Health Informatics

Lecture 2

Samantha Kleinberg
samantha.kleinberg@stevens.edu

Overview of today's class

- Where's health data collected?
- Why is it collected?
  - And why worry about why?

What health data are we talking about?

- Hospitals/providers
  - Electronic medical records (more detail next week)
  - ICU data (can be outside EMR)
- Claims data
  - Insurance companies, Medicare
- Patient generated data
  - Personal health records (next week)
  - Self tracking
  - Online forums

Different purposes

- Hospitals/providers
  - Documenting what was done and why
  - Documentation for reimbursement
  - Communication among care team
  - Legal
  - Prevention
  - Research
- Claims data
  - Mainly $
- Patient generated data
  - Personal interest
  - Social support
  - Share with provider

Different availability

- Hospitals/providers
  - Research collaboration
  - MIMIC III
- Claims data
  - See CMS
- Patient generated
  - See terms of service for apps/forums
  - Data can be donated

Why go digital?

- You can’t grep a dead tree (search)
- Ability to share data
- Prevent data loss
- Store more information than physically possible
- Standardize (more later)

A brief history

- 1960's Larry Weed introduces Problem Oriented Medical Record
  - Instead of just Dx/Tx, medical history

PROBLEM LIST

6/17 #1 Rheumatic Heart Disease
- a. Mitral insufficiency
- b. Atrial fibrillation
- c. Compensated congestive failure TTB
- d. Cardiac catheterization
- e. Successful cardioversion

#2 Presumed SBE
#3 Mild Diabetes Mellitus – adult onset
#4 Repeated pulmonary embolism
#5 Post. Inferior Vena Cava Ligation
#6 Allergic dermatitis
7/3 #7 Arthralgia
9/8 #8 Family problems

8/5 – CARDIOLOGY
TEMP – 36.5 WEIGHT 73.6 kg

#1 RHD:
Sx – excellent exercise tolerance – does housework, taking walks, etc. no SOB
Obj – wt. ↑ again 4 lbs P 100 reg. c̄ rare P /C BP 150/90
chest – few rales @ (L) base that do not clear c̄ cough; cor. – unchanged
Rx – unchanged – see flow sheet
Plans – in view of excellent clinical response and exercise tolerance I am not concerned about rales but will continue to watch
a. Quinidine 0/200 q2h #300
continue other meds

#5 Post IVC Ligation:
Sx – ō
Obj – leg swelling continues to be a problem esp. during the hot weather
Rx – unchanged
Plan – 1. ↑ Naqua to 0/002 QD
2. Coumadin 0/005 QD
3. protime today
RTC 3 mos.

9/8
#1 Arthralgias – see EW note 9-3-66
Sx – continues @ about same intensity but more concentrated in (R) arm (cath. done in that arm).
Obj – ASO neg. RH factor – not significantly ↑. Repeat sed rate – films of shoulders, elbows, wrists
Rx – symptoms *exascerbated* by ASA – some relief by heat
Plan – a. uric acid, serum glob, L.E prep
b. observe

#8 Family Problems:
pt. has been upset lately by husband's constant admonitions not to over-do herself and his general over protective attitude. Today was very upset, depressed and crying – it is now obvious that more fundamental conflicts exist in this marriage. Husband drinks, is jealous of attention she gives the children, etc.
Plan – have asked her to have husband call me and will get a greater feel for the situation starting with the part of the conflict revolving around her medical condition

9/23

Was pelvic (& pap) done during adm? if not, suggest having these done.

#1 RHD:
Sx – continued excellent exercise tolerance
Obj – wt ↑ 2 Kg B 160/70 P 100 reg: chest – clear; cor – as above
Rx – Digitalis 0/100 QD, Quinidine 0/200 qid

#5 Post IVC Ligation:
(R) leg now back to normal s̄ edema but (L) leg now swells even more and often does not go down @ night – becomes heavy and cumbersome
Rx – Naqua seems to help but not taking QD
Plan – a. Naqua QD
b. refer to peripheral vasc. clinic
c. D/C Coumadin

#7 Arthralgia:
Sx – comes and goes but essentially about the same overall. A.M. hand stiffness seems to be her biggest complaint.
Obj – joint films ⟶ osteoarthritis changes in elbows and hands
Rx – ō – heat, rest, ASA
Plan – continue above

#8 Family Problem:
marked improvement p̄ she mentioned to husband that I wanted to talk c̄ him. He has not called but has been much improved in his attitude toward her and the children.

FIGURE 3. *List of Problems and Associated Clinic Notes on a Patient Being Seen in a Busy Outpatient Department of a Large Urban Hospital.*

MEDICAL RECORDS THAT GUIDE AND TEACH

LAWRENCE L. WEED, M.D.*

- 1960s/70s – First EHRs, but they're $$$ and not widely adopted. VA adopts EHR
- 1990s – Rise of person computers + Internet
  - Institute of Medicine sets target for all physicians to use computers by 2000 (reality was <20%)
  - Many hospitals create their own record systems*
- 2000s – HITECH/ARRA and meaningful use
  - Incentives to encourage adoption

Meaningful use

- Incentives for not just adopting EHR, but using them to improve care
- 3 components from ARRA (2009)
  - Using EHR in meaningful way
  - Exchanging health information to improve quality of care
  - Using EHR to submit clinical quality and other measures

Examples of primary uses of EHR

- Order tests, medications
- Billing
- Documentation (admission, discharge, care plan, medical history, etc)

Stages

Stage 1	Stage 2	Stage 3
2011-2012	**2014**	**2016**
Data capture and sharing	Advance clinical processes	Improved outcomes

Stage 1: Meaningful use criteria focus on:	Stage 2: Meaningful use criteria focus on:	Stage 3: Meaningful use criteria focus on:
Electronically capturing health information in a standardized format	More rigorous health information exchange (HIE)	Improving quality, safety, and efficiency, leading to improved health outcomes
Using that information to track key clinical conditions	Increased requirements for e-prescribing and incorporating lab results	Decision support for national high-priority conditions
Communicating that information for care coordination processes	Electronic transmission of patient care summaries across multiple settings	Patient access to self-management tools
Initiating the reporting of clinical quality measures and public health information	More patient-controlled data	Access to comprehensive patient data through patient-centered HIE
Using information to engage patients and their families in their care		Improving population health

Healthit.gov

Patient Engagement Functionality	Percent of Hospitals with Capability			
	2012	2013	2014	Change (% point)
Do you currently have an electronic system that allows you to do the following?^				
Identify and provide patient-specific education resources	82.8%	90.2%	94.2%	4
Provide patients an electronic copy of their discharge instructions	82.7%	92.4%	N/A[1]	--
Provide patients an electronic copy of their health record within 3 business days	81.1%	91.7%	N/A[1]	--
Are patients able to do any of the following regarding their health/medical records?^				
View information from their health/medical record online	24%	39.8%	90.8	51
Download information from their health/medical record	14.3%	27.8%	82.2	54.4
Electronically transmit care/referral summaries to a third party	N/A[1]	11.6%	66.4	54.8
Request an amendment to change/update their health/medical record	30.9%	32.8%	72.4	39.6
Pay bills online	49.3%	55.4%	66.9	11.5
Secure Messaging*	N/A[1]	N/A[1]	51.3	--
Schedule appointments online	21.6%	29.8%	41.4	11.6
Request refills for prescriptions online	19.3%	27%	39.4	12.4
Submit patient-generated data (e.g., blood glucose, weight)	7.3%	12.5%	32.5	20

http://dashboard.healthit.gov/quickstats/pages/FIG-Hospital-Adoption-of-Patient-Engagement-Functionalities.php

Stage 2 core

Report on all 16 Core Objectives:

1. Use computerized provider order entry (CPOE) for medication, laboratory and radiology orders
2. Record demographic information
3. Record and chart changes in vital signs
4. Record smoking status for patients 13 years old or older
5. Use clinical decision support to improve performance on high-priority health conditions
6. Provide patients the ability to view online, download and transmit their health information within 36 hours after discharge.
7. Protect electronic health information created or maintained by the Certified EHR Technology
8. Incorporate clinical lab-test results into Certified EHR Technology
9. Generate lists of patients by specific conditions to use for quality improvement, reduction of disparities, research, or outreach
10. Use certified EHR technology to identify patient-specific education resources and provide those resources to the patient if appropriate
11. Perform medication reconciliation
12. Provide summary of care record for each transition of care or referral
13. Submit electronic data to immunization registries
14. Submit electronic data on reportable lab results to public health agencies
15. Submit electronic syndromic surveillance data to public health agencies
16. Automatically track medications with an electronic medication administration record (eMAR)

Stage 2 menu

Report on 3 of 6:

1. Record whether a patient 65 years old or older has an advance directive
2. Record electronic notes in patient records
3. Imaging results accessible through CEHRT
4. Record patient family health history
5. Generate and transmit permissible discharge prescriptions electronically (eRx)
6. Provide structured electronic lab results to ambulatory providers

Stage 3 - interoperability

- Share data
  - % of patients message provider
  - Electronic summaries for other providers
- Other
  - % of electronic prescriptions/orders
- Handle patient-generated data
  - % generated

Available data

- All providers demonstrating meaningful use and receiving payment listed publicly, updated quarterly

- http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/DataAndReports.html

Who's collecting data (hospital)?

