

Open Notes in Pediatrics & with Adolescents

Office Hours

Tuesday, February 23 • Noon-1pm Eastern



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Welcome & Introductions



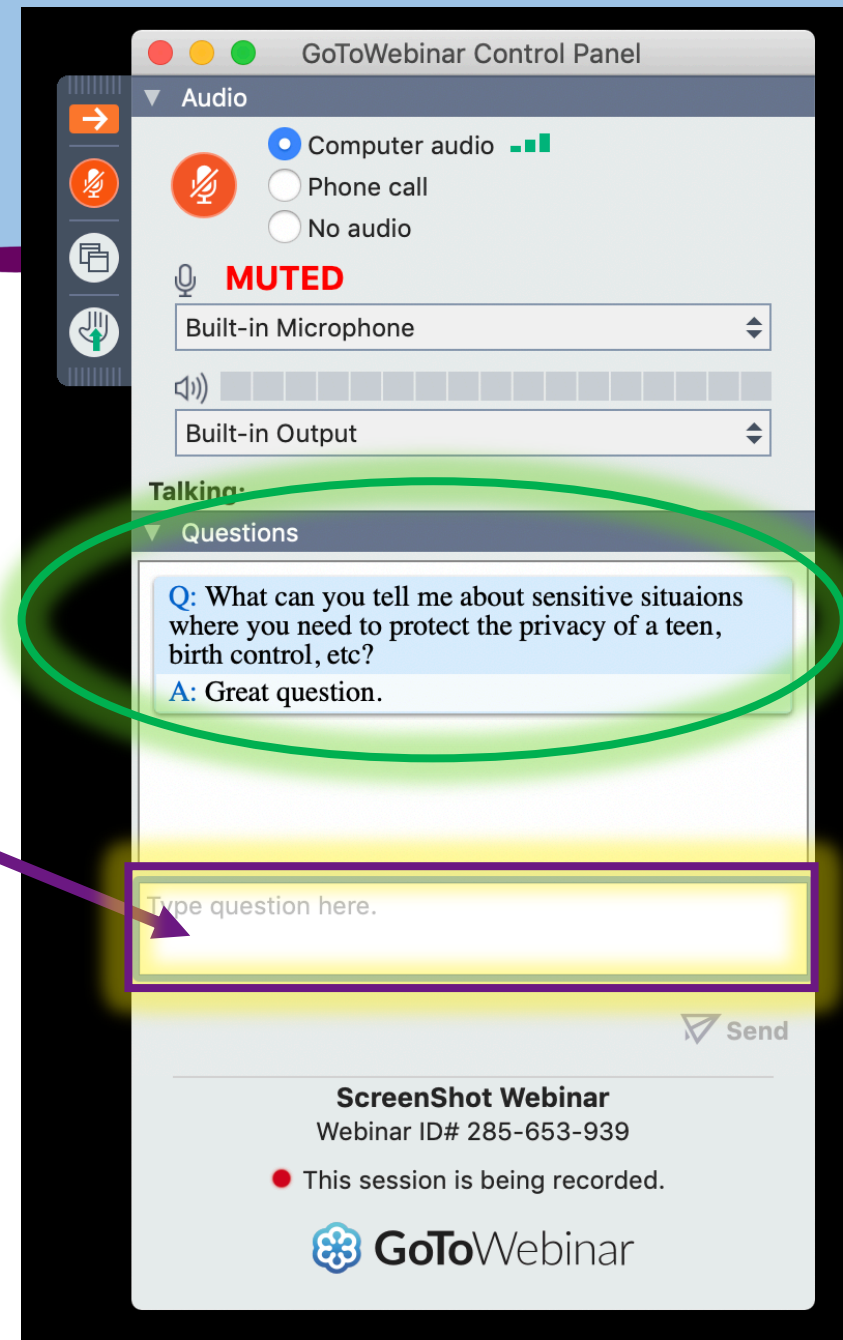
Liz Salmi

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

Beth Israel Deaconess
Medical Center



What is open notes?

