Electronic Medical Records and interoperability in the US: hits and misses …and new work at NLM

Clement J. McDonald, MD
Director, Lister Hill National Center for Biomedical Communications
U.S. National Library of Medicine

Hong Kong
2015 November 10

nǚ shì men, xiān shēng men
女士们，　　先生们，
dà jiā hǎo ！
大家好！
wǒ jiào Clem McDonald
我叫
jīn tiān / wǒ hěn gāo xìng
zài zhè
今天我很高兴在这。

wǒ hěn / xǐ huān xiāng gǎng 。
我很喜欢香港。
xiāng gǎng rén dōu hěn hǎo 。
香港人都很好。
。

。

duì bú qǐ 。

对不起。

wǒ de zhōng wén bú tài hǎo 。xiè xiè ！

我的中文不太好。谢谢！

Disclaimer / COI

- The ideas and positions expressed here are my own and do not necessarily represent those of NLM, NIH, or HHS.
- I have no potential conflicts of interest to report.

Spoke at Hong Kong International Medical Informatics Conference in 2003

Then I worked at the Regenstrief Institute and Indiana University

Indiana University Medical Center

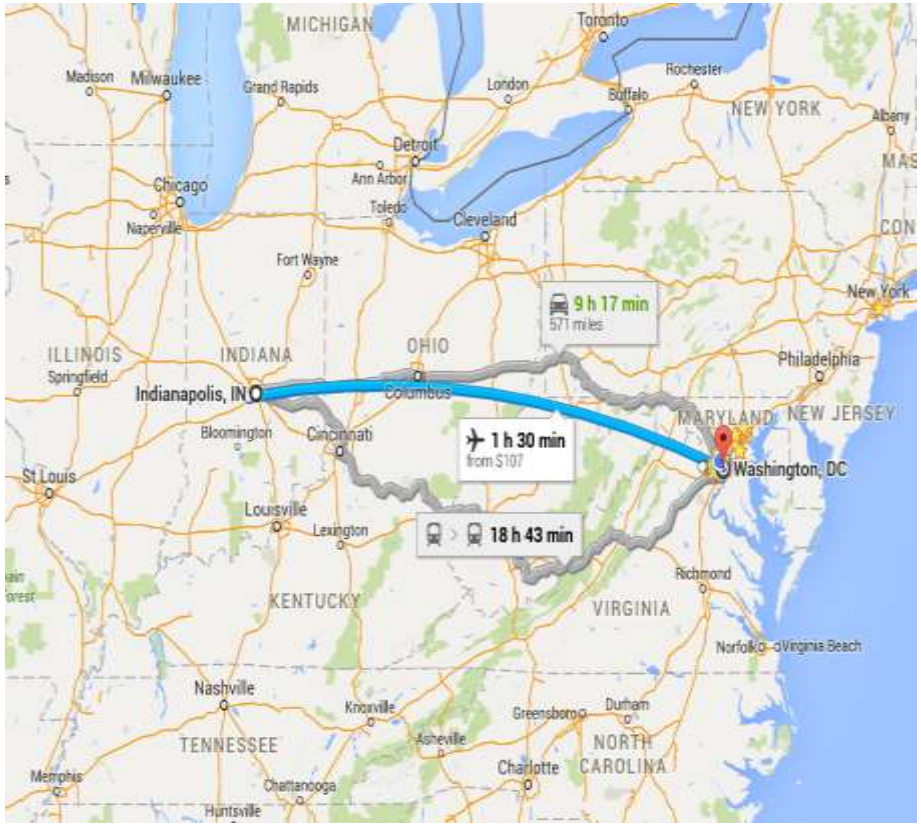
Regenstrief Institute -- Created by Sam Regenstrief, "Dishwasher king" in the US

Brand new Regenstrief Institute Building --
Grand opening November 2015

Now am director of the Lister Hill Center at the National Library of Medicine

Though I moved to the National Institutes of Health

- I continue to work on LOINC, other EMR standards and EMR tools for NLM.
- I "commute" from Washington DC to Indianapolis.



Background and definitions

- Clinical repositories versus physician work stations
  - Clinical repositories carry the content of the Medical Record and retain the structure delivered from source systems such as the lab.
    - The computer feeds data to the physicians
    - Data came from existing sources -- dictation systems, lab systems, ICU systems, EKG machines, etc.
  - Physician work stations
    - The roles reverse:
      - Physicians feed data to the computer
      - And can't do much without using them
    - Order entry, prescription writing, Note writing, problem list and allergy list maintenance
    - Other demands for attention (reminders) and data entry – (esp with meaningful use)

Background and definitions (2)

- In the 1980's and 1990's the clinical repository *was* the EMR. Physician work stations did not exist yet .
- Today the definition of the EMR has expanded to include both the clinical repository function and the work station function.
- Physicians generally love clinical repositories if they are well organized and fat with patient data.
- They don't generally love order entry, and things they have to do through the work station functions -- i

Rules the developers should live by

Rules that EMR developers should live by[1]

From Hong Kong (NT Cheung et al[1] – but paraphrased)

- Don't develop functions that help one group but steal time and flexibility from clinicians (paraphrased).
- Take one step at a time. (Develop organically and avoid the "big bang.")
  - *Dangerous Enthusiasms* documents the failures of "big bang" projects (80% of them).[2]
- Prioritize ruthlessly.
  - The leaders of the Internet Engineering Task force argue to put nothing in a standard for future possible use. Only include the immediate needs. When the future comes, something else is needed.
- Use the art of Medical informatics to balance between pressure for coded /structured data with clinical efficiency, flexibility and expressivity (paraphrased).

1. Cheung NT, Fung V, et al. Principles-based medical informatics for success: How Hong Kong built one of the world's largest integrated longitudinal electronic patient records. Presented at Medinfo 2007, Brisbane, Australia;307-10.
2. Gauld R, Goldfinch S. *Dangerous Enthusiasms, Computer failure and Information System development*. Dunedin, New Zealand: Otago University Press., 2006

Rules that EMR developers should live by (more)

From Regenstrief

- Being fast is a requirement not an "option".
  - One hundred milliseconds field-to-field response including time to generate menus is ideal.
  - Put response times on the screen as Google does.
- Give before you take.
  - E.g. provide a rich, well organized clinical repository before asking for physician input
- Provide escape option in the dialogue where the provider might get stuck because he/she did not know how to enter something.

Policy and trends regarding EMRs in the US

Meaningful use (MU) and Office of the National Coordinator

- MU is a regulation delivered in parts from 2 federal agencies. Most recently:
  - ONC: 2015 Edition Health IT Certification Criteria.
    - https://www.federalregister.gov/articles/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base
  - CMS: EHR Incentive Program-Stage 3
    - https://www.federalregister.gov/articles/2015/10/16/2015-25595/medicare-and-medicaid-programs-electronic-health-record-incentive-program-stage-3-and-modifications

- It facilitated the use of EMRs by launching standards projects requiring certain features and code systems in every EMR.
- Encourage EMR use through carrots and sticks- but has sometime lost focus on the most important thing- filling the clinical repository with data

Hospitals are merging together like crazy in the US

- When I left Indianapolis in 2006 the university hospital system (IU Health) had 4 hospitals – all in Indianapolis. Today IU Health has merged with 18 hospitals spread across the state of Indiana.
- Most academic health centers have done the same.[1,2]
- This bulking up of care systems has led to larger and more complete EMRs
- Also physicians are leaving their practices and moving into the hospital as employees
- This move explains much of the increase in EMR use

1. Dafny L. Hospital Industry Consolidation — Still More to Come? N Engl J Med 2014; 370:198-199. DOI: 10.1056/NEJMp1313948 PMID: 24328443
2. Baltic S. Monopolizing medicine: Why hospital consolidation may increase healthcare costs. *Medical Economics* 24 Feb 2014; http://medicaleconomics.modernmedicine.com/medical-economics/content/tags/hospital-employment/monopolizing-medicine-why-hospital-consolidation-?page=0,1

Adoption of today's EMR (Repository + work station)

- A hit -- if measured in terms of providers using EMRs.
- Big hospital systems have been working toward Clinical Repositories since the early to mid 1990's – they began to add work station functions in the early 2000's and accelerated the use of them in last 5-7 years under Meaningful use regulations.
- Office practices lagged behind – but began to implement EMRs aggressively in the last 5+ years -- under pressure from regulations.