- Doctors (attendings, residents, interns)
- Nurses
- Lab
- Radiology
- Pharmacy
- Admin/staff

Primary vs secondary use

- Example primary uses of EHR
  - Delivering care: ensuring continuity, document medical history
  - Billing: documenting services provided
- Example secondary uses of EHR
  - Research: find causes of disease, identify drug-drug interactions
  - Public health/policy: identify disease outbreaks

Information exchange



Healthit.gov

Information exchange

- Within hospital
  - Between units, people with different roles, etc
- Between multiple organizations
  - Primary care + specialist, etc

Exchange – within ICU

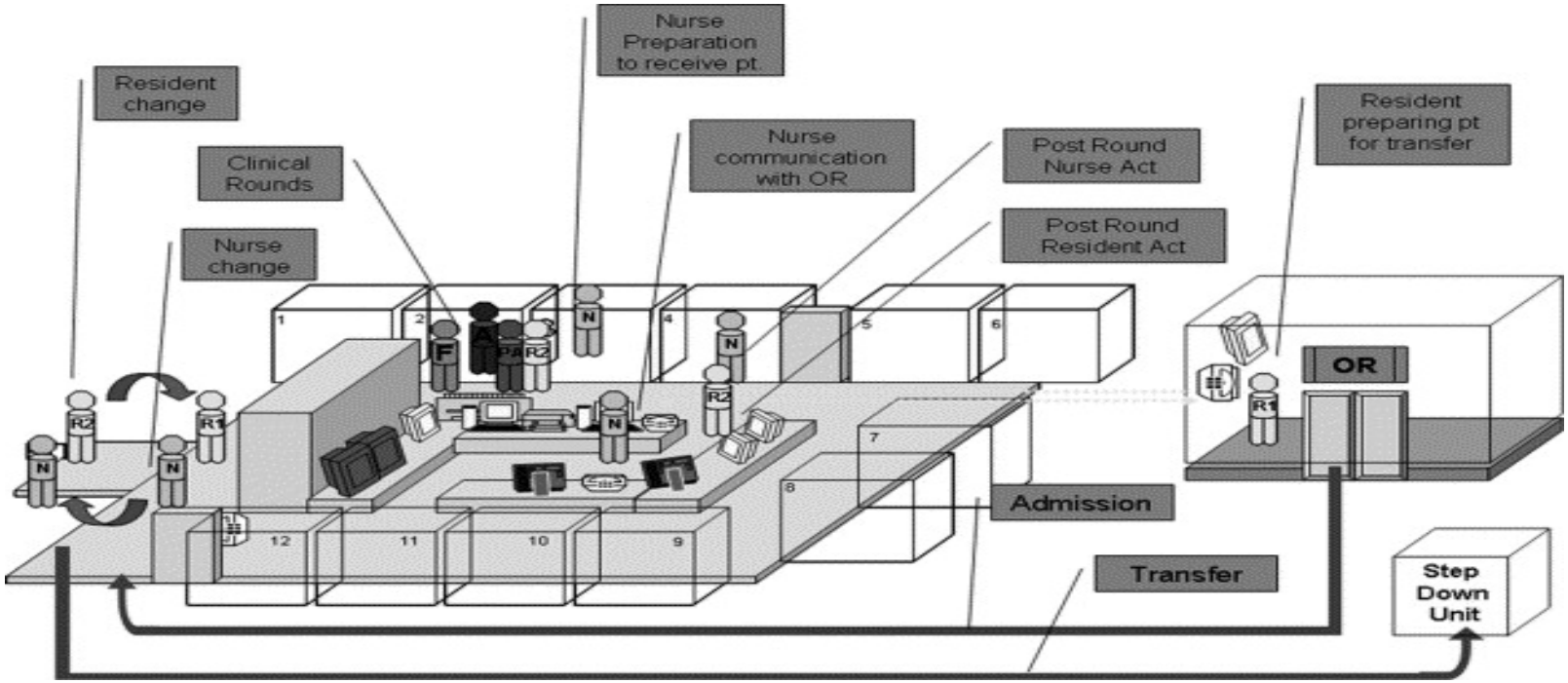
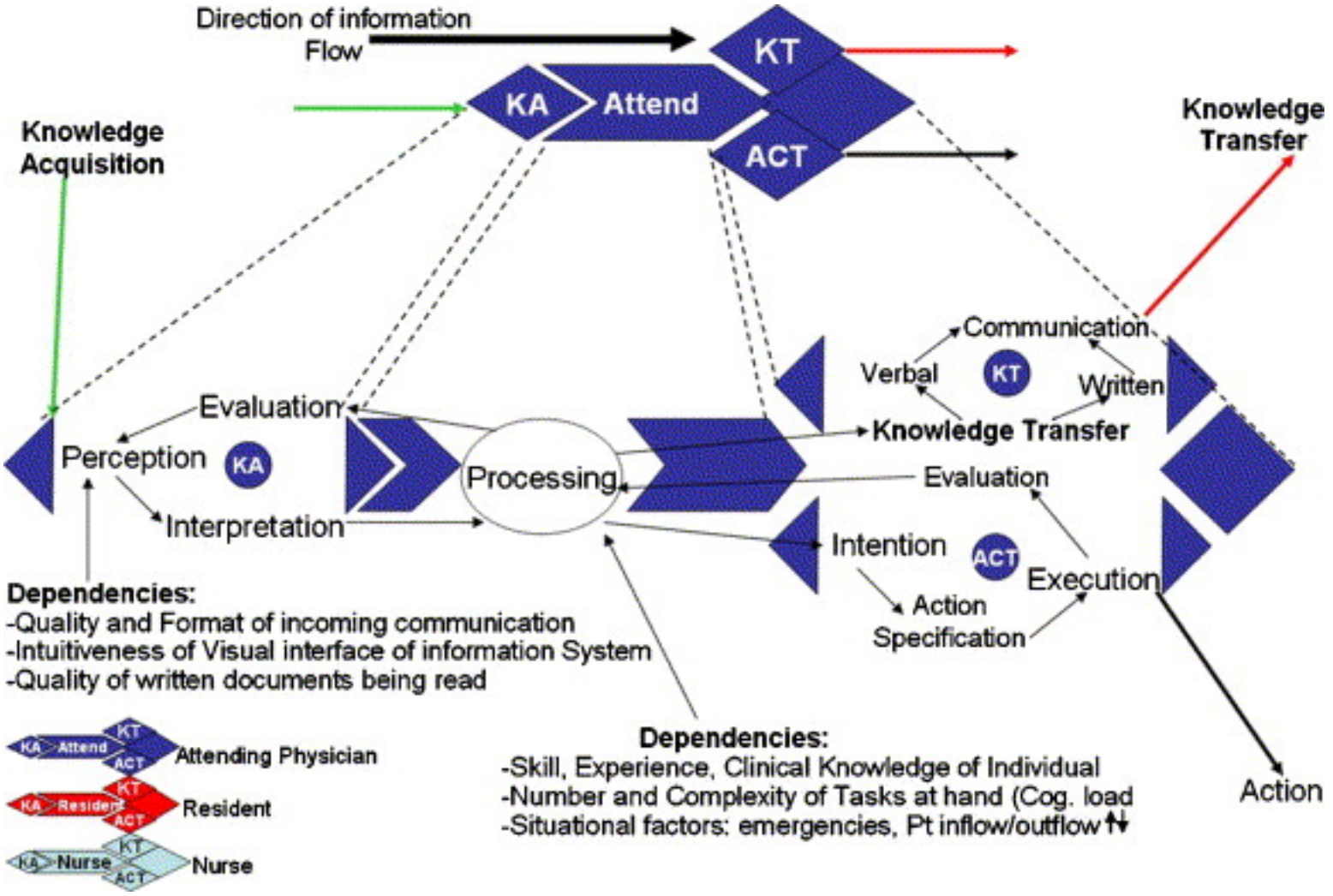


Fig. 2 Schematic layout of the CTICU and key activities during which observations were conducted. Patient cubicles surround the Nursing station where most of the clinical information systems lie. The letters on the human representations signify the followi...

