Open Notes in Pediatrics & with Adolescents

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
Welcome & Introductions

Liz Salmi
Senior Strategist, OpenNotes
Housekeeping

- Attendees are muted.
- During the session, type questions into the “question” section, and we will address them at end of prepared comments.
- Some answers may be provided during the presentation. Those answers will appear underneath your question.
- The presentation recording will be available at opennotes.org and youtube.com/myopennotes
- You will receive an email with links to these presentations.
Open Notes in Pediatrics and with Adolescents

1. Quick background on open notes
2. Open notes at Boston Children’s
3. Open notes at Rady Children’s
4. Q&A
Who/what is open notes?

Cait DesRoches, DrPH
Executive Director, OpenNotes
Associate Professor of Medicine, Harvard Medical School
What is open notes?

When patients can easily read visit notes

OpenNotes

CAMBIA health foundation

Peter G. Peterson Foundation

The Commonwealth Fund

Gordon and Betty Moore Foundation

Beth Israel Deaconess Medical Center

HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

crico

Robert Wood Johnson Foundation
Open Notes Across North America

- 260 organizations
- 54 MILLION people
Empowering Patients in the U.S. Health Care System

Patients in the U.S. need better access to information about their care – information ranging from their medical records to data about the costs and quality of the care they receive.

The Cures Act aims to empower Americans with their health data, delivered conveniently to computers, cell phones, and mobile applications.

Nationwide, patient-centric health IT, once achieved, can deliver a variety of benefits to patients, including:

- Transparency into the cost and outcomes of their care
- Competitive options in getting medical care
- Modern smartphone apps to provide convenient access to their records
- An app economy that provides patients with innovation and choice

Under HIPAA, patients already have a legal right to their data electronically. The ONC Cures Act Final Rule is one step in this process by enhancing access to clinical data.
There are 4 scenarios in which a provider may block information under the “Preventing Harm Exception”.

Under each of these 4 scenarios:

- The provider must reasonably believe that blocking access to information will substantially reduce the risk of harm to the patient or another person.
- Blocking access to information should be no broader than necessary to substantially reduce the risk of harm.
Boston Children’s

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OpenNotes: Opportunities

Benefits for Pediatric and Adolescent Population

• Assists in patient and family empowerment
• Information sharing among multiple caregivers
• Provides a longitudinal medical narrative
• Care coordination for patients with special healthcare needs
  • Combat fragmentation and incomplete health information
• Facilitates transition of care from adolescence to adulthood

C Sarabu et al, Pediatrics, 2018
Pediatric & Adolescent Challenges

1. Adolescent confidentiality
   • Reproductive health, sexually transmitted illnesses, substance abuse, mental health
   • Varies by state
   • Expectation information withheld from parent(s)

2. Information provided by parent with expectation of confidentiality
   • Adoption, misattributed paternity, parental substance abuse, domestic violence, maternal prenatal test results, etc.
   • Expectation information withheld from adolescent, other parent, or both

3. Impact on Patient/Parent-Provider relationship
   • Disagreements regarding diagnosis or treatment plan
   • Suspicion of medical child abuse
Open Notes at Boston Children’s

MyChildren’s Patient Portal

- 140,000 users
- 35,000 unique user logins/month
- Hybrid Cerner and Epic portals
- First launched 2007
<table>
<thead>
<tr>
<th>Patient’s Age</th>
<th>Parent/Guardian access</th>
<th>Patient Access</th>
<th>Registration</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 13 yrs</td>
<td>All medical information, except select confidential data</td>
<td>None</td>
<td>Registration by parent; Screening by PHR administrator.</td>
</tr>
<tr>
<td>13-17 yrs</td>
<td>Most information, except sensitive/confidential data</td>
<td>Most information except sensitive/confidential data</td>
<td>Patient registration at age 13; no parental consent; confidentiality and sensitive test rules in place.</td>
</tr>
<tr>
<td>≥ 18 yrs</td>
<td>None, unless access rights to others granted by patient, law or court order</td>
<td>All medical information except historical confidential data</td>
<td>Patient assumes sole ownership of PHR; Guardianship documents as needed.</td>
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Bourgeois et al, JAMIA, Nov/Dec 2008
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OpenNotes at BCH: Implementation