When patients can easily read visit notes

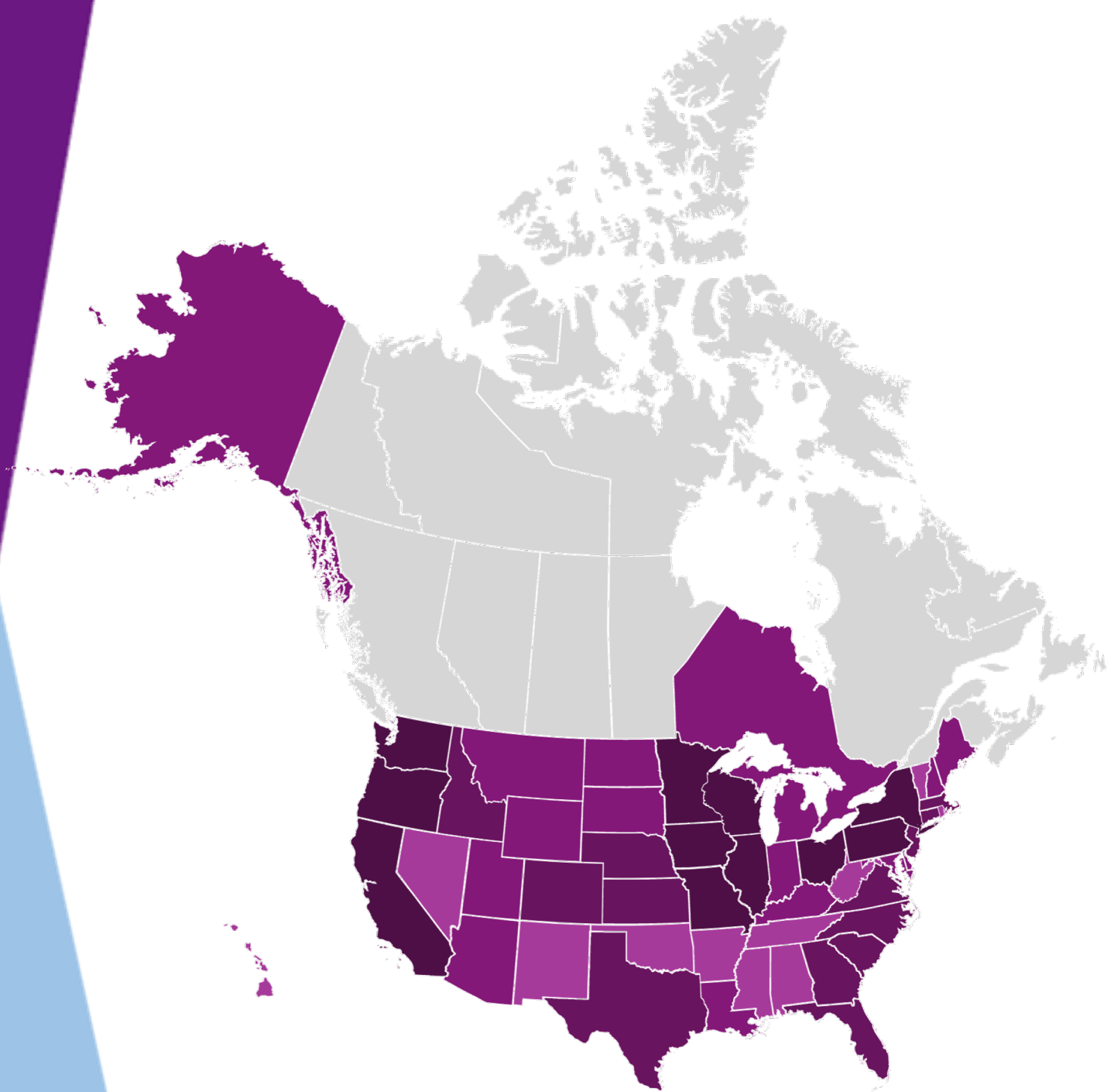


HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL





Open Notes Across North America

- ✓ **260** organizations
- ✓ **54 MILLION** people



April 5, 2021

 An official website of the United States government [Here's how you know](#) ✓

 **ONC's Cures Act Final Rule** MENU

[Home](#) > [Final Rule Policy](#) > Patient Access

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.



Clinical Notes ***NEW**

1. Consultation Note
2. Discharge Summary Note
3. History & Physical
4. Imaging Narrative
5. Laboratory Report Narrative
6. Pathology Report Narrative
7. Procedure Note
8. Progress Note

<https://www.healthit.gov/curesrule/final-rule-policy/empowering-patients-us-health-care-system>



Federal “Preventing Harm Exception”

(See 45 CFR § 171.201)

- 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

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

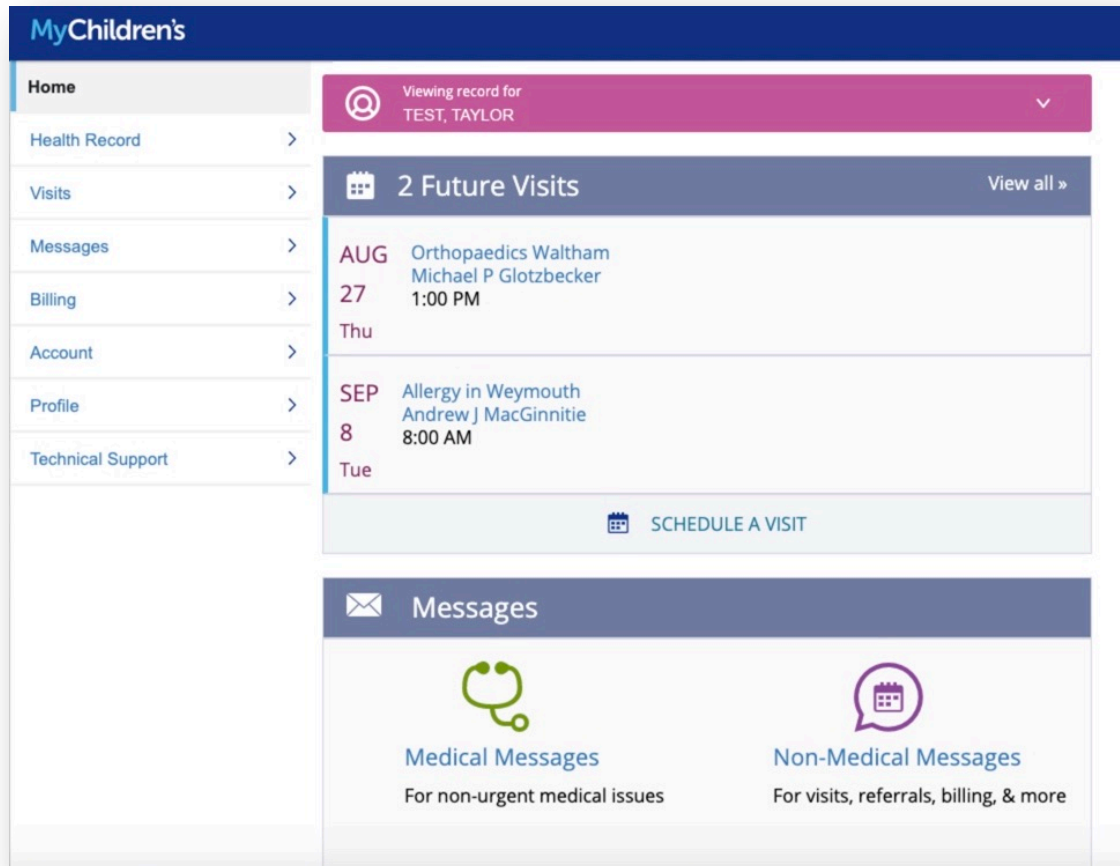
- Adoption, misattributed paternity, parental substance abuse, domestic violence, maternal prenatal test results, etc.
- Expectation information withheld from adolescent, other parent, or both

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



Patient' s Age	Parent/Guardian access	Patient Access	Registration
< 13 yrs	All medical information, except select confidential data	None	Registration by parent; Screening by PHR administrator.
13-17 yrs	Most information, except sensitive/confidential data	Most information except sensitive/confidential data	Patient registration at age 13; no parental consent; confidentiality and sensitive test rules in place.
≥ 18 yrs	None, unless access rights to others granted by patient, law or court order	All medical information except historical confidential data	Patient assumes sole ownership of PHR; Guardianship documents as needed.