Malhotra, S., Jordan, D., Shortliffe, E. & Patel, V.L., 2007, Workflow modeling in critical care: piecing together your own puzzle, *Journal of biomedical informatics*, 40(2), pp. 81-92

Critical zone (CZ)	Examples of activities	Description
Re-orientation	Resident change	Morning sign-out by (night) nurses and residents to their in-coming
Admissions	OR to Nurse information transfer	Information of patients due to be admitted from the operating room (OR) or emergency department (ED) is received
	Receipt of patient by resident	Based on the information preparations to received the patient are made
		Patient handover and determination of preliminary management (or continuation of the management as communicated by the personal handing over the patient)
Re-assessment	Evening clinical round	New admissions are assessed and initial management determined
		Next days step down/transfer/discharge plan for existing patients discussed
Evening sign-out	Resident change (handoff)	Information of patients handed off to the incoming night team (residents and nurses)
	Nurse change (handoff)	Overnight patient care activities carried out based on the information provided
		Documentation of overnight activities and preparation for morning sign-out (handoff to incoming team) are made
	Transfer of existing patient in ICU to floors (wards)	Transfer summary, continued management plan documented, initiated and communicated to the clinical unit receiving the patient



Malhotra, S., Jordan, D., Shortliffe, E. & Patel, V.L., 2007, Workflow modeling in critical care: piecing together your own puzzle, *Journal of biomedical informatics*, 40(2), pp. 81-92

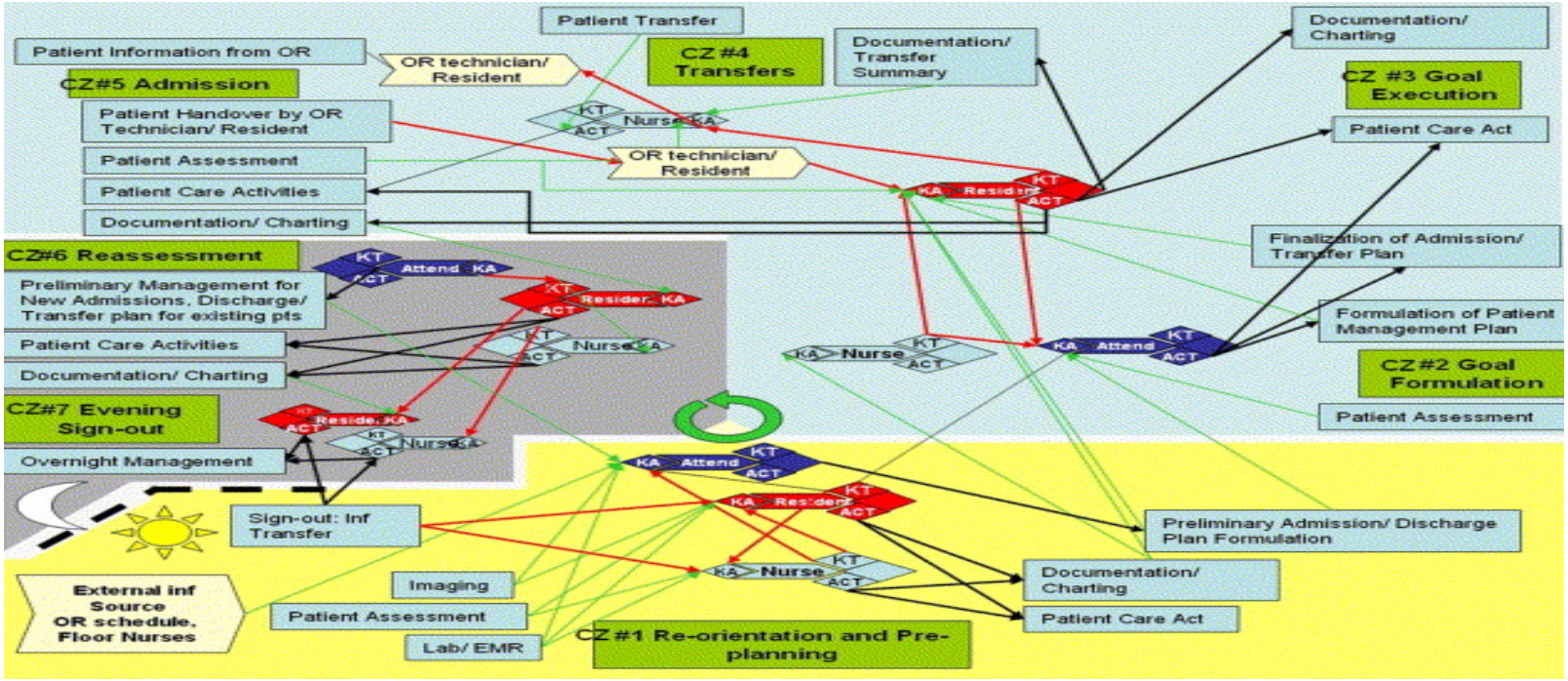


Fig. 6 The cognitive workflow model for inpatient care. The workflow flows in an anti-clockwise fashion. Although this being a continuous cycle with no start or finish, the symbol of the sun (morning) can be used as the starting point. Please note the three levels of abstraction (see text for details): (a) the complete workflow model as top level, (b) the grouped CZs shown with different background colors—1 through 3, (c) the individual critical zones—1 through 7. The 4th level is the individual level which was shown in Fig. 5 with the attending as an example.

Malhotra, S., Jordan, D., Shortliffe, E. & Patel, V.L., 2007, Workflow modeling in critical care: piecing together your own puzzle, *Journal of biomedical informatics*, 40(2), pp. 81-92

AMIA Annual Symposium Proceedings Archive

AMIA Annu Symp Proc. 2009; 2009: 662–666.

