Accommodating a Patient’s Request to Access and Amend the health record.

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Patient Advocacy Initiatives

“Control Your Future”
Physician’s Computer Company (PCC) Users’ Conference
July 21, 2017

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Certified professional medical auditor

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Head of non-profit

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Patient Access/Amend EHR

Healthcare is about to radically change as patients routinely access and amend their health record.
Patient Access/Amend EHR

Objectives:
• learn laws governing patient EHR access/amend
• anticipate what it will look like for patients to routinely access/amend their health record.
Digital Age of Healthcare

We are currently in transition from the Pre Digital Age to the Digital Age.
Healthcare documentation

Egyptian stone carvings up to 3,000 B.C.

Sir William Osler
William Osler, M.D.
“Father of Modern Medicine”
1849-1919

“Listen to the patient, he is telling you the diagnosis.”
Healthcare documentation

Lawrence Weed, M.D.
(1923-2017)
Father of the Problem-Oriented Medical Record

S.O.A.P. note

S = subjective
O = objective
A = assessment
P = plan

Standardize medical documentation late 1960’s
Healthcare documentation

S.O.A.P. note

S = subjective
O = objective
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P = plan

CMS medical encounter

History
Examination
Medical Decision Making

1995 & 1997 E/M Guidelines
CMS = Centers for Medicare and Medicaid Services
Data collection focus for billing and analytics

Standardize medical documentation late 1960's
The Digital Age

Prof. Charles Proteus Steinmetz
“Father of the US electrical grid”
“Wizard of General Electric”
1865-1923

Coined “hysteresis”
1892
“retentivity” on ordinate
The Digital Age

Prof. Charles Proteus Steinmetz
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Retained values above and below the abscissa enabled the future birth of binary code

Coined “hysteresis”
1892
“retentivity” on ordinate
World War II

Nazi Enigma Machine

Rotors and plug board

$= 159$ quintillion ($10^{18}$) combinations

Movie 2000
The Digital Age
British child math genius
1936 “On Computable Numbers...” paper
1938 Ph.D. Princeton University
1939 joined Bletchley Park “Ultra” (declassified 1974)
Cracked Nazi Enigma code

Alan Turing, Ph.D.
“Father of theoretical computation and artificial intelligence”
1912-1954

“The Imitation Game”
2014 movie
Benedict Cumberbatch as Alan Turing.
The Digital Age

1939 Electromechanical Bombe (solved Enigma)

1943 Colossus (first programmable, electronic, digital computer)

Turing Test

Turing Award (Association for Computing Machinery, est. 1966)

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The Digital Age

Gordon E. Moore, Ph.D.
born 1929, co-founder Intel Corp.
“Moore’s Law” coined by Carver Mead, Ph.D. based on 1965 article that questioned his friend about the future of the integrated circuit. Implied processor speed will double every 1-2 years.
Professor Ray Kurzweil
born 1948
author, inventor, futurist.
Pioneered text and speech recognition.
The Digital Age

The Spiritual Age of Machines – when computers exceed human intelligence © 1999
Digital Age of Healthcare

More than substituting a keyboard for a pen.

Digitalization of medical records is part of the Federal Health IT Strategic Plan.
Our government foresaw the digital age of healthcare
Federal Laws paved the way for improvement:

**HIPAA 1996**

Health Insurance Portability and Accountability Act of 1996

Initial focus: medical record storage and transmission

**HIPAA Privacy Rule 2001**

Standards for Privacy of Individually Identifiable Health Information

Further defined: individuals right to access and amend the medical record

**MACRA 2015**

Medicare Access and CHIP Reauthorization Act of 2015

New physician payment system that rewards quality. Data capture started January 2017 to pay 2019. Patient Generated Health Data (PGHD)/amend and patient access count toward physician $ bonus
The Privacy Rule of HIPAA

patient right to request to access and amend the health record

45 C.F.R. § 164.524
45 C.F.R. § 164.526
The Privacy Rule: Access

- Patient should submit a written request
- Provider has 30 days to respond with written notification
- Provider may deny access if content could “harm the patient”
- Provider may request an additional 30 days with written notification
- HIPAA exempt: psych notes, work comp, MVA
- May charge customary fee for photocopy & postage, CD, thumbdrive
- Nominal fee for search/retrieval (Act 26 in Penna) (18 V.S.A. §9419) = no charge search/retrieval, access charge $5 flat/$0.50 per page max)