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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



Effect of reading notes on patient and parent perceptions of ambulatory safety-related knowledge and behaviors

		Parent	Patient
Understand reason for test		N (%)	N (%)
	<i>Quite a bit</i>	451(32.4)	1745(33.4)
	<i>Very much</i>	598(43)	2102(40.2)
Remember to get tests done			
	<i>Quite a bit</i>	257(18.5)	1080(20.6)
	<i>Very much</i>	345(24.8)	1267(24.2)
Understand test result			
	<i>Quite a bit</i>	417(30)	1800(34.4)
	<i>Very much</i>	632(45.5)	2048(39.1)
Understand reason for referral			
	<i>Quite a bit</i>	207(32.6)	777(32.9)
	<i>Very much</i>	305(48)	1005(42.5)
Remember to go to referral appointment			
	<i>Quite a bit</i>	138(21.7)	498(21.1)
	<i>Very much</i>	233(36.7)	773(32.7)
Take medications better as prescribed			
	<i>Quite a bit</i>	184(17.7)	581(16)
	<i>Very much</i>	234(22.5)	708(19.5)

S Bell et al, *J Patient Saf*, 2018



Patient/Family Feedback on Visit Notes

Adult and Pediatric Sites

Adult Academic Hospital

- 2 primary care practices and OB/GYN practices

Children's Hospital

- Primary care and Subspecialty clinic notes (except confidential)

Atrium Health (NET)

- Primary care, urgent care and specialty clinics

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

Characteristics of Patient Reporting System Responses

Bourgeois et al, *JAMIA*, 2019

Reporting tool item	AD	PED	NET
Number of completed reports, n	780	402	258
Understood the note, n (%)	734 (94)	363 (90)	215 (87)
Understood the care plan, n (%)	739 (95)	377 (94)	225 (92)
Expected to follow the care plan, n (%)	313 (98)	367 (97)	N/A
Potential documentation inaccuracy, total n (%) [‡]	193 (25)	139 (35)	66 (28)
Yes	175 (22)	123 (30)	55(23)
Not sure	18 (2)	16 (4)	11 (5)
Concerning results identified n (%)	51(15)	57 (14)	N/A
Results not previously discussed with provider, n (%)	7 (14)	12 (21)	N/A
Bothersome words noted, n (%)	30 (9)	33 (8)	N/A
Positive feedback volunteered, n (%)	528 (68)	170 (42)	N/A

Continued

	AD	PED	NET	ALL
Symptoms	31 (16)	40 (29)	14 (21)	85 (21)
Health problems	38 (20)	33 (24)	13 (20)	84 (21)
Medications	40 (21)	24 (17)	10 (15)	74 (18)
Something important was missing	29 (15)	23 (16)	6 (9)	58 (15)
Family history	17 (9)	18 (13)	5 (8)	40 (10)
Physical exam	15 (8)	13 (9)	7 (11)	35 (9)
Social history	8 (4)	5 (4)	7 (11)	20 (5)
Names of health care providers	7 (4)	15 (11)	2 (3)	24 (6)
Appointment scheduling	2 (1)	6 (4)	2 (3)	10 (2)
Other	52 (27)	38 (27)	37 (56)	127 (32)

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

	AD	PED
Total Safety Concerns*, n	137	107
Resolved in Conversation, n (%)	44 (32)	9 (8)
Declined Intervention, n (%)	3 (2)	3 (3)
Change Made to Medical Record or to Patient's Care, n (%)	76 (55)	72 (67)
Request for Amendment Declined, n (%)	4 (3)	14 (13)
Formal Amendment Request initiated, n (%)	2 (2)	0
Defer to Patient Relations, n (%)	8 (6)	9 (8)

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

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.”

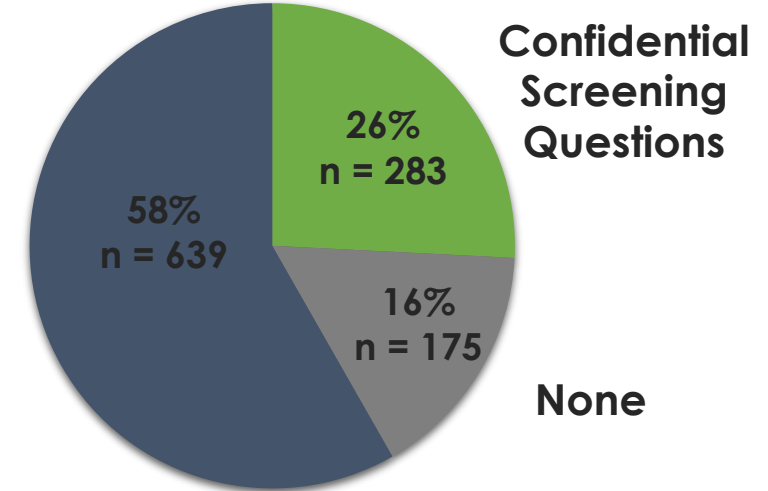
Confidential Notes: How are they used?

