OpenNotes

Susan Mende
Senior Program Officer
Robert Wood Johnson Foundation

Slides adapted from Jan Walker Co-founder, Open Notes
What are OpenNotes?

- Open notes are clinical visit notes that patients can access online through patient portals
- It’s a concept, not software

“How can patients participate if they can’t see what I see?”

Danny Sands, MD
Welcome to mychart

mychart offers Bon Secours patients personalized and secure online access to portions of their medical records. It enables you to securely use the Internet to manage and receive information about your health - online, anytime! mychart is a free service offered to Bon Secours patients.

With mychart, you can use the Internet to:
- Communicate with your doctor
- Request medical appointments
- View your health summary from the mychart electronic health record
- Access your test results
- Request prescription renewals
- View your recent doctor's visits

How do I sign up?

Bon Secours patients who wish to participate will be issued a mychart activation code during their doctor's visit. This code will enable you to login and create your own user ID and password.

About OpenNotes

- Began with three-institution study in 2010 at Beth Israel Deaconess Medical Center, Geisinger Health System, and Harborview Medical Center: 100 PCPs and 20,000 patients

- Now a national movement to make OpenNotes the standard of care

- Funder collaborative
Study Results: PCPs

- Few PCPs reported impacts on workflow
  - 2% reported longer visits
  - 3% reported spending more time on patient questions
  - 11% reported spending more time on documentation

- Email volume did not change

- Concerned about patients being confused, offended, or worried, but few patients reported that (1-8% at different sites)
Study Results: Patients

- 82% of patients who had a visit opened at least one note
  - Including patients who were older, sicker, less educated

- About 3 out of 4 reported benefits of reading notes
  - taking better care of themselves
  - understanding their health and medical conditions better
  - feeling more in control of their care
  - feeling better prepared for visits
  - doing better with taking their medications as prescribed
    - More likely to refill antihypertensives

- 99% wanted access to continue after the study
- 85% said availability of open notes would influence choice of future providers
Reading notes helps engage patients

• Reinforces clinical messages/improves recall
• Reminds patients to follow up
• Increases trust/ strengthens patient-clinical relationship/litigation
  • “He really listened”
• Improves understanding of clinical rationale- seeing in writing can increase personal accountability and motivate behavior change
• Better informed consent/shared decision making
• Promotes organizational transparency and inclusivity and patient empowerment
More than 12 million patients have easy access to their clinicians’ notes
“If this had been available years ago I would have had my breast cancer diagnosed earlier ... A previous doctor wrote in my chart and marked the exact area but never informed me. This potentially could save lives.”  
(Patient)

“I feel safer, knowing there are more eyes on what I’m doing.”  
(PCP)

Need to enable patients speaking up
Care Partners
“Everything’s fine”
Mental Health

- Organizational decision on carve out
- Some
  - Mental health
  - Sensitive issues for adolescents
  - Abuse
  - Specific notes
Scenario:

Mr. A is a man with schizophrenia who believes that the FBI has placed “invisible” microphones and cameras in his apartment. He takes 1 mg of risperidone daily “to keep my family off my back,” but you are trying to get him to take a higher dose. You have tried to discuss his diagnosis with him, but he dismisses it, and believes that “schizophrenia was made up by the FBI to incarcerate subversives.”

Sample note: Mr. A says he is taking risperidone 1 mg daily but continues to be convinced that the FBI is monitoring him. We disagree on this, as we do about whether or not he has a psychiatric problem. I believe that a higher dose of risperidone would help him with the anxiety he feels about being monitored, but he firmly refused to increase the dose to 2 mg daily. I nevertheless urged him to consider a brief trial of the higher dose, to see if he noticed any subjective benefit. We will continue to assess his overall level of anxiety and how it affects his daily functioning. I am concerned that his anxiety limits his ability to feel safe on a day-to-day basis. He continues to be very interested in current events and reads newspapers and books extensively.
Implementation- with planning can be “non-event”

- Technically “flip switch”
- Realistically need to prepare staff and patients
- Review policies
- Educate and support clinicians about
  - Sensitive note issues
  - Privacy issues for adolescents
  - Proxy access to notes
  - Document mental health visits
  - Potential disagreements with patients
- Let patients know notes available and send reminder about new notes – provider encouragement
Some issues to consider

• Digital divide
  • Language read and spoken
  • Chronically ill
  • Vulnerable populations

• Potential solutions
  • Supply hard copy
  • Log on to patient portal in libraries
  • Link to health navigator projects
  • Proxy access

• IT priorities

• Some roll out in phases

As always-leadership
Where to find more information-opennotes.org

- FAQ
- Toolkits for patients and professionals
- Making the case
- How to start
- Videos and stories
Open Notes globally

- Estonia
- The UK
- Toronto
- Sweden
- Canada
- Others?