Leveraged an ambulatory-wide project in 2014

- Introduced confidential note types for every clinic
- Non-confidential notes released to patient portal

Individual meetings with high-risk clinics

- Psychiatry, Adolescent, Gynecology, Child Protection, Adolescent Substance Abuse Program
- Clinics asked for initial deferral and option to join later
- Technical limitation at the time requiring appropriate note selection at the time of note creation
  - Concern that rotating trainees would not choose the correct note type
  - Excluded inpatient and ED notes
<table>
<thead>
<tr>
<th></th>
<th>Parent</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Understand reason for test</strong></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>451(32.4)</td>
<td>1745(33.4)</td>
</tr>
<tr>
<td>Very much</td>
<td>598(43)</td>
<td>2102(40.2)</td>
</tr>
<tr>
<td><strong>Remember to get tests done</strong></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>257(18.5)</td>
<td>1080(20.6)</td>
</tr>
<tr>
<td>Very much</td>
<td>345(24.8)</td>
<td>1267(24.2)</td>
</tr>
<tr>
<td><strong>Understand test result</strong></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>417(30)</td>
<td>1800(34.4)</td>
</tr>
<tr>
<td>Very much</td>
<td>632(45.5)</td>
<td>2048(39.1)</td>
</tr>
<tr>
<td><strong>Understand reason for referral</strong></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>207(32.6)</td>
<td>777(32.9)</td>
</tr>
<tr>
<td>Very much</td>
<td>305(48)</td>
<td>1005(42.5)</td>
</tr>
<tr>
<td><strong>Remember to go to referral appointment</strong></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>138(21.7)</td>
<td>498(21.1)</td>
</tr>
<tr>
<td>Very much</td>
<td>233(36.7)</td>
<td>773(32.7)</td>
</tr>
<tr>
<td><strong>Take medications better as prescribed</strong></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>184(17.7)</td>
<td>581(16)</td>
</tr>
<tr>
<td>Very much</td>
<td>234(22.5)</td>
<td>708(19.5)</td>
</tr>
</tbody>
</table>
# Patient/Family Feedback on Visit Notes

## 10 item online feedback survey

- How well did the note describe the visit
- How well did the respondent understand the care plan
- Were there any inaccuracies in the note
- Was there any language that the respondent found bothersome
- Voluntary positive feedback for the provider

## Adult and Pediatric Sites

<table>
<thead>
<tr>
<th>Site</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Academic Hospital</td>
<td>2 primary care practices and OB/GYN practices</td>
</tr>
<tr>
<td>Children’s Hospital</td>
<td>Primary care and Subspecialty clinic notes (except confidential)</td>
</tr>
<tr>
<td>Atrium Health (NET)</td>
<td>Primary care, urgent care and specialty clinics</td>
</tr>
<tr>
<td>Reporting tool item</td>
<td>AD</td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Number of completed reports, n</td>
<td>780</td>
</tr>
<tr>
<td>Understood the note, n (%)</td>
<td>734 (94)</td>
</tr>
<tr>
<td>Understood the care plan, n (%)</td>
<td>739 (95)</td>
</tr>
<tr>
<td>Expected to follow the care plan, n (%)</td>
<td>313 (98)</td>
</tr>
<tr>
<td>Potential documentation inaccuracy, total n (%)</td>
<td>193 (25)</td>
</tr>
<tr>
<td>Yes</td>
<td>175 (22)</td>
</tr>
<tr>
<td>Not sure</td>
<td>18 (2)</td>
</tr>
<tr>
<td>Concerning results identified n (%)</td>
<td>51 (15)</td>
</tr>
<tr>
<td>Results not previously discussed with provider, n (%)</td>
<td>7 (14)</td>
</tr>
<tr>
<td>Bothersome words noted, n (%)</td>
<td>30 (9)</td>
</tr>
<tr>
<td>Positive feedback volunteered, n (%)</td>
<td>528 (68)</td>
</tr>
</tbody>
</table>

