The 21st Century Cures Act, Open Notes, and Nursing

Jan Walker, RN, MBA Beth Israel Medical Center, Harvard Medical School

Suzanne Leveille, RN, PhD Beth Israel Deaconess Medical Center College of Nursing and Health Sciences, UMass Boston

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Beth Israel Deaconess Medical Center



HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

Agenda

- The Cures Act
- Open notes
- Nurses and open notes
- Questions and discussion

We have no conflicts to report.

- **1996:** HIPAA
- 2009: HITECH
- 2016: 21st Century Cures Act passes in U.S. Congress
- **2020:** Interoperability & Information Blocking Rule



ONC's Cures Act Final Rule supports seamless and secure access, exchange, and use of electronic health information.

21st Century Cures Act

- Passed in 2016 with broad bipartisan support
- Focused on "expediting discovery, development, and delivery of new cures & treatments"
- Also has provisions to drive the electronic access, exchange, and use of health information



Dec 13, 2016

Key HIT provisions

- Gives patients more control of their medical record
- Promotes interoperability among disparate EHRs → seamless exchange
- Requires implementation of ONC's USCDI and HL7's FHIR[®] standards
- Defines and prohibits information blocking
- ONC is the federal presence to implement these provisions

Intended result:

Use health data in new ways in a new app ecosystem

- Patients
 - Modern access to chart
 - Choose which EHR data they want apps to receive
 - Better info about quality and costs
- Clinicians and hospitals
 - Make responding to most patient data requests easy and inexpensive
 - Freely choose software (vibrant, competitive marketplace)
- HIT developers
 - Lower costs with standardized datasets and FHIR programming standards
 - New protections for intellectual property

Cures Act Final Rule timeline

- Feb 11, 2019 Proposed rules published by ONC & CMS
- Public comment period, OMB review
- Mar 9, 2020 Final rule released
- Apr 5, 2021 Applicable date, information blocking USCDI
- Oct 6, 2022 Applicable date, information blocking *all* EHI
- Dec 31, 2022 Roll out standardized API functionality



Allergies and Intolerances	 Clinical Notes *NEW 1. Consultation Note 2. Discharge Summary Note 3. History & Physical 4. Imaging Narrative 5. Laboratory Report Narrative 6. Pathology Report Narrative 7. Procedure Note 8. Progress Note 	 First Name Last Name Previous Name Middle Name (incl. middle initial) Suffix Birth Sex Date of Birth Race Ethnicity Preferred Language Current Address *NEW Previous Address *NEW Phone Number *NEW Phone Number Type *NEW Email Address *NEW 	Smoking Status
 Substance (Medication) Substance (Drug Class) *NEW Reaction *NEW 			Unique Device Identifier(s) for a Patient's Implantable Device(s)
Assessment and O Plan of Treatment			
Care Team			 Vital Signs Diastolic Blood Pressure Systolic Blood Pressure Body Height Body Weight Heart Rate Respiratory Rate Body Temperature Pulse Oximetry Inhaled Oxygen Concentration BMI Percentile (2-20 Years) *NEW
	Health Concerns 🗩		
For more info:	Immunizations	Problems 😂	
	Laboratory • Tests	Procedures	
HealthIT.gov/USCDI	Values/Results	Provenance *NEW	 Weight-for-length Percentile (Birth - 36 Months) *NEW
	Medications	 Author Time Stamp Author Organization 	 Occipital-frontal Head Circumference Percentile (Birth - 36 Months) *NEW

Information blocking

"A practice ... that is likely to interfere with access, exchange, or use of EHI."

Up to \$1m per infraction

8 complex exceptions:

- If criteria met, an action cannot be considered information blocking
- Otherwise, an action may be considered information blocking

Information blocking exceptions

Not fulfilling requests

- Preventing harm to a patient or another person
- Protecting an individual's privacy
- Protecting the security of EHI
- Fulfilling a request is infeasible
- Taking actions to benefit overall HIT performance

Procedures for fulfillment

- Content and manner
- Certain fees
- Licensing interoperability elements

Information blocking complaints

• Information blocking complaints submitted through ONC's Health IT Feedback Form Information Blocking Portal





https://inquiry.healthit.gov/support/plugins/servlet/desk/portal/6



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*NEW

606

2.

Allergies and Intolerances

- Substance (Medication)
- Substance (Drug Class) *NEW
- Reaction

Assessment and Plan of Treatment

Care Team Members



For more info: HealthIT.gov/USCDI

Clinical Notes *NEW

Consultation Note

Discharge Summary Note

J.

- 3. **History & Physical**
- **Imaging Narrative** 4.
- Laboratory Report Narrative 5.
- Pathology Report Narrative 6.
- **Procedure Note** 7.
- **Progress Note** 8.

