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Rationale for Scientific & Policy session: What can we do to improve outcomes in the next five years?

Leveraging existing quality improvement & information sciences for greater application in epilepsy

Jeffrey Buchhalter MD, PhD

April 14, 2016

Disclosures

- No conflict of interests related to this presentation
- A very, very frustrated clinical pediatric epileptologist

Prevalence of Epilepsy in the USA

- The number of people with epilepsy, using prevalence numbers, ranges from **1.3 million to 2.8 million** (or 5 to 8.4 for every 1,000 people).

- The estimate currently thought to be most accurate is 2.2 million people or 7.1 for every 1,000 people.

- However, higher numbers of people report that they have active epilepsy, 8.4 out of 1,000 people. These numbers are even higher when people are asked if they have ever had epilepsy (called lifetime prevalence). 16.5 per 1,000 people reported that they had epilepsy at some point in their life.

IOM: Epilepsy Across the Spectrum, 2012; epilepsy.com

1968

THE PROGNOSIS OF PATIENTS WITH EPILEPSY

By

ERNST A. RODIN, M.D.

Chief of Neurology and Electroencephalography
Lafayette Clinic
Director of Medical Research
Michigan Epilepsy Center
Director of EEG Laboratory
Childrens Hospital of Michigan
Associate Professor, Department of Neurology
Wayne State University
Detroit, Michigan

But let us return to the quotation that "80 to 85 per cent of all patients with epilepsy can be controlled." Where did these figures originate? They are probably taken from a paper published in 1952 by Yahr et al. who stated in their summary that "The use of diphenylliydantoin (Dilantin) sodium and phenobarbital in this group of 319 patients resulted in 79 per cent control or improvement of seizures regardless of causation. The addition of other anticonvulsants added 6 per cent, giving an overall rate of 85 per cent improvement or control."

Prognosis- Recent Times

"In spite of medical therapy, seizures persist in approximately 20 percent of patients with primary generalized epilepsy and 35 percent of those with partial epilepsy."

Devinksy, **1999**;NEJM;340(20), 1565

"Unfortunately, in 20–30% of patients, epilepsy cannot be controlled."

Schmidt, **2009**;Epilepsy & Behavior;(15)56-65

Prognosis- 2016

- No change in the population-based estimates of control (20-35%)
- Recognition that *prognosis in individual groups much worse*
  - Dravet
  - Epileptic spasms
  - Lennox-Gastaut
  - Symptomatic causes with intellectual disability

Treatments- 2016

- Anti Seizure Drugs:
  - No significant improvement in efficacy
  - Improvements in tolerability
  - Limited added efficacy beyond first or second
- Surgery: under-utilized
- Dietary/metabolic:
  - Under-utilized
  - Under development
- Devices:
  - Efficacy equivalent to ASDs
  - Under development

Consequences of intractable seizures

- Accidents: falls, burns
- Aspiration
- Cognitive decline
- Psychiatric/behavioral co-morbidities: ADHD, depression, suicide
- Social isolation
- Unemployment
- Premature mortality including SUDEP (second largest cause of years of life lost#)
- Costs to society: costs of care ($12.5 B, 1995, intractable*) & lost human potential

#Thurman 2014
*Begley 2000

Response?

- Depression?
- Cynicism?
- Aggressive optimism

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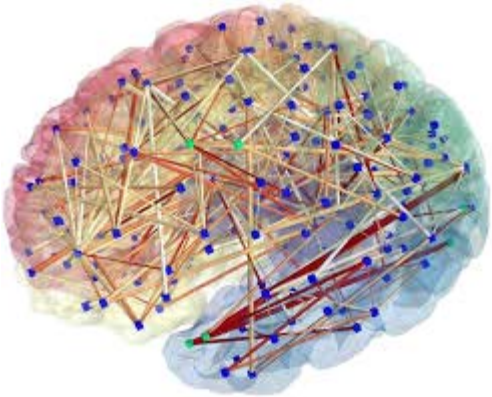
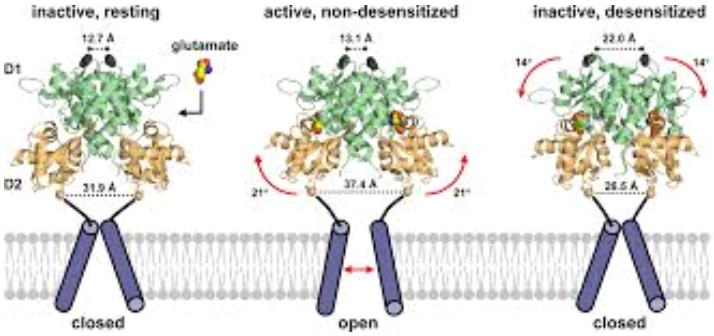
Status of Epilepsy Research

