A Comparison of Hemorrhagic and Ischemic Strokes among Blacks and Whites:

A Population-Based Study That Will Demonstrate Issues Surrounding EHR Access and Research

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Plan

- EHR: Clinician’s perspective
- EHR: Research perspective
  - Stroke Team examples: old and new
  - GCNKSS = Greater Cincinnati/Northern Kentucky Stroke Study
- Framing of some issues for discussion today
- Summary
Point of View: Clinician

- I am very much in favor of the EHR
- Good in many ways for patient care; i.e. safety
- Definitely has not made care easier to provide
- I am definitely less efficient in clinic
EMR pros and cons:

**PROS**

- Safer for patients
- All information in one place
- Easy to sort and find information
- No missing charts
- All typed/legible notes
- Better provider communication?

**CONS**

- Slow to access (logins)
- Slow to enter data
- Looking at screen, not patient
- Training!
- Complexity (Epic)
- Risk of copying info incorrectly
- HIPAA concerns
A true security story

- A neurology MA was fired for HIPAA violation
- All providers have full access to all patients in system
- Tracking system in background—can find inappropriate access
  - If accident, log in but then log out right away
  - She logged in and then looked for 8 minutes
- Algorithm for how to know if someone’s access is appropriate or not
Clinician (cont.)

- Stroke team clinical care = acute stroke care for every hospital in city
  - Multiple Systems = Duplicative training!

- HealthBridge = a unique resource that will ultimately allow me to access the electronic medical record at every system (via their portal)

- I’ll be one of the lucky few who can do this; Epic doesn’t talk across systems
Research & Medical Records: Example 1

- GCNK Stroke Team (NIH funding)
  - TASK: Acute stroke studies, multi site – study nurse needs to access patient’s chart after enrollment in study to gather data
  
  - OLD WAY: go to medical records and ask for it
    - They can ensure IRB approval, HIPAA authorized then can provide only the chart that is needed
  
  - NEW WAY: varies by site—show consent/waiver, get record (printed copy of chart) or full access (but keep log for some)
Research & Medical Records: Example 2

- NIH-NINDS R-01 NS30678, “Hemorrhagic and Ischemic Strokes Among Blacks and Whites”; in progress
  - with Dawn Kleindorfer, MD—Multiple PI’s
Population representative of U.S. - 15% African American versus 13% for U.S., economic and education distribution are also quite similar
Greater Cincinnati / Northern Kentucky Stroke “Laboratory”

**RESEARCH NETWORK**
- 15-18 Hospitals
  - 1 University
  - 3 Teaching
  - 1 Children’s
  - 13 Community

also provide acute stroke consultation for possible acute intervention


GCKNKS

- First six months of 1993 - inpatient screening for blacks only - pilot study (Stroke, 1998) = Phase I
- Next 12 months (7/1/93 to 6/30/94) - prospective screening of outpatient sites and all hospital encounters of possible stroke = Phase II
- Repeat in 1999 = Phase III
  - Prospective cohort for outcomes and genetics
    - In all subsequent phases
- Repeat in 2005 = Phase IV
- Repeat in 2010 = Phase V
Sampling Methods

- Retrospective Ascertainment
  - All inpatients with 430-436 codes (1st and all 2nd dxs.)
  - Eliminated 437-438 after initial experience

- “Hot Pursuit” for cohort
  - All ED log sheets

- All public health clinics

- All hospital-based outpatient clinics

- All five coroner offices
Sampling Methods (1993-94 numbers)

- Random sample of 50 of the 878 primary MD offices in five counties using Yellow Pages
- Random sample of 25 of 193 nursing facilities
Research & Medical Records: Example 2

- **GCNKSS:**
- OLD WAY: go to medical records and run many lists of admitted patients by ICD-9 code (10,000-14,000 medical records);
  - They ensure IRB approval, HIPAA waiver
  - Manual crosschecking for duplicates
- Hundreds of hours of gathering charts for physical review on site by small army of study nurses, medical record abstraction
- Physician review 4000 abstracts
Research & Medical Records: Example 2

- **GCNKSS:**
- **NEW WAY:** electronic list run by system after verifying IRB approval, HIPAA waiver
- Record review: varies by site/system—
  - show consent, get record (printed copy of chart) or
  - put into queue to access electronically or
  - full access (but keep log for some)
- Latter two options for record review do not require on site nursing
Age-Specific Risk of First-Ever Stroke in Blacks as Compared to Whites (1993-94)

Blacks have higher risk
Blacks have lower risk

Kissela, et al. Stroke 2004
Our data from 1993-94, generalized to the U.S. population, suggest that 705,000-740,000 strokes occur in the U.S. each year:

- 616,000 ischemic strokes
- 67,000 intracerebral hemorrhages
- 22,000 subarachnoid hemorrhages