Some numbers

- As of 2013 -- Nearly 78% of providers use EMRs, in the US but few, 14%, are getting data from outside of office. Solo practitioners and specialists are lagging.[1]

- As of 2014 -- More than half of hospitals have at least basic EMR -- but success is greatest at largest hospitals.[2]

1. Furukawa MF, King J, Patel V, Hsiao CJ, Adler-Milstein J, Jha AK. Despite substantial progress In EHR adoption, health information exchange and patient engagement remain low in office settings. Health Aff (Millwood). 2014 Sep;33(9):1672-9. doi: 10.1377/hlthaff.2014.0445. Epub 2014 Aug 7. PMID: 25104827
2. Adler-Milstein J, DesRoches CM, Furukawa MF, Worzala C, Charles D, Kralovec P, Stalley S, Jha AK. More than half of US hospitals have at least a basic EHR, but stage 2 criteria remain challenging for most. Health Aff (Millwood). 2014 Sep;33(9):1664-71. doi: 10.1377/hlthaff.2014.0453. Epub 2014 Aug 7. PMID: 25104826

Physicians' attitude about EMRs in the US –

What they like

- They like the clinical repository function when they are well organized and rich with data. But all repositories statisfy those requirments
- Physicians mostly like e-prescribing because:
  - It provides a medication profile and makes it easy to renew prescriptions.
  - Their patients' prescriptions are ready for them at the pharmacy soon after they leave the office.

Their feelings about the rest of the work station functions

THEY HATE THEM

EHR State of Mind" Rap video lyrics by Dr. Zubin Damania, aka ZDoggMD.
http://zdoggmd.com/ehr-state-of-mind

Switched me to that EMR, meaningless abuse,
Now catch me at the nurses station mashin' that F2 key
Notes used to be our story, narrative, but yo
Replaced with copy paste, now a bloated ransom note
Me, I'm at that bedside, focused like a laser beam
On the patient, naw come on, I'm treatin' the computer screen

I was confronted with the problem at a family party circa 2009

- My brother bragged (at my niece's graduation party) that I had invented the Electronic Medical Record.
- Two women at the party -- both MDs -- cornered me and accused me of ruining their lives.
- They couldn't get home in time to see their little kids since the EMR was installed. Tears welled up.
- I was worse for inventing EMRs than Oppenheimer for inventing the H bomb.

We conducted a large survey in 2012 of American College of Physician (ACP) members.[1]

- Respondents used more than 50 different systems and 80% had 1-5 years of experience with EMR. Most (70%) used all listed EMR functions.
- 65% of attending staff reported free time loss a mean of 48 minutes per clinic day.
- For those who lost any time, the mean time loss was 78 minutes.

1. McDonald CJ, Callaghan FM, Weissman A, Goodwin RM, Mundkur M, Kuhn T. Use of Internist's Free Time by Ambulatory Care Electronic Medical Record Systems. JAMA Intern Med. 2014 Nov;174(11):1860-3. doi: 10.1001/jamainternmed.2014.4506. PMID: 25200944

Study of physician time usage in Emergency Department[1]

- Use of EMR took 4000 clicks per 8 hour shift
- Doubled time to do orders and paper work compared to paper system
- 44% of their time with computer, only 28% with patients.

1. Hill Jr. RG, Sears LM, Melanson SW. 4000 Clicks: a productivity analysis of electronic medical records in a community hospital ED. The American Journal of Emergency Medicine. Nov 2013;31(11):1591–1594.

Lots of other studies say the same thing -- here are a few

- 2010 family medicine study.[1]
- 45 minutes extra per clinic day.[2]
- Poor EHR usability, time-consuming data entry,..., inefficient …work content, inability to exchange health information…degradation of clinical documentation.[3]
- Satisfaction in EMRs is dropping.[4]
- ECRI says EMRs are top prescribing safety concern.[5-6]

1. Bloom MV, Huntington MK. Faculty, Resident, and Clinic Staff's Evaluation of the Effects of EHR Implementation. Fam Med 2010;42(8):562-6. https://www.stfm.org/fmhub/fm2010/September/Michael562.pdf
2. Pizziferri L, Kittler AF, Volk LA, et al. Primary care physician time utilization before and after implementation of an electronic health record: a time-motion study. Journal of biomedical informatics 2005;38:176-88.
3. Friedberg MW, Chen PG, Van Busum KR, et al. Factors Affecting Physician Professional Satisfaction and Their Implications for Patient Care, Health Systems, and Health Policy: RAND Corporation; 2013.
4. Brookstone A. HIMSS13 — EHR Satisfaction Diminishing. American EHR blog2013. http://www.americanehr.com/blog/2013/03/himss13-ehr-satisfaction-diminishing/
5. Manchikanti L, Hirsch JA. A Case for Restraint of Explosive Growth of Health Information Technology: First, Do No Harm. Pain Physician 2015; 18:E293-E298 • ISSN 2150-1149
6. Wortman D. Top 10 health technology hazards for 2015. A report from Health Devices, ECRI Institute, November 2014. www.ecri.org/Resources/Whitepapers_ and_reports/Top_Ten_Technology_Hazards_2015.pdf 10.

It did not have to be this way

At Regenstrief/Indiana care providers were happy

- Physicians and other clinical people loved the repository function –It was well organizd and as luxurious in content.
  - 30-40 years of patient history, almost every kind of test report, prescribed drugs, operative notes, discharge summary, vital signs, encounters and more.
  - Could click from radiology content to the images, EKG variables/reports to the tracings, etc.
  - Included results from other institutions in the home institution's flowsheet.
  - Most content could be reviewed by report type, in time order, or in a time ordered flowsheet, as follows.

Regenstrief Flow sheet display for EKG.

(click to get tracing)

Select a patient | Record | Other

Chronologic Results
Flowsheet
Flowsheet (Advanced)
Clinical Synopsis
REPORTS
ALL REPORTS
Discharge Summaries
Miscellanous
Operative
Pathology
Radiology
Face Sheet
Orders
ENCOUNTERS
Brief
Detailed
Master
PRESCRIPTIONS
Inpatient
Outpatient
Advance Directive
Surgery Log

