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

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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
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
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

https://inquiry.healthit.gov/support/plugins/servlet/desk/portal/6
Open Notes
OpenNotes pilot 2010 - 2011
OpenNotes pilot 2010 - 2011

- 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

All 3 expanded across ambulatory care by 2014
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

DesRoches. JAMA Network Open. 2018
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=xO4g7Ahlxow
Nurses and Open Notes
AAACN calls for nurses in ambulatory care:

“to practice at the top of their license, education, and expertise to affect quality and cost through patient engagement, care coordination, enhanced teamwork, resource reduction, improved access, and quality and outcome improvement.”
Nurses can
Engage 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
Encourage 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

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<thead>
<tr>
<th>Tip</th>
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<tbody>
<tr>
<td>Be clear and succinct</td>
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<td>Directly and respectfully address concerns</td>
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<td>Use supportive language where possible</td>
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<td>Try to include patients in the note-writing process</td>
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<td>Encourage patients to read their notes</td>
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<tr>
<td>Ask for feedback</td>
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<td>Be familiar with your organization’s process for amending notes</td>
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Everyone on the Same Page

OpenNotes is the international movement promoting and studying transparent communication in healthcare. We help patients and clinicians share meaningful notes in medical records. We call these open notes.

ON Website: [https://www.opennotes.org/](https://www.opennotes.org/)
Case Study: Open Inpatient Notes at UC San Diego Health
Tuesday, March 23, 2021 - Noon-1pm Eastern

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

Open Oncology Notes: Research & Real-World Experience Webinar

Open Oncology Notes: Research & Real-World Experience
Webinar: Monday, March 8, 2021 - Noon-1pm Eastern
+ Office Hours: Thursday, March 11, 2021 - 3-4pm Eastern

Open Notes in the Safety Net
Webinar: Thursday, April 15, 2021 - 4-5pm Eastern
+ Office Hours: Thursday, April 22, 2021 - 1-2pm Eastern

Open Notes in Pediatrics & Adolescents: Research & Real-World Experience
Webinar: Thursday, February 18, 2021 - Noon-1pm Eastern
+ Office Hours: Tuesday, February 23, 2021 - Noon-1pm Eastern

How to Write an Open Note: 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

ON Website: https://www.opennotes.org/
Thank you!

Questions & Discussion

www.opennotes.org