undergradtutorialblog.blogspot.com

www.ifmelranthezoo.com



cmtk.org



pharmrev.aspetjournals.org

web.stanford.edu

Status of Epilepsy Research

┬Potential Responses in the Near Term

- What about the patients who are suffering now? Dying now?
- Can we find strategies that have been demonstrated to improve outcomes in the short term?
- Can we supplement our research strategies to focus on meaningful outcomes for patients?
- Can we leverage existing resources for this purpose?

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What Can We Do Until Then?

- Adopt strategies known to reduce morbidity, mortality, and, when possible, reduce costs
- Implement meaningful, large scale data aggregation
  - Common definitions & data elements
  - Harmonize & Organize knowledge in a logical manner (ontologies)
  - Leverage the accumulated Big Data to inform personalized medicine
- Incentivize health system behavior that rewards active participation in improving outcomes for patients

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What is the Evidence that "Organized" Care Makes a Difference

The 100 000 Lives Campaign:
Setting a Goal and a Deadline for
Improving Health Care Quality

Berwick DM. JAMA 295:324–327, Jan.18, 2006.

The 100,000 Lives Campaign:

A Scientific and Policy Review

Robert M. Wachter, M.D.
Peter J. Pronovost, M.D., Ph.D.

The authors were invited by the Journal *to prepare a commentary on the Institute for Healthcare Improvement's 100,000 Lives Campaign, which had recently observed the end of its initial 18-month effort.*

On December 14, 2004, Dr. Don Berwick, the well-respected founder and chief executive offi-

Article-at-a-Glance

Background: On June 14, 2006, the Institute for Healthcare Improvement (IHI) announced that its campaign to save 100,000 lives had far surpassed its goal—by saving 122,300 lives.

Journal of Quality and Safety 2006 (32) 11 , 621-27

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More Evidence

Intensive Care Med (2010) 36:222–231
DOI 10.1007/s00134-009-1738-3

ORIGINAL

Mitchell M. Levy
R. Phillip Dellinger
Sean R. Townsend
Walter T. Linde-Zwirble
John C. Marshall
Julian Bion
Christa Schorr

The Surviving Sepsis Campaign: results of an international guideline-based performance improvement program targeting severe sepsis

- N = 15,000
- 2 yrs
- Mortality reduced 6.2%
- 930 people

World J Surg (2009) 33:1075–1086
DOI 10.1007/s00268-009-9959-8

Establishing the Evidence Base for Trauma Quality Improvement: A Collaborative WHO-IATSIC Review

Catherine J. Juillard · Charles Mock ·
Jacques Goosen · Manjul Joshipura ·
Ian Civil

- 34/36 articles reduced morbidity or mortality

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Stroke

Get With the Guidelines–Stroke Is Associated With Sustained Improvement in Care for Patients Hospitalized With Acute Stroke or Transient Ischemic Attack

Lee H. Schwamm, MD; Gregg C. Fonarow, MD; Mathew J. Reeves, PhD; Wenqin Pan, PhD; Michael R. Frankel, MD; Eric E. Smith, MD, MPH; Gray Ellrodt, MD; Christopher P. Cannon, MD; Li Liang, PhD; Eric Peterson, MD, MPH; Kenneth A. LaBresh, MD

Background—Adherence to evidence-based guidelines for treatment of stroke or transient ischemic attack is suboptimal. We sought to establish whether participation in Get With the Guidelines–Stroke was associated with improvements in adherence.