PMCID: PMC2815477

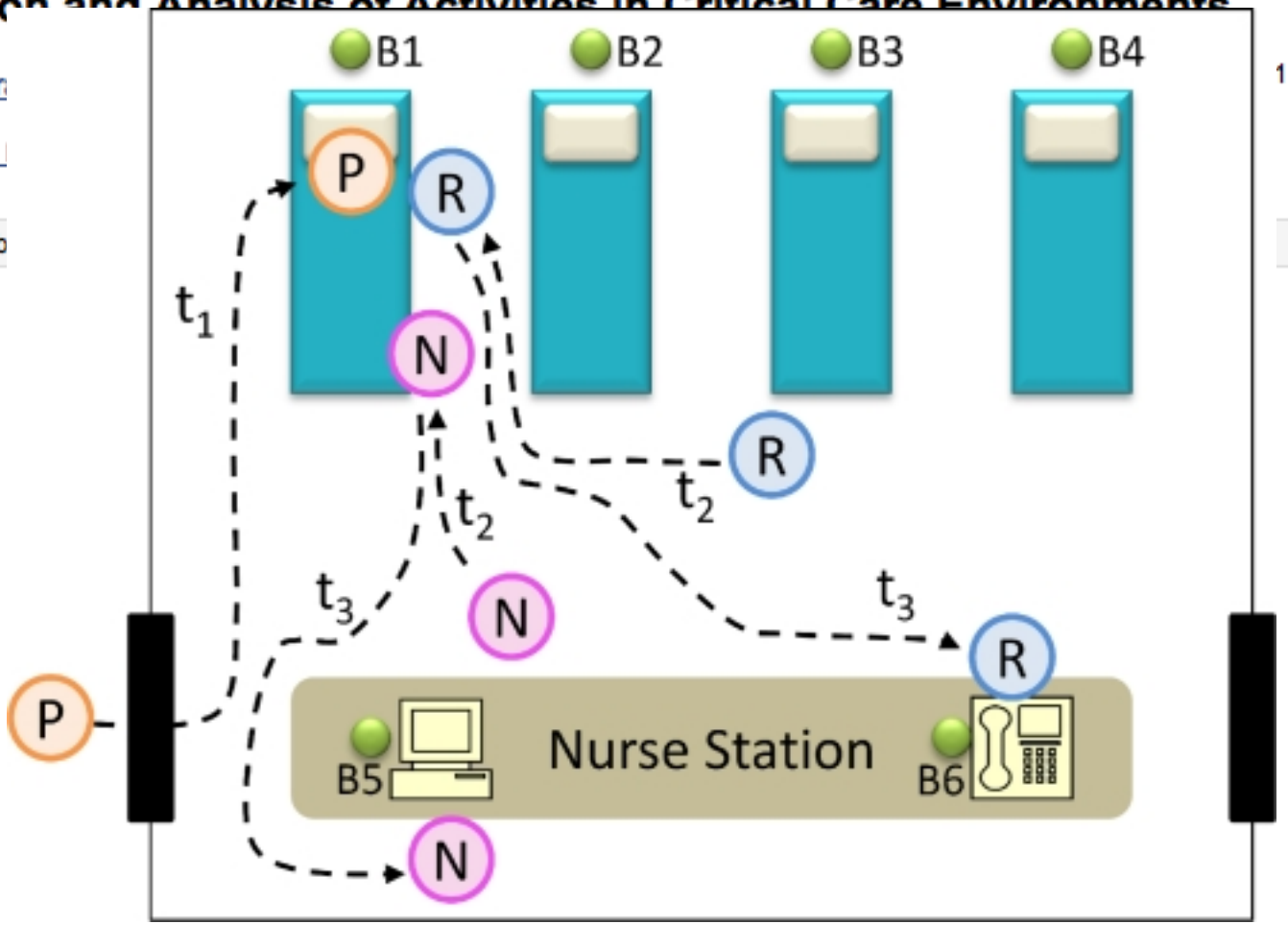
Published online 2009 November 14.

Visualization and Analysis of Activities in Critical Care Environments

Mithra Vankipur

Author information

This article has b



Visual TASK: A Collaborative Cognitive Aid for Acute Care Resuscitation

Michael J. Gonzales[1], Joshua M. Henry, MD[2], Aaron W. Calhoun, MD[2], and Laurel D. Riek, PhD[1]

[1]Dept. of Computer Science and Engineering
University of Notre Dame
Notre Dame, IN 46556
{mgonza14, lriek}@nd.edu

[2]Dept. of Pediatrics, Division of Critical Care
University of Louisville
Louisville, KY 40202
{joshua.henry,
aaron.calhoun}@louisville.edu

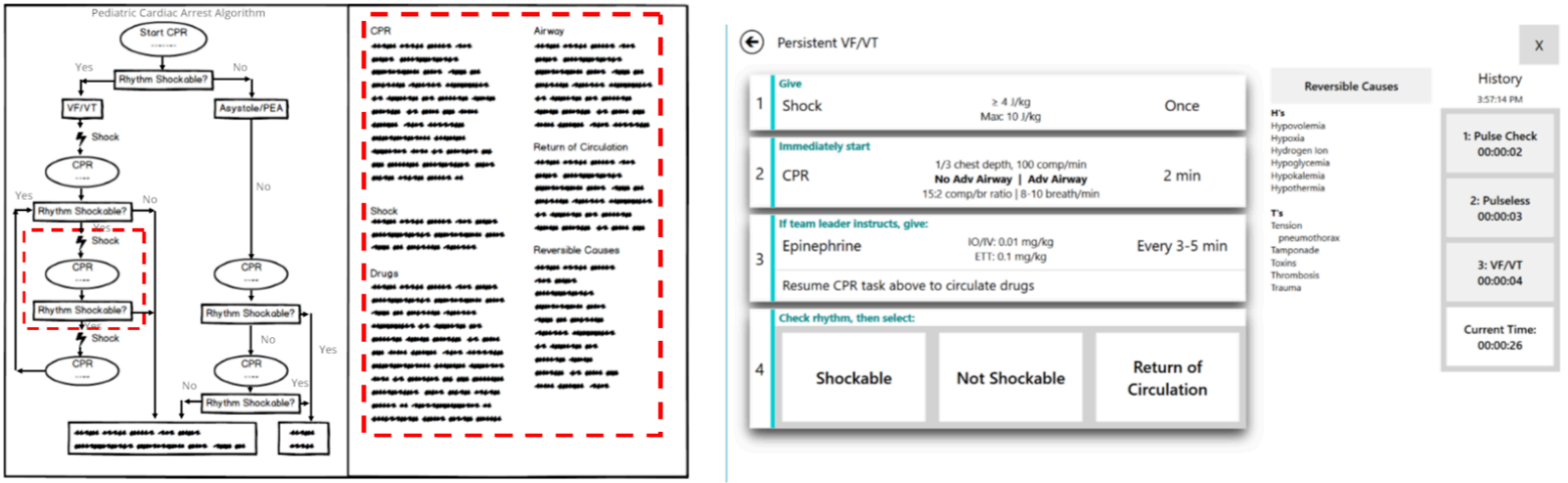
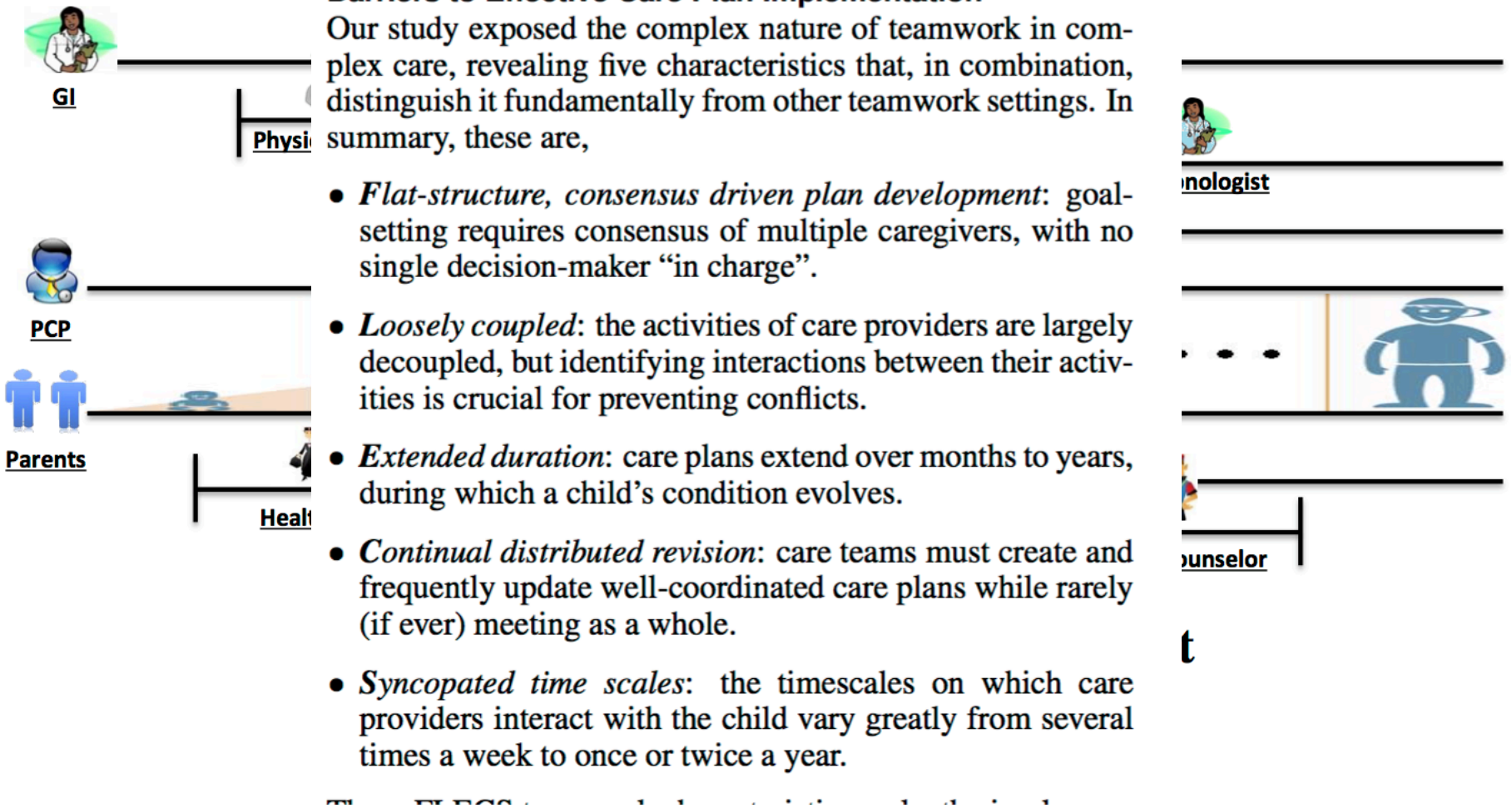