Laboratory

• Values/Results

Medications

• Tests

Goals



Patient Demographics

- First Name
- Last Name
- Previous Name
- Middle Name (incl. middle initial)
- Suffix
- Birth Sex
- Date of Birth

• Race

- Ethnicity
- Preferred Language
- Current Address *NEW *NEW

*NEW

*NEW

*NEW

- Previous Address
- Phone Number
- Phone Number Type
- Email Address

Problems

Procedures



- Author Time Stamp
- Author Organization

Smoking Status



Unique Device Identifier(s) for a **Patient's Implantable Device(s)**

Vital Signs



- Diastolic Blood Pressure
- Systolic Blood Pressure
- Body Height
- Body Weight
- Heart Rate
- Respiratory Rate
- Body Temperature
- Pulse Oximetry
- Inhaled Oxygen Concentration
- BMI Percentile (2-20 Years) *NEW
- Weight-for-length Percentile (Birth - 36 Months) *NEW
- Occipital-frontal Head Circumference Percentile (Birth - 36 Months) *NEW

Open Notes

OpenNotes pilot 2010 - 2011

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- 100 volunteer PCPs, 20,000 patients
- BIDMC (Boston), Geisinger (PA), Harborview (Seattle)
- PCPs
 - Little impact on workflow, email volume unchanged
 - Worries about patient impacts didn't materialize
 - After study, none stopped
- Patients
 - 80% read a note
 - 75% reported benefits
 - 99% wanted to continue
 - 85% would consider in selecting providers

- Original Research **Annals of Internal Medicine** Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead Tom Delbanco, MD*; Jan Walker, RN, MBA*; Sigall K. Bell, MD; Jonathan D. Darer, MD, MPH; Joann G. Elmore, MD, MPH; Nadine Farag, MS: Henry J. Feldman, MD: Roanne Meiilla, MPH: Long Ngo, PhD: James D. Ralston, MD, MPH: Stephen E. Ross, MD: Neha Trivedi, BS; Elisabeth Vodicka, BA; and Suzanne G. Leveille, PhD, RN Background: Little information exists about what primary care phyof electronic messages from patients did not change. After the sicians (PCPs) and patients experience if patients are invited to read intervention, few doctors reported longer visits (0% to 5%) or their doctors' office notes. more time addressing patients' questions outside of visits (0% to 8%), with practice size having little effect; 3% to 36% of doctors Objective: To evaluate the effect on doctors and patients of facilreported changing documentation content; and 0% to 21% reitating patient access to visit notes over secure Internet portals. ported taking more time writing notes. Looking ahead, 59% to 62% of patients believed that they should be able to add com-Design: Quasi-experimental trial of PCPs and patient volunteers in ments to a doctor's note. One out of 3 patients believed that they a year-long program that provided patients with electronic links to should be able to approve the notes' contents, but 85% to 96% of their doctors' notes. doctors did not agree. At the end of the experimental period, 99% of patients wanted open notes to continue and no doctor elected Setting: Primary care practices at Beth Israel Deaconess Medical Center (BIDMC) in Massachusetts, Geisinger Health System (GHS) to stop. in Pennsylvania, and Harborview Medical Center (HMC) in Limitations: Only 3 geographic areas were represented, and most Washington. participants were experienced in using portals. Doctors volunteering to participate and patients using portals and completing surveys Participants: 105 PCPs and 13 564 of their patients who had at may tend to offer favorable feedback, and the response rate of the least 1 completed note available during the intervention period. patient surveys (41%) may further limit generalizability. Measurements: Portal use and electronic messaging by patients Conclusion: Patients accessed visit notes frequently, a large majorand surveys focusing on participants' perceptions of behaviors, benity reported clinically relevant benefits and minimal concerns, and efits, and negative consequences. virtually all patients wanted the practice to continue. With doctors Results: 11 155 of 13 564 patients with visit notes available experiencing no more than a modest effect on their work lives, opened at least 1 note (84% at BIDMC, 82% at GHS, and 47% at open notes seem worthy of widespread adoption. HMC). Of 5219 patients who opened at least 1 note and com-Primary Funding Source: The Robert Wood Johnson Foundation, pleted a postintervention survey, 77% to 87% across the 3 sites the Drane Family Fund, the Richard and Florence Koplow Charitareported that open notes helped them feel more in control of their ble Foundation, and the National Cancer Institute. care; 60% to 78% of those taking medications reported increased medication adherence; 26% to 36% had privacy concerns; 1% to Ann Intern Med. 2012:157:461-470. www.annals.org 8% reported that the notes caused confusion, worry, or offense; For author affiliations, see end of text and 20% to 42% reported sharing notes with others. The volume * Dr. Delbanco and Ms. Walker contributed equally to this manuscript.
- All 3 expanded across ambulatory care by 2014

2012



Open notes across North America ✓ 250 organizations

✓ 53 million people

Dec 2020

Clinician Concerns

- 1/3 say they spend more time on documentation
- Patient confusion, worry
- Exercise clinical judgment to avoid patient harm
- Trivial requests to change notes

And yet, after several years experience

- 74% say open notes is a good idea
- 61% would recommend to colleagues

Open notes also help ...