Methods and Results—This prospective, nonrandomized, national quality improvement program measured adherence to guideline recommendations in 322 847 hospitalized patients discharged with a diagnosis of ischemic stroke or transient ischemic attack. A volunteer sample of 790 US academic and community hospitals participated from 2003 through 2007. The main outcome measures were change in adherence over time to 7 prespecified performance measures and a

Circulation 2009;119:107-115

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T

Glossary of Descriptive Terminology for Ictal Semiology: Report of the ILAE Task Force on Classification and Terminology

- Table of Contents
  - General Terms
  - Terms for describing epileptic seizure semiology
    - Motor
    - Non-Motor
    - Autonomic
    - Somatotopic modifers
    - Modifiers & descriptors of seizure timing
    - Duration
    - Severity!!

Blume et al, Epilepsia 2001:42;1212-1218

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Epilepsia, 52(6):1186–1191, 2011
doi: 10.1111/j.1528-1167.2011.03018.x

SPECIAL REPORT

Common data elements in epilepsy research: Development and implementation of the NINDS epilepsy CDE project

*†David W. Loring, ‡Daniel H. Lowenstein, ‡§Nicholas M. Barbaro, ¶Brandy E. Fureman, ¶Joanne Odenkirchen, ¶Margaret P. Jacobs, **Joan K. Austin, †††‡‡Dennis J. Dlugos, §§Jacqueline A. French, ¶¶William Davis Gaillard, ***Bruce P. Hermann, †††Dale C. Hesdorffer, ‡‡‡Steven N. Roper, §§§¶¶¶Anne C. Van Cott, ****Stacie Grinnon, and ****Alexandra Stout

Like the development of the Terminology Glossary, very thoughtful work has already been done for Common Data Elements

The challenge/opportunity is to take this work and adapt it to clinical epilepsy care

Need to harmonized & organize terms & concepts

- 'Harmonized' implies taking multiple descriptions of the same thing & agreeing on a common meaning (e.g. convulsions & grand mal)
- Need to include the multiple levels of information available (e.g. report, observation, EEG, MRI, genetic testing)
- Need to show relationships between concepts (e.g. child, staring, EEG)
- Have rules and be 'computable'

Past/Current classifications

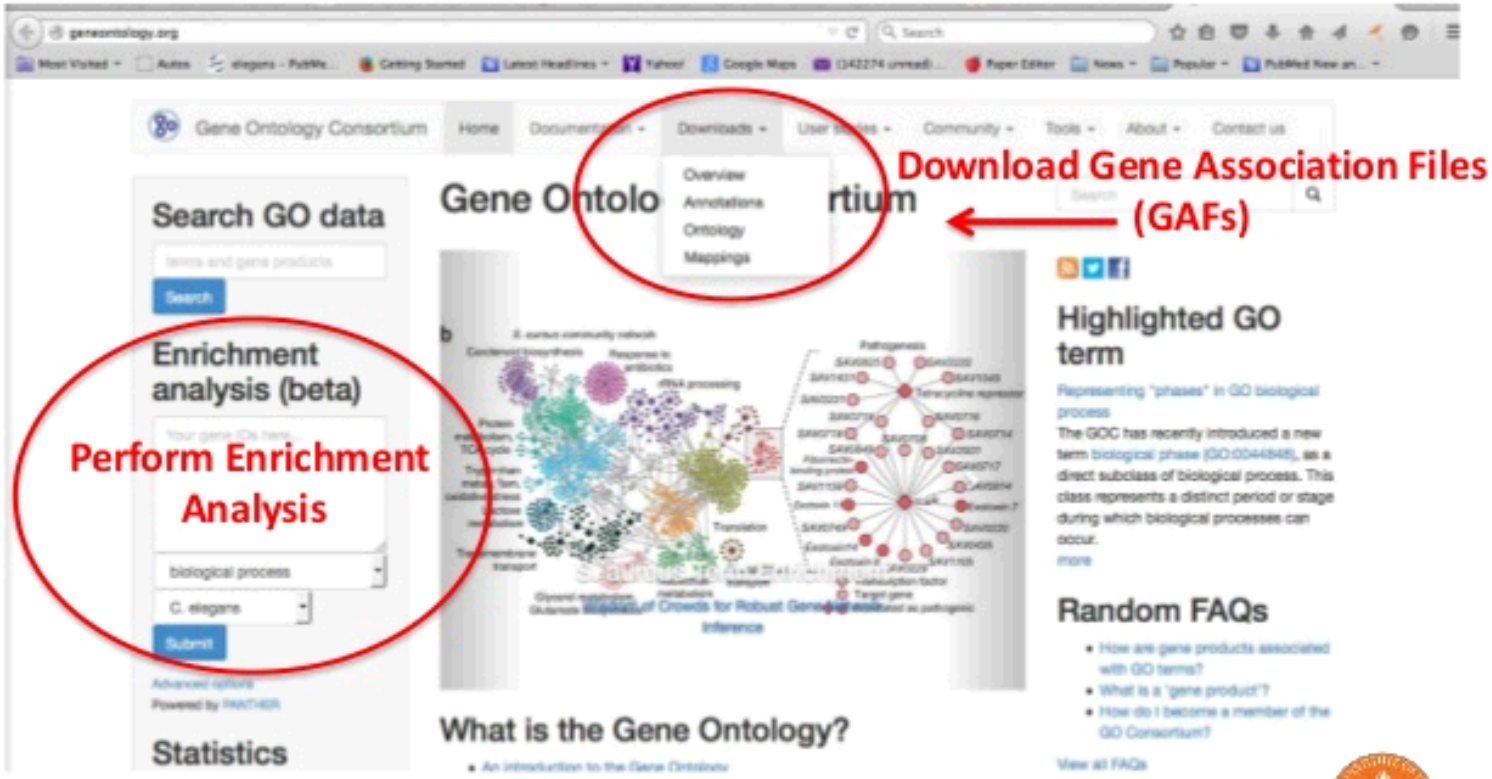
- ILAE C & T- seizures 1981
- ILAE C & T- syndromes 1989
- Semiology (Luders)- 1999
- ILAE 2010
- ILAE Epidemiology 2010
- ICD-9, 10, (11)
- SNOMED CT