Bourgeois et al, *JAMIA*, 2019
<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>PED</th>
<th>NET</th>
<th>ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptoms</strong></td>
<td>31 (16)</td>
<td>40 (29)</td>
<td>14 (21)</td>
<td>85 (21)</td>
</tr>
<tr>
<td><strong>Health problems</strong></td>
<td>38 (20)</td>
<td>33 (24)</td>
<td>13 (20)</td>
<td>84 (21)</td>
</tr>
<tr>
<td><strong>Medications</strong></td>
<td>40 (21)</td>
<td>24 (17)</td>
<td>10 (15)</td>
<td>74 (18)</td>
</tr>
<tr>
<td><strong>Something important was missing</strong></td>
<td>29 (15)</td>
<td>23 (16)</td>
<td>6 (9)</td>
<td>58 (15)</td>
</tr>
<tr>
<td><strong>Family history</strong></td>
<td>17 (9)</td>
<td>18 (13)</td>
<td>5 (8)</td>
<td>40 (10)</td>
</tr>
<tr>
<td><strong>Physical exam</strong></td>
<td>15 (8)</td>
<td>13 (9)</td>
<td>7 (11)</td>
<td>35 (9)</td>
</tr>
<tr>
<td><strong>Social history</strong></td>
<td>8 (4)</td>
<td>5 (4)</td>
<td>7 (11)</td>
<td>20 (5)</td>
</tr>
<tr>
<td><strong>Names of health care providers</strong></td>
<td>7 (4)</td>
<td>15 (11)</td>
<td>2 (3)</td>
<td>24 (6)</td>
</tr>
<tr>
<td><strong>Appointment scheduling</strong></td>
<td>2 (1)</td>
<td>6 (4)</td>
<td>2 (3)</td>
<td>10 (2)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>52 (27)</td>
<td>38 (27)</td>
<td>37 (56)</td>
<td>127 (32)</td>
</tr>
</tbody>
</table>
Bothersome Language

- Language related to stigmatized diagnoses
- Language perceived as being critical
- Misrepresentation of communication with other clinicians
- Language perceived as signaling distrust of information provided
<table>
<thead>
<tr>
<th>Safety Concern</th>
<th>AD</th>
<th>PED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Safety Concerns*, n</td>
<td>137</td>
<td>107</td>
</tr>
<tr>
<td>Resolved in Conversation, n (%)</td>
<td>44 (32)</td>
<td>9 (8)</td>
</tr>
<tr>
<td>Declined Intervention, n (%)</td>
<td>3 (2)</td>
<td>3 (3)</td>
</tr>
<tr>
<td>Change Made to Medical Record or to Patient’s Care, n (%)</td>
<td>76 (55)</td>
<td>72 (67)</td>
</tr>
<tr>
<td>Request for Amendment Declined, n (%)</td>
<td>4 (3)</td>
<td>14 (13)</td>
</tr>
<tr>
<td>Formal Amendment Request initiated, n (%)</td>
<td>2 (2)</td>
<td>0</td>
</tr>
<tr>
<td>Defer to Patient Relations, n (%)</td>
<td>8 (6)</td>
<td>9 (8)</td>
</tr>
</tbody>
</table>

* 59% at AD and 54% at PED were identified as actual or possible safety concerns

Bourgeois et al, JAMIA, 2019
Positive Feedback

“I love this feature of being able to view the note! It perfectly summarized the visit and was nice to be able to reference and share with my husband who wasn't able to make the appointment. I appreciate Dr [...] taking the time to write such a detailed update.”

“I greatly appreciate the level of detail and thought put into these notes. I realize this takes a lot of time and I am grateful for that time. The notes accurately reflect my concerns and show you really listened as well as provided concrete steps for a path forward and reassurance.”

“We are so grateful to have the notes to review of [Patient’s] apts. It is overwhelming as a parent to absorb all of the information at the time of the visit so the notes are very helpful to review.”
Confidential Notes: How are they used?