45 C.F.R. § 164.524
The Privacy Rule: Amend

- Patient should submit a written request
- Provider has 60 days to respond with written notification
- Provider may deny
- “link & notify” – check health record activity log to identify who to notify
- Provider who receives notification must review the record to see if Medical Decision Making requires alteration
- Provider must avoid any evidence of retaliation
- Provider may not charge for amendment work

45 C.F.R. § 164.526
Privacy Rule Enforcement

Office for Civil Rights (OCR)
complaint investigations
www.ocrportal.hhs.gov
800-368-1019

compliance reviews
enforcement of policy
empowered to assign civil money penalties
and (with DOJ) criminal prosecution against medical providers. Penalties skyrocket if evidence of retaliation.
MACRA calls for patient access and patient amendment of the health record as part of the physician payment formula.

MACRA promotes PGHD.

Patient Generated Health Data (PGHD), which is defined as including the History, as part of an objective to coordinate care through patient engagement.

MACRA = The Medicare Access & CHIP Reauthorization Act of 2015, data capture starts January 1, 2017
Federal Information Technology Strategic Plan

HITECH Act of 2009
Health Information Technology for Economic and Clinical Health Act

allocated $25.9 billion to be paid to doctors and health systems for the adoption and meaningful use of electronic health records (EHRs)

Doctors using EHR systems rapidly grew

2008 17% to 2012 78%

2015: financial penalty if not using certified EHR
Federal Strategic Information Technology Plan anticipates a return on investment regarding healthcare quality, cost and satisfaction.

Quality: #42 life expectancy/223 for 2011
#169 infant mortality
64/100 National Scorecard 2011
67/100 in 2006

Cost: $3 trillion per year
17.5% GDP 2014, projected 34% by 2040

Satisfaction: 66% of Americans approve of the way the healthcare system works for them
Healthcare communication challenges

Patient has an average of 3 concerns to address at a medical encounter ¹

Interrupted in the first 12 seconds ²

Once interrupted, has only 1/52 chance of returning to the three original concerns ³

77% of interviews documented in the medical record fail to fully elicit why the patient came to see the doctor ⁴

¹, ³, ⁴ The Medical Interview, 2014
² Improving Diagnosis in Health Care, National Academies of Science, 2015
History/Exam/MDM 3 key components

History – about 30 questions, takes time to ask each question, wait for response and document

Chief complaint
History of Present Illness
(location, quality, severity, duration, timing, context, modifying factors, associated signs and symptoms)
Status of Chronic Disease
Review of Systems
(head to toe, mind body inventory)
Past Family Social History
(includes medication & allergy lists)
Compared what the patient reported in the waiting room to what the doctor, moments later, documented in the health record. Poor correlation.

Patient reported “eye pain”, then “eye pain missing 26.5% in EHR.”
Watson shows poor medical performance

IBM supercomputer Watson ceased work with MD Anderson Cancer Center at the University of Texas on a “promise to transform cancer care with the help of artificial intelligence.” (WSJ 9march2017)

Watson wins on Jeopardy!

$62 million  5 years

Investigators cited Watson’s trouble “reading relevant information in patient charts.”

If the eye center records looked anything like the cancer center records, Watson never stood a chance!
What is the purpose of the medical record?

