



AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



# Advancing High-Value Pediatric Care: Using Data, AI, and Family Engagement to Improve Outcomes

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Agency for Healthcare Research and Quality

April 28, 2026

# Agenda



- Welcome and Introductions
- Presentations
- Q&A Session With Presenters
- Instructions for Obtaining CME Credits

Note: You will be notified by email once the slides and recording are available

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**Esi M. Morgan, M.D., M.S.C.E.**  
Presenter



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**Edwin Lomotan, M.D., CPMAI, FAMIA**  
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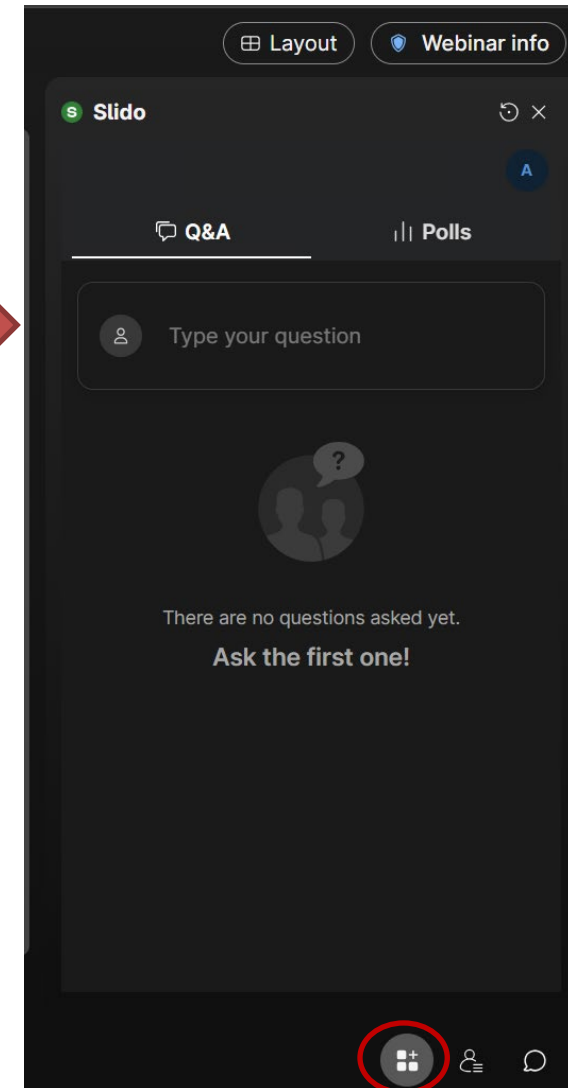
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- Questions will be read aloud by the moderator.



# Learning Objectives

**At the conclusion of this webinar, participants should be able to—**

1. Discuss challenges in managing pediatric chronic conditions with respect to variability in treatment responses and explore visual approaches to support patient-centered decision making.
2. Apply insights from machine learning–based clinical decision support (CDS) tools to pediatric clinical workflows to improve care delivery.
3. Describe how inpatient portals support parent engagement and patient safety during pediatric hospitalizations.



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# **Inform Shared Decision Making with Advanced Bayesian Causal Inference to Improve Quality of Pediatric Rheumatology Care**

**Esi M. Morgan, M.D., M.S.C.E.**

Professor, University of Washington

Chief, Division of Rheumatology, Seattle Children's Hospital

# Research Impact



To aid physicians and families in making efficient, evidence-based treatment decisions, we developed a robust Bayesian advanced causal inference digital health solution to support patient-centered shared decision making at the point of care.

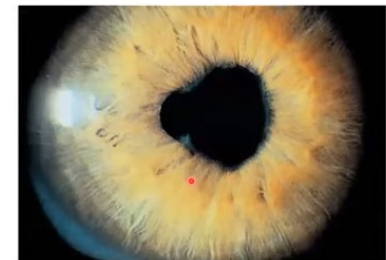
# More Than a Swollen Knee

- Your 3-year-old daughter Ella starts limping and her knee is swollen.
- The pediatrician refers her to see a pediatric rheumatologist.



# More Than a Swollen Knee

- Your 3-year-old daughter Ella starts limping and her knee is swollen.
- The pediatrician refers her to see a pediatric rheumatologist.
- 6 weeks later you learn the ‘swollen knee’ is due to juvenile idiopathic arthritis (JIA). Ella has a “polyarticular” form (many joints)
  - Impacts her neck so she cannot turn it
  - Impacts her jaw (TMJ) so it is hard open her mouth and to chew
  - Impacts many other joints that are swollen and limited in movement
  - JIA is associated with inflammation in the eye that could threaten her eyesight
- Your previously healthy toddler has a chronic disease without cure



# How to Treat?

- Consider values and preferences
  - ‘Treat to Target’ approach
  - ‘Issue cards’
- Review medication classes:
  - ‘disease modifying anti-rheumatic drug,’ aka ‘DMARD,’ e.g., methotrexate
  - ‘biologics’, ‘small molecules’
- Routes: oral, injection, infusion
- Potential harms:
  - ‘chemotherapy’, black box warning (cancer risk), infection risk, no live vaccines
- Strategies:
  - “step up” – methotrexate, +/- biologic
  - “early combination”



## Treatment Tools

Keeping It Safe?

Side Effects?

How Often?

Cost?

## Assessment Tools

Disease Activity?

cJADAS Calculation?

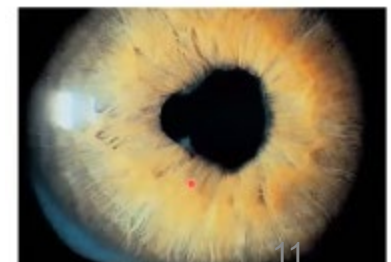
JADAS – juvenile arthritis disease activity score

What should I do?  
Does Ella need all  
this medicine? Which  
is best for her? I want  
more data



# Background - Juvenile Idiopathic Arthritis

- Juvenile Idiopathic Arthritis (JIA)
  - Autoimmune/inflammatory arthritis - 1:1000 children affected
  - Multiple categories (oligoarticular, polyarticular, +more)
- Children are highly heterogeneous in their responses to treatment
- Evidence guiding clinical treatment decisions is primarily generated for the “average patient”
- Personalization of data and real-world evidence to inform shared decision making is lacking



# Average vs. Individual



# Why Causal Inference

Treatment	Success	Failure	Total
A	100 (83%)	20	120
B	94 (78%)	26	120

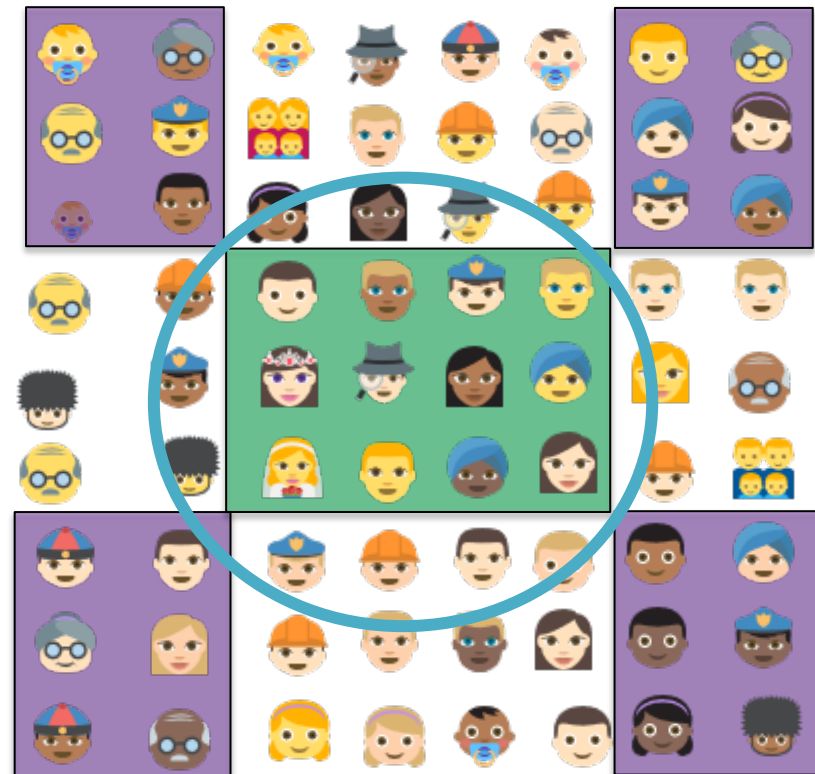
Mild

Treatment	Success	Failure	Total
A	90 (90%)	10	100
B	19 (95%)	1	20

Severe

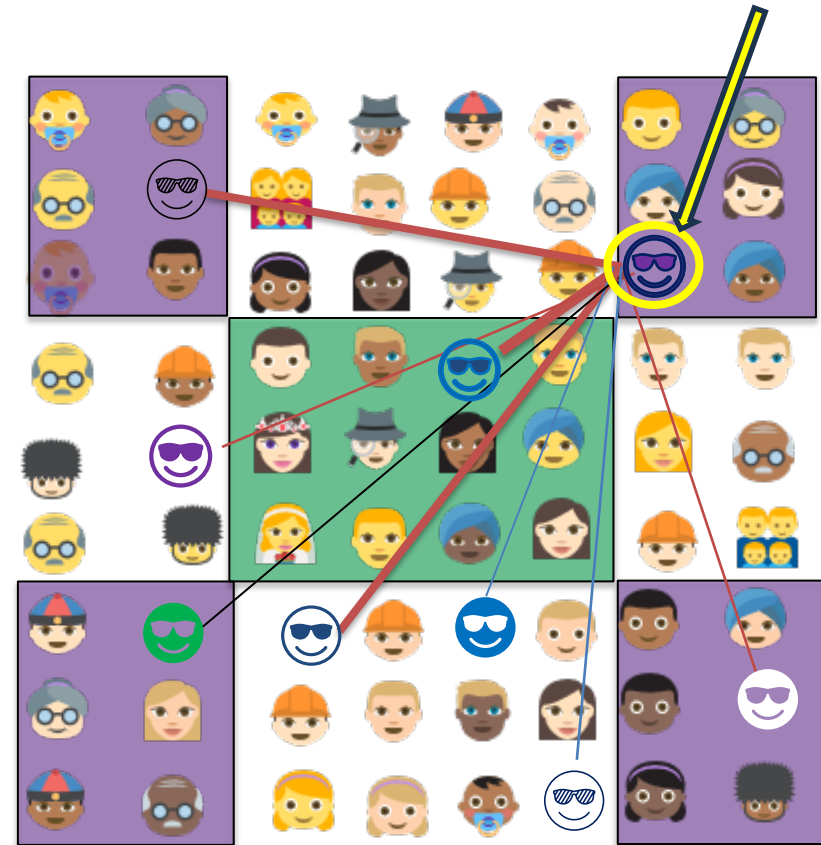
Treatment	Success	Failure	Total
A	10 (50%)	10	20
B	75 (75%)	25	100

# Randomized Clinical Trial (RCT)



# An Individual Centered Causal Inference

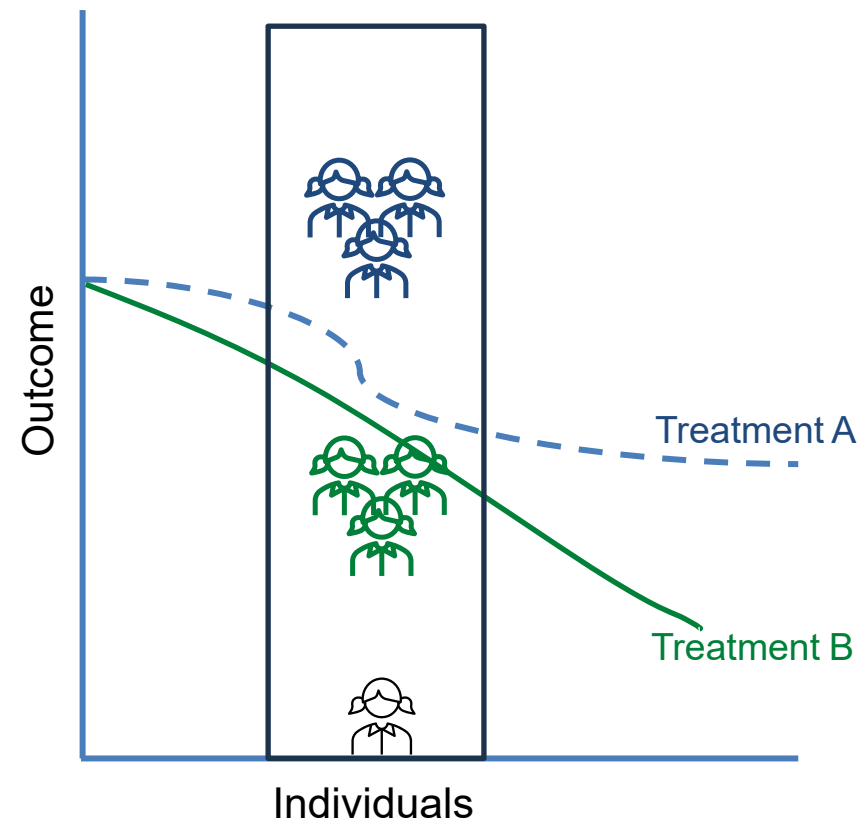
- Match
  - By the features of each unit
  - Weighted by their similarities
- Nonparametric Model
  - Lessen model dependence
  - Not discard data points
- Patient Centered Adaptive Treatment Strategies (PCATS)
  - Complex Treatment; time-varying treatment; Bounded outcomes