June 1, 2016– May 31, 2017 (patients <18 years only)

<table>
<thead>
<tr>
<th>Clinic Notes Created</th>
<th>402,964</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidential Visit Note**</td>
<td>9,346 (2.3% of all notes)</td>
</tr>
<tr>
<td>Confidential Notes Reviewed</td>
<td>1,100 (12.5% of confidential notes)</td>
</tr>
</tbody>
</table>

**Excluded clinics that had opted out of the initial go-live (ASAP, GYN, Adolescent, Child Protection, Psychiatry)

Confidential Screening Questions

- Confidential Information
  - 58\% \( n = 639 \)
- Confidential Screening Questions
  - 26\% \( n = 283 \)
- None
  - 16\% \( n = 175 \)

C Parsons et al, JAMIA, 2020
Confidential Notes: Results

- Female sex: 2.69% (vs 1.98% for male sex), p < .001
- Increased age: 4.2% (>13 yrs) vs 1.8% (<13 yrs)
Confidential Information

- Patient's Mental Health
- Patient's Substance Abuse
- Patient's Sexual Hx / Health
- Patient's Violence / Abuse
- Guardian's Mental Health
- Guardian's Substance Abuse
- Guardian's Sexual Hx / Health
- Guardian's Violence / Abuse
- Social Situation
- Legal Connotation
- Disagreements
- Foster Family / Custody
- Medical Child Neglect
- Paternity

C Parsons et al, JAMIA, 2020
Behavioral and Mental Health Concerns

• Included in 53.8% of notes reviewed

• Providers often documented meeting separately with patient and parent

• Some notes noted mental health diagnoses in family members
  • 15.9% of notes documented parental mental health diagnosis
  • Impact on ability to manage the patient’s medical care
  • Documented in mental health provider, primary care, and subspecialist notes
Other Confidential Information

Sexual /reproductive health and gender identity
- Patient related information (12.5%)
  - Sexual practices, STIs, contraceptive use
  - Gender identity and management
- Maternal information (2.5%)
  - Neonatal infectious diseases clinic
  - Perinatal exposure to HIV and Hep C

Physical and/or sexual abuse
- Patient (3.1%) or Parent (1.5%)

Social Services involvement (1.5%)

Complex Social Situations (10.5%)

Disagreements related to diagnosis or plan of care (1.7%)
Exceptions Under Which Information Does Not Need to Be Shared

Preventing Harm
- A clinician may choose not to provide access, exchange, or use of an individual’s EHI to prevent physical harm to a patient or another person

Privacy
- A clinician may choose not to provide access, exchange, or use of an individual’s EHI if doing so fulfills the wishes of the individual

Required by Law
- Where a particular access, exchange, or use of EHI is prohibited by applicable Federal, State, or tribal law, a clinician may choose not to provide access, exchange, or use of an individual’s EHI

Psychotherapy Notes
- A clinician may choose not to provide access, exchange, or use of an individual’s notes recorded by a health care provider who is a mental health professional documenting or analyzing the contents of a conversation during a private counseling session and that are maintained separate from the rest of the patient's medical record

Legal Proceedings
- A clinician may choose not to provide access, exchange, or use of an individual’s EHI if the information is compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding.
21st Century Cures Act: BCH Strategy

Current State

• Release of inpatient, ED and outpatient notes
  • Unless designated confidential based on appropriate exception
  • Unique Exceptions:
    • Child Protection Team
    • Inpatient Psychiatric Unit

• Autotext for justification of confidential status
  • This note has been denoted confidential due to the 21st Century Cures Act [dropdown: Privacy, Preventing Harm, Child Protection, Protected Minor Information] exception.
Thank you

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| Integrated delivery network with acute, primary and specialty care |
| Enterprise Epic with patient portal MyChart |
| 68% of patients MyChart active as of January 31, 2021 |
| 260,000 MyChart users |
| Telemedicine platform relies on MyChart |

| Unique patient logins/month |
| 16,000 via web |
| 10-35,000 via mobile app |

![Graph showing mobile users logged in from August 2020 to March 2021.](image_url)
Our Open Notes Journey

- 2/17 Family Advisory Council letter to CMIO
- 11/17 Call for opt-out in all areas
- 5/18 Inpatient discharge summaries opt-out
- 8/18 Emergency Department and Urgent Care opt-out
- 8/15 Developmental Services pilot opt-in
- 9/16 Developmental Services all notes opt-in
- 4/17 Specialty Clinics opt-in
- 9/17 Primary Care opt-out
- 2/18 Specialty Clinics opt-out
- 7/17 Primary Care pilot – 6 providers. Initially opt-in then quickly to opt-out
- 2/16 Teen MyChart live
- 12/16 Developmental Services opt-out
Are You In or Are You Out? Provider Note Sharing in Pediatrics

