



COMMUNITY  
HEALTH CARE  
ASSOCIATION  
of New York State

*CHCANYS NYS-HCCN is partnering with  
Pivot Point Consulting to present*

Empowering Patients Through Information Sharing:  
Cures Act Compliance Series

## **OpenNotes Overview**

**December 1, 2021**

For more information, please email us at [HCCN@chcanys.org](mailto:HCCN@chcanys.org)

# OpenNotes Overview

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# Disclaimers/Disclosures

- This presentation is for informational purposes only.
- It does NOT, and is not intended to, constitute legal advice.
- Only your attorney can provide assurances regarding the application of this information to your particular circumstances.
- The statements, views and opinions expressed in this presentation are solely those of the presenters, and not those of CHCANYS.
- John Santa and Amy Fellows have no financial conflicts of interest to disclose.



# About the Empowering Patients Educational Series

- Designed to support CHCANYS members as they work toward compliance with information blocking regulations stemming from the 21<sup>st</sup> Century Cures Act
- November 2021-March 2022
- Includes:
  - **Webinar** presentations providing foundational knowledge for all member roles (provider, compliance, HIM, IT)
  - **Ask the Experts** interactive Q&A sessions focusing on information needs of specific member roles
  - **Supporting resources** to help members operationalize the regulations within their organizations



# Today's Learning Objectives

- Understand the risks and benefits of easy patient access to electronic health information, especially clinician notes, to patients and clinicians
- Assist in the development of methods and materials that explain notes to patients and how they can access them
- Contribute to the improvement of workflows that anticipate the changes needed to maximize this transparency
- Recognize the requirements of the Cures Act, including the exceptions it creates to sharing notes





# What is OpenNotes?

- International movement committed to spreading and studying the effects of transparent communication among patients, families and clinicians
- Motivated by evidence indicating that when health professionals offer patients and families ready access to clinical notes, the quality and safety of care improves
- Associated with an academic medical center and is philanthropy funded
- NOT software; OpenNotes has no vendor financial relationships



# Thank You to OpenNotes



- Much of the content of this presentation comes from the OpenNotes website.
- The OpenNotes.org website is a terrific resource for everything related to open notes – research studies, implementation tools, links to others involved in open notes.
- The term “open notes” is now used across the country to describe the process of releasing notes to patients electronically.



# Federal Rules Related to OpenNotes

- On April 5, 2021, federal rules implemented the bipartisan 21st Century Cures Act specifying that eight types of clinical notes are among electronic information that must not be blocked and must be made available free of charge to patients.
- The rules allow specified exceptions including prevent harm and privacy.





# Eight Note Types Specified

- Consultation notes
- Discharge summary notes
- History & physical
- Imaging narratives
- Laboratory report narratives
- Pathology report narratives
- Procedure notes
- Progress notes – focus of OpenNotes



# History of OpenNotes

- 1973 NEJM: “Giving Every Patient His Medical Record: A Proposal to Improve the System”
- 1991 NAM: *The Computer-Based Patient Record: An Essential Technology for Patient Care*
- 1996 HIPAA: National Standards for Electronic Health Care
- 1998: Patient Portals developed
- 2001 Salzburg Global Seminar: “Nothing About Me Without Me”
- 2012: OpenNotes founded; first research published
- 2013: VA shares notes systemwide



# OpenNotes in New York State

- By Spring 2021 at least 17 health organizations had implemented OpenNotes including multiple FQHCs and Community Clinics
  - New York Health and Hospitals
  - Care for Homeless
  - Institute for Family Health
  - BronxCare
  - Community Health Center of Richmond
- Several did so as grantees of New York State Health Foundation
- Hundreds of FQHCs and Community Clinics have implemented across the country



# What Benefits Do Patients Report from Reading Notes?

- Improved understanding of their health and medical conditions
- Recall their care plan more accurately
- Better prepared for visits
- More in control of their care
- Take better care of themselves
- Take their medications as prescribed more frequently
- Have more successful conversations and stronger relationships with their doctors



# What About Care Partners?

- Many patients, particularly those chronically ill or elderly, rely on family members or other care partners to coordinate appointments, tests, medications and care plans.
- Unfortunately, care partners today are increasingly stressed, often to the point of being at risk for illness.
- Parents especially report significant benefits from access to their children's notes.
- Data indicate that care partners may benefit from note sharing as much as patients themselves.