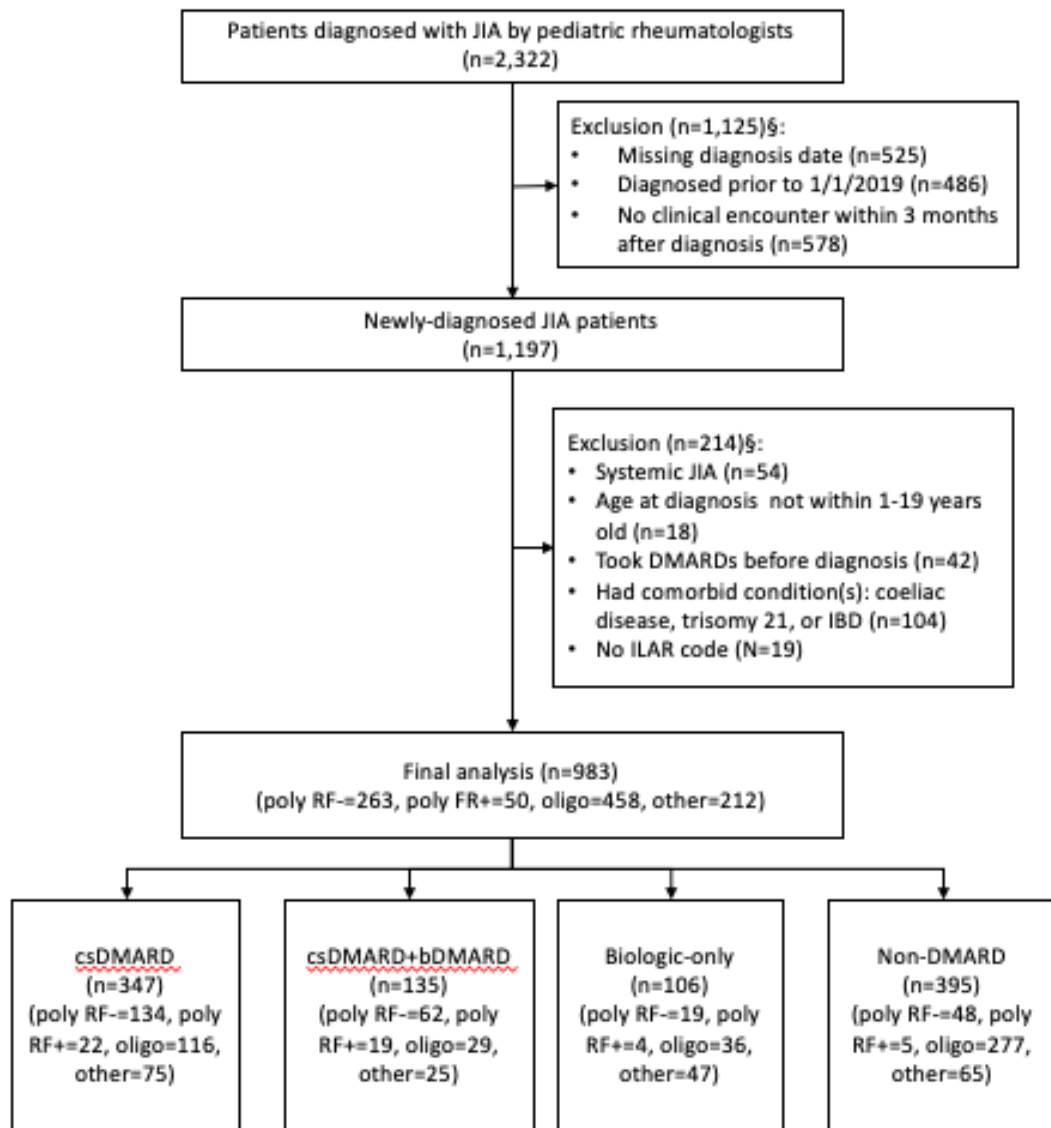
# Patient-Centered Treatment Effect

For every new patient facing a treatment decision:

- Utilize data from clinical encounters of real patients
- Learn from patients with similar disease features, considered “alike”
  - Defined by important clinical and patient characteristics
  - Learn from their existing experiences
  - Quantify associated uncertainties in treatment outcomes



# Data Source and Analytic Challenges



- **Single Center EHR**

- Data entered by providers in routine care
- Training for shared understanding and method
- Importance of Data Quality
  - accurate, complete, consistent, timely, valid
- Quality checked against NIH funded prospective JIA cohort

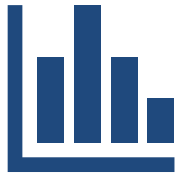
- **Heterogeneous Treatment Effects**

- Requires large sample size (4 X RCT)
- May need to combine data sets for unique patients
- Multiple HTE methods and performance
- Potential for over/underestimation requires multiple validation

Data extraction (9/22/2023)

§ Numbers reported in each exclusion criteria are not mutually exclusive

# Planned Approach to Digital Health Technology (DHT) Enabled Shared Decision Making



**Use advanced comparative effectiveness statistical methods**



**Leverage learning health system (LHS) real world clinical data**

Common data model established for learning health network in chronic disease condition

Arguably more generalizable and robust evidence than single center data

Timely generation of data-informed evidence



**Present patient-specific data dashboard at point of care**

Organize and present evidence centered around the individual patient

Inform and support shared decision making

# Recommendations on Decision Making for Pediatrics

Pediatric bioethicists considered the question: “what moral precepts ought to guide parents and clinicians in medical decision making for children”

Salter EK, Hester D.M, Vinarsik L, et al.  
Pediatric Decision Making: Consensus  
Recommendations. Pediatrics. 2023;152(3):  
e2023061832

## Consensus Recommendations

1. Parents should be presumed to have wide, but not unlimited, discretion to make health care decisions for their children.
2. Parents should protect and promote the health interests of their child, while balancing practical constraints and/or other important obligations and interests.
3. A clinician’s primary responsibility is to protect and promote their pediatric patients’ health interests. Clinicians’ recommendations should be informed by professional judgement and the best available evidence.
4. To respect children and promote their wellbeing, clinicians and parents should inform pediatric patients of salient information and invite their perspective to the degree that doing so is developmentally appropriate.
5. In addition to state mandated reporting requirements, clinicians should seek state intervention when all less-restrictive alternatives have been exhausted and a parental decisions places at the child at significant risk of serious imminent harm or fails to meet the child’s basic interests.
6. Clinicians and parents should collaborate in a shared decision-making process to promote the child’s interests.

# Major Project Goals

## R33 Phase

### R21 Phase:

Patient Centered Adaptive Treatment Strategies (PCATS) algorithm with multiple statistical validation methods

Development of:  
\*system architecture for use in any FHIR enable EMR  
\*portal App  
\*interface prototype

### Goal 1: “Doctor in the Loop” Validation

Clinicians as experts

Increase system usability and acceptance

### Goal 2: Implement in 3 clinical practices

Leverage quality improvement science for reliability of use

Implementation science framework for sustainability

### Goal 3 : Track outcomes of implementation

Patient-centeredness:  
Shared decision making

Improved clinical outcomes

# Development Activities

- Requirements analysis
  - Qualitative interviews – what do providers and patients think?
    - Persona development
  - Literature review to inform use cases and models
    - Information flow, children in decision making
  - Development of user evaluation tools
- Validating methodology via extensive simulation studies
  - A commonly taken approach for validating data analytical method
  - ‘Doctor in the loop validation’
- Piloting and usability testing in multiple settings
  - Information flow, workflow

# Design Criteria

## Trustworthiness

Data security and privacy  
Transparency, Reliability

## Interpretability

Explainable  
Clear Output

## Accessibility

Inclusive design  
EHR system agonistic

## Confidence

Clinical Validation  
Professional endorsements

## Understandability

User friendly design  
Clear instruction

## Impact

Evidence-based, patient-centric  
care  
Equitable care, Scalable

# Prototype Interface

**Please input patient status:**

**Gender:**  
 Female  Male

**Insurance**  
 Private  Public

**How old were you when you were diagnosed?  
Please enter in month.**  
 age at diagnosis calculator

**JIA ILAR subtype:**  
 Polyarticular RF-  Polyarticular RF+  
 Oligoarticular  Other

**Morning stiffness:**  
 None  <= 15 mins  > 15 mins  Unknown

**Did you take glucocorticoids within 3 months:**  
 No  Yes

**Were you treated with injections within 3 months:**  
 No  Yes

**MD global assessment (0-10):**

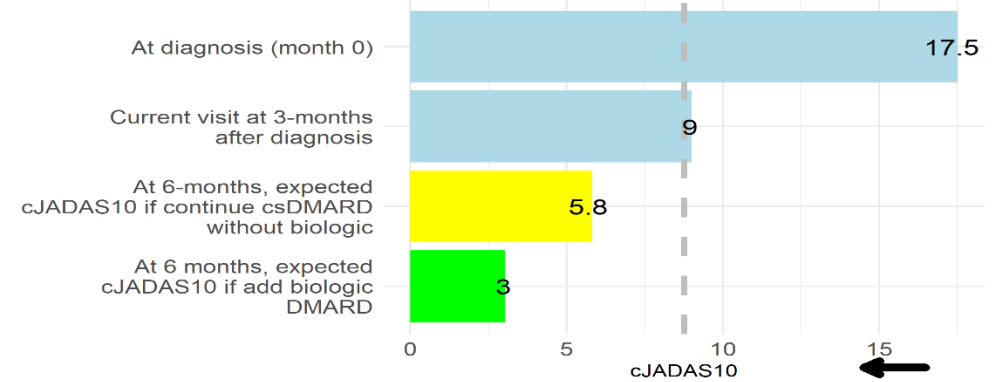
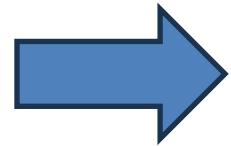
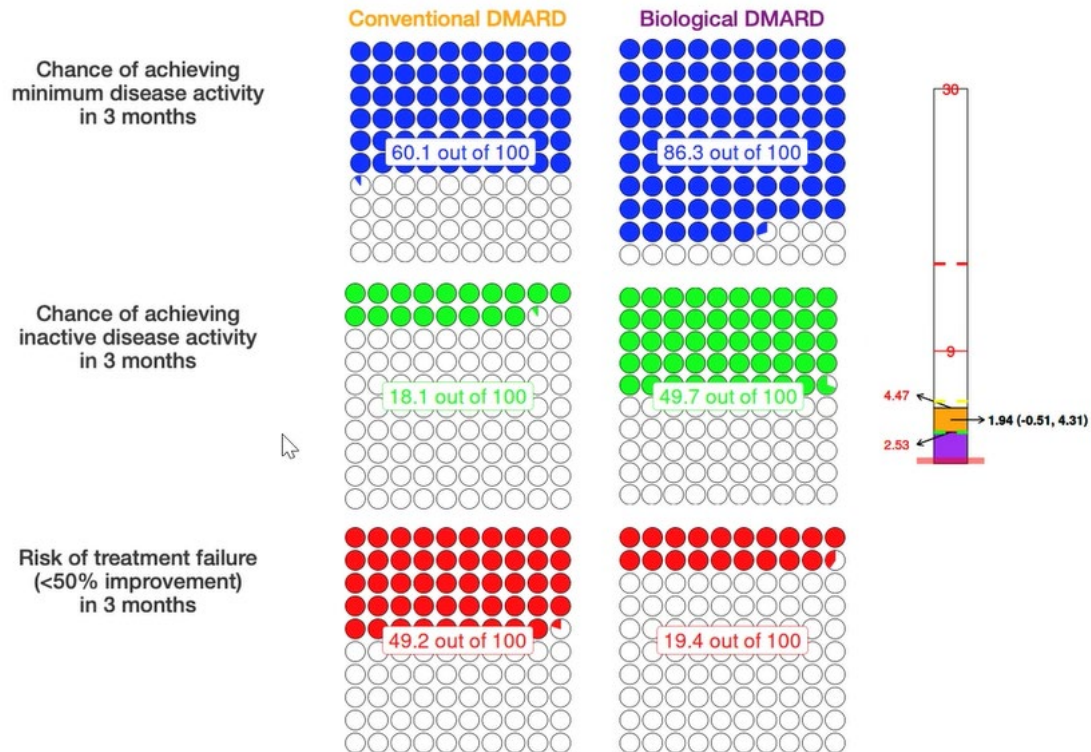
**Patient Wellbeing (0-10):**

**Active joint count (0-10):**

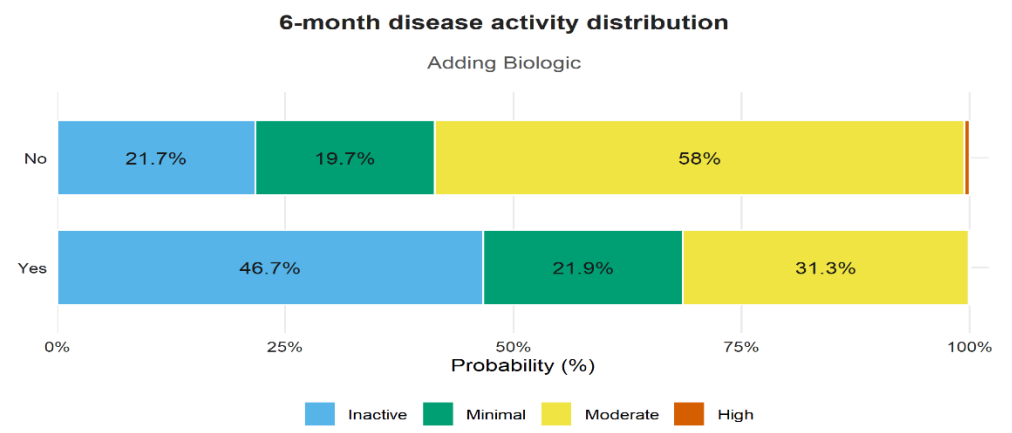
Components of the  
Clinical Juvenile  
Arthritis Disease  
Activity Score –  
cJADAS\*

\*Requires training of  
providers as well as  
patients/parents  
on scoring

# Iterative Changes to Design (Output)



NOTE: The desired direction for improvement is to the left. Dashed line indicates 50% improvement in cJADAS10 compared to time of diagnosis (month 0).



# Current Project Activities

- “Doctor-in-the-loop” Validation Survey with 20 pediatric rheumatology providers (Alabama, Ohio, Washington state)
- 14 profiles – patient clinical cases followed by questions on next treatment step based on experience
- Same 14 profiles now presented with probability of treatment effectiveness based on PCATS algorithm
  - Does this match physician expectations?
  - What is next recommended treatment including their experience and this data?
- Analysis of agreement
- Clinical workflow design

# Survey – Part 1

## Survey: PCATS Digital Health Tool

AAA  
 

### Part 1

For this first part, we will review 14 different patient profiles.

Each patient profile represents a patient with **JIA diagnosed 3 months earlier**, and contains clinical information. **You will be asked about recommendations for treatment starting at the 3-month time point.**

In a real-world setting, the patient/family values and preferences will also be part of shared decision making. There are no right/wrong answers so please respond as you would approach each patient in clinical practice. You will have the opportunity to share what additional information would be helpful in your decision making.

### Profile 1 (Z1051698)

Patient is a 3 years, 10 months old female followed for JIA, first diagnosed 3 months ago.

- The ILAR category: **Polyarticular JIA (RF-)**
- Age at time of diagnosis: **3 years, 7 months**
- Symptoms began: **1 year prior to diagnosis**

	At diagnosis:	At current visit:
Morning stiffness	None/zero	None/zero
Patient global assessment of overall wellbeing (Pt OWB, 0=well, 10=poor)	10	0
Physician/provider global assessment of disease activity (PGA, 0=none, 10=severe)	8	1
Active joint count on exam	10	2

They have received the following treatment since diagnosis 3 months ago:

- Joint Injections: **No**
- Taken glucocorticoids: **No**
- Taken NSAIDs: **No**
- Taken methotrexate: **Yes**
- Uveitis history: None, with **normal recent eye exam.**

Family has no specific preference on choice of medication and asks for your recommendation

Based on this information, what would you recommend as next best treatment option?