Ontologies

- = formal specification of **terms** in the domain *(e.g. epilepsy)* and **relations** among them *(e.g. complex partial is a type of partial seizure which is a type of seizure)*
- Why make one?
  - Share common understanding of information
  - Enable reuse of information
  - Make assumptions explicit
  - Analyze domain knowledge

Annotation Files and Enrichment Analysis: Gene Ontology Consortium

http://geneontology.org/



WormBase

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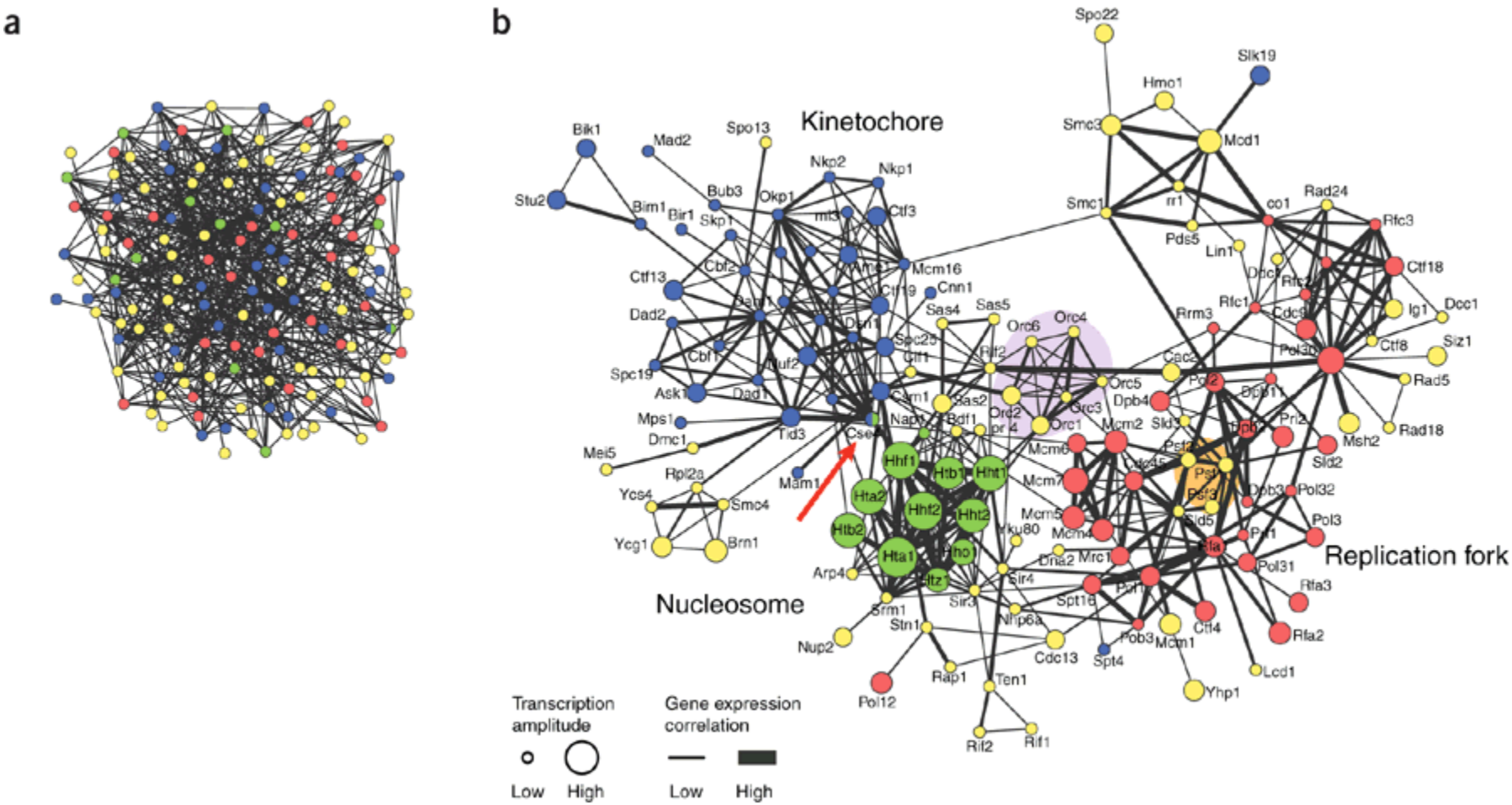
GO- Relationships