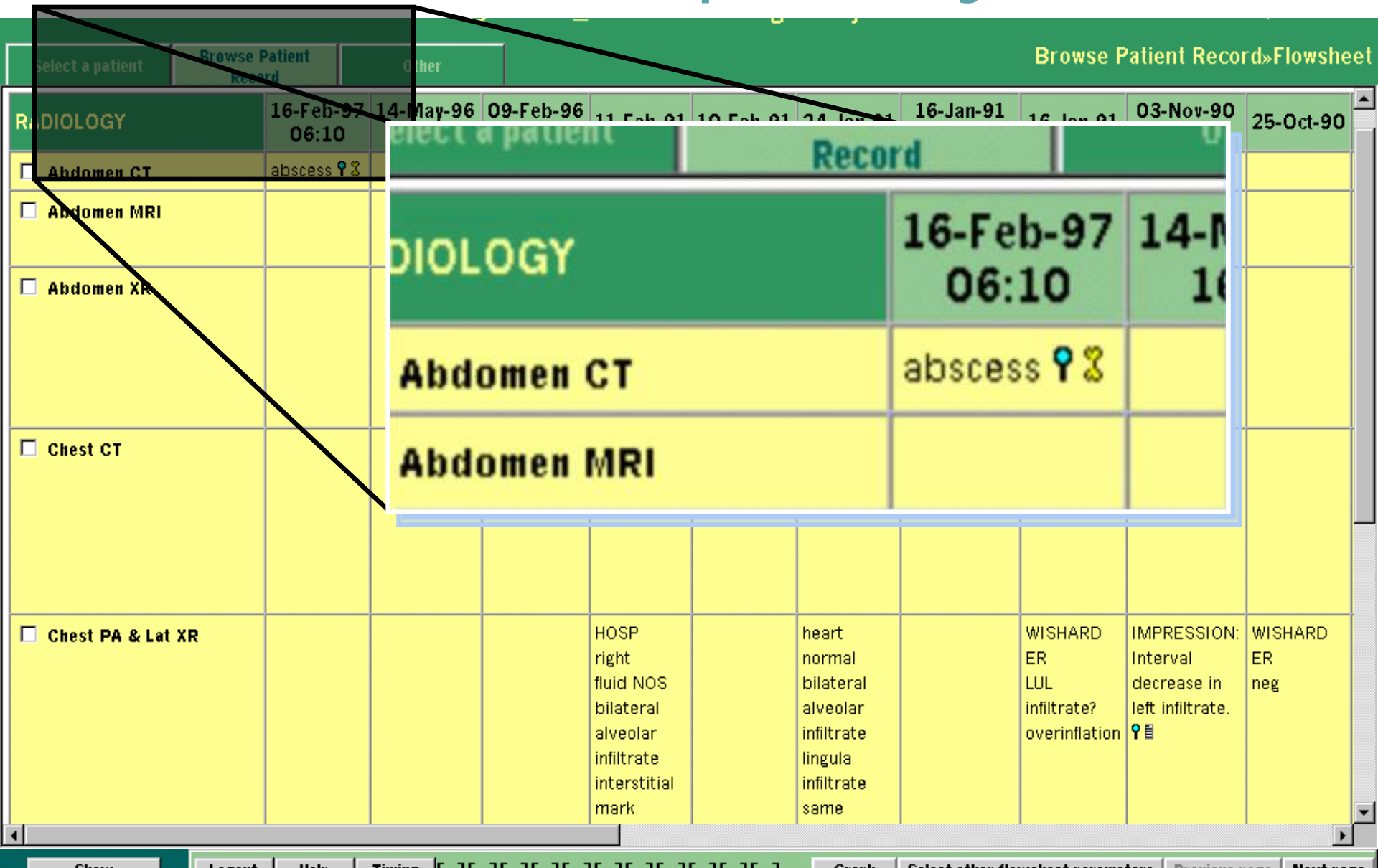
Flowsheet

EKG MEASURES	30-Mar-98 15:18	29-Mar-98 06:34	28-Mar-98 11:06	27-Mar-98 10:40	26-Mar-98 17:47	25-Mar-98 06:49	23-Mar-98 15:18	08-Mar-98 06:34
EKG	normal sinus rhythm, normal ECG	normal sinus rhythm, improper standard, normal ECG	sinus tachycardia, possible left atrial enlargement, QUESTION PRECORDIAL LEADS, poor quality tracing, borderline ECG	normal sinus rhythm, sinus arrhythmia, moderate left axis deviation, NONSPECIFIC ST-T, abnormal ECG	normal sinus rhythm, low QRS voltage in chest leads, CONSISTENT WITH PULMONARY DISEASE, abnormal ECG	normal sinus rhythm, low QRS voltage in chest leads, atypical ECG	normal sinus rhythm, normal ECG	normal sinus rhythm, improper standard, normal ECG
P-Axis	48	52	37	5	43	38	48	52
QRS-Axis	29**H	44**H	69**H	-24**H	30**H	26**H	29**H	44**H
T-Wave Axis	52	11	2	104	16	6	52	11
Pulse EKG	75	95	126	71	93	96	75	95
PR Interval	180	184	160	128	164	172	180	184
RR Interval	791	629	474	845	640	623	791	629
QRS Interval	88	88	92	112	84	88	88	88
QT Interval	364	348	336	448	340	344	364	348
QT Corrected	393	401	411	470	391	397	393	401

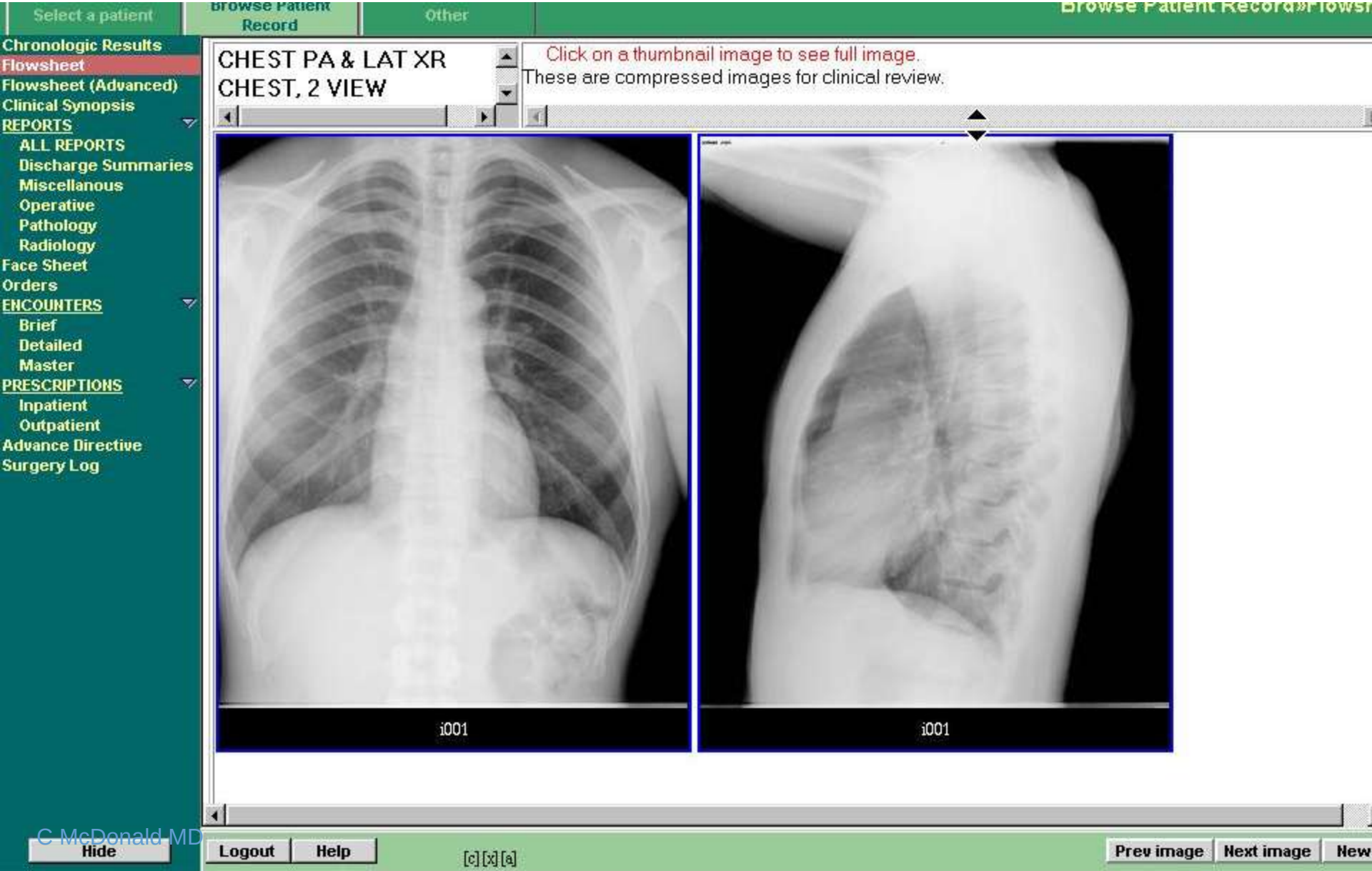
Hide | Logout | Help | [c] [x] [a] | Graph | Select other flowsheet parameters | Previous page | Next page

form: MRF_TBL_DISPLAY | Internet

Regenstrief Flowsheet for radiology impressions- Click to see full reports or images