\* must provide value

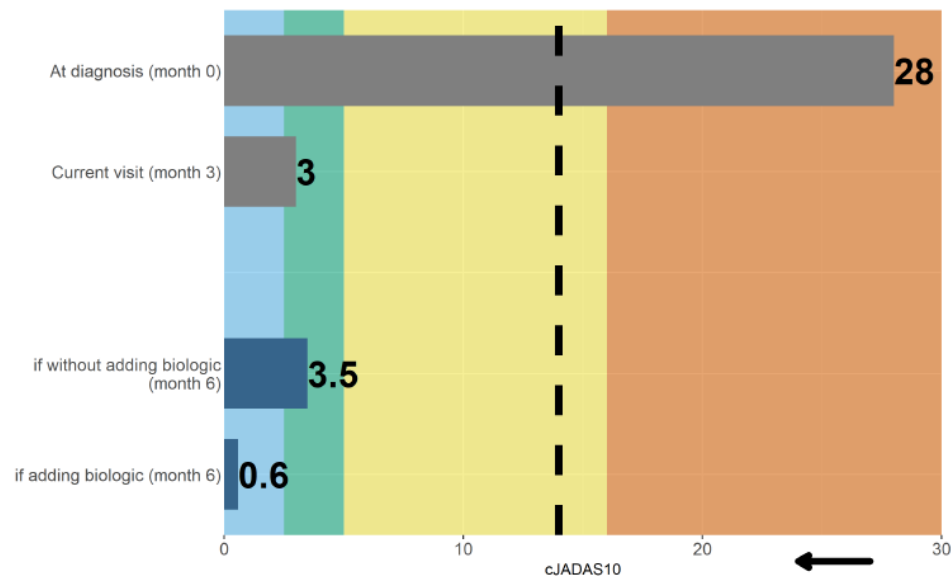
- Continue current therapy
- Add or switch conventional synthetic disease modifying anti-rheumatic drug (csDMARD), (e.g., methotrexate, leflunomide).
- Stop csDMARD (e.g., methotrexate), and switch to biologic DMARD (bDMARD), (e.g., adalimumab, etanercept ...).
- Continue csDMARD and ADD a biologic DMARD (combination therapy).
- Other recommendation.

# Part 2 – Data Informed Decision

The output, shown below, is from a review of data based on patients like Profile 1, coupled with the clinical information in the Profile. This displays the probability of improving over the next 3 months based on the different pathways: continuing csDMARD vs. adding a biologic DMARD.

What would be your next choice of treatment?

## Disease Activity Levels (cJADAS10) Over Time



NOTE: Dashed line indicates 50% improvement in cJADAS10 compared to time of diagnosis (month 0). cJADAS10 = Physician Global Assessment (PGA) + Parent/Patient Global Assessment (PaGA) + Active Joint Count (max 10).

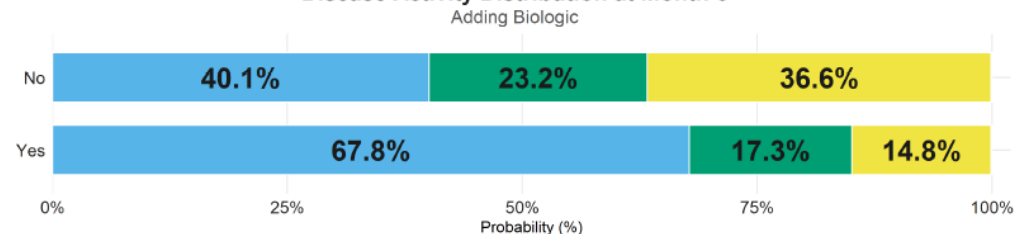
Background colors of both figures reflect disease activity levels (cJADAS10 score cutoffs)

- Inactive (<=2.5)
- Minimal (2.6-5)
- Moderate (5.1-16)
- High (>16)

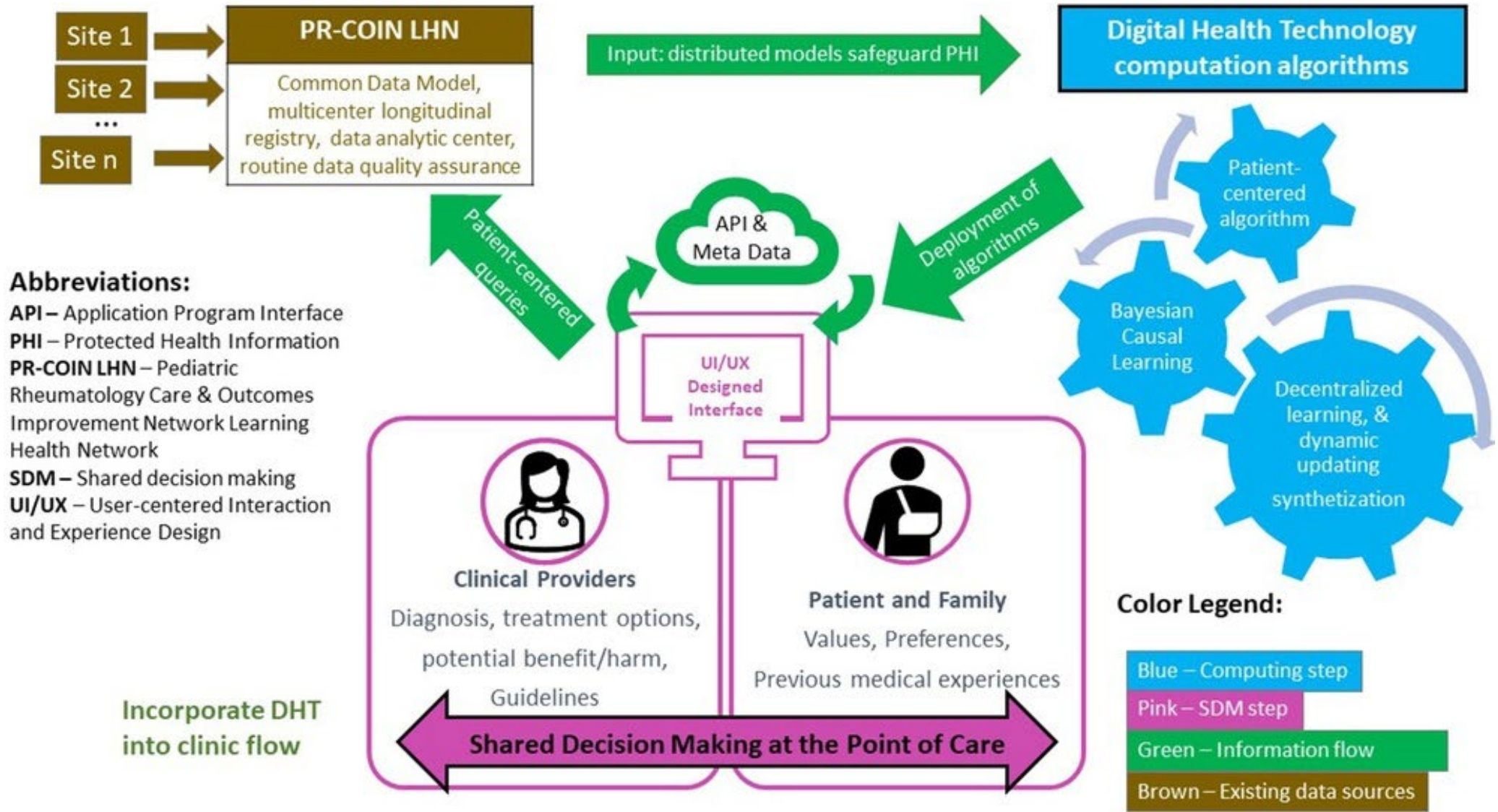
Bars of top figure indicate disease activity scores at visits

- Observed cJADAS10 score (diagnosis and month 3)
- Projected cJADAS10 score (month 6)

## Disease Activity Distribution at Month 6



# Putting it All Together: Conceptual Framework



**Abbreviations:**  
**API** – Application Program Interface  
**PHI** – Protected Health Information  
**PR-COIN LHN** – Pediatric Rheumatology Care & Outcomes Improvement Network Learning Health Network  
**SDM** – Shared decision making  
**UI/UX** – User-centered Interaction and Experience Design

**Incorporate DHT into clinic flow**

# Anticipated Challenges in Clinical Use

- Managing pediatric chronic conditions – the impetus for the project
  - Heterogeneous, rare; some patients are “unique” challenging model generalizability; eager to use larger data sets
- Introduction of new technology into real-world clinical workflow
- Complexity of shared decision-making involving parent and child
- Pediatric developmental considerations in presentation of new types of data and prognostic information
- Dynamic environment with new emerging therapeutics, changing treatment guidelines, insurance formulary restrictions

# Lessons Learned and Opportunities

- Iterative nature of tool development and testing; adapt to different clinical workflows
- Adaptation to changing medical and information technology environments
- Importance of training providers on delivery of personalized/prognostic information and incorporation into shared decision making
- Analytic challenges reflects quality and size of data sets; larger data sets required for generalizability and validity, and for the ‘most unique’ of patients
- Working within the setting of learning health network is fortunate and essential
  - Quality Improvement trained teams and QI Specialist support
  - Teams primed in measurement of disease activity, SDM intervention
  - Reliable data collection and real-world registry data source feed algorithm and track outcomes
- Potential extension to other chronic conditions, JIA as case study

# Acknowledgements



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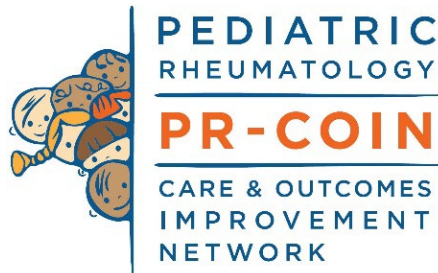
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Michal Kouril, PhD



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# ML-ROVER: Machine Learning to Reduce Laboratory Test Overutilization

**Sareen S. Shah, M.D.**

Assistant Professor, Pediatrics, Cedars-Sinai Health Sciences University  
Scientific Advisor, VPICU, Children's Hospital Los Angeles

# Research Impact



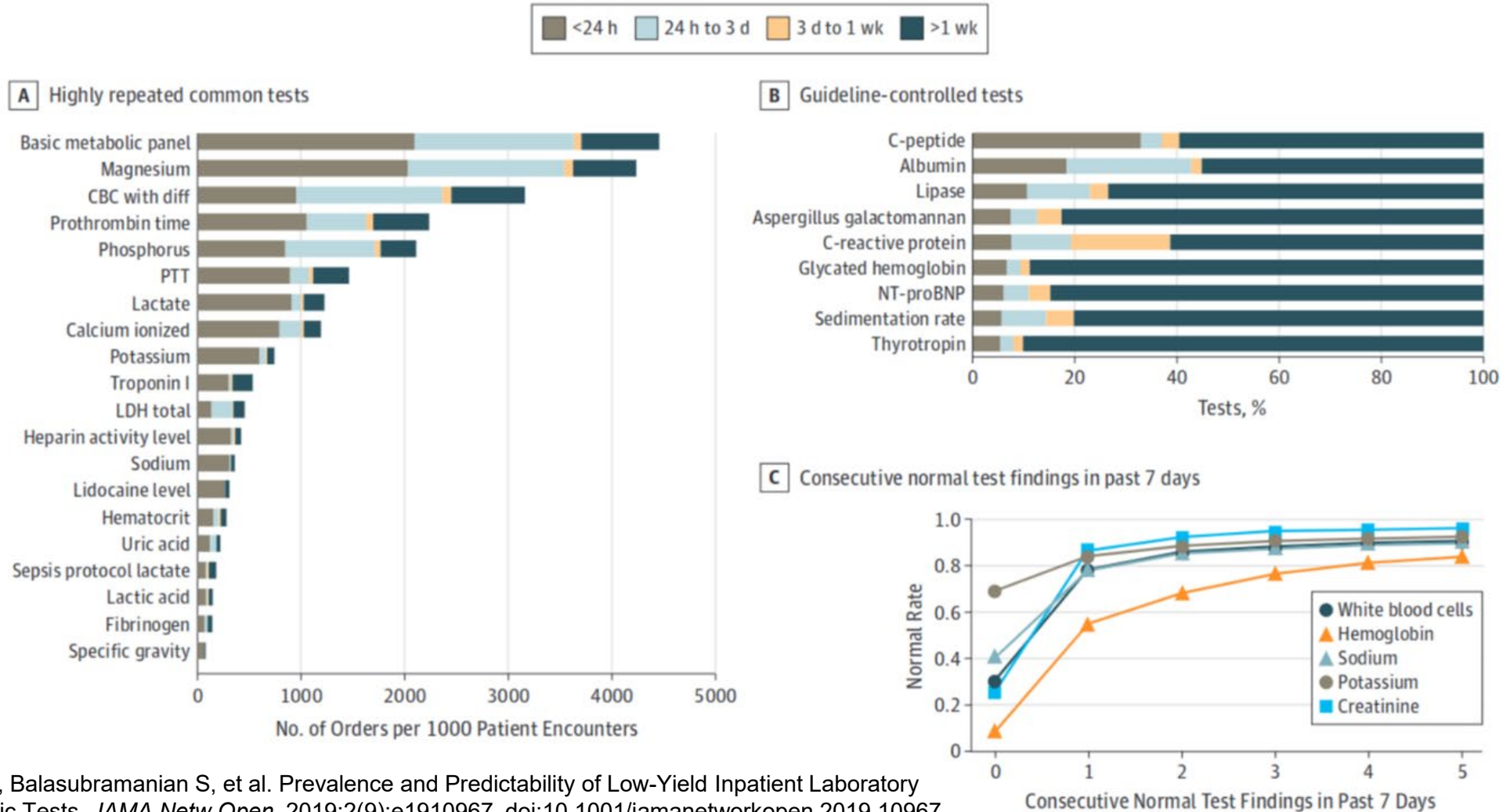
By integrating machine learning with user-centered design, we aim to create sustainable and generalizable clinical decision support tools that reduce laboratory test overutilization in critically ill children.

# Background

- Phlebotomy accounts for 73% of daily blood loss in PICU patients
- Laboratory testing is often performed on a scheduled basis - e.g. CBC qday, BMP q12h
- Requires **active decision-making to discontinue lab collection**, even after patient stabilizes
- Overutilization may be as high as 60% in some settings
- Multiple harms from excessive testing:
  - Iatrogenic anemia
  - Increased transfusions
  - Infection
  - Unnecessary treatment
  - Increased costs

# Prevalence and Predictability of Low-Yield Inpatient Laboratory Diagnostic Tests

Figure 2. Prevalence of Repetitive Tests and Their Diminishing Information Gain



# ML Failure to Improve Delivery of Care



Few ML models make it to clinical decision support (CDS)



>95% of CDS alerts are overridden → alert fatigue → patient harm and burnout



Most CDS implementation does not leverage user-centered design

# Specific Aims



## **R21 phase (Sept 2024 - Aug 2026)**

**Aim 1**: Develop and validate ML models to forecast laboratory test results (BMP and CBC components) using the PICU Data Collaborative dataset

**Aim 2**: Assess contextual factors to inform the design of a CDS tool that is locally relevant and scalable

## **R33 phase (Sept 2026 - Aug 2029)**

**Aim 3**: Extend, deploy, prospectively evaluate, and calibrate the ML models

**Aim 4**: Develop an EHR-embedded CDS tool and assess usability by applying principles of user-centered design

# PICU Data Collaborative (PDC) and Sites

PCCM CONFERENCE REPORT & EXPERT PANEL

The PICU Data Collaborative: A Novel, Multi-Institutional, Pediatric Critical Care Dataset

PICU Data Collaborative



<https://pedsdata.org/>

# Scope of the PDC Dataset



Full hospital admission row-level data for any encounter where the patient was in a pediatric ICU at some point.