(imagine same for seizure/epilepsy concepts & relationships)



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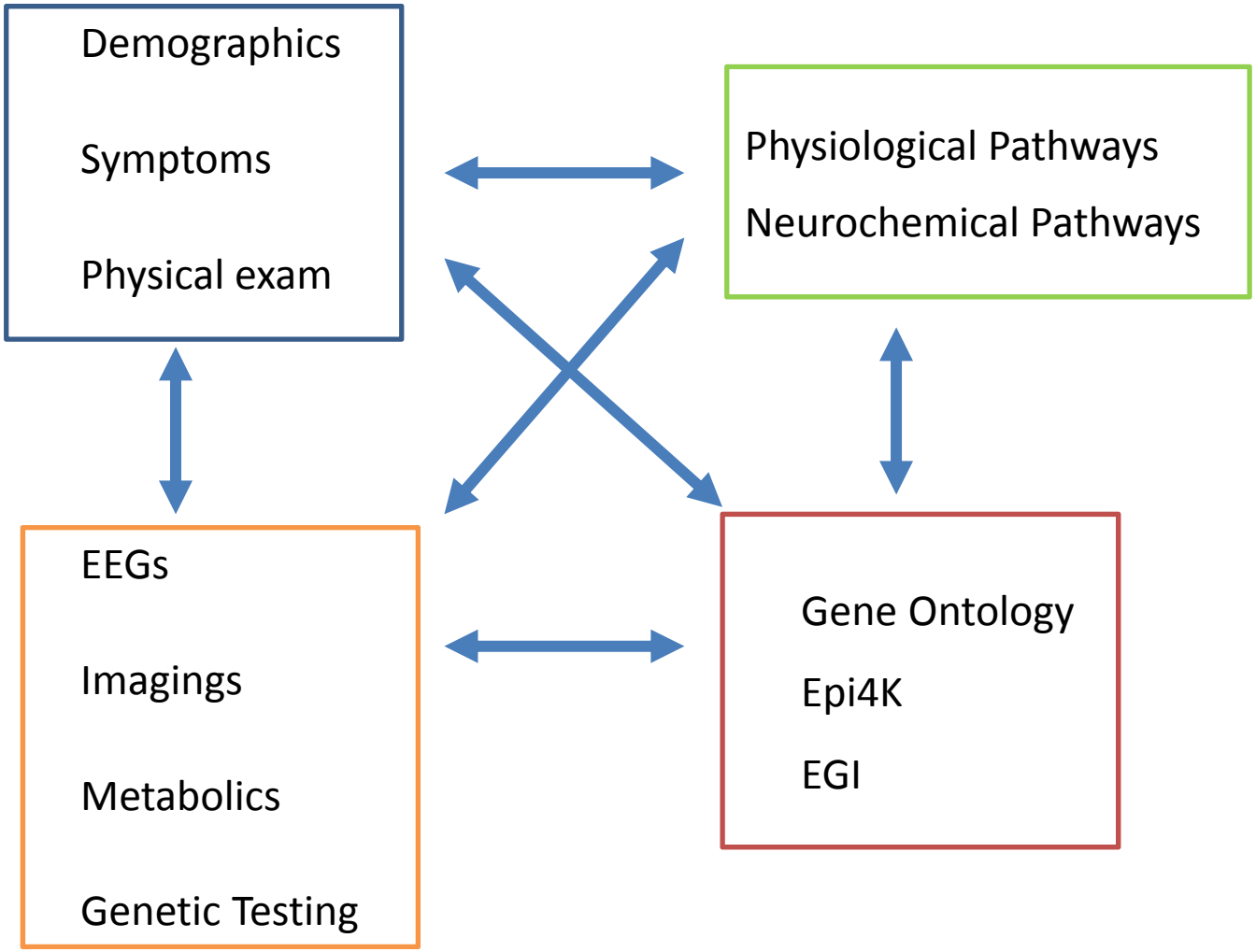
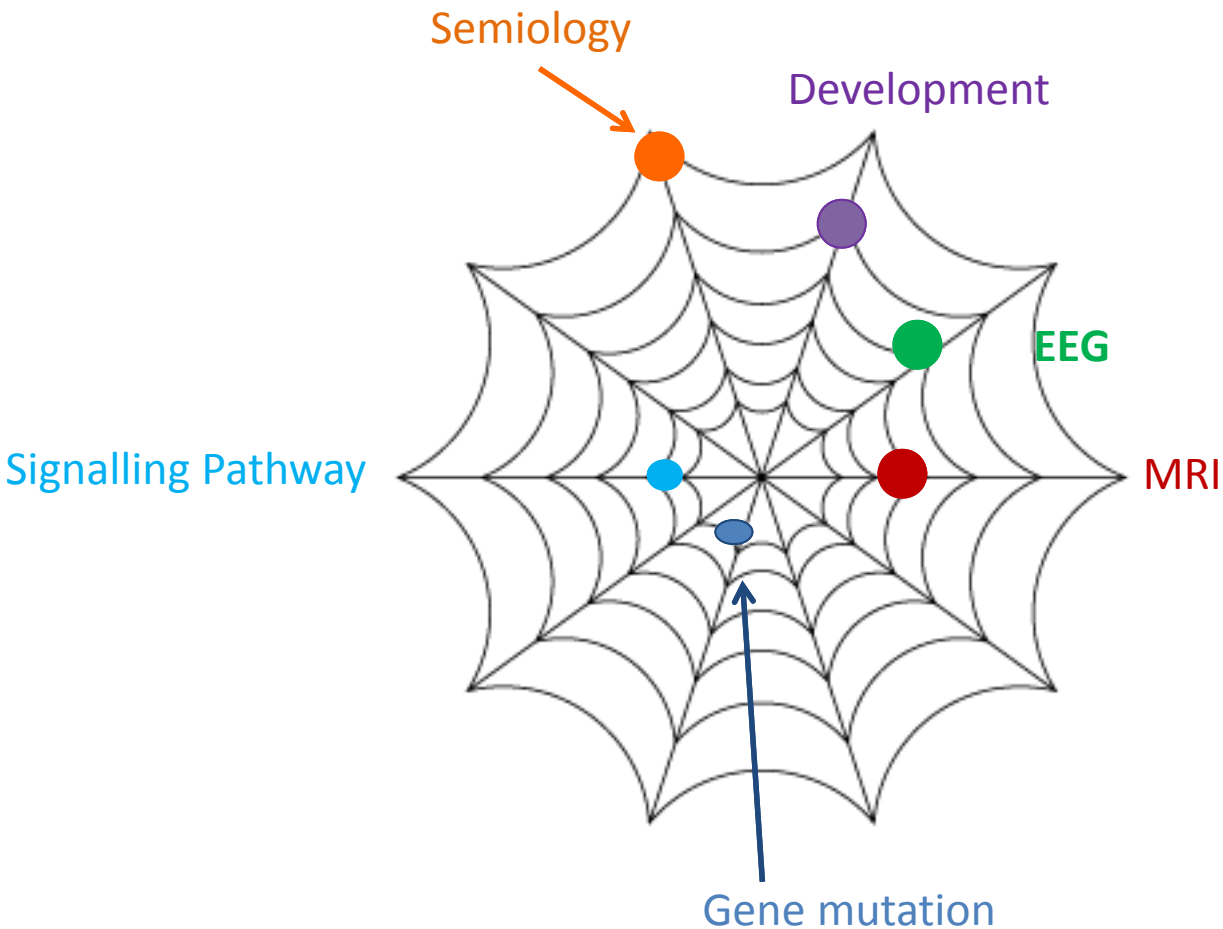
Seizure/epilepsy Ontology