“Retell the story”

Annuals of Internal Medicine, vol. 162 No. 4, 17feb2015

Billing & Coding, Reimbursement for services rendered or supplies utilized, Data for population health, Data to develop personalized health algorithms, Continuity of Care, Assure quality care, Identify best practices, Identify cost effective care

Information technology terms: Exploration (gather information), Exploitation (use information)

However, to be data ready, the information must be accurate and structured.
The History (PreHistory is a replica) asks about 30 questions.

Questions are not difficult, but do take time to reflect upon and answer.

Rather than expect the doctor to ask all 30 questions, wait for an answer for each, then type/dictate response into computer/EHR, why not let the patient consider and answer these questions in advance?

www.PatientAdvocacyInitiatives.org
Invited patients to co-author the History component of the health record by completing a PreHistory. Three page 30 question = History per CMS E/M Guidelines.

Patients submitted the PreHx as a written request to amend their health record per the HIPAA Privacy Rule [45 C.F.R. § 164.526]
Patient authored PreHistory allows for subjective input into the electronic health record, improves the patient experience and accommodates federal law.

JAOA Feb 2017

263 individuals co-authored health record as part of a face-to-face visit with a medical provider

64% participation rate

60% male

Ages 14-94

Often, with the help of a family member, friend, or caretaker
Patient authored PreHistory allows for subjective input into the electronic health record, improves the patient experience and accommodates federal law.

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Likert Scale</th>
<th>Time Point</th>
<th>N</th>
<th>Mean</th>
<th>Difference in Means, (Post - Pre)</th>
<th>percent change, (Post-Pre)/Pre</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>How satisfied were you with your experience as a patient in this office?</td>
<td>0 - 10</td>
<td>Pre</td>
<td>255</td>
<td>9.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post</td>
<td>134</td>
<td>9.7</td>
<td>0.2, improved</td>
<td>2%</td>
<td>.048&lt;sup&gt;1,2&lt;/sup&gt;</td>
</tr>
<tr>
<td>Completing the Pre-History made me feel more empowered in my healthcare.</td>
<td>1 - 5</td>
<td>Pre</td>
<td>249</td>
<td>2.5</td>
<td>-0.6, improved</td>
<td>-23%</td>
<td>&lt;.0005&lt;sup&gt;1,2&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post</td>
<td>131</td>
<td>2.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I appreciate being given the chance to co-author my medical record.</td>
<td>1 - 5</td>
<td>Pre</td>
<td>260</td>
<td>2.2</td>
<td>-0.4, improved</td>
<td>-18%</td>
<td>&lt;.0005&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post</td>
<td>132</td>
<td>1.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I will be better heard and understood by having submitted a Pre-History.</td>
<td>1 - 5</td>
<td>Pre</td>
<td>254</td>
<td>2.4</td>
<td>-0.4, improved</td>
<td>-18%</td>
<td>&lt;.0005&lt;sup&gt;1,2&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post</td>
<td>131</td>
<td>1.9</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Some violation of Normality assumption

2 Unequal variances assumed
JAOA clinical research study focused on patient satisfaction/experience. Efficiency was targeted as all documentation was completed by the end of each patient visit within a 15-min office visit schedule.

The government and health insurance companies already monitor quality and cost.
Patient Request to access/amend drill

Conduct a drill during a meeting with your staff and enter your exercise into your compliance manual. This will prepare you for specific instances.

- Patient asks for a copy of his/her record
- Authorized personal representative requests access
- Patient with severe and escalating depression requests access
- Patient reads health record and disputes what is written
  - MRI order for wrong shoulder
  - Patient believes story is inaccurate and is angered
- Patient requests to amend health record
  - “Didn’t we discuss my back pain?”
- Doctor approves request to amend, then “link & notify”
- Provider receives notification of amendment to record
Patient Advocacy Show on YouTube

“Craziest System”  Communication

Quantified Self

Orbitz.com  What Doctors Want

Paradigm Shift Dr. Thomas Kuhn

Pandora’s Box

Blind Men & Elephant

Elaine Benes

Empathy

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