# How About Patients Who Are Socio-economically Disadvantaged?

- Individuals who do not usually speak English at home or are less educated, nonwhite, older or Hispanic are not as likely to register on patient portals and are therefore less likely to read their notes.
- However, in repeated studies, when these patients do get to read notes, they are most likely to report benefits from note reading.
- Safety net institutions around the country are increasingly participating in the OpenNotes movement and offering favorable reports.



# Patients Understand Notes

- More than 95% of patients with diverse educational histories and socio-economic circumstances report understanding their notes well.
- Even if patients don't understand everything, they indicate strongly that this type of transparency and partnership is valuable to them. It sends a strong message about inclusivity, builds trust, and turns patients into active safety partners.
- Moreover, open and honest communication can help decrease litigation, as demonstrated repeatedly in studies addressing medical error disclosure.



# Patients Want Easy Access to Notes

- Multiple patient surveys in multiple organizations, regions, and subpopulations show very strong support for easy access to notes.
  - Results are often in the high 90% range
- Patient trust in clinicians grow when they read notes, even when they notice errors, and especially when those errors are corrected.





# What Are Risks of OpenNotes?

- May increase level of anxiety among some clinicians
  - A small number of patients may be confused by a note.
  - Workflow, primarily related to documentation, may be affected for some clinicians.
  - Some IT resources are required.
  - As of April 2021, if notes are blocked without meeting exception criteria, penalties are possible.



# What Are Effects on Clinician Workflow?

- In advance of open notes, clinical staff often anticipate changes to workflow and workload. This worry appears to be misplaced.
- None of the >250 organizations that implemented open notes prior to November 2020 reported a significant increase in visit time with patients or in e-mail traffic. In fact, some organizations reported a decrease in e-mail, as patients are able to resolve confusion or forgetfulness by reading their notes.
- Some organizations acknowledge there are poor documenters in their workforce and anticipate that these individuals will have to change their practice to come into closer line with peers. Indeed, some organizations feel that sharing notes has helped some practices and individuals resolve long-term problems.



# Will There Be Disruptions in Workflow?

- Significant disruptions in workflow were not seen in hundreds of voluntary implementations.
- Email traffic did not increase and in some cases decreased.
- Reports of errors were modest, and most were dealt with easily.
- About 20% of clinicians need to make changes in documentation that take about 6-8 weeks to incorporate.
- Clinicians worry that there will be a tsunami of note reading. Instead, we saw a trickle that eventually grows to modest levels. Note reading is highly dependent on clinician promotion and the ease of patient portal navigation.



# Writing Notes

- Avoid abbreviations. For example, “SOB” does not mean Shortness of Breath to most patients!
- Avoid language that may seem judgmental or stigmatizing, such as “noncompliant” and “unreliable.” These observations are better off documented behaviorally, rather than using an adjective to describe a patient, e.g., “Patient reports he did not take medications as suggested.”
- Avoid copying and pasting information into a note. Both patients and clinicians often take umbrage at such practice.
- Use plain language.
- Sign notes in a timely manner.



Write what you discuss.  
And discuss what you write.



# Do Patients Notice Errors?

- Patients notice errors in their notes, and they find some that their doctors feel are serious. Correcting errors helps make the record more accurate and can improve patient safety.
- But changing a record, even in pursuit of clarity or correction, is not easy. It is highly dependent on where you practice.
- Bottom line: Whether by addendum, correspondence back and forth, or actual revision...there's a way to pursue accuracy, and it's often well worth doing.



# Correcting Notes

- 24% of doctors who had been using open notes for a year or more reported that a patient had identified an error that the doctor characterized as “serious.”
- Changing a note, whether or not at a patient’s request, is at the clinician’s discretion.
- If you feel the change improves the note, you can simply document the change as an addendum or use mechanisms in place at your institution to edit/correct a note.
- Overall, institutions report little or no uptick in requests for changes to the record after the implementation of open notes.



# Communicating With Clinicians

- Messaging to patients
  - For example, some patients don't know what notes are
- FAQs for clinicians
- Tips on writing notes
- Refer to notes, in general or specifically, when able on call or virtual interactions
- Coding issues?





