How OpenNotes and the Patient Portal Improve Safety and Outcomes
One Teen's Difficult Medical Journey

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Quick Overview

Thank you

OpenNotes

We are Partners

Josh's Story

How PHR and OpenNotes Improve Health and Outcomes

Action Steps for Future

What is OpenNotes?

- A foundation-funded movement to give patients access to their medical providers' chart notes via patient portals

- Not a product or software

- OpenNotes now implemented in 150 health systems reaching more than 27.5 million patients.

OpenNotes Engages Patients and Families

- See full care team chart notes
- Gives holistic view, perspective
- So much more than an after visit summary
- Patients have federal right to chart

What's Your Patient Portal Experience?

- How many of you have been on your portal?

- Were you able to find what you were looking for?

- How many clicks did it take you?

➢My story highlights importance of transparency and portal access to make things easier and safer

My Family's Story

The Question that Changed Everything…

Josh's Difficult Journey

- A whole different take on being unique and special

- 8-month hospital stay in two hospitals in 2015

- Dramatic medical flight to CHOP

Josh's Challenging Journey

- Imagine being in hospital most of 8th and 9th grade

- So grateful for nurturing care at Rainbow

- Ancillary conditions, challenges

- Stages of anger to coping, maturing

Angie's Garden at
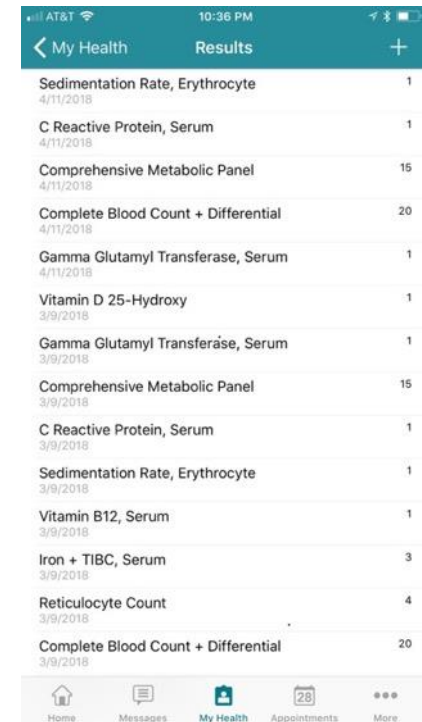
Rainbow Babies
& Children's Hospital

Josh's Challenging Journey

- Fulfillment from being part of NIH research

- Fighting spirit and hope for the future

- Biomedical engineering to invent devices and help people

- Learning self-care and advocacy

Why the Personal Health Record (PHR) is Important:

- Empowers patients with access to information

- Enhances patient safety, experience, communication

- Critical role in chronic illness to learn what to track and monitor

- Healthy patients to ensure preventive care, monitor annual PCP visits, vaccinations to avoid developing problems

- Important for self-care and self-advocacy

- Physician and nursing tool to coach and motivate patients

PHR As Coaching Tool By Care Team

- Teaching us what we need to understand about the disease

- Communicating results promptly while showing us what we can monitor ourselves

- Lets medical team focus on big picture; how best to help patient rather than endless details

PHR gives sense of control that chronic illness takes away
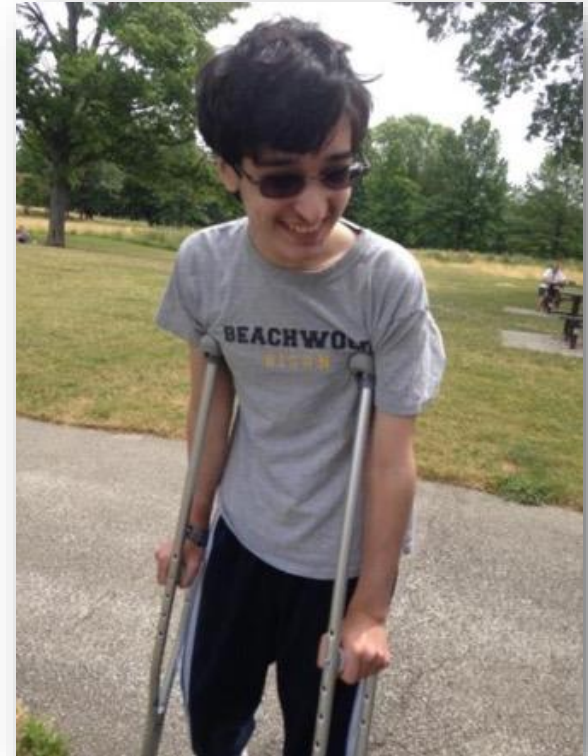
PHR Saves Patient and Family Time