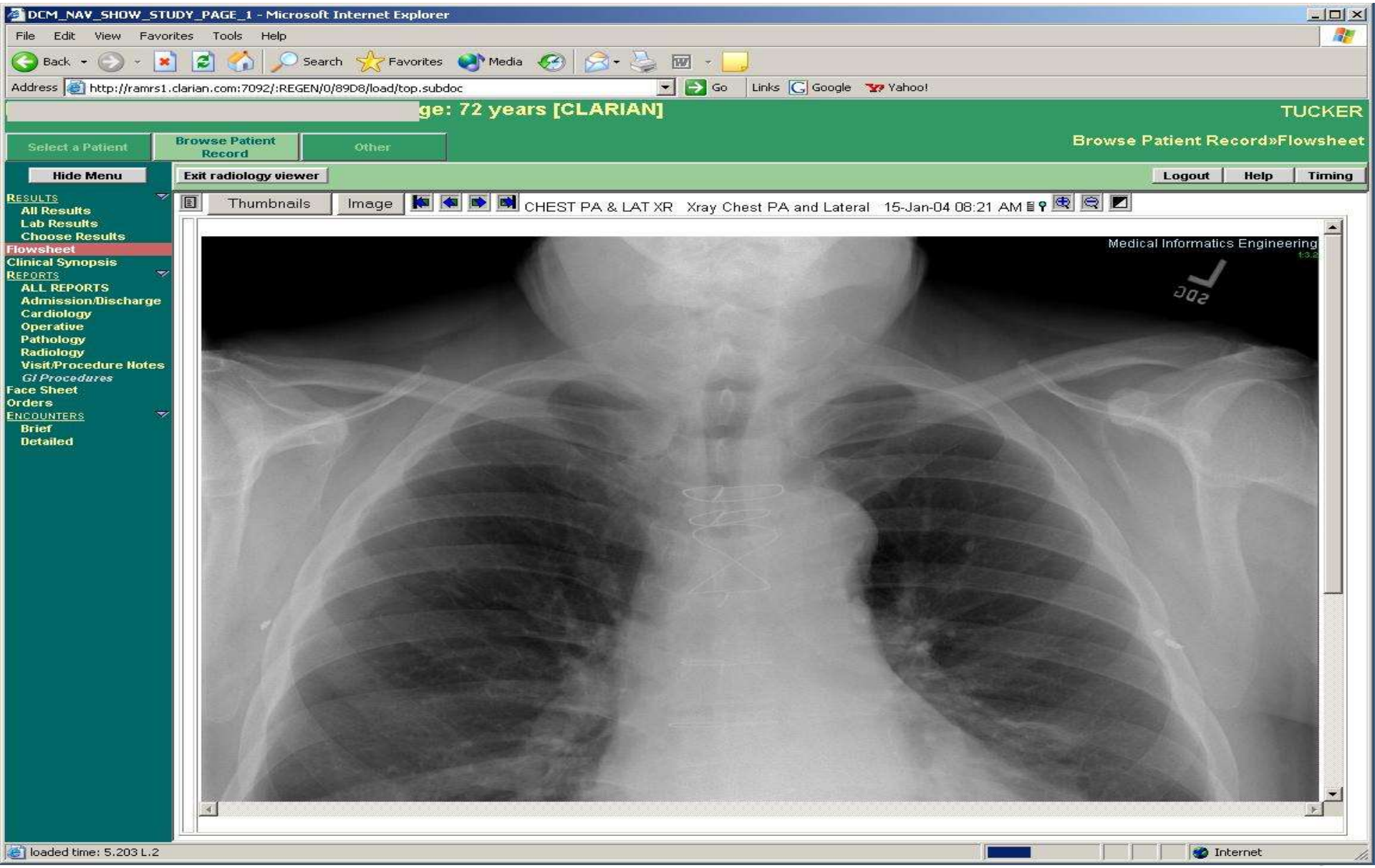


Click on icon for one report and see 2000x3000 x12 JPEG images



C McDonald MD

BIGGER


DCM_NAV_SHOW_STUDY_PAGE_1 - Microsoft Internet Explorer
File Edit View Favorites Tools Help
Back Search Favorites Media
Address http://ramrs1.clarian.com:7092/:REGEN/0/89D8/load/top.subdoc
Go Links Google Yahoo!
ge: 72 years [CLARIAN]
TUCKER
Select a Patient
Browse Patient Record
Other
Browse Patient Record»Flowsheet
Hide Menu
Exit radiology viewer
Logout Help Timing
RESULTS
All Results
Lab Results
Choose Results
Flowsheet
Clinical Synopsis
REPORTS
ALL REPORTS
Admission/Discharge
Cardiology
Operative
Pathology
Radiology
Visit/Procedure Notes
GI Procedures
Face Sheet
Orders
ENCOUNTERS
Brief
Detailed
Thumbnails
Image
CHEST PA & LAT XR Xray Chest PA and Lateral 15-Jan-04 08:21 AM
Medical Informatics Engineering
loaded time: 5.203 L.2
Internet

Regenstrief's Physician work station

- Physicians were also mostly happy with the work station, which we called the Gopher.
  - We followed the rules.
- Introduced order entry very slowly -- early experiments in medicine clinic circa 1986.[1]
- A PC per physician (in Novell network) VERY FAST – almost no central load.
- Order writing provided lots of guidance, defaults and panels so could write fairly fast. And computer was blazing (0.1 second responses). But still it took a bit longer than before. (Per randomized trial.[2])

1. McDonald CJ, Tierney WM. The Medical Gopher-A Microcomputer System to Help Find, Organize and Decide About Patient Data. West J Med 1986;145:823–9.
2. Tierney WM, Miller ME, Overhage JM, McDonald CJ. Physician Inpatient Order-writing on Microcomputer Workstations: Effects on Resource Utilization. JAMA. 1993 Jan 20;269(3):379-83.PMID: 8418345.

Regenstrief physician work station features [1-3] (2)

- Free text escape almost everywhere.
- Almost no more fields to be entered compared to the manual order form.
- Rules for drug interactions, allergies and reminders constrained to reasonable specificity (30-50%) – no interruption.
- Only orders, allergies and problems were required to be entered.
- Note writing into computer was voluntary – Could use or not -- (about ½ did).
- 2 years ago I ran into 5 medical residents during a Kenya project -- who treated me as a rock star and wanted me in a picture with them when they found I developed the Gopher.

1. McDonald CJ, Tierney WM. The Medical Gopher-A Microcomputer System to Help Find, Organize and Decide About Patient Data. West J Med 1986;145:823–9.
2. McDonald CJ. The medical gopher-a microcomputer based physician work station. West J Med 1986;453–9.
3. Bakker A, Whlers C, editors. H.I.S. and the Physician: Direct Inpatient Order Entry by Physicians through Medical Gopher Workstations - Problems and Promises. In: H.I.S. Scope, Design, and Architecture. New York: North Holland; 1992. page 1–10.

What went wrong and why?

A perfect storm of mis-directed regulations, administrative forces, and flawed systems

Administrative: Malpractice and billing documentation requirements produced:

- Bloated notes with no clear message about what was going on with the patient.
- Caused by cut and paste of full lab reports, past notes.
- And by big templates (e.g. for review of systems) that yielded bulky mindless lists.
- 33% of providers in our ACP survey said it was easier to access and digest the paper notes than the EMR notes!!

1. Weir CR, Hammond KW, Embi PJ, Efthimiadis EN, Thielke SM, Hedeen AN. **An exploration of the impact of computerized patient documentation on clinical collaboration**. *Int J Med Inform*. 2011 Aug;80(8):e62-71. PMID: 21300565
2. Thielke S, Hammond K, Helbig S. **Copying and pasting of examinations within the electronic medical record.** Int'l J Med Inf. 2007;76S:S122-8. PMID: 16899403
3. Wrenn JO, Stein DM, Bakken S, Stetson PD. **Quantifying clinical narrative redundnancy in an electronic health record**. J Am Med Inform Assoc 2010;17:49e53. PMID: 20064801

Meaningful Use regulations: added work and reduced flexibility

- New required sections for MD notes e.g Separate care plan that previously was implied by orders and/or embedded in routine note.
- Forbad use of handwriting.
- Silly quality rules with excessive data requirements -- that require a manual chart review and extra input to satisfy. (e.g. code presence of herpes Simplex *on breast* to get exemption from rule that demands mothers breast feed exclusively on day of birth).
- Indiscriminate alert overload.

Meaningful Use regulations did very little for interoperability

- 1/3 of ACP respondents said test results were easier to find in paper system than EMR !!! (astounding)
- No attention or requirements for the delivery of radiology reports, ECGs and other diagnostic studies to the ordering physician's EMR.
- So test results that got into the EMR were often PDFs with no annotation beyond the date scanned.
  - EMRs should at least OCR every PDF and use one of the spectacular Lucene-based Open source indexing tools to access it.
- For practical purposes, only the big institutions have been able to build useful repositories.

EMR inbox and work shifting

- EMRs all have inboxes for physicians.
- All kinds of content and emails in Physicians' inbox -- most of which was previously managed by nursing staff.
- EMR made it too easy for anyone in hospital to copy everything to the Primary Care Provider (PCP) and shift legal risk to the PCP.
  - The result: a torrent of useless notes to primary care.
- Lab results trickled into the inbox as separate messages
  - Often many per test – e.g. Urine culture no growth at 24 hours, No growth at 48 hours, etc.
  - No attempt to aggregate them into one or a few boluses or link to an upcoming appointment.
- To improve the office morale, a great paper advised the use of Scribes, and use of voice rather than email for all in-clinic communication.[1]
  - But Meaningful use restricts.

1. Sinsky CA, Willard-Grace R, Schutzbank AM, Sinsky TA, Margolius D, Bodenheimer T. In search of joy in practice: a report of 23 high-functioning primary care practices. *Ann Fam Med*. 2013;11(3):272-278. PMID: 23690328

Developers did not follow the Hong Kong rules

- Expansion of required data over the manual system and too much coding
- Too few narrative text options.
- Not always fast, not always up.
- Repositories with no externally produced data.
- Poor data organization.
  - In some systems, very difficult to find the most recent previous result with which to compare a new test value.

Nonspecific Alerts

- Policy makers (MU) viewed drug interaction and allergy alerts as life saving essentials, and hospitals fearing malpractice are afraid to turn off the less important ones.

- The Majority (90%) of Drug interactions are of little use because
  - Disagreements about what is important differs among drug knowledge vendors.