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

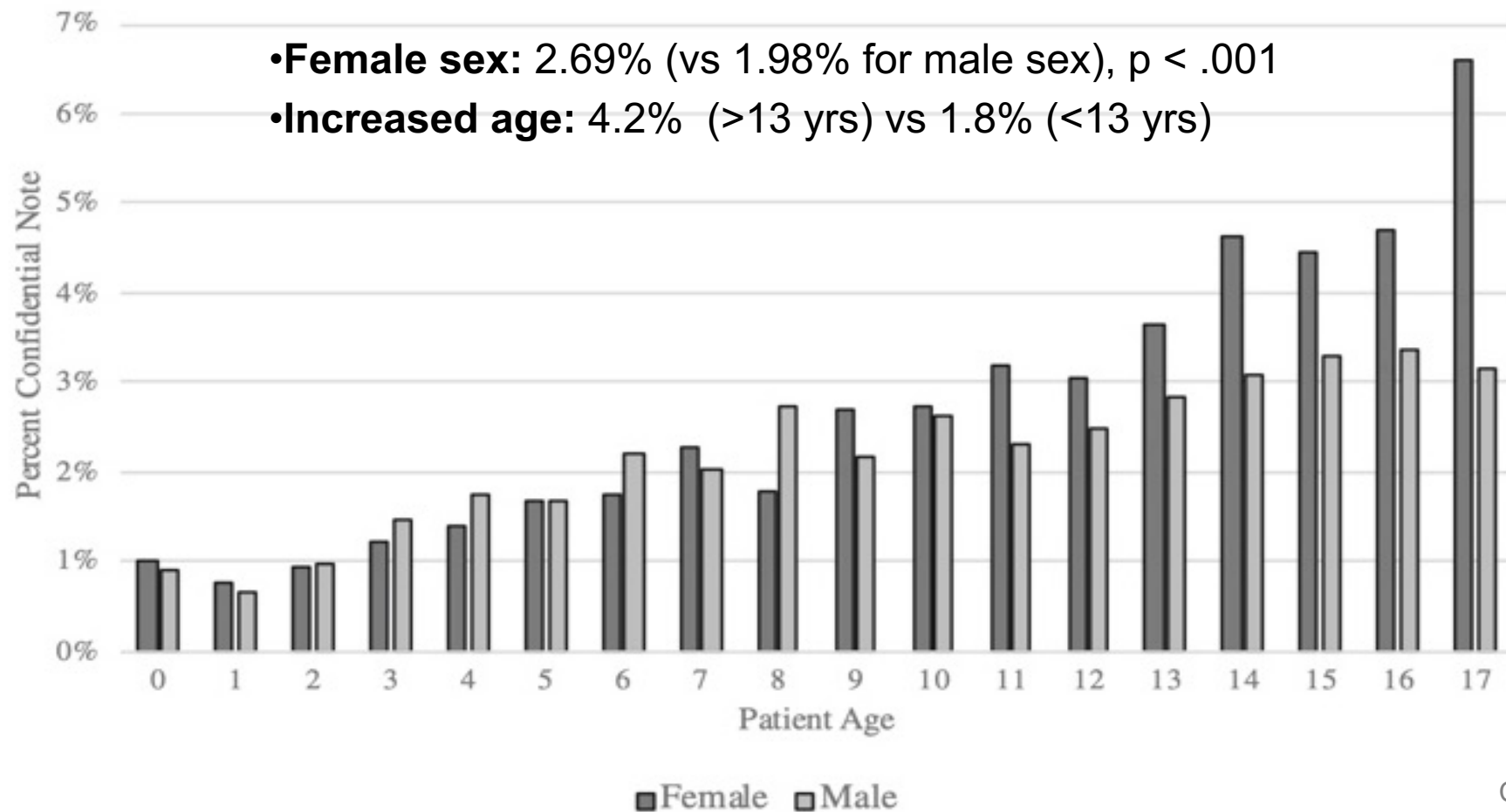
Clinic Notes Created	402,964
Confidential Visit Note**	9,346 (2.3% of all notes)
Confidential Notes Reviewed	1,100 (12.5% of confidential notes)