- Quickly see context of lab values and trends

- Use physician messaging to ask a quick question

- Access PHR through the app during an ER visit

- Coordinate care, share labs, tests, chart notes between health systems
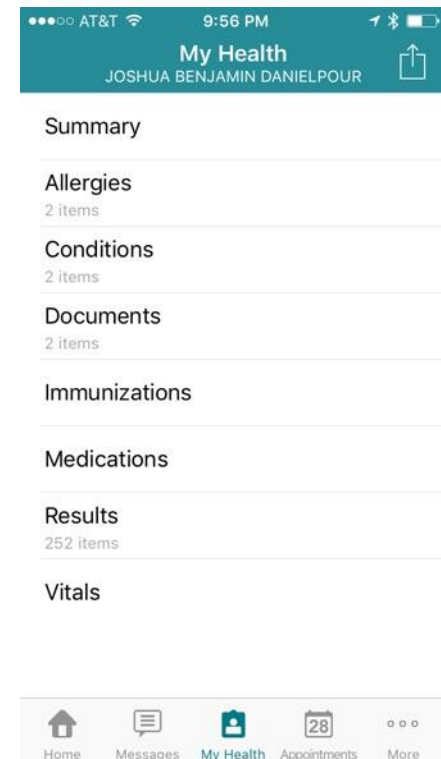
OpenNotes Improves Quality of Documentation

- Traditionally purpose of chart note = communication with other clinicians + billing

- New way = Co-generation of notes

- Collaboration of care between provider, patient and family

- Builds strong relationships

OpenNotes Improves Quality of Documentation

- Problem of poor documenters leads to more adverse events, patient safety risk

- Transitioning from traditional language, ie "patient denies, admits"

- Acronyms are a safety issue

- Using pejorative terms hurts trust

Consider this: 1 out of every 2 adults in the U.S. have a chronic disease, according to the CDC

OpenNotes Increases Transparency, Safety

- Many sets of eyes safer than just the clinician

- Catch problems before they happen

- Asking questions saves lives, improves quality of care

- Identify incorrect medications, dosages, diagnoses, descriptions, symptoms, history, clinician names

OpenNotes Engages Patients and Families

- Colors in the lines of the patient experience
- Helps patient & family review information in their own time
- Reinforce details hard to remember after the visit
- Remember instructions
- Make sure on same page…
- Even if you don't agree with the care plan

> **Are you involved in a PFAC?**

How Patient & Family Advisory Councils Improve Care and Safety

Collaboration of committed patients, families, medical staff and professionals:*

- Make policy and program decisions
- Enhance patient and family experience
- Invite patients/family to be member of health system committees
- Advocates in implementing OpenNotes

**New National Health IT PFAC
sponsored by OpenNotes
and PFCCpartners**

*See related information on PFACs on AHRQ and PFCCpartners web sites, and NEJM Cataylst articles

OpenNotes – Join the Movement

ACTION STEPS

- Patient and Family Advisors as advocates

- OpenNotes.org as a resource – toolkits, FAQs, research

- PFAC toolkit: https://www.opennotes.org/pfac-toolkit

- Find out if your health systems use OpenNotes. Check map listing health systems offering OpenNotes at https://www.opennotes.org/join/map.

