteinuria"	8/36 (22)	7.8 (1.7–50)	
Present >60 days	"Urine protein"	7/23 (30)	14.7 (3.3–96)	
Pancreatitis	"Pancreatitis," "Lipase"	5/8 (63)	11.8 (3.8–27)	
Antiphospholipid antibodies	"Aspirin"	6/51 (12)	1.0 (0.3–3.7)	

* In all cases, the sentences surrounding the keywords were manually reviewed to determine their relevance to our patient. Pancreatitis was defined as an elevated lipase level (twice the upper limit of normal) coexisting with abdominal pain. We used the word "aspirin" as a proxy for antiphospholipid antibodies, since it is standard practice at our institution to give all patients with these antibodies aspirin; if "aspirin" was found in the chart, than antiphospholipid-antibody status was confirmed by investigating the laboratory results.

•		
on which to draw?	of our collective Level V evidence,	review board.
We recently found ourselves in	so to speak - was equally fruit-	Of the 98 patients in our pedi-
such a situation as we admitted	less and failed to produce a con-	atric lupus cohort, 10 patients de-
to our service a 13-year-old girl	sensus.	veloped thrombosis, documented

Health

Health Affairs, July 2014

By Christopher A. Longhurst, Robert A. Harrington, and Nigam H. Shah

A 'Green Button' For Using Aggregate Patient Data At The Point Of Care

DOI: 10.1377/hlthaff.2014.0099 HEALTH AFFAIRS 33, NO. 7 (2014): 1229-1235 © 2014 Project HOPE---The People-to-People Health Foundation, Inc.

ABSTRACT Randomized controlled trials have traditionally been the gold standard against which all other sources of clinical evidence are measured. However, the cost of conducting these trials can be prohibitive. In addition, evidence from the trials frequently rests on narrow patientinclusion criteria and thus may not generalize well to real clinical situations. Given the increasing availability of comprehensive clinical data in electronic health records (EHRs), some health system leaders are now advocating for a shift away from traditional trials and toward large-scale retrospective studies, which can use practice-based evidence that is generated as a by-product of clinical processes. Other thought leaders in clinical research suggest that EHRs should be used to lower the cost of trials by integrating point-of-care randomization and data capture into clinical processes. We believe that a successful learning health care system will require both approaches, and we suggest a model that resolves this

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Figure 1 – The Green Button in Action



Combining healthcare data from across the six University of California medical schools and systems



UC Health Data Analytics Platform

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UC Health COVID-19 Patients



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All five University of California academic medical centers provide health data to patients through Apple Health



bit.ly/ucappleh

Al AT&T M-Cell						
Kealth Data						
Health Records						
• •						
Health Records on iPhone (Beta)						
Keep track of clinical health records from multiple sources and automatically receive updates. To get started, add your account information from participating health networks and haspitals.						
About Health Records & Privacy						
Get Started						
■ =	IJ					
Today Health Data Sources Medical ID						



UC San Diego Health

JAMA, January 2019

UCSD TO PILOT APPLE'S NEW MEDICAL RECORDS PORTAL

12 health systems

Apple's new medi cal record system puts patients' da from mult ple providers int one centralized location.

4.00

VIEWPOINT

Christian Dameff, MD Department of Emergency Medicine, University of California, San Diego.

Brian Clay, MD Department of Medicine, University of California, San Diego.

Christopher A.

Longhurst, MD Department of Medicine, University of California, San Diego; and Department of Pediatrics, University of California, San Diego.

Personal Health Records More Promising in the Smartphone Era?

As health care delivery organizations shift from implementation of electronic health records to optimization of these systems, the persistent problem of patient data interoperability is becoming increasingly relevant. Interest in accessing medical information from hospital records and databases and providing convenient patientcontrolled portable records is increasing. Technology companies are seeking to develop innovative solutions to meet these demands.

Interoperable personal health records are not a novel concept; unsuccessful attempts to collect digital patient records have been pursued by several major technology companies. As 1 of the first 12 health care organizations to integrate one company's next-generation approach (Apple Health Records) into a patient portal, UC (University of California) San Diego Health is assessing whether this new functionality can overcome prior challenges and catalyze systemic change toward meaningful patient-controlled interoperability.¹ reported improvement with all 3 of these outcomes. As of fall 2018, UC San Diego Health has hundreds of personal health record users who have downloaded thousands of clinical results and other pieces of medical information though the platform.

selected a dozen health systems

from coast to coast to pilot auto-

As with many other new products and solutions, such enthusiasm is common from early adopters. The platform will need to prove that it is useful, sustainable, scalable, and actually improves health outcomes. The key questions are whether this personal health record will improve patient outcomes and lower costs while also increasing quality. Why might this time be different? Three key developments may contribute to success: the ubiquity of mobile technology, the maturation of health data communications standards, and the widespread use of mobile software distribution platforms.

When Microsoft introduced HealthVault (2007) and Google launched Google Health (2008) personal health records, the first iPhone and Android devices

How do we ensure our healthcare system learns from every patient, at every visit, every time?



Thank you!

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hand handharade

Advances at the Intersection of Digital Health, Electronic Health Records and Pragmatic Clinical Trials

Use of EHR in Collaboratory Projects

Rachel Richesson, PhD Co-Chair of the EHR Core Duke University School of Nursing



Use of EHR in Collaboratory Projects

Trial	Eligibility	Intervention Delivery	Outcome Assessment
Acu-OA			
NOHARM			
FM TIPS			
OPTIMUM			
ACP PEACE			
HiLo			
PRIM-ER			
EMBED			
Nudge			
GGC4H			
ICD-Pieces			
TSOS			
SPOT			
PROVEN			
LIRE			
РРАСТ			
STOP-CRC			
TIME			
ABATE			



EHR integration challenges and lessons from ICD Pieces



Care. Compassion. Community.

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June 26, 2020





Combining Data From:

- EHR: EPIC, Allscripts, VA Vista
- Hospital Claims: Commercial Claims, ResDAC
- National Death Index

Use the Data for:

- Unified patient selection algorithm
- Primary and secondary outcome from hospital claims

Begin with the End in Mind

• Final Patient Follow up will be completed Monday!



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Parkland















<u>ISTA</u>

Largest Provider of Renal Replacement services, alternate resources

- In transition EMR:Vista->Cerner
- PHI restrictions
- Most standard
 - Embeded LOINC
 - NDC codes
 - Value Set Authority Center

Lesson Learned:

Embedded analyst >> remote/limited access

Privacy Challenges balanced against expanded trial applicability

Cluster Randomization does not insulate from cluster related challenges



Geographic and Demographic representation with a private practice Northeastern location

- Change in Partner Organizational structure
- Change in Medicare FFS data mid trial QIO->ResDAC
- Change Data warehouse mapping after integration with OptumCare
- Non-Hospital affiliate status gave different data access to claims data
 - Better access in some areas
 - Extra approval steps for Commercial claims
 - Budget implications on ResDAC



No Pain, No Gain

Emerging Challenges

- Data Structure:
 - EHR upgrade cycles
- Workflow
 - Personnel turnover
- Integration
 - Minimum necessary
 - Testing, validation, guardrails
- Standards
 - LOINC-wonderful where available
 - Claims, Labs, Vitals are safe spaces
 - Medication metrics robust to visibility

- EHR upgrade cycles
- Turn around time issues for claims and partners with adhoc resource allocation
- Missing Woman Month: tough transitions between analysts
 - Good Documentation
 - Code Handoffs are never complete
 - Version control/Task tracking