Figure 3: Left: Part of a PALS reference guide for the Pulseless Arrest Algorithm. Right: Visual TASK, our redesigned PALS guide. The red/dashed highlighted region shows the current split of information on PALS cards, whereas our redesign pairs this information with its associated task.

Information exchange – over time



Barriers to Effective Care Plan Implementation

Our study exposed the complex nature of teamwork in complex care, revealing five characteristics that, in combination, distinguish it fundamentally from other teamwork settings. In summary, these are,

- ***Flat-structure, consensus driven plan development***: goal-setting requires consensus of multiple caregivers, with no single decision-maker "in charge".
- ***Loosely coupled***: the activities of care providers are largely decoupled, but identifying interactions between their activities is crucial for preventing conflicts.
- ***Extended duration***: care plans extend over months to years, during which a child's condition evolves.
- ***Continual distributed revision***: care teams must create and frequently update well-coordinated care plans while rarely (if ever) meeting as a whole.
- ***Syncopated time scales***: the timescales on which care providers interact with the child vary greatly from several times a week to once or twice a year.

Amir, O., Grosz, B.J., Gajos, K.Z., Swenson, S.M. and Sanders, L.M. From care plans to care coordination: Opportunities for computer support of teamwork in complex healthcare. In *CHI*, 2015.

Why is information exchange important?

- Reduce duplicate tests
- Improve diagnosis and treatment
  - E.g. Medication interactions, allergies
  - Results of prior testing/diagnoses ruled out
- Reduce errors/improve efficiency
  - Eg. Asking for family history repeatedly

- Research! Feedback loop, missing data

Why is information exchange hard?

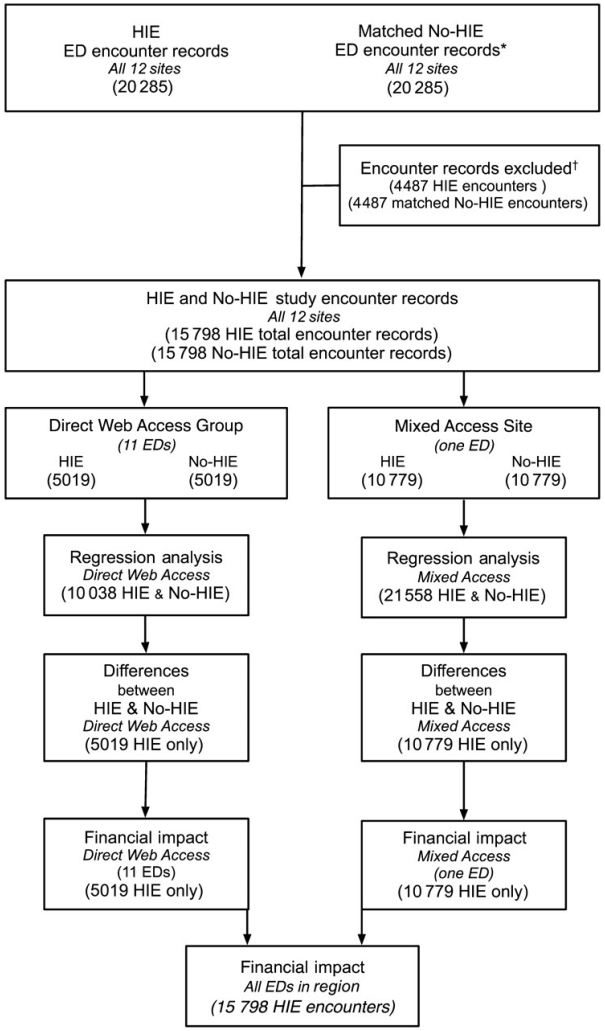
- Patient matching
- Preserving privacy
- Differing data formats

What's the practical impact?

- Study took all major emergency departments in Memphis, compared outcomes with HIE and without
- Access: 6.8% of ED visits (12 EDs), associated with decreased hospital admissions
- Cost: estimate HIE reduced overall cost by $1.07 million (primarily due to reduced admissions)

The financial impact of health information exchange on emergency department care
Mark E Frisse, Kevin B Johnson, Hui Nian, Coda L Davison, Cynthia S Gadd, Kim M Unertl, Pat A Turri, Qingxia Chen
J Am Med Inform Assoc amiajnl-2011-000394Published Online First: 4 November 2011 doi:10.1136/amiajnl-2011-000394

Study design.



Frisse M E et al. J Am Med Inform Assoc doi:10.1136/amiajnl-2011-000394

Copyright © by the American Medical Informatics Association. All rights reserved.

HIE Models

- Direct exchange between care providers
  - Ex: Doctor refers patient to specialist for follow-up, and sends brief history
- Central organization
  - many-to-many
- Patient mediated
  - EX: PHR, bringing paper records to appointment

Direct exchange

- Pushing info to public health registries, sending orders and results to clinicians

- Challenges?

- Different data formats
- Depends on individuals requesting/matching patients

Patient exchange

(consumer mediated exchange)

- Patients share access with their providers
- In some cases, can correct errors, add information

Note on patient access…

- Patients have the right to see their medical record
  - And to have record sent to a third party
- Demonstrating access is important for meaningful use!