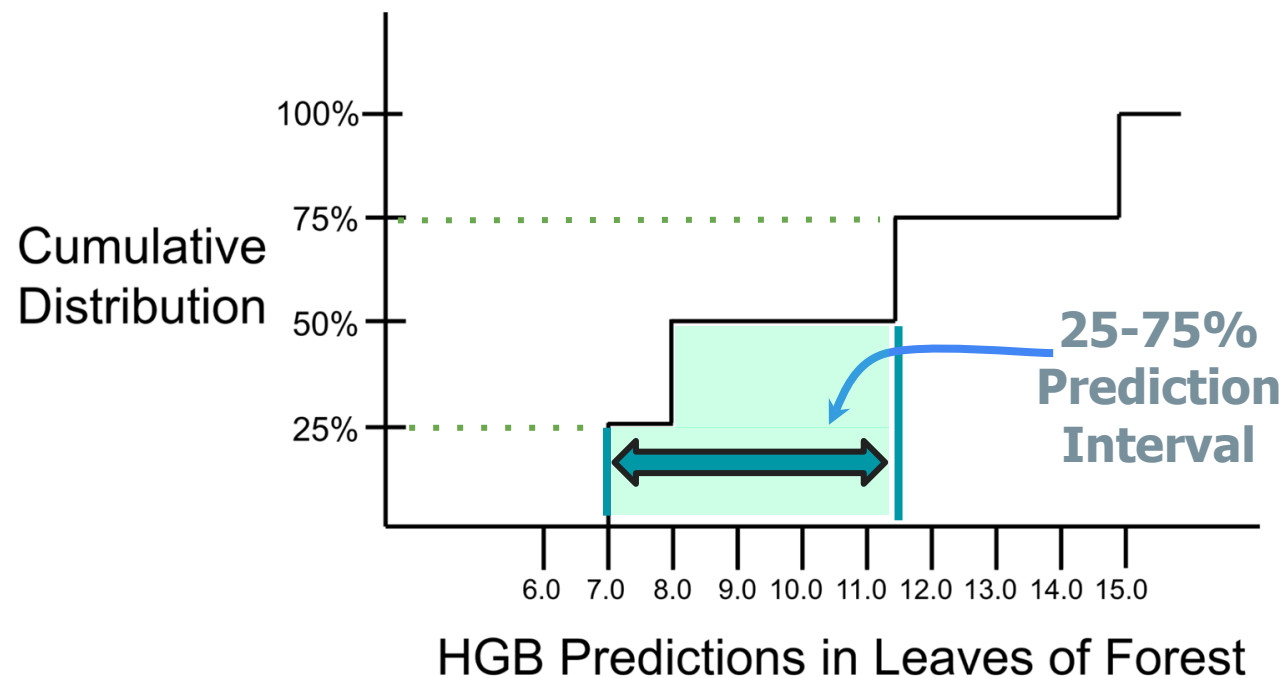
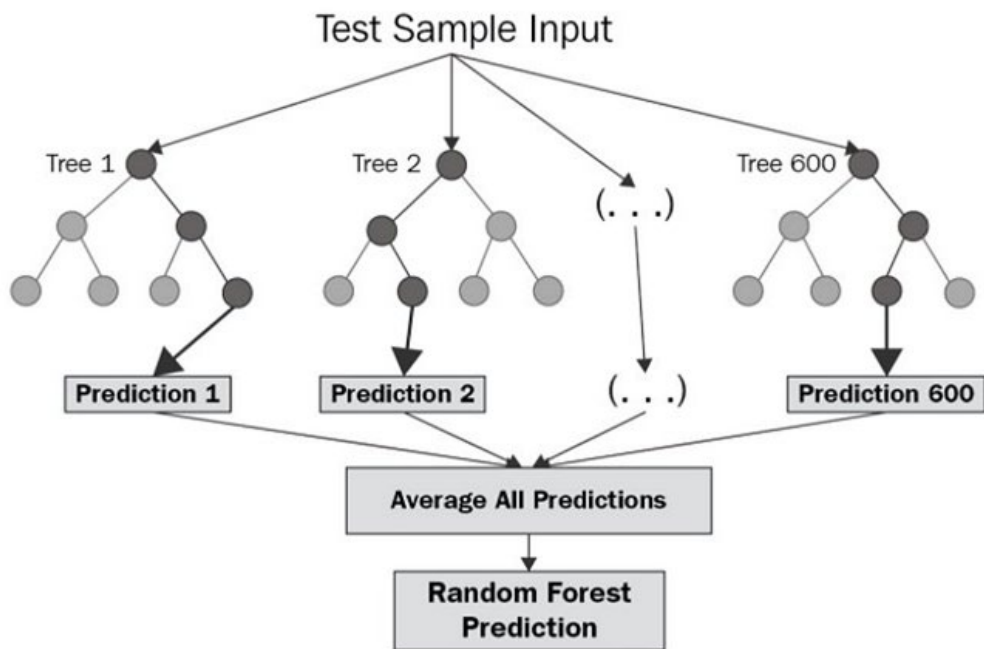
## **Current Statistics**

- >182,000 unique patients
- >261,000 hospital admissions
- >600,000,000 vital sign values
- >129,000,000 lab values
- >248,000,000 medication administrations

# Quantile Regression Forest

Generate prediction intervals for CBC components

- Target **80%** capture



# Dataset Partitions

250301_PDC8Site_v0.0.0 (Final CBC3 Dataset) # CBC Tests (ICU encounters)					
Year of Admission	Development Set			Test Set	Excluded Other Sites
	Site 1	Site 2	Site 3	Site 5&6	
2012-2016	60700 (8515)	23097 (3303)	35686 (6293)	42771 (7800)	
2017-2018	26396 (3680)	14372 (1701)	17642 (3179)		
2019-2023					

Train

Valid

Test

Excluded

## Inclusion Criteria:

- Pediatrics ICU encounters with  $\geq 1$  CBC test from 2012-2018

Total 220,604 CBC tests:

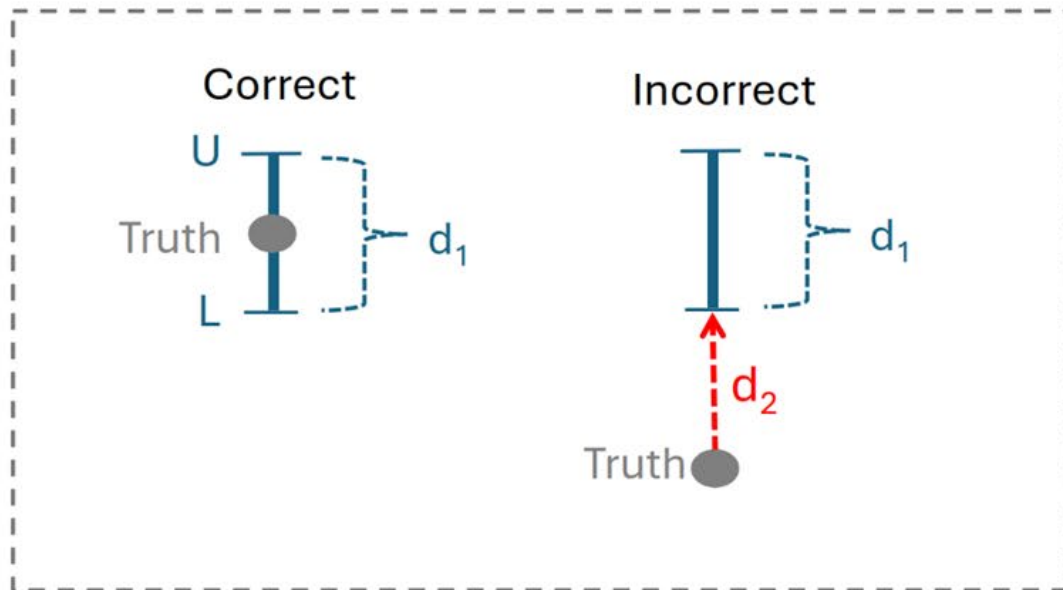
- 80.6% for development set
- 19.3% for evaluation

Four models developed on dev set and evaluated on external sites

- Three single-sites
- One composite (site 1-3)

69 features: Demographics and lab history

# Winkler Interval Score



## Winkler Interval Score

$$W(L, U, y, \alpha) = \begin{cases} U - L, & \text{if } y \in [L, U] \\ (U - L) + \frac{2}{\alpha}(L - y), & \text{if } y < L \\ (U - L) + \frac{2}{\alpha}(y - U), & \text{if } y > U \end{cases}$$

⏟
⏟

Width:  $d_1$     Penalty Term:  $d_2$

*Prediction Coverage* =  $1 - \alpha$

If  $[Q_{10}, Q_{90}] = 80\%$ , then  $\alpha = 0.20$

When prediction interval (PI) captures truth → Winkler = PI width

When it doesn't → Winkler = PI width + **penalty**

# Results

<b><u>WBC</u></b>	<b>Site 1</b>	<b>Site 2</b>	<b>Site 3</b>	<b>Composite</b>
<b>Accuracy</b>	78.2%	81.1%	80.0%	79.2%
<b>Median Winkler [IQR]</b>	8.79 [6.04, 14.28]	9.19 [6.39, 14.40]	9.23 [6.57, 14.18]	8.81 [6.10, 14.08]
<b>VS Composite</b>	+0.01 [-0.01, +0.03]	+0.35 [+0.33, +0.38]	+0.43 [+0.41, +0.46]	—

<b><u>HGB</u></b>	<b>Site 1</b>	<b>Site 2</b>	<b>Site 3</b>	<b>Composite</b>
<b>Accuracy</b>	77.8%	77.4%	81.0%	79.0%
<b>Median Winkler [IQR]</b>	3.14 [2.41, 4.61]	2.92 [2.37, 4.40]	3.32 [2.71, 4.42]	3.12 [2.43, 4.50]
<b>VS Composite</b>	+0.01 [+0.00, +0.03]	-0.09 [-0.10, -0.07]	+0.16 [+0.15, +0.17]	—

<b><u>PLTS</u></b>	<b>Site 1</b>	<b>Site 2</b>	<b>Site 3</b>	<b>Composite</b>
<b>Accuracy</b>	79.4%	80.4%	82.1%	80.3%
<b>Median Winkler [IQR]</b>	110.1 [74.4, 199.5]	118.8 [75.4, 210.0]	119.1 [82.1, 199.5]	112.2 [75.1, 198.3]
<b>VS Composite</b>	-0.10 [-0.40, +0.20]	+3.75 [+3.35, +4.10]	+4.30 [+0.41, +0.46]	—

# Lessons Learned and Future Directions



## **Greatest Impact on Success**

- Learning from the many experts in the PICU Data Collaborative and PALISI
- ML development with specific goal of implementation

## **What was Less Effective**

- Trying to get better results by extensive refining instead of re-thinking methodology

## **Implementation Insights**

- Define success using clinically meaningful metrics

## **Opportunities for Future Research**

- Extension to other forms of diagnostic overutilization in critical care

# Understanding Lab Ordering Practices



Created by ChatGPT

## Guided by PRISM-REAIM framework

- Quantify Laboratory Ordering
- Qualitative Assessment

### Multilevel Partner Engagement

- Understand the clinical workflow
- Identify key functions and proposed forms
- Conceptualize the CDS intervention & implementation strategy

**Internal & External Environment**

**Individual ICU clinicians and leaders perspectives**

**Implementation & Sustainability Infrastructure**

# Quantifying Laboratory Ordering Practice

**Objective:** Measure laboratory ordering practice variation to identify opportunities for test reduction and workflow characterization

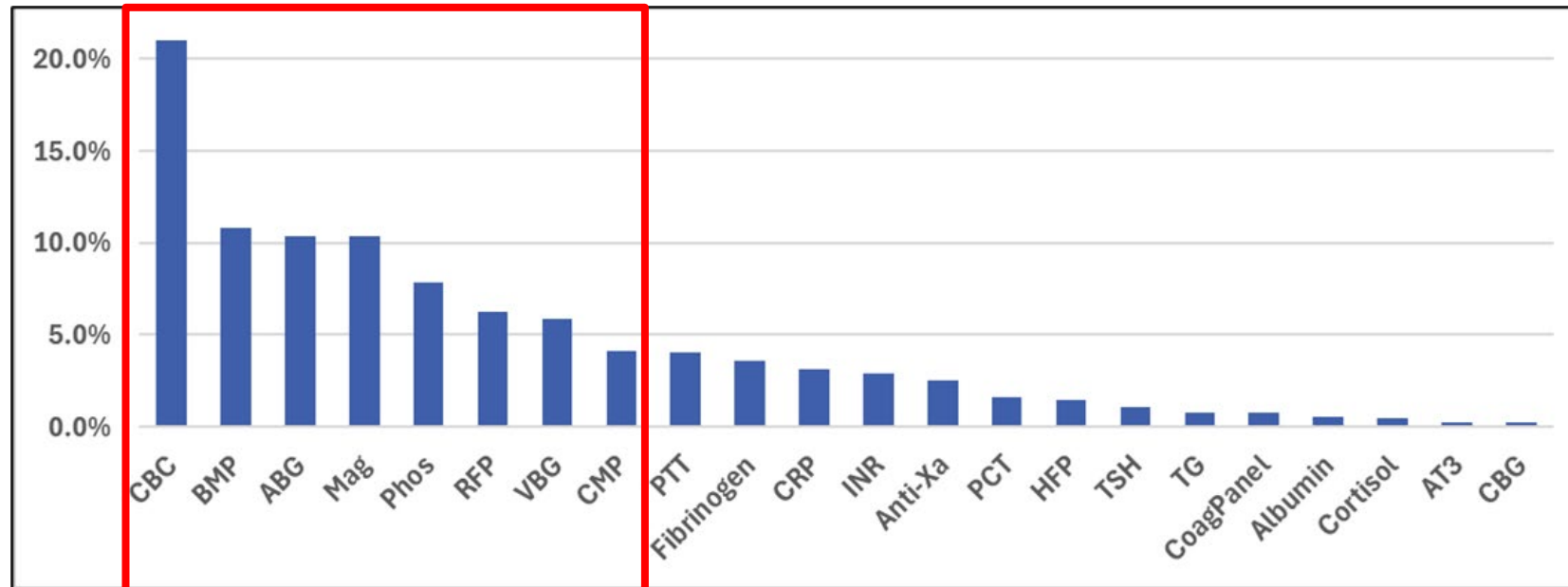
**Methods:**

- Central query and analysis script development
- “Placed” vs “Instantiated” orders
- Comparison of characteristics (e.g., type, frequency, order set usage, urgency level, ordering provider) across sites