Connecting the dots (nodes)



http://www.sciencedirect.com/science/journal/09521976/13/6

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PREDICTIVE ANALYTICS

By David W. Bates, Suchi Saria, Lucila Ohno-Machado, Anand Shah, and

Big Data In Health Care Analytics To Identify Ar High-Risk And High-Cos

doi:10.1093/brain/awr212 Brain 2011: 134; 2948–2959 | 2948

BRAIN
A JOURNAL OF NEUROLOGY

Data mining neocortical high-frequency oscillations in epilepsy and controls

Justin A. Blanco,[1,2] Matt Stead,[3] Abba Krieger,[4] William Stacey,[5,6] Douglas Maus,[7] Eric Marsh,[8,9] Jonathan Viventi,[2] Kendall H. Lee,[10] Richard Marsh,[10] Brian Litt[2,9] and Gregory A. Worrell[3]

ABSTRACT The US health care system is rapidly adopting electronic health records, which will dramatically increase the quantity of clinical data that are available electronically. Simultaneously, rapid progress has been made in clinical analytics—techniques for analyzing large quantities of data and gleaning new insights from that analysis—which is part of what is known as *big data*. As a result, there are unprecedented opportunities to use big data to reduce the costs of health care in the U six use cases—that is, key examples—where sor opportunities exist to reduce costs through th patients, readmissions, triage, decompensatio condition worsens), adverse events, and treatr diseases affecting multiple organ systems. We that are likely to emerge from clinical analytic to obtain such insights, and the infrastructure registries, assessment scores, monitoring devi organizations will need to perform the necess implement changes that will improve care wh findings have policy implications for regulatory oversight, ways to address privacy concerns, and the support of research on analytics.

Research and applications

Editor's choice
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Heart beats in the cloud: distributed analysis of electrophysiological '*Big Data*' using cloud computing for epilepsy clinical research

Satya S Sahoo,[1] Catherine Jayapandian,[1] Gaurav Garg,[2] Farhad Kaffashi,[3] Stephanie Chung,[2] Alireza Bozorgi,[2] Chien-Hun Chen,[1] Kenneth Loparo,[3] Samden D Lhatoo,[2] Guo-Qiang Zhang[1,3]

Sahoo SS, *et al. J Am Med Inform Assoc* 2014;**21**:263–271.

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Big Data from an EHR

Biomedical Informatics Insights

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CASE REPORT

Personalizing Drug Selection Using Advanced Clinical Decision Support

John Pestian[1], Malik Spencer[1], Pawel Matykiewicz[1], Kejian Zhang[2], Sander Vinks[3] and Tracy Glauser[4]

[1]Clinical Linguistic Group, Division of Biomedical Informatics. [2]Division of Human Genetics. [3]Division of Clinical Pharmacology. [4]Division of Neurology. Department of Pediatrics, Cincinnati Children's Hospital Medical Center, University of Cincinnati, Cincinnati, OH 45229. Email: john.pestian@cchmc.org.