e-Patient Dave

- https://www.youtube.com/watch?v=cxZy-Vnu0c0

However…

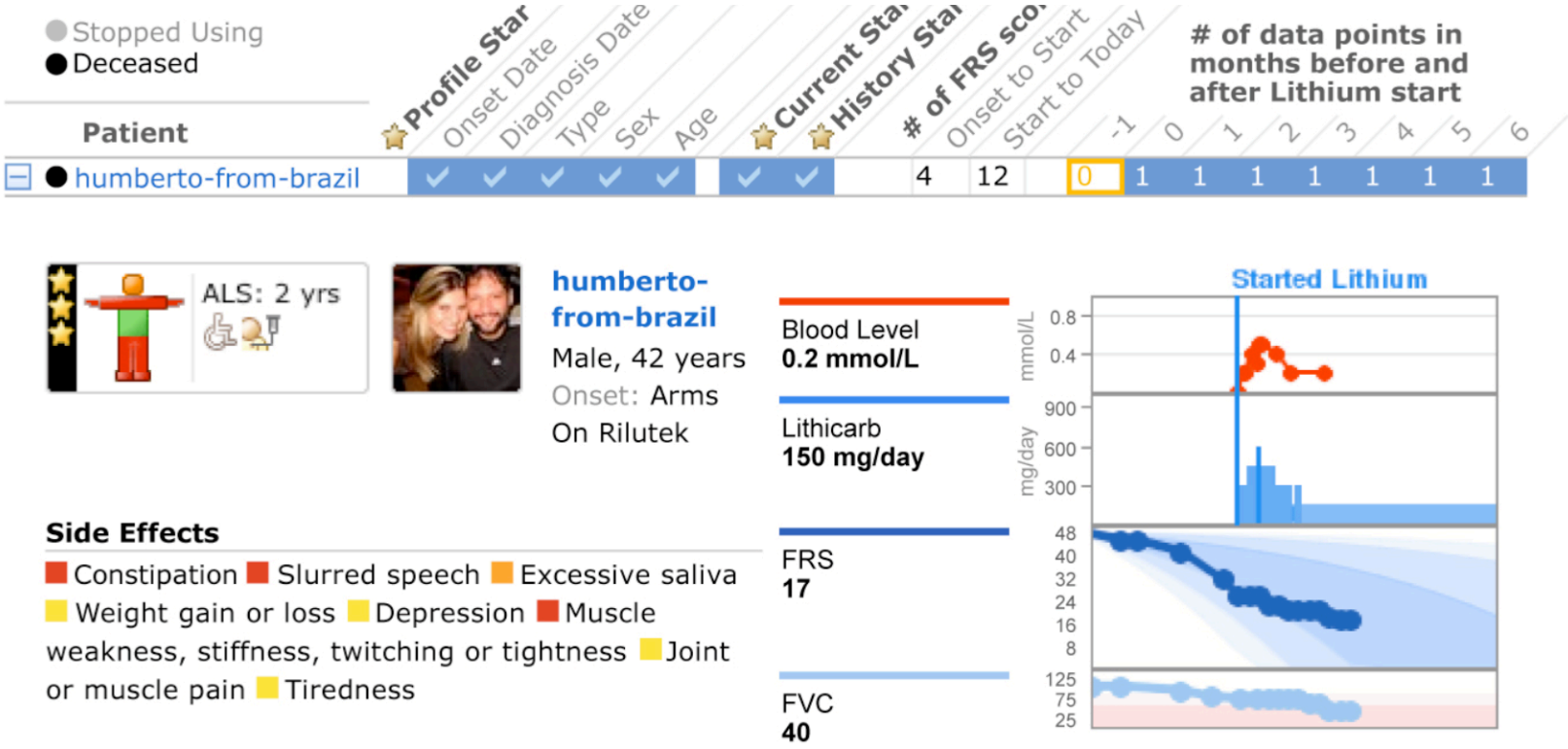
People hide information

- Lab tests under assumed name
- Seeking an out of state provider rather than primary care
- Giving false information
- Simply not giving information when requested

13-17% of consumers in recent surveys say they've engaged in information hiding in their record

Today's paper

- What's the problem? Why is the approach novel?
- What challenges come with non-randomized non-blinded trials?
- What results should we be skeptical about?
- What did they find and how?
- Can non-randomized trial results ever be stronger than RCT results?
- Questions/criticisms?


Stopped Using
Deceased
Patient
Profile Star
Onset Date
Diagnosis Date
Type
Sex
Age
Current Star
History Star
# of FRS sco
Onset to Start
Start to Today
# of data points in months before and after Lithium start
-1 0 1 2 3 4 5 6
humberto-from-brazil
4
12
0 1 1 1 1 1 1 1
ALS: 2 yrs
humberto-from-brazil
Male, 42 years
Onset: Arms
On Rilutek
Blood Level
0.2 mmol/L
Lithicarb
150 mg/day
FRS
17
FVC
40
Started Lithium
mmol/L
0.8
0.4
mg/day
900
600
300
48
40
32
24
16
8
125
75
25
Side Effects
Constipation
Slurred speech
Excessive saliva
Weight gain or loss
Depression
Muscle weakness, stiffness, twitching or tightness
Joint or muscle pain
Tiredness

XMRV leads to CFS?

Detection of an Infectious Retrovirus, XMRV, in Blood Cells of Patients with Chronic Fatigue Syndrome

Vincent C. Lombardi,[1]* Francis W. Ruscetti,[2]* Jaydip Das Gupta,[3] Max A. Pfost,[1] Kathryn S. Hagen,[1] Daniel L. Peterson,[1] Sandra K. Ruscetti,[4] Rachel K. Bagni,[5] Cari Petrow-Sadowski,[6] Bert Gold,[2] Michael Dean,[2] Robert H. Silverman,[3] Judy A. Mikovits[1]†

Chronic fatigue syndrome (CFS) is a debilitating disease of unknown etiology that is estimated to affect 17 million people worldwide. Studying peripheral blood mononuclear cells (PBMCs) from CFS patients, we identified DNA from a human gammaretrovirus, xenotropic murine leukemia virus–related virus (XMRV), in 68 of 101 patients (67%) as compared to 8 of 218 (3.7%) healthy controls. Cell culture experiments revealed that patient-derived XMRV is infectious and that both cell-associated and cell-free transmission of the virus are possible. Secondary viral infections were established in uninfected primary lymphocytes and indicator cell lines after their exposure to activated PBMCs, B cells, T cells, or plasma derived from CFS patients. These findings raise the possibility that XMRV may be a contributing factor in the pathogenesis of CFS.

Chronic fatigue syndrome (CFS) is a disorder of unknown etiology that affects multiple organ systems in the body. Patients with CFS display abnormalities in immune system function, often including chronic activation of the innate immune system and a deficiency in natural killer cell activity (*1*, *2*). A number of viruses, including ubiquitous herpesviruses and enteroviruses, have been implicated as possible environmental triggers of CFS (*1*). Patients with CFS often have active β herpesvirus infections, suggesting an underlying immune deficiency.

The recent discovery of a gammaretrovirus, xenotropic murine leukemia virus–related virus (XMRV), in the tumor tissue of a subset of prostate cancer patients prompted us to test whether XMRV might be associated with CFS. Both of these disorders, XMRV-positive prostate cancer and CFS, have been linked to alterations in the antiviral enzyme RNase L (*3*–*5*). Using the Whittemore Peterson Institute's (WPI's) national

[1]Whittemore Peterson Institute, Reno, NV 89557, USA. [2]Laboratory of Experimental Immunology, National Cancer Institute–Frederick, Frederick, MD 21701, USA. [3]Department of Cancer Biology, The Lerner Research Institute, The Cleveland Clinic Foundation, Cleveland, OH 44195, USA. [4]Laboratory of Cancer Prevention, National Cancer Institute–Frederick, Frederick, MD 21701, USA. [5]Advanced Technology Program, National Cancer Institute–Frederick, Frederick, MD 21701, USA. [6]Basic Research Program, Scientific Applications International Corporation, National Cancer Institute–Frederick, Frederick, MD 21701, USA.

*These authors contributed equally to this work.
†To whom correspondence should be addressed. E-mail: judym@wpinstitute.org

XMRV leads to CFS?

August 23, 2010

Study Links Chronic Fatigue to Virus Class

By DAVID TULLER

When the journal Science published an attention-grabbing study last fall linking chronic fatigue syndrome to a recently discovered retrovirus, many experts remained skeptical — especially after four other studies found no such association.

Now a second research team has reported a link between the fatigue syndrome and the same class of virus, a category known as MLV-related viruses. In a paper published Monday by The Proceedings of the National Academy of Sciences, scientists found gene sequences from several MLV-related viruses in blood cells from 32 out of 37 chronic-fatigue patients but only 3 of 44 healthy ones.

The researchers did not find XMRV, the specific retrovirus identified in patients last fall. But by confirming the presence of a cluster of genetically similar viruses, the new study represents a significant advance, experts and advocates say.

"I think it settles the issue of whether the initial report was real or not," said K. Kimberly McCleary, president of the CFIDS Association of America, the leading organization for people with chronic fatigue syndrome.

Leonard A. Jason, a professor of psychology at DePaul University and a leading researcher on the syndrome, agreed. "This class of retroviruses is probably going to be an important piece of the puzzle," he said.

Chronic fatigue syndrome, estimated to afflict at least one million Americans, has no known cause and no accepted diagnostic tests, although patients show signs of immunological, neurological and endocrinological abnormalities. Besides profound exhaustion, symptoms include sleep disorders, cognitive problems, muscle and joint pain, sore throat and headaches.