Mario Bialostozky\textsuperscript{1,2} Jeannie S. Huang\textsuperscript{2,3} Cynthia L. Kuelbs\textsuperscript{2,4}

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2 Department of Pediatrics, University of California, San Diego, California, United States
3 Division of Pediatric Gastroenterology, Hepatology, and Nutrition, Rady Children's Hospital-San Diego, San Diego, California, United States
4 Rady Children's Hospital-San Diego, Division of Pediatric Gastroenterology, Hepatology, and Nutrition, 3020 Children's Way, San Diego, CA 92123, United States

Address for correspondence Mario Bialostozky, MD, Department of Emergency Medicine, Rady Children's Hospital–San Diego, 3020 Children's Way, San Diego, CA 92123, United States

Notes Shared by Month

- Opt-Out Note Sharing
- Opt-In Note Sharing
Current Settings

- Every clinical note written by a provider shared by default unless marked sensitive or from a confidential department.
- For patients < 12 years of age and/or with diminished capacity, default release is to proxy.
- **For those aged 12 years and older, notes released to the patient.**
- **Teen access requires parental consent.**

Beginning March 1, 2021 will share all notes in the 21st Century CURES data set unless marked sensitive.
Adolescents and Young Adults

• Is it worth sharing notes with AYA?
• Do they understand the notes?
• Is this something valuable?
Adolescents and young adults (AYA) with chronic GI/liver disease provided most recent medical visit note to read:

<table>
<thead>
<tr>
<th>Surveyed on accuracy of information/how visit events documented</th>
<th>Characterized their health status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Took the short Test of Functional Health Literacy in Adults</td>
<td>Asked if change in medical management occurred</td>
</tr>
<tr>
<td>Two physicians read the notes and answered same questions about health status and medical management</td>
<td>Asked if wanted to edit the note</td>
</tr>
</tbody>
</table>

% patients whose medical note comprehension agreed with physician readers calculated:

Medical note sharing enhances patient–physician relationships, increases medication adherence, and improves self-care. However, many institutions do not release medical notes to adolescents, citing poor understanding and patient harm concerns. We evaluated the results of medical note sharing among adolescents with chronic disease and found high satisfaction and adequate comprehension. (J Pediatr 2019;215:264-8).
Patients reported high satisfaction with health status documentation (8.7/10) as well as with documentation of visit events (9.2/10).

Majority (62-64%) of participants had similar interpretation on whether change in management occurred and overall health status when compared to physician reader.

Health literacy, satisfaction and comprehension did not differ across AYA by age, ethnicity or gender.
Inpatient Mental Health Notes

AYA with active behavioral health concerns understand and express satisfaction with their medical documentation.

Adolescents and young adults (AYA) admitted to inpatient psychiatric unit given most recent medical note to read.

N=20, mean age 16 years, 55% white, 30% Black, 15% > 2 races

Surveyed on understanding of/satisfaction with:
- Description of health issues
- Reason for inpatient admission
- Whether note needed edits

19 of 20 demonstrated adequate functional health literacy on the short Test of Functional Health Literacy in Adults.

The psychiatry provider who authored the notes was surveyed at least the next day to assess impact note sharing had on subsequent inpatient counseling sessions and therapy compliance.

Participants comprehended their note, were satisfied with the content of their note, regarding description of mental health issues and reasons for inpatient admission/care.
Six participants suggested edits to their note; none cited confidentiality concerns.

The psychiatry provider reported that note sharing had an overall positive or negligible effect on inpatient counseling sessions and therapy compliance.