- Interaction alerts should be limited -- perhaps to the ONC developed list.[1]

1. Hsieh TC, Kuperman GJ, Jaggi T, Hojnowski-Diaz P, Fiskio J, Williams DH, Bates DW, Gandhi TK. Characteristics and consequences of drug **allergy alert** overrides in a computerized physician order entry system. J Am Med Inform Assoc. 2004 Nov-Dec;11(6):482-91. Epub 2004 Aug 6. PMID: 15298998

Nonspecific Alerts (2)

- Allergy alerts are also very non specific because of the inaccuracy of patient reports allergy reports(on the order of 90% are not real allergies[1]) -- and some alerts are based on chemical class, or outdated info.
  - For example, Patients with sulfonamide allergies get allergy alerts when furosemide (structurally a sulfa) is ordered, though no case of a real allergy to furosemide has ever been reported in patients allergic to antibiotic sulfas.
  - (Egg and flu shot allergies also probably nonexistent with the new highly purified shots.)

1. Holm A, Mosbech H. **Challenge Test Results in Patients With Suspected Penicillin Allergy, but No Specific IgE.** Allergy Asthma Immunol Res. 2011 Apr; 3(2): 118–122. Published online 2011 Feb 14. doi: 10.4168/aair.2011.3.2.118 PMCID: PMC3062790

The IOM error report

- Had a shrill message that painted physicians as error prone, and the excesses in the current EMRs were justified by that characterization.
- But the assertion of 98,000 deaths in the IOM report is false.
- And the oft-quoted statement that 8,000 deaths per year are caused by prescription errors is also false.

Why the 98,000 deaths figure is wrong

- Errors do occur and computers can help them, But that 98,000 figure was ridiculous and wrong.
- The paper on which the IOM report was based sampled a 1984 population from NY State public health records (30 years ago !!).
- That population was selected to be the sickest patients -- for example it included ALL patients who died or had to return to the OR as emergencies
- 1/7th of this population had adverse events

Why false (2)

- they did not report the death rate in the 6/7^{ths} of the population that did not experience an adverse event. To get to the 98000 deaths, they assumed it was zero.
- In 2000 we accessed the same NY public health data from 1984
- Because they defined their population to include all deaths, we coulc calculate the death rate of their sample - including the 6/7^{ths} without adverse events and the 1/7th with adverse events
- That death rate in both populations was bout 13.8%,.
- There was NO excess death rate compared to their selected population !!!

1. McDonald CJ, Weiner M, Hui SL. Deaths due to medical errors are exaggerated in Institute of Medicine report. *JAMA*. 2000;284(1):93-95

IOM Claim of 8000 deaths due to Medication prescribing errors – was also false

- This claim came from a Lancet paper that misinterpreted the ICD9 code for accidental poisonings to mean prescription errors.[1]
- This mistake was clearly exposed in a long (6-page) Lancet commentary within the same year,[2] but the IOM report ignored that.
- These deaths are now known to be misuse or abuse of prescribed narcotics (Vicodin) and other psychoactive drugs -– and that cause is now recognized in the nightly news because it has grown to nearly 18,000 deaths per year.

1. Phillips DP, Christenfeld N, Glynn LM. Increase in US medication-error deaths between 1983 and 1993. *Lancet*. 1998;351:643-644. PMID: 9500322
2. Rooney C. Increase in US medication-error deaths. *Lancet*. 1998;351:1656-1657. PMID: 9620737

To be fair, can't blame all of the problems on EMRs

In US we experienced a mindless growth of documentation requirements before the EMR

- Long term study of internist trainees showed a doubling of documentation time in last 20 years to almost half of resident and fellow time.
- Documentation has become *The Blob* (1958 movie). It soaks up "all" provider time like a blob.[1-4]
- No evidence base to justify.

1. American College of Physicians. "A Two-pronged Strategy to Improve American Health Care: Make the Health System More Effective AND Remove Barriers to the Patient-Physician Relationship," A Report from the American College of Physicians on the State of the Nation's Health Care. 20 February 2013. Accessed at: http://www.acponline.org/advocacy/advocacy_in_action/assets/snhcreport13.pdf on 5 June 2015.
2. Advancing Primary Care. Twentieth Report of Council on Graduate Medical Education. Accessed at http://www.hrsa.gov/advisorycommittees/bhpradvisory/cogme/Reports/twentiethreport.pdf on 5 June 2015.
3. Casalino LP, Nicholson S, Gans DN, et al. What Does It Cost Physician Practices To Interact With Health Insurance Plans? Health Aff (Millwood). 2009 Jul-Aug;28(4):w533-43. doi: 10.1377/hlthaff.28.4.w533. Epub 2009 May 14. PMID: 19443477
4. Brookstone A. Computerized Provider Documentation and its Relationship to User Satisfaction, American EHR Blog. Accessed at http://www.americanehr.com/blog/2013/02/computerized-provider-documentation/ on 5 June 2015.

Mindless growth of documentation requirements (Continued)

Cause is multi factorial and thus hard to combat.

- Point-based billing requirements
  - (Remember organized medicine in US negotiated that deal.)
- Malpractice concerns
- One escape might be to record (sound or video) the whole visit (à la customer calls) as protection against malpractice and billing fraud lawsuits (automatic voice to text is getting better), and just write the note we need for clinical care.[1,2]

1. Gottschalk, A., & Flocke, S. A. Time spent in face-to-face patient care and work outside the examination room. *Annals of Family Medicine.* 2005;3(6):488–493.

2. Hollingsworth, J. C., Chisholm, C. D., Giles, B. K., Cordell, W. H., & Nelson, D. R. How do physicians and nurses spend their time in the emergency department? *Annals of Emergency Medicine.* 1998;31:87–91.

The strategy for expanding EMRs in the US had problems

Strategy

- The aim was to put EMRs in every office practice
  - At that time about 400,000 of them
- 40 B USD was invested in incentives.
- Little attention to the interconnection between data sources and clinicians (Labs->offices, Hospitals->offices etc
- Bad plan
  - Little offices lacked the expertise for installation, back up, security, etc, etc.
  - Having an EMR in office without inter operability provided almost no data to the office beyond what they already had in heir dictated note
  - The EMRs ended up demanding more input from the Physician them selves, gave them little

A betterapproach – A central system for a whole community or region

Combines health data (or federated networks) of EMRs from many organizations within a geographic region.

Think of it as:

- One big clinical repository record for the providers in one region.
- Interfaces flow in from many sources:
  - hospitals (radiology reports, dictation, laboratory results, encounters, etc.).
  - laboratories.
  - stand alone radiology testing units,
  - insurance payers,
  - and more
- One "complete" patient record instead of many fragmented ones.
- One place to do back up, security, provide redundancy, and keep system tuned.