- Patients understand medications and take them as prescribed
- Care partners rate the benefits of open notes even higher than patients
- Patient safety
- Patient trust in clinicians
- Greatest benefits reported by patients with less education, minorities, sicker, English not spoken at home

An example of what patients have to say about reading open notes:

https://www.youtube.com/watch?v=xO4g7AhIxow

Nurses and Open Notes



<u>AAACN</u> calls for nurses in ambulatory care:

"to practice at the top of their license, education, and expertise to affect quality and cost through <u>patient engagement</u>, care coordination, enhanced teamwork, resource reduction, <u>improved access</u>, and quality and outcome improvement."

Nurses can <u>Engage</u> patients and families

- Based on a trusting relationship
- Attention to individual needs and skills
- Promote shared decision making
 - Patients need information: EHR source of knowledge about personal health and health care
 - Open notes: "seeing it in black & white"

Nurses can <u>Encourage</u> patients and families to:

Sign up for patient portal

Read their full records including notes

Speak up about errors

• Ask questions. It's a partnership!

Suggestions for the future

- Training for nurses regarding open notes
- Policies and procedures for making amendments to notes
- Educate patients about reading notes
- How to handle sensitive information, such as domestic violence, mental health

Tips for writing notes when your patients can read them

Be clear and succinct

Directly and respectfully address concerns

Use supportive language where possible

Try to include patients in the note-writing process

Encourage patients to read their notes

Ask for feedback

Be familiar with your organization's process for amending notes





ON Website: https://www.opennotes.org/

Case Study: Open Inpatient Notes at UC San Diego Health





Brian Clay, MD Chief Medical Information Officer Inpatient and Hospital Affiliations, UC San Diego Health Clinical Professor of Medicine, UC San Diego School of Medicine

Executive Director, OpenNotes Associate Professor of Medicine, Harvard Medical School

Case Study Webinar on March 23: Open Inpatient Notes at UC San Diego Health

Open Oncology Notes: Research & Real-World Experience Webinar: Monday, March 8, 2021 · Noon-Ipm Eastern + Office Hours: Thursday, March 11, 2021 • 3-4pm Eastern **Everett Weiss, MD** Bertram Yuh, MD **Dosie Bartel** Associate Chief Health Associate Chief Medical Information Office Patient advocate Informatics Officer Clinical Professor Collaborator OpenNote Memorial Sloan Kettering Cancer Center City of Hope National Cancer Center

Open Oncology Notes: Research & Real-World Experience Webinar

How to Write an Open Note: **Research & Real-World Experience**

Webinar: Friday, January 29, 2021 • 1-2pm Eastern + Office Hours: Tuesday, February 2, 2021 • 11am-Noon Eastern





Leonor Fernandez, MD Director of Patient Engagement, Health Care Associates, Beth Israel Deaconess Medical Center, Assistant Professor of Medicine, Harvard Medical School

CT Lin, MD Chief Medical Information Officer, UCHealth Professor of Medicine, University of Colorado School of Medicine

How to Write an Open Note: Research & Real-World Experience: Webinar

Open Notes in the Safety Net

Webinar: Thursday, April 15, 2021 · 4-5pm Eastern + Office Hours: Thursday, April 22, 2021 • 1-2pm Eastern







Anshu Abhat, MD, MPH Director of Transitions of Care & Patient Engagement, LA County Department of Health Services

Nandini Shroff. MPH Research Committee Administrator and Grants Manager. The Institute for Family Health

Ruth Lesnewski, MD Attending Physician, Beth Israel Residency Program in Urban Family Practice, Clinical Director, MyChart MyHealth, The Institute for Family Health

Open Notes in the Safety Net: Webinar & Office Hours, April 15 and April 22

Open Notes in Pediatrics & Adolescents: Research & Real-World Experience

Webinar: Thursday, February 18 • Noon-Ipm Eastern + Office Hours: Tuesday, February 23 • Noon-1pm Eastern



Fabienne Bourgeois, MD Pediatric Hospitalist Associate Chief Medical Information Officer. Boston Children's Hospital

Cynthia L. Kuelbs, MD Chief Medical Information Officer, Rady Children's Hospital, Clinical Professor of Pediatrics, University of California, San Diego

Open Notes in Pediatrics & With Adolescents: Research & Real-World **Experience:** Webinar Recording

OpenNotes Drop-In Clinic

March 29-April 2: Experts "standing by" to answer your questions

opennotes.org





ON Website: https://www.opennotes.org/

Thank you!

Questions & Discussion



www.opennotes.org