Dohil I, Cruz R, Sweet H, Huang JS. Sharing Notes with Adolescents and Young Adults Admitted to an Inpatient Psychiatry Unit. JAACAP, 2020 October
Child Abuse

- Can some child abuse consult notes be shared?
- What protections should be considered if abuse an issue?
Rady Child Abuse Reporting

Created an electronic process which would:

- Meet the California state requirements for child abuse reporting
- Be easy/accessible for mandated reporters
- Provide easy access for case review
- Generate data for analysis
- Work in all environments for all clinicians
- Protect child abuse records from being inappropriately released
Child Abuse Report Filed

- Automated by note type
  - If child abuse report filed, flag is automatically set that restricts portal functionality
  - No past visit information
  - Can still see upcoming appointments, lab and imaging results and can message care teams
  - Currently no end date to this restriction – working to define process to rescind restriction. Can incorporate into existing audit process
  - Working on standardizing approach to review whether the offending parent/legal guardian’s access to the portal should be deactivated

- Child Protection Team Consult notes defaulted to sensitive and aren’t shared

Can some child protection team consult notes be shared?
Medical Child Abuse

• Formerly known as Munchausen Syndrome by Proxy
• Term used to describe unnecessary and harmful, or potentially harmful, medical care at the instigation of a caregiver
• Caregivers exaggerate, fabricate, or induce symptoms that result in unnecessary and potentially dangerous medical procedures
• The medical system is manipulated into taking part in a child’s physical and/or psychological maltreatment
Medical Child Welfare Taskforce

• Providers may have concerns about medical child abuse, are reluctant to document those concerns or feel pressured to engage in the interventions being requested by parents
• Worry that notes documenting concerns will be released to parent and result in harm to patient
• Multidisciplinary team reviews cases and supports medical decision making by treating providers to empower them to provide standard care and reduce/prevent ongoing medical child abuse

• Accomplishments to date:
  • Clinician education on warning signs of medical child abuse
  • Identification and tracking of patients through registry
  • System alerts
  • Follow-up initiated with outside physicians/institutions when patients leave the RCHSD health system so that MCA can be more easily identified and treated
Electronic Medical Record Tools

- Problem list entry
  - Risk of harm due to overutilization of healthcare – Z91.89
- Disease registry to manage children where concern identified
- Emergency care plan to communicate concerns to and provide guidance for clinicians
- Medical child welfare smart form to capture referrals, concerns, overview of case, time spent
- InBasket workflow to communicate concerns to specialists engaged in care for these patients
Electronic Medical Record Tools

- Child abuse report
- Not all patients have child abuse report to trigger action

Medical child welfare case summary in the displays in the registry with hyperlink to smartform.
I am one of the members of the RCHSD Medical Child Welfare Task Force. We review cases in which there is a concern for overutilization of the medical system and possible Medical Child Abuse (formerly known as Munchausen Syndrome by Proxy). Upon review by our multidisciplinary team, we have determined that there is a concern that this patient may be having unnecessary and potentially dangerous medical evaluations/procedures at the insistence of their caregiver. Our current recommendation is that no additional testing/procedures be ordered without significant consideration being given to their necessity for this child's overall health and well-being.

Should you have any questions regarding this please feel free to contact us for further clarification.
Emergency Care Plan: A Provider-to-Provider Communication Tool

Background

- Patients with rare or complex medical conditions often have specific needs that must be quickly addressed in emergency care situations.
- This information is usually documented in Epic within specialty notes.
- Due to the time constraints and high patient volume faced by emergency care providers, review of all pertinent information may be missed or delayed when relying only on electronic medical records, which can result in inappropriate or delayed treatment.

Methods: Build

Figure 1. Emergency Care Plan Note SmartForm

- New Build:
  - Emergency Care Plan (ECP) (Figure 1).
  - Note Type: Emergency Care Plan with prior note copied forward.
  - Providers complete and sign individual ECPs.
  - FYI flag with type “Emergency Care Plan”.
  - FYI flag triggers a banner which alerts all providers that the patient has an ECP with direct link to an ECP report.
  - ECP note content displayed at top of “Review Visit” for the Emergency Department (ED).

- Education:
  - Hospital-wide committee meetings.
  - Division leadership and Medical Informatics Champions.
  - Individual division meetings (ongoing).

- Data Collection:
  - One year post-implementation survey sent to ED providers, including a balancing measure of whether ECP was disruptive.
  - Evaluated # ECP notes by specialty, and # distinct patients.