The new paper, by researchers from the National Institutes of Health, the Food and Drug Administration and Harvard Medical School, was accepted for publication in May. Social networks and online communities soon learned the general findings and were eagerly awaiting the paper.

But in July, researchers from another federal agency, the Centers for Disease Control and Prevention, published a

"I think it settles the issue of whether the initial report was real or not"

Antiretrovirals for CFS?

Off-Label Use of H.I.V. Medications Is Catalyst for More Controversy

By SCOTT JAMES SEPT. 23, 2011

At a cafe on 18th Street in San Francisco, David sipped coffee and talked about the regimen of daily H.I.V. pills he recently started: Viread in July, and then last month, Isentress. He looked exhausted.

David does not have H.I.V. For 20 years he has endured a debilitating case of chronic fatigue syndrome, which has left him unable to work.

"All of a sudden my brain dies," said David, who asked that only his first name be used for privacy reasons. "I have such a narrow range of concentration." He hopes the medications will help.

Thirty years into the AIDS epidemic, the antiretroviral drugs that have provided lifesaving treatment for many of those infected with H.I.V. — 1.1 million in the United States today — are now being used or considered for treating other ailments.

RELATED COVERAGE

TIMES TOPIC
AIDS / H.I.V.

menu

john

But …

RETRACTION

Post date 23 December 2011

Science is fully retracting the Report "Detection of an infectious retrovirus, XMRV, in blood cells of patients with chronic fatigue syndrome" (*1*). Multiple laboratories, including those of the original authors (*2*), have failed to reliably detect xenotropic murine leukemia virus–related virus (XMRV) or other murine leukemia virus (MLV)–related viruses in chronic fatigue syndrome (CFS) patients. In addition, there is evidence of poor quality control in a number of specific experiments in the Report. Fig. 1, table S1, and fig. S2 have been retracted by the authors (*3*). In response to concerns expressed about Fig. 2C [summarized in (*4*)], the authors acknowledged to *Science* that they omitted important information from the legend of this figure panel. Specifically, they failed to indicate that the CFS patient–derived peripheral blood mononuclear cells (PBMCs) shown in Fig. 2C had been treated with azacytidine as well as phytohemagglutinin and interleukin-2. This was in contrast to the CFS samples shown in Figs. 2A and 2B, which had not been treated with azacytidine.

Given all of these issues, *Science* has lost confidence in the Report and the validity of its conclusions. We note that the majority of the authors have agreed in principle to retract the Report but they have been unable to agree on the wording of their statement. It is *Science*'s opinion that a retraction signed by all the authors is unlikely to be forthcoming. We are therefore editorially retracting the Report. We regret the time and resources that the scientific community has devoted to unsuccessful attempts to replicate these results.

BRUCE ALBERTS
Editor-in-Chief

References

1. V. C. Lombardi *et al.*, *Science* **326**, 585 (2009); 10.1126/science.1179052.
2. G. Simmons *et al.*, *Science* **334**, 814 (2011); 10.1126/science.1213841.
3. R. H. Silverman *et al.*, *Science* **334**, 176 (2011); 10.1126/science.1212182.
4. J. Cohen, *ScienceInsider* (4 October 2011); http://scim.ag/_Mikovits.

NATURE NEWS BLOG

Another XMRV study retracted

28 Dec 2011 | 13:23 GMT | Posted by Heidi Ledford | Category: Biology & Biotechnology, Health and medicine

Five days after *Science* withdrew a controversial study linking chronic fatigue syndrome (CFS) to a virus, another research paper on the topic has been retracted.

This study, retracted by the *Proceedings of the National Academy of Science* on 27 December, was widely seen as supportive of the proposed link between a virus and CFS, so its retraction is another blow to those who back that connection. It had found that people with chronic fatigue syndrome were more likely than healthy controls to harbour MLV-like viruses in their blood. (MLV stands for murine leukaemia virus; and the virus singled out for attention by the *Science* paper, XMRV, is a member of the MLV-like family of retroviruses).

Publication of the PNAS study had been delayed last year, while it underwent a last-minute additional round of review (see 'Chronic fatigue findings were held back'). It was eventually published in August 2010 (see 'Delayed chronic fatigue syndrome paper to be published'), but even then the authors acknowledged that they were unable to provide the additional evidence requested by the last panel of reviewers.

Query model

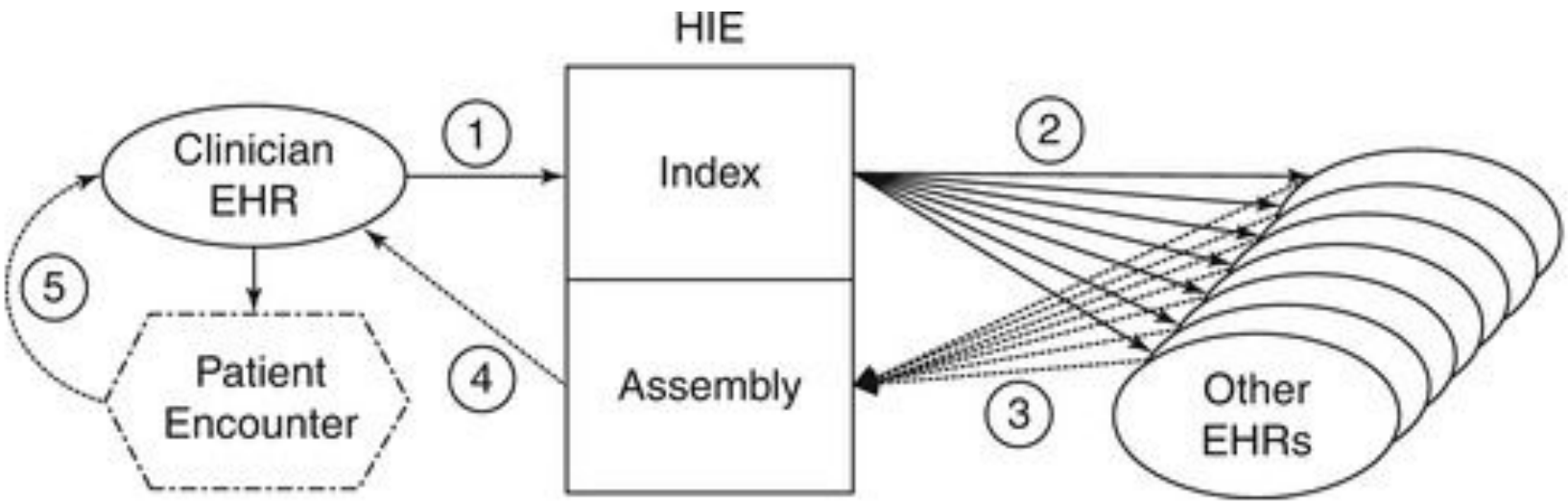
- Alice comes to emergency room, physician wants to get all of Alice's records from all of her providers