# Common Lab Orders are Common Across Sites

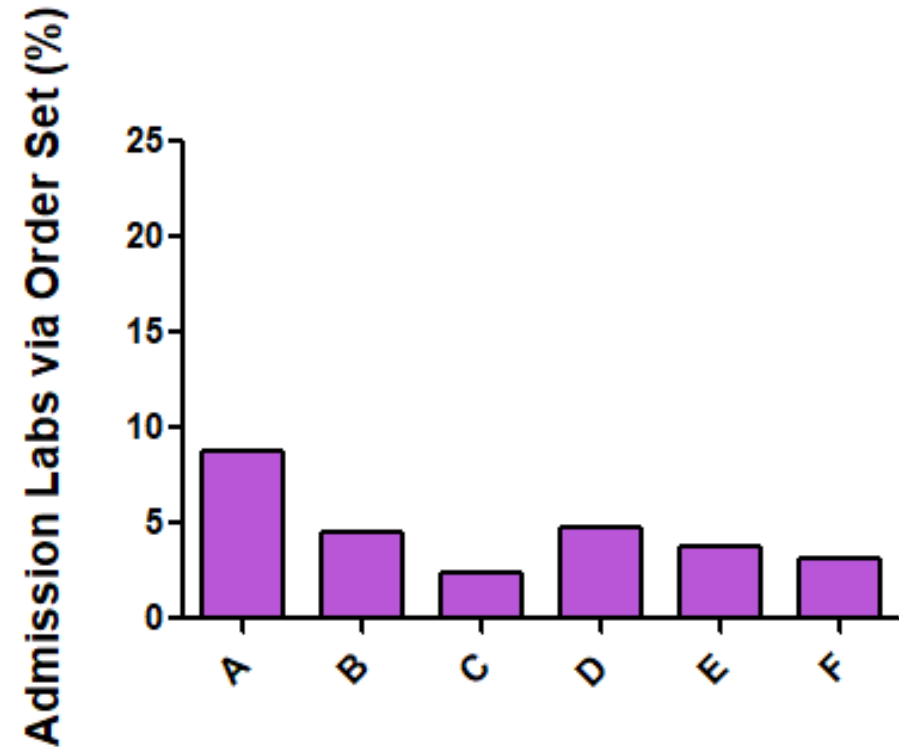
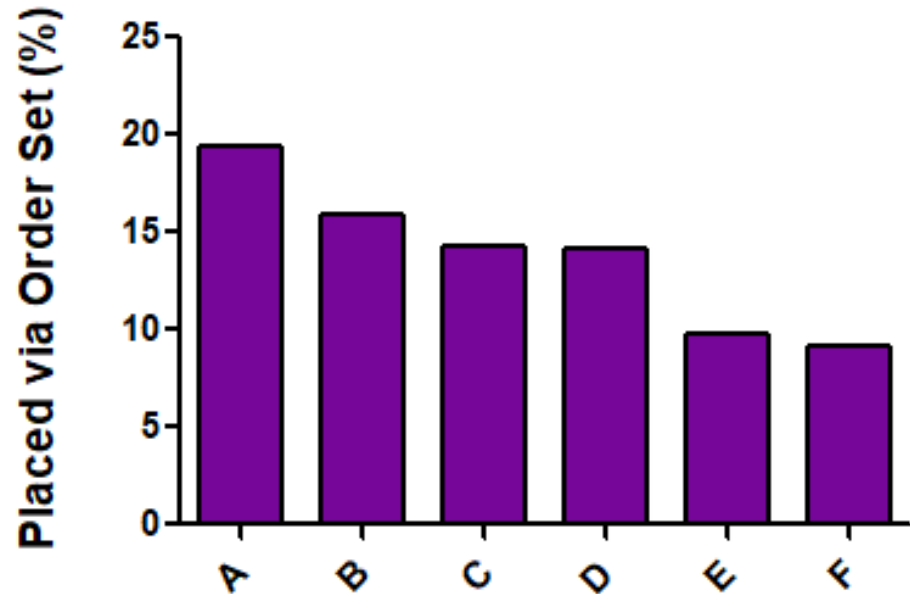
**Results:** 154,152 ICU encounters from 6 sites

6.5m “placed” lab orders, 10.0m “instantiated” orders



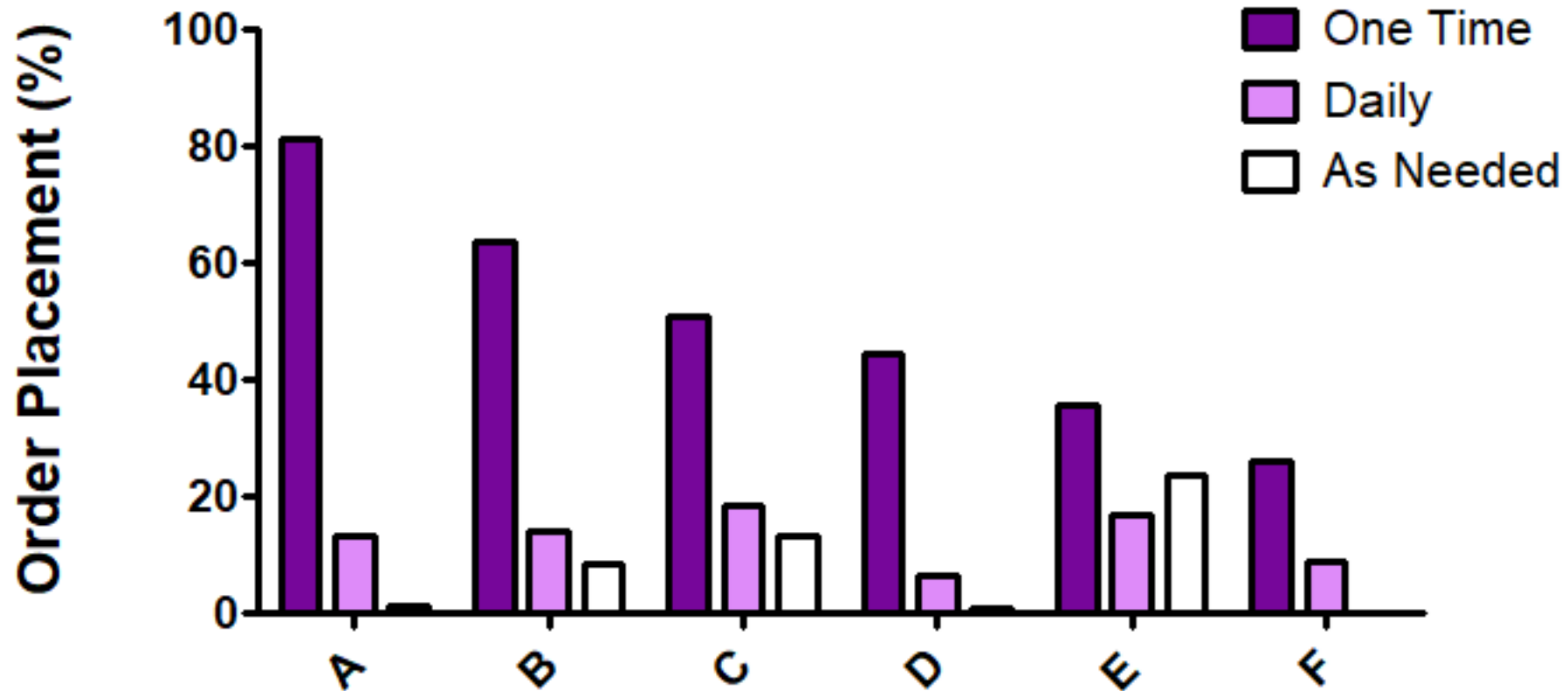
Focused opportunities for improvement

# Order Set Usage Varies Across Sites



Lab orders (%) placed via Order Set varies by site, as does % placed within several hours of admission

# Order Placement Frequency Varies



Wide variation exists among sites between order frequencies

# Focus Groups to Inform Workflow



**Objective:** Identify ordering practices, key partners, and decision support best practices

- Methods:**
- Focus groups (by role) with qualitative thematic analysis
  - Attending providers, nurses, and front line ordering clinicians
  - Key topics: lab ordering, barriers, decision support

# Preliminary Lab Ordering Themes



## Results:

16 stakeholder participants (10 attendings, 4 nurses, 2 front line ordering clinicians)

## Factors Impacting Ordering:

- Rounds discussions: “Is there an opportunity to reduce the patient's number of labs on rounds?”
- Resident autonomy: “... it’s a nice place for residents and fellows to have some autonomy in decision-making
- External factors: protocol-driven or consultant “requests”
- Individual Partner-Driven: “nursing-driven” versus “admission orders all checked”

# Opportunities for Decision Support



## Factors Influencing ML Trust:

- Degree of certainty: “the degree to which the patient would decompensate if it were wrong”
- Trust: “... demonstrate that machine learning gets it right when humans get it wrong”
- Absolute Value and Change: “so if the sodium was 142, and it goes down to 135 in a two-hour period”

## Specific Interventions:

- Rounding Report: “a daily summary of the labs that are ordered at given frequencies, and the predicted values of those”
- Interruptive Alert: targeted, limited to specific times (e.g., rounds), focused on specific labs, easily overridden

# Acknowledgements



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**VPICU at Children's Hospital Los Angeles**

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**PICU Data Collaborative**

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**PALISI**

## Other Key Personnel

- Nelson Sanchez-Pinto, M.D., M.B.I.
- Tellen Bennett, M.D., M.S.
- Katy Trinkley, Pharm.D., Ph.D.

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AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



# Getting on the Same Page: Leveraging an Inpatient Portal to Engage Families of Hospitalized Children

**Michelle Kelly, M.D., Ph.D.**

Professor, Department of Pediatrics

Pediatric Hospital Medicine and Complex Care Research Program

University of Wisconsin School of Medicine and Public Health



# Research Impact



By giving families real-time access to inpatient notes, Bedside Notes promotes transparent, family-centered care, enhances engagement, and improves safety—showing how simple, scalable tools can reduce anxiety and improve outcomes in high-stress settings.