# Communicating with Patients

- “Sharing your open notes with you is a transparency we are excited to observe by putting the notes your clinician writes on the patient portal.”
- “Your open notes are available through [portal name].”
- “If you need help finding them, contact support at [portal support email] OR view this short video [show step by step navigation to notes].”
- “For help understanding what an open note is, check out this FAQ from (organization name).”



# Communicating with Patients

- Key messages to patients
- Patient FAQs
- Waiting room information and posters
- Registration to patient portals (remember proxy access)
- Note available reminders
- Get ready for third-party apps



# Helping Patients Navigate to Notes

- Patient portal navigation can be challenging
- Remind patient that note is available and quicklink to it
- Link to notes on home portal page
- Link to notes on Medical Records menu
- Provide “how do I find my notes?” instructions on key pages



# Hiding Notes

- OpenNotes identified the option of hiding individual notes as a Best Practice for EHRs in 2015.
- Many EHRs did not initially provide that option but now do.
- Data regarding note hiding is limited.
- In most organizations modest numbers of notes are hidden initially, with hiding rates declining over six months as clinicians realize benefits outweigh risks.
- Most note hiding eventually focused on children/adolescents and in behavioral health settings.



# Pediatric and Adolescent Notes

- Open notes give parents, patients, and care partners the ability to access medical information wherever and whenever they choose to remind themselves and their children about what was discussed during an office visit.
- There's ample evidence that patients and families often forget what was said during a medical encounter. Reviewing the record and the notes can help make sure that everyone understands the treatment plan and next steps.



# Benefits of Sharing Mental Health Notes

- Demonstrates respect and reduces stigma
- Empowers patients
- Organizes care and tracks progress
- Provides a tool for behavior change
- Enhances trust and the therapeutic relationship
- Makes care safer



# Next Up

- Bring your **OpenNotes** questions to the **Ask the Experts** session
  - Wednesday, **December 15**, 12-1 p.m.
- January: **Information Blocking Exceptions**
  - **Webinar**: Wednesday, **January 12**, 12-1 p.m.
  - **Ask the Experts**: Tuesday, **January 18**, 12-1 p.m.
- Use the QR code or register for January's sessions [here](#)
- CHCANYS Virtual Interoperability Workshop: Innovations in Policy, Technology, and Workflows. Register [here](#).
  - Tuesday, **December 7** & Wednesday, **December 8**, 2-4 p.m.



# Additional Resources

- OpenNotes: [opennotes.org](https://opennotes.org)
- Legal Health Information Exchange compliance library ([table of contents](#))
  - If you are interested in getting an account to the Legal Health Information Exchange Compliance Library, please email Amy Freiman at [Afreiman@chcanys.org](mailto:Afreiman@chcanys.org)
- [Information Blocking resources](#) on CHCANYS website
  - Includes links to resources on Office of the National Coordinator for Health Information Technology (ONC) website





**Please share your feedback using the QR code or the link in the follow-up email. The survey will also pop up on your screen when the meeting ends!**



# Educational Series Schedule

Additional Ask the Experts sessions will be scheduled based on member interest. We welcome your suggestions!

[HCCN@chcanys.org](mailto:HCCN@chcanys.org)

Month	Topic	Webinar Date	Ask the Experts (ATE) Date(s)	
November 2021	<b>Cures Act Overview</b>	<b>Wed, Nov 10</b> Noon-1 ET	All roles <b>Wed, Nov 17</b> Noon-1 ET	
December	<b>OpenNotes Overview</b>	<b>Wed, Dec 1</b> Noon-1 ET	Providers <b>Wed, Dec 15</b> Noon-1 ET	
January 2022	<b>Information Blocking Exceptions</b>	<b>Wed, Jan 12</b> Noon-1 ET	Compliance, HIM <b>Tue, Jan 18</b> Noon-1 ET	
February	<b>Preparing for Cures Act Compliance, Part 1</b> (organizational readiness)	<b>Wed, Feb 16</b> Noon-1 ET	Compliance, HIM, IT <b>Wed, Feb 23</b> Noon-1 ET	
March	<b>Preparing for Cures Act Compliance, Part 2</b> (communication of records)	<b>Wed, Mar 16</b> Noon-1 ET	Providers <b>Wed, Mar 23</b> Noon-1 ET	Compliance, HIM, IT <b>Wed, Mar 23</b> 2-3 ET



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