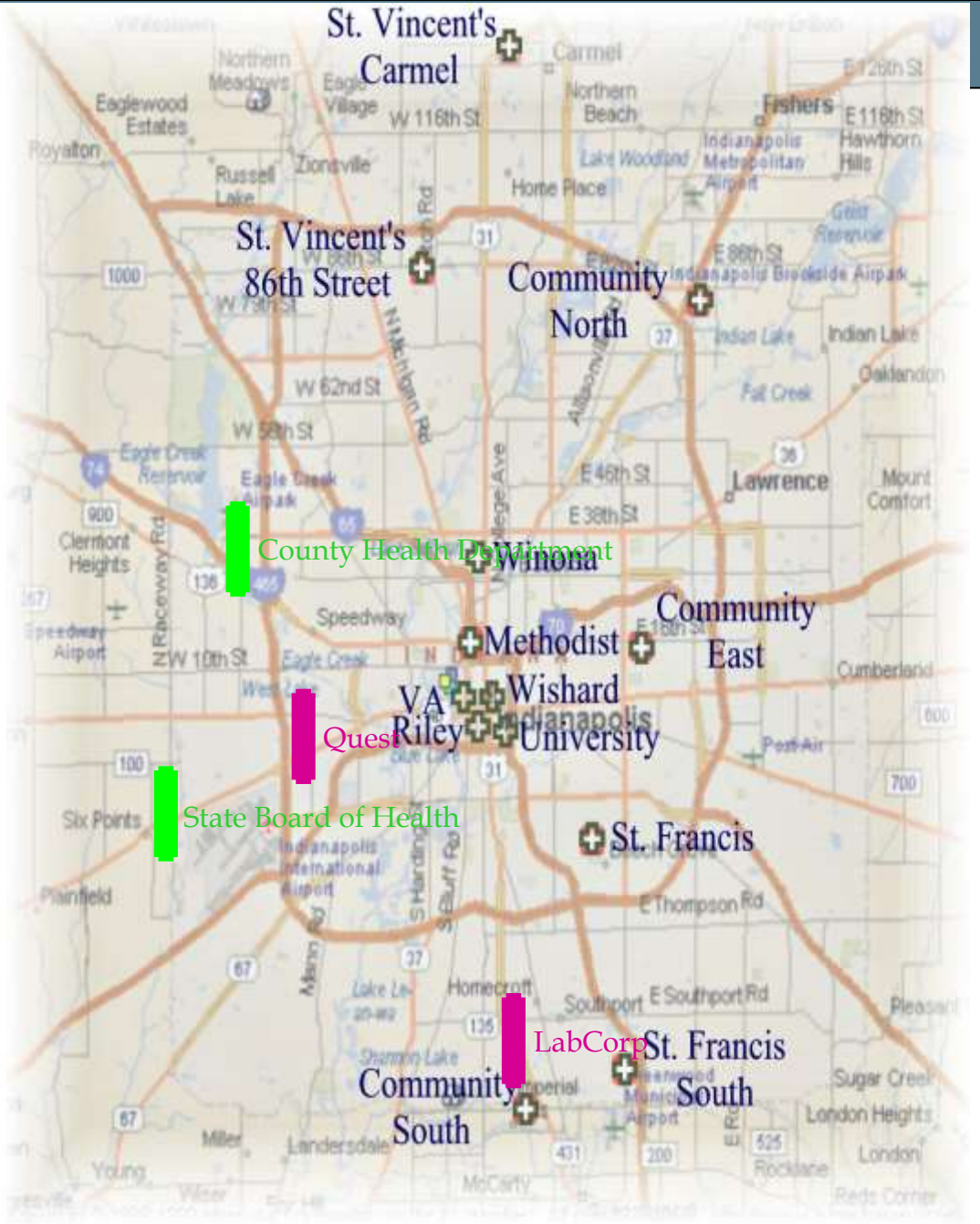
The Hong Kong eHealth Record System

- One repository for all of Hong Kong.
- You are doing it absolutely right.
- In the US we call them Health information exchanges (HIEs) and they are mostly performing the repository function only.
- At least two other countries (Thailand and Philippines) are hoping to move in the same direction.

We built the first US HIE in Indianapolis

- Started in 1994 with three independent hospitals in Indianapolis.
- Was a centralized system – the only kind that has worked.
- Delivery of data to the central system as it is produced permits the discovery of problems in data and interface and time to fix them before provider makes a request for data. Also permits the development of a critical mass of informatics expertise.

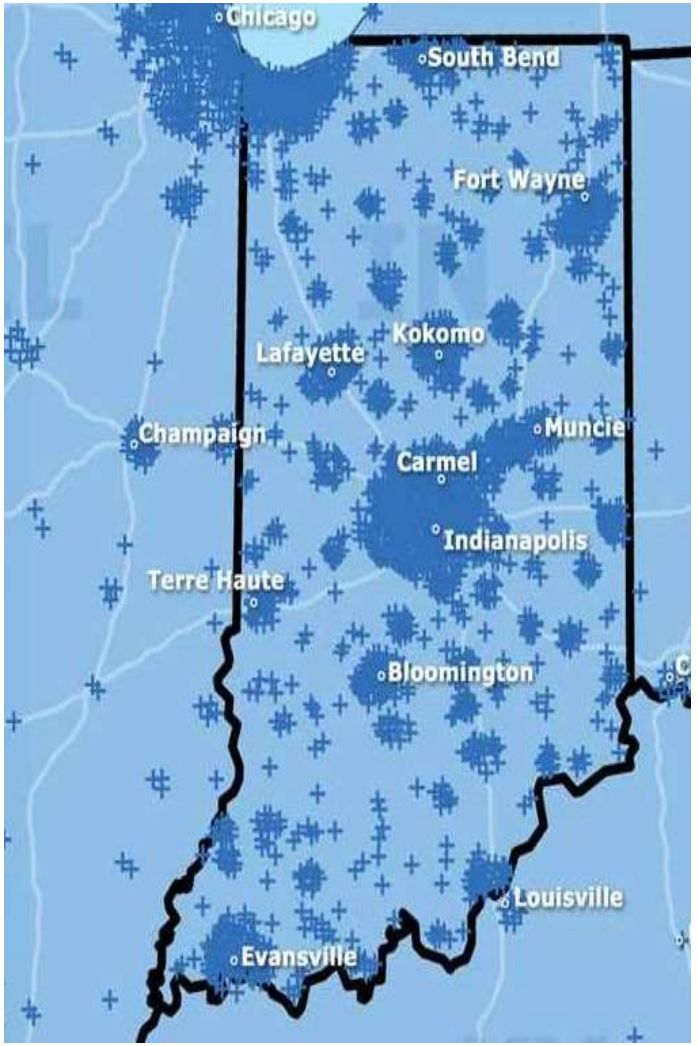
I showed this slide at my first visit to Hong Kong in 2003. At that time the Indianapolis HIE included about 11 hospitals.



By 2011 the Indiana HIE included most of the hospitals in the state (Indiana) and nearly 20,000 providers

Hospitals in the Indiana HIE

Providers in the Indiana HIE



As of 2014, the Indiana HIE[1] had:

- > 1500 separate interfaces from 88 different care systems/hospitals
- 182 million unique HL7 messages per year (about 900 million distinct observations including ,laboratory results, blood pressures, x-ray reports, EKG measures, etc.)
- 10.5 million unique patients
- 4.7 Billion discrete observations[1]
- 162 million narrative reports

1. McDonald CJ, Overhage JM, Barnes M, et al [2005]. The Indiana Network for Patient Care: A Working Local Health Information Infrastructure (LHII). *Health Affairs* (Millwood). 24(5):1214-20. PMID: 16162565

HIEs can save money and reduce testing

1. Frisse ME, et al. **The financial impact of health information exchange on emergency department care.** Am Med Inform Assoc. 2012 May-Jun;19(3):328-33. doi: 10.1136/amiajnl-2011-000394. Epub 2011 Nov 4. PMID: 22058169
2. Bailey JE, et al. **Health information exchange reduces repeated diagnostic imaging for back pain.** Ann Emerg Med. 2013 Jul;62(1):16-24. doi: 10.1016/j.annemergmed.2013.01.006. Epub 2013 Mar 7. PMID: 23465552
3. Overhage J M, et al. 2002. A randomized, controlled trial of clinical information shared from another institution. Annals of Emergency Medicine 2002;39(1):14–23. PMID: 11782726
4. Ross SE, et al. 2013. Effects of health information exchange adoption on ambulatory testing rates. Journal of the American Medical Informatics Association : JAMIA 2013;20(6):1137–1142. PMID: 23698257
5. Yaragachi N. The benefits of health information exchange platforms: Measuring the returns on a half a billion dollar investment. Center for Technology Innovation, Brookings institute, 2015. http://www.brookings.edu/research/papers/2015/05/28-health-information-exchange-roi-yaraghi
6. Bailey JE, et al. Does health information exchange reduce unnecessary neuroimaging and improve quality of headache care in the emergency department? J Gen Intern Med. 2013 Feb;28(2):176-83. doi: 10.1007/s11606-012-2092-7. Epub 2012 May 31. PMID: 22648609

There are many successful Health Information Exchanges

- Southern Maryland and District of Columbia -- CRISP Regional Health Information Exchange.
  - https://crisphealth.org/ABOUT/General-Info
- MidSouth eHealth Alliance Memphis, Tennessee
  - Frisse ME, King JK, Rice WB, et al. A regional health information exchange: architecture and implementation. *AMIA Annu Symp Proc*. 2008:212-6. PMCID: PMC2655967
  - http://www.midsoutheha.org/about.php
- The Ontario Children's network (all test results from all pediatric hospitals made available to all pediatricians) -- Gill Hill
  - http://www.echn.ca/about-news.php#3
- Massachusetts eHealth Collaborative (MAeHC) - five practices, many sites (David Bates)
  - http://www.maehc.org/about/
- New England Healthcare Electronic Data Interchange Network, a Massachusetts-based group that designed and implemented secure electronic commerce for reducing administrative costs (John Halamka)
  - http://www.nehen.org/about/home.aspx
- Utah Health Information Network, a coalition including the Utah state government that created a secure, electronic network to exchange administrative health data and electronic commerce
  - https://www.uhin.org/who-we-are
- Delaware Health Information Network
  - http://dhin.org/
- New York eHealth Collaborative (NYeC)
  - http://nyehealth.org/
- HEALTHeLINK, Western New York Department of Health and Hospitals
  - http://www.wnyhealthelink.com/WhatWeDo/StatewideNetworkSHINNY
- Statewide Health Information Network of New York (SHIN-NY)
  - http://www.nyehealth.org/shin-ny/what-is-the-shin-ny/
- CurrentCare - RI's healthcare community working together dedicated to you.
  - http://www.currentcareri.org/
- Louisiana Health Information Exchange (LaHIE)
  - http://www.lhcqf.org/for-providers/lahie
- Kentucky Health Information Exchange
  - http://khie.ky.gov/Pages/aboutkhie.aspx

But too few because:

- Without standard HL7 message contaiing universal codes (LOINC to identify the tests, very costly to build interfaces
- ONC and Meaningful Use did little to reduce this barrier.
  - After ten years of existence they did little to stimulate use of standard test codes in laboratory messages and NOTHING to encourage the delivery of other kinds of diagnostic studies in a standard interoperable form.
- ONC funded a more tightly defined HL7 V2 message with LOINC codes for labs and included requirements to use it in a proposed rule, but dropped this requirement in the final 2015 rule. (Complicated political forces.)
- So the HIEs faced the large cost barrier of mapping the proprietary test codes from each lab to a common standard, or just take PDFs.