- Results

Since go-live in March 2018, a total of 229 Emergency Care Plan notes have been filled for 186 unique patients (Figure 4).

Most common subjects in ECPs included:

- Emergency treatment plans for patients with rare disorders (e.g., metabolic disorders, bleeding disorders).
- Management recommendations (chronic pain, medication therapy, etc.).

- Porcelain stenosis, ED providers surveyed (n=18).
- Average of 5 patients with ECPs. Of those seen in one ECP (n=15), a majority felt that the ECP was helpful, improved care, and prevented them from ordering repeat radiographs.

Limitations

- Study did not include the subjectivity of survey data.
- Despite high variability of ECP content, highlights patients with new disorders or ECPs, objectives such as patient education are more challenging to obtain.

Inclusions/Next Steps

- ECP has been widely used at RCHSD as a tool for other care providers to communicate information and other crucial information with emergency care providers with ECPs now documented on 177 patients.
- ED providers reported high satisfaction with the ECP 1 year post-implementation, and none found it disruptive.
- Next steps include additional targeted education to other specialty providers and further analysis of the time to obtaining recommended treatment for similar patients (e.g., patients with metabolic disorders) with and without an ECP in place.

Acknowledgements

Thanks to other members of the Emergency Care Plan workgroup: Daniel Heidelpy, MD, Katherine Friesma, MD, Jerry Kim, MD, Rebecca Bennett, FCPPID-BC, Denise Ogueme, APNP-BC, and Brian Demers.

Address correspondence to Amy Chang at achong@rchsd.org.
Release Restriction

- Only trigger currently is for those patients with a child abuse report filed
- Problem list entry is sensitive
- *Child protection team notes are automatically marked sensitive but other notes may contain information detailing concerns for medical child abuse*
- Can trigger note release restriction based on problem list entry

Notes containing information detailing concerns for medical child abuse meet the preventing harm standard with 21st Century CURES
Other Designated Caregiver and Adult Application for MyChart Proxy Access

Completion of this application is not a guarantee that MyChart access will be provided. Foster parents applying for access: please note that this request will be sent to a San Diego County Social Worker for their review and approval. For other requestors requesting access to a minor child’s MyChart account, a Caregivers’ Authorization Affidavit must be on file for this patient in order for you to be considered.

The individual completing this form is requesting access (“Proxy Access”) to portions of the above named patient’s records via Rady Children’s Hospital-San Diego MyChart.
Patients with Eating Disorders

• Questions:
  • Should the weights be shared? Would it be therapeutic or harmful?
  • Should the notes be shared? Is it therapeutic or harmful?
  • Should portal access be blocked for a defined period of time?

• 21st Century CURES clear that must be individualized

"Only in specific circumstances do we believe delaying patients’ access to their health information so that providers retain full control over when and how it is communicated could be both necessary and reasonable for purposes of substantially reducing a risk of harm cognizable under § 171.201(d)."

“Circumstances where § 171.201 would apply to such delay are those where a licensed health care professional has made an individualized determination of risk in the exercise of professional judgment consistent with § 171.201(c)(1)’’

- (c) Type of risk: The risk of harm must: (1) Be determined on an individualized basis in the exercise of professional judgment by a licensed health care professional who has a current or prior clinician-patient relationship with the patient whose EHI is affected by the determination;
Thank you

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

### Open Oncology Notes
**MONDAY, MARCH 8: Webinar @ noon ET**
- Rosie Bartel, patient advocate
- Everett Weiss, MD, Memorial Sloan Kettering
- Bertram Yuh, MD, City of Hope Cancer Center

### Open Inpatient Notes at UC San Diego Health
**TUESDAY, MARCH 23: Webinar**
- Brian Clay, MD, UC San Diego Health

### OpenNotes Walk-In Clinic
**MARCH 29-APRIL 2: Live, 2-hours, every day**
- John Santa, MD, MPH
- Deb Wachenheim, MPP
- Liz Salmi
- + special guests
Q&A

Open Discussion
Open Notes in Pediatrics & with Adolescents

Office Hours
Tuesday, February 23 • Noon-1pm Eastern

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