  - ✓ If your health system is on the list, ask your clinicians if they are participating in OpenNotes and how to access them
  - ✓ If your health system is not on the list and is sharing notes, contact Deb Wachenheim, Assistant Director, Dissemination at OpenNotes
  - ✓ If your health system is not on the list but you wish they were, explore opennotes.org, contact for support, bring to PFAC or others
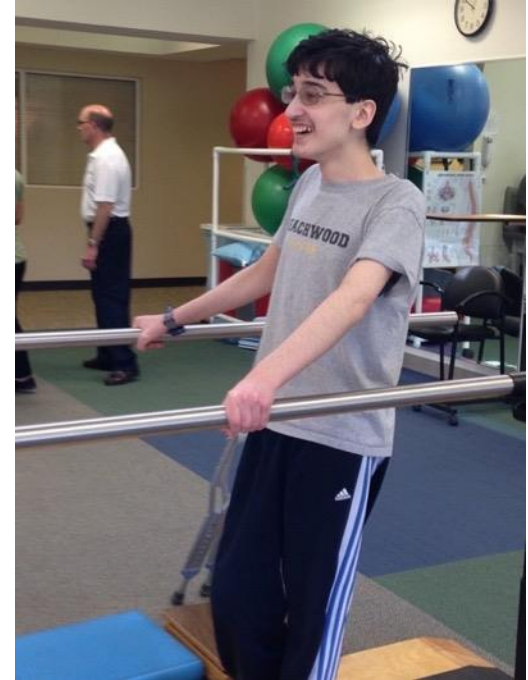
You make all the difference.

Thank you for all you do for patients.

ACTION STEPS

How you can maximize the PHR as a tool:

- Create education and coaching with your PFAC on how to best use the patient portal for patient family needs

Action Steps:

- Make sure front line staff have knowledge to help patients/family.

- Encourage patients/families to sign up for PHR.

- Coach what to watch for; tools they can use.

- Be positive about benefits of registering for and using PHR.

- Plan for patient service issues. If a patient has problem signing up or accessing PHR, what do staff tell them?
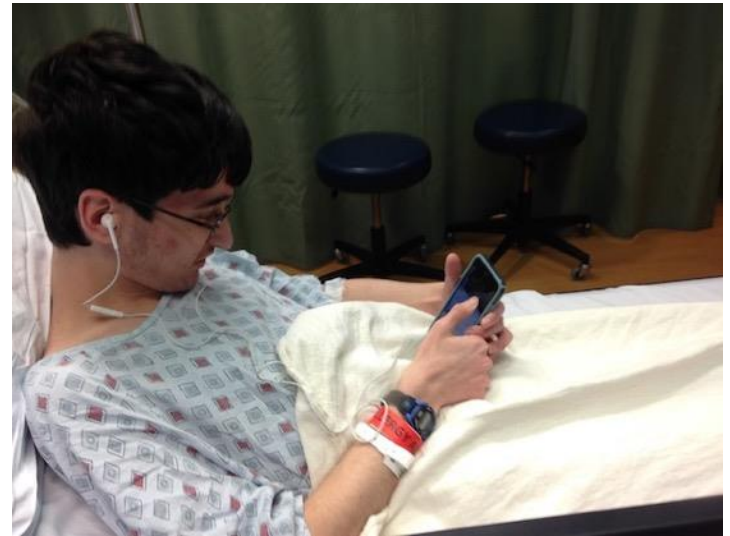
The Portal is Truly a PERSONAL Health Record

- Yes, it's a regulatory requirement, but it is so much more

- PHR is vital part of your patient relationship

- Use it to educate, coach, and engage.

- Improve health and outcomes

Think about…

- **One or two simple action steps you can take when you get home**

Making a Difference from My Son's Journey

University Hospitals Rainbow Babies & Children's Hospital Patient and Family Partnership Council Vice President

University Hospitals Patient-Facing Technology Governance Committee

New National I.T. Patient and Family Partnership Council co-founded by OpenNotes and PFCCpartners

Thank You!

Questions?

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