Approximately 500,000 first-ever strokes

Kissela, et al. Stroke 2004
Including Out-of-Hospital

<table>
<thead>
<tr>
<th>Type</th>
<th>Black</th>
<th>White</th>
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<tbody>
<tr>
<td>All subtypes</td>
<td>355 (318, 392)</td>
<td>334 (300, 368)</td>
</tr>
<tr>
<td>Ischemic</td>
<td>303 (269,337)</td>
<td>291 (259, 323)</td>
</tr>
<tr>
<td>ICH</td>
<td>57 (42, 72)</td>
<td>58 (44, 70)</td>
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<tr>
<td>SAH</td>
<td>15 (8,22)</td>
<td>15 (8, 21)</td>
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<table>
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<tr>
<th></th>
<th>1993/94</th>
<th>1999</th>
<th>2005</th>
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<tbody>
<tr>
<td>Age (SD)</td>
<td>71.3 (13.6)</td>
<td>70.9 (14.4)</td>
<td>68.4 (15.4)</td>
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<tr>
<td>% &lt; 45 yo</td>
<td>4.5%</td>
<td>5.5%</td>
<td>7.3%</td>
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<tr>
<td>Rates</td>
<td>45 (30-60)</td>
<td>48 (33-64)</td>
<td>57 (40-74)</td>
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<tr>
<td></td>
<td>12 (9-15)</td>
<td>17 (13-21)</td>
<td>25 (20-30)</td>
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Kissela, et al. in press, Neurology 2012

Kissela, et al. Diabetes Care, 2005
A Pilot Population-Based Outcomes Study using a Health Information Exchange: Preliminary Feasibility Results

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Cerebrovascular Disease & Stroke Center
Introduction

- Post-stroke outcome studies:
  - Disposition
  - Mortality
  - Direct follow-up interview of stroke victims

- Expensive, time consuming and can lead to a biased cohort

- There is a need for a population-based stroke outcomes study
Introduction

- **GOAL:** to evaluate the feasibility of facilitating outcomes assessment using a Health Information Exchange (HIE)
  - HIE (HealthBridge): regional network for sharing healthcare data among providers

- **HYPOTHESIS:** HIE-facilitated cohort identification with phone-call follow-up would enable more efficient population-based outcomes determination compared to traditional approaches
Methods

- All regional ischemic strokes during 2010 identified by screening all ER/hospital admissions for stroke cases (HOT PURSUIT)
  - HIE computerized algorithm--filtered by key words for stroke and zip code
  - human-screening to identify actual stroke cases
  - 2000 admits, 60 possible, 20 stroke

- Cases were then enrolled into one of two cohorts in a non-random fashion
Methods

- First 500 cases were assigned for “hot pursuit” and in-person interview (traditional cohort)
- Those cases not enrolled in the traditional cohort assigned to have HIE-data review and phone call interview (HIE cohort) at 3 months only
- Primary endpoints of the pilot:
  - feasibility of contacting patients and assessing outcomes by phone
  - time spent and cost - not be discussed here
Methods

- **Cooperation rate**
  - \#contacted / \# eligible

- **Completion Rate:**
  - \# of completed interviews / \# contacted
Results

- 17,671,258 HIE messages about 1,967,415 unique patients seeking care at hospitals within the study region in 2010

- The computerized algorithm identified 5,082 potential strokes for human review
Results—Traditional Cohort

- In-person interviews were attempted on 793 subjects
- 689 eligible for interview
  - 516 agreed to participate in the traditional cohort.
- Immediate cooperation rate was 75%
- 408 completed a 3-month follow-up interview (approximates 59% completion rate)
Results—HIE cohort

- For the HIE cohort, 581 subjects were identified for potential phone interviews
- 491 calls were placed at 3 mo post-stroke
- 320 subjects were reached
  - 204 completed the interview
- Cooperation rate was 52%
- Completion rate was 64%
- Quality of outcomes data were similar with both approaches
Summary of GCNKSS

- Almost 20 consecutive years of NIH funding with important findings regarding temporal trends in stroke
  - Incredible THANKS to all local hospital personnel who have helped

- Addition of HealthBridge informatics facilitated pilot study for population-based outcomes after stroke

- We are only just beginning to consider the research possibilities in our community with the EHR and HealthBridge
Issues for today

- What is the proper balance between HIPAA compliance and ability to do research?
  - Is it possible to allow access and monitor somehow in background for HIPAA compliance?
Issues for today

- Can we agree upon basic principles for research access to EHR across the community?
  - Would be beneficial to IRB’s at all systems
  - Would be beneficial to researchers
  - This is a crucial topic that is causing angst
    - Few projects will have needs like our stroke studies, but still a worry for EVERYONE
Issues for today

- HealthBridge??
- One system created by city-wide collaboration that can bridge multiple systems
  - Clinically, patients FREQUENTLY go to different hospital systems or get transferred
  - Could share info across health systems
  - Could make Cincinnati the epicenter of epidemiology research, similar to Olmstead County (Mayo)
  - Endless possibilities for quality of care improvements and research
Summary

- EHR: Changing the way we practice medicine
  - I love me some Epic
- Positive change but not without limitations clinically
- For research: informatics and EHR could revolutionize the research enterprise in our city, especially epidemiology
  - Good for Cincinnati’s economy, research/medical community, and community health
  - We have amazing city-wide collaboration, this conference is a beginning for trying to find consensus
Questions? Discussion?