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

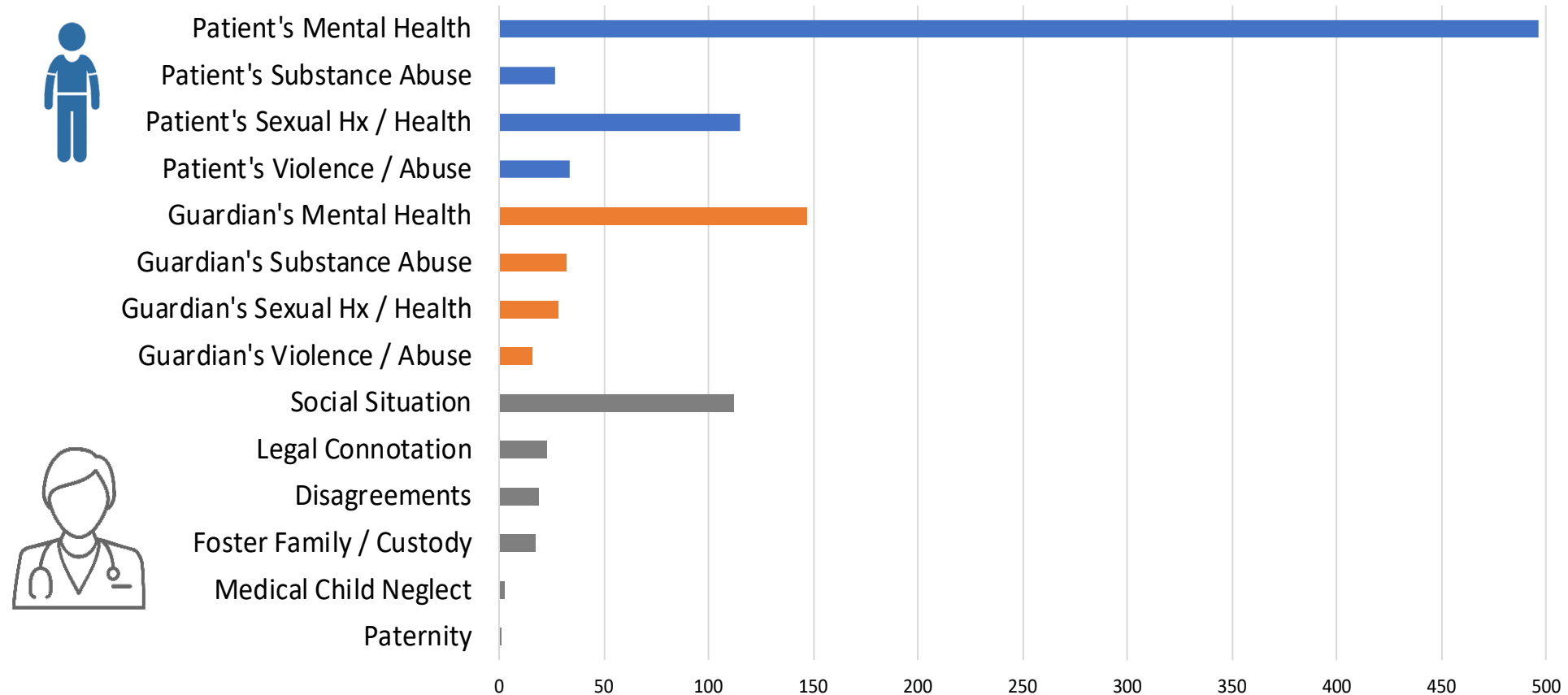
Confidential Information



Confidential Notes: Results



Confidential Information



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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Rady Children's



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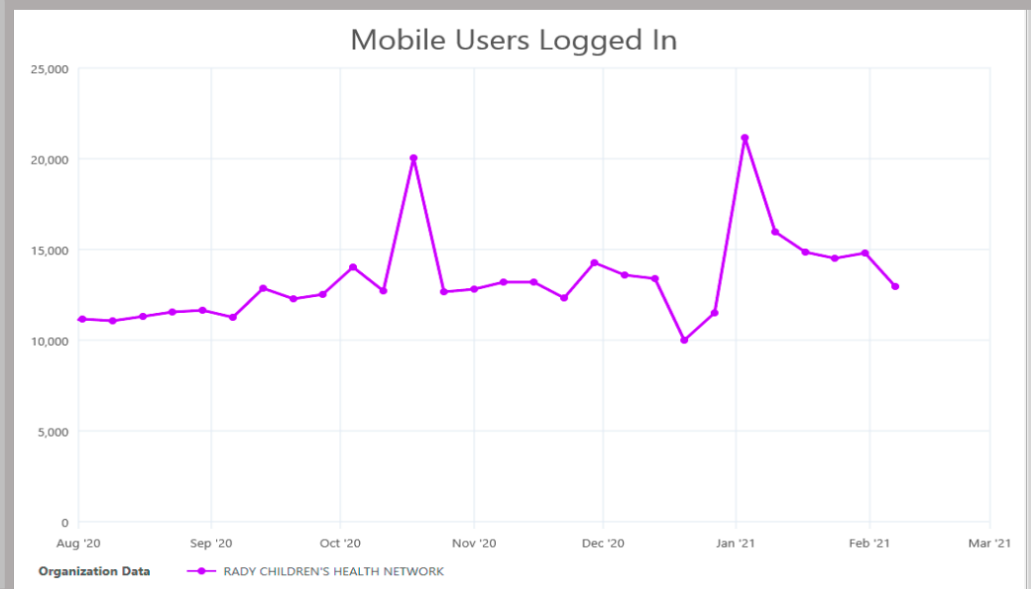
Clinical Professor of Pediatrics,
University of California, San Diego



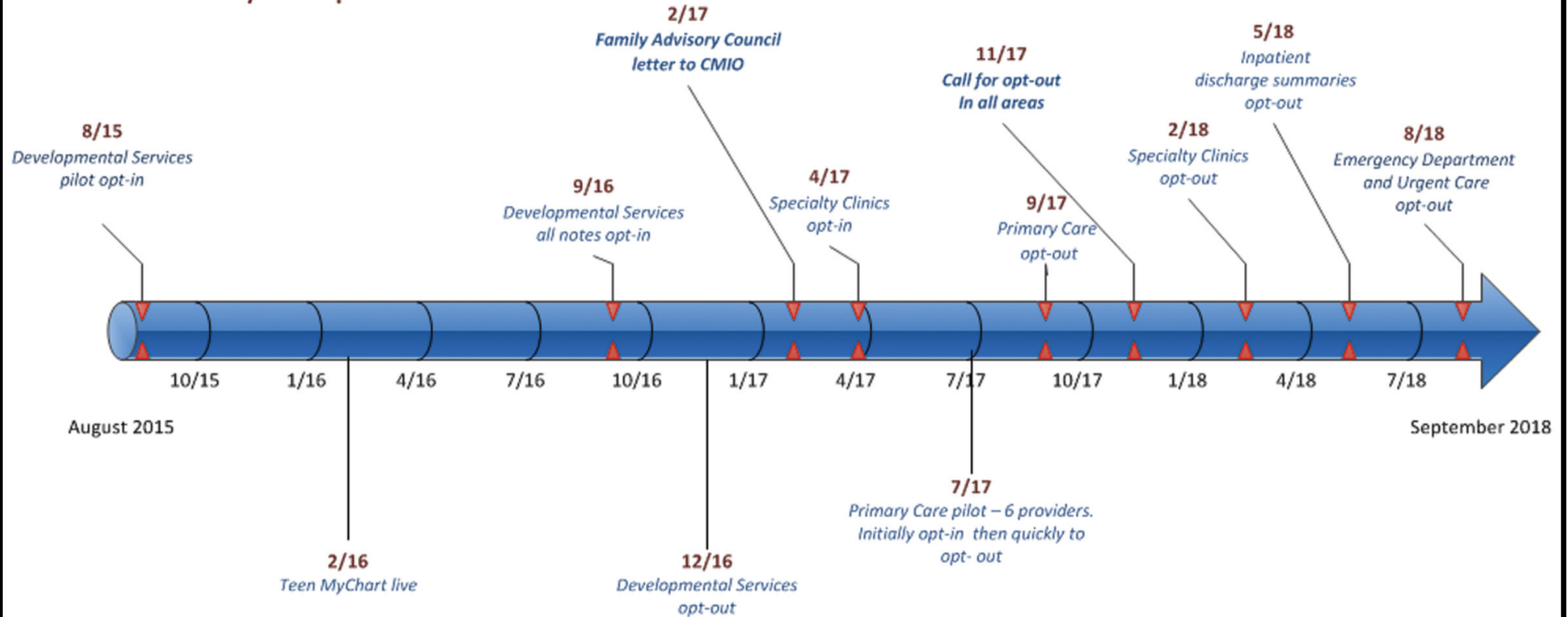
Rady Children's

- 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



Journey to Open Notes



Are You In or Are You Out? Provider Note Sharing in Pediatrics

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

¹ Department of Emergency Medicine, Rady Children's Hospital-San Diego, San Diego, California, United States