Hope for the future of fully standardized tests messages in the US

- In fairness, MU does require EMRs to use LOINC internally and that has stimulated requests from all of the big Instrument and test kit manufacturers for LOINC codes.
- These vendors can tell the laboratories what codes apply to their test results and make it easier for everyone.
- Without regulations lots of labs offer standard messages with LOINC codes to identify each result
- So believe we will get there some day

New technologies and their use at NLM

New Medical informatics message standards

- FHIR[1]
  - Elegant, gorgeous, readable.
  - But imposes no discipline on codes and offers too many ways of doing things. Am optimistic but not confident.
- CDA[2]
  - Is being required by MU. (That's good.)
  - Too hard to read – that's bad.
  - Stronger requirements on codes (that is good).
  - Some crazy structures.(Bad)
  - No facility for delivering results to ordering providers.
  - Will be helpful if it is implemented well – We'll see.

1. https://www.hl7.org/fhir/overview.html
2. http://www.hl7.org/implement/standards/product_brief.cfm?product_id=258

Medical informatics standards (2)

- HL7 version 2.x lives.[1]
  - In fact it is the only one that really works today in the US.
  - The only way to send requests for tests and get back results.
  - Now up to v2.9.

1. http://www.hl7.org/implement/standards/product_brief.cfm?product_id=185

Super indexing systems – easy to use and to integrate into existing systems

- SOLR and Elasticsearch both built on Lucene and both Appache Open Source projects
- These are SPECTACULAR. Powerful, blazing fast, easy to use, can complement existing applications.
- Especially good for unstructured data, but will work with structured data, as well.
- Work very well with single hierarchy data structure and unstructured data (PDFs, Dictation).

New technology (2)

- NoSQL databases
  - SOLR, MongoDB, CouchDb
  - Some say, applications can be built and changed faster and easier than with Relational data bases
  - Example from NIH: application for finding, organizing and making forms out of NIH's common data elements built with MongoDb and Elastic Search
    - https://cde.nlm.nih.gov/cde/search
  - They are new; so there are still growing pains.

New technology links

- SOLR
  - http://lucene.apache.org/solr/
- Elasticsearch
  - https://www.elastic.co/products/elasticsearch
- MongoDB
  - https://www.mongodb.com/
- CouchDb
  - http://couchdb.apache.org/

New Technology (3)

- JavaScript and JSON
  - Pretty amazing evolution from a slow scripting language that ran on one web browser…
  - Now it is a very fast, and ubiquitous language
    - Runs on phones
    - Runs inside of browsers to yield snappy applications
    - Runs on servers. (Indeed NodeJS is a web server written entirely in JavaScript.)
  - We (NLM Lister Hill) are building EMR tools in JavaScript.

NLM Lister Hill tools built with this technology

- Personal Health Record
- Try out the system on our demonstration site at: https://phr-demo.nlm.nih.gov
- Mix of Ruby on Rails and JavaScript

NLM is building EMR tools with these search and web technologies

Auto complete menu tools and special vocabulary tables

- Providing standard tables for lots of content especially that needed for genetic testing
- Have seven tables but that is just a start

Demo access to clinical tables and auto complete

https://lforms-service.nlm.nih.gov/

Available Terminology Lists

What follows is a list of currently available lists and the base URLs for using them. Additional query-string parameters (at a minimum "terms"), need to be specified to get output.

Description	Try It	Base API URL	Source
Prescribable Drug Ingredients	Ingredient	https://lforms-service.nlm.nih.gov /drug_ingredients	RxTerms/RxMix
Medical conditions (over 5000, hand-edited with synonyms)	Condition	https://lforms-service.nlm.nih.gov /conditions	NLM PHR
Disease names (over 21,000) from NCBI	Disease	https://lforms-service.nlm.nih.gov /diesase_names	ftp://ftp.ncbi.nlm.nih.gov/pub/clinvar /disease_names
Gene symbols (HGNC)	Gene symbol	https://lforms-service.nlm.nih.gov /genes?df=symbol	ftp://ftp.ebi.ac.uk/pub/databases /genenames/new/tsv /hgnc_complete_set.txt
Gene region names (HGNC)	Gene region	https://lforms-service.nlm.nih.gov /genes?df=location	ftp://ftp.ebi.ac.uk/pub/databases /genenames/new/tsv /hgnc_complete_set.txt
Gene reference sequence accession numbers (HGNC)	Accession number	https://lforms-service.nlm.nih.gov /genes?df=refseq_accession	ftp://ftp.ebi.ac.uk/pub/databases /genenames/new/tsv /hgnc_complete_set.txt
ICD-10-CM	skis	https://lforms-service.nlm.nih.gov /icd10cm?sf=code,name	CDC

V00.321S - Fall from snow-skis, sequela
V00.321A - Fall from snow-skis, initial encounter
V00.321D - Fall from snow-skis, subsequent encounter

Query string parame

On the fly input forms

- Every LOINC panel definition can generate a web based input form – 2000 of them
- The form generator reads a the definition and immediately creates a user input form
- Two examples in the slide set
  - The US surgeon general's family history
    - Lets you enter your history of diseases and to the same from each of your family members
  - The set of observations for reporting a genetic mutation

1. LOINC panels and forms file: https://loinc.org/downloads/accessory-files/resolveuid/2c424518ba026f1848dcd5a47a0f4830

Part of the LOINC family history panel as presented by Relma (one of 2000 LOINC panels)

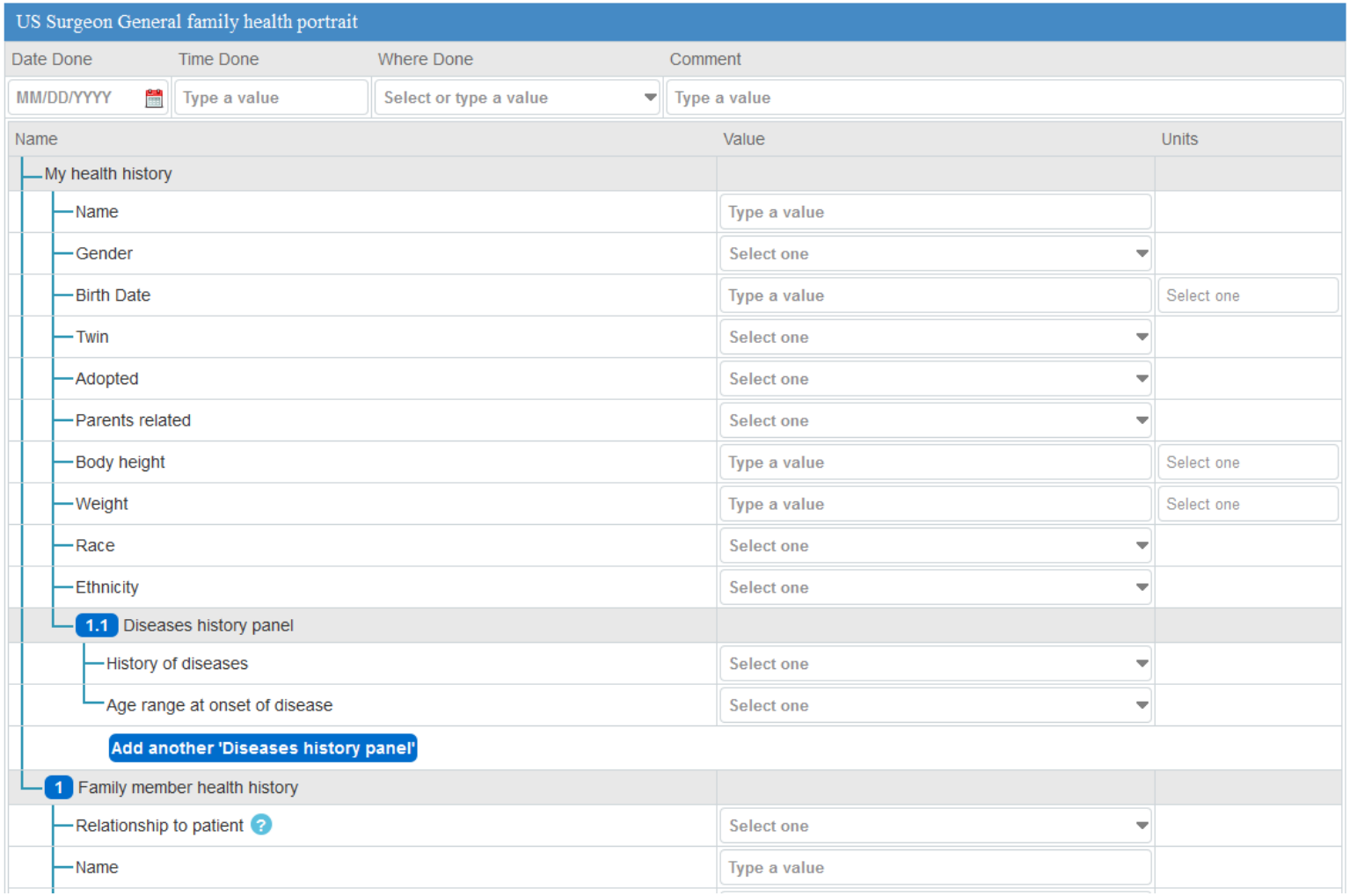
54114-4 Family member health history [USSG-FHT] family member