HIOs

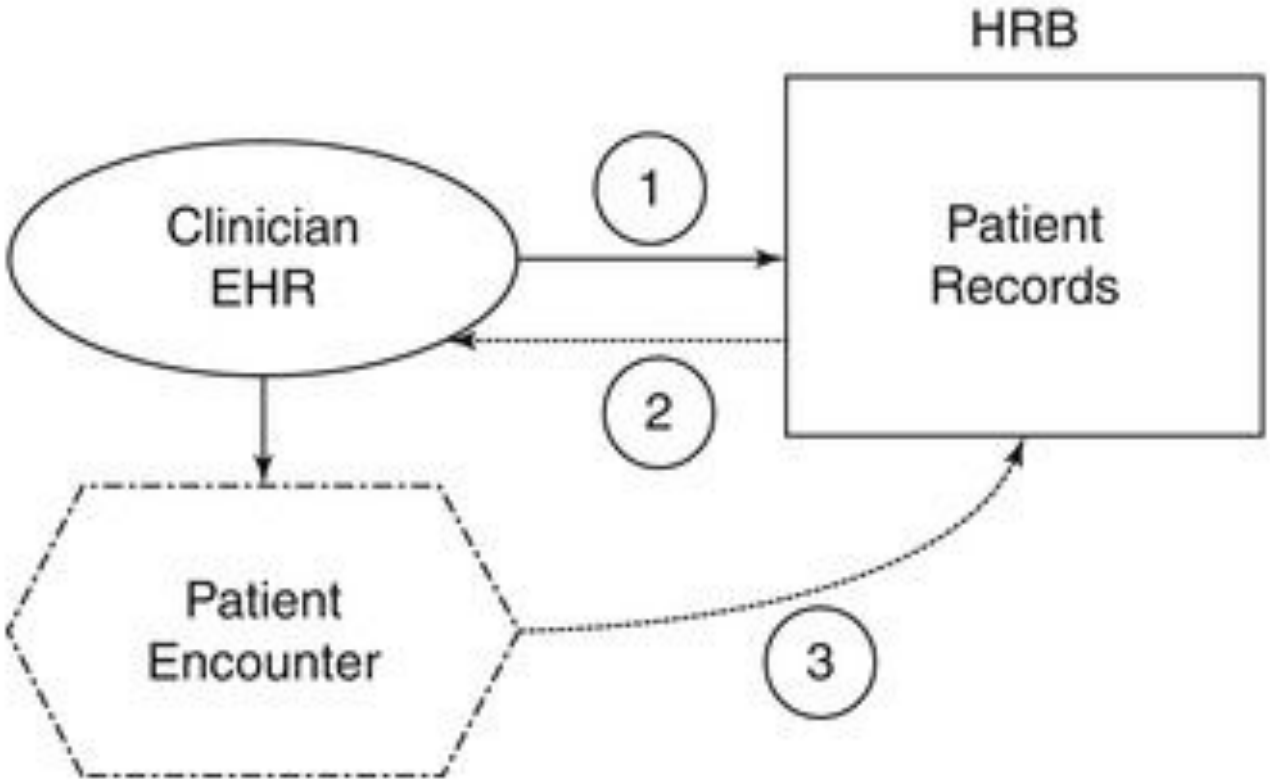
- Health Information organizations
- Regional HIO
  - Serves a specific geographic area
- HII (health information infrastructure)
- NHII = national HII, e.g. connected RHIOs

Why NHII?

- Biosurveillance
- Full sharing of records
- Integration with public health
- Clinical trials



Shortliffe, E.H. & Cimino, J.J., 2013, *Biomedical Informatics: Computer Applications in Health Care and Biomedicine,* Springer Verlag.



Shortliffe, E.H. & Cimino, J.J., 2013, *Biomedical Informatics: Computer Applications in Health Care and Biomedicine,* Springer Verlag.

Patient matching

- Basic problem: How do we know Joe Smith at Hospital A is the same Joe Smith at Hospital B?
- Effects of incorrect match
  - Medical errors: e.g. missing allergy/incorrect allergy
  - Loss of privacy: disclosing another patient's info
- Challenges
  - Missing data, highly scattered records, common characteristics

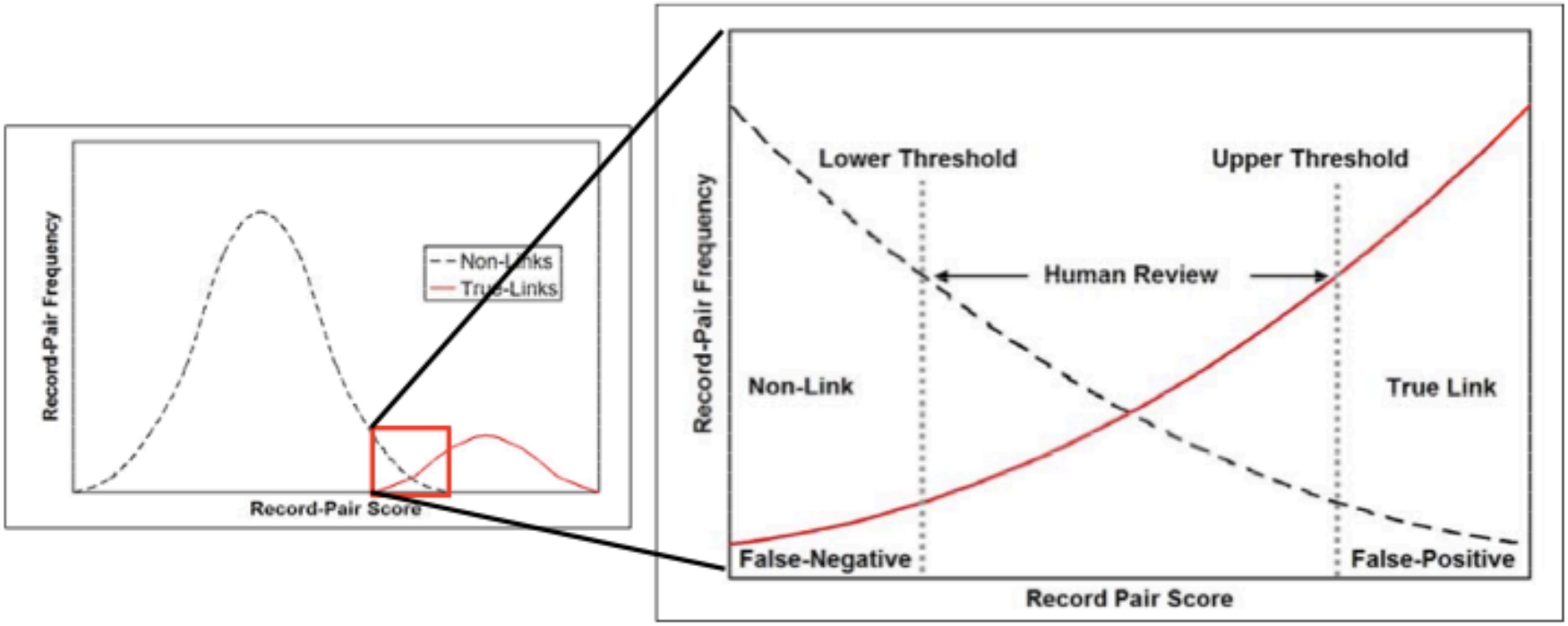
UPI

- Everyone gets a “unique patient identifier” (UPI)
- SSN often used, this would replace that

- What’s are pros/cons? Is it a bigger security risk?
- Note: congress has banned funding HHS to investigate UPIs

Other approaches

Figure 5-1. Illustration of the Intermediate Score Range Where Both True Matches and Non-Matches Are Present



NOTE: To disambiguate these linkages, human review is often necessary.

http://www.healthit.gov/sites/default/files/patient-matching-white-paper-final-2.pdf

Table 6-1. Summary of HIO Matching Approaches

Attribute	Results
Number of unique patients in HIO	■ 225,000 to 9.4 million
Software type	■ Use commercial product: 5 HIOs ■ HIOs using commercial software that make some adjustments to the system: 3 HIOs ■ Use own matching solution: 2 HIOs
Type of matching	■ Probabilistic: 4 HIOs ■ Deterministic: 1 HIO ■ Combination of probabilistic and deterministic: 1 HIO ■ Fuzzy match based on heuristics: 1 HIO
Manual review component	■ 0 FTEs (full-time equivalents): 2 HIOs ■ 0.5 to 1.0 FTEs: 3 HIOs ■ Will use manual review, but number of FTEs TBD: 2 HIOs
Summary of all variables used by the HIOs for matching (note: not all HIOs use all of these methods)	■ Medical record number ■ First name ■ Middle name ■ Last name ■ Maiden or alias names ■ Gender ■ Date of birth (as single value or separate fields for month, day, and year) ■ Social security number (whole number or last four digits) ■ Phone numbers ■ Street address ■ City ■ County ■ State ■ Zip code ■ Driver's license number ■ Race ■ Marital status ■ Date of encounter

http://www.healthit.gov/sites/default/files/patient-matching-white-paper-final-2.pdf

Challenges

- Data may be…
  - Missing
  - Incorrect
  - Outdated

Data from outside hospital?

http://vimeo.com/81272562

For next week

Read:

S. Abhyankar, D. Demner-Fushman, F. M. Callaghan, and C. J. McDonald. Combining structured and unstructured data to identify a cohort of ICU patients who received dialysis. Journal of the American Medical Informatics Association