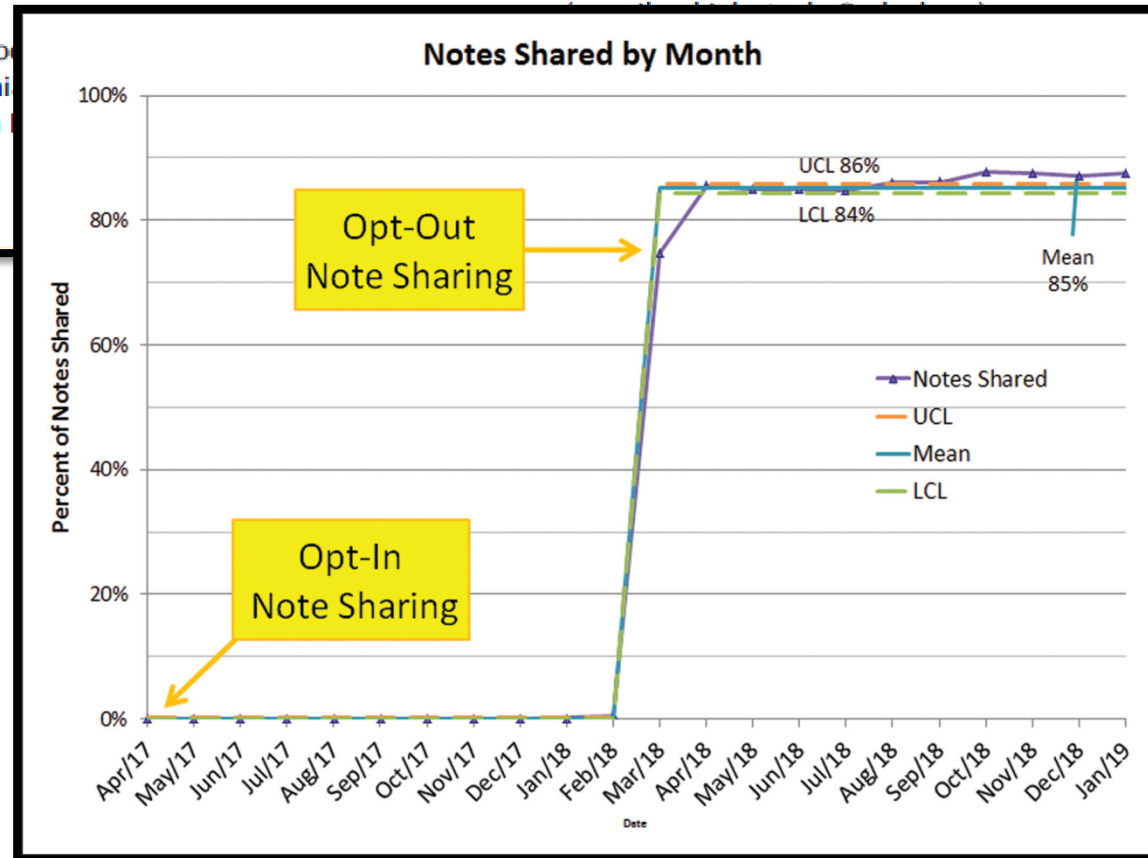
² Department of Pediatrics, University of California, San Diego, California, United States

³ Division of Pediatric Gastroenterology, University of California, San Diego, San Diego, California, United States

⁴ Rady Children's Hospital-San Diego, San Diego, California, United States

Appl Clin Inform

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



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
can
understand
their medical
information!

Adolescents and young adults (AYA) with chronic GI/liver disease provided most recent medical visit note to read

N=55, mean age 16 years, 71% white, 12.7% Asian, 3.6% Black, 12.7% other

Surveyed on accuracy of information/how visit events documented

Characterized their health status

Asked if change in medical management occurred

Asked if wanted to edit the note

Took the short Test of Functional Health Literacy in Adults

Two physicians read the notes and answered same questions about health status and medical management

% patients whose medical note comprehension agreed with physician readers calculated