PANEL HIERARCHY

LOINC#	LOINC Name	R/O/C
54114-4	Family member health history [USSG-FHT] family member	
54136-7	Relationship to patient family member [USSG-FHT]	
54138-3	Name family member	
54123-5	Gender	
54139-1	Living family member	
54124-3	Birth date family member	
54141-7	Current age family member [USSG-FHT]	
54112-8	Cause of death family member [USSG-FHT]	
54113-6	Age range at death family member [USSG-FHT]	
54121-9	Twin family member	
54122-7	Adopted family member	
54119-3	Race family member [USSG-FHT]	
54120-1	Ethnicity family member [USSG-FHT]	
54118-5	Parents related family member [USSG-FHT]	
54117-7	Diseases history panel [USSG-FHT] family member	
54116-9	History of diseases family member [USSG-FHT]	
54115-1	Age range at onset of disease family member [USSG-FHT]	

Demo the family history

- https://lforms-demo.nlm.nih.gov



55207-5 Genetic analysis discrete result panel - Blood or Tissue by Molecular genetics method

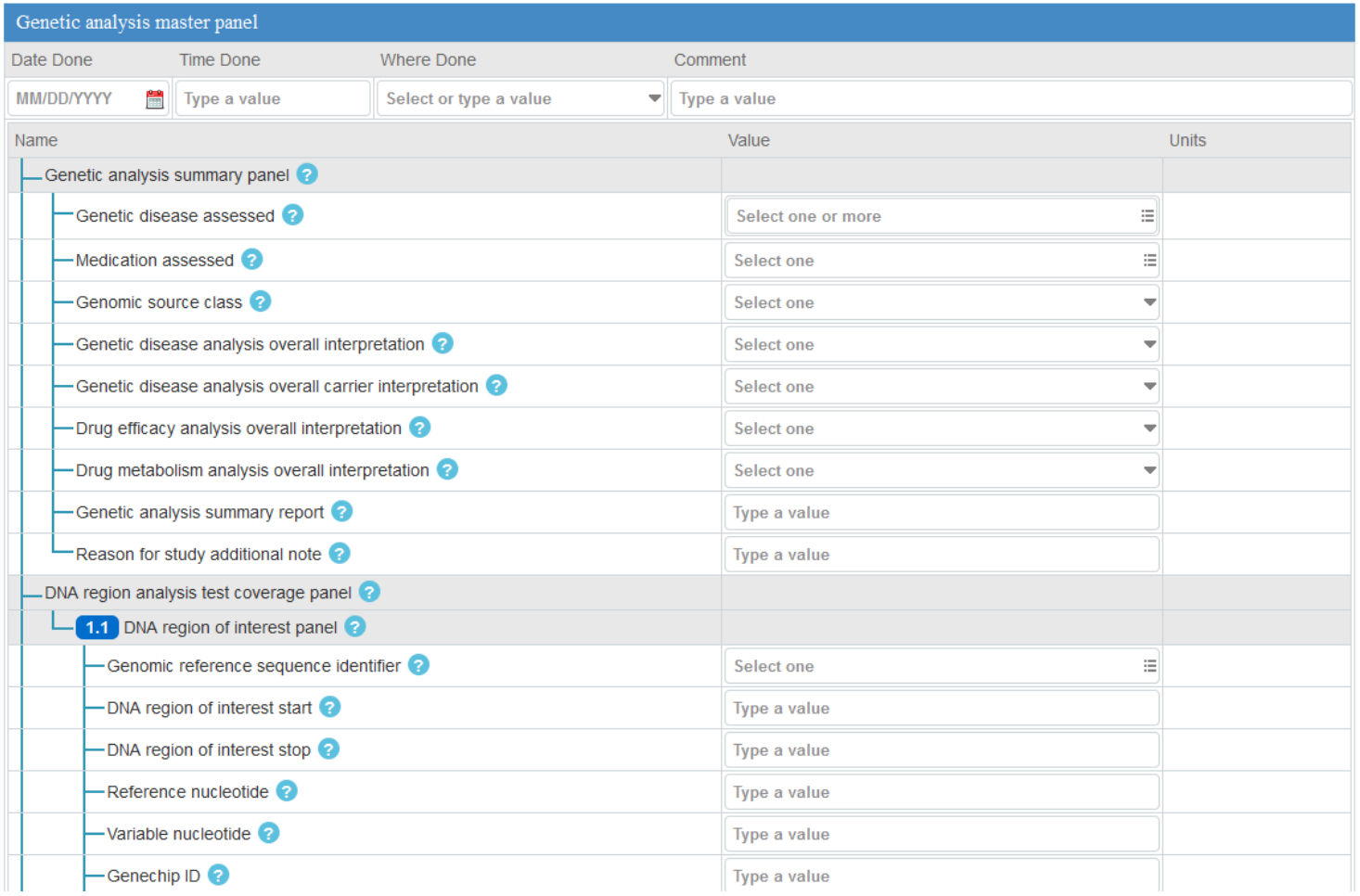
PANEL HIERARCHY (view this panel in the LForms viewer)

LOINC#	LOINC Name	R/O/C	Ca
55207-5	Genetic analysis discrete result panel - Blood or Tissue by Molecular genetics method	R	1..
55208-3	DNA analysis discrete sequence variation panel - Blood or Tissue by Molecular genetics method	R	1..
48018-6	Gene [Identifier] in Blood or Tissue by Molecular genetics method	O	0..
48013-7	Genomic reference sequence [Identifier] in Blood or Tissue by Molecular genetics method	C	0..
51958-7	Transcript reference sequence [Identifier] in Blood or Tissue by Molecular genetics method	C	0..
48008-7	Allele name [Identifier] in Blood or Tissue by Molecular genetics method	O	0..
48003-8	DNA sequence variation identifier [Identifier] in Blood or Tissue by Molecular genetics method	O	0..
48004-6	DNA sequence variation in Blood or Tissue by Molecular genetics method	C	0..
48019-4	DNA sequence variation type in Blood or Tissue by Molecular genetics method	O	0..
48005-3	Amino acid change in Blood or Tissue by Molecular genetics method	C	0..
48006-1	Amino acid change type in Blood or Tissue by Molecular genetics method	O	0..
47999-8	DNA region name [Identifier] in Blood or Tissue by Molecular genetics method	O	0..
53034-5	Allelic state in Blood or Tissue by Molecular genetics method	O	0..
48002-0	Genomic source class [Type] in Blood or Tissue by Molecular genetics method	O	0..
47998-0	DNA sequence variation display name [Text] in Blood or Tissue by Molecular genetics method Narrative	O	0..
53037-8	Genetic disease sequence variation interpretation [interpretation] in Blood or Tissue by Molecular genetics method	C	0..
53040-2	Drug metabolism sequence variation interpretation [interpretation] in Blood or Tissue by Molecular genetics method	C	0..
51961-1	Drug efficacy sequence variation interpretation [interpretation] in Blood or Tissue Qualitative by Molecular genetics method	C	0..
69548-6	Genetic variant assessment in Blood or Tissue by Molecular genetics method		

NAME

Demo the Genetic variation panel – for reporting mutations

- https://lforms-demo.nlm.nih.gov



NLM tools – links to download software

- Personal Health Record
  - https://github.com/lhncbc/phr
- Auto complete service and access to clinical vocabulary tables
  - http://lhncbc.github.io/autocomplete-lhc/
- On the fly data capture form builder
  - https://github.com/lhncbc/lforms

Lister Hill National Center for
Biomedical Communications
An Intramural Research Division of the U.S. National Library of Medicine

NATIONAL LIBRARY OF MEDICINE

Thank you!

Questions?

http://www.lhncbc.nlm.nih.gov