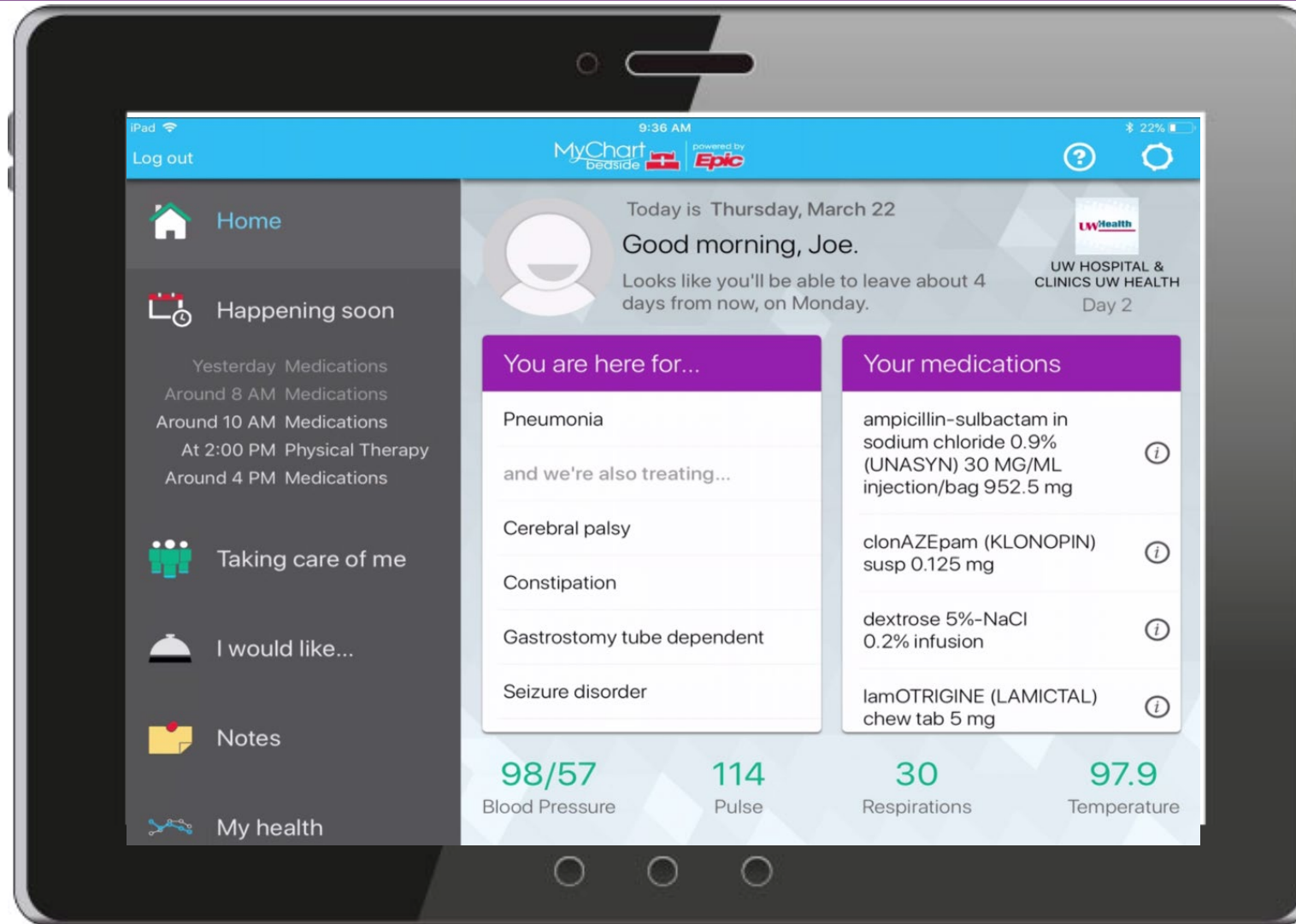
# Supporting Families in Pediatric Care



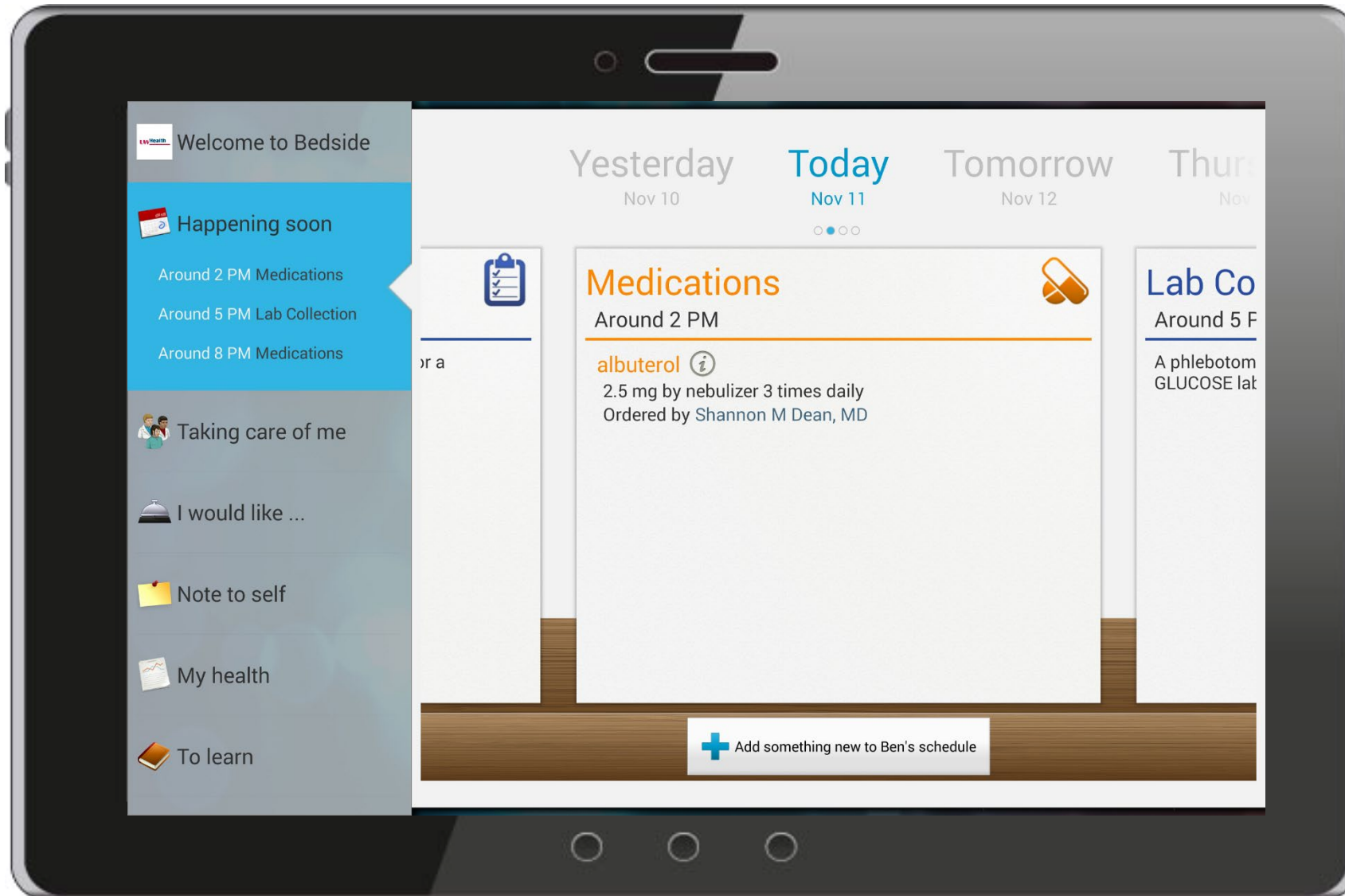
# Inpatient Portal: MyChart Bedside



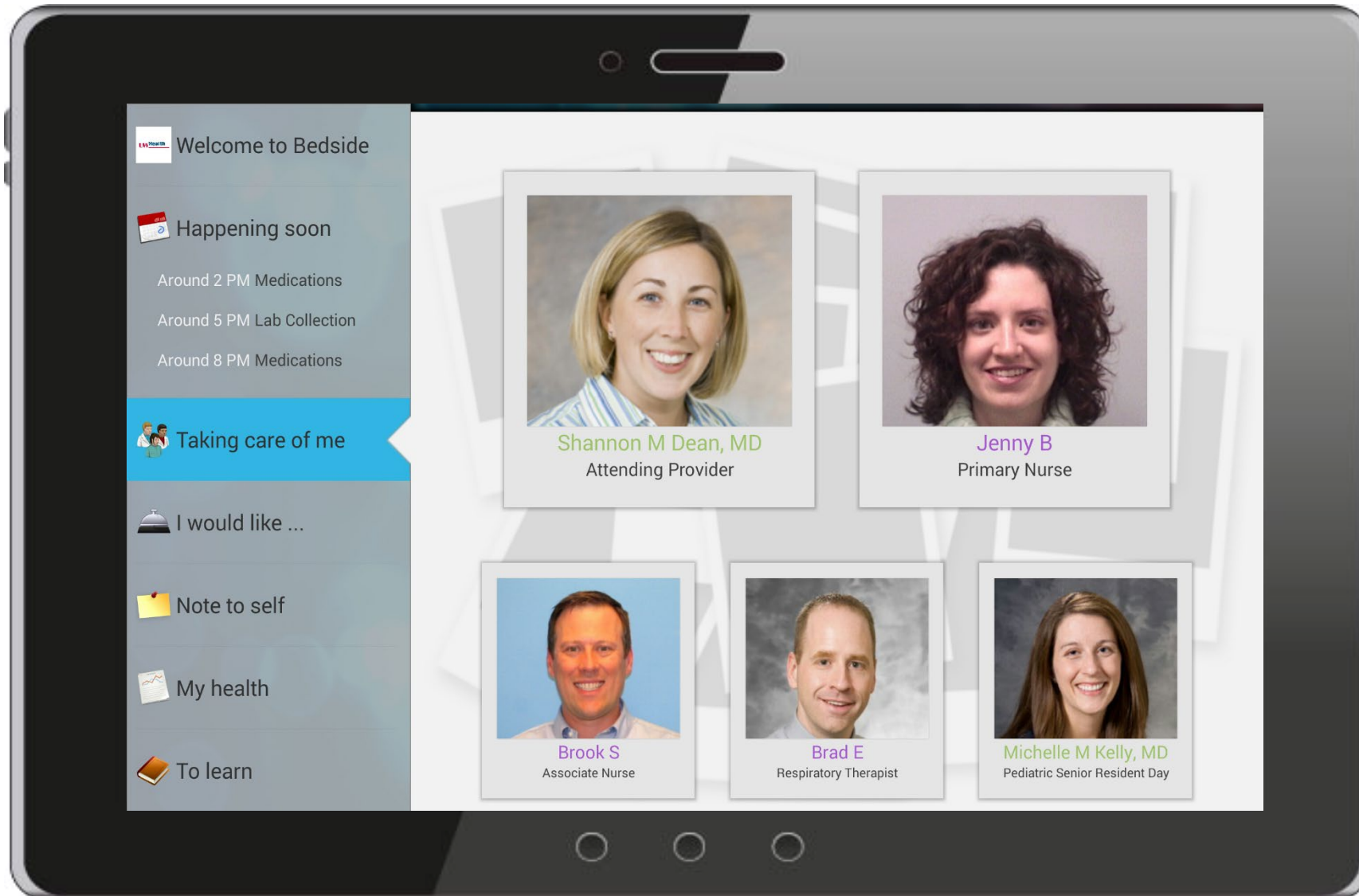
# MyChart Bedside Features: Inpatient Dashboard



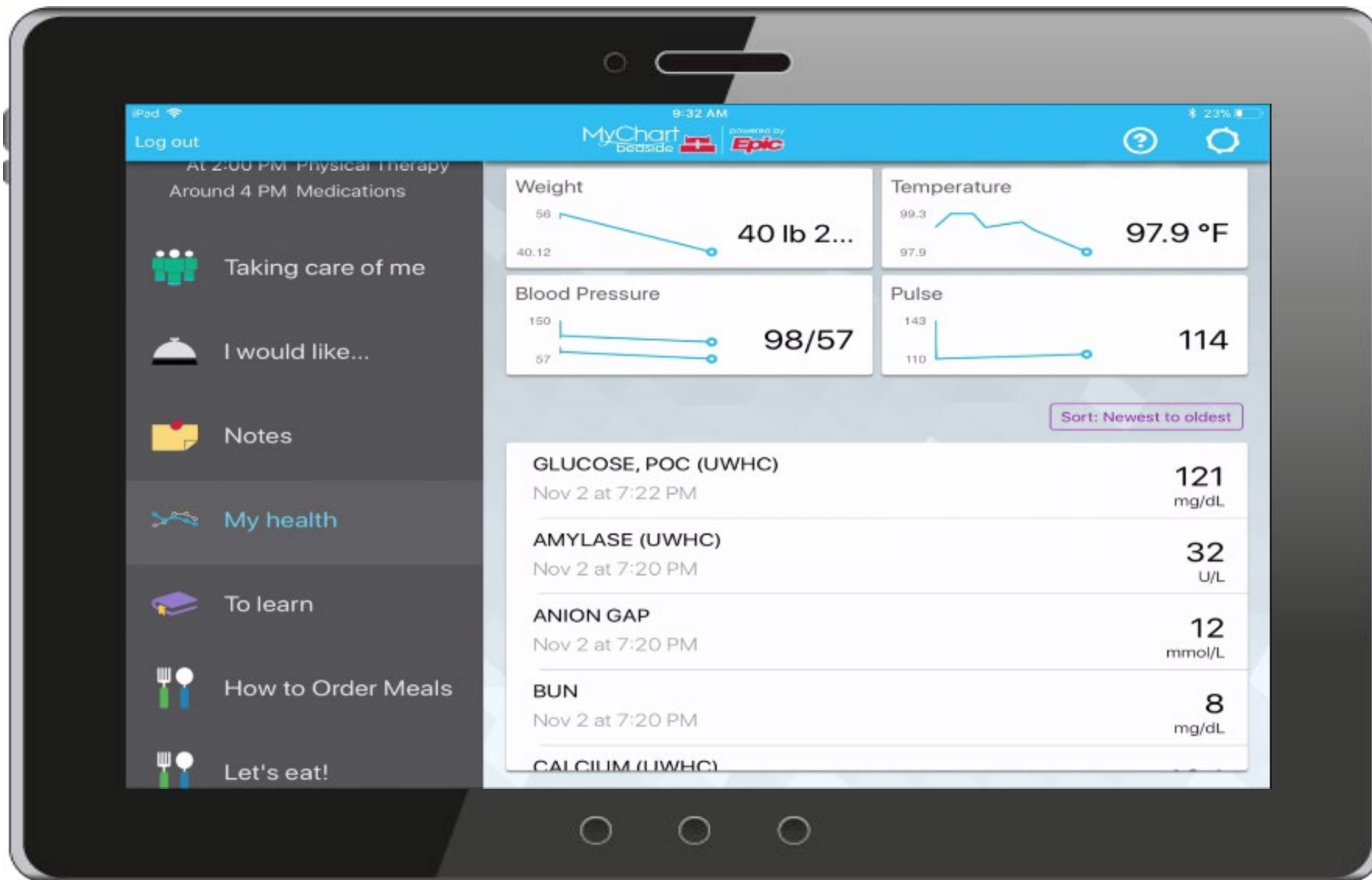
# MyChart Bedside Features: Daily Schedule



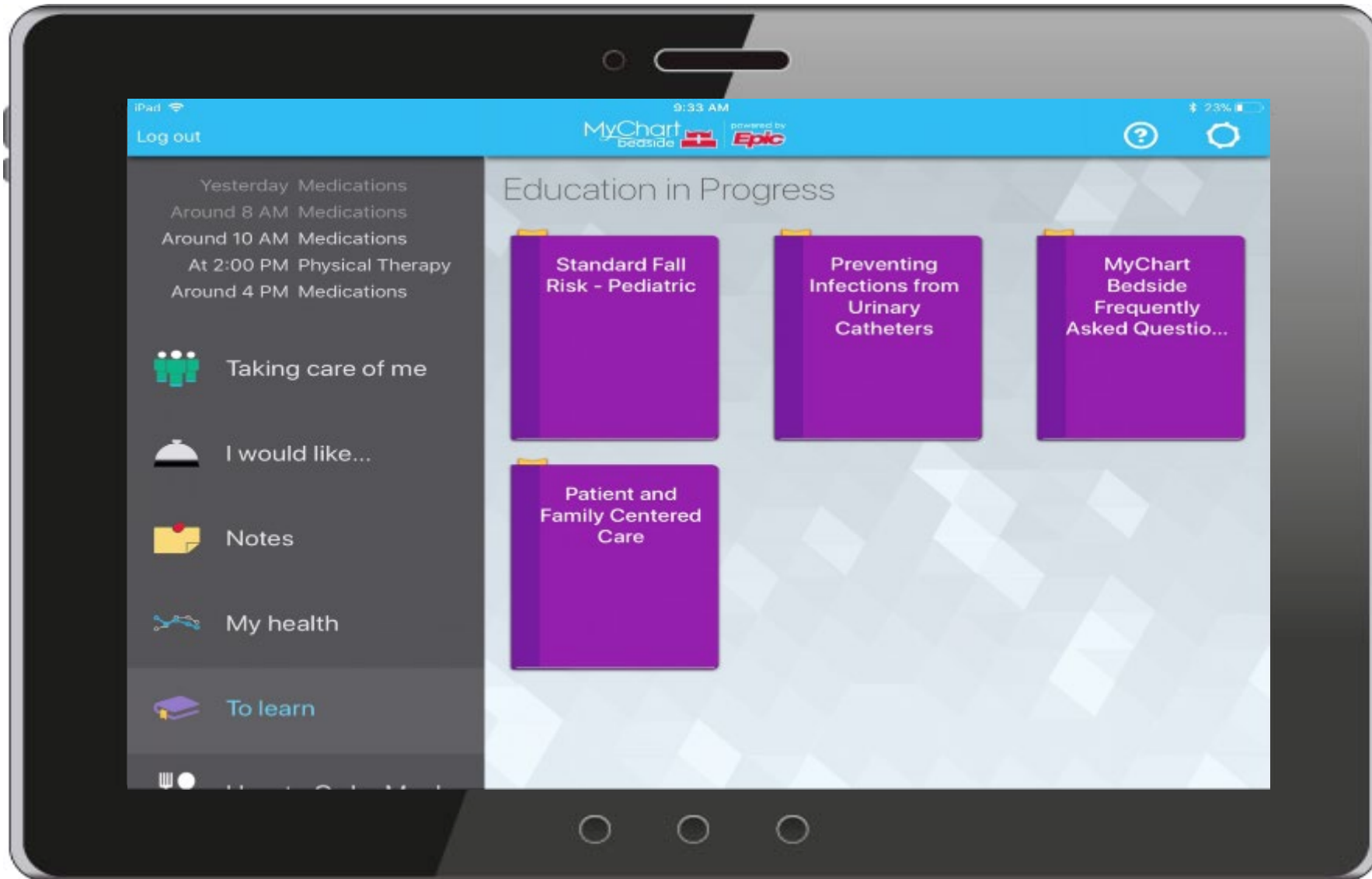
# MyChart Bedside Features: Providers



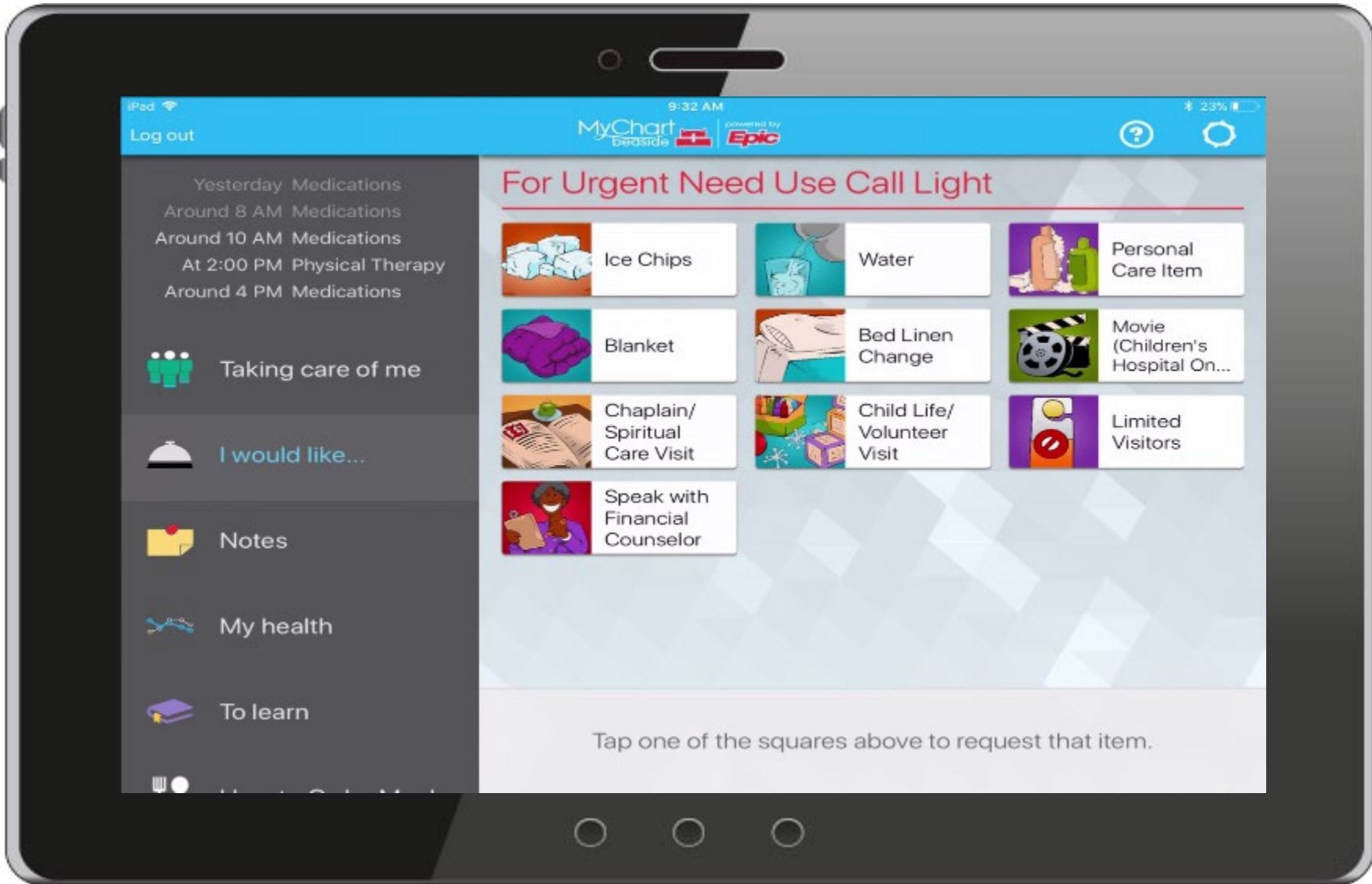
# MyChart Bedside Features: Vital Signs & Labs