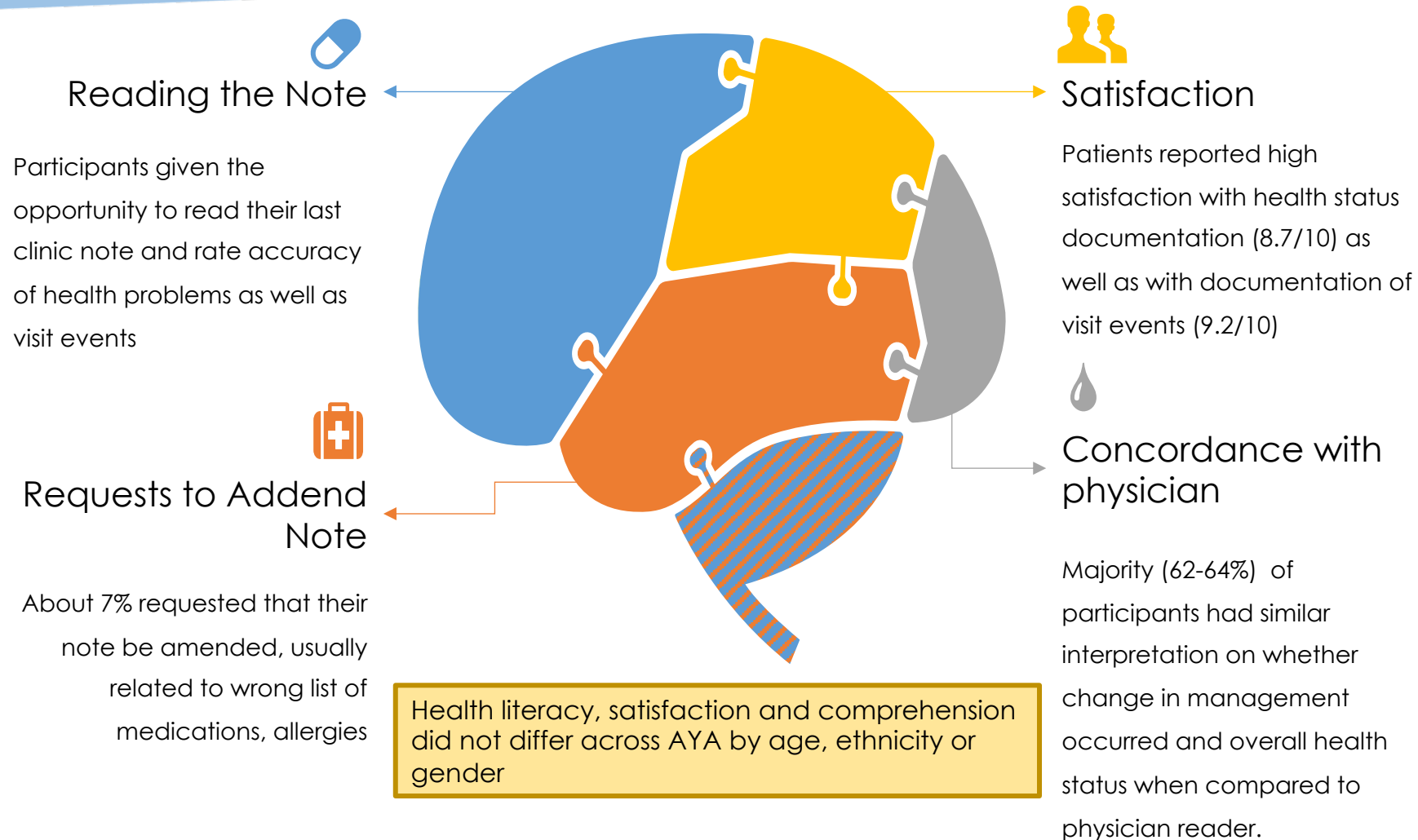


Adolescents' and Young Adults' Satisfaction with and Understanding of Medical Notes from a Pediatric Gastroenterology Practice: A Cross-Sectional Cohort Study

Jeannie S. Huang, MD, MPH^{1,2}, Ryan Yueh, BS², Stacy Ma, BS², Rusvelda Cruz, MPH², Laura Bauman, MD^{1,2}, and Lillian J. Choi, MD^{1,2}

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;215:264–6).