Biomedical Informatics Insights 2009:2 19–29

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Big Data from a claims database

56(2016) 32-37

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Changing the approach to treatment choice in epilepsy using big data

Orrin Devinsky [a,*], Cynthia Dilley [b], Michal Ozery-Flato [c], Ranit Aharonov [c], Ya'ara Goldschmidt [c], Michal Rosen-Zvi [c], Chris Clark [b], Patty Fritz [b]

- IMS Healthcare Surveillance Data Incorporated medical claims database
- ICD 9 codes for patient ascertainment

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AAN-Epilepsy Update
Performance Measure Set- 2014

Epilepsy Evidence Based Processes and Desired Outcomes

The Work Group identified the following evidence based processes and desired outcomes for patients with epilepsy prior to drafting the measurement set:

Desired Outcomes:

1. Freedom from seizures
2. Reduction of seizure frequency
3. Reduced risk of death associated with seizures (e.g., sudden unexpected death in epilepsy (SUDEP), accident, or suicide)
4. Reduce and address safety issues (e.g., falls, injury, etc.)
5. Increased independence
6. Reduction of mental health and behavioral health comorbidities
7. Recognition and reduction of cognitive morbidity
8. Increased patient engagement in care and self-management
9. Referral to appropriate testing and reduction of unnecessary testing (e.g., neuroimaging, EEG, etc.)
10. Reduction of Emergency Department visits and emergency services
11. Improved quality of life
12. Reduction of cost of care
13. Improved patient experience

N Fountain, P Van Ess

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AAN-Epilepsy Update
Performance Measure Set- 2014

Evidence Based Processes:

1. Timely and appropriate referrals to an epilepsy specialist for patients with refractory epilepsy
2. Early and accurate diagnosis
3. Reduction of and monitoring of anti-seizure medication side effects
4. Improved coordination of care
5. Patient centered care provided

N Fountain, P Van Ess

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CMS Quality Strategy 2013 – Beyond

November 18, 2013

For Public Release

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NQF #1953 Seizure type(s) and current seizure frequency(ies), Last Updated Date: Oct 21, 2015

NATIONAL QUALITY FORUM

BRIEF MEASURE INFORMATION
De.1 Measure Title: Seizure type(s) and current seizure frequency(ies)
Co.1.1 Measure Steward: American Academy of Neurology
De.2 Brief Description of Measure: All visits for patients with a diagnosis of epilepsy who had the type(s) of seizure(s) and current seizure frequency for each seizure type documented in the medical record.
2a1.1 Numerator Statement: Patient visits with seizure type(s) specified and current seizure frequency for each seizure type documented in the medical record.

Quality Measures for Neurologists

- Physician Quality Reporting System
- Started in 2007, eliminated going forward

Epilepsy **PQRS #266**

Seizure Type(s) and Current Seizure Frequency(ies)

*This measure is to be reported for all patients with epilepsy — at **all visits** during the reporting period for patients with a diagnosis of epilepsy.*

Measure description

Percentage of patient visits with a diagnosis of epilepsy who had the type(s) of seizure(s) and current seizure frequency(ies) for each seizure type documented in the medical record

What will you need to report for each patient with epilepsy for this measure?

If you select this measure for reporting, you will report:

- Whether or not you documented seizure type(s) and frequency(ies)

What if this process or outcome of care is not appropriate for your patient?

There may be times when it is not appropriate to document seizure type and frequency, due to:

- Medical reasons (eg, patient is unable to communicate and no informant is available) OR
- Patient reasons (eg, patient and/or informant refuses to answer or comply)

In these cases, you will need to indicate which reason applies, and specify the reason on the worksheet and in the medical chart.

Cohen etal, Neurol Clin Pract. 2013 Feb; 3(1): 44–51.

PQRS- 2016

Measure #268 (NQF 1814): Epilepsy: Counseling for Women of Childbearing Potential with Epilepsy – National Quality Strategy Domain: Effective Clinical Care

2016 PQRS OPTIONS FOR INDIVIDUAL MEASURES:
CLAIMS, REGISTRY

DESCRIPTION:
All female patients of childbearing potential (12 - 44 years old) diagnosed with epilepsy who were counseled or referred for counseling for how epilepsy and its treatment may affect contraception OR pregnancy at least once a year

In Summary

- There is clearly the need to be better soon
- There needs to be outcomes that are meaningful to patients, families, payers and society
- There is the strong suggestion from other areas of medicine that organized care can produce measure improvements in outcomes
- There is a requirement for consistent, detailed data collection & analysis