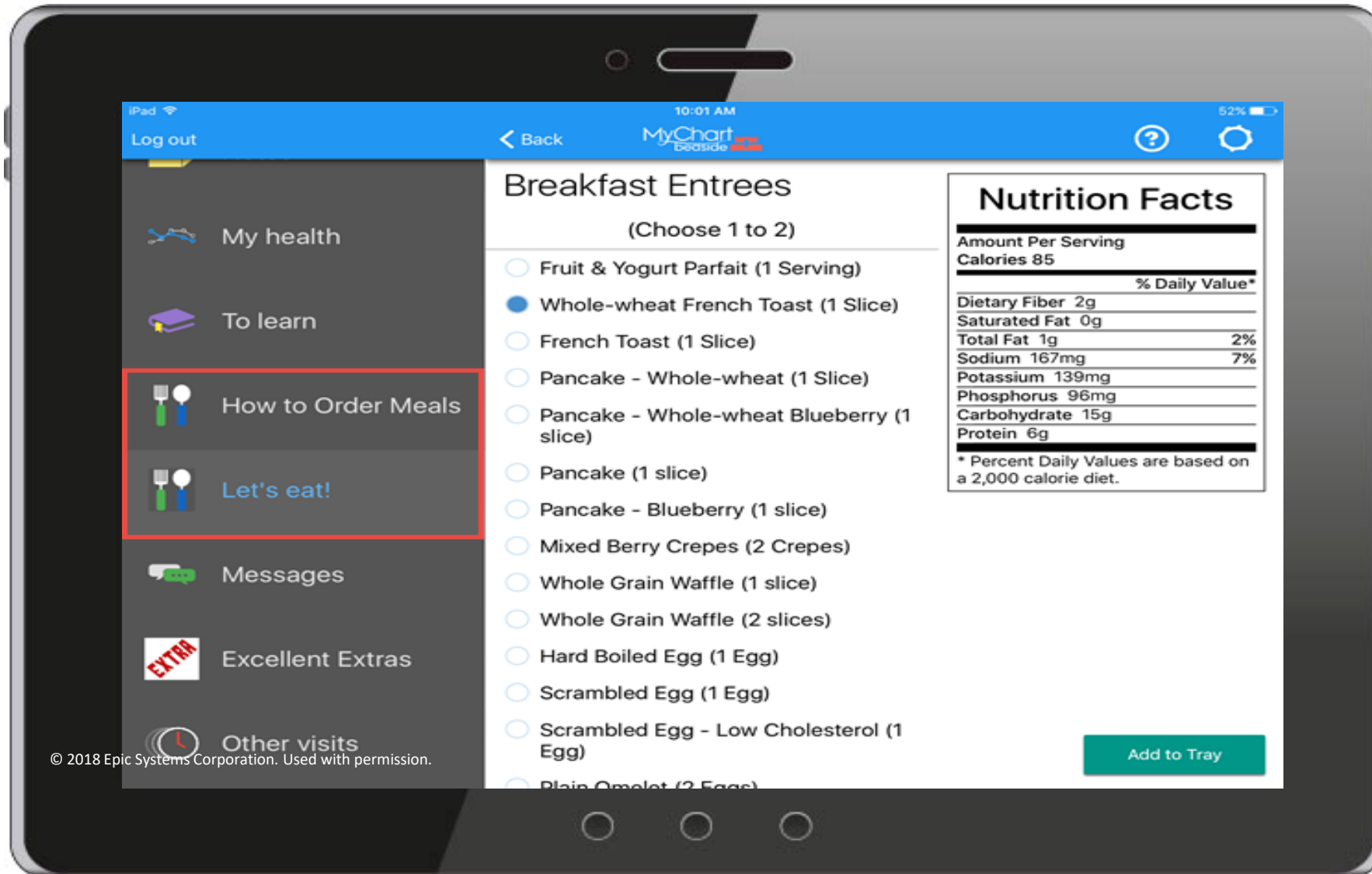
# MyChart Bedside Features: Admission Packet



# MyChart Bedside Features: Non-Urgent Requests

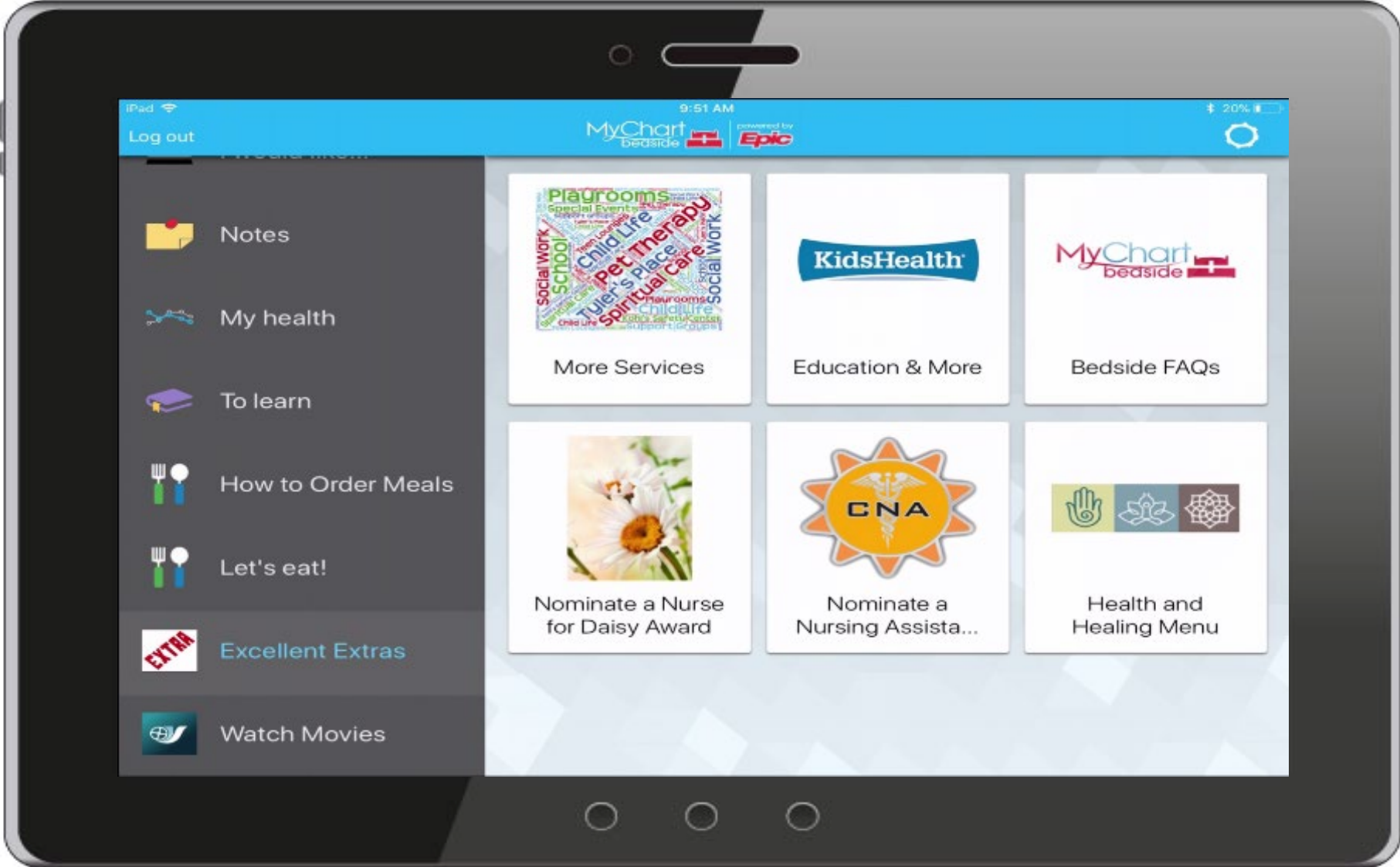


# MyChart Bedside Features: Menu

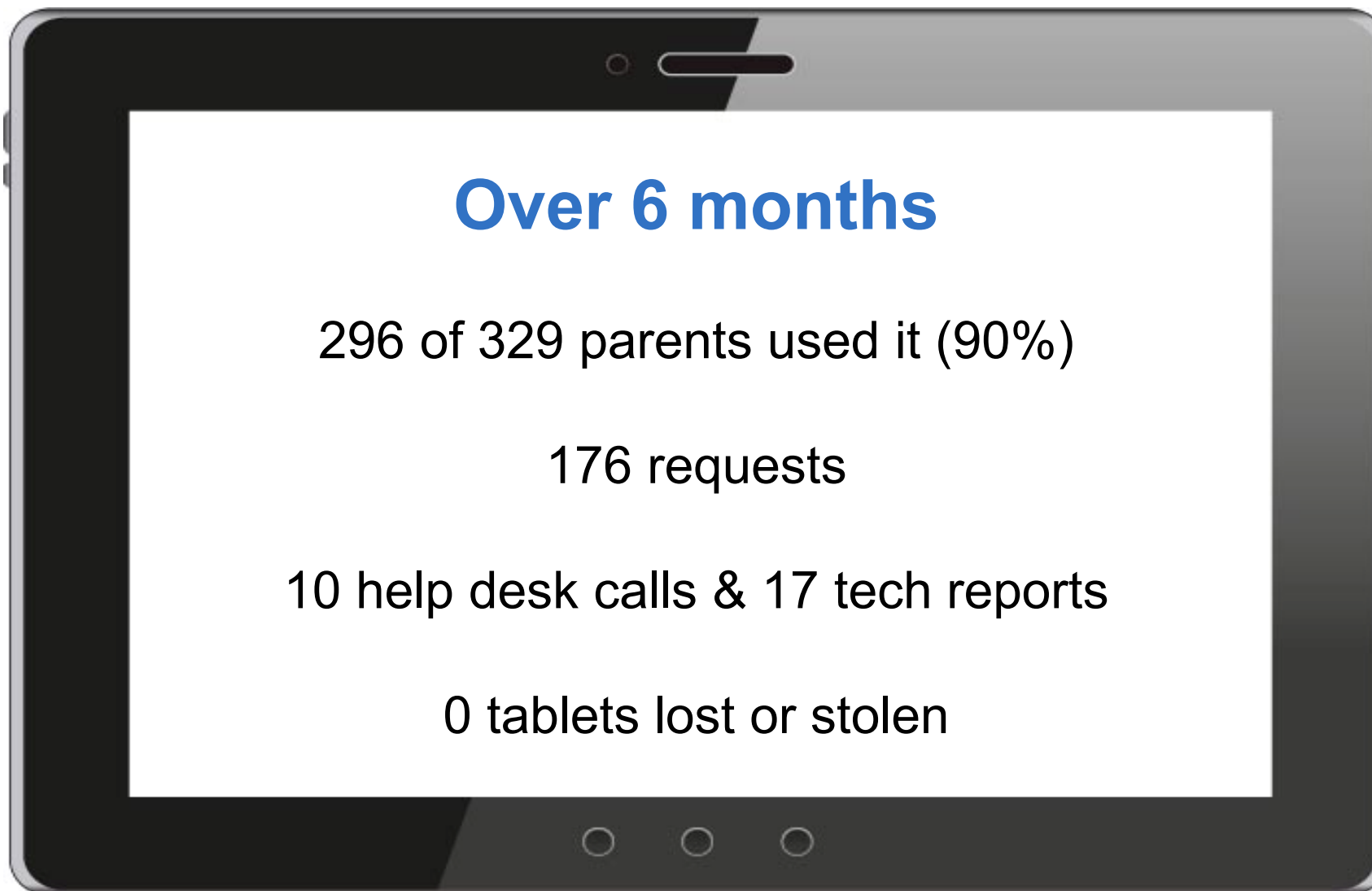


© 2018 Epic Systems Corporation. Used with permission.

# MyChart Bedside Features: Additional Apps



# MyChart Bedside: Adoption and Use



# Improving Parent–Provider Communication



**“It gives you a sense of control...** I don't always want to have to ask, “Did this happen, did this get done”? It’s not that I'm worrying about bothering people, but you also recognize that there's a lot going on, and some of those questions you might have you can get answered with this.”

- *Parent*

# Inpatient Portal Toolkit



Browse Toolkits

About HIPxChange ▾

Log In

<https://www.hipxchange.org/Inpatientportal>

## Partnering with Parents of Hospitalized Children Using an Inpatient Portal

[View the Toolkit](#)

\*Free registration is required to use the toolkits provided within HIPxChange. This information is required by our funders and is used to determine the impact of the materials posted on the website.

🔍 Children/Young Adults Health IT Engagement in Care Quality & Safety Engagement in Research

### > What is an inpatient portal?

An inpatient portal is a patient-facing web-based application intended to engage hospitalized patients and their caregivers by providing secure access to their personal health information.

Linked to the the hospital electronic health record (EHR), these portals provide hospitalized patients and their families real-time clinical information (e.g., vital signs, medication list, test results), personalized education, and a way to recognize and communicate with their care team.



# Featured in the Media



Sections

The Washington Post  
Democracy Dies in Darkness

Health & Science

## For hospital patients, bedside tablets and apps are providing some control over care

[https://www.washingtonpost.com/national/health-science/for-hospital-patients-bedside-tablets-and-apps-are-providing-some-control-over-care/2019/04/05/9d545de0-3c67-11e9-aaae-69364b2ed137\\_story.html](https://www.washingtonpost.com/national/health-science/for-hospital-patients-bedside-tablets-and-apps-are-providing-some-control-over-care/2019/04/05/9d545de0-3c67-11e9-aaae-69364b2ed137_story.html)



Navigation bar for Children's Hospital Association website with links: About Us, Directories, Newsroom, Resources, Log In, My Member Center. Main menu items: CHILDREN'S HOSPITAL ASSOCIATION, ISSUES & ADVOCACY, QUALITY & PERFORMANCE, RESEARCH & DATA.