Adolescents and Young Adults



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

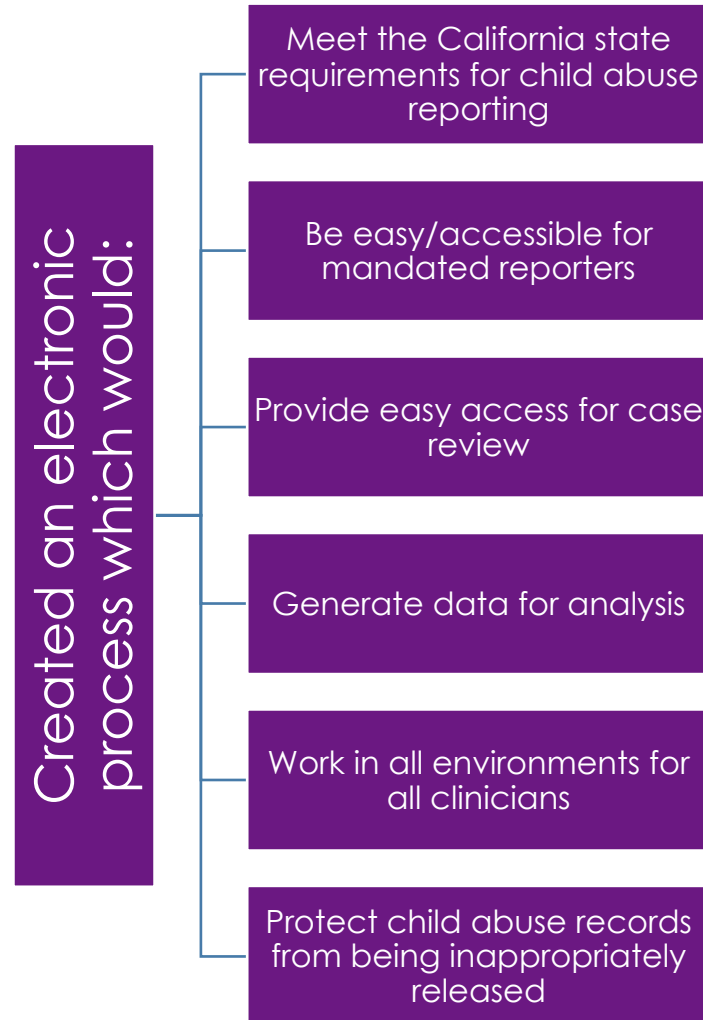


Child Abuse

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



Rady Child Abuse Reporting



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




Case Status ³	Date Referred	Date Reviewed	Child Abuse MD Note (85)	MyChart Last Login	MyChart Logins ¹	Number of Specialties ²	No Shows	Social Risk Score	M Risk Stratification Score	ED Visits (Internal)	ED Visits (External)	Admissions (1 yr)	Child Abuse MD Note	Imaging Studies	# Surgeries (1 yr)
Active	10/25/2019	10/9/2020 1316		10/14/2020	785	5	7	●	6	1	0	1	11/19/2019	17	2
Active	11/19/2018	10/9/2020 1305	018	10/14/2020	118	5	39	●	10	14	0	13	2/13/2020	64	6
Active	5/1/2020	7/17/2020 1239		10/14/2020	117	8	2	●	4	4	0	3		12	3
Active	11/25/2019	9/30/2020 1105		10/13/2020	95	3	9	●	9	6	0	4	1/28/2020	32	5
Closed	8/2/2018	5/5/2020 1145		10/14/2020	75	5	0	●	8	0	0	0		1	0
Monitoring	10/1/2020	10/9/2020 1323		10/14/2020	28	0	4	●	6	2	0	0		3	0
Active	9/1/2020	10/13/2020 0942		10/14/2020	23	2	2	●	10	3	0	2		14	1
Active	8/29/2020	10/9/2020 1301	05/07/2020	10/2/2020	12	2	6	●	14	3	1	4		6	1
Active	9/1/2020	10/9/2020 1329	08/12/2019	10/14/2020	10	7	14	●	8	3	0	5		58	6
Active	11/19/2018	9/30/2020 1027	08/05/2019	10/13/2020	6	0	0	●	8	0	1	0	10/15/2019	0	0
Active	1/31/2019	10/9/2020 1031	03/13/2020	6/20/2020	5	1	3	●	11	2	0	7	4/27/2020	11	1
Closed	4/19/2019	5/5/2020 1142		9/23/2020	4	2	5	●	5	0	0	0		1	0
Closed		5/5/2020 1141	02/08/2019	2/21/2019	1	0	0	●	7	0	0	0		0	0
Closed	9/1/2019	5/5/2020 1136		9/18/2019	1	0	0	●	6	0	9	8		0	0
Closed	1/19/2019	7/17/2020 1055		12/26/2019	1	0	0	●	2	0	0	0		0	0
Closed	11/19/2018	10/12/2019 0833		6/12/2020	1	0	2	●	6	0	0	0	11/30/2018	1	0
Monitoring	9/29/2020	9/29/2020 1304		5/14/2020	1	0	3	●	9	2	0	1		5	0
Closed		10/12/2019 0836	03/19/2019	6/23/2020	1	1	0	●	3	0	0	0	6/7/2019	0	0
Closed	12/13/2019	5/5/2020 1139	12/11/2019	4/28/2020	1	0	0	●	0	1	3	1		7	3


Medical child welfare case summary in the displays in the registry with hyperlink to smartform





Tools

Medical Child Welfare

Date of case referral 

Assigned MCW member 

Case status 

Reason for closure 

Case notes

Obese teenager w "Chro
most likely MSK but has
overutilization/MCA. Calif

- InBasket message dot phrase sent to specialists ".mcwtphrase"
 - *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.*

Time spent on review



Minutes

Hours

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 this information can be missed or delayed when relying on specialty notes, which can result in inappropriate or delayed care.

Objective

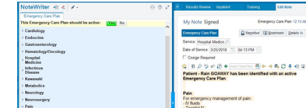
- The goal of this project was to create a tool that allows patient's primary providers to easily communicate emergency situations with emergency care providers.

Methods

- Multidisciplinary team created including: Hospital Information Officer, Physician Informatics, Systems team, Director of Inpatient Services, and representatives from Hematology/Oncology, Genetics, Pediatrics, Emergency Medicine, and Hospital Medicine.
- New Build:**
 - Emergency Care Plan (ECP) (Figures 1, 2)
 - Note Type: Emergency Care Plan (Note is created from prior note copied forward).
 - Providers complete and sign individual ECPs.
 - FYI flag with type "Emergency Care Plan" (FYI flag = BPA).
 - 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 balancing measure of whether ECP was disruptive.
 - Evaluated # ECP notes by specialty, and # distinct patients.

Methods: Build

Figure 1. Emergency Care Plan Note SmartForm



Hospital Medicine
****Patient followed by**
Medical Child Welfare
Committee.

☐ Hover for details

Upon review by our multidisciplinary team, we have determined that there is a concern for Medical Child Abuse. 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. Please feel free to contact CPT on call for further clarification/discussion.

Results

Since go-live in March 2018, a total of **229 Emergency Care Plan notes** have been filed 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 management, etc.)
- Contraindications to specific treatments due to underlying medical problems.

In a survey of ED providers surveyed (n=18) on the implementation, an average of 5 patients with ECPs. Of those who have an ECP (n=15), a majority felt that the ECP improved clinical care, helped them order necessary treatments, and prevented them from ordering unnecessary tests, saving them time, and no providers felt that the ECP was disruptive (Figure 5).

Limitations

Limitations include the subjectivity of survey data. There was an expectedly high variability of ECP content. The survey highlighted patients with rare disorders or complex conditions (e.g. recommendations), objective metrics such as time to treatment are more challenging to obtain.

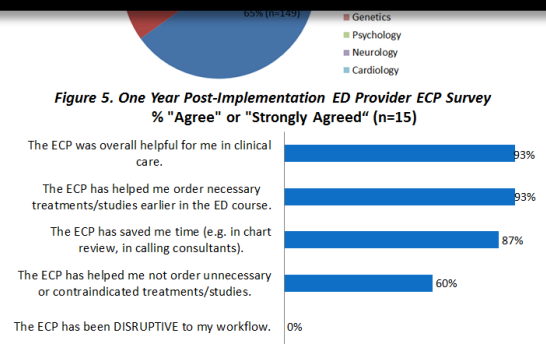
Conclusions/Next Steps

- The ECP has been widely used at RCHSD as a tool to communicate with other care providers to communicate emergency situations and other crucial information with emergency/acute 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 Hershey, MD, Annette Feigenbaum, MD, Jenny Kim, MD, Rebecca Bennett, PPCNP-BC, Denise Givens, APRN-BC, and Brian Denney.

Address correspondence to Amy Chong 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



Foster Parents



Rady Children's Hospital - San Diego
3020 Children's Way
San Diego, CA. 92123



DTF1429

PATIENT INFORMATION

Name: _____

MR#: _____ Finance: _____

DOB: _____

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 Caregiver's 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



Fabienne Bourgeois, MD

Pediatric Hospitalist,
Associate Chief Medical Information Officer,
Boston Children's Hospital

Cynthia L. Kuelbs, MD

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