ARTICLE | August 2, 2017

### Tablets for Everyone: How One Children's Hospital is Engaging Patients and Families

Share 89 Tweet 20 Google+ 1 in Share 1 Email Print

Tablet-based app helps parents review real-time information about their child's health.


"It gives you a sense of control...I don't always want to have to ask, 'Did this happen? Did this get done?'" This is how one parent of a patient at American Family Children's Hospital (AFCH) in Madison, Wisconsin, describes a new tablet-based app that AFCH rolled out hospital-wide this year. Called MyChart Bedside, the app provides families with real-time information about their child's health, the care plan and what to expect during their hospital stay.

Every parent—or the patients themselves, if they are adolescents—receives a tablet computer loaded with the MyChart Bedside app, including families in the neonatal and pediatric ICUs. The app provides access to key portions of the child's hospital medical record, such as lists of medications and diagnoses, test results in real time, personalized education and discharge information. It also details the child's daily schedule and provides a way to communicate with the inpatient care team.


"Parents have given us a lot of positive feedback," says Michelle Kelly, M.D., pediatric hospitalist and assistant professor of pediatrics at the University of Wisconsin School of Medicine and Public Health. "They look at the lab results and often can have their questions answered without the help of the medical team. We meet every morning with the families at the bedside, so that creates an opportunity to set the stage for what's going to happen and what they're going to see on their tablet."

Based on a successful pilot

# Parent Perceptions of Real-Time Medical Record Access



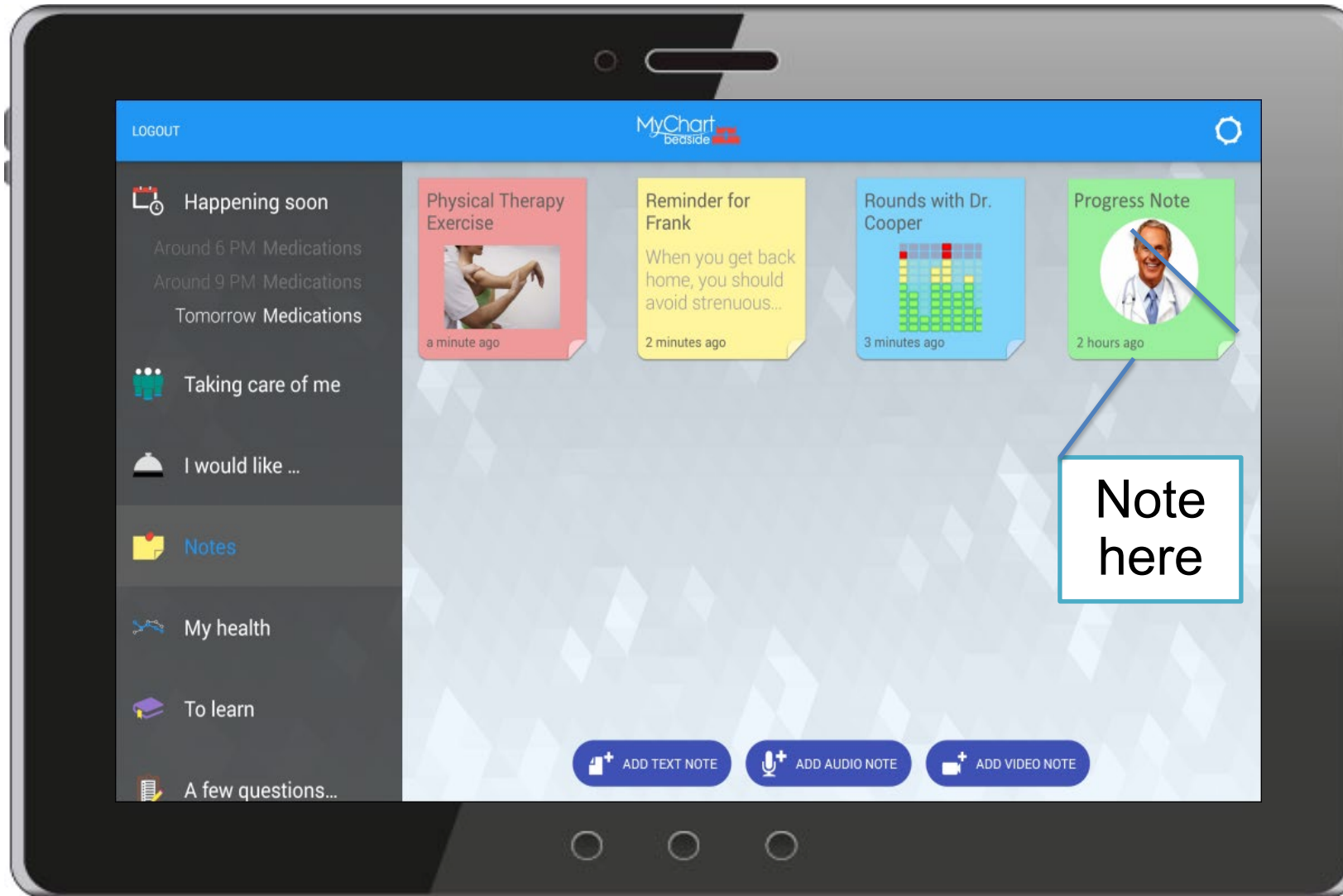
“In my son's entire medical history, I've only had one doctor really turn the screen to me and sit there and say like, ‘here's what we're seeing, here's what's happening.’ So, if I could see things like notes in here, that would be amazing.”



“Sometimes talking is different with writing... With access to [doctors'] notes, we'll know where is the problem and what's the next step.”

Kelly MM, et al. Parent perceptions of real-time access to their hospitalized child's medical records using an inpatient portal: A qualitative study. *Hosp peds*, 2019

# Notes and Reminders



# Pilot Study Objective



Evaluate parent access to and experiences with clinical notes using a bedside tablet during their child's oncology hospitalization.

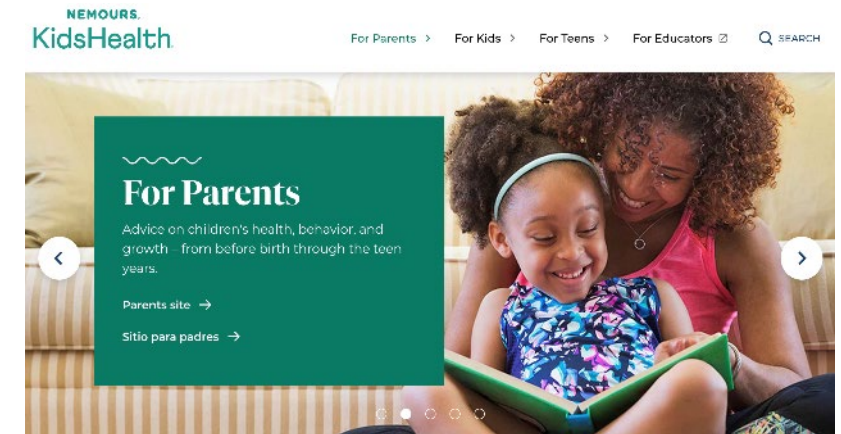
# The Bedside Notes Intervention



Bedside tablet to access notes



Orientation video



Link to educational resources

# Study Design

## Enroll Parent

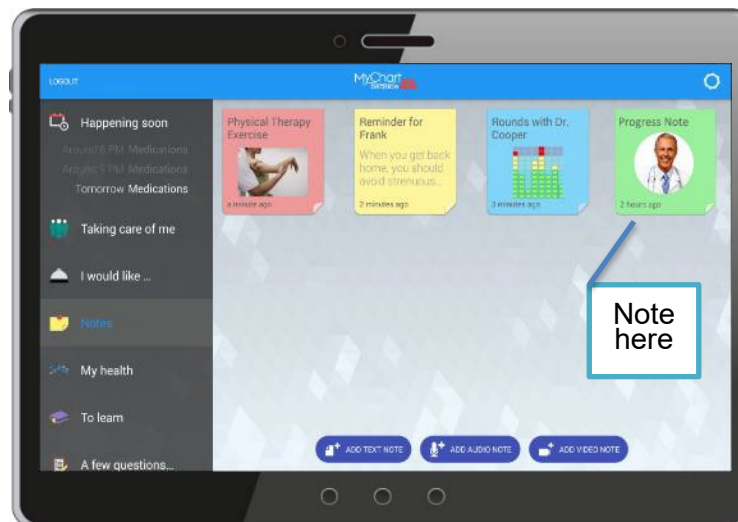
- Child <12 years old
- English-speaking
- Hematology / Oncology service
- Length of stay >24hrs
- No non-accidental trauma concern
- Survey completed

## Share All Inpatient Notes

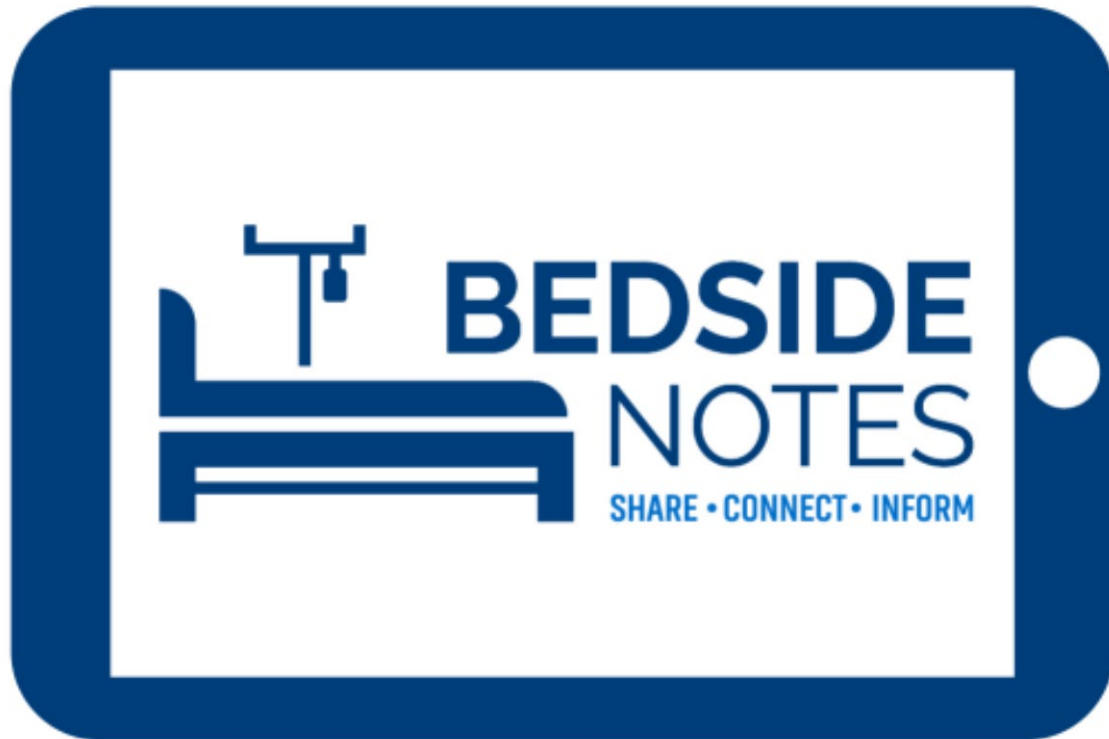
- Admission notes
- Progress notes

## Obtain Feedback

- Survey
- Interview



# Results



- 96% accessed 2 or more notes
- 14-fold increase from prior
- 1 in 5 parents identified a safety concern
- 60% confirmed safety issues
- Improved parent engagement and experience
- Decreased anxiety

# Parents as Partners in Care

*“[Note access] helps the parents feel like they're more involved. It also gives us a way of making sure that everything is accurate ... for parents to be able to look at [notes] and be able to make their voices heard as well and then be able to keep up [with the care team]”*

Kelly MM, et al. Parent perspectives on sharing pediatric hospitalization clinical notes. *Pediatrics*, 2023

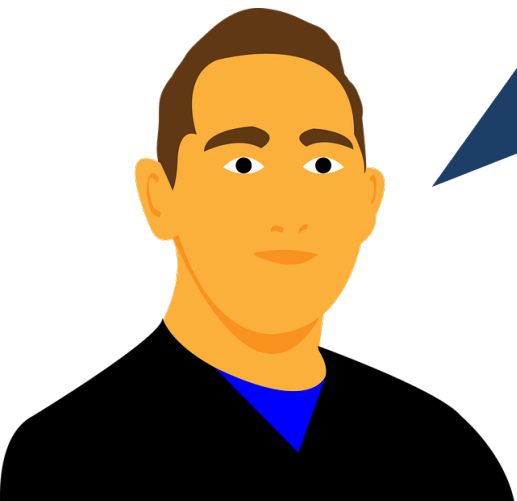


# Parents as Partners in Care

“Last night, his O2 kept dipping below 90 ... the night nurse came in, was like, ‘Oh, no, it’s below 90.’

And I was like, ‘Well, in the notes, it said that 88 is okay.’

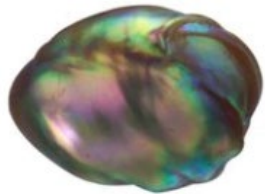
I was able to facilitate information that didn’t get to the nurse who was responding to an alarm ... and be like, ‘Oh, don’t worry, we’re okay with this.’ **It made me feel more of a part of the healthcare team.”**



# Recommendations From Parents & Physicians



Parents understand that notes are meant for clinician communication



Include parent concerns, as objectively as possible



Include differential, rationale, next steps and contingency plan



Ideally sign by evening (or before next days rounds)

# Also Consider...



## Tweaking your template

- Assessment and Plan first
- Refine and collapse some subheadings
- Change colors for lab values
- Use family-friendly terms as available
- Summary or update in attending addendum



Preparing parents: notifying when notes are available and including a disclaimer with expectations



Using abbreviation exchanges



Including a glossary, hyperlinks and/or recommended sites for information

# Looking Back



# Lessons Learned

- Families recognized that notes are primarily tool for healthcare team communication
- All wanted access to notes in future hospitalizations
- Consider pearls to support usefulness notes for families and limit workload of clinicians
  - Introduction to notes
  - Educational supports
  - Training for physicians and trainees
  - Translation and AI options...

# What's Next?

Multicenter randomized controlled trial to evaluate the impact of the Bedside Notes intervention on inpatient note access and parent-reported safety outcomes for hospitalized children.

O'Hare, et al. A multicenter randomized trial to improve family clinical note access and outcomes for hospitalized children: the Bedside Notes protocol. *J Hosp Med*, 2025

# Acknowledgements



Agency for Healthcare  
Research and Quality

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- ❖ Pediatric Hospital Medicine and Complex Care Research Team
- ❖ American Family Children's Hospital Leadership
- ❖ Patient and Family Advisory Council
- ❖ Patients, parents, nurses, residents, fellows, attendings, staff, and administrators

## Additional thanks to:

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| ▶ Carrie Cronk           | ▶ Peter Hoonakker  | ▶ Carley Sprackling |
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| ▶ John Frohna            | ▶ Jamie Limjoco    | ▶ Anna Uhing        |
| ▶ Norm Fost              | ▶ Kristin McArdle  | ▶ Ann Viet          |
| ▶ Miguel Garcia          | ▶ Megan Moreno     | ▶ Ellen Wald        |
|                          | ▶ Carrie Nacht     | ▶ Ben Zellmer       |

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